

**FETAL ALCOHOL SPECTRUM DISORDER:  
CIRCLES OF HEALING, TRANSFORMATION AND  
RECONCILIATION**

*Ke-ge-na-thee-tum-we-in*

**A Thesis Submitted to the College of  
Graduate Studies and Research  
In Partial Fulfillment of the Requirements  
For the Degree of Doctor of Philosophy  
In the Department of Interdisciplinary Graduate Studies  
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Saskatoon**

**By**

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## ABSTRACT

**FETAL ALCOHOL SPECTRUM DISORDER:  
CIRCLES OF HEALING, TRANSFORMATION AND RECONCILIATION,  
*Ke-ge-na-thee-tum-we-in***

The Ph.D. dissertation encompasses an interdisciplinary study exploring qualitative, holistic strategies for individuals with Fetal Alcohol Spectrum Disorder (FASD) in integrated areas of law, medicine, education, psychology and justice, through both inductive analysis of field research as well as through relevant documentary analysis, incorporating a global or comparative component. Compliance with Guidelines for Research Involving Aboriginal Peoples has been sustained through community partnerships with various First Nations and Métis Communities, Elders and Parents, as well as with an FASD Parental Advocacy Group, advised by a team of interdisciplinary researchers in the academy. Accordingly, emergent research protocols were co-constructed through ongoing collaboration with the various community partners. In Aboriginal research, it is essential not to parachute in and out of communities with the data, but rather to forge genuine, collaborative, long term partnerships, and to build capacity in those communities.

The dissertation format approved by the Student Advisory Committee is Manuscript Style, a format approved by the University of Saskatchewan's College of Graduate Studies and Research (formerly referred to as X-Format) similar to a self-edited book or collection of articles with introduction, sub-text, intra-text and general discussion to link the manuscripts. The various manuscripts comprising the present thesis include:

1. Framing the Research Anthology: A Vision Quest, *Ékehohksimoht Ke-kiss-see Muya*

Section One situates the research style, process, approach, substance and rationale of the dissertation. It is largely situated within holistic Indigenous epistemologies, which may require a paradigm shift, in contrast to more bounded western world views.

Interdisciplinary, holistic, community-based research on the topic of FASD, including a search for solutions, extends globally, across the lifespan, and across sectors.

II. Indigenous Disadvantage and Despair, An Evaluation of Recent Strategies and Alternatives: Healing and Transformation, Pluralism and Reconciliation,  
*Ne wah kuma ka tik*

Section Two explores historical and contextual factors leading to a high prevalence of FASD, as well as strategies to overcome disadvantage, including Reconciliation, Treaty Processes, and Research as Reconciliation. Local Narratives are privileged over Meta-narratives, to counter the power of global market forces usurping the sphere of family, community and culture.

III. Disjunctures and Discontinuities in the Law of Mental Intent: FASD as a Site of Resistance and Transformation, *Esquiskuit*

Section Three examines the disconnect between medical knowledge of FASD, on the one hand, and the Laws of Mental Intent, on the other, inspiring a search for a unified, integrated theory of mental disorder and criminal responsibility that takes into account modern neurocognitive conditions like FASD. Section Three further explores the present piecemeal and compartmentalized rules for fitness, responsibility, various levels of mental intent, and a resultant rationale, substance and process of law reform and systemic change.

IV. FASD and Holistic Literacies: A Talking or Sharing Circle, *Wa-sa-cam-e-be-ke-skue*

Section Four's inductive themes comprise model practice guidelines for the gestalt of Literacy and FASD, derived from inductive analysis of qualitative data collected in the field research. The data was collected using Sharing Circles with Aboriginal Elders, Parents, and Mentors of Individuals with FASD; Conversational Interviews with Parents and Children with FASD; as well as Interviews and Focus Groups with various Professionals who support individuals with FASD and their Families. Special protocols were followed in creating and participating in the Indigenous Research, Sharing Circles and Conversational Interviews. Meta-paradigmatic analysis situates Indigenous Research Methodologies among emerging, multi-disciplinary, inductive methodologies suitable for understanding the infinite complexity of natural phenomena, such as FASD.

V. Epilogue: An Honour Song, *Kethou-ne-ka-mon*

*Circles of healing, transformation and reconciliation* heal wounds, reconcile differences, and transform paradigms of justice, health, education and governance, through the incorporation of models of equitable, holistic relationships with one another and with Mother Earth. Multidisciplinary and cross-cultural perspectives, dialogues between local and global, and particular and universal, become matrices to support new paradigms embodying broader reflections of reality.

## ACKNOWLEDGEMENTS

Few complete a thesis entirely on their own, and in my case I have been most fortunate as there are many whose assistance I have the pleasure to recognize. First is my family: my husband, George; my children Samantha in Spirit, Cherie, Joseph and Robert, and my grandchildren, Preston, Austin, Ivory, River, Cash, Scarlett, and Gage. I could not have completed this research without their unfailing inspiration, patience and support. I acknowledge, too, the influence of my parents and extended family, and the important foundation they provided. For the sustaining power of friends and mentors who kept the faith, I am most grateful.

To my Advisor, Dr. Linda Wason-Ellam, Advisory Committee Chair, Ruth Thompson, and Advisory Committee Members, Dr. Mary Ellen Turpel-Lafond, Associate Dean of Law Norman Zlotkin, Dr. Stephen Wormith, and Dr. Patricia Blakley, sincere appreciation for your faithful and enlightened support throughout the extensive process of planning, researching, drafting and defending the PhD dissertation. Thank-you to the University of Saskatchewan and the Colleges of Education, Law, Medicine, and Psychology, which have served as crucibles, where fired by the search for knowledge and justice, ideas could take form. Special acknowledgement is extended to my External Examiner, Dr. Heather Douglas, T. C. Beirne School of Law, University of Queensland, Australia, who expertly, thoroughly and thoughtfully reviewed my work, enhancing *inter alia* the global perspective. The logistics and challenges of scheduling, conducting and concluding a Defense via video-conferencing across time zones and date line proved to be a memorable finale for all involved.

Without the invaluable cooperation and collaboration of the community partners in the field research, the Saskatoon Tribal Council, the FASD Support Network of Saskatchewan, the Central Urban Métis Federation, and Elders Walter and Maria Linklater, this research could not have been undertaken. Sincere appreciation is also extended to the Native Law Centre, for sustaining and supporting me throughout this venture, including the founder, the late Professor Emeritus Roger Carter who allowed me to share his beautiful office space, Research Director Sakej Henderson, Ruth Thompson, Marg Brown, Diane Kotschorek, Wanda McCaslin, Zandra Wilson, Terry Bahr, Duy Hoang, Janet Drysdale and Carol Reader.

I am indebted for the financial assistance of IPHRC, NAHO, SSHRC, SHRF, and University of Saskatchewan, which made this research possible.

I cannot conclude without further, special mention of my Supervisor, Dr. Linda Wason-Ellam, and her exceptional efforts beyond the call of duty over the lengthy and complex process of this research, involving writing grant proposals, working with a large interdisciplinary team, as well as with diverse community partners, and in joint dissemination of research results in papers and conference presentations. We have gone through so much together in this challenging, yet rewarding endeavour, which I could not have completed without her enduring support and appreciation of the pressing need for research in this area.

To all of who assisted in so many ways, making the research journey a transforming one, my sincerest and most heartfelt appreciation. To Professors John Kleefeld and Felix Hoehn, and to ITS Help Desk, for kind and generous technical assistance with formatting, as well as the Centre for Writing Help Desk for advice on advanced word processing issues, all of the University of Saskatchewan, please accept my gratitude. If I have inadvertently omitted expressly thanking any of those who assisted me, please accept my sincere appreciation and apologies. While I have attributed much inspiration and assistance to others throughout this acknowledgement, as a final caveat, all limitations, errors, lacunae, or other inadequacies in the dissertation are mine alone.

Thank-you, *E'Kosi*, from the bottom of my heart!

## **DEDICATION**

**To the Circle of Elders, Parents and Individuals  
with Fetal Alcohol Spectrum Disorder (FASD)  
who Guided the Research Journey**



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**Framing the Research Anthology:**  
**“As Long as the Grass Grows and the River Flows”**  
**A Vision Quest: *Ékehohksimoht Ke-kiss-see Muya***

**By H. Rae Mitten**

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It is fitting to begin this collection of articles, a variety of anthology, with a story, a narrative, deeply textured, immersed in the field of study and in the community-based research undertaken on the topic of Fetal Alcohol Spectrum Disorder (FASD). The narrative symbolizes what is attempted through a holistic approach to research involving individuals with FASD, their families, and communities. It involves the story of an Honour Shawl. Recently, I was presented with an Honour Shawl, made for me by a traditional Cree woman, knowledgeable about FASD and about this research. In such a case, the hands of the maker and the reason for making it, as each stitch is carefully and purposefully placed, are as significant as the garment. The Shawl per se consists of a subtle gold satin on one side; on the reverse, a print of buffalo and green grass traversed by a stream, evocative of the sacred Treaty promise, “as long as the grass grows and the river flows.” Evenly hand-stitched, the edges of the Shawl are bordered by a golden fringe descending. Such a beautiful, unique, handcrafted garment has to have a spiritual connotation, but what is it? A Shawl is a protective garment, but protective of what? Enlightenment eventually came through an Elder, who, upon presentation of tobacco, smudged the Shawl.<sup>1</sup> A

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<sup>1</sup> Sylvia McAdam, Saskatchewan Indian Cultural Centre, *Cultural Teachings: First Nations Protocols and Methodologies* (Saskatoon, Saskatchewan, Canada: Saskatchewan Indian Cultural Centre, 2009) at 18-19. Smudging is a ritual cleansing ceremony, using smoke from sweetgrass, sages, cedars and other plants heated over hot coals or lit with matches. Smudging is used to prepare an individual to enter into prayer or sacred learning, or to purify and bless special objects, such as clothing or ceremonial objects such as totems and drums. As the smoke rises, a supplicant wafts it over herself, her prayers rise to the Spirit World, and negative energy, feelings and emotions are lifted away, producing healing and restoring balance.

Shawl is usually given to honour a woman for leadership or learning, in order to protect her family, but protection can extend further than what is usually meant by family. Not merely a garment to wear about one's shoulders as an outward sign of honour, the Shawl is constantly with the recipient, a garment that cannot be removed.<sup>2</sup> Presented in recognition of the research journey with FASD, the Shawl symbolically represents protection and care for all individuals with FASD, their families and communities. Throughout the research journey my goal has been to honour the duty of care epitomized by the Shawl. Spiritually, I am merely an instrument for the process, spreading the metaphysical Shawl wide to include all with FASD beneath its sheltering folds.

Although it is unusual to include the spiritual dimension in Western research, Aboriginal research is holistic, encompassing mind, body, emotions and spirit, as depicted in the Medicine Wheel. Without spiritual strength and enlightenment, I would not have been able to persevere in a journey long and arduous, with many a barrier along the way. Without the assistance of my Advisor and Advisory Committee, Community Partners, various funding agencies (SSHRC, IPHRC and NAHO) and the Native Law Centre, I would not have been able to continue this pursuit. Margaret Kovach in her award winning treatise on Indigenous Methodologies, observes that graduate students are experiencing much resistance in attempting to use these methodologies, terming them "resistance research." In construing Indigenous research as "resistance research," reminiscent of anti-oppressive research methodologies, but moreover based on Indigenous worldviews of which spirituality forms an integral part, Kovach posits that Indigenous research methodologies are thus more of a challenge to Western perspectives, and consequently may meet with increased resistance.<sup>3</sup> What is needed is a decolonizing lens,<sup>4</sup> an integral part of the process of reconciliation to bridge differences.

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<sup>2</sup> Alan Peshkin, "In Search of Subjectivity: One's Own" (1988) 14 (198) *Educational Researcher*, 17-22, cited in Susan D. Dion, *Braiding Histories, Learning from Aboriginal Peoples' Experiences and Perspectives*, (UBC Press: Vancouver, 2009) at 83.

<sup>3</sup> Western perspectives may be unaware of the influence of religion on their own views, and on the interrelationship between religion, world view and science in Western, as well as Indigenous spheres. Vine Deloria, *Evolution, Creationism and Other Modern Myths* (Golden, Colorado: Fulcrum Publishing, 2002). Deloria attributes linearity of concepts of time and causation in Western scientific traditions to Judeo-Christian roots, as illustrated in the creation story in the book of *Genesis*.

Although the present research journey has been difficult, the challenges largely involved breaking new ground to conduct complex, holistic research across both disciplines and cultures. Difficulties include challenges of ethos, essence and uniqueness of perspectives and modes of communication and inquiry across sectors, as well as the complexity of real world versus laboratory research. Moreover, different disciplines have distinctive conventions regarding what are admissible problems, legitimate solutions, and what constitutes scholarly research. However, various protective forces, perhaps collectively forming the warp and woof of the Shawl, have sustained and facilitated the research throughout the long, challenging, yet transformative journey.

Consonant with the purpose of the Shawl, the researcher's enduring vision quest has been to find supports, services and solutions for vulnerable individuals with FASD. Denying a condition like FASD, identified by medical science, will only force matters underground where problems fester. Indeed, such denial in itself stigmatizes individuals affected by FASD, preventing them from receiving needed diagnosis, treatment, and supports to ameliorate their disability. When I first commenced FASD research in the community, families seemed reluctant to admit the condition perhaps because of stigmatization. But as the possibility of supports and solutions emerged, the climate of chill surrounding FASD began to ease, and courageous participants gradually stepped forward.

Through these slings and arrows, the spirit of the Shawl has been with both researcher and research participants. Elders prayed, smudged, held sweats and other ceremonies to support the research. As researcher, I found strength and voice, and, in turn, honoured the voices of the powerless, standing shoulder to shoulder with vulnerable participants throughout the critical, emancipatory, participatory action research process embedded within emerging Indigenous methodologies. A Circle Methodology was adopted for the research to honour both Aboriginal

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<sup>4</sup> Margaret Kovach, *Indigenous Methodologies, Characteristics, Conversations, and Contexts* (Toronto: University of Toronto Press, 2009) at 18 and chapter 4, 55-74.

and FASD peoples' epistemologies and perspectives through a process of dialogical reframing,<sup>5</sup> employing Conversational Interviews and Sharing Circles. May the spirit of the Shawl endure through dissemination of research findings, publication, and eventual implementation.

Interdisciplinary, and pluralistic, involving Aboriginal and non-Aboriginal people from all walks of life, the holistic, qualitative research undertaken followed Aboriginal Research Guidelines, requiring community as well as individual consent, appropriate protection for vulnerable individuals with FASD, community-involvement in the planning of the research, in the sharing of costs and benefits, and in capacity building for students and community members. Community partners included a Tribal Council, a Métis Federation, a Circle of Elders and an FASD Support Network. Although reliable prevalence data for FASD is not available in Canada, the condition does affect all racial and cultural groups. Among populations affected, Aboriginal peoples have unique, holistic insights into effective approaches for those with FASD, their parents, and communities. They remind us that "It takes a community to raise a child," an observation particularly true for children who have FASD. Qualitative, open-ended Conversational Interviews were conducted with individuals affected by FASD, with their families, and with various professionals: teachers, educators, physicians, psychologists, speech therapists, occupational therapists, social workers, lawyers, mentors, and others who work with FASD clients. Transcripts of Conversational Interviews, Focus Groups of key informants, and Aboriginal Sharing Circles were analyzed inductively to systematically document holistic, experiential models of policy and practices that the extensive sample found had worked for individuals with FASD.

An Academic Advisory Committee "dream team" consisting of researchers from fields of Law, Medicine, Education, Psychology and Justice was recruited, with a chair from Native Law. The Advisor is from Curriculum Studies in Education, focusing on English as an Additional Language, Struggling Readers, Aboriginal pedagogy, as well as the methodology of qualitative, participatory action research. The member from Law focuses on Aboriginal, Constitutional and Criminal Law and has worked with many Indigenous organizations across Canada; while

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<sup>5</sup> Linda Tuhiwa Smith, *Decolonizing Methodologies: Research and Indigenous Peoples*. (New York: Zed Books, 1999).

Medicine contributes a pediatric specialist from the College of Medicine, who *inter alia* diagnoses and treats children with FASD, as well as some adults. Psychology provides a Professor of Forensic Psychology and Chair of the Centre for Forensic Behavioral Sciences and Justice Studies. Justice furnishes a First Nation's Judge on leave from the Saskatchewan Provincial Court while acting as British Columbia's Representative for Children and Youth. Native Law bestows the Chair, who is Director of the Program of Legal Studies for Native People, Coach of the International Jessup Moot and Lecturer on International Indigenous Issues.

A global component complements the research as interviews were conducted with nationals from Canada, South Africa, New Zealand, United States, and Australia. The present author was privileged to visit South Africa where she conducted interviews and presented the background to her research at an international conference. South Africa has the highest known incidence of FASD due to a combination of contributing legal, social, economic and political factors.<sup>6</sup> Conference participants from South Africa commented that, although HIV-Aids is in crisis proportions, FASD will be a more enduring challenge. Significantly, similar conditions give rise to both HIV-Aids and FASD, among them inequality and gender issues.

In addition, a literature review of relevant legal, medical, scientific, educational and historical research, as well as the *Constitution Act, 1982*,<sup>7</sup> including Treaties with the Indians recognized and affirmed in s. 35 of the *Constitution Act*, Hansard Official Reports of House of Commons Debates, parliamentary committee hearings and accompanying oral and written submissions and final reports, royal commission reports, legislation, and common law and commentary both domestic and comparative, was undertaken, then analyzed and synthesized in edited articles that comprise the thesis. As knowledge in the field is expanding exponentially, the literature review and analysis has proven to be an extensive, ongoing process. Closure has to be achieved at some point, however, for purposes of publication within the limits of time

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<sup>6</sup> Philip A. May, Lesley Brooke, J. Philip Gossage, Julie Croxford, Colleen Adnams, Kenneth L. Jones, Luther Robinson and Denis Viljoen, "Epidemiology of Fetal Alcohol Syndrome in the South African Community in the Western Cape Province" (2000) 90 Am. J. of Public Health 1905; and Alex John London, "Offshoring Science: The Promise and Perils of the Globalization of Clinical Trials" (2011) 33(1) IRB: Ethics and Human Research, 18-20. Ethical clearance has been easier to obtain in some countries and some sectors of society in contexts of minimum regulation, low expectations of incentives for local researchers, as well as availability of treatment naïve subjects.

<sup>7</sup> *Constitution Act, 1982*, being Schedule B to the *Canada Act 1982* (U.K.), 1982, c. 11.

constraints imposed and the capacity of one researcher in such a broad field. It is not known if similar broad, interdisciplinary study, encompassing a significant field research component, consultation and collaboration with Aboriginal groups, and compliance with Aboriginal research protocols, has been previously attempted within the parameters of a Ph.D. program.

The format selected for presentation of results of the research and approved by the Advisory Committee is a “paper format,” consisting of a collection of edited articles written by the present author about various topics comprising the research, and including an introductory section to frame the collection. The second substantive section sets forth the historical, cultural, environmental and legal context to the emergence and prevalence of FASD as well as ameliorative approaches, and the third section analyzes the disconnect between FASD and the justice system, into which individuals with FASD often fall by default. The fourth section presents and interprets findings of qualitative field research regarding holistic literacy strategies, informed by diagnostic brain domains, for individuals with FASD. Education and Justice comprise large, related issues, as youth with FASD frequently struggle, drop out of school, then are drawn into negative peer groups which can lead to involvement in the justice system either as perpetrators or as victims. Assumptions underlying education and justice systems generally do not fit well with the cognitive and behavioral deficits with which individuals with FASD must contend. While the educational system often treats them as disposable, suitable only for behavioral classrooms with subsequent absenteeism and dropping out, criminogenic environments contribute to their further deterioration. After over 40 years of medical recognition of fetal alcohol conditions, no literature exists regarding a comprehensive, holistic, FASD pedagogy that takes into consideration sensory, behavioral, attentional, volitional, and most importantly, cognitive challenges in the context of holistic literacies and life skills. Whereas mandatory minimum sentencing (including capping and other limits on the amount of credit an offender could receive at sentencing for the time spent in remand)<sup>8</sup> takes away discretion from

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<sup>8</sup> *An Act to amend the Criminal Code (limiting credit for time spent in pre-sentence custody)*, short title, *Truth in Sentencing Act*, R.S. 2009, c. C-46, s. 719(3), Bill C-25. The passage of Bill C-25 amended s. 719(3) of the *Criminal Code* to cap the amount of credit that can be given for time served in remand from a previous ratio two to one, to a ratio of one day for one day, unless exceptional circumstances exist, such as physical conditions. In exceptional circumstances, a judge may grant a ratio of 1.5 to 1, but is required to justify the reasons for the

judges to frame fit, rehabilitative sentences for individuals with FASD who appear before them, while at the same time tasked with striving to reduce over-representation of Aboriginal and mental disordered offenders in custody. In a similar vein, in the educational context, commercial for-profit programs imposed top-down interfere with the professional judgment of teachers to address holistic learning needs of children and youth with FASD whom they see regularly in their classrooms. Such issues will be fully addressed in Sections three and four, respectively. Much about FASD per se will be discussed throughout this collection of papers, but for preliminary purposes, FASD includes a spectrum of conditions characterized by a constellation of symptoms resulting from exposure to alcohol in utero, including *inter alia*, growth impairment, cognitive and behavioral deficits, and on occasion, facial dysmorphism such as thin upper lips and small eye slits. The role of alcohol in society, and resultant policy, treaty and legislation is an ongoing issue generally, and in particular when FASD is considered. However, the critical gaze should be cast not upon women, but rather on the manner in which society both benefits from legalization, sale and use of alcohol, and contributes to and is implicated in its inappropriate use. Alcohol, being an intoxicating, addictive, teratogenic substance, has a harmful side which needs to be regulated. A critical component of such regulation includes a need for mandatory warnings to consumers on labels of all beverages containing alcohol, as well as mitigation of damages through accessible, specialized, evidence-based addiction treatment programs, and diagnosis and effective accommodation of FASD. Although not as yet universal, the global trend is toward regulation and labeling of contents of food and drugs with reference to international standards, partially enforced by trading regimes such as WTO and NAFTA. Currently, the Government of Canada affixes warning labels on alcoholic beverage containers for export only. FASD, addictions, traffic injuries and fatalities and other health issues, constitute part of the collateral damage that can result from improper use of alcohol. “Drug harms in the U.K., a Multicriteria Decision Analysis,” released Nov. 1, 2010, evaluated alcohol, cocaine, heroin, ecstasy, marijuana and other drugs, ranking them based on how destructive they

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additional credit over the 1 to 1 ratio. A judge can, however give less than 1 to 1 credit, including no credit, without explanation, and the exceptional circumstances do not apply to those who have violated conditions of bail or have been denied bail because of their criminal record.



are to an individual who consumes them and to society as a whole. Researchers analyzed how addictive a drug is, how it harms the human body, as well as environmental damage caused by the drug, its role in breaking up families, its economic costs, such as health care, social services and prison. Heroin, crack cocaine and methamphetamine or crystal meth, were most lethal to individuals, but considering wider social effects, alcohol, heroin and crack cocaine were deadliest. In overall harm both to individual and to society alcohol outranked all other substances.<sup>9</sup>

Of course, individuals affected by FASD are innocent of and blameless for their resultant disabilities, as alcohol affects the developing brain resulting *inter alia* in impulsiveness, memory gaps and difficulty learning from consequences and other abstractions. Yet such individuals are often misunderstood and further victimized by society, rather than being supported, accommodated, and fully included. Hopefully, the present research can contribute incrementally to changing that landscape through study of the lives of those who struggle with FASD and insights and experiences of those who support them in their life journeys. An alcohol ban on First Nation's land was one of the Treaty promises never honoured, although included in Treaties between the Crown in Right of Canada and First Nations at the behest of the First Nations.<sup>10</sup> Reconciliation requires collaborative action to redress wrongs created through breaches of Treaty promises made in perpetuity, so eloquently expressed by First Nations treaty signatories, "for as long as the grass grows and the river flows." Such is the vision quest that impels this research.

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<sup>9</sup> David J. Nutt, Leslie A. King, and Lawrence D. Phillips, on behalf of the Independent Scientific Committee on Drugs, "Drug Harms in the UK: A Multi-criteria Decision Analysis," 2010, 376 (9752) *The Lancet*, 1558-1565.

<sup>10</sup> Although prohibitions are not always effective, the existence of an alcohol ban in the historical numbered Treaties at the behest of First Nations formally indicates their concern regarding the devastation wrought by alcohol on their peoples. The failure of the North West Mounted Police and their successors to enforce the constitutionalized treaty alcohol ban gives rise to a need for reconciliation and remedies to redress wrongs that alcohol perpetuates. The Treaties containing the alcohol bans were constitutionalized in the *Constitution Act, 1982*, being Schedule B to the *Canada Act, 1982* (U.K.), 1982, c. 11, and are therefore recognized and affirmed under s. 35.

**Indigenous Disadvantage and Despair: An Evaluation of Recent Strategies and Alternatives**

**Healing and Transformation, Pluralism and Reconciliation: *Ne wah kuma a tik***

**by Rae Mitten**

**and the Circle of Elders, Parents and Individuals  
with Fetal Alcohol Spectrum Disorder (FASD)  
who Guided the Research Journey**

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## **1. Guiding Principle for Overcoming Indigenous Disadvantage: Collaborative Strategies, Respectful of Indigenous Autonomy and Self-determination**

Among approaches to overcoming Indigenous disadvantage, the underpinning principle of most successful approaches is encapsulated in a Lakota proverb: “Tell me and I will listen. Show me and I will understand. Involve me and I will learn.”<sup>1</sup> Rather than being imposed from outside, strategies or interventions are best developed collaboratively, respecting Indigenous autonomy and self-determination *ab initio*. In place of colonial power, control, and coercion, emancipatory approaches entail building relationships and opening communication at the grass roots level. Privileging grass roots discourse in the colonial or post-colonial context resonates with Lyotard’s priority of the local-narrative over the meta-narrative as a model of discourse neither created nor reinforced by dominant power structures.<sup>2</sup> Habermas, more currently, views colonization as an ongoing, universal process of detaching power from family, culture and institutions of the public sphere, while at the same time increasingly shifting strategic decisions to non-transparent market forces or administrative experts. As a consequence of this trend towards commercialization and bureaucratization of the public sphere, bases of action and decision are removed from scrutiny and democratic control. According to the Habermasian model, social pathologies including apathy, alienation, disintegration, demoralization, despair and social instability result from such disempowerment.<sup>3</sup> Consequently, Indigenous peoples struggling to emancipate themselves from the impact of their historic colonization by European

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1 Saskatchewan Indian Cultural Centre, “Our Languages” accessed on the world wide web December 12, 2009 at <http://www.sicc.sk.ca/heritage/sils/ourlanguages/lakota/eldersquotes/index.html>. Lakota (also referred to as Sioux by Americans) under the leadership of Chief Sitting Bull took refuge in the Wood Mountain area of western Saskatchewan, following their defeat of the United States Cavalry under General Custer at the Battle of the Little Big Horn in 1876. Some 6000 Lakota remained in Canada, but were officially considered refugees from the United States and therefore not allowed to take Treaty in Canada. A number of Lakota/Dakota First Nations Bands in Saskatchewan and Manitoba, including Wood Mountain, White Cap, Whapeton, Standing Buffalo, Canupawakpa, Sioux Valley and Dakota Plains either have commenced or are contemplating commencing legal action to establish Aboriginal title, Treaty Adhesions, or Modern Treaties like those in British Columbia, in recognition of their rights to lands in Canada which they have traditionally occupied.

<sup>2</sup> Jean-Francois Lyotard, *The Postmodern Condition: A Report on Knowledge*, accessed from the worldwide web on November 18, 2009 at <http://www.idehist.uu.se/distans/ilmh/pm/lyotard-intro.htm>, 1979 at xxiv – xxv.

<sup>3</sup> Jurgen Habermas, *The Theory of Communicative Action, Volume Two, Lifeworld and System: A Critique of Functionalist Reason*, trans. By Thomas McCarthy (Boston: Beacon Press, 1984); James Gordon Finlayson, *Habermas, A Very Short Introduction* (New York: Oxford University Press, 2005) at 56-57.

powers, must, in addition, contend with erosion of self-determination by the Leviathan of market forces of global proportions.

Reconciliation is a strategy proposed to heal rifts created by ongoing injustices of historical colonization. At the same time, reconciliation is a means to counter overwhelming forces of colonization exerted through global markets. Contemporaneous with, as well as a component of reconciliation strategies, collaboration among various Indigenous and non-Indigenous stakeholders, sharing similar concerns and values, can forge alliances of resistance to the new age colonial Colossus.

In conformance with Lyotard's model of meta-narratives or analyses, as opposed to local-narratives, the present discourse transitions from contextual meta-analysis of Indigenous disadvantage, transforming into a local-narrative at the strategy phase. The meta-analysis considers at some length the larger theoretical, historical and social context of Indigenous disadvantage from a thematic perspective, while the local-narrative situates itself within a particular Indigenous grassroots setting. In a familiar voice, utilizing a circular, narrative style evocative of that setting, the local narrative illuminates a recent collaborative, holistic strategy of overcoming disadvantage. The local strategy addresses overcoming disadvantage through fashioning culturally appropriate, collaborative responses to the needs of vulnerable individuals with Fetal Alcohol Spectrum Disorder (FASD) in a number of stakeholder communities.

Fetal Alcohol Spectrum Disorder (FASD), a symptom of disadvantage, is a constellation of characteristics caused by prenatal exposure to alcohol. These characteristics can include impaired growth, facial anomalies and pervasive cognitive and behavior problems.<sup>4</sup>

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<sup>4</sup>Albert E. Chudley, Julianne Conry, Jocelynn L. Cook et al, "Fetal Alcohol Spectrum Disorder: Canadian Guidelines for Diagnosis" (2005) CMAJ 172 (5 suppl) S1-S21. The prevalence of FAS in the United States has been reported as 1-3 per 1000 live births and the rate of FASD as 9.1 per 1000 live births. However, the most recent studies indicate much higher prevalence rates of 3 per 1000 for FAS, with the range being at least 2-7 per 1000, and 2-5 out of **100** for the full spectrum of FASD in the USA and some western European countries, based on school age children (**Philip May and Phillip Gossage, "Estimating the Prevalence of Fetal Alcohol Syndrome: A Summary," National Institute of Alcohol Abuse and Alcoholism: 2009**). There are as yet no national statistics for Canada, although studies have estimated its prevalence between 7.2 per 1000 to 101 per 1000 in small Aboriginal populations using active case ascertainment methods, while data based on referrals to a diagnostic clinic in Saskatchewan over a four year period yielded a rate of 0.589 per 1000. However, such data is neither generalizable to other communities in Canada, nor to the national level (**Michael Pacey, "Fetal Alcohol Syndrome & Fetal Alcohol Spectrum Disorder Among Aboriginal Peoples, A Review of Prevalence," National**

## 2. Undoing the Legacy of Colonial Practices such as the Fur and Whiskey Trade and Residential Schools

After contact and during colonization, Europeans introduced distilled alcohol globally to Indigenous peoples. Through the fur and whiskey trade in North America, hand in hand with conquest and trade in precious metals in Spanish America, via the wine industry in South Africa, and in Oceania by way of European sailor's *grog*, alcohol was used by Europeans to colonize and control Indigenous populations.<sup>5</sup> Alcohol and its companion disability, Fetal Alcohol Spectrum Disorder or FASD, caused by prenatal exposure to alcohol, were not endemic to Indigenous communities. In fact, before contact, no distilled alcohol existed in such societies. Wine produced by fermentation was intended for ceremonial use, as was the custom with tobacco. Distilled alcohol was introduced to North America through the whiskey trade to facilitate the lucrative fur trade, while a contributing joint causal factor in Aboriginal<sup>6</sup> communities was the Indian Residential School System. Such schools played a role in the intergenerational loss of parenting skills, resulting in survivors turning to substances to ease pain of separation from family, community, culture and language.<sup>7</sup>

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**Aboriginal Collaborating Centre for Aboriginal Health: 2009).** Experiential evidence for FASD's existence is widespread, however access to diagnosis and national reporting mechanisms are barriers to national data collection.

<sup>5</sup> World Health Organization, *Alcohol Policy in Developing Societies: A Public Health Approach* (Geneva: WHO, 2002); Kenneth R. Warren & Brenda G. Hewitt, National Institute on Alcohol Abuse and Alcoholism, National Institutes of Health, "Fetal Alcohol Spectrum Disorders: When Science, Medicine, Public Policy and Laws Collide" (2009) 15 *Developmental Disabilities Research Reviews* 170.

<sup>6</sup> "Indigenous" is an international law term, whereas "Aboriginal" is the term used in the *Constitution Act, 1982*, being Schedule B to the *Canada Act 1982* (UK), 1982, c.II. Under s. 35(2) of the *Constitution Act, 1982*, the Aboriginal peoples of Canada include the Indian, Inuit and Métis peoples of Canada. However, Indian people usually prefer to be known as First Nations.

<sup>7</sup> Caroline L. Tait, *Fetal Alcohol Syndrome Among Canadian Aboriginal People in Canada: Review and Analysis of the Intergenerational Links to Residential Schools* (Ottawa: Aboriginal Healing Foundation, 2003); *Canada, Report on the Royal Commission on Aboriginal Peoples, vol. 1, Looking Forward Looking Back, Part One The Relationship in Historical Perspective, and Part Two False Assumptions and a Failed Relationship*, Ottawa: Supply and Services Canada, 1996.

FASD affects communities globally, tending to be prevalent where poverty, racism, gender issues,<sup>8</sup> and other forms of oppression abound. The highest known prevalence of FASD is in the winelands of the Western Cape of South Africa,<sup>9</sup> where Blacks were used as colonial slaves, and after emancipation, as low paid workers in vineyards and fruit farms. Part of their meager salaries consisted of dregs referred to as “tots” or “dops,” hence the system became known as the “tot system” or “dop system.” With wine the staple drink throughout the life cycle, intergenerational FASD is common there. Blacks also had to contend with a form of racial segregation known as apartheid, modeled on Canada’s Indian reserve and pass systems,<sup>10</sup> notwithstanding that geographic and racial segregation were embedded in the global colonial context. Apartheid evolved gradually, becoming official policy after the election of the Afrikaner Nationalist Party in 1948, lasting until the multi-racial election of the African National Congress in 1994, led by Nelson Mandela.<sup>11</sup> Though the tot system was banned in 1960, enforcement against abuse is sporadic even in the post-Apartheid era.<sup>12</sup> Even if the ban is

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<sup>8</sup> Women tend to experience more poverty, violence and oppression than do males. In South Africa, female black slaves were often also sexual slaves of the white male plantation owners, giving rise to “coloured” or “mixed-race” people, who also served as slaves and later as workers. Sexual assaults against girls and women are still prevalent today as is prostitution, a means of survival among the poor. In some cultures in Africa certain kinds of violence against women is sanctioned by custom or religion, such as the practice of Female Genital Mutilation (FGM) or female circumcision.

<sup>9</sup> Philip A. May, Lesley Brooke, J. Phillip Gossage, Julie Croxford, Colleen Adnams, Kenneth L. Jones, Luther Robinson and Denis Viljoen, “Epidemiology of Fetal Alcohol Syndrome in the South African Community in the Western Cape Province” (2000) 90 Am. J. of Public Health 1905; Philip A. May & J. Phillip Gossage, “Estimating the prevalence of Fetal Alcohol Syndrome: A Summary” (2009) National Institute on Alcohol Abuse and Alcoholism, accessed on Dec. 16, 2009, from the worldwide web at <http://pubs.niaa.gov/publications/arh25-3/159-167.htm>.

<sup>10</sup> William M. Dobell, “A Partner in Africa? Canada and Post-Apartheid South Africa” (1998) 5:2 Canadian Foreign Policy Journal 59 at 65-76, based on documents provided by the High Commission of the Republic of South Africa (RSA); Heather Smith, “Stories we Have Not Been Told: The Indigenous Voice in Canadian Foreign Policy,” Abstract of Paper presented at the annual meeting of the ISA’s 49<sup>th</sup> Annual Convention, Bridging Multiple Divides, San Francisco, CA: March 26, 2008; Ron Bourgeault, “Canadian Indians: The South Africa Connection” (1988) 21:8 Canadian Dimension 6 at 7-8; Palmer Patterson, “The Colonial Parallel: A View of Indian History” (1971) 18:1 Ethnohistory 1 at 7-8. On the positive side, after 1994, RSA modeled their governance and court structure on Canada’s, including modeling their *Bill of Rights* on the *Canadian Charter of Rights and Freedoms*.

<sup>11</sup> Anton D. Lowenberg and William H. Kaempfer, *The Origins and Demise of South African Apartheid, A Public Choice Analysis* (Ann Arbor: The University of Michigan Press, 2001) p. 2 and p. 249.

<sup>12</sup> Leslie London, “The Dop system, alcohol abuse and social control amongst farm workers in South Africa: a public health challenge” (1991) 10 *Social Science & Medicine* 1407; Leslie London, “Alcohol consumption amongst South African farm workers: a challenge for post-apartheid health sector transformation” (2000) 59 *Drug*

enforced, it does not end the cycle of addiction created by the tot system. This tot system parallels the use of alcohol as a tool of colonization in North America, where, as noted, the whiskey trade evolved after contact as an integral part of the fur trade. The whiskey trade greased the wheels of the fur trade, facilitating the expansion of colonization. It has been aptly termed the glue that held the British Empire together. Whiskey flowed from Europe to the colonies, and, on the return trip, furs flowed to Europe.

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and Alcohol Dependence 199; Ilana B. Crome and Yvette Glass, "The Dop system: a manifestation of social exclusion: A personal commentary on 'Alcohol consumption amongst South African farm workers: a post-apartheid challenge, by L. London 1999'" (May 1, 2000) 59 *Drug Alcohol Dependence* 207; Maggie Brady and Kristie Rendall-Mkosi, *Tackling Alcohol Problems, Strengthening Community Action in South Africa* (Cape Town, South Africa: University of the Western Cape, School of Public health: 2005) at 4-20; and Denis L. Viljoen, J. Phillip Gossage, Lesley Brooke, Colleen M. Adnams, Kenneth L. Jones, Luther K. Robinson, H. Eugene Hoyme, Kwadwo Ohene Asante, et al. "Fetal alcohol syndrome epidemiology in a South African community: a second study of a very high prevalence area" (September 2005) 66(5) *Journal of Studies on Alcohol and Drugs* 593; Kenneth R. Warren, Faye J. Calhoun, Philip A. May, prevalence of Fetal Alcohol Syndrome: A Summary" (2009) National Institute on Alcohol Abuse and Alcoholism, accessed on Dec. 16, 2009, from the worldwide web at <http://pubs.niaa.gov/publications/arh25-3/159-167.htm>.

<sup>12</sup> William M. Dobell, "A Partner in Africa? Canada and Post-Apartheid South Africa" (1998) 5:2 *Canadian Foreign Policy Journal* 59 at 65-76, based on documents provided by the High Commission of the Republic of South Africa (RSA); Heather Smith, "Stories we Have Not Been Told: The Indigenous Voice in Canadian Foreign Policy," Abstract of Paper presented at the annual meeting of the ISA's 49<sup>th</sup> Annual Convention, Bridging Multiple Divides, San Francisco, CA: March 26, 2008; Ron Bourgeault, "Canadian Indians: The South Africa Connection" (1988) 21:8 *Canadian Dimension* 6 at 7-8; Palmer Patterson, "The Colonial Parallel: A View of Indian History" (1971) 18:1 *Ethnohistory* 1 at 7-8. On the positive side, after 1994, RSA modeled their governance and court structure on Canada's, including modeling their *Bill of Rights* on the *Canadian Charter of Rights and Freedoms*.

<sup>12</sup> Anton D. Lowenberg and William H. Kaempfer, *The Origins and Demise of South African Apartheid, A Public Choice Analysis* (Ann Arbor: The University of Michigan Press, 2001) p. 2 and p. 249.

<sup>12</sup> Leslie London, "The Dop system, alcohol abuse and social control amongst farm workers in South Africa: a public health challenge" (1991) 10 *Social Science & Medicine* 1407; Leslie London, "Alcohol consumption amongst South African farm workers: a challenge for post-apartheid health sector transformation" (2000) 59 *Drug and Alcohol Dependence* 199; Ilana B. Crome and Yvette Glass, "The Dop system: a manifestation of social exclusion: A personal commentary on 'Alcohol consumption amongst South African farm workers: a post-apartheid challenge, by L. London 1999'" (May 1, 2000) 59 *Drug Alcohol Dependence* 207; Maggie Brady and Kristie Rendall-Mkosi, *Tackling Alcohol Problems, Strengthening Community Action in South Africa* (Cape Town, South Africa: University of the Western Cape, School of Public health: 2005) at 4-20; and Denis L. Viljoen, J. Phillip Gossage, Lesley Brooke, Colleen M. Adnams, Kenneth L. Jones, Luther K. Robinson, H. Eugene Hoyme, Kwadwo Ohene Asante, et al. "Fetal alcohol syndrome epidemiology in a South African community: a second study of a very high prevalence area" Denis L. Viljoen et al. "Fetal Alcohol Syndrome: An International Perspective" (May Supplement 2001) 25(5) *Alcoholism: Clinical & Experimental Research* 202S; Jake McKinstry, "Using the past to step forward: Fetal Alcohol Syndrome in the Western Cape Province of South Africa" (July 2005) 95(7) *American Journal of Public Health* 1097.

Chief Crowfoot, ~1830-1890, leading Blackfoot and Treaty 7 Negotiator, vanquished many enemies, but alcohol abuse among his people was one enemy he could not defeat. Crowfoot struggled valiantly to ward off devastation wrought by alcohol, cooperating with the newly formed North West Mounted Police (NWMP) in driving whiskey traders from Montana south across the Medicine Line.<sup>13</sup>

. . .The advice given me and my people has proved to be very good. If the police did not come to the country, where would we all be now? Bad men and whiskey were killing us so fast that very few, indeed, of us would have been left today. The police have protected us as the feathers of a bird protect it from the frost of winter. I wish them all good, and trust that all our hearts will increase in goodness from this time forward. I am satisfied.

I will sign the Treaty.<sup>14</sup>

This mutually beneficial relationship with the nascent NWMP, under the trusted leadership of Colonel James McLeod (*Stamixotokon*), convinced Crowfoot to sign Treaty 7 in 1877, despite prescient misgivings about the impact the influx of white settlers would have on the supply of buffalo, as well as the impact on the taking of his people's best land and resultant loss of their livelihood and nomadic way of life. However, Crowfoot saw no alternative as settlement was advancing rapidly.<sup>15</sup>

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<sup>13</sup> Hugh A. Dempsey, *Crowfoot, Chief of the Blackfeet* (Edmonton: Hurtig Publishers, 1976) at 73-81; Alberta Online Encyclopedia at [http://www.abheritage.ca/alberta/en/fn\\_metis/crowfoot\\_bio.html](http://www.abheritage.ca/alberta/en/fn_metis/crowfoot_bio.html). Note that the Medicine Line is the 49<sup>th</sup> parallel, the border between Canada and the United States. The Indians considered that there was good medicine to the north of the line, and Long-knives and other forms of bad medicine to the south. The name, "Long-knives" referred to American soldiers who used long swords or sabres in Indian wars, similar to those utilized during the American Civil War.

<sup>14</sup> *Ibid.* at 103. Hugh A. Dempsey, *Crowfoot, Chief of the Blackfeet* (Edmonton: Hurtig Publishers, 1976) at 103; Alexander Morris, *The Treaties of Canada with the Indians of Manitoba and the North-West territories: including the negotiations on which they were based, and other information related thereto* (Saskatoon: Fifth House, c1991) at 272. Crowfoot's eloquent words, spoken and recorded at the time of the signing of Treaty 7, epitomize the spirit of reconciliation that the Treaties of the late 19<sup>th</sup> century represented, culminating in the inclusion of all Indian Treaties in the repatriation of the Constitution in the late 20<sup>th</sup> century.

<sup>15</sup> *Ibid.* at 103-107.



### 3. Impact of Colonial Legacy on Women and Children

Contemporaneously with the spread of alcohol, colonial interventions often focused on women and children. Removal of traditional status from Indigenous women when they married out, as well as from their children, state apprehension of children into residential schools and foster homes, related stigmatization, marginalization, victimization, even detention of Indigenous women and their progeny resulted. Of particular concern has been the justice system as Indigenous people remain disproportionately represented there.<sup>16</sup> Those affected by FASD, without accommodation for their cognitive disabilities, end up, by default, in the justice system.<sup>17</sup> The rate of incarceration of women, particularly Aboriginal women is growing.<sup>18</sup> Typically, women's drinking has been the focus of blame for Fetal Alcohol Spectrum Disorder, without acknowledgement of many other contributing, causal factors, such as poverty, racism, marginalization, gender discrimination and violence against women.<sup>19</sup> Many women become single parents struggling alone to raise children who may have disabilities such as FASD. If they falter, their children are apprehended and the cycle continues.<sup>20</sup> However, the prospects for

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<sup>16</sup> Office of the Correctional Investigator, *Good Intentions, Disappointing Results: A Progress Report on Federal Aboriginal Corrections*, 2009: [http://www.legalresourcecentre.ca/sites/default/files/SapersReport11\\_09.pdf](http://www.legalresourcecentre.ca/sites/default/files/SapersReport11_09.pdf) at p. 5 and 18. In 1997 Aboriginal people constituted 3 % of the population of Canada and yet amounted to 12% of all federal inmates. In 2007-8, 17.3% of the total federal offender population was Aboriginal compared to being 4% of the Canadian adult population. The overall incarceration rate of Aboriginal Canadians is almost nine times higher than the rate for non-Aboriginal people. Aboriginal incarceration rates are often related to substance abuse, intergenerational abuse, residential schools, low levels of education, employment and income, and substandard housing and health care. Compared to non-Aboriginal offenders, they are younger, more inclined to have gang affiliations, and to have more health problems, including FASD and mental health issues. Aboriginal offenders are disproportionately assessed as high need and high risk on most criteria, due, in large part, to a social history of disadvantage and discrimination.

<sup>17</sup> *Ibid.* at p. 20 and 32. Ten to 12 per cent of the prison population have significant diagnosed mental illnesses. Awareness is gained every day around fetal alcohol syndrome and the number of offenders who are, in fact, brain-injured as a result of fetal alcohol disorders. While FASD has clearly been acknowledged as a significant mental health factor disproportionately affecting Aboriginal offenders for at least a decade, an FASD assessment and diagnostic protocol for Corrections Canada has yet to be completed and implemented. Absent adequate protocols to diagnose offenders with FASD, it is difficult to apply *Gladius* or restorative principles to their classification, segregation and parole decisions.

<sup>18</sup> *Ibid.* at p. 5. Aboriginal women represent 33.1% of all women in federal penitentiaries.

<sup>19</sup> Amnesty International, *Stolen Sisters: Discrimination and Violence Against Indigenous Women in Canada* (Ottawa, ON: 2004).

<sup>20</sup> Office of the Auditor General, *May 2008 Report of the Auditor General of Canada, Chapter 4 First Nations Child and Family Services Program—Indian and Northern Affairs, Canada* at [http://www.oag-bvg.gc.ca/internet/English/parl\\_oag\\_200805\\_04\\_e\\_30700.html#hd3b](http://www.oag-bvg.gc.ca/internet/English/parl_oag_200805_04_e_30700.html#hd3b). There are more First Nations children in the

children and youth in foster care are not good. They are 17 times more likely to be hospitalized for mental health issues than the general population. By the age of 21 years, 41% of children and youth in care have been in contact with the justice system, compared to 6.6% of the general population in that age group. Seventy-two per cent of those in contact with the justice system have been reported, while in school, to have had a serious mental illness, behavioral problems or Fetal Alcohol Spectrum Disorder.<sup>21</sup> Assimilative practices and policies of dominant colonial legal orders continue to have the greatest impact on these most vulnerable, Aboriginal women and their children, rendering adverse effects intergenerational and ongoing, creating a perfect storm of disadvantage.

#### **4. Constitutionalized Treaties and Legal Pluralism**

In late nineteenth century western Canada, Numbered Treaties were signed with Indigenous peoples enabling sharing of land and resources, in exchange for *inter alia* mutual recognition, education, farm supplies and instruction, health care, relief from pestilence and famine, and an alcohol ban on Indigenous lands. The alcohol ban in Treaties 2 to 6 was included at the insistence of Indigenous leaders as introduction of distilled alcohol had led to many traumas. One enduring effect has been the legacy of intergenerational Fetal Alcohol Spectrum

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care of child welfare today in Canada than were forced to live in residential schools at the peak of their operation. Today, First Nations children are 8 to 10 times more likely to go into Foster Care than other children. Between 1997 and 2001 there was a rapid increase in the number of on-reserve children placed in care. Over this period, the total number of children in care increased by 65 percent, from 5,340 to 8,791 children. At the end of March 2007, there were about 8,300 on-reserve children in care, a little over 5 percent of all children aged from 0 to 18 living on reserves. This proportion is almost eight times that of children in care living off reserves. The federal government provides 22% less funding per capita for child welfare care on reserves than other children receive. Some First Nations note that the number of First Nations children born addicted to drugs is increasing. This causes strains on child welfare resources as these children require special medical or social services that are not always covered by existing funding. In addition, First Nations children receive substantially less elementary and secondary school funding from the federal government per capita than do other Canadians children who are largely funded by the provinces.

<sup>21</sup> Representative for Children and Youth of British Columbia, *Kids, Crime and Care, Health and Well-being of Children in Care: Youth Justice Experiences and Outcomes* (Victoria, BC: A Joint Project of the Representative for Children and Youth and the Office of the Provincial Health Officer, 2009).

Disorder (FASD), resulting from prenatal exposure to alcohol.<sup>22</sup> Treaty Alcohol Ban clauses, however, have never have been properly enforced by police. Treaty 6, considered the most sophisticated of the numbered treaties, included *inter alia* a medicine chest or health care clause, relief in the event of famine or pestilence,<sup>23</sup> and an education clause. Assimilative pressures increased thereafter and in subsequent treaties neither alcohol ban nor medicine chest clauses were included, while education clauses, though included, were considerably diminished. These various treaty provisions were part of the “bounty and benevolence” promised to the Indians, in order, not only to acquire their consent to surrender to the Crown 121,000 square miles of Aboriginal title land in present day Alberta and Saskatchewan, and to facilitate immigration and white settlement, but also to ensure the peace and good will of the Indians in Treaty 6 territory when these settlers did arrive. *R. v. Wolfe*<sup>24</sup> upheld the validity of the Treaty 6 Alcohol Ban in the context of a wildlife police sting operation which improperly used alcohol on reserve as an enticement, and in so doing the Court accepted statistical evidence of the pandemic of alcohol problems among Indian peoples.

## 5. Reconciliation Between the Crown and Aboriginal Peoples

Treaties, constitutionalized in the *Canada Act*, 1982, have resulted in a line of jurisprudence upholding the existence of Aboriginal and Treaty rights, in principle, albeit not always holding that particular cases meet the difficult and costly evidentiary burdens. Due to these difficulties, courts urge resolution of Aboriginal and Treaty rights through negotiation rather than litigation.<sup>25</sup> Consequently, a new pluralism recognizing an Aboriginal legal order has

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<sup>22</sup> *Supra* notes 4 and 7.

<sup>23</sup> Small Pox and Tuberculosis were epidemics that devastated the Indigenous population which had no immunity to these diseases introduced by colonization.

<sup>24</sup> [1995] S. J. No. 502 (Sask. C.A.), leave to appeal to SCC dismissed. [*Wolfe*]

<sup>25</sup> *R. v. Sparrow*, [1990] 1 S.C.R. 1075; *R. v. Van der Peet*, [1996] 2 S.C.R. 507; *R. v. Marshall*, [1999] 3 S.C.R. 456; *R. v. Marshall*, [1999] 3 S.C.R. 533; *Delgamuukw v. British Columbia*, [1997] 3 S.C.R. 1010; and *R. v. Marshall*; *R. v. Bernard*, [2005] 3 S.C.R. 220.

been efficacious in the process of building healthy lives and strong relationships. In *Mitchell*, Justice Binnie, citing findings of the *Royal Commission on Aboriginal Peoples*,<sup>26</sup> gathered from extensive, broad-based public consultations across Canada, concluded that Aboriginal and non-Aboriginal peoples have a shared sovereignty within Canada:

...[T]he Royal Commission considered it to be "essential that any steps toward self-government be initiated by the aboriginal group in question and "respond to needs identified by its members" (*Partners in Confederation: Aboriginal Peoples, Self-Government and the Constitution* (1993), at p. 41). It rejected the "one size fits all" approach to First Nations' self-governing institutions in favour of a negotiated treaty model. The objective, succinctly put, is to create sufficient "constitutional space for aboriginal peoples to be aboriginal": D. Greschner, "Aboriginal Women, the Constitution and Criminal Justice", [1992] U.B.C. L. Rev. (Sp. ed.) 338, at p. 342. See also J. Borrows, "Uncertain Citizens: Aboriginal Peoples and the Supreme Court" (2001), 80 Can. Bar Rev. 15, at p. 34. The Royal Commission Final Report states:

Section 35 does not warrant a claim to unlimited governmental powers or to complete sovereignty, such as independent states are commonly thought to possess. As with the federal and provincial governments, Aboriginal governments operate within a sphere of sovereignty defined by the constitution. In short, the Aboriginal right of self-government in section 35(1) involves circumscribed rather than unlimited powers.

It is unnecessary, for present purposes, to come to any conclusion about these assertions. What is significant is that the Royal Commission itself sees aboriginal peoples as full participants with non-aboriginal peoples in a shared Canadian sovereignty. Aboriginal peoples do not stand in opposition to, nor are they subjugated by, Canadian sovereignty. They are part of it.<sup>27</sup>

Affirming a process of reconciliation between Aboriginal and Non-Aboriginal peoples as they attempt to share this land and its governance, Canada's Chief Justice Lamer in *Delgamuukw* noted:

Finally, this litigation has been both long and expensive, not only in economic but in human terms as well. By ordering a new trial, I do not necessarily encourage the parties to proceed to litigation and to settle their dispute through the courts. As was said in *Sparrow*, at p. 1105, s. 35(1) "provides a solid constitutional base upon which subsequent negotiations can take place". Those negotiations should also include other aboriginal nations which have a stake in the territory claimed. Moreover, the Crown is under a moral, if not a legal, duty to enter into and conduct those negotiations in good faith. Ultimately, it is through negotiated settlements, with good faith and give

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<sup>26</sup> Canada. Royal Commission on Aboriginal Peoples. *Partners in Confederation: Aboriginal Peoples, Self-Government, and the Constitution* (Ottawa: The Commission, 1996).

<sup>27</sup> *Mitchell v. Canada (Minister of Natural Resources)*, [2001] S.C.R. 911, at para. 133-5.

and take on all sides, reinforced by the judgments of this Court, that we will achieve what I stated in *Van der Peet*, supra, at para. 31, to be a basic purpose of s. 35(1) – "the reconciliation of the pre-existence of aboriginal societies with the sovereignty of the Crown".

Let us face it, we are all here to stay.<sup>28</sup>

Reconciliation of the pre-existence of Aboriginal societies with the sovereignty of the Crown seems to imply an end to the cycle of colonization, dominance and oppression. To employ terms from the liberal enlightenment, reconciliation entails an end to epistemologies of ‘othering,’ involving dichotomies of difference, such as ‘self’ and ‘other’, ‘master’ and ‘slave’, or ‘civilized’ compared to ‘savage’<sup>29</sup> However, the Court’s conceptualization of reconciliation falls short of recognizing the sovereignty of pre-existing Aboriginal societies comparable to the sovereignty of Canada and the provinces, albeit operating within a sphere of *suis generis* sovereignty and self-government as defined by s. 35 of the *Constitution Act, 1982*.<sup>30</sup> Moreover, the Court’s use of reconciliation as a basis to justify Crown infringement or limiting of Aboriginal rights in *Sparrow*,<sup>31</sup> *Van der Peet*<sup>32</sup> and *Gladstone*,<sup>33</sup> actually impedes any process of good faith negotiation among equals that is at the core of reconciliation. Aboriginal peoples may come to view ‘reconciliation’ as another colonial device to empower the non-Aboriginal majority in depriving them of lands, resources and rights without their consent.<sup>34</sup> This is especially true as the grounds for justification of such infringement have been extensively broadened in *Van der Peet*<sup>35</sup> and *Gladstone*<sup>36</sup> to ultimately include “objectives of sufficient importance to the broader community as a whole”.<sup>37</sup> A disconnect exists between the ideal of reconciliation as a negotiated bridge or middle-ground between Aboriginal and non-Aboriginal peoples presented in the

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<sup>28</sup> *Delgamuukw v. British Columbia*, [1997] 3 S.C.R. 1010 at para. 186.

<sup>29</sup> Thomas Hobbes, *Leviathan* [1651] Edited by Richard Tuck (Cambridge: Cambridge University Press, 1991) at 121-129.

<sup>30</sup> Being Schedule B to the *Canada Act*, 1982 (U.K.), 1982, c.II.

<sup>31</sup> *R. v. Sparrow*, [1990] 1 S.C.R. 1075.

<sup>32</sup> *R. v. Van der Peet*, [1996] 2 S.C.R. 507.

<sup>33</sup> *R. v. Gladstone*, [1996] 2 S.C.R. 723.

<sup>34</sup> John Burrows, “Uncertain Citizens: Aboriginal Peoples and the Supreme Court” (2001), 80 *Can. Bar. Rev.* 15 at 29-36.

<sup>35</sup> *Supra* note 32. (*Van der Peet*)

<sup>36</sup> *Supra* note 33. (*Gladstone*)

<sup>37</sup> *Ibid* at para. 73. (*Gladstone*)

jurisprudence, on the one hand, and the application of this principle through costly, skewed, adversarial processes of infringement-justification under the same rubric, on the other hand.

A further court constructed bridge, to mediate the relationship between Aboriginal and non-Aboriginal peoples, is the duty to consult, engaged under the aegis of the Honour of the Crown. The duty arises when the Crown has knowledge of the existence of potential Aboriginal rights or title and contemplates conduct that might adversely affect these rights once proven. Thus, the duty to consult may be viewed as another curial manifestation of the process of reconciliation, albeit with roots in Aboriginal traditions. As the magnitude and seriousness of the impact on potential Aboriginal rights increases, so proportionately does the Crown's duty progress from mere notification, to consultation, accommodation or even compensation. Honourable dealings in good faith should be the hallmarks of the duty to consult.<sup>38</sup> The Court in *Mikisew* situates the duty to consult as follows:

The principle of consultation in advance of interference with existing treaty rights is a matter of broad general importance in the relations between aboriginal and non-aboriginal peoples. It goes to the heart of the relationship.<sup>39</sup>

Justice Lamer, in *Delgamuukw*, posited that reconciliation should be achieved through a process of good faith negotiation and compromise on both sides. Other than these general curial pronouncements encouraging a consultation-negotiation approach, a comprehensive process or model for reconciliation has not been formulated.

Although a comprehensive model is lacking, a great deal of discourse by courts and academic commentators has surrounded the interpretation and substantive meaning of the concept of reconciliation to be gleaned from the *Sparrow*,<sup>40</sup> *Van der Peet*,<sup>41</sup> *Gladstone*,<sup>42</sup> *Delgamuukw*,<sup>43</sup> *Mitchell*,<sup>44</sup> *Haida*,<sup>45</sup> *Taku River Tlingit*<sup>46</sup> and *Mikisew Cree*<sup>47</sup> line of Supreme

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<sup>38</sup> *Haida Nation v. British Columbia (Minister of Forests)*, [2004] 3 S.C.R. 511.

<sup>39</sup> *Mikisew Cree First Nation v. Canada (Minister of Canadian Heritage)*, [2005] 3 S.C.R. 388 at para. 3.

<sup>40</sup> *Supra* note 31. (*Sparrow*)

<sup>41</sup> *Supra* note 32. (*Van der Peet*)

<sup>42</sup> *Supra* note 33. (*Gladstone*)

<sup>43</sup> *Supra* note 28. (*Delgamuukw*)

<sup>44</sup> *Supra* note 27. (*Mitchell*)

<sup>45</sup> *Supra* note 38. (*Haida Nation v. British Columbia (Minister of Forests)*, [2004] 3 S.C.R. 511.)

<sup>46</sup> *Taku River Tlingit First Nation v. British Columbia (Project Assessment Director)*, [2004] 3 S.C.R. 550.

<sup>47</sup> *Supra* note 39. (*Mikisew Cree First Nation v. Canada (Minister of Canadian Heritage)*, [2005] 3 S.C.R. 388.)

Court cases.<sup>48</sup> In *Mitchell*, citing and concurring with Professor John Burrows, Justice Binnie in *obiter* emphasizes the positive aspect of pluralism created by the presence of both Aboriginal and non-Aboriginal peoples in Canada, suggesting by implication that Aboriginal rights should not be viewed as diminishing, but rather enhancing, rights of other citizens:

I agree with [John] Burrows that accommodation of aboriginal rights should not be seen as a zero-sum' relationship between minority rights and citizenship, as if every gain in the direction of accommodating diversity comes at the expense of promoting citizenship.<sup>49</sup>

The roots of the concept of reconciliation are redolent of South Africa's attempt to deal with the aftermath of the oppressive Apartheid regime through a process of "Truth and Reconciliation,"<sup>50</sup> now being attempted in Canada to deal with injustices of an oppressive colonial legal order and its assimilative residential school system.<sup>51</sup> Aboriginal children were removed from their homes, communities, language, and culture and placed in residential schools where emotional, physical, and sexual abuses were not uncommon.<sup>52</sup> Moreover, Truth and Reconciliation processes are akin to Aboriginal restorative justice concepts and practices, where the ideal is to restore the harmony of the community that a wrong has disrupted.<sup>53</sup> In other words, truth and reconciliation processes can serve as means of healing and peace-making through ending the cycle of harm and retribution. The parties, then, can move on together to create social justice through both fuller implementation of the Treaties that assimilative

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<sup>48</sup> Dwight Newman, "Reconciliation: Legal Conception(s) and Faces of Justice" 80, John D. Whyte (Ed.) *Moving Toward Justice: Legal Traditions and Aboriginal Justice* (Saskatoon: Purich Publishing Limited: 2008). Professor Newman summarizes and synthesizes the jurisprudence on the concept of reconciliation.

<sup>49</sup> *Supra* note 27 at para. 164. *Mitchell* quotes John Burrows who was actually himself citing Will Kymlicka & Wayne Norman, eds. *Citizenship in Diverse Societies* (New York: Oxford University Press, 2000) at p. 39. As noted by Dwight Newman in his article, *Supra* note 47, where he comments on errors in Supreme Court citation which compound difficulties in probing intellectual influences on the Court.

<sup>50</sup> *Promotion of National Unity and Reconciliation Act*, No. 34 of 1995, Republic of South Africa.

<sup>51</sup> *Indian Residential Schools Settlement Agreement* (Court Approved) Schedule N: *Mandate for the Truth and Reconciliation Commission*, at [http://www.residentialschoolsettlement.ca/SCHEDULE\\_N.pdf](http://www.residentialschoolsettlement.ca/SCHEDULE_N.pdf). Through agreement with the Parties, The Government of Canada, The Assembly of First Nations, The Métis National Council, The Inuit Tapiriit Kanatami, The Congress of Aboriginal Peoples, The Aboriginal Healing Foundation, Indian Residential School Survivors Society, and others, May 10, 2006, Court Approved.

<sup>52</sup> Deborah Chansonneuve, *Reclaiming Connections: Understanding Residential School Trauma Among Aboriginal People* (Ottawa: Aboriginal Healing Foundation, 2005).

<sup>53</sup> *R. v. Gladue*, [1999] 1 S.C.R. 688.

processes disrupted and through utilization of Treaty processes as a platform for transformative change.

However, a relevant Aboriginal perspective of reconciliation is neither a well represented, nor a determining factor in the jurisprudence, or both, at least outside of the criminal law context of restorative justice. A Plains Cree Aboriginal perspective of the broader process of reconciliation envisions working together in the spirit of the treaty relationship, constitutionalized under s. 35.<sup>54</sup> Ideally, reconciliation in the spirit of the treaty relationship should be attempted in partnership with Aboriginal communities, through processes developed in consultation with Aboriginal people concerned. Furthermore, model Treaty processes may best be renewed initially as local rather than meta-narratives, in order to perfect strategies of eliminating hierarchies and inequalities before moving onto larger forums where hegemonies are more pronounced and resistant to change.<sup>55</sup>

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<sup>54</sup> Harold Cardinal and Walter Hildebrandt, *Treaty Elders of Saskatchewan: Our Dream is That Our Peoples Will One Day Be Clearly Recognized as Nations* (Calgary: University of Calgary Press, 2000). This book examines the treaty relationship in Saskatchewan from past, present and future perspectives. Over 160 Elders contributed their understandings of the treaty relationship. Some of the Elders comments appear in print for the first time in this book.

<sup>55</sup> The present author notes that for the most vulnerable, larger forums often neither address nor serve to meet their needs and any general benefits derived are slow to trickle down. Many voices, particularly vulnerable voices, tend to be lost when forums become larger. An example of dominance co-opting larger narratives is addressed by Andries Du Toit, Sandra Kruger and Stefano Pointe in “Deracializing Exploitation? ‘Black Empowerment in the South African Wine Industry’” (2008) 8(1) *Journal of Agrarian Change* 6-32. The South African wine industry used the discourse and practice of Black Economic Empowerment (BEE) to avoid more transformative, structural changes such as land redistribution, import boycotts, improved working conditions, and employment security for grape pickers. Despite organizing large, publicized consultative forums dominated by diverse Black voices, a few key Black urban elites were co-opted by the dominant white Afrikaner wine industry. By ideological sleights of hand, these self-serving parties contained and captured the transformation agenda for their own benefit. Under brands similar to Black Empowerment or Fair Trade, they were able to market their wines in European markets that had boycotted South African wines under Apartheid. Root causes of inequity were sidestepped and remain unaddressed. Instead, the dominant parties used the alleged “transformative” agenda to brand their endeavours as progressive and worthy of acclaim, producing a “halo effect” for them, while at the same time blaming the poor Blacks for systemic alcoholism, fetal alcohol syndrome, lack of education and inability to respond to the new agenda. Attempts at monitoring BEE initiatives through a BEE Charter, Codes of Conduct, Scorecards and Auditing, shifted accountability away from the public domain to a managerial, technocratic domain, thereby further marginalizing any grassroots involvement in decision-making. Similar scenarios come to mind globally, where initiatives proposed to assist marginalized Indigenous people become enterprises that benefit only members of the dominant classes. Initiatives to challenge the impoverishment of the many became strategies to benefit or enrich the favoured few. Du Toit concludes that the critical gaze should never be turned away from addressing underlying power relations, whether based on race, class, gender, employment security or other factors.



From a First Nation's perspective, Sakej Henderson, in a recent analysis of the underpinnings, purpose and nature of reconciliation in a pluralist context, recommends a dialogical approach to consultation, negotiation, and all facets of the governance relationship between Aboriginal and non-Aboriginal peoples in Canada. He sets forth a number of general principles of dialogical governance, considering it "an ongoing process of constitutional governance monitored by judicial review".<sup>56</sup> The manifestations of dialogical relationship include negotiation, consultation, accommodation, litigation, and reconciliation, "creating a shared cognitive multiplicity without cognitive walls or barriers."<sup>57</sup> Tactics which are internal to the colonial narrative such as quibbling, avoidance and abeyance should have no place in good faith, innovative, consensus-building processes mandated by the legal pluralism created in the Treaties and constitutionalized in the *Canada Act*, 1982.<sup>58</sup> Trans-systemic understanding and respect for diversity require openness, and deep or prismatic listening, in place of familiar closure.<sup>59</sup> Stories from the oral tradition, spirituality, ceremonies, and dreams help transcend the dominant or familiar through engagement in dialogic cycles of vision, disclosure and response, followed by deep discussion, honest reflection and committed, cooperative action. Reconciliation is deeper than the "getting to yes" of conventional dispute resolution as reconciliation uncovers shared, pluralistic meanings in a context of convergence and new relationships from which transformative agreements can emerge. In a pluralistic, transcendent framework, grassroots movements of Aboriginal peoples can become liberating, interactive sources of dynamic governance and constitutional dispute resolution.<sup>60</sup>

A specific process in the spirit of renewed Treaty relationship is being attempted at the grass roots level in one case to be considered, that of an evolving search for effective approaches to FASD, to be discussed in Section IV. Cree possesses a word for the transcendent, dynamic pluralism referred to herein as the foundation of Treaty relationship, *Ne wah kuma ka tik*. *Ne wah kuma ka tik* translates as "All my Relations," and connotes the ideal of both reconciliation

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<sup>56</sup> Sakej Y. Henderson, "Dialogical Governance: A Mechanism of Constitutional Governance" (2009) 72 Sask. L. Rev. 29 at para. 62.

<sup>57</sup> *Ibid.* at para. 64.

<sup>58</sup> *Ibid.* at para. 4.

<sup>59</sup> *Ibid.* at para. 65.

<sup>60</sup> *Ibid.* at para. 67 and 92-95.

and unity among human kind as well as with the natural world. Significantly, *Ne wah kuma ka tik* refers to the unity of all peoples, as we are all related in an intimate and meaningful way in sharing this earth, especially when we work together in the spirit of the Treaties. *Ne wah kuma ka tik* is an ancient protocol used at the beginning and end of ceremony and is deeply spiritual in nature. It encompasses the living (humans, animals and plants), the non-living environment, our ancestors in the spirit world, as well as future generations. When we are in relationship with one another through family, community, treaty making, governance, teaching, and research, in a profound sharing and working together for the purpose of enhancing the good of one another, then such endeavours are intrinsically ceremonial and spiritual in nature, enabling us to envision and honour the good in one another and in the earth and all things in it. Self-interest yields to altruism and sharp dealing to honour and integrity, as the Creator is called through Ceremony to be a part of the process.

## **6. A Local Narrative: Case Study of a Specific Grass Roots Strategy, Involving Research as Reconciliation, Collaboration and Bridge-Building**

When faced with the challenges that FASD can present, how can individuals living with FASD, their parents, families, communities, courts and different levels of government best respond? Such challenge can be a wake-up call or turning point for all involved as we<sup>61</sup> gradually begin to realize that a significant difference cannot be made acting alone. In responding to FASD, life's parameters expand as we reach out to other people, groups and communities, nationally and even globally, in search of ongoing solutions. Elders speak of *miyo-pimatisiwin* and *miyo-wichihtowin*, traditional Cree teachings meaning good health, good life and good relations with others. Shared vulnerabilities unite those of us with FASD in family and community in that good way of which the Elders speak, and together we are stronger in our

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<sup>61</sup> When discussing the specific project in Section VI, the narrative becomes more localized and personal, including utilization of the first person.

search for full, healthy lives for our children.<sup>62</sup> We learn from each other, build bridges, navigate rapids, stand together to overcome barriers and to become, hopefully, a more compassionate, inclusive, and connected society. Our work is never complete in this respect but the torch is passed along . . . “Never doubt that a small group of thoughtful, committed people can change the world. Indeed, it is the only thing that ever has.”<sup>63</sup>

When commencing a study of FASD in community a decade ago, this writer was met with a wall of silence. FASD was too stigmatizing to discuss despite medical identification of the disorder.<sup>64</sup> The landscape is much different today. Parents and communities of all stripes are coming forward, seeking supports and services for children of various ages from infancy to adulthood. Non-judgmental attitudes have largely replaced blaming and shaming. Collectively, we have come to realize that all of society is complicit in the problem use of alcohol and therefore all should be involved in the solution. I now partner in community-based FASD research with a First Nations Tribal Council, a Métis Federation and an FASD Parents Network, and hold Circles with Elders, as well as with Elders and Parents. Circle methodologies were initiated in consultation with and at the suggestion of Elders. Circles provide an appropriate forum, in the first instance, to learn about conducting respectful community-based research with Elders,<sup>65</sup> and then to move forward to discuss parenting, care and teaching of children with FASD. Elders present provided ongoing support to parents and children in the Circles and thereby helped ensure a culturally appropriate, safe environment. Voices of Elders were valued, including a balance of numbers and strengths of male and female voices in the Circle. Adults living with FASD were present in these Circles, to give voice, in a respectful environment, to

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<sup>62</sup> Elizabeth Renzetti, “Vulnerability brings us Together,” *Globe and Mail*, December 26, 2008. This article is about Jean Vanier, founder of L’Arche, an international organization which creates caring communities for people with developmental disabilities.

<sup>63</sup> Margaret Mead, American Anthropologist and Author, accessed from the world wide web on Dec. 28, 2008 at [http://en.wikiquote.org/wiki/Margaret\\_Mead](http://en.wikiquote.org/wiki/Margaret_Mead).

<sup>64</sup> Kenneth L. Jones, D. W. Smith, C.N Ulleland, A.P. Streissguth, “Patterns of malformation in offspring of chronic-alcoholic mothers” (1973) *Lancet* 1, 1267-1271.

<sup>65</sup> Margaret Kovach, *Indigenous Methodologies, Characteristics, Conversations, and Contexts*, Toronto: University of Toronto Press, 2009. Bringing together views of Vine Deloria, Gregory Cajete, Marie Batiste, Willie Ermine and Shawn Wilson, Margaret Kovach emphasizes the link between Indigenous research methodology and an inclusive, relational, holistic, experiential, narrative-based world view. For research to be both ethical and valid, there must be a fit between Indigenous epistemology and the research methodology selected. Research must be done in a good way, with a sense of collective responsibility, it must decolonize and empower, rather than further exploiting Indigenous people.

what it is like to walk in their moccasins. Offerings of sacred tobacco and cloth of the four sacred colours of the Circle (red, yellow, blue and white) were consecrated by Elders in Prayer and Ceremony<sup>66</sup> and constituted traditional consent to the research process. In the Circle no hierarchies exist; every voice is of equal value, in accordance with *miyo-wichihtowin*. *Miy-Wichihtowin* is a very important principle of reconciliation, as no voices are privileged or dominant, rather all are equal. Prayer and smudging<sup>67</sup> ceremonies to commence the Circle were conducted in the Ceremonial Room of White Buffalo Youth Lodge, a location culturally familiar to participants where Elders anticipated that privacy and confidentiality of participants could be maintained more readily. All participants were seated in a Circle on the floor, grounded as close as possible to Mother Earth on whom all depend for life and sustenance.

Initially, several Elders' Gatherings or Circles, to provide guidance for the research, were held in a Tribal Council Board Room on First Nations land in an urban reserve. Elders approved the following questions about the research process and these questions framed the discussion in initial Elders Circles, guiding the development of the research methodology to be used:

- What protocols are required to respectfully access and acknowledge traditional knowledge?
- How can traditional knowledge and experience inform our study of Fetal Alcohol Spectrum Disorder? How can we approach the study from an Aboriginal perspective(s)?
- In what ways can this research be conducted respectfully and ethically? How should Aboriginal communities, agencies, families and individuals be approached?
- How can Aboriginal communities benefit from this study of Fetal Alcohol Spectrum Disorder?

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<sup>66</sup> Shawn Wilson, *Research is Ceremony: Indigenous Research Methods* (Winnipeg, MB: Fernwood Publishing, 2008).

<sup>67</sup> Sylvia McAdam (Saysewahum), Saskatchewan Indian Cultural Centre, *Cultural Teachings: First Nations Protocols and Methodologies* (Saskatoon, Saskatchewan: Saskatchewan Indian Cultural Centre, 2009) at 8-9. Various medicine plants, such as sweet grass, sages, and cedars are burned to make a smudge. Smudging is a ritual cleansing ceremony. Negative energy, feelings and emotions are lifted away with the smoke as it rises and one is prepared to enter into prayer or sacred learning.

- How can the knowledge gained about Fetal Alcohol Spectrum Disorder in this study be given back to Aboriginal communities?

In this manner, Aboriginal cultural and local knowledge was incorporated into the research methods.

A number of community research partners participated in the research, all well grounded in FASD. One community research partner, an urban Métis Federation, provides a mentoring and supported housing program for individuals with FASD, the present researcher being a member of the Supported Housing Supervisory Committee. Another research partner, the FASD Parent Support Network, of which the present researcher is a board member, advocates with government for access to FASD diagnosis for individuals of all ages, as well as for accommodation, education, awareness and supported housing across the province. This Parents Network provides a toll free hot line for parents and others, assisting with FASD- related concerns across the province. It also provides resource materials, workshops and retreats for parents and families. All of these activities build capacity in the community to enhance services, supports and advocacy for individuals with FASD and their families, which in turn may contribute to the continuity, sustainability and empowerment of families and communities. Researchers did not “parachute” in and out of these communities to gather data about FASD, rather relationships were established and ongoing partnerships in support and advocacy were developed and sustained, creating a reciprocal relationship and enhancing sharing of benefits of the research. The present researcher was one member of an interdisciplinary academic research team, comprised of six other members from fields of Education, Psychology, Medicine, Native Studies, Law and Justice. Action research models adopted for the field aspect were framed by Aboriginal perspectives, protocols and guidelines.<sup>68</sup> Many inter-positionalities existed among academic researchers and community partners, including such overlapping factors as FASD in families, First Nation and Métis identities and values, and various other nexuses. In addition to Circles, individual interviews were held with consenting parents and their children recruited from outside the Circle. A number of focus groups also were conducted with professional

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<sup>68</sup>Canadian Institutes of Health Research, *CIHR Guidelines for Health Research Involving Aboriginal People* (Canada: 2007).

groups, including members of interdisciplinary FASD diagnostic teams and other community groups. Qualitative results of these processes analyzed inductively reveal common themes as presented in Section 4, “FASD and Holistic Literacies: A Talking or Sharing Circle, *Wa-sa-cam-e-be-ke-skue*.”

A breakthrough in the climate of acceptance for parents came with the highly publicized decision of First Nations Judge Mary Ellen Turpel-Lafond,<sup>69</sup> regarding a young person with FASD who appeared in her Court. Finally, someone in authority understood what led many individuals with FASD into trouble with the law. Aspects of this disability, including impulsiveness, memory gaps, lack of cause and effect thinking, little ability to foresee or predict consequences of actions, as well as limited ability to generalize from one situation to another in order to learn from mistakes, contributed to having trouble with the law. Judge Turpel-Lafond attempted to mandate supports and services for young persons in the community, rather than relying on punishment. She was overruled on appeal.<sup>70</sup> Nevertheless, her landmark judgment functioned as a wake-up call, indicating that something was amiss in our systems as far as accommodating needs of children who daily struggle with FASD. A youth court judge who saw children with FASD face to face on a regular basis in her Court, and in Circles, and Conferences she convened, who was familiar with their background in home, school, and community, was proclaiming that our systems had failed these children from the beginning. By default they had ended up in her Court, until then undiagnosed, with their needs not addressed. Was punishment the appropriate response? She concluded not. These young persons do not learn from consequences nor comprehend why they are being punished. Therefore, sentencing principles of general or specific deterrence<sup>71</sup> will not work for them. Penal sanctions only victimize and frustrate individuals with FASD, leading to further deterioration.

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<sup>69</sup> Judge Turpel-Lafond is a member of the interdisciplinary research team.

<sup>70</sup> *R. v. L.E.K.* 2001 SKCA 48. However, due to circumstances, a challenge under s. 7 and 15 of the *Charter of Rights and Freedoms, Part 1 of the Constitution Act, 1982, being Schedule B to the Canada Act 1982 (U.K.), 1982*, c 11, was not initiated at the trial level and, therefore, could not then be utilized on appeal. The effect of such a *Charter* challenge remains moot.

<sup>71</sup> *Criminal Code*, R.S.C. 1985, c. C-46, s. 718 (b). General deterrence is aimed at deterring others from committing offences, and specific deterrence is aimed at deterring the offender from re-offending. Deterrence in this context means the same as punishment.

A parallel breakthrough occurred in 1992 when, in recognition of the growing number of cases of Fetal Alcohol Syndrome (FAS), the United States Congress mandated the Institute of Medicine (IOM) to conduct a study of Fetal Alcohol Syndrome and related birth defects. Accordingly, the Committee to Study Fetal Alcohol Syndrome was convened in 1994, comprised of experts from pediatrics, developmental psychology and neurology, obstetrics, teratology, epidemiology, sociology, substance abuse prevention and treatment, and psychiatry to carry out the study mandated. In 1996, this Committee released its comprehensive report, *Fetal Alcohol Syndrome, Diagnosis, Epidemiology, Prevention and Treatment*<sup>72</sup> with summary findings of the current state of knowledge, as well as recommendations for the future in the areas of diagnosis, prevalence, prevention and treatment.

Contemporaneously, the U. S. Centre of Disease Control and Prevention (CDC) funded Dr. Anne Streissguth's large scale, longitudinal, prospective research study, at the University of Washington Fetal Alcohol and Drug Unit, of secondary disabilities associated with Fetal Alcohol. Findings of this study demonstrated that mental health issues, school leaving (suspensions and dropouts), alcohol and drug problems, inappropriate sexual behavior, dependent living arrangements, difficulties with employment, trouble with the law and other so called secondary disabilities could accompany FASD, unless protective factors such as early diagnosis and effective interventions were in place.<sup>73</sup> Subsequently, with her colleagues, she initiated a five year study (2002-2007) of MRI, MRS and fMRI brain imaging, neuropsychological and psychiatric functioning of people with FASD, compared to healthy peers with no prenatal alcohol exposure. The purpose of the study was to non-invasively determine if neuro-abnormalities could be identified across the spectrum of FASD, as assessed using IOM four digit diagnostic code.<sup>74</sup> Results indicate that children across the spectrum of FASD have

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<sup>72</sup> Kenneth Stratton, Cynthia Howe, & Frederick Battaglia (eds.), Committee to Study Fetal Alcohol Syndrome, Institute of Medicine, *Fetal Alcohol Syndrome, Diagnosis, Epidemiology, Prevention and Treatment* (Washington, D.C.: National Academy Press, 1996).

<sup>73</sup> Ann P. Streissguth, H. M. Barr, J. Kogan and F. L. Bookstein. *Understanding the Occurrence of Secondary Disabilities in Clients with Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE), Report to the Centers for Disease Control and Prevention on Grant No. R04/CCR08515* (Tech. Report No. 96-06). Seattle: University of Washington, Fetal Alcohol and Drug Unit, 1996.

<sup>74</sup> Under the IOM Four Digit Diagnostic Code system, the FASD spectrum includes the four diagnostic categories as follows: Fetal Alcohol Syndrome (FAS) and Partial Fetal Alcohol Syndrome (pFAS) which are dysmorphic, and

structural brain alterations, not just those with full-blown FAS facial features. Also, results confirm that the FAS and pFAS facial phenotype dysmorphia<sup>75</sup> is an external biomarker for certain underlying alterations in brain structure and function. Similarly, but independent from the facial phenotype, as cognitive and behavioral dysfunction increases from mild, to moderate, to severe, the prevalence and severity of underlying structural brain alterations increases linearly, with frontal lobe, caudate and hippocampus most impaired. Poor working memory performance is associated with lower activation of these areas of the brain on the MRIs among the FASD subgroups. Neuro-imaging studies provide convincing evidence that cognitive and behavior deficits among alcohol-exposed individuals are brain-based, and that CNS damage detected is a result of prenatal exposure.<sup>76</sup>

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Alcohol Related Neurodevelopmental Disorders (ARND) and Static Encephalopathy, Alcohol Exposed (SE/AE) which are nondysmorphic.

<sup>75</sup> The facial phenotype is as measured by the Washington four digit code. The four digits in the Code reflect the magnitude of expression of the four key diagnostic features of FAS in the following order: (1) growth deficiency, (2) the FAS facial features, (3) central nervous system (CNS) damage/dysfunction, and (4) prenatal alcohol exposure. The magnitude of expression of each feature is ranked independently on a 4-point Likert scale with 1 reflecting complete absence of the FAS feature and 4 reflecting a strong "classic" presence of the FAS feature. The facial features of diagnostic significance are the palpebral fissure length [measured from the outer corner of eye (exocanthion), to inner corner of eye (endocanthion)], the thickness and appearance of the red or vermilion portion of the upper lip, and the smoothness of the philtrum (groove or fissure) in the upper lip. The most current version of the FASD 4-Digit Diagnostic Code and photographic Lip-Philtrum Guides is found in Astley SJ (2004) *Diagnostic Guide for Fetal Alcohol Spectrum Disorders: The Four-Digit Diagnostic Code*, Third Edition, University of Washington Publication Services, Seattle WA at <http://depts.washington.edu/fasdpn/pdfs/guide2004.pdf>.

<sup>76</sup> Susan J. Astley, Heather Carmichael Olson, Kimberly Kerns, Allison Brooks, Elizabeth H. Aylward, Truman E. Coggins, Julian Davies, Susan Dorn, Beth Gendler, Tracy Jerikowic, Paul Kraegel, Kenneth Maravilla, and Todd Richards, "Neuropsychological/Behavioral Outcomes, a Comprehensive Magnetic Resonance Study of Children with Fetal Alcohol Spectrum Disorders" (2009) 16 (1) Canadian Journal of Clinical Pharmacology e178-e201; Susan J. Astley, Todd Richards, Elizabeth H. Aylward, Heather Carmichael Olson, Kimberly Kerns, Allison Brooks, Truman E. Coggins, Julian Davies, Susan Dorn, Beth Gendler, Tracy Jerikowic, Paul Kraegel, and Kenneth Maravilla, "Magnetic Imaging Outcomes from a Comprehensive Magnetic Resonance Study of Children with Fetal Alcohol Spectrum Disorders" (October, 2009) 33(10) Alcoholism: Clinical and Experimental Research, 1671-1689; Susan J. Astley, Heather Carmichael Olson, Kimberly Kerns, Allison Brooks, Elizabeth H. Aylward, Truman E. Coggins, Julian Davies, Susan Dorn, Beth Gendler, Tracy Jerikowic, Paul Kraegel, Kenneth Maravilla, and Todd Richards, "Functional Magnetic Resonance Imaging Outcomes from a Comprehensive Study of Children with Fetal Alcohol Spectrum Disorders" (2009) 1 Journal of Neurodevelopmental Disorder 61-80; and Susan Astley, Todd Richards, Elizabeth H. Alyward, Heather Carmichael Olson, Kimberly Kerns, Allison Brooks, Truman E. Coggins, Julian Davies, Susan Dorn, Beth Gendler, Tracy Jerikowic, Paul Kraegel, and Kenneth Maravilla, "Magnetic Resonance Spectroscopy Outcomes from a Comprehensive Magnetic Resonance Study of Children with Fetal Alcohol Spectrum Disorders"(2009) 27(6) Magnetic Resonance Imaging 760-788.



A further study, led by Catherine Lebel at the University of Alberta, using diffusion tensor imaging (DTI) found that four different brain areas show correlations between structure and cognitive assessments of mathematical ability in children with FASD: two regions in the left parietal area, the cerebellum and the brain stem. Furthermore, varied, more difficult mathematical processes involve more areas of the brain which are interrelated in “networks”. Visual and auditory processing occur in the parietal lobes, while the cortex is the site for executive function or problem solving, whereas integration of information between the two hemispheres of the brain occurs through the corpus callosum. Networking between and within hemispheres occurs at the cellular level via axons in white matter transferring nerve impulses or signals to dendrites in grey matter. Consequently, white matter defects and deficits caused *inter alia* by environmental influences such as prenatal exposure to alcohol can disrupt these networking pathways required for more complex learning and self-regulation.<sup>77</sup> Findings of this study demonstrate a link between brain structure and cognition that provides insight into how the FASD brain works, with implications for better treatment or accommodation.

The synergy of these seminal medical and legal advances opened the floodgates for dialogue, and led to families and individuals “coming out of the closet” about FASD. Both collectively and individually, parents became more vocal. They reached out to one another on a volunteer basis, sharing experiences of what had worked for them. Parent support groups formed and expanded, gradually evolving into a very effective form of peer support. Though parents try their best, they make mistakes as they do not fully grasp or remember on an ongoing basis that consequences do not work well with FASD children. Yet, they persevere and try again in a different way. No detailed road map exists for parents; they discover the way collaboratively as they journey forward. As capacity and cognitive processing issues persist throughout the life span, parents are invaluable as lifelong mentors for their offspring with FASD. Because of their pivotal role and insight, parents are considered of central importance in the research. In addition,

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<sup>77</sup> Catherine Lebel, Carmen Rasmussen, Katy Wyper, Gail Andrew, and Christian Beaulieu, “Brain Microstructure is Related to Math Ability in Children with Fetal Alcohol Spectrum Disorder” (February, 2010) 34(2) *Alcoholism: Clinical & Experimental Research*, 354-363.

their presence at the Circles or interviews serves as a protective factor for their vulnerable children and is an essential component of the consent process.

## 7. Concluding Comments

Reconciliation is needed at all levels, personal, interpersonal, community, regional, national and international, in a general context, as well as in the specific context of FASD. Just as parents must expand their normal parameters to deal effectively with FASD children, so, too, professionals of all stripes need to step outside their roles to some extent. Otherwise, individuals with FASD continue to fall through unanticipated gaps. Judge Barry Stuart of the Yukon Territorial Court, in the context of an FASD decision, reminds us that it is not a sacrilege to step outside the boundaries of professional roles. In fact, in the face of failures with FASD, he states that it is morally repugnant to remain within such arbitrary boundaries. “When the evidence for changing to a holistic, coordinated, value-based approach is so overwhelming, how can the justice system remain a jungle of complex, disjointed interactions that preserve numerous self-serving fiefdoms, all with different values, different objectives?”<sup>78</sup> The same is true of any system where vulnerable people with FASD continually fall through lacunae within a system and gaps between systems. Strategies that Judge Stuart advocates involve both investing in communities in order to advance social capital at the community level, and empirically evaluating systems, including the justice system, in terms of the number of positive outcomes each system produces. The criminal justice system is likely low in terms of reducing recidivism and preventing further crime. Judge Stuart’s stated intention is not to blame individual professionals, most of whom try their best, but to ensure that all are aware that systemic change is required, that there is ethical work to be done that may transcend dominant formalistic laws and policies as they stand. All need to step back, take a broader perspective, and view society through a more inclusive social justice lens. In this context, collaborative FASD action research should function as a site of resistance against oppressive and unjust laws, policies, and practices.

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<sup>78</sup> *R. v. M.N.J.* 2002 YKTC 15 at para 129, [2002] Y. J. No. 49. [*R. v. M.N.J.*]

Such resistance could potentially benefit everyone, through facilitating creation of a more informed, just and caring society.

Reconciliation involves stepping outside dominant positions, perspectives and parameters in order to situate oneself within emerging Aboriginal methodologies, processes and perspectives.<sup>79</sup> This is so whether addressing Aboriginal rights and Treaty rights (including self-government) or redressing past wrongs caused by assimilative pressures of the dominant culture. Only then can healing and transformation, pluralism and reconciliation be achieved.

In the Research Circle, the Elder and Pipe Carrier affirmed the inclusive nature of FASD and the need for all peoples to work together, in the spirit of *miyo-pimatisiwin* and *miyo-wichitowhwin*. This was his closing prayer for us. All my Relations, *Ne wah kuma ka tik!*

*Ekosi, Ay ay*<sup>80</sup>

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<sup>79</sup> Linda Tuhiwai Smith, *Decolonizing Methodologies: Research and Indigenous Peoples* (London: Zed Books, 1999).

<sup>80</sup> Traditional Cree prayer closing, perhaps similar to “Amen” or “The mass is ended, go in peace.”

## **Disjunctures and Discontinuities in the Law of Mental Intent:**

### **FASD as a Site of Resistance and Transformation,**

# *Esquiskuit*

**By H. Rae Mitten**

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### ***1. Introduction***

Reasoning, judgment, memory, information processing, understanding, executive functioning, adaptive functioning, impulse control, in fact, most cognitive and self-regulatory functions, are affected by FASD. These deficits, in turn, affect both capacity and culpability or criminal liability. Capacity and culpability are prerequisites, respectively, in order to receive a fair trial and to be held responsible for a criminal act. While, according to the philosophical underpinnings of western law, crime is an absolute wrong that has to be atoned for or annulled by punishment, in more modern times H. L. Hart tempered this harsh, retributive view of crime and punishment, holding that punishment is justified only if the offender is responsible, acting voluntarily and possesses the necessary mental element.<sup>1</sup>

The Justice system is based on presumptions of fitness, freedom of choice and individual responsibility that often do not fit well with the cognitive, adaptive, affective and volitional

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<sup>1</sup> H. L. Hart, *Punishment and Responsibility* (Oxford: Clarendon Press, 1968) at 183-4 and 152.

deficits of FASD. A disconnect exists between modern neurological conditions like FASD and our laws on mental intent, that needs to be addressed if Hart’s enlightened moral imperative is to be honoured.

## ***2. Fitness to Stand Trial: Conflict and Confusion over Standards of Rationality Required***

Recently, *R. v. Jobb*<sup>2</sup> brought the matter of capacity to public attention in the context of a young man with FASD and ADD.<sup>3</sup> Christopher Jobb was found unfit to stand trial<sup>4</sup> by the trial judge, based on persuasive evidence regarding his capacity in the expert testimony of the attending psychiatrist. Persons with a mental disorder<sup>5</sup> found unfit to stand trial are not morally blameworthy and therefore should not be punished; instead, they may require treatment in the community or care in a hospital or treatment facility. The trial transcript reveals an interesting dialogue between the officers of the court and the expert witness, in an attempt to “fit” a complex, modern medical diagnosis into the rigid, procrustean bed of the 1843 McNaughton

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<sup>2</sup> [2008] 314 Sask. R. 236, 2008 SKCA 156. [*R. v. Jobb*]

<sup>3</sup> The Saskatchewan Court of Appeal, however, did not overrule the trial judge’s finding that FASD is a mental disorder. Please note that ADD is the acronym for Attention Deficit Disorder.

<sup>4</sup> *Criminal Code*, R.S.C., 1985, c. C-46, s. 2: “**unfit to stand trial**” means unable on account of mental disorder to conduct a defense at any stage of the proceedings before a verdict is rendered or to instruct counsel to do so, and in particular, **unable** on account of mental disorder to:

- (a) understand the nature or object of the proceedings,
- (b) understand the possible consequences of the proceedings, or
- (c) communicate with counsel;

<sup>5</sup> *Criminal Code*, amended by R.S. c. C-34, s. 2 and s. 16, 1991, c- 43, s. 2:

### **Definition of Mental Disorder.**

2. Mental Disorder means a disease of the mind. (Formerly was defined as “natural imbecility” or “disease of the mind.” *Criminal Code*, S.C. 1892, c. 29, s. 11)

**Defense of Mental Disorder.** (Formerly the “instanity defense,” *Criminal Code*, S.C. 1892, c. 29, where “and” was used in place of “or”.)

16(1) No person is criminally responsible for an act committed or an omission made while suffering from a mental disorder that rendered the person incapable of *appreciating* the nature and quality of the act or omission or of knowing that it was wrong.

(2) Every person is presumed not to suffer from a mental disorder so as to be exempt from criminal responsibility by virtue of subsection (1), until the contrary is proved on the balance of probabilities.

(3) The burden of proof that an accused was suffering from a mental disorder so as to be exempt from criminal responsibility is on the party that raises the issue. [Italics added.]

Rules<sup>6</sup> and resulting jurisprudence, the foundation on which the fitness test and notions of mental capacity, culpability, excuses and defenses rest. The expert witness remarked that Jobb's intellectual and cognitive deficiencies impacted adversely on his fitness to stand trial. He commented that, while Jobb seemed to appreciate the meaning of a guilty plea and to possess a rudimentary knowledge of the role of officers of the court, the prosecutor, defense attorney and judge (probably due to repeated coaching by his foster mother), his ability to follow proceedings was less evident. Although Jobb maintained that he could follow and understand the

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<sup>6</sup> The Queen against Daniel McNaughton – State Trials Report (1843) 4 St. Tr. New Series 847, cited in Dalby, J. T., “The Case of Daniel McNaughton: Let’s get the story straight” (2006) 27 American Journal of Forensic Psychiatry, 17. Under the influence of a paranoid delusion regarding the government, Daniel McNaughton fatally shot Edward Drummond, secretary to the Prime Minister, in broad daylight in front of witnesses. Afterwards, he did not attempt to flee and, in fact, tried to fire another shot while being restrained by an off-duty police officer who happened to be in the vicinity. The offence occurred in the same year that *Christmas Carol* was published, and social conditions in London, England were deplorable as depicted in Charles Dicken’s novel. Although knowledge of mental conditions were rudimentary at the time, and the discipline and medical specialty of psychiatry did not exist, all six medical doctors or surgeons who clinically examined McNaughton, and two medical experts that did not examine him, testified that he had acted under an insane delusion. On this basis, the 12-man jury acquitted and McNaughton spent the rest of his days in “Bethlem” asylum, or similar facility. The case raised a storm of controversy, largely because of recent, similar attempts on the lives of Queen Victoria (then age 22) and Prime Minister Robert Peel, and the fact that McNaughton appeared rather normal on casual observation by the general public, that is his mental disorder was largely invisible in the court room where he did not testify. The trial ended on Saturday, March 4, 1843 and on Monday March 6, 1843 the *McNaughton* decision was raised in the House of Lords. To quell the public outcry at the anticipated floodgate of acquittals for insanity and other changes to the weighing of intent in criminal matters, the House of Lords, in a rare procedure, presented to the twelve judges of Queen’s Bench five questions relating to insanity in the courts. On June 19, 1843, eleven of the judges replied to the questions with four formulated “rules”, constituting the “McNaughton Rules.” One judge provided a dissenting opinion. The four rules formulated were adopted by the House of Lords and eventually by all common law countries. Although the McNaughton decision and resultant House of Lord rules were very advanced for 1843, considering the rudimentary state of related scientific knowledge at the time, the most astonishing aspect is that they remain basically unaltered today, despite modern advances in fields unknown at the time of McNaughton, including psychiatry, psychology, behavioral science and neuroscience. As great weight was placed on expert evidence (six physicians and surgeons had clinically examined him and testified, and two others gave “scientific” evidence independent of a personal examination) at the McNaughton trial and resultant House of Lords’ rules, updating the rules in the light of the much accumulated modern, scientific evidence of expert witnesses would be consistent with the origin of the rules. The cognitive test of knowledge of right and wrong, including the terminology “nature and quality of the act,” “appreciate” and distinction of “right from wrong,” date back to the McNaughton case and to the subsequent formulation and adoption of the House of Lords’ rules. Dalby concludes “Daniel McNaughton’s case will remain a key to the genesis of behavioral science in the courtroom.” He also concludes that the spelling, “McNaughton” is the original, correct spelling in the State Trials Report, that was subsequently morphed into many incorrect forms (M’Naughton, M’Naughten, McNaghten, McNaghton, MacNaughten, MacNaughton) by the media and secondary records and sources, including subsequent case law and commentary.



proceedings, the expert witness speculated that this assertion revealed more about Jobb's wish to be regarded as normal than it did about his ability to concentrate and comprehend the process. The expert opined that, in reality, fitness was not simply a matter of one extreme or the other, being fit or not fit, that is, an all-or-none state, but rather, by implication one presumes a matter of degree along a continuum. The accused, the expert concluded, was not fit to participate in his defense in a meaningful way, nor to assist his counsel during the course of the trial.<sup>7</sup> Notwithstanding this conclusion, the expert witness readily (and insightfully) admitted that he did not understand how the official legal test for fitness would apply to this context:

One of the areas that I find is more difficult to reach the determination on is the individual's ability to instruct counsel. I'm not sure of the official definition, but I suspect it's [not static] . . . it's a dynamic process involving the individuals in court listening to what is being said. During a break or during the proceedings the individual may want to talk to counsel and say – add comments or whatever. And I think in that area is where he is likely compromised because of his mental disorders. That it's not clear how much of what is going on that he's taking in, and therefore how much a part of the process he is. Most of us have the choice whether we want to tune in or tune out, but I think someone like Christopher, I mean, he still has that choice, but even if he chooses to tune in his capabilities are limited and what he gets out of tuning in is obviously a lot less than the next person. So that's where I see the problem lying.

Q. Dr. Menzies, are you of the opinion that Christopher would be able to communicate with his lawyer, his counsel and adequately instruct them?

A. It is a question of degree. I think his recollection of things isn't terribly strong, so depending when it is or what event he's talking about, when it happened, whether it was last week or a year ago, I think basically he can communicate, but it's a question of what quality of instruction [he can provide to counsel]. Because if he's not fully there for reasons that aren't his fault, during the process I think that's the area where it falls down and where he's not, in my opinion, fit to stand trial.

Q. Thank-you, Dr. Menzies. Another area I'd like you to comment upon is your opinion as to Christopher's ability to give assistance to his counsel in legal proceedings. For example, if a trial

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<sup>7</sup> In *State v. Brett* 2001, 16 P. 2d 601 No. 63835-7, 142 Wash. 2d 868, Jan. 25, 2001, Washington Supreme Court vacated a death sentence, holding that the appellant had been denied effective assistance of counsel during the penalty phase of his prosecution for murder, as it turned out that the appellant had FASD and the issue of his disabilities had not been addressed before the Court. "When defense counsel knows or has reason to know of medical and mental health problems that were relevant to making an informed defense, defense counsel has a duty to conduct a reasonable investigation into the defendant's mental health, have such problems fully assessed and, if necessary retain qualified experts to testify accordingly." In another proceeding, Brett's defense counsel was disbarred for related contemporaneous conduct. Cited in T. E. Moore and M. Green, "Fetal Alcohol Spectrum Disorder (FASD): A need for Closer Examination by the Criminal Justice System" (2004) 19 C.R., 99-108 at 106.

were to happen and the normal trial process then ensues, what would Christopher's ability be to assist counsel in that process?

A. Well, I don't think he would have absolutely no ability. I think he would certainly have some ability, but it would be not the degree of ability that somebody who had an IQ of a hundred, say, was able to provide. I think he has—for instance I talked about the charges he faced, he was very vague and you know, I talked about the numbers [of charges], and he said well, too many. And [he] put it all down to being intoxicated on either drugs or alcohol. Sort of vague stuff, but I mean, if you put the police report in front of him and say, does this sound like what happened—this sort of thing? I don't think you can take for granted that just because he said, “yeah, I know that,” that that necessarily is the case. [In other words, the FASD accused might agree with what the police or prosecutors say, due to a combination of suggestibility, compliance, confusion or memory gaps, even though that is not what in fact actually happened.]

Q Thank you. Getting back to some direct questions in terms of Christopher's ability to deal with the court process, would you be able to offer an opinion as to Christopher's ability to be examined by a prosecutor, or by myself, cross-examination and those sorts of things?

A. Well, he could certainly be examined. And as I say, I think if his deficiencies are taken into consideration in terms of the sort of questions asked or the time he's given to respond, or whether he understands what the question is, then certainly he can do those things to some degree. I guess the issue is the degree of these things, you know. He can communicate, he can share a joke, he can remember things, he can come up with original thought, but he's got problems which make all those areas more difficult for him to deal with. [Note: Bracketed inserts throughout are editor's comments.]

Because of the accused's inability to concentrate and extreme distractibility, the psychiatrist concluded that Mr. Jobb would not be able to follow the proceedings sufficiently to instruct counsel during the dynamic process that involved listening in court to what is being said and communicating to his lawyer about it. As instructing and communicating with counsel are critical components of the fitness test, the trial judge, Judge Sheila Whelan, interpreted this evidence to mean that Mr. Jobb was unfit to stand trial.

While having neither the accused nor the expert witness appear before them, the Saskatchewan Court of Appeal overturned the *Jobb* decision,<sup>8</sup> primarily as the trial judge had not

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<sup>8</sup> *Supra* note 2. [*R. v. Jobb*, 314 Sask. R. 236, 2008 SKCA 156]. Applying *Jobb*, Judge Agnew in *R. v. RCMc*, 2011 SKPC 61, overturned a previous finding of unfit to stand trial for a 17 year old defendant, despite the fact that the defendant had a range of complex mental health issues, including autism spectrum disorder, ADHD, epilepsy, probable bipolar disorder, and mild to moderate mental retardation. During the court proceedings, the defendant, holding onto a stuff toy, became inattentive, restless, agitated, moving, shifting, and pacing, and making vocal outbursts, growls and gestures. When the deputies tried to restrain him, he bit at least one of them. His behavior improved somewhat following short breaks in the court proceedings, but the effects did not last. This case was covered by CBC Radio One, Saskatoon, May 9, 2011, in news broadcasts and in the afternoon talk show, Blue Sky,

properly applied the “operating mind” or “limited cognitive capacity test” from *R. v. Taylor*<sup>9</sup> and *R. v. Whittle*<sup>10</sup> to the expert evidence:

It [the test for fitness] is predicated on the existence of a mental disorder and focuses on the ability to instruct counsel and conduct a defence. . . .

It requires limited cognitive capacity to understand the process and to communicate with counsel. In *R. v. Taylor* (1992), 77 C.C.C. (3d) 551, the Ontario Court of Appeal, after reviewing the authorities, held that the trial judge erred in concluding that the accused must be capable of making rational decisions beneficial to him. . . . Accordingly, provided the accused possesses this limited capacity, it is not a prerequisite that he or she be capable of exercising analytical reasoning in making a choice to accept the advice of counsel or in coming to a decision that best serves her interests.<sup>11</sup>

The trial judge in *Whittle*<sup>12</sup> was of the view that the limited cognitive capacity or operating mind test would one day be expanded to include a separate consideration of the “awareness of consequences” as set out by Madam Justice Wilson for the majority in *R. v. Clarkson*, [1986] 1 S.C.R. 383. Accordingly, in *Whittle*, the trial judge concluded that the

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“Mental Illness and the Justice System,” with guest, Dave Nelson, Canadian Mental Health Association and host, Garth Materie, at <http://www.cbc.ca/bluesky/episodes/2011/05/09/mental-illness-and-the-justice-system/>, asking if people are being charged and tried for criminal behavior when they needed treatment for mental illness instead. Defense counsel, Joan Khan, expressed the opinion that the case, *R. v. RCMc*, would likely be appealed.

<sup>9</sup> 1992 77 C.C.C. (3d) 551 [Taylor, Ontario Court of Appeal].

<sup>10</sup> [1994] 2 S.C.R. 914 at para. 33 [Whittle, S.C.C.]. The Supreme Court of Canada, in *Whittle*, considered the admissibility of statements to the police made by an accused person alleged to suffer from mental incapacity and, therefore, not capable of understanding the implications of waiving the right to silence and right to counsel. A fit accused must be able to instruct counsel, understand the function of counsel, and comprehend that he or she can dispense with counsel. The Supreme Court held that a fit accused need not be capable of exercising analytical reasoning, but rather must possess only the mental capacity of an operating mind. It further held that different standards of competency should not be applied for different aspects of criminal proceedings, whether at pretrial activities or trial processes (e.g. deciding whether to assert or waive the right to counsel, instructing counsel either before or during trial, deciding how to plead, participating in a plea bargain, deciding to give or not to give evidence, dispensing with counsel even though it may not be in the accused’s best interests, and so forth), but rather just one standard of competency or fitness should apply in all criminal proceedings. However, the Court did qualify this one standard through the assertion that different considerations may apply to states such as drunkenness or hypnosis. [Editor’s note: does this create a space for different considerations for those with permanent cognitive damage caused by prenatal exposure to alcohol?] The operating mind test includes a limited mental component which requires that the accused have sufficient cognitive capacity to understand what he or she is saying and what is said in the court process. If he possesses this limited cognitive capacity, it is assumed that he also has the ability to understand a caution that the evidence he gives can be used against him.

<sup>11</sup> Supra note 10, at para. 32 & 33. [Whittle]

<sup>12</sup> Supra note 10, at para. 17. [Whittle, citing trial judge]

psychological condition of the accused prevented him from an awareness of the consequences which would flow from giving the statements in question, and his inability to appreciate what was at stake nullified any alleged waiver of his right to counsel. However, both appellate courts in *Whittle* found that the trial judge had erred in finding that the expert witness testified that Whittle did not understand the consequences of making a statement; rather, the appellate courts held that the expert witness had testified that Whittle did understand the consequences of making a statement, but that he did not care about them.<sup>13</sup> Accordingly, the appellate courts upheld Whittle's waiver of right to counsel and, consequently, the admission of his inculpatory statement.

Following the precedent set in *Whittle* and *Taylor*, the appellate court in *Jobb*, held that the trial judge had erroneously applied an "analytical cognitive capacity test" which raised the bar too high for being fit to stand trial. The "limited cognitive capacity test" is rudimentary and requires only that an accused be able to recount the necessary facts of the alleged crimes to legal counsel,<sup>14</sup> and the Saskatchewan Court of Appeal concluded that Mr. Jobb could do that, at least at the outset of the trial. Notwithstanding the narrowness of the test, the expert witness opined that the accused's ability even to correctly recount the facts of the alleged crime might be compromised during the progress of the trial. In view of the accused's memory and other cognitive problems, along with his suggestibility and compliance (eagerness to please and to appear normal), such arbitrary and narrow application of the test probably is not adequate in the context of FASD and would require modification if scrutinized under the social justice lens. Under such lens we should not subject individuals to a trial process in which they do not have the capacity to participate sufficiently. Although the threshold for fitness is lowered in *Taylor* and

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<sup>13</sup> Doug Whittle was schizophrenic; while detained for questioning, the investigating officers referred to him as a "loon" or a "nutbar". Rather than "not caring," Doug Whittle and persons with FASD or other mental disorders often lack appropriate affect. This is so because they may be able to parrot back what is said to them, without fully appreciating it, may not comprehend social cues and appropriate affect, or may be suffering from a mood disorder, rather than "not caring." Sometimes vulnerable suspects just want to "get things over with," without regard to the serious consequences of doing so in an adversarial system.

<sup>14</sup> The Saskatchewan Court of Appeal chose to rely on the report of a psychiatrist at the Saskatchewan Forensic Hospital who had assessed Jobb in 2006, before the current offences had taken place, and found Jobb to be fit to stand trial, but this psychiatrist had been unaware of Jobb's previous diagnoses of FASD and ADD, and for these reasons probably was not called upon by the Crown to testify in the trial court, where he could have been cross-examined regarding the implications of the intervening information and events on Jobb's fitness.

*Whittle* in order to protect liberty interests, including the right of the accused to have a trial within a reasonable time and to have a say in the defense, it cannot be so low that a fair trial to determine innocence or guilt is jeopardized. Otherwise, the spectres arise of either wrongful conviction, or of punishing individuals not responsible for their actions through no fault of their own, or of both. Unfortunately, both are not uncommon occurrences for accused individuals who have FASD.<sup>15</sup> Such travesties of justice are likely outcomes, particularly if similar narrow and arbitrary parameters (in the light of modern advances in medical science) are employed in the defense of “not criminally responsible due to mental disorder”<sup>16</sup> as were used in the test for “fitness to stand trial”.

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<sup>15</sup> T. Moore and M. Green, “Fetal Alcohol Spectrum Disorder (FASD): A need for Closer Examination by the Criminal Justice System,” (2004), 19 C.R. 99-108 at 106. The authors cite Professor Yarmey of the University of Guelph who cautions: “What is the worth of a confession given by someone who is intellectually handicapped, and/or extremely frightened, anxious, hyper-suggestible and overly compliant? Probably very little.” Although it may be inaccurate in the circumstances, the inculpatory value of a confession is significant, for once obtaining it, police and prosecutors have little incentive to look beyond the admission of guilt to verify if the crime was even committed, or if the accused was the real perpetrator. Conviction where the key or sole evidence is a confession is problematic with these defendants, and prudent policy could require that more than a confession is needed to justify commencement of prosecution. However, such is not currently the case. *R. v. L.T.H.*, [2008] 2 S.C.R. 739, 2008 SCC 49, deals with the issues of voluntary waivers of rights and statements to police in the context of capacity issues for youth and formulates guideline for enhanced procedural protection for young persons. Youth, including those with disabilities, have a right to be informed about their rights in a language that they can understand. Those functioning at a comprehension level similar to a youth, even though their chronological age may be in the adult range as with individuals affected by FASD, will also require similar enhanced protection. Many would not have the capacity to waive rights no matter how explained to them, and could not validly dispense with a lawyer or parent or other adult being present during interrogation and the taking of statements. In addition to problems with comprehension and memory, individuals with FASD have a limited understanding of consequences and time. As a result, they may agree to a waiver of rights just to “get it over with,” and may be scared or full of braggadocio. According to *R. v. Oickle* [2000], 2 S.C.R. 3, a non-voluntary statement casts doubt on reliability, as voluntariness can be vitiated by threats, promises, oppression, and other police trickery, exacerbated even further if there is also lack of an operating mind. An unreliable statement can constitute a false confession. [Editor’s comment: For these reasons, law and policy should require that more evidence than a confession be required to justify commencement of a prosecution.]

<sup>16</sup>*Criminal Code*, R.S., c. C-34, s. 16.; 1991, c. 43, s. 2: **16(1)** No person is criminally responsible for an act committed or an omission made while suffering from a mental disorder that rendered the person incapable of appreciating the nature and quality of the act or omission or of knowing that it was wrong. The test for “Not Criminally Responsible (NCR),” sometimes termed the insanity defense, has been successfully employed for very few individuals with FASD found guilty at trial. As very few accused with FASD are found “Unfit To Stand Trial” (UST), most proceed to trial where they are similarly not excused from punishment due to a finding of NCR. Once found guilty, if not excused as NCR, mental disorder may be considered a mitigating factor

*Taylor* and *Whittle* set the test for fitness as the “limited cognitive capacity test” requiring the accused to have only a rudimentary factual understanding, rather than a rational understanding, of his legal predicament. Nor is it necessary for the accused to be able to act in his or her own best interests in order to be considered fit according to the *Taylor* and *Whittle* test. This precedent setting test established in *Taylor* and *Whittle* is a very limiting device and not a good “fit” with the complex, subtle and pervasive realities of mental disorders. As a consequence, it is likely to give rise to many false negatives (finding accused individuals fit when they are really unfit) who should really not be proceeding to trial:

The *Taylor* decision reflects the difficulty courts have in understanding the depth and scope of mental illness and its infiltrative quality, and the extent to which it can interfere with a person’s capacity to enlist *normal* self-preservational functions; these functions do not just depend on cognitive abilities, but on other areas of intrapsychia functioning, such as motivation, insight, affect and volition. Cases where accused are unfit due to a reason other than cognitive impairment and overt psychosis are often more subtle. Both counsel and the forensic psychiatric examiner should maintain a high index of suspicion when certain information suggests the possibility or likelihood of a deficit. The test consequently fails to filter out a number of different types of accused who are probably not fit, and having regard to the purpose and intent of the fitness rules to begin with, should not be proceeding to trial.<sup>17</sup>

In fact, the “limited cognitive capacity test” is problematic for both psychotics (from which it originated) and other mental disorders, as well:

“Unfit to stand trial” was defined in the *Criminal Code* of Canada for the first time with the proclamation of Bill C-30 in 1992. Commentators have suggested that the new statutory provisions are merely a re-articulation of the law as it has evolved in Canadian judicial decisions. While this view, upon a reading of the provisions, is apparently accurate, considerable confusion has resulted in both the psychiatric and legal professions with the first judicial consideration of the test for “unfit to stand trial” in *R. v. Taylor*. The test as articulated by the Ontario Court of Appeal in *Taylor* establishes a lower threshold of understanding and ability on the part of the accused in respect of his legal predicament than most psychiatric and legal professionals had previously

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reducing their culpability at the sentencing phase. However, the latter is at curial discretion. No universal, formal mechanism exists to impose a rehabilitative rather than a penal disposition on a convicted mentally disordered youth or adult not found UST and not excused as NCR. Those with mental disorders, including those with FASD, whatever the disposition, do not fare well in the justice system, and yet for lack of mental health resources in the community often end up there by default (*D.J.* case).

<sup>17</sup> H. Y. Bloom and R. D. Schneider, *Mental Disorder and the Law, A Primer for Legal and Mental Health Professionals*, Toronto: Irwin Law, 2006, at p. 76.

applied.

Notwithstanding the new *Criminal Code* definition for “unfit to stand trial,” the foundations of the fitness rules and their application in a number of cases decided prior to *Taylor* make it clear that the *Taylor* decision has so narrowed the fitness standard that it is out of keeping with the realities of mental illness and the true impact of mental disorder on an accused’s ability to assume the role of the accused. . . . [Emphasis added.]

The phrase “**limited cognitive capacity**” does not appear in any earlier reported jurisprudence. It is a descriptive label for a test which was distinguished in *R. v. Taylor* from the higher threshold “**analytic capacity**” test (also undefined) which would require an accused to be able to act in his own best interests before he could be pronounced it to stand trial. . . .<sup>18</sup> [Emphasis added.]

R. D. Schneider, lawyer, professor of psychiatry, and now Justice of the Toronto Mental Health Court, and H. Bloom, psychiatrist, professor and lawyer, reviewed the case law prior to *Taylor* in order to shed further light on the cognitive aspect of fitness or competency as construed by the courts. In *R. v. Pritchard* (1836) 7 Car. & P. 303 (Shropshire Assizes), standards based on knowing and understanding were officially adopted in the common law. Those fit to stand trial had to have sufficient intellect to comprehend the course of the proceedings so as to make a proper defence and to comprehend the details of the evidence, which could constitute a minute investigation.<sup>19</sup> The landmark Daniel McNaughton case of 1843 set the standard test for criminal responsibility at “knowing the nature and quality . . .,” later mitigated to “appreciating” the nature and quality of the act, thereby raising the standard of rationality required for the defence of insanity, eventually replaced by the defence of mental disorder.<sup>20</sup> In 1892, Canada’s first *Criminal Code*, s. 11, codified the insanity defence, so that this defence became available to an accused person, who because of “natural imbecility” or “disease of the mind,” was incapable of *appreciating* the nature and quality of the act or omission and of *knowing* that it was wrong. Bill C-30, proclaimed in 1992, adopted more politically correct language of mental disorder, as well as mitigating the second branch of the test

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<sup>18</sup> R. D. Schneider and H. Bloom, “*R. v. Taylor*: A Decision Not in the Best Interests of Some Mentally Ill Accused,” 38 *Crim. Law. Q.* 1996 183 at 185-6. Richard D. Schneider is both a Doctor of Psychology and lawyer by training, as well as the Justice of the Toronto Drug Treatment Court, so has expertise in both law and mental illness. He has published widely in the fields of mental disorders and the law and specialized courts.

<sup>19</sup> *Ibid.* at p. 184.

<sup>20</sup> S.C. 1991, c. 43, s. 2. Note that most provisions of Bill C-30, including s. 16, Defence of Mental Disorder, were proclaimed in force on February 4, 1992.

from a conjunctive to a disjunctive construction, so that one could be excused either on the basis of being incapable of appreciating the nature and quality of the act or omission, or on the basis of being incapable of knowing that the act or omission was wrong. After 1992, both arms of the test were not required for the mental disorder defence, as they had been for the insanity defence in Canada's first *Criminal Code* of 1892.

Moreover, many clinicians contend that “appreciating” should be impliedly inferred into the test for fitness, as well as for criminal responsibility, thereby enhancing the cognitive capacity required to be fit to stand trial and to conduct a defence, from mere factual knowledge to rational appreciation of both the nature, object and consequences of the proceedings, and of the process of instructing and communicating with counsel.<sup>21</sup> The “best interests” component of the analytical capacity test in *Taylor* was improperly introduced as it is not the condition precedent to be considered with respect to communicating with counsel in part (c) of the fitness test. Rather, Taylor's *rationality* or understanding being compromised by delusions resulted in him not knowing or acting in his own best interests, that is, rationality was the prime factor or condition precedent for determining fitness. Acting in his own best interests is a result of being rational, and not the criterion at issue *per se*; if one is rational, one usually makes decisions in one's own's best interests,”<sup>22</sup> but other factors are involved as well, such as incomplete information, acting for a higher purpose, and so forth. The so-called “analytic capacity test” was thus distinguished from a “limited cognitive capacity” as, according to *Taylor* and *Whittle*, the former required that the accused be capable of making decisions beneficial to himself which would have raised the bar for fitness too high, rather than more properly construing the analytical capacity test as requiring that the accused be merely rational.<sup>23</sup> People can be reasonably rational, yet not act in their own best interests all the time, if they do not know all of the factors involved, or weigh them incorrectly, or have a higher ethical purpose, and so forth. Accordingly, the “acting in one's own best interests” criterion is the root cause of the problem with the court's construction of the analytic capacity test as it over-extends the rationality argument, thereby rendering it vulnerable. So, in this sense, the “best interests” construction for the analytical

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<sup>21</sup> *Supra* note 18 at 192. [Schneider & Bloom]

<sup>22</sup> *Supra* note 18 at 20. [Schneider & Bloom]

<sup>23</sup> *Supra* note 18 at 193. [Schneider & Bloom]



cognitive capacity test was a proverbial “straw man” to be struck down, yielding way to the limited cognitive capacity test. The Court struck down the analytical cognitive capacity test by substituting “best interests” for the more moderate rationality argument, and then defeating “best interests” as a too demanding criterion for fitness, thereby avoiding addressing the validity of the key component of the analytical cognitive capacity test, which is rationality. To employ another metaphor in countering the Court’s position, the rationality criterion for the analytical cognitive capacity test thus became the “baby” that was thrown out with the best interests “bath water”.

The two tests of fitness or competence, the analytical cognitive capacity test and the limited cognitive capacity test, trace a divergent path through the common law. Rather than the mere factual understanding required in Canada’s *Taylor* case’s limited cognitive capacity test, the U.S. Supreme Court in *Dusky v. United States*, 362 U.S. 402 (1960), required a rational level of understanding similar to an analytical cognitive capacity test, absent a best interests component:

. . . [I]t is not enough to find that the defendant is oriented in time and place and has some recollection of events, but the test must be whether he has sufficient present ability to consult with his lawyer with a reasonable degree of rational understanding—and whether he has a rational as well as a factual understanding of the proceedings against him.<sup>24</sup>

Pre-*Taylor* Canadian cases requiring a rational level of understanding similar to the analytical cognitive capacity test in *Dusky* are *R. v. Gibbons* (1946), O.R. 464 (C.A.), *R. v. Woltucky* (1952), 6 W.W.R. 72 (Sask. C.A.), *R. v. Hubach* (1966), 55 W.W.R. 536 (Alta. S.C.) and *R. v. Roberts* (1975), 3 W.W.R. 742 (B.C.C.A.).

On the other hand, the approach taken by the English Court of Appeal in *R. v. Robertson*, [1968] 3 All E.R. 557, appears to be the approach endorsed by the Canadian court in *Taylor* and identified for the first time therein as the “limited cognitive capacity test,” eschewing the “best interests” construction of a so-called “analytical cognitive capacity test” and “throwing the baby out with the bathwater”:

Counsel for the accused submits that the accused on the evidence here appears to have had a complete understanding of the legal proceedings and all that is involved and, although he suffers from delusions which at any moment might interfere with a proper action on his part, that is not a matter which should deprive him of his right of being tried . . . the mere fact that the accused was not capable of doing things

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<sup>24</sup> Supra note 18 at 194 citing *R. v. Dusky*, 362 U.S. 402 (1960).

which were in his best interests was not sufficient to justify a finding of unfitness.<sup>25</sup>

On its facts, however, *Robertson* is somewhat of an anomaly. Robertson appealed a successful Crown application for unfitness to plead on the grounds that although he killed under an insane delusion, he had acted in self-defense. The Court found that while Robertson lacked capacity to act in his own best interests, he nevertheless was rational enough to stand trial and potentially be excused on the basis of self-defense. The alternative was that he be held indeterminately at the Queen's pleasure in a hospital or asylum under the *Insanity Act*, 1964. The Court preferred the closure that an exit from the system would bring and seemingly searched for a device through which to overturn the finding of unfitness to plead and allow the appellant to stand trial.

In entirely different contexts, *Taylor* and *Whittle* in the Canadian Courts used the device of eschewing the "acting in one's own best interest" component in *Robertson* to inappropriately jettison the whole rationality standard from the fitness test. In doing so, they invented the undefined tests of "limited cognitive capacity" and "analytical cognitive capacity," bringing confusion into the mental disorder and fitness arena.

*R. v. Taylor* (1992), 11 O.R. (3d) 323 (C.A.) at p. 564 extends *Robertson* to find:

. . . [T]he presence of delusions does not vitiate the accused's fitness to stand trial unless the delusion distorts the accused's rudimentary understanding of the judicial process . . . under this test, a court's assessment of an accused's ability to conduct a defence and to communicate and instruct counsel is limited to an inquiry into whether an accused can recount to his/her counsel the necessary facts relating to the offence in such a way that counsel can then properly present a defence. It is not relevant to the fitness determination to consider whether the accused and counsel have an amicable and trusting relationship, whether the accused has been cooperating with counsel, or whether the accused ultimately makes decisions that are in his/her best interests. [Emphases added.]<sup>26</sup>

From a psychiatric perspective, the scope and ambit of the fitness test should address the following two questions:

. . . [T]he first asks what degree or level of understanding and ability to respond is required of an accused in respect of his/her legal predicament before he/she is

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<sup>25</sup> *R. v. Robertson*, [1968] 3 All E.R. 557 (C.A. Crim. Div.) at 560 D, cited in Schneider and Bloom, *Supra* note 36 at p. 194.

<sup>26</sup> As cited in Schneider and Bloom, *Supra* note 18 at p. 193.

deemed competent or fit to stand trial.

The second deals with the degree to which an abnormal mental state, if present, interferes with the accused's ability to participate in his/her defence.<sup>27</sup>

Taylor acted irrationally while under the influence of delusions of persecution and, thus, not in his own best interests when conducting a defence, even going so far as deciding to dispense with counsel. Unwillingness to accept the stigma of a psychiatric defense, or being paranoid of the legal process and counsel, is a characteristic of many accused who suffer from schizophrenia or psychotic delusions, compounded by the limited cognitive capacity test which is wilfully blind to the pervasive, ongoing effects of the delusions on their rationality. The concern is not that such an individual be able to exercise good judgment or make the right choice, but the extent to which his or her capacity to do so is affected by a mental disorder.<sup>28</sup>

The rationality criterion being improperly conflated with the more taxing criterion of acting in one's own best interests has given the edge to the limited cognitive capacity test over the analytic capacity test when assessing competence and capacity. Such a common logical fallacy in the jurisprudence has compromised subsequent accused found fit who lack the ability to give full answer and defense to the charges against them. As a result, they may be either wrongfully convicted or punished without having the requisite degree of responsibility for their actions. The logical fallacy at the root of this problem stands to be corrected as it contributes to an inequitable situation for such accused. Would it not be wrong-headed to persist in doing harm through an inadvertent curial error that could be so easily corrected?

Justice R. D. Schneider, in *R. v. Tracy Xu*,<sup>29</sup> explains the problem with the limited cognitive capacity test as follows:

In *Taylor* the court, in respect of the issue of an accused's ability to communicate with counsel, articulated a 'limited cognitive capacity test'. At the risk of oversimplification, a distillation of the decision is that in order to be fit to stand trial

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<sup>27</sup> *Supra* note 18 at 193-4. [Schneider & Bloom]

<sup>28</sup> *Reference Re: R. v. Gorecki (No. 1)* (1976), 32 C.C.C. (2d) 129. Dr. Gorecki had a mental disorder but opposed a defense of insanity, notwithstanding its viability. However, Gorecki did not have an active thought disorder that rendered him incapable of rational decisions in respect of his legal predicament. Instead, he had another viable defense. The *Gorecki Reference* therefore, on the facts, does not stand for the proposition that a thought-disordered accused, thereby incapable of making rational decisions or acting in his/her own best interests, is fit to stand trial, although it has tended to have that influence.

<sup>29</sup> 2007 Ontario Court of Justice, Court File No. 0710000305, at para. 8 and 9

an accused need only have a rudimentary factual understanding of his/her legal predicament. It is not necessary that the accused have a 'rational' understanding of his legal predicament or be able to act in his 'own best interests'.

The court in *Taylor* felt that this standard struck 'an effective balance' between the objectives of the fitness rules and the right of the accused to choose his own defence and have a trial within a reasonable time. While expediency must be considered in setting the fitness standard, it may be the case that the 'right to choose' [one's own defence] is a rather empty right where the accused does not have a rational understanding of his legal predicament; where choice is not rational choice. The right to choose must be read as 'rational choice' otherwise, from a protection perspective, it is a 'right' of questionable worth. Against the concern for expediency is the rationale for the rules in the first place. Principally, the rules are in place to ensure that an accused who is ill-equipped as a result of mental disorder is not subject to the prosecution machinery of the state. The rules are to protect the accused. They operate to hold the prosecution in abeyance until the accused is fit to respond.<sup>30</sup> [Editor's comment in brackets].

### ***3. Low standard of Rationality in the Limited Cognitive Capacity Test May Affect Charter Rights***

In sum, the limited cognitive capacity test falls short of fulfilling the rationale for the fitness rules. It does not protect the accused who is unprepared because of mental disorder to give full answer and defense<sup>31</sup> before the complete prosecutory machinery of the state. The test does not hold the prosecution in abeyance until such time as the accused may become able to choose a defense and to participate rationally in the defense, which may be indeterminately for those with permanent cognitive disabilities such as FASD. Post *Charter* jurisprudence in *Swain*<sup>32</sup> and *Demers*,<sup>33</sup> mentally disordered accused are no longer to be held indefinitely on a Lieutenant Governor's Warrant, but have the right to liberty under s. 7 of the *Charter*, and the right not to be deprived thereof except in accordance with the principles of fundamental justice,<sup>34</sup>

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<sup>30</sup> Ibid. at para. 8 and 9. [Xu]

<sup>31</sup> Either directly or through communicating with counsel in order that counsel may do so.

<sup>32</sup> *R. v. Swain* (1991) 63 C.C.C. (3d.) 481 (S.C.C.).

<sup>33</sup> *R. v. Demers* [2004] 2 S.C.R. 489 (S.C.C.).

<sup>34</sup> Just what these principles are has been determined to an extent through the a synthesis of the related jurisprudence, and includes administrative fairness [i.e. natural justice]; "substantive justice" [i.e., principles of criminal responsibility; the autonomy cases]; and fundamental justice in the criminal justice system

provided they do not present a risk to public safety which would constitute a reasonable limitation of the right under s. 1. Under the *Charter*, they have additional rights, some of which are in addition to those in s. 7 and some of which reinforce rights which may be subsumed under the right to life, liberty and security of person in s. 7 or under the principles of fundamental justice also included therein. For instance, a right to a fair trial within a reasonable time and a right to be presumed innocent until proven guilty are guaranteed by s. 11. Under s. 10, persons have the right not to be denied reasonable bail without just cause, and a right not to be arbitrarily detained or imprisoned under s. 9. Pursuant to s. 10, upon arrest or detention, persons have a right to be informed of the reasons for the arrest or detention, the right to retain and instruct counsel and to be informed of that right, and to have the validity of the detention determined by way of *habeas corpus*, which entails being brought forward to a fair hearing. It may be that the limited cognitive capacity test with its low threshold for fitness compromises these rights by requiring mentally disordered accused to stand for trial when they are not reasonably capable of giving full answer and defense to the charges brought against them. As a result, they stand liable to incurring stigmatization, punishment, loss of liberty and arbitrary detention or imprisonment. Detaining for assessment is also an issue, as they could be released on bail unless a just cause exists not to release them, such as evidence of risk of flight or risk to safety.

With an eye to law reform, one also needs to consider that functional capacity in criminal proceedings is not static, but rather dynamic or fluid. The capacity required can depend on the complexity and significance of the matter at issue, a higher threshold being required for a complex defence where greater participation of the accused to strategize and work with defense counsel is needed. Competency, therefore, can vary case by case, or it can even vary during a case whether deciding whether to waive rights, or how to plead, to participating in a complicated

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[i.e., fair trial; requirement for mens rea; full answer and defence; right to remain silent] Though the focus will be on s.7 of the Charter, aspects of fairness explicitly included under ss. 8-14 are also broadly subsumed by the fundamental principles of justice in s. 7. Laws that are vague are void under s. 7, arbitrary laws can be struck down, those that are overbroad can be read-down, and those that are underinclusive can have exclusions read-in. Or if such an approach would leave a gap in the laws, or for other reasons, Courts may make delayed declarations permitting parliament a time limit in which to change the legislation to correct the *Charter* problem.

trial or sentencing hearing, or at the highest threshold, giving testimony.<sup>35</sup> Competency can be raised at any time prior to a verdict, according to s. 2 of the *Criminal Code*: “‘unfit to stand trial’ means unable on account of mental disorder to conduct a defense at any stage of the proceedings before a verdict is rendered.” However, concerns remain regarding competency during the sentencing portion of the proceedings where past record, mitigating and aggravating factors, risk assessments and pre-sentence reports have to be prepared, identified, verified, or evaluated. Competency issues during such proceedings are particularly concerning when Dangerous Offender applications are made by the Crown, requiring complicated evidentiary issues and involving significant consequences in terms of stigmatization and potential indeterminate detention for life.<sup>36</sup>

The Taylor line of cases appears to be fraught with difficulties, not restricted to the limited cognitive capacity test but also underlying the rationale for the fitness requirement. The Supreme Court of Canada in Whittle, affirming Taylor with regard to the “limited cognitive capacity test,” further held that the rationale behind requiring accused persons with mental disorders to stand trial, through the device of selecting a very low standard of cognitive capacity for fitness through the “limited cognitive capacity” test, was not only to strike an effective balance between the constitutional right of the accused to choose his own defence and to have a trial within a reasonable time, but also to ensure that the regime established for treatment of persons who are mentally ill would not be by-passed. The rationale of the need to ensure that the treatment regime for unfit accused not be by-passed is invalid, as those found unfit to stand trial fall under the jurisdiction of and are subject to conditions imposed by the Review Board for the Mentally Disordered. Since passage of Bill C-30, *An Act to amend the Criminal Code (mental disorder) and to amend the National Defence Act and the Young Offenders Act in consequence thereof*, S.C. 1991, C.43 (most of the legislation within being proclaimed on 4 February, 1992) an accused found unfit to stand trial could either be released in the community subject to approved conditions or be detained in a hospital subject to conditions the Review Board approves. The Review Board was to select the least onerous and restrictive of these two options, taking into consideration the need to protect the public from dangerous persons, the mental

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<sup>35</sup> *Supra* note 18 at 197-8.

<sup>36</sup> *Criminal Code*, Part XXIV.

condition of the accused, the reintegration of the accused into society and other needs of the accused.<sup>37</sup> Therefore, those found unfit to stand trial have not been eluding the regime of treatment for mental disorders, although it is recognized in the regime that the most efficacious treatment is consensual and voluntary.<sup>38</sup> On the contrary, rather than eluding treatment, accused found unfit to stand trial are held to a higher standard in this respect. This is so because, while offenders found not criminally responsible who are not considered a significant threat to the safety of the public are discharged absolutely,<sup>39</sup> an absolute discharge is not a disposition available under the Criminal Code to those found to be unfit to stand trial who similarly are not considered a significant threat to the safety of the public. The only limit on the supervisory jurisdiction over those found unfit to stand trial is that the Crown is required to establish, at

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<sup>37</sup> Criminal Code, R.S.C. 1985, c. C-46, s. 672.54 “Dispositions that May be Made by a Court or Review Board: Where the court or Review Board makes a disposition under subsection 672.45(2) or section 672.47 or 672.83, it shall, taking into consideration the need to protect the public from dangerous persons, the mental condition of the accused, the reintegration of the accused into society and the other needs of the accused, make one of the following dispositions that is the least onerous and least restrictive to the accused:

(a) where the verdict of not criminally responsible on account of mental disorder has been rendered in respect of the accused and, in the opinion of the court or Review Board, the accused is not a significant threat to the safety of the public, by order, direct that the accused be discharged absolutely;

(b) by order, direct that the accused be discharged subject to such conditions as the court or Review Board considers appropriate; or

(c) by order, direct that the accused be detained in custody in a hospital, subject to such conditions as the court or Review Board considers appropriate. 1991, c. 43, s. 4; 2005, c. 22, s 20.”

<sup>38</sup> *Ibid* s. 672.55: “No disposition made under section 672.54 shall direct any psychiatric or other treatment of the accused be carried out or that the accused submit to such treatment except that the disposition may include a condition regarding psychiatric or other treatment where the accused has consented to the condition and the court or Review Board considers the condition to be reasonable and necessary in the interests of the accused.”

However, under s. 672.58 there is provision for mandatory, involuntary treatment of the unfit accused if it would return the person to fitness within 30 days, subject to s. 672.59 which further stipulates that this can only be done if psychiatric treatment and any other related medical treatment recommended by a medical practitioner and approved by the Review Board, would restore the accused to a state of fitness within 60 days. The risk of harm to the accused from such treatment must not be disproportionate to the benefit anticipated to be derived from the treatment, and it must be the least restrictive and least intrusive treatment that could be used in the circumstances. S. 672.61 excludes the use of electro-convulsive therapy or psychosurgery under 672.58, as well as the use of any other prohibited treatment. Co-occurring conditions for FASD, such as psychoses, depression or bipolar disorder, may be treated involuntarily under such a regime, if it is thought that such treatment could affect fitness.

<sup>39</sup> *Ibid.* at s. 672.54 (a) where a verdict of not criminally responsible on account of mental disorder has been rendered in respect of the accused and, in the opinion of the court or Review Board, the accused is not a significant threat to the safety of the public, by order, direct that the accused be discharged absolutely.

biannual intervals, that it possesses a prima facie case against them.<sup>40</sup> This limitation is lessened in Bill C-30, as affidavits and oral testimony from previous hearings are acceptable prima facie evidence in such cases, so that the inability to contact a witness or the death of a witness does not terminate the supervisory jurisdiction of the Review Board over unfit accused. In conclusion, no rationale remains to justify such a narrow and arbitrary approach to the fitness test.

#### ***4. Inequalities Created in Mental Disorder Provisions Between those Found UST and NCR***

Accordingly, mental disorder provisions under the *Criminal Code* should be applied in an equitable manner to people with intellectual and cognitive disabilities. Under the present provisions, those with cognitive disabilities found unfit to stand trial, even if not considered a significant threat to the safety of the public, could potentially remain under the jurisdiction of the criminal justice system for life, constituting an unwarranted infringement of their liberty rights under Sections 7 of the *Charter of Rights and Freedoms*.<sup>41</sup> Such an infringement is neither in accord with the principles of fundamental justice in section 7, nor justifiable under section 1 of the *Charter* as a reasonable limit of the right to liberty. In *R. v. Demers*<sup>42</sup> a permanently unfit accused who posed no significant threat to public safety was discharged conditionally for the above reasons, as well as for a violation against arbitrary detention under s. 9. For other unfit accused in similar circumstances, the Supreme Court issued a 12-month suspended declaration of invalidity to Parliament to address the infringement of s. 7 in s. 672.54 of the *Criminal Code*, S.C. 1992.

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<sup>40</sup> *Ibid.* at s. 672.33(1): *Prima Facie Case* to be Made Every Two Years, with provision to extend the period for holding an inquiry, on the basis of an application by the prosecutor or the accused, where extension is required for the proper administration of justice. 1991, c. 43, s. 4; 2005, c. 22, s. 13.

<sup>41</sup> *R. v. Swain* (1991), 63 C.C.C. (3d) 481 (S.C.C.) and *R. v. Demers* [2004] 2 S.C.R. 489.

<sup>42</sup> [2004] 2 S.C.R. 489. For unfit accused, proposed, but unproclaimed, capping provisions for the period under which they would remain under the supervision of the Review Board were repealed by Bill C-10, 2007. It is doubtful if such provisions would have qualified as a reasonable limitation of s. 7 liberty rights and probably explained why Bill-C 10 repealed them.



Parliament responded by adopting Bill C-10, *An Act to amend the Criminal Code (mental disorder) and to make Consequential Amendments to Other Acts*, S.C. 2005, c. 22,<sup>43</sup> which, *inter alia*, included in s. 672.85 a stay of proceedings in the case of mentally disordered, permanently unfit accused who do not pose a significant threat to the safety of the public.<sup>44</sup> However, a stay of proceedings is not equivalent to an absolute discharge, as in a stay the suspension of proceedings is indeterminate but potentially finite in nature, rather than permanent as is an absolute discharge, and, furthermore, the particular statutory provision formulated in Bill C-10 creates a very high threshold for such a stay. Pursuant to s. 672.85, after a suitable assessment and hearing, the Review Board may make a recommendation to the court for a stay. The court, in turn, may order an assessment and hold an inquiry, either on its own motion or on recommendation of the Review Board, and determine, on the basis of clear information, the outcome based on the following 3-pronged test:

- that the accused remains unfit and is not likely to ever become fit to stand trial;
- that accused is not a significant threat to the safety of the public; and
- that the stay is in the interests of the proper administration of justice.

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<sup>43</sup> S.C. 2005, c. 22; House of Commons Standing Committee on Justice and Human Rights, Public Safety and Emergency Preparedness, *Review of Bill C-10, An Act to amend the Criminal Code (mental disorder) and to make consequential amendments to other Acts*, December 2004.

<sup>44</sup> *Criminal Code*, R.S., 1985, c. C-46.

**672.85** (1). The Review Board may, of its own motion, make a recommendation to the court that has jurisdiction in respect of the offence charged against an accused found unfit to stand trial to hold an inquiry to determine whether a stay of proceedings should be ordered if

(a) the Review Board has held a hearing under section 672.81 or 672.82 in respect of the accused; and  
(b) on the basis of any relevant information, including disposition information within the meaning of subsection 672.51(1) and an assessment report made under an assessment ordered under paragraph 672.121(a), the Review Board is of the opinion that

(i) on the basis of any relevant information, including disposition information within the meaning of subsection 672.51(1) and an assessment report made under an assessment ordered under paragraph 672.121(a), the Review Board is of the opinion that

- (i) the accused remains unfit to stand trial and is not likely to ever become fit to stand trial, and  
(ii) the accused does not pose a significant threat to the safety of the public. 2005 c. 22 s. 33.

The third prong of the test, “that the stay is in the interests of the proper administration of justice,” itself has a four-part test to apply following consideration of any submissions of the prosecutor, the accused and all other parties. The four-part test entails consideration of the following four factors:

- the nature and seriousness of the alleged offence;
- the salutary and deleterious effects of the order for a stay of proceedings, including any effect on public confidence in the administration of justice;
- the timing that has elapsed since the commission of the alleged offence and whether sufficient evidence can be adduced to put the accused on trial; and
- any other factor that the court considers relevant.

The third prong and its four factors raise the threshold very high for a stay of proceedings for unfit accused, potentially leaving many unfit accused under long term jurisdiction of the criminal justice system. Suitable test cases remain to determine whether and if so under what circumstances these judicial stay provisions are an infringement of s. 7, s. 9 and s. 15 rights under the *Charter*. Release of NCR offenders can also affect public confidence in the administration of justice, yet they are not subject to such stringent consideration; such disparity, in itself, might not constitute equitable treatment under s. 15. Although public confidence in the administration of justice is a desired characteristic, it can be achieved by the state upholding *Charter* rights that are in accordance with the principles of fundamental justice, and subject to the limitations in s. 1. Furthermore, an implied duty exists to keep the public informed of how the *Charter* impacts upon the administration of justice to properly balance liberty and equality rights of the individual, on the one hand, with concern for utilitarian rights such as public safety, on the other. Public confidence in the administration of justice is not likely sufficiently precise to be considered a fundamental principle of justice under s. 7, but it could perhaps qualify as a reasonable limit prescribed by law under s. 1 of the *Charter*. Even so, the judicial stay provisions may infringe s. 15 of the *Charter* due to inequalities created between NCR and UST accused.

Moreover, in *Demers*, the constitutional remedy of suspended declaration of invalidity under s. 52, along with the presumption against a s. 24 remedy (such as a stay, in this case) when a law is found invalid under s. 52 by way of a suspended declaration, have set a precedent for *Charter* remedies that creates concerns, especially in the criminal context where crucial rights such as liberty are at issue:

Although 12 months may not be a long time for Parliament to fix an unconstitutional law, it is a long time for someone detained or restrained under an unconstitutional law. The accused in *Demers* was fortunately not detained under the unconstitutional law. He was discharged subject to the condition that he live with his family, keep the peace and establish a consensual treatment regime together with his parents and medical professionals. . . .

[However] the presumption against combining s. 52 and s. 24 remedies to the criminal and non-pecuniary context are extremely unfortunate developments that could produce a situation in which people are detained under unconstitutional laws during the long periods—between 6 and 18 months—during which declarations of invalidity are suspended.

The new rule in *Demers* can deprive a successful *Charter* applicant of an effective and meaningful remedy for the duration of the suspended declaration of invalidity. It puts judges in an unnecessary and difficult position of either not suspending a declaration of invalidity when necessary to protect public safety and to allow Parliament to enact comprehensive reforms or of denying the successful accused a meaningful remedy.

The rule against combining remedies under s. 52 and s 24 is formalistic and artificial . . . . It should not be used to restrict access to remedies such as *habeus corpus*. Prior to

*Demers*, the rule had never been applied in criminal cases and it was often avoided in civil cases. There is nothing in the drafting of the *Charter* to suggest that there must be two watertight remedial tracks. If anything the lesson of the drafting of the *Charter* is that we should not have rights without meaningful remedies.<sup>45</sup>

## ***5. Rehabilitative and Treatment Facilities***

Ideally, rehabilitation and treatment facilities for those with intellectual or cognitive disabilities are community-based. Most individuals with intellectual or cognitive disabilities really do not belong in psychiatric facilities and institutions. Furthermore, due to lack of space in

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<sup>45</sup> K. Roach, “New and Problematic Restrictions on Constitutional Remedies: *R. v. Demers*,” 49(3) *Criminal Law quarterly*, December 2004, at 253-255.

designated forensic hospital facilities, many languish in inappropriate detention centres awaiting therapeutic space or suitable community placements with therapeutic supports.<sup>46</sup> Such a state of affairs is unjustifiable as people with intellectual and cognitive disabilities, as noted, need community-based supports, not institutionalized medical or psychiatric treatment, or worse, being warehoused in detention centres with no therapeutic treatment available.<sup>47</sup> Appropriate services in the community to meet their needs are, however, not sufficiently resourced at present. Lack of resources in community is the perennial Achilles' heel for FASD and the crux of any judge's moral dilemma. If community resources cannot adequately control risks, there is often little recourse for judges but to either incarcerate or institutionalize an FASD individual brought before them.<sup>48</sup> Much reform is required if we view individuals with FASD as legitimate seekers of justice in our systems, communities and institutions.<sup>49</sup> FASD individuals are generally not "bad actors" or "delinquents" requiring punishment, but rather, disabled individuals requiring external supports in the community. Our justice system needs to be retooled to enable it to make this distinction correctly, with the assistance of medical experts, and then to respond to the situation therapeutically, without unduly restricting freedom.<sup>50</sup>

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<sup>46</sup> *J. (D.) v. Yukon Review Board*, [2000] YSTC 513 (Y. Sup. Ct.).

<sup>47</sup> The Canadian Association for Community Living, "Reviewing the Mental Disorder Provisions of the Criminal Code through an Intellectual Disability Lens, To be submitted to the House of Commons Sub-Committee on Justice and Human Rights," April, 2002, accessed from the world wide web on July 11, 2009, at [http://www.camh.net/Public\\_policy/Public\\_policy\\_papers/criminalcodeprovisions](http://www.camh.net/Public_policy/Public_policy_papers/criminalcodeprovisions).

Canada. Parliament. House of Commons Standing Committee on Justice and Human Rights, *Review of the mental disorder provisions of the Criminal Code, Report of the Standing Committee on Justice and Human*, Published in 2002, The Committee ([Ottawa], accessed from the world wide web on July 11, 2009, at <http://openlibrary.org/b/OL3728024M/Review-of-the-mental-disorder-provisions-of-the-Criminal-Code>.

<sup>48</sup> The other branches of government, legislative and executive, have a role in creating a just society by providing such community-based resources. They need to "step up to the plate" to ensure that this is done in a coordinated manner. Effective, co-ordinated alternatives would likely reduce overall costs to society.

<sup>49</sup> The term "FASD as seekers of justice" is attributed to Professor Roderick A. MacDonald, Faculty of Law, McGill University, in his presentation "Contemporary Dimensions of Access to Justice" at The Access to Justice for Individuals with FASD Conference in Whitehorse, Yukon, September 18, 2008. He contends that if individuals such as those with FASD enter the justice system from a situation of disadvantage or inequity, the justice system should attempt to ameliorate the inequity, rather than perpetuating or exacerbating it. However, inequitable inputs need to be addressed, not only by the justice system, but by all branches of government. There is a limit as *R. v. L.E.K.* 2001 SKCA 48 demonstrates, to what the Courts alone can do in mandating equitable inputs or in creating systemic change.

<sup>50</sup> Dr. Sterling Clarren, CEO and Scientific Director, Canada Northwest FASD Research Network, "Access to Justice for Individuals with FASD, Exploring the Issues: Structural Brain Alteration from *in utero* Alcohol Exposure and Lifetime Maladaptation," presented at Conference in Whitehorse, Yukon, September 18, 2008.

## **6. *Process for Reform of Laws on Mental Intent***

In view of these concerns, how, then, can fitness cases best be handled? The present author recommends, in a process similar to the one in which the trial judge and the expert psychiatric witness participated in *Jobb*,<sup>51</sup> that an interdisciplinary approach involving judges, lawyers and medical professionals be used to revise the fitness test and make other changes to the weighing of intent in criminal matters so that our legal tests for mental intent or *mens rea* are in accord with advances in medical science since the development of the McNaughton Rules of 1843 and resultant jurisprudence, particularly in the areas of cognitive disabilities and FASD, but also for other mental disorders. It is not defensible policy to continue applying a legal test that is out of step with advances in medical science and would, in the respectful opinion of the present author, be a justifiable reason for the Court to modify the test, in collaboration with medical experts, and considering the issues raised. Such a process would be an evolution of the process begun with the 1843 *McNaughton* decision and the House of Lord's rules in response.

House of Commons Standing Committees, such as the Standing Committee on Justice and Human Rights, are a modern attempt to implement a consultation process. The *14<sup>th</sup> Report of the Standing Committee on Justice and Human Rights: Review of the Mental Disorder Provisions of the Criminal Code* (Ottawa, November, 2002), undertaken under Order of Reference from the House of Commons, sought the input of non-governmental organizations, provincial and territorial officials, review boards and members of the public, to amendment of the 1992 mental disorder provisions in the *Criminal Code*. *Lists of Witnesses* appearing before the Standing Committee and a *List of Briefs* presented to the Standing Committee's reports, are reproduced in Appendix B and C, respectively, of the present document. It should be noted that none of the witnesses presenting, nor any of the briefs submitted, involved known or published experts on FASD, although some, such as the Mental Health Law Program of the B.C. Community Legal Assistance appeared to have some awareness of this condition and related issues. In addition, of the 19 recommendations submitted unanimously by the all-party House of Commons Standing Committee on Justice and Human Rights, five were set aside by the

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<sup>51</sup> Supra note 2. [*Jobb*]

government, even though the committee had proposed them unanimously.<sup>52</sup> The consultation and collaboration attempted by the Committee, although useful, had its limitations, and, ultimately, the package of recommendations as a whole was not adopted by Parliament. Critically, four of the five omissions included those recommendations related to the fitness test and resulting dispositions, and one related to the defense of Automatism. None of the Committee's unanimous recommendations regarding fitness and capacity were adopted by Parliament. For instance, with respect to the definition of "unfit to stand trial" the Committee had recommended:

. . . [T]hat the federal Minister of Justice review the definition of "unfit to stand trial" in section 2 of the *Criminal Code* to consider any additional requirements to determine effectively an accused's fitness to stand trial, including a test of real or effective ability to communicate and provide reasonable instructions to counsel.<sup>53</sup>

Committee discussion is instructive regarding the debate of the issues related to the preceding recommendation:

During the course of this review, the Committee heard conflicting opinions as to the adequacy of the present test for fitness to stand trial. For example, Malcom Jeffcock of Nova Scotia Legal Aid argued that the accused should be able to demonstrate an awareness of the consequences of decisions he or she must make, in order to be considered fit. Similarly, the Canadian Bar Association took the position that the integrity of the justice system requires that an accused be able to communicate effectively and provide reasonable instructions to counsel. The Canadian Psychiatric Association and L'Institut Phillippe Pinel, for their part, Expressed the view that a higher level of functioning should be required of persons attempting to defend themselves. In contrast, the Mental Health Law Program of the B.C. Community Legal Assistance Society recommended simplifying the test [for fitness], arguing that some accused who are developmentally delayed, or have organic brain injuries or fetal alcohol syndrome could remain unfit indefinitely under the current criteria [without a means of exiting the justice system, such as an absolute discharge]. [Please note that editor's comments are in brackets].

Although a more rigorous test for fitness could expand the class of individuals whose "unfit" status is not amenable to treatment, we are of the view that the problem of permanent "unfitness" should be dealt with by providing expanded powers to the courts, as set out elsewhere in this report. Concerning the

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<sup>52</sup> House of Commons Debates, Volume 140, Number 014, 1<sup>st</sup> Session, 38<sup>th</sup> Parliament, Official Report (Hansard), Friday, October 22, 2004.

<sup>53</sup> The 14<sup>th</sup> Report of the Standing Committee on Justice and Human Rights: *Review of the Mental Disorder Provisions of the Criminal Code* (Ottawa, November, 2002), at p. 8-9.

threshold test for “unfit to stand trial,” we are aware of the merits of a test that allows for a speedy resolution of criminal charges for as many accused as possible. However, in light of concerns expressed that the existing common law test could result in an unfair process for some, the Committee would ask the Minister of Justice to consider an amendment to section 2 of the Code that an accused at least possess the capacity to make rational decisions or act in his or her best interests, notwithstanding a refusal to do so.<sup>54</sup>

Expanding powers of the courts to deal with unfit accused so that they do not remain indefinitely under the jurisdiction of the justice system was dealt with in the following recommendation:

The Committee recommends that section 672.65 of the Criminal Code be amended to allow the courts to absolutely discharge a permanently unfit accused either on its own volition or following the recommendation of a review board.<sup>55</sup>

Again, discussion concerning this recommendation is instructive:

A number of those making submissions to us expressed serious concerns about the treatment under Part XX.1 of the *Criminal Code* accorded to unfit accused persons with little or no prospect of becoming fit and being sent to trial. These concerns were expressed with respect to those suffering from Fetal Alcohol Syndrome/Effect, organic brain damage, intellectual disability or developmental delay. These conditions are not easily amendable to treatment or cure—and the consequence is that those suffering from there are unlikely to be capable of becoming fit enough to face trial. Many of these people do not represent a risk to the community.

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The current state of available dispositions assumes that an accused’s unfit condition is a temporary one that can be addressed through treatment or medication, thus enabling the accused to become fit and face trial.

Many of those making submissions to us have addressed this issue. The Criminal Lawyers Association, the Canadian Association for Community Living, the Mental Health Law Program of the B.C. Community Legal Assistance Society, Malcolm Jeffcock of Nova Scotia Legal Aid, the Mood Disorder Society of Canada, the Empowerment Council, the Association of Canadian Review Board Chairs, and the British Columbia Civil Liberties Association all recommended the review boards have the power to absolutely discharge unfit accused persons.

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<sup>54</sup> *Ibid.*

<sup>55</sup> *Ibid.*

The Committee agrees that the difference in the dispositions available to unfit and not criminally responsible accused persons must be addressed. . . . Steps must be taken to ensure that the same array of dispositions available to not criminally responsible accused persons is also available to unfit accused persons suffering from conditions or disabilities that are not amenable to medication or treatment to make them fit to stand trial.<sup>56</sup>

A recommendation requiring the inclusion of fitness to be sentenced in the definition of fitness in s. 2 of the Criminal Code was made:

The Committee recommends that the definition of “unfit to stand trial” in section 2 of the *Criminal Code* be amended by adding the words “and to be sentenced” to the title and the words “or sentence impose” after the words “verdict is rendered” in the definition itself. As well, section 672.11(a) of the *Code* should be amended to allow the court to order an assessment in such cases. Finally, subsection 672.38(1) of the *Code* should be amended to give the Review Board jurisdiction in such cases.<sup>57</sup>

Discussion of the preceding recommendation is illuminating:

The test for “fitness to stand trial” is dealt with in great detail elsewhere in the report. A gap in the definition has been brought to the Committee’s attention by several of those participating in its review process, including the British Columbia Civil Liberties Association, the Mental Disorder Advisory Committee to the Attorney General of Ontario, and the Association of Canadian Review Board Chairs.

The definition of unfitness to stand trial found at section 2 of the *Criminal Code* in its present form covers the criminal proceedings at any stage up to the rendering of the verdict. The *Code* does not provide for the accused who is fit at the time of conviction, but becomes unfit between that day and the imposition of the sentence by the court having jurisdiction. The court cannot order a fitness assessment under section 672.11 of the *Code* and the Review Board cannot assume jurisdiction over the convicted accused at this stage of the proceedings under section 672.38 of the *Code*.

In such a situation, the unfit convicted person cannot participate meaningfully in the pre-sentence process and is not likely to be able to properly instruct Counsel. As the Committee was told by some of those sitting in our courts and having direct experience with these types of situations, the law in its present form leaves judges with the prospect either of sentencing unfit convicted persons or distorting the law to avoid doing this. This puts sentencing judges in an untenable situation.

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<sup>56</sup> *Ibid.*

<sup>57</sup> *Ibid.*



The Committee believes that this gap in the present law must be filled. This can be easily done . . . .<sup>58</sup>

While the House of Commons Standing Committee process provided an airing of views on the topic of mental disorder provisions in the Code, the Committee pre-dated the development of the *Canadian Diagnostic Guidelines for Fetal Alcohol Spectrum Disorder* in 2005 by a sub-committee of the Canadian Public Health Agency's National Advisory Committee on Fetal Alcohol Spectrum Disorder. No national FASD Society existed to advocate or submit expert briefs to the House of Commons Standing Committee in one voice, as with other Mental Disorders. A dearth of data and statistics affects both FASD, specifically, and mental disorders, generally, and this dearth was identified by the Standing Committee as one of the systemic issues, along with lack of resources for treatment, and lack of education to overcome stigmatization, impacting mental disorders in the criminal justice system. The Federal Department of Justice dealt with this issue at some length in its response to the Standing Committee's recommendations to that effect:

The Committee's report is highly critical of the lack of research and data available from the Department of Justice to assist in the parliamentary review. . . . Contrary to the Committee's allegation that the Department of Justice is "not in a position to respond knowledgeably and comprehensively to the findings and recommendations contained in this report" owing to a lack of data, the Department is confident it has the requisite expertise and knowledge to determine the extent and nature of necessary reforms. . . .

The research and data provided to the Standing committee on Justice and Human Rights by the Solicitor General in the course of the Committee's Review of the *Corrections and Conditional Release Act* is indeed an excellent example of a comprehensive review. However, it should be noted that the Solicitor General of Canada is solely responsible for the policy and implementation of the *Corrections and Conditional Release Act*.

The *Criminal Code*, although a federal statute, is not solely a federal responsibility. The provinces are responsible for both law enforcement and the administration of justice. Moreover, the Department of Justice's criminal law research program must address the whole range of criminal law issues. Unfortunately, no dedicated resources were made available to the Department following the parliamentary committee's inclusion of

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<sup>58</sup> *Ibid.*

a review clause in the 1992 legislation reforming the mental disorder provisions.

In preparation for the anticipated review of the mental disorder provisions which was to have occurred in 1997, and as part of the Department's research plan to monitor the implementation of Bill C-30, the Department of Justice made efforts in the early 1990s to work with the Canadian Centre for Justice Statistics (CCJS) to collect data from Review Boards across Canada. However, the legislative changes that came into force in February 1992 increased the workload of Review Boards, and implementation of the new Law took precedence over data collection. . . .

To collect the data necessary for a further parliamentary review, two currently available data sources will need to be further examined. The files from the Review Boards across Canada are one, while the other source is the annual Adult Criminal Court Survey (ACCS) conducted by the CCJS. . . . Unfortunately, most Review Boards across the country do not have compatible computerized systems that would allow automated data collection. . . . [T]he CCJS does not include data from Superior Courts. . . . Furthermore, the CCJS does not routinely present data on these two groups in their annual *Juristat*.

. . . .

In order to respond to the Committee's concern about the inadequacy of data, the Department of Justice is exploring two options. One is to work with the Review Boards to collect more detailed data, and the second is to work with CCJS to collect reliable data on the number of mentally disordered accused appearing before the courts each year. . . . In addition, qualitative interviews or surveys might be conducted with officials from Review Boards across the country. This would assist in determining how the provisions are working and identifying any new concerns or emerging issues. The focus would be on the operational issues facing the Review Boards.

However, the availability of financial resources to undertake data collection efforts and qualitative interviews or surveys must be considered. . . . It would be necessary to contract out the data collection and database maintenance. In addition, any tracking study would require substantial commitments of both time and money to follow mentally disordered accused individuals through the system. . . .<sup>59</sup>

The foregoing information does little to reassure us to entrust blindly mentally disordered accused to the great maw of the justice system where it would seem that they are largely forgotten. Even tracking them has not been a funding priority, rendering the need for absolute discharges and other viable exits from the system more urgent.

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<sup>59</sup> *Ibid.*

In the House of Commons Debate, Peter Julian, Member for Burnaby—New Westminister, on Friday, October 22, 2004, surrounding the adoption of *Bill C-10*, commented on the process from the perspective of a Member of Parliament:

Generally, Bill C-10 seems to be a good response to the report of the Standing Committee on Justice, Human Rights, Public Safety and Emergency Preparedness. It [Bill C-10] deals with complex issues in obscure legalese, and requires a high degree of legal proficiency.

I would like to take this opportunity to emphasize the importance of setting standards for clear and simple language in legislation and legal documents. Should a member of Parliament have to be a lawyer in order to be able to do his or her work and understand a bill? In order to read and understand Bill C-10 properly, one needs a copy of the Criminal Code.

I urge the government to introduce bills that are written in plain and accessible language. Please do not tell me those who want to participate in democratic life in this country need to be lawyers. We should not write bills that can be deciphered only by a few hand-picked lawyers who are paid \$400 an hour.

I also want to emphasize the absolute necessity that people with a mental Disorder be well represented. This brings up the fundamental issues of access to justice. . . .<sup>60</sup>

Despite an intelligible Standing Committee Report having been filed, this MP sounds overwhelmed by the technicalities of the mental disorder provisions in *Bill C-10*, and one is skeptical, despite a process which incorporates expert consultation and advice, whether the parliamentary process which ultimately is resolved by individual members voting on the floor of the House, has the “capacity” to make informed decisions regarding the complex topics of this nature brought before them. Where such complex decision-making of this nature is required, courts should perhaps be hesitant to defer too much to Parliament.

The Right Honourable Beverley McLachlin, C.J.C., noting the need for a more appropriate response from our courts and justice system concerning the prevalence of mental illness and addictions, and the corresponding need to look at underlying factors bringing such individuals into conflict with the law, called for collaboration among interdisciplinary professional teams and community to fashion solutions, including new approaches such as specialized courts, specifically making mention of mental health, drug treatment, *Gladue* courts,

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<sup>60</sup> Hansard, House of Commons Debates, Volume 140, Number 014, 1<sup>st</sup> Session, 38<sup>th</sup> Parliament.

and community courts with standby triage teams.<sup>61</sup> The goal of such specialized courts is diversion of those that appear before them from the justice system to more effective treatment and supports in the community.

As the Supreme Court of Canada in *Whittle* created, or rather lent its imprimatur to the “limited legal capacity test,” the test being court-made rather than a creature of statute, the courts can therefore change it, interpret it differently or limit its application. Parliament could also amend relevant sections of the *Criminal Code*. However, such amendment could be a lengthy and fraught process as the information presented for the eventual adoption of *Bill C-10* demonstrates, not likely matching the expeditious six weeks that it took for British Queen’s Bench judges in 1843 to present the fully formulated McNaughton Rules in reply to the House of Lord’s request. In the meantime, the fitness and culpability net may be cast too wide for individuals with complex cognitive disabilities such as FASD, or with other diagnoses not contemplated by the rudimentary conception of mental disorders that underlies the McNaughton Rules and their legacy. This is so because mental disorders considered when framing the McNaughton rules were primarily psychotic delusions. The Anglo-American system of law is based on presumptions of fitness, freedom of choice and individual responsibility for such choices, presumptions difficult to rebut, barring psychotic delusions, automatism or other profound impairment:

This constellation of deficits poses significant obstacles to the fair treatment of FASD persons in the criminal justice system. Persons with FASD, as a group, challenge the underlying premise that defendants understand the relationship between actions, outcomes, intentions and punishment. The treatment of FASD defendants raises fundamental questions about how we assess individual responsibility, both at the guilt-determining and sentencing stages of the adjudicative process.<sup>62</sup>

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<sup>61</sup> Remarks of the Right Honourable Beverley McLachlin, P.C., “Medicine and the Law: The Challenges of Mental Illness,” February 17 and 18, 2005, University of Alberta; Remarks of the Right Honourable Beverley McLachlin, P.C., Presented at the Empire Club of Canada, Toronto, March 8, 2007, “The Challenges We Face”.

<sup>62</sup> Moore, T. E., PhD, C Psych. & Justice Melvyn Green, “Fetal Alcohol Spectrum Disorder and the Criminal Justice System,” *Criminal Reports*, Vol. 19, Part 1, July 2004, p. 14.

## 7. *Paradigm Shift*

Advances in medical science, such as the identification and understanding of complex neurological conditions like FASD, can do much to fine-tune traditional presumptions of the justice system and provide an evidence base for exceptions, or ideally revision, to them. The prevailing view that has persisted for centuries, namely that mental disorder is not a valid excuse (unless it is so extreme that the person is not even aware of what they are doing or that it is wrong), and that psychiatry inappropriately interferes with society's ability to punish those who have been engaged in criminal acts,<sup>63</sup> will be resistant to revision. Such revision requires a paradigm shift as profound as when Galileo's telescope and resulting heliocentric views challenged the sacred geocentric or earth-centered model of the universe. Insanity or mental disorder defense jurisprudence is both incoherent<sup>64</sup> and controversial, and tends to defy rational unpacking due to layers of fear, myths and misconceptions.<sup>65</sup> If this area of the law is not to

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<sup>63</sup> Michael L. Perlin, "Unpacking the Myths: The Symbolism Mythology of Insanity Defense Jurisprudence" (1990) 40 Case W. Res. 599.

<sup>64</sup> There is no unified, integrated theory of mental disorder and criminal responsibility, but rather a number of piecemeal, disconnected and compartmentalized rules, for: fitness, being not criminally responsible, various levels of intention (specific or general intent), other gradations of mens rea (knowingly, willfully, etc.), negligence, defenses and excuses, and mitigating and aggravating factors at sentencing, altogether creating a disjointed, arcane and often irrational maze.

<sup>65</sup> Jennifer S. Bard, "Re-arranging the Deck Chairs on the Titanic: Why the Incarceration of Individuals with serious Mental Illness Violates Public Health, Ethical, and Constitutional Principles and Therefore Cannot be Made Right by Piecemeal changes to the Insanity Defense" (Spring, 2005) 5 Hous. J. Health L. & Policy 1, at \*2 and \*5. There are many inconsistencies in the legislation and case law, often in reaction to controversial cases and public outcry in response. An ongoing public discourse about the intersection of mental illness and the law might allay some of the emotional reaction to sensational cases, including those rare cases where either NCR or UST acquittees, or mentally disordered detainees prematurely released, reoffend. As mental illness becomes less stigmatizing, individuals with mental illness feel more able to tell their stories and bring the issue out of the shadows, to dispel ignorance and fear. Adequate access to mental health treatment and supports in the community (subsequent to the massive de-institutionalization that occurred in the 1960s and 1970s] would do much to prevent the tragedies that result in controversial cases, resultant public outcries and pendulum swings to over-incarceration of the mentally disordered. Following the public outcry in the United States over the acquittal of John Hinckley, the modern equivalent of Daniel McNaughton, as Hinckley attempted to assassinate President Reagan, wounding his Press Secretary and killing a policeman instead, many states modified their insanity defense and Idaho, Montana, Utah and Kansas removed the insanity defense from their legislation. Through removal of the insanity defense, by default, the law reverted to a pure mens rea standard of guilt. However, the pure mens rea standard of guilt yields results similar to the McNaughton rule's requirement of a complete lack of knowledge or awareness, as the latter is the equivalent of a complete lack of criminal intent or mens rea. Hinckley's mental state was at issue, because although his defense team provided expert testimony that he was psychotic, Hinckley claimed neither to have been unaware of what he was doing, nor that his act was based on a decree from a higher power. He was acting out of an extreme, deluded obsession with movie actress, Jodie Foster, attempting to get her attention through the fame that would result from murdering the President. At that time, in the District of Columbia, there was a combined McNaughton-rule insanity

remain gridlocked in an incoherent jurisprudence, these fears, myths and misconceptions must be brought to light and replaced with medical and scientific understandings.

A disparity tends to exist between scientific and empirical research, on the one hand, and public attitudes, on the other, whether manifested in judicial and legislative decision making, media coverage or how we think about the mentally ill. The stigma of the eighteenth century “wild beast” conceptions of the mentally ill<sup>66</sup> persist in public perception, rather than reflecting our current knowledge of the subject. We remain willfully blind to the new scientific and empirical evidence, apparently stuck in a medieval culture of punishment flowing from notions of sin, evil and fear associated with mental illness.<sup>67</sup> Post-*Swain* and *Demers*, mentally disordered offenders cannot be indeterminately held on a Lieutenant Governor’s warrant, and if considered non-dangerous, must be released into the community. No longer are they to be shut forever away in secure, forensic institutions, but are to be free to wander amongst us, perhaps bringing to the fore renewed public fears and concerns over such defenses, such acquittees and the experts involved in their release. The Schizophrenia Society of Canada addresses these fears in their Presentation to the Standing Committee on Justice, Human Rights, Public Safety and

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and irresistible impulse defense as recommended by the American Law Institute that encompassed Hinckley’s insane obsession. In addition, the prosecution bore the onus of proving sanity beyond a reasonable doubt once the defense had presented enough evidence to raise the issue of insanity. Hinckley was indeterminately detained in a secure, forensic psychiatric hospital, eventually granted escorted leaves in the Washington area and unsupervised leave to visit his parent’s at their home. In spite of his hospitalization, Hinckley did not fade from the public spotlight. Shortly after commitment and perhaps as part of his obsession, he further fueled the flames of public outrage when he gave an interview to *Penthouse* magazine in which he described a typical day at St. Elizabeth’s Hospital: “I see a therapist, answer mail, play my guitar, listen to music, play pool, watch television, eat lousy food, and take delicious medication.”

A very different outcome occurred in the Andrea Pia Yates case, on the other side of the debate, which was equally controversial. Andrea Yates drowned her five children believing she was saving them from God’s judgment. She was suffering from post-partum depression, as well as a long term severe psychotic depression, but because she was aware of what she was doing at the time of the offence and did not claim to act under a deific decree, she was found guilty of murder by a Texas jury, rather than “not guilty by reason of insanity,” and sentenced to life imprisonment. Bard concludes, “the dissatisfaction with the Yates’ conviction exposes a serious lack of societal consensus regarding how mental illnesses affects behavior, and more importantly, how we should assign criminal responsibility to people that we know experience some impairment in brain function” (\*8).

<sup>66</sup> *Rex v. Arnold*, Y. B. 10 Geo. 1 (1724), reprinted in *A Complete Collection of State Trials*. Judge Tracy, in this case, formally recognized the “wild beast” standard of insanity, by stating that for someone to be insane, he must be totally deprived of his understanding and memory, and not know what he was doing anymore than an infant, a brute or a wild beast.

<sup>67</sup> *Supra* note 65. [Bard]

Emergency Preparedness, regarding *Bill C-13, an Act to amend the Criminal Code, the DNA Identification Act and the National Defence Act*,<sup>68</sup> submitted February 1, 2005:

The Schizophrenia Society of Canada (SCC) acknowledges that there is a relationship between mental illness and violence. To ignore this relationship would be a disservice to both ill individuals and their families. But, it is extremely important to remember two points:

1. Research indicates that the risk associated with mental illness is “modest” relative to risk associated with gender, age, education and previous history of violence.
2. Violence is not a symptom of schizophrenia.

According to Dr. E. Fuller Torrey, there are 3 primary predictors of violence:

1. History of past violence – applies to individuals with or without mental illness.
2. Drug and alcohol abuse –applies to individuals with and without mental illness.
3. Failure to take medication.

By providing more resources for treatment programs, that include [supervision of the taking of] medication, the relationship between mental illness and violence can be addressed in a way that is beneficial to all individuals, their families and public safety.<sup>69</sup> [Please note that editor’s comments are in brackets.]

## ***8. The Strained Encounter Between Absolute Law & Uncertain Science***

Western positive law and psychiatry often appear incompatible, the former being determinate, reductionist and objective, assuming behavior originates from free will; the latter indeterminate, contextual and subjective, assuming behavior is influenced by a host of biological, psychological, physiological, environmental and social factors, and frequently is driven by unconscious forces. The former assumes a definite tipping point of basic awareness of

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<sup>68</sup> <http://www.schizophrenia.ca/TreatmentNotPunishment.pdf>

<sup>69</sup> *Bill C-13* was proclaimed in 2007. It provided for the making of DNA data bank orders against a person who has committed an offence but who was found not criminally responsible by reason of mental disorder. A person found not criminally responsible by reason of mental disorder is neither found guilty of the offence, nor convicted. Including mentally ill individuals with convicted criminals, in requiring DNA samples, thus perpetuates the stigma and discrimination endured by a severely marginalized section of the community.

reality that clearly separates the sane from the insane,<sup>70</sup> and the latter, degrees of responsibility that can affect mental intent and culpability all along the continuum of mental disorder, in varying degrees:

If contemporary society shares the belief of post-McNaughton Victorian England that only those who do not know what they are doing can be exempted from criminal responsibility, then we need to acknowledge that individuals will be responsible for their actions unless they demonstrate this [extreme] lack of awareness. Such a belief is not the same as an appreciation of mental illness as a continuum, because it only recognizes mental illness that takes the form of blocking awareness. It is for this reason that measures like the “guilty but mentally ill” type of verdict are inherently unsatisfactory to those who see mental illness as having a wide-ranging impact on human behavior. . . . [By overlooking this wide-ranging impact of mental illness on behavior], we abandon the basic tenets of fairness that underlie the Anglo-American principle of holding people responsible for their actions according to their capacity to understand and obey societies rules.<sup>71</sup> [Please note that editor’s comments are bracketed.]

Brain imaging (MRI, fMRI and DTI) of persons with FASD, compared to healthy peers with no prenatal alcohol exposure, non-invasively confirm underlying alterations in brain structure and function of persons with FASD, including lower activation of relevant areas of the brain, with frontal lobe, caudate and hippocampus being most impaired.<sup>72</sup> Moreover, white matter defects and deficits, and structural deficits in the parietal area, cerebellum and brain stem of the prenatally alcohol exposed detected during brain imaging act to disrupt neural networking

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<sup>70</sup> Ibid. at \*23, quoting from Scott Turow’s *Reversible Errors*, 13 (Farrar, Straus & Girous, 1st ed. 2002) where he portrays a lawyer’s initial assessment of a client on death row for murder: “Looking at Rommy’s eyes zaq about like frenzied bugs near a light, Arthur held little doubt why his prior lawyers had focused on a psychiatric defense. As people commonly used the word “crazy,” Rommy Gandolph without question was. Yet not crazy enough. Sociopathic. Borderline personality disorder, maybe even flat-out schizoid. But not thoroughly lost in the wilderness, not so entirely without a compass that he did not know wrong from right, which was what the law required for a defense.” Automatism is another condition that can render one removed from reality and from knowing right from wrong.

<sup>71</sup> *Supra* note 65. Bard, J. S., “Re-arranging Deck chairs on the Titanic: Why the Incarceration of Individuals with Serious Mental Illness Violates Public Health, Ethical, and Constitutional Principles and Therefore Cannot be Made Right by Piecemeal Changes to the Insanity Defense” (Spring, 2005) 5 Hous. J. Health L. & Policy 1, at \*56 and \*57.

<sup>72</sup> Susan J. Astley, Heather Carmichael Olson, Kimberly Kerns et al. “Neuropsychological/behavioral outcomes,” *Canadian Journal of Pharmacology: Fetal Alcohol Research* (in Press, 2009); “MRS,” *Magnetic Resonance Imaging* (in Press, 2009); “fMRI,” *Journal Neurodevelopmental Disorder* (In Press, 2009), “fMRI,” *Journal of Neurodevelopmental Disorder* (In Press, 2009); “MRI,” (Submitted/Under Review). All are available at <http://depts.washington.edu/fasdpn/htmls/research.htm>.



pathways between different areas of the brain required for visual and auditory processing, complex learning including complex mathematics, executive functioning and self-regulation.<sup>73</sup>

However, clinical research with FASD is subject to limitations not encountered in animal studies where recruitment of alcohol exposed participants is not an issue, and maternal alcohol dose, timing and duration of exposure and developmental stage of fetus can be controlled, as well as human research requiring the highest standards of ethical and consent protocols. Replication of study results required for generalizability is therefore more challenging for human studies. Notwithstanding the foregoing, brain imaging studies affirm the negative effects of alcohol exposure on the developing fetal brain, derived from autopsy studies and neuropsychological findings, adding to the weight of quality evidence. Further neuroimaging research will, no doubt, expand understanding of the brain-based nature of FASD.<sup>74</sup>

Nevertheless, although caution is required in the use of brain scans as evidence in particular criminal cases,<sup>75</sup> the current state of knowledge is sufficient to challenge the black and white dichotomy of existing legislation and jurisprudence regarding *mens rea* and responsibility. In reality, responsibility for criminal action is much more complex than an “on” or “off” or “black” or “white” state. Such a simplistic conception does not consider the evidence of modern brain science which indicates a continuum of brain functioning rather than a dichotomy or “on” and “off” nature of cognitive functioning, awareness, and impulse control, except perhaps for psychotic states where awareness of external reality may be blocked off during these episodes.

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<sup>73</sup>Catherine Lebel, Carmen Rasmussen, Katy Wyper, Gail Andrew, and Christian Beaulieu, “Brain Microstructure is Related to Math Ability in Children with Fetal Alcohol Spectrum Disorder” (2010) 34(2) *Alcoholism: Clinical & Experimental Research* 354-363.

<sup>74</sup> Andria L. Norman, Nicole Crocker, Sarah N. Mattson & Edward Riley, “Neuroimaging and Fetal Alcohol Spectrum Disorders” (2009) 15 *Developmental Disability Research Review*, 209-217.

<sup>75</sup> Helen Mayberg, “Does Neuroscience Give Us New Insights into Criminal Responsibility?” Law and Neuroscience Project (developed by Michael S. Gazziniga and Jed S. Rakoff, Judge, United States District Court, Southern District of New York) Andrew S. Mansfield, ed., *A Judge’s Guide to Neuroscience* 37 (Sage Centre for the Study of the Mind, University of California, Santa Barbara: 2010), accessed from the worldwide web April 20, 2011 at <http://www.sagecenter.ucsb.edu/A%20Judges%20Guide%20to%20Neuroscience.pdf>. Introducing neuroscience evidence in a particular case can be a double edged sword, however, as it can be perceived as a risk factor increasing judge’s propensity to incarcerate, notwithstanding that FASD alone, without accompanying neuroscience evidence can have that effect.

On the evidence, a measured consideration of varying levels of responsibility based on brain functioning of all those with serious mental disorders is required.

Our laws are artificial, socially constructed, ad hoc and contingent, a shorthand way of describing a complex matrix of social and political forces, and interpreted by a judiciary that is relatively homogenous in terms of class, race and gender. More specifically, law is about power, as it constitutes and legitimizes the power relations in society. As such, it is a terrain of struggle over the meaning and quality of societal existence, not based on social consensus when deep cleavages abound in society, but rather in such circumstances, based on power and powerlessness. Witness the over-representation of Aboriginal peoples in our justice system, despite *Gladue* factors which are broadly circumvented through mandatory minimum sentencing provisions and other principles and practices of sentencing, compared to the relative lenient treatment of white collar crime. Deeply embedded in the power dynamics of society, law either reinforces disadvantage or challenges it.<sup>76</sup> On the cusp of change and reform, law makers have the opportunity to do justice to the powerless, the vulnerable and disabled. Any process of reform should include representation from the less elite or less powerful groups, such as parents of individuals with FASD or other disabilities, as well as from a broad cross-section of Aboriginal peoples.

Schneider and Bloom address the strained, but necessary relationship between law's reductionism and psychiatry's holistic approach, contrasting ways of knowing often involving differing methodologies and purposes:

The unsteady and sometimes rocky relationship between law and psychiatry owes much of its ambivalence to the fact that the two disciplines are somewhat ill-assorted. The law calls for exactitude in its understanding of accused persons who come before it—precision that psychiatry concedes it cannot supply. Nevertheless, psychiatric expertise is inextricably tied to a number of issues that arise in the everyday practice of criminal (and civil) law. Difficulties occur when the law, in the course of preserving an interest it holds sacred, tries to reconfigure psychiatric wisdom and expertise to fit its perceived needs. Doing so is equivalent to forcing the wicked stepsisters' feet into the glass slipper destined only for Cinderella.<sup>77</sup>

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<sup>76</sup> Richard F. Devlin, "Jurisprudence for Judges: Why Legal Theory Matters for Social Context Education," presented at the 2001 Canadian Judicial Council, 27 *Queen's L.J.* 161-205.

<sup>77</sup> *Supra* note 18 at p. 183. [Schneider & Bloom, "R. v. Taylor: A Decision Not in the Best Interests of Some Mentally Ill Accused."]

Yet, both being human endeavours, an area of overlap or common ground needs to be found where law and psychiatry can collaborate on relatively equal footing without reverting to rigid procrustean beds or one-size only glass slippers.

Returning to original principles may be of assistance in such reconciliation. The modern, moral basis of the insanity defense is attributed to H. L. Hart's ethical imperative that there is no just punishment without deserts and no deserts without responsibility.<sup>78</sup> However, responsibility or lack thereof is not a clear dichotomy, not an all-or-none state. Rather a large unexplored area exists between individuals who are fully responsible and those who bear no responsibility at all.<sup>79</sup> This large unexplored area, containing people with mental disorders who do not exhibit a total loss of contact with external reality, in which most cases of FASD fall, requires consideration:

There is also a moral principle that requires not just the excusing of "some crazy" people, but rather measured and compassionate consideration of the varying levels of responsibility of all people with serious mental illness. It is easy to set such a high standard for excusing behavior that almost no one ever meets it. However, society is not absolved of moral responsibility by excusing people who are the most severely impaired by mental illness, while treating all other mentally ill people exactly like ordinary criminals. I suggest that the moral obligation to consider the whole range of mental illness in assessing criminal responsibility co-exist with the moral obligation to provide access to appropriate treatment and care for all people with mental illness.<sup>80</sup>

Competence, fitness or capacity is not a binary variable, with discrete categories of "fit" or "not fit," but rather is a continuous variable or spectrum of criminal responsibility that exists in a certain context. As a result, we need to eschew the Procrustean nature of standard legal tests and other reductionist tendencies. Instead, we should make provision for a process that takes into consideration the holistic background of the offender and the offence, the circumstances leading up to the offence, as well as evidence from modern medical science as to the nature of cognition, intention, volition, affect and responsibility, along with expert evidence as to the state of these in the offender at the time of the offence and how they would affect his or her degree of culpability.

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<sup>78</sup> *Supra* note 1. [Herbert Lionel A. Hart, *Punishment and Responsibility* (Oxford: Clarendon Press, 1968) at 44, 183-4 and 152.

<sup>79</sup> *Supra* note 65 at \*4. [Bard]

<sup>80</sup> *Ibid.* at \*5. [Bard]

## **8. Need for Public Discourse in the Face of Controversial Cases**

These changes require a paradigm shift in our thinking about fitness which cannot be achieved without controversy, absent a public discourse about whether it is morally, legally and scientifically valid to excuse from responsibility only those who essentially lack all awareness of external reality,<sup>81</sup> or whether other forms of mental illness might diminish responsibility as well. The belief underlying the insanity or mental disorder defense, that unless mental illness results in a complete lack of awareness of external reality, it cannot affect determinations of criminal responsibility, needs to be rationally unpacked through open, informed public discussion:

Without open discussion about the effect of mental illness on the brain and on our current beliefs about personal responsibility, it will not be possible to take any meaningful measures to avoid unjust treatment of people with mental illness who commit crimes.<sup>82</sup>

Without such public discourse, the outcry from controversial cases, such as the *Hinckley* insanity acquittal (following the gradual widespread adoption of the American Law Institute's *Model Penal Code*,<sup>83</sup> designed *inter alia* to address the reliance of McNaughton Rules' jurisprudence solely on cognitive powers, through supplemental inclusion of affective and volitional components of behavior) and resultant pendulum swings in legislation and jurisprudence, may not be avoided. Post-*Hinckley*, the Guilty But Mentally Insane (GBMI) amendment adopted in many states was largely a result of such a pendulum swing, subsequently

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<sup>81</sup> Basically, the impact of the limited cognitive capacity test.

<sup>82</sup> *Supra* note 65 at \*6. [Bard]

<sup>83</sup> § 4.01(1), (Proposed Office Draft, 1962), "A person is not responsible for criminal conduct if at the time of such conduct as a result of a mental disease or defect he lacks substantial capacity to either appreciate the criminality [wrongfulness] of his conduct or to conform his conduct to the requirements of the law." A number of other jurisdictions have adopted legislation to expand McNaughton Rule jurisprudence to include a volitional component encompassing lack of impulse control, "the capacity to control the person's actions," including but not limited to England (*Homicide Act*, 1957, s. 2, which reduced murder to manslaughter in such cases), Australia's Northern Territory (*Criminal Code* (NT) s. 237), New South Wales (*Crime Act* 1900 (NSW) s. 23A, note that s. 23A, like the *Model Penal Code*, required that responsibility for any act or omission be substantially impaired, rather than either complete impairment, or merely trivial or minimal impairment); *Crime Amendment (Diminished Responsibility) Act*, 1997 (NSW), and Queensland (*Criminal Code* (Qld) s. 304A, which like the *Model Penal Code* applies to all acts or omissions, not merely homicide), as well as the *Rome Statute of the International Criminal Court* which Canada ratified in 2003. In addition, McNaughton Rule jurisprudence per se expanded in some jurisdictions to include the volitional component, or alternatively, diminished responsibility provisions took over aspects that would have been previously within the ambit of the McNaughton Rules [*HM Advocate v. Dingwall* (1867) 5 Irvine 466; *R. v. Byrne* (1960) 2 QB 396 (Court of Appeal, Birmingham Assizes) which required that responsibility be substantially impaired; *R. v. Tumanako* 64 A Crim R 150; and Nigel Walker and Sarah McCabe, *Crime and Insanity in England*, vol 1 (Edinburgh University Press, 1968) ch 8] accessed from the worldwide web on April 21, 2011 at <http://www.ipc.nsw.gov.au/lrc.nsf/pages/DP31CHP4.>]

criticized as adding nothing but stigma to the guilty verdict, with no increased access to therapeutic approaches which the designation implies. As a safety valve for any lag between legislative or jurisprudential reform, on the one hand, and public opinion, on the other, meaningful consultation regarding public policy in this area might avoid bringing the administration of justice into disrepute through such controversial insanity or mental disorder acquittals,<sup>84</sup> particularly when cases involve issues of national security which strike at the very heart of the state, as in *Hinckley*<sup>85</sup> and *McNaughton*,<sup>86</sup> or which offend widely held core values, as in the macabre cases of Jeffrey Dahmer<sup>87</sup> or Vince Li.<sup>88</sup> It should be noted, however, that it was not as much the volitional component of the *Model Penal Code* that contributed to the controversial insanity acquittal in *Hinkley*'s case, as it was the onus which the *Model Code* placed on the prosecution to prove the accused sane once sufficient evidence to the contrary had been entered. This reverse onus in the presumption of sanity incorporated into the *Model Penal Code* tipped the balance too far, not the inclusion of the volitional component *per se*. Responsible and informed media coverage which provides a balanced view, rather than the fanning of flames of controversy, is an additional factor often lacking in the context of high profile mental disorder or insanity acquittals. In this vein, the *Globe and Mail* deserves kudos for their recent, excellent sequel of articles on individuals dealing with mental illness outside the context of sensational criminal charges, where more light than heat can be shed on the issue.<sup>89</sup> The 2002 House of Common's Standing Committee on Justice and Human Rights when

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<sup>84</sup> The role of the media in such furor also needs to be addressed, perhaps through means such as codes of ethics for journalists and for the industry.

<sup>85</sup> *United States v. Hinckley*, 525 F Supp. 1342 (D.D.C. 1981), clarified 529 F. Sup. 520 (D.D.C.), aff'd. 617 F.2d 115 (D.D.C. 1982).

<sup>86</sup> Supra note 6. [*McNaughton*]

<sup>87</sup> In 1991, Jeffrey Dahmer of Michigan was charged with the torture, killing, necrophilia and cannibalism of 17 young men. He pled not guilty by reason of insanity, but was found guilty. In 1994, he was killed in prison by another inmate.

<sup>88</sup> In July 30, 2008, Vince Li decapitated and cannibalized Tim McLean, a fellow passenger travelling on a Grey Hound Bus heading for Winnipeg. Mr. Li, suffering from schizophrenia, was found NCR and detained in a forensic psychiatric hospital until recovery when he might no longer be a threat to public safety. The family of Tim McLean are calling for a life time institutional detention for Mr. Li which, should he recover to a point where he is no longer a threat to public safety, would require a change in legislation.

<sup>89</sup> *Toronto Globe and Mail*, 2008: <http://v1.theglobeandmail.com/breakdown/>

reviewing the mental disorder provisions recommended education and awareness to counter the perception that all mentally disordered people are violent and dangerous and will remain so:

The committee recommends that the federal, provincial and territorial ministers responsible for justice take the necessary steps to ensure that education programs on the mental health and forensic systems, and related issues, are developed for, and delivered to, judges, lawyers, court personnel, law enforcement personnel, corrections staff, and others coming into contact with mentally disordered accused offenders. As well, a similar education program should be developed for delivery to the public to dispel stereotypes surrounding mental illness.<sup>90</sup>

## ***9. Summary of Concerns with the Current System for Determining Capacity and Culpability***

Many problems exist with the present system for determining capacity and criminal culpability, whether considering solely FASD or mental disorders generally. Eight concerns have been discussed at some length and bear reviewing at this point. First, the effect of the *Taylor* decision's narrowing of the fitness standard to a limited cognitive capacity test, which is not compatible with current medical and scientific understanding of mental disorders and their impact on an accused's capacity at various stages in the criminal justice process, from consenting to a waiver of rights, to advising counsel and making full answer and defense, and finally, to being held responsible or culpable for one's actions. Secondly, rather than mere rudimentary factual knowledge as required by the limited cognitive capacity test, a rational appreciation of both the nature, object and consequences of the proceedings and of the process of instructing and communicating with counsel should be required for fitness, just as an accused with a mental disorder is not to be held criminally responsible unless they are capable of *appreciating* the nature and quality of the act or omission at issue or of knowing that it is wrong.

The third concern raised, also arising from *Taylor*, is the implicit sleight of hand of eschewing a rationality criterion from the analytic capacity test in favour of an escalated standard

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<sup>90</sup> Canada, House of Commons, Report of the Standing Committee on Justice and Human Rights, *Review of the Mental Disorder Provisions of the Criminal Code* (Bill C-10), Recommendation 17, June 2002.

of “acting in one’s own best interests,” which the court then readily rejects as being too high a threshold. While rationality and acting in one own’s best interests are related, and in the present writer’s opinion both valid criteria for fitness, acting in one’s own best interest implies a higher standard.

Fourthly, the effect of the limited cognitive capacity test in creating an on-off, all or nothing standard, where an accused must be either completely cut off from awareness of reality or else is deemed fully culpable, thereby excluding all those with mental disorders in between these extremes from consideration for capacity, intent or culpability prior to a guilty verdict. As has been noted, the effect of a mental disorder on personality is pervasive, whether it be cognitive, affective, volitional or delusional, and can affect self-preservational functions needed to navigate the various phases of the criminal justice process.

Fifthly, the omission of any volitional component or inability to control impulses when determining capacity, culpability and excuses, especially in view of those with FASD where such a deficit is so pervasive, is no longer tenable. Ability to control one’s behavior is a necessity in order to conform to the requirements of the law, which can also vary along a spectrum, and thus is not a black and white issue.

The sixth issue is the omission of fitness and capacity concerns at the sentencing phase, particularly with respect to Dangerous Offender applications, where loss of liberty stakes are high requiring active, rational participation of the offender in all aspects of the pre-sentencing and sentencing process.

The seventh concern deals with the disconnect between the underlying protective rationale for the fitness test and the court’s affirmation of the limited cognitive capacity test. The limited cognitive capacity test requires only basic awareness, thus lowering the threshold for a mental disordered accused being required to face the full prosecutory machinery of the state through a trial process, even when the individual’s rationality and ability to give full answer and defense is compromised by mental disorder, thus jeopardizing their right to a fair trial.

The eighth and final concern discussed in the capacity context, is the disposition for permanently unfit accused not a significant risk to public safety, but who nevertheless are inequitably deprived of the opportunity for an absolute discharge and resultant freedom from the

jurisdiction of the criminal justice system, compared to those found not criminally responsible and not a risk who are discharged absolutely.

## ***11. Creative, Remedial, Multi-disciplinary Strategies to effect Broad-based Systemic Change***

In addition to much needed public policy and legal reform, multiple, creative, remedial, inter-disciplinary strategies should be pursued at every level in order to effect broad-based systemic change.

Just as parents must expand their normal parameters to deal effectively with FASD, so too professionals need to step outside of their roles to some extent, otherwise individuals with FASD continue to fall through unanticipated gaps. Judge Barry Stuart of the Yukon Territorial Court reminds us that it is not a sacrilege to step outside the boundaries of our professional roles. In fact, in the face of our failures with FASD, he states that it is morally repugnant to remain within such arbitrary boundaries. “When the evidence for changing to a holistic, coordinated, value-based approach is so overwhelming, how can the justice system remain a jungle of complex, disjointed interactions that preserve numerous self-serving fiefdoms, all with different values, different objectives?”<sup>91</sup> The same is true of any system where vulnerable people with FASD continually fall through the lacunae within a system and between systems. The solutions that Judge Stuart advocates involves both investing in communities in order to advance social capital at the community level, and empirically evaluating systems, including the justice system, in terms of the number of positive outcomes each system produces. The criminal justice system is likely low in terms of reducing recidivism and preventing further crime. A need exists to get tough on *causes* of crime, rather than merely tough on crime. Judge Stuart’s stated intention is not to blame individual professionals, most of whom try their best, but to ensure that all are aware that systemic change is required, that there is ethical work to be done that may transcend formalistic laws and policies as they stand. We must step back, take a broader perspective, and

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<sup>91</sup> *R. v. M.N.J.* 2002 YKTC 15 at para 129, [2002] Y. J. No. 49. [*R. v. M.N.J.*]



view society through a social justice lens. In this context, FASD advocacy should function as a site of resistance against oppressive and unjust laws, policies, and practices. Such resistance could potentially benefit every person, through facilitating the creation of a more just and caring society.

A discussion of four creative, interdisciplinary strategies to effect systemic change and enhance social justice for individuals with FASD follows.

## 11.1 Specialized Courts

One such remedial interdisciplinary strategy is the creation of Community Wellness Courts with a Focus on FASD,<sup>92</sup> a form of specialized, therapeutic courts to divert individuals suspected of having FASD from the regular justice system which operates on premises not consistent with this disability. Such therapeutic courts may be viewed as an attempt to decriminalize those with mental disorders and as mitigation for lack of community mental health resources and early intervention; however, therapeutic courts are not widespread and those in existence can accommodate only a limited number of defendants. Specialized courts to deal with FASD should include a triage team with training in screening for FASD, as well as FASD-specific case management services to connect individuals to diagnoses and support services that

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<sup>92</sup> Existing mental health and addiction courts typically do not have personnel trained in the diagnosis and assessment of FASD, nor do they understand or screen for the condition. Perhaps if and when FASD is included in the DSM-IVR the situation may change. In the alternative, in the interim, personnel could be trained to diagnose and assess the condition. The debate about inclusion in the DSM-IVR apparently concerns whether FASD is a purely mental condition, or is primarily physical or “brain-based,” so potential inclusion of FASD in the DSM-IVR depends on the ultimate resolution and outcome of this debate, which appears to be a rather “thorny” one, engaging as it does the age-old, body-mind dichotomy.

However, some existing specialized or “problem solving” courts, where judges and other personnel involved have knowledge and experience with FASD, find ways to circumvent this problem and to deal directly with FASD accused referred to their courts. The Manitoba Youth Court Justice Program is a model of court-ordered assessment and provision of supports for youth with suspected FASD, as is the Yukon Community Wellness Court. In addition, for youth with FASD who are primarily visual learners because of their receptive language disabilities, the Manitoba Youth Justice Project is piloting the use of “Probation Icons” to accommodate youth with FASD to understand the conditions in their orders, through visual symbols for “no alcohol or drugs,” “no weapons,” “no contact,” and so forth.

can maintain them safely in communities,<sup>93</sup> as continuing to punish such disadvantaged and disabled persons simply does not work and can exacerbate their condition.<sup>94</sup> FASD courts could collaborate with interdisciplinary professional teams, and with family and community, to adopt new approaches such as Aboriginal restorative justice approaches similar to those used in *Gladue* Courts,<sup>95</sup> combined with holistic models of treatment that are cognizant of the nature of FASD. Both solutions proposed, law reform and FASD courts, are necessary, as only certain types of less serious, non-violent offences are deemed suitable for diversion to specialized courts. Moreover, the usual adult age restrictions applied to specialized courts should be waived as early diagnosis and treatment are central to positive outcomes for children and youth with FASD. It remains to be seen, as they increase in number, whether specialized, therapeutic courts will serve to reduce incarceration of the mentally ill through connecting them with appropriate community-based services, treatment and supports. As always, the weakest point in the equation will be access to the latter. For FASD defendants, there is added concern that these courts and services be adapted to their special therapeutic needs, otherwise they will continue to fall through the proverbial gaps. The paradigm-shift, dedication, determination, commitment, and vision necessary on the part of therapeutic courts in order to effect positive change in the lives of people

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<sup>93</sup> Personnel involved should not interpret the tendency of individuals with FASD to “fall through the gaps” as non-compliance, but rather as a component of their disability that requires accommodation. Individuals with FASD need experienced mentors to accompany them to classes, appointments and appearances and to assist with other daily tasks, otherwise due to their disability, they cannot “comply.”

<sup>94</sup> *R. v. D.B.* 2008 ABQB.

<sup>95</sup> *R. v. Gladue*, [1999] 1 S.C.R. 688, at para. 71. The type of sentencing approaches that might be appropriate to an offender because of his or her Aboriginal heritage are broadly termed “restorative justice” approaches. Gladue describes restorative justice as “an approach to remedying crime in which it is understood that all things are interrelated and that crime disrupts the harmony which existed prior to its occurrence, or at least which it is felt should exist. The appropriateness of a particular sanction is largely determined by the needs of the victims, and the community, as well as the offender. The focus is on the human beings closely affected by the crime.” Sentencing circles and specific community run alternative justice programs are examples of restorative justice approaches to sentencing. *Gladue* briefs, that document systemic and background factors for the offender, as well as resources in the community to support the offender, often are included as part of the Predisposition Report, and are used extensively in *Gladue* courts. Since *R. v. Kakekagamick*, [2006] O.R. (3d) 664 (Ontario Court of Appeal), it is clear that *Gladue* briefs are considered essential for all courts when dealing with aboriginal offenders. A failure to give appropriate consideration to an offender’s Aboriginal status through the gathering of such information is considered an error of law on the part of a sentencing judge, *Kakekagamick* at para. 31.

who appear before them is described by Judge Ginger Lerner Wren, Broward Country, Fort Lauderdale, Florida.<sup>96</sup>

## 11.2 FASD Accommodation Counsel Position

To attempt to short circuit the problem, Manitoba Legal Aid has implemented an FASD Accommodation Counsel position for Youth Living with FASD. A lawyer with extensive knowledge, training and experience with FASD is available for consultation with other defense lawyers. The overall goals of the accommodation counsel are to improve services and outcomes for FASD youth clients through a combination of direct advocacy and legal representation; collaborative case management; professional consultation; development of provincial resource guide for defense counsel representing youth clients who have an FASD; developing a resource guide for parents and other caregivers of youth affected by FASD at risk of becoming involved with the criminal legal system; provision of FASD training for Legal Aid lawyers, articling students, paralegals and law students; and development and implementation of a screening, referral and client tracking protocol for Legal Aid. Specific project objectives include: identification of youth clients impacted by FASD; effective lawyer-client communication; a protocol to ensure that the client understands the court process (or is found unfit); procedures and mentorship to assist the client to remember and to attend court and related appointments; appropriate client referrals and linkages to community services and appointments; timely access to client assessment and diagnosis; appropriate and meaningful diversion; provision of assistance to the Court to understand the client's unique needs, circumstances and abilities; provision of assistance in the preparation with Gladue/FASD briefs and PDRs for the Court; and provision of assistance to the Court to fashion appropriate dispositions that reflect and accommodate the

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<sup>96</sup> Judge Ginger Lerner Wren, "Mental Health Courts and Repairing the World," *A Community of Visionary Leaders for a New Paradigm in Law, Cutting-Edge Law*, accessed from the worldwide web 15-06-2011 at <http://www.cuttingedgelaw.com/video/judge-ginger-lerner-wren-mental-health-courts-repairing-world>.

client's unique needs, circumstances, and abilities, as well as a consideration of relevant mitigating factors.<sup>97</sup>

### 11.3 Accommodation for FASD throughout the Court Process

In *Jobb*, Dr. Menzies, the expert witness, in some of his comments, supplemented in a follow-up interview with the author, alluded to possible accommodation of disabled accused through the court process:

I think his [Christopher Jobb's] recollection of things isn't terribly strong, so depending when it is or what event he's talking about, when it happened, whether it was last week or a year ago, I think basically he can communicate, but it's a question of what quality of instruction. Because if he's not fully there for reasons that aren't his fault, during the process I think that's the area where it falls down and where he's not, in my opinion, fit to stand trial.<sup>98</sup>

For instance, would frequent breaks (say every 10 to 15 minutes) in the court proceedings accommodate and enhance the defendant's abilities to concentrate and follow the proceedings? Could defense counsel and aids cue defendant's memory of past events (without alteration) during these breaks, through the use of visuals, photos, videos, relevant excerpts from documents, and so forth? Could officers of the court be reminded to use concrete and specific language, with one idea presented at a time, and presented slowly with more response time provided?

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<sup>97</sup>Kent Roach and Andrea Bailey, "The Relevance of Fetal Alcohol Spectrum Disorder in Canadian Criminal Law From Investigation to Sentencing" (2009) 42 University of British Columbia Law Review 1, at 21; and Heather Douglas, "Sentencing and Fetal Alcohol Spectrum Disorder (FASD)" Sentencing Conference 2010, Canberra, 6 February 2010 at 15, retrieved from the worldwide web on 4 February 2011 at <http://njca.anu.edu.au/Professional%20Development/programs%20by%20year/2010/Sentencing%202010/Papers/Douglas%20FASD%20Sentencing%202010.pdf>. In United States and Canada, evidence of FASD has been identified as a mitigating factor in some cases and an aggravating factor in others.

<sup>98</sup> Supra note 2. [*Jobb*]

## **11.4 Use of an Intermediary for Vulnerable and Intimidated Witnesses in Investigative and Court Processes**

The United Kingdom's *Youth Justice and Criminal Evidence Act*<sup>99</sup> legislates that a range of special measures be made available to help vulnerable and intimidated witnesses give their best evidence. These measures include giving evidence by TV link or being screened from the defendant in court, video-recording of the evidence-in-chief; removal of wigs and gowns by officers of the court; clearing the public gallery; and aids to communication. Section 29 of the *Act* makes available the use of an intermediary in investigative and court processes to three categories of vulnerable witnesses: those under 17; adults whose quality of evidence is likely to be affected by a mental disorder or impairment of intelligence and social functioning; or those who have a physical disorder or disability. Intermediaries are approved for use by the Court and following assessment of the witness, their role is to enable complete, coherent and accurate communication to take place. Intermediaries are allowed to explain questions and answers to witnesses, but not to change the substance or meaning of evidence. One of the findings during the evaluation phase of a pilot stage of the intermediaries program was that witnesses' comprehension levels were lower than they appeared to be in most cases, in other words comprehension levels were overestimated, whereas the extent of communication problems was underestimated. Evaluators recommended facilitating communication in a neutral, non-leading way and ensuring that witnesses understood everything said to them, including explanations and instructions. The intermediaries program helped inform decisions about witness suggestibility, ability to cope with cross-examination, and the manner in which witness should give evidence. One of the challenges identified was the low identification of witness vulnerability by the system, including apparently low receptivity of criminal justice practitioners to the automatic eligibility of witnesses under 17 to such assistance. In addition, an unintended negative consequence was that Judges and counsel tended to intervene less during questioning that was oppressive and repetitive, when an intermediary was present, leaving it to the intermediaries to speak, rather than adapting their own approaches to vulnerable witnesses. Evaluators recommended that ongoing data be collected on the types and prevalence of miscommunications

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<sup>99</sup> *Youth Justice and Criminal Evidence Act 1999*, U.K. c. 23, Parts II and III.

experienced by witnesses when being questioned and that special needs of cultural minorities and those using languages other than English be addressed.<sup>100</sup> Employing such intermediaries would no doubt be useful with FASD witnesses, especially if the intermediaries had knowledge, training and experience regarding FASD. Currently, the United Kingdom *Act* excludes accused individuals from the intermediary program but a counterpart amendment to the Saskatchewan *Evidence Act*,<sup>101</sup> or the *Canadian Evidence Act*<sup>102</sup> could be drafted to be inclusive in that respect.

## 11.5 Circles of Support and Accountability

Circles of Support and Accountability have been initiated primarily by the Mennonite Central Committee, as well as some by other faith-based groups. Programs are instituted formally with the institution and with the offender when an offender is about to be released from prison. Some months before release, volunteers come to the institution, are granted access to the offender's records, may meet with the offender, and then develop a plan to assist the offender to integrate into society. The Circle of Support and Accountability provides assistance in finding accommodation, a job and positive social contacts, as well as support in dealing with banking or financial issues and in finding activities that would keep the offender away from the temptation of alcohol and drugs, or away from children or minors, or from being alone with members of the opposite sex when drinking, and away from gangs and illegal activities, if these have been factors in his or her offending. Some Circles of Support and Accountability provide access to psychologists, job training and sex offender treatment programs, as well as culturally relevant programming. Some Circles of Support and Accountability provide volunteer work for the offender through their Churches and Thrift Stores. A group of volunteers meet regularly in a group or circle with the offender and discuss problems, progress or issues, as well as providing social and emotional support and attempting to prevent re-offending. Even if offenders relapse,

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<sup>100</sup> Joyce Plotnikoff & Richard Woolfson, Edited by Emma Marshall, "The 'Go-Between': Evaluation of Intermediary Pathfinder Projects," Ministry of Justice: June, 2007.

<sup>101</sup> S.S., 2006, c. E-11.2, s. 13.

<sup>102</sup> R.S., 1985, c. C-5, s. 6, 1998, c-9, s. 1

the Circle of Support and Accountability is usually willing to continue to be engaged with them throughout any further custody and eventual resultant release. They are willing to work with both offenders with FASD or with Dangerous Offenders, or with Dangerous Offenders who have FASD, if they determine that they have the capacity to do so while controlling risk and if the offender agrees.<sup>103</sup>

The Circle of Support and Accountability examines the offender's institutional risk assessments, including the triggering circumstances for the offence to determine how they can support the offender safely in the community. Some have worked with police with respect to reframing media releases so that the offender can function in the community. These media releases inform the public of the offences committed by the individual to be released, but also state that the risk to reoffend is being controlled by certain supports and careful monitoring in the community. The Circle of Support and Accountability stays in communication with the police, invites representatives to join the circle and undertakes to inform the police if the situation destabilizes. Offenders need accountability and supervision, but also some freedom, at the same time, so it is a delicate balance, especially complicated when the individual has cognitive, volitional and self-regulatory problems that can accompany FASD. When surrounded by the Circle of Support and Accountability, offenders are usually totally immersed in a positive life style, but if surrounded by drugs, aggression and violence, they are often swayed in that direction. Without close supervision, it can be difficult to keep them away from the prison culture or the street culture. Supported housing (with curfews) and mentorships by those experienced with FASD is an important feature for those with FASD who frequently require a constant external good brain to avoid re-offending.<sup>104</sup>

In conclusion, a number of remedial, creative, interdisciplinary options have been proposed. The question becomes how does one decide how to allocate resources in a way that minimizes the social harms from both crime and efforts to prevent crime? How do we decide how much to spend on the criminal justice system and crime control and prevention generally, versus other pressing needs? These questions are the bases of benefit-cost analysis, which is beyond the scope of the present research. Benefit-cost analyses begin with the crucial and often

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<sup>103</sup> *R. v. W.E.J.M.*, 2009 ONCA 844.

<sup>104</sup> Interview with a Circle of Support and Accountability volunteer, Sept. 3, 2009.

under-appreciated first step of successfully identifying the impact of a policy or program. However, challenges facing attempts to monetize costs and benefits are pervasive. For example, some of the most important costs and benefits come from intangible, complex or difficult to measure aspects of well-being for which monetary values are not easily attached,<sup>105</sup> as in the case of many of the proposed strategies for FASD.

## ***12. Transformative Change Required for FASD: Weaving a Less Arbitrary Legal and Social Fabric***

Reality is more complex and nuanced than is contemplated by the philosophy of the “fitness test,” and other tests of requisite mental intent to be found guilty of a criminal act. The ideal is to cut the Gordian Knot and “to recognize the whole range of human potential, and so weave a less arbitrary social fabric . . .”<sup>106</sup> Universalist, one-size solutions are neither effective nor fair for all; rather, the varied aspects of human diversity need to be accommodated. As our state of knowledge in this area is evolving and tentative, an open, pluralistic stance may be more appropriate than a narrow, deterministic one. FASD affects competence and fitness across the spectrum, whether it be fitness itself, the requisite intention or guilty mind, termed *mens rea*, the array of excuses and defenses which could apply to exonerate an offender, or to mitigate or lessen her sentence.<sup>107</sup> Many FASD accused may not have committed an *actus reus* or guilty act, but may confess due to confusion, pressure, suggestibility or the desire to appease someone in authority without fully realizing consequences of so doing in an adversarial system.<sup>108</sup>

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<sup>105</sup> Roseanna Ander and Jens Ludwig, “Transcript: Benefit Cost Analysis for Crime Policy,” National Institute of Justice, accessed from the worldwide web on April 20, 2011 at <http://www.nij.gov/nij/multimedia/presenter/presenter-ander-ludwig/data/resources/presenter-ander-ludwig-transcript.htm>.

<sup>106</sup>M. Margaret, “Sex and Temperament,” in *The Gendered Society Reader*, (Ed.) M.S. Kimmel & A. Aronson, New York: Oxford University Press, 2000, 38-42.

<sup>107</sup> In the sentencing process, if the risk presented by untreated secondary disabilities cannot be adequately controlled in the community, then FASD may be considered an aggravating factor and a more restrictive sentence imposed, such as a custodial sentence.

<sup>108</sup> Julianne Conry and Diane K. Fast, 2000, *Fetal Alcohol Syndrome and the Criminal Justice System*, Vancouver: Fetal Alcohol Resource Centre, Funded by the Law Foundation of British Columbia, at p. 37. The authors cite the



Understanding FASD involves the intersection of the fields of law and medicine, as well as the intersection of different world views and values, as FASD, found among peoples of all cultures, is a global phenomenon.

In *R. v. Harris*,<sup>109</sup> the British Columbia Court of Appeal revealed a tentative, open stance when dealing with an Aboriginal offender with FASD. Despite errors made by the trial judge, the Court of Appeal deferred to her judgment. In B.C., under anomalies of their particular enabling legislation, no FASD diagnosis is available to adult offenders;<sup>110</sup> in the circumstances, the trial judge, based on her own knowledge and observations, found the adult offender to be FASD. On this basis, she imposed a conditional sentence applying only *Gladue* principles, and not the other sentencing principles of deterrence, denunciation and separation. The Court of Appeal noted the obvious errors made, but, nevertheless, unanimously deferred to the expertise of the trial judge who had a great deal of firsthand experience with FASD offenders in her Court. In so doing, the Appellate Court grappled with the dilemma presented them by opting for a just outcome not contemplated in existing legislation.

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case of Bryan Tait, from the Oct. 7, 1991, *Montreal Gazette*. An individual with FASD, made a false confession to a crime which put him behind bars for a double murder for 11 months. It was later discovered that he had been behind bars for another unrelated offence at the time the double murder was committed. He at first had vehemently denied any involvement, but eventually broke down and repeated the story that the police read to him.

T. E. Moore and M. Green, "Fetal Alcohol Spectrum Disorder (FASD): a need for Closer Examination by the Criminal Justice System" (2004) 19 C.R., 99-108. Moore and Green describe problems with suggestibility of youth witnesses, as well as FASD witnesses, and the spectre of false confessions by FASD accused.

K. A. Kelly, Fetal Alcohol Diagnosis Unit, University of Washington, "Charting the Path to Justice for FASD, Changing Attitudes and Actions" September 19, 2008, Access to Justice for FASD Conference, Whitehorse, Yukon. Validity of waiver of rights to counsel upon arrest, false confessions, being found competent to stand trial when they really are incapable, and diminished capacity can contribute to wrongful convictions for FASD accused.

<sup>109</sup> 2002 BCCA 152 (BCCA = British Columbia Court of Appeal).

<sup>110</sup> *R. v. Gray* [2002] BCJ No. 1989; 169 C.C.C. (39) 194.

### ***13. How do Legal Tests of Mens Rea, Excuses, Defenses, Degree of Responsibility and Mitigating Factors Apply to FASD?***

Collectively, we need to be asking the broader question, “How do legal tests of *mens rea*, excuses and defenses, and considerations of responsibility and mitigating factors in sentencing apply to someone possessing the characteristics of FASD?” As the question implies, such legal tests need to be subjective from the perspective of an FASD person in order to yield just results for these individuals and they need to take into consideration the degree of responsibility of the accused and other mitigating factors.

#### **13.1 Subjective Test for the Defense of Duress for FASD**

As a case in point, in *R. v. Faulkner*<sup>111</sup> an interesting dialogue occurred between the trial judge and the expert medical witness, Dr. Rosale, as to how the test of duress could be applied to an accused person with FASD. When asked how the test of duress applied to Mr. Faulkner, Dr. Rosale testified:

Dennis knows enough to understand basic concepts of right from wrong but he does not have the mental ability to appreciate (pre-frontal lobe function) consequences of “instinctive/ reflexive/emotion” based actions, especially under duress of physical harm from those who take advantage of his mental limitations. FASD affected individuals can easily be coerced to do anti-social and unlawful acts even without undue coercion in some instances. . . . FASD affected individuals require a “good” extra brain all their lives to a minimal/maximal degree.

The “good” second brain or extra brain that usually advocates for them in structured programming can be replaced by a “bad” brain [in the form of negative peers] that could induce or influence them to do unacceptable acts/behaviors. This latter scenario usually happens after they reach the age of majority and they are essentially left on their own devices by agencies previously providing some guidance/supervision.<sup>112</sup>

An opportunity was missed by the trial Judge to step outside established parameters, adopt a more open stance, and modify the test of duress in accordance with expert medical testimony, so that it would more appropriately apply to FASD accused. Dr. Rosale concluded

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<sup>111</sup> 2007 N.J. 46. [*R. v. Faulkner*]

<sup>112</sup> *Ibid.* at para. 13 and 17. Please note that comments in square brackets are editor’s comments.

that Dennis Faulkner had been coerced by his older and more sophisticated companion to commit the offence. As a result of FASD symptoms, Dennis lacked the capacity to act rationally and to choose not to commit the offence, though a normal person could have been expected to see a logical way out and to have chosen not to commit the offence. Had the trial judge opted to modify the test of duress in line with the medical and clinical knowledge possessed by the expert witness, his decision might have been over-ruled by a higher court. In that event, the process of appeal may have served as an impetus to begin a dialogue, as in *L.E.K.*,<sup>113</sup> with potential to effect enhancement of social justice for individuals with FASD by our courts. In the case of *L.E.K.*, a non-violent youth, the media coverage was generally informed and responsible, demonstrating a concern for the issue of FASD in the justice system.

### **13.2 Defense of Diminished Responsibility for FASD, not limited to Chronological age, but based on Developmental Level, and applied on the basis of a Continuum as in the Youth Criminal Justice Act**

Some critics of the status quo contend that the defense of diminished responsibility or diminished moral culpability should be available in such cases, as it is in the United Kingdom and a number of other Commonwealth Countries, including various jurisdictions in Australia. In Canada, the Supreme Court has recognized an explicit diminished responsibility or moral culpability defense for youth based on their degree of responsibility.<sup>114</sup> This, one could argue, should be extended to apply to individuals though not chronologically youths, nevertheless, are scientifically assessed as functioning at the same level due to intellectual and cognitive impairments. Failure to do so may engage liberty interests under s. 7 of the *Charter of Rights*

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<sup>113</sup> *R. v. L.E.K.*, [2001] 203 Sask. R. 273; 2001 SKCA 48.

<sup>114</sup> *R. v. D. B.* 2008 SCC 25 at para. 63-69. Due to developmental factors, there is a presumption of law of diminished responsibility and moral culpability for young persons. This is so because young persons act out of immaturity and impulsiveness and are not as mature, reflective or considered as adults. They lack judgment and knowledge, do not respond well to punishment, and consequently punishment does not reduce youth crime. Their degree of responsibility for an offence is an important factor in sentencing.

*and Freedoms*,<sup>115</sup> as it did for a youth in *R. v. D.B.*<sup>116</sup> Adults with FASD, like those of a younger chronological age but of a similar level of functioning, have diminished moral blameworthiness or culpability flowing from the fact that they have heightened vulnerability (due to their cognitive disability and low level of adaptive functioning), have less maturity (because their intelligence is less developed, have less experience or less ability to learn from experience, and are more impulsive) and have a reduced capacity for moral judgment (lacking the degree of abstract thinking, generalization and rational thought required for this kind of judgment). Perhaps a diminished responsibility defense for them could be extrapolated from *D.B.* and applied along a continuum according to their degree of responsibility based on their level of cognitive and adaptive functioning, rather than according to chronological age. Or the defense could imported and adapted from other jurisdictions cited to apply along such a similar continuum rather than merely substituting a lesser offence, such as manslaughter in place of murder. At any rate, doing the same old thing in the same old way while it may seem the safe way out, is neither good law nor good policy in a landscape of change such as FASD presents. In this vein, alternatives proposed merit consideration.

Accordingly, the concept of diminished responsibility in the context of an adult FASD accused who functioned at the level of a 6-8 year old child was advanced by Judge Heino Lilles of the Yukon Territorial Court.<sup>117</sup> Jason Harper, a 34 year old Aboriginal male was charged with touching for sexual purposes a person under the age of 14. Jason was placed on recognizance in relation to the above charge, and accumulated a second charge when he was found in violation, on one occasion, of the prohibition against alcohol consumption. Although excused on the basis of neither of the stringent tests of “unfit to stand trial” nor “not criminally responsible” on account of mental disorder, Judge Lilles determined that Jason’s degree of responsibility for these offences was reduced, nevertheless, due to his significant cognitive disabilities resulting from FASD. Accordingly, he sentenced Jason to two years probation with terms modified to fit his cognitive and adaptive functioning levels. In order to forestall repeated process offences, Judge Lilles phrased prohibition terms more permissively and concretely as follows, “*You will do*

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<sup>115</sup> Part I of the *Constitution Act*, 1982, being Schedule B to the *Canada Act* 1982 (U.K.), 1982, c. 11.

<sup>116</sup> *Supra* note 114. (*R. v. D.B.*)

<sup>117</sup> *R. v. Harper*, 2009 YKTC 18.

*the best you can to*” . . . stay away from people who are drinking; not drink any alcohol, meaning beer, wine or liquor; stay away from the liquor store, off-sales and bars; not be alone with females under the age of 16 or any females who are drunk; and so forth. To supervise the accommodated order, the trial judge retained jurisdiction over the case to ensure that incidental slips or breaches would not be prosecuted, but rather would be the basis for discussion, teaching and learning for Jason, unless it appeared that Jason was not trying to comply to the best of his ability and in effect, “thumbing his nose” at the probation officer.

The reasons given for the diminished responsibility defense and for the modified probation terms are most instructive. Jason Harper’s full-scale IQ is 59, indicating that he is not able to function independently in society and requires interactions to be significantly modified for him so that he can understand what is expected of him. He is a concrete thinker and requires real-life hands-on learning in his own environment. As his functional adaptive skills, as well as his receptive language skills, are similar to a 6-8 year old, Jason requires significant modification to the language used when giving him instructions or explanations. Consequently, communication with him needs to be direct, concrete, specific, and concise. As his short term memory is severely impaired, he can parrot back exactly what is said to him at the time and thus may appear more capable than he is; however, he cannot retain information long enough to reason with it, apply it or encode it into long-term memory. He requires the same level of supervision and protection as a 6-8 year old child, although he may resent it in comparison with peers his age. Having experienced significant trauma in the past without being able to process these past events, he remains hurt and frightened with a diagnosed anxiety disorder. While held in custody on the charge and breach at issue, Jason was sexually assaulted by two inmates. For these reasons, he needs to be protected in society at a level commensurate with his adaptive level of functioning, that of a 6-8 year old. While not a sexual predator, his behavior is impulsive, immature and uninformed by an understanding of social boundaries, rather than being purposeful and intentional. Therefore, he requires supervision rather than punishment:

. . . Jason is not a sexual predator. His problems are likely due to his impulsiveness and the fact that he has an immature understanding of social distance, social awareness and personal space. At the same time, Jason struggles to filter his urges and tends to react to base urges.

Couple this with a childlike view of boy-girl relationships and inappropriate relationships are inevitable.<sup>118</sup>

Like Christopher Jobb, to mask his deficits and appear normal, Jason Harper tends use a “fun” presentation which can give the misleading impression that he is more sophisticated than he actually is.<sup>119</sup>

In applying the purposes and principles of sentencing as set out in the *Criminal Code*, particularly the Fundamental Principle in s. 718.1, that a sentence must be proportionate to the gravity of the offence and the responsibility of the offender, the trial judge considered the application of this two-pronged principle to an offender like Jason, who suffers from an organic brain disorder that affects not only his ability to control his actions, but also his understanding of the consequences that flow from them. In such a context, he considered that moral blameworthiness would figure more prominently than the gravity of the offence, citing the Ontario Court of Appeal in *R. v. Hamilton*<sup>120</sup> as authority for sentencing decisions where one side of the proportionality calculus will figure more predominantly in the disposition than the other. For instance, there may be cases where the gravity of the offence points strongly in one sentencing direction, while the culpability of the individual points in the other. Due to Jason Harper’s severe level of cognitive impairment, Judge Lilles concluded that Jason’s lack of moral culpability would tip the balance in favour of a lesser sentence, as moral blameworthiness is the key ingredient to the determination of a just sentence. Without moral blameworthiness, punishment or criminal sanction, even for a serious offence like sexual assault against a young person, may run the risk of violating s. 12 of the *Charter of Rights and Freedoms* and its guarantee that everyone has the right to be free from cruel and unusual treatment or punishment.<sup>121</sup>

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<sup>118</sup> Neuropsychological FASD Evaluation of Jason Harper from Medigene Services, Calgary, Alberta.

<sup>119</sup> *Ibid.* at para. 17, from Medigene Services Neuropsychological Report, Calgary, Alberta.

<sup>120</sup> (2004), 72 O.R. (3d) 1 at para. 94. (*R. v. Hamilton*).

<sup>121</sup> *R. v. C.A.M.* [1996] 1 S.C.R. 500 at para. 79 and 41.

### 13.3 The Other Side of the Coin: Imposition of an Adult Sentence on an FASD Youth

A related issue, is the reverse of the above, namely the imposition of an adult sentence on a young person or youth.<sup>122</sup> An adult sentence may be imposed if the young person is found guilty of a presumptive offence, which is by its nature a serious, violent offence,<sup>123</sup> or is an indictable offence for which an adult is liable to imprisonment for a term of two years and the indictable offence is committed after the young person has attained the age of fourteen years.<sup>124</sup> If the youth is considered “dangerous” within the meaning of the *Criminal Code*,<sup>125</sup> the issue arises of therapeutic, residential placement and treatment versus an adult sentence. Intensive rehabilitative custody and supervision orders (IRCS) are an option under s. 42(7) of the *Youth Criminal Justice Act*. However, if a Court deems that protection of the public could not be achieved through an IRCS sentence, as in *R. v. I.D.B.* 2005 ABCA, involving the death of a twenty year old female child care worker at the hands of a 14 year old Aboriginal youth under her supervision, then an IRCS sentence is not an option. Accordingly, in *I.D.B.*, the Court held that the 14 year old male Aboriginal youth’s FASD-related condition, exacerbated by trauma, was so severe and permanent that no rehabilitation could reduce the risk that he would re-offend, and therefore there was no alternative to an adult sentence. Accordingly, I.D.B. was sentenced to life imprisonment, with no parole eligibility for seven years.<sup>126</sup> He was to be placed in a young offenders’ institution until he reached the age of 20 and then transferred to the appropriate federal institution, as determined by the penal authorities.<sup>127</sup> The sentencing judge applied

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<sup>122</sup> *Youth Criminal Justice Act*, S.C. 2002, c. 1, s. 61-81.

<sup>123</sup> *Ibid.* s. 2(1). [YCJA]

<sup>124</sup> *Ibid.* s. 61. The lieutenant governor in council of a province may by order fix an age greater than fourteen years but not more than sixteen years for the purpose of the application for adult sentencing related to presumptive offences. [YCJA]

<sup>125</sup> *Ibid.* s. 74: *Application of Parts XXIII and XXIV of Criminal code* – Parts XXIII (sentencing) and XXIV (dangerous and long-term offenders) of the *Criminal Code* apply to a young person in respect of whom the youth justice court has ordered that an adult sentence be imposed. [YCJA]

<sup>126</sup> *R. v. I.D.B.*, 2005 ABCA 99.

<sup>127</sup> *Supra* note 122, s. 76(1), (2) and (9): *Placement when subject to adult sentence* – subject to subsections (2) and (9) and sections 79 and 80 and despite anything else in this Act or any other Act of Parliament, when a young person who is subject to an adult sentence in respect of an offence is sentenced to a term of imprisonment for the offence, the youth justice court shall order that the young person serve any portion of the imprisonment in (a) a youth

*Gladue*<sup>128</sup> to reduce the parole ineligibility period for first degree murder from 10 years to 7 years. Other innovative applications of *Gladue* could include applying *Gladue* factors at other phases, such as at arrest, charging, extrajudicial measures or diversion, fitness, determination of intention, defenses and excuses, as the type of systemic and direct discrimination and resultant trauma that *Gladue* encompasses can affect all of these aspects. Furthermore, the same conditions that give rise to *Gladue*-type trauma, also produce FASD, and the factors of trauma, FASD and substance abuse work hand in hand to hand to confound age old presumptions of justice, that may not apply with the same force in a modern, enlightened, scientific, pluralist society.

An adult sentence was imposed in the shockingly, unprecedented, recent case of Melissa Todorovic (M.T.)<sup>129</sup> who was not quite 16 when she repeatedly badgered her 17-year-old boyfriend to kill 14 year-old Stefanie Rengel whom she had never met but somehow perceived

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custody facility separate and apart from any adult who is detained or held in custody; (b) a provincial correctional facility for adults; or (c) if the sentence is for two years or more, a penitentiary.

(2) *When young person subject to adult penalties* – The youth justice court that sentences a young person under subsection (1) shall, unless it is satisfied that to do so would not be in the best interests of the young person or would jeopardize the safety of others, (a) if the young person is under the age of eighteen years at the time that he or she is sentenced, order that he or she be placed in a youth custody facility; and (b) if the young person is eighteen years old or older at the time that he or she is sentenced, order that he or she not be placed in a youth custody facility and order that any portion of the sentence be served in a provincial correctional facility for adults, or, if the sentence is two years or more, in a penitentiary.

(9) *Limit – age twenty* – No young person shall remain in a youth custody facility under this section after the young person attains the age of twenty years, unless the youth justice court that makes the order under subsection (1) or reviews the placement under subsection (6) is satisfied that remaining in the youth custody facility would be in the best interests of the young person and would not jeopardize the safety of others. [YCJA]

<sup>128</sup> *R. v. Gladue*, [1999] 1 S.C.R. 688, deals with the interpretation of s. 718.2(e) of the *Criminal Code* of Canada. Section 718.2 (e) states: “A court that imposes a sentence shall also take into the consideration the following principles: all available sanctions other than imprisonment that are reasonable in the circumstances should be considered for all offenders, with particular attention to the circumstances of aboriginal offenders.” This section was designed to address the overreliance upon incarceration in the general population, and the much greater concern for the aboriginal population. At para. 68, the Court makes this very significant finding: . . . “as has been emphasized repeatedly in studies and commission reports, aboriginal offenders are, as a result of these unique systemic and background factors, more adversely affected by incarceration and less likely to be ‘rehabilitated’ thereby, because the internment milieu is often culturally inappropriate and regrettably discrimination towards them is so often rampant in penal institutions.” The Court identifies a different methodology for each sentencing judge in determining the nature of a fit sentence for an aboriginal offender, which involves a consideration of both the systemic and background factors which often play a part in bringing a specific offender before the courts and the types of sentencing approaches that might be appropriate to the offender because of his or her Aboriginal heritage (para. 66).

<sup>129</sup> *R. v. Todorovic* 2009 OJ 3246 (Ontario Superior Court of Justice, Toronto).



as a romantic rival. To gain her boyfriend's compliance Todorovic used the threat of breaking up or of withdrawing sexual favours. Many of her demands and threats were made and documented over social networking on-line sites. Had Todorovic been sentenced as a youth, she would have faced a maximum 10-year sentence for first degree murder with a maximum six years in closed custody, and the remaining four years under supervision in the community.<sup>130</sup> Her identity would have been protected under the *Youth Criminal Justice Act*<sup>131</sup> and her record expunged five years after her sentence was completed.<sup>132</sup> However, sentenced as an adult, she received a life sentence and must serve seven years before she is eligible to apply for parole.<sup>133</sup> If granted, she

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<sup>130</sup> *Supra* note 122, s. 42(2) *Youth sentence* – when a youth justice court finds a young person guilty of an offence and is imposing a youth sentence, the court shall, subject to this section, impose any one of the following sanctions or any number of them that are not inconsistent with each other and, if the offence is first degree murder or second degree murder within the meaning of section 231 of the Criminal Code, the court shall impose a sanction set out in paragraph (q) or subparagraph (r)(ii) or (iii) and may impose any other of the sanctions set out in this subsection that the court considers appropriate. . . . (q) order the young person to serve a sentence not to exceed (i) in the case of first degree murder, ten years comprised of (A) a committal to custody, to be served continuously, for a period that must not, subject to subsection 104(1) (continuation of custody), exceed six years from the date of committal, and (B) a placement under conditional supervision to be served in the community in accordance with section 105, and (ii) in the case of second degree murder, seven years comprised of a committal to custody, to be served continuously, for a period that must not, subject to subsection 104(1) (continuation of custody) exceed four years from the date of committal, and (B) a placement under conditional supervision to be served in the community in accordance with section 105. [YCJA]

<sup>131</sup> *Ibid.*, s. 110 (1) *Identity of offender not to be published* – Subject to this section, no person shall publish the name of a young person, or any other information related to a young person, if it would identify the young person as a young person dealt with under this Act. (2) *Limitation* – Subsection (1) does not apply (a) in the case where the information relates to a young person who has received an adult sentence . . . . [YCJA]

<sup>132</sup> *Ibid.*, s. 117 and 118. *Access to Records* s. 117. *Exception – adult sentence* – Sections 118 to 129 do not apply to records kept in respect of an offence for which an adult sentence has been imposed once the time allowed for the taking of an appeal has expired or, if an appeal is taken, all proceedings in respect of the appeal have been completed and the appeal court has upheld an adult sentence. The record shall be dealt with as a record of an adult and, for the purposes of the *Criminal Records Act*, the finding of guilt in respect of the offence for which the record is kept is deemed to be a conviction.

s. 118 (1) *No access unless authorized*. Except as authorized or required by this Act, no person shall be given access to a record kept under sections 114 to 116, and no information contained in it may be given to any person, where to do so would identify the young person to whom it relates as a young person dealt with under this act. [YCJA]

<sup>133</sup> *The Criminal Code*, R. S. C. 1985, chap. C-46, s. 745.1: The sentence to be pronounced against a person who was under the age of eighteen at the time of the commission of the offence for which the person was convicted of first degree murder and who is to be sentenced to imprisonment for life without eligibility for parole until the person has served (a) such period between five and seven years of the sentence as is specified by the judge presiding at the trial, or if no period is specified by the judge presiding at the trial, five years, in the case of a person who was under the age of sixteen at the time of the commission of the offence; (b) ten years, in the case of a person convicted of

would remain under parole supervision for the rest of her life. Her identity is public and her record is permanent. Justice Nordheiner stated that the central question he had to deal with in making his decision was whether a youth sentence would be of sufficient length to hold Todorovic accountable for repeatedly pressuring her boyfriend to kill Rengel.<sup>134</sup> The Judge reported that Todorovic had a frightening character flaw (one expert referred to it as borderline personality disorder due to her instability, anger, and lack of compassion and remorse) and that a youth sentence would fail to adequately protect the community. The defence had argued that a youth sentence was appropriate since Todorovic's role had been secondary as she hadn't actually done the stabbing. However, Justice Nordheimer rejected the defense argument stating emphatically, "the puppetmaster is not less blameworthy than the puppet." He noted that Todorovic had all the advantages of a pro-social environment with hardworking, loving parents, yet engaged in a murder he termed "malevolent and shocking." Psychiatric reports indicated concerns about her risk to reoffend and her lack of remorse. A surreal youth culture involving thousands of internet messages to her 17 year old boyfriend, D.B., badgering him to kill Rengel, were a unique evidentiary feature of the case. Notwithstanding that an immature appreciation of consequences or of right and wrong were ruled out, the dynamics of some mental disorders in volatile youth remain uncharted territory, albeit that FASD per se was not an identified factor in this case.

A different result occurred in *R. v. L.A.B.* 2007 ONCJ 538, where it was held that protection of the public could be achieved through an IRCS order in the case of a 14 year old

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first degree murder who was sixteen or seventeen years of age at the time of the commission of the offence and (c) seven years, in the case of a person convicted of second degree murder who was sixteen or seventeen years of age at the time of the commission of the office. 1995, c. 22, ss. 6, 21.

<sup>134</sup> *Supra* note 122, s. 72. (1) *Test – adult sentences* – In making its decision on an application heard in accordance with section 71, the youth justice court shall consider the seriousness and circumstances of the offence, and the age, maturity, character, background and previous record of the young person and any other factors that the court considers relevant, and (a) if it is of the opinion that a youth sentence imposed in accordance with the purpose and principles set out in subparagraph 3(1)(b)(ii) and section 38 would have sufficient length to hold the young person accountable for his or her offending behavior, it shall order that the young person is not liable to an adult sentence and that a youth sentence must be imposed; and (b) if it is of the opinion that a youth sentence imposed in accordance with the purpose and principles set out in subparagraph 3(1)(b)(ii) and section 38 would not have sufficient length to hold the young person accountable for his or her offending behavior, it shall order than an adult sentence be imposed.

female Aboriginal youth with FASD who smothered her foster parents' three year old son. An adult sentence was considered too severe given L.A.B.'s age and limitations, and it was expected that her impulse control would improve with maturity. Unlike to I.D.B., L.A.B. could benefit from the programming in an IRCS disposition.

The two FASD comparison cases, *L.A.B. and I.D.B.*, raise concerns. First, in situations where an adult sentence is imposed, such as in I.D.B.'s case, the determination of dangerousness and risk needs to be assessed in the context of an understanding of FASD, trauma and *Gladue* factors.<sup>135</sup> Secondly, even then, if the youth requires separation for the protection of the public, a secure, therapeutic disposition is appropriate. Even if sentenced as an adult, youth should be incarcerated in units separate from adult populations. Excessive use of punitive measures and force<sup>136</sup> with vulnerable, traumatized, disabled individuals is contra-indicated and, in addition, may constitute cruel and unusual punishment under s. 12 of the *Charter*. However, since an IRCS disposition is not available to anyone sentenced as an adult, the legislative authority to impose a non-civil, secure, therapeutic disposition may depend on a finding of UST or NRC, replete with all the concomitant problems previously discussed where FASD accused are concerned. Again, in the context of presumptive offences, the concern is raised regarding the need for a paradigm shift when FASD individuals, usually by default, end up in the great maw of the Justice system. This is so because our positive system of law is based on premises of free will, individual choice and responsibility, along with a *de facto* presumption of mental competence and fitness, that may not be applicable to those with cognitive and behavioral difficulties arising from prenatal exposure to alcohol. The presumptions of mental competence and fitness are given effect through the vehicle of the tests for NCR and UST, which are designed to raise the bar for these presumptions so that few elude criminal liability; however, these presumptions may well be overbroad *de jure*, in that they do not recognize how cognitive impairments like modern, medical conditions such as FASD function to diminish culpability. Being overbroad and raising the bar for exceptions too high, may result in loss of liberty and

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<sup>135</sup> *R. v. Gladue*, [1999] 1 S.C.R. 688; *R. v. Kakekagamick*, 81 O.R. (3d) 664 (ONCA).

<sup>136</sup> Excessive use of force includes the use of restraining holds, batons, and tasers. *The Amnesty International Report, Canada, Inappropriate and Excess use of Tasers*, May 2007. Refer to *R. v. J.W.* 2006 ABPC 216.

security under s. 7 of the *Charter* that is not in accord with the principles of fundamental justice and cannot be justified by s. 1.

### **13.4 Out of the Shadows at Last? The Issue of Resources**

The 1843 *McNaughton* case rests on the principle that the Crown must prove not only that a wrongful act was committed by the accused, but also that the accused had the requisite guilty mind. In 1892, Canada's first *Criminal Code*, s. 11, codified the so-called insanity defence, so that it became available to an accused person who, because of "natural imbecility" or "disease of the mind," was incapable of appreciating the nature and quality of the act or omission, and of knowing that it was wrong. The burden of proof still rests on the party who raises the issue of such a defense, most often the accused. To determine fitness, the courts themselves further raised the bar for the insanity defense by employing the "operating mind" or "limited cognitive capacity test" for fitness, which was affirmed by the Supreme Court of Canada in *Whittle*.<sup>137</sup> Although for reasons of policy, it is in the public interest to ensure that those who are culpable for their wrongful acts do not elude criminal liability, that interest needs to be balanced against an equally compelling interest not to punish those who lack criminal culpability for their acts. The present thesis is that the fine balancing between these competing interests needs to be re-examined in the light of modern medical evidence regarding complex cognitive disabilities such as FASD. It has been continuously and widely recognized that there is an over-representation of mentally ill and disabled persons in our prisons, and that a criminogenic environment is not the ideal setting for treatment and other assistance they require.<sup>138</sup> Tinkering around the edges of the problem will not address all concerns, rather the

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<sup>137</sup> *Supra* note 10. [Whittle].

<sup>138</sup> Josiah D. Rich, Sarah E. Wakeman and Samuel L. Dickman, "Medicine and the Epidemic of Incarceration in the United States" (2011) 364 (22) *New England Journal of Medicine* 2081-2083. United States has only 5% of the world's population, yet has 25% of the world's prisoners, that is one out of every 100 adults or 2.3 million people behind bars in United States in January 2008, rendering it the country that locks up more of its citizens than any other country. The authors attribute this high U.S. prison census to be the result of the "War on Drugs" and lack of

root cause needs attention from both legal and medical experts. Lack of access to mental health and addiction services in the community further exacerbates the problem. It seems we have taken the presumption of fitness to heart, not only in the courts, but in all aspects of community, and those with mentally disabilities remain in the shadows . . . .

Judge Robert Kilpatrick of the Nunavut Court, used the metaphor of Humpty Dumpty to emphatically convey the plight of a deeply disturbed, homeless, substance abusing,<sup>139</sup> pedophilic Aboriginal man in a quandary due to lack of resources to accommodate his needs.<sup>140</sup>

Reluctantly, Judge Kilpatrick found himself with no other sentencing option than long term incarceration for this mentally disabled offender who had progressed to committing serious personal injury offences:

For want of resources, Mr. Partridge's special needs remain unaddressed and he has now

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medical treatment for addictions and mental illness partly due to deinstitutionalization of the mentally ill over the last 50 years. Many of those behind bars would be better served by being linked to community-based diagnosis and treatment in lieu of incarceration, as well as linking those patients who have been incarcerated to care after release. Sadly, the largest facilities housing the mentally ill are not hospitals but jails. Correctional facilities are designed to confine and punish, not to treat disease; harsh, socially isolating conditions in jail or prison exacerbate mental illness, especially when solitary confinement is used (p. 2081). With the growing number of drug users in correctional facilities, the prevalence of infectious diseases such as HIV and Hepatitis C is high. Other chronic medical conditions such as diabetes, hypertension, myocardial infarction, kidney problems, asthma, and cirrhosis are prevalent among Federal and State prisoners, as well as jail inmates. Discharge planning is lacking and as a result those released are at high risk for adverse consequences such as re-incarceration, drug overdose and death from other causes. Most released inmates lack medical insurance and Medicaid benefits are often terminated upon incarceration. With no primary care follow-up they end up in emergency rooms financed at higher cost by the public sector. The authors conclude that as no other country has ever incarcerated people at such high rates, the full extent of social and public health consequences are not yet known (p. 2082). The average cost of incarcerating an inmate for a year is ~\$50,000.00, while for an inmate in maximum security the cost jumps to ~\$110,000.00 annually. Five states spend more on corrections than they do on higher education which one would expect to prevent crime. The authors advocate for evidence-based alternatives to imprisonment, drug-policy reform, and increased public awareness of the crisis caused by mass incarceration and its collateral consequences (p. 2083).

<sup>139</sup> Canada Centre for Justice Statistics, *Special Study on Mentally Disordered Accused and the Criminal Justice System* (Catalogue No.1 85-559-X1E), Minister of Industry (Minister responsible for Statistics Canada), Ottawa, January 2003, p. 10, available at: <http://www.statcan.ca/english/freepub/85-559-XIE/85-559-XIE00201.pdf>.

Tim Riordan, *Exploring the Circle: Mental Illness, Homelessness and the Criminal Justice System of Canada*, PRB 04-02E, Parliamentary Information and Research Service, Library of Parliament, Ottawa, 23 April 2004, available at: <http://lpintrabp.parl.gc.ca/lopimages2/prbpubs/bp0402-e.asp#amentaltxt>, accessed from the world wide web July 11, 2009. The chaotic, desperate life of a homeless person contributes to both mental deterioration and criminality. For many, prison is the only option for secure shelter as well as treatment.

<sup>140</sup> *R. v. Partridge*, 2009 NUCJ 13, [2009] Nu. J. No. 13, at para. 67-70.

fallen off the wall. All the king's horses and all the king's men are not able to reassemble the pieces of a life shattered by a toxic combination of profound mental illness and enduring criminality. The fall of Mr. Partridge was to be expected.

The treatment of the mentally ill requires a sustained commitment of resources. These resources, both financial and physical, are not presently available in this jurisdiction. It takes more than government pronouncements of policy to effect real change in the lives of citizens devastated by mental illness.

There is a critical need . . . for interdepartmental cooperation to coordinate the services and resources needed in this type of case. Justice and Corrections, Health and Social services, the medical community, the Department of Education, all need to be involved in a cooperative effort to develop a treatment plan and coordinate resources in the search for a long-term solution. Cooperative case management and a holistic response are required. This is not presently provided by government . . .

The coordination of scarce government resources is not the mandate of the judiciary. This is the mandate of government. Therapeutic intervention and support should be available in the early stages of illness. It should not be accessed as an option of last resource, and only in circumstances of acute crisis.<sup>141</sup>

The Crown's position was its standard in such cases, that whatever the cause, Mr. Partridge was too great a risk to be managed outside a secure facility. In this case, designated as a dangerous offender, Mr. Partridge received an indeterminate penitentiary sentence. Through drawing narrow parameters around the circumstances of the offender and around public responsibility to redress past wrongs, including lack of treatment for those with a mental disability, the Crown's position prevailed in our compartmentalized system of law. However, many would join Judge Kilpatrick in seriously questioning whether justice had been done. Protection of the public is a priority, but it can best be achieved through early intervention and social programs, and as a last resort, through disposition in a secure, therapeutic facility rather than in a carceral setting which needlessly exposes vulnerable, disabled persons to harsh, punitive, criminogenic environments. The use of metaphor to express judicial consternation at systemic problems is a creative, innovative device, in effect "resistance through metaphor." This use appears to be very much in tune with the etymology of Humpty Dumpty<sup>142</sup> and other nursery rhymes originally framed as covert political satire in an earlier age when freedom of speech did

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<sup>141</sup> *Ibid.* [*R. v. Partridge*]

<sup>142</sup> Humpty Dumpty is said to have referred to Richard III in England who fell off his horse at the Battle of Bosworth Field and was hacked to death, or to Cardinal Wolsey's fall from grace under Henry VIII of England after Wolsey failed to obtain from the Pope a divorce for the King so that King Henry could marry Anne Boleyn.

not exist.<sup>143</sup> From a critical perspective, one wonders if law inadvertently is perpetuating inequalities for the disabled and vulnerable, and if so, what can be done to redress this unintended consequence and ensure that governments step up to the plate, recognize mental disabilities and provide needed, coordinated resources for them.<sup>144</sup>

### **13.5 FASD and Criminal Negligence: A Wake-up Call?**

The context of FASD and criminal negligence is another related topic for examination. To be negligent one must possess sufficient degree of responsibility in the first place, and the question arises whether an FASD accused possesses the requisite degree of responsibility and foresight of risk to be held criminally negligent. Is an accused person with FASD capable of appreciating the nature and quality of his or her act or omission, and of knowing that it was wrong? Can an accused person with FASD appreciate the risk involved in his or her conduct or omission in the context of criminal negligence? Do accused persons with FASD have sufficient objective foresight of risk, considering their relevant personal characteristics, such as FASD? The legal question is whether the reasonable person in the position of the accused would have foreseen that as a result of his or her actions or inactions a victim was exposed to the risk of bodily harm. If not, the principle that we punish only those who are responsible, act voluntarily and possess the necessary mental intent should be applied.<sup>145</sup>

The case of Christopher Pauchay<sup>146</sup> raises this conundrum most dramatically and tragically. The central factors missing from the facts of this case are any neuropsychological and medical assessment to determine Mr. Pauchay's adaptive level of functioning and his cognitive

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<sup>143</sup> Acknowledgement to Debra Ram, former legal aid counsel in Iqaluit, Nunavut, for bringing this case to the present author's attention.

<sup>144</sup> Eliabeth Cormack (Ed.), *Locating Law: Race/Class/Gender/Sexuality/Disability Connections*, 2<sup>nd</sup> Edition. Halifax: Fernwood Publishing, 2006.

<sup>145</sup> *R. v. Creighton*, [1992] 3 S.C.R. 3 at pp. 65-66, cited in *R. v. C.P.F.* 2006 NLCA 70 at para. 16-20. Note: C.P.F. was an individual with FASD.

<sup>146</sup> *R. v. Pauchay* 2009 SKPC 35.

deficits, nor to confirm a diagnosis of FASD, although such condition appears apparent to many from Mr. Pauchay's facial features, understanding and behavior,<sup>147</sup> including to those in the community who have known him over the years and have some familiarity with FASD. These factors might well have affected his ability, or the ability of a reasonable person with these characteristics, to appreciate the risk involved. Why an assessment was not ordered by the Court, is unknown. Perhaps it was thought that the sentencing circle<sup>148</sup> convened by the Judge would uncover the complete picture, or address the issues in a restorative manner. However, the extremely tragic and controversial nature of the case, involving the freezing deaths of his two infant daughters, alone in his care on the evening January 29, 2008, whom he "lost" when he wandered out in a blizzard at -40 to -50 °C in a drunken stupor to allegedly find help for one of the children, likely played a role. Public outcry demanded that justice for the deceased little girls be seen to be done, and anything short of penitentiary time in such a climate, no matter what the extenuating factors, might have brought the administration of justice into disrepute.<sup>149</sup> Be that as it may, when all facts or evidence have not been considered, the underlying cause of the tragedy

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<sup>147</sup> A mild looking young man, small of feature, of 24 years of age, Christopher Pauchay appears and acts younger than his chronological age. His history with addictions and involvement in the criminal justice system through early association with negative peers and perpetuated by system generated offences, begin early in life, at least by the age 14. Conventional addiction treatment methods proved ineffective with him, leading to relapses and, accordingly, he was unable to abstain from alcohol consumption as required by the terms of his court release prior to sentencing. He has had difficulty keeping appointments and reporting to probation officers in the past. The trial judge remarked that Mr. Pauchay lacked insight into the reasons for his offending behavior, and did not seem to be making a commitment to get his drinking problems under control, despite the fact that his abuse of alcohol was a significant contributing factor in the offence. Mr. Pauchay tended to blame Social Services for the apprehension of his third daughter, born April 2008, while failing to acknowledge that he was charged with committing an assault on the mother, Tracey Jimmy. He expressed remorse for the freezing deaths of his two daughters in January, 2008, was appreciative of the decision to grant him a sentencing circle, but questioned in a childlike manner what prison would do for him as "it would keep him from doing the things he loved to do."

<sup>148</sup> Refer to Appendix A, "Christopher Pauchay's Sentencing Circle."

<sup>149</sup> Pursuant to the release of Judge Barry Morgan's written decision of January 7, 2009 to grant a sentencing circle to Christopher Pauchay who had pleaded guilty to criminal negligence causing death, the Minister of Justice of Saskatchewan, the Honourable Donald Morgan, publically called for penitentiary time for an offence of this magnitude. The Minister's comment was *sub judice* in nature, as the case was before the Court and under judicial consideration. The legal question at issue is whether the Justice Minister's public statement usurped the role of the courts or prejudiced Mr. Pauchay's case, constituting improper or inappropriate influence. Such urging of the court by the Minister to reach a particular result in a matter before it usually constitutes a breach of the *sub judice* rule. Whether it did or not in this particular case remains moot as defense counsel did not pursue this issue through the appeal process.



cannot be addressed and similar catastrophic occurrences prevented. Hypothetically, if Christopher Pauchay were found to have FASD, to be functioning at a lower level than required for a person to be the primary and sole caregiver of infant children, as well as unable, because of prenatal alcohol exposure to control his craving for alcohol or to benefit from conventional cognitive-based addiction treatment programs, what then is a just outcome of the case and the solution to prevent future tragedies? Who is responsible in each instance? What responsible parties omitted to take ameliorative action?

Some critiques note the marked difference in approach between the treatment of intentional Aboriginal freezing deaths caused by police in Saskatchewan, in comparison with the unintentional freezing deaths in the *Pauchay* case,<sup>150</sup> notwithstanding differential evidentiary gaps and ages of victims. Christopher Pauchay (for all intents and purposes appearing to suffer from a form of organic brain impairment) received a penitentiary sentence of three years, whereas the fully capable officers in the Neil Stonechild case, notwithstanding the gravity of the situation, were not criminally charged.<sup>151</sup> Instead, a Judicial Inquiry was convened to investigate Stonechild's freezing death. The Inquiry did not conclusively find that Constables Larry Hartwig and Brad Senger dropped Stonechild off in an area remote from Saskatoon on a very cold evening. Instead, these officers were cited for failing to follow proper procedures after they arrested the 17 year old Aboriginal teen, and for failing to tell the officer investigating the death that Stonechild had been in their custody. Issues of race, class and disability pervade the comparison cases and conventional wisdom confounds a legitimate search for solutions. More open, public discourse about FASD in society and its institutions, including courts, might have assisted in illuminating the *Pauchay* tragedy. Without it, very little about the case makes sense.

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<sup>150</sup> Conversation with Wanda McCaslin, Research Officer, Native Law Centre, University of Saskatchewan, January 2009.

<sup>151</sup> Based on the Commission's findings, the officers were dismissed from the Saskatoon Police Force, a matter which they appealed unsuccessfully all the way to the Supreme Court of Canada. Constables Munson and Hatchen from the same police force were convicted of unlawful confinement of Darrel Night, the only Aboriginal man known to have survived after being dropped off outside Saskatoon limits on another bitterly cold evening. Munson and Hatchen's request for a sentencing circle was denied and they were sentenced to eight months in jail. Other Aboriginal men whose bodies were found frozen in a similar location on the outskirts of the city include Lloyd Dustyhorn, Rodney Niastus and Lawrence Wegner. The practice of police dumping intoxicated Aboriginal men outside the city limits on frigid evenings came to be known in common parlance as "starlight tours".

The potential implications for Christopher Pauchay, personally, in not having a neuropsychological and medical assessment for organic brain impairments such as FASD, are serious. Without accommodation for a disability he appears to possess, he is liable to continue to breach the conditions of his release, accumulate more charges through the justice system,<sup>152</sup> not be able to deal with his addictions through conventional cognitive-based treatment modalities, and eventually accumulate enough charges to be designated a long term or dangerous offender.<sup>153</sup> In the interim, he may have more children, and their fate may be affected by his untreated disability. Due to being easily influenced by negative peers, impulsive, unable to appreciate consequences, generally functioning at a comprehension and adaptive level years below his chronological age, and addicted to substances since an early age, he had accumulated 51 charges<sup>154</sup> prior to the charges and breaches related to the freezing deaths of his two daughters. Such can be the pattern of unheeded warning signals and revolving door offences for those accused who have an undiagnosed FASD:

What judges see is defiance of court orders. What judges see is the absence of remorse. What judges see is a criminal record of incorrigibility, calling, of course, for stiffer penalties in the cause of individual deterrence. What is missed is the etiology of the apparent incorrigibility and, with it, the chance to fashion a disposition that's responsive to the special needs of the defendant.<sup>155</sup>

One can only speculate that had an assessment been provided for Pauchay during his infancy or childhood, or ordered at one of his early sentencing hearings for any one of his 51 prior offences,<sup>156</sup> this sad litany could have been prevented altogether. This is a true story, the only redeeming merits of which are that it may function as an urgent wake-up call for change.

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<sup>152</sup> Approximately one-half of the charges dealt with in the courts are for these system generated offences and the proportion likely rises when considering only FASD offenders.

<sup>153</sup> However, with the July 2, 2008 "three strikes" legislative amendment in s. 753 (1.1) of the *Criminal Code*, courts do not have the discretion of designating an offender long term rather than dangerous. Under s. 753 (1.1), there is a reverse onus on the accused to prove non-dangerousness if the accused has committed a third primary designated offence and has been sentenced to at least two years of imprisonment for each of these offences.

<sup>154</sup> Christopher Pauchay's criminal record commenced when he was 14-years old: 16 convictions for failing to comply with court orders, 10 thefts, 8 break and enters, 5 counts of possession of stolen property, 4 counts of mischief, 3 counts of failing to attend court, and one count each of careless use of a firearm, attempted theft, being unlawfully at large, and an assault.

<sup>155</sup> Justice Melvyn Green, "A Judicial Perspective." Presentation at the Fetal Alcohol Syndrome Symposium for Justice Professionals, March 1, 2006.

<sup>156</sup> John Howard Society of Ontario, Housing and Homelessness Branch, *The Missing Link: Discharge planning, Incarceration and Homelessness*, October 2006. Accessed from the World Wide Web at

A follow-up on the Pauchay Sentencing Circle with the community of Yellow Quill was held, to review the Sentencing Circle, to receive an update on Christopher Pauchay's progress and on the community's readiness to receive him back.<sup>157</sup> After Pauchay has made progress with programs in the penitentiary and been favourably assessed, he could move to Willow Cree Healing Lodge at Beardy's & Okemasis First Nation to begin the process of re-integration which would likely culminate in return to his home community at Yellow Quill First Nation at some point. This is so because the *Corrections and Conditional Release Act* includes a provision for release of federal inmates into the Aboriginal Community:

Section 81(3) of the *Corrections and Conditional Release Act*: (3) In accordance with any agreement entered into under subsection (1), the Commissioner may transfer an offender to the care and custody of an aboriginal community, with the consent of the offender and of the aboriginal community. 1992, c. 20, s. 81; 1995, c. 42, s. 21(F).

Accordingly, pursuant to s. 81(3), the Yellow Quill First Nation (or in combination with some other approved First Nations such as Beardy's & Okemasis) and Corrections Services Canada could enter into a custody agreement to release Christopher Pauchay into the community for the remainder of his penitentiary sentence. Such initiatives under s. 81 should complement existing community-based federal initiatives such as diversion projects, victim assistance programs and Aboriginal sentencing circles. To be approved by Corrections Canada, the release plan proposed by the community must meet the needs of the Aboriginal offender in a manner that does not present undue risk to the community. The community must clearly outline its objectives and address key issues related to the criminogenic needs of the offender (such as employment, marital and family issues, associates and social interactions, addictions, community

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<http://www.johnhoward.on.ca/pdfs/The%20Missing%20Link%20-%20Aug%202007.pdf>, July 11, 2009. Mental illness is a risk factor both for homelessness and involvement in the criminal justice system. Individuals with mental disorders are more vulnerable to arrest and detection for nuisance offences. They are more likely to be remanded into custody for these minor offences, to spend more time on remand awaiting a sentence disposition, and to receive longer sentences. Mental health problems tend to be exacerbated by the prison experience, but as a consequence of deinstitutionalization of the mental health system, more people are being processed through the criminal justice system. Many have a dual diagnosis of both mental illness and addiction problems and without adequate discharge planning, they are at a very high risk of becoming homeless, which is associated with further crime.

<sup>157</sup> Refer to Appendix E: "Follow-up on the Sentencing Circle and Commentary."

functioning, personal and social issues, emotional orientation, and attitude), as well as the presentation of programs in a culturally appropriate and acceptable manner, and clear demonstration of the ability to meet certain residential facility standards for the offender. The key issues for the community to address are considerable. Upon approval of a sufficiently detailed feasibility study, Corrections Services of Canada undertakes the obligation to pay for the care and custody of any Aboriginal offenders who are transferred to Aboriginal communities under a s. 81 agreement. In Pauchay's case, one would expect his healing path to include a full neuropsychological assessment so long overdue, followed by appropriate treatment plans (including specialized-FASD addiction treatment if he is found to have an FASD, training and employment, marital and family counseling and supports, and ongoing mentorships in all of these areas) that address strengths and deficits revealed in the assessment, as well as a close association with Aboriginal spiritual leaders and Elders as recommended by the sentencing circle.<sup>158</sup> Through the vehicle of s. 81, the recommendations of the sentencing circle may have a second chance of being honoured and implemented,<sup>159</sup> despite the intervening imposition of a penitentiary sentence. Pauchay has suffered some harassment from inmates in the Prince Albert Penitentiary, who are aware of his widely publicized offence, necessitating his transfer to a facility in Alberta. He is apparently eager to continue with programming in a new facility with a view to his eventual release into the community. It is to be hoped that the programming offered in the penitentiary, or later, in the community, can be tailored to accommodate his particular

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<sup>158</sup> Individuals with FASD who have executive function deficits like Pauchay displays, need supports to comply with conditions of release into the community. Pauchay will need ongoing programs, supports and mentorships designed with his needs in mind. Executive function deficits do not simply reflect the presence of fetal alcohol facial stigmata or deficits in IQ, as the decrease in executive functioning is greater than would be predicted from IQ scores alone. This is so because the most significant damage to the brain caused by alcohol probably occurs in the prefrontal cortex, which controls what are called the executive functions, relating to impulse control and judgment, including inhibition, problem solving, planning, time perception, internal ordering or sequencing, working memory, motor control and self-regulation. Even those individuals who have normal intelligence or higher, cannot fully use their intelligence due to deficits in executive function that effectively block them from using many of their abilities without accommodation. For instance, without time perception or an ability to organize, an individual can neither get ready for work, school or a meeting with a probation officer, nor get there on time. Typical release conditions and programs often require cognitive, adaptive and executive functioning skills that persons with FASD lack. If so, the programs are setting the persons with FASD up for failure, and will not succeed in breaking the cycle.

<sup>159</sup> As the Sentencing Circle is a sacred ceremony in which Spirits are called on for guidance and transformation, circumventing its decisions may be considered not only disrespectful of the process, but also sacrilegious.

cognitive needs and deficits in order to be of benefit, and is not merely an arbitrary hoop through which he has to jump. In order to program properly, a neuro-cognitive assessment would be a first step. If individuals like Pauchay are not diagnosed, but rather misidentified as non-compliant, oppositional defiant, personality disordered or anti-social, then resultant punitive or corrective action does not respond effectively to their underlying needs and may be counter-indicated. Decreased attachment to programming, institution or community that is not accommodated to their needs can result in inevitable lack of engagement on the part of cognitively impaired offenders and corresponding lack of positive outcomes. Personnel with FASD competence and skills training would be a critical factor as early diagnosis of FASD accompanied by effective follow-up supports function as resiliency factors for individuals with FASD.<sup>160</sup>

In the United States, a statutory right to effective assistance of counsel has been employed on appeal, with some success, in cases where an FASD diagnosis was improperly omitted at the trial level.<sup>161</sup> A similar right has been found as an aspect of sections 7 and 11 (d) of the Canadian *Charter*,<sup>162</sup> but it is as yet a moot point whether this right will extend to cases where counsel has improperly omitted an FASD diagnosis as part of the defense. The accused who appeals a conviction relying on the basis that he did not receive effective assistance of counsel must establish three things: (1) the factual foundation of the claim; (2) that the acts or omissions of the trial counsel fell below the standard expected of a reasonably competent lawyer; and (3) that the conduct of the trial counsel caused a miscarriage of justice by undermining either the fairness of the trial or the reliability of the verdict.<sup>163</sup> Although the test is similar in both U.S. and Canadian jurisdictions, the latter lacks both the urgent context of a death penalty and access to funded diagnosis through the vehicle of *The Americans with Disabilities Act*<sup>164</sup> or *The*

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<sup>160</sup> Vancouver & Surrey FASD Collaboration Roundtables, *FASD Community Action Agenda: 3 Year Strategic Plan*, 2009.

<sup>161</sup> This test is often referred to as the “Strickland” test because it was adopted from the United States Supreme Court decision in *Strickland v. Washington*, 466 U.S. 688 (1984).

<sup>162</sup> *R. v. G.D.B.*, [2001] 1 S.C.R. 520.

<sup>163</sup> *Ibid.*

<sup>164</sup> 42 U.S.C. §§ 12101 et seq, and *The Americans with Disabilities Amendment Act*, 2008, declared into law Jan. 1, 2009.

*Individuals with Disabilities Education Act*,<sup>165</sup> or through the Department of Justice for federal offences or the Public Defenders Office for state offences, which can be accessed as soon as charges are laid, depending on the income of the offender and the seriousness of the charge, including death penalty and, more recently, three strikes offences. In Canada, defense counsel, without private funding and with limited timely access to the publicly funded diagnostic system, especially for adults, would likely have to wait until Court to request a court-ordered assessment and in so doing risk the client being detained until an assessment could be completed, which might be a number of months. Forensic assessments provided the system typically do not include an FASD diagnosis. FASD clients, because of their disability, often lack a future or long term perspective, and therefore might be resistant to incurring such risk of detention when they might otherwise be released on bail. For minor offences, defense counsel in Canada might justify the omission of a diagnosis on the basis that in some cases diagnosis functions as an aggravating factor. At best, its impact is uncertain.

#### ***14. Dangerous Offender: The Ultimate Jeopardy for Undiagnosed, Untreated FASD Offenders***

The ultimate jeopardy for FASD offenders who do not receive accommodation for their disabilities, will be navigating the new Dangerous Offender legislation in Part XXIV of the *Criminal Code*, due to the so-called “three strikes” amendment. This amendment takes discretion away from a Judge to modify a Dangerous Offender application to a more lenient Long Term Offender designation if there have been three so called designated or violent offences.<sup>166</sup> In addition to the “three strikes”, there is a reverse onus, in such an instance, on the

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<sup>165</sup> 20 U.S.C. §§ 1400 et seq.

<sup>166</sup> S. 752.01. If the Prosecutor is of the opinion that an offence for which an offender is convicted is a serious personal injury offence that is a designated offence and that the offender was convicted previously at least twice of a designated offence and was sentenced to at least two years of imprisonment for each of those convictions, the prosecutor shall advise the court, as soon as feasible after the finding of guilt and in any event before sentence is imposed, whether the prosecutor intends to make an application under subsection 752.1(1). 2008, c. 6, s.41.

offender to prove that he or she is not dangerous.<sup>167</sup> Prior to the “three strikes” amendment,<sup>168</sup> Wayne Edward Mumford<sup>169</sup> pled guilty to two counts of aggravated sexual assault and two counts of choking to commit the offence of aggravated sexual assault. These are primary designated offences under Part XXIV of the *Criminal Code* which deals with Dangerous Offenders and Long-Term Offenders. Designated offences involve serious personal injury and in this case, as in many cases considered under the designation, also involve a failure to control sexual impulses. Through potential future failure to control sexual impulses, a likelihood exists of such offender causing injury, pain or “other evil” to other persons. The accused, Mumford, had a prior related and unrelated criminal record. Considering that there was a reasonable possibility of control in the community, the Court designated him a long-term offender. With 2:1 credit for time spent in pre-sentence custody, his determinate sentence translated into ten years in prison, followed by supervision in the community for 10 years under conditions suggested by the Court to the parole board. As Mr. Mumford had FASD and there was a reasonable possibility that he could be treated and managed in the community,<sup>170</sup> the Court

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<sup>167</sup> S. 753.(1) On application made under this Part after an assessment report is filed under subsection 752.1(2), the court shall find the offender to be a dangerous offender if it is satisfied (a) that the offence for which the offender has been convicted is a serious personal injury offence described in paragraph (a) of the definition of that expression in section 752 and the offender constitutes a threat to the life, safety or physical or mental well-being of other persons on the basis of evidence establishing (i) a pattern of repetitive behavior by the offender, of which the offence for which he or she has been convicted forms a part, showing a failure to restrain his or her behavior and a likelihood of causing death or injury to other persons, or inflicting severe psychological damage on other persons, through failure in the future to restrain his or her behavior, (ii) a pattern of persistent aggressive behavior by the offender, of which the offence for which he or she has been convicted forms a part, showing a substantial degree of indifference on the part of the offender respecting the reasonably foreseeable consequences to other persons of his or her behavior, (iii) any behavior by the offender, associated with the offence for which he or she has been convicted, that is of such a brutal nature as to compel the conclusion that the offender’s behavior in the future is unlikely to be inhibited by normal stands of behavioral restraint.

(b) that the offence for which the offender has been convicted is a serious personal injury offence described in paragraph (b) of the definition of that expression in section 752 and the offender, by his or her conduct in any sexual matter including that involved in the commission of the offence for which he or she has been convicted, has shown a failure to control his or her sexual impulses and likelihood of causing injury, pain or other evil to other persons through failure in the future to control his or her sexual impulses.

<sup>168</sup> Introduced in Bill C-21 and passed in February, 2008.

<sup>169</sup> *R. v. Mumford*, [2007] O.J. No. 4267.

<sup>170</sup> Dr. Gojer, the defense psychiatrist who assessed Mumford, testified that since Mumford had never had any treatment for FASD, various cognitive therapies and drugs such as Ritalin and SSRI’s could be used, along with antabuse to deter alcohol use and anti-androgen drugs to control sexual impulses. Also recommended were adapted

exercised its discretion to decline to declare him a Dangerous Offender.<sup>171</sup> This decision was affirmed by the Ontario Court of Appeal, subject to a publication ban.<sup>172</sup>

However, following the coming into force of Bill C-2 in July 2, 2008, including the “three strikes” amendment of s. 753 (1.1) of the *Criminal Code*, courts have no such discretion. If the accused has committed a third primary designated violent offence<sup>173</sup> and has been sentenced to at least two years of imprisonment for each of these offences, under s. 753 (1.1), there is a reverse onus on the accused to prove non-dangerousness in order to avoid a dangerous

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sex offender treatment, and upon release in the community, assistance from Circles of Support and Accountability and other agencies. Dr. Gojer referred to the “burn-out” factor whereby offender sexual offending against adult women decreases between the ages of 40 and 60 years, due to the decline of testosterone. Note that the sentence imposed will take Mumford past the high risk years, to age ~50 years.

<sup>171</sup> The evidence of an FASD expert and father of an FASD adopted son, Dr. Barry Stanley, in *Mumford* was illuminating and persuasive. Dr. Stanley opined that FASD is grossly under diagnosed and misdiagnosed. As a result of research, tools have been created to diagnose FASD. The FAS Diagnostic Clinic at St. Michael's Hospital in Toronto uses a system based on the 4-Digit Diagnostic Code that was developed at the University of Washington, Seattle and is widely used throughout North America. Dr. Stanley referred to national statistics that indicate that 10% of Canadians have mental health problems. If 1% of Canadians have FASD, then he reasoned that 95% of those with FASD have mental problems, yet FASD is rarely diagnosed. FASD is a neuro-psychiatric condition and attention disorder. Primary disabilities are inherent in FASD individuals and are a consequence of the neurological damage and impaired neurological function. Individuals with FAS/FAE develop a range of secondary disabilities which could be ameliorated with appropriate interventions. These secondary disabilities include mental health problems, disrupted school experience, trouble with the law, confinement/incarceration, inappropriate sexual behaviour, alcohol and drug problems, dependent living and problems with employment. According to Dr. Stanley, 40% to 50% of juvenile and adult offenders are FASD. Recidivism, probation and parole violations are inevitable. Typically an individual with FASD perseverates and has difficulty in abstract thinking: she or he only understands what is literally said. Often they present with disorganized narration. Dr. Stanley noted that those with FASD are not able to process accurately every word said to them and sometimes compensate by filling in gaps with similar sounding or meaning words. They sometimes make up what they cannot remember, which often leads to misunderstandings and accusations of lying. The average IQ for those with FAS is 79-72 and with FAE (or pFAS) it is 90. Of those afflicted with FASD only 10% have an IQ below 70. Ninety per cent have an average or higher than average IQ. However, all have a significantly lower AQ (Adaptive Abilities) than would be expected. Adaptive abilities are those needed to perform the daily activities required for personal and social sufficiency. Dr. Stanley used a diagram to illustrate the developmental stages of an 18 year old child with FASD: actual and physical age of 18; expressive language may be at the age of 20 . . . [receptive language at age 10] and reading ability might be at the age of 16; however living skills might be at 11 years, money and time concepts at 8 years, social skills at 7 years and comprehension and emotional maturity at 6 years of age. FASD cannot be cured, however, cognitive therapy and drugs are used to respond to symptoms: ritalin and other drugs are used for the attention deficit issues; SSRI's are used for mood issues; and anti-psychotics are used for mood and cognitive stabilization. Trials of individual drugs and combinations must be done under supervision and methodically to achieve optimum results. FASD is caused by a pregnant mother drinking alcohol. Dr. Stanley reported that the official position of the Canadian government is that no amount of alcohol is safe. Research does indicate that severity of FASD is related to quantity, frequency, time and manner in which alcohol is taken during pregnancy, but as a result of this exposure, an individual with FASD has a brain injury.

<sup>172</sup> *R. v. W.E.J.M.*, 2009 ONCA 844.

<sup>173</sup> It does not matter how far apart such offences occurred, or how much progress the individual has made in the interim, or any other mitigating factors.



offender designation, but there is discretion in ss. (4) whether to impose the indeterminate sentence even if the accused does not meet the reserve onus. The reverse onus in the legislation might infringe s. 7 of the *Charter*, due to the fundamental principle of justice embodied in the presumption of innocence. Even if the reverse onus is found to be an infringement of the s. 7 right to life, liberty or security of the person, which is not in accord with the principles of fundamental justice, it may be further justified under s. 1 of the *Charter*, in the circumstances of designated violent offences and related concerns for public safety.<sup>174</sup>

The “three strikes” and “reverse onus” provisions underline the importance of early assessment of offenders, even for minor offences, so they get access to diagnosis and treatment, rendering them less likely to progress into more serious offences. Individuals with FASD, who are impulsive, do not appreciate consequences and therefore do not learn readily from mistakes, are liable, without therapeutic intervention, to be caught in this non-discretionary, mandatory, dangerous offender net. Such a result is a travesty, because most are not “dangerous” per se, but rather disabled, and like W.E.J.M., could be controlled in the community with proper diagnosis and supports in place. To disability, add trauma and disadvantage, as experienced by many Aboriginal offenders, many of whom suffer from intergenerational effects of the residential school experience, and the situation becomes more fraught. *Gladue* factors in s. 718.2(e) cannot be applied in such a mandatory sentencing context, nor can sentences be fashioned so that they are proportional to the degree of responsibility of such an offender. With these considerations in mind, the “three strikes” amendment appears far too broad and arbitrary. It is overbroad as it catches traumatized, disabled, disadvantaged and addicted individuals in its three strikes’ net, where they become labeled as dangerous on the basis of recidivism (which is inherent in their un-accommodated disability). Recidivism is an arbitrary indicator, as it can be related to mental disorder and trauma, more so than to dangerousness. Once caught in this overbroad net cast on the basis of an arbitrary criterion, offenders are thus stigmatized and labeled a “Dangerous offender” subject to various forms of incarceration, including indeterminate incarceration.<sup>175</sup>

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<sup>174</sup> R. v. Lyons [1987] 2 S.C.R. 309, para 69 to 79.

<sup>175</sup> S. 753(4). If the court finds an offender to be a dangerous offender, it shall(a) impose a sentence of detention in a penitentiary for an indeterminate period;

This is so unless they can carry the burden and costs of proving that they are “not dangerous,” or can adduce evidence to satisfy the court there is a reasonable expectation that a lesser measure will adequately protect the public.<sup>176</sup> While the law’s objective is to protect the public from incurable dangerous offenders, under the Dangerous Offender regime it tends to lock up and further stigmatize mentally disabled people who would not be a danger if they were to have access to treatment and accommodation for their disabilities. The Dangerous Offender legislation is overbroad because the “three-strikes” and “reverse onus” provision goes further than necessary to protect society by presuming an over-inclusive number of offenders to be dangerous.

In *R. v. C.P.S.* 2006 SKCA 78, the Saskatchewan Court of Appeal dismissed C.P.S.’s appeal from a declaration that he was a dangerous offender. Although C.P.S. is disabled, testing in the mildly mentally retarded range of IQ, presumed to be suffering from FASD, with a history of victimization and abuse throughout his life, unable to adjust to the penitentiary setting as evidenced by numerous charges he has amassed there and the number of suicide attempts he has made in that setting, and while treatment options were not broadly canvassed by the trial judge, the Court of Appeal concluded that there appeared to be no possibility of eventual control of C.P.S. in the community and that he would likely die in prison. Dr. Nicholaichuk, regional psychologist for CSC, commented:

Ideally, he [C.P.S.] should be treated in a manner more consistent with a mental health as opposed to a correctional perspective. Staff need to be aware that he is cognitively impaired. It is too easy to assume that because he does not look unusual that his abilities are intact. They are not. Staff working with Mr. C.P.S., will have to take care to not react to his outbursts,

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(b) impose a sentence for the offence for which the offender has been convicted—which must be a minimum punishment of imprisonment of two years—and order that the offender be subject to long-term supervision for a period that does not exceed 10 years; or

(c) impose a sentence for the offence for which the offender has been convicted. . . .

(4.1) The court shall impose a sentence of detention in a penitentiary for an indeterminate period unless it is satisfied by the evidence adduced during the hearing of the application that there is a reasonable expectation that a lesser measure under paragraph 4(b) or (c) will adequately protect the public against the commission by the offender or murder or a serious personal injury offence.

<sup>176</sup> S. 753(4.1) The court shall impose a sentence of detention in a penitentiary for an indeterminate period unless it is satisfied by the evidence adduced during the hearing of the application that there is a reasonable expectation that a lesser measure under paragraph 4(b) or (c) will adequately protect the public against the commission by the offender or murder or a serious personal injury offence.

as intense, negative reactions on the part of staff exacerbate the problem. [Thus, the importance of de-escalation techniques]. Over the short term, efforts will have to be made to provide Mr. C.P.S. with a supportive, predictable and stable environment in which exposure to unusual stressors are as limited as possible. Employment and occupational therapy will be more relevant than active correctional programming which he will have trouble understanding and retaining. . . .

Early diagnosis and intervention might have been able to reverse this tragic outcome for C.P.S. and his sexual assault victims. Indeterminate detention in a penal, criminogenic environment is likely going to further exacerbate his condition. Victimized, traumatized and disabled, C.P.S. is now, for all intents and purposes, a disposable person. In *R. v. Lyons*<sup>177</sup> the constitutional validity of the dangerous offender designation was based on the possibility of obtaining release on parole. However, in practice, this possibility is lessened as there is often little access to effective treatment in the institution, particularly for those designated as dangerous offenders. It is concerning to think that such fate is a potential outcome for vulnerable individuals with FASD, when access to diagnosis and intervention early in life could protect against such tragic, adverse outcomes, and alleviate and control symptoms of FASD at all stages of life. For those disabled who are not inherently dangerous, the “three strikes,” “reverse onus” legislation is surely an infringement of their *Charter* rights to life, liberty and security of the person, as it is arbitrary, overbroad and offends against presumption of innocence.

## ***15. Conclusion and Retrospect***

FASD affects capacity, culpability and fitness across the spectrum, whether it be fitness itself, the *actus reus* or *mens rea*, or the array of excuses, defenses and consideration of degree of responsibility or other mitigating factors that can apply to exonerate an offender, or to mitigate or lessen degree of guilt and sentence if found guilty. Collectively and collaboratively, consideration needs to be given to how these factors apply to someone possessing the characteristics of FASD, ever mindful that punishment is justified only if the individual actually committed the guilty act or acts, was responsible for her actions, acted voluntarily and possessed

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<sup>177</sup> [1987] 2 S.C.R., 309.

the necessary mental element. It is clear that Individuals with FASD are over-represented in our custodial institutions and that a criminogenic environment is not the ideal setting for the treatment and assistance they require. Furthermore, many of the law's notions of *mens rea* are not compatible with medical and scientific understanding of mental disorders like FASD and their impact on an accused's capacity and responsibility at various stages in the criminal justice process. From consenting to a waiver of rights, to advising counsel, to entering a plea and to making full answer and defense, which may include being a witness, being held responsible or culpable for one's actions and being sentenced if found guilty, FASD impacts an accused person's capacity. Moreover, responsibility, capacity or culpability is not an "on or off," "black or white," or "all or none" dichotomy as envisaged in the common law's limited cognitive capacity test, but rather varies along a continuum of degrees, requiring a more nuanced, individualized, complex and measured response along that continuum, not merely a "fit" or "not fit" response. In addition, a volitional component needs to be included in the fitness assessment, especially in view of those with FASD whose ability to control impulses has been adversely affected by prenatal exposure to alcohol. Present laws have evolved in a piecemeal, incoherent manner, through irregular, somewhat happenstance, dialogue between the Courts and Parliament. This dialogue could be compared to a marriage or other complex human interaction, where the parties to the marriage or relationship, even though wise and compassionate, seldom directly converse to clarify complicated meanings and intentions, let alone to consult comprehensively with medical or scientific experts to confirm that their assumptions and decisions are based on evidence. The progeny of such a marriage would be confused and dysfunctional, much as the law of capacity, *mens rea*, responsibility and culpability is confused and dysfunctional, especially in the context of complex conditions such as FASD. No unified, integrated theory of mental disorder and criminal responsibility exists, but rather a number of piecemeal, artificial, disconnected and compartmentalized rules for fitness, criminal responsibility, various levels of intention (specific or general intent), other gradations of *mens rea* (knowing, willfully, intentionally), negligence, defenses and excuses, and mitigating and aggravating factors in sentencing, altogether create a disjointed, arcane, often irrational maze. Rationality and

coherence should be brought into the system from a social justice rationale and from a scientific and medical evidence base.

Although law reform (based on awareness of advances in medical science) and innovations in the justice system (such as specialized courts with a focus on FASD and other forms of accommodation) can play a significant role in change, more holistic approaches are required to effect the kinds of broad systemic changes that Judge Stuart deemed necessary.<sup>178</sup> Such change must involve all branches of government, executive and legislative, as well as judicial, to provide the coordinated range of services for vulnerable individuals with FASD and similar conditions.<sup>179</sup> Because FASD impacts every aspect of life, a broad-based interdisciplinary approach is required within each branch of government to address needs of individuals with FASD in dealings with that branch. In the courts, interdisciplinary approaches involving judges, lawyers, medical professionals and other experts have been recommended. All systems must work together to provide a seamless web of evidence-based decisions and services. To expedite such inter-sectoral approaches, models of integrated service delivery are being developed, some centered around schools, primary health care centres, specialized courts, or some more mobile focus. Various models of child-centered, integrated, one-stop services may be tried in different jurisdictions and compared for efficacy. However, whatever model is adopted, service delivery needs to respect and empower individuals and families it serves. This is best done by actively engaging individuals and families in the design of services and programs. The principle “Nothing is to be done to me or for me without FIRST consulting me” is key.

While the medical definition of disability is widely used in the justice system, the social definition of disability is useful when designing services and supports for individuals with FASD. This social model focuses on barriers in community to full inclusion of all individuals, rather than concentrating on deficits in individuals. Collectively, we have an “ableist” approach and expect that everyone can fit into society centering on the able-bodied and able-minded. We forget that some cannot walk, some cannot see, some cannot hear, some have intellectual and

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<sup>178</sup> *Supra* note 91. (*R. v. M.N.J.*)

<sup>179</sup> “Dialogue” is the term used by Professor Peter Hogg to refer to the kind of communication that can legitimately occur between Courts and Parliament or the Executive.

cognitive disabilities, and so forth. The challenge is to design society and institutions in society to include fully the whole range of human potential. Achieving such is going to be a transformative experience for parents, individuals with FASD, teachers, doctors, judges, lawyers and other professionals and caregivers, communities and governments, all fellow travelers on the journey . . . let us travel forward together, companions in a quest for social justice. The needs are great, and a sense of urgency impels us.

***Appendix A: Sentencing Circle***

## **Christopher Pauchay's Sentencing Circle**

**Notes of April 24, 2009 Meeting held at Beardy's & Okemasis First Nations,**

**Between Doug Gamble, Director of Community Justice, Willow Cree First Nations,**

**Beardy's & Okemasis and Facilitator of the Pauchay Sentencing Circle, and Rae Mitten**

**Note: These notes have been reviewed and approved by Doug Gamble. A traditional consent protocol was used. These notes are written largely in the voice of the Doug Gamble, at least when a first person voice is used.**

Facilitating the Pauchay Sentencing Circle at Yellow Quill First Nation on Feb. 13, 2009, was a challenging opportunity for me. I was able to tackle it because I understand the community and the support networks there. I made two visits to the community of Yellow Quill prior to the Circle. The community wanted the Circle. Dr. Raj Hathiramani mental health therapist there, was my immediate resource, and eight other people, including Elders and Band Councillors. There were Elders from Muskeg Lake and James Smith First Nations, as well as from Yellow Quill. Two of the Elders did not speak English. Yellow Quill Elders spoke a Saulteaux dialect. One Elder spoke in Cree in the Circle. Harold Walker, an Elder from Sturgeon Lake First Nation, interpreted in Cree and English.

A traditional approach was used, everyone sat in a circle formation; prayer and a smudging ceremony begin the Circle process. The Circle was actually an oval, with an open entrance in the southern direction. Two Elders sat at the open entrance, one on each side. The Circle represents the womb, and the two Elders, one on each side, represent that two are needed



for conception. The Circle, thus, is the entrance to a new life, a rebirth into society. One needs to appreciate the sacredness of the Circle and to understand that the Circle Ceremony is a very powerful, sacred ceremony. The attached diagram shows where participants sat in the Circle. The offender and applicant, Christopher Pauchay and his family, defense counsel, facilitator and Judge sat on the east side of the circle and the surrogate victim, Sabrina Pauchay (sister of the offender and Aunt of the deceased), while grief counselors, RCMP, probation officer, prosecutor and Elder sat on the west side of the circle. At the north end, opposite the open entrance, was an empty chair representing Christopher Pauchay's deceased daughters, three year old Kaydance and fifteen month old Santana. On the floor in front of this empty chair was a stone on a leather mat (belonging to an Elder), representing Mother earth. A Bundle on the chair represented the spirits of the Grandfathers and the spirits of the two deceased little girls, Santana Pauchay and Kaydance Pauchay.

The Circle can be very emotional, evoking tears, and a sense of remorse and loss. We need to consider that Christopher fell eleven times out in the snow. A victim of hyperthermia himself, he knelt at the door of the house where he sought assistance. We don't know if he carried the children out of the house or if they followed him. His offence was not intentional, but alcohol was a factor, as well as the extreme cold and the dark. The Circle effectively reduced his sentence from the five years which the Crown was requesting, to a sentence of three years. In 6 – 8 months Christopher may be reintegrated back into the community at the Willow Cree Healing Lodge, a Federal facility on Beardy's & Okemasis designed for low minimum to medium risk federal inmates.

Christopher is about 5'8" tall and weighs ~ 170 pounds. He is likely to be victimized in the prison system. He may spend 2/3 of his time in the penitentiary, taking their programs, and then be programmed out and released to a lower security level of facility, from medium to minimum security at Riverbend or at Willow Cree Healing Lodge on Beardy's & Okemasis. Willow Cree is a 40 bed unit run by Corrections Canada. Christopher has a support network and Dr. Raj will likely be able to visit him.

Doug Gamble attended as a facilitator at Christopher Pauchay's sentencing circle. John Pauchay, a Yellow Quill Band Councillor was present. The mechanics of sentencing circles are

interesting. Doug has been involved in other sentencing circles. The mechanics involve a number of elements, including participants, seating arrangement, ceremony and protocol. Doug met with Judge Barry Morgan a week before the circle and held a mock circle at that time.

Most of the participants at Christopher Pauchay's sentencing circle were from Yellow Quill First Nation. Because of the deaths of the two little girls, there was a high level of emotional content in the Circle and due to this factor it was recommended that a number of ladies from Victims Services be present to comfort those who were in distress. Marilyn Gilbert is the Justice Worker at Yellow Quill and the liaison into that community. The host of the Sentencing Circle is the accused, in this case, Christopher Pauchay. Alcohol use in the community was an issue and the community is trying to deal with that, to hold feasts and round dances and similar activities where no alcohol is allowed and yet people can gather together to support one another. Addictions services and the health workers are involved and were part of preliminary discussions, recommendations and referrals. Hopefully, this tragic event can turn a negative into a positive and be transformative for the community of Yellow Quill, as well as for Christopher.

The Sentencing Circle begin with an Opening Prayer requesting respect, honour, humility and responsibility from everyone, including those in the outer areas, too. The facilitator posed the questions "What is the purpose of the Circle? What would you like to hear at the end of the day?" The answer that eventually emerged from the process was that the Circle is about taking responsibility and about healing, and that the Circle would like to see Christopher serve his sentence in the community and serve the Elders in the community for the rest of his life. Elder Cecile Nippi was called in from the outer Circle to speak. It is important to hear from and to ask for Guidance from the Creator that healing can begin for Christopher, his family and the community. The Elder and his assistant, Derek Cameron Oskapaos, smudged with sweet grass and sage, and everyone participated in this smudging ceremony.

The introduction dealt with the purpose of the Circle, who is it for, the importance of confidentiality, and rules forbidding angry outbursts and pointed fingers. The Court officials were welcomed. Doug introduced everyone. Judge Barry Morgan was low key and respectful and allowed frequent breaks. Chris stayed in focus. The first round was about two hours. The

following two main questions were posed, "What are you here for? What are the recommendations for Mr. Pauchay?" Participants were asked to speak in condensed form, to speak to the point. What did they experience, what did they feel and what recommendations did they have for the Circle?

There was a 45 minute to one hour break at 12 noon for a lunch of traditional hamburger soup, sandwiches, salad, fruit, juices and fried and baked bannock.

At 1:00 pm the Circle began again, until 2:30 pm. Participants tried to reach consensus on sentencing. The Chair/Facilitator called on five or six Elders to address sentencing recommendations. Also, the Crown, Defense, RCMP, probation officers, Dr. Raj and the Judge were asked to speak to this matter. They formed a kind of a huddle to formulate the recommendations.

Editor's Note: The sentencing circle was held on February 13, 2009. On March 4, 2009, the Court heard closing arguments on sentencing from the Crown and defense, and on March 6<sup>th</sup>, the judge imposed a term of incarceration in a federal penitentiary for a term of three years for criminal negligence for failing to protect Santana and Kaydance Pauchay from exposure to the elements, causing their death. The Crown argued that a conditional sentence under s. 742.1 of the *Criminal Code* was no longer available for a "serious personal injury offence" under the amendments to that section of December 2007, as interpreted in *R. v. Nusrat*, 2009 ONCA 31, judgment released January 15, 2009: "the new language would preclude an offender convicted of criminal negligence causing death from being eligible for a conditional sentence." The prosecutor requested a penitentiary term of between 2.5 and 5 years. The sentencing circle may have influenced Judge Barry Morgan to favour the lower end of this range to impose a sentence of three years. However, in imposing a penitentiary term, Judge Barry Morgan considered Christopher's alcohol abuse and inadequate efforts to address this abuse over time as an aggravating factor which indicated a lack of responsibility for his actions.

In most sentencing circles, sentencing occurs just before conclusion of the Circle. In this case, such procedure was not followed and instead the Judge passed sentence at a date subsequent to the Circle. In a sense, this procedure disempowered the Circle. However, that is not to say that the Circle was not effective; some critics and members of the public wanted a

retributive sentence and the Circle may have functioned to reduce the strong need for retribution, at least to some extent.

Did the Elders feel disrespected by the results? The Minister of Justice took power away from the sentencing circle through his public remarks stating that anything but a penitentiary term would not be appropriate in this case.

Doug Gamble: On May 1, 2009, the Beardy's & Okemasis justice committee, in support of the teepee concept of restorative justice, is scheduled to meet with Judge Timothy White, the Crown prosecutor Matt Miazga, the court worker, and the Legal Aid lawyer Pat Funvold about increasing the commitment to use restorative justice, mediation, sentencing circles and healing circles for people from the community involved in the justice system. Mediation is recommended for offences involving only minor violence, such as some domestic abuse cases, and can provide the counseling and support required to restore the relationship. The Beardy's & Okemasis Justice Committee will re-emphasize that sentencing decisions must be made in the Circle. The values of honesty, fairness, equality, compassion, humility, respect and responsibility are the hallmarks of Aboriginal Restorative Justice Programs and Circles.

There will also be a follow-up on the Yellow Quill Sentencing Circle with the community of Yellow Quill to review the Circle, to receive an update on Mr. Pauchay's progress and on the community's readiness to receive him back. After he has made progress with programs in the penitentiary and been favourably assessed, he may move to Willow Cree Healing Lodge at Beardy's Okemasis First Nation to begin the process of re-integration which would likely culminate in return to Yellow Quill First Nation at some point. The *Corrections and Conditional Release Act* has a number of provisions for release of inmates into the Aboriginal Community: Section 81(3) of the *Corrections and Conditional Release Act*:

(3) In accordance with any agreement entered into under subsection (1), the Commissioner may transfer an offender to the care and custody of an aboriginal community, with the consent of the offender and of the aboriginal community. 1992, c. 20, s. 81; 1995, c. 42, s. 21(F).

And section 84: Where an inmate who is applying for parole has expressed an interest in being released to an aboriginal community, the Service shall, if the inmate consents, give the aboriginal community

(a)adequate notice of the inmate’s parole application; and

(b) an opportunity to propose a plan for the inmate’s release to, and integration into, the aboriginal community.

Accordingly, pursuant to s. 81(3), the Aboriginal Community and Corrections Services Canada could enter into a custody agreement to release Christopher Pauchay into the community for the remainder of his penitentiary sentence. Such initiatives should complement other community-based federal initiatives, such as diversion projects, victim assistance programs and Aboriginal sentencing circles. The release plan must meet the needs of the aboriginal offender in a manner that does not present risk to the community. The federal Minister undertakes the obligation to pay for the care and custody of any Aboriginal offenders who are transferred to Aboriginal communities under a s. 81 agreement.

Several views of a drawing illustrating the seating protocol at the Pauchay sentencing circle are attached on the following pages (Figure A.1 and Figure A.2).

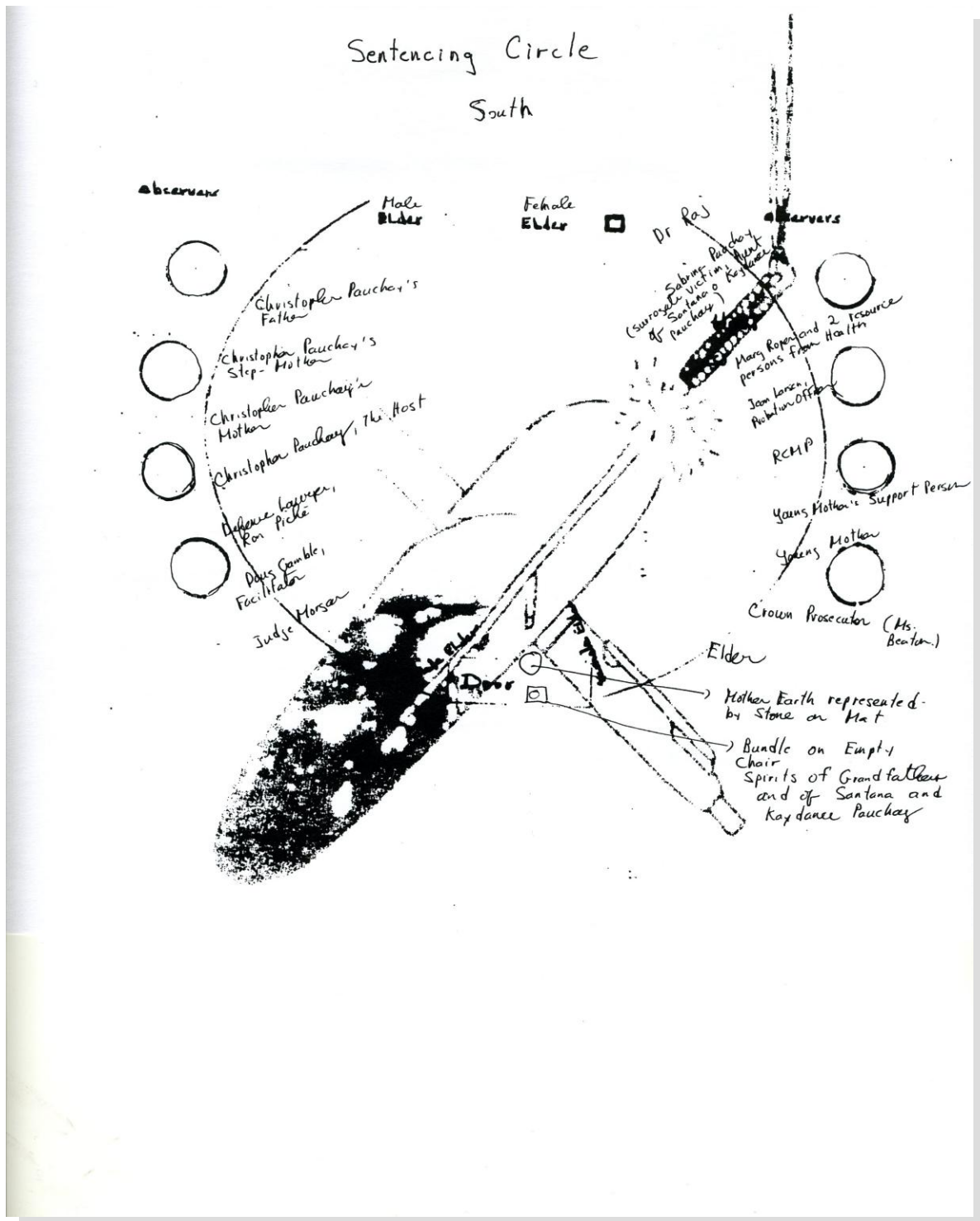


Figure A.1: Sentencing Circle Seating Protocol, View One

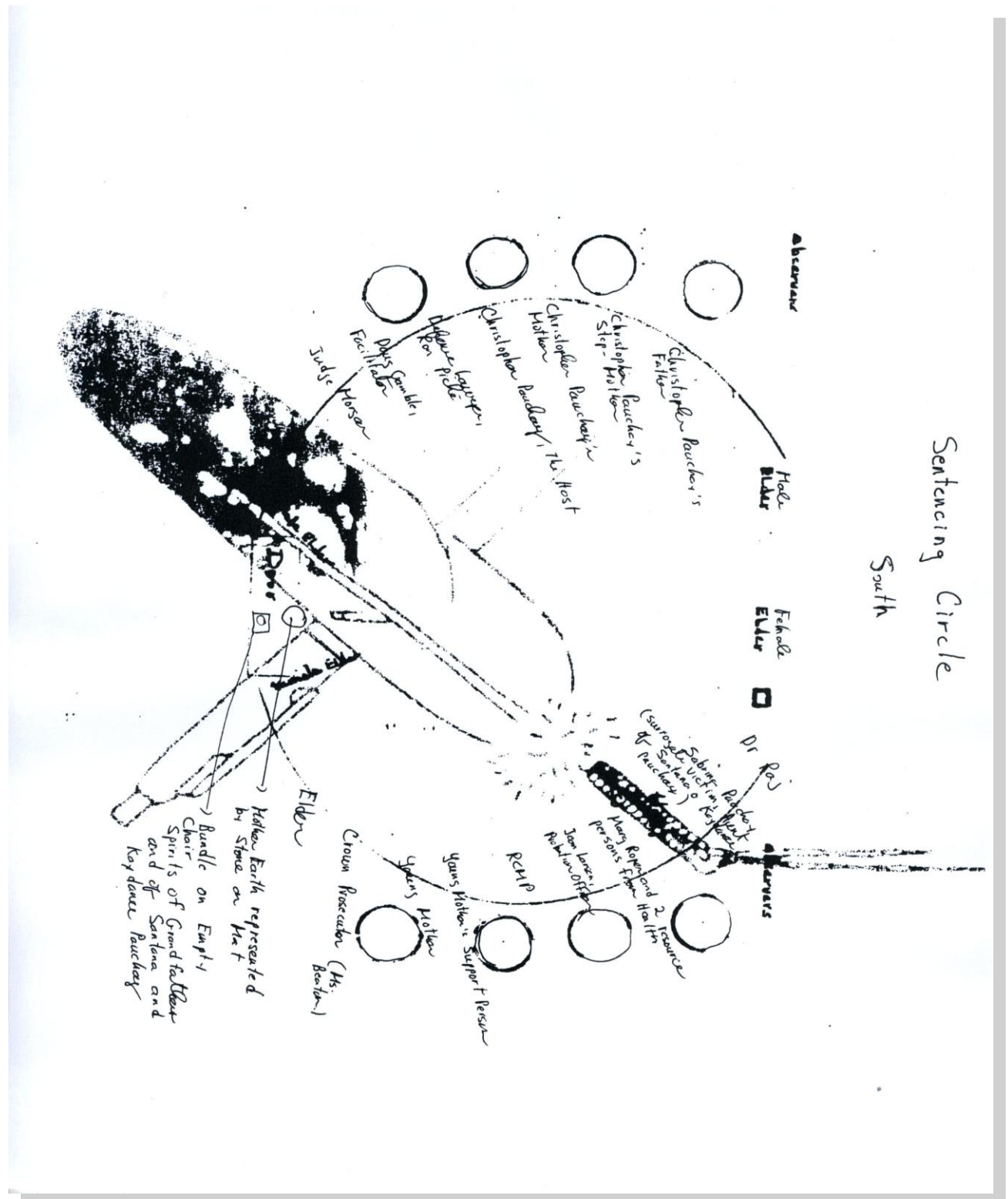


Figure A.2: Sentencing Circle, Seating Protocol, View Two

***Appendix B: List of Witnesses before the House of Commons Standing Committee on Justice and Human Rights, Review of the Mental Disorder Provisions of the Criminal Code (Bill C-30)***

**2002**



## **Appendix B**

### **List of Witnesses**

**Report of the Standing Committee on Justice and Human Rights, Review of Mental Provisions of the Criminal Code, Honourable Andy Scott, M.P., Chair, House of Commons Canada, June 2002, pp. 37-40.**

#### **Associations and Individuals**

##### **Department of Justice**

Douglas Hoover, Counsel

Catherine Kane, Senior Counsel

Greg Yost, Legal Counsel

##### **Royal Ottawa Hospital**

Dr. John Bradford, Clinical Director

##### **Criminal Lawyers' Association**

Carol Ann Letman, Director

##### **Queen's University**

Dr. Julio Arboleda-Florez, Professor and Head, Department of Psychiatry

##### **Canadian Association for Community Living**

Orville Endicott, Legal Consultant

John Mahaffy, CACL Board Representative of NAACJ

**“Institute Philippe Pinel de Montréal”**

Dr. Louis Morissette, Psychiatrist

**Canadian Resource Centre for Victims of Crime**

Steve Sullivan, President and Executive Director

**St. Joseph’s Healthcare**

Dr. Chris Webster

**B.C. Forensic Psychiatric Services Commission**

Barbara Fisher, Legal Counsel

Dr. Mark Riley, Psychiatrist

**Community Legal Assistance Society**

Carey Bow, Lawyer

Diane Nielsen, Lawyer

**Canadian Psychological Association**

Dr. Canny Bubber

Dr. Jordan Hanley

**As an Individual**

Hon. Justice Edward F. Ormston

**As Individuals**

Dr. Derek Eaves

Ronal Roesch

**“Association des groupes d’intervention en défense de droits en santé mentale du Quebec”**

Paul Morin, “Coordonnateur do Collectif de defense des droits del la Montérégie”

Jean Yves Pronovost, Administraot

**“Bureau du Québec”**

Giuseppe Battista, Lawyer

June Delaney, Lawyer

**British Columbia Civil Liberties Association**

Lindsay Lyster, Policy Director

**Ministry of the Attorney General of Ontario**

Curt Flanagan, Crown Attorney for Leeds and Grenville

Robert Gattrell, Assistant Crown Attorney for Simcoe

**Nova Scotia Legal Aid**

Malcolm S. Jeffcock, Lawyer

**Schizophrenia Society of Canada**

Tony Cerenzia, President

**Association of Canadian Review Board Chairs**

Maureen Forestell, Counsel to Ontario Review Board and alternate chair of Ontario and Nunavut Review Boards

**Quebec Defence Attorneys Association**

Lucie Joncas, Lawyer

**Canadian Bar Association**

Heather Perkins-McVey, Chair

Tamara Thomson, Director

**East Coast forensic Psychiatric Hospital, Nova Scotia**

Dr. Emmanuel Aquino

**Empowerment Council**

Jennifer Chambers, Empowerment Facilitator

**As an Individual**

Dr. Stanley Semrau

**Canadian Police Association**

David Griffin, Executive Officer

**Centre for Addiction and Mental health**

Dr. Howard Barbaree, Professor and Clinical Director, Law and Mental Health Programs,  
Department of Psychiatry, University of Toronto

Gail Czukar, General Counsel

**As an Individual**

Dr. Syed Akhtar

***Appendix C: List of Briefs Presented to the 14<sup>th</sup> Standing Committee on Justice and Human Rights, Review of the Mental Disorder Provisions of the Criminal Code, Bill C-30***

## Appendix C

### List of Briefs

**Report of the Standing Committee on Justice and Human Rights, Review of Mental Provisions of the Criminal Code, Honourable Andy Scott, M.P., Chair, House of Commons Canada, June 2002, pp. 41-42.**

Syed Akhtar

American Psychological Association

“Association des groupes d’intervention en défense de droits en santé mentale du Québec”

Association of Canadian Review Board Chairs

B.C. Forensic Psychiatric Services Commission

“Barreau du Québec”

Canadian Academy on Psychiatry and the Law (The)

Canadian Association for Community Living

Canadian Bar Association

Canadian Criminal Justice Association

Canadian Mental Health Association

Canadian Psychiatric Association

Canadian Psychological Association

Centre for Addiction and Mental Health

Community Legal Assistance Society

East Coast Forensic Psychiatric Hospital, Nova Scotia

Derek Eaves

Empowerment Council

Federal/Provincial/Territorial Working Group

“Institut Philippe Pinel de Montréal”

John Howard Society of Kingston & District

Ministry of the Attorney General of Ontario

Mood Disorders Society of Canada

Nova Scotia Legal Aid

Nova Scotia Review Board

Office for Victims of Crime

Psychiatric Patient Advocate Office

Quebec Defence Attorneys Association

Queen’s University

Ronal Roesch

Royal Ottawa Hospital

Schizophrenia Society of Canada

Stanley Semrau

St. Joseph’s Healthcare

Edwin A. Tollefson



***Appendix D: List of Recommendations from the House of Commons Standing Committee on Justice and Human Rights, Review of the Mental Disorder Provisions of the Criminal Code (Bill C-30), 2002***

**Appendix D:**  
**List of Recommendations**

**Report of the Standing Committee on Justice and Human Rights, Review of  
Mental Provisions of the Criminal Code, Honourable Andy Scott, M.P.,  
Chair, House of Commons Canada, June 2002, pp. 27-30.**

RECOMMENDATION 1

The Committee recommends that the defence of “mental disorder” in section 16 and the definition in section 2 in the *Criminal Code* be retained in their present form.

RECOMMENDATION 2

The Committee recommends that the definition and application of the law relating to “automatism,” both sane and insane, be left to the courts.

RECOMMENDATION 3

The Committee recommends that the federal Minister of Justice review the definition of “unfit to stand trial” in

RECOMMENDATION 4

The Committee recommends that the definition of “unfit to stand trial” in section 2 of the *Criminal Code* be amended by adding the words “and to be sentenced” to the title and words “or sentence imposed” after the words “verdict is rendered” in the definition itself. As well, section 672.11(a) of the Code should be amended to allow the court to order an assessment in such cases. Finally, subsection 6872.38(1) of the Code should be amended to give the Review Board jurisdiction in such cases.

#### RECOMMENDATION 5

The Committee recommends that section 672.54 of the *Criminal Code* be amended to allow the courts to absolutely discharge a permanently unfit accused either on its own volition or following the recommendation of the review board.

#### RECOMMENDATION 6

The Committee recommends that subsection 672.5(5) of the *Criminal Code* be amended to require a court or Review Board conducting a hearing to so notify a victim, if an interest in being notified is given by that person. As well, the Code should be amended to require that victims be notified of their rights and entitlements.

#### RECOMMENDATION 7

The Committee recommends that subsection 672.51(7) and (11) of the *Criminal Code* be amended to allow the court of Review Board conducting a disposition hearing to issue a publication ban for the benefit of third parties.

#### RECOMMENDATION 8

The Committee recommends that section 672.541 of the *Criminal Code* be amended to allow for the oral and other form of presentation of Victim Impact Statements at disposition hearings held by the court or Review Board.

#### RECOMMENDATION 9

The Committee recommends that sections 672.85 and 672.91 of the *Criminal Code* be amended to allow for interim temporary detention until appearance before a disposition hearing or a justice as the case may be. The Committee further recommends that the *Criminal Code* be amended to establish an offence of failing to comply with a disposition order made by a court or Review Board.

#### RECOMMENDATION 10:

The Committee recommends that the definition of “assessment” in section 672.1 be amended to expand, but not make mandatory, the class of persons qualified to assess whether an accused is unfit to stand trial.

#### RECOMMENDATION 11

The Committee recommends that federal, provincial and territorial ministers responsible for Justice review procedures at disposition hearings to determine whether the public interest would be better served by the mandatory representation of provincial Crown attorneys.

#### RECOMMENDATION 12

The Committee recommends that federal, provincial and territorial ministers responsible for Justice review practices and procedures for transferring youth to other forensic psychiatric facilities and accused to other jurisdictions to determine whether the *Criminal Code* should be amended to provide greater clarity.

#### RECOMMENDATION 13

The Committee recommends that sections 672.65, 672.66, 672.79 and 672.8 of the *Criminal Code* (Capping of Dispositions) be repealed.

#### RECOMMENDATION 14

The Committee recommends that sections 672.65, 672.66, 672.69 and 672.8 of the *Criminal Code* (Dangerous Mentally Disordered Accused) be repealed.

#### RECOMMENDATION 15

The Committee recommends that sections 747-747.8 of the *Criminal Code* (Hospital Orders) be repealed.

#### RECOMMENDATION 16

The Committee recommends that the federal, provincial, and territorial ministers responsible for Justice review the level of resources available to deal with the needs of mentally disordered accused and offenders so as to determine whether they are being used effectively and to see if the level of budgetary allocations is adequate to meet those needs.

#### RECOMMENDATION 17

The Committee recommends that the federal, provincial, and territorial ministers responsible for Justice take the necessary steps to ensure that education programs on mental health and forensic systems, and related issues, are developed for, and delivered to, judges, lawyers, court personnel, law enforcement personnel, corrections staff and others coming into contact with mentally disordered accused and offenders. As well, a similar education program should be developed for delivery to the public to dispel stereotypes surrounding mental illness.

#### RECOMMENDATION 18

The Committee recommends that the Department of Justice and other relevant departments and agencies, in collaboration with their provincial and territorial counterparts, collect, process, and analyze the data necessary to facilitate a further parliamentary review of Part XX.1 of the *Criminal Code* in 2007.

#### RECOMMENDATION 19

The Committee recommends that the legislation implementing the recommendations contained in this report include a requirement for a further review of the provisions and operation of Part XX.1 of the *Criminal Code* within five years of the legislation coming into effect. If no such legislation is adopted by Parliament, it should designate a committee to review the provisions and operation of Part XX.1 of the *Criminal Code* in 2007.

## **Appendix E: Follow-up to the Sentencing Circle and Commentary**

**September 11, 2009**

**Follow-up to the Pauchay Sentencing Circle**

**Chaired by First Nations Facilitator**

**Notes and Commentary in Retrospect by Rae Mitten**

The First Nations Facilitator at the Christopher Pauchay Sentencing Circle made this follow-up meeting available to parties who had participated in the Feb. 13, 2009 Sentencing Circle and to members of Yellow Quill First Nation.

On September 11, 2009 at 9:30 a.m., participants begin to gather at the community hall at Yellow Quill First Nation. The sentencing circle Facilitator and his Assistant, both First Nations, and the Justice Coordinator at Yellow Quill First Nation, sat at the head table. To their left sat two Elders, a woman from Sturgeon Lake First Nation and a man from Muskeg Lake First Nation. The Justice Co-ordinator from Saskatoon Tribal Council was in attendance. Two officials attended from Saskatchewan Justice, one from Prince Albert and one from Regina. Six members of Christopher Pauchay's family attended, his father, two of Christopher's sisters, two brothers and several brothers-in-law.

Several Yellow Quill Band Councillors as well as members of the Yellow Quill Justice and Health Committees attended. A number of additional members of the Yellow Quill Band attended. An inner "circle" of participants and an outer "circle" of spectators gradually took shape. Twenty-seven participants (mostly from the inner circle) signed the attendance roll.

When Christopher Pauchay's father arrived, he walked around the inner circle and shook everyone's hand.

The meeting was opened with an Elder's prayer.

The Facilitator explained his role and the purpose of the meeting. He is the Justice Coordinator at another First Nation and also was the Facilitator at Christopher Pauchay's Sentencing Circle. He also helps other communities and does training, which is important as a Sentencing Circle is a sacred practice and must conform with protocols.

Facilitator: Some issues arising from the Feb. 13, 2009 Sentencing Circle should be discussed today. Setbacks, negative feedback from individuals and reporters critical of the Sentencing Circle process have been noted. The community was split, and the public. Now it is important to try to bring some closure to the Sentencing Circle. We are interested also in an update on Christopher, the host of the Sentencing Circle, where he is and how he is doing.

I considered it an honour to have been selected to facilitate the Sentencing Circle. I visited Yellow Quill the week before the Sentencing Circle. I was impressed with the community's openness and support and I utilized that. Some time before the actual Sentencing circle, we held a mock circle here in this room, with Judge Barry Morgan from the Provincial Court and others present. At the Feb. 13th Sentencing Circle, held in Rose Valley, my assistant and the Yellow Quill Justice Coordinator were there to assist. I found that the Sentencing Circle had an openness and a lot of consideration was shown for the process and those involved. News of the Sentencing Circle was covered in the national press and all communities in Saskatchewan felt the loss of the two little girls. Participants came to the Sentencing Circle with an open mind and were prepared to participate in the work of the Circle. There was no self-promotion or marketing of positions [courtroom adversarial roles were suspended]. Participants were cooperative, they listened to others, and respected the sacredness of the Sentencing Circle. I was impressed with how emotions were expressed and the healing process that took place for this community and the families that were involved. Healing is a very important aspect of a Sentencing Circle.

I would like to know where community is at today, seven months later.

I was informed that "the Circle fell apart". Why? Because of the Judge. . .

Two young children perished in a snow bank on a bitterly cold evening, we cannot forget that tragedy. However, although we will not forget, neither is it our place to go on judging. The impact of what happened was acknowledged and was felt in the family, in Yellow Quill and across Saskatchewan and Canada. It was dealt with by law, by the community and by the Sentencing Circle and it is not our place to go on blaming. The critics did not attend the Sentencing Circle and did not experience firsthand the feeling of its sacredness and empowerment.



Should I have taken the Elders and walked out of the Sentencing Circle? In every other Circle, the Circle passed sentence, but the Judge took that away. The Elders' recommendation was weakened in that way. My aim or philosophy as Facilitator was Healing for the individual and for the community.

Where is the individual today and how is he doing?"

Justice Coordinator at Yellow Quill: When the issue of a Sentencing Circle came up, I asked myself, "Am I going to have enough energy to organize a Circle, to go through with it?" It was 50/50, ½/ ½, as previous circles had turned out well but had also started out ½ for and ½ against.

Christopher is still being held. Unfortunately, Dr. Raj couldn't be here today.

Member of Justice and Health Committee, Yellow Quill: The Circle recommendations weren't adhered to, were not taken seriously. What about our natural laws, our jurisdiction over justice on our own land. Our laws are oral laws, not in written form. They need to be put in a written form. The community came up with a case plan. . .

Justice Coordinator at Yellow Quill: But the plan needed to be on paper, the Judge said. There was a form and 10 to 12 sections of it were to be filled out for the Court. We only did one section as we were only given permission to do one.

Member of Justice & Health Committee, Yellow Quill: The Judge's lack of experience with sentencing circles was a factor, including his inexperience with the circle process. There were Elders from Yellow Quill and other communities at the Sentencing Circle. We needed an action plan to educate them as to how the Sentencing Circle plan works. Now there is a precedent of not following the Elder's decision. It was a controversial case and the mainstream system prevailed over ours.

Facilitator's Assistant: Restorative justice and Circles, we need to get back into these processes and affirm them. We need to make sure that the main stream Justice system understands our systems and our ways.

Facilitator: The Healing started the day of the Circle when the accused and victims opened up. It was tunnel vision on the part of the Judge and the Crown that they were going to

impose the sentence and not follow the Circle's recommendation. It was sad and a tragedy—but a wake up call for us. Three weeks ago at Beardy's there was a tragic loss of three youth.

As the Report [April 29, 2009] we distributed points out, the law was amended regarding conditional sentences, and cases involving serious personal injury offences were excluded. That created or caused the problem. The Crown used that to advocate against a community-based sentence. It weakened the Defense argument.

In the portion of the Sentencing Circle that dealt with sentencing, the Elders were relied on to speak to the sentence. Our Elders' recommendations were not honoured.

Woman Elder: It has been a difficult time for the immediate family, but Christopher had tremendous support from his family, Charlie, Joann and Pearl. Our spirituality has been tampered with in many ways over the years, resulting in pain, loss, going in the wrong direction into alcohol and drugs, and losing the spirituality of First Nations. We need to get that back for healing processes to work. Circle processes and protocol were not followed by the Court. We could have regained our spirituality. Elders not being part of the actual sentencing, not even being there and included when it was done did not help. When sentencing was done in the Court we could at least have learned Canadian law by being there. They show respect in the law for Hindu turbans. Now the Circle is our culture, it is our ways, and it is not being similarly respected. Our language and culture were not based on reading and writing. Instead, Elders were the prestigious people traditionally and they passed on the oral traditions. Canadian Law is always thrown in our face. We thought our laws would prevail in the Circle but not so. Some of the Elders could have assisted the Yellow Quill Justice Coordinator. Howard Walker translated three languages. We always have a cultural protocol to follow. We could feel the Pauchay family working through this. Outsiders came in for money. We don't have a big budget to get resources in, but Yellow Quill has come a long ways. Dr. Raj, Leonard and Marilyn work 24/7. Something good has to come out of something bad. Christopher Pauchay has moved to another place and we can't get hold of him yet. He is preparing to go to Willow Cree. He is doing well, taking classes, going to school, taking the programming. We know because the Elders working with him there say he is doing good.

Elders need someone to write and read for them if that is how the Court and justice is going to work. We had only a short time to prepare and meet the community, only two to three times prior to the Sentencing Circle.

Facilitator: It was a high profile case. Administration of the Circle, preparation of the community and those involved, were big jobs.

Elder and Support Worker at Yellow Quill: When the Sentencing was done in the Court, I felt that my community was let down by not honouring the Elders. As a community member, I felt that this let Chris down. After the sentencing came down, Chris was left out there by himself. No one was there to comfort him.

When at the end of our rope, we need the help of Elders and friends (e.g. when we are weak from alcohol and drugs). No one was there to help Chris stay away from bad influences. His family was doing alcohol also. As a community we should have helped him. We should not be afraid of outside influences, such as someone coming to see Chris. We can tell them to leave if they are a bad influence. We should be there for people that want to better themselves. It is not easy being a parent. Parents need help, encouragement from a Sweat, that kind of thing. Our people need to feel protected, to heal, to get wisdom, understanding and knowledge. We need a safe house.

Our community let Chris down. There was not the protection that he needed. We are all in a place where we cannot see clearly the traditional way.

The White man comes on our reserve and tries to tell us what to do. This is our land. The voices of Elders were muffled by the sounds of money and external power.

People wanted money to be a part of the Circle, even Elders did. I prayed about it . . . but these ones here [those that wanted money] did not.

The Circle opened eyes but it caused me to think what if I was down and hurting, not putting my full being into the Circle because of that.

What our Elders do is sacred: Circles, Rain Dances, Feasts, Lodges. . .

We are in need of a lot of healing and education about our ways, and our Elders. Without full understanding of our natural culture, it is difficult . . .

Justice Co-ordinator, Saskatoon Tribal Council: The Sentencing Circle took a lot of emotional energy from all involved, also time as well as energy. There was a mock Circle held prior to the actual Sentencing Circle. There was a point in Rose Valley at the actual Sentencing Circle when everyone had tears in their eyes; it was emotionally charged. It was not a failure. Everyone came together. Elders were there to support us.

I know that people are discouraged by the Elders' recommendation not being honoured in the final court sentencing. But positive things are still happening. Yesterday I spent all day at the Saskatchewan Court of Appeal in Regina. A young man from the Saskatoon Tribal Council had been sentenced for a serious sexual assault offence against his common law partner. The Community sent twelve letters of support to the Court for this young man. The Crown asked for three years in custody. The young man received a sentence of four month's custody and was to be eligible for release after serving 2/3 of that four month sentence. The Crown appealed the sentence to the Court of Appeal. At the appeal, the three judges on the panel at the Court of Appeal took restorative justice into account. Representatives from the community and justice workers were all there. After two hours, the Court of Appeal upheld the sentence. The Director of Prosecutions was prosecuting the case and still the Crown lost. The panel of judges acknowledged that Aboriginal people have restorative justice, and peace and harmony needs to come back, they need to take their own back.

Christopher Pauchay's Father: Thank-you for helping for my son, otherwise he would have got a longer sentence. Thank-you. Still hard for me . . . [quietly crying] . . . still a lot of pain . . . I try to comfort him . . . hard for me to get through the days, through the evenings . . . I miss them so much . . . I miss him so much.

He [Christopher] was going to another pen [penitentiary] in Alberta somewhere. He was moved on Monday [September 7, 2009]. He was supposed to phone me back yesterday.

He was doing OK when I visited him on Saturday and Sunday [presumably, Sept. 5<sup>th</sup> & 6<sup>th</sup>, 2009]. He was supposed to be transferred on August 29<sup>th</sup>, but they were too full over there [in the new facility in Alberta].

I feel sorry for what he did . . . for his daughters.

I am trying to keep up with work. . . me and my wife . . . Christopher wants to come back. He talks to counselors and goes to programs. He has a long ways to go yet.

Thank-you, all of you.

Thank-you, Facilitator, for coming over here.

Facilitator: Did Christopher show responsibility and accountability for what occurred? His expression and showing of emotions throughout the Sentencing Circle revealed a lot of remorse on his part. He was able to do that. He followed any directions from the Circle and sat up and faced the Circle.

At the end of the Circle, he felt some relief, he was happier, waving at people, facing them . . .

It was a very restorative experience.

Christopher was educated by the Circle, by the Elders and by the process.

He took a good stand for himself and said he was sorry . . .

The Facilitator asked the two Band Members present where the community was at today. Is there a division regarding this?

Answer by the Band Members: We are waiting for something good to happen out of this. Our young people talk to the Chief more. The Band Councillors are more active and listen more to the people. . . . as they are wanting a release to help them on the walk of life.

Another Band Member: Band Councillors need to understand, respect and support what is going on. . . a misunderstanding. The Elders understand their roles, but need to put it on paper as a back-up, so it is followed by the Justice System. No disrespect is meant for the Elders or their guidance . . . perhaps it could be on video or something to record it. The Sentencing Circle . . . it is everyone's fault that it did not go through . . .

Christopher Pauchay got the right to a Sentencing Circle. Then he made the mistake of going to a bar to party to celebrate winning a chance for a Sentencing Circle. He needed an Elder to work with him all along and teach him respect for the Circle. Our community Elders should be here for him. The gift of tobacco should be enough, as not everyone has money. We don't want to see our people in jail. Individuals have to respect the Elders, too.

But the Sentencing Circle should have been held here, on Yellow Quill First Nation's land, not in Rose Valley.

Justice Coordinator, Yellow Quill First Nation: There were security problems. The Police came and looked at our Community Hall and did not think that they could keep Christopher safe in the transporting and so forth, so it was moved to Rose Valley.

Facilitator's Assistant: For Yellow Quill it was an eye-opener.

Band Member: This is the natural law of our territory. We need to document this natural law and take it to Court in order for it to be understood and upheld. We must adapt to changes around us. We are always adapting to changes around us, so why not in this way? [By putting our laws into written form.]

I feel for Christopher Pauchay. The alcohol led to this. Christopher is a trailblazer in a sense, as his case presents a window of opportunity for the community to change. The little girls did not perish for nothing—let's document the natural laws for the future, in their honour . . . honour their leaving in this way.

Female Speaker [Band Councillor ??]: There was a lack of help for the family and Christopher Pauchay. There is another child [Miracle] that needs the parents [Chris and Tracy]. They drift apart, and it is the kids who suffer. Support was lacking to help Christopher and Tracy stay together. We need to help them grieve together and stay together. No one is there to support our young people in their relationships. We need a workshop on building healthy relations for young couples. There is a lack of guidance from Elders. Without that we have alcohol and violence. Lack of support for Chris and Tracy as a family was and is a factor. Chris had the courage to stand up and face it in the Sentencing Circle—we need support to do that.

Facilitator's Assistant: The community was there for me. . . when parents were not there, community members were there to guide you or discipline you. When parents came home they did not take your side against the community member who tried to guide or discipline you.

Get Elders involved. Offer them tobacco. They will come forward. We went through that process back home [at Beardy's] and it worked.

Male Elder from another First Nation: Elders and Ceremonies, keep that up, talk to them, learn. Hold a Pipe Ceremony, a Sweat Lodge, a Sundance, a Rain Dance. Tobacco comes first,

then the Elders will open up. After an offering of a cigarette or other form of tobacco, then we as Elders can open up. You have to come to us with tobacco. We cannot seek people out. It is up to a person seeking help to at least have a cigarette to give an Elder. You can buy a pack of beer or go to a bingo and you seem have money for that, so you can have tobacco or cotton print with you all the time. There are lots of hidden Elders on this Reserve. You need an offering of tobacco before they can open up to you. That is the protocol. Give the Elder a lift, say “Have a smoke with me.” There are a lot of hidden good ones. Work with the Chief and Council, do not blame them. There are many problems in small communities, but do not resort to negativity.

When I first went to A.A. many years ago, I was the only native person there when I started. I was afraid, but I realized that we were all there to solve problems. One of those present was a lawyer in a shirt and tie, but those were his work clothes. I was afraid to talk before them. But you can be on a level with all the others, take yourself up to that level, but not higher. Do not fall into making comparisons with others, their car, their house, their money. They earned and worked hard for it – respect it.

Ask Elders to come. Invite them and give them tobacco and then they will come.

I earned my pipe. It was not handed over to me, the drum and the rattle. Not proper ones, anyway. They were not from some second hand store—beware of those kind, they are only after the money and are not good. They did not hold a sweat lodge and earn it. They did not go to a Round Dance.

I saw a sweat lodge written up in a paper, how to build it and do it. Selling it, it is not right! You have to earn it and then it will be given to you by the Elder.

I had strict teachers. Many a times I cried, but today I understand. It was very hard sometimes.

Official from Provincial Justice, Regina: The whole process was unusual, so high profile, such a negative reporting spin. The reporting did not focus on the community coming together.

Official from Provincial Justice, Prince Albert: I work with Doug through the Beardy’s Okemasis Justice Program. I know his work and I have confidence in Douglas Gamble [the Facilitator].

Yellow Quill Man: Re-examine what you should do here in Yellow Quill. There are lessons to be learned as individuals and as a community. Take control of our community. Hold more Circles to create the experience and expertise with them. Education, not just about the provincial system, but about Creator's Laws and teach our values to our children. There are many child-raising and child correction issues to consider.

Charlie, Christopher's Father: Doug, keep the Community moving in a positive direction. Have a healthy social function every month. Keep moving on.

Justice Coordinator from Yellow Quill: As far as moving on in a positive direction, we plan to do so by appropriately marking the loss of the two girls and to address prevention by setting up a security system patrol so that if someone needs help they can call. Many people are afraid of the police, but they can then call our patrol. I intend to write a newsletter for Yellow Quill on Justice, but I need to be able to find the time . . .

I am starting to fund raise for a Memorial Park for Kaydance and Santana. There have been five kids lost from that one family. We are thinking of marble stone markers for them and a park to place them in.

In the U.S. a world-renounced architect designed such a park and made a 3D representation of it. We would like to do that and have it drafted into 3D pictures for the newspaper and ask them to publish it and to support the project. The newspaper people made enough money out of our tragic story . . . now they can give some back and help the community. I have asked the Star Phoenix and Leader Post to donate funds for this and to support and publish our plans through their papers. I am waiting for an artist's drawing of our plans to give to the papers.

Facilitator: Facilitator thanked everyone and adjourned the meeting as a nutritious hot lunch was ready to be served.

Informal visiting took place during and after the lunch.



## Author's Commentary:

The author is reminded of a presentation by a Maori Law Professor at Auckland University, Kylee Quince,<sup>180</sup> on the Youth Justice program in New Zealand, begun through legislation enacted in 1989,<sup>181</sup> its hub being the Family Group Conference. The legislation intended to address the disproportionate number of Maori youth offenders through application of restorative and diversionary principles, although the legislation applied to all youth ages 14 to 17, not solely to Maori youth. Through the legislation and the Family Group Conferences, youth justice cases were to be diverted, at first instance, to the family and community. Only if they could not be dealt with there would they be turned over to the Court System.

Khylee Quince, spoke from a Maori perspective on New Zealand's Youth Justice System. The New Zealand Youth Justice System and Family Group Conferencing does not work with Maori youth although it works with Pākeha or white and other non-Indigenous youth. It does not work for Maori youth for the following reasons:

1. It denies Maori autonomy over justice. It pays lip service to "partnerships" but they are not equal partnerships.
2. It misappropriates the Maori culture by taking something vaguely or broadly Maori and applying it to Maori people without really understanding their circumstances or their culture.. Such co-opting does not work and can, in fact, do harm.
3. It fails to address the structural causes of youth offending: poverty, dislocation, urbanization, effects of colonization, e.g. their equivalent of our residential schools, and so forth.
4. It does not have Maori people as Staff, Family Group Conference Facilitators or Coordinators or as Judges, who might understand the nuances of the culture or the circumstances of the people.
5. It can do harm because it can misinterpret culture. It is also devastating for Maori people to fail at something that is supposed to be inherently Maori. It is one thing to fail at

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<sup>180</sup> Khylee Quince, "Well, it's not our custom, but it's not all bad—a Maori Perspective on New Zealand's Youth Justice System," October 7, 2009, University of Saskatchewan Department of Sociology, ABJAC and IPJP programs.

<sup>181</sup> *Child*

*ren, Young Persons, and Their Families Act*, 1989, No. 24, Public Act of New Zealand.

something Pākeha (Pākeha are white persons), but something very different to fail at being Maori.

According to Kylee Quince, one devastating effect of the Family Group Conferences is a consequence of dysfunctional families. Accordingly, sometimes no one at all shows up for the Maori youth at the Conference, no parent or community member, so he (most are male Maori youth) feels abandoned and most frequently is sent back to court to receive a harsher sentence. Often only the youth and his mother appear at the Family Group Conference.

Also, many cultural differences exist for a Maori youth interacting with adults present that do not fit the Eurocentric model of the Family Group Conference. The Maori cultural protocol for such a youth is to remain silent and to take the punishment meted out to him by the Maori adults, whereas the legislation pertaining to the Family Group Conference requires him to speak up and personally admit his guilt. In the Maori culture, the mother would be the one to speak and admit guilt for her child. The child's failure to formally admit his guilt would mean that the diversion to the Family Group Conference had failed and he would be returned to Court for harsher sentencing. Therefore, the youth is placed in a difficult position because in order to conform with the law, the youth has to choose to disregard his culture, or vice versa.

Some points raised in the Maori youth justice context can give food for thought in light of the outcome of the Pauchay Sentencing Circle and other restorative justice initiatives in Canada. There are both differences and similarities in such a comparison. In Christopher Pauchay's case, he was an adult not a youth, and his family and community were present at the Circle to support him. As well, the Facilitator of the Sentencing Circle was a First Nations person who understood the cultural protocol and nuances, as well as the circumstances and challenges of First Nations people. However, the partnership between the Crown and First Nations People with respect to restorative justice initiatives such as Sentencing Circles, was not equal; the Circle was not held on First Nations Land and the Judge was not First Nations. Some aspects of First Nations Sentencing Circle principles were applied by the Judge, but not the most important, that is the role of the Sentencing Circle to have a say in the sentence, a role usurped by the Judge. By usurping this role, the Judge took away the autonomy of the Circle and First Nation's jurisdiction

over restorative justice.<sup>182</sup> By contrast, New Zealand Judges, by legislation, never interfere with the decision of Family Group Conferences. In addition, the structural causes of Christopher's offending, including the possibility of an FASD diagnosis, were not given full consideration. Such mainstream co-opting or misappropriation of traditional First Nation's culture, traditions and jurisdiction disempowered not only the Pauchay family and the Yellow Quill community but also all First Nations. Two recommendations were made by the Sentencing Circle. First, that Christopher Pauchay and Tracey Jimmy, mother of the two deceased girls and Christopher's common law partner, be allowed to be together (they were under a no-contact order at the time of the Sentencing Circle) as it was very difficult to deal with their parental grief apart. Second, that Christopher Pauchay serve his sentence in the community as an Elder's helper under their care and guidance. Christopher and Tracey had a new infant, Miracle, who had been apprehended and they remained in a state of crisis due to issues of family loss and separation. The healing promised by the Sentencing Circle process had been abruptly terminated by the Judge's unilateral action, signifying a lack of trust of those involved, the family, the Elders and the community.

The outcome of the intense process of ceremony and dialogue in the Circle, which is inherent in First Nations culture since time immemorial, was annulled, recalling times past in the history of Canada when First Nations ceremonies were feared and consequently outlawed by the *Indian Act*.<sup>183</sup> In 1884, the religious 'Potlatch' or "Give-away' Ceremony and the 'Tamanawas' dance, a part of the ceremony, was proclaimed a misdemeanor punishable by imprisonment. In 1921 at Village Island, British Columbia a religious potlatch ceremony and Tamanawas dance was held. Forty- five people were arrested and twenty-two of those arrested were imprisoned. In

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<sup>182</sup> The Minister of Justice's public statement supportive of penitentiary time in the Pauchay case and stating that a sentencing circle was an interim step, with the Circle making a recommendation that would not be binding on the Judge who retains the final decision on a sentence, may have been a factor in the Judge's decision. As discussed in the body of the chapter, such action on the part of the Minister of Justice was probably not appropriate.

<sup>183</sup> *An Act further to amend "The Indian Act, 1880,"* S.C. 1884, c. 27 s. 3 (47 Vict.), [assented to 19<sup>th</sup> April, 1884]: "Every Indian or other person who engages in or assists in celebrating the Indian festival known as the "Potlatch" or in the Indian dance known as the "tamanawas" is guilty of a misdemeanor, and shall be liable to imprisonment for a term of not more than six nor less than two months in any gaol or other place of confinement; and any Indian or other person who encourages, either directly or indirectly, and Indian or Indians to get up such a festival or dance, or to celebrate same, or who will assist in the celebration of the same is guilty of a like offence, and shall be liable to the same punishment."

1886, the Sundance ceremony was also proclaimed a misdemeanor punishable by imprisonment.<sup>184</sup> Similarly, in 1906, attendance of an Indian at dances held off the Indian's own reserve was prohibited in the western provinces and Territories; in addition, the appearance of an Indian in any show, exhibition, performance, stampede or pageant in Aboriginal costume without the consent of the Indian Agent was prohibited.<sup>185</sup> The bans on the Potlatch, Tamanawas dance, Sundance, and other Indian dances and regalia (off reserve) were not lifted until 1951 when a new *Indian Act* was proclaimed omitting these prohibitions.<sup>186</sup>

As illustrated, colonial power has had and continues to have an adverse effect on Aboriginal culture, rights and well-being, even in a post-colonial age. In analyzing jurisprudence in the Northern Territory of Australia, Heather Douglas, in the context of customary punishments such as physical punishment,<sup>187</sup> banishment, or reconciliation meetings, postulates that the judiciary developed a kind of soft legal pluralism, where judges take into account customary punishment but do not necessarily condone it. In doing so, they have attempted to maintain control over customary punishments, while at the same time being beholden to Aboriginal

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<sup>184</sup> *The Indian Act*. R.S.C. 1886, c. 43., s. 114: Every Indian or other person who engages in, or assists in celebrating or encourages either directly or indirectly another to celebrate, any Indian festival, dance or other ceremony of which the giving away or paying or giving back of money, goods or articles of any sort forms a part, or is a feature, whether such gift of money, goods or articles takes place before, at, or after the celebration of the same, and every Indian or other person who engages or assists in any celebration or dance of which the wounding or mutilation of the dead or living body of any human being or animal forms a part or is a feature, is guilty of an indictable offence and is liable to imprisonment for a term not exceeding six months and not less than two months; but nothing in this section shall be construed to prevent the holding of any agricultural show or exhibition or the giving of prizes for exhibits thereat.

<sup>185</sup> *Indian Act*. R.S.C. 1906, c. 81, s. 8: Any Indian in the province of Manitoba, Saskatchewan, Alberta, British Columbia, or the Territories who participates in any Indian dance outside the bounds of his own reserve, or who participates in any show, exhibition, performance, stampede or pageant in aboriginal costume without the consent of the Superintendent General of Indian Affairs or his authorized Agent, and any person who induces or employs any Indian to take part in such dance, show, exhibition, stampede or pageant, or induces any Indian to leave his reserve or employs any Indian for such a purpose, whether the dance, show, exhibition, stampede or pageant has taken place or not, shall on summary conviction be liable to a penalty not exceeding twenty-five dollars, or to imprisonment for one month, or to both penalty and imprisonment.

<sup>186</sup> *The Indian Act*. S.C. 1951, c. 29.

<sup>187</sup> Physical punishments, termed "pay back" are controversial. For instance, the customary punishment for taking a life was spearing in the thigh, not intended to cause death. In *R. v. Jadurin* (1982), 44 A.L.R. 424, the victim's relatives encircled Jadurin and on cue let fly with boomerangs, nulla nullas and spears. A tribal elder signaled when the punishment was sufficient.

communities for evidence of appropriate customary responses, and for carrying out promised punishments. She concludes:

In the past judges have imagined that white society and its laws could be placed like a grid over Aboriginal society and laws. They expected that eventually the struts of white society and law would be able to be laid firmly in place and customary law would disappear. However, it has not disappeared, and in response to a situation of perceived social crisis judges in the Northern Territory have recognized the durability of Aboriginal laws and their potential use in disciplining Aboriginal people and restoring peace to Aboriginal communities. In this sense there is a kind of “weak” legal pluralism in operation. “Weak” because there is informal recognition of Aboriginal customary law which gives some small space for an alternative legal authority to operate albeit under conditions purported to be scrutinized by the white legal authority.<sup>188</sup>

Instructively, in *Miyatatawuy*, the victim of an assault (the husband of the defendant) provided a statement to the court which said, in part:

. . .[T]his customary law system has already decided that the issue is finished. If the prosecution proceeds, not only does it discredit our decision to deal with our problems through our cultural law, but the defendant would be tried twice for the offence.<sup>189</sup>

The judge also received a written statement from about 140 members of Miyatatawuy’s community stating that the defendant had already been dealt with by customary law, through a period of banishment, supervision, and promises of good behavior. Ultimately, the judge accepted both pieces of evidence in support of mitigation of punishment.<sup>190</sup> Heather Douglas from the Australian context, comments that while customary law ultimately cannot override judges’ control over sentences, it can effectively exert its own independent force. When judges understand this they appear to be more flexible about considering the kind of sentence imposed.<sup>191</sup> However, in the present author’s opinion, a soft or weak pluralism need not remain soft or weak, but could be nourished to evolve and emerge into a more robust pluralism, with an enhanced role for customary law which after all has withstood the test of time for millennia, despite encounters with powerful, external forces.

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<sup>188</sup> Heather Douglas, “Customary Law, Sentencing and the Limits of the State” (2005) 20(1) Canadian Journal of Law and Society, 141 at 155 and 156.

<sup>189</sup> *R. v. Miyatatawuy* (1996) 6 NTLR 44, cited in Heather Douglas, “Customary Law, Sentencing and the Limits of the State” (2005) 20(1) Canadian Journal of Law and Society, 141 at 146. (Note that some of the editing has been removed from the quote cited for easier reading.)

<sup>190</sup> *Ibid.*

<sup>191</sup> *Supra* note 188 at 148-149. [Heather Douglas]

Accordingly, Foucault proposed five ‘shaping processes’ which can identify and shape the values of institutions and similar entities and aid in a broader analysis of power relations within and among these entities:

- (1) systems of differentiation that define the status of people who have the authority to ‘know’ (e.g. titles and roles such as professor, associate professor, assistant professor, lecturer, student, lay person; or judges, lawyers, social workers, parole officers, police officers and expert witnesses versus accused persons, community members, and so forth)
- (2) definition of objectives that shape what each person expects to do and how to act in relation to others (legislation, policy, protocols, professional codes of conduct, rules of order and so forth)
- (3) processes that offer incentives for compliance with power relations either through force, rewards, economics or surveillance systems (e.g. civil and criminal law sanctions, discipline, salaries and bonuses, supervision, monitoring, reporting, evaluation, promotion, awarding or withholding of honours and degrees, inclusion or isolation and so forth)
- (4) management structures for decision making, disseminating information and mobilizing resources (e.g. Ministers of the Crown and CEO’s control the deployment of resources and information down the hierarchy; electronic communication and data storage, retrieval and transfer systems render this process extremely efficient); and
- (5) rationalization, the degree to which these processes are supported and imposed by an all-encompassing technical apparatus (data gathering reporting and monitoring mechanisms, evaluations, record keeping, such as number of publications, conference presentations or number of citations of articles in an academic setting, or billable hours or sales in a business setting, or number of cases lost in a legal setting or decisions appealed in a judicial setting, criminal record, mass media messages, interpretation, mechanisms of enforcement and so forth).<sup>192</sup>

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<sup>192</sup> Michel Foucault, “The Subject and Power,” in Hubert L Dreyfus and Paul Rabinow, eds., *Michel Foucault, Beyond Structuralism and Hermeneutics*, 208-226 at 223-224.

In the Yellow Quill Sentencing Circle context, ultimately, the Judge was considered to have more status than the Elders in the Circle. The Elders and other participants were either conditioned to show deference to the Judge, or feared being found in contempt of court, as mainstream law and the force of state power through the police were on the Judge's side. More external incentives, as well as deterrents, were in place to ensure compliance with the Judge and mainstream law than were in place to uphold Aboriginal jurisdiction and rights over justice. The justice system privileged its own mainstream law over Indigenous law and customs, devaluing and re-defining Indigenous laws, values and epistemologies for their own purposes, thereby legitimizing and maintaining their own hegemony or position of dominance. Powerful institutional forces, ideological dominance, and a mainstream mass media helped to reinforce such dominance.

More fluid, respectful, ecological, non-coercive, un-codified, community-based, contingent, situated, negotiated, non-institutionalized ideologies, ceremonies and customs of Indigenous people, were marginalized and ultimately their recommendation was dismissed or rejected. Mainstream justice had ready access to resources to enforce its judgments, as well as a system of formal charges and a means of institutionalized enforcement for any infringements. Electronic systems of communication, storage and retrieval of data supported the mainstream justice system, along with mass media, in contrast to the oral tradition, individual integrity and non-coercive and grounded nature of the Elders. The levers of power were in control of the mainstream justice system and the discourse of dominance continued, apparently without concern for the notion that they were circumventing Aboriginal rights, or, conversely, considering that such circumvention of Aboriginal rights was justified in the circumstances.

Thus, the phenomenon of domination, rather than equal partnership, is manifested in the Yellow Quill Sentencing Circle's encounter with mainstream justice. Unfortunately, perhaps due to circumstances, the Judge did not make his quandary clear to the Elders at the time of the Sentencing Circle, so they assumed that their recommendation would be accepted.

According to Foucault, domination serves to continue the relationship of struggle between two adversaries, with potential conflicts and cleavages, resistance and revolts

ensuing.<sup>193</sup> As in Hobbes's dichotomies of self-other, master-slave or civilized-savage,<sup>194</sup> domination diminishes both sides of a dichotomy in that each side loses the positive qualities of the "other," for it is the "other" that we attempt to dominate rather than respect and include.<sup>195</sup> If our ideal is a pluralistic, compassionate society, we could benefit from finding ways of joining the Circle of equality and inclusion, rather than perpetuating hierarchies of domination that breed division, alienation and disparity.

A Foucauldian analysis also includes examining the strategy used by the dominant party, in this case, mainstream justice, to arrive at a winning solution, often through inducing the opponent to give up the struggle. The means chosen to obtain such a victory in the Yellow Quill Sentencing Circle when viewed through a Foucauldian lens appear circuitous and beguiling. First, the Court granted the Sentencing Circle, disarming its Aboriginal opponents who considered, once granted, that the Circle's recommendation would be honoured in the final decision with respect to sentencing, as had been customary with Sentencing Circles.<sup>196</sup> Although such Circles operate under some judicially imposed constraints, but without a solid legislative foundation except for s. 718.2(e) of the *Criminal Code* as interpreted in *Gladue* and *Morin*, circle sentencing does have the potential to shift the locus of decision-making authority in a manner

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<sup>193</sup> *Ibid.* at 224-5. [Michel Foucault]

<sup>194</sup> Thomas Hobbes, *Leviathan* [1651], Richard Tuck, ed. (Cambridge University Press, 1991) at 121-129.

<sup>195</sup> Georg Wilhelm Friedrich Hegel, *The Phenomenology of Spirit*, translated by A.V. Miller, with analysis of the text and forward by Findlay, J. N. (Oxford: Clarendon Press, 1977) at 124.

<sup>196</sup> The Crown could then appeal the decision, if deemed unfit, or if the criteria for holding a Sentencing Circle were not met, as in *R. v. Morin* [1995] S.J. No. 457 (SKCA). However, in the interim between the decision to have the Pauchay Sentencing Circle (*R. v. Pauchay*, 2009 SKPC 4, January 7, 2009) and the actual Sentencing Circle on February 13, 2009, the Ontario Court of Appeal released *R. v. Nusrat*, ONCA 31, January 15, 2009, which was used by the Crown and was a persuasive factor in the Judge's final sentencing decision (*R. v. Pauchay*, 2009 SKPC 35, March 6, 2009). *Nusrat*, in *obiter*, opined that criminal negligence causing death in that case constituted a serious personal injury offence, although not explicitly listed as such under s.752, but could be so construed. Therefore, a conditional sentence (or community-based sentence) under s. 742.1 was interpreted as not applicable under the 2007 revisions to s. 742. The Crown in *Pauchay* argued the following as cited in the decision: "Dealing with specific sentencing options that are available to me, she argues that neither a fine nor probation could possibly be appropriate in these circumstances, as neither sentence would accord with the required sentencing principles. Her position is that even if I were to consider a conditional sentence as an option (and she is certainly not suggesting such a sentence is appropriate), such a sentence would not be legally possible. This is so, she points out, because s. 742.1 of the Code, the section that allows for the imposition of a conditional sentence, was amended in December of 2007 such that such a sentence is no longer available for a "serious personal injury offence" as that term is specifically defined in s.752. In support of that position she relies on the decision of the Ontario Court of Appeal in the case of *R. v. Nusrat*, 2009 CarswellOnt 114, 2009, 31, which held, at paragraph 32, that the effect of the amendment is that "the new language would preclude an offender convicted of criminal negligence causing death from being eligible for a conditional sentence" (*R. v. Pauchay*, [2009] 2 CNLR 314, at para. 21).



which is consistent with the aspirations and asserted rights of First Nation communities for greater autonomy in the administration of justice.<sup>197</sup> The Crown has appealed the decision of a sentencing circle if they deemed it unfit or if there were not valid grounds to hold a sentencing circle in the first place,<sup>198</sup> but a Circle once granted raises different concerns for a Judge to drastically alter the sentence arrived at by the Circle. Following the Pauchay Sentencing Circle, the Judge who had presided at the Circle, in the community's opinion, usurped their jurisdiction and sovereignty to determine the sentence. As a result, the Circle was discontinued, broken, dispirited and dispersed without resources to regroup. While the Judge, as a matter of law has that right, in practice, to do so removes the motivation for community members to continue to participate in sentencing circles for which they are volunteers.<sup>199</sup> As a result, once granting the right to a sentencing circle, judges generally look for ways to honour the sentencing circle recommendations, or at the very least make it clear to the participants at the time of the sentencing circle, if possible, why according to law, this cannot be done.

Weeks later, in regular Court, Judge Barry Morgan convened a sentencing hearing, and at its conclusion sentenced Pauchay to a three year term in a penitentiary, over-ruling the recommendation of the Circle that Pauchay serve a life sentence of containment in the community assisting the Elders and learning their ways. As the Judge has no jurisdiction under the *Criminal Code* to order a life sentence, altering the term of the sentence would have been a permissible modification of the Circle's sentence, but instead the Judge chose a penitentiary sentence.

Furthermore, no mechanism was put in place to deal with the aftermath facing the Yellow Quill community, already reeling from loss and grief, and the disrespect and disempowerment they felt due to the disregard shown for their beliefs, culture and system of justice. They were

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<sup>197</sup> Luke McNamara, "The Locus of Decision-Making Authority in Circle Sentencing: The Significance of Criteria and Guidelines" (2000) 18 Windsor Y.B. Access Just. 60.

<sup>198</sup> *R. v. Morin*, [1995] S.J. No. 457 9 SKCA.

<sup>199</sup> Heino Lilles, Territorial Judge, Whitehorse, Canada, "Circle Sentencing: Part of the Restorative Justice Continuum," Plenary Speaker, Third International Conference on Conferencing, Circles and other Restorative Practices, August 9, 2002, Minneapolis, Minnesota; Barry Stuart, "Building Community Justice Partnership: Community Peacemaking Circles," Aboriginal Justice Section, Department of Justice Canada, accessed on the worldwide web 26-11-10 at

<http://www.justice.gc.ca/eng/pi/ajs-sja/ub/bcp-cpic/bcp-cpic/pdf on 26-11-10>.

once again victimized and presented as unworthy or blameworthy in the national press. No mass media exists to present their side of the story or to legitimate their ideology or epistemology. The faults, flaws and inequities of the mainstream justice system and its deplorable success rate with Aboriginal people,<sup>200</sup> remain largely unaddressed. In fact, the decision serves to further aggravate Aboriginal over-representation in Canadian prisons.<sup>201</sup> Instead of moving past domination and retributive justice, the collaboration and restorative justice of the Circle that could have transformed these bad news stories was circumvented with implications beyond the Pauchay case. Such are the dynamics of power relations rooted deep in the social nexus:

Between a relationship of power and a strategy of struggle there is a reciprocal appeal, a perpetual linking and a perpetual reversal. At every moment the relationship of power may become a confrontation between two adversaries. Equally, the relationship between adversaries in society may, at any moment, give place to the putting into operation of mechanisms of power. The consequence of this instability is the ability to decipher the same events and the same transformations either from inside the history of struggle or from the standpoint of power relationships. The interpretations which result will not consist of the same elements of meaning or the same links or the same types of intelligibility, although they refer to the same historical fabric and each of the two analyses must have reference to the other. In fact it is precisely the disparities between the two readings which make visible those fundamental phenomena of “domination” which are present in a large number of human societies.<sup>202</sup>

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<sup>200</sup> Law breaking may function as a form of inadvertent resistance for the otherwise powerless. It may be a symptom of their oppression and alienation. Similarly, the use of alcohol may function as a form of resistance, as well as a symptom of oppression and alienation. Lisa Ford in *Indigenous People-Settler Sovereignty, 1788-1836* (Boston: Harvard University Press, January, 2010) contends that early settler societies in America and Australia understood conflicts with Indigenous peoples, such as frontier theft and violence, as war to be resolved by diplomacy; later such legal pluralism was eschewed as settler societies desired absolute sovereignty over a once shared territory. Acts once considered political in a contested territory begin to be treated as criminal. Harry Blagg in *Crime, Aboriginality and the Decolonising of Justice* (Sydney, Australia: Hawkins Press, 2008) argues for the recognition of Aboriginal Customary Law as a solution to continued incarceration of Aboriginal peoples. He explores the potential for hybrid initiatives in the complex liminal space between Aboriginal and mainstream domains.

<sup>201</sup> Office of the Correctional Investigator, *Good Intentions, Disappointing Results: A Progress Report on Federal Corrections*, 2009: [http://www.legalresourcecentre.ca/sites/default/files/SapersReport11\\_09.pdf](http://www.legalresourcecentre.ca/sites/default/files/SapersReport11_09.pdf) at p. 5 and 18. In 1997 Aboriginal people constituted 3% of the population of Canada and yet amounted to 12% of all federal inmates. In 2007-8, 17.3% of the total federal offender populations was Aboriginal compared to being 4% of the Canadian adult population. The overall incarceration rate of Aboriginal Canadians is almost nine times higher than the rate for non-Aboriginal people. Aboriginal incarceration rates are often related to substance abuse, intergenerational abuse, residential schools, low levels of education, employment and income, and substandard housing and health care. Compared to non-Aboriginal offenders, they are younger, more inclined to have gang affiliations, and to have more health problems including FASD and mental health issues. Aboriginal offenders are disproportionately assessed as high need and high risk on most criteria, due, in large part, to a social history of disadvantage and discrimination.

<sup>202</sup> *Supra* note 192 at 226. [Michel Foucault]

Is there no way out of this perpetual cycle of domination, on the one hand, and resistance or revolt, on the other, that is present in a large number of human societies? Our Aboriginal ancestors preferred to eschew the politics of domination and instead welcomed newcomers to their land to join in the Circle and share with them the abundance thereof. John Ralston Saul's thesis in *A Fair Country: Telling Truths about Canada*<sup>203</sup> is that this preference for eschewing strategies of dominance in favour of equality, sharing, inclusion, negotiation and treaty making is what makes Canadian society unique from newcomers' European roots,<sup>204</sup> albeit encumbered as Canadian society is with a legacy of the feudal system, the family compact, and other hierarchical structures of social and economic organization. Large, public institutions and entities such as the justice system, through incorporation of hierarchies of domination legitimated through British-based laws and traditions, perpetuate the phenomenon of domination and are thus a disconnect with these fundamental defining Canadian values Ralston Saul terms "Métis values." Recognizing such disconnect is the first step toward finding solutions--solutions to be arrived at through negotiation in a Circle of equals, the potential longed-for redemption circumvented by the mainstream justice system, under both political and mainstream media pressure, in the Yellow Quill experience.

Construing the conflict and resolution in a Hegelian or Kantian dialectical triad,<sup>205</sup> domination is the thesis, resistance and revolt the antithesis, and collaboration among equals the transformative, redemptive synthesis of such a metaphysical triad. That transformative synthesis evolved long ago by Indigenous peoples is of great value, and is ours to continue to utilize in shaping the character of Canadian society from pre-contact, contact, treaty-making, and constitutional reframing and patriating, to present day sentencing circles, negotiations, consultations, and other opportunities for meaningful conversation, collaboration and reconciliation. However, it will take constant vigilance and a principled approach to resist the

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<sup>203</sup> (Toronto: Penguin Canada, 2008).

<sup>204</sup> John Ralston Saul, 2009 UBC-Laurier Institution Multiculturalism Lecture, "Aboriginals and New Canadians: the Missing Conversation," *Ideas*, CBC Radio, Oct. 16, 2009.

<sup>205</sup> Georg W. G. Hegel *The Phenomenology of Spirit*, translated by A.V. Miller (Oxford: Clarendon Press, 1977) at 124; and Immanuel Kant, *Critique of Pure Reason*, trans. J. M. D. Meiklejohn (New York: P. F. Collier, 1901) at B110.

strategies of domination of the Old World, especially when these strategies are modeled globally by super-powers, often for ulterior motives.

**FASD and Holistic Literacies: A Talking Circle  
(or Sharing Circle)  
*Wa-sa-cam-e-be Ke-skue***

**By H. Rae Mitten**

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## **1 Presumptions of Educational System do not Fit FASD**

Just as the Justice system is based on presumptions of fitness, freedom of choice and individual responsibility that do not apply to FASD, so too are learning theories, on which the education system is based, grounded in assumptions that may not fit persons with FASD. These assumptions include: consistent age-based functioning level; normal auditory and cognitive processing speeds; ability to appreciate cause and effect or consequences, to think abstractly, sequence, generalize, predict and comprehend abstract concepts such as time and money; to self-regulate one's attention and energy or arousal levels; to be able to plan and organize; and to have short term memory skills. Short term working memory is the ability to temporarily retain information, perform some mental operation or manipulation on it and produce a result, essential

for other higher order cognitive processes. All of these can be problems for individuals with cognitive disabilities such as FASD.

## **2 Individuals with FASD if not Engaged in Education may Fall by Default into Justice System**

It is not surprising, then, that two of the most common secondary disabilities associated with FASD are problems with school (including early school leaving) and problems with the law. In 1998, Boland and Burrill in *Fetal Alcohol Syndrome: Implications for Correctional Service*, “Although there is substantial evidence suggesting a link between FAS and crime, there is a dearth of research examining FAS/FAE in the criminal justice system.”<sup>1</sup> Subsequently, in 1999, a study of a youth psychiatric inpatient assessment unit in British Columbia confirmed an FASD diagnosis for 23.3% of the youth remanded there in a one year period.<sup>2</sup> Furthermore, in 2007, 10% confirmed cases and 18% possible cases of FASD were found among 91 male inmates over 30 years of age in the Stony Mountain Penitentiary in Manitoba, over an 18 month period. This was so despite researchers adopting a conservative diagnostic approach and contending with problems related to adult diagnosis, such as growth changes, including changes in hallmark facial features, cumulative environmental influences (acquired brain injury, mental health problems, and alcohol and drug use) as well as requiring historic confirmation of maternal alcohol consumption during pregnancy, often dependent on collateral validation, particularly in penitentiary populations. It should be noted that Aboriginals were over-represented in the Stony Mountain Penitentiary at 60%, compared to 17% for Aboriginal males in overall Correctional Services Canada facilities.<sup>3</sup> Relative to the most recent overall prevalence rates of FASD in U.S.A. and western Europe at 2 to 5%, the incidence in Stony Mountain is ten times greater than

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<sup>1</sup> Fred J. Boland, Rebecca Burrill, Michelle Duwyn and Jennifer Kamp, *Fetal Alcohol Syndrome: Implications for Correctional Service* (Ottawa: Research Branch, corporate Development, Correctional Service Canada, July, 1998).

<sup>2</sup> Diane Fast, Julianne Conry and Christine Loock, “Identifying Fetal Alcohol Syndrome Among Youth in the Criminal Justice System” (October, 1999) 20(5) *Journal of Developmental and Behavioural Pediatrics*.

<sup>3</sup> Patricia MacPherson and Albert Chudley, “Screening and estimating incidence in an adult correctional population” (2007) Presented at the 2<sup>nd</sup> International Conference on Fetal Alcohol Spectrum Disorder, Victoria, B.C. March 7-10.

best estimates available for comparable general populations, albeit that no such estimates are available for Canada.<sup>4</sup>

In fact, although a causal connection cannot as yet be scientifically claimed, problems with school, including early school leaving, are related to increasing involvement with the justice system. In a longitudinal prospective study of a large cohort of individuals diagnosed with FASD in northwest United States, 60% experienced problems with school such as suspensions and dropping out and 60% experienced problems with the law. The incarceration rate among this sample of individuals with FASD in the U.S.A. was 32% for adolescents and 42% for adults.<sup>5</sup> Being grounded in the educational system throughout one's childhood and youth is an important component of socialization. Without this grounding, chances of positive outcomes in adult life are adversely affected.

### **3 Holistic, Engaging Approaches that are Responsive to Culture, Diversity and Brain Domains**

It is of prime importance, then, to engage the child in learning activities from an early age, including the pre-school years. Approaches that can engage the child and meet holistic literacy needs must be cognizant of and responsive to cognitive and behavioural challenges in order to be effective. These approaches must not punish children for what they cannot help, but rather “try differently, not harder.”<sup>6</sup> For instance, expressive language skills of individuals with FASD are greater than their receptive language skills, so that they can “talk the talk, but not walk the walk.” In other words, they can parrot back what is said to them by a parent, teacher, judge, or social worker, but they cannot fully comprehend it, nor consistently apply it to real life situations. Their executive functioning skills are impaired; they will need assistance to “get

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<sup>4</sup> Philip A. May, J. Phillip Gossage and Wendy O. Kalberg et al. “Prevalence and epidemiologic characteristics of FASD from various research methods with an emphasis on recent in-school studies” (2009) 15 Dev. Dis. Res. Rev. 176-192.

<sup>5</sup> Ann P. Streissguth, HM Barr, J Kogan and FL Bookstein (1996) *Understanding the occurrence of Secondary Disabilities in Clients with Fetal Alcohol Syndrome and Fetal Alcohol Effects (FAE), Report to the Centers for Disease Control and Prevention on Grant No. R04/CCR08515* (Tech. Report. No. 96-06). Seattle: Washington, Fetal Alcohol and Drug Unit), cited in Ann Streissguth, *Fetal Alcohol Syndrome, A Guide for Families and Communities* (Paul H. Brookes Publishing Co.: Toronto, 2001) at 109.

<sup>6</sup> Diane Malbin, *Trying Differently Rather than Harder*, 2nd ed. (Portland, Oregon: Tectrice, 2002).



themselves organized and multi-task” in order to comply with instructions, rules, deadlines, court orders, and so forth. Executive functioning includes the capacity for goal-directed behaviour, including self-regulation, initiation, working memory, planning, organizing and self-monitoring.<sup>7</sup>

Moreover, no literature exists regarding a comprehensive FASD pedagogy that takes into consideration sensory, behavioural, attentional, volitional, and most importantly, cognitive challenges. This is the case some 40 years after medical identification of fetal alcohol related conditions. Such a treatment gap provides insufficient guidance for those teaching and caring for individuals with FASD.<sup>8</sup> While recommendations from psychologists, speech and language, and occupational therapists are fairly well documented, if fragmented, in this regard, input from experts in the teaching of literacy and language, who are informed about and experienced with FASD in the context of classroom and curriculum, is largely absent from the literature. This is a systemic problem that needs addressing, lest one should conclude that children and youth with FASD are considered disposable in the educational system.<sup>9</sup>

A growing trend exists for-profit, commercial programs to be imposed top-down, with a focus on standardized testing and system accountability. When children with cognitive problems like FASD fail to meet the standards they may be relegated to special education or behavioural classrooms, often practicing the so-called Pedagogy of Poverty.<sup>10</sup> The Pedagogy of Poverty is a reductionistic form of pedagogy based on a deficit-perspective, rather than being rich, dynamic and strength-based. In such an impoverished context, children and youth with FASD often lose interest, remain behind, drop out, and the downward cycle continues. Prescriptive phonics programs and worksheet-driven curricula are often a feature of these classes, persisting despite joint expert group statements admonishing the use of such developmentally inappropriate

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<sup>7</sup> Jeannette Lang, “Ten Brain Domains: A Proposal for Functional Central Nervous System Parameters for Fetal Alcohol Spectrum Disorder Diagnosis and Follow-Up” (June 26, 2006) JFAS Int. © The Hospital for Sick Children.

<sup>8</sup> Sahar Ismail, Stephanie Buckley, Ross Budacki et al, “Screening, Diagnosing and Prevention of Fetal Alcohol Syndrome: Is This Syndrome Treatable?” (2010) 32(2) Developmental Neuroscience 91. Insights from basic research on how alcohol affects the developing brain have not been translated into the clinical or practice domain to any appreciable extent. There is also a lack of sensitive and specific diagnostic tools to identify the syndrome. Ongoing research aimed at better diagnostic tools, including the search for a panel of genes that are altered in a developing fetus and chemical biomarkers in a newborn’s stool may prove fruitful.

<sup>9</sup> Kelly Edmonds & Susan Crichton, “Finding Ways to Teach Students with FASD: A Research Study” (2008) 23 (1) Canadian Journal of Special Education, 54 at 68; Gal Koren, Ellen Fantus, Irena Nulman, The Hospital for Sick Children, Motherisk Program, Toronto, Canada; University of Toronto, Toronto, Canada, “Managing Fetal alcohol Spectrum Disorder in the Public School System: A Needs Assessment Pilot” (2010) 17(1) Can. J. Clin. Pharmacol. e79.

<sup>10</sup> Martin Haberman, “The Pedagogy of Poverty Versus Good Teaching” in *The Jossey-Bass reader on teaching*, foreword by Ann Liberman (San Francisco: Wiley & Sons, c2003) at 239.

curriculum for children who are emerging in their literacy skills, whether developmentally delayed or in pre-school or primary grades, or some combination.<sup>11</sup> Children may be required to sit and attend to rote paperwork or listen to didactic teaching for extended periods of time, which respect neither their physical, developmental, social, cognitive nor individual learning needs and are devoid of any meaningful context for many students. Such practices can restrict and limit literacy acquisition and have been termed the “pedagogy of control” by Lesley and Labbo.<sup>12</sup> Rather than relying on “one-size fits all” phonics and work sheets and easily measured but isolated skill drills, it is preferable to teach children to read and write using real texts which are attuned to the developmental complexities of the child and to recognizing and facilitating emergent literacy.<sup>13</sup> Lesley and Labbo conclude:

[We] am reminded of Calkins’s (1994) caution that “our teaching matters more than we ever dreamed possible” [p. 517). This is especially true for special needs children. Every method is a critical juncture between making progress, not making progress, and regression. Even something so “simple” as a worksheet can make this difference.<sup>14</sup>

There is an absence of definitive research with which to resolve the issue of reductionism versus a more holistic approach in the context of literacy instruction in the particular form of literacy termed “learning to read”. In a pilot study in the Western Cape of South Africa, after nine months of treatment and training one hour a week on phonological awareness by speech and language pathologists, the experimental group of children with FASD aged 9 and 10 years, in their third formal year of school, improved significantly in tests of phoneme knowledge and pre-literacy skills compared to a control group with FASD who received no such phonological awareness training. However, the experimental group’s reading, spelling, addition and subtraction skills on general scholastic tests did not improve significantly in comparison to the control group. Mathematical skills were assessed pre- and post- treatment as it was thought that deficits in literacy skills contributed to difficulty in mathematics. As the skills in reading had not improved with the phonological training, the relationship between deficiencies in math and

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<sup>11</sup> Melinee Lesley and Linda D. Labbo, “A Pedagogy of Control: Worksheets and the Special Needs Child” (2003) 80(6) *Language Arts*, 444, at 444-446. The National Association for the Education of Young Children and the National Association of Early Childhood Specialists in State Departments of Education [NAEYC, 1990] released the joint statement referred to in the text.

<sup>12</sup> *Ibid.*

<sup>13</sup> *Ibid.* at 449-451.

<sup>14</sup> *Ibid.* at 452.

literacy skills remains a moot point.<sup>15</sup> However, the study does illustrate that reading involves more than the ability to decode the sounds that letters and groups of letters represent.

Rather than being a reductionistic and mechanistic rote process, literacy is a complex, creative, multi-faceted, contextual, problem solving process. Like all forms of knowing, literacy is a complex search for meaning, in which the whole is more than the sum of its parts, situated and meaningful within a physical, cultural, linguistic, historical and epistemological context. Others have grappled with its indeterminate nature:

“Reading, then,” Alberto Manguel writes, “is not an automatic process of capturing text in the way photosensitive paper captures light, but a bewildering, labyrinthine, common and yet personal process of reconstruction. Whether reading is independent from, for instance, listening,” Manguel continues, “whether it is a single distinctive set of psychological processes or consists of a great variety of such processes, researchers don’t yet know, but many believe that its complexity may be as great as that of thinking itself.”<sup>16</sup>

Literacy, like science, philosophy or art, and other forms of meaning-making, has an element of indeterminacy that goes to the very essence of our humanity, eluding effective reductionism. Accordingly, awareness of metacognitive processes and strategies used in learning to read can be modeled and coached so that students can gradually take more responsibility for selecting, managing and monitoring their own individual learning processes. In this way diversity in learning styles and pace can be respected and honoured. Moreover, Frank Smith emphasizes that children learn to read by reading, not by doing rote, reductionist activities such as worksheets or flash cards. Instead, reading is a meaningful activity. There is nothing passive nor mechanical about it. It is dependent on prior knowledge and expectations of readers as they engage in a purposeful and rational activity. Accordingly, novice readers need to see, through appropriate experience and exposure to reading, that reading makes sense and has a purpose. Reading is not a sound-symbol decoding activity; it is a complex process of making sense of written language, just as one learns to “read the universe.” By “reading the universe” Smith refers to the many ways in which human beings over the ages problem solve or make sense of the world around them, the sky, the stars, the seasons, weather patterns, animal tracks,

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<sup>15</sup> Colleen M. Adnams, Pharyn Sorour, Wendy O. Kalberg et al, “Language and Literacy Outcomes from a Pilot Intervention Study for Children with Fetal Alcohol Spectrum Disorders in South Africa” (2007) 41 *Alcohol* 403-414 at 411.

<sup>16</sup> Denny Taylor, “Beginning to Read and the Spin Doctors of Science: An Excerpt” (1999) 76(3) *Language Arts* 217 at 218.

animal behaviour, behaviour of other humans, behaviour of falling and moving objects, flowing water or fluids, matter, fire and light, sounds and other entities and phenomena they encounter in their environment.<sup>17</sup>

However, Frank Smith acknowledges that public opinion and entire theories of teaching reading on which commercial, published educational tests and instructional materials are based, rely on the false assumption—“Just Sound Out, and you can read.” He contends that this could be termed the “flat earth theory of reading,” which true to its namesake is resistant to change. Sounding out is not reliable, as there are too many inherent inconsistencies and exceptions. Every letter can be represented by more than one sound and vice versa, in fact there are more than 300 ways in which letters and sounds can be related. Moreover, most of the words in the English language are spelled irregularly. Computer programs that “read” English text aloud do not read phonetically, rather they “read” by recognizing entire words or syllables, rather than individual letters and sounds. Moreover, the purpose of reading is not to produce sounds of words, but rather to understand their meaning and to do so one must understand what he or she is reading about before one can read aloud. Smith contends that no research has ever demonstrated that children learn to read solely through phonics--that would be cruel and unnatural treatment. On the contrary, people learn to read by recognizing words, just as they learn to recognize objects and faces. In fact, the Chinese and other peoples learn to read languages that are non-alphabetic. Furthermore, words are not learned by rote, rather they are learned as they make sense and it is only by reading that one learns to read.<sup>18</sup> Smith has an interesting explanation to account for the hegemony of phonics or sounding out:

So why is a fallacious story so popular, apart from being so obvious? A significant reason in the politics and economics of the education industry is that sounding out can be reduced to small steps, pre-packaged in instructional materials, dealt out one bit at a time, and tested and monitored every step of the way. With sounding out, teachers and students can be publicly “held accountable” for learning. Without sounding out, teachers have to be trusted to exercise their professional expertise and judgment.

. . . .  
Don't tell them they're wrong; tell them there's a better way. . . . We are not talking about abstract theories, but about how children are treated in school, and whether they are helped or handicapped.<sup>19</sup>

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<sup>17</sup> Frank Smith (2004). *Understanding Reading: A Psycholinguistic Analysis of Reading and Learning to Read*. (Sixth Edition). Hillsdale, NJ: Lawrence Erlbaum.

<sup>18</sup> Frank Smith, “The Just so Story—Obvious but false,” (2003) 80(4) *Language Arts* 256-257.

<sup>19</sup> *Ibid.* at 258.

## 4 Social Justice and Equity Issues in Education

### 4.1 *Class, Race, Gender and Disability Issues in Education*

The educational system is a site of contestation for social justice, as class, race, gender and disability factors often are determinants of success or failure, rather than being a matter of equal opportunity for all. Significantly, First Nations people remind us that all children are gifts of Creator and that each child has special gifts; they have a special word for the sacredness of the child and that is *Awasis* in Cree, referred to a transfigured, illuminated, sacred child representative of the sacred spirit we need to respect in all children. Children are always accorded a special place in the sacred Circle, usually at the centre. Often we do not foster and celebrate the special gifts of the disabled to nearly the same extent that we do for those of other children. Particularly this is pronounced if the disabled are also disadvantaged by class, race and gender. Disability, furthermore, is an orphan among equity seeking groups, largely excluded from discourses on pedagogy and curriculum; this trend is particularly pronounced for the disability of FASD. In fact, discourses on educational equity primarily focus on race, class and gender. While race, class and gender are not impediments to the inclusion of disability, disability does need to be fulsomely included in educational and curriculum discourse, particularly the disability of FASD which is the most prevalent of the cognitive disabilities. Despite lip service paid to accommodating individual differences, a culture of ableism, the notion that it is preferable to be physically, psychologically and cognitively like the majority or “able,” predominates in education.<sup>20</sup>

Language and reading theory have been dominated by psychological learning theories, which have tended to view reading as a perceptual activity centered on sound/symbol relationships, involving coding, decoding and encoding text, characterized by rigid, sequenced, hierarchical presentation of isolated bits of phonemes, phonics and language mastery before

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<sup>20</sup> Rachel Heydon and Luigi Iannacci, “Biomedical Approaches to Literacy: Two Curriculum Teachers Challenge the Treatment of Dis/Ability in Contemporary Early Literacy Education” (Fall, 2005) 7(2) *Language & Literacy*; and Heinz Wimmer, Karin Landerl, Renate Linortner, Petter Hummer, “The Relationship of Phonemic Awareness to Reading Acquisition: More Consequence than Precondition but Still Important” 40 *Cognition* 219-249.

learners were considered able to derive meaning from texts.<sup>21</sup> Gradually, literacy educators have come to appreciate broader notions of reading and writing, reconfigured as situated practices and processes of making meaning through sign or symbol systems, within larger socio-cultural frameworks and involving a complexity of physical, cognitive, affective and discursive factors.<sup>22</sup> Literacy includes the ability to identify, understand, interpret, create, communicate and compute along a continuum of learning, enabling individuals to achieve goals, develop knowledge and potential, and to participate fully in community and wider society.<sup>23</sup> A disconnect between literacies and language in a child's home, community and culture with school-based literacies and language, is an example of a common discursive difficulty which needs to be recognized and bridged through pluralistic understandings and approaches, without problematizing either the child or the home.<sup>24</sup> Moreover, recognition of the generation of meaning in multi-modal ways not solely alphabetic or textual, such as fine arts and applied arts, has led to the realization of the plurality or multiplicity of literacies per se.<sup>25</sup> Children learn through interaction with environment, culture, family, community, peers, teachers and knowledgeable others, so that family, community and cultural literacies are as important as school-based literacies, although the latter have tended to privilege only certain textual and language literacies.<sup>26</sup> Multi-modal literacies are closer to traditional ways of knowing, more visual, hands-on, and relational, often family or community oriented in nature, and thus may be more culturally appropriate for some learners and better suited to their learning styles. As literacy is a plural and dynamic concept no definition is going to constitute the final word.<sup>27</sup>

Like curriculum and instruction, assessment and evaluation should be a teacher domain, an integral and continuous part of the learning process, rather than decision makers conceding this field to corporate publishers. The growing trend towards commercialization and corporatization of schools, tests and curriculum materials is concerning, as professional educators do not have the advertising budget that publishers and their marketing agents often do. Educational policy makers, school boards and administrative decision makers need to consult

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<sup>21</sup> *Ibid.*

<sup>22</sup> UNESCO Education Sector, *The Plurality of Literacy and its Implications for Policies and Programs* (Paris, France: United Nations Educational, Scientific and Cultural Organization, 2004).

<sup>23</sup> UNESCO EFA Global Monitoring Report, *Literacy for Life*, 2006 (Paris: UNESCO, 2005).

<sup>24</sup> *Supra* note 20 (Rachel Heydon and Luigi Iannacci).

<sup>25</sup> *Ibid.*

<sup>26</sup> *Ibid.*

<sup>27</sup> *Supra* note 23.

professional educators in their systems, the ones to whom they entrust their children's education and their children's teachers' education, before yielding to marketing claims and pressures. This is especially important before evidence is in regarding independent scientific verification of holistic, long term outcomes and implications of marketed programs for student populations similar to samples used in validation studies. If publishers are neither experts in literacy and multiliteracies,<sup>28</sup> nor experts in accommodating cultural and linguistic diversity, but instead tend to universalize a one-size fits all approach, they can perpetuate a *Pedagogy of Oppression*.<sup>29</sup> Rather than a "banking model" of education utilized in the Pedagogy of Oppression, wherein a student is considered empty and the teacher fills her or him up with knowledge, implying a clear dichotomy between teacher and student, ideally, education should be liberating and transformative through respectful, inclusive, active, dialogic, collaborative processes among all participants.

#### ***4.2 Aboriginal Equity Issues in Education: A Component of Reconciliation***

Reconciliation between the Crown and the Aboriginal Peoples of Canada entails collaborative efforts to fashion a system that respects Aboriginal languages, traditions, cultures and epistemologies while at the same time enabling them to "learn the cunning of the white man," as Western knowledge is so aptly termed from a First Nations perspective in the education clauses of the Treaties, particularly considering the decline of the buffalo herds that had been their mainstay and a need to find other forms of livelihood. Education was to become the "New Buffalo:"

Treaties were negotiated in good faith to provide, among other services, an education that would enable First Nations to enrich their new livelihood.

This transformative education has not been delivered. Instead policies built on supremacy of European heritages have left a legacy of trauma as a by-product of an education system meant to "kill the Indian in the child." In

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<sup>28</sup> The New London Group, "A Pedagogy of Multiliteracies: Designing Social Futures" (1996) 6 (1) Harvard Educational Review, ISSN 0017-8055. Multiliteracies is a term used by the New London Group to describe the shift to multiple kinds of literacies used to effectively communicate within diverse culture and social settings, as well as multiple modes of delivery of communications.

<sup>29</sup> Paulo Freire, *Pedagogy of Oppression*, trans. By Myra Bergman Ramos (New York: Herder and herder, 1970).

1982, the *Constitution of Canada* affirmed Aboriginal and Treaty rights, and in so doing generated the shared competency of the federal and provincial/territorial governments and First Nations to take action to preserve and promote the distinct knowledge, traditions and distinctive cultures that underlay these rights.<sup>30</sup>

First Nations and other Aboriginal peoples wanted to learn “the cunning of the white man,” but in doing so they did not want to give up their own highly developed language, culture, values, spirituality, knowledge systems, justice and governance processes, nor give up their rights to control the education and rearing of their children in their own communities:

Prior to formal schooling, Indigenous learning was responsive to the needs of families within an ecology that cultivated holistic lifelong processes that were the foundations of Indigenous knowledge and culture (IK). These educational processes of the Aboriginal peoples of Canada created vast learning civilizations based on multiple competences in Aboriginal languages and knowledge, facilitating Indigenous peoples connections with their own communities and with large Aboriginal confederacies and alliances. The success of these holistic processes for lifelong learning created a collective, sustainable lifestyle that contributed sufficiently to the needs of the present and took into consideration the needs of the future seven generations (Battiste & Semegani, 2002).

These educational processes continued as Aboriginal rights.<sup>31</sup>

Contrary to these rights, enactments under amendments to the *Indian Act* in 1894 officially created the first Indian industrial or boarding schools,<sup>32</sup> making attendance compulsory by law, with accompanying powers of arrest, conveyance and detention, and punishment by fine or imprisonment, or both, of parents and guardians who failed, refused or neglected to cause their children to attend such schools. These provisions had the force of law for the committal by justices or Indian agents of Indian children under the age of sixteen years to such industrial or boarding schools, where there were to be kept, cared for and educated for a period not extending beyond the time when the child reached the age of eighteen years.<sup>33</sup> Truant, expelled or suspended students were to be deemed juvenile delinquents within the meaning of *The Juvenile*

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<sup>30</sup> Marie Battiste, “Constitutional Reconciliation of Education for Aboriginal Peoples” (2009) Canadian Race Relations Foundation at 81. Please note that the term “New Buffalo” is attributed to Blair Stonechild, *The New Buffalo: The Struggle for Aboriginal Post-Secondary Education in Canada* (Winnipeg, MB: University of Manitoba Press, c2006).

<sup>31</sup> *Ibid* at 81. (Marie Battiste)

<sup>32</sup> *The Indian Act*, R.S.C. 1886, c. 28, s. 138 [en. S.C. 1894, c. 32, s. 11]. Some were day schools, but most were boarding schools run by the under-resourced churches. Any annuities and interest moneys of Indian children, such as there was, was to be directed to the maintenance of such schools. It is well-documented that the schools were seriously under-funded.

<sup>33</sup> *The Indian Act*, R.S.C. 1886, c. 28, s. 137 [en. S.C. 1894, c. 32, s. 11].



*Delinquents Act, 1929.*<sup>34</sup> A sad chapter of history resulted from forced attendance through seizure, detention and committal at these schools, and criminalization of attempts to resist for both parents and children. Often separated from the care and control of parents for long periods of time, children became vulnerable to mental, emotional, physical and sexual abuse in these institutions, as well as loss of language and culture. Frequently they lost connection with family and community during their long absences.

At an Aboriginal Residential School Survivors' Circle, held at the opening of the Indian Residential School Systems Truth and Reconciliation Commission in Winnipeg, June 20, 2010, Lynn Bishop, a neutral observer and commercial bush pilot, shared his poignant story of having to pick up children from northern lake shores in his pontoon plane to take them to residential schools further south. He remembers vividly parents waiting on the rocky shore (there was no dock or dwelling) to turn their children over to him, their terrible grief, fear and anguish, and that of the young children whom he had to transport, neither knowing when they would see one another again. As a kindness, on take-off he flew back over to dip his wings to the parents waiting on shore, but that proved too much for his child passengers to bear. When they did arrive at their destination in Kenora, there was a taxi waiting, but no chaperone from the school or words of welcome for the children. It was so cold and uncaring he often wonders whatever happened to those children as we now know a number did not survive, while many who did survive were damaged, turning to substance abuse for solace, with devastating personal and intergenerational impacts, including lack of positive parenting skills. The pilot, like the parents, felt powerless to effect any change.<sup>35</sup> This is the legacy and context of great strengths, great tragedy, yet amazing resilience with which we come to address the reconciliation between Aboriginal and Western perspectives of education today. Ever cognizant of the mistakes of the past, our challenging task is to chart a new and better way together. Only then "will truth bring reconciliation:"

The need for constitutional reconciliation is rooted in the failure of existing federal and provincial systems to recognize the needs of Aboriginal peoples, both parents and children. The Auditor General of Canada (2000) has estimated that First Nations students will require twenty years of accelerated and restorative education to catch up to the national average for high school graduation. Despite the termination of federal residential schools, the contractual transfer of education authority over First Nations to

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<sup>34</sup> *Indian Act*, S.C. 1951, c. 29, s. 119.

<sup>35</sup> Darrell Dennis, "Will the Truth Bring Reconciliation?" *ReVision Quest*, CBC Radio, July 7th and 20th, 2010, accessed from the worldwide web on July 9, 2010 at <http://www.cbc.ca/revisionquest/>.

the province, and the restoration of some educational policy to First Nations, none has resulted in significant changes. The result has been consistently a failure with only 40% of Aboriginal students aged 20-24 having graduated from secondary schools through the last three censuses (Howe, 2008). Only about 8% of Aboriginal students have graduated from post-secondary schools (RCAP, 1996).<sup>36</sup>

### ***4.3 Systemic Discrimination in Education: Accommodation of Disabilities & Affirmative Action for Aboriginal Peoples***

While the overt, direct racial discrimination represented by forced attendance of Aboriginal peoples at Residential Schools is in the process of being addressed through the Truth and Reconciliation Commission, the existence of more subtle, systemic discrimination with respect to education of those with disabilities within the public system is upheld and thoroughly documented in *Moore v. BC (Ministry of Education) & School District No. 44*.<sup>37</sup> Central to the systemic discrimination found in *Moore* were the use of Block Funding Caps and Stringent, Arbitrary Cutoff Criteria for services, based on economic and administration efficiency, rather than being proportionate to the actual numbers and needs of students across the spectrum of disabilities. Resorting to a formal equality analysis, the above enlightened decision of the BC Human Rights Tribunal (BCHRT) was overturned at the both the BC Supreme Court (BCSC)<sup>38</sup> and the BC Court of Appeal (BCCA),<sup>39</sup> the latter ultimately concluding that the appellant, Moore, was given the same opportunity or benefit under the law to receive a general education as was given to all other students. *Moore* (BCCA) is reminiscent of the “rogue” formal equality decision in the health care context involving access to services for autistic children, namely *Auton v. B.C. (Attorney General)*.<sup>40</sup> Earlier, Justice LaForest, in the seminal decision, *Eldridge v. B.C. (Attorney General)*,<sup>41</sup> dismissed such an approach outright, as it would allow legislation to be drafted to circumvent s. 15 of the *Charter of Rights and Freedoms* (a part of the *Constitution Act*, 1982 and as such the supreme law of Canada) and thereby deny meaningful access to services for disabled people,

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<sup>36</sup> *Supra* note 30 at 83. [Marie Battiste]

<sup>37</sup> 2005 BCHRT 500.

<sup>38</sup> *British Columbia (Ministry of Education) v. Moore*, 2008 BCSC 264.

<sup>39</sup> *British Columbia (Ministry of Education) v. Moore*, 2010 BCCA 478.

<sup>40</sup> [2004] 3 S.C.R. 657.

<sup>41</sup> [1997] 3 S.C.R. 624.

whether in health care or educational contexts.

Of equal and related concern is the funding and programming offered for various educational equity programs for Aboriginal peoples. In both cases, regular monitoring and accountability is required to ensure that substantive equality (equality of outcome), not merely formal equality (equal treatment), is being maintained for equity seeking groups, and that criteria are based on actual numbers, needs and characteristics of Aboriginal students, not on Funding Caps nor Stringent, Arbitrary Cutoff Criteria driven by economic or administrative efficiencies. Nor should equality of outcome mean solely the granting of a formal diploma, rather it should entail a commensurate level of skills to accompany the diploma to serve as a ready platform to subsequent professional success. Otherwise, systemic discrimination could perpetuate itself resulting in another generation of inequitable educational outcomes.<sup>42</sup> An Aboriginal lens is needed to reframe educational programs so that they mirror Aboriginal peoples' realities, living conditions and aspirations, developing services and supports from evidence-based and practice-based criteria of success, as assessed from a learner perspective.

That said, rich, holistic tutorial services and culturally appropriate pedagogy and curricula, inclusive of Elders, family and community, as well as Indigenous world views, are also critical to success of affirmative action programs for this group. However, a focus on testing and standardized direct, didactic instruction has resulted in a decline in approaches that are culturally responsive for Indigenous students. In addition, secondary and post-secondary educational institutions should consider providing in-house day care services to accommodate students who are single parents or parents of other family constellations with children. Often, as in the past, responsibility for childcare falls more squarely on the mother and thus accommodation needs to address this fact to avoid further gender discrimination, while not omitting the needs of fathers or other family members who have care giving responsibilities. Health and housing needs of Aboriginal learners and their families are also critical factors contributing to educational success. Addition of community outreach liaison coordinators by educational institutions is recommended to connect Aboriginal students to needed services and supports in the community.<sup>43</sup>

In framing culturally responsive schooling for Indigenous students, Castagno and Brayboy (2008) advocate for a more central and explicit focus on sovereignty and self-determination, as well as racism and Indigenous epistemologies, including Indigenous ways of knowing and learning, as avenues more likely to bring lasting, substantive change, not merely minimalistic modifications.<sup>44</sup> A culturally responsive curriculum is one which “validates the cultures and languages of students and allows them to become co-constructors of [contextualized] knowledge in the school setting”.<sup>45</sup> Other aspects of culturally responsive curricula and pedagogies cited include (1) capitalizing on students’ cultural backgrounds rather than overriding or negating them; (2) curricula which are integrated and interdisciplinary, and connected to student’s real lives; (3) curricula and pedagogies which incorporate cooperative learning and whole language strategies; and (4) caring, trusting and inclusive classrooms.<sup>46</sup> Further, they maintain that the entire educational process needs to be addressed, including disciplinary policies (such as zero tolerance policies which can target Aboriginal and FASD students), classroom management, building design, and cultural competence of staff and administrators so that they can be flexible and adaptive to the cultural component and responsive to the circumstances of students’ daily lives.

Critical Race Theory offers a broad-based discourse on racism in society, while Red Pedagogy sheds light on various forms of racism which affect Indigenous students. Racism is seen as a pervasive and consistent element in educational experiences of Indigenous students, manifested through paternalism, prejudice, harmful assumptions, low expectations, stereotypes, violence, and biased curricular materials which serve to widen the achievement gap between Indigenous students and the majority.<sup>47</sup> Somewhat paradoxically, euphemisms which one might think are intended to reduce racism actually play a large role in perpetuating it. This is so because through euphemisms, issues of concern are framed in ways that do not make the

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<sup>43</sup> Council of Ministers of Education, Canada (CMEC), with assistance of Statistics Canada, *A Literature Review of Factors that Support Successful Transitions by Aboriginal People from K-12 to Postsecondary Education*. Retrieved from the worldwide web 18-1-11 at

<http://www.cmec.ca/Publications/Lists/Publications/Attachments/255/transitions-aboriginal-2010.pdf>.

<sup>44</sup> Angelina E. Castagno & Brian McKinley Jones Brayboy, 2008 “Culturally Responsible Schooling for Indigenous Youth: A Review of the Literature,” 78(4) *Review of Educational Research*, 941-993. Note: Word in bracket added by editor.

<sup>45</sup> *Ibid.* at 950, citing Belgarde, Mitchell and Arquero (2002) at 43.

<sup>46</sup> *Ibid.* at 950, citing King and Whitfield (2003), Ismat (1994), Pewewardy and Hammer (2003), and Phuntsog (1998).

<sup>47</sup> *Ibid.* at 952 citing Deyhle (1995); Hickling-Hudson & Ahlquist (2003), Sparks (2000) and Ward (1998).

dominant group uncomfortable,<sup>48</sup> resulting in the omission or minimization of racism from discussions of pedagogy, curriculum, assessment, classroom management, or discipline. At the same time, Indigenous students may be portrayed as “having too many problems,” thus absolving educators, administrators and school boards from addressing systemic issues.<sup>49</sup> Reconciliation is the ideal remedy for racism in all of its manifestations, both overt and subtle, but reconciliation based on truth and compassion, ever mindful to avoid blaming victims. In the context of systemic issues, Aboriginal learners may require assistance to deal with personal challenges unique to Aboriginal people and linked to their historical legacy and circumstances. That being said, it is well recognized that Aboriginal people are not a homogeneous group; to be successful, policy changes and interventions must be decided in conjunction with Aboriginal groups and organizations involved. More data and research are needed on the efficacy of various approaches being used for different groups and sub-groups of Aboriginal learners situated in diverse social, cultural and geographic contexts.<sup>50</sup>

Given its broad implications, access to education is an important component of access to justice, particularly social and economic justice, which are even more important for disadvantaged people, a situation which Aboriginal statistics clearly bear out.

## **5 Brain Domains in the Diagnostic Protocols**

The following discussion of brain domains, included in the various diagnostic protocols under the FASD aegis, is made from an interdisciplinary perspective, with novices to the diagnostic field in mind, such as parents, teachers, teacher aides, social workers, lawyers, justice workers, addictions counselors, anger management counselors, other support workers, and mentors.

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<sup>48</sup> *Ibid.* at 952-3, citing Hilliard (1978), Bernal (2002), Delgado & Stefancic (2001), Ladson-Billings & Tate (1995), Tate (1997), Deloria (1970), Castagno (2005) and Castagno & Lee (2007).

<sup>49</sup> *Ibid.* at 953.

<sup>50</sup> *Supra* note 43. [CMEC, Literature Review of Factors that Support Successful Transitions by Aboriginal People from K-12 to Postsecondary Education.]

## 5.1 CDC Guidelines

Brain domains, identified as an important component of the diagnostic categories under FASD umbrella, can be relevant to how people with FASD learn and should be accommodated through holistic literacy programs. However, domains per se, while often listed, are not adequately defined in the diagnostic guidebooks reviewed.<sup>51</sup> They have been identified in the federal, congressionally mandated *Fetal Alcohol Syndrome: Guidelines for Referral and Diagnosis*, July 2004, by the National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention (CDC) in the United States Department of Health and Human Services (DHHS), in coordination with the National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect, referred to herein as the CDC Guidelines. The CDC Guidelines were federally mandated by a 2002 DHHS Appropriations Bill, to update and refine diagnostic criteria in light of scientific and clinical advances in the understanding of FAS and other birth outcomes resulting from prenatal exposure to alcohol during the past 30 years, since first described in U.S. medical literature.<sup>52</sup> Through discussions with stakeholders, it was subsequently determined to first develop guidelines for the full FAS diagnosis and to expand and refine for inclusion other alcohol-related disorders in due course. Impairment in three or more Central Nervous System or Brain Domains is a requirement for a confirmed diagnosis of FAS, and, as indicated, the current CDC Guidelines deal only with FAS. The other diagnostic categories under the umbrella of FASD, Partial FAS and ARND, although prevalent, are not recognized as yet in ICD9, ICD10 or other diagnostic coding systems used in the USA, although they are addressed in a number of other diagnostic protocols. Central Nervous System or Brain Domains comprise central nervous system structural abnormalities; head circumference below the 10<sup>th</sup> percentile adjusted for age, sex and overall size; clinically significant brain abnormalities observable through imaging; neurological problems not due to a postnatal insult or fever, or other soft neurological signs outside normal limits; and global cognitive or intellectual deficits. The global cognitive or intellectual deficits represent multiple domains of deficit (or significant

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<sup>51</sup> *Supra* note 7 at 1. (Jeannette Lang, “Ten Brain Domains: A Proposal for Functional Central Nervous System Parameters for Fetal Alcohol Spectrum Disorder Diagnosis and Follow-up” (2006) 43:12 JFAS Int. at 1.)

<sup>52</sup> National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, Department of Health and Human Services, in coordination with National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect, American Academy of Pediatrics, American College of Obstetricians and Gynecologists, March of Dimes, National Organization on Fetal Alcohol Syndrome, *Fetal Alcohol Syndrome: Guidelines for Referral and Diagnosis* (July 2004) at 1.

developmental delay in young children), operationally defined in the CDC Guidelines as global performance 2 standard deviations below the mean or functional deficits one standard deviation below the mean in a least three of the following domains (a) cognitive or developmental deficits or discrepancies (b) executive functioning deficits (c) motor functioning delays (d) problems with attention or hyperactivity (e) social skills and (f) other, such as sensory problems, pragmatic language problems, memory deficits, and so forth.

Functional abilities affected vary depending on the amount of prenatal alcohol exposure, timing of exposure and pattern of exposure (e.g. whether chronic or binge drinking episodes), as well as variability in exposure impact on the embryo or fetus. It is generally accepted that variable, multiple locations in the brain are affected and to address this issue a global cognitive deficit, such as decreased IQ or significant developmental delay in children too young for an IQ assessment, or deficits in three or more specific functional domains are required. Neither the list of domains presented in the CDC Guidelines nor their descriptors are intended to be exhaustive, nor to be used as a checklist in place of a reliable and valid assessment. Behaviours may be observed and recorded, but for diagnostic purposes should be also be assessed by standardized testing.<sup>53</sup>

Functional Domain definitions are provided on pages 14 to 18 of the CDC Guidelines<sup>54</sup> and summarized as follows. Cognitive deficits or significant developmental discrepancies, include math and/or visual-spatial deficits, an uneven profile of cognitive skills, poor academic achievement, discrepancy between verbal and nonverbal skills and slow or poor information processing (sensory or auditory).<sup>55</sup> Executive functioning deficits include poor organization and planning, concrete thinking, lack of inhibition, difficulty grasping cause and effect, inability to delay gratification, difficulty following multistep directions, perseveration, poor judgment and inability to apply knowledge to new situations. Whereas motor functioning delays and deficits may include impairments in visual-motor-spatial coordination such as delayed motor milestones, difficulty with writing or drawing, clumsiness, balance problems, tremors, poor dexterity, and for infants, a poor suck may be observed. Attention and hyperactivity problems are noted for

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<sup>53</sup> *Ibid.* at 14.

<sup>54</sup> *Supra* note 52. [National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, Department of Health and Human Services, in coordination with National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect, American Academy of Pediatrics, American College of Obstetricians and Gynecologists, March of Dimes, National Organization on Fetal Alcohol Syndrome (July 2004) *Fetal Alcohol Syndrome: Guidelines for Referral and Diagnosis*].

<sup>55</sup> *Ibid.* at 15.

children with FAS, due to problems with encoding information and shifting attention or making transitions when required, rather than the more classic ADHD problems with focus and sustaining attention. In addition, impulsivity may lead to increased energy levels similar to hyperactivity. They may have difficulty calming down, may be overly active, easily distracted, have difficulty completing tasks and have trouble making transitions from one task to another. Inconsistencies from day to day may occur, as they may have “on” days and “off” days.<sup>56</sup> Executive, attention and developmental problems described previously, including not understanding consequences, can affect social perception and social communication. Consequently people with FAS may have problems interacting with peers and others. As social functioning is a multifaceted domain, it can be difficult to assess and several types of assessments may be required. Behaviours that can be observed include lack of stranger fear, often being scapegoated, naiveté and gullibility, easily taken advantage of, inappropriate choice of friends, preference for younger friends, immaturity, adaptive skills significantly below cognitive potential, difficulty understanding the perspective of others, including difficulty reading facial expressions or other nonverbal cues, difficulty understanding boundaries leading to inappropriate sexual behaviours and related issues.<sup>57</sup>

Other domains than these five cited present at a lower frequency by expert consensus including sensory problems (sensitivity to light, sound, touch, taste), memory deficits (forget well-learned material, need many trials to remember) and difficulty responding to cause and effect discipline. All domains should be assessed by appropriate professionals using norm-referenced, standardized, reliable and validated instruments.<sup>58</sup> Difficulties in the functional domains can lead to maladaptive behaviours and mental health problems that although not used for diagnosis of FAS, if present should trigger a referral for appropriate diagnosis and treatment. Thus, co-occurring mental health problems are prevalent, such as conduct disorders, oppositional defiant disorders, anxiety disorders, adjustment disorders, sleep disorders and depression.<sup>59</sup>

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<sup>56</sup> *Ibid.* at 15.

<sup>57</sup> *Ibid.* at 16.

<sup>58</sup> *Ibid.* at 15-16.

<sup>59</sup> *Ibid.* at 17.



## 5.2 FASD: Canadian Guidelines for Diagnosis

The Canadian Diagnostic Guidelines for the full spectrum of FASD recommend using neurobehavioural assessments which include the following domains: hard and soft neurological signs (including sensory/motor signs), brain structure (head circumference and magnetic resonance imaging, etc.), cognition (IQ), communication (receptive and expressive), academic achievement, memory, executive functioning, abstract reasoning, attention deficit/hyperactivity, adaptive behaviour, social skills and social communication. A domain is considered impaired, when on a standardized measure, scores are 2 standard deviations below the mean, or there is a discrepancy of at least 1 standard deviation between sub-domains (for example verbal v. non-verbal ability, expressive v. receptive language or verbal v. visual memory), or there is a discrepancy of at least 1.5 to 2 standard deviations among subtests on a measure. The Canadian Guidelines use the Washington Four Digit Code to differentiate between the different conditions under the FASD umbrella, including FAS, pFAS and ARND. There is a more complete set of notes defining “assessment” and “impairment” in the Canadian Guidelines and examples of standardized tests used to assess the domains and their criteria are provided in Appendix 3, but no domain definitions per se are provided, although the standardized tests cited may serve as a starting point to operationally define some of the domains.<sup>60</sup>

MacPherson and Chudley comment that assessment of brain domains in the Canadian Diagnostic Guidelines may limit recognition of some FASD affected individuals<sup>61</sup> and thus brain domains are a topic worthy of further, broad consideration across the life span. Appendix 3 of the Canadian Guidelines under the heading “Adaptive behaviour, social skills, social communication” notes that assessment of social and adaptive skills is considered most important, but the available standardized instruments do not adequately tap the usual adaptive problems found in FASD.<sup>62</sup> The Vineland Adaptive Behaviour Scale is considered inadequate at higher ages and the Adaptive Behaviour Assessment System is not FASD-specific. Moreover, observational data is dependent on raters’ perceptions and familiarity with the individual being

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<sup>60</sup> Albert E. Chudley, Julianne Conry, Jocelynn L. Cook, Christine Loock, Ted Rosales, Nicole LeBlanc, “Fetal Alcohol Spectrum Disorder: Canadian Guidelines for Diagnosis” (Mar. 1, 2005) 172 (5 suppl) CMAJ 51 at 9-10 and S20 to S21.

<sup>61</sup> Albert E. Chudley, Andrea R. Kilbour, Meghan Cranston, and Michelle Edwards, “Challenges of Diagnosis in Fetal Alcohol Syndrome and Fetal Alcohol Spectrum Disorder in the Adult” (2007) 145C American Journal of Medical Genetics, Part C (Seminars in Medical Genetics) 262-272; and *Supra* note 3. (MacPherson & Chudley, 2007)

<sup>62</sup> *Supra* note 60 at S21.

rated, as well as the environment in which the rating is done. Rating done in a federal penitentiary, where so much of the inmates' lives are structured and organized, may not reveal problems that the individual might have coping independently with everyday life in the community. As well, if raters are not independent enough of the institution, they may be reluctant to rate individuals at a level that could reflect adversely either on the rater's job performance or on the institution. This may sometimes be the case for foster parents and new teachers. Interviews, school reports, previous assessments, informal assessment of language pragmatics (not standardized) as well as of social communication, may provide useful insights about adaptive behaviour, social skills and social communication.<sup>63</sup> However, cultural and linguistic differences, and social and economic disadvantage are not systematically recognized and accommodated in the ratings or other measures. Moreover, ratings and measures may be neither culturally nor linguistically relevant to learners who may have had limited access to the academic language.

### **5.3 IOM Domains**

The Institute of Medicine (IOM)<sup>64</sup> suggest using as domains evidence of a complex pattern of behavioural or cognitive abnormalities which are inconsistent with developmental level and cannot be explained by genetic predisposition, family background, or environment alone, including: marked impairment in the performance of complex tasks such as complex problem solving, planning, judgment, abstraction, metacognition and arithmetic tasks; high level receptive and expressive language deficits, and disordered behaviour (difficulties in personal manner, emotional lability, motor dysfunction, poor academic performance and deficient social interaction). Domain definitions are not included in the document.<sup>65</sup>

The IOM attempted to rationalize diagnosis through selection of the following categories: Fetal Alcohol Syndrome (FAS) with confirmed maternal alcohol exposure, FAS without confirmed maternal alcohol exposure, Partial FAS with confirmed maternal alcohol exposure,

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<sup>63</sup> *Supra* note 60 at S20-21.

<sup>64</sup> Kathleen Stratton, Cynthia Howe, and Frederick Battaglia, Editors, *Fetal Alcohol Syndrome, Diagnosis, Epidemiology, Prevention and Treatment*, for Institute of medicine (Washington, CD: National Academy Press, 1996) at 78.

<sup>65</sup> *Supra* note 7.

and two categories of Alcohol-Related Effects where there is a history of maternal alcohol exposure (although not as excessive, substantial, heavy and regular as for FAS) and clinical or animal research has linked maternal alcohol ingestion to an observed outcome. One category of alcohol related effects is Alcohol-Related Birth Defects (ARBD) characterized by congenital physical malformations and dysplasias and the other category is Alcohol-Related Neurodevelopmental Disorder (ARND) characterized by central nervous system neurodevelopmental abnormalities. However, both ARBD and ARND diagnoses can be present in the same individual and both can be rendered for that individual, or alternatively, only one may be present and only one assigned. The term Fetal Alcohol Effects, FAE, has been used in animal models of alcohol teratogenesis and in prospective large group studies of humans exposed to alcohol prenatally, but is not meant to be used as a diagnostic term with individual patients. Instead, alcohol related effects, namely ARBD or ARND, should be used in its place.<sup>66</sup> However, the IOM Committee could find no perfect solution for the naming of the diagnostic category presenting with confirmed exposure to substantial amounts of alcohol in gestation, and possessing some, but not all, components of the facial features of FAS, as well as any of the following: evidence of growth deficiency, central nervous system neurodevelopmental abnormalities or behavioural and cognitive abnormalities. With reservations, Partial FAS was selected by the Committee as the contentious compromise, as the Committee did not intend to imply by the use of the term “partial” that the condition is less severe than FAS.<sup>67</sup> In fact, problems in those with Partial FAS may be just as severe, even though they may lack some of the hallmark facial features.

#### ***5.4 Washington 4-digit Code***

While documenting the presence of prenatal alcohol exposure and thus potential teratogenic insult, and eliminating alternate contributing factors and related syndromes, the Washington Four-Digit Code, nevertheless, does not presume a causal role for prenatal alcohol

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<sup>66</sup>*Supra* note 64. [Kathleen Stratton, Cynthia Howe, and Frederick Battaglia, Editors, *Fetal Alcohol Syndrome, Diagnosis, Epidemiology, Prevention and Treatment*, for Institute of medicine (Washington, CD: National Academy Press, 1996) at 78].

<sup>67</sup> *Ibid.*

exposure.<sup>68</sup> For this reason the Washington protocol prefers the designation static encephalopathy, alcohol exposed, to ARND which does imply an alcohol-related condition. Furthermore, it attempts to accumulate objective evidence for more precise, probability-based diagnoses of the full spectrum of FASD. Most domains are quantified as ratings on a four-point Likert scale ranging from 4 to 1, interpreted respectively as severe, moderate, mild to none. The higher the assigned rank from 1 to 4, the stronger the evidence for, or the greater the probability of, underlying CNS damage and the more severe and global the brain dysfunction. Again, domain definitions of brain dysfunction are not included in the Guidebook cited,<sup>69</sup> but are discussed in the Psychometric Training Guide<sup>70</sup> and incorporated in the Standardized Measures and Non-Standardized Observational Measures in the FASD Diagnostic Form, pages 9-18 of the Guidebook.<sup>71</sup> These include cognition, academic achievement, adaptive behaviour/social skills, neuropsychological, motor/sensory integration, language/social communication, mental health/psychiatric conditions, behaviour/attention/activity level, and development. It includes a useful Caregiver Interview rating scale containing more specific descriptors. The most complete of these is the Behavioural Regulation/Sensory Motor Integration domain, where caregivers are asked to rate the person they care for on a four point Likert scale with respect to the following characteristics: poor management of anger/tantrums, mood swings, impulsive, compulsive, perseverative, inattentive, inappropriately high or low activity level, lying/stealing, unusual (high or low) reactivity to sound, touch or light and a category for other characteristics under this domain.

### ***5.5 Attempted Synergy of Brain Domains***

An initial synergy of brain domains, along with definitions based on consistent descriptors used by caregivers, teachers, social workers, and others, has been attempted by the Fetal Alcohol Diagnostic Program (FADP, Duluth, MN, USA) in order to rationalize and clarify

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<sup>68</sup> Susan Astley, *Diagnostic Guide for Fetal Alcohol Spectrum Disorders: The Four-Digit Code*, Third Edition, 2004, FAS Diagnostic and Prevention Network, University of Washington.

<sup>69</sup> *Ibid.*

<sup>70</sup> H. C. Olson and T. Jirikowic, *Psychometric and Behaviour Observations Training Guide*, 2005, 1999. FAS Diagnostic and Prevention Network, University of Washington, second revision, 4-13.

<sup>71</sup> Supra note 68. (Astley)

the situation across the various Guidelines and to aid in development of practical, usable intervention recommendations for the individuals with FASD they diagnose. Accordingly, the Fetal Alcohol Diagnostic Program proposes the following ten brain domains with definitions:

**Achievement:** Achievement domain assesses skills in core academic areas—reading, math, and written language.

**Adaptive:** the degree to which a person is able to meet the challenges of daily living when compared to others their age.

**Attention:** processing capacity for selective, focused, sustained and flexible attention, as seen in behaviours of concentration, hyperactivity and impulsivity.

**Cognition:** the general level of thinking ability. An important facet in this domain is comparison of verbal with nonverbal abilities.

**Executive Functioning:** capacity for goal-directed behaviour, including self-regulation, initiating, working memory, planning, organizing, and self-monitoring.

**Language:** encompasses all aspects of expressive and receptive language, including the ability to integrate specific language skills and the use of words to convey meaning.

**Memory:** the capacity to consolidate, store, and retrieve information for short and long term application.

**Motor:** general abilities to use and coordinate large and small muscles. Gross motor skills include walking, running, hopping and climbing. Fine motor skills include hand writing and eating. Eye hand coordination refers to the ability to coordinate vision with movement.

**Sensory/Soft Neurological:** refers to individual's ability to process and make sense of incoming sensory information from the surrounding environment. Soft neurological signs are indicators of an immature nervous system, including motor control, balance, rhythm, strength, motor planning and sequencing.

**Social Community:** refers to the ability to communicate appropriate and effectively in a variety of social situations with both peers and adults, including the ability to relay verbal information coherently and cohesively.<sup>72</sup>

While details of methodology employed are lacking for the FADP synergy, whether content analysis or an alternative, increasing consistency in identifying brain domains through

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<sup>72</sup>*Supra* note 7 at 4-6. [Jeannette Lang]. Note that the definitions of the brain domains have been summarized by the present writer/editor. Also note that Lang includes a discussion of clinical implementation of brain domains as well as areas for further work and discussion, so this is a work in progress.

such a synergy could improve diagnosis by enhancing reliability and validity, as well as providing useful information for clinical recommendations. Although analysis of brain domains provides useful information related to accommodation of disabilities, it is a time consuming and costly endeavour contributing to long wait lists and lack of timely access to diagnosis. There is ongoing research aimed at identifying more efficient, sensitive and specific diagnostic tools, including the search for a panel of altered genes in an alcohol exposed developing fetus and chemical biomarkers in a newborn's stool or meconium. If such tools prove viable, one could hone in more quickly on a confirmed diagnosis, although in almost any system of diagnosis, no matter how rigorously scientific it purports to be, there can be false positives and false negatives.<sup>73</sup> One need only consider the rash of pathologists' misdiagnosed cancer tests, botched lab results and CT scans, from Newfoundland to at least as far west as Saskatchewan, as no matter how objective a procedure is alleged to be, there is a margin of error in identification and in subjective interpretation of results, and thus room for a legitimate error rate that nevertheless does not overreach an established threshold. Better quality control of all diagnostic procedures, as well as redundancy or second opinions where capacity permits, and a protocol for reporting and analyzing errors in the system are procedures recommended to enhance such quality control, along with comprehensive diagnostic guidelines, regular monitoring or audits and mandatory levels of professional in-service and accreditation. Judicial inquiries have been used in cases of large scale, systemic problems. Access to appropriately anonymized electronic health records could facilitate quality control audits and aid in the search for consistency, reliability and validity.<sup>74</sup> If new technologies prove viable, once an initial diagnosis is confirmed, a more detailed analysis of brain domains and other assessments could follow on an expedited basis. Such a process would aid acquisition of prevalence and incidence data for FASD, which is now problematic due to lack of access to timely diagnosis, along with coordinated provincial and/or national tracking systems for the number of cases diagnosed.

Significantly, detailed information on brain domains acquired through a neuropsychological assessment along with an evaluation of classroom and adaptive skills are better indicators on which to base educational programming and individualized learning plans

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<sup>73</sup> *Supra* note 8. (Ismail, Buckley & Budacki)

<sup>74</sup> Nicholas Bala, Queens University Law Professor and Tim Caulfield, Canada Research Chair of Health Law and Policy, Patient Safety Issues, "The Current," CBC Radio, 8:30 a.m. CST, July 15, 2010, accessed from the worldwide web at <http://www.cbc.ca/thecurrent/> on July 15, 2010.

than global IQ-values.<sup>75</sup> Although students with FASD may have IQs in the normal range, they may possess deficits in specific neurocognitive domains that impact learning. Educators' pre-service and post-service education needs to specifically address these aspects of FASD (neurocognitive assessment and adaptive skills) so that teachers are better prepared to accommodate the complexities and individual needs of learners with FASD in their classrooms.<sup>76</sup>

Unlike many disorders in the DSM-IV-TR, the disorders under the FASD umbrella do have an established etiology, but like the DSM-IV-TR conditions, the set of identifying symptoms represent extremes on either end of a continuum, for instance, being either over-stimulated or under-stimulated and being hypoactive (shut-down) or hyperactive (over-active), analogous to indicators of climate change being extreme conditions at either end of a weather continuum, so as such are not unscientific, despite objections from some quarters. However, in both cases, one cannot predict the direction of symptoms, only extremes at either end of a symptom continuum. A culture of disclosure of limitations and errors in diagnostic procedures is also recommended, as only with transparency and accountability can problems be addressed to ensure optimum patient safety. There are many risks for an undiagnosed individual with FASD, as without the interventions and supports that should accompany a diagnosis, adverse life outcomes are more likely.

## 6 Challenge for Educators

The challenge for educators is to balance the sometimes disparate requirements of brain domains and other neurological and psychological factors, with the need to fashion rich, dynamic, holistic, transformative literacy curricula for children with FASD from a culturally contingent perspective, without unduly resorting to reductionistic, mechanistic, impoverished, controlling or oppressive forms of pedagogy. Moreover, the brain domain requirements per se are sometimes disparate, and require balancing, as while a child with FASD may be prone to

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<sup>75</sup> Elizabeth Bredberg, "FASD and Education Policy: Issues and Directions" in Edward P. Riley, Sterling Clarren, Joanne Weinberg, and Egon Jonsson, eds., *Fetal Alcohol Spectrum Disorder—Management and Policy Perspectives of FASD* (Chichester: John Wiley, 2010) at 321. Departments of Education in many jurisdictions have published guides for teaching children with FASD and while useful as far as they go, such guides do not integrate brain domains with what is known about transformative pedagogy, equity, and cultural issues.

<sup>76</sup> *Ibid.*

sensory over-stimulation, at the same time they may also be attention deficit so needs a certain amount of stimulation to be engaged and moreover may have memory deficits that require visuals and hands-on activities to reinforce. The brain is stimulated through oral, visual and kinesthetic representations that can build cognitive connections between what students know and what they are learning as they read. Having a quiet, enclosed but comfortable and pleasant space in the classroom for the student to retreat to when over-stimulated may help the student with FASD to learn to manage these conflicting needs. Literacy, like any process of meaning making, whether it be science, fine arts, law, or philosophy, is a fascinating, creative, pluralistic, complex, varied, holistic, indeterminate, semiotic, dialogic or relational process, which is neither reductionistic nor mechanistic. Literacy depends on a number of cues, the last of which is phonics, as English language is not phonetically consistent. The primary literacy cues are semantic and syntactic. Phonics still needs to be addressed, as it is a third tier literacy cue, but educators must be first and foremost cognizant that literacy occurs within situated social, relational, cultural, linguistic and environmental frameworks while focusing on enriching the primary cues of context and background knowledge, and by addressing phonics as it arises in the reading process. Accordingly, a pluralistic approach to literacy attempts not to privilege one situated framework over another.

## **7 Qualitative Research: Evolving FASD and Holistic Literacy Practice Guidelines**

### ***7.1 Goals of the Research***

Indigenous research methodology, in which participatory action research<sup>77</sup> is embedded, employs a decolonizing perspective in a narrative, constructivist paradigm framed within

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<sup>77</sup> Stephen Kemmis and Robin McTaggart, "Participatory Action Research" in Norman K. Denzin and Yvonna S., Lincoln, eds., *Sage Handbook of Qualitative Research*, Third Edition (London: Sage Publications, Inc., 2005) 559-603. Participatory Action Research (PAR) is applied to a variety of research approaches employed in a diversity of fields and settings. Kemmis and McTaggart prefer the term Collaborative Action Research (CAR), to emphasis the collaborative research undertaken between academy and community, in particular, while recognizing that PAR is the most widely used and over-arching designation among many related approaches. Shared ownership and control of research project, community-based analysis of social problems, and an orientation toward community action and solutions in response to the needs and opinions of ordinary people (in contrast to the wealthy and powerful) are the hallmarks of both PAR and CAR. Kemmis and McTaggart contend that orthodox social sciences, despite claiming



Indigenous epistemologies.<sup>78</sup> Indigenous research methodology, undertaken by the current researcher in partnership with Elders and Indigenous communities, is the starting point in an ongoing attempt to address the gap in formulating an evolving FASD and Holistic Literacy Framework,<sup>79</sup> useful as a guide for effective practice across disciplines and sectors, as well as across the life cycle. The goal was to gather experiential data observing participants and their children in their natural surroundings, and to elicit participants' first hand observations, stories, conversations and narratives describing the impact of FASD on their lives, including what practices and approaches worked and what did work for them.

Collectively, the research team struggled to find methodological space within Western academic research, discourse, policy and practice without ready models for carrying out large scale, holistic, relational, community-based Indigenous research. So often researchers, particularly graduate students, are misunderstood and discouraged in proceeding with the unique demands of a holistic, broad-based, pluralistic, relational, experiential and decolonizing approach to field research. This may be so because of the apparent privileging of the role of Indigenous culture, community, epistemology, spirituality, as well as subjective perspective and interpretation in the meaning-making process. Indigenous research is also a process which includes a strong narrative component, hopefully freer from exploitation of either Indigenous knowledges or Indigenous peoples, but also broader and more time consuming than current parameters contemplated for graduate studies, including interdisciplinary graduate studies.<sup>80</sup>

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neutrality, can be used to ideologically justify the positions and interests of the rich and powerful. PAR has its roots in the social transformation of the third world through liberation theology and neo-Marxist approaches to community development, particularly in Latin America. However, critics assert that such research can become too politicized for local participants, as "outsider" researchers may over-shoot "insider" epistemological willingness or readiness to participate in western-style reform. Researchers need to think critically about their approach and to recognize and respect how inquiry is shaped by historical and cultural context, particularly research based on ecological, spiritual and communal values that are not western. Thus, Kemmis and McTaggart, as do Indigenous Methodologies which incorporate components of PAR, emphasize the importance of ongoing community collaboration and partnership to ensure that there is a true meeting of minds about research values, methodology and nature of expected results. Further commentary on PAR and qualitative research is to be found elsewhere in this Section, as well as in the Conclusion.

<sup>78</sup> Margaret Kovach, *Indigenous Methodologies, Characteristics, Conversations, and Contexts* (Toronto: University of Toronto Press, 2009) at 30. Please Note: Indigenous Methodologies have been extensively addressed in *Section Two* of this collection or anthology.

<sup>79</sup> A definition and more extensive treatment of the elements of the tentative, evolving, FASD-Literacy Guidelines proposed is found in section 8.1.2, along with its application.

<sup>80</sup> *Supra* note 78 at 35-36.

## **7.2 The Research Question**

The research question framing the study is: How do individuals with FASD, their parents, caregivers, and service providers experience the impact of FASD on their lives, including a particular focus on holistic learning, literacies and life skills,<sup>81</sup> and the practices and approaches that work best for them, as interpreted and informed by knowledge of diagnostic brain domains. Accordingly, participants were observed and interviewed<sup>82</sup> were asked to describe the impact of FASD on their lives, including what practices and approaches worked and what did not work for them in relation to holistic literacies and life skills.

## **7.3 Participants or Key Informants**

Participants and key informants included individuals with FASD, Elders, parents, support persons and professionals. Seventy-five individuals were observed and interviewed, either individually or in family groups; an additional seventy-five participated in focus groups and Circles, the latter being whole days in length with a second day follow-up some months later. Circle discussions took place in the large group or Circle, as well as in smaller groups or Clusters, with a number of helpers assisting with note taking in the Circles and Clusters, and with facilitating the small group sessions. Of the six helpers, all but one was either First Nations or Métis. In addition, the researcher spent a half day at several urban, segregated FASD classrooms for grades 1-3 and grades 4-6, and participated in two weekend FASD Parent Residential Retreats organized by a community partner to the research, with approximately 80 parents in attendance at each. At total of 40 Elders assisted with the research.

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<sup>81</sup> Holistic literacies, learning and life skills are rooted in a philosophy based on the premise of finding identity, meaning and purpose through connections and understandings of self, community and the natural world, with significance placed on relationships, human values and the environment. Holistic approaches attempt to integrate multiple layers of meaning and experience, to connect parts of the whole to one another and to the whole. The system as a whole has a synergy that is greater than the sum of its parts, therefore, a reductionist approach does not suffice. In Cree Aboriginal epistemologies, the Medicine Wheel includes four components of a circle, mind, body, spirit and emotions, surrounded by the natural environment in the outer circle. Holistic literacies and learning are further elaborated in s. 7.6.2 and s. 7.6.2.1.

<sup>82</sup> *Supra* note 78 at 94-95. “Interviewed” is not the natural word that would be used by Indigenous peoples in their natural environments. Talked, discussed or shared would be more natural terms for the process, but its holistic essence is best captured by the terms “story” or “oral narrative.”

Of the individuals observed and interviewed, although there is some overlap among categories, the tallies are as follows: 13 adults with FASD; 9 children with FASD present at the interviews with parent(s) or family group; 10 children with FASD discussed by parent(s) but not present; 16 parents or caregivers of individuals with FASD, 5 being both individuals with FASD as well as parents of children with FASD, that is it was intergenerational; 16 mentors of individuals with FASD; 4 teacher-educators; 2 lawyers; 4 medical doctors; 12 other related professionals, 4 of which were also parents of individuals with FASD; 4 researchers, two of whom were parents of individuals with FASD; and individual or small group consultations with 5 Elders, 2 males and 3 females, on a number of occasions, always accompanied with gifts of tobacco. Focus groups and Circles were also organized by respective governing bodies or administrative personnel, including a focus group of 7 professionals who work as a team to assess, diagnose, and provide supports and therapy to children with FASD in a health district; a two-day Circle of 19 First Nations Elders held at an urban Tribal Council, followed by a two-day Circle of 17 Elders, Parents and Individuals with FASD; a two day circle of 7 Métis Elders and 7 FASD Mentors held at the premises of an urban Métis Federation, as well as a one day Circle of 27 community members of a remote, rural reserve, a number of whom were Elders, as a follow-up to a sentencing circle. In total, 40 Elders facilitated and/or participated in Circles or in consultations. Aboriginal communities are somewhat averse to quantitative aspects of FASD research, as it is so often these statistics are stigmatizing for them; none were anticipated by them in the qualitative research, therefore these tallies represent the sole pretention to any quantitative aspect. Overall, there was a considerable degree of gender balance maintained in the various categories, which is an important consideration when it comes to applying outcomes of the study to both genders.

#### ***7.4 Research Protocol and Ethical Review***

The research protocol, including the collective and individual consent processes, was reviewed and approved on ethical grounds by the University of Saskatchewan Advisory Committee on Ethics in Behavioural Science Research on Oct. 29, 2004. Transcribed transcripts of interviews and focus groups reviewed and approved by participants formed an important

component of the research, especially since voices of individuals with FASD and their families have not always been heard, but rather more often silenced by shame and marginalization. Notes were recorded on storyboard charts for all to see during the Sharing Circles and transcribed for review at follow-up Circles.

The present researcher consulted with numerous Aboriginal Elders, in order to ground the research in traditional, holistic ways of knowledge and knowledge gathering, and in holistic and spiritual traditions and protocols. The Elders chose either consent protocols traditional to their Lodge's spiritual practices (for example, involving gifts, sacred objects, prayers and songs in their own language, dances, and ceremonies)<sup>83</sup> or made use of consent protocols provided by the researcher, or some combination of both. First Nations Elders invariably chose traditional consent protocols.

A number of other participants were solicited from a cohort of diagnosed individuals, and their caregivers and service providers, many of whom belonged to a province-wide FASD support group, which is partnering with the researcher. A letter of support for the research was provided by the partner, as well as signing a research partnership contract.

Other community partners in the research, a First Nations Tribal Council and a Métis Federation, also signed research partnership agreements, but they wished to play a more active role in the planning and organizing of research. Accordingly, they invited participants to the Sharing Circles, mainly Elders, who then, in turn, when the parameters of the research had been established through two days of consultations, invited parents and individuals with FASD to Sharing Circles. Diagnosed participants and their parents or caregivers and service providers were sought as valued experiential sources. The majority of individuals with FASD in the sample were Aboriginal of various ages, genders and backgrounds, urban, rural, and northern. A commitment of the researcher was to honour their stories in their own words, without adulteration or truncation.

Indigenous Research Methodologies and protocols overlap with Participatory Action Research (PAR) to the extent that both approaches emphasize meaningful collaboration between community and researchers, including participation, capacity building, ownership of knowledge,

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<sup>83</sup> More specific details about such protocols are the intellectual and spiritual property of each Elder and can vary from Lodge to Lodge. The right to know such protocols (such as the sacred songs and prayers) or to disclose them is governed by strict customary laws. They must be earned through being invited to serve as a kind of acolyte under a Pipe Carrier in traditional and spiritual ways of each Lodge or territory.

and other forms of reciprocal empowerment. Roots of PAR lie in the transformative, anti-oppressive, liberation tradition originating in Latin America and the developing world, championed by Paul Freire and others,<sup>84</sup> whereas Indigenous Methodologies stress holistic spiritual, cultural, and decolonizing community-based and controlled research practices and protocols. Kovach comments that while she endorses the narrative, constructivist paradigm of qualitative research and its various approaches such as PAR, Indigenous epistemology does not fit neatly into PAR's western, cultural concepts or rubrics. This disconnect contributes to a tension involving insider-outsider dynamics which no doubt will persist until Indigenous research frameworks have methodological space within the academy.<sup>85</sup>

### ***7.5 Nature of Methodology and Data Analysis***

The data from the interviews, while not quantitative, consists of qualitative data, collected by means of direct observation and experience gathered during the interviews and then collated, coded and grouped into recurring themes and patterns as discerned the researcher, through an inductive process. An inductive process is the process of deriving general principles, theories, themes, models or frameworks from observations or particular instances, informed by the researcher's knowledge and understandings of the data and related areas. A model so derived may be altered with additional observations or experiences, or observations and experiences of a different nature (as in the case of Newton's versus Einstein's gravitational models). Generalizations from limited observations and experiences to an entire population are never certain, but approach greater probability the larger the sample and the more similar the sample is to the population on which it is based, which may be enhanced by selecting a random sample. Because of difficulties inherent in recruiting a sample of individuals with FASD for research purposes, random sampling was not a technique selected in the present research. Qualitative research is nevertheless very useful when the need is for in-depth information regarding complex human behaviour in real life situations, both of which involve many variables, although caution

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<sup>84</sup> *Supra* note 77 at 560 [Stephen Kemmis and Robin McTaggart, "Participatory Action Research" in *Sage Handbook of Qualitative Research*, Third Edition (London: Sage Publications, 2005) at 560.]

<sup>85</sup> *Supra* note 78 at 30-31. (Kovach)

must be exercised in generalizing and prescribing definitive solutions for which further study is usually recommended. Some topics, such as the present one, do not lend themselves to randomized, controlled trials that can provide probabilistic evidence on a narrow, quantifiable basis in a controlled environment. Furthermore, a participatory research approach involving qualitative research, respectful of Aboriginal traditional knowledge, culture, world view and community involvement and control is recommended as the preferred methodology in doing research with Aboriginal Peoples.<sup>86</sup> This recommendation overlaps with that of a special edition of the journal, *Exceptional Children*, recommending that researchers use a variety of research methodologies including qualitative, group design, quasi-experimental, and single subject to ascertain evidence-based practices that are effective with students who have a disorder within the spectrum of FASD.<sup>87</sup>

The experiences, words and stories of the participants enable them to become active co-constructors of knowledge, rather than having a construction imposed upon them. Kovach reminds us that stories or narratives incorporating traditional knowledge are a component of oral history, and as such are admissible as valid evidence in Aboriginal Title cases according to the Supreme Court of Canada in the 1997 *Delgamuukw* decision.<sup>88</sup>

Moreover, stories or narratives are open to subjective interpretation by the listener or reader who brings his or her related experiences to bear in constructing new holistic meaning to the stories. A parent of a child with FASD may gain more insight from the narratives of other parents, or the narratives of individuals with FASD, than would an outsider and that is why it is so important to include holistic narratives for the purposes of this research. A detail in the narrative that may appear inconsequential to someone without intimate experience of living with FASD, may serve as a revelation or “Eureka moment” to someone who encounters FASD on a daily basis. As a case in point, a grandmother of a fourteen year old grandson with FASD who was experiencing some trouble with the law arising out of an incident at school, told the present researcher with some reluctance and only after a number of conversations, that her grandson

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<sup>86</sup> Canadian Institutes of Health Research, *CIHR Guidelines for Health Research with Aboriginal Peoples*, 2007, s. 2.4 Participatory Research, Article 3, accessed on the worldwide web on Nov. 27, 2010 at <http://www.cihr-irsc.gc.ca/e/29134.html>.

<sup>87</sup> S. Graham, ed., (2005). “Criteria for Evidence-based Practice in Special Education.” *Exceptional Children*, 71, 137-208, cited in Sharon Bohjanen, Megan Humphrey and Susan M. Ryan, “Left Behind: Lack of Research-Based Interventions for Children and Youth with Fetal Alcohol Spectrum Disorders” (2009) 28(2) *Rural Special Education Quarterly* at 33.

<sup>88</sup> *Delgamuukw v. British Columbia* [1997] 3 S.C.R. 1010.

would not settle down at night to sleep and then could not get up in the morning. Out of desperation she had allowed him to sleep on one side of her bed so that eventually he would settle down and fall to sleep; otherwise, after a restless night he could not get up in the morning in time to get to school on time and then was in further trouble for being late so often. No health care provider in the area had expertise in FASD, and so no one had informed her that children and youth with FASD were subject to sleep disturbances as part of the self-regulatory function that is affected in a number of ways by pre-natal alcohol.<sup>89</sup> It was a great relief for her to hear that the problem was not peculiar to her grandson and herself, but rather shared by many children and youth with FASD and their caregivers, and other solutions were discussed, such as calming techniques, medication, and so forth. The Grandmother related this information to her Grandson's health care provider and was able to get professional assistance in addressing his sleep disturbance, which she had otherwise assumed was purely an idiosyncratic flaw.

Kovach explains further that Indigenous oral histories, stories or narratives are not meant to be oriented within a linearity of time, but rather transcend time and fasten themselves to places.<sup>90</sup> Coincidentally, Einstein's theories of special relativity have much to say about the concept of time, holding that time is not a linear constant as Newton had assumed, but that clocks slow down or time dilates at relativistic speeds. At the universal reference point, the speed of light, a timeless state of being is achieved. By accelerating or decelerating in four dimensional, warped spacetime time travel was theoretically possible.<sup>91</sup> For Einstein and

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<sup>89</sup> The FASD and Sleep Research Network and the Canada Northwest FASD Research Network are working to address the high-risk of developing sleep disturbances or sleep disorders among children with FASD. They classify these sleep disturbances or disorders as mainly Circadian Sleep Rhythm Disorders (CSR), which can result in additional co-morbidity, such as daytime sleepiness or inattention and hyperactive-like behaviour, and further physical, cognitive and emotional impairments. Pain, anxiety, restless legs, melatonin deficiency, and socio-cultural factors, but also seizures, structural brain lesions, and airway-obstructions can contribute to CSR. Their ongoing qualitative and quantitative research in patients with FASD has shown that clinical symptoms and behaviour are not often recognized as sleep-related, and that caregivers' reports about sleep problems are not given appropriate attention by health care professions. Children are thus often self-medicated with melatonin (an over the counter substance influencing circadian rhythm), while others are prescribed psychotropic substances without critical evaluation of the benefit or potential harm relationship. Source: Canadian FASD Northwest Intervention Nat ([inat@ualberta.ca](mailto:inat@ualberta.ca)) e-mail communication, 29 Jan 2011.

<sup>90</sup> *Supra* note 78 at 96. (Kovach)

<sup>91</sup> Albert Einstein, *Relativity: The Special and the General Theory* (New York, N.Y.: Henry Holt, 1916, 1920); Kip Thorne, Igor Novikov, Timothy Ferris, Alan Lightman, *The Future of Spacetime*. (New York, N. Y.: W. W. Norton & Company, Inc., 2002) p. 96. ISBN 0-393-02022-3; Stephen Hawking, "Chronology protection conjecture" (1992) *Physical Review D* **46**: 603–611. doi:10.1103/PhysRevD.46.603. <http://link.aps.org/abstract/PRD/v46/p603>.

Hawking, then, the separation of past, present and future was ultimately an illusion,<sup>92</sup> something which framers of Indigenous Epistemologies intuitively have long grasped.<sup>93</sup>

Criterion or purposeful sampling was used to select targeted participants. Purposeful sampling is used to select participants who can provide in-depth information on the topic studied, and is done to increase the utility of the information obtained from smaller, qualitative samples,<sup>94</sup> as compared to often larger quantitative samples. Participants diagnosed with FASD, selected in the same manner as all other participants, may stand out during and after the interview process by reason of their firsthand experience with the disorder and by reason of having partnered with other agencies regarding home and community-based care and learning opportunities, and thus may become key or important participants for the purposes of research analysis. Attempts were made to interview caregivers and service providers, as well as individuals with FASD. Other participants for interviews were gleaned anonymously by the community partner through such avenues as the posting of notices placed by the community partner in its newsletter, on its website, through its e-mail list serve or regular mail, or through posting on bulletin boards or placement on display tables of the FASD Support Network or through partnering agencies. In the notices, in order to protect anonymity, participants were asked to contact the researcher directly and researcher contact information was provided in the notices.

In the case of the Parent and Elders Sharing Circles, key Elders invited the participants. All individuals with FASD interviewed were given the option of having an adult friend, parent, family member, Elder, or other mentor of their choice with them during the interview. Due to the sensitive and personal nature of some of the interviews and the vulnerability of the participants, an experienced FASD mentor from the Circles Project was present at all interviews involving individuals with FASD and their families who were her clients and most of the interviews were held in their homes and natural surroundings. The Circles Project mentor supported these individuals on a regular basis, knew them well and was there to manage any concerns arising during and post-interview. In the Métis Circle, both Elders and FASD Mentors were present and they invited individuals with FASD who were interested in sharing experiences

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<sup>92</sup> Albert Einstein, *Relativity, The Special and the General Theory*. (New York: Henry Holt, 1920); Albert Einstein, Letter to Michele Besso's Family. Ref. Jeremy Bernstein, *A Critic at Large: New Besso*. *The Yorker* (1989).

<sup>93</sup> *Supra* note 78 at 57, 147, 176. Kovach cites the metaphysical, spiritual and collective knowledge revealed through creation stories, dreams, ceremony, prayer and intuition as important ways of knowing in Indigenous cultures.

<sup>94</sup> McMillan, J.H. & Schumacher, S. (2001). *Research on Education: A Conceptual Introduction*, Fifth Edition (Toronto: Longman) at 400-401.



in the Circle. In the First Nations Sharing Circles, the Elders invited the individuals with FASD and their families and provided similar, effective, ongoing support to them. In recognition of distances travelled to attend interviews, arrangements made for child-care and, in the case of Elders, for services rendered in administering and facilitating the Sharing Circles, or for their traditional, community-based knowledge, wisdom and support, honouraria were approved and offered according to Tri-Council guidelines. Participants were informed in the consent protocol that they could withdraw from the interview at any time and further that they could request their data be destroyed. The study focused solely on individuals with FASD and their families, caregivers and service providers' experiences and perspectives and appropriate community protocols were followed. Any themes or frameworks emerging are based on subjective accounts of participants' experiences and perspectives as described by individuals with FASD, family members, Elders and service providers. Participants were recruited through auspices of the community partners, but maintained a separate identity from the community partners for purposes of confidentiality and privacy of data. The study was not designed to elicit the experiences of inaccessible, vulnerable populations such as those who were incarcerated, although a sample of clients and staff of an urban homeless shelter participated. Some of those participating in these other categories had been incarcerated or had family members who were or had been incarcerated. Due to the sensitive and personal nature of the interviews, the interview protocol was largely unstructured, comprising a Conversational Interview methodology to complement the Sharing Circles. In each, a participant was free to determine the parameters of what he or she was willing to share. Moreover, the interview or conversation was discontinued if a participant became uncomfortable. On the other hand, some participants, particularly professional or more mature participants, once the interviewer had set the stage, carried the conversation requiring little intrusion from the interviewer. In earlier interviews, the interviewer would intrude, but begin to perceive that it was better not to do so, as richer, novel data often emerged in such cases without the interviewer's intervention. Such practice corresponds to the protocol and deference shown to Elders, experts in traditional knowledge, to speak freely without interruption.

A benefit of the research design included the broad scope of knowledge and insight provided by parents, mentors, service providers and Elders. These grounded experts were acutely aware of how FASD had impacted individuals, families and communities and they

generously shared their experiences, insights, knowledge, resources and support. Every effort was made to accommodate as many participants as possible, while neither rushing nor limiting the rich data derived from the interviews. Once the topic of FASD was broached, the individual participant needed to arrive at his or her own closure, so Conversational Interviews could last for one to two hours and Sharing Circles and Focus Groups usually lasted for a half to a whole day, with a follow-up session of the same length some months later for the Circles. In depth, holistic knowledge of participants in their natural environments was the result, rather than statistically generalizable knowledge derived from a controlled or artificial environment focusing on a few isolated variables.

A trust relationship had to be established and maintained with community partners. One could not helicopter in on rotating blades, decelerate, descend, hover, then ascend and accelerate out of the community with the data, rarely or never to be seen again. Research with Aboriginal peoples is not “a quick and easy in and out,” or as Margaret Kovach terms it, a “smash and grab” research approach.<sup>95</sup> Rather it took years of relationship and trust building to come to the point of signing partnership agreements, holding Sharing Circles or Conversational Interviews, and in communicating and maintaining the relationship throughout the research process. Draft research partnership agreements went back and forth a number of times before a meeting of minds of all concerned was attained.

Protocol had to be followed in the formation of Sharing Circles and notes of proceedings were returned to participants for approval and clarification at a follow-up Circle. Elders did not wish audio-tapes to be used in the Circles, so notes were written on large experience charts contemporaneously with the Circle discussion for all participants to see. If they disagreed with what was recorded or how it was recorded, changes could be made at the time of the discussion. Helpers, including helpers from the Tribal Council, assisted with the note taking on the experience charts. These notes were then transcribed and in due time returned to participants in a follow-up Sharing Circle for review and further discussion or clarification. Traditional foods, such as bannock, hamburger soup, muffins and fruit were served at the Circles. Several preliminary coffee and lunch meetings were held with key Elders to plan the organization of the Elders and Parents Sharing Circle and communication was ongoing throughout the process and

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<sup>95</sup> *Supra* note 78 at 28, 36, 99, and 145. [Margaret Kovach, *Indigenous Methodologies: Characteristics, Conversations, and Contexts* (Toronto: University of Toronto press) at 28, 36, 99, and 145.]

continues today. Numerous community events were attended to build and maintain relationships with community partners and to immerse researchers in culture and context.

## ***7.6 Principles Underlying Selection and Presentation of Inductive Themes***

Ten themes on the topic of FASD and holistic Literacy were identified from an inductive analysis of over a hundred unstructured interview sessions or group discussions (Focus Groups and Circles) with parents and caregivers of children with FASD, Elders, teachers, other professionals, and individuals with FASD, resulting in an estimated thousand pages of transcripts. The ten themes identified include: 1. Multi-Modal Learning; 2. Sensory Issues, Information Processing and Navigating Transitions; 3. Motivation and Engagement; 4. Scaffolding Memory and Sequencing; 5. Communication Skills; 6. Self-Regulation; 7. Behaviour, Personality Problems and Mental Health Issues; 8. Attentional issues; 9. Social Skills, Developmental Level and Life Skills; and 10. At Risk of School Leaving and Adaptations for Retention.

These themes collectively form the starting point of an inductively derived model of evolving FASD Practice Guidelines, for learning and instruction of holistic literacy and life skills, useful across sectors and age-levels, informed by the literature on holistic literacy and by the neuroscience underlying diagnostic brain domains. The model thus created is neither a model of literacy, nor a model of FASD complete with brain domains, but a fusion of the two creating a new gestalt, an “FASD-Literacy” *sui generis* model, much as Einstein’s “spacetime” model was unique and different from the separate concepts of either “space” or “time” that preceded it.<sup>96</sup>

The FASD-Literacy model is created primarily with novices in both the fields of FASD and of Literacy in mind in order to ensure that no gaps remain in an area of application; however,

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<sup>96</sup> Hermann Minkowski, English translation of an address given at the 80<sup>th</sup> Assembly of German Natural Scientists and Physicians at Cologne, 1908 [Represented in H. Minkowski, H.A. Lorentz, H. Weyl, *The Principle of Relativity*, (Dover, New York: 1923)]. Einstein’s tutor, Minkowski, described the enduring nature of the new gestalt of spacetime this way, “Henceforth space by itself and time by itself are doomed to fade away into mere shadows, and only a kind of union of the two will preserve an independent reality.”

experts in either field may collapse or combine themes or categories to suit their respective areas of expertise. Experts in various fields may wish to combine some of the themes, whereas novices may need them separated to ensure that they “pull all the required stops” in each important area of application. As novices become more expert, they can combine themes as best fits their purposes. However, as according to the consensus of medical science there are some ten diagnostic brain domains identified, further collapsing and combining of themes may not do justice to relevant brain domains and other complexities of FASD, as well as to holistic literacy and life skills. As noted by Wilkinson, the number of categories or themes which inductively emerge from data depend on a number of variables, such as the amount of data collected and the breadth of views it contains, as well as whether only a broad overview or a more detailed picture of the complexity inherent in the phenomenon the data represents is required.<sup>97</sup>

The complexity and diversity of effects of FASD on learning and behaviour, and the implications of that complexity for instructional planning for the individual learner have been documented.<sup>98</sup> Despite the many challenges that the breadth of effect within FASD poses to the development of instructional practice, minimal research exists about the efficacy of educational interventions for FASD, and even less of that research is either classroom based, or, more generally, literacy-based. Thus educators, and others that work with FASD in a variety of settings, are faced with a daunting combination of challenges: a complex and varied ranged of effects within FASD, limited research on effective instruction for individuals with FASD, and a high prevalence of FASD in the general population.<sup>99</sup>

Characteristic, but most salient portions of the interview data, not taken out of context, including cultural context, as context is of utmost importance, are quoted to clearly illustrate the substantive content of each theme in its multivariate, diverse manifestations in the lives of individuals with FASD. Relevant portions of the unstructured, interview dialogues are presented in order to honour the Conversational Interview protocol, including the participants’ words, stories and narratives, involving as they do an oft stigmatized, marginalized and silenced

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<sup>97</sup> David Wilkinson, “Analysing Data,” in David Wilkinson, ed., *The Researcher’s Toolkit: The Complete Guide to Practitioner Research* (London and New York: RoutledgeFalmer 2000), at 79-80.

<sup>98</sup> Wendy O. Kalberg and David Buckley, “Educational Planning for Children with Fetal Alcohol Syndrome” (2006) 42(1) *Ann Ist Super Sanita* 58.

<sup>99</sup> *Supra* note 75 at 317. [Elizabeth Bredberg, “FASD and Education Policy: Issues and Directions” in E. P. Riley, S. Clarren, J. Weinberg and E. Jonsson, eds., *Fetal Alcohol Spectrum Disorder, Management and Public Perspectives of FASD* (Chichester: John Wiley, 2010) 317 at 317].

group,<sup>100</sup> and to present sufficient experiential data to be meaningful to other individuals with FASD, their parents, caregivers and professionals as they struggle with similar challenges. When considering a complex condition like FASD, fragmented pieces of interview data, taken out of context, could be misleading; for instance, if a strategy worked well in one segment of the interview data, it might appear to be a panacea, but later in the same interview, it might prove otherwise. Those working with individuals having a dynamic condition like FASD need to see the whole picture.

Although narratives are often expunged from interview data as irrelevant or uncodable digressions, Mishler, contends that these narratives are cultural and context-sensitive, both in form and content, that is, in the way they are told and in the meaning they give to events, and therefore should not be arbitrarily truncated. Through story and narrative, participants may be empowered to share in the control of the interview process, by having a role in determining the introduction and flow of topics, thus extending their responses to what is important without being called “off point.”<sup>101</sup> The result is a body of rich, rare qualitative data about the lives of a group of people all too often considered disposable. A Dialogical or Conversational Interview approach has been selected as being more respectful of Aboriginal and disabled individuals and their families and more reflective of Indigenous Sharing Circle methodologies. No one would ask an Elder to stop speaking, as such is a sign of disrespect, nor would anyone alter Elder’s words, and likewise for other members of the Sharing Circles (*Wa-sa-cam-e-be Ke-skue*) and Conversational Interviews conducted. Wolcott maintains that the greater length of qualitative accounts should not be a concern, honouring as they do the words, context, culture and interactive communicative and narrative styles of participants.<sup>102</sup>

Correspondingly, Justice Murray Sinclair, Chair of the Indian Residential Truth and Reconciliation Commission (TRC), stated that the mandate of the TRC is to “ensure that the full

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<sup>100</sup> Maria Mies “Towards a Methodology for Feminist Research.” in *Theories of Women’s Studies II*, eds. Gloria Bowles and Renate D. Klein (University of California, Berkeley, 1981) at 25. Mies contends that positivist research based on methodological principles of a value-free, neutral, uninvolved approach, including an hierarchical, non-reciprocal relationship between research subject and research object, is antithetical to the needs of feminist research to address oppression. Rather, in Feminist Research, researchers and research participants stand in solidarity with one another by integrating research with reciprocal relationships, struggles and solutions. Mies dialogues or has conversations with her research informants and within this context, stories flow, creating a new collective consciousness and mobilizing participants for emancipatory social action.

<sup>101</sup> Elliot G. Mishler (1986). *Research Interviewing, Context and Narrative*. Cambridge, MA: Harvard University Press.

<sup>102</sup> Harry F. Wolcott, University of Oregon, *Writing up Qualitative Research*, 3<sup>rd</sup> edition (Thousand Oaks, California: Sage Publications, 2009).

and complete story is told,” and through this process “to show the pathway to reconciliation.”<sup>103</sup> Experts have identified FASD as one of the intergenerational effects caused by the residential school experiences<sup>104</sup> and thus a similar approach is justifiable when dealing with the stories of individuals with FASD, their families and people that work with them.

On October 27, 2010, the present researcher had the privilege of speaking to the Chief Justice of Canada, the Right Honourable Beverley McLachlin, following her presentation on Access to Justice at the University of Saskatchewan, College of Law, to discuss with her the particular case of Access to Justice for FASD. The Chief Justice recognizes both the complexity and urgency of the issue. Courts and Legislators are searching for effective, pragmatic and justiciable solutions from their contexts and perhaps our respective searches for solutions will have areas of overlap where we learn from one another. Access to Justice for FASD includes fully appreciating the lives and challenges individuals with FASD face in their circumstances and settings, often spaces and places that many of us do not inhabit. An FASD lens, in addition to an Indigenous lens, is needed to reframe justice and educational initiatives so that they take accommodate realities, living conditions, and experiences. Besides being cognitively disabled, individuals with FASD may be remote geographically without access to good housing, supermarkets and fresh produce, diagnosis and health care services, or similarly marginalized and disadvantaged on inner city streets, let alone considering the challenges they encounter when attempting to navigate the arcane complexities of the mainstream justice system. As noted, because of their disabilities, people with FASD can face a tragic life trajectory, including being raised out of their birth homes, followed by frequent moves from one foster home to another, dropping out of school, living on mean streets, recycling through the justice system, ultimately accumulating charges and eventually facing dangerous offender hearings and indeterminate sentences in harsh, criminogenic penal institutions. Although diversion to the community is the ideal, in the context of mandatory minimum sentences, caps on credit for time spent in pre-sentence custody, and absent resources in the community, diversion may not be an option. If diversion is not an option, offenders with FASD fall victim to laws that do not recognize the place in the continuum of diminished responsibility that they occupy. Their place in the

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<sup>103</sup> Justice Murray Sinclair, Address at Carleton University, ON, Canada, October, 15, 2010, as reported in 88 (17) *Prairie Messenger* 1, October 20, 2010.

<sup>104</sup> Caroline Tait, *FAS Among Aboriginal People in Canada: Review and Analysis of the Intergenerational Links to Residential Schools* (Ottawa: Aboriginal Healing Foundation, 2003).

continuum of diminished responsibility is incrementally too far along from the extreme blocking of reality required to be found unfit, or to meet the stringent test for not criminally responsible. As a result, they often are held fully responsible at the guilt-determining phase and then can be faced with mandatory sentencing, leaving little opportunity to address their form of diminished responsibility at the sentencing phase, either, as mandatory minimum sentences circumvent the restorative, rehabilitative approach elaborated in *Gladue*.<sup>105</sup> Their loss of liberty is at risk probably more so than any other group and thus they are due special consideration from a justice and human rights perspective. Therefore, in this research, special consideration is given to giving voice to these powerless, often misunderstood individuals and those caregivers and professionals with intimate knowledge about how they function.

Furthermore, when a complex, variable condition like FASD is being considered, whether in the justice system, the educational system, or in this research, a brief, generalized, or essentialized description taken out of context is often not enough to make adverse life experiences real and meaningful to others in the field and to cue them to the quixotic nature of the challenges these individuals encounter. One may not realize that underlying the behaviour and responses of the individual before them is an array of complex, neurological, affective, and sensorimotor challenges. Also instructive to note, are speech, language and social discourse patterns used by individuals with FASD, however rich or impoverished they may be by the effects of pre-natal alcohol exposure, during the back and forth flow of the largely unstructured interview, including comprehension demonstrated. It is so easy to assume that the person with FASD is non-compliant, a behaviour problem, or an unexcused offender, rather than seeing through to the disability behind the behaviour in order to determine how to best accommodate it. Exposure to alcohol prenatally can affect the brains and nervous systems of individuals in varying ways, depending on the amount, frequency and timing of exposure, genetic predisposition of the fetus and other factors in the pre- and post-natal environments, so one must be careful not to over-generalize when deriving themes and solutions, nor when applying them. In addition, pre-natal alcohol exposure during preconception, pre-implantation, and gastrulation,<sup>106</sup> along with environmental deprivation in infancy and early childhood, can lead to epigenetic effects, whereby the expression of key genes are turned off in an individual, but can

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<sup>105</sup> *R. v. Gladue*, [1999] 1 S.C.R. 688.

<sup>106</sup> An embryonic phase in which DNA duplication leads to cell differentiation resulting in the formation three germ cell layers.

be reversed or turned on by enriched experiences, particularly in early life.<sup>107</sup> Individual differences abound within the spectrum so that a one-size fits all, broad, generalized approach is not advised when working with individuals with FASD.

Sincere appreciation is extended to all participants for sharing experiences, insights and unresolved perplexities, as without their assistance this project could not have been undertaken. Sometimes tentative solutions are discussed to some of the participants' unresolved perplexities, but this is not meant to be disrespectful. The researcher is learning through making approximations and miscues, just like the children with FASD, and no doubt readers will notice some of the researcher's miscues, as well, and puzzling through such miscues is how meaning making and problem solving occur and how incremental advances are made. Moreover, qualitative observation of learners while they work, informed by approximation and miscue analysis techniques, can be utilized for purposes of individualized evaluation and assessment of learners with an FASD, along with samples of their work.

A goal of the research is that documented participants' experiences will enable others to navigate their journeys with FASD with greater ease, whatever their role in this process may be, and hopefully all so involved will continue learning about FASD and searching for solutions. The theoretical background, foundation and interpretation of the qualitative themes has been dealt with extensively in the preceding section on brain domains and holistic literacies; therefore, this section is primarily dedicated to the particular manifestation of the content of qualitative themes through citing dialogical conversations with FASD and FASD-informed participants, whether through Conversational Interviews, Focus Groups or Sharing Circles (*Wa-sa-cam-e-be Ke-skue*), complemented by limited researcher and expert commentary. Construct validity is thus obtained.

The overriding goal of the research is to honour participants' voices, stories and narratives, rather than speaking for or about them and thereby avoiding viewing them as the "Indigenous Other," the "FASD Other", or the "Disadvantaged Other." Some of their narratives are particularly distressing, especially those, who, because of lack of accommodation and supports for their disability, end up on the boundaries of society, precariously vacillating between street life, the justice system and homeless shelters. The pattern of dialogue in the

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<sup>107</sup> Philip C. Haycock, "Fetal Alcohol Spectrum Disorders: the Epigenetic Perspective" (2009) 81 *Biology of Reproduction*, 607-617. These findings are based on animal studies. More research is needed into the epigenetic basis of FASD, including expansion of the etiology of FASD to include "preconceptual effects."



interviews may also be of interest in the specialized study of FASD and communication, and so is generally reproduced verbatim in the segments cited, with the Interviewer designated by the letter “I” and other anonymized devices used for the persons being interviewed, in order to maintain confidentiality.

As FASD remains a stigmatizing condition for individuals and families, they were taking a risk participating in the research. Participating in treatment or diagnosis is very different from participating in research where the benefit to the individuals is more remote but the risks are ongoing. The interviews were situated in the natural, but often chaotic or unpredictable circumstances of daily lives of family and community and not in the controlled conditions of clinical trials. Accordingly, the researcher had to adapt to the situations as presented, which could end at any moment at the choice of the participants or their mentors. Trust and rapport had to be built in these fragile, dynamic interview settings and researcher’s discretion was used in posing queries, balancing time constraints and opportunity against more intrusive, or even leading questioning at times, an ongoing ethical dilemma for the researcher to navigate. As noted, by experience the researcher learned to intrude with questions less with interviewees who had expertise and experience about FASD that they wished to convey; whereas some interviewees were more reticent, or preferred a different style, and more queries were used. Such practice might be comparable to the deference accorded Elders and their expertise regarding traditional and cultural knowledge.

## ***7.7 Inductively Derived Themes***

### **7.7.1 Theme 1: Multimodal Learning**

Multimodal Literacy is a term first utilized by Carey Jewitt and Gunther Kress to encompass all the different ways in which meaning can be created and communicated in the world today. Multimodal communication, representation and learning involve as many senses as possible, as well as a variety of modes and media.<sup>108</sup> Multimodal, holistic approaches to

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<sup>108</sup> Gunther Kress and Carey Jewett, *Multimodal Literacy* (New York: P. Lang, 2003).

learning engage and stimulate children, accommodating their learning styles, whether visual (images, page or screen), auditory (music and sound), spatial, kinesthetic, or multimodal, rather than relying on mainly didactic oral or textual modes. For children with FASD, in particular, visual, spatial or kinesthetic stimulation may be important to activate certain parts of the brain or to find or generate new, alternate pathways to replace those damaged by prenatal exposure to alcohol. Children with FASD may be attention deficit and require a certain amount of stimulation to focus the brain and to maintain that focus, or may have poor auditory memory and slower auditory processing speed, but a more developed visual, spatial or kinesthetic memory, tending to remember and process what they see or do more readily than what they hear or read. They need to be actively engaged and immersed in learning through a variety of modalities, while monitoring for over stimulation or under stimulation. They may need more time not only to process auditory stimuli but also to code-switch between Aboriginal or additional languages and English. Emerging research on translation of neuroscience to clinical applications will assist educators with developmentally appropriate strategies that stimulate specific areas of the brain (thalamus, amygdala, hippocampus, and the frontal cortex) in order to focus attention, generate meaningful connections with prior knowledge and understandings, as well as maximize both short- and long-term memory.<sup>109</sup>

Bredburg points out that recommended environmental modifications to address sensory issues, like other recommended strategies, require research to translate them to the classroom context, so there is no hierarchy of categories of modifications. She further concludes that although much educational methodology has become established through a body of practice and expertise without the substantiation of research, a close relationship between research and practice is an important goal if teachers are not to remain under-informed and under-prepared to address the complexities posed by students with FASD.<sup>110</sup> Guidelines for the types of broad-based research platforms that would work in complex, diverse, dynamic environments such as

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<sup>109</sup> Stephen Rushton and Elizabeth Larkin, "Shaping the Learning Environment: Connecting Developmentally Appropriate Practices to Brain Research" (2001) 29 (1) *Early Childhood Education Journal*, 25 at 26. The recognition of the need for emerging research on translation of neuroscience and environmental adaptations to clinical practice in education of learners with FASD is attributable to the present author of this thesis.

<sup>110</sup> *Supra* note 75 at 320-322. (Bredburg).

classrooms has been previously discussed, including qualitative research, analyzed inductively.<sup>111</sup>

A mother complained that her disabled child was taught through the use of endless lists of sight words, and so became disengaged with school and the learning process. A young woman lamented that because she was FAS she had been taught mainly life skills in school. As an adult, she wanted to learn the academic skills she had missed as a child and youth, at a time when she was also attempting to navigate the tasks of earning a living, marriage and raising a family. Some of the life skills taught to her in school she had found particularly demeaning, such as repetitive toileting skills, as little attempt was made to tailor the life skills to her level of development, ability and interest. Perhaps she could have benefited from learning practical or applied arts, or perhaps she merely needed to learn at a slower, more flexible pace as novel, multimodal, hands-on experiences presented stimulated her brain to find alternate synapses to replace damaged ones, or to build completely new synapses. Visual memory aids might have facilitated her learning, as well, through scaffolding problems with memory, auditory processing and abstract thinking.

Interviews with a parent and an educator following describe experiences involving Multimodal Learning, as well as frustrations with other forms of learning. Some commentary by the researcher is also included. Moreover, Theme 1, “Multimodal Learning” is comprised of three sub-themes, “Experiential Learning,” “Holistic Language and Literacy Approach to Integrating Drawing and Other Visuals with Reading, Writing and Telling Stories,” and “Visual and Applied Arts.

**Interview with HM, Guardian of Robert, a First Nations boy Prenatally Exposed to Alcohol; Robert came into the care of HM at the age of 7, and at the time of this interview was 16 years of age.**

HM is the sole guardian of Robert, an alcohol exposed First Nations boy who came into her care at the age of 7 (Grade 2) and was age 16 (Grade 10-11) at the time of the interview. He

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<sup>111</sup> *Supra* note 86 and 87 pages 49-50. ( CIHR Guidelines for Research with Aboriginal Peoples, and Special Education Research Guidelines.)

is the only child in the home. While they both come from Saskatchewan and met there, they have lived in Quebec and British Columbia during their 9 years as a two-member family.

HM: When I broke skills down into simple steps and practiced those steps, my child caught on quite quickly in math and algebra - despite little practice. Language was a different story. When he was little he lacked the skills to tell me about things that happened elsewhere even when he wanted to. Now that he is past puberty he is starting to describe things that happened elsewhere as my niece and nephews have been able to do since they were young. His reading has also improved though I have stopped forcing him to practice. I wonder if it is really productive to humiliate a child by trying to force them to do something they are not ready for. You can't make a bird fly by tossing it out of the nest before it is ready. However, he has extraordinary skills with three dimensional puzzles. He can fix things that no one taught him how to fix. He can copy a complex drawing without having practiced. I think I will buy him a subscription to the *Mechanics Illustrated* magazine.

I was completely mystified about how to help him with literacy. I had always thought that bed time stories were the way to go but he would fall very soundly asleep after a paragraph or two. I spent a lot of time and money getting him tested, but none of this resulted in a consistent remedial program. When he was not succeeding, the schools accused him of not trying . . . and responded with punishments . . . and this made him shut down more. Math tests only gave "word problems," so even though he knew the mathematical operations required, he bombed the math tests because of his language difficulties!

### **Researcher's Commentary and Interpretation:**

HM notes the difficulties Robert experienced in learning to read with the reductionistic techniques employed, as well as his success in math being frustrated when word problems became prevalent in his math courses. Teachers punished him for "not trying," according to HM, when perhaps trying in a different way might have worked better, such as using a multimodal approach along with metacognitive techniques (thinking aloud to model problem solving) and miscue analysis to show him incrementally how to learn from his mistakes. No intention exists to blame the teacher, absent knowledge and information on FASD and effective strategies, and absent adequate systemic supports.

**Interview with an Educator who has many years of experience in classrooms as a Teacher or Teacher Supervisor and Professor, working with children, some of whom have diagnoses within FASD, as well as teaching future educators:**

Flash cards are isolated symbols with no context cues, as are workbooks, so are not recommended for wide use. Sometimes workbook pages even have inappropriate context cues, for example drawings of frogs with no content in the questions related to frogs, so often the context cues provided are inappropriate or misleading. Likewise, commercial psychological or reading tests will not assist much with diagnosing and developing engaging literacy programming for children FASD or other struggling readers. Standard scores are misleading, as reading levels fluctuate within age and grade groupings. What works is qualitatively observing and listening to children as they read, to determine the metacognitive strategies they use and particularly the miscues. The miscues are exciting, teachable moments and illustrate the learner's zone of proximal development, as coined by Lev Vygotsky. The approximations learners make as their reading strategies progress are a sort of "pushing of the envelope" onto new strategies and meanings. The key is to analyze these miscues and discern how to encourage the advancing learner through the miscue by modeling metacognition skills for them using problem solving self-talk. Students, then, do not become discouraged through the process, but rather view miscues or mistakes as a learning process through which they can problem solve and make their own meaning. Remember to avoid the Pedagogy of Poverty or the Pedagogy of Oppression through resorting overly to rote flash cards, workbook pages or computer drills that could rob them of the joy of learning.

Reading is many factors, not just phonics, and it is not a mechanistic process. Instead, it involves comprehension, memory and metacognition. It is also situated learning. Children bring the knowledge that they have to bear to make meaning of something new. Children come from a variety of cultures, backgrounds and environments, and it is important to reflect all of these in the reading materials selected, so as not to privilege one group over another, even inadvertently. Moreover, the English language does not make phonetic sense consistently, and the child must learn a variety of strategies to deal with that fact. Three cues are used in learning to read. They are meaning, word knowledge, and phonics which is used as a confirming cue. For instance, consider the sentence "The Plane soared in the sky, up, up in the air the plane soared." The child does not know the underlined word, "soared."

The child attempts to make a meaningful fit in interpreting the word "soared," using so-called semantic or syntactic substitutions, not just phonics. She will look at the picture in the book, look at the context of the story, and draw from her background information, word knowledge and from dialogue with the teacher and other students. A rich language background and dialogue with adults or peers helps her to learn to read. The child may make a semantic substitution and read that the plane "flies" in the sky, but then checks to see that the word starts with "s" so "flies" will not work. At this point, the metacognitive question is what word starting with "s" has a meaning that would fit in the sentence? This is where a rich language background and lots of dialogue in the home and school will help children to determine the unknown word and thereby learn to read. If from a rich English language background, the child may select the word "soared," and confirm it phonetically. If not, the teacher can dialogue with the child and provide further background regarding flight vocabulary. Therefore, a rich language background and lots of dialogue are key to helping children to learn to read. Read aloud to children from deprived backgrounds to instill language.

A lot of textual talk should accompany the readings, a lot of side stories that can relate the story to the child's life and environment. A great deal of traditional learning and community literacy occurs visually and hands-on, in the natural environment and in the culture; formal education, on the other hand, tends to be a text-centered, verbal-centered or language-centered process. Practical and professional arts are important as they draw on the former, traditional skills. Cluster webs, concept maps, storyboards, smart boards and stick puppets for facilitating dialogue, can reduce stress and enhance memory cues while the child learns vocabulary and makes meaning of her experiences in reading. There are many literacies and we should not privilege one dominant literacy, such as textual literacy. According to

Gardner, there are multiples intelligences, including but not limited to linguistic, mathematical, musical, kinesthetic, spatial and interpersonal, which all need to be recognized and honoured.<sup>112</sup>

As noted, Lev Vygotsky speaks of the child's zone of proximal development [his present level of development]. The child will make approximations as she reads; these are not errors, but rather are incremental steps in the metacognitive process of learning to read. The learner must be free to approximate the desired model and "mistakes" or approximations are essential for learning to occur.<sup>113</sup>

Brian Cambourne identifies seven conditions for learning. The most important of these are engagement, demonstration and immersion. The first step is to *engage* learners with demonstrations, field trips, concrete visuals and artifacts, otherwise it is unlikely that learning will be set in motion. The student needs to be *immersed* in the content and context, using a multisensory approach. Saturate the environment with meaningful and relevant context for the learner and give practical and concrete models. Have high expectations of learners and do not revert to the pedagogy of poverty or to the pedagogy of oppression which will disengage and de-skill the child. *Demonstrate* using explicit action, giving auditory and visual representations of new learning, and provide frameworks to aid memory or scaffold strategies. Provide rubrics (categories, guides, mnemonics, and sequences) and anchor charts for larger assigned tasks. Teach problem solving. Build in choices to the learning experience (for instance, allow the learner to choose a book) and empower them. Keep contexts authentic to the learning. Provide many opportunities for practice in whole group, small group and as an individual. Provide non-threatening feedback on strengths and weaknesses. Remember always that learners must be free to approximate the desired model and that mistakes are essential for learning to progress. When empowered, learners come to take *responsibility* for their learning.<sup>114</sup>

### **Researcher's Commentary and Interpretation:**

Phonics is like legal positivism, as neither are individualized nor contextual, but unfortunately, one size does not fit all for either reading or law and justice. Advances in neuroscience and brain imaging inform us that intelligence is fluid (termed plasticity of the brain), and not deterministic. Stimulation and proper conditions are required to enhance this plasticity. However, while neuroscience is pure research, the present research is solution oriented research and context dependent.

Unfortunately, limited attempts exist to translate scientific brain research on FASD to the strategies at the clinical or practical level. The *Gladue* principle in law illustrates the contextual nature of modern legal principles, an enlightened movement away from strict legal positivism. The *Gladue* principle encourages the consideration of traumatic background factors, such as

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<sup>112</sup> Howard Earl Gardner, *Frames of Mind: The Theory of Multiple Intelligences* (New York: Basic Books, 1983, 1993).

<sup>113</sup> Lev Vygotsky, *Thought and Language*, edited and translated by Eugenia Hanfmann and Gertrude Vaka (Cambridge: MIT Press, Massachusetts Institute of Technology, 1962).

<sup>114</sup> Brian Cambourne, *The Whole Story: Natural learning and the Acquisition of Literacy in the Classroom* (Auckland: Ashton Scholastic, c1988).

colonization and residential schools, and today's foster care, in framing restorative sentences for Aboriginal offenders. Such a consideration needs to be extrapolated into the educational system, as well, to ameliorate trauma, underachievement, absenteeism, failure, truancy, discipline and school leaving for this group.

Engagement is important for learners with FASD, as they are often attention deficit, so need purposeful and effective engagement to assist in initially focusing their attention and in maintaining that focus. Visuals, story walks through the book, creative play, and so forth, can assist with the process of engagement. Immersion is important to provide context for learning as context is an important aid to comprehension. Immersion using concrete props and visuals, creative play or field trips can assist those who have difficulty with abstract thinking. Drawing before, during, and after reading can scaffold memory, sequencing and meaning making, and text can be added to describe what is happening in the these series of drawings, creating a story board. Learners with FASD often have problems with memory, sequencing and meaning making. Students can read the story board they have created to their teacher and peers, first on a one to one basis, then in small groups. Interactions with parents, teachers and peers, reading, talking and discussing together provides a socially enriched, unhurried, fun, playful, warm and loving environment in which to learn.

In the *Hurried Infant*, April 21-22, 2010, CBC Radio Ideas producer, Mary O'Connell, points out that Einstein, a late bloomer, did not use flashcards and yet was indeed the proverbial tortoise who caught up with the hare!<sup>115</sup> Brain development is varied and stretches out for a long time and so children should not be hurried and discouraged. They learn best through being active, not passive, through integrated learning that is social, creative and innovative. Play is the work of childhood, as is storytelling and imagination, along with the joy of birds, animals, insects and nature. Learning self-restraint, taking turns, collaboration and cooperation are the most important curricula of childhood. Learning social skills, making hypotheses about the mind of another person through taking on another person's perspective is important and can occur through children's stories, like Arnold Lobel's *Frog and the Toad* collection.<sup>116</sup> It is best to learn mathematical relationships,  $3 + 3 = 2 + 2 + 2$ , concepts like number, length, quantity and volume, through making muffins or playing in the sandbox, than through flash cards or

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<sup>115</sup> Kathy Hirsch-Pasek and Robert Michnick Golinkoff, *Einstein Never Used Flash Cards* (New York, NY: Holtzbrinck Publishers, 2003).

<sup>116</sup> Arnold Lobel, *Frog and Toad are Friends* (New York: Harper & Row, 1970).

workbooks. The integrative processes in the brain required for reading development occur between the ages of 5-7 years when the neurons become myelinated enough to conduct messages faster, although in boys this myelination takes longer. Forcing children to learn to read before five is rushing biology, and those so rushed often neither read as well nor enjoy it as much. Paired associative reading, what pigeons do, is not how children learn to read, but rather they learn through being exposed to oral language, stories, nursery rhymes and conversations. As privileged children hear 33 million more words than poor kids do by the time they come to the kindergarten door, they have the advantage in learning to read.<sup>117</sup> Family and community literacy groups, early childhood education and pre-school initiatives may help to build readiness.

#### 7.7.1.1 Experiential Learning

John Dewey, in *Experience and Education*,<sup>118</sup> emphasized the intimate relationship between experience and learning, and the corresponding need for teachers to actively construct interactive processes involving hands-on, experiential learning for students, as well as through social interaction with teachers and peers. The teacher's role was vital in facilitating and guiding the active process of experiential learning, helping the child to connect new content to prior experiences and social relationships, thus fostering a sense of continuity in the learning. The teacher's role was as a facilitator, carefully selecting the influences or experiences and assisting the child in responding to them, thus enabling the child to construct meaning from experiences. While advocating for experiential, hands-on learning, Dewey did not favour unstructured, sometimes unduly chaotic, progressive methods with little role for either teacher or content. Inclusive social groups, incorporating a sense of continuity with family, community, language and culture, are considered integral to the process of constructing and co-

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<sup>117</sup> Maryanne Wolf, *Proust and the Squid: the Story and Science of the Reading Brain* (New York: Harper-Collins Publishers, 2007). Professor Maryanne Wolf is Director of the Centre for Reading and Language Research at Tufts University. At page 102, Wolf cites a study by Todd Risley and Betty Hart published in *Meaningful Differences in the Everyday Experience of Young American Children* (Baltimore, MD: Brookes, 1995). Hart and Risley's extensive prospective, longitudinal study of the vocabulary children in professional, working class and welfare homes were exposed to, and subsequent follow-up studies, yielded immense quantities of data documenting the differences. The study is informally referred to as "Hart-Risley 30 Million Word Gap Study."

<sup>118</sup> John Dewey, *Experience and Education* (New York: MacMillan, 1938).



constructing knowledge. Knowledge is socially co-constructed within such a framework of culture, community and experience. An emphasis on experiential learning and the significance it places on relationships and primary human values encompasses and integrates diverse layers of meaning and experience. Its natural trajectory is transdisciplinary inquiry, the making of connections rather than fragmentations, building meaningfulness, acquiring self-regulation through flexible pacing, especially important for those with FASD who require differing processing speeds and more time for memory retrieval. Facilitating a sense of continuity with community and culture is important, in contrast to the alienation often resulting if the dominant culture privileged by the school is different from that of the student or students. A reciprocity between student and teacher where both learn and both teach in a dialogical conversation rather than through a rigid curriculum or pedagogy is the ideal, in contrast to the banking model where the allegedly empty student's mind is filled by an all-knowing teacher. Freire's critical model of learning is considered emancipatory, rather than oppressive. As a method it transcends cultural, class and ability differences in the classroom, as well as differences in learning styles and processes, thereby extending the benefits of education to all without inadvertently privileging a few. Freire termed this method the *praxis* of freedom and transformation while observing its power in helping to liberate the people in his homeland of Brazil through building social capital. He realized that the oppressed do not want the oppressor imposed as a model, but instead wish to collectively select, construct or create their own models of learning and liberation.<sup>119</sup>

Interviews with Elders, parents, an educator, a teacher's assistant, and an individual with FASD illustrate the effectiveness of this first of three sub-themes under Multimodal Learning, namely, "Experiential Learning for individuals with FASD."

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<sup>119</sup> Supra note 29. (Paulo Friere, *The Pedagogy of the Oppressed*.) Naresh Singh, Canadian International Development Agency (CIDA), in his presentation based on the United Nations Development Program's (UNDP) Report on International Development, "Making the Law Work for Everyone: Legal Empowerment of the Poor," 17-1-11, College of Law, University of Saskatchewan, cited Paulo Friere's methods of transformative literacy as a model of how education can empower the poor. The UNDP Reports can be found at [http://www.undp.org/legalempowerment/clep\\_archive/index.html](http://www.undp.org/legalempowerment/clep_archive/index.html), retrieved from the worldwide web 21-1-11.

**Interview with PA, Adoptive Mother of Mark and Mary, two children who have a diagnoses within FASD, Mark with FAS and Mary with pFAS; Mark was 4.5 years old when adopted and 18 years of age at the time of the interview; Mary was 27 months old when adopted and 15 years of age at the time of the interview.**

PA, mother of Mary and Mark, who were adopted from Russia, is an Occupational Therapist who works in early childhood special education for 3 to 5 year olds, in a self-contained classroom for children with Autism Spectrum Disorder (ASD). Mark was 4.5 years of age and Mary was 27 months old when they were adopted from Russia in 1996. Mark has since been diagnosed with FAS and Mary with partial FAS. At the time of the interview, Mark was 18 and Mary 15 years of age. PA is a very important or key informant, as many skills she learned professionally as an occupational therapist working in an early childhood special education classroom for children with ASD are applicable to teaching her two children with FASD and provide her with much insight to share with parents, caregivers, teachers and others who work with individuals who have a diagnosis within FASD. In addition, both parents were active in engaging their children in various family and community literacy and learning experiences.

I: What kinds of learning experiences worked with your children?

PA, mother of Mary and Mark:

- lots of visits to children's museums for hands on learning experiences at early ages; working with my husband in his shop, measuring, sawing, painting and making things, taking care of our cars, and so forth, thus learning functional math skills and basic construction;
- helping to build tree forts at our cottage;
- measuring food and liquid items and reading recipes when helping me in the kitchen;
- taking trumpet and piano lessons;
- taking TAE Kwon Do lessons;
- lots of opportunities for art activities using a wide variety of media;
- to learn letters and number we used sandpaper letters and numbers so the kids could get the feel of them with their fingers;
- we also hid letters and numbers in different media such as beans or rice, and had them feel for the letter and identify it before looking at it;
- and actual hands on science projects in the kitchen and outside, to teach concepts.

I: What kinds of hands on learning experiences did they have at children's museums that worked well with your children?

PA: Some which I can remember:

- weighing and measuring items;
- motion and speed activities;
- mixing colors;
- obstacle courses involving motor planning;
- experimenting with textures, cutting, colouring and pasting; and

- re-enacting certain historical events using costumes and props of the times.

I: Do you remember any specific actual hands on science projects in the kitchen and outside that you did?

PA: I had a book of science experiments to do in the kitchen. . . My husband took care of this topic with the kids, more than I did.

PA: Both [of our children] needed a lot of "hands on" opportunities to learn, could not retain information well from reading and only partially from verbal instruction (auditory learning). However, retention and recall was great if it was something very meaningful to them. Retention and recall was also good if it involved "hands on" learning tasks. For instance Mary was obsessed with cell phones from a very early age and we gave her our old non-functioning ones to play with. By the age of 8 or 9 she had learned how to store information in our old cell phones and had figured out on her own how to set alarms to notify her of special events/dates, how to enter phone numbers, select ring tones, etc. She could recognize phone numbers when they appeared on the home phone screen and tell us whose it was. Around the age of 12 she snuck her brother's cell phone into bed with her one night and ran up a bill of \$156.00 in calls to celebrity 800 numbers (don't know where she ever found these) as well as text messages (we had no idea she knew how to text). We removed this feature from our phones after this as to Mary, "no" never meant "no" and her obsession with cell phones continues to this day. We could spot trouble on the horizon! I always thought she was a little OCD (obsessive compulsive disorder) or ASD (autism spectrum disorder).

PA: Both Mark and Mary loved games, especially those involving hands on learning and would play the same ones again and again with each other. I also enrolled both of them in Early Childhood Family Education classes when they were young so they both had opportunities for play with peers.

I: Can you remember how each one learned to read if they did learn to read, the stages and so forth? Did one to one, or small group situations work better, or home instruction?

PA: Mark learned to read by using a Phonics program at home (including tapes and headphones). He repeated this program several times but it was helpful. He always needed one to one instruction in order to process and retain information. Mary also used the Phonics program so I am assuming this also helped her. She also finally found several juvenile series of books which she loved, and of course we bought them all for her. She would reread them again and again.

I: Did visual techniques help as well, if so what specifically?

PA: The most effective visuals were simple visuals when they were young so they knew what was expected as far as daily activities were concerned. We included age appropriate chores (feed the pets, fold towels, walk to a neighbour's to drop something off, etc.). I put the individual pictures on a velcro strip and posted it on the fridge. They caught on quickly to this. The idea was to check this, complete the next task on the "do" strip, and when it was done, move it to the "done" strip. This encouraged more independence on their parts and less harping from us. Lots less stress too for all of us as my husband and I could just say "Please check your schedule" or "Your schedule says that you need to.....," so really only the schedule took the brunt of the blame if a task was not desired. I could then check the charts at the end of the day to see where things were at. This approach also helped Mary remember to brush her teeth each night and morning, and as she got a little older, reminded her to pick up her dirty clothing, etc. Mary has continued to use lists and visuals for things like the steps of laundry. This is left down on top of the washer so she can complete this task without having to ask us how to do it. She still needs to refer to it for the settings for the types of clothing she is washing/drying. She is now able to follow the pictures/directions on the side of a cake mix box and complete this on her own. This independence has helped her feel good about her abilities and has helped avoid power struggles with us. Mary now has a three-ring notebook with a list of activities which are to be completed each day (one page for each day). She helped put this together and decorated the cover. Behind each day's list is a place to check off the task when it is done.

Another useful visual was the universal circle/slash to indicate "no". I laminated a number of these visuals and placed them in locations which were off limits.

Another approach which worked with both kids was having them complete a less desired task before a desired one. E.G. I would say "first do this.... (less desired task) and then do.... (more desired task)".

### **Researcher's Commentary and Interpretation:**

PA and her family used a wealth of creative, experiential learning approaches with Mark and Mary involving both home and community literacies. The field trips to the museum engaging in hands on activities such as re-enacting historical events with costumes and props; working with their Dad in the shop or in taking care of the vehicles; weighing and measuring liquids for cooking in the kitchen when baking a cake; a wide variety of art activities involving experimenting with different fabric textures and colours, as well as colour mixing with paints; music lessons and Tae Kwon Do lessons, along with previous enrolment in an early childhood family education class are wonderful examples of active, engaged learning involving a number of styles, modes and media. These activities also engage both home and community literacies.

To supplement experiential learning, Mark and Mary also made use of an audio-taped phonics program PA provided which they could listen to and repeat, if needed, thus effectively addressing the three cues considered necessary for learning to read, which are vocabulary, semantics and syntactics, and phonics. It appears that PA made special attempts to provide high interest books to read at an appropriate developmental level for the children. Mary's experiences with mastering cell phones and texting illustrate what she was capable of learning when motivated and engaged. Other mothers have reported that their children with diagnoses within FASD, who may have never learned to write as a form of communication, do pick up digital text messaging, and thus have an important vehicle with which to communicate with friends, although supervision is usually required as in Mary's case.

**Interview with HM, sole Guardian of Robert, a First Nations boy prenatally exposed to alcohol; Robert chose to enter HM's care at the age of 7, and was 16 at the time of the interview. He is the only child in HM's home.**

HM is the sole guardian of Robert, an alcohol exposed First Nations child who came into her care at the age of 7 (Grade 2) and was age 16 (Grade 10-11) at the time of the interview. Both are originally from Saskatchewan, but have lived as a family of two in other provinces, Quebec and British Columbia.

HM: In grade 4, Robert worked with another student to make a life-sized man out of money and then an Egyptian mummy he did himself with lines so clean that it looked like the real thing. One project took a National Geographic photo of a mask, cut it in half and Robert drew the other half so well it looked professional. Projects also involved conveying information with pictures. In grades 5 and 6, Ms. K. made sure Robert got recognition in the areas where he excels. His drawing was chosen for the cover of the school year book the year he graduated from primary school (over 60 other kids) and he got an award for Art. He did not apply for choir but when they were looking for singers the choir teacher heard he had a good voice and asked him to join. He was also asked to do a solo dance in the school concert, but he declined my offer to pay for classes with that teacher.

I don't know about Ms. K.'s teaching methods but she was very popular with the kids and she advocated on their behalf with the administration that was always handing out punishments. She could be talking to a parent then out of the corner of her eye she would see a kid from last year & say "Hey Rahid. You've grown so much! How are you doing?" She made every kid feel important. I was amazed when she told me that Robert was very helpful and co-operative in school. It was the first time I had no complaints from the teacher about him. The discipline problems were all about things from out of the class room (He got suspended for throwing stones at squirrels). It may be that she did not have the optimal teaching methods, but her attitude made all the difference. He really made a lot of progress with her. She made it possible for him to open up about things that may have been troubling him. For example, she told me that Robert told her about the time that he slept in the car with his dad because his dad's girlfriend was throwing beer bottles at them.

Many things in his life experience were completely outside the norms in *Caillou's* family. I remember that my favourite story when I was little was *Fix it Please* about a dad who fixed things just like my dad. When I was in Newfoundland the kids loved *Blueberries for Sal* because they went picking berries. When kids have books that express something similar to their experience it is easier for them to learn to read. I am hoping that someday someone will write humorous and heart-warming stories about the night they slept in a car with their Dad or the time they were apprehended. . . or how they had to avoid a grandmother or grandfather that they were afraid of for good reason....or how they had to deal with racist kids or adults... If you have ever seen *Everyone Hates Chris*, I think that kind of mind set could do the trick.

Robert reads what he needs to know to play games on the internet. . .and he knows what buttons to push on the remote to fix it when I screw up the TV. I got a subscription to *National Geographic* and he reads some of the notes under the pictures of weird animals (that reminds me...I want to get him a subscription to something like *Popular Mechanics*).

### **Researcher's Commentary and Interpretation:**

Robert learns well through holistic fine arts and visual, experiential, hands-on approaches, combined with teachers who take an interest in his strengths and build on them. He has had a difficult early life, as well as having a disability, so he will need compassion and patience to find his way, but he definitely has strengths on which to build. Using his visual, spatial and mechanical strengths to engage him in reading would likely be a good strategy. In this vein, his Guardian mentioned purchasing a subscription to *Mechanics Illustrated* for Robert, as well as being Robert's strongest advocate generally.

### **Elders and Parents Circle**

Several Circles of First Nations Elders and Parents of children who have a diagnosis within the spectrum of FASD were held to discuss literacy and learning for individuals with FASD. They have their own unique ways, based on their culture and epistemology, of teaching and responding in a caring way to the child.

### **Elders and Parents Circle:**

A person with FASD is "a hands on" learner. Education by watching and doing is "hands on" education. "Hands on learners" like sewing, beading, and learning how to make moss bags. These are culturally relevant activities, as well as being "hands on."

Sports are important as individuals with FASD like to be active and also sports have built in reward systems. Playing on a team and team sports are important for them. By watching and doing, they learn how to be a team player, how to do things together, how to make friends, how to follow the rules, so that they can gradually come to cope with these important social skills. They won't learn these things if they are excluded.

They learn from puzzles and board games, if done together, as a family, in an intergenerational group. Again, they watch and do, and learn sharing, rules of the games, social skills, manual skills, spatial perception and communication skills.

In the family group, talk about family life with them, "This is our family, these are the members, and we do these things together." . . . Have lots of family events to do things together and to build trust in them is important. Older members of the family can be role models and family members learn from one another. Do not use shame and punishment to teach. One young girl with FASD remembered the birthdates of all the members of the extended family and made sure that no one's birthday was forgotten.

### **Researcher's Commentary and Interpretation:**

Traditionally, in Aboriginal communities learning is unhurried, holistic, multimodal, and relational, learning through seeing and doing, often in intergenerational social groups, such as the family and community, where the learner feels accepted and included. The context of a learner's background knowledge and environment is utilized to engage and make meaning of new experiences. Shame, punishment and other forms of alienation that interfere with learning are avoided.

### **Interview with an Educator who has many years of Experience in the Classroom as a Teacher or Teacher Supervisor and Professor, working with Children, some who have Diagnoses within FASD, as well as Teaching Future Educators:**

Aboriginal people learned not from textual materials, but from the environment, the bush, the prairie, the trap line, and the lake. They would learn to gather, cook, sew, trap, hunt and prepare the hides and clean the fish or prepare the berries and meat, by watching their family members and working with them in informal apprenticeships.

In the classroom, use lots of manipulatives, such as paper, fabric, ribbons and blunt sticks from which to make wands or little stick puppets. Carry on dialogues and tell stories using the puppets the children make. Have dress-up boxes, little houses with stoves and cupboards, and a little grocery store. Have a play store or restaurant with menus that they create, so they can play make-believe games. Have boxes of toy cars, buttons, particularly rusted buttons, toys and keys; use these concrete items to make up stories about or to use to play imaginary games. This stimulates socio-dramatic play, stimulates creativity and imagination which are the beginnings of abstract thought. Model and dialogue with them to coach creative play. Create a context for their make-believe stories with these props. Create an experience for them and then spring board stories from the experience. Children make meaning from their experiences and are able to transfer that meaning into stories or narratives. Memory, sequencing and comprehension can be further supported through visual representations such as drawings, models, storyboards, concept maps, plot diagrams, charts, digital photos and smart boards.

Literacy begins in the home and community. Every child is unique and comes from a unique background, so we should not essentialize about what skills a child will have. Instead, we should focus on flexible, dynamic, multi-modal programming that can stimulate the child whatever her individual differences and varied background may be. As teachers and parents, listen to the child read something that is relevant to her family, culture or environment and make qualitative observations about how the child reads, especially her mistakes or miscues. We term this miscue analysis which can provide insight into each child's metacognitive processes used in learning to read as she approaches the limits of her "zone of proximal development" (Vygotsky, 1978). Teachers can scaffold or guide this learning through focused questions and positive interactions that aid the child to push the boundaries of her learning. Vygotsky posits that rather than using standardized tests to assess intelligence or achievement, it is preferable to do a dynamic assessment by observing qualitatively how a child solves a problem independently and then with the assistance of an adult.

Flash cards are isolated symbols with no context cues, as are workbooks. Haberman speaks of the *Pedagogy of Poverty*, referring to the impoverished curriculum materials often used when teaching the

less privileged or more challenged students, rather than using rich, relevant, exciting, engaging materials for them, as we do for the so-called gifted students. Education, indeed, is a site for seeking social justice. Learners are to find their voice, orally, textually and through multi-modal literacies, and every voice is of equal value. The generative, creative part of literacy is finding one's own voice.

Invite children to "story" through active engagement before you start to read the story. Do so by creating play situations and props as described above, or by taking picture walks through the story book and personalize the context of the book for them. For instance, ask the child, "How are you like Charlotte, in the story, *Charlotte's Web*?" Make inferences, connections and interpretations, read beyond the lines of the story. Build the bridge between something that has no meaningful context for them to something that does in order to facilitate the making of deep meaning. Take a field trip to a farm, and so forth, to understand the context of *Charlotte's Web*, by E. B. White.

### **Researcher's Interpretation and Commentary:**

Experiential, traditional learning consists of informal family and community apprenticeships in natural environments, which can be partially translated to the classroom context through the use of such devices as: manipulatives (such as paper, fabric, and blunt sticks with which to make puppets to use a characters in a story); dressing up and make-believe play using props to facilitate playing house, store, or restaurant; the use of artifacts such as old buttons, keys or toys from which to construct stories; preliminary picture walks through story books before reading and ongoing side stories while reading; and field trips to expand experiences. All of these examples create concrete experiences and connections from which to springboard students into creative and imaginative stories and narratives, the precursors of abstract thought. Memory, sequencing and comprehension can be further stimulated and enhanced through utilizing drawings, models, storyboards, concept maps, plot diagrams, charts, digital photos and smart boards. Learning begins in home and community and new learning needs to be designed to connect to and build upon a variety of backgrounds, rather than privileging a certain class, culture or environment. Rich, relevant, exciting and engaging programs stimulate students to find their own voices through generative, creative literacies.



## **Interview with a Young Person Knowledgeable about Experiential Teaching of Science in a Science Summer Camp, to a Varied Group of Students:**

From the scientific literacy perspective, the University of Saskatchewan, SI-Fi Sciences Camps, offering a range of different camps for grades 2 to 9 of varying abilities, ensure that kids of varying abilities in these camps will not be spending all day cooped up in a lab or classroom. Even computer science camps include a healthy portion of outdoor activities. A variety of experiences are provided, with an emphasis on fun, “so it sticks to them better. It sticks to them better because they have the time to do things hands-on. If you have time to do it yourself you’re much more likely to remember. Kids have a kind of kinetic [kinesthetic] memory” (quoting Rena Bartsch, Director of Si-Fi Sciences Camps, in *Saskatoon Star Phoenix*, August 4, 2010, A11).

The technology camps are a huge draw because they get to use the Lego robotics systems. In the Lego robotics systems, students make robot figures, vehicles or other movable objects out of various lego pieces, insert electronic components and then program them with hand held computers to move in a certain pattern and at certain speeds. Students enjoy holding races with their lego robotics system vehicles.

In the general science camp, kids build a vacuum “bug-catcher” and then head outside to test it in the field. They make an enclosed habitat for the insects they catch, the habitat contains various obstacles such as leaves and blocks and students observe how the ant or whichever organism they collect navigates and becomes accustomed to the terrain created. They tour the Geology building, observing the fossils, life-size dinosaur models (including T-Rex), rocks and assortment of live plants and animals. To learn the water cycle, they observe and record the different stages of cloud formation and precipitation by making a model in a plastic bottle containing water and then adding a little dry ice. They watch and record seeds they planted germinate, sprout and grow. To study buoyancy, students make paper boats and airplanes and then determine which design can support the most weights when floating or flying.

The discovery of a series of 4 billion year old metamorphic and igneous boulders of various types on the University of Saskatchewan Campus, once part of a geologically historical more northern Precambrian Shield mountain range, presumably worn down by glaciers during the last Ice Age, carried long distances and eventually deposited here as glacial till, is a topic of discovery learning in the area of geology. The nearest similar outcropping of boulders is north of La Ronge. Professor Kevin Ansdell has made a map of the location of these boulders and other stone building materials used on the campus, such as various kinds of sedimentary rocks including Greystone, Tyndall stone and Fieldstone. Various geowalks, including the boulder geowalk, are marked in different colours on the annotated and illustrated boulder guide map,<sup>120</sup> a valuable guide for parents, teachers and students. Students can explore, first hand and out of doors, products of geological history and processes at their own level of understanding.

In Veterinary Medicine students dissect cow hearts, learning about their structure and function; build model chicken feet using pieces of drinking straws and strings of different colours to see how muscles and tendons work to control and move each toe; look at slides of various tissue samples or make their own slides to view; invite a ranger from the Forestry Farm to bring a peregrine falcon to learn about that species; visit the dairy barn to examine a cow with a fistula in its first stomach chamber through which students view the stomach and contents via a camera lens or insert their arm to feel the stomach wall and contents. As cows are ruminants with four stomach chambers, students take turns feeding the cow a food pellet, waiting a few minutes and then reaching into the stomach through the fistula to withdraw the food pellet and feed it to the cow again. The cow is quite delighted with all the treats and the process causes no apparent discomfort to the cow. The cow is very tame and sometimes becomes playful and picks up a little straw to throw back at the students when it wants more food pellets. Students can feel the valve or flap separating the first stomach chamber from the next stomach chamber of the cow.

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<sup>120</sup>Kevin Ansdell, Illustrated Geologic Boulder Guide Map, retrieved from the worldwide web 02-08-2010 at: <http://artsandscience.usask.ca/geology/department/pdf/boulder%20map%20download.pdf>.

Another activity involves each student being given an unstuffed teddy bear with a velcro opening in the back through which they add their own stuffing from a supply provided. While students are otherwise occupied, instructors insert a nut or bolt in their teddy bears, x-ray the teddy bears and present each student with a photocopy of his or her teddy bear's x-ray. Students are then challenged to pinpoint the location from the x-ray and make a small incision to surgically remove the foreign object from their teddy bear and carefully suture the incision. Another activity with teddy bears involves inserting a dowel in an arm or leg of each teddy bear, then breaking a dowelled arm or leg on each teddy bear and challenging students to wrap or cast their teddy bear's broken limb. At the final show for the parents of the older group, one of the instructor's teddy bears was dunked in water, then into liquid nitrogen and the instantly frozen teddy bear was used to hammer a nail into a board. For the younger students, a banana is used for this demonstration.

A field trip to the small animal clinic is always popular and students especially enjoy watching dogs that had injured or weakened limbs exercising on an underwater tread mill used to rehabilitate and strengthen their limbs. (Note that the tread mill offers more resistance when it is immersed under water and it is the tread mill that is under water, not the dogs.)

### **Researcher's Interpretation and Commentary:**

A wealth of creative, innovative examples in science camps illustrate active learning of scientific literacies in a wide variety of areas, including a healthy component of developmentally appropriate, active outdoor activities, all incorporating an element of fun with which to engage students, focus and maintain their attention, and stimulate comprehension and memory. Examples of active learning in the science camps include: making and programming lego robotics system vehicles with which to race; making a bug catcher and insect habitat complete with barriers for the bugs to traverse while being observed; the simulated water cycle using dry ice in a plastic bottle; geowalks examining four billion year old boulders carried to the locale by glaciers from the Ice Age; a cow with a camera and fistula in its stomach for students to observe and feel the progress of food pellets fed to the cow; model chicken feet made from pieces of straws strung with string to demonstrate how tendons and muscles function to control the movement of each toe; x-rays, surgery and incisions in teddy bears implanted with nuts and bolts for the purpose; preparation and microscopic viewing of various tissue slides; buoyancy experiments using a series of weights inserted in paper boats and airplanes; observing stages of development of germinating seeds; as well as demonstrations involving liquid nitrogen. Science camp activities never failed to engage the students in meaningful learning experiences which they could retain better than those learned through textual or oral didactic approaches.

**Interview with F., First Nations adult male diagnosed with FAS, age 29, accompanied by his First Nations' Mentor, D.:**

I: F., can you tell us about your experience having FASD and what sort of things seemed to work for you as you were growing up until today and then what kind of things you experienced that really didn't work?

F: Well I was a visual person. In math class, while the teacher was explaining it to us on the chalkboard I was fine, I could follow through. But then when we were left alone to do the work and there was no one there to explain it I was just lost. I had no way to comprehend what was going on with all these numbers in front of me or what to do with them. And I found myself very frustrated and I'd react to the circumstances that were coming at me at that time.

But fortunately I had a school teacher who took the time to take me out grocery shopping. He would take me out and he would hand me money and he would give me a list of things to pickup, and he would show me how much that would cost by showing me his money and showing me the change. And he would say okay, well if this costs a dollar fifty, out of five dollars how much would you get back. And I learnt a lot in a very short time that way because it was a visual, it was hands-on, it was real, it was something that I could see, it was something that I could touch, it was something that I could work with. Unfortunately the school board found out and they told him that he had to stop because they were not insured, and if he were to get in an accident or something, then they'd be held liable. So that was ended quite shortly. But that was one thing that was very beneficial to me was that I got to see money in action, like how it went from my hand into the cashier's hand and how I got the change back. And he'd ask me all the time, okay, now he would tell the cashier, don't tell him, don't tell him, let him try to figure this out.

He was very strict on that and this helped me out because I could see, and also at the time I was trying to learn how to tell time. And this helped a lot because it separated the quarter because you think of a quarter you think 25, but on a clock you think quarter and it's 15. And when I was younger trying to understand that I could not, I just couldn't get the concept of how a quarter could be 15 and a quarter could be 25 all at the same time. It just did not make any sense to me, but when I had a visual in front of me, like he would take the clock down and put it in front of me and he would turn the hands around, the arms or whatever you want to call them, and he'd place them in certain areas of the clock and then he would ask me, okay, now what time is this? And he would mark on a piece of paper where the 15, where the 30, where the 45 and where the 60 was on the clock, so that I could know. So that when he changed it on the clock I could look at the paper and then look at the clock and know that it was, you know, 8:30, even though there's a digit right there.

But when I went on from high school into community college a lot of the things that we did in community college were hands-on like carpentry. It was something that I could touch, I could feel, I could hold a hammer and a nail and see my work being created as I'm doing it in front of me. And the teacher would help me through, although I didn't know how to measure things, I just would take the tape measure and just go like this and hold it on there and then go over to the wood and then I'd put my hand down and then I'd mark it where my thumb was, and that's how I measured things. I didn't know what all the increments on the tape measure meant, like some were bigger, some were smaller, and some were even more smaller and I didn't really know what they meant. And still today I don't know really inches, centimeters, feet and all that.

I: So the fractions are still hard.

F: Fractions are hard. I'm better at math today because of games, and dice is one of the games that my sister taught me, and we would play this game. And I remember sitting there and watching them play this game for weeks. And then one day I just jumped in and said can I play and it took me a while to add things up. I knew a 6 and a 4 equal 10, and I knew, so eventually I kinda got the concept of the dice, that numbers, you know a 6 and a 4 equal 10, a 5 and a 5 equal 10. But when I was younger I couldn't understand how those two could actually be the same.

I: There should be only one combination that equalled 10?

F: Yes, there should be only one combination, but little did I know that there are many different combinations to it which made things complicated.

I: Good. You said you liked woodworking at school. Do you do any of that anymore?

F: Not any more. I made a bench. That was the last thing that I made. And just recently I found this carving or wood burning picture that I drew my mom of the bluenose. And on the back of the picture, like it was all carved out of wood and then wood burned on and then the picture was wood burnt, I had drawn the picture, but on the back it was all penciled in backwards, it was mirrored. And my name was written on it and it was really neat. And I saw it and I don't think I've seen it in like 20 years. And I looked at it and I said, oh, my God, where did you get this? I thought you lost that, I thought dad cut that up and used it for firewood or something. And it turns out that Mom was in the basement and they were cleaning up and they found it and she brought it up and put it on the shelf. And I thought, oh my goodness, I thought that was gone. So I looked at it and I made her a bench that she used for a good 15 years, and she just bought a new bench and then gave that bench to me so I have it now. I use it as a table in my living room.

I: Oh, good. And so do you do all your own self-care, too, your cooking, washing and cleaning?

F: Yes. I do all that.

I: And you manage your own money, you pay your rent?

F: Yes, my rent is direct, it goes direct, direct deposit so it goes right to the landlord, so I don't have to worry about over spending or getting stuck in a position where I'm like, "Oh man. I owe him 50 dollars," or something, and it just goes right to him, it's just less hassle.

### **Researcher's Commentary and Interpretation:**

F. learned best from visual and experiential, hands-on learning, such as learning grocery shopping and making change when his teacher took him on a field trip to the grocery store to do his shopping. Through this experience, F. could clearly see the price of each item, the total, and the change he received. In school, he could follow math when the teacher was demonstrating it on the board, but not when left to do it on his own. Perhaps visual anchor charts clearly showing the sequence of steps to follow would have helped F. Not understanding fractions, learning how to tell time was a challenge, especially "a quarter to" or "a quarter after" the hour. His teacher showed him how to use a visual support to figure these out on the clock. He learned basic math through games, like cards and dice, but fractions were more difficult. He enjoyed carpentry at community college, learning methods of measurement that did not rely on knowledge of centimetres or inches. Complete engagement and immersion involving as many senses, modes and media as possible, especially visual, spatial, and kinaesthetic modes, facilitated F.'s learning, enjoyment and independence. F.'s speech demonstrated strong expressive language skills.

### 7.7.1.2 Holistic Language and Literacy Approach to Integrating Drawing and Other Visuals, Reading, Writing and Stories

Evolving trends such as the movement from whole language to holistic language and literacy, and then to holistic education, have commonalities and refinements as these approaches transformed in response to both critiques and changing conditions. Chronologically, the Whole Language Movement precedes the others, influenced by various ideas from the 16<sup>th</sup> century up to and including the works of John Dewey in the 20<sup>th</sup> century, incorporating a focus on the learner over the content (but not unduly minimizing content), as well as the importance of enjoyable, meaningful learning experiences combined with use of the vernacular language of the child, and the role of the teacher as co-learner and guide. Noam Chomsky in the 1950's and '60's, attacked B.F. Skinner's behaviourism, and Kenneth Goodman, intrigued by Chomsky's notions of reading and oracy as components of an overall process of language development, conceived the naturalistic whole language approach, partly in response to the so-called emerging knowledge explosion. In such a context, learning had to be selective, as there was no longer a well-established canon of what to learn. Rather, students needed to experience the use of language to solve problems that were meaningful to them and to take more control of their own learning as choices expanded exponentially. As the content expanded, a focus on the process of learning became more important. The terms language, teachers and learners were reframed to adjust to the new reality.

In the 1950's and 60's, the work of Jean Piaget, a developmental psychologist, revealed that children on their own are active learners, developing their own conceptualizations of the world around them and learning language, both oral and written, with which to express these concepts to others. They do not learn in isolation, but learn in a social context of family, community, peers and teachers, whether in play, on a field trip, or in a didactic setting. Children learn language through hearing it and using it, and likewise learn to read through the experiences of being read to and through reading itself. Kenneth Goodman and Frank Smith, beginning in the 1960's and continuing to develop their approaches to the present day, begin to view reading as an integrated process of interaction, a kind of transaction, among reader, text and language. Students immersed in reading children's literature and experiencing the combined influences of being read to, as well as the nature of storytelling and narrative, were advantaged in both language development and learning to reading. However, critics contend that while oracy or oral

language is natural to the brain and has been for millions of years, reading is not and requires instruction. The instructional approach advocated by Goodman, an educator, and Smith, a psycholinguistic, became one of stimulating meaningful experiences through play, activity, story, or fieldtrip, drawing a picture of the experience, and telling a story based on the picture, followed by writing the story (at first with the teacher's assistance) and then finally reading aloud the story they have written. This integrated method may have many benefits for individuals with FASD, as it is active and engaging, scaffolding such common deficits for them as memory, sequencing, abstract thought and attentional deficits. Smith included the three tiers of cues required for learning to read: vocabulary, semantic and syntactic context cues, and phonics. Phonics was a third tier, confirming cue to be taught as the need for it arose in the reading context.<sup>121</sup>

As with any method, critics arose. Some were concerned alleging that teachers were doing most of the scribing in this instructional method. Some raised questions about the relationship between oral and written language, maintaining the separate nature of the writing process which could take forms and serve functions not directly related to oral language. Alvina Burrows stressed that children needed to write about their own experiences in a supportive environment and as a result of these concerns a stronger emphasis on learning to write was incorporated into the whole language movement. Daily journal entries were introduced, extending to incorporating writing and composition for varied functional purposes in all subjects in the curriculum, integrating all language areas while studying and understanding the relations between them. The concept of integrated language arts extended to integrated curricula, including sciences, history, mathematics, and so forth, along with the language arts. The artificial isolation of content in subject areas did not seem appropriate at the school level. With schools becoming more diverse in race, ethnicity, linguistic and cultural background, as well as socio-economic status, education needed to become more pluralistic, inclusive and dialogic, incorporating collaborative group settings into the process. Awareness of differing learning styles extended the approach to holistic literacies which are multi-modal, not solely oral, visual or textual.<sup>122</sup>

A narrow accountability ethos was countered with a re-examination of a range of evaluation issues for both teachers and students in whole language or holistic literacy programs,

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<sup>121</sup> Yetta M. Goodman, "Roots of the Whole-Language Movement" (1989) 90(2) *The Elementary School Journal* 113-127.

<sup>122</sup> *Ibid.*

with the realization that valid decision making had to be in the hands of teachers and learners on the scene, not imposed from above or from outside.<sup>123</sup>

Maori education initiatives attempted to integrate the school more fully with the community, culture, Elders, and families, along with whole language or holistic language and literacy approaches. Such integration is particularly important in view of the equivalent of painful residential school experiences (including removal from family, community, language and culture) as well as the importance of family, community and cultural literacies in strengthening and expanding children's connection to school and to learning. Maori world views and Aotearoa identity are embedded in the Wānanga contextualized approach.<sup>124</sup> Such a learner-centered, community-based approach is integral to situated, social practice discourse that is well-matched to Maori needs and aspirations, but at odds with a narrower, technical or economic-based learning discourse often advanced by the state funder.<sup>125</sup>

Payi Linda Ford, a *Rak Mak Mak Marranunggu* researcher from the Finnis River and Reynold River regions of the Northern Territory, Australia, strives to integrate Aboriginal cultural context, traditional knowledges and practices, including *Rak Mak Mak Marranunggu* epistemology and ontology involving a powerful spiritual connection to land, into academic landscapes of imperialistic ideology within which *Mak Mak* or *Tyikim* Indigenous education has been enclaved. Spiritual concepts of narrative and landscape are drawn upon both metaphorically, and in pedagogical practices and research protocols, to construct teaching and learning experiences for the advancement of *Tyikim* interests.<sup>126</sup> Payi Linda Ford notes:

We have survived all that was done to us by invaders, assimilationists, and interventionists, and we continue now and we shall at last walk country in peace and freedom.<sup>127</sup>

Ford elaborates:

The understandings of the spiritual connectedness and our practices of relatedness have drawn on *Pulitj*, our deep *awa mirr* spiritual philosophy that nourishes us in our country. This philosophy gave us our voice and our presence to act in our own ways of knowing

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<sup>123</sup> *Ibid.*

<sup>124</sup> Linda Leach, Nick Zepke, Penny Haworth et al, "One Size Does Not Fit All: How Five Tertiary Education Organisations Embed Literacy, language and Numeracy: Case Study Findings, the Wananaga Study" (June 2010) at 3, accessed from the world wide web Nov. 26, 2010 at [http://www.educationcounts.govt.nz/publications/tertiary\\_education/7](http://www.educationcounts.govt.nz/publications/tertiary_education/7).

<sup>125</sup> *Ibid.* at 7.

<sup>126</sup> Payi Linda Ford, *Aboriginal Knowledge Narratives & Country: Marri Kunkimb putj putj marrideyan* (Mt. Gravatt Qld: Post Pressed, 2010), ISBN 1921214716, 9781921214714.

<sup>127</sup> *Ibid.* at 5.

and being on the landscapes created by the Western bureaucratic systems of higher education in Australia, to bring forth our *Tyikim* knowledge systems to serve our own educational interests.<sup>128</sup>

The prime obstacle she identifies as western ideology which shapes the discourse and discursive practices of teachers, students and managers in these western institutional enclaves, rendering any alternative ways of thinking or practice alien and not worthy of consideration.

The following five interviews illustrate experiences with holistic language and literacy, including attempts to integrate drawing, other visuals, field trips, or other experiences into reading, writing, telling stories and communicating; this theme comprises the second sub-theme under Multimodal Learning. The interviewees include: an adoptive mother of a boy with FAS and a girl with pFAS; an educator who has experience working with children who have diagnoses within FASD, as well as those suspected of having a diagnosis within FASD; a female guardian of a First Nations boy prenatally exposed to alcohol; an Aborigine woman from Australia who is both a mother of two adult children who have diagnoses within FASD, as well as grandmother of seven children who have been prenatally exposed; an Australian researcher who describes her work using visual communication with the Koori of New South Wales to examine perceived efficacies of Koori education provided to their children. Some selected commentary is also included.

**Interview with PA, adoptive Mother of Mark and Mary, two children who have diagnoses within FASD, Mark with FAS and Mary with pFAS. Mark was 4.5 years of age when adopted and is 18 years old at the time of the interview; Mary was 27 months old when adopted and 15 years of age at the time of the interview.**

PA: Mary likes to journal now and keeps a diary. This has definitely helped develop her ability to write. She also likes to write stories and has a special book for this.

I: Does she use drawing or sketches or pictures when reading, writing or listening?

PA: No, although both Mary and Mark love to doodle and all of their school pages have drawings in the margins, they are the same doodles again and again. It was hard for them to draw anything original where they might have to conjure up images in their minds . . . out of the box stuff.

I: Pictures or drawings can help contextualize the story for them and help them to remember the story . . . Does Mary use drawings or sketches in her journal or diary? What are the stories like that she writes? What are the topics or themes? Does she read them aloud to you or show them to you?

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<sup>128</sup> *Ibid.* at 9.



PA: She writes about lost animals and children who are sad. She often reads them to us but I often search them out as I want to keep a handle on these depressing themes. She does not typically use drawings in her diagrams in her diary. . . . Our family facilitator through the Human Services office has been invaluable for my husband and I, to help us see clearly what has happened along the road, and for Mary who continues to have weekly sessions with this individual to help work on self-esteem issues and other things that crop up.

**Interview with an Educator who has many years of experience in the classroom as a teacher or teacher supervisor, working with children, some who have diagnoses within FASD, or diagnoses are strongly suspected; as well as she has experience teaching future educators:**

Children who do not like to draw sometimes enjoy finding pictures on the internet, printing them and using them in their stories. A group of boys I worked with liked to find pictures of cars and trucks from the internet to use in their stories about vehicles.

**Interview with HM, sole Guardian of a First Nations boy, Robert, who was prenatally exposed to alcohol**

HM is the sole guardian of Robert, an alcohol exposed First Nations child who came into her care at the age of 7 (Grade 2) and was age 16 (Grade 10-11) at the time of the interview.

I: Can you tell me about Robert's learning experiences?

HM: In Grade 4 in Montreal there was finally a good teacher. Her strategy was to get the kids drawing pictures which helped overcome their fears. By Christmas they started adding diary entries. Grade 5 and 6 had an even more gifted teacher who only saw the best in the kids and got great performance from them.

In Grade 3 in Montreal he was put in St. Raphael's School of the English Montreal School Board. This was supposed to be a remedial facility but it turned out to be a dumping ground for kids that teachers found to be trouble. (One class mate was an emotionally immature Chinese boy who finished the math too quickly then wandered around. He later became a chess champion in Quebec.) The children in this school were constantly having emotional melt-downs such as I have never seen before. Most were because of a point system that took off points every time they did something wrong. The worst melt downs happened when a kid managed to get to the end of the day with a perfect score then lost 5 points while putting on his coat. There was no orderly presentation of the subject matter that had been missed & a lot of very negative behavioural examples. He was on the bus for 3 hours a day and there were also a lot of behavioural problems there.

These teachers were in a remedial class at Westmount Park School which, unfortunately has since been cut. The grade 4 teacher was big on the Magic Tree House books. I could never get Robert interested when I read, but I once saw this teacher reading with the children seated around her. She was so absorbed and enthusiastic, it had to be catchy. I could not have read that kind of material with such

enthusiasm. She taught phonics and every kid had the "Dolch list" of words "all good writers know" to help with their writing...These were high frequency words...so they could copy them. One thing Robert really liked. When on a trip to Newfoundland, we had a blue berry book, *Blue Berries for Sal*, and went blueberry picking. We went on a field trip, picked the berries, talked about the experience, read the Blue Berry Book and drew and wrote about picking blue berries.

**Interview with LH, Aborigine woman from Queensland, Australia, birth mother of two adult children who have diagnoses within FASD and grandmother of seven children who have been prenatally exposed to alcohol**

The following interview with an Aborigine woman from Australia illustrates well the synergy that can occur between listener and speaker, yielding insights and changing the ways in which speaker and listener characterize the encounter, leaving both transformed in mind and spirit. An apt analogy is the story of a Kokum or Grandmother who was an Indian Residential School survivor. She wanted to finally tell her stories because, then, maybe, her children and grandchildren would learn what she had endured and would then be able to forgive her for failing them. She came to realize, that far from being a failure, she had held onto her humanity and Aboriginal identity despite all the trauma she encountered. In that sense, she came to the interview as a survivor and walked out a warrior.<sup>129</sup> As researcher, I have tried to preserve the holistic context of her story, because she is the only Aborigine person from Australia to be interviewed in this study, who is both a mother and grandmother of children with FASD, as well as a researcher on the subject of FASD. She has two daughters who have been diagnosed with ARND and seven grandchildren who have been prenatally exposed. LH was 69 years of age at the time of the interview. Some interviews were particularly chaotic, with ordinary life, noise and interruptions going on in the midst of the interview, and this one is a case in point.

I: This is L. from Queensland, Australia, speaking with Rae Mitten, researcher at the University of Saskatchewan in Canada. L. is a Aboriginal mother and grandmother of children with FASD. I heard L.'s presentation today and there were many interesting things she mentioned about FASD among the Indigenous people in Australia and her research and work with them. And one question I'd like to ask you about L., if you could enlarge a little bit on your health research with the people, your health policy research with the Indigenous people. It seemed to me it sort of reflected what we call the whole language and holistic language and literacy process here.

L: I call it a holistic approach.

I: Holistic approach. And have you heard about whole language teaching?

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<sup>129</sup> Rupert Ross, "When Survivors Become Warriors" (2010) 15(2) JAH 1 at 1.

L: No. Could you explain that to me?

I: Okay. Well, that's a system we use here in Canada especially with minority and First Nations children, and it's really engaging for them. They tell their stories from their own experiences. First, they may draw pictures or take pictures depicting their story and then we write their little story in words. They learn to read their own stories and then they learn to write their own stories from their own contexts or environments and to read them to others if they wish.

L: Alright.

I: So they're really engaged and it's culturally relevant and personally relevant to them..

L: Well, that's pretty much similar to what we developed in our health literacy program. We use their stories, they give stories about their issues whether it be alcohol use or family violence, poverty, or their experiences with having a child with FAS. So we use their stories and then we break their stories down to help them understand why they behave the way they do, as individuals and towards each other.

I: Do you say to them, tell me a story about alcohol use, or do you let them pick their own topic?

L: Yes, they pick their own topic.

I: And yet you can still use this kind of insightful method with them that other researchers would say that they're not capable of this kind of technique?

L: Well, we use pictures. We get them to draw the pictures and then write the story under it.

I: Depending on their literacy would be the length of the story, or just a few key words.

L: Or if they talk it out, you know, and we just, it's mainly, we're very visual. We don't like a lot of words.

I: And then would you give them the book of their story to keep?

L: Well they can but they don't really, they don't have a lot to do with it, those with FAS. But those without, we give them their books, they've got baby books.

I: And then do you give them their own books that they. . . have created.

L: Oh, yes.

I: To get the results for your study, do you analyze all their stories or how do you get the results for the conclusion of your study?

L: Well, I do like an ethnographic section in the reports and . . .

I: Okay. So you may quote from some of these stories?

L: Yes. And I can break the stories down and draw out information that I can analyze qualitatively, and it's usually a qualitative analysis of the stories.

I: Have you done any quantitative at all?

L: Not on the stories, no.

I: So in the qualitative analysis you look for themes and you quote from the stories to illustrate the themes.

L: Yes.

I: And have you found similar themes in the stories?

L: Well, yes, the majority of people in my studies have all been sexually abused as children; they all experience family violence, poverty, no education, no jobs. Because our aboriginal communities, our reserves, are located geographically where there is no employment and they're not in rich wealthy areas where you can get employment, except for two communities where they're mining bauxite. So they've only just now got a contract to say, well if you want the bauxite off our land you have to employ our people. But other than that, they're not economically viable areas that we live in. And due to the racism, they are not being employed anyway, even if they are near somewhere where they can get employment. And this all feeds into that drinking behaviour.

I: Yes, they're bored and there's no future and that type of thing.

L: No, there is no future.

### **Researcher's Commentary and Interpretation:**

L. health research with her people is a variant of the holistic literacy and language approach, involving sharing an experience through visuals, such as a picture or drawing, telling a story about the visual and then writing a story under the visual, which may be only a few lines in length, depending on the individual. Many of the experiences concern alcohol, domestic violence and sexual abuse in a context of Aboriginal poverty and unemployment. The process is part of a healing journey. In her research, L. analyses the stories quantitatively for recurring themes.

### **Christine Evans, University of Technology, Sydney Australia, "Yarning and Painting," Presentation on December 17, 2009, College of Education, University of Saskatchewan, describing her action research project in visual arts curricula with the Koori of New South Wales:**

The Aboriginal people of New South Wales, Australia, call themselves Koori rather than Aborigines. Consequently, learning centres there are called *Koori Rooms*. As researchers, if we had wanted written answers or oral interviews, the Koori community would have been "shamed out" as they have anxiety about their literacy levels and about the general school context. In such situations, researchers cannot just fly in and out again, they must get to know the people and their ways and build trust. Our key research question was what worked about the Quality Teaching of Koori in their schools. The Koori painted canvass to answer this question. As such, the communication process became visual dialogues or visual communication, a kind of "conversation over canvass." Painting served an agency to generate visual communication. Education becomes more complete as we increase the range of ways in which we describe, interpret and evaluate the world to recognize the uniqueness of communities and landscape.

Yarning is telling stories, personal truth telling, respectful of oral communication about Indigenous living experiences. As such, yarning is associated with ceremony. Some Koori were given the right to paint cultural stories associating with aboriginal dreaming about tracts of land, whale dreaming stories, family dreaming, inclusion of sacred sites, such as Ayers Rock and local sites, and how to care for these sites, totem heritage, motifs and body art, without commodification or piracy. In the long interim between Captain Cook's instructions to destroy the Indigenous People and the Rudd Government Apology for the Stolen Generation, a legacy of appropriation and piracy ensued. Inclusion of Indigenous art and culture in the curricula was repeatedly endorsed by the current research participants, while at the same time protecting it from appropriation and piracy. Care was taken neither to appropriate nor contaminate cultural transmission of knowledge, as it is held collectively by the community. Images related to family dreaming were often incorporated into carpet designs by the families. Litigation in the so-called "carpet" case followed attempts to appropriate and commercialize such designs.

Aboriginal cultural knowledge and practice were incorporated into planning the research methods as a benefit-added experience, respectful of participant's deep knowledge, collaboratively creating participation that was not tokenistic, but authentic and meaningful. Research was also done in a location that was culturally familiar to participants. Thus researchers attempted to bridge the tension between the

University's expectation, on the one hand, and what was culturally appropriate for the community, on the other, while privileging Indigenous voices and attempting to control for mainstream bias. A convergence between the two worlds was sought through reciprocity in the research journey. During the research process, traditional aboriginal foods were served and the uniqueness of landscape and communities, as well as the agency of the Aboriginal people, were honoured. Ethical protocols focused on research processes that reflected Indigenous self-determination and that were alive to a culture of "seizing the moment."

### **Researcher's Commentary and Interpretation:**

Another research project with Aboriginal people in Australia, in this case the Koori of New South Wales was collaboratively designed to evaluate Indigenous learning centres in the schools from the perspective of the Koori. The Koori participants responded by painting canvass in a location that was culturally familiar to them, rather than providing written or oral answers in a school setting as they had anxiety about their literacy levels and about the school context. Thus painting was their form of yarning or story telling about their art and culture which they would like to see respectfully incorporated into the schools, without either appropriation or contamination.

#### 7.7.1.3 Visuals, Art and Applied Arts

Visuals, such as drawings, paintings, models, sculptures, photographs, or film can be very motivating for individuals with FASD, scaffolding memory and abstract thinking deficits while creating meaningful context for learning. Visuals can also be used to cue and organize activities in the classroom or home. Examples include visual schedules to prepare students for daily routine and transitions, colour coding of student's books and binders, highly organized colour-coded shelves, visual clocks to enable students to observe the passage of time and clearly see how much time is left to complete a task,<sup>130</sup> visual anchor charts to sequence a series of steps in a

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<sup>130</sup> Visual clocks or timers are designed to help students understand, "how much longer;" no other teaching aid reinforces the concept of elapsed time like a visual clock. Visual clocks can take the form of hour glass sand timers (sand from an upper vertical glass bulb slowly passes through a narrow neck into a lower vertical glass bulb) or mechanical or electrical timers with moving red dials or red disks. The disappearing sand or the disappearing red disk allows students to "see" time elapse without knowing how to "tell" time. The visual clock is perfect for setting

procedure, coloured tape to delineate areas of the floor as a particular student's space rather than someone else's as students with FASD may not understand boundaries of personal space, and curtains to screen classroom clutter or displays that may become distracting or over-stimulating to students with sensory issues.

Art and Applied Arts, being hands-on, more concrete and involving more senses, often come more naturally to individuals with FASD and give them broader scope to express themselves. Being able to move around more freely in these activities they become less restless and better able to regulate energy levels. Working with clay, plasticine or paper mache may help address some tactile sensory issues, thus having a calming effect. These activities may also improve fine motor skills, whereas physical education and dance may assist with developing gross motor skills, coordination, as well as self-regulation, and along with social skills such as team work and taking turns. However, supervision is required for all of these activities. In general, students with FASD are concrete learners and remember better when they can use their senses of touch, sight, taste and hearing. Experiential learning, with supervision, has been shown to be very effective with FASD learners as it involves many senses, while visual learning is generally more effective than oral learning as individuals with FASD are usually stronger in processing visual stimuli than in processing auditory stimuli. The less concrete and more abstract material is, the more difficult it becomes for students with FASD to learn and remember. Generally these students remember and learn what they see, do and experience directly.

Appropriate work-experience placements for students in junior and senior high school, as well as post-secondary, may be beneficial if related to student's areas of strength and interest. However, work-experience activities need to engage the student's interests and be varied to a certain extent. One young woman spoke of doing a work placement in a florist shop where day after day she was given the sole task of cutting stems off roses. Also, students may need assistance in getting to the work placement and being on time. Sometimes taxis are contracted to pick them up in the morning and take them to work, which may include awakening them, as they may have problems with their internal clocks or their sleeping and waking cycles. For this reason, sometimes work placements later in the day are more successful.

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time limits, managing transitions and training students to understand and make better use of available time, making every moment count.

Applied arts translate aesthetic principles to the design or decoration of functional objects of everyday use, including but not limited to industrial design, bookmaking, illustration, printmaking, commercial art, clothing design, food preparation and presentation, to name a few. The applied arts are usually contrasted with the fine arts (drawing, painting, sculpture, fine printmaking and so forth), which are seen as serving no utilitarian purpose beyond providing an aesthetic experience. The importance of visual arts and applied arts in the lives and learning of individuals with FASD is demonstrated through the following three interviews: one with a First Nations adult male with FAS, one with the sole, female Guardian of a First Nations boy who was prenatally exposed to alcohol, and one with the adoptive mother of an Aboriginal boy with a diagnosis of FAS.

**Interview with F., Young First Nations adult male who has a diagnosis of FAS, accompanied by mentor, D.**

I: F. can you tell us about your experience having FASD and what sort of things seemed to work for you as you were growing up until today and what kind of things you experienced that really didn't work.

F: Well I was a visual person. I needed to, the teacher, for example through math class, while the teacher was explaining it to us on the chalkboard I was fine, I could follow through. But then when we were left alone to do the work myself and there was no one there to explain it I was just lost. I had no way to comprehend what was going on with all these numbers in front of me or what to do with them. And I found myself very frustrated and I'd react to the circumstances that were coming at me at that time. And fortunately I had a school teacher who took the time to take me out grocery shopping. He would take me out and he would hand me money and he would give me a list of things to pick up, and he would show me how much that would cost by showing me his money and showing me the change. And he would say okay, well if this costs a dollar fifty, out of five dollars how much would you get back. And I learnt a lot in a very short time that way because it was a visual, it was on hands, it was real, it was something that I could see, it was something that I could touch, it was something that I could work with

**Researcher's Commentary and Interpretation**

Visual anchor charts to sequence the series of steps in mathematical operations or problems might have served to scaffold some of F.'s learning difficulties in math class, especially when left to do the work independently. Supervised experiential learning in the grocery store proved beneficial, as F. was actively engaged in a process that was visual, tactile,

concrete and hands on. F. had a grocery list and a certain amount of money, and for each item selected F. would be asked to figure out the change remaining after purchase. By actually walking through these steps, he understood how the process worked and was able to shop for his own groceries independently.

### **Interview with HM, Guardian of Robert**

HM is the sole guardian of Robert, an alcohol exposed First Nations child who came into her care at the age of 7 (Grade 2) and was age 16 (Grade 10-11) at the time of the interview.

Robert has talent and did many interesting things. In grade 4 in Montreal, Robert worked with another student to make a life-sized man out of money and then an Egyptian mummy he did himself with lines so clean that it looked like the real thing. One project took a National Geographic photo of a mask, cut it in half & Robert drew the other half so well it looked professional. Projects also involved conveying information with pictures.

In grades 5 and 6, Ms. Kiley made sure that Robert got recognition in the areas where he excels. His drawing was chosen for the cover of the school year book the year he graduated from primary school (over 60 other kids) and he got an award for Art. He did not apply for choir but when they were looking for singers the choir teacher heard he had a good voice and asked him to join. He was also asked to do a solo dance in the school concert, but he declined my offer to pay for classes with that teacher.

### **Researcher's Commentary and Interpretation:**

Robert excelled in fine arts, whether visual arts, music or dance. He was specially selected to be in a choir, a dance group (which he, however, declined), and to design the school's yearbook cover, as well as given awards in Art. Not only did he express himself and learn from these activities, they enhanced his self-image giving him a sense of achievement. These activities being "hands on" likely also helped with sensory integration and self-regulation issues.



### **Interview with JD, adoptive mother of MN, a young Aboriginal Adult Male, age 27 years, with an FASD and ADHD**

I: What was the best learning experience for your son?

JD: The best time in my son's life was when he went to technical school to take commercial cooking; he even ended up receiving his diploma on time, getting in his apprenticeship hours and earning the Red Seal (interprovincial journey person's qualifications), passing the national journey person's test the first time around when in his early twenties, one of a few in his class to do so. He said he could learn because it was hands-on, learning by watching and then doing, or working side by side with the instructors. He could arrange the food in an artful presentation on the plate and the taste, flavours and textures were amazing. His sense of aesthetics and creativity really came out in his choices, cooking and presentation. He could plan a menu that was interesting and novel, shop for the ingredients, prepare it, cook it and serve it. He took great pride in doing so. There were no behaviour problems there as he was fitting in, enjoying the learning environment, making friends and getting along with the instructors, whereas in the primary grades especially he was often excluded from the classroom for behaviour problems related to ADHD and FASD. He had taken food preparation and cooking classes in junior high and high school which he enjoyed.

His only problem was getting up in the morning to get to class and baking class started very early. I would get him up and drive him to class every day and he would take the bus home after class.

He had trouble passing his final math exam in order to receive his diploma in commercial cooking and had to do a re-write. His Dad studied with him every day, going through the various math problems in his course materials. One day he could do them and the next day he could not, but they persevered. Finally the day of the rewrite came and we all anxiously anticipated the results. A call came from the technical institute, from the head of the commercial cooking diploma program, announcing that MN had passed his final math exam with a perfect mark! He had the motivation to persevere because he really liked the course and the instructors.

Once in the workforce, he derived less pleasure as many of the work places gradually moved to ordering in commercially packaged frozen food so there was not that opportunity for skill and creativity to be exercised in the cooking and the results were not the same, more of an assembly-line approach. It was not enough creative, positive stimulation to really keep him going, and he lost his passion. He has tried a number of cooking positions but none appealed to him for long. However, he still cooks for us at home on occasion and can make even ordinary ingredients into a very tasty meal. He is thinking about working in the field of commercial cooking again, but selecting a venue where he has a little more scope to actually cook from scratch. He also spent some time working with a dry waller and a plumber and picked up those skills quickly, as well.

He has a partner, and two young children of whom is he very fond, but after several bouts with addictions is not living with them. While experimenting with substances, he was in trouble with the law, both as an adolescent and as an adult. He attended residential addiction treatment last summer. Although he is a high functioning individual with FASD, he experiences problems with long term commitments. He cannot seem to appreciate the long term benefits of persevering in relationships whether primary or vocational, nor appreciate the consequences of not doing so, making his life unstable and dysfunctional, in many ways. Hopefully with experience and greater maturity this will improve. He did see a medical expert and tried medications (including Ritalin when a child and youth) but when doing shift work some medications were problematic, and then not advisable while using substances. Despite his many talents, his life remains somewhat chaotic. Due to disruptions in his early life, including time in foster care as a child and as an adolescent, and a later adoption in a family group of three siblings with FASD, he appeared to have attachment issues, along with FASD and ADHD, all of which are challenging, and more so in combination. He was diagnosed with FAE at age six, as he was prenatally exposed to alcohol, but less visibly alcohol affected.

### **Researcher's Commentary and Interpretation:**

Apprenticeship and trades, with the hands-on, experiential component worked well for MN, especially during the learning phase. Joining the workforce proved more challenging, and perhaps more initiatives are needed around making the transition from classroom to workplace, selecting the proper workplace niche for each individual, and workforce retention for at risk individuals with an FASD, ADHD, or both. Certainly, the dynamics of an educational setting are different from the dynamics of a workplace. Individuals with FASD or ADHD may need assistance in how to keep a task which becomes routine interesting and engaging, and how to deal with workplace frustrations. MN did have attention deficit difficulties, difficulties focussing, and was hyperactive, so perhaps some of the boredom or restlessness he experiences at work is related to those factors. Apparently he does not do a lot of long term thinking about the future benefits of keeping the same job, including salary increases, benefits, job security, and a good employment record for promotions or future employment, and tends not to foresee the pitfalls of quitting one job when bored or frustrated before finding another, or alternatively, he is aware of these factors but makes choices impulsively. When he has built up some benefits, he tends to quit work and use up the accumulated benefits, but then becomes discouraged when he is not progressing to more responsible positions. Despite being high functioning in many ways, he can be dysfunctional and unstable, but depending on the cause,<sup>131</sup> this may even out as he matures, or with treatment, and hopefully his life will become less chaotic. However, as a further hurdle, individuals with FASD, ADHD and substance use are challenging to get to treatment. They may make appointments, or have them made for them, but because of the characteristics of their disabilities getting there is another issue.

Counter-intuitively, behavioral problems are more prominent in youth exposed to alcohol who have a low dysmorphology score, that is those who are not visibly alcohol affected, which underscores the importance of care and services for those with prenatal exposure who are less visibly affected, as well as the consideration that many in this category are undiagnosed. The longer the time such youth have spent in residential care is a second factor which increases risk for behavioural problems. Children with a diagnosis within FASD in foster and residential care are at greater risk for behaviour and psychiatric problems, attachment disorders, poor interpersonal relationships, as well as rule-breaking, aggressive behaviour, poor school

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<sup>131</sup> Behavior associated with conduct and personality disorders tends to alleviate with age.

performance, and trouble with the law. Staff turnover, staff to client ratios, and frequent moves in residential and foster care can limit the close, continuous relationship with caregiving adults that children need to develop properly. As a consequence, neurological sequelae of FASD in combination with non-optimal rearing environments can place these children at risk for impaired behaviour control and coping problems. As a consequence, children growing up with FASD can face accumulating risk environments during development, increasing their overall vulnerability.<sup>132</sup>

The number of multiple comorbidities diagnosed in children with FASD can also add layers of risks. FASD, ADHD, and alcohol and other drug use, in combination, can be resistant to treatment. Problems with childhood ADHD continue to persist into adolescence and adulthood, and hyperactive, impulsive, inattentive individuals with ADHD have a strong predisposition to substance abuse as a form of self-medication. Cognitive behavioural therapy and semi-structured group therapy are not very effective with this cohort, but brief strategic therapy such as flexible, engaging interventions and motivational interviewing may have some efficacy, as well as treatment programs with monitoring, supervision, and consistent enforcement of rules, ever mindful of underlying disabilities. A high level of functioning does not insulate these individuals from problems, and, in fact, may increase their levels of frustration when achievement does not match their abilities.<sup>133</sup>

The U.S. incidence of ADHD is four per cent, and the global incidence is eight per cent while 50% of adults with ADHD develop a substance abuse disorder, including a more severe course of substance abuse, and the risk further increases for those with ADHD who have been involved in trouble with the law. ADHD causes impairment in interpersonal areas, as well as in occupations, school and family. Understanding ADHD and its treatment is an essential underpinning of risk reduction for substance abuse. As the ceiling of risk for alcohol and other substance abuse is so high for ADHD alone, it limits the additive effects of other factors such as

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<sup>132</sup>Ase Fagerlund, Ilona Autti-Ramo, Eugene H. Hoyme, Sarah N. Mattson, and Marit Korkman, "Risk Factors for Behavioral Problems in Fetal Alcohol Spectrum Disorders," accepted for publication 10-05-2011 in *Acta Paediatrica*, at 2-10. Accessed from the worldwide web 05-96-11 at <http://onlinelibrary.wiley.com/doi/10.1111/j.1651-2227.2011.02354.x/pdf>.

<sup>133</sup>Bradley H. Smith, Brooke S. G. Molina, and William E. Pelham, Jr., "Clinically Meaningful Links Between Alcohol Use and Attention Deficit Hyperactive Disorder" (2002) 26(2) *Alcohol Research and Health* 122-129; and In-Person Conversation with Dr. Olubusola Okunola, Consultant Psychiatrist, Saskatoon Inner city, 06-06-11.

family history, cognitive dysfunction, or neuropsychological/executive function deficits, and thus ADHD should be the first priority for treatment.<sup>134</sup>

In order to avoid the pitfalls of over-promising and under-delivery, parents and caregivers should be informed that to achieve even modest success with challenges one needs the right personnel, delivering the right treatment program, at the right time in the individual's life and in a supportive community, and as the stars do not always perfectly align, failure is possible.<sup>135</sup> Learning from failure occurs in all human endeavours, and particularly when working with the FASD and ADHD cohort. Those involved can expect to incrementally “Try Again, Fail Again and Fail Better,” and even the most successful have done that:

I missed more than 9000 shots in my career. I've lost almost 300 games.  
Twenty-six times I've been trusted to take the game-winning shot . . . and I missed.  
I've failed over and over again in my life. And that is why I succeed.

Michael Jordan<sup>136</sup>

### **7.7.2 Sensory Integration Issues, Information Processing Speed and Navigating Transitions**

Sensory integration is the integration of all the different sensory modalities in the brain to help us perceive, learn or perform even simple tasks. It origins can be traced back to the work of Wilder Penfield (1891-1976) pinpointing areas of the brain that respond to various types of stimuli, whether visual, auditory, olfactory, kinesthetic, proprioceptive (sense of one's position in space, vertical or horizontal) or vestibular (sense of balance). Penfield's work was an

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<sup>134</sup> Martin Korn, “Interview with Timothy E. Wilens” (May 11, 2004, New York) Medscape, accessed from the worldwide web on 06-06-2011 at <http://www.medscape.com/viewarticle/477487>; and Timothy E. Wilens, MaryKate Martelon, Gagon Joshi, Clancey Bateman, Ronna Fried, Carter Petty, and Joseph Biederman, “Does ADHD Predict Substance-Use Disorders? A 10 Year Follow-up Study of Young Adults with ADHD” (2011) 50(6) *Journal of the American Academy of Child and Adolescent Psychiatry* 543-553. Children and adolescents with ADHD (n=268) and a control group without ADHD (n=229) were followed prospectively and blindly over a 10-year follow-up period onto adult years. During this follow-up they were assessed for psychopathology and substance use disorders. ADHD was found to be a significant predictor of substance use disorders and cigarette smoking. Within ADHD, comorbid conduct disorder and oppositional defiant disorder were also found to be significant predictors of cigarette, alcohol and drug use disorders, but no clinically significant associations were found for social or family environment factors or for cognitive functioning factors.

<sup>135</sup> Aubrey Fox and Emily Gould, eds., *Daring to Fail: First Person Stories and Criminal Justice Reform* (New York: Centre for Court Innovation, 2011) citing Joan Petersillia at 107.

<sup>136</sup> Greg Berman, *Try Again, Fail Again, Fail Better: Lessons from Community Courts* (National Institute of Justice Seminar, Centre for Court Innovation: New York, April 21, 2011) accessed from the worldwide web on 08-06-11 at <http://www.nij.gov/nij/multimedia/presenter/presenter-berman/>.

inspiration for Jean Ayres (1920-1989) and her theory on sensory integration. Ayers posited that in order to fully develop sensory-motor and cognitive skills, the brain had to process continuing feedback from all the senses. At birth, the brain is immature and integration of sensory stimuli is not complete but develops with maturity, although the immaturity persists in a number of disabilities, such as ASD and FASD. Individuals in which sensory integration is not complete may exhibit sensory defensiveness, including tactile defensiveness, or may experience an under-responsiveness to some stimuli; they may have an aversive response to movement, experience gravitational insecurity if not upright, or not correctly perceive where their body is in space and experience balance, coordination and postural problems. With proper control of stimulation, affected areas of the brain can mature or adapt and the brain can begin to function as an integrated whole.<sup>137</sup> Some aspects of Ayres' Sensory Integration Therapy (SIT) remain controversial and unproven, but some are acceptable and widely used, or used in modified form.<sup>138</sup> Some of the theory is incorporated into the theory of Self-Regulation, but it is also dealt with separately in detail in the various brain domains related to FASD and so will be dealt with as a separate theme herein.

Interviews with individuals, as well as a family group, who have had experience with sensory issues and FASD follow. One of the individuals interviewed is an adult First Nations male with FAS, accompanied by his mentor who is also participates in the interview, one is an adoptive mother of two children with FASD, and one is a family group of two parents and three children all prenatally exposed to alcohol, including the woman's mother who lives with them. The interviews illuminate how sensory issues are manifested in their lives and the various strategies used to deal with these issues. These issues are relevant across settings, whether residential such as home, foster home, group home, or institutional, such as day care, school, work place, court room, or treatment, detention or correctional centres.

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<sup>137</sup> Jean A. Ayres, *Sensory Integration and the Child* (Western Psychological Services: Los Angeles, CA, 1970).

<sup>138</sup> Sensory integration, accessed from the worldwide web on Nov. 1, 2010 at :  
<http://www.atotalapproach.com/docs/SI.pdf>

**Interview with D., a First Nations woman who is an FASD consultant and mentor:**

D: People with FASD are affected by the environment. It is very important to know that the environment does affect them. Lights, sound, noise and movement all play a role in how FASD individuals react to their environment and how much overload is caused to the brain that, in turn, will cause a reaction or a behaviour which we look at as a behaviour. Therefore we need to look at what affects that child and what needs to be changed. Because this is due to an organic brain difference and making changes in the environment is a strategy rather than trying to change the child who does things because he or she has a disability. So some of the strategies for changing the environment would be:

- having more natural light versus fluorescent lights,
- having less decorations, less posters on the wall,
- having less noise in the classroom,
- having the child sit in the front of the classroom versus the back because he will be less distracted by the other movement and classmates,
- and having the same seating all year round because it causes less anxiety to the child to know that when they walk into the room that the room is going to be the way that it was left the day before.

I: It is important to prepare the individual with FASD for any changes or transitions.

D: So any changes being made to the classroom or to the bedroom or the living room, any changes, the strategy around that would be to include that person in the change and talk it through.

I: So they're prepared. So they're prepared, so they know that there are new cues?

D: Yes, and they will develop new cues instead of all of a sudden seeing there's been a big change and causing anxiety. So that's why they recommend the same seating all year and prepare the child for change, especially if they're going to go on to a new subject, if they're going to go out maybe for a walk that day which may be at a different time. Just prepare the child that what's going to happen next because they live in the here and now and they don't usually see into or anticipate the future or know how to look into the future for those changes. Yes, that would have been a good one I could have told today.

Oh, I know a story I was going to tell today. I'll tell you it now. One of the moms who had a child who had this disability decided that she was going to change the living room around when her son went to bed one night. And that when he came out of his bedroom in the morning she saw this startled look come over his face, and she said what's wrong. And he said I don't know where the bathroom is. And she said it's the same place it's always been. And his reply to her was, it's always been by the stereo. And so mom moved the stereo the night before and he didn't know where the bathroom was because he was using the stereo as a cue to where the bathroom was.

**Researcher's Commentary and Interpretation:**

This First Nations woman, FASD consultant and mentor has helpful suggestions for accommodating sensory issues in the classroom, such as using natural light rather than fluorescent lighting, having fewer decorations and posters in the classroom, controlling for noise in the classroom, having the student sit in the front of the classroom near the teacher, and minimizing change in the classroom seating arrangement. A student with FASD should be prepared ahead of time for any changes so that he or she can prepare for the transition and learn

new cues. D.'s story about the boy who could not find the bathroom upon awakening in the morning after his mother had re-arranged the furniture was instructive, as the boy had been using the position of the stereo as a cue for where the bathroom was, but his Mother had moved the stereo without preparing him for new cues to use to locate the bathroom.

**Interview with PA, Adoptive Mother of Mark and Mary; Mark has been diagnosed with FAS and Mary with pFAS. Mark was 4.5 years of age when adopted and was 18 at the time of the interview; Mary was 27 months old when adopted and 16 years of age at the time of the interview.**

**PA:** Mary has attention problems and is easily distracted in a busy environment. She has learned to cope by using head phones and special music which is calming to her and shuts out noises. At school she takes her tests in a quiet area and does homework/assignments away from the noise of the classroom. She continues to flit from topic to topic when engaged in conversations and needs reminders to slow down her thoughts and speech. She also pays better attention if she has something to fiddle with, so has fidgets to use at home and at school.

Mark was diagnosed as having ADD by a local psychologist when he was 12 or 13 and was on "meds" for a brief period of time. They seemed to help him focus better and pay more attention to detail. However when he became a runaway we terminated the meds as he was doing street drugs, etc. Both kids have always had difficulty with abstract concepts and out of the box thinking. Blacks and whites were always easier for them to understand than the grays of real life.

**I:** What did Mary use to fiddle with?

**PA:** She has small squishy porcupine balls, stretchy animals and bracelets, and she often just likes to wear hair scrunchies on her wrist, to pull and fiddle with. She often finds things she likes for fidgets when in a store. These items change occasionally based on her desires and she chooses which ones she wants to use. The fidgets have to be quiet ones, and small, as the rule at school is that she needs to keep them in her hands when they are out of her pocket. She can't share with other kids or use them to distract others. The fidgets seem to help calm her "engine" and help her better attend and concentrate. Chewing gum is another activity which helps her focus better, but we have not yet convinced her teachers to allow this in class. She chews gum on the bus to and from school. Personally I think all kids could benefit from chewing gum at times in school, but I understand the hesitation on the parts of educators, as they don't want it stuck all over the desks!!

Mary will always need something in her hands to fiddle with, or gum or chewy candy in her mouth, so she does not start to pick at her fingers or bite at her lips, when she becomes anxious or distressed. She needs these *calming crutches*.

### **Researcher's Commentary and Interpretation:**

PA reports that Mary has attention problems when she is distracted by a busy environment. Mary uses head phones and special music to calm herself and to screen out

distracting noises. She takes tests in a quiet area as well as doing her assignments away from the noise of the classroom. To calm her engine and to help her attend better, Mary needs something in her hands to fiddle with, such as squishy porcupine balls, stretchy animals and bracelets, or hair scrunchies to stretch, as long as the objects are quiet and small and don't distract other students. Gum or chewy candy provide oral stimulation which can calm her when she is anxious or disinterested.

Mark was diagnosed with ADD at age 12 or 13 and was prescribed medication, which helped him to focus and pay attention, but had to be discontinued when he started using street drugs, a more common phenomenon with males who have an FASD.

**Interview with F., a young, First Nations, adult male with FAS, accompanied by his First Nations Mentor, D., who is also interviewed:**

F: For money, I use my calculator. I have a calculator watch, a Casio that has schedules and phone numbers and stop-watch and timer and everything on it. When I go grocery shopping what I'll do is I'll take my watch with me, well it's on my arm. So I'll go into the aisles and I'll, I usually go late at night, that's something I never mentioned. But I'll go late at night like if it closes at ten I'll go at 9, 9:30 so it won't be so crowded, there won't be so many people. Now when I go in the middle of the day or at supertime you got parents that are there with their kids running up and down the aisles, knocking things down and getting in your way, and you're trying to push a cart through and you're trying to think, "okay, what's this, what's that, it just doesn't work." I get frustrated, I get mad, and usually I'll just leave the cart right there and I'll walk out. I know now that the best time to go is late at night or early in the morning when there's no one there because then I can take my time, I can think, I'm not pressured, I don't like large crowds. I get quite panicky around like parades and stuff, I went out with my sister . . .

I: Do you get over-stimulated do you think?

F: Yes, like it's just too much going on all around me at once, and I'm trying to take everything in all at once, right, and it's an overload on my system.

I: So you don't go to rock concerts and things like that.

F:..No, I don't. I usually stay home, I don't go out, I don't go to bars, I don't go to churches, I don't go to stuff like that.

I: So it's hard for you to function in larger groups.

F: Yes.

I: One to one, was that pretty good.

F: Well, I spend time at my sister's and I find that quite hectic sometimes because the kids are all yelling and arguing with each other and I feel like I'm just getting in the way sometimes. I'm like, okay, I'm going to go downstairs in the basement, I'm not getting in anyone's way, you guys just kill each other, I don't care. But I'm downstairs, and my sister asked me the other day, why are you always downstairs. And I told her, I said, well I'm out of the way. And she said, well you're never in the way. And I'm like, I just feel like there's just too much going on sometimes with the kids and then Calvin comes home and it's really hectic and it's just, so I just stay downstairs. And then on the weekends, like Friday night I'll go home and I'll spend Friday night home and relax and have that time to myself.



I: You have a job looking after an elderly man in the evenings, is that right?

F:..I take care of my brother-in-law's father. His wife just passed away not too long ago and I've been taking care of him in the evening. I just make sure that there's someone there in case he falls or if he needs something, he's pretty independent so he likes to do things himself, he likes to get his tea. So sometimes I don't do it, I'll let him, but I'm there, like if he needs me. I'll ask him, do you want me to do that? If he says yes then I'll go do it. But a lot of the times, if he's feeling good and feels like he can do it, then I'll let him do it. But if not then I'll just say, I'll do it, I'll make your tea, I'll make your breakfast, I'll go get the newspaper. I do that for him and make sure that he takes his medication and that it's all there. If he's getting low on milk or butter or eggs or bacon or whatever, he'll let me go get it and make sure that he's taken care of.

I: Do you like him?

F: Oh, yes. He's a nice man.

I: You talk to him and.

F: Yes, we sit up at night sometimes and talk about things and some days it's harder for him because he misses his wife. But we sit and talk and there's a lot of parties that go on at the house, not drinking parties but birthday parties for him. Like there's so many people in the family, there's nine children in his family, and out of that I think eight are still alive, and there's only, yes, there's eight of them that are there. And he has grandchildren and great grandchildren and he's quite happy. He loves it when the grandchildren come over and it just puts a smile on his face.

I: Good. Do you like the job?

F: Yes, I like it because I'm doing something that is helpful, it keeps the family from fighting, too. And that's a major thing.

I: So do you sleep during the night?

F: Yes, I sleep during the night and if he, usually I hear him get up in the night, so I can, I listen out for him, so if I hear a thud on the floor I know to get up. I woke up a couple of times and, are you okay? Pick him up and, you know. Because sometimes in the night, I think that's when he feels the best because I'll hear him and he'll walk around the house. And he'll walk around and I don't know why but he'll walk around and check the heat and go get himself a drink of milk or something, and then he'll come back and go back to bed. But the next morning he can hardly move, so sometimes it's good, sometimes it's not. I'm just there to make sure that he's okay.

I: And then you go home in the mornings?

F: Then I go home in the mornings and his niece shows up and then she cooks him breakfast and takes care of him there and makes sure that he has his eye drops in because he's had eye surgery. So she makes sure that he has his eye drops, and he has to go in December to get his other eye operated on because it was just a year ago he was driving. Now he can't drive, he can't see, he's losing his sight.

F: And that's another thing that, like when I did have a job at Frank and Gina's, that's something I never mentioned, was that I worked at Frank and Gina's and I worked there for awhile.

I: What is that?

F: It's a restaurant. I was O.K. at first but then not so good when they changed management and kept changing the schedule.

I: Oh, right . . .

F: And the schedule changed, the staff changed, the meals would change and along with that came changes in people's schedules because different people came in to work. So they may have kids so they have to book at a certain time. So they had to rearrange the schedule to try and fit everyone in. And it got to the point when I couldn't remember, I get Saturday and Sunday mixed up, I still do, I don't know which comes first, I don't know if it's Sunday or Saturday, or Saturday or Sunday. And I get those two days mixed up and when I worked I didn't know if I worked on Saturday from 7 til close or was it 4 o'clock til 7. I didn't know.

I: Because she made schedule changes.

F: Yes, it was changing quite often, and I just got so mixed up and confused that I was showing up three hours too late or two hours too soon, or not showing up when I was supposed to. Eventually they said,

well, you're fired, because you're not being consistent. And I'm looking at them and thinking, I'm not being consistent. You're the ones that are changing the schedule all around and screwing up my head.

D: How long did you work there before they changed management?

F: Probably about seven months, six, seven months before everything started to change.

I: And before they changed everything it was okay?

F: Yes, everything was fine, because I worked the same schedule every day. And I didn't have to worry about change. But as soon as the management and schedule changed I was confused and I lost my job, I lost my apartment, I lost everything that I owned, I ended up on the street again. And I was sitting at Della's desk in Halifax because I lived in Truro and I lived on the streets in Halifax. I knew how to live on the streets in Halifax because I knew where all the soup kitchens were and where all the free food was, and I knew people in the city that could help me. But in Truro I didn't know where to go, I'd probably die, there's no soup kitchens, there's no place to go eat. Now they do, they have a soup kitchen, they opened it up after that.

D: Oh, yes, patience, have lots of patience and give lots of time. Time is a gift because they think slower, they translate this information slower, process it slower, and a lot of times they may even speak slower because they're processing, as they're thinking they're processing it. So time is a gift and a strategy to eliminate anxiety and to allow that person to know that they can get things done, it just may take them a little longer. And that's really important for their self-esteem, to know instead of rushing people through because once anxiety sets in there's really not much, you're not able to think. And they get confused and frustrated and then you may have a reaction. So being patient and giving lots of time is a good strategy. Not to overload them with homework. I don't recommend homework because it's really hard to get through the day in school for them so they're exhausted. And then they have to do three or four hours of homework which a lot of students may be able to accomplish that in a half an hour. But for them because it's the end of the day, they're tired, their brain is not working as well, they're exhausted, it's just too much for them. And again, setting them up for failure and feeling that they can't do it. So if there is anything for them to do it should be something that will take them ten or fifteen minutes at the most.

Not to have a lot of items on a page because it will look overwhelming to them, everything will run together, so they will be able to stay calmer because it will stimulate them to see a busy page as it does to see busyness in the room or in a classroom or busyness in patterns, for instance.

So the strategy for that would be to keep things simple, keep them plain, and few in number, I guess. For instance, math problems. You would not put 40 or 50 math questions on one page. The strategy around that would be to do maybe three or four to a page. That will keep the individual calmer and lessen anxiety for them.

I: What about testing? Can there be a lot of testing done.

D: Testing as in writing tests.

I: Examinations.

D: I've heard that oral testing is much less stressful for them, that if you could ask them the question, because it has to do with actually hearing the question over reading the question that sometimes it comes clearer for them. So if a test is done, test in the room that they are studying in. For instance if they do study for a test in a resource room, a strategy would be to test them, to actually let them take their test in the resource room instead of taking them to another room to write it. Because they can pull out cues that will help them bring back information regarding what they studied. So when making a test it would be the same thing as the suggestion about not too much on a piece of paper, so you may write three or four pages but there'll be only one or two questions on that page. Whereas a person who hasn't this disability would get all ten say on one page and it wouldn't bother them. But for that individual less on a page for them would work best.

I: With their memory gaps, what about open book tests. Do you recommend that?

D: Personally I would recommend that, but I haven't read a whole lot about that.

I: It was recommended for my daughter and it seemed to work quite well for her.

D: Yes, open book certainly is a good strategy.

I: Open book in the resource room.

D: In the resource room, right on. I think that would work well. And I think the oral piece.

I: Maybe taking the test in the resource room reduces anxiety, too?

D: Yes.

I: And the oral?

D: I think the oral actually because there was a video that I saw, and actually I recommend it, and you might have seen it before, it's called The F.A.T. City Workshop. It's an awesome video, it's about learning disabilities and a number of people, parents, educators, psychologists and social workers are put through what students experience when they have a disability; it has a lot do with experiencing what learning disabled children experience in the classroom.

I: How they feel and the anxiety they experience?

D: How they feel and the anxiety and how they respond to things.

### **Researcher's Commentary and Interpretation:**

F., the young First Nations male with FASD, related how he used his calculator watch which has schedules, phone numbers, a stop watch and timer on it, to help him stay organized. He uses it when shopping to add up the total cost of items he purchases so that he can stay within his budget and not overspend. He has learned to shop later at night, when the stores are not crowded, as he gets over-stimulated and panicky trying to function in crowds. He describes his experiences in crowds as trying to take everything in all at once and becoming overwhelmed. He avoids crowds, stays home a lot, goes to his sister's place, but as she has children he stays downstairs out of the commotion, although she often wonders why he stays downstairs when he comes to visit. However, he is not anti-social, but rather it is his way of dealing with his sensory integration issues. He has a job caring for an elderly man, seeing that he takes his medication, gets groceries, eats properly, and does not fall when he gets up at nights. F. had a previous job at a restaurant, but when management changed, they kept changing the work schedules, the staff and the menu. He would confuse whether he worked Saturday from 7 to 12 or Sunday from 4 to 7, and other changes, and as a result lost his job, apartment, and was on the street again for a time.

D., the First Nations FASD mentor and consultant, pointed out that because individuals with FASD have a slower processing speed, you need to be patient with them, and should not rush or overload them, otherwise you are setting them up for failure. She recommends only 10 to 15 minutes of homework a day for them because they have to try harder to accomplish the same task as someone without a disability and their brains tire from the increased effort,

frustration and stress. She further recommends only a few simple questions on a page, for instance, three or four math problems per page that are plain and simple will keep these students calmer and better able to perform, whereas a page full of questions will be overwhelming for them. Oral testing is also recommended to reduce anxiety and to ensure that they understand the questions, as well as open book testing to calm them and to scaffold their memory problems. If they do their work in the resource room, they should also be tested in the resource room, so that environmental cues and associations are the same in both cases, and, furthermore, they feel more relaxed in a familiar, safe environment. D. recommended Richard Lavoie's video, F.A.T. City Workshop, where he sets up scenarios for participants such as parents, educators, psychologists and social workers to experience the frustration, anxiety and tension involved in learning a new task which children with disabilities experience in the classroom every day. F.A.T. stands for frustration, anxiety and tension, which learning disabled students often experience. When the adult participants cannot perform the tasks prescribed in the scenario, the instructor responds, "How hard can this be? Try Harder. Pay attention. Are you trying to be funny? Why can't you do this, everyone else can?" By experiencing the classroom through the eyes of such a child, the adults in the workshop gain insight into the resultant sometimes troubling behaviours of children with learning disabilities.<sup>139</sup>

### **Interview with AD, CBD, and family, all First Nations and affected by prenatal exposure to alcohol, with their Mentor, KSG, present**

AD and CBD, First Nations parents of a three year old boy, a 13 year old girl and an infant, all live together in a two storey house with CBD's mother. AD, CBD and the children all are affected by prenatal alcohol exposure, the parents having FAS. The interview took place in their two storey home, with CBD's mother and an FASD mentor from Circle Project, KSG, present. The audio-tape of this interview was destroyed as their three year old son kept pushing the buttons on the tape recorder during the interview. What is included herein is from notes and memory. AD, the father of the children, mentioned that he is very sensitive to certain sounds. He is glad that they live in a two storey house as when the baby cries, her cries are so high pitched and piercing that he cannot stand it. Once he even punched a hole in the wall. Now

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<sup>139</sup> Richard Lavoie, *How Difficult Can This Be? The F.A.T. City Workshop* (Alexandria, VA: PBS Video, 1989).

when the baby cries he can go to the other floor of the two-storey house to get away from the sound. Having his mother-in-law live with them also serves as a safeguard as she can help keep an eye on things and help manage the situation to keep things calmer. They do not panic as much with an older, understanding relative present.

### **Researcher's Comments and Interpretation**

AD's extreme sensory defensiveness to his baby's high pitched crying quite dramatically illustrates the impact of sensory issues, as well as a number of way of accommodating these issues, such as living in a two storey house so that AD can move away from the intensity of the piercing cries, and in their case inviting an older, understanding relative to live with them to keep things calmer and more secure.

#### **7.7.3 Theme 3: Motivation and Engagement**

Motivation and engagement are key to learning for all students, and particularly for those with an FASD. With attention deficit, sensory and self-regulatory problems, and slower auditory processing speeds, ongoing motivation and engagement are necessary to assist the individual with FASD in focusing her attention and in maintaining that focus. Motivation is thought to be more effective if it is intrinsic to the task, rather than extrinsic such as money, a token, or a piece of pizza, although both types of rewards have their roles. The key is to know the individual and her background so as to discover activities and modes of learning to which she can readily connect.

Rather than constantly scaffolding with auditory repetitions, it preferable to provide cues in the environment by which the individual with FASD can learn to monitor and manage her own memory and attentional scaffolding, and thereby gain confidence, self-reliance and independence, all of which are important motivators. None of us like to do activities at which we cannot succeed. If the individual cannot learn readily through textual and auditory modes, try visual, experiential, hands-on or interactive digital modalities, with supervision. Supervision is recommended because individuals with FASD tend not to foresee

consequences, and thus they may not understand the acceptable limits and parameters of an activity.

Moreover, to engage the individual, one needs to ensure that distracting stimuli are screened out through the use of ear protectors or head phones for noise, or carrels to screen out distractions in the visual field. Visual or auditory distractions which a normal individual can screen out, may seriously distract an individual with FASD. In addition, students with FASD may require a wiggle chair or a hand-held fidget object to regulate arousal levels so that they can better focus their attention. They may focus better apart from the distraction of other students, but then they miss the social stimulation of group learning which is a motivator, so some balancing of these aspects may be required. Many individuals with FASD are creative, in the areas of art, music, dance, storytelling, performing arts, or applied arts, so they may respond better to supervised activities that allow them to express their talents, rather than being relegated to rote or mechanistic activities.

Two interviews follow that illustrate the complex dynamics of motivation and engagement for individuals with FASD. One of these interviews is with a parent of two children who have diagnoses within FASD, and one is with an Occupational Therapist who works with children in dedicated FASD classrooms.

**Interview with PA, Adoptive Mother of Mark and Mary; Mark has been diagnosed with FAS and Mary with pFAS. Mark was 4.5 years when adopted, and was 18 years old at the time of the interview; Mary was 27 months when adopted and 15 years old at the time of the interview**

PA: Retention was difficult and recall was for the most part not good. Sometimes facts could be retained for a few minutes and spouted back, but generally much new learning was gone by the next day. However, retention and recall was great if it was something very meaningful to them. Retention and recall was also good if it involved "hands on" learning tasks.

For instance Mary was obsessed with cell phones from a very early age and we gave her our old non-functioning ones to play with. By the age of 8 or 9 she had learned how to store information in our old cell phones and had figured out on her own how to set alarms to notify her of special events/dates, how to enter phone numbers, select ring tones, etc. She could recognize phone numbers when they appeared on the home phone screen and tell us whose it was. Around the age of 12 she snuck her brother's cell phone into bed with her one night and ran up a bill of \$156.00 in calls to celebrity 800 numbers (don't know where she ever found these) as well as text messages (we had no idea she knew how to text). We removed this feature from our phones after this as to Mary, "no" never meant "no" and her obsession with

cell phones continues to this day. We could spot trouble on the horizon! I always thought she was a little OCD or ASD.

I: It takes extra energy for individuals with FASD to retain and recall, so they need more motivation to persist to find alternate brain pathways if there has been damage in the usual pathway. One mother told me that her son was finally learning to "write" through text messaging and text messaging language, and now communicates with his friends that way.

PA: Yes I have heard that and we were amazed at how quickly both kids figured out how to do this. But with the extra expense and them not being able to modulate the use of their cell phones for texting, we removed this feature from their phones. Mark got into a lot of trouble with the law when he was texting. Mary likes to journal now and keeps a diary. This has definitely helped develop her ability to write. She also likes to write stories and has a special book for this.

I: What worked as rewards?

PA: Money was a great reward for Mark when he was between the ages of 7 and 14, not so important to Mary. Can't think of anything else which worked with Mark - he became so defiant that he would do whatever he pleased (stay out after curfew, or not come home at all, not go to school, used terrible language at home). He wanted us to change the home rules (among other rules addressing respect and kindness, we have a zero tolerance policy regarding use of tobacco, alcohol or any illegal substances) but we refused to do so. His consequences were basically having to deal with the justice system, because he chose not to remain home and follow family rules.

Mary still likes to earn gum, candy, pop, special activities and staying up later. We also reward her with iTunes cards as she loves to download songs to her I Pod. At school she earns a can of pop at the end of each week if she has maintained her planner each day that week. This is pretty motivating right now, but you never know when things will change.

I: Has Mary's attention span become longer with age?

PA: Well, that is hard to measure, as when she is engrossed in something she loves to do, she displays very good attending skills. *She also does better in one to one situations or small groups than larger general education classes.* She is bothered a lot by all the noises which occur in busy classrooms (probably a sensory processing problem) and has difficulty filtering out what is important from what is not. But if the right crutches are in place she can attend pretty well (preferential seating up close to the teacher; having a quiet spot to retreat to, to do assignments and complete tests, etc.)

### **Researcher's Commentary and Interpretation:**

PA reports that attention and recall were great when Mary and Mark were engaged in activities that were meaningful to them, usually involving hands-on, experiential learning.

Programming and texting with cells phones is an example, although supervision and controls are necessary, as they discovered when Mary ran up a large bill calling celebrity numbers, and Mark got in trouble with the law for his cell phone use. In addition, gum, candy, pop, special activities, staying up later, and I-tunes for use on her I-pod were rewarding for Mary, but not for Mark. Mark refused to comply with the rules of the home, school or community and ended up dealing with the justice system. In school, Mary did better with preferential seating near the teacher, and with a quiet spot available to retreat to do her assignments and tests. The school

rewarded Mary with a pop at the end of each week if she maintained her planner for each day that week. PA observed that saying “No” was not enough to change behaviour, as ultimately they had to take away the cell phones to prevent further problems, despite the fact that both children found them very motivating and learned to fully program them. Apparently, Mary and Mark were not able to regulate their behaviour as to safe and responsible use of the cell phones. PA described Mary’s behaviour as compulsive and Mark’s as defiant, the former being easier to accommodate than the latter, at least at this point.

### **Interview with SM, Occupational therapist in two classrooms at a segregated, dedicated school for children with FAS**

As this segregated, dedicated school for children with FAS is the only school of its type in Canada, and the following professional in the school responded to a call to be interviewed, this interview is most valuable and is included here almost in its entirety. The professional, an occupational therapist, explains how complex sensory needs of students with FASD can be managed in the classroom context, but the techniques could be generalized beyond the classroom to other settings whether residential, educational or in work or justice settings, or wherever sensory regulation issues may affect motivation and behaviour.

**SM:** I’m an Occupational Therapist and I work with students with FAS in two discrete classrooms. One is a classroom for students in grades one through three, and the other is a classroom with grades three to five. And within those classrooms there are smaller classrooms, so there are only eight students in each classroom with a teacher and a teacher assistant support in the classrooms.

**I:** What sort of environmental adaptations and strategies would you use with these children?

**SM:** I would put, I think, most of the strategies probably into two categories. One I would say, are sensory strategies. Looking at managing sensory needs of students. And the second is environmental or structural adaptations.

**I:** Putting them in little carrels where their vision is a little bit restricted, where it’s more private, is an adaptation that can help with sensory over-stimulation.

**SM:** Yes, we call them (the carrels) “personal offices,” but they are like little voting booths that we set down on the desks to screen out some visual stimulation when they need to work in a quieter area, using headphones. They screen out the white noise and distractions. Sometimes the headphones just muffle things a little bit so that there’s not as many auditory distractions.

**I:** Okay, so with controlling the stimulus like this, have the students been able to focus better on their work?

**SM:** Absolutely. Absolutely.

**I:** It really works?



**SM:** It really works. So that's a really big part, just to allow them to be successful. And with putting those strategies into place in the classrooms the students, over time, have learned to use them. At first you're guiding them how to use the carrels, and now the students can use them independently. "Oh, I think I need the headphones now." "Or, I think I need to go get an office carrel for myself." And then they come back and they put it on their desk, and they're to use that.

**I:** So at first you have to model and coach them to get them comfortable using these techniques, then they use them themselves when they recognize they need them?

**SM:** They will. As long as they're available and they're just part of the classroom. There's no judgment laid on this. I mean, the judgment would be, "Oh good, you know what you need to work better." These are segregated classrooms. Both of these classrooms are segregated. They have eight students in each classroom and they are children with FAS. And then the other thing would be, sometimes kids are seeking out stimulation, so they're rocking back in their chairs, they're wanting to fidget with things. So we provide them with sensory outlets so they can use . . . again, we call them "listening helpers," but they are fidget objects to put in their hands if they need to listen to the teacher and concentrate on the story, or whatever. We let them hold things like squeeze balls and springy elastics, things like that.

**I:** And they don't distract the other students?

**SM:** No.

**I:** So, comparing the work with the grades one to three class with the grades three to five class, can you tell me what some of the differences are?

**SM:** As far as the grade one to threes, they have less insight into what they need. The grades three to five, who have been working with these strategies, and they also appear familiar, you only need to say something and they are choosing strategies more independently. I would say that the grades one to threes aren't choosing strategies independently yet.

**I:** Okay. So they still need quite a bit of help at the lower grades.

**SM:** Yes. We're offering strategies at this point. Or suggesting them.

**I:** Right. And by grades three to five they're getting so that they can select their own?

**SM:** That's right.

**I:** After grade five, do these students continue to get assistance in this way?

**SM:** I think it depends on the student. Some of the children are going now into an intermediate program, and that's more like an integrated program, but it's still low enrolment. And the other types of things that are structural adaptations are things like even spots or tape on the floor for where they are to line up. They need cues, lots of cues. So rather than when you say memory, right, just cognitively the students don't remember. You can tell them, make sure you leave space in line so we don't bump people. Well, that's not going to be enough.

**I:** You'll have to cue them.

**SM:** You need the cues. You need physical markers on the floor. Now in the integrated classroom, now this is specifically at our segregated FASD School, but if I were working with a child in an integrated classroom, I might teach him other strategies. So I might teach them to put their arm out. This is how much space you need between yourself and the next person. So again that visual, physical cue because words aren't sufficient . . . they aren't going to retain from just words. So yes, although I'm talking to all of these strategies within these two segregated classrooms, all of these same strategies I take and I use when I consult children with FAS in integrated classrooms, too, but might use slightly different cues.

**I:** Are the strategies accepted by the other students in integrated classrooms?

**SM:** But they would be slightly different ways because they are perhaps the only child who's using a weighted vest,<sup>140</sup> for example, in the integrated classroom. And that's why I like these segregated classrooms as all of the tools are just there . . .

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<sup>140</sup> Jennifer Stephenson and Mark Carter, "The Use of Weighted Vests with Children with Autism Spectrum Disorders and Other Disabilities" (2009) 39(1) *Journal of Autism and Developmental Disorders*, Jan. 2009, vol. 39, 105-114. Weighted vests and blankets are sometimes used with children who have a disorder under the umbrella of SI (sensory integration), such as ASD (autism spectrum disorder), ADHD (attention deficit, hyperactive disorder),

**I:** They become natural, and no one is staring at the child for using them.

**SM:** They just become natural. They just become part of the scenery. . .

**I:** Whereas in an integrated classroom, they might have to deal with a little bit of stigmatization.

**SM:** Right. Or the kids feel different, or what's wrong with you, or why does he get to do that?

**I:** Yes. They're included.

**SM:** The other students ask "Why does he get to hold a ball at circle and nobody else does? I thought we weren't allowed to have toys." The teacher replies "That helps him to listen if he holds that ball and squishes it."

### **Researcher's Commentary and Interpretation:**

SM, the occupational therapist is an advocate for segregated, low-enrolment classrooms for students with an FASD. In such environments, it is much easier to accommodate for over and under sensitivity to sensory input which can interfere with attention, self-regulation, motivation and engagement, without stigmatizing the student for being different in the process. She recommends various devices to screen out distracting visual or auditory stimuli, such as office carrels and head phones. Or conversely, they may need more stimulation in order to concentrate, and may select a "listening helper" such as a squeeze ball, springy elastic, or a wiggle chair or cushion to provide small increments of stimulation. At first the instructors guide, model and coach the students as to when and how to select these strategies, and then by grades three to five, students are able to select these devices independently. If these strategies are not effective, weighted vests may be used, the theory being that weighted vests provide deep pressure which has a calming and organizing effect on the central nervous system, assisting with inattentiveness, hyperactivity, self-stimulatory or stereotypic behaviours, and clumsiness. However, weighted vests need to be selected and used under the supervision of an occupational therapist, as there are risks involved with their use.

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PDD (pervasive developmental delay) or FASD (fetal alcohol spectrum disorder) and may therefore exhibit over or under sensitivity to sensory input. The theory is that weighted vests provide deep pressure which has a calming and organizing effect on the central nervous system, assisting with inattentiveness, hyperactivity, self-stimulatory or stereotypic behaviours, and clumsiness. However, such items should be selected and supervised by an occupational therapist as there are health and safety risks involved in their use. To date, methodological problems prevail in the research yielding no scientific evidence establishing efficacy of weighted vests. Stephenson and Carter conclude that future research needs to ensure that: criteria for participant selection are replicable; inter-observer reliability is satisfactorily established; observers are blinded to the presence or absence of weight in the vests; and stringent research design and interpretation take appropriate consideration of the functional magnitude of changes.

#### 7.7.4 Theme 4: Scaffolding Memory and Sequencing Skills

Memory requires the following brain-wide processes: focusing, selecting, encoding, storing, and retrieving. Learners must focus on, and select the relevant incoming sensory information while screening out that which is irrelevant, then encode and organize selected sensory input for storage in short-term or long-term memory, and lastly, be able to retrieve or access the material from memory when needed.<sup>141</sup> Encoding begins with perception through the senses. Various sense impressions (sight, sound, touch, and smell) are integrated in the hippocampus. The frontal cortex and the hippocampus analyze these various sensory inputs and decide if they are worth remembering. If so, they may become part of long-term memory and are stored in various parts of the brain in bits and pieces. Encoding refers to the processing of sensory input into memory. Material has to be meaningful and organized for both storage in and retrieval from memory. Problems can occur at any of the stages of memory processing.<sup>142</sup>

Perceptions are encoded and stored in the brain using electricity and chemistry. Nerve cells in the brain connect with other nerve cells through feathery extensions called dendrites at points called synapses, where electrical pulses carrying messages leap across gaps from cell to cell. Electrical firing of a pulse across a gap triggers release of chemical messengers termed neurotransmitters<sup>143</sup> which diffuse across the spaces between cells and attach themselves to neighbouring nerve cells.<sup>144</sup> Through this process, brains cells or neurons organize themselves together in networks, and the more signals that are sent between cells the stronger the connections in the network of cells becomes. As you learn and practice new information, these connections become stronger and more difficult to extinguish or forget. As you learn and practice playing the piano, or as you learn and practice reading, required neural networks and pathways strengthen, but if you stop, your speed and skill declines

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<sup>141</sup> Richard C. Mohs, "How Human Memory Works, Memory Encoding," Retrieved from the worldwide web 1-2-11 at <http://health.howstuffworks.com/human-body/systems/nervous-system/human-memory1.htm>.

<sup>142</sup> *Ibid.*

<sup>143</sup> Stephen Rushton, Anne Juola-Rushton, and Elizabeth Larkin, "Neuroscience, Play and Early Childhood Education: Connections, Implications and Assessment" (2010) 37 *Early Childhood Education*, 351 at 353. Neurotransmitters include substances such as dopamine, serotonin, norepinephrine, acetylcholine, and amino acids. These substances have different roles as neurotransmitters and can affect mood, excitation, inhibition, attention, the reward cycle, and learning. They can also stimulate the release of other neurotransmitters and hormones such as serotonin and cortisol which can decrease attention and learning, as when fearful or anxious. Through reinforcing learning in different contexts, the myelin sheath that surrounds the neuron axon thickens, enabling the electrical impulses to move down the neuron faster.

<sup>144</sup> *Supra* note 141. [Mohs]

somewhat and you become less proficient.<sup>145</sup> The development of these networks or pathways in the brain is dynamic and flexible, constantly changing dependent upon experience and stimulation, allowing the network to grow or rewire itself if damaged. Neuroscientists term this phenomenon “plasticity of the brain.” One could hypothesize that a stimulating environment, including multi-modal and experiential learning, is important for building neural networks or pathways in the brain.<sup>146</sup> A typical brain has about 100 trillion synapses to carry messages for storage, retrieval and thinking. The process by which bits and pieces of sensory input stored in different parts of the brain are retrieved as a cohesive memory is not yet known.<sup>147</sup>

Animals studies reveal that dendrites in the prefrontal cortex of alcohol-exposed fetuses and infants, compared to controls, have diminished feathery, filamentous, thorn-like or knob-like spines (termed lower spine density). As these dendritic spines function as sites for synaptic contact, a decrease in their density renders stimulation of adjacent neurons more difficult, lowering organisms’ performance in learning mazes.<sup>148</sup> Scientifically, however, without intervening supporting evidence to bridge the gap, one cannot extrapolate or generalize findings from neuroscience or animal studies in the laboratory to complex human learning and behaviour in classrooms. Attempts to translate neuroscience to clinical applications should be tentative and hypothetical, and should clearly acknowledge any evidentiary gap.

A sense of time, or temporal sense, is abstract, therefore sequencing or organizing memory in a sequential order of steps, or identifying stages of the plot of a story (such as beginning, middle and end) may be challenging for students with FASD. Individuals with FASD may not be able to discern what needs to be done first, second and third to complete a task, such as brushing one’s teeth, getting ready for school, or the steps involved in solving a mathematical problem. Visual anchor charts and lists of steps may serve to sequence the steps and prompt memory. Some children with FASD may find music a challenge, trying to remember lyrics and notes when the sound of instruments and voices or even the presence of others distract them causing sensory over-stimulation problems. Thus music may engage more auditory processing problems, but the issue is complex and some individuals with FASD may

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<sup>145</sup> *Ibid.*

<sup>146</sup> *Ibid.*

<sup>147</sup> *Ibid.*

<sup>148</sup> Lee T. Whitcher and Anna Y. Klintsova, “Prenatal Binge-Like Alcohol Exposure Reduces Spine Density without Affecting Dendritic Morphology in Rat mPFC” (2008) 62 *Synapse* 566-573; and Bryan Kolb, Robbin Gibb, and Terry E. Robinson, “Brain Plasticity and Behavior” (February, 2003) 12 (1) *Current Directions in Psychological Science* 1-5.

excel at music.<sup>149</sup>

Generally, directions and instructions using visual cues and fewer and simpler words will be understood easier by those with auditory processing delays.<sup>150</sup> In addition, learners with FASD need to feel safe and included, as negative emotions such as fear and anxiety can interfere with the hormones and upset the neurotransmission process.<sup>151</sup>

**Interview with PA, Adoptive Mother of Mark and Mary; Mark has been diagnosed with FAS and Mary with pFAS; Mark was 4.5 years of age when adopted and 18 years old at the time of the interview; Mary was 27 months when adopted and 15 years of age at the time of the interview.**

**I:** What learning challenges did they have?

**PA:** When young, Mark and Mary both had difficulty retaining basic information: the alphabet, numbers, their address and phone number, printing their first names, knowing their birth dates; information that their typical age peers were acquiring. They both acted as if they had an auditory processing issue as neither appeared to hear the beginning or end sounds of many words. They were unable to retain and spell simple words, even though everything was repeated. . . repeated and drilled again and again. Retention was difficult and recall was for the most part not good. Sometimes facts could be retained for a few minutes and spouted back, but generally much new learning was gone by the next day. However, retention and recall was great if it was something very meaningful to them. [Editor: it takes extra energy for individuals with FASD to retain and recall, so they need more motivation to persist to find alternate brain pathways if there has been damage in the usual pathway.]. Retention and recall was also good if it involved "hands on" learning tasks.

Neither child could ever learn to sing simple songs in Sunday School but did well with the craft type activities and always smiled at the right times and played quite well with other kids.

**I:** Any memory and sequencing problems early in life?

**PA:** Mary has always had problems in this area. From an early age we found that making pictures of what was expected helped, so we developed chore task lists, with a "do" and "done" column. She could look at the picture list of what needed to be done, do the task and then move this picture to the "done" column. This helped reduce our frustration and the power struggles which occurred. She still has her own "schedule book" here at home: one page for each day of the week (she has helped develop and decorate this) with a printed list of what needs to be done when she gets home from school, e.g. Monday: before supper: feed the animals, pick up your dirty clothes and toss down the laundry chute. After supper: clear the table, scrape the dishes, load the dishwasher, do homework for Tuesday, shower and wash hair. She has a check off form to use after each job is done. At the end of the week we sit down together and if everything has been done, she earns a bonus amount of money along with her

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<sup>149</sup> Healthy Child Manitoba and Manitoba Education, Citizenship and Youth, *What Educators Need to Know about FASD: Working Together to Educate Children in Manitoba with Fetal Alcohol Spectrum Disorder*, Retrieved from the worldwide web 1-2-11 at [http://www.gov.mb.ca/healthychild/fasd/fasdeducators\\_en.pdf](http://www.gov.mb.ca/healthychild/fasd/fasdeducators_en.pdf) at 32.

<sup>150</sup> *Ibid.*

<sup>151</sup> *Supra* note 141 [Mohs]

allowance. This continues to take the pressure off of my husband and I to always be on her back to get things done.

At school she keeps a daily schedule book of homework which needs to be done and gets help to maintain this by an aid and the social worker. She shows me each piece of completed work, I sign it, and she makes a copy of it so we have a record here at home. Mary has always been forgetful about handing things in at school and thus would get into trouble for not having it done! There is just too much to remember during the school day and she can easily become overwhelmed.

### **Researchers Commentary and Interpretation:**

Memory, sequencing and auditory processing issues are problems for Mary. Even with daily drilling, she often is not able to retain and recall material the next day. However, she can remember what she learns through hands-on, experiential learning. PA started utilizing lists and visual anchor charts to remind Mary of homework and daily chores. A daily schedule book of homework goes back and forth between home and school each day; PA signs each completed piece of homework and keeps a copy as Mary often forgets to hand work in to the teacher.

#### **7.7.5 Theme 5: Communication Skills**

Children with FASD usually exhibit some degree of language disability, either a language deficit or delayed language development. They may have problems in learning to produce certain sounds correctly and therefore their speech may be difficult to understand. They may have fluency problems, such as stuttering, characterized by sound or syllable prolongations or repetitions.<sup>152</sup> They may develop language skills at a slower rate, and may have immature vocabulary, grammar or syntax. For instance, they may have trouble putting words together to make a phrase or sentence. They may use the wrong pronoun or verb form, use plurals incorrectly, or omit prepositions. Often they know a word but cannot retrieve it from memory and may substitute another word from the same general category, like “sheep” for “goat,” or “muffin” for “cupcake”.

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<sup>152</sup> *Supra* note 149. [Healthy Child Manitoba and Manitoba Education, Citizenship and Youth, *What Educators Need to Know about FASD: Working together to Educate Children in Manitoba with Fetal Alcohol*, accessed from the worldwide web on 25-1-11 at [http://www.gov.mb.ca/healthychild/fasd/fasdeducators\\_en.pdf](http://www.gov.mb.ca/healthychild/fasd/fasdeducators_en.pdf)].

Communication skills can affect an individual's social, academic and employment adjustments. Language delay is commonly divided into receptive and expressive categories. Receptive language refers to the process of an individual understanding what is said to them, while expressive language refers to an individual's use of speech to communicate with others. Generally, expressive language skills exceed receptive language skills for individuals with diagnoses within FASD. Thus, they may be able to repeat or parrot back what a parent, teacher, employer, or judge says to them, but not understand the substance of what was said, and thus not be able to comply with orders nor follow directions. They may have trouble following when a story or instructions are relayed to them unless accompanied by pictures, symbols or other concrete representations, such as demonstrations, models, icons, digital photos or videos.

Likewise, when the terms of a probation or conditional sentence order are read to them, they may neither understand nor remember without the use of concrete, visual representations, combined with supervised hands-on, experiential learning. They may need to be walked through the instructions in order to be able to comply with the terms of the order or instruction, and if the order or instruction involves being on time, catching a bus, or getting to a correct address they may need special aids or a mentor to accompany them.

Because of problems with auditory processing, they may require considerably more time to respond to questions posed; this delay may cause problems in the classroom and disciplinary proceedings, or in encounters with police or in court, as it may be assumed that they are not going to answer or are being insolent. They may be passed over or not given the opportunity to make a response, or out of embarrassment may claim that they do not know the answer or that they are guilty of whatever is alleged against them. Using fewer and simpler words for them to sort out usually helps to alleviate the auditory processing difficulties,<sup>153</sup> but nevertheless one should ask them to repeat the instructions as a rough gauge of their comprehension, being mindful that comprehension does not always imply that they are capable of remembering and applying what was said. In the disciplinary, law enforcement, or justice contexts, a mentor who understands the individual with FASD and her challenges should be present to provide ongoing support to assist the individual and to help her to understand and respond appropriately (including asking for a lawyer first), as well as to remember and apply what is learned. Mediation in the criminal justice system needs to be modified in similar fashion to

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<sup>153</sup> *Ibid.*

accommodate these disabilities, and cannot rely solely on oral communication in an environment removed from the individual's daily life.

Children with FASD invariably demonstrate complex learning disorders, such as mathematics disorder, disorder of written expression or reading disorder, as well as a mixed receptive/expressive language disorder with deficits in social cognition and communication. Language disorder is not detected with standard school language proficiency screening tests, but rather is detected with formal or informal narrative discourse analysis.<sup>154</sup> Because of deficits in social cognition, communication, memory and self-regulation, these individuals have difficulty using language in more sophisticated social contexts. They lack critical communication abilities required to enter peer groups, resolve conflicts, negotiate compromises, and maintain friendships and primary relationships. The complex array of deficits in this clinical population creates special problems in social aspects of language use.<sup>155</sup>

Moreover, problems with executive functioning implies that these children will need assistance with components of social processing and language skills. Like every complex problem solving situation, they need to be able to encode, decode and interpret cues, identify and select goals and strategies, and evaluate the consequences of their choices, including the use of the most appropriate language forms in each social situation.<sup>156</sup> Modeling, role-playing, coaching and discussion in real life situations are useful teaching techniques to teach these social skills.<sup>157</sup> In one classroom visited, the teacher ate lunch with a small group of students all sitting around a circular table. Each student would respond to a simple, non-intrusive question in turn and would be coached to make eye contact while responding and to listen carefully to other students' responses when their turn to speak came. The students were coached to use appropriate language and tone of voice, to adapt their body language to show respect and interest, and to use polite table manners. They were role-playing the social situation of a

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<sup>154</sup> Kieran D. O'Malley, "Pathophysiology of ADHD in Patients with ADHD and Fetal Alcohol Spectrum Disorders. The Role of Medication." In Kieran D. O'Malley, ed., *ADHD and Fetal Alcohol Spectrum Disorders [FASD]*, (New York: Nova Science Publishers, Inc., 2007) at 52; Barbara Johnstone, *Discourse Analysis* (Blackwell publishing Ltd: Oxford, UK, 2002).

<sup>155</sup> Truman E. Coggins, GERALYN R. Timler, and Lesley B. Olswang, "Identifying and Treating Social Communication Deficits in School-Age Children with Fetal Alcohol Spectrum Disorders" in Kieran D. O'Malley, ed., *ADHD and Fetal Alcohol Spectrum Disorders [FASD]*, (New York: Nova Science Publishers, Inc., 2007) at 162; Lesley B. Olswang, Liselotte Svensson, and Susan Astley (December, 2010) "Do Children with Fetal Alcohol Spectrum Disorders Spend Their Time Differently than Their typically Developing Peers?" 53 *Journal of Speech, Language and Hearing Research*, 1687-1703.

<sup>156</sup> *Ibid.* at 171.

<sup>157</sup> *Ibid.* at 162-175.



polite, friendly dinner party with family or friends; the teacher would model, coach and discuss student responses as they went along, using metacognition or thinking aloud to shape their social processing and language skills. The teacher would try to help them understand each other's perspectives, such as why your friend was angry when you interrupted her and to understand the roles of parents and teachers.

Theme 5, "Communication Skills," is comprised of three two sub-themes, "Expressive Language Skills Exceed Receptive Language Skills" and "Speech and Language Challenges" with interview segments included to illustrate each sub-theme.

#### 7.7.5.1 Expressive Language Skills Exceed Receptive Language Skills

The first sub-theme under Theme #6 (Communication Skills) deals with the tendency for expressive language skills of individuals with FASD, that is what they say, to exceed their receptive language skills, that is what they can understand and apply. A retrospective study at the Manitoba FASD Centre of over 100 children under the age of three years, diagnosed with an FASD, confirms this gap, as well as confirming the delay in both receptive and expressive language skills for the children with FASD compared to children without FASD.<sup>158</sup>

**Interview with PA, adoptive Mother of Mark and Mary; Mark has been diagnosed with FAS and Mary with pFAS. Mark was 4.5 years of age when adopted and 18 years old at the time of the interview; Mary was 27 months when adopted and 15 years of age at the time of the Interview.**

**I:** Did the children have any comprehension problems regarding what was being said to them?

**PA:** The children both had difficulty locating some items ("please bring me the....") in the home environment because neither seemed able to hear the beginning and ending sounds of words, so did not know what we wanted. They both had difficulty with multi-step commands so we started using the KISS

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<sup>158</sup> Shelley L. Proven, "Receptive and Expressive Language Skills in Children 0-3 Years of Age with Prenatal Alcohol Exposure," Presentation at the 4<sup>th</sup> International Conference on FASD, Vancouver, BC, March 2-5, 2011. The Receptive Emergent Language Scale-3<sup>rd</sup> Edition (REEL-3) was used for the language testing.

("Keep it simple, stupid!") principle very early with them both so they would both be successful and less frustrated.

**I:** What is their speech vocabulary like?

**PA:** Both kids acquired what always appeared to be great vocabulary; however we figured out early on, that they had no idea what a lot of the words meant and could not use them functionally in every day conversation. Our rule has been "if you don't know what the word means, you shouldn't use it". Somehow they were able to retain many words they heard others use, but never really understood meanings or how to appropriately use many of them.

### **Researcher's Commentary and Interpretation:**

Mark and Mary appeared to have deficits and delays in speech and language, and probably delays in auditory processing. They had difficulty hearing the beginning and ending sounds of words, as well as understanding multi-step commands. Their expressive language skills exceeded their receptive language as they could use a large vocabulary but did not understand the meanings of the words or how to use them appropriately. The use of fewer and simpler words, one-step instructions, as well as concrete pictures, symbols, other visuals, hands-on experiences and walk-throughs with mentors and aids are recommended strategies to assist with these deficits and delays in speech and language.

#### 7.7.5.2 Speech and Language Challenges

The second sub-theme of Theme #5 (Communication Skills) deals with speech and language challenges, such as a language deficit or delayed language development, including problems learning to produce certain sounds correctly and fluently resulting in speech which may be difficult to understand. Children may have problems saying sounds, syllables, and words. This is not usually because of muscle weakness, but rather because the brain has problems planning to move the lips, jaw, or tongue in the coordinated fashion needed for speech. This problem is not due to the child not knowing what she wants to say, but her brain has difficulty coordinating the movements to speak clearly.

**Interview with S., First Nations woman with FAS age 29, birth mother of two boys with FAS, the eldest 8 years going on 9 and the youngest, age 7 years.**

The Interviewer met this family on the west side at their residence one morning. The Interviewer knocked at the door, and finally two little heads peeped out. The two little heads belonged to two small boys who said that their mother, S., was asleep. When the Interviewer told them she had arranged to meet with their mother this morning, they went and got their Mom from the bedroom. She was most apologetic, explaining that they had been watching movies late the night before. The Interviewer visited with the boys while the mother quickly got ready but she had not had breakfast. There was another adult woman, a relative, in the residence, so the Interviewer suggested that S. and she go out for breakfast and talk while eating breakfast. The relative agreed to stay at the home and take care of the boys and make breakfast for them.

**I:** Okay, so can you go back, to when your babies were infants. Did they have any problems, were they fussy, did they cry a lot?

**S:** My first one cried a lot.

**I:** Okay.

**S:** And it was, I don't know it seemed like he was always sick or, it took him a long time to crawl and you know it was . . .

**I:** He was a little bit delayed?

**S:** Yes.

**I:** Okay. And speaking and walking?

**S:** Yes, and speaking. My younger son, actually, he today, he can't speak properly.

**I:** He can't?

**S:** No, he can't. Some people can't understand him.

**I:** Does he go to speech therapy?

**S:** He will be starting this Fall.

**R:** So he may come along then?

**S:** Yes. My older one also had a speech problem but he went into speech therapy as soon as he was, I think as soon as he started talking.

**I:** Good. Then he progressed?

**S:** Yes, he progressed really well.

**I:** Oh, that is good. So the younger one, what kind of speech problems does he have?

**S:** It's just that you can't recognize what he's saying, like I don't know if it's his tongue that's too big or.

..

**I:** Okay.

**S:** You just can't really understand him.

**I:** Okay. But is he good natured? He appears very pleasant.

**S:** Yes, he is, yes. Everybody just adores him. It helps too when they're really polite.

**I:** And people like that, so they respond to them better.

**S:** Yes.

**I:** So did you raise them to be really polite?

**S:** That's how I was brought up with to have good manners.

### **Researcher's Commentary and Interpretation**

These young boys appeared to know what they wanted to say, but could not produce the sounds correctly in order to be understood. In such cases, the brain may be unable to send messages to coordinate the lips, jaw and tongue to clearly and fluently produce the required sounds, in order to be understood by those not familiar with their speech patterns. Speech therapy and maturity usually assist in dealing with such challenges. The researcher could not understand the speech of either child very well, although they were very polite and friendly, and really wanted to communicate, they did so mainly through smiles and gestures supplementing their speech.

**Interview with PA, Adoptive Mother of Mary and Mark, Children with pFAS and FAS respectively. Mary was 27 months at the time of adoption and 15 years of age at the time of the interview; Mark was 4.5 years of age at the time of adoption and 18 years old at the time of the interview.**

Mary did not talk or use any functional language until she had been home with us for 5 - 6 months. On the video we received from Russia, there was no evidence that she had any expressive language, although she was able to follow simple verbal directions to stack blocks, etc. Then when she started to talk there was no shutting her up. She has received Speech Therapy for the past 3 years, based on the need defined by a communication assessment by our SLP (Speech and Language Pathologist), which was part of a comprehensive assessment to determine her need for an IEP (Individual Educational Plan). She was a "marble mouth" and therapy has helped her slow down and improve her enunciation/clarity. Now only people who do not know her well, have difficulty understanding her.

Mark did not have significant problems with the spoken language other than he retained a Russian accent for a few years and had difficulty with word placement in sentences. Speech was a bit stilted and he was often slow to process verbal directions. Learning English was difficult for him.

### **Researcher's Commentary and Interpretation:**

PA describes Mary as having a "marble mouth" meaning problems with enunciation and clarity, for which she received speech and language therapy. However, despite problems with enunciation and clarity, she was very fluent and talkative. Mark's speech and language problems appear to be more in the nature of code-switching between Russian and English.

### 7.7.6 Theme 6: Self-Regulation

Stuart Shanker, Professor of Psychology and Philosophy, York University, is one of the leading thinkers on “kids with disorders” or struggling children. Whereas IQ was the major construct of the twentieth century, Shanker considers self-regulation to be the major construct for the twenty-first century, as it will determine how well a child will function in school and later as an adult, in work, family and community. Self-regulation involves the ability to concentrate, emotionally connect, calm down, remember and function cognitively. Neurobiologically, the anterior cingulate cortex<sup>159</sup> of the brain functions to control cognitive regulation, including sustaining attention, ignoring distractions, controlling impulses and dealing with emotional frustration in order to avoid tantrums and meltdowns, followed by sadness and depression. Any impairment in this function takes blood away from areas of the brain needed for cognitive tasks, resulting in ADHD and underachievement. Individuals so impaired may become hypersensitive to auditory, visual or tactile stimuli. If so, it takes all their energy to block out sensory stimuli (from a fan or other white noise, from fluorescent lights, from clothing that chafes or rubs) and therefore they cannot concentrate on what is being taught. In this case, turning down the ventilation system, turning off the fluorescent lights or changing the irritating clothing may help to alleviate the sensory distractions. Otherwise, such over-stimulation can make them initially hyperactive and then when exhausted they “shut-down” or become hypoactive.

A child who is hyperactive to visual and auditory stimuli may find didactic interaction stressful, even aversive, and accordingly exhibit defensive reactions like averting gaze, fidgeting, wiggling and so forth. Defensive reactions, in turn, can result in decreased input of information necessary for activation of neural areas involved in perception of facial expressions, emotions and social cues, which further constrain the child’s social inputs, social development and emotional attachment so necessary for learning, language acquisition and abstract or symbolic thought.<sup>160</sup> Experiential learning, not didactic learning, is the preferable mode in such a case, while at the same time Shanker recommends a social-emotional form of therapy to stimulate parts of the brain involved in the “emotion decoding network.” Lacking a language with which to label, understand and begin to regulate emotions, these children can become anxious (resulting

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<sup>159</sup> The anterior cingulate cortex (ACC) is the frontal part of the cingulate cortex, that resembles a "collar" form around the corpus callosum, the fibrous bundle that relays neural signals between the right and left cerebral hemispheres of the brain.

<sup>160</sup> Stuart Shanker, *Neuron Therapy, Ideas*, hosted by Paul Kennedy, CBC Radio, July 15, 2010.

in being labeled as hyperactive) and aggressive (leading to being labeled as conduct disordered). Lonely and isolated, they become susceptible to virtual friendships over the internet and all the inherent, associated risks. Shanker perceives self-regulation as a continuum, with normal at the extreme left and Autism Spectrum Disorder (ASD) at the extreme right. FASD and ADHD is on the right of the spectrum, as well. The child needs to be drawn into real social relations, where they can learn functional language, sharing, playing by the rules, responding and initiating (co-regulation and interaction), appropriate affect and empathy. Shanker concludes that self-regulation is a major determinant of a child's physical and mental health.

Two interviews related to self-regulation issues follow: one an extensive interview with an Occupational Therapist who has expertise and experience in monitoring such issues in special classrooms at an FASD dedicated school; and an interview with a family group of five, with both parents having a diagnosis of FAS, and their three children being prenatally exposed.

### **Interview with an Occupational Therapist who works with Students who have an FASD diagnosis in special classrooms, in a dedicated School for FASD**

Please note that more time and space is dedicated to this interview as the person interviewed works as an occupational therapist in the only FASD dedicated school in Canada, so has considerable expertise and experience, and consented to be interviewed largely due to the open-ended, qualitative nature of the interview protocol adopted, allowing her control over what information she conveys. She is an expert with experience in facilitating self-regulation skills in children with FASD in the classroom context, in both segregated and integrated classroom contexts. Because of her expertise and experience working with the needs of children in these classrooms who have a diagnosis within FASD, she is a key informant to the research.

**P:** I'm an Occupational Therapist and I work with students with FAS in two discreet classrooms. One is a classroom for students in grades one through three, and the other is a classroom with grades three to five. And within those classrooms there are smaller classrooms, so there are only eight students in each classroom with a teacher and a teacher assistant support in the classrooms. Now, as far as literacy, I have to admit that, that's not something that I as an occupational therapist specifically plan for.

**I:** But certainly life skills?

**P:** Yes, life skills I do. I guess as an Occupational Therapist, my major role in the classrooms consists of a couple of things. One of the primary things is looking at the classroom structural adaptations and environmental adaptations so the children can be successful in learning. So I would say my role is more to ensure that the environment is in place, and strategies are in place, so that then the students can be successful. So I wouldn't look at specifically teaching literacy skills, but helping the students be in a space so that they can learn those skills.

**I:** Their tendency for getting over stimulated, and things like that?

**P:** Yes. Children with FAS don't process sensory information well, and that can lead to being overwhelmed by sensory stimulation, and also seeking sensory stimulation. So you get children who both are defensive to information and seek stimulation. So if there's too much background noise, they can't function well. There's things happening in the hallway and they can't focus. There is too much visual information in the environment, things like that. So they need to kind of . . .

**I:** To screen some of it out?

**P:** Yes. So they don't screen out that information well on their own?

**I:** Right. So do you try to limit the information they receive then?

**P:** Yes. At times it's a matter of limiting information. Probably if you've seen that video in the classroom . . .

**I:** Oh, right, with the white sheets over the displays, bulletin boards and book shelves and things like that?

**P:** Yes, there's lots of things covered up.

**I:** Putting them in little desk carrels where their vision is a little bit restricted, where it's more private is another strategy.

**P:** Right, so we use the portable desk carrels, we call them personal offices, but little "voting booths" that we set down on the desks so that it can screen some visual information when they need to work in a quieter area, using headphones.

**I:** Screening out the white noise and distractions?

**P:** Sometimes the headphones just muffle things a little bit so that there's not as many auditory distractions.

**I:** Okay, so through controlling the stimulus in these ways, have the students been able to focus better on their work?

**P:** Absolutely. Absolutely.

**I:** It really works?

**P:** It really works. It's a really big part in allowing them to be successful. And with putting those strategies into place in the classrooms the students, over time, have learned to use them. At first you're guiding them how to use them, and now the students use them independently. "Oh, I think I need the headphones now. Or, I think I need to go get an office for myself." And then they come back and they put a portable carrel desk or headphones on their own desk, and they're there for them to use. (Note: A carrel desk is a small desk with high sides, intended to block out surroundings or distractions so that students can concentrate.)

**I:** So first you have to model and coach them to get them comfortable using these techniques, then they use them themselves?

**P:** They will. As long as they're available and they're just part of the classroom. There's no judgment laid on this. I mean, the judgment would be, "Oh good, you know what you need to work better."

**I:** Are they segregated or integrated classrooms?

**P:** These are segregated classrooms. Both of these classrooms I work in are segregated. They have eight students in each of children with FAS. And then the other thing would be, sometimes kids are seeking out stimulation, so they're rocking back in their chairs, they're wanting to fidget with things. So we provide them with sensory outlets so they can use . . . again, we call them "listening helpers," but they are fidget objects to put in their hands to manipulate when they need to listen to the teacher and concentrate on the story, or whatever. We let them hold things like squeeze balls and springy elastics, things like that.

**I:** And, again, they don't distract the other students? They don't get teased by the others?

**P:** No.

**I:** They don't. Well that's good. Because I remember my daughter at primary school age, she would wear beads or something. The teacher would complain she was always playing with those. So she said, please don't have her wear any.

**P:** And you know, sometimes it's more the teacher that gets distracted, more than the other students. But if I were seeing a student doing that, or playing with a necklace, or beads, or things, I would either think, that's meeting a sensory need they might have at that time, but if it is distracting other kids, and if it's not something that's appropriate, like maybe putting fingers in their mouth or something then substitute something more appropriate. So all of the kids have a water bottle on their desk because they might have oral needs just to suck and have that oral, tactile stimulus.

**I:** What other forms of stimulus, besides the tactile or the oral, do they need?

**P:** Movement. So we'll give them "move and sit" cushions. So cushions that they can just sit on in their chairs, but while they're on them, it will allow some movement of their body. And it would be quiet and help them not to seek more inappropriate means like tipping back two legs on a chair, for example. Or for some children, what we do is we put a stack of little carpet squares under one leg of their chair so they can wobble their chair back and forth, and get that movement, but while they're still sitting.

**I:** Are these cushions specially made that they use to rock on in their seats?

**P:** You can get them through therapy catalogues.

**I:** Oh, okay. And what kind of cushions are they called?

**P:** Move and sit cushions. And there's a variety of them. There's also sit-fit disks, or cushion disks. So there's a variety of different cushions that you can buy that will help provide the stimulation while the kids are sitting. So sometimes the kids will go and figure out what they need. So if it's silent reading time, for example, you might find one student who's gone into kind of a quiet area of the classroom in the back, where the lights are sort of dimmed, there's a little couch area, and they need this enclosed hiding, or quieter, private place to do their reading. Other children will get a pair of headphones and sit at their desk and read, or a move and sit cushion and headphones and sit at their desk. Some will put up an office. So the students will do things that help them.

**I:** So they learn to identify their needs and then find the right tool to help?

**P:** Yes, and learn when it's okay to use those tools. So they do a lot of that as far as working.

**I:** Do they become quite adept at identifying their needs?

**P:** I think so.

**I:** Or do they need a little prompting, too?

**P:** Kids at first need prompting. They definitely need prompting at first because they need to learn what the strategies are, and then at first the teacher, or therapist, or myself, whoever, teacher's assistant, will say, "Oh is your engine running too fast?" We use the How Does Your Engine Run Program, and I don't know if you're familiar with that? The Alert Program, or How Does Your Engine Run? It's Alert Program, How Does Your Engine Run? That's the same thing, but some people will refer to it as the Alert Program, some people will just call it, How Does Your Engine Run. The Program uses the analogy for children, that your car is like an engine, and when it's running too fast, racing around, it is a problem. You can't function well, you can't listen well, you can't attend, you can't do what you are to be doing when your engine's running too fast. When your engine's running too slow, that's what kids that are passive and they "head stand" on their desk, they look dozy, they're not going to function well, either. They need their engine speeded up. Their engine needs to be just right, not too fast and not too slow.

**I:** Right. And are these attention deficit kids the ones whose engines are too slow? In the Engine analogy?

**P:** We teach the Engine analogy over time of what does it look like when your engine's running too fast? What does it feel like? What does it look like, what does it feel like? So identifying it in self and others first. And then the realization, "Oh, I can change my engine." And using sensory strategies, and we all use them. I mean, when I wake up in the morning I need to get myself going. They're sensory strategies that everybody uses, but those children with more difficulty modulating themselves need to be specifically taught how to do that, and to be given the tools to do that. So we use a lot of that to help them.



**I:** Does this really control their feelings of hyperactivity and distraction?

**P:** Yes. Well, it helps them . . .

**I:** Hyperactivity can be quite extreme.

**P:** It meets the sensory needs so that if, for example, they are overactive and are wiggling all around, you might give them something to calm their engine down, or get their nervous system into a state where they can learn to be calmer again. So we might put a weighted vest on them. So we might use a weighted vest, we might use something like a weighted lap blanket, or a lap snake, or something. Something heavy with weight.

**I:** And do they consent to this? It's never forced or coerced.

**P:** They consent. No, no, no, it is never forced nor coerced.

**I:** He might ask you if he needs some help, if he can't sit still or calm down you might suggest a it?

**P:** That's right. So once they learn, then you might tell a child, and this isn't the real name, but "David, your engine seems to be running really high right now. What do you think we need?" Now that's a process where the children are identified. At first we might identify that. "Oh, your engine looks really hot. Do you know what, I think we need to take a little walk to the water fountain," to help modulate their engine. As teachers you get really good at knowing who needs what, and reading that, whether it's a movement break, whether it's a piece of equipment that will help them. You can pick up by observing which children need more toning down of visual stimuli or which children need headphones, perhaps, for screening out auditory stimulation.

**I:** These are really reading readiness skills, too, even though they're sensory and structural adaptations. You need to be that prepared.

**P:** Well, they're things that help you be prepared so that you can function in school or any life skill. Yes, and I would say, probably if you look into some of the literature on FAS, you'll find that sensory piece of it, or sensory strategies, in different manuals and different resources.

**I:** So, comparing the work with the grades one to three class with the grades three to five class, can you tell me what some of the differences are in terms of sensory and structural adaptations?

**P:** As far as the grade one to threes go, they have less insight into what they need. The grades three to five, who have been working with these strategies, and they also appear familiar, you only need to say it and they are choosing strategies more independently. I would say that the grades one to three students aren't choosing strategies independently yet.

**I:** Okay. So they still need quite a bit of help.

**P:** Yes. We're offering strategies at this point. Or suggesting them.

**I:** Right. And by three to five they're getting so that they can select their own? They are moving on to self-regulation.

**P:** That's right.

**I:** After grade five, do these students continue to get assistance in this way?

**P:** I think it depends on the student. Some of the children are going now into an intermediate program, and that's more than integrated program, but it's still low enrolment. It's low enrolment, and when I say integrated, I guess it's students with FAS, but also students with other needs. So it's still a low-enrolment program with students who need more support, but it's not only students with FAS.

**I:** You've told me some of your strategies to deal with the environment and sensory strategies and other structural adaptations. Do you have any strategies to deal with memory gaps or memory problems?

**P:** And that would be the other area. So the first area kind of would be sensory, and then the other one would be structural adaptations, using lots of visual supports. When I think of, what do we have in place as far as structure, we have things like visual daily schedules that are up on the wall so that the kids can see them and have that predictability and routine.

**I:** And are these pictorial schedules?

**P:** They're picture schedules. So with picture schedules there's no surprises in the day. Because here our days change so much and it's not the same every single day. So a good thing to do in the morning is look at the schedule. This is what's going to be happening, go through it, and it's there throughout the day for them to check.

**I:** And then they're not surprised with the transitions?

**P:** Right. And the other types of things that are structural are things like even spots or black tape on the floor for where they line up.

**I:** Cues. All kinds of visual cues.

**P:** Cues, lots of cues. So rather than when you say memory, right, just cognitively the students don't remember, they don't have good short term memory skills.. You can tell them, make sure you leave space in line so we don't bump people, but that telling them is not going to be enough.

**I:** You'll have to cue them visually . . .

**P:** You need the cues. You need physical markers on the floor. Now in the integrated classroom, now this is specifically at our segregated classroom school, but if I were working with a child in an integrated classroom, I might teach him other strategies. So I might teach them to put their arm out. This is how much space you need between yourself and the next person. So again that visual, physical cue because words aren't going to be enough . . . they aren't going to retain from words only. So yes, although I'm speaking to all of these strategies within these two segregated classrooms, all of these same strategies I take and I use when I consult children with FAS in integrated classrooms, too.

**I:** Would you change them in any way?

**P:** Yes, they would be slightly different ways because they are perhaps the only child who's using a weighted vest, for example, in an integrated classroom, but not so in a segregated classroom. And that's why I like these classrooms in our school as all of the tools are just a part of the classroom for everyone.

**I:** They become natural.

**P:** They just become natural. They just become . . . normalized here.

**I:** And no one's staring at you for using them.

**I:** Whereas in an integrated classroom, they might have to deal with a little bit of stigmatization.

**P:** Right. Or the kids feel different, or what's wrong with you, or why does he get to do that?

**I:** They're included in the segregated classroom.

**P:** Another student may ask, "Why does he get to hold a ball at circle and nobody else does? I thought we weren't allowed to have toys." The teacher can respond, "That helps him to listen if he holds that ball, he squishes it."

**I:** What about the concept of time? You talk about visual schedules. What other things do you do to help them judge the passage of time, or learn the concept of time?

**P:** Yes. There's physically a dial that you put down in front of them, and as you make it go, there's a big arc of red, and then as the time goes away, that red portion diminishes or goes away. So it's visual, the kids can visually see the passage of time as the red arc gets smaller.

**I:** It's visual and concrete.

**P:** Yes, it's concrete. The kids can see the passage of time. Or, with the younger kids, we tend to use sand timers a lot, too. Those are for when the time period is smaller, one, two, three minutes. And there are some really nice sand timers out there. So that the kids can visually see . . .

**I:** That time is passing and how much time is left?

**P:** That's right, you've got three minutes to finish up this whatever.

**I:** Having these concrete aids, does it transfer to developing a concept of time in other situations, or is it pretty specific to the situation? Do they generalize at all?

**P:** Right. That's a really good question. I think that some students, I mean, they're aware that time is passing. If they are using the concrete aids they start learning about time. Whether they ever really get very good at it without support is another issue. My feeling is that many individuals with FAS are always going to need support around things like time and ways to visually understand it.

**I:** Getting to work on time. Getting to appointments on time. That's probably always a problem. But I guess there is incremental progress.

**P:** I don't know if this is really getting what you want as far as literacy and life skills. As far as life skills, for example, dressing. How do you get ready in the morning? There's visual sequences of this is what you need to do. You need to get your coat off, your backpack off, so visual routines. If you go into the younger class, there's visual routines for hand washing. You need soap on your hands, you need to turn

the water on. So they're all sequenced, a picture sequence of how to do those tasks. When you go into their washroom, there's sequences of toileting procedures, steps and the order in which they are done.

**I:** So is this a gap in their mental functioning, sequences, or sequencing of steps? Or is that a gap, or it's related to time, isn't it? What do you do first?

**P:** What do you do next? Right. I think it's also . . .

**I:** Memory maybe?

**P:** Memories and just also staying on task. Sometimes we find that these kids are pretty scattered. They go in and, what am I supposed to be doing?

**I:** Right. They're distracted by something.

**P:** That's right. So it helps them stay on task, check what they need to do next, did I get everything done, am I finished?

**I:** Are there any other abstract thinking skills besides learning time and sequencing that you specifically address?

**P:** Well, again, even the kids who maybe are really messy when they're eating. We put up a mirror right on the table when they're eating snack or lunch to remember to wipe your face, or check your mouth.

You've got stuff all over it. Or take smaller bites. I would say that individual students have individual strategies, depending on what their needs are. So there's some strategies that are just classroom strategies and some are individual strategies.

**I:** So is it a matter of being able to see yourself as others might see you?

**P:** Again, it is a matter of poor sensory processing. They don't have that awareness of food all over their face. They need to see it to cue themselves. "Oh, I need to wipe my face, it's a mess." Or, because they don't necessarily feel it on their face, when we might actually feel it.

**I:** And does it help them realize without a mirror? Do they get to the point where they can realize without a mirror that their face is dirty? Or just as a routine, clean up after eating?

**P:** I'm just thinking. We don't use the mirrors as much when the kids are older, so have they learned that skill? That's a good question. Have they really learned that skill, or over time have they just gotten better at hitting their mouth? I'm not sure. I think that a lot of these things, some of the skills that kids learn over time . . .

**I:** Some is maturation, isn't it?

**P:** Some is maturation, and some things I think we have to remember that we just need to keep supporting individuals with FAS so that they can be successful, and figuring out just what kind of support that is.

**I:** You know the concept of external brain? Do you think all these things are functioning as an external brain?

**P:** Absolutely. All of these things were external brain things. Yes.

**I:** So that's kind of required lifelong.

**P:** Yes. And I think that they change life long, so whereas we might have needed a toileting schedule when they're little, that student, or that individual entering adulthood isn't still needing that toileting schedule, but they might need the same strategy for their work schedule. So the same types of sequences and strategies and individual aids, I think, are going to be important for life for many people.

**I:** Or just another abstract skill I thought of was cause and effect. You know, not appreciating the consequences of actions. I particularly thought of young men and women and pregnancy. Not being able to predict that outcome. Over and over again, not being able to predict that outcome.

**P:** Yes.

**I:** And that gets pretty serious. I'm sure you teach cause and effect in other ways throughout the school, but I guess it would have to be specifically taught for that.

**P:** I would think so. I never really thought about that with the age group here. But we talk a lot about choices, that's for sure.

**I:** I guess judgment would be another one. Using good judgment in making choices because they are prone to going with the wrong crowd, and being influenced to make the wrong choices.

**P:** And I think that that's really the strength of this program is everyday at lunch these teachers sit down with these students and they just talk and have conversation, and I think that's one of the things that struck me the most when I first worked with the older classroom last year, is the range of conversations that would come up around the lunch table. Things that would just naturally occur, or something that was spawned from the media. Oh, there was a baby that died last week. That mommy got mad at that baby and shook that baby, and that baby died. Is it okay to do that? How do you treat babies? So all that talking and problem solving. Is it ever okay to shake a baby? What should the parents have done? And just lots and lots of talking. And it's a little bit black and white, the kids' learning, go get help, so that provides answers for some issues. But it's things that, I guess what would strike you is I never taught my kids some of those things, or you never taught your kids explicitly because they just figure them out. But these kids don't figure them out, or don't know those things. Some of the conversations have come up around stealing, and around drugs . . . are important conversations to have.

**I:** Even at that age? Drugs?

**P:** Even at that age, yes. Sniffing and all kinds of things. I was thinking, these kids are too young to know about that. Evidently they're not.

**I:** So they're kind of vulnerable as far as negative peers are concerned.

**P:** Yes, I think that these students are definitely vulnerable. They have such a need to belong, and yet they don't have all of the social skills in place to do that well. So I think that leaves them very vulnerable.

**I:** Do any of them have problems with the law? They wouldn't be old enough to face charges yet?

**P:** Not to face charges, but there were a couple of students last year involved with the law. Some stealing.

**I:** Are most of them in their original homes, their birth homes?

**P:** No, I'd say more of them not. Some are with foster families, some are with grandmothers, some are with perhaps their mom and a myriad of others in the family. The dynamics are not necessarily stable that the kids have to work with, unfortunately.

**I:** Are the majority Aboriginal children?

**P:** I would say so, yes. The majority that I work with we try to supplement the work of the home. Even considering about nutrition, such as what you bring for lunch and what you don't. Tell your Granny that you need to have some fruit in your lunch everyday. Tell your Aunty that you need this or that.

**I:** Is any food preparation taught at school at this level?

**P:** You know what, they don't in this program because it's not a life skill. It's still more academically focused as far as a program.

**I:** Just stepping back a bit into our literacy and some of your sensory strategies, and adaptive strategies, do they really get into reading, and learning to read then as they progress?

**P:** Yes, absolutely. Absolutely.

**I:** They are capable of that?

**P:** Yes.

**I:** What about reading comprehension? Does that come, too?

**P:** Yes, I would say so. And the students are at different areas. And I would say that's the strength, again, of the program is that often I've seen children with FAS who have been integrated into other program, into just the mainstream classroom, and there's so many behavioural issues getting in the way, or such limited success that they don't have the same opportunity. The kids in the segregated program are supported so well, and their needs are met so beautifully in this program, that they are coming out as readers. They are learning to read because the teachers are meeting them at whatever level is required. And it might be a grade one student who comes in without knowledge of the alphabet. It was a grade three student last year, who had been in an integrated program and was moved to our program, who came in without knowledge of the alphabet. Well he learned that while he was in our program. Given the opportunity, given the support, they can learn. And now he's reading and he's starting to put or write words on paper.

**I:** Is he's excited about that?

**P:** Yes, he's excited. He is excited. He's doing really quite well.

**I:** So success like that improves their self-image?

**P:** I would say so, and that's the thing you will hear a lot if you were to do a visit to the classroom, "Oh you guys are so smart." The teacher's always say, "Oh, you guys are just so smart. How did you figure that out?" Challenging them to be learners, challenging them to think, and there's that excitement from learning. "Oh you guys are just the smartest kids in the world." Just that feeling of success. Now, are they at the normal grade level? Many of them aren't, and some of them . . . they've got strengths and they've got weaknesses, and bits and pockets, pockets of deficits, and scattered skills.

**I:** But they've still able to progress?

**P:** Right.

**I:** So then maybe they will be included more in society as they mature and so forth, which could be very important to them.

**P:** That's right. Literacy is so important.

**I:** And you mentioned, I think, teaching them to wash their hands. Hygiene skills, and something about nutrition, sequences to taking your clothes off and hanging them up or putting them on, and getting ready for class or work.

**P:** That's right. Or being responsible for your belongings. And what do you need to do? I need to put my backpack up, I need to put my chair down. These are the steps in the morning to taking care of the things I need to take to school. And my lunch needs to go here and so forth.

**I:** Are there any that come without lunches that you might provide a lunch for?

**P:** Yes, if the students don't have a lunch, something is put together for them. And there's a breakfast program, too, so a lot of them will eat breakfast at school.

**I:** Oh, they have that choice to come and eat breakfast, and then a lunch will be provided?

**P:** Yes.

**I:** What about things on the playground? What would you be doing differently on the playground?

**P:** Well, I think that to start with is at first, well for the younger class, they have recess at a different time, so it's always a teacher . . . at least one teacher with eight students, sometimes two. There is a teacher and a teacher assistant out on the playground at a different time, depending on scheduling.

**I:** I don't know why other schools haven't done that, but resources are an issue.

**P:** It's just too much otherwise. For the older students, the first month at least, the teacher goes out with them at recess and supervises carefully. So there's the recess supervisors, but there's also their teacher out there at all times watching.

**I:** But they go at the regular time for recess?

**P:** They go with the school recess. And then gradually the teacher withdraws from constant recess supervision, and then they're expected to go out independently and return independently.

**I:** So social skills are often a problem. There's often a lack of understanding of appropriate social skills for them.

**P:** And again, because in this program it's not integrated. They're working on social skills with their peers with FAS, but my sense is that in a typical classroom they would look different. They'll have social weaknesses. But I don't see them without their typical FAS peers, so that's a hard one for me to really say. Well, how would they look? I don't know because they look pretty good together here.

**I:** Do they?

**P:** They do. They look pretty good together. They get the sense of community with one another. They get this real sense of caring and support from each other. So that's really nice.

**I:** Well, my son when he reached about the grade five level, the teacher was saying, he's saying insensitive things to his peers, he's hurting their feelings. And he doesn't seem to understand when you tell him that.

**P:** Right. And that happens sometimes, and again it's mediated very quickly. Oh, was that a nice thing to say? And then again, it's talked about.

**I:** Modeling, feedback and coaching.

**P:** I think that there's a lot more feedback. With that ratio you've got the time to give that feedback. To get right on top of things when you see them and do it in context.

**I:** In a regular class, my son would be put out of the classroom a lot of the time. Now you wouldn't do that? You'd use your office carrels, ear phones or squidgy toys or something else "to slow your engine down"?

**P:** That's right.

**I:** But again, these skills would be less effective the more students you had to contend with.

**P:** I think, again, you need support, and that's the biggest thing that I would keep going back to. That these students need support. So in this environment, with lots of support, they do really nicely. And I don't see that, yes there's things happening, but there's not behavioural concerns spilling out all over the place. Things are dealt with much more quickly so there aren't ongoing problems. The response is, "Oh he just doesn't want to do that," rather than concluding that he's just uncooperative. There's not that type of judgment and blaming.

**I:** How do you stop the judgment and blaming?

**P:** I think there's an understanding of that disability. That this is a disability. Their brain doesn't . . .

**I:** What is the brain doing to cause this behaviour, and what can we do about it? Like that kind of reasoning?

**P:** Yes, and how can we structure it better for success next time? But some of the problems are coming, for example, on the bus which is a less structured environment. There isn't the same adult support. So you look at what happens comparing an environment of support, to one where there is less support.

**I:** So on the bus, could you try things like student mentors? An older student to mentor them?

**P:** First of all, these are special buses in the first place, so they're all special needs children on these busses. But sometimes they put them in little vests, little harnesses, that clip onto the back of the seats so they're not jumping around. They are handy-dandy seat belts basically. And some kids like the security of that, and other children they're used for is in this manner, "You didn't do really well on the bus, it looks like you need to wear a vest for awhile." I've seen that. But you know, I haven't seen a lot of proactive strategies to be honest, on the buses. People get negative. I'm thinking, now why haven't we used more proactive strategies on the bus because these kids are coming in with these slips, these bus reports for behaviour, and I'm thinking, I'll bet there's some ways we could problem solve around that and support the kids better so they aren't getting into trouble on the bus. Can we attach some toys to their backpacks to fidget with while they're on the bus. Or wiggle cushions to sit on. Can we give them a headphone on the bus, or music on the bus. I'm sure if we thought about it, there's probably a lot of things we could do better with that one. But no, we haven't really addressed the bus much.

**I:** What about anger and violence?

**P:** I haven't seen too much of that in the classroom. I think there's been a little bit out at recesses sometimes.

**I:** Well, if you're meeting their needs in the classroom, that could explain the lack of it. I think you see it more in the integrated classrooms where they don't get the support.

**P:** I think so. I'm just thinking about the kids that I've worked with in integrated classrooms and when it falls apart, what's happening. And I go back to the fact that those kids are not having great success at those moments, so that a task is too challenging. And I think that that's one thing that happens in integrated setting a lot, is that, not to blame the teacher, but the teacher doesn't have enough resources to modify everything to the degree that some of those kids need it. So I'm thinking about a student right now in my brain. She's in junior high. The school's frustrated with her behaviour, and I'm just looking, well what's in place for the student? And she really needs academic modifications to be successful. She needs environmental modifications to be successful, and some of the structural supports, and without those in place, now she has behaviour problems.

**I:** Secondary disabilities are just rearing their heads.

**P:** But she's a nice girl. I don't think that some of that stuff needs to be happening for her.

**I:** If her needs were accommodated, they'd subside.

**P:** That's right. But I don't think that the idea of, well, we'll just teach them to do this and then they'll be okay.

**I:** They need ongoing supports . . .

**P:** That's right. That's the mistake that people make is not really understanding that external brain.

**I:** Right. Or sending them out to the resource room for 30 minute and expect them to be able to function in the regular classroom for the rest of the day.

**P:** Absolutely not.

**I:** Now school leaving is supposed to be high amongst this population. You're working with the ones in school, I know. Are you aware of the number, particularly as they get a little older, that may not be in school, have dropped out or been suspended?

**P:** No, I don't have a lot of specific experience. Because, yes, you're right, the ones that I'm working with are somehow still in school.

**I:** And they attend pretty regularly, do they?

**P:** Well, in our program, very regularly. And I guess the other students I work with, yes, attendance is pretty regular. And I'm just thinking of three different ones, but part of that is again they're in foster care, so that tends to help with the consistency.

**I:** They have someone to help get them on the bus in the morning, and get them to school.

**P:** My sense is that there's probably lots of kids with chaotic families that don't show up, and those aren't the kids that I'm seeing right now, for whatever reason. And likewise, they're probably the kids who don't have a lot of success and drop out. That's just a thought.

**I:** I wonder if there's a system for tracking these kids, like a real system.

**P:** Yes, that would be very interesting. Who's dropping out, how many, and why, and how can they be retained.

**I:** Some students are expelled from school, and there's no alternative offered, yet they could have been in a segregated class, or a farm school, or special education, or something else. I'm thinking as they get a little older, and even some younger kids are falling through the cracks.

**P:** Yes. And again, I haven't seen that as much.

**I:** No, not in your school.

**P:** And I've really found in the other school division that I work within, too, I think they work a lot, too, to try to figure out how to keep those students in class, how to support them, how to do that. My feeling is sometimes it's not enough support, and it's not ongoing.

**I:** Does the school use home visits at all?

**P:** Not in our programs. I shouldn't say that, maybe the social workers do a little bit of that, but I don't.

**I:** So you wouldn't be aware of what things the caregivers are doing in the home to help reinforce what you are doing at the school?

**P:** No. There is a book that we send home for home reading, so the kids bring home reading to really encourage the recognition that they need to read to somebody, and that somebody marks it down, or that the kids mark down who that was. And because of the family dynamics, it's not always mom and dad. So it might be grandma, it might be an older sibling. Or it might be that, well you read it to your little brother. And they're not going to get that same feedback for solving their problems. Like, did you sound that out right, or help when they're struggling over a word, or whatever. But at least reading it to somebody is a start. But certainly, the idea if possible is to get an adult to read with the children.

**I:** But they bring back the books with the reading form filled out?

**P:** Yes. And if they're not, the teacher's following up and asking, why not?

**I:** I guess the other big question I had to ask you about was indicators of success of your strategies. What do you take as a sign that this is working? The smiles on their faces?

**P:** That's right. I would say it's observational.

**I:** Observational. Okay, that sounds qualitative. . .

**P:** I would say that when you see children that are using the strategies well, it doesn't take much to say, well, look at that. They went and they sought that out, and there's a child right over there who just went independently, put on headphones, and is working in an office space with the headphones. When I say office space, within a cardboard carrel, and is doing their work. And I also see that as the kids have gone into the next level up, and they don't have all of those things naturally within the classroom, I'm just talking with a teacher now on how do we put them in place because those students were supported really

well when they had them. So efficacy, have we done anything or researched? No, but definitely you can see when it's working, by observing the students.

**I:** Do you have individual program plans for each students?

**P:** Yes.

**I:** You keep detailed records of their progress?

**P:** Right.

**I:** Is there inconsistencies? Like one day they remember the skill and the next day they forget their office space, or something like that? Is there a lot of inconsistency where their reading goes back, or . . .?

**P:** No, but I would say again with the variability of a child's mood or nervousness. . . . A child comes in, something set them off at home or on the bus, they might need cues to use something when they might not on a good day. So, yes, we do see some variability in that, but I would say for the most part we just, oh, you know, it looks like you could use a listening helper. Or, I see your water bottle's empty. Why don't you go fill that up again. So reminders and cues sometimes.

**I:** Is it quite an intimate relationship that the students and teachers have?

**P:** Oh, yes. I mean, they call the teachers by their first names. So they get to know those teachers very well, the teachers get to know them very well, and the teachers really understand what their home life would be like. They have much more awareness and understanding of that than I would because I really only consult to those classrooms.

**I:** Is there a lot of teacher-home contact? Lots of parent-teacher interviews?

**P:** I'd say a fair amount. Well, I'm sure much more than your typical students because, again, the teacher only has eight students to look after. She has more time to make sure that, oh, well what's up with that, instead of just wondering what's up with that. She can call home, and she has the relationship with the home.. Yes, I'd say she has relationships formed with parents and caregivers.

**I:** So it's quite cooperative?

**P:** Cooperative. I don't know if that's always the word that I would use, as supportive. I'm just thinking about that. Again, you get parents in schools from the wealthier neighbourhoods . . . I guess, in my kids' schools, for example, you've got parents who come in and are very active and want to be cooperative partners. Here I would say it's teachers taking the lead role to be supportive of how parents can help at home. Do you see that difference?

**I:** Yes, I see that. So the caregivers or parents cannot really advocate for the kids with FAS in the same way . .

**P:** That's right, that you might find in other classrooms or schools. So I think that a lot of the times the teacher is the advocate for that child. I was in a classroom today and the teacher was on the phone arranging dental appointments for the students.

**I:** That's what I was asking next. About the school liaising with other agencies, like health agencies . . .

**P:** Yes. If the schools makes some of those contacts, the school advocates that the child needs an appointment with a health professional, or that child needs some particular service and the school or teacher facilitates that as much as possible.

**I:** Or would they communicate with the social worker?

**P:** Yes. And our social workers are consulted as opposed to doing the work within the schools, yes.

**I:** So the school has its own social worker, or government social workers?

**P:** Yes. Children would have social workers, but then there's a social worker assigned to the school as well, that might make the contact with that child's social worker if that child had a social worker outside the school. So if it was a foster child and there was a social worker involved, it might be the school's social worker contacting that social worker. But, yes, we do have our own social worker in the school.

**I:** Are there other professionals involved in the school?

**P:** Psychologists. We have psychologist, social work . . . We don't have medical doctors, but again I would say it's the school facilitating some of that connection with medical doctors, if needed.

**I:** And all your children are FASD, they have some diagnosis in that spectrum?



**P:** Yes. They've all been diagnosed, that's a condition of getting into this program. The child may have the characteristics, and the behavioural signs, but she doesn't have that maternal confirmation of alcohol consumption during pregnancy. And our physicians will not diagnosis an FASD without that.

**I:** It's a requirement in the national guidelines now, too.

**P:** That's right. So it smells like it, looks like it, tastes like it . . . So, you know what, it kind of looks like a duck, but I can't say that it's a duck because that part is missing. . . I'm not involved in the diagnosis. There is another OT who is part of that process at the hospital, Dorothy Schwab. She's done quite a few workshops on FASD and you might have heard of her. She was the one who first started this program.

**I:** Yes, I have heard of Dorothy's work. In the diagnosis process would an OT like Dorothy look more at coordination problems, sensory issues and self-regulation?

**P:** Sensory and self-regulation, for sure are big pieces of it, and sometimes fine motor function, which certainly gives an important part of the picture.

**I:** Would life skills or adaptive function, would she look at that, or would a psychologist?

**P:** You know, those are gray areas, right? Those are really overlapping areas. So I guess I would really . . . and she has an unconventional role, and there's probably lots of graying in that.

**I:** So it works more as a team?

**P:** Yes.

**I:** Well, I think I've covered all of the essentials. Is there anything else that you want to say, that you haven't had an opportunity to say?

**P:** No, not specifically. I think that again my whole theme would probably be in that these kids are functioning much better than I think a lot of people would expect. I think one of the reasons is because of the supports in place that allowed them to learn, the external brain.

**I:** That is a much more hopeful message than "nothing could be done".

**P:** And are we changing them? No. Are we supporting them and recognizing the needs for support so that they can learn? Yes.

**I:** I agree—compared to other disabilities, you can't change a blind person, either, but you can help them function in society.

**P:** That's right. You can teach them mobility skills. And the way you would teach a blind person mobility skills is different than the way you would teach mobility for FAS, but you still need to teach it.

**I:** So you're a great believer in supports and accommodation?

**P:** Absolutely. Yes.

**I:** Well, thank you very, very much. I really appreciate your time and the insights you have provided.

**P:** You're welcome.

### **Researcher's Commentary and Interpretation:**

The occupational therapist discusses academic, structural and environmental modifications that can be used to support learners with FASD in the classroom and help them to regulate their own sensory stimulation, energy levels, emotions, attention, and behaviour. By gradually learning how to make use of regulatory strategies on their own through modeling, demonstration, cues, practice, and metacognition, students with FASD can experience success in learning literacies and life skills. Head phones; carrels or mini offices; fidget objects such as squeeze balls; water bottles and straws for oral, tactile stimulation, and wiggle cushions;

weighted vests, blankets and snakes; and visual clocks, schedules, or anchor charts to sequence and scaffold a series of steps in a process; visual, personal boundary markers on the floor; a quiet, pleasant, calm, enclosed space with low lighting to retreat to in the classroom when over-stimulated, all of these can be adapted for use by students to regulate their energy levels, attention and behaviour so that learning can occur.<sup>161</sup> A smaller, segregated FASD classroom where these approaches are normalized and actively supported and monitored on an ongoing basis by an occupational therapist, teacher, or teacher assistants appears to be the most efficacious circumstance for learning self-regulation, a key pre-requisite for learning literacies and life skills. “How does your Engine Run” or the Alert Program is a useful program for helping students to recognize, visualize and think aloud about their sensory issues, energy, emotions and attention levels, and thereby learn to regulate them.<sup>162</sup>

Joanne Rovet, Margot Taylor, Jason Lerch and Gideon Koren, researchers at Toronto’s Hospital for Sick Children, are using magnetic resonance imaging to compare the brains of 40 children with FASD between the ages of eight and twelve, before and after 12 weeks of Alert Program therapy. They are also compared to pre- and post-test performance of a control group of 20 children of similar age range, but without exposure to the Alert treatment. The researchers are looking for changes in the brain related to impulse control (associated with self-regulation, emotional processing and social understanding) to see if the therapy changes or rewires their brains. The Alert program has strategies for teaching the children to “rev up” their engines if they are feeling tired or sad, or to “gear down” or put the brakes on if they are feeling angry or hyperactive. They can put on ear phones, close the blinds or dim the lighting, select a wiggle seat, or a fidget toy, select a carrel or individual office to screen out visual distractions, or move to a comfortable, quiet, enclosed space with low lighting, or even pull themselves around on a coaster board if they need physical activity.

To determine if Alert therapy changes their brains, the children play an impulse control game inside a functional magnetic resonance imager. The game is similar to the popular “whack-a-mole game” in which either a mole or a garden vegetable appears on the computer screen. If they see a mole they are to press a button, but not if they see a carrot or a head of

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<sup>161</sup> The Bridges Intermediate Classroom at David Livingstone School, *Living and Learning with FASD, Jilly’s Story* (Winnipeg: David Livingstone School Publishing House, 2009).

<sup>162</sup> Mary Sue Williams and Sherry Shellenberger, *An Introduction to “How Does Your Engine Run?” The Alert Program for Self-Regulation* (Albuquerque, NM: Therapy Works, Inc., 1996).

lettuce. The brain circuitry or network that usually gets activated in normal children to control the impulse to press the button when a carrot or head of lettuce pops up does not fire up in children with FASD. However, following the Alert therapy the hypothesis is that this will change due to the neuroplasticity of the brain in response to the Alert therapy or treatment.<sup>163</sup>

### **Interview with AD, CBD and family, with Mentor, KSG, Present**

AD and CBD, First Nations parents of a three year old boy, a 13 year old girl and an infant, all live together in a two storey house with CBD's mother. AD, CBD and the children all are affected by FASD, the parents having FAS. The interview took place in their two storey home, with CBD's mother and an FASD mentor from Circle Project, KSG, present. The audio-tape of this interview was destroyed as their three year old son kept pushing the buttons on the tape recorder during the interview. What is included herein is from notes and memory.

AD and CBD struggle with addictions. Last year, before Christmas, their cheque for the GST refund came earlier than they expected. Their FASD mentor from Circle Project was going to be there when the mail was delivered, but it came a few days earlier than expected, so the mentor was not there when the cheque arrived. The mentor was going to be there to pick up the cheque and then take AD and CBD Christmas shopping for gifts for the children. On their own when the cheque arrived, AD and CBD called a cab and took the cheque with them. They cashed it and were going to go shopping for the children's Christmas presents, but on the way they passed a bar. They could not resist stopping for a drink, and one drink lead to another. To make a long story short, the money ran out before the drinking did, and they had no money left to buy Christmas gifts for the children. When they sobered up and fully realized what they had done they felt very remorseful, but the damage was done. They wondered how they would face Christmas morning without any gifts or treats for the family.

The FASD mentor, KSG, seeing their distress, and in the Christmas spirit, somehow, somewhere found a Christmas tree and trimmings, as well as some funding to buy gifts and treats for their Christmas. AD told the story to me to illustrate what it was like to live with FAS and not be able to think or plan ahead, see the consequences or to control one's impulses. And yet, should something similar happen again, AD might not remember the lesson he has learned in time to forestall a problem, or be able to generalize from that situation to a new, slightly different situation.

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<sup>163</sup> Anne McIlroy, "Rewiring brains damaged in the womb by alcohol" (May 28, 2011) Toronto Globe and Mail A8.

### **Researcher's Commentary and Interpretation:**

Unfortunately, since the time of the interview, funding has been discontinued for Circle Project and the mentoring program. The interviewer seriously wonders how their former FASD clients are coping without the assistance of the mentorship program, which functioned like a caring “external-brain.” External brain is the term used by Dr. Sterling Clarren to describe the kind of constant, lifelong support that individuals with FASD require in order to make good decisions.

#### **7.7.7 Theme 7: Behaviour and Personality Problems and Mental Health Issues**

In a prospective longitudinal study of 415 individuals with a diagnosis within FASD, 90% developed mental health problems. Significantly, 80% of these individuals had not been raised by their biological mothers, but rather were raised in a series of foster homes or had been adopted. Children and adolescents in the cohort were more likely to have attentional deficits (61%), whereas depression was the most prevalent mental health problems for adults (more than 50%). Of the 90 adults in the sample, more than 40% had threatened suicide and more than 20% had attempted suicide. Thirty-five per cent of adolescents and adults had problems with alcohol and drugs. Twenty-eight present of the adults and 20% of the adolescents had been confined for inpatient mental health programs, and 20% of the adults and 12% of the adolescents had received inpatient alcohol and drug treatment programs. Forty-nine per cent of adolescents and adults and 39% of children had displayed inappropriate sexual behaviour. Promiscuity occurred twice as frequently for females (22%) as for males (11%). Among adolescents and adults, trouble with the law for inappropriate sexual behaviour was twice as frequent among males (19%) as among females (8%). Only seven of the 90 adults were living independently, while 80% were characterized by dependent living arrangements. Early diagnosis and intervention are key to preventing or ameliorating adverse live outcomes. Although CNS dysfunctions are inherent in an FASD diagnosis, these adverse life outcomes could be ameriolated through understanding and appropriate interventions. Furthermore, those who lack the characteristic facial features of FAS are more likely to miss being diagnosed, thus may not receive the services and supports

they require and may be more at risk for adverse outcomes.<sup>164</sup>

Five interviews follow on the pervasive and challenging topic of behaviour and personality problems and mental health issues that can co-occur with FASD. The five interviewees are: an adoptive mother of two children, the male diagnosed with FAS and the female with pFAS; a lengthy interview with the director of an inner city housing complex who cares for 67 high-risk clients, many of whom would otherwise be homeless and many with FASD, behaviour and personality problems or mental health issues; an adoptive mother of two adult Aboriginal children having diagnoses within FASD, who is also researcher on the topic of FASD and supported housing, many of the participants in the research having a diagnosis with FASD and reporting problems with homelessness, addictions and mental health; a First Nations adult male who has a diagnosis within FASD along with challenging mental health issues; and an Aborigine woman from Queensland, Australia, researcher, mother of children with a diagnosis within FASD, and grandmother of children who were prenatally exposed to alcohol.

**Interview with PA, Adoptive Mother of Mary and Mark, Children with pFAS and FAS, respectively, Adopted from Russia. Mary was 27 months old when adopted and 15 years of age at the time of the interview; Mark was 4.5 years of age when adopted and 18 years old at the time of the Interview.**

**I:** You mention belonging to a list serve with other parents of FASD children. What sort of things did you learn from the other parents that were useful? Can you give examples?

**PA:** I learn something every day from others on this FASD list (strategies/interventions which work to teach essential life skills, behavioural techniques, etc). One of the most important things I have learned is that FASD is a life-long disability, that there is no quick fix, and that things can change without warning. I have also learned that FASD kids are vulnerable and will probably always be, because of the brain damage, and despite the interventions/coping skills which are acquired. I have also learned that other families who are raising FASD kids have a much more difficult daily road to travel than we currently do with our daughter. (Mark was a different story, but he is now gone from our home and we are gradually

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<sup>164</sup> AP Streissguth, HM Barr, J Kogan & FL Bookstein (1996) *Understanding the Occurrence of Secondary Disabilities in Clients with Fetal Alcohol Syndrome and Fetal Alcohol Effects (FAE), Report to the Centers for Disease Control and Prevention on Grant No. R04/CCR08515* (Tech. Report. No. 96-06). Seattle: University of Washington, Fetal Alcohol and Drug Unit, 1996), cited in AP Streissguth *Fetal Alcohol Syndrome: A Guide for Families* (Toronto: Paul H. Brookes Publishing Co.: 1997) at 107-112 and in AP Streissguth and J Kanter, eds., *The Challenge of Fetal Alcohol Syndrome, Overcoming Secondary Disabilities* (Seattle, WA: University of Washington Press: 2002) at 25-39. Note: the patients in this study were largely ascertained through clinical referral over a 22 year period in NW United States.

coming to peace with this). I am shocked at some of the extreme behaviours which are shared by others on this list, behaviours so difficult to deal with, and the mental illnesses some of these kids develop as they get older. So at this time we are blessed with a happy 15 year old who loves school, loves doing things with our family, loves her pets, is great with younger kids, polite and respectful with people of all ages, and who seems to be slowly acquiring skills which will help her later in life.

Another thing I have learned is that my own country, Canada, is much more involved in research and development of programs for FASD kiddos than here in the US. Amazing!! Mark turned 18 (2/29) somewhere between last Sunday and Monday, so we celebrated our survival, but the sadness of the last 4 years continues to be great in our minds. He called my husband on March 1st to tell him that he was arrested for underage drinking again (drinking age here is 21). I assume this has a different meaning now that he is 18. I understand that there is still continued brain development between the ages of 18 and 22 so hope that there will be changes somewhere down the line for Mark.

### **Researcher's Commentary and Interpretation:**

PA belongs to a list serve with other parents of children with a diagnosis within FASD. From these parents' shared, collective experiences, she has learned a great deal, including the knowledge that children with FASD are volatile and can change without warning. The brain damage that prenatal exposure to alcohol caused renders individuals with FASD vulnerable to extreme behaviours and mental illnesses. PA and her husband still deal with the sadness around their 18 year old son's estrangement and drinking problems over the last four years. They take some comfort in the present happiness of their 15 year old daughter, who while being somewhat immature for her chronological age, loves school and her family and seems to be adjusting well.

### **Interview with J., Director of an Inner city Supported Housing complex, with many clients who have a diagnosis within FASD, and other co-occurring problems**

As J. cares for 67 high-risk clients in an inner city Housing Complex, many of whom have diagnoses within FASD, as well as co-occurring behaviour and mental health problems, this interview is lengthy and the issues presented are of a very sensitive and difficult or disturbing nature. J. is a key informant for the research as she is the only director of an inner city, supportive housing complex for high risk clients interviewed. During the interview, she was

constantly scanning a number of security video monitors fed by cameras distributed throughout key places in the shelter, as well as dealing with requests in person from clients at the front desk.

**I:** I'm at an inner city supported housing complex and I'm interviewing the Director, J. And this is, I believe, a supported housing complex, and I'll get J., the Director, to tell us some things about the complex, what they do and how they support their clients, particularly those who have a diagnosis within FASD. J. could you introduce us to this special place and generally to your clients?

**J:** Well, the complex has existed for nine and a half years now and it was previously called CP because we took over the hotel by that name. Our client base is primarily hard to house, high risk clients. So those are people with mental health disorders, chronic addictions, fetal alcohol, brain injury, and special needs physically. We've got seniors, we've got youth, we've got a real wide range of the population that we take. And we have made the decision to keep admission very open. We've got some working people in here that don't necessarily have any real serious issues other than the fact that they just like the convenience of being taken care of in a facility like this. So it's very much like a very compressed community.

**I:** About how many clients in total?

**J:** We've got 67 people here right now. And most of these people have come from homeless or near homeless situations. Many of them have come from very hostile environments, they've been abused, mistreated, or they've been abusers themselves. We've got several people that have come from jail. Many of the people who come to us have very intense needs when they first come and you see quite a dramatic change within the first month or so. So then they start feeling safe and they're being fed regularly, you see a big change in their attitude, and in their perception. But it requires a real determination to continue to work with them because they are quite challenging, they're destructive. A lot of times it's very much like parenting. You're dealing with people who have not developed social skills, and who have not had any positive role models in their lives. Many of them have developed very serious addiction behaviours, their health and their mental health have not been cared for. So they come to us with a real wide gamut of issues and concerns that have to be addressed. Our first order of business is just to house them and feed them. Usually for the first month there's not a real intense push on anything, other than we may try and get them in to see a doctor, especially if their physical health or their mental health seems to be quite disturbed. A lot of times it's a matter that they've been so frantic and distressed that they just need the time to settle down and be at peace. And they haven't been in a place, many of those, that's been safe for them for a long time. We restrict visitors so we can control who's coming at them. That also gives them a sense of security as they have many fears about who might be coming. The doors to their rooms lock automatically and they're the only one with a key, so they know that once they get into their space that's theirs and they're safe.

**I:** Okay. But still issues must arise?

**J:** And issues are confronted immediately, because if there's not an immediate response, it didn't ever really happen for a lot of them. It's like, "What are you talking about, that was yesterday or an hour ago!" So we try to be very responsive and quick and also very flexible. Our people come with diverse needs and issues and everything that's gone to put them together, so we have to be very flexible in how we deal with them. And not so much flexible in bending critical rules but in how we help them to develop an understanding of the rules. So if we have a rule that you're not allowed to be abusive, well some of them don't have an understanding of the word "abuse," so we have to explain that to them, what abuse is. Their behaviour may be just a matter of that's how they've learned to behave from watching others. So then it is a matter of learning how not to behave that way and learning what does "respect" mean, what does "courtesy" mean. So it takes a long time, it's a long term commitment.

**I:** So the average length of stay here for a client would be how long?

**J:** We have people who have been here for almost nine years. We have other people who stay very short term. We've just opened a hostel in our basement because it's very difficult, as we have people coming to

us in a homeless state and we don't like to turn them away. And up to now we've had to turn them away when we haven't had space for them. Now we have 17 beds that we could potentially let them be basically warehoused in until space opens up. So we can start responding to their needs right away rather than having them go back out into the community and continue to deteriorate. We had a situation with a young man just in the last couple of weeks that we've had to, we couldn't house him, our hostel wasn't cleared by the building inspector yet, so we had to put this boy back into the community. He had nowhere to go. And now he's in the psychiatric ward at the University Hospital because his state deteriorated to that point. He was being found sleeping in the streets and stuff. He's mentally challenged and has fetal alcohol syndrome and just didn't know how to respond to that situation. There was no room at Salvation Army, there was nowhere for him to go, his family couldn't manage him, and there was nothing for him and he didn't know what to do. So until the police picked him up he was just wandering aimlessly in the streets and sleeping wherever he could and going hungry. So opening the hostel or shelter is at least a gap filler in that area for a component of people.

**I:** Yes, it would be! But they all sleep in a large common area in the hostel? They don't share rooms?

**J:** In the hostel downstairs it's a big dormitory area. But upstairs each person has their own individual room with a private bathroom. The doors lock automatically. The entire building is camera monitored so we can keep track of what's going on down here. We can check things. Our people have a very flexible sense of truth so we need to be able to confront things. I had one girl this morning who told me that this guy was pounding on her door for 20 minutes and just scared the daylights out of her. Well, I checked on the camera and it was three minutes and he wasn't doing what she had said, but she also has fetal alcohol, and to her it seemed like 20 minutes.

**I:** Yes, because she's panicked and perceived it as much longer.

**J:** Yes, She was frightened and distressed, but you know, I'm not going to go back to her and say it wasn't 20 minutes, it was only three. But to her it was 20 minutes, it was very frightening for her. However, when I address the matter with the other fellow I can be honest in dealing with the situation and speaking with him about it, not accusing him of pounding on her door for 20 minutes.

**I:** What about violence in the hallways?

**J:** We surprisingly have had very little violence here. The people that we seem to largely have aggressive issues with are the people who have brain injuries and the people who have usually the drinking problems, not so much the drugs. But we have had a violent situation with someone who was drinking and on cocaine at the same time and had a mental health disorder as well. So we have had a few situations where there has been violence against staff or against another tenant and all the situations are dealt with quite differently. Our desire is for people to be well, so if there is a violent situation where somebody has assaulted a staff person then that staff person can make the choice. Am I going to involve the police or am I going set stipulations? Like one fellow, he was assaulted by a gentleman whose medication was completely wrong and his doctor had just continued to prescribe medication. Rather than put him in the hospital and adjust his medication appropriately he just kept writing prescriptions. So this fellow was poorly medicated and became very erratic, out of control and ended up striking my staff person. The police were called but decided not to charge but to remove him to the secure Hantelman Unit where he could be appropriately assessed and treated. Then we were able to contract with him when he returned so that his medications were adjusted. We saw a dramatic change in his behaviour, he apologized to the person that he had struck, and we were able to fix the damage that he was distressed about because he felt that his phone had been damaged. So we were able to put that all back together and then have a case meeting with home care, with the client, and with us to try to work the situation through.

**I:** And you work for the best outcome keeping safety in mind?

**J:** Quite often when it's client to client they'll report on each other.

**I:** Oh, they will?

**J:** So the police have been called, there's situations where the police refuse to be involved where there's been physical provocation and the other person doesn't want to charge so, and several times it's gone to mediation in recognition that there are special needs and it would be better to work it out through



mediation than to go through a big court case. As much as possible, we don't want the police involved, because the court system does not deal very effectively with our special needs people.

I: Court might be helpful in ordering assessments.

J: Yes, sometimes we'll deal it with it with the courts just because if they do need a mental health assessment and we can't get it done, then the courts can at least require that and maybe get something dealt with. But the court system is so sluggish and our people forget their appointments and then they get breeched and they get in this long string and then three or four years later they're dealing with a situation that doesn't mean anything to them anymore. So I really appreciate when the courts refer a lot of our people over to the mediation system because it's very quick and . . .

I: And more responsive and effective?

J: Yes, much more responsive, much more effective for this population.

I: And if they miss an appointment they're not breeched?

J: We've had DP from the John Howard Society, no Mediation Services and he'll even come over and meet with them here; he's just so responsive to the special needs of our people. And he actually continues to counsel one of our people who hasn't been effectively connected with Additions Services. He hasn't been able to connect appropriately, so DP's been helping him along. So there's a lot of service agencies out there that are taking that extra step.

I: One of my questions was how you liaise with other agencies in the community, so that's useful, that helps.

J: We have a lot of connections, like I said, we've been here for nine and a half years running this, actually ten. We just celebrated our tenth anniversary. But we've developed relationships with a lot of the agencies in the community primarily with chronic patient access services, the home care component, mental health services, and a lot of psychiatrists and pharmacies, and a few medical doctors, not that many but, in particular, the ones that run the medi-clinics downtown. We've also connected with crisis management, social services, we have a fairly tight relationship with them. Primarily our client population is funded by Social Services.

I: What about staffing?

J: We've got actually a very small staff to client ratio and it hasn't been a negative thing. It's allowed us to continue to be flexible and more of a home environment rather than an institution. Several of our people have come out of institutional settings and have had very negative experiences with that so around here it's more like I'm the mom . . .

I: And you approach it that way.

J: And the other people that are here are the babysitters, you know, like you better listen or Mom's going to get you later. And that's very much the way I feel though.

I: They seem like your children or your family.

J: They are. They're very much like my family. We spend a lot of time with them and like every other person they've got wonderful qualities about them, they've got despicable things about them, and there's a whole gamut in-between. And sometimes they're just work and sometimes they're a blessing, and you just have to find your way. . .

I: Are they unhappy with the no visitors or no substance or alcohol policy?

J: Most of them are told right away as soon as they come that I'm going to be very interfering in their lives, so they're told that. They know the rules straight up ahead of time and I don't hide any of it. But if I think you're using drugs I'll search you. If I think you've got something in your room you're not supposed to have you can bring it to me and turn it over or I'll come and get it. If you come into the building and you're under the influence and I know that you're dangerous I'm going to turn you back out. And if you refuse to cooperate I will phone the police on you. So they're told that before they ever even come into the building. But at the same time they're also told, we're going to feed you three meals a day. You're going to have your own space, you have cable tv, you have utilities, there's a phone for you to use. There's people for you to socialize with and if you have any problems you can come and talk to me and we'll see what we can do. We also make as much effort as possible to connect them with agencies within the community. Because if they don't always live here we want to know that somebody out there

in the community knows them because most of our people have fallen through the cracks and become invisible to society. So then you pull them out of the gap they've fall in, then you don't want them to ever fall back in. So it's important to connect them with whatever agency belongs to them, at least even to one person and that's very difficult. Their trust is a very delicate thing and it takes a long time, a very consistent determined effort to develop that trust with them. Because they've had a lot of people in their lives that have, like social workers and teachers, people who have kind of come in and told them, this is the way life is, this is what you have to do, and being very invasive but not with a sense of caring. I can be very invasive with them and they'll still come back and talk to me, but they know I love them, they know that I will go the extra mile for them, I'll do whatever I can to make sure that they're well. Whereas some of the other agencies are more this is the way it is. Comply or go.

I: I see. Have you been here for nine and a half years?

J: Yes.

I: So that's a lot of stability for them to have the same person in charge.

J: They like new staff just because they're interesting and it gets a little boring around here. But they also really benefit from people who have been here long enough to really get to know them. New staff are challenging because they come in and they know what the boundaries are and the policies and procedures and that type of thing, and they follow it very diligently when they first come. And it takes them a little bit of time to start to understand where can we be flexible and where can't we. Like simple things, like handing out morning medication. My night staff is not allowed to be flexible on that. It is not his job to hand out morning medication and he has no options on that issue. If somebody comes in and they've been drinking, we have a policy that you're not supposed to enter the building if you're under the influence, but we also have a group of people who are very vulnerable. If we were to put them back into the community and tell them to go to detox they're not going make it. So we may have to make the decision, do we phone the police to have them taken, do we ask them to leave the building, or do we allow them to go straight to their room and stay there, and it just becomes an invisible issue. So given our population, we have to be flexible in those areas.

I: If you think there's no safety issue you might allow them to go their room and stay there?

J: Right. But then it would have to be real low key, because if they go around bragging, oh yes, I came in drinking and I didn't get thrown out, then it's next time you have to leave, regardless, because we're not going to have you spreading the news that you got to come in late.

I: Flaunting it?

J: Yes, can't have them flaunt it because then everybody's confused. That's the rule but now I don't have to do it. And a lot of times they'll come to me and they'll say well he didn't have to do what I'm doing. And it's like, but he's not the same person as you are. He doesn't have the same issues, the same concerns, the same knowledge, so why would I make him into a copy of you when he's a separate person. We're going deal with this person's capacity to understand and cooperate, and it may be different from yours, so please understand that.

I: It's quite individualized?

J: Very individualized to a large degree. And I've been here long enough to really know them. And when they do the in-take interview when they first come there's quite an extensive application process. And as they're going through that application we're doing an interview and as often as possible we try to involve anybody who's working, any type of support agency or at least obtain knowledge of who those support agencies are so that we can make contact with them and confirm. We just had one boy came in and our suspicion was that there was fetal alcohol involved but we couldn't get any determination. . .

I: How young was the boy?

J: He's 23 but he looks 12.

I: And maybe acts 12.

J: Well, he lives in this almost like an absence of presence, I don't know how else to describe it. But he just kind of floats through, almost like a little wisp of a person. And we couldn't get any information on him. But it was very obvious, even social services recognized that there was obviously some issue here and actually contacted us and said, his first medical says there's nothing wrong with him, you have to get

this fixed because otherwise we can't keep funding him. So they sent me another medical and we worked with him to get it done. And we just got the medical back and it turns out he's got schizophrenia.

I: Oh my goodness, that is a difficult combination.

J: But he had no contact with any community service agencies at all, didn't know a psychiatrist's name, he is not medicated and his doctor was on holidays at the time so we couldn't contact him. Until the doctor was able to fill this gap in we didn't know what the fellow's issue was, but we knew that there was some kind of special needs involved. My suspicion is that there's a very good possibility he's fetal alcohol as well. But we have no way to confirm that because a lot of times the parent, because the message is starting to get out there the parents are also starting to have a sense of remorse and guilt, and denial sets in. They know in their own hearts but they don't want to say it out loud because then you know everybody will know and blame them. So in some ways it's almost an offence to ask the parents because you don't want their backs to get up; you may need to use them as another resource and support for that person, so if they're having a negative response to you then how do you get their support?

I: You almost need to build a relationship with that parent.

J: Yes, and as much as possible we try and build relationships with the client support network and that may or may not be possible. Most of our people have burnt their family relationship and a lot of the contacts, the support agencies, have had very negative experiences with them. But they're not taking into account that now these people are stabilized, medicated, supported, and their response is going to be significantly different. Some of them become extremely reclusive to our building. This becomes their neighbourhood. This is their safe zone because we will toss bad people out, I guard them fiercely. And especially our people with addictions, they lived in it out on the street and the street mentality is if you've got it, it's mine. And if I've got it you might be able to wrangle it out of me. So they've been victims and victimizers at the same time.

I: Right.

J: So then these people will try and follow them in. So one of the first things we do is when they first come, for 30 days you can have no visitors. And they're not even allowed to mix room to room with the other clients until they get the okay, because that gives us enough time to become comfortable with who they are, how they behave, how they interact with people, and so see who they're drawn to, because people with similar issues are drawn to each other.

I: You have double trouble then?

J: Pretty much. So quite often, especially the heavy drug users, somehow they just find each other and they're just drawn to each other. So the 30 day ban breaks that connection with the community. And it's not a complete ban, their support people can still come in and if they're positive family members they can come in. And if we assess that they have positive peers that are going to be a real positive supportive influence on them then those people may be cleared to come in, as well. And one of the questions that I usually ask them is who in your life would not harm you? And I get the list of people first, then we decide and then we talk about the room ban. So I find out who can come and who can't. And I ask them questions like who is harmful to you, who would ask you to do bad things, who would not support you in being addiction free? And then once we've developed that community around them, then we start weeding them out. So once we, we're watching and visitors from outside, when we turn them away the first 30 days they start thinking twice about even coming because it's embarrassing. Because we tell them, "You can't come in here, go away." And some of them you have to be quite belligerent with because they're very aggressive in coming after these guys.

We had one girl, she couldn't even walk out the door, she couldn't leave us. For months and months and months they [her pimps] would be standing outside waiting for her, sitting in cars reading newspapers, waiting. The girls are especially vulnerable because quite often they do get into the prostitution angle as well, just to meet their needs and they learn that's a very controlling area for them. They're quite manipulative so they're very difficult to deal with.

I: Do you ever have children coming in with. . .

J: Children are only allowed here if they're accompanied by their parents. No one under 17 is allowed to come here without an accompaniment. We have housed youths as young as 15.

I: With their parents?

J: No. They have come through youth services.

I: Oh, they were referred to you? Okay.

J: Yes. And quite often when they come to us, there's a real shortage of housing even for youth, like care homes and that kind of thing, and a lot of these kids that are coming to us have the same behaviours as our adults. They're very anti-social, they don't develop the social skills that are required to live in peace in a community environment. So here they're forced into community to some degree so their socialization does take place but just. . .

I: Gradually.

J: Yes, very discreetly. You tell them, straight out, you have to learn to say please and thank you. But when you see the guy in front of you say please and thank you and the staff responds positively, then you start thinking, "Oh maybe I could try that one!"

I: Do they all eat together in a common dining room?

J: Yes, a communal kitchen. And we just recently implemented a rule that they're not allowed to take their food out of the kitchen. For a while we were being really lax, primarily me, and allowing them to take their meals away because their behaviour was so inappropriate. But then they were becoming more and more reclusive and they were trashing the place and just dumping food. There's no regard for anything. And we had one guy, he would just smash the dishes because he didn't want to bring them down and he was embarrassed that he hadn't brought them. It was getting very, very costly. And they weren't developing the social skills that they needed to. So when we first implemented that new policy I had to actually sit in the café at the front door and turn people back. And I had to do it for three days and then I had to sit up at the front desk and watch for them during the mealtime and turn them back then. And now it's just once in a while I catch people and have to turn them back, but primarily they're cooperating. And I've had food thrown at me and I've been sworn at, but they always come back and apologize. It's just that their instant response is usually frustration and out of that frustration comes the anger and the foolishness, they don't think it through. But then when they go off and they think about it, it's like, "Oh no, what have I done!" And the door is open then for them to come back and say that they're sorry, but in some places. . .

I: You don't take it too personally when they. . .

J: No, how could I? It's not personal. They don't mean it, it's their frustration. But in some places, like even over at the Salvation Army, if somebody threw food or threatened somebody then they're barred out. They're required to leave, the police may be involved, but they're barred out then. So then if they need the housing the next time they can't go back.

I: And these are the people that will burn their bridges.

J: Yes, and these do. So with my staff and, for my security I primarily hire women now. Because women are more able to set that boundary whereas the men that I've hired have a tendency to take challenges personally.

I: Oh, get into fights or get angry at them.

J: Well, I've had one staff person say, okay let's just step outside then. You know, they've taken it personally and it's not personal. At no time is it personal, they don't know anything about us. They know what they see here at work but they don't know us, and they're not responding to us, they're responding to their own frustration and distress. And there's times where I just want to smack somebody because they just, they push you and push you and push you until you're right at the edge of maintaining control. But then there's value of having our other staff people, so then when one person has reached their limit, another person can come in alongside and start dealing with the issue. But it's very much like dealing with a family, it's not like an institutional setting, so you know. My boss Don W. is like the dad.

J: So he's the one that's kind of like the quiet force that comes in. And they're not quite sure how to deal with him so then they're more likely to just quiet down because they're not sure, he's the unpredictable one. Whereas I'm the one that's just open. And then we've got another staff person who's more likely to step back and come and tell me what's going on. So we've got this big mix of people who have great compassion for our clients and are gaining understanding each day. But they don't have the grace, they

don't necessarily have a lot of experience dealing with special needs people. So when our staff comes in one of the things that we're looking for is the ability to reason, a sense of calmness, like a sense of their own ability to manage and think things through, but degrees on paper are not necessarily a requirement, because we've had people here with paper work and degrees that haven't been effective.

I: Do you have diversity, I'm sure you have it in the clients, do you have it amongst the staff?

J: Oh, absolutely.

I: So there's First Nations staff and people of different cultures and genders?

J: Let me see. Well at one point in time we had an African American security guard, two Aboriginal security guards, and an Aboriginal front desk person who actually had fetal alcohol herself and just learning on the job. She thrived here as a result of the fact that we enough that we were able to work with her.

I: To accommodate her?

J: But she still finally kind of reached that max point and said "I can't cope" and left. But it was more her own personal issues that were impacting her, it wasn't the work situation, but she struck out at the work situation because that's what she could get rid of.

I: Right, and is she coping okay today?

J: Well, I think she's still looking for work, so it's quite challenging.

I: I noticed a number of the people in the community with FASD that I've been talking to, now they're really challenged with the rents going up. They just can't afford to rent a place any more. Now there's even been a greater influx of people competing for places to live.

J: Our rates aren't rising which is ironic and we've kept our cost capped even though the capping is not covering the costs that we need to cover. Our staff works at quite low rates without a lot of perks or benefits or anything like that, so they really work here out of their heart. And if we were being paid appropriately then of course our staff would see the benefit of that. But at this point in time the cost of living in the community and the cost of living here with full support is not that much different.

I: It isn't?

J: No. Because right now I've got people that are living in bachelor suites at \$495 a month.

I: And what do you charge here?

J: We charge \$770. That includes meals, utilities, cable, 24-hour staffing, everything. And free laundry. And sometimes the staff does it for you.

I: You get the help you need, the support you need.

J: Yes, I mean we would love to see the benefits. The services that we provide are probably beyond a lot of what the care homes are providing and many of them are getting two thousand dollars a month per person, but because we don't have that coding we don't qualify. But social services has been much more effective in responding to our special needs people as far as approving them to come here. Initially we had quite a challenge with social services recognizing that our people would benefit from support. But we've proven ourselves in the community and definitely to them and we've been able to house people that no one else could house. We've got several people here who have never spent more than a couple months out of jail and now we're looking at two years for one of our gentlemen.

I: That's really good.

J: And on the days I don't want to evict him he's doing fine. And he's fetal alcohol too and he's spent the majority of his life in prison.

I: And what age is he?

J: I think he's probably about 45 now. But almost his entire life from the time he was 18 until he came here, he spent 20 years in prison for violent offences. He is very aggressive but he is now chemical free, he doesn't drink, he's working, and most of the time he's able to control himself. And when we first got him he was ranting, raving and screaming and he was still into the drugs and the alcohol and just completely an extreme high risk.

I: Out of control? Oh dear.

J: And nobody thought that they could house him and everybody expected him to go back to jail. And now we're looking at two years that this guy is clean.

I: Wonderful.

J: We've got so many of them here, so many of them, but if you don't introduce some level of care, personal care, some person to person care, they don't grow. The ones that we see leave here are the ones that are very difficult to connect with. They don't relate with people and just . . .

I: Are they loners?

J: Not so much that they are loners but that their behaviour are very aggressive and abusive and just frightening. They're the kind of people that belong in scary movies, you know. If they weren't controlled to some degree you don't know what they would be capable of. And those are the ones that usually don't thrive, they may stay here but they don't thrive, and they increasingly become more and more isolated as they burn their bridges with family and peers. So with 67 people in the same building you're bound to find somebody you can get along with. And quite often what we see is they get along for a short period of time, then they hate each other, then they get along with a different group of people and then they just kind of keep rotating in and out. And that's fine. And then we've got other groups that they glue together and, that's it, you can't separate them.

I: So the addictions are a big problem, and you're limiting access to the substances helps, especially when they initially come.

J: Yes.

I: What is the success rate then when you bring them to treatment? Or do you?

J: Most of our people do not benefit from the present approach through addiction services.

I: That's what I was wondering.

J: They need one on one contact and they need one on one for a long period of time so you can't switch out workers because they have to build that level of trust before they even tell you anything. And you have to get to know them enough to know what's real and what's not, what are they making up and what could be real, and what are they not saying that should be said. And that doesn't come unless you're spending time with them.

I: So the making things up, the confabulation, is that from memory gaps or from lack of trust or something else?

J: I think part of it may be that, especially with the fetal alcohol, especially with the stuff that I've learned with the fetal alcohol is that because they have an information processing problem, a lot of times bits and pieces get through. So they, those bits and pieces, and they try to make sense out of it. So they fit it together, however it makes sense or whatever consistent pattern they've seen in their lives, and they put those pieces together and that's what they tell you because that's their understanding of the situation. Other times, one of the things I've really seen with a lot of our people with fetal alcohol is a fear of disapproval.

I: So they try to please you, say what you want them to say. . .

J: So they'll just cover their ass. It's like they don't want you to think badly of them so they protect themselves in whatever way makes sense. Very much like a small child.

I: Because they don't want the rejection.

J: Yes, they don't want the rejection because they don't know how to process that information and cope with it. So if somebody's mad at me that means my connection with security is broken, so who am I going to go to now? So a lot of my people that have the fetal alcohol are very childlike in their need for reassurance. I've got one fellow that if he's done something wrong, whether I know it not, whether I have any hope to find it out, it will gnaw away at his mind because he knows I care about him. And he can't stand the fact that he's done something that I would be distressed about. So he will come and he'll tell me all the information. He has the desire to have that reassurance that he's still cared for.

I: So it looks like they are really attaching and bonding to you and to the staff.

J: Yes, and that's what they need. They need that long-term consistent care, and not just in a professional manner. I mean I get into trouble all the time because I cross boundaries. But with these people if you have too many boundaries you don't connect.

I: Right. You're just not going to reach them.

J: Yes, because it has to be more than just somebody, a professional, that's helping you. And that's why they don't really connect with the agencies in the community very well. Because that means that you have to go in and you might have to talk to a different person each time. Or if you do go in and talk to that person it's only once in a while. But if people will come and connect with them here and develop that connection in their safe zone, then when they go back out into the community they can draw them back out.

I: Do you try to encourage the agencies to come here and connect with them?

J: So, I mean Client Access Services, CPAS, or home care for short, they'll come here, the mental health nurses will come here. They'll come out to us. They'll do their assessments here. They go into that person's environment, but the services they're able to provide are largely medical. But the mental health nurses will come and visit with our people in their environment, which is a bonus. If my guys are going out to the doctor or to a psychiatrist a lot of times they won't go to their appointments . . . Because it's too distressful. So I go with them and now I've finally figured it out, I take a bunch of them all at the same time. So I took five people all to one doctor in the afternoon rather than spending so many hours because when you go to a psychiatrist sometimes it's like two, three hours that you're just waiting just to get in. And he was fantastic, he's my favourite doctor, I just love him dearly, and he works with a lot of people that have fetal alcohol.

I: He does?

J: Yes, it's Dr. RP. And he's very good, he's fun.

I: That's good to know.

J: And he's sensitive, but he's tough. But he'll speak to them about tough issues, but he's very wise and he connects really well with support people. He's happy to relate with support people. So we've developed a rapport over the years as we've dealt with more and more people and I actually will refer most of my people to him just because he is so positive. And he's not a real big pill pusher, he'll prescribe medication but he's very careful in what he's prepared to give out. He doesn't want them just pumped up and sluggish. So I've really appreciated that connection. And with doctors, I have one fellow living here who is paranoid-schizophrenic and very drug impacted and has had several brain injuries, so he's got a real complicated combination of issues, and getting him to the doctor is nearly impossible. So he has to be in intense pain but by then he's so frantic and distressed. I had to go with him to the doctor the other day, sit there, and then I had to go in and speak with the doctor because the medication that he needed would be considered a narcotic and normally not prescribed to somebody with those special needs. So then I had to go in and attest to the doctor I will supervise that medication. Then they were willing to prescribe it, and then I go to the pharmacy and the pharmacy won't release it to him. They release it to me.

I: Oh good, and you can keep it secure?

J: And then it's stored at the front desk and we're able to follow through.

I: Is it locked there?

J: Definitely. So although our medication program is voluntary, sometimes the option is you volunteer to have your medication supervised or you volunteer not to live here. Because we will not keep you if you choose to be unwell. . . . I'm in a meeting, David.

David: I need my laundry.

J: You need to wait. Sit down.

David: I have to go to work.

J: Okay. Can I stop for a second?

I: Sure. . . .

I: How many of the clients would you say over the years have been FASD, what percentage do you suspect have an FASD?

J: Probably, I would say probably at least a third of our population, and many of them with other complicating issues on top of that. We actually had one fellow, he had been adopted and they had the information that the mother had been a drug addict and an alcoholic, but they were told that their child just needed a lot of nurturing and he would be fine. And of course he wasn't and the family ended up in a terrible situation. The boy ended up being thrown out, the mother ended up in counselling after a

breakdown, and the family was very traumatized by it. And I was actually speaking to someone from the Fetal Alcohol Support Network and I was talking to her about this and she said, but imagine if he hadn't had a good home with that level of support what situation this young man would be in today.

I: It could be even worse.

J: It would have been much, much worse. And now at least he's got the social skill development that was offered in a healthy, normal family.

I: And he probably still has them.

J: Well, I think they keep him at arm's length to prevent the harm and now he is the father of three children and has been able to maintain his parenting relationship with the girl that he's got the children with and has continued to be, you know, he's got the skills now to be able to parent his own children to some extent. Whereas if he hadn't had that family. . .

I: He wouldn't have had those skills. Amazing. After the clients come here and you get them stabilized in the first 30 days or so, how do you introduce positive life skills?

J: A lot of it is one on one and instantaneous. So it's a case of being out there, mixing with them, having contact with them, asking them to come in. That's one of the processes I go through, I try and draw them in here to make this a safe place for them to come. . . . So then they'll come and tell me things or talk to me and it's a sense of privacy and security, you know. And a lot of them, they'll act like they're being called to the principal's office, and sometimes it is, it's dealing with issues. If we're dealing with hard issues and there's no harsh response to it they start feeling a little more safe. And which one of us doesn't screw up whether or not it is deliberate or accidental. And when they know that it's okay to make mistakes, you're not going to get thrown out, you're not going to be abused, nobody's going to yell at you. You made a mistake and there's some choice here now. What are you going to do so that you don't do that mistake again? And teaching them life skills, like understanding what is abusive, what behaviour is inappropriate. I had a fellow this morning, he was following one of the girls around because she owes him smokes. So he feels that pounding on her door, rattling her door knob, and following her around the building is not harmful to her. So I clarified to him that this is harassment and abuse and it's actually against the law. So not only is he frightening her, he's breaking the law which is unacceptable, and that his continued behaviour would result in expulsion from the building because we can't have people frightened to be here. So we're starting to build that understanding, but I used the same tone I just used with you. I didn't yell at him, I didn't bawl him out or anything, he was just being told this is unacceptable and we can't tolerate it. So regardless of your interpretation, whether you think it's abusive or not, I'm telling you this is the boundary we're setting and you have to cooperate.

I: So a lot of it is learning the boundaries and the social skills.

J: Yes.

I: Do they learn things like keeping their room clean and. . .

J: We're working on that.

I: Do they just tend to let things go?

J: One of the things actually that we watch for is the state of their room because it tells us a lot about what state their emotions are in because their emotional state always is reflected by their surroundings. So they may be either extremely meticulous, so it tells me right away that there's so much tension there that they could be explosive. Or they could be relatively tidy, and those are the ones that I think are more secure. And then there's the complete slob, they don't care about anything. And quite often those are the ones that also have very little regard for anybody else, for not only themselves, but nobody else, either. And quite often if they're not feeling well their surroundings start deteriorating and then their emotions go with it. So we work on all of this stuff. We talk to them and a little while ago I posted a note that said I'm doing room inspections, 'cause normally we have a housekeeper, it's very difficult to keep a housekeeper here because our clients have a tendency to be afraid of me, but not necessarily transfer that to the other staff.

I: You're the only one with the power.



J: So they will swear, yell, threaten, and call the housekeeper names, so it's very difficult to get a housekeeper because she's going into their space, so it's like you're invading a foreign country kind of thing.

I: The housekeepers actually go in their rooms to clean?

J: Yes, so we've been without a housekeeper for a couple of months and we're looking at it and thinking that, we've been wanting to change that role anyways, and we'd rather have somebody who would come in and do life skills instruction. That is, come in and teach them what do you really want to keep and what don't you. We have some packrats who keep everything, absolutely everything. We've got one guy, he's obsessive-compulsive and a schizophrenic at the same time, and you could never go in and dust or wash his walls because every space is covered meticulously with little notes about everything. And yet he will come down and he needs to know that his bed's is going to be changed, he needs to know someone's coming to vacuum, and he needs to know someone's going to do the bathroom. So he wants his world to be kept orderly and. . .

I: But nothing was to be touched?

J: Yes, but there's certain things you just don't touch. I have to help him because that's him out there at the window now. . .

I: Sure, go ahead.

J: (Turning to the window) What do you need, Barry? He longs for mail. I keep telling these guys I'm going to start writing them notes myself because they're so sad when they don't get mail. They could get my mail which is mostly bills!

I: Okay. What do you think remains to be done? Like where are the gaps for your people?

J: One of the big gaps is socialization, the recreation building. That's something that we at one point, that was actually my role when I first got involved with the complex, I was in the role of program manager. So I organized the social activities and got them out into the community. Like I said, they've become very cloistered here and it's very challenging for them to go out into that unsafe zone again.

I: Or transfer what they've learned here to the outside world?

J: And take it away. So one of the things that I used to do was organize the activity and then I would just have to practically drag them, just beg them to come with me. And after a while once they got a positive experience, then they would go more often, but then I tried sending them without me. They wouldn't go, and they were very unsuccessful, so we just didn't do it long enough, I think. And there were too many new components to it and they actually lost somebody. But that's something that we don't have the staffing for right now and I think that's a real challenge for anybody with special needs, is to develop recreation. They don't know what to do with their time, but because of their social behaviours and their impulsivity it's very difficult for them to go out and mix with the average community population as well. Because they get a lot of negative feedback, they don't dress right, they don't act right, a lot of times they'll. . .

I: They'll look scary or something?

J: Yes, so people will, you know, show it. Sometimes I tell other people, these are the people that you avoid on the street, you walk around them, you ignore them, and you don't make eye contact. And it's because of the way they present themselves, and even if they're not necessarily dressed differently, they just have this presence about them that some people find very frightening.

I: Right.

J: And they'll, they don't respect your boundaries so they'll invade your bubble space and things like that. But they're very, I think they're really precious, they accept people no matter what. They're not judgmental which is wonderful. Anybody who comes in is welcomed.

I: Oh. Good hospitality then?

J: Well part of the issue is that they have no boundaries, so they don't know how to protect themselves in any way so anybody's welcome. And then hopefully it's a good person because if it's a bad person they're going to be exploited. So they're very susceptible to exploitation, but the fact that they just welcome people and. . .

I: How do you get them to respect other people's boundaries and possessions, you keep the doors locked, I guess.

J: Yes, the doors are locked and there's very clear specific rules that they're required to follow and there's a lot of support in co-operating with those. I mean the fellow that was harassing the other girl this morning, he had just come into my office and asked for a list of the rules. So I had copied the rules that we had in the application and nothing in there said you can't harass people. But it did say you need to respect other peoples, but he didn't make the connection with harassment and respect because he doesn't think what he's doing is harassment. So he maintains that it's not in the rules, so how can you say I'm not allowed to do it, it's not written down in the rules.

I: So he thinks quite concretely then

J: Oh, very. Very much so.

I: What about grooming and things like that? Do they have to wash and bath and wash their clothes?

J: We get after them if they're not, usually because their peers start complaining. We've got one lady in the building that has such a chronic issue that people, just as soon as they smell her they get mad and they'll actually be quite rude to her. And I've actually denied her meals and I've told her, you need to go and bathe. I'll put your meal away, but you need to go and bathe and change your clothes, because for a while there she was bathing but then she put the same clothes on, so she smelled the same. So she had to have that developed for her, that concept that your hygiene affects other people and that you need to get out of bed once in a while and wash your clothes. Don't tell me that you're wearing the same stinky clothes, that you can't bathe and change because you're too lazy to do your laundry. So she had to be taught that you need to come down, do your laundry so that you can bathe and change and then people will treat you kindly. So all of those social skills, she didn't have them, and we're still working on them. We still have to tell her two or three times a week, go and bathe.

I: And how old do you take them here? Is there any age cut-off?

J: There's no cap. They have to be able to self-care. So the oldest person we've had here is 92.

I: Oh, really.

J: And the youngest person's been 15. We've had a lot of people who have passed away.

I: Is that tough?

J: It's really tough. We had one guy here for three days, he'd come out of a care home and he was a crusty old guy. And he'd been addiction free in the care home probably largely because he couldn't access alcohol because he was also physically handicapped so he couldn't get to where he wanted to be. But he moved in here and the bar was still open next door as this was once a hotel, so that was a nightmare.

I: Oh. That would be a problem.

J: And he talked somebody into going to pick up alcohol, but he was also on Dilaudid, which is morphine.

I: Oh, no.

J: And at the time we didn't have the same type of controls in place on the medications, so he overdosed and died.

I: Oh, my goodness!

J: And I was the one who found him and he had actually died with a terrible odor, like people with diabetes also have this terrible smell that they put out when they die, and it was just very distressing to me. But we've also had people that we worked with that have been evicted from here, but maintained contact with our trustee program, who lived within the community that have pass away, as well, from overdoses. And it's hard because to me they're part of my family and I've invested a lot of time, energy and emotion into caring for this people. And sometimes you look back and you question, was there something I should have done, just one more thing that could have made a difference. Would that person have benefited if I just took the time to listen to that person talk.

I: It is almost like raising children, you feel responsible for them.

J: Yes, well they are because they're dealing with hard, hard lives. Some of these people are just, you wonder how they could be so well considering what they've been through and just been traumatized, victimized and abused. And the girls especially have just been through horrific things.

Most of them have been prostituted. One little girl that I worked with, she was fetal alcohol, her mom was a coke dealer, and was using her children as mules. And this little girl being fetal alcohol didn't keep her mouth shut. You know everything's exciting, you talk about it, right?

I: No discretion.

J: So she told, her mother went to prison, the little girl went to a foster home and was very ill-treated, there was no compassion for this little girl at all. If I could find that foster family, boy I would have some things to say. They had Christmas for their own children and didn't do anything for the foster children. And she spent her whole Christmas crying in her bed, and felt so completely unloved that she ran away. The person that she ran away to was a person she knew who was one of her mom's drug suppliers who also ran a triple X dirty dancing club, and she ended up being put in the back and taught how to do blow jobs. And then finally at the age of 11 she was raped by him and ended up with a child. Her mother gets out of prison and her mother gets the child. Her mother gets custody of the child and the daughter goes back to the streets. And then her mother has the nerve to stand in judgment over this little girl.

I: She contributed?

J: She did everything that she could possibly do to destroy this little girl, and at 24 years old this little girl couldn't take it anymore and overdosed.

I: Oh, no.

J: And, four children that she ended up having, and every child was taken away from her. She was wild and out of control, but she was the most amazing little girl. She could love people. And you'd think after all the abuse and terrible, terrible things that happened to her that she would lose that ability. We went to court because she had been attacked and raped, but because she was a prostitute and because she admitted on the stand that sometimes she doesn't tell the truth, the prosecution shut the case down. Even though when the police had shown up, this little girl was found naked outside this man's house pounding on the neighbour's door begging for help, the police showed up, went into the house, found the guns, she could describe the house perfectly, everything. All that came together, but because she admitted that she tells lies sometimes, and because she was attention deficit hyperactive (ADHD), the case was thrown out. When we first went to court she didn't have her Ritalin yet so we had to take a break in court and go get her Ritalin so that she was able to sit still and testify. But they decided that there wasn't enough evidence and this guy walked away. And yet she could still come in here and just bounce, she was the funniest girl I tell you 'cause she bounced all the time. Until she had her Ritalin she bounced and you could have a conversation with her and she would bounce in front of you in circles and almost make you dizzy. So you just had to keep working and listen.

I: And Ritalin would help?

J: Oh, as soon as she had the Ritalin she was down like that, and she could calm down and think but she had no impulse control and was so devastated by so many of the things that had happened, especially having these children pulled out of her arms. And there was no way for her to care for them, she couldn't, she just could not manage. But if she had been able to live in a home where her children were being raised and she could, when she was well, be a part of those children's lives.

I: Or have wrap-around family foster care, like care for her and her children together.

J: Well, her family was incredibly unhappy.

I: But have a foster family wrap around her and her family.

J: Right. If only they had wrapped around her early enough in the process. I mean her addictions were out of control and we couldn't manage her. We tried housing her here and she was the most out of control girl and pretty much brought everybody that she had contact with down. But she also came to my office one time with this little bearskin rug and she laid it on the floor and she said, can I just lay down on this in your office? She just needed to not be alone, and she curled up on that little bearskin rug and laid there and told me all her stories. And they were the most tragic, broken stories and she just wept and I

was feeling like, who's there to wrap their arms around these people, you know. So that is what we try to do.

### **Researcher's Commentary and Interpretation:**

J.'s poignant stories of emotionally connecting with and supporting traumatized, mentally ill individuals in an inner city homeless shelter, who are often struggling with a number of co-occurring conditions along with FASD, are illuminating. She has considerable insight into their lives and the challenges they encounter. For instance, she observed that conventional addiction, social welfare, and mental health services do not work well for them, as these individuals need to establish trust, intimacy and a stable relationship over time with one counsellor who understands them and the manifestation of their disabilities in daily life, as well as in the therapeutic encounter. In a safe, secure, accepting and familiar environment, they do best with patient, compassionate, consistent assistance in the context of learning to cope with the activities and responsibilities of their daily lives, without having to make transitions and generalize from one situation to another. Instead, they can focus on learning boundaries, impulse control, social and life skills in one context, and in the process experience acceptance and success. In any program, rules and their enforcement should take into consideration the disabilities of individuals with FASD. A harm reduction method is preferable, accepting that mistakes can happen, dealing with the consequences of mistakes (asking what can be done now?) as well as attempting to learn something from them (what can be done to try to prevent this happening in the future?) although external supports will likely be needed to implement the latter.

### **Interview with L., non-Aboriginal adopted parent of two adult Aboriginal children who have diagnoses within FASD; L. is also an occupational therapist and a researcher on FASD and supported housing**

L: People with FASD consume large amounts of their staff time and their caseload levels don't allow for that time. Often rules are too stringent for people with FASD to fit into, like if you miss three appointments, you're out. Because agencies themselves are being so constrained by their funding, they've had to set rules. And that's really important when you get to things like Community Living Division. So even if you have an IQ under 70, because it's voluntary services, what they say is that

voluntary service means that if you don't show up to appointments, you're voluntarily saying you don't want their services.

I: So they cut you off then, even though a sense of time is part of their disability?

L: Yes, and when you get into the shelters, inappropriate behaviour is enough to get you kicked out.

I: So these general services don't really fit?

L: Right. Now they could fit if they changed their mandate. And, of course, people also impulsively leave services of their own accord. So an agency may bend over backwards for somebody, work really hard just to have them all of a sudden disappear. *Another big problem is that many are not able to offer the practical hands-on training that's needed by people with FASD, so many, many, many of them take a cognitive behavioural approach, and it just doesn't fit for people with FASD.*

L: That's true of corrections as well.

L: So many of those services, that's also the approach they take. So when we say somebody has FASD, they say, then we won't provide services, it's because of that. So that's in general. Now, the emergency shelters absolutely lack the intensity needed. This is true for even places that have good staffing, such as relatively good funding in comparison to let's say the Salvation Army. The Salvation Army here has two staff that look after all of the beds that's at the Hostel and the transitional housing options.

I: That's not enough.

L: All they can hope to do is keep people alive. In terms of transitional housing, things like activities of daily living training are not part of the mandate of the halfway houses. Virtually, the only transitional housing that's available for men is halfway houses. That's virtually the only thing that's available in the city.

I: And they don't teach daily living skills?

L: No, that's not part of the mandate. They have some anger management courses, addictions courses, but they don't see it as their mandate to teach people how to cook, clean and grocery shop. Now, an individual worker may take that on, but again, at the Salvation Army transitional halfway house, you have 20 beds. How many people can you do that work with one staff on duty?

I: It's impossible.

L: And, of course, the offenders with FASD are likely to be victimized, we know that. Not just by other offenders, but also within the neighbourhoods where the halfway houses are located. The Salvation Army staff talked to me about how the chronic FASD who are basically living in the Salvation Army are typically victimized, beat up, people grab their money from them, whatever pennies they have. And of course, there's very limited availability of transitional housing here in the city period, for either men and women. The biggest gap in terms of transitional housing is ages 16 to 24, and for our FASD population, up to 29 year olds. I think that we have to extend the upper limit. . . the assumption is by age 24 you should be able to function as an adult, but not with our FASD population. I think you need two transitional housing levels for youths. Sixteen to 24 year olds would be one group, and then 24 to 29 year olds would be another. I don't think these two age groups should be in the same unit.

I: No. The 16 to 24 year olds function at a much younger level.

L: If you're going to maintain some order. There's almost no long term supported housing availability. There is very little low-income, long-term housing, period. And then very few of the FASD population fit into social housing. So they end up in really terrible living conditions, and what was described to me by the youth and the families was just again a complete heart breaker.

I: Can they get things like Home Care?

L: Usually that mandate doesn't cover such services for them.

I: If they've never kept house, or organized a house, or gone shopping, or cooked.

L: Yes, well exactly, that's one of my recommendations is that Home Care needs to be . . . the mandate needs to be widened to allow for that kind of training. They should be doing the training in supportive living. Yes, it's a difficult system. I can understand that. But we're not going to be able to build totally new systems.

I: I know. We have to use what's there, try to train them.

**L:** Yes. One of the things that I ran across here is the government people in BCRE said that they thought most of the supports could be done through volunteers.

**I:** HRSDC as well.

**P:** So I've also developed an argument around that because . . .

**I:** Volunteers aren't going to be 24-hours a day. And they're going to come and go, yet we need consistency for individuals with FASD.

**P:** Yes, so that's what I've done there. In terms of resources, people with FASD need lifelong consistent support plans, daily in-person contact, and 24-hour access to services. Adequate funding levels, so that they can carry consistent teams with low caseloads. And costs of providing services, of course, will vary depending on the person and the individualized assessment, what they need.

**I:** And your research:

**P:** I interviewed: 14 individuals with FASD, their families, NGOs and Government Agencies  
Demographics of FASD sample of 14 individuals-- average age: 24.2 years; range: 16-38 years; 30's (32 & 38), most were 16-27 years, in that range.

7% were involved in long term relationships with a partner. A hundred per cent of women were battered by partners; all of the women spent time in shelters; 30% were in transitional residence at the YWCA, 30% of the beds were taken up by FASD (5 beds). In Transition House there were 7 bed and one of these was always used by a woman with FASD. Eighty-six per cent of the 14 FASD individuals were parents; 21% of these had their children in their care; and 93% of their children had been in care at some point. Twenty-five per cent had completed grade 12; 21% were attending adult education programs (but two months later only 7% were attending adult education programs).

Many had relationship problems, had been in psychiatric wards, addiction crisis (100% had addiction problems), methadone program. Some had children with FASD, one mother admitted to use of alcohol during pregnancy. Problems with addictions and then pregnancy is very real with this group.

9 FASD interviews were conducted in Corrections through Parents/agencies/ youth justice forum (partly advisory regarding auto-theft)/ Circle Project/ Oksana Halfway House

Question: What can we do for other people who have similar problems? Answer: Respect and caring are important, and people who will stand by me and care for me.

86% were unemployed; 60% were incarcerated at least once; 60% had a formal diagnosis (mainly adoptees); they experienced significant intellectual disabilities when faced with school system.

Homelessness—one spent three months living in a field on the reserve; 93% had experienced absolute homelessness; 100% experienced relative homelessness; average number of moves: 3.6 times per year; 2 were homeless at the time of the interview; 22% had stable housing (1-2 months). The current Back-up Plan is either Regina Community Clinic and/or the Circle Project worker.

### **Researcher's Commentary and Interpretation:**

L. is very clear about the kinds of programs and supports that are effective for adults with FASD. Rules should not be so stringent that person with an FASD does not have the ability to comply with them, that is, rules should accommodate the disability. For instance, individuals with FASD may require someone to accompany them to appointments, rather than be expected to attend the appointments on their own. Supporting individuals with FASD requires more time than conventional support systems plan for or budget. Rather than either cognitive-behavioural

approaches using punishment and rewards, or didactic approaches using oral and textual instruction, individuals with FASD require consistent, practical, concrete, multi-modal, hands-on, experiential approaches in the context of their daily living. Moreover, people with FASD need lifelong consistent, specific, support plans, daily in-person contact with mentors, as well as 24-hour access to services. Such a level of support requires adequate funding levels, so workers with low caseloads can carry consistent teams of clients with FASD. Consequently, costs of providing services will vary depending on the person being supported and on the individualized assessment of what that person requires in the way of supports and accommodation

**An Interview with LR, a Man who has both FAS and Schizophrenia. LR's Mentor, J., was present during most of the interview.**

I: J. is here as a mentor to LR and she's going to be present during the interview at his request. LR is going to tell us about his experiences as an individual with FASD, the challenges he's encountered and how he's overcome them, and what seems to work for him so that we can share these kinds of solutions with other individuals with FASD to make their life adjustment easier. LR is there something in particular you'd like to say about growing up with FASD and how you learned to cope?

L: Basically I just, it all started off when I was like 5 or 6, 7 growing up. I didn't get into alcohol until I was 17. But I'm basically trying to learn from different people and other things. I have talked to other people. Basically I just try and stay out of trouble.

I: And have you been successful doing that?

L: Yes, I have.

I: Okay. Good. So did you grow up in your parents' home, in a foster home?

L: My parents' home.

I: Your parents' home. Okay. And how was it growing up with FASD? Was that easy?

L: Just learning disabilities.

I: Okay. So school was a bit tough?

L: Well welfare sort of put us in a program where you're grown up and it's like high school kind of thing but it was more like a job interview and stuff like that.

I: So it was sort of a self-training program?

L: Yes

I: And did you do some work experience and things like that?

L: Yes.

I: How did that go?

L: It went pretty well. I have worked in the past.

J: Tell her your favourite place to work.

L: Oh, my favourite place to work is the circus rides.

I: Oh. That would be interesting! Do you get to go on the rides too?

L: Not really because they want people working there.

I: Okay. Did you sell tickets or usher people onto the rides or what did you do?

L: I did both actually.

I: Oh good. It sounds like an exciting job, then?

L: Yes.

I: Are you going to be working there again this year?

L: I don't think so. I'm kind of afraid of getting another hernia I guess.

I: Oh. You got a hernia last time?

L: Yes.

I: Okay.

L: I've been really working out too much.

I: Oh, overdoing the weights were you?

L: Oh, no. It's not the weights. It's the heavy steel, setting it up.

I: Oh, for the rides you mean. Okay. So you had to set up the rides as well and it's heavy work is it?

L: Oh, yes.

I: And you got a hernia from that? Okay.

L: Yes, I was out in Great Falls Montana when it happened. And everyone else was getting sick from, I don't know, heat stroke.

I: And you had to do all the work, did you?

L: Yes. I just all of a sudden I felt that pain inside me and it went to my head and all I could hear is this ringing in my ear.

I: Did you get to a doctor.

L: Yes, and the hernia got operated on.

I: Oh, good.

L: I'm just afraid that I might get another one.

I: Right. So you can't do that heavy work anymore. Oh, that's too bad because you liked the circus. So, how was elementary school, how did you enjoy elementary?

L: Not good.

I: Not good. And they didn't find ways to help you?

L: Well, I got a little bit fed up with some of the girls would start bugging me, constantly bugging me.

I: Kind of teasing or?

L: It was nasty over there because they would call you down. I was just a scared little boy, that's what got me drinking. 'Cause my parents were drinking and I just basically started that because everything that was going through my head.

L: I was in that room and all I could hear was thousands and thousands of people talking to my head, my ears.

I: Did you know what it was?

L: I think it's just part of my condition.

I: Okay. Did you know at that time what it was? No?

L: No. I was just hearing voices and voices and more voices.

I: Oh, and what were the voices saying or what did they ask you to do?

L: Nothing.

I: Nothing, just a loud noise? Not one particular message or anything? So how were you able to cope with these voices? Did it cause you to drink to get rid of the voices?

L: I don't want to talk about it.

I: Okay, you look uncomfortable. Do you want me to stop the tape?

L: Nods in agreement. Tape was stopped.



### **Researcher's Commentary and Interpretation:**

LR was a very fragile, vulnerable person, diagnosed with two complex conditions, FASD and Schizophrenia, who experiences auditory hallucinations. He required considerable emotional support from the staff at the shelter, especially J., and the staff carefully supervised his medication. LR became obviously insecure and uncomfortable about the interview when J. had to leave to turn her attention to another issue at the front desk, and the topic of his voices or auditory hallucinations inadvertently came up. When asked if he wanted to discontinue the interview, he nodded affirmatively. Neither did he wish to resume the interview when J. returned. Perhaps he has experienced stigmatization with regard to his illness and did not wish to risk further negative consequences.

**Interview with PA, Adoptive Mother of Mary and Mark, Children with pFAS and FAS, respectively. Mary was 27 months at the time of adoption and 15 years of age at the time of the interview; Mark was 4.5 years old at the time of adoption and 18 years of age at the time of the interview.**

I: Does the family facilitator service worker or counsellor have any special techniques for working on self-esteem issues with Mary?

PA: She uses lots of different games which address feelings, talking about feelings, and problem solving social situations.

### **Researcher's Commentary and Interpretation:**

Talking about feelings and helping Mary to recognize her feelings is useful therapy. For instance, if Mary feels badly and recognizes that she feels sad, then she can do something she likes to raise her spirits, and thus learn to regulate her emotions. On the other hand, if she feels angry, frightened or panicked and can recognize or name that emotion, she can learn positive ways of handling these as well, such as calming techniques, taking deep breathes, counting to ten, thinking pleasant thoughts, doing something she enjoys such as writing in her journal or listening to her I-pod music, in order to reduce stress, build self-esteem and self-control.

## **Interview with Aborigine woman from Queensland, Australia, Researcher, Mother and Grandmother of Children with FASD**

I: Getting back to your research with your healing stories, have you been doing this for ten years, your stories. Yes and you see development in these people that have problems with alcohol or have FAS . . .

L: Yes. I see changes.

I: Changes. Are they becoming more functional?

L: Well, one example is one of the individuals is now studying psychology. So that's a big change coming from being someone who had a drinking problem, had a lot of children, a victim of family violence, she was being beaten all the time. And she's so empowered now, she's working and is studying to be a psychologist. So that's pretty amazing.

I: It is. It's incredible.

L: Yes. And she's now there as a role model to support other people.

I: Oh my. So it can be quite transformative . . .

L: It's a slow process, but that's fine if it's only one or two or three. It's a start.

I: Right. And then they're role models for others and it can grow and spread. Well that's hopeful.

L: It is.

I: Is there anything in particular you would like to tell me that could be useful to others with similar struggles?

L: No. I really do think that creating programs that centre around behaviour change is the key to success. If you can't get the individual to recognize why they behave the way they do, they really can't change that behaviour. They might for a brief time and have a relapse, then have another go, and then a relapse.

I: Like a diet.

L: Yes, up and down, yo-yo. But if you can get them to understand and support them in that behaviour change. And it's a long journey but it can be a successful one.

I: But it's not going to be a quick fix.

L: No. But it's probably more stable than like a yo-yo diet. So if they go into rehab, have some treatment, have a few programs, and when they come out they might stay dry for three to six months, then they go back again. And it's just a continual process throughout their life. Whereas if we can get some concrete changes within their behaviour and get them employment and probably a bigger house, education, and things like that.

I: Then it gives them a purpose or goal with which to go forward.

L: That's right, yes. And a reason. Because if you take something away you've got to give them something back to replace it with. That's what we really talk about a lot is if you're going to take my alcohol away from me I need something back to replace it.

I: Right. Because alcohol does at least dull the pain I guess for a while.

L: Yes. And you know if you take them out and do programs with them, you know, out in the bush. Their programs are not just specifically around alcohol and why they behave the way they do, but like raising their self-esteem and building up self-image, making them feel good.

I: So you're strong enough to make changes.

L: And we have a lot of women workshops where women go away together and through drama and music and song and dance that we can release our feelings. So we bond together and strengthen. That's been quite successful cause the women ask, when are they happening again. When's the next one, when's the next one?

I: Oh. That's a good idea. That's encouraging.

L: Yes, because we like our music and our dance and our singing. It's very important in our lives.

I: So there's a lot of profound messages in your music, songs and dances?

L: And it's really difficult if we run those programs without ensuring that their children and their family are going to be safe for that time they're away, it might be for a weekend or a couple of days, they won't come, or they'll go and then they'll leave and go home.

I: Drop out.

L: Yes, drop out because they need to get back to their family.

I: That's quite a massive effort then on your part.

L: It is a big effort. Well, it's a community effort and the community contribute to the whole process. So they have a lot of like these feelings weekends or times away from the community. And it's good for women to get out of the community to get a different sort of vision of what's away from the community.

I: Right. So do you think the key lies in the women?

L: Well, at the moment it has been. Women are the educators and the ladies, care givers and supporters. They're even educating the men to become educated. You know, like, "come on son, come along and we'll help you along your road," you know.

I: Oh. Amazing.

L: It is. It's incredible.

I: The women are the strong ones here too. And the caregivers for everybody.

L: Well that's what they're like over there.

I: Oh, good, if they're anything like you.

L: We have burnout with a lot of our women. But it's not for too long. The problem is that they die early.

L: So we just try and strengthen each other so we can live a bit longer.

I: Is it diabetes or what?

L: Diabetes, cardiovascular disease, renal failure, hypertension is the major, malignant hypertension and high blood pressure. They're the main ones. Now there's the few cancers coming in, people with cancer and lupus, but it's mainly diabetes, heart disease, hear failure and renal failure.

I: A lot of dialysis

L: Yes. And they have to travel to have that treatment, three hours or eight hours, a couple of days, you know, and they don't want to be away from their family too long.

I: No, especially not if you're kind of marginalized in the main stream.

L: We have a lot of suicides as well, and the majority of them it's alcohol related illness, even the diabetes, it can be caused from the alcohol.

I: It can make it worse.

L: Well, you know you could feed them, the pancreas can calcify and then there's no insulin, so they then become a diabetic on insulin, you know dependent. And they really do suffer. We're now starting to get men in the community with amputations from the diabetes, because they smoke cigarettes too. That's the hard thing is getting them off the cigarettes.

I: Is it? It gets very addictive.

L: Very hard. They can still have their feet cut off and they still sit there and have a cigarette. That's the tragedy of it all, but these are the main contributing factors to our ill health. But I keep telling everyone, there's so much money being poured into the chronic disease strategy in Australia, but fetal alcohol syndrome is the starting point of chronic disease. Because if you have these babies that are born with these birth defects and if their heart's undersized, their kidneys are undersized or a different shape. The liver, the lungs, they're going to contribute or not make their life journey easy in relation to responding to being a healthy fit person.

I: No, they're compromised from the beginning.

L: And they're influenced by all these other toxins in the environment.

I: Right. What about HIV/AIDS? Is that coming into your communities or?

L: Some communities more than others, others there's probably one or two. But it's starting to come in. That was not the common thing, it's only just starting to come through. And hepatitis C is a major concern. And we're all sort of vaccinated against hepatitis B. So, if we live long enough the cancer will get us, and normally there's no sign, they're in their 30s and 40s when they pass away. So that's very young, isn't it?

I: It is, when we have people in their 80s and 90s, lots of people.

L: Amazing. We don't, we're a very young population. I mean I consider myself still young, but in my community and in our communities in Australia, I'm one of the older ones.

I: Well, then you lose so much without that older generation to guide you.

L: See by my family statistics I'm probably, I shouldn't make it this year or next year. So if I go, then that's my generation starting to go and we've only got these other two generations who are alcohol affected.

I: Well, there goes the wisdom and the understanding.

L: And we've got kids with FAS that are gone anyway (in foster homes).

I: Anyway our time is expired, so I thank you very much and I wish you all the best and hope we meet again.

L: Thank you for showing an interest.

I: Thank you so much for being so open. I'll be thinking of you and your struggles.

L: If you have a people to save, you struggle on. I hope our paths cross again.

### **Researcher's Commentary and Interpretation:**

A component of L.'s research with Aboriginal women of Queensland consists of conducting healing narratives with them, which she has been doing for ten years now. The healing narratives help the women to gain insight into their own behaviour. An important goal is to create programs that centre around behaviour change, but the first step is recognizing why they behave the way they do in turning to addictions. However, when talking about giving up alcohol, you need something to replace it with something else, and you need to support them in their behaviour change. It is a long journey with many relapses and struggles along the way. As they enter rehabilitation and treatment programs, then get employment, better housing, and education, a better life style provides them with a reason to persevere in the journey so that relapse becomes less frequent. L. conducts programs with them out in the Bush, building up self-esteem. If they feel good about themselves, their culture and community, then they are likely going to be strong enough to make positive changes. Part of the program consists of having women's workshops where they release feelings through traditional drama, music, song and dance, which are very culturally important to the women, and through these activities the women bond with one another and strengthen. However, for these events to be successful community organizers need to ensure that the participants' children have a safe place to stay while the women participate, otherwise the women will not stay in the program, but instead return home to take care of the children, but then their own problems are not addressed.

Women return from the programs and try to help the men. It is primarily the women who are the strong caregivers in the community. Unfortunately, however, they burn out and die early, many in their 30's and 40's from chronic diseases, such as diabetes, renal failure, hypertension, suicide, hepatitis-C, and now HIV-Aids is starting in the communities. The starting point of chronic disease is FAS, as babies that are born with related birth defects may have undersized heart, and kidneys that are not only undersized but also of a different shape, such as a horseshoe kidney, or the liver and lungs may be affected, so they are more susceptible to the impact of environmental toxins and to subsequent onset of chronic diseases. Moreover, some of the children with FAS have been removed from the communities into foster homes and do not return as adults. The result is that the communities are left with fewer mature leaders to guide them and the cycle deepens.

### **7.7.8 Theme 8: Attentional Issues**

Deficits in attention have long been associated with prenatal alcohol exposure. Children display deficits in focusing, selecting, encoding, maintaining and shifting attention, as well as an increase in impulsive responding and sometimes hyperactivity.<sup>165</sup> With attentional issues in mind, it is important to engage the child before beginning to read a story, give instructions, or teach a lesson, in order to make sure that her attention is focused, then use interesting, relevant visual, tactile, and kinesthetic stimuli to maintain her attention. Prepare and cue her for transitions from one task or activity to another, or from one classroom to another, through the use of visual schedules or visual clocks. If impulsive blurting out is an issue, use a talking stick or similar concrete, tactile device that can be passed around to indicate when it is each child's turn to speak. Often children with FASD do not understand boundaries, including spatial boundaries, and if so, it may help to clearly demarcate work areas and floor space for personal use in the classroom using coloured tape so that they do not intrude inappropriately on another's space.<sup>166</sup>

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<sup>165</sup> Markhew J. Burden, Alissa Westerlun, Gina Nuckle, Neil Dodge, Eric Dewally, Charles A. Nelson, Sandra W. Jacobson and Joseph L. Jacobson, "The Effects of Maternal Binge Drinking during Pregnancy on Neural Correlates of Response Inhibition and Memory in Childhood" (January, 2011) 35(1) *Alcoholism: Clinical and Experimental Research* 69-82; Ann Streissguth & Jonathan Kanter (eds.) *The Challenge of Fetal Alcohol Syndrome, Overcoming Secondary Disabilities* (Seattle: University of Washington Press, 2002) at 9.

<sup>166</sup> *Ibid.* at 81-82.

Many of these techniques can be modified for use with adults who have a diagnosis within FASD and accompanying attention issues.

Individuals with prenatal alcohol exposure may have attentional issues, with or without sensory issues. They may be diagnosed with co-occurring conditions such as Attention Deficit Hyperactive Disorder (ADHD) or Attention Deficit Disorder (ADD), or attentional issues may be considered solely a component of FASD. Often, an initial diagnosis of ADHD is made before an FASD diagnosis, which has limitations as an ADHD diagnosis does not recognize the extent of the neurotoxic brain damage caused by prenatal exposure to alcohol.<sup>167</sup> In addition, attentional issues in the two diagnoses, ADHD and FASD, are different. Individuals with ADHD have problems focusing and sustaining attention, whereas Individuals with FASD have particular problems encoding and decoding information, as well as shifting their attention from one task or activity to another. They require more time for tasks such as auditory processing, as well as assistance in making transitions.<sup>168</sup> They need to be prepared for transitions and cued to when they will happen and what will be expected of them. A transition may be switching or moving from school subject to school subject, activity to activity, teacher to teacher, classroom to classroom, from one school to another, or from school to community. The transition from elementary school to junior high or high school is particularly difficult for them to navigate as more transitions are encountered. The difficulty of these transitions is compounded when the individual's home placement is not stable, as when moving from one home or residential placement to another.

Attentional issues are illustrated through interviews with an alcohol exposed birth mother of a 17 year old son diagnosed with FAS; and with an adopted mother of two children, one male adopted at the age of 4.5 years and 18 years of age at the time of the interview who had been diagnosed with FAS. His sister adopted at the age of 27 months and 15 years of age at the time of the interview, diagnosed with pFAS.

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<sup>167</sup> Kieran D. O'Malley, "Preface," in Kieran D. O'Malley, ed., *ADHD and Fetal Alcohol Spectrum Disorders (FASD)* (New York: Nova Science Publishers, Inc., 2007) at vi and viii, Retrieved 1-2-11 from the worldwide web at [http://books.google.ca/books?hl=en&lr=&id=rm1KsvyZ\\_p4C&oi=fnd&pg=PR7&dq=adhd+and+fetal+alcohol+spectrum+disorders+kieran+o+malley&ots=J3sDMX](http://books.google.ca/books?hl=en&lr=&id=rm1KsvyZ_p4C&oi=fnd&pg=PR7&dq=adhd+and+fetal+alcohol+spectrum+disorders+kieran+o+malley&ots=J3sDMX).

<sup>168</sup> *Ibid.* at 52. (Kieran D. O'Malley)

**Interview with T., alcohol exposed birth mother of John, age 17, prenatally exposed to alcohol and suspected of having FAS. Mentor, K. is present during the Interview.**

**I:** How old is John?

**T:** John was born in 1989, so he is 17 now. He was born in Edmonton and his birth weight was 5 lbs. 14 oz. He was in an accident at age 13 months and was then hospitalized for 6 months. At age 3 he was diagnosed at Wascana Rehabilitation Centre with both delayed speech and adjustment. He is not able to concentrate or focus for very long and he does not understand boundaries. He was in modified school programs when we lived in Edmonton. One year ago he was charged with sexual touching (in Regina), and has had to make 5-8 court appearances because of that. His arm accidentally touched the breast of a female classmate while they were both running to get the ball while playing in the school yard at recess. John did not even understand what a breast was or why what he did was wrong. I called the police wanting a male role model to explain the situation to him, so that he would understand from a male point of view why one cannot touch girls in that area of the body. Instead of explaining to him, the police charged him and he has been very traumatized by the resulting court processes, even to the point of urinating on his bed.

My parents begin to give me alcohol between the ages of 6-8 years of age. They did this to put me to sleep so they could go out and party. I became addicted from a young age. I was in detox three or four times until I could finally quit and that is how John got it. I have MS.

**I:** So they were able to diagnose John's condition. How did John's development go? Was there anything that ...?

**T:** He's developing fine.

**I:** He learned okay at school?

**T:** Oh, no. He's slower.

**K:** He was put into a . . . when John was, gee I can't remember the age now, was he three, TP's Mom had some concerns about his development then, and took him to Wascana Rehab, and John was assessed. And I've seen his papers from there, too, and it kind of looks around the idea of possibly FAS, but never actually goes into it.

**I:** It doesn't refer him on?

**K:** No, it just says that maybe John has FAS because the Grandmother says that the Mother drank during pregnancy, and that's it. So what they did was, they referred him because John was, at that time his speech was quite delayed, and everything like walking, potty training, all of that was delayed. And they referred him to a preschool program.

**T:** Yes. Sunrise Preschool.

**K:** Sunrise Preschool. And it was for children with disabilities, and I think from the reports that I read from there is John started to thrive. He started to do a lot better in that environment and he was doing well, and they have followed-up a couple times and they thought that he was on path and he was at his age level then and doing okay to some degree, so they've never followed anything further after that.

**T:** He still struggles at school, though.

**K:** Yes. When did he get into, he went to the regular school program, right, then he started in Kindergarten in the regular program?

**T:** Yes.

**K:** And then at some point, I'm too sure where it is, they put him into a behaviour modification classroom, and it still wasn't identified as FAS. T. has all of his Report Cards from the time he was in preschool until now, and I've read through all of them, and it's the same sort of thing that you'd see in probably any child's Report Card who had FAS, that John isn't able to concentrate, he doesn't understand boundaries and touches the other kids' properties, and so forth. And if John would just try harder, he could do it. So that was the basic gist of every Report Card that he's had, wouldn't you say?

**T:** Yes.

**I:** And every FAS student's Report Card.

**K:** Yes, exactly. So I mean, I think, this is my own opinion here, is that I think the system failed John from the beginning, like you were saying. And several systems have failed him throughout his life, so that first reach for help from T.'s Mom, they missed it. They didn't follow up. The school board never followed up. And I'm sure if you come tomorrow you'll see a lot more missed opportunities. But he could have gotten help a long time ago.

**I:** And now the Justice System.

**K:** Yes, it's failing him.

**T:** And now we have to go to Court tomorrow.

**K:** Yes, it's failing him hugely. So, when John was put into the behaviour modification, so you know what grade he was in T? Or age he was at about?

**T:** I can't remember, but he was quite young.

**K:** I'm going to guess like grade three or something is when he put him into that special system. And then he did well from the Report Cards, somewhat. His capability to learn and John's IQ is normal. He's not below average for his IQ or anything.

**T:** He's very, like, smart, but he's slow, slow, like when it comes to doing work.

**I:** His pace is slow?

**T:** Oh, yes. Like he's always has to bring homework home because he runs out of time to do it at school.

**I:** Yes, one child may work too slow and one works too fast. So the pacing and use of time is not well regulated.

**K:** Yes. And then last summer, no, the summer before, is when John moved . . . T. was living in Edmonton at the time, and John moved there, so that would be the summer of 2003. John moved to be with T. in Edmonton, and T. set him up at a school that was similar to what he was going to here. It was a modified program. And John did very well in it, right?

**T:** Yes, he did.

**K:** And he did so well that the teachers told T. that he didn't need to be in it. Am I right?

**T:** Yes, they were going to put him into a regular class.

**K:** Right. And then that's when T. explained to you where she tried to commit suicide, and because of that and this other stuff that was going on in her life, John and T. moved back to Regina to live with her Mom to have that support, and when she moved back, they put John in the regular program here. So that just brings us to a year ago, and that's where John was charged with the assault. The assault was an accidental touching on the school ground, but he has made from five to eight court appearances on this charge and it has been very stressful for both John and T.

### **Researcher's Commentary and Interpretation:**

John was aged 17 at the time of the interview, although he appeared younger. He has trouble concentrating, understanding boundaries, has a slower auditory processing speed, and has trouble shifting his attention in order to make transitions. Although he has a normal IQ, because of his attention deficit he cannot complete his assignments at school and thus has homework to bring home every day.

A year ago he was charged with sexual touching as on the playground when his arm reaching out to catch a ball accidentally touched an adjacent female student's breast. John was not sexualized and did not even understand what a breast was or why what he did was wrong.



His Mother called the police wanting a male role model to explain to him why one should not touch girls in that area of the body. Instead of explaining to John, the police charged him with sexual touching, for which had did not possess any intention. He has been very traumatized by the resulting court processes including 5 to 8 court appearances, even to the point of regression by urinating on his bed.

**Interview with PA, Adoptive Mother of Mary and Mark, Children with pFAS and FAS, respectively, Adopted from Russia. Mary was 27 months old when adopted, and at the time of the interview was 15 years of age; Mark was 4.5 years old when adopted, and at the time of the interview was 18 years of age.**

I: Has Mary's attention span become longer with age?

PA: Well that is hard to measure, as when she is engrossed in something she loves to do, she displays very good attending skills. She also does better in one to one situations or small groups than larger general education classes. She is bothered a lot by all the noises which occur in busy classrooms (probably a sensory processing problem) and has difficulty filtering out what is important. But if the right crutches are in place she can attend pretty well (preferential seating up close to the teacher; having a quiet spot to retreat to, to do assignments and complete tests, etc.)

### **Researcher's Commentary and Interpretation:**

PA aptly summarizes the key points of attention deficit, including the importance of the following: engagement in something individuals with FASD love to do, one to one learning situations, screening out auditory distractions, strategies such as preferential seating up close to the teacher, and having a quiet spot to retreat to complete assignments and tests.

### **7.7.9 Theme 9: Social Skills, Developmental Level, Life Skills and Adaptive Functioning Level**

Due to emotional and social delays, as well as delays in executive functioning and memory problems, including slower processing speed, individuals with FASD lag in age-appropriate development, termed adaptive functioning level. Expectations need to be adjusted to take into account each individual's adaptive functioning level, which can vary from skill to skill, as in some ways an individual with FASD may be ahead of her years, in others behind, or at age-level in other areas. For instance, an eighteen year old chronologically, may be physically mature with strong expressive language, but her social maturity may be that of a 12 year old, with math skills those of an eight year old, reading decoding skills at age 14, and reading comprehension at age nine.<sup>169</sup> Variability in adaptive functioning level that is not age-appropriate is termed dysmaturity. When dealing with inappropriate behaviour with FASD individuals it is recommended to “think younger,” and to consider that problem behaviour may be due to dysmaturity rather than non-compliance. For them, the timetable to achieve responsible behaviours and skills needs to be extended. Functional or adaptive level assessments were included as part of the discussion on brain domains, and these assessments should be incorporated as part of each individual's case management.

Inconsistent performance is characteristic of individuals with FASD, such as having “on” days and “off” days, which is characteristic of those with memory problems, other cognitive impairments, and dysmaturity. Such performance variability needs to be recognized as part of the disability, rather than assuming that they can do well all the time if they try harder. An eighteen year old with math skills of an eight year old, reading comprehension at age nine, and social maturity of a twelve year old, but who looks and sounds eighteen requires a very different approach in the family, classroom and community. Burnout can result if individuals with FASD feel they can never meet expectations and are penalized for it.<sup>170</sup> The gap between expectations and performance is greatest at adolescence, a time of rapid growth and development, along with increased freedom and responsibility.<sup>171</sup> So often adolescence is a time of crisis for individuals with FASD who functionally may not be ready for new responsibilities and challenges, but want

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<sup>169</sup> *Supra* note 6 at 26-29. [Diane Malbin, *Tryng Differently Rather than Harder*, 2<sup>nd</sup> ed. (Portland, Oregon: Tectrice, 2002) 26-29.]

<sup>170</sup> *Ibid.* at 28.

<sup>171</sup> *Ibid.* at 29.

to be treated like their age peers. Adaptive level functioning gaps can persist into adulthood and supports are often needed across the life span, especially if the individual affected is also parenting children with FAS.

The theme of Social Skills and Developmental Level, Life Skills and Adaptive Functioning Level is illustrated in the following two interviews: one with an adoptive mother of two siblings, a male with FAS and a female with pFAS; and one with a First Nations single mother who has a diagnosis of FAS, age 29, with two First Nations boys ages 7 and 8 years of age, both diagnosed with FAS.

**Interview with PA, Adoptive Mother of Mary and Mark, Children with pFAS and FAS respectively. Mary was 27 months at the time of adoption and 15 years of age at the time of the interview; Mark was 4.5 years old at the time of adoption and 18 years of age at the time of the interview.**

I: How are their life skills and social skills?

PA: Mark has never returned home but it seems from what I hear from people in the community, that he is retaining his dishwashing job at a local restaurant, pays rent on an apartment which he shares with two girls, and must be surviving. We are convinced that he developed strong survival skills in Russia in order to survive the neglect, etc. of his birth family; he is now able to utilize these skills to survive in the community. He refuses to follow any rules, needs to be in control off everything, and is an addicted person (cigarettes, alcohol and drugs), and has frequent problems with law enforcement. Mark is a very pleasant young man and well liked by others until they realize that he is manipulating them and using them for food or money. New friends only last for a couple of weeks until they figure out what makes Mark tick. He also steals and lies and conjures up huge stories which have no truth whatever, but is able to convince others that these stories are true. He has been described by one psychologist at the last treatment center as a "chameleon" as he is able to adapt to any situation he falls into. He does not seem to have a solid personality as this changes as his needs and circumstances change. He is impulsive and rarely thinks about consequences before acting.

Mary is very social and I am sure that this is why she loves school so much. However, she will rarely invite school friends over on week-ends but instead does most leisure activities with her best friend who is only 13 years of age. We see Mary as really younger than her 15 years, in many ways, so this strong friendship with this girl is OK for now. Mary loves playing with younger children and is a great babysitter. As far as life skills she is learning to be more independent caring for her own things and her room, loves to help in the kitchen and has mastered some very simple recipes. She is independent with showering and hair care, but needs lots of encouragement to shower each day and to keep up with laundry so she has clean clothing to wear. She is not into boys, and does not care what she looks like when she leaves for school. So it is a struggle to keep her clean and neat. She is able to find her way around our community if she is familiar with the area.

### **Researcher's Commentary and Interpretation:**

Dysmaturity in adaptive level, social skills and life skills are evidenced in Mark and Mary, and some of their behaviours may be based on their adaptive skills or developmental levels lagging behind their chronological age. Mark is very egocentric in development, characteristic of a younger age, becoming dysfunctional in terms of social relations, addictions and problems with law enforcement agencies. Mary, age 15, likes to play with younger children, and is not interested in boys nor personal appearance and grooming, again, characteristic of a younger level of development than her chronological age.

### **Interview with S., First Nations woman with FAS age 29, singlemother of two First Nations boys diagnosed with FAS, ages 7 years and 8 years of age**

I: You mentioned this Circle you go to.

S: Yes, it's this sharing Circle at Tamara's House. And we usually talk about how our week is and sometimes how it is with the kids and stuff like that. And like there's all just women and yes, we all share the same experiences, especially when it comes to children.

I: So you're mostly moms, young moms, fairly young moms, and you'd be about 30 now, would you?

S: I am 29.

I: 29, okay. So it's other young moms, are they mostly single moms too?

S: Some.

I: Some. So you're with people who have a somewhat similar life situation to yours that you can talk to. Do you find that helps at all?

S: It does. They actually mention some other situations and how it works for them and then you pick up stuff from that like that and well it helps.

I: You try what they suggest worked for them or you see that you are not the only one feeling this way or having these problems, that type of thing. You don't feel so alone. You mentioned you sometimes got out of patience because you have to repeat things so much to the children.

S: Yes, I usually just, when I go like that, when I'm just frustrated I'll go in the bathroom and kind of. . .

I: Calm down?

S: Calm down and I'll just let them do whatever they're doing until I calm down and then I'll, what helps too is my native culture.

I: Oh good, that helps, can you tell me how that helps?

S: Well, it just makes me centre myself more, and I smudge and pray.

I: You smudge and pray and calm yourself that way?

S: Yes.

I: So it helps you, your culture and your spirituality, to control frustration.

S: Yes, to control that and also.

I: The bad energy, or the anger and frustration. And also what other strategies do you use?

S: Just basically timeouts and my culture, even writing helps, like writing how I'm feeling, stuff like that.

I: Do you have a book you write in?

S: I did, but I'm thinking of getting another one here.

I: And then do you ever read through it again afterwards?

S: Yes, I do, like after maybe. I had like some from like years ago and I was like wow. You know, I've just really come a long way since, because I remember being, most of my life I've been a single parent. I left their dad, my boys' dad, when my baby was three months old.

I: Oh. Was he helpful or not?

S: No. He was abusive.

I: Oh no. With you or with the children?

S: With me.

I: So you had to leave him?

S: Yes.

I: Okay. Do you ever see him or does he see the children?

S: I don't know, maybe once a year, not even.

I: Okay. Does he help at all?

S: No. He doesn't help.

I: So do you feel sad about that?

S: No, because it's actually him missing out, not me.

I: Not you. He's missing family and the kids. Do you ever get depressed or things like that?

S: Yes, I get depressed a lot actually. When I was working and going to school I got really depressed where I just didn't want to do anything that was too overwhelming.

I: So you were kind of shutting down. So how did you get out of that?

S: Being around more people and talking about how I was feeling and I guess basically reaching out to people that care about me and stuff.

I: It seems like you're a nice warm person, so that's a skill that you have or a gift that you have to support and sustain yourself. What about managing money and things like that?

S: Budgeting?

I: Yes, some people have trouble doing that.

S: When I was in Brandon I actually took a budgeting, well that was one of the courses that was a must for parenting.

I: Oh good. Oh, that was part of the parenting class. And did they teach it in a way you could grasp it?

S: Yes.

I: Was it practical?

S: It was practical, yes.

I: Did they take you shopping and.

S: No, they would just like sit you in front of like a chalkboard or, you know, and just kind of explain, like okay, this is how much money you have and you have to like pay for the rent and pay for the bills and get clothes and stuff like that. And they would have like maybe three different cans where you'd put like the receipts from your rent or your bills and then, or your clothes.

I: Utilities?

S: Utilities and stuff like that.

I: Okay. And did that work?

S: It worked.

I: So it helped to organize you.

S: Yes.

I: Okay. And did anyone come to your home to help you or you just went to the centre?

S: I just went to the centre.

I: You did well then. So did they give you any strategies to use if you ran out of money? What would you do then?

S: Well, I would go to like maybe the food bank or somewhere, or yes that's the biggest place.

### **Researcher's Commentary and Interpretation:**

S. explains how an Aboriginal sharing circle with other women her age helped her to adjust to the many demands and frustrations of being a single parent who has FAS, as do her two young boys. She learned how to deal with emotions, such as anger and frustration, on the one hand, and depression, on the other. Life skills training in another program helped her to learn to deal with budgeting and running a household, thus helping to produce more stability in their lives. S. has a pleasant personality and is very sincere and eager to learn helpful skills, all of which are assets for her and her family.

#### **7.7.10 Theme 10: At Risk of School Leaving and Falling by Default into the Justice System: Structural Adaptations to Avoid Adverse Consequences**

As has been noted previously, 60% of a prospective longitudinal study cohort of 415 individuals with FASD experienced problems with school such as suspensions, expulsions and dropping out, and 60% experienced problems with the law.<sup>172</sup> Evidence indicates that problems with school leaving are related to increasing involvement with the justice system. Bredburg speculates that the reluctance of educational systems to address the medical model of disabilities such as FASD, is a contributory factor and could be ameliorated by viewing FASD as a functional diagnosis with something to contribute regarding eligibility criteria for special services and for planning effective programming and placements for students with FASD at their respective levels of adaptive functioning.<sup>173</sup>

Moreover, disciplinary measures should be informed by and accommodate students' disabilities, such as memory deficits, inability to appreciate consequences, dysmaturity, and aversive responses to over-stimulation, including the need for de-escalation and calming

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<sup>172</sup> *Supra* note 5. [AP Streissguth, HM Barr, J Kogan and FL Bookstein (1996) *Understanding the Occurrence of Secondary Disabilities in Clients with Fetal Alcohol Syndrome and Fetal Alcohol Effects (FAE)*, Report to the Centers for Disease Control and Prevention on Grant No. R04/CCR08515 (Tech. Report No. 96-06) Seattle, Washington, Fetal Alcohol and Drug Unit), cited in Ann Streissguth, *Fetal Alcohol Syndrome, A Guide for Families and Communities* (Paul H. Brookes Publishing Co.: Toronto, 2001) at 109.]

<sup>173</sup> *Supra* note 75 at 321-322. [Elizabeth Bredburg, "FASD and Education Policy: Issues and Directions" in Edward P. Riley (ed.) *Fetal Alcohol Spectrum Disorder, Management and Policy Perspectives of FASD* (Wiley: 2011) at 321-322.]

techniques, along with the risk that suspension and expulsion from programs pose for their involvement with undesirable, dangerous and criminogenic elements in the community. Law enforcement and probation officers should be similarly aware of these factors in their dealings with individuals with FASD. Functional behaviour analysis and positive behaviour support in an appropriate setting should be used in lieu of punishment. Input from parents and caregivers should be sought and respected, but due to the stress involved in parenting children or youth with FASD, parents should not be expected to intervene in behavioural episodes nor to supervise the child at school, including the dispensing of medication to the child while at school. Nor should a teacher be expected to cope with the student in a large instructional group without the assistance of teacher aides and special learning tools and strategies.

Special learning tools and strategies include those that assist with sensory issues, meet the needs for multi-modal, experiential, one to one instruction and full-time supervision. Due to functional deficits, learning takes longer for many of these students, so that rather than truncating their school careers through suspension, expulsions or other disciplinary measures, years spent in appropriate schooling might need to be lengthened for them, until their adaptive level of functioning progresses to the level required for independent living in the community. Students with disabilities should not be expected to accommodate to the school in ways that they cannot, rather it is the school system's responsibility to accommodate for the student's disability, which may be beyond the resources of an individual teacher in a classroom absent systemic supports.

**Interview with PA, Adoptive Mother of Mary and Mark, Children with pFAS and FAS, respectively. Mary was 27 months old at the time of adoption and 15 years of age at the time of the interview; Mark was 4.5 years old at the time of adoption and 18 years of age at the time of the interview.**

I: How did the school experience turn out for them? What sort of placements did they have?

PA: We enrolled Mark in our middle school for grades 7 and 8 as he kept telling us he wanted to attend school. He became truant from school and a runaway at the age of 14. When we finally located him he was in and out of treatment programs until the age of 16, had pretty good school experiences as part of the residential programs, small learning groups and lots of one to one. After he came back home from the last program he agreed to attend a small high school in a nearby town, where we were convinced he could get the special attention he needed. He refused to cooperate with the comprehensive assessment and development of an IEP, became truant again at the start of the 10th grade, ran away again and dropped out of school entirely before the middle of his 10th grade year. His probation officer felt that it was no longer

effective to keep picking him up and sending him to programs for several days, based on the fact that he was not in school, so we agreed at that time to let this go (it was costing us too much money with no returns) and we all encouraged him to get a job. So Mark has not lived at home since age of 16 and has nothing to do with us. Now at the age of almost 18 he has never finished 10th grade.

We enrolled Mary in a small private school for her 6th and 7th grades, and were very lucky to have dedicated staff to work with her. They were very willing to follow the recommendations of her IEP and she loved school. However, the cost of this private school became prohibitive so this past September she started her 8th grade studies in a small rural school. She loves school despite the fact that she is a struggling learner. Staff are wonderful and support any suggestions specialists and we, as parents, have.

I: Can you let me know generally what trouble with the law Mark got into while texting?

PA: Mark got involved with the wrong crowd after he became truant and a runaway at 14 and texting created contacts which were inappropriate and helped him get into the world of alcohol and drugs. There was a restraining order against the woman who harboured him when he was running and he continued to text her and her daughter, thus landing in jail again and again for violating this. This cost us big dollars as he was a minor and we were responsible for paying for his placements.

I: What was the outcome, besides taking away his texting? Was he charged. . .?

PA: We had a tracking system on his cell phone so could locate it and him anytime by accessing our computer. We could remove his service with a phone call and finally we confiscated the cell phone for good. Yes, he was continually charged, but as a juvenile, often got a slap on the hand depending on the severity of the crime, or a short stay in a juvenile jail. Not very effective - just got him off the street for a short time, then he was sent home and the cycle began again! Very much of an emotional roller coaster for us.

### **Researcher's Commentary and Interpretation:**

PA relates the family's struggles to find viable school placements for Mark and Mary and to attempt to retain them in school. Mark became truant in grades 7 and 8, a runaway at age 14, and when they finally located him he was in and out of probation treatment programs until age 16. His cell phone and texting had put him in touch with negative influences who connected him with alcohol and drugs, and harboured him when he was truant or a runaway. A restraining order was obtained against the woman who harboured him and a no contact order for Mark, with which he would not comply, ending up in juvenile jail. Mark was placed in youth residential treatment programs at the parent's expense as they reside in the USA. He did fairly well with the instruction provided in these programs, including lots of one to one and small group instruction. However, when released, he would not comply with the requirement to attend a grade 10 school placement, which included cooperating in the development of an IEP. As a consequence, his probation officer suggested that it was becoming pointless to keep picking him up, taking him to school for a few days, having him run away again, and suggested letting Mark go to work. The parents agreed as they had to pay for his costs while in these youth corrections programs and



could no longer afford them if no benefit was resulting. At his current age of 18, he has not completed grade 10. Mark's educational trajectory illustrates the association of school leaving with negative influences in the community and consequent involvement with the justice system. The latest communication from AP is that Mark became addicted and is under warrant of arrest for making and selling meth.

Mary attended a private school in grade 7 where the teachers were faithful in following the recommendations of her IEP and it worked well. She is now in 8<sup>th</sup> grade in a small rural school where the staff are willing to cooperate with any suggestions specialists or parents have that would assist Mary. Mary is cooperative and enjoying school at this point so her family is hopeful of retaining her in school. However, the future is difficult to predict for individuals with FASD, especially during the volatile years of adolescence, and in the most recent communication with PA things deteriorated with Mary lying, stealing, manipulating and in trouble with the law.

Theme 10, "At Risk of School Leaving" contains a sub-theme, "Structural Adaptations Instructional Groups and Settings," which itself has two further thematic sub-divisions.

#### 7.7.10.1 Structural Adaptations: Instructional Groups and Settings

Because of adaptive functioning delays, attentional and sensory issues, as well as memory problems, including slower processing speed, learners with FASD may benefit and thereby be retained in school by having a number of structural options with respect to the delivery of programming and instruction. Dedicated instructional programming for students with FASD is lacking, and research to identify classroom evidence-based interventions for this group are rare.

The placement of students with FASD in educational settings varies widely, and is often determined by behaviour, rather than learning needs or research regarding efficacy of differing placements, instructional settings and programming.<sup>174</sup> A flexible array of instructional groups, settings and placements may be ideal, so that the learner with FASD can traverse from one on one, to small group, or larger group instruction as needed to address her varying needs, as long as

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<sup>174</sup> *Ibid.* at 320-1. (Elizabeth Bredburg)

she is properly prepared and supported for these transitions. Likewise, settings in home, mainstream classroom, special education classroom, community, or segregated FASD school may be applicable at different times in the student's learning and development trajectory. Careful monitoring and record-keeping should follow student progress so that efficacy of various approaches utilized can be determined. Whatever the group or setting, individual planning using EIPs, assessments of student's cognitive and adaptive functioning, school records and qualitative observations in the classroom or in other instructional settings should be utilized and monitored to detect and effectively respond to patterns, peaks, and plateaus in development and achievement.

The sub-theme, "Instructional Groups and Settings" is further broken down into two parts, "Home Schooling, Special Education or Special Schools as Options," and "Individualized Learning and Instruction."

#### 7.7.10.1.1. Home Schooling, Special Education or Special Schools as Options

There are two further subdivisions under, "Instructional Groups and Settings." The first further subdivision under "Instructional Groups and Settings" is "Home Schoolings, Special Education or Special Schools as Options." Interviews follow with parents who have tried homeschooling with their children who had diagnoses within FASD, attempting to adapt experiential, holistic, multimodal curricula and pedagogy to the home and community setting.

**Interview with PA, Adoptive Mother of Mary and Mark, Children with pFAS and FAS, respectively. Mary was 27 months at the time of adoption and 15 years of age at the time of the interview; Mark was 4.5 years at the time of adoption and 18 years of age at the time of the interview.**

I: What methods and programs did you use in your home schooling until 6th grade? How did that go?

PA: Both Mark and Mary needed a lot of "hands on" opportunities to learn, could not retain information well from reading and only partially from verbal instruction. We did not use a formal curriculum to teach either of these two kids, but instead informally assessed their knowledge bases each year and targeted the

areas which were least developed. Also being in Minnesota, children do not have to engage in formal learning until the age of 7, so we took advantage of this law and could keep them learning at their own paces without standardized testing, with the hopes that they would be on target by age 7. Of course neither were. Homeschooling was very frustrating. I worked full time outside of our home and my husband stayed home with the kids. I was the one who organized the materials and established the plans and he rolled out the actual events each day. Home schooling these two kids was not at all the wonderful experience we had had with their older brother who was adopted at 2 days of age. Lots of frustration, lots of needing to adapt and change approaches, and lots of behaviour problems from Mary and Mark. No evidence of excitement regarding learning.

Both did best with experiential, hands on learning opportunities enhanced with lots of visuals. We also employed computer programs as part of learning and these were fairly successful until concepts became too abstract.

I: Can you remember how each one learned to read if they did learn to read, the stages and so forth? Did one to one, or small group situations work better, or home instruction?

PA: Mark learned to read by using a Phonics program at home (including tapes and headphones). He repeated this program several times but it was helpful. He always needed one to one instruction in order to process and retain information.

Mary also used the Phonics program so I am assuming this also helped her. She also finally found several juvenile series of books which she loved, and of course we bought them all for her. She would reread them again and again.

I: Feel free to tell me what you think is relevant to your situation and what you feel you have learned that could help someone else.

PA: I have learned:

1. The KISS principle is an essential tool to maintain harmony at school and at home. This has reduced frustration for us, the parents of two FASD kids, as it has reduced the number of power struggles our kids engage in, and has helped with processing and making experiences successful. Life has become a lot more peaceful for us all.
2. Use of visuals and printed lists help with organizing daily tasks/events.
3. Deal with sensory issues head on; provide calming strategies and alerting strategies as part of daily routines. Listen to what your child is telling you and watch her closely to determine what her needs are.
4. I believe that Tae Kwon Do has helped enhance the integration of all of our daughter's sensory systems, is a good physical outlet, which helps keep her lean and athletic, and gives her an opportunity to respond to directions from adults other than her parents and teachers, and to develop respect for others.
5. Develop open lines of communication with school staff and specialists who are versed in FASD. I have recently offered to provide an in-service on FASD, methods of coping with sensory issues, etc.
6. Mary benefits from taking Melatonin each evening before bedtime. She actually falls asleep more easily, and sleeps soundly, awaking rested and ready for the next day. We do not have the same struggles each morning getting her up and out to catch her bus. Although I am not an advocate of medications for my kids I decided to try this after reading about the possible positive effects for kids with FASD.
7. Parents need a strong support system for when the going gets tough. We have utilized all agencies in this city at one time or the other: social services, medical/mental health services, parenting resource center, worked closely with law enforcement, been involved in an adoption support group, etc. Our family facilitator service (through our Human Services office) has been invaluable for both my husband and I, to help us see clearly what has happened along the road, and for Mary, who continues to have weekly sessions with this individual to help work on self-esteem issues and other things that crop up. It is so valuable to have another person to bounce ideas off. I also am a member of a FASD list serve and am learning so much from other parents.

### **Researcher's Interpretation and Commentary:**

PA and her husband home-schooled Mark and Mary until Mark entered Grade 7 at the local middle school and until Mary entered Grade 6 at a small, private school. During home schooling they learned mainly through experiential, hands-on learning with lots of visuals and lists (or anchor charts) as well as one to one instruction, as the children could not retain information well from reading text and only partially from verbal instruction. They also utilized an audiotaped phonics program with headphones, along with computer programs which were fairly successful until concepts became too abstract. It was a lot of preparation to plan the lessons and find materials. PA was an occupational therapist in a special classroom and did the planning for Mark and Mary's homeschooling, while her husband rolled out the program as he was at home during the school day. They did not follow a formal curriculum, but rather informally assessed the skills Mark and Mary needed, targeting these in their lesson plans. PA describes home schooling as resulting in lots of frustration, frequently needing to adapt and change approaches, and lots of behaviour problems from Mary and Mark, without evidence of excitement regarding learning that they had experienced with homeschooling an older adopted son who did not have a diagnosis within FASD. PA recommends keeping things simple, using calming and alerting strategies for sensory issues, as well as activities such as Tae Kwan Do, not only for fitness, but also for sensory integration, including stimulating circulation, brain development and self-regulation. She found melatonin helped regulate Mary's sleeping and waking cycles, and recommended utilizing family support services available in the community, such as social services, health and mental health, human services, an adoption support group and law enforcement agencies.

### **Interview with B., Parent of an adopted daughter with FAS and Grandparent of a grandson suspected of having ARND**

B: We home schooled both of our FASD kids (a daughter and her son, our grandson) until 6th grade as we felt they needed an opportunity to learn at their own paces. It was obvious within the first year of having adopted them, that they had learning challenges and I was reluctant to turn them over to our educational systems until we could get a handle on their learning difficulties. K., my grandson, is way behind in both reading and printing, and has very weak motor skills. We're working on keyboarding by

using a Sponge Bob typing program in which he is in a racing car and the faster he types accurately the faster the car goes. The computer enables him to not only keyboard but to both print AND read! K. is somewhat computer intuitive and loves computers as they don't threaten him if he makes mistakes. He can choose between computer generated voices of "Jack" or "Mike" who read back what he has written! It is special computer and software called Read & Write Gold provided by the Toronto School Board that we work with in the home.

### **Researcher's Commentary and Interpretation:**

B. homeschooled in the early grades so that her adopted daughter, and then later her grandson from this daughter, would have a chance to learn at their own pace, and so that B. and her husband would gain an understanding of the children's learning challenges before turning them over to the educational system. Their grandson, K., is learning keyboarding, reading, and writing on his special computer with accompanying software. He loves computers and appreciates that they do not threaten him if he makes a mistake, but he can try again.

### **Interview with F., a First Nations man living with FAS, who describes his early learning experiences and makes an argument in favour of home schooling**

F: [As a young child] I would literally run around the house like a Tasmanian devil, destroying everything I touched. I was so hyper. . School came along and this was a nightmare. I can't describe the hell that I went through, let alone what my teachers went through. Just trying to sit in the classroom with thirty other children, with lights buzzing and humming and other noises was a problem. Things like learning to tell time were a major problem. I couldn't tell time until I was nineteen years old. On a regular clock, I found it hard to keep track of hands, where they're at, what the big hand means, etc. It was really hard for me to learn time. The teachers knew that there was something wrong. *This kid is just a classroom distraction.* They thought that what they could do about this. They thought about it and they put me in a box, a little cubicle. They thought that would keep me from distracting the rest of the class. In school I was teased a lot because I was in that box. As soon as I got out of that box, I had to socialize with my peers. When you're stuck in a box and then you have to come out and go out in the playground and play with your friends, it becomes quite obvious that you are a walking target to be picked on. Not only was I the only Native person in my community, I had FAS—trying to keep up with the classroom and being sick a lot when I was younger. School was a nightmare. I would get out in the playground and get picked on. Then I would get in trouble and didn't know why. *Why am I getting in trouble? They're the ones who are picking on me.* Of course, I would react and respond without thinking and that's what would get me in trouble. I would just attack a person that said something about me instead of walking away. I couldn't keep up with the work. I kept falling behind more and more.

It eventually came to Ritalin. The teacher said that this might help and it did. It kept me calm in the classroom and at that time, that was my saving grace. But it did not help me with trying to catch up with

the work. Here I am trying to write down something from the chalk board and I'm trying to follow what the teacher is doing and I would do one letter at a time for a word. By the time I got the first five words down, the teacher's wiping it all off!

One on one instruction was a very beneficial thing because then you didn't have that 34 other students that were raising their hands and asking questions and my one on one session was in the basement of the school. There was no windows, it was very quiet, you couldn't hear the road noises because it was in the back of the school, and I did very well. But as soon as I was taken out of that and put back into the classroom it just became very chaotic, and the change was quite substantial, like I couldn't follow through. I couldn't focus, I had no control over anything because where I had more control over with the one on one I could take my time and focus on what I had to focus on. Whereas if I was in the classroom and the teacher would ask me a question I'd sit there, and it would take me a while to think about it, but by the time, while I'm thinking about it some other student would just raise his hand and yell out the answer. And I'd be like, oh, I knew that. But it would take me longer to respond.

I: Right. To process do you think?

F: Yes. To process everything, the question and the answer takes longer. One on one is very good and like I said, visual. I did really well in carpentry. Calculators are a help, a big help. Unfortunately when I was going to school they weren't, it was called cheating. Today we got computers so I don't know what that's called, but, it's called technology I guess. Back then it was called cheating. So we've come a long ways with learning, we use the internet to access our, you know, when we do assignments. When we do our assignments, say you want to do an essay on, what's his name in South Africa, Mandela, say you're going do a story on Nelson Mandela, and back then you'd have to go through hundreds of books in the library and that was just boring. It was just a bunch of words that were so big and way over your head it just didn't make any sense. It was hard and it was frustrating, whereas the internet today is just so quick and easy to access things.

I: It is important to have something that motivates you.

F: Yes, something motivating. When I was younger I used to doodle in class. If I couldn't "get it" in the classroom I couldn't be bothered to raise my hand and ask because, you know, then I was the dumb one. So I just gave up raising my hand and I would just start to draw, drift off into my own little world and I would draw really nice pictures of boats and homes and scenery, really nice stuff. And now I have no desire to do anything like that because that stuff has been taken away. I wasn't allowed to do draw or doodle. .. One of the things that was quite critical when I was younger was they took away my gym class, and I was quite hyper when I was younger so I needed that time to get that energy out of me so that when I came back to the classroom I was more settled down . . .

I: And to learn the social skills you learn in gym class where you all interact. You missed that too.

F: But because I was so hyper in the classroom they punished me by taking away my drawing and my gym class, and that was, that's how they punished you. And to this day I don't understand that, to take something that you like away.

I: Did your coordination develop okay ?

F: Yes. I was quite good in gym class.

I: Yes, and you needed that experience of success.

F: When it came to high school, I wasn't ready for high school at all. The changing of the classrooms, going to the locker, grabbing your books, etc. Trying to figure out where to go, the constant movement and stuff really threw me off. I didn't have any clue as to what I was doing. I just walked the halls aimlessly sometimes until a teacher would come along and grab me.<sup>175</sup>

I: What about today?

F: Well today, first of all along with the diagnosis came understanding, and I think that was a major contributor coming to terms with myself.. Because before I had no understanding, I had nothing to work

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<sup>175</sup> Ontario Federation of Indian Friendship Centres (OFIFC), A Special Report, "The Boy in the Box," *Aboriginal Approaches to Fetal Alcohol Syndrome/Effects*, 2002, at 20-25. Part of the interview was a duplication of a presentation which F. did for the Millbrook First Nation, July 9, 2002, and published by the OFIFC.

with. I didn't understand why these other kids got everything just like that, and I'm sitting there not understanding anything. I just thought I was just dumb because I was quite ridiculed throughout school. But now I understand my limitations, I understand my disability and I have something to work with because, like I said, I know my limitations. I know when I'm getting worked up, I know when I'm getting frustrated, I know where to draw the line and say okay, that's enough. I just have to stop, walk away, take some breaths, you know, go out and meditate, go pray, do whatever, come back and then deal with it. But when I was younger I did not have the control, I just got upset and then the more upset I got the more the stress and anxiety built up, and the angrier I felt. I remember coming home and my mom knew I was home because my head was bouncing off the side of the house. I was literally trying to knock myself out because I just couldn't handle the pressure of that day. And my mom would come out and I would be sitting on the steps just bawling my eyes out. And my mom's saying, "You have to stop!" But I couldn't, I didn't have the ability to stop. I would get myself so worked up, so mad, so frustrated, and then it was just like a volcano. I'd just blow up, boom, I'd explode, and usually I'd end up breaking something, usually my favourite toy. And then after I broke my favourite toy I couldn't stop, I just kept smashing other things. I just did not have the ability to calm myself down, I did not have the ability to just stop. I just kept going and going and going, and then the lid blew off . . .

I: Like an uncontrollable rage?

F: Yes, and then my mom just did not know what to do. She just didn't know what to do, and she would sit at the table and she said that she would just cry because she didn't know how to help me. There was no way, like a child trips and falls and breaks his arm, you know you can help him. But when you have something that you cannot see and you have no way to understand what's hurting, how to make that better, you know, it was just hard.

I: Did she take you to a doctor at that time?

F: I went to a psychologist, a Dr. Morrow, she was a child psychologist and a speech therapist, and she helped me throughout elementary school. She helped a lot with just simple things. But still my anger was, just because of the throughout school the struggles that I had, I just was quite hateful to everyone, I was not a very good kid. But I just hated everything, I hated life, I hated school, I hated home, I hated myself, and I lashed out at everything. Even the people that loved me and I don't know, it was really hard growing up. But I thank God it's over. That part of my life anyway.

I: If you had a child with FASD how would you make it easier for that child growing up?

F: I don't know, not send them to school for one thing.

I: You think home schooling would be preferable?

F: I think home schooling would have been a much better environment because everything would be the same. But my mom was working and my dad was working, they were both teachers, and no one could really home school me. When I did get home from school my mom would sit me at the table and just drill, my spelling, mainly my spelling and reading. She would make me read a chapter every night, usually it was Hardy Boys or else Nancy Drew. My Dad was a teacher in the same school, and if I got in trouble at school, he would lecture me about it all the way home in the car.

I: The teachers told me to do school work with my daughter every night, too, instead of giving her the break. You know, to drill her every night, have her read an hour every night, have her go through flash cards and to finish incomplete assignments.

F: Yes, flash cards. I liked drawing and gym, but to punish me, the school took those away. I finally got to like computers, programs, they were motivating for me and I could do searches on the internet and liked that because the answer would come up right away.

I: So now you are able to control your anger, you see it building and you're able to control it.

F: I have more control over it because I can understand, like I've said I know my limitations, I know when I'm going to snap and I just think, okay this isn't going to work. If I just go off and get mad I know what's going to happen, so let's not go there. So I'll just go for a walk or listen to music, put head phones on and just try to forget it. Because if I don't I'm just going to get worked up and angry and then I'm going to get mad and then it's just going to boil into a volcano and I'm just going to erupt.

I: And you manage that yourself, do you?

F: Yes. So it's a lot easier now, but I did experience some trouble with the law before when I was so impulsive, frustrated and angry. . .and I came close to committing suicide, .but am doing better now.

### **Researcher's Commentary and Interpretation**

Even though PA in a previous interview was very frustrated with attempting to home school her son with FAS and her daughter with pFAS, this First Nations adult male with FAS, makes an argument for home schooling because of the difficult time he had in regular classrooms before there was much understanding of FASD. He was challenged by the distractions of the classroom, and the difficulty and amount of school work was such that he could not keep up, as well as being picked on and tormented by the other students because he was different. They called him "the boy in the box" as he worked inside what they referred to as "a box" to screen out distractions, which presumably was a carrel or mini-office. His anger and frustration grew, causing him further adjustment problems in life, eventually resulting not only in behaviour problems at school, but also in depression, a near suicide, and problems with the law. Since then he has learned to control his anger through meditation and other calming techniques, and now manages his disability better, but he believes that things would have gone smoother for him without having to face the frustrations of the school system. The fact that both his parents were teachers brought many benefits, as they could help and support him, but it also may have meant that there was not a clear break between home and school, and that there was a tendency for homework and problems at school to be carried over into the home more so than they might have otherwise. Applying what is now known about accommodating FASD in school may have alleviated the situation, including special programs for students who have an FASD or are at risk students. Even allowing F. to do some of the activities he liked, like drawing or doodling, but asking him to draw what the lesson or story was about, the beginning, middle and end, and recognize him for his efforts likely would have been more beneficial, as well as allowing him to participate in gym class at which he could excel and learn to be team member.

Some special schools, such as Foot Hills Academy in Calgary, allow learning disabled students ages 8 to 18 with sensory issues to regulate their conditions by having access to mini-trampolines and exercise bicycles in the classroom. When students become over or under-stimulated and lose their focus, they can spend a few minutes on a stationary exercise bike or



trampoline, to re-balance SNS (sympathetic nervous system) and PNS (parasympathetic nervous system) arousal and relaxation components, respectively, of the ANS (autonomic nervous system) and quickly return to concentrate on their work again. In this way, they are able to sustain attention most of the day on their school work, and thereby achieve success throughout the learning process, including graduating from high school, and entering university. Stuart Shanker contends that a connection exists between aerobic activities and academic development. There is a definite link between aerobic activity, self-regulation, self-control and the learning environment which can contribute to putting children on a path towards both emotional and intellectual health.<sup>176</sup> Although well-intentioned, unfortunately some of the strategies used in school served to frustrate and stigmatize F. further. More is known today about accommodating these issues and, consequently, more can be expected.

**Interview with HM, sole guardian of Robert; Robert is a First Nations boy who came under HM's care at the age of 7 years. At the time of the interview Robert was 16 years of age.**

HM more recently reported that Robert is entering grade 10 at an alternative education program designed for at risk youth, ages 15-19, grades 10-12. These youth have not experienced success in mainstream programs and are at risk of school leaving. She provided the web-site that describes the special program.

The three year program attempts to assist these students to develop positive behaviours and attributes required for a healthy life adjustment. Drawing largely on the principles of experiential learning, that students learn and develop best through direct experience, and the need for balance between academic and adventure-based activities, the program is designed to address learning difficulties and social and emotional needs of youth with challenges. Individual and small group instructional settings are utilized for developing self-paced academic skills. The adventure based component uses outdoor education and adventure-based activities to enhance both academic and personal objectives. Adventure-based activities include canoeing, hiking, backpacking, orienteering, camping, show shoeing, ropes courses and trust exercises. To enhance personal coping skills, both group and individual counselling is used.<sup>177</sup>

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<sup>176</sup> Stuart Shanker, Kaitrin Beechey, Reid Coolseat, Sylvia Ruegger and Alexander MacLeod, "Footprints, The Importance of Sport in Society," Ideas, hosted by Paul Kennedy, CBC Radio, 02-06-11, accessed from the worldwide web at <http://www.cbc.ca/ideas/episodes/2011/06/02/footprints-1/>; and Nathalie North, "New Research into Fetal Alcohol Spectrum Disorder Raises Hope" (May 25, 2022) Sanich Times, accessed from the world wide web 06-06-2011 at [http://www.bclocalnews.com/vancouver\\_island\\_south/saanichnews/news/122627694.html](http://www.bclocalnews.com/vancouver_island_south/saanichnews/news/122627694.html). Brian Christie and Kimberly Kerns' research suggests that regular, cardiovascular exercise can help repair damage to the brain caused by prenatal alcohol exposure, generating more neurons or nerve cells in the brain to repair damaged ones and increasing cognitive capacity. They track heart rate and brain function while children play computer games on recumbent exercise bikes.

<sup>177</sup> Vancouver School Board, "Alternative Education: Take a Hike Program," Accessed from the worldwide web 31-05-2011 at <http://www.vsb.bc.ca/programs/take-hike-program>.

### **Researcher's Commentary and Interpretation**

The innovative holistic, active, experiential, multi-modal, self-paced learning program, focusing on academic, personal, social and life skills, as well as outdoor adventure activities, utilizing both individual and small group instruction, sounds intriguing and no doubt will assist in engaging and retaining many students at risk of school leaving in the high school years. Some at risk students come from disadvantaged backgrounds and do not always have access to peak, motivating experiences as provided in the adventure-based activities. Such activities are not only motivating, but can help sustain individuals through life's difficulties, while furnishing alternatives to the highs provided by alcohol and drugs.

#### ***7.7.10.1.2 Individualized Learning and Instruction***

The second part, "Individualized Learning and Instruction," under sub-theme, "Instructional Groups and Settings," is illustrated with interviews of parents whose children are or have been involved with Individualized Educational Plans (IEPs) in the schools. Many of these address the FASD-learner's need for adaptations to manage self-regulatory and sensory issues. For the FASD learner in particular, IEPs need to expand to effectively address curricular, pedagogical and classroom designs which engage, motivate and address needs for multimodal and experiential learning, if the complex needs of these special learners are to be met.

**Interview with HM, sole guardian of Robert; Robert is a First Nations boy who came under HM's care at the age of 7 years. At the time of the interview Robert was 16 years of age.**

HM, guardian of Robert, sent copies of a number of Robert's IEP's (Individual Educational Plans) from throughout his school years. Sometimes they were adhered to, but most of the time not. They were reviewed by the interviewer/researcher.

### **Researcher's Commentary and Interpretation:**

Researcher notes that at first glance there are not many holistic, multimodal, experiential recommendations in Robert's IEP's which HM provided, as they are mostly reductionistic in nature.

Samples of Robert's pure copy work from his 2002 grade two "Structured for Success" class at a Community School in Montreal were provided, containing no drawings and no positive feedback, nor even any corrections, stars or stickers. HM reported that Robert did not know all the letters of the alphabet at the time and had trouble especially with the last letter of three-letter words. Through his entire writing journal she noted that there is no spacing between words and no apparent attempt to have him learn to do so or to even comment about it.

The same Community School employed a Behaviour Point System and Zero Tolerance policy on bullying, taxing (using threats to rob a student of their money, lunch, clothes or other items), fighting and other forms of violence, whether physical, verbal or in the form of vandalism. For admission to the program, a mandatory parent or guardian's authorization was required, consenting to use of either or both physical restraint and placement in a time-out room, in the event that the child's behaviour became difficult to control and alternative approaches were ineffective. According to HM, a student could end up spending considerable time in the time-out room for what she considered fairly minor infractions, thus missing out on instructional time.

An IEP from a High School in Montreal in 2007 identified Robert's needs as follows: needs extensive guidance and supervision with organization; enjoys school but has a difficult time completing work and staying on task; needs consistent organization; has a difficult time keeping track of school materials; needs to settle down to work immediately when class begins, needs to begin and complete assignments, needs to be more attentive; needs to develop positive peer relationships; needs to increase math skills; needs to increase reading comprehension and decoding skills; and needs to use an agenda book daily for communication between home and school. Many strategies are suggested to achieve these objectives, such as: establish classroom routines; monitor initiation and completion of assignments; provide student with a schedule of classroom activities at beginning of class; follow a less desirable task with a more desirable task; use mnemonics strategies as memory aids, e.g. FASD for Fetal Alcohol Spectrum Disorder; break projects broken down into smaller chunks; provide resource room support; scaffold

learning by teaching problem solving self-talk (metacognition); make use of visual imagery; make use of student's strengths; reinforce key themes; and teach test-taking strategies. As HM points out, the IEPs are only as valuable as the extent to which they are implemented, which may depend on resources and capacity in the school.

An IEP from British Columbia high school in 2009 identified the following specific areas of need: verbal functioning, working memory skills, written expressing, reading comprehension, math skills and social skills. The following strengths were identified; polite, easy going, works well with others, attitude is good, and always on time for class. The objectives and strategies for content areas were fairly conventional, such as daily drills to memorize basic number and operational skills (e.g. multiplication) in math; use of concrete materials, use of a calculator, adapt the number of questions assigned, and allow the use of a times table chart. In written expression, objectives and strategies included: encouragement to read more both on his own and aloud; creative writing and keeping a journal; instruction in spelling and vocabulary; expand knowledge of sentence structure; brainstorm, web diagram and pre-plan writing assignments; and instruction on how to write an expository essay. Subject matter objectives and strategies in Robert's IEP were not as successful as were the objectives and strategies for improving emotional self-awareness or social skills. For the latter, the objectives listed in the EIP were: to identify current emotional state when asked and to learn emotional self-awareness. Teacher strategies identified to help achieve these objectives were: model appropriate emotional responses, give positive feedback, encourage participation, pair with a peer in class when appropriate, give student opportunities to be successful socially, and have daily check-ins at the beginning of class to discuss how student is feeling. HM reported that the teachers were consistently acting as role models and following through on their social skills strategies which were very effective. Robert learned to recognize his emotions and then to regulate them better. However, for both spheres of objectives, if asked, Robert's teachers would be able to explain specifically what they were doing to try to improve each skill.

The needs identified for Robert are probably characteristic of many students with diagnoses within FASD. It is unfortunate, if recommendations in IEP's are neither informed by knowledge of FASD, including input from specialists in learning, literacy and FASD, and from parents and caregivers, nor adhered to for students with learning challenges such as FASD. On the other hand, kudos to those many teachers who do their best to implement such strategies,

even in larger groupings, especially considering that many students are undiagnosed and the queue for access to diagnosis is a long one.

**Interview with PA, Adoptive Mother of Mary and Mark, Children with pFAS and FAS, respectively. Mary was 27 months old at the time of adoption and 15 years of age at the time of the interview; Mark was 4.5 years old at the time of adoption and 18 years of age at the time of the interview.**

I: What recommendations were in Mary's IEP, if you can remember some of them?

PA: Adaptations which are specifically documented in her IEP include:

- second set of textbooks to be kept at home;
- textbooks and other educational materials provided in audio format;
- use of highlighting tape in her texts;
- provide copies of class notes or outlines to student before materials are presented in class [or written on the blackboard];
- large or multi-step assignments will be broken down into a series of smaller tasks;
- assignments will be shortened (e.g. she is required to only complete half the math questions assigned);
- use of fidget objects as needed;
- consultation services from Occupational Therapy to determine needs for ongoing adaptations/accommodations or sensory and self-regulatory strategies; and
- specific study skills and organizational skills training.

### **Researcher's Commentary and Interpretation:**

The nine adaptations recommended in Mary's IEP are very useful and practical, such as a second set of textbooks at home, textbooks and other learning materials in audio format; copies of class notes and outlines (including those written on the blackboard) to be given to student before being presented in class; large or multi-step assignments to be broken down into a series of smaller tasks; and shortening assignments (e.g. requiring the student to complete half the math questions assigned). In addition to those the parent mentioned, some teachers recommend recruiting a peer helper to assist students with FASD with organizational and executive functioning skills, such as selecting the correct text book and note book, sequencing in the sense of what subject or activity to do next, with what books and materials, and where to do it, what to

take home for homework, and other supports as needed. The use of peer helpers may also enhance social contacts for the students with FASD, and give them someone to relate to in the classroom or on the playground. Careful selection of peer helpers is key, as well as optimum use of their time, by having visual time tables, anchor charts or lists, visual clocks, and other strategies readily available in the classroom so that the student helper merely needs to cue the student to these supports.

The recommendations in the IEP are valuable but do not make mention of pedagogical ways of trying differently, rather than harder. For instance, if the student does not learn well with didactic oral and textual instruction, try differently using supervised experiential, multi-modal, active learning, with lots of hands-on, visual, spatial and kinaesthetic cues. Recommendations should also encompass cultural, social and environmental contexts of the learner, to create continuity and thereby enhance learning by connecting new concepts to be learned to the learner's background. Field trips, active outdoor activities, community activities, including inviting parents or key members of the community to the classroom, can help to make these linkages and at the same time keep the students engaged in school and in learning.

## **8 Conclusion: Situating Research Methodology and Results in Context**

### ***8.1 Methodology, Epistemology and Legitimacy***

Indigenous research methodology, in which participatory action research is embedded, is situated in the broader context of holistic, inductive research. Holistic, inductive research is a daunting endeavour, a passionate yet chaotic and unpredictable journey into the unknown, where one does not quite know at any particular time what one will discover, when the journey will end, or if closure will ever be achieved to one's satisfaction. At the creative edge, the process of knowing termed "science" is not dogmatic, but rather the quest for meaning and discovery impels one forward to think freely outside the box in order to better understand the infinite complexities of natural phenomena, of which FASD is a part. To grasp complexities, research needs to examine not only single transactions, but multiple interactions system-wide. Although there is a lot of dark matter or unknown to grapple with in natural phenomena such as FASD, surprises or unexpected outcomes can lead to major breakthroughs as science transitions from a mature static phase to an exciting, accelerated phase.<sup>178</sup>

The question becomes how best to support inquiry-based innovative, creative, complex research in interdisciplinary, multidisciplinary or transdisciplinary ecologies, enabling an

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<sup>178</sup> *Ideas*, CBC Radio, Feb. 3, 2011, "The Tao of Science," Host Paul Kennedy interviewed two of the ten scientists who were recent recipients of the Ontario Premier's Science Summit Awards of five millions dollars each. The two scientists interviewed were Dr. Janet Rossant, a stem cell researcher, and Dr. Jeffrey Wrana, a molecular geneticist, who attempt to translate their findings to clinical applications such as individualized and personalized medicine for the treatment of the spectrum of individualized disorders referred to as cystic fibrosis or breast cancer. Using stem cells, they foresee culturing each patient's unique type of cancer tumour, study the tumour's entire genome, and be able to influence outcomes, such as what treatment works to destroy each patient's genetically unique tumour. Cancer cells are adaptable and mutate, so often "you chase an enigma" Dr. Wrana explained. Holistic and systemic research, such as the study of complexity of networks of multiple molecular and lung cell interactions and signalling systems could also shed light on the mechanism and clinical treatment of patient's particular genetic form of cystic fibrosis. Similarly, at the 4<sup>th</sup> International Conference on FASD, Vancouver, BC, March 6, 2011, Kathleen Sulik, University of North Carolina, presented her epigenetic cell-signalling research on the etiology and prevention of FASD, utilizing several genetic pathways in the early embryonic development of alcohol exposed mice embryos and fetuses. "Tao," originating in East Asian religions, means the way, path, route, principle or doctrine, in this case, of science. It is difficult to predict the direction of rapid acceleration of change in science as science is moving from a mature, static phase to an exciting, accelerated phase of major breakthroughs. Dr. Wrana asserts that scientists should never be comfortable about the research they do, but should push the envelope and get working on the edge.

approach to problems from novel, holistic and systemic perspectives without reducing inherent complexity of phenomena studied.<sup>179</sup> Moreover, knowledge is constructed within a particular social, historical, spiritual, epistemological, and cosmological context, as has been clearly acknowledged for Indigenous research. Science, like all forms of knowing, is situated knowledge, where the knower rather than being an objective bystander is very much integrated into the process of knowing. Moreover, science is not a solo undertaking, but is a community enterprise. To understand science one must understand both the contemporary and intergenerational group that constructed it and the historical, cultural, spiritual, epistemological, and social context in which it was constructed.<sup>180</sup> Through the constructivist process, a complementarity exists between science and other narratives about the world, including among others, history, philosophy, literature, art, spirituality and religion.<sup>181</sup> In a similar vein, it helps to “demystify” the practice of science by showing its similarity to all creative human activity.”<sup>182</sup>

A corollary to the present discussion is rejection of over-reliance on reductionistic approaches, proposing instead transdisciplinary, holistic and systemic research platforms that offer broader, more open, transcultural, and multidisciplinary, innovative perspectives on the nature and practice of science. Moreover, holistic, transdisciplinary research platforms have implications for more complex, productive and heuristic research environments and outcomes.<sup>183</sup> Indigenous methodologies are the epitome of the guiding principles of transdisciplinary, holistic

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<sup>179</sup> Alfonso Montuori, “Transdisciplinarity and Creative Inquiry in Transformative Education: Researching the Research Degree,” in Mauro Maldonato and Ricardo Pietrobon, eds., *Research on Scientific Research, A Transdisciplinary Study* (Toronto: Sussex Academic Press, 2010) at 130-1. Multidisciplinarity approaches a problem from the perspective of more than one specialist; interdisciplinarity aggregates the knowledge coming from two or more specialist disciplines to create a new body of knowledge, whereas transdisciplinarity, while not striving for mastery of several disciplines, does aim to open all disciplines to what they share and to that which lies between them and beyond them. These approaches are instrumental in creating more productive and high-quality research environments resulting in novel, complex thought in tune with the complexity of reality itself.

<sup>180</sup> Thomas Kuhn, *The Structure of Scientific Revolution*, Third Edition. (Chicago: The University of Chicago Press, 1996) at 206.

<sup>181</sup> Maria Da Conceicao De Almeida, “Notes on the Complex Method and the Challenges of Research,” in Mauro Maldonato and Ricardo Pietrobon, Eds. *Research on Scientific Research, A Transdisciplinary Study* (Toronto: Sussex Academic Press, 2010) at 152.

<sup>182</sup> Stephen Jay Gould, “Darwin’s Untimely Burial,” 1976, from Michael Ruse, ed., *Philosophy of Biology* (New York: Prometheus Books, 1998) at 94.

<sup>183</sup> Santo Di Nuovo, “Research about Research, as a Psychologist Views it” in Mauro Maldonato and Ricardo Pietrobon, eds., *Research on Scientific Research, A Transdisciplinary Study* (Toronto: Sussex Academic Press, 2010) at 18-27.



research platforms, involving as they do elements of dialogism, situationalism, holism,<sup>184</sup> pluralism and interconnectivism, as well as consensus constructivism, where participants, community partners and researchers co-construct knowledge. Researchers need to focus on what questions to ask to understand an entire system of a complex network and to find the triggers to further study. New paradigms to describe and discuss systems as a whole and for interpreting these kinds of complex data from a global perspective are required. The emerging “Tao of Science” is as an uncontrollable, chaotic, discovery process where one may never know the ultimate answer, but continue the search for meaning by uncovering the intricate interconnections among factors.<sup>185</sup>

Moreover, awareness of the situated aspect of a researcher’s knowledge and approach can function to clarify that researcher’s perspective and world view, or utilize individual researcher connectedness to the area of study to enhance understanding, or through use of texts, travel, and experience, expand researcher horizons beyond individual identity, culture or worldview. However, the latter is challenging. Recruiting members of research teams from differing disciplines, environments, backgrounds, cultures and worldviews, locally, nationally or globally, can assist in bridging gaps in situated knowledge. Ongoing dialogue by members of the interdisciplinary research team, with participants, key informants and community partners is essential, as socially-constructed scientific knowledge cannot be developed and validated in isolation. Institutional policies that provide release time for researchers to consult are vital to facilitate this process. Such is the research platform that the present researcher attempted to utilize, and so this description provides a segue into discussion of research undertaken and reported herein.

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<sup>184</sup> Giuseppe Mininni, “Dilemmas as Complex Universes of Discourse,” in Mauro Maldonato and Ricardo Pietrobon, eds., *Research on Scientific Research, A Transdisciplinary Study* (Toronto: Sussex Academic Press, 2010) at 37.

<sup>185</sup> *Supra* note 178. *Ideas*, CBC Radio, Feb. 3, 2011, “The Tao of Science,” Host Paul Kennedy interviewed two of the ten scientists who are recipients of the Ontario Premier’s Science Summit Awards valued at five million dollars each. The two scientists interviewed were Dr. Janet Rossant, stem cell researcher, and Dr. Jeffrey Wrana, geneticist.

## ***8.2 The Present Research: Approaching the Complexity of Nature***

### ***Within***

From an inside perspective of FASD in family and community,<sup>186</sup> the present researcher strove to understand both the holistic complexity of FASD and its impact on the lives of individuals and their families, in order to propose working clinical applications in the form of the gestalt of evolving FASD-Literacy Practice Guidelines, an inductively derived model of how to guide learning and instruction of holistic learning, literacy and life skills, useful across sectors and age-levels, informed by the literature on holistic literacy and by the neuroscience underlying diagnostic brain domains.

Most researchers today agree that studies based *only* on discrete variables, on quantity in describing them, and on linearity in understanding their relations are not useful to explore theories about the human mind . . .

The research process should go far beyond quantitative and statistical analysis and put in place the bases for a different interpretative approach. The measurement of variables, quantitative statistical analyses, deductions based strictly on data fail to tell the whole story about the sense of the research—that is, about the meaning of the relations between events. Such a story would only be delivered by a *hermeneutic* approach, an approach grounded in the data but not ‘reduced’ to them. . .

Phenomena manifest themselves to the researcher often in an unexpected way, which may not be taken into account by the [reductionistic] instruments she is using.<sup>187</sup>

The present researcher discerned that the complexity of lived experiences with FASD could best be studied using multidimensional, inductive, qualitative techniques, embedded in Indigenous methodologies. Indigenous methodologies, in turn, incorporate components of participatory action research.

Several qualitative data gathering approaches including open-ended Conversational Interviews, Focus Groups, and Sharing Circles (*Wa-sa-cam-e-be Ke-skue*) were utilized for systematic observations, both direct and indirect, in natural environments suitable for dynamic systems. Denzin and Lincoln describe qualitative research and data as follows:

Qualitative research involves the studied use and collection of a variety of empirical

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<sup>186</sup> In addition, the present researcher is a former teacher and lecturer (including Physics, Chemistry, Biology, General Science, Psychology, Law and a component of Language Arts), member of the Law Society of Saskatchewan and the Canadian and Indigenous Bar Associations (inactive status while pursuing graduate studies), and a member of the Métis Nation of Saskatchewan.

<sup>187</sup> *Supra* note 183 at 18. [Santo Di Nuovo in Maldonato and Pietrobon]

materials--case study; personal experience; introspection, life story; interview, artifacts, cultural texts and productions; observational, historical, interactional, and visual texts—that describe routine and problematic moments and meanings in individuals’ lives. Accordingly, qualitative researchers deploy a wide range of interconnected interpretive practices, hoping always to get a better understanding of the subject matter at hand. It is understood, however, that each practice makes the world visible in a different way. Hence there is frequently a commitment to using more than one interpretive practice in any study.<sup>188</sup>

Multivariable, inductive techniques for data analysis of large numbers of open-ended Conversational Interviews, Focus Groups and Sharing Circles culminated in a meta-synthesis<sup>189</sup> comprising an evolving FASD-Literacy schemata, albeit absent validation in various instructional settings, whether homes and schools, or in work, correctional, and treatment settings. Multivariable, inductive techniques provide means of bringing order out of the random chaos of large amounts of data without sacrificing or reducing rich complexity of phenomena which the data represents:

. . . Regarding the sciences of matter, the first look only notices the disorder: when one looks at the sky, one sees a ‘bunch’ of stars scattered by chance. Looking a second time, one can notice ‘an uninterrupted cosmic order’—each night, apparently always and forever, the same starry sky, each star in its place, each planet doing its impeccable cycle. But then, a third look occurs: because there is an injection of new and formidable disorder in that order, we begin to see a universe in expansion and dispersal; the stars are born, explode, die. The third look requires us to conceive jointly order and disorder.

. . .  
[As for life sciences] at first sight, it was the fixity of species, reproducing themselves impeccably, so repetitive over the centuries, for millennia, in an impeccable order. Then, at the second look it seems there is evolution and revolution. How? By bursts of chance, accidents, and ecological and geo-climate disruption. . . and here we are faced with a third look, that is, to think together the order and disorder and to design the live organization and evolution.<sup>190</sup>

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<sup>188</sup> Norman K. Denzin and Yvonna S. Lincoln, “The Discipline and Practice of Qualitative Research” in Norman K. Denzin and Yvonna S. Lincoln, eds. *The Sage Handbook of Qualitative Research*, 3<sup>rd</sup> ed. (London: Sage Publications, 2005) 1 at 3-4.

<sup>189</sup> Gene V. Glass, *Primary, Secondary and Meta-Analysis in Social Research* (Beverly Hills, CA: Sage Publications, 1976). In the case at hand, the meta-synthesis was based on different methods used in one large study, rather than on an analysis and synthesis of results from many studies.

<sup>190</sup> Edgar Morin, *Ciencia Com Consciencia* (Science with Conscience). (Lisbon: Europa-America, 1982) at 71 as cited in Maria Da Conceicao de Almeida, “Notes on the Complex Method and the Challenges of Research” in Mauro Maldonato and Ricardo Pietrobon, eds., *Research on Scientific Research, A Transdisciplinary Study* (Toronto: Sussex Academic Press, 2010) at 146. Morin discusses the triangle of “order-disorder-complexity” in his conception of science and the practice of inductive research driven by complex thinking.

Scientists seek to discern patterns with which to describe the world more accurately, employing Edgar Morin's "feeling of order" and "feeling of truth," based partly on reason and partly on intuition.<sup>191</sup> Inductive researchers grapple with a so-called "order-disorder-complexity triangle" inherent in nature,<sup>192</sup> searching for ways to perceive patterns emerging from the apparent impenetrable randomness of phenomena, somewhat analogous to a physicist's use of a stroboscope to "stop" motion of a rapidly spinning object so that it can be clearly observed. The evolving FASD-Literacy Practice Guidelines *order* emerging from inductive analysis of the *chaos or randomness* of diverse, raw qualitative data in the present research is comprised of 10 substantive themes. These 10 themes are a synthesis of both FASD and Literacy, and form a new gestalt of FASD-Literacy, neither a Literacy model, nor an FASD model, but a synthesis of the two which is different from either alone, much as *spacetime* differs from the separate concepts of space or time. The present researcher deems that 10 themes will do justice to the complexity of both FASD and holistic Literacy without becoming too large and unwieldy in application. In specific cases, sufficient data is provided in descriptions accompanying each substantive theme that practitioners have the flexibility either to combine or to further divide the themes as they find useful to match particular expertise and experience. Collapsing complexity is a more flexible, feasible and scientifically valid process than unwrapping reductionist abstractions with less substance and context remaining to analyze.

However, after practice and familiarity with the current FASD-Literacy model in application it does become second nature and few gaps remain to confound its ultimate utility when working with individuals with FASD, a rich, complex, diverse, and anomalous group, requiring a paradigm shift in pedagogy and approach. That said, the FASD-Literacy gestalt models good teaching and learning methods, many of which may be applicable more broadly, as many learners, not only those with FASD, have differing learning styles, speeds of learning and varying needs to accommodate. Moreover, qualitative observation of learners while they work, informed by approximation and miscue analysis techniques, along with samples of their work, can be utilized for purposes of individualized evaluation and assessment of learners with an FASD.

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<sup>191</sup> *Supra* note 181 at 144. [Edgar Morin, *O Metodo*, Vol. 3: *O Conhecimento do Conhecimento*. (Porto Alegre: Sulina, 1999) at 160-2 cited in Maria Da Conceicao De Almeida, "Notes on the Complex Method and the Challenges of Research," in Mauro Maldonato and Ricardo Pietrobon, Eds. *Research on Scientific Research, A Transdisciplinary Study* (Toronto: Sussex Academic Press, 2010) at 144].

<sup>192</sup> *Ibid.*

An inclusive pedagogy defined as “a teaching and learning relationship that creates the potential for building learning conditions leading to full and equitable social participation”<sup>193</sup> is also critical for learners with FASD who so often have not been included fully and equitably in the educational system or in other aspects of society. When they are included in the present systems, disparities in outcomes have been the norm for this group.<sup>194</sup> The evolving FASD-Literacy Guidelines proposed are only a starting point, open and tentative, as attempts continue to conceptualize the “what,” “how” as well as the epistemological, decolonizing or anti-oppressive underpinnings of an FASD-Literacy pedagogy, including components of healing, reconciliation and transformation as discussed in *Indigenous Disadvantage and Despair*. Neurocognitive functioning of the brain in learners with FASD, as well as the primacy of experiential, multimodal, as well as socially and culturally constructed and contextualized learning for this group have been extensively addressed throughout the present section. Extensive observations of teaching and learning, followed by testing of the proposed FASD-Literacy model’s efficacy, in various sectors and for the various age groups are the next step in moving from practice guidelines to a full-fledged FASD pedagogy.

Substantive FASD-Literacy themes derived from the interview data are not meant to be applied in a formulaic or mechanistic manner, but rather require the discretion of the teacher, parent, caregiver or service provider in selecting and applying them on an individual basis, alone or in combination, in contexts varying across the lifespan and across sectors. Often a balancing process will be required in their application. The challenge is to balance sometimes disparate requirements of brain domains and other neurological and psychological factors, with the need to fashion rich, dynamic, holistic literacy curricula and pedagogy for children with FASD from a culturally contingent perspective, without resorting unduly to reductionistic, mechanistic, impoverished, controlling or oppressive forms of pedagogy.

As noted, brain domain requirements are sometimes disparate, and require balancing, for

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<sup>193</sup> Supra note 28 (The New London Group) at 1.

<sup>194</sup> Ann P. Streissguth, HM Barr, J Kogan and FL Bookstein (1996) *Understanding the Occurrence of Secondary Disabilities in Clients with Fetal Alcohol Syndrome and Fetal Alcohol Effects (FAE)*, Report to the Centers for Disease Control and Prevention on Grant No. R04/CCR08515 (Tech. Report. No. 96-06). Seattle: Washington, Fetal Alcohol and Drug Unit), cited in Ann Streissguth, *Fetal Alcohol Syndrome, A Guide for Families and Communities* (Paul H. Brookes Publishing Co.: Toronto, 2001) at 109; and Public Health Agency of Canada, *Early Primary School Outcomes in Children Associated with Maternal use of Alcohol and Tobacco during Pregnancy and with Exposure to Parent Alcohol and Tobacco Use Postnatally* (Her Majesty in the Right of Canada, Ottawa: 2010).

while a child with FASD may be prone to sensory over-stimulation, she may, at the same, also be attention deficit and so may need some amount of stimulation to become engaged in the learning. In addition, she may have memory deficits and problems with abstract thinking that require visuals and hands-on activities to reinforce. Having a quiet, pleasant and enclosed place<sup>195</sup> in the classroom for a student to retreat to when over-stimulated may help the student with FASD to calm down or “slow her engine” before incrementally reintroducing further enriching stimuli under a teacher’s guidance.

Understanding interactions among the 10 themes is also important for more individual and intricate translation to clinical applications in classroom, community or workplace. For example, the interaction of themes regarding attentional and sensory issues, as well as memory problems, slower processing speeds, self-regulatory issues and impulsiveness create deficits in adaptive functioning levels. As a further example, the themes of adaptive functioning levels, memory deficits, inability to appreciate consequences, aversive responses to over-stimulation, self-regulation and increasing processing time interact to create early school leaving and often consequent involvement with the justice system.

As with any difficult human endeavour, the tentative, evolving FASD-Literacy model proposed is not a magic recipe. With any complex endeavour, an element of ambiguity remains in its order-disorder-complexity triangle. One must develop a certain tolerance for ambiguity in science, and particularly in working with FASD. Both are highly complex, not completely known or even completely knowable, but rather are open and changing, “in a constant state of becoming:”

[U]ncertainty and ambiguity are not always indicative of a state of ignorance, far removed from a state of ‘complete’ knowledge and control, as well as from a state of Divine (or demonic) omniscience. On the contrary, they can be indicative of the fact that the ‘real’ and the ‘possible’ are not immutable domains, but rather processes in a constant state of becoming. From the very heart of the sciences emerges the possibility of an open future, where real innovations and creations can occur, and which is not completely determined by the present and the past.<sup>196</sup>

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<sup>195</sup> Some schools have pleasant, little play houses in the classroom for this purpose. A classroom with Aboriginal students utilized a small tepee to draw on the cultural component. One adult with FASD reported spending a lot of his school day as a child relegated to the inside of cardboard box in the classroom, which is stigmatizing and not appropriate. Upon release at recess, the other students tormented this student for being different and being kept in a box. Therefore, it is important that the area selected be a socially desirable area and going there should be the choice of the student, not a punishment imposed by the teacher. To be fair to the teacher, she does need assistants in the classroom to help implement and monitor these accommodations in a sensitive manner. The use of weighted vests and blankets for calming should be supervised by an Occupational Therapist experienced in risks involved in their use. Again, they should not be used as punishment, nor to stigmatize the student as different.

Knowledge of the context of FASD and Literacy, like all complex phenomena, is not absolute nor ultimate, but remains in flux, with creative ideas and new insights surfacing, indicating the possibility of an open and evolving future. As the field continues to unfold, the tentative, evolving FASD-Literacy model will require integration with emerging knowledge, as well as more trained personnel for optimum success. Even under ideal conditions no cure exists for the neurodevelopmental disorder of FASD; individuals with an FASD will not outgrow the need for ongoing supports. For optimum utility, the FASD-Literacy schemata requires that parents, caregivers, teachers, professionals and support staff be rested, not overly stressed, able to stop and think, not merely react to behaviour without recognizing the permanent disability behind the behaviour. This presents a challenge as the disability is largely invisible until the *pattern* of dysfunctional behaviours become apparent. Perceiving patterns is an inductive process which takes time, observation, understanding and complex thought, engaging the order-chaos-complexity triangle and the process of inductive thinking. Parents, caregivers, teachers and assistants, therefore, should not be unduly upset if they, not recognizing a pattern, make a mistake, but instead continue the journey on the long road of “observing, connecting what is observed to the disability of FASD, thinking creatively, and then responding compassionately.”

Ongoing respite is required for parents and caregivers as patience, time, creativity, and insight are constantly in demand. This is exhausting on a full-time, life-long basis. Support groups of parents and caregivers of individuals with FASD exist and one can put one’s experiences in perspective through connecting with others going through similar challenges, although support groups do not replace needed respite services. Professional associations of Teachers-of-Learners-with-FASD may also be a valuable resource and form of professional support in which to pool insights and resources.

The tentative, evolving FASD-Literacy Guidelines proposed should do no harm, as only positive options are proposed. However, one needs to be mindful always that learners with FASD process incoming information more slowly and therefore require more time to respond or to complete a task. It takes more effort on their part to do a task than it does for a normal

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<sup>196</sup> M. Ceruti, *Evolution without Foundations* (Cresskill, NJ: Hampton Press, 2008) at 9 in Alfonso Montuori, “Transdisciplinarity and Creative Inquiry in Transformative Education: Researching the Research Degree,” in Mauro Maldonato and Ricardo Pietrobon, eds., *Research on Scientific Research, A Transdisciplinary Study* (Toronto: Sussex Academic Press, 2010) at 118.

student, so they need opportunity to rest, relax, and take a break. Patience, compassion, understanding, and humility are essential when working with an individual with an FASD, being cognizant of not blaming the victim for her disability. However, compassion fatigue can quickly set in without supports and respite for teachers, parents and caregivers who are often blamed for the behaviour of the individuals with FASD in their care.

Over-crowded classrooms or foster homes are not appropriate settings for infants, children, or youth with FASD. Current systems are not prepared to assess and respond to the degree and complexity of disabilities such as FASD experienced by children and youth in their care. If parents are provided with sufficient supports in the home, children with FASD may not need to be taken into care where outcomes unfortunately are not always positive. From such adverse experiences individuals with FASD may be left without lifelong, strong, primary attachments to family, culture and community with which to transition to adulthood and beyond.<sup>197</sup> Best results in instructional settings are usually obtained from one-on-one encounters or in small group situations, where the individual is less distracted by the group and where instructors can modify their methods as they qualitatively observe learner behaviours of those with FASD. Opportunities to learn social skills in larger group settings are best introduced incrementally, with supervision.<sup>198</sup>

The themes comprising the tentative, evolving FASD-Literacy Guidelines should be learned and practiced in combination, by teachers, caregivers, and support persons, ideally first in an instructional, work-shop setting, then through interaction in a practicum, one on one, with individuals with FASD. Through metacognitive techniques such as modeling and thinking aloud about the process used, learners with an FASD can begin to manage and monitor their learning needs,<sup>199</sup> as described in the Self-Regulatory Theme and related information on FASD dedicated classrooms.

Children with an FASD can learn to recognize signs that they are becoming over or under- stimulated, select a readily available squeeze ball, a wiggle seat, a carrel, or go to a quiet, enclosed but pleasant place or space provided in the classroom. If experiencing a memory

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<sup>197</sup> Saskatchewan Child Welfare Review Panel Report, *For the Good of our Children & Youth, A New Vision, A New Direction*, Dec. 16, 2010. Accessed from the worldwide web at <http://saskchildwelfarereview.ca> on 8-1-11 at 30.

<sup>198</sup> Mary J. O'Connor, Fred Frankel, Blair Paley et al, "A Controlled Social Skills Training for Children with Fetal Alcohol Spectrum Disorders" (2006) 74 (4) *Journal of Consulting and Clinical Psychology* 639.

<sup>199</sup> J.A. Kable, C.D. Coles and E. Taddeo, "Socio-cognitive Habilitation using the Math Interactive Learning Experience Program for Alcohol Affected Children" 31 *Alcoholism: Clinical and Experimental Research* 1425-34.



gap, they can select a visual cue, such as a picture-dictionary, or refer to one of the visual vocabulary anchor charts, and so forth. If they cannot remember their homework consistently, a homework book that goes back and forth between teacher and parent may be used which both teacher and caregiver complete and sign each day. Caution should be used to assign only an amount and type of work that the learner with FASD can reasonably complete. Perhaps five drills would suffice, rather than ten. More visual, hands-on activities could be substituted when learning abstract concepts. More appropriate tasks could be substituted such as use of a digital rather than an analog clock for telling time, the latter being very confusing for individuals with FASD as many do not possess abstract thinking and memory required to master the skill. If the individual does not learn orally or through text, try multimodal visual, kinesthetic, hands-on and experiential modes of learning. Sometimes interactional, digital modes work well and can be motivational. It is important to “try differently, not harder.” That is where the skills of the teacher, parent or mentor come into play as facilitators. If something does not work well, don’t persevere, instead be flexible and creative, and try a different way.<sup>200</sup>

### **8.3 Closure**

Moving towards closure in the discussion, one needs to consider research findings in the context of the purpose, circumstances, legitimacy, implications and future directions of the research. The purpose of the present holistic, inductive, qualitative research was to gather experiential data observing participants and their children in their natural surroundings, and to elicit participants’ first hand observations, stories, conversations and narratives describing the impact of FASD on their lives, including what practices and approaches worked and what did not work for them. Participants or key informants included individuals with FASD, Elders, parents, caregivers, support persons, and professionals. An unstructured interview protocol was selected, employing techniques such as Conversational Interviews and Focus Groups, along with Indigenous Sharing Circle (*Wa-sa-cam-e-be Ke-skue*) methodologies.

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<sup>200</sup> *Supra* note 6 [Diane Malbin, *Fetal Alcohol Spectrum Disorders: Trying Differently Rather than Harder*, Second Edition (Portland, Oregon: Tectrice, Inc., 2002)].

The research protocol, including collective and individual consent processes, was approved on ethical grounds by the University of Saskatchewan Advisory Committee on Ethics in Behavioural Science Research on Oct. 29, 2004. Transcripts of interviews and focus groups formed an important component of the research, especially since voices of individuals with FASD and their families have not always been heard, but rather more often have been silenced by shame and marginalization. Notes were recorded on storyboard charts for all to see during Sharing Circles. Much can be learned from participants' voices and narratives. In 2009, a public consultation and review process was held regarding revisions to the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*, particularly Chapter 9, *FASD and Holistic Literacies*, and certain other sections of relevance to research with Aboriginal peoples. As part of the public consultation and review process, the present researcher submitted a memo of her responses to revisions prepared by the Interagency Advisory Panel on Research Ethics.<sup>201</sup> The memo referred to, reviewing ethical implications for research with Aboriginal peoples, is to be found in Appendix A.

As there are many ways of organizing presentation of qualitative research, the present author, immersed in the Elders' Circles, epistemology and approach to presenting ideas, followed Elders' philosophy in communication of various elements of the research methodology, that is to present information in an unpretentious manner reflective of the inductive method utilized, in the order the researcher perceives that the reader (or audience in the oral tradition) can best absorb it. Moreover, as qualitative accounts require an adequate, detailed, descriptive basis to honour both contribution, culture, and context of participants, as well as the inductive method, research protocol, and inherent complexity of the phenomena studied, the relatively greater length of qualitative accounts should not be of primary concern.<sup>202</sup> Such is somewhat reminiscent of the respect and deference accorded to Elders' discourses based on generations of insight transmitted orally.

A benefit of the research design included the broad scope of knowledge and insight provided by parents, mentors, service providers, and Elders. These grounded experts, acutely aware of how FASD had impacted individuals, families and communities, generously shared

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<sup>201</sup> Rae Mitten, Submission or Memo re Draft 2<sup>nd</sup> Edition of the Tri-Council Policy Statement: *Ethical Conduct for Research Involving Humans, Prepared by the Interagency Advisory Panel on Research Ethics, December 2009, For Public Consultations and Review*, Memo in Response submitted March 31, 2009, by Rae Mitten, Appendix A.

<sup>202</sup> *Supra* note 102. [Harry F. Wolcott, University of Oregon, *Writing up Qualitative Research*, 3<sup>rd</sup> edition (Thousand Oaks, California: Sage Publications, 2009)]

their experiences, insights, knowledge, resources and support. In depth, holistic knowledge of participants in their natural environments was the result, rather than more abstracted statistically generalizable knowledge derived from controlled or artificial environments focusing on a few isolated variables. However, as explained, the foregoing does not imply that Indigenous methodologies, participatory action research, and other holistic, complex, inquiry-based, inductive methodologies are poor Cinderella's among their richer step-sister "hard sciences" flaunting reductionist, quantitative, statistical methods.<sup>203</sup> All depends on the nature and stage of the research query as to which approach is the best fit. Inquiry-based, complex, multivariable, transcultural questions are best accommodated by the former methodologies. Quantitative topics of narrower scope such as pharmaceutical testing, or the testing of a specific biomedical procedure, are best accommodated by the latter.

Experienced qualitative researchers have commented wryly to colleagues, "You should give readers only enough information about how research was conducted to enable them to *discount* your findings."<sup>204</sup> Notwithstanding the foregoing rueful comment, qualitative research's examination of complex questions usually requires prudence and restraint in making definitive conclusions, especially if the number of participants is smaller or non-representative. Even for larger, representative groups, conclusions or implications drawn should be framed in tentative terms, tolerant of the considerable degree of ambiguity about such a complex condition as FASD-Literacy. The complexity of the "universe within" is as great as the external universe, but not as well mapped. One might ask, in what future direction do the 10 inductive themes derived from the research direct us. Neither final, complete, nor conclusive, the 10 inductive themes together comprise a proposed, tentative, evolving, holistic literacy model for individuals with FASD. A sequel or next step, is pilot, qualitative field testing of the fledgling model in home, community and classroom, as well as in health care and justice or correctional settings, to complete and refine the process for various age groups and settings, and to determine resources and professional supports required for equitable results. Because of the model's holistic, pluralistic, contextual, dynamic, learner-centered nature, it is not readily amenable or reducible

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<sup>203</sup> *Supra* note 183 at 26. [Santo Di Nuovo, "Research about Research, as a Psychologist Views it," in Mauro Maldonado and Ricardo Pietrobon, eds., *Research on Scientific Research, A Transdisciplinary Study* (Toronto: Sussex Academic Press, 2010) at 26.].

<sup>204</sup> *Ibid.* citing Taylor and Bogdan, 1984: 150; see also discussions on establishing *trustworthiness* in qualitative inquiry in Lincoln and Guba 1985: 289-331; Denzin and Lincoln, 2005: 202-203.

to being validly tested through the purported “gold standard” of randomized, controlled trial protocols.

Key personnel in implementing and testing the proposed, evolving FASD-Literacy model in schools are teachers and educational assistants who work directly with students on an ongoing basis and who have responsibility for educational processes in their classrooms. Professionals, from other disciplines, whether individually or collectively, may make useful suggestions and recommendations regarding *inter alia*: sensory stimulation, cognition, attention, activity levels, and mental and physical health issues. The teacher, however, is the “first among experts” when it comes to applying these in the holistic, dynamic context of classroom and curriculum. If interdisciplinary professional teams are added to the human resources complement of a school, such addition does not imply that fewer teachers or teacher assistants will be needed. In fact, probably more will be required to review recommendations provided, meet with interdisciplinary team members and parents, keep records, and attempt to properly model, implement and monitor appropriate recommendations on an on-going, individual basis in the classroom. Investment of public funds in the education system will likely prove efficacious and will help avoid costly, long term adverse outcomes to which the FASD population is susceptible if not properly supported early in life. Eventually, the evolving FASD-Literacy model could be tested and modified for use in other community settings, including homes, workplaces, health care settings, and addiction treatment or correctional centres.

Ideally, the evolving model could be pre-tested in experimental classrooms attached to Colleges of Education. Such experimental classroom arrangements do exist in the Ontario Institute of Studies in Education’s Institute of Child Study, termed a Laboratory School.<sup>205</sup> Dr. Peter Cowley, Education Policy Researcher at the Fraser Institute, reported that a presenter, Lord Putman, at the Third Plenary Session Question Period, World Innovation Summit for Education in Doha, Qatar, Dec. 7-9, 2010, commented that he would not trust an Education Faculty that did not have an operating, experimental school affiliated with its College of Education.<sup>206</sup> The

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<sup>205</sup> Dr. Eric Jackman Institute of Child Study, Ontario Institute for Studies in Education (OISE) at <http://www.oise.utoronto.ca/ics/LaboratorySchool/index.html>. Retrieved from the worldwide web 9-1-11.

<sup>206</sup> Peter Cowley and Ben Levin, “Merit Pay for Teachers,” Host Karen Wells, Sunday Edition, CBC Radio, January 9, 2011 at [http://www.oise.utoronto.ca/ics/Laboratory\\_School/index.html](http://www.oise.utoronto.ca/ics/Laboratory_School/index.html). Retrieved from the worldwide web 9-1-11. Peter Cowley is Education Policy Researcher at Fraser Institute, and Ben Levin is Canada Research Chair in Educational Leadership at OISE. Peter Cowley refers to the speaker, Lord Putman, at the Third Plenary Session Question Period, World Summit for Education, Doha, Qatar, Dec. 7-9, 2010. As no one can conclusively define what constitutes evidence-based, good teaching practices, merit pay for teachers is not justifiable and perhaps not

Laboratory School at Ontario Institute of Studies in Education (OISE) admits children ages 3-12 (nursery to grade 6). Teaching and learning at this school are anchored in inquiry, developmental readiness, and emerging research.<sup>207</sup>

As Canadian fifteen year old students ranked 6<sup>th</sup> out of 65 countries in reading literacy in the 2009 OECD Program for International Student Assessment, released December 7, 2010, ranking behind Shanghai-China, Korea, Finland, Hong Kong-China, and Singapore,<sup>208</sup> there is a concern that Canadian students be provided with evidence-based instructional opportunities to keep pace with international baselines. Ongoing research to determine best teaching and learning practices for varying student populations is required to help each student reach her potential and to maintain commensurate literacy levels in a rapidly changing, global landscape.<sup>209</sup> Addressing the gap between Aboriginal student achievement and graduation rates and those of non-Aboriginal students, in aggregate, is another discrepancy to consider through research, policy and practice, if equity is to be achieved.<sup>210</sup>

Although the present inductively derived FASD-Literacy model does not claim to be exhaustive or ultimate, it is a beginning as it covers aspects comprising the interface between FASD and Literacy, resulting in an initial, FASD-Literacy schemata to be further developed and field-tested in various environments and settings. This initial broad exploration might constitute a working model designed to guide future FASD, Literacy and Learning studies, bringing aspects of experiential knowledge of individuals with FASD and their parents, families and care

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desirable. Student outcomes are influenced by many factors, such as family, community, income level, not solely by teacher or school. Teachers in Finland, a country which scores consistently high on OECD measures of student outcomes, are carefully selected by Colleges of Education and are typically accorded a great deal of freedom and latitude in instructional methods which they select to use in their classrooms, but they are not paid under a merit pay system. Note that Lord Putman's comments at the World Innovation Summit For Education in Doha, Qatar are available at [http://web.dbee.com/wise/20101207\\_am/en/index2.php](http://web.dbee.com/wise/20101207_am/en/index2.php), e-mail from Peter Cowley, 11 Jan. 2011.

<sup>207</sup> *Supra* note 205.

<sup>208</sup> Shanghai (China) participated in OECD Program for International Student Assessment (PISA) for the first time.

<sup>209</sup> Statistics Canada, "Performance of Canadian Youth in Reading, Mathematics and Science," Retrieved from the worldwide web 9-1-11 at <http://www.education.gov.sk.ca/Default.aspx?DN=dfaff52e-a0f2-485e-9213-daaa59424ffe&l=English>.

<sup>210</sup> *OECD (2010), PISA 2009 Results: Executive Summary*. Retrieved from the world wide web 16-1-11 at <http://www.oecd.org/dataoecd/34/60/46619703.pdf>; *2009 Saskatchewan Education Indicators Report*, released Dec. 7, 2010; James Wood, The Star Phoenix, January 7, 2011, "School Disparity Between Aboriginals and Non-Aboriginals Due to Funding: FSIN Chief," Retrieved from the worldwide web 10-1-11 at <http://www.leaderpost.com/news/School+disparity+between+aboriginals+aboriginals+funding+FSIN+chief/4077353/story.html>. Twenty percent of students in Saskatchewan schools self-identify as Aboriginal and eighty percent are non-Aboriginal. The 2006 Program of International Student Assessment (PISA) and 2007 Pan-Canadian Assessment Program (PCAP) both indicate declining overall student achievement in Saskatchewan in math, reading and science in relation to the Canadian average.

providers together with professional expertise and scientific knowledge of the fields of both FASD on the one hand, and Literacy and Learning, on the other. Moreover, at the practitioner's level it is the beginning of an evidence-based matrix of guidelines for needed solutions and best practices in the wide-ranging gestalt of FASD, Literacy and Learning.

Although the present researcher does not presume to compare the work herein in any way to the widely acclaimed paradigm shift achieved by the inductive research journey of Charles Darwin in the *Origin of the Species*,<sup>211</sup> she, nevertheless, can relate to the tentativeness and humility Darwin expressed:

*If I lived twenty more years and was able to work,  
how I should have to modify the Origin, and how much  
the views on all points will have to be modified!  
Well it is a beginning, and that is something . . .*

Charles Darwin to J. D. Hooker, 1869<sup>212</sup>

The present author finds inspiration in Denzin and Lincoln's prescient comments about the future of qualitative research, raising concerns common to other researchers cited.<sup>213</sup> Denzin and Lincoln conclude that in qualitative research there have been many tensions (between postmodern and positivist approaches) as well transformations associated with paradigm, strategy and method. Participatory Action Research is one of these evolving transformations. Moreover, Denzin and Lincoln reflect that "the centre does not hold," and contemplate what should be the new centre for qualitative research in the formative years of the twenty-first century. They contend that qualitative researchers are entering a new age where messy (or chaotic), uncertain, multi-voiced texts, critical cultural methodologies (such as Indigenous Methodologies) as well as innovative forms of field work, analyses, intertextual representations, transdisciplinary perspectives, and interpretations will evolve to grapple with serious, complex issues (like FASD) that no doubt will continue to emerge and challenge both researchers and

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<sup>211</sup> Charles Darwin, *Origin of the Species by Means of Natural Selection, or the Preservation of Favoured Races in the Struggle for Life* (London: John Murray, 1859).

<sup>212</sup> Charles Darwin, *More letters of Charles Darwin, Vol II* (Teddington, Middlesex: Echo Library, 2006) "Letter 700 by J. D. Hooker, Down, January 22, 1869," at 642-3, Retrieved from the worldwide web 8-1-22 at <http://books.google.ca/books?id=X9vMhLOiTmQC&printsec=frontcover#v=onepage&q&f=false>.

<sup>213</sup> *Supra* note 188 at 26-27. [Norman K. Denzin and Yvonna S. Lincoln, "The Discipline and Practice of Qualitative Research" in Norman K. Denzin and Yvonna S. Lincoln, eds. *The Sage Handbook of Qualitative Research*, 3<sup>rd</sup> ed. (London: Sage Publications, 2005) 180 at 26-27.]

communities in their collaborative endeavours.<sup>214</sup> In so doing new nexus and relationships, such as Sharing Circles to co-construct and dialogically reframe knowledge and systems, may transform the world within as well as without.

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<sup>214</sup> *Ibid.*

## **9 Appendix A: Submission or Memo re Draft 2nd Edition of the Tri-Council Policy Statement**



Submission or Memo re Draft 2<sup>nd</sup> Edition of the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*  
*Prepared by the Interagency Advisory Panel on Research Ethics,*  
*December, 2008, For Public Consultation and Review*

**Memo in Response submitted March 31st, 2009**

**By Rae Mitten, B.A. (H. Hon.), B.Ed., M.A., J.D., LL.M., Ph.D.(c.),  
Researcher,**

**Community-based Researcher Partnering with First Nations &  
Métis Communities, and also partnering with  
An Interdisciplinary Team of Researchers from the Faculties of Law,  
Medicine, Education and Psychology**

From my positionality as a Community-based Researcher, partnering with First Nations and Métis Communities, and also partnering with an interdisciplinary team of researchers from the Faculties of Law, Medicine, Education and Psychology, I have a keen interest in Research Ethics issues and bring the current perspective from the field. Research participants' rights and protection in the research process, to be enshrined in the TCPS revisions, are of special concern to the people in Saskatchewan and the North, particularly with respect to Aboriginal research and/or research with people in remote areas. The TCPS has been termed the human rights protection for research subjects and these are among the most vulnerable of research subjects.

I did participate in the videoconference consultation in Saskatoon, SK on March 18, 2009, and also am submitting this written memo to the Interagency Advisory Panel on Research Ethics. The Saskatoon consultation was not face to face and I am not sure how much of my comments were received, understood and correctly documented due to technical and other difficulties related to nuances and barriers to meaningful two-way communication in that medium and forum. As I am very involved in the new Community-Based Aboriginal Research Methodologies, many of my comments, but not all, pertain to implications of the Draft TCPS for that research. I will outline my concerns as clearly and concisely as possible as follows:

- In Chapter 2 of the Draft TCPS under consideration, I am concerned about those situations where no REB review will be required. This is a particular concern in Aboriginal Research (Chapter 9 of the Draft TCPS), as Aboriginal people value their Traditional Knowledge, their Intellectual, Cultural and Heritage Property, Human Bodily Tissues and Genetics, Biodiversity (including all living things) and the Biotic and Non-Biotic Environment, all of which are protected under Constitutional Law and International Declarations and

Agreements. Situations which would require no REB review in Non-Aboriginal Research should, nevertheless, require REB Review in Aboriginal Research, as research involving matters outlined above would conceivably touch on content in the protected sphere for Aboriginal People and thus should not qualify as minimal risk in the Aboriginal context. Such changes and distinctions should be made explicit in the revision of the TCPS in both general (Chapter 2) and Aboriginal sections (Chapter 9) of the TCPS.

- Similarly, research circumstances that might qualify for waiver of fully informed consent in non-Aboriginal Research (e.g. Articles 1.1 and 3.8 in Draft TCPS) should not qualify for such a waiver in the Aboriginal Research Context, especially if they involved Traditional Knowledge, Intellectual, Cultural and Heritage Property, the Environment, Biodiversity, Human Bodily Tissues and Genetic Testing, and the Biotic and Non-Biotic Environment, including Sacred Sites, which are specially valued and protected in the Aboriginal Context. Any Articles, Provisions or General Principles in the Draft TCPS permitting waiver of fully informed consent in Non-Aboriginal Research should definitely not be applicable to Aboriginal Research where fully informed consent (both individual and collective) shall always be mandatory. The Draft TCPS should make this distinction clear and explicit in both general and Aboriginal sections of the TCPS.

- All bodily tissues, including *inter alia* hair, blood and saliva samples, which contain the genetic code, are considered of special significance to Aboriginal people and at best will be provided by them on loan to researchers. Secondary use provisions should be avoided and further consent should be required from Aboriginal communities and Aboriginal research participants. The *CIHR Guidelines for Health Research Involving Aboriginal People* sets forth in Article 13, the Aboriginal philosophy of full embodiment where every part and product of the body is sacred, and constitutes an essential part of the person. Therefore, researchers should be considered the steward, rather than the owner, of the samples. However, even anonymizing these samples cannot be assumed to address concerns with respect to the sacredness of these materials, as the CIHR Guidelines seem to imply. Much more work needs to be done in both sets of Guidelines with respect to bodily tissues samples and genetic testing as it applies to research with Aboriginal participants. In the TCPS this needs to be addressed in both general and Aboriginal sections. The history of mistrust of the research enterprise by Aboriginal peoples could be made more clearly manifest by specific real life examples in the Draft TCP, to make the

issues more concrete and enable researchers and REB members to recognize sensitive areas when they encounter them. The topic is too sanitized and abstract in the present version for this to happen in all cases. The genetic exploitation of Indigenous peoples' blood and other tissue samples for purposes not consented to by Indigenous donors in the Human Genome Project originating out of Stanford University and in the Nuu Chah Nulth project, the first phase of which was funded by Health Canada to Dr. Ward at the University of British Columbia, are important cautionary examples which represent serious ethical and human rights violations.

- The interface of the *Draft TCPS* and the *CIHR Guidelines for Health Research Involving Aboriginal People* should also be clarified in both documents, and the two should be reconciled with each other (in a manner that enhances the rights of Aboriginal research participants), so that researchers are not left in an “Ethical Guideline Limbo or Dilemma”.

- A related issue concerns the status of these documents as “Guidelines.” If they are Guidelines and not mandatory Standards, what are the implications for REBs and researchers not complying with them, and what of the concern for protection of vulnerable research subjects, including vulnerable Aboriginal research subjects if researchers choose not to follow the non-mandatory “Guidelines”? Should the public, as well as research subjects, be clearly informed that these documents are merely guidelines and may not necessarily be complied with? Should the public in general, as well as community research partners and research subjects in particular, be informed that even if there is compliance with the Guidelines, REB Review may be waived in some circumstances considered minimal risk, and even if REB review is not waived, fully informed consent of research subjects and communities may be waived if deemed for the greater good? Such situations would be of considerable concern to Aboriginal People.

- A concern arises when comparing provisions pertaining to Clinical Trials in Chapter 7 of the Current TCPS with the provisions in Chapter 11 of the Draft TCPS. The role of clinical equipoise has been lessened in the Draft TCPS, with a larger role for placebo-controlled studies. Clinical Equipoise requires that a new therapy or intervention be tested against an established effective therapy, whereas placebo-controlled studies would withhold such treatment from the control group. This increased trend towards placebo controls rather than clinical equipoise opens the door to interpret “established effective therapy” narrowly and therefore to withhold treatment that may have some merit from research subjects randomly assigned to control groups. In many cases, this can do harm to vulnerable research subjects, for instance, in

the addiction or substance abuse context, where established therapy that may have some efficacy is withheld to those randomly assigned to control groups. Some of the individuals in the control group may suffer further harm from the addiction, even harm to an embryo or fetus as some participants could be in the early stages of pregnancy at the time. Such potential resultant harm could have a chance of being ameliorated if clinical equipoise were the standard. The explanatory comments for Article 11.10 in the Draft TCPS go even further stating “if there are no established effective therapies *for the population*” leaving the door open to exclude established therapies that have some general efficacy but which have not been *specifically* tested on the Aboriginal peoples of Canada. Such a state of affairs should raise a red flag for all concerned about protecting research subjects from over-zealous withholding of treatment through the vehicle of enhanced use of placebo studies. Aboriginal participants assigned to control groups could be particularly vulnerable, as explained.

- A related concern with respect to Clinical Trial Budgets in Article 11.9 of the Draft TCPS, is the disclosure to REBs of the kinds and amounts of payments and other budgetary details. Such disclosure to the REB should be clearly mandatory in order to control for potential conflicts of interest, and any inducements paid to the researchers or institutions for the recruitment of subjects should be disclosed to the research participants or subjects as well. Unequal distribution of benefits and rewards versus risks is an ongoing concern for Aboriginal Communities and research participants when they contemplate partnering or participating in research; these concerns should be comprehensively addressed in the Draft TCPS through these and similar transparency requirements.

- The role of Aboriginal Research Participants, Aboriginal Community Research Partners and Aboriginal Researchers in the REB Review Process is also a critical issue. As very few REBs have Aboriginal Researchers as one or more than one member of the REB, it is recommended that Community Members of the REB be recruited from the Aboriginal Community, or that a special seat or seats be set aside for one or more Aboriginal Members of the REB. Calling them in on an ad hoc basis leaves them marginalized from the entire process and unaware of the ongoing discussion to which they are called upon to express an opinion. Funding may be required to accommodate childcare, eldercare, travel, accommodation and other expenses of Aboriginal REB members, as Aboriginal members may face many such barriers to participation in REBs. Aboriginal Research Participants should have a greater role in the REB

Review process and Aboriginal Community Research Partners in the Research should have an equal role to the Scientific Researcher in the REB Review process. Aboriginal Community Research Partners, like other researchers, should be able to have a role in presenting to the REB, in receiving a copy of the REB Minutes pertaining to the research review (including any dissent) and participating in the on-going process of REB Review.

- As the majority of members of REBs are not Aboriginal, but rather only a small minority, the role of Dissents become crucial to protect these minority rights, and minority rights, generally. There needs to be more emphasis on the right to dissent in the Draft TCPS in Chapter 6, “Governance of Research Ethics Review,” although it is recognized to some extent in Articles 1.7, 1.8 and 1.9 of the current TCPS, it needs to be further enhanced. To have the right to dissent, to have that dissent recorded in the minutes and to have the dissent reported to the researchers and to community research partners are essential procedural rights in the protection of Aboriginal Communities and individual Aboriginal participants in the research, and indeed, all research participants, and should be made explicit in the TCPS.

- The importance of Face to Face meetings for REB Reviews is critical. Electronic or video meetings can lead to errors and confusion, and lack of protection for the rights of vulnerable research participants, including Aboriginal Peoples.

- Face to Face meetings should be the norm for proper consultation process for the Draft TCPS approval, as well. This was not the case for Saskatchewan nor for the North, both of which have many vulnerable people, including Aboriginal people, in remote and/or northern locations. The consultation process cannot be considered legitimate without ample opportunity for people in Saskatchewan and in the North to be heard in face to face consultations. They are being targeted for large-scale, intrusive research and their voices need to be heard in the consultation process. Furthermore, many members of the community would not feel comfortable in a video-conferencing session, even if they were able to attend the one such session provided in Saskatchewan. None at all were scheduled in the North. I respectfully request that in the next round of consultation for the revised draft TCPS, numerous face to face consultation sessions at different dates, times and locations be scheduled in both Saskatchewan and the North, to ensure that people in these areas of Canada are accorded proper access to the consultation process. If there is no next round of full consultations, I strongly recommend that face to face consultations be held at least in Saskatchewan and in the North, either as an addendum to the first round of

consultations, or as a version of a follow-up round dealing with the revised draft TCPS created as a result of the first round, even if the follow-up is not scheduled in other areas of Canada that were included in the first round of face to face consultations.

- Accountability of REBs and REB Members is a major concern. A valid Accreditation process might address some of these concerns. In extreme cases of harm to research subjects, costly litigation may be resorted to, but expensive litigation is not feasible for most Aboriginal Research Participants and so is not a protection for them; other informed parties who might be concerned would not have legal standing in such cases. Greater transparency is required for research participants and communities to become aware of any infringements of their rights as research subjects. At present, they do not even have a right to see the REB Review results. There is definitely a public interest in having greater transparency and accessibility to these results, with protection provided for any bona fide trade secrets. Specifying that one member of the REB be a Member of a Law Society, rather than merely “knowledgeable in the law” (Article 6.4 of Draft TCPS) ensures that someone on the REB, if complaints were lodged, could be held accountable by his or her professional organization at no cost to the complainant research subjects.

Given the omnipresent inequity in our society, and the very large imbalance in power between big corporate, governmental and institutional researchers, on the one hand, and more vulnerable Aboriginal research subjects and other research participants, on the other hand, ensuring protection for research subjects through the REB process is an uphill struggle. It requires constant vigilance and strong, protective ethical guidelines and standards, as REB members may even inadvertently be influenced to favour the more powerful parties who can at some point reward or advance them. The dynamics of REBs are a study in themselves, a very illuminating process, as they are not immune from all of the weaknesses to which humans are subject. Some REB members do move on to more prestigious positions that vulnerable research subjects cannot provide them. Even the consultation process which you have implemented is structured to attract researchers and members of REBs who are researchers, more so than members of the community who may more closely represent the research subjects/participants. In a related vein, I have seen REBs evaluated by the researchers they review, but never by the participants/subjects or community-based research partners. Perhaps research could be done on the topic of REB outcomes and extent of protection accorded to research subjects versus

favouring the more powerful research enterprise. Is there a proper balance? How do we obtain a proper balance? Transparent monitoring and reporting, as suggested, may aid in the process of continually striving for a fair outcome.

Thank-you kindly in advance for your attention to the matters addressed in this memo and I look forward to the opportunity for further face to face consultation on these important issues. In the interim, please feel free to contact me if you require clarification of the issues raised herein.

## **Epilogue: Honour Song**

### ***Kethou-ne-ka-mon***

**H. Rae Mitten©Copyright H. Rae Mitten, August 11, 2010. All rights reserved.**

*Circles of healing, transformation and reconciliation* heal wounds, reconcile differences, and transform paradigms of justice, health, education and governance, through the incorporation of models of equitable, holistic relationships with one another and with Mother Earth. Elders' words of wisdom permeate the discourse, enriching our visions of a good and healthy way to live together, eschewing hierarchies and power differentials, greed and arrogance, replacing them with mutual respect, acceptance and communal values of sharing with one another.

The gift of spending so much quality time with Elders that this research afforded is indeed a vision quest beyond compare, a window on the essence of spirituality, epistemology, culture, symbols, and oneness with nature and the universe this has endured and been passed down since time immemorial. It is the source of resilience that has sustained a people through intergenerational traumas such as residential schools and loss of homeland, language and culture. Elders have been the inspiration for the Conversational Interviews and Sharing Circle methodologies used in the field research, ideal processes for relation-building and cross-cultural understanding, yielding holistic data and insights, in preference to "helicopter methods" where researchers use vertical landing and take-off, in quick succession, to obtain raw data, then take off again.

Far from producing sanctification of science or sanctification of traditional knowledge, the nexus between these two strategies for acquiring knowledge opens researchers to the surprises and mysteries of the world. Accordingly, multidimensional and cross-cultural perspectives, dialogues between local and global, and particular and universal, become matrices



to support new paradigms comprising broader reflections of reality.<sup>1</sup> In creating new paradigms for multidimensional, complex research, researchers may transcend recipe books presented in research manuals to create a unique set of strategies to link the fragment to the whole context, the local to the global, and to find the elusive pattern underlying phenomena and their interconnections.<sup>2</sup> Ultimately, the goal of any method or approach (whether Indigenous Methodologies incorporating a component of Participatory Action Research, or an alternative) is to help one think clearly for oneself, so as to answer the challenge of complex problems.<sup>3</sup>

This research journey, conceptualized as a vision quest, had a heuristic purpose, the search for a comprehensive, holistic FASD pedagogy that takes into consideration sensory, behavioral, attentional, volitional, and cognitive challenges in the context of holistic literacies and life skills, grounded in a better way of socially constructing knowledge as modeled by the Elders. Progress has been made in the Journey. The purpose is clear, but the Quest and Journey continue. When speaking to Elders about the next leg of the Journey proposed, an uncharacteristic, emotional break was heard in the voice of a male Elder, and obvious joy and excitement in the voice of a female Elder. Together they had organized and led the Elder and Parent Sharing Circles, as well as offering prayers for success of the research projects. Perhaps they had feared that once finished the first project, though lengthy, researchers would move on to something else and leave the community to its own devices. A proposed, sequel project entails screening for FASD and holistic Literacies in health, educational and justice sectors in Saskatchewan, to acquire prevalence data with which to press government for funding, to provide adequate access to diagnosis, and other supports and services for those with a disability within FASD. It is a daunting task to undertake but we do not do so alone.

Scents, sights and sounds from nature, as pungent as sweet grass, sage, tobacco, or kinnikinic, aromatic and redolent as naturally smoked and tanned leather, poignant and resonating as bird calls, or majestic as pristine mountains and lakes, ground us in what really matters.

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<sup>1</sup> Maria Da Conceicao De Almeida, "Notes on the Complex Method and the Challenges of Research," in Mauro Maldonato and Ricardo Pietrobon, *Research on Scientific Research: A Transdisciplinary Study* (Toronto: Sussex Academic Press, 2010) at 153.

<sup>2</sup> *Ibid.* at 151, citing Edgar Morin, *O Metado*, Vol. I: *A natureza da naturexa*. (Portugal: Europa-America, 1979)

<sup>3</sup> *Ibid.* at 151, citing Edgar Morin, *Sociologica*. (Madrid: Editorial Tecnos, 1995).

Maynard Dixon (1875-1946), who lived among the Blackfeet in Montana during the late nineteenth and early twentieth century, appreciated that “they lived and moved and had their being drawn from an older, better way of knowledge and behavior.”<sup>4</sup> An artist and photographer, he learned “much from the sincerity and simple directness of their art, and more from those elements in their philosophy of life.”<sup>5</sup> He expressed these sentiments vividly through the genre of poetry:

*Lodge Fires*

*Here as of old is the red-stone pipe,--  
With its legends of mystery power and war  
And the ceremonial block for tobacco,  
The sacred sweet-grass and charcoal,  
The mysterious medicine bundle with fringes  
descending,  
The robes and blankets and beadwork,  
The gun and the rawhide and saddle,  
And (silent witness) a moccasin print  
in the ashes.<sup>6</sup>*

Maynard Dixon, *Rim-Rock and Sage*, a selection from a collection of his poems written between 1896 -1937, (San Francisco: California Historical Society, 1977).

Dixon’s poetry, photography and paintings attest to his intimacy with Blackfoot culture and world view, while honouring Elders’ visual art, songs and stories, way of life, values and ceremonies, that appear paradoxically to be unique and yet, at the same time, to transcend

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<sup>4</sup> Donald J. Hagerty, “Where the Prairie Ends and the Sky Begins, Maynard Dixon in Montana” (Summer, 2010) 60 (2) Montana, the Magazine of Western History, p. 35.

<sup>5</sup> *Ibid.*

<sup>6</sup> *Ibid.*

boundaries.<sup>7</sup> Titles of his paintings alone are evocative: *Dream Pipe, Medicine Woman, Beaver Medicine Song, Blackfoot Elders, Blackfoot Camp, The Lone Warrior, Pony Boy, Little Sister, Home of the Blackfeet, Home of the Half-Breed, Mountain and Lake, Montana Prairie, Conversation, The Storytellers, Blackfeet Historians, and Picture Writing*. The latter two portray a group of Blackfeet in the process of documenting their pictorial personal and tribal histories using the medium of paint on hide, framed from above by a traditional pictographic history panel painted by Chief Stingy-with-his-Tobacco.<sup>8</sup> Dixon adopted a style of painting reminiscent of theirs, using vivid colours, strong brush strokes and simple, direct images, often based on photographs he took as he lived and moved through Blackfeet territory, managing to bridge his interest in Indian cultures and the old west with aspects of modern art.<sup>9</sup>

He described the oil sketches he painted while with the Blackfeet as “painted down the arm,” meaning painted by reflex, almost automatically, with “fluid draftsmanship,” attributable to the intensity of his attachment to Blackfeet culture.<sup>10</sup> The present author relates to the foregoing as she noted a similar phenomenon of what could be termed, “writing down the arm” or “researching down the arm” in somewhat parallel circumstances. Native culture and holistic epistemology awaken a well stream of consciousness transcending barriers to feelings, thought, expression, and relationship. Comparatively, a half century later, Allen Sapp, O.C., of the Red Pheasant Reserve in Saskatchewan visually represents the distinct culture, spirituality and way of life of his people, the northern Cree of Saskatchewan, as they transitioned from a nomadic hunting to a sedentary agricultural society. Fittingly, the Governor General of Canada selected

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<sup>7</sup> Neal McLeod, “Plains Cree Identity: Borderlands, Ambiguous Genealogies and Narrative Irony,” (2000) XX(2) 437-454 *Journal of Native Studies* at 444-450. With reference to Cree culture, in particular, McLeod expostulates that there are many layers of Cree culture and identity, it is not monolithic and unchanging, but open-ended and dynamic. One cannot essentialize Cree identity, there is no quintessential Cree culture, it is ambiguous, multi-layered, and changing, shaped by history, events and encounters with other peoples. Like a Trickster or *Wisakecahk* narrative it challenges boundaries and exists in a state of liminality at the interstitial threshold limits of “what we were and what we are to be.”

<sup>8</sup> *Ibid.* at 25-41 and back cover.

<sup>9</sup> *Ibid.* at 32-38.

<sup>10</sup> *Ibid.*

an Allen Sapp painting to include in his official 2010 Christmas greeting card, acknowledging both the contribution of the artist and of the Cree people.<sup>11</sup>

Just as Darwin perceived that species transform through natural selection, incorporating chance variations that increase fitness for survival in local environments, so too, must our public systems transform, adapting to changing circumstances such as the emergence of FASD and how health, justice, and education systems might best respond to individuals with characteristics such as FASD, guided by a better way of knowledge and behavior of which the Elders speak. A wise synergy of the best of old and new is possible . . . achieved together with the delicacy of moccasin prints in ashes.

Contemporaneously with drafting this Epilogue, the Canadian Bar Association's governing council urged federal, provincial, and territorial governments to fund resources for alternatives to incarceration for offenders with FASD. Incoming CBA President, Rod Snow, from Whitehorse, the first CBA President from North of 60, knows that courts in the Yukon deal with many cases in which FASD is an issue. He explains further that science informs us people with FASD are impulsive, do not learn from their mistakes, so that deterrence does not work with them.<sup>12</sup>

Over-incarceration of Aboriginals within the Canadian prison system may include many individuals with FASD. In addition, the "get tough on crime" agenda will widen the net bringing increased incarceration of vulnerable individuals with FASD, absent official efforts to divert them to community-based supports. On October 14-15, 2010, the federal, provincial and territorial ministers responsible for justice and public safety met in Vancouver to discuss FASD and Access to Justice as one of 10 key justice and public safety issues currently facing Canadians,<sup>13</sup> with a follow-up meeting on March 3-4, 2011. It is gratifying to end on a note of

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<sup>11</sup> Allen Sapp, *Through the Eyes of the Cree and Beyond, The Art of Allen Sapp: The Story of a People* (North Battleford, Saskatchewan, Canada: Allen Sapp Gallery, 2005).

<sup>12</sup> Tracey Tyler, Legal Affairs Reporter, "Lawyers call for 'decriminalization' of fetal alcohol offenders," Toronto Star, August 14, 2010, accessed on the worldwide web at <http://www.thestar.com/news/canada/article/848040--lawyers-call-for-decriminalization-of-fetal-alcohol-offenders>.

<sup>13</sup>News Release, Ref: 830-992/004, "Federal, provincial and territorial (FPT) ministers responsible for justice and public safety, concluded their meeting today, after in-depth discussions on key justice and public safety issues

hope as the Circle widens to include the national organization of the legal profession, composed not only of officers of the court and architects of law reform in their own right, but also the group from which all judges and many legislators are drawn, including federal, provincial, and territorial ministers of justice and public safety. Of them and of all contributors to this dissertation, Elders, individuals with FASD and their parents, service providers, and community members, words from the oral tradition attributed to Sitting Bull, *Tatanka Iyotanka*, reverberate across ages and cultures, words simultaneously imbedded in time and place, yet inherently timeless and comprehensible, words selected by this author as carefully and intentionally as hand stitches are sewn into an Honour Shawl, words that simply, poignantly, yet powerfully convey the essence of reconciliation:

*”Let us put our minds together and see what life we can make for our children.”*

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## **E-MAIL MESSAGES AND IN-PERSON CONVERSATIONS**

Canadian FASD Northwest Intervention Nat ([inat@ualberta.ca](mailto:inat@ualberta.ca)) e-mail communication, 29 Jan 2011.

Peter Cowley, Fraser Institute, e-mail communication with Peter Cowley, 11 Jan. 2011 regarding comments made by Lord Putman at the World Innovation Education Summit, December 7-9, 2010, Doha, in reference to experimental schools affiliated with Colleges of Education.

Dr. J. Thomas Dalby, e-mail communication Re: The Lunatic and the Lords and expected publication date, 17 July 2009.

Dr. J. Thomas Dalby, e-mail communication, Re. The State Trials Report or the Old Bailey Reports on the McNaughton case, in Harvard Medical School, 18 July, 2009.

Ben Levin, OISE, e-mail communication, Re. Experimental Classrooms & Related Comments on CBC Sunday Edition, 9 January 2011.

Dr. Ted Rosales, Pediatrician and Geneticist, Memorial University of Newfoundland-Labrador, St. John's, e-mail communication, Re. Your Expert Testimony in *Faulkner* case, 10-03-2009.

In-person Conversation with Wanda McCaslin, Research Officer, Native Law Centre, University of Saskatchewan, Saskatoon, January 2009.

In-Person Conversation with the Right Honourable Beverly McLachlin, P.C., following her presentation on "Access to Justice," College of Law, University of Saskatchewan, October 27, 2010.

In-Person Conversation with Dr. Robin Menzies, Consultant Psychiatrist, February 8, 2009, 2:30 p.m., Saskatoon.

In-Person Conversation with Dr. Olubusola Okunola, Consultant Psychiatrist, Saskatoon Inner City, June 6, 2011.

In-person Conversation with Debra Ram, Lawyer with legal aid practice experience in Nunavut, Re. the *Partridge* case, June 3, 2010.