# Disablement, Context and Quality of Life After Brain Injury: Measuring What Matters

by

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For my parents,

Fred and Johanna Nolte

## ABSTRACT

The purpose of this study was to examine the conceptual bases of research on the disablement experienced by individuals with acquired brain injury, and to identify factors contributing to their quality of life. Ninety-seven respondents shared their experience of living with the effects of moderate to severe brain injury through structured interviews. Relationships among measures representing impairment, disability, social support, handicap and quality of life were investigated using regression analyses. Handicap was represented first using a measure of participation, then using a measure of integration.

Several predictions were tested to examine support for three general hypotheses: 1) that the relationships among impairment, disability and handicap experienced by individuals with brain injury are described by the International Classification of Impairment, Disability and Handicap (ICIDH) model of disablement (World Health Organization, 1980), 2) that contextual factors such as social support are an important aspect of disablement, and 3) that impairment, disability, social support, and handicap influence quality of life. Support for these hypotheses was mixed.

1) The first hypothesis was partially supported. The impairment measure explained 43% of the adjusted variance in the disability measure. Impairment and disability predicted handicap, but only when handicap was assessed using the participation measure. (Impairment and disability each explained 6% of the adjusted variance in participation.)

2) Support for the second hypothesis was dependent on the aspect of handicap under consideration. Social support did not predict handicap when participation was

the aspect of handicap assessed, however the social support measure explained 16% of the adjusted variance in handicap when handicap was assessed using the integration measure.

3) Results pertaining to the third hypothesis were also mixed. Impairment and handicap (assessed using the participation measure) did not predict quality of life. Disability explained 5%, and handicap (assessed using the integration measure), explained 6% of the adjusted variance in quality of life. Social support was the strongest predictor of quality of life, accounting for 13% of the adjusted variance. The prediction that the ICIDH model could be extended to include quality of life with a link from handicap to quality of life was not supported, as neither participation nor integration contributed to the prediction of quality of life when added to impairment, disability and social support.

The pattern of relationships that emerged among the ICIDH constructs supports the use of the ICIDH as a general conceptual framework for considering the experience of disablement, insofar as the injury-related factors of impairment and disability are concerned. The ICIDH model is less effective in describing the relationships between the injury-related factors and handicap. This finding emphasizes the need to develop measures that are valid, reliable and comprehensive representations of the handicap construct.

Finally, the results provide empirical support for the inclusion of contextual factors in the consideration of disablement and in the ICIDH framework, by demonstrating that social support is a better predictor of handicap and quality of life than are injury-related factors for this sample of people who are living with the effects of brain injury.

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## Introduction

In an effort to "measure what matters" (Whiteneck, 1994), this study was designed to examine the conceptual bases of research on the disablement experienced by individuals who have sustained brain injury, and to identify factors that contribute to quality of life for these individuals.

Recent advances in emergency medical care have resulted in a dramatic reduction in loss of life due to traumatic and other acquired brain injuries (Wilberger, 1993) and a corresponding increase in the number of individuals surviving serious injury to the brain. The resulting urgent demand for brain injury rehabilitation services and the coincident ideological movement towards self-determination for people with disability (Batterham, Dunt, & Disler, 1996; Wolfensberger, 1972) have precipitated a rapid and extensive expansion of community-based post-acute rehabilitation services (Evans, 1997; Fuhrer & Richards, 1996; Johnston & Lewis, 1991; Willer & Corrigan, 1994).

Escalating health care costs coupled with limited resources have exerted pressure to demonstrate the value and cost-effectiveness of these rehabilitation services (Cervelli, 1997; Evans & Ruff, 1992; Hall, 1997; Hall & Cope, 1995). This pressure for accountability has resulted in a proliferation of research on the experience of disablement and on the outcomes of rehabilitation for survivors of brain injury. A consequence of the rapid growth of this research and of its origin in the context of service provision is that assessment of disablement and rehabilitation following brain injury has become "somewhat chaotic" (Oddy & Alcott, 1996). A bewildering array of measures has been derived from a variety of theoretical perspectives, in a variety of disciplines. Furthermore, these measures have been designed for a number of purposes, including diagnosis, monitoring, prediction, and service evaluation (Fuhrer, 1995; Oddy & Alcott, 1996; Wade, 1992).

The publication of a system of classification for the consequences of disease or injury, the International Classification of Impairments, Disabilities, and Handicaps (ICIDH) by the World Health Organization (1980), has provided a means of imposing order on research on disablement and rehabilitation. The conceptual structure embodied by the ICIDH not only has encouraged the classification of measures according to levels of impairment, disability and handicap (Chamberlain, Neumann & Tennant, 1995; Oddy & Alcott, 1996; Wade, 1992), but also has influenced approaches to service provision and research design by promoting the consideration of disablement as a multi-dimensional phenomenon.

The ICIDH model of disablement, however, fails to consider explicitly the impact of contextual factors on the experience of disablement, or the impact of disablement on quality of life. The existing literature consists primarily of descriptive research that focuses on the outcomes of rehabilitation at the levels of impairment and disability. An implicit assumption of rehabilitation is that reductions in impairment, disability, and handicap are related to enhanced quality of life. The present study examined this assumption by empirically investigating the relationships among the ICIDH constructs, considering quality of life in conjunction with injury-related and contextual factors. Although investigation of the subjective experience of persons with disability has been acknowledged as legitimate and desirable, much of the existing research relies on archival data or on reports from family members or professional caregivers. The present study addressed this issue by investigating the subjective experience of people living with acquired brain injury through personal, structured interviews.

## Acquired Brain Injury

The term "acquired brain injury" refers to injury to the brain that is not of a degenerative or congenital nature, and that results in the impairment of normal brain function. Acquired brain injuries include those caused by trauma, such as a blow to the head, as well as those due to intracerebral events such as tumour, anoxia, haemorrhage or infection.

Open head injuries are caused by forces penetrating the skull, and typically result in damage to a specific, clearly defined area of the brain. In contrast, closed head injuries can occur when the head sustains a blow or is subject to a sudden change in movement, and can result in both localized and diffuse damage. Motor vehicle collisions tend to be particularly destructive because the impact of the brain against the skull can result in contusion in the area of impact, and differential deceleration of the brain can cause diffuse injury by tearing neural fibres and blood vessels (Povlishock & Valadka, 1994).

### Etiology

Motor vehicle collisions are by far the leading cause of traumatic brain injuries. When collisions involving occupants of motor vehicles, motorcyclists, bicyclists and pedestrians are considered, motor vehicle-related collisions account for more than 50% of all traumatic brain injuries. A further 20% of injuries are caused by falls. Other common causes include assault (including gunshot wounds), and activities related to sport and recreation (Kraus, 1993; Sorensen & Kraus, 1991).

## Severity

The severity of brain injury is classified according to duration of coma, duration of post traumatic amnesia (Russell, 1932), and/or depth of coma as determined by the Glasgow Coma Scale (Teasdale & Jennett, 1974). Mild injury is characterized by loss of consciousness of less than 20 minutes, post traumatic amnesia of less than one hour, or a Glasgow Coma Scale score between 13 and 15. Moderate injury is defined by coma of between 20 minutes and 1 hour, post traumatic amnesia of up to 24 hours, or a Glasgow Coma Scale score of 9 to 12. Indicators of severe injury are coma of more than 1 hour, post traumatic amnesia of more than 24 hours, or a Glasgow Coma Scale score of 8 or less (Vollmer, 1993).

Overall, approximately 80% of persons admitted to hospital with brain injury have experienced mild injury to the brain, 10% are affected by moderate injury, and 10% are left with severe injury. Of those admitted with mild or moderate brain injury, 100% and 93% respectively survive to be discharged from hospital. Of those admitted with severe brain injury, only 42% survive to be discharged (Kraus, 1993).

## Incidence

Estimation of the incidence of brain injury has been impeded by inconsistency in definition, data collection, and reporting procedures, as well as by variation in incidence according to such factors as age, gender, and environment.

In the UK, 1986 figures provide an overall estimate of 297 cases of brain injury per

100,000 people. However, the incidence of brain injury is much higher among the young and the elderly than among those of middle age, and the rate of injury for males is twice that for females (Tennant, 1995).

The estimated overall incidence of brain injury in the US is consistently reported as approximately 200 per 100,000 individuals (Kraus, 1993; Max, MacKenzie & Rice, 1991). Applied to the 1990 US population of 250 million, this rate results in an estimated figure of 500,000 people sustaining brain injury in the US each year (including those admitted to hospital for treatment and the estimated 50,000 who die before reaching hospital). North American data show a peak incidence among people aged 15 to 24 years, and, like the British data, show a ratio of male to female cases of at least 2:1, regardless of age (Kraus, 1993). In Canada in 1996 the estimated incidence of brain injury was 158 per 100,000, or 45,589 people, with 36,935 people admitted to hospital (Ontario Brain Injury Association, 1996 census data). The incidence rate reported for the province of Ontario is 149 per 100,000 people, with approximately 16,000 individuals sustaining a brain injury each year, and about 80% of these (12,500 people) being hospitalized for their injury (Ontario Brain Injury Association, 1991 census data).

The number of individuals living with ongoing disability attributable to brain injury in the US each year has been estimated at between 33 and 45 per 100,000, or approximately 83,000 to 112,000 people (Kraus, 1993). In Ontario each year, it is estimated that for about 2,200 (approximately 20 per 100,000) people, consequences of brain injury make it impossible to resume their prior life (Ontario Brain Injury Association, 1991 census data).

Although accurate estimates of the overall prevalence of brain injury and resulting disability are difficult to obtain (Kraus, 1993; Max et al., 1991), it is clear that the total number of persons requiring ongoing care or personal assistance as a result of brain injury is significant and is rapidly increasing (DeJong, Batavia & Williams, 1990).

## Cost of Brain Injury

During the last two decades, brain injury has come to be recognized as one of the most critical problems facing health care systems (Cope, 1995; Goldstein, 1990). Increased attention to initial resuscitation, rapid transportation, and effective emergency care has reduced the overall mortality from brain injury from 22 deaths per 100,000 people in the 1970s to 15 per 100,000 in the early 1990s (Wilberger, 1993). The dark side of this remarkable achievement is that many of those who survive face a lifetime of severe disablement.

The personal cost of brain injury can be devastating, with deleterious effects in terms of physical, cognitive, emotional, behavioural and social functioning. These pervasive and often permanent effects of brain injury can generate lifelong requirements for support, including medical and personal care, homemaking, supervision, and respite care.

For survivors of brain injury, life expectancy is similar to that of the uninjured population (Conroy & Kraus, 1988; Trieschmann, 1990). As the peak incidence of brain injury occurs in adolescents and young adults, a lifetime of disablement can easily involve a period of 50 years or more. Estimates of the cost of care over the life span of an individual with severe brain injury have been placed in the range of $3 to $5 million

(Bush, 1990). In the US, the overall financial cost per year approaches $44 billion, with 4.5 billion being spent on direct costs such as acute care and rehabilitation services (Max et al., 1991). In Ontario in 1994, approximately $62 million was spent by the Ministry of Health to support hospital and community-based services for people with acquired brain injury (Continuum of Opportunity Task Force, 1994). In a recent review of rehabilitation outcome literature, Hall & Cope (1995) articulated the impact of these figures, observing that "a persistent and troublesome question for insurers, health care professionals and clients and families alike is whether the benefit of acute and post-acute rehabilitation for individuals with traumatic brain injury outweighs the formidable costs of such care" (p. 1).

High costs and increasing competition for limited resources emphasizes the need for accountability for all health care spending (Condeluci, Ferris & Bogdan, 1992; Cope, 1995; Hall, 1997; Hall & Cope, 1995). In a comprehensive review of the clinical benefit of rehabilitation for people with traumatic brain injury, Cope (1995) noted that the results of most of the studies reviewed demonstrate significant improvement (over and above that explained by spontaneous recovery) following rehabilitation. Cope concluded that although the overall efficacy of brain injury rehabilitation is strongly supported, rehabilitation can currently be described as a "black box" of interventions in which the nature of the effect, its magnitude, and its cost are not easily determined.

The assessment of outcome for people who survive injury to the brain is particularly challenging because the consequences of brain injury vary, depending on the severity and type of injury and the influence of personal and environmental factors. Fordyce (1994) comments that demonstrating clear patterns of clinical efficacy may be difficult, given the early developmental stage of brain injury rehabilitation and the complexities of human behaviour and the environment.

## Consequences of Brain Injury

The literature is replete with descriptions of the multiple physical, cognitive, emotional and behavioural difficulties faced by individuals who have sustained a brain injury (Brooks, 1990; Lezak, 1986; Stratton & Gregory, 1994).

Paralysis, motor slowness, poor balance, epilepsy, visual and auditory impairments and receptive and expressive language impairments comprise some of the physical difficulties often experienced by survivors of brain injury (Stratton & Gregory, 1994). Cognitive problems include deficits in attention, concentration, memory, perception, judgement, comprehension, language and self-awareness (Ben-Yishay & Diller, 1983; Brooks, 1990). These cognitive problems are often reflected in diminished executive functioning, that is, the capacity for control, regulation and adaptation of complex behaviour (Lezak, 1986). Affective and behavioural changes include emotional lability, aggression, flattened affect, apathy, lethargy, impulsivity, disinhibition, irritability, anxiety and depression (McKinlay, Brooks, Bond, Martinage & Marshall, 1981; Stratton & Gregory, 1994; Willer, Allen, Durnan & Ferry, 1990).

Physical, cognitive, emotional and behavioural problems together contribute to the challenge of resuming normal roles and to the social isolation frequently experienced by people who have sustained brain injury (Stratton & Gregory, 1994). Social isolation and diminished social contact are, in fact, reported to be the primary concern of many individuals with severe brain injury (Karpman, Wolfe, & Vargo, 1985; Klonoff, Snow &

Costa, 1986; Thomsen, 1974, 1984). For example, Thomsen (1984) found that at 10 to 15 years post injury, 68% of relatives report that diminished social contact is a problem for the injured family member. Weddell, Oddy and Jenkins (1980) reported that by two years after the injury the number of close friendships had diminished and had been substituted by casual acquaintances (of 44 subjects, 21 had no friends they saw once a week, and 6 had no friends at all). Kozloff (1987) found that as the time since the injury increased, the size of the head injured person's social network decreased and its density increased, with family members serving progressively more functions as nonrelatives became less involved.

Loneliness and depression also remain persistent, long-term problems for many survivors of brain injury (Morton and Wehman, 1995). Harrick, Krefting, Johnston, Carlson and Minnes (1994) found that whereas functional status remained stable or improved between admission and one and three years after discharge from a community-based post-acute rehabilitation program, loneliness and depression increased to become the two problems most frequently reported. By three years after injury, 29% of their respondents reported loneliness and 19% reported depression as concerns. Oddy, Coughlan, Tyerman and Jenkins (1985) noted that loneliness was reported as the greatest difficulty in a 7-year follow-up in which most subjects lived with parents and were restricted in opportunities for leisure activities by loss of skills, lack of interest and initiative, problems with mobility, and inadequate facilities. Kinsella, Moran, Ford and Ponsford (1988) found that 33% of their 39 subjects suffered from depression, and that the availability of a confidant was an important predictor of depression (those without being more likely to be depressed). Linn, Allen and Willer (1994) found that an average of six years after injury, 70% of their severely brain-injured respondents acknowledged symptoms of depression and 50% demonstrated symptoms of anxiety.

The physical and functional consequences of brain injury are serious problems that can be ameliorated to some extent by rehabilitation. However, the overwhelming consensus is that the psychosocial problems associated with brain injury constitute the major challenge to successful rehabilitation (Elsass & Kinsella, 1987; Gomez-Hernandez, Max, Kosier, Paradiso & Robinson, 1997; Harrick et al., 1994; Morton & Wehman, 1995; Thompsen, 1984; Trieschmann, 1990). The consistency of this finding suggests that the investigation of social and emotional consequences of brain injury should be considered an important aspect of research in brain injury rehabilitation.

## History of Post-Acute Rehabilitation for Individuals with Brain Injury

The history of post-acute rehabilitation for individuals living with the effects of brain injury is brief, spanning at most two decades (Cope, 1995; Evans, 1997). As recently as 1978 it was reported that most preventable head injury deaths were due to "inappropriate management of patients who reach hospitals alive" (Jennett and Carlin, 1978, p. 38). By 1985, a national US task force had identified serious inadequacies in emergency trauma care and had become the driving force behind the development of improved emergency responses and trauma care (Wilberger, 1993). In 1988, in Ontario, two comprehensive reviews were conducted with specific regard to the provision of service for people sustaining brain injury. Reviews by the Ministry of Health and the Ministry of Community and Social Services independently determined that services were insufficient in every part of the continuum from acute inpatient care to ongoing rehabilitation in the community (Rempel, 1994).

Prior to the late 1970s, people surviving the acute phase of brain injury had languished indefinitely in acute-care settings or had been discharged to their homes, to long-term nursing facilities or to inpatient psychiatric programs. In the United States, a system of trauma care delivery had been established for survivors of spinal cord injury, but little was available in terms of coordinated service delivery for survivors of brain injury (Ragnarsson, Thomas & Zasler, 1993). In Britain, this remained the case through the 1980s, with little, if any, post-acute rehabilitation available (Tyerman, 1996).

As emergency care procedures improved and the number of people surviving brain injury increased, attention was drawn to the urgent need for long-term rehabilitation services. The result was the sudden, rapid, and consequently fragmented development of service provision and research. In 1987, the US National Institute on Disability and Rehabilitation Research initiated its Model Systems of Care project to address planning and program development, to demonstrate comprehensive service delivery, and to coordinate research, public education and prevention (Ragnarsson et al., 1993). As part of the Model Systems project, a national database and five demonstration service provision programs were established. These programs are among those which now form an extensive network of post-acute rehabilitation programs in the US (Tyerman, 1996).

Concurrent with the increasing number of brain injury survivors was the movement towards self-determination for people with disabilities. A number of social movements in the 1960s and 1970s together influenced the subsequent "emancipation of the disabled"

(Condeluci, Cooperman & Seif, 1987, p. 309). Among these were the civil rights movement, deinstitutionalization, and consumer involvement (DeJong, 1979).

In 1978, due for the most part to grassroots advocacy by people with disabilities, comprehensive services for independent living for people with disabilities were legislated in the US. This legislation defined independent community living as a system of service provision and authorized the development of independent living centres throughout the US (Condeluci et al., 1987; Matthews, 1990). Matthews (1990, p. 24) notes that "A basic philosophical tenet common to these programs is that people with severe disabilities are capable of exercising self-determination and participating in all aspects of society given the presence of appropriate support services, accessible environments, and the necessary information and skills".

## Models of Disablement

Disablement refers to the process or experience of being deprived of a legal right, qualification or capacity, or of being made incapable or ineffective (Webster's New Collegiate Dictionary, 1977). Disablement is also the term selected by the World Health Organization to refer, collectively or separately, to the dimensions of health-related experience addressed in the ICIDH classification system: impairment, disability and handicap.

Two general approaches to conceptualizing disablement are discussed in the literature: the social model and the medical model. The emphasis described by Matthews (1990) on self-determination, participation, and the availability of appropriate support services, necessary information and skills, and accessible environments, is characteristic of the social model of disablement. The social model locates the responsibility for the construction of disablement directly in the social / political arena, conceptualizing disablement as the result of the inability or unwillingness of the society to meet the needs of all of its constituents. According to the social model, the experience of disablement should be alleviated, not primarily by restoring function or teaching compensatory strategies that will enable the individual to take on normal social roles, but by eliminating physical and attitudinal barriers to opportunities that are accessible to the rest of society (French, 1992; Furrie, 1995; Imrie, 1997; Marks, 1997a, 1997b; Sara-Serrano Mathiason, 1997; Trieschmann, 1990). The perspective of the person whose life has been altered by disablement is considered to be central to understanding the experience of disablement (Condeluci et al., 1992; French, 1992; Peters, 1995; Whiteneck, 1994).

It is the medical model of disablement, however, that forms the foundation on which the provision of rehabilitation services and the research on disablement and rehabilitation is based. Historically, Western medical science has focused on acute illness, which is characterized by a specific underlying cause, sudden onset of symptoms, near-total prostration, and limited duration, with the resolution of the crisis being death or recovery. Responsibility for making an accurate diagnosis and for prescribing the intervention is ascribed to the health professional, the patient being relieved of any responsibility other than "unquestioning capitulation to professional advice" (World Health Organization, 1980, p. 23). The key to treatment lies in diagnosis, which is a process of categorization based on the observation of symptoms: The presence or absence of specific symptoms reveals the category to which the disease should be assigned. The disease or disorder is located in the individual, and intervention is seen to be successful when the individual is restored to normal functioning.

The effectiveness of the medical model as an approach to controlling acute illness is evidenced by the decreasing prevalence of acute illness over the last century. However, the medical model is less effective as an approach to health care needs arising from chronic conditions, as these needs cannot be predicted solely on the basis of diagnosis. For this reason, the ICIDH was proposed as a means of classifying and assessing the consequences and the experience of ongoing health conditions, with a view to facilitating the evaluation of health care provision (Badley, 1993; World Health Organization, 1980, 1997).

## The ICIDH

The ICIDH (World Health Organization, 1980) is a widely accepted system of classification that offers a means of considering the numerous and disparate effects of disablement from the vantage point of a general theoretical perspective.

The ICIDH differentiates impairment, disability and handicap as three distinct classifications, each of which relates to a different plane of experience arising from disease or injury (World Health Organization, 1980). Impairment refers to a loss or abnormality of psychological, physiological or anatomical structure or function. Disability describes a limitation in performing activities involved in daily functioning, that arises as a result of impairment. Handicap is defined as a disadvantage that results from an impairment or a disability, and that limits or prevents fulfilment of a social role that is normal (depending on age, sex, and social and cultural factors) for that individual.

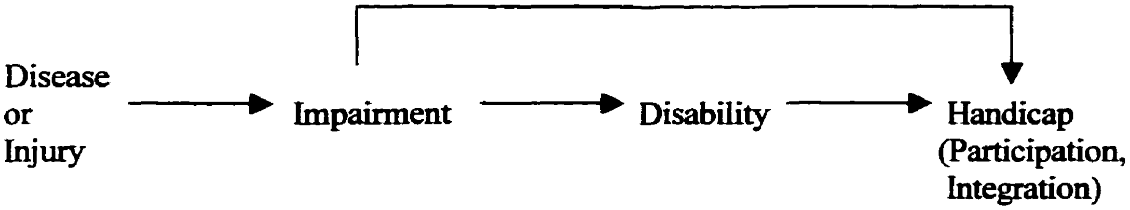
These distinctions are reflected in a framework in which impairment represents the consequence of disease or injury at the organic level, disability represents limitations at the level of the person's functioning as an individual, and handicap represents the disadvantage faced by the person as a member of the larger society. According to the ICIDH (1980), disease or injury may give rise to impairment, impairment may lead to disability and/or handicap, and disability may lead to handicap (See Figure 1).

The purpose of the ICIDH is to provide a framework for the conceptualization of the consequences of disease and injury that moves away from a solely medical model and facilitates consideration of the social implications of those consequences (World Health Organization, 1980). Although the social implications of the consequences of disease and injury are implicitly incorporated in the ICIDH framework within the definition of handicap, true integration of the medical and social models requires explicit consideration of contextual factors as well as injury-related factors in describing the experience of disablement.

## Goals and Assumptions of Rehabilitation

In the rehabilitation literature, there is growing consensus regarding the importance of the subjective experience of the individual living with disablement (Gill & Feinstein, 1994; Batterham et al., 1997; Peters, 1995; Rempel, 1994; Whiteneck, 1994). The movement toward self-determination for people with disabilities has been accompanied by the recognition of individuals with brain injury as consumers and as experts regarding their own experience. For example, one of the recommendations of the Acquired Brain Injury Continuum of Opportunity Planning Framework for services for people with head

Figure 1. ICIDH Model of Disablement.



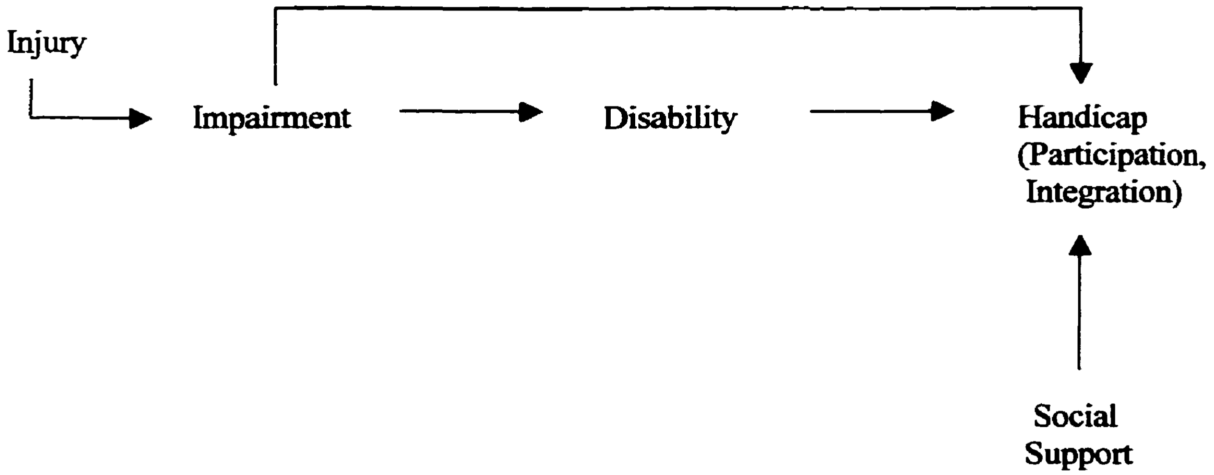
injury in Ontario states that families and survivors of brain injury should be involved extensively in the planning and in the evaluation of services they will be receiving (Continuum of Opportunity Task Force, 1994).

As yet, however, little work has been done to define what people with disabilities consider to be high quality outcomes (Batterham et al., 1996; Condeluci et al., 1992; Keith, 1995; Peters, 1995; Whiteneck, 1994). An exception is a study which reports that on admission to a community-based post-acute rehabilitation program, the majority of clients identify three goals as important: independent living, employment or other productive activity, and increased social interaction (Harrick et al., 1994). Another exception is a series of studies investigating survivors' perceptions of the outcome and value of rehabilitation. Condeluci et al. (1992, pp. 41-42) report that the results of these studies indicate that "satisfaction with life after a traumatic brain injury depends as much on the opportunities and supports found in the community as on the inpatient rehabilitation focused on functional skill development".

These findings support the literature discussing the need to consider the influence of factors other than those relating directly to the injury (Badley, 1995; Batterham et al., 1996; Fougeyrollas, 1995; Verbrugge & Jette, 1994; Whiteneck, 1994). For these reasons, the present study includes social support as a contextual factor (See Figure 2).

The goals of rehabilitation may vary, depending on the interest of the party involved; whether it be the insurer, the service provider, the family member, or the person who sustained the injury (Condeluci et al., 1992; Evans & Ruff, 1992; Zasler, 1996). Commonly described goals of intervention, in addition to those described by Harrick et al.

Figure 2. ICIDH Model of Disablement with Social Support added.



(1994), are those of restoring function, reducing economic burden, and improving quality of life (Condeluci et al., 1992; Fuhrer, 1995; Keith, 1995; Peters, 1995).

Although enhanced quality of life is cited as the ultimate goal of rehabilitation (e.g., Continuum of Opportunity Task Force, 1994; Fuhrer & Richards, 1996; Hall, 1997; Johnson, 1997; Keith, 1995; Oddy & Alcott, 1996; Tennant, Hughes, Ward, Warnock and Chamberlain, 1995; Whiteneck, 1994), outcomes of rehabilitation for people living with the effects of brain injury have seldom been assessed in terms of subjective well-being, life satisfaction or quality of life. Instead, they have been assessed almost exclusively in terms that evaluate the restoration of function: medical stabilization, the extent of residual impairment, and the amount of assistance required to perform activities of daily living (Whiteneck, 1994). This discrepancy between a major goal of rehabilitation and the evaluation of outcomes has been attributed to the development of outcome measures in the context of service provision (Fuhrer, 1995) that is based on assumptions derived from a medical model (Keith, 1995).

The medical approach is less suited to the complex and changeable nature of the ongoing consequences of disease and injury than to acute illness. Service providers working under the medical model are predisposed to focus on physical and functional problems. Because funding decisions regarding provision of service have been based primarily on measurable functional improvement, there has been a need to demonstrate physical and functional change to secure further funding (Batterham et al., 1996; Trieschmann, 1990). Therefore, outcomes selected for assessment tend to be those to which numbers can be easily assigned, such as independence in activities of daily living, hours of attendant care, residential status, and productivity (Vollmer, 1993).

These measurement practices "implicitly assume that maximizing the client's score on some measure of nondependence gives the client the best chance of achieving a high quality of life in the long run. Thus, services are planned to achieve functional improvements" (Batterham et al., 1996, p. 1219).

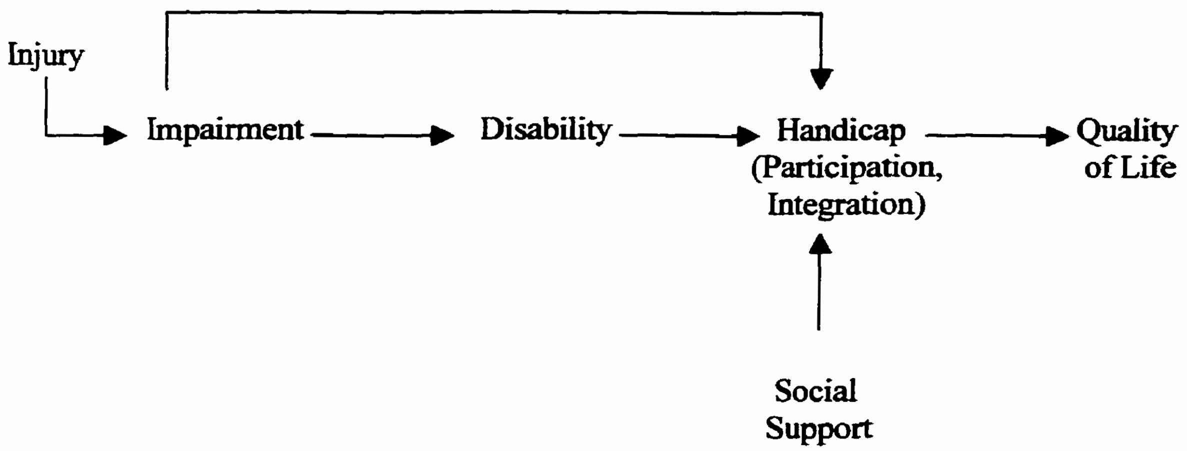
With the concentration of effort on the development of measures assessing change in physical and functional status, the less tangible concepts of handicap and quality of life, for the most part, have been neglected. Accountability to all who are involved in receiving or providing brain injury rehabilitation, however, requires that quality of life be included in the assessment of disablement and rehabilitation outcome, and that implicit assumptions be acknowledged and tested. Therefore, the present study includes quality of life as the final outcome variable, testing the underlying assumption that reduced impairment, disability and/or handicap are associated with enhanced quality of life (See Figure 3).

## Research on Disablement and Rehabilitation Outcome

### Impairment

Assessment of impairment after brain injury typically focuses on outcomes such as mortality and injury severity, and is conducted during the acute phase of trauma and recovery. Severity of the injury most commonly is evaluated using the Glasgow Coma Scale to assess depth of coma, and using post traumatic amnesia to determine the length of time required to regain continuous day-to-day memory. The Glasgow Coma Scale has been shown to predict costs and mortality, and post traumatic amnesia has been shown to

Figure 3. ICIDH Model of Disablement with Social Support and Quality of Life added.



predict costs and general outcomes (Hall, 1997).

The Galveston Orientation & Amnesia Test (Levin, O'Donnel & Grossman, 1979) assesses orientation to person, place and time, and strongly predicts outcome as measured by the Glasgow Outcome Scale (Jennett & Bond, 1975), the Disability Rating Scale (Rappaport, Hall, Hopkins, Belleza & Cope, 1982) and the Functional Independence Measure (Granger, Hamilton & Sherwin, 1986). Another scale measuring both coma and orientation is the Rancho Los Amigos Levels of Cognitive Function Scale (Malkmus, 1980). Heinemann and Whiteneck (1995) reported consistent relationships between these measures of impairment (coma, post traumatic amnesia and the Rancho Los Amigos scale) and measures of disability derived from the Disability Rating Scale, the Functional Independence Measure and the Functional Assessment Measure (Hall, Hamilton, Gordon, & Zasler, 1993) and between Glasgow Coma Scale scores and time to return to work.

Relationships between these measures of impairment and more complex measures of disability and handicap are more tenuous. Fuhrer, Rintala, Hart, Clearman, and Young (1992) explained that weaker associations can be expected between impairment and handicap because handicap is conceptually more distant from impairment than is disability. Keith (1995) noted that there is no particular relationship between severity of impairment (injury) and consequences for disability or handicap. Malec, Smigielski, DePompolo and Thompson (1993), for example, found no association between length of coma and return to work, or emotional, functional or physical abilities as assessed by the Portland Adaptability Index (Lezak, 1987).

It can be argued that measures based on depth or duration of coma or duration of post traumatic amnesia are not measures of impairment, but rather are measures of the severity of the injury. The severity of injury is not necessarily related to impairment, which refers to the immediate consequence of the underlying pathology as perceived by the individual (Wade, 1992). Kay, Cavallo, Ezrachi & Vavagiakis, 1995, for example, found no relationship between neurological severity, as measured by duration of coma or post traumatic amnesia, and the Problem Checklist, which reflects the reported presence of common sequelae of brain injury and the degree to which they are perceived as problematic by respondents.

Also classified as measures of impairment (Oddy & Alcott, 1996) are behavioural rating scales such as the Neurobehavioral Rating Scale (Levin et al., 1987) and the Katz Adjustment Scales (Katz & Lyerly, 1963), as well as symptom checklists (e.g., Brooks & McKinlay, 1983; Kay et al., 1995; and Oddy, Humphry & Uttley, 1978).

A variety of specific measures exists for motor and sensory impairments. Assessment of cognitive impairment includes memory, learning, attention, verbal and perceptual abilities, reasoning, and executive ability, most commonly measured by the Wechsler Adult Intelligence Scales (Oddy & Alcott, 1996).

The Problem Checklist from the Head Injury Family Interview (Kay et al., 1995) was selected as the measure of impairment for the present study because it is a recently published, widely used measure that assesses the nature and severity of the impairment as it is experienced by the respondent. The Problem Checklist provides a comprehensive list of the diverse symptoms that may be experienced after brain injury. Respondents' subjective report of whether they experience various symptoms and the degree to which these symptoms constitute a problem for them provides detailed and clinically useful information regarding the type and degree of impairment experienced.

## Disability

Assessment of disability (i.e., of functional limitation at the level of the individual) is generally undertaken after the injured person has been medically stabilized, primarily with the purpose of informing inpatient rehabilitation. Hannay, Ezrachi, Contant and Levin (1996) recommend the Glasgow Outcome Scale and the Disability Rating Scale because of confirmed validity and reliability; the Functional Independence Measure and the Functional Assessment Measure are also commonly used (Oddy & Alcott, 1996).

These measures are less useful when the person with the brain injury has recovered to the point where he or she is receiving outpatient rehabilitation services, because of their lack of sensitivity and their focus on level of arousal, bodily functioning, and basic self-care routines. The Glasgow Outcome Scale identifies the potential outcomes of brain injury as death, vegetative state, severe disability, moderate disability, and good recovery. The Disability Rating Scale assesses four categories of outcome regarding a) eye opening, and best verbal and motor responses, b) cognitive ability to undertake eating, toileting, and grooming activities, c) level of dependence, and d) psychosocial adaptability, regarding domestic, academic and employment responsibilities. The Functional Independence Measure focuses on levels of motor and cognitive independence in personal care, sphincter control, mobility, locomotion, communication, and social cognition. The Functional Assessment Measure, an extension of the Functional Independence Measure, includes cognitive and psychosocial factors (Oddy & Alcott, 1996; Wade, 1992).

A number of commonly used measures defy unequivocal classification into one or another of the impairment, disability or handicap categories. The Disability Rating Scale, for example, contains items pertaining to both impairment and disability (Oddy & Alcott, 1996), and Wade (1992) describes the Glasgow Outcome Scale as a measure of handicap rather than as a measure of disability.

The Patient Competency Rating Scale (Prigatano et al., 1986), which was used in the present study, assesses perceived limitations in activities of daily living, emotional functioning, and cognitive functioning. With a sample of respondents with brain injury living in the community, the Patient Competency Rating Scale is less likely to demonstrate a ceiling effect than scales such as the Glasgow Outcome Scale or the Disability Rating Scale. Unlike the behavioural rating scales described above, the Patient Competency Rating Scale is a questionnaire in which respondents report their perception of the degree of ease or difficulty with which they carry out various activities or respond to various situations.

### Handicap

Handicap is more complex and more abstract than the other ICIDH constructs, reflecting the cultural, social, economic and environmental consequences of the injury. The assessment of handicap, which represents disadvantage at the level of the person's interaction with society, becomes the focus of interest as the time since injury increases and the person is discharged from inpatient rehabilitation into the community.

The ICIDH (World Health Organization, 1980) designates six dimensions of experience as "survival roles", that describe, for purposes of classification, the circumstances in which competence is expected of individuals: orientation, physical independence, mobility, occupation, social integration, and economic self-sufficiency. Each of these dimensions is rated on a scale that ranges from no disadvantage to complete or almost complete disadvantage.

Recently developed measures of handicap include the Craig Handicap Assessment and Reporting Technique (Whiteneck, Charlifue, Gerhart, Overholser, & Richardson, 1992), which was based on the ICIDH survival roles and developed for use with individuals with spinal cord injury, and two measures which were developed specifically for use with people with brain injury: the Community Integration Questionnaire (Willer, Rosenthal, Kreutzer, Gordon & Rempel, 1993) and the Community Integration Measure (McColl, Johnston, Carlson, Minnes, Davies, & Karlovitz, 1998). The Acculturation, Integration, Marginalization, Segregation (AIMS) measure (Buell & Minnes, 1994) is a measure of the support available to individuals living with disablement in the community. Other commonly used indicators of handicap include living arrangement, functional status, resource use (such as hours of attendant care and cost), and productive activity (Hall, 1997; Keith, 1995).

The use of the necessarily general ICIDH terms, such as handicap, to describe measures assessing qualitatively different constructs can lead to confusion regarding the meaning of the results. In research in the area of brain injury, therefore, it is important to describe clearly the construct being assessed and to develop measures that comprehensively reflect that construct, or, alternatively, to specify which aspect of the construct is being represented by the measure used.

The present study included two measures of handicap. The first, the Community Integration Questionnaire (Willer et al., 1993), assesses the disadvantage experienced with regard to limitations in participation in social roles. In this measure, participation in social roles is characterized by the degree of independence in domestic activities, the frequency of participation in social activity, and the extent of participation in volunteer, school or work activities. The second measure of handicap (the Community Integration Measure; McColl et al., 1998) assesses disadvantage in terms of limitations in integration. Integration refers to the extent to which respondents report feeling that they belong, that they are "of", as opposed to merely "in" the community, with reference to independent living, social interaction and occupation.

### Social Support

Social support refers most commonly to helpful functions performed for an individual, which can be categorized as emotional, instrumental and informational support, and measured in terms of their objective availability or use, or in terms of the subjective perception that such support would be available if needed (McColl & Skinner, 1988). Other measures of support are based on the number, frequency and density of the individual's social contacts (Kozloff, 1987). Despite the difficulties of assessing a construct that is operationalized in so many ways, several reviews of the support literature have reached the conclusion that "socioemotional support from significant, or primary, others appears to be the most powerful predictor of reduced psychological distress or disorder, whether stressful circumstances are present or absent" (Thoits, 1985, p. 54). Although research supports both direct and buffering effects, Thoits pointed out that neither interpretation is in itself complete, suggesting that we currently lack an understanding of the means by which supportive relationships can result in psychological benefits.

Thoits (1985) hypothesized that it is regularized social interaction, not emotional support per se, that is responsible for maintaining well-being, suggesting that emotional support is obtained from ongoing role relations as a by-product of social interaction. Role relationships are thought to be psychologically beneficial in three ways: by providing a set of identities, as sources of positive self-evaluation, and as bases for a sense of control or mastery.

Thoits (1985) proposed that involvement in role relationships is the essence of social integration. The individual is thought to be tied to the norms of society by being embedded in a system of relationships with others. In this formulation, the reciprocal duties and privileges invoked by the role simultaneously define who the individual is and provide a sense of belonging. Role relationships describe how the individual belongs to the wider social network, and provide a sense of security, self-esteem, and comparative mastery. To the extent that one possesses few roles, loses roles, or observes one's relative inadequacy in role performance, these positive feelings will diminish and negative feeling states will emerge, building to a state of psychological distress.

Although research corroborates the conclusion that contextual factors, particularly social support, influence the experience of disablement for people with brain injury (e.g., Dawson & Chipman, 1995; Elsass & Kinsella, 1987; Gomez-Hernandez et al., 1997; Harrick et al., 1994; High, Boake & Lehmkuhl, 1995; Kaplan, 1991; Kozloff, 1987), the relationships between social support and impairment, disability, handicap, and quality of life have been neglected in studies of brain injury rehabilitation outcome (Keith, 1995).

Social support was assessed in the present study using a version of the Interpersonal Support Evaluation List (Cohen, Mermelstein, Karmarck, & Hoberman, 1985) that has been adapted for use with people with disabilities (McColl & Skinner, 1995). This measure assesses the perceived availability of instrumental, informational and emotional support.

### Quality of Life

Enhanced quality of life has been acknowledged as the ultimate goal of rehabilitation (e.g., Continuum of Opportunity Task Force, 1994; Cope, 1995; Fuhrer & Richards, 1996; Hall, 1997; Johnson, 1997; Keith, 1995; Oddy & Alcott, 1996; Tennant et al., 1995; Whiteneck, 1994), and is assumed to be associated with a lesser degree of impairment, disability and handicap (Batterham et al., 1996). Empirical research is needed to validate this assumption, and to determine specifically what is relevant, in terms of enhancing quality of life, for people who have sustained brain injury.

Although measures of quality of life have been developed and used in research in other areas of disability, it remains a nebulous construct that resists definition and quantification. The terms quality of life and subjective well-being have been used synonymously, to refer to "individuals' global judgements of their life experience along a continuum that ranges from positive to negative", emphasizing that "(1) these judgements reflect the individual's implicit standards rather than any particular objective condition, and (2) both cognitive and emotionally toned judgements are involved" (Fuhrer, 1994, p.

359). Quality of life and subjective well-being are thought to be comprised of such component concepts as life satisfaction, happiness, and morale. Despite efforts to discriminate among these components, they tend to be substantially correlated (Fuhrer, 1994).

Attempts have been made to find a place for the quality of life construct within the ICIDH framework (Oddy & Alcott, 1996; Wade, 1992). However, Tennant et al. (1995), with specific reference to quality of life as a measure of outcome following brain injury, have commented that "Concepts such as 'quality of life' have yet to be both clearly defined and seen to be relevant. The development of appropriate classifications and measures of these concepts is urgent." (p. 225).

Gill and Feinstein (1994) have pointed out that many quality of life measures are beleaguered by poor face validity. Their review of 75 papers in which the term "quality of life" appeared in the title revealed that measures purportedly reflecting quality of life ranged from the assessment of eating behaviour, cognitive impairment, and employment status to the Katz Adjustment Scales (Katz & Lyerly, 1963). Some measures used to represent quality of life, such as the Sickness Impact Profile (Bergner, Bobbitt, Carter, & Gibson, 1981), contain items from all three ICIDH categories, measuring dysfunction in aspects of life ranging from sleep, eating and mobility to social interaction and employment. Other measures, such as the Life Satisfaction Index (Neugarten, Havighurst, & Tobin, 1961), are conceptually closer to quality of life, but were developed for use with specific populations; in this case, the elderly.

Wade (1992) described two main approaches to the assessment of quality of life:

the single-item global quality of life question, and the multi-item index. Wade noted a disadvantage of the latter approach: Because quality of life is potentially influenced by so many factors, the importance of each component thought to contribute to quality of life may vary considerably among individuals, and the sum of the component scores may result in a total score that does not reflect the global quality of life of the individual. Oddy and Alcott (1996) concurred that differences in values and expectations among individuals suggest that the development of a universally applicable multi-item measure of quality of life may not be possible. Gill and Feinstein (1994) suggested that when specific domains of quality of life are investigated, respondents should be invited to rate the importance of those domains to their quality of life, and to include additional items that may be important to them.

Gill and Feinstein (1994) have recommended the use of subjective, single-item global quality of life ratings because this type of rating reflects the values and preferences of the individual respondent, and is not constrained by specific item content. It can be argued that this rationale undercuts the use of all measures which involve specific item content. However, constructs such as impairment and disability, for example, are far more concrete and narrower in scope than that of quality of life, and lend themselves to the use of multi-item scales because the range of symptoms or experiences that commonly occur within the construct can be approximated more closely.

The global single-item measure is accompanied by a number of disadvantages as well. First, internal consistency cannot be calculated, and it is difficult to separate true change from measurement error in test-retest reliability. In addition, the single-item global measure, by reason of its being composed of a single item, cannot differentiate the relative contributions of the various domains of life to the respondent's overall quality of life.

However, temporal reliability has been found to be relatively high for single-item global measures, with 15-minute reliabilities for the delighted-to-terrible scale averaging .66, and a 6-month reliability of .40 (Deiner, 1984). In terms of validity, Andrews and Withey (1976) have demonstrated that the results obtained with these measures converge with those obtained with other measures of subjective well-being, and Larsen, Emmons and Diener (1983) noted that these single-item global measures generally are not affected by social desirability.

A single-item global quality of life question was used in the present study because of the importance of understanding the subjective experience of the respondent, and also to facilitate comparison with the existing literature. Information provided by the global measure was supplemented with an emotion-based multi-item assessment provided by Bradburn's Affect Balance Scale.

The association between quality of life and demographic and injury-related factors such as age, gender, age at injury, and time since injury has been shown to be relatively weak (Diener, 1984). In general, relationships between quality of life and measures of functional independence are also weak. Fuhrer et al. (1992), for example, found that quality of life was unrelated to respondents' degree of impairment or disability (as reflected by dependence on others in daily living activities). On the other hand, quality of life appears to be strongly influenced by the characteristics of the individual, such as self esteem, subjective health, perceived choice / control, and by social and environmental factors such as satisfaction with intimate relationships, availability of social support, social contact, and employment (Batterham et al., 1996, Diener, 1984).

Studies on quality of life with individuals with spinal cord injury have found quality of life as assessed by the Life Satisfaction Index-A to be positively related to self-reported health, income, involvement in social activity, perceived social support, satisfaction with the quality and quantity of social contacts, and perceived control of one's life (Fuhrer, 1994). Life satisfaction was also related to three dimensions of handicap assessed by the Craig Handicap Assessment and Reporting Technique, with greater life satisfaction reported by persons doing more to maintain customary social relationships, spending more time in ways customary to their gender, age and culture, and moving about more in their surroundings. However, Fuhrer et al. (1992) noted that handicap did not appear to be directly influencing life satisfaction, because none of these variables accounted for a significant portion of the variance when entered into a regression equation also containing self-assessed health, perceived control, and social support.

### Relationships among Impairment, Disability, Handicap, Contextual Factors and Quality of Life

Although the relationships between the consequences of brain injury and social support and quality of life issues for people with brain injury have been alluded to by numerous researchers (Karpman, Wolfe & Vargo, 1985; Lezak, 1987, 1988; Morton & Wehman, 1995; Oddy, 1984), investigations of relationships among these constructs have only recently begun to appear in the brain injury literature (Dawson & Chipman, 1995; Heinemann & Whiteneck, 1995; Webb, Wrigley, Yoels, & Fine, 1995).

Heinemann and Whiteneck's (1995) study of relationships among impairment, disability, handicap and quality of life for 758 people with brain injury and Dawson and Chipman's (1995) study of disablement based on the 1988 Canadian Health and Activity Limitation Survey provide a starting point for research in this area. Using an adaptation of the ICIDH model of disablement (Badley, 1987), Dawson and Chipman reported a high prevalence of long-term negative consequences of brain injury, with 66% of their sample of 454 people with traumatic brain injury reporting a need for ongoing assistance with activities of daily living, 75% not working, and 90% indicating some limitation or dissatisfaction with their social integration. Also adapting the ICIDH model, Heinemann and Whiteneck demonstrated that 13% of the adjusted variance in quality of life was accounted for by variables reflecting demographic characteristics, impairment, disability and handicap.

Generally, Heinemann and Whiteneck's (1995) findings are consistent with a theoretical model of disablement based on the ICIDH classification. The finding that impairment is the strongest predictor of disability and disability the strongest predictor of handicap supports the proposed relationships from impairment to disability to handicap. In addition, the finding that two aspects of handicap were the strongest predictors of life satisfaction suggests that the model could be extended with a link from handicap to life satisfaction (Heinemann & Whiteneck, 1995).

Specifically, Heinemann and Whiteneck (1995) found that gender, age, education, time since injury and loss of consciousness explained 6% of the variance in level of disability. When extent of disability was added to these variables, they explained 24% of the variance in home handicap, 23% of the variance in social handicap, and 27% of the variance in productive activity handicap. In Dawson and Chipman's (1995) study, gender, age, education, years since injury, income, living situation, environmental barriers and extent of disability explained 27% of the variance in physical independence handicap, 14% of the variance in social integration handicap, and 16% of the variance in working handicap.

The authors of these studies were constrained, however, by the limited measures of impairment, disability and quality of life that were available for the large number of respondents in their data bases. Heinemann and Whiteneck (1995) acknowledged that their use of duration of loss of consciousness as an indicator of impairment was less than ideal. Their disability measure was limited by its low ceiling, with 84% of respondents reporting having received no assistance on any of its five items. Furthermore, this measure assessed only physical disability (eating, toileting, grooming, bathing and walking), despite evidence indicating that cognitive, emotional, and behavioural consequences of brain injury figure prominently in the brain injured person's experience of disability (Kay, Cavallo, Ezrachi, & Vavagiakis, 1995; Morton & Wehman, 1995; Stratton & Gregory, 1994).

Dawson and Chipman (1995) assessed disability using questions about limitations in activity, each of which was rated according to whether performance of that activity was independent, partially independent or dependent. Their measure addressed limitations in communication, behaviour, physical activity and personal care. Dawson and Chipman's approach to assessing disability was also hampered by lack of face validity, however, as behavioural disability was inappropriately defined as the existence of a diagnosed learning disability, and as memory difficulties constituted the only measure of cognitive impairment.

Dawson and Chipman's (1995) study reflects an understanding of how the environment contributes to the experience of disability. Their results demonstrated that although disability predicted their measure of handicap to some extent, more of the variance in handicap was explained by environmental factors. For example, physical independence handicap (amount of assistance needed for activities of daily living) was determined by living situation, presence of physical environmental barriers, level of education and personal-care disability; working handicap (no difficulties working vs. prevented from working due to health) was explained by age, education, physical environmental barriers and motor disability; and social integration handicap (frequency of and satisfaction with social activities) was associated with age, gender, education and personal-care disability.

In Heinemann and Whiteneck's (1995) investigation, handicap was assessed using a measure of the degree of independence in home activities and the extent of social activity and productive activity. Their results showed that independence in home activities was not related to quality of life. Other research on community integration for people with developmental disabilities has revealed that, contrary to the assumption on which community integration is based, in some situations independent living is negatively associated with quality of life. McGrew, Johnson and Bruininks (1994) reported, for example, that individuals with mild to severe developmental disability who were more independent in their living arrangements tended to report lower personal satisfaction than those with less independent living arrangements. According to the McGrew et al. study, the assumption that living in the community and independence in activities of daily living necessarily enhance quality of life may not hold true for everyone. In fact, independent living without adequate support may even detract from quality of life.

Heinemann and Whiteneck (1995) assessed quality of life with responses to a single item ("Overall, how do you feel about the quality of your life in the last month or so?"). Their results indicated that social activity and productive activity were the strongest predictors of self-reported quality of life.

In summary, the ICIDH model of disablement offers a promising foundation on which to build research in brain injury rehabilitation. However, the development of this model has been hindered by difficulties related both to the measurement of the constructs and to the integration of the social and the medical models of disablement. In terms of measurement, the existing research, which is based on archival samples of several hundred respondents, is restricted by the amount and the detail of the data that are consistently available for all respondents. Consequently, the underlying constructs of impairment and disability, with respect to brain injury, are not well represented by the measures that have been used to assess them. Assessment at the level of handicap, which is the point in the ICIDH framework at which the integration of the medical and the social approaches becomes critical, has been hindered by the complexity of the handicap construct. In terms of the conceptual development of the model, issues that need to be addressed are the relationships among impairment, disability and handicap; the impact of contextual factors such as social support on the experience of disablement; and the impact of disablement on quality of life.

## Hypotheses and Predictions

The first goal of this study was to examine the conceptual bases of research on the disablement experienced by individuals with brain injury. The second was to identify factors contributing to their quality of life. Based on the literature on disablement, it was hypothesized that the ICIDH model of disablement describes the relationships among impairment, disability and handicap experienced by people with brain injury. It was also hypothesized that contextual factors such as social support are an important aspect of disablement, and that impairment, disability, social support and handicap influence quality of life.

Based on these general hypotheses, the following predictions were made:

1) The ICIDH model of disablement will represent relationships among impairment (as measured by the Problem Checklist), disability (as measured by the Patient Competency Rating Scale) and handicap (as measured by the Community Integration Questionnaire and the Community Integration Measure). Impairment will predict disability, and both impairment and disability will predict handicap, with disability being the greatest predictor of handicap (See Figure 1).

2) The perceived availability of social support will predict handicap, and a regression model including social support will explain more of the variance in handicap than one including only the injury-related constructs impairment and disability (See Figure 2).

3) The ICIDH model can be extended to include quality of life, with handicap being the strongest predictor of quality of life (See Figure 3).

# Chapter 2: Method

## Sample

The sample for this study was comprised of 97 respondents, of whom 76% were men and 24% were women. At the time of the interview, respondents ranged in age from 20 to 73 years, with a mean age of 39 years.

Criteria for inclusion in the study required that the potential respondent have sustained a moderate to severe brain injury at least one year prior to the interview, be at least 18 years of age at the time of the interview, and be able to respond to the interview questions in English.

Information about severity of injury was obtained for most respondents through records detailing one or more of the following: Glasgow Coma Scale score (12 respondents), post traumatic amnesia (34 respondents), or loss of consciousness (58 respondents). When this information was not available, a psychologist who had assessed or treated the respondent was consulted regarding injury severity (6 respondents). In 12 cases, severity of injury was inferred through information about loss of consciousness provided by the respondent and corroborated by a person who knew the respondent well. Because of the variation in the information available for each respondent regarding severity of injury, this information was used for determining respondents' eligibility for the study and for descriptive purposes only.

Initially only potential respondents living in the Kingston area were contacted; later, in order to increase the size of the sample, the area was extended to include potential respondents living throughout south-eastern Ontario. Three respondents living in southwestern Ontario also participated in the study.

## Procedure

Information regarding the study and a letter of support from the Director of the Regional Community Brain Injury Services in Kingston were sent to former clients who had moderate to severe injuries and who were living in the Kingston area. The letters were followed by a phone call from the Client Information Systems Coordinator at the agency to inquire about the individual's interest in participating in the study and to request permission for an interviewer to call with further information. Those who agreed were called by one of two interviewers in the Kingston area to answer further questions and to schedule the interview. In January, 1997, information about the study was published in the agency newsletter and sent to all clients and former clients of the Regional Community Brain Injury Services. The interviewers telephoned those who met the study criteria and scheduled interviews for those who were interested in participating.

Information and a letter of support were sent to potential respondents in the Ottawa area who were clients or former clients of the Robin Easey Centre by the psychologist at the Centre. They were then contacted by a third interviewer, who conducted the interviews in the Ottawa area. This interviewer attended a number of events at the Phoenix Network and the Ottawa Valley Head Injury Association, explaining the purpose of the study and inviting participation. Information regarding the study was also published in the September 1997 issue of the Ottawa Valley Head Injury Association newsletter. Two respondents were made aware of the study by friends who had been interviewed.

The response rate generated by the newsletter articles and the letters of support could not be calculated, however the response rate to the phone call follow-up was 83%, with 22 negative and 111 positive responses.

Of the 111 respondents interviewed, data for 14 were subsequently excluded from the study. Four respondents did not meet the severity of injury criterion, and one had been injured less than a year prior to the interview. Data for three respondents were excluded because the extent of their disability precluded their answering the majority of the interview questions, and data for three respondents were excluded because more than 10% of their data were missing on key variables. One respondent could not complete the interview due to illness, and two could not be reached for a second appointment to complete the interview.

Interviews were scheduled at a time convenient to the respondents, at their home or in a private office at one of the referring agencies. About two thirds (68%) of the interviews were completed in a single session; 32% required further appointments. The time required for the interview for the 89 cases for which this information was available varied from a minimum of one hour to a maximum of 6.5 hours; the mean duration of the interview was 2.7 hours, and the median 2.5 hours. The interview included two additional questionnaires that were part of a related study.

Prior to administration of the interview, an information letter was given to the respondent outlining the purpose of the study and the limits of confidentiality, and pointing out that respondents were free to withdraw at any time. This information was reviewed with the respondent and written consent was obtained. The administration of the interview followed a standard procedure in which the interviewer read the items to the respondent and recorded the responses. This procedure was used to increase the likelihood of consistency of the data collection and facilitate timely progress of the interview. A copy of the questionnaires was given to respondents so they could follow the items as they were read. The questionnaires were presented in random order, with two exceptions: Demographic information was always asked first, and the global quality of life question was asked once after the demographic information and again at the end of the interview.

Additional efforts made to maximize consistency in data collection included interviewer training and observation (by video and in person). Interviewers contacted each other regularly regarding procedure and answers to common questions from respondents. Analysis of variance revealed that there were no differences attributable to the three interviewers among the variables representing impairment, disability, participation, integration, social support, and quality of life.

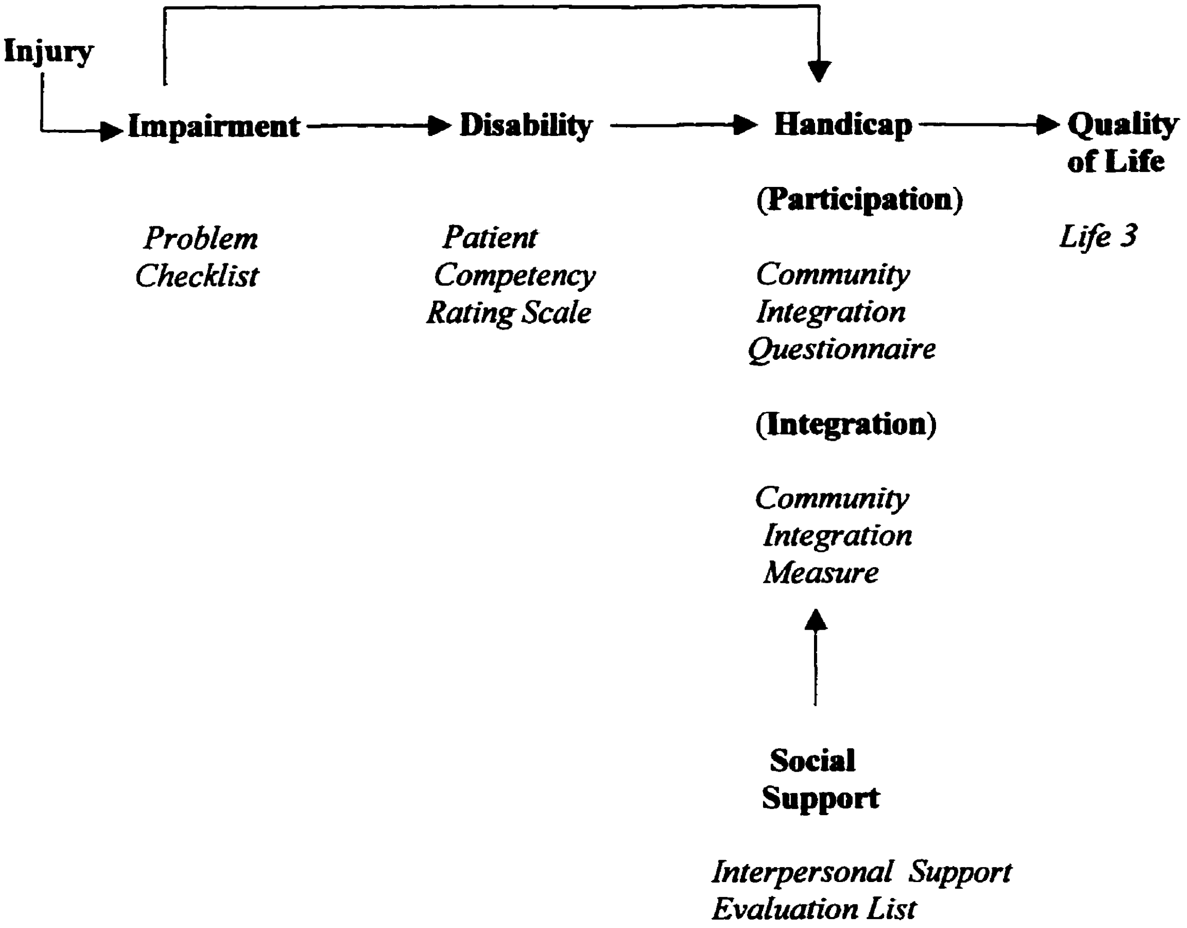
## Measures

Copies of the questionnaires are provided in appendices F to K. Figure 4 illustrates the constructs under consideration and the corresponding measures.

### Impairment

The Problem Checklist (Version 1.2) is a 33-item checklist of affective, cognitive and physical symptoms often encountered by a person after brain injury. Developed by Kay, Cavallo, Ezrachi and Vavagiakis (1995) as a part of the Head Injury Family Interview, the Problem Checklist can be completed by the person with the brain injury or by a significant other. The Problem Checklist first asks whether the person with the brain injury is experiencing the symptom (Yes / No). If so, they are asked to rate

Figure 4. Measures corresponding to disablement constructs.



its severity as a problem on a seven-point scale where (1) represents no problem and (7) represents a severe problem.

Using principal components analysis with 31 experience items (2 items were excluded from the analysis because of missing data), Kay et al. (1995) derived three subscales: an affective / behavioural subscale, a cognitive subscale, and a physical / dependency subscale.

The affective / behavioural subscale is comprised of items reflecting such symptoms as mood swings, irritability, complaining, depression, anxiety / tension, headaches, temper outbursts, and getting into arguments. The cognitive subscale is characterized by such symptoms as difficulty concentrating, planning, organizing, setting goals, and following through; being forgetful and distractible, and fatiguing quickly. Items such as dysarthria, poor balance, lack of initiative, doing things slowly, and needing supervision represent the physical / dependency subscale.

When the Problem Checklist was completed by the person with the brain injury (for the 31-item scale), the internal consistencies of the three subscales were .87 for the 14-item affective / behavioural subscale, .84 for the 9-item cognitive subscale and .65 for the 8-item physical / dependency subscale.

Although the 31-item version of the Problem Checklist for which the subscales were developed was used in the analyses in the present study, the interview included all 43 items of version 2.0 (See Appendix F). Items not included in the 31-item version are hearing difficulties, problems with coordination, dizziness/vertigo, sensitivity to noise, sensitivity to light, problems with taste or smell, loss of confidence, changes in appetite, sleep disturbance, low sex drive, and high sex drive.

Disability

The Patient Competency Rating Scale (Prigatano et al., 1986) is a 30-item scale that assesses brain injury survivors' and / or caregivers' perception of the survivor's competence in a variety of activities (See Appendix G). Responses to the items are made on a five-point scale ranging from (1) can't do to (5) can do with ease. For the present study, the wording of the questions was adapted to reduce the emphasis on problems in one's life and to be consistent with the approach of McColl, Carlson, Johnston, Minnes, Shue & Willer (1997), such that the question asked was "Can you . . . " as opposed to "How much of a problem is it for you to . . . ".

Ezrachi, Kay and Cavallo (1993) conducted a principal components analysis with the Patient Competency Rating Scale which resulted in three components: activities of daily living, executive functions / memory, and emotional functioning / regulation. The six items comprising the activities of daily living subscale are preparing meals, washing dishes, doing laundry, dressing oneself, taking care of personal hygiene, and driving a car. The executive functions / memory subscale (12 items) is represented by such activities as remembering one's daily schedule, remembering important things to do, remembering names of people one sees often, scheduling daily activities, keeping appointments on time, meeting daily responsibilities, understanding new instructions, and getting help when confused. The 12 items reflecting the emotional functioning / regulation subscale include accepting criticism, controlling one's temper, handling arguments with familiar people, adjusting to unexpected changes, acting appropriately around friends, showing affection, and controlling laughter and crying.

McColl (1993, cited in McColl et al., 1997) conducted a principal components analysis with the Patient Competency Rating Scale, obtaining three factors that were designated "social competencies", with an internal consistency of .89, "functional competencies" (.76), and "organizational competencies" (.80). Prigatano, Altman and O'Brien (1991) demonstrated internal consistency for the total scale of .97 for individuals with brain injury and .92 for relatives answering the same questions with regard to the person with the brain injury.

## Social Support

Social support was assessed using a version of the Interpersonal Support Evaluation List (ISEL; Cohen, Mermelstein, Kamarck, & Hoberman, 1985) adapted by McColl and Skinner (1995) for use with individuals with disabilities. The adapted measure (ISEL-A) consists of three subscales reflecting the perceived availability of instrumental, informational and emotional support. The subscales were constructed with the tangible subscale of the Interpersonal Support Evaluation List corresponding to instrumental support, the appraisal subscale corresponding to informational support, and a selection of belonging and self-esteem items corresponding to emotional support. In the adapted version, the wording of some items was altered, (e.g., from "There is really no one I can trust to give me good financial advice" to "There is someone who can give me advice about money"), and some items were dropped altogether (e.g., "If for some reason I were put in jail, there is someone I could call who would bail me out"). In addition, four response options were provided instead of the true / false format of the original measure.

Principal components analyses and reliability assessment provided empirical support for the three-component structure for the social support construct (McColl & Skinner, 1995).

Internal consistency reported by McColl and Skinner (1995) for the subscales derived from their principal components analyses was .76 for the instrumental subscale, .66 for the informational subscale, and .71 for the emotional subscale. Using the coefficient of determination as an indicator of reliability, McColl and Skinner (1995) reported reliability of .99 for the instrumental subscale, .91 for the informational subscale and .92 for the emotional subscale.

In the present study, the social support measure was further adapted by expanding the set of response options in an effort to increase the potential variability of the responses (See Appendix H). Almost never true and almost always true were added to the never true, sometimes true, usually true and always true response options provided in the adapted version of the scale. In the resulting 6-point scale, higher values reflect higher levels of perceived availability of social support.

In addition, based on suggestions from respondents in the McColl and Skinner (1995) study, two items were added to the instrumental scale, one item was added to the informational support scale, and six items were added to the emotional support scale.

The instrumental support subscale used in the present study is comprised of eight items reflecting the perceived availability of practical support (e.g., "If I needed someone to drive me to an appointment I could find someone"), the informational support subscale is comprised of ten items relating to being able to obtain advice or guidance about matters of concern (e.g., "There is someone who can give me advice about money") and the emotional support subscale is comprised of sixteen items having to do with understanding, acceptance and friendship (e.g., "I have friends I feel very close to").

Two questions, which were added to each of the subscales for supplementary information but were not used in the present study, asked from whom the support was received and the extent to which the respondent was satisfied with the support received.

Handicap

Participation. The Community Integration Questionnaire is a measure designed to assesses role performance in community settings (Willer et al.,1993). It consists of 13 items, for which the total score ranges from 0 to 29. Responses for each item are selected from a group of categorical statements that are assigned values of zero, one or two. For example, responses for the item "Who usually prepares meals in your household?" can be selected from yourself alone, yourself and someone else and someone else. A score of two is given if the activity is performed alone, a score of one if it is performed with someone else, and a score of zero if it is performed by someone else. A higher score indicates greater independence. A second scoring procedure, based on frequency of participation, is used for a number of items. Participating in the activity less than once a month merits a zero score, between one and four times a month merits one point, and more than five times a month merits two points.

Three subscale scores have been constructed by Willer, Linn and Allen (1994): independence in domestic activity (five items), participation in social activity (six items), and participation in productive activity (two items). The internal consistency of the total scale for a sample of 49 individuals with severe brain injury was .76. Internal consistency for the home integration subscale was .84, and for the social integration subscale, .73. For the productivity subscale (in which four items were combined to make two), internal consistency was only .35 (Willer et al., 1993). With a sample of 16 people with moderate to severe traumatic brain injury, test-retest reliability was high for both individuals (r = .91) and family members (r = .97). With the same sample, each of the subscales had high internal consistency, with the lowest being for self-reported productive activity (.83). Correlations between scores reported by the individual with the brain injury and by a family member answering the same questions with regard to the person with the brain injury were similarly high, at .89 for the total score, .81 for home integration, .74 for social integration, and .96 for productive activity. Concurrent validity is suggested by correlations between the Community Integration Questionnaire and the Craig Handicap Assessment and Reporting Technique of .62 ($p < .05$) for scores reported by persons with brain injury and .70 ($p < .05$) for those reported by family members (Willer et al., 1993).

A subsequent investigation of the psychometric characteristics of the Community Integration Questionnaire found the total score and the home and social integration subscales to be normally distributed with internal consistencies ranging from .79 for responses obtained from a sample of people with brain injury retrospectively referring to their pre-injury situation, to .89 for responses obtained from a sample of people with "other disabilities" at follow-up (Corrigan and Deming, 1995).

However, the range of responses to the productive activity subscale in the Corrigan and Deming study (1995) was severely restricted, and internal consistency was lacking (ranging from .18 to .57). The distributions for four samples (pre-injury and follow-up data for respondents with brain injury and for respondents with other disabilities) were irregular. In light of its poor internal consistency and distribution, Corrigan and Deming (1995) recommended that the productive activity subscale not be used independently from its contribution to the total score.

In the present study, a question regarding the respondent's satisfaction with the situation described in each item was added to the Community Integration Questionnaire, as was an open-ended question regarding what would need to happen to facilitate the respondent being able to do things the way he or she would prefer. A question regarding participation in religious activities was added and questions regarding volunteering, school and work training, and work around the house were expanded to provide more detailed information about participation in the community for another study. Only the items comprising the original Community Integration Scale were used in the present study. Items one to five comprised the home activity subscale, items six to nine, and eleven and twelve comprised the social activity subscale, and items thirteen, fourteen-b, fifteen-b and sixteen-b comprised the productive activity subscale (See Appendix I).

Integration. The Community Integration Measure (Appendix J) is based on a definition of integration that was derived from the perspective of respondents who were experiencing the consequences of brain injury (McColl et al., 1998). This measure assesses three dimensions of integration: how respondents feel about their relationships with others (social support), their independence in their living situation (independent living), and the activities in which they engage (occupation). The Community Integration Measure consists of 10 items (e.g., "I feel like part of this community, like I belong here", "I feel that I can be independent in this community", and "I have something to do in this community during the main part of my day that is useful or productive"), which are scored on a 5-point scale ranging from always agree to always disagree. The alpha coefficient of .87 obtained by McColl et al. (1998) reflects good internal consistency. The Community Integration Measure demonstrates discriminant validity by differentiating between survivors of brain injury and non-disabled students ($F(9,21) = 5.5$, $p < .006$).

Quality of Life

Global quality of life was assessed in the present study using the question "Overall, how do you feel about the quality of your life during the last month or so?" at the beginning and at the end of the interview. A similar question, "How do you feel about your life as a whole?" was asked by Andrews and Withey (1976) as part of their comprehensive research on the social indicators of well-being. This question (designated "Life 1" and "Life 2") was asked twice during their interview, separated by about twenty minutes of interviewing time. Responses were then averaged to obtain the final "Life 3" measure.

The average of two responses was used in the present study because Andrews and Withey's (1976) averaged "Life 3" item was found to be a more reliable and valid indicator of respondents' feelings about life as a whole than either of its constituent parts, because it correlated more highly with all of the other quality of life measures with which Life 1 or Life 2 correlated, and because it had the highest average correlation with the other measures of quality of life of any single-item measure in their survey.

Heinemann and Whiteneck's (1995) adaptation of the quality of life question ("life during the last month or so" vs "life as a whole") was used in the present study in order to facilitate comparison with existing research, to make it comparable with the time frame of other questionnaires in the present study, and to get a sense of the respondents' feelings about the quality of their lives at the present time as opposed to their "life as a whole".

Service providers experienced in helping clients respond to rehabilitation program evaluations and follow-up questionnaires have suggested that it would be helpful to respondents to have descriptive markers for responses to the question "How would you rate the quality of your life?" (personal communication, Regional Community Brain Injury Services staff). Andrews and Withey's (1976) "Life 3" response format meets this requirement: Their seven-point scale is labelled (1) delighted, (2) pleased, (3) mostly satisfied, (4) mixed (about equally satisfied and dissatisfied), (5) mostly dissatisfied, (6) unhappy, (7) terrible. In the present study, coding for quality of life was reversed to facilitate interpretation.

Andrews and Withey (1976) obtained correlations of .68, .61, .71, and .64 for four independent national random samples of over 1000 respondents each for the two administrations of their global quality of life question. Cross tabulations conducted for their data indicated that 54% of the group of 1,376 respondents for which the correlation of .68 was obtained gave identical answers, and 93% chose identical or immediately adjacent answers. Andrews and Withey (1976) state that in this situation, a correlation of .68 is indicative of substantial agreement between the Life 1 and Life 2 measures.

In order to obtain more detailed information about the affective components of quality of life, Bradburn's (1969) Affect Balance Scale was included in the interview (See

Appendix K). The Affect Balance Scale is comprised of two parts: the Positive Affect Scale and the Negative Affect Scale. Each of the positive and negative scales consists of five items asking about how respondents felt during the past few weeks. The Positive Affect Scale asks whether, during the past couple of weeks, respondents had ever felt particularly excited or interested in something, proud because someone had complimented them, pleased about having accomplished something, on top of the world, or that things were going their way. The Negative Affect Scale asks whether respondents had felt restless, very lonely or remote from other people, bored, depressed or very unhappy, or upset because someone had criticized them. Yes answers are given one point, and no answers are given zero points.

Internal consistencies for a sample of 140 respondents with psychiatric disabilities have been found to be .68 and .62 respectively for the positive and negative affect scales (Kennedy, 1989). Andrews and Withey (1976) extended these scales by asking about the frequency with which these feelings were experienced; whether it was once, several times, or a lot. Andrews and Withey's adaptation is used in the present study because of its greater potential variability.

Bradburn's research on the structure of psychological well-being indicated that items assessing positive and negative affect were independent ($r = .07$, $p > .05$), leading to the proposition that happiness is composed of two separable components, positive and negative affect (Bradburn & Caplovitz, 1965; Bradburn, 1969). The lack of a relationship between positive and negative affect has been reported in numerous studies using varying methodologies, and they frequently have shown independent correlations with life as a whole, satisfaction, and happiness (Andrews & Withey, 1976; Diener, 1984).

Bradburn proposed that happiness reflects a global judgement people make by comparing their negative affect with their positive affect. Therefore, the Affect Balance Scale score is derived by subtracting the sum of the scores of the negative items from that of the positive items (Diener, 1984, p. 547).

Bradburn's proposition regarding the independence of positive and negative affect generated considerable controversy, with detractors pointing out that the relative independence of positive and negative affect may be a result of weaknesses inherent in Bradburn's measure. However, as mentioned above, the near independence of positive and negative affect has been confirmed using other measures and methodologies. There are also studies, however, that demonstrate a strong negative correlation between positive and negative affect when the scale is worded in terms of the frequency of occurrence of the feelings (Diener, 1984). Diener's (1984) research comparing between- and within- subject data suggested that positive and negative affect are negatively correlated at particular moments in time, but that the correlation decreases as the time interval increases. When the levels of positive and negative affect that a person experiences are considered over a period of a few weeks, the average levels experienced by the person are independent, even though it is unlikely that the person would experience the two simultaneously.

Diener (1984) explained the relationship of positive and negative affect by pointing out that because positive and negative affect tend to suppress each other, they are not independent at a particular moment in time. Therefore, the two types of affect are not independent in terms of their frequency of occurrence. However, when average levels of positive and negative affect are evaluated over a period of time, they show a low correlation with each other because mean levels of affect are a result of both the frequency of the type of affect and of the intensity. Across persons, the intensity of positive and negative affect correlates positively in the range of $r = .7$. Because duration of affect and intensity of affect are generally uncorrelated, and combine in an additive way to produce mean affect, the resulting influence of their positive relationship in terms of intensity across persons cancels their negative relationship in terms of frequency (Diener, 1984). In support of this explanation, Diener, Larsen, Levine, and Emmons (1985) demonstrated that when emotional intensity was statistically removed from the relationship between average levels of positive and negative affect, the correlation between them became strongly negative. Bradburn's positive and negative affect scales measure mean affect; because the present study assesses frequency of positive and negative affect with Andrews and Withey's (1976) adaptation, the positive and negative affect scales should be expected to be correlated to some extent.

Andrews and Withey (1976) reported that the Affect Balance Scale, which represents the preponderance of positive over negative feelings, related more strongly to the other quality of life measures in their study than did either positive or negative affect alone. Given this finding, and in keeping with Bradburn's (1969) hypothesis that it is not the absolute amount of positive or negative affect, but rather the relative strength of one as compared to the other that predicts one's sense of well-being, the Affect Balance Scale was used in the present study to supplement the global quality of life question.

# Chapter 3: Results

## Data Preparation

### Missing Data

The accuracy of the raw data file was verified on a case by case basis and corrected as necessary. Treatment of missing data was dependent on the variable for which the data were missing. For demographic or background variables, descriptive statistics were calculated excluding the missing data. For variables in the analyses, cases were excluded when they were missing data for more than 10% of the items on any scale. Missing data were replaced with the sample mean for the item in question when cases were missing 10% or less data per scale.

For two items on the Interpersonal Support Evaluation List ("People I know think highly of me" and "There is someone I could turn to for advice about changing my job or finding a new one") data for three and seven cases respectively were missing. T tests indicated that cases missing data on either of the above items were not different than the other cases in their relationships with the impairment, disability, participation, integration, or quality of life variables.

### Internal Consistency

Internal consistency was computed for all scales and subscales (See Table 1). Opinion varies regarding acceptable levels of alpha for research scales. DeVellis (1991) suggests that values between .65 and .70 are minimally acceptable; Carmines (1979), on the other hand, suggests that a scale should not be used if alpha is below .80.

All total scale scores used in the analyses have an internal consistency of at least

Table 1
<u>Reliability Coefficients Derived from Scales and Subscales</u>

| Variable | # Items | Alpha |
|---|---|---|
| Impairment | | |
| Problem Checklist Total | 31 | .90 |
| Affective/Behavioural Problems | 14 | .86 |
| Cognitive Problems | 9 | .84 |
| Physical/Dependency Problems | 8 | .70 |
| Disability | | |
| Patient Competency Rating Scale Total | 30 | .88 |
| Executive Functioning/Memory | 12 | .79 |
| Emotional Functioning/Regulation | 12 | .83 |
| Activities of Daily Living | 6 | .77 |
| Social Support | | |
| Interpersonal Support Evaluation List Total | 34 | .94 |
| Practical Support | 8 | .82 |
| Information Support | 10 | .87 |
| Emotional Support | 16 | .90 |
| Participation | | |
| Community Integration Questionnaire Total | 13 | .70 |
| Participation in Home Activity | 5 | .86 |
| Participation in Social Activity | 6 | .30 |
| Participation in Productive Activity | 2 | .08 |
| Integration | | |
| Community Integration Measure | 10 | .80 |
| Affect | | |
| Positive Affect | 5 | .67 |
| Negative Affect | 5 | .70 |

.70, with most having a level of at least .80. Test-retest reliability of .68 was obtained for the single-item quality of life measure. Fifty-one percent of respondents endorsed identical answers, and 96% endorsed answers adjacent on the 7-point delighted to terrible scale for the quality of life measure.

Alpha coefficients were calculated for subscale scores in preparation for post-hoc analyses. For two subscales (the social activity and productive activity subscales of the Community Integration Questionnaire) internal consistency failed to reach a minimally acceptable level (.65). Because their internal consistency was inadequate, these subscales were not used in further analyses except in their contribution to the total score.

### Normality, Linearity, and Homoscedasticity

Steps were taken to ensure that the assumptions of multivariate normality were met. When distributions of total scores were checked for univariate outliers, two data points were discovered to lie more than three standard deviations from the mean of their respective scales. The influence of these outliers was reduced by recoding the raw scores to within three standard deviations of the scale mean. This was accomplished by assigning a value of one unit smaller than the next lowest score in the distribution, as both outliers were at the low end of the distribution (Tabachnick & Fidell, 1989). No variable or case contained more than one outlier.

Following recoding of the univariate outliers, the assumptions of normality were checked by comparing skew and kurtosis to their standard errors. None of the variables included in the regression analyses had a ratio of the skew to its standard error of more than 3, and kurtosis was within acceptable limits for all variables.

Three subscale scores were skewed, however: the affective / behavioural subscale of the Problem Checklist, the activities of daily living scale of the Patient Competency Rating Scale, and the home activity scale of the Community Integration Scale. The affective / behavioural subscale and the home activity subscale, which were positively skewed, were subjected to square root transformation, whereas the activities of daily living subscale was transformed using the log of the reflected variable because of its more extreme negative skew. The resulting transformed scales correlated well with the originals, with original and transformed affective / behavioural subscales correlating at $r = .99$ ($p < .001$), the activities of daily living subscales correlating at $r = -.96$ ($p < .001$), and the home activity subscales correlating at $r = .99$ ($p < .001$). Normality was restored, with no evidence of skew or kurtosis. Although three outliers had been evident on these subscales prior to transformation, all were within three standard deviations of the mean after transformation.

A check of Mahalanobis distances revealed no multivariate outliers. The assumptions of linearity and homoscedasticity appeared to be met following examination of residuals scatter plots and normal probability plots for variables in each multiple regression analysis.

### Multicollinearity

A correlation matrix of the variables in the analyses was calculated in order to detect possible multicollinearity among the independent variables. No correlations equal to or greater than .70 (Tabachnick & Fidell, 1989) were obtained, although this criterion was approached by the correlation between the measures of impairment and disability

($r = -.66$, $p < .0001$).

### Group Differences

T tests and ANOVAS were conducted to determine whether differences existed for impairment, disability, participation, integration, social support or quality of life, depending on a number of demographic and background variables. No differences were found on the basis of gender, age at injury (under age 15 vs. over age 50), education (up to and including secondary school diploma vs. some college, university or specialized training), cause of injury, or loss of consciousness (hours, days, weeks, months) for any of the above variables. Respondents who were married or living with a partner reported significantly more social support than those who had never married, or were separated, divorced or widowed ($t(95)=2.706$, $p = .008$). Respondents who lived alone reported significantly more independence in participation in overall home, social and productive activity than those living with others ($F(2, 94) = 21.3$, $p < .001$).

## Descriptive Statistics

### Demographic and Background Variables

Demographic and background information is presented in detail in Table 2.

Of the 97 respondents participating in the study, 22% had experienced a brain injury of at least moderate severity as defined by a Glasgow Coma Scale score of 9 to 12, loss of consciousness of 20 minutes to 1 hour, or post traumatic amnesia of 1 to 24 hours. The remaining 78% had experienced a severe injury, defined by a Glasgow Coma Scale score of 8 or less, loss of consciousness of at least 1 hour, or post traumatic amnesia of at least 24 hours (Vollmer, 1993).

Table 2

Demographic and Background Information

| Continuous Variables (N=97) | Mean | SD | Med | Min | Max |
|---|---|---|---|---|---|
| Age | 39.4 | 10.6 | 39.0 | 20.3 | 72.9 |
| Age at Injury | 29.2 | 12.4 | 27.5 | 7.0 | 71.0 |
| Years since Injury | 10.2 | 7.9 | 7.4 | 1.3 | 32.7 |
| Paid support (hours)* | 44.2 | 67.4 | 7.8 | 0.5 | 170.5 |

* (N=42)

Categorical Variables

| Sex | (N=97) | (%) |
|---|---|---|
| | Male: | 76 |
| | Female: | 24 |

| Marital Status | (N=97) | (%) |
|---|---|---|
| Never married | | 43.3 |
| Cohabiting, unmarried | | 10.3 |
| Married | | 23.7 |
| Separated | | 6.2 |
| Divorced | | 12.4 |
| Widowed | | 4.1 |

| Education | (N=97) | (%) |
|---|---|---|
| Partial K-12 | | 30.9 |
| High School diploma | | 26.8 |
| Partial college | | 18.6 |
| College diploma | | 13.4 |
| Partial university | | 2.1 |
| Undergraduate degree | | 3.1 |
| Graduate/Professional degree | | 5.2 |

| Living Situation (with whom) | (N=97) | (%) |
|---|---|---|
| Alone | | 30.9 |
| Spouse/Partner | | 11.4 |
| Spouse/partner & children | | 22.7 |
| Parent(s) | | 10.3 |
| Sibling or other relative | | 3.1 |
| Housemates/friends | | 5.2 |
| Other residents | | 13.4 |
| Professional care provider | | 1.0 |
| Boarder | | 2.1 |

| Living Situation (where) | (N=97) | (%) |
|---|---|---|
| House/Apartment | | 88.6 |
| Group/boarding home | | 1.0 |
| Residential program | | 6.2 |
| Retirement home | | 2.1 |
| Nursing home | | 2.1 |

| Cause of Injury | (N=97) | (%) |
|---|---|---|
| Motor Vehicle Accident | | 70.1 |
| Cerebrovascular | | 13.4 |
| Trauma | | 11.3 |
| Other | | 5.2 |

| Loss of Consciousness | (N=58) | (%) |
|---|---|---|
| 20 min to 23 hrs | | 6.9 |
| 24 hrs to 1 week | | 10.3 |
| 1 week to 1 mo | | 32.8 |
| 1 month to 6 mo | | 50.0 |

| Financial Situation | (N=96) | (%) |
|---|---|---|
| Excellent | | 15.6 |
| Good | | 31.3 |
| Satisfactory | | 35.4 |
| Barely adequate | | 12.5 |
| Inadequate | | 5.2 |

| Income per Month | (N=90) | (%) |
|---|---|---|
| Less than $500 | | 5.5 |
| $500 to $1000 | | 34.5 |
| $1000 to $2000 | | 36.7 |
| $2000 to $4000 | | 18.9 |
| More than $4000 | | 4.4 |

Glasgow Coma Scale scores were available for 12 respondents: the minimum score was 3 and the maximum 11, with a mean of 6. Information regarding loss of consciousness was available for 58 respondents, and ranged from 20 minutes to 180 days, with a mean of 41 days and a median of 29 days. Post traumatic amnesia for 34 respondents ranged from 36 hours to 301 days, with a mean of 65 days and a median of 36 days.

The age of respondents at the time of their injury ranged from 7 to 71 years, with a mean of 29 years. The number of years since the injury ranged from 1 to 33, with a mean of 10 years.

Motor vehicle collisions and collisions involving motor vehicles and pedestrians or cyclists were the main cause of injury, responsible for 70% of the injuries in this sample.

Most respondents had received at least elementary and some secondary school education (31%), with an additional 27% receiving a secondary school diploma.

Forty-three percent of respondents had never married, 34% were married or living in a spousal relationship, and 23% were separated, divorced or widowed. Almost equal numbers of respondents lived alone (31%) or with their spouse / partner or spouse / partner and children (34%).

The most common type of accommodation for respondents in this sample was the private family home, with 89% living in a house or apartment. Twenty percent of respondents lived in supported housing (i.e., housing was arranged and ongoing formal support was provided) whereas 80% were not formally supported in terms of housing.

Almost half (46%) of the respondents reported currently receiving some form of paid assistance with such activities as nursing, personal care, rehabilitation, or homemaking. The number of hours per week of paid assistance was not easily estimated by respondents, 3 of whom could not provide this information. Of the remaining 42 respondents, the number of hours of paid assistance ranged from half an hour to 170.5 hours (which constituted full-time attendant care and 2.5 hours per week of other paid assistance). Although the mean number of hours of paid assistance per week was 44, the median was only 7 hours per week.

Forty percent of respondents reported receiving unpaid assistance, but because of the nature of this assistance (e.g., parents taking the respondent to their home for dinner, or a volunteer coming occasionally to take the respondent shopping) most were unable to determine the number of hours per week that they received this assistance.

Ninety respondents reported their estimated gross monthly income. Three respondents were unable to estimate their income, and four declined to provide this information. Thirty-five percent of the respondents who answered this question reported a gross monthly income of $500 to $1000, with another 38% reporting $1000 to $2000; however, the minimum gross monthly income was less than $100 per month, and the maximum more than $4,000 per month. Forty-seven percent of respondents reported their financial situation as being excellent or good, 35% reported it as satisfactory, and 18% reported it as being barely adequate or inadequate. Most respondents (68%) were supported financially by insurance settlements or disability pensions; only five percent were supporting themselves with full time employment.

## Variables in the Analyses

Descriptive information for variables relevant to the analyses is summarized in Table 3. Table 4 lists the means and percentages of responses in each category for quality of life in a national random sample (Andrews & Withey, 1976), the present sample, and another sample of respondents with brain injury (Heinemann & Whiteneck, 1995). The distribution of responses for the Affect Balance Scale, which is used in the supplementary analyses, is presented in Table 5.

## Correlations

Correlations were computed for the continuous demographic / background variables (age, income, age at injury, time since injury) and the independent and dependent variables (impairment, disability, social support, participation, integration and quality of life). None of these demographic / background variable was entered into the regression equations because none met the significance of $p = .002$ required by the Bonferroni correction for 24 comparisons.

The correlations among all total and subscale scores are presented in Appendix A, with correlations between variables included in the analyses shaded. Double asterisks indicate correlations meeting the significance level required by the Bonferroni correction for 171 comparisons ($p < .0003$), and single asterisks indicate correlations meeting the uncorrected significance level of .05.

Table 3

Descriptive Statistics for Continuous Variables

| Variable (N = 97) | Obtained Min | Obtained Max | Mean | SD |
|---|---|---|---|---|
| Impairment | | | | |
| Total Impairment | 0.0 | 147.0 | 55.6 | 33.9 |
| Affective/Behavioural | 0.0 | 5.7 | 1.5 | 1.2 |
| Cognitive | 0.0 | 6.3 | 2.2 | 1.5 |
| Physical/Dependency | 0.0 | 5.1 | 1.7 | 1.2 |
| Disability | | | | |
| Total Disability | 80.0 | 150.0 | 123.2 | 14.7 |
| Executive/Memory | 31.0 | 60.0 | 48.4 | 6.7 |
| Emotional | 32.0 | 60.0 | 48.6 | 7.0 |
| Activities of Daily Living | 8.7 | 30.0 | 26.2 | 4.7 |
| Social Support | | | | |
| Total Support | 93.0 | 204.0 | 162.1 | 27.8 |
| Practical Support | 23.0 | 48.0 | 39.9 | 7.1 |
| Information Support | 20.0 | 60.0 | 46.8 | 10.3 |
| Emotional Support | 30.3 | 96.0 | 75.3 | 15.0 |
| Participation | | | | |
| Total Participation | 5.0 | 27.0 | 17.4 | 4.8 |
| Home Activity | 0.0 | 10.0 | 5.7 | 2.9 |
| Integration* | 29.0 | 50.0 | 43.1 | 5.3 |
| Affect | | | | |
| Positive Affect** | 0.0 | 14.0 | 6.9 | 3.4 |
| Negative Affect*** | 0.0 | 15.0 | 3.8 | 3.4 |
| Affect Balance**** | -11.0 | 14.0 | 3.2 | 5.6 |
| Quality of Life | 2.0 | 7.0 | 5.3 | 1.2 |

* N = 64

** N = 95

*** N = 96

**** N = 94

Table 4
<u>Distribution of Responses for Quality of Life</u>

| Score | Response | Andrews & Withey (May, 1972)<br>National (US) Sample[1]<br>N=1,297 | Present Study<br>Brain Injury Sample[2]<br>N=97 | Heinemann & Whiteneck (1995)<br>Brain Injury Sample[2]<br>N=758 |
|---|---|---|---|---|
| Score | Response | % | % | % |
| 7.0 | Delighted | 7.0 | 11.3 | 10.0 |
| 6.5 | | 9.2 | 8.2 | |
| 6.0 | Pleased | 23.5 | 19.6 | 16.0 |
| 5.5 | | 21.8 | 17.5 | |
| 5.0 | Mostly Satisfied | 23.2 | 14.4 | 20.0 |
| 4.5 | | 6.8 | 10.3 | |
| 4.0 | Mixed | 4.7 | 9.3 | 35.0 |
| 3.5 | | 1.9 | 3.1 | |
| 3.0 | Mostly Dissatisfied | .9 | 3.1 | 9.0 |
| 2.5 | | .2 | 2.1 | |
| 2.0 | Unhappy | .2 | .0 | 6.0 |
| 1.5 | | .2 | .0 | |
| 1.0 | Terrible | .4 | 1.0 | 4.0 |
| Means: | | 5.5 | 5.3 | 4.5 |

[1] "Life as a whole"
[2] "Life during the last month or so"

Table 5

Distribution of Responses for Affect Balance Scale[1]

| | Andrews & Withey (Nov. 1972) | Present Study |
|---|---|---|
| | National (US) Sample N=1,072 | Brain Injury Sample N=94 |
| Score | % | % |
| -5 | <1 | 0 |
| -4 | 1 | 1 |
| -3 | 2 | 2 |
| -2 | 5 | 4 |
| -1 | 8 | 15 |
| 0 | 13 | 12 |
| +1 | 17 | 18 |
| +2 | 17 | 10 |
| +3 | 16 | 12 |
| +4 | 14 | 21 |
| +5 | 6 | 5 |

[1] non-expanded scale

## Evaluation of Hypotheses and Predictions

### Prediction 1

The first prediction was that the ICIDH model of disablement would represent relationships among impairment, disability and handicap such that impairment (as measured by the Problem Checklist) would predict disability (as measured by the Patient Competency Rating Scale), and that impairment and disability would each predict handicap. An added stipulation was that disability would be the greatest predictor of handicap.

To test this prediction, a series of regression analyses was conducted. The first equation regressed disability on impairment. Impairment predicted disability, accounting for 43% of the adjusted variance (Table 6a). In a separate simple regression equation, impairment also accounted for 6% of the adjusted variance in participation (Table 6b). In a third simple regression equation, disability accounted for 6% of the adjusted variance in participation (Table 6b). Consequently, the first prediction was partially supported. Impairment predicted disability, and each of impairment and disability predicted participation. As impairment and disability predicted participation equally, however, disability was not the strongest predictor of participation.

When impairment and disability were entered together in an equation with participation as the dependent variable, the addition of disability explained only 1% more adjusted variance than was accounted for by impairment alone (Table 6c). Although the overall prediction of participation by impairment and disability was significant at the .05 level, both the regression coefficient for impairment and that for disability failed to reach

Table 6 Results of Regression Analyses Pertaining to Prediction 1

Table 6a
Simple Regression of Disability on Impairment

| Variable | R | $R^2$ | Adj. $R^2$ | Beta | F | df | p |
|---|---|---|---|---|---|---|---|
| Impairment | .66 | .43 | .43 | -.66 | 72.52 | (1,95) | .00001 |

Table 6b
Simple Regressions of Participation on Impairment and Disability

| Variable | R | $R^2$ | Adj. $R^2$ | Beta | F | df | p |
|---|---|---|---|---|---|---|---|
| Impairment | .27 | .07 | .06 | -.27 | 7.33 | (1,95) | .008 |
| Disability | .27 | .07 | .06 | .27 | 7.36 | (1,95) | .008 |

Table 6c
Hierarchical Regression of Participation on Impairment and Disability

| Variable | R | $R^2$ | Cum. $R^2$ | Cum. Adj. Beta | p | F | df | p |
|---|---|---|---|---|---|---|---|---|
| Impairment | .27 | .07 | .06 | -.16 | .222 | 7.33 | (1,95) | .008 |
| Disability | .29 | .09 | .07 | .16 | .218 | 4.45 | (2,94) | .014 |

Table 6d
Simple Regressions of Integration on Impairment and Disability

| Variable | R | $R^2$ | Adj. $R^2$ | Beta | F | df | p |
|---|---|---|---|---|---|---|---|
| Impairment | .09 | .01 | .00 | -.09 | .54 | (1,62) | .464 |
| Disability | .22 | .06 | .03 | .22 | 3.00 | (1,62) | .088 |

significance. In other words, when the effect of impairment was controlled, disability no longer predicted participation. Similarly, impairment failed to predict participation when disability was controlled.

The first prediction was then retested, substituting integration (as measured by the Community Integration Measure) for participation (as measured by the Community Integration Questionnaire) as the dependent variable. Simple regressions of integration on impairment and disability were non-significant (Table 6d). As neither impairment nor disability contributed to integration, the first prediction was not supported when integration was the outcome of interest.

Thus mixed support was obtained for the first hypothesis, that the ICIDH model of disablement describes the relationships among impairment, disability and handicap. Impairment predicted disability, but impairment and disability predicted handicap only when the aspect of handicap assessed was participation.

Prediction 2

The second prediction stated that a regression model including social support would explain more of the variance in handicap (participation or integration) than a model not including social support. This prediction was also tested separately for the participation and integration measures.

When social support (as measured by an adapted version of the Interpersonal Support Evaluation List) was the independent variable in a simple regression with participation as the dependent variable, there was no significant result (Table 7a).

However, when a simple regression was conducted with social support as the

Table 7 Results of Regression Analyses Pertaining to Prediction 2

Table 7a
Simple Regression of Participation on Social Support

| Variable | R | $R^2$ | Adj. $R^2$ | Beta | F | df | p |
|---|---|---|---|---|---|---|---|
| Social Support | .03 | .00 | .00 | -.03 | .10 | (1,95) | .748 |

Table 7b
Simple Regression of Integration on Social Support

| Variable | R | $R^2$ | Adj. $R^2$ | Beta | F | df | p |
|---|---|---|---|---|---|---|---|
| Social Support | .41 | .17 | .16 | .41 | 12.69 | (1,62) | .001 |

Table 7c
Hierarchical Regression of Integration on Impairment, Disability and Social Support

| Variable | R | $R^2$ | Cum. $R^2$ | Cum. Adj. Beta | p | F | df | p |
|---|---|---|---|---|---|---|---|---|
| Impairment | .09 | .01 | .00 | -.07 | .681 | .54 | (1,62) | .464 |
| Disability | .22 | .05 | .02 | -.10 | .552 | 1.61 | (2,61) | .209 |
| Social Support | .44 | .19 | .15 | .40 | .002 | 4.75 | (3,60) | .005 |

independent variable and integration as the dependent variable, the relationship was significant (p = .001), explaining 16% of the adjusted variance in integration (Table 7b). This finding supports the hypothesis that the perceived availability of social support is an important predictor of handicap, but only when handicap is assessed using a measure of integration.

When social support was added to a hierarchical regression equation already containing impairment and disability, the regression coefficient for social support was significant, as was the overall regression equation, which explained 15% of the adjusted variance in integration (Table 7c).

Thus results pertaining to the second hypothesis (that contextual factors such as social support are important aspects of disablement) were also mixed, with analyses involving one aspect of handicap (integration) supporting Prediction 2, and analyses involving the other aspect of handicap (participation) failing to support it.

### Prediction 3

The third prediction stated that the ICIDH model could be extended to include quality of life, with handicap most strongly predicting quality of life. Again, two series of regression equations were conducted, one for each of the two aspects of handicap: participation and integration.

Simple regressions with quality of life as the dependent variable were significant for disability, integration, and social support, and non-significant for impairment and participation (Table 8a). A hierarchical regression analysis was then conducted with forced entry of impairment first, disability second, and participation third,

## Table 8 Results of Regression Analyses Pertaining to Prediction 3

### Table 8a
Simple Regressions of Quality of Life on Impairment, Disability, Participation, Integration and Social Support

| Variable | R | $R^2$ | Adj. $R^2$ | Beta | F | df | p |
|---|---|---|---|---|---|---|---|
| Impairment | .18 | .03 | .02 | -.18 | 3.00 | (1,95) | .087 |
| Disability | .27 | .07 | .06 | .27 | 7.42 | (1,95) | .008 |
| Participation | .00 | .00 | .00 | -.02 | .04 | (1,95) | .840 |
| Integration | .25 | .06 | .05 | .25 | 4.12 | (1,62) | .047 |
| Social Support | .38 | .14 | .13 | .38 | 15.69 | (1,95) | .0001 |

### Table 8b
Hierarchical Regression of Quality of Life on Impairment, Disability and Participation

| Variable | R | $R^2$ | Cum. $R^2$ | Cum. Adj. Beta | p | F | df | p |
|---|---|---|---|---|---|---|---|---|
| Impairment | .18 | .03 | .02 | -.01 | .925 | 3.00 | (1,95) | .087 |
| Disability | .27 | .07 | .05 | .29 | .033 | 3.67 | (2,94) | .029 |
| Participation | .29 | .08 | .05 | -.10 | .332 | 2.76 | (3,93) | .046 |

### Table 8c
Hierarchical Regression of Quality of Life on Impairment, Disability, Social Support, and Integration

| Variable | R | $R^2$ | Cum. $R^2$ | Cum.Adj. Beta | p | F | df | p |
|---|---|---|---|---|---|---|---|---|
| Impairment | .15 | .02 | .01 | -.21 | .203 | 1.36 | (1,62) | .249 |
| Disability | .17 | .03 | .00 | -.06 | .724 | .95 | (2,61) | .393 |
| Social Support | .42 | .18 | .13 | .37 | .009 | 4.24 | (3,60) | .009 |
| Integration | .43 | .18 | .13 | .09 | .490 | 3.28 | (4,59) | .017 |

with quality of life as the dependent variable. Social support was not included in this regression equation, as it did not contribute to the prediction of participation (Table 8b).

Impairment and disability together significantly predicted quality of life, accounting for 5% of the adjusted variance, but the addition of participation did not add to the amount of adjusted variance explained (Table 8b). As participation failed to contribute to the prediction of quality of life, the hypothesis that the ICIDH model could be extended to include quality of life was not supported when participation was the aspect of handicap that was the final predictor variable in the model.

The third hypothesis was then tested with integration as the variable of interest. A hierarchical regression analysis was conducted, with forced entry of impairment first, disability second, social support third, and integration fourth, with quality of life as the dependent variable (Table 8c). Impairment and disability together did not predict quality of life, but when social support was added, the model accounted for 13% of the adjusted variance in quality of life. The addition of integration to the equation added nothing to the variance accounted for in quality of life.

Thus the third prediction was also not supported when integration was the aspect of handicap under consideration. Although integration alone predicted quality of life, it failed to contribute to the prediction of quality of life when it was included with impairment, disability and social support.

Overall, the third hypothesis, that impairment, disability, social support and handicap (participation or integration) influence quality of life, received mixed results. Simple regressions indicated that disability, social support and integration predicted quality of life, whereas impairment and participation did not. With impairment, disability, social support and integration entered hierarchically as predictors, only social support predicted quality of life.

In summary, support for the predictions and hypotheses was mixed, depending on the outcome variable of interest. Impairment predicted disability. Both impairment and disability predicted handicap when it was assessed as participation, but not when it was assessed as integration. The second prediction (that social support would add to the variance explained in handicap) was not supported when the aspect of handicap being assessed was participation, but was supported when handicap was assessed as integration. The third prediction was not supported for either aspect of handicap. When included with impairment and disability (and social support, in the case of integration) as predictors, neither participation nor integration contributed to the explanation of the variance in quality of life. Instead, social support emerged as a significant predictor of quality of life.

# Chapter 4: Discussion

The results of the present study contribute to the research in disablement and rehabilitation for persons with brain injury with respect to the conceptual development of the ICIDH model, as well as highlight challenges regarding measurement in this area of research.

The ICIDH was published in 1980 in an effort to provide a coherent conceptual framework with which to consider the consequences of disease. The use of the ICIDH since 1980 has generated considerable discussion about the need for the continued development of the framework and the need to explicitly incorporate contextual factors in any consideration of disablement. The 1980 model included contextual factors implicitly, within the definition of Handicap, but the proposed revised version, the International Classification of Impairments, Activities and Participation: A Manual of Dimensions of Disablement and Functioning (ICIDH-2; WHO, 1997) explicitly describes the interaction between injury-related and contextual factors. The ICIDH-2 states as its purpose that it

> . . . serves as a conceptual framework to bring together the physiological, personal and societal aspects of consequences related to health conditions and provides a model of biopsychosocial integration for the phenomenon of disablement (WHO, 1997, p.4).

The original version of the ICIDH secured agreement on a preferred terminology to identify the key concepts of impairment, disability and handicap. As noted in the ICIDH (WHO, 1980, p. 32), colloquial language displays a "trend to euphemism", with terminology relating to disablement acquiring negative connotations over time, and being replaced in the continuing search for a respectful way to communicate these concepts. The ICIDH-2 introduces new terminology in an effort to represent life functioning in a neutral, non-evaluative way, and to broaden the scope of the model to include people who do not live with the effects of disablement as well as those who do. The terms "activity" and "activity limitation", and "participation" and "participation restriction" thus replace the ICIDH terms disability and handicap.

The results of this study support the broadening of scope of the ICIDH-2 in its inclusion of contextual factors (See Figure 5) by demonstrating the relative importance of contextual factors such as social support over that of injury-related factors as predictors of integration and quality of life.

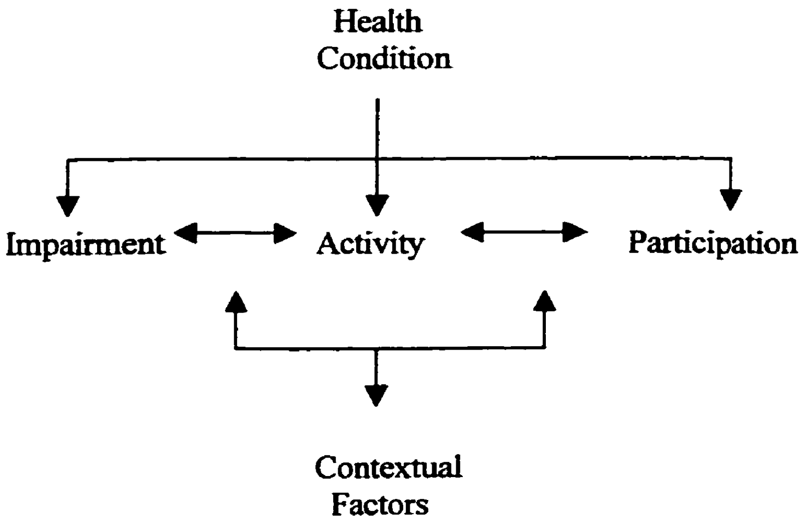
## Hypotheses and Predictions

### Hypothesis 1

Partial support was obtained for the first hypothesis, that the relationships among impairment, disability and handicap represented by the ICIDH model of disablement describe the experience of respondents with acquired brain injury.

The ICIDH model effectively describes the relationship between impairment and disability in the present sample, with impairment (as measured by the Problem Checklist) accounting for 43% of the adjusted variance in disability (as measured by the Patient Competency Rating Scale). Evidence of this relationship is consistent with the results of Kay et al., (1995) who found that higher Problem Checklist ratings of problem severity (impairment) corresponded with lower Patient Competency Rating Scale ratings of disability. The pattern of correspondence among the subscales also was replicated in the

Figure 5. ICIDH-2 Model of Impairment, Activity and Participation.



present study, supporting Kay et al.'s (1995) observation that the Problem Checklist and the Patient Competency Rating Scale appear to be tapping related but distinguishable constructs, the former at the level of impairment and the latter at the level of disability.

The proposed relationships between handicap and the other constructs, however, were not so clearly supported in the present sample. Partial support for the ICIDH model was obtained when handicap was measured as participation (using the Community Integration Questionnaire), but not when it was measured as integration (using the Community Integration Measure). As the sole predictor variable, impairment and disability each predicted participation. However, when impairment and disability were entered consecutively into a hierarchical regression equation, the latter failed to make a significant contribution to the variance explained. This suggests that it is the variance shared by impairment and disability that is contributing to the prediction of participation.

Together, impairment and disability accounted for 7% of the adjusted variance in participation, leaving much of the variance unexplained. One explanation for the extent of unexplained variance is that the participation measure (the Community Integration Questionnaire) does not adequately reflect the handicap construct. Another explanation suggests that factors other than those directly related to the injury play a major role in the construction of handicap.

Unlike participation, integration was predicted neither by impairment nor by disability. In other words, although perceived symptom severity and perceived disability in terms of physical, emotional and executive functioning predicted some of the variance in handicap when it was assessed in terms of participation in overall home, social and productive activity, impairment and disability did not predict handicap when it was assessed in terms of the perception of being a part of one's community. These data suggest that one's sense of being a part of a community (with respect to independent living, social interaction and occupation) is not related directly to the severity of one's impairment or disability. This result again indicates the need to investigate the impact of contextual factors that might be related to community integration, such as daytime activity, employment, financial resources, family relationships, interpersonal connection, locus of control, self-esteem, and introversion / extraversion, both prior to and after the injury. The finding that perceived impairment and disability have only a weak to moderate relationship with participation and no relationship with integration also suggests that the notion that intervention at the level of one element of the impairment / disability / handicap sequence has the potential to modify succeeding elements (World Health Organization, 1980) may not hold true with respect to handicap.

In summary, the results of this research suggest that the ICIDH framework describes the experience of disablement for individuals with brain injury insofar as it reflects the relationship between impairment and disability. Evidence of the relationship described by the framework between impairment and disability and the handicap construct is less clear. Handicap, however, has proven to be particularly difficult to assess because of its abstract and multifaceted nature.

Handicap is based on the concept of disadvantage arising out of an impairment or disability that limits or prevents the fulfilment of normal social roles, and occurs when there is interference with the ability to sustain these normal social roles (World Health

Organization, 1980). The six dimensions of handicap listed by the ICIDH (physical independence, social integration, occupation, orientation, mobility, and economic self-sufficiency) represent circumstances which depend not only on the consequences of the injury but also on the physical and social environment and the resources and limitations of the person involved. The participation and integration measures used in the present study assess three of these handicap dimensions (physical independence, social integration and occupation), but do not differentiate the contribution of the injury-related factors or other, contextual factors.

The results of the present study are consistent with the notion that handicap reflects the combined effects of injury-related and other factors, and suggest that injury-related factors should not be the only factors considered in the evaluation and prediction of handicap.

### Hypothesis 2

The hypothesis that contextual factors such as social support are an important aspect of disablement was investigated with the prediction that a regression model including social support would explain more of the variance in handicap (participation or integration) than a model not including social support. This prediction was not supported for participation, but was supported for integration.

Respondents' perceptions of the overall availability of practical support, information or advice, and emotional support were not related to their overall participation in home, social and productive activities. Their perceptions of the availability of these types of social support, however, significantly predicted integration, (i.e., their feeling of being a part of their community). Perceived availability of social support accounted for 16% of the adjusted variance in integration for individuals living with the effects of brain injury.

The presence of a relationship between social support and integration but not between social support and participation can be explained by considering the content of the social support and the participation and integration measures. Correlations (See Appendix A) indicated that for this sample, emotional support was the component that had the strongest relationship to total social support ($\underline{r} = .93$, $\underline{p} < .00001$) and that had the strongest relationships with the other variables, particularly the emotional competence component of the disability measure ($\underline{r} = .31$, $\underline{p} = .002$), integration ($\underline{r} = .46$, $\underline{p} = .0001$), and quality of life ($\underline{r} = .41$, $\underline{p} < .00001$). This suggests that it was the emotional support subscale that was primarily responsible for the association of total social support with other variables.

When the items comprising the emotional support subscale are considered, it appears that this measure primarily assesses perceived interpersonal connection, or friendship, as opposed to perceived availability of intentional support. As Thoits (1985) noted, in general use

> "Support" connotes intentional action--words said or deeds done with a helpful purpose in mind. Yet many of the supportive aspects of role relationships . . . are essentially unintentional byproducts of regularized interaction. . . . Meaning, purpose, and inclusion are not offered explicitly or deliberately to him/her by others. Similarly, evaluations from others are most often perceived implicitly--in

> body language, tone of voice or the sheer fact of continued or noncontinued interaction--rather than in explicit feedback (p. 64).

For the most part, the items comprising the emotional support component of the social support measure concern activities that don't necessarily presume distress or a need for support, for example: "People invite me to do things with them", "People I know think highly of me", "If I wanted to go for coffee with someone, I could find someone to join me", " I know people who enjoy the same things I do", and "I feel that I belong in my circle of friends". Perhaps the construct assessed by the measure used in the present study would be more accurately described as "interpersonal connection", or simply "friendship".

Viewing this measure as one of interpersonal connection or friendship rather than as one primarily of intentional support facilitates interpretation of the relationship (or lack thereof) between social support and the participation and community integration variables. The participation measure assigns higher scores to those who participate in activities independently and more frequently, and lower scores to those who participate with someone else and less frequently, whereas the social support measure assigns higher scores to those who perceive that there are friends and acquaintances who are available to talk with and to do things with them.

The relationship between social support and the integration measure can be explained in that with friends, one is more likely to feel accepted, as though one belongs, to have people one feels close to, and to have things to do for fun in one's free time.

Again, this finding emphasizes the importance of establishing the nature of the construct that is being assessed and of clarifying how a particular measure represents that construct. It is clear that the perceived availability of social support does not influence participation in social roles (as measured by the Community Integration Questionnaire), but does contribute to one's perception of belonging, of being a part of one's community (as measured by the Community Integration Measure).

Hypothesis 3

The third hypothesis, that impairment, disability, handicap, and social support influence quality of life was partially supported, although the prediction that the ICIDH model could be extended to include quality of life, with handicap being the strongest predictor of quality of life (See Figure 3), was not supported.

Neither impairment nor handicap (when assessed as participation) predicted quality of life, but disability predicted 6%, and handicap (when assessed as integration) predicted 5% of the adjusted variance in quality of life.

These results are consistent with those of Heinemann and Whiteneck (1995), who found that quality of life was significantly but weakly related to physical disability, but not to impairment (as represented by loss of consciousness). In their study, which reported only the results based on the Community Integration Questionnaire subscales, quality of life was not predicted by the home activity subscale. In the present study, neither the total participation score nor the home activity score predicted quality of life.

Social support was included in the regression equation among the independent variables hypothesized to predict quality of life because it had previously predicted handicap (when assessed as integration). When added to a regression equation already including impairment and disability, social support accounted for an additional 12% of the adjusted variance in quality of life. Integration did not contribute to the explained variance in quality of life when added to impairment, disability and social support.

This finding indicates that social support contributes to quality of life directly, rather than through handicap, as originally hypothesized. A simple regression confirmed that social support is the strongest predictor of quality of life, predicting 13% of the adjusted variance. It appears, therefore, that social support is in its own right an important predictor of quality of life for persons with brain injury.

The finding that social support predicts more of the variance in quality of life than any of the injury-related factors in this study again emphasizes the relevance of contextual factors to quality of life, and suggests that contextual factors should be included as a part of the ICIDH model of disablement.

## Supplementary Analyses

One of the purposes of the study was to identify factors contributing to quality of life for people with acquired brain injury. This process involved examining how people with brain injury evaluated their quality of life, and exploring the factors they considered in arriving at their evaluation.

### Global Quality of Life

The distribution of the responses to the global quality of life question from a US national sample, the present sample, and the Heinemann and Whiteneck (1995) sample indicate that respondents in the present sample report quality of life in a manner more similar to that of individuals who have not experienced brain injury than to the other sample of respondents with brain injury. Approximately 40% of the national and present samples (39.7% and 39.1% respectively), and 26% of the Heinemann and Whiteneck sample reported feeling pleased or better about the quality of their life (See Table 4). The distributions of the national sample and the samples of persons with brain injury diverged at moderate levels of satisfaction, with 85% of the national sample, 71% of the present sample, and 46% of the Heinemann and Whiteneck sample reporting being mostly satisfied or better. At the lower end of the scale, 2% of the national sample reported feeling mostly dissatisfied or worse about the quality of their life, compared to 6% of the present sample and 19% of the Heinemann and Whiteneck sample.

The mean response for quality of life for the present sample (5.3) is consistent with those reported for national samples by Andrews and Withey (1976) at 5.5, 5.3 and 5.4; however it is significantly higher than the recoded mean of the Heinemann and Whiteneck sample (4.5; $t(96) = 6.80$, $p = .001$).

One explanation for the higher mean quality of life reported by the present sample than the other sample of persons with brain injury is the possibility that adjustment to the effects of brain injury occurs in part as a function of time, and that quality of life increases with adjustment. The average time since injury for the present sample was 10.2 years; for the Heinemann and Whiteneck sample, 5.4 years. In addition, the Heinemann and Whiteneck sample included persons with mild injuries, and 13% of their data was reported by proxy.

The similarity of the pattern of responses between the present sample and the national sample is consistent with previous observations (Batterham et al., 1996; Mehnert, Krauss, Nadler & Boyd, 1990) that little difference has been found in reported quality of life between people with disabilities and those without. Hall (1997) suggested that this might be attributable to an adjustment of an individual's life values and/or a lowering of expectations. An alternative explanation consistent with the results of the present study is that impairment and disability per se matter less in terms of quality of life than do contextual factors (e.g. interpersonal connection), which can be experienced equally by people who are living with the consequences of brain injury and those who are not.

However, the percentage of respondents with brain injury in the present sample and in the Heinemann and Whiteneck sample who reported feeling mostly dissatisfied or worse about their quality of life, although small relative to those who report being satisfied, was considerably greater than that in the national sample. Fuhrer et al. (1992) reported a similar finding for people with spinal cord injury, and Brown and Vandergoot (1998) found that respondents with traumatic brain injury rated their quality of life as significantly lower than respondents with no disability. In the same study, respondents with brain injury also reported significantly more important unmet needs than respondents without disability for 11 of 15 areas of need. The concept of "unmet need" (Flanagan, 1978, 1982) may be an important area for investigation in terms of what it is that contributes to the feeling of dissatisfaction with one's quality of life.

In Brown and Vandergoot's (1998) study, diminished quality of life was most highly correlated with important unmet needs in areas that were very similar for respondents with no disability and for those with traumatic brain injury. The four highest ranked of fifteen correlations between quality of life and important unmet needs for respondents without disability included work, material comforts, significant other, and understanding self; for respondents with traumatic brain injury, the four highest ranked correlations included work, material comforts, socializing and close friends. Research examining the effect of impairment and disability on these factors would help to determine whether and how injury-related factors might be indirectly related to quality of life.

In the brain injury literature, social isolation and loneliness have been well-documented as chronic concerns. In the present study, 46% of respondents endorsed loneliness as a problem, and 40% acknowledged having felt very lonely or remote from other people during the last few weeks. These figures are considerably higher than those cited for the general population in the US, with approximately 25% of Americans having felt very lonely or remote from others during the past few weeks (Bradburn, 1969), and an estimated 10% having experienced severe and persistent loneliness (Peplau & Perlman, 1982). Thus individuals with brain injury report loneliness as a problem to a much greater extent than the general population. The impact of the physical, cognitive and emotional sequelae of brain injury (e.g., fatigue, forgetfulness, emotional lability, disinhibition) on social support (interpersonal connection) is an important issue for further research.

However, evidence that 54% of respondents in the present sample did not endorse loneliness as a problem suggests that loneliness and social isolation are not an inevitable consequence of brain injury. Research comparing the injury-related factors and the personal and environmental factors influencing respondents who report feelings of loneliness and isolation with those who don't would provide insight into possible strategies for relieving these problems.

## Affect Balance

The similarity between the distributions of the ratings of individuals in the present study who are living with the experience of brain injury and those of the national sample who are not, continues when the balance of positive and negative affect is the variable under consideration. As Table 5 illustrates, the pattern of responses for the Affect Balance Scale for the present sample is similar to that for Andrews and Withey's (1976) national sample. Sixty-six percent of the present sample (vs. 70% of the national sample) reported more positive than negative feeling, 12% (vs. 13%) reported an equal amount of positive and negative feeling, and 22% (vs. 17%) reported more negative feeling. The 22% figure for negative affect is also consistent with that obtained by Harrick et al. (1994), who found that depression was a concern reported by 19% of respondents at three years after discharge from community-based rehabilitation.

Again, these findings demonstrate that individuals with brain injury report quality of life and affect in much the same way as individuals without brain injury. This supports the suggestion that it may not be the brain injury per se that affects quality of life, but that individuals with brain injury are subject to determinants of quality of life that impinge on the lives of individuals without brain injury as well.

## Aspects of Quality of Life

Respondents were asked what they had considered while evaluating the quality of their life. Although positive experiences and concerns varied with the individual, themes emerged in the areas of work, financial security, and interpersonal relationships. Respondents who reported feeling mixed about their life quality mentioned both negative and positive feelings:

> I'm unemployed--my feeling worthwhile is down a bit. I know I'm doing something my wife appreciates (looking after the baby). Things are going well--my friendship with my wife, our relationship with our families, my Christian beliefs--that helps.

Another respondent commented:

> On the good side, I've got some money--I got my GST back, so I'm moderately comfortable as far as money goes--enough to get by on. Things are going reasonably well with my girlfriend and I--social contact with a few friends has been satisfactory. . . . My concerns are the mildest concerns. The building superintendent has been replaced. The new super is more efficient and does all his work, so there's none for me, so the few extra dollars are gone. So, it's a relief and a disappointment. Also, we've been thinking about Christmas--my family have cut themselves off from me. One brother and one sister live nearby, but they have their own families. . . there's not much contact with my sisters or brothers.

The similarity of these themes with results of other research (e.g., Brown & Vandergoot, 1998) supports the observation that people with brain injury appear to evaluate the quality of their lives using the same criteria as people without disability, and suggests that contextual factors such as work, financial security/material comfort and interpersonal relationships are worthy of continued investigation.

## Limitations of the Research

The process of conducting the present study has revealed a number of limitations that highlight the challenges of research in disablement and brain injury rehabilitation. The following issues merit discussion, and consideration in future research.

### Design and Analyses

As this study was based on a correlational design, causal inferences cannot be drawn. The association between perceived availability of social support and global quality of life, for example, does not imply that improving social support for an individual will necessarily result in enhanced quality of life; only that on average, respondents reporting higher levels of social support also report higher quality of life. Longitudinal intervention-based research would provide valuable information regarding such issues as the effect of change in the level of social support on quality of life.

Ideally, models like the ICIDH model of disablement would be tested using structural equation modeling. The data provided by the measures used in this study, however, were not suited to this type of analysis. Although the total scores for all of the variables in the analyses were normally distributed, the structure of the impairment, disability, and social support measures resulted in non-normal distributions for many of the item scores, with large numbers of respondents endorsing extreme responses or not applicable responses. In addition, linear dependency existed among some items, for example where the mean of the other items in the scale was substituted for not applicable responses. Finally, testing the predictions under consideration in the present study with structural equation modeling would have required a larger sample. Klein (1991) points out that latent variable path analysis is applicable mainly in relatively "mature" clinical research areas, and that without an adequate measurement model it is unlikely that any model would fit the sample data.

Because the risk of overall Type I error is increased with multiple tests, corrected probability levels were used for comparisons of means and with correlations. The adjusted $R^2$ was reported for the regression analyses to compensate for expected inflation in the sample multiple correlations when estimating the population values (Stevens, 1992).

### Power

Cohen (1969) suggests $r = .30$ as a convention for the definition of a medium effect in linear correlation, noting that this value implies that nine percent of the variance in the dependent variable is attributable to the independent variable, and that this corresponds to a medium effect in the difference between two means. Power analysis indicated that with an anticipated correlation of $r = .30$, a desired power value of .80 and a non-directional test with a significance criterion of $a = .05$, a sample size of 84 would be sufficient to detect an effect. The sample size for all of the variables in the analyses except integration was 97. Because the Community Integration Measure became available after a number of interviews had been completed, the number of cases available for analyses involving integration was 64, and power was reduced from .80 to .68. The correlations obtained between integration and impairment ($r = .09$) and integration and disability ($r = .22$) indicate that at a desired power of .80, samples of approximately 800 and 200 cases respectively would be required to detect a significant effect (Cohen, 1969). The analyses, therefore, would have produced similar results had the number of cases for the Community

Integration Measure been the same as that of the other variables.

## Sample Selection

Attempts were made to contact all present and former clients of a community-based post-acute rehabilitation service agency if they met the criteria for inclusion in the study. However, many of the potential respondents could not be located, and several declined to participate in the study. It is possible that those potential respondents were dissimilar from those who did participate in a non-random way that may have influenced the results of the study. As the sample may not be representative, the results may not generalize to other samples of individuals sustaining moderate to severe brain injury.

## Measures

Due to its role as one of the main outcome measures in the Model Systems National Data Base, the Community Integration Questionnaire now forms the basis of a considerable body of literature assessing community integration (Dijkers, 1997). Recent reports of the psychometric properties of the Community Integration Questionnaire are inconsistent, however, and concerns have been voiced regarding its use (Corrigan & Deming, 1995; Dijkers, 1997; Hall, Mann, High, Wright, Kreutzer & Wood, 1996). Corrigan and Deming (1995), for example, suggested that the productive activity subscale is sufficiently unreliable as to warrant its use only in its contribution to the total score. Hall (1997), on the other hand, advocated that only the productive activity subscale be used in the proposed National Information System data base, having found ceiling effects for the home activity and social activity subscales with a non-injured sample.

Dijkers (1997) reports concerns relating to lack of content validity, lack of consistency in scoring, lack of norms, and age and gender effects. Use of the Community Integration Questionnaire with the present sample has raised additional concerns.

Internal consistency obtained for the Community Integration Questionnaire total score with this sample met DeVellis' (1992) suggestion for minimal adequacy (.70) and the home activity subscale showed good internal consistency (.85); however, the alpha coefficients for the social activity (.30) and productive activity (.07) subscales were not adequate. Examination of the items suggests that the alpha coefficient for both the home activity subscale and the Community Integration Questionnaire total score are artificially inflated for samples in which a large number of respondents do not live with children. The home activity subscale is comprised of five items related to independence in performing domestic activities: shopping, preparing meals, doing housework, looking after the children, and making social arrangements. In situations where there are no children, the mean of the other four items in the subscale is substituted for the score relating to that item.

In this sample, item four ("Who usually takes care of the children in your home?") was endorsed as not applicable by 72% of respondents. Therefore, the mean of the other four items was substituted for the score for item four in 72% of the cases. When internal consistency was calculated without this item, it dropped to .59 for the total score and to .77 for the home activity subscale.

Willer et al. (1994) reasoned that the low internal consistency (.35) they obtained for the productive activity subscale might be attributed to the fact that the subscale is comprised of only two items. The exceptionally low internal consistency for the productive activity subscale obtained for this sample (.07) may also be attributed to problems stemming from the validity of the items.

One source of measurement error lies in the interpretation of the item worded "How often do you travel outside the home?". Willer, Linn & Allen (1994) labelled this item "Use of transportation", although other possible interpretations range from "How often do you leave the house?" to "How often do you travel?" (e.g., on a holiday or business trip).

Furthermore, the potential responses for this item consist of almost every day, almost every week and seldom / never (less than once a week). This response format is problematic, because the second and third choices are almost identical in meaning. Almost every week is, by definition, less than once a week. Not surprisingly, response to the "travel outside the home" item is highly skewed, with 90% of the sample endorsing the option indicating the highest frequency (almost every day).

The ambiguity of the wording and the problematic response choices result in an item which, in this sample, correlates neither with the total score nor with any of the other items. Similarly, the job/school variable has no correlation with the total score for the Community Integration Questionnaire or with any other variables in this sample. Therefore, with this sample, it is not only the minimal number of items comprising the subscale which contributes to its lack of internal consistency, but also ambiguity in the wording of the item and in the response choices offered.

Willer et al. (1994) derived the home activity, social activity, and productive activity subscales using principal components analysis, requesting three components with

Varimax rotation. The first component consisted primarily of items inquiring about whether the respondent engages in the activity alone, with others, or not at all. The second component corresponded with items relating to frequency of shopping, leisure activities, and visiting friends or relatives, as well as to whether the respondent has a best friend, participates in leisure activities alone or with others, and looks after his or her own personal finances. Finally, the third component was comprised of the "travel outside the home" item and the combined job /school /volunteer item.

It may be that the first component represents primarily an "independence" component, where the items reflect whether the respondent engages in the activity independently or with someone else, and the second component represents a "frequency" component, where most items reflect how often the respondent engages in various activities.

Despite these concerns, the total Community Integration Questionnaire score was used in the present analysis for the purpose of comparison with existing research. Included in the Model Systems database, the Community Integration Questionnaire is currently the most commonly used measure of handicap (Dijkers, 1997).

However, the accumulation of data in the present study adding to the concerns regarding the use of the Community Integration Questionnaire suggests that caution be used in interpreting the results obtained with it. It is possible, for example, that participation does play an important role in predicting quality of life, but that the relationship was not evident in this sample because this measure failed to reflect adequately the construct of participation. It is also possible that participation does not predict quality of life. Continued development of alternative measures of handicap is needed to strengthen this element of weakness in the ICIDH model.

## Inflated Correlations

Relationships among variables are inflated when measures are in part comprised of identical or similar items. In the current set of measures, for example, items inquiring about depression are included on the Problem Checklist and the Patient Competency Rating Scale, and items inquiring about loneliness and restlessness are included on the Problem Checklist and the Affect Balance Scale. The latter was not considered to be a problem as the Affect Balance Scale was used for supplementary purposes, and not included in the regression analyses. Although the depression items are approached from different perspectives (i.e., how much of a problem depression presents in the respondent's daily functioning versus how easy is it for the respondent to keep from being depressed) they tap the same underlying content. It is acknowledged that this item may have inflated the relationship between the Problem Checklist and the Patient Competency Rating Scale. The depression item was retained in these measures when they were entered into the analyses, because it was only one of several items for which the content was in some way represented on both measures. As Kay et al. (1995) have pointed out, the Problem Checklist and the Patient Competency Rating Scale appear to be measuring approximately the same content at different levels of functioning: impairment and disability.

The argument that the Problem Checklist (symptom severity and frequency) and the Patient Competency Rating Scale (disability) measure essentially the same thing must be considered; however, correlations with other variables (e.g., affect balance) demonstrate stronger relationships with the Patient Competency Rating Scale ($\underline{r}$ = .40, $\underline{p}$ = .00007) than with the Problem Checklist ($\underline{r}$ = -.27, $\underline{p}$ = .008). This suggests that although the two measures may reflect much of the same content, different aspects of that content are distinguished (e.g., severity of the symptom vs. one's ability to perform activities requiring the use of that function).

## Awareness

An issue of concern in subjective research with respondents with brain injury is that cognitive impairments such as poor self-awareness compromise the validity of self-report information. Some research (Prigatano, Altman & O'Brien, 1991; Oddy, Coughlan, Tyerman & Jenkins, 1985) has suggested that individuals with brain injury underestimate their difficulties in comparison with family members.

Prigatano et al. (1986), for example, compared patients and family members' ratings on 18 of the 30 items of the Patient Competency Rating Scale. Rates of agreement ranged from 20% to 77%. Highest levels of agreement were for physical self-care activities, whereas the lower levels of agreement were for emotional and behavioural activities.

Other research demonstrated that individuals with brain injury report both higher and lower levels of problem severity relative to family members. Cavallo, Kay and Ezrachi (1992) investigated levels of agreement on ratings on the Problem Checklist for 34 patients and their relatives. Thirty-five percent of the cases agreed on at least 75% of the items. A further 23% of the patients reported greater difficulty than family members, and 32% of the patients reported less difficulty than family members.

Willer et al. (1993) reported generally high correlations between Community Integration Questionnaire scores reported by the individual and those reported by a family member (.89 for the total score, .81 for home activity, .74 for social activity and .96 for productive activity).

Seel, Kreutzer, and Sander (1997) tested levels of agreement between individuals with brain injury and their family members regarding neurobehavioural symptoms and daily living problems. These authors reported that individuals with brain injury did not underestimate their difficulties on the 70 items tested on the Neurobehavioural Functioning Inventory. Significant differences emerged for patient and family ratings for only 13 of the 70 items, and in all cases patients reported greater severity of the problem than their family member. Seel et al.'s (1997) research further demonstrated that levels of agreement appear to be related to severity of injury, and to the content and specificity of the item.

On the basis of their results, Seel et al. (1997) suggested that when individuals with brain injury are unable to provide information themselves, information provided by family members constitutes a reasonable facsimile. Conversely, when individuals with brain injury are capable of living independently and are within normal limits in many areas of cognitive functioning, "discounting their perceptions and desires is a questionable practice, even though they may seem disparate from those of family and staff members" (Seel et al., 1997, p. 1259). The present research is based on the premise that it is essential to consider the issues addressed in this study from the perspective of the person who is living with the effects of brain injury because the subjective experience of those living with disablement must be heard in order for it to be understood and respected.

### Response Bias

It is possible that response bias has occurred with this set of questionnaires, as several were comprised of items that were all coded in the same direction. However, as the questionnaires were administered as a structured interview as opposed to a paper-and-pencil format, there was discussion involving almost every item. Most respondents did not respond immediately, but took time to consider the questions, thinking aloud, giving examples, and talking about past experiences. This suggests that the automatic selection of the same response option was not a pervasive problem in this situation.

### Social Desirability

An issue related to response bias is that of social desirability. It is possible, for example, that some respondents answered in a way they believed would make them appear in a more positive light, or in a way that would please the interviewer. A measure of social desirability was not included in the study, as norms for this population were not available for existing measures, and as it was necessary to keep the interview as brief as possible.

The respondents appeared to consider the questions carefully, and invested considerable effort in trying to distil their experience into the alternatives provided by the response format. Finally, the original version of at least one of the questionnaires included in the study, the Interpersonal Support Evaluation List, has been shown in previous research not to be associated with social desirability (Cohen et al., 1985).

### Organic Versus Reactive Consequences of Injury

A question that arises with regard to the effects of brain injury and quality of life has to do with whether aspects of psychological well-being (which is strongly associated with quality of life) might be an organic consequence of the injury as opposed to a reaction to the changed life circumstance. Prigatano's (1987) review of the literature tentatively suggested that emotional and motivational disturbances that may be neuropsychologically mediated include impulsiveness, socially inappropriate behaviours, emotional lability (including poor frustration tolerance) agitation, paranoia and apathy. In contrast, such emotional disturbances as anxiety, depression, feelings of hopelessness and helplessness, anger, and possibly irritability, are thought to be reactive in nature, as they show no correlation with either the amount or the location of brain dysfunction. While the former problems may contribute to the latter, it is the latter that are typically considered to reflect diminished psychological well-being. The possibility that disturbances such as anxiety and depression may be reactive in nature suggests that they may be amenable to remediation, and that research investigating their relationship to impairment, disability, handicap, social support and quality of life should not be dismissed as an unwarranted expenditure of funds.

### Pre-injury Status

Another issue which must be acknowledged when conducting research with this population is that of pre-injury status (Hall, 1997). Although recognized as important determinants of long-term behavioural outcome (Prigatano, 1987), pre-injury factors have been difficult to assess, as this information is by nature retrospective. Prigatano's (1987) research with children (for whom school records provide pre-injury information) suggested that some of the problems of adaptation after brain injury may reflect a combination of pre-injury difficulties and post-injury impairments. Because of time constraints, an already lengthy questionnaire, and the focus on respondents' current situation, retrospective pre-injury data were not included in the present study.

### Control Group

McKinlay and Brooks (1984) pointed out that symptoms experienced by individuals who have sustained a brain injury may not be specific to brain injury, but may include effects experienced by individuals who have sustained other types of traumatic injury. These researchers suggested including a matched control group in the study as a means of resolving this issue. Given the scope of the present study, however, obtaining a matching sample for 97 respondents was deemed to be unfeasible.

It is acknowledged that these issues detract from the impact of the present study; however, they are issues which are applicable to much of the existing research. Clearly there is a need to address these issues in future research.

## Directions for Future Research

### Theoretical Implications

Evidence that the ICIDH model of disablement describes the experience of disablement for people who have sustained brain injury was mixed. A strong relationship was demonstrated for the proposed link between impairment and disability, but the link between the first two components of the model and the handicap construct was weaker, and was dependent on the measure of handicap. Impairment and disability predicted handicap when it was assessed in terms of one's overall participation in home, social and productive activity but not when it was assessed in terms of one's sense of integration into the community.

The results of the analyses clearly indicate that research in this area would benefit from consideration of contextual factors as well as injury-related factors. When the outcome of interest was community integration or quality of life, the perceived availability of social support (interpersonal connection) emerged as an important predictor of that outcome (predicting 16% and 13% of the adjusted variance respectively). This suggests that social support is a key variable that should be included in research investigating disablement and rehabilitation outcomes for people with brain injury.

At this point, neither the Model Systems database nor the proposed National Information System (Hall, 1997) includes a measure of social support. Similarly, in a description of the research battery recommended for following patients with head injuries by the Outcome Measures Subcommittee of the National Institutes of Health / National Institute of Neurologic Disorders and Stroke Head Injury Centers, Hannay et al. (1996) list measures of orientation, post traumatic amnesia, cognitive, motor and neurobehavioural impairment, disability, and handicap, but fail to mention measures of social support or quality of life.

The research battery does measure behavioural and psychosocial changes with the Head Injury Family Interview (Kay et al., 1995), which includes questions about friendship and intimacy, but not about quality of life. Hall (1997, p. s8) suggests that "possibly one or two key questions" would be an adequate measure of family support, but fails to mention any need to assess social support or interpersonal connection. Regarding quality of life, Hall (1997) states that

> Global quality of life is an ultimate aim of rehabilitation, and a measure of the impact of rehabilitation on it would be ideal. However, rehabilitation success may have little to do with an individual's experience of life satisfaction, consequently, it is recommended that the National Information System minimize expenditure of resources on this issue (p. s8).

This statement exemplifies the manner in which progress in research and service provision can be constrained by existing ways of thinking and by alternate agendas, in this case, the "unprecedented pressure from payers to demonstrate value and cost effectiveness when serving persons with disabilities and handicaps resulting from brain injury" (Hall, 1997, p. s5). If the ultimate goal of rehabilitation is to enhance the quality of life of the person undergoing rehabilitation, some measure of quality of life should at least be included in research investigating the experience of disablement. If multi-center databases continue to neglect social support and quality of life, a valuable opportunity to obtain information regarding the ultimate goal of rehabilitation will be lost.

The results of the study also have a number of measurement-related implications for future research. First, the study demonstrated the importance of developing and using measures that are valid, reliable, and comprehensive representations of the construct of interest. Some of the confusion that is present in the literature regarding the use of various outcome measures to represent impairment, disability and handicap, would be clarified by explicit attention to and explanation of the content of the measures used. Previous research, for example, has relied almost exclusively on measures that assess impairment using severity of injury, and disability using measures of levels of consciousness or independence in basic self-care activities. This approach does not reveal whether the impairment experienced by the respondent involves a cluster of symptoms reflecting a particular aspect of impairment, or a general limitation in functioning in many areas. Neither does this approach capture possible differences in the impact of various aspects of impairment on other variables. Similarly, at the level of disability, a focus on the performance of self-care routines and activities of daily living neglects the cognitive and emotional limitations in functioning that are important aspects of disability for people with brain injury. The Problem Checklist and the Patient Competency Rating Scale address these issues by comprehensively assessing the perceived symptoms of impairment and limitations in functioning respectively. Correlations between the subscales of these measures and the other variables reveal relationships that are specific to certain aspects of impairment and disability. For example, the negative association between participation and physical impairment is stronger than that between participation and cognitive or affective impairment. Similarly, integration has a strong positive relationship with emotional support that is not present to the same extent with practical or information support (See Appendix A).

The need to clarify which aspects of the various constructs are being measured is also demonstrated by the results involving the handicap construct. The weakness of the relationship between participation and integration ($r = .26$, $p = .04$) and differences in the way in which each relates to the other variables in the analyses suggest that participation and integration represent qualitatively different aspects of handicap.

Further development of measures to reflect the handicap construct is necessary. Handicap is the component of the ICIDH model at which the medical and social paradigms merge, that is, where the consequences of the injury and the personal, social and environmental resources and limitations of the individual interact to the greatest degree.

The Flanagan Scale of Needs (Flanagan, 1982), as used by Brown and Vandergoot (1998) is based on an approach to measurement that would lend itself well to assessing the handicap construct. This approach could be used to assess both personal and injury-related factors and also to incorporate the perspective of the respondent. In Brown and Vandergoot's (1998) study, respondents were asked to rate the importance of 15 needs in defining their quality of life, and then to rate how well their needs were being met in each area. This measure is scored by multiplying the importance rating by the difference between the maximum possible attainment rating and actual attainment of the need, thus reflecting only unmet needs that are moderately or very important to the respondent. This approach has the advantage of using the respondent's sense of the subjective importance of a need in determining whether that need contributes to the total score. The list of needs could be adapted to include both injury-related and contextual factors, and left open-ended to incorporate any additional factors the respondent wishes to include. Respondents could then be asked to rate the importance of each need in terms of their experience of disadvantage regarding their interaction with society.

In summary, the results of the present study suggest that in order to "measure what matters", change must take place in both the conceptualization and the measurement of disablement. First, research must broaden its focus to consider medical and social approaches to disablement in conjunction with each other. The present study demonstrates that the social approach to disablement remains to be integrated into the ICIDH model. Support for the model is strong at the levels of impairment and disability, but breaks down at the level of handicap, where the integration of the social approach with the medical approach becomes necessary. Future research needs to consider how injury-related factors might be related to contextual factors that in turn might influence quality of life.

In terms of the measurement of disablement, measures should be used that accurately and comprehensively reflect the constructs under investigation. The content of measures reflecting particular aspects of the impairment, disability or handicap constructs should be clearly specified.

### Applied Implications

Although respondents' assessments of the severity of their impairment and of the extent of their disability were related to their reported overall participation (in home, social and productive activity), participation was not related to respondents' reported quality of life. This lack of a relationship between participation and quality of life emphasizes the need to determine what it is that matters, in terms of rehabilitation and quality of life. If enhanced quality of life is the ultimate goal, then level of handicap, as assessed by this measure of participation in this study, is of no direct consequence to that goal. This suggests that an exclusive focus in rehabilitation on reducing impairment and disability with a view to increasing participation in social roles is not likely to influence the individual's reported quality of life.

The results suggest that what matters more, in terms of quality of life, is social support (interpersonal connection). It is the feeling typified by statements such as "I feel as though I belong in my circle of friends" and "I have friends I feel close to" that predicts one's reported quality of life. Rehabilitation efforts, therefore, should focus on increasing the perceived availability of social support for clients with brain injury.

The variable most strongly related to quality of life in the present study was the balance of positive over negative affect. The correlation between the Affect Balance Scale and quality of life ($r = .71$, $p < .00001$), indicates that reported global quality of life was strongly related to the degree to which respondents reported feeling excited, interested, pleased because of accomplishing something, proud because of receiving a compliment, on top of world, and that things were going their way, as well as the degree to which they reported not feeling restless, lonely, bored, depressed, and upset.

According to Bradburn (1969), efforts to enhance psychological well-being must involve both an increase in positive affect and a reduction in negative affect. Providing opportunities for persons living with disablement to experience accomplishment, pride, interest and excitement, and to establish feelings of connection with others; as well as helping them to find ways to alleviate boredom, loneliness, and depression are strategies for enhancing quality of life that should be an important aspect of rehabilitation.

Hall (1997) pointed out that an individual's experience of life satisfaction may have little to do with rehabilitation success. The results of the present study are consistent with this statement, when rehabilitation success is defined in terms of participation in social roles, or even in terms of feeling integrated into the community. However, the results of this study (and others, e.g., Brown & Vandergoot, 1998; O'Neill et al., 1998) also suggest that if rehabilitation success were to be defined in terms of meeting the needs of the individual, for example for social support (interpersonal connection), work (something done in a job or at home that is interesting, rewarding and worthwhile), or other aspect of life that is important to the individual, this statement would no longer hold true. If rehabilitation success were to be defined in terms of the degree to which the needs deemed important by an individual have been met, it is possible that rehabilitation success would be more strongly and consistently related to quality of life.

Intervention to meet the needs of individuals with brain injury can be provided by rehabilitation at each of the levels of impairment, disability and handicap. Education regarding the effects of brain injury, efforts to increase self-awareness (e.g., of when sensory overload is contributing to fatigue or irritability), and compensatory strategies such as the use of day planners, are examples of interventions that may ultimately contribute to quality of life (e.g., through improving one's ability to establish and maintain social connections or to engage in meaningful activity). Day programs, support groups, and recreational and social activities provide opportunities to meet and interact with others, to experience interest and excitement, and to alleviate boredom and loneliness. The effect of these interventions on injury-related and contextual factors and quality of life, however, needs to be evaluated in order to disentangle what is occurring in the present "black box" of interventions described by Cope (1995).

## Conclusion

The results of the present study are consistent with the observation that research in disablement and rehabilitation for persons with brain injury is still in the early stages of development (Fordyce, 1994). The continuing need for acute medical and post-acute community-based rehabilitation is undisputed; however, in the present environment of health care restructuring and fiscal restraint, the luxury of a "black box" approach to rehabilitation is no longer tenable. Accountability requires evidence of the effectiveness of the intervention with respect to short-term goals, but even more critical is an understanding of how that intervention makes a difference to the quality of life of the individual.

The results of this study indicate that an exclusive focus in rehabilitation on reducing impairment and disability is unlikely to influence the individual's quality of life; intervention solely at the level of injury-related factors is not sufficient. It is critical to consider the person as a whole, in terms of his or her personal, social, and physical context, and to provide appropriate services and supports.

The comments of one respondent illustrate the combined positive effects of medical intervention, rehabilitation, and environmental adaptation and support on quality of life:

> Why shouldn't I be delighted (with the quality of my life)? 'Cause I'm living in a home (an apartment with another individual with brain injury, and with 24-hour support)--something I've always wanted. Another thing that makes me feel delighted is a kind of medication that controls my epilepsy. And going to work. . .

> it's a sitting-down job, and I can concentrate more on my work, because I don't have to watch my balance. It's putting information into the computer. . . . It's a work program. I go from 8:30 to 4:00 Monday and Wednesday, and Fridays half a day, and I get paid for it too. I get paid for something I like to do a lot.

The situation of this respondent exemplifies the positive effect of an integrated approach to service provision. The medical approach, through consideration of impairment and disability, indicates the strengths that may be emphasized and the limitations that may be compensated for. The social approach identifies the person who sustained the injury as the expert in the experience of his or her own disablement, and determines, through the perceptions of that person, the social and environmental context, the barriers and resources, and the intermediate goals that will ultimately contribute to that person's quality of life. Rehabilitation efforts working from this perspective involve community, social, and political forces in arranging the opportunities and resources required to help the person to meet his or her goals.

With the number of persons with brain injury increasing by more than 2000 every year in Ontario, and health care restructuring imposing dramatic changes in service provision, the need to develop effective rehabilitation interventions is critical. Whiteneck (1994) described rehabilitation success in terms of a person who, "despite significant disability, is an active, productive member of society, well integrated into the community, and satisfied with a high quality of life" (p. 1073).

The first step towards achieving this kind of successful rehabilitation is to measure what matters. The results of this study suggest that what matters, and therefore what should constitute the focus of research, goes beyond the injury-related factors of impairment and functional limitation. Future research must focus on the personal, social and physical context affecting the person's experience of disablement--on the resources and barriers that assist or limit the person in achieving the fundamental aspects of life to which we all aspire.

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# APPENDIX A

## Correlation Coefficients Among Independent Variables, Subscales and Dependent Variables

Correlation Coefficients Among Independent Variables, Subscales, and Dependent Variables

| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 | 13 | 14 | 15 | 16 | 17 | 18 |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| 1 Impairment | | | | | | | | | | | | | | | | | | |
| 2 Physical | ,77** | | | | | | | | | | | | | | | | | |
| 3 Cognitive | ,88** | ,71** | | | | | | | | | | | | | | | | |
| 4 Affective | ,85** | ,42** | ,56** | | | | | | | | | | | | | | | |
| 5 Disability | -,66** | -,60** | -,68** | -,44** | | | | | | | | | | | | | | |
| 6 ADL | ,39** | ,53** | ,32* | ,24* | -,65** | | | | | | | | | | | | | |
| 7 Executive | -,57** | -,52** | -,70** | -,30* | ,86** | -,44** | | | | | | | | | | | | |
| 8 Emotional | -,58** | -,40** | -,55** | -,50** | ,82** | -,30* | ,56** | | | | | | | | | | | |
| 9 Social Support | -,04 | ,06 | -,05 | -,07 | ,25* | ,01 | ,24* | ,33* | | | | | | | | | | |
| 10 Practical | -,08 | ,08 | -,14 | -,09 | ,14 | ,15 | ,14 | ,30* | ,73** | | | | | | | | | |
| 11 Inform | ,02 | ,08 | ,02 | -,02 | ,19 | -,02 | ,20* | ,24* | ,85** | ,47** | | | | | | | | |
| 12 Emotional | -,05 | ,02 | -,05 | -,08 | ,26* | -,03 | ,24* | ,31* | ,93** | ,56** | ,66** | | | | | | | |
| 13 Participation | -,27* | -,38** | -,25* | -,12 | ,27* | -,36* | ,28* | ,04 | -,03 | -,18 | ,09 | -,04 | | | | | | |
| 14 Home Activity | -,23* | -,37** | -,18 | -,11 | ,24* | -,43** | ,20 | ,02 | -,20* | -,30* | -,04 | -,20* | ,85** | | | | | |
| 15 Integration | -,09 | -,02 | ,10 | -,26* | ,21 | -,27* | ,11 | ,19 | ,41* | ,25* | ,26* | ,46** | ,26* | ,15 | | | | |
| 16 Life Quality | -,17 | -,04 | -,07 | -,28* | ,27* | -,12 | ,21* | ,29* | ,38** | ,20 | ,28* | ,41** | -,02 | -,12 | ,25* | | | |
| 17 Affect Balance | -,27* | -,11 | -,18 | -,33* | ,40** | -,15 | ,37** | ,39** | ,44** | ,17 | ,37** | ,48** | ,01 | -,12 | ,29* | ,71** | | |
| 18 Positive Affect | -,15 | -,06 | -,12 | -,16 | ,32* | -,13 | ,34* | ,28* | ,41** | ,18 | ,40** | ,41** | ,02 | -,08 | ,30* | ,59** | ,81** | |
| 19 Negative Affect | ,29* | ,12 | ,17 | ,38** | -,31* | ,12 | -,26* | -,33* | -,30* | -,10 | -,20 | -,37** | ,00 | ,12 | -,18 | -,57** | ,82** | -,33* |

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*p < ,05
**p < ,0003 (Bonferroni Correction)
Shading indicates correlations between variables in regression analyses

# APPENDIX B

## Letter of Support

Providence
Continuing Care
Centre

**Regional Community Brain Injury Services**

January 25, 1996

Dear

A group from the Psychology Department at Queen's University is working with us at the Regional Community Brain Injury Services on a very important study. This group is interested in learning about how people become a part of their community following the experience of brain injury. This group also hopes to discover how well treatment programs are working and what people feel about their current situation.

I am writing to ask if you would be willing to be involved in this study. If so, you will be asked to participate in 2 interviews, either at our office or at your own home. In the interviews, you will be asked about your activities in the community and your feelings about your involvement.

While the present study may not help you directly, we hope the information provided will improve the service given to people with brain injuries.

We would really appreciate your time and assistance with this project. Our Follow-up Co-ordinator, Lynn Harrick, will be calling you soon to see whether you are willing to participate and also if you have any questions.

Thank you and best wishes for 1996.

Yours Sincerely,

Jane Johnston

Jane Johnston, Director
Regional Community Brain Injury Services

303 BAGOT ST, LaSALLE MEWS, STE 401, KINGSTON, ONTARIO K7K 5W7 (613) 547-6969 FAX 547-6472

# APPENDIX C

## Information Letter

## Queen's University
## Study on Integration of Persons with Disabilities

Dear

Thank you for agreeing to help us look at some of the issues involved in community living. As you know, you have agreed to speak to us about living in the community and about the kinds of support that may be available for you. One of our research assistants has arranged to meet with you and to ask you some questions. These questions will be about the way you live, the things you do, and how you feel about them. We will also ask about problems you may be having and about things that are going well for you. We will write the answers you give to the questions we ask, and we will be pleased to answer any questions that you may have.

Our interview can be completed in about two hours. However, it can take as much as three or four hours to answer all the questions if we get talking about things. If it looks like it's going to take more than two hours, we will ask if we may meet with you a second time.

Before starting the interview, we will ask that you complete a consent form that says you agree to participate. It is okay to stop at any time and to withdraw or change your consent. We prefer to speak to you privately, if possible. This will in no way affect the help you may be receiving from the Regional Community Brain Injury Services. All of the information that you give us will be kept confidential. It will be kept in a secure place and no one who is not involved in the project will know your answers.

Several people are working on this project. Some people you may know at the Robin Easey Centre in Ottawa (Dr. Fred Pelletier) or at the Regional Community Brain Injury Services in Kingston (RCBIS) (Ms Jane Johnston, Director, and Ms Lynn Harrick, Follow-up Coordinator). Others work at Ongwanada (Dr. Katherine Buell and Dr. Patricia Minnes), at the Kingston and District Association for Community Living (Peter Sproul), and at Queen's University. Money for the project has been granted by the federal government in order to look at how people with disabilities live successfully in the community. Because Canada has so many different cultures, we like to think it is possible to include persons with disabilities as part of our cultural mix.

Although there may be no direct or immediate benefits from your participation in this project, we hope that you will benefit indirectly by helping us to gain a clearer understanding of your needs and experiences. If you have any questions, concerns or complaints about this project, please feel free to contact Mary-Lou Nolte at Queen's University (613 542-7043), Dr. Fred Pelletier at the Robin Easey Centre (613-726-1558), Dr. Katherine Buell at Ongwanada, (613 548-4417, ext. 263) or Dr. Patricia Minnes at Queen's University (613 545-2885). If your questions are not answered to your satisfaction, you may also contact Dr. D. A. DeForge, Chair of the Research Ethics Committee at the Rehabilitation Centre, Royal Ottawa Health Care Group (613 737-7350), or Dr. R. Kalin, Head of the Department of Psychology at Queen's University (613 545-2492).

Sincerely,

Patricia Minnes, Ph.D.
Associate Professor

Katherine Buell, Ph.D.,
Psychologist

# APPENDIX D

## Consent Form

## Consent Form

## Queen's University

## Study on Integration of Persons with Disabilities

I, ________________________ agree to participate in a research study about the integration of persons with disabilities being conducted by Dr. Patricia Minnes of Queen's University in Kingston, with the Robin Easey Centre in Ottawa and a number of other agencies. The purpose of the study is to investigate whether people with disabilities who are living in the community are truly integrated.

I understand that I will be asked a number of questions during an interview about the way I live, the things I do, how I feel about my life, and the problems I may be having. The interview will take between two and four hours. Although there may be no direct or immediate benefit from my participation in this project, I understand that I may benefit indirectly by helping the researchers to gain a clearer understanding of the needs and experiences of persons with disabilities and those who care for them in the community.

I agree to participate in this study with the understanding that information will be collected and used for research purposes only and will be treated as confidential. I have been informed about the purpose of this study and realize that I am under no obligation to participate and may withdraw at any time. Refusal to participate or withdrawing from the study will in no way affect my present and/or future treatment at The Rehabilitation Centre.

If I have any questions, complaints, or concerns about this project, I may contact Ms Mary-Lou Nolte (613-542-7043), Dr. Fred Pelletier at the Robin Easey Centre (613 726-1558), Dr. Katherine Buell (613 548-4417 ext. 263) or Dr. Patricia Minnes (613 545-2885). If my questions are not answered to my satisfaction, I may also contact Dr. D. A. DeForge, Chair of the Research Ethics Committee at The Rehabilitation Centre, Royal Ottawa Health Care Group (613 737-7350), or Dr. R. Kalin, Head of the Department of Psychology at Queen's University (613 545-2492).

Signed: ________________________________

Date: ________________________________

# APPENDIX E

## General Information

## GENERAL INFORMATION

NAME: ____________________ DATE: ______________

ADDRESS: ____________________ PHONE: ______________

____________________

GENDER: ☐ Male ☐ Female AGE: ______________

EDUCATION: (Highest grade/year completed) ________

DATE OF INJURY: ________________________

CAUSE OF INJURY: ________________________

GLASGOW COMA SCALE: ________ DURATION OF PTA: (hours) ________

DURATION OF LOC: (hours) ________

MARITAL STATUS:

☐ Never Married
☐ Married
☐ Living with Partner
☐ Separated
☐ Divorced
☐ Not Applicable

LIVING SITUATION:

Where:

☐ House
☐ Apartment
☐ Hotel Room
☐ Halfway House
☐ Hostel
☐ Institution
☐ Group Home
☐ General Hospital
☐ Psychiatric Hospital
☐ Skilled Care Nursing Home
☐ Other Housing (Please specify)
(______________________)

With whom:

☐ Alone
☐ Spouse
☐ Partner (not married)
☐ Parents
☐ Siblings
☐ Children (under 21)
☐ Other relatives or adult children
☐ Housemates/Friends
☐ Other residents
☐ Other patients
☐ Professional care provider

## QUALITY OF LIFE

..."Now I'd like to ask you a general question about your quality of life. Overall, how do you feel about the quality of your life during the last month or so?"

- ☐ (1) Delighted
- ☐ (2) Pleased
- ☐ (3) Mostly Satisfied
- ☐ (4) Mixed (about equally satisfied & dissatisfied)
- ☐ (5) Mostly Dissatisfied
- ☐ (6) Unhappy
- ☐ (7) Terrible

## FINANCIAL SITUATION

1) How would you rate your financial situation during the last month or so?

- ☐ (1) Excellent
- ☐ (2) Good
- ☐ (3) Satisfactory
- ☐ (4) Barely Adequate
- ☐ (5) Inadequate

2) How are you supporting yourself?

- ☐ Employment (full time)
- ☐ Employment (part time)
- ☐ Insurance/Pension
- ☐ Self-Supported (e.g. investments, business)
- ☐ Family
- ☐ No Income
- ☐ Other ________

3) What is your approximate income level (approximate gross monthly income)?

- ☐ a) < $100
- ☐ b) $100 - 300
- ☐ c) $300 - 500
- ☐ d) $500 - 700
- ☐ e) $700 - 1000
- ☐ f) $1000 - 1500
- ☐ g) $1500 - 2000
- ☐ h) $2000 - 3000
- ☐ h) $3000 - 4000
- ☐ i) > $4000

## PAID AND UNPAID ASSISTANCE

1) Do you receive assistance in any housework, self-care or other activities <u>from people who get paid to help you</u>?

☐ YES ☐ NO

If "yes", for each service listed below, state the usual <u>number of days each week</u> that you receive this service. Then write in the usual <u>number of hours</u> each day that the service is received.

| | | NUMBER OF DAYS EACH WEEK | NUMBER OF HOURS ON DAYS HELPED |
|---|---|---|---|
| a. | Nursing | _____ | _____ |
| b. | Personal Care | _____ | _____ |
| c. | Rehabilitation, e.g., physio, speech, occupational therapy | _____ | _____ |
| d. | Homemaking | _____ | _____ |
| e. | Other services that help you maintain your current living situation (please explain) | _____<br>_____ | _____<br>_____ |

______________________________

2) Do you receive any assistance in your activities from people <u>who do not get paid</u> to help you? (e.g. friends, relatives, volunteers)

☐ YES ☐ NO

If "yes", for each person listed below, state the usual <u>number of days each week</u> and the <u>number of hours each day</u> that this person helps you.

| | | NUMBER OF DAYS EACH WEEK | NUMBER OF HOURS ON DAYS HELPED |
|---|---|---|---|
| a. | family members | _____ | _____ |
| b. | friends | _____ | _____ |
| c. | other people (please explain) | _____ | _____ |

______________________________

# APPENDIX F

## Problem Checklist

## PROBLEM CHECKLIST

On the left you will find a list of symptoms often encountered by a person after a head injury. Next to each item, you are asked to indicate whether this is something you experience. If you answer YES, then you will be asked to indicate how much of a problem this presents in your daily functioning. Circle one of the numbers from 1 (NO PROBLEM) to 7 (SEVERE PROBLEM). The higher the number you circle, the more of a problem it is for you.

| **Do you experience....?** | | YES | NO | **If yes, how much of a problem does this present in your daily functioning?** 1 No Problem | 2 | 3 | 4 Moderate Problem | 5 | 6 | 7 Severe Problem |
|---|---|---|---|---|---|---|---|---|---|---|
| 1. | Visual problems; difficulty seeing | Y | N | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 2. | Hearing difficulties | Y | N | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 3. | Poor balance | Y | N | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 4. | Doing things slowly | Y | N | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 5. | Difficulty pronouncing words clearly (dysarthria) | Y | N | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 6. | Problems with coordination | Y | N | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 7. | Fatiguing quickly; getting tired easily | Y | N | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 8. | Headaches | Y | N | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 9. | Dizziness/vertigo | Y | N | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 10. | Sensitivity to noise | Y | N | 1 | 2 | 3 | 4 | 5 | 6 | 7 |

| Do you experience....? | | YES | NO | If yes, how much of a problem does this present in your daily functioning? | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | | | | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| | | | | No Problem | | | Moderate Problem | | | Severe Problem |
| 11. | Sensitivity to light | Y | N | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 12. | Problems with taste or smell | Y | N | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 13. | Difficulty remembering the right word (word-finding) | Y | N | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 14. | Expressing self in a wordy, roundabout way | Y | N | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 15. | Being easily distractible (e.g. in a noisy room) | Y | N | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 16. | Poor concentration for extended periods of time (e.g. reading in a quiet room) | Y | N | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 17. | Being forgetful; difficulty remembering things | Y | N | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 18. | Difficulty thinking clearly and efficiently | Y | N | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 19. | Difficulty planning and organizing things | Y | N | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 20. | Difficulty setting realistic goals | Y | N | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 21. | Difficulty following through or finishing things | Y | N | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 22. | Apathy, lack of interest in things | Y | N | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 23. | Lack of initiative, don't start things up | Y | N | 1 | 2 | 3 | 4 | 5 | 6 | 7 |

| **Do you experience....?** | YES | NO | **If yes, how much of a problem does this present in your daily functioning?**<br>1<br>No Problem | 2 | 3 | 4<br>Moderate Problem | 5 | 6 | 7<br>Severe Problem |
|---|---|---|---|---|---|---|---|---|---|
| 24. Irritability | Y | N | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 25. Restlessness | Y | N | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 26. Temper outbursts | Y | N | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 27. Mood swings, quick emotional shifts | Y | N | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 28. Difficulty bringing emotions under control once expressed | Y | N | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 29. Getting into arguments with others | Y | N | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 30. Being physically violent | Y | N | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 31. Getting bored easily | Y | N | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 32. Complaining about things | Y | N | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 33. Dependency on others | Y | N | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 34. Needing supervision | Y | N | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 35. Anxiety/tension | Y | N | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 36. Depression | Y | N | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 37. Loneliness | Y | N | 1 | 2 | 3 | 4 | 5 | 6 | 7 |

| Do you experience....? | YES NO | If yes, how much of a problem does this present in your daily functioning?<br>1 No Problem | 2 | 3 | 4 Moderate Problem | 5 | 6 | 7 Severe Problem |
|---|---|---|---|---|---|---|---|---|---|
| 38. Loss of confidence | Y | N | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 39. Changes in appetite | Y | N | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 40. Sleep disturbance | Y | N | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 41. Low sexual drive | Y | N | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 42. High sexual drive | Y | N | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 43. Changed personality | Y | N | 1 | 2 | 3 | 4 | 5 | 6 | 7 |

# APPENDIX G

## Patient Competency Rating Scale

## PATIENT COMPETENCY RATING SCALE

The following is a questionnaire which asks you to judge your ability to do a variety of very practical skills. Some of the questions may not apply directly to things you often do, but you are asked to complete each question as if it were something you "had to do." On each question you should judge how easy or difficult a particular activity is for you and circle the appropriate number. Please rate your ability to do these activities now.

| Can you... | Can't Do | Very Difficult to do | Can do With Some Difficulty | Fairly Easy to do | Can do With Ease |
|---|---|---|---|---|---|
| 1. ...prepare your own meals? | 1 | 2 | 3 | 4 | 5 |
| 2. dress yourself? | 1 | 2 | 3 | 4 | 5 |
| 3. take care of your personal hygiene? | 1 | 2 | 3 | 4 | 5 |
| 4. wash the dishes? | 1 | 2 | 3 | 4 | 5 |
| 5. do the laundry? | 1 | 2 | 3 | 4 | 5 |
| 6. take care of your finances? | 1 | 2 | 3 | 4 | 5 |
| 7. keep appointments on time? | 1 | 2 | 3 | 4 | 5 |
| 8. start up a conversation in a group? | 1 | 2 | 3 | 4 | 5 |
| 9. stay involved in work activities even when bored or tired? | 1 | 2 | 3 | 4 | 5 |
| 10. remember what you had for dinner last night? | 1 | 2 | 3 | 4 | 5 |
| 11. remember names of people you see often? | 1 | 2 | 3 | 4 | 5 |
| 12. remember your daily schedule? | 1 | 2 | 3 | 4 | 5 |
| 13. remember important things you must do? | 1 | 2 | 3 | 4 | 5 |
| 14. drive a car if you have to? | 1 | 2 | 3 | 4 | 5 |

| | **Can you...** | Can't Do | Very Difficult to do | Can do With Some Difficulty | Fairly Easy to do | Can do With Ease |
|---|---|---|---|---|---|---|
| 15. | get help when you're confused? | 1 | 2 | 3 | 4 | 5 |
| 16. | adjust to unexpected changes? | 1 | 2 | 3 | 4 | 5 |
| 17. | handle arguments with people you know well? | 1 | 2 | 3 | 4 | 5 |
| 18. | accept criticism from other people? | 1 | 2 | 3 | 4 | 5 |
| 19. | control crying? | 1 | 2 | 3 | 4 | 5 |
| 20. | act appropriately when you're around friends? | 1 | 2 | 3 | 4 | 5 |
| 21. | show affection to people? | 1 | 2 | 3 | 4 | 5 |
| 22. | participate in group activities? | 1 | 2 | 3 | 4 | 5 |
| 23. | recognize when something you say or do has upset someone else? | 1 | 2 | 3 | 4 | 5 |
| 24. | schedule daily activities? | 1 | 2 | 3 | 4 | 5 |
| 25. | understand new instructions? | 1 | 2 | 3 | 4 | 5 |
| 26. | consistently meet your daily responsibilities? | 1 | 2 | 3 | 4 | 5 |
| 27. | control your temper when something upsets you? | 1 | 2 | 3 | 4 | 5 |
| 28. | keep from being depressed? | 1 | 2 | 3 | 4 | 5 |
| 29. | keep your emotions from affecting your ability to go about the day's activities? | 1 | 2 | 3 | 4 | 5 |
| 30. | control laughter? | 1 | 2 | 3 | 4 | 5 |

# APPENDIX H

## Interpersonal Support Evaluation List (Adapted)

## TYPES OF SUPPORT

Below is a list of statements about various types of support that people might receive from others. For each statement, please tell me whether or not it is true about you. Please remember that this is not a test and there are no right or wrong answers. We are just interested in knowing what you think.

| | **Practical Support:** | Never True | Almost Never True | Some-times True | Usually True | Almost Always True | Always True |
|---|---|---|---|---|---|---|---|
| | | ( ) | ( ) | ( ) | ( ) | ( ) | ( ) |
| 1. | If I had to go out of town for a few weeks, I could find someone to look after my home/ plants/pet/etc. | ( ) | ( ) | ( ) | ( ) | ( ) | ( ) |
| 2. | If I needed someone to drive me to an appointment I could find someone. | ( ) | ( ) | ( ) | ( ) | ( ) | ( ) |
| 3. | If I needed a quick emergency loan of $100, there is someone I could get it from. | ( ) | ( ) | ( ) | ( ) | ( ) | ( ) |
| 4. | If I were sick, there would be someone who would help me with my daily chores. | ( ) | ( ) | ( ) | ( ) | ( ) | ( ) |
| 5. | If I had to mail an important letter at the post office by 5:00 and couldn't make it, there is someone who could do it for me. | ( ) | ( ) | ( ) | ( ) | ( ) | ( ) |
| 6. | If I needed a ride to the airport early in the morning, I could find someone to take me. | ( ) | ( ) | ( ) | ( ) | ( ) | ( ) |
| 7. | There is someone I can call upon to fix or repair things for me if necessary. | ( ) | ( ) | ( ) | ( ) | ( ) | ( ) |
| 8. | There is someone to help me with personal care if I need it. | ( ) | ( ) | ( ) | ( ) | ( ) | ( ) |

8a). From whom do you get this kind of PRACTICAL support?

☐ family ☐ friends ☐ professionals

8b) How do you feel about the PRACTICAL support you receive (How satisfied are you)?

☐ (1) Delighted
☐ (2) Pleased
☐ (3) Mostly Satisfied
☐ (4) Mixed (about equally satisfied & dissatisfied)
☐ (5) Mostly Dissatisfied
☐ (6) Unhappy
☐ (7) Terrible

| **Information Support:** | | Never True | Almost Never True | Some-times True | Usually True | Almost Always True | Always True |
|---|---|---|---|---|---|---|---|
| | | ( ) | ( ) | ( ) | ( ) | ( ) | ( ) |
| 9. | There is someone who can give me advice about money. | ( ) | ( ) | ( ) | ( ) | ( ) | ( ) |
| 10. | There is someone who can give me honest/objective feedback about how I'm handling my problems. | ( ) | ( ) | ( ) | ( ) | ( ) | ( ) |
| 11. | When I need suggestions for how to deal with a personal problem, there is someone I can turn to. | ( ) | ( ) | ( ) | ( ) | ( ) | ( ) |
| 12. | There is someone who I feel comfortable going to for advice about sexual problems. | ( ) | ( ) | ( ) | ( ) | ( ) | ( ) |
| 13. | There is someone I can turn to for advice when I have trouble at home. | ( ) | ( ) | ( ) | ( ) | ( ) | ( ) |
| 14. | I feel that there is someone that I can share my most private worries and fears with. | ( ) | ( ) | ( ) | ( ) | ( ) | ( ) |
| 15. | If there was a family crisis, my friends would be able to give me good advice about how to handle it. | ( ) | ( ) | ( ) | ( ) | ( ) | ( ) |
| 16. | There is someone I can trust to help solve my problems. | ( ) | ( ) | ( ) | ( ) | ( ) | ( ) |
| 17. | There is someone I could turn to for advice about changing my job or finding a new one. | ( ) | ( ) | ( ) | ( ) | ( ) | ( ) |
| 18. | There is someone I can ask for information or advice related to my disability. | ( ) | ( ) | ( ) | ( ) | ( ) | ( ) |

18a) From whom do you get this kind of GUIDANCE AND INFORMATION?
☐ family ☐ friends ☐ professionals

18b) How do you feel about the GUIDANCE and INFORMATION you receive?
☐ (1) Delighted
☐ (2) Pleased
☐ (3) Mostly Satisfied
☐ (4) Mixed (about equally satisfied & dissatisfied)
☐ (5) Mostly Dissatisfied
☐ (6) Unhappy
☐ (7) Terrible

| **Emotional Support:** | | Never True | Almost Never True | Some- times True | Usually True | Almost Always True | Always True |
|---|---|---|---|---|---|---|---|
| | | ( ) | ( ) | ( ) | ( ) | ( ) | ( ) |
| 19. | If I decided on a Friday afternoon that I would like to go to a movie that night, I could find someone to go with. | ( ) | ( ) | ( ) | ( ) | ( ) | ( ) |
| 20. | There are people who invite me to do things with them. | ( ) | ( ) | ( ) | ( ) | ( ) | ( ) |
| 21. | Most people I know think highly of me. | ( ) | ( ) | ( ) | ( ) | ( ) | ( ) |
| 22. | If I wanted to go for coffee with someone, I could find someone to join me. | ( ) | ( ) | ( ) | ( ) | ( ) | ( ) |
| 23. | I know people who enjoy the same things that I do. | ( ) | ( ) | ( ) | ( ) | ( ) | ( ) |
| 24. | When I feel lonely, there is someone I could call and talk to. | ( ) | ( ) | ( ) | ( ) | ( ) | ( ) |
| 15. | I have friends or family members with whom I meet or talk regularly. | ( ) | ( ) | ( ) | ( ) | ( ) | ( ) |
| 26. | I feel that I belong in my circleof friends. | ( ) | ( ) | ( ) | ( ) | ( ) | ( ) |
| 27. | I have friends I feel very close to. | ( ) | ( ) | ( ) | ( ) | ( ) | ( ) |
| 28. | If I wanted to go out for the day, I could find someone to go with me. | ( ) | ( ) | ( ) | ( ) | ( ) | ( ) |
| 29. | People I know accept me as I am. | ( ) | ( ) | ( ) | ( ) | ( ) | ( ) |
| 30. | There is at least one person who really understands me. | ( ) | ( ) | ( ) | ( ) | ( ) | ( ) |
| 31. | There is someone I can depend on if I just need to talk. | ( ) | ( ) | ( ) | ( ) | ( ) | ( ) |
| 32. | I receive encouragement and moral support from a friend or family member. | ( ) | ( ) | ( ) | ( ) | ( ) | ( ) |
| 33. | People I know understand my disability and my problems. | ( ) | ( ) | ( ) | ( ) | ( ) | ( ) |
| 34. | There is someone who can cheer me up when I feel down. | ( ) | ( ) | ( ) | ( ) | ( ) | ( ) |

34a) From whom do you get this kind ofEMOTIONAL support? ☐ family ☐ friends ☐ professionals

34b) How satisfied are you with the EMOTIONAL support you receive?

☐ (1) Delighted
☐ (2) Pleased
☐ (3) Mostly Satisfied
☐ (4) Mixed (about equally satisfied & dissatisfied)
☐ (5) Mostly Dissatisfied
☐ (6) Unhappy
☐ (7) Terrible

# APPENDIX I

## Community Integration Questionnaire (Adapted)

## COMMUNITY INTEGRATION QUESTIONNAIRE

Please answer the following questions, thinking about how you usually do the following activities.

*1.* ***Who usually does shopping for groceries or other errands in your household?***

☐*yourself alone*
☐*yourself and someone else*
☐*someone else*

How do you feel about this (arrangement/situation)?

☐ (1) Delighted
☐ (2) Pleased
☐ (3) Mostly Satisfied
☐ (4) Mixed (about equally satisfied & dissatisfied)
☐ (5) Mostly Dissatisfied
☐ (6) Unhappy
☐ (7) Terrible

If satisfaction ranges from (3) to (7) ask:

1) How would you prefer it to be different?

________________________________________________

2) What would need to happen for you to be able to do things the way you would prefer?

________________________________________________

*2.* ***Who usually prepares the meals in your household?***

☐*yourself alone*
☐*yourself and someone else*
☐*someone else*

How do you feel about this (arrangement/situation)?

☐ (1) Delighted
☐ (2) Pleased
☐ (3) Mostly Satisfied
☐ (4) Mixed (about equally satisfied & dissatisfied)
☐ (5) Mostly Dissatisfied
☐ (6) Unhappy
☐ (7) Terrible

If satisfaction ranges from (3) to (7) ask:

1) How would you prefer it to be different?

________________________________________________

2) What would need to happen for you to be able to do things the way you would prefer?

________________________________________________

3. ***In your home who usually does the housework?***

☐ *yourself alone*
☐ *yourself and someone else*
☐ *someone else*

How do you feel about this (arrangement/situation)?

☐ (1) Delighted
☐ (2) Pleased
☐ (3) Mostly Satisfied
☐ (4) Mixed (about equally satisfied & dissatisfied)
☐ (5) Mostly Dissatisfied
☐ (6) Unhappy
☐ (7) Terrible

If satisfaction ranges from (3) to (7) ask:

1) How would you prefer it to be different?

______________________________________________

2) What would need to happen for you to be able to do things the way you would prefer?

______________________________________________

4. ***Who usually takes care of the children in your home?***

☐ *yourself alone*
☐ *yourself and someone else*
☐ *someone else*
☐ *not applicable/no children under 17 in the home*

How do you feel about this (arrangement/situation)?

☐ (1) Delighted
☐ (2) Pleased
☐ (3) Mostly Satisfied
☐ (4) Mixed (about equally satisfied & dissatisfied)
☐ (5) Mostly Dissatisfied
☐ (6) Unhappy
☐ (7) Terrible

If satisfaction ranges from (3) to (7) ask:

1) How would you prefer it to be different?

______________________________________________

2) What would need to happen for you to be able to do things the way you would prefer?

______________________________________________

5. ***Who usually plans social arrangements such as get-togethers with family and/or friends?***
☐ *yourself alone*
☐ *yourself and someone else*
☐ *someone else*

How do you feel about this (arrangement/situation)?
☐ (1) Delighted
☐ (2) Pleased
☐ (3) Mostly Satisfied
☐ (4) Mixed (about equally satisfied & dissatisfied)
☐ (5) Mostly Dissatisfied
☐ (6) Unhappy
☐ (7) Terrible

If satisfaction ranges from (3) to (7) ask:

1) How would you prefer it to be different?

______________________________________________

2) What would need to happen for you to be able to do things the way you would prefer?

______________________________________________

6. ***Who usually looks after your personal finances, such as banking or paying bills?***
☐ *yourself alone*
☐ *yourself and someone else*
☐ *someone else*

How do you feel about this (arrangement/situation)?
☐ (1) Delighted
☐ (2) Pleased
☐ (3) Mostly Satisfied
☐ (4) Mixed (about equally satisfied & dissatisfied)
☐ (5) Mostly Dissatisfied
☐ (6) Unhappy
☐ (7) Terrible

If satisfaction ranges from (3) to (7) ask:

1) How would you prefer it to be different?

______________________________________________

2) What would need to happen for you to be able to do things the way you would prefer?

______________________________________________

*Can you tell me approximately how many times **a month** you now usually participate in the following activities <u>outside your home</u>?*

7. ***SHOPPING***

☐ *less than once a month* ☐ *1-4 times a month* ☐ *5 or more times a month*

How do you feel about this (arrangement/situation)?

| | |
|---|---|
| ☐ (1) Delighted | ☐ (5) Mostly Dissatisfied |
| ☐ (2) Pleased | ☐ (6) Unhappy |
| ☐ (3) Mostly Satisfied | ☐ (7) Terrible |
| ☐ (4) Mixed (about equally satisfied & dissatisfied) | |

If satisfaction ranges from (3) to (7) ask: 1) How would you prefer it to be different?

________________________________________________

2) What would need to happen for you to be able to do things the way you would prefer?

________________________________________________

(You can begin by asking "What do you do for fun(outside your home?")

8. ***LEISURE ACTIVITIES, SUCH AS MOVIES, SPORTS, RESTAURANTS...***

☐ *less than once a month* ☐ *1-4 times a month* ☐ *5 or more times a month*

How do you feel about this (arrangement/situation)?

| | |
|---|---|
| ☐ (1) Delighted | ☐ (5) Mostly Dissatisfied |
| ☐ (2) Pleased | ☐ (6) Unhappy |
| ☐ (3) Mostly Satisfied | ☐ (7) Terrible |
| ☐ (4) Mixed (about equally satisfied & dissatisfied) | |

If satisfaction ranges from (3) to (7) ask: 1) How would you prefer it to be different?

________________________________________________

2) What would need to happen for you to be able to do things the way you would prefer?

________________________________________________

9. ***VISITING FRIENDS OR RELATIVES***

☐ *less than once a month* ☐ *1-4 times a month* ☐ *5 or more times a month*

How do you feel about this (arrangement/situation)?

| | |
|---|---|
| ☐ (1) Delighted | ☐ (5) Mostly Dissatisfied |
| ☐ (2) Pleased | ☐ (6) Unhappy |
| ☐ (3) Mostly Satisfied | ☐ (7) Terrible |
| ☐ (4) Mixed (about equally satisfied & dissatisfied) | |

If satisfaction ranges from (3) to (7) ask: 1) How would you prefer it to be different?

______________________________________________

2) What would need to happen for you to be able to do things the way you would prefer?

______________________________________________

*10.* ***ATTENDING RELIGIOUS ACTIVITIES***

| | | |
|---|---|---|
| ☐ *less than once a month* | ☐ *1-4 times a month* | ☐ *5 or more times a month* |

How do you feel about this (arrangement/situation)?

| | |
|---|---|
| ☐ (1) Delighted | ☐ (5) Mostly Dissatisfied |
| ☐ (2) Pleased | ☐ (6) Unhappy |
| ☐ (3) Mostly Satisfied | ☐ (7) Terrible |
| ☐ (4) Mixed (about equally satisfied & dissatisfied) | |

If satisfaction ranges from (3) to (7) ask: 1) How would you prefer it to be different?

______________________________________________

2) What would need to happen for you to be able to do things the way you would prefer?

______________________________________________

*11.* ***When you participate in leisure activities do you usually do this alone or with others?***

☐ *mostly alone*
☐ *mostly with staff*
☐ *mostly with friends who have disabilities*
☐ *mostly with family members*
☐ *mostly with friends who do not have disabilities*
☐ *with a combination of family and friends*

How do you feel about this (arrangement/situation)?

| | |
|---|---|
| ☐ (1) Delighted | ☐ (5) Mostly Dissatisfied |
| ☐ (2) Pleased | ☐ (6) Unhappy |
| ☐ (3) Mostly Satisfied | ☐ (7) Terrible |
| ☐ (4) Mixed (about equally satisfied & dissatisfied) | |

If satisfaction ranges from (3) to (7) ask: 1) How would you prefer it to be different?

______________________________________________

2) What would need to happen for you to be able to do things the way you would prefer?

______________________________________________

*12.* ***Do you have a best friend with whom you confide?***

☐*YES*

☐*NO*

How do you feel about this (situation)?
☐ (1) Delighted
☐ (2) Pleased
☐ (3) Mostly Satisfied
☐ (4) Mixed (about equally satisfied & dissatisfied)
☐ (5) Mostly Dissatisfied
☐ (6) Unhappy
☐ (7) Terrible

If satisfaction ranges from (3) to (7) ask: 1) How would you prefer it to be different?

2) What would need to happen for you to be able to do things the way you would prefer?

*13.* ***How often do you travel outside the home?***

☐*almost every day*
☐*almost every week*
☐*seldom/never (less than once a week)*

How do you feel about this (arrangement/situation)?
☐ (1) Delighted
☐ (2) Pleased
☐ (3) Mostly Satisfied
☐ (4) Mixed (about equally satisfied & dissatisfied)
☐ (5) Mostly Dissatisfied
☐ (6) Unhappy
☐ (7) Terrible

If satisfaction ranges from (3) to (7) ask: 1) How would you prefer it to be different?

2) What would need to happen for you to be able to do things the way you would prefer?

**14a) Are you employed?** ☐ YES ☐ NO

If yes: (a) Where do you work ______________________________

(b) What kind of work do you do? ______________________________

(c) How many hours a week do you work? ______________________________

(d) Do you receive any help to be able to do your job (e.g. job coach, special mechanical aids)?

☐ YES ☐ NO If yes, is this help ☐ permanent or ☐ temporary?

(e) How do you feel about your employment (work)?

☐ (1) Delighted
☐ (2) Pleased
☐ (3) Mostly Satisfied
☐ (4) Mixed (about equally satisfied & dissatisfied)
☐ (5) Mostly Dissatisfied
☐ (6) Unhappy
☐ (7) Terrible

If not entirely satisfied (3 to 7), how would you prefer it to be?

______________________________________________

***14b) Please choose the answer below that best corresponds to your current (during the past month) work situation:***

*☐ full-time (more than 20 hours per week)*
*☐ part-time (less than or equal to 20 hours per week)*
*☐ not working, but actively looking for work*
*☐ not working, not looking for work*
*☐ not applicable, retired due to age (see # 15)*
*☐ not applicable, in day program (see # 15)*

**15a) Are you currently going to school or participating in work training?** ☐ YES ☐ NO

If yes, please describe______________________________________________

(a) How do you feel about your school/work training?

☐ (1) Delighted
☐ (2) Pleased
☐ (3) Mostly Satisfied
☐ (4) Mixed (about equally satisfied & dissatisfied)
☐ (5) Mostly Dissatisfied
☐ (6) Unhappy
☐ (7) Terrible

If not entirely satisfied (3 to 7), how would you prefer it to be?

______________________________________________

***15b)*** ***Please choose the answer below that best corresponds to your current (during the past month) school or training program situation:***

*☐full-time* *☐not attending school or training program*
*☐part-time* *☐not applicable (see # 14)*

**16a)** **Are you involved with volunteer work?** ☐ YES ☐ NO

If yes: (a) Please describe________________________________________

(b) Do you receive any help to be able to do your volunteer work? ☐ YES ☐ NO

If yes, is this help permanent or temporary? ☐ Permanent ☐ Temporary

(c) How do you feel about your volunteer work?
☐ (1) Delighted
☐ (2) Pleased
☐ (3) Mostly Satisfied
☐ (4) Mixed (about equally satisfied & dissatisfied)
☐ (5) Mostly Dissatisfied
☐ (6) Unhappy
☐ (7) Terrible

If not entirely satisfied (3 to 7), how would you prefer it to be?

________________________________________

***16b)*** ***In the past month, how often did you engage in volunteer activities?***
*☐never*
*☐1-4 times*
*☐5 or more*

**17.** **Are you responsible for looking after your home, for example doing housework or looking after the yard?** ☐ YES ☐ NO

If yes: a) Do you receive any help to be able to do your work around the house?

☐ YES ☐ NO If yes, is this help ☐ Permanent or ☐ Temporary

(b) How do you feel about doing your work around the house?
☐ (1) Delighted
☐ (2) Pleased
☐ (3) Mostly Satisfied
☐ (4) Mixed (about equally satisfied & dissatisfied)
☐ (5) Mostly Dissatisfied
☐ (6) Unhappy
☐ (7) Terrible

If not entirely satisfied (3 to 7), how would you prefer it to be?

________________________________________

# APPENDIX J

## Community Integration Measure

## COMMUNITY INTEGRATION MEASURE

Please describe the community that you are currently living in.

For the following 10 questions, please indicate whether you agree or disagree.

1. I feel like part of this community, like I belong here.

____________________

| | | | | |
|---|---|---|---|---|
| always agree | sometimes agree | neutral | sometimes disagree | always disagree |

2. I know my way around in this community.

____________________

| | | | | |
|---|---|---|---|---|
| always agree | sometimes agree | neutral | sometimes disagree | always disagree |

3. I feel like I know the rules in this community and I can fit in with them.

____________________

| | | | | |
|---|---|---|---|---|
| always agree | sometimes agree | neutral | sometimes disagree | always disagree |

4. I feel that I am accepted in this community.

____________________

| | | | | |
|---|---|---|---|---|
| always agree | sometimes agree | neutral | sometimes disagree | always disagree |

5. I feel that I can be independent in this community.

____________________

| | | | | |
|---|---|---|---|---|
| always agree | sometimes agree | neutral | sometimes disagree | always disagree |

6. I like where I'm living now.

____________________

| | | | | |
|---|---|---|---|---|
| always agree | sometimes agree | neutral | sometimes disagree | always disagree |

7. There are people I feel close to in this community.

____________________

| | | | | |
|---|---|---|---|---|
| always agree | sometimes agree | neutral | sometimes disagree | always disagree |

8. I know a number of people in this community well enough to say hello and heve them say hello back.

____________________

| | | | | |
|---|---|---|---|---|
| always agree | sometimes agree | neutral | sometimes disagree | always disagree |

9. There are things that I can do in this community for fun, in my free time.

____________________

| | | | | |
|---|---|---|---|---|
| always agree | sometimes agree | neutral | sometimes disagree | always disagree |

10. I have something to do in this community during hte main part of my day that is useful or productive.

____________________

| | | | | |
|---|---|---|---|---|
| always agree | sometimes agree | neutral | sometimes disagree | always disagree. |

(McColl, Davies, Karlovits, Carlson, Johnston, Minnes, Shue & Willer, 1996)

# APPENDIX K

## Affect Balance Scale

## AFFECT BALANCE SCALE

"Now I have some questions about how you have been feeling recently. You can just answer "yes" or "no". During the past few weeks did you ever feel..."

| | YES | NO | | Once | Several Times | A lot |
|---|---|---|---|---|---|---|
| 1. | ☐ | ☐ | Particularly excited or interested in something? | ☐ | ☐ | ☐ |
| 2. | ☐ | ☐ | Did you ever feel so restless that you couldn't sit long in a chair? | ☐ | ☐ | ☐ |
| 3. | ☐ | ☐ | Proud because someone complimented you on something you had done? | ☐ | ☐ | ☐ |
| 4. | ☐ | ☐ | Very lonely or remote from other people? | ☐ | ☐ | ☐ |
| 5. | ☐ | ☐ | Pleased about having accomplished something? | ☐ | ☐ | ☐ |
| 6. | ☐ | ☐ | Bored? | ☐ | ☐ | ☐ |
| 7. | ☐ | ☐ | On top of the world? | ☐ | ☐ | ☐ |
| 8. | ☐ | ☐ | Depressed or very unhappy? | ☐ | ☐ | ☐ |
| 9. | ☐ | ☐ | That things were going your way? | ☐ | ☐ | ☐ |
| 10. | ☐ | ☐ | Upset because someone criticized you? | ☐ | ☐ | ☐ |

(Ask this question for each item to which the respondent answered "yes"). "You mentioned that you had felt __________. How often during the past few weeks did you feel this way? Was is just once, several times, or a lot of times?"