

PHYSICAL MOBILITY AND AGING IN INTELLECTUAL DISABILITY

by

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Abstract

Background: The growing population of older adults with intellectual disabilities is likely to experience secondary disabilities that affect well-being. Despite the established importance of mobility in the general population, there is little evidence of a scientific base on mobility limitations for people with intellectual disabilities.

Objectives: The aim of this study was to better understand mobility limitations in adults with intellectual disabilities, age 45 and over, by describing the prevalence and severity of mobility limitations and determining the association with living in a high support setting.

Methods: A systematic review of published literature on mobility limitations among adults with intellectual disabilities was conducted using a pre-determined search and extraction strategies. A cross-sectional study was then conducted among a representative sample of adults, age 45 and over with intellectual disabilities in South Eastern Ontario. Data was collected through standardized proxy response telephone surveys and analyzed descriptively to determine the prevalence and severity of mobility limitations in this population. A multivariate logistic regression model was then used to examine the association between mobility limitations and residential status.

Results: The systematic review identified 32 publications that met all inclusion criteria. Publications were generally not focused on mobility, cross-sectional in design and few investigators addressed key methodological features in their report. Original data was collected for 128 older adults with intellectual disabilities. The prevalence of mobility limitations varied according to the definition employed. Using comparable definitions, this prevalence was higher than what is seen in the general Canadian population. The prevalence of mobility limitations was not found to increase with age but was greater in

females than males. People with intellectual disabilities and mobility limitations had 3.6 times greater odds of living in high support residential settings than those without mobility limitations. This difference was statistically significant.

Conclusion: Past epidemiological research on mobility limitations for people with intellectual disabilities is of poor quality. In addressing these limitations, this study found that mobility limitations are common among people with intellectual disabilities and are associated with meaningful outcomes, such as the place in which a person lives.

Co-Authorship Statement

This thesis presents research conducted by Shaun Cleaver, under the supervision of H el ene Ouellette-Kuntz and Duncan Hunter.

Manuscript 1: Physical Mobility Limitations in Adults with Intellectual Disabilities: A Systematic Review.

The idea to systematically review published epidemiological literature on mobility limitations of people with intellectual disabilities was initially proposed by Shaun Cleaver. Duncan Hunter supported this idea and provided methodological guidance in the conduct of a systematic review. H el ene Ouellette-Kuntz provided content guidance in the field of intellectual disability. The establishment of a protocol, publication search and strategy and the creation of an extraction form was the work of Shaun Cleaver with feedback from Duncan Hunter and H el ene Ouellette-Kuntz. The process of screening and selecting articles was performed by Shaun Cleaver. Included articles were reviewed by combinations of two of the three individuals involved and all partook in discussions to refine methods and operational definitions. The first manuscript was written by Shaun Cleaver with constructive feedback from Duncan Hunter and H el ene Ouellette-Kuntz.

Manuscript 2: The Prevalence and Severity of Physical Mobility Limitations in Older Adults with Intellectual Disabilities and Manuscript 3: The Relationship between Mobility Limitations and the Places where Older Adults with Intellectual Disabilities Live.

The motivation to conduct a primary research study on the prevalence of mobility limitations among people on the Geographic Registry in Intellectual Disability was the

product of a discussion between H  l  ne Ouellette-Kuntz and Shaun Cleaver. H  l  ne Ouellette-Kuntz proposed that this study seek to further understand the importance of mobility limitations by examining the association with a meaningful outcome, residential setting. Shaun Cleaver designed the protocol for this study with feedback from H  l  ne Ouellette-Kuntz and Duncan Hunter. Contact with agencies was established by Maureen McDonald, community liaison at the South Eastern Ontario Community University Research Alliance in Intellectual Disabilities (SEO CURA), and maintained by Shaun Cleaver. Shaun Cleaver and Sarah Moffat, research assistant at SEO CURA, conducted all interviews. Data entry was performed by Shaun Cleaver with the assistance of Robyn Goldberg, Hilary Brown and Grace Tso, research assistants at SEO CURA. Data analysis was performed by Shaun Cleaver. Manuscripts two and three were written by Shaun Cleaver with significant involvement of H  l  ne Ouellette-Kuntz and Duncan Hunter.

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This project would not have been possible without the help of the staff and collaborators at the South Eastern Ontario Community-University Research Alliance in Intellectual Disabilities. Thank you for creating a stimulating environment and for helping me take care of the details. In similar fashion, I would like to thank this study's participants, respondents and agency contacts.

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Outside of the Queen's world, I would like to recognize the role played by my colleagues in clinical practice, professional leadership, global health and social justice. Thank you for reminding me why this degree is important.

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Chapter 1: General Introduction

General Overview

Mobility refers to the quality of moving freely. When applied to human activity this term refers to the ability of an individual to move from place to place, generally by walking, but occasionally through the use of another medium, such as a wheelchair or a scooter. (Bussmann & Stam, 1998) The spectrum of abilities related to mobility is wide and multidimensional. It is affected by a person's body structures and functions, and can be further modified by equipment. (World Health Organization) When a person's ability to move from place to place is below accepted norms or insufficient for what is required for participation in necessary or desirable activities, mobility is said to be limited.

Consideration of the word "free" in the definition of mobility is important. If a person's capacity to be mobile in an unmodifiable environment is insufficient, the person will have to either forego the activity or seek the assistance of others in order to safely and effectively complete the task. Limited mobility can thus increase the dependence of an individual upon others or preclude participation. In practice, this situation can be addressed through compensation (changing the environment) or remediation (improving the underlying body functions as to improve mobility).

People with a pre-existing disability are particularly susceptible to the effects of additional limitations. People with intellectual disabilities have impaired intellectual functioning associated with impaired adaptive behaviour that begins prior to age 18. (American Association of Intellectual and Developmental Disabilities, 2002) This disability is therefore lifelong by nature. Recently there has been a substantial increase in the life expectancy of people with intellectual disabilities and a resulting increase in the

population of older adults with intellectual disabilities. (McCallion & McCarron, 2004) With aging comes physical changes. (Nochajski, 2000) Research on aging for people with intellectual disabilities is a small but growing field. It has been established that people with intellectual disabilities generally age in a similar manner to the general population, (Davidson et al., 2004) but that changes may come earlier, some health-related conditions may be more common, (van Schrojenstein Lantman-de Valk, 2005) and these processes may be modified by related to etiologic syndromes such as Down syndrome or cerebral palsy. In the general population there is a notable rise in the prevalence of mobility limitations among adults as they get older. (Statistics Canada, 2002) The extent to which this phenomenon is similar or different for adults with intellectual disabilities has not yet been rigorously addressed.

Our current era is one of changing environments for people with intellectual disabilities. Similar to many other jurisdictions in industrialized countries, the Province of Ontario is in the final stages of a period of deinstitutionalization for people with intellectual disabilities. All of the remaining residents of the province's last three long-stay institutions will be living in the community by the end of 2009. (Livingston, 2004) Many of these residents are over the age of 55 and have multiple disabilities.

At the same time there are many people with disabilities who never entered into the institutional system, many having continued to live with their families, particularly their parents, well into adulthood. This group represents the first large-scale wave of a process that will only grow: older people with intellectual disabilities who have grown up in the community and are dependent upon their parents who are older still.

As previously mentioned, a limitation becomes a problem when present in an environment that is not accommodating. On a societal level, there has been the growth of a “new” population of older people with intellectual disabilities; people who have a lifelong disability and could possibly acquire new limitations as part of the aging process. At the same time there has been an emergence of a “new” environment; community-based living, with associated support needs, for older adults with intellectual disabilities. The interaction of these two factors creates new opportunities for individuals and families. Unfortunately, however, there could also be substantial problems if the environment is not accommodating to the limitations.

This thesis seeks to further the understanding of mobility limitations among older adults with intellectual disabilities. It is designed to follow a logical progression, with each component of the thesis intended inform subsequent processes. It is comprised of: 1) A systematic review of relevant literature, 2) A description of the extent that people with intellectual disabilities in South Eastern Ontario experience mobility limitations and finally 3) An analysis of the relationship between the presence of a mobility limitation and where a person lives.

Empirical objectives

1. To determine the prevalence and severity of mobility limitations in adults with intellectual disabilities, age 45 and over.
2. To examine the association between mobility limitations and living in high support residential settings in adults with intellectual disabilities, age 45 and over.

Thesis Organization

This thesis conforms to the framework provided by the “General Forms of Theses” as outlined by the School of Graduate Studies at Queen’s University. (School of Graduate Studies and Research, 2007) The second chapter of this thesis is the first manuscript, a systematic review of published literature describing the epidemiology of mobility limitations among adults with intellectual disabilities. Chapter three is the second manuscript, and addresses objective 1. This manuscript has been prepared for submission to the Journal of Applied Research in Intellectual Disabilities. The fourth chapter, third manuscript, addresses objective 2 and has been prepared for submission to the Journal of Policy and Practice in Intellectual Disabilities. Chapter five contains general conclusions, discussion and a summary of the study. Additional documentation supporting the methods and conduct of this project is found in the Appendices.

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Chapter 2: Manuscript 1

Title:

Physical Mobility Limitations in Adults with Intellectual Disabilities: A Systematic Review

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Background: Mobility limitations increase with age in the general population. Despite a growing population of older adults with intellectual disabilities, mobility is rarely explored in the intellectual disability literature.

Specific Aim: To identify and summarize primary literature addressing mobility limitations in adults with intellectual disabilities.

Materials and Methods: This study was a systematic review of the literature addressing the epidemiology (incidence and prevalence) of mobility limitations among adults with intellectual disabilities. Four electronic databases were screened from January 1980-May 2007 for publications according to pre-defined inclusion/exclusion criteria. Additional sources were consulted. Two reviewers extracted data from each of the included articles.

Results: Thirty-two publications representing 31 studies were ultimately included. Most included studies did not focus on mobility but were conducted for other purposes. All studies were conducted in industrialized countries. Only one study used a longitudinal design; the remainder were cross-sectional. Few investigators reported upon the representativeness of the sample or the validity of the measurement tool. Some studies have, however, analyzed the prevalence of mobility limitations across age, gender and etiologic groups.

Conclusion: Although there are numerous publications on the topic, the epidemiological evidence base assessing mobility limitations among adults with intellectual disabilities is weak.

Introduction

Physical mobility refers to the human activity of moving from place to place, generally by walking or using a wheelchair. (Busmann & Stam, 1998) A person's ability to be mobile depends upon his or her body functions and structures and will influence the person's ability to participate in life situations. (World Health Organization) Problems with this activity are broadly classified as mobility limitations. In practice, this term requires further definition as an individual's conceptualization of a mobility limitation may be dependent upon his or her experiences, needs, environment and values. Generally speaking, however, this disability can be considered a level of mobility-related function that is below that of the accepted norm. In the general population, mobility limitations increase with age. (Statistics Canada, 2002) Immobility (i.e. limited mobility) has been considered to be among the "Four I's" that stand as the pillars of geriatrics, alongside incontinence, instability and intellectual impairment. (Dwolatzky, 2006)

For people with a pre-existing disability, the addition of subsequent disabilities can create a compounding effect that limits participation and involvement even further. By definition, people with intellectual disabilities have co-impairments in intellectual functioning and adaptive behaviour with onset prior to age 18. (American Association of Intellectual and Developmental Disabilities, 2002) With an established lifelong disability, people with intellectual disabilities are likely to experience the compounding effects of multiple disabilities as they age. Increasing life expectancies and a rapidly growing population of older adults with intellectual disabilities (McCallion & McCarron, 2004) make secondary disabilities in this population an important and timely issue.

Mobility limitations are of particular note to people with intellectual disabilities. The nature of the etiologies of some intellectual disabilities has a direct impact upon mobility. For example, cerebral palsy is a condition that often affects both intellectual and motor functioning. In other cases, the effects of an intellectual disability upon mobility could be more indirect. Certain physical differences are seen in people with Down syndrome, such as ligamentous laxity or premature aging, which could impact upon the development or progression of mobility limitations. (Carmeli et al., 2002) A cognitive impairment in and of itself may have effects upon fitness or health conditions that could in turn influence mobility.

A scan of recent review articles on health and aging for adults with intellectual disabilities uncovered regular mention of the importance of mobility. (Haveman, 2004; Hatzidimitriadou & Milne, 2005; van Schrojenstein Lantman-de Valk, 2005; Walsh, 2005) Unfortunately, statements on mobility are based exclusively on one (Walsh, 2005) or two sources, (Haveman, 2004) on original research that does not address mobility directly, (van Schrojenstein Lantman-de Valk, 2005) or without any source literature at all. (Hatzidimitriadou & Milne, 2005) Older review articles have more comprehensive reviews on mobility, (McCarthy & Mullan, 1996; Nochajski, 2000) but these reviews are based on limited and rather weak original research.

The objective of this study was thus to identify and summarize research on the occurrence of mobility limitations among adults with intellectual disabilities. A systematic strategy was used to review published literature addressing the epidemiology (incidence or prevalence) of mobility limitations of adults with intellectual disabilities. The emphasis was on describing the number of publications, analyzing key design and quality factors of

the included studies and identifying analyses of variables within studies that could influence the incidence or prevalence of mobility limitations.

Materials and Methods

This systematic review sought to identify publications (peer-reviewed journal articles and books) that quantified the incidence or prevalence of mobility limitations in adults with intellectual disabilities. Four major databases of medical literature (Medline, Embase and PsychInfo from January 1980 to May 2007; CINAHL from January 1982 to May 2007) were searched using the following combination of subject headings: intellectual disability and (physical mobility or aging) with results restricted to adults (≥ 18 years of age). The actual terms varied depending on database. The full search strategies were reviewed by a scientific librarian to ensure their appropriateness. This initial search was not limited by language.

The titles and abstracts (where available) of all identified publications were screened by one reviewer. Publications with titles and/or abstracts that mentioned the analysis of mobility (or a synonym), activities of daily living, motor function or physical health in people with intellectual disabilities were retained for full-text review. The reference lists of review articles on the health of adults with intellectual disabilities were also scanned. In addition, researchers were contacted through the International Association for the Scientific Study of Intellectual Disabilities (IASSID) Special Interest Research Group on Aging for any publications that may have been undetected through other search methods.

Full-text publications were screened in detail by one reviewer to determine their eligibility. The ultimate inclusion/exclusion criteria for publications are presented in Table 1. Although specific study design was not a basis for inclusion or exclusion, only publications that quantified the epidemiology (incidence or prevalence) of mobility limitations were included. Accordingly, studies that measured physical fitness, (Rimmer, 1996) gait characteristics, biomechanics (Carmeli et al., 2002) or presented mobility findings as a group average instead of in terms of individual limitations (Janicki & Jacobson, 1986) were not included. Although articles in any language were permitted at the database search stage, only those confirmed to be in English or French were retained to accommodate the language capabilities of reviewers. Studies with a mixed population of adults and children or people with and without intellectual disabilities were initially retained but excluded in the full-text review if it was found that there was no separate analysis for a discrete population of adults with intellectual disabilities. Finally, studies in which the population was defined according to mobility (Sackley et al., 2005) were excluded.

Two reviewers extracted data from each study using a standardized extraction form that confirmed inclusion and sought information on the study's population and sample, methods, results and quality. Disagreements were resolved through consensus. Quality was assessed on a yes/unclear/no basis for two factors deemed important to studies of incidence and prevalence: the representativeness of the study sample to the underlying population and the validity of the tool used to identify mobility limitations. (Glasziou et al., 2001) As a systematic review is essentially a study of studies through their reports, the focus of the quality measurement was on the exploration of these factors in the

publication. Studies for which investigators discussed the representativeness of the sample in the text were scored as ‘yes’ for that item. Studies for which there was a comparison of the baseline population and the sample but no explanation as to the representativeness were scored ‘unclear.’ All other studies were scored ‘no’ on the quality item addressing representativeness. If investigators stated that a tool was valid or reliable and offered a citation, the validity quality factor was scored as ‘yes.’ If the tool used to quantify mobility was identified and a reference was provided, or if an attempt to validate the tool was made in the same study the reporting of the validity was scored as ‘unclear.’ All other studies were scored as ‘no’ for this quality factor.

Data were analyzed in a descriptive format. Publications were summarized using the characteristics provided by authors. All studies for which a final total prevalence could be calculated were entered into a balance sheet. This technique allows heterogeneous information to be condensed and offers a platform for initial comparisons. (Mulrow et al., 1998) Variables with multiple categories were collapsed into two or three categories to facilitate comparison. Studies that analyzed the epidemiology of mobility limitations in subgroups of their sample were further analyzed. Global observations on the literature were also made.

Results

A total of 1994 publications were identified through the databases and an additional 11 publications were identified through other sources. The flow of citations through the identification process is outlined in Figure 1. Forty-five publications were retained for extraction. All of these publications were in English. Thirteen publications were

subsequently excluded after discussions between reviewers. Four publications from the United States were excluded as their study population was people with developmental disabilities and a small portion of participants did not have intellectual disabilities. (Brzezniak, 1998; McKee & Bodfish, 2000; Hsieh et al., 2001; Traci et al., 2002) In two studies mobility was quantified as “gait decline” without indicating the timeframe in which the decline occurred, allowing for neither the calculation of incidence nor prevalence of mobility limitations. (Prasher, 1995; Prasher, 1996) In one study, mobility was quantified using a clinical outcome measure but the authors did not use the instrument to categorize mobility limitations. (Bruckner & Herge, 2003) Another study was performed with participants with Down syndrome who had hip radiographs in their medical records. (Hresko et al., 1993) It was suspected that people with mobility limitations were far more likely to have had hip radiographs performed; therefore the study was excluded for having a population chosen on the basis of their mobility status. A further five publications were excluded during the extraction phase because of important inconsistencies in the report, for example, data in tables or figures that were contradicted in the accompanying text, (Strauss & Zigman, 1996; Tyler et al., 2000) and a stated prevalence of mobility limitations or other important characteristics that is inconsistent throughout the text. (Hogg et al., 1988; Cooper, 1998; McCarron et al., 2005) Ultimately, 32 publications were included in the review. In some cases the same study was presented in multiple publications with only minor differences. In this case, only the most comprehensive publication was reviewed. Examples include data from the New York Office of Mental Retardation and Developmental Disabilities, (Janicki & MacEachron, 1984; Jacobson et al., 1985b) from community homes in one NHS Trust in

England (Jones et al., 1996; Jones et al., 1997) and from service providers in Israel. (Lifshitz, 2001; Lifshitz & Merrick, 2004) In 1989 and 1990, Haveman and Maaskant published a series of papers stemming from one study in the Netherlands. (Haveman & Maaskant, 1989; Haveman et al., 1989; Maaskant & Haveman, 1989; Maaskant & Haveman, 1990) Because each paper addresses a different study population through a unique combination of participants, these are presented as four publications. These studies should not, however, be considered to be independent. In addition, there were two publications that used data collected from 1987 onwards from the Leicestershire learning disabilities register. (McGrother et al., 1996; Tyrer et al., 2007) From the methods reported, it appeared that many of the participants from the second study were also analyzed in the first. Whereas Tyrer et al (2007) report on a larger sample using a clearer definition of mobility impairment, McGrother et al (1996) offer different comparison groups for mobility prevalence and a perspective of the effect using a different definition upon the prevalence of mobility limitations. Both of these publications are presented in the results, but again it must be recognized that they are not completely independent.

In only one included publication was mobility analyzed in both a cross-sectional and longitudinal manner. (Evenhuis, 1997) All other studies analyzed mobility in a cross-sectional fashion to provide a prevalence of mobility limitations. Most studies were observational in nature although one included publication presented baseline data on an intervention (Podgorski et al., 2004) and another included study reported upon the characteristics of the sample during a validation study. (Jones et al., 1997)

The role of the mobility limitation variable was different among studies. No attempt was made to clearly classify this role, but it could be broadly grouped as 1) a main outcome of

interest, (Evenhuis, 1997) 2) one outcome among many, (Hand 1996) 3) an exposure, (Lohiya et al., 2004) or 4) a descriptor of study participants. (O'Neill, 1985) Due to this variety, the attention devoted to mobility in these publications was highly variable; ranging from as little as one sentence to as much as a substantial part of all sections of the publication. For the most part, these studies were not focused on mobility limitations. The word “mobility” appeared in the title of only one publication. (Evenhuis, 1997) Broader, but similar, terms such as “motor disability” or “physical impairments” appeared in the titles of another four publications. The titles of most articles addressed health, medical co-morbidities or seemingly unrelated phenomena such as osteoporosis.

Table 2 presents a summary of cross-sectional studies for which a pooled prevalence was reported or could be calculated. The characteristics presented in Table 2 are dependent upon those reported by authors. Some variables likely to confound results, such as age and gender distribution were well-reported among studies; others, such as the prevalence of cerebral palsy were often neglected. The prevalence of level or degree of intellectual disability was generally well-reported, but the categories and definitions used varied widely. Many studies were restricted to a given type of residential setting and most others quantified the distribution of residential settings of participants in the results. The presence of epilepsy, Down syndrome and visual impairments were well-reported. One study used different age ranges for men and women that make the pooled mean age and gender balance deceiving. (Jaffe et al., 2005) The results of Jaffe et al (2005) are therefore presented as two studies; one for men and women 60 years and over, and another for men between the ages of 20 and 59. One study was restricted to women with Rett syndrome. (Witt-Engerstrom & Hagberg, 1990) This condition affects motor

function by definition, but the extent of these effects is variable. There is debate as to whether people with Rett syndrome actually have an intellectual disability, but they often receive services from the same provider agencies and are conventionally included in this population. Publications which report upon the prevalence of mobility limitations in subgroups, but where a pooled prevalence was not available, are presented in Table 3.

The following section highlights studies in which there was an intra-study comparison of subgroups. Ten publications analyzed the prevalence of mobility limitations across age groups. Table 4 presents the findings of these studies. Unless otherwise indicated, the authors did not report the statistical significance of any trends or differences between age groups. Some studies stratified the analysis of age by another characteristic. Haveman and Maaskant (1989) present results separately for people with and without Down syndrome. Since there is neither a statistical test showing differences between groups nor an indication of differential sampling based upon Down syndrome status, the groups are pooled to present the prevalence by age group. Three studies present results separately for people with different levels of intellectual disability. (Janicki & MacEachron, 1984; Maaskant & Haveman, 1990; Moss, 1991) Differential age trends were observed for various levels of intellectual disability in two of these studies, (Maaskant & Haveman, 1990; Moss, 1991) although this was only tested for statistical significance in one. (Maaskant & Haveman, 1990) The information provided in Maaskant and Haveman (1990) and Moss (1991) does not permit the calculation of a pooled prevalence by age category.

An additional four studies sought to compare mobility limitations across levels of intellectual disability (without necessarily accounting for age). The range, categorization

and definitions of levels of intellectual disability varied between these studies making direct comparison difficult. Similar to Maaskant and Haveman (1990), Janicki (1984) found a higher prevalence of mobility limitations among the group with more severe intellectual impairment. Interestingly, the reverse was found in 3 studies, (Gostason, 1985; O'Neill, 1985; Day, 1987) and one study found no relationship between mobility limitations and level of intellectual disability. (Jacobson et al., 1985a) Statistical tests comparing the prevalence across levels of intellectual disability were not performed in any of these studies.

Only two studies reported findings separately for men and women. Looking exclusively at participants 60 years of age and older, Jaffe (2005) found a higher prevalence of mobility limitations among females, although this difference was not statistically significant (65.8% vs. 57.6%; Chi-square, $p=0.41$). Tyrer et al (2007) report a higher prevalence of mobility limitations among females (43% vs. 31%), although no statistical tests are given. One study compared people with Down syndrome to those without. (Haveman et al., 1989) The overall prevalence of mobility limitations was lower for people with Down syndrome (9% vs. 16%), but this was not tested statistically. This study shows an apparent trend where the prevalence of mobility limitations and Down syndrome is modified by age: mobility limitations being less common among people with Down syndrome under 50 years of age and much more common for those 60 years of age and over. As there were only seven participants with Down syndrome age 60+, this result cannot be considered conclusive.

There were three studies which compared mobility limitations across residential settings. In the southern Netherlands during the late 1980s, Haveman (1989) found a higher

prevalence of mobility limitations among people living in institutions than those in group homes (Chi-square, $p < 0.001$). In England during the late 1980s and early 1990s, the prevalence of mobility limitations was also found to be lower among adults with intellectual disabilities living in the community than among those in hospitals, although this was not tested statistically. (McGrother et al., 1996) Freedman and Chassler (2004) found a differential prevalence of mobility limitations across residential settings in one US state in 2000. The prevalence of mobility limitations among people living with family was 7%, whereas it was 11% in community residences and 38% in an institution.

Mobility limitations among people with fair/poor overall health were compared to those with excellent/good health in one study. (Freedman & Chassler, 2004) The results showed that limitations were more prevalent in the group with worse health (22% vs 13%, Chi-square, $p < 0.01$).

One study included in this review analyzed mobility using a longitudinal design. Heleen Evenhuis, a family physician in the Netherlands, monitored the mobility status of 70 of her patients with intellectual disabilities, aged 60 years and over, during a 10-year period. (Evenhuis, 1997) The results of this study are stratified by the presence of a mobility limitation at the start of each interval and are presented in 5-year intervals. Forty participants died during the study period, with a higher cumulative mortality among those with limited mobility at the start of intervals. Of the 30 survivors, 18 were able to ambulate without help at the conclusion of the study period. The author provides a list of 15 variables that she interpreted as being explanatory of the decline in mobility among participants. Such a list, however, does not account for a process that is likely to be multifactorial, nor does it allow for a thorough analysis of the influence of any one variable.

Discussion

The main objective of this systematic review was to identify and summarize literature on the epidemiology of mobility limitations in people with intellectual disabilities. A reasonable number of publications, 32, were identified and met all inclusion criteria. These publications represented 31 studies. Only one study used a longitudinal design; all others quantified mobility limitations using a cross-sectional design. Most of these publications did not have mobility as their main focus and few authors reported upon the representativeness of the study sample. Seven studies quantified mobility limitations using tools that were named and used in prior research. None of the included studies reported upon the validity or reliability of the measurement approach. An additional 13 publications addressed mobility in people with intellectual disabilities but were ultimately excluded for presenting results in a format not amenable to this review, including a small percentage of participants without intellectual disabilities or the presence of inconsistencies in the publication.

A key strength of this review was the use of a systematic search strategy to identify literature. Using such a strategy makes the search reproducible and reduces the probability of bias in study selection. (Counsell, 1998) Nearly one quarter of the extracted publications (11 of 45), however, were not found through the database search. A post-hoc review of these publications revealed that eight of these were peer-reviewed journal articles that were indexed on the databases used, but they were not detected in the search. This could be indicative of a search strategy that was insufficiently sensitive to identify all appropriate literature from the databases. Systematic reviews generally aim to identify all applicable research meeting certain criteria to answer a given question,

including 'grey' literature. (Glasziou et al., 2001) Although it is possible that a wealth of grey literature exists on the subject of physical mobility for people with intellectual disabilities, this study focused on published literature to maintain an efficient and systematic search strategy. Nonetheless, high quality analyses focusing on the subject of mobility limitations are more likely to be published and indexed on databases. As it was, most relevant studies did not have mobility limitations as a main focus. Although the search may not have had ideal sensitivity, a more sensitive search would have required scanning a much larger pool of potentially included research. To do so was well beyond the resources available for this project. Moreover, the ultimate gain in quality studies would likely be minimal and not influence conclusions. Systematic review methodology suggests that two reviewers scan and select articles for inclusion. (Glasziou et al., 2001) Due to limited resources, only one reviewer was available for this process.

The definition of an epidemiological study on mobility limitations used in this review was very inclusive; a study needed only to quantify the frequency (prevalence) or the rate of development (incidence) of mobility limitations in adults with intellectual disabilities. Thirty-two publications were found to meet all inclusion/exclusion criteria for the period 1980-2007. Although this number of publications does constitute a body of findings, it is small considering the volume of research published during this timeframe. In part, this could be due to the area of emphasis of primary investigators. An array of publications addressing outcomes interrelated to mobility were found during the search; examples include physiological systems (i.e. musculoskeletal problems), pathologies (i.e. dementia or arthritis), other activities of daily living or composite scores of gross motor function. There were also studies that analyzed mobility in similar populations (such as people with

cerebral palsy) where a sizeable portion of the sample did not have an intellectual disability. (Janicki, 1989; Dauvergne et al., 2007) All of the included studies were conducted in industrialized countries and 71% (22 of 31) were the product of English-speaking countries. This could be reflective of more or better research in industrialized and Anglophone countries or a detection bias. The initial search phase of the study did not exclude publications in other languages, but a total of seven articles with promising abstracts were excluded due to having been written in Japanese, Spanish or Norwegian. If the probability of acceptance for review was the same for these publications as for those in English or French, one or two would have been retained for extraction, an insufficient number to affect this geographic and cultural imbalance.

Few included studies satisfied the quality criteria established for this review. In part, this is a reflection of the definition: the focus was upon *what was reported*, not necessarily the underlying truth. The decision to focus upon reporting was made to avoid negatively biasing the quality of studies where explanatory documents were published in another language or difficult to obtain. Having reviewers seek primary sources would also raise the question of “What level of psychometric assessment constitutes sufficient validity?” With such a wide pool of measurement approaches being used among studies this would be a difficult process to standardize. Nonetheless, in an accurate study of incidence or prevalence, the primary investigators should have considered these issues and reported upon them. To do so is a reflection of quality. With regards to studies being representative, many authors may have chosen to not discuss the issue since the sample effectively was an entire population. Even in these cases, however, there was still a gradient in representativeness. In some studies the entire population was used as a

sample but participation was incomplete, likely skewing the representativeness. In other studies, the participation was complete, but the population was limited; for example the participants of a given program or residential centre, with no indication of how this population compares to any greater population (i.e. programs or residential centres in general). Therefore, for standardization purposes, quality was determined by the author addressing the issue in the report.

The pooled prevalence of mobility limitations varied between 3% and 63% (if we exclude the study of women with Rett syndrome as an outlier). A partial explanation to this variation is the differences in the study populations and samples, including: the prevalence of other disabilities, the distribution of age, gender or level of intellectual disability and the use of specific residential settings or programs that may serve people with a certain profile of disability. After all, the intellectual disability population is heterogeneous. Substantial international and temporal variation in definitions and service provision models further complicates the comparison of studies. Even within a country and a well-defined population there could be a significant cohort effect upon mobility limitations as the health and life expectancy of adults with intellectual disabilities has improved greatly in recent years. Through the use of the table it is possible to compare the findings of different studies, but because of the substantial variation in studies this should be done only as part of hypothesis generation or preliminary analysis. This report also highlights studies that made internal comparisons of the prevalence of mobility limitations between groups. This was performed to offer background on the comparisons made in past literature, but this analysis cannot be considered conclusive as there was no consideration for residual confounding within individual studies.

The biggest cause for variation among studies, however, is likely related to measurement. Mobility limitations were loosely defined in studies and the measurement approach was rarely justified. In some cases the strategy used may have been deemed apparent. For example, dichotomizing a population into those who use wheelchairs and those who do not may seem to be an inherently valid method of discriminating two levels of mobility and function. How would we then classify a person who walks independently in the home but tires quickly and therefore uses a wheelchair on outings? What about the person who has excellent command of a wheelchair and is able to independently overcome physical barriers? How do we account for people with very poor mobility but do not use wheelchairs out of choice or the lack of availability? The poor use of definitions came to the forefront in one included study where mobility status was divided into three categories, the most restricted defined as “not being able to walk independently and at best he can move by wheelchair.” (Maaskant & Haveman, 1989) The percentage of people meeting this definition ranged from 1-7% across age categories. The results of individual items measured in a composite scale to measure motor function were presented in the same publication. One item that was reported upon was percentage of people not able to walk independently. Here the results range from 0.0-0.7%. Since these results reflect “different” measurement strategies, the study was not excluded from the review for inconsistent reporting; the apparent problem is measurement that is inconsistent, and therefore inaccurate. More problematic yet, the authors do not address this discrepancy in the report.

The main implications of this systematic review are directed towards further research. Studies addressing the epidemiology of mobility limitations in adults with intellectual

disabilities, although reasonable in number, are predominantly cross-sectional in design and of insufficient quality to draw conclusions upon the frequency or rate of development of mobility limitations. Future researchers can address this void with the use of validated tools and through further consideration of the representativeness of a given study sample to a greater population. Increased focus on mobility, particularly through longitudinal research, will lead to an improved understanding of the epidemiology of mobility limitations in people with intellectual disabilities.

In conclusion, the epidemiological evidence of mobility limitations among adults with intellectual disabilities is weak. This evidence base does, however, permit hypothesis generation and preliminary comparative analyses between segments of the intellectual disability population.

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Tables

Table 1 – Inclusion and Exclusion Criteria for Publications

Inclusion	Exclusion
Original published research	Article in a language other than English or French
Measurement of the prevalence of mobility limitations	All analyses include people without intellectual disabilities
Participants with intellectual disabilities	All analyses include children
Participants are 18 years of age or older	Population defined by level of mobility

Table 2 – Characteristics of Cross Sectional Studies with Pooled Mobility Limitation Prevalence Results

Author (Year)	Country	Population	N	Age	Other	% Male	Definition	Prevalence	Representative	Validity
Janicki & Mac-Eachron, 1984	United States	Needing or receiving services from government agency	6401	53-62=53% 63-99=47%	CP=5% Epilep=15%	49%	Not being independent in mobility	23%	No	Unclear
Gostason, 1985	Sweden	All people with ID in one county, age 20-60	122	20-39=57% 40-60=43%	Epilep=11%	60%	Unable to walk without help or technical walking aid	6%	No	No
Jacobson et al., 1985b	England	Registry, age 55+	1007	55-64=53% 65+=47%		50%	Non-ambulatory	6%	No	No
O'Neill, 1985	United States	ID/multiple handicaps undergoing deinstitutionalization	27	Mean=34 Range=18-57	DS=26%	52%	Wheelchair	44%	No	No
Day, 1987	England	Residents of a longstay hospital, age 65+	99	Mean=79 Range=66-91	Epilep=12% Impaired vision=24%	33%	Mobility problems	34%	No	No
Haveman et al., 1989	Netherlands	Residents of group homes or institutions, age 20+	509	20-39=38%; 40+=62%;		55%	Bedridden or wheelchair	14%	No	No

ID = intellectual disabilities; CP = cerebral palsy; DS = Down syndrome; Epilep = Epilepsy

Author (Year)	Country	Population	N	Age	Other	% Male	Definition	Prevalence	Representative	Validity
Haveman & Maaskant, 1989	Netherlands	Severe ID in institutions or sheltered homes	510	20-39=38% 40+=62%	DS=25%	55%	Unable to walk independently or with the help of others	19%	No	No
Maaskant & Haveman, 1989	Netherlands	Residents of group homes	416	20-39=34% 40+=66%		48%	Unable to walk or able to walk but not climb stairs	9%	No	No
Witt-Engerstrom & Hagberg, 1990	Sweden	Women with Rett Syndrome diagnosed by authors	30	Range=22-44	Rett=100%	0%	Unable to walk	80%	No	No
Rogers et al., 1991	England	Residents of hospital	236	Mean=50.1 Range=24-82	Epilep=27% Impaired vision=13%	86%	Use of a wheelchair or walking aid	10%	No	No
Hand, 1994	New Zealand	All people with ID in country, age 50+	1063	51-60=55% 61-88=45% Range=51-88	DS=13% CP=4% Epilep=17%	50%	Unable to walk independently	23%	No	Unclear

ID = intellectual disabilities; CP = cerebral palsy; DS = Down syndrome; Epilep = Epilepsy; Rett = Rett syndrome

Author (Year)	Country	Population	N	Age	Other	% Male	Definition	Prevalence	Representative	Validity
Beange et al., 1995	Australia	Known to local agencies, age 20-50	202	20-39=81% 40-49=19% Range=20-50		49%	Need assistance for walking or in wheelchair	11%	Yes	No
Ashman & Suttie, 1996	Australia	Database, age 55+	446	55-64=60% 65-74=30% 75+=10%	DS=6% Epilep=14%	43%	Unable to walk independently	23%	No	Unclear
McGrother et al., 1996	England	Known to services, age 20+,	2117	20-39=59% 40+=41%		56%	Needs help to walk	18%	No	Unclear
Chung et al., 1997	England	Register	98	Mean age=39 Range=18-76	Epilep=29%	50%	Not mobile	35%	No	Unclear
Evenhuis, 1997	Netherlands	Resident of centre for people with ID, age 60+	70	Mean=70 Range 60-92		37%	Requires aids, is hardly ambulatory or non-ambulatory	31%	Yes	No
Jones et al., 1997	England	Living in community homes	71	Mean=58 (SD=16.7) Range=21-93		79%	Partly ambulant or non-ambulant	32%	No	Unclear

ID = intellectual disabilities; DS = Down syndrome; Epilep = Epilepsy;

Author (Year)	Country	Population	N	Age	Other	% Male	Definition	Prevalence	Representative	Validity
Fernando, 2001	England	Learning disability register	15	Mean age=35 Range=19-67	DS=7% Epilep=40% Impaired vision=40%	27.0%	Mobility difficulties	47%	No	No
Anderson, 2002	United States	Women age 30+	226	30-39=37% 40+=63%		0%	Difficulty walking	29%	Yes	Unclear
Bland et al., 2003	England	Known to a community health trust, age 65+	94	Mean=73 (SD=6.9) Range=65-93		36%	Mobility problem	49%	Unclear	No
Espie et al., 2003	Scotland	Adults with ID and epilepsy	186	Mean age=36%		58%	Non-ambulant	25%	Yes	No
Freedman & Chassler, 2004	United States	Receiving services from government agency	629	Mean=44 Range=18-89		52%	Non-ambulatory	15%	No	No
Lifshitz & Merrick, 2004	Israel	Service recipients	108	Mean age=51 (SD=8.1)		55%	Wheelchair	3%	No	No
Lohiya et al., 2004	United States	Residents of a Developmental Disabilities Center	562	30-45=55% 46-65=42% 65+=3%	Epilep=53%	61%	Unable to walk independently	20%	No	No

ID = intellectual disabilities; DS = Down syndrome; Epilep = Epilepsy

Author (Year)	Country	Population	N	Age	Other	% Male	Definition	Prevalence	Representative	Validity
Podgorski et al., 2005	United States	Attend a day habilitation center	47	40-59=62% 60+=38%	DS=15% Epilep=45%	55%	Wheelchair	48%	No	No
Jaffe et al., 2005 (analyzed as 2 studies)	United States	Residents of an institution, Age 60+	112	Mean=73		29%	Need assistance from a caregiver, or the use of a walker or wheelchair	63%	No	No
		Male residents of an institution, Age 20-59	99	Mean=42.7 (SD=10.1)	100%	25%				
Schrager et al., 2007	United States	Women seen in a collection of family medicine clinics	93	18-40=43% 41+=67% Oldest age category 60+	DS=25% Epilep=29%	0%	Any notion of being in a wheelchair in medical records	15%	No	No
Tyrer et al., 2007	England	Moderate-profound ID on register	2453	Not reported		57%	Unable to walk everywhere unaided	36%	Yes	No

ID = intellectual disabilities; DS = Down syndrome; Epilep = Epilepsy

Table 3 – Characteristics of Cross Sectional Studies where a Pooled Mobility Limitation Prevalence is not Available

Author Year	Country	Population	N	Age	Definition	Representative	Validity
Jacobson et al., 1985b	United States	Needing or receiving services from government agency, age 55+	Approx. 1300	Not reported	Mobility limitation present	Yes	Unclear
Maaskant & Haveman, 1990	Nether- lands	Residents of institutions, age 20+	356	20-39=38% 40+=62%	Unable to walk independently	No	No
Moss, 1991	England	Registry, age 20+	2239	Age totals not reported	Severe or moderate mobility problem	Yes	Unclear

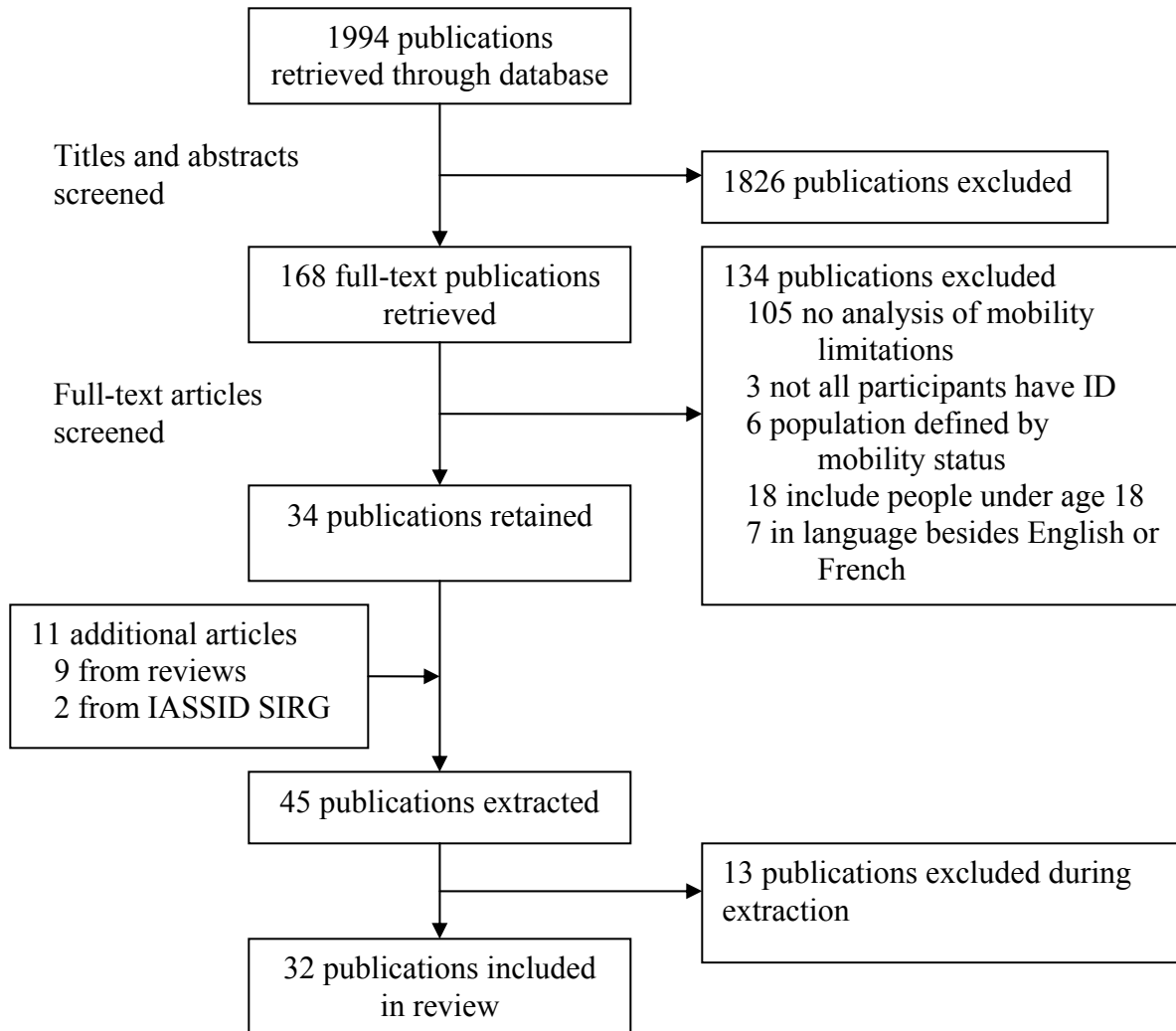
Table 4 – Studies comparing Mobility Limitations with Age

Authors	Age Comparison*			
Janicki & MacEachron, 1984	53-62= 20%	63-72= 23%	73-99= 35%	
Jacobson et al., 1985b	55-64= 16%	65+= 21%		
Jacobson et al., 1985a	55-64= 6%	65+= 5%		
Day, 1987		65-69= 21%	70-74= 31%	75+= 57%
	Greater mobility limitations in 75+ group (test not identified, p<0.01)			
Haveman & Maaskant, 1989	20-39= 16%	40-49= 3%	50-59= 11%	60+= 27%
Maaskant & Haveman, 1989	20-39= 5%	40-49= 11%	50-59= 8%	60+= 21%
	Mobility limitations increase with age (Kendall's Tau, p<0.01)			
Maaskant & Haveman, 1990	Mobility limitations increase with age in adults with severe ID (Kendall's Tau, p<0.01) but not in adults with profound ID (Kendall's Tau, p<0.11)			
Moss, 1991	Mobility limitations rise steadily after the age of 65 in people with moderate ID, but remain steady for those with severe ID			
Evenhuis, 1997		60-64= 23%	70-74= 85%	80+= 56%
		65-68 = 29%	75-79= 50%	
Jaffe et al., 2005	Men 20-59= 25%	Men 60+= 58%		

*Expressed in prevalence of mobility limitations per age group, unless otherwise indicated

Figure

Figure 1 – Flow of Citations through the Publication Identification Process



IASSID SIRG = International Association for the Scientific Study of Intellectual Disabilities Special Interest Research Group on Aging

Chapter 3: Manuscript 2

Title:

The Prevalence and Severity of Physical Mobility Limitations in Older Adults with Intellectual Disabilities

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Structured summary (145 words; limit 150 words)

Background: The population of older adults with intellectual disabilities is growing, creating new challenges for individuals, families and service providers. Although there has been increased research of the aging process for adults with intellectual disabilities, there is little focused research investigating physical mobility.

Materials and Methods: A proxy-response telephone survey was conducted to establish the prevalence and severity of mobility limitations among adults with intellectual disabilities, aged 45 and over, using validated instruments to quantify mobility in a representative population-based sample.

Results: Surveys were completed for 128 people. Mobility limitations were common, but the prevalence varied depending on the definition of mobility limitation. The prevalence of limitations was greater among females than males, but no clear age trend was seen.

Conclusions: The common nature of mobility limitations among the growing population of older adults with intellectual disabilities has implications for service providers and policy makers.

Introduction

The life expectancy of people with intellectual disabilities has risen substantially in recent years. (Cooper, 1998; Horwitz et al., 2000; Hatzidimitriadou & Milne, 2005) This increase in longevity has been accompanied by a dramatic increase in the number of older adults with intellectual disabilities. (Salvatori, 1998; McCallion, 2004) As adults with intellectual disabilities get older, age-related disabilities compound lifelong disabilities, causing additional disadvantages for this population. (Bland et al., 2003) The significant growth of this group has created new challenges for service providers who have not previously served large numbers of older clients.

In response to these challenges, investigators have called for more epidemiological research in older people with intellectual disabilities to establish the prevalence and incidence of morbidities and secondary conditions. (Davidson et al., 2004; Hatzidimitriadou & Milne, 2005) Research suggests that people with intellectual disabilities follow a similar qualitative aging process as those without. (Davidson et al., 2004) There is evidence, however, that some age-related disabilities are more prevalent among adults with intellectual disabilities and occur at younger ages than is seen in the general population (for example, hearing and vision loss), (Fisher, 2005) creating the impression that people with intellectual disabilities age faster. (Haveman, 1989; Brzezniak, 1998; Salvatori, 1998)

Physical mobility, often referred to simply as mobility, describes the human activity of moving from place to place. (Bussmann & Stam, 1998) Generally this concept refers to walking, although the use of a wheelchair is also a strategy that enables mobility.

Mobility limitations have been identified as a predictor of mortality, (Strauss et al., 1996;

Connolly, 2001; Tyrer et al., 2007) are associated with low bone mineral density (osteopenia and osteoporosis), (Tyler et al., 2000; Jaffe et al., 2005) and have been proposed as a factor leading to secondary health conditions (van Schroyen Lantman-De Valk, et al., 2000) for people with intellectual disabilities. Moreover, in the general population, mobility was found to be important for quality of life among long-term care residents (Williams et al., 2005) and “the most significant factor to elders' perceived levels of health and well-being.” (Bourret, 2002)

Despite the importance of mobility limitations for people with intellectual disabilities, there has been relatively little focused research on the subject. A recent systematic review of the literature identified 32 publications pertaining to mobility for adults with intellectual disabilities, yet many of these studies used crude measures of mobility status, did not report on the validity of their measurement strategies and did not discuss the representativeness of their samples to the baseline population. (Cleaver et al., Submitted.) These weaknesses are likely due to the fact that most of these studies assessed mobility as one of many health-related factors. Nonetheless, the preliminary analysis of these studies' results suggests that mobility limitations do increase with age (different age thresholds have been proposed), are more common in females and vary according to the level of intellectual disability. (Cleaver et al., Submitted.) Registry data suggests that mobility limitations are more common in people with intellectual disabilities (Ouellette-Kuntz & Burge, 2004) and that the prevalence of these impairments rises at younger ages than is seen in the general population. (Ouellette-Kuntz & Burge, 2004) The objective of this study was to examine the prevalence and severity of mobility limitations in adults with intellectual disabilities, age 45 years and over.

Materials and Methods

This cross-sectional study was conducted with a representative group of adults with intellectual disabilities, age 45 years and over, in South Eastern Ontario, Canada.

Participants

Potential participants were identified from the Geographic Registry in Intellectual Disability (GRID) using a ‘proportional to population size’ stratified random sampling technique based on gender, age category and residential setting. GRID is a database of people with intellectual disabilities in the six counties of South Eastern Ontario, Canada (total population= 503,668), (Statistics Canada, 2007) and administered by the South Eastern Ontario Community University Research Alliance in Intellectual Disabilities (SEO CURA in ID; www.seocura.org). In this paper, GRID will be referred to as ‘the Registry’ and SEO CURA in ID as ‘the Alliance’. A minimal amount of anonymous information about service recipients is submitted to the Alliance on an annual basis by partner agencies offering services for people with intellectual disabilities. By comparing the number of people on the Registry with the expected number of people with intellectual disabilities in the region, it is estimated that the Registry contains information on 85% of the area’s intellectual disability population.

Recruitment

Figure 1 outlines the recruitment process for this study. Sampling was performed by the investigators who were aware only of the date of birth, gender, residential setting, initials, a unique identifier and the associated agency for each of the potential participants. Each agency was formally approached to participate in the study. Upon acceptance, agencies were asked to decode the anonymous information and designate a staff member to

approach the potential participant to seek their consent. If the participant was unable to understand the study sufficiently to provide informed consent, a substitute decision maker/next of kin was sought. Once consent was obtained from or on behalf of the participant, a proxy respondent was identified and approached to provide consent and contact information, which was then submitted to investigators.

Data Collection and Analysis

One of two trained interviewers performed a 30-minute telephone survey with the proxy respondents, using a standardized script and booklet. Responses were collected in the paper booklet which was later double-entered into an electronic database. Mobility status was ascertained through the use of two well-established tools included in the survey: the Rivermead Mobility Index (RMI) (Collen et al, 1991) and the Participation and Activity Limitation Survey (PALS) mobility section. (Statistics Canada, 2004) These two instruments offer slightly different perspectives on mobility. The Rivermead Mobility Index aims to quantify the *severity* of a mobility limitation by exploring a person's capacity to do various activities, ranging from bed mobility to being able to run. This tool provides a score on a 16-point scale (0-15) where the ability to perform a given activity adds one point. (Collen et al., 1991) The items of the Rivermead Mobility Index are arranged in order to form an approximate hierarchy. (Collen et al., 1991) The Rivermead Mobility Index was developed for both clinical and research purposes (Collen et al., 1991) and it has proven to have excellent inter-rater and intra-rater reliability when used to assess the mobility of people with intellectual disabilities receiving physiotherapy services. (Sackley et al., 2005)

The PALS is a population-based interview developed by Statistics Canada to collect information on various aspects of life for people with disabilities. (Statistics Canada, 2004) The PALS aims to *identify* various limitations, including mobility. A person who has problems with any one of five activities is classified as having limited mobility. In addition, the PALS includes items regarding the use of mobility equipment or specialized features in the home to overcome limitations. The PALS is conducted every five years in a stratified sample of people with disabilities as identified by a filter question on the Canadian census. (Statistics Canada, 2004)

The survey also sought information on various aspects of the participants' health and disability to allow for further description of the study sample. Data were analyzed descriptively using SAS 9.1 (Cary, North Carolina, USA) in order to calculate the prevalence of mobility limitations in this population using various definitions. The prevalence of mobility limitations was expressed as a percentage, with 95% confidence intervals. The sample was compared to the baseline population for the sampling frame criteria (gender, age category and residential setting). A weighted prevalence of mobility limitations was then calculated according to certain key definitions to adjust for any differences between the sample and baseline population. The crude prevalence of mobility was compared between groups based on key characteristics. For dichotomous characteristics, such as gender, this comparison was made using chi-square tests (Fisher's Exact test was used if the expected size of any cell was less than five). The Cochran-Armitage test for trend was used where there were more than 2 ordinal categories. (Margolin, 1988) In order to allow comparison with general Canadian population, the results of this study were recategorized according to the age groups used by Statistics

Canada in the 2001 PALS. (Statistics Canada, 2002) Finally, the percentage of study participants using mobility facilitating devices and those with reported unmet needs were calculated. This study was reviewed and approved by the Queen's University Health Sciences Research Ethics Board.

Results

Of 970 adults with intellectual disabilities aged 45 years and over receiving services in this region, 400 people from 34 service provider agencies were sampled for this study (41% of study population). The number of potential participants selected per agency varied from one to 57 with a median number of seven.

Nine service provider agencies either refused to participate or did not respond to repeated requests, effectively eliminating their service recipients from the study. An additional service provider left the decision up to individual case managers, some of whom agreed to participate, others who did not. Agency non-participation eliminated 109 potential participants from the study.

Of the remaining 291 potential participants, consent forms were received and interviews were completed for 128. Of those not participating, 82 returned consent forms confirming refusal, 60 were unaccounted for and an additional 21 were lost due to various causes, such as the unavailability of a person willing to sign the consent form or a transfer of services to another agency since the most recent update of the Registry. Ultimately, interviews were completed for 32% of the individuals sampled for this study. The proxy respondents in this survey were family members, agency support workers or home share

providers; the latter are adults who welcome adults with intellectual disabilities in their home in exchange for a per diem from an agency. Ninety-five percent (95%) of proxy respondents had known the participant for more than one year, 70% normally saw the participant at least a few times per week or more and 92% had seen the participant within the last month. Three high functioning participants (2% of participants) responded to the survey themselves because they did not feel that there was another person available to respond on their behalf.

The demographics of the study sample are presented in Table 1, with a comparison to the underlying population. The distribution of participants among the three age categories was similar to the underlying population, as was the distribution for gender and people with Down syndrome or cerebral palsy. The distribution of participants across residential settings, however, was not equivalent to that found in the population: there was a disproportionately high number of participants in the formal support category (those living in group homes or nursing homes) and lower numbers in the family (living with parents or siblings) and low support categories (those living alone, with roommates or with a spouse or their children).

Among participants, 14.1% had a visual impairment, 10.2% were injured due to a fall in the 12 months preceding the survey, 36.7% had a problem being understood when speaking and 15.6% had at least one seizure in the past 5 years. According to the Scales of Independent Behavior – Revised, short form, 36.7% had a support score in the extensive, pervasive or frequent levels and 63.3% had scores in the no, infrequent, intermittent or limited support levels. Participants in this sample ranged in age from 45 to 76 years of age (mean=56.3; SD=7.76).

The distribution of scores on the Rivermead Mobility Index is shown in Figure 2. Most participants scored in the upper ranges of the scale (Median score=14; interquartile range 11-15), although it should be noted that this tool has a ceiling effect. Precise statistics on mobility limitations, based on various definitions are shown in Figure 3. Selected meaningful scores from the Rivermead Mobility Index (RMI) were chosen to represent various degrees of mobility limitation severity: a person with a score less than 2 is likely to be considered bedridden; a person with a score less than 7 is likely to be wheelchair dependent; and a person with a score less than 12 is likely to have substantial difficulty independently participating in activities inside and outside of the house without notable compensatory strategies and equipment.

The percentages of respondents with reported difficulties to each of the individual activities of the PALS mobility section are also shown in Figure 3, along with a category representing people who had difficulty with at least one PALS item. In order to account for the residential status imbalance in the sample, the prevalence was recalculated, weighted on this variable, using two notable definitions of mobility limitation. The results of the weighted calculations were very similar to the crude results: RMI score < 12, weighted=24.6%, crude=25.8%; any limitation on PALS mobility scale weighted=59.2%, crude=59.4%.

Table 2 presents mobility statistics separately for men and women. Interestingly, mobility limitations were more prevalent in women and this difference was statistically significant for most definitions of mobility limitations.

The prevalence of mobility limitations by age category is presented in Table 3. Most definitions of mobility limitation showed little difference between age categories and no

trend. By contrast, the proportion with reported difficulty rose steadily between the three age categories for some definitions of mobility impairments, such as having difficulty climbing stairs or having difficulty standing in line. In order to allow for comparison with the general Canadian population, the prevalence of mobility limitations was recalculated according to the age categories presented for the 2001 PALS. Using the Statistics Canada definition of a mobility limitation (any limitation on the PALS) the prevalence among adults with intellectual disabilities was found to be 56.5% (95% CI= 47.1 – 65.8%) for those age 45-64 years and 73.7% (95% CI= 53.9 – 93.5%) for those age 65-74 years (see Discussion section).

The percentages of participants who used various mobility facilitating devices (mobility equipment or specialized features) are presented in Table 4. In total, 35.9% of the sample used at least one item of mobility equipment and 48.4% used at least one specialized feature. It should be noted that bathroom grab bars were categorized as a specialized feature and often accounted for the only specialized feature used by a participant.

Transfer equipment, such as sling lifts and change tables were also considered specialized features. Wheelchair use was relatively high among this sample, although in many cases the wheelchair was only used for long distances, such as day outings. Nine participants (7.0%) required their wheelchair to move independently from one room to another and an additional 5 (3.9%) were not able to move independently from one room to another, even with a wheelchair.

Some participants in this study had mobility needs that were not currently being met (refer to Table 5). Proxy respondents were asked if there were any items of mobility equipment or specialized features in the home that the participant needed but did not

have. Respondents reported that nine participants (7.0%) were in need of either one or two items of mobility equipment such as a cane, a walker, a scooter or orthopedic footwear. Specialized features in the home were reported as a need for 15 people, 11.7% of the sample. Individuals were reported as needing between one and four specialized features, including bedside poles, additional railings, larger doors, non-slip floors and raised toilet seats. Respondents for six participants (4.7%) reported that the layout of the participant's home limited activities within the past year. The explanations behind this problem were varied. In one instance a broken elevator made it difficult for the participant to enter and exit the apartment. For one participant living independently, the cupboards and closets could not be used since they could not be reached from a wheelchair. In another situation, participation was limited because the participant needed either an enclosed area or supervision when outdoors; since moving into a condominium there had been no outdoor area for this person to go outside independently. Respondents for nine people (7.0%) reported that the person's current living environment was inappropriate. For only one person was this due to mobility.

Discussion

This study clearly demonstrates the significance of mobility limitations in older adults with intellectual disabilities. While the prevalence and severity of mobility limitations vary according to definition, they are nonetheless very common in this population. Mobility is estimated in this study through the use of established tools to quantify mobility limitations and a population based sample that has permitted an analysis of the representativeness of participants. The definitions of mobility limitations allow for the

comparison with the general Canadian population and provide practically meaningful interpretations. These design characteristics improve upon the weaknesses of past research examining mobility limitations for adults with intellectual disabilities.

The 2001 PALS found that the prevalence of mobility limitations in the general Canadian population was 12.3% for adults age 45-64 years and 23.3% for adults age 65-74 years. (Statistics Canada, 2002) These values are significantly lower than the results found in this study, clearly demonstrating a higher prevalence of mobility limitations among people with intellectual disabilities.

The results of this study do not lend clear support to an increasing prevalence of mobility limitations with age for older people with intellectual disabilities, at least not in the age categories examined here. The fact that some definitions yield statistically significant results could be due to chance alone, considering the multiple definitions for mobility limitations used in this study and the increased probability of significant findings with multiple comparisons. (Greenland & Rothman, 1998) It is possible that a trend does in fact exist, but the sample size studied did not allow for a statistically consistent analysis across the definitions. It must be acknowledged that in order to reduce recall bias in this cross sectional study, the survey did not seek information on the onset of mobility limitations. This in turn makes it impossible to differentiate age-related mobility limitations from those that were lifelong in nature. Some investigators have noted higher mortality (Tyrrer et al., 2007) and greater numbers of gross motor impairments (Maaskant & Haveman, 1990) among people with intellectual disabilities age 20-40 as compared to older groups. This may be indicative of a “healthy survivor effect” in which people with the most severe lifelong disabilities are underrepresented among the older age groups. An

analysis focusing on age-related disabilities would likely provide a clearer impression on the age trends associated with the development of mobility limitations.

The prevalence of mobility limitations was higher among females than males. This is consistent with the two past studies with adults with intellectual disabilities that reported mobility limitations by gender (Jaffe et al., 2005; Tyrer et al., 2007) and with analyses in the general population. (Clark et al., 1998; Statistics Canada, 2002)

The use of mobility facilitating devices was widespread in this sample: 36.6% used personal mobility equipment and 52.9% used specialized features in the home.

Considering the high prevalence of mobility limitations detected in this study, widespread use of mobility facilitating devices seems appropriate. The need for additional mobility facilitating devices was expressed for small percentages of participants (6.5% reported the need of at least one piece of mobility equipment and 12.2% reported the need for at least one specialized feature item). It should be noted that these answers reflect a proxy respondent's perception of potentially beneficial devices, therefore the actual number of participants who would benefit from additional mobility facilitating devices may in fact be larger or smaller than these estimates.

This study is not without limitations. The proportion of individuals included in this study relative to the number sampled was relatively low (32%). Participants were lost due to both agency non-participation and individual non-participation. Biased or misleading results are always a concern when participation rates are low. (Webb et al., 2005) In this case the sample of participants was similar to the underlying population with regards to age and gender, but not in terms of residential status. Nonetheless, when estimates of the prevalence of mobility limitations were weighted according to residential status, the

change from the crude estimate was minimal. It would therefore appear that the non-representative proportions of residential status in the study sample did not affect estimates of the prevalence of mobility limitations.

It is possible that non-participation was more common among adults without mobility limitations. Some agencies initially refused the invitation to participate in this study, for the reason that “we serve few people with mobility problems.” All of these agencies eventually did agree to participate after further discussion with regards to the study goals. Other agencies may have not verbalized this thought, thus possibly “masking” portions of the study sample where mobility limitations were less prevalent. Individuals refusing to participate may have done so for similar reasons. If this was in fact true, the actual prevalence of mobility limitations in this population would be lower than the study’s estimate. In addition, some agencies refused to include potential participants who were not able to consent for themselves and did not have a family member available to act as a substitute decision maker. Individuals who are more disabled and older are more likely to fit this profile, thereby eliminating potential participants with greater mobility problems from this study. Should this have been the case, the actual prevalence of mobility limitations in the population would be greater than observed through this study.

It must be noted that these results are rooted in contextual factors which should be considered before comparing the results of this study to other jurisdictions or time periods. Increased life expectancy among people with intellectual disabilities now means that even people with severe or multiple disabilities are living into old age. (Bittles et al., 2002) This reduction in “selective mortality” would mean that the number of older

people with lifelong mobility problems would rise; increasing the prevalence of mobility limitations in this population.

In addition, many of the people in this study have spent portions of their life in institutions. Whether institutionalization would have been a factor leading to increased or decreased physical mobility is unknown. Due to policy changes in Ontario, the next generation of older adults with intellectual disabilities will not have had similar life experiences, potentially affecting the future prevalence of mobility limitations among older adults with intellectual disabilities. At the time that this study was conducted, there were three institutions in Ontario for people with intellectual disabilities that remained open, one of which was within the study area.¹ The majority of the 1000 residents of these facilities are age 55 or older, (Livingston, 2004) and many have more severe disabilities. These institutions are scheduled to close in 2009 at which time all residents will live in the community. Readers looking to generalize these findings to other areas or even the same area in the future should consider these factors.

As the number of people with intellectual disabilities living into old age continues to rise, families and service provider agencies will be challenged to keep pace with the special needs of this growing population. Improved knowledge of impairments that are common in older people with intellectual disabilities will assist with service planning and advocacy efforts. Although this study has permitted an accurate description of mobility problems among adults with intellectual disabilities aged 45 and over, there remain many questions that are beyond the scope of this particular research. Through this study it was not possible to identify factors that may have led to increased or decreased mobility.

¹ This institutionalized group is not included in the Registry and is therefore excluded from this study.

Moreover, it was beyond the scope of this study to evaluate the meaning of a mobility limitation to an individual or family or examine interventions aimed at improving mobility among adults with intellectual disabilities. Now that the prevalence and severity of mobility limitations among older adults with intellectual disabilities have been established it would appear that the time has come for such further investigation.

In conclusion, mobility limitations are common among older people with intellectual disabilities and more common in females than males. This information can be used to assist in service provision and planning and as a platform for further research on mobility for adults with intellectual disabilities.

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Tables

Table 1 – Demographic Characteristics of Study Sample and Underlying Population

Characteristic		Sample (n=128)	Population (N=970)	p-value (chi-square)
Age	45-54	44.5%	50.6%	0.14
	55-64	39.8%	32.2%	
	65+	15.6%	17.2%	
Gender	Male	55.5%	55.1%	0.92
Residential Setting	High support	53.9%	43.6%	0.05
	Low support - with Family	21.1%	24.5%	
	Low support - other	25.0%	31.5%	
Down Syndrome		9.4%	7.9%	0.52
Cerebral Palsy		10.2%	7.0%	0.14

Table 2 –Mobility Impairments by gender – Total (n=128)

Item		Men (n=71)	Women (n=57)	p-value
RMI	score <2	0.0%	3.5%	0.20*
	score <7	5.6%	19.3%	0.02
	score <12	16.9%	36.8%	0.01
PALS	Difficulty moving around in the house	7.0%	19.3%	0.04
	Difficulty carrying 5 kg for 10 m	22.5%	49.1%	<0.01
	Difficulty standing in line for 20 minutes	29.6%	47.4%	0.04
	Difficulty walking 3 blocks	29.6%	63.2%	<0.01
	Difficulty walking up and down a flight of stairs	29.6%	63.2%	<0.01
	Any mobility limitation on PALS	45.1%	77.2%	<0.01

*Fisher's exact test used due to small expected cell size.

RMI = Rivermead Mobility Index

PALS = Participation and Activity Limitation Survey

Table 3 – Mobility Impairments by age category – Total (n=128)

Item	Age 45-54 years (n=57)	Age 55-64 years (n=51)	Age 65+ years (n=20)	p-value*
RMI score <2	1.8%	2.0%	0.0%	0.68
RMI score <7	10.5%	11.8%	15.0%	0.61
RMI score <12	21.0%	27.5%	35.0%	0.20
PALS: Difficulty...				
Moving around in the house	8.8%	13.7%	20.0%	0.18
Carrying 5 kg for 10 m	35.1%	33.3%	35.0%	0.94
Standing in line for 20 minutes	29.8%	37.3%	60.0%	0.02
Walking 3 blocks	45.6%	41.2%	50.0%	0.91
Walking up and down a flight of stairs	35.1%	49.0%	60.0%	0.04
Any mobility impairment on PALS	57.9%	54.9%	75.0%	0.32

*Cochran-Armitage Test for Trend

RMI = Rivermead Mobility Index

PALS = Participation and Activity Limitation Survey

Table 4 – Percentage of Participants Using Various Mobility-facilitating Devices

Item	Percentage Using
Cane	3.9%
Walker	9.4%
Wheelchair	18.0%
Orthopedic footwear or braces	14.1%
Other mobility equipment*	3.1%
Lift	5.5%
Ramps	28.1%
Easy-to-open doors	9.4%
Elevator	7.0%
Grab bars or bath lift	46.1%
Lowered kitchen counters	4.7%
Other specialized feature**	18.0%

*The following items were considered as ‘other mobility equipment’: white canes, below knee prostheses, extra wide shoes, crutches and scooters.

**The following items were considered ‘other specialized features’: commodes in bedroom and additional hand support (railings) on stairs/steps or walls/halls, lowered beds, shorter steps, wood floors, extra space under the sink to permit a wheelchair to enter, increased lighting, transfer chairs, transfer disks and bath chairs.

Table 5 – Participants with Unmet Needs or Problems

Issue	Percentage affected
(Additional) Mobility equipment needed	7.0%
(Additional) Specialized features needed	11.7%
Layout of home limits participation	4.7%
Current residential setting inadequate	7.0%

Figures

Figure 1 – Recruitment Process

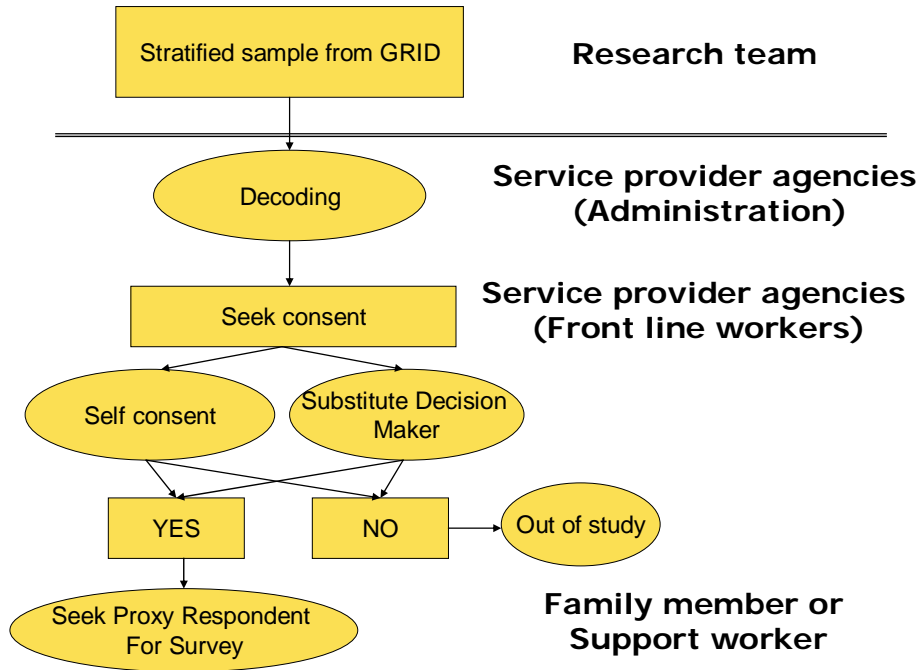


Figure 2 – Distribution of Rivermead Mobility Index Scores

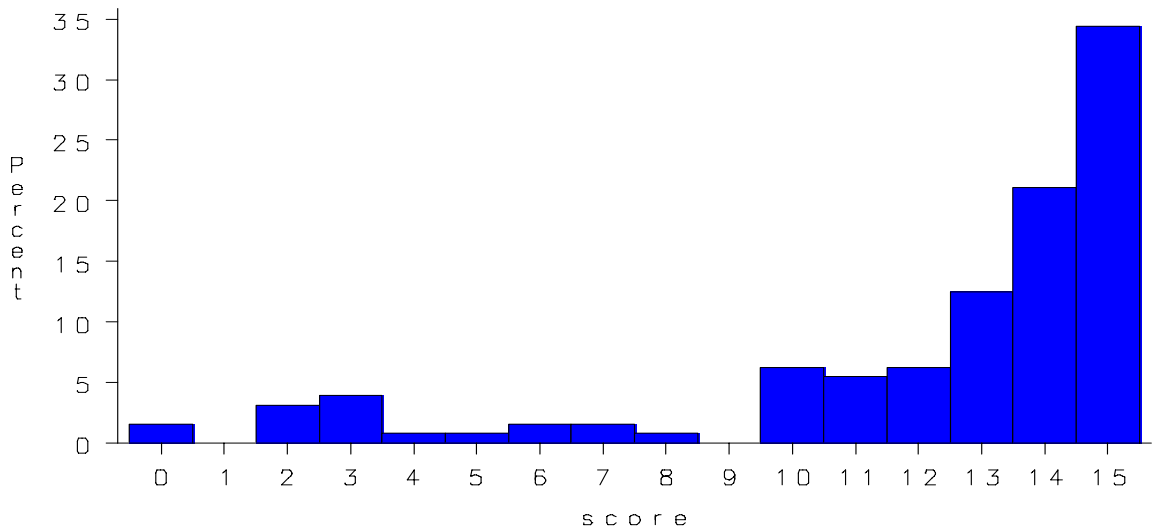
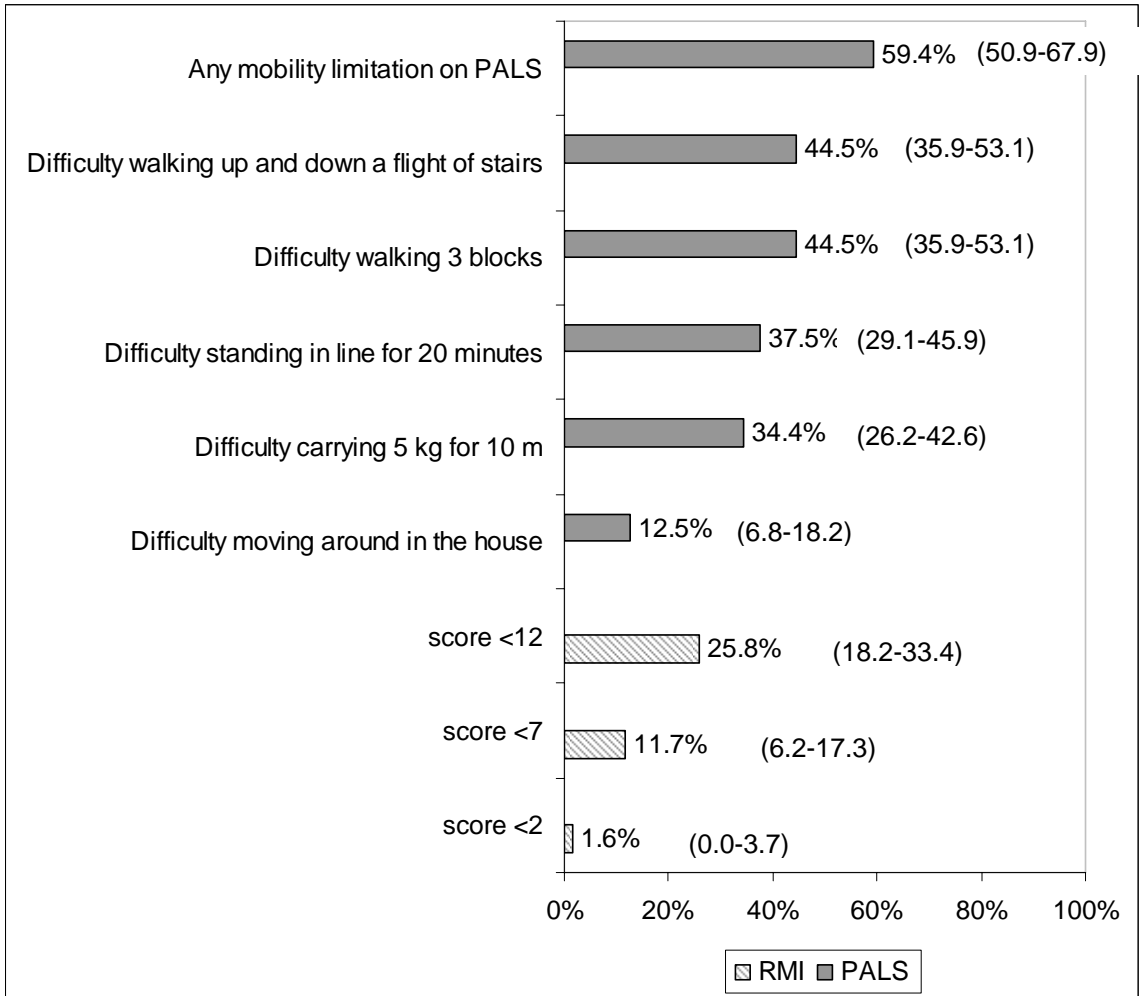


Figure 3 – Prevalence of Mobility Limitations According to Various Definitions



Chapter 4: Manuscript 3

Title:

The Relationship between Mobility Limitations and the Places where Older Adults with Intellectual Disabilities Live

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Structured summary (247 words; limit 250 words)

Background: Mobility limitations are common in people with intellectual disabilities and likely increase with age. The population of older people with intellectual disabilities is growing. Mobility limitations are associated with increased mortality and negative health related states in both the general population and among people with intellectual disabilities. The influence of mobility limitations upon the lives and lifestyles of people with intellectual disabilities remains poorly understood. Specifically, the extent to which mobility limitations might limit residential options for individuals and families has not been evaluated.

Specific Aims: To determine the relationship between mobility limitations and place of residence for adults with intellectual disabilities, age 45 and over.

Methods: A proxy-response telephone survey was completed for 128 adults with intellectual disabilities in South Eastern Ontario. A participant's place of residence was categorized as being high support (group homes and nursing homes) or low support (living alone, with family, roommates or host families). People with a score of 12 or less on the Rivermead Mobility Index were considered to have a mobility limitation. The relationship between mobility limitations and high support residential settings was analyzed using a multivariate logistic regression model.

Findings: After adjusting for age, gender, cerebral palsy, communication problems and behaviour problems, people with mobility problems had 3.6 times greater odds of living in high support settings.

Discussion: Mobility limitations are associated with residence in high support settings. Further investigation is needed to determine the direction of causality and to create programs and services that equalize opportunities.

Introduction

The term mobility describes the human activity of moving from place to place.

(Bussmann & Stam, 1998) This term normally refers to walking, but many people are mobile through the use of assistive devices such as wheelchairs or scooters. Although there is no universal definition of a mobility limitation, the concept describes the mobility status of people who are unable to complete certain mobility-related tasks.

The prevalence of mobility limitations is higher among people with intellectual disabilities than it is in the general population. (Cleaver et al., Submitted) Mobility limitations are more common with advanced age in the general population (Statistics Canada, 2002) and a similar trend is suspected for people with intellectual disabilities. (Day, 1987; Evenhuis, 1997) With a growing population of older people with intellectual disabilities (McCallion & McCarron, 2004) this secondary disability is poised to be of substantial importance to the community.

In people with intellectual disabilities, the presence of a mobility limitation is predictive of increased mortality (Tyrer et al., 2007) and likely contributes to future health problems. (van Schroyen Lantman-De Valk, H.M. et al., 2000) Cross-sectional studies have shown a strong relationship between mobility limitations and low bone mineral density (osteoporosis and osteopenia). (Tyler et al., 2000; Jaffe et al., 2005) Aside from these health-related outcomes, the effects of a mobility limitation on the lives and lifestyles of people with intellectual disabilities are not well understood. In older non-intellectually disabled adults in nursing homes, mobility has been shown to be related to a person's sense of well-being, (Bourret, 2002) and mobility status is the most

important variable determining whether a person who has experienced a stroke will be discharged home or to a nursing home. (De Quervain et al., 1996)

Being able to choose where to live is an important issue for adults with intellectual disabilities. (American Association of Intellectual and Developmental Disabilities, 2004)

Although housing options for people with intellectual disabilities could be classified in many ways, a standard method is to relate the separation or integration of support structures to the housing environment. (Bigby, 2004) Using this method, residential settings can be dichotomized into high support and low support settings. Because of their structured nature, high support settings are often seen as more restrictive and regimented, (Blumberg, 2001) an undesirable option for many.

Two studies have examined the association between mobility limitations and community housing options and both found a greater prevalence among those living in higher support residential options such as group homes, nursing homes or institutions for individuals with intellectual disabilities. (McGrother et al., 1996; Freedman & Chassler, 2004) The extent to which mobility limitations versus other factors might influence where a person can safely live has not however been examined. Although the two studies noted suggest that mobility limitations are associated with living in high support residential settings, only crude analyses are presented. Without controlling for other variables, the higher levels of mobility limitations may simply be representative of other associated underlying phenomena (i.e. confounding), limiting the conclusions that can be made from these studies. This recognition led to the current study, informed by the model depicted in Figure 1, which seeks to examine this proposed association between mobility limitations among older adults with intellectual disabilities and where they live.

Societies and their respective governments have made a commitment to providing supports to individuals with intellectual disabilities in the community. (Canadian Association for Community Living, 1987; Australian Institute of Health and Welfare, 2001; Department of Health (UK), 2001) In many jurisdictions, the traditional long-stay institutions have not accepted new admissions for many years and have been phased out. A significant proportion of adults with intellectual disabilities in the community have never known institutional living and are expecting, as are their families, to be supported in their communities to continue to enjoy the level of independence to which they are accustomed as they age in their family home or their own apartments. As individuals and families change, adaptations to the environment can allow for the continuity of a safe and healthy living arrangement without necessitating a change in location. (American Association of Intellectual and Developmental Disabilities, 2004; Bigby, 2004) In some instances, a change in environment may be desirable or necessary, and these additional options should be available.

The development of different community living options offers great potential for individuals, families and service providers to optimally meet unique needs and situations of individuals with intellectual disabilities as they change with time. Certain factors could, however, limit these options. These factors include: personal characteristics of the adult with an intellectual disability himself, his family, his community or the service provision options that are available to him. (Bigby, 2004) A higher than expected percentage of people living in high support settings with a given characteristic may indicate that the needs of people with this issue are not being met in low support settings. Identifying these variations and finding ways to address them, be it through the

remediation of a given characteristic or a compensation that reduces its influence could enhance the residential options available for individuals.

Method

This cross-sectional study was conducted with a representative sample of adults with intellectual disabilities, age 45 years and over, using a proxy-response telephone survey. The baseline population and recruitment process are described in detail elsewhere. (Cleaver et al., Submitted) Briefly, a stratified random sample of 400 people was selected from the Geographic Registry in Intellectual Disability. This registry includes 970 people with intellectual disabilities age 45 and over receiving services from provider agencies in South Eastern Ontario, Canada. The stratification was based on information available in the database: age category, gender and residential setting (high or low support). Participating service provider agencies contacted potential participants and respondents to explain the study and seek their consent.

Data collection

Data was collected by telephone by one of two trained interviewers using a standardized script and booklet. A proxy-respondent who knew the participant well completed this 30-minute survey on the participant's behalf. The exposure variable of interest in this study was the presence of a mobility limitation, established using the Rivermead Mobility Index (RMI). (Collen et al., 1991) The Rivermead Mobility Index is a 16-point scale (scored 0-15) consisting of items ranging from turning in bed to running. Higher scores indicate better levels of mobility. This tool has proven to have excellent inter-rater and

intra-rater reliability when used to assess the mobility of people with intellectual disabilities receiving physiotherapy services. (Sackley et al., 2005) There is no established score on the Rivermead Mobility Index that indicates a mobility limitation. For the purposes of this study, participants with scores less than 12 were categorized as having limited mobility. A person with a score less than 12 is likely to have substantial difficulty independently participating in activities inside and outside of the house without notable compensatory strategies and equipment.

The outcome of interest was residential status, which was determined by a question asking which of a series of housing options best described the participant's current home. Housing options were then dichotomized into high support settings (those where 24-hour paid support is present i.e. nursing homes and group homes) and low support settings (living with host family, in a home alone, with family or roommates or in a domiciliary hostel).

The survey also sought information on various disability, health and home-related characteristics that could potentially confound or modify the relationship. The presence of Down syndrome or cerebral palsy was ascertained. General health status was established through a single question with five possible responses that were then dichotomized as excellent/very good/good or fair/poor. A person was considered to have a seizure disorder if they had experienced at least one seizure in the last 5 years. (Schmidt, 1996) Visual and communication limitations were established through questions from the Canadian Community Health Survey. (Statistics Canada, 2005) Participants with scores less than -10 on the Maladaptive profile of the Scales of Independent Behavior – Revised were considered to have a behavioural problem.

Information on the cognitive function of participants was not easily available, therefore the Scales of Independent Behavior – Revised Adaptive Behavior Short Form was used to calculate an age equivalent score.

The survey also contained questions from the Participation and Activity Limitations Survey regarding specialized features (adaptations) to the home and accessibility problems in the home. (Statistics Canada, 2004) In order to account for participants who may be living in a setting that did not meet their needs due to administrative reasons or choice, respondents were asked about the appropriateness of the participant's living arrangement. In the case of participants in high support residential settings, details of the most recent move, including the reason for the move, were sought.

Data Analysis

All analyses were undertaken using SAS 9.1 (Cary, North Carolina, USA). The main objective of this study was addressed through a multivariate logistic regression model. All potential variables of interest were entered into a model and a backwards deletion process was used to remove variables that changed the estimate of effect by less than 10%. (Rothman & Greenland, 1998) Due to the presence of mobility items in the calculation of an age equivalent score, potentially making this variable collinear to mobility, this variable was initially left out of the logistic model. A sensitivity analysis was then conducted incorporating the age equivalent score. Data regarding the appropriateness of residential setting and most recent move were summarized as general observations.

This study was reviewed and approved by the Queen's University Health Sciences Research Ethics Board.

Results

Of the initial 400 people selected for the study, 109 were excluded due to the non-participation of service providers, an additional 82 returned consent forms refusing participation, 60 were unaccounted for and 21 lost to various causes. The survey was completed for the remaining 128 people, 32% of those sampled. Compared to the underlying population of 970 adults with intellectual disabilities 45 years and older, the final sample was not significantly different in terms of age and gender but did have a higher proportion of people living in high support residential settings. (Cleaver et al., Submitted)

Slightly more than half of the participants were male (55.5%), 9.4% had Down syndrome and 10.2% had cerebral palsy. Table 1 presents the distribution of other categorical variables that were measured with 95% confidence intervals. The mean age of participants in this study was 56.3 years (SD = 7.76). The mean age equivalent score for the sample was 5 years, 2 months. The distribution of the participants' actual residential settings is shown in Table 2. A majority of participants (53.9%) were living in high support settings at the time of the survey.

Associations between mobility limitations and participant characteristics are presented in Table 3. The mean age of participants with mobility limitations (58.4 years) was slightly higher than for those without (55.5 years), although this difference was not statistically significant (t-test, $p=0.07$). The mean age equivalent of participants with mobility limitations (3 years, 3 months) was lower than for those without limitations (8 years, 0 months). This difference was statistically significant (t-test, $p<0.001$).

Table 4 shows the unadjusted and multivariate adjusted odds ratios between individual variables and residence in a high support setting. Using the backwards deletion method, variables were removed from the model in the following order 1) visual impairment, 2) general health, 3) seizure disorder and 4) Down syndrome. In the final model, adjusted for age, gender, behaviour problems, cerebral palsy and communication problems, the odds ratio between having a mobility limitation and living in high support residence was 3.58 (95% CI = 1.22-10.54).

In order to assess the potential influence of cognition, a sensitivity analysis was performed with an age equivalent variable entered into the full logistic regression model. In this model, the odds ratio of mobility and living in a high support residence falls to 1.78 (95% CI = 0.46-6.85). The odds ratio for communication problems (1.28; 95% CI = 0.44-3.77) also drops notably. The changes in magnitude of effect for age, gender, behaviour and cerebral palsy are all under 15% in this sensitivity analysis model. The age equivalent variable was statistically significant, with an odds ratio of 0.95 (95% CI = 0.93 – 0.98) for each increase of 1 interval on the 162 point W score scale.

Respondents reported that the current living environment of seven of the 59 (11.7%) participants living in low support was inappropriate. In one case this was due to a mobility-related issue; the cupboards and closets could not be reached from a wheelchair. In the remaining cases the stated reason for the living environment being inappropriate was due to problems with dementia, self-care or home maintenance in people without mobility limitations. For the two participants living in inappropriate high support residences, behaviour problems were the stated issue.

The 69 residents of high support settings had been at their current location for between 0 and 24 years (mean 9 years). For 14 participants (20.3%) the most recent move was from a low support residential setting (parental home, home alone, host family etc.). The stated reasons for the moves were varied. Participant-focused reasons included behavioural problems (four participants) or medical or self care needs such as diet control or incontinence (four participants). Family-focused reasons (divorce, parents who are aging or have passed away etc.) were offered as the stimulus for the move for five participants.

For the remaining residents of high support settings, the most recent move was from another high support setting (43.5%) or from an institution (37.7%). Once again, the reasons for the move were varied. In many cases group home residents had moved as service provider agencies purchased new houses or shuffled residents to better accommodate personalities. In one instance a participant moved to a different group home because of accessibility issues. For nearly all participants whose last move was from an institution, the stated reason was that the institution was closing or downsizing.

Discussion

This study has found an association between having a mobility limitation and residing in a high support setting among older adults with intellectual disabilities. This finding is in accordance with past studies that have examined the prevalence of mobility limitations and compared them across residential settings. (McGrother et al., 1996; Freedman & Chassler, 2004) Indeed, the unadjusted odds ratio between mobility and living in a high support residence calculated in this study is very similar to the crude odds ratios that can

be calculated from past studies. Summarizing data from McGrother et al (1996), a prevalence of walking problems of 22.3% was found in the high support residential settings whereas the prevalence in low support settings was 14.8%. Using these prevalence values, an odds ratio of 1.65 can be calculated. In the study by Freedman and Chassler (2004), 11.1% of people in high support settings were nonambulatory versus 6.5% in low support settings. The calculated odds ratio was therefore 1.80. In the current study the unadjusted odds ratio was 1.71. The consistency between studies becomes more interesting when we consider that these 3 studies were performed in different countries using different definitions of mobility.

The main strengths of this study were the use of a clearer definition of a mobility limitation and the analysis of results using a multivariate model. Evidently, mobility is merely one of numerous characteristics that could affect the type of residential setting in which one lives. While simultaneously controlling for other factors, these results show statistically significant associations between living in a high support residential setting and having a mobility problem or a behaviour problem or impaired verbal communication.

The associations between these variables merit further exploration. In this sample there was a highly significant inverse relationship between having a behaviour problem and a mobility limitation, despite the fact that both were directly related to living in high support residential settings with a similar magnitude. This finding would suggest that mobility and behaviour are independently associated with the outcome. In fact, there were only a small number of participants (six) who met both of these criteria and all of them lived in high support settings. If the crude relationship between mobility and high

support residential setting is stratified for behaviour problems, the odds ratio is much higher in those with behaviour problems than those without, suggesting an effect modification. This finding does make intuitive sense: if a person has merely one problem or another he/she could possibly live in a lower support setting, but the combination of the two may lead to higher support needs. With so few participants in the group with both behaviour and mobility problems, it is not possible to statistically verify such an effect modification, and the addition of one or two participants with these problems would change the estimates greatly. Although an inverse relationship between behaviour problems and mobility limitations was anticipated, (Williams et al., 2005) an effect modification between the variables was not; therefore the results were pooled, leading to an accentuation of the odds ratios for both variables.

There are threats to the validity of these findings that must be addressed. The first deals with the potential for participation bias to affect the results. Thirty-two percent of those sampled for this study participated, a response that was lower than predicted. Data from the Geographic Registry in Intellectual Disability database indicates that there was higher participation in the high support residential setting category. In the communications to service provider agencies, participants and respondents, this study was promoted as being about physical mobility. It is therefore possible that there was better participation from people with mobility limitations than those without. If participation did in fact bias the results, however, there must be differential participation related to both the exposure and outcome of interest. (Pearce, 2003) There is no evidence that would indicate that the participation of people with mobility problems was differential across residential settings.

Although the possibility of participation bias cannot be completely discounted, it does appear unlikely to have influenced the results greatly.

The second threat to the validity of these results is more problematic: residual confounding. Due to the design of this study, a variety of covariates were identified *a priori* as potentially being influential. The selection of a limited number of covariates that were more readily quantifiable reduced the potential for misclassification, missing data and kept the time needed to complete a survey to under 30 minutes. Variables were chosen based on their presence in past literature or their suspected relationship between the exposure or outcome.

The disadvantage of this strategy is that some important variables may either be neglected or difficult to quantify. For this study, it was suspected that cognition and/or intelligence would be independently related to both exposure and outcome, (Young, 1994) thus influencing the association. Unfortunately, these constructs are not collected routinely in the database and could not be measured reliably and efficiently through the proxy-response telephone survey. As a compromise, the Scales of Independent Behavior – Revised was used to calculate adaptive behaviour as a proxy for cognition. Although adaptive behaviour is a construct that is separate from cognition, the two are often related. Adaptive behaviour is relatively easy to quantify through an estimation of performance on a series of activities. These activities do, however, include items that are independently measured in this survey, such as mobility and communication.

Accordingly, adaptive behaviour (age equivalent) was strongly related to both mobility and communication and the inclusion of this variable in the model caused a substantial attenuation of the odds ratios of these 2 variables. Although this could be an accurate

adjustment for cognition, it is much more likely that it is primarily a reflection of collinearity between the variables. Despite the attenuation caused by including adaptive behaviour, mobility limitations remain directly related to the outcome of interest, albeit not with statistical significance. This finding suggests that if the odds ratio of having a mobility limitation could be adjusted for cognition, the magnitude would likely be weaker, but the direction of effect would remain unchanged.

Interestingly, despite the significant odds ratio found for mobility in this study, it was rarely stated as the reason leading to the most recent moves of high support residents. Explanations abound as to why this might be the case. First of all, in an attempt to reduce misclassification and recall bias, the question addressed the *last* move, which in many cases was not the initial move into a high support setting. Moreover, respondents tended to rationalize moving as being the product of an event rather than a personal characteristic. Families may be able to cope very well, even with a person with an intellectual disability and a mobility limitation, until the death or declining function of a parent. In this case, if there are insufficient accommodations or supports for people with mobility limitations in other low support settings, the person may “need” to move to a high support setting, with the causal explanation being “aging parents.” A parallel argument could be made for “institutional closure.” Mobility limitations could thereby be an unrecognized but important component in the web of causality that leads to moves to high support residences. (Webb et al., 2005)

It must be noted, however, that this study is cross-sectional and therefore does not establish causality. It is possible, moreover, that mobility status is influenced by

residential setting. Indeed, there is some evidence to support this argument, (O'Neill, 1985; Heller, 1999) although this explanation does seem less probable than the reverse.

Regardless of the direction of causality, these findings come with important implications. There is a need to further examine the factors leading to high support placements (such as mobility limitations) for people with intellectual disabilities in an effort to increase the number of options available to individuals and families. Should mobility be declining at a faster rate for those living in high support residential settings, there is a need to investigate why this may be so in order to implement strategies which maintain or improve the mobility status of people with intellectual disabilities.

Although this study was conducted in one area of Canada, the findings are likely transferable to other jurisdictions where definitions of disability and service provision models and policies may be different. Previous studies suggest that these results are consistent with those of other countries; the United States and the United Kingdom at very least.

This study is premised on the assumption that low support settings are preferable in terms of flexibility and quality of life for people with intellectual disabilities and in terms of cost for service provider agencies and families. There are undoubtedly instances where people prefer high support residential settings, possibly for the social atmosphere or sense of community. This is completely reasonable and understandable, but if there is truly to be an equalization of opportunities, these instances should not be differential to those with specific disabilities. It is hoped that the continued investigation of these disabilities further leads to the reduction of their impact, in turn increasing options and opportunities for people.

In conclusion, mobility limitations are associated with living in high support residential settings for older adults with intellectual disabilities. Improving the mobility status of people with intellectual disabilities or identifying and addressing barriers that prohibit living in low support settings could contribute to increasing the residential options available to people with intellectual disabilities as they age.

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Tables

Table 1 – Distribution of Categorical Variables in Sample

Characteristic	Percentage n=128	(95% CI)
Mobility Limitation (RMI < 12)	25.8%	(18.2-33.4)
General Health (fair/poor)	26.6%	(18.9-34.2)
Seizure Disorder	15.6%	(9.3-21.9)
Visual Impairment	14.1%	(8.0-20.1)
Impaired Expressive Communication	36.7%	(28.4-45.1)
Behaviour Problem (SIB-R <-10)	38.3%	(29.9-46.7)

RMI = Rivermead Mobility Index

SIB-R = Scales of Independent Behavior – Revised (Maladaptive profile)

CI = Confidence Interval

Table 2 –Distribution of Actual Residential Settings among Study Participants

Item	Percentage
<i>High Support Settings</i>	53.9%
Nursing Home or Long Term Care	1.6%
Group Home	52.3%
<i>Low Support Settings</i>	46.1%
With Host Family	13.3%
With Family – Parents, Siblings, Extended family members	7.8%
With Family – Spouse and/or Children	6.3%
With Roommates (including Domiciliary Hostel)	8.6%
Alone	10.2%

Table 3 – Association of Variables with Mobility Limitations – Total (n=128)

Item	Unadjusted Odds Ratios (95% CI)	
Gender –Male	0.38	(0.15-0.79)
Down Syndrome	1.50	(0.42-5.35)
Cerebral Palsy	5.76	(1.73-19.62)
General Health (fair/poor)	2.29	(0.98-5.36)
Seizure Disorder	2.21	(0.81-6.02)
Visual Impairment	16.76	(4.97-56.56)
Impaired Expressive Communication	1.64	(0.73-3.68)
Behaviour Problem (SIB-R <- 10)	0.27	(0.10-0.71)

Table 4 – Association of Variables with High-Support Residence – Total (n=128)

Item	Unadjusted Odds Ratios (95% CI)		Multivariate adjusted Odds Ratios (95% CI)	
Mobility problem (RMI < 12)	1.71	(0.76-3.87)	3.58	(1.22-10.54)
Age (per year increase)	1.02	(0.98-1.07)	1.01	(0.96-1.07)
Gender –Male	1.61	(0.80-3.25)	1.98	(0.84-4.66)
Down Syndrome	1.80	(0.51-6.32)	-	
Cerebral Palsy	0.32	(0.10-1.18)	0.27	(0.07-1.14)
General Health (fair/poor)	0.42	(0.18-0.93)	-	
Seizure Disorder	1.72	(0.64-4.66)	-	
Visual Impairment	1.86	(0.65-5.31)	-	
Impaired Expressive Communication	4.03	(1.83-8.89)	3.78	(1.58-9.04)
Behaviour Problem (SIB-R <-10)	3.31	(1.54-7.10)	3.94	(1.61-9.65)

RMI = Rivermead Mobility Index

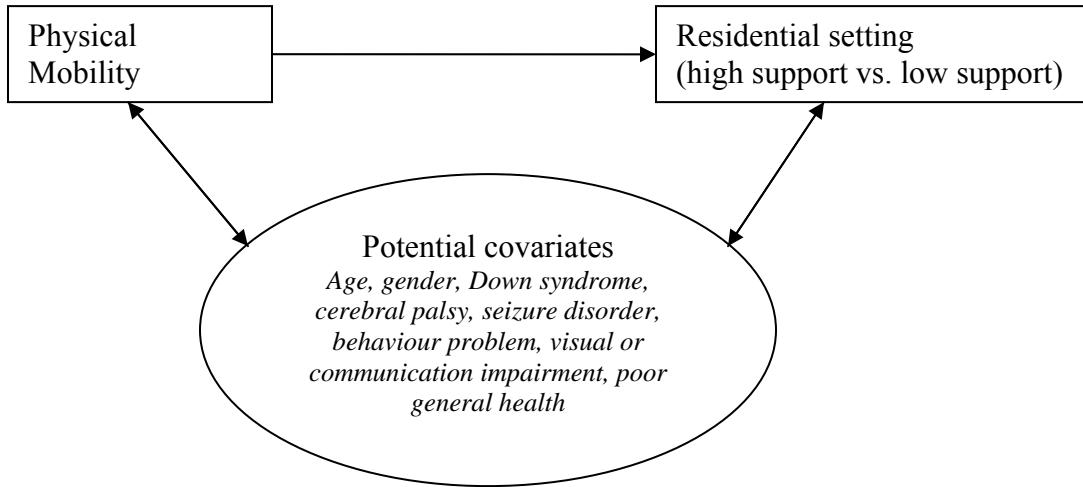
SIB-R = Scales of Independent Behavior – Revised (Maladaptive profile)

CI = Confidence Interval

- = The variable was not included in the final model.

Figure

Figure 1 – Conceptual model of Study Design



Chapter 5: General Discussion

Summary of Study

The three manuscripts of this thesis were designed to be rigorous sub-analyses of one sequential process. Manuscript one aimed to identify an extensive and unbiased sample of publications that addressed mobility limitations among adults with intellectual disabilities. Manuscripts two and three were informed by primary data regarding adults with intellectual disabilities in South Eastern Ontario.

The main conclusion of the first manuscript is that past research on the frequency of mobility limitations among adults with intellectual disabilities is generally of low quality. Most studies addressing mobility limitations were not focused on this issue. Few studies addressed the representativeness of the study sample to a larger underlying population or discussed the validity of the tool being used to quantify mobility limitations. Glaring inconsistencies in reporting were commonplace. Only one study meeting inclusion criteria analyzed mobility in a longitudinal manner.

The second manuscript sought to determine the prevalence and severity of mobility limitations among older adults with intellectual disabilities. This research was designed to address weaknesses identified in past studies, particularly through the use of established measurement tools and by considering the representativeness of the study sample. The main conclusion in this manuscript was that older adults with intellectual disabilities have variable levels of mobility abilities and that the specific prevalence of mobility limitations is highly dependent upon definition. Using equivalent age categories and measurement strategies to Statistics Canada, mobility limitations were substantially higher among adults with intellectual disabilities as compared to the general population.

Mobility limitations did not increase significantly per 10-year age group, but were more prevalent among women than men.

Manuscript three sought to understand the implications of a mobility limitation upon individuals by analyzing the association with residential setting. The results of this manuscript showed that mobility limitations are associated with residential setting for older adults with intellectual disabilities. While simultaneously adjusting for behaviour, age, gender, presence of cerebral palsy and communication problems, the odds of living in high support residential settings were 3.6 times greater for people with mobility limitations. This association was statistically significant. The relationship was attenuated in a sensitivity analysis that included developmental age in the model, becoming statistically insignificant, but the direction of effect remained unchanged (OR = 1.8).

General Strengths and Limitations

By focusing on mobility, this study was able to address gaps in knowledge that had been left untouched by previous research. The systematic review was able to link a pool of evidence that had not otherwise been assembled and scrutinized in its totality. The original primary research incorporated the use of a representative population, established tools to measure exposures and a multivariate model to examine the association between mobility and residential setting. Quality data has been generated that could permit further analysis should resources be made available.

The most notable limitation of this study is related to participation in the collection of original data. Various challenges were encountered during the recruitment phase including agency non-participation and difficulty obtaining consent for potential

participants deemed unable to provide self consent and without next of kin. Ultimately, surveys were completed for 32% of the individuals sampled. Low response rates to population studies introduce the possibility of bias (Webb et al., 2005) and reduce the statistical confidence with which one can make conclusions. A comparison of the sample to the underlying population demonstrated no differences in age or gender distribution, but a disproportionately high level of participants living in high support settings. The calculation of a weighted prevalence (manuscript two) produced little change in estimates.

Implications

The most direct and practical implications of this study are at a local level. This research was conducted through a partnership between local service provider agencies and Queen's University, namely the South Eastern Ontario Community-University Research Alliance in Intellectual Disabilities. The results of manuscripts two and three are applicable to the region without need for further extrapolation or generalization. These findings are useful for advocacy efforts as well as for the development of supports for the service population. The preliminary results of this study have been disseminated to the community through newsletters and presentations and will be outlined in further detail through a report that is currently being developed.

This study also has direct local implications for the completion of research in this population. Large scale projects are being designed to analyze psychiatric and behaviour problems and support needs. The challenges involved with recruitment for this study have helped alert investigators and informed the design and planning of future research.

In a broader sense, these findings have a more indirect application with other communities of adults with intellectual disabilities by increasing the attention on mobility issues. Through publication, these results will reach other researchers, advocates, service providers, health professionals and policy makers working in the field of intellectual disability. The findings in manuscript three are consistent with research conducted in the United States and the United Kingdom, adding strength to those results. The results of this study are thus likely generalizable to these similar international jurisdictions. Indeed, this project has already garnered international interest. The methods of this study were outlined in a submission to the newsletter of the Association of Chartered Physiotherapists for People with Learning Disabilities, a professional organization in the United Kingdom. (Cleaver, 2006)

Epidemiological studies have been identified as a key component to appropriate and effective intervention and an important need for the intellectual disability community. (Haveman, 2004) The sound methods used in this study provide a platform from which further initiatives can be built with the incorporation of additional energy, creativity and the influence of regional variation.

Conclusion

Mobility limitations are common among adults with intellectual disabilities, age 45 and over. These limitations potentially influence the lifestyles of individuals, at very least through their association with residential setting. The findings of this thesis have implications in the health and human services domains. There is little quality epidemiological research on mobility limitations. Future research on the subject should incorporate the use of validated tools and representative samples and further explore the

etiology behind the development of mobility limitations as well the meaningful repercussions of having such a limitation.

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Appendix A:

Boolean Search Strategy for Systematic Review

Database 1: CINAHL

Database: CINAHL - Cumulative Index to Nursing & Allied Health Literature <1982 to May Week 2 2007>

Search Strategy:

- 1 exp Mental Retardation/ (6303)
- 2 Disability Evaluation/ (2201)
- 3 Physical Mobility/ (1268)
- 4 Movement Disorders/ (738)
- 5 exp Psychomotor Performance/ (4932)
- 6 Psychomotor Disorders/ (233)
- 7 WALKING/ (3849)
- 8 Functional Status/ (5826)
- 9 2 or 3 or 4 or 5 or 6 or 7 or 8 (17646)
- 10 1 and 9 (212)
- 11 limit 10 to middle age <45 to 64 years> (35)
- 12 limit 10 to aged <65 to 79 years> (21)
- 13 limit 10 to "aged <80 and over>" (4)
- 14 exp AGING/ (7719)
- 15 1 and 14 (48)
- 16 limit 10 to adult <19 to 44 years> (83)
- 17 11 or 12 or 13 or 16 (89)
- 18 15 or 17 (137)

Database 2: EMBASE

Database: EMBASE <1980 to 2007 Week 19>

Search Strategy:

- 1 Mental Deficiency/ (22075)
- 2 Intellectual Impairment/ (2897)
- 3 learning [disability.mp.](#) (1149)
- 4 1 or 2 or 3 (25702)
- 5 exp WALKING/ (19235)
- 6 DISABILITY/ (22562)
- 7 Psychomotor Disorder/ (1507)
- 8 psychomotor performance/ (2832)
- 9 Motor Dysfunction/ (14079)
- 10 5 or 6 or 7 or 8 or 9 (58802)
- 11 4 and 10 (1302)
- 12 limit 11 to adult <18 to 64 years> (371)
- 13 limit 11 to aged <65+ years> (98)
- 14 12 or 13 (397)
- 15 AGING/ (72499)
- 16 4 and 15 (284)
- 17 14 or 16 (665)

Database 3: Medline

Database: Ovid MEDLINE(R) <1950 to May Week 2 2007>

Search Strategy:

- 1 disability evaluation/ (20314)
- 2 exp Psychomotor Disorders/ (7925)
- 3 exp Movement Disorders/ (65108)
- 4 exp Psychomotor Performance/ (51607)
- 5 mobility limitation/ (198)
- 6 Walking/ (8019)
- 7 Gait/ (10537)
- 8 Locomotion/ (13018)
- 9 Motor Activity/ (47165)
- 10 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 (208098)
- 11 exp Mental Retardation/ (65854)
- 12 10 and 11 (3578)
- 13 limit 12 to "middle aged (45 plus years)" (382)
- 14 limit 12 to "adult (19 to 44 years)" (961)
- 15 13 or 14 (1045)
- 16 limit 15 to yr="1980 - 2007" (768)

Database 4: PsychINFO

Database: PsycINFO <1967 to May Week 3 2007>

Search Strategy:

- 1 exp mental retardation/ (31041)
- 2 exp physical mobility/ (529)
- 3 physical disorders/ (6148)
- 4 2 or 3 (6646)
- 5 exp developmental disabilities/ (6790)
- 6 exp aging/ (16488)
- 7 1 or 5 (36844)
- 8 4 and 7 (476)
- 9 6 and 7 (247)
- 10 limit 8 to "300 adulthood <age 18 yrs and older>" (193)
- 11 9 or 10 (440)
- 12 limit 11 to yr="1980 - 2007" (424)

Appendix B:

Systematic Review Extraction Form

Article UI: _____

Reviewer's Initials: _____

**Mobility Study – Systematic Review
Data Extraction Sheet**

Inclusion/Exclusion Criteria

1. Is there a quantifiable analysis of mobility in a discrete population of people with ID? Yes -> *Include* No -> *Exclude*

2. Is the population described using quantifiable characteristics? Yes -> *Include* No -> *Exclude*

3. Do all analyses include people less than 18 years of age? Yes -> *Exclude* No -> *Include*

Study Design Information (circle one)

Cross-sectional? (*complete pgs 1 & 2*) Longitudinal? (*complete pgs 1,2 for baseline & 3 for F/U*)

A. Participant Information

A1. What was the study population? (*describe; including inclusion/exclusion criteria if applicable*)

A2. How was the population sampled? (*circle one*)

Convenience/volunteers?

Purposive sampling?

N/A – entire population?

Other? Describe _____

A3. How were the participants recruited?

A4. Sample size:

A5. Sample Characteristics

<i>A5a. Continuous Characteristic</i>	<i>Range</i>	<i>Mean (SD)</i>
Age		
Other:		
Other:		
<i>A5b. Dichotomous Characteristic</i>	<i>Proportion with</i>	
Gender – Male		
Down Syndrome		
Cerebral Palsy		
Other:		
Other:		

Article UI: _____ Reviewer's Initials: _____

A5c. Multi-categorical Characteristics

Level of Mental Retardation/Intellectual Disability (describe system and proportions)

Place of Residence (describe proportions)

Other

Notes:

B. Classification of Mobility

B1. What tool was used for data collection?

Was this a... (*circle one*)

Clinical assessment? Self-questionnaire/survey? Proxy questionnaire/survey?
Administrative data?

Other? (*explain*) _____

Name of tool: _____

B2. What question was asked? How was a mobility problem identified or defined?

B3. What were the categories of impairment? (*state and define/describe*)

Notes:

C. Results

C1. Prevalence of each type of mobility limitation by sample category:

(*include confidence intervals if available*)

C2. Were any statistical tests performed? (*describe tests, comparisons and results*)

Notes:

D. Methodological Quality Assessment

D1. Was this a representative sample of the study population? (*circle one*)

Yes No Unclear

D2. Was the validity of the measurement tool reported? (*circle one*)

Yes No Unclear

Notes:

Appendix C:

Information Letter and Consent Form

Physical Mobility and Aging in Intellectual Disability

As we get older, many of us start to have trouble getting around. In some cases this only means that we start to do activities a bit more slowly. In other cases this has big effects on our life, affecting what we are able to do and even where we can live. We have designed a study to understand how problems with walking or moving around in a wheelchair affect people with intellectual disability. We need your help to do this important project.

What is the purpose of this project?

Our goal is to describe how individuals with intellectual disability, 45 years of age or older, are able to get around. We also want to understand how problems with walking or moving around in a wheelchair affect where people can live. The information from this project will help us understand what supports people need now and in the future.

What are the benefits of participation?

Service providers we are working with will get a copy of our report to help them plan future services.

If I participate, what do I have to do?

We are asking people who know a person with an intellectual disability well (like a family member or a caregiver) to tell us about the person's situation. This information will be collected by telephone in an interview that will last 20 to 30 minutes. A member of the project team will call those who agree to participate over the next few months. Participants will not have to answer questions they do not want to answer. **If people choose not to participate in this project, the services and supports that they receive will not be affected in any way.**

What about confidentiality?

All information will remain confidential and will be stored so that only the research team can access it. The results of this study will be reported in grouped form so that individuals cannot be identified.

Who do I contact if I have questions or concerns?

Please feel free to contact us with any questions or concerns you may have. We would be glad to help you in any way we can. Our contact information is provided on the other side.

If you have questions regarding your rights as a research subject you can contact Dr. Albert Clark, Chair, Queen's University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board, at (613) 533-6081.

If you wish to participate in this project, please read and sign the consent form and send it back to us in the envelope provided. ***With your help, we will come to a better understanding of issues for people with intellectual disability in South Eastern Ontario!***

Thank you kindly.

Shaun Cleaver
Graduate Student
Department of Community Health & Epidemiology
Queen's University
Telephone: (613) 533-6000, ext. 75483
email: 5src@qlink.queensu.ca

Hélène Ouellette-Kuntz
Associate Professor
Department of Community Health & Epidemiology
Queen's University
Director, South Eastern Ontario Community-University Research Alliance in Intellectual Disabilities
Telephone: (613) 548-4417, ext. 1198
email: oulette@post.queensu.ca

Encl. Consent form
Return Envelope

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Physical Mobility and Aging in Intellectual Disability

A study by the South Eastern Ontario Community-University Research Alliance in Intellectual Disability

SECTION A: Agency Representative

The above information letter was read and explained to the person selected as a potential participant in this study.

Signature of Agency employee: _____ Date: _____

- The potential participant did not understand this study sufficiently to give consent (Complete top portion of Section C)**

Potential Participant

I have read or been read the information letter describing the above project and understand the purpose of this study, what is required of my participation, and that all information will remain confidential. I also understand that if I choose not to participate, the services and supports that I receive will not be affected in any way.

- I do not wish to participate in this study (Return to SEO CURA in ID)**
- I would like you to ask a respondent of my choice to answer this survey (sign below and Complete Section B)**

Signature of Potential Participant: _____ Date: _____

SECTION B: Potential Respondent

Name of person with ID

Name of potential respondent

Relationship to person with ID

Potential Respondent

I have read the information letter describing the above project and understand the purpose of this study, what is required of my participation, and that all information will remain confidential. I also understand that if I choose not to participate, the services and supports offered to the person listed above will not be affected in any way.

- I agree to be contacted by a member of the study team (complete section below and return to SEO CURA in ID; keep the COPY for your record)**

Signature: _____ Date: _____

Telephone number (with area code): _____

What is the best time to contact you by telephone? _____

- I do not wish to be contacted (return to: Agency contact, Address, City, Ontario, Postal code)**

--	--	--	--	--	--	--	--

SECTION C: Substitute Decision Maker and Potential Respondent

Name of person with ID

Name of substitute decision maker

Substitute Decision Maker

I have read the information letter describing the above project and understand the purpose of this study, what is required of my participation, and that all information will remain confidential. I also understand that if I choose not to participate, the services and supports offered to the person listed above will not be affected in any way.

I agree that the study team contact me to answer this survey (complete information below and return to SEO CURA in ID; keep the COPY for your record)

Signature: _____ Date: _____

Telephone number (with area code): _____

What is the best time to contact you by telephone? _____

I agree that the study team contact a respondent of my choice to answer this survey (complete top portion of Section B and return to **Agency contact, Address, City, Ontario, Postal code**)

Signature: _____ Date: _____

I do not agree want the person listed above to be included in the study (Return to **Agency contact, Address, City, Ontario, Postal code**)

South Eastern Ontario Community-University Research Alliance in Intellectual Disabilities
 Queen's University
 191 Portsmouth Avenue, Kingston, Ontario, K7M 8A6
 phone: 613-548-4417 x. 1207
 fax: 613-548-8135

Appendix D:

Standardized Interview Booklet

Int: _____ Proxy: Y N Phone: Y N

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Physical Mobility for People with Intellectual Disability Survey Telephone Interview Guide

In this guide, interviewer's script is bolded and instructions to the interviewer are italicized. Have the consent form and a blank interview guide ready. Dial phone number provided on consent form.

Introduction

Hello. May I please speak to (name of person on consent form).

If person is available:

This is (interviewer's first and last name) calling from the Southeastern Ontario Community University Research Alliance in Intellectual Disabilities. You sent in a consent form agreeing to take part in a telephone interview about (person with ID)'s physical mobility. This should take no more than 30 minutes. Is now a good time for you to do the interview?

If person answers yes -> proceed with interview

If person answers no -> arrange an alternate time to call

Excellent! All of these questions will be about (name of person with ID). Some questions are general, others are specific to mobility. As stated in the consent form, this information will remain completely confidential and you are free to stop this interview at any time. In addition, some questions are a little long. Feel free to ask me to repeat any question for clarification. You should also know that a few of these questions are repetitive, that's the way the survey is designed. Did you have any questions before we start? (Address question, if necessary) Okay, let's begin.

Section A: Questions regarding demographics and relationship between proxy and study participant.

To start, I'd like to confirm some information about (person with ID)

A1. Could you tell me what (person with ID's) date of birth is?

(mmm/dd/yyyy) _____ -> *if unable to answer question easily, proceed to A1A.*

A1A. Could you tell me how old (person with ID) is? _____

A2. Is (person with ID) male or female? (No need to ask if obvious from name)

1 MALE

2 FEMALE

The next few questions ask about your relationship to (person with ID), so that we can get an idea of how well you know him/her.

A3. How long have you known (person with ID)?

Write in actual response _____

Circle only one as per the answer provided.

- 1 ONE MONTH OR LESS
- 2 MORE THAN 1 MONTH BUT NOT MORE THAN 3 MONTHS
- 3 MORE THAN 3 MONTHS BUT NOT MORE THAN 1 YEAR
- 4 MORE THAN 1 YEAR
- 77 DON'T KNOW
- 88 REFUSAL

A4. In general, how often do you see (person with ID)?

Read list, circle only one.

- 1 **DAILY**
- 2 **A FEW TIMES A WEEK**
- 3 **A FEW TIMES A MONTH**
- 4 **LESS THAN MONTHLY**
- 77 DON'T KNOW
- 88 REFUSAL

A5. When was the last time you saw (person with ID)?

Write in actual response _____

Circle only one as per the answer provided.

- 1 WITHIN THE LAST WEEK
- 2 MORE THAN 1 WEEK AGO, BUT NOT MORE THAN ONE MONTH AGO
- 3 MORE THAN 1 MONTH AGO, BUT NOT MORE THAN 3 MONTHS AGO
- 4 MORE THAN 3 MONTHS BUT NOT MORE THAN 1 YEAR
- 5 MORE THAN 1 YEAR AGO
- 77 DON'T KNOW
- 88 REFUSAL

Section B: Questions regarding health-related covariates.

These questions deal with different aspects of (person with ID)'s health.

B1. In general, would you say (person with ID)'s health is ...

Read list, circle only one.

- 1 **EXCELLENT?**
- 2 **VERY GOOD?**
- 3 **GOOD?**
- 4 **FAIR?**
- 5 **POOR?**
- 77 DON'T KNOW
- 88 REFUSAL

B2. Is (person with ID) able to see at all?

- 1 YES
- 2 NO -> *Go to B3*
- 77 DON'T KNOW -> *Go to B3*
- 88 REFUSAL -> *Go to B3*

B2A. Is (person with ID) able to see well enough to recognize a friend on the other side of the street without glasses or contact lenses?

- 1 YES -> *Go to B3*
- 2 NO
- 77 DON'T KNOW -> *Go to B3*
- 88 REFUSAL -> *Go to B3*
- 99 NOT APPLICABLE -> *Go to B3*

B2B. Is (person with ID) usually able to see well enough to recognize a friend on the other side of the street with glasses or contact lenses?

- 1 YES
- 2 NO
- 77 DON'T KNOW
- 88 REFUSAL
- 99 NOT APPLICABLE

B3. Is (person with ID) able to be understood completely when speaking with those who know him/her well?

- 1 YES
- 2 NO
- 77 DON'T KNOW
- 88 REFUSAL

B4. In the past 12 months, that is, from [date one year ago] to yesterday, was (person with ID) injured seriously enough to limit his/her normal activities?

- 1 YES
- 2 NO -> Go to B5
- 77 DON'T KNOW -> Go to B5
- 88 REFUSAL -> Go to B5

B4A. Was the injury the result of a fall?

Interviewer: Select "No" for transportation accidents.

- 1 YES
- 2 NO
- 77 DON'T KNOW
- 88 REFUSAL
- 99 NOT APPLICABLE

B5A. In the last 12 months did (person with ID) exercise within his/her home?

Interviewer: Read answer categories. Circle one only.

- 1 **EVERYDAY**
- 2 **AT LEAST ONCE A WEEK**
- 3 **AT LEAST ONCE A MONTH**
- 4 **LESS THAN ONCE A MONTH**
- 5 **NEVER**
- 77 DON'T KNOW
- 88 REFUSAL

B5B. In the past 12 months, how often did (person with ID) do physical activities such as exercise, walk or play sports outside his/her home?

Interviewer: Read answer categories. Circle one only.

- 1 **EVERYDAY**
- 2 **AT LEAST ONCE A WEEK**
- 3 **AT LEAST ONCE A MONTH**
- 4 **LESS THAN ONCE A MONTH**
- 5 **NEVER**
- 77 **DON'T KNOW**
- 88 **REFUSAL**

B6. Does (person with ID) have epilepsy or a seizure disorder?

- 1 **YES -> Go to B6A**
- 2 **NO**
- 77 **DON'T KNOW**
- 88 **REFUSAL**

B6A. When was (person with ID)'s last seizure?

- 1 **WITHIN THE LAST YEAR**
- 2 **BETWEEN 1 AND 5 YEARS AGO**
- 3 **MORE THAN 5 YEARS AGO**
- 77 **DON'T KNOW**
- 88 **REFUSAL**
- 99 **NOT APPLICABLE**

B7. Does (person with ID) have Down syndrome?

- 1 **YES**
- 2 **NO**
- 77 **DON'T KNOW**
- 88 **REFUSAL**

B8. Does (person with ID) have cerebral palsy?

- 1 **YES**
- 2 **NO**
- 77 **DON'T KNOW**
- 88 **REFUSAL**

Section C – Participation and Activity Limitation Survey:

The next few questions are about (person with ID)’s ability to move around, even when using an aid or specialized equipment such as a cane or crutches. For these questions, I am asking about difficulties that have lasted or are expected to last 6 months or more.

C1. Is (person with ID) able to walk?

- 1 YES
- 3 NO -> *Go to C5*
- 77 DON’T KNOW
- 88 REFUSAL -> *Proceed to section D*

C2. Does (person with ID) have any difficulty walking half a kilometre or a quarter mile, that is, about three city blocks, without resting?

Interviewer: Circle one only.

- 1 YES, SOMETIMES
- 2 YES, OFTEN OR ALWAYS
- 3 NO (*confirm that this is never a problem*) -> *Go to C3*
- 77 DON’T KNOW -> *Go to C3*
- 88 REFUSAL -> *Go to C3*
- 99 NOT APPLICABLE -> *Go to C5*

C2A. How much difficulty?

Interviewer: Read list. Circle one only.

- 1 **SOME DIFFICULTY**
- 2 **A LOT OF DIFFICULTY**
- 3 **COMPLETELY UNABLE**
- 77 DON’T KNOW
- 88 REFUSAL
- 99 NOT APPLICABLE

C3. Does (person with ID) have any difficulty walking up and down a flight of stairs, about 12 steps, without resting? Interviewer: Circle one only.

- 1 YES, SOMETIMES
- 2 YES, OFTEN OR ALWAYS
- 3 NO (*confirm that this is never a problem*) -> Go to C4
- 77 DON'T KNOW -> Go to C4
- 88 REFUSAL -> Go to C4
- 99 NOT APPLICABLE -> Go to C5

C3A. How much difficulty?

Interviewer: Read list. Circle one only.

- 1 **SOME DIFFICULTY**
- 2 **A LOT OF DIFFICULTY**
- 3 **COMPLETELY UNABLE**
- 77 DON'T KNOW
- 88 REFUSAL
- 99 NOT APPLICABLE

C4. Does (person with ID) have any difficulty carrying an object of 5 kg or 10 pounds, like a bag of groceries, for 10 metres or 30 feet? Interviewer: Circle one only.

- 1 YES, SOMETIMES
- 2 YES, OFTEN OR ALWAYS
- 3 NO (*confirm that this is never a problem*) -> Go to C5
- 77 DON'T KNOW -> Go to C5
- 88 REFUSAL -> Go to C5
- 99 NOT APPLICABLE -> Go to C5

C4A. How much difficulty?

Interviewer: Read list. Circle one only.

- 1 **SOME DIFFICULTY**
- 2 **A LOT OF DIFFICULTY**
- 3 **COMPLETELY UNABLE**
- 77 DON'T KNOW
- 88 REFUSAL
- 99 NOT APPLICABLE

C5. Does (person with ID) have any difficulty standing in line for more than 20 minutes?

Interviewer: Circle one only.

- 1 YES, SOMETIMES
- 2 YES, OFTEN OR ALWAYS
- 3 NO (*confirm that this is never a problem*) -> *Go to C6*
- 77 DON'T KNOW -> *Go to C6*
- 88 REFUSAL -> *Go to C6*

C5A. How much difficulty?

Interviewer: Read list. Circle one only.

- 1 **SOME DIFFICULTY**
- 2 **A LOT OF DIFFICULTY**
- 3 **COMPLETELY UNABLE**
- 77 DON'T KNOW
- 88 REFUSAL
- 99 NOT APPLICABLE

C6. Does (person with ID) USE any aids or specialized equipment for persons who have difficulty moving around?

- 1 YES
- 3 NO -> *Go to C7*
- 77 DON'T KNOW -> *Go to C7*
- 88 REFUSAL -> *Go to C7*

C6A. Does (person with ID) now USE . . .
Read list.

Record the use of aids even if their use is temporary. Is this the case?

- | | | | | | |
|-----------------------------------|-----|----|------------|---------|----|
| (a) orthopaedic footwear? | YES | NO | DON'T KNOW | REFUSAL | NA |
| (b) a cane or walking stick? | YES | NO | DON'T KNOW | REFUSAL | NA |
| (c) crutches? | YES | NO | DON'T KNOW | REFUSAL | NA |
| (d) a manual wheelchair? | YES | NO | DON'T KNOW | REFUSAL | NA |
| (e) an electric wheelchair? | YES | NO | DON'T KNOW | REFUSAL | NA |
| (f) a walker? | YES | NO | DON'T KNOW | REFUSAL | NA |
| (g) a scooter? | YES | NO | DON'T KNOW | REFUSAL | NA |
| (h) braces or supportive devices? | YES | NO | DON'T KNOW | REFUSAL | NA |
| (i) lifts or lift type devices? | YES | NO | DON'T KNOW | REFUSAL | NA |
| (j) grab bars or bathroom aids? | YES | NO | DON'T KNOW | REFUSAL | NA |
| (k) another aid? | YES | NO | DON'T KNOW | REFUSAL | NA |

— specify _____

C7. Does (person with ID) have any difficulty moving from one room to another?

Interviewer: Circle one only.

- 1 YES, SOMETIMES
- 2 YES, OFTEN OR ALWAYS
- 3 NO (*confirm that this is never a problem*) -> Go to C8
- 77 DON'T KNOW -> Go to C8
- 88 REFUSAL -> Go to C8

C7A. How much difficulty?

Interviewer: Read list. Circle one only.

- 1 **SOME DIFFICULTY**
- 2 **A LOT OF DIFFICULTY**
- 3 **COMPLETELY UNABLE**
- 77 DON'T KNOW
- 88 REFUSAL
- 99 NOT APPLICABLE

If the response to C6 was 'yes' (person uses equipment – besides grab bars) AND the responses to C7 and C7A were anything except YES, OFTEN OR ALWAYS and COMPLETELY UNABLE. Otherwise, proceed to C8.

C7Ba. Does (person with ID) need this piece of equipment to move from one room to another by himself/herself?

Name piece of equipment _____

- 1 YES
- 2 NO
- 77 DON'T KNOW
- 88 REFUSAL
- 99 NOT APPLICABLE

C7Bb. Does (person with ID) need this piece of equipment to move from one room to another by himself/herself?

Name piece of equipment _____

- 1 YES
- 2 NO
- 77 DON'T KNOW
- 88 REFUSAL
- 99 NOT APPLICABLE

C7Bc. Does (person with ID) need this piece of equipment to move from one room to another by himself/herself?

Name piece of equipment _____

- 1 YES
- 2 NO
- 77 DON'T KNOW
- 88 REFUSAL
- 99 NOT APPLICABLE

C8. Are there any aids or specialized equipment for persons who have difficulty moving around that (person with ID) thinks he /she NEEDS but does not have?

- 1 YES
- 3 NO -> *Go to C9*
- 77 DON'T KNOW -> *Go to C9*
- 88 REFUSAL -> *Go to C9*

C8A. Which aids does (person with ID) NEED but does not have?

Do not read list. Circle all that apply.

- A ORTHOPAEDIC FOOTWEAR
- B CANE OR WALKING STICK
- C CRUTCHES
- D MANUAL WHEELCHAIR
- E ELECTRIC WHEELCHAIR
- F WALKER
- G SCOOTER
- H BRACES OR SUPPORTIVE DEVICES
- I LIFTS OR LIFT TYPE DEVICES
- J GRAB BARS OR BATHROOM AIDS
- K OTHER, SPECIFY
- 77 DON'T KNOW
- 88 REFUSAL

Record the aids needed even if this need is temporary. Is this the case?

C9. Because of his/her condition, does (person with ID) usually RECEIVE help moving about inside his/her residence?

- 1 YES
- 3 NO -> *Go to C10*
- 77 DON'T KNOW -> *Go to section D*
- 88 REFUSAL -> *Go to section D*

C9A. WHO usually helps (person with ID) with moving about inside his/her residence? I will read you a list. Please answer yes or no to each.

Read list.

- | | | | | | |
|---|-----|----|------------|---------|----|
| (a) Family living with him/her | YES | NO | DON'T KNOW | REFUSAL | NA |
| (b) Family not living with him/her | YES | NO | DON'T KNOW | REFUSAL | NA |
| (c) Friends or neighbours | YES | NO | DON'T KNOW | REFUSAL | NA |
| (d) Organization or agency (<i>include voluntary, private and government agencies</i>) | YES | NO | DON'T KNOW | REFUSAL | NA |
| (e) Other | YES | NO | DON'T KNOW | REFUSAL | NA |

C9B. Does (person with ID) need ADDITIONAL help moving about inside his/her residence?

- 1 YES -> *Go to section D*
- 3 NO -> *Go to section D*
- 77 DON'T KNOW -> *Go to section D*
- 88 REFUSAL -> *Go to section D*
- 99 NOT APPLICABLE

C10. Does (person with ID) think he/she NEEDS help moving about inside his/her residence?

- 1 YES -> *Go to section D*
- 3 NO -> *Go to section D*
- 77 DON'T KNOW -> *Go to section D*
- 88 REFUSAL -> *Go to section D*
- 99 NOT APPLICABLE

Section D – Rivermead Mobility Index

D1. Turning over in bed: Does (person with ID) turn over from his/her back to his/her side without help?

- 1 YES
- 2 NO
- 77 DON'T KNOW
- 88 REFUSAL

D2. Lying to sitting: From lying in bed, does (person with ID) get up to sit on the edge of the bed on his/her own?

- 1 YES
- 2 NO
- 77 DON'T KNOW
- 88 REFUSAL

D3. Sitting balance: Does (person with ID) sit on the edge of the bed without holding on for 10 seconds?

- 1 YES
- 2 NO
- 77 DON'T KNOW
- 88 REFUSAL

D4. Sitting to standing: Does (person with ID) stand up from any chair in less than 15 seconds and stand there for 15 seconds, using hands and/or an aid if necessary?

- 1 YES
- 2 NO
- 77 DON'T KNOW
- 88 REFUSAL

D5. Standing unsupported: **Does (person with ID) stand for 10 seconds without any aid?**

- 1 YES
- 2 NO
- 77 DON'T KNOW
- 88 REFUSAL

D6. Transfer: **Does (person with ID) manage to move from bed to chair and back without any help?**

- 1 YES
- 2 NO
- 77 DON'T KNOW
- 88 REFUSAL

D7. Walking inside (with an aid if necessary): **Does (person with ID) walk 10 metres, with an aid if necessary, but with no standby help?**

- 1 YES
- 2 NO
- 77 DON'T KNOW
- 88 REFUSAL

D8. Stairs: **Does (person with ID) manage a flight of stairs without help?**

- 1 YES
- 2 NO
- 77 DON'T KNOW
- 88 REFUSAL

D9. Walking outside (even ground): **Does (person with ID) walk around outside, on pavements, without help?**

- 1 YES
- 2 NO
- 77 DON'T KNOW
- 88 REFUSAL

D10. Walking inside, with no aid: **Does (person with ID) walk 10 metres inside, with no orthotic, splint, or other aid (including furniture or walls) without help?**

1 YES

2 NO

77 DON'T KNOW

88 REFUSAL

D11. Picking up off floor: **Does (person with ID) manage to walk five metres, pick something up from the floor, and then walk back without help?**

1 YES

2 NO

77 DON'T KNOW

88 REFUSAL

D12. Walking outside (uneven ground): **Does (person with ID) walk over uneven ground (grass, gravel, snow, ice etc) without help?**

1 YES

2 NO

77 DON'T KNOW

88 REFUSAL

D13. Bathing: **Does (person with ID) get into/out of a bath or shower and to wash himself/herself unsupervised and without help?**

1 YES

2 NO

77 DON'T KNOW

88 REFUSAL

D14. Up and down four steps: **Does (person with ID) manage to go up and down four steps with no rail, but using an aid if necessary?**

1 YES

2 NO

77 DON'T KNOW

88 REFUSAL

D15. Running: **Does (person with ID) run 10 metres without limping in four seconds (fast walk, not limping, is acceptable)?**

- 1 YES
- 2 NO
- 77 DON'T KNOW
- 88 REFUSAL

Section E-Scales of Independent Behavior-Revised (SIB-R)

Refer to Scales of Independent Behavior-Revised (SIB-R) booklet and complete directly in booklet

Section F-Residence situation

The following questions ask about the home where (person with ID) currently lives.

F1. Does (person with ID) currently live in a...

Choose the most appropriate response from the list

- A-1 **HOSPITAL** -> if yes, go to F2
- B-2 **LONG TERM CARE FACILITY/NURSING HOME/CHRONIC CARE FACILITY** -> if yes, clarify that there is 24-hour staffing and go to F2
- C-3 **GROUP HOME** -> if yes, go to F2
- D-4 **WITH AN ASSOCIATE/HOST/HOMESHARE FAMILY**->if yes, go to F1A
- E-5 **HOME ALONE** -> if yes, go to F1A
- F-6 **WITH FAMILY** -> if yes, specify who _____ -> go to F1A
 - F1 WITH HIS/HER SPOUSE AND/OR WITH HIS/HER CHILDREN?
 - F2 WITH OTHER FAMILY
- G-7 **HOME WITH ROOMMATES/HOUSEMATES** -> go to F1A
- H-8 **DOMICILIARY HOSTEL** -> go to F1A
 - F1A. **Is (person with ID) currently receiving visiting services from an agency?**
 - 1 YES
 - 2 NO
 - 77 DON'T KNOW
 - 88 REFUSAL
 - 99 NOT APPLICABLE

F2. Because of (person with ID)'s condition, does (person with ID) use any specialized features to enter his/her residence, or inside his/her residence?

- 1 YES
- 2 NO -> Go to F4
- 77 DON'T KNOW -> Go to F4
- 88 REFUSAL -> Go to F4

F2A. Does (person with ID) now use:
Read list. Circle all that apply.

Record the use of specialized features even if their use is temporary. Is this the case?

- (a) **Ramps or street level entrances?** YES NO DON'T KNOW REFUSAL NA
- (b) **Automatic or easy to open doors (includes lever handles)?**
 YES NO DON'T KNOW REFUSAL NA
- (c) **Elevator or lift device?** YES NO DON'T KNOW REFUSAL NA
- (d) **Visual alarms or audio warning devices?**
 YES NO DON'T KNOW REFUSAL NA
- (e) **Grab bars or a bath lift (in the bathroom)**
 YES NO DON'T KNOW REFUSAL NA
- (f) **Lowered counters in the kitchen?** YES NO DON'T KNOW REFUSAL NA
- (g) **Other?** YES NO DON'T KNOW REFUSAL NA
 — specify_____

F3. Does (person with ID) need any other specialized features, which he/she does not already have?

- 1 YES -> Go to F4A
- 2 NO -> Go to F5
- 77 DON'T KNOW -> Go to F5
- 88 REFUSAL -> Go to F5
- 99 NOT APPLICABLE

F4. Are there any specialized features that (person with ID) needs but does not have?

- 1 YES
- 2 NO -> Go to F5
- 77 DON'T KNOW -> Go to F5
- 88 REFUSAL -> Go to F5
- 99 NOT APPLICABLE

F4A. Which specialized features does (person with ID) need but not have?

Read list. Circle all that apply.

Record the need for specialized features even if this need is temporary. Is this the case?

- (a) **Ramps or street level entrances?** YES NO DON'T KNOW REFUSAL NA
- (b) **Automatic or easy to open doors (includes lever handles)?**
YES NO DON'T KNOW REFUSAL NA
- (c) **Elevator or lift device?** YES NO DON'T KNOW REFUSAL NA
- (d) **Visual alarms or audio warning devices?**
YES NO DON'T KNOW REFUSAL NA
- (e) **Grab bars or a bath lift (in the bathroom)**
YES NO DON'T KNOW REFUSAL NA
- (f) **Lowered counters in the kitchen?** YES NO DON'T KNOW REFUSAL NA
- (g) **Other?** YES NO DON'T KNOW REFUSAL NA

— specify_____

F5. Has the design and layout of (person with ID)'s home, including entrance and exits, made it difficult to participate in the activities that he/she wants or needs to do? (Include ALL activities of daily living, not just leisure or recreational activities).

- 1 YES
- 2 NO -> Go to F6
- 77 DON'T KNOW -> Go to F6
- 88 REFUSAL -> Go to F6

F5A. In the past 12 months, how often has the design and layout of (person with ID)'s home, including entrance and exits, made it difficult to participate in activities he/she wants or needs to do? (Include ALL activities of daily living, not just leisure or recreational activities).

Interviewer: Read list. Mark one only.

- 1 **DAILY**
- 2 **WEEKLY**
- 3 **MONTHLY OR LESS OFTEN**
- 77 DON'T KNOW
- 88 REFUSAL
- 99 NOT APPLICABLE

F5B. When this problem occurred, was it a big problem or a little problem?

- 1 BIG PROBLEM
- 2 LITTLE PROBLEM
- 77 DON'T KNOW
- 88 REFUSAL
- 99 NOT APPLICABLE

F6. Is (person with ID) currently living in an environment that is appropriate to meet his/her needs?

- 1 YES -> Go to F7edit.
- 2 NO
- 77 DON'T KNOW
- 88 REFUSAL

F6A. For what reason is the current environment inadequate? _____

F7edit. *If the person with is ID currently living in a high-support residence, answer F6. If not, the interview is complete.*

F7A. In what year did (person with ID) move into this location? _____

F7B. From where did he/she move? _____

F7C. What was the main reason for this move? _____

We are now at the end of the survey. Thank you very much for your participation! Should you have any questions or comments, please feel free to contact the researcher, Mr. Shaun Cleaver at 533-6000 ext. 75483.

Date survey completed: _____

Appendix E:
Ethics Approval

**QUEEN'S UNIVERSITY HEALTH SCIENCES & AFFILIATED TEACHING
HOSPITALS RESEARCH ETHICS BOARD**



Queen's University, in accordance with the "Tri-Council Policy Statement, 1998" prepared by the Medical Research Council, Natural Sciences and Engineering Research Council of Canada and Social Sciences and Humanities Research Council of Canada requires that research projects involving human subjects be reviewed annually to determine their acceptability on ethical grounds.

A Research Ethics Board composed of:

Dr. A.F. Clark	Emeritus Professor, Department of Biochemistry, Faculty of Health Sciences, Queen's University (Chair)
Dr. S. Burke	Emeritus Professor, School of Nursing, Queen's University
Rev. T. Deline	Community Member
Dr. M. Evans	Community Member
Mr. C. Kenny	Community Member
Dr. J. Low	Emeritus Professor, Department of Obstetrics and Gynaecology, Queen's University and Kingston General Hospital
Dr. H. Murray	Assistant Professor, Department of Emergency Medicine, Queen's University
Dr. W. Racz	Emeritus Professor, Department of Pharmacology & Toxicology, Queen's
Dr. H. Richardson	Assistant Professor, Department of Community Health & Epidemiology Project Coordinator, NCIC CTG, Queen's University
Dr. B. Simchison	Assistant Professor, Department of Anesthesiology, Queen's University
Dr. A.N. Singh	WHO Professor in Psychosomatic Medicine and Psychopharmacology Professor of Psychiatry and Pharmacology Chair and Head, Division of Psychopharmacology, Queen's University Director & Chief of Psychiatry, Academic Unit, Quinte Health Care, Belleville General Hospital
Dr. M. Sommerfeld	Physician and Assistant Professor, Department of Family Medicine, Queen's University
Ms. K. Weisbaum	LL.B. and Adjunct Instructor, Department of Family Medicine (Bioethics)

has examined the protocol and consent form for the project entitled "Physical Mobility and Aging in Intellectual Disability" as proposed by Mr. Shaun Cleaver, Dr. H. Ouellette-Kuntz and Dr. Duncan Hunter of the Department of Community Health and Epidemiology at Queen's University and considers it to be ethically acceptable. This approval is valid for one year. If there are any amendments or changes to the protocol affecting the subjects in this study, it is the responsibility of the principal investigator to notify the Research Ethics Board. Any unexpected serious adverse event occurring locally must be reported within 2 working days or earlier if required by the study sponsor. All other serious adverse events must be reported within 15 days after becoming aware of the information."

Albert Clark

Chair, Research Ethics Board

Date

Aug 2, 2006

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