

The Mobility Study
Physical Mobility and Aging in Intellectual Disability
DRAFT REPORT

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in Intellectual Disabilities

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Thank you to all those who participated, including agency employees, family members and the participants themselves.

In particular, we would like to recognize the following agencies for their contribution in a partner capacity:

Agencies

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Impact Residential Services
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Kingston Community Counseling Centre
Lanark Community Programs
Lanark County Support Services
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ABOUT SEO CURA in ID

The South Eastern Ontario Community-University Research Alliance in Intellectual Disabilities (SEO CURA in ID) includes partners from across South Eastern Ontario as well as collaborators and ex-officio members from other areas. The community partners are primarily developmental service sector agencies across the six county catchment area and the primary researchers are based at Queen's University in Kingston. The complete list of researchers and partners can be found on our website (www.seocura.org). Our vision is to augment the quality of life for individuals with intellectual disabilities and their families through enhanced inclusion, sense of belonging and support. Our goals are that research findings be used to inform policies and practices of service providers and government ministries and that the partnering experience inform future research areas and approaches.

DISCLAIMER

The views expressed in this study report are not necessarily the views of all SEO CURA in ID partners, researchers, collaborators or members or SSHRC.

Note to agencies and families

The following report outlines the methods and findings of the mobility study. This study was conducted between January and June 2007 as part of a Master's thesis in the Department of Community Health and Epidemiology at Queen's University. The project was completed with the support of the South Eastern Ontario Community-University Research Alliance in Intellectual Disabilities (SEO CURA in ID).

This report is intended to be a concise synopsis of the study written in accessible language. Please feel free to disseminate this report freely or share the findings orally with anyone who may be interested. We sincerely hope that this study can be used by agencies and families as part of planning and advocacy efforts.

More detailed accounts of the different facets of the study were submitted for publication in scientific journals as three manuscripts in August 2007. Updates on the publication status and availability of these articles can be found on the SEO CURA in ID website (www.seocura.org). For additional correspondence, please contact H el ene Ouellette-Kuntz, the Director of SEO CURA in ID at oulette@queensu.ca.

Summary

This report presents a study about how older people with intellectual disabilities get around. We talked to friends or family members of 128 people with intellectual disabilities, age 45 and over, from South Eastern Ontario. We asked them questions about how the person with an intellectual disability got around. Specifically, we were looking to see how many people had problems walking or doing other similar activities. We also asked questions about their health and the places where people live.

We found that problems getting around were more common for older people with intellectual disabilities than for older people without intellectual disabilities. The number of people who had problems walking depends on what we considered to be a problem. Many people, even some of the oldest people in the study, had no problems getting around whatsoever. We also found that more people with walking problems live in nursing homes and group homes than people without such problems.

The results of this study can be useful for people. More people with intellectual disabilities are living into old age. Agencies can better plan for the future needs of older people if they know more about problems that older people often have, like walking problems. These results can also be helpful for individuals and families as they plan for the future.

Background

As we all know, there are more people with intellectual disabilities (ID) living into old age. When people grow older, they sometimes experience physical changes or slow down. These physical changes may cause problems for some people and make it difficult to do what they need to. In other people these same physical changes may not cause any problem at all. Whether or not a physical change causes a problem will depend on what the person wants or needs to do, what kinds of help or equipment they have available and what is expected of them.

There has been a lot of research done in the general population to help us understand how people change when they get older. Because of this research we understand aging quite well. This understanding helps people prepare for the future. There has not been as much research looking into how people with intellectual disabilities change as they get older.

We do know that people with intellectual disabilities experience similar changes to the general population as they age. Some things are different though. For example, it is more common for people with intellectual disabilities to have problems hearing and seeing and these problems often start at a younger age. There are many things involved with the aging process for people with intellectual disabilities that we do not understand well. Mobility is one of these things.

Mobility is the word that describes how people get around. Many people get around by walking, but others need a wheelchair or a scooter. Some people can walk, but need extra equipment like a cane or a walker. Others may need to have another person

help them. When someone is having trouble getting around, we sometimes say that they have a mobility problem.

Mobility means a lot to people. For older people living in nursing homes, being able to get around was an important factor in people feeling healthy and good about themselves. In people with intellectual disabilities, people who have good mobility are more likely to live longer and less likely to have problems with their bones (like osteoporosis).

We know from research done in the general population that mobility problems are not very common among young people. As people get to be 60 or 70 years old, mobility problems become much more common. According to Statistics Canada, almost one half of Canadians over the age of 75 have a mobility problem.

When we started this project we knew a little about how people with intellectual disabilities got around, but not much. We wanted to learn more about the ways that people get around and problems that they may have. We also wanted to learn a little more about how a mobility problem affects a person. We decided to look at older people since there are now so many people living into old age.

The Purpose of the Mobility Study

We designed this study to answer two questions:

- How many adults with intellectual disabilities have problems getting around?
- Does having problems getting around affect where people live?

We chose to focus on people age 45 and over. Before we started we thought that there might be an age where there is a big increase of mobility problems, but we were not sure at what age that would happen. We were also particularly interested in people who

might be thinking about leaving the family home as their parents became older and were maybe undergoing physical problems themselves. We thought that including people as young as 45 would help us see any major changes that come with older age.

How the study was done

To answer the study questions, we collected information about how people with intellectual disabilities get around. We were interested in people age 45 or older who were on the Geographic Registry in Intellectual Disability (GRID). GRID is basically a database that counts people who live in South Eastern Ontario and receive services because of their intellectual disability. From the 970 people over the age of 45 counted in GRID, we chose 400 whom we wanted to ask to be part of the survey.

To get in touch with people, we worked together with the service provider agencies. If an agency agreed to help us, they would tell their clients about the study using a letter that we prepared as a guide. They would then ask the clients if they wanted to take part. People were free to say yes or no. Saying no did not affect the services that people received. In some cases the person with an intellectual disability was not able to understand the study well enough to decide on their own. When this happened, the agency had to get in touch with a family member to make the decision.

The information that we needed for the study was collected during a telephone interview. The interview took about half an hour and was done with a person whom the person with an intellectual disability knew well. We asked many questions about how people got around and a few other questions about where they lived. Some of the questions where we asked about mobility can be seen in Appendix A.

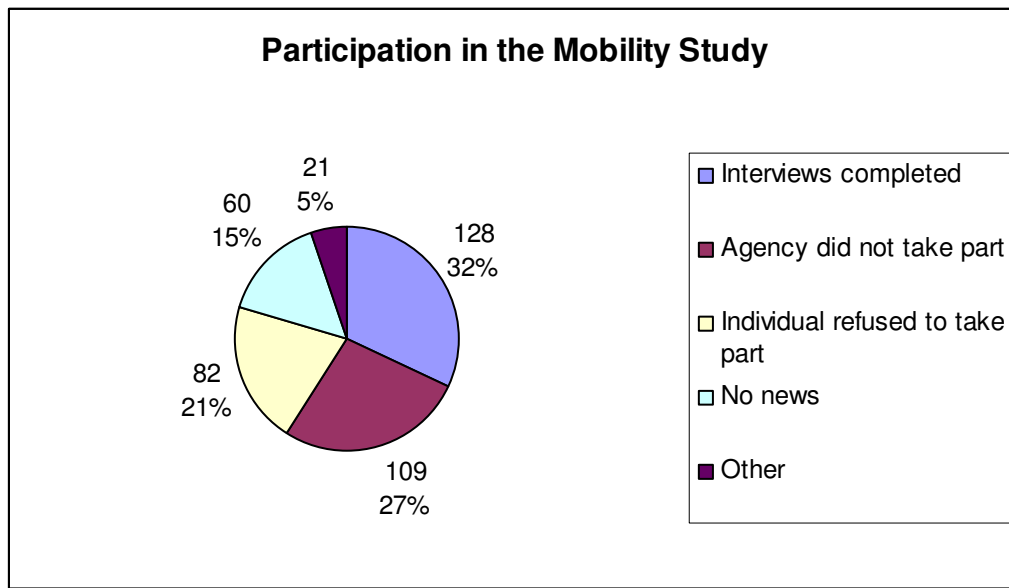
Results

Participation

The initial group of 400 people we selected were receiving services from 34 different agencies. Eight of these agencies chose to not take part in this study. Another agency left the decision up to individual case workers and half of these workers agreed to help us. When an agency did not take part, all of the people who were from that agency were automatically out of the study. In our study, this added up to a total of 109 people.

There were 291 people selected from the agencies that did take part in this study. Of these, 128 completed the interview with us. We received forms for 82 who told us they did not want to take part. Another 21 people were out of the study for various reasons, like not being able to understand the study and not having a family member available to sign the consent form. We never heard news from the remaining 60 people, which meant we could not complete the interview for them. Figure 1 shows the breakdown of people selected for the study.

Figure 1 – Participation of study sample



The Participants

We asked a few questions about other things, so that we could know our participants better. The results to these questions are listed in Table 1. When we talk about residential setting, high support means nursing homes and group homes. Low support describes people who live with family, friends, in a homeshare or on their own. We compared some characteristics of our group to the characteristics of everyone on GRID. We found that we had a similar percentage of men and that the percentages by age group were similar. Compared to GRID, there were more participants living in high support.

Table 1 – Characteristics of Mobility Study Participants

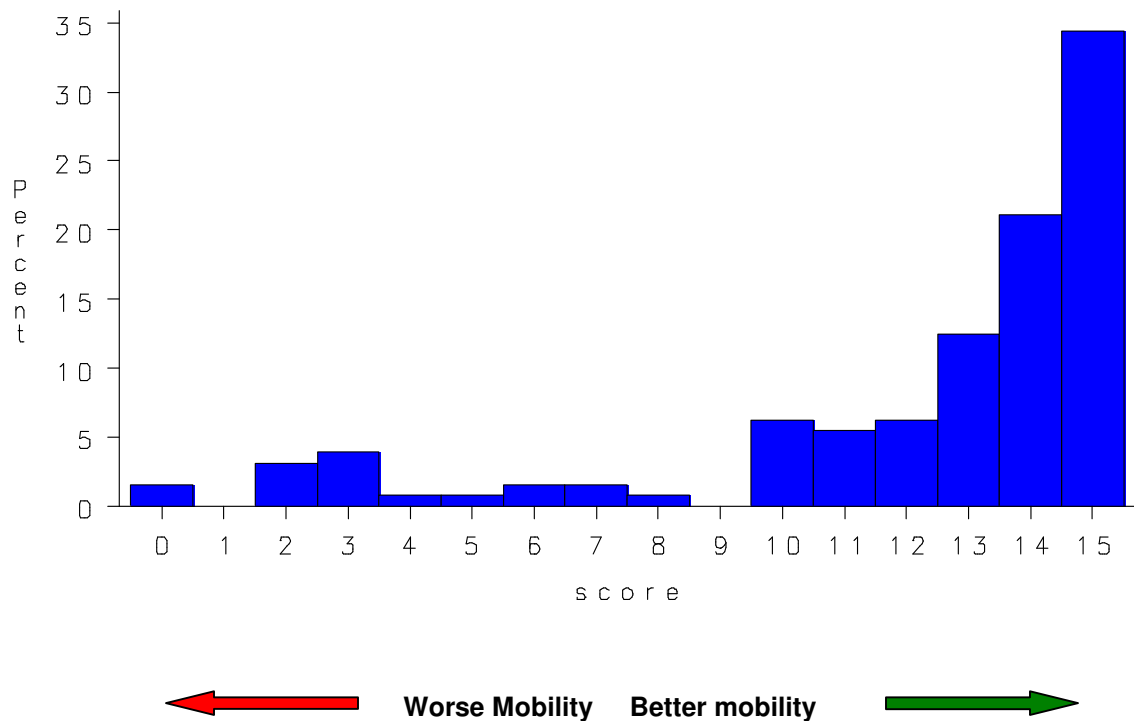
Characteristic	Sample (n=128)
Age	
45-54	45%
55-64	40%
65+	16%
Gender	
Male	56%
Residential Setting	
High support	54%
Low support	46%
Down Syndrome	9%
Cerebral Palsy	10%
Fair/Poor General Health	27%
Seizure Disorder	16%
Visual Impairment	14%
Impaired Speech	37%
Behaviour Problem	38%

Mobility

We used different ways to describe how people get around. One way to do this was to use a scale that therapists use to determine if a person's mobility is getting better or worse. This scale is called the Rivermead Mobility Index (RMI). To use this index,

we ask 15 questions about what the person is able to do (see Appendix 1). The person gets one point if they can do that thing. A person with really good mobility could then get a score of 15. If a person has really bad mobility they will have a low score, possibly as low as zero. Figure 2 shows the percentage of people who received different scores.

Figure 2 – Mobility of participants according to Rivermead Mobility Index



In this study, we considered anyone who had a score below 12 on the Rivermead Mobility Index as having a mobility problem. A person with a score below 12 will probably have problems doing things inside and outside of the house without special equipment or help. Among our participants, 26% scored below 12; that is about one person in four.

We also asked if people had any difficulty doing certain activities that are important for many people. These questions come from a survey that is managed by

Statistics Canada, the Participation and Activity Limitation Survey (PALS). If a person had any difficulty at all, even if it was only some of the time, we considered them to have difficulty. The results for these questions are shown in Table 2. We also calculated how many people had at least one of these problems. We found that 59%, or nearly six in ten people, have difficulty with at least one of those five activities.

Table 2 – People with difficulties with certain activities

<i>People with difficulty...</i>	
Moving around in the house	13%
Carrying 5 kg for 10 m	34%
Standing in line for 20 minutes	38%
Walking 3 blocks	45%
Walking up and down a flight of stairs	45%
Any mobility difficulty on PALS	59%

We asked people whether or not they needed equipment to help them get around. The results for some of those items are in Table 3. We must remember that these results only show us the people needing the equipment and having it. It is possible that others could benefit from the equipment, but have never learned to use it or never received it. These results also do not tell us how badly a person needs their equipment. For example, just over half of the people using wheelchairs need the wheelchair to move from one room to another. The others only use wheelchairs when they are going on longer outings, like shopping.

Table 3 – People who use mobility equipment

Item	Percentage Using
Cane	4%
Walker	9%
Wheelchair	18%

Who is more likely to have a mobility problem?

This study did not try to determine the causes of people's mobility problems, nor did it try to determine what factors lead to mobility problems. What this study did do is see if the percentage of people with mobility limitations is higher in some groups than others. This finding can tell us who is more likely to have a mobility problem and can help provide ideas of some of the causes of mobility problems.

We found that women had more problems with mobility than men. This was true for every definition of a mobility problem. We also looked to see if the oldest people in the study had more problems with mobility than the youngest. To do this we divided the group up into three age categories (45-54; 55-64 and 65+). When we compared mobility problems across these age categories it was not clear that mobility problems were more common as people got older. Even some of the oldest people in the study were found to have no mobility problems at all.

We also looked at some other factors and found that people with problems seeing or cerebral palsy were more likely to have mobility problems than people without these conditions. The opposite was true for people with behaviour problems, they were less likely to have mobility problems. We did not find any relationship between mobility problems and problems speaking, seizure disorders, Down syndrome or fair or poor general health.

Mobility and the Places where People Live

We looked to see if there were more people with mobility problems living in high support settings (like nursing homes and group homes) than there were in low support settings (living with family, friends, in a homeshare or own home). In other words, we want to see if mobility limitations are related to place where people live.

This type of a study can be tricky; sometimes there are other factors that may be related to mobility or housing that may be important. These factors may reduce or increase the importance of what we are trying to see. For example, people who have problems seeing may be more likely to have problems walking. People who have problems seeing may also be more likely to live in a high support setting. If we find that people who have problems with their mobility are more likely to live in a high support setting, then we have to make sure that this is not because of another related characteristic, like having problems seeing. We use a process called ‘adjusting’ to account for other factors that may be important. In the above example, we would want to look at the relationship between mobility limitations and where people live, while adjusting for problems seeing.

In this study we found that mobility limitations are related to people living in high support settings. The odds of living in high support settings were 3.6 times higher for people with mobility limitations than those without these limitations. This result is adjusted for other factors which are shown in Table 4. The number next to the variable (the odds ratio) shows if people with this characteristic were more (number greater than one) or less likely (number less than one) to live in high support environments. We looked at other factors too and found that they were not important. These factors are

shown in Table 5.

Table 4 – Final Logistic Regression Model

Item	Odds Ratio
Mobility problem	3.6
Age (per year increase)	1.0
Gender –Male	2.0
Cerebral Palsy	0.4
Problems Speaking	3.8
Behaviour Problem	3.9

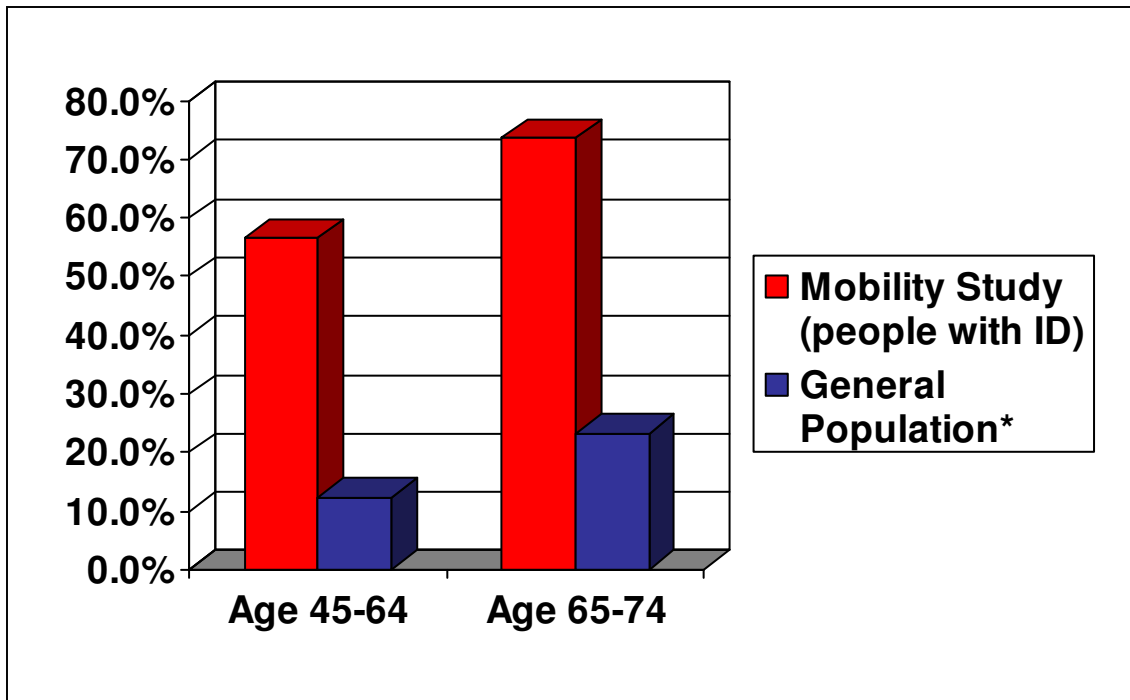
Table 5 – Variables that were removed from final model due to lack of effect

Item
Problems Seeing
Fair/Poor General Health
Seizure disorder
Down syndrome

What these results mean

The most important result from this study is that mobility problems are very common in older people with intellectual disabilities. The actual percentage of people with mobility problems changes depending on what we mean by a “problem.” We used the same questions as a large survey that collected data from the general population of all of Canada. The results of the mobility study found that the percentage of people with mobility limitations is much higher than in the general population (Figure 3).

Figure 3 – Comparison of Mobility Study with General Population



*Statistics Canada, Participation and Activity Limitations Survey, 2001

Even though mobility problems were very common, there were many people who did not have any problems getting around, even in the oldest age groups. This means that just because a person is older and had an intellectual disability, we cannot expect them to have mobility problems. Very senior people who still have very good mobility may be able to serve as a good example or inspiration of how to keep walking well. They may also serve as the standard of what types of activities we should try to adapt or improve so that people with mobility problems are able to fully participate in the activities that they want or need to do.

Our results showed that women have more problems with mobility than men. We are not sure why this is the case, but other studies have found the same thing. We did not find an increase of mobility problems with age. This is similar to some studies but different than others. This may simply be because we did not ask how long people had their mobility problems. It is possible that our study participants who were 45 or 50

years old had had their mobility problems since birth; whereas our 65 or 70 participants may have only had their mobility problems for a few years.

We found that people with mobility problems were more likely to live in high support environments (nursing homes and group homes) than people without such problems. This was still true after we adjusted for other factors. This could be because group homes and nursing homes are easier to get around than other types of homes. It could also be that the current way that we provide services makes it hard for people with mobility limitations to live in low support settings.

We also found that people with problems speaking or behaviour problems were more likely to live in high support environments. It looks as if men may be more likely and people with cerebral palsy may be less likely to live in high support settings, although these findings were not as strong or statistically significant.

What we can do with the results

Knowing this information can be very useful for people to plan into the future and develop services. Sometimes we need to work with organizations such as governments or other community groups to make sure that service needs are covered or ask that more and better services are available. Having good information that is relevant for an *entire* population makes these discussions easier. The mobility study incorporates the realities of people in different situations from all over South Eastern Ontario. By asking people the same questions we are able to make comparisons and provide information that can be useful to families, agencies, governments and others.

Appendix A

Rivermead Mobility Index Questions

Does the person...

- 1) Turn over from his/her back to his/her side without help?
- 2) Get up to sit on the edge of the bed on his/her own?
- 3) Sit on the edge of the bed without holding on for 10 seconds?
- 4) Stand up from any chair in less than 15 seconds and stand there for 15 seconds, using hands and/or an aid if necessary?
- 5) Stand for 10 seconds without any aid?
- 6) Manage to move from bed to chair and back without any help?
- 7) Walk 10 metres, with an aid if necessary, but with no standby help?
- 8) Manage a flight of stairs without help?
- 9) Walk around outside, on pavements, without help?
- 10) walk 10 metres inside, with no orthotic, splint, or other aid (including furniture or walls) without help?
- 11) Manage to walk five metres, pick something up from the floor, and then walk back without help?
- 12) Walk over uneven ground (grass, gravel, snow, ice etc) without help?
- 13) Get into/out of a bath or shower and to wash himself/herself unsupervised and without help?
- 14) Manage to go up and down four steps with no rail, but using an aid if necessary?
- 15) Run 10 metres without limping in four seconds (fast walk, not limping, is acceptable)?