Barriers to Participation in Literacy Activities Facing People with Physical Disabilities

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The Neil Squire Foundation

Mission

The Neil Squire Foundation (NSF) is a Canadian not-for-profit organization that provides education, technology and career development for people with disabilities. Through direct interaction with these individuals we research, develop, and deliver appropriate innovative services and technology to meet their needs.

For information contact: info@neilsquire.ca or visit www.neilsquire.ca

INTRODUCTION

Definitions of Literacy

Literacy is a basic requirement for participation in educational, vocational and other community activities. Definitions of literacy developed in the past decade have become more unified and comprehensive and, as such, are becoming more and more relevant as society becomes more knowledge and information based. A common definition of literacy used by many organizations today is:

> Literacy includes the basic skills of reading, writing, and numeracy as well as computer skills and the 'soft skills' of leadership, problem solving, critical thinking, conflict resolution and communication with co-workers and customers in the workplace.

Learning@WORK website, (1999) *http://www3.sk.sympatico.ca/liters/*

In the Statistics Canada report (1996) *Reading the Future*, based on the findings from the International Adult Literacy Survey (IALS), literacy is defined as "the ability to understand and use written information to function in society, to achieve goals, and to develop knowledge and potential"(p. 4). This definition further divides the concept into three sub-types:

(1) Prose literacy: the ability to understand and use information from texts, including labels, pamphlets and media articles.
(2) Document literacy: the ability to identify and utilize information from a variety of formats including charts, tables, graphs and maps.
(3) Quantitative literacy: the ability to identify and manipulate numbers from a variety of formats using text instruction.

The Western Canada Workplace Training Network (1996) identified five levels of literacy for each of these sub-types (i.e. prose, document and quantitative types):

Level 1 indicates very low literacy skills, where the individual may, for example, have difficulty identifying the correct amount of medicine to give a child from the information found on the package.

Level 2 respondents can deal only with material that is simply, clearly laid out and in which tasks involved are not too complex. This is a significant category, because it identifies people who may have learned to use their lower literacy skills in everyday life, but who would have difficulty learning new job skills requiring a higher level of literacy.

Level 3 is considered as the minimum desirable threshold in many countries but some occupations require higher skills.

Level 4 and 5 show increasingly higher literacy skills requiring the ability to integrate several sources of information or solve complex problems.

Literacy Competence

Macht (2000) in his report *Literacy and Disability* found competent literacy skill to be associated with employment stability, higher incomes and access to knowledge – based employment. Literate individuals have a greater opportunity to receive training and improve their employability. Literacy skills are linked to work skills, health and self-esteem. Poor literacy skills reduce a person's opportunities in the labour market and these individuals are more likely to live in poverty than those who are more highly educated (pp. 8 - 11).

Literacy and Disability

Kapsalis (1999) reported the results of a statistical analysis of the IALS entitled *The Effects of Disabilities on Literacy* and found that 77% of people with learning disabilities (52% at Level 1) and 48% of people with physical disabilities in Canada function below Level 3 (15% at Level 1). The definition of "disability" used in this analysis was very broad and the report did not include those individuals over the age of 55; however, the report does draw attention to the complexity of the issues related to physical disability and the fundamental impact on an individual's quality of life of not attaining a minimum of Level 3 literacy and not having the opportunity to practice literacy skills in a social, volunteer or work context - the well-documented "use it or lose it" phenomenon (Statistics Canada, 1996).

People with physical disability often have a lower likelihood of employment success and of succeeding in a competitive job market because they are more frequently faced with multiple barriers as a result of their disability (Macht, 2000). Many people with significant disabilities have not had the opportunity to participate in basic educational programs within the conventional school system. This unfortunate situation has usually been attributed to barriers relating to access and communication, for example, the poor levels of literacy within the community of people with disability is related to the lack of opportunities for education (Darville, 1992). Panitch and Ticoll (1995) concluded that the legacy of a segregated education system and few literacy program options for people with disabilities in Canada is lower educational attainment, poor literacy skills and high unemployment rate.

A number of studies (Neil Squire Foundation, 1999; Panitch & Ticoll, 1995; Lockert, 1999) identified the lack of accessible literacy programming and services for people with disabilities that are learner-centred and inclusive. Learning disabilities, environmental barriers and health concerns also exclude this population from participating in currently available programs. Many people with complex multiple physical and learning disabilities require one-to-one attention, a specially designed environment and specialized equipment in order to make learning accessible and to facilitate learning new skills. Based on these previous studies and an extensive literature review Macht (2000) made the following general recommendations aimed at improving literacy opportunities and outcomes for people with disabilities:

1. Make all mainstream literacy programs accessible to people with all types of disabilities.
2. Foster cooperation and linkages within and between the literacy and disability communities.
3. Facilitate the documentation and widespread dissemination of best practices.
4. Provide opportunities for trainer education.

By providing effective literacy training the potential for some of this group to move on to further educational and career development activities can be facilitated. This would increase the opportunities for community integration or "full citizenship" for those who are most marginalized by their disability and ultimately create opportunities for improvements in their vocational, social, and economic status (Macht, 2000).

Considerable work has been done over the past decade in determining the critical role of language acquisition and the complex barriers to achieving literacy competency experienced by children with disabilities who use augmentative and alternative communication (ACC). These authors stress the need to balance a variety of academic and social literacy activities and the importance of weaving reading, writing and communicating together, and involving others in the learning activities, such as parents, family members and friends within the context of the learner (Sturn & Clendon, 2004; Paul, 1997). In contrast, Brewster (2004) suggests that "adult literacy has been seen as a set of neutral, measurable, asocial technical skills" (p. 46) and as primarily an individual achievement. He also notes that this remains the dominant conception in almost every sphere of adult literacy teaching and intervention. This "autonomous" approach parallels society's attitude towards disability as an individual problem of disease, incapacity, impairment and tragedy (Hammell, 1992) and contributes to the marginalization of people with disability. Literacy is not a single entity; there are multiple ways in which we act out our uses and meanings of reading and writing in different social contexts (Brewster, 2004; Street, 1994).

Little research has, however, been conducted to explore these multiple interpretations of the meaning of literacy from the perspective of the individuals with physical disability (Brewster, 2004; Butler, 1991). This type of consultation is a crucial component in developing effective literacy programs that address the needs of both this population and specific individuals (Macht, 2000). Practitioners in the literacy community have been extensively consulted with regard to professional development needs; however, "there seems to be very little information about any concerns people with disabilities themselves have regarding literacy programs" (Macht, 2000, p. 27).

Purpose of the Project

The purpose of this project, funded by the Canadian National Literacy Secretariat (NLS), is to explore issues of accessing and participating in literacy programs and otherwise improving literacy skills from the perspectives of people who have a physical disability. Information, based on their perceptions and experiences, has been sought about the factors – both personal and systemic – that facilitate and prevent people with

disabilities from participating in literacy initiatives. The study findings will be used to generate meaningful recommendations for improving the accessibility[1] of literacy programs and learning activities for people with disabilities.

Rationale for the Project

Literacy training for many people with disabilities plays a critical role in helping them move from a place of marginalization towards the mainstream of society. As a review of the literature revealed there is little or no available data describing the personal experiences of people with disabilities *who have difficulties with literacy*. This absence of information collected directly from people with disabilities who experience firsthand the disadvantages of low levels of literacy skill makes it difficult to state categorically what they perceive the barriers to developing and improving their literacy skills to be.

Our experience at the Neil Squire Foundation over the past twenty years has led us to believe that limited literacy presents a barrier to independence, community integration, education, employment, and, in general, adversely impacts one's self- esteem and a sense of self-worth. Conducting research in this area has enabled us to identify and better understand the impact that limited literacy skills has on one's quality of life, and the complex barriers presented to those who wish to develop and improve their literacy skills.

STUDY PROCESS

Data Collection

This study employed a qualitative research approach and used semi-structured interviews as the method of data collection. These interviews involved a series of pre-determined; open–ended questions (refer to Appendix 1). The interview schedule was used as a guide for all the interviews and allowed both the interviewer and the participant to maintain the focus of the interview and yet have the flexibility to probe for details about a specific topic or discuss issues as they arise. Each interview was audio-taped and transcribed verbatim with the permission of the participant.

Interviews were conducted in a number of different locations in British Columbia, New Brunswick, Ontario and Saskatchewan. The project manager (BC) conducted the interviews in British Columbia. Research assistants who conducted the interviews in the other provinces were recruited by advertising the position through various faculty members at the Universities of New Brunswick, Ottawa, Regina and British Columbia and via the regional offices of Neil Squire Foundation. These individuals were mostly graduate students in the health sciences and were provided with some written guidelines (refer to Appendix 2) and reported to the local Neil Squire Foundation offices.

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[1] For the purpose of this project, the term "accessibility" has been defined in the broadest terms to include not only access into buildings and premises and availability of support services, such as, attendant care, technical aids or assistive devices etc., but also the attitudes of others to disability.

They were also asked to commit to maintaining confidentiality and to provide field notes in which they reflected on the interview process after each interview.

Participant Involvement

In accordance with the qualitative research approach a "snowball" sampling method was a used by which representatives of the participant group were approached and asked to suggest names of, and even make the initial contact with, other people who might be interested in participating in the study. Permission was obtained to call these people or they were encouraged to contact the researchers directly expressing their interest.

Participants recruited self-identified as having 'difficulties with reading and writing.' The inclusion criteria were minimal, namely; participants were over 19 years of age, had a physical disability related to mobility and agility, had not attended a formal adult literacy program or had attended and dropped out before completion, and had the cognitive and intellectual capacity to appropriately give informed consent to participate in the interview process. The purpose of the study and their involvement was explained at the beginning of each interview and a verbal consent recorded on the tape. Throughout the study, and in disseminating the results, the participants will be referred to by a code derived from the abbreviation for the province they were interviewed in and an interview number.

Participant Profile

Twenty-seven participants with diverse disabilities were involved in the study (Table 1: Profile of the Participants); 12 in British Columbia, 6 in New Brunswick, 7 in Ontario and 2 in Saskatchewan. The participant group consisted of sixteen women and eleven men. The age of the participants ranged between 19 and 58 years, while the age of two participants was not known. The average age based on the obtained data was 40 years and the mean was 38 years. Twenty-five of the participants live in urban (large city) locations, such as, Moncton, Fredericton, Ottawa, Regina, Vancouver and Victoria while the remaining two live in the more rural areas of Perth-Andover and Bath, New Brunswick. The participants self-identified as having a diversity of disabilities (see Table 1), one participant was non-verbal and one had significant speech difficulties. Two participants (NB4 and NB5) had acquired their disability since attaining adulthood. Three participants spoke more than one language; one (ON3) spoke Greek, English and French and also knew American sign language, two (NB5, NB6) spoke English and French, and one participant's (BC3) first language was Finnish. Two participants were working at the time of the interview for Statistics Canada and as a Licensed Practical Nurse (LPN). Four participants (NB5, ON2, ON4 and SK2) identified that they had children and were actively parenting.

Table 1: Profile of the Participants

Participant code	Gender	Age	Location	General description of disability	Literacy level (self-defined)
BC1	F	41	Vancouver	Unknown	3
BC2	M	41	Vancouver	Cerebral Palsy	3
BC3	M	41	Vancouver	Unknown	3
BC4	M	43	Vancouver	Cerebral Palsy Epilepsy	1
BC5 Recording incomplete	F	43	Richmond	Cerebral Palsy	3
BC6	F	47	New Westminster	Right Hemiplegia	3
BC7	F	51	Vancouver	Cerebral Palsy Non-verbal uses speech synthesizer	3
BC8	F	44	Aldergrove	Cerebral Palsy	3
BC9	F	58	Vancouver	Cerebral Palsy	Not identified
BC10	F	26	Victoria	Cerebral Palsy	Not identified
BC11	M	21	Victoria	Cerebral Palsy	Not identified
BC12	F	35	Vancouver	Cerebral Palsy	Not identified
NB1	M	40	Fredericton	C6-7 Quadriplegia	Not identified
NB2	F	53	Fredericton	Juvenile Rheumatoid Arthritis	3
NB3	M	30	Perth-Andover	Spinal Cord Injury	Not identified
NB4	M	58	Bath	Acquired disability 'blood clot in heart'	3
NB5	M	51	Moncton	Epilepsy Acquired disability	Not identified
NB6	M	19	Moncton	C6-7 Quadriplegia	Not identified **Literacy level**

Participant code	Gender	Age	Location	General description of disability	(self-defined)
ON1	F	43	Ottawa	Psychiatric /back problems	3
ON2	F	30	Ottawa	Spinal Bifida Paraplegia	Not identified
ON3	F	35	Nepean	Chronic pain	3
ON4	F	44	Ottawa	Left hemiplegia	3
ON5 Poor quality recording - No transcript	F	Not known	Ottawa	Cerebral Palsy	Not identified
ON6	M	41	Ottawa	Cerebral Palsy	3
ON7	F	Not known	Ottawa	Cerebral Palsy Speech difficulties	3
SK1	M	30	Regina	Muscular Dystrophy	3
SK2	F	43	Qu'Appelle	Cerebral-vascular accident	Not known

STUDY FINDINGS

Twenty-six interview transcripts were analysed by the researchers and constituted the data in this study. One transcript (BC5) was incompletely recorded resulting in 50 percent of the question responses being unavailable for analysis and one interview (ON5) was not transcribed due to poor recording quality and therefore not included in the analysis. The transcripts were read several times in detail by the researchers and a number of dominant themes were identified. These themes were further defined and illustrated using data (participant verbatim quotations). They represent the topics discussed most frequently and in the most depth by the participants.

Description of Self-defined Literacy Difficulties

The purpose of the study was to explore issues of literacy from the perspective of individuals who described themselves as having literacy difficulties. To better understand the extent of their perceived literacy problems each participant was asked to identify the definition which best described their literacy problem. The definitions used corresponded with Levels 1 - 3 (Western Canada Workplace Skills Training Network, 1996) provided earlier in this report and were as follows:

1. I can't read or write at all.
2. I have trouble reading and writing anything.
3. I can read and write some things but have problems with others.

Sixteen participants identified the third definition as best describing their current literacy status. One participant (BC4) chose the first definition as best describing their literacy difficulties. Nine participants either did not choose to use these definitions in describing their perceived literacy issues or, in some instances, the interviewer did not give them the choices in the interview. It would appear that at least sixty-two percent of the participants in this study were functioning at a literacy level considered to be the minimum desirable threshold.

Learning Assessment

Three participants (BC12, NB1, and NB6) remembered during their school years having learning assessments administered and that a learning disability was identified.

Several participants said that teachers or family members had told them they had a learning disability but did not remember having any formal testing. None of the participants recalled having the results of formal tests or what it meant to have a learning disability explained to them.

As one participant (BC12) said:

> *"I was told I had a learning disability a lot … meaningless.
> Meant they didn't look deeper – considered that I had
> nothing to achieve so why bother to ensure that I learnt?"*

Several participants (ON7, SK2, and SK3) have been tested in more recent years and understanding more about learning disabilities has assisted them to better understand the difficulties they experienced in school.

Barriers to Learning

- **The Emotional Response to Literacy Difficulties**

The experience of having literacy problems was clearly associated by a majority of the participants with a wide range of emotional responses related to an undermined sense of self worth and self-esteem, anger, frustration, inability to contribute fully to society, lack of motivation, embarrassment and fear of censure. Seventeen participants used words connoting intense and sustained emotion related to their perceived lack of literacy competence. These interviews also showed that these participants had also reflected on their literacy problems and their impact on their lives and were generally more articulate and comfortable discussing more personal issues related to the topic. The following examples of participants' words illustrate the depth of emotion and impact on their quality of life:

> *"It's such a struggle … frustrated … overwhelmed, I cry a lot
> … get self-doubt … it all takes so long … I'm stuck, never
> gonna get out of this situation … degrading … I developed a
> hostile attitude … I get mad … such a struggle … feel stupid
> … panicked … afraid to ask for help … don't want people to
> know… I'm so shy … stumbling along by myself."*

The participants, in making these comments, were sharing the feelings related specifically to their literacy problems. These feeling are additional to the emotional energy required of individuals managing a disability in society. Literacy is seen as a "normal" taken-for-granted activity; a way of maintaining a connection with the able-bodied community which is however, denied them. These emotional responses reflect an underlying theme of judging oneself as "inferior" or "incompetent" and internalizing a depreciated view of one's own potential. Such emotions are barriers to learning and need to be acknowledged and accommodated for by those who plan and implement adult literacy programs for people with disability.

- **Attitudes and Expectations of Others**

Twelve participants (46%) poignantly identified how the attitudes and expectations (and on occasion the misplaced best intentions) of teachers and family members (primarily mothers and foster mothers) influenced their ability to access support, information, and technology. The expectations and priorities of others, particularly in the participants' formative years, were perceived as negatively influencing their performance and ability to learn the basics of reading and writing. Inherent in these

comments was the impact and influence of their disability. Having a disability appeared to be associated by others with a low expectation or value of the individual as a contributing member of society, and the disability influenced decisions made by important others at an early stage in the participants' lives.

> *"My family labeled me as feeble or mildly mentally retarded."*
> (BC6)

> *"People see the disability and don't expect much of you but you expect a lot of yourself – so it's really an unfair assessment."* (BC12)

The participants recognized that their teachers had no experience working with people with disabilities, were mostly ill-prepared and not adequately supported to address academic issues and disability. This lack of experience and ability is reflected in some of the participant's comments:

> *"The teachers told my parents that I was too much trouble."*
> (BC9)

> *"Teachers paid attention to the "best" ones and the "worst" ones were left behind."* (NB5)

> *"Teachers seemed insulted if you asked a question – took it personally."* (NB2)

> *"I was told that I was never gonna do anything, go to College, excel academically."* (BC2)

> *"School considered me lazy, unteachable, told me I was unemployable, not prepared to waste time or money on me."*
> (BC6)

Several participants spoke of the option of segregated classes in school often in derogatory terms related to the stigma of being grouped with others with a diversity of physical and mental disabilities.

> "*Mum didn't want me relegated to the "opportunity class" – those were for retards."* (NB2)

> *"They wanted to put me in the "crayola" class, so I quit."*
> (NB3)

> *"I was in "special" class, I was never in regular class, I needed a slower pace, more attention … it's O.K. in a*

> *sheltered learning environment, but you still have to cope*
> *with the outside world." (BC12)*

The participants spoke of the impact their disability had in terms of needing time, a slower pace, an accessible environment and adaptive technology and the lack of adaptation by others or expertise in teaching "outside the box." One participant (BC12) compared her experience with the "freedom" and "choice" of able-bodied learners when she made the following comments:

> *"For an able bodied person they can choose when to cook*
> *dinner … when to clean or whatever … for the person with*
> *the disability it's kind of challenging to hear about that kind of*
> *freedom 'cause its always been about time and structure …*
> *it gets scary out in the world."*
>
> *"It's difficult to be a self-advocate because I'm always*
> *subject to other people's schedule and structure."*
>
> *"You gotta learn but they make you do it in their timeframe –*
> *not positive or constructive – feel pressured by other*
> *people's expectations and time limits."*

As another participant said:

> *"I never seemed to live up to their expectations, sent a*
> *wrong message, that the level you achieved isn't good*
> *enough" (NB5)*

The expectations of parents have been identified as a strong indicator of a child's success in developing literacy skills in terms of encouraging and monitoring schooling, providing opportunities to participate in literacy activities at home and motivating and encouraging the child to learn (Browning, 2002). Participants spoke primarily of the negative (although occasionally well-intended) influence of parents:

> *"Mum tried to console me by saying "education isn't*
> *everything"." (BC2)*
>
> *"Dad couldn't read himself; I guess I'm just like him." (BC4)*
> *"They [the family] called me stupid and lazy compared to my*
> *two brothers." (NB2)*
>
> *"My parents didn't have much schooling themselves." (NB5)*

Where people did offer constructive help in learning to read and write, the participants primarily identified their mothers (or foster mothers) and friends who "got books," "practiced writing with me," and "taught me to use a computer."

It appeared that "being different" influenced the expectations of those people who could have had a beneficial impact on the participants' learning. As one participant said "*people don't want to put themselves in my shoes or think about the reality of living with a disability*" (BC12). A general lack of understanding about the consequences of a physical disability and unchallenged myths about the capabilities of people with disabilities appeared to permeate the participant's accounts of their learning experiences. These experiences suggest that designers and instructors of literacy programs involving people with disability need to engage in disability awareness training initiatives. Such initiatives need to provide the opportunity for instructors to ask questions and increase their comfort level by actively involving learners with disabilities.

- **Negative Experience of School**

Twenty (77%) participants spoke at length about their negative experiences at elementary and high school. These experiences focused primarily on their perception that they did not fit into the existing education system:

> "*The system caters for groups of 30-40 people, if you need help one-to-one or you don't fit in, you have no chance of learning anything.*" (BC1)

The participants' perceived that rather than address the accommodations they needed to support their learning, the education system, particularly the teachers, "just wanted to push me through the system" (BC2). As a result, several of the participants found themselves in upper Grades with minimum ability to read and write, with "*no F's, A's or B's, nothing on my school record but P's*" (BC1). These participant comments reflect some of the problems:

> "*After trying Grade 11 three times and failing, they got tired of me so they put me in Grade 12 – I managed until exam time but then panicked – couldn't read the instructions.*" (NB2)

> "*Did Grade 1 twice, didn't pass Grade 2 but moved on to Grade 3 and 4 anyway.*" (NB6)

> "*I resubmitted some assignments (cheated), but the teachers didn't care. Got A's but didn't know anything. You think you're getting away with it, but your screwing yourself and don't realize it until later.*" (NB3)

Participants felt that "*school made it hard to learn*" (SK1), "*the teachers didn't know how to help,*" "*felt under pressure to produce, needed more time, slower pace, large print books*" (BC10) and "*had to repeat Grades with younger kids who would make fun of me*" (NB6). Some participants were offered assistance in the form of scribes

and tape recording as an alternative to writing English exams, but these well-intentioned accommodations inserted into the regular system added another layer of complications and meant that the participants did not actually learn the basics of reading and writing.

A number of participants identified that they were easily distracted when younger, that they became discouraged when they did not appear to be achieving in the same way as their able-bodied classmates. Some of the participants were also coping with associated physical problems, such as, poor coordination and vision difficulties. One participant gave an example of the school's inability to make even a small accommodation:

> *"I had to sit at the back because my name was later in the alphabet and I couldn't see properly." (NB2)*

Another participant described the humiliation of not being able to get into the classroom:

> *"I ended up sitting out in the hall, used to drop my papers on the floor, they gave up on me." (BC4)*

Twenty of the participants (77%) are over 30 years of age and as such their experiences and perceptions of the school system may not reflect the current situation. In Canada, the approach during the 1960's was the creation of segregated classrooms, schools and institutions. In the 1970's, the typical response was a creation of special classrooms and developmental centres with a diagnostic-remedial approach. In the late 1970's to the mid 1980's, there was a move towards integration of children with special needs into regular classes. While younger people with disabilities may have an improved and more positive experience of the school system, those experiences shared by the predominantly older participants in this study provide valuable information for adult literacy program developers. It is this group of learners who may choose to upgrade their literacy skills. Negative experiences of this nature may present significant barriers to learning for this age group must also be acknowledged by planners and instructors.

- **Access to Programs and Technology**

This category – access to programs and technology - is addressed briefly as it is most commonly associated with physical disability. In this study, however, it did not emerge as a significant theme. A few participants identified that they did not have a computer; one person identified that he had wanted to enroll in a computer class but was told he had to have Grade 12 in order to do so (he has Grade 6), and several participants knew that "*there were programs out there but they were difficult to get to" (BC7*) mostly due to lack of transportation.

Motivation to Upgrade Literacy Skills

The participants in this study were asked to explain how increasing their literacy skills would enhance or improve their lives. Seventeen participants (66%) addressed the question and their responses revealed not just the perceived advantages of greater literacy skills but also their sadness and the sense of loss resulting from living a life without these essential skills. As several participants said:

> *"Sentenced to a life of academic poverty, education gives credibility to life but that was denied me."* (BC2)

> *"Dream of future taken away from me."* (SK2)

> *"I've not had the ability to read what I want – comic books or Shakespeare."* (BC12)

> *"You can train your head and then there's nothing stopping you, I try to tell my kids not to end up like me."* (NB5)

The participant's insights have been organized under the following headings:

- Reclaim self-esteem
- Afford new interests / opportunities
- Enjoy reading and writing
- Communicate with the world

- **Reclaim Self-esteem**

The participants spoke of the increase in self-esteem and confidence they anticipated gaining with increased literacy skills, and that they would stop feeling *"stupid," "self-doubt," "regain a sense of lost potential," "feel like I measure up to my able-bodied friends,"* and *"be less afraid to ask for help."* As two participants said: "*I'd be a lot further ahead if someone had taken the time to teach me to learn the basics of reading and writing*" (BC2), and "*my life could have been a different story … who knows what I would have been able to do*" (SK1).

- **Afford New Interests / Opportunities**

Participants spoke of the possibility of pursuing further education, volunteering, getting a job or a better job "*an enjoyable one instead of anything that came along or is offered,*"(SK1), applying for promotion, "b*e less afraid of someone finding out what I can't do at work,*" and achieving a Grade 12 education.

- **Enjoy Reading and Writing**

Several participants identified that they loved reading and just wished that it could be less effort for them. Many participants wanted to enjoy reading for the relaxation and intellectual improvement they associated with it. Their comments illustrate this desire:

> "*Oh my goodness, the finest works in literature you miss out on … that could have been as basic as a comic book or as advanced as Shakespeare.*" (BC2)
>
> "*It's all to do with your imagination – stretching it."* (BC8)
>
> "*I'd be able to understand more, about things I've not seen yet*" (BC10), and *"nothing beats first hand experience but if you can read you can get all sorts of interesting information*." (BC11).

Two participants (SK1, NB5) identified how frustrating it had been for them not to be able to read their children's school books and not to be able to help them with their homework, problems which they saw as being resolved had they had the opportunity to learn to read and write earlier. Several participants wanted to be able to write their life stories, letters, e-mail messages to friends, and reports at work.

- **Communicate With the World**

Several participants spoke of sharing their knowledge and experience, both in terms of living with a physical disability and in their work, volunteer and advocacy activities, with a larger audience. This desired ability was associated with an increased contribution and acceptance by society. For one participant (BC11) it was critical to offset physical disability by compensating, or being more competent, in other areas of life and being able to read and write competently gave that person the ability to effectively do that. Several participants spoke of relating to the world more effectively than they currently felt able to do.

The participants provided a number of specific activities that they were unable to currently do because of their lack of literacy skills. These included writing a resume, work-related reports, letters, day-to-day filling, signing forms, reading work-related manuals and interesting books, using a computer, going to school or college, finishing Grade 12, becoming a counselor and getting a job.

Pervasive in the participants' responses to this question was a sense of "lost resources," "the missed contributions to society" that these individuals, constrained by their lack of literacy skills, represented. There was a sense of the "frustrated intellects," the exclusion from full participation that the added handicap of literacy difficulties causes in addition to a physical disability. The frustrations involved "living a dumbed down life" the long term impact and the undermining of the self-esteem and confidence desperately needed by these individuals to manage social interactions with a physical disability.

Identifying Specific Literacy Problems and Strategies to Promote Learning

The participants were asked to identify their specific problems with reading and writing and to share strategies which they found useful in promoting learning. The participants spoke of the difficulties caused by physical problems resulting from their disability, such as, poor coordination, difficulty holding / manipulating a pen or a book, spasticity, and inability to read small print.

- **Writing Problems and Strategies**

It was clear from the participant's comments that problems with writing were impacted more by the disability consequences and were associated with more expressions of frustration. It can be speculated that this may arise from the fact that writing is a more public activity, and depending on the demands placed on the individual, can be open to more scrutiny (and therefore, more negative attitudes and comments) than reading which tends to be a more private activity.

Twenty-three participants (88%) specifically identified problems with writing. These ranged from knowing how "to lay out and word things" [structure of language], "creating a sentence that someone else can understand," "write more than just simple words," "spell simple common words like chocolate" [difficult to access dictionary or Internet for information], and "use grammar correctly." As one participant said: "learning to write has been very important to me" (BC10). Many participants were only able to print large and they found writing to be tediously slow. As one participant explained: "*I physically can't keep up with what my head is thinking, so I miss words and sections in my writing*" (BC2). The writing problems they described were in sharp contrast to the verbal skills that many of them felt they had. Several participants described themselves as "articulate," "good communicators," "good verbally" and as "having a good vocabulary."

Few of the participants provided specific examples of strategies that assisted them in improving their writing. Most strategies involved "practicing," "taking it step-by-step" and using the computer and spell / grammar checks.

- **Reading Problems and Strategies**

Twenty-four participants (92%) identified a diversity of complex problems, involving both the mechanics of reading and comprehension, which they experienced when trying to read. Many participants could read the newspaper headlines but not the content; children's or teenager's books but nothing more complicated; content accompanied by pictures like flyers or comic books but not dense paragraphs like those found in the Bible or complex forms, or content structured in columns or tables or technical and legal language. Participants spoke of how they remembered with apprehension being made to read in front of others and as one person said; "*I have to read alone, I don't want anyone around me, it's too embarrassing*" (ON3). A number of the participants commented that they "had difficulty understanding words," "got them mixed up" or "forgot the earlier part of what they had read." As one

participant said: "*I might be able to write and read difficult words, look them up in the dictionary but I'd still draw a blank as to what they meant an hour or so later*" (SK2).

Eleven participants shared specific strategies they found useful in reading. These included: using verbal cues; listening to an audio-book and reading the book at the same time; underlining words but not understood and asking someone to explain; using a marker to track the words; and reading aloud to themselves.

- **Facilitators of Literacy Learning**

 Nearly all the participants offered general examples of either technology or instructional strategies that did, or that they felt could potentially facilitate their learning. The most common one was using a computer and having access to software programs like *Dragon Naturally Speaking* (turns speech input into text output) and *Speech Assisted Reading and Writing Program* (SARAW). Other technology assistance was gained from computer keyboards with bigger keys, using adapted input devices (e.g. track balls, adapted mouse), having the option of changing the computer font size, using computer games, watching educational and close caption television, and accessing the Internet.

The participants also spoke of how important it was to be consulted about how they learn in order to help them establish their own learning goals, make learning positive and not feel judged or pressured by those people assisting them. They frequently identified valued friends or roommates, knowledgeable teachers or support groups who motivated them to keep trying to learn, and who at the same time allowed them to go at their own speed and as such made learning fun (like a game or charades).

One-to-one instruction in their home or in a small structured environment was considered to be important by many of the participants, and they gave examples of instructional strategies that they had found useful in these one-to-one situations: using diagrams and pictures, singing the words, the instructor reading aloud with them and visualizing the words in a sentence. They considered it important to build confidence, make learning relevant to their lives and "to start simple."

RECOMMENDATIONS / USEFUL STRATEGIES

Awareness

As evidenced by our initial difficulties in recruiting participants for this project, this group is by definition hard to reach. Effective strategies are needed to get the message across that literacy programs are available to them. Individuals with physical disability need support in getting plugged into the system. Potential learners frequently do not realise that colleges do provide literacy programs which they can attend even though they have reading and writing difficulties. There is also a need to create awareness of disability-related issues amongst literacy practitioners.

Assessment

A thorough assessment of each individual learner at the start of any literacy program would allow those providing the service to be fully informed about the person's unique learning needs and to determine the exact nature of the person's literacy issues. It would also allow service providers to gauge the level of support and instructional level that the learner requires.

The following factors could be included in such an assessment:

- Literacy level (e.g. comprehension, reading, writing levels and abilities)
- The learner's level of interest / motivation / own attitude
- Learning disability
- Cognitive difficulties (e.g. memory problems, attention deficit)
- Psychiatric problems
- Mobility and agility and whether mobility aids are needed
- Social factors
- Social and family circumstances - support network, community involvement
- Financial circumstances
- Perceptual problems
- Sensory impairment – need for sensory aids
- Insight (e.g. some participants do not recognise the extent of their literacy problems)
- Emotional state – there are some powerful emotions, notably anger and frustration associated with literacy problems

Principles of Adult Education

In order for learners to improve their literacy skills, the service provider must be knowledgeable of these principles and innovatively incorporate them in facilitating learning.

- **Pacing**
  In order to address the different learning needs and styles of the adult learner it is critical that the learning takes place at a pace and in a manner that suits the learner. People with physical disabilities often comment that information is presented in a manner that is too fast for them to comprehend or in a way that they find inaccessible due to complicating factors such as sensory impairment. It is also crucial that the persons learning style is understood and addressed (e.g. some people learn better from visual information, others from auditory instruction).

- **Autonomy and Self-direction**
  Learners need to be free to direct themselves. Instructors must actively involve them in the learning process and serve as facilitators for them. Specifically, instructors must get the participants' perspectives about what topics to cover and let them work

on projects that reflect their interests. Instructors need to act as facilitators, guiding participants to their own knowledge, rather than supplying them with facts.

- **Life Experience**

Learners have accumulated a foundation of life experience and knowledge that may include work-related activities, family responsibilities and previous education. They need to connect new learning to this existing knowledge and experience base. It is important that these adult experiences and capabilities are fully acknowledged.

- **Goal Orientation**

Instructors must clearly demonstrate to program participants how each part of the program has been designed to assist them to attain their personal goals.

- **Relevancy**

Learners need to understand the reason for learning something. Instructors need to collaboratively develop learning objectives with individual participants at the beginning of the course and be prepared to revise them as the course progresses. Such objectives used as a dynamic rather than static mechanism promotes relevancy of content and instruction and ensures accountability.

- **Practicality**

The adult learning literature suggests that adults are frequently motivated to learn by the desire to achieve a specific task or acquire a skill that has a practical function in their lives. Learners need not necessarily be interested in knowledge for its own sake. As such, instructors need to explicitly demonstrate how the topic being taught will be useful to the learners.

- **Respect**

Instructors must acknowledge the wealth of experience that adult participants bring to the classroom. Learners must be regarded as equal partners in the educational process and be encouraged to freely express their opinions in class, one-on-one sessions and at key points during the program. Learners should also be given the opportunity to provide feedback to the instructor and see this input acted upon in revising and modifying course content and instructional strategies.

- **Self-Esteem / Confidence**

Issues of self-esteem and confidence are deeply personal and sensitive, and, as such, can cause people to become defensive and embarrassed. It is therefore imperative that instructors are aware of the potential learning barriers that these issues represent and act appropriately. Being disillusioned with the education system and demoralized by the lack of constructive support can potentially prevent individuals from accessing appropriate services and claiming their right to support and assistance. The attitude of others may result in low expectations, teasing and rejection. It is critical that instructors are sensitive to these issues and work to build confidence and promote self-esteem.

Professional Development of Literacy Practitioners

- **Previous Experience**

Previous experience, on the part of learners and instructors, of learning situations involving people with special needs represents a valuable resource. Accessing instructors that are knowledgeable about physical disabilities has been identified as beneficial for both learners and instructors involved in providing new programs.

- **Peer Instructors**

Hiring people with physical disabilities as instructors can assist in ensuring an understanding of the issues of living with a physical disability and how these might present barriers to learning. Peer instructors can also act as influential role models and assist with problem solving using their own experiences of living with a disability.

- **Need for Sensitivity Training**

Given the negative experiences articulated by many of the participants in this study, it is essential that the learning environment be equitable and inclusive. The quality and effectiveness of the learning relationship developed between the instructor and the learner are crucial in establishing the support and trust necessary to promote learning and encouragement.

- **Support for Literacy Practitioners / Instructors**

This is a difficult undertaking and it is important that those providing the service have access to appropriate support and constructive and systematic performance evaluation.

Accommodation

- **Resources, Learning Materials and Technology**

Accessing and choosing effective resources, learning materials and technology to support individual learners is of central importance. Many of the participants in this study mentioned the value of having access to a computer and appropriate software. Assistive technology has the potential of assisting the learner to interface comfortably and productively with the computer.

- **Approaches to Learning and Teaching Techniques**

In order to make learning accessible it will sometimes be necessary to creatively adapt teaching methods used in a more conventional educational environment (e.g. T.V., CD-ROM, DVD, Computer), and to develop instructional strategies specifically to meet individual needs.

- **Opportunity to Practice**

Having the time and space in which to practice skills in order to consolidate learning can be critical in assisting the learner to succeed.

- **The Learning Environment**

It is necessary to ensure that the learning environment facilitates learning rather than inhibiting it. This includes ensuring physical comfort, limiting distracters, balancing group and individual instruction according to the learners' needs and ensuring that all learning media are accessible to the learner.

Architectural Modifications

There are many features of a building and the surrounding environment, such as stairs and narrow entrances, which can make access and egress difficult for a person with a physical disability. Care should be taken to locate literacy programs in buildings and locations which conform fully to accessibility standards and requirements and which facilitate full participation for all learners.

Funding

A lack of adequate funding is clearly a barrier to the provision of literacy education, but it is also a political issue. Given the well-established connection between limited literacy and poverty, we recommend that funding is made available to assist learners with physical disabilities to take full advantage of available literacy programs. The provision of adequate and sustainable funding depends on the will and commitment of provincial and federal governments and continued lobbying by advocacy organizations and the able-bodied population is also necessary.

Transportation

Many people with physical disabilities do not have their own vehicle and have problems accessing appropriate public transportation. Program developers in choosing a location need to also consider and investigate the availability of transportation and parking options for people with physical disabilities. We need to either assist the learner to get to the program or deliver the program to them in their home. This is especially important in small rural communities where there are fewer transportation options and suitable literacy programs are not as readily available.

Partnership

Collaboration between stakeholders – advocacy organizations and program providers – is needed to build partnerships, capitalize on experience and minimize overlap and redundancy in program provision. Linkages between disability groups and literacy groups must be established at the program level.

CONCLUSION

People with significant physical disabilities that have literacy needs are among the most marginalised and difficult to reach people in Canadian society.

We can define "significant" in terms of the impact of the disability upon a person's ability to achieve citizenship. "Citizenship is composed of three analytical dimensions: (1) rights and responsibilities, (2) access, and (3) a feeling of belonging. All three dimensions must be present in order for someone to be a full citizen, although not everyone has the same rights, responsibilities, access or feelings of belonging" (Valentine 2001).

It is clear from the findings of this study that having a physical disability *and* literacy needs makes it more difficulty for individuals to achieve full citizenship. It is, therefore, our intention to disseminate the findings of this study as widely as possible (i.e. to academics, people with disabilities, literacy practitioners, government policy makers, and organizations supporting people with disabilities and the media) in the hope that we can contribute to the development, promotion and adoption of best practices and guidelines for establishing accessible literacy programs for people with physical disabilities.

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APPENDIX 1: Interview Questions / Guide

- Thank you for agreeing to help us with our research. You are helping us because you feel you have some trouble with reading and writing. Can you tell us how you think your trouble with reading and writing has made a difference in your life?
- How is your reading and writing? Which of these sentences describes your reading and writing best?
    - (1) I can't read or write at all
    - (2) I have a lot of trouble reading and writing anything
    - (3) I can read and write some things but have problems with others
- Would you like to be able to read and write better? If yes, why? If no, why not?
- How has learning to read and write been for you? Would you say it has been easy or difficult hard?
- Have other people tried teaching you to read and write in the past? Who were they?
- How do you feel about being able to read and write?
- What has made it hard for you to learn to read and write?
- Do you think your physical disability made it harder for you to learn to read? If yes, how.
- Has it made it harder for you to learn to write? If yes, how
- What helped you to learn to read the way you can now? (Were there books, tools/equipment, people etc.)?
- What do you think would help you to improve your reading skills in the future?
- How do you think reading and writing better would change your life?
- Have you ever been told you have a learning disability? If yes, do you know what kind(s)?
- If yes, did the places where you learned to read and write know that you have a learning disability?
- Do other people know you have trouble reading and writing? If so, what do they think? If not, why don't they know?
- Do you know anyone else who has trouble reading and writing who might be interested in helping us with this research?
- Once we have some more information to share, would you like to take part in a group discussion about what we learned?

Appendix 2: Guidelines for Research Assistants

The Interviews
- This is a very sensitive issue which can cause people to become defensive and embarrassed. It is therefore imperative that you are aware of this and act appropriately.
- We anticipate that each interview will last for an hour.
- You should be prepared to allow it to continue after an hour has elapsed if you have not asked all the relevant questions or if the participant is still offering appropriate information.

- Semi-structured interviews are conducted with a fairly open framework which allow for focused, conversational, two-way communication. They can be used both to give and receive information.
- Unlike the questionnaire framework, where detailed questions are formulating ahead of time, semi-structured interviewing starts with more general questions or topics.
- Not all questions are designed and phrased ahead of time. Some questions are created during the interview, allowing both the interviewer and the person being interviewed the flexibility to probe for details or discuss issues.

Confidentiality
- At the start of each interview the participant should be told that all replies will be kept confidential.
- You should ask if he/she has any questions and obtain verbal consent for us to record and use the interview responses for research purposes before the interview begins.
- This conversation should be recorded on the audiotape.
- We will use ID numbers instead of names to identify each interview.
  (They will be coded according to the Province and the number of interviews completed, e.g. SK 1, SK2.)
- All records of the person's name and corresponding interview code will be destroyed once the research project is concluded.

Interviewing Technique
Semi-structured interviewing is guided only in the sense that some form of interview schedule, in this case a list of questions, is prepared beforehand, and provides a framework for the interview. Please use the questions as written. You will need to review them and think about possible probes and prompts which could follow from answers that might be given.
In designing these questions we aim to:
- Avoid jargon.
- Think of the language of the respondent and frame the questions in a way they will feel familiar and comfortable with.
- Try to use open not closed questions.
  (Closed questions encourage Yes/No answers rather than getting the respondent to open up about his or her thoughts and feelings).
  e.g. Closed - Should the president resign?
   Open - What do you think the president should do now?
- A strategy often employed in this type of interviewing is to try to encourage the person to speak about the topic with as little prompting from the interviewer as possible. One might say that you are attempting to get as close as possible to what your respondent thinks about the topic, without being led too much by your questions. Good interview technique therefore often involves a gentle nudge from the interviewer rather than being too explicit.

♦ If the respondent has difficulty, says he or she doesn't understand, gives a short or tangential reply, then the interviewer can move to the prompt which is more specific. Hopefully this will be enough to get the participant talking.
♦ It may not be necessary to ask ALL of the proposed questions. The participant may provide comprehensive information in answering earlier questions which may render some of the other questions redundant.
♦ Make sure you are really entering the personal/social life world of the participant rather than forcing him or her, perhaps reluctantly, to enter yours.

Recording the Interviews
♦ Before you conduct your first interview you will need to pick up 2 cassette recorders from the Neil Squire Foundation branch office in your region. You will need to familiarise yourself with their operation prior to conducting interviews.
♦ Each interview must be recorded on both machines so that we have a back-up tape in case of equipment failure.
♦ You will also need a power supply and/or batteries for each cassette recorder.
♦ If you are using mains power you will also need an extension cord with power bar to accommodate both cassette recorders.
♦ If you are using batteries please make sure they have sufficient charge in them to last for the whole interview.
♦ You will also need two 90-minute cassette tapes for each interview – one for each machine.
♦ At the start of each interview conduct a short test to make sure that both you and the participant are being picked up satisfactorily by the cassette recorder. If either are too faint then move the cassette recorder (or external microphone if you are using one) nearer to that person.
♦ You must remember to turn over the cassettes in both machines at the end of side A in order to capture the entire interview.
♦ At the end of the interview label each cassette "Neil Squire Foundation Literacy study" and add the participant's code # and the date of the interview.

Mailing Instructions
♦ Mail both cassette tapes from each interview via Canada Post "Express Post" to Tim Readman, Project Manager.
♦ Please mail them on the day after the interview at the latest.
♦ Please pack the tapes in a padded/bubble mailer and mark the outside 'Fragile'.
♦ The following information will be sent by each interviewer after each interview via e-mail to Tim Readman, Project Manager, for reference purposes. This will be kept in a secure place.
    Interview ID #:
    Respondent Name
    Age: Gender:
    Address:
    Phone:
    E-mail:

General description of disability: (Based on the clients own description)
- ♦ Once you get confirmation that this e-mail has been received you must delete it from your 'sent mail' and 'trash/recycle' mailboxes

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