

## Literacy and Disability: A Study of Transformation

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## Literacy and Disability: A Study of Transformation

### Diane Driedger and Nancy Hansen

Low literacy rates and unequal access to education are a huge form of exclusion for disabled people worldwide. It has been estimated that around 50% of disabled adults experience literacy barriers, such as lack of access to information and physical, print and verbal barriers (Literacy and Disabilities Study Fact Sheet, 2004). This reality persists, despite the fact that access to education is one of the main human rights highlighted in the United Nations Convention on the Rights of Persons with Disabilities (2006): "States parties recognize the right of persons with disabilities to education. With a view to realizing this right without discrimination and on the basis of equal opportunity. States parties shall ensure an inclusive education system at all levels and lifelong learning..." (Article 24, p.

In hopes of remedying this situation for persons with disabilities in Canada, we, as co-investigators, worked with Making a Connection, a three-year Canadian participatory action research study, with Independent Living Canada (ILC), the national organization of independent living centres, (a national group of organizations run by and for disabled people to provide consumer-run services). We carried out research in conjunction with five ILC locations across Canada: Thunder Bay, Ontario; Halifax, Nova Scotia; Saskatoon, Saskatchewan; and Duncan and Vernon, British Columbia, thus, encompassing both large urban cities and small town regional settings.

This project defined literacy as "meaning-making" in peoples' lives. People with various types of disability, mental and physical, defined their own personalized literacy goals. This chapter explores whether disabled people felt that they improved their quality of life through improved literacy skills.

## Literacy and People with Disabilities in Canada

Although slowly changing, the education system historically has not served disabled people well. The standard of education offered disabled people rarely matched the academic rigor that non-disabled people experienced (Sutherland, 1981). Medical labeling has dominated the education process of disabled people (Barnes, 1991). Many individuals were considered "unteachable" simply because of their impairment (Hansen, 2005). Caught in a cycle of low expectations, spaces of disabled education were often remote, residual and focused on time filling rather than actual education (Ibid.). Consequently, many disabled adults have very weak literacy and numeracy skills.

People with disabilities experience low functional literacy rates in all societies, including Canada. This means that people have difficulty navigating the systems of everyday life in terms of reading, writing, and interpreting numbers. According to the literacy.ca website, 20% of adults with disabilities have less than a ninth grade education, as compared to 8.1% of adults without a disability. "Disabled people make up a disproportionate amount of the 48% of Canadian adults who function at the two lowest literacy levels" (Literacy and Disabilities Study Fact Sheet, 2004, p.1).

Carpenter and Readman (2004) examine why people with physical impairments have such a low rate of literacy. Based upon interviews with 27 disabled people in four Canadian provinces, their study points to attitudinal barriers as limiting factors for the disabled people they interviewed about their experiences in literacy programmes. The first barrier is the disabled person's own atti-

Diane Driedger, PhD, University of Manitoba. Nancy Hansen, PhD, University of Manitoba. tude toward learning and school, and the teachers' and schools' attitudes toward the disabled person. Often, these attitudes have been negative, as the learners have been labeled by parents and teachers as slow or special learners and have not fit in with other nondisabled students. The primary difficulty was that "'being different' influenced the expectations of those people who could have had a beneficial impact on the participants' learning" (Carpenter and Readman, p. 16). Indeed, expectations of parents and teachers tended to be low: "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" (Carpenter & Readman, p. 16).

Some students perceived that rather than accommodating their learning needs, teachers just wanted to push them through their grades and this became a problem for these students as "...several of the participants found themselves in upper grades with minimum ability to read and write" (Carpenter & Readman, p. 16). Thus, the disabled people in the study experienced the education system in a negative way.

Other participants had physical access problems, such as not being able to see the board properly and not being allowed to sit up front. Another student had to sit out in the hall because the classroom was not accessible: "I ended up sitting out in the hall, used to drop my papers on the floor, they gave up on me" (Carpenter & Readman, p. 17).

Most of the participants in their study were over 30 years of age and thus present-day disabled students may have a better classroom experience with current accommodation and improved attitudes toward disabled people. However, for disabled students with low literacy levels, negative experiences concerning learning are an important backdrop to any teaching and learning.

## The Making a Connection Project Methodology

This project was a participatory action research (PAR) project and therefore, it was carried out in consultation with the IL Centres in the five sites,

and our research team (composed of the co-investigators), the national project coordinator, and the IL Canada executive director. Participatory action research is undertaken with a community of people, not just by an academic researcher alone who "studies" the community. In the case of this project, the five IL Centres participated in the crafting of the research This idea is important to the philosophy of independent living because, disabled people themselves are involved in directing the research and its outcomes.

Traditionally, disabled people have been studied by medical professionals and academics. This project ensured that disabled people who ran the programmes and participated in the project had input into the project. To help everyone understand the process and idea of PAR, we drafted a background paper on PAR and circulated it to all the literacy coordinators in the five locations. We then discussed PAR at a think tank meeting at the beginning of the project.

Because Making a Connection employed a PAR approach, we did consultations with the five pilot sites. The sites also conducted ongoing monthly interviews with each participant to see how the literacy programme was working for that person. Each participant developed a literacy program with a local literacy partner to meet individual needs and goals. The role of the pilot site literacy coordinators was to support each participant in his or her literacy journey and to keep in regular touch with the literacy partner to further facilitate this process. In addition, final questions were drafted to ask each participant in an exit interview. This interview would occur once a participant completed the programme. The programme took place over a three-year period.

The participants were 22 men and 37 women of all ages with various types of disabilities. In this paper, participants are also referred to as "learners" or "consumers." It is interesting to note that many participants in Saskatoon, Vernon, and Halifax were in their 20s. With this participation, the project met the goal of working with approximately 50 to 55 individuals and all sites met the goal of working with 10 or 11 participants. In fact, at two sites 14 individuals took part. The numbers of par-

ticipants at each pilot site are listed in the following table.

In addition to the monthly interviews with the literacy participants, the research team had a conference call at least once a month to discuss the program's progress and whether we needed to adjust anything to achieve better outcomes for the participants. These calls were a time for sharing best practices in literacy and success stories of the participants at the five sites. In addition, we traveled to the five sites twice during the project to meet the project participants and observe how the literacy project functioned in each location. Dr. Hansen visited Halifax and North Saskatchewan centres. Dr. Driedger visited Duncan, Vernon and Thunder Bay. In the end, the final report was vetted with the five sites to ensure that quotes and interpretations were correct.

In addition, the IL Centres and community literacy providers built successful partnerships with each other. These partnerships will be continuing beyond the Making a Connection project, as the IL Centres and the literacy providers have seen the positive impact of sharing their knowledge and expertise with each other to improve literacy education for disabled people. We hope these successes, which were recorded as part of this project in a partnership manual in the form of tips for IL Centres, will help guide those who wish to cultivate such partnerships in their communities in the future.

#### What is Literacy?

This was one of the first issues that our project considered. We produced a discussion paper for our think tank. The think-tank engaged all the project actors, the literacy partners and the representatives from each of the five centres as well as the research team. Literacy was defined in our process as more than simply reading and writing skills—literacy became "meaning-making." That is, any skills that people needed to improve how they interpret signs and systems, such as computer literacy, learning how to ride the bus, learning how to live on a budget, creative writing, as well as gaining the general education development diploma (GED) and improving reading, writing, and numeracy skills.

As the project progressed, each disabled participant picked their own area to study. This was self-defined, as they knew best what kinds of skills they needed to improve their quality of life. Traditional approaches to literacy have emphasized reading, writing and numeracy (Wiebe, Steinstra, & Perron, 2002). In recent times, literacy still means how well you interpret print and how you are able to function in our society with your level of knowledge. However, literacy can also be seen as more that just reading, writing, and arithmetic. It can be seen as skills that people use to interpret symbols in our society.

This approach to literacy is important. Perhaps a person does not want to read many books, but

# of participants to complete literacy program/goals	# of participants to complete final interview
14	14
10	10
14	7
10	6
11	11
59	48 (81%)
	literacy program/goals  14  10  14  10  11

needs to know how to read a bus schedule to be more independent. Perhaps a person does not need to know complex math theorems, but needs to be able to compare prices in a grocery store in order to get the best deal. Perhaps a person needs to make a time schedule for their attendant and then interpret it again to him or herself and the attendant, so that they have a common understanding.

Why is it important to see literacy as the interpretation of signs? It will help consumers and literacy teachers identify the types of teaching methods that are required for the skills a person would like to have. For instance, perhaps literacy lessons will take place in the grocery store for the person who wants to learn how to read and compare prices.

Sometimes, the teaching environment is not a traditional classroom and learning is not done at a desk. Literacy for disabled people needs to include creativity in instruction. Wiebe, Stienstra, and Perron (2002) reiterate this point: "Several respondents [literacy providers in Manitoba] emphasized the importance of literacy instructors not getting 'stuck' on any method, particularly if that method adversely affected learners" (p. 68). In addition, the voice of the consumer participants (the person enhancing their literacy skills) has to be the foremost consideration in the literacy process—what does the consumer want to learn?

### What is Quality of Life?

There was a debate in the project as to how to define quality of life. Over the years, rehabilitation professionals, doctors and social workers have written articles about the quality of life of their "patients" and "clients." There is a lot of journal literature about what this means for people with various disabilities. (Ahlstrom & Karlsson, 2000; Kovacs, Abraira, Zamora, Gil del Rea, Llobera, Fernández, the Kovacs-Atención Primaria Group 15, 2004: Merkelbach, Sittinger, Koenig. 2001; Sokoll & Helliwell, 2001; Stein & Kean, 2000). For the most part, these professionals were not disabled persons themselves. The IL philosophy promotes self-definition of one's own life, and thus, in the end, the project opted for each student in the project to define their own quality of life--

that is, what did they think they needed to live a better life?

## **How Does Literacy Relate to Independent Living?**

Wiebe et. al (2002) discuss the relationship between low literacy rates among disabled people and their lack of independent living options. A high rate of literacy is linked to economic success in our society and this is related to safe, accessible housing options, a healthy diet and the ability to enjoy a quality of life that is above subsistence living. The more ability an individual has to generate an income, the better independent living options he or she is likely to experience. Previous research on literacy and disabled people has tended to focus only on whether improved literacy affects their ability to become employed. Our Making a Connection project was different in that we examined the literacy skills that disabled people wanted to learn for their own independent living. For example, a disabled person may wish to learn to read and write more proficiently so that she can do homework with her children. Or, perhaps a person with intellectual disabilities would like to learn how to read a bus schedule so that he can move about independently in the community to attend recreational activities.

## **How Did We Construct the Literacy Programme?**

Many disabled people did not have positive experiences in school. Therefore, part of working with disabled people is looking to find ways to think in imaginative and novel ways. Since most literacy programmes have probably not enacted many of the accessibility accommodations or changes in how the classes are delivered, we all need to look at creative ways to approach the teaching of disabled people. This does not mean a curriculum will be different in its content. It may mean that it needs to be delivered differently. For instance, perhaps a consumer participant (those enhancing their literacy skills) has a difficult time coming out to class due to poor weather conditions and mobility difficulties. That person could take the class on speaker phone or via the computer. In addition, perhaps the teacher can travel to where the student is. In other cases, a consumer participant may have difficulty with fatigue and pain and may not be able to sit for more that an hour at a time. The person may need to take more breaks than other students, walk around, or lie down. It would be a good idea to have a couch available at the course location so that person can rest.

One way of delivering instruction that works well with people who are marginalized by society is the method proposed by Paulo Freire (1970), the Brazilian literacy educator, who organized tutors to travel to the countryside to instruct peasants to interpret their world through reading and writing. Traditional teaching methods are "banking methods" according to Freire (1970). That is, instructors "deposit" information into the heads of learners and the learners are expected to accept it wholesale. In Freire's proposed method, the instruction started where the peasants were at. The actual texts were those generated by the peasants about their own realities. In the process, they became able to read their situations and begin to think about what they would like to have changed.

Driedger (2004) taught creative writing to women with disabilities based on Freire's model in Trinidad and Tobago. As a result of this instruction, the women were able to generate a poem or a song about their own experiences. An anthology of their writings was produced from these workshops. Having people write their own stories at the level of literacy that they are at and then having their work published seems to increase self-esteem. In fact, after the publication of the women with disabilities' anthology, one woman with a disability became known as "the author" in her rural village, rather than the woman who walks with a cane.

Few studies focus on disabled people and their adult literacy experiences. In an article about Australian adult literacy tutors' attitudes to working with people with intellectual disabilities, it was found that the adults who volunteered to be tutored wanted to pursue "...literacy related activities that were connected to their lives, for example, reading magazines and writing about their experiences" (Moni, Jobling and van Kraayenoord, 2007, p. 443).

Furthermore, in a British study of online publishing activities of people with intellectual disabilities, it was found that parents or support workers

did most of the writing and setting up of home pages. The homepages became a "family" page or there was a joint responsibility for writing narrative. The study found that this may seem to be pragmatic in terms of getting the writing done, but people with intellectual disabilities need to be supported to write and publish their own online content. The support workers sometimes underestimated the ability of intellectually disabled people to work on their own contributions and to deal with the risk of internet use.

How did we find out where our participants are at in this project? The participatory research model that we used assisted in this task. We consulted with the consumer participants at each of our five sites to find out what their literacy goals were and how these could contribute to their independent living goals. We started our instruction with the question: what were his/her dreams for the future? His/her goals may be increasing literacy skills to obtain a GED, pursuing more training, or learning to write well enough to participate in online chat rooms.

The Making a Connection literacy project participants discovered new ways of learning, along with the literacy partners and the staff of the IL Centres involved in the project. As Kailtin Schiedendorf, literacy coordinator at the Thunder Bay Centre, said:

Staying away from 'cookie cutter programs' and strict program guidelines are an important part of helping to enhance one's literacy skills. Individualized skills sessions are perhaps the most effective 'tool' that our centre offers to consumers. Skills sessions are designed to enhance specific skills that the consumers themselves would like to improve. These individualized skills sessions are tailored to meet the needs and learning styles of each consumer (IL Canada Partnership Manual, pp. 7-8).

#### Literacy as Transformative

The disabled people who participated in our project experienced an increase in their quality of life as they defined it. There were three areas of quality of life that consistently appeared in the interviews with participants: changes in self-esteem, gaining literacy skills, and furthering edu-

cation.

Many of the participants reported that their self-esteem increased as a result of the programme and this increased their quality of life. Many alsore-ported that they had had negative experiences in the school system as they were growing up. The system did not know how to teach them and they were left behind, and their self-esteem had been crushed around their ability to learn new things. The Making a Connection literacy project helped to show the participants other ways of learning that increased their self-esteem:

There were people in this program who had a hard time even entering the building because of their fear of past school experiences. Now, they are here and learning. The coordinators and tutors are really changing people's lives. Bev, Halifax

These past experiences often involved instances of bullying, according to Barb from Halifax:

I had some bad experiences in school when I was growing up and I have been scared to go back to classes. The teasing and the name calling don't seem to leave you.

Indeed, often the lack of literacy skills results in people feeling shame and isolation about their lives and feeling a lack of belonging. When people become shut in, they lose the confidence to embark on new activities, as Polly from Halifax reported:

Before this literacy program, I was scared to try anything new. I would keep myself in the house believing that I didn't deserve to be out there with everyone else. I guess you can say that I didn't feel like I belonged.

The literacy program changed life for Polly. She went out into the community, improved her literacy skills and this resulted in her developing supportive friendships.

A number of study participants felt that their self-esteem had increased to the point where not only did they want to participate in activities, they knew that they could do anything that they chose to do:

My self confidence has gone up. I know I'm

capable of almost anything now because I got my GED [high school equivalency] and it gave me more confidence that, yes, I can do anything if I put my mind to it ... Sally, Saskatoon

Not only did the literacy project encourage people to participate in new activities in the community, it also built confidence in new skills such as public speaking, being assertive and finding meaningful relationships:

Through the literacy program I gained the confidence to speak in front of a group and I also gained enough confidence that I met someone who I love very much. I am able now to speak my mind.

Franca, Duncan

The participants' improved reading skills had a far reaching impact on participants' view of themselves as competent:

My confidence is returning and now I am a person who can read 'better.' A person who can read with more confidence.

Don, Halifax

Being confident enough to read without prompting or encouragement was not uncommon:

I do a lot of reading on my own now. Mandy, Saskatoon

Improving literacy skills led to an improvement in how participants carried out every day (life skills) domestic tasks, preparing meals, and taking care of themselves and their families. Many people unfamiliar with the realities of low literacy skills often take these so-called basic skills for granted. But for the participants they were life changing:

We went to our cooking class a couple days ago and I helped out the nutritionist fix us some lunch. I helped her mix and measure the ingredients. It was a blast. I am thinking about going to school at the community college to learn how to cook properly. I am buying magazines now to read and not just look at the pictures...My reading is 100% better than

what it used to be. I cook three times a week for my family with the help from my mother, but I am getting better.

Sam, Halifax

Being able to read a bedtime story to her daughter gave Bev a new sense of confidence as a mother and homemaker:

I can read my daughter bedtime stories because she picks the books with the little words and sentences. I can at least sign my name and write a few words down on paper. I don't have to rely on the pictures of food on packages to help me. No more coming home with the wrong things. Bev, Halifax

Being able to read advertisements enabled Stella to choose inexpensive groceries and prepare meals on her own enabling her to budget and save money for other things:

I started looking in the flyers and it helped because I've put aside some money for other things that I need. Instead of buying take out, it was cheaper to prepare at home.

Stella, Duncan

Improved reading skills built strengths in areas that are not readily perceived as being related to low literacy:

It does help me a lot with my speech and, and it helps me out with my money, like ... how to budget my money a little bit better...My reading skills I think have improved, have come a long way.

Pam, Thunder Bay

Some participants also worked on creative writing projects and this increased their confidence in reading and writing as well as their sense of accomplishment. In addition, it provided an outlet for people to share their experiences of disability. In Vernon, the participants of the literacy programme published an anthology of their writings to share with each other. One woman wrote:

### Challenges

Waking up Standing Getting dressed
Making breakfast
Only just started
I have the rest of the day yet
Don't forget meds
Tired already. . .

(Excerpted, ILV Literacy Anthology, p. 4)

In Thunder Bay, one woman had her writing published in the Thunder Bay Literacy Group Plain Language Newsletter. In Duncan, the literacy project participants compiled a book of helpful hints for living on a limited budget.

For some unemployed participants, the gaining of literacy and numeracy skills was a direct line to getting a job. In Thunder Bay, one participant obtained employment as a security guard in the course of the project. In Halifax, Cindy reported:

When I began I could only read certain words and now I am online and working a cashier job...I learnt more here than in school.

The project participants also saw that increased literacy skills helped them in their current positions:

It has helped me in my everyday life...The numeracy and literacy program has given me new tools to use in the work field.
Fred, Halifax

Don, also in Halifax, reported that teaching geared to the needs of the learner helped him to show up for learning sessions:

I am still here. It isn't going too bad. I am going at my own pace. It gets frustrating but I am not giving up. My tutor is working with me on the things I want to improve; I like that. I don't feel pressured and there are no grades or performance checks. The staff actually cares about you while you are here. It isn't, come in and get out.

Don, Halifax

The class provided a supportive positive space for learning and developing new strengths:

The class helped me the most because I did

not read out loud or to myself. I felt stupid and no one was patient enough for me to try. I left being able to read out loud. I completed my own portfolio for high school and never would have done that without being in this class. Ian, Duncan

Others, such as Sally, learned that she had talents and could be a teacher as well:

I actually found something I am good at. I am teaching the class how to make their own bread...Everyone is working on something different but something that they enjoy. We aren't forced to learn through an old book. We learn through what helps us. What we enjoy. I really like that approach.

Sally, Halifax

# **Building Community Connections and Gaining Independence**

Participants also reported that they felt a sense of community and independence in being part of the literacy programme, both within the programme itself and in starting to feel like a part of the greater community.

I am now a better speaker so my communication skills have improved. I am better able to communicate my feelings and emotions. I can better talk over issues so that I can navigate through life easier.

Sean, Duncan

Participants found new friends and a sense of community that they had been unable to find elsewhere:

It is hard for me to make new friends. I made some new friends through the program and because some of the other students attended social clubs, I did too.

Sam, Halifax

Literacy fostered independence, freedom and choice:

The...program is awesome and...you would do stuff that you would never do in a good way; I learned how to take the bus.

Wes, Halifax

I do things on my own now that I didn't do before. I can go read the bus schedule ... now and don't have to ask when the next bus is coming. I can count out my money and pay things by myself. I have a part-time job now. I am better on the computers now.

Stan, Halifax

#### **Barriers to Literacy**

Participants also experienced several barriers while taking the literacy programme, which were related to disability, housing or family crises, poverty, weather, illness and transportation. Some people needed to leave the project early. This was particularly the case in North Saskatchewan, where 31 people started the program and then 17 left it prematurely. In the end, 14 people completed the programme at that location.

Other participants completed the programme, but they had to miss some of the literacy activities for various reasons. Disabled people often provide care for others. However, program flexibility provided an alternate means of program access:

I haven't made it to all my classes this month because my wife has been sick. She has MS and when she gets sick, it is me who cares for her. But, I was given a few exercises to work on at home and my tutor has been great. Don, Halifax

In addition, weather conditions, especially in the winter, affected participants' attendance:

I missed a day or two this month because of the weather. I can't get out without the bus being on schedule and it was too stormy to leave the house.

Tom, Halifax

### Conclusion

Overall, disabled people gained many skills in the project. Weak literacy skills are not simply a natural by-product of impairment. In the past, medical labels often served as the primary focus for disabled people's education and the quality rarely matched that of their non-disabled counterparts. However, as demonstrated through the Making a Connection project, historical legacies and lack of imagination can be overcome with creative thinking and new ways of understanding the meaning of access to literacy and literacy itself in the lives of disabled people.

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Note: Pseudonyms have been used to protect the participants in this study.