



Making a Connection:

Literacy, Disability and Quality of Life,

Participatory Action Research Approach

Final Report

Submitted by

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This is the final research paper for the “*Making a Connection: Literacy, Disability and Quality of Life*” project, 2007-2010. The project was highly successful, in that it increased the quality of life for the vast majority of the project participants with disabilities—56 out of the 59 participants. The project also demonstrated that a nonprofit, national organization could engage in a Participatory Action Research (PAR) project at five locations, and through this process train pilot site Literacy Coordinators on how to do research. There were some difficulties along the way in doing the research, as is typical with PAR. However, these were solved as the project progressed.

The successes of this project will be reported in the voices of the people who participated as learners. Of special note, the five sites established partnerships with literacy providers that were ongoing throughout the project and which will continue after it ends. This report will also define key terms in the study, and then proceed to report findings and the PAR process. As the name of the project is lengthy, it is referred to throughout this final paper as “Making a Connection”.

Who is disabled?

Traditionally, rehabilitation, medical and social work professionals have defined disability according to a person's impairment. This approach defines individuals as dependent and who need to be taken care of by "non-disabled" family members, medical professionals, and society. Therefore, individuals with disabilities have been seen to have limited control over decision-making in their own lives

The Independent Living (IL) Movement has existed in Canada since the early 1980s. The IL philosophy, upon which the movement is based, supports the social model of disability. From an IL perspective, the question of who should be considered disabled is self-defined. Each individual will define whether society disables them, that is, holds the person back through physical, attitudinal, and systemic barriers. This is known as the "*social model*" of disability. It puts the cause of disability not in the individual, but in society which discriminates against and imposes limitations on the person who happens to have a disability (Oliver, 1990 in Appendix 1, National Research Team, 2007, p. 1).

What is Literacy?

This was one of the first issues that we looked at. We produced a discussion paper, “Disability and Literacy: Making Connections”, for our Think Tank that took place in November 2007 (see Appendix 1). The Think Tank engaged all the project actors: literacy partners; representatives from each of the five IL Centres; and the Research Team. From the ideas presented in this discussion paper and as an outcome of our conversations during the Think Tank we decided to view literacy as more than simply reading and writing skills – rather we defined literacy as “meaning-making”. That is, any literacy skills that people chose to improve were the ones which became meaningful to them. One example of this is how participants interpreted signs and systems. This could translate into improving computer literacy, learning how to ride the bus, learning how to live on a budget, completing high school (GED) and improving creative writing, and numeracy skills.

As the project progressed, each participant chose activities to pursue. This was self-defined as the individuals knew best what kind of skills they needed to improve their quality of life (see Appendix 1).

What is Quality of Life?

There was a debate in the project about the definition of 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” (Ahlstrom & Karlsson, 2000; Kovacs, Abraira, Zamora, Gil del Rea, Llobera, Fernández, the Kovacs-Atención Primaria Group¹⁵, 2004; Merkelbach, Sittinger, Koenig; 2001; Sokoll & Helliwell, 2001; Stein & Kean, 2000). The IL philosophy promotes self-definition of one’s own life, and thus, in the end, the project opted for each participant in the project to define their own quality of life--that is, what did they think they needed to live a better life?

What is Participatory Action Research (PAR)?

Participatory Action Research (PAR) is research undertaken with a community of people, not just research done by an academic researcher who “studies” the community. In the case of this project, the five IL Centres and project participants took part in the “crafting” of the project. The IL Centres also reviewed this report, and will continue to review any future publications sent out to journals. It is important to note too that a majority of

the IL Centre Literacy Coordinators were themselves persons with disabilities. This idea is central in the philosophy of IL because individuals with disabilities are involved in directing the research and its outcomes.

Traditionally, people with disabilities have been studied by medical professionals and academics and they have not had input into research projects. This initiative ensured that people with disabilities who participated in the project had input into it. To help everyone understand the process and the idea of PAR, the research team drafted a second background paper on PAR that was circulated to all the Literacy Coordinators in the five pilot site locations, prior to the Think Tank. PAR was then discussed at this event. (See Appendix 2 for discussion paper, “Participatory Action Research: Research for Change”).

The Making a Connection Project

Overall, the outcomes of the project were successful. The project was held at five Independent Living (IL) Centres across Canada. The five pilot site locations were chosen through an RFP process; interested members from the IL Canada network submitted an application. The five pilot sites chosen were Cowichan Independent Living in Duncan, Independent Living Vernon

(both in British Columbia), North Saskatchewan Independent Living Centre (ILC) in Saskatoon, Independent Living Resource Centre Thunder Bay in Ontario, and Independent Living Nova Scotia in Halifax. In the rest of this paper, each pilot site is referred to by its location. Each of the pilot sites established a partnership with one or more literacy providers in their communities. These are listed in Appendix 3.

The Think Tank was held on November 24 and 25, 2007 in Ottawa. This meeting brought together all stakeholders involved in the project: Literacy Coordinators from each of the five sites; a literacy provider partner from each of the five sites; and members of the Research Team, an Investigator and a Research Associate. The concepts of the project were introduced and, as noted previously, papers on Participatory Action Research and on Disability and Literacy were discussed (see Appendices 1 and 2).

There were a number of “growing pains” in the first seven months of the project, as terminology and the project were defined between the Investigator and the Literacy Coordinators at the five sites. Definitions of what PAR meant and how the project should proceed were debated and contested between the Investigator, the IL Centers, and IL Canada.

Unfortunately a positive resolution did not occur.

In the end, it was decided by IL Canada and the IL Centres that a new Investigative Team, who fully understood the IL philosophy, should replace the first Investigator. After a new selection process took place, two co-investigators, both women with disabilities who had been involved in the IL movement and the disability rights movement in Canada, were hired. Dr. Nancy Hansen is Director of the Interdisciplinary Studies Master's Programme in Disability Studies at the University of Manitoba. Dr. Diane Driedger was teaching Disability Studies at the University of Manitoba during the tenure of this project.

1. Methodology

Because Making a Connection employed a PAR approach, it was carried out with consultation with the five pilot sites and the Co-investigators. It was decided that there would be an ongoing monthly interview 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. (For the monthly questions and end of project or “exit” interview questions, see Appendix 4).

In addition to the monthly interviews with participants, the Research Team (consisting of the Co-investigators, pilot site Literacy Coordinators and the IL Canada Project Manager) held a conference call approximately once a month. The purpose of these calls was to discuss progress, and whether any adjustments in methodology or approach were required to achieve better outcomes for the participants. These calls were a time for problem-solving, for sharing best practices in literacy supports and to talk about the success stories of participants at the five sites.

The Co-investigators also traveled to each of the five sites twice during the project to meet the participants and to observe how the project and the relationship with the literacy partner functioned in each location. Dr. Hansen visited two IL Centre pilot sites located in Halifax and Saskatoon, while Dr. Driedger visited three pilot sites located at the IL Centres in Duncan and Vernon (British Columbia) and in Thunder Bay.

In keeping with the PAR approach, this final report was vetted with the five sites to ensure that quotes and interpretations were correct.

2. Participants

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 twenties. There were a total of 59 participants. With this result 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 participants at each pilot site are listed in the following table.

IL Centre Pilot Sites	# of Participants to complete literacy program/goals	# of Participants to complete final interview
Duncan	14	14
Vernon	10	10
Saskatoon	14	7
Thunder Bay	10	6
Halifax	11	11
Total	59	48 (81%)

Several participants did not go through the final interviews after completing their literacy programmes and goals because they went on to other personal pursuits. The Literacy Coordinators at each site attempted to contact these individuals, but they did not wish or were not able to come in for a final interview, or they may have moved away and lost touch with the IL Centres. However, a majority of participants (81%) did take part in the exit interviews.

3. Partnerships with Literacy Providers

Successful partnerships were built between IL Centres and Literacy Providers at all five sites. 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 people with disabilities. These successes were recorded in a Partnership Manual (2010) in the form of tips for IL Centres who wish to cultivate such partnerships in their communities (See Appendix 5).

One success, noted in the Partnership Manual, is worth repeating here. Each year an honoraria was given to each of the literacy partners for

their work on the project. In Vernon, one of the IL Centre's literacy partners, Okanagan College, decided that it would use these funds to establish a scholarship for students with disabilities who attend their programme.

Gains from the Literacy Program

Participants reported positive changes in their defined quality of life based on six different areas that were included in the interviews. These areas were defined as: (1) Changes in Self-Esteem; (2) Gaining Literacy Skills; (3) Employment; (4) Further Education; (5) New Ways of Learning; and (6) Building Community Connections and Gaining Independence.

1. Changes in Self-Esteem

Many of the participants reported that their self-esteem increased as a result of the literacy programme. This in turn increased their quality of life.

For example, Norma and Polly noticed these changes:

"I'm more outgoing now. Before I was kind of in a rut and you kind of don't want to go out of your home. I didn't know what was going on with my vision and stuff like that. I ended up on [social] assistance and trying to go to school ... It helped me to get out and want to do something. I was motivated to keep busy and to focus on myself and to make some decisions - whatever I have to do to achieve my goals! I've kind of got my bubbly personality back. ... I feel I'm able to talk to people and I don't want to bury my head in the sand sort of thing. I want to be out there doing things. I look forward to going out every day."

Norma (pseudonym), Saskatoon

“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. But that all changed. I have friends who support me and believe in me. I wanted to improve my life in general and hoped improving or updating my reading and writing would help with that. I suggest the program to everyone who wants something better.”

Polly (pseudonym), Halifax

Similarly, Sally reported that as a result of the Making a Connection project she felt that she could do anything she wanted.

“My self-confidence has gone up. I know I’m capable of almost anything now because I got my GED and it gave me more confidence that Yes, I can do anything if I put my mind to it. Knowing what I’m capable of.”

Sally (pseudonym) Saskatoon

Many participants in the project explained that they had had negative experiences in the school system as they were growing up. They were not understood by their teachers and peers. Therefore, they did not receive the appropriate learning method to support them to be literate. Consequently, they adopted the belief that they could not learn new things. The Making a Connection literacy project has helped participants to realize their potential and to increase their self-esteem.

According to Bev (pseudonym) from Halifax, *“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.”*

Similarly, Barb from Halifax stated that she became more involved in her community after participating in the programme.

“The past two years have been a wonderful experience. I began the program thinking that everyone would be miles ahead of me but we did it together. 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. But with some motivation from the literacy coordinator and the tutors, I did it. I found out that I had skills to offer and that I could be an active member of my community. Two years ago, I don’t even know who that person is anymore. I have changed so much.”

Gaining self-esteem around learning also helped the participants to feel that they belonged to the community like everyone else:

“I like the learning activities in the classroom but I enjoy going outside the classroom and using what I learnt in there in the real world. Feels good to do that, I feel normal, like everyone else.”

Sam (pseudonym) Halifax

“My confidence has increased from coming here and I, like I see the results of striving for things and I feel socially accepted here [at the IL Centre] and that’s helped and what else, I’ve learned a lot here so I’ve got some more skills, so I feel more confident.”

Wanda (pseudonym) Thunder Bay

“I feel uh confident talking to strangers and uh you know if someone needs help with a baby carriage or something I I’m not shy now to just walk by.”

Tori (pseudonym) Thunder Bay

“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 (pseudonym) Duncan

“I’m not afraid to speak up for myself when something’s bothering me. I wouldn’t have been able to do that before, well because I was a much shyer person and wasn’t able to speak up for myself.”

Nancy (pseudonym) Duncan

2. Gaining Literacy Skills

Improving reading skills also increased peoples’ self-esteem:

“You wouldn’t believe me if I told you. My confidence is returning and now I am a person who can read better. A person who can read with more confidence.”

Don (pseudonym) Halifax

“I’m starting to read more ... I do a lot of reading on my own now.”

Mandy, (pseudonym) Saskatoon

Gaining better literacy skills led to an improvement in how participants carried out everyday tasks (life skills) when they were taking care of themselves and their families:

“I did improve my reading because I am getting better at my day to day things. 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 (pseudonym) Halifax

“I am reading now, not the best reading, but I get through it... 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 (pseudonym) Halifax

"I started looking in the flyers and checking the menu. 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 (pseudonym) Duncan

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

Pam (pseudonym) Thunder Bay

Working on creative writing projects also led to increased confidence in reading and writing and a sense of accomplishment. In addition, it provided an outlet for sharing the experience of disability with people.

In Thunder Bay, one woman had her writing published in a local newsletter.

Let Go of Hate

Let go of hate
For if hates dies
Life is a soaring plane
That will take me to Florida.

Let go of fear
For when fear passes
Life is a breathtaking pasture
That takes my breath away.

(Thunder Bay Literacy Group Plain Language Newsletter, p.3)

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
Not yet noon
Tidy up some
Supper time already
Not enough time
Just tired
Still I managed
Now time for bed
New day tomorrow

(Independent Living Vernon Literacy Anthology, p. 4)

In Duncan, the literacy project participants are currently writing a book of helpful hints for eating a healthy diet for people with disabilities living on a small income. It is provisionally going to be titled “Living Well on What You’ve Got”.

3. Employment

For some participants improving literacy and numeracy skills was a direct line to gaining employment, especially for those who had not been working before. In Thunder Bay one participant became employed as a security guard during 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 at the dollar store. I learnt more here than in school.”

Cindy (pseudonym) Halifax

The project participants also saw that increased literacy skills could help them in their work and in finding work:

“It has helped me in my everyday life; it also gave me confidence to use a better way of speaking and other areas. The numeracy and literacy program has given me new tools to use in the work field.”

Fred (pseudonym) Halifax

4. Further Education

Many participants were so strongly encouraged by the programme that they decided to further their education:

“I have been inspired to go and apply at SIAST. I applied for the adult education program. I wrote the pre-test and did well on that so when I get my transcripts and everything; when I finish school and take them in I’ll be on the waiting list and they’ll put in the adult 12 program. I’m thinking about going for the full grade 12. I want to

especially understand more science and different things – just to get more understanding of the subjects; more knowledge. I just want to upgrade and go for the full grade 12”.

Ann (pseudonym) Saskatoon

“Can you believe that I am working on a computer program now? Didn’t think that would happen. When my tutor is busy with another learner, I just know it go to the computer and start the program. It actually allows me to do my own thing, you know.”

Don (pseudonym) Halifax

“I am even thinking about taking my GED. Never thought that I would but I am thinking about it.”

Bev (pseudonym) Halifax

In addition, **Katherine in Vernon** is going on to complete her secondary education with the goal of taking a course in practical nursing.

5. New Ways of Learning

The participants discovered new ways of learning, along with the literacy partners and the staff of the IL Centres involved in the project. As Literacy Coordinator, Kailtin Schiedendorf wrote:

“First of all, it is important for each learner/consumer to self-identify what their goals are. We always tell people that they are steering their own ship, and that we are merely helping in facilitation of their learning. Many have had unpleasant experiences in the school system, and for them to know that they have a say in their own learning plan is empowering and motivating to continue....

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. Facilitation and delivery methods change with each consumer as every person's learning style is different. For example, working with someone with a visual impairment may require materials to be emailed ahead of time, and information delivered orally, while working with someone with a learning disability may require a hands on/repetitive task approach. It is important to remember that even persons with the "same" disability may have completely different needs and learning styles, and thus their learning plans would look completely different. In this light, I think it is hard to illustrate specific tools to help consumers, as these tools should be constantly changing depending on who you are working with!" (Literacy, Disability and Quality of Life Participatory Action Research Partnership Manual, pp. 7-8)

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

"For starters, 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 (pseudonym) Halifax

"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 (pseudonym) Duncan

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

“Well. I actually found something I am good at. I am teaching the class how to make their own bread ...I have to say that I like the program. 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 (pseudonym) Halifax

6. 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 feel that 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 (pseudonym) Duncan

“I get to go on the computers and I now have an email address to go to Facebook. We need to do some work on my social skills. A little bit at a time because 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. I don’t go to all of them but they get me out and about.”

Sam (pseudonym) Halifax

“The ... program is awesome and you get to become good friends with the teachers and you would do stuff that you would never do in a good way; I learned how to take the bus.”

Wes (pseudonym) Halifax

“I do things on my own now that I didn’t do before. I can go read the bus schedule like everyone 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 (pseudonym) Halifax

Barriers to Literacy

Participants experienced some barriers while taking the Literacy Programme, which were related to their disabilities, housing crises, poverty, weather, illness and transportation. Some participants needed to leave before the end of the Making a Connection project. This was particularly the case in Saskatoon, where 17 people started and then left the programme. In the end, 14 people took part in the monthly interviews and completed the programme, but only seven people did the exit interviews prior to leaving the project. Other participants completed the programme, but they had to miss some of the literacy activities for similar reasons:

“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 (pseudonym) Halifax

“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 (pseudonym) Halifax

“The weather has been an issue for me this month. The snow storms make it hard for me to get out. Also, I have had the flu. Stuck in bed and no energy for anything.”

Ray (pseudonym) Halifax

Disseminating the Findings

This final paper will be circulated to interested literacy providers and IL Centres across Canada. As the project progressed, the independent living community and the community at large were apprised of the aims and successes of the project through two Research Bulletins. These were circulated electronically and then distributed to all member Centres at the IL Canada 2010 Annual General Meeting conference. Dr. Hansen presented a paper on behalf of the project entitled, “How Independent Living and Literacy Work Together” at the Disability Studies Conference, 7-9 September 2010, at the University of Lancaster, U.K.

In addition Dr. Hansen and Dr. Driedger plan to write a journal article on project findings which will be submitted to an internationally well-known

disability journal. Finally, there will be an article on the Making a Connection project in an upcoming 2011 edition of *Abilities Magazine: Canada's Lifestyle Magazine for People with Disabilities*.

Conclusion

This final paper for the “Making a Connection: Literacy, Disability and Quality of Life, Participatory Action Research Approach” has demonstrated that a majority of project participants (56 out of 59) did experience positive changes in their defined quality of life in six areas. These areas were increased self-esteem; gaining literacy skills; finding employment; seeking further education; using new ways of learning; and building community connections and gaining independence.

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