

**The Impact of Independent Living Resource Centres
in Canada on People with Disabilities**

by

Peggy Hutchison
Alison Pedlar
John Lord
Peter Dunn
Mary McGeown
Andrew Taylor
Chris Vandetelli

Canadian Journal of Rehabilitation
1997, 10:2, p. 99-112.

The Impact of Independent Living Resource Centres in Canada on People with Disabilities

The United Nations declared 1981 the International Year of Disabled Persons. This provided an impetus for addressing the urgent and extensive needs of individuals with disabilities (Driedger, 1989; Federal Government of Canada, 1981; Malinga, 1992). During the last decade, social policies and practices related to disability issues have changed dramatically. There is now widespread interest in independent living, consumer control and self-determination for people with disabilities (Dunn, 1990; Hutchison, Lord & Osborne-Way, 1986; MacPherson, 1990; Percy, 1989; Winter, 1993).

The IL paradigm was formulated during the late sixties in the United States in response to consumer and advocacy movements (Berkowitz, 1979; DeJong & Lefchez, 1983; Hahn, 1985). The Canadian disability self-help movement promoted human rights, deinstitutionalization and full participation (COPOH, 1985; Pedlar, 1992; Scotch, 1988). The IL movements in Canada and the U.S. played an important role in this change because of its sharp contrast to the rehabilitation paradigm and traditional services for people who have disabilities which are professionally controlled, focused on remediation, and treat people as dependent clients (Canadian Association for Independent Living Centres, 1991; DeJong, 1979, 1981; Enns, 1986; Federal Government of Canada, 1981). In this historical sense, disability needs to be understood in a political and sociological context, rather than an individualistic view separate from any sense of power and social structure (Jongbloed & Crichton, 1990; Oliver, 1990; Oliver & Zarb, 1989; Zarb, 1992). The IL paradigm emphasizes that the problem lies in the environment, in segregation, discrimination and in a dependency upon professionals and others (Carpenter, 1991; Crewe & Zola, 1984; DeJong, 1981; DeLoach, 1983; McKnight, 1989; Robinson, 1991).

Independent Living (IL) is a concept which is well known by people with disabilities, advocates, and government (DeJong, 1981; DeLoach, 1983; Enns, 1986; Worth, 1993). The IL paradigm has been an important part of new thinking about how to provide community supports and what role the consumer has in that process (Racino, 1992; World Institute on Disability, 1987). It was concerned with quality of life issues, consumer control, and choice within the community (Zola, 1982). The IL paradigm emphasizes that people with disabilities can best identify their own needs and can have productive lives in the community through self-help, empowerment, advocacy, and the removal of barriers (Crewe & Zola, 1984; Dunn, 1987; Lord, 1991; Rappaport, 1986). CAILC defined independent living in Canada as "a process whereby disabled citizens achieve their desired individual lifestyle by assuming responsibility for the development and management of personal and community resources" (Coalitions of Provincial Organizations of the Handicapped, 1986, p. 29). Not surprisingly, the IL movement in Canada has demonstrated and encouraged new service delivery models and research directions (DeJong & Lifchez, 1983).

In Canada, consumer advocacy groups were responsible for the initiation of the Canadian Association for Independent Living Resource Centres (CAILC) and its local affiliates known as Independent Living Resource Centres (ILRCs) (COPOH, 1986; Enns, 1991). Emphasizing individual empowerment and control over decision-making, rather than systemic advocacy, this movement now includes more than twenty IL Centres across Canada and widespread interest in many of the IL concepts (Lord, McGeown, Taylor, & Young, 1992).

As a vehicle for responding to the new IL paradigm (Hahn, 1985), each centre had its own unique characteristics, with guiding principles that were central to the philosophy of all ILRCs: consumer controlled, cross disability, community based, non-profit, and promotion of integration and full participation (Canadian Association for Independent Living Centres, 1991; Valentine, 1994). The ILRCs provide people with disabilities with

self-management skills, self-confidence, tools, support, and resources that make it possible for individuals to achieve their personal goals. The main methodologies they use to achieve this include information and referral, peer counseling and support, individual advocacy, service development such as attendant care, and monitoring of services (Canadian Association for Independent Living Centres, 1991). In order to ensure consumer controlled policy directions and insights, the majority of the staff, volunteers, board members and membership are persons who have disabilities (Canadian Association for Independent Living Centres, 1990; Simpson, 1993; Valentine, 1994).

It has been demonstrated that as the individual becomes empowered, participation in community life increases (Friedmann, 1992; Lord, 1991; McKnight, 1986); in turn, the community becomes educated and significant changes occur, both within the life experiences of the individual and the community as a whole. Empowerment has been an important part of the IL movement. Empowerment refers to a process of people gaining control over their lives, increasing participation in community life, and accessing valued resources (Lord, 1991; Rappaport, 1986). ILRCs serve as a mediating structure for change between the IL paradigm and the community. This study examined individuals within the community and investigated the mediating role of the ILRCs and the possibility that individual empowerment through ILRCs has a ripple effect on change in the community (Valentine, 1994).

There is very little current research on the impact of ILRCs in Canada or elsewhere (Budd, Petty, & Nelson, (n.d.). Research on ILRCs in Canada has focused on describing the *processes* involved, that is, what ILRCs do and how they work with people with disabilities (Lord, McGeown, Taylor, & Young, 1992). This study on impact was needed to inform policy development and to contribute to building theory around the IL paradigm (DeJong, 1981; Dunn, 1987, 1994; Oliver, 1992).

Objectives

This two year study involved an in-depth analysis of the *impact* of ILRCs in Canada. The main objective of this research program was to answer the following questions:

1. Do Independent Living Resource Centres have an impact on individuals with disabilities who use the Centres, and if so, what are the impacts? (Year 1)
2. Do Independent Living Resource Centres have an impact on the community, including formal services/agencies, informal groups, families and friends, as well as ILRC staff, volunteers and board members, and if so, what are these impacts? (Year 2)

This study was conducted within a collaborative, innovative partnership which was formed for the research between the Canadian Association for Independent Living Centres (CAILC) and a community-based research centre, namely the Centre for Research and Education in Human Services, as well as researchers from three universities. The research topic was jointly defined by the partners and built upon the IL paradigm (Krogh & Matanga, 1994; Lord, 1994). This paper will report on the findings of Year 1 of the study, that is, the impact of ILRCs on individuals with disabilities who use the ILRCs.

The Methodology

A qualitative approach was used in the first year of this study. Little was known about the possible impacts of ILRCs, so an open-ended, inductive approach enabled study participants to identify impacts (Guba & Lincoln, 1989). Accordingly, an approach that is consistent with the IL paradigm was used because we believe that impacts must be identified by ILRC users from their own point of view. Also, a qualitative methodology was chosen because it is the most sensitive to the lived experience of people with disabilities (Alary, 1990; Barnes, 1992; Chesler, 1991; Krogh & Petric, 1994; Patton, 1990). Impact or outcomes referred to both direct and indirect effects of an intervention

(Brown, Boyer, & Brown, 1992; Gardner, 1992). In this study, outcomes of the ILRCs on people who have disabilities who were users were examined.

Site Selection

A purposive sample of three ILRCs was selected for the first year of the study. The research committee of CAILC assisted the researchers in selecting the three representative ILRCs from across Canada which best met the following criteria: the Centre had to have been long-standing (e.g., over five years) and well-established; the Centre must have had a relatively strong funding base; and the Centre must have had key core IL components in place (Canadian Association for Independent Living Centres, 1989). In addition, it was hoped that the selected sites would have geographic diversity.

Four sites across Canada applied to be in the study. One was selected to be a pilot site because it varied in structure from the other three sites, and because of its close proximity to the researchers. Two of the sites selected were in medium size urban centres with a wide regional base. The remaining site was in a medium to large urban centre. While the findings of the study may not be generalizable to all ILRCs, this sample was identified as indicative of ILRCs which have been well established with basic funding sources.

Participant Selection

It was decided that each site would send a letter inviting all users of the ILRC to participate in the study. It was hoped that a high level of interest by potential participants would allow the researchers to apply purposive sampling, however, the response to this letter was poor in two of the three sites. The three ILRCs provided the research team with a complete list of their users from which to do the sampling. Those who returned the "informed consent" form were considered. The following criteria for participant selection was developed so that as diverse a group as possible could be included in the qualitative data collection phase of the project: people who have accessed a wide range of ILRC program areas; people who have accessed a narrow range of ILRC program areas (e.g.,

only one of the program areas such as peer support, housing, employment or leisure); people regarded as long-term users (i.e., more than 12 months); people regarded as short-term users (i.e., less than 12 months); people who represented a range of different disabilities served at the ILRCs (e.g., physical disabilities, visual and hearing impairments, learning disabilities, developmental disabilities, mental health problems).

Data collection took place in six focus groups in each of the three sites, giving a total number of 18 focus groups for all three sites. There were 3-4 people in each focus group. In the end, a total number of 70 participants were involved in focus groups from all three sites. Focus groups were held in one location at each site over a two or three day period and people were telephoned so they could choose the most suitable time. People were only allowed to attend one focus group.

Originally, 18 individual interviews were going to be held with one person randomly selected from each of the focus groups. However, there were several people who did not show up due to illness, transportation problems, forgetting, and bad weather. All people who did not show were phoned to see if they would agree to an individual interview. A total of 18 individual interviews were conducted, mostly in person but a few by phone if they were unable to get out. Some of these were people randomly selected from the focus groups and some were people who missed the focus groups.

Data Collection

The individual and focus group interviews were held in community settings which were fully accessible and personalized. Focus group interviews were small, ensuring greater participation and comfort (Morgan, 1988). These lasted approximately two hours and were conducted by the researchers using a detailed interview protocol as a guide. A nominal group strategy was utilized to maximize individual response (Siegel, Attkisson & Carson, 1987). The group discussion focused on learning more about the participants' views of the impact of the ILRCs on their personal lives. Focus groups were used to provide a broader base of information, while the individual interviews provided more in-

depth information. Hence, the individual interviews utilized a more simplified and personalized interview guide, adapted from the focus group interview protocol. An example of a question from the individual interview guide was "Are there areas of your life where you think the ILRC has made a difference, either positively or negatively?" All interviews were typed as people spoke, as well as tape-recorded for back-up purposes.

Analysis and Interpretation

The transcriptions of the interviews and the focus group discussions were organized and interpreted in accordance with the procedural stages for inductive analysis described by Patton (1990). Using NUD*IST qualitative analysis software (Richards & Richards, 1994), the initial stage involved detailed content coding of all transcripts, followed by the development of a hierarchical system of categories which was closely linked to the original research questions, but also sufficiently open-ended to identify and incorporate unsolicited information. Once content coding was complete, NUD*IST allowed for the generation of a comprehensive system of coding categories indexed through a network of key words, providing for a rich variety of comparisons and breakdowns.

This capability was useful during the second phase in Patton's approach to qualitative analysis - thematic analysis. We began to identify general trends or common themes which could effectively summarize and crystallize the impacts which ILRCs were having on individuals. Using NUD*IST to search the data and identify key links emerging themes were clarified and refined. We were also able to confirm themes, an important index of the credibility of qualitative research (Patton, 1990) by returning to the data to search for further examples which might support or refute an interpretation which was suggested by a few key passages. On completion of analysis, four major themes had been identified in the data. Each of these themes is addressed below, along with the principal patterns which help explain the themes.

Results

The four major themes were:

- 1) People were treated differently at the ILRCs than in the community, that is, as valued citizens rather than clients and disabled persons, resulting in a sense of empowerment.
- 2) ILRCs were narrowing the gap between the way people with disabilities were treated at the ILRCs and in the community by working towards community change.
- 3) Participation through the ILRCs led to a clearer understanding of the IL philosophy and movement.
- 4) Management and implementation difficulties diminished the overall positive impact.

Included here are specific comments from study participants which allowed for clarification of individual and collective experiences across study sites. The words of participants (italicized quotations below) most adequately illustrated the thematic explanations that emerged from the findings.

THEME 1: Empowerment at the ILRCs

The experience of research participants was that people were treated differently at the ILRCs, not as clients and disabled persons, but as valued citizens and full contributing members of the community. This was significantly different from the sort of treatment people experienced elsewhere. This treatment contributed to a sense of empowerment for people.

How people were empowered at the ILRC

Most of the research participants emphasized having experienced positive treatment at the ILRCs. At all three ILRCs, people talked about the dignity that came from being cared for and listened to; treated with respect, equity and fairness; having access to information; having good communication; being seen as full contributing

members of the same movement, which led to acceptance of their disability; and being able to count on the ILRC for support while trying to achieve more independence.

They treat you equal. . . they don't make you feel like you are inferior. They give a whole new look to what a social worker should be. They become your friend and work side by side. Their goal is independence, and they are by your side until you are ready to fly.

Positive impacts of being treated in a valuing way at the ILRCs

People felt well connected to the ILRC, almost part of a family, because it was here that they made friends and met people who made a difference in their lives. At the same time, they gained a sense of accomplishment through making a contribution, through volunteering, involvement in committee work, and participation in education sessions and peer support groups.

When I came out of the hospital I was very ill. They offered me personal and moral support. They were there for me when nobody else was. My mother had just died a few weeks before. I had come out of the hospital and she died a week later. So my family wasn't available at the time and they literally became my family. My brother and sister-in-law tried to put me into a residence.

My first contact was to get a new place to do volunteer work. I was looking for a job and because I was mentally ill I couldn't get a job. I first came in '91 and I would sort of drop in. I would be really lonely on weekends. I made it my whole life, I was eating here. I come here to get positive support from the people because I'm mentally ill. Its a nurturing place or me. They take the time. I realize I can't work there. I smoke and have coffee it's a good place to be. I volunteer one day a week.

At the same time, they acquired confidence and useful skills such as leading or facilitating groups, problem-solving skills, career skills, writing, and public speaking.

They also said their ILRC involvement contributed to the empowerment process. They had more control over their lives, in the sense that the ILRCs recognized that they were in charge of their own lives, and in turn people began to feel more control over their lives. Their self-esteem was higher, as reflected in greater self-confidence and assertiveness.

They foster an idea of you can do it on your own. They empower you with the person of one. You can make a difference, one person can make a difference.

Since I started going to the ILRC my family and friends say there is such a change in me. I am not as uptight. You know when you get disabled you wonder why you should wake up. I said that if I couldn't get there (to the ILRC) on my wheelchair I would crawl there.

In the community, people with disabilities continued to be devalued

Despite the empowering treatment at the ILRC, people felt they continued to be devalued in the community. Professionals and agencies displayed negative attitudes; the general public continued to have low expectations and misconceptions of people with disabilities; and family members often exhibited inappropriate attitudes and behaviour towards their family member with a disability.

I just hate that they see the handicap first and then us. They should see us first and then the wheelchair. Or maybe they would see us and forget about the wheelchair.

Some of the people who felt the barriers in the community were still extensive expressed their frustration that the ILRCs could not really eliminate all these barriers.

With the general public there is low impact, but with more formal service there is higher impact. It is so focused, so specialized that it can't really affect everyone.

THEME 2: Narrowing the Gap

The ILRCs were trying to narrow the gap between the way people were treated at the ILRCs and the way they were treated in the community by working towards community change.

Complexity

In general, traditional or discriminatory attitudes form part of the context within which ILRCs must function, and social change efforts must focus outward, towards changing society, as well as towards supporting and empowering individuals who have disabilities.

I've gone to the conferences. It would appear that the ILRC has been a strong enough voice to be noticed. They have been strong enough to draw the attention of the MPs and the MPPs. So, I've seen them in the paper. The

ILRC has some impact on the community. That is what the ILRC represents to me.

Working with community agencies through research, development and community consultation was an important vehicle for community impact

At a community level, ILRCs were endeavoring to change attitudes through work with employers, non-disabled college students, other service providers, and family members. The effort was clearly being made through forming partnerships with community agencies and groups; monitoring and service development; and education, using both formal and informal approaches.

They work in a lot of partnerships with a lot of community agencies. They do have a lot of community support and they are in communication with a lot of groups. Probably on a very general basis they keep an eye on other agencies.

Ongoing effort

Other people perceived the barriers in the community to still be extensive, and may have therefore concluded the ILRCs were not having enough impact. They felt much more aggressive action was needed by the ILRCs if any significant progress was going to be accomplished.

The IL model has come but also existing were many other models of disability like the social political model. Rather than working with all models, they try to set a square page around one and establish a new model, yet it hasn't taken root and taken into account the handicapping factors affecting disability. They're not reaching the medical community or the government and they don't network with other consumer groups. They are also not connecting with other people such as the political community and legal community. These all have very powerful systems affecting the political community. All of these preexist prior to the IL model.

THEME 3: Clearer Understanding of IL Philosophy

Contact with the IL movement through the ILRCs and other channels has led some people at each site to develop clear understandings of the IL philosophy and movement. These people have a strong belief in the potential of the ILRCs.

People had a belief in the potential of the ILRCs

Many who believed in the potential of the ILRC saw it as an important tool for furthering the application of the IL movement. These quotations suggested that the ILRCs had the potential for greater impact, at the individual level, but particularly at a broader social level.

I would like to see more funding going into the Centre. Not only for myself or my son, but for the others around me who are seriously affected. If somehow we would work together and make committees stronger. If we had enough voices I think our government would have to listen.

I wish there were more IL services and Centres available throughout the country. It is a lot more available throughout the States. I wish we were at least at their level. I know they are funded federally so that each service doesn't have to fight for funding. The need is there. IL Centres need to concern themselves with how things are done rather than just what things are done. The fact that the ILRC is consumer based, it ensures that they meet the needs of the consumers.

Strong visionary leadership played a key role in nurturing the IL philosophy

As the primary agents involved in translating the IL vision into something meaningful for individual lives, staff were seen as being critically important. People were clear that they needed strong leadership, and when it was somewhat shaky, people were very concerned. Leaders needed to be knowledgeable, have strong IL values, and have good management skills.

[The director] gives us our fulfillment that we can do it. You're not dumb, we may have disabilities, but that is not terms for knocking people. [The director] recognizes us for who we are. We're just as normal as anybody else. [The director] accepts us.

The ILRCs had a positive impact in raising awareness

There was evidence that the ILRCs were having positive impacts in many people becoming more aware of issues and involved in the movement.

I was termed a volunteer but it was really a job placement. After I started here I realized that these inequities in life have to be stood up to. I believe that I have to do my part.

The individual empowerment skills development program plays a key role by supporting independent lifestyles and facilitating empowerment. Staff at all sites have assisted ILRC users in a wide variety of ways including assistance with getting unemployment insurance or disability pensions; avoiding institutionalization; personal problems and family problems; getting transportation; job searching skills and work skills; moving to new living arrangements or dealing with housing issues; assistive devices; and managing finances.

Research and renewal played an important role in linking action to philosophy

A clear mission statement was what brought the spirit and work of the ILRC together and kept it focused, as evidenced particularly in one site. A good system of feedback and renewal helped to maintain the link between vision and practice, and lead to impacts such as increased consumer control.

In other areas, they talk over you, they make decisions for you, then some people go back into their shell. The ILRC never does that; they always give you the feeling that you are in control. They give you the feeling you can do it. They work with you and then you can do it. It shocks people that we can come out and say what we want. For psychiatry people they want to take care of you, and when they talk to the ILRC they are shocked because we can do it, but the psychiatry people never give us a chance.

THEME 4: Management and Implementation Difficulties

When ILRCs experienced management and implementation difficulties because of external constraints and/or internal challenges, the positive impacts of the ILRC were reduced.

Two major external constraints - transportation and funding - negatively affected the impact of the ILRCs

Transportation in the community was a significant barrier at each site, making it difficult for the ILRCs to do their job. This included concerns about both the public and

parallel systems. Most ILRC users recognized this situation and the impact it had on the ILRCs' functioning and other major aspects of their lives.

Getting back to peer support, I think you can see that the main problem is transportation. Right now I am the chair person for membership committee... We have a number of active members. We have found that we have had a lot of memberships expire, and a number of people that are not using it... If you can get out to a meeting where you can be picked up and dropped off it is a marvelous thing. It has been very unfortunate with government cuts.

Unreliable and limited funding made it difficult for the ILRCs to do their job. This made it difficult for new initiatives to get started or sustained over long periods of time. Creative approaches to fundraising were seen as being especially important at this time, to reduce the negative impact on ILRC programs, in addition to continuing to work with the federal and provincial governments towards an adequate funding base .

There's a whole committee working just on funding for everything. As of '95 federal funding support for the ILRC is going to be cut and we will receive no more funding on the federal level, and there is a lot of costs. I see the ILRCs as tremendous and they are the best things that have happened right across Canada. They are to be commended, they are very committed people. I would hate to see them dissolve.

Several major internal constraints related to staffing, the cross disability mandate of the ILRC, peer support, and links to parent organizations

First, in regards to staffing, when difficulties were experienced in this area, ILRC users sometimes felt negative impacts. Some ILRC users talked about concerns around staff roles, e.g., lack of flexibility and users' confusion around the advocacy function of ILRCs; hiring dilemmas, including the issue of non-disabled staff; differences between staff and users; and communication difficulties.

It affected office morale and the consumers' morale. It wasn't just between myself. This was a known problem. It was then on the management. There was no clear process in dealing with the problem, so it was put to the management. There was no evaluation system.

While most people agreed with the cross disability mandate of the ILRCs, there was concern that improvements could be made in this area. In general, people felt the

ILRCs did best in terms of serving the needs of people who have physical disabilities. However, since their mandate included other disabilities such as mental health problems, developmental disabilities, head injuries and visual and hearing impairment, more attention was required to respond to the large variety of needs and issues of these groups.

Even though the Centre has a cross disability focus, the sponsoring group has an image related to physical disabilities so they assume that the ILRC does also and doesn't know that it applies to other disabilities... I think they have to advertise more.

One of the main programs or services offered by ILRCs was peer support. Peer support includes such things as one-on-one counselling, peer support groups, a one-to-one matching, and educational events. Peer support was the one area people seemed to notice most when it was either missing or not being run effectively, which occurred in all three sites. Consumers felt strongly that peer support should be an important part of the foundation of the ILRC.

To me the most important part is the peer counseling and support.

Peer support is the whole center of the organization.

Finally, independence from more traditional organizations was sometimes lacking. People seemed to understand that they were treated differently at the ILRCs and that the reason this happened was because the IL philosophy was so different from most traditional service providers. In order for people to continue to be treated differently, that was in a valuing, egalitarian way, independence from other traditional services was needed, especially the sponsor or parent organization.

I think the ILRC should be separate from our sponsor - I have heard this from people. If I hadn't started working here I wouldn't even know about it. I wouldn't be surprised if others told you this.

Discussion

The four central themes identified in our analysis suggest that ILRCs have had positive impacts at an individual level. Our conclusions also point to some success in influencing the larger community and identify some on-going challenges. Perhaps most

importantly, it seems clear that ILRCs succeed, in large part, not simply because they provide an opportunity to learn skills, access information, or receive support, but because they do so in a way which is consistent with the IL philosophy - a way which builds on the strengths and capacities of the individual, promotes consumer control and empowerment, and works for individual change which is embedded in the realization of life as a valued member of a community.

Working in a Way Which is Consistent With the IL Philosophy

People we spoke with saw the ILRCs as an important resource, with the potential to make major contributions to change for individuals and communities. The ILRCs in Canada continue to play a significant role in the promotion of IL, as they have throughout North America for 20 years (Carpenter, 1991a; Enns, 1991; Lord & Osborne-Way, 1987). In the U.S., they remain involved with the grassroots consumer and self-help movements from which they began (Berkowitz, 1979; DeJong & Lefchez, 1983; Hahn, 1985).

At the ILRCs, users were respected and were seen as having an important contribution to make to the work of the ILRCs. They were seen as being valuable members of the ILRC team and were treated with equity and fairness. According to study participants, this sense of membership was closely linked to the good communication processes within the ILRC, having access to information, and being able to count on the ILRC to respond to their concerns.

Our analysis suggested that this inclusive approach succeeded partly because it allowed ILRCs to continually link their practice to the IL vision or philosophy, through the process of open communication and mutual respect, a concept also supported in the literature (Canadian Association for Independent Living Centres, 1990; Lord & Osborne-Way, 1987). Clearly, the ILRCs have developed a way of involving people with disabilities which serves to maintain and develop the IL philosophy. In explaining why they felt that ILRCs have had more positive impacts on their lives than rehabilitation-

oriented formal service agencies, people identified the way they were empowered as decision-makers and the driving principles or philosophy as the key factors. As people described their experiences, we sensed for many a deep personal commitment to the IL paradigm. Being part of an ILRC, they not only achieved personal outcomes, but genuinely internalized the IL philosophy.

Impact of ILRCs on Individuals

Treating people as valued citizens is still something which differentiates ILRCs from many other parts of the community. Our participants indicated that, unfortunately, negative attitudes and misconceptions still exist and that the lives of people with disabilities are often dominated by professionals and services. Improvement in the quality of life for people with disabilities requires both skill development as well as the removal of environmental, social, and economic barriers. These goals are inseparable (Crewe and Zola, 1984, DeJong, 1981, Dunn, 1987; Rappaport, 1986). However, it was also equally evident from this research that the problems which need to be addressed are complex and will require on-going effort on the part of consumer groups over a long period of time. Furthermore, the data indicated that Canadian ILRCs are not expected to accept sole responsibility for removing the barriers facing people with disabilities in the community, in order to avoid duplication with the more social policy mandated consumer advocacy groups like the Council of Canadians With Disabilities (CCD), formally the Coalition of Provincial Organizations for the Handicapped (COPOH), which is a more explicitly collective advocacy-oriented organization (Simpson, 1993). However, CAILC acknowledges that its role is not always easy to play, as ILRC users often assume and desire that the ILRCs play a stronger advocacy role in fighting community barriers. A number of potential applicants to CAILC have been refused membership if their major function is systemic advocacy (CAILC, 1989).

Despite these persistent challenges, the inclusive approach taken by these three ILRCs has had positive impacts on individuals. Participants reported acquiring useful

skills, a sense of accomplishment through making a positive contribution to the ILRCs, as well as increased control and self-esteem. As Zola (1982) argued, it appears that fostering consumer control and choice is a powerful means to build skills and promote autonomy (COPOH, 1986).

Personal empowerment is often characterized by increasing competence and confidence (Lord, 1991). The individual empowerment afforded through involvement with the ILRCs seems to have been particularly important in relation to people being able to become competent in a variety of community living skills, as well as foster increased confidence and self esteem. In large part, this success appeared to be tied to the individual attention and flexibility, which the ILRC skills development program offered, enabling people to make positive changes in their lives, live more independently, and experience empowerment.

All core programs, which have the same guiding principles of empowerment, inclusion and consumer control, contributed to an overall IL environment at the three ILRCs, each uniquely operating in line with the IL philosophy. In some areas, there was an ongoing struggle to implement these principles, and to provide a variety of opportunities for people to connect with one another, share experiences, and talk in depth about the issues that concern them. There is growing recognition in the literature of the importance of increasing one's own independence through building community and strong social networks (Hutchison, 1990; Hutchison & McGill, 1992; Lord & Osborne-Way, 1987; McKnight, 1986, 1989; Pedlar, 1991; Seed & Montgomery, 1989; Taylor, Biklen & Knoll, 1987). The experiences at ILRCs suggested that they were having a positive impact on people's sense of connectedness and access to support from peers. This was beneficial and challenging, involving a combination of formal programming and ensuring an atmosphere of on-going, informal support in the day-to-day operation of the ILRC. In this study, due to financial, transportation, and management constraints, some people felt

that their needs for peer support were not always able to be met, again issues raised previously in the literature (Neufeldt, 1993; Valentine, 1994).

Although the three ILRCs have been successful in supporting skills development and fostering empowerment, they continue to face a number of challenges. New strategies, for instance, are needed to reach out to others still struggling to overcome decades of discrimination and exclusion. As well, participants mentioned internal challenges, such as the continuing need to find ways of involving people with all types of unique disabilities. A variety of issues related to staffing, including the roles staff members play in relation to other ILRC members, the commitment of staff to the larger IL movement, and the sensitivity of employing staff who do not have disabilities, reflected the on-going struggle to further ILRC goals.

The challenges which ILRCs faced in their attempts to incorporate their values in their function as an employer may have reflected a broader theme in our findings. Specifically, the relationship of ILRCs to the larger IL movement required that they balance several responsibilities which may in fact produce operational tensions. For example, there is tension in being a government funded resource centre, while also being committed to being a supporter of people with disabilities to be their own voice and a contributor to a grassroots movement, issues raised by others (DeJong, 1993; Lefebvre, 1992). Our results suggested that the ILRCs experienced difficulties which are common to many organizations, as noted in the growing literature on leadership and organizational change (Covey, 1991; Peck, 1991; Rappaport, 1986; Schwartz, 1992) but which are aggravated by the unique role or mandate of the ILRC.

Community Impacts

As noted earlier, the results presented here are from the first year of a two year study. The focus in year one was on individual level impact. However, individual impact is often intimately linked to efforts to change the environment. In some American IL literature, it is emphasized that disability needs to be understood in a political and societal

context, rather than simply from an individualistic perspective (Jongbloed & Crichton, 1990; Oliver, 1990; Oliver & Zarb, 1989; Zarb, 1992). Initial findings related to community impact will be further developed in year two, when we focus explicitly on the impact of ILRCs on the community. However, since year 2 did not survey users of the ILRC's, their input regarding community impact was included here.

Even though these preliminary data suggest that ILRCs have had less direct impact on the community than they have had on individuals, it is important to note that the ILRC approach to supporting individuals is designed to have a "ripple effect" and through the process of individual and collective empowerment, ultimately lead to significant change in the community. One of the key findings from the first phase of this study, namely that the ILRCs have impact because their work is done in the spirit of fostering fundamental changes in personal communication processes and power relations, highlights the indivisibility of personal and political change. ILRCs have been working hard to collaborate with community agencies to create change, by forming partnerships, educating community groups, monitoring the community's sensitivity to disability issues, and helping to develop new services. However, preliminary indications from the second year of this study as well as the literature suggest that more work is needed in assisting groups to learn how to bring about community change (Neufeldt, 1993; Robertson, 1991).

Conclusion

One of the fundamental beliefs of the ILRCs is that people can make profound positive changes in their lives if they are treated with respect, valued as members of a community, and provided with opportunities to recognize and exercise their personal decision-making and risk-taking. Findings from this partnership study, which highlight the individual level outcomes of the ILRCs, provide evidence for the power of this approach and reaffirm what has been asserted and illustrated in the IL literature for twenty years. Canadian ILRCs are an effective means for building social networks, teaching new skills, improving self esteem, and fostering personal empowerment. Many participants in

this study also internalized a strong understanding and commitment to the IL philosophy as a result of their involvement. This study indicated that the positive impacts were not solely related to core programs, but were rather more a result of a combination of factors, ranging from the philosophy, the approach, and the commitment to empowering people.

Fifteen years after the International Year of Disabled Persons, this study also highlights some of the issues and challenges still facing the ILRCs. In the community, progress has been considerable but funding and transportation problems are persistent barriers in some ILRCs. Within the ILRCs, there is a need to continue to develop the cross-disability focus and deal with internal management issues. There is a growing awareness of the need to create innovative partnerships throughout the community and across the country. Articulating the roles which ILRCs should and should not play within the broader movement for individual rights as full citizens.

In the second year of this collaborative project, a national survey will focus on the impacts which ILRCs have had on the community as a whole. The conclusions reached to date underscore the importance of considering personal empowerment and long term societal impacts on how people with disabilities are respected and invited to be full decision- makers and managers of their own destiny. Evidence suggests that the value of the ILRCs is that individuals are being supported to grow within the context of community life, in ways which facilitate understanding and change in these contexts, through partnership with community members, including other people with disabilities.

References

- Alary, J. (Ed.) (1990). *Community care and participatory research*. Montreal: NU-Age Editions.
- Barnes, C. (1992). Qualitative research: Valuable or irrelevant? *Disability, Handicap and Society*, 7(2), 115-124.
- Berkowitz, (1979). *Disability policies and government programs*. New York: Praeger Publishers.
- Brown, R., Boyer, M., Brown, P. (1992). *Empowerment and developmental handicaps: Choices and quality of life*. North York: Captus Press.
- Budde, J., Petty, R., & Nelson, C. (n.d.). *Problems and benefits associated with consumer satisfaction evaluation at Independent Living Centers*. Kansas: University of Kansas Research & Training Center on Independent Living.
- Canadian Association for Independent Living Centres. (1989). *Eligibility criteria for CAILC membership*. Ottawa, ON.
- Canadian Association for Independent Living Centres. (1990). *A guide to Independent Living Centres*. Ottawa, ON: Canadian Association of Independent Living Centres.
- Canadian Association for Independent Living Centres. (1991). *Guidelines for Independent Living Centres in Canada*. Ottawa, ON: Canadian Association of Independent Living Centres.
- Carpenter, S. (1991, Spring). The role of Independent Living Centres in the lives of Canadians: Colouring outside the lines. *Abilities*, 35-36.
- Carpenter, S. (1991a). The Canadian model of Independent Living Centres: Trends and issues. *Rehabilitation Digest*, 22(2), 3-7.
- Carpenter, S. (1993). Independent Living Centre perspectives on cross-disability and consumer control. In A. Neufeldt (Ed.), *Independent living: An agenda for the '90's*. (pp.83-98). Ottawa: Canadian Association for Independent Living Centres.

- Chesler, M. (1991). Participatory action research with self-help groups: An alternative paradigm for inquiry and action. *American Journal of Community Psychology*, 19(5), 757-768.
- COPOH. (1985, March). *Conference report of Coalition of Provincial Organizations of the Handicapped*. Montreal, Quebec: COPOH, 14-17.
- COPOH. (1986). *Defining the parameters of independent living*. Winnipeg, Manitoba: COPOH.
- Covey, S. (1991). *Principle-centered leadership*. Toronto: Simon & Schuster.
- Crewe, N., & Zola, I. (1984). *Independent living for physically disabled people*. San Francisco: Jossey-Bass Inc.
- De Jong, G. (1979). Independent living: From social movement to analytic paradigm. *Archives of Physical Medicine and Rehabilitation*, 60, 435-446.
- De Jong, G. (1981). *Environmental accessibility and independent living outcomes*. East Lansing, Michigan: University Centre for International Rehabilitation.
- De Jong, G. (1993). Three trends to look for in the American Independent Living movement in the 1990's. In A. Neufeldt (Ed.), *Independent living: An agenda for the '90's*. (pp.109-120). Ottawa: Canadian Association for Independent Living Centres.
- De Jong, G., & Lifchez, R. (1983). Physical disability and public policy. *Scientific American*, 248(6), 40-49.
- De Loach, C. (1983). *Independent living: Philosophy, process and services*. Baltimore: University Park Press.
- Driedger, D. (1989). *The last civil rights movement: Disabled Peoples International*. London: Hurst.
- Dunn, P. (1987). *The impact of housing upon the independent living outcomes of individuals with disabilities*. Unpublished doctoral dissertation, Waltham, Massachusetts: Brandeis University.

- Dunn, P. (1990). The impact on the housing environment upon the ability of disabled people to live independently. *Disability, Handicap and Society*, *5*(1), 37-52.
- Dunn, P. (1994). Government policy innovations in barrier-free housing, accessible transportation and personal supports. Winnipeg: National Independent Living Conference.
- Enns, H. (1986). An excerpt from the historical development of attitudes toward the handicapped: A framework for change. In A. D'Aubin (Ed.), *Defining the parameters of independent living*. Winnipeg, Manitoba: Coalition of Provincial Organizations for the Handicapped.
- Enns, H. (1991). Introduction to independent living. *Compass*, *2*(9), 1.
- Federal Government of Canada. (1981). *Obstacles*. Report of the Special Committee on the Disabled and the Handicapped, Ottawa.
- Friedmann, J. (1992). *Empowerment: The politics of alternative development*. Cambridge, Massachusetts: Blackwell.
- Gardner, J. (1992). *Outcome based performance measures*. Washington, D.C.: The Accreditation Council on Services for People with Disabilities.
- Guba, E., & Lincoln, Y. (1989). *Fourth generation evaluation*. Newberry Park, California: Sage Publications.
- Hahn, H. (1985). *Disability and rehabilitation policy*. Washington, D.C. : Government Printing Office.
- Hutchison, P. (1990). *Making friends: Developing relationships between people with a disability and other members of the community*. Toronto: G. Allan Roeher Institute.
- Hutchison, P., & McGill, J. (1992). *Leisure, integration and community*. Toronto: Leisurability Publications.

- Hutchison, P., Lord, J., & Osborne-Way, L. (1986). *Participating: With people who have experienced the mental health system*. Toronto: Canadian Mental Health Association.
- Jongbloed, L., & Crichton, A. (1990). Difficulties in shifting from individualistic to socio-political policy regarding disability in Canada. *Disability, Handicap & Society*, *5*(1), 25-35.
- Krogh, K., & Petric, L. (1994). *Choice, flexibility and control in community research: A guidebook*. Ottawa: The Canadian Association of Independent Living Centres.
- Krogh, K., & Matanga, Z. (1994, August). *Negotiating partnership agreements*. Winnipeg: National Independent Living Conference.
- Lefebvre, N. (1992, Winter). Independent Living Centres: Meeting the challenge. *Abilities*.
- Lord, J. (1991). *Lives in transition: The process of personal empowerment*. Kitchener, ON.: Centre for Research & Education in Human Services.
- Lord, J. (1994). Genuine partnerships: Challenges and opportunities. Winnipeg: National Independent Living Conference.
- Lord, J., McGeown, M., Taylor, A., & Young, S. (1992). *More than just another human service*. Ottawa: Canadian Association of Independent Living Centres.
- Lord, J., & Osborne-Way, L. (1987). *Toward independence and community: A qualitative study of three independent living centres in Canada*. Ottawa: Secretary of State.
- MacPherson, G. (1990). Are you ready for the revolution? *Canadian Journal of Rehabilitation*, *3*(1).
- Malinga, J. (1992, Spring). Disabled Peoples International holds World Congress in Vancouver. 142-143.
- McKnight, J. (1986). Regenerating community. In K. Church (Ed.), *From consumer to citizen*. Toronto: Canadian Mental Health Association.

- McKnight, J. (1989). *Beyond community services*. Evanston, IL: Center for Urban Affairs and Policy Research. Unpublished document.
- Morgan, D.L. (1988). *Focus groups as qualitative research*. Newbury Park: California: Sage Publications.
- Neufeldt, A. (1993). Signs of the times and their implications for independent living. In A. Neufeldt (Ed.), *Independent living: An agenda for the '90's* (pp.83-98). Ottawa: Canadian Association for Independent Living Centres.
- Oliver, M. (1990). *The politics of disablement*. London: Macmillan.
- Oliver, M. (1992). Changing the social relations of research production? *Disability, Handicap and Society*, 7(2), 101-114.
- Oliver, M., & Zarb, G. (1989). The politics of disability: A new approach. *Disability, Handicap & Society*, 4, 221-239.
- Patton, M. (1990). *Qualitative evaluation and research methods*. Beverley Hills: Sage Publications.
- Peck, C.A. (1991). Linking values and science in social policy decisions affecting citizens with severe disabilities. In L. H. Meyer, C. A. Peck, and L. Brown (Eds.), *Critical issues in the lives of people with severe disabilities* (pp. 1-15). Baltimore: Paul H. Brookes.
- Pedlar, A. (1991). Supportive communities: The gap between ideology and social policy. *Environments*, 1(2), 1-7.
- Pedlar, A. (1992). Deinstitutionalization and normalization in Sweden and Ontario, Canada: Supporting people in leisure activities. *Therapeutic Recreation Journal*, 26(2), 21-35.
- Percy, S. (1989). *Disability, civil rights, and public policy: The politics of implementation*. Tuscaloosa: The University of Alabama Press.
- Racino, J. A. (1992). Life in the community: The independent living and support paradigms. In F. R. Rusch, L. DeStefano, J. Chadsey-Rusch, L.A. Phelps, and D.E..

- Szymanski (Eds.), *Transition from school-to-work for youth and adults with disabilities*. Sycamore: Ill.:Sycamore Publishing Co.
- Rappaport, J. (1986). Collaborating for empowerment: Creating the language of mutual help. In H. Boyte, and F. Reissman (Eds.), *The new populism: The politics of empowerment*. Philadelphia: Temple University Press.
- Richards, T.J., & Richards, L. (1994). Using computers in qualitative research. In N. Denzin and Y. Lincoln (Eds.), *A handbook of qualitative research* (pp. 445-462). Thousand Oaks, Calif.: Sage.
- Robertson, R. (1991, Summer). Canadian Independent Living Centres: Growing pains and empowerment. *Abilities*.
- Robinson, R. (1991, Summer). Canadian Association of Independent Living Centres: Growing pains & empowerment. *Abilities*, 16-19.
- Schwartz, D.B. (1992). *Crossing the river: Creating a conceptual revolution in community and disability*. Pennsylvania: Bookline Books.
- Scotch, R. (1988). Disability as the basis for a social movement: Advocacy and the politics of definition. *Journal of Social Issues*, *44*(1), 159-172.
- Seed, P., & Montgomery, B. (1989). *Towards independent living: Issues for different client groups*. London: Jessica Kingsley.
- Siegel, L.M., Attkisson, L.L., & Carson, L.G. (1987). Need identification and program planning in the community context. In F.M. Cox, J.L. Erlich, J. Rothman, and J.E. Tropman (Eds.), *Strategies of community organization* (pp. 71-97). Itasca, IL: F.E. Peacock.
- Simpson, A. (1993). Individual advocacy through the Independent Living Centre. In A. Neufeldt (Ed.), *Independent living: An agenda for the '90's* (pp.5-14). Ottawa: Canadian Association for Independent Living Centres.
- Taylor, S., Biklen, D., & Knoll, J. (1987). *Community integration for people with severe disabilities*. New York: Teachers College, Columbia University.

- Valentine, F. (1994). *The Canadian Independent Living Movement: An historical overview*. Ottawa: Canadian Association for Independent Living Centres.
- Winter, M. (1993). The growth and development in independent living in America. In A. Neufeldt (Ed.), *Independent living: An agenda for the '90's* (pp.121-136). Ottawa: Canadian Association for Independent Living Centres.
- World Institute on Disability. (1987). *Attending to America: Personal assistance for independent living*. Report of the national survey of attendant services programs in the United States. Berkeley, CA.
- Worth, P. (1993, June). Keynote address. Third International People First Conference. Toronto.
- Zarb, G. (1992). On the road to Damascus: First steps towards changing the relations of disability research production. *Disability, Handicap and Society*, 7(2), 125-138.
- Zola, I. (1982). *Disincentives to independent living*. Monograph 1. Kansas: The Research and Training Center on Independent Living, University of Kansas.