

**Canadian Independent Living Centres:
Impact on the Community**

by

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The International Year (1981) and Decade (1983-92) of Disabled Persons provided an impetus for addressing many important needs of citizens with disabilities. There is now widespread interest in developing social policies and practices which are grounded in principles of independent living (Lord & Hutchison, 1996; Schwartz, 1992). The Independent Living (IL) paradigm reflects a shift in thinking away from more traditional, professionally based approaches. The IL movement emphasizes people with disabilities having control over their own lives through self-help, self determination, and empowerment (Council of Canadians with Disabilities, 1995; Budde, Feighny, White, Altus, & Snyder, 1993; Rappaport, Reischl, & Zimmerman, 1992). Services in the community are beginning to adopt IL principles of consumer control/self-direction, options/choice, flexibility, and freedom (Dunn, 1998; Woodill, 1992).

Independent Living Centres (ILCs), which started in the early 1970s in the United States, and in the 1980s in Canada, are now a major force in the promotion of the IL concept worldwide (Drieger, 1989). A national organization, the Canadian Association of Independent Living Centres (CAILC), and over twenty local affiliates, support consumers/individuals with disabilities to achieve quality of life in the community and simultaneously promote community change. CAILC approves, monitors, and supports centres to ensure the guiding principles of these non-profit, community based centres are followed: an empowerment framework, consumer control, cross disability support, and promotion of inclusion and full participation (Canadian Association of Independent Living Centres, 1989; Carpenter, 1993; Valentine, 1994). Core programmes and functions of the ILCs in Canada include: information and referral; individual advocacy and consultation; peer support; and research and development (Canadian Association of Independent Living Centres, 1991; Simpson, 1993). These functions enable Canadian

centres to maintain a strong "resource" function, in contrast to many American centres which also provide direct services such as innovative attendant services and employment initiatives (DeLoach, 1983).

There is a growing body of literature about ILCs. Some researchers have focused on the assessment of individual IL skills and outcomes (Boschen & Gargaro, 1998; Nosek, Fuhrer, & Howland, 1992) and others on how ILCs work with consumers (Lord, McGeown, Taylor, & Young, 1992). A limited body of research on *impact* of ILCs has also been undertaken, mostly in the U.S. (Budd, Petty, & Nelson, 1989; Budd, Petty, Nelson, & Couch, 1986; Crewe & Zola, 1984). In light of the paucity of work in this area, researchers and others began to question the limited foundation upon which public policy was being developed. If public policy and funding in the 90's and beyond is going to be based on the assumption that the ILCs are a major force and mediating structure in the promotion of the IL paradigm, there is a need for current research and analysis which assesses the impact of ILCs, including the Canadian model and context of these centres.

Accordingly, a two year study was designed to examine the impact of ILCs in Canada on the lives of people with disabilities and on the community as a whole. Year 1 of the study focused on the impact of ILCs on *people with disabilities* who use the Centres (Hutchison, Pedlar, Lord, Dunn, McGeown, Taylor, & Vanditelli, 1996). However, the ILC's work is premised on the understanding that direct work with people with disabilities alone can not accomplish their objectives. Hence, ILCs use an IL philosophy to work with key stakeholders in the community to encourage them to change their attitudes, to increase accessibility of their settings, and to implement inclusive practices and policies. They believe this is essential, so that individuals with disabilities are not confronted by a multiplicity of barriers as they seek access to what may be described as their "communities of interest". The 2nd year of the study was designed to investigate of the impact of ILCs on their communities of interest— the individuals, groups, and organizations in the community with which the ILCs have worked. It is the

2nd year of the study that is the focus here, but the findings of both Year 1 and Year 2 will be addressed in considering the implications of this research.

Consistent with the IL's emphasis on consumer controlled research (Krogh & Petric, 1994; Woodill, 1992), the study was initiated within a collaborative, innovative partnership between: 1) the Canadian Association of Independent Living Centres (CAILC); 2) a community-based research centre with extensive IL research experience; and 3) researchers from three universities. Every stage of the project, from the research topic, to the methodology, to final reports, was jointly defined by the partners as a way of building on the IL paradigm. The intent of the collaboration was that the findings from this study inform policy development and practice in the field and contribute to building theory around the IL paradigm (DeJong, 1993; Dunn, 1998; Peck, 1991; Pedlar, 1991). Government officials, researchers and educators, IL organizations, and other disability groups would all benefit from information about the impact of these centres and the issues which they confront in developing and expanding this model of service throughout Canada.

Theoretical Framework

The IL analysis emphasizes that the problem of "disability" lies in the environment—in segregation, discrimination, and dependency on professionals (DeLoach, 1983; Enns, 1986; McKnight, 1995). This analysis provides a *political and sociological context* for change (Jongbloed & Crichton, 1990; Zarb, 1992). People with disabilities experience significant barriers as they attempt to live independently in the community participating in normal activities of education, work, and leisure (Fawcett et al., 1994; Hutchison & McGill, 1998). These obstacles are more often the result of barriers in the community. An extensive range of barriers to independent living, including inaccessible housing, public buildings, transportation, inadequate wages, and poverty-

level social assistance, result from society's continuing discriminatory and exclusionary practices (Dunn, 1998; Oliver, 1996; Schwartz, 1992).

The Independent Living Centres (ILCs) are considered as the vehicle for responding to the socio-political context of the IL movement. The ILCs emphasize quality of life issues including empowerment, control over decision-making, and promotion of integration and full participation (Valentine, 1994). Thus, IL theory incorporates a broader environmental context, advocating not only individual empowerment, but community change as well (Jongbloed & Crichton, 1990). In relation to this "mediating" potential of the ILCs, the current study examined this interface and began asking questions about the impact of the ILCs: Are ILCs perceived as being helpful in overcoming the myriad of community obstacles experienced by people with disabilities? How do the specific programmes and services offered by ILCs contribute to their impact? These questions led to the inclusion in the research of a more critical examination of change process in organizations, the community, and society at large (Forester, 1993).

Social change theory is useful because the IL movement is grounded in the notion of community change. Social change or "second order change" differs from organizational change or "first order change". It involves fundamental change to the basic assumptions and rules of the broader system within which institutions function (Etzioni, 1991). While social change theory shows that social change is a normal process, it also appears to occur in various directions and rates depending on multiple factors such as leadership, openness, awareness, and "bottom-up" participation (Covey, 1991; Raeburn, 1996). Second order change contributes to a shift in assumptions and values, to changing structures and processes, and to reallocation and realigning resources. In this sense, the IL movement and the ILCs are attempting to alter basic assumptions of society. The paradigm shift that is gradually occurring, from traditional medical or rehabilitation approaches to a community integration and empowerment framework, is evidence of the focus and direction of the IL and other disability movements.

Conflict is ubiquitous or ever present in change processes (Lauer, 1991). It is reasonable, therefore, to approach the process of change incrementally, whereby the influence of mediating structures allows for a gradual overcoming of perceived threats and shifting in ideas and practices. The ILCs can be seen as working toward incremental change in the relationships they have with community stakeholders which, in this study, are referred to as communities of interest. Effecting change with these communities of interest could be regarded as "second order change" leading, over time, to broader systemic change, and a reallocation of societal resources. Thus, change within any community of interest might begin with individuals within an ILC, gradually impacting community agencies and structures, and eventually influencing change at the regional and national policy level, acting as a ripple effect.

Methodology

As noted above, Year 1 of this two-year research project focused on the impact of the ILCs on primary users of the Centres—individuals with disabilities. Year 2 examined the impact of the ILCs on their communities of interest. Since little was known about the impact of the ILCs on other major stakeholders that access the ILCs, that is the communities of interest, the focus of the research in Year 2 was to answer the following research questions:

1. How familiar and involved are community groups and individuals with the ILCs, including formal services/agencies, informal groups, and families/friends?
2. Do ILCs have an impact on these community groups/organizations and individuals, and if so, what are these impacts?
3. What does the community perceive as the strengths of these ILCs and what areas of activities at the centres are seen to require further development?

Using a standardized, self-administered survey, data were collected from formal services/agencies, informal groups, and families/friends involved in a sample of ILCs in Canada.

Site Selection

A sample of three ILC sites were selected for this research, since there were too many centres and respective community respondents to examine in Canada. At the time of the study, there were around 20 ILCs in Canada, although most were in a formative stage of development. ILCs which were selected for this study fulfilled the following selection 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 i.e., information and referral, individual advocacy/consultation, peer support, and research and development (Canadian Association of Independent Living Centres, 1989). This sample was stratified by location to ensure that sites which were geographically diverse were represented. The three sites which were selected included a western centre, one representing a more northern community, and a third from central Canada.

Change theory, particularly issues pertaining to process and complexity, was the basis for the decision that only well established Centres with basic funding sources would provide a sufficiently strong foundation for studying the concept of impact in this study. It was felt that centres in a formative stage would not have the opportunity to impact the overall community. Ultimately, the choice of sites was limited by the fact that most ILCs were still in relatively preliminary stages of development. This study focused on the impact of established ILCs in Canada with core ILC services.

Participants

One question that needed to be reflected in the design of the study was: to what degree are the ILCs addressing the needs of diverse stakeholders in the community—professionals working in formal agencies, informal groups, and families/friends? The

results of Year 1 dealt with the impact upon consumers with disabilities? These communities of interest represent the major stakeholders in the day-to-day operation of the ILCs. Therefore, the research focused upon the perceptions of three groups in the communities of interest at each of the study sites. The first group included staff of *formal organizations* in the community (e.g., agencies such as Community Living Association, government departments, hospitals, businesses, schools, unions, and funders). The second group included individuals involved with *informal groups* (e.g., self-help groups, parent support groups, community clubs, neighbourhood associations, churches). The third group was referred to as *family/friends* (e.g., family members, friends, and acquaintances of people with disabilities/users of the ILCs).

Each ILC study site was asked to provide a list of all formal and informal groups with whom they had contact, as well as family members and friends of persons who used the ILC. From these lists, a total sample of 211 was identified, stratified by group, i.e., stakeholder groups that comprised the study sites or ILC's communities of interest. These homogeneous groups or subsets of the communities of interest (Babbie, 1992, p. 215) represented formal organizations (53%), informal groups (32.4%), and family/friends (14.6%).

Table 1.
Response Rate By Participant Group

CATEGORY OF STUDY PARTICIPANTS	TOTAL NUMBER OF SURVEYS	NUMBER OF RESPONDENTS	RESPONSE RATE (%)	PERCENT OF RETURNS (%)
Formal Organizations	112	65	58.0	58.6
Informal Groups	68	32	47.1	28.8
Family/ Friend/ Acquaintance	31	14	45.2	12.6
TOTAL	211	111	52.6	100.0

From the 211 surveys distributed to the community, 111 were returned after two mailings; giving a response rate to (52.6%). The response rate for each of the groups or subsets of the community that received the survey was relatively consistent across groups:

formal organizations (58.0%), informal groups (47.1%) and family/friends (45.2%) (see Table 1). As well, consistent with the original stratification, the distribution of responses across the groups was such that the largest proportion of returns was from the formal organizations (58.6%; secondly, the informal groups (28.8%); and finally, the smallest group, family/friends (12.6%).

Survey Instrument

The survey questionnaire was developed by the research team because of the absence of existing measures of positive and negative "impact". Recognition in the theoretical framework that social change occurs at different levels meant that the survey had to examine impact, as well as other centrally related concepts of familiarity and involvement with the services of the centres. Some people may simply know of different programmes or components of an ILC and others may have extensive involvement. These different levels of familiarity and involvement needed to be captured.

As a result, the survey was organized according to four major areas. One section contained questions related to people's *familiarity* with different components of the ILC, including the four core areas of the ILC i.e., information and referral, individual advocacy/consultation, peer support, and research and program development. To ensure content validity, questions were developed to cover all aspects of the four core programs. A second section focused on the nature and extent of their actual *involvement* with each of the four core areas of the ILC. The third area involved questions related explicitly to people's experiences in relation to *impact* of the ILCs in the same four core areas, as well as impacts connected to experiences such as empowerment, the cross-disability mandate, and the IL movement in general. The final open-ended section invited people to provide their ideas about the ILC's strengths and weaknesses and to make suggestions for improving the ILCs in the future. The instrument was pre-tested and revised accordingly.

Data Analysis

The Statistical Package for the Social Sciences (SPSS) was used to assist in this analysis. Data analysis involved simple frequencies and percentages of responses to survey items. Calculations of mean responses to questions by individuals in the different categories of participants (e.g., formal organizations, family/friends) was done. A comparison of responses by the different categories of participants using the chi square statistic was also completed.

Results

The results are presented under four categories as follows: familiarity with the ILCs; involvement with the ILCs; impact of the ILCs; and recommendations for the future of these organizations. For simplicity, statistically significant differences between the three stakeholder groups (formal, informal, family/friends) are noted in the text, rather than in the tables.

Familiarity with the ILCs

Participants indicated that their overall general familiarity with the ILCs was higher than their familiarity with specific programmes (mean=3.297, st.dev.=.804). As well, the participants were more familiar with the philosophy of independence and self-determination of the ILCs (mean=3.545, st.dev.=.964) than they were with any of the specific core programmes i.e., information and referral, advocacy/consultation, peer support, research and program development. Of these four, participants were most *familiar* with the information and referral programmes (mean =3.282, st.dev.=.92) and least with research and development (mean=2.57, st.dev.=1.0651) (see Table 2).

In general, the three groups (formal agencies, informal groups, and family/friends) did not differ in their familiarity with different aspects of the ILC except for their familiarity with individual advocacy/consultation. Individuals in the formal agencies rated higher familiarity on this item than informal groups or family/friends.

Table 2.
Familiarity With Independent Living Centres

FAMILIARITY WITH INDEPENDENT LIVING CENTRES	n	Mean	St. Dev.
Familiar with philosophy of independence and self-determination?	110	3.545	0.964
General familiarity with ILC	111	3.297	0.804
Familiar with information and referral?	110	3.282	0.92
Familiar with individual advocacy/consultation? ^a	109	3.11	0.975
Familiar with peer support?	108	2.833	0.962
Familiar with research and development?	107	2.57	1.065

* $p < .05$

Involvement with the ILCs

On average, the participants indicated that they had been involved with the ILCs for approximately 4.1 years (st.dev.=3.1 years). Responses on the length of involvement with the ILCs ranged from 1 month to 15 years, indicating a great amount of variability in their involvement.

Core programmes. Overall there were notable differences in the participants' involvement in the different aspects of the ILC's *information and referral programmes* offered (see Table 3). All ILCs produce a newsletter as a major information source for people. Many participants indicated that they share the newsletter with others (n=70, 90.9%). The ILCs helped in referral, for instance, providing appropriate community resources (n=44, 89.8%), and in turn, many participants had referred people to the ILCs (n=69, 75.0%). Relatively few people had used the other information and referral programmes offered by the ILCs, for instance, very few had used the ILCs for grant writing (n=3, 3.2%), technical assistance (n=10, 10.9%), or library or resource centre (for tapes, books, etc.) (n=25, 22.9%). While a larger number attended awareness sessions/workshops presented by the ILCs (n=42, 39.3%).

With respect to *individual advocacy and consultation*, as shown in Table 3, many participants knew of individuals receiving practical, physical, or emotional support from the ILCs (n=59, 55.7%) and a lesser number who had been part of a consultation around a person (n=38, 35.8%). In terms of differences amongst groups, perhaps predictably given

Table 3.
Involvement With Independent Living Centres

INVOLVEMENT WITH INDEPENDENT LIVING CENTRES	n (yes)	Pct.
INFORMATION & REFERRAL		
Do you share the newsletter with others?	70	90.9%
Could the ILC provide you with an appropriate contact?	44	89.8%
Do you receive the newsletter?	88	80.7%
Do you refer/send people to the ILC?	69	75.0%
Have you used ILC information?	72	66.1%
Have you used the ILC referral?	56	54.4%
Does the ILC refer/send people to you?	46	50.0%
Been involved with awareness sessions/workshops?	42	39.3%
Do you use the resource centre?	25	22.9%
Have you used the ILC for technical assistance?	10	10.9%
Have you used the ILC for grant writing? *	3	3.2%
ADVOCACY/CONSULTATION		
Know someone who has received practical physical or emotional support?	59	55.7%
Has the ILC helped someone you know become more independent?	47	50.0%
Aware of someone who has obtained support?	42	40.4%
Have you been part of a consultation around a person? *	38	35.8%
PEER SUPPORT		
Do you know someone referred to ILC for peer support?	34	31.8%
Do you know someone who has had involvement with social/recreational activities? **	21	20.0%
Know someone involved with informal, drop-in peer support?	19	18.3%
Have you been part of a self-help activity? ***	11	10.3%
RESEARCH & DEVELOPMENT		
Are you aware of research the ILC has carried out?	52	48.1%
Do you serve on a community committee with ILC staff? *	49	45.8%
Were you involved with the ILC on a special project or partnership?	40	37.7%

Note: Percentages have been calculated using only those who responded yes or no to the questions asked. Individuals who indicated that the question was not applicable, or left the question blank, were not included in this calculation.

* $p \leq 0.05$ ** $p \leq 0.001$ *** $p < 0.001$

the nature of individual needs versus agency or organization needs, family/friends indicated the greatest involvement with individual advocacy and consultant ($\chi^2=8.93$, $df=2$, $p=.011$).

Peer support offered by the ILCs includes social or recreational activities, informal drop-in support, and peer support groups. Generally fewer participants indicated involvement or association with peer support than was the case with the information and referral and advocacy and consultation components of ILC activity. Thirty-four participants (31.8%) indicated that they knew someone who had been referred to the ILCs for a peer support group. Again, perhaps not surprisingly given the nature of the programmes, family/friends were more likely than formal agencies and informal group members to know someone involved with social or recreational activities ($\chi^2=14.25$, $df=2$, $p=.001$). As well, participants from this group were more involved in self-help activity than those from other stakeholder groups ($\chi^2=16.62$, $df=2$, $p=.000$).

In connection with the *research and program development* program, almost half of the participants ($n=52$, 48.1%) indicated that they were aware of at least one research project that the ILCs had carried out (e.g., needs assessments, program evaluations, action research). Forty-nine participants (45.8%) indicated that they sat on community committees where a representative of the ILCs was a member. More participants in the formal and informal group indicated that they served on a community committee with ILC staff than was the case for those in the family/friends category ($\chi^2=8.69$, $df=2$, $p=.013$).

Impact of the ILCs

Core programmes. Participants rated the impact of various aspects of the core programmes on 5-point Likert Scale. The impact of *information and referral programmes* were rated relatively highly and participants considered the ILCs to be a valuable resource (mean=3.68, st.dev.=.886) (see Table 4). However, they felt that the ILCs were less

effective in changing the general public's perception and awareness of individuals with disabilities and informing them of the role of ILCs.

In the area of individual *advocacy and consultation* programmes, participants saw staff of the ILCs as very supportive of consumers during consultations or meetings (mean=4.12, st.dev.=.821) (see Table 4). In addition, the helpfulness of the ILCs around integration issues was evident (mean=3.63, st.dev.=1.087) and in this regard, family/friends indicated a very positive perception of the ILC's impact (mean=4.111).

Participants were asked to indicate how helpful and responsive each of the following *peer support* activities of the ILCs has been: peer support group, social/recreational activities, and informal unstructured participation. Overall, while rated lower than the other core programmes, peer support activities were considered somewhat helpful (see Table 4). Informal unstructured participation in peer support activities (mean=3.162, st.dev.=1.068) was rated highest of the peer support activities. This was followed by social/recreational activities (mean=3.105, st.dev.=1.1). Interestingly, peer support was not rated highly in terms of its helpfulness (mean=2.977, st.dev.=1.171).

It was generally felt that *research and program development* activities (such as participation in community committees, special projects or partnerships, and research activities) had a positive impact. Participants indicated that involvement with the ILCs on special projects or partnerships was very positive (mean=3.857, st.dev.=1.03) (see Table 4). It was generally felt that the contribution of the ILC's staff on community committees was worthwhile (mean=3.676, st.dev.=.932) and the research activities of the ILCs had an impact on their communities (mean=3.333, st.dev.=1.0).

Overall impact. Based on the assumption that ILC impact is not limited to only core programmes, several other impact questions were asked (see Table 5). Participants indicated that they felt that *ILCs promote the independent living movement* to a high degree (mean=4, st.dev.=.791). They indicated that the ILCs have been very *responsive to*

Table 4.
Impact of Independent Living Centres

IMPACT OF THE INDEPENDENT LIVING CENTRES	n	Mean	St. Dev.
INFORMATION AND REFERRAL			
ILC seen as a valuable resource?	100	3.68	0.886
How well has the staff been able to answer questions re: disability issues? *	71	3.676	0.997
Is the information in the newsletter useful?	88	3.42	0.867
How well has the public awareness work of the ILC informed the public about how to treat individuals with disabilities?	88	3.08	0.937
To what extent is the ILC changing attitudes and misconceptions?	86	3.023	0.881
How useful is the resource library?	62	2.919	1.191
How well has the public awareness work of the ILC informed the public about the role of the ILC?	96	2.875	0.921
INDIVIDUAL ADVOCACY/CONSULTATION			
Are staff supportive of consumers during consultations?	75	4.12	0.821
Has ILC been helpful around integration issues for someone you know? **	54	3.63	1.087
How helpful is the ILC in assisting individuals around issues and problems?	78	3.615	0.957
PEER SUPPORT			
Has informal unstructured participation been helpful?	37	3.162	1.068
Have social/recreational activities been helpful?	38	3.105	1.11
Has peer support group been helpful?	44	2.977	1.171
RESEARCH AND DEVELOPMENT			
Was your involvement with ILC on special projects/partnerships positive?	63	3.857	1.03
Does the ILC staff make a worthwhile contribution on community committees?	74	3.676	0.923
Did the research activities of the ILC have an impact on the community?	63	3.333	1

* $p \leq 0.05$ ** $p \leq 0.005$

the participants' requests (mean=3.988, st.dev.=.861). The ability of the ILCs *to meet their cross disability mandate* was the item that received the lowest rating (mean=3.386, st.dev.=.94).

The participants also had the opportunity to comment on the extent to which the ILCs are empowering for people in six areas. Participants were very positive for all areas, with the highest being impact in enhancing self-esteem and self-confidence (mean=3.739,

st.dev.=.837), followed by gaining knowledge and awareness (mean=3.737, st.dev.=.732), gaining control over their lives (mean=3.71, st.dev.=.788), strengthening social networks (mean=3.65, st.dev.=.816), contributing to the community (mean=3.62, st.dev.=.85), and building new skills (mean=3.5, st.dev.=.91) (see Table 5).

Table 5.
Overall Impact of Independent Living Centres

PERCEIVED IMPACT ON COMMUNITIES	n	MEAN	ST. DEV.
Promotion of the independent living movement?	100	4.000	0.791
Responsiveness to your requests?	86	3.988	0.861
Meeting their cross-disability mandate? **	88	3.386	0.94
Empowerment			
Helping individuals enhance self-esteem and self confidence? *	92	3.739	0.837
Helping individuals gain knowledge and awareness?	95	3.737	0.732
Helping individuals gain control over their lives?	93	3.710	0.788
Helping individuals strengthen social networks?	93	3.645	0.816
Helping individuals make a contribution to community?	92	3.620	0.85
Helping individuals to build new skills? ***	88	3.500	0.91

* $p < .05$. ** $p < .005$. *** $p < .001$

The Future

This section asked participants some broader questions related to their perceptions of the overall strengths and weaknesses of the ILCs.

Effect of the ILC's philosophy, leadership, and programmes on positive community impact. Participants were asked to indicate on a 5-point Likert Scale the extent to which the following components contributed to the positive impact of the ILCs on their communities: the ILC's philosophy, the ILC's leadership, and the ILC's programmes. All of these aspects appeared to have relevance. The philosophy of the ILCs was clearly seen to contribute positively (mean=3.88, st.dev.=.875), with leadership also making a notable impact (mean=3.655, st.dev.=.925) (see Table 6). For both of these items, participants in the family/friends group responded more positively than those in the formal and informal groups.

Table 6.

Effect of the ILCs Philosophy, Leadership and Programs on Positive Community Impact

ASPECTS OF THE ILC CONTRIBUTING TO POSITIVE COMMUNITY IMPACT	n	Mean	St. Dev.
Contribution of ILC philosophy *	92	3.88	0.875
Contribution of ILC leadership *	87	3.655	0.925
Contribution of ILC programmes	93	3.548	0.95

* $p < .05$.

Perceived causes of weaknesses and limitations of the ILCs. Using a 5 point Likert Scale, participants were asked to rate possible causes of weaknesses/limitations of the ILCs, and mostly clearly, lack of funding was seen as problematic (mean=3.29, st.dev.=1.177) (see Table 7). Inadequate transportation (mean=2.774, st.dev.=1.086) and a limited range of programmes (mean=2.644, st.dev.=1.141) were also seen as limitations of the ILC's effectiveness.

Table 7.

Perceived Causes of Weaknesses and Limitations of the Independent Living Centres

CAUSES OF WEAKNESSES/LIMITATIONS	n	Mean	St. Dev.
Lack of funding	69	3.29	1.177
Inadequate transportation	53	2.774	1.086
Limited range of programs	59	2.644	1.141
Staff problems	50	2.02	1.134

The last question on the survey was open-ended and invited participants to provide suggestions for making the ILCs more effective in the future. Sixty-four participants commented, with the majority of comments falling into two categories: increasing the profile of the ILC in the community (n=22) and funding (n=20).

Suggestions to increase the profile of the ILCs in their communities included: "better marketing to better sensitize the larger community to the mandate, programmes, and philosophy", "get the community at large more interested and involved in the ILCs", and "more information to care providers regarding philosophy and services".

Regarding funding, participants stated that more stable funding was required for the ILCs. As one respondent stated, "settle funding concerns one way or the other—be aggressive". Another participant stated that there was a need for "broader means of obtaining funding—more government money".

Discussion

Individual impact is often intimately linked to efforts to change the environment. IL literature emphasizes that disability needs to be understood in a political and societal context, rather than simply from an individualistic perspective (Jongbloed & Crichton, 1990; Oliver, 1996; Zarb, 1992). The ILC approach to supporting individuals is designed to have a "ripple effect", and through a process of individual and collective empowerment, ultimately lead to significant change in the community. One major finding from Year 1 of this study, namely that the ILCs 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. Indeed, as the results of the Year 1 study mentioned, the more people with disabilities use ILCs, the more they are aware of the broader role and impact of the ILCs (Hutchison et al., 1996). ILCs 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, Year 2 of this study, as well as the literature, suggest that more work and resources are needed in assisting groups to bring about community change.

The survey results showed that stakeholder groups were *familiar*, albeit moderately so, with the ILCs. They were familiar with the ILCs, as well as with its philosophy of independence and self-determination. Such familiarity should not be surprising given that these 3 ILCs are well established in their communities. On the other hand, these groups were not as familiar with the specific programmes offered by the ILCs.

This is not surprising given that these ILCs are relatively small and have very limited budgets, not to mention that some participants had been involved for as little as a month.

In terms of *involvement* of the four core programmes, the heaviest *involvement* of the community was with information and referral. Almost half were also involved in advocacy and research activities. It is interesting that so many were involved in research and collaborative service development. By far the fewest number of community members were involved with the peer support programme. This situation may be explained by the fact that respondent groups were less likely to be direct users of the ILC and hence not likely to be part of peer support programmes. However, some of these participants may have been in a position to refer individuals to peer support programmes and hence at least knowing of the existence of such support would be important. This situation suggests that deliberate strategies and resources would be needed to improve the profile and usage of peer support programmes.

When considering *impact*, communities of interest participants perceived the overall impact of the ILCs on their communities to be moderately high. The ILCs were seen as very responsive to individual requests. When asked to rate the various aspects of the four core programmes in terms of impact, the following rank order emerged: individual advocacy/consultation (especially staff supportive of consumers during consultations); research and programme development (especially involvement with ILCs on special projects); information and referral (especially ILCs as a valuable resource and staff ability to answer questions); and lastly, peer support. ILCs contributed to the empowerment of consumers by helping them gain knowledge and awareness; increase self-esteem and self-confidence; gain control over their lives; and strengthen their social networks. However, peer support again was rated lower than the other activities. These results indicated the unique processes and messages of the ILCs were being incorporated by various groups in the community. This reaffirmed the ILCs goals to be accountable to the community through specific programmes such as "information and referral", as well

as working towards building more responsive communities by addressing environmental barriers (Canadian Association of Independent Living Centres, 1990; 1991; DeJong, 1993).

At this point, it is helpful to revisit the findings from the Year 1 study (Hutchison et al., 1996). Year 1 examined the perceptions of individual ILC consumers about the impact of ILCs on people with disabilities. During qualitative interviews and focus groups, consumers expressed high support for the ILCs and a deep personal commitment for the IL movement. They believed ILCs worked in ways which were consistent with the IL paradigm: their work was done in the spirit of fostering fundamental changes in personal communication processes and power relations; people were treated as valued citizens, something which differentiated ILCs from many other aspects of the community; and the ILCs were seen as the most reliable and effective source of support for many people with disabilities in the community. They said that the core programmes and the approach taken by the ILC resulted in consumers acquiring useful skills, feeling a sense of accomplishment through making positive contributions at ILCs, gaining control and self esteem, and acquiring personal empowerment.

Taken together, the results of Year 1 and Year 2 of the study provided a clearer picture of what it was about the ILCs which enabled them to act as a significant mediating structure. Programmes like information and referral made the ILCs more accessible to both people who have disabilities and the community. And the ILCs were seen as democratic organizations which provided citizens with the opportunity to participate in ways that were community friendly (Berger & Neuhaus, 1996).

Year 1 identified several problems which limited the effectiveness of the centres. These centres were small and chronically underfunded. The results also indicated the need to strengthen the cross disability focus; deal with staffing challenges; expand peer support programmes; and resolve the conflict between the ILC's role as resource centres versus stronger advocacy organizations. Similar problems were identified in the Year 2

findings: address the problem of limited and unstable funding needed to provide extensive programmes; increase the ILC's profile in the community; change public attitudes; strengthen the cross-disability mandate; and promote more peer support programmes which stress self-help, not just social activities.

The results from Year 2 indicated that ILCs have had less impact on the community in contrast to the significant impact experienced by individuals with disabilities noted in Year 1. However, it was possible that a ripple effect could happen—as ILCs develop in the community, their impact may first be with individuals with disabilities, then local community organizations, and finally, regional and provincial governments. In other words, individual empowerment would eventually lead to significant changes in communities, although it is unlikely unless the relationship between the ILCs and the community at large is strengthened. Both Year 1 and Year 2 findings point to the belief expressed by participants that considerable barriers continue to exist in communities, and thus far, ILCs have only demonstrated their *potential* to contribute to significant community change. Facilitating partnerships, educating community groups, monitoring the community's sensitivity to disability issues, and helping develop new services were all examples of valuable contributions to community change which needed to be continued and expanded.

This synthesis provides valuable insight into what it is about the ILCs which enabled them to act or not act as a significant mediating structure. The results indicated that the ILCs may have partially lost sight of this mediating role. Important to note in this regard, however, was the instability of funding and resources. Social change or "second order change" was clearly more complex and fraught with constraints. While the "communities of interest" felt the ILCs had contributed to a shift in assumptions and values, their record in contributing to changing structures and processes was somewhat less apparent. Their contribution to reallocation and realigning resources was also limited, although they have certainly begun to demonstrate alternative approaches to dealing with

disability issues, the IL movement, and individual empowerment, all relevant factors in the overall process of social change.

Conclusions and Policy Implications

The results of this study pointed to ILCs as potentially powerful vehicles for promoting the IL philosophy. Results suggested that ILCs experienced difficulties which were common to many organizations. These constraints which are part of the change process can be seen as positive challenges and tensions which result from efforts to create consumer driven, community based alternatives.

The ILCs in this study were having a significant impact at an individual level and within their communities of interest. The findings add to the knowledge base of the IL paradigm, most especially with respect to the evidence that community change can be affected through the IL concept and participation of people with disabilities in community life (Friedmann, 1992; McKnight, 1995; Valentine, 1994). In consideration of both the strengths and weaknesses of ILC's activity in relation to their potential as mediating structures, some key *policy* implications have been identified.

Firstly, recent Federal and Provincial cutbacks to human services, including to ILCs, need to be reassessed in light of the significant contribution the IL concept is making in the lives of people who have disabilities. IL organizations need adequate stable funding to continue to provide the key services which they offer consumers and other community stakeholders. These innovative services are vital to the community.

Secondly, ILCs and other like-minded organizations need to be encouraged to build on their strengths in promoting a strong community context for individual change through innovative community partnerships, education, networking, and resource reallocation. A ripple effect appears to be beginning, that is, ILCs seem to be serving as a mediating structure for change between the IL paradigm and the community. As individuals with disabilities become empowered through involvement in the ILCs, participation in community life increases; in turn, the community becomes educated and

significant changes occur in the community as a whole (Balcazar, Mathews, Francisco, Fawcett, & Seekins, 1994; Fawcett et al., 1994; Friedmann, 1992; Valentine, 1994). At the same time, it is particularly interesting to consider these findings in light of the role of Canadian ILCs compared to American ILCs, the latter of which have a much stronger systemic advocacy function (Balcazar et al., 1994). It appears that ILCs can have a significant impact on the community with a strong education and resource function. The question for future policy development is whether this impact could be even stronger with an added systemic or collective advocacy role.

Thirdly, the ongoing evolution of ILCs as an alternative human service organization and the challenge of creating a responsive structure which builds on an empowerment philosophy need to be promoted within communities and demonstrated to government. The ILC's role is consistent with current thinking about emerging disability policy i.e., community infrastructures need to support people to be independent and support the capacity of the community to include people with disabilities. This is in contrast to earlier disability policy which maintained people with disabilities in states of dependency and did not include a role in the community or for the community (Schwartz, 1992). The findings of this study add to the knowledge base of the IL paradigm, most especially with respect to the evidence that community change can be affected through the participation of people with disabilities in community life within the framework of the IL concept.

Fourthly, further research is warranted which builds on both years of this study, their limitations, and their implications. Impact research with a large number of ILCs would be possible now, since so many new centres have been established. Future impact research on ILCs should consider a cross site analysis to enable the IL movement to learn which centres are having the greatest impact and why. To increase ownership of the research process and enable change to be made in organizations as the research progresses, future research with consumer organizations could utilize a participatory

action research approach (Whyte, 1991). Research which clarifies the ripple effect would be helpful: as the individual becomes empowered, and participation in community life increases, the community in turn changes. And a comparison of ILCs with other more traditional agencies might conclude that ILCs have even greater influence than we have been able to ascertain in this study.

In conclusion, this study has demonstrated the important contribution that ILCs are making in Canada. Innovative, consumer-driven services like ILCs need to be pushed to the forefront of our communities to ensure that the paradigm shift that is occurring around disability issues evolves in a more noticeable and influential way in the future.

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