

Research In Action

A research report on the

Role of Consumer Driven Disability Organizations in the Non-profit Sector

*** Supplemental Edition**

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Introduction

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Introduction *continued from page 1*

With the growing strength and influence of the consumer driven disability organizations, there has been some attempt to understand the contribution of these groups within a broader social movement framework (Council of Canadians with Disabilities, 1995; Lavoie & Stewart, 1995; Scotch, 1988). While traditional social movements are characterized by a focus on social and economic issues, new social movements represent a concern with quality of life, equality, self-realization, participation, and human rights (Habermas, 1981). New social movements also assist in creating the foundation for social change in contemporary society (Rifkin, 2000).

This study addresses disability policy and the future role of consumer driven organizations in the non-profit sector as it examines the role of such organizations in the shifting disability movement into the new social movement. Four national consumer organizations were examined throughout the course of the study: 1) Council of Canadians with Disabilities (CCD) 2) Canadian Association for Independent Living Centres (CAILC) 3) National Network for Mental Health (NNMH) and 4) People First of Canada (PFC).

¹ As a subcategory of voluntary associations, nonprofit corporations are those that are governmentally identified as publicly chartered tax-free organizations. These associations are “certified to perform a wide range of charitable functions in society, and in return for their tax-free status, they are required to provide public accounting for their actions” (Van Til, 1988, p. 8).

Research Methods

A Case Study Approach

One of the ways that individuals find research to be useful and personal to their lives is when they are included in the process as equal players (Alary, Guedon, Lariviere, & Mazer, 1990; Patton, 2002; Ristock & Pennell, 1996; Taylor & Botschner, 1997). In this project, the researchers worked in tandem with the four partner organizations to generate the research plan and research methods. Specifically, the partner organizations helped in the generation of focused research questions and were invaluable in refining the study’s findings.

The researchers used a variety of methods in three separate phases to gain a greater understanding of the role of national consumer organizations in the non-profit sector in Canada. By using a collective case study approach, the research team was able to gain an understanding of a collection of cases and begin the process of theory development (Patton, 2002; Stake, 1994). Four national consumer organizations (CCD, CAILC, PFC and NNMH) helped build the collective case studies for this two-year project.

Participants

In accordance with strong collective case study research, participants were purposefully chosen to represent information-rich cases (Patton, 2002). Case studies focused on four national consumer organizations that were recognized as leading and influential players in the disability movement. Data for the case studies included information from consumer driven organizations (both national representatives and their affiliates), national service organizations, federal government personnel, and selected policy groups. Participants from government sites were identified by consumer organization representatives as individuals with whom national disability organizations had regular contact. Participants from national service organizations were representatives recognized by their own organization and by national consumer organizations as leaders and influential players.

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Data Collection

Obtaining different types of data through various collection methods leads to cross-data validity and strengthens the research project as a whole (Patton, 2002; Reinharz, 1992). Within the study there were four distinct phases that encompassed a variety of research methods.

During the *initial phase*, policy reviews and key informant interviews were conducted.

Extensive document analysis was conducted with the four partner organizations, government and research institutes for the purpose of reviewing existing disability policies at the local, provincial, and national levels. As recognized by Patton (2002), the organizational documents provided a particularly rich source of information, and were used to increase knowledge and understanding of ongoing activities in each organization. The document review included policy documents, directional statements, and other relevant materials guiding the actions of consumer organizations.

Because there has been a lack of research connecting consumer organizations to the non-profit sector and to social movements, the research team first used qualitative approaches to explore their research questions (Alary, et al., 1990; Barnes, 1992; Patton, 2002; Zarb, 1992).

In the *second phase*, interviews were used to facilitate access to people's thoughts, ideas, and impressions, and provided the opportunity to clarify, describe and discuss more complex issues (Reinharz, 1992). These interviews were conducted with participants from consumer organizations (our four national partners), five national service organizations—for lack of a better term (Canadian Association for Community Living, Canadian National Institute for the Blind, The Canadian Paraplegic Association, the Canadian Mental Health Association, and Easter Seals/March of Dimes), and federal government personnel. A document analysis process was conducted with three

independent policy groups, Caledon Institute, Canadian Centre for Disability Studies, and the Roeher Institute.

Some of the key areas that were addressed in the interviews were the relationship between national organizations and their affiliates, their role in policy development and advocacy, informants' perceptions of consumer driven organizations relative to service organizations, the non-profit sector in general, and perceptions of the disability movement as a new social movement.

During the *third phase*, the qualitative data was used to develop a quantitative survey to examine the relationship of consumer driven organizations with their affiliates and also with service organizations. This survey was sent to more than 300 provincial and regional affiliates of the four partner organizations. In total, 51 surveys were completed and returned for a response rate of 37.0%. The survey addressed issues similar to the ones examined in the interviews from the perspective of the affiliate organizations.

In the *final phase*, the themes and patterns from the previous phases were used to build collective case studies of each of the consumer driven organizations. All of the data were then amalgamated for final analysis, which included the interpretation of individual cases and case comparisons. Six themes were developed. As researchers have a great deal of power in interpreting and labelling the findings of their research projects (Caplan & Caplan, 1994), participants from the four national consumer organizations were consulted before the findings were finalized. Specifically, focus groups were conducted with each of the four national consumer partners to review the study's findings, the six themes, and draft report.

Collective Case Studies

Council of Canadians with Disabilities (CCD)

Council of Canadians with Disabilities (CCD), Canada's first national cross disability consumer driven advocacy organization, was founded in 1976 as the Coalition of Provincial Organizations for the Handicapped (COPOH). CCD formed to provide a united voice for consumer driven disability organizations, and to ensure the right of persons with disabilities to be heard in social policy debates. In 2001, Boyce and his colleagues described the philosophical position of CCD as adhering, "to the principle of independence and dignity for disabled persons, full participation in the community, working toward equal opportunity" (Boyce, Trembley, McColl, Bickenbach, Crichton, Andrews, Gerein, D'Aubin, p. 77). CCD is a non-profit advocacy organization that works within the new social movement to ensure full citizenship rights of people with disabilities economically, socially, and physically in all spheres of society. It is committed to achieving these rights through the removal of barriers to human rights, transportation, employment, income, housing, and community participation.

CCD was the founder of the Independent Living philosophical position in Canada and began to change society's antiquated ideologies of the notion of "disability" (Valentine, 1994). Allan Simpson, a long time disability organizer who had been instrumental in creating CCD, was first involved in several provincial initiatives. Simpson realized that the movement needed a national, as well as a regional presence to influence public policy. After conversing with groups that pursued a similar ideological perspective around the need to promote the voice of people with disabilities in all aspects of society, COPOH came into existence. In 1993, COPOH changed its name to The Council of Canadians with Disabilities (CCD) to reflect more appropriate terminology (disability versus handicap) and to include other national

organizations such as the Canadian Association for the Deaf.

Today, CCD is composed of representatives from provincial and national consumer driven organizations across Canada. It has its own board and committee structure and policies for decision making. All services and managerial structures are controlled by a majority of disabled persons (COPOH, 1986). CCD enhances the support for specific issues and is particularly instrumental in taking a lead role in policy and legislative activities.

CCD receives funding from a variety of sources, including federal government and foundations, in order to do disability rights advocacy with the goal of full participation of Canadians with disabilities. In particular, the government, through HRDC funding (now called Social Development Canada), plays a significant role in supporting the activities of this organization. Sometimes special funds are received to carry out a particular project or advocacy strategy, such as researching the impact on different policies of sentencing in the Latimer case (funded by The Court Challenges Program).

In summary, CCD concentrates on equality rights advocacy as a way of influencing public policy. CCD advocates for public policy which will contribute more to the full participation, equality, citizenship, access to valued resources, and inclusion of people with disabilities in Canada and abroad. CCD primarily concentrates its efforts on the Federal political level in Canada (COPOH, 1986) through presentations before the Senate and Parliament Justice Committee or lobbying activities such as demonstrations and media coverage (www.ccdonline.ca).

Canadian Association of Independent Living Centres (CAILC)

The Canadian Association for Independent Living Centres (CAILC) is a national non-profit, bilingual consumer driven disability organization that promotes the independent living (IL) philosophy through independent living resource centres (ILRCs). CAILC, founded in 1986, provides direct support to its member ILRCs and other organizations concerned with IL in Canada (Kowbuz, 1993).

The mission of CAILC is “to promote and enable progressive process of citizens with disabilities to take responsibility for the development and management of personal and community resources” (CAILC Membership Committee, 2000). Compared with CCD, which takes a lead role in policy and legislative activities, CAILC encourages its centres to assist individuals with disabilities by providing information and resources, negotiating or accessing service, and developing personal skills (Boyce et al., 2001).

During the 1980’s, COPOH had a desire to shift the dominant approach in Canadian society from a medical and rehabilitation model to a consumer/citizen approach to meeting the needs of people with disabilities. As a national umbrella consumer disability advocacy organization, it believed that local or regional consumer driven centres were needed to promote services based on the IL philosophy, leaving other organizations like CCD to continue with systematic advocacy (Phillips, 2002). By 1985, a total of five centres were operating (or in the development stages) in cities across Canada: Waterloo, Winnipeg, Thunder Bay, Calgary, and Toronto (Valentine, 1994). There are now more than 25 ILRCs across Canada.

The Board of Directors for CAILC has 10 provincial representatives and 8 members at large from local ILRCs from across the country.

The members at large are identified by the personnel committee, but elected by the general membership at an Annual meeting (CAILC Membership Committee, 2000). Consumers represent 51% of CAILC’s board and membership (CAILC Membership Committee, 2000).

In 1988, CAILC had secured a 5-year funding base from the Federal Government (Valentine, 1994). In 1991, the Federal Government announced the re-commitment to the Canadian Independent Living Movement, with the extension of financial support to the ILRCs until March 1996. Periodically, CAILC receives funding for specific initiatives, such as the Drug and Alcohol Initiative, which was funded by Health and Welfare Canada (Valentine, 1994). Other sources of funding included: municipal government, provincial government, fundraising events, membership fees, and publication sales. CAILC currently provides direct funding to each of its affiliates.

CAILC follows and promotes four key principles: (1) consumer control; (2) cross disability; (3) community based; and (4) promotion of integration and full participation (CAILC Membership Committee, 2000). These principles guide the development of CAILC’s approach with their affiliates and advocacy strategies, as they participate in collective research and development and collaboratively work with other organizations, such as CCD, on federal policy development to ensure the citizenship rights of people with disabilities.

National Network for Mental Health (NNMH)

The National Network for Mental Health (NNMH) is a non-profit national consumer driven network providing a united voice for citizens with mental health disabilities (NNMH, 2002a). NNMH was formed because mental health consumers felt the need for more involvement in the planning and decision making of mental health initiatives (NNMH, 2002b). NNMH's mission statement is as follows: The Canadian consumer/survivor community will become empowered by equality, respect, policy input, informed choice, inclusion, and ownership by mental health consumers themselves (NNMH, 2002b).

During the 1980's, the Canadian Mental Health Association (CMHA) started the "Consumer Participation Task Group" because their national search conference identified a need to involve mental health consumers in the planning and decision making of mental health services (NNMH, 2002b). By 1991, one territorial and ten provincial networks were in place (NNMH, 2002b). At this time CMHA's "Consumer Participation Task Force" changed its name to the National Network for Mental Health (NNMH, 2002a) and became an officially incorporated body.

NNMH is 100% consumer driven (NNMH, 2002a), and is run by and for persons who directly experience mental health system services and supports. Yearly membership is free and includes a subscription to the newsletter (NNMH, 2002b). NNMH promotes shared leadership, team approach, and executive/committee leadership (NNMH, 2002c). As volunteers are an integral component of NNMH, members are given access to training manuals, which includes information on community participation, self help group development, advocacy, policy and standards

development, mental health maintenance, and leadership development (NNMH 2002a).

There are 70 consumer driven member organizations, 4 project offices, and an additional 68 community mental health organizations in NNMH (NNMH, 2002a). Member organizations include: National Reference Group for People with Disabilities, ARCH (a Legal Resource Centre for Persons with Disabilities), National Consumer Advisory Council (NNMH, 2002a). The NNMH is a founding member of the Canadian Alliance on Mental Illness and Mental Health. NNMH is also a member of CCD.

NNMH has several business partnerships including: JKR Financial Group, National Insurance Program, Janssen-Ortho Pharmaceuticals (NNMH, 2002a). NNMH has several federal and provincial funding partnerships, such as Human Resources Development Canada (now called Social Development Canada) - National and Newfoundland; Ministry of Community Services in Ontario; Health and Community Services Departments of Nova Scotia; United Way of Calgary; and the Calgary Foundation (NNMH, 2002a).

NNMH uses these funds for specific projects such as the Self-Employment Project (funded by the Opportunities Fund and SDC) and for other projects related to systematic, individual, and self advocacy, which often involves lobbying activities to change legislation, like the Canada Health Act. Currently, NNMH is working on expanding their services into New Brunswick, and is advocating changing the Canadian Health Act to reflect the new paradigm through the recognition of psychologists and alternative and complementary therapies (NNMH, 2002b).

People First of Canada (PFC)

People First of Canada (PFC) is a national self-advocate group of members who are labeled as having an intellectual challenge. It springs from the international People First movement, comprised of individuals who have felt the hurt of being labeled: “We are people first” (Park, Monteiro, & Kappel, 2003). People First started in Canada because people with intellectual disabilities wanted to speak for themselves, develop leadership skills, and become more effective self advocates. The founding convention of PFC occurred in 1991 using the same name as the international movement. Prior to that convention, there were several important meetings that were influential in the development of PFC. In 1973, people labeled “mentally handicapped” came together at the *British Columbia Association Conference* in Canada. The following year another conference for people with mental disabilities was organized in Oregon. From that conference, the name “People First” emerged. The name is synonymous with “self-advocacy” and more recently, “consumer control.” The mission of PFC is to support people who have been labeled speak for themselves and be heard, and to help them help each other (People First of Canada, 2002). PFC oversees several provincial affiliates, which in turn have numerous local or regional groups. Currently, PFC is involved in outreach to local chapters and new group development.

People First groups from all ten provinces and two territories are represented on the Board of Directors of PFC (People First Canada, 2002). PFC embraces citizen participation and maintains the philosophy and guiding principles through its organizational structures. For example, 100% of its members are consumers

with intellectual disabilities. Advisors, who are people without disabilities, do not have a vote at meetings. PFC predominantly receives government funding from Human Resource Development Canada (HRDC). Other funds come from membership dues, fundraising events, and conferences (People First Canada, 2002).

Although PFC receives most of its funding from HRDC, they foster a proactive and assertive role in government relations. In their approaches to influence policy and decision-making in the legislature, this consumer organization takes part in systematic, legal advocacy, self advocacy, and individual advocacy.

Initially, the goal of People First was: To gain a voice of their own. However, over time, the organization has adopted more complex goals that reflect dreams of consumer control, full participation, and empowerment. PFC addresses a range of community concerns that include housing, employment, education and inclusive schools projects, de-institutionalization, and human rights.

The issues currently being addressed by the People First movement in Canada are nicely summarized in the headings in a recent book on advocacy: “it’s my life,” labeling, the name change of associations from mentally retarded to community living, sterilization and “it’s my body,” “fighting for our lives,” Tracy Latimer, women’s leadership, and “keeping the voice alive” (Park, Monteiro, & Kappel, 2003).” People First Canada is also a member of CCD.

Themes

Theme 1: Consumer Driven Organizations Reflect New Paradigm & Give Voice to People with Disabilities

Summary of the theme: In keeping with van Til's (1988) identification of different forms of volunteering in the non-profit sector (service, self-help, and grassroots), a mosaic of disability-related non-profit organizations has emerged in our communities. Traditional disability advocacy groups that began to develop in the 1950s, focused primarily on service volunteering activity. The early consumer organizations in the 1960s and 70s focused primarily on self-help. This theme shows that current national consumer driven organizations reflect the new social movement, which is revealed by the nature of the values, language, and initiatives of an authentic consumer voice.

Shift to equality and inclusion with new paradigm and new social movement values: National consumer organizations believe that what they do is a reflection of the new paradigm. The new paradigm is grounded in concepts of equality, citizenship, human rights, and inclusion (Carling, 1995; Federal Task Force on Disability Issues, 1996). There has been a shift from earlier times when institutionalization, medicalization, and rehabilitation drove the disability movement and were accepted as appropriate ways to meet the needs of individuals with disabilities. One way they do this is by playing an active role in national debates and policy making, which eventually filters down to changes in service delivery. These statements from interviews with leaders reflect the important role played by national consumer organizations:

CCD has always said there's a strong role for rehab, but rehab is a specific process and it is time limited. At some point, the rehab stuff is done and then it really is just me as an individual living in my community and what I need in order to do that. And it is not an issue of rehab, it is an issue of citizenship...The Canadian Association of Independent Living Centres had a role in promoting the IL philosophy and is consumer driven and directed and has promoted a paradigm shift in service delivery...They are a player in some of the national debates. (Consumer organization 1)

But we all have the same end in mind, all of the organizations, all the disability organizations. I would say all of the organizations who have the true interests of the consumers in mind, have the same end. (Service organization 7)

The following statement from a member of a consumer organization highlights the need to be vigilant of human rights issues because many people with disabilities continue to be housed in segregated settings like institutions and group homes.

Most of the members have lived in institutions but people in society haven't. There is a hospital, that's a form of an institution...Even a group home, to my way of thinking, is an institution. Anywhere where you lose control of your life. (Consumer organization 4)

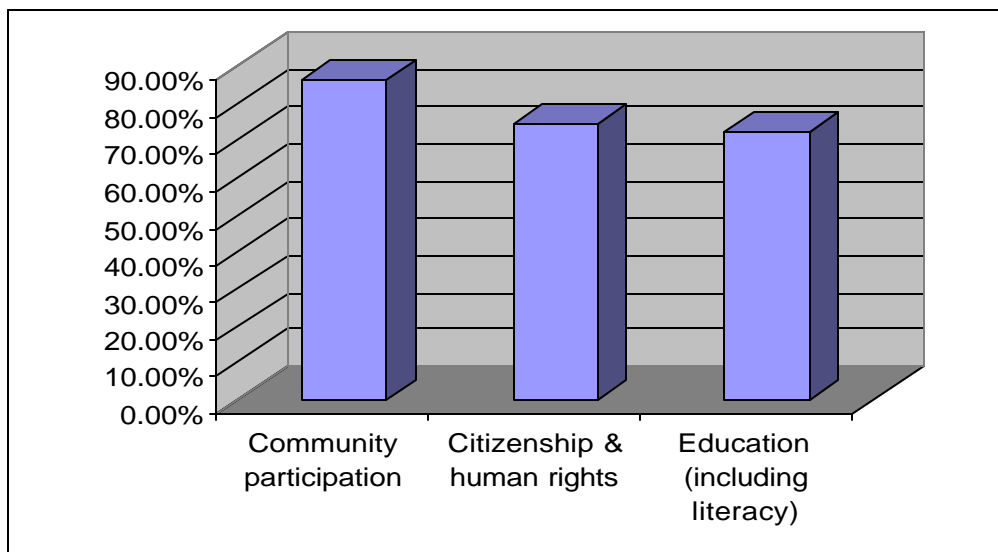
Language in consumer organizations reflects new paradigm: Another indication of a new paradigm is the language that is used by consumer and other organizations. The values of citizenship, human rights, choice, and participation are reflected in the language used by national organizations. For example, People First Canada was behind the name change of the Canadian Association for the Mentally Retarded to the Canadian Association for Community Living (CACL). A CACL participant reflects on the significance of language in the new paradigm: "It was People First that forced the name change and there was a board and a federation that wanted to respond, thank goodness, and leadership within the association of CACL to respond. But language has been absolutely critical." (Service organization 5) In terms of social change, language is often a precursor to more substantive change. The following statements describe the importance of positive language emphasizing human rights and inclusion.

CACL has tried to work on rights, international work, and language. It had a real painful struggle around language in the name change. There's a whole cluster of terms and language, from community inclusion, community living that really have been the foundation for thinking about community inclusion in a much broader way. And I think CACL, of all of the disability organizations, has been a leader, and that language now has been picked up, not only in the disability movement, but much broader. (Service Organization 5)

The language of the movement has been usurped by many others. It does not mean that they... understand it or that they live by it. At times our own organizations are using language that they are not necessarily living by. And that's where the open process of anybody with a disability wanting to become a member at our local level is so critical. In some other organizations, there has been a sort of usurping of our consumer language to give the appearance of a substantive change, but in reality may not be there. Virtually everybody now talks about independent living, or living independently. They just turn the words around, living independently in the community. But what does that mean? And does it mean that individuals really have choice, and that they have control, and that they direct the service, and that they determine how the resources will be spent? In some of the agencies, that's not the case. (Consumer organization 1)

Affiliates also reflect the new paradigm & important role of national consumer organizations: Evidence of the new paradigm is also reflected in the actions of affiliate organizations of the four national consumer organizations. Survey results with the affiliates indicate a strong connection with new paradigm values. The top three initiatives undertaken by affiliates in the past two years characterize new paradigm issues: community participation, citizenship and human rights, and education. There were no significant differences between the four organizations. The following graph highlights the percentage of projects and issues of affiliate organizations that reflect the new paradigm during the last two years.

Projects and Issues of Affiliate Organizations (last two years)



For additional breakdown of the four consumer organizations, see the partial table below.

	Overall %	NNMH %	PFC %	CAILC %	CCD %
Community participation	86.3%	83.3%	80%	92.9%	88.9%
Citizenship & human rights	74.5%	55.6%	70%	85.7%	100%
Education (including literacy)	72.5%	77.8%	40%	78.6%	88.9%

Additionally, affiliates' *value statements* parallel the new paradigm language used by leaders of their national groups—from equality, respect, social supports, and citizenship, to consumer control. When asked about *their values* 84.3% of the affiliate participants indicate that the values are similar, very similar, or the same as their corresponding national organization. When asked about *their mission*, 45.1% of affiliates indicate that their mission statement is directly influenced by their national organization (CAILC-85.7%, CCD-33.3 %, PFC-60%, NNMH- 5.6 %). Extensive research and literature confirm these important findings about the new paradigm in national consumer organizations and affiliates (de Jong, 1993; Friedmann, 1992; Rappaport, Reischl, & Zimmerman, 1992; Valentine, 1994).

Consumer voice distinct from service voice: Consumer organizations fundamentally exist because they understand that people with disabilities need a strong voice in the disability movement. Having a voice through a strong consumer movement contributes to feelings of empowerment for people with disabilities (Hutchison, Pedlar, Dunn, Lord, & Arai, 2000). The formation of consumer organizations was a response to a long and dark history of exclusion of people with disabilities. At the same time, there is a belief that consumer organizations need to be seen as distinct from non-consumer driven disability organizations, many of which continue to act as the voice on issues that most affect the lives of people with disabilities. A distinction is being made between organizations traditionally involved in service delivery and consumer organizations focused on self-help and citizenship.

Representatives from two consumer organizations note the distinction:

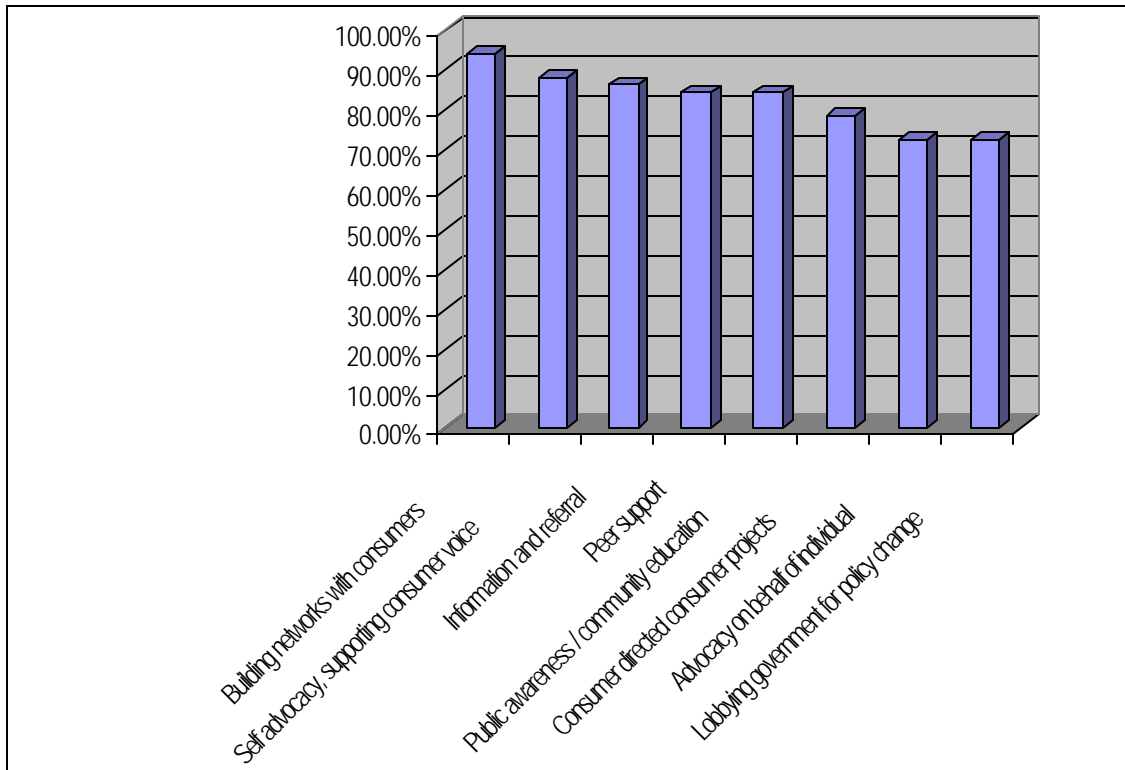
I wasn't around when {the consumer movement} began back in the mid-seventies. But my understanding is that it came from people with disabilities who felt that their issue, or their concern, or their life circumstance was somehow being dealt with by rehab professionals and agencies in which they had no voice, agencies that provided services, agencies that at that time also became the spokesperson on disability issues... People with disabilities looked at other sectors of our society that were disadvantaged and said, "We need a voice as well" and began to organize. (Consumer organization 1)

Service organizations are very controlling and if you look at the composition of most of their boards in terms of people who are out there working on their boards and you take a look at the composition of our folks, our folks are all grassroots who got involved because they either got screwed by the system or they got recruited by CMHA or some sit on a committee and now they're involved. Whatever it is that really brings them here is why they are here. Some people have really strong skills in some different departments. The Chair of our board used to be a bank manager and the Vice President, multi-millionaire. And then you have people who live on social assistance, some people who, you know, the secretary was a teacher... When I look at CMHA national where we burst from, I guess, you know, I don't even understand them to a great extent because all they do is policy and all they do is plan to plan. I am more into getting out there and getting your hands dirty and then we will plan and figure out what we did later. (Consumer organization 3)

National consumer organizations believe that they are a unique and valuable entity within the non-profit sector precisely *because* they serve as an outlet for consumers to voice their opinions. They pride themselves on their sensitivity to the experiences of consumers and see themselves as well positioned to educate the public about the differences between consumer organizations and more traditional service agencies. In the table below, survey

findings with affiliate organizations identify some of the most important ways that consumer organizations implement a consumer voice.

Processes and Strategies of Affiliate Organizations



For additional information on the above chart comparing the four consumer organizations, see the table below.

	Overall %	NNMH %	PFC %	CAILC %	CCD %
Building networks with consumers	94.1%	88.9%	100%	92.9%	100%
Self advocacy, supporting consumers to have a voice	88.2%	77.8%	90%	100%	88.9%
Information and referral	86.3%	88.9%	50%	100%	100%
Peer support	84.3%	94.4%	60%	100%	66.7%
Public awareness campaigns/ community education	84.3%	94.4%	50%	85.7%	100%
Consumer directed consumer projects	78.4%	88.9%	70%	71.4%	77.8%
Advocacy on behalf of individual	72.6%	83.3%	80%	64.2%	55.5%
Individual skill and capacity development (including education)	72.5%	77.8%	30%	92.9%	77.8%
Lobbying government for policy change	72.5%	72.2%	90%	42.9%	100%

A member of a service organization talks about the importance of hearing the voice of the consumer:

I think in our movement, more than so many others, it is about a struggle over whose knowledge counts, whose voice counts, and I think if we are going to move our agenda forward we need to find ways of making the knowledge of people with disabilities, of families of those who have worked from that perspective matter (Service organization 5).

A member of a consumer organization identifies changes that have taken place in their organization:

We used to have the money in CACL, and that where when we gained financial autonomy and that was positive in many different respects because I think people began to take us more seriously. (Consumer organization 4)

A service organization leader talks about a new paradigm issue:

I think the natural position of a consumer organization, I don't know what NNMH had said, but I would imagine it would be against community treatment orders. Most consumers, vocal sort of advocate consumers, are against consumer community treatment orders, although not all individual consumers are. And some of our individual CMHAs have gone on record against them as well. At the national level our board does contain consumer families, so we've had many debates about this topic because of the varying perspectives. In the end we did not come up with a strong stand against community treatment orders. There were just too many differing perspectives at the table... We culminated in the development of what we call the Consumer Involvement Task Group which was a task group dedicated to promoting the involvement of consumers within our organization and outside as well. And that task group evolved into two parts. One part was focused inward on CMHA and it became what is now the Consumer Advisory Council which persists to today. The other part broke away, with our support, from CMHA and became the nucleus of what is now the NNMH. So I guess we take some pride in having something to do with the roots of the NNMH. (Service organization 6)

Legitimate and authentic voice: Consumer organizations are considered to be the “authentic” voice of people with disabilities. They are seen as authentic because the people running them understand the issues as they live them each day. This belief is expressed by one consumer organization leader: “*CCD is recognized as a leader in the disability community and is recognized both by the disability community and by governments as a legitimate voice that has advanced the rights of people with disabilities in Canada.*” (Consumer organization 1) The following statements by representatives from consumer organizations, service organizations and government, emphasize the importance of hearing that authentic voice.

People First has got to be promoted, resourced, protected, supported as the voice of people with intellectual disabilities, not as the only voice, but as a really important, essential voice of people with intellectual disabilities... That’s why these partnerships, these joint task forces, that we begin to develop a common discussion and dialogue around a particular issue like deinstitutionalization. That’s part of it. The other piece is to make sure that People First are always included in the national forum and supported to be there. (Service organization 5)

What I say to people is we are not consumer driven in that we don’t have an all consumer board. But our organization is a mix of consumer, families, service providers, and community, the board and volunteers... But we’re connected through our project work with HRDC. We have in the past certainly been at many of those cross-disability meetings or rather HRDC has held stakeholder group meetings. That’s not the right word. I guess our closest ally is, of course, NNMH because we have so many issues in common. (Service organization 6)

So what I’ve seen is that many individuals can relate to and identify with the stories that these people have to tell... The consumer driven organizations represent people with disabilities. Their members identify what works for them, what doesn’t work for them in removing barriers and creating more inclusive society. (Government 11)

The membership of the organization are people that have been labelled, that have labelled themselves as having a mental handicap or whatever the term is today. And well, they have support people or advisors that are not labelled. So you can say like the board is all made up of People First members across Canada, the provinces, and territories. (Consumer organization 4)

Essentially, consumer organizations are authentic because they are accountable to their members who are themselves citizens with disabilities. Much literature supports the importance of the consumer voice (Boyce et al., 2001; Canadian Association of Independent Living Centres Membership Committee, 2002; NNMH, 2002b; Phillips, 2002; Valentine, 1994); however, the dichotomy between service and consumer organizations continues to influence the issue of “whose voice counts” and how best to represent the voice of people with disabilities.

Theme 2: The Paradox of Leadership in Consumer Driven Organizations – Leadership Critical and in Need of Rejuvenation

Summary of the theme: We know that leadership is critical to creating social change and the new paradigm. How leadership is actually understood is often less well defined. The importance of good leadership has been critical throughout the history of the non-profit sector (Light, 1998) and has been recognized as a requirement for the sustainability of the disability movement. In this study, it was found that both individuals and organizations provide leadership. We learned that good leaders make a difference, especially some of the early leaders; and that new leadership is needed, particularly through nurturing more young people to become involved in the consumer movement. Good leaders are also recognized for their ability to connect with others and inspire. Allan Simpson realized that the movement needed a national and regional presence to influence public policy and ultimately initiated the creation of Canada’s first disability organization, Coalition of Provincial Organizations of the Handicapped, which eventually became CCD (Boyce et al., 2001). Henry Enns’

and Simpson's association with local affiliates enabled them to make connections with others who had similar concerns, join forces to advocate for the values of the Independent Living and disability movements, and build trust and respect in these relationships that extended to the consumer movement, government, and service organizations alike (Boyce et al., 2001; Valentine, 1994). In this sense, leaders build social capital through central features such as trust, the sharing of values, and development of networks (Arai, 1999). As new leadership is crucial to the future of the movement, it may be important for consumer disability organizations to look to the broader non-profit sector for solutions, as they are also seeing a decrease in volunteerism. Since the first national survey on giving, volunteering and participation in 1997 in Canada, the decline in volunteerism has led many non-profit groups to search for new approaches to understanding and addressing this problem (Hall, McKeown, & Roberts, 2001).

Leaders make a difference: Each of the consumer organizations have leaders who are making a difference. Sometimes these leaders are with the national group, and other times they are involved with an affiliate organization (or both). The leaders of the consumer movement are described as visionaries and strong advocates for the new social movement. As examples, both Henry Enns and Allan Simpson, men with disabilities who are now deceased, are recognized as key catalysts of the Independent Living Movement. A few personal qualities of leaders are mentioned here. The strongest leaders are articulate and informed, as noted by a representative from government:

The thing is that when you're talking and philosophizing about the human rights issues, the visionaries out there are not by the thousands and the ones that have your attention are the ones that can stand up and speak to those issues super eloquently. (Government 12)

There is agreement that the majority of leadership should come from people with disabilities (Kowbuz, 1993) because they contribute to the credibility of the movement and are perceived as role models for others because they exemplify the ability to survive and succeed despite their disabilities. All services and managerial organizations of CCD, for example, are primarily controlled by people who are disabled (COPOH, 1986). They have strong motivation and a clear vision of what is needed. This is reflected in comments about current leaders:

Craig's not 50 yet. He's not like silver or anything, but he's a very successful guy and he's been involved in the movement for probably 20 years, the grandfather of the movement, I guess. The reason he drives everyone crazy is because he's got this global sense of how things should be and it's got to be done today right? It can't be done five years from now. (Consumer organization 3)

National organizations support affiliates: One way of thinking about leadership qualities is to think in terms of the national consumer organizations themselves and what they do. For example, national organizations might support affiliates in a variety of ways, including "in principle" (a term used on the survey with affiliate organizations), through financial supports, and/or through the provision of other resources such as on-site consultation. Overall, support from the national organizations for projects and issues are higher "in principle" than in financial resources provided. Generally, affiliates of CAILC and CCD report a higher degree of all forms of support "in principle", while this was less apparent for affiliates of NNMH and PFC.

National Organization Support for the Processes and Strategies of the Affiliate Organizations

	<i>Member or Affiliate Organizations Engaged in Process/Strategy</i>		<i>National organization supports "in principle"</i>		<i>National organization provides financial support</i>		<i>National organization provides support through other resources</i>	
	n	%	n	%	n	%	n	%
	Out of the organizations using this process/strategy							
Building networks with consumers	48	94.1%	28	58.3%	16	33.3%	13	27.1%
Self advocacy, support consumer voice	45	88.2%	30	66.7%	13	28.9%	18	40.0%
Information and referral	44	86.3%	28	63.6%	15	34.1%	17	38.6%
Peer support	43	84.3%	23	53.5%	12	27.9%	15	34.9%
Public awareness/ community education	43	84.3%	27	62.8%	15	34.9%	19	44.2%
Consumer directed projects	40	78.4%	21	52.5%	10	25.0%	11	27.5%
Individual skill & capacity development	37	72.5%	24	64.9%	12	32.4%	13	35.1%
Advocacy on behalf of the individual	37	72.6%	24	64.9%	9	24.3%	11	29.7%
Lobbying government for policy change	37	72.5%	21	56.8%	8	21.6%	10	27.0%
Workshops/conferences for policy dev.	32	62.7%	19	59.4%	15	46.9%	12	37.5%
Research to support policy development	27	52.9%	17	63.0%	10	37.0%	13	48.1%
Community (economic) development	25	51.0%	14	56.0%	6	24.0%	5	20.0%

Overall, members and affiliates of the four national organizations report receiving the most support in principle for projects or initiatives for community participation and citizenship & human rights, with lesser support around issues related to recreation and poverty.

National Organization Support for the Projects and Issues of the Member or Affiliate Organizations

	<i>Member or Affiliate Organizations Engaged in the Project/Issue</i>		<i>National organization support "in principle"</i>		<i>National organization provides financial support</i>		<i>National organization provides support through other resources</i>	
	n	%	n	%	n	%	n	%
	Out of the organizations involved in project or issue							
Community participation	44	86.3%	30	68.2%	14	31.8%	19	43.2%
Citizenship & human rights	38	74.5%	27	71.1%	7	18.4%	17	44.7%
Education (including literacy)	37	72.5%	25	67.6%	8	21.6%	14	37.8%
Employment & income support	37	72.5%	25	67.6%	13	35.1%	18	48.6%
Transportation	37	72.5%	22	59.5%	10	27.0%	13	35.0%
Access to social services	36	70.6%	20	55.6%	4	11.1%	6	16.7%
Access to health care/ mental health	33	64.7%	20	60.6%	6	18.2%	8	24.2%
Housing	32	62.7%	20	62.5%	5	15.6%	9	28.1%
Recreation	29	56.9%	17	58.6%	6	20.7%	7	24.1%
De-institutionalization	28	54.9%	18	64.3%	7	25.0%	9	32.1%
Family issues, violence	25	49.0%	16	64.0%	2	8.0%	8	32.0%
Poverty	25	49.0%	13	52.0%	3	12.0%	4	16.0%
Crime prevention	16	31.4%	11	68.8%	3	18.8%	7	43.8%
Respite	14	27.5%	10	71.4%	2	14.3%	4	28.6%
Substance use (drug and alcohol)	13	25.5%	7	53.8%	1	7.7%	2	15.4%

The leadership of the national consumer associations is important to affiliates. In particular, the leadership “in principle” and project leadership provide guidance and inspiration for the new paradigm approach. Additionally, written documents from one national organization promote a reciprocal team approach concept of leadership whereby people with disabilities share the responsibility for leadership (NNMH, 2002c). Another organization has four basic programs, including peer support, which is there in part to develop leadership skills (Canadian Association of Independent Living Centres Membership Committee, 2002; Phillips, 2002). Finally, People First started because people with intellectual disabilities wanted to speak for

themselves, develop leadership skills, and become more effective self advocates (People First of Canada, 2002).

With regards to support received from the national organization, all of the members and affiliates of CAILC indicate their national organization provides them with a high or very high level of support on the work that they do. CAILC’s scores are the highest because of their structure. CAILC’s affiliates are required to work closely when developing a new centre, accessing resources and gaining final approval from the national organization.

Indicators of Member or Affiliate Perceptions of Support Received from the National Organization

	<i>NNMH %</i>	<i>PFC %</i>	<i>CAILC %</i>	<i>CCD %</i>
Very High	11.1%	50.0%	78.6%	55.6%
High	0%	0%	21.4%	7.8%
Medium	5.9%	20.0%	0%	0%
Low	0%	20.0%	0%	0%
Not at all	9.8%	0%	0%	0%

Concerns regarding future leadership: While the consumer movement has had many strong and influential leaders in the past, it is currently faced with a need for new leadership. Old leaders are passing away or retiring, and many current leaders are becoming overworked. One consumer leader expresses this concern:

It’s always the same person that they call on for everything. You know, I started doing this in ‘93 and there are probably only five people around the province that go back to that time... Like, I can look at them and say oh, they are still working in the movement. And there were thirty-six groups at that time. They burn out, the politics, you know. (Consumer organization 3)

The tables above showed that affiliates are not receiving equal support across all issues. The interviews also confirm that new leadership is needed. Simply put, there are currently not enough people in leadership positions to support the consumer movement. Most organizations recognize that new leadership is needed. While consumers have made a definitive mark in the new paradigm, the search for new leaders is becoming a major concern. One consumer leader emphasizes the problem:

It was really difficult and so we have leadership changes too. I don’t know what will happen. I pray, thank goodness it will be in the right direction. But there is a problem. We don’t have enough people who are ready to take over these disability organizations. I hope that it stays. I think we’ve got enough done and we’ve at least paved the road, that consumer control is here to stay. I don’t think we are going to have to worry about that. (Consumer organization 2)

While a lot of energy of consumer organizations is focused on advocacy and influencing public policy, there may be limited resources available to develop strategies for developing new leadership. While consumer organizations understand the importance of having strong leaders for continued success of the movement, they will have to develop new recruitment strategies for sustainability. Investing in youth to become the new leaders of tomorrow is seen as critical by consumer organizations, however, the recruitment process is not so easy. Young people come from a generation that has experienced the benefits of the consumer and disability movements—such as inclusion—and do not necessarily have the same desire as the previous generation to participate in advocacy and public policy issues. A government representative reflects on this issue :

The volunteer sector is having a really hard time recruiting young people... Young people won’t work for the level of money that you get paid in the volunteer sector. These kids now, including the disabled kids coming out of

university, have the pick of jobs in the private sector. They're going into good government jobs... So, if you were a disabled kid who just managed to get your way through university, would you go work for one of these advocate organizations where you spend your whole life trying to become mainstream? In fact, if that was the message that you were sent while in integrated schools, why would you go work for an advocacy organization? (Government 10)

Recognizing that their future leaders are a different generation with different concerns and needs, a couple of consumer organizations mentioned that their recruitment and leadership development strategies require a makeover:

Maybe our organizations have to find new ways of being attractive to young people. My sense is that many of the younger people are interested, do have passion... but their commitment is probably shorter term and their focus is much more specific. They're not taking a twenty-year view, they're taking a two or three year view. So I think our original leaders, which were taking a twenty five year view of what we might look at, are leaving us frankly, are dying or retiring, and the young folk just aren't coming up... It is not a top-down, national-down initiative that is going to have the most impact. It has got to be people at the local level using local resources for all of those kinds of things that will maximize their capacity... Well, what can you do when you're an appointed board by the members? I mean we can't say "You've got to send us somebody who's 25." You send us who you send us. So we did a youth leadership development training event – brought 25 people together from across the country. (Consumer organization 1)

Theme 3: Resource Mobilization - Diverse Strategies Develop Social Capital

Summary of the theme: Part of the success of consumer organizations is largely dependent on the mobilization of resources through the development of social capital. Social capital refers to relationships and mutual support, cooperation, trust, and organizational effectiveness (Putnam, 2000). Consumer driven organizations use a variety of strategies to foster social capital: having a clear sense of direction, working at the grassroots level, and accessing valued resources and promoting civic engagement.

Minkoff (1997) suggests that although the connection is not clear, new social movements may play a role in the formation of trust between national movements and local mobilizing structures. While national organizations are sometimes criticized for their hierarchical structures and potentially divisive goals, they also produce a kind of symbolic affiliation and social integration (Minkoff, 1997). Our data suggests that affiliates see the national organizations as a catalyst for the development of local social capital. This occurs by sponsoring projects that have a local component and by the sharing of a vision and set of values that can serve to help people organize at the local level.

In addition, giving back to the community, civic engagement, is recognized as being important for creating a more civil society (Torjman, 1997). Both consumer organizations and individuals with disabilities must see civic engagement as a way to strengthen their organizations and the community. Recognizing the gifts of individuals with disabilities, rather than treating them as a liability to be rehabilitated, contributes to consumer organizations feeling a stronger sense of social capital--they are seen as a valuable resource in creating more welcoming communities (Kretzmann & McKnight, 1997).

Consumer organizations have clear goals and direction: All consumer organizations in this study have a clear set of policies and guidelines based in new paradigm values. Social capital includes relationships and social life in a community that enables people to act together effectively to achieve a common goal (Putnam, 1995). For one consumer organization, maintaining a clear focus on public policy is an important goal:

I think our policy focus is our strength. Our policy focus, frankly, will always keep us relatively small because there aren't a lot of funders for that stuff. But I do think the organization, by keeping that focus, does build a knowledge base and an expertise base that becomes recognized.... having people and board members and committees that are committed to a focus on policy, on improving the status of people with disabilities and people who come with the values and understanding of the pitfalls. (Consumer organization 1)

Literature affirms that organizations such as the Council of Canadians with Disabilities (CCD) expect that their members adhere to the principles of full participation in the community and equality (Boyce et al., 2001). In order to uphold their policies, most consumer groups mention the importance of strategic planning as a way of helping them achieve their goals and build stronger organizations. Strategic plans often include the processes by which they work towards their goals. They are generally democratic in nature and strive to ensure a forum for consumers to participate. This comment from one consumer organization reflects this understanding:

This year we are planning to do board governance and strategic planning. We've never had a strategic plan. We are planning to do that in March... We need to make sure that every part of those bylaws are shared values, that everyone can buy into... We try to build transparency at every level. (Consumer organization 3)

A government representative reflects on goal setting and capacity building of the consumer driven organizations :

I think you are into questions of capacity, ability to organize, ability to identify what the objectives are, abilities to plan out strategies for meeting those objectives... I think that requires a set of skills that even some of the larger organizations who aren't consumer driven do not possess. So in my mind it's not a consumer or not consumer question. It is a question of capacity of a voluntary organization, the kind of strategies that they employ, and resource issues and that kind of thing. (Government 11)

A comment from a service organization, on the importance of staying true to their goal:

People First has been a really interesting organization. I think because it's been absolutely in its roots, you know, self-advocacy caucuses and before that the sort of formal, national organization was formally launched. They made it absolutely clear that this agenda has got to be maintained as a priority...Its commitment to deinstitutionalization, it really led the way and continues in terms of ensuring and calling for that to be on the agenda. (Service organization 5)

Work at local grassroots level builds capacity: Consumer organizations work most effectively when their efforts are grounded at the community level, because consumers are considered to be the grassroots of the disability movement. One national consumer organization believes, that with its approximately 25 local centres across the country, it is effectively organized to develop social capital. Local involvement is critical to social capital, because by its nature, social capital is about people who know one another connecting with each other. Working directly at the local level enables people in organizations to feel connected within the organization, instill a sense of ownership, increase the opportunity for immediate action, and build the personal resources and skills (capacity building) of its members by participating in the social policy work within the larger disability movement:

There are these series of projects that go on and what's really neat about those projects is from their conception the centres are always pre-eminent, that their delivery is always based on the centres, and that's why it actually sells with government. Because government knows that their money is going to go right to the local level because it's administered here, but it's delivered at the local level...I think why the CAILC model works, is there isn't an additional bureaucracy. We don't have provincial affiliates and we can reach people instantly. (Consumer organization 2)

Another consumer organization, with quite a different set up, also believes that it is well organized to contribute to social capital by building capacity of its organizations and its numerous loosely affiliated member organizations. This national organization is currently working to develop an accreditation process for consumer driven organizations that is consistent with their philosophy:

There is nothing, no big national programs that we are involved in right now other than what we are doing. Trying to become organizationally structured, you know, has become the priority...It's all about building capacity of mental health consumers across the country. You know, there are two different types of capacity-building that we are trying to do, one is organizational...and then there is the capacity building of consumer survivors themselves... We get memberships... I think the receptionist told me we have 280 organizations on file now... Now not all of them are members. Some of them exchange newsletters... These are just membership organizations and what I am working on now is the affiliation process...and the accreditation process agreements because of course there are going to be two different things...The affiliation would be for organizations that strongly believe in our philosophies but don't meet the standards of accreditation...because they are not consumer driven, they would never be accredited. (Consumer organization 3)

We start working with people primarily at that stage with peers, people who have been through the experience themselves who have recovered fully and are role models and can act as a friend, as a buddy, as a colleague, not as a professional counsellor, but just as another person who has been there can start providing support first to the family and second to the individual who has been injured. (Service organization 7)

People First are experiencing some struggles with regards to mobilizing resources and developing social capital at the local level:

People First members need to...meet face-to-face so that people can see people's expressions...Conference calls do not work. HRDC didn't like hearing that though...People have to figure out ways to involve People First, one of the most important players... They assume that people can read. Well, people might not be able to read...But they have got to involve them and quit using these acronyms and these short forms...Literacy can mean it can be done in picture form for some people or something like that. There are other ways of looking at things and People First recognizes that. They also recognize at the same time that there ought to be a support person to that person at any meeting...to help that person through the meeting, but before and after the meeting too! Also how to accommodate different members in different ways at different times... Literacy is education, but there is also educating the people in the fact that People First take their time in doing things, but do them well. (Consumer organization 4)

Accessing valued resources and civic engagement: Consumer driven disability organizations play an important role in assisting people with disabilities to access valued resources, that is, resources such as affordable housing, education, recreation and leisure, adequate income, and social justice infrastructures that are available to other citizens. People with disabilities and consumer organizations need access to valued community services and opportunities to promote citizenship, empowerment, hope, and trust. In addition, resources are needed for organizational effectiveness to promote the goals of the movement. Each of the consumer organizations understands that access to valued resources goes well beyond traditional services. Two leaders from different service organizations express it most clearly:

What people with serious mental illness need is not just formal mental health services, but a variety of other kinds of resources that are available in the community. Some of them are self-help, family and friends, generic community groups, organizations. And also what we call the elements of citizenship which some call 'the determinates of health'-- access to real education, normalized education, work, housing, income. So this model broadens the perspective of what people with mental illness need beyond just the surface, just a paradigm. (Service organization 6)

While we are working with the individual who is returning to the community we are also working with the community to help the community to be receptive to those people coming back in...But at the same time as we're

doing that we're also opening doors, as best we can, for consumers to seek other opportunities and follow their hearts, follow their minds where they want to go so there's a lot of good people who I've had working here who go off and work for CBC, the Royal Bank and Toronto Dominion Bank and I sure as hell wish they were here but they're making a lot more money. They're getting promotions and they're doing what we're supposed to be doing for people that we're serving... It is that kind of thing where we wanted to see that organization have some increased visibility. (Service organization 7)

National consumer organizations play a role in enabling local affiliates to access valued resources. This is particularly true for CAILC that provides direct resource support for each of its affiliates, and is very engaged in supporting its member organizations. NNMH, on the other hand, uses a more informal networking approach and has few resources to share with its affiliates.

Both consumer organizations and individuals with disabilities must see civic engagement as a way to strengthen their organizations and the community. One consumer organization demonstrates how they became a valued resource for the community in the face of various tragedies:

September 11-- what happened in some of these areas like St. John's Newfoundland, is that ILCs opened their doors to the entire community. There were so many people stranded that the centre became a place that the kids could come to play, where people could get their emails. They have lots of computers, like they opened it up to the whole community. When there was a big flood in Winnipeg, Allan set up a response centre where they could go. You had to think of all these elderly people living in these areas where they had to move them into places where they could have their needs met, arrange all kinds of things. So I think now the disability community has to be less concerned about me, me, me stuff... The public doesn't really buy into that, you know, poor me... IL centres have to open their doors to the community... for September 11th, I was saying to the centre in Kingston that maybe everybody was in shock... Whenever there is a crisis in a community the centre should be out there right away, you know, what can we be doing? (Consumer organization 2)

In this theme, we have seen how mobilizing resources contributes to social capital in national consumer organizations. Not all national organizations play the same role in mobilizing resources to assist their local affiliates, but such intentions are vital to building local capacity. Organizations with strong social capital are more likely to contribute to building strong communities where mutual support and participation are valued (Coleman, 1990; Putnam, 1995).

Theme 4: Advocacy Role Defines Unique Place of Consumer Driven Organizations in Non-Profit Sector

Summary of the theme: Advocacy is well recognized as a tool for change in the disability movement, including the consumer movement (Cunconan-Lahr & Brotherson, 1996; Racino, 1999). The national consumer organizations in this study see their advocacy role as central to how they define themselves. Typically, there are different approaches to advocacy, and these four national organizations reflect the varying types of advocacy. Some primarily use systemic advocacy to influence public policy, while others primarily promote self-advocacy and individual advocacy within their affiliate organizations. Regardless of their advocacy orientation, all national groups understand the importance of advocacy if vulnerable people are to experience the full rights of citizenship. In all cases, research informs this advocacy thrust. The advocacy role contributes to consumer driven organizations having a unique place in the non-profit sector.

Advocacy central to definition of consumer organizations because it is used to influence public policy as well as individual change: Systemic advocacy, advocacy which primarily enables consumer organizations to influence public policy, is central to how consumer organizations see themselves:

CCD is a national advocacy association that monitors federal legislation, programmes, and initiatives as they affect people with disabilities and injects the voice of people with disabilities into those discussions and debates... The primary criteria for membership in CCD is that they must be consumer-controlled, driven, and directed, and their primary purpose has to be advocacy... We're not going to get into service delivery. We're an advocacy body... So we've been to the courts in the Latimer case and others ... We organize around social policy issues of employment, access, income support, disability support, transportation access. (Consumer organization 1)

And then there is the capacity building of consumer survivors themselves. I know from my own experience when I first started, I didn't know the difference between what a policy was and a bylaw. And I think we have to teach people that. I didn't know the appropriate way to advocate. We have to teach people the steps to advocacy, what advocacy is and what advocacy isn't. We have to build in them a sense of confidence whether it's themselves talking to their own doctor or if it's them standing up and doing something publicly. I know I was setting precedence at the beginning and I didn't even know what a precedent was... I look at it now politically and I think wow all the strings that had to be pulled to get some of these things happening and I didn't even know what the processes that were happening behind the scenes would have had to have been to have pulled off some of the things that we did. (Consumer organization 3)

Another national organization primarily supports its affiliates to do self-advocacy and individual advocacy:

CAILC and Independent Living promotes individual skills development and education... We advocate and provide solutions... this is where the grassroots fits into here. I always say, without us enabling citizenship development, you have no CAILC or CCD... We have to support them in learning to advocate, so that they can speak up, right, some people need that support. (Consumer organization 2)

Two service organizations further highlight the role of advocacy:

CCD has consistently been pushing that kind of envelope in terms of using the legal system. I think in terms of putting independent living out there as an agenda and ensuring that both provincial and federal governments have that on their radar screen. They have been really important in developing the political networks to keep that visible and it's been really important in securing a funding base, CCD, for both its national organizations and its provincial/territorial organizations. (Service organization 5)

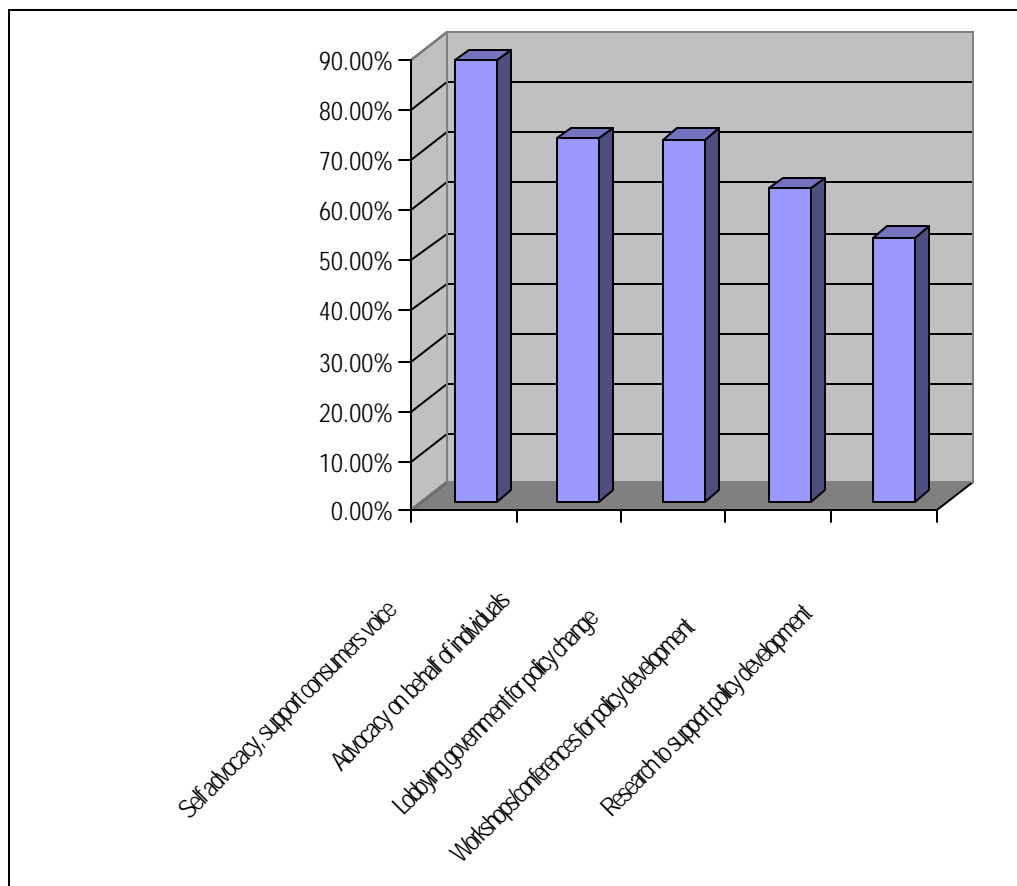
And some of the differences I see in some of the other consumer driven agencies and at the national level... the primary purpose for some of them is advocacy. It is to be the voice of disabled people in terms of influencing policy and procedures at the national level, provincial level and at the local levels. And again, in areas like health care, in areas like transportation... I always have seen consumer advocacy organizations as a way of extending, sort of being that muscle that we don't have in our own arm and that by reaching and bonding and binding with those characters and uniting with them, we can do more in the area of advocacy. (Service organization 7)

Despite CAILC's focus on self and individual advocacy, they also build relationships and connections that assist them politically. In 1988, for example, CAILC moved its head office from Winnipeg to Ottawa to be closer to the national political scene, and has subsequently established several relationships and contacts within the bureaucratic structures and Ministers of the Government. They regularly deliver presentations to government committees and commissions to ensure national exposure on disability issues (Neufeldt, 1993; Valentine, 1994).

Affiliates of the four national organizations are engaged in a range of advocacy approaches. The survey data in the following graph on processes and strategies of affiliate organizations reflects this range. Other information from the national organizations shows that CAILC affiliates are most active in self-advocacy, with less activity focused on systemic advocacy. CCD, on the other hand, is known for its systemic advocacy

capacity, and its affiliates are active in lobbying government, but less engaged in advocacy on behalf of individuals.

Processes and Strategies of the Member or Affiliate Organizations



Projects support education and advocacy for change. All four national organizations promote projects with their local affiliates as a way of demonstrating innovation and as a tool for education and advocacy for change. When CAILC does a project on literacy, for example, it is not just about advocacy. Through its projects, CAILC demonstrates IL, a new way of supporting people with disabilities in community. As the learning from a local project becomes clear, it may be possible for local affiliates to use the insights for policy or program change. One CAILC affiliate, the Independent Living Resource Centre in Winnipeg, runs 28 different programs with 40 partnering organizations.

Projects among the affiliates of the national organizations range from system change issues to personal empowerment and skills development. Survey data indicate a range of projects conducted by affiliates within the last five years including: participation in long term mental health planning; abuse of women with disabilities; reducing stigma; crime prevention – high risk youth with disabilities; parenting with a disability; volunteering and the wider community; developing a barrier-free universal design CD-ROM; and deinstitutionalization initiative. Many of the affiliate projects are partnership oriented. What we see most often is the consumer driven organization collaborating with other organizations to address an issue of prime concern to people with disabilities. While some local projects are financially supported by the national organization, many local projects are independent from national, while at the same time still reflecting the principles of the new paradigm approach to disability and community. When done well, local

projects contribute to advocacy for change within a broader sphere:

There are these series of projects that go on and what's really neat about those projects is from their conception the centres are always pre-eminent, that their delivery is always based on the centres, that you, and that's why it actually sells with government. You know, if we really ever wanted to totally mobilize we would be able to do it really quick... We had, as a grassroots organization, the ability to develop the institute, the network, and to work on the funding. You know, people have to learn about systemic advocacy, they have to learn about issues. We have to support them in learning that they can speak up. That's why I say, without a grassroots connection, you will not have social policy participation because unless people believe in themselves, want to learn about issues, want to be compassionate about issues, feel good about doing that, and have access to information and know that their voice counts you won't have that. I think we need more of this in organizations to build our capacity. (Consumer organization 2)

Good research important strategy for influencing public policy: National consumer organizations mention the importance of good research to support their advocacy work:

We believe we need a research arm or a research department... We just submitted a proposal for a centralized database... where we can gather everything that has been done... So when researchers are doing their work, trying to find out what's been done, we're going to have it all centralized on a database ... We haven't been too involved, but now we have committee people on the research and programming end of things... We're rebuilding. But for a long time the research committee wasn't that active. (Consumer organization 2)

A government representative speaks about how government often funds research by consumer organizations focusing on gaps in research and policy:

The Disabled Persons Unit program funded consumer driven organizations with some pretty broad perspectives. It looked at issues around how people participated in community, both socially and economically, looked at how we could make improvements to any kind of gaps in research... It is research in the context of building from the grass roots up, representation of the consumer groups themselves in changing, in identifying gaps in changing policy and providing some direction to government in terms of what their best advice to government would be on what would be the most effective practices. (Government 12)

A member of a service organization identifies their role in identifying future research agendas:

One of the roles that we have played in the past, and would play in the future is being at the table and continually demanding to see more consumer participation in setting research agendas, adjudication, application of results as opposed to researchers running off on their merry way doing all kinds of research that interests them and doesn't have any impact, or marginal impact on the people they're proposing to provide benefits to. (Service organization 7)

Recently, consumer organizations are becoming involved in doing research in accordance with the new social movement. They are no longer only the subject of research, which often focused on issues that reinforce the old paradigm. Rather, these consumer driven organizations are being encouraged to have control over the research process and promote new paradigm research (Campbell, Copeland, & Tate, 1998; Krogh & Petric, 1994). Participatory action research and emancipatory research are two examples of new paradigm research. This trend of building the capacity to conduct new paradigm research will ensure that advocacy efforts by consumer organizations continue to define their unique place in the non-profit sector.

Theme 5: Financial Support from Government Both Constrains and Mobilizes Consumer Movement

Summary of the theme: As with all organizations, consumer driven organizations require adequate funding to maximize their potential. An important aspect of social change theory is resource mobilization, which in this case, means how financial resources are used to fuel the social change activities of disability organizations.

Consumer driven disability organizations require adequate funding to contribute to the non-profit sector and the lives of people with disabilities. The findings from the study reveal a reliance on core funding from government, although this government support tends to fluctuate. While the contribution of voluntary organizations to citizenship is important, it is a challenge during this period of economic constraint. The role of government in providing support for non-profits is essential for the building of civil society (Brown, 1996; Torjman, 1997).

Securing funding important but funding persistently constrained: Many national consumer organizations receive core or operational funding from government, namely the Department of Social Development through the Office of Disability Issues (formerly HRDC). One consumer organization reflects on the fact that the advocacy work of its organization does not tend to invite private, corporate, or charitable donations, and thus leads to a reliance on government:

We live on government grants... Our membership generally are poor people. They are not going to be able to sustain the organization through charitable donations. We have had since 1979 operational grants from some form of federal government departments. We do not ever wish to compete with our member groups for dollars at a provincial level. We presently have a core funding arrangement with Human Resources Development Canada... We expect it will be continued, but we live on year-to-year funding and ninety-five percent of our money is federal government money in one form or the other... We have virtually no corporate dollars. When you consider that we have, in the past six or seven years, probably taken all of the banks to court, Via Rail, Air Canada, they're not likely to fund us. The private sector is more interested in supporting service delivery than they are in supporting the advocacy efforts to consumer organizations. (Consumer organization 1)

A government representative discusses some of the types and conditions of the funding that they provide to consumer organizations:

We fund consumer organizations... through contribution agreements to national disability organizations through the Office for Disability Issues or in fact in any component of Social Development Partnerships Program... So the values of equal participation of people with disabilities in community and in the labour force, which ties into the department's mandate, are then translated in some basic funding priority themes... Our grants support organizational or capacity building of recognized national disability organizations. There are currently eighteen national organizations that receive funding through SDPP/Disability Component... SDPP supports best models or best practices of including people in community. (Government 11)

However, some consumer organizations feel their ability to build capacity within their affiliates and communities are constrained by insufficient financial resources:

The Social Development Partnership Program actually gives us \$80,000 a year to operate a national organization which, as you can very well imagine, doesn't cover stamps. It's not that much money. The project funding that they give pays for projects like the Capacity Building for People with Disabilities which would be the Consumers in Action Project... We asked them for over one quarter million dollars at the last decision table. (Consumer organization 3)

A representative from a service organization sums it up:

Disability organizations across the country have an important role and important voice and the federal government has a responsibility to ensure those organizations exist. (Service Organization 5)

Our survey data with affiliates confirm this concern. Affiliates receive almost no financial support from national organizations. For example, People First Canada has been unable to provide financial support for the processes and strategies of the affiliate organizations. The exception is CAILC, where affiliates receive partial funding which can be applied to projects or infrastructure. This enables their centres to have much more impact at the local level and facilitates more consistency between national and local affiliates.

Problems with government constrain financial situation for consumer organizations: Throughout this study, disability organizations often compared different periods of history of government support for the consumer movement with the present. One government person reflects on the 1980's when support for disability issues gradually gained in stature and attention with increased resources:

In the early 1980s, I was the only person probably they could find in the entire government who had anything to do with disabilities and community-based disability issues. So I started...to develop a new program and so what we had to do was really basically change people's conceptual framework from one of health and illness to citizenship and participation. And that was the key thing with the movement from Health to Secretary of State...The Federal role is now diminishing ever more so and most of this all plays out at the provincial level so the national groups are really at sea. (Government 10)

A consumer organization also raises these issues about changing times and implications for support and funding for the consumer movement:

When you look at the voluntary sector initiative, way before they did get recognition, it was the disability community that fought in the mid '90s when the federal government was devolving and they were sort of eliminating any funding to any social issues. And it was the disability groups that fought that battle and then eventually some of the outcome was years later there would be an initiative... it was us who actually fought the Federal Government stand in 1996 and 1995 which lead to the Liberal Task Force. (Consumer organization 2)

A government representative echoes the changes in policy:

But the reality is that the voluntary sector in Canada is the brunt of the downsizing that occurred from the feds in '95 and then to the provinces and then to the municipal level. And so the voluntary sector is not very strong in Canada right now and I would say the disability groups are suffering as a result of all of this...It's like one-handed clapping, unless you have real partnerships with these organizations...Is an overloaded department, was, still is, and ever will be so, can't manage that many files. It's impossible...The long and the short of it is that disability issues really got buried in the department...and in a department as large as HRDC, your issues are lost, unless they are really important like economics. (Government 10)

This consumer organization also believes the Federal government has responsibility to support consumer movements:

The Federal government has a role to play to ensure we are able to network with the Canadian movement, between provinces, to share concerns, and for people at the local level to understand what they need to do ...There is no question that there is tension between our organization and government...There is no question that funding is one reason. I think the other reason is the political and economic environment in which voluntary organizations developed in the '70s and '80s- it has significantly shifted in the '90s because of the onset of neo-liberalism. (Consumer organization 2)

However, comments from service providers also caution against heavy reliance on government :

I think that's one of the reasons why the policy agenda hasn't moved forward...you've got a number of people sitting around that table, and frankly, many people in the disability community could run circles around them in terms of their policy knowledge. And yet invested in that group of middle level bureaucrats...is way too much power. (Service organization 5)

The Office with Disability Issues of HRDC...is not a leader in the government of Canada today in disability issues. It has neither the budget nor resources, good people. There is no impact. They're having little or no impact on the social policies. Not because they're not trying, but because it is not being resourced, it is not being taken seriously...They are just weak. I know everybody there. People aren't weak, the office is weak...The era of the disability initiatives of the mid 90's are gone and therefore what is at stake? The support to employment services across this country for disabled people...has never been weaker and the policies on accessibility of devices. You go into a supermarket and take a look at a stove. There is not one button on that stove, yet we allow it in this country. The Council of Canadians with Disabilities will put out a pamphlet. They don't have the resources, the money. So I believe in an independent consumer movement, philosophically, but in this country where the population of Canada is less than the state of California, where most consumer groups will tell you they spend most of their money just to meet, there's nothing left over to do anything. (Service organization 8)

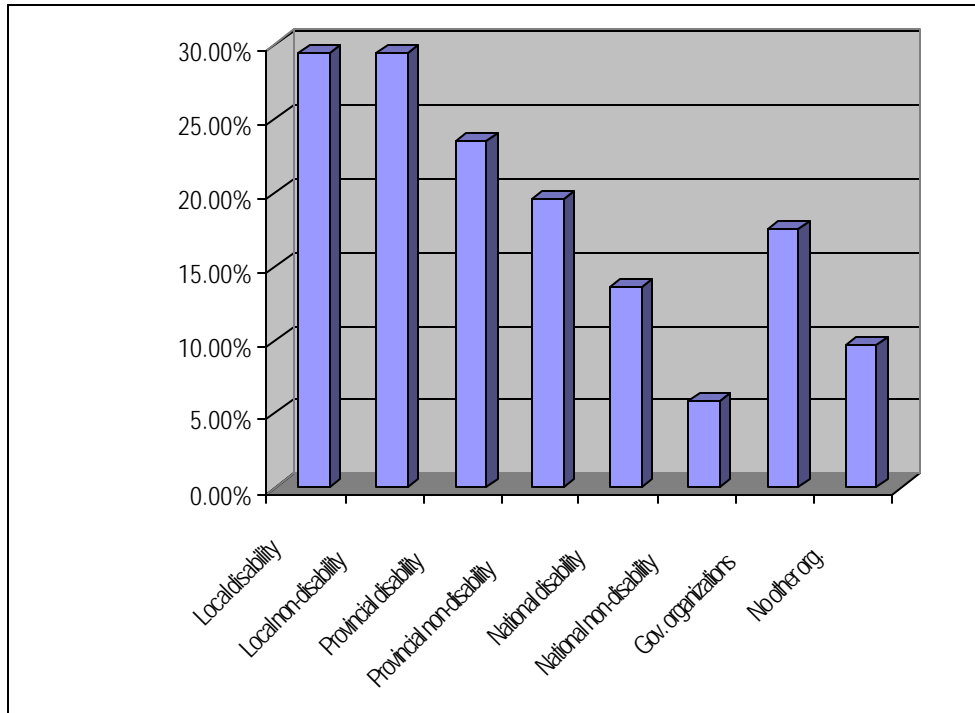
Theme 6: While Linkages Give Strength and Hope, Unresolved Issues Must Be Addressed

Summary of the theme It is clear from this study that there is hope in the future of the consumer disability movement and that linkages with a variety of organizations play an important role in creating this picture of a viable future. At the same time, there are significant constraints that must be addressed if this kind of future is to be realized.

In summary, linkages are very important to non-profit organizations, including consumer driven organizations because they increase their ability to work together for common purposes (Coleman, 1990; Putnam, 1993a; 1993b; 1995). However, it is possible to see that there are many unresolved issues in the consumer movement which must be addressed in order for the potential impact of the movement to be realized. The following future directions provide some concrete suggestions that emerge from this study.

In the survey with affiliates of national consumer organizations, the graph on the next page shows that they have a range of connections, from local disability and non-disability groups to connections with national disability and non-disability to government. The highest percentages are recorded for connections at the local level (29.4%). Of the four organizations, CAILC affiliates report the highest connections (42.9%). It is interesting to note the diversity of responses across the four partners in terms of connecting with non-disability groups for example.

Other Organizations Involved in Independent Projects of Affiliate Organizations



For additional breakdown of the role of the affiliates in projects, either independently or with their national organization, please note the following graphs.

Role of Affiliate Organizations in Independent Projects

	Total %	NNMH %	PFC %	CAILC %	CCD %
Leader	51.0%	22.2%	30%	78.6%	88.9%
Partner	25.5%	27.8%	50%	14.3%	11%
Participant	9.8%	5.6%	40%	0%	0%

Role of Affiliate Organizations in Projects with the National Organization

	Total (%)	NNMH %	PFC %	CAILC %	CCD %
Leader	25.5%	11.1%	60%	28.6%	11.1%
Partner	27.5%	22.2%	40%	14.3%	44.4%
Participant	31.4%	16.7%	10%	42.9%	66.7%

Linkages give strength and hope: The major finding of this study, that linkages with consumer organizations, service organizations, funding bodies, government departments, and businesses are very important to the work of consumer organizations, is also evident in other research (Boyce et al., 2001). In discussing these links, people talk about collaboration, connections, networking, coalitions, and alliances. The progress toward building alliances both within the consumer movement and outside is slow but sure. Connections between consumer organizations create a network of support within the consumer movement. One consumer organization speaks eloquently about the future and how working together enables organizations to have a stronger voice and create a sense of solidarity to their cause:

If we are going to create change...we can't be going in and delivering five different messages. We need to focus on some priority... That's why the priority of the community right now is disability support...It has only been in the last

ten years that there is a more collaborative process between consumer and service organizations... I do believe there is a disability rights movement, but there are many players within that and there are various organizations with different mandates related to that...we certainly coordinate our message...I think it [the movement] has shared values, objectives, some shared strategies ... But the world is not going to change overnight. It is going to be an incremental process. (Consumer organization 1)

It's a difficult one because we all have different philosophies but we agreed when we first started to get into bed together, and that's how it was seen that we would leave all of the issues that we didn't agree with at the door. So we can sit down and say, you know, the Federal Government needs to have some sort of an action plan. You know, they have to be guiding the provinces and telling them that we need to have so many members of this or we need to have so many different community support and that kind of stuff. We can agree on that. There is no national action plan (Consumer organization 3).

Two service organizations and a representative from a consumer organization talk with optimism about these linkages with consumer and other organizations:

You know, there is some feeling of solidarity where we have issues in common and we have common advocacy agendas... It's been quite encouraging that we are speaking more with one voice...In some ways there are some issues that the disability movement has a common voice about in terms of access and citizenship...The voice is getting stronger so I think it will continue to strengthen. (Service organization 6)

Through our national office and through our provincial partners, we are working together, through meetings and correspondence and networking and assisting in whatever it is that we can assist in, everything from phone calls to MPs, whatever, to act on behalf of the consumers as well as the service providers. (Service organization 9)

We've always been concerned with empowerment, quality of life and that sort of thing. But the way we achieve the end is different now than it was back 17 years ago. Like then...you could go out and do things on your own almost to a certain extent. Now it's a case that you got to work together with another organization in order to get the proper resources to do it...I see CACL as a parent organization that has resources to do things that we may not see as that important, but when we take on an issue and if CACL happens to be working on an issue that's related or that very same one, like deinstitutionalization, is a good example. (Consumer organization 4)

A service organization talks about linkages with consumer organizations around advocacy issues:

The few meetings I've been at I've seen examples of both. I've seen us pulling together. A good example recently is the disability tax credit and the CPP disability work that we've done as part of a cross disability coalitions where we've realized that we are all saying the same thing... The best example is the income support work that's been done recently... We were trying to find out to what extent does home care address the needs of people with psychiatric disability, and if not, how might it? ... What we found was not surprisingly -- that the access to home care for people with psychiatric disabilities is very variable across the country. In many cases, if not most, if you have a primary diagnosis of mental illness, you are not eligible for home care, which is quite shocking... We found in an informal way that there are approaches that are very effective for people with mental illness. For example, for people who have a hard time holding onto their housing, home care makes a huge difference. Also, in one of our pilot, we found that it's possible to make very positive linkages between home care and the mental health system so that both can be mutually reinforcing. (Service Organization 6)

A service organization talks further about when linkages are appropriate:

And I think we need to pick perhaps that one federal issue as a disability movement, community and structure it so that it recognizes you can't favour one over the other but recognizes that nobody but a blind person is going to read Braille and nobody but a person with hard of hearing is going to use a hearing aid. So get the experts in both, put a structure in place and do it. And if we don't do that what we are going to end up with is what we have now; Atlantic Canada, nothing, Manitoba, nothing, BC, nothing. Quebec, limited up to age 40 for employment and I am repeating what I said but I am doing that for emphasis, that's how I believe we will all work together. And that's why I believe that we can work with the Council of Canadians with Disabilities and other groups to petition the federal government for an assistive devices federal policy and delivery plan if all of the groups come together and say yeah. If at the service delivery level it has to be disability specific or it won't work. (Service organization 8)

Unresolved issues cannot be ignored & must be addressed in near future: The dilemma is that there is a lack of clarity about what consumer driven means. A federal government official explains "I also think that you need a new dialogue about this notion of consumer driven ... They all now consider themselves to be consumer directed because... they've got lots of people with the conditions on their boards now.

There were strong views about why the policy agenda has not advanced more than had been hoped for by now and what can be done by all involved. These unresolved issues present challenges to the consumer movement. There are three main challenges that emerge from the research: the need for a common political agenda; the need to address turf struggles or competition; and a minority of service organizations that still believe their single focus disability organization is most effective for advocacy and policy development. There were many comments about these issues, such as:

There's a lot of work to be done and there has to be much more unification and there has to be a much more serious level of assertiveness in the movement to bring about the kind of changes that are going to bring about long lasting permanent changes. (Service organization 7)

There's always some dissatisfaction when one group gets a large amount of money and another group doesn't. I think that's a reflection of the times and I don't think that it is a reflection of the relationship that exists between these groups. If anything, it's a very cooperative, amicable relationship, except when resources are introduced into the equation. (Government 11)

Council of Canadians with Disabilities do not represent blind people at all. They have some blind people who are members and who are on their board but they have had no impact on improving circumstances for blind people... because my requirements for social change in this country, as a blind person, have more in common with you as a sighted person than they do with somebody who is deaf, or who is mobility impaired. (Service organization 8)

Representatives from a service organization and consumer organization both question why things are not moving faster. It also suggests we are moving in the direction of new social movement:

We've got to ask ourselves as a movement why we have not moved this agenda forward despite the years and years of research, despite the evidence in an age of evidence based policy making that's on the table... We need a federal transfer from the federal government to the provinces and territories to enhance their capacity to deliver services and income to people. But the political momentum for that is spin. So we are straddling both, but I see moving in the direction of new social movement, to use that term, for very strategic reasons. And that is, Canadians need to understand the reality of people with intellectual and other disabilities in their families. (Service organization 5)

I think there certainly is trust among the consumer-directed organizations. There is some greater trust or willingness to collaborate with some of the traditional service agencies on pieces... But the world is not going to change overnight. It is going to be an incremental process. (Consumer organization 1)

Further, a government representative comments on why things are not moving faster:

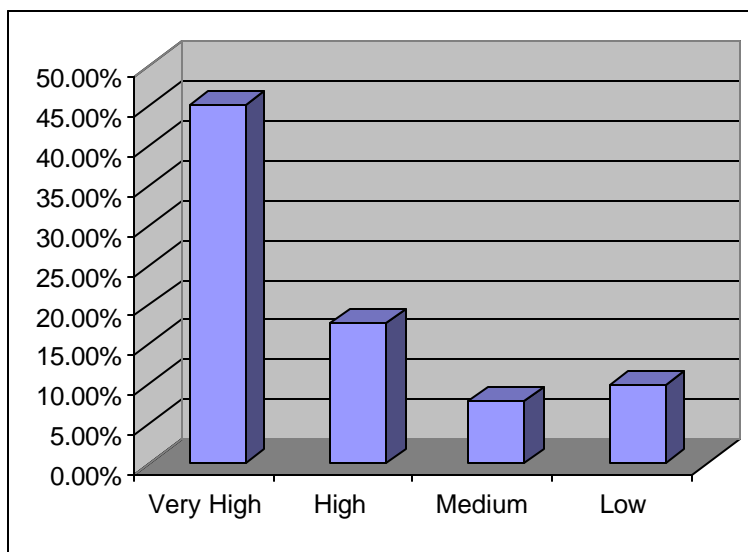
As organizations furthering the issues, well that's another matter altogether. Then I think you are into questions of capacity, ability to organize, ability to identify what the objectives are, abilities to plan out strategies for meeting those objectives. And consumer or not consumer, I think that that requires a set of skills that even some of the larger organizations who aren't consumer driven do not possess. So in my mind it's not a consumer or not consumer question. It is a question of capacity of a voluntary organization, the kinds of strategies that they employ, and resource issues and that kind of thing. (Government 11)

A comment from a consumer organization underlines the need for change:

There isn't the political will or any of these other things around now that there used to be and people didn't, don't want to maybe work as hard, to achieve something today as they did 10 years ago. I don't think there is that feeling. Why be involved... Why rock the boat... OK around the issue of jobs, if it is going to affect my disability pension, and since I don't want to pursue that at all, people are scared to take a risk, although genuinely... Well when you think they haven't even revamped the system to give people a raise over the monies gone up, the cost of living has gone up, not the money that people get. They are still getting what they got back in early '80's. (Consumer organization 4)

For this new social movement to evolve more rapidly, affiliates and their national organizations will need to be more cohesive and work in a more collaborative way towards movement goals. The survey research showed that there is wide diversity amongst the affiliates in terms of their perceptions of their national organizations' contribution to the disability movement. In the future, as the new social movement evolves, we might anticipate that all national consumer driven organizations will be seen as making major contributions to the disability movement.

Member or Affiliate's Perception of the National Organizations' Contribution to the Disability Movement



For further expansion of the above chart, with details on each consumer organization see the table below.

Indicators of Member or Affiliate’s Perception of the National Organization’s Contribution to the Disability Movement

	NNMH %	PFC %	CAILC %	CCD %
Very High	(11.1%)	(30.0%)	(78.6%)	(77.8%)
High	(16.7%)	(10.0%)	(21.4%)	(22.2%)
Medium	(0%)	(40.0%)	(0%)	(0%)
Low	(27.8%)	(0%)	(0%)	(0%)

Future Directions

1. Consumer controlled disability organizations and affiliates need to be more recognized by government and organizations involved in disability issues, as the authentic voice of persons with disabilities.
2. Consumer controlled disability organizations need to continue to have as a priority, educating and influencing the broader disability movement, as well as society in general.
3. Consumer controlled disability organizations need to continue to emphasize their distinct role, at the same time be open to collaborating as part of strategic alliances with service organizations and the broader non-profit sector around particular issues of mutual concern.
4. Consumer controlled disability organizations and their affiliates need to continue to develop their capacity for building networks, self-advocacy, information and referral, peer support, and consumer directed projects.
5. Consumer controlled disability organizations need to intentionally and strategically build next generation leadership by providing leadership opportunities, mentoring, workshops, and long term planning that identifies next generation leadership as a priority.
6. Several national consumer controlled disability organizations need to make a conscious effort to ground their work in local capacity building by encouraging and supporting strong local affiliates. CAILC and CCD are strong because they have a clear purpose that is grounded in grassroots activity. Such a focus will build social capital locally, provincially, and nationally.
7. Because advocacy is central to the definition of all consumer controlled disability organizations, it is important that better resources for advocacy and policy development be made available to enable them to make a stronger contribution to the non-profit sector. Government has an important role in promoting and funding consumer driven organizations and their research that is the foundation of their advocacy.
8. Given the vulnerability of the consumer controlled disability movement, the federal government needs to work closely with the consumer disability organizations to develop strategies and funding mechanisms that will build the capacity of the movement from the grassroots. Currently most consumer disability organizations are not able to contribute financially to the local level in any way that has an impact.
9. The major hope for a strong disability movement is in building linkages with other like-mind consumer organizations, other equality rights sectors such as the women's movement, gay/lesbian movement, and poverty coalitions, as well as with service organizations, and other non-profit sector parties, and communities. Although there can be compromises for consumer disability organizations when building linkages, these kinds of relationships are crucial to having an impact both with the disability movement and within the broader non-profit sector.
10. Consumer controlled disability organizations need to re-evaluate their vision and their relationship with citizens with disabilities and to consider a variety of ways they can make their organizations

more welcoming, inclusive, and inspiring for the many people with disabilities currently not involved, as well as for the broader community.

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