Shared Values, Networks and Trust Among Canadian Consumer Driven Disability Organizations

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Abstract

This article focuses on the development of social capital among consumer-driven disability organizations in Canada. A new social movement focuses on issues of identity, quality of life and the lifestyle of people within the movement rather than solely on rights, income security and provisions of the welfare state. Reported here are survey findings revealing the network and values that form the relationship between four national consumer-driven disability organizations (Council of Canadians with Disabilities, the Canadian Association of Independent Living Centres, People First of Canada, and the National Network for Mental Health) and their member or affiliate organizations. Study results reveal features within the new social movement that contribute to, and diminish, social capital, including issues around the development of shared values, establishment of networks and supports within an atmosphere of trust and mutuality. Study findings expand on the mobilizing and political capacity found among consumer-driven disability organizations in Canada.

Keywords: consumer-driven organizations, disability movement, social capital, new social movements, trust

Introduction

This article examines the development of social capital within a new social movement in Canada; specifically, consumer-driven disability organizations and social capital that forms between national organizations and their affiliates. National social movement organizations provide a critical function in linking organizations (Minkoff, 1997) and developing a collective identity and solidarity among otherwise isolated members of society. Social movements make individuals more visible in the public sphere by promoting public dialogue and debate. This article reports on one phase of a larger instrumental case study[1] of national consumer-driven disability organizations in Canada and their member or affiliate organizations. National social movement organizations in this study included the Council of Canadians with Disabilities (CCD), the Canadian Association of Independent Living Centres (CAILC), People First of Canada (PFC), and the National Network for Mental Health (NNMH).

Social capital is a useful concept for examining capacity within consumer-driven disability organizations. The concept of social capital focuses on the development of shared norms, networks, and trust which enables people to

work together for common purposes (Coleman, 1988; 1990; Fukuyama, 1995; Putnam, 1993a, 1993b, 1995); underlying this is a focus on the emergence of social networks and the power to create social change. The capacity of non-profit and voluntary organizations in general is a concern following the shift to a neo-liberal era in social policy that emerged in Canada more fully in the 1990s. Several authors (cf. Arai, 1999; Arai & Reid, 2003; Scott, 1992) point to the negative impact on communities through the loss of funding and the mounting pressures placed on volunteers in non-profit and voluntary associations. As government funding declined and downloading occurred from the Federal to Provincial and ultimately to local communities, in several instances we saw volunteer burnout, a shift toward fundraising and *mandate drift* as organizations struggled to keep their doors open, or the closure of organizations. Therefore, in part, this article provides a picture of the state of consumer-driven disability organizations in the face of this policy shift.

Consumer-driven disability organizations emerged in recent decades to recognize people's ability and need to be involved in decisions affecting their lives. The shift from more traditional rehabilitation-oriented services to community-based, consumer-driven approaches brought an emphasis on quality of life, consumer choice and control, empowerment, self-determination, and an independent living philosophy (Campbell & Oliver, 1996; Canadian Association for Independent Living Centres, 1990; de Jong, 1993; Enns, 1991; Hutchison, Pedlar, Dunn, Lord, & Arai, 2000; Rappaport, Reischl, & Zimmerman, 1992; Valentine, 1994).

The idea that consumer-driven disability organizations played an important role in shifting the disability movement into a new social movement is gaining support in the literature (Campbell & Oliver, 1996; Roeher Institute, 1996). The four national organizations in this study emerged in the last three decades to contribute to the agenda of the new social movement. In the 1970s Canada's first national cross disability organization, the Council of Canadians with Disabilities (CCD), provided a united voice to ensure the rights of persons with disabilities were heard in social policy debates and to advocate for public policy supporting inclusion and full participation, equality, citizenship, and access to valued resources (e.g., transportation, housing) for people with disabilities in Canada and elsewhere. In the 1990s, People First of Canada (PFC) emerged from the international movement of People First as a national self-advocacy group comprised of consumers with intellectual disabilities. The goals of PFC include citizen participation, empowerment, system change, and advocacy. The Canadian Association for Independent Living Centres (CAILC), founded in 1986, promotes the independent living (IL) philosophy and key principles of consumer control, a cross disability focus, a community based approach, and the promotion of integration and full participation of persons with disabilities (CAILC Membership Committee, 2002). The National Network for Mental Health (NNMH) began as a task group of the Canadian Mental Health Association and became a consumer-driven non-profit organization in 1991 to increase involvement of mental health consumers in planning and decision making around mental health initiatives.

Previous studies focused on local organization affiliates (Hutchison, Pedlar, Dunn, Lord & Arai, 2000) or national organizations (Valentine, 1994), although few have examined the relationship between the two. In this study there was a particular interest in relationships between national consumer-driven disability organizations and their members and affiliates (hereafter referred to as affiliates). The aim of this article is twofold: to develop a description of the relationship between national consumer-driven disability organizations and their affiliates; and to contribute to the empirical literature on social capital as it develops within a new social movement. Consequently, this article will specifically address three research questions: What type of network exists among national consumer-driven disability organizations and their affiliates? To what extent are norms and values shared between national consumer-driven disability organizations and affiliates? What contributes to or diminishes trust within this new social movement?

Review of Literature

New Social Movements and Social Capital

With the growing influence of consumer-driven disability organizations there has been some attempt to understand the contribution of these groups in a social movement framework (Campbell & Oliver, 1996; Council of Canadians with Disabilities, 1995; Lavoie, & Stewart, 1995; Scotch, 1988), and more recently, there has been shift to thinking about these organizations within a new social movement framework. New social movements move beyond rights to also focus on issues such as quality of life, inclusion, and expanding opportunities for the expression of people's differences in society. As a result, new social movements create opportunities for change among people in the movement through active citizenship and participation in decision-making around the issues that affect them. A key focus is also the transformation of community to recognize the strengths and assets of individuals and the different ways people construct their lives (Habermas, 1981; 1987). The strength of a new social movement lies in the ability to advance the interests of the movement through policy shifts and social change through the politics of participation. New social movements involve "networks of networks" that are more loose-knit, and less bureaucratic and hierarchical than traditional parties and interest groups (Newton, 1997, p. 582). These social networks and social infrastructures contribute to building civil society and expanding the national movement sector, which provides opportunities for activism by marginalized groups (Minkoff, 1997).

During the 1950s there was a proliferation of disability organizations which were predominantly parent and professionally driven and focused on issues such as rights and access to public education (e.g., Canadian National Institute for the Blind, Canadian Association for Community Living). The 1960s human rights movement raised consciousness about social injustice and the violation of the rights of many vulnerable individuals, including people with disabilities (Lord & Hutchison, 1996; Rioux, Bach & Crawford, 1997). As described by Habermas (1981, 1987), traditional social movements (e.g., labour organizations) focus on rights, developing the welfare system, and mediating between government and interest groups to achieve changes in social policy. Where earlier decades focused on traditional rehabilitation-oriented services, the 1970s brought the emergence of consumer-driven disability organizations controlled by people with disabilities which recognized people's ability and need to be involved in decisions affecting their lives. These organizations were committed to issues of quality of life, consumer choice and control, empowerment, self determination, and independent living (CAILC, 1990; Campbell & Oliver, 1996; COPOH, 1985; de Jong, 1993; Enns, 1991; Hutchison, Pedlar, Dunn, Lord & Arai, 2000). It was during this time period that consumer driven organizations played an important role in shifting the disability movement into the form of a new social movement (Campbell & Oliver, 1996; Roeher Institute, 1996). The 1980s and 1990s brought further transformation to the disability movement through an emphasis on more holistic approaches to supporting individuals with disabilities including empowerment, community membership (Kretzmann & McKnight, 1993; Schalock, 1997) and more individualized, or person-centred, approaches to supporting people in community (Bradley, Ashbaugh & Blaney, 1994; Hutchison et al., 2000; Lord & Hutchison, 1996; Pedlar, Haworth, Hutchison, Taylor & Dunn, 1999). At the very time that the disability movement was transforming, the tides began to turn in Canada and a neo-liberal era began, and so a question is raised about the movement's ability to maintain momentum and continue to mobilize for social change for individuals with disabilities. The concept of social capital is relevant to this context.

Social capital is a useful concept for understanding new social movements and their ability to mobilize policy change and create opportunities for

individuals to define their own lives through participation in the policy process. Differentiating it from human capital (individual knowledge and skills), social capital is created when relations among people change to facilitate action (Coleman, 1988; 1990). Building upon Coleman's discussion, Putnam (1995) defined social capital as the "features of social life — networks, norms, and trust — that enable participants to act together more effectively to pursue shared objectives" (pp. 664-665). An examination of social capital incorporates an analysis of networks and social structures and the cultural aspects (i.e., values, ideology) within social movements (Edwards and Foley, 1997). As Hemingway (2006) notes, trust and norms have mistakenly been emphasized as the core components of social capital (i.e., co-equal with social networks); but as he notes, Putnam's (2000) later work revised his definition to focus on reciprocity and trustworthiness *that arises from* social networks. Several authors describe social capital as a feature of the social networks through which social, economic, and political power are sustained (cf. Bourdieu, 1987; Hemingway, 2001; 2006). Helpful in further understanding the analysis of power arising from social capital is to think in terms of Wood's (1997) distinction between the mobilizing capacity (interpersonal ties and relational network) and political capacity (the organization's culture) of the new social movement. These ideas are discussed in the following section.

Capacity Building through Networks, Culture and Trust in the New Social Movements

According to Wood, social capital emphasizes interpersonal ties and relational networks which help to explain the *mobilizing capacity* of an organization. Policy networks, then, are an important aspect of mobilizing capacity. A policy network includes government and social actors in the policy process (Coleman & Skogstad, 1990; Howlett & Ramesh, 1995) and includes a subset of community members who interact on a regular basis, share an information base, and some material interest that encourages or allows regular contact (Howlett & Ramesh, 1995). These networks mobilize a wide range of personal contacts and are crucial to social, political, and economic life (Fukuyama, 1995; Newton, 1997; Putnam, 1993a; 1993b; 1995). As Coleman and Skogstad (1990) note, involving groups in formulating and implementing policy depends upon the network's strength.

In addition to a focus on networks and mobilizing capacity, social capital also considers the *political capacity*, or culture of the organization, required to understand the overall capacity of the new social movement. An organization's culture includes the symbols, language, values, and assumptions that people use to interpret their world (Wood, 1997) and make sense of politics, in order to engage in collective social action. Political capacity includes not only the power to define ourselves, but also to challenge how others define us, particularly how we are defined in social policy. Members of a policy network may "constrain the options available to policy makers and reinforce particular values and beliefs in the policy process" (Coleman & Skogstad, 1990, p. 15). Political capacity within a new social movement and the networks formed create opportunities for people with disabilities to participate as citizens and to collectively define themselves and reject labelling and prescribed identities such as "the disabled". Habermas (1981, 1987) refers to this as the creation of the "lifeworld". The lifeworld provides a space for a group of individuals to develop knowledge and relationships based on self understanding and shared meaning. The lifeworld is essential to experiences of empowerment, self-determination and self-realization.

Related to the idea of mobilizing capacity and political capacity in social movements are the notions of trust and reciprocity. Putnam (1993a) argues that citizens who are highly involved with a dense network will trust each other and are more likely to participate in community and organizing to sanction government (Newton, 1997; Putnam, 1993a). They will treat

each other as fellow citizens rather than as strangers, competitors, or enemies. Trust may take on different forms in the development of social capital. Newton (1997) distinguishes between thin, thick, and abstract forms of trust (see Table 1). Each form of trust is useful for understanding capacity in the new social movement.

Table 1. Types of Trust in the Development of Social Capital

	Thick Trust	Thin Trust	Abstract Trust
Description	• generated by intensive daily contact between people • where there is direct political participation and involvement in decision-making (Newton, 1997)	• associated with looser forms of relationship • where there are overlapping and interlocking networks of voluntary associations	• the foundation of imaginary, empathic, or reflexive communities
Where it develops	• small face-to-face communities (e.g., small isolated communities) • organizations (churches, voluntary associations) • to a lesser extent in consciousness-raising groups, self-help groups and mutual support groups • between an organization and community partners where there is ongoing positive interaction	• when local organizations gather together around some project or issue • between organizations in the new social movement • between organizations in the social movement and other sectors (e.g., government, business)	• in new social movements abstract trust forms between national movements and local mobilizing structures

Thick trust is associated with trust that develops in small, rural communities through intense direct contact, civic participation, and involvement in decision-making (Newton, 1997). To some extent, this form of trust may also be found in non-profit organizations or between two or more non-profit organizations where there is regular contact and interdependence. In comparison, modern society builds upon a form of thin trust associated with looser forms of relationship and interlocking networks or partnerships. Thin trust creates weak ties that are a powerful and enduring foundation for social integration in large modern societies (Newton, 1997). We may envision that thick or thin trust forms between national consumer-driven disability organizations and their local level affiliates. Social movement organizations at the national level provide a foundation for the development of a symbolic affiliation or collective

identity — abstract trust — which provides a different form of social integration and social capital (Minkoff, 1997). Newton notes that abstract trust may be of growing importance as the fragmented, large, complex, fast paced and impersonal nature of modern society makes it difficult to depend on more personal forms of trust. The strength of a social movement relies upon the existence of these three forms of trust (thick, thin, abstract) creating bridges and bonds within and among organizations across the new social movement.

Methods

To examine social capital among consumer-driven disability organizations a questionnaire was sent to the affiliate organizations of the four national consumer-driven disability organizations (CAILC, CCD, NNMH, and PFC). Additional information was drawn from reports and policy documents collected from the four national organizations. These findings emerge from phase two of a three-phase study examining the role national consumer-driven disability organizations play in the non-profit sector in Canada. The purpose of the questionnaire was to develop a picture of the affiliates and their relationship with their national organizations. The list of affiliates was developed with the assistance of staff from the four national organizations (CAILC, CCD, NNMH and PFC). The questionnaire along with a cover letter and stamped return envelope were mailed to the Executive Director or Board President of affiliate organizations of the four national consumer-driven disability organizations. Three weeks later, organizations who had not responded to the survey were again sent the entire package. Individuals from PFC who had not yet responded were also telephoned to remind them about the questionnaire and to advise them that a second questionnaire was being mailed to them. In total, 138 questionnaires were mailed out and 51 (36.96%) were returned.

Participants from organizations were asked to respond to questions about the mission statement and values of the organization; processes or strategies used by the organization to achieve their mission; projects or issues the organization has been involved in during the last two years; and the relationship of the affiliates with their national organization. The questionnaire consisted of Likert scale questions and lists in which individuals were asked to check off items pertaining to their organization. Frequencies and percentages were calculated for check off and Likert scale questions. For Likert items, means and standard deviations were also calculated. Correlations were calculated to explore the relationship between trust and variables such as affiliate perceptions of the national organization's contribution to the disability movement, perceived support received from the national organization, support for the work of the national organization, and the affiliate's similarity of values with national organization. The questionnaire also included open-ended questions that asked the affiliate to provide the organization's mission and value statements and elaborate on responses to scale or check off questions. Responses to open-ended questions were grouped according to major themes. This was done simultaneously by two independent researchers. Results of the independent analyses were compared and differences in the development of themes were resolved. Groups of themes were clustered together. For example, within the mission statements themes corresponding to broad principles were grouped together, as were themes related to the supports provided to consumers, and aspects of the mission statement focusing on broad systemic change.

Results

Networks of National Consumer-Driven Organizations

Important to understanding social capital, specifically mobilizing capacity, is to develop a picture of the networks between national organizations and their affiliates. The networks of the four national organizations extend across the Provinces and Territories of Canada, permeating and making

connections through three levels of organization (national, provincial, local). Response rates from affiliates of the four national organizations are reported in Table 2.

Table 2. Response Rates from Member and Affiliate Organizations

	Number mailed	Number returned	Response rate
Can. Assoc. of Independent Living Centres	22	14	63.6%
Canadian Council on Disabilities	16	9	56.3%
National Network of Mental Health	83	18	21.69%
People First Canada	17	10	58.5%
Totals	138	51	36.96%

CAILC provided direct support to its member independent living resource centres (ILRCs) and other organizations concerned with IL in Canada. CAILC included 22 organizations among its affiliates.**2** The 16 affiliates of CCD included representatives from provincial and national consumer-driven organizations across Canada. While NNMH included 83 affiliates in its original list, the low response rate is explained in part by the different meaning that NNMH places on the notion of "affiliate" compared to the other three groups. An affiliate for NNMH included all groups receiving their newsletter. This looser network of affiliates with more limited knowledge of NNMH may have affected their interest in responding. PFC identified 17 provincial affiliates, which in turn had numerous local or regional groups not included in this study. Local or regional groups of People First were not included as they differed significantly from other affiliates involved in this study. These local organizations are more informal in structure; have a looser affiliation with, and receive no resources from their national organization (PFC); and have weaker ties to the national organization than other affiliates. These organizations are a particularly unique aspect of the consumer movement and warrant further investigation.

Shared Norms and Values Within the Movement?

Examination of ideas expressed in mission and values statements of national and affiliate organizations reflected a shared language and symbols in the new social movement**3**. This contributes to the development of political capacity within the movement. The mission statements for the four national organizations were as follows:

- CCD provides a united voice for consumer-driven disability organizations, and ensures the right of persons with disabilities to be heard in social policy debates (Hutchison et al., 2004).
- CAILC promotes and enables progressive process of citizens with disabilities to take responsibility for the development and management of personal and community resources (CAILC Membership Committee, 2002).
- NNMH works toward a Canadian consumer/survivor community becoming empowered by equality, respect, policy input, informed choice, inclusion, and ownership by mental health consumers (NNMH, 2002, p.13).
- PFC supports people who have been labelled speak for themselves and be heard, and to help them help each other (People First of Canada, 2002).

Affiliates were asked about the development of their mission statement and whether it was influenced by their national organization. Among the responses from 45 organizations, 51.1% (n=23) indicated their mission statement was influenced by the national organization, and a similar proportion of organizations indicated it was not (n=22, 48.9%). However, when asked how similar their organization's values were to those of the national organization (1=not at all, 3=similar, 5=the same), the majority of affiliate organizations indicated their values were very similar (mean = 4.09, SD=.741). Overall, 29.5% (n=13) indicated their values were the same, and 68.2% (n=30) of the affiliates indicated their values were very similar or similar. Only one organization (2.0%) indicated that its mission was only somewhat similar.

Qualitative analysis of mission and value statements of affiliate organizations reveals a coherent set of ideas in keeping with the consumer movement. As described in Table 3, key ideas in the mission statements of affiliate organizations are divided into three main categories: principles, addressing broader systemic issues, and supports provided for consumers.

Table 3. Contents of Mission Statements of Member and Affiliate Organizations

Content of Mission Statements	n (out of 38)	%
Principles		
self determination	12	31.6
inclusion and equal participation	10	26.3
empowerment and self confidence	10	26.3
quality of life	5	13.2
Addressing broader systemic issues		
community education and awareness	8	21.1
advocacy for individuals	4	10.5
network and community capacity	3	7.9
improve legislation and policy	2	5.3
Types of supports		
self help and mutual support	11	28.9
social support/supportive environ.	10	26.3
information and referral	6	15.8
education training and skills	5	13.2
recreation activities	2	5.3
provide economic opportunities	2	5.3

Among the mission statements reported, the most frequently described principles were self-determination, inclusion and equal participation, empowerment and quality of life (see Table 3). Mission statements also included addressing broader systemic issues and creating change through community education and increasing awareness, individual advocacy, and networking. Provision of supports in terms of self help and mutual supports, social supports, and information and referral were the most frequently mentioned supports within mission statements of affiliates.

In addition, 29 affiliates provided information about their organization's values. Qualitative analysis revealed a broad range of value statements. Rights received some emphasis (e.g., rights to equality, respect, dignity). There was a strong emphasis on full and equal participation in community and social support (see Table 4).

Table 4. Frequency of Value Statements Reported by Affiliate

Organizations

	N (out of 29)	%
Full & equal participation in community	14	48.3%
Equality (including right to equality, to equal inclusion)	11	37.9%
Political (citizenship) rights (to make decisions, have choice, vote, representation)	9	31.0%
Right to respect, right to dignity	7	24.1%
Social supports (including friendships and networks, supportive environments)	5	17.2%

Comments received through open-ended questions indicated a shared philosophy or set of values supports the affiliate's ability to work with their national organization. As one individual stated, "our common beliefs, goals and value systems allowed us to provide this program". Another respondent commented, "they come from the same culture, belief and philosophy." Other affiliates noted, "[w]e use the same information and we use the same policy" and "All [our organizations] are based on these values." Similar ideas expressed in mission and value statements of the national and affiliate organizations represent the shared language and symbols that contribute to the development of political capacity, and therefore, to the social capital of the movement.

Information and Resource Exchange Within the Networks

As another aspect of mobilizing capacity, affiliates indicated their national organizations play a strong role in providing information on policy, standards, accountability, referral supports, and serve as a source of knowledge on current research. Results also indicated national organizations play a role in connecting affiliates to information about policies, legislation, and other organizations operating at the provincial level. As indicated in Table 5, more than half of the affiliates describe a *very high* or *high* level of support received from their national organization. Similarly more than half of the affiliates indicated a high or very high level of support for the national organization's work (see Table 5). Again, affiliates noted their ability to work with the national organization is facilitated by the quality of the network including "strong, close relationships with national staff and membership involvement" and positive communication and working relationships. Another respondent noted, "[o]ur organization's support for [our national organization] and our Board's commitment to national disability issues was the deciding factor [in one issue]. There was no question of our involvement if [our national organization]requested it."

The strength of a network also depends on communication between national organizations and their affiliates about the work of each organization, and support provided for their strategies, initiatives and projects. When asked what helped or enabled their organization to work on a project or issue, affiliates indicated it was the national organization's ability to share or provide resources (funding, information, technology, leadership, legal) as required by the affiliates. This was reflected in the following responses:

"They were there when we needed them."**4**.

"If we are in crisis they would come to our support."

"[Our national organization] always is ready to listen and give advice, available for consultation."

Some respondents described the experience affiliates bring to the national organization. As one affiliate stated, "*our* proven experience in working with offenders with disabilities" combined with board leadership enabled then to work on a project with the national organization. Mutuality between the national and affiliate organizations was also reflected by one respondent, "[the national organization is] receptive to suggestions from our organization."

Table 5. Affiliate's Perception of the National Organization

Indicators of affiliate's perception of…	Very High n (%)	High n (%)	Medium n (%)	Low n (%)	Not at all n (%)	No response n (%)	Total n (%)
Support received from the National Organization	23 (45.1%)	7 (13.7%)	5 (9.8%)	2 (3.9%)	5 (9.8%)	9 (17.6%)	51 (100%)
Support for the work of the National	16 (31.4%)	8 (15.7%)	7 (13.7%)	4 (7.8%)	3 (5.9%)	13 (25.5%)	51 (100%)

As indicated in Table 6, affiliates adopted a number of different strategies including those that focus on self-help, developing consumer capacity, and addressing broader systemic issues. A large proportion of affiliates indicated they are involved in building networks among consumers, self advocacy and supporting consumers to have a voice, information and referral services, peer support, public awareness campaigns and community education. Advocacy, individual skill and capacity development, and lobbying government for policy change were also described by a high proportion of organizations (see Table 6). The direct provision of services (e.g., housing, day programs) was described by only 31.4% of the affiliate organizations.

Table 6a. National Organization Support for the Strategies of the Affiliate Organizations: Strategies to Support Individuals

	Affiliate organizations engaged in strategy		Out of the organizations using this strategy					
			National supports "in principle"		National provides financial support		National supports through other resources	
	n	%	n	%	n	%	n	%
Building networks with consumers	48	94.1%	28	58.3%	16	33.3%	13	27.1%
Self advocacy, supporting consumers voices	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%

	n	%	n	%	n	%	n	%
Peer support	43	84.3%	23	53.5%	12	27.9%	15	34.9%
Consumer directed consumer projects	40	78.4%	21	52.5%	10	25.0%	11	27.5%
Individual skill and capacity development	37	72.5%	24	64.9%	12	32.4%	13	35.1%
Direct provision of services (e.g., housing, programs)	16	31.4%	11	68.8%	7	68.8%	6	37.5%
Community (economic) development	25	51.0%	14	56.0%	6	24.0%	5	20.0%

Table 6b. National Organization Support for the Strategies of the Affiliate Organizations: Strategies for Systemic Change

	Affiliate organizations engaged in strategy		Out of the organizations using this strategy					
			National supports "in principle"		National provides financial support		National supports through other resources	
	n	%	n	%	n	%	n	%
Public awareness campaigns/ community education	43	84.3%	27	62.8%	15	34.9%	19	44.2%
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 and conferences for policy development	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%

National organizations were described as supporting the affiliate's projects either directly or indirectly. As one respondents described, "we have support from [our national organization] in what we do and are trying to do." Some form of support from the national organization (financial, other resources, or support in principle) was received by affiliates for their processes and strategies. Respondents were asked to check all that apply to indicate the form of support they receive. Overall, more than half of the affiliates reported receiving support in principle from their national

organization for their strategies (range 52.5% to 68.8%, mean 60.9%) (see Table 6). Results of the study revealed that national organizations provide support to affiliates through funding (conference and travel money, funding initiatives, core funding, skill development, employment programs). In general, a lower proportion of affiliates reported receiving financial support (range 21.6% to 68.8%, mean 33.8%) or receiving support through other resources (range 20.0% to 48.1%, mean 34.4%).

People were asked to identify barriers they experienced working on projects and issues with the national organization. Many respondents indicated a lack of funding and time as barriers. Where connections between affiliates and their national organization were identified as a barrier, references were made to the "time involved, distance to travel", the "availability to meet face-to-face", and delays in receiving information. Poor communication between the national organization and funders, or national organizations and affiliates was also identified. Many barriers to partnerships between national organizations and their affiliates included difficulties in working with government bodies. Some respondents spoke about barriers created by government reporting standards. One respondent stated, "[i]n the past, Human Resources and Development Canada (HRDC) reporting criteria and low funding has stopped us from partnering in their employment program." Others indicated a "difficulty in getting information from government", or that "government was not forthcoming with information and policy changes." The sentiments expressed by consumer-driven disability organizations were reflective of those shared across non-profits as neo-liberal policy shifts took hold in Canada.

Trust Within Networks?

Trust between national organizations and their affiliates is an essential feature to the development of social capital and mobilizing capacity in a new social movement. Overall, affiliate organizations expressed a high level of trust in their national organizations. On a 5 point scale (five being high) the mean score was 3.98 (SD= 1.27). Among respondents to the questionnaire, the greatest proportion indicated a very high or high level of trust in their national organization (n=21, 41.2%; n=9, 17.6% respectively), and 11.8% (n=6) of affiliate organizations indicated a medium level of trust in their national organization. Only 5.9% (n=3) of affiliates indicated a low level of trust in their national organization. Three affiliates (5.9%) indicated they did not have any trust at all in their national organization. Nine (17.6%) affiliates did not respond to this question.

Survey results indicated the affiliate's trust in the national organization was connected to four main qualities: (1) credibility of the national organization, (2) perceived support the national organization has for the affiliate, (3) mutuality of support between national and affiliates, and (4) similarity in values, as noted below.

First, trust was associated with perceived credibility of the national organization. As indicated in Table 7, trust is highly associated with the perceived contribution of the national organization to the disability movement (see Table 7). Results suggest that affiliates perceive the national organization's contribution to the disability movement to be high (mean= 4.20, SD=1.07). Those describing high levels of trust described their national organization with words like: "respect", "professionalism", "integrity" and "credible". Almost eight percent (7.8% of n=4) of the affiliates indicated a medium level of contribution from their national organization, while 9.8% (n=5) indicated a low level of contribution. The national organizations' credibility was closely related to their ability to provide affiliates with leadership (lobbying) and information support around advocacy (e.g., development of position papers). Members also described that trust is related to a dependence on the national organization for funding and advocacy, and provision of quality information. As one

respondent described, "I trust that all information that they supply to us is very important." Another organization noted that "[our national organization] has gained our trust by presenting very well researched position papers. They also lobbied for all people with disabilities in Canada by Latimer, Via Rail, human rights etceteras."

Second, an affiliate's trust in their national organization was strongly related to perceptions of support received from the national (see Table 7), which they deemed to be high (mean=3.95, SD= 1.41). Respondents noted that trust had been built through their interactions with specific national organization staff, often mentioning them by name. Staff persons were described as being "easy to work with", "up-front", and "willing to explore". Affiliates also stated that trust relies on positive communication.

Third, open-ended responses indicated that trust depends on mutual support between affiliates and their national organization (reciprocity). Thus, as in table 7, high levels of trust are also highly correlated with the level of support affiliates provide to the work of the national organization. One respondent described the trust relationship as being mutual, "[c]onfident they support our organization to the greatest extent possible and firmly believe that [our national organization] has placed a similar level of trust in us." Fourth, as indicated in Table 7, affiliate's trust in the national organization is also highly correlated with perceived similarity in values.

Table 7. Relationship of variables related to trust

	f	Mean	SD	Correlations of variables related to trust	
				Pearson Correlation	**Sig. (2 tailed)**
National's contribution to the disability movement	40	4.20	1.07	.829	.000**
Support received from the national organization	41	3.95	1.41	.858	.000**
Support for the work of the national organization	42	3.86	1.26	.811	.000**
Similarity of affiliate's values with national	39	4.07	0.74	.382	.016*

Note. *. Correlation is significant at the 0.05 level (2-tailed)

**. Correlation is significant at the 0.01 level (2-tailed)

Several respondents provided insight into features that challenge trust. One affiliate network consistently described the importance of staff who are recognized members of the consumer movement. Other affiliates indicated a lack of trust based on previous experiences where: the national organization has not supported the affiliate, there has been a lack of communication, or funding delays have been experienced. A lack of knowledge of the national organization was also described as limiting the level of trust the affiliate has for the national. As one respondent notes, "[s]ometimes [we are] unsure as to what [our national organization] is working on and how we could assist. Need clarity on agendas." Diminished trust was also associated with the lack of opportunity to develop relationships with individuals in the national organization. As one individual described, "[it is] hard to say. Board has changed a lot. So we don't know them very well. Connections are hard to make because of their many changes."

Discussion

The success of this new social movement in negotiating the challenging times of the neo-liberal era has been in its ability to develop strong and flexible networks built on different forms of trust and reciprocity; in other words, to build mobilizing and political capacity within the movement. Results of this study of consumer-driven disability organizations create a picture of the ways this new social movement forms social capital and increases the mobilizing and political capacity of the movement. Mobilizing capacity is tied to the creation of networks and information and resource exchange which leads to the development of thick and thin forms of trust described in the literature. Findings from the study reveal trust is enhanced when there is mutual respect and reciprocity between national and affiliate organizations, and when the national organization is viewed as being credible and having integrity, transparency, and a willingness to explore issues and engage in open clear communication. Through relationships built on thick or thin trust, national consumer-driven disability organizations work collectively with affiliates to engage in projects, to mutually support each other's work, and move toward systemic change around issues affecting the lives of consumers.

The results of this study reveal a shared culture and set of values held by national organizations and their affiliates. Political capacity of a movement is advanced when there is similarity in the symbols, values and language, and mutual understanding (Wood, 1997) held by national organizations and their affiliates, and when the network creates spaces and broadens opportunity for the development of a collective identity and promotes a new way of viewing and valuing people with disabilities. The formation of abstract trust, or a collective identity, across the social movement as a whole and the values of consumer-driven approaches that are given expression within the new social movement, act to carve out and define a new space for persons with disabilities and move beyond the labelling and controlling approaches that characterize much of the earlier history of persons with disabilities. As the study reveals, these values include a focus on full and equal participation of persons with disabilities, consumer control, and equality. Within the movement, organizational structure and the way persons with disabilities are involved in discussions, decision-making and the development of policy directions at the grassroots act to further define spaces for people with disabilities.

Consumer-driven disability organizations may also act to promote these values in the spaces beyond the new social movement — to expand the lifeworld — through public awareness campaigns and community education efforts. Further, interaction between organizations in the new social movement and organizations in the broader community act to expand the lifeworld of consumers; that is, positive interactions act to directly expand broader acceptance of that identity. As national consumer-driven disability organizations and their affiliates connect with organizations and partners in other sectors through projects and partnerships, this expands societal understanding of the nature of citizenship and social rights of persons with disabilities and their right to self-determination. The partnerships that consumer-driven disability organizations form with other community organizations requires further investigation for its contribution to the development of social capital and the strength of movement.

Study results also reveal aspects that block or diminish the development of social capital. Limits on trust include a lack of communication and face-to-face contact between national organizations and their affiliates, and high staff or board turnover that occurs within the national organizations resulting in affiliates feeling like they have a lack of knowledge of their national organization. These situations act to limit the establishment of trust, and mutual understanding of the extent to which values are shared. Further limits on trust described by participants are directly linked to the shifts in funding and social policy that occurred with the rise of the neo-liberal era. Affiliate organizations described having difficulty working on projects due to: a lack of government funding, the reporting criteria implemented by government bodies, and a lack of

information received from government bodies around funding and policy change.

From this study several implications arise for policy, future research, and future action within the consumer-driven disability movement. In terms of policy implications, first, the research documents the new social movement's contribution to developing social capital and how values of self-determination, empowerment and inclusion are being mobilized by the movement. From a policy perspective this provides key areas in which investments may be made by government, national social movement organizations and their affiliates to increase social capital and advance the goals of the consumer-driven disability movement. Second, the results of the study indicate how social capital is diminished in the movement through problems in funding, a lack of transparency, and a lack of regularized, face-to face contact between national social movement organizations and their affiliates.

Future study on social capital within this new social movement would benefit from an examination of the ways in which conflict, inevitable in any network, is resolved and how that contributes to or diminishes trust and reciprocity within the network. An analysis of conflict is central to understanding power within a social movement. For example, how do staff and Board members resolve conflict that arises from different values held between organizations? How is conflict resolved when organizational practices do not reflect the values of the new social movement? Essential to understanding a new social movement is not only the coherence of values and ideas expressed within the movement but also the openness to the expression of diversity within the lifeworld. The focus on self-determination necessitates that conflict will arise and as the results of this study indicate, while there is agreement upon a set of core values, there are also other values and approaches expressed (e.g., direct service delivery rather than self-help). For a new social movement to truly address issues of diversity there needs to be increased dialogue around points of conflict and differences in values. The barriers to social capital (i.e., barriers to network formation, or the development of reciprocity and trustworthiness) such as a lack of communication or funding, difficulties with leadership, or differences in organizational practices need to be addressed directly in a way that engages the voices of people with disabilities.

In addition, two main implications for action arise from the study. First, there is a need for the continued presence of the national organizations in the public sphere. When national organizations and their leaders have a sustained presence and credibility it goes a long way to opening up spaces for participation for people with disabilities. It also helps to build trust within the movement. Second, there is a need to advocate for investments to be made by government to enable national social movement organizations and their affiliates to increase social capital and advance the goals of the consumer-driven disability movement (e.g., increased communication, face-to-face meetings, projects involving national organizations and their affiliates). The consumer-driven disability movement has successfully negotiated the neo-liberal shifts of the last decade and to a large extent this is the result of the twinned focus on the political capacity (symbolic or cultural) and mobilizing capacity (information and resources, interpersonal and relational networks) of this new social movement. These will prove to be areas in which investments can help to sustain future success.

References

Arai, S. (1999). *Voluntary associations as spaces for democracy: Towards a critical theory on volunteers*. Unpublished doctoral dissertation. University of Geulph, Guelph, Ontario.

Arai, S. & Reid, D. (2003). Impacts of a Neo-Liberal Policy Shift on Citizenship and the Voluntary Sector: A Policy Delphi with Social Planning Organizations. *Canadian Review of Social Policy, 52*, 67-92.

Bourdieu, P. (1987). What makes a social class? On the theoretical and practical existence of groups. Translated by L.J.D. Wacquant & D. Young. *Berkeley Journal of Sociology, 32*, 1-18.

Bradley, V. J., Ashbaugh & Blaney, B.C. (Eds.). (1994). *Creating individual supports for people with developmental disabilities: A mandate for change at many levels* (pp. 2-32). Baltimore, MD: Paul H. Brookes.

Canadian Association for Independent Living Centres. (1990). *A guide to Independent Living Centres*. Ottawa, ON: Canadian Association of Independent Living Centres.

Canadian Association of Independent Living Centres Membership Committee (2002, May). *Eligibility criteria for CAILC membership*. Ottawa, ON: Author.

Campbell, J., & Oliver, M. (1996). Understanding our past, changing our future. New York: Routledge.

Carling, P (1995). *Return to community: Building support systems for people with psychiatric disabilities*. New York: The Guilford Press.

Coleman, J. (1988). Social capital in the creation of human capital. *American Journal of Sociology, 94* supplement: S95-S120.

Coleman, J. (1990). *Foundations of social theory*. Cambridge, MA: The Belknap Press of Harvard University Press.

Coleman, W. D., & Skogstad, G. (Eds.). (1990). *Policy communities & public policy in Canada: A structural approach*. Mississauga: Copp Clark Pittman.

COPOH. *(1986). Defining the parameters of independent living*. Winnipeg, MB: COPOH.

Council of Canadians with Disabilities. (1995). *A voice of our own*. Winnipeg, MB: Author.

de Jong, G. (1993). Three trends to look for in the American Independent Living movement in the 1990's. In A. Neufeldt (Ed.), *Independent living: An agenda for the '90's* (pp.109-120). Ottawa, ON: Canadian Association for Independent Living Centres.

Edwards, B., & Foley, M. W. (1997). Social capital and the political economy of our discontent. *American Behavioral Scientist, 40*, 669-768.

Enns, H. (1991). Introduction to independent living. *Compass, 2*(9), 1.

Fukuyama, F. (1995). Trust: The social virtues and the creation of prosperity. Toronto, ON: Penguin Books.

Habermas, J. (1981). New social movements. *Telos, 49*, 33-37.

Habermas, J. (1987). *The theory of communicative action. Lifeworld and system: A critique of functionalist reason*. Translated by Thomas McCarthy. Boston, MA: Beacon Press.

Hemingway, J. (2001). What goes around comes around: Teaching for and about social and human capital in leisure studies. *Schole, 16*, 1-13.

Hemingway, J. (2006). Leisure, social capital and civic competence. *Leisure/Loisir, 30*, 329-355.

Howlett, M., & Ramesh, M. (1995). *Studying public policy: Policy cycles and policy subsystems*. Toronto: Oxford University Press.

Hutchison, P., Pedlar, A., Dunn, P., Lord, J. & Arai, S. (2000). Canadian Independent Living Centres: Impact on the Community. *International Journal of Rehabilitation Research, 23*, 2, 61-74.

Kretzman, J. P., & McKnight, J. L. (1997). Mapping community capacity. In M. Minder (Ed.), *Community organizing and community building for health* (pp. 157-172). New Brunswick, NJ: Rutgers University Press.

Lavoie, F., & Stewart, M. (1995). Mutual-aid and support groups: The Canadian context. *Canadian Journal of Community Mental Health, 14* (2), 5-12.

Lord, J., & Hutchison, P. (1996). Living with a disability in Canada: Toward autonomy and integration. In The National Forum on Health (Ed.), *Canada health action: Building on the legacy* (pp. 376-431). Ottawa, ON: Les Editions MultiMondes.

Minkoff, D. (1997). Producing social capital. *American Behavioural Scientist, 40*, 606-619.

National Network for Mental Health (2002). *Consumer/survivor: Leadership* [Brochure]. St. Catharines, ON: Author.

Nelson, G., Lord, J., & Ochocka, J. (2001). *Shifting the paradigm in community mental health*. Toronto, ON: University of Toronto Press.

Newton, K. (1997). Social capital and democracy. *American Behavioral Scientist, 40*, 575-586.

Pedlar, A., Haworth, L., Hutchison, P., Taylor, A., & Dunn, P. (1999). *A textured life: Empowerment and adults with developmental disabilities*. Waterloo, ON: Wilfrid Laurier Press.

People First of Canada. Who we are, what we do. Retrieved August 16, 2002, from http://www.interlog.com/~pfc/pfo/aboutus.html.

Phillips, C. (2002). *Steering your own ship: The growth and development of the Canadian Association of Independent Living Centres*. Unpublished manuscript.

Putnam, R. (1993a). *Making democracy work: Civic traditions in modern Italy*. Princeton, NJ: Princeton University Press.

Putnam, R. (1993b, Spring). The prosperous community: Social capital and public life. *The American Prospect*, 27-40. [Available from: http://epn.org/prospect/13/13putn.html.]

Putnam, R. (1995, December). Tuning in, tuning out: The strange disappearance of social capital in America, *Political Science & Politics*, 664-683.

Putnam, R. (2000). *Bowling alone: The collapse and revival of American community*. New York: Simon & Schuster.

Rappaport, J., Reischl, T., & Zimmerman, M. (1992). Mutual help mechanisms in the empowerment of former mental patients. In D. Saleebey (Ed.). *The strengths perspective in social work practice* (pp. 64-79). New York: Longman.

Rioux, M., Bach, M., & Crawford, C. (1997). Citizenship and people with disabilities in Canada: Towards an elusive ideal. In P. Ramcharan, G. Roberts, G. Grant & J. Borland (Eds.), *Empowerment in everday life: Learning disability* (pp. 204-221). London: Jessica Kingsley Publishers.

Roeher Institute. (1996). *Disability, community and society: Exploring the links*. North York, ON: Author.

Schalock, R. L. (Ed). (1997). *Quality of life, Vol II: Application to persons with disabilities*. Washington, DC: AAMR.

Scotch, R. (1988). Disability as the basis for a social movement: Advocacy and the politics of definition. *Journal of Social Issues, 44*(1), 159-172.

Scott, J. T. (1992). *Voluntary sector in crisis: Canada's changing public philosophy of the state and its impact on voluntary charitable organizations*, Unpublished Ph.D. dissertation. University of Colorado at Denver.

Stake, R. E. (1998). Case studies. In N. K. Denzin & Y. S. Lincoln (Eds.), *Strategies of qualitative inquiry* (pp. 86-109). Thousand Oaks, CA: Sage Publications.

Stake, Robert E. (2005). Qualitative case studies (pp. 443-466). In N.K. Denzin & Y. S. Lincoln (Eds.). *The Sage handbook of qualitative research* (3rd ed.). Thousand Oaks, CA: Sage Publlications.

Valentine, F. (1994). *The Canadian Independent Living Movement: An historical overview*. Ottawa, ON: Canadian Association for Independent Living Centres.

Wood, R. L. (1997). Social capital and political culture. *American Behavioural Scientist*, 40, 595-605.

Endnotes

1. An instrumental case study uses a case to provide insight into an issue, the case plays a supporting role to facilitate understanding of something else (Stake, 1998; 2005); in this study, the case provides insight into the development of social capital among new social movement organizations. Return to Text

2. CAILC now includes 28 organizations among its affiliates. Return to Text

3. Although there can be differences between mission statements and actual organizational practices, the use of mission statements in this study provided an insight into the language and discourse that is being publicly transmitted across the network. The purpose of the study was not to look internal to the organization, but rather across the social networks formed between organizations in this new social movement. Return to Text

4. Statements in quotation marks indicate direct quotes from respondents to open-ended questions. Return to Text

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