



Analysis Paper To HRDC, Social Policy Unit

**Disability Community Capacity:
A Framework For Preliminary Assessment**

May 31st, 2002

Introduction

Disability Community Capacity: A Framework For Preliminary Assessment began on April 1st, 2002 and concluded on May 31st, 2002. This venture was undertaken by the Canadian Centre on Disability Studies (CCDS) for the Social Policy Unit of Human Resources Development Canada. CCDS is a consumer-directed, university-affiliated Centre focusing on research and education in Disability Studies.

The disability community is filled with both strong and effective voices among individuals with disabilities and within organizations. Associations are working in extremely difficult circumstances and are continually being asked for more without being afforded sufficient resources. People with disabilities are living longer and experiencing increasing needs for services and advocacy support resulting in higher demands being placed on the limited resource capacities of organizations. In addition, all levels of government and the private sector are requesting greater organizational participation in consultations on disability issues and policy development to advance the disability agenda. This is not a sustainable situation, and it is a critical time in which to develop support to enhance the capacity of the disability community.

While the last five years have been difficult for all voluntary organizations, the situation has been even more challenging for disability associations because of issues related to the increased costs of inclusion such as ASL interpreters and the need to provide alternate format and plain language materials.

In this paper, we will outline the project purposes, present a definition of community capacity, delineate the methodology and discuss the study findings in detail.

Project Purposes

The Community Capacity qualitative research project provides a preliminary assessment of disability community capacity with the objective of developing:

1. A framework for assessing disability community capacity in terms of possible outcomes and indicators;

2. A qualitative assessment of community capacity within the disability community based on the above-mentioned framework using a convenience sample of disability organizations and individuals.

Definition Of Community Capacity

Community capacity is a broad concept that refers to the ways and means in which things are done within communities. Capacity includes not only skills, people and plans, but also commitment, resources and all dimensions of a process to make it successful. Community capacity building is based on the premise that community sustainability can be improved over time. A community's capacity, or the lack of it, is reflected in the people, economy, environment, culture, attitude and appearance of that community.

For the purposes of this research, HRDC defined "community capacity" as "the extent to which persons with disabilities participate as partners in identifying issues and in the development of policies and programs, both as individuals and through involvement with voluntary organizations representing their interests." Strengthening the capacity of the disability community to participate in this way is essential to achieving the vision of full citizenship. At a later point in the paper, we will suggest changes to this definition recommended by the individuals and organizations we interviewed.

Project Methodology

Deborah Stienstra, CCDS Royal Bank Research Chair and Colleen Watters, CCDS Research Associate, were hired as project staff.

This project was designed in accordance with the document entitled: Societal Outcomes and Indicators in the Federal Report on Disabilities (October 2001) and information from the Voluntary Sector Initiative.

A framework was first developed to assess disability community capacity utilizing the outcomes and indicators outlined in the above-mentioned relevant documents suggested in the HRDC request for proposals. Second, an interview guide was prepared to assess the validity of the preliminary framework. This guide was designed to confirm the suggested outcomes and indicators and make recommendations for changes to the framework. A list of key informant disability organizations was also developed. Comments on the framework, the interview guide and the above-mentioned list were obtained from HRDC prior to the commencement of interviews. The Ethics committee of CCDS reviewed and approved the ethical components of the project. Third, data collection and analysis was undertaken, and this paper outlines the findings and highlights areas for inclusion in the Federal Report on Disabilities.

Following approval of the above-mentioned deliverables, CCDS utilized the key informant list to contact the executive directors or key leaders of at least 15 national and provincial disability organizations in five Canadian Provinces: Alberta, Manitoba, Ontario, Quebec and Nova Scotia. This provided a balance in regional representation (including the Francophone population), and

the Centre had contacts in these locations who assisted us in recruiting participants. CCDS also attempted to achieve equal representation of cross-disability and uni-disability associations involved in both advocacy and service provision with individuals with a wide range of disabilities. (See below for a discussion of the sample).

These interviews determined the extent to which:

- A. Disability organizations and individuals are actively engaged with elected and non-elected officials at all levels of government in policy-making;
- B. Governments are responsive to interventions by community organizations;
- C. Disability organizations have the human and financial resources to identify disability issues, undertake program and policy development and fulfil the expectations of members and their organizational mandates;
- D. Organizations and individuals are involved in employment-related pursuits (including self-employment), the nature of voluntarism among these persons and associations and organizational and individual capacity to respond to societal change.

In addition, data was collected on the extent to which disability organizations were involved in research and knowledge generation to support policy and program developments, and respondents were asked to assist in recruiting citizens with disabilities for the individual portion of the study.

Project personnel also planned to conduct interviews with 15 members of disability organizations and a sample of non-members to assess the extent to which associations are guided by and responsive to the voices of their membership and people with disabilities in general. Unfortunately, due to time constraints and the fact that interviewing began later than expected, only seven individual interviews could be accommodated.

Organizational Sample:

The organizational sample included 11 national disability associations and seven provincial groups in five provinces: Alberta, Manitoba, Ontario, Quebec and Nova Scotia. Table One lists the organizations in the sample, indicates whether they are national or provincial, notes their mandates (e.g. service, advocacy, research, etc.), outlines the population served and the number of organizational or individual members (where available).

Recruiting in Quebec was more difficult because the interview guide was not available in French due to time constraints. In addition, interviews conducted in French would have required additional time and resources. As a consequence, only one Quebec organization was included in the sample. Three additional national groups and one provincial one were approached but were not interviewed due to time constraints or their executive directors or presidents indicated they did not have the time to participate. Two other organizations did not respond to the request for interviews.



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Table One: Organizational Characteristics

Organization	Scope	Location	Founded	Mandate	Constituency Served	Size
Canadian Association for Community Living	National	Toronto	1958	Service and support	Families of persons labeled intellectually disabled	40,000+ members/12 provincial & territorial associations
Canadian Association of the Deaf	National	Ottawa	1948	Advocacy	Persons who are deaf	?
Canadian Association of Independent Living Centres	National	Ottawa	1985	Service, based on Independent Living model	Cross-disability population	24 affiliate centres
Canadian Hard of Hearing Association	National	Ottawa	1982	Advocacy	People with hearing loss	48 branches, 8 provincial chapters, 2200 members
Canadian Paraplegic Association	National	Ottawa	1945	Service and advocacy	Persons with spinal cord injuries	Over 30,000 members
Council of Canadians with Disabilities	National	Winnipeg	1976	Advocacy	Cross-disability population	14 member organizations
Learning Disabilities Association of Canada	National	Ottawa	1971	Advocacy	Persons with learning disabilities	10,000 members
National Educational Association of Disabled Students	National	Ottawa	1986	Advocacy and research	Students with disabilities (cross-disability population)	1200 members

Organization	Scope	Location	Founded	Mandate	Constituency Served	Size
People First of Canada	National	Winnipeg	1991	Advocacy	Persons labeled intellectually disabled	?
Roeher Institute	National	Toronto	1970	Research on inclusion and education	Cross-disability population	N/A
Neil Squire Foundation	National	Burnaby, BC	1984	Service and research on assistive technology	Persons with physical disabilities	N/A
Alberta Association for Community Living	Provincial	Edmonton	?	Advocacy and support	Families of persons with intellectual disabilities	40 member organizations
Alberta Committee of Citizens with Disabilities	Provincial	Edmonton	1973	Advocacy	Cross-disability	?
People United for Self-Help (North-West)	Provincial	Thunder Bay	?	Advocacy	Cross-disability	?
International Network for the Disability Creation Process	Regional	Quebec City	?	Knowledge generation and research, human rights, advocacy	Cross-disability population	100 members
Network for Entrepreneurs with Disabilities	Provincial	Halifax	1995	Service and business-related supports	Entrepreneurs and potential entrepreneurs	?
Assembly of Manitoba Chiefs (Disability Program)	Provincial	Winnipeg	1992	Advocacy	First Nations people with disabilities	N/A
Aboriginal	Provincial	Edmonton	?	Service	Cross-disability	?

Organization	Scope	Location	Founded	Mandate	Constituency Served	Size
Disability Society of Alberta						



Organizational Findings

Interviews took place between April 25 and May 10, 2002 and included the opportunity to meet with several of the national disability associations in Ottawa in conjunction with a consultation meeting facilitated by the Council of Canadians with Disabilities (CCD). The findings of the organizational interviews are set out below.

Organizational Mandate/Mission:

Executive directors and key leaders were asked whether their respective organizations had made any recent changes to their mandates or missions and whether modifications were planned in the near future. Of the 18 associations in the sample, ten indicated there had been no recent changes in their mandates with none being contemplated. Of the remaining eight groups, three national bodies and five provincial ones noted they had revisited their mission statements to make wording changes, to embark on a strategic planning process and to clarify future visions. One national service provider is attempting to broaden its outreach efforts to encompass individuals with a wider range of disabilities which will involve obtaining increased monetary resources to support a broader constituency. Within the provincial realm, one group expanded its focus from knowledge development that promotes social change to include advocacy and disability rights. As a consequence, funding opportunities were enhanced. A provincial group serving Aboriginal and First Nations people with disabilities said that they planned to combine their resources with another association resulting in a broader mandate with increased services. Since the details are still being worked out, she could not provide specifics at this time.

Involvement With Elected And Non-Elected Officials:

Ten national bodies and six provincial organizations stated they had been involved in various ways with elected officials at the federal and provincial levels over the past year. Two national uni-disability groups indicated minimal involvement citing time constraints as the main factor limiting participation, while a third mentioned her group participated on an as-needed basis. One national service provision and advocacy association was involved at the federal level but organizational affiliates at the provincial level participated to an even greater extent. Although this would seem to suggest more frequent involvement on the part of provincial affiliates, since only one interview cited this finding, it is impossible to draw firm conclusions.

Participation at both provincial and federal levels was fairly uniform, and organizational mandate and uni-disability versus cross-disability constituency did not significantly affect the nature of involvement. Of the two organizations indicating they did not work with elected officials, one provincial group stated the association's need to focus on its mandate of service provision

precluded participation in the political arena, while the other (an advocacy body) noted they supported the efforts of a national disability advocacy group to get involved at the political level.

The types of involvements were numerous and the scope of issues wide ranging. Associations were involved in letter writing, preparing briefs or attending meetings with provincial and federal ministers of health, education, employment, social services, Human Resources Development and transportation. Some organizations fostered individual relationships with specific parties, caucuses or political officials, presented to parliamentary committees and participated in Federal/Provincial/Territorial Working Groups. The working group on Benefits and Services is an example of this type of involvement. Participation in reference groups and advisory committees on disability issues through various government departments were also noted. Examples included: The Human Resources Development Canada Sub-Committee on Disability, reference groups on various aspects of disability, the Advisory Committee on Accessible Transportation through Transport Canada and consultations and round tables on a variety of topics.

Coalitions were another common strategy utilized by groups working with elected and non-elected officials. Examples included: the Alberta Disabilities Forum and the coalition formed in Manitoba to work on the advancement of the disability agenda being implemented through the Department of Family Services and Housing.

Groups were involved in a myriad of issues. These included: the Disability Tax Credit, CPP Disability Benefits, employment for people with disabilities, disability supports, a health sector study on home care, accessible transportation, etc. Groups also participated in sessions to develop consultation mechanisms to advance the disability agenda.

All associations worked with non-elected officials on a variety of issues as noted above. Involvements took the form of correspondence with government officials, preparation of briefs, attending meetings, consultations or round tables and ongoing contact through telephone conversations. As was the case with elected officials, involvement with non-elected individuals within government at both provincial and federal levels was fairly uniform, and organizational mandate and uni-disability versus cross-disability constituency did not significantly affect the nature of participation.

For the most part, participants said responses from elected and non-elected officials were positive. They noted the common understanding of disability issues achieved as a consequence of discussions, a willingness to work with disability organizations to move the agenda forward, particularly at the provincial level, and, in a couple of cases, groups received assistance in resolving organizational issues or influencing the provincial agenda by lessening the impact of funding cutbacks on persons with disabilities. Also mentioned were "thank you for your input" responses and situations where no replies to correspondence were received.

Two organizations (one national and the other provincial) indicated the response from elected and non-elected officials was poor. One national body noted that, at the federal level, there has been little movement to advance the policy agenda to the point where erosion of programs and services is taking place and it is necessary to fight to maintain the status quo.

We were fighting battles of maintenance, but now we are seeing an erosion of programs and services and supports. We are fighting cuts around the Disability Tax Credit, the CPP Disability Benefits and erosion of transportation access. Accessible systems are being replaced with inaccessible systems, particularly in smaller communities. (Quote from Executive Director of national cross-disability advocacy body).

Although statements such as the above were not a central theme of the interviews, they indicate frustration with the slowness of the advancement of the federal disability agenda at the political level and the sense of discouragement which comes from years of advocacy, resource limitations and the need to juggle priorities to fulfill organizational mandates within the political sphere and in other types of policy work.

The Coordinator of a provincial cross-disability organization expressed the same frustration with the pace of progress on the provincial disability agenda at the political level. She stated that the government does what it wants because it has the power, and every now and then it consults with the organization. Funding cutbacks are occurring in income and support programs, with the consequence that people with disabilities are living below the poverty line. Gains have occurred, but these have been few and far between, such as a small amount of additional money for income support.

One national respondent noted that to move the disability agenda forward, it is necessary to develop the leadership within the disability community to target key political officials and apply public pressure to bring about political will. Although this was mentioned by one interviewee, the strategy has merit and is worthy of further consideration.

Financial And Human Resources Capacity:

Not surprisingly, only one out of the 18 organizations in the sample (this was a provincial body) indicated it had the financial and human resources capacity to undertake its mandate related to policy development. The remainder noted their capacities were limited and either staying the same or diminishing and that stable, multi-year sources of funding were unavailable.

Financial Capacity of Federal Organizations:

At the national level, eight associations reported they received core grants on a yearly basis from the Social Development Partnerships Fund of HRDC and supplemented those with project funding from a variety of sources, membership fees, research ventures (where applicable) and fund raising, such as donations, direct mail campaigns, publication sales, etc. The portion of the budget covered through the core grant varied depending upon the organization, and, in many cases, interviewees did not provide percentages. Those who did said the core grant was between 1/3-1/5 of the total budget. Social Development Partnership funding has been frozen since 1997, and associations must re-apply on a yearly basis.

Two of the above-mentioned national bodies indicated their situations were better. One had a fairly significant project from the Opportunities Fund while the other received support from two separate HRDC sources (the Social Development Partnerships Program and the Inclusion Fund) because of its mandate to provide advocacy support to persons who had been labelled intellectually disabled. In another case, the national body also received funding through assessment fees from its affiliates. Two other national groups obtained primary funding from government contracts and research projects respectively. A national service-provider and its affiliates operated on a federated model where, in addition to several core grants, they received assessment fees from the provinces and undertook corporate fund raising. The respondent noted the relationships with their funders were good and, although the amount received from the Opportunities Fund had been reduced, they were in a better situation financially than many other organizations. Because this uni-disability body provided services within the rehabilitation sphere, this widened the variety of available funding opportunities, as many funding sources are more likely to support rehabilitation-based and service provision groups than advocacy associations.

Some organizations had attempted to diversify their funding base, but they encountered fierce competition and funders whose criteria did not fit well with organizational mandates.

Interviewees reported that project grants have become harder to obtain. They cited a variety of sources through this type of funding was obtained. Examples included: Social Development Partnerships Program of HRDC, Opportunities Fund (which is renewed yearly) Status of Women Canada, the Office of Learning Technologies, as well as other government departments.

Table Two lists both the sources of core and non-core funding received by organizations in the sample.

Table Two: Core And Non-Core Sources of Funding

Organization	Core Funding	Other Funding Sources
Organization 1	Federal government	Assessment fees from affiliates, project grants
Organization 2	HRDC Social Development Partnership Program	Projects, direct mail campaigns, membership fees
Organization 3	Office for Disability Issues, Social Development Partnerships Fund, Opportunities Fund	Project funding, assessment fees from affiliates
Organization 4	ODI Social Partnerships Program	Project funding, a legal association, membership fees
Organization 5	ODI Social Partnerships Program	Membership fees from affiliates, donations from the community and corporations

Organization	Core Funding	Other Funding Sources
Organization 6	ODI Social Development Partnerships Program	Project funding (mostly HRDC), donations from the community, publication sales
Organization 7	Canadian International Development Agency	Contract funding, project funding
Organization 8	Contractual funding through Opportunities Fund	Provincial governments, research grants (e.g. CIHR and other peer-reviewed competitions)
Organization 9	HRDC Social Partnership Program	Project funding from Social Development Partnerships Program, Office of Learning Technologies, Trillium Foundation
Organization 10	Social Development Partnerships Program, Community Inclusion Fund (HRDC)	Donations, membership fees
Organization 11	Opportunities Fund (provincial affiliates have provincial government funding), other funders not specified	Assessment fees from affiliates, project funding
Organization 12	Provincial government	Revenues from non-profit business, membership fees, donations, project funding
Organization 13	Federal and provincial governments	Project grants from federal government (e.g Status of Women Canada), membership fees, fundraising, community events (e.g. hockey games)
Organization 14	No	Civic, donations, community events, others not specified
Organization 15	No	Training contracts with government, provincial grant, research projects, membership and conference fees
Organization 16	Atlantic Canada Opportunities Agency	Project funding
Organization 17	Federal department of Indian Affairs, Health Canada, HRDC, provincial government	Project funding

Organization	Core Funding	Other Funding Sources
Organization 18	Federal department of Indian Affairs	Not specified

Human Resource Implications For National Groups:

Participants outlined the implications of the current unstable funding climate on the financial and human resources capacities of their organizations. The core grants did not cover all the overhead costs and some project funds were not designed to support administrative expenses, which resulted in associations being squeezed. Costs continued to rise and, with Social Development Partnership funding remaining frozen, organizations were forced to cut back on services, lay off staff or reduce operational expenditures.

Many of the national bodies outlined the increased operational costs given that their affiliate and member groups are located in different parts of the country. Meeting expenditures were also going up and, although conference calls and electronic communications had to some extent replaced face to face meetings, this presented difficulties for individuals with various types of disabilities (e.g. those who have been labelled intellectually disabled or are deaf) and communicate more effectively within in-person settings. Respondents also reported expenses associated with being multi-lingual and employing sign language interpreters. Maintaining a national office in Ottawa was also felt to be more costly. Project and contract funding was more difficult to obtain, and donations from corporations, third party sources and other fund raising efforts had decreased.

With respect to human resources, CCDS was impressed with the dedication and quality of staff and the amount accomplished within a very unstable funding climate. Many of the groups noted that committed cadres of volunteers supplemented the work carried out by staff and played vital roles in the ongoing work of the organizations. Depending upon the group, the number of staff ranged from two to 14 and fluctuated depending upon the number of projects in progress at any given time. Personnel worked long hours, often at wages which were non- competitive with the private sector and felt pressured, over-worked and burned out. They spent inordinate amounts of time scrambling for dollars to the detriment of their day to day work and taking on short-term projects to make up funding shortfalls.

Several national groups addressed the difficulties inherent in paying staff and the issue of staff reductions. One respondent noted that the financial aspects of his organization were "an ongoing traumatic struggle" and that there had been major staff cuts over the past couple of years to the point that the amount spent on salaries had been reduced by one-third. He also mentioned that, at times, he was forced to pay existing personnel despite revenue reductions because of their long-term services and the regulations of labour standards. Another national body laid off two employees within the last year so that a greater portion of their core funding from HRDC could be devoted to supporting its members and undertaking litigation work. A third group noted that a long-term staff person was about to retire, and the association could not begin to think about replacing her because they could not pay competitive wages. Still another body mentioned that

HRDC was behind on its core grant and project payments and that she would not be able to make payroll unless she got her funding soon.

One participant summed up the situation this way:

It makes it difficult to plan; it makes it difficult to make commitments to people who have mortgages or who have rents, who have children. It makes it difficult to bring people on staff to do work that you want to do. And in the event that you have to let people go, you still have to comply with labour standards, you can't just stop paying them, if they've been with the organization for quite a while, you've got to continue paying. So it's one of significant difficulty and the kind of reporting and accountability regime that we're now living in takes up a disproportionate amount of everyone's time, just to comply with that...I understand the need for accountability and to show results for public dollars, but it's really a difficult and not very pleasant situation that we're dealing with. (Quote from an Executive Director of a national organization).

The majority of participants reported organizational capacities had diminished or stayed the same over the past year, and one individual said this was partially due to the Canada Health and Social Transfer Payments and the funding crisis at HRDC. Others attributed it to the funding climate as a whole. Most outlined how diminished capacities compromised and restricted their abilities to carry out their mandates in advocacy, research and service provision and to effectively communicate with members and constituents on a regular basis.

All respondents at the national level emphasized the need for disability organizations to receive multi-year stable funding primarily from various levels of government. Some government departments currently provide multi-year support, (CIDA and Status of Women Canada were noted as examples), and interviewees recommended that a process of providing multi-year funding to disability organizations should be implemented by HRDC. CIDA and HRDC were mentioned as viable sources of multi-year funding to support the work of disability associations. Interviewees stated that disability organizations require funding for development and consultation work, and research (which are currently unavailable or very unstable) and respondents recommended that one pot of money be designated within governments for ongoing operational costs, another for development and consultation work, and a third for research to advance the disability agenda within Canada.

Financial and Human Resource Capacities of Provincial Groups:

Provincial groups faced similar situations to national bodies. Four of the seven provincial organizations in the sample received core funding from a variety of sources while three did not. (See Table Two.) Of those which did, one offered advocacy support to families of those who have been labelled intellectually disabled, while the other provided support to entrepreneurs with disabilities. The remaining two were groups meeting the needs of First Nations and Aboriginal peoples. Due to the small sample size, firm conclusions on the above-mentioned point should not be drawn. However, based on the statements of interviewees, it would seem that funders are more willing to support service-related rather than advocacy organizations and those serving

specific disability or population groups such as families and Aboriginal and First Nations peoples.

Funding sources for provincial organizations were varied (see Table Two). They included: Federal government grants such as HRDC or Status of Women Canada, provincial support, grants from their national affiliates, projects, research ventures, training, corporate and civic funding, third party fund raising, community events such as bingos or walk-a-thons, donations, memberships and, in one case, profits from an organizational business. One group was funded by a federal-provincial cooperation agreement, but this has now expired, so staff and volunteers were formulating new partnerships to locate new sources of revenue. The two associations meeting the needs of aboriginal people with disabilities received core funding from Indian Affairs and supplemented this with funds from other sources which, in one case, included research projects. One of these associations was in danger of losing its support for 2002, but luckily funding was restored for this year.

Provincial groups faced similar situations to national groups in terms of the lack of financial stability and diminished human resources capacity, and groups indicated they required stable, multi-year sources of funding. Only one association reported that it currently had stable sources of support and that about 65 percent of their budget came from membership fees, fund raising by third party sources or through community events. Revenue from the federal and provincial governments and its national affiliate made up the rest. The responding CEO reported that her organization's capacity had remained the same over the last several years.

Organizational Partnerships:

Organizations reported involvement with numerous partnerships for a variety of purposes. Ten of eleven national groups noted that their affiliate chapters, member associations or individual board representatives across the country partnered with them to work on disability issues at federal and provincial levels and to facilitate communication and information-sharing. The remaining group focused on research-related activities so formed partnerships to undertake specific contracts or projects. In addition, provincial bodies were involved in partnership building. No significant differences were found between the abilities of advocacy, service or research groups to formulate collaborative relationships.

Disability organizations also collaborated among themselves, with other equality-seeking groups and with governments to work on issues around the disability policy agenda and to advocate for change. For example, the Council of Canadians with Disabilities recently convened a consultation of national disability organizations on the development of future directions for the disability agenda. Partnerships were also formed to undertake projects, apply for joint funding or facilitate research.

Besides collaborations within the disability community, respondents also noted joint ventures with governments, organizations within the voluntary sector, corporations, businesses, the banking industry, service clubs and with academics or universities. Sub-contracting was also described as a partnership by one respondent.

By way of illustration, the National Educational Association of Disabled Students is partnering with the Canadian Centre on Disability Studies and HRDC on a transition from school to work project with students with disabilities and the Roeher Institute is undertaking a project with the Universal Design Institute (University of Manitoba) and a corporation. The Canadian Association for Community Living, the Council of Canadians with Disabilities (among others) are collaborating on a voluntary sector venture around the theme of community capacity of individuals and organizations with disabilities.

The types of partnerships described above bring both challenges and opportunities. If partnerships are solid, those involved can build on their collective strengths to make the collaboration successful and effectively accomplish their objectives. One person mentioned the opportunities to build partnerships between political leaders, governments, the disability community, the private sector and others arising out of the follow-up discussions around the "In Unison" documents, providing that sufficient resources could be mobilized to create an effective collaboration. Participants also stated that, in many instances, initiatives are more effectively accomplished in partnership than if organizations were to work alone.

However, numerous challenges to building effective partnerships were identified. Partnerships are difficult to build within a competitive financial environment and must be carefully cultivated. Prior to launching the relationship, all parties must be aware of the issues of concern to the disability organizations involved, and negotiate common philosophical principles, agendas and strategies for moving the relationships and the work forward. Some groups stated they are sometimes reluctant to enter into collaborations of this type because they fear that potential partners from the non-disability sectors would not understand their issues, and it would take much work to bring the partners on side. Geographic distances can also make partnership building more challenging.

Although partnerships can be formulated to mobilize additional human and financial resources, it is difficult to cultivate and nurture partnerships in a climate where these resources are limited and time is at a premium. According to the majority of those in the sample, it would appear that, in order to embark on partnership building, that core resources are required to enable organizations to move beyond the survival mode to a point where they can work on resource development. One respondent noted that within this type of milieu, disability organizations have become increasingly isolated from the broader community and, with an insufficient resource base and diminishing capacities, it is challenging to cultivate and grow long-term sustaining partnerships. Interviewees also pointed out the absence of development funding to initiate these types of relationships.

Media Releases:

Organizations were asked how many media releases they had issued in the past year and how many of these releases had resulted in stories. Of the 11 national associations in the sample, seven indicated they had issued media releases in the past year while four did not. Of those which did, five put out less than half a dozen releases while the remaining two national groups

produced 12 and 36 respectively. The organization reporting the largest number of releases was a national, uni-disability service provider with affiliates in every province and territory, with the majority of releases being developed at the provincial level.

Four national organizations had not produced any media releases in the past year for a variety of reasons. One respondent felt that the question was not particularly applicable to his group because of its research mandate). One respondent indicated his organization was working on a media strategy plan with the help of a member of his board. The remaining two participants mentioned that their organization supported the work undertaken by a national advocacy group rather than embarking on their own releases. Both interviewees anticipated greater involvement with the media in the future. Of the seven national bodies who produced media releases, five indicated whether or not these efforts had resulted in media stories, with three responding in the affirmative and two in the negative.

At the provincial level, five of the seven groups had issued media releases in the past year. Three associations released less than half a dozen, one reported 12 and a third 15. All five provincial groups received at least some media coverage. The organization that had produced the most media releases (15) noted that all of them resulted in stories. This may be partially because their offices were housed in a small city with fewer media outlets and where this group experienced a higher profile. The interviewee also indicated that her organization provided excellent background information to the media. Two service providers opted to spend their time meeting the needs of their constituents rather than getting involved with the media. Service providing organizations which do not include advocacy work as part of their mandates have fewer reasons to approach the media to bring prominent issues to the attention of the public in an attempt to bring about needed changes.

Media stories covered a wide range of topics. Some profiled organizational work, such as a project or newly released report, while other stories were of a local, provincial or national nature. For example, one interviewee mentioned articles about the Disability Tax Credit, new reproductive technologies, deaf culture, a recent accessibility challenge surrounding railway cars which had made it to court, and a couple who had chosen to end the life of their adult child. Other associations were asked to react to already existing stories or issues such as cutbacks to services for students in British Columbia, or a deaf lesbian couple who wanted to have a deaf child.

Although the media can enhance awareness of disability issues, there is the possibility that issues or stories can be misinterpreted resulting in the depiction of incorrect images of disability. Some interviewees expressed the view that, despite the advantages of media releases, these documents take time and energy to produce in associations where monetary and human resources are often stretched to the limit and where returns can be minimal.

Good Quality Information About Disability:

Disability organizations require good-quality information about disability policies, services, statistics, etc. to carry out their mandates. For those involved in service provision, this type of information is essential in developing priorities and supporting the need for additional funding to cover service provision activities. Good-quality information informs advocacy work, and researchers require up to date materials on which to build further work.

Three organizations in the sample stated that acquiring good quality information about disability-related issues was no problem and that groups were more than willing to share what they had. In contrast, another interviewee pointed out that information exchange between disability groups is not that effective, particularly when it comes to filtering the material down to consumers. One individual noted that it was difficult to know where to look for information, particularly when in a hurry while another finds she does not have sufficient time to read the breadth of reports and other printed material she receives in the mail. One respondent noted that one of her staff is particularly adept at interpreting documents and applying the material to organizational requirements. Other participants indicated whether good-quality information was available largely depended on the specific issues and what data sources were being tapped. The Roehrer Institute was mentioned as an excellent source of information.

A frequent concern identified by national and provincial advocacy organizations and researchers, was the difficulty obtaining relevant government-related information in a timely manner and keeping abreast of constant policy developments, in light of regional differences in programs and services from department to department and at federal, provincial and territorial levels. Mechanisms need to be put in place for tracking this type of policy data and ensuring it is disseminated to those requesting it. This would be a viable project for a disability organization to undertake if funding could be located.

Researchers and national advocacy groups mentioned that it was particularly difficult to obtain good quality and up to date statistical information about disability, data on the economics of disability, cost-benefit analysis, labour market dynamics, disability supports, etc. The disability statistics which do exist (such as the "Health and Activity Limitation Survey") are extremely out of date, and one person noted that some types of Statistics Canada information (particularly on the labour market) could only be obtained by special request. These factors present barriers for those undertaking disability research or seeking materials to support recommendations for policy change.

Those who are deaf or who have been labelled intellectually disabled experience information-related challenges of a different type. A representative of an organization of the deaf noted he received a wealth of documentation on disability from government and non-government sources. However, a large portion of the membership have low literacy levels in English or French and would not be able to comprehend the above-mentioned materials. The organization lacks the financial and human resources to translate these documents into American Sign Language, LSQ (the sign language utilized in Quebec) and French, with the result that the members do not have access to relevant and up-to-date information. Additional monetary resources from HRDC were suggested as a solution to this issue.

Those who have been labelled intellectually disabled require information in plain language, as well as materials in large print or on cassette, as some individuals need large print or cannot read print. Although material is obtainable in alternate formats, in some cases it is outdated or made available after the fact. The group in question does not possess the human and financial resources to re-write documents in plain language. Governments, disability organizations and others must be made aware of this fact and produce reports understandable by people with a wide range of abilities, but additional resources are required to make this a reality.

Response of Clients/Members To Organizational Mandates:

Interviewees raised a variety of points with respect to client/member response to the ability of organizations to carry out their mandates and plans to address clients'/members' concerns. In the majority of situations (with the exception of four groups) organizations had not conducted formal surveys of their members or constituents, but utilized informal sources of feedback, symposia, annual general meetings, newsletters and websites to solicit opinions. The majority of participants stated their members/clients were satisfied with the ability of groups to carry out their mandates but wished that more could be done in terms of advocacy or service provision. One national body which operates within a federated model and whose members pay national assessment fees is currently clarifying the roles of the national association and its provincial affiliates in terms of structure and how the various entities can more work together more effectively.

Organizations identified several areas for improvement noted by members/constituents. A sampling includes the following:

(1) When they call, clients would prefer to talk to staff rather than voice mail, and many of them had difficulties pushing the correct extensions due to the nature of disabilities.

(2) The access to information difficulties noted in the previous section with respect to those who are deaf or who have been labelled "intellectually disabled".

(3) Communication difficulties posed by geographic distances and insufficient resources were important issues, particularly for national service providers and advocacy organizations. One organization noted plans to apply for funding to develop an independent living think tank to assist in addressing information gaps experienced by their affiliates.

(4) The need for additional information about specific disabilities. Groups are attempting within their current resource base, to develop communication strategies and strengthen networks to address these gaps.

(5) The need to move forward on the development of a national agenda on disability supports, a labour market strategy and to strengthen relationships with the federal government to address disparities in service across the country. A recent consultation of national disability groups was held to initiate discussion on these issues. Additional government resources are required so the consultation process can continue.

(6) To address the need for leadership development within the disability community, one organization initiated a project where current leaders are being matched with those wishing to develop leadership skills. This will ensure that new leaders have the abilities to assume

responsibilities within the organization and to replace those wishing to step down from prominent positions.

(7) Organizations are not visible enough within society, and strategies should be developed to raise their profiles.

(8) Organizations need to increase efforts to communicate the benefits of organizational involvement to members and encourage them to participate.

Opportunities For Organizations of Aboriginal People to Work With The National Assembly To Advance Aboriginal Issues:

The two Aboriginal organizations surveyed indicated that working with the Assembly of First Nations would strengthen their efforts to raise the issues that concern Aboriginal people with disabilities among governments, and help to advance policies for Aboriginal people with disabilities. There is a greater need for governments to deal with issues of concern to aboriginal persons with disabilities through a bi-lateral rather than a pan-aboriginal process. This means that, rather than bringing all the groups of aboriginal people together, First Nations, Inuit and Metis people should meet separately with governments because these groups have separate agendas.

Disability Research:

With the exception of two organizations, (one each at the national and provincial levels), those surveyed indicated their groups were involved in disability-related research. With the exception of one national association whose mandate related entirely to research, groups generally applied for research funding to fulfil those parts of their mandates dealing with research, to inform their work in service provision and advocacy and to overcome shortfalls in core funding.

The interviews did not deal in any great detail with the differences in the research activities of federal/provincial groups and service/advocacy bodies. Further in-depth interviews would need to be carried out to glean further information in this area.

Respondents reported that the research conducted by their organizations was primarily based on the social model of disability, with most of the projects being qualitative in nature. Some, however, related to quantitative aspects while others were a combination of the two. Topics were wide ranging, and examples included the following: children, families and disability, the ability of employers to hire persons with disabilities, entrepreneurship and disability, independent living, violence and women with disabilities, the economics of learning disabilities, the accommodation needs of those with intellectual disabilities, research related to the needs of post-secondary students with disabilities, social supports, income security, the psycho-social aspects of disability, rights and inclusion research, disability and literacy technology, the ethics of disability, disability-related costs and various types of policy research.

Only a few organizations said their research was conducted in-house, with the remainder indicating they hired individuals and/or contracted out to other groups such as the Roehner

Institute, the Caledon Institute or private consultants. Not all participants addressed the qualifications of those conducting the research. Those who did mentioned that researchers were trained consultants and that they possessed good verbal, written, proposal writing and statistical skills.

Associations stated they formed research partnerships with disability and non-disability organizations, various government departments, the business, banking and corporate sectors, voluntary groups and, less frequently with universities and colleges. Where collaborations involved the academic sector, it was usually the academics who applied for and received the research funds, although less than half a dozen organizations indicated they conducted research with universities. This was because the majority of this research did not fit well with organizational mandates and because the associations in question were not eligible to apply for funding from sources such as SSHRC.

Participants reported that the majority of their research was funded through projects or federal and provincial governments (most notably Human Resources Development Canada), but also through Status of Women Canada and the Office of Learning Technologies. Other funders were business and industries, civic sources and foundations (although this was minimal) and academic sources such as SSHRC. As mentioned earlier, less than half a dozen groups collaborated with academics and universities. In these cases, it was most often the universities or individual researchers associated with disability groups who applied for the grants because the community associations did not qualify. Obtaining support for academic research is difficult because these funders do not understand the value of disability research that embraces the social model of disability rather than medical or rehabilitation paradigms and because the work done by researchers within community groups is not fully recognized by their academic institutions. This is problematic for disability associations seeking new sources of funding to support their work and to foster and strengthen research partnerships with universities and colleges. In addition, national disability organizations have begun discussions on the development of a national agenda for disability research. This includes emphasizing to elected and non-elected officials the importance of Social Sciences and Humanities Research Council (SSHRC) and Canadian Institutes for Health Research (CIHR) funding for Disability Studies research based on a social model of disability.

In terms of successful and unsuccessful research applications, one respondent indicated that, over the last year or so, only one in ten applications had been turned down, while another person told us that, of the four proposals currently under consideration by funders, he had received a definite commitment on one of them. Another group said three of four had been successful, while the majority of others stated they had not had a proposal turned down in the last couple of years. We believe that the number of successful and unsuccessful applications to academic institutions are not reflected here because the respondents were not the primary applicants and may have been unaware of the status of these proposals or forgotten about the collaborations.

What can be concluded from the foregoing discussion is that HRDC would appear to be one of the primary funders of disability research in Canada and that there is currently no stable funding base for this type of research. Organizations are constantly scrambling for funding and, in many

cases, competing for research dollars. Furthermore, many groups are ineligible for financing from academic related sources.

The Council of Canadians with Disabilities (CCD) convened a consultation of national disability organizations in Ottawa from May 25th to 28th, 2002. The event was made possible through the support of HRDC and CCDS, and a half-day session was devoted to disability research and a discussion of strategies to move forward on a national research agenda. The organizations reaffirmed the need for this type of agenda and that ongoing consultations are necessary to share information between groups and to identify research priorities. Participants noted that it will be impossible to carry out research unless there are stable, strategic and consistent sources of funding for this work. It was recommended that Office for Disability Issues create a separate pool of money to support disability research within government, or designated funds should be set aside outside government. Organizations also noted that Disability Studies research based on a social model of disability should be given greater priority within the Canadian Institutes for Health Research (CIHR) and the Social Sciences and Humanities Research Council (SSHRC) and the need to bring this to the attention of elected and non-elected officials.

Community Capacity:

In this research, HRDC defined "community capacity" as "the extent to which persons with disabilities participate as partners in identifying issues and in the development of policies and programs, both as individuals and through involvement with voluntary organizations representing their interests". 11 of 18 organizations were comfortable with this definition, while the remaining seven groups suggested changes. Proposed modifications included the following:

(1) "Community capacity is about enabling the informational, human resource, financial, organizational capacities of various sectors in the community to deliver on the human rights agenda." (Quote from Executive Director of national disability association.) (Permission pending).

(2) The definition should integrate the notion of families and enhancing their capacities to support individuals with disabilities.

(3) The definition should encompass the capacities of government to provide resources to support persons with disabilities.

(4) The definition focuses on the individual and his or her involvement with organizations and in policy. It should also include associations as the analysis unit and their capacities to mobilize the resources to support their employees and volunteers in their work in carrying out organizational mandates. Some respondents believed that individual capacity would precede that of organizations.

(5) The definition must take into account the perspectives of aboriginal and First Nations people.

(6) The definition is not understandable by those with intellectual disabilities because it is not written in plain language.

In response to the question of what would strengthen the capacity of the disability community, participants provided a number of recommendations. There are no major differences between the recommendations of service providers and those of advocacy associations.

1. A recognition that federal, provincial and territorial governments need the disability community to advance the disability agenda, and they could not survive without us.

2. Governments require the input of the disability community in their discussions and consultations, but it cannot be done without increased monetary and non-monetary resources. It is up to the governments to provide long-term core stable funding to disability organizations to ensure that the disability community can be equal partners in the consultation process. This involves paying associations to be fully involved and not just covering basic expenses. At this point, associations are expected to come to the table with limited human and financial resources and assume key roles in the consultation process on the disability agenda. This is an unfair expectation and is severely straining organizational capacities.

3. Additional government support is needed for research, organizational development and consultation, which should be separate from core operational funding. This would enable the community to gather the research-related knowledge to inform the consultations and also to meet together as disability organizations to discuss strategies through to move forward on the disability agenda. Staff development could also be provided through this type of funding mechanism.

Interviewees stated that recommendations two and three will only come about if there is the political will.

4. Coalition building between organizations is important to strengthen community capacity. This can only happen if organizations can move beyond the mode of survival into partnership development and working together on common initiatives.

5. First Nations people need to undertake research in order to move forward on their agendas.

6. Individuals with disabilities need meaningful lives and careers to increase their capacities for societal participation.

7. Families require support services to raise their children with intellectual disabilities at home to increase the possibility that families can more fully participate in society.

8. Individuals should be acquainted with the fact that they have rights within communities as well as the right to advocate and speak on their own behalf.

9. Awareness and education activities are required to change the attitudes of the general public about people with disabilities.

10. Consumers with disabilities require additional resources so they can be equal participants with service providers in designing programs and services which meet their needs.

11. Resources are also required to assist in the development of leadership skills within the disability community to bring new strength to organizations and to motivate additional individuals involved.

Consumer Findings

To locate individuals with disabilities for the consumer portion of the study, researchers asked the Executive Directors and key leaders of disability organizations to assist in the recruitment process, utilized snowball sampling techniques and placed an advertisement on the CCDS website. Seven interviews were conducted with citizens with disabilities: one person in Saskatchewan, three in Manitoba, two in Ontario and one in Nova Scotia.¹ The sample included two individuals with learning disabilities, two who were blind or visually impaired and three with mobility impairments. Five were female and two were male and they ranged in age from their middle 30s to over 65 years. Although age-related differences with respect to responses were not significantly reflected in the findings, we will note those instances where age was thought to be relevant. Four individuals were members of disability organizations at civic, provincial and national levels. Two of the three others reported involvement in volunteer activities with disability associations related to service provision and policy development. Four of the seven interviewees stated they had been or were currently employed with disability organizations.

Participant responses are summarized below.

Services Received:

Of the seven interviewees, six received services, while the remaining person did not, and there were no differences in service use between members and non-members of disability organizations. Two respondents reported they received information and support from disability-related organizations and the World Wide Web when needed. One of these individuals commended the excellent support provided through Learning Disabilities Associations, both at national and provincial levels while the other took advantage of massage therapy from a disability organization to assist her in dealing with stress and anxiety experienced at work. These offerings were highly rated, although one participant indicated that additional funds should be provided to disability associations to enable increased advertising of their services to enhance visibility.

¹ We also made contact with a person with disabilities in Quebec and we had hoped she would respond to the questions by e-mail, as this method was easier for her due to her hearing impairment. However, we did not receive her responses. This was unfortunate, as the Quebec perspective would have added a further dimension to the analysis.

Two individuals received homemaker services (one from a private association on an as-needed basis and the other from a government agency three hours per week). Both these citizens expressed dissatisfaction with the level and quality of service. The need for better staff training was cited by the consumer of the private service, while the person in receipt of government homemaking support had been cut from six hours per week to three when she relocated from a one-bedroom apartment to a three bedroom house. She noted that her service was about to be cut again, and she would no longer be able to get assistance with household responsibilities such as vacuuming and washing floors, as provision of assistance with these tasks was being dropped from the program. This consumer lives in the province of Ontario where service levels are being decreased and only those needing personal care assistance will be eligible for support. She noted the inherent difficulties with this situation and her need to find alternative forms of assistance. She is aware of other sources of support but she is convinced that others with disabilities will not be so lucky. She stated that if the current cuts continue:

There will be a lot more people in institutions. Disabled people don't have the resources, and if you are already sick, you are going to get sicker. We are trying to work on these things and not get discouraged. (Quote from consumer with disabilities).

The above-mentioned individual also noted dissatisfaction with the level of income support she received from the Province and the difficulties in obtaining mobility aids through a provincial-government program designed to cover the costs of these items.

Another consumer living in Ontario commended the province for its Aids and Devices Program which pays 75 percent of the costs of computers and software for people with disabilities, with consumers financing the remaining 25 percent. In the late 1980s, she had difficulties getting her first computer because she was not employed, but she advocated successfully on her own behalf since she required the equipment for her volunteer work. Individuals no longer have to be employed to be eligible for this type of support.

Other services mentioned by respondents included: Specialized transportation services financed by a civic government, handicapped parking identification stickers through a provincial handicapped parking program and library services from the Canadian National Institute for the Blind. Except for a comment that the specialized transportation vehicles were sometimes overcrowded, general satisfaction was expressed with the above-mentioned services. This would suggest that, in the opinion of those sampled, disability organizations were generally responsive to the voices of their members/clients and the views of people with disabilities in the general population.

Advocacy Role:

All interviewees noted that they had assumed advocacy roles on their own behalf or worked with others to solve disability-related problems. In the majority of cases, individuals and organizations were available to support them in their efforts. In one instance, an interviewee even sought the assistance of candidates running for an upcoming provincial election to facilitate successful approval of her application for a disability pension. However, mobilizing support for advocacy

initiatives was not always successful. This was illustrated by one participant who unsuccessfully called on the support of a university disability services department to facilitate policy changes with respect to meeting the needs of students with learning disabilities. Although the individual in question was successful in bringing about policy change, he felt disappointed that the disability resource centre failed to provide the expected assistance. One consumer preferred to call his involvement in lobbying "advocacy and education" to distinguish it from the work of professional lobbyists who possess more resources for their work than are available in the disability community. Although all interviewees reported situations of advocacy-related involvements, members of disability associations mentioned more frequent advocacy efforts.

Disability Policy Changes in Last Two Years:

The four consumers who were members of disability organizations possessed a greater degree of knowledge of disability-related policy changes that had occurred over the past two years, which is not surprising given that non-members reported less frequent participation in policy-related pursuits. Both positive and negative disability-related policy changes were evident over the past two years at civic, provincial and federal government levels. At the federal level, one participant who is a member of the Advisory Committee on Accessible Transportation for the National Transportation Agency commended the efforts of the committee in providing alternate format materials to enable members to participate equally in its work. Increasing attention has also been devoted to accessibility within hotels. Also worthy of mention were efforts on the part of disability associations to bring about changes related to the Federal Disability Tax Credit, and the initiation of descriptive video in movies (which provides description of silent moments through a headset to persons who are blind without disrupting the movie soundtrack).

At the provincial level, a participant from Ontario indicated that the Ontarians with Disabilities Act would hopefully be influential in changing disability-related policy. An interviewee from Manitoba mentioned the positive changes with respect to Social Assistance, which enables individuals in receipt of benefits to work part time and that monies can now be held in trust for these people without affecting their benefits. At the civic level, individuals noted the introduction of audible pedestrian signals at street crossings, which came about through the advocacy efforts of persons with disabilities and in the launching of Human Rights complaints. A participant noted that the introduction of a universal design policy in Winnipeg was an achievement. It was also his opinion that many of the gains have occurred because of Supreme Court decisions or challenges to Section 15 of "The Canadian Charter of Rights and Freedoms" and continuing advocacy and education efforts on the part of individuals and organizations. The other changes noted were small-scale in nature and local in scope, such as minor improvements in homecare and transportation policies.

Respondents offered examples of negative changes in disability-related policy. At the federal level, the purchase of inaccessible rail cars by a major rail carrier was mentioned and, provincially, major cuts to the home care program in Ontario. At the civic level, one participant noted the decrease in the number of accessible housing units being constructed.

Non-members of disability organizations provided a variety of responses. Some said they had not observed any policy changes while others mentioned they did not know if any such changes had taken place. There were also comments about an increase in awareness of disability on the part of the general public because individuals with disabilities were being hired more frequently in stores or for television commercials. One non-member indicated the government was unlikely to make any policy changes unless they were pressured to do so.

Role Of Disability Organizations In Advancing Disability-Related Policy:

As alluded to above, the four members of disability groups believed these associations at federal and provincial levels have played a major role in advancing disability policy through constant advocacy efforts, launching Human Rights complaints and Charter challenges and through involvement in coalitions to work on common agendas. Consultations with all levels of government were also mentioned. One respondent indicated that if disability associations worked more effectively together, this would increase the power and efficiency of advocacy efforts. However, organizations and persons with disabilities are becoming tired and lack sufficient resources to effectively carry out their activities. Additional monetary support is necessary, as is new leadership and revitalized energy if advocacy work is to continue. The interviewee in question was middle aged and was becoming emotionally drained as a result of involvement in constant advocacy work. Lack of political will on the part of policy makers was also noted as a prominent factor which inhibits the abilities of disability organizations to effectively change disability-related policy.

In general, non-members of disability associations were unaware of the roles assumed by these organizations in policy change. However, one non-member mentioned the collaboration of governments, disability organizations and the media to bring about policy changes.

Governments As Partners With Disability Organizations:

Both members and non-members of disability organizations in the sample agreed that all levels of government do work as partners with disability organizations on disability-related policy, although to some extent this depends on the particular government and its priorities. The fact that individuals with disabilities and representatives of disability associations are involved in government-related committees is an important vehicle to promote awareness of disability concerns and create mechanisms for consultation and policy change. It is vital to go beyond the level of awareness to a plan of action which moves the disability agenda forward. One consumer emphasized the role of offices for disability issues in sharing information about government services with persons with disabilities.

Several areas for improving the partnership were outlined by six participants, with the seventh person (a non-member) being unable to provide suggestions. There is a need for governments at all levels to put more effort into hiring people with disabilities in addition to improving already existing programs to assist this population to locate employment. These comments were made by respondents in their 30s and 40s who were currently looking for work or would shortly be

entering the employment market. Governments should "really listen" to the views of people with disabilities and consult on an ongoing basis with this constituency before taking action. As one consumer put it: "You may have all the heart and all the desire" but unless one has a disability, a person doesn't know what life as a disabled individual is really like. In addition, governments should assume greater responsibility for moving the disability agenda forward and for forming partnerships with this sector which will result in action rather than off-loading tasks to the disability community which has insufficient resources to undertake its current work. "Passing the buck" from one level of government to another with respect to providing resources for the disability agenda does little to promote action and policy development.

Policy changes would also occur if persons with disabilities were to become involved as elected officials to champion the priorities of people with disabilities. If governments provided additional monetary support to the disability community, organizations would be able to rely less on third-party fund raising which is unreliable. Legislative changes are also required on the part of the Canada Customs and Revenue Agency to equalize the playing field for those engaged in this type of fund raising. At the present time, this legislation stipulates that, if organizations bring in charitable dollars, 80 percent of the monies raised must be devoted to service delivery with the remaining 20 percent being allocated for administration. This is a problematic situation given that the fund raiser is retaining 50 percent of the money raised to pay his own staff. This means that more than 20 percent is being utilized for administrative purposes, and the profits to disability organizations are extremely small.

Community Capacity:

Of those sampled, four participants were comfortable with the definition of community capacity proposed by HRDC, while three offered suggestions for change. A non-organizational member indicated she did not understand the definition and that the language was unclear. A member of a disability organization noted that the definition should reflect the fact that persons with disabilities also participate in neighbourhood and community activities in addition to their work with disability associations. Another stated that if the current definition assumed that individuals were only a part of the community if they were actively involved in it, this is a mistaken assumption. Citizens with disabilities are integral community members whether or not they choose to fully participate in society.

A number of suggestions for strengthening the community capacity of disability organizations were offered.

1. Government organizations should send out client surveys to determine satisfaction with the services provided and should then make changes based on the feedback they receive.

2. Awareness of disability within the general population is poor and requires strengthening. Awareness generation should begin in elementary school and continue throughout life. People with disabilities and radio and television can facilitate the enhancement of this type of awareness.

Recommendations one and two came from non-members of disability organizations.

3. Governments, corporations, etc. need to recognize that people with disabilities are valuable assets within society and the disability community is vibrant and alive. This type of recognition would pave the way for governments and corporate entities to strengthen their involvement with disability organizations.

4. Governments should consult on an ongoing basis with people with disabilities and really listen to their ideas for policy change. Communication mechanisms need to be put in place to provide information to those submitting ideas for improvement as to what actions have been taken on their suggestions.

5. There is a need for disability organizations to engage in additional leadership, particularly in terms of reaching out to younger individuals to communicate the advantages of participating in policy change. Many of the advances in this area have occurred because of the efforts of current leaders. If disability organizations were to work more effectively together, this would increase the strength of advocacy efforts to bring about policy change. This comment was made by a middle-aged advocate within the disability community who was becoming burned out from constant organizational involvements.

6. The disability community requires additional resources to advance the disability policy agenda.

Conclusion

Throughout this project, CCDS was impressed and heartened by the ability of disability organizations to carry out their mandates in policy and program development and in service provision and to respond to the voices of their membership within a climate where human and financial resources are stretched to the limit. This is not a sustainable situation, and it is a critical time in which to develop support to enhance the capacity of the disability community. The wealth of involvement with elected and non-elected officials, the efforts to foster strong partnerships to undertake research and to consult with government and within the disability community are commendable. The Federal Report on Disabilities should clearly document these efforts, as well as the recommendations of the project participants to strengthen partnerships to undertake good-quality research and to enhance the capacity of the disability community.

The above-mentioned report should also emphasize the overarching finding in the current research that organizations require additional human and financial resources to effectively carry out their mandates and to undertake ongoing research to find solutions to issues raised by the disability community. Support is also needed to assist disability associations to form viable partnerships and to consult among themselves and with governments to advance the disability agenda within Canada. Organizations are looking to governments for these additional resources to strengthen the capacity of the community to be equal participants at the policy table.

Although alternative sources of funding are being explored, it is the responsibility of government to provide sufficient resources to enable the disability community to be equal participants in the consultation process.

APPENDIX ONE: PREMABLE

Canadian Centre On Disability Studies
56 The Promenade
Winnipeg, Manitoba, R3B 3H9

Interview Guide For Community Capacity Project

April 17, 2002

Preamble: (To be reviewed with participants on the phone).

The Community Capacity Project is being undertaken by the Canadian Centre on Disability Studies (CCDS) in Winnipeg with funding from Human Resources Development Canada, Strategic Policy Branch. CCDS is a consumer-directed, university-affiliated Centre focusing on research and education in the area of Disability Studies.

This qualitative research project will provide a preliminary assessment of disability community capacity with the objective of developing:

1. A framework for assessing disability community capacity in terms of possible outcomes and indicators;
2. A qualitative assessment of community capacity within the disability community based on the above-mentioned framework using a convenience sample of disability organizations and individuals.

Community capacity is a broad concept that refers to the ways and means in which things are done within communities. Capacity includes not only skills, people and plans but also commitment, resources and all dimensions of a process to make it successful. Community capacity building is based on the premise that community sustainability can be improved over time. A community's capacity, or the lack of it, is reflected in the people, economy, environment, culture, attitude and appearance of that community.

For the purposes of this research, community capacity is defined as the extent to which persons with disabilities participate as partners in identifying issues and in the development of policies and programs, both as individuals and through involvement with voluntary organizations representing their interests.

CCDS is interviewing the executive directors, coordinators or other key leaders of at least 10 uni-disability and cross-disability organizations in five Canadian provinces: Manitoba, Alberta, Ontario, Quebec and Nova Scotia. These associations include both consumer-directed self-help groups and service providers. These interviews will assess the extent to which:

- disability organizations and individuals are actively engaged with elected and non-elected officials at all levels of government in policy-making;

- governments are responsive to interventions by community organizations;
- disability organizations have the human and financial resources to identify disability issues, undertake program and policy development and fulfil the expectations of members and their organizational mandates;
- and organizations and individuals are involved in employment-related pursuits (including self-employment), the nature of voluntarism among these persons and associations and organizational and individual capacity to respond to societal change.

These outcomes are extremely important in increasing the self-worth of people with disabilities and facilitating full participation in Canadian society.

In addition, researchers are seeking to determine the extent to which disability organizations are involved in research and knowledge generation to support policy and program developments.

The Centre will also be conducting telephone interviews with at least 15 individuals who are members of the disability organizations noted above and a sample of non-members. Associations are being asked to assist in recruiting participants for this process. These interviews will seek to determine the extent to which organizations are guided by and responsive to the voices of their membership and people with disabilities in general.

This interview will take approximately 45 minutes of your time.

APPENDIX TWO

Interview Guide For Executive Directors, Coordinators And Key Leaders Of Consumer Groups And Service Providers

1. Please identify any recent changes in your organization's mandate or mission and any changes your organization intends to take in the near future.
2. How has your organization been involved with elected or non-elected officials in policymaking over the past year? If so, to what extent? How have government representatives responded to your involvement? Examples of involvements could include: correspondence, meetings, participation in coalitions with other groups, letter writing, preparing briefs, etc.
3. a) How would you describe the financial capacity of your organization to carry out its work in service provision, issue identification and policy and program development? Please explain. Does your organization have stable, predictable sources of funding? How important is it to your organization to obtain (more/additional) multi-year funding?

b) How would you describe the human resources capacity of your organization to carry on its work in service provision, issue identification and policy and program development?.
4. Does your organization usually/often work in partnership with other organizations within the disability sector? The larger voluntary sector? Other sectors? What are the challenges/obstacles and opportunities arising from such collaborations?
5. How many media releases on disability issues has your organization issued in the past year? How many have resulted in media stories?
6. To what extent can you obtain good quality, timely information about disability services, policies, etc? What are the barriers to getting this information?
- 7 a) Have you assessed your clients' response to your ability to undertake your mandate? How have your members/clients responded to your organization and its ability to provide services, identify issue areas, or engage in program and policy development? Outline areas where members/clients have expressed satisfaction and those where improvement is indicated.

b) How does your organization plan to address those areas where improvement is needed?

c) **For Aboriginal organizations only:** What opportunities do you see for working with the national Aboriginal organizations to advance disability issues for Aboriginal people within Canada?
8. a) Is your organization involved in research to promote policy and program developments within the disability community? What types of research- related activities does your association conduct?

[b) Do you conduct research in-house? If so what type of training does your staff have to undertake research?

c) Do you undertake research in collaboration with other NGO and research institutions? If yes, which ones? On what basis?] can be deleted if time is a problem

d) How are your research activities funded? (e.g. government grants, i.e. Social Sciences and Humanities Research Council of Canada, Canadian Institutes for Health Research, Human Resources Development Canada, private sector funding, other?) Over the past year, how many of your applications for funding were successful and unsuccessful?

9. In this interview, we have defined community capacity "as the extent to which persons with disabilities participate as partners in identifying issues and in the development of policies and programs, both as individuals and through involvement with voluntary organizations representing their interests." Are you comfortable with this definition? How would you change it?

10. Based on your definition of community capacity (previous question) can you identify the one most important change that would strengthen the capacity of the disability community?

APPENDIX THREE

Questions For Members And Non-Members Of Disability Organizations (only ½ hour at most)

1. a) Do you currently receive services from disability organizations? What services do you receive? From whom? How often or to what extent?

b) Are you satisfied with the services you receive? If yes, what contributes to your satisfaction? If not, why not? What do you suggest for improving the services you are receiving?

c) **For Aboriginal individuals only:** Are these organizations sensitive to any unique issues arising from your status as (e.g.) a Mohawk, First Nations, Inuit, etc.

2. As an individual, have you ever acted as an advocate on your own behalf or for others to solve disability-related problems? Are there others you can call upon or work with to help you to address disability issues?

3. Are you a member of or have you worked (as an employee or volunteer) with any disability organizations to promote disability policy development within Canada, i.e. lobbying, research, coalitions, other networks, etc.? Have these organizations been at the national, provincial, regional, or local levels?

4. a) Do you see any changes in policy related to disability in the past two or three years? What are they? Who is responsible for making these changes?

b) How have disability organizations been involved in changing disability policy? (eg lobbying, using media, strategic use of research, courts, etc) What have been their strengths and weaknesses?

5. Do governments work as partners with disability organizations to improve disability policy? Can you suggest ways to improve the partnership?

6. **For Aboriginal individuals only:** What organizations have been most important in raising the unique needs of (Aboriginal First Nations, Inuit, Metis, etc) people who have disabilities? Do you think there is a need for more disability organizations for Aboriginal people?

7. In this interview we have defined community capacity "as the extent to which persons with disabilities participate as partners in identifying issues and in the development of policies and programs, both as individuals and through involvement with voluntary organizations representing their interests." Are you comfortable with this definition? How would you change it?

8. Based on your definition of community capacity (previous question), can you identify the single most important change that would strengthen the capacity of the disability community?

APPENDIX FOUR

Websites For Disability Organizations Participating in the Research

Canadian Association for Community Living: <http://www.cacl.ca>

Canadian Association of the Deaf: <http://www.cad.ca>

Canadian Association of Independent Living Centres: <http://www.cailc.ca>

Canadian Hard of Hearing Association: <http://www.chha.ca>

Canadian Paraplegic Association: <http://www.canparaplegic.org>

Council of Canadians with Disabilities: <http://www.pcs.mb.ca/~ccd>

Learning Disabilities Association of Canada: <http://www.ldac-taac.ca>

National Educational Association of Disabled Students: <http://www.neads.ca>

People First of Canada: <http://www.interlog.com/~pfc>

Roeher Institute: <http://www.roeher.ca>

Neil Squire Foundation of Canada: <http://www.neilsquire.ca>

Alberta Committee of Citizens with Disabilities: <http://www.accd.net>

Alberta Association for Community Living: Linked from Canadian Association for Community Living site: <http://www.cacl.ca>.

Persons United for Self-Help North West: <http://www.tbaytel.net/pushnwo>

Network for Entrepreneurs with Disabilities: <http://www.entrepreneurdisability.org>

Assembly of Manitoba Chiefs: <http://www.manitobachiefs.mb.ca>

Aboriginal Disability Society of Alberta: No website.

International Network On The Disability Creation Process: No website.