Lessons Learned Disability Policies and Programs

Final Report

Evaluation and Data Development
Strategic Policy
Human Resources Development Canada
November 2000

This report is a re-edited version of the October 1997 *Disability Policies and Programs: Lessons Learned - Final Report* (Catalog number SP-AH038E-06-97). Changes made to the 1997 report are only stylistic in nature. The content of the study has not changed.

SP-AH144-11-00E

Acknowledgements

This study summarizes lessons learned from the Department of Human Resources Development Canada's (HRDC) disability programs, as well as from disability programs in other countries. Burt Perrin of Burt Perrin Associates was largely responsible for the development of the methodological approach and the analysis of the existing information on disability programs.

The project team conducted the study to respond to a need for information from Evaluation and Data Development and various other stakeholders.

The study benefited from the contributions of David Baker, Harry Beatty and Patti Bregman. Mr. Baker wrote the major part of the chapter on barrier removal legislation; Harry Beatty drafted much of the chapter on disability income systems; and Patti Bregman was principally in charge of writing the chapter on independent living and community support systems.

The project team also included a working group from HRDC. This group included Marie Lemieux from the Office for Disability Issues (ODI), Joan Johnson from the Income Security Policy (ISP), and Frank Yam from Evaluation and Data Development (EDD). We are grateful to the many people who assisted the evaluation team.

Series

Human Resources Development Canada (HRDC) and the organizations that came together to form it have long and proud traditions of continuous learning and improvement.

Over the years, the Evaluation Services Directorate (ESD) of the Evaluation and Data Development Branch at HRDC has produced numerous evaluations on a wide range of departmental programs. In 1996-97, ESD initiated a new series of evaluation studies with the object of taking the findings of earlier reports and updating them with new literature reviews and expert opinion. The primary goal of the new exercise is to identify the lessons that can be learned from past experience — to focus on what has worked, what has not, and for which client groups. Another important goal is to develop evaluation measurement tools in areas where such tools are non-existent. Finally, the studies take the information available on a topic and make it readily accessible to all.

Not surprisingly, this new initiative has come to be known as the "Lessons Learned" series. The intended audience includes senior managers, program managers and policy analysts both within and outside the federal government, members of the academic research community and all stakeholders who will benefit from having a clearer idea of the lessons learned based on evaluation studies of past and present programs.

HRDC is pleased to present the second study of this new series. It focuses on the lessons learned from disability policies and programs over the period of 1980 to 1997. There is a wide range of programs aimed at assisting persons with disabilities in Canada. In the last few years, it became clear that there was a need to bring together the information on all of these programs, both in Canada and abroad, in a compact synthesized report on disability issues. As with all our Lessons Learned studies, the aim is to determine what works best and why. This report answers this need and adds to the pool of knowledge on disability programming.

As a learning organization, HRDC will continue to experiment with new approaches and evaluate their effectiveness. HRDC recognizes the vital importance of the evaluation process and is committed to continuing its work in this area.

Table of Contents

1.	Introduction1
2.	General Lessons Learned3
3.	Specific Lessons Learned: Employment7
4.	Specific Lessons Learned: Barrier Removal Legislation11
5.	Specific Lessons Learned: Disability Income Programs 13
6.	Specific Lessons Learned: Independent Living and Community Support Services
7.	Specific Lessons Learned: Implications for Future Evaluation
Sele	ected Bibliography21

1. Introduction

This report summarizes lessons learned about what works or does not work in a variety of areas related to disability policy and programs. It is based on a review of evaluation information from a variety of sources within Canada and many other countries.

Disability is a major public policy issue in Canada for many reasons. One is the size of the disabled population. Statistics Canada reported that there were 4.2 million Canadians with disabilities in 1991, up from 3.3 million in 1986, the increase being associated with an aging population. This represents 15.5 per cent of Canada's population. Another concern about disabled people is the fact that many live below the poverty line. Surveys indicate that 22 per cent of people with disabilities in Canada (15 years of age and older) live below the poverty level while only 12.6 per cent of others without disabilities in the same age category are poverty stricken. While the full costs of disability to society are not known, Human Resources Development Canada (HRDC) estimates that the annual costs to the federal government of income support programs and provision of goods and services to the disabled are more than \$6 billion. That does not include the costs to provincial programs and private sector insurance plans, or the lost income and foregone taxes from people who are capable of work but who face barriers, which prevent them from employment. Therefore, disability is likely to continue as a major public policy issue, and in the absence of effective interventions, this is likely to lead to increased pressure for income support and services, and increased overall costs to governments.

Another reason disability is a public policy issue is because disability has been recognized as a citizenship and human rights issue. Section 15 of the *Canadian Charter of Rights and Freedoms* grants people with mental or physical disabilities the right to equality under the constitution. National reviews, starting with the 1981 report, *Obstacles: Report of the Special Committee on the Disabled and the Handicapped*, have identified the right of people with disabilities to full participation in society, and the need for coordination between governments' visions and actions. There has also been comparable international recognition of inclusion and equality as rights of people with disabilities. This has created responsibilities for governments to remove barriers that prevent people with disabilities from exercising their rights and participating fully in the activities of their societies.

...there were
4.2 million
Canadians with
disabilities in
1991...

This represents 15.5 per cent of Canada's population...

Disability has been recognized as a citizenship and human rights issue.

The federal government, in response to the report of the Federal Task Force on Disability Issues, has indicated its intention to take steps to address inequities, to increase access by people with disabilities to government services and to provide increased opportunities for participation in society. Recently, some action has been taken. For example, the 1997-98 federal budget contained a number of measures taken from the Task Force recommendations.

These measures included: the Opportunities Fund of \$30 million per year for three years; broadening the list of eligible expenses for medical expense tax credits; higher limits on the deduction for attendant care expenses and increased limits of part-time attendant care to \$10,000; and a new refundable tax credit to cover high medical expenses for low-income working Canadians with disabilities. The Minister of Human Resources Development has acknowledged his responsibility for disability issues and has indicated that he would be placing priority on improving access of people with disabilities to HRDC services and programs.

Nevertheless, in the current fiscal and social environment, there is general recognition that all publicly funded programs and services must be as cost-effective as possible. Given the need for programs to be as focused and effective as possible, and the recent interest in addressing barriers to equitable participation in society of people with disabilities, it is appropriate and timely to take stock of what is known from evaluations about what works or does not work in the disability area. In this way, future policy and program directions can build upon lessons learned from evaluation information from Canada and from other countries.

...a major "lesson learned"...is the importance of interrelationships ...across seemingly distinct policy and program areas. One of the challenges to developing, implementing and evaluating public policy regarding disability is the complexity of the subject. People with disabilities are not a homogeneous group. Their interests and capabilities vary, as do the types of barriers they face and the forms and levels of interventions that would enable them to participate as fully as possible in society. Also, a major "lesson learned" from this study is the importance of interrelationships and linkages across seemingly distinct policy and program areas. Decisions in any one area can influence effectiveness in others. For example, success in employment is affected not only by employment and training initiatives, but by the availability of personal support, transportation and housing, the flexibility and support for return-to-work efforts in income programs, the availability of jobs, the attitude of employers, taxation and other factors. These findings suggest that holistic and coordinated approaches would be the most effective to assist people with disabilities.

The Federal Task force was appointed in 1996 by the Ministers of Human Resources Development, Finance, Justice and National Revenue.

2. General Lessons Learned

1. Disability issues and topics are inter-related and require a coordinated approach.

There is substantial evidence, from Canada and abroad, of relationships and linkages among employment, transportation, housing and living arrangements, personal support, income support, access to rehabilitation and training, and others.

A coordinated and holistic approach across federal government departments and other jurisdictions is needed to address the complexity of disability issues and their linkages in order to provide coordination between policies and approaches. Without some form of coordination, the result is frequently a fragmented effort, with inconsistencies, overlaps, and gaps within and across jurisdictions. For example, some income programs have an all-or-nothing approach inherent in their eligibility requirements, which label people as either fully employable or unemployable. This approach may act as a major disincentive to employment and reinforces the welfare trap.

...the all-or-nothing approach...which labels people as either fully employable or unemployable... reinforces the welfare trap.

2. Environmental barriers are a greater impediment to participation in society and to employment than functional limitations.

Barrier removal through legislation, provision of workplace accommodations and other means, has been identified as the key to social integration of people with disabilities.

The most commonly accepted definition of disability is from the World Health Organization (WHO). This definition states disability involves an interaction between the individual and the environment. Therefore, an individual's ability to function in society and to be employed depends as much on the openness of society to accommodate people with their differences as on the specific functional limitations that identify a person as "disabled". This principle has important implications for the development of policies and for the focus of evaluations.

...an individual's ability to function in society...depends as much on the openness of society...as on the specific functional limitations that identify a person as "disabled".

3. People with disabilities vary in their characteristics and needs.

Persons with disabilities form a very diverse group, with very different life circumstances, types and severity of disability, and face a range of different barriers. A teenager with an invisible disability, such as a learning disability, finds herself confronted not only with the difficulties associated with a disability, but also with the lack of understanding and recognition

...personalized approaches...are most likely to be successful.

of that disability by other people. Consequently, a range of interventions is required. In particular, personalized approaches, with services adapted to the particular needs of each individual, are most likely to be successful.

4. Many approaches to permit participation of people with disabilities can be low-cost, but require involvement of different sectors in society, frequently on a partnership basis.

A variety of approaches that facilitate participation of people with disabilities in employment and in independent living have proven cost-effective in reducing the direct and indirect costs of disability. This report identifies the cost-effectiveness of a number of interventions, such as disability management, workplace accommodations and supported employment, as well as measures intended to permit independent living in the community. In particular, early intervention in facilitating the return to work of employees who develop disabilities can be very cost-effective.

Costs are...minimal when accessibility is built into the design of facilities and generic programs, as opposed to retrofitting.

Most workplace accommodations are low in cost and many, such as modifications to the work task or rearrangement of the work site, require no additional expenditures. Costs are also minimal when accessibility is built into the design of facilities and generic programs, as opposed to retrofitting.

Attitudinal barriers and lack of information about the capabilities of people with disabilities have been found to be among the biggest obstacles to independent living and to employment. These can result in systemic discrimination and lack of opportunities for people with disabilities. The United States' experience with its own disability legislation, the *Americans with Disabilities Act (ADA)*, has demonstrated that changes in attitudes can effectively follow changes in behaviour when standards and expectations are clearly set out. The provision of clear standards and the availability of technical information and support have increased compliance by American employers and private and public facilities with the accessibility requirements of ADA.

 Direct involvement of disabled individuals with programs, services and policies that affect them increases satisfaction and support, produces higher levels of functioning and greater success at community integration.

Direct funding to enable people with disabilities to purchase and direct their own attendant care and personal support services has been shown to be more effective and to result in greater satisfaction than traditional approaches, where professionals decide upon the needs without involving the individual. Direct involvement of people with disabilities in policy reviews, such as with the Mainstream 1992 Review and the 1996 Federal Task Force on Disability Issues, has demonstrated effectiveness in developing consensus and support for the directions that need to be taken.

Similarly, there is evidence that the involvement of people with disabilities in evaluation studies can improve the quality and credibility of the evaluation, lead to more relevant and improved policies and programs and also lead to improved functioning of the individuals involved.

...the involvement of people with disabilities in evaluation studies can improve the quality and credibility of the evaluation...

3. Specific Lessons Learned: Employment

1. There are many misconceptions about the potential of people with disabilities to work.

A common perception is that persons with disabilities who are not in the labour force are either unable or unwilling to work. There is strong evidence, however, that a substantial proportion of people with disabilities who are not currently in the labour force are capable of being employed in some way, given proper supports and removal of barriers. One study demonstrated that the lack of availability of accommodations and supports is a bigger barrier to employment than severity of disability. Also, some people with severe disabilities, while limited in the amount of work they are able to do, can still do productive work given the proper support. Saying that it is possible for people with severe disabilities to work does not mean that it is easy. Since many barriers must be overcome, successful intervention may require significant up-front costs, although there is potential for long-term savings.

...the lack of availability of accommodations and supports is a bigger barrier to employment than severity of disability.

Barriers to employment include lack of affordable transportation, limited education and training opportunities, various disincentives, lack of supports, and other factors. Failure to recognize and address these barriers may result in discrimination and exclusion of people with disabilities from the workplace. The need for a coordinated approach has been well documented, but has proved elusive at the policy level.

2. An all-or-nothing view of employability results in disincentives to work.

Eligibility requirements of disability income systems such as the Canada Pension Plan (CPP), which defines people as either "employable" or "unemployable", act as a powerful disincentive for people receiving social benefits to search for and to accept employment. Many people with disabilities are nonetheless capable of some degree of work, or can work if they are given appropriate supports.

3. Job accommodations, usually of nominal cost, can enable many people with disabilities to be fully employed.

Accommodations are "any modification of the workplace, or in workplace procedures, that make it possible for a person with special needs to do the job." Accommodations include technical aids and devices as well as physical alterations to the workplace. Current experiences in this area indicate that most accommodations are of low cost, with half costing less

Eligibility
requirements of
disability income
systems...act as a
powerful
disincentive...to
search for and to
accept employment.

Employers who have provided job accommodations say that the savings they have achieved average 27 times the cost of providing accommodations.

...up to 10 per cent of CPP beneficiaries have potential for rehabilitation and return to the workforce.

> ...the biggest limitation to the effectiveness of rehabilitation is lack of access...

than \$250 and many not involving any cost. Employers who have provided job accommodations say that the savings they have achieved average 27 times the cost of providing accommodations. Barriers to accommodation include both attitudes and lack of information about the potential of accommodation, as well as the methods to implement accommodation requirements in specific situations.

4. Disability management and return-to-work strategies offer considerable potential for very significant cost savings.

Disability management, or active follow-up and management of employees who are off work due to work-related or non work-related disabilities or injuries, has been shown to result in cost savings. Because of these savings, disability management strategies are becoming more commonplace, especially in the private sector. Disability management can also be effective in enabling participants on disability benefit programs such as CPP to re-enter the workforce. It has been estimated that up to 10 per cent of CPP beneficiaries have potential for rehabilitation and return to the workforce. Lessons learned from evaluations of return-to-work programs in a variety of settings emphasize the importance of early intervention and active case management.

5. Vocational rehabilitation has the potential to enable people with disabilities to get into employment.

Evaluations have identified a significant cost benefit of rehabilitation to the taxpayer, to income support programs and insurers. In general, vocational rehabilitation is most effective when it is individualized and closely oriented to the labour market. A recent evaluation of the pilot project on the CPP National Vocational Rehabilitation shows that the biggest limitation to the effectiveness of rehabilitation is lack of access. Indeed, only a small proportion of people who could benefit from rehabilitation services are able to access them. Also, without attention to respond to needs after a person starts or returns to work, short-term gains may not endure.

The effectiveness of wage subsidies and employer incentives is mixed.

Wage subsidies are put in place by governments as an incentive to the private sector to increase the training and employment opportunities for persons with disabilities. They are intended to compensate employers for lost productivity, and are of limited duration. Their effectiveness is mixed.

Wage subsidies are intended to help with entry into the labour market, especially for people with little or no work experience. They can provide work experience for people who may have trouble obtaining it without

some form of assistance. But subsidies can have a number of disadvantages. For example, being categorized as eligible for a wage subsidy can reflect negatively on the capabilities of those so categorized and lessen their chances of employment. In particular, people not retained following a subsidized placement may have difficulty obtaining employment in the future. Thus it is not certain whether wage subsidies, once completed, will result in long-term employment. Alternative approaches, such as barrier removal, generally appear to be more successful.

Subsidies appear to be most effective when they are part of a coordinated approach with other forms of support for the individual and the employer. The supports usually are specifically tailored to address the identified needs of the individual, and include follow-up and monitoring processes.

7. Supported employment has proved a better and more cost-effective alternative to sheltered work.

Supported employment involves training and work at regular work settings. Its unique feature is the provision of a job coach who gives support and training to the individual using the program. As the worker demonstrates independence, the amount of support is gradually reduced. Supported employment has been used primarily with people who are considered unable to work competitively, and who would otherwise be placed in a sheltered workshop. The supported employment model of integration provides opportunities to work in regular employment settings, and results in a higher degree of satisfaction among participants in this program over those participating in sheltered workshop placements.

Wage subsidies...
can provide work
experience for
people who may
have trouble
obtaining it without
some form of
assistance. But
subsidies can have
a number of
disadvantages.

The supported employment model...provides opportunities to work in regular employment settings...

4. Specific Lessons Learned: Barrier Removal Legislation

Barriers are the major stumbling block to full participation for many people with disabilities, and legislation is needed to accelerate changes.

There is evidence from the Health and Activity Limitations Survey, as well as from a variety of studies and reviews, indicating that it is the presence of barriers, rather than characteristics of the disability itself, that is the major factor preventing people with disabilities from equitable access to employment, community services and participation in Canadian civil society. Consequently, identification and removal of these barriers will level the playing field for persons with disabilities to achieve greater equity.

However, those responsible for barriers may occasionally remove them out of goodwill or out of desire to expand market share, but there is no proof that awareness campaigns and public relations campaigns have had more than a marginal impact. As a result, there is a clear international trend in all industrial, and many developing countries, to enact barrier removal legislation.

2. Clear and precise standards have been identified as being far more effective in removing barriers than generalized criteria.

The evidence indicates that clear and precise standards, such as those provided under the *Americans with Disabilities Act (ADA)*, which identify specifically what needs to be done or achieved in order to be in compliance, are effective in removing barriers.

The Canadian experience of human rights commissions and employment equity legislation have been limited in their effectiveness in addressing the barriers faced by people with disabilities. Because the standards are unclear, it relies upon litigation for enforcement and the costs have been high.

3. The Americans with Disabilities Act has been successful in enabling access for people with disabilities in a number of different areas.

A number of evaluations have indicated that ADA has succeeded in generating considerable support from the business sector, from the public at large, and among people with disabilities. The ADA experience ...there is a clear international trend in all industrial, and many developing countries, to enact barrier removal legislation.

...clear and precise standards...are effective in removing barriers. ...support from the business community comes after implementation, not before. Attitudes follow behaviour.

indicates that support from the business community occurs after implementation of legislation, not before. Attitudes follow behaviour. In addition, the availability of technical assistance, such as provided in the United States to support implementation of the ADA, results in a constructive, rather than adversarial approach, and is important in generating support and facilitating compliance.

4. "Redistributive" or "grant-levy" approaches can permit stable participation of the significant minority of individuals with severe disabilities whose labour market attachment is marginal.

"Redistributive" approaches ...place some responsibility for employment of people with disabilities on employers...

Such systems are used in Germany, France, Japan and a number of other countries, where incentives are provided for employers to hire individuals with disabilities, or taxes are levied on those who do not hire persons with disabilities. These approaches are "redistributive" in the sense that they shift resources from employers who are unable or unwilling to include employees with disabilities to those who are. This model places some responsibility for employment of people with disabilities on employers, but provides options for how this is to be done, as opposed to imposing direct quotas on employers.

Evaluation studies suggested that such a system provides permanent incentives of stable participation for individuals with severe disabilities whose labour market attachment is marginal. While the overall effectiveness of this particular method is still not clear, this policy approach is considered as an additional tool to improve employment opportunities for the disabled. In addition, this system is an improvement over the direct quota system, which socially stigmatizes the participants and is considered ineffective.

5. Specific Lessons Learned: Disability Income Programs

There is a range of disability income programs in Canada, which are, at best, loosely interrelated. The seven major disability income programs in Canada are: (1) Social Assistance for Persons with Disabilities; (2) Canada Pension Plan/Québec Pension Plan Disability Benefits; (3) Workers' Compensation; (4) Long-term Disability Insurance; (5) Motor Vehicle No-Fault Accident Benefits; (6) Personal Injury Awards and Settlements; and (7) Income Tax Credits. A significant number of Canadians are totally or partially dependent on these programs. Each program has strengths and weaknesses. Reviews and evaluations of these programs have tended to focus on each system "one at a time" with no consideration of interrelationships across programs. This can result in a misleading picture of the overall impact of income security on people with disabilities and on society.

1. Disability definitions for eligibility purposes have become a major contentious issue in virtually every system.

In general, disability programs have their own differing objectives, and consequently different eligibility criteria are used to target the intended population. However, eligibility criteria are often taken to be synonymous with "how a program defines disability". While it seems obvious and appropriate that different programs have different eligibility criteria, the fact that different programs "define disability" differently is sometimes seen as leading to inconsistencies, complexity and confusion — both from the perspective of applicants and also from the perspective of policy development and evaluation. It is important that the relationship among programs be taken into account, and any contemplated changes should be examined from a systemic rather than a program perspective. Tightening eligibility criteria in one program most likely will lead to increased costs in another, or worse, will let individuals who use and need these programs fall between the cracks.

...the fact that different programs "define disability" differently is sometimes seen as leading to inconsistencies...

2. All-or-nothing definitions of employability perpetuate the "welfare trap".

Requiring individuals to be completely unemployable to be eligible for benefits acts as a powerful disincentive to seek employment. Many people with disabilities are capable of some degree of work, but still would require some income support. They face the prospect, however, of losing their disability income eligibility entirely by undertaking rehabilitation, training, or education or, yet again, returning to work. A more realistic

Requiring individuals to be completely unemployable to be eligible for benefits acts as a powerful disincentive to seek employment.

view of employability could enable more persons with disabilities to work — which, in turn, could result in major cost savings to the income security system. There is a documented need for a more flexible approach, to provide continued eligibility, particularly for drug costs and essential health benefits to those at lower income levels and those able to work only part-time or periodically.

Although a number of reviews and evaluations have inevitably identified that the all-or-nothing approach creates the "welfare trap", none have arrived at a solution. It is extraordinarily difficult to "balance opportunity and security" within a single program design. Therefore, the critical lesson learned in this area is that one must be aware of unintended impacts and effects within each program, as well as possible unintended outcomes when program changes are considered.

3. A significant number of CPP disability beneficiaries have the potential to return to work with appropriate vocational rehabilitation services.

This has been demonstrated, for example, through evaluation of the National Vocational Rehabilitation Pilot Project and experiences in other jurisdictions. Early intervention has been identified in other systems as a critical factor in successful return-to-work, with a high payback. This may require coordination between CPP and EI, provincial governments, insurers, and employers. CPP is currently pilot testing coordinated approaches.

4. Even limited success in enabling people to return to work can result in very significant cost savings.

The United States General Accounting Office (GAO) has prepared several recent reports on the American Social Security Administration (SSA) and its Disability Insurance (DI) and Supplemental Security Income (SSI) programs. DI is the pension program for contributors (workers) while SSI is the needs-tested program for non-workers. A major focus of these critical reports is the general failure of rehabilitation and return-to-work. Less than half of 1 per cent of DI recipients ever return to work, despite the fact that they all have a work history.²

The GAO correctly emphasizes that rehabilitation and work incentive efforts can show big "dividends" even if there is only a little bit of success. It is *essential* to keep emphasizing that apparently very small, marginal gains in this area can have a very significant long-term effect on the costs

Early intervention has been identified...as a critical factor in successful return-to-work.

This observation can also be made about Canada's CPP disability pension program, although the CPP record is somewhat better.

of a disability income program. It is not necessary to have immediate spectacular successes.

The GAO evaluators suggest that the SSA should adopt the "best practices" of the social insurance programs in Germany and Sweden and of private employers in the United States. These systems are seen as effective in returning persons with disabilities to the workplace. The three leading strategies of these systems are:

- Intervention as soon as possible after an actual or potentially disabling event to promote and facilitate return-to-work;
- Identification and provision of necessary return-to-work assistance and management of cases to achieve return-to-work goals;
- Structuring cash and medical benefits to encourage people with disabilities to return to work.

5. Prospects for comprehensive disability income reform may not be realistic.

The gaps and overlaps across the various disability income schemes in Canada have generated proposals for a comprehensive disability income system to replace the current configuration of systems and programs. Although advocates of "one big system" argue that this would be administratively more efficient, as well as fairer and more equitable, there is not a *priori* reason to suggest that a unified system would be more effective than the existing system. Further, consensus is lacking on what a unified system might involve and how it would alleviate many of the limitations of current approaches. Consequently, consideration of a more coordinated system might be a more meaningful intermediate step towards reform.

6. Specific Lessons Learned: Independent Living and Community Support Services

1. Most people with disabilities, if they have the supports they need, can live independently and participate in the community.

Many different studies and reviews have provided overwhelming evidence of the capacity of most people with disabilities to live in community settings. But they also identify the critical importance of personal supports and community-based services to make this possible. People with disabilities strongly favour community living, in particular the independent living model, which gives them control over their lives. Family members are sometimes concerned about the potential impact of relocation of their relatives with disabilities from institutional to community settings, but in most cases are strongly supportive afterwards.

2. Individual control is associated with success.

Individual control and empowerment has been identified as one of the most important factors to the success of community services in facilitating skill development, community and social integration, consumer satisfaction and improvements in quality of life. Services based upon independent living principles are more effective in this regard than traditional, professionally driven services. Advocacy, support and training services provided through Independent Living Centres have been documented as effective resources in providing the support and skill development necessary to enable people to make effective use of support service programs and to make decisions about their own lives.

3. Direct funding has been documented as an effective model for the provision of services.

Also referred to as "individualized funding", "service brokerage" or "self-managed attendant care", direct funding permits individual consumers to hire and direct their own staff. Evaluations in a variety of jurisdictions have documented the effectiveness of direct funding in terms of improvements in consumer satisfaction, dignity and well-being, control over their own lives, and positive impacts on family members.

Services based upon independent living principles are more effective... than traditional services.

4. While the "open house" vision is increasingly accepted in principle, many services are slow in adapting to the new philosophy.

The Mainstream 1992 Federal/Provincial/Territorial Review of Services Affecting Canadians with Disabilities, endorsed by all social service ministers in Canada, articulated an "open house" vision. This reflects a shift from a philosophy of paternalism to one which respects and supports independence and responsibility, and acknowledges the responsibility of society to accommodate the differences of all citizens. This direction is in keeping with the independent living philosophy; key principles of which include autonomy and control by individuals over their own services, and differs from the traditional model where these decisions tend to be made by professionals.

...many services are still based upon the medical/ rehabilitation model. However, one of the core values of the independent living movement is empowerment. This is a term, which is also used to describe the purpose of attendant care and other community-based services, which support people living in the community. Some researchers have suggested that while the term is frequently used, there is little agreement as to how it can be implemented in practice. Consequently, a number of studies have indicated that many agencies are slow in actually incorporating the independent living principles into their day-to-day practice and many services are still based upon the medical/rehabilitation model.

7. Specific Lessons Learned: Implications for Future Evaluation

1. Evaluation paradigms and approaches have been evolving.

There is a strong trend in the evaluation field towards participatory and empowerment evaluation, with greater involvement of consumers in the process. As well, there is a need for evaluation which is practical and timely and takes a "utilization" focus on helping programs improve. This approach can provide a better understanding of what works best under given circumstances and can identify implications for future directions.

2. There is insufficient information about the full costs of disability, and the fiscal relationships among disability programs are unclear.

More research is needed to identify clearly the full range of direct and indirect costs of disability, which in turn will permit more meaningful determination of the cost-effectiveness of various programs and measures.

The fact that benefits from program measures and expenditures may accrue in different cost centres is one of the biggest obstacles to systemic change. Disability management interventions have sometimes failed to obtain the support of senior management and human resource officials, despite an impressive return on investment, because expenditure reductions accrue to programs other than those that incur the cost.

3. Greater consensus is needed on appropriate outcome measures for evaluating disability policy.

A consolidation of success criteria will enhance measurability of disability-related programs. To this end some suggestions are presented in the section on evaluation implications. However, additional conceptual and methodological explorations are needed, to generalize objective criteria as well as to generalize indicators. Quality of life and cost-effectiveness are two general areas suggested for consideration. More specific examples of measurements of quality of life could look at successful completion of training programs; labour force participation; community work or alternatively, less dependency on income support programs. In cost-effectiveness we need to estimate the full cost of disability to society (income support and other programs from federal and

provincial governments and the private sector, and the under-utilization of disabled individuals).

Without agreement on at least the general goals of policies, it can be difficult or impossible to focus evaluation efforts. Without agreement on at least the general goals of policies, it can be difficult or impossible to focus evaluation efforts. Consequently, evaluation findings may not be considered meaningful or accepted. There is particular potential for using the concept of quality of life as a primary outcome indicator, along with considerations of cost-effectiveness.

Quality of life is commonly thought of as having two dimensions: subjective assessments by individuals about various aspects of their life experiences, and objective indicators of life conditions. It includes considerations such as independent living, community inclusion and integration. It provides a way of thinking about outcomes from the perspective of the consumer and from a quality point of view. Quality of life now represents a major field of study in the disability area, and has been receiving extensive international attention.

Cost-effectiveness has also been identified as an important measure of effectiveness. It is therefore striking that so little conceptual attention has been paid to what this concept means in practice for assessing the costs and benefits of disability policies and programs. In particular, there has been limited work done to identify the full costs of disability. Cost-effectiveness analyses of disability policies and programs also need to take into account the full costs and benefits, recognizing that costs can occur in one program area, with savings and benefits in another, or over an extended time frame. Without a proper consideration of all costs and benefits, it is not possible to conduct meaningful cost-effectiveness analysis.

Selected Bibliography HRDC Evaluation Studies on Disability Policies and Programs

- 1. Analysis of Corporate Data on the Implementation of the Designated Group Policy. Phase 1, 1994.
- 2. Assessment of the Implementation of the Designated Group Policy. Phase II Report, 1994.
- 3. CPP Disability Incidence Study: Main Report, 1995c.
- 4. Canada Pension Plan. *Fifteenth Actuarial Report*, December 31, 1993.
- 5. Evaluation and Future Directions for the Job Accommodation Network (JAN) in Canada. Final Report, 1995.
- 6. Evaluation of the Canada Pension Plan (Disability Component): Final Report, September 1996a.
- 7. Evaluation of the Employability Improvement Program. Final Report, December 1995a.
- 8. Evaluation of the HRDC Initiatives Under the National Strategy for Integration of Persons with Disabilities (NSIPD): Phase II, June 1995b.
- 9. Evaluation of the National Vocational Rehabilitation Project, 1996.
- 10. Evaluation of the National Vocational Rehabilitation Project, 1996b.
- 11. An Evaluation of the Program for the Employment Disadvantaged, March 1984.
- 12. Exploring the Effectiveness of Canada Employment Centres for People With Disabilities. Final Report, 1994.
- 13. Final Report: *Evaluation of the Federal Contractors Program*, June 1992.

- 14. Final Report: Evaluation of the Legislated Employment Equity Program, June 1992.
- 15. *The Future of JAN: Evaluation and Identification of Future Options.* Final Report, 1990.
- 16. Improving Social Security In Canada. Persons With Disabilities: A Supplementary Paper, 1994.
- 17. Interdepartmental Evaluation of the National Strategy for the Integration of Persons with Disabilities, 1995.
- 18. Living with Disability in Canada: An Economic Portrait, 1996.
- 19. Returning to Work: Removing the Barriers, 1996c.
- 20. A Review of the Disability Management Pilot Project, 1996.