

PATHWAY TO INTEGRATION

**FINAL REPORT
MAINSTREAM 1992**

May, 1993

Report to Ministers of Social Services

on

**The Federal/Provincial/Territorial Review
of Services Affecting Canadians With Disabilities**

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Cat. No. H74-53/1993E
ISBN 0-662-20857-9

TABLE OF CONTENTS

EXECUTIVE SUMMARY	i
1. INTRODUCTION	1
a. Mainstream 1992	2
b. Report Organization	4
2. ENVIRONMENT	6
a. Attitudes	6
b. International Context	6
c. Canadian Context	8
d. Demographic and Fiscal Pressures	11
3. COMMUNITY CONSULTATIONS	14
a. Process	14
b. The Current System	14
c. Consultations: Paradigm	15
d. Consultations: Principles	16
e. Consultations: Goals and Objectives	17
f. Consultations: Policy Directions	18
1. Independence and Empowerment	18
2. Disability-Related Supports	19
3. Portability	20

4. TOWARD A COMMON STRATEGIC FRAMEWORK	21
a. Introduction	21
b. Vision	22
c. Principles	25
d. Strategic Directions	28
1. Disability-Related Supports	28
2. Role of Social Services	30
3. Employment-Related Services	34
4. Community/Independent Living	37
5. Promotion/Prevention	40
6. Income Support/Replacement	42
5. PATHWAY	46
a. Destination	47
b. Pathway	48
1. Fiscal Realities	48
2. Fiscal Arrangements	49
3. Disability-Related Supports	50
4. Role of Social Services	51
5. National Standards/Objectives	52
6. TOWARD THE VISION	53

Appendices:

- A. Terms of Reference
 - B. Community Consultation: Final Report
 - C. The "Open House" Vision
 - D. List of Research Reports
 - E. List of Committees and Staff
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PATHWAY TO INTEGRATION

FINAL REPORT MAINSTREAM 1992

EXECUTIVE SUMMARY

1. INTRODUCTION

The Conference of Federal/Provincial/Territorial Ministers of Social Services initiated the Mainstream 1992 review in order to develop "a collective strategic framework which ... explores from a social perspective the full integration of Canadians with disabilities in the mainstream of Canadian society." Ministers directed that the review also explore whether governments and individual Canadians with disabilities could agree upon a vision and a statement of principles. These would form the core of the strategic framework.

Furthermore, Ministers directed that the process consider the strategic directions which flow from this vision and from these principles in a number of policy and program areas: the role of social services, employment-related services, community/independent living, promotion/prevention and income support/replacement. The review also considered the strategic directions associated with the issues surrounding the disability-related supports which people with disabilities require. These issues were of fundamental importance to consumers involved in the Mainstream 1992 process.

Timing of the Mainstream 1992 report could be problematic if it unduly raises expectations for program initiatives which require net additional resources. Given the serious fiscal situation, governments do not have the current capacity to undertake new initiatives requiring additional resources. On the other hand, this could be a positive time to bring this report forward. While governments are not in the best position to develop new spending programs, they are in a position to challenge existing programs and to rethink their current directions. This type of challenge and thinking may be the foundation for continuing progress toward the realization of shared objectives for Canadians with disabilities.

2. ENVIRONMENT

The attitudes of people with disabilities, and the attitudes of others toward people with disabilities, have changed significantly over the years. Internationally and in Canada there are new understandings about the nature of disabilities and the importance of the social, economic or physical environment.

These understandings have led consumers and governments alike to recognize that two courses of action are required if people with disabilities are to participate equally in society:

- first, efforts are required to remove the discriminatory barriers - social, economic and physical - which exist in society; and
- second, people with disabilities will require special disability-related supports which accommodate and respect their differences.

Canadians have pursued both of these courses simultaneously. The most significant developments have been the inclusion of persons with disabilities in the equality rights section of the Canadian Charter of Rights and Freedoms and in provincial, territorial and federal human rights codes. Yet, in spite of these efforts, the majority of people with disabilities are under-educated, under-employed and among the very poorest in Canada.

People with disabilities contend that an understanding of their historical and current treatment by society must be placed in the context of discrimination and equality. Many of the circumstances in which they find themselves are the result of discrimination. While disability-related discrimination may not necessarily be motivated by lack of goodwill, the effects of such discrimination can be just as damaging as those experienced by other minority groups.

3. COMMUNITY CONSULTATIONS

This environment presents many challenges to governments, to the social services sector, to community-based organizations and to consumers. The Mainstream 1992 process, in building a strategic framework, was intended to bring together the different perspectives, views and experiences of a wide range of Canadians. It, therefore, included consultations with policy experts, with representatives of consumer, service and advocacy organizations and with individual Canadians with disabilities. It included periodic meetings of a reference

group, focus group sessions in cities across Canada, and written submissions from major national associations and organizations working with or representing people with disabilities. It included also a series of research reports prepared by experts in a number of fields. These reports examined disability-related issues concerning, for example, women, aboriginal people and the income security system in Canada.

The Mainstream 1992 report which emerged from these consultations gives expression to the views of consumers on the many issues. But, most importantly, the report attempts to build upon the common elements and values which exist. And it constructs a strategic framework on the basis of this consensus, in the hope that it can equally serve governments, community organizations and people with disabilities. The strategic framework can provide all of them not with a specific action plan for the short term, but with a pathway upon which they can travel over time.

4. STRATEGIC FRAMEWORK

This framework includes, first, a vision, a long-term goal toward which Canadians can strive. Second, it includes a statement of principles to guide societal efforts toward that vision in both the short and the long term. And, third, the framework includes a series of strategic directions, in key policy and program areas, which both flow from the vision and principles and, at the same time, give them greater shape, meaning and coherence.

a. Vision

Through the course of the Mainstream 1992 process, governments have articulated an "Open House" vision which emphasizes the importance of people with disabilities being able to participate fully in the mainstream of Canadian society. Ministers have asked whether this vision would be validated by consumer groups and by individual Canadians with disabilities as representing a common set of understandings and goals.

During the consultations, consumers developed a comprehensive "Equality and Citizenship Rights" paradigm. This paradigm is premised on the belief that people with disabilities have a right to participate fully in their communities on equal terms as other Canadians. It further

emphasizes that special efforts and accommodations are required in order to equalize opportunities and ensure equity of outcomes for people with disabilities.

There are certainly differences between the government and consumer visions, especially with regard to the scope of the government role. Yet, at the same time, there are many common elements in these two concepts of the future. By and large, these are captured in the "Open House" vision:

- . The "Open House" vision looks forward to a society in which people with disabilities enjoy the same rights and the same benefits as do other Canadians.
- . It is a society in which people with disabilities are participating fully in all aspects of community life, including school, work and recreation. They are able to participate in the mainstream because discriminatory barriers have been removed and disability-related supports have been provided.
- . Finally it is a society in which people with disabilities have the same degree of control as other Canadians over the decisions which affect them and which influence their lives.

b. Principles

Emerging from the Mainstream 1992 process were two statements of principle concerning the relationship among society, government and people with disabilities: the first statement was developed by governments prior to this review, while the second flowed from the "Equality and Citizenship Rights" paradigm articulated by consumers during the course of the review.

There are some clear differences between the approaches. The consumer statement is in some ways more specific, more directive and broader in scope.

Despite these differences, there are common values underlying the two statements of principle. The following represents a statement which builds upon those elements which are common to both governments and consumers:

Rights and responsibilities: people with disabilities have the very same rights, and the same responsibilities, as other Canadians. They are entitled, as others are, to the equal protection and the equal benefit of the law and require measures for achieving equality.

Empowerment: people with disabilities require the means, including disability-related supports, to assume responsibility for their own lives and their own well being. Efforts are required to encourage them to take control, and to support and promote their efforts in this regard.

Participation: people with disabilities require full access to the social, economic and physical infrastructure of our society so that they can participate fully and equally in their communities.

c. Strategic Directions

The strategic framework provides governments and the social services sector with directions, in a broad range of policy and program areas, for moving toward the open house vision:

Disability-related supports: The strategic direction would be toward providing disability-related supports which people with disabilities require if they are to participate in community life and to provide for their own well-being as other Canadians can.

Role of social services: The vision suggests that mainstream sectors - education, housing or employment for example - should ensure that their mainstream services are as accessible to people with disabilities as they are to other Canadians.

In order for this shift to occur, the social services sector would have to play a more vocal role in ensuring that the traditional programs respond more adequately to the unique situation of persons with disabilities. Part of that role would be educational and facilitative, within government and within the larger community, assisting others to adapt their services so as to accommodate people with disabilities.

Additionally, the framework implies that the social services sector examine how it provides services. First, it could ensure that its own "mainstream" services - child care or income support for example - are adequate and accessible, and are providing

opportunities for people with disabilities to realize the same outcomes from these programs as do others. Second, the framework implies a shift to an individualized service model which empowers people and enables them to retain responsibility for their own well-being.

Employment-related services: The open house vision suggests concerted and coordinated efforts in two directions - toward removing the discriminatory social, economic and physical barriers which exist in the workplace and toward providing people with the training and disability-related supports which they require in order to participate equally in the workplace. The vision also suggests efforts to remove the barriers in a range of income support and income replacement programs which prevent people with disabilities from remaining in or returning to the paid labour force.

Community/Independent Living: There is a wide variety of efforts which could move the social services system, and society in general, in the direction of supporting community and independent living. Some could be undertaken in the short term, redirecting current expenditures, sharing decision-making responsibilities and developing new processes for accountability for example. Other efforts will require a longer-term commitment, for example developing funding arrangements which enable individuals to purchase, organize, manage and control the disability-related supports they require.

Promotion/Prevention: Efforts in this direction will involve developing an understanding that handicaps emerge, not from people's impairments, but from a social, economic and physical environment which may be intolerant of the many differences which exist among people in our society. Efforts would be in the direction of not only preventing disabilities, primarily a health-related matter, but also eliminating handicapping conditions which place people with disabilities at greater risk of poverty and of exclusion from the social and economic mainstream.

Income Support/Replacement: The vision suggests efforts in the direction of ensuring that the programs of income support and income replacement provide adequately for the basic and the disability-related needs of people. Importantly, efforts would also be required to remove inequities across programs and to remove the barriers which currently prevent some people with disabilities from participating in the paid labour force.

5. PATHWAY

The strategic directions considered during the Mainstream 1992 process provide governments with a pathway toward their vision. Progress on that pathway, however, will require considering a number of very significant fiscal and policy issues.

Foremost among these involves reconciling what people with disabilities need - currently and in the future - with the fiscal realities confronting governments today. The challenge facing governments is not simply one of containing costs; that may not be a reality given the growing number and needs of people with disabilities, and given the social and legal changes taking place in Canada.

Instead, the challenge facing governments will be to reconsider their current spending and to shape it in a way which is consistent with the strategic framework and the open house vision. Closely related to this is the need for the different orders of government to develop fiscal arrangements among themselves which respect the principles and support the directions outlined in the strategic framework. Any modifications of existing arrangements or any new arrangements must take into account the fiscal consequences of moving in this direction.

Furthermore, movement along that pathway will require efforts to ensure that people with disabilities have access to the full range of disability-related supports which they require, regardless of where they live and regardless of their particular circumstances at any given time. These efforts will require considering the feasibility and the desirability of developing national objectives and national standards.

6. TOWARD THE VISION

Overall, the pathway presents a tremendous challenge - to individuals, to families, to employers, to governments, to providers of mainstream services, and certainly to the social services sector. The pathway, and the Open House vision, challenge them all to reconsider what they are doing currently and how they are doing it; and invite them to reorganize their efforts in a way which emphasizes equality, empowerment and participation.

The Mainstream 1992 process brought together a variety of people over an extended period of time. It provided them with an opportunity to explore their differences, to discuss their different concepts and, most importantly, to identify what values and goals they share. The process affirmed the value of an open, inclusive approach, by developing a strategic framework which can serve as a goal and a guide for all of Canadian society.

PATHWAY TO INTEGRATION - FINAL REPORT, MAINSTREAM 1992

1. INTRODUCTION

The Mainstream 1992 report is not intended to raise expectations unduly for program initiatives which require net additional resources. Given the serious fiscal situation, governments do not have the current capacity to undertake initiatives requiring additional resources.

Rather, the Mainstream 1992 report is intended to present a strategic framework for governments to consider in their approach to integration of persons with disabilities in the mainstream. While governments are not in the best position to develop new spending programs, they are in a position to challenge existing programs and to rethink their current directions.

Throughout Canada, people with disabilities are asserting a right to participate fully in their communities and to share in the full range of benefits available to other citizens in Canadian society.

This assertiveness is very much part of an international trend and reflects changes occurring more broadly in society. In Canada many people who in the past have been relegated to the margins of society are demanding to be part of the mainstream with all the rights and all the responsibilities that entails.

The reality is that Canadians with disabilities still constitute a substantially disadvantaged minority within Canadian society. They are at a disadvantage in all aspects of community life. In addition, they see a need to dispel faulty assumptions about their ability to live and work in the community.

People with disabilities contend that an understanding of their historical and current treatment by society must be placed in the context of discrimination and equality. Many of the circumstances in which they find themselves are the result of discrimination. While disability-based discrimination may not necessarily be motivated by lack of goodwill, the effects of such discrimination can be just as damaging as those experienced by other minority groups.

a. Mainstream 1992

From 1986 until 1988 the federal, provincial and territorial governments undertook a review of fiscal arrangements affecting persons with disabilities. Their goal was to improve the financial arrangements in place so as to ensure that they better accommodate the changing goals and needs of Canadians with disabilities. The review resulted in a number of modifications to the Vocational Rehabilitation of Disabled Persons (VRDP) Agreement (1961) and to the Canada Assistance Plan (CAP) Guidelines (1966) concerning eligibility.

The overall conclusion of this review, however, was "that CAP and VRDP in their present forms are not flexible enough to provide fully for provincial support for the mainstream (generic) approaches." (Mainstream 1992, Interim Report:11)

Subsequently the Conference of Federal/Provincial/Territorial Ministers of Social Services¹ approved Terms of Reference for a broader examination of services affecting Canadians with disabilities. Mainstream 1992 is "directed to the enhancement of the personal capabilities of persons with disabilities ... [thereby enabling them to achieve] optimal independence and participation in the mainstream of social, economic and cultural life of their community." (Mainstream 1992, Terms of Reference) Its objective is:

To provide Federal/Provincial/Territorial Ministers of Social Services with a collective strategic framework which, in the current fiscal, constitutional and environmental context, explores from a social perspective the full integration of Canadians with disabilities in the mainstream of Canadian society.

This framework is not intended to provide a specific action plan for the different governments to adopt in the short-term. That approach would be neither practical nor useful given that each jurisdiction has its own capacities, its own needs and its own priorities.

Instead the framework is intended to provide governments with a long-term vision, with guiding principles and with strategic directions that reflect the rights and needs of people with disabilities. Each government, and the consumer organizations in each jurisdiction, can

¹ At this time the government of Quebec had withdrawn from multilateral, intergovernmental activities and thus did not participate in Mainstream 1992.

use the framework as a compass, allowing them to set their directions and to ensure that their every day efforts are consistent with that long-term vision.

The framework was to be sufficiently broad as to include the full range of disabilities, all age groups and all jurisdictions in Canada. However, some of the unique issues confronting both women and aboriginal people with disabilities could not be given full consideration at this time. Discriminatory barriers which exist in our society compound the problems facing them and require deeper, broader and more fundamental changes if they are to participate on equal terms and exercise the same rights as other Canadians.

Thus the Mainstream 1992 process could serve only as a transitional step for women and for aboriginal people with disabilities. Two background papers were prepared identifying the range of issues which require attention, with implications for further efforts to address their specific needs: "Issues and Perspectives of Women with Disabilities" (1992) by Mary Reid and Regina Ash, and "An Overview of the Situation of Aboriginal Persons with Disabilities" (1992) by New Economy Development Group Inc.

In the case of women with disabilities, the research suggests that they are obliged to confront three barriers: those associated with their being women; those associated with their being disabled; and those associated with their being women with disabilities. "These three sources of prejudice are each different and when combined resulted in a unique form of disempowerment." (Reid and Ash, 1992:2)

The authors draw particular attention to two areas of concern. The first has to do with the level and degree of violence directed at women with disabilities and the inaccessibility of the support systems and even the escape mechanisms which are available to other women, for example, women's shelters. The second area of concern, and possibly the most fundamental, has to do with the poverty of women in general in Canada and the even greater poverty evident among women with disabilities. "These realities," the authors suggest, "are creating disabilities, as well as working to compound existing disabilities." (Reid and Ash, 1992:12)

With regard to aboriginal people with disabilities, the research suggests they face a variety of barriers having to do not only with their disability but with their aboriginal status, their poverty and their isolation. Furthermore, the research emphasized that aboriginal people with disabilities have very different needs than do other people with disabilities who are more

in the mainstream. As a result, aboriginal people themselves will have to develop their own service models, ones which are consistent with the cultures and customs of the different First Nations.

In addition to this research, Ministers committed themselves to a review process which was open and inclusive. First, it was a cooperative, intergovernmental initiative. Second, it involved consultations with individuals with disabilities, with consumer, service and advocacy organizations, and with experts in the disability policy field.

Ministers directed that the review examine, first, the role of social services in achieving the goals of the strategic framework and second, four important policy and program areas: employment-related services, community/independent living, promotion and prevention, and income support/replacement. The consultation process was to examine and explore whether a statement of vision and principles, developed by government following the earlier review, could be validated by consumers.

Finally, Ministers directed that Mainstream 1992 proceed "on the assumption that we are operating in a fiscally restricted environment. Any strategies to be considered must recognize this fact." (Mainstream 1992, Interim Report:11)

b. Report Organization

This report to Ministers represents the results of the Mainstream 1992 consultation, the considerations of officials and the background work prepared for the review. Following this introduction, section 2, ENVIRONMENT, examines both the international and the Canadian contexts in which the review is taking place as well as the demographic and fiscal pressures which must be considered when developing the strategic framework.

It is followed, in section 3, COMMUNITY CONSULTATIONS, by an outline of the community consultations and by a presentation of consumer views concerning a paradigm, a statement of principles and the policy directions which they believe are most appropriate for Canada through the long term.

That participatory process, along with the research undertaken specifically for Mainstream 1992 and the intergovernmental discussions, has produced the vision, principles and strategic

directions which constitute the strategic framework presented in section 4, **TOWARD A COMMON STRATEGIC FRAMEWORK**.

Section 5, **PATHWAY**, identifies a pathway for governments to pursue this vision. It analyzes several of the broad, intergovernmental issues which were addressed through the course of the review, for example the need for new fiscal arrangements to support the achievement of the vision. Finally section 6, **TOWARD THE VISION**, summarizes the achievements of the Mainstream 1992 process.

2. ENVIRONMENT

a. Attitudes

Attitudes have fundamentally affected the way in which people with disabilities have been able to participate in community life. These of course have varied tremendously over time and through different societies.

In Europe and subsequently in North America, the cities and workplaces of the industrial age were inhospitable places for people with disabilities. Institutions and segregation became the service model, an approach which continued well into the twentieth century even though the "care" given to most people with disabilities improved significantly through that time. More recently still the medical model often focused attention upon an individual's impairments rather than his or her abilities, and assumed that people with disabilities were permanently incapacitated. The approach emphasized the differences between people with disabilities and others in the community, and led to myths, stereotypes, segregation and isolation.

Attitudes continue to change, however. In 1975 for example, the World Health Organization published its International Classification of Impairments, Disabilities and Handicaps and provided a new conceptual model for understanding both the nature of disabilities and the support needed by people with disabilities. These definitions emphasize the importance of the environment in determining the degree of "handicap" which a person with a disability experiences. And since the environment can be changed, the focus has now shifted to measures to make these changes and to facilitate the full participation of persons with disabilities in their communities.

b. International Context

Both this shift in attitude and this new focus received significant impetus during the 1980s through the activities of the United Nations and its member countries. First the U.N. declared 1981 the International Year of Disabled Persons and then the period 1983 to 1992 as the Decade of Disabled Persons. This latter declaration established three broad objectives for governments:

- . to enhance the awareness of disability as an issue facing governments throughout the world and of the poverty, isolation and discrimination facing people with disabilities;
- . to create an awareness of the need to address the issue of disability within a context and to understand the environmental factors at work; and
- . to gain recognition for the rights and capacity of people with disabilities to speak for themselves and to define their own vision and goals.

Overall these provided a conceptual framework for a variety of important international initiatives, for example the World Programme of Action, the Long-Term Strategy, and the emergence of new uni- and cross-disability coalitions and policy networks, such as Disabled Peoples' International, to promote an international understanding of the human and legal rights of people with disabilities.

The framework itself recognizes that efforts must be directed both at removing the barriers which inhibit the aspirations and abilities of people with disabilities, and at meeting their specific disability-related needs.

In work prepared for Mainstream 1992, Disabled Peoples' International draws attention to the Scandinavian countries where discriminatory barriers and disability-related needs are being addressed simultaneously through:

- . clear national standards and framework legislation;
- . wide authority at the local level to implement national objectives; and
- . formal input and control by strong and inclusive organizations representing people with disabilities.

Central to the Scandinavian approach is a philosophy which ensures that it is people with disabilities who are making the decisions affecting them. In Denmark, for example, disability organizations have the statutory right to negotiate with governmental bodies and to determine, with those governments, the nature and direction of community and governmental activities.

The United States provides another example. First there are a number of legislative enactments which operate primarily within a social services and rehabilitation philosophy and focus on the disability-related income, employment and "rehabilitation" needs of people with disabilities. Foremost among these is the Rehabilitation Act of 1973.

Second, operating more within a rights philosophy, the United States has recently enacted the Americans with Disabilities Act. In many ways its most significant aspect is to extend the human rights protection of the Civil Rights Act of 1964 to people with disabilities. Its purpose is to address the discriminatory barriers which exist throughout society, with particular reference to employment, government services, public accommodations, and commercial facilities.

Third, the United States has income security legislation under which the national government, rather than state governments, has responsibility for providing income support to people with disabilities.

These pieces of American legislation, along with others, address both aspects of the needs experienced by people with disabilities: they provide certain disability-related supports so as to enable people with disabilities to participate in the mainstream and, at the same time, address the barriers in their way.

c. Canadian Context

Internationally Canada has been an active participant in United Nations and other efforts to ensure both that the rights of people with disabilities are recognized and that the range of their disability-related needs are more adequately met. Canada is recognized as a leader for its own efforts to promote community accessibility, self-help approaches and consumer-controlled organizations.

Canada's efforts are reflected in various federal and provincial legislative initiatives. Foremost among these is the specific inclusion of people with mental and physical disabilities in the equality rights section of the Canadian Charter of Rights and Freedoms.

Section 15(1) of the Charter affirms that:

Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age, or mental or physical disability.

The provisions of the Charter apply to all orders of governments and to their various agencies. Furthermore the rights of people with disabilities are also affirmed in the federal, provincial and territorial human rights codes, applying not only to the public sector but to the private sector as well.

Giving precise and full meaning to Section 15, and to the Charter as a whole, is an evolutionary process which will build not only upon Canadian jurisprudence but upon Canadian history, Canadian traditions and Canadian commitments to equity and fairness.

In this regard, the Supreme Court of Canada, in Andrews v. Law Society of British Columbia (2 February 1989), affirmed that equality, as provided for in s.15 of the Charter, does not mean sameness since "identical treatment may frequently produce serious inequality" in terms of benefits derived. Justice McIntyre elaborated on behalf of the court when he wrote:

Recognizing that there will always be an infinite variety of personal characteristics, capacities, entitlements and merits among those subject to a law, there must be accorded, as nearly as may be possible, an equality of benefit ... In other words, the admittedly unattainable ideal should be that a law expressed to bind all should not because of irrelevant personal differences have a more burdensome or less beneficial impact on one than another.

At the same time, the Charter does provide for a test of reasonableness. Section 1 states that the Charter's guarantee of rights and freedoms is "subject only to such reasonable limits prescribed by law as can be demonstrably justified in a free and democratic society". In this regard, however, Justice McIntyre, again in the Andrews case, writes that "It is for the citizen to establish that his or her Charter right has been infringed and for the state to justify the infringement".

Governments have undertaken reviews and other efforts to ensure that their legislation conforms to the equality provisions of the Charter. Most recently, at the urging of consumer groups, the government of Canada enacted Bill C-78 affecting various pieces of federal legislation concerning, for example, voting and communications.

The second approach addresses the disability-related needs of people with disabilities. These needs are met, to various levels and degrees, through a variety of governmental and community programs supported by the federal, provincial and territorial governments. In certain important cases, the cost of these programs is shared, through the Canada Assistance Plan and the Vocational Rehabilitation of Disabled Persons Agreement, by the different orders of government. For the most part these programs provide disability-related services within a social services or health framework.

There are in Canada also a number of programs which provide income replacement and income support to people with disabilities, including:

- . tax-based benefits for those with taxable income;
- . the tort or legal system for those whose disability resulted from negligence.
- . private insurance coverage for a small portion of the paid labour force;
- . the national pension plan disability benefits for those with a history of involvement in the paid labour force;
- . Workers Compensation for those whose disability was work-related;
- . automobile insurance for those whose disability resulted from an automobile accident;
- . various provincial programs which provide support to individuals on the basis of their disability; and
- . social assistance, the program of "last resort", for those with virtually no other resources and very few assets.

While Canada has this extensive array of income replacement and income support programs, it does not have a comprehensive system which coherently addresses the income needs of people with disabilities. According to the Roeher Institute:

Each [program] has its own criteria for eligibility and its own schedule of benefits and supports. In this system, what a disabled person receives depends primarily on

how they became disabled." (Roeher Institute, Comprehensive Disability Income Security Reform, 1992:1)

d. Demographic and Fiscal Pressures

Canadians, and governments throughout Canada, are coming to recognize the rights of people with disabilities and their need for disability-related financial and personal support. Yet there remains a significant gap between this recognition and the reality of life and work for people with disabilities. And there is a gap also between this recognition and the fiscal capacity of governments to meet the level and scope of need which exists.

The significance of the first gap is captured in the data collected for the Health and Activity Limitation Surveys conducted by Statistics Canada and employing as a definition:

In the context of health experience, a disability is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.

The 1991 data, as well as the 1986 data analyzed for Mainstream 1992 by Eric G. Moore and Mark W. Rosenberg ("A Review of Demographic Studies of Persons with Disabilities," 1992) provide a background for the development of the Mainstream 1992 strategic framework:

1. The data concerning demographics and living arrangements make clear that the challenge of meeting the needs of people with disabilities will grow through the years given the rate at which the Canadian population is aging.
 - . 4.2 million Canadians, 15.5% of the population, reported some level of disability in 1991. Of these, approximately 7% are under the age of 15 while 46% are 65 years and older. The overwhelming majority of these individuals - almost 94% - live in private households and only 6% live in health-related institutions.
 2. The data also indicate that there are important costs associated with a disability for which most receive no assistance.
-

- . Between 32% and 38% of people with disabilities report expenses associated with their disability and not reimbursed by any private or public plan.
3. The data show that a high proportion of persons with disabilities rely on income support or replacement programs of various kinds.
- . Approximately 56% of working age persons with disabilities reported that part or all of their income in 1985 was from a source related to their disability. Almost half of these receive benefits from disability-related income replacement insurance programs, for example CPP disability benefits or Workers Compensation, with many others receiving income support from social assistance or other sources.
4. The data also indicate why this reliance upon public programs of income support is so significant. Most Canadians with disabilities are unemployed; and those who are employed nevertheless have relatively low incomes.
- . People with disabilities have significantly lower incomes from employment and lower total incomes than do other Canadians. About 60% of people with disabilities have incomes below \$10,000.
 - . 40% of working-age adults with disabilities, living in private households, reported some employment activity in 1986, compared to 70% of the general population. Slightly over half indicated that they were no longer in the labour force.
5. The data confirm what Canadians know to be the relationship between education, employment and income. The data suggest the importance of early, mainstream efforts to ensure that people with disabilities can prepare themselves for the paid labour force. The data also indicate the importance of adapting training and retraining programs for those who become disabled later in life.
- . People with disabilities are at a significant educational disadvantage when they attempt to participate in the paid labour force. 56% of people with disabilities have eight or more years of schooling compared to 83% of the general population.
-

Clearly, people with disabilities constitute a group which is increasing in numbers and which will continue to do so through the coming years. They constitute a group which currently does not have the opportunity or the tools to participate equally in Canadian society. They cannot share in the benefits of citizenship because of the environmental barriers which exist and because the supports which they require are not available to the degree and level which are necessary.

These realities are placing significant pressures on governments across Canada. On the one hand there is pressure to meet the needs more fully. On the other hand there is the priority assigned to deficit reduction and the general restraint measures which have resulted from this. These measures include, for example, the "cap on CAP" and its recent extension - in British Columbia, Alberta and Ontario - for an additional three years. These have led also to the Fiscal Transfer Review, by federal and provincial finance officials, examining certain arrangements (CAP, equalization payments and Established Programs Financing) which, a decade ago, could be used by governments to respond more fully to the needs of people with disabilities.

Adding to the pressure are decisions of the courts and human rights tribunals in Canada, and the reviews undertaken, action plans developed and reports prepared in the federal and provincial jurisdictions, usually with considerable consumer input.

3. COMMUNITY CONSULTATIONS

a. Process

The Mainstream 1992 consultation process involved a series of components. First, it included periodic meetings of a Reference Group consisting of individuals associated with 10 different national organizations representing people with disabilities. This group reviewed the terms of reference and workplan for Mainstream 1992, reviewed the "Community Views and Themes" paper prepared for this review, acted as a focus group for considering certain key issues, and advised on the consultation process.

The Reference Group is also being asked to review the open house vision and the Mainstream 1992 final report.

Second, the Mainstream 1992 process included a series of focus group meetings on a variety of important issues: employment, empowerment, transitions, income support/replacement, community/independent living and promotion/prevention. These took place in different cities across the country and brought together close to 70 people, each with their own contribution to make. Participants in the focus groups included people with disabilities as well as policy experts in this area. These focus groups were chaired by the Roeher Institute, a national research institute for the study of public policy affecting persons with disabilities.

The Roeher Institute, on behalf of Mainstream 1992, also invited written submissions from major national associations and organizations representing or working with people with disabilities.

b. The Current System

The Mainstream 1992 process was designed to enable consumers and other participants to contribute positively to the shaping of a strategic framework for governmental efforts in the future. This shaping began, however, by examining what exists currently.

On the one hand consumers suggested that many - perhaps most - of the services and programs currently in place were valuable and important. However, they said, "the current

set of arrangements for framing and addressing the need[s] of people with disabilities for disability-related supports are inadequate, inappropriate, inefficient and outmoded." (Roehrer Institute, Consultation Summary, 1992:4)

Furthermore, the report goes on to say that:

... people with disabilities struggled to ensure that they would be specifically recognized under the equality provisions of the Charter, with the expectation that provincial/territorial legislation -- including social services legislation -- would be reconciled with those provisions. The latter has not happened to the extent anticipated, effectively denying the full and proper exercise of citizenship, equality and human rights to many. (Roehrer Institute, Consultation Summary, 1992:8)

Consumers suggested that current arrangements set directions almost diametrically opposite to what they viewed as appropriate. They described these arrangements as stigmatizing, disempowering and disrespectful; as inadequate in terms of the level or kind of support provided; as complex and fragmented; and as restrictive, inflexible and inequitable. (Roehrer Institute, Consultation Summary, 1992:4-7)

Finally, consumers showed themselves to be fully aware of the very significant financial resources currently being committed to disability-related supports and to income support for people with disabilities. And they suggested, throughout the consultations, that greater effectiveness and appropriateness could be achieved if they were involved in planning services, in setting priorities and program criteria, and in directing or redirecting expenditures.

c. Consultations: Paradigm

Participants in the consultation process discussed at length the range of current programs and arrangements within the health and social services framework, and the problems confronting people with disabilities. The Roehrer Institute summarized their views and described an "Equality and Citizenship Rights" paradigm. They said that the shift to this paradigm " is viewed as necessary because the access of people with disabilities to disability-related supports is ... a basic condition that must be satisfied to ensure that people with disabilities

will participate on equal terms with and exercise the same rights as other Canadian citizens." (Roeher Institute, Consultation Summary, 1992:7)

Overall, the consumer paradigm is unequivocal and suggests a broad governmental responsibility to ensure that their equality and citizenship rights are respected everywhere in Canada, regardless of the funding and legislative arrangements required to bring this about. (Roeher Institute, Consultation Summary, 1992:11-12)

d. Consultations: Principles

The Roeher Institute drew from the focus groups and the other consumer input a series of principles which it believes are inherent in the Equality and Citizenship Rights paradigm and which might provide a framework for governmental and community policy and program directions. These were described in the consultation summary as:

- . the right to full participation in all aspects of society, and the right of all people with disabilities to have access to the level and kinds of supports that enable this to occur (regardless of the province/territory or other status);
 - . instead of charity, entitlement to adequate supports for living independently in the community;
 - . respect for and trust in, not mistrust of, the consumer with a disability;
 - . access to disability-related supports that are geared to individual needs as defined by the consumer;
 - . consumer control and choice (empowerment) in all support arrangements that directly affect their life;
 - . significant involvement by consumers with disabilities in the design and evaluation of public policy and programs that directly affect their lives; [and]
-

- societal responsibility to ensure that these principles are realized through law, public policy, social programs and funding commitments. (Roeher Institute, Consultation Summary, 1992:8)

e. Consultations: Goals and Objectives

As the next step in developing their paradigm, the Roeher Institute provided a succinct articulation of the most basic goals of people with disabilities living in Canada. With the Equality and Citizenship Rights paradigm, programs should enable people with disabilities to:

- live independently as citizens and empowered members of the community;
- have a decent quality of life;
- make the critical life transitions as these emerge; and
- take part in the labour force. (Roeher Institute, Consultation Summary, 1992:8-9)

More concretely, consumers identified the most urgent and most fundamental needs of people with disabilities in Canada and suggested that the objective of governmental and community efforts should be to:

- cover the additional costs of disability;
- address the poverty of people with disabilities;
- ensure the availability of social services and other supports that are consistent with the Equality and Citizenship Rights principles; [and]
- help remove the barriers (in society at large, in government, in public programs, and in social services) that prevent the realization of the principles. (Roeher Institute, Consultation Summary, 1992:9)

Those consulted during the Mainstream 1992 process believe that these goals and objectives can be pursued within the current social, fiscal and constitutional structures of Canada. With regard to the fiscal situation of governments, consumers suggested that:

Having access to the [policy] process, they [people with disabilities] would become better informed about the financial capacities and limitations under which public agencies operate. As responsible and informed citizens, they would also be in a much better position to work with others to help strike a balance between individual consumer needs and the interests of the public at large.

Access to the policy process would also enable people with disabilities to feed insight into decisions about resource allocations, which in turn would yield, if not cost savings, more prudent public investments in disability-related supports. It was felt that, because people with disabilities have little access to the process, financial commitments are made to fund services and items that may in many instances be unnecessary or for which equally effective but less costly alternatives can be found. (Roehrer Institute, Consultation Summary, 1992:25-26)

At the same time, however, consumers viewed the goals which they articulated as imperatives if society is to acknowledge and adhere to the Equality and Citizenship Rights paradigm.

f. Consultations: Policy Directions

Consumers participating in Mainstream 1992 offered an extensive list of policy directions and specific recommendations for moving from the current set of programs and arrangements toward the new paradigm and the goals and objectives identified above.

The following is a brief synthesis of the policy directions suggested by consumers, organized by the three themes which dominated the consultations: (1) independence and empowerment, (2) disability-related supports and (3) portability.

1. Independence and Empowerment

- . Recognition of the equality rights of people with disabilities, and the entitlements which they believe flow from those rights.
-

- . **Direct funding approaches which empower individuals by giving them the ability to be both responsible and accountable for the variety of goods and services which they require.**
- . **Enhanced ability of mainstream programs to ensure full access to people with disabilities as to other Canadians.**
- . **Service arrangements based upon respect, trust and the equality model which enable the person with a disability to determine the extent of his or her disability-related need, and the supports and services required.**
- . **Direct involvement of people with disabilities in developing and evaluating all policies and programs affecting them, in designing and delivering the range of services which they require, and in all appeal mechanisms affecting them.**
- . **Enhanced responsibility for and support to community-based, consumer-directed service and advocacy organizations.**
- . **Public support only for those organizations, whether private or community-based, which adhere to the equality and citizenship rights philosophy.**

2. Disability-Related Supports

- . **Governmental recognition of its responsibility for disability-related supports which enhance their ability to participate equitably in community activities including education and employment opportunities.**
 - . **Coverage of these disability-related supports on the basis of a rights orientation rather than a welfare model.**
 - . **Rationalization and integration, on the basis of the rights model, of the funding currently provided to people with disabilities.**
-

3. Portability

- . **Provision of disability-related services and supports in a manner which ensures equity across communities and jurisdictions so that, as Canadians, they enjoy equal rights regardless of where they may live.**
- . **Provision of disability-related services and supports across the many life situations of people with disabilities, for example home, school, work, and community, and as they make the transition between these.**
- . **A commitment to portability of goods and services in order to enhance the choices available to people with disabilities, based upon certain nationally-applicable objectives and standards.**

Most often participants did not elaborate on how the policy directions and recommendations might be put in place or who might be responsible for one or another aspect of the strategy. To consumers, the responsibility for sorting these out lay with governments working in cooperation with people with disabilities.

4. TOWARD A COMMON STRATEGIC FRAMEWORK

a. Introduction

The objective of the Mainstream 1992 review is to develop a collective strategic framework for governments in Canada. Given the complexity of the task, and of the issues which required attention, governments adhered to an open and iterative process which attempted to build upon those elements which were common to both consumers and governments.

Contributing to the process was the collective experience and diverse perspectives each jurisdiction brought to the discussions. There were the many reports and studies undertaken previously, dating back to the Obstacles report of 1982 and beyond. Importantly, there were the consultations described in the previous section. And there were the research reports commissioned by Mainstream 1992 and prepared by people with expertise in the different areas under consideration. These examined some of the key issues of concern to people with disabilities, namely:

- . **Prevention/Promotion** - Beth Hoen and Mary Thelander, "Role for Social Services in Prevention and Promotion as Related to Persons with Disabilities: Preliminary Conceptual Framework";
 - . **Demographics** - Eric G. Moore and Mark W. Rosenberg, "A Review of Demographic Studies of Persons with Disabilities";
 - . **Income Support Reform** - Harry Beatty, "The Case for Comprehensive Disability Income Reform";
 - . **Women** - Mary Reid and Regina Ash, "Issues and Perspectives of Women with Disabilities: Background Paper";
 - . **International Context** - Disabled Peoples' International, "International Implications for the Development of a Canadian Framework for Action";
 - . **Aboriginal People** - New Economy Development Group Inc., "An Overview of the Situation of Aboriginal Persons with Disabilities".
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Altogether these reports and contributions provided a wealth of information, data, ideas and analysis for shaping the discussions and developing the strategic framework which follows in this section of the report.

A strategic framework is about knowing where we want to go in the long term; and using that knowledge as a screen for decisions which are being made, in the short term, about policies, programs, services and funding priorities. A strategic framework can be a valuable and practical tool for giving greater shape and coherence to what we do every day.

The framework which is emerging from Mainstream 1992 is built upon those ideas and values which are shared by Canadians, with or without disabilities, and by their governments. This framework consists of a vision and a statement of principles. It includes also consideration of a series of those key strategic directions which flow from the vision and principles. These concern the disability-related supports required by people with disabilities, the role of social services and the four areas identified by Ministers at the outset of this process: employment-related services, community/independent living, prevention/promotion, and income support/replacement.

b. Vision

Issue

The project's Terms of Reference asked for validation of the "Open House" vision as a collective statement of the place of people with disabilities in Canadian society, in the Canadian "house."

Discussion

Following the 1986 to 1988 review of fiscal arrangements, governments began developing an "Open House" vision of the place of people with disabilities within Canada. The purpose of articulating this vision was to arrive at common understandings and common goals among governments, consumer groups and individual Canadians with disabilities.

The open house concept evolved from earlier approaches adopted by society for providing services to people with disabilities. These earlier approaches, characterized as the "warehouse model" and the "greenhouse model":

- . viewed people with disabilities as a homogenous group rather than as individuals, and as incapable of assuming responsibility for their own well-being;
- . adhered to a medical model, emphasizing treatment and efforts to cure while stopping short of supporting ongoing disability; and
- . segregated people with disabilities, sometimes in institutions and very often in separate programs rather than within mainstream services.

In contrast, the open house philosophy and vision, which can be found as Appendix C of this report, emphasizes the importance of people with disabilities being able to integrate into the mainstream of Canadian society. In essence:

The "Open House" vision looks forward to a society in which people with disabilities enjoy the same rights and the same benefits as do other Canadians.

It is a society in which people with disabilities are participating fully in all aspects of community life, including school, work and recreation. They are able to participate in the mainstream because environmental barriers have been removed and disability-related supports have been provided. Finally, it is a society in which people with disabilities, like other Canadians, have control over the decisions which affect them and which influence their lives.

This vision recognizes the diversity of Canada and acknowledges people with disabilities as being part of that enriching diversity. It looks forward to a society which adjusts to accommodate diversity rather than expects individuals to adjust to a status quo which does not reflect the abilities and the aspirations of people with disabilities. And it looks forward to a society which adjusts both its physical infrastructure and its social values so as to accommodate people with disabilities.

The vision anticipates a society which rejects paternalism and excessive dependence upon government. It is a society in which individuals, families and communities are jointly responsible for making decisions and for developing solutions to the issues of the day. This vision assumes that people with disabilities will possess the tools - including the disability-related supports which they require from governments - for exercising this responsibility. And it assumes that, with those supports, they will exercise that responsibility in a manner which benefits all of society.

Finally the vision looks forward to a society in which every person is treated equally and equitably, as a matter of right rather than of privilege. For people with disabilities, that means a society in which all the benefits of citizenship which are available to others - whether education, employment, recreation, transportation, communication or housing - are available equally to them.

Implications

Emerging from the governmental discussions and the community consultations which made up Mainstream 1992 is a single vision incorporating the open house and the consumer concepts. This vision reflects the willingness of our society - governments, communities and individuals together - to accommodate people with disabilities. It acknowledges both their rights and their responsibilities, emphasizes empowerment and recognizes the necessity of adapting the social and physical environment so as to remove handicapping conditions.

More fundamentally, the vision suggests that people with disabilities should have access to the supports which will enable them to participate fully in society. The broad objective of this vision is to work toward a position of equality for persons with disabilities. And that equality does not mean only treating them exactly the same as everyone else; instead it means that people with disabilities have a right, equal to that of other Canadians, to share equitably in the benefits which Canada offers all its citizens.

This vision would imply that special measures may be required to ensure this equity, measures which:

- . in the long term, remove those barriers which create handicapping conditions and, in the short term, reduce their effect; and
-

- in the long term, provide individuals with the full range of disability-related supports which will enable them to participate equally in the mainstream of Canadian society and, in the short term, provide services in a manner which is consistent with the vision.

Importantly the vision implies also that governments have a very significant role to play in leading society toward this vision. Part of that role would be educational; part would be facilitative. And to be consistent with the vision, governments would have to consider incorporating approaches within their current activities which empower people, which respect their rights and which enable them to assume and fulfil their responsibilities.

The outcome of this vision would be a society which not only would open its doors to people with disabilities, and become an open house, but one which would recognize their share in the ownership and responsibilities of that house. In other words, the open house would become "Our House," shared equally by all Canadians.

c. Principles

Issue

The Terms of Reference developed for Mainstream 1992 also asked whether individuals and consumer groups would validate the draft statement of principles prepared for the consultation process.

Discussion

In undertaking Mainstream 1992, Ministers developed a statement of principles which was intended to be consistent with the open house vision and to give shape to the strategic framework which would emerge from the process. This statement of principles reads as follows:

Canadians recognize that persons with disabilities should expect:

- the opportunity to participate in all aspects of the economic, social and cultural life of Canada;
-

- . access to goods and services which give them equality of opportunity;
- . the least restrictive environment possible;
- . participation in decision-making regarding programs providing goods and services which affect them;
- . accessibility to general systems of society, provided by the public and private organizations which operate those systems; [and]
- . development by society of effective measures to prevent impairments, disabilities and handicaps.

Emerging from the Mainstream 1992 process, then, are two broad statements of principle concerning people with disabilities: the one articulated above which governments brought into the process and one which emerged from the consumers involved in the process, as presented on pages 16 and 17 of this report.

The content of each statement is very similar and is entirely consistent with the vision discussed above. Both speak, for example, of full participation by people with disabilities in all aspects of mainstream Canadian life, of access to services and of involvement in making those decisions affecting them.

These are important common elements and provide important directions for governments and society. But at the same time the two statements of principle incorporate some equally important differences in tone and strategy. The consumer statement of principles, for example, is more directive than the government statement. In some ways its scope is also broader, suggesting that the framework which emerges from the principles "would be more than a new set of social services arrangements. It would be a new policy and legal framework, with corresponding funding and social services implications, to realize the Equality and Citizenship Rights principles." (Roche Institute, Consultation Summary, 1992:8)

Furthermore the consumer statement offers more specific directions for putting the principles into practice. For example, while both suggest empowerment as a principle, the consumer

statement suggests that people with disabilities be directly involved in the design and evaluation of all public policies and programs which affect them. (Roehner Institute, Consultation Summary, 1992:8)

Implications

While the differences in strategy inherent in the two statements of principle are undeniably important, they do not take away from the commitments and directions which both are outlining. Governments and the community of people with disabilities involved in *Mainstream 1992* appear to have reached a point where they are sharing certain principles.

Building upon these common values, the following concepts constitute a statement of principles which both consumers and governments alike may be able to validate:

Rights and responsibilities: people with disabilities have the very same rights, and the same responsibilities, as other Canadians. They are entitled, as others are, to the equal protection and the equal benefit of the law and require measures for achieving equality.

Empowerment: people with disabilities require the means to assume responsibility for their own lives and their own well being. Efforts are required to encourage them to take control, and to support and promote their efforts in this regard.

Participation: people with disabilities require full access to the social, economic and physical infrastructure which supports our society so that they can participate fully and equally in their communities.

These principles imply very clearly the need for both on-going and new efforts to adapt the social and economic environment, to provide opportunities equal to those enjoyed by other Canadians, to ensure access to the goods and services which people with disabilities require and to adhere to an empowering model in decision-making processes.

For governments, these principles can be used to establish a clear policy and program screen for their decision-making processes. They provide a pathway toward a common vision, with the specific actions being determined within the particular fiscal, policy and program context of each different jurisdiction.

d. Strategic Directions**Issue**

What are the main strategic directions which governments must consider if they are to accept the vision and principles emerging from the Mainstream 1992 process, with respect to:

- . the consumer concern that society assume responsibility for the specific disability-related supports required by people with disabilities;
- . the most appropriate role for social services; and
- . the four policy areas identified by Ministers in the Terms of Reference, namely employment-related services, community/independent living, prevention/promotion and income support/replacement?

1. Strategic Direction: Disability-Related Supports**Discussion**

During the Mainstream 1992 consultation process, consumers emphasized that they will enjoy a position equal to other citizens only when society assumes direct and full responsibility for providing the specific disability-related supports which they require. They described this as their most critical long-term concern and objective.

There are often significant costs associated with a specific disability. To participate in the paid labour force or in training programs for example, the person with a disability might have to incur the expenses associated with his or her attendant services, with sign language interpretation or with a host of other supports depending upon the individual's abilities and circumstances, and upon the environmental conditions which he or she must face. The need for these specialized supports is, of course, unique to people with disabilities and comes in addition to those needs experienced by other Canadians, child care for example.

If a person with a disability cannot afford the costs associated with acquiring these supports, or if they simply are not available, he or she is denied the opportunity to participate equally, whether in employment, education, training or any other activity available to other Canadians.

Furthermore, even if people with disabilities had jobs and incomes on a par with other Canadians, what would be left after disability-related expenses are provided for is a disposable income well below that of the rest of the population. This situation exists in spite of successive tax measures intended to benefit some persons with disabilities, for example the attendant care deduction. Thus again, consumers argued that they are being denied an equal place in Canadian society on the basis of their disability.

Implications

To achieve the equal status articulated in the vision, the strategic framework implies that this economic barrier, like other discriminatory barriers, be removed. The consumer strategy suggests "public coverage for disability-related costs ... as being the only viable way to promote and safeguard the exercise of Equality and Citizenship Rights by people with disabilities." (Roeher Institute, Consultation Summary, 1992:10)

The consumer strategy suggests that society make available the full range of these supports to all those who require them, when and as they need them through their different life situations and transitions. These supports would be available equally across Canada and equally to all Canadians with disabilities regardless of their income. In this regard consumers suggested a system similar to that provided by governments, for those who require medical care. Furthermore they suggested this approach should not be premised upon a welfare model regardless of what restraint and controls might be built into the system in order to ensure accountability and fiscal responsibility.

This suggestion raises certain important and difficult questions. Perhaps the most fundamental of these concerns who is responsible for the financial costs associated with a disability. Is it the individual, his or her family, or society as a whole? A second question concerns the basis upon which society, and government, would determine priorities and would provide - or even ration - services.

A third question concerns the cost of such an approach, and essentially asks whether it is affordable in Canada today. The consumer discussions made clear, however, that for them the issue at this time is one of principle; and that there were many options to consider relating to accountability, cost-effectiveness and efficiency within the current expenditures on disability-related supports. Overall, however, the cost of providing these supports presents a formidable barrier to achieving the vision enunciated through the Mainstream 1992 process.

2. *Strategic Direction: Role of Social Services

Discussion

Consumers and consumer organizations used the consultation process to reconsider the role which the social services sector has played relative to people with disabilities. Traditionally this has been a large and very important role which has attempted to meet the full range of needs which exist. At the same time, however, it has not been an entirely appropriate role.

In the past, many mainstream agencies have not necessarily adapted their services so that they are accessible to people with disabilities as they are to other Canadians. For example, many transportation, education and job training services:

... present barriers that prevent people with disabilities from taking the same advantage as other citizens of the services and opportunities they offer. As a result of these barriers, the social service system has become bogged down in its attempts to pick up the pieces left by the failure of other sectors to assume their social responsibilities. A parallel structure -- indeed a large industry -- of costly disability-related services has been spawned outside of the social mainstream that tends to keep people with disabilities out of the social mainstream." (Roehrer Institute, Consultation Summary, 1992:37)

Consumers are reconsidering the most appropriate role for social services at a time when social services agencies themselves are rethinking their place in society and in the spectrum of government services. There is a recognition that, alone, social services is not capable of resolving the broad range of economic and social problems which have created their "caseloads." Addressing these problems requires concerted efforts across society, for

example, from a range of health, education, transportation, and housing organizations. It requires new models and methods which address the complexity of providing social and income security to all Canadians.

The Mainstream process, and the vision which is emerging, provide social services with a strategic framework for clarifying its role in relation both to people with disabilities and to other agencies of government.

With regard to these other agencies, the consultation process suggested that the social services sector should no longer be responsible for the full range of needs experienced by people with disabilities. Rather the responsibility for providing conventional services - health, housing and transportation services for example - should lie with those departments and agencies which bear the same responsibility for other Canadians.

In other words, people with disabilities should receive services equal to those received by other Canadians from the mainstream agencies that serve other Canadians. These mainstream services, however, will have to be adapted to the needs of people with disabilities so that they can share equitably in what is provided. Similarly "mainstream" social services - child care, income support, job readiness training - should themselves be adapted so as to be fully accommodating to people with disabilities.

Clearly the status quo is becoming ever less practical and viable. The financial and service demand burden on social services is outstripping its ability to respond in an effective, timely and sensitive fashion, especially given the limits imposed by the climate of fiscal restraint. At the same time, demographic trends mean that the costs associated with providing services are going to increase significantly through the years. A new role for social services is required if the vision and principles are to be achieved in a manner which is fiscally responsible and cost effective.

Implications

Consumers and the social services sector alike are looking for a new role for the sector, one which is consistent with the open house vision and principles, and one which reflects the

fiscal realities of Canada through both the short and the long term. That search for a new role raises important implications in three main areas:

Shifting to the Mainstream

The Mainstream 1992 vision implies a narrower albeit no less important role for social services across Canada. They would no longer have primary responsibility for providing people with disabilities with the full range of services which they, like other Canadians, require. Instead that responsibility would devolve to mainstream departments, and to other sectors of society. The mainstream concept suggests a role for families, communities and all private and public sectors in enhancing opportunities for participation by persons with disabilities.

The vision may also imply that there be a transitional period during which social services could come to understand and adapt to the principles themselves, and then assume an education and advocacy role, both within and outside of government. The purpose of this role would be to ensure that those mainstream agencies having to adapt their services would come to understand and fulfil their roles and responsibilities for people with disabilities as they do for other Canadians. This transitional phase would help to ensure that the social services sector does not divest itself of its responsibilities until those other departments and agencies are prepared to meet the new challenges before them.

This sort of transitional period may be essential in part to assure consumers that divestment of mainstream activities from social services to mainstream sectors is not merely an off-loading exercise driven by considerations relating to cost. It is critically important that divestment be, and be seen as part of a well-considered action plan designed to facilitate the integration of people with disabilities into the mainstream of Canadian life.

Accommodations within Social Services

Within the social services sector, the vision requires and the principles define a role which fully includes people with disabilities within conventional social services programs.

This means that social services programs and services would have to be adapted so as to be available equally to people with disabilities as to other clients. This approach would apply, for example, to child care for sole support mothers with a disability, to employment programs for social assistance recipients with a disability, and to services for unemployed youth with a disability. Such commitments to include people with disabilities would also affect government contracting policies with non-governmental agencies.

Beyond this, the vision and principles, and in particular the consumer concept of these, imply that social services strive:

- . to accommodate the range and level of needs which exist among consumers; and
- . to provide services in a manner which empowers individuals and looks to them for accountability.

Disability-related supports

The continuing role of social services in providing disability-specific programs and services was affirmed throughout the Mainstream 1992 process. The implication, however, is that the objectives and delivery mechanisms shift to emphasize the provision of disability-related supports on an individualized, empowering basis.

The vision further implies that social services explore different models for providing the goods and services for which it would continue to be responsible. To be consistent with the principles identified above, social services may wish to reconsider, for example, their traditional concepts of employability and their current means of assessing need, determining eligibility and ensuring accountability.

A further example - and a critical one given the vision - would involve the social services approach to funding services for people with disabilities. The empowerment principle would imply that funding for services be directed not to agencies but to the individual with the disability. This individual would then be empowered to determine the extent of service he or she requires, and the source of that service. This approach would mean that service providers would become accountable to the consumer as well as

to the funding agency; and it would mean that consumers themselves would have to assume some responsibility and accountability for decisions around rationing and service priorities.

3. Strategic Direction: Employment-Related Services

Discussion

In our society, employment is the key to independence, self-sufficiency and economic well-being. Yet all sources, including the Statistics Canada data presented in section 3, indicate the low participation rate of people with disabilities in the paid labour force. Their exclusion from the paid labour force:

- . is inconsistent with the vision being articulated through the Mainstream 1992 process;
- . creates a very significant cost to society which must provide support to these individuals; and
- . represents a tremendous lost opportunity not only to the individuals involved but to employers and society as a whole.

The low participation rate of people with disabilities is due to a variety of forces including the low educational and skills level of some. In many cases, however, it is due to the barriers which exist in society and in the workplace. These barriers often prevent people with disabilities from acquiring the education and skills which they require to participate equally in the work force; and certainly these barriers prevent even those with the education and skills from acquiring suitable employment.

Increasingly governments, and departments or ministries of social services, are attempting to understand and address these barriers and the cumulative impact which they have on the ability of individuals and groups to participate in society.

Efforts to remove these barriers for people with disabilities and to ensure their ability to participate in the paid labour force require efforts along two routes. One route would

address the environmental barriers which inhibit their ability to participate; the other would address the personal supports which they require in order to participate.

Environmental Barriers

Efforts are required in order to modify the environment so as to remove discriminatory barriers to employment.

On one level, this means changing and adapting the workplace so people with disabilities can participate as others do. It means changing attitudes and coming to recognize and understand the potential of people with disabilities. It means a new focus for society and employers, a focus on abilities rather than disabilities. It also means providing new opportunities by removing systemic barriers, for example adverse recruiting policies, and accommodating individual needs.

On another and more fundamental level, removing barriers will require broader and more comprehensive efforts which reach back into the mainstream educational system, at all levels, and into the full range of training programs. Without such efforts, people with disabilities will be denied the skills and experience they require to compete within the paid labour force.

These efforts will mean modifications, for example, to public transportation systems so people with disabilities can get to work. And they will mean changes to the various programs of income security available in Canada so that these support the efforts of people with disabilities to remain in the paid labour force or to return to the paid labour force.

Personal Supports

At the same time as the environmental barriers are removed, there would have to be efforts - comprehensive and individualized efforts - to provide people with disabilities with the specific, disability-related supports they require in order to participate in the paid labour force. The list of possible supports is extensive; but what any particular person with a disability might need is very much an individualized matter which depends upon his or her own ability, disability and circumstances.

Individual consumers and consumer organizations provided clear descriptions of the shortcomings within the Canadian efforts to provide these disability-related supports: some are available to some people but not to others because of program or budget limitations; some are available in the home but not in the work place; some are available in larger cities but not in smaller communities or rural areas; and some are available in one jurisdiction but not in another. Unlike in the health system, need does not guarantee that the disability-related supports will be available.

Implications

Governments and consumers clearly share a concern that people with disabilities should participate, equally, in the paid labour force. Yet the implications of adhering to the open house vision and principles in terms of addressing employment-related services are often viewed as far-reaching in terms of potential costs, employment equity policies and the demands of other individuals and groups who face similarly profound barriers to labour force participation.

At the same time, the strategic framework emerging from the Mainstream 1992 process implies a long-term approach which in this case is essential for addressing the problems, and the barriers, in an effective manner.

The framework implies extensive efforts throughout our society. For example, it suggests public information strategies and other measures targeted to employers which would assist them to assume their responsibilities for accommodating the special needs of people with disabilities. It implies efforts to ensure accessibility and participation.

The framework also implies extensive governmental efforts at all levels to remove environmental barriers within their own mainstream services. An educational system which fully accommodates the special needs of people with disabilities will provide opportunities for them to acquire the education and skills which they need to participate in the labour force. A transportation system which treats all Canadians equally would enable them equally to reach the work site and ensure that this alone does not preclude them from labour force participation.

Similarly, a social services system which provides specialized supports to people with disabilities, in addition to those other services which it provides to others attempting to enter the labour force, would again enhance their opportunity to participate equally and to become self-sufficient.

In the shorter term, meanwhile, the framework implies efforts on the part of the social services sector to assess how they provide support, how they can reduce the barriers and how they can introduce modifications which move their programs along the vision's pathway while respecting the fiscal imperatives which currently exist.

4. Strategic Direction: Community Living/Independent Living

Discussion

Community living and independent living are both broad concepts which derive from what consumers perceive as their right to participate fully in their communities.

These concepts encompass the full range of community-based activities rather than being a discrete area which can be considered separate from, for example, employment-related issues. In this vein, the community/independent living concepts involve two fundamental principles: the right of people with disabilities to live and work in their communities and their right to control their own lives.

Participants in the Mainstream 1992 consultations endorsed the concepts inherent in the community/independent living themes. At the same time, some of the consumer organizations offered a broad range of specific recommendations which constitute a long-term strategy for entrenching these principles in the everyday reality of life for people with disabilities. The list of recommendations reflects the comprehensiveness and inclusiveness of the concepts, and the "basic entitlements" which they perceive as essential for ensuring rights in this area. (For example, see the Roehrer Institute Consultation Summary, pp. 19-21)

Consumers also suggested that their on-going experience with policies and programs reveals a number of disincentives to community integration: attitudinal barriers to integration, the multiplicity of uncoordinated programs, ambiguity in mandates for services, "gatekeepers"

for access who do not involve consumers, program conditions which limit potential for independence, inadequate funding of community-based as opposed to institutional services, and lack of consumer decision-making authority, responsibility and accountability.

Implications

The community/independent living concepts are broad and encompassing, and are central to the mainstream vision and the strategic framework emerging from the Mainstream 1992 process. Because of this, the implications for social services and for governments are similar to those identified in regard to the other strategic directions:

- . They involve efforts, first, to devolve responsibility from the social services sector to mainstream agencies. People with disabilities cannot be considered equal to others while their services are provided within a separate and segregating model.
- . Second, they involve the provision of a broad range of disability-related supports so that persons with disabilities can utilize mainstream services and can live and work in the community.
- . And third, they involve efforts to change attitudes and to remove environmental barriers.

The strategic framework implies a broad strategy for social services. Part of the strategy would involve efforts to educate and to develop an awareness and a commitment to service within mainstream departments of government and within the community. The second part of the strategy would be to provide those supports which address the functional limitations of people with disabilities and which inhibit their integration in the social and economic structures of the community.

Perhaps most importantly, the implications of the community/independent living concepts imply the full empowerment of people with disabilities. Most significantly, it is suggested this may lead, through the long term, to:

- . directing funds to individuals to enable them to purchase, organize, manage and control the supports they require;
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