

- . providing support for as long as it is required, through the different life transitions experienced by people with disabilities;
- . ensuring that disability-related supports are portable across provinces and territories; and
- . ensuring a major role for consumer groups in the delivery of these supports.

In the shorter term, the concepts imply a range of pragmatic modifications by the social services sector in the way services are provided. For example, it would be possible to:

- . identify the rehabilitation and support services needed to enhance the individual's capacity for full participation in his or her community, including employment;
 - . pursue alternatives for those not accommodated by mainstream programs;
 - . enhance the resources available to families and peer support groups, including respite care;
 - . develop more extensive and more effective links with other professional supports within communities and integrate further the network of supports which already exist in many communities;
 - . develop community services to meet needs of specific elements of population - children, youth, women, seniors, aboriginal people - while recognizing the specific cultural or gender needs of each individual;
 - . develop shared decision-making processes so as to enhance the responsibilities as well as the rights of people with disabilities;
 - . support leadership development among consumers as well as other empowerment initiatives; and
-

- develop new processes for accountability which ensure that service providers are answerable both to funders and to consumers and that consumers have some responsibility for ensuring that funds are used reasonably.

These policy directions are important components of the strategic framework in that they can give concrete form to the vision and principles emerging from the Mainstream 1992 process. They invite change - both fundamental and incremental - in the way in which the social services sector provides services and they raise implications concerning cost, accountability, cost-benefit and the degree of priority which society attaches to services for people with disabilities.

At the same time, however, the social services sector, across Canada, is experiencing tremendous fiscal and policy pressures and is itself seeking changes. For this sector, the objective of change is not only equality but greater responsiveness, greater cost-effectiveness and a better distribution of responsibilities among governmental and non-governmental partners including consumers. The community/independent living concept and the framework of which it is part suggests a path toward these objectives.

5. Strategic Direction: Promotion/Prevention

Discussion

Another area identified by Ministers at the outset of the Mainstream 1992 process concerned prevention and promotion. As with community/independent living, however, the prevention and promotion concepts permeate the full range of issues and approaches of concern to people with disabilities.

Both the governmental and the consumer visions under consideration during the Mainstream 1992 consultations address the prevention/promotion concepts. On the one hand, the concepts reflect those trends evident in many developed countries and in the United Nations declarations concerning the rights of people with disabilities. On the other hand, they also reflect the commitments made by Canadians in their Charter of Rights and Freedoms and in their human rights codes. These commitments affirm that our society values diversity and

respects the right of people to be different, whether in terms of religious belief, race, physical or mental ability.

The prevention/promotion concepts go well beyond mere acceptance or accommodation of the needs of people with disabilities. Instead they seek to ensure that the same respect which is accorded all Canadians is given to them also.

As is the case with the other strategic directions, there are two approaches toward this destination. One, concerning promotion, would involve shaping public attitudes, promoting equality rights, social empowerment, respect and the social and economic well-being of people with disabilities. It would mean promoting an understanding that people are handicapped not by their impairment but by a social, economic and physical environment which can be intolerant of the many differences which exist in our society.

The second approach, concerning prevention, would involve a variety of efforts also. To some extent, this would involve preventing disabilities but only in a way which does not devalue the human dignity of those Canadians with disabilities. More in line with consumer thinking, prevention would entail eliminating the conditions and hostile environments which place people with disabilities at greater risk of poverty, of exclusion from the social and economic mainstream, of powerlessness and of dependence upon medical and other "gatekeepers."

Implications

As in the other areas, the strategic considerations which flow from the prevention/promotion concepts imply efforts to promote consumer control and to eliminate hostile environments. Furthermore efforts would be required to ensure that people with disabilities, like other Canadians, have

- . access to the full range of opportunities available in Canada, e.g. employment, education, training, transportation; and
 - . access to the range of social supports which they require in order to promote their ability to live in their communities.
-

Consumers suggested that governments have a particular and active role to play in this effort; and that the social services sector be only a part of the total government effort in this regard. The mainstream vision implies, for example, that prevention initiatives, directed toward primary prevention of impairments leading to disabilities, are most properly in the realm of health rather than social services.

The vision, as far as prevention/promotion is concerned, would also imply that social services has an important and challenging responsibility to eliminate obstacles within its own programs, to develop standards and safeguards, and even to serve as a model. Consumers in the prevention/promotion focus group suggested that the Mainstream 1992 process itself represented a social services-initiated model for consultation, for involving those most directly affected and for forging partnerships.

6. Strategic Direction: Income Support/Replacement

Discussion

The Statistics Canada data presented in S.2(d) reflect the importance of the income support and replacement programs in place across Canada for people with disabilities. Many are obliged to rely upon these programs on account of both the discriminatory barriers to their participation in the paid labour force, and the often very substantial costs associated with their disability.

Essentially there is an array of income support and income replacement programs in Canada providing assistance to people with disabilities. These programs, however, provide very different levels and kinds of benefits largely on the basis of the cause of a person's disability rather than on the basis of his or her abilities and needs.

During the consultations, consumers suggested that these programs, and the welfare and medical models upon which they often are premised, are seriously flawed:

- . First, they do not provide adequately for the specific disability-related needs of people. This is a serious shortcoming in the absence of a national program specifically addressing these needs.
-

- . Second, the existing programs do not generally provide adequate levels of income to people with disabilities.
- . Third, there are a number of inequities across the various welfare and insurance programs, and in different parts of the country, which result in people, with possibly the same needs and the same circumstances, being treated very differently and receiving very different kinds and levels of support.
- . Fourth, the different programs of income support and income replacement for people with disabilities often include various criteria and rules which undermine the efforts of individuals to live and work within their communities.

In this regard, consumers suggested that there are significant barriers - within welfare and pension programs for example - to participating in the paid labour force:

- . Within social assistance programs, their income benefits may be reduced if they consider themselves to be "employable" rather than "unemployable."
- . Within pension programs, they may be precluded from efforts to participate in the paid labour force in a manner which reflects their abilities.
- . In some programs, the wages they earn, perhaps through part-time employment, may be inadequate to compensate for the in-kind benefits they lose, for example extended health care.
- . Particular supports may be available in their home but not in the work place.

Overall consumers placed considerable emphasis on the barriers to their entering the paid labour force.

At the same time, consideration is required of a range of administrative and delivery issues which constitute further inequities within the programs of income support and income replacement. The manner in which program benefits are made known to those who are eligible, the manner in which applications are handled, the manner in which eligibility

criteria are determined and the timeliness of the support provided not only serve to create barriers for people with disabilities but often differ from program to program.

Implications

The issues raised in Mainstream 1992 concerning the income support/replacement programs have implications not only for people with disabilities but for many other groups and individuals. Within social assistance there arises the question of whether governments can address the needs of one group of individuals without taking a more inclusive approach - to benefit levels, to the supports provided - that applies equally to single parents, unemployed youth or aboriginal people for example.

At the same time, the strategic framework challenges governments to address the specific needs of individuals within a group. People within the disability community are as diverse as those within any other group. Each has different abilities and can participate - in the community and in the paid labour force - to different degrees if an appropriate and individualized array of supports is available.

The Mainstream 1992 vision invites governments and the social services sector to address a range of questions relative to income support and income replacement, for example:

- . What constitutes a basic level of adequacy and can Canadian society afford either to provide or not to provide an adequate level of income support given the relationship between low income, inequity and opportunity? In this regard, the inequities between programs become obvious as different programs, targeted to different groups of individuals, rely upon different definitions of adequacy.
- . What are the long-term costs and benefits of providing more adequate income support to individuals and the possibility of reorganizing the current expenditures in ways which more fully recognize the needs of people with disabilities?

In this regard, a research paper prepared for the Mainstream 1992 process identified what consumers consider a "more realistic" approach to determining cost-effectiveness by incorporating:

- . a long-term perspective on the cost-effectiveness of reforms;
- . a recognition that any short-term savings from reform will create even bigger long-term 'pay-offs' if they are used to further improve the programs rather than being diverted;
- . a commitment to tempering cost-effectiveness criteria with considerations of social equity and justice, so that reforms designed to provide a better system in the long run will not penalize persons with disabilities in the short term; and
- . an understanding of the essential relationship between the effectiveness of disability income programs and broader socio-economic policies, particularly those related to employment. (Harry Beatty, "The Case for Comprehensive Disability Income Reform," 1992:4)

This research paper also discusses the concept of a Comprehensive Disability Protection Program.

The Roeher Institute contributed a further perspective suggesting that society "is already making a substantial financial commitment to fund the additional costs of disability. A key problem is that the funding and spending does not correspond to a coherent vision or policy on how to address disability and the related costs as a basic fact of life." (Roeher Institute, Consultation Summary, 1992:27)

Ultimately then the vision and principles emerging from the Mainstream 1992 process imply that governments examine their programs of income support and income replacement with a view to equity across programs, adequacy within programs and reducing barriers to community and independent living, including employment. Furthermore they invite governments also to examine the delivery systems employed within each of the programs so as to ensure that they are consistent with the principles underlying the strategic framework.

5. PATHWAY

The Mainstream 1992 review provided governments, individual Canadians with disabilities, consumer organizations and service providers with an opportunity to share their knowledge and experiences, and to examine both their concepts of the future and their specific ideas for that future. This coming together of people and ideas reflects the goals inherent in the commitment to a mainstream approach. It recognizes that governments cannot alone be responsible for removing the barriers and providing all of the supports required by people with disabilities if they are to participate fully in their communities. Instead this is a responsibility which all Canadians share.

Governments have a definite role to play - to provide leadership, direction and support. They can facilitate the process. But individuals, with and without disabilities, have a responsibility as well, to respect the rights of other Canadians and both to support and to encourage efforts to end discrimination. Employers have a role to play, making their workplaces accessible and providing opportunities for people with disabilities in the same way they provide opportunities to other Canadians. Schools, post secondary institutions and training programs have to ensure that they are open, accessible and well suited to the particular needs of all Canadians; programs and institutions have a responsibility to meet the needs of their clients rather than the other way around. Service organizations and community-based groups, recreational and sporting groups all have a role and a responsibility in moving Canada ever closer toward the mainstream vision of a society which is open to people with disabilities and to all other Canadians.

In other words, all Canadians have both a role and a responsibility to ensure that their society includes rather than excludes people. The Mainstream 1992 process recognized that the vision would not be achieved without everyone being prepared to contribute in this way.

An objective for the review was to develop a strategic framework which would promote a respect for appropriate roles and responsibilities. At the same time the framework respects the differing contexts and capacities of individual governments, communities and organizations. These differences might mean that there would not be one timetable for moving along the pathway to the vision. Each jurisdiction and agency involved in this process operates within a different context. Each has its own mix of priorities and pressures,

fiscal and other, which oblige it to proceed in different ways and at different speeds, and to wait and rest at different junctures.

Recognizing that reality in no way detracts from the value and importance of the strategic framework. By adhering to a collective framework, governments, communities and individuals can travel together in a coherent manner toward the vision which they share. This section of the report presents the key components of that destination and the issues which governments will want to address as they move along the pathway.

a. Destination

The Mainstream 1992 process made it very clear that, although differences certainly exist, there is generally speaking a consensus on the destination which consumers and governments alike want to reach. This destination is expressed in the "Open House" vision and incorporates three closely interwoven and inextricably linked principles:

Rights and Responsibilities

The vision is predicated upon a recognition that disability is a basic condition which transcends categorization in terms of traditional approaches such as welfare, medical, or employment paradigms. This basic condition - the disability - must be addressed before people with disabilities will be able to participate on equal terms as other Canadians, exercise the same rights as other Canadians and benefit in the same ways as other Canadians.

Empowerment

Empowerment means equipping people with the tools necessary for them to assume responsibility for their own lives and well being, encouraging them to take control, and supporting and promoting their efforts in this regard. Empowerment means that individuals can control the decisions that affect them, the policies that influence their lives and the programs established to meet their needs.

Participation

Full participation of persons with disabilities in the educational, employment, consumer, recreational, community and domestic activities that typify everyday Canadian society requires a range of efforts to facilitate access to these. It means that discriminatory barriers - social, economic and physical - will have to be removed and accessibility enhanced for people with disabilities.

b. Pathway

The strategic framework provides governments with a pathway for progressing toward their destination and for ensuring that these three interwoven principles become entrenched in all the programs and services available to people with disabilities. While progressing on that pathway, however, governments will want to address a number of broad issues, identified below, which extend beyond the social services sector and well into the intergovernmental realm.

1. Fiscal Realities

In moving toward the destination, governments will have to work within the context of the current fiscal realities. Both consumers and other participants in the Mainstream 1992 process recognized that at this time and within existing expenditure levels, there is not the capacity to achieve all the elements of the vision or to meet all of the needs which exist. The consultations made clear the extent of the shortcomings within the current array and level of services.

This is a population which is underserved in relation both to their disability-related needs and their situation in their communities. Some suggest that people with disabilities are more underserved than any other population in Canada. This means that there is some catching up to do just to bring people with disabilities to a point where they are as advantaged - or no more disadvantaged - than any other group of Canadians. The additional disability-related burdens imposed upon this population need to be removed if our society is to make significant progress toward the open house vision.

At the same time, it is clear that the current systems already carry significant costs and that these are likely to increase in the future given the demographic, social and legal shifts occurring in Canadian society. The challenge facing governments, therefore, is not simply one of containing costs; instead it is to shape current and future expenditures in a way which is consistent with the strategic framework and the "Open House" vision.

Governments can progress along the pathway by identifying what and how they are spending now and assessing whether these expenditures are consistent with the strategic framework. It means asking whether the services already being provided are the right ones, the most effective ones and the ones which are most acceptable to people with disabilities.

There may well be room for governments to redirect and reinvest their current expenditures in ways which bring them, and bring people with disabilities, closer to the vision being articulated through the Mainstream 1992 process. But the vision cannot become a reality, for all people with disabilities, without a further investment of financial resources.

The framework, and the success of the Mainstream 1992 process, suggests that governments involve people with disabilities in the decision-making and rationing processes which are required. Such an approach may well help to ensure that expenditures, and current levels of expenditures, are most effectively spent.

2. Fiscal Arrangements

The current federal/provincial/territorial cost sharing arrangements relating to people with disabilities (i.e., Canada Assistance Plan (CAP) and the Vocational Rehabilitation of Disabled Persons (VRDP) Agreement) are often viewed as presenting a formidable barrier to working toward the vision. While both sets of arrangements have very many strengths, they are simply not adequately supportive of the new directions which emerge from the Open House vision.

These directions have been pursued in the strategic framework which this Mainstream 1992 report presents. Although the framework does not suggest any specific areas for program change or innovation, it is recognized that the present fiscal arrangements are

not entirely consistent with the directions indicated. In order to support the new directions, changes to these arrangements may be necessary in the future.

People with disabilities describe present cost sharing arrangements such as CAP and VRDP as being inadequate in that they do not assure equality and are ultimately unacceptable and unworkable as means of adequately addressing the additional costs of disability for those who require this. They suggest that new funding arrangements will be required. (Roeher Institute, Consultation Summary, 1992:11-13)

Various approaches and arrangements are available to governments, including the establishment of new fiscal arrangements which would enhance the lives of Canadians with disabilities. Any modifications to existing arrangements or any new arrangements must take into account the strategic framework of the Mainstream review and the fiscal consequences of moving in this direction.

3. Disability-Related Supports

The issue of most fundamental importance to consumers concerned a new approach for addressing, outside of the current income support/replacement system, the need for a range of disability-related supports and the cost of these to people with disabilities. In order to promote equality for people with disabilities, the vision implies that it is necessary:

- . first, to ensure that these supports are available to people with disabilities regardless of where they live and their life circumstances; and
- . second, to address the significant burden which the cost of these currently imposes upon the individual.

The strategic framework provides a mechanism to begin addressing these disability-related supports and costs by adopting an incremental approach, and by reassessing what we are doing now. Such an incremental approach would necessarily be taken within the current and future fiscal capacity of each jurisdiction.

4. Role of Social Services

The strategic framework emerging from the Mainstream 1992 process suggests a fundamentally different role for the social services sector across Canada.

First, social services would have an enhanced responsibility to ensure that their "mainstream" programs and services - child care and employment programs for example - are adapted so that they accommodate the specific needs of people with disabilities. Efforts would be required to ensure that they are as accessible and available to people with disabilities as they are to other Canadians.

Second, the breadth of the social services role could be significantly changed. The vision suggests that within government, mainstream departments would ensure that their services are accessible to people with disabilities. There would no longer be one service, provided by social services departments or ministries, for people with disabilities and another service, provided by mainstream agencies, for other Canadians. Social services would have an important role in assisting these mainstream agencies to assume their responsibilities and in ensuring that the transition from social services to mainstream delivery is smooth.

A third aspect of the social services role would be in terms of providing specific disability-related supports to people with disabilities. This would entail efforts to meet those needs which are specific and unique to this group of individuals. Finally, a fourth role would entail promotion and prevention initiatives in the larger community undertaken in concert perhaps with organizations representing people with disabilities.

Most fundamentally, however, the social services sector would want to consider not only what they do but how they do it. And in this regard, especially given the fiscal resources which are available, the "how" is every bit as important as the "what" in arriving at the destination.

That "how" would be defined by the principles which flow from the vision and would entail approaches - in what social services is doing now - which respect rights, facilitate empowerment and seek accommodation. The vision implies greater involvement by consumers in planning processes. It implies on-going consultation with consumer groups

and greater involvement by people with disabilities in planning the range of services which they require in order to participate equally in society.

5. National Standards and Objectives

The strategic framework implies services and supports being available to people with disabilities across their many life situations and across the many geographic and jurisdictional boundaries that exist in Canada. The framework implies also a certain level and quality of service.

In other words, the framework invites governments and the social services sector to consider national objectives and national standards concerning the services available to people with disabilities. Currently, objectives and standards certainly exist, but only within particular programs. There are few which transcend programs or transcend provincial and territorial boundaries.

Individual consumers and consumer organizations involved in the Mainstream 1992 consultations articulated their belief in the desirability of national objectives and national standards. To move in that direction, however, requires consideration of a host of complex, intergovernmental issues: how should these be defined; who should define them; how should they be enforced if they are to be enforced at all. Perhaps the most critical of these issues concerns the fiscal ability of governments to respect whatever objectives and standards are developed.

Meeting national objectives and respecting national standards may involve significant new costs for many administrations. And there is not in Canada, currently, the set of fiscal arrangements necessary or appropriate for supporting such standards. Funding and fiscal arrangements will have to evolve significantly in order to support the development and implementation of any such objectives and standards.

6. TOWARD THE VISION

The Mainstream 1992 consultation sought the views, the perspectives and the experience of individual Canadians with disabilities, consumer, service and advocacy organizations, experts in the disability-related field, and government participants. This review invited them to explore both their different perspectives and their common values.

These participants and each part of the process - the reference group meetings, the focus groups, the community consultations and the background research - contributed toward the development of a collective strategic framework for governments in Canada. That framework, described in the previous sections, presents a vision and a statement of principles for governments, and raises the key strategic directions which governments will wish to consider.

By adhering to a collective framework, governments, communities and individuals can travel together in a coherent manner toward the vision which they share. They can build on each others' experiences and strengths.

The Mainstream 1992 process made clear that there is a single destination toward which our society wishes to progress; but that there is not - and cannot be - a single timetable for getting there. This was part of the uniqueness of Mainstream 1992 in that it sought to accommodate the priorities and concerns of each of the participating sectors. The potential in this approach is very significant.

The strategic framework which is emerging from this process directs public attention to two levels of activity:

- . it implies very clearly a need to remove the barriers which exist still in Canadian society; and
 - . it implies efforts to change how governments and agencies operate and how they support the efforts and activities of people with disabilities.
-

The strategic framework is a valuable tool for taking the vision, the principles and the considerations surrounding the strategic directions and applying them to decisions which are being made every day. It invites participants - governmental and non-governmental alike - to reassess, on an on-going basis, what they are doing and how they are doing it. And it challenges governments and communities to align their programs, their policies and their practices with the vision and framework.

Mainstream 1992 brought together people, perspectives and views. And it proved the value of this interactive approach as it revealed not the differences between people and organizations but their common values, their common goals and their common commitments. These provide a foundation for collective efforts toward our collective future.

APPENDIX A

**MAINSTREAM 1992
TERMS OF REFERENCE**

MAINSTREAM 1992
A FEDERAL/PROVINCIAL TERRITORIAL REVIEW OF SERVICES
AFFECTING CANADIANS WITH DISABILITIES

TERMS OF REFERENCE

BACKGROUND

Interest in continuing cooperative work on services affecting persons with disabilities was confirmed by the Conference of Federal/Provincial/Territorial Ministers of Social Services in June, 1991.

MISSION

The Review is directed to the enhancement of the personal capacity of persons with disabilities, thereby enabling the achievement and maintenance of a mental, physical and/or social functioning level with optimal independence and participation in the mainstream of social, economic and cultural life of their community.

OBJECTIVE

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.

PRIORITY AREAS

This strategic framework will address four priority areas:

1. Employment Related Services,
2. Community/Independent Living,
3. Promotion/Prevention, and
4. Income Support/Replacement.

SPECIFIC TOPICS

Explicitly, the Review will seek to:

- o Clarify the role of "social services" (as opposed to other mandates/partners) in the four priority areas.

Role is defined here in a conceptual sense. It is recognized that individual jurisdictions may choose to assign operational or delivery responsibility to "social service" departments that fall outside the conceptual framework (and vice versa).

o Report on the responses to the Strategic Framework which addresses:

- Policy and Fiscal Pressures,
- Federal/Provincial Roles,
- Social Services and Other Mandates,
- National Standards/Objectives,
- Fiscal arrangements.

These responses will be based on input from the consultation process and will address each of the priority areas identified above.

CONSULTATION

Consultation with national organizations representing persons with disabilities, service providers and interested individuals will be carried out in a way which:

- o recognizes other previous or currently active federal, provincial or territorial consultations,**
- o reflects the joint federal/provincial cohesive nature of the Review,**
- o relies primarily on the input from representatives of national consumer-run organizations,**
- o is sensitive to the importance of input from individual consumers,**
- o provides opportunity for on-going dialogue,**
- o validates the "open house" concept as articulated in initial federal/provincial/territorial analysis and the following draft principles:**

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;

- development by society of effective measures to prevent impairments, disabilities and handicaps.

STRUCTURE AND PROCESS

Organization

o Steering Committee

There is a Steering Committee of the Deputy Minister of Health and Welfare Canada and several provincial Deputy Ministers, with federal and provincial co-chairs.

o Executive Committee

An Executive Committee, mirroring the Deputy Ministers' Steering Committee, with federal and provincial co-chairs, will be responsible for the ongoing activities of the Review.

o Federal/Provincial/Territorial Committee

There will be a Federal/Provincial/Territorial Committee made up of the Executive Committee and representatives from all other participating provinces and territories with federal and provincial co-chairs. In addition, representatives from other federal and provincial departments may be invited as appropriate.

o Secretariat

Day-to-day activities will be undertaken by a secretariat, in order to limit the demand on members of the above groups.

TIME FRAME

The exercise will be completed in 1992

REPORTING RELATIONSHIPS

Reports will be made by the Steering Committee of Deputy Ministers to the Federal/Provincial/Territorial Conference of Deputy Ministers of Social Services and, through the Conference, to Ministers as required.

A draft of the final report will be presented to the Conference of Federal/Provincial/Territorial Deputy Ministers in 1992.

APPENDIX B

COMMUNITY CONSULTATION: FINAL REPORT

COMMUNITY CONSULTATION: MAINSTREAM 1992 - FINAL REPORT

Annex i	Community Views and Themes Regarding Services Affecting Persons with Disabilities
Annex ii	Plain language questions for consultation
Annex iii	Focus Group participants
Annex iv	List of Written Submissions

COMMUNITY CONSULTATION:

MAINSTREAM 1992

FINAL REPORT

COMMUNITY CONSULTATION: MAINSTREAM 1992
FINAL REPORT
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COMMUNITY CONSULTATION: MAINSTREAM 1992

FINAL REPORT

Submitted by

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Consultants, Mainstream 1992

THE ROEHER INSTITUTE

to

THE EXECUTIVE COMMITTEE

MAINSTREAM 1992

October, 1992

Prepared by Cameron Crawford

INTRODUCTION

The Roeher Institute was contracted by the Executive Committee for Mainstream 1992: 1) to conduct focus group consultations; and 2) to review documentation submitted by consumer and other organizations in the disability field in response to "Views and Themes", the discussion paper prepared under contract to the Executive. The purpose of the focus group consultations was identify the key issues facing people with disabilities, and to look at concrete solutions to those problems. The purpose of the call for written and other prepared responses to the "Views and Themes" paper was similar.

During the focus group consultations, a wide range of issues pertinent to Mainstream 1992 were examined. The consultations involved a total of 79 participants, identified jointly by the Executive Committee and National Reference Group. The focus groups were held on the themes of: employment-related services; empowerment; transitions; prevention and promotion; income support/replacement, and community/independent living. Draft summaries of the key issues, themes, and policy directions/recommendations that emerged during the consultations were prepared and returned to focus group participants for comment. An effort was made to incorporate participant feedback into the final focus group reports. These reports in turn served as an important basis for this Final Report.

In some instances, focus group participants made comments arising from the focus group papers that pertained less to the actual substance of the focus group discussions and more to important issues that arose as an afterthought, or to the issues under examination in Mainstream 1992 as a whole. Rather than incorporating those comments into the focus group reports, these were incorporated into this Final Report.

Disability organizations (consumer, advocacy / representational organizations and service-providing) were invited to participate in Mainstream 1992 by submitting their responses to "Views and Themes". Efforts were made to ensure the present report reflects the input of the organizations that responded.

There is a high degree of consensus within the disability community on basic principles that participants believe should be guiding how disability and responses to disability-related issues, including social services, ought to be framed. Considerable consensus is also found

on matters of detail pertaining to the operation of new social service arrangements to address disability-related needs.

Part I of the following discussion briefly outlines some general concerns with the present policy and program arrangements, and outlines several new principles for which there is agreement. These principles constitute a new paradigm for thinking about disability-related support issues. Part I also briefly outlines how new social service arrangements would be organized to ensure individuals with disabilities obtain the supports they require. Part II examines these ideas in more detail, and examines how they would look in practice. Part III looks at issues concerning the specific focus areas for the review that require more attention than what is provided in Part II, including national standards and the role of social services.

Generally, the term "supports" in this report includes disability-related social services and disability-related aids and devices.¹ The term "participants in the consultation" should be taken to mean those who took part in the focus groups and those who submitted documentation.

It is important to clarify at the outset that this report is a synthesis of views gleaned throughout the consultation. It was found that many of the ideas that were raised "fit" within or accorded with a single, coherent framework, the outlines of which participants in the consultation had opportunities to elaborate in varying degrees of detail. The articulation of that outline, and the integration within it of the specific ideas and proposals that were made, was the unique challenge in preparing this Final Report. Given the range of issues covered during the consultation, it was not possible to do adequate justice to each and every contribution made by each participant. Again, what is presented here reflects the general themes, issues and considerations that emerged.

¹ It should be pointed out, however, that some important supports are neither social services nor aids/devices. These include informal peer support and the support provided by family members. To the degree that peers and family members are involved in providing support and need financial and other resources to perform such a role, they too would be included within the sense of the term "support" as used in this report.

PART I

There was general agreement that the current set of arrangements for framing and addressing the need of people with disabilities for disability-related supports are inadequate, inappropriate, inefficient, and outmoded.

A. Problems with the present arrangements

A large number of problems with current arrangements to provide disability-related supports were identified during the consultation. Many of the issues identified are consistent with those presented in the Views and Themes paper. Some of the more major problems are briefly summarized below.

1. Stigma and lack of respect

The social welfare framework was seen as stigmatizing to the individual who must rely upon it. It is based on the assumption that the individual is dishonest, and that elaborate screens are necessary to prevent and address consumer abuse of the system. On the basis of such assumptions, people with disabilities are required to undergo repeated assessments that shed little light on their needs or on how the system can more appropriately respond to those needs.

2. Inadequacy

Once eligibility has been granted, people often do not have access to the level or kinds of support they require. The conditions on which these supports are delivered mitigate against the realization of Equality and Citizenship Rights principles.²

² The ongoing investment in segregated, institutional services and the diversion of funds from community supports in the process was identified as contributing to the inadequacy problem. Serious concerns were also expressed about the inadequate support available to family members supporting children / youth with disabilities, and to family members who continue to support individuals into their adult years because of a lack of alternatives in the community.

3. Disempowerment

Present arrangements are disempowering to the consumer with a disability. The medical profession has been mandated to diagnose and validate the presence and type of disability. The medical profession has thus been mandated to grant and deny consumers the "passports" to the supports they require. This was widely felt to be a humiliating and unacceptable arrangement. Social welfare workers also function as "gatekeepers" to essential disability-related supports. Yet they often lack insight into the problems and issues that people with disabilities face. Social service providers are also in a position to dictate to consumers what they do and do not need, and the supports and services to which they will and will not have access.

4. Restrictive criteria

The criteria that social welfare workers and other "gatekeepers" (e.g. vocational rehabilitation counsellors) administer are restrictive. Such criteria may, as in the case of the "unemployable" criterion, require individuals to be designated in ways that are personally offensive or that frustrate full participation in society in return for essential supports. Other criteria, such as cause of disability, severity of disability, and whether people have been recently involved in the labour market, bar many others from obtaining essential supports through other delivery systems (e.g. Workers' Compensation, C/QPP, EIC/UI).

5. Lack of entitlement

Unlike health care, a major problem under present social service arrangements is that there is no clear entitlement to disability-related supports. Workers within the social welfare, vocational rehabilitation, and other mainstream delivery systems have considerable discretion to refuse supports. Partly because of their use of discretion, and partly due to the unequal fiscal capacity of the provinces/territories to take full advantage of cost-sharing under CAP and VRDP, many are denied the supports they require.

6. Lack of an effective appeal process

The appeal procedures for consumer to challenge refusal of service or inappropriate service and treatment by providers are either non-existent or ineffective.

7. Lack of portability

A critical problem is the lack of portability of supports once they are obtained. People with disabilities are often frustrated in their attempts to move across their province/territory/country because arrangements guiding the delivery of the supports do not enable the consumer to retain or have access to these where and as needed. Other arrangements make delivery of supports conditional on the individual participating and remaining "tied" to a particular program, delivery site or other situation. For example, funding for support provided at home is often not available in the workplace.

8. Disincentives/barriers to participation

Another critical set of problems are the disincentives to participation that face many consumers as a result of how present disability-related policy and programs are organized. In order to take part in the paid labour market or to engage in volunteer work, many would have to forfeit the attendant support, medications or other essential services that are available under the disability components of welfare or C/QPP. Yet for many those supports are vital conditions of participation in the labour market and of health and well-being.

9. Lack of flexibility

The lack of systemic flexibility hampers the present social service system's ability to respond to individuals' often widely varying and shifting needs. Some features of the system leave it unable to adequately address episodic needs. Other features of the system render it incapable of responding to long term needs or to needs that fluctuate.

It was pointed out how 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.

Inherent in the new paradigm are the following principles:

- o 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 support that enable this to occur (regardless of province/territory or other status);
- o instead of charity, entitlement to adequate supports for living independently in the community;
- o respect for and trust in, not mistrust of, the consumer with a disability;
- o access to disability-related supports that are geared to individual needs as defined by the consumer;
- o consumer control and choice (empowerment) in all support arrangements that directly affect their life;
- o significant involvement by consumers with disabilities in the design and evaluation of public policy and programs that directly affect their lives;
- o societal responsibility to ensure that these principles are realized through law, public policy, social programs and funding commitments.

The new framework 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 service implications, to realize the Equality and Citizenship Rights principles.

However, in the consultations and in the documentation, there was general agreement that how funding is organized to address disability-related needs is central to whether or not the

Equality and Citizenship Rights principles are realized. The funding arrangements have a direct bearing on whether or not consumers will:

- o live independently as citizens and empowered members of the community,
- o have a decent quality of life,
- o make the critical life transitions as these emerge, and
- o take part in the labour force.

Thus, the funding arrangements are key to promoting the conditions that support Equality and Citizenship rights and well-being, and to preventing the conditions opposed to that objective.

There was general agreement that, one way or another, the new framework for guiding the allocation and deliver of the funding in the area of disability-related supports, must do the following:

- a) cover the additional costs of disability;
- b) address the poverty of people with disabilities;
- c) ensure the availability of social services and other supports that are consistent with the Equality and Citizenship Rights principles;
- d) help remove the barriers (in society at large, in government, in public programs, and in social services) that prevent the realization of the principles.

PART II

The new framework has direct implications for how social services and income support are organized, and for the relations between social service departments and other government, private and voluntary sector stakeholders in the citizenship and rights of people with disabilities. The following discussion looks at each of the issue areas that participants in Mainstream 1992 indicated the new framework on disability should address.

A. COVER THE ADDITIONAL COSTS OF DISABILITY.

1. Public responsibility

It was the view of participants in the review that the additional costs arising from disabilities are costs that should be borne by society at large. For many individuals, these costs are substantial. Because consumers usually lack the private means to cover these costs, they are unable to secure the supports they require and thus cannot fulfil the conditions necessary for participation in jobs, education, training, etc. In short, because consumers cannot cover these costs privately, they are prevented from exercising the right to participate as equal citizens.

The point was also made that, even if people with disabilities had jobs and incomes on a par with other Canadians³, what is usually left after disability-related expenses are covered is a disposable income well below that of the rest of the population. Thus, financial inequalities can only be overcome if people with disabilities earn well above what other Canadians earn. But present conditions in the labour market can hardly be said to facilitate this.

Worse still, after the disability-related costs are privately covered, many people with disabilities are left in financial ruin, which simply compounds the disadvantages they face and which can even aggravate disability and the associated costs.

Thus, public coverage for disability-related costs was seen as being the only viable way to promote and safeguard the exercise of Equality and Citizenship Rights by people with disabilities.

³ This is far from being the case.

There was some concern that the new costs involved in such a public commitment should not be under-played.⁴ Yet there was a widespread sense in the consultations that the current spending on disability, if re-organized and re-invested in a more intelligent and equitable set of arrangements, would significantly contribute to the realization of the Equality and Citizenship Rights principles. In other words, re-investment is a crucial first step.

2. What is the system and its policy/funding base?

It was the view of participants that the new system to cover disability-related costs requires a new legal and policy framework, and a new set of delivery arrangements. Several ideas were raised about the kind of system this would be and where responsibility for it would be vested.

There was general support for the notion that it should be based on neither a welfare nor a medical model, and thus should be autonomous from the welfare and health systems.⁵

Also fundamental to those consulted was the principle that funding to cover the additional costs of disabilities should be allocated in the first instance to the consumer with a disability.⁶ Consumers could then use either direct cash transfers or credit arrangements to purchase/contract for the supports they require.

Participants were hard-pressed to see how, outside of a strong national framework, the additional costs of disability could be addressed in ways consistent with Equality and Citizenship Rights principles. In fact, participants were generally in agreement that there is a strong and critically important role for the federal government to play in devising, funding, and ensuring the integrity of the new system. There was also agreement that some kind of

⁴ Participants did not have a clear idea of what the new costs would be.

⁵ Linkages between the new system and the welfare and health systems were not precluded.

⁶ It was recognized that family members who are providing support to other family members who have disabilities have a legitimate claim to the resources and other assistance they require to carry out that role properly. Better arrangements are required to effectively ensure that these resources are in place.

national legislation would be required to set such a system in place, to outline national objectives and standards, and to ensure adherence to those guidelines.

However, participants were aware of constitutional realities and recognized that a number of issues concerning the federal/provincial division of powers have to be taken into account. While there was much support for a national system, nationally administered, the notion of federal-provincial/ territorial accords, with provincial/territorial administration of a program designed to realize national objectives within a national framework, was seen as a potentially workable way to implement the new system.

There was wide recognition of the need for the federal government to play a strong funding role. However, conventional cost-sharing arrangements, such as CAP and VRDP were seen as being inadequate in that they do not assure equity: the poorer regions of the country are not as able as the richer provinces to take advantage of cost-sharing. Thus, people with disabilities do not have equitable access under CAP/VRDP to the conditions necessary to promote rights and citizenship in all parts of the country. Moreover, CAP assistance is essentially for people who are so poor that they cannot function without public support, and the focus of the welfare service provisions on funding "prevention" services means that those dollars for disability-related services are very narrowly targeted. In either event, CAP-type arrangements were seen as being ultimately unacceptable and unworkable as means of adequately addressing the additional costs of disability for all who require this. The "cap on CAP" was also seen as problematic. Moreover, the point was made that arrangements like EPF have not assured that the goods and services to be provided on the basis of block funding are in fact be provided on an equitable basis across the country. Thus, new funding arrangements will be required.

It was conjectured that a new and more sophisticated approach to block funding, one that takes into account the fiscal capacity of the provinces/territories and that is not simply based on a "head count", may be a way to ensure the provinces/territories have adequate resources to administer.⁷ Other transfer payment arrangements to ensure the promotion and safeguarding of rights were also discussed.

⁷ This notion assumes that provincial/territorial administration of the national program to cover the additional costs of disability is to be an option.

Another alternative was to have the program federally funded and administered, not unlike the old polio compensation program, the war veterans program, or UI. If this tact is to be taken, the new program would be universal and much more comprehensive in that it would make provision to cover the costs of a much broader range of disability-related needs than any of those models.

3. How the individual secures cost-coverage

The criteria for access

Two key requirements were raised as being the only criteria that should need to be satisfied for individuals to gain access to funding to cover the cost of disability: the presence of disability and the presence of disability-related need.⁸ However, much of what was proposed in terms of new arrangements for delivering disability-related supports would shift a number of risks and responsibilities from the social service system to the consumer. "Willingness to assume risks and responsibilities (with the option of delegating / contracting with others to fulfil responsibilities)" would thus appear to be another important criterion.⁹

Determination of disability

In gaining access to funding to cover the additional costs of disability, an initial step in the process would be to determine that the individual indeed has a disability. There was wide support for the notion of revising present procedures so that self-declaration of disability would become the norm. It was felt that individuals are unlikely to indicate that they have a disability if they do not have one. Thus, concerns that individuals may be "faking" or "out to

⁸ It was generally agreed that criteria such as "employable" and "unemployable" should be altogether disbanded as eligibility criteria, as should type of disability, cause of disability, duration of disability, and so on.

⁹ The point was made on a number of occasions that it should not be assumed that, because an individual has a given limitation (e.g. cognitive disability), they are in virtue of that fact incapable and thus ineligible to assume risks and responsibilities. Barriers that make it difficult for these individuals to legally assume risks and responsibilities, such as competency tests and guardianship legislation, need to be revised.

abuse the system" were felt to be misplaced, exaggerated, and grounded in outmoded social welfare philosophy.

However, it was suggested that some criteria may need to be used to determine whether the limitation/condition the individual declares to be a disability is to be considered a disability for the purpose of qualifying for coverage. The WHO and CIDIH indicators of disability were presented as being potentially useful in this regard.¹⁰

To whom the individual would self-declare disability, and how this declaration would be recognized for the purposes of eligibility for cost coverage, was not entirely resolved. However there was considerable support for the notion that use of a peer counselling process would be an appropriate way to have the self-declaration validated.

There was also sensitivity to the importance of peer counsellors having real insight into the situation of those declaring disability. Thus, implicit in the peer counselling model is the notion that the counsellors and those counselled would be peers in terms of disability type.

Regardless of how the process of identifying disability is to be managed, there was wide support for the notion of eliminating the requirement for the consumer to undergo medical diagnosis, assessment and certification. Such procedures were seen as humiliating and as giving disproportionate power to the medical profession, and thus as inconsistent with the Equality and Citizenship Rights principles.

Currently, public programs have varying definitions of what constitutes a disability. This means that people with disabilities may frequently be required to have themselves "re-certified" for the purpose of establishing eligibility under the various systems. This requirement was viewed as administratively cumbersome, humiliating and inconvenient, not

¹⁰ It was conjectured that a few people may attempt to take unfair/dishonest advantage of the system. Accountability checks and penalties may have to be invoked when such abuses are identified. However, it was suggested that these measures should be as non-intrusive as possible, people with disabilities being no less honest than others, and deserving no more than others in the general public to be subject to draconian procedures. It was suggested that accountability measures to screen for abuses, if necessary, could perhaps be organized along the lines of the random audits conducted by the tax system or along the "consumption of services" model used by the Canada/Ontario Student Loans programs.

to mention costly to the public and to consumers with disabilities. The alternative proposed was that once an individual has been identified as having a disability, he or she would retain that designation (perhaps in the form of something like a driver's licence) for the purposes of being recognized as such by all programs. However, the designation would not be framed in terms of diagnostic categories. Instead it would amount to a simple affirmation that the individual has "a disability". Such a general affirmation would be in keeping with the individual's privacy rights.

The identification of needs

Having identified that the individual has a disability, a key issue is to identify the disability-related needs for which the individual is seeking cost-coverage. Again, there was wide support for a new process that would enable consumers to self-identify what they consider to be their needs. The system should not only listen to this self-declaration, but should be mandated to act on that basis.

The needs identification process should look at the whole person -- at their requirements across a broad range of situations -- rather than focusing exclusively on one or two areas, such as employment or education.

Concerns were repeatedly raised about the present over-reliance of various systems on formal assessment procedures.¹¹ It was felt that, generally, formal assessments are not necessary to identify needs because generally people with disabilities have a good understanding of their own needs. Thus, people should not be required to undergo formal assessments.

However, it was recognized that formal assessments may be required by people with fluid, rapidly emerging needs (e.g. accident victims) or people with needs that are difficult to determine on the basis of informal approaches (e.g. people with highly specific learning disabilities and other learning challenges). The principle would remain, however: individuals would not be required to undergo assessments. Where these services are required, they should be available according to expressed consumer demand.

¹¹ The over-reliance of systems on medical-styled clinical assessment models was singled out in particular for criticism.

While assessments may in some instances be necessary, the shortcomings of present assessment procedures received critical attention. Typically they focus on basic, functional needs and shed little light on quality of life issues and on the barriers that people with disabilities must overcome in order to exercise their rights and participate as equals in society. It was felt that formal assessment procedures (where necessary at all), as well as less formal approaches to needs identification, should be designed to take into account quality of life and the disability-related challenges that people experience and that can be traced to environmental factors (e.g. barriers analysis¹²). It was pointed out that the shortcomings of assessment instruments could be offset by having people with disabilities more directly involved in their design.

It was recognized that sensitivity should be exercised during the needs identification process to the particular "transition" through which the consumer feels he/she is moving at various points in the lifespan.¹³

It was granted that, where formal assessments are not required to identify needs, consumers may nonetheless require assistance from others. For this purpose, consulting/counselling services, with a high degree of sensitivity to consumers with disabilities and grounded in the Equality and Citizenship Rights philosophy, should be more available in the community. Peer counselling was widely regarded as the preferred option,¹⁴ with some participants indicating

¹² Concerning the deaf community in particular, the barriers analysis would need to take into account how deaf culture and language (e.g. ASL) are marginalized, and how social integration without the loss of cultural distinctiveness can be facilitated.

¹³ The range of potential transition-related needs is very broad: the emotional and economic transitions that occur upon the death of a spouse; the emotional and economic transitions that occur upon moving from an institution to the community; particular needs that arise upon making the transition from school to work, or from work to unemployment. (Some particularly difficult transitions are outlined in the focus group paper on Transitions.) It was felt that discrete programs to deal with specific transitions are unnecessary and unacceptable. A broader, flexible set of arrangements to address the full range of needs as they arise was considered the most appropriate way to deal with such issues.

¹⁴ The peer counselling model would involve counsellors with disabilities similar to those of the people being counselled. Concerns were expressed about the likelihood of people who are deaf or blind receiving adequate peer counselling support from people who do not share those disabilities.

a strong preference for such services to be entirely operated by disabled consumer organizations, and to be staffed largely if not entirely by people with disabilities.

As with informal counselling/consulting services to consumers in needs determination, it was the view of participants that formal assessments, where required at all, should also be administered by people who are highly sensitive to disability issues and who are well anchored in the Equality and Citizenship Rights principles. Again it was pointed out that many people with disabilities could, as peer counsellors, provide effective assistance to consumers in the form of assessment services, if mandated more broadly and funded more adequately to do so. At the very least, people with disabilities should have significant input into how assessment services are organized and delivered.

In that consumers may very well choose to use consultancy / counselling or assessment services to assist in identifying needs, more coherent arrangements than the present ones are required to ensure these services are more broadly available and more easily accessible.

Eliminating potential conflicts of interest

Participants in the focus groups drew a clear distinction between eligibility determination and needs identification (including the assessment process). The point was made that needs identification should not be used to screen for eligibility, but should instead be a service to identify consumer need and demand, and to serve as a basis for the arrangement of appropriate responses to needs. Thus, current (and costly) arrangements requiring people to undergo repeated assessments for little purpose other than to determine ongoing eligibility for services should be eliminated.

The potential for conflict of interest inherent in the widespread vesting of responsibility in the same agencies/personnel for both identifying needs and determining eligibility was recognized. New social service arrangements should keep these two functions systemically / administratively separated from one another. In no case should the person or agency identifying consumer needs also be empowered to determine whether individuals are eligible for cost coverage for those needs.

Consumer validation of needs

Participants in the focus groups recognized that governments are accountable to the public for the fairness and reasonableness of the processes that are used to identify and respond to the needs of people with disabilities. However, it was maintained that people with disabilities, perhaps through consumer organizations, could be effective partners with government if mandated to play a role in overseeing that needs are being identified in a responsible fashion. Exactly how consumer validation of needs would look in practice requires further clarification.

Determining responses/supports appropriate to need

While needs identification and the process of identifying the supports that are appropriate to individual needs can be conceptually distinguished from one another, in many cases these processes take place simultaneously. The principles that are to underlay the identification of supports appropriate to need would be similar to those outlined in the needs identification section. The basic norm would be consumer articulation of the supports that are required, with backup assistance (counselling/consulting as needed) by peers to help the consumer determine the supports that are most relevant to their situation.

Costing and verifying the reasonableness of the support package

Eventually, costs would have to be assigned to the supports that the individual is seeking. Some determination would have to be made about the reasonableness of the support package and the related costs.

The point was made that people with disabilities have become skilled at making the most of scarce resources. Consumer peer-counselling in working out cost-effective ways to address support needs was seen as one tactic that could be adopted to ensure that effective use is made of the resources that are available.

It was also suggested that, once the support package has been designed and the costs determined, some form of higher peer review could be invoked to oversee and ensure reasonableness of what is being proposed. Several peer review models were proposed as

options: adaptation of existing peer review processes (such as Arts Councils) for use in the disability field; use of a community panel at the local level, made up of people with disabilities, that might be linked to a professional panel and to the macro-level decision-making about the fiscal capacity and limitations of the funding system (see below).

Entitlement

A common thread throughout the consultation was the principle that people should be entitled to cost-coverage according to need.

This principle raises the obvious question: what are people entitled to? If financial considerations are not to be the only considerations guiding decision-making concerning cost-coverage, what are the other criteria?

Some participants felt that having recourse to a "list" of fundable supports would seriously inhibit the flexibility of the system to respond to needs. Lists typically do not evolve in light of emerging technology and other discoveries. Then again, what is a disability-related support for one person (e.g. an air purification system for person with asthma; a homemaker service) would not necessarily be a disability-related need for another. The list of all supports that could conceivably be construed as disability-related would likely be so long that it would be little if any use.

Preference was expressed for moving away from a "list approach" to entitlements to a more flexible framework of basic entitlements. Concerning the system to address the additional cost of disability, the following were identified as basic entitlements that should be available to all people with disabilities:

- a) Publicly funded supports (including but not limited to fundamental living services/supports that are basic to functioning) that cover disability-related costs in ways that:
 - ensure choice and self-determination
 - ensure the right of the individual to assume risks

- are universally available on the basis of disability-related need (i.e. not on the basis of cause or type of disability, individual/family income, residency, age, gender, ethnicity, presumed competence, stage in the life-cycle, labour force status¹⁵, or any other status aside from disability-related need)
 - are available on an equitable basis throughout the country and are fully portable
 - are based on self-identification of needs¹⁶
 - ensure the individual's full participation in society and empowerment
 - are made available through a single funding system (i.e. instead of through multiple systems that can affect whether individuals have access)
- b) Information
- c) Access to a process for articulating need, and for having this articulation heard and acted upon.
- d) Access to an effective appeals process

In short, entitlement means having access to disability-related supports that assist in the realization of the Equality and Citizenship Rights principles.

By the same token, nowhere in the consultation was the point made that people with disabilities should have access to a narrower range of supports than the range to which they already have access. Some participants adopted a broad categorical approach to identifying the general categories of support to which people with disabilities should have entitlement.

¹⁵ Specifically, people should not have to be involved in a vocational rehabilitation program or in the labour force in order to qualify for essential disability-related supports for daily living.

¹⁶ This principle includes the notion that people may have shifting/cyclical needs, and that arrangements should have the flexibility and responsiveness to enable these to be addressed as they arise.

These categories included: a) support services, whether required at home, in the community, or in some form of care facility; b) orthotics, prosthesis, and other technological aids; c) necessary long-term medications and medical supplies; adaptations to home, vehicle, school and work environments; e) special services at school and at work.

Participants who developed the broad model of entitlement did not exclude in their deliberations any of the supports that would be included in the general categories. The issue, here, is how to ensure entitlement to the supports that might fall within the categories but without ruling out entitlement to supports that may fall outside of those categories. Both approaches seem complementary. More clarification seems needed to determine how these two approaches can be reconciled.

The decision to fund

The final decision to approve or to withhold funding for the proposed support package is a critical decision. It was not entirely clear how this decision is to be made or who is to make it.

Some participants maintained that, at the very least by having people with disabilities involved in the decision-making (or functioning as decision-makers) about what is and is not to be funded, greater fairness would result than having non-disabled "gatekeepers" unfamiliar with the realities of disability making these decisions unilaterally.

While such decisions are highly political in nature, whether they are to be made exclusively within government, or by community groups, or through some kind of partnership arrangement involving government and consumer/representational groups, needs to be clarified.

System flexibility

Setting aside exactly how and where the decision to fund is to be made, it was clear that people with disabilities want to be able to re-negotiate their support requirements, and the associated costs and funding coverage, as their needs warrant. This again would require a system more open and accessible than the patchwork of programs and agencies currently in

place. It would also require a much more flexible system that could keep pace with shifting needs rather than locking consumers into rigid support parameters.¹⁷

Appeal

Participants felt that much better access to a much more effective appeal mechanism is required in the event that the system refuses to cover disability-related costs, or falls short of providing coverage according to need. How such an appeal mechanism would look in practice requires more clarification. However, it would seem that, at the very least, people with disabilities would be strongly represented as adjudicators.

It was also proposed that, short of a formal appeal process, people should have access to a mechanism like an ombudsman's office that would handle routine complaints concerning not only the refusal to fund, but concerning a variety of other issues around social services more generally. Such an advocacy role internal to the system responsible for funding might be a way of addressing consumer concerns before they escalate to the point where formal appeal becomes necessary.

It was further proposed that funding should be available at the provincial/territorial level, along the lines of the Court Challenges Programme, to facilitate consumer litigation on matters concerning social services.

4. Consumer control once cost-coverage is in place

Once the funding commitment has been made to cover the costs of the additional costs of the consumer's disability, the principle would be that the consumer would be left free to exercise spending power and to enter into the contracts / arrangements for support that they deem appropriate.

¹⁷ Many people have cyclical needs, episodic needs, and needs that shift according to a range of factors. Many other people's needs only become apparent once they are involved in a particular situation, such as employment or education. Such needs cannot be accurately identified in advance of the individual's actual involvement in those situations.

Consistent with this principle (choice/control: empowerment) would be the option of self-management of supports by consumers who make this choice.¹⁸

On the other hand, some consumers may choose to have their supports managed in part or entirely by others (including by individuals or by agencies in the community). Again, participants in the consultation generally considered that it should be a consumer choice to make this kind of determination. The point was also made, however, that consumers who contract with providers (whether individuals or agencies) to manage and/or deliver supports should be assured the right to direct the process. Safeguards to ensure the compliance of providers with the Equality and Citizenship Rights principles need to be implemented and enforced (discussed in Section II).

Individualized income transfers

Consistent with the notion that cost-coverage for disability-related supports should be flowed in the first instance to consumers, is the notion that some new kind of funding transfer mechanism should be established.

A number of options were discussed in this regard. A clear preference seemed to be for an arrangement to flow dollars directly to consumers, who in turn would spend the dollars on the supports they require and as agreed to between the consumer and the funding system.¹⁹

It was pointed out, however, that such an arrangement could be problematic on several grounds. First, the prospect of having access to large amounts of money (e.g. for "large ticket" items) might be an inducement for some people (not necessarily with disabilities) to try to take advantage of the system. Here, it was suggested that something like an account could be established in the consumer's name for large ticket items. (Consumers would

¹⁸ A number of benefits to the consumer's confidence and skill have been identified where self-management of supports is chosen. Inherent in such a choice is a willingness to assume risks and legal liabilities.

¹⁹ Legal restrictions prevent children and youth from entering into contracts. Thus, there would be problems relating to the age of the consumer in implementing a direct transfer system. Some other arrangement, such as a direct transfer to parents in the name the child/youth, who would then undertake contracting for supports, would have to be devised.

continue to receive direct cash transfers for routine needs and for supports that are not considered "large ticket" items.) The consumer in turn could secure the needed support on that account, and the provider would invoice the funder accordingly.

Second, direct cash transfers would be problematic for people who simply do not want to be responsible for personally handling the many financial transactions concerning their disability that would have to be handled along with the many other routine transactions that are not related to disability. Here, the option of having the funding flow directly from funder to provider selected by the consumer may be an option. As intermediary, the consumer would arrange with the provider to deliver agreed upon supports according to specified conditions, and, if the conditions are met, the consumer would "okay" disbursement by the funder to the provider. The consumer may choose to have many transactions handled in this way, or only a few, preferring instead to directly manage most of the transactions using normal payment methods (on account; cash; cheque) themselves.

Participants seemed to generally agree that, underlying how the income transfers are to be delivered should be the principle that the consumer ought to have as much control over the spending as he/she deems appropriate. Thus, it would appear that a number of income transfer options should be developed and legitimized. Consumers could negotiate which of these is most appropriate for their particular situation.

Assistance with support arrangements

Consumers may need assistance in drawing up contracts and making other arrangements to secure and manage the supports they require. It was maintained that assistance services of this kind should be available from a range of community agencies (e.g. Independent Living Centres), who should receive adequate funding to deliver those services.

Consumer Accountability

Consumer accountability for the dollars transferred from the funder to cover the costs arising from disability-related needs could be addressed in a number of ways. The principles articulated, however, were that the dignity and choice of the consumer must be safeguarded, and that consumer responsibility and trustworthiness must be assumed. In other words,

accountability measures themselves should accord with the Equality and Citizenship Rights principles. Thus, any number of accountability measures that seem reasonable to the consumer and funder would be negotiable and legitimate.²⁰ These options could include a negotiated reporting procedure (monthly or quarterly financial statements), routine submission of bills, etc.

Portability

It was widely viewed that access to adequate supports should be a basic entitlement for people with disabilities across regions of the country, and across the situations in which people take part (e.g. school, work, home, community affairs). The principle of portability is thus central to the new arrangements for addressing disability-related needs.

In some instances it is clear that the particular support the consumer requires should be physically portable from one region or situation to the next (e.g. attendant support). In other situations, actual physical portability of the support may not be so crucial as entitlement and access to that support, regardless of region or situation (e.g. as in the case of some health care services).

How portability is to be assured, and the linkages between the various government departments and programs in ensuring portability, requires more clarification.

Accessibility

As discussed above, in the new arrangements the consumer would be able to redefine needs and re-negotiate cost coverage on an as-needed basis. This would involve an open, flexible system with a physical presence in most communities.

Participants in the consultation wrestled with the question of whether a "one stop" approach for gaining access to the system was an appropriate model, or whether consumers should have many points of access to the system. There was general agreement that the preferable

²⁰ The measures should ensure consumer accountability with the least possible intrusion and administrative cost/involvement.

model would to have many points of accessing a single, unified, coherent funding system. Many consumer / representational organizations could, in partnership with the funding system, assist with the preliminary identification of needs and supports. (Presumably a referral would then be made to whoever makes the actual decision to fund.) The process for gaining access to the needs and support identification process would be the same in all parts of the country. How the process works would be clearly spelled out and widely disseminated in a variety of media. The principles that guide decision-making at all steps of the process for securing funding would again be clear, widely disseminated in a variety of media, and consistently interpreted regardless of province/territory/sub-region.²¹

Participants in the consultation were quite clear that a "one stop" approach would be particularly unacceptable if it were to mean that a single agency in the community identifies needs and arranges supports. Such an arrangement would violate the principle of choice and has proven in practice to be administratively unworkable. (There are long line-ups/waiting lists for consumers to get service, and a single "globalized" disability-related agency cannot possibly help all consumers consider the full range of relevant support options²².)

Of course, the system would be fully accessible to people with mobility, hearing, speech, visual and other limitations. The point was also made that people who need additional help to understand how the process of securing supports works (e.g. people with cognitive disabilities), or who simply want trusted others to be involved with them in the process, should have that assistance available to them. Realizing physical accessibility standards was not seen as inherently problematic. The details of how communication services and supports for decision-making would be linked into the needs and support identification process (and into the actual decision-making about funding) requires clarification. The organizations that have traditionally made communication services available are not present in all communities at this time, and have limited staff capacity to address the volume of consumer demand.

²¹ On several occasions concern was expressed about the "climate of secrecy" that surrounds much of the decision-making about what is fundable and about how the decisions get made. Participants wanted an end to the climate of secrecy.

²² Neither can a range of smaller agencies with a general mandate in the area of disability but lacking particular expertise concerning needs and issues arising from particular disabilities.