# 5. The policy process and the fiscal capacity of the system

The decision to provide or not to provide cost-coverage according to need is framed in the context of the fiscal capacity of society to make this funding commitment. People with disabilities have had little access to the policy process through which public budgets are established and allocations are made. It was strongly urged that mechanisms need to be implemented that would bring people with disabilities into this process. Having access to the process, they 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. However, because decision-makers do not usually avail themselves of the expertise people with disabilities can bring to decision-making on public spending, the decision-making is less well informed than it could and should be.

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. Instead, policy and funding is scattered across numerous government departments and programs. In the words of some participants, the net result is a patchwork "system" that is "totally incomprehensible". No one seems to know just how much is being spent in the process, although most participants suspect that the sum is enormous.

As mentioned earlier, one option for rationalizing the funding is to re-organize it from across the departments and programs where it is currently being spent into a single, coherent policy and funding/program framework. Another option would be to establish a coherent policy and program framework, and then to establish a series of "charge back" relations from that central program to the existing programs (C/QPP, Worker's Compensation, Welfare, etc.) In

that way, a new program would be "injected" to coordinate and rationalize a variety of disparate policy and program frameworks.

The argument was also made that some of the costs relating to disability should be shouldered by the private sector as ordinary costs of doing business, especially where needs and the related costs arise specifically in the workplace. It was recognized that determining the balance between public and private sector responsibilities in this regard is problematic, but that an appropriate balance is necessary and coherent principles and accountability mechanisms need to be developed to determine who is responsible for funding what. This is an area that requires more clarification.<sup>23</sup>

On balance, participants seemed to prefer a single, comprehensive, coherent policy and program framework to deal with the full spectrum of costs arising from disability-related needs.<sup>24</sup> A suggestion was made that a variety of means could continue to be used to collect revenues to fund the program: taxation, C/QPP premiums, employment-based disability premiums, etc. However, in that the new program would cover all people with disabilities, regardless of whether they are in the labour force, revenue generation would reflect a combination of contributory and non-contributory approaches.

#### **B. ADDRESS THE POVERTY OF PEOPLE WITH DISABILITIES**

It is quite widely recognized that people with disabilities face many disadvantages and as a result are generally poor. Poverty was articulated as a major issue for which more adequate provision must be made.

The notion of penalties for private sector failure to make the necessary funding commitments to fulfil its responsibilities in the area of equality and citizenship rights was raised, i.e. employers should be held accountable for covering the costs of supports that could be construed specifically as workplace accommodations. The point was also made that private sector disability insurance programs are not presently held accountable to minimum standards. If insurance companies are to continue charging premiums for disability, legislation ought to ensure insurance companies are held universally accountable for consistently delivering a range of basic benefits.

They did not preclude private sector responsibility for funding some costs, however.

#### 1. The need for basic income security reform

Many participants felt that, by implementing a system that would deal specifically and effectively with the additional costs arising from disability, many of the disadvantages individuals with disabilities are facing could be overcome. Because such a system would better enable people than present arrangements to exercise the right to participate in the economic life of their community, the economic picture facing people with disabilities would improve accordingly. For this reason, participants focused primarily on the new framework for ensuring provision of cost-coverage for disability-related costs.

However, attention was focused on basic income support issues and on a number of measures that could be implemented to address basic needs.

There was general support for the notion that welfare is an inappropriate vehicle for addressing the basic needs of Canadian citizens, regardless of whether they happen to have disabilities. Throughout the consultations, there was philosophical support in the direction of Guaranteed Annual Income, with basic entitlement to an income at least on a par with the poverty line (many people with disabilities live well below the poverty line), and preferably above it.

There was also support for the notion of removing the disincentives and barriers to participation inherent in income support arrangements. (e.g. claw backs on earnings; allowable liquid assets levels that prevent the amassment of the capital necessary for entrepreneurial activity; asset levels that prevent people from having their own personal safety net, etc.)

Modifying or adapting the OAS/GIS program to include people with disabilities was seen as one way to address basic needs outside of the welfare framework.<sup>25</sup> Questions that would have to be answered, however, are: On what basis are the basic needs of people with disabilities to be addressed outside of the welfare framework? If people with disabilities are to be included in a program designed along the lines of OAS/GIS, would they be entitled to a higher basic level of income support than others? If so, on what basis?

Other options were also presented. See the "Income Support/Replacement" focus group document.

To these questions it was pointed out in the consultations that: a) people with disabilities are not, generally speaking, poor by choice, but as a result of the inequitable levels, the widespread and the unique disadvantages they face; and b) that it generally costs more to live with a disability than without one, but that many costs are difficult to calculate or to anticipate.

#### 2. The focus on disability-related funding reform

It was acknowledged that several attempts have been made to reform the income security system in Canada, but that little real progress has been made in the process. In that the additional costs of disability can be distinguished from the costs arising from more general needs, and that reform might be more possible on the disability front, there seemed to be general support for the notion of making adequate coverage of disability-related costs the primary focus of reform efforts.<sup>27</sup>

# C. ENSURE THE AVAILABILITY OF SOCIAL SERVICES AND OTHER SUPPORTS THAT ARE CONSISTENT WITH THE EQUALITY AND CITIZENSHIP RIGHTS PRINCIPLES

Assuming that the consumer has been assured that the costs relating to his or her disability would be publicly covered, it was recognized that a social service system must be in place and have the capacity to respond to consumer need/demand, regardless of the province or territory. This means that steps would need to be taken within the new framework to ensure that a supply of supports for consumer purchase and use is in place in all parts of the country.

e.g. the additional cost of consumer goods because of limited opportunities to move about in the community and to take as full advantage of the market system as other citizens.

The point was also made that there is a need for more liberal tax policies that would enable individuals to claim more ample credits on a broader range of non-reimbursed disability-related expenses. Disengaging eligibility for certain tax credits from labour force participation was seen as a necessity, as was the need for a tax system that would grant credits for disability-related expenses that consumers presently pay for out of their welfare cheques.

#### 1. A new policy and funding framework

Generally, participants in the consultation preferred that direct income transfers to individual consumers be used to fund the supply of disability-related supports in the community. Such an arrangement would, it was believed, ensure the ongoing relevance of supports and the accountability of the providers to consumers and their needs.

However, it was also recognized that, while consumers would, in principle, be funded and empowered under the proposed arrangements to use funds to purchase/secure supports in the community, there is no guarantee that the aggregate demand would be great enough to generate the market forces to adequately address consumer need/demand in all provinces/territories/sub-regions. The latter problem is most likely to occur in poorer and less densely populated areas. In such instances the notion of entitlement and choice become almost meaningless. Thus, the new framework would entrench provisions to ensure reasonable availability of disability-related supports in all parts of the country. Again, participants in the consultation process generally viewed a strong national framework as essential, but allowed for the possibility of provincial/territorial administration within such a context.

If consumer spending power is no guarantee of the emergence of an adequate infrastructure of support providers, neither is there any guarantee that the amount allocated by the funding system to cover the consumer's required support package would actually, in all cases, be sufficient to cover the real costs. Some arrangement would likely be necessary, then, perhaps only on an interim basis in many situations, to "seed" the development of a support provision system that can begin to address consumer needs and demands. Some core administrative capacity for providers, along with a core fiscal capacity to respond to needs that are not adequately cost-covered through the individual income transfers, may also be necessary until the consumer funding levels are adjusted to entirely cover the costs of the supports.<sup>28</sup> It was

It was pointed out that conditions should be attached to the seed and core funding. Provincial contracting policies, together with consumer participation in the monitoring and evaluation of the support provision agencies, would be used to ensure compliance of support providing agencies/organizations with the Equality and Citizenship Rights principles. Evidence of the provider's failure to comply with those principles could be used to deny ongoing developmental or core funding.

in seeding the development of and in ensuring the delivery of core dollars for such an infrastructure that participants saw an important role for social service departments.

Indeed, ensuring the provision of disability related supports is and is likely to remain a provincial/ territorial responsibility. However, the provinces and territories are not equally equipped to provide a base of funding adequate to ensure that even the developmental and core costs for the infrastructure of support providers is available on an equitable basis. This once again points to the need for some kind of federal transfer arrangement to ensure that the provinces/territories have a basic capacity to ensure that an infrastructure of disability-related supports is in place in the community. The federal contribution would be an equalization transfer to ensure the protection and promotion of equality and citizenship rights through the assurance of access to essential (disability-related) social services and supports. The formula for such a transfer was not worked out in the consultation.

#### 2. Government and Consumer/Representational Groups: Partners in Delivery

Currently, consumer/representational groups are playing an important role in providing a range of services and supports that are directly relevant to people with disabilities. These services include:

- o Advocacy
- o Service monitoring and evaluation
- o Research and analysis
- o Policy involvement
  - at the macro resource allocation level
  - through "vision articulation" and policy development/program design with government
- O Consulting with government departments and mainstream providers (on a "one shot" basis in reference to specific issues; on a "partnership" basis in reference to particular projects; on an ongoing basis in reference to a wide range of issues.)

- o "Hard" service delivery (attendant care, interpreter services, intervenor services, instruction on use of white cane, braille instruction, other forms of instruction for consumer skill development, etc.)
- o Training of professionals involved with disability issues
- o Personal counselling to consumers
- o Information services to consumers and others
- o Assistance to consumers with service arrangements
- o Informal peer support (emotional, problem-solving, etc.)

It was a general view in the consultation that consumer / representational groups should be much better funded than they are at present to continue providing these services and other supports/resources to people with disabilities. The point was made on several occasions that the organizations often have to "scrape by" on whatever short-term project funding they can muster. Typically the funding disappears, and along with it, vital supports to consumers. In other instances organizations are pitted against one another in a competitive "scramble" to prove which is most deserving of the scarce resources that are deemed to be available. In still other situations, dollars are earmarked for "special" programs for which only a select few can qualify. It was pointed out that underlying these funding arrangements is the notion that disability is somehow a transitory thing, for which only tentative, sporadic funding commitments are required and not a fundamental characteristic of the human condition, for which long-term planning and a sustained funding commitment is required. The argument was made that, because disability is a basic fact of life, sustained funding commitment for Community Supports should be arranged accordingly.

For many participants in the consultation, their goal is that consumer dollars, together with fees for service paid by the public and private sectors, be used to cover most of the costs of the majority of the above services. In the interim, however, federal-provincial/territorial collaboration in funding was seen as essential if the organizations are to provide these services according to the (growing) volume of demand. Such funding may even be required as a permanent feature of the policy and funding environment to offset the cost of delivery,

regardless of the intended (and considerable) economic power of the disabled consumer of the future to fund service delivery.<sup>29</sup>

During the consultation there was repeated allusion to the notion that consumers themselves should be mandated and funded to play a much larger role in service delivery. Roles in which individual people with disabilities should, with the backing of public funding, be much more visible include:

- o direct providers of service, support and other resources to consumers with disabilities:
- o key executive decision-makers and board members in agencies arranging/providing supports required by consumers;
- o exclusive providers of support, executive services, and volunteer services as board members in organizations completely controlled and operated by consumers;
- o researchers of consumer needs;
- o researchers of effective support provision options for "difficult to serve" and other consumers;
- o program designers
- o program evaluators (not only in the voluntary/private sector, but in government as well)
- o educators/consultants to the public and private sectors

As well, Section A in Part I outlined several other junctures at which the delivery of supports by individuals with disabilities (disability determination, peer counselling, needs identification, etc.) is required and where funding for the provision of these supports would be necessary.

A more or less constant base of funding may be needed to enable the organizations to pilot and evaluate innovative and potentially effective modes of support provision for which there is as yet only emerging consumer demand.

3. Consumer/representational groups and disability-related services: providers of not just social services

It was maintained that several of the services currently being provided by consumer/representational groups do not and should not fall exclusively under the jurisdiction of social service policy, funding arrangements and administration. Advocacy, service monitoring and evaluation, general disability-related research and policy analysis, and policy development are required across a variety of policy domains. It should be expected that all policy and program sectors, including the private sector, will shoulder their responsibilities in this regard and ensure that consumer/representational organizations are adequately funded to carry out these critically important functions.

If no single public sector should have primary responsibility for funding consumer / representational groups to provide these services, the argument was made that much more funding and policy support is required from those policy and program sectors responsible for citizenship, rights, and justice. Advocating for more fair social service arrangements is a tenuous proposition when the funding to do so comes principally from social service departments. Advocacy, consultancy and policy analysis concerning employment programs are tenuous activities when important criticisms must be made about the training programs and the policies implemented under the training system that funds the advocacy, the consultancy, and the policy analysis. Thus, another base of funding that would enable consumer/ representational groups to operate more freely across policy and program domains in the interests of Equality and Citizenship Rights was seen as essential.

4. Support provision within the context of accountability

There was widespread agreement within the consultation that community providers of supports to people with disabilities are too seldom accountable to consumers for the quality and kinds of service they provide. A variety of measures were proposed for dealing with this problem.

First, the direct income transfers to consumers of services would serve as a powerful accountability lever. On the basis of consumer decision-making, providers that deliver appropriate, quality supports would probably continue to receive consumer funding.

Providers who do not satisfy the test of consumer satisfaction would eventually face a clear economic choice: either begin delivering quality, relevant supports or lose funding from the consumer. If the provider cannot muster a "critical mass" of consumer confidence, they would have no legitimate claim to be a provider.

Second, government contracting policy, together with consumer (individual and organizational) participation in the review and evaluation of how the providers of supports are responding to consumers, would be used to ensure compliance of providers to the

Equality and Citizenship Rights principles.<sup>30</sup> Again, providers who are found to comply with the principles are likely to retain consumer confidence, which in turn would signal that it would be appropriate to continue public investment (in the form of core or developmental funding). However, those who fail to comply with the principles would again be faced with an economic choice: comply with the principles or lose public funding.

5. Government commitment and human resource development: ensuring quality of support and viable career paths in the human services sector

In the consultation, the problem of human resource development in the human service sector was raised. Currently, individual providers of support services to people with disabilities tend to be poorly paid, to operate on short-term or unstable contracts, and to lack background on disability issues. This is hardly conducive to the provider's job satisfaction, to loyalty to the consumer, or to quality support provision.

While many concerns have been articulated about the serious need to curb professional domination in the field of disability, the point has also been made that people with disabilities

This would be a set of arrangements not unlike existing government Contract Compliance programs for the private sector, but applied to social services and with a much more rigorous focus on provider compliance with the Equality and Citizenship Rights principles. A full articulation of ideas implicit in the principles would raise a range of specific criteria for measuring provider compliance, including: the physical accessibility of the provider's office(s) and delivery site(s); full accessibility of information in a variety of formats on the supports that can be accessed through the provider; compliance by staff with indicators of respect for the consumer (which could be entrenched in legislation); and proactive employment equity practices, in which a proportion of the provider's workforce would be people with disabilities.

have the right to expect that the people who they hire/contract to deliver services will be competent to the task at hand. Better opportunities for professional development within the human services field is thus essential. So is some form of job security and satisfaction with the work to be performed.

Few specific proposals were presented on how the challenge of human resource development in the field of disability-related social services is to be managed. Making bursaries available to encourage the emergence of better trained support workers was suggested, as was broader use of the community college system, distance education, in-service training, and other ongoing professional development opportunities.

Implicit in the concern about human resource development is that government departments have a key role to play in ensuring that effective professional development programs are in place and funded, and that people with disabilities would have a key role to play in the policy development, design and delivering of such programming.

D. HELP REMOVE THE BARRIERS (IN SOCIETY AT LARGE, IN GOVERNMENT, IN PUBLIC PROGRAMS, AND IN SOCIAL SERVICES) THAT PREVENT THE REALIZATION OF THE EQUALITY AND CITIZENSHIP RIGHTS PRINCIPLES.

A range of mainstream systems (e.g. transportation, education, job training and job development, etc.) all deliver -- or should be delivering -- services and be making available opportunities that are relevant to the needs of people with disabilities. Yet most of these systems 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. It was the view of participants in the consultation that the new framework on disability must address these problems.

1. Removing barriers within the jurisdiction of social service departments: partnership with consumers

Social service departments could send a clear message that government is serious about barrier removal by using funding and contracting policies as outlined in Section C to exact compliance of providers in the human service sector to the Equality and Citizenship Rights principles. As discussed above, consumers would play a key role in the evaluation of social services, upon which government decision-making about ongoing funding for social services would be based.

The departments could also provide funding for "professional updating" and for the transformation of organizational culture within the social service system. This funding would provide opportunities for those who dominate the strategic centres of control within various programs, and who may be resistant to realizing the Equality and Citizenship Rights principles, to rethink their position. Again, the transformation of organizational culture would require the involvement of people with disabilities as educators and consultants to the process.

2. Consumers and social service departments: partners in removing barriers in other systems

It was felt that, together with consumer/representational organizations funded for the purpose, social service departments could play an important role in spearheading greater social responsibility across public departments and programs. Consumer/representational groups could help social service departments and other departments and programs conduct barriers analyses and develop strategies to remove barriers. However, there was scepticism about how far social services could go, or would be permitted by other line departments to go, in performing such a leadership role alone.<sup>31</sup>

<sup>31</sup> It was suggested that it may make more sense to mandate some other, powerful department more central to government operations, such as Treasury, to play a more vigorous leadership and funding role in this regard.

#### 3. Broader collaboration between consumers and government departments

Social service departments, together with departments responsible for citizenship, rights and justice, could jointly fund consumer/advocacy organizations to develop and focus political pressure across a range of departments and programs for the removal strategically significant barriers. The organization of more focused political pressure would in turn, it was conjectured, create a climate more receptive than the present climate to the concerted removal of barriers.

#### 4. Penalties and "charge back" relations

Clearly, responsibility for barriers rests with no single system. Each government department, public system of services, and the private sector presides over barriers that thwart the inclusion of people with disabilities. Accordingly, it was proposed that all departments and publicly funded programs should be held accountable for making services and opportunities as available to people with disabilities as to other citizens. To that end, it was suggested that public funding should be suspended from or stiff penalties imposed on systems, programs and employers that are not doing their fair share to serve people with disabilities. Failing that, social service departments could perhaps be mandated to "charge back" to the various line departments and the private sector the costs incurred to social services as a result of their failure to include individuals and to help realize the Equality and Citizenship Rights principles.

# 5. Consumers and local/municipal governments

The point was made during the consultation that it is in the interests of local/municipal governments to plan for the removal of barriers in local communities. If they do not do so, they will find themselves funding a range of expensive "special" programs and services to address the needs of people with disabilities. Many of these costs could be avoided if urban planning departments, social planning councils, and elected bodies were to better understand the wisdom of designing and making determined planning efforts to create inclusive communities and services in the first instance. The view was expressed that consumers with disabilities have an important role to play as educators and consultants to these bodies, and

that there may be a role for social service departments to play as funder of such consumer involvements.

#### 6. Barriers analysis in needs-identification

The inclusion of barriers analysis in consumer needs identification as outlined in Section A would serve as a basis of information for research, and for sustained and coherent policy development, planning, and strategy design for barrier removal on a systemic level.

#### 7. Responsibility for barrier removal

Exactly where ultimate responsibility for barrier removal should be vested remains unclear. What was clear to participants in the consultation is that vesting responsibility for removing barriers in departments/units that have little real "pull" inside government and public programs (e.g. special offices or units on disability) has not been effective where this has been the only approach. Nor have approaches that vest responsibility across departments and programs, but that vest responsibility nowhere in particular. Here the problem is a lack of coordination, systematic planning, sustained implementation of measures to remove barriers, and the lack of a place of final responsibility where the buck ultimately stops.

#### PART III

#### A. Specific themes of focus for Mainstream 1992

Participants in the consultations were generally of the opinion that there was a need for a new legal, policy, funding and delivery framework to more effectively address disability-related support issues. The framework as outlined in Part II of the report would address many of the difficulties people encounter in exercising their rights as equal citizens. In short, such a framework would address a wide range of problems individuals with disabilities are encountering in:

- o being able to live with the additional costs of disability;
- o securing and exercising their fair share of economic, social and political power;
- o gaining access to and remaining in the labour market;
- o living independently in the community; and
- o making the critical transitions all citizens have to make at one time or another.

The framework as proposed would serve a strong basis for promoting the realization of Equality and Citizenship Rights. It would also prevent/curb the emergence and impact of conditions that undermine the realization of those rights.

The discussion in Part II, sections A and B, provides a fairly detailed set of insights and proposals for the reform of the income support/replacement system. This was widely seen as a central issue. As discussed, there was a general sense that, by strategically focusing on funding arrangements for cost-coverage of supports that are disability-related, a major advance would be made. Supposing that the proposals were implemented, there would no doubt be remaining income support issues. However, these are at the present time difficult to "disentangle" from disability-related funding support issues, and are likely to remain so until progress is made on the disability front.

Indeed it was felt that by establishing an Equality and Citizenship Rights framework on disability, many of issues concerning consumer empowerment would resolve themselves. Again, reform of funding arrangements was seen as central to the problem.

Moreover, if the new framework was implemented, provisions would be established to enable most, if not all, significant "transitions" to get identified and addressed. Indeed, a strong preference was expressed for there <u>not</u> to be discrete transition programs, and for there to be an entirely different approach, as outlined in this report. Discrete "transition programs" were seen as tending to set artificial boundaries around some life changes and as identifying some changes as being more significant or deserving of attention than others. It was felt that what is a significant transition is a highly individual matter, and that consumers should have taken at face value the life changes they identify as significant.

There are numerous issues to be resolved in addressing the very limited participation of people with disabilities in the labour market. Many problems require that concerted efforts be made across a range of public programs and the private sector. Again, however, a great many problems that people with disabilities encounter arise because of inadequate access to supports that will enable participation in the labour market, which in turn can be traced back in large part to funding and policy arrangements guiding the provision of disability-related supports.

In terms of community living and independent living, it was clear during the consultation that both philosophies converge in the Equality and Citizenship Rights principles. While there are differences in nuance between the two philosophies, and while the support arrangements that have been put in place by the constituencies of each philosophy may differ, participants saw the differences as ones of detail rather than substance. Many of the differences at the operational level were traced to disability-related policy and funding, which hamper the full realization of these philosophies.

It was felt that a major "prevention" focus should be placed on eliminating the conditions and "hostile environments" that place people with disabilities at risk of poverty, devaluation, exclusion from the social mainstream, powerlessness, losing control over their own lives, and subjection to domination by medical and other professionals, service providers and social welfare workers. Conditions that promote the equality, rights, empowerment, respect and

social well-being of people with disabilities should be the major focus of "promotion".

Again, this points to the centrality of the Equality and Citizenship Rights framework, and the reform of funding, policy and program arrangements necessary for implementing that framework.

#### **B.** National Standards

During the consultation, participants widely agreed on the need for national standards to ensure that the Equality and Rights framework is properly implemented in all parts of the country. Participants also realized that the constitutional process, together with the trend to "devolve" responsibilities to the provincial/territorial governments in any event, create significant problems with the implementation of national standards. However, participants felt that there is a critically important role for the federal government to play in implementing the framework, developing standards, working with the provinces/territories to ensure a national program is in place that accords with the standards, and in providing funding to the provinces/territories that would enable such standards to be realized.

There was fundamental agreement on the central point: that there should be a national legislative and policy framework to ensure the entitlements outlined in Section A of this report, and that this framework should include indicators of respect for the consumer and consumer empowerment to which providers of support would be held accountable.<sup>32</sup>

#### C. Role of social services

Section II of this report outlines a number of roles that need to be played and funded in order to implement the Equality and Citizenship rights framework. The point has been made that the roles and funding responsibilities do not fall exclusively within the jurisdiction of social services, but that social services nonetheless should be assuming some of the responsibilities.

Participants had some difficulty in defining with more precision the role that social services should be playing. Several issues were clear, however. First, until such a time as the

<sup>32</sup> These need to be worked out in more detail.

Equality and Citizenship Rights framework is fully implemented and full inclusion of people with disabilities has been achieved across public programs and society at large, social service departments should not be "off-loading" their responsibilities onto other departments unwilling or unable to take up the slack.

Second, people with disabilities are not looking for less support than what they are currently receiving through social service departments. However, they are looking for different ways of organizing the funding and of making the supports available. These new approaches will call for social service departments to play a different role in the future than they do today.

Third, much of the responsibility for the policy and funding around disability-related supports falls to social service departments. They thus have an important role to play in shifting the system towards the kinds of reforms outlined in Section II of this report.

Fourth, more time is required for consultation between representatives of social service departments and people with disabilities. Owing to the staggering complexity of current arrangements and of reforming these arrangements, systematic planning and detailed, thoughtful examination of new roles and responsibilities in the reform process is critical.

Fifth, shifting the present arrangements towards the new framework will involve strategic planning that must involve people with disabilities in a very significant way. Social service departments have a role to play in facilitating this involvement. Social service departments also have a role to play in determining with other government departments where and how ultimate responsibility for managing the change should be vested, a deliberation that again, it was felt, must include people with disabilities in a meaningful way.<sup>33</sup> Interim funding during the shift towards the new framework -- to allow for the reorganization of present modes of support delivery -- would have to be allocated, and a variety of issues such as job dislocation and retraining will require sustained attention.

<sup>33</sup> The "Empowerment" focus group paper has some specific suggestions in this regard.

# APPENDIX B, Annex i

Community Views and Themes Regarding Services Affecting Persons with Disabilities

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

# COMMUNITY VIEWS AND THEMES REGARDING SERVICES AFFECTING PERSONS WITH DISABILITIES

A report compiled from a variety of submissions and position papers of organizations concerned with the situation of persons with disabilities.

prepared for:

Executive Committee Mainstream 1992

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#### 1. PURPOSE OF PAPER

This paper pulls together and highlights themes emerging from a variety of studies, reports and submissions by consumer groups and other non-governmental bodies which have been presented to government over the last several years and which have implications for Mainstream 1992 (the Review).

One essential component of the Review is a consultation process with consumer associations, other organizations and individuals. At the same time, the Executive Committee recognizes that there have already been numerous representations, at the federal and provincial/territorial levels, which are relevant to its mandate.

This paper, for the most part, is organized in accordance with the major outcome categories of the Review. To the extent possible, comments are grouped in accordance with these outcome areas. In addition, Chapter 3 summarizes comments which have implications for the Review but which do not fit or transcend specific outcome categories.

The emphasis of this paper is on themes and commonalities from across the documents which were reviewed. In particular, it focuses on statements and considerations relevant to the scope of the Review. Thus, for example, it emphasizes comments which have national implications, rather than considerations specific to a particular jurisdiction.

This paper is expected to have a number of uses, including:

- Ensuring that the preliminary approach of the Review is consistent with what advocacy groups and independent bodies have been saying;
- Providing a structure for the planned consultation process. For example, consumers and others can be asked to review the paper and to indicate to what extent it has identified what they view as the priority themes and issues.

#### Limitations

This paper only deals with those aspects of those reports examined which are directly relevant to the mandate of Mainstream 1992. Thus it is not intended as a complete review of all the information contained in these documents nor as a review of all possible documents.

This paper attempts to present and reflect the spirit and contents of the reports which were reviewed. It is not intended as an analysis or critique. It does not necessarily reflect the viewpoints of the Review.

Thus this paper should be viewed as a starting point. It can provide an opportunity for consumers to indicate the extent to which the themes in this paper represent their perspectives, and a basis for identifying any additional considerations.

#### **Consistency**

A major finding emerging from this paper is the high degree of consistency found in the reports which were reviewed. As discussed in the following pages, the same themes come up again and again irrespective of who made the comments, what part of the country they came from, and which disability group they refer to.

Specific service needs vary in accordance with individual requirements. For example, the types of accommodations for employment required by a person with a hearing impairment would differ from those required for persons with other forms of disabilities. Mental health services are organized somewhat differently from other social services. Nevertheless, it is apparent that the same issues apply to all persons irrespective of their type of disability.

#### 2. VISION

The vision as expressed by consumers is simple and straightforward. It can be summarized under the following headings:

# A. Opportunity for Full Participation in All Aspects of Community Life

The opportunity for full participation means that people with disabilities. just like everyone else, should be able to live in the community and to have access to regular community structures, opportunities and services. It means the right to participate fully within an environment that enables maximum independence. It means the economic integration of persons with disabilities into society. It means integration, not segregation.

Most profoundly, full participation means a society which is accommodating of all persons with their differences, including functional limitations and disabilities. This means that the social and physical environments need to be adapted as necessary in order to eliminate direct and systemic barriers, rather than requiring individuals to change.

#### B. Personal Autonomy and Choice

Autonomy means that people with disabilities have control over their own lives and well being. It means that they can make their own decisions about all aspects of their lives. In a word, it means choice.

The right to make one's own choices carries with it consequences, in particular the right to take risks. Individuals with disabilities, just like everyone else, may not always make what others, including professionals, caregivers and family, feel is the "correct" decision. The response in such situations, rather than coercion, should be the same as for others in society. For example, the approach to the general population regarding lifestyle choices consists of education and health promotion activities.

#### C. Respect for Individual Dignity and Autonomy

Respect for individual dignity means recognizing people with disabilities as having equal status to that of other residents in the community. It means that people with disabilities are entitled to the same level of respect and consideration for their abilities as are accorded to others.

A related consideration is access to all services in a way which respects individual dignity. Consumers have expressed strong concern over the manner in which services are provided and the attitudes of service workers.

# D. Supports to Permit Equality of Opportunity

In order to foster equality of opportunity in the community and the ability of people with disabilities to achieve their full potential, adequate personal and financial supports need to be available in accordance with individual needs. Supports and benefits should be viewed as a means of "levelling the playing field" for people with disabilities in order to provide for full integration into society.

Thus it is critical that support services actually support independence rather than reinforce dependence. As stated repeatedly by numerous commentators, support services should be under the control of the consumer.

# E. Participation in Decisions Affecting Their Lives

A common theme is that persons with disabilities should be included in planning and decision making, at all levels, regarding programs and services which may affect them.

#### 3. OVERRIDING CONSIDERATIONS

This chapter discusses significant themes in the documents reviewed which have implications for the Review but which do not fit or transcend specific categories.

#### A. Need for "Action, not Advice"

Obstacles, the Report of the Special Committee on the Disabled and the Handicapped, including the Follow-Up Report: Native Population, in particular created great expectations among consumers for the United Nations Decade of Disabled Persons: 1983-92. But the general feeling is that action to date has consisted only of dribs and drabs. This in turn has resulted in considerable frustration for many consumers.

For example, the Standing Committee on Human Rights and the Status of Disabled Persons pointed out that by and large, the same issues before Obstacles are still on the table. The words "action, not advice" in this section heading are those of the Committee, which also chose to entitle the first chapter of its report on economic integration: "History of an Impasse". The Committee said that the response to Obstacles has been mainly words rather than action. For example, it says that the government response: "did not address the broader issues of systemic discrimination in employment nor the means of promoting greater economic integration and independence of disabled persons for which the advocacy groups had been calling."

The strongest language, by and large, can be found in the words of the Standing Committee. Nevertheless, words like "angry" and "frustration" work their way into many other documents. It is apparent that many consumers are seething at what they perceive as a large number of studies and acknowledgement of issues and needs, yet little action to date.

As the Standing Committee stated: "[We] share the frustration of those who have been calling for comprehensive action. . . . The reports, responses, studies, briefing books, that have resulted have consumed as much time and energy as it would have taken to act."

#### **B.** A Comprehensive Approach

A term used by numerous commentators in describing the array of services and programs for persons with disabilities is "patchwork". A common theme is the importance of the big picture and interconnectedness of issues cutting across the

different outcome categories of the Review. For example, as the Standing Committee has stated:

"We have been repeatedly struck by the interconnectedness of disability issues. Employment levels, for example, are directly affected by the structure of income support, taxation and social assistance programs which, in some cases, create powerful disincentives to employment. They are also affected by the accessibility of education and training which, like employment levels, are affected in turn by the accessibility of transportation and the availability of adequate sources of income, particularly when the costs of assistive devices are borne by the user."

A "comprehensive approach to these issues is needed, if inconsistent and incompatible policies are to be brought to light... A comprehensive approach to economic integration, which pays special attention to the linkages between disability issues and programs, is now an indispensable precondition for significant progress."

Considerations such as the above have led to calls for some form of comprehensive or universal disability scheme. This topic is revisited later in this paper.

There are numerous references to the lack of consistency across jurisdictions at all levels, and of policies and programs fighting one another — frequently to the detriment of the consumer. This is a major consideration behind the desire, discussed in Chapter 7, for a strong federal presence, for national standards of some form, and for more cross-jurisdictional cooperation.

Another related theme is that, partly as a result of the patchwork and lack of an overall approach, there are numerous systemic barriers and disincentives to full participation in the community. The general feeling is that "tinkering" with existing programs is not sufficient and that the only way to effectively address these disincentives is through a comprehensive approach of some form.

#### C. Focus on Net Costs

Again, partly due to patchwork approaches and to consideration of expenditures in isolation from resulting benefits, the true costs of services and programs for persons with disabilities can be distorted. Commentators say that a lack of a comprehensive approach to calculating the true costs of services, for example, only taking into account expenditures on specific program areas, ignoring

offsetting savings in other areas and longer-term benefits, results in absurdities, producing greater cost to the taxpayer in many instances.

Consumers, in various representations, have provided examples of this, such as:

- The high cost of care in a custodial care institution versus the much lower cost of support which would be needed to enable people to live in community settings;
- The cost of welfare for someone excluded from the labour market to that of an employed person. As one person who was formerly considered "unemployable" but is now employed in a management position stated, she now pays "more in taxes than I used to receive in social assistance payments."

Thus there appears to be a need for a cost-benefit approach, which takes into account *net* costs. As the Standing Committee stated, it is necessary to:

"Direct attention away from individual program costs and towards net costs, which is where attention should be focused if scarce resources are to be used efficiently. Costs of employment programs or accommodation initiatives, for example, need to be set against the substantial savings of public money achieved when the dependence of people with disabilities on social assistance is reduced."

# D. Pivotal Importance of Rights and Advocacy

#### Awareness of Rights

Some commentators have pointed to the lack of awareness of rights among many persons with disabilities and how to act upon them.

For example, some have observed that many persons do not know what their sights are and that others are afraid of repercussions, such as losing their job, if they assert themselves. Others, speaking specifically of how psychiatric patients have been demoralized and disenfranchised through their experiences with the mental health system, point to their need for assistance in achieving their goals and exercising their rights.

# Strengthened Protection for Rights

A major theme is the need for strengthened protection for rights. A number of commentators indicate that discrimination is rampant in Canada. Others point out the importance of human rights legislation and the importance of amending the Canadian Human Rights Act so that the duty to accommodate is included. But they also say that rights, on paper, are not enough. They say that there is a need for a stronger and more proactive role in the enforcement of rights.

#### Other consumers have called for:

- The provision for class action suits in human rights legislation;
- Strengthening the rights of persons with disabilities in the Charter;
- Introducing an omnibus bill, federally and also provincially, to amend existing legislation that discriminates on the basis of disability.

# Stronger Enforcement of Rights

Some have observed that rights established on paper but without support for legal action have no impact. Thus there is a call, among consumers and others, for a strong enforcement mechanism.

Another common theme is the need for an independent appeal mechanism with respect to all social services.

# The Court Challenges Program<sup>1</sup>

Numerous submissions point to the critical importance of the Court Challenges Program as one mechanism for the enforcement of rights and of raising important legal issues. Some even call for an expansion of the program.

<sup>&</sup>lt;sup>1</sup>Note that all comments regarding the Court Challenges Program were made prior to the March 1992 Budget which announced the cancellation of the program.

#### Support for Consumer Participation and Advocacy

A common theme is the need for adequate support for community advocacy associations to provide people with disabilities with the opportunity for meaningful involvement in decisions that affect their lives.

Others have pointed out that some consumers, for example persons with mental disabilities who have had little experience in group participation, as well as others who have had decisions made on their behalf for much of their lives, may require help with self advocacy. They assert that advocacy should be an integral part of mental health services and that clients have the right to be informed of their legal rights, entitlements and available resources.

Benefits arising from consumer participation in self-help groups which have been identified include:

- Mutual support and aid;
- Increased self confidence and skills that can carry over into other aspects of life,
- Involvement in decisions about services which they are or could use themselves.
- Involvement in advocacy with respect to broader policies.

#### E. Involvement of Persons with Disabilities in Planning

A major theme, stated repeatedly, is the need for governments to involve people with disabilities in the planning of programs and services. This appears to be a key concern of the disability community.

# F. Control by the Individual

An overriding theme is the strong desire of persons with disabilities to have control over their own lives, to have control over the services which they receive and on what basis these services are provided.

There is a desire for programs and policies to support, rather than detract from, individual control over their life choices and the services they receive. Virtually everyone, however, describes the present situation as the reverse of this.

# 4. TOWARDS INDEPENDENCE: COMMUNITY/ INDEPENDENT LIVING, EMPLOYMENT AND INCOME SECURITY

#### A. The Interconnection

Community/Independent Living, Employment, and Income Support/Replacement represent three separate categories for the Review. One of the strongest themes which emerges, however, is the strong interrelationship among these categories. Section 3.B already spoke of the interconnectedness of issues and the need for a comprehensive approach.

The overriding importance of employment to people with disabilities — and its interrelationship with everything else — emerges quite strongly from the various documents and submissions. For example, one commentator observed that employment involves far more than just a job, that it provides a way for people to participate in social life and is closely associated with self-esteem.

The Standing Committee observed that people with disabilities have consistently chosen economic priorities in their representations before this Committee. Their concerns are amply supported by the evidence. Others speak eloquently of the desire of people to be employed and independent of social assistance, as well as of the many barriers and disincentives standing in their way.

Furthermore, poverty is not just a lack of money. It also makes community integration impossible. As discussed later, the most common complaint regarding the income support "system" (or non-system) is that it contains so many disincentives that it militates against, rather than facilitates community/independent living, employment and economic independence.

#### B. Community/Independent Living

#### **Poverty**

Many have pointed out that community integration and participation in community life is impossible for persons living in poverty. Lack of funds effectively excludes persons from being able to participate in the community and in the political process. For example, persons who are not working and have no funds suffer more stress and find it more difficult than persons who do have jobs to maintain their identity and sense of self-worth.

As others indicate, most persons with disabilities live well below the poverty line.

#### **Employment**

As indicated above, employment represents far more than a source of funds. It also involves a sense of self-worth. People in the community are respected and valued by their work, while persons who are on welfare are looked down upon. Few of the documents reviewed spoke of community living without also speaking of employment.

#### Accessibility and Public Attitudes

Physical and communication accessibility within the community is a prerequisite to full participation and equality of opportunity. Yet numerous reports indicate that many publicly supported and government facilities are not accessible, let alone workplaces, housing and other buildings in the community.

Others have noted that accession and matter of physical access. Many speak of overt as well as system mination and the lack of welcoming in the community. Attitudes of profile in accepting persons with disabilities are also critical. Reports discussion with psychiatric disabilities speak most directly about the stigmatization and devaluing which they face. It is clear from other reports, however, that persons with other forms of disabilities frequently receive similar treatment.

A number of reports suggest that there should be more public education activities. National Access Awareness Week was frequently mentioned positively.

# Transportation

Transportation includes access to community-based public transportation, parallel transportation systems, and all forms of inter-city transportation. It also involves barrier-free pedestrian access.

Transportation is a major concern among persons with disabilities. Inadequate or non-existent accessible transportation is cited frequently as a major barrier preventing participation in the community and employment.

#### Support and Attendant Care

A major barrier to full participation and a central concern of many consumers is the lack of sufficient and appropriate individual attendant care. For persons requiring attendant care, this is a basic prerequisite to living and working in the community.

#### Housing

Lack of affordable, accessible housing is another frequently mentioned barrier to community/independent living. For people with mobility limitations, lack of availability of accessible housing can mean that they have no other alternative than being forced to live in some form of institutional accommodation. For all people with disabilities who have a limited income, the lack of affordable housing is a major problem. For persons who require some form of support services, lack of portable support services acts as an effective barrier to a choice of housing.

#### Other Barriers

Some other requirements for effective independent/community living include:

- Rights and enforcement mechanisms, as discussed earlier;
- Access to a full range of access and services, including not just those traditionally considered social services, but to others such as child care, recreation, and those discussed above;
- Access to information, in understandable and accessible forms, support networks and other resources.

# C. Employment

The prevailing theme is very simple — persons with disabilities want to be able to work. Many suggest that employment is "the" big issue among consumers.

But various reports point to numerous barriers keeping persons out of the labour force. For example, many people with disabilities feel that many services supposedly intended to help instead frequently do more harm than good, making it more rather than less difficult for them to be employed. There is a feeling that the "patchwork" of training programs and the poor record of government itself in hiring and retraining persons with disabilities suggest that employment of disabled persons is not a priority.

Considerations regarding employment cover a number of subsidiary issues which are briefly highlighted below.

#### Education and Literacy

Many persons who were educated in segregated schools have expressed dissatisfaction with the education they received. Deaf consumers add that various types of educational programs or settings designed and/or controlled by hearing professionals that are appropriate for hearing students are not necessarily good for the Deaf. As a result, many consumers lack both basic skills, necessary for further training and for employment, and even the basic prerequisites, such as minimum educational requirements, in order to be eligible for more training.

As a result of the above, the lack of sufficient literacy skills has also been identified as a major concern. Indeed, this has been identified as the primary barrier preventing persons from entering the labour force.

There is considerable support for people with disabilities to use regular literacy training. Many existing literacy programs, however, are not accessible.

#### Need for Effective and Appropriate Employment Training

The availability of training has been identified as a key need if persons with disabilities are to acquire the skills and qualifications needed for employment, as well as critical social skills.

But considerable concern has been expressed over how training and employment supports are presently provided. For example:

- Some have called for a more coordinated, consolidated and aggressive approach to the provision of training.
- Others have pointed out that employment rehabilitation services do not often consider non-traditional approaches to meaningful work.

- A common theme is that employment training should be at the worksite
   (i.e. via supported employment) rather than in segregated settings such as
   sheltered workshops. There have been suggestions that government
   funding be denied to those who operate sheltered workshops, with the
   funding redirected towards supported employment.
- Some training programs, while well-intentioned, impose small, unintended barriers of their own.
  - Many post-secondary educational and other training programs require that all participate on a full-time basis and are unwilling to accommodate persons who cannot participate on this basis;
  - Programs frequently do not provide sufficient flexibility to accommodate persons with special needs;
  - These unintended barriers are attributed to the lack of involvement of consumers in planning and the lack of sufficient ongoing contact between funders and students in training programs.

The above, and related factors, have led to recommendations that all employment training programs be required to accommodate clients with a disability. The need has been identified for the funding of training programs to provide for ongoing accommodations of persons with disabilities, e.g. for interpreters, readers, or other needed ongoing assistance. A common theme is the importance of an individualized approach to training.

# Barriers to Employment

Numerous submissions speak of many of the barriers to employment which people with disabilities face. Following are only examples.

- Lack of adequate and appropriate training and educational opportunities, as discussed above.
- The manner in which income support is provided, as discussed in the following section, operates as a major disincentive to employment and serves as a major barrier.
- Attitudes of employers, co-workers and the public.

- The poor example set by government, with the federal government cited as having one of the worst records in hiring people with disabilities.
- The need for accessible training and accessible workplaces.
- Lack of accommodation at the workplace.
- Inadequate supports, including a lack of job coaches for people with developmental disabilities, attendant care for people with mobility limitations, readers for people with visual impairments, interpreters for people with hearing impairments.
- Lack of access to information. Few persons with disabilities, for example, understand the Employment Equity Act.
- Some mention that interested employers need help in locating persons with disabilities who could be potential employees.

#### Need for Stronger Legislation

A major theme emerging from the documents is the need for stronger legislation, such as:

- Amendments to the Canadian Human Rights Act similar to Ontario's Human Rights Code, to include legally binding guidelines regarding accommodation at the workplace.
- Employment Equity legislation, with mandatory targets and timetables, and onerous penalties for non-compliance, to be evaluated in conjunction with the disability community. It has been suggested that revenues from non-compliance could be used to fund accommodations when needed by employers who encounter undue hardship.

# **D. Income Support**

# Disincentives to Employment and to Community Participation

One of the major themes, spoken of with considerable frustration and in numerous representations, is the way in which income support discourages employment and community participation.

Of particular concern, resulting in considerable comment, is how the present manner of provision of income security, in all jurisdictions, acts as a disincentive to employment. Most definitions of disability require a person to be completely and totally disabled to be eligible for benefits, and to be "unemployable". Gradations in employability, as well as the reality of new models of support provided directly at the workplace, run counter to the philosophy of current income support programs. This situation does not encourage people to try to work. They are afraid of losing their benefits and of not being eligible for benefits again if a job, for whatever reason, comes to an end.

Another major disincentive concerns taxback rates as high as 100 percent on any earned income, which numerous commentators say provides no incentive for someone to attempt to find work and reduce their dependency on social assistance. This problem is cited across many different jurisdictions.

Many have called for removing the employment disincentives in income security programs and for reducing taxbacks to employment, for example to no larger than 50%.

#### Administration

Another concern expressed about social support programs is how they are administered. In particular, there is a feeling that the manner of administration tends to result in a loss of dignity and self respect for recipients.

#### **Poverty**

Insufficient benefits leave people in poverty. This in turn, as indicated earlier, precludes participation in community living. As the Standing Committee, for example, stated: "Like other Canadians, people with disabilities need an adequate standard of living in order to have an acceptable quality of life."

# Extraordinary Costs of Disabilities

Disability-related expenses, some of which are covered while on social assistance, are a powerful disincentive to employment. Due to these expenses, people may be financially worse off employed than on welfare. As the Standing Committee pointed out:

"The low exemptions for earnings and assets in both pensions and social assistance programs keep disabled individuals from building up their own contingency fund. They cannot work without giving up their entitlement to welfare or to the benefits such as extended health coverage or technical aids that come with a disability pension."

Costs associated with the disability, in particular costs for specialized medical care and equipment, can be onerous for many persons. The availability of needed medical equipment and specialized aids can make the difference between dependence and independence, between living in an institutional setting versus living in the community. The cost of employment-related supports can be extensive for some people.

This situation has led to calls for acknowledgement of disability-related expenses, for example with a more generous earnings exemption and provision for additional expenses above the standard amounts to be itemized.

There have been various calls for reforms in the tax system, so that persons with disabilities are treated equitably. These include, for example, refundable income tax credits. Others have indicated that assistive devices required for employment are not items of discretion and that the present tax system does not provide for full deductibility of employment-related expenses.

# Need for Overhaul of Present System

Many have noted that income security for persons with disabilities, rather than a coordinated system of any form, instead consists of numerous inter-jurisdictional inconsistencies and a range of private, provincial and federal programs which work at cross purposes to one another, resulting in numerous anomalies and inconsistencies. Most indicate, in one way or another, that the present system is archaic, based upon obsolete philosophies and information.

As a result, there have been numerous calls for major changes to the present manner in which income support is provided. Indeed, some speak of the need for a comprehensive, coordinated rehabilitation system providing for harmonization of services, noting that across the country, there is "no systematic approach to identifying or addressing the problems of people with disabilities." Others have indicated the need for a universal disability insurance plan, while still others have called for a guaranteed annual income, as part of an overall reform of income security for all Canadians.

#### 5. PREVENTION/PROMOTION

There is limited discussion of prevention in documents which were reviewed in the preparation of this paper. Interest in the topic varies considerably within the communities of persons with disabilities.

Some individuals and organizations haved expressed concern that prevention activities have the potential to do some harm, if they inadvertently result in devaluing persons with disabilities. On the other hand, there are those who see a need for development of positive approaches to prevention.

Interest in the concept of "prevention" may depend upon how it is defined. In the mental health context, for example, there is considerable interest in the topic, where prevention is defined as preventing the need for hospitalization via community supports and alternatives. Some have spoken of the appropriateness of a health promotion approach focusing on the promotion and maintenance of optimal health and of healthy lifestyles. There has also been some interest expressed in minimizing the loss of functioning which may result from the aging process, so as to reduce any impact on overall health and independence.

Another way of looking at prevention may be to focus on the distinction between the World Health Organization's definitions of disability and handicap. Some have pointed out, for example, that handicap is a function of society and the environment, not the person, and that a way to prevent handicap is to provide a fully accessible environment for persons with disabilities.

There has been some suggestion that if society recognizes that the entire population is at risk of becoming disabled, through sickness, accident or the ageing process, then prevention of handicap, along with societal modifications to permit full participation by people with disabilities, may be a higher priority. The problem, as some have indicated, is that people with disabilities are marginalized, their needs viewed as expensive "add-ons" rather than as basic rights. If persons with disabilities are viewed as full participants, then accommodations would be provided as a matter of course and need not represent additional costs. In other words, if all public washrooms were designed so that they were usable by all, if transportation systems and facilities were designed to be accessible to all, then retrofitting and special accommodations would not be necessary.

# APPENDIX B, Annex ii

Plain language questions for consultation