



IRIS

Institute for Research and Development on Inclusion and Society
Institut de recherche et de développement sur l'intégration et la société

DISABILITY AND INCLUSION BASED POLICY ANALYSIS



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Institute for Research and Development on Inclusion and Society (IRIS).

Published by:

Institute for Research and Development on Inclusion and Society (IRIS)

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The recommended citation for this publication is:

Institute for Research and Development on Inclusion and Society (IRIS). 2012.

Disability and Inclusion Based Policy Analysis. North York: Author.

ISBN: 978-1-897292-06-8

Acknowledgements

IRIS gratefully acknowledges the input of a number of advisors and reviewers including Laurie Beachell, Gary Birch, Audrey Cole, Johanne Bourbonnais, Janet Forbes, Bendina Miller, Dulcie McCallum, Norm McLeod, Vangelis Nikias, Gordon Porter, Dr. Michael Prince, Doris Rajan, Diane Richler, Lorraine Silliphant, Dr. Tim Stainton, Heather Tracey, Una Tucker and Marie White. We also extend our appreciation for the generous financial contributions to the development of this guide, to the Canadian Association for Community Living Foundation, and the Community-University Research Alliance – ‘Disabling Poverty/Enabling Citizenship’ led by the Council of Canadians with Disabilities and funded by the Social Sciences and Humanities Research Council of Canada.

About The Institute for Research and Development on Inclusion and Society (IRIS)

The Institute for Research and Development on Inclusion and Society (IRIS) provides policy research and social development leadership that encourages new ways of thinking, inspiration, and education to advance the citizenship, inclusion, human rights and well-being of people with intellectual and other disabilities. It builds on the legacy of L'Institut Roehar Institute. IRIS is an independent Institute working on behalf of the community living movement in collaboration with the broader disability and social justice communities.

Specific areas of research and development include: social inclusion and life beyond institutions; disability-related supports; education, literacy and learning; child development and family life; human rights, ethics and technology; personal safety and security, employment and income; social policy and change.

Our grounding assumptions are that, like others, people with intellectual and other disabilities want to be safe, included, valued, equal, and free.

IRIS:

- Liaises and collaborates with other experts;
- Analyzes the social and economic realities facing people with intellectual and other disabilities and gives voice to their lived experiences;
- Links issues of disability to broader research, policy, program and social development issues and agendas;
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- Distributes others' research and resources that warrant positive attention;
- Provides a broad Canadian perspective and in-depth coverage;
- Ensures its research and social development efforts are non-partisan, objective and meet the highest quality standards;
- Points to supportive policy and program options; and
- Helps move research and new knowledge into action through seminars, presentations, training and other knowledge mobilization strategies.

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Introduction

'Disability and Inclusion Based Policy Analysis' (DIBPA) is a process designed to assist policy makers and analysts in departments and agencies across government in developing policies and programs that are fully inclusive of people with disabilities. It provides guiding principles for inclusive policy development and points to key factors affecting the lives of people with disabilities – like poverty, inadequate access to education and training, lack of disability-related supports, violence and abuse, denial of autonomy and self-determination. It identifies some of the main policy implications that result, and provides a set of guiding questions for undertaking policy formulation, implementation, evaluation, revision and policy coherence. The guide concludes with some suggestions for assessing capacity to initiate disability and inclusion based policy analysis or DIBPA within a government context and sustaining it over the long term. Together these principles and questions provide a lens for assisting policy makers to advance public policy to address historically entrenched patterns of exclusion and marginalization experienced by people with disabilities.

With Canada's ratification in 2010 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD), supported by all provinces and territories, this guide is of particular importance. The Convention makes clear in its 'General Obligations' on States Parties that its provisions "extend to all parts of federal states without any limitations or exceptions." All levels of government have a primary obligation under the CRPD to respect, protect and promote the rights of persons with disabilities, and to address long-standing barriers to full participation, inclusion and citizenship. While ratification signals that governments in Canada have determined that our legal framework is in compliance with the CRPD, this does not mean that the inequality gap between Canadians with and without disabilities is closed. Ratification means that we commit to abiding by the CRPD obligations in undertaking policy development to address this gap. This guide is meant to assist in a policy development process that will enable governments in Canada to comply with the

CRPD over the long term, and in a way that has a real impact in advancing equality of Canadians with disabilities.

Changing Perspectives on Disability

Policy development to advance inclusion begins with a recognition that our understanding of disability has shifted over time. Historically, disability was seen as a deficit or 'deformation' of a person's intellectual, physical, sensory, communication or psychological characteristics. Disability was something inside the person and the focus was exclusively on diagnosis, treatment, cure and prevention. In this model, if a person could not be cured of disability, at best he or she deserved to be taken care of, often through segregated services, because it was assumed people with disabilities could not participate as full members of society.

Increasingly disability has come to be understood as the result of the interaction between some of a person's characteristics, sometimes called 'impairments', with their physical and social environments in which people live. Consequently, the focus of intervention has shifted to changing the social, economic and environmental barriers that surround the person, and providing the person with supports needed to fully participate. For example, a person who uses a wheelchair in effect only becomes disabled when there is no ramp to access a building; or when other supports are not available to access opportunities on an equal basis with others; or when others devalue the person in some way because he or she uses a wheelchair for mobility.

The CRPD characterizes disability in just this way:

Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

Defining Disability for Public Policy

This general approach to characterizing disability provides some guidance in defining disability for the purposes of public policy. There are a few important guidelines to remember:

- Place the person first – in the North American context, it is generally accepted to use the term ‘person with a disability’, rather than a ‘disabled person’ (although in the European context, the opposite approach tends to be taken in order to make clear that the person is ‘disabled’ by structures outside of him or her).
- People with ‘physical disabilities’ generally include people with some form of mobility or agility challenge.
- People with ‘intellectual disabilities’ refers to people who have historically been referred to as ‘mentally handicapped’. This group is also referred to as people with ‘developmental disabilities’ which is inclusive of people with intellectual disabilities, but may also include people with cerebral palsy, fetal alcohol syndrome, autism spectrum disorder, and other developmental challenges. Intellectual or developmental disability is associated with onset of conditions before age 18 and which are related to significant challenges in intellectual capacity or adaptive behaviour which can include life and social skills.
- People with ‘learning disabilities’ refers to people who experience a number of challenges with acquisition, organization, retention, understanding or use of verbal or nonverbal information. People with learning disabilities otherwise demonstrate at least average intellectual abilities, and are distinguished from people with intellectual disabilities (although in the European context learning disability or difficulty is equated with intellectual disability).
- People with ‘memory’ or ‘cognitive’ disabilities includes those with acquired brain injuries or neurological disorders such as dementia or Alzheimer’s which affects intellectual functioning.
- People with ‘psychological’ or ‘psychosocial disabilities’ refers to people with mental health issues. Consistent with a shift to a social model, many disability organizations are moving away from the language of ‘mental illness’ and ‘mental disorder’ although these terms are still used in public policy and some legislation.
- ‘Blind’, ‘deaf-blind’ and ‘partially sighted’ people are the terms generally used for people with some form of visual impairment.
- Both ‘hard of hearing’ and ‘Deaf citizens’ or ‘Deaf people’ are used in the Canadian context. The Deaf community and their organizations generally do not refer to deafness as a disability – that is, deafness is not seen as an impairment; but rather represents a diverse and minority culture in a predominantly hearing culture.
- ‘Speech-related’ disabilities refer to difficulties in speaking or being understood by others.
- People with pain-related disabilities are affected in the amount or kind of activities they can perform because of long-term pain that is constant or recurring.

Eligibility for disability-related programs often use a variety of criteria. Depending on the purpose of the program, narrow or broad criteria may be used to define who is eligible from among the population of people with disabilities. In and of itself this need not be a problem. Governments target programs to sub-populations all the time. However, because disability-related policies and programs have evolved over time, in the context of a changing perspective on disability, there are likely to be contradictions between the definitions currently in place across programs. For example, a 2003 study of federal laws, programs and tax measures targeted to people with disabilities found that no single definition of disability existed across programs, and found “sometimes competing perspectives of disability definitions, objectives and eligibility” (Government of Canada, 2003). It should be understood that these “definitions” often are not definitions of disability but rather a way of determining who would be eligible for the program or service. These contradictions can be addressed by applying DIBPA to current disability-related eligibility criteria.

Disability in Canada

Rates of disability in Canada and globally are growing. The World Health Organization and World Bank recently issued a global report estimating almost 1 billion people worldwide have a disability, and the number is growing with the aging of populations (World Health Organization, 2011).

Similar trends are evident in the Canadian context. Just over 14% of Canadians report having a disability, and prevalence rate is growing. For adults age 15 and older, the rate in 2001 was 14.6%; by 2006, the rate was 16.5%. Increasing prevalence is due in part to the aging of the population and medical technology advances.

The largest group of people by disability type is those with pain-related disabilities which is 11.7% of adults, followed by those with mobility and agility disabilities (just over 11%). While the survey data suggest a relatively small proportion of people with intellectual disabilities (0.5%) in the general population, it is important to note that the source of the data, the 2006 Statistics Canada Participation and Activity Limitations Survey (PALS), incorporates a screen for identifying people with intellectual disabilities that primarily identifies those with 'severe' or 'very severe' disabilities and does not include those with milder disabilities. Other prevalence data suggest people with developmental disabilities make up 1% to 3% of the population.

PALS indicates those with psychological disabilities represent 2.3% of the population, although other estimates report a much higher prevalence rate.

Please note, the above groups are not mutually exclusive – i.e. many respondents report having more than one disability.

What is Disability and Inclusion Based Policy Analysis?

Public policies are decisions about who gets what, where, when and how. Public policy is also 'non-decisions' – decisions not to allocate resources in certain ways to certain groups or objectives. Policy is based on values and assumptions about normal paths of human development, what quality education is, how the labour market should be shaped, and to what end. It involves implicit and explicit assumptions about the 'public good' and the range of 'private goods' individuals should be able to pursue, or not, in their daily lives.

DIBPA places people with disabilities at the centre of policy analysis. It does not assume that this is the only lens to bring to public policy and program development, but that it is often a missing perspective. People with disabilities have historically been disadvantaged by public policy either because it has been assumed that they do not have equal rights or because their isolation kept them 'invisible' in the policy making process. Public policy has been used to confine, separate or exclude people with disabilities in some way as the history of institutionalization, separate schooling, and labour market exclusion so clearly demonstrates. This historic isolation and exclusion has meant that people with disabilities are often not taken into account in developing policies for the mainstream of society.

Disability and inclusion based policy analysis is the process of bringing into view the sources of disadvantage that result in unequal opportunities and outcomes for people with disabilities, and of using the tools of public policy to overcome these disadvantages.

Why Use Disability and Inclusion Based Analysis?

Policy analysis conducted with a disability and inclusion lens is an integrated, systematic and cross-departmental process of inquiry that takes people with disabilities into account in formulating, implementing, evaluating, revising and seeking coherence across policies and programs.

There are five main reasons to apply a disability and inclusion lens in policy analysis:

- **Public policy should benefit all citizens.** Many policies which do not incorporate a gender analysis have historically had a negative impact on girls and women. It is the same for people with disabilities. Unless the policy process looks at policy goals, programs and outcomes from the vantage point of people with disabilities in all their diversity (e.g. gender, ethno-racial-cultural status, and Aboriginal status), the barriers people with disabilities face will remain in place and largely invisible.
- **We know that public policy has historically not served people with disabilities well.** Rates of poverty, unemployment/exclusion from the labour force, access to post-secondary training and education, health status, illiteracy, violence and abuse, and other factors show that this population has been and remains systematically marginalized in society. Public policy decisions, or non-decisions, can be seen as directly contributing to these outcomes. Policy analysis can show a path to begin addressing these issues.
- **There are policy disincentives and gaps to enabling inclusive outcomes for people.** Public policy can be more effective in achieving objectives and targets if we identify and address the built-in disincentives and gaps that leave people with disabilities without needed supports and opportunities. These include, for example, disincentives to move from social assistance to the labour market; gaps in supports and services when a youth with a disability turns age 18; lack of community-based options which result in inappropriate, and often more expensive 'placement' in institutional environments such as nursing homes and other facilities. Policy analysis for inclusion helps to identify these disincentives and gaps, and to consider policy options to address them.
- **Public policy should ensure equality of opportunity and outcomes.** Policies that result in inclusion, participation, contribution and full citizenship of all people including people with disabilities are good policies. DIBPA assists policy analysts in crafting policy options to enable these outcomes.
- **Policy development to advance full inclusion requires vertical and horizontal coherence.** The barriers and inequalities people with disabilities face do not fall neatly into one program or policy area. Addressing barriers to education, for example, requires policies and programs that cut across many domains. Achieving inclusive education requires a policy agenda that addresses teacher training (post-secondary education policy), family supports, early learning and child development, education policy and programs (curriculum modification, in-class supports to teachers and students), school-based health care and therapies, labour market policies that provide parents with needed flexibility, and community-based services that enable effective transition to post-secondary opportunities and employment, etc. DIBPA examines the incentives and disincentives for achieving policy coherence between programs within and across departments at one level of government (horizontal analysis); and coherence between programs at different levels of government (vertical analysis).

Guiding Principles for Disability and Inclusion Based Analysis

Engage the Disability Community in Policy Dialogue

Article 4.3 and Article 33 of the CRPD require governments to engage people with disabilities and their organizations in both policy development and monitoring effectiveness.¹ Article 4.3 states:

In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations.

The rationale for including Article 4.3 was that, just as meaningful engagement of civil society in negotiating the Convention made it a stronger and more inclusive treaty, the same principle must hold for its implementation. Ongoing engagement brings a critical dimension of policy knowledge to the table – about how various policies and programs intersect and operate in the lives of actual people, households and communities. Because policy makers are bound by the accountabilities of a particular program, policy framework, and departmental mandate, it is often difficult to see how a program plays out in a person's life, beyond the 'silos' of these specific mandates and operations.

People with disabilities, their families and organizations bring knowledge and experience to the policy making process that can assist in evaluating current policies and programs, and in pointing towards options for reforms. In order to effectively engage participation in policy dialogue and development a number of considerations need to be addressed:

- establishing effective mechanisms for ongoing policy dialogue and engagement;

- resourcing organizations to consolidate their experience into information and knowledge to share;
- providing disability-related and other supports (e.g. child care) to assist individuals to participate and engage; and
- resourcing representative organizations to participate.

Start with a Vision for an Inclusive and Accessible Society

Canadians with disabilities, their families and organizations have been consulting with governments and other stakeholders to develop a shared vision and action plan for an inclusive and accessible Canada (www.ccdonline.ca). Together, they have identified six core goals which provide a clear vision:

1. Canadians with disabilities - children, youth, working-age adults, and seniors - have the necessary support to fully access and benefit from all that Canada has to offer.
2. Independent Living principles of choice, consumer control and autonomy are made real.
3. Canadians with disabilities have safe, adequate, accessible housing in their community and live free from residential institutions and confinement.
4. Canadians with disabilities and their families have the income, aids and devices, personal supports, medications and environmental accommodations that make social, economic, cultural, and political citizenship accessible and inclusive of all.
5. Women with disabilities, Aboriginal People with disabilities, persons with disabilities from visible minority communities, and those from other marginalized communities are equally able to access all aspects of and benefit from Canadian society.
6. Canadians with invisible disabilities, chronic illness, episodic disabilities or environmental sensitivities, or living in rural or remote areas are equally able to access and benefit from Canadian society. The result is that people with disabilities are able to contribute to, and benefit from, Canadian society in the same way as other Canadians.

A similar vision for an inclusive society was adopted by Federal and Provincial/Territorial (FPT) governments in *In Unison: A Canadian Approach to Disability Issues*, the only FPT accord or agreement on disability (Quebec did not sign the accord, but committed to its vision and principles).

In Unison calls for a Canada in which:

Persons with disabilities participate as full citizens in all aspects of Canadian society. The full participation of persons with disabilities requires the commitment of all segments of society. The realization of the vision will allow persons with disabilities to maximize their independence and enhance their well-being through access to required supports and the elimination of barriers that prevent their full participation.

In Unison went on to define the principles for a policy framework for inclusion, and identified three central building blocks as the focus of public policy – disability supports, employment and income support.

Recognize Human Rights Obligations for an Inclusive and Accessible Society

A vision of full inclusion also has a foundation in law. At the international level, the United Nations Convention on the Rights of Persons with Disabilities sets out in fifty Articles the recognized rights of people with disabilities. Having ratified the treaty the governments of Canada and the Provinces and Territories declare to be legally bound by its 'General obligations' stated in Article 4 which include:

- To ensure and promote the full realization of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability;
- To adopt all appropriate legislative, administrative and other measures for the implementation of the rights recognized in the present Convention;
- To take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities;

- To take into account the protection and promotion of the human rights of persons with disabilities in all policies and programs.

At the national level, the Canadian *Charter of Rights and Freedoms* is a central element of the legal framework for recognizing rights and obligations with respect to people with disabilities. Section 15, the 'Equality rights' section of the *Charter* recognizes:

- (1) Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability.
- (2) Subsection (1) does not preclude any law, program or activity that has as its object the amelioration of conditions of disadvantaged individuals or groups including those that are disadvantaged because of race, national or ethnic origin, colour, religion, sex, age or mental or physical disability.

Thus, the *Charter* assures equal benefits and outcomes of all laws, policies and programs, and also provides in subsection (2) that programs targeted to people with disabilities for the purpose of addressing their historic disadvantage do not in themselves constitute discrimination against other groups.

As well, Legislatures in the provinces and territories have adopted Human Rights legislation to prevent discrimination in education, employment, housing and services generally available to the public, on the basis of disability and other grounds.

A human rights framework is essential in both understanding the disadvantage that people with disabilities have faced, and in guiding governments and society in overcoming discrimination. Justice LaForest eloquently articulated this point in the Supreme Court of Canada ruling *Eldridge v. British Columbia* about the right of Deaf persons to sign language interpretation in order to access health care services.²

It is an unfortunate truth that the history of disabled persons in Canada is largely one of exclusion and marginalization. Persons with disabilities have too often been excluded from the labour force, denied access to opportunities for social interaction and advancement, subjected to invidious stereotyping and relegated to institutions... This historical disadvantage has to a great extent been shaped and perpetuated by the notion that disability is an abnormality or flaw. As a result, disabled persons have not generally been afforded the "equal concern, respect and consideration" that s. 15(1) of the *Charter* demands. Instead, they have been subjected to paternalistic attitudes of pity and charity, and their entrance into the social mainstream has been conditional upon their emulation of able-bodied norms... One consequence of these attitudes is the persistent social and economic disadvantage faced by the disabled.

Examine Values and Assumptions about Disability and Inclusion

DIBPA involves critically examining the values and assumptions which guide and underpin policies and programs. Sometimes the underlying assumptions have never been made explicit, and have been inherited from earlier perspectives about disability which are no longer consistent with the vision for full inclusion, participation and accessibility. The process for policy analysis should consciously surface underlying values and assumptions regarding disability to see if they are consistent with the following starting points:

Disability should be understood from a social and human rights perspective. As discussed above, the perspective on disability for guiding public policy has changed from one of individual deficit to a social and human rights perspective which identifies and addresses the social, architectural, cultural, political and economic barriers that result in disability. In Canada, this perspective is grounded on the Canadian *Charter of Rights and Freedoms* and the United Nations Convention on the Rights of Persons with Disabilities. Because public policy

development is often incremental, building on existing policy frameworks, many mainstream and disability-specific policies and programs are still guided by the individual deficit model of disability. Programs that segregate people on the basis of disability are usually based on a deficit model of disability and a belief that people with disabilities require services that can only be provided in 'special' environments. DIBPA should begin with examining whether policies and programs fully recognize the barriers people with disabilities face, and provide at least some of the tools for overcoming them.

Inclusion is the starting point for a democratic society. DIBPA starts from the assumption that inclusion is the test for whether a society is fully democratic. Democracy cannot be achieved without full social, economic, cultural and political inclusion of all citizens. As such, governments cannot equivocate on inclusion. It is fundamental to good governance to develop and implement policies that result in inclusion of all. To do so requires understanding the unique circumstances and barriers to inclusion that different population groups face. Because people with disabilities have faced historic disadvantage it is incumbent on governments to examine the sources of this disadvantage and ensure public policies address them.

In a democratic society all citizens, including people with disabilities, should be supported to develop and pursue their own vision of a good life – individually and collectively – provided it does not bring harm to others. It is not up to the state to decide what a good life is for each citizen. 'Public goods' are those goods that provide citizens with the tools, means and conditions (education, public services, transportation systems, etc.) to develop and pursue their personal vision. Anti-hate, criminal and human rights law set broad boundaries for what can count as a good life. Within those parameters, the scope is immense for individuals to pursue their own path. However, because people with disabilities were for centuries seen as less than full citizens, the state assumed a 'protective' role at best, deciding what was best and good for people with disabilities. This denied to a person with a disability the opportunity to

develop and exercise self-determination in the pursuit of his or her own vision of a good life. Public policies should be examined to ensure they are providing people with disabilities equal access to the public goods required to pursue and realize a personal vision of a good life.

All people have a unique developmental path – diversity is the only norm. There is no ‘normal’. Normalcy is the statistical effect of drawing a bell curve. While most people may reach certain developmental milestones within certain time periods, doing so does not mean that this is the only or best way for all people to develop. A central goal of public policy is to create the conditions for each citizen to maximize his or her developmental potential along their unique path. This does not mean that people do not require rehabilitation, physio, speech or occupational therapies, behavioural or other interventions. It means that the goal of such interventions must be to maximize a person’s unique developmental potential, and to do so in ways that result in inclusion. Inclusive public policy in a democratic society enables people who are diverse – by reason of gender, linguistic diversity, religion, national origin, ethno-racial-cultural status, sexual orientation and identity, and disability – to pursue their unique paths individually and collectively. People with disabilities are just as diverse, in all the same ways, as the non-disabled population.

Achieving equality does not necessarily mean treating everyone the same. Canada is a leader internationally in the interpretation it has given to what equality rights mean. Treating men and women equally, treating First Nations and non-aboriginal people equally, and treating disabled and non-disabled citizens equally – sometimes means providing different treatment. People with disabilities may require unique support arrangements to participate in education and the labour market, just as women may require access to particular forms of health care or labour market accommodations, and First Nations people may require particular education and health services arrangements to maximize their collective self-determination. The focus must be on the *outcomes* recognizing that different people may require different inputs. The question is: Are men, women, First Nations and

non-aboriginal, disabled and non-disabled Canadians able to achieve access to education, transportation, community services, health care, etc. in ways that result in equal opportunities to maximize their unique developmental paths and secure their well-being?

Governments have a responsibility to provide ameliorative policies and programs to address historically disadvantaged groups. Public policy decisions, and *non-decisions*, have played a primary role in the disadvantage, exclusion and marginalization that people with disabilities still face today. Providing affirmative action and other types of ameliorative programs does not undermine equality. Protected under section 15(2) of the *Charter*, such programs help to create the ‘level playing field’ where citizens, long excluded, are given the opportunity and resources to pursue their own vision of a good life, along a developmental path that is unique to each and every one of us. However, such programs must be inclusive in design and outcome. Programs that are targeted to people with disabilities are not by definition ‘ameliorative’. They are only ameliorative if they enable equality, which the Supreme Court of Canada has equated with a ‘norm of inclusion.’

Acknowledge the Realities of People with Disabilities and their Families

Policy analysis to advance inclusion must begin with an understanding of the realities faced by people with disabilities and their families. When we start analysis from the objectives and benefits of a particular program, and do not take the vantage point of actual people into account, our analysis is confined to what that program is trying to do, and whether or not people are accessing its benefits and to what extent. Because the barriers people with disabilities face are multiple and intersecting, policy analysis must include the vantage point of people with disabilities and their families on the path to full inclusion – social, economic, cultural and political.

Some key facts reflecting the realities of people with disabilities and their families, and the potential policy implications they raise, are outlined below.

This is not an exhaustive accounting of either current realities or policy implications. Rather, the data is presented to illustrate the wide range of issues, realities and implications that come into view when considering disability from an inclusion and human rights perspective.

KEY FACTS: CHILDREN AND FAMILIES³

- Nearly 20% of parents of young children with disabilities would like to access childcare service but do not, with cost being cited as the most common reason.
- 13% of families report that their child was refused childcare because of their disability.
- Children with disabilities are overrepresented in provincial/territorial child welfare systems (e.g. Manitoba 17% - FASD, Ontario 68% - 'special needs')
- Parents of children with disabilities report that as a result of their child's condition they worked fewer hours (38.4%), changed their work hours (36.5%), did not take a job (26.4%), quit work (21.6%), or did not take a promotion (19.7%). The employment situation of mothers (64%) is most affected.
- Children with disabilities are twice as likely as other children to live in households that rely on social assistance as a main source of income.
- 38% of working age adults with an intellectual disability live with their parents, as compared to 18% of working age adults without disabilities.

Policy implications:

- Inadequate access to early intervention, inclusive early childhood education and care, therapy services, family supports, and respite often results in crises for families and contributes to an alarming overrepresentation of children with disabilities in the child protection system.
- Caring for children with disabilities at home has significant impact on employment patterns of parents, with parents often having to downgrade careers, take time off work for disability-related caring, and/or forego employment all together.

- Inclusion in early years has dramatic positive impacts on nearly all later life indicators such as higher education, employment, income levels and increased community participation.
- Provision of needed supports to families with children with disabilities is likely to decrease incidence of family crisis, and reduce need for more critical supports and intensive interventions throughout the lifetime of the child.
- The care-giving role provided by families requires greater recognition within income security systems and tax measures.

KEY FACTS: GENDER⁴

- Women with disabilities are more likely than men to report disability (53.2% and 46.8%, respectively)
- Working-age men with disabilities earn on average approximately \$10,000 more in total income than working-age women with disabilities.
- 18.4% of working-age women with disabilities in low income households are lone parents, compared to 4% of men with disabilities who live on low incomes are lone parents.
- Over 40% of women with disabilities who live in low income households, have one or more unmet disability-related needs, compared to 30% of men who have unmet needs.
- Women with disabilities are sexually assaulted at a rate at least twice that of the general population of women in Canada. The rate for women with intellectual disabilities and Deaf women is even higher than for other women with other disabilities.

Policy implications:

- Women tend to assume responsibility for childrearing and elder care and are more likely to be lone parents and to have fewer opportunities for stable, high-paid employment.
- Mothers carry greater caregiving responsibilities for children with disabilities than fathers and thus tend to face greater barriers to secure labour force attachment and career advancement.

- High rates of sexual assault, violence and abuse against women indicate a need for targeted prevention, awareness and response mechanisms.
- Women with disabilities face barriers in accessing and being accommodated in women's shelters.

KEY FACTS: ABORIGINAL AND ETHNO-RACIAL STATUS⁵

- The disability prevalence rate among Aboriginal persons is approximately one and a half times higher than the general population
- First Nations persons with disabilities are 1.7 times more likely than their non-disabled counterparts to have an income less than 15,000.
- An increasing proportion of Aboriginal persons with disabilities are living off reserve and settlements, and increasingly in urban areas.
- First Nations adults of working age with disabilities are less likely than their non-disabled counterparts to be employed (37% versus 52%) and also less likely to be employed than those with disabilities in the general population (59%).
- People who identify as being a member of a visible minority who have a disability are more likely to live on low income than those with disabilities who are not a member of these groups (22% versus 19.5).

Policy implications:

- With over 30% of Aboriginal persons having a disability, inadequate funding for community support systems – on and off reserve – means many needs go unmet. This contributes to impoverishment in many households and communities, and continued barriers to education and employment.
- Jurisdictional disputes about what level of government is responsible for ensuring access to supports for children with disabilities has led the First Nations Child and Family Caring

Society to advance 'Jordan's Principle' – to establish that in policy development and resource allocation the needs of the Aboriginal child should be met first, and levels of government should resolve their disputes about 'who pays what' after the fact.

- Jurisdictional issues are resulting in major barriers to accessing needed supports and services.
- The disability-related barriers faced by people with disabilities of Aboriginal and diverse ethno-racial communities are compounded by the barriers experienced on the basis of ethno-racial status.
- Applying for immigration to Canada poses particular barriers for persons with disabilities because of assumptions that disability imposes 'excessive burdens' on education, social services and health care systems. Those immigrants and refugees with disabilities who do obtain entry often experience negative attitudes within settlement services and more generally.

KEY FACTS: INCOME⁶

- People with disabilities of working age are about twice as likely to live on a low income as their counterparts without disabilities (20.5% versus 11%).
- After age 65 the rate of low income among people with disabilities drops significantly and stays low during the retirement years. This may be because government benefits help supplement incomes and reduce costs for seniors with and without disabilities.
- Nearly half (48.2%) of people with disabilities living below the low income cut-off (LICO)⁷ received provincial social assistance in 2005 and more than one in five (22.3%) received the Canada / Quebec Pension Plan Disability benefit.
- People with disabilities are as much as 6 times more likely to be in the social assistance system than those without disabilities.

- A higher percentage of Aboriginals with disabilities live on low incomes (38.1%) than Aboriginals without disabilities (19.5%).
- The chances of living on a low income increase as the severity of disability increases. Among people with disabilities who have low incomes 52.7% have a severe to very severe level of disability.

Policy implications:

- People with disabilities endure far greater rates and depth of poverty than those without disabilities.
- Social assistance systems are not designed or equipped to act as a long-term income support program for persons with disabilities. Such systems often provide inadequate benefits to meet the cost of living and often do not take into account additional disability related costs.
- Income support programs for people with disabilities create a poverty trap that is difficult to escape. Such systems are often based on a welfare model that undermines efforts in areas such as employment, education and housing.

KEY FACTS: EDUCATION AND TRAINING⁸

- 28% of persons with disabilities do not have a high school diploma compared to 19% of those who do not report a disability.
- Only 13.2% of people with disabilities have a university degree or certificate as compared to 20.7% of people without disabilities.
- 11.3% of students with disabilities had to leave their community to attend school
- 13.1% had additional expenses for schooling;
- 18.2% of students attended a special education school or special education classes.
- Among working-age women with disabilities who live in low income households, nearly four in ten (38.6%) have not received a high school graduation certificate and only one in four are working. Among women without disabilities, only 17.5% haven't received a high school graduation certificate and most (70.7%) are employed.

Policy implications:

- Despite many gains that have been made toward inclusive education, segregation and streaming into separate programming remains a reality for many students with disabilities.
- Transition planning for students graduating from high school and going on to post-secondary education and employment has shown positive outcomes for students with disabilities. This type of planning and coordination requires cooperative effort across different areas of government policy such as education, employment, disability supports, housing and other community supports.
- Participation in colleges, training and post-secondary education remains low among students with disabilities.
- Students with disabilities have reported taking longer to achieve their level of education than students without disabilities, which has policy implications regarding student loans, supports and accommodations required, taxation and other related matters.

KEY FACTS: EMPLOYMENT⁹

- Employment rates are far lower for working age adults with disabilities (51.3%) than those without (75.1%). Among working age people with intellectual disabilities, labour force participation rate is even lower at only 30%. Only 59.6% of people with disabilities are participating in the labour force as compared to 80.2% of people without disabilities.
- People with disabilities who are employed are more likely to have all of their needs for disability supports met (60.4%) than people with disabilities who are not in the labour force (only 51.0% not in the labour force have their needs met).
- Approximately 18% of people with disabilities not in the labour force are discouraged from looking for work because of the risk of losing some or all of their income assistance, and 11.5% are concerned about losing access to their drug benefits or housing subsidies.

- 26.1% of people with disabilities believe they have been refused jobs because of their disabilities.

Policy implications:

- People with disabilities who depend on social assistance payments often face great disincentives to employment due to claw back of benefits and other rules that undermine their efforts in this area.
- Funding and delivery of employment supports for people with disabilities is often highly fragmented and restricted to training and employment opportunities outside the mainstream labour market.
- Research has shown excellent outcomes for employment of people with disabilities in the open labour market when high-quality supports for employment are provided and focused 'Employment First' strategies are in place.

KEY FACTS: HOUSING¹⁰

Households are in 'core housing need' if they do not live in and do not have sufficient income to access suitable housing in adequate physical condition,

- About 62% of children with disabilities who are living in a household with core housing need, live in a family that is headed by a lone parent, compared to 49% of children without disabilities.
- 19% of people with intellectual disabilities in Canada aged 15 years and older live in a household in core housing need. This is compared to 9% of people who do not report a disability. This figure does not include people with intellectual disabilities who live in 'collective dwellings'.
- 19% of children under 15 years old with disabilities live in a household in core housing need, compared to 14% of children without disabilities.
- 21% of people with a mobility disability who live in core housing need report that they need special features to assist them in their home. Of those who need such features, about a third report that their needs go either partially unmet (9%) or having none of the features that they need (23%).

- According to 2006 Census data, more than 57,000 people were living permanently in collective dwellings that are facilities designated for people with disabilities.
- Among people with disabilities living on a low income, 15.5% live in housing that is in need of major repairs (problems with plumbing, electrical wiring, structural issues) compared with 9.8% of people without disabilities who live on low incomes.

Policy implications:

- There is continuing great need for affordable and accessible housing and living supports that are based on principles of choice, self-determination and individualization.
- People with disabilities continue to be inappropriately placed in nursing homes, congregate living and other institutional settings. Such placements generally reflect a lack of needed and portable disability supports, rather than a choice of people with disabilities.
- People with disabilities are often unable to access available and affordable housing units because of features that limit accessibility and /or lack of access to needed disability-related supports.
- Housing and disability-related supports continue to be provided through funding and program models that bundle these supports together. Such models deny people with disabilities choice as to where and with whom they will live.

KEY FACTS: PERSONAL SAFETY AND SECURITY¹¹

- 41% of children with disabilities felt threatened at school or on the school bus within the past year and more than a third (36%) were assaulted at school or on the school bus.
- 80% of psychiatric inpatients have experienced physical or sexual abuse in their lifetime.
- Children with disabilities are more than two times more likely to be victims of child abuse than children without disabilities.

- Statistics Canada reports that people with some form of cognitive or mental disability, including intellectual disability, are four times more likely to be victimized than those without.
- While people with disabilities are more likely than those without to report violence to police and victim services, they are less likely to be satisfied with the police response and with the ability of courts to deal with the incidents in a timely manner.
- 62.9% of Canadian adults with disabilities report needing help with everyday activities.
- 44.6% of adults who require some help with everyday activities report having an unmet need in one or more areas. The most common reason given for needs being unmet was that the cost of obtaining help is too expensive.

Policy implications:

- Generic systems, including police and other law-enforcement services mandated to respond to incidents of violence and abuse and provide necessary supports to victims, are not adequately equipped to respond to people with disabilities.
- People with disabilities face many barriers to justice – for example, lack of accommodations in the justice system, and determinations that people with intellectual or psychosocial disabilities are incapable of giving testimony about their own victimization which results in relatively few prosecutions.
- Prevention strategies and public awareness activities can assist the public in recognizing signs of abuse and neglect of people with disabilities, and in encouraging reporting to appropriate authorities.
- Anti-bullying campaigns and programs need to give particular attention to children and youth with disabilities.
- Working-age people with disabilities who live on low incomes are more likely than their counterparts with higher incomes to need help with everyday activities because of disability (66.3% compared to 58.9%).
- Working-age people with disabilities who receive only some or none of the help they need with everyday activities are more likely (24.8% and 35.8%, respectively) to have a low income than people with disabilities who do not need or receive any help (16.8%).
- Among working-age people with disabilities who do not require help with everyday activities, 16.8% live on low incomes. Among people who have some needs for help met, 24.8% live below the LICO and among those whose needs are completely unmet, 35.8%.

Policy implications:

- Effective disability-related supports can be the catalyst that opens the door to community when based on the principles of portability, flexibility, affordability and individualization.
- Individualized funding for disability-related supports is a recognized best practice. Such a funding mechanism provides a person with a disability with choice and control over his or her disability-related supports.
- Eligibility for and access to disability-related supports tied to means-tested income programs perpetuates a cycle of poverty that is difficult to escape.

KEY FACTS: DISABILITY-RELATED SUPPORTS¹²

Disability-related supports are any good, service or environmental adaptation that assists people with disabilities to overcome limitations in carrying out cultural activities of daily living and in participating in the social, economic, political and life of the community. Daily living activities include preparing meals, housework, errands, personal care, in-home medical care, moving around within the personal residence, and child care due to the parent's disability.

KEY FACTS: PERSONAL CHOICE, CONTROL AND LEGAL CAPACITY¹³

- Among adults with disabilities who receive support from others with everyday activities, over 10% (nearly 208,000 people) make none or only some of the decisions about their everyday activities.
- Among adults with intellectual, learning, memory or psychosocial disabilities, over 17% (nearly 107,000 people) make none or only some of the decisions about their everyday activities.

Policy implications:

- Current arrangements for funding programs and services for people with disabilities tend not to give funding or contractual status to individuals with disabilities to make their own decisions about what supports they will access.
- Substitute decision making regimes are in place through provisions of public and private guardianship and adult protection; which require that people with intellectual or psychosocial disabilities meet a mental capacity test in order to maintain their right to legal capacity – to make their own decisions.
- ‘Supported decision making’ is emerging as an alternative in some jurisdictions – to recognize that, with support of trusted family members and friends, people can be supported to make their own decisions.

Gather Comprehensive Information

In order to make policy decisions informed by an understanding of the implications for people with disabilities, DIBPA requires that an information-gathering strategy be incorporated into all aspects of the policy-making process. A cross-departmental audit that identifies disability-related information needs and data sources for this information is the first step in developing a data strategy to ensure policy development is as data- and evidence-driven as possible. In identifying data needs, reporting requirements under existing legislation,

federal-provincial/territorial agreements and the UN Convention on the Rights of Persons with Disabilities and other international treaties should all be taken into account. Engaging the disability community in this exercise is essential, in order to identify key factors affecting the lives of people with disabilities and their families for which data sources should be found or created.

It is important to note that availability of disability-specific data is changing in the Canadian context. Since 1986, Statistics Canada has administered a post-censal survey, first known as the Health and Activity Limitations Survey (HALS), and since 2001, known as the Participation and Activity Limitations Survey (PALS). There are also other surveys like the General Social Survey, the Survey of Labour and Income Dynamics, and the Canadian Community Health Survey and income tax data that have high-level indicators of disability. However, limited sample sizes make it difficult to analyse the socio-economic status of people with disabilities at a provincial/territorial or census metropolitan area. In order to provide access to more timely and comprehensive disability-specific data, a new disability data strategy is under development by Human Resources and Skills Development Canada.

Administrative program data is also a useful source for disability and inclusion based policy analysis. Data sources on disability are found across government programs which collect such information. One of the challenges in obtaining the ‘big picture’ of disability from these sources is that various definitions of disability are used depending on program eligibility criteria.

Incorporate Disability into the Communications Strategy

Reporting on and communicating about investments in advancing the full inclusion of people with disabilities helps inform people with disabilities, the public and private sectors, and the general public about steps the government is taking. Such communications should highlight the realities

people with disabilities face, and the difference that is being made in advancing shared goals of inclusion, through public investment, and partnerships with people with disabilities, their families and organizations. As well, communications should point to work still to be done in closing the gap.

In order to ensure communications of disability-specific investments, as well as reporting on government policy and program development and outcomes more generally, steps should be taken to ensure that all policy documents and communication material (including electronic media, web sites, etc.) are, or can be readily made, fully accessible and available in plain language and alternate formats, and that people with disabilities and their organizations are informed about this availability.

Guiding Questions for Disability and Inclusion Based Policy and Program Analysis

Disability and inclusion based policy analysis involves asking questions about existing and proposed policies and programs in order to ensure they maximize the potential for people with disabilities to be fully included.

Analysis is applicable at different levels of policy formulation and evaluation:

- o Broad cross-government mandates and

priorities (as reflected in Platform commitments, Throne Speech, Budget, etc.)

- o Policy framework – vision, mission, values and beliefs, guiding principles, policy goals, roles and responsibilities of government in relation to other partners/entities in a particular domain (labour, health care, social development)
- o Specific policies – set of specific policy objectives, resource allocation to achieve these objectives, and the set of programs and services to achieve objectives and outcomes within the context of the policy framework
- o Programs – the means by which policy objectives are achieved

While the analysis can be undertaken at any of these levels, it works best – in terms of developing coherent policy and programs, and maximizing successful outcomes – if it is applied in an intentional way at all levels. Its impact is maximized by integration into policy development and policy evaluation, and application across government departments. Some of the questions may either be less applicable, or require some adaptation, depending on the level of analysis.

Answers to the following set of questions are not ‘right or wrong.’ Rather, they provide information on which policy makers can revise policies and programs to result in more inclusive outcomes.

The questions to guide analysis are divided into four main parts, each related to different stages in policy development and implementation. The five main questions for analysis are provided below, and followed by more specific sub-questions:

Policy and Program Design

- A. Does the policy framework (policy vision, goals and mandate) recognize the needs of and barriers faced by people with disabilities, and is it consistent with the values and assumptions of inclusion?
- B. Are associated (mainstream or disability-specific) programs and services (objectives, eligibility criteria, or benefits) designed to enable equality of opportunities and outcomes consistent with the UN Convention on the Rights of Persons with Disabilities (CRPD)?

Implementation and Evaluation

- C. Does the policy or program for mainstream services and benefits in this policy area enable access and outcomes for people with disabilities consistent with the CRPD?
- D. For the policy or program targeted or specific to people with disabilities, does it enable access and outcomes consistent with the CRPD?

Policy and Program Revision

- E. What options would best address known gaps to achieving equitable and inclusive outcomes in the context of the CRPD, government platform commitments, and fiscal realities?

Policy Coherence

- F. Are the horizontal implications (between programs within and across departments at one level of government) and vertical implications (between programs at different levels of government) of the policy or program considered and effectively addressed?

POLICY AND PROGRAM DESIGN

- A. Does the policy framework (policy vision, goals and mandate) recognize the needs of and barriers faced by people with disabilities, and is it consistent with the values and assumptions of inclusion?
 - 1. In what ways does the policy framework, directly or indirectly, affect people with disabilities and their families?
 - 2. What are the underlying values and assumptions of the policy and are they consistent with full inclusion and participation?
 - 3. Are policy goals framed in inclusive ways?
 - Are some or all people with disabilities excluded – by design or unintentionally?
 - If there are exclusions, is there a justifiable rationale consistent with equality rights, non-discrimination and ameliorative programming (for example, programs targeted to people with 'severe' disabilities only)?
 - 4. Are policy goals based on evidence and reflective of good practices that address the needs of and barriers faced by people with disabilities?
 - 5. Have people with disabilities and their families, and their organizations, effectively participated in identifying their needs, barriers experienced, and desired policy goals?
 - Are people with disabilities, their families and organizations actively and meaningfully engaged in policy development?
 - Are public consultations about the policy held in accessible venues? Are they conducted in plain language?

B. Are associated (mainstream or disability-specific) programs and services (objectives, eligibility criteria, or benefits) designed to enable equality of opportunities and outcomes consistent with the UN Convention on the Rights of Persons with Disabilities (CRPD)?

1. Is the design of the programs and services consistent with relevant Articles of the CRPD?
For example:
 - Is the program designed on the basis of Article 3 (Principles), Article 4 (General Obligations) and other Articles specific to the policy/program area?
2. Are the objectives of programs or initiatives to achieve policy goals framed in inclusive ways?
3. Are programs/initiatives designed to address the full range of barriers people with disabilities face in this policy area? If not, is the program designed strategically to maximize the impact on existing barriers, recognizing that not all barriers can be addressed at once?
4. Do policy or program requirements serve as disincentives to people with disabilities accessing the program, service or benefit?
5. Are the criteria against which the program/service will be measured and evaluated consistent with the CRPD and other relevant human rights instruments?
6. How will the program be evaluated against these criteria on an ongoing basis? How will people with disabilities, their families and organizations be involved in this evaluation?
7. Are there independent appeal/grievance processes in place?

IMPLEMENTATION AND EVALUATION

C. Does the policy or program for mainstream services and benefits in this policy area enable access and outcomes for people with disabilities consistent with the CRPD?

1. Do people with disabilities access programs, services and benefits on an equal basis with others?
 - By disability type
 - By language, family status, age, gender, ethno-racial-cultural status, aboriginal status
 - By geography – urban, rural
 - Other factors considered relevant
2. Does participation enable outcomes for people with disabilities consistent with the CRPD?
3. If unequal patterns of access and outcomes exist, what factors account for this?
 - Lack of reasonable accommodation and disability-related supports
 - Costs (e.g., to the individual/family, to government, to service providers)
 - Physical accessibility
 - Attitudes (of service providers, families, employers)
 - Existence of a parallel system
 - Lack of affordable, accessible transportation
 - Urban/rural differences
 - Other systemic barriers
4. Are all policy documents and communication material (including electronic media, web sites, etc.) fully accessible and available in plain language and alternate formats, and are people with

disabilities informed about this availability?

D. For the policy or program targeted or specific to people with disabilities, does it enable access and outcomes consistent with the CRPD?

1. Does the policy or program result in the congregation or separation of people solely based on disability-related need?
2. Where policies or programs result in such outcomes, are there current incentives or strategies to transition to services that result in outcomes that are in accord with the CRPD?
3. Are all policy documents and communication material (including electronic media, web sites, etc.) fully accessible and available in plain language and alternate formats, and are people with disabilities informed about this availability?

POLICY AND PROGRAM REVISION

E. What options would best address gaps (as identified in C. and D. above) to enabling equitable and inclusive outcomes in the context of the CRPD, government platform commitments, and fiscal realities?

1. What is needed, and for whom, in order to:
 - enable people with disabilities to have equal access to mainstream programs, services or benefits that result in equitable and inclusive outcomes?
 - transition from parallel/specialized programs and services to inclusive approaches?
2. What department, and what policy and program framework should this option be provided under, in order to achieve the outcomes in #1 above?
3. Does the solution impose disproportionate costs to the person with a disability, solely on the basis of their disability?
4. To deal with this gap/issue, what is the best mix of investments in:
 - Individuals with disabilities
 - Families and support networks
 - Community sectors
 - Systems (education, labour market, transportation, health care, government services)
5. In examining options for the best mix of investments, identify and describe how each:
 - enhances self-determination and autonomy;
 - avoids further stigmatization, isolation or separation of people on the basis of their disability;
 - promotes true inclusion in the community;
 - serves as an incentive for stakeholders to advance inclusion and universal access in this or any other policy domain;
 - increases the capacity of community programs and services to include and support people with disabilities;
 - enhances knowledge, skills and competencies among key sectors to include and support people;
 - maximizes efficiencies while providing needed incentives to transition outmoded models of services and support to approaches more consistent with the CRPD;
 - leverages individual, family, community and private sector resources without compromising equitable access and outcomes.

POLICY COHERENCE

F. Are the horizontal implications (between programs within and across departments at one level of government) and vertical implications (between programs at different levels of government) of the policy or program considered and effectively addressed?

1. Is Departmental policy and program design as it relates to people with disabilities, coherent with policies and programs across the Department?
2. Is Departmental policy and program design as it relates to people with disabilities, coherent with policies and programs of other Departments and other levels of government?

Examples:

- Child to adult transitions (supported by a range of programs within and across Departments)
 - School-to-work transition (drawing on inputs across Departments)
 - Health and social support services (linking health and community services)
 - Coordinating services and supports across jurisdictions – e.g.; for First Nations children with complex needs (Jordan’s Principle)
3. Does participation in one program create disincentives for people with disabilities to access other needed programs, benefits or services provided by another level of government (i.e. federal, municipal)?
 4. Is there an intra- and inter-Departmental mandate to address the horizontal and vertical implications of the policy?
 5. What coordinating mechanisms exist or need to be created to identify and effectively address horizontal and vertical implications?

Setting Policy Priorities

Because of the extent of disadvantage faced by people with disabilities, and glaring gaps in unmet needs, DIBPA will generate policy issues and options that no government will be able to meet all at once. Moreover, if the analysis is conducted across departments of government, each of which has engaged the community in undertaking the analysis (as is ideally the case) there will be pressure coming from many quarters for new policy development and additional resources. At the same time, there is a broader social and economic context which is increasing demands on government and affecting resource availability, including factors such as: global economic uncertainty; pressures for fiscal constraint; structural economic and labour market changes (i.e. shift from manufacturing sector); increasing proportion of people with disabilities and older persons; growing income inequality; demand for environmentally sustainable economic growth; changing roles of government; and changes in federal-provincial/territorial transfers and relationships.

The CRPD and related international law and interpretation anticipate the challenges of governance and scarce resources and provide some general direction for managing the priority-setting process in this context.

First, the CRPD obliges governments to implement measures to realize economic, social and cultural rights recognized in the CRPD “to the maximum of its available resources... with a view to achieving progressively the full realization of these rights, without prejudice to those obligations contained in the present Convention that are immediately applicable according to international law [i.e. civil and political rights].” The principle of ‘progressive realization’ does not mean that governments are excused from acting to implement the provisions of the CRPD. On the contrary, it does mean “that a State’s compliance with its obligation to take appropriate measures is assessed in light of the resources – financial and others – available to it.¹⁴

Drawing on guidance by the Office of the United Nations High Commissioner for Human Rights and others,¹⁵ about how the obligations for 'progressive realization' apply under the CRPD, governments must give priority focus to measures for immediate implementation which:

- eliminate discrimination;
- meet basic obligations related to the freedom of association (right to join trade unions), protection of children and youth from exploitation, and access to society (universal primary education, for example);
- satisfy minimum core obligations "to meet the minimum essential levels of each of the rights" with a focus on those most vulnerable;
- address sources of structural disadvantage and barriers to participation in society (in the case of disability barriers to education, the labour market, disability supports);
- ensure people affected have information about entitlements and rights;
- engage affected groups in ongoing policy development which includes decisions about trade-offs to be made with scarce resources; and
- do not result in "retrogressive" impact, or undermine progress made.

Even where resources are extremely limited, governments still have an obligation under the provisions for progressive realization, to assess needs, develop and implement plans and measure progress. As stated by the Office of the United Nations High Commissioner for Human Rights, under the CRPD governments must make constant effort to improve the enjoyment of the protected rights, and such steps "should be deliberate, concrete and targeted as clearly as possible, using all appropriate means."¹⁶ The Office suggests that in order to meet these obligations within the context of progressive realization, governments should:

- assess the current state of enjoyment of rights;
- formulate strategies and plans, with indicators and time-bound targets;
- adopt necessary laws and policies, and allocate necessary resources;
- regularly monitor and assess progress; and

- establish grievance mechanisms so individuals and organizations can lodge complaints if the government is not meeting its responsibilities.

Second, principles are evolving to bring focus to particularly vulnerable groups, and to impact of policy options on family members. For example, a case brought under the European Social Charter about access to education in France by children with autism ruled that:

... a State Party must take measures that allow it to achieve the objectives of the Charter within a reasonable time, with measurable progress, and to the extent consistent with the maximum use of available resources. States Parties must be particularly mindful of the impact their choices will have for groups with heightened vulnerabilities as well as for other persons affected including their families on whom falls the heaviest burden in the face of institutional shortcomings.¹⁷

In this regard, the Office of the United Nations High Commissioner for Human Rights has established that "Even if a State has clearly inadequate resources at its disposal, the Government must still introduce low-cost and targeted programmes to assist those most in need so that its limited resources are used efficiently and effectively."¹⁸ Here the Office has very low-income countries in mind, but the general principle of targeting to those most vulnerable and in need, once minimum core obligations are met applies more generally when resources are scarce and competing demands must be managed.

Third, taken as whole, the CRPD recognizes that the State has obligations focused on individuals with disabilities, families, and a range of community sectors and larger systems – health care, education, labour market, recreation, transportation and others. Investments are needed at all levels. In selecting policy priorities, it is essential to examine how investments at each of these four levels – individual, families, the community, and larger systems – interact. Assessment of individual support needs, for example, cannot be isolated from the support needs of their families, or the capacities of the communities in which they are living.

Oftentimes, overcoming the physical and social barriers an individual faces is better accomplished by investing in community capacity rather than exclusively through individual- or family-based supports. For example, enabling students with intellectual disabilities to fully participate in education is often more effectively achieved by attaching resource teachers to regular classroom teachers, rather than attaching teaching assistants to individual students. Finding the right mix of investments at all of these three levels, even when targeted, maximizes efficient use of resources and outcomes.

Fourth, the CRPD recognizes that it is not only governments which are responsible for ensuring conditions are in place for people with disabilities to enjoy and exercise their rights. The Convention obliges States Parties to ensure other actors – employers, education systems, the private sector, civil society are playing their role in advancing implementation. Given the scale of change the CRPD envisions, and the current social and economic context, full realization of the rights recognized will require governments and other actors to work together to initiate and sustain social innovation – to meet unmet needs in new ways.

A number of models and proposals are being developed in Canada¹⁹ and internationally for governments to play proactive roles in maximizing innovation through new partnerships with civil society and the private and non-profit sectors. Proposals include a proposed 'Community Enterprises Act' to enable non-profit corporations to issue shares to investors in social ventures; making 'innovativeness' a main criterion in public procurement; designating a proportion of departmental funds for innovation activities; using outcome based funding models; decentralizing resources to communities with the freedom to innovate in meeting local needs; creating innovation 'zones' where the usual rules that apply in public services are lifted; and establishing 'innovation units' in government to connect public, private and community actors to work together in new ways and create a context for social experimentation.²⁰

The literature on social innovation and public policy stresses the need for ongoing evaluation to ensure best practices are being identified which are worthy of further investment to bring them to scale. Accessing private capital and leveraging the organizational capacity and assets of the non-profit sector (i.e. assets that non-profit providers currently have in outmoded residential and training/employment-related facilities) to meet new social goals for inclusion represent enormous potential for investment to meet social needs. Tapping this potential will require governments to create mechanisms which connect and mobilize human, organizational, community and financial assets and capital in new and innovative ways to advance full inclusion and participation.

Fifth, the CRPD recommends that States Parties consider the creation of a 'coordination mechanism' to guide implementation. Such coordination will be essential to maximize implementation in the face of multiple policy demands and scarce resources. To be effective, a coordination mechanism would be needed in the central agencies of government where policy coordination and cross-government resource allocation is managed – Departments of Finance, Treasury Boards, Privy Council or Executive Council of Government, or some other structure which reports directly to the Executive arm of government. It is at this level that criteria can best be applied to ensure core obligations are being met.

In summary, central agency policy coordination mechanisms are needed in government to bring policy coherence to DIBPA if priorities are to be effectively managed in the context of competing demands and limited resources. In setting priorities within this context, the general directions outlined above point to 10 guidelines to apply in selecting priorities:

1. Will the measures meet basic needs – the minimum core rights which are non-negotiable?
2. Does the investment constitute measurable progress in meeting needs for supports and services to realize rights?

3. Will the measures meet the needs of at least some of the most disadvantaged and vulnerable within the groups targeted – even if this means that fewer will be served or reached by the policy/program? This ensures that governments are taking leadership to demonstrate that the rights of people with the most significant disabilities, for example, can be realized in community and society. This principle addresses built-in disincentives in funding for employment support programs, for example, that prioritize those with milder disabilities who may not need as much ongoing support in order to participate in the labour market.
4. Will the measures address the structural sources of disadvantage and exclusion?
5. Will the measures leverage the resources of individuals and families, but in ways that do not impose unfair burdens or opportunity costs (like having to withdraw from the labour market in order to provide disability-related care)? In other words, will the measures 'strike the right balance' between investments in individuals, families and community capacity, and in ways that advance inclusion?
6. Do the measures create incentives to maximize investment by non-government sectors in ways that advance equality of opportunity, outcome and inclusion for people with disabilities?
7. Will the measures create triggers for further social innovation and investment by community and private sectors to advance implementation of CRPD obligations?
8. Have people with disabilities, their families and their organizations been engaged to help determine the trade-offs being made, given their knowledge about disadvantage and priorities?
9. Is information provided to affected groups about their rights and entitlements, even if governments cannot provide all the resources to enable these rights to be fully enjoyed in the short term, and are mechanisms in place to lodge complaints that governments are not meeting their obligations?
10. Is there a robust monitoring and evaluation strategy to measure progress and ensure:
 - 1) that effective strategic planning is being undertaken to maximize resources given priorities and the scale of the need;
 - 2) that measures are having a positive impact in closing the gaps;
 - and 3) that government is continually assessing the scale of need to be addressed and setting priorities in ways that have maximum positive impact?

Developing Organizational Capacity for Disability and Inclusion Based Analysis

Undertaking disability and inclusion based policy analysis and managing priorities requires capacities that governments generally do not yet have in place. Five main building blocks are needed:

- Policy framework of commitment and mandates
- Accountability framework to ensure mandates are met
- Disability data strategy
- Machinery for managing the process
- Partners in the analysis process

The first step is to establish the policy framework for undertaking DIBPA. Political commitment is an indispensable beginning. A legislative framework that establishes clear requirements and process will likely be needed over the long-term. Legislation can be mandated by obligations in the Canadian *Charter of Rights and Freedoms* to assure equality rights without discrimination on the basis of disability, the obligations in the CRPD, and the protections against discrimination in Human Rights Codes.

Second, accountability for implementing DIBPA will be necessary. Accountabilities on the part of Ministers, Deputy Ministers, senior officials and managers must enable them to lead the way and ensure that the analysis is integrated into government departments' ongoing operations.

Third, a disability data strategy must be designed and resourced in order to provide the disability-disaggregated information required to measure progress on key indicators related to priorities.

Fourth, machinery to manage the process is needed, which can include establishing departmental and interdepartmental champions, mentors, committees, and training in conducting the analysis. Two critical pieces of the machinery include: a cross-

government focal point for resourcing and supporting the process; and a central agency policy coordination mechanism. The coordination mechanism must have the authority to ensure that mandates for conducting DIBPA are fulfilled, policy priorities are selected and integrated into the budget cycle, and that the process is managed effectively.

Design and accountabilities of both the policy coordination mechanism and the focal point will determine effectiveness. Some jurisdictions are establishing a disability policy office, within a particular department, or a 'disability advisory council'. While useful in bringing profile to disability policy issues, neither approach will be sufficient on its own to provide the cross-government coordination needed at the Executive level, or the capacity to resource departments in fulfilling their mandate to undertake DIBPA. Line accountabilities within a particular department, or an 'advisory' council model, do not impose the needed accountability at a central agency of government for ensuring policy analysis is conducted and acted upon in a manner that substantially impacts the policy decisions of government.

Fifth, a partnership approach is required to engage partners both within government and beyond, particularly with the disability community, keeping in mind the guidelines outlined above for 'Engaging the Disability Community in Policy Dialogue.'

DIBPA is ideally part of the ongoing process of policy analysis and development, much like gender based analysis is becoming. Appendix A provides a tool, adapted from Status of Women Canada for gender based analysis,²¹ to assist policy makers in determining their readiness and capacity to undertake DIBPA.

Conclusion

Disability and inclusion based policy analysis makes for good public policy. The analysis helps to reveal underlying assumptions and values in policies and programs which may lead to allocating resources in ways that are not fully consistent with the vision of an inclusive and accessible society and the roles and responsibilities of governments under the UN Convention on the Rights of Persons with Disabilities.

While the disadvantage that people with disabilities still face in Canada today has roots that stretch back centuries, and is embedded in outmoded approaches to understanding disability, new perspectives are beginning to take root. It will take leadership and partnership from all sectors of society – people with disabilities and their families and their organizations, community sectors and leaders, the private sector, and governments. Disability and inclusion based policy analysis provides policy makers, the disability community and other partners with the tools to critically examine how public policy is currently shaped to advance or undermine inclusion, and provides practical steps for charting the path to inclusion.

Public policies and programs to enable inclusion will not be changed overnight. Policy development is by its nature an incremental process of change. However, it can be strategically incremental and progressively realized, provided that governments have the tools and the machinery for effective priority setting that maximizes investment and monitors progress, even in a context of limited resources. Or, public policy development can remain a process that often, unwittingly, reproduces the very sources of disadvantage that leave people with disabilities without the equality and participation we hold as a basic tenet of democratic society. The choice is ours.

Appendix A – Evaluating Organizational Capacity for Disability and Inclusion Based Policy Analysis²²

BUILDING BLOCK FOR ANALYSIS	YES!	NO, BUT...	NOT AT ALL, BUT ALL IS NOT LOST!
1. Policy framework			
Statement of intent regarding disability and inclusion based policy analysis (DIBPA)			
Declares political and policy commitment to DIBPA	My organization has a strong statement of intent regarding DIBPA (i.e. departmental DIBPA policy)	My organization can rely on a government-wide statement that clearly establishes the importance of DIBPA	My organization is considering adopting a statement of intent on DIBPA My organization is disability inclusion aware and/or favorable to DIBPA
Legislative framework			
Sets the stage and gives momentum to DIBPA Contributes to creating an inclusive organizational culture Establishes a legislative requirement Based on <i>The Canadian Charter of Rights and Freedoms, Human Rights Code/Act</i> and UN Convention on the Rights of Persons with Disabilities (CRPD) Ensures compliance and harmonization with the CRPD for all law reform and policy development	My organization relies on the equality provisions of the <i>Canadian Charter of Rights and Freedoms</i> , and the federal and/or provincial/territorial Human Rights Codes My organization is responsible for and is guided by a specific piece of legislation that underlines the need to practice DIBPA My organization relies on/ is guided by the principles established in international conventions/ instruments such as the CRPD	My organization can rely on Employment Equity, Pay Equity, Human Rights frameworks or programs	
2. Accountability framework			
Sets desired outcomes, standards and timeframes - planning documents that:			
Ties DIBPA to Policy Design Avoids DIBPA being an end unto itself Goes beyond measuring activities and outputs Linked to specific policies and reporting mechanisms	Disability and Inclusion is a component of our organization's strategic plans, evaluation and public reporting processes		

BUILDING BLOCK FOR ANALYSIS	YES!	NO, BUT...	NOT AT ALL, BUT ALL IS NOT LOST!
Roles and responsibilities			
<p>DIBPA is a shared responsibility</p> <p>Different levels of responsibility:</p> <ul style="list-style-type: none"> Organizational heads: leadership, vision Senior managers: guidance Centre of responsibility: DIBPA Champion All individuals: use DIBPA in all activities 	<p>The heads of the organization have a clearly defined role in promoting DIBPA both internally and externally</p> <p>Senior management has a clearly defined role in promoting DIBPA both internally and externally</p> <p>The DIBPA Champion has a clearly defined role in promoting DIBPA both internally and externally</p> <p>All employees of the organization are aware of the existence of DIBPA and understand its implications</p>	<p>Senior management of the organization has a clearly defined role in promoting DIBPA both internally and externally</p> <p>A limited number of employees of the organization are aware of the existence of DIBPA and understand its implications</p>	<p>The DIBPA Champion has clearly defined role in promoting DIBPA both internally and externally</p>
Statistics & indicators			
<p>Data, information and research on the inclusion and status of people with disabilities relative to those who do not have a disability</p> <p>Can point to areas of strength and those needing improvement</p>	<p>Disability-disaggregated data is collected</p> <p>My organization has developed a set of DIBPA indicators</p>	<p>My organization uses Disability-disaggregated data developed by other organizations</p> <p>My organization relies on DIBPA indicators developed by another organization</p>	
Evaluation			
<p>Creation of tools to assess the application of DIBPA and how well DIBPA is being used in the development of policies, programs or legislation</p>	<p>My organization has disability-inclusive, results-based monitoring and evaluation tools</p>	<p>My organization is in the process of developing disability and inclusion results-based monitoring and evaluation tools</p>	

3. Institutional machinery

Status of Persons with Disabilities machinery

<p>DIBPA responsibility designated</p> <p>Network of disability and inclusion mentors</p> <p>Human and financial resources allocated for this purpose</p> <p>Promote DIBPA; undertake DIBPA capacity; monitor and report progress on application of DIBPA</p>	<p>My organization has a disability inclusion focal point that has a clear responsibility for leadership and support of DIBPA</p> <p>Sufficient human and financial resources are allocated specifically for the integration of DIBPA in the organization</p>	<p>Human and financial resources are allocated for the implementation and integration of DIBPA</p>	<p>Minimal resources are allocated to the implementation and integration of DIBPA</p>
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BUILDING BLOCK FOR ANALYSIS	YES!	NO, BUT...	NOT AT ALL, BUT ALL IS NOT LOST!
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Committees

Coordinate, facilitate and support DIBPA activities	The organization has an internal committee that focuses on the creation, coordination, facilitation, support and integration of DIBPA across a range of sectors and sub-sectors	The organization has an internal committee that focuses on DIBPA	
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Training

Transfer of knowledge for practical implementation Goes beyond disability experts Training for DIBPA is delivered	Training for DIBPA is provided in my unit	Employees in my organization have access to DIBPA training, through another organization	Employees in my organization do not have access to training, but my organization is presently developing DIBPA training
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Tools

Guides, manuals, checklists	My organization has developed tools such as DIBPA guides and checklists	My organization uses DIBPA tools created by other organizations	My organization is planning on developing its own DIBPA tools
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4. Partners

Initiatives (Policy outcome & Capacity building)

<p>Targeted DIBPA in selected policy/program areas – and engaged organizations/units for that purpose</p> <p>Engaged people with disabilities, families and their organizations in a DIBPA initiative</p> <p>Working in partnerships within and across units and Departments for: research, analysis, policy design, program assessment</p> <p>Criteria</p> <ul style="list-style-type: none"> • Commitment of partners to DIBPA • Leadership: senior management and middle management support • Measurable results and outcomes of DIBPA <p>DIBPA Training undertaken</p>	My organization participated in and/or led a DIBPA initiative	My organization is presently negotiating a DIBPA initiative	My organization is presently negotiating an initiative that focuses on DIBPA training only
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Bibliography and Information Resources

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In Canada

ARCH Disability Law Centre: www.archdisabilitylaw.ca

Canadian Association for Community Living: www.cacl.ca

Canadian Centre on Disability Studies: www.disabilitystudies.ca

Centre for Inclusion and Citizenship: www.cic.arts.ubc.ca

Council of Canadians with Disabilities: www.ccdonline.ca

DisAbled Women's Network (DAWN) Canada: <http://www.dawncanada.net/>

Ethno-racial People with Disabilities Coalition of Ontario: <http://www.ryerson.ca/erdco/>

Inclusive Education Canada: www.inclusiveeducation.ca

Independent Living Canada: www.ilcanada.ca

Institute for Research and Development on Inclusion and Society: www.irisinstitute.ca

International

Centre for Disability Law and Policy: <http://www.nuigalway.ie/cdlp/>

Disability Rights International: <http://www.disabilityrightsintl.org/>

Disability Rights Promotion International: <http://drpi.research.yorku.ca/>

Global Partnership for Disability and Development: <http://www.gpdd-online.org/>

International Disability Alliance: www.internationaldisabilityalliance.org

Mental Disability Advocacy Centre: www.mdac.info

United Nations Enable – Secretariat for the Convention on the Rights of Persons with Disabilities: <http://www.un.org/disabilities/>

SOME RESOURCES ON DISABILITY AND PUBLIC POLICY

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