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Duncan H. Blackman

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Current Developments in Services for People with Intellectual Disabilities

Abstract
[Taken from Executive Summary]

This literature review is the culmination of the Saskatchewan Community Living Division jurisdictional study which began in the autumn of 2003. Following a brief survey of developments in providing services to people with intellectual disabilities (hitherto the People) for creating the questionnaire for this study, information was gleaned from the provinces and territories on their services. The CLD Jurisdictional Project was completed in the spring of 2005. Subsequently, a thorough search and examination of pertinent resources for serving this People and for policy development was conducted. From over 800 documents about 350 were selected for this literature review.

The material is recorded in the following chapters: Public Consultation and Policy Development; Social Philosophy: the philosophical influence on contemporary social issues; Definition of disabilities; Needs assessment systems; Human Rights; Advocacy; Community services & Deinstitutionalization; Issues and Influences; Citizenship; Inclusion; Self-determination; Person-centered planning; Supports; Respite; Individualized funding; Canadian governmental initiatives; Provincial Services.

Keywords
Saskatchewan, study, disability, people, development, group, service, public, review, resource, information, bibliography

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Saskatchewan
Community Living Division

Policy and Service Delivery
Advisory Committee

Current Developments in Services for People with Intellectual Disabilities

Literature Review
Resource Information and Bibliography

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2005

Saskatchewan Community Living Division
Current Developments in Services for People with Intellectual Disabilities
Literature Review: Resource Information and Bibliography

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Notes on the conventions used in this report:

Report Format

This literature review is intended to serve as a resource guide for the development of policy and services for people with intellectual disabilities. Each chapter begins with an overview of the issues and concepts reflected by its title. This is followed by an annotated bibliography approach of the selected documents.

The details were summarized where that made sense; however, in most cases, reporting was facilitated by quoting relevant portions, sometimes extensive, of the source documents. This practice was adopted to facilitate the communication of the relevant detail to the members of the CLD Policy and Service Delivery Advisory Committee with the benefit being that they weren't required to study the original documents.

Throughout the quotes, words, sentences or paragraphs that were skipped are denoted by the standard ellipsis (i.e., three periods) surrounded by brackets (e.g., [...]). Similarly, if words are added within the quoted material, they are surrounded by brackets.

Respectful Language

Except for quoted material, this report uses gender-neutral language according to the 1999 UNESCO guidelines. The rationale for gender-neutal language is to avoid discrimination and to promote inclusive practices. This was emphasized in the UNESCO guidelines:

> This development indicated a growing awareness that lanquage does not merely reflect the way we think: it also shapes our thinking. If words and expressions that imply that women are inferior to men are constantly used, that assumption of inferiority tends to become part of our mindset. Hence the need to adjust our lanquage when our ideas evolve. (pg. 4)

As much as possible, substitutions for pronouns are achieved by rewording or pluralizing the text or by using the plural pronouns (e.g., they, them, their) as replacements for the singular. The

latter method has historical precedence (UNESCO, 1999; Jacobson, 2004) and has become popularized into the common, everyday language. (Jacobson, 2004).

People First Language

Somewhat similarly, "people first" language is used to refer to the People for whom this report is focussed. This is

> [t]he practice of using care in language when talking about people with disabilities. For example, one would say "child with a disability" versus "disabled child." This puts the person first and emphasizes the person instead of the disability. (Urban Dictionary, 2005)

Repetitious use of the phrase, people with intellectual disabilities, is a cumbersome approach to identifying the target population of the People on whom this report is based. As well, though it is a vast improvement over the use of labels and terminology which identifies people by their disability, it still includes the impairment as part of the focus in the text and presents similar problems to those identified by UNESCO (1999).

Acronyms (e.g., PWD) are broadly used by authors in this field to denote the people with disabilities. While this simplifies the presentation, the approach is depersonalizing and dehumanizing. People without disabilities are not referred to by their characteristics and there is no need to use acronyms to refer to them.

Hence this author suggests the adoption of a somewhat novel convention throughout this and similar documents to refer to the target group (i.e., people with intellectual disabilities) by utilizing the word, People, with an uppercase first letter. Where necessary, clarification could be provided with people first language. To avoid confusion, where reference is made to all people regardless of distinguishing characteristics, then other inclusive words (e.g., humanity, society, the public, women and men) are suggested for use.

(Note: Quoted sections from the reference documents and internet links appear as in their original passages and haven't been revised according to the preceding conventions.)

Terminology

The use of the phrase, intellectual disabilities, and its variants has recently emerged in the literature and is commonly utilized in Saskatchewan to refer to people who are

> characterized by significantly subaverage intellectual functioning (an IQ of approximately 70 or below) with onset before age 18 years and concurrent deficits or impairments in adaptive functioning. (American Psychiatric Association, 2000, pg. 39)

Other terms which are quoted in the report include:

- Developmental disabilities. This is a somewhat broader category, including those with autism, epilepsy, severe cerebral palsy as well as those with intellectual disabilities.

> According to the federal definition referenced in P.L. 95-602, a developmental disability is a severe, chronic disability that: (a) is attributed to a mental or physical impairment or combination of mental and physical impairments; (b) is manifested before the person attains the age of 21; (c) is likely to continue indefinitely; (d) results in substantial functional limitations in three or more of the following major life activity areas: self care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self sufficiency; and (e) reflects the person's need for a combination and sequence of special and interdisciplinary or generic care, treatment, or other services which are of lifelong or extended duration and individually planned and coordinated. (Institute for Community Inclusion, 2001)

- Learning disabilities. This is the term used in the United Kingdom to refer to people with mental retardation. This is not the same as the term, learning disorder.
- The phrase, people with disabilities, is gaining broad acceptance to refer to all categories of disability regardless of type or cause.

Reference Format

For the ease of the reader, the references are provided at the beginning of the relevant quoted sections. Complete details are provided where possible so the reader can acquire the documents. (Note: This author can be contacted to provide copies if required.)

Each chapter ends with a list of additional resources. These were documents which paralleled the contents of the annotated bibliography or provided useful information not directly relevant to the focus group for this review, namely the People. (Copies of these documents can be made available upon request.) Also, Internet web links to related topics are provided at the end of each chapter..

As much as possible, the scientific style was used for reporting the reference documents. Since much of the material was located from the Internet, the web address and the date accessed, enclosed in parentheses, were included. [Note: Since web addresses have a tendency to change over time, this author recommends the use of a search engine (e.g., Google) with a significant phrase from the title (i.e., at least 6 consecutive words) enclosed within double quotation marks (i.e., " ") to find the title if the location for the reference changes.]

Some Internet documents were not dated. In those cases, the date was arbitrarily selected from date modified on the "Page Info" view as provided in the Netscape 7.1 web browser. This doesn't necessarily represent the date that the author last revised the document; however, it is the date that they or the organization which posted the document last handled it. In those cases where no date was available according to this approach, then the initials, "n.d." (i.e., no date), were used.

Acronyms used in this report:

(See page 78ff of the chapter, Canadian governmental initiatives, for a list of relevant abbreviations commonly used in Canada.)

CLD - Community Living Division (Saskatchewan)
P&SDAC - Policy and Service Delivery Advisory Committee (CLD)

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Executive Summary

Since this literature review is intended as a resource document, there are no conclusions or recommendations. Hence this executive summary will provide a brief overview of the contents of each chapter.

Introduction
This literature review is the culmination of the Saskatchewan Community Living Division jurisdictional study which began in the autumn of 2003. Following a brief survey of developments in providing services to people with intellectual disabilities (hitherto the People) for creating the questionnaire for this study, information was gleaned from the provinces and territories on their services. The CLD Jurisdictional Project was completed in the spring of 2005. Subsequently, a thorough search and examination of pertinent resources for serving this People and for policy development was conducted. From over 800 documents about 350 were selected for this literature review. This material is recorded in the following chapters.

Public Consultation and Policy Development
In the twenty-first century, new rules apply for public consultation and policy development. With the availability of increased resources through such media as the radio and television, the Internet, and e-mail, the general public has become much more aware of potential solutions for the issues they are faced with on a daily basis. These new communication tools have enabled people to unite both locally and globally for work towards common goals and to accomplish major changes to benefit the lives of themselves and others.

It is in this new culture that government consultants and policy advisers must change from outdated practices to new modalities of change technologies. The following articles discuss the influences and social atmosphere which affect policy development, the resources which the general public bring to this process, and solutions for consulting with an informed public of the twenty-first century.

Social Philosophy: the philosophical influence on contemporary social issues

Significant changes that have occurred over the past 50 years in the services for this People were largely due to shifts in prevailing attitudes guided by new social philosophies. Early approaches were based on the medical model with an emphasis on physical care and rehabilitative treatment. Subsequently, driven in part by the parents' associations, an educational or developmental model prevailed with priorities given to changing this People through the new technologies (e.g., behavior management, developmental programming, special education) of the day.

During the last couple of decades, a new model -- the social model of disability -- has emerged and become dominant. For this people, the philosophies of normalization and social role valorization merged with the social model to lend credence to the self advocacy movement. The social model, birthed from the of human rights movement by people with disabilities, has been instrumental in the promotion of non-discrimination, self-determination, inclusion, citizenship, participation and belonging.

The chapter provides an overview of the social model -- what it is, the social philosophy which supports it, and the potential metamorphosis or changes to the model in the future.

Definition of disabilities

Influenced in part by the social model, the definition of disabilities has moved from a categorization of impairment to an identification of the degree to which the physical, cognitive/learning, and mental difficulties limit inclusion in the mainstream of society.

Definitions of disability are used to treat eligibility criteria for the delivery of services. Canadian services and programs have been influenced by these changes to the point where the definition or classification criteria differ from one initiative to the next. Unfortunately this creates confusion and works to the disadvantage of some individuals who only meet the criteria for certain services and not for others which they might need.

An emerging solution is to provide programs and services delivered according to the required need for supports rather than being based on a classification process.

The articles reflect the changing definition and its influence on the delivery of services.

Needs assessment systems

One common approach used to identify the necessary supports required by these People is through the use of various needs assessment systems.

Although the Saskatchewan CLD has developed and uses the Daily Living Support Assessment, information was sought from other jurisdictions for comparison purposes.

Human Rights

During the last half century, universal human rights for all of humanity have been recognized, proclaimed, established in statutory law, and used to promote the inclusion and participation of all people, regardless of their differences and limitations, in society.

With the formation of the United Nations, the Universal Declaration of Human Rights established the principles upon which modern nations -- their laws and policies -- are based. In 1982, the Canadian Charter of Rights and Freedoms make provision in section 15 to ensure that no groups of people were excluded from the fundamental provisions of federal law. Additionally the provinces have enacted legislation to support the human rights of all people in their jurisdictions.

Currently from global perspective, a relatively recent initiative of the United Nations has been to draft an international convention on the rights of all persons with disabilities. The following excerpts from documents provide a foundational knowledge pertaining to the protection of human rights for people with intellectual disabilities.

Advocacy

While the word advocacy is most commonly used in the legal context, it has gained greater meaning for the People as a social and rights movement. Empowerment and self advocacy become important tools for people who are working to achieve their rights and to receive the necessary supports for living in a diverse and increasingly complex society. The self advocacy movement, has transcended its initial groups of social involvement to become a powerful force in accomplishing international change in a way that supports and services are provided to this People. An example this is contained in excerpts of the speech by Robert Martin who is currently a member of the Ad Hoc Committee to develop the new convention of rights for people with disabilities.

The articles illuminate the issues pertaining to family advocacy, self advocacy and empowerment. Within the list of Internet links, reference is made to a number of legal documents showing the role of law in upholding the rights of the People.

Community services & Deinstitutionalization

Reliance on community services has become well-established over the last three decades. There are a plethora of advantages including individualized supports, choice, participation in every day society, flexibility and diversity of opportunities, etc.

This section of the literature review provides details on existing community models, the progress towards deinstitutionalization, results of cost-benefit analysis, and overall trends.

Issues and Influences

A number of issues which have an impact on services and programs are presented. These include. Examples include fiscal restraints, the availability of resources, family support issues, global pressures, poverty, marginalization, staffing issues and social policy changes.

Other

In any project of this scope, there are articles which don't readily fit into other categories. These have been added to this section roughly grouped according to the following headings: system change, means tests, quality management, and quality of life.

Citizenship

Full citizenship means participation and belonging to the society and nation in which one lives. It transcends the simplistic role of being a recipient only to more complex and contributory roles which are valued, needed, recognized, and supported by one's local community. It is to these ends that the People are actively pursuing through such involvements as the human rights movement, social activism, and self advocacy.

Inclusion

Inclusion has moved into the realm of social theory with ramifications for public policy. Originally born out of the European context on the analysis of social exclusion, inclusion has become widely used to promote acceptance of diversity, removal of barriers to participation and identification of idicators of success in promoting citizenship for all people in Canada. Definitions and interpretations of inclusion abound. However, the fundamental elements of inclusion are belonging, participation, acceptance, and value.

Target groups encompass anyone isolated or excluded from normal social, economic, political, cultural and spiritual involvement as a result of differentness, poverty, race or other potential barriers to status and recognition in today's society. As such they include people with disabilities, the impoverished, seniors, the chronically ill, immigrants, and any others who have traditionally been marginalized or excluded from normal society and community life.

The documents included in this section provide multiple definitions of inclusion and initiatives to promote inclusive communities.

Self-determination

This initiative has been broadly promoted and accepted as part of an individualized funding and person-centered planning system. The concept is self-determination originated in the language of human rights. In the context with this People, it has become one of the very many initiatives for being supported in the community.

Person-centered planning

The articles selected in this brief overview of person centered planning present the principles, planning approaches, supports and follow-up guidelines.

Supports

The trend in residential services is away from larger groups towards smaller more personalized service settings (e.g., supported living, small care homes, shared apartments). Similar individualized support approaches to enable people to become employed.

Respite

Families are the primary providers of supports to these people. Respite, the system of providing support to families and caregivers, has been transformed by many new initiatives in the past few years.

Individualized funding

Individualized funding is a system tailored to individual need to enable them to manage their own care and supports according to their preferences and priorities.

Canadian governmental initiatives

To understand the diversity of approaches and services for people with disabilities in Canada one needs to be aware of the unique relationship of the provinces to the federal government as highlighted by the new federalism and by such agreements as the Social Union Framework Agreement (SUFA). This sections covers the political process behind the policies and the various programs and initiatives for people with disabilities provided through the auspices of the Canadian federal government.

Provincial Services

The information in this section is supplemental to the CLD jurisdictional project which was completed in the spring of 2005. There's no particular order to the material from various provinces nor is this meant to be comprehensive. It simply provides some additional detail which came to our attention during the past few months.

Saskatchewan Community Living Division
Current Developments in Services for People with Intellectual Disabilities
Literature Review: Resource Information and Bibliography

Current Developments in Services for People with Intellectual Disabilities
Literature Review: Resource Information and Bibliography

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Introduction

This literature review and subsequent resource binder is the culmination of a project which began in the autumn of 2003 to complete a jurisdictional review of the services delivered by the Canadian provinces to people with intellectual disabilities. In order to properly prepare for the jurisdictional review and to apprise the Community Living Division of the recent developments pertaining to worldwide service delivery systems, there was need to examine articles and reports from agencies and authors who were working with the People.

This is accomplished through an extensive Internet search, correspondence with experts in the field, the examination of research articles, and follow-up of reference material suggested by the various provincial/territorial staff contacted during the jurisdictional study. From over 800 documents (e.g., articles, reports, research papers, websites, books) , about 350 were selected for inclusion in the literature review. This material is summarized in the following chapters. (Note: The printed copies require over 7 feet of shelving and about 400 documents weren't printed. So this consultant has studied several thousand pages to develop this report.)

The topics covered include public consultation and policy development, philosophical issues, definition of disabilities, needs assessment, human rights, advocacy, community services, issues, citizenship, inclusion, self-determination, person-centered planning, supported living and employment, respite, individualized funding, Canadian government initiatives, and additional information about the provinces.

The CLD jurisdictional project was completed in the spring of 2005. The information in the study was gleaned through telephone interviews, websites searches of provincial programs, e-mail correspondence, and short questionnaires. Details on respite and/or family care programs were received from all the provinces and territories. More complete information on services for the People was obtained from Alberta, British Columbia, Community Living BC, Manitoba, New Brunswick, Newfoundland, Nova Scotia, Ontario, Prince Edward Island and Quebec (through translation of documents). The results of this study are contained in the report entitled CLD Jurisdictional Project (2004) which was submitted to the CLD Policy and Service Delivery Advisory Committee.

The material contained in this literature review is meant to serve as a resource to the CLD Policy and Service Delivery Advisory Committee. Unlike the traditional literature review which summarizes material to express particular point of view, this document provides selected quotations. These quotes provide useful details on trends, current developments, theoretical writings and applicable research on service initiatives and related topics (e.g., public consultation) pertinent to the People targeted in this review.

In addition to being a source of information, this document contains the raw material for educational bulletins and presentations to community-based organizations, families and staff. It is anticipated that this document will facilitate the development of revised or new policy and programs by the CLD.

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Public Consultation and Policy Development

Introduction

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It is in this new culture that government consultants and policy advisers must change from outdated practices to new modalities of change technologies. The following articles discuss the influences and social atmosphere which affect policy development, the resources which the general public bring to this process, and solutions for consulting with an informed public of the twenty-first century.

Issues: *Complex Problems*

Place-based public policy: Towards a new urban and community agenda for Canada
Bradford, N. (Canadian Policy Research Networks, Ottawa, ON)
March 2005 (www.cprn.org)

"Recently there has been growing awareness of the importance of cities, large and small, as strategic spaces in the age of globalization. Knowledge-based innovation is the critical ingredient for prosperity and well-being in the 21st century, and it seems to thrive in local places that value diversity, encourage the flow of ideas, and include all residents in the economic, social, and political life of the community. [...] Canada is one of the most urbanized nations in the world, with fully 80 percent of its citizens living in urban areas, and some 64 percent of the population living in the country's 27 Census Metropolitan Areas, cities with populations greater than 100,000." (pg. 1)

"Recent research has clarified several key aspects of Canada's shifting and diverse urban landscape. Three major themes are evident:

- Cities are the engines of national economic prosperity. [...]

- Poverty and polarization evident at the national level have become more pronounced in cities. [...] In addition, the risks of exclusion and isolation disproportionately impact those already vulnerable, including Aboriginal peoples, recent immigrants, lone-parent families and elderly women.
- There is a widening gap between growing and stagnant or declining cities. Of the 140 urban areas that had populations over 10,000 in Canada in 2001, more than 40 percent saw an absolute decline in population during 1996-2001 [...]. The larger cities face challenges in managing rapid growth and population diversity whereas many smaller communities confront population and employment decline, and need to retain their young people and recruit immigrants. [...]

[...] At present, the problems of ageing infrastructure, insufficient affordable housing, spatially-concentrated poverty, traffic congestion and lowered air quality are piling up at the doorstep of the municipal governments." (pg. 2)

"The attention now being paid to urban places by governments at all levels reflects the fact that many of today's most important public policies exhibit the characteristics of "wicked problems." Wicked problems are the ones that "cross departmental boundaries and resist the solutions that are readily available through the action of one agency [...]. Wicked problems highlight critical information gaps about what precisely is required to help, and large coordination failures in terms of channelling the appropriate resources to the right target. They cannot be solved through "off the shelf solutions." With their inherent complexity, these problems are resistant to traditional sectoral interventions designed and delivered in a top-down fashion by individual government departments. Required instead are place-sensitive modes of policy intervention - strategies constructed with knowledge of the particular circumstances in communities, and delivered through collaborations crossing functional boundaries and departmental silos.

A prime example of such a wicked problem is Canada's growing income gap and its increasing spatial concentration in particular places across city-regions [...]. Low-income people find themselves "trapped" in deteriorating urban neighbourhoods. The poverty afflicting residents is rooted in a mix of difficulties ranging from labour market weaknesses and racial, gender or other discrimination to limited social contacts and a fraying community infrastructure of housing, education, health, transit, and so forth. [...]

Any effective solution to social exclusion and spatial isolation will need to co-ordinate the efforts of many actors, agencies and governments." (pg. 4)

"discussion of wicked problems and complex files brings into focus the limits to the ideas and practices of governments that work in departmental silos and through immutable hierarchies. [...] See like a community, therefore, requires a new approach to government decision-making [...]. Such unacknowledged forms increasingly take localized expressions, bridging outdated divides between experts, citizens, and community-based organizations. [...] This local knowledge has three interconnected aspects as it relates to the new challenges of urban policy-making:

- Knowledge *of* communities: input from the "policy clients" themselves based on their lived experience and intimate familiarity with conditions "on the ground and in the streets" of their place. [...]
- Knowledge *about* communities: statistical data disaggregated to the local scale, tracking trends in the city or community [...] that provide a profile of the place. [...]
- Knowledge *for* changing communities: theoretical models that articulate plausible links between reform strategies and outcomes. Such models build on understandings of the factors

that have produced success or failure in different places, and they guide community-based practitioners and policy makers in setting priorities. [...]
[...]
Here, conventional understandings of evidence-based policy-making are recast quite broadly. Citizens and community groups are recognized for their particular kind of expertise, and invited to participate in policy formation. stories of the obstacles and barriers they encounter, some undoubtedly resulting from existing government policies and programs, are heard by the official policy experts. [...] [G]overnment policy makers increasingly are called on to play a dual role, acting as a technical expert in substantive policy matters, and as a facilitator of, and participant in, community-driven learning, planning, and action. Their most important role might be that of knowledge broker. The locally engaged civil servant mediates between government expectations, departmental protocols, and community practices, generating new opportunities for dialogue where more distant bureaucracies cannot connect.
Policy development becomes "a two-way translation process" that involves "on the one hand breaking down and re-working formal research so that it can be applied to specific practical contexts and, on the other, articulating the practitioner insights and know-how so that these can be shared as formal knowledge" (Leviten-Reid, 2004: 8). When the "facts" relevant to policy-making are seen as constituted by the particular contexts and experiences, rather than as external objective truths, governments cannot generate meaningful policy knowledge on their own, detached from the problems at hand or distant from the people living with them." (pg. 5-6)
"[A] number of specific points follow about how the local milieu impacts key aspects of citizen well-being and liveable human settlements:

- *Economic Innovation.* Cities [...] represent an ideal space for the idea fermentation and organizational synergies in knowledge-intensive production. [...] It is the social networks, personal interactions and distinctive amenities that spur the learning and innovation process. [...]
- *Social Inclusion.* Cities have become more polarized and segregated in terms of living spaces, as different socio-economic classes and ethno-cultural groups cluster together in particular neighbourhoods. Studies of community life across urban space reveal how distressed areas with limited connections and inadequate services multiply the constraints on people already in difficulty [...].
- *Environmental Sustainability.* Cities [...] face complex challenges to ensure air and water quality, effective waste management, and preservation of greenspace and ecosystems. [...]
- *Citizenship Rights.* [R]esearchers now describe a politics of community life that engages the fundamental issues of human well-being [...]. [I]ssues of access and inclusion in local places make a significant difference to the quality of life for all citizens. The effects are manifest in prospects for employment, housing, health, personal safety, and cultural recognition. [...]
- *Sense of Belonging.* Through such localized struggles, residents can develop a new sense of meaning and belonging." (pg. 7-8)

"Place-based policy targets specific neighbourhoods or communities for integrated interventions that respond to location-specific challenges, and engage fully the ideas and resources of the residents. The aim is both better government policy and more community capacity. [...] for social inclusion and citizenship, the focus of mobilization is to *democratize the place* by expanding economic opportunity or validating diverse cultures. To nurture the sense of belonging, citizens mobilize to *plan the place* such that there are public spaces for participation and dialogue. [...]

If conceived too narrowly, a place-based approach can have a variety of unintended consequences [...]. Policy coordination may be more difficult as government interventions proliferate and become too fragmented [...]. Moreover, place-based policy can further stigmatize targeted areas within a metropolitan region, increasing the concentration of problems [...]. Alternatively, the targeting could produce greater tension among proximate neighbourhoods based on which area receives assistance." (pg. 8)
"One size-fits-all policy delivered from above is not conducive to integrated place-sensitive solutions. State bureaucracies no longer can claim a monopoly on policy knowledge, and they encounter more resistance in imposing their will on other actors. In order to meet the policy challenges, new relations must be forged among the state, civil society, and the economy, and within the different branches and levels of government. [...]
While the concept of governance is attracting considerable support as a strategy for overcoming the observed shortcomings of bureaucratic and market steering mechanisms, there are grounds for caution. [...] Relying on negotiation more than hierarchical commands or market signals, effective governance depends on actors and organizations, often unfamiliar with one another, finding ways to work together and share responsibility. Managing the *transaction costs of collaboration* will require new styles of leadership and facilitation, and the cultivation of trust and respect among the players." (pg. 10)

"Federalism is an institutional system that allows sub-national jurisdictions to act as "laboratories of democracy," experimenting with new ideas and testing out novel approaches (Osborne, 1990). Certainly in Canada, the provinces have often lived up to this promise. In numerous policy fields, across the 20th century, they have been innovators. Health care, labour market policy, industrial strategy, and child care are all examples where provincial experimentation has helped reshape the national policy landscape. Lasting change occurs as the federal government scales up the initiatives, or the provinces share lessons among themselves about the new strategies.
[...] A number of factors will influence the prospects for urban innovation. Among these, three stand out: political leadership, social trust, and policy accountability.
With *political leadership*, prevailing habits and practices need rethinking. traditional political leadership relies on issuing commands, taking ownership, seeking credit, avoiding blame, and declaring victory in a policy field or moving rapidly on if the progress appears slower than expected. This kind of leadership corresponds to the logic of policy unilateralism.
However, the multi-level collaboration described in this research report points to a different direction. [...] Accepting limits on their ability to make a difference on their own, politicians support the needed collaborations [...] This means valuing the leadership skills of listening, earning, and communicating, and it means applying them to network management, cross boundary working, and public deliberation. [...] Political leadership also needs to help ensure that community processes include balanced representation of societal interests and address systemic differences in the ability of different partners to engage. Finally, patient leadership accepts that collaborative policy-making is not tied to the political tides but to the community's rhythms. [...]
In addition to political leadership, collaborations depend on *social trust* for their viability and durability. [...] Actors become partners, willing to put their interests on the line by delegating authority to others who are assumed to be competent, and not disposed to free ride or off-load responsibilities. [...] [T]here is little systematic understanding of how social trust develops [...] But research has shed light on some key dynamics. [...] [E]ngagement among actors will initially

be tentative and then coalesce into a trusting relationship as the collaboration operates. As people and organizations interact, they study one another's behaviour and performance, continuously updating their assumptions regarding trustworthiness and also discovering new ways to settle differences. [...] In short, social trust is only built over time through practice. New institutional settings for public policy development, such as community roundtables and stakeholder dialogues, help cultivate the shared understandings of localized problems that bridge different interests and reveal common ground. [...]
[A]ppreciation of the benefits from collaboration must be tempered by recognition that such policy partnerships raise difficult *accountability* questions. [...] Who then is responsible for the results or, indeed, the lack of results? what factors or inputs led to which aspect of the overall outcome? [...] [M]ulti-level collaborations propose that each level of government is responsible to one another, and as well that community groups balance accountability to governments with constituency representation. [...] The development of new relationships, local capacities, and partnership structures are key "process" milestones that not only take time but are the necessary building blocks for producing more measurable outputs, whether these be more jobs, safer streets, better health, and so forth, in the locality. [...] Certainly, a viable multi-level collaboration must rest on a sound financial management system and clear delineation of the roles and responsibilities of the different actors. These issues should be built into the governance structure of the collaboration from the outset [...] Such clarity of purpose, transparency, and dialogue may be the keys to successfully managing the challenges inherent in multi-level governance." (pg.45-47)

Issues: *Political context*

An evaluative approach to public policy
Andrea Simpson (Optimum Online: The Journal of Public Sector Management, Vol. 35(3), www.optimumonline.ca)
Sep 2005

How is it possible to develop effective public policy in times of political change? To answer this question, one must begin with what is meant by "in times of political change"? Apart from the obvious markers of minority government rule and a variant of asymmetric federalism, there is another dimension to probe: there is a noticeable change in what we would consider "givens" in public policy decisions. Questions such as: "Who knows best?" and "What makes a decision right or wrong?" rarely point to neat solutions.
If the conditions of public policy-making are less predictable and more complex today than in the past, then evaluation is more useful (and probably more difficult) than ever. [...]
How to combine high-risk decisions with greater transparency and good value for Canadians is the ultimate evaluation challenge. In essence, the evaluation function is about governance because it refers to the values and practices that will guide public policy decision making in the twenty-first century. [...]
The word "value" is at the centre of evaluation. Evaluation means to place a value on, to judge the worth of something. However, on the administrative side of government, evaluation practices can sometimes belie the true function of evaluation. The general thinking goes: if it's measurable, it's evaluation. To avoid the smudged areas of subjectivity, quantifiable methods of tracking are preferred because they create the semblance of neutrality (as if decisions about methodology

were neutral). But, being objective in evaluation does not mean being neutral; neither does it mean abandoning judgment. [...]
Evaluation that is one-sided - either too focused on politics or too bent on measurement - is not particularly useful. The challenge arises not from balancing evidence and reason against values. It issues from having to weigh political value judgments (which tend to be short-term) against public service and public interest value judgments (which are usually longer-term). [...]
It follows that the challenges associated with the task of evaluation are strong motivators for finding acceptable analytical methods to guide the work of policy makers, even though they also appear to be strong deterrents. One finds that evaluation is difficult to separate from decision making (which is difficult to separate from governance). A commitment to evidence-based policy is part of an overall commitment to enhance the four core areas of policy-making: judgment (including experience and values), reason, evidence, and imagination.
This paper posits that the importance given to evaluation can also be a predictor for the use of evidence in decision making: evidence includes the spectrum of observable, measurable, reliable and verifiable facts and observations known to decision makers at a given point in time. That evidence is essential to evaluation may be stating the obvious. However, if extended to decision making, the same is not necessarily true. There is an argument to be made because decision making and evaluation are really opposite sides of the same coin. The culture of decision making defines the culture of evaluation, and vice versa. [...]
Evaluation begins with a clear articulation of the policy's rationale, objectives, and expected outcomes. So, when we talk about evidence in policy evaluation, we are really signalling an approach to policy work that is logical and transparent. [...]
One of the challenges to evaluating public policy, therefore, has to do with the degree to which politics (and partisanship) can be made explicit in the policy development (evaluation) process. Most policies are born of political tradeoffs, so why pretend that policy occurs apart from politics, or the pragmatics of governing? [...]
It's no wonder that evaluation is a prickly fruit for both decisions makers and implementers to handle because in order for evaluation to mean anything all, there is the need for transparency - and with transparency comes a new kind of vulnerability in governing. Senior policy managers provide advice and expertise to decision makers, and in this capacity they too are answerable to Parliament. However, this is not a straightforward matter because it is not always possible to ascertain the degree of political influence in public policy.[...]
Making it easier for policy managers to recognize the boundaries of their authority would improve accountability all around. Otherwise, there is the risk that those charged with evaluation will be isolated in their efforts to understand what is working to good effect, and where public policy performance might be compromised. This could result in a double disservice if public servants were held accountable to Parliament with insufficient means to do so.[...]
Public policy evaluation should also be viewed in light of the trend to public service accountability in Westminster-style systems of government (versus the convention of anonymity). The move to modernize government is really another way of saying that decisions must pass the test of public scrutiny. However, early expressions of this operating principle seem to equate evaluation with blame (or, more politely, responsibility) rather than treat it as value-added.[...]
The move to modern management, with its attendant focus on results and accountabilities, may also have the unforeseen consequence of curtailing the policy function in government. This is

because efforts to assign greater responsibility to public servants for policy decisions (and outcomes) are out-of-step with a public policy environment in which authority is more fragmented, expertise is more diffuse, and state and society are interdependent.[...]
Today, most complex public policy questions are housed in a risk-elevated environment - where there can be less certainty about what we know, and where the consequences of our actions can be far-reaching and enduring. In the words of Ulrich Beck, "scientific knowledge is creating consequences that the knowledge itself is unable to cope with effectively after the fact."
Thinkers such as Beck suggest that public policy-making must adapt to a context where:

* the intelligence gap has widened (invoking the precautionary principle);
* more decisions have consequences that can extend farther into the future, with fewer known consequences (invoking intergenerational equity, duty of care);
* ethical considerations are more difficult to tackle and more significant.

Given these conditions, the obvious question is: How can we make effective public policy decisions in a risk-elevated environment? Here are some partial answers.

* We need to be able to imagine outcomes better.
* We need better governance structures.
* We need better ways of brokering knowledge.
* We need to reinforce evidence and ethics in decision making. [...]

There is an approach to problem-solving called scenarios. This technique involves developing plausible storylines that lead to different visions of the future. Getting better at imagining "what could be" requires the capacity to accept new knowledge, and the discipline to use that knowledge effectively.
A concrete example is provided to illustrate how this method applies to policy evaluation (in the broad sense of assessing the merits of a particular policy option). [...]
This paper has put forth a preliminary template for what could be called an evaluative approach to public policy design, development, and implementation. I have suggested that the evaluation challenge is really about making evidence and reason more prominent in public policy, and combining judgment with imagination to breed a decision-making culture that is not stunned by what it cannot prove or predict.
There are no hard-and-fast solutions to the public policy conundrums that confront decision makers and policy managers today. However, if we take an approach to evaluation that more honestly reflects the real-world pressures and constraints that come to bear on policy decisions, and if we shore up our capacity to deal with the difficult value judgments that will inevitably arise, a brave new policy praxis can take its rightful place in the complex work of government today.
(pg. 1-10 (print copy format))

Process methodology: *Consumer participation*

A National snapshot of home support from the consumer perspective: Enabling people with disabilities to participate in policy analysis and community development

Krogh, K., Ennis, M. (Council of Canadians with Disabilities, www.ccdonline.ca/publications) Feb., 2005

People with disabilities have considerable and valuable knowledge about home support policy and service by virtue of their intimate experience with the home support system. Yet, the perspectives of people with disabilities concerning home support policy and service have not been widely solicited by government officials or home support administrators. When people with disabilities are consulted about these issues, their perspectives are rarely translated into meaningful changes to home support policies and services. This lack of acknowledgement of their perspectives is a major source of frustration among home support users and leads to a sense of disempowerment, hopelessness and further isolation for many individuals. The reasons why the perspectives of people with disabilities are routinely ignored or disregarded are multiple and complex, but they have their roots in unquestioned and ubiquitous ideologies of disability and impairment. Normative ideas of what constitutes authoritative, credible knowledge also tend to diminish the value of consumers experiential knowledge as does the dominant position of "experts" in interpreting and constructing credible knowledge. These ideologies all act to devalue and marginalize the knowledge of people with disabilities.

Social perceptions of people with disabilities are variable, but insofar as they are based on inadequate knowledge of people with disabilities' lives, they are often stereotypical in nature and inaccurate. Such stereotypes include characterizations of people with disabilities as passive [...], dependent [...], incapable or childlike [...]. Those with chronic illness, pain, severe fatigue or other non-visible impairment are often seen as malingerers or hypochondriacs by home support and medical personnel [...]. Home support staff who adopt or accommodate these stereotypes come to view clients who express their discontent with policy or service as ungrateful or selfish [...]. People with disabilities encounters these stereotypes from medical professionals, home support administrators, workers, family members, co-workers, in the media and among the general populace. These stereotypes collectively instruct people in how to understand and respond to people with disabilities. When users of home support are seen as passive, childlike, incapable, dependent or lazy, it is unlikely that their views and concerns about policy reform will be actively solicited or that their knowledge of home support will be considered credible and authoritative. Consumer use of home support services to facilitate community engagement, e.g., paid employment, may not be deemed a funding priority by policy-makers. Insofar as stereotypes lead to specific actions, they can seriously undermine the efforts of people with disabilities to challenge home support policy and service and live engaging and fulfilling lives.

In addition to damaging stereotypes of people with disabilities, normative ideas of what constitutes credible and authoritative knowledge also act to marginalize the perspectives of people with disabilities. [...]

Science is hegemonic in our society, meaning that it has achieved a status of unquestioned dominance in relation to other, nonscientific ways of knowing. Nonscientific knowledge is considered to be inadequate compared to authoritative scientific knowledge. People with disabilities' knowledge of the support policy and service is not achieved through scientific experimentation, but rather through their personal observation and experience. Although a home support user often has considerable knowledge of home support policy and service by virtue of their daily experience with home support, their knowledge is not highly regarded in part because it is not seen as scientific and thus, by implication, is deemed subjective or biased. [...]

Connected to the notion that science is the only credible and authoritative knowledge is the role of the experts in interpreting and perpetuating authoritative knowledge. In the fields of home support policy making and service delivery, structured as they are by economic efficiency and medicalization, certain groups of actors are considered to be more authoritative and credible than others. Economists, medical professionals and scientists all have various kinds of credentials or professional connections such as university degrees, professional certification and affiliation and government or corporate positions that are widely regarded as valuable. [...]
The ubiquitous nature of negative stereotypes about people with disabilities, the hegemony of scientific knowledge and the acknowledgement of claims of certain experts to the exclusion of others all contribute to the marginalization of the insights of people with disabilities concerning home support policy and service. These values are often not explicitly articulated, yet their effect can be stifling for people with disabilities.
(pg. 67-69)

Process methodology: *Community/citizen participation*

Community Participation - Learning from the Murray Darling Basin Experience
Boully, Leith (Community Advisory Committee of the Murray-Darling Basin Ministerial Council)
2003
Participatory democratic theory - public participation essential to advise decision-makers of community needs and preferences, while ensuring the public is obliged to consider issues of common interest.

"In an democracy people have the right to have their say and be heard, no matter what their 'position' in society." (p.4)

"What is clear is that agreement on what is negotiable and what is not negotiable must be reached at the beginning. Roles and responsibilities must be articulated, understood and agreed. At minimum, the purpose of community participation should be to provide feedback to inform decision-makers and ensure that their decisions bring about changes in behaviors, with a minimum of conflict, to achieve the needed outcomes." (p.5)

"Stakeholders themselves are articulating the need for much more participatory processes in decision-making than traditional 'consultation'. . . for the most part it represents a genuine commitment to working together." (p.5)

Areas of conflict in community involvement:
- self interest
- different value or belief systems
- data (disputes over legitimacy of information, lack of understanding about data, not enough data, incorrect data, etc.)
- labelling or stereotyping of stakeholders
- conflict inherent in organisational structures (e.g., between or within government agencies).

Development of shared values for community consultation - examples:
- Courage to provide leadership

- Inclusiveness in the development of user relationships based on trust and sharing
- Commitment to a long-term perspective
- Respect for the diversity of views among stakeholders
- Honesty in negotiations
- Flexibility and openness to learning and adapting to change
- Mutual obligation for responsibility and accountability among the different levels of government, and between governments and the community
- Practicability to choose practicable, long-term outcomes and ensure that all partners have the capacity to play their agreed part. (p.7)

Measures of success in community participation:

- be a process of influence, or a vehicle for influencing policy agendas and the system processes
- support community learning, recognizing that significant time may be required to achieve substantial changes
- ensure legitimate representation
- provide a community forum for coordination of effort, networking and social learning, while ensuring that decision-making is based on negotiated accommodation of explicitly stated interests and social learning of new, shared perspectives rather than entrenched positions
- build trust and effective interactions amongst stakeholders, to deal sensitively with conflicts and maintain productive interactions
- ensure fairness of process [by] . . . establishing decision-making approaches based on processes that seek consensus amongst stakeholders while respecting and accommodating ongoing differences
- have long-term government agency commitment to the process

Community Participation in DAIS
Government of South Australia, Department for Administrative and Information Services 2005

Participation of the community in the decision making and policy development processes of government agencies is a cornerstone of open and accountable government.
Consulting the community and encouraging worthwhile participation is a complex process and to be effective it must be context sensitive rather than prescribed.
(pg. 2)
Even on a small scale consultation with stakeholder communities is essential to full acceptance of policy change.
Other reasons for promoting community participation include:

- Community participation is a democratic extension of rights and values;
- Community participation can provide budgetary benefits -- that is, good consultation promotes rational decision making;
- Policy developed with community participation will better reflect society and communities of interest;
- Community participation can build capacity in the community and in the project team; and community participation can operate as a risk management tool.

(pg. 4)

[...] participation of the public can range from:
Tell: where the agency goes to the stakeholder community and informs them of what decisions have already been made.
Sell: where the agency uses its resources to convince their stakeholder community of the suitability of the decision that has already been made.
Test: where the agency takes a tentative decision to its stakeholder community and is prepared to change or modify the decision based on sound advice from stakeholders.
Participation: where the agency takes a problem to the stakeholder community and uses advice and objections to make its own decision or invites its stakeholder community to participate in making the decision.
(pg. 7)
[*The attached chart from the report illustrates these dimensions.*]
Community participation does not necessarily mean achieving consensus. However it does involve seeking agreement and the best possible solution for the agency and the community.
(pg. 9)
Consultation is a complex process. Following is a list of issues that should be considered by agencies in developing a culture of effective community participation. [...]

- Public Service staff involved in community participation activities may need training and support [...]
- Research is required to identify stakeholders. [...] An otherwise well conducted consultation/participation process that has missed a key stakeholder can lead to a project suddenly stalled at the last moment or a protest registered with the agency or the Minister about the integrity of a finished project. [...]
- The amount of time and resources required for a consultation process has a direct relationship to the complexity, controversy and number of stakeholders and must be factored into the budgets and timelines of projects. [...]
- The process must recognize that not all members of the community will be able to participate to the same degree. [...]
- Consideration needs to be given to the advantages and disadvantages of the agency staff running the consultation process themselves. [...]
- Expectations must be managed. It is important that participants be aware of how much influence they can have on decisions that have been or will be made.
- The success of the participation exercise can be improved by ensuring that is conducted at the most appropriate time in the process of developing a new policy or developing/planning a service.

(pg. 12-13)
[*Note: This document contains an appendix which lists resources and models for conducting community participation processes, Australian commonwealth government and government resources from other state jurisdictions, engaging Queenslanders framework, Australian local government resources, UK government resources, other international resources, online consultation forums/e-democracy, articles and conference papers.*]

How Citizens can take part in Developing and Implementing Public Policy? Part 2
Curtain, Richard (Australian Public Policy Research Network)
June 5, 2003

Innovative ways of engaging citizens

Four essential elements of a proactive approach to consulting citizens:

- allow enough time for discussion so that people can form their own opinions with the issues involved
- provide comprehensive and balanced information well in advance of the discussion of an issue
- the citizen engagement process needs to be iterative (Characterized by or involving repetition, recurrence, reiteration, or repetitiousness); part of a deliberative process with the support of facilitators to set up and guide the discussion; methodology to identify priorities, propose solutions and suggest needed actions.
- the value of the citizen exchange needs to be confirmed by feedback about how the input provided has been used.

UK survey of local authorities - 4 forms of citizen participation:

- traditional forms: public meetings, consultation documents, committees, question and answer sessions
- customer-oriented feedback in the form of service satisfaction surveys, complaints/suggestions schemes
- participative methods: interactive websites, citizens' panels (sounding board focusing on specific service or policy issues or on wider strategy and/or feedback to assess the quality of local services and identify future needs and goals), focus groups (discuss a specific issue) and referenda
- active citizen deliberation: citizens' juries (small group of citizens to consider a particular issue with evidence from expert witnesses, opportunities to cross-question the experts, and the development of a report to set out the views of the jury, including differences in opinion), community plans/needs analysis, visioning exercises, issue forums (large-scale model (e.g., 100 people) to focus on particular issues, work in small groups with a facilitator to register responses on specific issues)

Process for developing public policy

- define the problem
- identify the criteria to be used in evaluating alternative solutions
- generate alternative solutions to the problem
- evaluate the alternative solutions based on the evaluation criteria
- recommend an option

different functions of citizen participation

discovery - refers to exploring the range of different aspects of a particular problem or issue, to identify a common definition of the problem, for agreement on the criteria or principles to be used to assess the relative merit of the proposed solutions

education - the task of providing an understanding of the issues; identify what information or research is needed to address the gaps

measurement - to show the state of public opinion regarding a set of options, seek input from a statistically representative group of citizens chosen at random

persuasion - persuade the public of a recommended option or approach

legitimation - applies particularly where there are high-conflict issues; used for gaining wider public acceptance of the final outcome

"Citizen engagement in developing and implementing policy is one way to reconcile competing values and perspective to produce a 'joined up' solution." (p.10)

Roundtable on the democratic deficit: Citizen engagement and consultation
Rapporteur's Report (Institute on Governance, Ottawa)
March 28, 2005
What does "citizen and engagement and consultation" mean? How can citizen engagement take a firmer place in our democratic system? These questions, central to the diagnosis of the challenges of improving democracy in Canada, formed the basis for the March 2005 roundtable discussion in Toronto led by the Institute on Governance [...]. Seventeen participants including academics, journalists, a federal public servants, an Ontario Deputy Minister, a pollster, several practitioners in private practice, a senior official from the City of Toronto, and experts from several non-profit to organizations, took part in [...].
A major focus of the discussion was the issue of citizen engagement. [...] Among the views expressed by different participants were:
- citizens are often not "engaged" because politicians are not talking about issues that matter to them and/or the way these issues are addressed seems predigested - there is no room for meaningful input
- governments and elected officials need to find ways to make sure citizens' voices are heard

[...]
- there is a need to enhance accountability [...]

[...]
- Public servants are key players in fostering civic engagement.

(pg. ii)
The whole world is not made up of mini-political scientists who care deeply about politics... Citizens are pulled in many different ways so it is no surprise that we fall short of the image of well-informed, news-watching, participatory public. We need to step away from that image of a civic textbook citizen and approach it from a different angle.
Yet citizens still want to know that there are opportunities to influence the way Canada is governed. This gives citizens comfort and legitimacy to government decisions. Moreover, there was general agreement around the table that while most citizens, most of time, are not actively engaged in politics, people *do* engage when they believe an issue is important and that they can make an impact. There is a lot of evidence of people coming together to tackle complex issues, to debate topics and offer input. [...]
Most participants said that a fundamental problem is that citizens do not see their participation as *consequential*. [...]
People feel disconnected because they are not being listened to, rather than because they are not being agreed with. [...]
Many participants said that people are not paying attention because politicians are not talking about issues that matter to them, or not doing it in a way that connects well to people's concerns. [...]

Participants also spoke of the responsibility that governments and elected officials have to find ways to make sure citizens voices are heard and reflected in the decisions that affect our lives. [...]
Participants agreed that while most citizens generally do not participate in the political system, they do engage when they believe their participation will be consequential and that the government can do things to connect with citizens' interests. [...]
Several said there is a need to ensure that the language of consultation is appropriate and to help people understand what highly technical and complex terms like "primary care reform" actually mean.
(pg. 4-6)
Another reason for the declining role for parties in citizen engagement has to do with changes in Canadians' values. Over the last decade or two, according to several participants, the values of Canadians have changed in terms of our priorities and what we want out of life. As one noted, a generation ago, we taught our kids about hard work and obedience. Four years ago, when asked Canadians gave a different answer: imagination and independence are most important. This reflects the reality that hierarchical institutions [...] play a far less important role in our lives. [...] Today's public servants are constantly balancing competing values -- the "new" professional values of innovation, initiative, creativity and service to clients, with the "traditional" values of effectiveness, probity, excellence, and fidelity to the public trust. [...]
Part of the reason for resistance to change is a prevalence of a risk-averse culture. Despite the efforts of many dedicated civil servants, large bureaucracies tend to rest on a command-and-control hierarchy -- a culture that resists openness, transparency and change.
(pg. 9-10)
The theme for the afternoon roundtable discussion was citizen engagement. [...]
Participants thought that citizen *consultation* tends to connote conventional, more limited methods of citizen participation, such as town hall meetings. Citizen *engagement*, however, is about the concept of *deliberation*: the thoughtful exchange of views and the resolution of different opinions, not only between government officials and the public but among members of the public themselves. Engagement includes the need to:

- ensure that different and varied voices are heard
- design processes and make use of expertise (such as trained facilitators) such that respectful discourse takes place, not confrontation
- provide information for citizens that is balanced, factual, and understandable
- expose citizens to different points of view on complex or contentious policy issues
- determine when and how to apply the power of information and communications technologies to extend the reach of engagement processes, without compromising its human dimensions
- use engagement exercises to address those kinds of issues where citizens' input is likely to be most valuable
- ensure that decision-makers are willing to treat engagement seriously and make use of its results. (pg. 11)

Process methodology: *Participation - Policy dialogue*

A code of good practice on policy dialogue
Voluntary Sector Initiative

The "Code of Good Practice on Policy Dialogue [...] is a tool for deepening the dialogue between the Government of Canada and the voluntary sector at the various stages of the public policy process in order to achieve better policies for Canadians." (pg. 2)

"Signed in December 2001, An Accord Between the Government of Canada and the Voluntary Sector [...] contain[ed] a number of commitments [...] related to policy dialogue:

- *The Government of Canada recognizes the need to engage the voluntary sector in open, informed and sustained dialogue in order that the sector may contribute its experience, expertise, knowledge, and ideas in developing better public policies and in the design and delivery of programs. It also recognizes and will consider the implications of its legislation, policies and programs on voluntary sector organizations including the importance of funding policies and practices for the further development of the relationship and the strengthening of the voluntary sector's capacity.*
- *The voluntary sector is committed to serving as a means for the voices and views of all parts of the voluntary sector to be represented to and heard by the Government of Canada, ensuring the full depth and diversity of the sector is reached and engaged.*
- *Both the voluntary sector and the Government of Canada recognize that sharing ideas, perspectives, and experiences contributes to better understanding, improved identification of priorities, and sound public policy, and agree that dialogue should be open, respectful, informed, sustained, and should welcome a range of viewpoints.*

In addition, the Code builds on the values of democracy, active citizenship, equality, diversity, inclusion and social justice, and the principles of independence, interdependence, dialogue, co-operation and collaboration and accounting to Canadians. [...] The Code also affirms the importance of a respectful, transparent and inclusive policy dialogue that acknowledges the independence and interdependence of both sectors." (pg. 2-3)

"Building on the Accord, this Code is based on the following shared principles:

The Voluntary Sector's Value

A healthy and active voluntary sector plays an important role in helping the federal government identify issues and achieve its public policy objectives. [...]

Mutual Respect

Both sectors will listen to and consider the views of all participants and respect their legitimacy and input.

Inclusiveness

[...] Increasingly, policy development must take into account of the specific needs, interests and experiences of the diversity of the voluntary sector including, for example, groups representing women, visible minorities, persons with disabilities, Aboriginal people, linguistic minorities, sexual orientation, remote, rural and northern communities and other hard-to-reach subsectors. Policies must also respect the *Canadian Charter of Rights and Freedoms*, the *Canadian Human Rights Act*, the *Employment Equity Act*, the *Official Languages Act*, the *Multiculturalism Act* and the United Nations *Universal Declaration of Human Rights*, as well as Canada's obligations as a signatory of relevant international treaties and conventions, for example, on the rights of children, women and indigenous peoples. [...]

Accessibility

Both sectors will take the appropriate measures to ensure that all those invited to participate in a dialogue have access to the process. [...]

Clarity
[...] both sectors will establish the terms of the policy dialogue in advance and communicate them to participants.
Transparency
To build trust, both sectors will establish open lines of communication, provide information readily and invest in working relationships. [...]
Responsibility
Both sectors will participate in good faith and recognize that adequate resources and time are required for an effective process.
Accountability
Both sectors will provide feedback to their respective constituencies on the full range of views expressed, and clearly communicate how this input has been considered in the public policy process." (pg. 6-7)
"The Stages of the Public Policy Process [...]
Issue Identification
Voluntary sector organizations can play a particularly valuable role in the identification of emerging policy concerns. [...]
Agenda-Setting
Issues come onto the public policy agenda from various sources, including: political platforms, research and analysis, academe, the private sector and voluntary sector organizations. Based on its in-depth knowledge and understanding of the emerging and important issues, the voluntary sector can bring key information to the development of public policy priorities. [...]
Policy Design
The voluntary sector can contribute its ideas, knowledge, expertise and experience to the various steps in public policy design, including research, analysis, drafting and testing models, and developing design options.
Implementation
The voluntary sector can play a role in proposing appropriate policy implementation approaches and mechanisms that reflect and enhance policy goals. [...]
Monitoring
[...]
Impact Assessment
[...] the voluntary sector can play a valuable role in assessing the impact of policy [...] and in making recommendations for change." (pg. 8-9)
"The Accord identifies six values that are most relevant to the relationship between the Government of Canada and the voluntary sector:

> Democracy - *upholding the right to associate freely, to express views freely and to engage in advocacy.*
> Active Citizenship - *welcoming the active involvement or engagement of individuals and communities in shaping society whether through political or voluntary activity or both.*
> Equality - *respecting the rights of Canadians under the* Canadian Charter of Rights and Freedoms *and the* Canadian Human Rights Act, *and the rights of individuals worldwide as defined by the United Nations* Universal Declaration of Human Rights.
> Diversity - *respecting the rich variety of cultures, languages, identities, interests, views, abilities, and communities in Canada.*

Inclusion - *welcoming the expression and representation of diversity and upholding the right of each to speak and be heard.*
Social Justice - *ensuring the full participation in the social, economic and political life of communities.*" (pg. 13 - 14)

Process methodology: *Consultation*

What Role for Citizens in Developing and Implementing Public Policy? Part 1
Curtain, Richard (Australian Public Policy Research Network)
June 5, 2003

Role of citizens in developing public policy

The OECD (Organisation for Economic Co-operation and Development http://www.oecd.org/ - Canada is a member; The OECD plays a prominent role in fostering good governance in the public service and in corporate activity. It helps governments to ensure the responsiveness of key economic areas with sectoral monitoring. By deciphering emerging issues and identifying policies that work, it helps policy-makers adopt strategic orientations.)- 3-stage model of gauging the nature and extent of citizen relations in policy making:

1. provision of information - both information on request (passive) (objective, complete, relevant, easy to find, easy to understand) and dissemination of information (active)
2. consultation - citizens provide feedback on specific issues based on the government's prior definition of the issue and government providing background information (e.g., *Consulting Canadians website - Canadian federal govt - The Consulting Canadians site has three key objectives:*
   1. To enhance public awareness of government consultation activities;
   2. To provide opportunities for Canadians to participate in government consultations, both online and off-line;
   3. To develop the government's capacity for engaging Canadians online and improve horizontal management of government consultations.
   http://www.consultingcanadians.gc.ca/cpcPubHome.jsp?lang=en)
3. active participation - based on a partnership relationship. role of citizens in proposing policy options and shaping the policy dialogue. "However, it is accepted that the final decision on policy or policy formulation rests with government." ... citizens actively engage in the policy process.

focus of the paper

more public into policy analysis:
organised interests - clear role but definite limits for range of suitable policy options.
3 perspectives of citizens as individuals: perspective of the taxpayer; expectations about the quality of service; members of a community, local and national.
Citizens - better educated, more diverse, less deferential than any previous generation.
"The concept of a 'democratic deficit' has been proposed to highlight the declining levels of citizen trust in political institutions." To overcome this, "governments have to demonstrate that they are open to citizen input and are responsive to their concerns."

How to make consultation work better

- a legal requirement for governments to consult those affected
- clear objectives for citizen input and utilization of input

- clarify how the results of the consultation will be used
- "clear feedback loop from the policy makers about their reasons for adopting a particular option and how the points raised by the consultation process were addressed"

citizen engagement in policy development

- use of citizens with professional expertise and experience
- providing local knowledge about what is likely to work or not
- gain citizen commitment to accept the outcome of the policy development process
- opportunity for the careful working through of complex information to deliver viable options and to gain agreement of the community to support one of the options.
- ownership of the local community of the final outcomes
- The "stage of citizen engagement requires a reciprocal process where the local community learns from experts about the results of their modelling of the different options and the experts learn from the local residents about the local factors they may have not considered."

WHY?:

- initial discovery process to do with a search for definitions or to identify the underlying principles
- education role
- to measure the range of public opinion about a set of options.
- to persuade the public to accept the recommended option.
- the intention of legitimizing a decision already taken.

Public Consultation Guide: Changing the Relationship between Government and Canadians
Sterne, Peter (Canadian Centre for Management Development)
May, 1997

As the Public Policy Forum observed in a 1994 publication, " process does not automatically guarantee sound public policy. But we know from experience that poor process rarely gives good policy."

This guide contains a good deal of excellent material and experience called from others. It is not an academic treatise; it is meant to be practical. The approach to content was inclusive, rather than exclusive. Readers will be able to select what they want to focus on, according to their needs. Some readers may use it from the beginning to end in a public consultation process. Others may refer to it at various stages of consultation initiatives.

(pg. v)

The International Association for Public participation sees consultation as

- a process and a result
- an exchange of information, discussion and decision making
- an investment of time, energy and resources
- a tool for achieving an end
- a recognition of the legitimacy of public concerns and input
- an understanding that public participation results in greater effectiveness and legitimacy in decision making
- a recognition of the values and cultures of others
- an act of sharing power
- an opportunity for innovation, creativity, improved service and conflict resolution

- a consensus-seeking process
- an act of relationship building
- a learning experience.

(pg. 5)

Public consultation is a strategy designed to involve the general public and thereby generate trust. A well-designed public consultation program insures that the public feels listened to. Even unpopular decisions, such as new taxes, can be accepted by the public if the consultation process is perceived as having integrity.

(pg. 8)

More appropriate measures of success involve assessments of whether

- the interests of all parties have been served
- expectations concerning the process have been met
- consensus, consent and commitment have emerged
- the process has encouraged generation of the best possible options
- objective criteria have been used to assess the different options under consideration
- understanding has been enhanced
- the relationship has been enhanced
- the decisions resulting from consultation have been stable and enduring

[...] consultation processes tend work better with

- a coordinated effort and synergy throughout a department, across departments and between governments
- trained and skilled practitioners, both in managing and in participating in consultations with a level of authority appropriate to their role
- participants and leaders who enjoy working with people, who are comfortable with dialogue, discussion, debate and disagreement, and who can manage conflict and differences
- an informed, organized and empowered team to match the capabilities of stakeholders (including the use of facilitators or key experts)
- an adequate investment of time and resources to make the consultation productive, including financial assistance for participants with a vital interest in the issue but lacking the resources to join the process
- effective management of information in relation to the consultation initiative (from the preconsultation meeting to follow-up), internal decision makers and the need for practitioners to access the corporate memory (lessons learned)
- particular attention to logistics (location, room set-up) and scheduling (when and to whom to send invitations, how participants may provide input, time of day).

(pg. 15-16)

The four models or frameworks for public consultation [...] help in understanding what consultation is all about. Each has a somewhat different slant or approach, and each will be useful at different stages in the consultation initiative, depending on the perspective of the principals involved, whether they are decision makers, managers or teams, citizens, or stakeholders.

[Note: These models will not be presented here. Extensive details are provided on the Roadmap Model. However the total report can be made available for anybody who wishes additional information.]

(pg. 17)

Recommended Practices: Governance models

Strategy, capacity and horizontal governance: Perspectives from Australia and Canada
Lindquist, Evert (Optimum Online: The Journal of Public Sector Management, www.optimumonline.ca)
Dec., 2004

There has been an explosion of academic and professional literature on horizontal management and whole-of-government perspectives on public sector governance. It reflects growing awareness of the complexity of policy and management problems, the many kinds of expertise and governance tools that need to be brought to bear on them, the demands of citizen and other groups for coordinated policy development and service delivery, the interest in discerning overall outcomes of government interventions, and recognition of the extent to which public servants at all levels work across traditional boundaries to meet these demands. [...]

This paper attempts to further thinking about strategic dimensions of horizontal governance at the system level. The points of departure are two recently published reports, Connecting Government from the Management Advisory Committee of the Australian Public Service and The Horizontal Challenge from the Canada School of Public Service. Each study identifies ways to improve the management of specific horizontal initiatives, and each broaches the matter of how the system might handle them in aggregate on a rolling basis. This paper suggests that a crucial consideration concerns how the centre allocates its attention and whether and how it builds distinct capacity to ensure horizontal initiatives are nurtured, designed, navigated for decision, implemented, and assessed. [...]

Reports on horizontal issues are often animated by one big question, like "Are we doing policy well?" or "Are we providing seamless service delivery to citizens?" or "Do we have accountability right?" [...]

Beyond calls to improve culture and provide new administrative tools, it has been understood that "the centre" can have a critical role to play in furthering horizontal initiatives. There have been several suggestions about how to improve the capacity of the centre, particularly with respect to horizontal initiatives. However, little thought has been given to how the proposed capabilities differ from each other, and how such units might be constructed. In what follows, I review the literature and capabilities in Ottawa to show that there are many distinct capabilities for horizontal management. [...]

However, three Canadian case studies of comprehensive policy initiatives (what we would now term "horizontal") for the National Energy Program, the National AIDS Strategy, and the Green Plan show how policy and coordinating capacity can be created. Each case reviewed initial attempts by departments to respond to government intentions, how they initially failed to meet expectations, and how governments installed new coordinating capabilities, which we described as "temporary administrative adhocracies". The adroit leaders and senior staff of these adhocracies knew how to (1) tap into, but rise above, the technical and professional expertise in their departments, to design complex policy initiatives; (2) draw on the expertise of other departments and deal with outside actors; (3) draw diverse expertise and information into a coherent and politically sensitive policy plan; and (4) deal with and manage the central agencies and cabinet. Moreover, in two cases, parallel coordinating committees were created to concert with central agencies and navigate cabinet decision-making processes. [...]

When thinking about the institutional arrangements to buttress horizontal initiatives, ministers and deputy ministers typically prefer to avoid major structural change to the machinery of government. They seek to avoid the dislocation associated with the restructuring of the Canadian public service in 1993, or particular portfolios and departments. The literature essentially argues that (1) political and administrative leaders do not have time to initiate projects and cope with the upheavals associated with significant restructuring; (2) designs for significant restructuring are premised on priority horizontal issues at points in time and certain levels of analysis, and may not adequately address the needs of other horizontal issues or ones yet to emerge; and (3) the benefits of large-scale restructuring may not be as clear as the costs. These instincts and logic can be found in other jurisdictions, but they fail to account for the cumulative impacts of "soft" and "hard" change flowing from horizontal initiatives.
While horizontal strategies are often depicted as avoiding restructuring, they often involve what I term "soft change" that may include inculcating new perceptions and expectations in staff, new styles of policy-making, innovative approaches to service delivery, and new patterns of coordination, interaction, and oversight. The effects of such soft – or supposedly non-structural – change can accrete over time, and may lead to different styles, patterns, and structures in governance. Indeed, an important question is whether we can adequately describe what emerges as a result of horizontal initiatives across government, which is a subset of the broader challenge of conveying emergent, evolutionary, and often experimental change in public service institutions in a coherent manner to ministers, citizens, and the public service.
Moreover, a short-term focus on horizontal strategies may ignore their impact on longer-term structural decisions. Consider the Whole of Government Indigenous Trials of the Council of Australian Governments: pilot projects seeking to improve on-the-ground delivery and coordination across levels of government in collaboration with Aboriginal communities. The trials led not only to new ways of working, but eventually to significant machinery change when the Commonwealth government later dissolved the Aboriginal and Torres Island Strait Commission. Such ultimate outcomes – along with creating new coordinating adhocracies, secretariats, or other structures when launching horizontal initiatives – can be considered "hard change". [...]
(pg. 1-13 (print copy format))

An evaluation of the sectoral involvement in departmental policy development (SIDPD) (Final Evaluation Report)
Audit and Evaluation Directorate, Stategic Direction, Social Development Canada
March, 2004
The Sectoral Involvement in Departmental Policy Development (SIDPD) is a five year $28.5 million program aimed at creating a closer policy development relationship between the federal government and the voluntary sector. The purpose of the SIDPD was: a) to enhance policy development in departments by strengthening opportunities for input by voluntary sector organizations; and b) to strengthen policy capacity within the voluntary sector to contribute to departmental policy development.
(pg. Preface)
Horizontal Management
As society becomes more complex -- more multicultural, more mobile, more diverse in the number of ways -- resulting social issues and problems require more thoughtful insights. The

joint contribution of multiple federal departments, agencies and Crown corporations; other levels of government; and non-governmental organizations must come together to share responsibility for the solutions. Managing a horizontal initiative involves entering into an arrangement with partners where there is shared authority and responsibility among partners; joint investment resources (such as time, funding, expertise); shared risks among partners; mutual benefits; and common results. Indeed the ability to build alliances, form partnerships and effectively manage *horizontal* initiatives is in many cases key to delivering high-quality, cost-effective services to Canadians. In light of these benefits, significant efforts have been undertaken to improve the management of horizontal initiatives.
(pg. 9)
Lessons Learned

- Governance and Accountability Mechanisms - Complex horizontal initiatives require governance frameworks and clear lines of accountability. The time has to be taken to develop mechanisms including [...] the co-ordination aspects essential for creating shared accountability. In addition, an understanding must prevail amongst all parties that adjustments to those mechanisms will be required over time. Without such shared understanding, good will deteriorates and [...] significant success in past relationship building is debased. Lastly, it must be noted that large-scale, high-profile, horizontal initiatives that involve program management should be managed by departments and staff with significant program management expertise.

[...]

- Program Design - Good program designed backed up by analysis is essential to ensure that measurable objectives and intended outcomes are developed. [...]
- Government Commitment to Change - The use of a broad definition of policy development in terms of the engagement of the voluntary sector in the development of federal departmental policy was an important success factor for many projects. Yet, many federal departments continue to equate voluntary sector 'consultation' with 'collaboration'. They held the view that it was a process that relies on the status quo whereby the federal departments define and develop the policy issues of concern, and then invite voluntary sector representatives to comment. While there is no question that consultation forms one aspect of 'collaboration', clearly the development of collaborative working relationships in SIDPD projects that acknowledged and took into account differences in resources and power were more successful. These projects, which tapped into the knowledge within the voluntary sector, which in turn was used on behalf of both sectors by the federal government, appeared to be more sustainable.
- Good Project Management - Successful projects had several similar characteristics including project management that started with a management committee comprised of all relevant partners that met early and often. They also developed a project plan that identified roles and responsibilities, had consistent, open dialogue and leadership from both the federal and voluntary sector partners. Characteristically, they involved the major partners through the life of the project from issue and or priority identification through implementation, evaluation and follow-up.

[...]

- Monitoring and Evaluation - Adequate staff resources should have been available to regularly monitor project progress, or at least to identify potential content and administrative problems in advance. [...]

- Horizontality and Collaboration - [...] Partnership arrangements within the federal government are a promising step, but additional mechanisms are needed to facilitate and encourage such arrangements. Streamlined funding formulas, common reporting formats, clear lines of accountability and dedicated resources (including staff) are required if horizontality is to be taken seriously by senior managers.

(pg. 50-51)

Recommended Practices: Accountability

Performance measurement and management in the public sector
Thomas, P.G. (Optimum Online: The Journal of Public Sector Management)
www.optimumonline.ca/print.phtml?id=225
July, 2005

In government, performance is usually thought of as progress toward goals and objectives, but measurement is complicated by the fact that the outcomes being sought are often multiple, vague, shifting, and even conflicting; this reflects the fact that they emerge out of the wider political process of competitive political parties and public debate. In a diverse country like Canada, individuals, groups, and regions will often disagree strongly over what constitutes good performance. Also, government performance is more subject than corporate performance to continuous, usually critical, scrutiny by opposition parties, interest groups and the media. So for governments, appearances matter almost as much, or more than, the reality of performance. For public managers who operate programs, part of the performance equation is no surprises and keeping the ministers they serve out of political trouble. Maintaining legitimacy and support for the policies and programs of government is also a legitimate performance goal.

[...]

Measuring and reporting on performance is a necessary, but not sufficient, requirement for improving performance and for assuring the public that they are receiving value for money from public programs and public organizations. A related, but somewhat different activity, "performance management," is meant to build upon measurement by using performance information in conjunction with strategic planning, budgeting, policy/program evaluations, organizational reviews, and performance appraisals for managers. In this way, performance measurement potentially becomes central to the processes of direction setting, control, quality assurance, accountability, improvement and learning within the public sector.

[...]

There is a growing commitment by politicians at all levels of government to the idea of regular and meaningful reporting on performance, both for internal management purposes and for accountability to the public. [...] Demonstrating the linkages between inputs, outputs and outcomes remains a significant challenge in many areas (especially where horizontal policy and program initiatives are involved), but even here governments have made headway with techniques like service effort and accomplishment (SEA) reporting, data envelopment analysis (DEA) and results chains.

[...]

Canada is one of the few countries in the world to combine departmental business-line reporting (DPR) with a whole-of-government, social indicators approach.

[...]

In government, of course, the goals are multiple, vague, contentious and shifting. Lack of knowledge, multiple uncertainties and various kinds of risk are involved with the pursuit of such goals. Rather than being stable and relatively predictable, the governmental system changes direction and content in response to election outcomes and shifts in public opinion, often reflecting short-term, high profile events.

Measures are generally considered "good" if they are tangible, valid, reliable, understandable, comparable, timely and economical. At the highest levels of decision making within government, few measures meet these criteria, and intuitive decision-making predominates. Intuitive decision-making occurs when facts are limited or in dispute, when values and interests are in conflict, when future consequences of action are uncertain, when there are several plausible alternatives, and when time is limited. Cabinet ministers and senior public servants operating in the intuitive mode are not likely to draw upon "hard" measures, preferring to rely on "softer" forms of knowledge.
[...]
Despite analytical advances, it remains difficult to attribute societal outcomes to government interventions, especially when more than one program or level of government is involved. Lack of agreement on what qualifies as "success" leads to a lack of clear standards to judge performance. [...] Aggregation of data necessary to avoid information overload, leads to the loss of information and the contextual knowledge needed to support fully informed decision-making. Finally, providing complete, meaningful and actionable information to the right people in the right format, at the right time represents both an analytical and practical challenge.
[...]
Another consequence of pragmatism is to measure what is measurable about performance rather than what is truly important, such as the quality of services and the progress achieved within society.
[...]
In the future, less emphasis should be placed on reporting data and more should be placed on allowing program managers to tell "the performance story." [...]
For the future, we should see PMM [Performance Measurement/Management] as less about sophisticated conceptualization and precise analysis and more about interaction and seeking a consensus on what should be measured, how and with what consequences. The process should be less top-down and bureaucratic. It should involve consultation with the key stakeholders and the public at large, so that the results of the PMM system have more legitimacy and support, especially among the people most directly affected by programs.
(pg. 1-7)

Recommended Practices: Good public policy making

Good Public Policy Making: How Australia Fares
Curtain, Richard (Agenda: a Journal of Policy Analysis and Reform, 8(1), pg. 33-46
2000
Elements of good public policy

"There is an emerging consensus in the UK, Canada, US and New Zealand that the reforms [undertaken in the last decade] have been mostly about internal restructuring to the detriment of good public policy making." (Curtain, 2000)
"The opposite of good policy is an *ad hoc* or short-term policy response to an immediate problem. Poor policy making often results from unintended consequences that a piecemeal approach has not taken into account." (Curtain, 2000)
"public policy has to be effective (achieve its goals) and efficient (do so in a way that achieves the greatest possible benefits at the least possible cost). Goal setting in public policy needs to be long-term in perspective."
"starting with a comprehensive understanding of the current environment"
"defining what society's needs are in a way that an appropriate policy response can address."
"developing likely 'futures' scenarios in which a proposed policy might need to operate."
"attention to process"
"includes giving the end users ample opportunity to participate in a variety of ways"
minimize independent operation of departments
"ensure that the policy has a strategic focus in terms of becoming more forward- and outward-looking"
"identifying carefully how the policy will deliver desired changes in the real world"
"take full account of the needs and experience of all those likely to be affected"
"involving those outside government in policy making" includes target recipients, outside experts, program deliverers (i.e., " those who are to implement the policy")
"careful appraisal of the benefits any measure seeks to achieve, the costs it entails and the cumulative burden of regulation on those responsible for implementing the policy." (assessment of the risks and costs)
"improve the way risk is assessed, managed and communicated to the wider community."
"based on learning from experience"
"a continuous, learning process"
"making use of evidence and research about the problems being addressed"
"making more use of pilot schemes to encourage innovation and to test whether proposed options work."
"clearly specifying and evaluating independently the objectives of all policies and programmes and making public the lessons of success and failure and acting upon them"
"obtaining feedback from those who implement and deliver policies and services"
"consulting ordinary citizens" - public surveys, 'deliberative polling' - random sampled, public small group discussions regarding complex public policy issues; 'deliberative dialogue' - structured face-to-face small group public interaction at a community level over an extended time
"fostering alternative sources of policy advice" - problem with government bureaucracies being "most conservative about new ideas because they have the most emotional capital tied up in defending past policy actions". - "independently funded public policy think tanks"; "provide 'venture capital' for new policy initiatives"; e.g., Research Council
Modern Policy-Making: Ensuring Policies Deliver Value for Money
U.K. National Audit Office 23 October 2001
What is policy?
Policy is the translation of government's political priorities and principles into programmes and courses of action to deliver desired changes.

Policy-making is becoming more complex

- Citizens are better informed and have rising demands and expectations for services that meet their individual needs, for example, 24 hour access to advice about health.
- Policy issues can often switch rapidly from the domestic to the international arena, for example, the impact of the Bovine Spongiform Encephalopathy crisis on the international market for British beef.
- Solutions that work across organisational boundaries are often required, for example, in tackling the drugs problem or social exclusion.
- Events often require a swift response, for example, the fuel shortage of September 2000.
- Increasingly diverse interests need to be co-ordinated and addressed, for example, in tackling environmental problems.
- There is increasing pressure to design and implement policies that bring about desired changes for citizens, for example, a healthier population or a better skilled and more competitive workforce.

Source: National Audit Office and Cabinet Office

Identifying the need for a policy requires:

1. Forward looking thinking.
2. Reliable and comprehensive information.
3. Consideration of a range of scenarios.
4. Assessing the interconnection between sometimes competing policy needs.
5. Being able to respond quickly to unforeseen events.
6. Having early warning indicators.
7. Drawing on existing knowledge and experience.
8. Consulting stakeholders.
9. Understanding the needs of the client group.

Typical problems during implementation include:

1. Overambitious time scales;
2. Those implementing the policy not having the appropriate skills or training;
3. Poor project management;
4. Inadequate contingency planning; and
5. Roles and responsibilities not being clearly defined.

Examples of the types of analyses which can improve policy-making:
Modelling to predict likely outcomes in different circumstances.

1. Organizational mapping which sets out in a diagrammatic form the formal and informal relationships between and within organizations. It is particularly important in establishing the various responsibilities in partnerships and other forms of joint service delivery.
2. Logic models to map out the various interventions and their interrelationships, required to deliver a policy.
3. Cost-benefit and effectiveness analysis to estimate the costs (direct and indirect) and expected benefits from policy outcomes to determine whether the policy is likely to deliver value for money.

4. Longitudinal analyses traces the life histories of projects and programmes across time, often for many years for example, the impact of measures to reduce juvenile crime. Such analysis can help establish the causal links between inputs and policy outcomes and learn lessons for future policy development.
5. Comparative analysis drawing on relevant experience and good practice in other countries tackling similar policy issues.
6. Multi-criteria analysis to take explicit account of multiple, conflicting criteria in the process of informing decision-making.
7. Social research ranging from analyses of consultation on public policy through to surveys of public opinion.

Key characteristics which Departments should demonstrate to achieve professional policy-making

Forward Looking:
Scenario planning is testing policy options against possible futures based on how current trends could lead to different outcomes.
Futures thinking looks beyond what is happening now to think about what should come next in an innovative way.
Contingency planning is having arrangements in place to ensure that declared policy is delivered and to minimise the impact of something going wrong or the unexpected happening as the policy is implemented.
Outward looking:
Benchmarking promotes improvement by learning from others and identifying where change is needed to modernise the policy-making process.
Building in communication strategies helps the management of change in the real world go smoothly by:

- planning stakeholders into the policy process from the outset;
- basing policy on awareness of the political and wider context;
- targeting different audiences using a range of media; and
- involving all those affected by policy presentation - including deliverers and implementers.

Innovative and creative
Regulatory impact assessments add transparency to the process of assessing impacts of policies on citizens, business and charitable organisations.
Project management provides a mechanism for ensuring that communication and stakeholder analysis become an integral part of the policy process.
Identification, assessment and management of risk help to provide an environment in which innovative and creative ideas can emerge and be tested, and to inform policy decisions.
Encouragement of new and creative ideas is 'thinking outside the box' through brainstorming sessions and bringing people into the policy team from outside.
Experimentation with different options through pilots and trials as part of policy development and implementation allows lessons to be learned, and variation and flexibility to be introduced into policies where appropriate.
Examining evidence to understanding the problem, including why previous policy solutions failed.

Using evidence

Drawing on quality information from a variety of sources helps to establish 'what works' and to identify optimum opportunities for intervention. To be effective, information needs to be provided and/or interpreted by experts in the field working closely with policy-makers.

Stakeholder analysis helps policy-makers to ensure that they have identified and thought about the role of all those groups and interests affected by the policy.

Cost-benefit analysis helps to consider a range of properly costed and appraised options.

Economic modelling can bring robustness to an understanding of how a policy might play out in the real world and what factors and behaviours might influence the policy.

Developing an 'intelligent customer' capability to improve policy-makers' ability to access evidence-based advice swiftly and to use approaches such as interim findings, qualitative work and omnibus surveys to inform policy development early.

Identifying research priorities helps make the best use of research to deliver policy objectives and to formulate strategy for the long-term.

Development of a 'policy researcher' role to improve specialism in evidence gathering to ensure that expertise and familiarity with use of evidence is extended to the policy area.

Interviews and surveys of front line staff delivering and implementing policy to find out about the policy situation and why previous initiatives have failed.

Inclusive:

Impact assessments can examine the effect of policies on different groups who are affected by the policy.

Consultation can enable policy-makers to see a proposed policy's operation from the point of view of the implementers, those who would be at the receiving end or otherwise affected by the policy, thus reducing the likelihood of unintended consequences.

Stakeholder analysis can identify those who might be affected by the policy and at whom the policy is directed.

It can also help to identify those who might be able to promote or deliver a policy or part of a policy.

Feedback on the operation of policy from those at the receiving end and from front line deliverers enables corrections to be made so that the policy reaches those intended.

Joined up:

Strategies to overcoming barriers to effective joined up working can help organise the policy around user needs rather than institutional convenience, for example through joint working groups or other clearly defined and understood arrangements.

Building in implementation as part of the policy-making process through close collaboration with operational staff improves the chances of a policy being implemented as intended.

Secondments into policy teams and drawing on outside sources of expertise help to bring understanding and wider experience to a policy problem.

Job shadowing of operational staff by policy-makers has the potential to improve enormously policy-makers understanding of the organisational and wider context their policies will play in.

Peer review helps provide

- a greater sense of corporacy for the civil service by enhancing cross departmental understanding of issues and problems to foster a stronger sense of endeavour to achieve shared goals;
- better understanding of others in the organisation;

- an opportunity to learn from peers and share relevant experiences.

Evaluates

Specifying precise outcomes, products and milestones early on helps policy-makers to build systematic evaluation of effectiveness into the policy-making process from the outset, to find out from experience what works and what does not and enabling others to learn from it too.

Evaluation of new policies and regular review of existing policies is the principal mechanism for learning lessons and helps to improve the design and delivery of current and future policies, as well as helping to find out what works. Its objective is to provide useful information and reduce uncertainty, though it cannot replace judgement in decision making.

Project management which makes policy-makers specify outcomes from the outset can help departments to integrate evaluation into the policy-making process, and enable the impacts of greater innovation or risk taking in policy-making to be assessed.

Building intelligent customer capability to commission, plan and determine evaluation and research priorities helps to determine how a policy should be evaluated against its objectives and helps to improve the supply of evaluation by encouraging development and management of evaluation resources.

Peer review can help raise standards in evaluation by giving departments the opportunity to learn from each other how to improve their own systems and approach to evaluating policies and programmes.

Setting up feedback loops to allow policy deliverers to inform policy-makers in departments about how policy is received and works in practice over time.

Use of early warning mechanisms so that policy-makers have up to date information about changes in circumstances that may affect the outcomes the policy is designed to deliver.

Reviews

Performance measurement helps identify whether a policy is performing as expected and whether modifications need to be made.

Feedback mechanisms help monitor the progress of the work to keep the policy process on track.

Learn lessons

Knowledge pooling and management can improve the accessibility and user friendliness of research evidence and encourage sharing of information about new policy objectives, relevant research and consultations, the results of impact assessments and other evaluation material to inform future policy-making.

Capturing institutional memory can help build a historic record of success and failure over time across government departments and enable lessons from implementation and previous research and analysis to be drawn on to prevent the repeat of costly policy failures or reinvention of the wheel.

Other

Social Capital Think Tank: A case study of evidence-based public policy development
Falk, Ian
Feb. 20, 2002

"Policy is characterised ... by reciprocity between those affected by the policy, and those who need to develop and implement it. That Policy may entail:

- Clarification of public values and intentions;
- Commitments of money and services;
- Granting of rights and entitlements." (p.8)

"The 'new way'for policy development and implementation, however, is characterised by sectoral collaboration in the *development* as well as in the *implementation* processes; input and evidence from stakeholder groups is called for in order to justify why certain policy developments are taken; cross-sectoral flexible and responsive policy advice mechanisms are put in place; a great reliance is placed on evidence; continuous evaluation procedures are conducted from the outset; frequent whole-of-government policy processes involving the cooperation of two or more departments; and there is a devolution of accountability for policy outcomes 'down the line'. Accountability in new policy terms is not simply in terms of treasury, but to the people for whom it is intended, and the policy processes and outcomes are accounted for by reference to evidence." (p.11)

Making statistics more meaningful for policy research and program evaluation
May, H. (American Journal of Evaluation, 25(4), pp. 525-540)
2004
The best policy and evaluation research exhibits accommodation of expert analytic skills and well-developed communication skills. [...] Explaining the results of statistical models in a manner that is understandable and acceptable to multiple audiences can be a difficult task. [...] Results ultimately must be interpretable at a level that requires no knowledge of the statistical techniques used. Clearly, the method of analysis is only a means to an end. Statistics are simply tools for addressing a research problem or question, and policy and evaluation research questions are customarily phrased in plain language [...]
The purpose of this article is to illustrate several techniques for making statistics more interactive and meaningful in the context of policy and evaluation research and to identify general themes common among these methods that can serve as guidelines for other analyses [...]
The first guideline essential to making statistics meaningful is to improve the understandability of results. [...] Researchers in the policy and evaluation arena should recognize that public policy is heavily influenced by public knowledge and opinion. If we ignore the general public as potential consumers of research, we are drastically limiting the ability of our research to inform public policy and promote effective programs. Furthermore, it is crucial to recognize that making statistics understandable does not imply "dumbing-down" the level of information. It simply means that statistical jargon is reduced or eliminated, and inferences are explained. [...] With creativity, the policy researcher can make a few small changes to the presentation to get comparability (an example is presented later), while limiting the use of statistical jargon and making minimal assumptions about the audience's statistical knowledge.
(pg. 526-528)
Descriptive statistics used to describe some aspect of the statistical distributions of policy relevant variables. Percents, proportions, averages, ratios, and many other statistics are commonly used to describe or gauge problems. These metrics are familiar to many audiences due to their common use in political surveys, weather forecasts, and other areas. These simple

statistics are popular in policy and evaluation research for relating basic information and making elementary comparisons. Other descriptive statistics such as variance or skewness, which convey very important information, are not widely understood.
(pg. 530)
By far, the most widely used class of methods that produce relational statistics is linear modeling. Examples of popular linear models are analysis of variance (ANOVA) and its varieties, correlation, regression analysis, path models, and hierarchical linear models (HLM). [...]
Most analytic approaches will produce a variety of statistics which can be used to represent effect size. Correlations or coefficients of determination are often more popular in non-experimental studies because they quantify the strength of relationships that exist among two or more variables of interest. Treatment parameters from ANOVA or slope coefficients from regression analysis are often preferred in experimental or quasi-experimental studies because of their straightforward representation of size and direction of treatment effects. While any of these estimates could be used in policy or evaluation research to convey the size of the net effect, they may not be sufficiently meaningful to non-technical audiences.
(pg. 532)
The examples presented here by no means exhaust the possible alternatives for presenting statistical information in policy research. However, they do illustrate some general approaches to making statistics meaningful.
(pg. 539)

There is a vertical fiscal imbalance: Breau's sophistry
Paquet, G. (Optimum Online: The Journal of Public Sector Management)
http://www.optimumonline.ca/print.phtml?id=228
July, 2005
Any unilateral action of one level of government impacts on the tax receipts of other levels of government if the additional fiscal pressure generated by a new tax initiative at one level triggers more tax avoidance or evasion *in toto*. A government that would increase taxes without taking into account what is already imposed on the citizenry by other levels of government may, indeed, generate an erosion of the tax base for everyone and trigger a drop in tax receipts for all levels of government. So one can meaningfully talk about a "sharing" of the potential tax pool.
[...]
[It] also defines all federal transfers not as ad hoc ways to deal with vertical fiscal imbalance but, simply and exclusively, as an instrument designed to remove "horizontal" inequalities among the provincial fiscal capabilities. Through that sleight of hand, any inequality or lack of uniformity (observed or perceived) across jurisdictions may legitimately trigger federal intrusion in the name of "egalitarianism." The recipient must then render account (directly or indirectly) to the federal government for these expenditures since it is the level of government that raised the money. This is tantamount to legitimizing any intervention by the federal government in any field of provincial or local jurisdiction in the name of "egalitarianism" or "uniformity" and thereby to providing a license for making it "federal."
[...]
Federalism was designed to ensure a division of labour among levels of government based on the dual principles of (1) efficiency and (2) decision making as close as possible to the citizen. Indeed, the existence of multi-level governance provides an opportunity for higher-level decision

making only if the lower-level processes prove incapable of handling these responsibilities efficiently.
(pg. 2-3)

Additional Sources

A Fresh Approach to Policy Research
Curtain, Richard (Canberra Bulletin of Public Administration, 98, 50-52)
Dec., 2000
[This article provides a brief history and overview of Canada's policy research initiative. "The PRI has been highly successful in promoting what it calls 'horizontal' policy research capacity. It has done this by bringing together federal and provincial Public Service departments, university-based policy research centers and think tanks in government and other non government groups. (policyresearch.gc.ca)]

A multiple account framework for cost-benefit analysis
Campbell, H.F., Brown, R.P.C., (Evaluation and Program Planning, 28, 23-32)
2005
Cost-benefit analysis (CBA) has been accepted as an appropriate tool for appraising proposed public projects since the middle of last century. [...]
CBA was originally conceived to apply to projects undertaken by the public sector. It was seen as the public sector equivalent to the discounted cash flow analysis which would normally be applied to a private sector project proposal. [...]
The purpose of this paper is to describe a multiple account, spreadsheet-based framework for CBA of public projects incorporating a private interest, or private projects incorporating a public interest.
(pg. 23-24)

A new social architecture
Maxwell, J. (Canadian Policy Research Networks, Ottawa, ON)
May 9, 2005

Assuring the quality of evaluative information: theory and practice
Schwartz, R., Mayne, J. (Evaluation and Program Planning, 28, 1-14)
2005
There is now a plethora of evaluation information available to public sector managers, senior government officials, legislators and the public at large. Evaluation, performance reporting and performance auditing provide considerable amounts of evaluative information about government activities. While evaluative information has become widely available, relatively less attention has been paid to issues of quality including reliability, validity, credibility, legitimacy, functionality, timeliness and relevance. Yet evaluative information that lacks these characteristics stands little chance of legitimately enhancing performance, accountability and democratic governance. [...]

The article explores how various national and international organizations ensure the quality of evaluative information. The purpose is to describe and compare quality assurance approaches for evaluative information.
(pg. 1)

Building a Creative Community
Hay, D. (Canadian Policy Research Networks, Ottawa, ON)
Feb. 26, 2005

Connecting People to Policy: A National Initiative to Build the Capacity of the Disability Community to Participate in and Contribute to the Policy Process
John Lord, Project Evaluator
March, 2003
This is an overview of the evaluation process entitled, a framework for evaluating what is learned and what is achieved.

Horizontal management of disability issues
Muir, C. (Office of Disability Issues, Canada, http://www.tbs-sct.gc.ca/rma/eppi-ibdrp/hrs-ceh/13/HMDI-DCPH_e.asp)
April 8, 2005

Policy Research Initiative
http://policyresearch.gc.ca/page.asp?pagenm=root&langcd=E
02/12/2005
[The Policy Research Initiative conducts research in support of the Government of Canada's medium term agenda. Its core mandate is to advance research on emerging horizontal issues, and to ensure the effective transfer of acquired knowledge to policy-makers.]

Internet resources (links)

Articles by Michael Kendrick
http://www.socialrolevalorization.com/resource/MK_Articles/content.html

BoardSource: helping build strong and effective nonprofit boards
http://www.boardsource.org/

Building Community
http://www.syrculturalworkers.com/catalog/catalogIndex/CatBuildingCommunity.html

Caledon Institute of Social Policy
http://www.caledoninst.org/

Canadian Centre on Disability Studies (CCDS)
http://www.disabilitystudies.ca/

Canadian Council on Social Development
http://www.ccsd.ca/home.htm

Canadian Policy Library
http://www.policylibrary.com/canada/

Canadian Social Research Links
http://www.canadiansocialresearch.net/index.htm

Centre for Evidence-Based Social Services
http://www.cebss.org/
http://www.ripfa.org.uk/aboutus/archive/

Center for International Rehabilitation Research Information and Exchange
http://cirrie.buffalo.edu/

Center for Quality Assessment & Improvement in Mental Health (National Inventory of Mental Health Quality Measures)
http://www.cqaimh.org/quality.html

Center for the Study and Advancement of Disability Policy (CSADP)
http://www.disabilitypolicycenter.org/

Consulting With Canadians
http://www.consultingcanadians.gc.ca/cpcPubHome.jsp?lang=en

Council of Canadians with Disabilities
http://www.ccdonline.ca/index-new.htm

Eurofound: European Foundation for the Improvement of Living and Working Conditions
http://www.eurofound.eu.int/

Funding Matters: The Impact of Canada's New Funding Regime on Nonprofit and Voluntary Organizations
http://www.ccsd.ca/pubs/2003/fm/

Institute for Research on Public Policy (IRPP)
http://www.irpp.org/indexe.htm

Institute of Intergovernmental Relations at Queen's University
http://www.iigr.ca/iigr.php/

Institute on Community Integration
http://ici.umn.edu/

International Association for Public Participation
http://www.iap2.org/

Human Services Research Institute (HSRI)
http://www.hsri.org/index.asp?id=home

Kendrick Consulting International
http://www.kendrickconsulting.org/

Milbank Memorial Fund Reports
http://www.milbank.org/reports/reportstest.html

National Centre for Independent Living
http://www.ncil.org.uk/

National Core Indicators
http://www.hsri.org/nci/

National Council on Disability (NCD)
http://www.ncd.gov/

National Guideline Clearinghouse
http://www.guideline.gov/

National Low Income Housing Coalition (NLIHC)
http://www.nlihc.org/

National Residential Information Systems Project - Research and Training Center on Community Living
http://www.rtc.umn.edu/risp/index.html

Nothing is more rational than a rationalization: words of caution about public policy marksmanship (Gilles Paquet, Faculty of Administration, University of Ottawa)
http://www.gouvernance.ca/index.php?page=embed&lang=ce&embed=publications/96-63.pdf

Optimum Online
http://www.optimumonline.ca/frontpage.phtml

Organisation for Economic Co-operation and Development
http://www.oecd.org/home/

Policy.ca, Canada's premier non-partisan resource for public discussion of issues in Canadian public policy
http://www.policy.ca/

Policy Research Initiative
http://policyresearch.gc.ca/page.asp?pagenm=root&langcd=E

Qualitative Research
http://gsociology.icaap.org/methods/qual.htm

Rehabilitation Research and Training Center on Aging with Developmental Disabilities
http://www.uic.edu/orgs/rrtcamr/

Research and Training Center on Disability in Rural Communities
http://rtc.ruralinstitute.umt.edu/

Roots of Canada's Social Deficit
http://www.oneworld.net/article/view/69805/1/

Social Policy Research Unit
http://www.uregina.ca/spr/

The Center on Human Policy
http://thechp.syr.edu/

The ESRC Research Centre for Analysis of Social Exclusion (CASE)
http://sticerd.lse.ac.uk/case/

The Evaluation Center
http://www.wmich.edu/evalctr/

The Fraser Institute is an independent public policy organization
http://www.fraserinstitute.ca/

The Institute on Public Policy for People with Disabilities
http://www.instituteonline.org/

The State of the States in Developmental Disabilities
http://www.cusys.edu/ColemanInstitute/stateofthestates/

Wordbank on the Mental Health Foundation website
http://www.learningdisabilities.org.uk/wordbank.cfm?wordid=201&wbletter=S

This literature review was assembled for the principal use of the Saskatchewan Community Living Division and the CLD Policy and Service Delivery Advisory Committee. Additional copies have been circulated to the respective governmental agencies responsible for the delivery of services to people with intellectual disabilities in the Canadian provinces and territories.

Note: Since this document conveys large portions of directly quoted material from several source documents, it is to be regarded as **confidential** and not released for general circulation. I have provided the most complete information possible for referencing this material. Copies of most of the source documents are available upon request to Duncan Blackman (Sask. CLD).

Social Philosophy: the philosophical influence on contemporary social issues

Introduction

Significant changes that have occurred over the past 50 years in the services for this People were largely due to shifts in prevailing attitudes guided by new social philosophies. Early approaches were based on the medical model with an emphasis on physical care and rehabilitative treatment. Subsequently, driven in part by the parents' associations, an educational or developmental model prevailed with priorities given to changing this People through the new technologies (e.g., behavior management, developmental programming, special education) of the day.

During the last couple of decades, a new model -- the social model of disability -- has emerged and become dominant. For this people, the philosophies of normalization and social role valorization merged with the social model to lend credence to the self advocacy movement. The social model, birthed from the of human rights movement by people with disabilities, has been instrumental in the promotion of non-discrimination, self-determination, inclusion, citizenship, participation and belonging.

This chapter provides an overview of the social model -- what it is, the social philosophy which supports it, and the potential metamorphosis or changes to the model in the future.

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Note: A Google search produced 6,900 references to "Social Model of Disability" (originally largely a UK theory but now accepted by self advocates worldwide).
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History

Equal rights for people with cognitive impairments: the international impact of Nordic welfare policy - Bradley, V. (Human Services Research Institute)(2003)

In the U.S., in the 1970's and 1980's normalization provided a construct for criticism that resulted in: legal assaults on institutions, creation of group homes and Community Day services, right to education and continued changes in definition of intellectual disabilities.
Shift in power: for people to have lives that they choose and to be supported in ways that facilitate their preferences, people must have control over the distribution of resources.
Requirements of Olmstead decision: comprehensive plan for moving individuals out of institutions and accommodating those on the waiting list, reasonable assessments by state's professionals, plans to ensure that residents are placed in the community at a reasonable pace, identified necessary funds including potential new or expanded resources and take steps to obtain new resources.
Recent innovations: there is a continuing if qualitatively different role for central leadership; in order to ensure compatibility of services, have to ensure that workers are trained in values and relevant skills; it is important to have a basic entitlement; specialized systems have to become part of broader generic systems; and need to involve larger community.
Challenges: need to find ways to allocate scarce resources while recognizing the choices and preferences of individuals. Development of a cadre of leaders to carry the values of normalization and inclusion far into this century.

Rights

Foreign policy and disability: legislative strategies and civil rights protections to ensure inclusion of people with disabilities - National Council on Disability (2003)

More than six hundred million people, almost 10 percent of the world's population, have a disability. No nation in the world will achieve its full potential for economic development while leaves out to people with disabilities. No society will be a complete democracy unless people with disabilities can participate in public life. Failure to respond to the concerns of people with disabilities ignores one of the great humanitarian and human rights challenges of the world today. A recent study done by the World Bank found that people with disabilities have less access to education and lower income levels than the rest of the population and are thus more likely to live below poverty levels than the rest of the population in most countries. The lack of protection against discrimination and exclusion of people with disabilities weeks to economic hardship and a loss of productive capacity in every society. The 1993 World Development Report of the World Bank has documented that discrimination against people with disabilities impedes economic development. The World Bank has adopted a new program, the World Institute on disability which is premised on to the idea that economic development and the inclusion of people with disabilities are closely linked.

Social model: defining

Implementing the Social Model of Disability - Birmingham City Council (6 April 2005)

http://www.birmingham.gov.uk/GenerateContent?CONTENT_ITEM_ID=1196&CONTENT_ITEM_TYPE=0&MENU_ID=11130&EXPAND=10613
http://tinyurl.com/28ze2

What is the Social Model?

In 1975 a group of disabled people in a recently formed group called the Union of Physically Impaired Against Segregation (UPAIS), published a short book called the "Fundamental Principles of Disability." Shortly after that a disabled lecturer Mike Oliver was trying to introduce the concepts contained in the Fundamental principle to a group of social work students. This is when the term Social Model was first used.The Social Model since has become internationally recognised as the driving force behind the disability agenda and a cornerstone of the disabled people's movement.The Social Model in its simplest changes the focus away from people's impairments and towards removing the barriers that disabled people face in every day life.

The barriers can be
Environmental
For example : Lack of accessible information

Systematic
For example : Segregated provision

Attitudinal
For example : Disabled people being seen as expensive, useless or needy

In the main it is not the impairment that is the problem, or the disabled person, rather it is society's failure to take into account our diverse needs. The Social Model shifts policy away from a medical, charity, care agenda into a rights led, equalities agenda. Without the Social Model the City Council would not see the need to have a disability team located in the Equalities Division.

For more information on the Social Model visit the website of the British Council of Disabled People at www.bcodp.org.uk

Social model: philosophy

The Organization of Difference: People With Intellectual Disabilities and the Social Model of Disability
Alex McClimens
Mental Retardation: Vol. 41, No. 1, pp. 35–46.
2003

[Note: The following quotes are intended to illuminate the highly theoretical analysis and discussion which is occurring concerning the philosophical models used to understand the nature of disability. The article can be supplied on request to those who want the full arguments and discussion.]

In the following pages I give some consideration as to why this situation persists. My comments are focused on one particular line of inquiry that has perhaps done more than any other to propel

discussion within the emerging field of disability studies. The sheer volume of debate occasioned by what has come to be known as the "social model of disability" (Finkelstein, 1980: Oliver, 1992; Union, 1976) would demand attention if only for its impressive word count. However, the implications for people with disabilities themselves, for their supporters, for social policy, and for academics are so pervasive that this perspective fully merits the attention it continues to generate.

My particular interest here is with the theoretical space offered by the model to those people variously labeled as having learning difficulties (the preferred terminology of the United Kingdom self-advocacy movement) or mental retardation, which will be more familiar to readers of this Journal.

When Bogdan and Taylor (1994) stated that "Mental retardation does not exist" (p. 8), their comment was, I suggest, designed to imply that the category had a conceptual rather than an actual existence. Now perhaps better known internationally as intellectual disability, the term nevertheless retains for some an empirical foundation at odds with its socially constructed nature.

[...]

As is often the case, this apparent neglect of intellectual disabilities by mainstream academics/activists has some history attached. In what follows, I attempt to outline the theory proposed by proponents of the social model, with some reference to its origins and purpose. This is the main focus of Part One. I then offer a critique based on recent work being undertaken by commentators operating from a perspective more closely aligned to the sole concerns of intellectual disability studies. I also provide some historical reflections on the organization of difference. [...]

The Report of the Professional Affairs Board of the British Psychological Society into Psychology and Physical Disability in the National Health Service (1989) provoked Finkelstein and French (1993, pp. 26–33) into compiling a working definition of disability and impairment that removed the notion of personal tragedy from the conditions described.

Finkelstein and French (1993) did this by rejecting the medical assumptions prevalent at the time and replacing them with a perspective that located disability within the social realm. They based their definitions on previous work carried out by the Union of the Physically Impaired Against Segregation and Disabled People's International in an effort "to avoid confusion and to provide a more fruitful way of looking at the psychological aspects of impairment and disability" (p. 28). The following definitions are the result.

> Impairment is the lack of all or part of a limb, or having a defective limb, organ or mechanism of the body. Disability is the loss or limitation of opportunities that prevents people who have impairments from taking part in the normal life of the community on an equal level with others due to physical or social barriers. (p. 28)

[...]

The insistence on unburdening the individual allows the emergent social models to relocate the negative effects of disability—however defined, however measured—within a social and organizational setting.

[...]

The situation of people with intellectual disabilities isolates the dilemma that the interpretation of impairment forces onto the debate. It is by now axiomatic that disability is socially constructed.

However, by the same method of analysis, intellectual disability is also a social construction. Impairment, however, clings to the individual due to its biological origins. Although people with physical disabilities conceptually separate the notions of impairment and disability, the lives of people with intellectual disabilities reunite the two into a fusion of disability/impairment.
[...]
How the social model then impacts, or fails to impact, on the lives of people with intellectual disabilities will be the focus of the second section.
[...]
This returns us to some of the ideas discussed earlier and offers some clues to the nature of the contested identity that people labeled as having an intellectual disability must live with. Is intellectual disability inherent within the person or socially constructed? Or is there some middle position that allows for the experience of intellectual disability to be understood as an amalgam of both? To suggest that impairment and disability can be appreciated within one framework seems to be an advance on a position that separates them.
Within this dilemma people with intellectual disabilities remain adrift from the tides that drive theoretical work. This is despite the best efforts of researchers to "get it right" and include their voices (Knox, Mok, & Parmenter 2000; March, Steingold, Justice, & Mitchell, 1997; Minkes, Townsley, Weston, & Williams, 1995; Rodgers, 1999; Williams, 1999). What is inescapable is that many authors and commentators active within this field are making a contribution to the debate by proxy due to the intellectual disability of their colleagues. This has effectively rendered much of this population silent, and only more recently has the self-advocacy movement offered a voice.
[...]
Caught between these rocks and hard places, it might be worth recalling Wittgenstein's (1961) remarks. He clearly recognized the limitations of inquiry when he said, "When all possible scientific questions have been answered, the problems of life remain completely untouched" (pp. 6.52–6.522). To investigators in the social sciences, it is a worthwhile caution and should act as a spur to those who would make a meaningful contribution to the lived experience of people classified with an intellectual disability.
My argument has concentrated on divisions. However, such divisions can be useful because it is precisely at these points of intersection that debate emerges. This, then, is not an attempt at closure, but an invitation to more discussion. The differences and divisions suggested here may be more imagined than real, but it remains in the interests of all parties to negotiate, communicate, and join the debate. We must all be suitably reminded (again) that in any commentary on disability, the analysis must address the question of intellectual disability.

Social model: metamorphosis

The social model of disability: an outdated ideology?
Shakespeare, T., Watson, N. (Research in Social Science and Disability, 2002, 2, p. 9-28)
"disability as the disadvantage or restriction of activity caused by a contemporary social organisation which takes little or no account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities." (p.3-4)

"The British social model therefore contains several key elements. It claims that disabled people are an oppressed social group. It distinguishes between the impairments that people have, and the oppression which they experience. And most importantly, it defines 'disability' as the social oppression, not the form of impairment."(p.3)
"the North American approach has mainly developed the notion of people with disabilities as a minority group, within the tradition of US political thought."(p.3)
Outcomes of this model:
barrier removal and civil rights
people with disabilities empowered to work for equal citizenship, demand their rights
simplistic model; reduced to slogan; easy tool for evaluating services; some effectiveness
transformed people's self-esteem

Argument or thesis of article:
Success of the social model is now its main weakness; 'sacred cow';
"You can't be a proper activist, unless you accept the social model as your creed." (p.6)
"failure of the model to encompass the personal experience of pain and limitation which is often a part of impairment."(p.9)
'the British version of the social model has outlived its usefulness."(p.9)

3 main criticisms of the Bristish social model of disability:
<u>Impairment, the absent presence</u>
the denial of difference is a problem for disability studies
impairment is part of the daily personal experience, and cannot be ignored in our social theory
different impairments impinge in different ways
"People are disabled both by social barriers and by their bodies."(p.15)

<u>A sustainable dichotomy?</u>
"Social model theory . . . rests on a distinction between *impairment*, an attribute of the individual body or mind, and *disability*, a relationship between a person with impairment and society."(p.15)
similar to the issues of the sex/gender distinction found in the early feminist movement. This has now been abandoned as a distinction.
"We see no reason why we cannot accept that not everyone will be able to achieve inclusion into the economy, and argue instead that a mature society supports everyone on the basis, not of the work they have done, buts of the needs they have."(p.18)
"Social model theory has worked within a modernist context and within rules of logic which are now actively being contested. . . . These modernist principles have been applied to disability, to deny that both the body *and* social barriers together can be the cause of disablement, and to argue against a middle ground between the medical model and the social model.. . . We believe that an adequate social theory of disability would include all the dimensions of disabled people's experiences: bodily, psychological, cultural, social, political, rather than claiming that disability is either medical or social".(p.19)

<u>Only and always disabled?</u>

"Many disabled people do not want to see themselves as disabled, either in terms of the medical model or the social model. They downplay the significance of their impairments, and seek access to a mainstream identity. . . . This refusal to define oneself by impairment or disability has sometimes been seen as internalised oppression or false consciousness by radicals in the disability movement. . . . People do have a choice as to how they identify . . . identity politics can be a prison, as well as a haven."(p.20-21)
"But most of them [the disabled children in a recent UK study] wanted to be seen as normal, though different, and actively resisted definition as disabled" (p.21)
"Most people are simultaneously situated in a range of subject positions. To assume that disability will always be the key to their identity is to recapitulate the error made by those from the medical model perspective who define people by their impairment. Any individual disabled person may strategically identify, at different times, as a person with a particular impairment, as a disabled person, or by thei particular gender, ethnicity, sexuality, occupation, religion, or football team. Identity cannot be straightforwardly read off any more, it is, within limit, a matter of choice."(p.22)
Conclusion
"A model which was developed in the early 1970s no longer seems as useful at the beginning of the twenty-first century."(p.23)
"we require a more sophisticated approach to disability."(p.24)
"1. Impairment and disability are not dichotomous, but describe different places on a contiuum, or different aspects of a single experience. . . . Disability is a complex dialectic of biological, psychological, cultural and socio-political factors, which cannot be extricated except with imprecision.
2. Much opposition to the 'medical model' is an opposition to being defined solely on the basis of impairment, or having clinicians rule our lives. . . . Disability should not be reduced to a medical condition . . .[,] overlaid with negative cultural meanings . . . [, or] reduced to an outcome of social barriers alone . . .
3. It remains vital to distinguish between the different levels of intervention . . . Intervention at physical, psychological, environmental and socio-political levels is the key to progressive change, yet one cannot be a substitute for the other. . . .
4. . . .disabling social relations are everywhere. . . . theoretical responses must be situated in specific contexts. . . . it is tempting to generalise, but that temptation should be resisted. [this addresses the tendency of research to overgeneralize results.]
5. Currently, disability studies and disability politics share the assumption that we know who the disabled subject is. . . . Failure to follow a social model line, or join with the disability movement, may be . . . a limitation of the model or movement itself."(p.24-25)

"Acceptance of the ubiquity [existence everywhere or in every person as has been proposed by some theorists] of impairment and physical limitation offers a different definitional strategy for disability studies. . . . An embodied ontology [the principles and causes of being] would argue instead that there is no qualitative difference between disabled people and non-disabled people, because *we are all impaired*. Impairment is not the core component of disability (as the medical model might suggest), it is the inherent nature of humanity. . . . Clearly, the limitations which individual bodies or minds impose (always in specific contexts) vary from the trivial to the profound. . . . Our point is that everyone has limitations and will, through the ageing process,

inevitably experience functional loss and morbidity. Many of us will be supportive of attempts to minimise or eliminate these limitations, wher possible, which does not mean 'cure at all costs'. . . . societies have evolved to minimise the problems of the majority of people with impairment, but have failed to deal effectively with the problems of a minority of people with impairment. . . . It is difficult to achieve a core definition of 'disabled people', because it is not clear who counts as disabled or not. This is because different societies treat particular groups of people with impairments in different ways. . . . Rather than trying to break the definitional link between impairment and disability, we should expose the essential connection between impairment and embodiment. . . . part of the psychological origins of hostility to disabled people may lie in the tendency of non-disabled people to deny their vulnerability and frailty and mortality, and to project these uncomfortable issues onto disabled people, who they can subsequently oppress and exclude and ignore. . . . Understanding these processes of exclusion and discrimination is where the core focus of an empowering disability studies should lie.
The central argument of this paper has been that the British social model has been an excellent basis for a political movement, but it is now an inadequate grounding for a social theory."(p.26-29)

Philosophical quotes

"We may not be perfect and we may not be fast, but we do know a lot of other things that maybe other people don't understand." *(featured in Freedom, Equality and Justice for All)*
~ Brian Bell (Self-Advocate)
ACT Self-Advocacy Resource Network (http://www.selfadvocacy.com/SARN/MLK/index.htm)

"Everybody can be great, because anybody can serve." How's that for an un-American value? This powerful statement, by *Martin Luther King Jr.*, runs counter to most of what our modern culture bombards us with every day. Our culture tells us that people are great when they are highly educated, famous, rich, athletic, successful, young and/or beautiful. MLK's statement helps us remember that the self-advocacy movement, where every member's contribution is valued and sought, will always be a movement of truly great people.

Each of us matters. Each of us is important. Each of us is great. Greatness is about serving others, about doing our little bit to make a difference, about being motivated by love to help improve the world.

For many persons with developmental and mental health disabilities, decisions that affect the basic quality of life are made by others - family members, professional care givers, state-assigned guardians. Their lives and abilities are often viewed through the blinders of a medical paradigm, a point of view in which disabilities are defined as problems to be overcome, as deficiencies in the individual person. In the medical model, resources are devoted exclusively to curing and preventing developmental disabilities, and persons with disabilities are trained to adapt their lives to whatever extent possible to the demands of mainstream society.

This point of view does not acknowledge the integrity of persons with developmental disabilities. Over the past several decades, a different point of view has emerged among people with disabilities that more fully recognizes the self worth and human dignity of every person,

emphasizes the unique capabilities of every person, and demands changes in society to improve the quality of life for individuals. From this point of view - the minority group model - the potential contributions of all individuals are valued, and resources are devoted to removing obstacles in society that keep individuals from living their lives with integrity and self determination.

The realities of developmental disabilities test the commitment of our society to the concepts of individual liberty and self determination. Because people with disabilities often require more support to assume and maintain control of their lives than do other people, their potential for self determination is frequently unrealized. Through community organizing, however, people with disabilities are finding the collective strength to successfully demand the resources they need to exercise control over their lives, and to fight for the removal of barriers to their full participation in society.
(http://www.selfadvocacy.com/need_for_common_vision.htm)
[Advocating Change Together (ACT) is a self-advocacy disability rights organization, started in 1979, whose goal is the advancement of self-advocacy as a civil right for persons with developmental and other disabilities. ACT has developed tools and materials that help individuals and groups promote self-advocacy in their lives and work..]

A Simple Half Hitch - Deborah McLean
It's naught but knots that tie me up,
But for knote, naught binds me.
The very same rope that gives me hope
Could be the rope that winds me
Belaying out, belies within,
Be lies where truth be laying.
The very words that seem so clear,
Are knot, the words I'm saying.

"To put it simply, I do not see person-centered planning as the cause of change. I see it as a way to improve the odds that purposeful change will happen." *-John O'Brien*

Internet resources (links)

Implementing the Social Model of Disability
http://www.birmingham.gov.uk/GenerateContent?CONTENT_ITEM_ID=1196&CONTENT_ITEM_TYPE=0&MENU_ID=11130&EXPAND=10613
or http://tinyurl.com/28ze2

Self-advocacy, “learning difficulties” and the social model of disability
http://www.shef.ac.uk/inclusive-education/research/researchprojects/selfadvocacy2.htm

Social Philosophy Today
http://www.pdcnet.org/spt.html

Social Role Valorization (SRV)
http://www.socialrolevalorization.com/

The Medical and Social Model of Disability
http://www.selfdirection.org/dat/training?cmd=guest&p=%2Fcourse01%2Fwelcome.html

Saskatchewan Community Living Division
Current Developments in Services for People with Intellectual Disabilities
Literature Review: Resource Information and Bibliography

This literature review was assembled for the principal use of the Saskatchewan Community Living Division and the CLD Policy and Service Delivery Advisory Committee. Additional copies have been circulated to the respective governmental agencies responsible for the delivery of services to people with intellectual disabilities in the Canadian provinces and territories.

Note: Since this document conveys large portions of directly quoted material from several source documents, it is to be regarded as **confidential** and not released for general circulation. I have provided the most complete information possible for referencing this material. Copies of most of the source documents are available upon request to Duncan Blackman (Sask. CLD).

Definition of disabilities

Introduction

Influenced in part by the social model, the definition of disabilities has moved from a categorization of impairment to an identification of the degree to which the physical, cognitive/learning, and mental difficulties limit inclusion in the mainstream of society.

Definitions of disability are used to treat eligibility criteria for the delivery of services. Canadian services and programs have been influenced by these changes to the point where the definition or classification criteria differ from one initiative to the next. Unfortunately this creates confusion and works to the disadvantage of some individuals who only meet the criteria for certain services and not for others which they might need.

An emerging solution is to provide programs and services delivered according to the required need for supports rather than being based on a classification process.

The following articles reflect the changing definition and its influence on the delivery of services.

Global definition

Chair's Draft Elements of a Comprehensive and Integral International Convention on Protection and Promotion of the Rights and Dignity of Persons with Disabilities - December, 2003
http://www.un.org/esa/socdev/enable/rights/wgcontrib-chair1.htm

"Disability" is the loss or limitation of opportunities to take part in the life of the community on an equal level with others due to physical, social, attitudinal and cultural barriers encountered by persons having physical, sensory, psychological, developmental, learning, neurological or other impairments (including the presence in the body of an organism or agent causing malfunction or disease), which may be permanent, temporary, episodic or transitory in nature

"Discrimination on the ground of disability" includes:

(1) any distinction, exclusion, restriction on the ground of disability which has the purpose or effect of nullifying or impairing the recognition, enjoyment or exercise of human rights and fundamental freedoms in the political, economic, social, cultural, civil, or any other field;

(2) any act, criterion, provision, practice, policy, rule or arrangement which, although not explicitly based on disability-

(a) has the purpose or effect of nullifying or impairing the recognition, enjoyment or exercise of their human rights and fundamental freedoms in the political, economic, social, cultural, civil, or any other field; and

(b) cannot be objectively justified as a reasonable and proportionate means of achieving a legitimate aim;

(3) a failure to make reasonable accommodation,

(4) less favourable treatment of an associate of a person with a disability because of that other person's disability or because of the association, and a reference to disability includes a suspected, imputed, assumed or possible future disability, perceived disability, a past disability or the effects of a past disability, or the characteristics of a disability.

Canadian perspective

Advancing the inclusion of persons with disabilities: A Government of Canada report
Office for Disability Issues, Social Development Canada
2004

Recently there has been much activity within the disability community, and action by the Government of Canada, to address the issue of defining disability. Disability is difficult to define because it is a complex concept with both objective and subjective characteristics. When interpreted as an illness or impairment, disability is seen as fixed in an individual's body or mind. When interpreted as a social construct, disability is seen in terms of the socio-economic, cultural and political disadvantages resulting from an individual's exclusion by society.
No single definition of disability exists at the federal level. In national surveys the Government relies on self-identification based on a set of standardized questions. These questions are designed to identify a broad range of individuals whose ability to carry out everyday activities is limited by a physical or mental condition or a health problem. [...]

The Government of Canada [...] published Defining Disability--A Complex Issue in December 2003. [...] It concludes that a single harmonized definition may be impossible given the many realities [... and] may not capture the different policy objectives and needs of Canadians with disabilities. [...] The Government of Canada is now exploring how it could use the ICF [International Classification of Functioning, Disability and Health, a framework of the World Health Organization] to improve data collection, policy development and program design. [...] (pg. 11-12)

Health Canada uses a population health framework to explore Canadians' health and the factors that influence it. A population health approach focuses on improving the health of the entire population rather than just that of individuals. [...] The biomedical approach to disability views disability as a personal condition, the direct result of a disease or injury. Treatment and rehabilitation are therefore seen as a solution. In contrast, the social approach views disability as

a condition created by society. From this perspective, the social environment creates barriers to integration, and the solution is to develop strategies to remove the barriers.
The WHO's International Classification of Functioning, Disability and Health (ICF) reconciles both approaches [...] Under the ICF, *impairment* includes the dysfunction of body functions and body structures. *Activity limitations* refer to an individual's difficulty executing tasks. *Participation restrictions* refer to the difficulties an individual may face in the areas of life he or she is involved in. Finally, there are *environmental factors* that affect the other three areas. The ICF model makes a link between health, disability and quality of life. (pg. 73)

Legal definition

The duty to accommodate in the Canadian workplace: what is, "disability"?
WORKink - Virtual Employment Resource Center (http://www.workink.com)
2001
All human rights statutes in Canada prohibit discrimination on the grounds of "disability" or "handicapped". The prohibition is also found in the Canadian Charter of Rights and Freedoms which made Canada the first country in the world to include the protection of persons with disabilities in its constitution
The terms " disability " and " handicapped " have been given a broad meaning in Canadian law. (There is no difference in law in the legal meaning attached to these two terms). The leading definition of the terms within the context of human rights legislation is [. . .] an illness, injury or disfigurement that creates a physical or mental impairment and thereby interferes with the person's physical, psychological and/or social functioning.
[...]
The courts, human-rights tribunals and labour arbitration boards have placed a wide number of impairments under the legal definition of " disability " or " handicapped " over the past 20 years. (pg.1-2)

Twenty years of litigating for disability equality rights: Has it made a difference?
Peters, Y. (Council of Canadians with Disabilities, www.ccdonline.ca)
Jan. 26, 2004
Generally for term "disability" has been broadly defined to include physical, mental and psychological disabilities. However, in 2000, the SCC [Supreme Court of Canada] clarified that a "handicap" may be real or perceived; that is, a person may have no limitations in everyday activities but may still be subject to prejudice and stereotypes because of a perceived disability. For example, discrimination based on a perceived disability occurs where a person is denied a job because a pre-employment medical discloses that she/has a defect of the spinal column even though the person experiences no discernible physical limitations.
Consequently, it is now clear that the term disability goes beyond a medical diagnosis to include the circumstances in which a distinction is made. As stated by the Court: "The emphasis is on the effects of the distinction, rather than the precise cause or origin of the handicap."
(pg. 25)

Eligibility issues

Disability Tax Fairness: Report of the Technical Advisory Committee on Tax Measures for Persons with Disabilities (Department of Finance Canada, Ottawa, www.disabilitytax.ca) December 2004

The question arises as to how to define disability in order to determine eligibility. [...] While tax measures and other disability supports require that lines be drawn for eligibility purposes, all such lines are arbitrary to some extent. Inevitably, the difference between those who qualify and those who do not is often small. [...]

The proposition that disability should be understood as the effects of impairment within a given context is consistent with work under way throughout the world.

In 2001, for example, the World Health Organization released the latest version of the International Classification of Functioning, Disability and Health, in which disability was seen to arise from the interaction between impairment and externally imposed limitations on activity. [...]

The key feature of the social model of disability is a recognition that a disability does not lie solely in the individual, in his or her genetic differences, disease, long-term health condition, or impairment in physical, sensory or mental functioning. Disability is also determined by the limitations in carrying out activities of daily living, and in participating in the social, economic, political and cultural life of the community. These limitations can derive from the condition or impairment itself, in the context of other individual conditions and factors, from social attitudes toward such conditions and/or from ways of designing and organizing social, economic and built environments. Often the limitation that arises from a particular condition can be significantly ameliorated if the social stereotypes, need for supports and environmental barriers are adequately addressed. (pg. 15-17)

In our view, if we were to apply social model framework to disability tax credit, the eligibility criteria could incorporate the following components: (i) and impairment in function, (ii) the effects of the impairment on the individual's activities, and (iii) biological, psychological, social and environmental factors necessary to assessing impairment in function and its impact on activity.

In our discussions, we recognize health practitioners might be confused by the inconsistent classification of functions and activities. [...] We considered a broader list of functions for the disability tax credits that would reflect impairment in both mental and physical functions. These functions would include:

- neurological functions - diseases and conditions affecting the brain and spinal cord;
- mental functions - diseases and conditions affecting memory, problem-solving, judgment, perception, learning, attention, concentration, verbal and non-verbal comprehension and expression, and the regulation of behavior and emotions;
- motor functions - diseases and conditions affecting the movement and coordinated use of limbs;
- sensory functions - diseases and conditions affecting sight, hearing, taste, smell or touch;
- comprehension and expressive functions - diseases and conditions affecting the processing and production of language; and
- structure, organ and other physiological systems - diseases and conditions affecting bodily organs such as heart, lungs, liver, pancreas, bone and other structures, and endocrine and other regulatory systems.

Impairment in these functions then must result in a marked restriction in certain designated activities. In the case of a measure designed around a marked restriction in activities of daily living, such as the disability tax credit, the list of activities might include the following:

- self-care, such as eating, bathing or dressing;
- health and safety, such as managing necessary medications and risks to personal safety; and
- essential life management skills, such as paying bills, using public transportation, purchasing groceries, communicating and getting along with others.

[...]

A social model of disability also helps ensure that the determination of disability keeps pace with changes in individual and social circumstances. While additional individuals may become eligible for various programs as their circumstances evolve, it is equally likely that others will go off these programs as their abilities are modified through the provision of supports, therapy or treatment. Perhaps the key dimension of a social model - the factor that distinguishes it from current tax measures and programs - is the recognition of the significant role of accommodation and its influence upon the real-life impact of the impairment. Marked restriction in activity is determined by the amount and effectiveness of accommodation in place in a given environment. Understanding and applying the concept of accommodation would move a long way toward putting into practice a social model of disability.
(pg. 114-117)

Changing perspectives

Defining Disability A complex issue
Human Resources Development Canada
2003

This document provides a review of, and framework for understanding, disability definitions in key Government of Canada initiatives.

Overall, the report illustrates and seeks to clarify the complex and multi-dimensional nature of the concept of disability found in policy, programs and benefits. It highlights the fact that confusion exists between definitions, eligibility criteria and program objectives. The paper concludes that a single harmonized definition of disability across the Government of Canada may not be desirable or achievable and that the scope of solutions to address the broader issues identified go beyond definitions. In reaching these conclusions, the paper illustrates the various tensions between the concept of disability, program design and the horizontal nature of disability programs.
(pg. 2)

Concerns regarding definitions and eligibility criteria were brought forward in 2001, 2002 and 2003 by disability organizations, academics and professional associations, during hearings of the House of Commons Subcommittee on the Status of Persons with Disabilities. [...]

In addition, in June 2002, the Standing Committee on Human Resources Development released *Promoting Equality in the Federal Jurisdiction: Review of the Employment Equity Act*. In this report the Committee expressed concerns about the definition of disability and recommended amending portions of the Act related to disability definitions. The issue relates to linking "disability" and "disadvantage" Many working people with disabilities do not consider themselves disadvantaged in employment and may not self identify as such on workforce

surveys. As a result employment equity statistics may under represent the number of employees with disabilities.
The Government, in its response to *A Common Vision*, stated that it
"Agrees with the recommendation to study the definitions of disability in federally administered disability programs. Human Resources Development Canada will undertake a review of the definitions of disability with all federal departments involved in disability issues and will report on its progress on a regular basis."
As a result, in 2002 the Office for Disability Issues, part of Human Resources Development Canada (HRDC), set up a working group to gather information and begin reviewing Government of Canada disability programs.
(pg. 3-4)
Disability is difficult to define because it is a multi-dimensional concept with both objective and subjective characteristics. When interpreted as an illness or impairment, disability is seen as fixed in an individual's body or mind. When interpreted as a social construct, disability is seen in terms of the socio-economic, cultural and political disadvantages resulting from an individual's exclusion.
Persons with disabilities, advocacy groups, medical practitioners and the general public all have a different view of disability. And the meaning of disability has evolved over the years through various perspectives such as a moral perspective, a medical model as well as social and human rights perspectives. Three major classification systems or disability perspectives which have helped define disability over the decades are discussed below.
The various perspectives have an effect not only on how we define disability but also on program design and how decisions are made regarding program eligibility.
IMPAIRMENT PERSPECTIVE
The impairment perspective considers disability a health problem or abnormality that is situated in an individual' body or mind. This perspective is best expressed by the medical model which views disability in terms of disease, illness, abnormality and personal tragedy. The medical model assumes that disability is an intrinsic characteristic of individuals with disabilities. This assumption translates into practices that attempt to "fix" individuals' abnormalities and defects, which are seen as strictly personal conditions. [...]
FUNCTIONAL LIMITATIONS PERSPECTIVE
The functional limitations perspective arose from attempts to expand the medical model to include non-medical criteria of disability, especially the social and physical environment. Nonetheless, the notion that impairments are the direct cause of disability remains central to this perspective. Also, like the impairment perspective, the functional limitations perspective considers disability in quantitative terms, measuring functional restrictions against a standard.
[...]
The WHO's 1980 International Classification of Impairments, Disabilities and Handicaps (ICIDH) is the first major classification system to focus specifically on disability. According to the ICIDH, disability refers to any reduction or lack of ability, caused by impairment, to perform an activity in a way considered normal for a human being. The ICIDH framework presents disability as a linear process that begins with an underlying cause, which brings about an impairment, which in turn causes a disability that may result in a handicap. Many have criticized ICIDH's linear explanation of disability.
ECOLOGICAL PERSPECTIVE

The ecological perspective arose in the 1970s, but became more prevalent in the mid- 1990s in response to criticism of the impairment and functional limitations perspectives. Like the latter perspective, the ecological perspective rests on three distinct disability concepts: pathology (or abnormality), impairment and disability. However, it sees disability as resulting from the interaction of impairment, activity limitations and participation restrictions in a specific social or physical environment such as work, home or school. [...]

There are many variations of the social model, but all portray disability as a social construct created by ability-oriented and ability-dominated environments. The social model rejects the linear causality. According to the social model, even though impairment has an objective reality that is attached to the body or mind, disability has more to do with society's failure to account for the needs of persons with disabilities.

The human rights model is a distinct subgroup of the social model. It understands disability as a social construct. The model is primarily concerned with the individual's inherent dignity as a human being (and sometimes, if at all, with the individual's medical characteristics). [...]

The general term "functioning" refers to all body functions, activities and participation while the term "disability" is understood to encompass the interaction between impairments and externally imposed activity limitations or participation restrictions.

(pg. 5-7)

The inclusion in the Charter of both mental and physical disabilities as prohibited grounds of discrimination represents an important evolution in Canadian legislation, for until the Charter, Canadians with mental disabilities received limited protection. The Charter's recognition of both types of disability was underscored in 1996, when a Supreme Court of Canada decision called it discriminatory to treat people with mental disabilities differently from those with physical disabilities. [...]

The purpose of the 1977 *Canadian Human Rights Act* (CHRA) is to ensure equality of opportunity without the hindrance or prevention by discrimination in federal jurisdiction. [...]

In section 25, disability is defined as meaning "any previous or existing mental or physical disability and includes disfigurement and previous or existing dependence on alcohol or a drug." The definition has been interpreted broadly to include perceived disability as well as actual disability. The CHR Tribunal has held that discriminating against someone because of a perception of disability has the same effect as discriminating against someone that is disabled.[...]

Courts will interpret and give meaning to the term disability if definitions are not expressly provided. In the case of human rights, courts tend to define disability broadly to ensure the greatest protection possible for the equality rights of persons with disabilities. These "common law" definitions are an important source of definitions that inform other contexts.

(pg. 13-14)

The *Employment Equity Act* (EEA) (1995) [...] defines "persons with disabilities" in section 3:

"Persons with disabilities" mean persons who have a long-term or recurring physical, mental, sensory, psychiatric or learning impairment and who

a) consider themselves to be disadvantaged in employment by reason of that impairment, or

b) believe that a [*sic*] employer or potential employer is likely to consider them to be disadvantaged in employment by reason of that impairment, and includes persons whose functional limitations owing to their impairment have been accommodated in their current job or workplace.

Viewing disability as a functional limitation rather than a medical impairment represents a significant step in the evolution of conceptual perspectives. The *Employment Equity Act* includes as persons with disabilities those whose functional limitations have been accommodated in their current jobs.
(pg. 15-16)
Neither the new *Immigration and Refugee Protection Act* nor the legislation it replaced contains a definition of disability. However, the evolution of the inadmissibility criteria is important to this discussion. [...]
In the new *Immigration and Refugee Protection Act*, the inadmissibility criteria, which are listed in section 38, use the words "health grounds" instead of the term "disability" As a result, admissibility is now clearly based on an applicant's health, not the presence or absence of a disability. Section 38 states as follows:
(1) A foreign national is inadmissible on health grounds if their health condition
a. is likely to be a danger to public health;
b. is likely to be a danger to public safety; or
c. might reasonably be expected to cause excessive demand on health or social services.
In determining inadmissibility, a complex formula is used to project the cost of an applicant's health condition. The cost is considered to cause "excessive demand" if it is likely to exceed the average cost of caring for a Canadian citizen or permanent resident.
(pg. 16-17)
The *Broadcasting Act* (1991) sets out Canada's broadcasting policy. [...]
Paragraph 3(1) (*p*) of the Act states that "programming accessible by disabled persons should be provided within the Canadian broadcasting system as resources become available for the purpose." Although the Act does not define disability, the main impairments that the broadcasting system has targeted for accessibility are visual and hearing impairments.
(pg 17)
The *Canada Transportation Act* (1996) does not specifically define disability. The Act does, however, address accessibility and obstacles.
(pg. 18)
The *Canada Evidence Act* provides for the right of persons with disabilities to participate as witnesses in civil and criminal proceedings, subject however to some reservations in the case of persons with a mental disability. The Act does not define disability. It does, under section 6, state that a witness who has difficulty communicating because of a physical or mental disability can give evidence "by any means that enables the evidence to be intelligible."
Section 16 (1) of the Act states that, where a proposed witness is a person under fourteen years of age or a person whose mental capacity is challenged, the court shall, before permitting the person to give evidence, conduct an inquiry to determine:
a. whether the person understands the nature of an oath or a solemn affirmation; and
b. whether the person is able to communicate the evidence.
(pg. 19)
The disability tax credit (DTC) [...] provides tax assistance to individuals who, due to the effects of a severe and prolonged mental or physical impairment, are markedly restricted in a basic activity of daily living, or would be if not for extensive therapy to sustain a vital function, as certified by a medical practitioner.
(pg. 21)

There are two aspects that are key when CCRA considers whether or not a person is dependant on an individual or an individual and others for support because of the person' physical or mental infirmity. The dependency must be brought on solely by reason of the infirmity, and the degree of infirmity must be such that it requires the person to be dependant on the individual for a considerable period of time.
(pg. 25)
The *Canada Pension Plan Act* is the legislation that governs the CPP. This Act in subsection 42(2) defines who is considered disabled and when a person is deemed to have become or ceased to be disabled. It also defines severe and prolonged:
a) a person shall be considered to be disabled only if he is determined in prescribed manner to have a severe and prolonged mental or physical disability, and for the purposes of this paragraph,
(i) a disability is severe only if by reason thereof the person in respect of whom the determination is made is incapable regularly of pursuing any substantially gainful occupation, and
(ii) a disability is prolonged only if it is determined in prescribed manner that the disability is likely to be long continued and of indefinite duration or is likely to result in death
(pg. 28)
EAPD [Employability Assistance for People with Disabilities (now Multilateral Agreement)] does not define disability. The provinces determine individuals' eligibility for EAPD programs and services, while the Government of Canada determines which programs are eligible for funding.
(pg. 33)
The Canada Student Loans Program [...] has a number of non-repayable Canada Study Grants for students with particular needs, including students with permanent disabilities. [...]
[P]ermanent disability means "a functional limitation caused by a physical or mental impairment that restricts the ability of a person to perform the daily activities necessary to participate in studies at a post-secondary school level or the labour force and is expected to remain with the person for the person's expected life." [...]
Individuals who apply must first show that they meet the definition of permanent disability. The CSLP accepts any one of the following documents: a medical certificate, a psycho-educational assessment or a document proving that the applicant receives federal or provincial disability assistance.
(pg. 34-35)
The disability policy and programs have different purposes and intents. The tension between programs that use definitions based on somewhat competing conceptual models makes pursuing the goal of a single, generic definition of disability difficult. Indeed, similar to the experience in other jurisdictions, the understanding of disability from the social and human rights perspective are broader than for entitlement to programs providing income support benefits. Not surprisingly, Government of Canada income support programs and tax measures tend to use eligibility criteria based on a combination of the medical and functional limitation approach. For example, both the CPPD and the DTC collect and process medically certified information on the type and severity of disability, assessed in terms of impairment that result in a certain degree of functional limitations. Not everyone can reasonably claim entitlement to disability-related income support, and tax relief.
The social and human rights conceptions of disability have influenced more recent legislative, policy and program developments. Anti-discrimination legislation is perhaps the most prominent

example of a legislative outcome based on this newer conception of disability. Of course, human rights legislation aims to include everyone with a disability, regardless of degree or type of limitation. Additionally, there are also examples of program developments from the social and human rights model. The Opportunities Fund for instance, focuses on removing social barriers by attempting to reduce the impact of disability-related economic and social disadvantages.
(pg. 37-38)
Although Government of Canada initiatives may target the same type of disability i.e. severe and prolonged mental or physical impairment, as is the case for CPPD and the DTC, or permanent physical or mental impairment for OF and CSLP, they have very different objectives as well as eligibility criteria. For instance, CPPD aims to provide earnings replacement to a contributor who is no longer able to work, while the DTC provides tax relief to a person who is markedly restricted in his or her ability to perform a specific basic activity of daily living. OF assists individuals normally not eligible for Employment Insurance to find work and CSLP helps students pursue a post-secondary education. Clients must demonstrate that they meet the eligibility criteria which differ depending on the purpose of the program.
(pg. 41)
Implicit in all the confusion and misunderstanding between definitions, objectives and eligibility criteria is the need for more effective communication and awareness by the Government of Canada. For example, recent PALS (Participation and Activity Limitation Survey) data indicate that many Canadians are unaware of their situation with respect to the DTC. Indeed about 925,000 Canadians with activity limitations indicated that they did not know that the DTC existed (these tended to be persons with more severe disabilities). However, many Canadians depend on others to complete their tax forms and some may not be fully aware of the details regarding their returns, and may in fact be receiving the credit. More clear descriptions of the various disability programs and who they target are required for both clients and the medical professionals that must provide medical information.
(pg 44)
[The following section might be of use for further details on the conundrum that consumers find themselves in regarding the definitional issues in Canada's programs.]
Annex A
Disability Definitions — Selective quotes from witnesses who appeared before the Standing Committee on Human Resources Development and the Status of Persons with Disabilities and its Sub-Committee on the Status of Persons with Disabilities between 2001 and 2003.
(pg. 50 ff)

Additional Sources

Historical review of the descriptions and explanations of mental retardation
Hitzig, Sandra (Presented at the eleventh annual convention of the American Psychological Association - Toronto convention)
August 8, 2003

Internet resources (links)

Center for International Rehabilitation Research Information and Exchange
http://cirrie.buffalo.edu/

Center on State Systems & Employment - Glossary of Key Terms
http://www.communityinclusion.org/rrtc/Research/StateProfiles/Glossary.htm

Definition of Disability (Government of Canada)
http://www.hrsdc.gc.ca/asp/gateway.asp?hr=en/hip/odi/documents/Definitions/Definitions006.shtml&hs=hze

Definition of Mental Retardation
http://www.aamr.org/Policies/faq_mental_retardation.shtml

Disability Research Institute
http://www.dri.uiuc.edu/default.htm

Human functioning and disability
http://unstats.un.org/unsd/demographic/sconcerns/disability/

Intellectual Disability Services Council (Australia)
http://www.idsc.sa.gov.au/

One-Stop Toolkit for Serving People with Disabilities Web site: United States Department of Labor, Employment and Training Administration
http://www.onestoptoolkit.org/

The World Bank and Disability
http://web.worldbank.org/WBSITE/EXTERNAL/TOPICS/EXTSOCIALPROTECTION/EXTDISABILITY/0,,menuPK:282704~pagePK:149018~piPK:149093~theSitePK:282699,00.html
or http://tinyurl.com/dso84

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Needs assessment systems

Introduction

One common approach used to identify the necessary supports required by these People is through the use of various needs assessment systems.

Although the Saskatchewan CLD has developed and uses the Daily Living Support Assessment, information was sought from other jurisdictions for comparison purposes.

Supports assessments

Integrating Supports in Assessment and Planning
Thompson, J.R., Hughes,C.,Schalock, R., Silverman,W., Tasse,M., Bryant,B., Craig,E.M.,& Campbell,E.M. (Mental Retardation, 40(5), 390-405)
2002

A "supports paradigms" has been gaining prominence in recent years, evolving from the philosophy of normalization [...], the community-based movement [...], and the contemporary emphasis on quality of life [...]. The paradigm shift involves a movement away from a principal focus on individuals' deficits to one concerned primarily with self-determination and inclusion. [...]
Despite its conceptual appeal, the transition to a supports paradigm presents a number of clear challenges. First, people with disabilities, as consumers of supports, must be described on the basis of their personal needs and aspirations. [...] Second, the traditional focus on supports that address basic personal care and maintenance must be expanded to include the enhancement of personal development, empowerment, inclusion, and valued social roles. Systems of support implementation, in order to meet these challenges, need to be designed to assess a wide range of support needs, be person-centered, be sufficiently flexible to accommodate substantial variation in the individual priorities, and provide a means to regularly evaluate each individual's changes in status and needs over time.
(pg. 390)

The Supports Intensity Scale -- SIS [...] is a multidimensional measure designed to determine the intensity of an adult's support needs. This instrument was designed to assess support needs, determine the intensity of needed supports, monitor progress, and evaluate the outcomes.

Moreover, SIS results can be useful for projecting support costs and justifying access to certain types of funded service/programs (e.g., supported employment, supported living). The SIS, which is in its second stage of field development, assesses support needs according to:
Eight support areas: home living, community living, education/training, employment, health and safety, behavioral, social, and protection and advocacy
Four medical areas: respiratory care, feeding assistance, skin-care, and "other exceptional medical needs"
Four challenging behavior areas: externally directed destructiveness, self-directed destructiveness, sexual problem behavior, and "other challenging behaviors"
(pg. 395)

Classification of support needs in a residential setting
Vivienne Catherine Riches
Centre for Developmental Disability Studies University of Sydney Australia
Journal of Intellectual & Developmental Disability, Volume 28(4), 323 - 341
December 2003
Abstract:
A supports classification and assessment system is required in residential settings that enables accurate classification and resource allocation in the context of limited resources. In developing such a system, the American Association on Mental Retardation intensities of supports framework was used and consultation with all stakeholders resulted in a process and instrument that examined support needs in a community living environment across key domains. In all, 116 clients who had an intellectual disability were assessed and classified during 1999. The instrument was favourably received by all stakeholders and validity and reliability results were sound. A multidimensional scoring model and multiple regression analyses were used to evaluate how well the five domain scales and the risk profile predicted current support, measured by current staff hours per 24-hour period. Results are reported along with recommendations for future research and development.

Functional limitations

A National Measure of Functional Dependency for Home and Community Care Services in Australia
Centre for Health Service Development, University of Wollongong, Australia
Report of commissioned research carried out for the Commonwealth, State and Territory Departments administering the Home and Community Care Program
This report was prepared by the Centre for Health Service Development, University of Wollongong
Dec., 2001
The Home and Community Care (HACC) Program, in consultation with State and Territory governments and other stakeholders, has continually searched for improvements in methods of funding and service delivery. The task is not easy. The community care sector is inherently complicated. Each year, the community care sector provides services to literally thousands of clients, undertakes millions of processes, and produces a complex array of outcomes. The sector is also at the interface between the acute care, residential care and housing sectors and requires ways of relating its work to activities in those other sectors. [...]

Each client treated in the human services sector is unique and it is fundamental to high quality care that this uniqueness be recognised. But uniqueness does not preclude or negate the usefulness of adopting standard measurement tools, or of classifying clients according to their need for care. Clearly, it is preferable to classify consumers based on their own needs and not merely in terms of their use of different programs and service types. [...]

A measure of 'functional dependency' identifies key areas in which a person requires assistance with daily living and quantifies the extent to which the person has to rely on someone else to help them carry out normal activities of living in their own home and in the community. Functional measures may also need to capture factors in the external environment such as accessibility to transport and the layout of the home. Clearly, measures of dependency should be able to assist services consistently record the needs of clients.

(pg. 1)

The Home and Community Care (HACC) Program provides 'basic care and maintenance services designed to assist in meeting the physical, psychological, daily living, and social needs' of the frail aged and other people with disabilities and their carers (HACC Review Working Group, 1988:2). The program targets persons living in the community whom, in the absence of basic maintenance and support services, are at risk of inappropriate long-term residential care.

(pg. 2)

The first stage of the research was aimed at determining what reliable measures of dependency might be suitable for use by HACC services. It covered two main activities. The first was a comprehensive review of the literature that described the performance of established measures of dependency. The second was a review of current practice that described client dependency assessment instruments currently in use in the aged care, disability and community sectors in Australia and the elements the instruments had in common. The suitability of the existing scales and instruments to the HACC target group was also reviewed with the view to recommending on whether one or more existing measures should be selected or whether a new measure is required.

(pg. 7)

A search of the literature failed to identify a screening instrument designed specifically for an environment such as Home and Community Care services. Indeed, much of the literature was concerned with screening for comprehensive geriatric assessment in a more medical environment. As such, the instruments that we regarded as "assessment scales" for use in the 2nd tier of assessment were frequently considered in the literature as "screening" instruments for needs identification, prior to more in-depth geriatric/comprehensive (medical) assessment. Consequently, no suitably brief screening tools were able to be identified in the literature, resulting in the less satisfactory option of either testing a widely used, although unvalidated tool, or designing an instrument. In the end, the latter course of action was chosen.

(pg. 13)

For various reasons, there would not appear to be a reliable and validated screening instrument for use in the HACC services, whose use has been evaluated in that context. The literature search identified six screens that measured functional dependency and that would seem to be relevant for use on community dwelling individuals. However, each one has limitations.

- the Rapid Disability Rating Scale (RDRS-2) rates people based on observation and is so not suitable for administration by telephone;

- the EARRS and RDRS-2 scales include predominantly more ADL than IADL items. As ADL functions are lost last, this suggests that the scales might have a ceiling effect if used in community dwelling individuals;
- the EARRS, RDRS-2 and Maly et al. screen include items that are not within the realm of functional impairment, and so are perhaps outside the scope of this project;
- the length of the 14-item OARS screen and the 18-item GARS scale is such that they are effectively equivalent to a screen consisting of the Barthel ADL and Lawton's IADL, the two recommended scales for measuring physical function;
- the 5-item OARS screen, seemingly the most appropriate of the six reviewed, has not been evaluated as to its effectiveness identifying patients for further assessment or in need of services.

(pg. 100)
Appendix 11: National HACC Functional Screening Instrument
(pg. 133)
Appendix 12: National HACC Functional Assessment Instrument
(pg. 135)

Assessment issues

A National snapshot of home support from the consumer perspective: Enabling people with disabilities to participate in policy analysis and community development
Krogh, K., Ennis, M. (Council of Canadians with Disabilities, www.ccdonline.ca/publications) Feb., 2005

In order to receive home support benefits, people with disabilities must first undergo an assessment process that is meant to evaluate their eligibility for home support services as well as the level (i.e., number of hours) and type of assistance (e.g., bathing, meal preparation) or service required. Home support users are usually required to undergo periodic reassessments on an annual or semiannual basis in order to determine any changes in health or living circumstances that would justify the change in service. The assessment, usually conducted by a home support administrator, social worker, registered nurse, or in consultation with a physician, consists of a series of standardized questions and tests designed to measure a person's degree of functional impairment, current economic resources and amount of informal support available from friends or family members. Home support services and funding are then assigned based on the assessment, to satisfy needs that cannot be met through current financial resources or social networks.

Due to the allocation of fewer dollars to government-subsidized home support and the resulting restrictions on services, the assessment process has become increasingly rigid and exclusionary. People with disabilities have found it harder to qualify for an adequate level of home support while current home support users must fight simply to maintain their present level of service, regardless of whether their disabling condition is stable or deteriorating.
(pg. 40)

According to many of the participants in the study, the assessment process for home supports is often overly restrictive, disproportionately emphasizes biomedical functional impairments to the exclusion of chronic and less visible impairments (e.g., those associated with pain, fatigue, or mental health) and often does not provide an adequate level of support. Consumers involved in this research project feel strongly that an appeal process should be a mandatory element of

eligibility assessments. Currently, however, there is much variability between provinces and territories regarding the nature of appeal procedures in home support systems across Canada. [...] Another significant problem with current appeal mechanisms is that there is a pervasive lack of confidentiality. [...] The lack of confidentiality in most appeal mechanisms discourages home supports users from filing an appeal for fear of retribution. [...] Many homes support users feel that the current appeal processes are intimidating and unfairly biased against consumers. Very few appeal committees involve representation from home support users or self-directed disability advocacy organizations, and as a result, many users feel that appeals are not impartial.
(pg. 47-48)

Additional Sources

A national classification system and payment model for private rehabilitation services
Centre for Health Service Development, University of Wollongong, Australia
Nov., 1999
On page 6 we summarise the result of our literature review. Over 800 papers were reviewed and approximately 40 papers were identified as being relevant to the project. Topics covered by the papers are discussed in the report under four headings:
§ rehabilitation outcomes and outcome measurement tools;
§ the details of classification systems, including the criteria to be considered in the decision to adopt a particular funding model;
§ the assessment of variables considered to be important in classification; and
§ funding models.
(pg. i)

Developmental disabilities profile: instructions for completing the developmental disabilities profile - Indiana Bureau of developmental disabilities services (2001)
The Developmental Disabilities Profile is not meant to be an all encompassing picture of the individual. Instead it is a "snap shot" of what the individual is capable of at the time of the assessment.

Developmental Disabilities Profile (DDP) Users' Guide
NYS Office of Mental Retardation and Developmental Disabilities (OMRDD)
Dec. 31, 1969

Guidelines for Interviewing People with Disabilities: Supports Intensity Scale
Tasse,M.J., Schalock,R., Thompson,J.R.,& Wehmeyer,M. (American Association on Mental Retardation)
2005

Supports Intensity Scale: Information
American Association on Mental Retardation (www.aamr.org)
2004

Internet resources (links)

Assessment of Disability and Needs

http://www.soton.ac.uk/~shec/assessmentdiscussionpaper.htm

Committee on Disability Determination for Mental Retardation
http://www4.nas.edu/webcr.nsf/CommitteeDisplay/BCSS-I-99-04-A?OpenDocument

Community care assessment and care management
http://www.northlan.gov.uk/caring+for+you/community+care+services/referral+assessment+and+care+management/community+care+assessment+care+management.html
or http://tinyurl.com/bxbup

Evaluation Center@HSRI (Human Services Research Institute)
http://tecathsri.org/
http://www.hsri.org

Functional Assessment Rating Scales
http://outcomes.fmhi.usf.edu/

Functional Independence Measure (FIM)
http://www.tbims.org/combi/FIM/

Medicaid Health and functional criteria for service eligibility
http://communitygateway.org/faq/medicaid/chapter_3.htm

NYS-OMRDD: DDP Users' Guide
http://www.omr.state.ny.us/wt/manuals/wt_ddp2guide.jsp#The%20DDP%20Forms

NYS OMRDD DDP USERS' GUIDE
http://www.omr.state.ny.us/wt/manuals/wt_ddp2toc.jsp

Supports Intensity Scale (SIS)
http://www.siswebsite.org/index.ww

Uniform Data System for Medical Rehabilitation
http://www.udsmr.org/

This literature review was assembled for the principal use of the Saskatchewan Community Living Division and the CLD Policy and Service Delivery Advisory Committee. Additional copies have been circulated to the respective governmental agencies responsible for the delivery of services to people with intellectual disabilities in the Canadian provinces and territories.

Note: Since this document conveys large portions of directly quoted material from several source documents, it is to be regarded as **confidential** and not released for general circulation. I have provided the most complete information possible for referencing this material. Copies of most of the source documents are available upon request to Duncan Blackman (Sask. CLD).

Human Rights

Introduction

During the last half century, universal human rights for all of humanity have been recognized, proclaimed, established in statutory law, and used to promote the inclusion and participation of all people, regardless of their differences and limitations, in society.

With the formation of the United Nations, the Universal Declaration of Human Rights established the principles upon which modern nations -- their laws and policies -- are based. In 1982, the Canadian Charter of Rights and Freedoms make provision in section 15 to ensure that no groups of people were excluded from the fundamental provisions of federal law. Additionally the provinces have enacted legislation to support the human rights of all people in their jurisdictions.

Currently from global perspective, a relatively recent initiative of the United Nations has been to draft an international convention on the rights of all persons with disabilities. The following excerpts from documents provide a foundational knowledge pertaining to the protection of human rights for people with intellectual disabilities.

Historical context

Council of Canadians with disabilities: Towards a UN disability convention - (2003)
www.ccdonline.ca

Six hundred million people in the world with a disability
Recognize disability as a part of human diversity rather than as a medical problem
Paradigm shift from disability as a social welfare/medical issue to disability as a human rights issue
Rest on the fundamental human rights values of the International Bill of human-rights: dignity and self determination, equality and social justice.
Fundamental rights include: right to live, freedom from torture and inhuman and degrading treatment, bodily and psychic integrity, liberty, equality, association, family/privacy rights, recognition as a person before the law, freedom of expression, vote and stand for election, citizenship, recognition of people with disabilities as a minority, education, work, health, access, standard of living, culture, and right to development.

Reviewing the Terms of Inclusions: Transactional Processes, Currencies and Context (Witcher, Sally (Centre for Analysis of Social Exclusion, London), April, 2003 CASE)
"It is presupposed that different types of rights exist, notionally, to perform certain functions. Rights, whether morally or legally based, can be construed as tools for rendering visible societal norms, to the degree that society tolerates individuals acting independently from it or in opposition to it, i.e. the space available for individuals to exercise agency in contravention of those norms. They can be devices for making explicit resource adjustments in order to achieve greater balance, or imbalance, between individuals in terms of participation or ownership of different types of scarce resources. They thus play an important role in making explicit the terms of inclusion, and in constructing the various roles in transactional processes." (p.59)

Persons with disabilities: CESCR general comment 5.
U.N. and Office of the High Commissioner for Human Rights
Sept. 12, 1994
The term "disability" summarizes a great number of different functional limitations occurring in any population. . . People may be disabled by physical, intellectual or sensory impairment, medical conditions or mental illness. Such impairments, conditions or illnesses may be permanent or transitory nature. Since the International Covenant on Economic, Social and Cultural Right's provisions apply fully to all members of society, persons with disabilities are clearly entitled to the full range of rights recognized in the covenant.
The obligation in the case of such a vulnerable disadvantaged group is to take positive action to reduce structural disadvantages and to give appropriate preferential treatment to people with disabilities in order to achieve the objectives of full participation and equality within society for all persons with disabilities. This almost invariably means that to additional resources will need to be made available for this purpose and that a wide range of specially tailored measures will be required.
The duty of States parties to protect the vulnerable members of the societies assumes greater rather than less importance in times of severe resource constraints.
In addition, it has been consistently acknowledged by the international community that policy-making and programme implementation in this area should be undertaken on the basis of close consultation with, and involvement of, representative groups of the persons concerned.
For the purposes of the Covenant, "disability-based discrimination" may be defined as including any distinction, exclusion, restriction or preference, or denial of reasonable accommodation based on disability which has the effect of nullifying or impairing the recognition, enjoyment or exercise of economic, social or cultural rights.
Comprehensive anti-discrimination legislation should not only provide persons with disabilities with judicial remedies as far as possible and appropriate, but also provide for social-policy programmes which enable persons with disabilities to live an integrated, self-determined and independent life.
Disability policies should insure the access of [persons with disabilities] to all community services.

The integration of persons with disabilities into the regular labour market should be actively supported by States.

The "right to everyone to the opportunity to gain his living by work which he freely chooses or accepts" is not realized where the only real opportunity open to disabled workers is to work in so called so-called "sheltered" facilities under substandard conditions. Arrangements whereby persons with certain category of disability are effectively confined to certain occupations or to the production of certain goods may violate this right. Similarly "therapeutical treatment" in institutions which amounts to forced labor is also incompatible with the Covenant. In this regard, the prohibition on forced labor contained in the International Covenant on Civil and Political Rights is also of potential relevance.

Disabled workers may not be discriminated against with respect to wages or other conditions if the work is equal to that of non-disabled workers. States parties have a responsibility to ensure that disability is not used as an excuse for creating low standards of labor protection or for paying below minimum wages.

Organizations of persons with disabilities should be consulted regularly by government bodies and others in relation to all matters affecting them; it may also be necessary that they be supported financially and otherwise so as to ensure their viability.

Institutionalization of persons with disabilities, unless rendered necessary for other reasons, cannot be regarded as an adequate substitute for the social security and income-support rights of such persons.

States should ensure that teachers are trained to educate children with disabilities within regular schools and that the necessary equipment and support are available to bring persons with disabilities up the same level of education as their non-disabled peers.

In order to facilitate the equal participation in cultural life of persons with disabilities, Governments should inform and educate the general public about disability. In particular, measures must be taken to dispel prejudices or superstitious beliefs against persons with disabilities ... Similarly, the general public should be educated to accept that persons with disabilities have as much right as any other person to make use of restaurants, hotels, recreation centers and cultural venues.

Beijing declaration on the rights of people with disabilities in the new century - Asian and Pacific decade of disabled persons, 1993-2002 -(2000)

Adopted at the world NGO summit on disability

This included the leaders of Disabled People's International, Inclusion International, Rehabilitation International, the World Blind Union and the World Federation of the Deaf, as well as national non-governmental organizations (NGOs).

We emphasize that the continued exclusion of people with disabilities from the mainstream development process is a violation of fundamental rights and an indictment of humankind at the inception of the new century.

We share the conviction that the full inclusion of people with disabilities in society requires our solidarity in working towards in an international convention that legally binds nations, to reinforce the moral authority of United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities.

We hereby send out a call to action to all concerned with equality and human dignity, to join together in widespread efforts to ensure the adoption of an international convention on the rights of all persons people with disabilities.
We commit our respective organizations to strive for a legally binding international convention on the rights of all people with disabilities to full participation and equality in society.

Of interest is the involvement, as advocates and participants, of Global Non-Governmental Organizations on Disability (NGOs) in the development of the new UN convention:

* Disabled Peoples' International (DPI)
* Inclusion International
* Rehabilitation International (RI)
* World Blind Union (WBU)
* World Federation of the Deaf (WFD)
* World Network of Users and Survivors of Psychiatry (WNUSP)

Human-rights and disability: the current use in future potential of United Nations human-rights instruments in the context of disability
Gerard Quinn and Teresia DeGener, United Nations, New York and Geneva
2002

A dramatic shift in perspective has taken place over the past two decades from an approach motivated by charity towards the disabled to one based on rights. In essence, the human-rights perspective on disability means viewing people with disabilities as subjects and not as objects. It entails moving away from viewing people with disabilities as problems towards a viewing them as holders of rights. Importantly, it means locating problems outside the disabled person and addressing the manner in which various economic and social processes accommodate the difference of disability or not, as the case may be. The debate about the rights to the disabled is therefore connected to a larger debate about the place of difference in society.
Seeing people with disabilities as subjects rather than objects entails giving them access to the full benefits of basic freedoms that most people take for granted and doing so in a way that is respectful and accommodating of their difference. It means abandoning the tendency to perceive people with disabilities as problems and viewing them instead in terms of the rights.
Four values-dignity, autonomy, equality and solidarity.
The "Medical model" of disability has frequently been a contrast in recent years with the "Human Rights" model. This human-rights model focuses on the inherent dignity of the human being and subsequently, but only if necessary, on the person's medical characteristics. It places the individual centerstage in all decisions affecting him/her and, most importantly, locates the main "problem" outside the person and in society.
To state the matter in positive terms, the end goal from the perspective of the human-rights model is to build societies that are genuinely inclusive, societies that value difference and to respect the dignity and equality of all human beings regardless of difference.
Societies have not done enough to enable those with disabilities who have a clear capacity for moral freedom to exercise their right of self-determination.
All persons not only possess inestimable inherent self-worth but are also inherently equal in terms of self-worth, regardless of the difference.

Solidarity - social support for a free and equal people
Civil rights - protecting people against the abuse of power
Human-rights are not merely about protecting people against the abuse of power - they are also about giving people access to power.
Economic, social and cultural rights - empowering people in their own lives. The right to housing is also of vital importance to people with disabilities for two reasons. First it is essential to have an affordable and accessible housing stock. It is also important to insure that the housing environment is "visible" so that people with disabilities can participate in the life of the community.
To sum up, one might say that the above values - and the human-rights they underpin - presuppose adequate protection against power, access for people to power, especially over their own lives and the life of the political community, and an elaborate social support structure designed to liberate people in their own lives and not to imprison them in gilded cages.
The right to freedom from torture and from inhuman and degrading treatment may also be violated where people with disabilities are institutionalized.
The right to liberty is affected by institutionalization.
The relative or absolute invisibility of persons with disabilities has meant that the legal structures created to advance private freedom and public freedom have either not been applied or have been applied with less rigour in the case of people with disabilities. This has produced a category of person who, while being dependent on the public sphere for survival, lacks access to or influence over public policy. Such persons are denied full admission to public power and full control over their individual destiny. They remain outside the mainstream of civil society.
Persons with disabilities are human beings and therefore share the same human-rights as everybody else and the right to enjoy them to the same degree.

This document provides an analysis of the application of the various United Nations conventions on rights to people with disabilities. This provides a foundation for the work which is being done internationally toward securing the rights of people with disabilities. Of particular note is the role that organizations of people with disabilities should have in the development of public policy.

International human rights and mental health legislation
Rosenthal, E., Sundram, C., Mental disability rights international, www.MDRI.org
Feb. 10, 2003
This article was originally written as a background paper to assist the World Health Organization in drafting a manual on mental health legislation. This article describes some of the elements of international human-rights law that government should take into account when drafting domestic legislation affecting people with mental disabilities.
It is not yet certain that the United Nations will adopt an international convention on the rights of people with disabilities, and even if it does so, governments will have to ratify a convention before it becomes legally binding.
In many cases, the laws do not actively discriminate against people with mental disabilities, but they may place improper or unnecessary barriers or burdens on individuals with mental disabilities.

While the Universal Declaration of Human Rights establishes a fundamental set of human-rights that applies to all nations, the UN drafted two international human-rights conventions to promote the implementation and oversight of the rights its established. The 2 core UN human-rights conventions are the International Covenant on Civil and Political Rights and the International Covenant on Economic, Social and cultural rights. Together with Universal Declaration of Human Rights, they make up what is known as the "International Bill of Rights".
In 1993, the World Conference on human-rights meeting in Vienna reemphasized the fact that people with mental and physical disabilities are protected by international human rights law and that governments must establish domestic legislation to realize these rights. In what has come to be known as the "Vienna declaration," the world conference declared that "all human-rights and fundamental freedoms are universal and thus unreservedly include persons with disabilities. "
The United Nations General Assembly adopted a new resolution (1993), the "Standard rules on equalization of opportunities for persons with disabilities". The standard rules established citizen participation by people with disabilities as an internationally recognized human right. The standard rules call on every country to engage in a national planning process to bring legislation, policies, and programs into conformity with international human-rights standards.
Human-rights conventions require governments to report regularly on the legislation they adopt and the policies they establish to implement the provisions of conventions.

The role of international human rights in national mental health legislation
Rosenthal, E., Sundram, C.J. (Department of Mental Health and Substance Dependence,World Health Organization, Geneva, Switzerland)
2004
Over the last half century, the importance of human rights has been recognized progressively by the international community, commencing with the adoption of the Universal Declaration of Human Rights in 1948 and followed periodically by human rights conventions which more specifically address certain aspects of human rights. At present, no convention addresses the special concerns of individuals with disabilities or the subgroup of people with mental disabilities. [...]
It is not yet certain that the United Nations will adopt an international convention on the rights of people with disabilities, and even if it does so, governments will have to ratify the convention before it becomes legally binding. This process is likely to take years. Until that time, governments are under an obligation to abide by the requirements of existing international human rights conventions and customary international law. [...] This document provides a broad overview of some of the most important protections that now exist under international human rights law for people with mental disabilities.
(pg. 1)
The requirements of international human rights law should be a major consideration in any legislation concerning people with mental disabilities or regulating mental health and social services systems. Article 1 of the Universal Declaration of Human Rights, adopted by the United Nations in 1948, provides that "all people are free and equal in rights and dignity" -- establishing that people with mental disabilities are protected by human rights law by virtue of their basic humanity. [...]
While the Universal Declaration of Human Rights establishes a fundamental set of human rights that applies to all nations, the UN drafted two international human rights conventions to promote

the implementation and oversight of the rights it established. The two core UN human rights conventions are the International Covenant on Civil and Political Rights (ICCPR) and the International Covenant on Economic, Social, and Cultural Rights (ICESCR). Together with the Universal Declaration of Human Rights, they make up what is known as the "International Bill of Rights." [...]
[A] number of specialized conventions have been established through the United Nations to provide the detailed and specific provisions needed to protect the rights of people who may be particularly vulnerable to discrimination and abuse -- including women, children, workers, and people subject to custody or detention. Politically, specialized conventions are important because they draw regular attention to the concerns of marginalized populations who may be overlooked by the mainstream human rights system.
(pg. 3-5)
In recent years, there have been a number of important developments that greatly aid the application of convention-based rights. In 1991, the United Nations General Assembly adopted the "Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care" (the MI principles). [...]
In 1993, the World Conference on Human Rights meeting in Vienna reemphasized the fact that people with mental and physical disabilities are protected by international human rights law and that governments must establish domestic legislation to realize these rights. [...]
Pursuant to the recommendations of the World Conference on Human Rights, the United Nations General Assembly adopted a new resolution, the "Standard Rules on Equalization of Opportunities for Persons with Disabilities" ("Standard Rules"). The Standard Rules are a revolutionary new international instrument because they establish citizen participation by people with disabilities as an internationally recognized human right. To realize this right, governments "*are under an obligation*" to provide opportunities for people with disabilities, and organizations made up of people with disabilities, to be involved in drafting new legislation on matters that affect them. The Standard Rules call on every country to engage in a national planning process to bring legislation, policies, and programs into conformity with international human rights standards. [...]
While the MI principles and the Standard Rules provide detailed guidance to legislators as to the requirements of international human rights law, the fundamental obligations of governments are established by the international human rights conventions. Human rights conventions require governments to report regularly on the legislation they adopt and the policies they establish to implement the provisions of conventions. Until recently, few governments have reported on the steps taken to ensure realization of the rights of people with mental or physical disabilities. [...]
This document will review international human rights law to provide a resource to legislators, policy-makers, mental health professionals and activists about government obligations that should be reflected in domestic mental health and disability rights legislation. The document will review a few of the most important convention-based rights and United Nations human rights standards, such as the MI principles and the Standard Rules. It will describe how these standards can be used as a guide to the requirements of international human rights conventions.
(pg. 6-9)
There are a number of important legal differences between international human rights conventions, such as the ICCPR and the ICESCR, and UN General Assembly resolutions, such as the MI principles and the Standard Rules. Conventions fall into the category of "hard"

international law and General Assembly resolutions fall into the category of "soft" law. Soft law instruments in the human rights field are also referred to as international human rights "standards." Soft law is considered "non-binding" and hard law is considered "binding." [...]
While this document focuses primarily on conventions, it is important to note that there are two main sources of binding international human rights law - customary international law and conventions. Customary international law is made up of legal principles so widely accepted by governments and legal scholars as binding that they need not even be written legal principles. [...] The "Universal Declaration of Human Rights" (UDHR) is the best example of a soft law (it was adopted in 1948 as a non-binding UN General Assembly resolution) that is widely considered to have become binding, customary international law. [...]
The others source of hard international law is convention-based law (conventions can also be referred to as treaties, pacts, or charters). The UN charter is perhaps the most important treaty since it establishes a framework for the United Nations and commits member states to promote universal respect for human rights. Unlike General Assembly resolutions, treaties are binding on governments (known as States Parties) that ratify them. [...]
Because the most specific human rights instruments relating to mental health and disability are non-binding resolutions rather than binding conventions, there is a widespread misconception that legislation to protect people with mental disabilities or regulate the operation of mental health and social service systems is subject only to the domestic discretion of governments. This is not the case. Governments are under an *obligation*, under international human rights law, to ensure that government policies and practices conform to binding international human rights law. [...] International human rights law creates a number of broad protections that provide important rights to people with mental disabilities. This document will review a few of those, including: (1) the right to with the highest attainable standard of physical and mental health; (2) protections against discrimination (3) protections against torture, inhuman, or degrading treatment; (4) protections against arbitrary detention. [...]
Within the regional human rights systems of Africa, the Americas and Europe, there is a highly developed system for enforcing human rights conventions. Individuals can bring complaints against governments in commissions or courts established under these conventions, and these bodies can arrange friendly settlements or issue binding decisions. [...]
Cases decided by the regional conventions are binding only within the human rights system created by the respective convention. However, these decisions can be useful in the interpretation of a similar protections in other conventions. [...]
Even where no international enforcement mechanism is available, many human rights conventions create a system for international monitoring. The major UN conventions, including the ICCPR and the ICESCR, create treaty-based supervisory bodies. Governments that ratify conventions agree to report regularly on the steps that they have taken to implement the convention -- through changes in legislation, policy, or practice. Non-governmental organizations can also submit information for review by oversight bodies. Oversight bodies review both the official and non-governmental reports and publish their findings, which may include the determination that governments have not met their international obligations under the convention. The international oversight and reporting process thus provides an opportunity to educate the public about a specialized area of rights. This process can also be a powerful way to pressure governments to realize convention-based rights.
(pg. 10-13)

Article 2 (1) of the ICCPR requires governments to "respect and ensure" the enforcement of human rights under the covenant. This clause has been characterized as an "obligation of result" because it requires governments not only to "respect" rights as a matter of law, but to "give effect" to these rights, i.e. to "ensure" their enforcement. [...]
The ICESCR creates immediate obligations on governments to begin planning ("to undertake to take steps") to bring about the full enforcement of the rights recognized under the ICESCR. [...]
The ICESCR may require governments to reform social and medical policies to bring about reform of rights under the covenant. [...]
The closer one examines any given right, the more it is clear the rights under the covenants are overlapping and mutually reinforcing. For example, a government may be under an obligation to create community-based services for people with mental disabilities under the ICESCR. The failure to create community-based services is likely to lead to "arbitrary detention" in psychiatric facilities under the ICCPR.
(pg. 16-17)

The following is a brief review of the most important UN human rights standards related to relating to people with mental disabilities. [...]
In 1971, the UN General Assembly adopted the "declaration on the rights of mentally retarded persons" (MR Declaration). The MR Declaration is in many ways dated. For example, the very term "mental retardation" is now widely viewed as derogatory, and the major international advocacy organization for people with intellectual disabilities, Inclusion International, opposes this terminology (this document will use the more current term "intellectual disability"). Despite its limitations, the declaration does establish some important rights. The person with intellectual disability has "the same rights as other human beings" which cannot be restricted without due process that "must contain proper legal safeguards against every form of abuse."
The MR Declaration protects against the common practice in some countries of stripping away a person's rights through a finding of mental incompetence or by placing people with an intellectual disability under guardianship for lifetime without due process. Instead of relying simply on the medical diagnosis, the MR declaration provides every person with an intellectual disability a right to evaluation of his or her "social capability" by a "qualified expert." Any determination of incompetence must be reviewed periodically, and an individual whose rights have been limited has a right to appeal to a court.
The MR Declaration recognizes the right to community integration and inclusion in society by establishing that "the mentally retarded person should live with his own family or with foster parents and participate in different forms of community life." The MR Declaration permits institutionalization if it should "become necessary," a vague standard that could easily be clarified in domestic legislation. [...]
The MI Principles have been recognized as "the most complete standards for the protection of the rights of persons with mental disabilities at the international level." [...]
The MI Principles establish standards for treatment and living conditions within psychiatric institutions, and they create protections against arbitrary detention in such facilities. These principles apply broadly to persons with mental illness, whether or not they are in psychiatric facilities, and they apply to all persons admitted to a mental health facility, whether or not they are diagnosed as mentally ill. [...]

The MI Principles protect a broad array of rights within institutions, including protections against "harm, including unjustified medication, abuse by other patients, staff or others..." [...] The MI Principles require treatment "based on an individually prescribed plan," and they require that "the treatment of every patient shall be directed towards preserving and enhancing personal autonomy." [...]
As a product of the Vienna Declaration's call for increased attention to the human rights of people with disabilities, the United Nations General Assembly in 1993 adopted the "Standard Rules on Equalization of Opportunities for People with Disabilities" (Standard Rules). The Standard Rules have major implications for the very process of developing mental health legislation because they recognize the right of people with mental disabilities -- and by extension organizations made up of people with disabilities -- to participate in national planning for mental health and social service reforms needed to bring countries in line with international human rights standards [...]
There is no more fundamental principle in the Standard Rules than the recognition of the rights of people with mental and physical disabilities to participate fully in matters that affect them. This specifically includes a right of people with disabilities to be included in a public process of legislative drafting. Governments are required to review legislation regularly and to establish national planning committees, and these committees must include representation of people with disabilities.
The Vienna Declaration similarly identifies rights of people with disabilities to "active participation in all aspects of society" as one of the specific rights established under international law.
What is intended by the Standard Rules is [...] a meaningful voice and participation in the process of developing legislation and monitoring its implementation. [...]
To implement the right to participate, people with disabilities, their family members, and community allies and advocates should be included in all aspects of planning, design, implementation and evaluation of services, supports and human rights oversight programs. [...] Governments should support the formation of such NGO groups and provide for their training to be effective advocates in performing these roles.
(pg. 19-23)
Article 12 of the ICESCR establishes "the right of everyone to the enjoyment of the highest attainable standard of physical and mental health." [...]
Instead, Article 12 has been interpreted as an obligation on governments to take specific steps to protect and promote health. The right to health can be viewed both as a "positive" right to government action or services necessary to maximize health and as a "negative" right to protection against unhealthy or dangerous conditions.
(pg. 27)
The right to the highest attainable standard of mental health under Article 12 entails a right on the part of people with mental disabilities to services that are (a) available (b) accessible (c) acceptable and of (d) appropriate and good quality. To be appropriately available, services must be provided in "sufficient quantity" by "trained medical and professional personnel." The concept of accessibility goes beyond physical access -- it also requires that services be affordable and available in a non-discriminatory manner. [...]
Principle 4 requires that "a determination that a person has a mental illness shall be made in accordance with international accepted medical standards." [...] These principles implicate the

relatively brief and informal process of the evaluation of patients that exists in many countries, which results in the diagnosis of mental illness which can have severe and lasting consequences for the individual's health and liberty. [...]
The principle that people with mental disabilities have right to individualized treatment is emphasized throughout the MI Principles. [...] The right to individualized treatment entails an obligation on governments to provide professional services tailored to individual needs (a) in the best judgment of professionals but also (b) respecting the preferences of the individual receiving services. Thus, one of the goals and requirements of individualized treatment is respect for individual choice in treatment. [...]
Both the MR Declaration and the MI Principles recognize that all treatment must be directed toward the enhancement of the autonomy and skills of each individual. [...]
The UN Economic, Social and Cultural Rights Committee interprets the right to health under the ICESCR to place great emphasis on promoting individual independence and social integration. [...]
The MI Principles have a number of provisions that promote the right to individual independence and autonomy within mental health care treatment. Under MI Principle 9(1), every individual "shall have the right to be treated in the least restrictive environment and with the least restrictive or intrusive treatment appropriate to the patient's health needs and the need to protect the physical safety of others. " [...] Principles that treatment should be the least restrictive possible is built into protections against such practices as physical restraints or involuntary seclusion. Principle 11(11) states that such practices should be used "only when it is the only means available to prevent immediate or imminent harm to the patient or others." [...]
In addition to recognizing the right to independence within mental health services, MI Principle 3 recognizes that " [e]very person with a mental illness shall have the right to live and work, as far as possible, in the community." [...] The MI Principles also recognize the right to community-based services and support systems necessary to promote this right. [...]
The Convention on the Rights of the Child (CRC) provides the strongest convention-based statement of the right to services that promote community integration. [...] Article 23(3) requires that service systems be:

> designed to ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child's receiving the fullest possible social integration and individual development. [...]

MI Principle 11 establishes that "no treatment shall be given to a patient without his or her informed consent...." Implicit in the formulation of Principle 11 is the concept of right to refuse treatment since a person may choose to withhold consent.
(pg. 29-34)
The concept of non-discrimination is closely linked with the concept of equality stated in Article 1 of the Universal Declaration of Human Rights: "[a]ll human beings are born free and equal in dignity and rights." The protection against discrimination is, first and foremost, a promise that people with disabilities will enjoy the same legal rights as all other individuals. [...]
The UN Human Rights Committee, established by the ICCPR to assist in the interpretation of the convention, defines discrimination as "any distinction, exclusion, restriction, or preference.... which has the *purpose or effect* of nullifying or impairing the recognition or enjoyment or exercise by all persons on an equal footing, of all rights and freedoms."

Thus, protections against discrimination under international law go much further than simply outlawing laws that explicitly or purposefully exclude or deny opportunities to people with disabilities. Legislation that has the *effect* of denying rights and freedoms is discriminatory, as well. [...]
For people with mental or physical disabilities, the protection against discrimination would be of limited value if it only meant that people situated similarly are treated equally. [...] Under the ICCPR, special protections or "affirmative action" is permissible -- and at times required -- to bring about equal protection under the law. [...] The Standard Rules also support the idea that resources may be needed in order to protect equal rights [...]
International human rights law creates direct legal obligation only on governments and not on private actors although governments can be required to adopt legislation that protects vulnerable populations even in the private sphere. Thus, the right to reasonable accommodation under the ICESCR is at its strongest in the area of public accommodations, particularly with the impact on the right to health. Public programs that allow non-disabled people to live in the community and avoid institutionalization may, for example, need to be crafted so that they meet the needs of individuals with mental disabilities. [...]
General Comment No. 5 recognizes that the right to community integration - including the right to medical and social services to permit people to participate fully in the community - is needed to protect people with disabilities against discrimination under is the ICESCR.
(pg. 38-44)
The Article 7 protection in the ICCPR against "inhuman and degrading treatment" is one of the most important protections under international human rights law for people with mental disabilities. Article 7 reads in full:

> No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his free consent to medical or scientific experimentation.

[...] Article 7 of the ICCPR requires governments to establish protections that would prevent unnecessary physical or mental suffering.
(pg. 47)
In recent years, the UN Human Rights Committee has taken a strong stand on the application of Article 7 of the ICCPR to all people in detention, including individuals in psychiatric facilities. General Comment 20(44) states that Article 7 "is complemented by the positive requirements of Article 10, paragraph 1 of the Covenant, which stipulates that 'All persons deprived of their liberty shall be treated with humanity and with respect for the inherent dignity of the human person.' "
(pg. 49)
MI Principle 13(2) specifically requires conditions to be age appropriate. It is common in institutions for adults with mental disabilities to be limited to activities that would be completely inappropriate to people of their age in society at large. Adults may be given children's stories or activities or may be left to repetitive tasks that they find mind numbingly boring. More pervasively, adults in institutions often spend their days without any purposeful activity at all. The absence of opportunities to engage in normal adult activities contributes to a progressive deterioration of their functioning abilities and a loss of skills. [...] The Human Rights Committee has stated that the duration of a particular practice is one factor is that would be taken into consideration in the determination as to whether treatment is inhuman and degrading.