



# Disability Policy: From Remedies to Rights

Prepared for Maytree by Sherri Torjman

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## Introduction

Persons with disabilities face a formidable policy Catch-22 when they seek assistance related to an impairment in physical and/or mental functions. In order to be eligible for any public program, such as financial aid or disability supports, applicants need to show proof of severe limitation in functional capacity.

Here's the irony: Positive public attitudes as well as self-confidence on the part of persons with disabilities are essential to encourage meaningful participation in society [WHO and World Bank 2011: 6]. However, this participation is often possible only with some form of aid or support, which requires proof of incapacity.

The primary way in which many persons with disabilities gain independence is to demonstrate serious dependence. The greater their incapacity, the more supports they receive. In short, *doing worse means doing better*.

Yet the reverse is also true. Once eligible for assistance, persons with disabilities who manage to improve their circumstances typically get penalized by various programs that effectively disincentivize their behaviour. In this case, *doing better means doing worse*.

Unfortunately, the policy focus for too long has been upon the people deemed to require assistance because of their limitations. It is time to tackle the many impairments in our public policies.

But while the repair of existing programs and services is necessary, it is by no means sufficient. This paper discusses the need to move beyond policy remedies toward a more robust conceptualization of disability rooted in human rights.

## Challenges in understanding disability: Conceptual frameworks

Disability is often equated with visible conditions that are observable and identifiable. In fact, the international symbol of disability is a person in a wheelchair. That icon is far too narrow a representation.

The term “disability” refers not to a single state but rather to a wide spectrum of conditions. These consist of physical limitations, such as mobility, visual, and hearing impairment. A range of invisible disabilities are less readily identifiable

but can be equally challenging. They include mental health conditions, such as cognitive and behavioural impairment, or mood disorders.

There is also a cluster of conditions known as developmental disabilities. Sometimes the latter term is used synonymously with intellectual disabilities. In other cases, it comprises a much wider spectrum. The US-based Centre for Disease Control, for example, includes in this category conditions such as autism, behavioural disorders, brain injury, cerebral palsy, Down syndrome, fetal alcohol syndrome, and spina bifida. The US *Developmental Disabilities Assistance and Bill of Rights Act* sets out an extensive definition of developmental disabilities.<sup>1</sup>

Another complication: Recent years have seen a rising incidence of chronic illness in Canada and throughout the developed world. Because of medical, technological, and social advances, people are now living longer with conditions that used to mean certain incapacitation or death [PHAC 2013].

Some chronic conditions, such as HIV/AIDS and multiple sclerosis, are considered “episodic” in nature. (Because of the challenges these conditions present, several groups are trying to introduce alternative terms, such as “fluctuating disabilities.”) While these conditions are long term and permanent in duration, they are nonetheless deemed episodic because their associated symptoms are expressed only intermittently. Persons with these conditions often function well and may experience few limitations for long periods. At other times and unpredictably, they contend with serious and debilitating symptoms that limit their ability to work or to participate in the community.

Many individuals are born with some form of functional limitation while others experience a functional limitation throughout the course of their lifetime due to an accident, injury, or illness. Still others face functional limitations involving hearing, sight, cognitive, and mobility impairment as a result of aging.

In fact, the experience of disability is intrinsic to the human condition. All individuals cope with some type of functional limitation to varying degrees and at different times in their lives. Temporary impairment is a normal part of living and may occur at any time. Moreover, the need for support at some point in later life is not the exception but the rule. The presence of functional impairment in the population is more prevalent than immediately apparent.

The translation of this variability into disability policy results in inequitable treatment between individuals who may have similar conditions. A person who is paraplegic as a result of birth trauma, for example, is eligible only for inadequate, rule-bound social assistance. By contrast, a person who is paralyzed as a result of a work accident may be entitled to compensation for loss and a stable income from provincial/territorial workers' compensation. Injured workers can also gain access to disability supports through various programs and services. They are part of an income and employment-based system which, in theory at least, is set up to meet their unique needs.

As if this complexity were not enough, there are questions as to whether certain conditions, such as addiction, should be considered a medical problem or a disability. The *Canadian Human Rights Act*, for example, employs a broad definition of disability, including previous mental or physical disability as well as disfigurement and past or previous dependence on alcohol or drugs.

The challenges in understanding disability have given rise to different conceptual frameworks to explain its various dimensions and provide guidance as to possible interventions.

The so-called medical model used to be the primary conceptual framework for understanding disability. Persons with disabilities typically were seen to have a medical condition in which their disability resulted from an impairment in physical and/or mental functions.

The medical model focuses on managing, minimizing, or curing the identified illness or disability. While a disabling condition is likely to reduce an individual's quality of life, it is assumed that medical intervention will limit or correct the problem. The medical model generally views disability as a personal abnormality or health condition to be fixed.

The purpose of medical intervention is to improve and/or expand functioning, and to enable persons with disabilities to lead a more "normal" life. Physicians and health professionals, including psychologists, physiotherapists, and occupational therapists, are the primary actors in the medical model.

This dominant conceptual framework began to be challenged in the 1970s on the grounds that it was both inaccurate and too narrow a conceptualization:

A legacy of medicalization of disability has meant that disability continues in many parts of the world to be considered as a health issue to be prevented, cured or treated. This has often meant few hours of actual treatment or rehabilitation but a reliance on medical professionals rather than educators or employers and little or no support for the family [Inclusion International 2012: 8].

Through both academic papers and informed debate, disability activists began to shape a new discourse in reaction to the medical model, which they felt did not adequately reflect their personal experience. Neither did the health-based approach encourage the adoption of inclusive measures.

In 1983, UK academic Mike Oliver coined the phrase “social model of disability” to portray the evolving conversation [Oliver 2013]. The social model views disability not as a problem embedded in a person’s difference or impairment. Rather, it reflects the way in which society is organized. The source of incapacitation is the broader society that makes it difficult for persons with impairment in physical and/or mental functions to engage as active participants. When physical and social environments are adapted to individual need, the impact of a disabling condition can change in severity or even disappear.

The social conceptualization targets the physical, policy, and attitudinal barriers that tend to segregate or exclude persons with disabilities. Attitudinal barriers, in particular, are rooted in false assumptions and lack of understanding of capacity. In this conceptualization, solutions focus more on social change than on the individual with the disability.

To capture this new thinking and bring greater conceptual rigour to the field, the World Health Organization (WHO) introduced a framework for understanding disability. In 1980, it published the *International Classification of Impairments, Disabilities and Handicaps*, which made a distinction among three linked, but distinct, terms [WHO 1980].<sup>2</sup>

In this framework, *impairment* is a long-term limitation of a person’s physical, mental, or sensory function. *Disability* refers to any limitation or functional loss deriving from impairment that prevents the performance of an activity in the time considered normal for a human being. *Handicap* is the disadvantaged condition deriving from impairment or disability that limits a person from performing a role considered normal in respect of age, sex, and social and cultural factors.

The social model of disability has had a profound impact upon the disability narrative. A medical or health-related condition need not be disabling in itself. At the heart of the problem is the exclusion resulting from current social arrangements.

Unfortunately, however, the eligibility criteria for disability-related programs focus almost exclusively on individual capacity – or lack thereof. This causes problems when various benefits, programs, and services are delivered solely on the basis of disability definition.

## Challenges in defining disability for policy design

Definitions play a central role in policy design because they shape the eligibility criteria for certain benefits, programs, and services. Determination of eligibility typically involves objective criteria such as age, gender, net income, citizenship status, or designated status, such as Indigenous Canadian or veteran.

Programs and services intended for persons with disabilities also employ a set of eligibility criteria, all of which require proof of incapacity. Here's where the challenges arise. As we have seen above, disability is far from black or white, present or not. Rather, it is a matter of degree along a continuum.

In fact, the UN *Convention on the Rights of Persons with Disabilities* recognizes the intrinsic complexity of this term. Its Preamble states that “disability is an evolving concept resulting from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others” [United Nations 2006: 1].

Moreover, various disability-related programs are designed for distinct purposes:

- Provincial/ territorial workers' compensation programs recognize reduction in or loss of function;
- Federal Employment Insurance and the Canada Pension Plan Disability Benefit replace employment income interrupted as a result of short-term illness or long-term disability, respectively;

- The Canada Workers Benefit (the former Working Income Tax Benefit) bolsters low earnings and provides a supplement to workers with disabilities;
- Provincial/territorial social assistance (welfare) pays income benefits; and
- The federal Disability Tax Credit (DTC) helps offset additional costs linked to some form of functional limitation.<sup>3</sup>

Because the purpose of these programs is distinct, each program employs a different definition of disability. The result is a plethora of eligibility criteria, some of which incorporate capacity to work, while others do not [Thornton and Lunt 1997: 70]. See Appendix for selected definitions.

Despite their distinct purposes, there is an implicit hierarchy to these programs, as noted.

Beneficiaries of work-related income programs, in particular, are seen to have contributed to society through their labour market participation and, in the case of Canada Pension Plan Disability Benefit (CPPD), have made requisite financial contributions to the plan. Social assistance recipients, by contrast, may not have had significant work experience or any at all. The latter program is more punitive, requiring a stripping of assets and steep repayment of earnings in the form of a “welfare taxback.”

In fact, the federal government used to apply at least ten different definitions of disability across its suite of programs. Even the title of the 2003 government report *Defining Disability: A Complex Issue* speaks volumes about the eligibility challenges [Government of Canada 2003: 2]. The report highlighted the confusion among definitions, eligibility criteria, and program objectives, and concluded that solutions will need to address broader issues beyond just definitions:

...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 [Government of Canada 2003: 2].

The problem of defining disability in a clear and consistent way is not unique to Canada. Definitions of disability vary widely throughout the world. In 2002, for example, the European Commission published a study entitled *Definitions of Disability in Europe: A Comparative Analysis*. The multiple definitions of disability were creating challenges related to cross-border claims of social security benefits and access to welfare services [Government of Canada 2003: 66].

A study of disability-related employment policy in 13 industrialized countries found wide variations in definitions not only between but also within countries [Thornton and Lunt 1997]. In Australia, for instance:

There is some controversy over definitions between organisations of disabled persons and the State and Commonwealth Governments. Definitions of disability can also differ between Departments, making it difficult to determine exactly which groups of people are being referred to and whether programmes are able to meet a range of needs depending on type and level of disability [Thornton and Lunt 1997: 13].

While some observers have called for a single definition of disability, most agree that it likely is not possible to capture the wide-ranging complexity within a single construct. The Government of Canada in its 2003 report *Defining Disability* explicitly notes that:

...there is no simple way of defining disability, and that one definition of disability that fits all circumstances may not be possible nor desirable. Disability is difficult to define because it is a multidimensional concept with both objective and subjective characteristics [Government of Canada 2003: 41].

Because a single definition appears neither practical nor feasible, both consumers and policy advocates have proposed simplified administrative processes in order to reduce the multiple and onerous application procedures. The Government of Canada (2003) noted that concerns around eligibility criteria were brought forward on several occasions by disability organizations and academics:

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. The Subcommittee

reflected these concerns in three reports. The first, in June 2001, was *A Common Vision*, in which Recommendation 6 specifically asked the Government of Canada to study the harmonization of disability definitions in federally administered programs [Government of Canada 2003: 4].

In recognition of these complexities, the federal government attempted to reduce access barriers by introducing a “gateway” process. Eligibility for certain disability-related programs would mean that the applicant had passed a rigorous screen and could automatically qualify for other programs as well. Ottawa began to use the Disability Tax Credit (DTC) as the access door to a range of disability-related benefits and programs, including the Registered Disability Savings Plan (RDSP), Child Disability Benefit, and disability supplement to the Canada Workers Benefit.

On the one hand, use of the DTC as a screen for several other benefits helped simplify multiple administrative processes, and saved time and resources for both consumers and the government. But it is difficult to qualify for the DTC because of the challenges in assessing functional capacity.

One of the most significant problems involves the high rate of rejection among persons with impairment in mental functions, in particular [Standing Senate Committee on Social Affairs, Science and Technology 2018; Dunn and Zwicker 2018; Department of Finance Canada 2004; HUMA 2001, 2002]. Another concern relates to perceived unfairness. People with the same medical diagnosis are not necessarily treated the same way – someone with a diagnosis of schizophrenia or bipolar disorder, for example, might qualify for the DTC while others with the same condition do not. The difference is the degree of functional incapacity. The Minister of National Revenue has appointed a Disability Advisory Committee to address these challenges.<sup>4</sup>

There are also debates as to what comprises an “activity of daily living.” Some definitions include work as a basic life activity while others do not. Questions also arise about the meaning of severity. Is a condition considered severe if symptoms appear 50 per cent, 75 per cent, or 90 per cent of the time? While the 90 per cent guideline is currently in place for the DTC, it is difficult to apply, especially in the case of impairment in mental functions and for episodic disabilities. The Standing Senate Committee on Social Affairs, Science and Technology recognized this concern in a 2018 report:

The committee also heard about the significant barriers that people living with episodic disabilities such as Multiple Sclerosis (MS) experience when trying to access the DTC. At present, a person's disability must last for a continuous period of at least 12 months. This is problematic for people with chronic diseases that present episodic symptoms. For example, MS is a chronic, degenerative disease with no known cure. Symptoms can come and go unpredictably, being very severe and debilitating at some times and then abating for periods of time. The current criteria for the DTC do not capture the reality of those living with unpredictable, episodic experiences of disability, even though they face the same higher costs of living, economic challenges and income insecurity [Standing Senate Committee on Social Affairs, Science and Technology 2018: 11].

Despite the multiple complexities, one thing is certain. When applying for any disability benefit, program or service, it is always better to be deemed as incapacitated as possible. The more severe the disability, the better off the applicant from an eligibility perspective. The implication in practice is: *Doing worse means doing better.*

But the challenges don't end there. The reverse (perverse) is also true. Individuals who are able to improve their circumstances often get penalized, especially if they are eligible for some form of income support. In this case, *doing better means doing worse.*

Both scenarios, along with proposed policy remedies, are discussed below. These policy remedies are crucial short-term actions to fix the current policy Catch-22s in which doing worse means doing better and doing better means doing worse.

## **Policy challenges and remedies**

### **i. DOING WORSE MEANS DOING BETTER**

Because eligibility for disability-related benefits, programs, and services is determined not on the basis of diagnosis but rather functional capacity, the assessment process is necessarily subjective.

A functional capacity assessment means that a designated health professional must attest to the presence of serious impairment. In order to qualify, there must be clear evidence as to the persistence and severity of disability.

In fact, the more severe the incapacity the better when it comes to qualifying for key benefits, programs, and services. Eligibility for the federal Disability Tax Credit, for example, is determined by severe and prolonged impairment in capacity. Individuals who show signs of progress in their functioning risk not qualifying for the credit, despite substantial costs associated with their condition. Or they may not requalify for the credit if they were initially deemed eligible for a designated period.

Even if more clear definitions were in place, it will likely never be possible to eliminate concerns regarding unfair disability assessments. Unfortunately, errors in judgment and perceived inequity invariably will arise when eligibility involves a determination of functional incapacity.

Strategic policy remedies would help address these problems. Any assessment process should have in place several layers of checks and balances. Safeguards could be introduced to improve the assessment process and to reduce questionable refusals and inequitable treatment.

First and foremost, it is essential to ensure that the government assessors who are assigned to review applications have adequate and consistent training, particularly around impairment in mental functions. This assessment tends to be more subjective and complex than a determination of impairment in other functional areas, such as vision, hearing, or mobility.

In a recent review of the Canada Pension Plan Disability Benefit, the Auditor General found great variability in the way in which similar eligibility applications were assessed [Office of the Auditor General 2015]. He recommended a quality assurance framework to improve the effectiveness and consistency of decisions regarding eligibility:

We found that the Department did not have a quality assurance framework in place to ensure that medical adjudicators followed the adjudication framework to make appropriate and consistent decisions. We also found that the Department did not analyze program data, such as trends in regional granting rates, as a way to identify areas for improvement. Finally, we found that the Department did not analyze the Tribunal's appeal decisions to determine why it had overturned the Department's decisions, and to adjust the adjudication framework to reflect the rationales in those appeals [Office of the Auditor General 2015: 6.58]

The Auditor General concluded that a quality assurance framework likely would have reduced the variability in eligibility decisions:

We also noted that the Department's data on granting rates for initial applications varied significantly across the regional service centres. For example, the national average was 43 percent for the 2014-15 fiscal year, but granting rates for individual service centres ranged from 35 to 49 percent. Granting rates for reconsideration decisions also varied by regional service centre, ranging from 31 to 45 percent. There may have been valid reasons for these variations; however, without a quality assurance framework, the Department had limited means of knowing whether the variations were acceptable [Office of the Auditor General 2015: 6.65].

Other quality assurance procedures include second-opinion screening. Cases that are considered to be particularly difficult to assess, especially those that involve impairment in mental functions or episodic disabilities, could require a compulsory independent assessment screening.

A second, independent team would review any application for benefits or services that has been refused when required forms, duly completed by the appropriate health practitioner, would indicate otherwise. The opinions of relevant health professionals, such as psychiatrist or psychologist for cases of impairment in mental functions, could be sought for complex cases.

While some form of second-level screening would add to the cost of assessment, there may be considerable savings in the long run. Cases are often overturned at the appeal stage, which represents a costly quasi-judiciary process that ideally should be avoided.

The Auditor General noted, for example, that an estimated 33 per cent of refused applications for the Canada Pension Plan Disability Benefit were overturned on appeal, even when significant new information was not provided.

In our opinion, this calls into question the appropriateness of the initial and reconsideration decisions, and supports our previous observation about the lack of quality assurance and its implications for applicants. Moreover, in our review of appeal files in which the Department had overturned previous denials, we found that most did not contain significant new information [Office of the Auditor General 2015: 6.102].

It would also be helpful to set up a central application point in order to reduce the time and effort involved in qualifying for disability supports. The Disability Strategy introduced in 2015 by the Government of Saskatchewan called for the creation of an online portal to apply for disability-related services. This arrangement would avoid the unnecessary use of health care personnel in completing multiple forms for a given individual [Government of Saskatchewan 2015].

But while this approach enables access to a range of programs and services, a single assessment process can also close the eligibility door. The Disability Tax Credit, as noted, acts as a gateway for a range of federal disability-related programs, including the Registered Disability Savings Plan (RDSP). Individuals who are refused DTC eligibility find that they are cut off from other essential supports. One solution is to identify a cluster of gateway programs, such as long-term social assistance and the Canada Pension Plan Disability Benefit in addition to the DTC.

Finally, while quasi-judicial appeals are to be avoided, they are an essential secondary safeguard. However, the current appeal process requires substantial reform. It can be complex and intimidating for applicants. Moreover, the substantial backlog of cases in disability-related programs makes for justice delayed, which often means justice denied.

## **ii. DOING BETTER MEANS DOING WORSE**

There is another side to the disability story and it is the reverse of the first: Doing better means doing worse. While the issue is distinct, it is nonetheless linked to the first policy concern. There are two dimensions to this issue.

Sometimes doing better means doing worse because entitlement to support is based on the extent of functional impairment. But if a new treatment/technology helps reduce the impairment, program applicants are deemed less disabled and receive fewer supports.

The second dimension to the problem is financial. When individuals who receive income assistance try to improve their circumstances, they rarely come out ahead. In fact, they typically must pay for the health- and disability-related supports for which they previously had received assistance. They end up no better off.

Perhaps the most egregious example of this problem is rooted in social assistance. The Caledon Institute coined the term “welfare wall” to describe the problem and identified the multiple bricks that comprise this wall [Torjman and Battle 1993].

Welfare recipients who try to return to work or take some employment must pay back to government most of their earnings through a mechanism known as the welfare taxback. While the rules vary by jurisdiction, recipients effectively return to government much of their outside pay. In addition, income taxes and payroll taxes, notably Employment Insurance premiums and Canada Pension Plan (CPP) contributions, can further reduce overall income. Higher earnings also mean lower tax credits, such as the GST Credit or Canada Child Benefit.

While all social assistance recipients experience a welfare wall, those with disabilities may face additional consequences. The loss of income-in-kind, including supplementary health, dental, and drug benefits, can be financially devastating. In a detailed analysis, a 2017 *Toronto Star* article described the serious problems encountered by one woman, Michelle Kungl, who has tried over the years, despite the presence of a severely disabling condition, to improve her circumstances [Monsebraaten 2017]. Unfortunately, her case is not unique but represents typical government policy.

Michelle was born with a disability so severe (broken neck) that no one expected her to survive. She is alive today thanks to medical intervention. She requires a ventilator to breathe, on-site attendants, and multiple accommodations to her physical environment. At the time of the article, she was earning more than \$42,500 a year as a credit card fraud investigator for a bank.

Michelle receives financial support under the Ontario Disability Support Program (ODSP) to help pay thousands of dollars for essential disability supports and accommodation. But if her work earnings happen to exceed the allowable ODSP income cut-off, this special assistance is suspended:

The bad news comes first thing in the morning on July 6, when Michelle's ODSP worker calls to say her provincial support has been suspended for about the 50th time in almost 14 years. Today, it is because she received three bi-weekly paycheques in June and has – once again – exceeded the program's monthly income threshold [Monsebraaten 2017].

Special assistance should not automatically be cut off at certain trigger points. Rather, the assistance should remain in place when it clearly acts as a vital enabler of survival, participation, and inclusion.

The reality is that Michelle's condition is not going to improve. She will always require extra supports not only to work and to participate in society but also to survive. Instead of recognizing these circumstances and enabling her independence, the program requires the re-establishment of eligibility and proof of need. It is difficult to imagine why someone who needs a ventilator in order to breathe is asked to continually renew her application for assistance.

The policy approach should be to celebrate resilience and enable achievement. But current policies have the opposite effect. In this case, the income test embedded in the welfare system acts as a disincentive to work by making Michelle ineligible for assistance with essential disability supports.

It should be noted that these problems are not unique to persons with physical disabilities. They apply to persons with impairment in mental functions as well:

If a person with an intellectual disability gets a job and begins to move towards independence in the community, their income will often render them ineligible for assistance making it impossible for them to stay in the workforce. Policies that link eligibility for disability supports to income needs effectively trap people and prevent them from participating in the community and the labour market [Inclusion International 2012: 72].

An important policy remedy is to remove the provision of disability supports from income programs, including social assistance. Disability supports refer to various goods and services that help offset the effects of a disabling condition. These generally fall into two categories: technical aids and equipment, and personal services including attendant care, homemaker services, and personal assistance with the activities of basic living [Torjman 2015].

The Caledon Institute had proposed the introduction of a national Disability Supports Plan to improve the availability of these essential supports. A federal investment would bolster provincial/territorial capacity to provide these supports. The proposed plan would embed clear guiding principles, such as self-determination, accessibility, and portability. There is policy precedent in the *Canada Health Act*, which sets out the key principles that provinces and territories must respect in order to receive federal transfers [Torjman 2000].

A national Disability Supports Plan would establish a mechanism separate from income programs for the provision of disability-related goods and services. Persons with disabilities would no longer need to apply through social assistance or rely on an income program in order to obtain essential supports.

The UN *Convention on the Rights of Persons with Disabilities* encourages State Parties to undertake or promote research and development, as well as availability and use of new technologies, including information and communications technologies, mobility aids, devices, and assistive technologies [United Nations 2006: 6]. While Canada is a signatory to the Convention, no order of government appears to have taken noteworthy action in this area, despite recent federal interest and investment in innovation.

One such example of a federal initiative that could house research and development is Ottawa's Innovation Strategy, which seeks to promote an entrepreneurial mindset in Canada. Its Innovation Superclusters Initiative will invest up to \$950 million by 2022 to accelerate the growth and development of business-led superclusters in highly innovative industries, such as advanced manufacturing, agri-food, clean technology, digital technology, health/bioscience and clean resources, infrastructure, and transportation [Department of Finance Canada 2017: 79].

Investment in disability supports would appear to dovetail perfectly with this initiative, given their links to both digital technology and health/bioscience. But relatively small markets for certain aids and equipment tend to deter investment. There may well be substantial markets for assistive devices if they were developed as innovations with a potential global market.

Another important policy remedy is to fast-track reinstatement of income benefits if a work experience is not successful. Fortunately, there are some notable policy developments.

Several changes have been made in recent years to remove disincentives from the Canada Pension Plan Disability Benefit (CPPD). The program used to have strict rules regarding work and volunteer participation. The CPPD now allows beneficiaries to volunteer, go back to school to upgrade or complete a degree, or take a re-training program. It also permits recipients to have modest earnings (\$5,500 before taxes in 2018) without any loss to their income benefit.

In an effort to provide positive incentives, CPPD beneficiaries may also be eligible for vocational counselling, financial support for training, and job search assistance through the Disability Vocational Rehabilitation Program. The CPPD will continue to be paid, including during job search.

Automatic reinstatement is another crucial reform. In the past, CPPD beneficiaries used to be cautious about testing out possible work arrangements. If the latter were unsuitable for whatever reason, these individuals would lose eligibility for the program. That hurdle has now been bridged.

If the disability recurs within two years, making it impossible to continue working, benefits can be automatically reinstated without having to go through the usual reapplication process. Beneficiaries whose disability recurs after they have been working for more than two years and up to five years may qualify for fast-track reapplication.

There are still multiple problems in the CPPD program, especially around initial eligibility. But at least some of the glaring disincentives to work and community participation have been reduced or removed.

## **From remedies to rights**

The policy remedies approach seeks to fix problems in the current system, whether these arise from multiple challenges in accessing programs or from being trapped in them once eligible. A suite of policy actions must be taken to tackle the dual perversity in which doing worse means doing better and doing better means doing worse.

While policy remedies are necessary, they are not sufficient. The evolving narrative on disability, while rooted in the social model, has embraced a human rights approach, which seeks to enshrine in legislation the right of persons with disabilities to participate as full citizens. A 2003 Government of Canada report states that:

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) [Government of Canada 2003: 8].

A human rights approach contends that all persons, regardless of ability or other differences, are entitled to the full rights and privileges of citizenship even though they may require differential treatment and conditions, including modifications of various environments, in order to exercise those rights [United Nations 2006: 4]. This approach to disability is more proactive than simply reducing or removing the multiple barriers that the policies and programs themselves have created.

A human rights approach to disability implies a *positive obligation* in which governments are both expected and required to put in place measures to ensure full participation in society. Public and private institutions must not only respond to the claims of persons with disabilities and other marginalized groups; they also have a duty to ensure that conditions are in place for the exercise of rights.

The UN *Convention on the Rights of Persons with Disabilities*, which was adopted in 2006 and entered into force in 2008, makes clear this obligation:

To enable persons with disabilities to live independently and participate fully in all aspects of life, the Covenant requires States Parties to take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas. These measures shall include the identification and elimination of obstacles and barriers to accessibility [United Nations 2006: 9].

Canada ratified the Convention in 2010. There are several components to this obligation, which involve universal design and welcoming communities, reasonable accommodation, and authentic inclusion related to education, housing, and the labour market.

## **i. UNIVERSAL DESIGN AND WELCOMING COMMUNITIES**

Part of the answer to active citizenship lies in universal or inclusive design, which refers to the design of products, environments, programs, and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design. Universal design is helpful not only for persons with disabilities but for all community members, including parents with babies, young children, and seniors.

The concept and practice of universal design would apply to homes, workplaces, and communities right from square one. It would not be necessary to spend substantial sums on retrofit because accessibility would be baked into the initial planning and design.

On a positive note, the federal government tabled Bill 81: *Accessible Canada Act* in June 2018. The purpose of the bill is to make Canada barrier-free in areas under federal jurisdiction. The bill outlines how to identify and remove accessibility barriers and prevent new barriers under federal rule, including in:

- built environments (buildings and public spaces)
- employment (job opportunities and employment policies and practices)
- information and communication technologies (digital content and technologies used to access it)
- procurement of goods and services
- delivering programs and services
- transportation (by air as well as by rail, ferry, and bus carriers that operate across a provincial or international border).

While a major advance, the Act would apply only to spaces and procedures in the federal domain. Provincial/territorial governments and municipalities must take similar proactive steps in their respective jurisdictions. Several have already moved in this direction.

Ontario assumed a leadership role by enacting legislation that requires municipalities, businesses, and voluntary organizations to meet designated standards of accessibility. The *Accessibility for Ontarians with Disabilities Act* lays out the goal of an accessible Ontario by 2025. Every private and non-profit organization with one employee or more is required to take specific steps to fulfill the obligations under the Act.

Québec launched a program to support municipalities in their efforts to create age-friendly communities. Changes to the *Community Planning Act* in New Brunswick make mandatory the adoption of the Barrier-Free Design Building Code for new construction province-wide.

At the municipal level, the City of Vancouver announced in November 2013 a new regulation on accessible construction, which applies to *all* new home construction and renovations, and not just public buildings. Mandatory accessibility features include wider doors, hallways, and stairs, and lever handles on all doors and plumbing fixtures.

But the goal of inclusion involves more than just physical presence, which alone does not necessarily lead to genuine participation. People with intellectual disabilities often take part in community-based activities in segregated spaces intended only for them. Inclusive communities help create meaningful relationships, not just accessible physical place [Wilson and Jenkin 2010]. The Canadian Association for Community Living (2011) lays out the different components of social inclusion:

.... the core components of social inclusion for people with intellectual disabilities are: development of a wide range of personal relationships across all aspects of community life, the building of social networks and enjoying a variety of social interactions with non-disabled others in which people are valued for their unique identities and contributions. They also identify a sense of belonging as another key component [CACL 2011: 5].

A noteworthy development related to authentic inclusion involves a partnership of 11 national organizations taking steps to end the isolation of persons with disabilities – The Belonging Initiative.<sup>5</sup> The Initiative is informed by the direct experience of these individuals, and a recognition that more work needs to be done:

Despite our awareness of isolation and loneliness among people with disabilities, despite the growing body of knowledge related to promoting relationships, and in spite of our respective efforts to assist people who live on the margins, we have a long way to go. Far too many people with disabilities are alone except for the persons who are paid to be with them [“The Belonging Initiative” n.d.].

The Belonging Initiative is establishing a No One Alone Fund to stimulate social innovation and finance work to end social isolation. It is also creating a social learning network to share collective expertise, and to develop and disseminate new knowledge [“The Belonging Initiative” n.d.].

While effective policy measures are essential, they only go so far. Meaningful human relationships that emerge through authentic engagement in society lie at the heart of the solution.

## **ii. REASONABLE ACCOMMODATION**

Even with universal design and welcoming communities, additional modifications will always be required in order to accommodate individual need. In fact, the *Canadian Charter of Rights and Freedoms* recognizes that advancing equality does not necessarily mean treating all individuals the same way. Rather, it means accommodating difference.

The *Convention on the Rights of Persons with Disabilities* defines reasonable accommodation as:

necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms [United Nations 2006: 4].

An accommodating society would make disability supports readily available and affordable, as discussed. These supports would not be embedded in income programs but would be delivered separately to encourage participation in society and reduce disincentives to work.

## **iii. AUTHENTIC INCLUSION**

Perhaps the most important action in moving toward a human rights approach to disability is to ensure access to opportunities in education, housing, and employment, which are available to all Canadians. A report by Inclusion International [2012] highlights the importance of inclusion across all facets of community life:

Unless communities are organized to be inclusive of people with disabilities through education, employment, social, cultural and political processes, investments in services alone will not enable the realization of the right to live and be included in the community [Inclusion International 2012: 5].

Authentic inclusion means fewer disability-specific programs. The Catch-22 policy traps, earlier described, would be not so problematic because there would be less need for disability assessment. Fewer individuals would be hampered by disincentives such as the welfare wall.

At the same time, it is important to recognize that there will always be a need for additional supports for some individuals. This provision must be understood as an essential part of the equation.

Moreover, the direct engagement of persons with disabilities in the policy process is vital to any transformative change because they are best able to speak to the effects of changes in policy. As Bach and Gallant [2012] note, this direct engagement highlights problems and opportunities that are not immediately apparent to policymakers:

Ongoing engagement brings a critical dimension of policy knowledge to the table – about how various policies and programs intersect and operate in the lives of actual people, households and communities. Because policy makers are bound by the accountabilities of a particular program, policy framework and departmental mandate, it is often difficult to see how a program plays out in a person’s life, beyond the “silos” of these specific mandates and operations [Bach and Gallant 2012: 5].

## Education

Children with disabilities must attend regular schools like all other children. While these children may need additional assistance or accommodation, they still should be able to participate in a classroom with peers their age. Bach and Gallant [2012] note that addressing barriers to education requires policies and programs that cut across many domains:

Achieving inclusive education requires a policy agenda that addresses teacher training (post-secondary education policy), family supports, early learning and child development, education policy and programs (curriculum modification, in-class supports to teachers and students), school-based health care and therapies, labour market policies that provide parents with needed flexibility, and community-based services that enable effective transition to post-secondary opportunities and employment [Bach and Gallant 2012: 4].

## Housing

Persons with disabilities must have greater choice in their housing options. Right now, many “choose” between institutional or group home settings, and life with their parents or other family members. Living independently with a friend and/or personal support assistant is not an option due to the lack of accessible and/or affordable housing.

In Canada, modest progress has been made in recent years, but more investment is required. As part of its National Housing Strategy, the federal government announced in May 2018 a new \$13.2-billion National Housing Co-Investment Fund for affordable housing initiatives across the country. Over the next 10 years, Ottawa will work with partners to create up to 60,000 new affordable units and repair an estimated 240,000 existing affordable and community units. These investments will also support the creation of 2,400 new affordable units for persons with developmental disabilities [CMHC 2018].

The National Housing Strategy is also committed to achieving positive outcomes for persons with disabilities by improving social inclusion and accessibility:

The National Housing Strategy is expected to have a positive impact on people with disabilities, especially women by improving social inclusion, including accessibility of housing units as well as other accessibility measures, such as proximity to transit, services and supports, and employment opportunities. The National Housing Co-Investment Fund sets accessibility requirements for new and renewed projects and targets the construction, repair and renewal of housing for people with developmental disabilities [Government of Canada 2018: 26].

## Employment

In a fully inclusive society, there would be no more sheltered or segregated workshops for persons with disabilities.<sup>6</sup> Various training initiatives would be carried out in regular training facilities intended for all Canadians. Once again, modest additional assistance or accommodation might be required for some participants. CACL (2011) highlights that there has been notable, but insufficient, progress on this front:

While there was a significant effort to close sheltered workshops and move toward supported employment in the 1970's and 1980's, this progress has stalled. Efforts at transition from sheltered workshops appear to have more often resulted in programs oriented toward social and community integration or to employment supports that still retain an enclave model rather than labour market inclusion. Many services that continue to operate on a sheltered workshop model have reframed their activities as “training programs,” “life skills” and “work preparation” but are not demonstrating employment outcomes. Being clear about what labour market inclusion and employment are, and what they are not, is an essential first step for policy and program initiatives aimed at increasing labour market inclusion for this group [CACL 2011: iii].

Similarly, employment opportunities would mean real jobs – not specially-funded make-work projects. People with disabilities should have the same employment opportunities as those without. Those who are unable to participate in the paid labour market fully or at all should be eligible for an income top-up or guarantee.

## Conclusion

Over the years, the public discourse on disability has evolved from a predominant focus on medical interventions to a social model to remove the barriers that many persons with disabilities face as a result of functional limitations. At the very least, governments should introduce policy remedies that enable access to essential programs and services, and remove multiple disincentives to work that various programs themselves have created.

In the longer term, there is a need to shift thinking away from segregated interventions toward inclusive education, housing, and employment. The human rights approach to disability offers a framework for this shift, as it is concerned not only with introducing essential policy remedies, but also with enabling participation in all facets of community life. Public policies must focus on a world designed, both physically and socially, for all.

## Endnotes

1. The US *Developmental Disabilities Assistance and Bill of Rights Act* defines developmental disability as a severe, chronic disability which:

- originated at birth or during childhood;
- is expected to continue indefinitely; and
- substantially restricts the individual's functioning in several major life activities.

More specifically, a developmental disability is a severe, chronic disability which:

- is attributable to a mental or physical impairment or a combination of mental and physical impairments;
- is manifested before the person attains age 22;
- results in substantial functional limitations in three or more of the following areas of major life activity:
  - self-care
  - receptive and expressive language
  - learning
  - mobility
  - self-direction
  - capacity for independent living
  - economic self-sufficiency
- reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated;
- except that such term when applied to infants and young children means individuals from birth to age five, inclusive, who have substantial developmental delay or specific congenital or acquired conditions with a high probability of resulting in developmental disabilities if services are not provided.

2. The document was updated in 2001 and released under a new name, the *International Classification of Functioning, Disability and Health*.
3. In order to establish eligibility, each disability program has an associated set of forms that must be completed by a qualifying professional. The application process generally involves a medical doctor. In some cases, such as the Disability Tax Credit, forms may also be completed by other health practitioners for specific functional limitations, such as audiologists for hearing and physiotherapists for walking.
4. Sherri Torjman is Vice-Chair of the Disability Advisory Committee.
5. Partners in the Belonging Initiative include the Canadian Abilities Foundation, Canadian Association of Independent Living Centres, Canadian Association for Community Living, Canadian Down Syndrome Society, Developmental Disabilities Resource Centre of Calgary, Inclusion Press, Laidlaw Foundation, *L'Arche* Canada Foundation, Philia Dialogue on Caring Citizenship, PLAN Institute for Caring Citizenship, and Planned Lifetime Advocacy Network.
6. “From the early 1970s to mid-1980s, sheltered workshops had become an integral part of an evolving Canadian welfare state that provided employment to people who were unable to compete in an exclusive capitalist labour market due to physical impairments, intellectual disabilities, or mental health issues.”  
[Galer 2014]

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## Appendix: Selected definitions of disability

### CANADA PENSION PLAN DISABILITY BENEFIT\*

To qualify for a disability benefit under the Canada Pension Plan (CPP), a disability must be both “severe” and “prolonged,” and must prevent an individual from being able to work at any job on a regular basis. Both the severe and prolonged criteria must be met simultaneously at the time of application.

- Severe means that a person has a mental or physical disability that regularly stops him or her from doing any type of substantially gainful work.
- Prolonged means that the disability is long-term and of indefinite duration or is likely to result in death.

When determining eligibility, medical adjudicators consider several factors together including:

- nature and severity of the medical condition;
- impact of the medical condition and treatment on capacity to work;
- prognosis;
- personal characteristics such as age, education, and work history; and
- work performance, productivity, and earnings.

\*The following note to potential applicants appears on the Government of Canada website: There is no common definition of “disability” in Canada. Even if you qualify for a disability benefit under other government programs or private insurers, you may not necessarily qualify for a CPP disability benefit. Additional details are available at: <https://www.canada.ca/en/services/benefits/publicpensions/cpp/cpp-disability-benefit.html>

## **WORKPLACE SAFETY AND INSURANCE BOARD (WSIB)**

Eligibility for workers' compensation in Ontario involves an assessment of abilities and of restrictions. A functional assessment determines the extent of capacity or limitation in the following areas:

### ***Abilities:***

- walking
- standing
- sitting
- lifting from floor to waist
- lifting from waist to shoulder
- stair climbing
- ladder climbing
- travel to work

### ***Restrictions:***

- bending/twisting repetitive movement
- work at or above shoulder activity
- chemical exposure to (specify)
- environmental exposure to
- limited use of hands
- limited pushing/pulling with hands
- operating motorized equipment
- potential side-effects from medications
- exposure to vibration

## **SOCIAL ASSISTANCE**

### ***Ontario Disability Support Program (ODSP)***

A person is considered to be in financial need if the household's basic living expenses are more than the household's income and assets as determined by the ODSP caseworker. An applicant is deemed to have a disability if:

- the person has a substantial physical or mental impairment that is continuous or recurrent and expected to last one year or more;
- the direct and cumulative effect of the impairment on the person's ability to attend to his or her personal care, function in the community, and function in a workplace, results in a substantial restriction in one or more of these activities of daily living; and
- the impairment and its likely duration and the restriction in the person's activities of daily living have been verified by a person with the prescribed qualifications.

It should be noted that members of a "prescribed class" do not have to meet this qualification. Prescribed class includes, but is not limited to, Canada/Québec Pension Plan disability beneficiaries, a person who currently resides in a home under the *Homes for Special Care Act*, or a person already determined eligible for services and supports under the *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act*, 2008.

### ***Saskatchewan Assured Income for the Disabled (SAID)***

Applicants may be eligible for the Saskatchewan Assured Income for the Disabled program if they have a significant and enduring disability that is of a permanent nature, substantially impacts daily living activities, and results in a person requiring assistance in the form of an assistive device, assistance of another person, a service animal or other accommodation. A Medical Professional Information Sheet must be completed by a physician.

### ***Assured Income for the Severely Handicapped (AISH)***

To be medically eligible for AISH, an Albertan must have a "severe handicap" defined as follows (detailed eligibility criteria are set out in a 25-page *AISH Adjudication Guide*):

- an impairment of mental and or/or physical functioning;
- this impairment causes a substantial limitation in the person's ability to earn a livelihood; and
- the impairment is likely to continue to affect that person permanently because no remedial therapy is available that would materially improve the person's ability to earn a livelihood.

Applicants must also meet two criteria in the AISH Regulation (Section 5), which says they are expected to:

- look for, accept or maintain reasonable employment, and
- make use of suitable training or rehabilitation.

## **DISABILITY TAX CREDIT\*\***

There are different ways in which a person can be eligible for the disability tax credit (DTC). In all cases, the impairment must be prolonged. The person also must meet one of the following criteria:

- is blind;
- is markedly restricted in at least one of the basic activities of daily living;
- is significantly restricted in two or more of the basic activities of daily living (can include a vision impairment); and
- needs life-sustaining therapy.

In addition, the person's impairment must meet all of the following:

- is prolonged, which means the impairment has lasted, or is expected to last for a continuous period of at least 12 months, and
- is present all or substantially all the time (at least 90 per cent of the time).

A person is markedly restricted if he or she is unable, or takes an inordinate amount of time, to do one or more of the basic activities of daily living, even with therapy (other than life-sustaining therapy) and the use of appropriate devices and medication. This restriction must be present all or substantially all the time – i.e., at least 90 per cent of the time.

“Inordinate amount of time” is a clinical judgment made by a medical practitioner who observes a recognizable difference in the time it takes a patient to do an activity. Usually, this equals three times the average time needed to complete the activity by a person of the same age who does not have the impairment.

Significantly restricted means that although the person does not quite meet the criteria for *markedly restricted*, their vision or ability to do a basic activity of daily living is still greatly restricted all or substantially all of the time (at least 90 per cent of the time).

*Basic activities of daily living are:*

- speaking
- hearing
- walking
- eliminating (bowel or bladder functions)
- feeding
- dressing
- mental functions necessary for everyday life

Mental functions necessary for everyday life include:

- adaptive functioning (e.g., abilities related to self-care, health and safety, abilities to initiate and respond to social interactions, and common, simple transactions);
- memory (e.g., the ability to remember simple instructions, basic personal information such as name and address, or material of importance and interest); and
- problem-solving, goal-setting, **and** judgment, taken together (e.g., the ability to solve problems, set and keep goals, and make appropriate decisions and judgments).

A restriction in problem-solving, goal-setting, or judgment that markedly restricts adaptive functioning all or substantially all the time (at least 90 per cent of the time) would qualify.

### *Life-sustaining therapy*

Applicants under this category must meet the two following criteria:

- the therapy is needed to support a vital function, even if it eases the symptoms, and
- the therapy is needed at least 3 times per week, for an average of at least 14 hours a week.

\*\*Additional details are available at: <https://www.canada.ca/en/revenue-agency/services/tax/individuals/segments/tax-credits-deductions-persons-disabilities/information-medical-practitioners/eligibility-criteria-disability-tax-credit.html>