

Towards a Statistical Model for Monitoring the Exercise of Human Rights under the UN Convention on the Rights of Persons with Disabilities – Canadian Case Study

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Abstract: Monitoring the Convention on Rights of Persons with Disabilities (CRPD) is important to ensure full participation of persons with disabilities in society. Statistical information on disabled population is used to develop policies that improve the lives of disabled people. In this article, we propose a model for statistically tracking the realization of CRPD rights.

Keywords: disability rights, disability rights monitoring, statistical monitoring

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Introduction

People with disabilities comprise a large proportion of the population, internationally and in Canada – about 10% internationally (World Bank, 2005) and in Canada, about 14% (Statistics Canada, 2007). In both developed and developing countries, people with disabilities face difficult challenges. For instance, it has been estimated that, internationally, people with disabilities comprise 20% of people living in poverty (World Bank, 2005) – twice the poverty rate of people without disabilities. In Canada, adults with disabilities are also about twice as likely as their counterparts without disabilities to be living in poverty (Council of Canadians with Disabilities [CCD], 2009; Fawcett, 1996; Fougeyrollas et al., 2005). Forms of systemic human rights violations against people with disabilities include lack of access to education and significant levels of low literacy (Rioux et al., 2003; Zubrow et al., 2009; Statistics Canada & OECD, 2005), denial of medical care (Frazee et al., 2005), limited access to adequate and accessible housing (Canadian Mortgage and Housing Corporation [CMHC], 2003), lack of access to transportation and homecare services (Boucher et al., 2003, Fougeyrollas et al., 2008), and the marginalization and exclusion of disability issues and people with disabilities in civil society organizations (Rioux, 2003). Lack of employment and discrimination in the labour force are also daily facts of life for many people with disabilities around the globe and in Canada (e.g. United Nations [UN], 2008; Canadian Council on Social Development, 2005; Roeher Institute, 2004; Human Resources Development Canada, 2002).

In this context, given the commitments of the international community to furthering the human rights of people with disabilities, it is imperative that a more systematic approach be developed to track how these rights are being realized, supported or hampered. This paper presents a proposed model for statistically tracking the extent to which people with disabilities are exercising their human rights as set out in the recently promulgated United Nations Convention on the Rights of Persons with Disabilities (United Nations [UN], 2006) and the factors that hinder and support the attainment of those rights.

Statistical Monitoring

The key purpose of the CRPD implementation is to gather information on the extent to which people with disabilities have the possibility to participate in society and access their rights on equal basis with others. Statistical information provided by population surveys around disability is key in providing snapshots of the population of people with disabilities and identifying the main issues faced by this population at national and various smaller-scale levels. The knowledge gained from statistical profiles is valuable in designing adequate policy responses. Recognizing the importance of gathering and making accessible information on the situation of people with disabilities, the CRPD asks the States to “collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention.”(CRPD, Article 31). Yet, as a recent report by the Secretary General of the United Nations has observed, “few countries collect information on disability through either censuses or surveys. To a significant extent, the dearth of socio-economic data on persons with disabilities reflects the social welfare and/or medical approach to disability that still prevails in many countries” (United Nations [UN], 2009). While there is some activity internationally to monitor the human rights situation of people with disabilities (Disability Rights Promotion International, 2003; International Disability Rights Monitor, 2004; Emerson et al., 2007), there is no systematic approach in place to monitor the implementation of the Convention. In the absence of such a system, how would we know about the extent to which people with disabilities are attaining and exercising their rights?

This paper endeavours to answer this question by looking at how national-level statistical data can be ‘mined’ to shed light on the socio-economic and human rights situation of people with disabilities. It draws practical examples from Canadian statistical sources to illustrate a methodological approach to *the kind of monitoring* that could be implemented more systematically in Canada were such data sources consistently available in this country and which could be implemented internationally were similar data sources available on the global stage. While the methodological approach is illustrated using the right to work, this approach is also applicable to all the rights articulated in the CRPD.

Disability - Theoretical and Operational Perspectives

In order to map out the conceptual framework and data elements in a statistical system for monitoring the rights of people with disabilities, it is important to understand what is meant by ‘disability’ on a theoretical level and how the concepts are operationalized by statistical information available. Historically, the longstanding ‘biomedical model’ has tended to frame disability as an individual pathology to be prevented and cured (Rioux & Valentine, 2006). From this perspective, ‘disability’ has been framed in light of explanatory factors such as the nature and degree of functional impairment (Judd et. al., 2008) and the availability of and individual participation in clinical and rehabilitation services, or use of medications, prostheses and other aids and devices, to ameliorate the disabling effects of impairment or underlying health conditions (Cook et al., 2005). This traditional approach continues to inform the design of many

income supports, taxation-based and other social programs in Canada (Government of Canada, 2003).

More recently, proponents of the ‘social model’ of disability have framed disability as the disadvantages that accrue to the individual with impairment as a result of his/her interactions with built-environmental, social, economic and other contexts. In this model, impairment is de-emphasized, and major attention is placed on understanding and addressing the environmental conditions that ignore, stigmatize, devalue, exclude and even oppress people with functional impairments (Oliver, 1990; Finkelstein, 1993). Taking the social model to its logical term, Roulstone & Barnes (2005) argue that, in order to understand disability in a given context, a critical analysis is required of the disabling effects of society, as well as analysis of prevailing levels of human capital among persons with disabilities, market characteristics and the interplay between the state and market. Some, however, see the dualism between the medical and social models of disability as simplistic and have argued for a more nuanced approach that takes into account as fully as possible the effects of impairment on daily living as well as the complex effects of various contextual factors that create obstacles to daily living that people without functional impairments typically do not face (Shakespeare, 2006; Thomas, 1999; World Health Organization [WHO], 2001; Fougeyrollas et al. 1998; Fougeyrollas & Beauregard, 2001).

In practical terms, one of the main difficulties in measuring outcomes for people with disabilities is the identification of those people classified as ‘disabled.’ Clearly, the way in which people with disabilities are identified has significant implications on the indicators measuring their access to various domains of life, for example, the percentage of people with disabilities who graduate from university or secure employment. For the purpose of an effective CRPD monitoring, ascertaining the population of disabled people is essential. This information is key in order to monitor any progress made in the removal of barriers that hinder the enjoyment of rights. There is currently no international agreement on the definition of ‘disabled person,’ for which reason the CRPD does not provide an exhaustive definition, but clearly identifies the inequality of social participation as the outcome of the interactive process between individual and physical, social and attitudinal environment (Fougeyrollas, 2010; 2011). This raises interesting questions about the relationship between the CRPD approach and the national definitions. For monitoring purposes, some States might need to broaden their domestic interpretation of ‘person with disability’ in case this is narrower than the one employed by the CRPD. At the level of statistical sources, this is translated into looking at what approaches are employed by population surveys existent in various countries to flagging disability and whether these approaches are similar across the surveys in order to produce comparable information.

Method

Conceptualizing a Robust Statistical Monitoring System

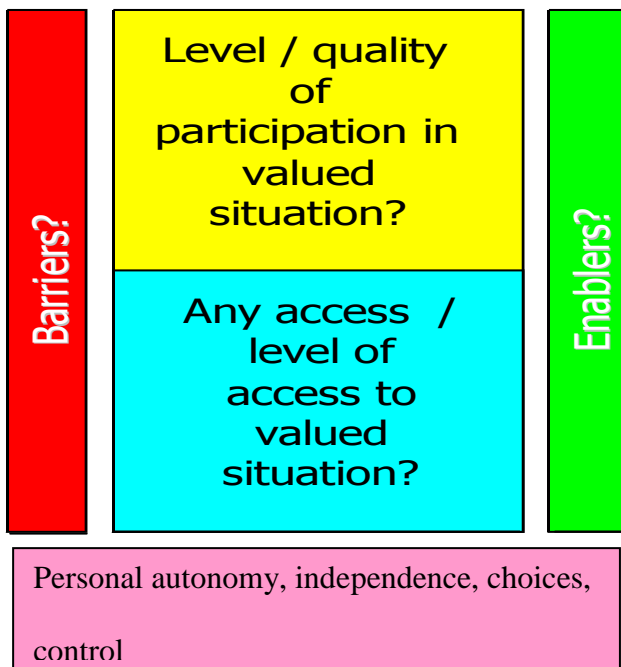
The CRPD emphasis on realizing in concrete terms the full inclusion and participation of people with disabilities in all facets of society should be key in thinking through the dimensions of a statistical monitoring strategy. The CRPD seeks to realize among other things a high-level, twofold objective: a) the access of people with disabilities to a range of socially *valued situations* that are – or that should be – open and accessible to all citizens; and b) the full participation of

people with disabilities to these situations as *valued equals*. Furthermore, the CRPD expresses the commitment of States Parties to ensuring that the necessary conditions of attaining those outcomes – *enablers* of the outcomes – are in place and that *barriers* that inhibit and prevent attainment of the outcomes are removed.

These key dimensions are translated into a heuristic model grounded in the underlying assumption that people with disabilities, like others, should have access to valued situations and the participation to these situations should maximize the personal autonomy, independence, choices and personal control of people with disabilities as highlighted by various Convention articles (e.g. Preamble n and Articles 3, 9, 12, 19, 20). A visual representation of this model is provided in Figure 1.

Figure 1. Dimensions of the proposed

statistical monitoring model



Key Elements of the Proposed Model

The proposed model consists of two main elements to be used in order to assess the statistical information: 1. *access to a valued situation as articulated in the CRPD* and 2. *level of participation once in a valued situation*. *Barriers/enablers* and *intersectionality* lenses are also key lenses employed across the model components in order to obtain a better understanding of people’s experiences in a specific situation.

Equal Access to Valued Situations

The CRPD posits that, like others, people with disabilities should have equal access to the full range of socially valued situations such as decent and affordable housing, employment, education, community leisure and cultural activities and so on. Accordingly, in mapping out the elements of a statistical monitoring system, it is important to identify and track the extent to which people with disabilities have *access* to the socially valued situations articulated in the CRPD.

Level of Participation in Valued Situations

The CRPD also posits that people with disabilities should have scope to participate in those situations as fully as possible as valued equals. In line with this, the statistical monitoring system should track the extent to which the full participation of people with disabilities is being realized, once in one of those valued situations articulated in the CRPD. The participation in a valued situation is seen as an outcome assessed through either or both quantitative and qualitative indicators in the statistical model.

Key Cross-Model Lenses

Enablers and Barriers to Access and Participation in Valued Situations

Across the two main components of the model, an enabler/barrier lens is employed in order to provide a more complex view on the access and quality of participation to various valued situations. The CRPD articulates the commitments of States Parties to ensuring that the necessary conditions are in place for people with disabilities to gain access to valued situations and to participate on equal terms. Accordingly, the model for the statistical monitoring of human rights needs to be attentive to the extent to which enablers of access and sought-for outcomes are in place and the extent to which barriers are operative that impede access and attainment of the outcomes.

In this connection, we argue that ‘disability supports’ are positive enablers of the attainment of the outcomes and that, where needed, their absence amounts to barriers. We define a ‘disability support’ as any good, service or environmental adaptation that assists persons with disabilities to overcome limitations in carrying out activities of daily living and in participating in the social, economic, political and cultural life of the community (Roehrer Institute, 2002).

At the *individual* level such support ‘attaches’ to the individual person or his/her immediate environs and includes human assistance (e.g. help with a range of activities at home, school, work, in various activities in the community), assistive aids and devices (e.g. hearing aids, voice synthesised computers, wheelchairs), modifications to the built personal environment (e.g. grab bars, ramps, accessible parking and entrance ways), modification of routines (e.g. different job duties, modified hours or days of work, a modified schedule of study to accommodate issues of mental health or fatigue), medications (e.g. to help manage issues of pain, chronic illness or emotional well-being) and specialized services (e.g. physiotherapy, occupational therapy, speech therapy, personal, school, career and psychological counselling).

At the *community* level such support ‘covers’ people with disabilities as a broad group and includes: accessible community infrastructure (e.g. accessible buildings, sidewalks,

transportation services and public technologies such as computers with adaptive peripherals at schools or libraries); and human capacity at the community level to fully include people with disabilities in regular community activities (e.g. child care workers, teachers and recreation workers who have the knowledge and skills needed to respond to the needs of children with disabilities in regular child care, school or recreational settings; employers and employment consulting organizations who have a sound base of knowledge about how to adapt the work environment and work routines so as to enable job applicants and workers who become disabled to perform essential job functions).

The antonyms of enablers are barriers to people with disabilities gaining access to valued situations and participating as valued equals, there. We define the absence of positive supports that may be needed – the absence of enablers – as critically important barriers. Other barriers include forms of overt discrimination such as being refused a job, job interview or promotion on the basis of disability, being paid less than other workers in similar employment, being refused access to work-related training or to school and so on.

Intersectionality

The rights protected by the CRPD apply to all people with disabilities, regardless of types of impairments, gender, age, and ethnicity. In line with this, it is essential that monitoring processes are designed and implemented in a manner that captures these differences and intersectionality. Particular attention therefore should be given to most vulnerable groups of people with disabilities to ensure that they are not excluded from the monitoring exercises. Article 31, which imposes an obligation on State Parties to collect relevant statistical and research data, also requires that the data collected to be disaggregated to allow the situation of particular groups of people to be extracted and examined. Accordingly, the statistical monitoring model should design indicators that identify particular levels of disadvantage or exclusion that may affect those groups of people with disabilities facing multiple forms of discrimination.

The proposed statistical model can be applied to all valued situations covered by the CRPD such as independent living and inclusion in the community, access to and participation in community recreation and cultural activities, adequacy of living standards and social protection. The rest of the paper provides an illustration of how this model works taking as an example the *valued situation of work* and exemplifying with data available in the Canadian flagship survey on disability. Furthermore, the illustration focuses on the vulnerable group of people with disabilities in low income in order to illustrate how intersectionality can be taken into account in the statistical monitoring.

Case Study – Statistical Monitoring of the Right to Work in Canada

Participation and Activity Limitation Survey (PALS)

PALS has been Statistics Canada's 'flagship' survey on disability. Conducted following the 2001 and 2006 Censuses of population, it gathered a wealth of information about socio-demographic characteristics of people with disabilities – both adults and children; the nature and degree of functional difficulties experienced, as well as various disability-related issues, such as

the types of supports required in various settings and the types of barriers to participation in those settings.

As operationalized in PALS, a ‘disability’ is any ongoing or recurring difficulty hearing, seeing, communicating, learning, walking, bending or doing any similar activities or, because of a physical or mental condition or health problem, a reduction in the kind or amount of activity that a person can do at home, work, school or in other settings. In order to be selected into PALS as having a disability, a respondent had to indicate any limitation on the disability filter questions of the Census long form, which was administered to about 20% of the Canadian population. A second stage of filtering, that again employed the disability filter questions several months following the Census, resulted in some people who indicated disability at Census time being reclassified as non-disabled because several months later they did not answer “yes” to any of the filter questions. People retained in the PALS sample were those who again answered “yes, sometimes” or “yes, often” to the Census questions, which were asked at the beginning of the PALS interview several months following the Census. The total size of the PALS 2006 sample was 47,793 - 8,954 children (persons under 15 years of age) and 38,839 adults (15 years of age and over). The retained sample represents 202,350 children and 4,215,530 adults with disabilities (Statistics Canada, 2007).

For the rest of the paper, we illustrate with PALS data how the proposed statistical model can be used in practice to track how the right to work is being realized or hampered.

Illustration of Statistical Monitoring

The most recent submission by Canada (2009) to the UN Human Rights Council in the Universal Periodic Review of Canada’s compliance with its international human rights obligations is virtually silent with respect to persons with disabilities’ right to work, except for the vague and general mention of legal prohibitions against discrimination and brief descriptions of a few potentially relevant program measures at the provincial level (UN Human Rights Council, 2009). Canada has had a fairly robust set of statistical instruments for tracking a range of issues concerning people with and without disabilities. Yet, if even under such circumstances a country as Canada is virtually silent in terms of the attainment and exercise of so fundamentally important a right as employment, how would we know whether and to what extent progress is being achieved in this area? The rest of this section illustrates how the proposed statistical data can be used to shed light on this type of questions.

Access to the Valued Situation of Work

Based on the information provided by PALS, it is possible to gauge the extent to which people with disabilities in general, and those in low income in particular, are in the socially valued situation of ‘employment.’ As provided by most recent PALS data, the overall labour force participation rate for working-age adults with disabilities is 59.6% comparing to the participation rate of adults without disabilities of 80.2% (Human Resources and Skills Development Canada [HRSDC], 2010). This shows that, in spite of the fact that Canada led the G8 countries in employment growth from 2001 to 2006 and the employment situation of people with disabilities improved slightly over those years, Canadians with disabilities have persistently

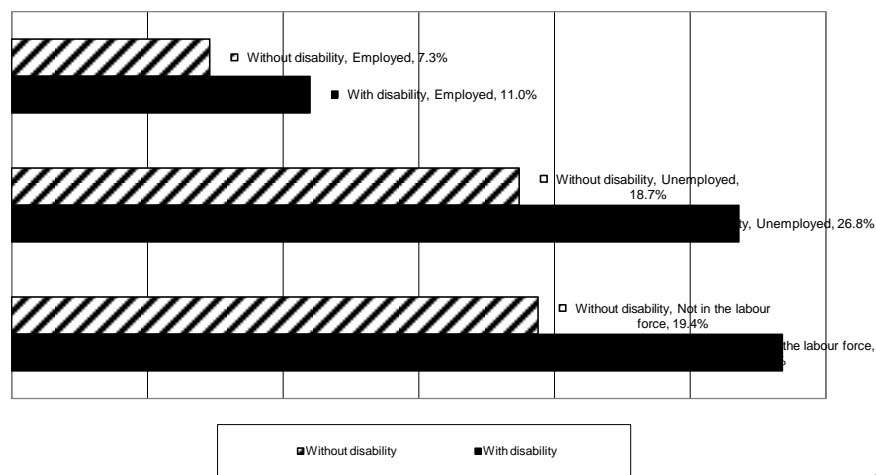
remained much less likely to be employed than their counterparts without disabilities. Using statistical information, it is also possible to ascertain the comparative labour force status of people with and without disabilities. For example, the employment rate for working-age adults with disabilities is significantly lower than that for their counterparts without disabilities (53.5% vs. 75.1%). At the same time, the unemployment rate for those with disabilities is higher than for those without disabilities (10.4% vs. 6.8%) (HRSDC, 2010).

Barriers/Enablers and Intersectionality Lenses

Employing a barrier/enablers lens, we can obtain a more complex profile of those not getting access to the right of work, specifically those not in the labour force. Statistical data provided by PALS shows that in 2006, 43.8% working-age adults with disabilities were not in the labour force. The greatest barriers to get access to work for these people are inadequate training (19.3%), fear of losing partially or completely their current social transfer income if they work (17.6%), and lack of accessible transportation (12.8%). Discrimination, fear of losing access to drug plans and housing subsidies, and lack of accessible information on job opportunities are other barriers uncovered by statistical information (HRSDC, 2010).

Looking at the vulnerable group of people with disabilities in low income, statistical data suggests that the gap between this group and their counterparts in low income without disabilities increases over the progression away from the labor force (Figure 2). Even when working, people with disabilities are more likely than people without to have low incomes (11% vs. 7.3%). The gap widens for those who are unemployed and not in the labor force, with the rates of low income among these people with disabilities being about 1.5 times higher than for their counterparts without disabilities (Crawford, 2010).

Figure 2. After tax low income status by disability status and labour force status (Source: PALS 2006)



Economic vulnerability is also highly associated with barriers encountered by this multiple-discriminated group in exercising its right to work. For example, statistical data shows that lack of training is a significant barrier to employment, those with low incomes being significantly less likely to have taken training than their counterparts not in low income (17.3% vs. 34.8%; Adele Furrie Consulting Inc., 2010).

This type of information obtained through ‘mining’ statistical data available is essential in order to obtain accurate portraits on the access to work for people with disabilities and the main issues they face in exercising this right. The longitudinal trend of statistical indicators as those described above can be used to assess the effect of the CRPD implementation across time in conjunction with legal and other community-based information. Although exemplified with the right to work, the proposed approach can be applied, given data available, in order to assess the impact of the CRPD in relation to each right outlined in the Convention.

Level/Quality of Participation in the Valued Situation of Work

Once in the valued situation of employment, the quality and/or quantity of participation may be reported as an outcome. Based on statistical data, it is possible to ascertain and compare, for instance, the distribution of employed people with and without disabilities across various occupations and industrial sectors, employment earnings and the number of hours per week or weeks per year that were worked for pay. For people with disabilities it is possible to ascertain whether they had to change their jobs because of disability, difficulties changing the jobs and whether their education and skills on the job are underutilized. All these indicators speak indirectly to the issue of participation of people with disabilities as valued equals in paid work. For example, PALS data shows that only about half (48.9%) of people with disabilities do the same work as they did before acquiring their disabilities. Further, because of disability onset, more than three quarters (77.5%) of those who changed their jobs also changed their work responsibilities (HRSDC, 2010).

Barriers/Enablers and Intersectionality lenses applied

The barriers/enablers lens facilitates a further understanding of the quality of participation once in the valued situation of work (those employed). Using this approach, the profile of unmet needs of employed people with disabilities can be determined. For example, PALS data shows that only 60.4% of employed people with disabilities have all their needs for aids and devices met (HRSDC, 2010). Among those who did not receive the workplace accommodations needed, the main reasons for not getting these accommodations were the employers’ refusal because modifications were considered too expensive (12.6%) or because they were afraid to ask (14.7%). (HRSDC, 2010). Further, by taking into account the intersectionality, it is possible to ascertain the specific issues faced by the vulnerable group of interest. For instance, those in low income are about a third as likely to receive training as their counterparts not in low income (10.1% vs. 27.8%), with the lack of training representing a significant barrier to better employment and hence to participation of better quality (Adele Furrie Consulting Inc., 2010). Among those who reported employment discrimination in the past five years, about a quarter (22.4%) are in low income, this percentage significantly dropping among

those who did not experience discrimination (12.7% – Crawford, 2010). These numbers speak indirectly about the vulnerability of those in poverty to work-related discrimination. An extended list is provided below with other indicators that can be developed based on PALS in order to assess the quality of participation once in the employment situation (Table 1). The list is, however, adaptable to statistical data available and similar indicators can be extracted for various vulnerable groups, depending on the focus of monitoring process.

Table 1. Barriers/enablers lenses to assess the level/quality of participation of people with disabilities in employment – PALS		
Indicators /measures	Barriers	Enablers
Workplace accommodations	Needed job accommodations not available	Needed job accommodations available
	<ul style="list-style-type: none"> – Modified work structures (e.g. modified workstations; accessible washrooms/elevators; accessible parking; accessible transportation) – Work aids/job modifications (e.g. modified days/hours of work; human support; assistive technologies;) 	<ul style="list-style-type: none"> – Modified work structures (e.g.modified workstations; accessible washrooms/elevators; accessible parking; accessible transportation) – Work aids/job modifications (e.g. modified days/hours of work; human support; assistive technologies;)
Work-related training	Have not recently participated in work-related training	Have recently participated in work-related training
	<ul style="list-style-type: none"> - classroom-based training - on-the-job training - other training 	<ul style="list-style-type: none"> - classroom-based training - on-the-job training - other training
Educational attainment	Low level of formal educational attainment	High level of formal educational attainment
Workplace discrimination	Discriminatory employer practices based on disability	No discriminatory employer practices based on disability
	<ul style="list-style-type: none"> - Have been refused a job/job promotion - Have been given less responsibility than co-workers - Have been denied work-related benefits 	<ul style="list-style-type: none"> - Have not been refused a job/job promotion - Have not been given less responsibility than co-workers - Have not been denied work-related benefits

Summary and Conclusion

This paper has provided background on the need for a statistical monitoring strategy to track whether and to what extent the human rights of people with disabilities are being achieved as set out in the UN Convention on the Rights of Persons with Disabilities. It has taken the right

to work without discrimination based on disability as an example. It shows how it is possible to use data that exist in the Canadian context, and that by a reasonable stretch of the imagination would continue to exist in one form or another in this country and that could become more widely available on the global stage, to comparatively track human rights issues along two key dimensions: access to socially valued situations and extent of participation as valued equals in those situations. Barriers to gaining access to the situations and to full participation, enablers of access to the situations and to full participation, and intersectionality were the key lenses applied across the dimensions of the proposed model.

As pointed out by the Secretary General of the United Nations, the international statistical data ‘system’ for monitoring the human rights of people with disabilities is neither clear nor strong. Even in a developed country such as Canada, where political leaders, government officials, academic and community-based experts on disability, statisticians and policy analysts have dedicated considerable energy and careful thought to developing and analyzing the results of statistical tools for tracking and exploring issues of disability, the statistical data ‘system’ is far from secure. It has undergone many changes over the years that have been driven largely by concerns about costs to the taxpayer.

A new round of cost reduction measures is in effect, so the ‘disability file’ in Canada is taking another ‘hit.’ It is to be trusted that the paper will help decision-makers – in government, in the disability community, in academia and ordinary citizens – to find new paths to effective, efficient and timely monitoring and reporting of human rights issues that are of vital concern to one in seven people on the planet who live with a disability and to the countless others who are their siblings, parents, spouses, children, friends, co-workers and colleagues.

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