



### MONITORING THE HUMAN RIGHTS OF PEOPLE WITH DISABILITIES IN CANADA

# MONITORING SITE REPORT VANCOUVER

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"My husband left me when I became disabled. He told me it was too much for him to take it." (DVC06, Female – age 57)

"I don't go out very much because there's usually not an attendant available for something I might want to do during the day. People have their lives, so it's very hard to find somebody to accompany me in a reclining wheelchair... this affects my getting dressed and stuff like that. So the help I have is so minimal, it's like 6 hours a week. That's barely enough to make me a meal that you can put in the fridge or freezer and get the laundry done and the bed changed and a shower." (DVB04, Female – age 63)

"I use a manual wheelchair to get around, and I think that we're fortunate living in the lower mainland here in B.C. because for the most part it is very accessible for people who use wheelchairs. We're also seeing more changes being made to improve the lives of people with other disabilities, other than mobility disabilities." (DVC12, Male – age 61)

"They know I have a disability, they know that I'm deaf, but they don't necessarily think about how to adjust accordingly for a deaf person or anyone else with a disability. So I know that if I wanted to move up to a position or move up to be considered for a promotion, I've been told that I can't because of my disability, because I wouldn't be able to use a telephone, for example. (DVE01, Female – age 41)

"I think I've progressed a lot since I've been working here, and I've found the acceptance that I wouldn't necessarily find in other settings. There are a lot of other people here who have disabilities as well, and yet that doesn't prevent them from leading a full life... or acting or being responsible for certain things." (DVi01, Male – age 50)

#### INTRODUCTION

#### **Background of the project**

Canada is signatory of a number of international human rights treaties, including the most recent *Convention on the Rights of Persons with Disabilities*. Canadians with disabilities, regardless where they live, should therefore be entitled the same human rights and freedoms that are granted to all other citizens. Monitoring studies are crucial to measure to what extent the commitments made by Canada in paper are translated on the ground.

DRPI-Canada is a collaborative project funded by Social Science and Humanities Research Council (SSHRC), working to establish a sustainable monitoring system to address disability discrimination in Canada. The project employs a human rights approach to disability, which focuses on the way that systemic discrimination and social exclusion increase vulnerability to abuse, poverty, unemployment, and other forms of discrimination and inequitable social conditions. Evidence-based knowledge regarding the extent to which people with disabilities face discrimination will inform effective societal, policy and program change to improve the lives of people with disabilities in Canada.

The project adopts a holistic framework in order to develop a sustainable system to monitor the human rights violations of people with disabilities in Canada by integrating *four focus areas*: *individual experiences monitoring* (gathering information about the actual human rights situations of people with disabilities in the communities where they live); *media monitoring* (examining the depiction of disability issues and persons with disabilities in the media); *systemic monitoring* (examining the effectiveness of laws, policies, and programs in protecting disability rights); and *monitoring survey datasets* (examining the information collected by Canadian population surveys on the situation of people with disabilities from a human rights perspective). DRPI-Canada is also grounded in the general human rights principles: *dignity, autonomy, non-discrimination, inclusion, respect for difference, and equality.* 

This report is based on the work done within the Individual experiences monitoring area of the project. Related monitoring activities took placeat four monitoring sites, chosen to reflect the social and cultural diversity of the nation: Quebec City, St. John's Newfoundland, Toronto and Vancouver. This report presents data from Vancouver monitoring site.

#### Partners and people involved

At Vancouver monitoring site, DRPI-Canada partnered with the BC Coalition of People with Disabilities (BCCPD) which took leadership on all stages of the monitoring activities. The BCCPD has been a provincial, cross-disability voice in British Columbia for over 30 years. Its

mission is to raise awareness around issues that affect the lives of people with disabilities and facilitate their active participation in community.

The BCCPD took leadership in coordinating all monitoring activities (e.g. recruitment of monitors and interviewees; the process of data collection). The monitoring site was coordinated by the site coordinator Sam Bradd. Eight persons with disabilities - Jennifer Anthony, Linda Bartram, Debbie Brkich, Lorraine Irlam, Chloe Krause, Tom McGregor, David Schaefer and Jewelles Smith - were trained as *monitors* by means of a training workshop that took place in Vancouver in May, 2009. During the training, monitors gained valuable skills on how to conduct monitoring interviews in the field (e.g. specific interview techniques; how to use the DRPI interview guide; how to obtain free and informed consent of the interviewees; how to protect data confidentiality). They were also given opportunities to practice interviewing skills with one another and with people with disabilities from local community.

#### Methodological approach for field work

Monitoring data has been collected through face-to-face interviews with people with various types of disabilities on their lived experiences of human rights violations. 41 interviews were conducted by monitors, people with disabilities themselves after receiving ethics approval from York University. Informed consent was obtained from participants who were recruited by the BCCPD using a mixed approach. Initially, the "snowball" sampling technique was employed, a strategy recognized for its ability to recruit difficult to access groups (Lopes et al., 1996). At the end of each interview, participants were asked to refer other people who would fit the sampling criteria. The people referred were then contacted, and an interview was arranged. This strategy was reiterated several times, until the desired sample size was achieved. In order to get to isolated people, usually not connected through personal networks, the snowball technique was complemented by recruitment through the networks of our partner. The sample size was considered appropriate given the nature of this study which is mainly directed at an in-depth understanding of the *meaning*, *context*, and *processes* involved in the human rights experiences of people with disabilities. In light of this perspective, a qualitative approach employing intensive interviews on relatively small samples was favoured over a quantitative approach using large representative samples.

Each interview lasted on average two hours and was conducted using an interview guide previously developed by the larger international DRPI project and adapted to the Canadian context. The semi-structured interview initiated with two broad questions, *«Which things have you found more satisfying in your life over the last five years? And which things have presented the greatest obstacles or barriers?*». Typically, interviewees named two or three key situations that monitors followed up to engage a conversation, probing into the lived experiences of the interviewees in order to explore their linkages with the human rights principles. Once collected, the interviews were transcribed, coded using a coding scheme developed by the international

DRPI and then analysed using NVivo 8 software. The coding process was supervised by two experienced researchers who ensured inter-reliability and consistency of coding by comparing and contrasting codes throughout the coding process.

In this study, five key human rights principles - autonomy; dignity; participation, inclusion &accessibility; non-discrimination & equality; and respect for difference - were explored in connection to key domains of life for people with disabilities. The key domains considered in this study are: social participation; privacy and family life; education; work; information and communication; access to justice; income security and support services; and access to health, habilitation and rehabilitation.

#### **KEY FINDINGS**

#### **Experiences of Human Rights across Domains of Life**

Overall, the findings indicate that individuals with disabilities encounter both positive and negative experiences in exercising their rights. Although the instances of denial of human rights tend to outnumber positive experiences, the fact that the latter were also identified may signal that, despite ongoing disparities, positive change is also underway for persons with disabilities in Vancouver area.

Social participation, Income security & supports and Work are the areas where negative experiences predominate, whereas Family is the realm of life with more positive experiences of inclusion and human dignity.

**Social participation** emerged as the most significant domain for participants, involving the greatest number of reports. In particular, interviewees reported devalued human dignity on the grounds of disability in their interactions within the public space. They also denounced experiences of exclusion related to lack of accessibility in the built environment and transportation system. At the same time, a number of interviewees, however smaller, reported situations of inclusion in social, cultural, and sports activities and instances when they felt their dignity affirmed.

**Income security & support services** is another area where many barriers were reported. According to participants' reports, lack of adequate disability-related supports hinders their full and effective participation in the community.

In the domain of *Work* and access to the labour market, interestingly, varied results were found, with high proportion of both positive and negative experiences. While many participants mentioned barriers to get paid work, a similar proportion reported accommodated needs at their workplace.

Comparing to the other domains, *Family life* mostly consisted of positive experiences. Approximately one in two interviewees felt valued and supported in their family life and relationships.

Regarding *Education*, the results were ambiguous: while one third of the interviewees reported feeling included, a similarly high proportion reported barriers and exclusion at school and the

larger education system. Most of the reports emphasized unmet accessibility needs and the lack of appropriate supports as main cause for exclusion.

*Health, habilitation and rehabilitation* domain abounded in reports of devalued dignity around experiences of denial of access to health services. In particular, psychiatric survivors and other participants using psychiatric services reported several instances of disrespect on the grounds of their disabilities in their attempts to access the health system.

Access to justice and access to Information and communication systems are two other realms of life where people with disabilities faced significant disadvantage and exclusion. Lack of adequate supports for people with various disabilities such as hearing, sensorial and psychosocial, leads to exclusion from a variety of communication venues, with negative impact on personal dignity and worth. Erosion of dignity was also emphasized by the interviewees in relation to access to justice, financial and legislative barriers emerging as the main causes of exclusion from the legal system.

Facing disadvantages, most participants cited *economic factors* as the primary *cause of discrimination*, perceiving the economic infrastructure as the major challenge to the fulfilment of their rights.

Despite their negative encounters with justice, participants tend to take a proactive attitude when facing discrimination. In fact, over three quarters of those interviewed chose to *report or file an official complaint* against an experienced violation. For those who did not take any formal action, the main reason was that they considered a formal action as not effective to change their situation.

#### **Intersectional Analyses**

The study also explored the exercise of rights by people with disabilities as affected by **gender** and **age**<sup>1</sup> in order to provide a better contextualization for their experiences.

*Gender* was found to affect participants' experiences in the domains of privacy and family life, health, habilitation& rehabilitation, education and access to justice, although in different ways. Men tend to report significantly more instances of discrimination and ill-treatment than women in relation to access to justice, whereas women tend to report more on issues of discrimination in health, habilitation& rehabilitation and in education. Family life also emerged as a greater source of support among women than men.

Age seemed to impact participants' experiences particularly in the following domains: work, privacy and family life and access to justice. Younger people reported experiences mainly in relation to work and family life. Access to justice emerged as an issue only for older participants who also seem to be able to exercise their self-determination more than younger people.

<sup>&</sup>lt;sup>1</sup> It was not possible to conduct the analysis by types of disability due to small size cells once disaggregating by various types of disability represented in the sample.

#### RECOMMENDATIONS

Disability rights monitoring involves efforts to measure the gap between guarantees offered in the law and the actual experiences of persons with disabilities in their daily lives. The data collected through monitoring studies is instrumental to inform political change towards more social justice and improved access to human rights for persons with disabilities.

Findings from this study emphasize the range of problems that persons with disabilities in Vancouver face to exercise their rights. Drawing from these data and from discussions held with members of the disability community in Vancouver, the following recommendations are put forward to improve access to human rights for persons with disabilities in British Columbia:

1. Raise the income level and review the eligibility rules regarding the provincial income assistance program, to ensure the right to a decent living to all persons with disabilities across the province.

This study showed that many persons with disabilities in Vancouver are experiencing economic insecurity. The level of income provided through the existing support program is considered inadequate to face the high cost of living in the province. Economic insecurity creates many barriers to people with disabilities including significant challenges in finding adequate housing. Adequate housing is a significant problem in the Vancouver region, as shown by the high rates of homeless people found in the city, many of whom are persons with disabilities. Living with economic insecurity creates a vicious circle of marginalization, isolation and exclusion that places an additional strain on the mental and physical health of people with disabilities.

Social and economic rights need to be more strongly protected in BC to make them comparable to what is provided in other provinces (e.g. Quebec). The current support system makes it difficult for people with disabilities to access what they need and creates fear rather than encouraging social participation. An example is the number of restrictions that are placed on applicants and benefits recipients on the level of assets and income they are allowed to have, which is seen as a discentive to people with disabilities in seeking employment or living in intimate relationships with a partner. The Province is therefore urged to improve the level of supports provided and review the current rules concerning access to provincial disability benefits.

2. Stimulate and support the employment of persons with disabilities by creating supports to employers who hire persons with disabilities and supports to persons with disabilities in the workplace.

Accessing and retaining a well-paid job is essential to enjoy economic security. Data from this study suggests that people with disabilities in the metro Vancouver face significant obstacles

with respect to employment. Indeed, despite the high qualifications of the interviewees - over 58% have a post-secondary degree - only 41% of them held a job at the time of the interview. Statistical data available in the province further show that people with disabilities participate in the labour force significantly less than the non-disabled (64.6% vs. 78.5%). This represents a waste of human resources that is urgent to reverse. **The Province is therefore urged to create a system of incentives and supports to employers who hire people with disabilities so that they employ workers with disabilities and provide them with the supports they need.** 

### 3. Consider the creation of a specific Ombudsman-type body to work on disability discrimination issues.

Unequal and discriminatory treatment of people with disabilities is happening at all levels of society, including the government level. An example is the number of websites which do not comply with accessibility standards for blind people. A complaint was taken to court on this and the plaintiff won. Unfortunately, the government tried to narrow the application and made an appeal to the Supreme Court in order to modify the decision. In this process, significant resources are being spent that could be more appropriately channeled to the implementation of accessibility norms in accordance with human rights principles and norms. **Therefore, thorough consideration should be given to the creation of a new mechanism – an auditor or Ombudsman-type body - to work specifically on disability discrimination issues in order to ensure and compel the government to act on its human rights obligations.** 

# 4. Improve the HandyDART transportation system to support mobility and the social participation of persons with disabilities.

Social participation emerged as the most significant domain for participants in this study. Within this domain, and among other instances, interviewees specifically denounced experiences of exclusion related to lack of accessibility to the transportation system, including HandyDART, the customized transit system. The number of available HandyDART service hours does not meet the demand and the service does not equate with the mainstream public transit system for those who cannot access it. People with disabilities in need of HandyDART wait too long to get the service and often are unable to go to the grocery store, medical appointments, or get to work on time, which severely impacts their ability to participate as equals in social and economic life. An urgent reform of the HandyDART transportation system and particularly an increase in the supply of service hours is required to support mobility rights and the social participation of people with disabilities in Metro Vancouver.

#### 5. Invest in disability services and supports now, to save money in the future.

Almost three in four individuals in this study reported barriers and challenges to accessing disability services and supports, imposing serious restrictions in various aspects of people's lives, from enjoying good health, through getting adequate education and jobs, to living full lives. As this study shows, lack of adequate disability supports and assistance creates isolation and

marginalization and fosters personal and economic dependency. Underfunding of disability services and supports affects the availability and quality of service provision and risks to increase public expenditure in the future, by denying people the means to live independent lives.

With adequate provision of disability supports and services, on the contrary, more people with disabilities will move out of poverty and achieve a better quality of life. They will be able to participate in social, cultural and economic activities as equals in society. Allocating adequate resources to disability assistance and support services today is therefore a smart option that will save money in the future.

In the provision of assistance and supports, it is also important to ensure consumer choice and control, and guarantee flexibility and individualized solutions rather than "one size fits all", agency-based controlled services. Consulting with people with disabilities and their organizations, involving them in decisions on issues that concern them directly and adequately addressing current disability support needs is crucial.

### 6. Improve psychosocial support services and care in the province and work to reduce the stigma associated with mental health problems.

Individuals with psychosocial disabilities suffer wide stigmatization and experience profound discrimination in society. As reported in this study, many are unable to get or keep a job, and lack adequate income to live a life with dignity. Moreover, mental health services are a poorly funded area of the health services system in the region, which affects the availability and quality of services provided. **The government is thus urged to take action to raise awareness and understanding about mental health issues and to confront negative perceptions about people with psychosocial disabilities. In addition, the government is also urged to invest more in mental health services.** Canada has signed and ratified the UN Convention on the Rights of Persons with Disabilities and must ensure that services provided are in accordance with a human rights approach thus ensuring full respect for the person with psychosocial disabilities, enabling them choice, dignity and control over the services provided.

# 7. Make use of social networks (e.g. Facebook) to raise awareness among people with disabilities about their rights.

In today's society, social networking is playing a huge part in getting messages out. This potential should also be tapped by the disability community. Many people with disability still lack knowledge about their rights and live very isolated lives. Having a forum to exchange experiences, tell their stories and learn from each other could be an important step towards realizing their rights.

Social networks (e.g. Facebook) should be used more to promote and increase communications among people with disabilities, and to disseminate results of rights monitoring studies, not just within the province of British Columbia or even Canada, but also internationally.