

# **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)*

## Executive Summary

According to *Statistics Canada*, 18.4% (or 612,120 persons) of the population aged 15 and over in British Columbia are limited in their daily activities due to a physical or psychological condition (BC Stats, 2009). Many of these persons also experience significant barriers in the exercise of their rights.

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 systemic discrimination and social exclusion increase vulnerability of persons with disabilities 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.

This report is based on 41 individual interviews conducted in the Great Vancouver Area with persons with various types of disabilities to document their lived experiences in exercising their rights. DRPI-Canada partnered with the BC Coalition of People with Disabilities (BCCPD) which took leadership on all stages of the monitoring activities. Monitoring data has been collected through face-to-face interviews conducted by previously trained *monitors*, persons with disabilities themselves. The interviews were taped, transcribed and coded using a coding scheme developed by the international DRPI project, and then analysed using NVivo 8 software.

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 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*.

### 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.

Facing ableism in their daily life, participants made a number of recommendations to improve the situation and circumstance of people with disabilities. ***Educating the public about disability*** and ***increased social supports*** emerged as the key recommendations from participants. Specifically, participants recommended that the government create stronger mechanisms to support decent living conditions and income for people with disabilities.

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<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.

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# INTRODUCTION

## Background of the project

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 place at 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.

### ***Strengths and Limitations of the Project***

A core dimension of the individual experiences monitoring process advanced by this project is the direct involvement of people with disabilities as *monitors* and that of local disability organizations as partners in all stages of monitoring. The fact that people with disabilities are the monitors in charge of interviewing other persons with disabilities is a clear advantage in that it creates an environment of mutual trust and respect between the interviewer and the interviewee that facilitates information sharing within a rigorous methodological framework. Furthermore, the leadership role played by the local partner in coordinating monitoring activities represents a key step to ensure capacity building within disability community on disability rights monitoring.

Regarding the process of data collection, the semi-structured approach employed by this project enabled the interviewees to focus on those topics most important to them rather than imposing a battery of questions. This way, it provides a better understanding of the actual meaning of human rights in the lives of the participants.

It is also important to acknowledge project limitations. The snowball technique employed by the project as its main sampling strategy is conducive to the recruitment of people with similar profiles leading to overrepresentation of some characteristics in the sample. In order to overcome this limitation, the snowball technique was complemented with supplementary efforts by the local partner to include in the sample certain underrepresented subgroups of people. Another limitation is related to the small non-probabilistic sample employed by the project which doesn't allow for generalizations beyond the population interviewed. However, given the nature of this project 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, a qualitative approach with a small sample was considered more appropriate than a large-scale quantitative study.

# MONITORING INDIVIDUAL HUMAN RIGHTS EXPERIENCES IN VANCOUVER

## Part I – Context to ground monitoring efforts

### Demographic and socio-economic profile of monitoring site

This section provides a proxy demographic and socio-economic picture of people with disabilities living in the areas where the monitoring site was located. It is meant to provide contextual information within which to place the findings of this monitoring project. The project included participants from Metro Vancouver and two rural areas– Oliver and Penticton which are parts of the Okanagan Valley. Current data at the local level on the demographics of people with disabilities is not available. However, data available at provincial level and estimations when possible at sub-provincial levels can provide a proxy snapshot of the context in which study participants live.

#### *Demographic profile*

According to the most recent data on disability provided by Statistics Canada<sup>2</sup> in 2006, 18.4% (or 612,120 persons) of the population aged 15 and over in BC indicated that they were limited in their daily activities due to a physical or psychological condition (BC Stats, 2009). Females reported higher rates of disability than males both overall and within various age categories. Disability increases with age, ranging from 6.3% of those between the ages of 15 and 29 to a high of 45.7% among those aged 65 and over. On a sub-provincial basis, the disability rate was higher outside of the Lower mainland and Southern Vancouver Island and increased to a greater extent with age. The most common types of disabilities among the working age population were those related to mobility limitations, followed by psychological, learning and hearing disabilities. Almost all types of disability also increase with age. Compared to the Lower Mainland and Southern Vancouver Island, each type of disability was more prevalent in the rest of the province for both males and females (BC Stats, 2009).

#### *Socio-economic profile*

##### **Education**

Based on PALS 2006 data, more people with disabilities in BC did not graduate high school than their counterparts without disabilities (23.4% vs. 15.4%) and fewer attained a university certificate, diploma or degree (17.1% vs. 28.7%). In addition, fewer males than females with disabilities achieved a high school education, this gap between disabled and non-disabled persons being three times larger for males (BC Stats, 2009). In general, the educational attainment of people with disabilities living in the Lower Mainland and Southern Vancouver Island was higher than the rest of the province. Furthermore, more disabled persons living in the rest of the province had less than high school.

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<sup>2</sup> Participation and Activity Limitation Survey (PALS) 2006. <http://www.statcan.gc.ca/pub/89-628-x/89-628-x2007002-eng.htm>

For students with disabilities, school boards in Vancouver, Oliver and Penticton offer various speech and language services, instruction for and teachers for people who are visually impaired, hard of hearing or deaf. However, according to the BC Teachers's federation, about 604 special education teachers have been lost between 2001 and 2008 (BC Teacher's Foundation).

### ***Income***

According to PALS 2006 data, there was an obvious differential between the median income of people with disabilities (\$19,486) and people without disabilities (\$27,748) in BC that is exacerbated by age. Only two-thirds (66.8%) of disabled people had at least some employment income, compared to 82.3% of non-disabled (BC Stats, 2009). BC had the highest child rate poverty in Canada 5 years in row (Social Planning and Research Council of BC -SPARC BC). There is a range of programs such as the *People with Disabilities (PWD) Assistance Program* offered by the BC Ministry of Housing and Social Development and the *Persons with Persistent and Multiple Barriers Program (PPMB)* designed to support people with disabilities in financial need. However, as noted in an article published by BCCPD, there are currently significant gaps in the disability benefit process and many people with disabilities encounter difficulties benefiting from these supports due to the complicated application process, narrow eligibility guidelines and extensive delays (BCCPD, 2007).

### ***Employment***

In 2006, persons with disabilities participated in the labour force significantly less than persons without disabilities (64.6% vs. 78.5%). Further, this gap widens as age increases from 11.5 percentage points for the age group 15 to 29, to 16.3 for the age group 55 to 64. People with disabilities were also significantly more often not in labour force than their counterparts without disabilities (38.5% vs. 21.5%). Employment assistance to those in financial need is available through the *BC Employment Program (BCEP)*. In addition to BCEP, the ministry also funds the *Employment Program for People with Disabilities (EPPD)*, an employment support component specifically for persons with disabilities. However, these programs have been questioned for their main focus on those people with disabilities able to participate in the workforce on an equal footing with non-disabled peers when provided with limited accommodation and unbiased opportunities (Cohen at al., 2008).

### ***Housing***

Homelessness is an increasing problem in Vancouver and surrounding areas. As stated in a report by Greater Vancouver Steering Committee on Homelessness, the number of homeless people in Metro Vancouver has grown by 22% since 2005. Further, approximately 84% of the homelessness population reported at least one complex health condition: physical disability (31%); psychiatric disability (35%); addiction (61%). People with disabilities face even greater challenges than the general population with respect to finding houses that accommodate their disabilities. In response to this situation, there are a number of services in BC such as Metro

Vancouver Affordable Housing and the Vancouver resource Society among others that work to provide housing assistance for people with various types of disabilities.

## Part II - Discussion of findings

### People interviewed

This study is based on 41 interviews conducted through face-to-face interviews with males and females of different age groups and who live with various types of disabilities. The specific socio-demographic and disability-related characteristics of these participants are summarized in Table 1 below.

**Table 1 - Socio-demographic characteristics of the sample**

ATTRIBUTES	NUMBER OF PARTICIPANTS	ATTRIBUTES	NUMBER OF PARTICIPANTS
<b>AGE</b>		<b>EDUCATION</b>	
18-24	2	Elementary	0
25-34	7	Secondary	8
35-44	7	Short Course/Diploma	5
45-54	9	Vocational	3
55-64	9	College/University	24
65+	4	Unassigned	1
Unassigned	3		
<b>SEX</b>		<b>PRESENCE OF DISABILITY</b>	
Female	22	Since birth	20
Male	19	Last 5 years	0
		6 years or more	19
		Unassigned	2
<b>TYPE OF DISABILITY</b>		<b>HOUSING SITUATION</b>	
Mobility	6	Owner	6
Sensory	8	Rental/lease	27
Intellectual	1	Unassigned	8
Psychiatric	6	<b>EMPLOYMENT</b>	
Intellectual & Psychiatric	3	Yes	17
Mobility & Intellectual	3	No	23
Mobility & Sensory	3	Unassigned	1
Other Multiple Disabilities	8		
Other	1		
Unassigned	2		

The sample is almost gender balanced with slightly few more females than males (54% females). Most interviewees are middle-aged, 44% being between 45 and 64.

Regarding the types of disability, a high proportion (41%) of participants identify as having multiple disabilities. A significant number of individuals (59%) have attended college and/or university. However, despite this high percentage, 56% indicated that they were unemployed at the time of the interview.

The socio-demographic profile of this group might be different, and therefore not representative of all individuals with disabilities in the areas monitored. Therefore, it is important to consider this profile that provides the context for interpreting the results of the study.

## Domains of life and human rights principles

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

In order to gain better insights into the range of participants' experiences, their reports were explored in relation to each domain of life and, within each domain, in relation to the five human rights principles.

Social participation, Income security & support services, and Work were the domains with the highest number of reports. At the opposite end, there were the domains of Access to justice and Health, habilitation& rehabilitation (Table 2).

**Table 2 Experiences reported by participants by domain of life**

Domain of Life	Number of Reports	Percentage
<b>Social Participation</b>	40	98%
<b>Income Security &amp; Support Services</b>	37	90%
<b>Work</b>	34	83%
<b>Privacy &amp; Family Life</b>	33	80%
<b>Education</b>	24	59%
<b>Information &amp; Communication</b>	23	56%
<b>Health, Habilitation &amp; Rehabilitation</b>	22	53%
<b>Access to Justice</b>	13	32%

Across all domains, both positive and negative experiences on grounds of disability were reported, although negative experiences slightly outnumbered the positive ones (Table 3). In fact, all participants talked about instances in which they experienced lack of respect and dignity as well as exclusion and inaccessibility. At the same time, they also reported situations when they felt included and their needs being accommodated. This outcome may signal that, despite ongoing disparities, positive change is also underway for persons with disabilities in Vancouver areas monitored.

**Table 3 Experiences reported by participants by human rights principles**

Human Rights Principle	Percentage
Lack of Respect	100%
Lack of Dignity	100%
Exclusion & Lack of Accessibility	100%
Inclusion & Accessibility	100%
Discrimination & Inequality	98%
Dignity	95%
Self-Determination	56%
Respect	44%
Non-Discrimination & Equality	32%
Lack of Autonomy	17%

***Social participation***

Social participation emerged as the most significant domain of life for the interviewees (Table 4). It is a complex category which entails, for the purpose of this study, experiences related to social life in a broad sense - cultural and political life, sports, leisure, and recreation.

**Table 4 - Experiences reported in the domain of Social Participation**

Principle		Number of Persons	Percentage <sup>3</sup> (%)
<b>Dignity</b>	Dignity	30	73%
	Lack of Dignity	38	93%
<b>Autonomy</b>	Self-Determination	9	22%
	Lack of Autonomy	16	39%
<b>Participation, Inclusion &amp; Accessibility</b>	Inclusion & Accessibility	35	85%
	Exclusion & Lack of Accessibility	37	90%
<b>Non-Discrimination &amp; Equality</b>	Non-Discrimination & Equality	7	17%
	Discrimination & Inequality	31	76%
<b>Respect for Difference</b>	Respect	12	29%
	Lack of Respect	30	73%
<b>Total</b>		<b>48</b>	<b>98%</b>

<sup>3</sup>These categories are not mutually exclusive as each participant could report up to three different situations, and each situation reported could involve both negative and positive experiences. The percentages throughout this section are calculated on the basis of the total number of interviewees. The total in each table indicates the number of participants who reported experiences related to a specific domain considered in the study.

A wide range of experiences have been reported by participants in their exercise of rights in relation to various aspects of social participation. Many experiences evolved around loss of dignity – participants reported feeling disrespected and devalued in their own opinions and experiences, as well as being unable to voice opinions without fear of physical, psychological and emotional harm when attempting to participate in different sectors of social life:

*“... I’ve had to deal with the fact that I was different from other people, that people treated me differently because of my disability and so... I tend to look at myself as a bit weak and not very confident and not as strong as people without disabilities.” (DVC01, Female – age 32)*

*“When I had a brace I was really hunched over, so sometimes people called me hunchback... so that’s derogatory. That’s another form of verbal abuse. I’ve got scoliosis, so I’m always aware... having a curvature in my back, people comment on that throughout my life.” (DVC05, Male – age 59)*

*“I felt ignored. I mean sometimes if you’re blind you can’t totally tell if people are in front of you. If they’re in front of you, you try and say hi or try and talk to them. Sometimes people don’t talk to you, or they just pass you... it just makes me feel absolutely disgusting. Like I’m not a person.”(DVC08, Female – age 30)*

An overwhelming number of interviewees reported instances of exclusion and lack of access to various aspects of social life. Many negative experiences were experienced by the interviewees because of inaccessible transportation and built environment or ‘erosion of access’ as one of the participants framed it. Discrimination and unequal treatment in social life were also identified by people as key factors preventing their participation on equal basis with others in various social and cultural activities, as well as in sports and recreation:

*“One time last year, I had my brace on... I got on the bus at UBC and nobody would give me a seat... quite often when I get on the bus, I have to ask for a seat and demand it because a lot of times people won’t give up their seat for me. That happens frequently.” (DVC05, Male – age 59)*

*“The issue of inclusion comes into play with a lot of things where you’re dealing with accessibility because sometimes accessibility is provided, but it’s totally segregated... the newer types of cinemas... with the stadium-style seating. Before, when you just had theatre type of seating, someone like myself could transfer to any isle seat going up and down as far back as you wanted. But now, there’s a specific area for those in wheelchairs to sit. Again, it’s another form of what I’ve come to call erosion of access. They’ve taken something that was more accessible before, and made it less accessible.” (DVC12, Male – age 61)*

*“I had a very large problem... they actually did prevent me from flying independently. They told me I needed to have a babysitter to come with me and they wanted me to pay for this person to fly with me... that’s not really fair... that’s discrimination. I was completely discriminated*

*against... just because we're deaf blind doesn't mean anything...they just don't get it, so it's a huge discrimination factor.” (DVF01(1), Male – age 49)*

In spite of various obstacles to social participation, a high proportion of participants also reported positive experiences of inclusion and accessibility in various areas of social life as this interviewee commented:

*“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)*

### ***Income security and support services***

The domain of Income security and support services involves experiences related to access to or denial of income and social supports. The lack of these supports increases the vulnerability of people with disabilities to poverty and societal exclusion.

**Table 5 -Experiences reported in the domain of Income Security & Support Services**

Principle		Number of Persons	Percentage (%)
<b>Dignity</b>	Dignity	14	34
	Lack of Dignity	22	54%
<b>Autonomy</b>	Self-Determination	2	5%
	Lack of Autonomy	9	22%
<b>Participation, Inclusion &amp; Accessibility</b>	Inclusion & Accessibility	23	56%
	Exclusion & Lack of Accessibility	29	71%
<b>Non-Discrimination &amp; Equality</b>	Non-Discrimination & Equality	2	5%
	Discrimination & Inequality	10	24%
<b>Respect for Difference</b>	Respect	1	2%
	Lack of Respect	4	10%
<b>Total</b>		<b>37</b>	<b>90%</b>

Almost three in four individuals in this study reported experiences of exclusion from social protection schemes on grounds of disability (Table 5). They also experienced a lack of adequate support and assistance for their unique needs, leading to serious restrictions in various other aspects of people's lives as one interviewee confided:

*“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)*

Inadequate income supports represent a huge barrier to a life mastered by the persons with disabilities themselves as one of the interviewees stated:

*“With welfare, I don't have enough to rent a one bedroom suite. If I had disability benefits that would be the first thing I'd probably do, a dumpy old apartment or something that would give me my independence... hopefully give me enough money to somehow restart my life.” (DVC11, Male – age 48)*

Beyond their negative impact on the economic situation of persons with disabilities, barriers to adequate disability-related supports significantly contribute to the erosion of person's worth and dignity:

*“It's frustrating because you have to fight for everything and try to get everything that you possibly can and sometimes it's very stressful... Sometimes you get nervous because you think they're going to say no or they're going to fight me or argue with me or this can't be done or she can't do this a certain way or whatever it is...” (DVA11, Female – age 36)*

*“I'm angry at the system... You feel more normal when your place is clean, when it's not dusty, when there are no leaves on the floor, because it maybe hasn't been vacuumed in a month, or swept, because that's not a priority...” (DVB04, Female – age 63)*

## **Work**

The Work domain entails experiences related to access, retention and progression in the labour market. The data indicates interesting varied results, with high percentages of both positive and negative experiences. Table 6 summarizes the outcomes from the stories collected in relation to work.

**Table 6 -Experiences reported in the domain of Work**

Principle		Number of Persons	Percentage (%)
<b>Dignity</b>	Dignity	18	44%
	Lack Of Dignity	17	42%
<b>Autonomy</b>	Self-Determination	2	5%
	Lack of Autonomy	7	17%
<b>Participation, Inclusion &amp; Accessibility</b>	Inclusion & Accessibility	22	54%
	Exclusion & Lack of Accessibility	23	56%

<b>Non-Discrimination &amp; Equality</b>	Non-Discrimination & Equality	4	10%
	Discrimination & Inequality	15	37%
<b>Respect for Difference</b>	Respect	6	15%
	Lack of Respect	13	32%
<b>Total</b>		<b>34</b>	<b>83%</b>

While slightly over half of participants encountered exclusion and/or barriers to obtain paid jobs, a similar proportion also indicated that their needs have been accommodated at their workplaces. Instances of exclusion at the workplace primarily involve situations where one’s disability is not accommodated at all; often discouraging individuals to fight for changes or even voice their needs:

*“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 find with the level of stiffness and pain, I would never be able to do a traditional nine to five job, like at a bank or for any kind of company. I find that to be a challenge because I really wouldn’t even know how to approach a company to ask them for non-traditional work hours... like it’s so hard for me to get there.” (DVC08, Female – age 30)*

On the other side, participants also reported positive experiences when their work-related needs have been accommodated. For example, one interviewee reported:

*“There was a big company, and I was interested in a work opportunity there. They said, ‘we’ve got all these deaf people, we’ve hired all of them and they’re all very different...’, and I felt like they understood that not every deaf person is the same. They have different levels of literacy, different experience, different skills, and this company was a lot more open to that. When I submitted my resume they said that they would find me the right match, and that I wouldn’t be in a job that was below my skill level.” (DVE01, Female – age 41)*

People’s stories related to their workplace experiences evolved around both respect and erosion of dignity. For instance, a number of individuals who felt disrespected and devalued noted the discrepancy between the values upheld by the employers in their claims and their actual practices:

*“I’m frustrated, not satisfied, and I also feel that there’s a conflict with the organization that I work for and their mandate. I mean, everything they say that they’re about, seems to conflict*

*with the way that they've treated me. They claim to support and advocate for deaf and hard of hearing people, but I haven't really felt that myself, personally.*" (DVE01, Female – age 41)

Other interviewees, however, reported positive experiences and shared stories of fulfilled life due to inclusive workplace environment:

*"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)

### ***Privacy and Family life***

Family life and personal relationships often have a tremendous impact on people's daily experiences. Interactions with family members and privacy-related issues were explored throughout the interviews. Interestingly, many of the reported experiences in this domain of life were positive. For example, one in two individuals felt valued in their family and personal relationships and their privacy respected. However, approximately half of the interviewees also reported opposite stories.

**Table 7 - Experiences reported in the domain of Privacy and Family Life**

Principle		Number of Persons	Percentage (%)
<b>Dignity</b>	Dignity	21	51%
	Lack Of Dignity	10	24%
<b>Autonomy</b>	Self-Determination	2	5%
	Lack of Autonomy	1	2%
<b>Participation, Inclusion &amp; Accessibility</b>	Inclusion & Accessibility	16	39%
	Exclusion & Lack of Accessibility	9	22%
<b>Non-Discrimination &amp; Equality</b>	Non-Discrimination & Equality	0	0%
	Discrimination and Inequality	5	12%
<b>Respect for Difference</b>	Respect	3	7%
	Lack of Respect	6	15%
<b>Total</b>		<b>33</b>	<b>80%</b>

Many participants stated that family represents an important source of emotional and material support and that connectedness with family members makes them feeling proud and useful.

*“My family... they are very important and it’s always been something that I’ve tried to stay close to. I’ve got siblings in the lower mainland, in Vancouver Island. So, I try to stay in touch with them... looking after the house and looking after each other.”* (DVC12, Male – age 61)

*“My relationship with my family is quite satisfying. I keep in touch with them. My nephew’s wife is going to give birth to a child, and I’m going to be a great uncle. That gives me a lot of pride.”* (DVi01, Male – age 50)

In contrast to stories of supportive families, there were also other stories around resentful feelings because of the attitudes of family and friends, poor treatment or lack of support from the close network once the person became disabled:

*“When I became disabled, I found that my relationship with my family and friends changed. They were used to me being the person that took care of things... I thought they would step up and help me, but I didn’t realize that many of them actually were angry that I couldn’t do the babysitting or do physical things for them. It was like I had spoiled them... they were actually quite resentful... and my mother and father don’t really care... they’re not very supportive.”* (DVA07, Female – age 52)

*“I find that it’s constantly where I’m in the way, I’m slowing things down. Even at home, with my wife... I’ll say look, I can’t do that, I can’t move that fast. I don’t like it because I’m made to feel as if I’m holding things up. I’m late or I’m making you late.”* (DVB01, Male – age 68)

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

Furthermore, the lack of understanding and support from participants’ close networks affected their sense of belonging and inclusion.

*“My daughter is in New West but she hasn’t spoken to me or seen me for a couple of years.”* (DVB04, Female – age 52)

*“I think my parents just thought, that’s life, and that happens in a school. So they never advocated for me... We didn’t have a bond at all... We are not a very close family at all.”* (DVC13, Female – age 37)

*“I feel like there is a hearing world and there is a deaf world and then there is me in the middle. I am in the middle of both. I don’t get the respect of the signers of the deaf world and ...because I’m not deaf, it’s not the same level of need... so I’m kind of just there in the twilight zone between the two worlds.”* (DVG03, Female – age 48)

Individuals felt often disrespected in their family relationships and endured stigmatization because of family’s stereotyped perceptions on disability.

“...my ex husband... he tells the kids that he’s so glad that we’re not together because of my illness.” (DVG04, Female – age 51)

For others, these misconceptions about persons with disabilities created huge barriers to even get into a relationship:

“I find that the common perception is that I’m asexual, therefore I don't need companionship. That’s my real barrier now... just trying to find someone who can look past the... disability which is a really hard... the fact that they don't want to date a disabled person just because they label me asexual.” (DVE04, Male – age 22).

### Education

The domain of education involves personal experiences in the interaction with the education system.

**Table 8 -Experiences reported in the domain of Education**

Principle		Number of Persons	Percentage (%)
<b>Dignity</b>	Dignity	9	22%
	Lack of Dignity	11	27%
<b>Autonomy</b>	Self-Determination	2	5%
	Lack of Autonomy	4	10%
<b>Participation, Inclusion &amp; Accessibility</b>	Inclusion & Accessibility	15	37%
	Exclusion & Lack of Accessibility	13	32%
<b>Non-Discrimination &amp; Equality</b>	Non-Discrimination & Equality	1	2%
	Discrimination & Inequality	11	27%
<b>Respect for Difference</b>	Respect	1	2%
	Lack of Respect	9	22%
<b>Total</b>		<b>29</b>	<b>59%</b>

The principle of participation, inclusion and accessibility was mostly evoked in participants’ stories (Table 9). Over one third of the participants reported feeling included and having their accessibility needs accommodated in the education environment.

“I didn’t have to explain myself or prove myself in order to be accepted. It’s like this program was built for me.” (DVC01, Female – age 32)

On the other hand, a similarly high proportion of individuals reported experiences of exclusion and facing various barriers in accessing the education system. The main reasons identified by

the participants for these situations were lack of accessibility and appropriate supports to facilitate their participation in education, as well as stereotyped attitudes of teachers and staff.

*“The educational system...it’s in shambles right now as far as education for deaf people. We have a very small segregated program, and it’s not a mainstream program... it is mainly because of language issues.”* (DVE05, Male – age 54)

*“I contacted the school about accommodation and they didn’t really give me a straight answer. They told me to contact the instructor of that course, which I did, and she said ‘if you’ve got a visual impairment...I don’t think you could handle it’. She just pretty much told me that I should just give up and don’t even bother signing up for the class... and during the time in that class I can tell you I didn’t have a good time at all. She was pretty harsh, and she left me out group discussions when I had the answers to the questions that most students didn’t know...she would just ignore me as if she didn’t hear me.”* (DVA02, Female – age 29)

As some participants revealed, in certain situations the only alternative was to give up their education prospects:

*“I told the guy ‘I have difficulty with essays, is there any way we could do multiple choice, is there any way we could do other projects?’ and he said ‘No, if you can’t do essays, get out of my course.’”*(DVA06, Female – age 41)

*“It was a very difficult time for me to give up what I was studying and switch to something else... so in that sense I didn’t feel cared about... maybe one person cared,... but the rest seemed like they were putting up barriers.”* (DVA01, Male – age n.a.)

A number of people in this study reported experiencing ableism in school life, which made it difficult to enjoy an educational experience equal to their able-bodied peers. The attitudes of their peers and instructors had a detrimental effect on people’s self-esteem and confidence, turning their educational experience into the opposite of what meant to be – a way to create confident and fulfilled individuals.

*“My peers made fun of me. They talked about me behind my back. They bullied me. I was picked on all the time... my teachers picked on me too.”* (DVC13, Female – age 37)

*“The pressure to perform was huge. It not only came from my classmates, it came from me teachers. They were awful. I think my confidence and self-esteem have taken a beating, but I think that the further I get away from that department, the better I’ll feel.”* (DVC04, Female – age 34)

## *Information and communication*

Information and communication represents an essential aspect of life in our knowledge society. It is an area of particular concern for people with disabilities as usually the communication venues are not adapted so that they have equal access to information as their non-disabled counterparts.

**Table 9 – Experiences reported in the domain of Information & Communication**

Principle		Number of Persons	Percentage (%)
<b>Dignity</b>	Dignity	5	12%
	Lack of Dignity	10	24%
<b>Autonomy</b>	Self-Determination	2	5%
	Lack of Autonomy	2	5%
<b>Participation, Inclusion &amp; Accessibility</b>	Inclusion & Accessibility	10	24%
	Exclusion & Lack of Accessibility	17	42%
<b>Non-Discrimination &amp; Equality</b>	Non-Discrimination & Equality	0	0%
	Discrimination & Inequality	7	17%
<b>Respect for Difference</b>	Respect	0	0%
	Lack of Respect	2	5%
<b>Total</b>		<b>23</b>	<b>56%</b>

According to participants’ responses (Table 10), the most infringed principle within this domain of life is that of participation and accessibility -a large number of interviewees reported feeling segregated or isolated because of their lack of access to various communication means:

*“For access... for deaf people, they don't have access to communication. They're always waiting for an interpreter...”* (DVE05, Male – age 54)

*“The government should be providing library services universally for the disabled and for blind people that need alternate print. We should have the same access to information as sighted people, and I shouldn't have to knock on people's doors and ask for money so I can read a book.”* (DVC02, Male – age 68)

*“In the workplace... a number of issues in terms of the telephone and being asked again and again to find out information on the telephone and... I try to do some of it, but it just ends up being frustrating. Meetings... they get in to a meeting and everybody starts talking to each other and you're lost with it all, which is really hard on the self-esteem...and it's really hard on your stress management.”* (DVG01, Female – age 58)

About one in four interviewees linked their negative experiences around communication and access to information to diminished dignity (Table 10). Many participants reported situations of

embarrassment, frustration, and disrespect in their human interactions because of the communication barriers:

*“It’s just hard to strike conversation with strangers and sometimes even with people that I know... I don’t know whether or not they would have walked away. I frequently have to check because... there are no verbal cues that they are physically there, and I find that hard for me... sometimes it makes me feel pretty stupid after you talk for a few minutes and then realize that either the other person is not paying attention or they in fact walked away. That’s pretty embarrassing...”* (DVi02, Male – age 31)

*“Basically left out and angry... you want to say to yourself, well who the hell are you supposed to talk with about this. Who is giving out this free ticket and who is giving out this free information? No one sends anything to me or to people with disabilities at all.”* (DVF02(2), Male – age 67)

### ***Health, habilitation and rehabilitation***

Accessing the highest available standard of health and health services is an important aspect in the lives of numerous people with disabilities. Individuals may encounter difficulties in dealing with health care practitioners, as well as in accessing various health-related services. Table 11 summarizes the results of this study in relation to health domain.

In their encounters with the health system, many participants reported feeling devalued as a result of poor treatment received from various practitioners:

*“So I thought, I’m going to talk to my doctor, she’ll get something going... but nothing. Then I got angry... She didn’t want me in her practice. It made me feel, on a scale of one to ten, that I was less than zero. That’s how I felt with her. I can tell you that whenever I had an appointment, I hated it because I had to try to find some kind of strength to sit in the appointment and not show my feelings.”* (DVC09, Female – age 66)

Users and survivors of psychiatric services, in particular, expressed their dissatisfaction and frustration with the treatment received and the attitudes of health care workers that affect their dignity:

*“As a person with a mental health disability, the unaccountability of psychiatry, the arrogance of psychiatrists who are almost infamous... with most of them, in my experience... I find that in the system itself the mental health system, on a very real level, it has more to do with controlling people and doesn’t really offer me a lot of hope, it’s forced me to seek out other alternatives... I’m angry, I’m still angry with my doctor.”* (DVC10, Male – age 49)

**Table 10 - Experiences reported in the domain of Health, Habilitation and Rehabilitation**

Principle		Number of Persons	Percentage (%)
<b>Dignity</b>	Dignity	10	24%
	Lack of Dignity	17	42%
<b>Autonomy</b>	Self-Determination	8	20%
	Lack of Autonomy	12	29%
<b>Participation, Inclusion &amp; Accessibility</b>	Inclusion & Accessibility	13	32%
	Exclusion & Lack of Accessibility	13	32%
<b>Non-Discrimination &amp; Equality</b>	Non-Discrimination & Equality	1	2%
	Discrimination & Inequality	12	29%
<b>Respect for Difference</b>	Respect	2	5%
	Lack of Respect	14	34%
<b>Total</b>		<b>22</b>	<b>53%</b>

Another cause of feeling devalued in accessing health services came from not being allowed to voice up their concerns. For example, interviewees described various situations dealing with physicians insensitive to people’s health concerns, this contributing to their wider social exclusion:

*“It made me feel frustrated because I knew what the problem was and he didn’t believe me. He told me I had migraine headaches. I never had migraine headaches. I know my symptoms when my shunt locks up and he doesn’t. He doesn’t know me... so it just made me really frustrated that he wouldn’t believe me.”* (DVA04, Female – age 44)

*“The orthopaedic surgeon, when I was 45, refused to repair my knee. He said I was too fat, too old and diabetic. ... So I stopped playing floor hockey and field hockey...”* (DVA07, Female – age 51).

One third of individuals in this study reported various experiences of lack of respect in medical settings. They felt misunderstood and stigmatized through the medical treatment that objectifies them. Again, this is particularly the case of individuals with psychiatric disabilities:

*“I went to the hospital and there were tons and tons of doctors and nurses and lab technicians seeing me... they thought I was like a spectacle...”* (DVC13, Female – age 37)

*Access to justice*

The domain of access to justice was the least discussed by participants. It encompasses people’s experiences in their interaction with the legal system, as well as liberty and security of the person.

**Table 11 - Experiences reported in the domain of Access to Justice**

Principle		Number of Persons	Percentage (%)
<b>Dignity</b>	Dignity	2	5%
	Lack of Dignity	7	17%
<b>Autonomy</b>	Self-Determination	1	2%
	Lack of Autonomy	2	5%
<b>Participation, Inclusion &amp; Accessibility</b>	Inclusion & Accessibility	5	12%
	Exclusion & Lack of Accessibility	6	15%
<b>Non-Discrimination &amp; Equality</b>	Non-Discrimination & Equality	0	0%
	Discrimination & Inequality	2	5%
<b>Respect for Difference</b>	Respect	0	0%
	Lack of Respect	1	2%
<b>Total</b>		<b>13</b>	<b>31%</b>

Few individuals expressed feeling a loss of dignity or being disrespected and devalued in interacting with the legal system (Table 12). One participant said:

*“I feel very frustrated by going back and forth to court. You’re going there for nothing for one, and you’re wondering in your mind, is it worth it...?”* (DVF01(2), Male – age 67)

Some individuals also felt largely excluded in their access to justice system, mainly because of financial and legislative barriers. As a result, people with disabilities are not able to bring legal actions to an end, feeling as they cannot rely upon the system to protect them against unfair treatment. For example, one interviewee reported difficulties in dealing with law enforcement officials themselves, when he sought help in dealing with the owner of a restaurant who refused to receive him because of his assistant dog:

*“I called for help and the police... pointed me to nowhere. I think they could do better. I understand that it is not an emergency, but at least they could give me better direction or maybe I expected more support from them than saying ‘we don’t help’. As if this is not their issue and I should deal with someone else.”* (DVI02, Male – age 31)

Another respondent commented on possible lower standards of legal aid in Vancouver, particularly when compared with other major cities in Canada – and cited this as a barrier to taking legal action:

*“If I’d been in Toronto or Montreal, where I would have had access to a good lawyer, I would have taken legal action.”* (DVC02, Male – age 68)

### **Intersectional analysis**

In this section, the exercise of rights by people with disabilities was explored in connection with other characteristics – mainly gender and age<sup>4</sup> – in order to better contextualize people’s experiences. These important attributes were also examined in the context of the key human rights principles employed in this study. However, it is important to note that this study includes slightly more females than males, and also a higher number of individuals over 35, the age group of 18-34 being less represented. The distribution of participants across the two main characteristics is summarized in the table below:

<b>GENDER</b>		<b>AGE</b>			
<b>MALE</b>	<b>FEMALE</b>	<b>18 - 34</b>	<b>35-54</b>	<b>55 and over</b>	<b>UNASSIGNED</b>
19	22	9	16	13	3

### **The impact of gender**

When exploring how gender affects experiences of discrimination in the eight domains of life examined in this study, interesting differences were found between the reports of men and women, particularly in relation to four domains: Privacy and family life, Health, habilitation & rehabilitation, Education and Access to justice. Privacy and family life, Health, and Education were the domains more discussed by women than men (Table 13). On the contrary, access to justice, although generally a not very discussed domain, was more often addressed by men. It is also interesting to note that certain areas such as social participation, work and income security & support services, were similarly addressed by both women and men, denoting their central role in the well-being of persons with disabilities, regardless their sex.

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<sup>4</sup>Analysis by type of disability was not possible due to small cell sizes once disaggregating by various types of disability reported by participants in this study.

**Table 12 - Experiences reported by sex and domain of life**

<b>Domains of Life</b>	<b>Female</b>	<b>Male</b>
<b>Social Participation</b>	22	18
<b>Privacy &amp; Family Life</b>	21	12
<b>Health, Habilitation &amp; Rehabilitation</b>	15	7
<b>Information &amp; Communication</b>	13	10
<b>Work</b>	19	15
<b>Income Security &amp; Support Services</b>	20	17
<b>Education</b>	15	9
<b>Access to Justice</b>	2	11
<b>TOTAL</b>	<b>22</b>	<b>19</b>

Women's and men's experiences were also very similar in relation to their access or denial of human rights principles (Table 14). Both groups reported both negative and positive experiences and no significant pattern emerged differentiating women from men regarding the human rights principles examined.

**Table 13 - Experiences reported by sex and human rights principle**

<b>Human Rights Principles</b>		<b>Female</b>	<b>Male</b>
<b>Dignity</b>	Dignity	22	19
	Lack Of Dignity	21	18
<b>Autonomy</b>	Self-Determination	4	3
	Lack of Autonomy	12	11
<b>Participation, Inclusion &amp; Accessibility</b>	Inclusion & Accessibility	22	19
	Exclusion & Lack of Accessibility	22	19
<b>Non-Discrimination &amp; Equality</b>	Non-Discrimination & Equality	4	9
	Discrimination & Inequality	22	18
<b>Respect for Difference</b>	Respect	10	8
	Lack of Respect	22	18
<b>Total</b>		<b>22</b>	<b>19</b>

## The impact of age

The study also examined the impact of age on participants` experiences across the eight domains of life. Some interesting relations were found concerning three domains – work, privacy & family life and access to justice. Findings are reported in Table 15.

**Table 14 - Experiences reported by age and domain of life**

Domains of Life	18-34	35-54	55+
Social Participation	7	14	8
Privacy & Family Life	6	12	5
Health, Habilitation & Rehabilitation	2	9	4
Information & Communication	2	7	7
Work	7	13	4
Income Security & Support Services	6	13	8
Education	6	5	3
Access to Justice	0	3	4
<b>TOTAL</b>	<b>9</b>	<b>16</b>	<b>13</b>

Younger participants (18-34 and 35-54 age groups) reported their human rights experiences in the domains of Work and Family life more often than the older interviewees. This may be explained by the greater relevance of these domains in the lives of younger people. On the contrary, Access to justice, although the least addressed topic overall, was only discussed by mature participants (55+ and 35-54 age groups), which may also indicate the relevance of this domain for people within these age groups. All age groups, however, gave prominence to issues related to Social participation.

**Table 15 - Experiences reported by age and human rights principle**

Human Rights Principles		18-34	35-54	55+
<b>Dignity</b>	Dignity	7	13	8
	Lack of Dignity	7	14	8
<b>Autonomy</b>	Self-Determination	2	7	6
	Lack of Autonomy	3	3	1
<b>Participation,</b>	Inclusion & Accessibility	7	14	8

<b>Inclusion &amp; Accessibility</b>	Exclusion & Lack of Accessibility	7	14	8
<b>Non-Discrimination &amp; Equality</b>	Non-Discrimination & Equality	3	3	4
	Discrimination & Inequality	7	14	8
<b>Respect for Difference</b>	Respect	3	7	4
	Lack of Respect	7	14	8
<b>Total</b>		<b>9</b>	<b>16</b>	<b>13</b>

Regarding the human rights principles evoked by the stories collected (Table 16), there were little differences across the age groups with no pattern emerging. Regardless of age, participants reported instances of both confirmation and denial of certain human rights principles with, for example, equal proportion of stories dealing with aspects of exclusion and inclusion. Some interesting differences were found in relation to the principle of autonomy, otherwise not too often emphasized in the stories. Cross-age analysis suggests that the older groups were more able to exercise self-determination than youngest people. It is possible that with mature age it also comes a greater ability for self-assertion, in spite of other hostile factors. At the same time, youngest people might also value autonomy more than the older ones, experiencing this way more distress when this is denied on grounds of disability.

## **Analysis based on participants' responses to discrimination**

### **Responses to Abuse and Discrimination**

In this section, the analysis is based on the interviewees' responses on their own actions when facing discrimination. A wide range of responses was provided. Some interviewees chose to **distance** themselves from the contexts in which they faced discrimination in order to avoid further discrimination; others **resisted** by trying to change specific situations and contexts; while others **reported the discrimination to a local authority or had taken legal action**. Results of this analysis are presented on Table 17.

**Table 16– Responses to Abuse & Discrimination**

<b>Response</b>	<b>Number of Persons</b>	<b>Percentage (%)<sup>5</sup></b>
Avoid and seek distance from the discrimination	17	42%
Choose to return to the situation to try to change it	12	2%
Choose to report and complain about the situation	31	76%
Other ways of responding to abuse and discrimination	5	12%
<b>Total</b>	<b>36</b>	<b>88%</b>

The majority of participants chose to report or file an official complaint in their encounters with certain situations of abuse, which shows a high degree of proactivity. Many of the reported instances of discrimination seem to occur in the area of services provision and emphasized the multitude of barriers people faced in their efforts to get issues addressed:

*“I had a human rights complaint against the service provider, alleging that they denied me housing because of my disability.” (DVC03, Male)*

*“I tried everything. I talked to the MP’s... my whole phone book has got little squiggly lines in it because I used to go through and look up human rights. I phoned every office that I thought would help me in there.” (DVC11, Male – age 48)*

On the other hand, many participants chose to avoid or distance themselves from those situations and contexts of abuse or ill-treatment.

*“People insult me... and I can’t really do anything about it. I don't want to start creating more issues or more problems... I just don't want to cause more stress on my shoulders so I just ignore it and stay calm... I just want peace, so I don't say anything to anybody.” (DVF01(1), Male – age 49)*

### **Reasons for Not Reporting**

Not all interviewees, however, sought remedy to an offence or discrimination. This study also explored the reasons why the interviewees decided not to report the instances of rights violations. Results are summarized in Table 18.

**Table 17 - Reasons For Not Reporting**

<b>Reasons</b>	<b>Number of Reports</b>	<b>Percentage (%)</b>
"Nothing would have happened"	14	34%
Lack of access	13	32%
Fear	6	15%

<sup>5</sup>Since each respondent may have reported up to three different incidents, percentages were calculated on the basis of the whole sample and do not sum up to 100%

Lack of financial means	0	0%
Corruption	1	2%
Self-blame	2	5%
Other	9	22%
➔ Complex Process	(3)	(7%)
<b>Total</b>	<b>28</b>	<b>68%</b>

Many people didn't report their experiences of abuse or discrimination for different reasons. Mostly often, participants reported that nothing would have happen as a result of their action.

*“Even if I do stick up for myself and push myself and never let people walk on me, sometimes... I just let things roll because I don't know if they can do anything about actually fixing that washroom because of how small the restaurant is... I don't think they can fix it anyway.”*  
(DVA11, Female – age 36)

*“We've been to a number of forums... seniors forums and disability communities have written in and talked about all of these things...it's so much lip work., but nothing ever actually seems to happen... I'm sixty-five. I've been talking about the same stuff for forty years.”* (DVC02, Male – age 68)

Some participants also pointed out the lack of access to appropriate information and resources in order to proceed with a claim:

*“I already have a disability...with all the forms and things it was just really difficult... I had a lot of problems... some stuff I didn't understand and I wasn't really getting any help with the forms, so I just gave up.”* (DVA02, Female – age 29)

“Other” reasons were mentioned by some interviewees for not reporting on discrimination. A number of interviewees described the substantial efforts involved in order to take legal action; the complexity of the process often leading to frustration and discouragement:

*“I just was too mad. I reported to the one at the front desk, and there was so much commotion, then three others came up to the front. At this point I have four people to deal with... so I just decide I'm getting out of there.”* (DVG03, Female – age 48)

### **Systemic Roots of Discrimination**

Systemic roots of discrimination comprise social, legislative and economic factors which lead to mal treatment on grounds of disability. Throughout the interviews, respondents reflected on their experiences and linked them with broader factors that impact their exercise of rights. Findings are presented in Table 19.

**Table 18 - Systemic Roots of Discrimination**

	<b>Number of Reports</b>	<b>Percentage (%)</b>
Economic	23	56%
Social	12	29%
Legislative	8	20%
<b>Total</b>	<b>27</b>	<b>66%</b>

More than half of the interviewees cited economic factors as primary systemic root of discrimination. People’s experiences touched upon various economic aspects such as living in poverty and lack of appropriate supports from government, making it impossible to live a decent life:

*“Not being poor is a source for...not being ill. People with physical disabilities develop mental disabilities because they’re ill and they’re not getting the help that they need,”* (DVC10, Male – age 49)

*“It’s more the financial issue that really becomes in a factor. I wish I just had more money, more than anything else.”* (DVB02, Male – age 29)

*“It’s very hard not to have money to buy food... It’s not a matter of me not knowing how to budget. There’s just not enough money to budget with. I would love if I had \$200 more a month... I just think it’s strange if the BC government is cutting back... how can there be money for people to live better?”* (DVB04, Female – age 63)

### **Interviewees’ recommendations for political action**

Participants made a number of recommendations to improve the situation and circumstances of people living with disabilities (Table 20).

**Table 19 - Recommendations**

<b>Responses</b>	<b>Number of Reports</b>	<b>Percentage (%)</b>
Raise Awareness	29	71%
Economic Supports	12	29%
Social Support	17	41%
Representation	3	7%
Respect	14	34%
Legislation	8	20%
Peer Support	4	10%
Other	15	37%

→ Access to Information	(2)	(5)%
→ Improved Accessibility	(7)	(17)%
<b>Total</b>	<b>38</b>	<b>93%</b>

Almost three quarters of the participants suggested that educating the public about disability and raising awareness around less visible disabilities is essential in order to improve the situation of people with disabilities.

*“Education, I think, is a huge aspect in change, which leads to understanding, which also leads to... equality.” (DVC01, Female – age 32)*

*“I think that in education... it would be nice to see tolerance policies... they always talk about the main disabilities that are very visible, but... to talk about the ones that are not so visible... to say, just because you can’t see a disability doesn’t mean that somebody doesn’t have a disability. Don’t assume that everyone is fully capable of something... a little more emphasis on that...” (DVB02, Male – age 29)*

*“I think it’s more... awareness and understanding, and knowing that everybody is treated equal and everybody is given the same opportunities. I think there are some people that are... just really ignorant.” (DVA02, Female – age 29)*

Provision of better social supports emerged as another important recommendation. Specifically, participants pointed to the need for stronger mechanisms to be created by government in order to address chronic poverty faced by people with disabilities.

*“Give them more money. I believe in a guaranteed liveable income for everybody... there’s no reason not to have that, especially not in a country like ours where we’re a lot more fortunate than most countries in the world and have loads of wealth... All they would need is the political will to eliminate poverty... it could actually be done within a few years.” (DVC10, Male – age 49)*

Other recommendations included improved accessibility which is essential to participating in all aspects of life on equal basis with other members of society.

*“How do they expect somebody with a disability to function and get through their work day, or their shopping day, or their appointment in a quick and fast way? First of all, we lose track of time... our mental function isn’t as easy because we’re pressed to do things. We’re absorbed in trying to manage the physical problems that we may be having that day. Not having to report to the ferry more quickly than a regular person would be really helpful. If a disabled person could arrive even fifteen or twenty minutes before the ferry sailed, that would be really nice...” (DVB01, Male – age 68)*

## CONCLUSIONS

People with disabilities participating in this study reported a range of 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.

Among the eight domains of life considered in this study - Social participation; Privacy and family life; Education; Work; Information and communication; Access to justice; Income security and services; and Health, habilitation and rehabilitation services - *Social participation* emerged as the domain with the highest number of reports, which denotes its importance for the well-being of persons with disabilities. *Income security & support services* came next, followed by **Work** domain. Across all these domains, the reported experiences emphasized the denial or violation of human rights principles more often than advancement of human rights and freedoms, reflecting a disadvantaged citizenship status for people with disabilities at the areas monitored. However, the domain of **family life** revealed more positive experiences of inclusion and human dignity than negative ones.

**Gender** was found to affect human rights experiences of participants in the areas of Privacy and Family life; Health, Habilitation and Rehabilitation; Education and Access to justice, with women more prone to discuss the first three areas while men were more vocal about the last one. However, no gender differences were found in relation to Social participation, Work and Income security & Support services, inferring the central role of these domains in people`s lives, regardless their sex. Similarly, no significant pattern emerged in relation to human rights principles examined.

**Age** was also found to impact people`s experiences in three domains – Work, Family Life and Access to Justice. Younger participants reported more in relation to Work and Family Life, while older participants voiced experiences around Access to Justice, a domain otherwise not discussed at all by the youngest interviewees. Except autonomy, little differences were found across age groups in what concerns the human rights principles.

Regarding the responses to situations of abuse and discrimination, most participants reported taking formal action, which reflects a high level of activism and proactivity related to the high level of education of participants in this study.

## 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 demonstrate 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 disincentive 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.**



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**Annex I: Interview guide**

**Annex II: Consent form**

**Annex III: Graphs**

## INTERVIEW GUIDE

for the study called

### Monitoring the Human Rights of People with Disabilities in Canada

#### A. Beginning the Interview

##### Introductions:

- [Introduce everyone present (monitors, field assistant, aide and anyone else attending the interview)]
- [Record the interviewee's name on the *Coding Sheet*.]

##### *Request Written, Free and Informed Consent:*

- [Review the *Information Sheet* with the interviewee.]
- [Ask the interviewee if she/he will consent to participate by signing the *Free and Informed Consent Form*.]
- [If the interviewee signs the participation line on the *Free and Informed Consent Form*, proceed with interview.]
- [If the interviewee refuses to sign the participation line on the *Free and Informed Consent Form*, thank the interviewee for his/her time and END the interview. Do not proceed any further.]

##### Request Written Permission to Record the Interview:

- [Ask the interviewee if she/he will consent to having his/her interview recorded.]

- [If consent to record *is given*, the interviewee must sign the applicable line on the *Free and Informed Consent Form*.]
- [If consent to record the interview is *not given*, the interview can still proceed with someone taking notes.]

**[IF WRITTEN CONSENT TO RECORD GIVEN – BEGIN RECORDING NOW]**

## **B. Situations faced by the Interviewee:**

- (a) Please tell me a little about your life during the past five years. What things do you do? Where do you go? Who do you meet?
- (b) What are the things in your life that are most satisfying?
- (c) What are the most difficult barriers or challenges that you face in your life?

### **[1<sup>st</sup> SITUATION]**

- 1.1 Do you recall a particular time or event in the last five years when you were left out or treated badly or prevented from participating because of your disability?
- 1.2 WHAT happened? WHERE and HOW did it happen?
- 1.3 Is this still happening or did it just happen once?
- 1.4 Are there other details that you want to share with us about what happened, when and how in this situation?

### **[ Dignity ]**

- 1.5 HOW did this situation make you feel and WHY? (For example, did you feel respected/not respected, ignored/cared for, worthy/unworthy?)
- 1.6 WHAT made you feel that way?
- 1.7 WHY do you think people treated you that way?

### **[ Autonomy ]**

1.8 Did you feel that you had a choice about what happened to you?  
WHY? or WHY NOT?

1.9 If you had a choice, would it have made a difference to what happened?

**FOR SITUATIONS WHERE THERE ARE CLEAR ISSUES RELATED TO CHOICE AND MAKING A DECISION YOURSELF (SELF-DETERMINATION) ASK:**

(a) Did you want to make a different decision or did you want to do something else? WHAT was the different decision or what did you want to do?

(b) Did you have enough information to make that decision?

If not, WHY NOT?

What prevented you from having enough information?

(c) Did you feel pressured to act the way you did? WHO/WHAT was pressuring you? HOW did it make you feel?

**[ Inclusion ]**

1.10 Did people in your community who knew or saw what happened to you do anything about it?

If yes, WHO?

**[MONITOR: interviewee does not need to give someone's name here – can give general description of the person e.g. “neighbour”, “sister”, etc.]**

WHAT did they do?

**FOR SITUATIONS WHERE THERE ARE CLEAR ISSUES RELATED TO INCLUSION ASK:**

(a) Were you kept apart or left out in this situation?

(b) Did you need a service or some assistance so that you could participate?

If YES, what service(s) or assistance did you need?

Did you receive it?

If you did not receive it, HOW did that affect you?

**[ Non-Discrimination & Equality ]**

- 1.11 How do you think your disability affected what happened to you?
- 1.12 Do you think that people without disabilities would be treated the same way you were?

WHY or WHY NOT?

HOW would they have been treated?

**FOR SITUATIONS WHERE THERE ARE CLEAR ISSUES of DISCRIMINATION AND INEQUALITY ASK:**

- (a) Do you know anyone else who was treated in the way you were?

**[ Respect for Difference ]**

- 1.13 Were you treated the way you were because people thought you were different?

If yes, WHY?

- 1.14 Do you think that a person without a disability would have been treated in a similar way in this situation?

WHY? or WHY NOT?

- 1.15 Do you feel that people label you and then treat you differently because of the label?

If YES, what label do they use?

HOW does this label affect you?

**FOR SITUATIONS WHERE THERE ARE CLEAR ISSUES RELATED TO RESPECT FOR DIFFERENCE ASK:**

- (a) Would someone of a different ethnicity be treated that way?

WHY? or WHY NOT?

- (b) Would a woman be treated that way?

WHY? or WHY NOT?

(c) Would a poor person be treated that way?

WHY? or WHY NOT?

1.16 Did you report the situation to anyone?

yes  no

• If you REPORTED the situation, what kind of person/organization did you report it to?

government official

police officer

army officer

NGO employee

religious leader

cultural leader

ombudsperson

other: \_\_\_\_\_

(specify)

• how did that person react?

• what action was taken?

• If you did NOT REPORT the situation to anyone:

- WHY did you not report it?

1.17 In your opinion, what action[s] should be taken to improve [or prevent] the situation in the future?

1.18 Is there anything else that you would like to tell us about that situation?

\_\_\_\_\_

**[MONITOR: HERE YOU WILL MOVE ON TO THE 2<sup>nd</sup> SITUATION ...]**

Do you recall *another* particular time or event in the last five years when you were left out or treated badly or prevented from participating because of your disability?

2.2 WHAT happened? WHERE and HOW did it happen?

2.3 Is this still happening or did it just happen once?

2.4 Are there other details that you want to share with us about what happened, when and how in this situation?

## [ Dignity ]

- 2.5 HOW did this situation make you feel and WHY? (For example, did you feel respected/not respected, ignored/cared for, worthy/unworthy?)
- 2.6 WHAT made you feel that way?
- 2.7 WHY do you think people treated you that way?

## [ Autonomy ]

- 2.8 Did you feel that you had a choice about what happened to you?  
WHY? or WHY NOT?
- 2.9 If you had a choice, would it have made a difference to what happened?

## FOR SITUATIONS WHERE THERE ARE CLEAR ISSUES RELATED TO CHOICE AND MAKING A DECISION YOURSELF (SELF-DETERMINATION) ASK:

- (a) Did you want to make a different decision or did you want to do something else? WHAT was the different decision or did you want to do?
- (b) Did you have enough information to make that decision?  
  
If not, WHY NOT?  
What prevented you from having enough information?
- (c) Did you feel pressured to act the way you did? WHO/WHAT was pressuring you? HOW did it make you feel?

## [ Inclusion ]

- 2.10 Did people in your community who knew or saw what happened to you do anything about it?  
If yes, WHO?

[MONITOR: interviewee does not need to give someone's name here – can give general description of the person e.g. “neighbour”, “sister”, etc.]

WHAT did they do?

## FOR SITUATIONS WHERE THERE ARE CLEAR ISSUES RELATED TO INCLUSION ASK:

- (a) Were you kept apart or left out in this situation?
- (b) Did you need a service or some assistance so that you could participate?  
If YES, what service(s) or assistance did you need?  
Did you receive it?  
If you did not receive it, how did that affect you?

**[ Non-Discrimination & Equality ]**

2.11 How do you think your disability affected what happened to you?

2.12 Do you think that people without disabilities would be treated the same way you were?

WHY or WHY NOT?

HOW would they have been treated?

**FOR SITUATIONS WHERE THERE ARE CLEAR ISSUES of DISCRIMINATION AND INEQUALITY ASK:**

(a) Do you know anyone else who was treated in the way you were?

**[ Respect for Difference ]**

2.13 Were you treated the way you were because people thought you were different?

If yes, WHY?

2.14 Do you think that a person without a disability would have been treated in a similar way in this situation?

WHY? or WHY NOT?

2.15 Do you feel that people label you and then treat you differently because of the label?

If YES, what label do they use?

HOW does this label affect you?

**FOR SITUATIONS WHERE THERE ARE CLEAR ISSUES RELATED TO RESPECT FOR DIFFERENCE ASK:**

- (a) Would someone of a different ethnicity be treated that way?  
WHY? or WHY NOT?
- (b) Would a woman be treated that way?  
WHY? or WHY NOT?
- (c) Would a poor person be treated that way?  
WHY? or WHY NOT?

**2.16 Did you report the situation to anyone?**

yes  no

- If you REPORTED the situation, what kind of person/organization did you report it to?

- government official
- police officer
- army officer
- NGO employee
- religious leader
- cultural leader
- ombudsperson
- other: \_\_\_\_\_

(specify)

- how did that person react?
- what action was taken?
- If you did NOT REPORT the situation to anyone:
  - WHY did you not report it?

**2.17 In your opinion, what action[s] should be taken to improve [or prevent] the situation in the future?**

**2.18 Is there anything else that you would like to tell us about that situation?**

\_\_\_\_\_

**[MONITOR: HERE YOU WILL MOVE ON TO THE 3<sup>rd</sup> SITUATION ...]**

- 3.1 Do you recall *another* particular time or event in the last five years when you were left out or treated badly or prevented from participating because of your disability?
- 3.2 WHAT happened? WHERE and HOW did it happen?
- 3.3 Is this still happening or did it just happen once?
- 3.4 Are there other details that you want to share with us about what happened, when and how in this situation?

**[ Dignity ]**

- 3.5 HOW did this situation make you feel and WHY? (For example, did you feel respected/not respected, ignored/cared for, worthy/unworthy?)
- 3.6 WHAT made you feel that way?
- 3.7 WHY do you think people treated you that way?

**[ Autonomy ]**

- 3.8 Did you feel that you had a choice about what happened to you? WHY? or WHY NOT?
- 3.9 If you had a choice, would it have made a difference to what happened?

**FOR SITUATIONS WHERE THERE ARE CLEAR ISSUES RELATED TO CHOICE AND MAKING A DECISION YOURSELF (SELF-DETERMINATION ASK:**

- (a) Did you want to make a different decision or did you want to do something else? WHAT was the different decision or did you want to do?
- (b) Did you have enough information to make that decision?  
If not, WHY NOT?  
What prevented you from having enough information?
- (c) Did you feel pressured to act the way you did? WHO/WHAT was pressuring you? HOW did it make you feel?

**[ Inclusion ]**

**3.10 Did people in your community who knew or saw what happened to you do anything about it?**

**If yes, WHO?**

**[MONITOR: interviewee does not need to give someone's name here – can give general description of the person e.g. “neighbour”, “sister”, etc.]**

**WHAT did they do?**

**FOR SITUATIONS WHERE THERE ARE CLEAR ISSUES RELATED TO INCLUSION ASK:**

- (a) Were you kept apart or left out in this situation?**
- (b) Did you need a service or some assistance so that you could participate?**

**If YES, what service(s) or assistance did you need?**

**Did you receive it?**

**If you did not receive it, how did that affect you?**

**[ Non-Discrimination & Equality ]**

**3.11 How do you think your disability affected what happened to you?**

**3.12 Do you think that people without disabilities would be treated the same way you were?**

**WHY or WHY NOT?**

**HOW would they have been treated?**

**FOR SITUATIONS WHERE THERE ARE CLEAR ISSUES of DISCRIMINATION AND INEQUALITY ASK:**

- (a) Do you know anyone else who was treated in the way you were?**

**[ Respect for Difference ]**

**3.13 Were you treated the way you were because people thought you were different?**

**If yes, WHY?**

**3.14 Do you think that a person without a disability would have been treated in a similar way in this situation?**

**WHY? or WHY NOT?**

**3.15 Do you feel that people label you and then treat you differently because of the label?**

**If YES, what label do they use?**

**HOW does this label affect you?**

**FOR SITUATIONS WHERE THERE ARE CLEAR ISSUES RELATED TO RESPECT FOR DIFFERENCE ASK:**

**(a) Would someone of a different ethnicity be treated that way?  
WHY? or WHY NOT?**

**(b) Would a woman be treated that way?  
WHY? or WHY NOT?**

**(c) Would a poor person be treated that way?  
WHY? or WHY NOT?**

**3.16 Did you report the situation to anyone?**

**yes**  **no**

**• If you REPORTED the situation, what kind of person/organization did you report it to?**

**government official**

**police officer**

**army officer**

**NGO employee**

**religious leader**

**cultural leader**

**ombudsperson**

**other: \_\_\_\_\_**

(specify)

- how did that person react?
- what action was taken?
- If you did NOT REPORT the situation to anyone:
  - WHY did you not report it?

3.17 In your opinion, what action[s] should be taken to improve [or prevent] the situation in the future?

3.18 Is there anything else that you would like to tell us about that situation?

---

**[TURN TAPE RECORDER OFF NOW]**

### **C. Follow-up & Verification Information:**

Is there anyone we could contact who saw what happened to you or who could provide us with more information about the situations you have raised?

#### **FOR 1<sup>st</sup> SITUATION:**

- What is their name? [record name on *Coding Sheet*]
- Can we contact this person?  YES  NO
- If yes, what is the best way for us to contact him or her?  
[record details on *Coding Sheet*]

#### **FOR 2<sup>nd</sup> SITUATION:**

- What is their name? [record name on *Coding Sheet*]
- Can we contact this person?  YES  NO
- If yes, what is the best way for us to contact him or her?  
[record details on *Coding Sheet*]

**FOR 3<sup>rd</sup> SITUATION:**

- What is their name? [record name on *Coding Sheef*]
  - Can we contact this person?  YES  NO
- If yes, what is the best way for us to contact him or her?  
[record details on *Coding Sheef*]

**[TURN TAPE RECORDER BACK ON NOW]**

*D. Background Information:*

Now, if you don't mind, we would like to ask you a few questions about yourself.

4.1 What is your sex?

4.2 In what year were you born?

4.3 How would you describe your disability? [choose as many as apply]

- mobility
- sensory – if so,  blind  low vision  deaf  hard of hearing
- intellectual
- psychiatric
- other \_\_\_\_\_

(ask interviewee to specify)

4.4 How long have you had your disability?

- since birth
- since \_\_\_\_\_ (ask interviewee to specify the year)

4.5 Did you go to school?

- yes  no

- If YES, what kind of school? [choose as many as apply]

- primary  secondary  trade school
- college or university

4.6 Is there a specific place where you live?

- yes
- no

- If YES, do you
- own that place?
  - lease that place?
  - rent that place?

Is the place in a permanent building?

- yes
- no \_\_\_\_\_  
(please explain)

IF YES, what is the building made of?

4.7 How far do you live from the City Centre?

4.8 Who lives with you?

**[MONITOR: interviewee should identify as many as apply]**

- no one
- spouse
- children [if yes, how many children ?]
- parent(s) [if yes, how many parents ?]
- other family member(s) [if yes, how many other family members ?]
- friend(s) [if yes, how many friends ?]
- other \_\_\_\_\_ (specify) [if yes, how many?]

4.9 How far is the closest police station to where you live?

4.10 How far is the nearest health centre from your house?

4.11 What type of care is offered by the health centre?

- homeopathic
- primary care physicians
- western medicine
- natural medicine
- other \_\_\_\_\_  
(ask interviewee to specify)

4.12 Do you have a job?

yes

no

If yes, what is your job? \_\_\_\_\_ (specify)

Do you get paid?

yes

no

4.13 Would you say that the area where you live is accessible for people with disabilities?

yes

no

4.14 What makes the area where you live accessible or not accessible?

## E. Ending the Interview & Identifying Other People to Interview

- *Do you have anything else that you would like to add?*
- *Do you have any final questions for us? [MONITOR: Answer these questions]*

*[Monitor: Review briefly what will happen with the information the interviewee has provided the purpose of the project, and the relevant timeframes.]*

***[STOP RECORDING THE INTERVIEW NOW]***

- **Do you know someone with a disability who lives in your community who we could interview for this study?**

**What is his or her name?**

**What type of disability does he or she have?**

**How can we contact him or her?**

[Record this information on the *Coding Sheet*.]

[MONITOR: Thank the interviewee very much for his/her time.]

#### *F. Completing Notes & Transferring Data*

[Remove the USED cassette tape from the recorder and write the applicable Interview Code (from *Coding Sheet*) on the cassette.]

- ***[As soon as possible afterward, monitoring pairs should listen to the tape recording of the interview. If part of a recording is not clear, monitors should clarify these areas on the Interview Notes.]***
  
- **[The *Interview Notes* should also contain the following observations:**
  - (a) **details about the location of the interview (e.g. held indoors/outdoors, type of building, type of room, who else was around, etc.)**
  - (b) **details about any challenges faced or interruptions that occurred during the interview (i.e. airplane flew overhead making it difficult to hear responses, lost electrical power so could not see, etc.), at what stage in the interview they occurred and what steps were taken to address them;**
  - (c) **any concerns about the truthfulness of the statements made in the interview – outlining the reasons for these concerns (e.g. answers were very inconsistent, answers seemed rehearsed, etc.)**
  
- **[Provide the Project Coordinator with the following documents:**
  - **cassette recording of the interview labeled with the Interview Code**
  - **completed *Interview Notes***
  - **completed *Coding Sheet***
  - **signed *Free and Informed Consent Form* - remember to leave the first three pages - the Information Sheet - with the interviewee for his/her reference.]**

[END]

## **Annex II: Consent Form**

# **INFORMATION SHEET & FREE and INFORMED CONSENT FORM**

for the study called

## **Monitoring the Human Rights of People with Disabilities in Canada**

### **INFORMATION SHEET**

This information is provided so that you can make a decision about whether or not you want to participate in this study. We are giving you a lot of information because we want you to be able to make the decision that is best for you.

#### **Sponsors:**

The study is being sponsored by:

- [insert the names of each of the partner organizations of people with disabilities participating in the study, in alphabetical order, with a separate bullet point for each organization]
- Disability Rights Promotion International (DRPI) which is a research project based at York University in Toronto, Canada

#### **Why are we doing this study?**

We are collecting information about the lives and experiences of people with disabilities by talking directly to people with disabilities. We want to see if their human rights are being respected. The information we collect will be studied and reports will be written. The names of participants will not be mentioned in the reports unless they have given us clear permission to do so. The reports will be available to organizations of people with disabilities, other groups working to improve the lives of people with disabilities, the media and governments.

The reports made will be used to:

- let people know about violations of the rights of people with disabilities
- help stop human rights violations
- provide facts to back up arguments for changes in laws, policies, and programs to improve the lives of people with disabilities

- keep track of the steps that the government has taken or has failed to take in order to fulfill the promises it has made to people with disabilities when it signed agreements at the United Nations saying that it would protect, promote and fulfill the rights of people with disabilities

### **What will happen in this study and what will you be asked to do?**

Our project is going to various countries around the world to talk to people with disabilities about their lives and their experiences.

If you agree to participate, you will be asked a series of questions about your life and your experiences. We will particularly want to know if your human rights have been violated and how they have been violated. In other words, we will want to know if there are unfair things that have happened to you which have stopped you from participating in society in the way that people without disabilities participate in society.

If you agree to participate, you will be interviewed by one or more people with disabilities who are members of a local organization run by people with disabilities. We call these people the "monitors". We know that, in the past, people with disabilities have often been left out of research about people with disabilities. We think that it is only fair that people with disabilities play an active role in any research about them.

During the interview, the monitor(s) will take notes. If you give them permission to do so, they will also tape or digitally record the interview so that we can be sure to get all of the information you provide accurately.

Depending on the methods of communication that are used, the complete interview should take approximately 1 to 3 hours to complete.

After the interview, the monitor(s) will give all of their notes and the tape/digital recordings to the person in charge of the project who we call the Site Coordinator. The monitor(s) will not keep any copies and will not talk to anyone except for the Site Coordinator about what you said. The interview will be confidential.

The Site Coordinator will pass the notes and recordings of your interview to the researchers who will study them. Your name will not be on any of the information given to the researchers, they will not know whose information they are studying.

After looking at your information and the information from interviews with at least 50 other people with disabilities in your country, the researchers will write reports that will be given to organizations of people with disabilities, other groups working to improve the lives of people with disabilities, the media and governments. Your name will not be mentioned in the reports without your clear permission.

### **Are there possible negative things that might happen if you participate in the study?**

There are no negative things that will happen to you by participating in this study. However, you may feel uncomfortable when you start thinking about some of the questions that you are asked. For example, you may remember some things that have happened to you that are not pleasant to think about. If that happens, you can take a break from the interview or, if you want, you can stop the interview completely.

If you want to continue to talk about these things, that's fine, too. If you feel upset about these things, you can ask the monitor(s) for the name of someone you can talk to about your feelings after the interview is over.

### **Are there good things that might happen if you participate in this study?**

You may or may not receive any direct benefit from participation. You might find that it makes you feel better to talk about some of your experiences. Also, we hope that organizations of people with disabilities, the media and governments learn from the studies and reports that are made and take steps to improve the lives of people with disabilities in your country.

### **Can you decide if you want to participate in the study?**

You are free to choose to participate or not to participate in the study and you may choose to stop participating at any time. Your participation is completely voluntary. Your decision not to participate in the study will not influence your ongoing relationship with any of the study sponsors, monitors or any other person or group associated with the project.

### **Can you stop participating if you don't want to continue participating?**

If, at *any* time during the study, you want to stop participating, for *any reason*, just let the monitor(s) know and they will stop asking you questions. If you want to answer some questions, but not others, you can do that, too. It is entirely your decision.

If you decide not to participate in the study, or if you decide to stop participating in the study, we will not use your information for our research. Any notes or recordings made up to the point you decided to stop will be destroyed. No one will treat you any differently if you decide that you do not want to participate in the study.

**Will your information be kept confidential?**

The information you provide will be kept confidential within the limits of the law. Unless you specifically provide your consent, your name will not appear in any report or publication of the research. The notes and recordings of your interview will be safely stored in a place that is locked and will be destroyed at the end of the project.

**Costs and Compensation**

You may need some money to cover your transportation to the interview location and the cost of any disability-related supports or assistance that you will need in order to participate in the interview. If this is the case, please let the monitors know the details in advance and the Project Coordinator will make the necessary arrangements.

**If you have questions about the study**

If you have questions about the research in general or about your own role in the study, please feel free to contact:

**[Insert Name & Contact Details of the Site Coordinator]**

by regular mail: \_\_\_\_\_

by telephone: \_\_\_\_\_

by email \_\_\_\_\_

**OR**

**Dr. Marcia Rioux**

Principal Applicant, Monitoring the Human Rights of People with Disabilities in Canada (DRPI-Canada)

Co-Director, Disability Rights Promotion International (DRPI)

Professor, School of Health Policy and Management, Disability Studies,  
Faculty of Health, York University

by regular mail: York University, 441 HNES Building, 4700 Keele Street, Toronto, ON,  
M3J 1P3, Canada

by telephone: +1-416-736-2100 extension 22112

by email: mrioux@yorku.ca

**FREE and INFORMED CONSENT FORM:**

I have read and understood the preceding pages of this Information Sheet. The research procedures mentioned above have been explained to me and all of my questions have been answered to my satisfaction. I have been informed that I can withdraw from the study at any time without penalty and that, if I choose to do so, any data collected as a result of my participation will be destroyed. The potential discomforts that I might experience because I have participated in the study have been explained to me. I also understand the potential benefits of being a part of this study.

I know that I may ask now, or at any time in the future, any questions I have about the study. I have been assured that the records, transcripts, and tapes related to this study will be kept confidential to the limits of the law. I have also been assured that no information will be released or printed or made public that would disclose my personal identity unless I give permission for that to happen.

**I hereby consent to participate in the study:**

Printed Name of Participant: \_\_\_\_\_

Signature of Participant: \_\_\_\_\_

Date of Signature: \_\_\_\_\_

**I hereby consent to having my interview recorded**

Signature of Participant: \_\_\_\_\_ Date: \_\_\_\_\_

\_\_\_\_\_

Signature of Principal Investigator: \_\_\_\_\_ Date: \_\_\_\_\_

**PLEASE NOTE:**

This research has been reviewed by the Human Participants in Research Committee, York University's Ethics Review Board, and conforms to the standards of the Canadian Tri-Council Research Ethics guidelines and the York Senate Policy on research ethics. If you have any questions about this process, or about your rights as a participant in the study, please contact:

**Ms. Alison Collins-Mrakas**

Manager, Research Ethics, York University

mail: 277 York Lanes, York University, Toronto, ON, M3J 1P3, Canada

telephone: +1-416-736-5914

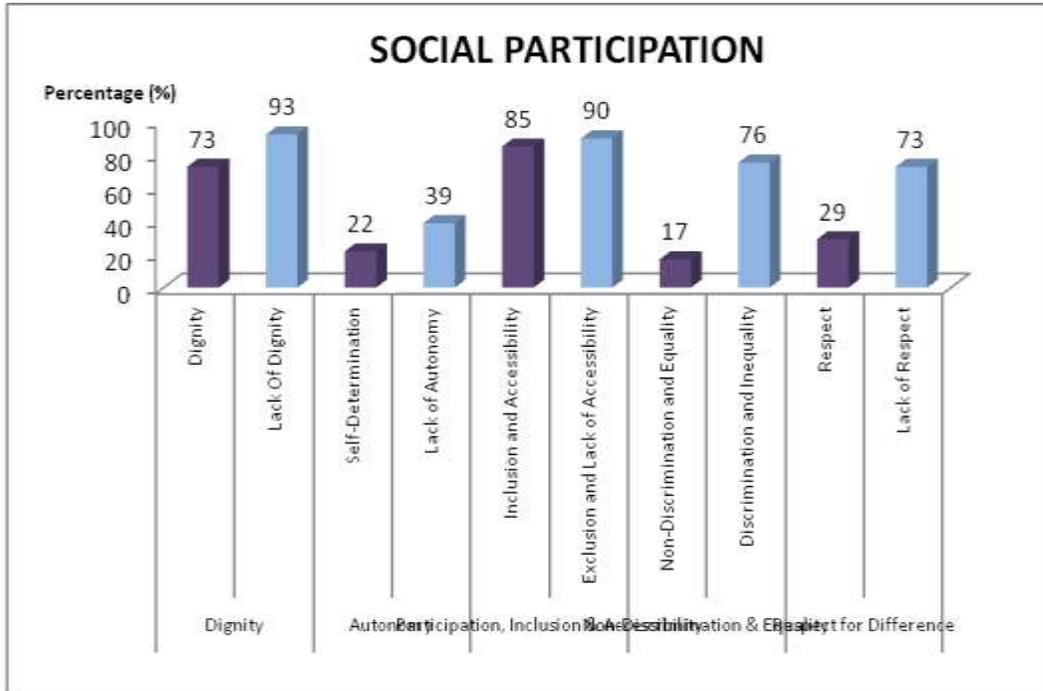
email: acollins@yorku.ca

If you would like to contact the Human Participants in Research Committee, please send your correspondence care of Ms. Collins-Mrakas at the above regular mail or email address.

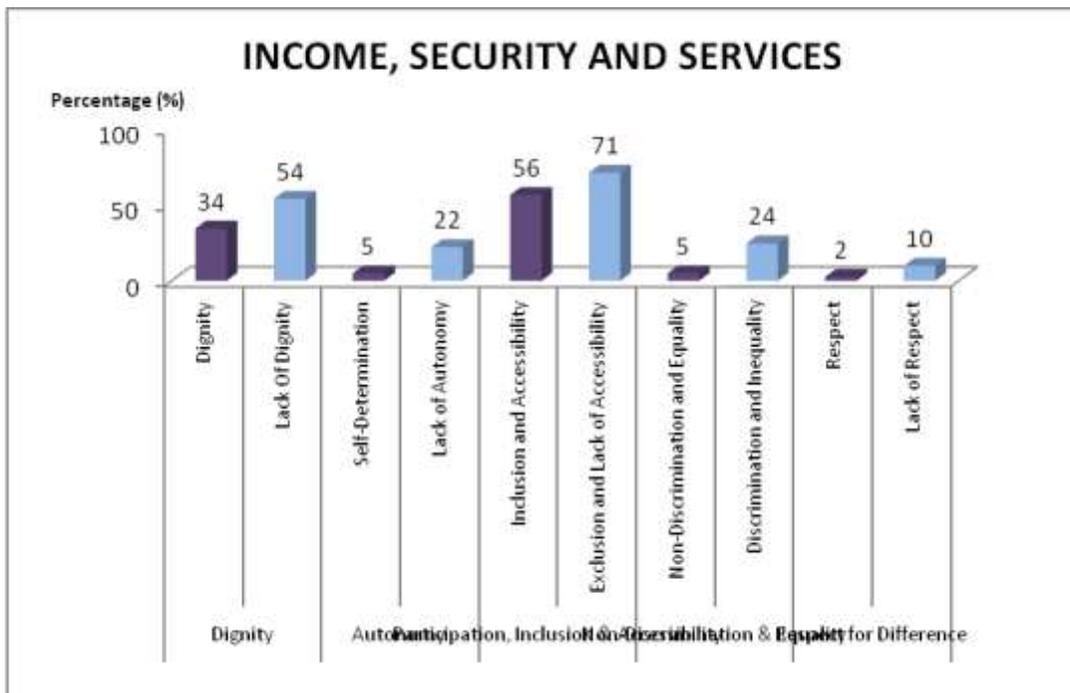
### Annex III: Graphs

The same information available in table format in the report is also displayed in graph format in this annex.

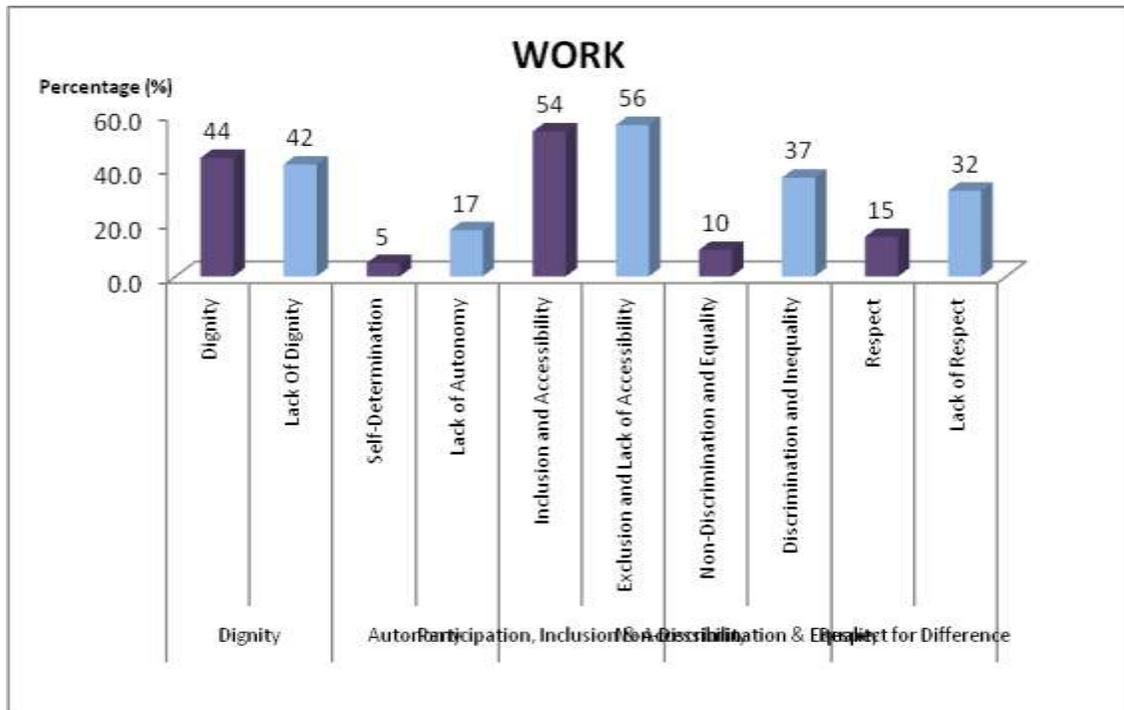
**Figure 1 - Experiences reported in domain of Social Participation**



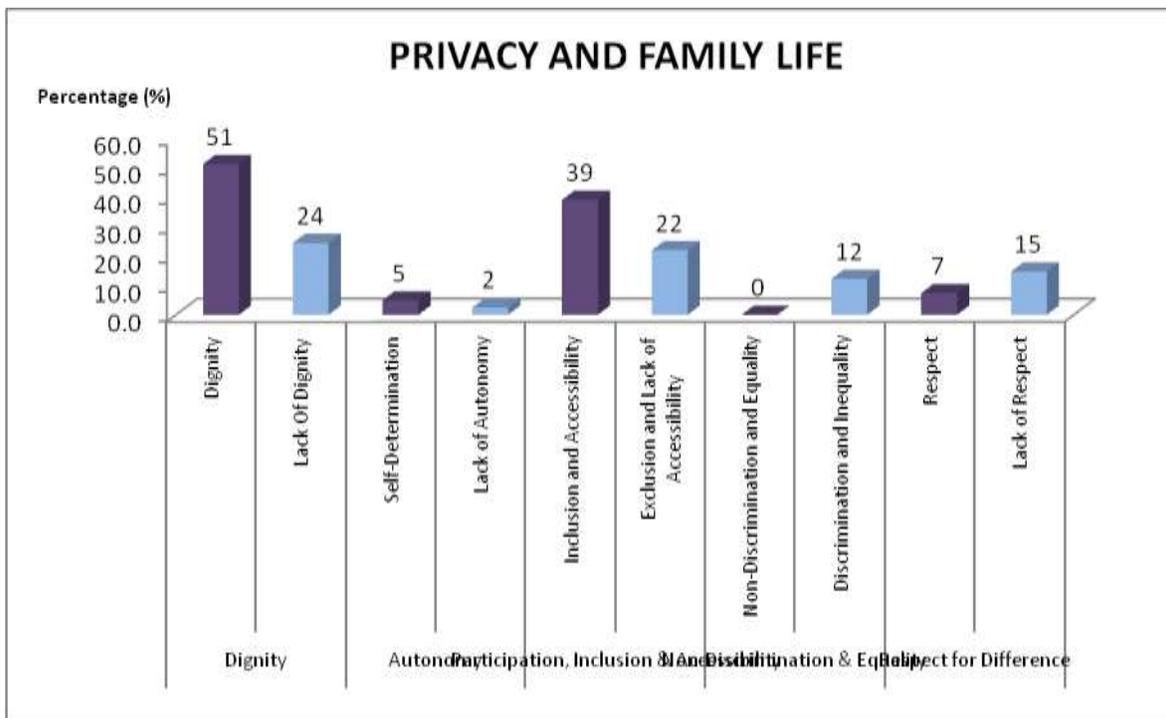
**Figure 2 - Experiences reported in domain of Income Security and Support Services**



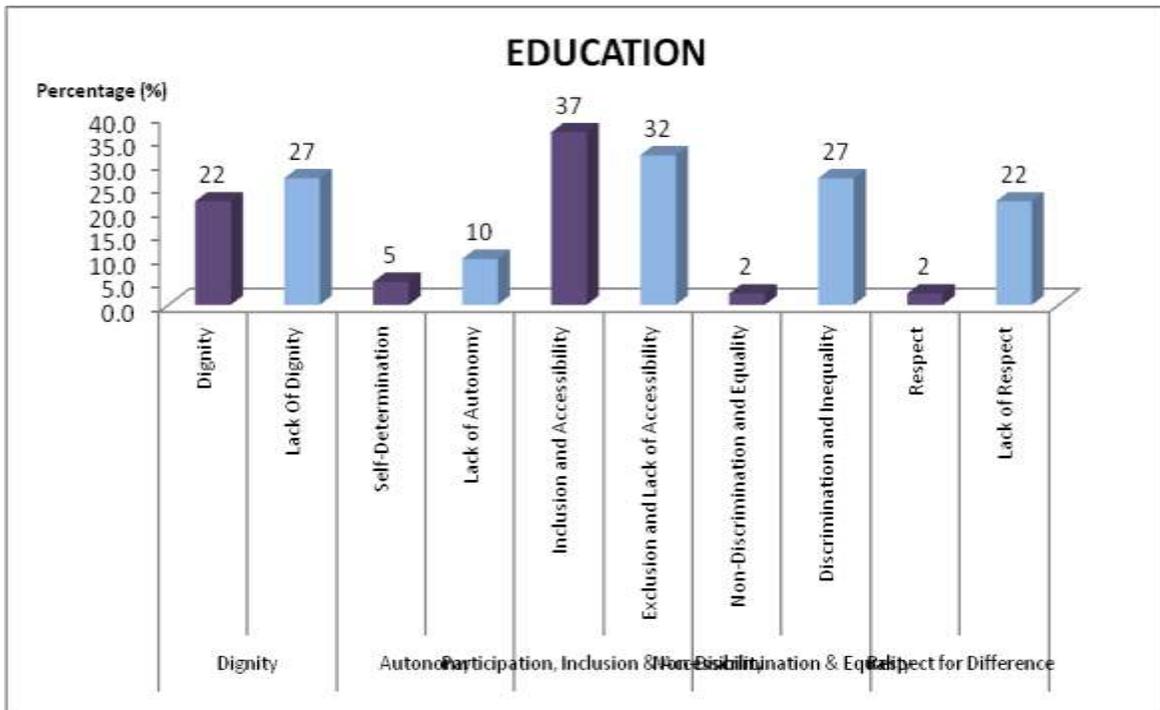
**Figure 3 - Experiences reported in domain of Work**



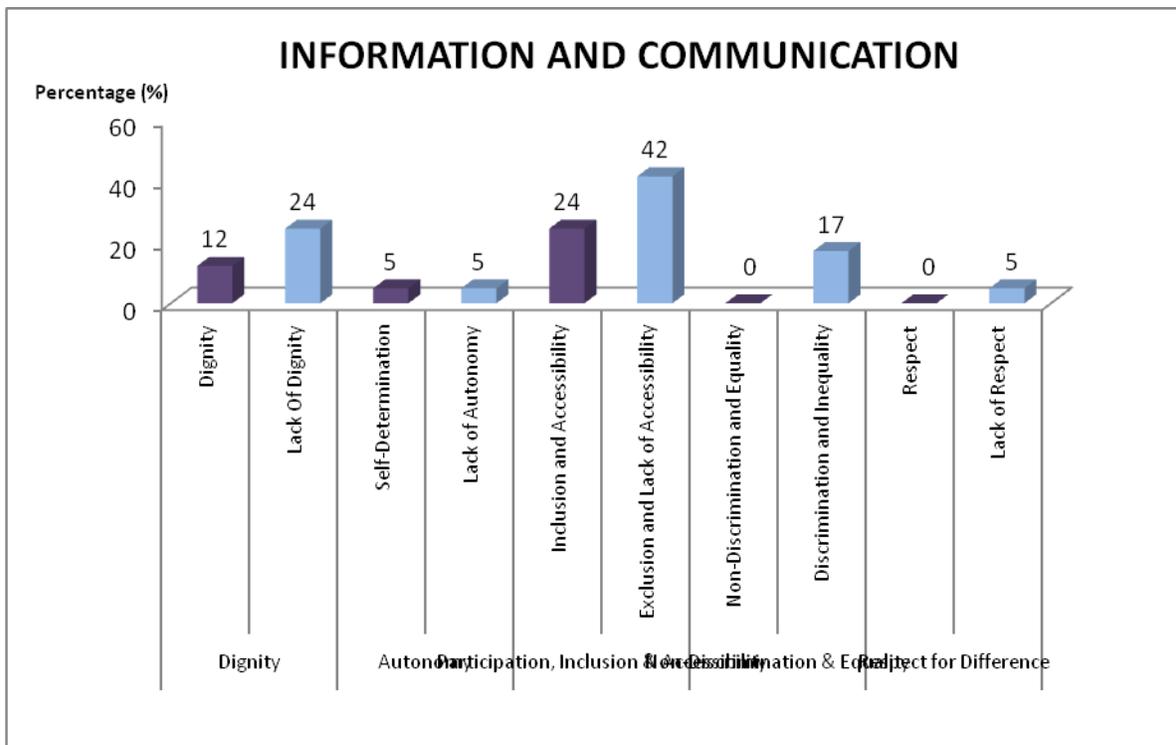
**Figure 4 - Experiences reported in domain of Privacy and Family Life**



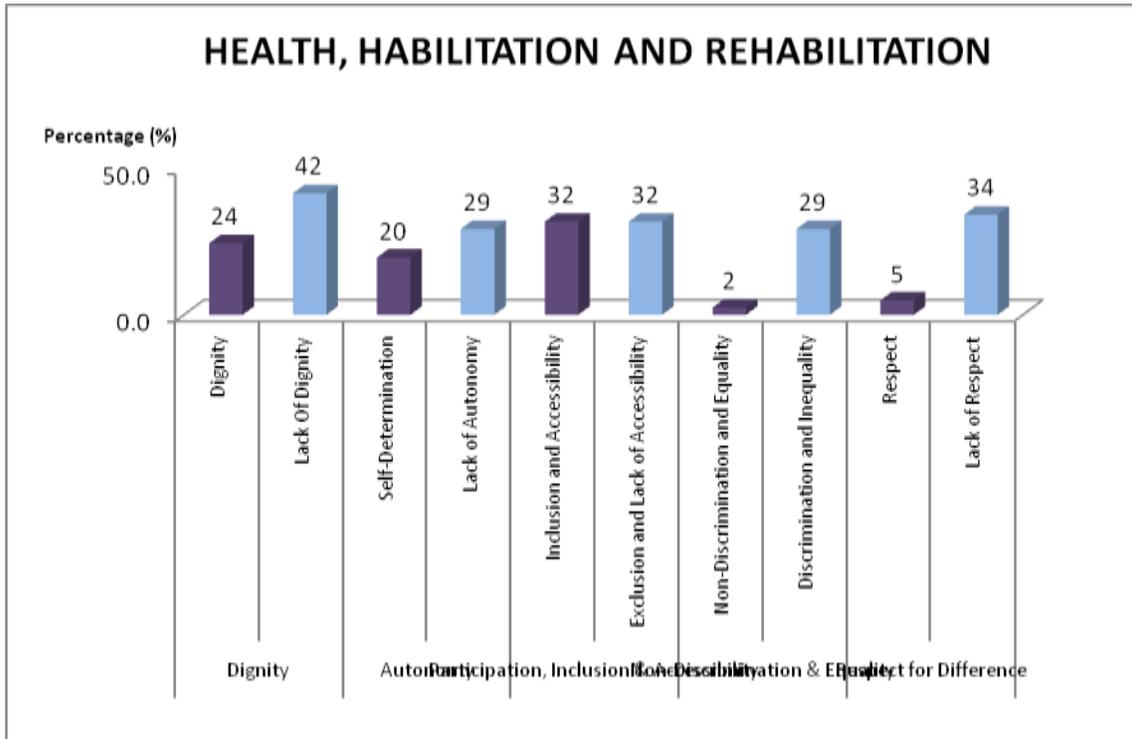
**Figure 5 - Experiences reported in domain of Education**



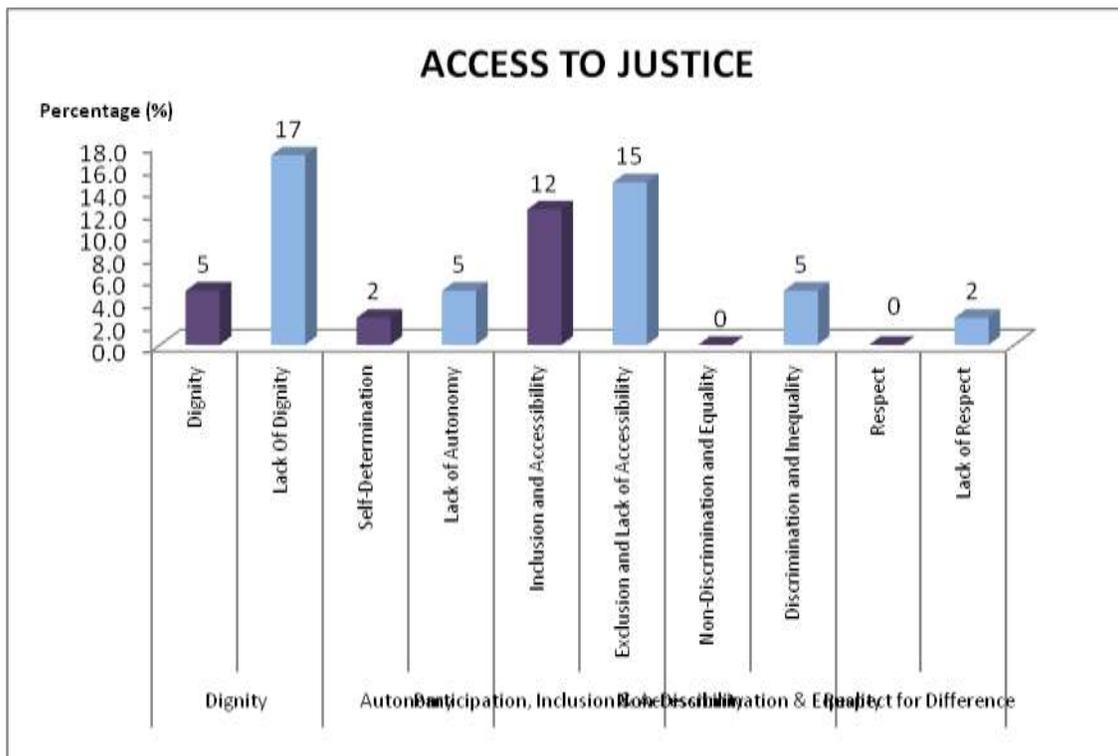
**Figure 6 - Experiences reported in domain of Information and Communication**



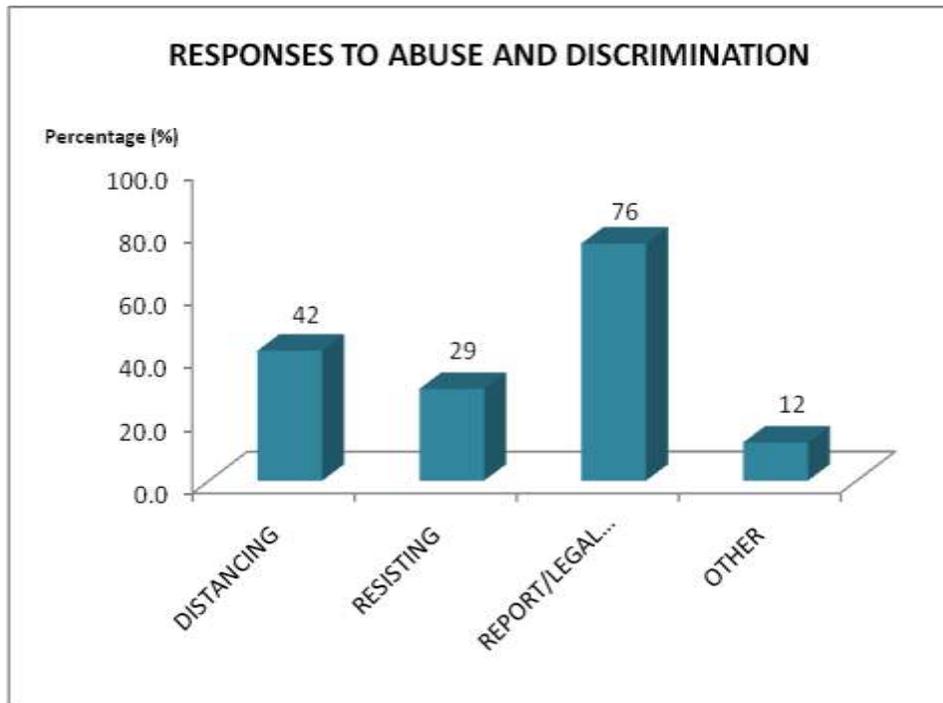
**Figure 7 - Experiences reported in domain of Health, Habilitation and Rehabilitation**



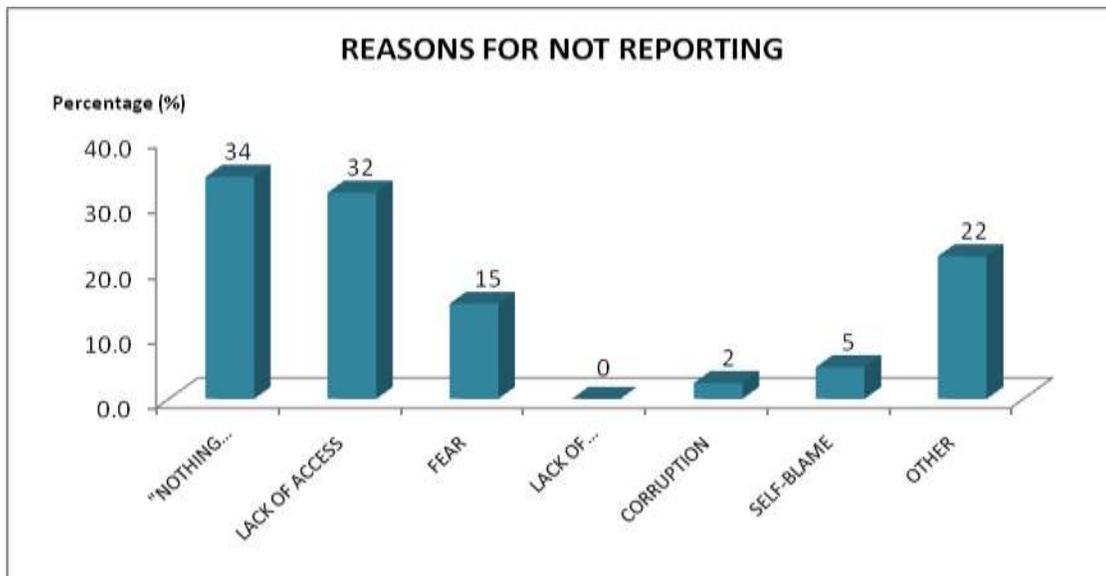
**Figure 8 - Experiences reported in domain of Access to Justice**



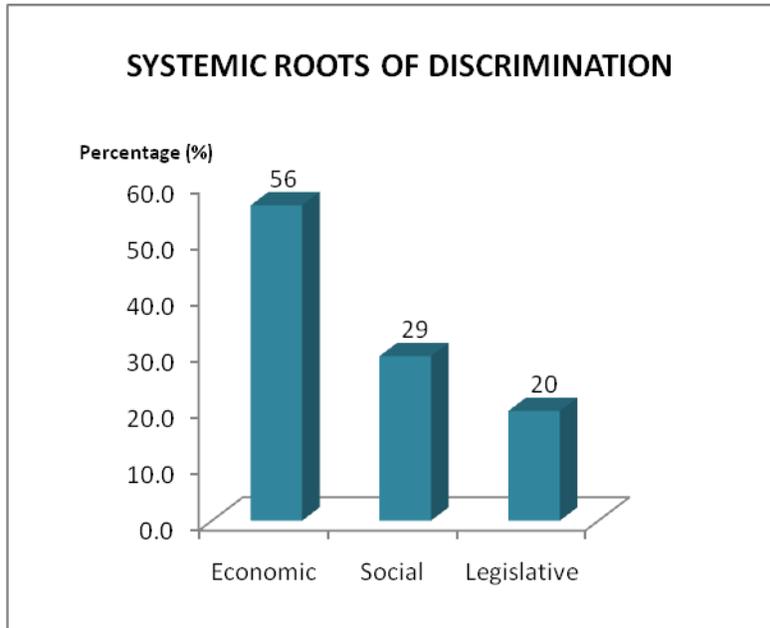
**Figure 9 - Response due to Abuse and Discrimination**



**Figure 10 - Reasons for not Reporting**



**Figure 11 - Systemic Roots of Discrimination**



**Figure 12 - Recommendations**

