MONITORING THE HUMAN RIGHTS OF PEOPLE WITH DISABILITIES IN CANADA

MONITORING SITE REPORT
ST. JOHN'S

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"The sidewalks at Brian are not fit to anyone to walk, let alone a wheelchair, so when I do get out on the side of the road, people put their middle finger up to me. I get people swearing at me... it's stuff that I had to deal with most of my life." (Woman, age n.a.)

"I feel frustrated. I feel hurt, I feel betrayed and I feel that the health care system should come and save me for all the trouble that I endured and that I have been forced to put up with… I see nothing but barriers and more barriers that we try to take down, but the health care puts more in the way… I was pushed away like yesterday's garbage." (Man, 52 years old)

"Accessing support services that treat people with dignity, even housing, is difficult. … My landlord has had my shower leaking for a year. He temporarily fixed it, now it's leaking again. I have no access to my shower and my workers are refusing to give me a shower in any other part of the building. In order to get proper care right now, I feel like I have to go to acute care system, to a hospital." (Woman, 41 years old)

"My wife has to drag the manual wheelchair down six stairs and put it in the vehicle and bring me down to my doctor and then take it out of the vehicle, you know, it's terrible. It' downright terrible" (Man, 53 years old)

Executive Summary

According to *Statistics Canada*, 12% (or approximately 60,500 people) of the population in Newfoundland and Labrador reported limitations in their daily activities due to a physical or psycho-social condition.

Canada is signatory of a number of international human rights treaties, including the most recent *Convention on the Rights of Persons with Disabilities.* Regardless of where they live, Canadians with disabilities should therefore be entitled to the same human rights and freedoms that are granted to all other citizens. Monitoring studies are crucial to measure whether Canadian commitments 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 applies a human rights approach to disability, which focuses on the way systemic discrimination and social exclusion increase vulnerability to abuse, poverty, unemployment, 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 48 individual interviews conducted in St. John's with persons with various disabilities, with a view to monitor their actual experiences of access or denial of human rights. DRPI-Canada partnered with ILRC which took leadership on all aspects 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 project DRPI, and then analysed using NVivo9 software.

In this study, five key human rights principles - ***autonomy; dignity; participation, inclusion & accessibility; non-discrimination & equality***; and r***espect for difference* -** were explored in connection with the following key domains of life: ***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***.

Experiences of Human Rights across Domains of Life

Overall, reports of denial and violation of human rights were more prevalent than access to and exercise of rights. ***Social participation, Income security & support services*****,** and ***Work*** were the domains most discussed. The realms of social participation and work were also those where more negative experiences were found, while ***Family life*** was the area where interviewees encountered more positive experiences of inclusion and human dignity.

Almost all participants told a story involving the domain of ***Social participation*****.** The large majority of these reports discussed the prevailing physical barriers in the built environment and transportation systems in St. John's and the demeaning attitudes towards people with disabilities in the community, causing loss of human dignity as well as the exclusion and isolation of many persons with disabilities.

In relation to accessing ***Income security & support services*****,** half of the participants felt included without significant barriers to needed supports such as homecare or social benefits. However, a similar proportion expressed a loss of dignity in the way services and supports were provided and one third reported being excluded from needed supports. As a result, in multiple aspects of life they cannot enjoy a quality of life that is equal to that of their non-disabled peers.

Similarly, in the area of ***Work*** and access to the labour market, a majority of negative experiences was found. Lack of disability-related accommodation and prevailing demeaning assumptions about the abilities of workers with disabilities made the interviewees vulnerable to exclusion and discrimination. This explains in part why one in three of all participants did not have jobs, despite the fact that over half of them have attended some form of post secondary education.

Health, habilitation and rehabilitation was another problematic realm, with many participants sharing instances of exclusion and loss of dignity as a result of poor treatment and lack of support to their heath care needs.

Reports about ***Family life*****,** on the contrary, were found to be mostly positive. Approximately one third of the interviewees reported feeling valued in family life and relationships and matters of privacy, and one third felt being included.

In the domain of ***Education***, experiences were mixed. If one in four interviewees reported a story involving loss of dignity in the education system; at the same time, one in five shared stories about accessibility and inclusion.

Regarding ***Access to justice*** and ***Information and communication,*** people with disabilities interviewed in St. John's faced more disadvantages and exclusion. For example, interviewees with sensory impairments reported feeling excluded from a variety of communication systems and mechanisms. Devalued dignity was also expressed by almost one in five interviewees in relation to encounters with the justice system, with financial and legislative barriers being mentioned most frequently by the participants.

Despite their negative encounters with justice, people with disabilities in St. John's tended to take a proactive attitude when facing discrimination. In fact, almost one in three persons chose to

report or file an official complaint over personal encounters with abuse or ableism. Those who did not report, however, reported ***fear of negative consequences*** as the key cause for not taking formal action.

Overwhelmingly, the participants perceived economic factors as the primary ***systemic root of discrimination***, poverty being the major challenge in the fulfilment of their human rights.

Intersectional Analyses

The study further undertook a comparative analysis of participants' experiences based on their **gender** and **age**[1]**. Gender** was found to affect the experiences in the areas of ***Privacy and family life*** and ***Income security and social supports***, although in different ways. Women tended to report more experiences than men in relation to family life, whereas men were more prone to discuss the domain of income and support services. Women also reported more negative experiences where they were disrespected, labelled or stigmatized, that might signal multiple forms of discrimination.

The impact of **age** was also found significant in two domains **–** ***Health, habilitation and rehabilitation***, and ***Education***, with younger cohorts discussing primarily experiences in relation to education. Age was also associated with experiences of self-determination and inclusion, with the proportion of positive reports increasing as participants grow older. In contrast, experiences of discrimination and lack of respect were more frequent among younger people. Reasons for this contrast may be related to the perception of disability as a natural and expected facet of senior life, whereas it is commonly viewed as a negative trait worthy of stigmatization when experienced at earlier stages in life.

Recommendations

The participants in this monitoring project made a number of recommendations to improve the situation and circumstances of people living with disabilities. The most discussed were ***increasing social supports*** (35%) and raising awareness through ***educating the general public about disability and persons with disabilities*** (27%). Participants were particularly vocal in demanding the government to create stronger mechanisms to support and improve the living conditions and income of people with disabilities.

- Several participants noted that many cases of using the human rights commission on Newfoundland and Labrador to file complaints when violations occurred. This was felt to be an extremely effective vehicle for dealing with discrimination; Many called for more

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[1] It was not possible to conduct analysis by type of disability due to small size cells once disaggregating by various types of disability represented in the sample.

information about filing complaints and using the system efficiently. While there was recognition that filing a complaint was a time-consuming, and potentially expensive, process participants endorsed the approach both as a way to deal with immediate issues and as a way to promote a 'rights-based' understanding of disability in Canadian society.

- Another key area where consensus emerged was the importance of investing and supporting disabled peoples' organizations (DPOs) at a grass –roots level. People spoke of the need to support people to learn about their rights and to speak out collectively in instances where these rights are violated.

- A third recommendation flowed from discussion about challenges people face in the job market and enjoying their own right to work. Participants felt that often there was a misunderstanding on the part of employers about costs associated with job accommodations, and employment-related supports. Further to this they suggested that DPOs do more to expose these myths in an effort to promote employment opportunities.

- Finally, when asked specifically about ongoing monitoring of human rights for people with disabilities in St. John's and beyond, the participants agreed that any ongoing monitoring work would require financial and institutional support to make it sustainable. They suggested that the ILRC needs resources to continue this sort of monitoring over time, with a view to tracking trends and identifying opportunities to promote human rights for persons with disabilities.

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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 attention on the way that systemic discrimination and social exclusion increase vulnerability to abuse, poverty, unemployment, 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'sNewfoundland, Toronto and Vancouver. This report presents data from the St. John's monitoring site.

Partners and people involved

At St. John's monitoring site, DRPI-Canada partnered with the Independent Living Resource Centre (ILRC) which took leadership on all stages of the monitoring activities. The ILRC is a consumer controlled organization committed to providing supports, resources and opportunities for empowerment, which enable persons with disabilities to make informed choices about their lives

The ILRC 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 Susan Ralph. Ten persons with disabilities - Mary Anthony, Brian Conway, Deborah

Gilbert, Stephanie McGrath, Paul Morgan, Mary-Jo Power, Mike Ryan, Lynn Seward, Kim Underhay, and Sandra Yetman - were trained as *monitors at* a training workshop that took place in St. John's in August, 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 fieldwork

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. 48 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 ILRC in St. John's. A mixed research methodology was used for the study. 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 general human rights principles. Once collected, the interviews were transcribed, coded using a coding scheme developed by the international DRPI and then analysed using NVivo 9 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 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 has the benefit of enabling the interviewees to focus on those topics of the most importance to them rather than imposing a battery of questions. This way, it leads to a better understanding of the actual meaning of human rights as connected to the lived experiences of people interviewed.

Besides the strength of this project, it is also important to acknowledge its limitations. The snowball technique employed by the project as its main sampling strategy has the benefit that usually is able to overcome the problem of recruitment of people with similar profiles leading to overrepresentation of this group in the sample. In this case, this did not happen. Because that did not happen in this case, the sample had to be corrected by complementing it with supplementary efforts by the local partner to include in the sample certain underrepresented subgroups of people. Another limitation is related to the training guide. Given that the guide was conceived with the primary scope of identifying the situations of denial of rights, the participants focus less on the identification of those situations when their rights were respected. In light of this limitation, comparative analysis between situations of positive and negative experiences should be interpreted with caution.

MONITORING INDIVIDUAL HUMAN RIGHTS EXPERIENCES IN ST. JOHN'S

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 St. John's. 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 *Statistics Canada*[2], in 2001 approximately 60,500 people in Newfoundland and Labrador, which represents 12.3% of the total population, had disabilities. From this data, it can be estimated that about 21,269 St. John's residents had disabilities (http://www.statcan.ca). It should be noted, however, that it is also possible that this estimate is too low, based on the greater number of disability services and advocacy groups, as well as a more accessible infrastructure, such as audible crosswalk signals and the Para-transit system, factors which might make this area somewhat more attractive to people with disabilities. The most common types of disabilities among the working age population were those related to mobility limitations, followed by hearing and visual disabilities. Almost all types of disability also increase with age.

Socio-economic profile

Income

According to *Statistics Canada*, in 2006, the average weekly earnings of a Canadian with disabilities were $696.36, in contrast to the $747.08 made by Canadians without disabilities (http://www.statcan.ca). Currently, income supports are not adequate given the high costs of accessibility. According to an article entitled *ILRC Focus Groups: Housing-2008* – produced by the St. John's Independent Living Resource Centre – the lack of adequate income is a severe barrier to a number of needed supports, including accessible housing – which typically costs 30% more than standard housing – as well as adequate transportation (http://www.ilrc-nl.ca/). The province offers *Income Support Benefits* which provide a fixed monthly financial benefit to support people living with difficult circumstances (http://www.hrle.gov.nl.ca/hrle/income-support/overview.html).Such supports, however, are criticized for not providing enough aid to

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[2] Participation and Activity Limitation Survey (PALS) 2001 http://www.statcan.gc.ca/pub/89-577-x/index-eng.htm

people with disabilities, who often live in poverty due to inadequate income supports (http://www.ilrc-nl.ca/).

Employment

According to Statistics Canada (2006), the overall unemployment rate in Newfoundland for those with a disability was 24.8%, compared to 19.4% for those without a disability. As stated by the ILRC's report *Why Don't Those People Work?* (2009), there is a widespread belief amongst people with disabilities in St. John's that they are not contributors to the well-being of Newfoundland and Labrador. Consumers and persons with disabilities can and do want to work, yet it is difficult to find gainful employment. Many donate volunteer time and various types of expertise. The report cites four important barriers to employment for people with disabilities. These include a genuine fear of losing essential supports, poor medical coverage, lack of access to reliable transportation, and poor home supports. Provincial assistance for employment is provided through the *Employability Assistance for Persons with Disabilities* (EAPD) program. This program assists individuals with disabilities in acquiring skills, experience and necessary supports to enter and remain in the workforce (http://www.hrle.gov.nl.ca/hrle/disabilities/services.html).

Housing

People with disabilities face a number of barriers that prevent them from obtaining accessible housing in St. John's. These include high rates of poverty, attitudinal barriers and communication issues. According to a report by the ILRC (2008), the city of St. John's is lacking accessible housing. Currently, wait times for accessible housing ranges from 1 to 3 years. As a result of these long waiting periods, people with disabilities tend to "settle" for less than ideal housing for their unique needs. This situation leads to increased isolation amongst those in this group, as well as being forced to leave preferred communities and peer groups in search of better housing (http://www.ilrc-nl.ca/). In response to this situation, there are a number of organizations such as the ILRC and the Coalition of Persons with Disabilities that work to provide housing assistance for people with various types of disabilities.

Part II - Discussion of findings

People interviewed

Participants in this study include both males and females of different age groups who live with various disabilities. The specific socio-demographic characteristics of the participants are summarized in Table 1 below:

Table 1: Socio-demographic attributes of the sample

ATTRIBUTES	NUMBER OF PARTICIPANTS	ATTRIBUTES	NUMBER OF PARTICIPANTS
AGE		**EDUCATION**	
18-24	2	Elementary	4
25-34	7	Secondary	14
35-44	17	Short Course/Diploma	2
45-54	13	Vocational	3
55-64	5	College/University	23
65+	3	Unassigned	2
Unassigned	1		
SEX		**PRESENCE OF DISABILITY**	
Female	27	Since Birth	22
Male	21	Acquired last 5 years	3
		Acquired 6 or more years ago	21
		Unassigned	2
TYPE OF DISABILITY		**HOUSING SITUATION**	
Mobility	21	Owner	7
Sensory	3	Lease	2
Intellectual	3	Rental	33
Psychiatric	9	Unassigned	6
Multiple Disabilities	11		
Other	1	**EMPLOYMENT**	
Unassigned	0	Yes	15
		No	31
		Unassigned	2

The sample is almost gender balanced with somewhat more women than men (56% women). Most of this group is middle-aged, with 50% of the interviewees being in the age group of 25-44, and 38% in the group of 45-64. The majority of participants have a mobility disability and most of them were born with a disability. The group is fairly well educated, with 48% of participants having attended university or college. Despite this high percentage, 65% indicated that they were unemployed at the time of the interview.

The data presented here may be unique to this particular group of individuals and therefore might not be representative of all individuals in the areas monitored. It is important to consider this distribution of socio-demographic characteristics when interpreting the findings of this study.

Domains of life and human rights principles

In this study, five key human rights principles were explored and analyzed as they pertain to eight important domains of life: *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 services.* The key human rights principles considered foundational to this project include: *autonomy; dignity; participation; inclusion & accessibility; non-discrimination & equality; and respect for difference*. For each domain considered in this study, participants' experiences were also explored 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. In contrast, the domains of Access to justice and Information and communication counted the lowest number of reports (Table 2).

Table 2: Experiences reported by participants by domain of life

Domains of Life	No. of persons	Percentage
Social Participation	47	98%
Income Security and Support Services	37	77%
Work	36	75%
Health, Habilitation and Rehabilitation	34	71%
Privacy and Family Life	33	69%
Education	18	38%
Information & Communication	11	23%
Access to Justice	11	23%
Total	**48**	**100%**

Under all human rights principles, both positive and negative experiences on the grounds of disability were reported, although negative experiences either outnumbered or closely matched the positive responses (Table 3). Participants reported situations when they felt disrespected and their dignity devalued, and also experienced discrimination as the most prominent negative experiences. At the same time, many people reported situations when they felt included as well as instances when their dignity promoted. This more positive outlook may signal that, despite ongoing disparities, positive changes are also underway for persons with disabilities at this monitoring site.

Table 3: Experiences reported by participants by human rights principle

Principle		Percentage
Dignity	Dignity	12%
	Lack of Dignity	15%
Autonomy	Self-Determination	6%
	Lack of Autonomy	8%
Participation, Inclusion & Accessibility	Inclusion and Accessibility	14%
	Exclusion and Lack of Accessibility	14%
Non-Discrimination & Equality	Non-Discrimination and Equality	2%
	Discrimination and Inequality	12%
Respect for Difference	Respect	4%
	Lack of Respect	12%

Social Participation

Social participation emerged as one of the most significant domains in the lives of people with disabilities in this study, garnering responses from nearly all interviewees (Table 4). For the purpose of this study, social participation is defined in a broad sense, including cultural and political life, sports, recreation and leisure activities. Participation and daily living experiences are of central importance to understanding significant aspects of life for people with disabilities.

Table 4: Experiences reported in the domain of Social Participation

Principle		Number of Persons	Percentage[3] (%)
Dignity	Dignity	25	53%
	Lack of Dignity	39	81%
Autonomy	Self-Determination	8	17%
	Lack of Autonomy	9	19%
Participation, Inclusion & Accessibility	Inclusion and Accessibility	36	75%
	Exclusion and Lack of Accessibility	35	73%
Non-Discrimination & Equality	Non-Discrimination and Equality	2	4%
	Discrimination and Inequality	24	50%
Respect for Difference	Respect	8	17%
	Lack of Respect	29	60%
	Total	**47**	**98%**

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[3] These categories are not mutually exclusive as each participant could report up to three different situations and each situation reported could involve both positive and negative 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 this study.

As with other domains, lack or loss of dignity represented the key concern of the participants in relation to social participation. The majority of individuals voiced feeling devalued and disadvantaged because of their disabilities. The participants shared stories of isolation and feeling unworthy in different aspects of their lives:

"I have been judged because of my disability. In my last year of coaching I was told that because I have a mental illness, I'm not competent for coaching... I coached for eleven years, and being told that all of a sudden… it hurt me a lot and that was a big barrier there because they basically told me, we don't want you because of your disability." (DSA08, Female – age 38)

"During the previous five years I've had done relatively nothing. I've been confined to my home for most of the time… I felt like I was not unworthy… I felt like somebody buried alive…I want to get out, I want to be part of society … I have become so incapacitated over the last five years. I don't even know if I would be any good if I had the means to be able to participate in anything." (DSB01, Male – age 54)

"It made me feel angry because a person without a disability can get what he or she so desires, but then a person with a disability is pushed into a corner and their rights are violated and they're basically not allowed to enjoy a quality of life that they deserve." (DSB06, Male – age 52)

Three in four individuals also shared stories of exclusion or lack of accessibility in situations involving cultural, political, recreational and social aspects of their lives. Specifically, many of the reports evolved around barriers to physical environment, particularly public transportation, leading to isolation and difficulties in daily life activities:

"Right now I've been experiencing difficulties with transportation, and just getting around the city. It's difficult even to get groceries." (DSB05, Female – age 43)

"I don't think we are as accessible as we should be. We should be making requirements for any new business that starts up. They should have accessible ramps and doors." (DSC08, Female – age 36)

"In a wheelchair accessible home… when the doors are wider you get to access the bathroom. Here, I can't get into the bathroom with my wheelchair, and I really can't get in through any of the doors." (DSB01, Male – age 54)

Being disrespected in own experiences and feeling labeled and stigmatized because of disability represented another common theme emerging from the interviews. Much of this was fuelled by a lack of understanding about disability from those without disabilities, leading to discrimination:

"I even find relationships very difficult because a lot of people don't understand people with disabilities. I found the social aspects, even with friends, very difficult. Sometimes I don't hear properly and that can be very frustrating too because if you don't hear something and you say

something to someone then you could be laughed at and made fun of.” (DSD04, Female – age 37)

“There is such a level of fear around mental illness. I can’t even believe it. People have such a lack of understanding… and who wants that label?” (DSA04, Male – age 49)

Half of the participants in this study felt discriminated against in various social aspects of their lives. As one participant stated, those situations of discrimination so often encountered in the lives of persons with disabilities convey fear and insecurity:

“For the past five years, due to my injuries and disabilities, I personally limit my exposure to the outside world to places where I can feel safe. Otherwise I have already been introduced into the realm of social prejudice and discrimination throughout the whole system of court, doctors, lawyers… so for that reason I stay within the confines of where it’s safe.” (DSE05, Male – age 58)

Income security and support services

The domain of income security and support services involves experiences related to access and denial of services and supports essential to an independent living. This domain is particularly important to the group interviewed, given that many of these individuals face barriers to employment. One in three participants did not have a job, despite the fact that over half of the participants have attended some form of post secondary education (Table 5). Without adequate supports and income, people with disabilities may face poverty, exclusion and numerous other barriers to equal participation.

Interestingly, half of the participants reported access to needed supports, including devices and various disability-specific services. In general, the interviewees expressed satisfaction with government benefits programs and supports from non-profit:

“I have a pension which is subsidized by social services.” (DSC04, Female – age 65)

“Right now I have a homecare worker. She has been with me since I had my brain operation, but for 3 hours a day… She comes in and she does my personal care” (DSD01, Female – age 63)

Table 5: Experiences reported in the domain of Income Security and Support Services

Principle		Number of Persons	Percentage (%)
Dignity	Dignity	7	15%
	Lack of Dignity	23	48%
Autonomy	Self-Determination	5	10%
	Lack of Autonomy	8	17%
Participation,	Inclusion and	24	50%

Inclusion & Accessibility	Accessibility		
	Exclusion and Lack of Accessibility	15	31%
Non-Discrimination & Equality	Non-Discrimination and Equality	1	2%
	Discrimination and Inequality	9	19%
Respect for Difference	Respect	2	4%
	Lack of Respect	4	8%
Total		**37**	**77%**

At the same time, one in three participants reported lack of access to adequate supports and services. People's stories emphasized barriers to home care support or lack of financial means to purchase needed equipment and devices:

"I had to fight for the funding… I had to go for re-testing for my learning disability. I had to go through a psychologist... because I needed more proof for my learning disability" (DSD04, Female – age 37)

"My recreation time and my ability to enjoy things right now is very limited because I find difficulty accessing grocery stores, medical appointments with supports, recreational events and other things that are basically out of the question… both transportation and access to support services …"(DSB05, Female – age 43)

"They just refused to accommodate me, which did not make any sense. I have a manual wheelchair. Workers compensation never even paid for that… I've received nothing…my family even had to buy me a manual wheelchair, and I asked them for a bed."(DSB01, Male – age 54)

Nearly half of the participants shared stories of feeling disrespected and devalued when receiving or trying to get access to needed services. Participants voiced their stress and frustration in their encounters with the supports system, in most of the cases feeling powerless to make any change:

"In one year we lost everything. I lost my home…when that fell apart, I fell apart. I rock bottomed, where I stayed and have been…confined to the home ever since, despite many attempts. According to the medical community workers compensation, who was supposed to provide me with a motorized wheelchair and a wheelchair accessible van…the never did. They didn't make the home wheelchair accessible… they did nothing and basically left me like someone in solidarity confinement and I've been that way ever since….I was very angry for a long period of time." (DSB01, Male – age 54)

"The social work system is not supposed to be like this. These social workers are supposed to help their clients out of situations, not make it worse than it already is. It's so bad. I'm so stressed out…" (DSB10, Male – age 39)

"I'm living in the senior's home, and I'm disabled, and all I get right now is a very small piece of welfare every two weeks. A while back, Canada pension… wrote a letter saying that the only thing I was getting from them was $147 dollars ...so basically that's my life down here in Newfoundland. That's all I get… it makes me feel neglected. It makes me feel that no one wants to help me. Nobody cares... every time I've tried, I have lost… that's the way it is." (DSD01, Female – age 63)

Work

The domain of work entails experiences related to access, retention and progression in the labour market. Three in four participants shared experiences, both positive and negative, in relation to work. Most of the stories evolved around lack of dignity, exclusion, discrimination and inequality (Table 6). Almost half of the interviewees reported feeling undervalued and discouraged about poor treatment they encountered in the employment context.

Table 6: Experiences reported in the domain of Work

Principle		Number of Persons	Percentage (%)
Dignity	Dignity	14	29%
	Lack of Dignity	22	46%
Autonomy	Self-Determination	3	6%
	Lack of Autonomy	6	13%
Participation, Inclusion & Accessibility	Inclusion and Accessibility	15	31%
	Exclusion and Lack of Accessibility	22	46%
Non-Discrimination & Equality	Non-Discrimination and Equality	2	4%
	Discrimination and Inequality	14	29%
Respect for Difference	Respect	4	8%
	Lack of Respect	9	19%
	Total	**36**	**75%**

Participants with invisible disabilities confronted with demeaning attitudes of their employers and co-workers, making them vulnerable to exclusion and discrimination. For example, one individual spoke of the challenges associated with the lack of understanding of mental health issues at the workplace:

"I think when you have somebody who has a disability that's invisible, especially around mental health, it's very difficult to pin point… there are situations at work that I feel not included

because I think that people don’t understand mental health issues… it’s very difficult when you have a mental health issue… there is a lot of blame from employers. Employers and coworkers say that they understand mental health as a disability, but they don't… I am afraid to have my performance review because the last time I had one, it was the most disgusting experience I have ever had in my life in a workplace.” (DSB02, Female – age 49)

Limited education, as well as limited opportunities given the small size of the province, were also identified as obstacles in finding a job:

“I have tried going on job banks and stuff like that, but I don’t have any trade so they won’t let me” (DSB07, Female – 28 years old).

“I have done some art work from my home but I think because Newfoundland is such a small population I don’t think I have been able to advance my art work” (DSC05, Male-age 48)

Nearly half of the persons with disabilities in this study encountered various barriers at the workplace or couldn’t access the labour market because of the lack of accessibility:

“The barrier was having to give up my work because I couldn’t continue on walking stairs, carrying things, and moving, that was a barrier… we had no escalators or elevators; everything had to go from the first floor to the fourth if you had a room to clean. You carried all your supplies with you. Sometimes you had to make two or three trips because the stuff was too heavy to carry in one try.” (DSE02, Female – age 55)

Many individuals reported incidents of discrimination in the workplace, where they were treated differently than their able-bodied counterparts. This presence of ableism in the employment sector often leads to exclusion from the labour market:

“I’m really tired of people without disabilities making decisions for people with disabilities… strangers making the decisions that affect my life and the lives of other people with disabilities.” (DSA04, Male – age 49)

“There is a tremendous amount of discrimination that goes on… it’s not easy having a mental illness and competing against people who don't. Because when you’re in the workplace you are competing against people who don't have metal illness and you’re supposed to be just as good as them and that's difficult.” (DSD06, Male – age 42)

“I feel that employers can be very judgmental and very prejudice. If you tell them that you have a disability, you’re not going to get hired…you’re not going to get. I have tried that approach before and I wasn’t able to get a job, so I went with the other approach of not saying I had a disability and then I got the job.” (DSD04, Female – age 37)

Health, Habilitation and Rehabilitation

Access to services of good quality is an essential aspect of the lives of people with disabilities. This domain entails participants' experiences in dealing with health care practitioners and in accessing various health-related services. Table 7 summarizes the results of this study in relation to health domain.

Table 7: Experiences reported in the domain of Health, Habilitation and Rehabilitation

Principle		**Number of Persons**	**Percentage (%)**
Dignity	Dignity	6	13%
	Lack of Dignity	23	48%
Autonomy	Self-Determination	7	15%
	Lack of Autonomy	7	15%
Participation, Inclusion & Accessibility	Inclusion and Accessibility	13	27%
	Exclusion and Lack of Accessibility	19	40%
Non-Discrimination & Equality	Non-Discrimination and Equality	1	2%
	Discrimination and Inequality	9	19%
Respect for Difference	Respect	2	4%
	Lack of Respect	13	27%
	Total	34	71%

Most of the participants experienced ill-treatment in health settings, leading to feelings of worthlessness and powerless:

"The hospital system is pathetic. I was dealing with pneumonia and they wouldn't feed me. They didn't want to help me use the bathroom. They wouldn't use the lift and they wouldn't lift me. They wouldn't turn me. They wouldn't move me. I'm supposed to take in all this food and fluids because I have pneumonia, but I can't eat, can't drink, and can't use the bathroom. I'm supposed to be moved every so many hours and I can't do that on my own, but they won't send anyone in to do it... they think that because I've got a disability, if they touch me they will get the disease." (DSA10, Male – age 40)

"I feel frustrated. I feel hurt, I feel betrayed and I feel that the health care system should come and save me for all the trouble that I endured and that I have been forced to put up with… I see nothing but barriers and more barriers that we try to take down, but the health care puts more in the way… I was pushed away like yesterday's garbage." (DSB06, Male – age 52)

"I have been discriminated against the most in mental health system itself. They have done the most damage to me… It was horrible. The things that I went through then are still probably happening to people. You know people are still being injected with needles and not told what the needles are for, and people are still being restrained, and people are still being overmedicated, and all these things continue to happen…"(DSD06, Male – age 42)

Many participants also reported various barriers in their attempts to access the health care system which prevented them from receiving the services they were entitled to on an equal basis with their counterparts without disability:

"Hospitals are a nightmare, believe it or not. I find that the newer ones are better than the older ones, but the older ones… I can't even go there. What always amazes me about a hospital is that they can have a big door – 48 inches – into a room to get in, but yet the bathroom door might be 24 inches. It's ridiculous."(DSE04, Female – age 48)

"It's difficult to get help accessing medical services, like doctor's appointments, tests, and these types of things." (DSB05, Female – age 43)

In a number of instances, individuals also felt stigmatized and their concerns not being taken seriously because of their disabilities. The negative attitudes and assumptions made by practitioners about disability also contributed to the participants' feelings of disrespect:

"I have chronic pain. I have gone to doctors or emergency rooms with chronic pain, and they see that mental illness or depression is written on the chart and make certain assumptions… so you're not taken seriously." (DSB02, Female – age 49)

"I find the regard of people who work in hospitals – nurses, doctors, and physiotherapists – have a real problem with listening and hearing what a person with a disability says when they're admitted to a hospital…" (DSE04, Female – age 48)

Privacy and Family Life

This domain encompasses participants' experiences in their private lives and their interactions with family members. Personal relationships represent an important facet of people's lives. Interestingly, many of the reported experiences in this area were positive.

Table 8: Experiences reported in the domain of Privacy and Family Life

Principle		Number of Persons	Percentage[4] (%)
Dignity	Dignity	15	31%
	Lack of Dignity	10	21%
Autonomy	Self-Determination	2	4%
	Lack of Autonomy	0	0
Participation, Inclusion & Accessibility	Inclusion and Accessibility	17	35%
	Exclusion and Lack of Accessibility	2	4%
Non-Discrimination & Equality	Non-Discrimination and Equality	1	2%
	Discrimination and Inequality	2	4%
Respect for Difference	Respect	1	2%
	Lack of Respect	3	6%
	Total	**11**	**23%**

Many participants reported positive experiences in their family relations, about one in four interviewees feeling included and supported by their family members. These people felt valued and strongly supported by their families who sustained them emotionally and materially:

"My wife… had approval from the hospital to take a year off with no pay to come in and accommodate me in rehabilitation at the centre." (DSB01, Male – age 54)

"When I was struggling to find employment, when I first started out, my mother made a lot of calls. She advocated for me a lot." (DSC08, Female – age 36)

"My family doesn't see me as somebody with a disability at all… to your friends and your family who know you it doesn't matter that you have a disability because it's part of who you are." (DSD09, Female – age 43)

One participant spoke of the importance of educating those from the close network as key factor to strength the relationships with those from this network:

"My husband, once he understood that I was in pain and that it was real, had no complaints and helps out with everything and anything…I think the important thing with your family, if you want them to understand, is that you have to give them the information… so with my husband, I'm

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[4] 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.

really mindful to take him to appointments and give him the information… because if he doesn't know about it, how can I get mad at him for not understanding?" (DSB08, Female – age 38)

Similarly, about one in three participants felt valued in their families, emphasizing the support and sense of security received from family members:

"My mother is really great. If not for her, I don't know what I would do." (DSB07, Female – age 30)

In contrast, one in five participants shared stories of feeling misunderstood, devalued, and, in some cases, left by the closest persons once acquiring disability:

"With my husband, that's one thing that causes a lot of friction with us. He doesn't understand the amount of pain… a couple of weeks ago I was home and I was having pain in my chest… I ended up speaking with this nurse and they tried to calm down my breathing and she said… you need to go to emergency, and my husband had made me feel so bad about going to emergency over the past few months that I didn't want to go." (DSA06, Female – age 43)

"My wife refused to help me and she divorced me." (DSE05, Male – age 58)

Education

The domain of education encompasses personal experiences in the interaction with the education system. Participants reported various negative experiences in relation to education, mainly stemming from the lack of needed accommodations (Table 9).

Table 9: Experiences reported related to Education

Principle		Number of Persons	Percentage (%)
Dignity	Dignity	1	2%
	Lack of Dignity	12	25%
Autonomy	Self-Determination	2	4%
	Lack of Autonomy	2	4%
Participation, Inclusion & Accessibility	Inclusion and Accessibility	10	21%
	Exclusion and Lack of Accessibility	9	19%
Non-Discrimination & Equality	Non-Discrimination and Equality	0	0
	Discrimination and Inequality	6	13%
Respect for Difference	Respect	0	0
	Lack of Respect	6	13%
	Total	18	38%

Many stories evolved around the lack of accessibility of the education system, participants experiencing discomfort and discouragement in pursuing their education prospects:

"With regards to the education… they didn't include me, they undervalued me, they disrespected me, treated me like I didn't know what I was talking about, basically like an imbecile. In the first field placement I was into, the university expelled me." (DSB05, Female – age 43)

"I have tried to get education before, but I found university wasn't accommodating…even though the school is accommodating, you can feel that you are separated because you're labeled. I needed to have a note taker and one wasn't provided outside of school so… one of the students in my class was the note taker… and I'm even older than the students so that made me feel really uncomfortable to have another student teach me." (DSD04, Female – age 37)

"The fire drill was the worst day… they had to keep someone with me because I had to stay by the front doors over there and then they said there was a fire. How were they going to get me out of there? They would have to lift me in my chair down more than three flights of stairs to get me outside…. there is no accessibility. I don't think it should be allowed." (DSB04, Female – age 34)

Many stories emphasized ableism in school life, leading to stigmatization and discrimination of persons with disabilities in their encounters with the education system:

"Now in the education system there is discrimination… I was in social work for eight years and I had to fight for four years to get a right that everybody else had automatically." (DSB05, Female – age 43)

"The system that normal people go through, they are treated differently than people with disabilities. I mean the fact that they can get funding within three months, and it took me two years. That is unacceptable." (DSD04, Female – age 37)

"Indirectly, they think I'm dumb. They think I'm stupid." (DSB05, Female – age 43)

Lack of access and exclusion was particularly emphasized by persons in deaf community in their attempts to get their needs accommodated and, at the same time, facing the negatives attitudes of some of the instructors:

"…the teacher was hearing, and I couldn't really grasp the communication. I couldn't understand a lot of what the teacher was saying and I did not have an interpreter at that time… I had no supports." (DSC05, Male – age 42)

"There was one incident where a professor refused to wear a deaf system and he said that it would interfere with his teaching." (DSC08, Female – age 36)

At the same time, positive stories of inclusion in the education system were also reported, some of the interviewees emphasizing the improvements being made to support students with disabilities:

"As far as post -secondary education, they have come a long way. They are stepping up quite a bit… the classes have actually been slowed down to make sure that [he] is not falling behind at all, to make sure he completely understands what they were doing." (DSC09, Male – age 25)

Information and Communication

Information and communication might be an area of particular concern for persons with disabilities as usually the communication venues are not adapted to facilitate full access to information. This domain wasn't identified as key by the participants in this study, only one in four participants reporting experiences around information and communication (Table 10).

Table 10: Experiences reported in the domain of Information and Communication

Principle		**Number of Persons**	**Percentage (%)**
Dignity	Dignity	0	0
	Lack of Dignity	4	8%
Autonomy	Self-Determination	0	0
	Lack of Autonomy	1	2%
Participation, Inclusion & Accessibility	Inclusion and Accessibility	3	6%
	Exclusion and Lack of Accessibility	8	17%
Non-Discrimination & Equality	Non-Discrimination and Equality	0	0
	Discrimination and Inequality	2	4%
Respect for Difference	Respect	0	0
	Lack of Respect	0	0
	Total	11	23%

Exclusion and lack of accessibility emerged from most of the stories which evolved around the lack of support participants needed in order to participate in various aspects of live:

"I need this voice program, which costs a bit of money. If I can't get the employer covered with that, then it's a real turnoff for them. Then the computer system itself – whether or not it's accessible – that's another barrier." (DSE01, Female – age 38)

"The airport really bothers me that it is not hearing accessible... announcements are on the PA system and I have no clue what they're saying… there is no written sign… there is no close captioning. Let's say there is a change in the gate number, I wouldn't get that…. I don't even know if I could possibly travel alone. I don't know if I could. I suppose I could manage it, but it would be very stressful." (DSC08, Female – age 36)

The lack of information in accessible formats or lack of adequate supports responsive to people's communication needs lead in most of the cases to feelings of frustration, discouragement, and disrespect:

"The other biggest barrier for me, that's frustrating, is inaccessible materials – which is the CNIB's responsibility because I need material… I've usually got to have somebody read it to me because I never have anything available to me. If they are passing out stuff, it's always just written, or I have to ask them to e-mail it to me. There is no consideration. Even beforehand when I go to workshops and stuff that I've been to, they ask you ahead of time if you need any accommodations, and what format you want it in. Many times have I responded to that request, and it has not been available in my format... that's frustrating and not acceptable… I have to get someone else in the group or someone next to me, or ask the host, to read it to me. That's what I usually get them to do. I get them to read it. They don't make it available to me in Braille or electronically ahead of time so that I can read it instead of being put on the spot when I get there…" (DSE01, Female – age 38)

Access to Justice

The justice system is an important channel through which people with disabilities can assert their rights. This domain involves people's experiences in their interaction with the legal system in a broad sense, including status before the law and access to the court 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 (%)
Dignity	Dignity	0	0
	Lack of Dignity	9	19%
Autonomy	Self-Determination	1	2%
	Lack of Autonomy	2	4%
Participation, Inclusion & Accessibility	Inclusion and Accessibility	0	0
	Exclusion and Lack of Accessibility	5	10%
Non-Discrimination & Equality	Non-Discrimination and Equality	1	2%

	Discrimination and Inequality	2	4%
Respect for Difference	Respect	0	0
	Lack of Respect	2	4%
Total		11	23%

One in five participants reported feeling devalued as a result of poor treatment in interacting with the legal system and its representatives. For example, some stories highlighted the lawyers' lack of understanding of disability and the difficulties to get their support with the legal process. In essence, the interviewees shared a common feeling of loneliness in their attempts to claim for their rights, with no hope for aid from the agents of the justice system:

"I went to several lawyers in Newfoundland…they said I had no rights at all. I had to take it outside of Newfoundland into a disability organization, and get them to organize. When I asked them for an opinion on it, they told me to bring it back to human rights… which I did. I brought the issues back to human rights and when I… explained the problems… in terms of accommodation, such as transportation, the washroom, and all of those types of things… the human rights said no…"(DSB05, Female – age 43)

"The most highlighted was talking to a lawyer. He didn't understand the nature of my disability and how it affects me, and he got quite angry after reading five minutes of paper work without me following along… so while instructing him to be a little more aware of what's going on with me and my disability, he just couldn't grasp it and I had to get angry with him. I had to literally tell him that he lacks the skills necessary to understand what my disability is and how it affects me…" (DSE05, Male – age 58)

"I actually went to a lawyer… and I ended up getting nothing out of it... I couldn't get workers compensation because the company was such a big company. I think the lawyer got scared off and probably paid off." (DSD04, Female – age 37)

Participants also expressed an overall distrust in the legal system and law enforcement, this being the main reason they wouldn't look for a formal action to get their rights protected:

"Legal aid… they just made a half hearted attempt… I had no legal support." (DSE05, Male – age 58)

"Six months after the damage is done, I'm supposed to press charges. I waited probably eight months and then it's six months before the restraining order…. it doesn't seem right…it's the justice system I guess." (DSE08, Female – age 27)

Intersectional Analysis

In this section, the exercise of rights by people with disabilities was explored in relation to gender and age[5] to provide a better context of people's experiences. Important to note, this study involved slightly more females than males, as well as a higher number of individuals between the ages of 35 and 54, while the age groups of 18-34 and 55+ being less represented. The distribution of the participants in this study according to age and gender is summarized in the table below:

GENDER		AGE			
MALE	FEMALE	18 - 34	35-54	55 and over	UNASSIGNED
21	27	9	30	8	1

The Impact of Gender

When exploring how gender affects the human rights experiences of men and women in the eight domains of life considered in this study, interesting differences were found in relation to two of these domains - Privacy and family life and Income security and support services (Table 12). There were more women discussing privacy and family matters than men, whereas more men than women discussed issues related to income and support services.

Interesting to note, certain areas such as Social participation, Health, and Work were similarly addressed by both men and women, denoting their equal importance in people's lives, regardless of gender.

Table 12 - Experiences reported by sex and domain of life

Domains of Life	Female	Male
Social Participation	96%	95%
Privacy & Family Life	81%	48%
Health, Habilitation & Rehabilitation	70%	67%
Information & Communication	19%	24%
Work	78%	71%
Income Security & Support Services	70%	81%
Education	33%	43%
Access to Justice	19%	24%
TOTAL	**27 = 100%**	**21 = 100%**

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[5] 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.

Women's and men's experiences were also similar in relation to their access or denial of human rights principles (Table 13). However, a particularly striking contrast was noticed under the principle of Respect for difference, where significantly more women reported negative experiences than men, which may link to multiple forms of discrimination experienced by women.

Table 13 - Experiences reported by sex and human rights principle

Human Rights Principles		**Female**	**Male**
Dignity	Dignity	93%	67%
	Lack Of Dignity	93%	100%
Autonomy	Self-Determination	48%	29%
	Lack of Autonomy	48%	57%
Participation, Inclusion & Accessibility	Inclusion & Accessibility	89%	95%
	Exclusion & Lack of Accessibility	85%	90%
Non-Discrimination & Equality	Non-Discrimination & Equality	11%	19%
	Discrimination & Inequality	77%	81%
Respect for Difference	Respect	30%	24%
	Lack of Respect	85%	5%
	Total	**27 = 100%**	**21=100%**

The Impact of Age

In this study, the impact of age on participants' experiences across the eight domains of life was also examined. Given that there were significantly more participants in the age group of 35-54, we need to look at the percentage distribution within each age group (Table 14).

Table 14 - Experiences reported by age and domain of life

Domains of Life	**18-34**	**35-54**	**55+**
Social Participation	100%	97%	100%
Privacy & Family Life	78%	67%	63%
Health, Habilitation & Rehabilitation	56%	70%	88%
Information & Communication	22%	13%	50%
Work	78%	80%	63%
Income Security & Support Services	78%	73%	88%
Education	67%	33%	25%
Access to Justice	22%	20%	25%
TOTAL	**9=100%**	**30=100%**	**8=100%**

Younger participants (18-34 and 35-54 age groups) reported their human rights experiences in the domain of Education more often than the older interviewees. This may be explained by the greater relevance of this domain in the lives of younger people, given that they are more connected to education at this stage of their lives. In contrast, the domain of Health was discussed more by mature participants (55+ and 35-54 age groups), indicating its greater importance at this stage in life.

Table 15 - Experiences reported by age and human rights principle

Human Rights Principles		**18-34**	**35-54**	**55+**
Dignity	Dignity	89%	83%	75%
	Lack of Dignity	100%	97%	100%
Autonomy	Self-Determination	22%	43%	50%
	Lack of Autonomy	67%	43%	75%
Participation, Inclusion & Accessibility	Inclusion & Accessibility	89%	93%	100%
	Exclusion &Lack of Accessibility	89%	87%	100%
Non-Discrimination & Equality	Non-Discrimination & Equality	11%	13%	25%
	Discrimination & Inequality	89%	83%	63%
Respect for Difference	Respect	33%	27%	25%
	Lack of Respect	89%	83%	63%
	Total	**9=100%**	**30=100%**	**8=100%**

Regarding the human rights principles, there were few differences noted across the age groups (Table 16). Within this sample, it seems that age was associated with experiences of self-determination and inclusion, the proportion of positive reports increasing with age. In contrast, the experiences of discrimination and lack of respect were more frequent among younger interviewees. Reasons for this contrast may be grounded, in part, in the general belief that disability represents a natural facet of senior life, whereas more prone to stigmatization when experienced at earlier stages in life.

Analysis based on participants' responses to discrimination

Systemic Roots of Discrimination

Systemic roots of discrimination comprise of various social, legislative and economic factors that lead to discrimination on grounds of disability. Throughout the interviews, respondents reflected on their experiences within a broader socio-economic context that impacts their exercise of rights. Findings are summarized in Table 16.

More than half of the interviewees highlighted economic factors as a primary systemic root of discrimination, many people with disabilities living in poverty and being deprived of a decent standard of life:

"I can't do anything. Other people… I could see somebody going up there and maybe going to a movie or up to a dance or going somewhere and I say, I'd like to do that or even go too. I don't go to an amusement park or anything that you have to pay money to see… I wish I could go in there, I wish I could do that, but I can't because I don't have the funds to do it." (DSD01, Female – age 63)

"I don't know if I would have the finances, I don't have the ability to keep the house going… most of the housing is subsidized. Where I'm working I do earn a good wage so I don't know how much of that is taken, and how much rent I would have to pay. I heard that people who live in subsidized housing, if they work and make a decent wage, the rent goes sky high on some of these units. How much of a struggle would I have to put up if I needed anything done? How much would I be paying for a housekeeper to come in and do some house cleaning for me? Maybe give me some assistance with cooking meals… I wouldn't want my disability supports to become a disincentive to going to work because that's very important to me…"(DS02, Female – age 35)

Table 16– Systemic Roots of Discrimination

Systemic Roots of Discrimination		
	Number of Persons	**Percentage (%)**[6]
Economic	31	65%
Social	7	15%
Legislative	8	17%
Total	34	71%

The poor socio-economic status of most of the people with disabilities was also identified as a significant barrier to get access to the justice system as one of the interviewees stated:

"I'm very well sure that if I had the money to throw at a lawyers pocket, that he would do anything I asked him to do with due diligence. However, when you are poor, and you cannot afford a lawyer … you are left completely and utterly without a voice, marginalized, ignored… the legal support, I didn't have because I didn't have the money and legal aid…" (DSE05, Male – age 58)

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[6] 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%

Responses to Abuse and Discrimination

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

Table 17– Responses to Abuse & Discrimination

Responses to Abuse & Discrimination		
Response	**Number of Persons**	**Percentage (%)**
Avoid and seeks distance from the discrimination	10	21%
Choose to return to the situation to try to change it	5	10%
Choose to report and complain about the situation	15	31%
Other ways of responding to abuse and discrimination	2	4%
Total	**27**	**56%**

One in three participants decided to report or file an official complaint in their encounters with situations of abuse. In some cases, it led to improvement, while in others the official action didn't make any difference:

"I had done a training program and I met a woman there and she… told me that it shouldn't take that long for me to get my funding and that I should write to my MP. So I actually had to do that, and within three days of writing the government, I got an answer back from the head person in EI and he said my funding was going to go through." (DSD04, Female – age 37)

"I've wrote numerous letters to the judicial system and to the ministers of justice… it's very difficult to be able to effectively carry on communication and get this to a point where no other Newfoundlander has to experience this."(DSE05, Male – age 58)

In a number of instances, the participants decided to advocate for themselves to get their situation improved. One participant described the risks and difficulties that can arise with self-advocating:

"Being an advocate in university, it can get you in a lot of trouble…I advocated with the university, and with some help from some other people, to try and get automatic doors put in. I learned a lot because you need to have respect for policy, and how to create new policy, and how to make it work and maintain respect for the systems that are already in place. The difficulty is how it's perceived by those on the other side that can impact you and negatively affect how you get work in the future, because it labels you as a trouble…" (DSD09, Female – age 43)

On the other hand, many participants chose to avoid or distance themselves from the contexts of abuse or ill-treatment, general perception being that the official action will not change their situation.

"There's a lot of politics when you're trying to change things… it's not easy. It can be exhausting." (DSD02, Female – age 35)

Reasons for Not Reporting

This study also explored the reasons why the participants decided not to report their experiences of abuse or discriminatory treatment. A variety of reasons were reported by the interviewees from the belief that nothing would have happened as a result of their action to the fear of consequences (Table 18).

Table 18 - Reasons for Not Reporting

Reasons For Not Reporting		
Reasons	**Number of Persons**	**Percentage (%)**
"NOTHING WOULD HAVE HAPPENED"	5	10%
LACK OF ACCESS	4	8%
FEAR	6	13%
LACKOF FINANCIAL MEANS	0	0
CORRUPTION	0	0
SELF-BLAME	0	0
OTHER	4	8%
Total	**13**	**27%**

Most often, the participants did not report instances of abuse or discrimination because of fear. These interviewees reported being afraid of the consequences of their legal actions given the risk to be punished for these actions:

"I don't want to jeopardize myself any further than I am. You understand what I'm saying? If I make stuff public, it could make it even worse." (DSB05, Female – age 43)

"So what happened is that they pulled all the articles and I got called into the student dean's office and basically told I had to be very, very careful because… people are watching me and it will impact my job… and it will impact my ability to get a job in the future for what I was doing." (DSD09, Female – age 43)

"I didn't report it any further because I felt, at that moment, when somebody said no, you can't get another person to help you do this, I just felt that by going over that person's head it might of caused more trouble than what it was worth. I just put my back against the wall and said I wouldn't ask anymore for anything." (DSE02, Female – age 55)

Second to "fear" as a reason for not reporting, participants also voiced the feeling that nothing would change as a result of their actions. As a result, they chose not to take action.

"They can't do anything about it, I don't think."(DSA02, Male – age 66)

"I never got any response…sometimes I've got some question for human resource reporting, but I never got any improvement or answers from them." (DSC03, Male – age 60)

In addition to a general sense that reporting or taking legal action against ill-treatment will not result in any change, there were some participants who pointed out the lack of access to appropriate information, as well as the lengthy and complicated system in place that discouraged most people to take action.

"I didn't report it to anybody because I didn't know who to report it to…. there was no building manager there or anything like that." (DSD02, Female – age 35)

"The human rights commission… the ability to make society accountable for human rights violations against people with disabilities is so long and drawn out that most people with a disability… just let it go."(DSD09, Female – age 43)

Recommendations from Interviewees

Participants made a number of recommendations to improve the situation and circumstances of people living with disabilities (Table 19).

One third of the interviewees recommended increased social supports as a means to improve the lives of people with disabilities. Specifically, they emphasized the need for better government mechanisms to support and improve the living conditions, income, health care, housing and access to a number of disability-related services for people with disabilities. In essence, steps must be taken to account for the exclusion and discrimination that persons with disabilities encounter on daily basis, leaving them in an unequal position comparing with their able-bodied counterparts. It is often these increased barriers – that people with disabilities face – that make stronger social supports a necessity in order for them to enjoy a fully inclusive and accessible social life:

"I would say that the biggest thing that I would like to see changed is…timely access to health care. That's something we don't have." (DSB08, Female – age 38)

"Deaf people need more access to interpreters to be able to participate in activities. We need more interpreters for the deaf, and more interpreters need to be hired." (DSC05, Male – age 42)

"You just don't have the supports and there is not enough. I mean, for someone with a disability there should be more supports. Even just for security for housing… I'm in a situation now where

I don't know where I'm going, and I don't know where or if I'm going to end up on the street..."(DSD04, Female – age 37)

Table 19 - Recommendations

Recommendations		
Responses	**Number of Persons**	**Percentage (%)**
Raise Awareness	13	27%
Economic Supports	7	15%
Social Support	17	35%
Representation	3	6%
Respect	3	6%
Legislation	2	4%
Peer Support	1	2%
Other ➔ Improve Accessibility	8 (5)	17% (10%)
Total	**33**	**69%**

Educating the public about disability and people with disabilities emerged as another important recommendation to improve the situation of the disabled in society.

"You can't stop the way people think. They're going to think the way they're going to think… the only thing that you can really do is disability awareness training, or media promotion…" (DSD02, Female – age 35)

"If you are aware of what's going on, then you can be more empathic. You already have the awareness, but when you have someone in a position of power who has no awareness , you're fighting a brick wall…. I'm still trying to get people to have awareness." (DSE05, Male – age 58)

Educating the public about mental health and campaigning against the stigma associated with this disability was recommended as a key component of raising awareness initiatives recommended:

"I'd like to see education in the school curriculum to include sensitivity training about people with mental illness, because I think that that's the last remaining acceptable prejudice in our society…" (DSA06, Female – age 43)

"The whole idea is the lack of understanding about mental illness… you would think that non-profit organizations… or disability organizations should get it… but there needs to be another level of understanding."(DSA04, Male – age 49)

“I think people in the health care system have to be educated specifically about mental health issues and they have to change their attitudes.” (DSC04, Female – age 65)

Other recommendations included improved accessibility, particularly of the built environment, that is essential to participation in all aspects of life on equal basis with other members of society.

“Anywhere public should be accessible to people with disabilities.” (DSD02, Female – age 35)

“The government should be accessible… everything should be automatic when one walks into a building.” (DSC09, Male – age 25)

Conclusion

The stories collected through this study revealed an overall pattern of denial of human rights of people with disabilities who live in St. John's.

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 access to health, habilitation and rehabilitation services - the domain of ***social participation*** was the one which gathered the greatest number of reports, denoting the importance of social inclusion for the well-being and human rights of people with disabilities. The domain of access to ***income security & support services*** was next in importance for the interviewees, followed closely by the domain of ***work***. In relation to ***social participation*** and ***work*** the reports collected emphasized the denial or violation of human rights principles more often that the full exercise of human rights and freedoms, thus documenting a disadvantaged status for people with disabilities living in St. John's. However, in the sphere of ***family life***, interviewees encountered more positive experiences of inclusion and human dignity than negative ones. In accessing ***income security and supports*****,** participants reported both negative and positive experiences.

Gender was found to affect people's experiences in relation to aspects of privacy and family life and income and support services. Women tended to report more experiences (both positive and negative) than men in the sphere of family life. Men, in contrast, were more prone to discuss instances of denial of human rights in relation to income security and support services. Significantly more women than men also reported instances of feeling disrespected, labelled or stigmatized which may be linked to the multiple forms of discrimination experienced by women.

The impact of ***age*** was also found significant in two domains – health, habilitation &rehabilitation, and education. Younger participants (18-34 and 35-54 age groups) reported their human rights experiences in the domain of Education more often than the older interviewees. In contrast, the domain of health was of greater importance for mature participants (55+ and 35-54 age groups).

In response to situations of abuse and discrimination, about one third of the participants reported taking legal or formal action. However, almost a quarter chose to avoid those situations and places where they experienced discrimination instead of taking action.

RECOMMENDATIONS

Based on the results and the issues identified above, the recommendations from this study are as follows:

A) The virtual consultation:

The recommendations that follow were generated from an on-line meeting between participants (both monitors and interviewee's) and Steven Estey, who was has been part of the DRPI work in Canada since it began in 2007, his involvement included co-facilitating the training of the St. John's monitors in August of 2009. Originally the plan had been to host a one-day session to review findings and make recommendations, but planning and coordination for this proved to be a significant challenge and in the end it was decided that on on-line consultation would have the best chance of success.

Before proceeding to the specific recommendations it is worth taking a moment to discuss the online format, as it is something that may have potential for DRPI at an international level, where travel and access costs are often a good deal more expensive than they are in Canada. Indeed the opportunity to test this in with St. John's participants was one factor making the decision to proceed with this "virtual" consultation in the first place.

We were fortunate that the ILRC has access to an online communication and training package that they use for other purposes. They also had a technical support person who was able to assist with configuring the system for the meeting, and was on stand-by during the meeting to assist if there were any difficulties. What actually happened on the day of the consultation is that Steven Estey made a web-based presentation of the findings of the research, this was with a combination of a web Camera and software that facilitated the presentation of a power point presentation, which Estey spoke to over the webcam. Participants were logged on both at the ILRC and from their homes.

While the presentation itself went smoothly and was fully accessible to all particiants, it was noted by several people that interaction in such a sphere is unfamiliar to most people, and on balance the sense of the group was that the approach was not as participatory or engaging as it would have been "live." Nevertheless the potential for this sort of engagement and consultation was apparent, and may be something that DRPI wishes to develop in the future.

B) What the participants had to say:

As noted above the format for this consultation was less interactive than a face-to-face exchange, but participants did offer some specific recommendations for the continued advancement of human rights for persons with disabilities, as follows:

- Several participants noted that there were many cases of using the human rights commission on Newfoundland and Labrador to file complaints when violations occurred. This was felt to be an extremely effective vehicle for dealing with discrimination; Many called for more information about filing complaints and using the system efficiently. While there was recognition that filing a complaint was a time-consuming, and potentially expensive, process participants endorsed the approach both as a way to deal with immediate issues and as a way to promote a 'rights-based' understanding of disability in Canadian society.

- Another key area where consensus emerged was the importance of investing and supporting disabled peoples' organizations (DPOs) at a grass –roots level. People spoke of the need to support people to learn about their rights and to speak out collectively in instances where these rights are violated.

- A third recommendation flowed from discussion about challenges people face in the job market and enjoying their own right to work. Participants felt that often there was a misunderstanding on the part of employers about costs associated with job accommodations, and employment-related supports. Further to this they suggested that DPOs do more to expose these myths in an effort to promote employment opportunities.

- Finally, when asked specifically about ongoing monitoring of human rights for people with disabilities in St. John's and beyond, the participants agreed that any ongoing monitoring work would require financial and institutional support to make it sustainable. They suggested that the ILRC needs resources to continue this sort of monitoring over time, with a view to tracking trends and identifying opportunities to promote human rights for persons with disabilities.

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Annex I: Interview guide

Annex II: Consent form

Annex III: Graphs

Annex I: Interview Guide

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?

[1st 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 2nd 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 3rd 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 1st 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 2nd 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 3rd 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*]

[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 Privacy and Family Life

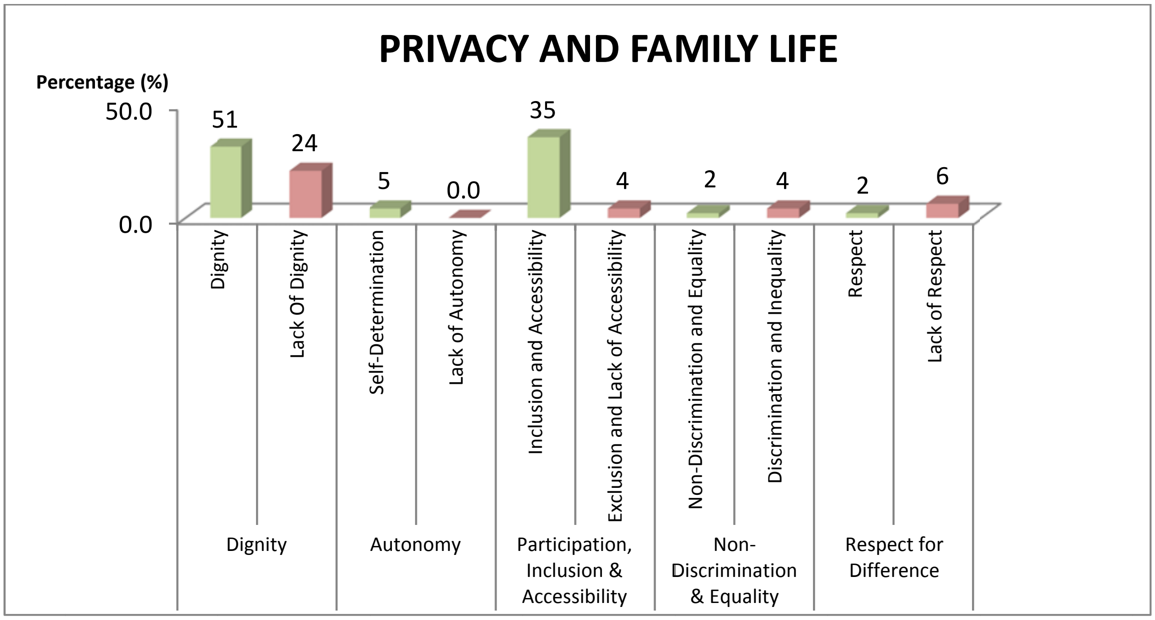

Figure 2 - Experiences reported in domain of Education

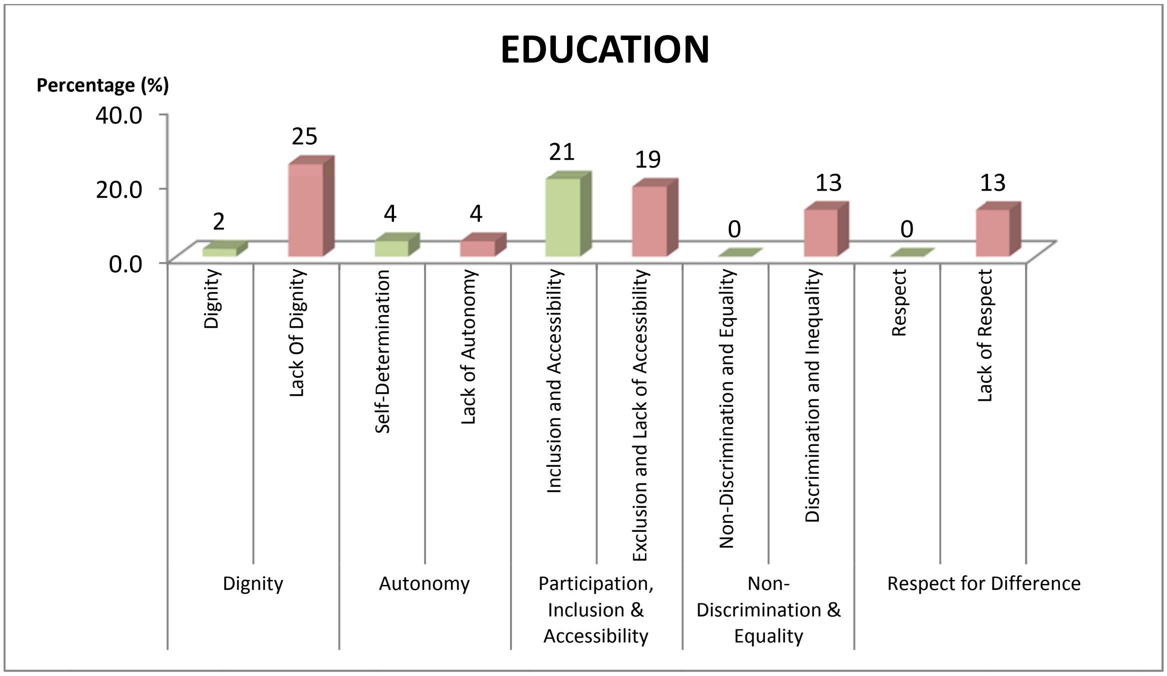

Figure 3 - Experiences reported in domain of Work

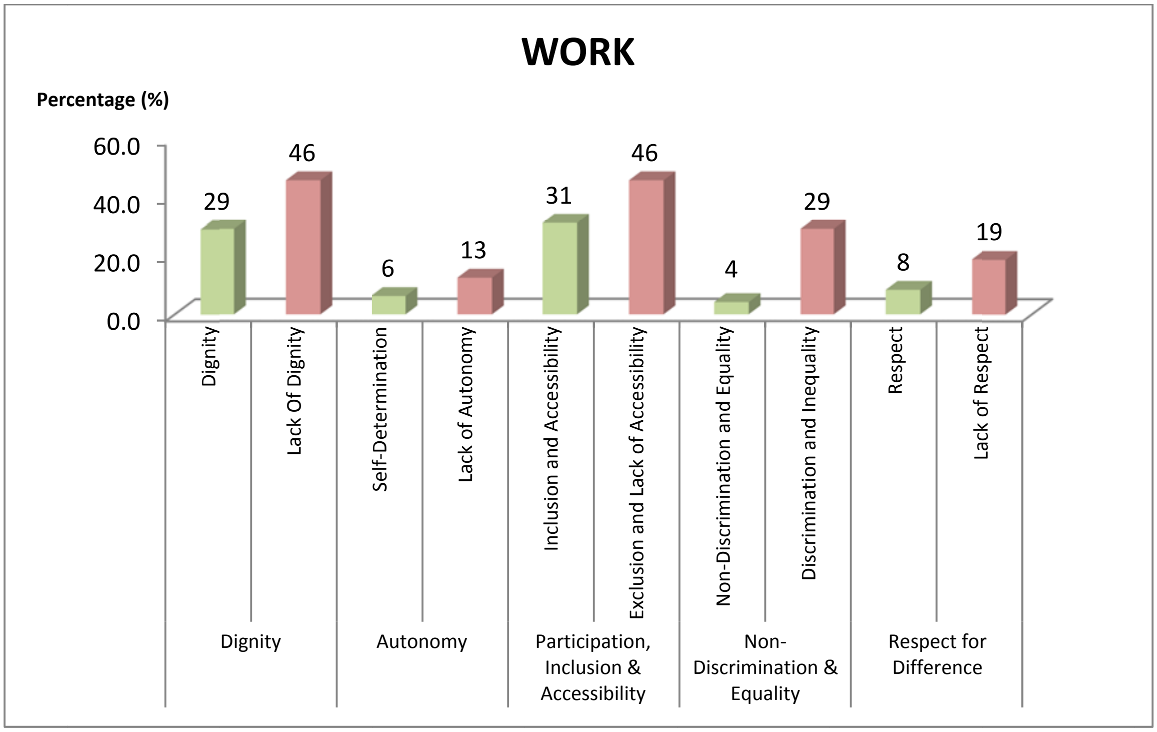

Figure 4 - Experiences reported in domain of Social Participation

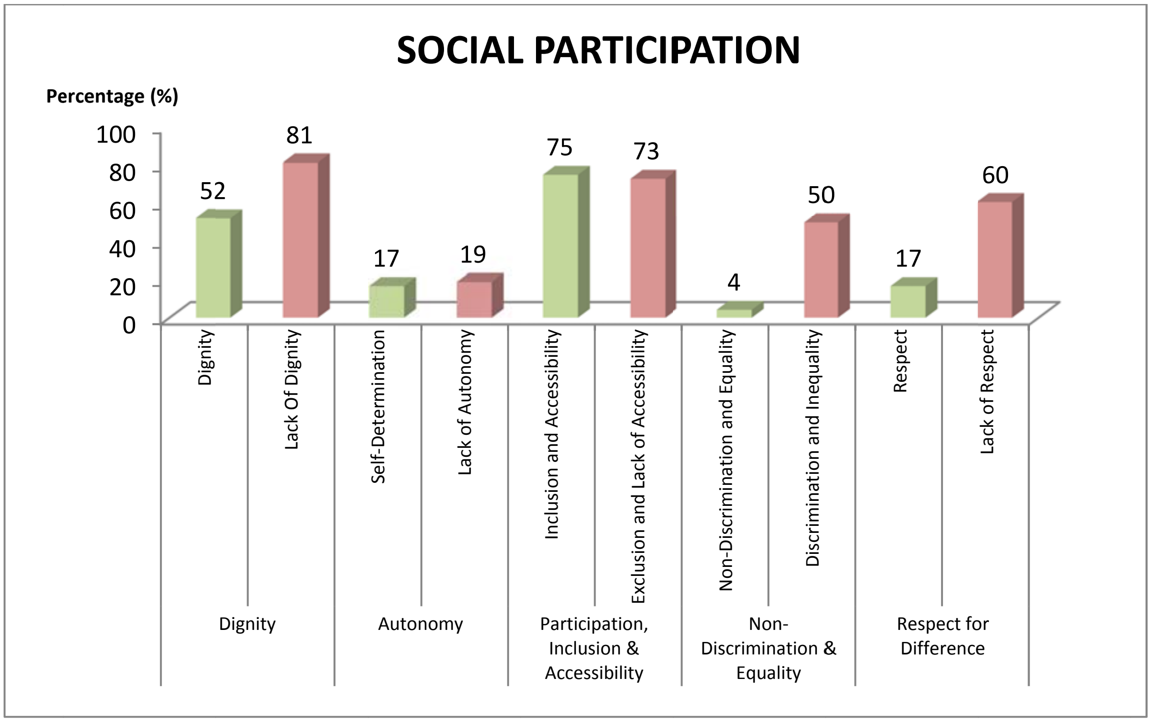

Figure 5 - Experiences reported in domain of Information and Communication

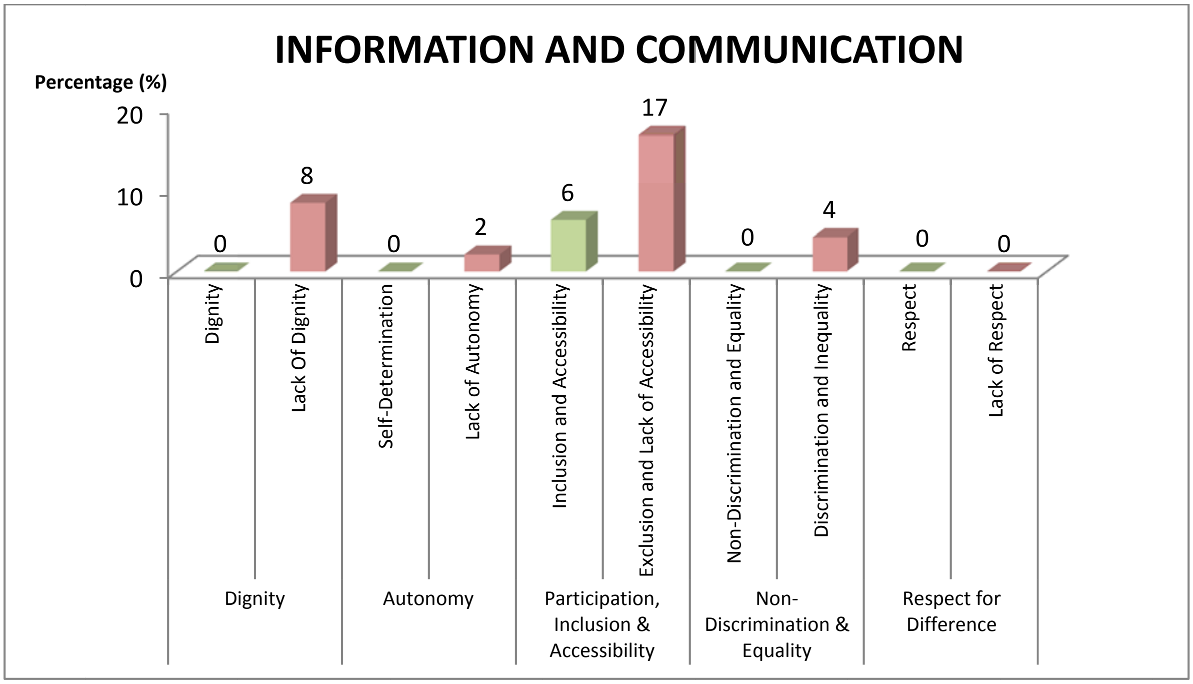

Figure 6 - Experiences reported in domain of Access to Justice

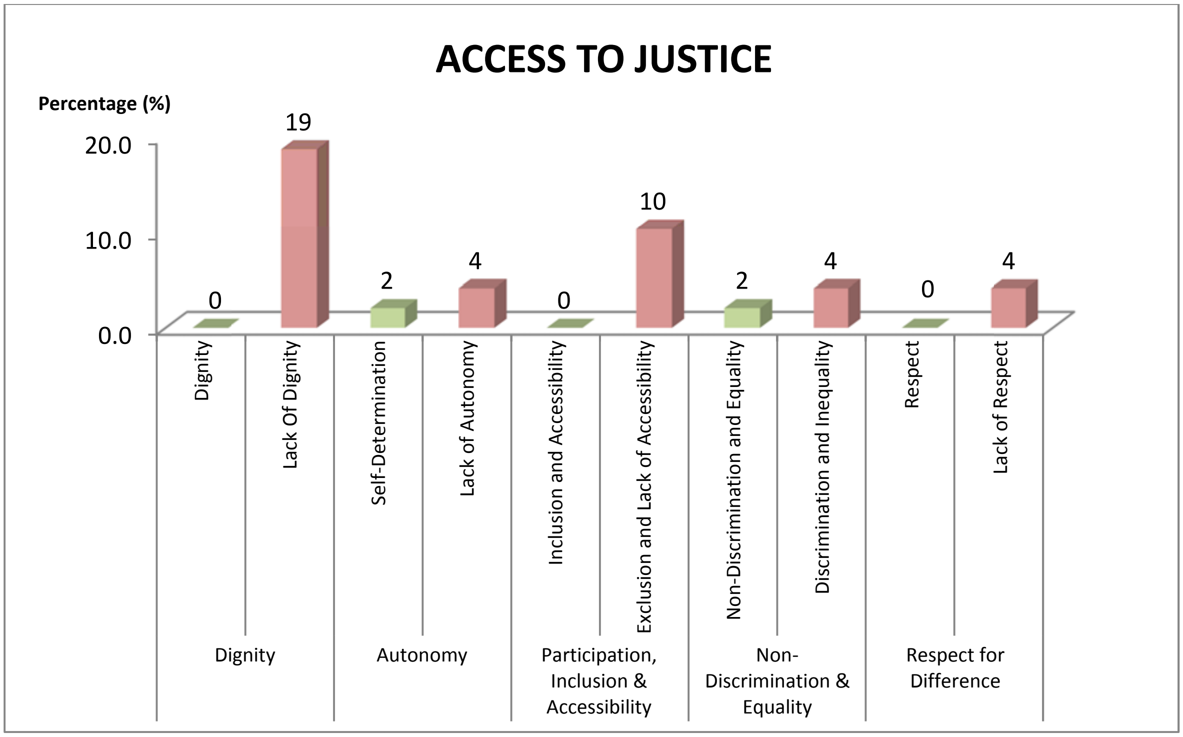

Figure 7 - Experiences reported in domain of Income, Security and Support Services

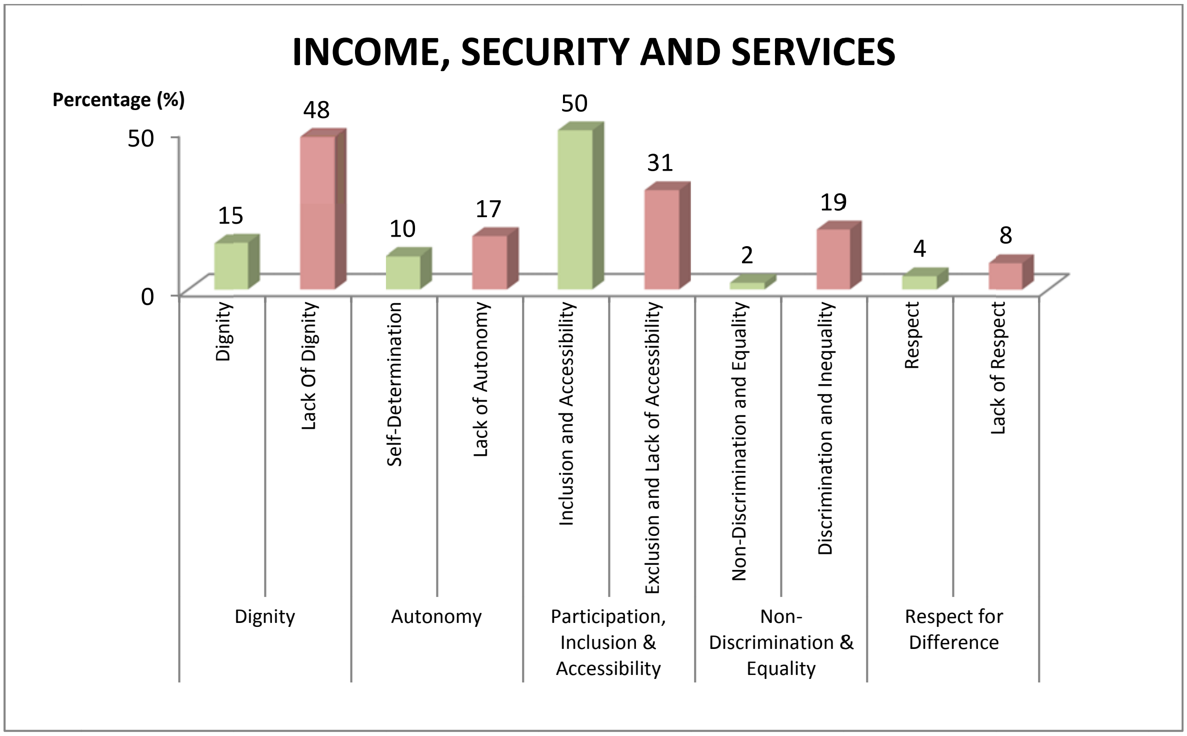

Figure 8 - Experiences reported in domain of Health, Habilitation and Rehabilitation

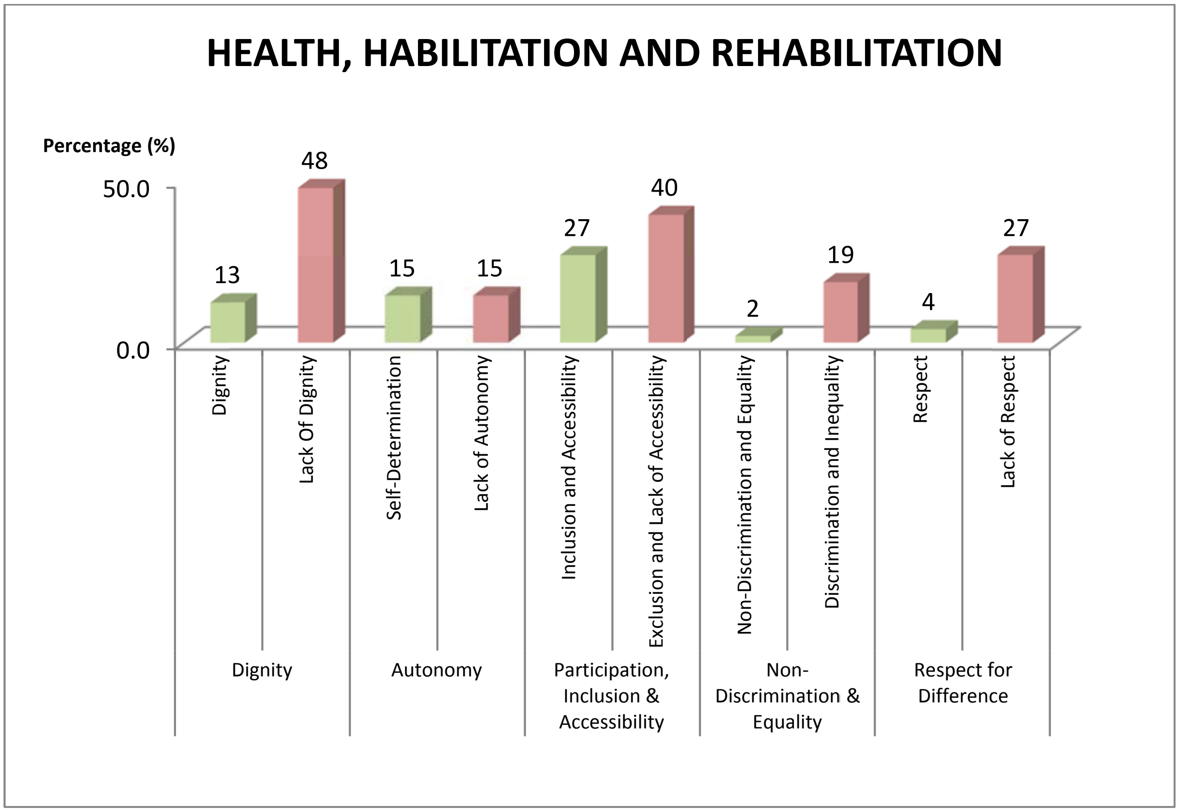

Figure 9 -Systemic Roots of Discrimination

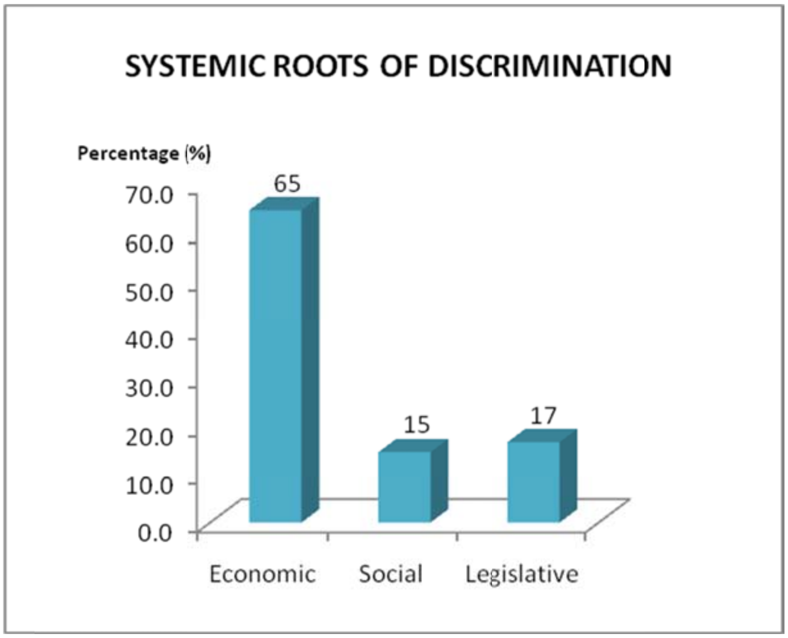

Figure 10 -Response due to Abuse and Discrimination

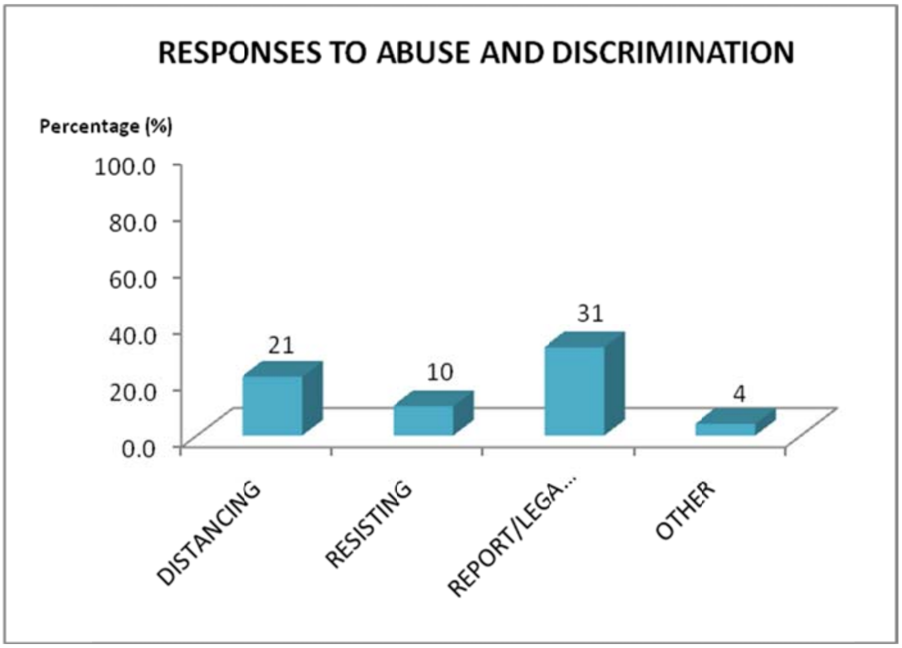

Figure 11 -Reasons for not Reporting

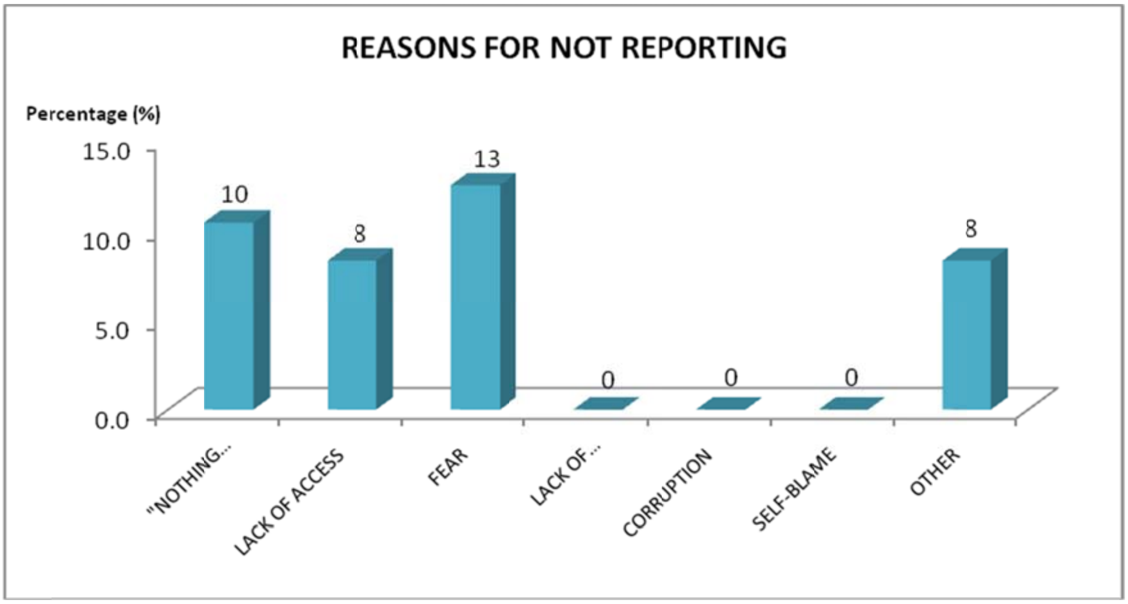

Figure 12 -Recommendations