

# NWT Disability Services Project 2015

## Summary of Findings



Created by the NWT Disabilities Council

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## Forward

Between 2004 there was focused interest in addressing the issues concerning people living with disabilities in the North. By 2008 an Action Plan was produced and this was to set in motion on-going changes to meet the needs and to improve the lives of people living with disability in the North.

However, between 2008 and 2015 there seemed to be a shift in focus away from disability. Through the daily work and feedback of the Council it began to raise the question over and over, what has been done since the Action Plan was produced? This question prompted our call for a grant from the Stabilization Funding for NGOs to evaluate the action plan and feedback on services in the North from multiple vested groups.

The resources available to us were slight and we relied on our relationships with communities and community champions to obtain the information and participation. The Territory responded and we had substantial feedback and are truly grateful to all those who shared their personal stories, those who openly shared the work they do and departments for sharing information and status on programs and services.

Having poured over the information for months, it is clear that there are gaps and there needs to be a re-opening of conversation and movement to a new strategic plan with measureable outcomes and on-going evaluation. The one certainty is that the number of persons living with disability in the North is not declining. This may be due to; the population aging, increased awareness of rights, more complex needs presenting themselves and economic and logistics. Even the old conservative numbers are clear, approximately 14.6% of the population lives with disability and 1 in 9 people are directly impacted by disability. We believe this underestimates the numbers in the North.

Therefore, we proudly present these two documents, the full Final Report and the brief Summary of Findings report, in order to restart the conversation and refocus the lens back to those people living with disability in the North and the people and families that support and care for them.

Denise McKee,



Executive Director  
NWT Disabilities Council

## **Introduction**

The survey responses came from 321 people throughout the territory, including 115 people living with disability, 58 parents or caregivers of people living with disability, and 148 service providers. These people came from 32 communities (all except Kakisa).

### Definition of Disability:

For the purpose of this survey, a disability is defined as, "any restriction or inability (resulting from an impairment) to perform [a daily] activity in the manner or within the range considered normal for a human being" (World Health Organization, 1980). Any level of limitation in your daily activity or participation is accepted, we want to hear from you regardless of the severity of the limitation and whether or not you have a formal diagnosis. (as cited in the Personal and Parent/Caregiver surveys, 2015)

The most common types of disability experienced by the Personal Survey respondents were physical (57.4%), chronic pain (35.7%), and mental/psychological (33.9%). The most common disability types experienced by the people who the Parent and Caregiver Survey respondents were caring for were physical (67.2%), learning (46.6%), and developmental (41.4%).

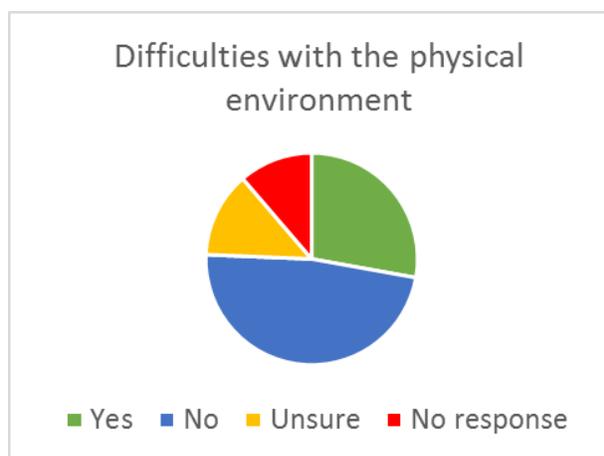
The project sections were divided using the 5 Building Blocks from the NWT Action Plan for Persons with Disabilities (2008): Education, Employment, Income, Disability Supports, Housing. Within each section, five priority areas have been identified using the perspectives of respondents, gathered through the three surveys.

## Education

### Accessibility & Physical Barriers

With approximately a third of respondents identifying difficulty with physical barriers, its significance should be addressed in education settings. Several adult respondents said that distance education was a useful alternative when physical barriers were encountered. Respondents said that ramps and elevators should be in good working condition and should be shared by all who access the buildings rather than just those living with disability. Accessible design (easy to open doors, light switches, layout of buildings etc.) should also be taken into consideration, as described by respondents. Physical barriers mean that some people do not have the same access to education as others.

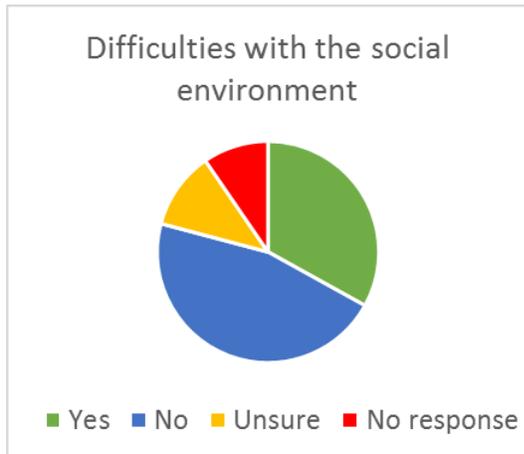
Graph 7: Physical Barriers to Education



### Stigma & Attitudinal Barriers

With approximately a third of respondents identifying difficulty with attitudinal barriers, this barrier's significance should be addressed in education settings. Respondents to the Personal Survey described encountering stigma and attitudinal barriers at school, at home, and within themselves. Stigma is a concerning barrier because it can directly impact a person's access to education, like when a primary school student is forced to only study part-time, or when a person's self-esteem becomes too low to continue.

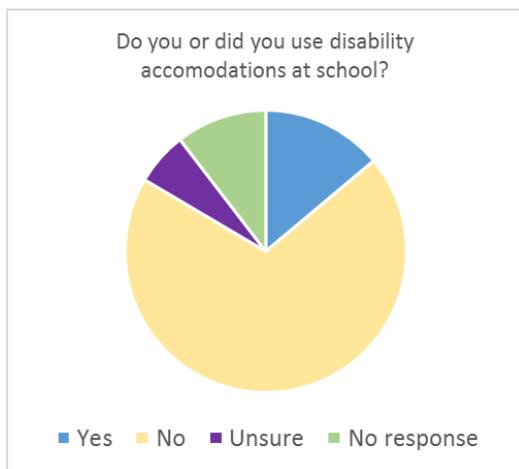
Graph 8: Attitudinal Barriers to Education



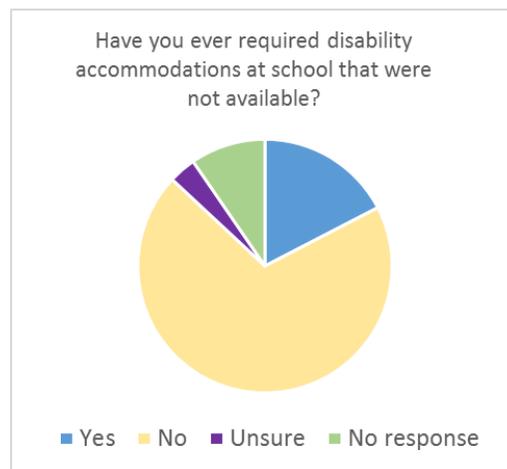
### Access to Accommodations

Nearly 70% of respondents to the Personal Survey said that they did not access accommodations while they were in school. Still, 17.4% said that they had required accommodations and supports that were not available to them. Early intervention supports and one on one tutoring and classroom supports were also identified as services that some respondents required but did not have access to. Parent advocacy was identified as a factor that contributes to access to accommodations, but it is not always enough to ensure access.

Graph 9: Accommodations in School



Graph 10: Accommodations Not Available



## **Mental Health & Self-Esteem**

Mental health and self-esteem are important factors for people's ability to pursue education. 7% of Personal Survey respondents identified this as a priority area. Both personal doubts and struggles (internal) and frustration experienced through the education system (external) were raised here. 51.7% of parents and caregivers stated that the person they care for had never had support program access to a life or social skills class or peer support program.

*“Everything was a struggle. EVERYTHING. Nothing was easy or straightforward. The amount of effort, energy, time and cost I had to put into getting my rights and accommodations weren't worth it. I got too discouraged to continue. Depressing as hell” (PSR, 2015)*

## **Funding & Training**

Survey respondents from all three groups identified public funding, personal funding and training in the education sector as concerns. Specifically a lack of available funding, and difficult to navigate application processes were seen as barriers. A useful suggestion made by one survey respondent was to have an identified professional at ECE whose job is to assist people living with disability to pursue their education.

### **Education Section Action Points**

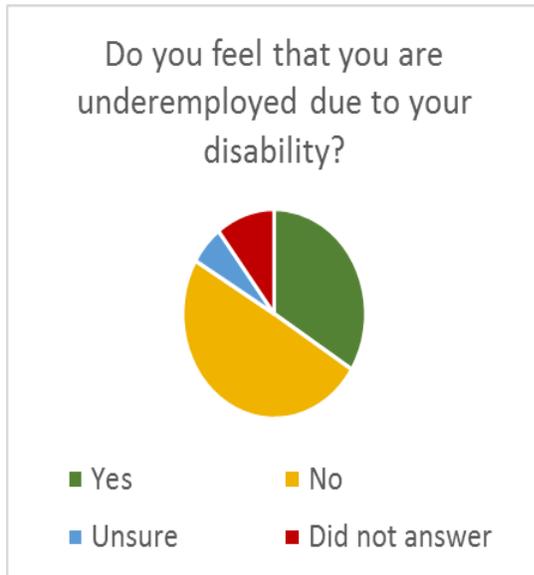
- Funding for education both at the institutional and personal levels, which impacts both access to education and quality of education, were concerns raised by respondents, and should be addressed.
- Training for educators at the primary, secondary, and post-secondary levels needs to be addressed, so that educators are knowledgeable, compassionate, and well-equipped to support students living with disability.
- Physical accessibility to educational institutions must be addressed and maintained. Whenever possible all students should use the same entrance so that students living with disability do not feel isolated.
- Access to accommodations is vital for the success of students living with disability. When needed, alternative arrangements for tests/exams, note taking, assignments, etc. should be made. Supports such as one on one tutoring and classroom supports as well as early childhood intervention, should be prioritized.

# Employment

## Employment Opportunities

33.9% of respondents to the Personal Survey said that they felt they were underemployed due to their disability. 26% were temporarily unemployed at the time of the survey and an additional 15.7% stated that they were completely prevented from working due to their disability. Both people living with disability and parents and caregivers noted significant adjustments that had to be made to their work lives. Employability of people living with disability, and representation of people living with disability in services organizations, were recognized as important issues.

Graph 15: Underemployment



Graph 16: Adjustments to Employment



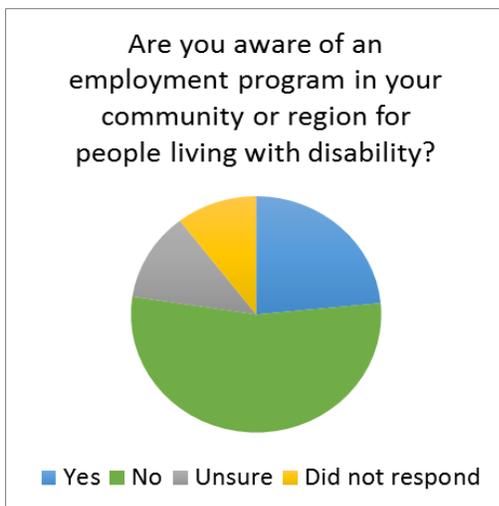
## Access to Accommodations

Many survey participants identified access to accommodations as an important area for employment. 30.4% of Personal Survey respondents said that they did not believe their workplace was equipped to support their needs as a person living with a disability while another 15.7% of respondents were unsure. Meanwhile, 40% of respondents said they would access employment training if it were available and 33.9% said they would access an employment program if it were available. These types of supports should be explored, especially where job placement and employer training and support occurs.

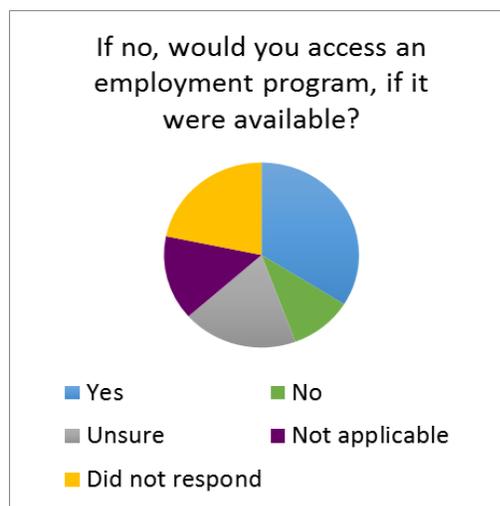
Graph 18: Workplace Properly Equipped



Graph 21: Employment Program



Graph 22: Desire for Employment Program



*“There is an overall lack of services for youth throughout high school but most importantly in preparation for transition from school to work or post-secondary education.” (PCR, 2015)*

### Accessibility & Physical Barriers

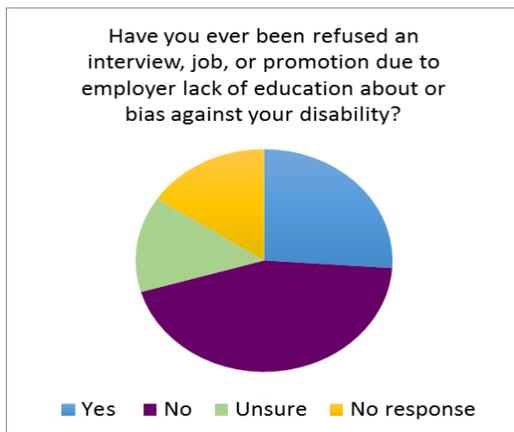
13% of Personal Survey respondents recognized accessibility and physical barriers as an important area for employment. Even buildings that are recognized as accessible are often not fully so, if bathrooms or office spaces are not independently accessible. There is currently no legislation that can guarantee or even encourage full building accessibility. Transportation was also recognized as a physical barrier to employment.

*“I cannot think of a single workplace or government building in the NWT that is accessible to persons with disabilities. To hire me would entail a significant outlay to make a workplace accessible. When I ask for a fully accessible (including toilets) location for an interview I never hear back or get some ‘hired internally’ excuse” (PSR, 2015).*

### **Stigma & Attitudinal Barriers**

26% of Personal Survey respondents stated that they believed they had been refused an interview, job, or promotion because the employer was uneducated about or biased against people living with disability. Respondents described fear of being treated differently or upsetting their employer, lack of understanding or unwillingness to learn about their disability, and active attempts to terminate their employment due to their disability. Stigma is a barrier to employment that needs to be addressed.

Graph 23: Workplace Discrimination



### **Personal Limitations**

7.8% of respondents to the Personal Survey specifically mentioned personal limitations as a barrier. 15.7% stated that they were completely prevented from working due to their disability. Even after all other barriers to employment have been addressed; some people will still be unable to work. Because of this, sufficient income supports must be available so that all people can live comfortably.



*“I’m worried that if I learn at such a slow pace I will not be able to obtain employment in the field I have chosen to sign up for at Aurora College. I quit my last job because I was not capable of the physical work. If I cannot do physical work, and I struggle with academia, what work will I be able to do?”  
(PSR, 2015).*

### **Employment Section Action Points**

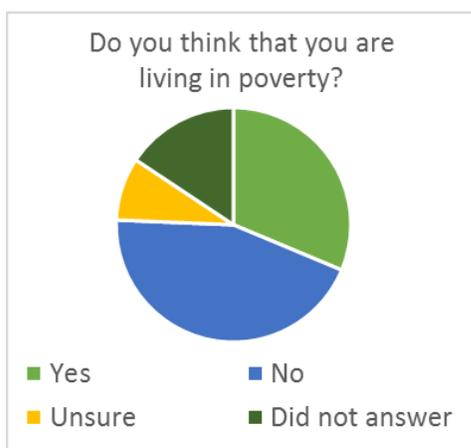
- Extend Duty to Accommodate to the private sector, extend authority and resources of the GACE so that a body exists to review accommodation standards & provide assistance where needed.
- Put in place a funding/resource program for workplace accommodations to support people living with disability in gaining and maintain employment.
- Employer training for awareness of disability issues and accommodations. An employer incentive for participation so that more businesses are reached.
- Physical access to workplaces and public space in general must be prioritized. A territory-wide accessibility initiative that goes further than the Building Code could be a starting point.
- Reassess income support to ensure that people who are completely prevented from working due to disability have sufficient income to live comfortably.

## Income

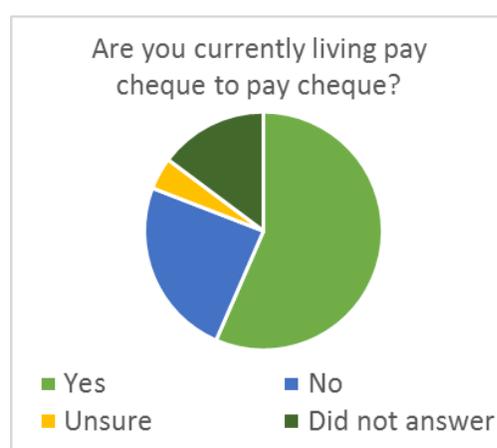
### Poverty & Insecurity

A substantial proportion of survey respondents are living in poverty. Significantly more are living pay cheque to pay cheque and therefore at risk of falling into poverty. People living with disability were more likely to be living in poverty than parents and caregivers. Poverty and insecurity was identified by survey respondents as a high priority area for the Income building block.

Graph 24: Living in Poverty



Graph 25: Living Pay Cheque to Pay Cheque



*“[p]overty means constant fear, going without basics and no hope” (PSR 2015).*

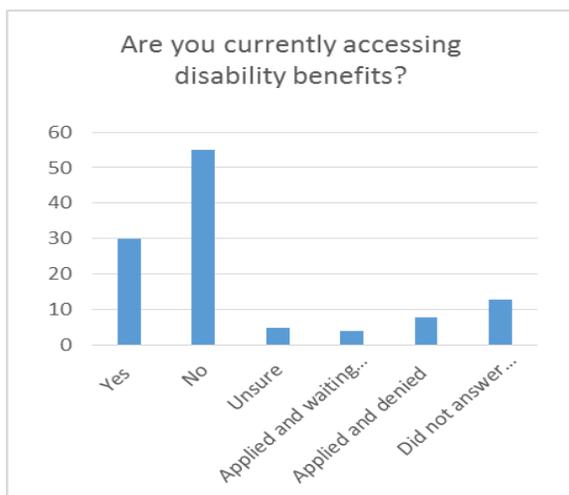
*“I cannot find the words to tell you about the fear that grips my soul and makes my stomach lurch from being threatened with eviction every other month or so” (PSR, 2015).*

### High Cost of Living & Benefits

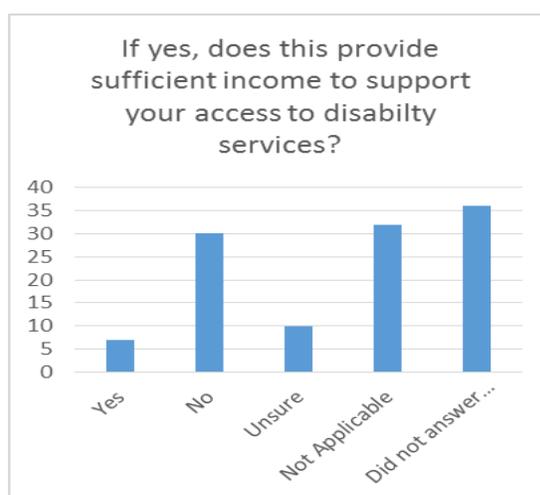
Cost of living is high in the Northwest Territories and the benefits that people who are unable to work due to disability receive are often insufficient to meet their needs. While people living with disability tended to access CPPD most often, parents and caregivers tended to access tax credits more. People living with disability were more likely than

parents and caregivers to find their income insufficient, most likely because parents and caregivers use benefits as supplementary income rather than replacement income.

Graph 28: Respondents Accessing Benefits



Graph 29: Benefits - Sufficient Income



*“Stay home, alone, in poverty and without hope is the message I receive every month” (PSR, 2015), “It’s hard to live on the funds I receive” (PSR 2015), “income support is a life of grinding poverty [...] no increases for inflation. prices for everything go up but the income support amount never changes” (PSR 2015).*

### Cost of Programs and Services

36.5% of people living with a disability, 12% of parents and caregivers, and 16% of service providers say that cost is a barrier to service. People living with disability spend a significant amount of their income on programs, services, equipment, treatment, and transportation all related to their disability. Contrary to the perception among service providers that much of this is covered or provided free of cost, in practice people tend to encounter barriers and therefore have to pay out of pocket or go without.

20% of the 115 Personal Survey respondents stated that in the last year alone they had spent over a thousand dollars out-of-pocket on help and support related to their disability. These amounts ranged from several hundred dollars in a year to

*“everything I have” and “all my savings, retirement funds” and “more than I could afford” (PSRs, 2015).*

## **Accessible, Affordable Housing**

While housing could be seen as a separate issue from income it was identified by 20% of respondents to the Personal Survey as being a priority under income. Access to housing that is both accessible, affordable and financially sustainable is closely linked to income security.

*“I will run out of personal funds in about 3 years if I remain living in my home”  
(PSR, 2015)*

*“If I do not get disability pension I will loose everything I own, house, car, etc.  
I will not afford to live here” (PSR, 2015)*

and *“I try not to think about it. I know eventually I will lose my apartment. I’m  
just trying to keep it for as long as I can” (PSR, 2015)*

## **Employment Opportunities**

While employment can be seen as a separate issue from income especially when the focus of the conversation is on benefits and supports, employment opportunities are closely linked to income security. 14.8% of Personal Survey respondents identified employability and employment opportunities as priorities for income.

*I am not guaranteed to keep my job for much longer and feel I am walking on egg shells in order to maintain an income to support my family. An emergency support fund to help individuals in the first few months after having to resign/are fired because you can no longer do all aspects of the job due to your disability. This would allow for time to try to find a new position and/or figure out what training you will require to enter the job market. The financial insecurity causes a substantial amount of stress (PSR, 2015).*

### **Income Section Action Points**

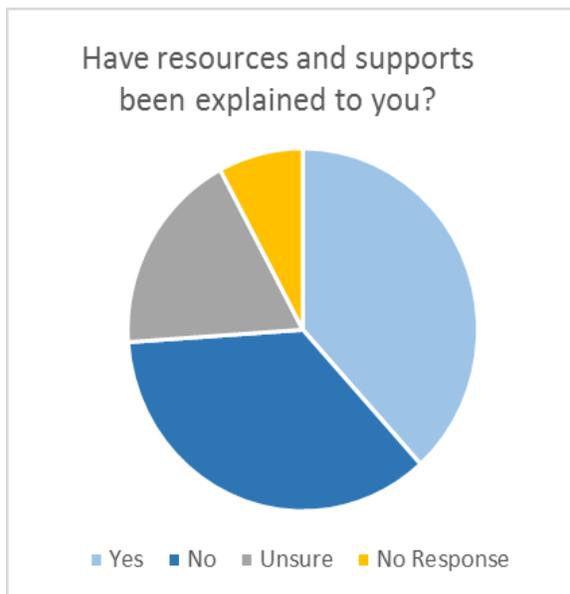
- Poverty and low-income families and individuals should continue to be prioritized. Support should also be extended to families and individuals who are at risk of poverty and living pay cheque to pay cheque, who often do not qualify for benefits but may still be struggling.
- Income exemption amounts and overall long term disability structure for IA should be assessed. It is recommended that the BC model be explored further.
- Emergency funds should be in place to assist people living with disability who need immediate support, who may not qualify for IA.
- Assess how many NWT applicants have had benefit applications denied due to doctor error or doctor turnover, and work to identify the root of this problem so that it can be addressed.

## Disability Supports

### Access to Supports & Information

When asked if resources and supports had been explained to them, 29.3% of parent and caregiver respondents said no and another 19% were unsure. When asked about assistive devices used and needed, respondents who were people living with disability said that the main reasons they did not have access to needed aids was cost (27%) and the aid not being covered by insurance (17.4%). The next reasons were availability of the needed aid where they live (15.7%) and being on a waitlist (6.1%). This shows that availability and cost tend to be barriers to accessing supports. Transportation and supports for caregivers (such as respite) were also identified as priorities.

Graph 33: Resources and Supports, Personal



Graph 34: Questions, Personal

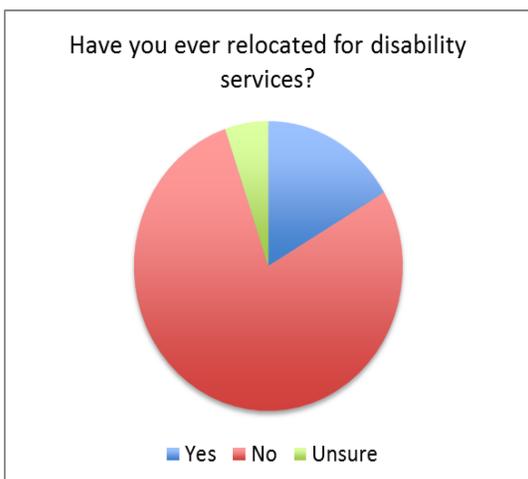


*“Because I cannot afford to purchase what I need (help in the home, rehab, assistive devices) I am isolated and stuck in my home. If I could leave I could get a very well paying job and have a life. The minimal services that are available [...] are a band aid at best, and often so far from what is needed that I struggle to find the effort to bother with them [...] what I need [...] homecare won’t do” (PSR, 2015).*

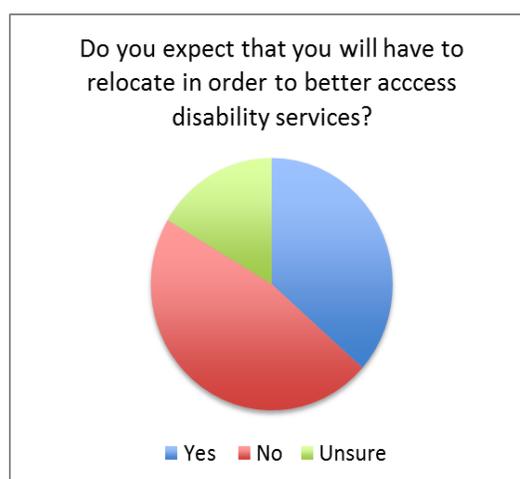
### Relocation for Services

When asked if they had ever had to relocate in order to have better access to disability services, 16.5% of people living with disability and 20.7% of parents and caregivers said yes. When asked if they expected they may have to relocate in the future, 36.5% of people living with disability and 31% of parents and caregivers said yes. Relocation was noted as sometimes being a productive choice in order to have better access to services, while other times it was seen as a measure taken out of lack of other options, at great personal cost to families. Measures to keep families together and people in their home communities for as long as possible, if this is what they desire, should be addressed.

Graph 36: Relocation, Personal



Graph 37: Future Relocation, Personal

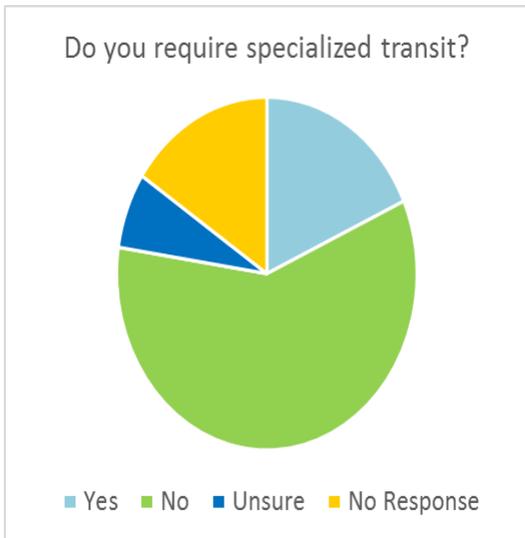


*“I know if I complain too much or ask for too much I will again be threatened with living in an institution or segregated housing. I’d kill myself rather than do that” (PSR, 2015).*

### Transportation and Community Accessibility

25.2% of Personal Survey respondents identified a lack of transportation to and from services as an obstacle to disability supports, and 15.7% said that inaccessible public spaces were an obstacle. Availability of accessible transit and accessible public spaces and community events is essential in order to support people’s access to disability supports and general wellbeing. A territory-wide initiative in order to promote this shift is needed.

Graph 40: Accessible Transportation Needs



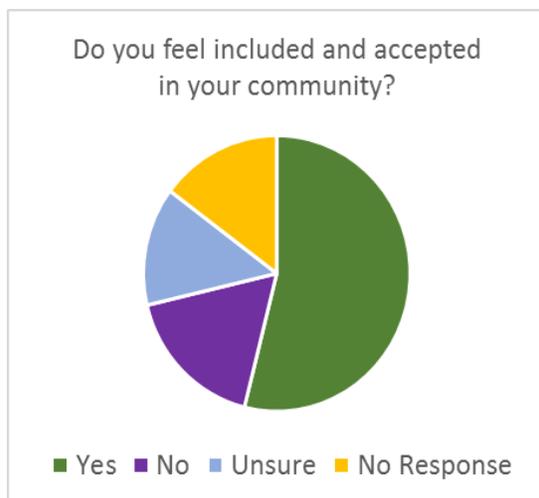
Graph 41: Accessibility of Public Spaces



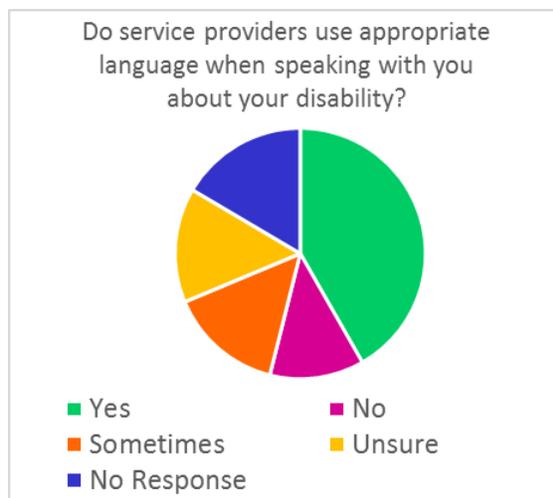
**Stigma & Attitudinal Barriers**

9.6% of respondents who were people living with disability stated that stigma and attitudinal barriers impacted their ability to access disability supports. While at times this was the product of specific bad experiences with service providers, other times it was seen through difficult to navigate policies and processes that made people feel undignified and less valuable than Canadians living without disability.

Graph 42: Community Inclusion, Personal



Graph 44: Appropriate Language, Personal



*“Afraid to go to doctor to find out as have been treated very poorly in the past. May never know what will truly help as I do not want to ever experience that again” (PSR, 2015).*

*“I have often found that people do not bother to talk to the disabled person but relay all information to the caregiver. It is rude and unprofessional, more awareness is needed” (PCR, 2015).*

### **Trained Professionals, Continuity of Care and Follow Up**

34.8% of people living with disability and 37.9% of parents and caregivers identified a lack of trained professionals as a general concern. These issues could arise in recruitment and retention (actual presence of the needed professionals) or training (qualifications and compassion of professionals present). 1.7% of personal survey respondents and 6.9% of parents and caregivers said that a lack of continuity of care and follow up created barriers to access disability support. Sometimes this was referred to in lack of coordination of service, lack of consistency with service providers, lack of documentation and information provided to patients or clients, and worries about future availability of these supports.

#### **Disability Supports Action Points**

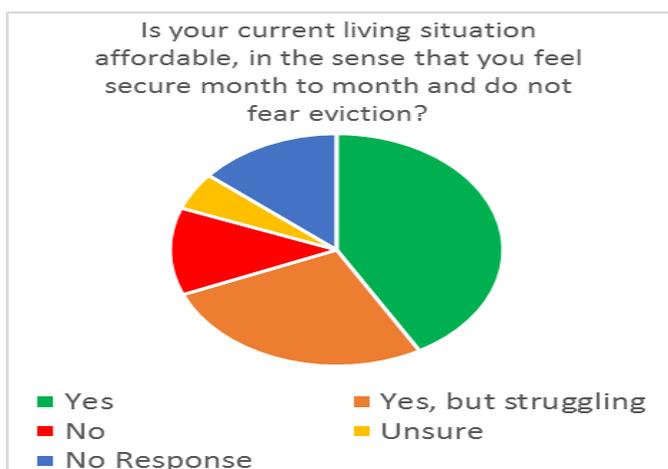
- Address relocation concerns so that all possible measures are taken to keep people as close to home as possible, if that is what they want.
- Address availability and affordability of aids and assistive devices, and work to ensure that information about how to access disability supports is widely available.
- More than a third of personal and parent/caregiver respondents said that a lack of trained professionals is an obstacle to their access to disability supports. Recruitment and retention should continue to be a priority, and increases in staffing where waitlists are long should be prioritized.
- An updated information guide to disability supports and services, such as the ‘Where Can I Find...’ guide created through the Action Plan (now out of date), is needed in order to simplify personal research, so that people living with disability can choose to self-advocate rather than having to go through a disability organization, if that is what they want/

## Housing

### Affordability

Of the 19% of parents and caregivers who said that their housing situation was not by choice, 8.6% said this was because they could not afford to change it. Of the 31.3% of people living with disability who said that their housing situation was not by choice, 25.2% said that this was because they could not afford to change it. This section demonstrates that many people living with disability and their families are living in situations that are not ideal due to a lack of affordable housing.

Graph 50: Affordable Housing, Fear of Eviction, Personal

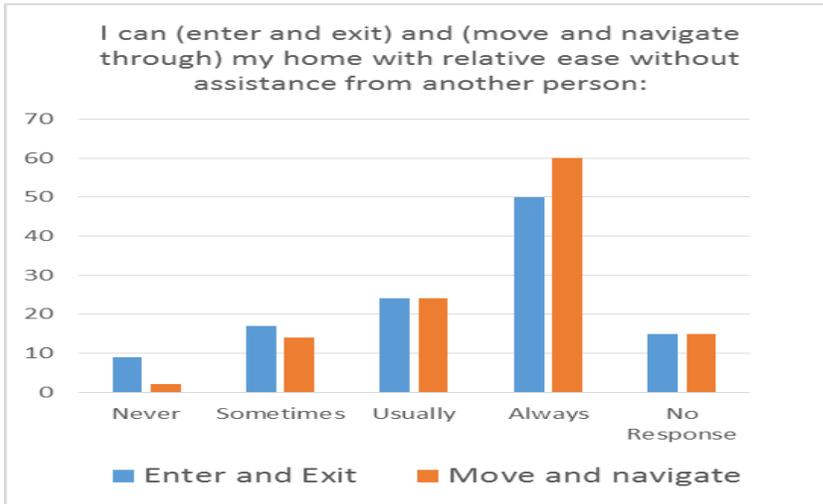


*“It is heartbreaking and deeply depressing never knowing if I’m going to have to leave my home because I live in poverty due to the poor luck of being disabled. I get an eviction notice under my door almost every month because ECE is late paying rent” (PSR, 2015).*

### Accessibility

When asked about their ability to enter and exit their home, and to move and navigate through their home without the help of another person, nearly 50% of Personal Survey respondents were unable to do so at least some of the time. While for some people this was dependent on personal limitations related to their disability, for many, the lack of accessibility of the home was the issue. 20.9% identified physical barriers as the reason for their limited mobility in the home.

Graph 51: Home Accessibility, Personal

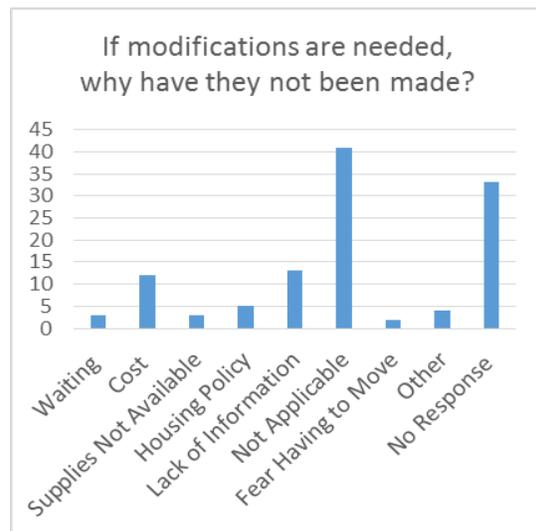
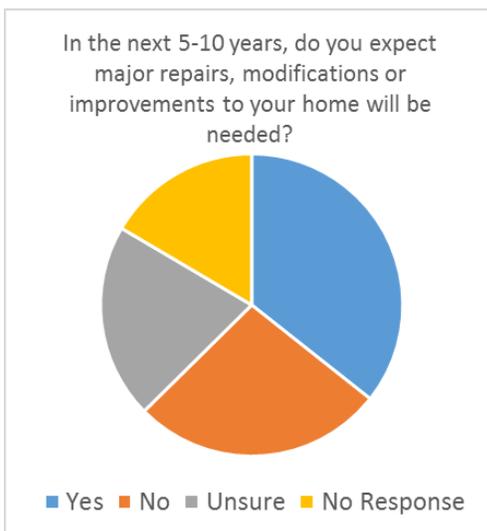


### Modifications & Renovations

35.7% of respondents who were people living with disability said that they anticipate needing major repairs, modifications, or improvements to their home in the next 5-10 years, in order to assist them with their disability. When asked why these had not yet been made, the most common reasons were not knowing who to ask or where to go for this service (11.3%) and the cost of the equipment and labour (10.4%).

Graph 52: Modifications 5-10 Years, Personal

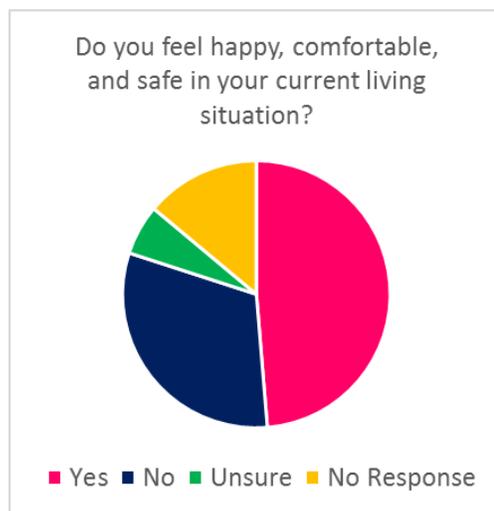
Graph 53: Modifications Needed But Not Done, Personal



### Safety, Inclusion, Community

31.3% of respondents who were people living with disability said that they do not feel happy, comfortable, and safe in their current living situation. These concerns could refer to no pet policies in limited affordable and accessible living options, unsafe or insecure buildings, and people feeling that accessible housing options meant segregation from those people who do not live with disability.

Graph 54: Happiness, Comfort, Safety



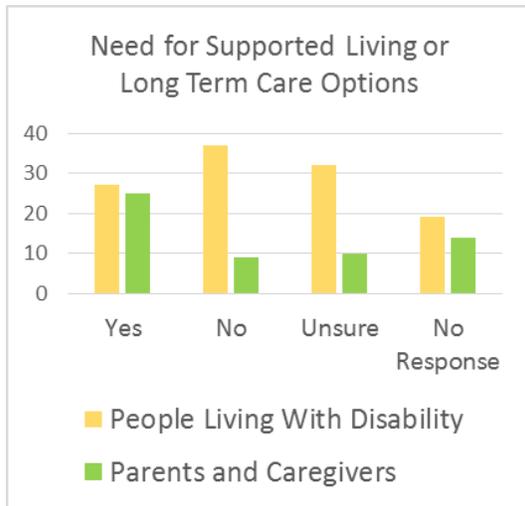
*“we should be able to live in the community with everyone else and not be shoved into the one or two buildings that are accessible. It’s mean and makes me feel bad” (PSR, 2015).*

*“I do not feel safe we have had the battery of our car stolen damage to halls crack pipes in stairwells my grandchildren are not allowed to come visit its note safe”(PSR, 2015).*

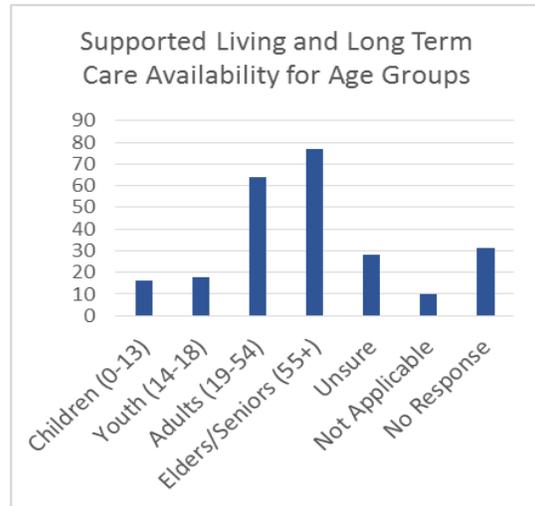
### Long Term Care & Supported Living

43.1% of parents and caregivers said that the person they are caring for either currently needs and does not have access to, or in the next 5-10 years will require long term care or supported living. 23.5% of people living with disability said the same. Concerns about having to leave the community in order to access these services were raised by several respondents. It should be a priority to ensure that these supports are in place when people need them, as close to home as possible.

Graph 55: Supported Living and Long Term Care Needs, Current to 10 Years



Graph 56: Long Term Care and Supported Living Availability, Age Groups



### Housing Section Action Points

- Prioritize Long Term Care and Supported Living within the territory so that the system is well prepared for those people who will need it in the coming years, and so that wherever possible, people can continue to live in their home communities.
- Continue to prioritize and promote funding for housing modifications and renovations. Expand this support to include “middle income” people who are renting in the private market.
- Address safety and inclusion concerns by building affordable and accessible housing into existing buildings and neighbourhoods, so that people living with disability do not feel isolated and segregated.
- Consider a rent cap or other strategy to address the large number of people who struggle to afford their housing but do not have access to limited public housing units.
- Expand accessible design and implement an initiative to promote and encourage builders to use high accessibility standards in their design.

## **Recommendations for Moving Forward**

This project was created as a much needed follow up to the *Living with Disability... Living with Dignity: Needs Assessment of Persons with Disabilities in the NWT* of 2000 and the *NWT Action Plan for Persons with Disabilities* of 2008. In 2000 major gaps in supports and services were identified and important information collected to move this conversation forward. Since then, the *Framework* and *Action Plan* provided important prioritizing and goal setting for the future of disability services in the Northwest Territories. In the fifteen years since the *Needs Assessment* and the nearly seven years since the last update of the *Action Plan*, much of what was identified as a priority remains to be addressed. Here we have identified 5 main Recommendations for Moving Forward, pulled from the survey respondents' feedback, for next steps:

**1. Mandate a comprehensive research study in order to obtain up to date and accurate information on the number of people living with a disability in the territory and their needs.** This project only scratches the surface of identifying priority needs, and the overwhelming response we received points to the need for a more comprehensive research approach. Include Mental and Psychological disabilities in this study, and continue using the same definition and frameworks used here.

**2. Initiate a territory-wide accessibility project, which goes beyond the National Building Code to address functional accessibility and social inclusion for people living with disabilities.** This would include an assessment of the physical accessibility of all public buildings as well as those that are privately owned. Duty to Accommodate would be extended to the private sector and funds would be assigned for assisting businesses and educational institutions in making modifications needed to ensure accessibility. GACE would also be expanded as a body that exists to review accommodations standards and provide assistance.

**3. Reassess income support both for ease of access for people living with long term or permanent disability, and for income exemption amounts.** Ensure that people who are prevented from working due to disability have enough financial support to live comfortably. Ensure that income exemption amounts are high enough that people are not

being “encouraged not to work”. Further research needs to be done into the number of NWT residents who are denied benefits due to doctor error or lack of regular family doctor, in order to establish how best to address this issue.

**4. Address affordable and accessible housing concerns as soon as possible, so that all people have access to safe and comfortable housing that they can afford.** Especially keep in mind that many people living with disability said they want accessible housing to be integrated in the community, so that they do not feel isolated and segregated. Middle-income families and individuals who rent privately and are struggling need to be supported as well. Currently support is mainly only available for low-income families and individuals and homeowners, which leaves a significant gap.

**5. Continue to work to ensure all items from the NWT Action Plan for Persons with Disabilities, now available with updates for 2015, are complete.** As seen in the updated version of the Action Plan, and throughout this report, there is still much work to be done. While important progress has been made in some areas, significant gaps still exist, and many items are still considered Incomplete or Ongoing. The NWT Action Plan for Persons with Disabilities should continue to be reviewed, updated, and consulted regularly.

**This document is only a brief summary. Please see the full length report: NWT Disability Services Project 2015 - Final Report, for a full detailed account of the project and survey findings, including the Updated Status of the 2008 NWT Action Plan for Persons with Disabilities.**



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**NWT Disability Services Project  
Summary of Findings  
2015**