

*Living with Disability...  
Living with Dignity*

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Needs Assessment of Persons  
with Disabilities in the NWT  
**Summary Report**

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GNWT Health and Social Services  
Yellowknife Association for Community Living  
GNWT Education, Culture and Employment (College and Careers Division)  
YWCA of Yellowknife  
Human Resources Development Canada  
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A full report on the Needs Assessment is available from the partners.

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# 1. About the Needs Assessment



## Disability

Disability is described by the World Health Organization (WHO) as *“the loss or reduction of functional ability and activity due to any disturbance of, or interference with, the normal structure and functioning of the body, including the systems of mental function.”* In this Needs Assessment, a more simplified definition is used.

**A disability is any degree of physical, sensory, psychiatric, cognitive, intellectual or learning limitation which causes difficulty in the usual activities of daily living.** Persons with disability may experience varying degrees of limitation ranging from mild to moderate to severe. Difficulties in usual activities of daily living may result from limitations caused by one or more disabilities, for example a physical disability and a learning disability.

Disability can affect people of all ages and from all backgrounds. Persons may be born with disability. Some may develop a disability over the course of their life. In addition to persons with disability, parents, unpaid caregivers and community service providers are other people who are affected by disability.

## Why a Needs Assessment?

The Canada Census identifies people with disability in the NWT and asks these people to participate in the Health and Activity Limitation Survey (HALS). The HALS asks people to describe their disability in detail. HALS information tells us that over 5,400 people in the NWT may have a disability.<sup>1</sup>

HALS:

- collects information on mobility, agility, seeing, hearing and speaking disability among adults in the NWT but very little information on children.
- groups persons with intellectual, learning, cognitive and psychiatric disabilities together as ‘other’ disabilities, so we really don’t know much about these disabilities.
- does not collect information about other people in the NWT who are affected by disability, for instance parents and caregivers.
- does not release information on disability by NWT community or region.

<sup>1</sup> Based on 1991 HALS and the Government of the NWT (GNWT) 1999 population estimates for the new Northwest Territories (excluding Nunavut). These numbers do not include persons with disability living in institutions.

The gaps in information about disability make it difficult to plan and allocate resources to assist persons affected by disability. In 1998, a partnership was formed to conduct a Needs Assessment of Persons with Disabilities in the NWT. Over the course of the Needs Assessment, two levels of government, a First Nation organization, territorial and community-based non-government organizations and a self-advocate participated in the partnership.

The NWT Council for Disabled Persons coordinated the Needs Assessment.

### The Process

The purpose of the Needs Assessment was to **determine the nature and distribution of disabilities within the NWT population, and the gaps in, and future requirements for, services among this population.** This would be done by developing an information base on:

- the number and percentage of the NWT population with intellectual, sensory and/or physical disabilities; the nature and

distribution of these disabilities; day-to-day living needs by main type of disability; and issues faced by persons with these disabilities and the issues faced by their families.

- existing programs/services available to persons affected by intellectual, sensory and/or physical disabilities, and the current and projected (5-10 year) service needs of this population.

After beginning work on the Assessment, the partners broadened the study to include:

- cognitive and learning disabilities.
- psychiatric disabilities where this disability accompanied one or more of the other disabilities under investigation.<sup>2</sup>

Both diagnosed and undiagnosed disabilities acknowledged by persons with disability or his/her parent/caregiver were included in the Assessment.

The partners were:

- NWT Council for Disabled Persons
- GNWT Health and Social Services
- Yellowknife Association for Community Living
- GNWT Education, Culture and Employment (College and Careers Division)
- YWCA of Yellowknife
- Human Resources Development Canada
- MaryAnne Duchesne (self-advocate)

The Metis Nation of the NWT was also a partner between August and December 1999.

<sup>2</sup> GNWT Health and Social Services is committed to completing a separate needs assessment of persons with psychiatric disability.

The Needs Assessment partners and the research team from Lutra Associates collaborated to:

- develop definitions of disability.
- design and test questionnaires to collect information from community service providers, persons with disability, and parent/caregivers.
- identify information needed from regional program managers.
- inform people about, and encourage participation in, the Assessment.

At the front line, workers in all NWT communities were asked to collaborate to identify and engage people with disability in this Assessment. Many front-line workers had difficulty dedicating time and priority to this Assessment due to heavy workloads, staff shortages and lack of client information.

## Who Participated

This Needs Assessment heard from 1,259 people in the NWT who are affected in some way by disability. Questionnaires were completed by:

- 807 persons with disability who acknowledge their disability.<sup>3</sup>

- 227 parents/caregivers of persons with disability.
- 181 community service providers working for non-government and government agencies.
- 44 regional program managers were also interviewed.

Persons with disabilities who participated in this Assessment make up:

- 2% of the whole population in the NWT, and
- 15% of the NWT population with disability. (Table 1)

Children (0-14 years of age) make up:

- 27% of the population in the NWT, and
- 15.7% of persons with disability in the NWT. (Table 1)

Elderly people (65 years of age or more) comprise:

- 4% of the NWT population, and
- 16% of persons with disability in the NWT. (Table 1)

Compared to the whole NWT population with disability, this Assessment involved a greater proportion of elderly people, a similar proportion of children and a much smaller portion of adults. (Table 1)

The Needs Assessment of Persons with Disabilities was the first research to:

- assess the needs of persons with disabilities in the NWT, those who care for them and are not paid to do so, and those who are paid to provide services.
- be managed by a multi-interest partnership and coordinated by a non-government organization.

<sup>3</sup> Acknowledgement of disability by the individual him/herself was required to participate in the Assessment.

More than two-thirds of all persons with disability in the NWT have a mild disability. Persons with mild, “hidden”, or less widely understood disabilities may not acknowledge disability. Also, they may not use or need programs/services to cope with disability. Persons with visible, moderate to severe and/or more widely understood disabilities such as physical or visual disability, are more likely to talk about them. This Assessment involved:

- 33% of all NWT persons with a moderate to severe degree of disability. (Table 2)
- only 2% of NWT persons with a mild degree of disability.

This Assessment found that a severe disability of one type may be accompanied by a moderate or mild disability of another type(s). The severity of disability can change over time.

- Cognitive disability is a degenerative condition which by definition, does get worse.

- Learning and intellectual disability do not change over time but personal, home and community factors can influence the extent to which these disabilities limit daily living activities.
- The degree of physical and sensory disabilities can worsen over time.

This Assessment found that 85% of persons with disability either don't know the future of their disability or expect it to get worse in the future. Uncertainty about the future may be due to limited understanding of the disability or hopes that services or aids can be found to manage the effects of the disability.

Disability is an intensely personal and emotional issue. Disability may be viewed negatively, not acknowledged or not understood.

- Generally, people with disability and parents/caregivers of persons with disability who are uncomfortable talking about disability chose not to participate in the Needs Assessment.

**Table 1: 1999 NWT Population and Needs Assessment Respondents with Disability by Age, 2000**

Age Groups	NWT Population	Needs Assessment Respondents with Disability	% of NWT Population with Disability <sup>1</sup>	Needs Assessment Respondents as a % of NWT Population
<b>Total</b>	<b>41,606</b>	<b>807</b>	<b>13.1%</b> N=5,453	<b>14.8%</b> N=807
Children 0-14 years	27.2%	12.7%	15.7%	12%
Adults 15-64 years	68.7%	51.5%	67.8%	11%
Elderly 65 + years	4.1%	32.2%	16.5%	29%
Unknown	-	3.6%	-	-

1. Estimate based on HALS 1991 and GNWT population estimates for 1999.

N = Number of Respondents

- People affected by disability who have participated in surveys in the past and seen no action from them, refused to participate in yet another survey.
- Some persons affected by disability, including community service providers, did not have the literacy skills to participate in the Assessment.

Some of these barriers were overcome by hiring community-based researchers to assist persons affected by disability to participate in this Assessment.

### Disability in the NWT in the Future

In 1999, 1,780 persons with moderate to severe disability and 3,674 with mild disability lived in the NWT. By the year 2004, there may be 5,910 persons with disability, of which 1,982 will have moderate to severe disability. Most (81%) community service providers participating in this Needs Assessment expect that increases in the number of persons with disability will be driven by:

- the high use of alcohol, drugs and solvents.
- abuse/neglect.
- an aging population.

### Caution: When Using This Information

The information in this Assessment is based on one-third of the 1,780 NWT citizens living in households who are identified as having a moderate to severe disability. This Assessment also documents the needs of parents/caregivers of persons with disability, which is the first time this information has been recorded.

Persons with moderate to severe disability each face unique personal and life circumstances, making it difficult to draw generalized conclusions about the entire population affected by disabilities.

It is important to note that while a non-random sampling technique was used in this research, the sample is large enough to provide a useful basis for planning programs and services and allocating resources to the needs of people with disabilities and families.

The Needs Assessment has five limitations.

1. The needs of persons with mild disability are not well understood through this Assessment.

**Table 2:** Degree of Severity of Disability by Percent of the NWT Population with Disability

Degree of Disability	NWT Persons with Disability in 1999 <sup>1</sup> (N=5,453)		2000 Needs Assessment Percent of Persons with Disability (N=807)	
Mild/Slight	67%	(N=3,674)	2%	(N=85)
Moderate	23%	(N=1,259)	16.6%	(N=209)
Severe	10%	(N=521)	73%	(N=379)
Moderate/Severe	32.6%	(N=1,780)	33%	(N=588)

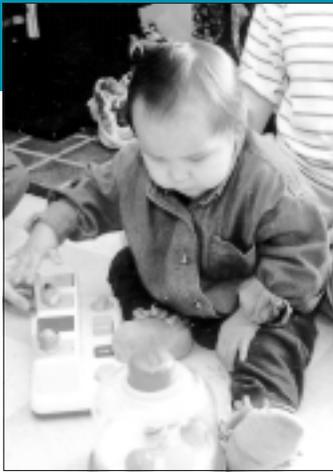
1. People living in households not institutions, based on the 1991 Health and Activity Limitation Survey.

N = Number of Respondents

2. "Hidden disabilities" or "brain-related disabilities" are not widely understood, accepted or acknowledged. Persons with these disabilities may have confused one disability for another. Others may not have recognized or acknowledged this disability and did not participate.
3. This Needs Assessment provides no new information on the characteristics of children with disability. Slightly more than 100 children with disability participated in this Assessment. Small numbers limit the extent to which definitive statements can be made about children with disability. At the same time as this Assessment was being done, NWT schools were assessing student needs including those of students with disabilities. Sharing information from the two Assessments will be important to understanding the needs of NWT children with disability.
4. Data presented on psychiatric disability refer only to those persons who have one or more of the other disabilities under investigation as well as a psychiatric disability. No definition of psychiatric disability was provided. Data on psychiatric disability should be treated as a very limited perspective of this disability. More complete information on psychiatric disability will be available when the GNWT Health and Social Services and its partners complete a mental health needs assessment.
5. Economies of scale significantly influence the human services/programs available to the NWT citizens. Larger communities have a greater range of programs/services. Program/service needs now and in the future may be under-represented by persons affected by disability living in smaller communities who are not exposed to program/service options. People don't ask for things that they do not know exist.

Should the needs of persons with mild disability change, for example due to employment or lifestyle circumstances, the needs presented in this Assessment would be severely under-represented. Just think about George!

*George has a mild physical disability due to a back injury. When George changed jobs, he didn't realize that he would have to do more lifting and move heavier objects. His mild back problem is now causing a great deal of difficulty for him.*



## 2. The Disabilities We Have

If the types of disability experienced by Needs Assessment respondents with disability are typical of all NWT persons with moderate to severe disability:

- 88% have physical or sensory disability.
- 64% have physical disability.
- 32% have learning disability.
- 29% have visual disability.
- 27% have hearing disability.
- 25% have intellectual disability.
- 20% have cognitive disability.
- 19% have speech disability.
- 10% also have a psychiatric disability.

Six of every ten people with disability participating in this Assessment have more than one disability.

Among children 0-14 years of age who participated in this Assessment:

- 70% have learning disability.
- 56% have intellectual disability.
- 50% have speech disability.

***“Doctors don’t know about Dene medication. They don’t understand us elders.”***

(from Personal Questionnaire)

Among persons 15-64 years of age who participated in this Assessment:

- 64% have physical disability.
- 34% have learning disability.
- 28% have intellectual disability

Among persons 65 or more years of age who participated in this Assessment:

- 78% have physical disability.
- 41% have hearing disability.
- 27% have cognitive disability.

***“Loudspeakers and public address announcements are rarely clear. Theatres are TOO loud and blast you. We need to educate and make the public aware of hearing needs.”***

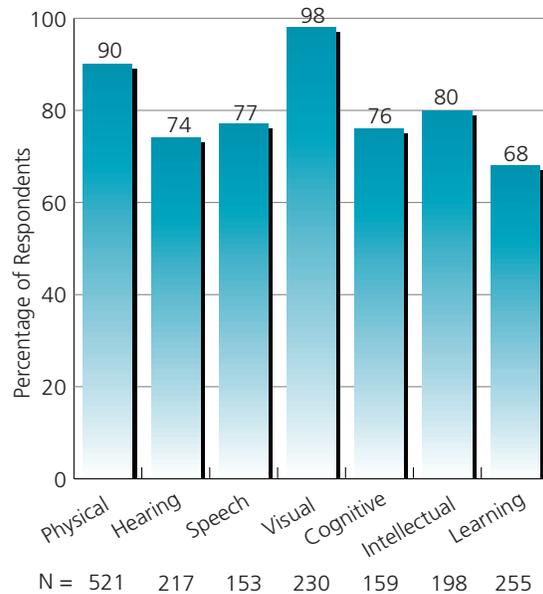
(from Personal Questionnaire)

Assessment and diagnostic services for persons with disability are not available in all NWT communities on a regular basis. Those who have not had their disability assessed, diagnosed or named by a professional, may not acknowledge their disability and would not have participated in this Assessment. In this Assessment:

- 92% of persons have disabilities which have been assessed, diagnosed or named by a professional.
- persons with a visual disability are most likely to have an assessed/ diagnosed/named disability.
- persons with learning disability are least likely to have their disability assessed/ diagnosed/named. (Figure 1)

***“There are no services for the disabled in this community, no advocacy.”***  
 (from Personal Questionnaire)

**Figure 1:** Percent of Needs Assessment Participants Having an Assessed/Diagnosed/Named Disability, 2000



Note:

1. N = Number of Respondents
2. Among those people identifying a psychiatric disability in addition to one or more of the disabilities under investigation, 82% stated that the psychiatric disability had been assessed/diagnosed or named by a professional.

### 3. The Reasons for Disability



The health and lifestyle circumstances of NWT residents are described in a Government of the NWT report entitled *The NWT Health Status Report* (Health and Social Services, 1999).

Some health and lifestyle circumstances can lead to untimely death, illness/disease, injury or disability. These circumstances include poverty, poor nutrition, alcohol/drug use, and certain social and physical behaviours.

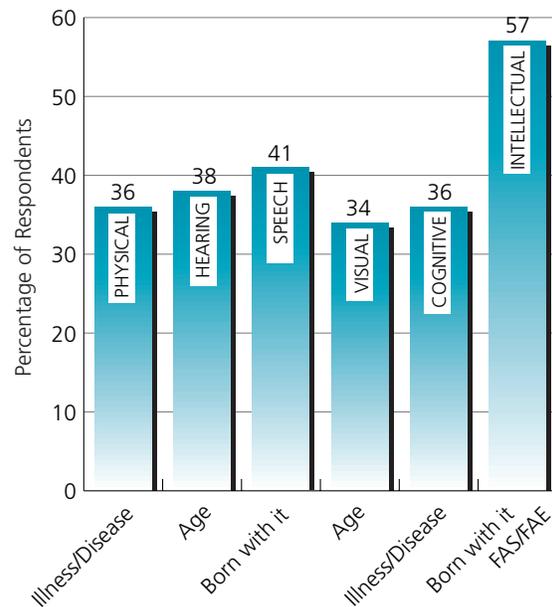
This Needs Assessment found that:

- many persons with disability live in poverty.
- illness/disease, age and the circumstances before, during and at birth are the main reasons for disabilities. (Figure 2)

*“Dealing with difficulty is a way of life if that is all you’ve known.”*

(from Personal Questionnaire)

**Figure 2:** The Main Reported Reason for Disability among Persons with Disability, NWT Needs Assessment 2000



*“How can you do a health survey without reference to smoking? It has played hell with my breathing and circulation. It has left me able to walk maybe a block at the most.”*

(from Personal Questionnaire)

## 4. Who We Are



Disability affects people of all ages and from all backgrounds.

### Gender and Age

Males and females in the NWT are equally as likely to have disability.

Elderly people are more likely than any other age group to have disability. The *1994 National Population Health Survey* found that elderly people in the NWT are:

- four times more likely to have disability than persons 45 to 64 years of age.
- twice as likely to have a disability than other Canadian seniors.

### Place of Residence

This Assessment found that:

- compared to children and adults (less than 65 years of age), elderly persons with disability are least likely to live and be cared for in a family home.
- persons with disability not living in a family home, live in an institution such as an extended care facility, live alone or live with non-family members.

This Assessment found that:

- non-Aboriginal and Aboriginal persons with disability living in Yellowknife and Hay River likely were not born in these communities/regions.

- regardless of ancestry or place of birth, 96% of persons with disability consider their home to be in the community or region in which they now live.

### Ethnicity and Language

Citizens of Aboriginal and non-Aboriginal ancestry comprise roughly an equal portion of the NWT population. NWT communities with mainly Aboriginal populations had better participation in this Assessment than communities with large populations of non-Aboriginal people. This is one reason that:

- 79% of persons with disability participating in this Assessment have Aboriginal ancestry.

Another reason for the large portion of Aboriginal persons with disability is due to a higher rate of disability among Aboriginal people.

- The *1991 Aboriginal Peoples Survey* reported that 27% of persons with Aboriginal ancestry in the NWT have disability, more than twice the rate of disability within the whole population.

*“(I am) very lonely.”*

(from Personal Questionnaire)

The NWT has eight official languages. Six of these are Aboriginal languages.

This Needs Assessment found that:

- 24% of persons with disability understand another language better than English.
- Dogrib and Slavey are the best understood Aboriginal languages.

### Marital Status and Dependents

Adults with disability are unlikely to be in a marital relationship. This Needs Assessment found that:

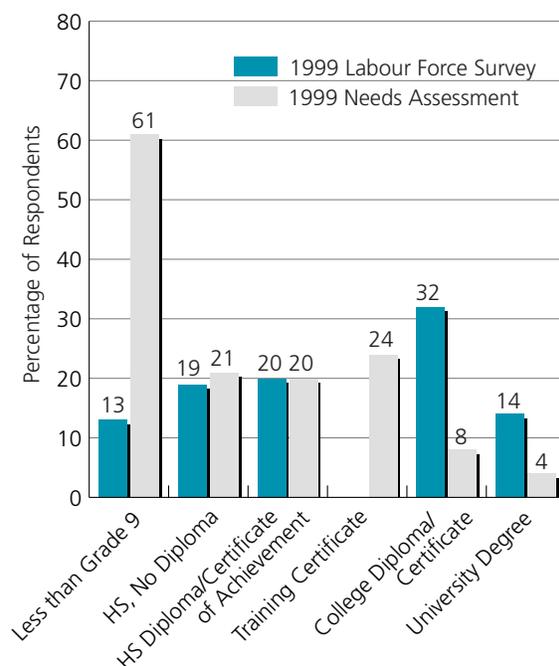
- 67% of persons with disability 15 or more years of age are single, divorced/separated or widowed.
- 44% have someone depending on them for food/shelter/clothing.
- 22% have three or more dependents.
- An equal proportion of males and females with disability have dependents.

### Education, Employment and Income

The 1999 NWT Labour Force Survey reported that 13% of the whole NWT population and 26% of the Aboriginal population 15 years of age and older have less than grade nine education. Less than grade nine education is used in the NWT to describe illiteracy. In this Assessment:

- 61% of persons with disability 15 or more years of age have less than grade nine education. (Figure 3)
- 44% of persons with disability 15-59 years of age have less than grade nine.
- persons 40 to 59 years of age have the highest level of education compared to other adults with disability.
- more than half (58%) of persons with disability 25-39 years of age and 60+ years (57%) have not achieved grade nine.

**Figure 3:** Formal Education of Adults with Disability Participating in the Needs Assessment 2000 Compared to the 1999 NWT Labour Force Survey



Note:

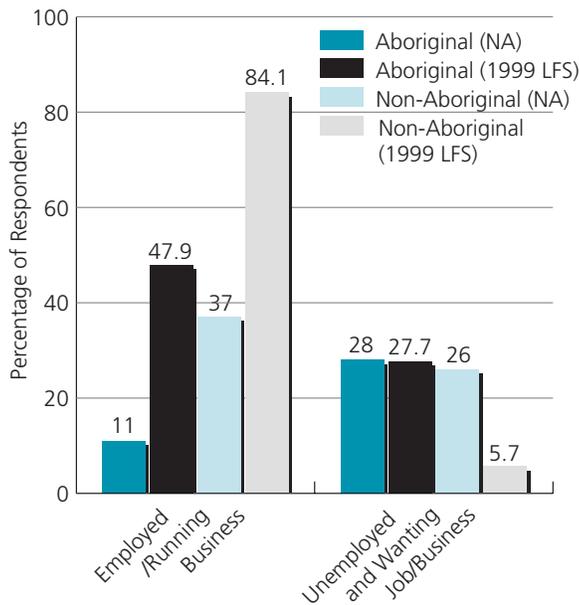
1. Percentages do not total 100% due to multiple responses (eg. less than grade nine and a training certificate).
2. Both the Needs Assessment and the GNWT's 1999 NWT Labour Force Survey consider adults as persons 15+ years of age.

In the NWT, unemployment among adults 15 or more years of age is 13.7% overall and 26.7% among Aboriginal adults. (1999 NWT Labour Force Survey) This Needs Assessment found that:

- 84% of persons 15 or more years of age and 75% of persons 15-64 years are not employed or running a business.
- even fewer persons with disability of Aboriginal ancestry are employed or running a business. (Figure 4)
- among persons with disability who are 15-64 years of age, 46% would like to be employed or running a business but can't due to disability, illness or age.

- disability seems to have a greater effect on the employment activities of non-Aboriginal people than on persons of Aboriginal ancestry. (Figure 4)

**Figure 4:** Employment Activity among Adults with Disability by Ethnicity, NWT Needs Assessment 2000 Compared to the 1999 NWT Labour Force Survey



Note:  
LFS = Labour Force Survey, NA = Needs Assessment

Sources:  
1999 NWT Labour Force Survey and Needs Assessment of Persons with Disability, 2000

The NWT does not have an established “poverty line”, but elsewhere in Canada poverty is having income of less than \$20,000 each year. Among adult persons with disability participating in this Needs Assessment:

- 80% have personal incomes of less than \$20,000/year.
- 48% have personal incomes of less than \$10,000/year.

- 44% live in households with less than \$20,000/year in total income.
- 4% have personal incomes of \$30,000-40,000/year, a range that is similar to the average NWT personal income of \$33,712. (Bureau of Statistics)
- 16% have personal incomes of more than \$40,000/year.

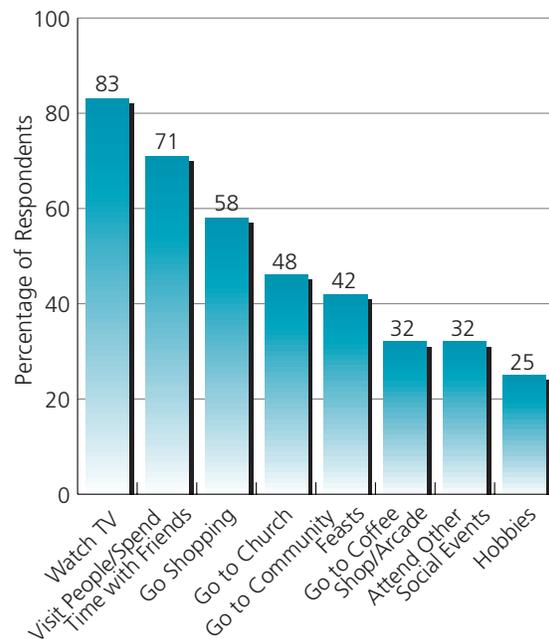
## Work, Home, School, Social, Recreation and Leisure Activities

Of the 807 persons with disability participating in this Assessment:

- 68% described their work, home, and/or school activities.
- 88% described social, recreation and leisure activities.

People who did not describe these activities may not be engaged in these daily activities.

**Figure 5:** Daily Social, Recreation and Leisure Activities of Persons with Disability by Percent, NWT Needs Assessment 2000



Note:  
N (Number of Respondents) = 710

This Assessment found that:

- adults and elderly persons with disability are mainly engaged in work in the home including sewing or harvesting/land-based activities.
- 96% of children of school age go to school full or part-time or attend a supervised day program.

Recreation, fitness, sports and active living add to life expectancy, physical and mental health, and overall well-being and quality of life. Only two-fifths (40%) of adults in the NWT are considered to be active enough for optimal public health benefits. (GNWT Municipal and Community Affairs, 2000) This Assessment found that the main social, recreation and leisure activities of persons with disability in the NWT are:

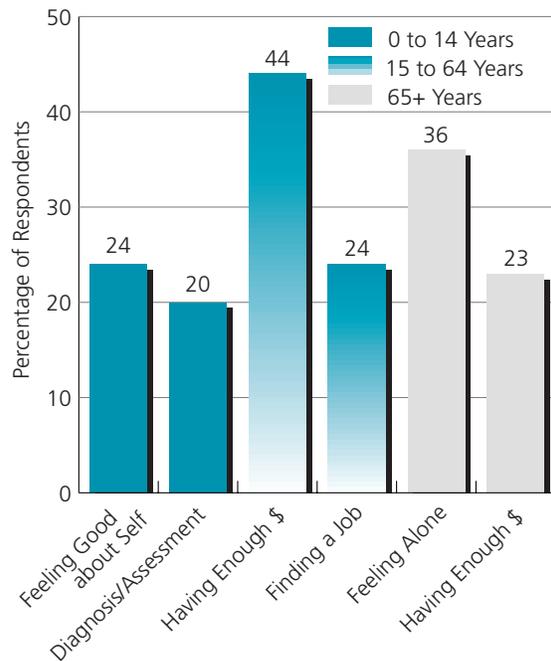
- watching TV (83%); and
  - visiting or spending time with people (71%).
- (Figure 5)

In the NWT, persons with disability may not enjoy the same quality of life as other members of society. Lack of money, loneliness, and poor self-esteem are the main problems affecting the quality of life. (Figures 6 and 7)

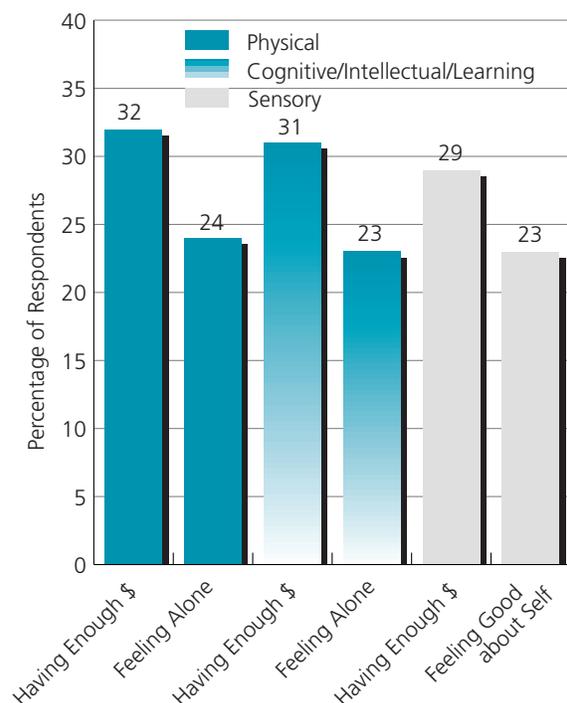
*“(I am) unable to attend special cultural gatherings. (I) would like assistance to attend youth conferences, treaty gatherings, etc.”*

(from Personal Questionnaire)

**Figure 6:** Main Problems Faced in Daily Living by Age, NWT Needs Assessment 2000



**Figure 7:** Main Problems Faced in Daily Living by Type of Disability, NWT Needs Assessment 2000



## 5. Aids and Supports



Aids/equipment (or assistive devices) and supports (including classroom aides) may help persons with disability to overcome limitations in daily living activities, live independently and live with dignity. The use and need for special aids or supports may be affected by:

- understanding of the disability.
- living and lifestyle activities and circumstances.
- awareness of or access to aids or supports.
- attitudes toward disability.

This Needs Assessment heard mainly from adults with known moderate to severe disability who do not work outside the home. This Assessment found that persons with:

- physical and visual disability use special aids and supports more than persons with other types of disability. (Figure 8)
- cognitive disability are least likely to use special aids or supports.
- physical or sensory disability use the most extensive range of special aids or supports.

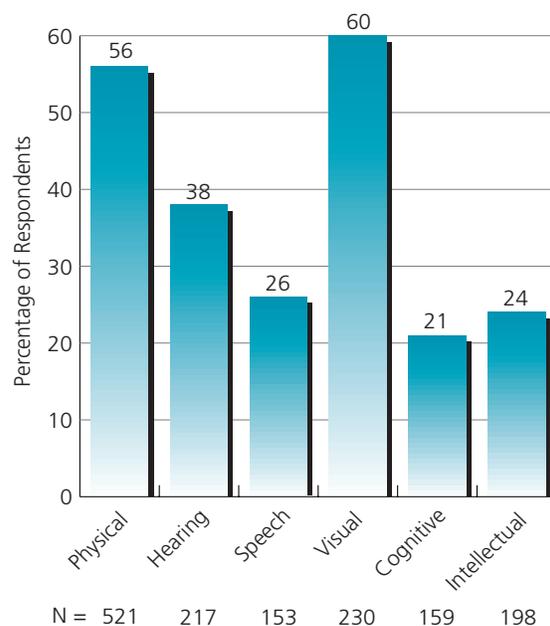
Some persons with disability may use a special aid or support but also need the same aid/support. For example, some people using a hearing aid now also need a hearing aid.

Malfunctioning or inappropriate aids/supports may be the reason that people say they need

aids/support that they already have. This Assessment found that persons with:

- speech disability have a great need for special computer equipment and software. (Figure 9)
- visual disability have a particular need for large print materials.
- intellectual disability mainly need equipment to help learning.

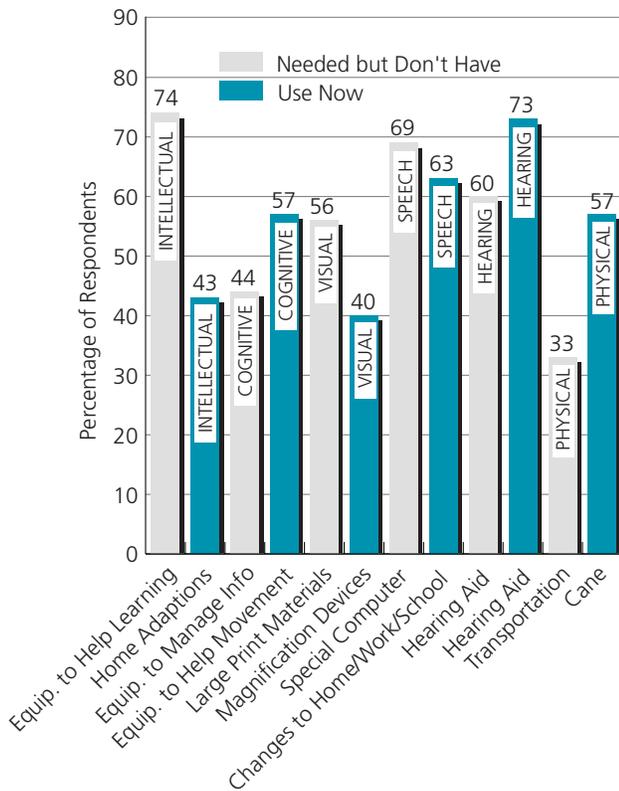
Figure 8: Use of Special Aids/Equipment/Supports by Type of Disability, NWT Needs Assessment 2000



Note:

1. Data were not collected from persons with learning disabilities.
2. N = Number of Respondents

**Figure 9: Main Special Aids/Equipment/ Supports Used and Needed by Type of Disability, NWT Needs Assessment 2000**



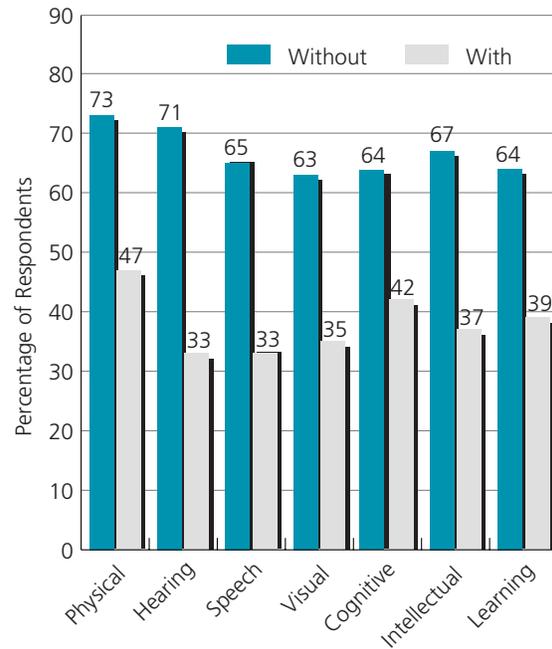
Note:  
Special aids/equipment/supports for learning disabilities were not investigated.

Actions taken to care for ourselves and participate with others are typically understood as the usual activities of daily living. Persons with disability in the NWT have fewer difficulties in the activities of daily living with the use of special equipment/aids/supports. (Figure 10)

*“(She was) offered a hearing aid but they wanted her to pay over \$400, couldn’t afford to pay for it and was having difficulty using – it kept falling out/off and her hands are too stiff to put it back in.”*

(from Parent/Caregiver Questionnaire)

**Figure 10: Difficulties Encountered With and Without the Use of Special Equipment/Aids/ Supports by Frequency, NWT Needs Assessment 2000**



Both with and without special aids and supports, persons with disability in the NWT are limited in their participation with others and in their ability to care for themselves. This Needs Assessment found that:

- physical disability creates difficulties lifting, carrying, moving, standing and walking.
- visual disability creates reading difficulties.
- hearing disability excludes persons from verbal communications and limits understanding.
- persons with cognitive, intellectual or learning disabilities are limited in their understanding and participation in the home, work, school and community environments, and have difficulty caring for themselves.

## 6. Use and Need for Programs and Services



The need and use of programs and services depends on the severity of disability and the awareness and availability of supports/assistance. This Needs Assessment found that:

- the current demand for programs/services by persons with disability exceeds the availability and/or the capacity of existing programs/services.
- there are nearly as many people with disability who still need services as there are people receiving them now.
- programs/services in greatest demand are rehabilitation, assessment, specialized/individualized intervention, alternative treatment, financial assistance and advocacy/information.
- programs/services unable to meet the demand today will not be able to cope with expected increases in demand in the future.

The main programs and services used and needed now (but not received now) by persons with disability in the NWT are shown in Table 3.

### Medical Health Services

Chronic pain or discomfort are faced daily by many persons with disability. Medical health services are available in some form in every NWT community. They are the most widely used of all services among persons with disability in the NWT.

- General medical care/treatment and testing/diagnostic/assessment services have the greatest use.
- These programs/services together with Occupational and Physical Therapy and home/personal care services, will be needed the most in the future.

Community service providers say that there are not enough staff to serve persons affected by disability who need or want occupational therapy or physiotherapy, speech/language pathology/development, and alternative therapy/treatment.

### Social and Mental Health Supports

Low self-esteem, loneliness and lack of support are among the problems which cause persons with disability to seek social and mental health supports. Most NWT communities offer these supports through a government agency(ies), First Nation or a community organization.

- Personal supports such as local support groups, are used the most now by persons with disability.
- Special aids, equipment and tools are the greatest unmet needs among persons with disability. Workshops and resource materials are examples of special aids/tools needed.
- The current need for addictions counselling/treatment services and alternative therapy exceeds present use.

**Table 3:** The Number of NWT Persons with Moderate to Severe Disability Using Services Now, Needing Services and Not Getting Them Now by Main Type of Program/Service, 2000 and Expected Demand in 2004 and 2009

Program/Service	Use Now	Needed Now and Not Getting	Total 2000 Demand N=1,780	Total 2004 Demand N=1,982	Total 2009 Demand N=2,276
<b>Medical Health Services</b>					
General Medical	1,194	141	1,335	1,487	1,707
Testing	1,026	198	1,224	1,368	1,570
<b>Social and Mental Health</b>					
Personal supports	531	249	780	872	1,001
Special aids	393	303	696	773	888
<b>Accommodation/Housing</b>					
Subsidy/Money	330	252	582	654	751
<b>Income</b>					
Income support	501	219	720	793	910
<b>Life Skills, Employment and Residential</b>					
Personal/Family Support	189	159	348	396	455
In-Home Support	156	159	315	357	410
<b>Education and Training for Adults</b>					
Academic Upgrading	126	199	324	357	410
Job Training	114	168	282	317	364
<b>Other Programs/Services</b>					
Transportation	324	324	648	714	819
Advocacy to get Services	216	255	417	515	592

Note:

1. N = Number of Respondents
2. This Needs Assessment involved one-third of the estimated 1,780 persons with moderate to severe disability in the NWT. The demand for 2000 is three times the amount that was identified in the Needs Assessment. The demand for programs/services in 2004 and 2009 assumes the same ratio of demand as in 2000.

Community service providers see the current demand for psychological or psychiatric help and alternative therapy/treatment as much greater than the capacity of staff to deliver these services.

### **Accommodation/Housing Services**

Accommodation/housing services are available in every community in the NWT, mainly through local housing organizations or municipal/First Nation governments.

- Housing subsidies are used and needed now among persons with disabilities.
- The need for help fixing or adapting the home is more than double the current use of these services.

### **Income**

Persons with moderate to severe disability have personal/household incomes that are below the national poverty line.

- The main problem persons with disability face is not having enough money.
- Next to medical and social/mental health services, income support is in the greatest demand by persons with disability.
- Persons with disability also need financial assistance and advice

*“I have to fly out of town to get services.”*

(from Personal Questionnaire)

### **Life Skills, Employment and Residential Supports**

Opportunities to secure a job and have enough money to live independently and with dignity are limited, particularly when:

- 61% of adults with moderate to severe disability have less than grade nine education.
- 84% are unemployed.
- aids and supports are needed to participate in daily living activities at home, work, school and in the community.

Compared to medical and social services, few persons with disability use life skills, employment and/or residential supports. Unavailability of these services in smaller NWT communities may be the reason for this. Overall, the need for these services is as great as or greater than current use.

Community service providers say that there are not enough staff to meet the current demand for paid residential support.

### **Education and Training for Adults**

Aurora College Community Learning Centres operate in 11 NWT communities. Few other organizations in the NWT offer adult literacy and basic education programs.

- Education/academic upgrading and job training are in demand by persons with disability.
- The need now for education/academic upgrading is greater than current use (126 people compared to 198).

Community service providers say that adult-focused education and training programs and services are severely understaffed to meet the demand.

## Education and Training for Children

This Needs Assessment provides limited information on children with disability. An assessment of student needs in NWT classrooms undertaken by the GNWT Department of Education, Culture and Employment will provide more comprehensive information on program and services needs among this segment of the population.

## Legal and Protection Services

The GNWT identifies brain-related disabilities (eg. cognitive, intellectual and learning) as one of the reasons that children/youth come into care or into the legal system. Mediation, negotiation and advocacy are the main legal services used and needed by persons with disability. Emergency care and shelter are the main protection services needed. In this Assessment, protection and legal services were the categories of services with the lowest use and unmet need.

## Information, Advocacy and Other Programs and Services

A variety of other programs and services for persons with disability are available in some NWT communities.

- Guardian/trusteeship or supported decision-making, transportation services, and general information/referral/support services have the greatest use now among persons with disability.

- The greatest unmet need is for transportation, advocacy and disability awareness/education services.

Community service providers believe that information, advocacy, transportation, communications and respite programs/service that may be available in some communities, are not staffed adequately to meet the demand for these services.

Almost two-thirds of persons with disability (62%) believe that programs and services do not meet their needs. There are four main reasons for this:

1. General lack of understanding, support and recognition of disabilities.
2. Lack of awareness and sensitivity toward Aboriginal languages/customs.
3. Lack of access to service in the (home) community.
4. Lack of care and attention by community and service providers.

*“Not being able to participate in a group discussion or conversation, because not able to hear everyone else’s comments, leaves a person feeling left out and makes you wonder if people question your intelligence. Tend to avoid groups or gatherings of more than a couple of people.”*

(from Personal Questionnaire)

*“We need more programs and service  
HERE.”*

(from Personal Questionnaire)

## 7. Caregivers



This Needs Assessment heard from parents and other caregivers who are not paid to care for persons with disability.

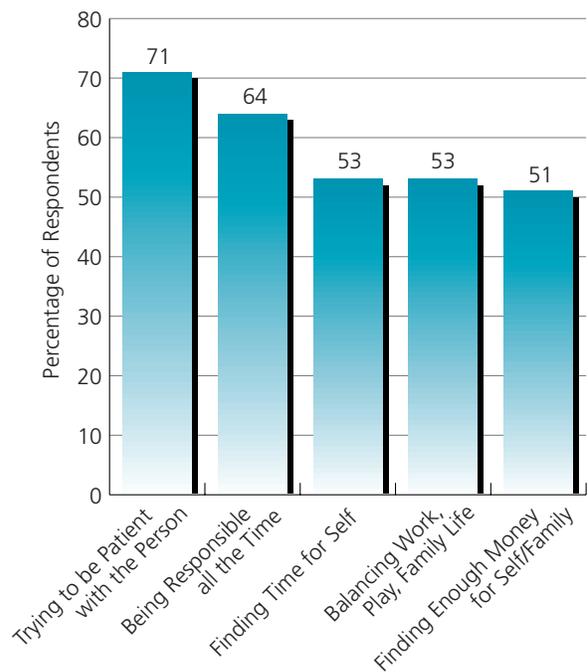
- 87% care for persons with moderate to severe disability.
- 57% care for a male child or adult (younger than 65 years of age).
- 71% care for people whose disability has been assessed, diagnosed or named by a professional.
- Caregivers say that physical disability is most likely to have been diagnosed/named while cognitive disability is least likely to be known.
- 37% care for persons with multiple disabilities.
- 49% provide 24-hour care/supervision.

Parents/caregivers were asked to describe the main behaviours/characteristics of the disability of the person they care for. Most often they identified difficulty with and/or loss of:

- ability to move quickly or easily.
- strength or ability to hold/lift things.
- understanding words/verbal comprehension, remembering, learning new things.
- controlling emotions (eg. anger, fear).
- focussing or paying attention.
- writing, spelling and reading.

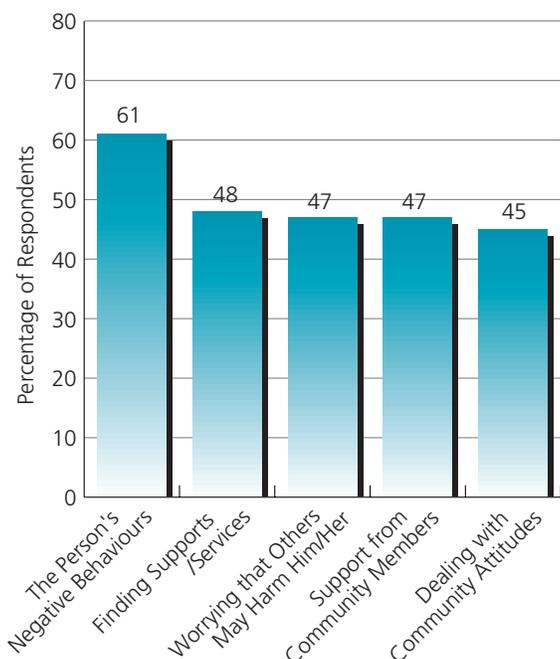
Parents/caregivers face tremendous challenges. The main personal challenges are being patient and responsible all of the time. (Figure 11) Dealing with negative behaviours is the main challenge to providing care and support. (Figure 12) Respite, caregiver training and support services would help caregivers to cope with these challenges.

**Figure 11:** Personal Challenges Faced by Parents/Caregivers, NWT Needs Assessment 2000



Note:  
N (Number of Respondents) = 217

**Figure 12: Other Challenges Faced by Parents/ Caregivers, NWT Needs Assessment 2000**



Note:  
N (Number of Respondents) = 195

Giving and receiving love from the person they care for are among the greatest rewards for parents/caregivers of persons with disability. (Figure 13)

Parents/caregivers of persons with disability use a variety of programs/services to help them to give care. Special equipment/supports and transportation to get to appointments are two of the services most frequently used. (Figure 14)

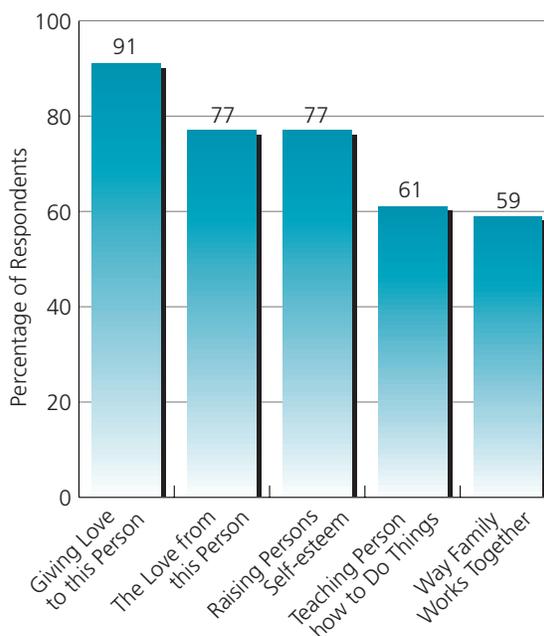
*“My child faces problems at school – fighting with peers at school, teasing and bothering her.”*

(from Personal Questionnaire)

To help them to give care, parents/caregivers of persons with disability identify a range of unmet needs.

- They need information, understanding, support and financial resources the most. (Figure 15)
- These needs may be met through respite, counselling, advocacy and caregiver benefit programs.

**Figure 13: “Good” Things about Caring for Persons with Disability by Percent of Parents/ Caregivers, NWT Needs Assessment 2000**

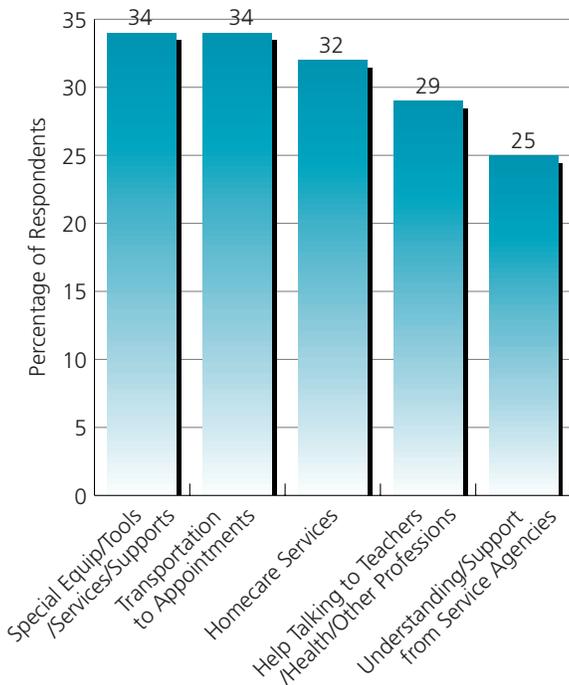


Note:  
N (Number of Respondents) = 218

*“No one asks me what I need.”*

(from Personal Questionnaire)

**Figure 14:** Programs and Services Used by Parents/Caregivers of Persons with Disability, NWT Needs Assessment 2000

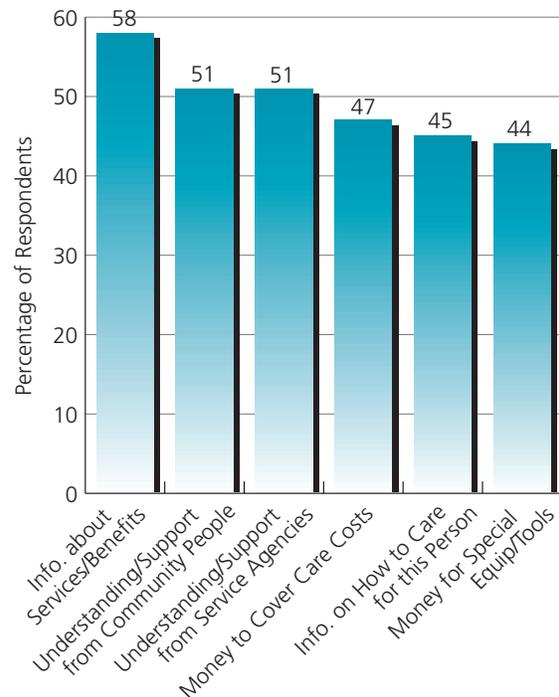


Note:  
N (Number of Respondents) = 158

*“I want to have dry meat, see moose and go fishing but can’t.”*

(from Personal Questionnaire)

**Figure 15:** Programs and Services Needed by Parents/Caregivers of Persons with Disability Participating in the Needs Assessment, 2000



Note:  
N (Number of Respondents) = 185

*“(There is) no funding what-so-ever to raise a learning disabled child!”*

(from Personal Questionnaire)

## 8. Programs and Services – Best Practices



Community service providers listed the challenges they face in delivering programs/ services to meet the needs of persons affected by disability as:

- access to qualified staff.
- appropriate materials.
- adequate financial resources.
- limited awareness/support for disability in the community.

Other barriers are high staff turnover, poor understanding of disabilities, and poor collaboration and information sharing among service providers. These same circumstances also created difficulties completing this Needs Assessment.

People in the NWT with disabilities describe five main ingredients of the programs/services which meet their needs as:

1. giving a sense of peace and security about/ within their environment.
2. support to participate in community events, particularly cultural activities.
3. access to country foods and help with such activities as sewing, drying meat and getting ice.
4. receiving services in one's own community.
5. receiving services in Aboriginal languages.

This Assessment identified appropriate programs/services for persons affected by disability as those focussing on:

1. Collaboration to advocate for persons and parent/caregivers affected by disability.
2. Outreach to persons affected by disability to provide relief from isolation and loneliness.
3. Physical and intellectual stimulation for persons with disability to enhance capacity to participate in and contribute to the community.
4. Early intervention to detect and develop skills/techniques to cope with disability.
5. Rehabilitation services and tools to help manage daily living activities.
6. Respite and supports for caregivers.
7. Transportation services and adaptations to facilitate access in the community.

***“(I) would appreciate more traditional food and more people who could speak in my language.”***

*(from Personal Questionnaire)*

## 9. Taking Action



Many of the people affected by disability participating in this Needs Assessment doubt the will of government, other organizations, communities, families and individuals to address disability issues. Taking action from this Needs Assessment will demonstrate this will. It is recommended that:

1. The partners sponsoring this Needs Assessment of Persons with Disabilities in the NWT, use the findings to plan appropriate programs and services for people in the NWT affected by disability.
2. The partnership established for this Needs Assessment continue in order to ensure that appropriate programs and services for people in the NWT affected by disability are implemented.
3. The partnership established for this Needs Assessment communicate the findings and intended actions to the general public.
4. Responsibility for disability issues within the Government of the NWT be clearly identified and communicated to the public.
5. Those factors limiting collaboration in this Needs Assessment be addressed by the partners both in the example that they set and the message they send to service providers and organizations delivering programs/services/supports to persons affected by disability.
6. The partners begin discussions with the GNWT Department of Education, Culture and Employment to identify complementary approaches to addressing the needs of children/youth with disability and their parents/caregivers, as identified in this Needs Assessment and the Department's Student Needs Survey.
7. Lessons learned from this Assessment be applied to Phase 2 research into psychiatric disabilities.

*“I don't know what my personal income is or how that is defined in a subsistence lifestyle.”*

(from Personal Questionnaire)

A partnership of:



N.W.T. COUNCIL FOR DISABLED PERSONS



MaryAnne Duchesne