

Living with Disability.....Living with Dignity

**Needs Assessment of Persons with
Disabilities in the NWT -
Findings Report**

Final Report

**Research conducted by Lois Little, Sandy Auchterlonie and
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on behalf of the partnership of:**

- **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**
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Needs Assessment of Persons with Disabilities in the NWT - Findings

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EXECUTIVE SUMMARY

A disability is any degree of physical, sensory, psychiatric, cognitive, intellectual or learning limitation which causes difficulty in the usual activities of daily living. Approximately 13% of the NWT population have a disability. Based on 1999 population estimates, this means that there are 5,453 people with disability in the NWT.

This Needs Assessment of Persons with Disabilities in the NWT was undertaken 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 Assessment was undertaken by a unique, multi-sector partnership involving two levels of government, territorial and community-based non-government organizations, a self-advocate and a First Nation organization. The voices of almost 1260 NWT people are reflected in this Assessment and 807 of these are people with disability. Parents/caregivers (227), community service providers (181) and regional program managers (44) are the other voices heard in this Assessment.

This Needs Assessment collected sufficient information to make statements about the whole NWT population with moderate to severe disability. The number of persons with moderate to severe disability not living in institutions in the NWT is 1,779. The remaining 3,674 NWT persons with disability have a mild degree of disability. This Needs Assessment did not hear from persons with mild disability, perhaps because they do not acknowledge disability or do not need help in daily living activities. The Needs Assessment also did not hear from many children (0-14 years) with disability and therefore adds little to the poor state of knowledge about NWT children with disability.

This Needs Assessment provides information on five disabilities - physical, sensory, cognitive, intellectual and learning - as well as some information on psychiatric disability.

People with Disability in the NWT

Males and females are equally as likely to have disability. People of Aboriginal

ancestry in the NWT have a rate of disability that is twice that of the population as a whole. The prevalence but not necessarily the severity of disability increases with age.

Over three-quarters of NWT persons with moderate to severe disability understand English the best. Those who understand another language better than English are likely to be Dogrib or Slavey speakers.

Most persons with moderate to severe disability live in a family environment. Compared to other persons with disability, elderly people with disability are most likely to live alone and to feel alone.

People with disability 15 or more years of age are unlikely to be in a marital relationship but 44% have dependents. This same age group has low literacy levels (61% have less than grade 9 education). Among the small number of persons with disability with grade 12 or more education, the employment rate is 10 times that of persons with less than grade 9. Only one-quarter of persons with disability 15-59 years of age and 16% of all persons with disability 15 or more years of age, are employed or run a business. Low education and poor employment circumstances are the main reasons that 80% of working age and elderly persons with disability have personal incomes of less than \$20,000/yr. Almost half (48%) earn less than \$10,000/yr. Over half of persons with disability 15 or more years of age use, need or will need income support. Insufficient financial resources is the most pressing problem faced by adults with disability.

Type, Severity and Assessment of Disability

The main reasons for disability in the NWT are illness/disease, age or conditions before or at birth.

Sixty percent (60%) of persons with moderate to severe disability in the NWT have multiple disabilities. Within the NWT population with moderate to severe disability:

- 65% 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 psychiatric disability.

NWT front-line workers say that the number of persons with brain-related disability may be conservative given significant and sustained levels of high risk behaviours such as alcohol abuse. These workers also see high risk behaviours as contributing to expected increases in disability in the coming decade.

In this Needs Assessment, the small number of NWT children (0-14) who participated, mainly have learning, intellectual or speech disability. Adults of all ages are more likely to have physical disability than any other disability. The disability of 92% of persons participating in this Needs Assessment has been diagnosed/assessed/named by a professional. About 85% of persons with disability expect that their disability will get worse or they are uncertain about the future condition of their disability.

Living with Disability

Over half of persons with disability (57%) use special aids/equipment/ support in daily living. By using special equipment/aids/supports persons with disability have fewer difficulties in daily living. Without special aids/supports, persons with disability have difficulty participating in their communities, caring for themselves, and living independently and with dignity. Aids/supports are more likely to be used by persons with physical and visual disability than persons with cognitive disability. Awareness or availability of aids/supports are issues for persons with lesser known or brain-related disabilities.

The low level of participation of adults with disability in the work place, in training or education, and in social activities is evident throughout the Needs Assessment. The main social/leisure activity of persons with disability (83%) is watching TV. Less than 13% participate in physical fitness, sport or exercise.

The challenges associated with living with disability are influenced by age. Children with disability have problems feeling good about themselves. Persons 15-64 years of age with disability have problems getting enough money and elderly persons are lonely. Lack of adequate financial resources is the most

significant problem facing persons with disability in the NWT. Parents/caregivers of persons with disability also struggle with this problem. They also encounter tremendous difficulty getting professional or community support to fulfill their role as caregivers.

Programs and Services

The NWT population with moderate to severe disability will continue to grow. An aging population and continued high risk behaviours are the main factors expected to contribute to anticipated increases in the population with disability. Within the context of a growing population with moderate to severe disability,

- the current demand for programs and services exceeds the availability and capacity of existing programs/services.
- nearly as many people still need services as are receiving them now.
- rehabilitation, assessment, individualized intervention, alternative treatment, financial assistance and information programs are needed the most.
- parents/caregivers receive very little assistance/support to give care.
- programs/services unable to meet current demand will be ill-equipped to respond to a growing population with disability.

Delivering appropriate programs/services to persons affected by disability is made difficult by high staff turn over, large caseloads, poor understanding of disability and lack of opportunities to work with other service providers. There are several examples of programs/services in the NWT which meet the needs, including the cultural needs of persons affected by disability. These programs/services are generally not available to persons with disability living in small communities.

It is recommended that the Needs Assessment partners use the research findings to plan appropriate programs and services for persons affected by disability in the NWT.

1. An Introduction to the Needs Assessment of Persons with Disabilities

1.1 Overview

Disability is described by the World Health Organization (WHO) as the “*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 was 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.¹ Persons with disability may experience various degrees of limitation ranging from mild to moderate to severe. Difficulties in usual activities of daily living (eg. taking care of oneself, participating with family, in work/school and in community/social events) may result from limitations caused by more than one disability, for example a physical disability and a learning disability.

The Needs Assessment of Persons with Disabilities determines the nature and distribution of disabilities within the NWT population, and the gaps in services and future service needs of persons affected by disabilities. This Needs Assessment was the first research of its kind 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; and
- be sponsored by a multi-sector partnership with a common interest in

¹Definitions for each of the five types of disability under investigation in this Needs Assessment are provided in Appendix C. A definition was not developed for psychiatric disability.

disability, and coordinated by a non-government organization.

This Assessment involved two levels of government, a First Nation organization, territorial and community-based non-government groups, and a self-advocate. The partners functioned as the Disabilities Needs Assessment Project Working Group. The NWT Council for Disabled Persons coordinated the Assessment on behalf of the partners and was the chair of the Working Group. The partners were active in all aspects of this Assessment and worked closely with the research team from Lutra Associates Ltd.

Information collected in the Needs Assessment is presented in this report and a popular summary entitled **Living with Disability.....Living with Dignity Needs Assessment of Persons with Disabilities in the NWT - Summary Report**. The presentation of information is in keeping with the manner in which it was collected. To maintain confidentiality, information has not been presented where small numbers of people participated or the potential exists for individuals to be identified.

1.2 Objectives and Parameters

The purpose of the Needs Assessment of Persons with Disabilities in the NWT is to provide information for planning appropriate programs and services for persons affected by disability. The Assessment was designed to determine: (Appendix A: Terms of Reference)

- 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.

Early in the research design phase, the Needs Assessment partners broadened the scope of the research to include cognitive (including Alzheimers and late stage alcoholism) and learning disabilities. The broader scope was an effort to recognize an aging NWT population and a perceived high rate of learning disability among persons of school age. It was decided that a separate assessment would examine the extent of psychiatric disabilities and the program/service needs of this population. Psychiatric disabilities were included in cases where this disability accompanied one or more of the other disabilities under investigation. Each disability was defined to ensure consistency of data and enable comparisons with other research. Both diagnosed and undiagnosed disabilities acknowledged by persons with disability or his/her caregiver were included.

The partners determined that the Needs Assessment would include NWT residents of all ages; collect key demographic data; identify the current place of residence of persons with disabilities; and focus on the characteristics/manifestations of disability rather than diagnostic names or labels. The Assessment would not have any individual identifiers or include persons with disabilities living outside the NWT.

1.3 Needs Assessment Methodology

The Needs Assessment began in January 1999 and was completed in June 2000. As shown in the chronology in Appendix B, the Assessment was undertaken in three phases:

1. Planning and Design (January 1999-August 1999)
2. Field Work (August 1999-March 2000)

3. Data Compilation and Reporting (December 1999-June 2000)

During the three phases, the Disabilities Needs Assessment Project Working Group had 16 meetings. These meetings together with other intergroup communication, enabled the partners and Lutra's research team to collaborate on:

- defining each of the five types of disability under investigation.
- the design, testing (in Yellowknife and Rae-Edzo) and revamping of questionnaires.
- promoting and encouraging participation in the Needs Assessment.
- responses to various concerns, for example limited capacity of front-line workers to participate and inadequate resources for the Assessment.

Good communications among the partners was essential to managing the many challenges associated with building an unique partnership within the context of a difficult and sensitive research study.

Consistent with the basic premise of social programs in the NWT, a collaborative approach was adopted for the Needs Assessment. The approach and methodology for the Assessment were influenced by five factors:

1. a target population largely unknown to the general public;
2. a lack of baseline or similar studies on disabilities in the NWT;
3. the interests and mandates of the partners;
4. a short time frame;² and
5. limited resources.

Collaboration among, and active participation of front-line workers were central to effectively dealing with these factors. To this end, the Assessment relied

²Initially, a three-month time frame was envisioned for the Needs Assessment.

heavily on front-line human service workers in NWT communities to identify, engage and assist persons affected by disability to participate. It was assumed that:

1. front-line workers would most likely be aware of persons affected by disability; able to differentiate activities associated with disability from those related to poor socio-economic circumstances; facilitate disclosure of disability; and provide ongoing support to persons affected by disability.
2. front-line collaboration would improve community participation in the research, increase ownership and recognition of disability issues, and maximize resource efficiencies.

Multiple research instruments were developed for the Needs Assessment.

(Appendix C) Each had a distinct target:

1. a preliminary scoping interview guide to focus discussions with program managers about regional programs/services for, and clients affected by disability. Lutra's research team conducted 44 interviews with program managers in Inuvik, Norman Wells, Fort Simpson, Hay River, Fort Smith and Yellowknife.
2. a self-administered Community Service Provider Questionnaire to enumerate direct client services, and current and future service uses and needs. This questionnaire was provided to over 300 human service agencies in NWT communities.
3. a self-administered Personal Questionnaire to collect information on persons with disability and their perspectives on living with disability. This questionnaire was mainly distributed to persons with disability known to community service providers. Some Personal Questionnaires were mailed directly to persons known to have a disability by the Workers

Compensation Board of the NWT, the NWT Income Support Program in Yellowknife and the NWT Council for Disabled Persons.

4. a self-administered Parent/Caregiver Questionnaire to collect information on the needs of unpaid caregivers. This questionnaire was mainly distributed to caregivers by community service providers and local researchers.
5. a focus group discussion guide to refine and confirm the data collected. This guide was developed as a companion to community reports on disability in Yellowknife and Fort Smith.

Many front-line workers had difficulty dedicating time and priority to the Assessment due to heavy work loads and vacant positions. In addition, persons affected by disability required considerable assistance to complete the questionnaires. This was mainly due to low literacy levels and discomfort or unfamiliarity with the concept or language of disability. Additional resources brought into the Assessment mid-way through the field work enabled the hiring of skilled and trusted local researchers to work with front-line community service providers. Researchers assisted persons with disability and parents/unpaid caregivers to complete questionnaires. Front-line workers and researchers involved in the Needs Assessment are listed in Appendix D.

Data from the three questionnaires were compiled in ACCESS data bases and data analyses were undertaken using SPSS software. Questionnaires were reviewed and entered on a community by community basis to enable the research team to discern data problems and trends. For example, in communities such as Rae-Edzo and Holman where a language other than English dominates, there was some confusion in the interpretation of cognitive, learning and intellectual disabilities which required verification. In other communities, genetic conditions might contribute to higher rates of sensory or

physical disability. The reasons for high rates of a particular type of disability were discussed with community service providers and/or local researchers in some communities.

To assist in data analysis, focus groups were conducted in Yellowknife and Fort Smith. A full day workshop was also held in Yellowknife to review the draft findings report, make recommendations for changes, and plan for follow-up. The workshop was attended by the Needs Assessment partners, representatives from non-profit organizations, CEOs from regional health and social services boards, and persons interested in disability.

1.4 Participation

In total, the voices of 1259 NWT people affected by disabilities are presented in this Needs Assessment of Persons with Disabilities. (Table 1)

- 44 regional programs managers participated in scoping interviews.
- 807 people with disabilities completed Personal Questionnaires.
- 227 people completed Parent/Caregiver Questionnaires.
- 181 people completed Community Service Provider Questionnaires.

Table 1: Regional/Community Participation in the NWT Needs Assessment, 2000

Region and Community	Questionnaires Completed		
	Personal	Parent/Caregiver	Community Service Provider
Beaufort	64	18	18
-Paulatuk	3	1	5
-Holman	29	9	5
-Sachs	2	-	3
-Tuktoyaktuk	30	8	5

Region and Community	Questionnaires Completed		
	Personal	Parent/Caregiver	Community Service Provider
Delta	112	42	27
-Inuvik	38	15	13
-Aklavik	30	9	6
-McPherson	26	15	4
-Tsiigehtchic	18	3	4
Sahtu	33	13	30
-Norman Wells	4	-	7
-Good Hope	10	2	6
-Deline	4	3	7
-Tulita	12	5	6
-Colville	3	3	4
South Slave	154	28	18
-Hay River	58	7	4
-Enterprise	1	0	0
-Fort Smith	75	4	8
-Resolution	19	10	5
-Lutsel K'e	1	7	1
Dogrib Region	106	32	9
-Rae-Edzo	87	20	7
-Wha Ti	6	6	1
-Rae Lakes	12	6	1
-Snare Lake	1	0	0
Deh Cho	83	27	14
-Simpson	22	5	8
-Providence	31	7	2
-Kakisa	0	0	0
-Wrigley	8	6	0
-Liard	8	3	2
-Trout Lake	7	4	1
-Nahanni	0	0	0
-Jean Marie	2	1	1
-Hay River Reserve	5	1	0
-Yellowknife	241	62	64
-Dettah/Ndilo	11	5	1

Region and Community	Questionnaires Completed		
	Personal	Parent/Caregiver	Community Service Provider
Total	807*	227	181

*Three questionnaires were received from people living outside the NWT (Hinton, Iqaluit, Edmonton).

The opportunity to describe daily life with disability and express views on disability was greatly appreciated by participants. At the same time, a variety of barriers were identified as limiting participation. These barriers are the main reasons that the Needs Assessment did not achieve a census of persons with disability in the NWT. The questionnaires were intimidating, unappealing or difficult for some respondents. The participation of community service providers was negatively effected by: staff-turnover, heavy work loads and limited time availability; lack of knowledge about disability and/or poor client information; and a perception that the Assessment was irrelevant to their program/service or client base. Parents/ caregivers and persons with disabilities who declined to participate, may also have felt that the Assessment was too personal or emotional. Others were sceptical about the value of participating in another survey.

Perceived stigmas and lack of awareness or any previous discussion about disability created difficulties engaging persons with disabilities, parents/ caregivers and service providers in this Assessment. Front-line workers and local researchers reported that many individuals are unaccustomed to talking about disability, particularly disabilities which are not visible. In some communities, disability is not recognized or distinguished from social dysfunction while in others, disability is acknowledged but not openly discussed for the shame, fear, anger or despair such discussion may elicit. On an

individual level, disability is not a well understood concept. *“I never learned to talk about my disability to anyone. It was good to talk to somebody that understood.”* (from Personal Questionnaire) In some situations, individuals passively accept the limitations and difficulties of daily living with disability. Others live with the hope that the condition will go away. *“First time I thought of having a disability. (I was) hoping that (my) back problem can be cured.”* (from Personal Questionnaire) Some service providers wished to avoid discussion of disability in order not to create expectations for services for which there are no resources.

The quality and completeness of information collected in this Assessment was greatest among persons with disabilities. Information from the 807 Personal Questionnaires is the basis for this report. These data are supported by information collected in Parent/Caregiver and the Community Service Provider Questionnaires, anecdotal information gathered throughout the Assessment process and to a limited extent, by information drawn from other research.

1.5 Other Research on Disability in the NWT

In the last two decades, information on disabilities has increased mainly due to the 1986 and 1991 national Health and Activity Limitation Surveys (HALS). HALS is the most complete source of information on disability in the NWT. Less complete information on disabilities in the NWT was collected in the 1991 Aboriginal Peoples' Survey, the 1996 Canada Census, and the 1994 National Population Health Study. The GNWT, Health and Social Services, Aged, Disabled and Chronically Ill studies, NWT Housing Corporation Housing Needs Studies, and the most recent (1999) NWT Labour Force Survey also provide some information on disability. (see Appendix E - Bibliography)

Number of Persons with Disability

The 1991 HALS found that 12.6% of the population in NWT/Nunavut have a disability compared to 15.5% in Canada. This means that in 1999 an estimated 5,453 NWT residents have a disability. The 1996 Census also identified a lower rate of disability in the NWT than in Canada as a whole, 6.3% of the population compared to 10%. (Table 2) A greater proportion of elderly people in the Canadian population than in the NWT, is given as the main reason for lower rates of disability in the north.

Compared to the 1991 HALS, people with mild disabilities are not well identified through the Census. HALS uses a number of detailed questions which result in more persons with mild disabilities being identified.³ The 1991 HALS found that two-thirds of persons with disability in the NWT have a mild degree of disability. This means that in 1999 an estimated 3,674 NWT residents have a mild degree of disability.

Table 2: The NWT/Nunavut Population with Disability by Percent and Age, 1986, 1991 and 1996

Age Group	Canada						NWT/Nunavut		
	1986		1991		1996	1986	1991	1996*	
	Census	HALS	Census	HALS	Census	HALS	HALS	Census	
All	9.3	13.2	8.4	15.5	10	8.7	12.6	6.3	
0-14 years	2.3	5	2.6	7	3	5.5	7.5	2.8	
15-64 years	8.2	11	7.2	13	8.5	7.9	13.1	6.4	
65+ years	32.4	46	27.5	46	31.4	65.6	59.9	36.1	

*The 1996 Canada Census refers to the NWT only. Nunavut is not included.

Notes:

Disabilities included in HALS are mobility, agility, seeing, hearing, speaking and other (psychiatric, intellectual and learning).

The Canada Census considered long term physical and mental conditions, health problems and disabilities.

³Housing, Family and Social Statistics Division. no date. User Guide, Disability Data in the 1996 Census. Statistics Canada

The 1991 Aboriginal Peoples Survey (APS) investigated disability among NWT/Nunavut adults of Aboriginal ancestry and found that 26.7% (4,695 people) have a disability. More than three-quarters (77%) of Aboriginal adults with disability in NWT/Nunavut have a mild degree of disability. The APS found that disability increases with age. Among Aboriginal adults, the disability rate among persons:

- 15-34 years of age is 19%;
- 35-54 years of age is 31%; and
- 55+ years of age is 57%.

The 1994 National Population Health Survey estimates that 16% of the NWT population 12 or more years of age have a long term physical or mental condition or a health problem limiting activity. (Table 3) This compares to 20% in Canada as a whole. As shown in Table 3, the rate of disability among elderly persons is almost four times that of persons 45-64 years of age. This same survey also found that NWT people 65 or more years of age are almost twice as likely as Canadians of the same age to report long-term disability or activity limitation.⁴

Table 3: Percent of the NWT Population 12 Years of Age and Older Reporting a Disability by Age, 1994

Self-Reported Long-Term Activity Limitations	PERCENT OF NWT POPULATION				
	12 Years & Older	12 to 24 Years	25 to 44 Years	45 to 64 Years	65+ Years
	16%	13%	13%	19%	74%

⁴Health and Social Services. 1999. The NWT Health Status Report. Government of the NWT

Source: 1994 National Population Health Survey and the NWT Health Status Report, 1999
based on the question -“Because of a long-term physical or mental condition or a health
problem,

are you limited in the kind or amount of activity you can do?”

Note: Data for the 65+ age group should be used with caution given the small number of people
interviewed

A study into disability in Nunavut in 1998 drew from the 1991 Aboriginal People's Survey to report that 25.5% of the adult population in the new territory have a disability.⁵ The study also collected additional information from 112 Nunavut residents with disability. The small number of people surveyed did not provide any new information on disability in Nunavut.

The Territorial Hospital Insurance Act provides the framework for data collection by those agencies delivering mandated services under the act. Data are coded (known as ICD-9 or 10 codes) in accordance with guidelines. Data collected relate to the presenting problem at the time of a visit/admittance to a health facility. Data are not linked to disability or overall health condition of individuals.⁶

Other information has been collected on disability in the NWT through surveys and assessments conducted in specific regions/communities. In 1999, the NWT Labour Force Survey found that 6% of the NWT population 15 or more years of age were unable to work due to age or long-term disability. The majority of persons unable to work for these reasons are 65 or more years of age and 2.5% are 15-64 years of age.

⁵Adele Furrie Consulting Inc. June 1998. Disability in Nunavut A Demographic Profile. Nunavut Implementation Commission

⁶The Stanton Regional Hospital Rehabilitation Team has identified a need for better client data. They are optimistic that new technologies will encourage greater consistency in client data collection and allow for the integration of inpatient and outpatient data to provide more complete client information. Currently, in and outpatient data are maintained separately.

Research on disability among children is limited in Canada and in the NWT. In 1993, GNWT Education, Culture and Employment examined the needs of school age children and found that almost one-third of NWT/Nunavut students have special needs that are not met by the regular school program. An estimated 6% of students had an individualized education plan (IEP) but 13% required this assistance. It is unknown whether the IEP was linked to disability. The research also reported that less than 1% of students were receiving and/or required signing assistance, mobility support or physical therapy. Unpublished information available through District Education Council's in the NWT suggest that more than 40% of students have special needs and learning and speech/language disabilities may be present in more than 10% of the NWT student population.⁷ The Learning Disabilities Association of Canada estimates that 10%-15% of Canadians may have a learning disability. The Association admits that this disability is not widely understood either by professionals (including educators) or by those having learning difficulties.

At various times in the 1980s and 1990s, GNWT Health and Social Services (H&SS) conducted aged, disabled and chronically ill assessments to identify the level of care required by these populations. The early assessments did not always include children or "hidden" disabilities such as intellectual, learning or cognitive disability. In 1990, GNWT H&SS identified 296 persons in the NWT with disabilities.

Various other research into disability in the NWT has identified:

- an aging NWT population, an incidence of disability that increases with age, and a need for up to 130 more acute care beds and at least 50 more

⁷Personal communication: Doug Blakey, Sahtu District Education Council

independent housing units to accommodate NWT seniors by the year 2006. In the same study, service providers suggested that persons who have cognitive disabilities (including those who are not seniors) represent a major challenge for providers of northern housing and social services. People with cognitive disability are expected to place added pressures on the service system in the NWT.⁸

- over 5% of the households in Rae-Edzo are likely directly affected by intellectual disability.⁹
- learning problems and fetal development impacted by alcohol among portions of the school age population in Inuvik.¹⁰

While information on disabilities has improved, the understanding of disability in the NWT continues to be limited by:

- different definitions, standards, norm-references and service orientations;
- poor access to and/or inappropriate diagnostic services/tools;
- wrong diagnoses and/or reluctance to discuss, label or name disability;
- reluctance to seek assessment/diagnosis;
- lack of programs/services to help or provide information;
- different expectations and priorities, limiting cooperative efforts, appropriate resource allocations, and clearly defined responsibility; and
- lack of disclosure and trust around disability issues.

⁸Treeline Planning Services Ltd. April 1995. *Seniors Housing and Social Needs Study - A Planning Tool to the Year 2005 The Beginning*. the NWT Seniors' Advisory Committee

⁹Lutra Associates Ltd. June 1995. *Coming Home - Community Research into Intellectual Disabilities in Rae-Edzo*. Yellowknife Association for Community Living

¹⁰Dr. J.C. Godel for the Inuvik Regional Health and Social Services Board. unpublished.

Regional scoping discussions conducted to launch this Needs Assessment provided little information on the number and distribution of disability. For example, some Inuvik Region Health and Social Services staff suggested that the oil/gas boom and a high level of substance use in the 1960s and 1970s have contributed to the rate of intellectual and learning disability among young adults, and to cognitive disability among older people in the region. The incidence of these disabilities is unknown. In the Sahtu Region, there is a perceived high level of special needs among school age children. The extent to which these needs can be attributed to disability is unknown. Most people with disabilities requiring services must seek them outside the region thus, it is thought that there are few people with disabilities in the region. In Fort Smith, the local Society for Disabled Persons maintains a confidential list of 60 persons with disability in that community.

Elsewhere in Canada, research into disability has been influenced by public attitudes and policy, and by the activism of persons and organizations affected by disability. To some extent, the research has endeavoured to debunk myths about persons with disabilities.

- ***Myth - Persons with disabilities are unemployable. Fact - Persons with disabilities have greater difficulty securing employment.*** Studies into employment challenges faced by persons with disability urge consideration of both the disability and the environment when putting supports in place;¹¹ educational campaigns about disability, funding for supports such as job coaches;¹² and a wide range of holistic professional

¹¹Fawcett, Gail. 1996. *Living with Disability in Canada: An Economic Portrait*. Office for Disability Issues Human Resources Development Canada, Ottawa.

¹²Persons with Disabilities Project. October 1998. "Potential...Opportunity...Progress..." Human Resources Development Canada, Yellowknife

and peer counselling services to help persons with disabilities adjust after the onset of a disability.¹³

- ***Myth - The risk of abuse increases with disability. Fact - The evidence is inconclusive.*** Sexual abuse of children and sexual assault of adults with disabilities are widespread phenomena. Research does not exist to either debunk or affirm this notion.
- ***Myth - The full rights of citizenship are not exercised by persons with disabilities. Fact - The full rights of citizenship may not be exercised by any group of people marginalized in society.*** Research into disabilities in Rankin Inlet, Nunavut in 1994 found that people may not consider themselves to be disabled but are marginalized by policy makers and by the lack of resources allocated to meet their needs.¹⁴ Low literacy and high risk social behaviours have a particular impact on the participation of persons with disabilities (eg. ability to be informed and make decisions). Achieving the full citizenship of persons with disabilities is the intent of the recent federal/provincial/ territorial vision paper **In Unison: A Canadian Approach to Disability Issues.**
- ***Myth - Changes in social programs and funding have enhanced the life of persons with disabilities. Fact - Changes in social programs may be causing more people with disability to live independently within their communities but service reductions may be affecting the ability of these people to live safely, securely and with dignity.*** Closure of community facilities is impacting persons with psychiatric disabilities, those on

¹³Canadian Paraplegic Association. 1997.

¹⁴Sappujjijit Friendship Centre. Fall 1994. Enhancing the Life of Persons with Disabilities. Rankin Inlet.

income support, and those relying on medical and social supports.¹⁵

While the knowledge of disabilities has increased in the last two decades, Canadian jurisdictions have been slow to give priority to disability issues. Some have launched initiatives to respond to disability issues. In British Columbia for example, a “disability lens” is being considered to provide policy and program developers with a tool to address the impacts of government programs/services on persons with disabilities. A recent report of the GNWT does not identify disability as a priority issue.¹⁶

1.6 Validity of the Needs Assessment

In total, 807 persons with disabilities participated in this Needs Assessment. This represents:

- 2% of the estimated 1999 NWT population;
- 15% of the estimated population with disability in the NWT in 1999; and
- 33% of persons with moderate to severe disabilities living in households/ non-institutionalized settings in the NWT in 1999. (Table 4) (Only those persons incarcerated or living in extended care facilities/hospital wards are considered to be living in institutionalized settings.)

Compared to the whole NWT population with disability (Table 4), the Needs Assessment involved:

- more elderly people,

¹⁵SKR (Stan K. Remple) Management Consulting. 1995. *A Proposal for Community Supports to Enhance Independent Living for Persons with Intellectual Disabilities in the Northwest Territories.* for the Yellowknife Association for Community Living

¹⁶Minister's Forum on Health and Social Services. January 2000. *Our Communities Our Decisions - Let's get on with it! Final Report.* Health and Social Services Government of the NWT

- a similar portion of children, and
- fewer adults.

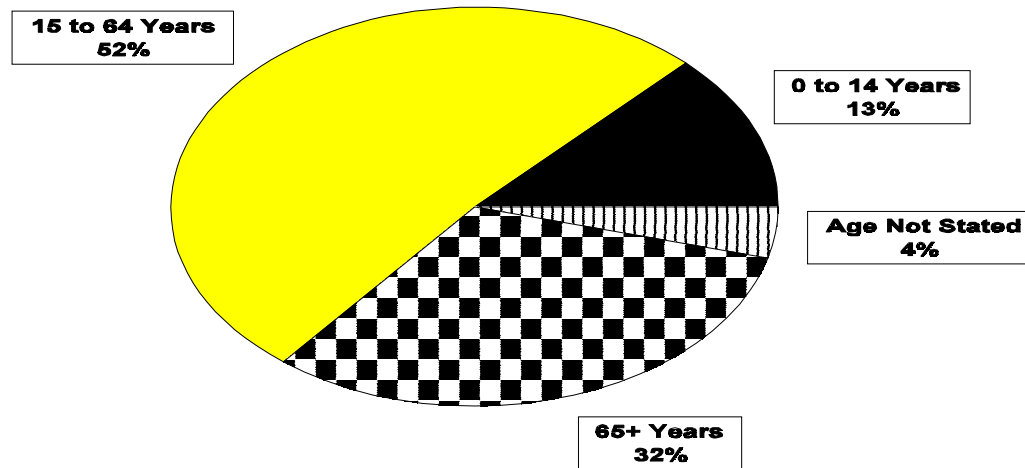
Table 4: Distribution of the NWT Population in 1999 and NWT Needs Assessment Respondents with Disability by Age, 2000

Age Groups	NWT Population	NWT Population with Disability ¹	Needs Assessment Respondents with Disability
Total	41,606	5,453	807
0-14 years	27.2%	15.7%	12.7%
15-64 years	68.7%	67.8%	51.5%
65+ years	4.1%	16.5%	32.2%
unknown	-	-	3.6%

¹: Estimated based on HAL and GNWT population estimates for 1999

More than one-half of persons with disabilities participating in the Needs Assessment are between 15 and 64 years of age and 13% are children 0 to 14 years of age. (Figure 1)

Figure 1: Persons with Disability by Age, NWT Needs Assessment 2000



N (Number of Respondents) =807

This Needs Assessment involved more persons with moderate to severe than mild disability.(Table 5) Persons with moderate to severe disability are more likely than those with mild disability to:

- accept or acknowledge disability and therefore have participated in the Assessment.
- have an assessment/diagnosis or a disability named by a professional.
- have multiple disabilities.
- be known or to use services in the community.

As shown in Table 5, persons with mild/slight disability make-up the majority (67%) of persons with disability in the NWT. The tendency toward mild disability was also found among Aboriginal adults in NWT/Nunavut reporting disability in

the 1991 Aboriginal Peoples Survey. This Assessment involved only 2% of NWT residents who reported mild disabilities in HALS.¹⁷

Table 5: Severity of Disability by Percent of the NWT Population Reporting Disability in 1999 and in the 2000 NWT Needs Assessment (as a Percent of the NWT Population with Disability)

	Estimated 1999 NWT Population with Disability Living in Households n = 5,453 ¹	2000 Needs Assessment Percent of Persons with Disabilities ² n = 807
Mild/Slight	67% (n=3,674)	2% (n=85)
Moderate	23% (n=1,259)	17% (n=209)
Severe	10% (n=521)	73% (n=379)
Moderate/Severe	33% (n=1780)	33% (n=588)

¹ Based on rates derived from 1991 HALS and 1999 NWT population projections.

² 2000 Needs Assessment data are presented as a percent of the estimated 1999 population with disability by severity based on 1991 HALS rates.

In this Needs Assessment, the representation of persons with moderate to severe disability living in households (rather than institutions) is a valid base for projecting to the whole NWT population with moderate to severe disability living in households. (A detailed discussion generalizing the results of the Needs Assessment to the total population with disabilities in the NWT is provided in Appendix F.) Should the needs of NWT persons with mild disability change for example, due to employment or lifestyle circumstances, the needs presented in this Assessment would be severely under-represented. For instance, changes in family or economic circumstances for some persons with intellectual disability could reduce the structure and routine available to support daily living activities.

¹⁷The 1991 Health and Activity Limitation Survey was used as a benchmark to estimate the total number persons with disability and the severity of disability in the NWT.

For some persons with intellectual disability, these changes could cause an otherwise mild disability to be seen as a moderate or severe disability.

1.7 Projections of the NWT Population with Disability

It is estimated that the total number of persons with disability living in households will grow from 5,453 in 1999 to 7,883 in 2019.¹⁸ (Table 6) Appendix F provides a discussion of the methodology used to calculate projected changes in the NWT population with disability.

Table 6: Projected Number of Persons Living in Households in the NWT with Disability by Severity, 1999-2019

	1999	2004	2009	2014	2019
Mild	3674	3928	4239	4616	4964
Moderate	1259	1379	1548	1740	1903
Severe	521	603	728	885	1016
Total	5453	5910	6515	7241	7883

1.8 Research Notes

The Needs Assessment of Persons with Disabilities has the following limitations.

- **Comparability of Data**

The 1991 Health and Activity Limitation Survey (HALS) provides the most complete data on disability in the NWT. While definitions developed for this Needs Assessment endeavoured to enable comparability of data, HALS does

¹⁸Projections are derived from the 1991 HALS and population projections for the NWT.

not:

- define physical disability (but rather the imitations associated with mobility and agility),
- disaggregate data on cognitive, intellectual, learning or psychiatric disabilities, or
- collect detailed information on children or the ethnicity of persons with various types of disability.

These factors limit comparability of data.

- **Cognitive, Intellectual and Learning Disability**

Cognitive, intellectual and learning disabilities are not widely understood, accepted or acknowledged. Persons of all backgrounds had difficulty understanding the subtle differences for example, between intellectual and learning disability (eg. rate of learning verses the way of learning). These challenges were particularly great among Aboriginal language users. Other persons may not have recorded these “hidden” disabilities in their Personal Questionnaire or may not have participate in the Needs Assessment at all.

- **Participation of Children**

The information on disability among children is sparse in the 1991 HALS, the 1991 Aboriginal Peoples Survey and the 1996 Canada Census. Unfortunately, this Needs Assessment provides little additional information on this segment of the population. Slightly more than 100 children with disability participated in this Needs Assessment. This small number limits the extent to which definitive statements can be made about NWT children with disability. Concurrent to this research, NWT schools were assessing student needs including those of students with disabilities. Linking information from the two assessments will be important to understanding the needs of NWT children with disability.

- **Psychiatric Disability**

Data presented on psychiatric disability refer only to those persons who also have one or more of the other disabilities under investigation. No definition of psychiatric disability was provided. Data on psychiatric disability should be treated as a very limited perspective on the needs of persons with this disability.

- **Needs of Persons with Mild Disability**

Persons with a mild degree of disability did not participate in this Assessment and may not be known by community service providers. As such, the needs of persons with mild disability are not well understood through this Assessment.

- **Under-Representation of Service Needs**

This Needs Assessment sought information on a broad range of programs and services which may be available in the NWT. A variety of programs/services may exist in some communities but not in others. In other cases, services/programs may be available but delivered to the individual in a location outside of the NWT. Lack of understanding, experience or exposure to a full range of programs and services may limit the extent to which individuals (especially those in smaller communities) can assess their program/service needs now and in the future. Data on service use and needs provided by community service providers were incomplete, limiting their usefulness in corroborating information provided by persons affected by disability.

2. People with Disabilities in the NWT

This chapter contains a demographic profile of persons with disability in the NWT. It also offers a description of the types and severity of disability within the NWT population. Unless otherwise specified, descriptions of persons with disabilities refer to persons with moderate to severe disability living in households in the NWT.

2.1 An Introduction to People with Disability

Gender

Both the 1991 Health and Activity Limitation Survey (HALS) and the 1996 Census found that a slightly higher proportion of NWT persons with disability are males, 52% compared to 48% female.¹⁹ An equal percentage of males and females with disability participated in this Needs Assessment.

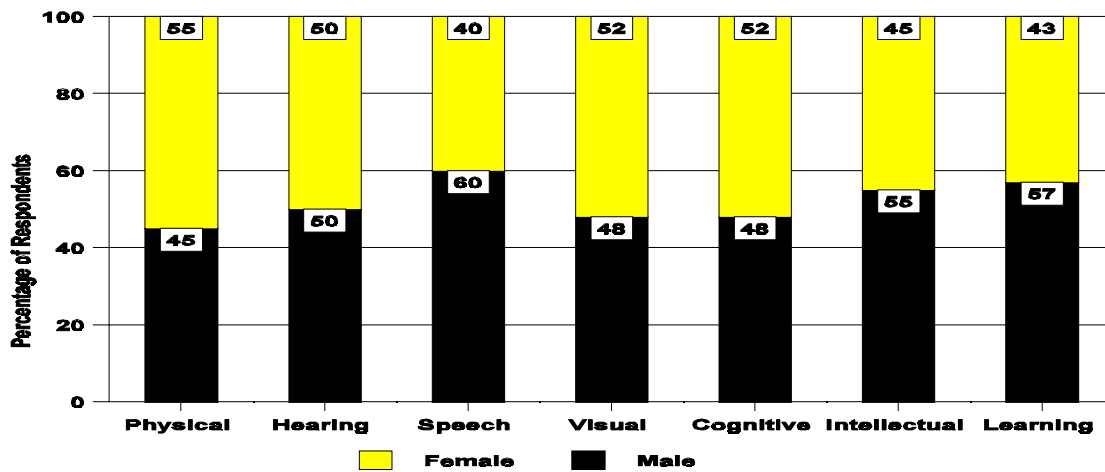
Gender may be a factor in some types of disability. Physical disability is frequently associated with industrial work and work place health-related conditions. Physical disability tends to be more prevalent among Canadian males than females. This Needs Assessment found that more NWT females than males have physical disability. Illness/disease are the main reason for physical disability in the NWT. (see Figure 13, pg. 45) Males in the NWT are more likely than females to have speech, learning and intellectual disabilities. (Figure 2 pg.25) Speech, learning and intellectual disabilities among males may be linked to foetus size or more frequent difficulties at birth.²⁰

¹⁹NWT HALS data include Nunavut. 1996 Canada Census data are reported for the NWT only.

²⁰from statements made at the April 2000 Disabilities Needs Assessment partners and stakeholders workshop.

This Needs Assessment also found that males (57%) are more likely to have unpaid caregivers/parents than females (44%).

Figure 2: Gender of Persons by Type of Disability and Percent, NWT Needs Assessment 2000



Ethnicity and Language

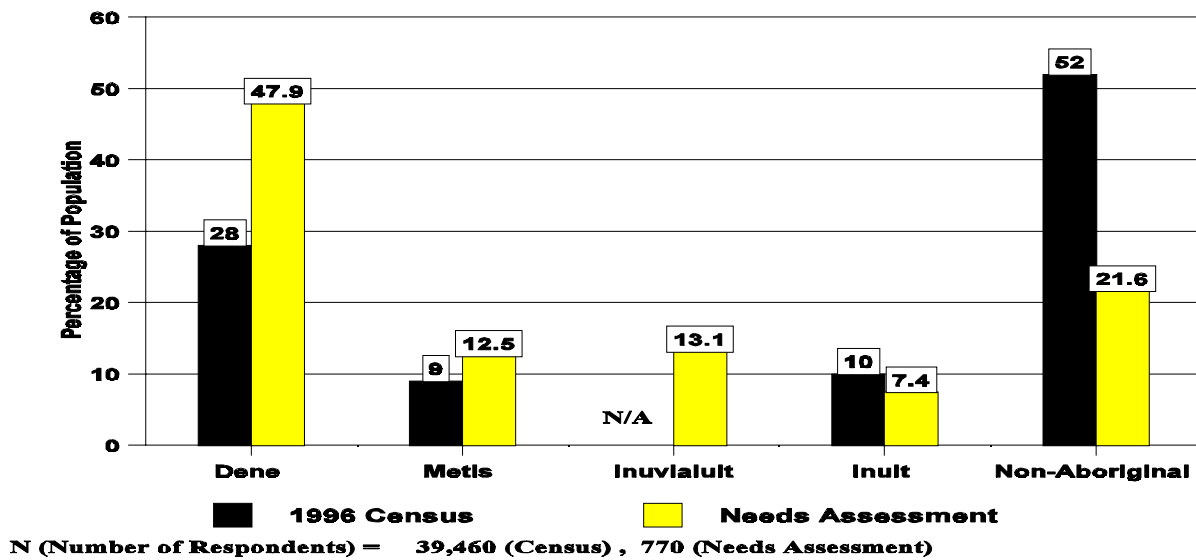
The GNWT's 1999 population estimates for the NWT show slightly more Aboriginal people (51%) than persons of non-Aboriginal ancestry. In 1996, non-Aboriginal people made-up 52% of the population. The disability rate within the Aboriginal adult population in the NWT is about 27%, more than twice the rate for the NWT population as a whole.²¹

Almost eight of every ten people with a disability participating in this Needs Assessment have Aboriginal ancestry. Compared to other Aboriginal people, the incidence of disability is greatest among the Dene. (Figure 3) Higher rates of

²¹1991 Aboriginal Peoples Survey and 1991 HALS

disability among Aboriginal people may partly account for over-representation of this population in the Assessment. Good participation of persons with disability in predominantly Aboriginal communities (where they are known by front-line workers) also contributes to the larger number of Aboriginal persons with disability in this Assessment.

Figure 3: Ethnicity of Persons with Disability, NWT Needs Assessment 2000 Compared to the 1996 Census

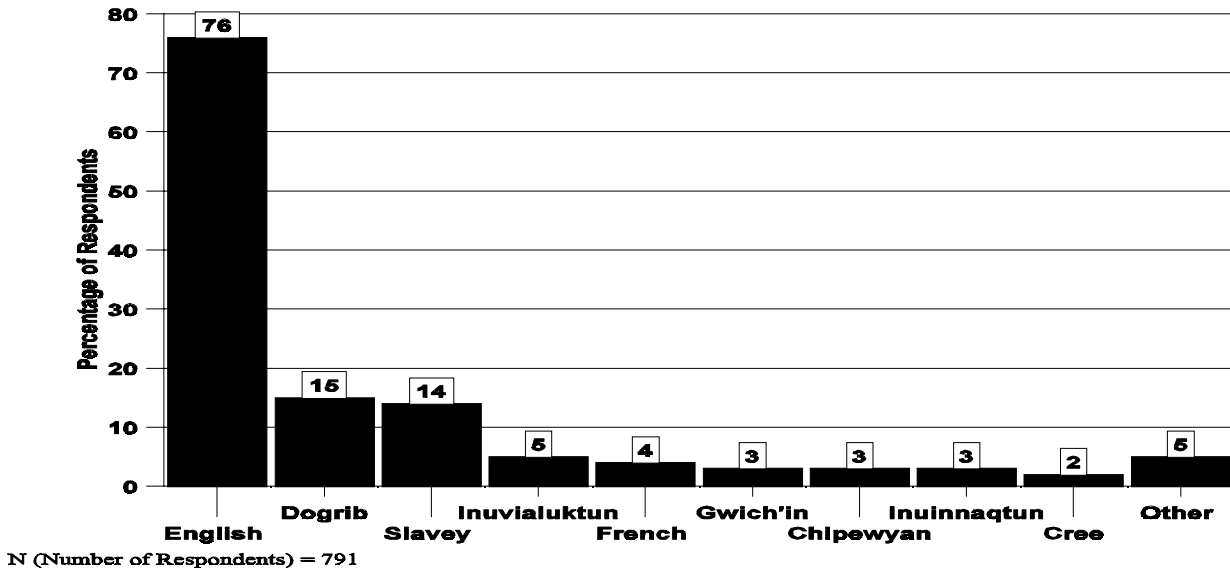


Note: This Assessment did not involve individuals living outside the NWT

The NWT has eight official languages. Six of these are Aboriginal languages. The 1996 Canada Census identified English as the home language of 92% of NWT residents. Home language is synonymous with the language best understood. Over-three quarters (76%) of persons with disabilities participating in this Needs Assessment say they understand English best. (Figure 4) The remaining one-quarter understand a variety of other NWT official languages and other languages of the world (eg. German and Italian) best. Persons with disability who understand a language better than English are most likely to identify Dogrib

or Slavey.

Figure 4: Language Understood Best by Percent of Persons with Disability,



NWT Needs Assessment 2000

Note:

Percentages do not sum to 100 due to multiple responses. "Other" includes Inuktitut, American Sign Language and other languages.

Residency and Care

People with disability in the NWT are not a mobile population. Compared to all other communities in the NWT, persons with disability living in Yellowknife and Hay River are most likely to have been born outside the NWT. (Table 7)

Regardless of ancestry or place of birth, almost all persons with disability (96%) consider their home to be in the same community or region in which they now live. This also holds true for the City of Yellowknife, where 94% of persons with

disability consider this community or the Yellowknife region to be their home. This might suggest that persons coming from other communities to Yellowknife for services, easily accept the City as their home. It might also speak to the notion or sense of community among persons with disability.

Table 7: Number of Persons Born and Residing in NWT Regions by Current Residence and Ethnicity, NWT Needs Assessment 2000

N=	Residing in Yellowknife		Residing in Hay River/Hay River Reserve		Residing in Inuvik		Residing in Fort Smith	
	104	112	42	16	27	3	57	13
Born in	Abor	Non-Abor	Abor	Non-Abor	Abor	Non-Abor	Abor	Non-Abor
Yellowknife	23	12	0	0	0	0	1	1
North Slave	13	0	0	0	0	0	0	0
South Slave	9	1	20	2	0	0	36	2
Deh Cho	9	0	13	0	0	0	0	0
Sahtu	5	0	1	0	1	0	0	0
Beaufort/Delta	17	1	0	1	20	1	2	0
Outside NWT	27	98	8	13	3	2	18	10
Bush	1	0	0	0	3	0	0	0

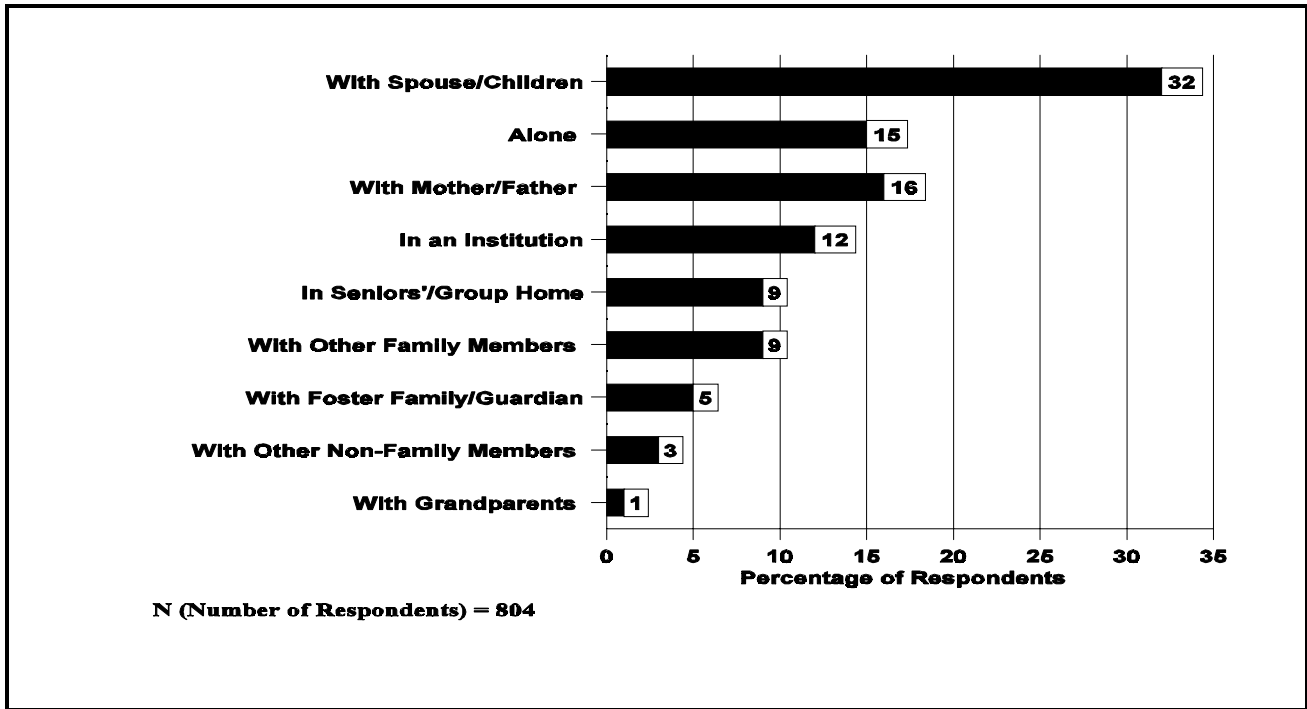
Note:

“Abor” = person of Aboriginal ancestry “Non-Abor” = person of non-Aboriginal ancestry

The HALS does not provide detailed information on persons with disability living in institutions or persons younger than 15 years of age. For the rest of the population, HALS reports that 69% of adults with disability residing in

households in Canada and 83% in the NWT/Nunavut, live in a (Census) family household.²² Among persons with disability participating in this Needs Assessment, most live in a family environment. (Figure 5) Compared to all other age groups, persons with disability 65 or more years of age are least likely to live in a family environment. The availability of housing and/or care options and/or a reluctance to move away from family or community may be the main influences on the living circumstances of persons with disability in the NWT.

Figure 5: Place of Residence of Persons with Disability, NWT Needs Assessment 2000



Note: This Assessment did not involve individuals living outside of the NWT.

²²A Census household is defined as a now married couple or a couple living common-law with or without never-married children of either or both spouses, or a lone parent of any marital status with at least one never-married son or daughter living in the same dwelling.

Marital Status and Dependents

Both the 1991 HALS and this Needs Assessment found that NWT persons with disability 15 years of age and older, are unlikely to be in a marital relationship. This Needs Assessment found that over two-thirds (67%) of persons of adults 15 years and older were single, divorced, separated or widowed. More than half of adults with disability (56%) have no one depending on them for food/shelter/clothing but almost one-quarter (22%) have three or more dependents. (Table 8) An equal number of male and female adults with disability have dependents.

Table 8: Family Circumstances of Persons with Disability 15 or More Years of Age by Percent, NWT Needs Assessment 2000

Marital Status	
-Married/Common-Law (n=207) 32%	
-Single (n=246)	40%
-Divorced/Separated/Widowed (n=174) 27%	
Dependents (eg. for food/shelter/clothing) (n=605)	
-None	56%
-1 or 2	22%
-More than 3	22%

Education, Employment and Income

In the NWT, less than grade 9 education is defined as functional illiteracy. Rates of illiteracy are linked to opportunities to access and achieve successes in education. The 1999 NWT Labour Force Survey found that 13% of the whole NWT population and 26% of the Aboriginal population 15 years of age and older have less than grade 9 education. HALS reported that 40% of NWT/Nunavut adults with disability 15 to 64 years of age have less than grade 9. More than half of the adults (61%) with disability participating in this Needs Assessment have this

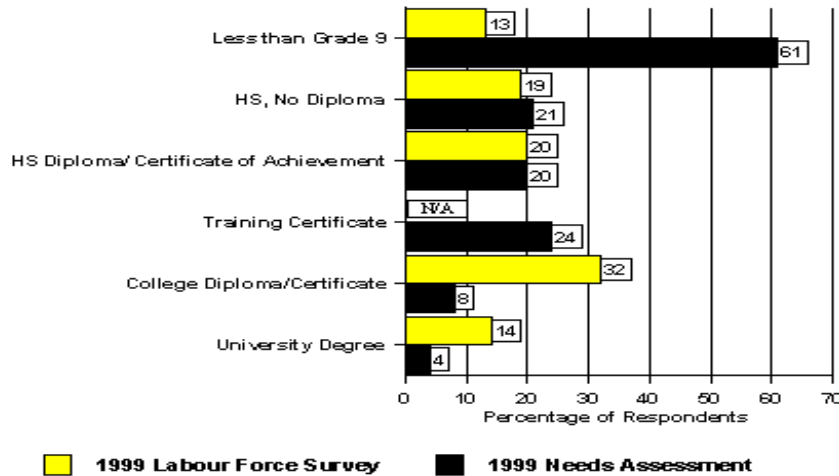
level of education. (Figure 6) The high rate of illiteracy among persons with disability may be linked to the lack of representation by persons with mild disability, and high proportion of persons with Aboriginal ancestry and elderly persons in this Needs Assessment.

Education levels vary by age among persons with disability. (Table 9) Among persons with disability 15 years of age and older participating in this Assessment,

- the highest levels of education are among persons 40-59 years of age.
- more than half (58%) of persons 25-39 years and 60+ years (57%) have not achieved grade 9.

Figure 6: Formal Education of Adults with Disability, NWT 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 9 and a training certificate).
2. Both this Needs Assessment and the GNWT's 1999 NWT Labour Force Survey consider adults as

persons 15+ years of age.

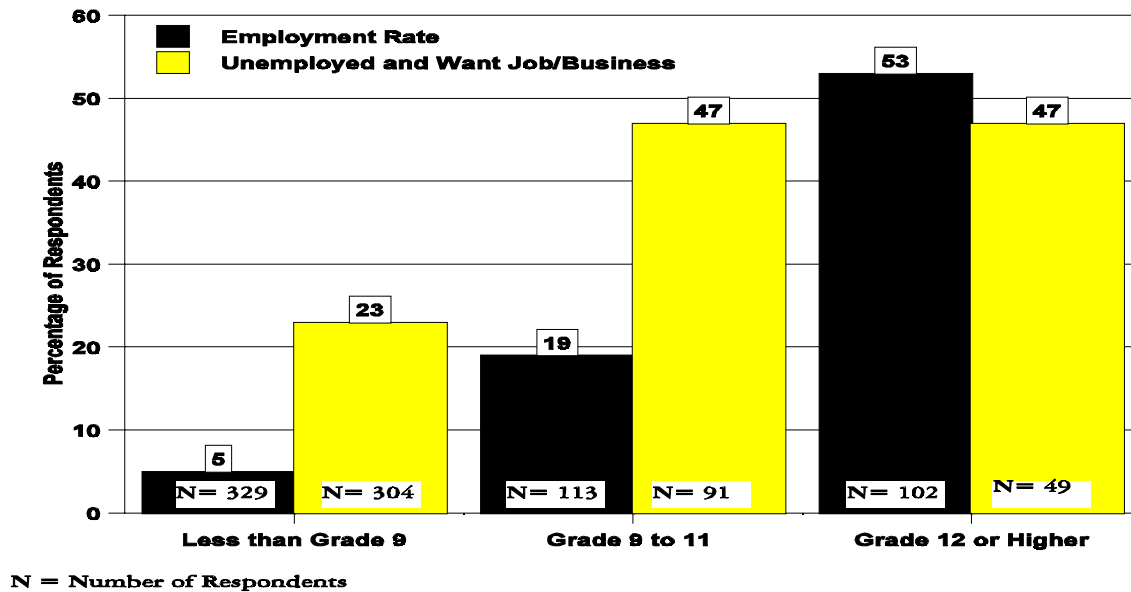
The 1999 NWT Labour Force Survey reported a strong correlation between education and employment rates.²³ This Needs Assessment corroborates this finding. The employment rate for persons with disability with grade 12 or more education participating in this Assessment is ten times the rate for persons with less than grade 9 education. (Figure 7)

Table 9: Education of Persons with Disability by Age, NWT Needs Assessment 2000

	15-24 years	25-39 years	40-59 years	60+ years
Less than Grade 9	36%	58%	39%	57%
High School/No Diploma	38%	15%	25%	9%
High School Diploma/Certificate of Achievement	21%	14%	21%	11%
Training Certificate	14%	14%	30%	13%
College Diploma/Certificate	-	5%	12%	5%
University Degree	-	4%	11%	5%
n=	58	111	197	309

²³The employment rate is the percent of persons 15 or more years of age who were employed at the time of the Labour Force Survey.

Figure 7: Employment Activity of Adults by Level of education, NWT Needs Assessment 2000



Note: The employment rate is based on the percentage of persons with a job or running a business.

In 1999, the employment rate in the NWT for persons 15 to 59 years of age was 71% and 53% for persons of Aboriginal ancestry.²⁴ The employment rate is 26% among people with disability in this age group. Just over one-half (51%) of adults with disability 15 to 59 years of age would like to work but can't due to disability or illness. Overall, 16% of persons 15 or more years of age with disability participating in this Needs Assessment are employed/running a business.

Average personal income in the NWT is \$33,712. (Bureau of Statistics) In other

²⁴1999 NWT Labour Force Survey

regions of Canada, poverty is defined as having income of less than \$20,000 per year. The NWT does not have an established “poverty line”. Among adults with disability participating in this Needs Assessment, 80% have personal incomes of less than \$20,000/year and 48% have personal incomes of less than \$10,000/year.

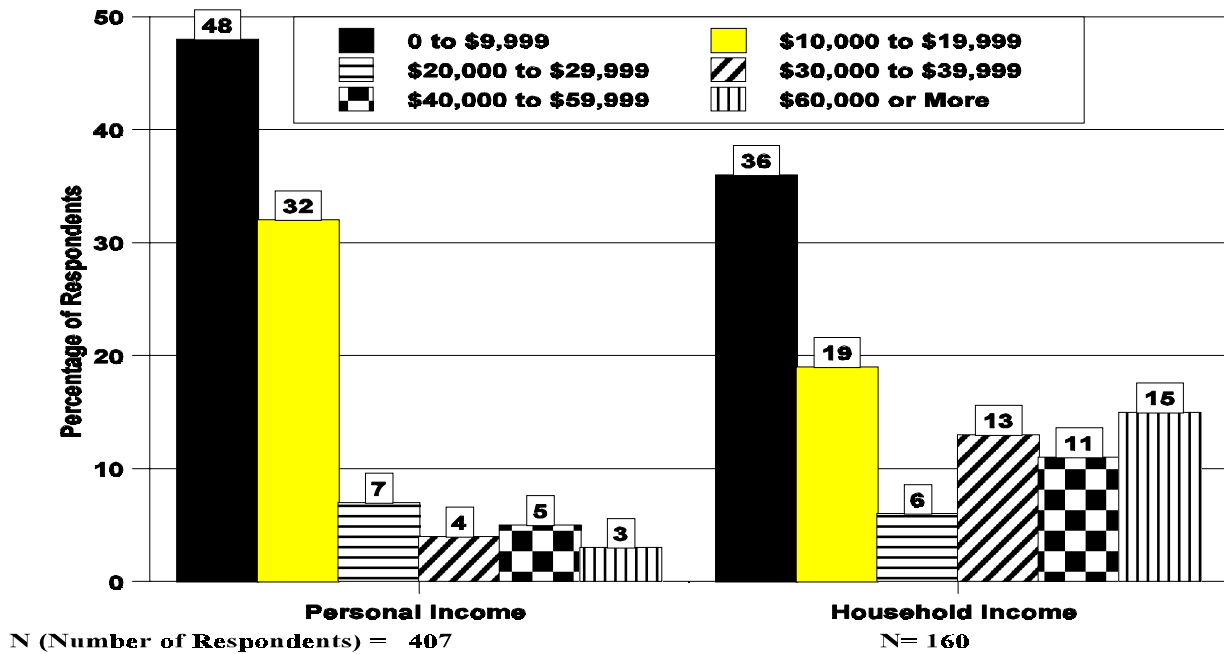
A large percentage of adults with disability (44%) live in households with less than \$20,000 in total household income. (Figure 8) Low levels of income create significant challenges for persons participating in this Needs Assessment.

Throughout this Needs Assessment, the lack of sufficient financial resources was identified as the most pressing issue faced in daily living with disability.

“I don’t know what my personal income is or how that is defined in a subsistence lifestyle.” (from Personal Questionnaire)

Approximately one-half (52%) of adults participating in this Needs Assessment are currently receiving income support, need it now but are not receiving it, or may need it in the future. Over half (56%) of adults currently receiving income support live with other people and 27% live alone.

Figure 8: Personal and Household Income Levels by Percent of Respondents, NWT Needs Assessment 2000

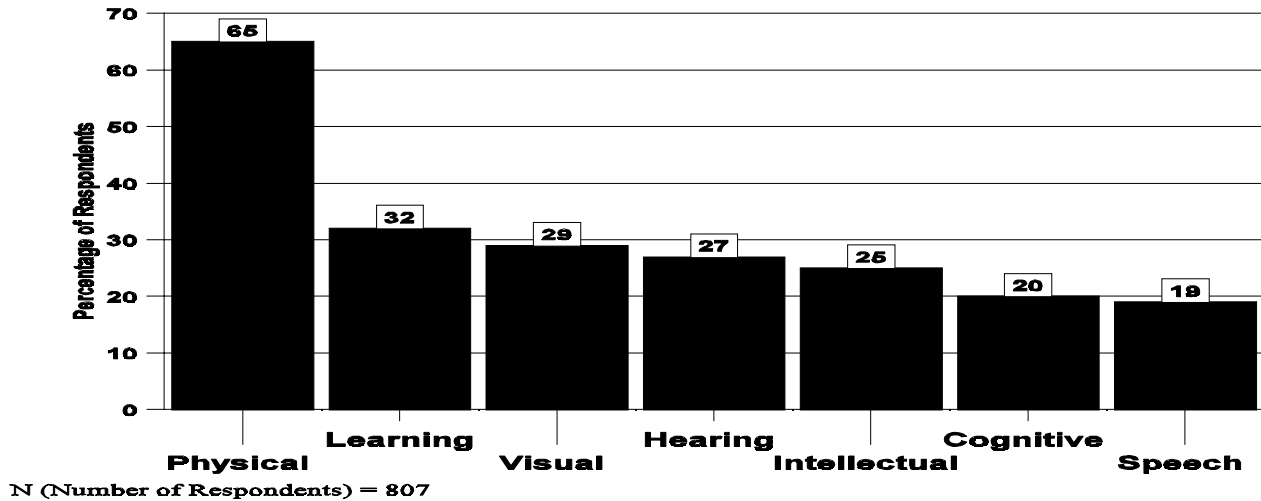


2.2 Describing Disability

Type of Disability

Among persons with moderate to severe disability living in NWT households, 88% have a physical or sensory disability. Learning disabilities affect almost one-third of persons with disability. (Figure 9) Approximately 60% are living with more than one disability. Almost 10% also have a psychiatric disability.

Figure 9: Type of Disability by Percent, NWT Needs Assessment 2000



Compared to the HALS and Aboriginal Peoples’ Survey,²⁵ fewer Needs Assessment respondents have hearing disability and more have speech disabilities. (Table 10) The high rate of hearing disability in Nunavut may account for these differences.²⁶ Higher rates of speech disability may be associated with the difficulties developing language skills and in learning, recorded in this Assessment. Higher rates of visual disability in the NWT may be due in part, to the:

- excellent participation in this Assessment of the Canadian National Institute for the Blind (CNIB), and/or
- extent of known genetic conditions impacting on vision in some communities around Great Slave Lake and the efforts by service providers to include these persons in this Assessment.

²⁵Both surveys do not separate NWT and Nunavut data.

²⁶1991 Aboriginal Peoples Survey and the 1998 Nunavut Needs Assessment

Table 10: 1991, 1994 and 2000 Percent of the NWT Population with Disability by Type

	NWT/Nunavut (Aboriginal Peoples' Survey 1991)	NWT/Nunavut (HALS 1991)	NWT (1994 National Population Health Survey)	Needs Assessment 2000*
Physical	-	-	-	65%
-Mobility	33.5	35%	36.4%	-
-Agility	25.3	30%	-	-
Hearing	41%	47%	41.5%	27%
Speech	7%	7%	29.3%	19%
Visual	22%	10%	20.8%	29%
Mental	32.4	32%	-	-
-Cognitive		(including		20%
-Intellectual		psychiatric,		25%
-Learning		intellectual & learning)		32%

Notes:

*Refers to percentage of persons participating in this Assessment.

Almost 10% of persons with one or more of the five disabilities under investigation in the Needs Assessment also identified a psychiatric disability.

The Learning Disabilities Association of Canada estimates that 10%-15% of the Canadian population may be affected by learning disability.

- Almost one-third of persons with disabilities participating in this Needs Assessment identified a learning disability.
- One-fifth of persons participating in this Assessment identified a cognitive disability.
- One-quarter identified an intellectual disability.

Community service providers and program managers suggest that the rates of brain-related disability may be conservative. These professionals explain this point of view by the sustained levels of high risk behaviours including substance

abuse, in many NWT communities for at least three decades.

Table 11 compares the distribution of disability in the NWT by age reported in the 1991 HALS and in this Needs Assessment.

Table 11: The Nature of Disability by Age, 1991 Health and Activity Limitation Survey for NWT/Nunavut and the NWT Needs Assessment, 2000

Type of Disability	0-14 years		15-64 years		65+ years		Total	
	1991	2000	1991	2000	1991	2000	1991	2000
	1425	103	4785	414	855	261	7065	807**
Physical		30		265		204		521
Mobility	--	--	1875	--	585	--	2460	
Agility	--	--	1645	--	495	--	2140	
Seeing	140	13	405	107	200	94	745	230
Hearing	430	11	1765	87	375	108	3315	217
Speaking	225	51	290	76	--	23	515	153
Other	110*	--	1520	--	250	--	1880	
Cognitive	--	20		62		67		159
Intellectual	--	58		116		17		198
Learning	--	72		140		37		255
Mental Health Condition**	135							
Nature Not Specified	---	---	355		--		370	

Source: 1991 Health and Activity Limitation Survey - Total Population is for Persons 15+.

Notes: HALS data do not include persons in institutions.

Other includes: intellectual disability, mental health condition, or learning disability.

*children 0-14, the classification is Other Condition or Health Problem and includes a long-term condition or health problem which is not included in the above categories

**Mental Health Condition in the case of HALS includes long-term emotional, psychological, nervous or mental condition. In the case of the Needs Assessment, refers to psychiatric disability

***Includes 29 individuals who did not state their age.

As shown in Table 11:

- HALS reported that 30% of NWT children (0 to 14 years of age) with disability have a hearing disability and about 16% have difficulty speaking. Among this age group, this Needs Assessment found that:
 - 70% have learning disability;
 - 56% have intellectual disability; and
 - 50% have speech disability.
- HALS found that mobility, hearing and agility limitations are encountered by 34%-39% of working age adults (15-64 years) in the NWT/Nunavut with disability. Among this group age, this Needs Assessment found that:
 - 64% have physical disability;
 - 34% have learning disability;
 - 28% have intellectual disability; and
 - 26% have visual disability.
- HALS found that among persons 65 years of age or more with disability, mobility, agility and hearing difficulties were the main difficulties faced. This Needs Assessment found that:
 - 78% have physical disability;
 - 41% have hearing disability;
 - 36% have visual disability; and

Severity and Assessment of Disability

The vast majority (92%) of persons with disability participating in this Assessment reported an assessed/diagnosed/named (by a professional) disability. The reasons for the high level of known disability may be due to:

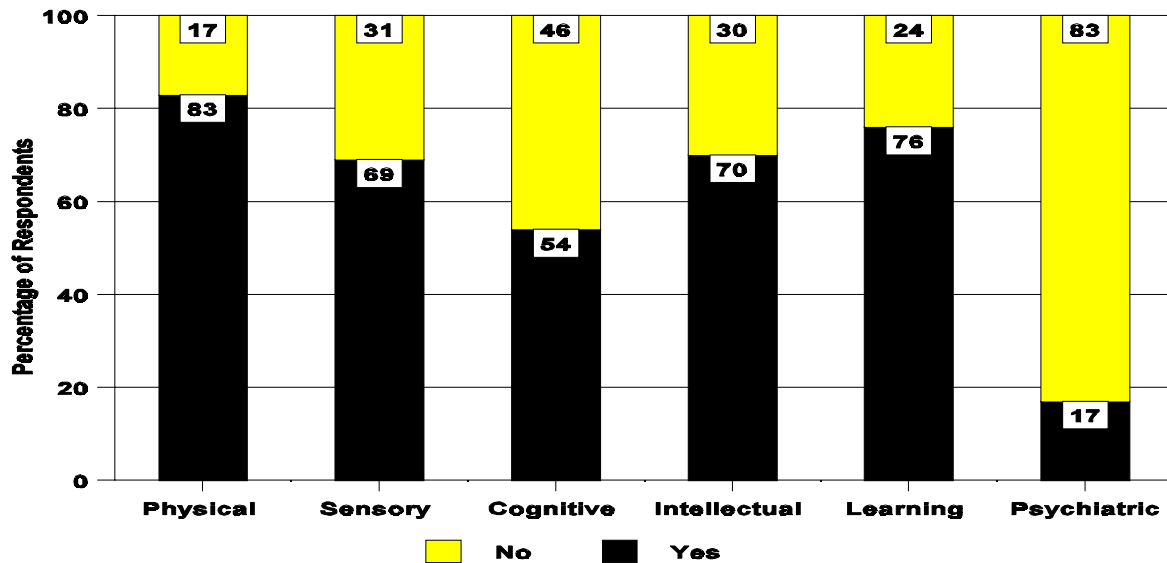
- the methodology employed for this Needs Assessment, namely the requirement for persons to acknowledge and accept their disability;
- the involvement of community service providers in identifying and inviting

participants (eg. those with known disabilities and those using services);and

- the inclusion of naming by a professional as an option to assessment or diagnosis.

Parents/caregivers of persons with disability confirm the high level of assessment/diagnosis/naming among the persons they care for. (Figure 10)

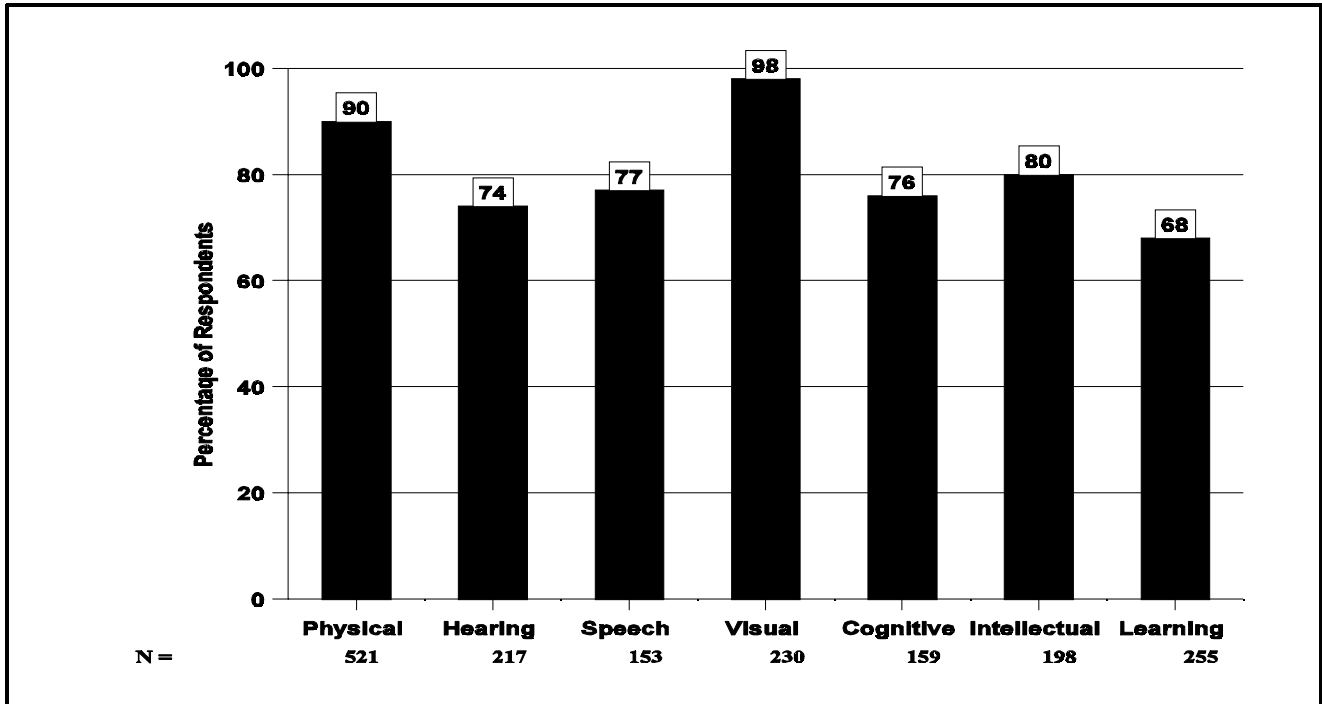
Figure 10: Diagnosed and Assessed Disability (including those named by a professional) by Percent of Parents/Caregivers Caring for Persons with Disabilities, NWT Needs Assessment 2000



As shown in Figure 11, persons with visual disability are most likely and persons with learning disability are least likely to have an assessed/diagnosed/named disability. A lower level of assessment/diagnosis/naming of learning disability may be due to limited assessment/diagnostic services in the NWT combined with less understanding or recognition of this disability. Difficulties associated with

understanding/naming learning disability were exemplified in this Assessment by the caregivers/parents of children/youth attending education programs endorsed by the Learning Disabilities Association in Yellowknife. Most declined to assist their children/youth to complete a Personal Questionnaire.

Figure 11: Percent of Persons Having an Assessed/Diagnosed/Named Disability, NWT Needs Assessment 2000



Note:

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.

This Needs Assessment showed a high level of assessment/diagnosis/naming of intellectual disability (80%). This may be due to the tendency of persons to have moderate to severe intellectual disability, the inclusion of naming by a professional as an option to assessment/diagnosis or to recent efforts to bring attention to the impact of alcohol and drug use on fetal development.²⁷

²⁷For example the Yellowknife Association for Community Living's video and handbook "Helping Families Helping Children" to assist families raising children affected by Fetal Alcohol

The detailed questions included in the 1991 HALS tended to identify persons with mild, moderate and severe disabilities while the 1996 Census tended not to include persons with mild disabilities. In 1991, HALS reported that 33% of persons with disabilities in the NWT/Nunavut had moderate or severe disabilities and 67% had mild disabilities. The majority (77%) of Aboriginal adults enumerated in the 1991 Aboriginal Peoples Survey also identified a mild disability. As shown in Table 5 (page 20), only 2% of persons reporting mild disability in the HALS are represented in this Assessment.

Among persons with disability participating in this Needs Assessment, 60% have multiple disabilities. Most persons participating in this Needs Assessment tended to assess their disability (or at least one of their disabilities) as moderate to severe. (Table 12) Only 12% of Needs Assessment respondents described their disability (or all disabilities) as mild.

Parents/caregivers of persons with disability also tended to assess the disability of the person cared for as moderate to severe. Only 12% of parent/caregivers described the person in their care as having a mild disability. The remaining parents/caregivers described the disability of the person cared for as moderate (32%) or severe (56%).

Table 12: A Self-Assessment of Disability by Persons with Disabilities, NWT Needs Assessment, 2000

% of Persons with Disability	Mild	Moderate	Severe
Physical (n=511)	14%	30%	57%
Hearing (n=207)	24%	34%	42%
Speech (n=150)	24%	31%	44%
Visual (n=226)	25%	29%	46%
Cognitive (n=155)	23%	31%	46%
Intellectual (n=190)	20%	32%	48%
Learning (n=248)	16%	38%	46%

Note: Percentages due not total 100% due to multiple disabilities of differing degrees of severity.

Despite greater participation of persons with mild disability in HALS and greater participation of persons with moderate to severe disability in this Needs Assessment, HALS data draws a stronger relationship between age and severity of disability than this Needs Assessment. (Table 13) This might suggest that while the prevalence of disability in the NWT is influenced by age, the severity is not.

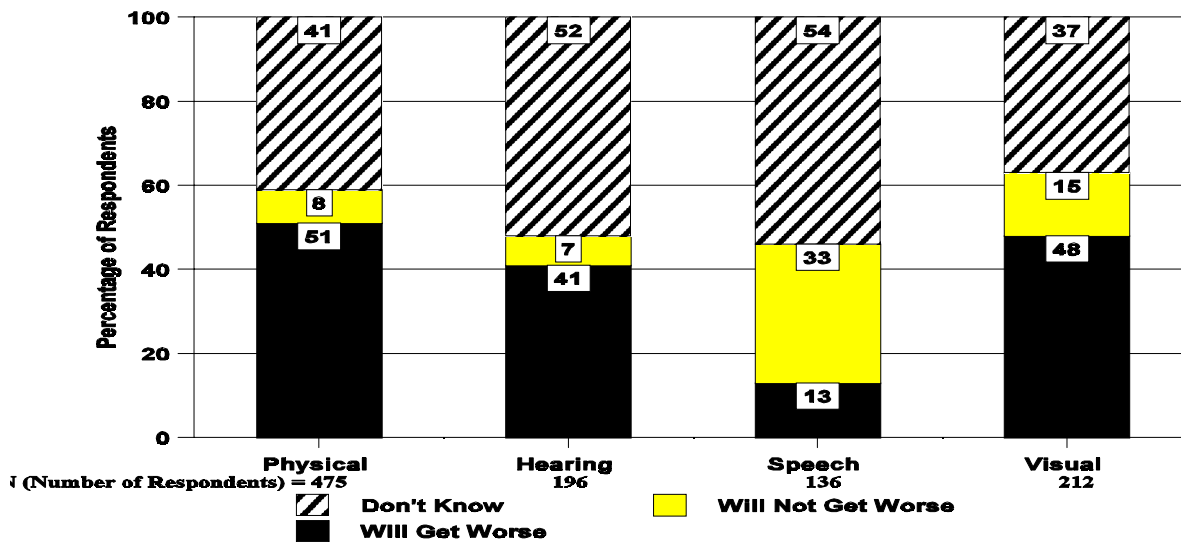
Table 13: Severity of Disability by Age of Persons with Disabilities, NWT Needs Assessment 2000 Compared to the Estimated NWT Population with Disability in 1999

	Needs Assessment 2000			1999 NWT Population with Disability ¹		
	Mild/Slight	Moderate	Severe	Mild/Slight	Moderate	Severe
0-14 years	14%	28%	58%	89%	8%	3%
15-64 years	11%	31%	58%	68%	26%	6%
65+ years	12%	29%	59%	42%	28%	30%

¹ Rates derived from the 1991 HALS and the estimated NWT population in 1999.

Approximately 85% of persons with physical, hearing, speech and/or visual disability expect their disability to worsen (50%) or are uncertain about the future condition of their disability. (Figure 12) Compared to persons with physical and/or visual disability, persons with speech and/or hearing disability express the greatest uncertainty about the future of their condition. Uncertainty may be associated with a lack of information or understanding of these disabilities.

Figure 12: Self-Assessment of the Future Condition of Disability by Percent, NWT Needs Assessment 2000



Note: These data were not collected for other disabilities under investigation. The definition of cognitive disability described the condition as usually degenerative. Intellectual and learning disabilities are static conditions usually present at birth.

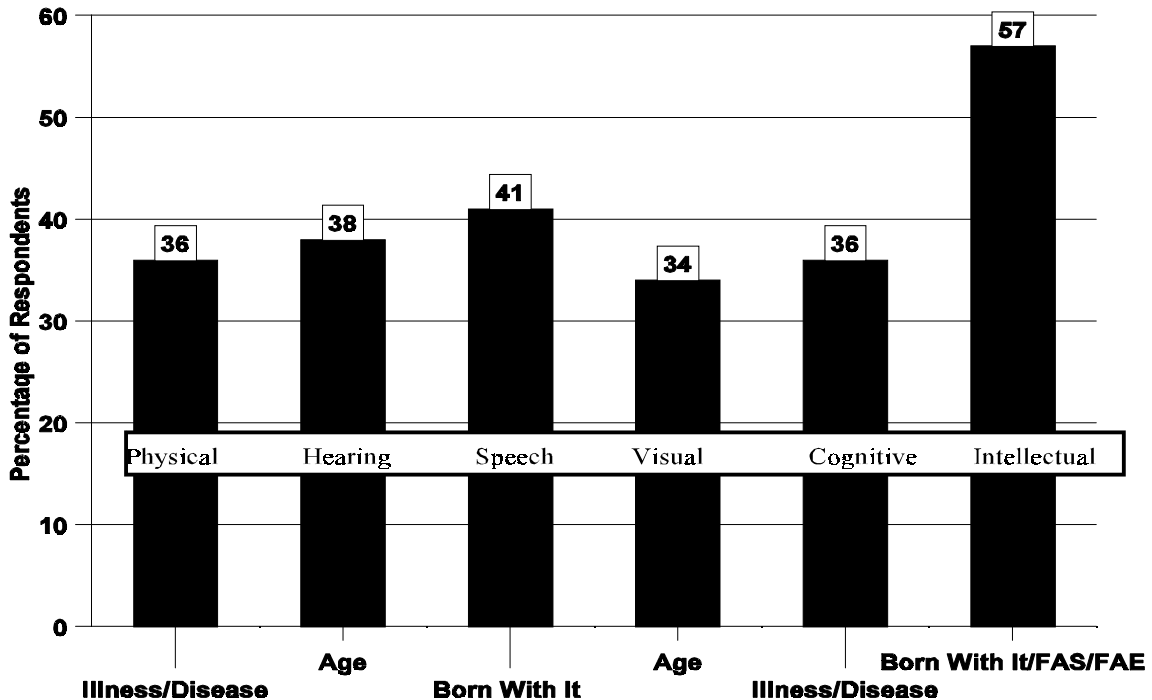
Among persons with disabilities participating in this Needs Assessment, illness,

disease or age are the main reasons for physical, hearing, visual and cognitive disability. (Table 14 and Figure 13) Other reasons account for the presence of speech, intellectual and learning disability. Intellectual disability and learning disability are seen as conditions present at birth. The largest proportion of persons with speech disabilities also say that this condition was present at birth.

Table 14: The Reported Reasons for Disability by Percent of Persons with Disability, NWT Needs Assessment 2000

Reasons	Physical n=518	Hearing n=210	Speech n=150	Visual n=227	Cognitive n=154	Intellectual n=198	Learning n=247
Born with it	15%	11%	41%	20%	3%	47%	34%
Work Injury	11%	9%	1%	4%	2%	1%	1%
Neglected/ Violence/Abuse	1%	3%	4%	3%	6%	4%	6%
Age	22%	38%	7%	34%	32%	4%	10%
Illness/Disease	36%	18%	25%	21%	36%	19%	20%
Accident	13%	7%	2%	10%	4%	5%	3%
Genetic	7%	1%	2%	5%	4%	3%	6%
Don't Know	7%	17%	11%	11%	7%	11%	16%
Pre-Natal Exposure to Alcohol/Drugs	2%	-	4%	-	3%	10%	6%
Own Use of Alcohol/Drugs	4%	2%	5%	3%	14%	6%	9%
Other	2%	2%	4%	6%	2%	3%	4%

Figure 13: The Main Reported Reason for Disability by Percent of Persons with Disability, NWT Needs Assessment 2000



3. LIVING WITH DISABILITY

Actions taken to care for ourselves and participate with others are typically understood as the usual activities of daily living. What special aids, equipment and supports are needed to cope with daily living activities? How does the use of special aids, equipment and supports help people to cope with disability? How do the challenges of daily living activities vary with the type and severity of disability? What work, school and social activities do persons with disabilities participate in? What are the major challenges of living with disability? What are the circumstances and issues

faced by parents/caregivers of persons with disability? These are the questions answered in this chapter.

3.1 Use of and Need for Special Aids, Equipment and Support

A variety of special aids, equipment and supports are used by persons with disability to cope with daily living activities. Special aids, equipment and supports can assist persons with disability to overcome limitations in daily living activities, live independently and live with dignity. The use and need for special aids, equipment or supports may be affected by:

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

The extent to which these factors influence the use or need for aids and support can vary with age, and type and severity of disability.

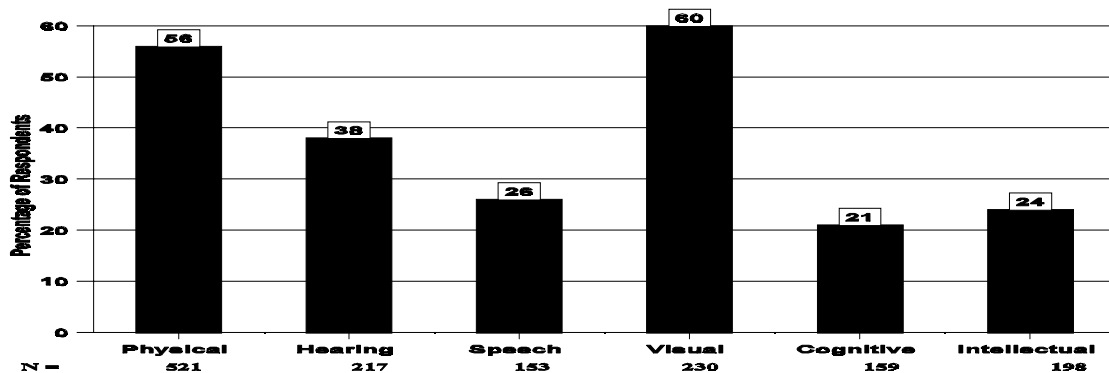
The use of special aids, equipment and support among persons with disability participating in this Needs Assessment should be understood within the context of their main living circumstances. The greatest number of persons with moderate to severe disability living in NWT households:

- are adults or elderly people.
- have a disability assessed/diagnosed/named by a professional.
- live in a family environment but are unlikely to be in a marital relationship.
- are considered illiterate (eg. have less than grade 9 education).
- are not employed or running a business.
- have personal and household incomes of less than \$20,000 per year.

In light of these circumstances, this Assessment found that 57% of persons with moderate to severe disability use special aids/equipment/support now. Comparatively, the majority of NWT/Nunavut Aboriginal adults with disability enumerated in the 1991 Aboriginal Peoples Survey, had mild disability. In that same survey, less than one-quarter (24%) reported using specialized aids, equipment or systems and only 3% identified the need for special aids/ equipment/services to be able to work.

This Assessment found that persons with physical and visual disability are more likely to use special aids/equipment/supports than persons with other types of disability. Persons with cognitive disability are least likely to use them. (Figure 14) Persons with learning disabilities were not asked about their use of aids/supports.

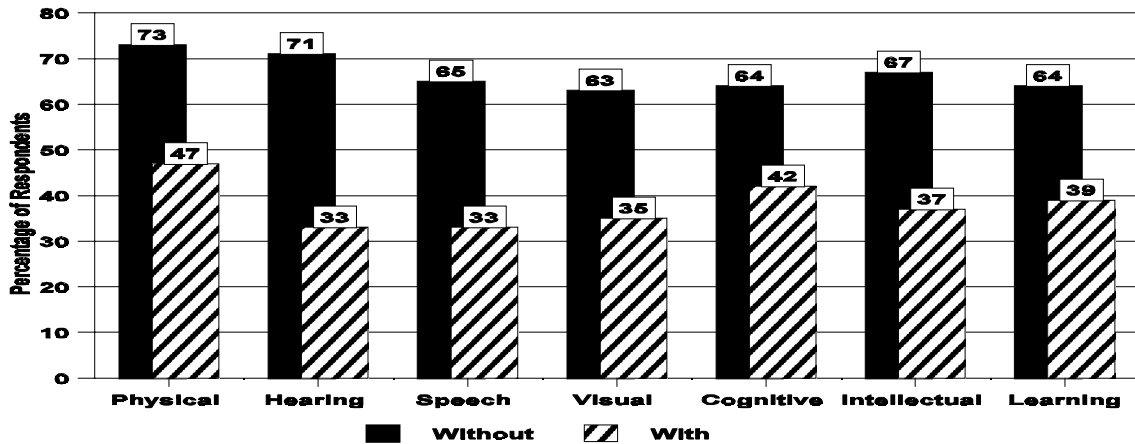
Figure 14: Use of Special Aids/Equipment/Support To Help Cope With Disability by Percent of Respondents, NWT Needs Assessment 2000



Note: Persons with learning disabilities were not asked about their use of special aids/equipment/support. With the use of special equipment/aids/supports, persons with all types of disability have significantly fewer difficulties in the activities of daily living. (Figure 15)

Figure 15: Reported Difficulties Encountered With and Without the Use of

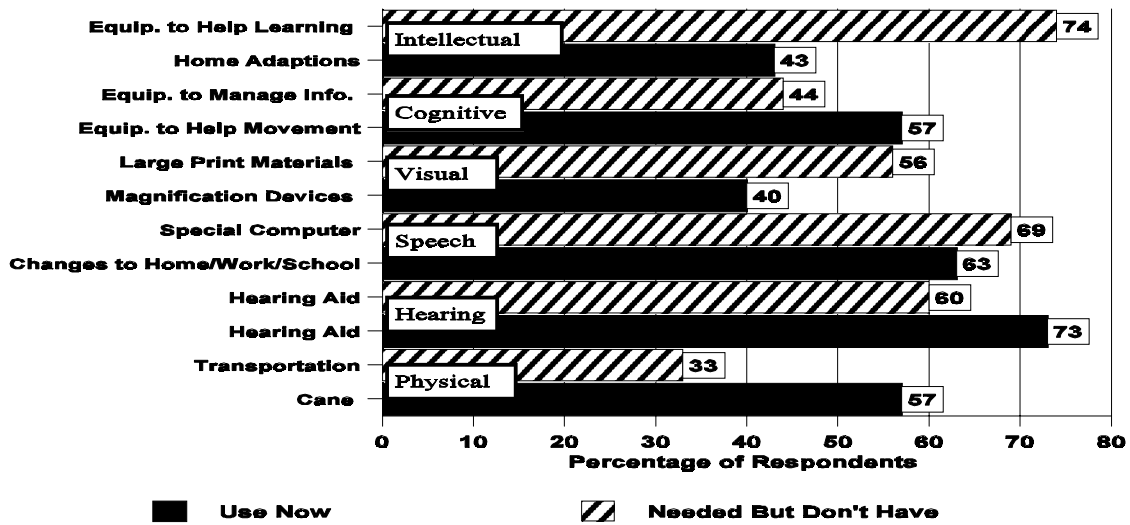
Special Equipment/Aids/Supports by Frequency, NWT Needs Assessment 2000



As shown in Figure 16, the need now for special aids/equipment/support (because persons with disabilities do not have them), is great among persons with disability in the NWT. Need may be driven by the absence of aids/ equipment/supports or by the suitability or functionality of them. This was made clear by the significant number of persons with disability who use a special aid/support but also need the same aid/support. For example, some people currently using a hearing aid also identified a need for a hearing aid now. Some people using home care support also identified a need for this support.

Persons with intellectual and speech disabilities have the greatest need for aids/supports. Among persons with speech disability, there is a significant need for special computer equipment and software. The need for equipment to help learning is greatest among persons with intellectual disability. (Figure 16)

Figure 16: Main Special Aids/Equipment/Support Used and Needed by Type of Disability, NWT Needs Assessment 2000



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

The 1991 Aboriginal Peoples Survey asked Aboriginal adults with disability in the NWT/Nunavut to identify daily living tasks for which help was needed (eg. preparing meals, shopping for groceries, doing everyday housework, personal care, personal finances, moving about within one’s residence, doing heavy household chores). Most Aboriginal adults with disability needing help with these tasks were getting the help they needed.

3.2 Living with Various Types of Disability

Both with and without special aids/supports, persons with moderate to severe disability in the NWT face a variety of difficulties in daily living activities. Daily living challenges vary with the type of disability.

Physical Disability

Lifting, carrying, moving, standing and walking pose the greatest difficulties for persons with physical disabilities. (Table 15) Fewer people with physical disabilities have difficulties associated with working/participating in school or getting/keeping a job. Few people of working age (15-64 years) with physical disability participating in this Assessment are engaged in these daily living activities.

Table 15: Reported Difficulties With Daily Living Activities With and Without the Use of Special Equipment/Aids/Support by Persons with Physical Disabilities, NWT Needs Assessment 2000

Daily Living Activities	With n=244	Without n=379
Feeding, dressing, caring for self	97	155
Lifting, carrying, moving things	144	260
Standing for long periods	157	247
Walking	150	249
Getting in/out of bed	93	149
Bending down	117	184
Reaching, grasping or handling things	96	170
Picking things up	102	185
Working or participating in school	53	91
Getting or keeping a job	54	103
Participating in social/recreational activities	89	147
Playing sports	81	150

Note: A small number of persons with physical disabilities using special equipment/aids/supports also reported difficulty writing and doing housework. Those without special equipment/aids/supports also reported difficulty sewing, bathing, sitting and using stairs.

Persons with physical disability participating in this Assessment use an extensive range of special aids/equipment/supports. Among persons with physical disability:

- over one-half use a cane;
- more than one-quarter use a wheel chair;
- one-fifth use special transportation; and
- one-fifth have adaptations in the home. (Table 16).

Smaller numbers of persons with physical disability use other aids/equipment/ supports.

Table 16: Number of Persons with Physical Disability Who Use and Need Special Aids/Equipment/Support, NWT Needs Assessment 2000

Type of Special Aids/Equipment/ Support	Use Now (n=341)	Need Now (n=179)
Back brace	53	27
Prosthesis	13	6
Cane	194	29
Scooter	4	18
Wheel chair	95	24
Voice activated controls	4	8
Positioning devices	26	23
Special transportation	69	61
Adaptions to motor vehicles	11	32
Adaptions to home	69	70
Adaptions to work	21	35
Adaptions to community buildings	23	36
Special computer equipment	15	20
Long term care	11	11
Oxygen	8	0
Hand/wrist/arm/shoulder brace	8	1
Custom made shoes	5	2

Note: One or two people mentioned other supports such as PT/OT, support groups, various magnets/grabbers, and medications.

Persons with physical disability need adaptations to the home, work/school and community environments as well as special transportation. Persons with physical disability see their ability to participate in their communities being severely limited. They are unable to use fitness facilities, attend the theatre, find suitable housing, access some medical facilities or public services, or use public transportation. *“Doctors send us to physical fitness facilities that are not wheelchair accessible..... medical clinics such as (name of clinic) do not regularly or often enough, clean sidewalks of ice and snow. ...the clinic also does not move chairs aside to make (the) foyer wheelchair accessible....(name of another medical clinic) is inaccessible to persons with wheelchairs completely and dangerous to those with other limitations.”* (from Personal Questionnaire)

Hearing Disability

Even with the use of aids/supports, active and passive communication are the greatest challenges for persons with hearing disability. (Table 17) This Assessment found that only 9% of persons with hearing disabilities use sign language and 15% are able to speech or lip read. Hearing disability has significantly less impact on other facets of daily living, for example playing sports or getting/keeping a job. The reasons for this are likely related to the higher rate of hearing disability among elderly persons, who are less likely to be playing sports or to be in the workforce.

Table 17: Reported Difficulties With Daily Living Activities With and Without the Use of Special Equipment/Aids/Support by Persons with Hearing Disabilities, NWT Needs Assessment 2000

Daily Living Activities	With (n=71)	Without (n=155)
Communicating with others	42	100

Hearing what is being said	61	134
Understanding other people	49	110
Maintaining balance or posture	22	44
Hand/eye or physical coordination	16	31
Getting or keeping a job	12	32
Participating at work or school	16	34
Playing sports or keeping physically fit	13	31
Participating in social/recreation activities	25	58

Note: Without aids/supports, a small number of persons with hearing disabilities also identified difficulty in academic learning, attending public meetings, and using public or business facilities such as movie theatres.

The majority of persons with hearing disabilities who use special aids, equipment and/or support, have hearing aids. These aids are also needed by persons with hearing disability. (Table 18) Volume controlled phones are also used and are needed by about one-third of persons with hearing disability. Relatively few persons with hearing disability use adaptations in the home or in the work/school or community environments but these adaptations are needed.

Table 18: Number of Persons with Hearing Disability Who Use and Need Special Aids/Equipment/Support, NWT Needs Assessment 2000

Special Aids/Equipment/ Support	Use Now (n=97)	Need Now (n= 92)
Hearing aid	71	55
Caption decoder	8	15
Amplification/FM system	18	20
Special computer equipment	4	9
Oral/sign trans/interpretation	23	14
Other translation/aids	9	14

Flashing/visual alarms	12	21
Volume control phone	29	33
Home adaptations	7	21
Work/school adaptation	6	16
Community adaptations	2	21
Long term care	6	6

Speech Disability

Compared to persons with physical or other sensory disability, persons with speech disability experience more difficulties in daily living activities both with and without supports. They face particular difficulty in the work/school environments and in participating in social/recreation activities. (Table 19) The reasons for this may be related to the more youthful population who are affected by this disability.

Table 19: Reported Difficulties With Daily Living Activities With and Without the Use of Special Equipment/Aids/Support by Persons with Speech Disabilities, NWT Needs Assessment 2000

Daily Living Activities	With	Without
Making others understand	44	88
Getting or keeping a job	12	34
Participating at work or at school	21	55
Playing sports or keeping physically fit	15	37
Participating in social/recreation activities	29	54

Note: A small number of persons with speech disabilities also experience difficulty visiting within their communities and making/expressing decisions.

Unlike physical and hearing disability, the need for special aids/equipment/support among people with speech disability is greater than the current use. (Table 20) Among persons with speech disability, there is a significant unmet need for special computer equipment and software to cope with disability. They also need adaptations in the school/work environment.

Table 20: Number of Persons with Speech Disability Who Use and Need Special Aids/Equipment/Support, NWT Needs Assessment 2000

Special Aids/Equipment/ Support	Use Now (n=38)	Need Now (n=48)
Communication board	2	18
Special computer equipment/software	4	33
Speech viewer	6	17
Home adaptations	12	14
School/work adaptations	12	19

Community adaptations	0	15
Long term care	5	5
Speech therapy	3	0

Note: One or two people also mentioned tracheotomy tube, sign language, support workers, oxygen concentrator, prompt cards, medication and the special attention/support of caregivers/SNA.

Visual Disability

Even with supports/aids, persons with visual disability identify reading as the main difficulty encountered in daily living activities. (Table 21) Having access to appropriate materials/devices to enlarge or focus print is part of this problem. It is interesting to note that relatively few people with visual disability identify difficulty in the work/school environment. The reasons for this could be that younger persons with visual disability receive support in the school environment and elderly persons with visual disability tend not to participate in school or work environments.

Table 21: Reported Difficulties With Daily Living Activities With and Without the Use of Special Equipment/Aids/Support by Persons with Visual Disabilities, NWT Needs Assessment 2000

Daily Living Activities	With (n=81)	Without (n=144)
Feeding, dressing and/or caring for self	36	58
Moving around	38	81
Reading	52	101
Writing	39	82
Getting and keeping a job	20	36
Understanding things around me	33	62
Participating at work/school	12	25

Playing sports or keeping physically fit	26	39
Participating in social/recreation activities	28	53

Note: A small number of persons identified difficulty with or without aids/support sewing, housecleaning, watching TV and preparing food for family members.

Among persons with visual disabilities, magnification devices are the main aid used but large print materials are the aids needed the most. (Table 22) The need for adaptations, particularly in the home environment, is also substantial among persons with visual disability.

Table 22: Number of Persons with Visual Disability Who Use and Need Special Aids/Equipment/Support, NWT Needs Assessment 2000

Special Aids/Equipment/Support	Use Now (n=104)	Need (n=86)
Large print materials	27	48
Large computer monitor	10	46
Special computer software	8	25
Magnification devices	42	27
Braille materials	7	11
Braille equipment	3	7
Audio tapes	15	23
Mobility supports	21	17
Home adaptations	9	26
Work/school adaptation	8	11
Community adaptations	2	17
Glasses	23	0
Long term care	5	5

Note: One or two persons with visual disabilities also mentioned using laser surgery, a signature guide, or a TV reader/spectrum and needing larger print on community/business facilitates such as bank machines, more funding in schools to manage these disabilities or the need for a TV reader/spectrum.

Cognitive, Intellectual and Learning Disabilities

Persons with brain-related disabilities (eg. cognitive, intellectual or learning disability) face similar difficulties in daily living activities. (Table 23) Persons with these disabilities have difficulty understanding things around them, managing money and taking care of themselves, to name a few. These difficulties are more similar to those encountered by persons with speech disability than by persons with physical, hearing or visual disability. The difficulties faced by persons with cognitive, intellectual or learning disability are substantially diminished by the use of special aids/supports/equipment.

Table 23: Daily Living Activities Difficult With and Without the Use of Special Equipment/Aids/Support for Persons with Cognitive, Intellectual and Learning Disabilities, NWT Needs Assessment 2000

Daily Living Activities	Cognitive	Intellectual	Learning
Feeding, dressing and/or caring for self/home			
-With special equipment/aids/support	40 n=67	42 n=75	43 n=99
-Without special equipment/aids/support	60 n=102	84 n=132	80 n=163
Managing Money			
-With	-	46	48
-Without	-	88	91
Moving Around			
-With	37	28	32
-Without	47	45	54
Reading and/or Writing			
-With	34	45	58
-Without	58	86	105
Getting or keeping a job			
-With	20	35	33
-Without	33	75	73
Being understood by others around me			
-With	31	46	54
-Without	65	89	101
Understanding things around me			
-With	36	48	53
-Without	73	98	108
Participating at work or school			
-With	17	36	42
-Without	37	85	99
Playing sports or keeping physically fit			
-With	18	35	31
-Without	32	70	68

Participating in social/recreation activities			
-With	28	50	54
-Without	44	88	93

Note: A small number of persons with cognitive disability mentioned difficulties controlling physical strength or emotions, and remembering. A small number of persons with intellectual disability commented on the embarrassment they feel due to poor memory or difficulty getting to know people.

Similar aids/equipment/supports are used and needed by persons with cognitive and those with intellectual disabilities. (This Assessment did not collect information on special aids/equipment or supports used or needed by persons with learning disabilities.) Among persons with cognitive or intellectual disability, the need for special aids/equipment/supports is greater than current use. (Table 24) Barriers to using aids/support may be related to costs that are not covered by health insurance plans or the availability of the service (due to lack of home/community support workers oriented/skilled to provide services).²⁸

Table 24: Number of Persons with Cognitive or Intellectual Disability Who Use and Need Special Aids/Equipment/Support, NWT Needs Assessment 2000

Special Aids/Equipment/Support	Cognitive		Intellectual	
	Use Now (n=46)	Need Now (n=43)	Use Now (n=56)	Need Now (n=74)
Equipment to help learning	-	-	16	55
Equipment to help movement	26	13	-	-
Equipment to manage/ organize info	3	19	18	47

²⁸ issues raised by Stanton Regional Hospital's Rehabilitation team.

Special computer equipment	0	17	7	51
Home adaptations	12	16	24	25
Work/school adaptations	9	12	23	36
Community adaptations	5	13	5	25
Long term care	8	6	2	0
Support workers/special needs assistant	-	-	12	2

Note: One or two persons with intellectual disabilities also identified the use of literacy workshops and medication, and the need for peer support.

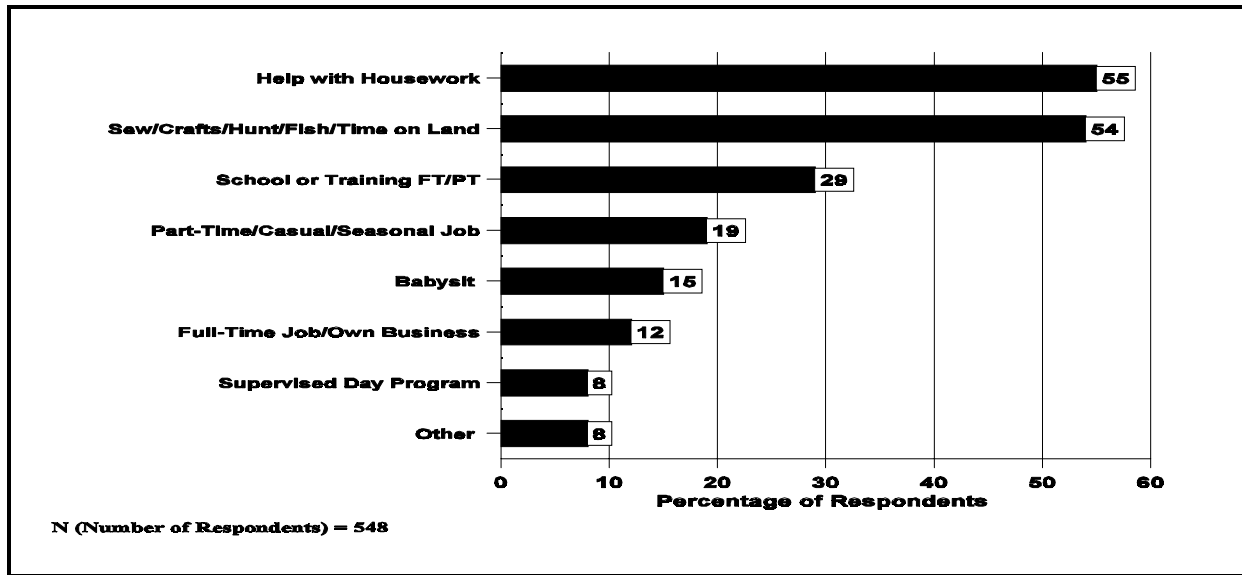
Currently, persons with cognitive disability use equipment to assist in movement while persons with intellectual disability mainly use adaptations in the home and work/school environment. The need for equipment to help in learning is great among persons with intellectual disabilities. Among persons with a cognitive or an intellectual disability, the need for equipment to manage/organize information is high.

3.3 Work, Home, School, Recreation and Leisure Activities

Of the 807 persons with disability who participated in this Needs Assessment, 68% described their work, home and/or school activities, and 88% described social recreation and leisure activities. Those who did not provide information may not be engaged in any of these activities.

Figure 17 displays the main daily work, home and/or school activities of persons with disability. Adults and elderly persons with disability participating in this

Figure 17: Daily Activities at Work, Home and/or School by Percent of Persons with Disability, NWT Needs Assessment 2000



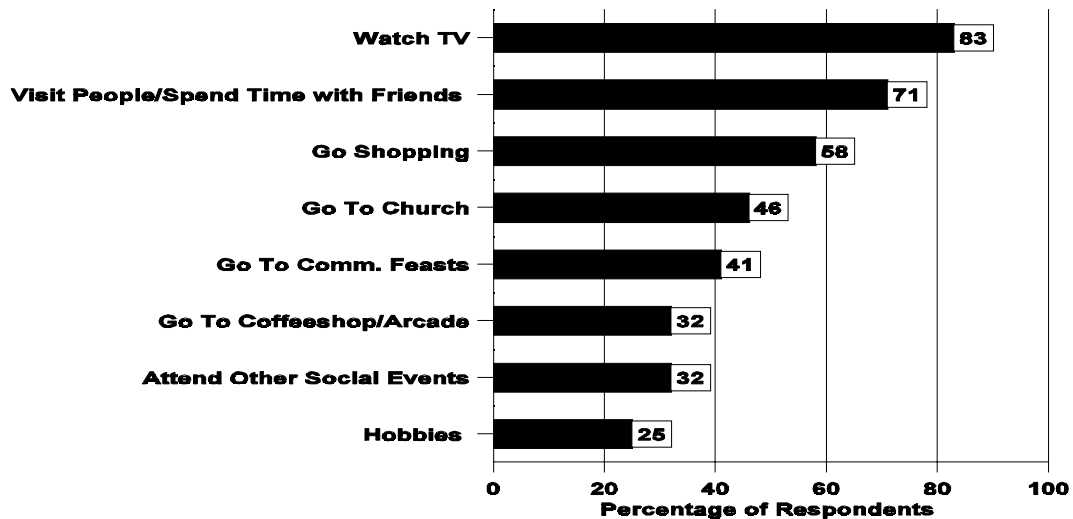
Assessment are engaged mainly in work in the home including sewing or harvesting/land-based activities. Almost all (96%) children of school age participating in this Assessment go to school full or part-time or attend a supervised program for children.

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.²⁹ The 1991 HALS reported the main social, recreation and leisure activities of NWT/Nunavut persons with disability as: watching television/listening to radio/music, shopping, and attending social activities including visiting with family and friends. As shown in Figure 18, this Assessment found that watching TV (83%) and visiting or spending time with people (71%) are the main social/ leisure activities of

²⁹ from the Canadian Fitness Leisure Research Institute republished by GNWT Municipal and Community Affairs, 2000

persons with disability in the NWT.

Figure 18: Daily Social, Recreation and Leisure Activities by Percent of Persons with Disability, NWT Needs Assessment 2000



N (Number of Respondents) = 710

This Needs Assessment found that the social, recreation and leisure activities of persons with disabilities do not vary substantially with the size of community and presumably, the variety of social, recreation and leisure options available. Among persons with disabilities living in smaller communities:

- 82% of persons with disabilities watch TV;
- 75% visit people or spend time with friends;
- 59% go shopping;
- 59% go to community feasts;
- 57% go to church; and
- 49% go to community dances.

Among persons with disabilities living in the larger communities of

Yellowknife, Hay River, Fort Smith and Inuvik:

- **84% of persons with disabilities watch TV;**
- **67% visit people or spend time with friends;**
- **57% go shopping;**
- **37% go to coffee shop; and**
- **35% go to church.**

The 1994 National Population Health Survey provides information on the level of physical activity among NWT persons 12 years of age and older. Just over half (51%) of this population were considered inactive; 18% had a moderate level of activity; and 31% were considered active. This Assessment did not ask persons with disability specific questions about their level of physical activity but a small percentage (13%) indicated that they have joined a physical fitness or sports group and 3% said that they exercise.

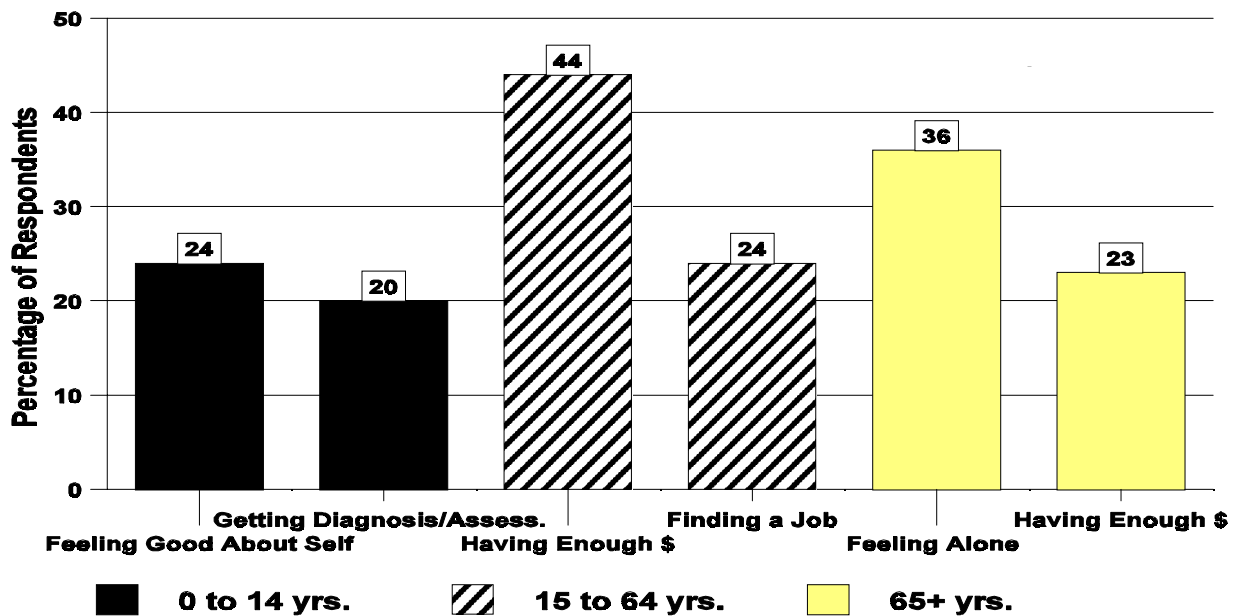
3.4 The Major Challenges of Living with Disability

Persons with disability in the NWT encounter tremendous challenges in daily living. Problems most frequently identified are:

- having enough money (33%).
- feeling alone (23%).
- feeling good about myself (19%).
- getting help from family members (18%).
- getting help with day to day living (17%).

The challenges faced by persons with disability change with age. (Figure 19)

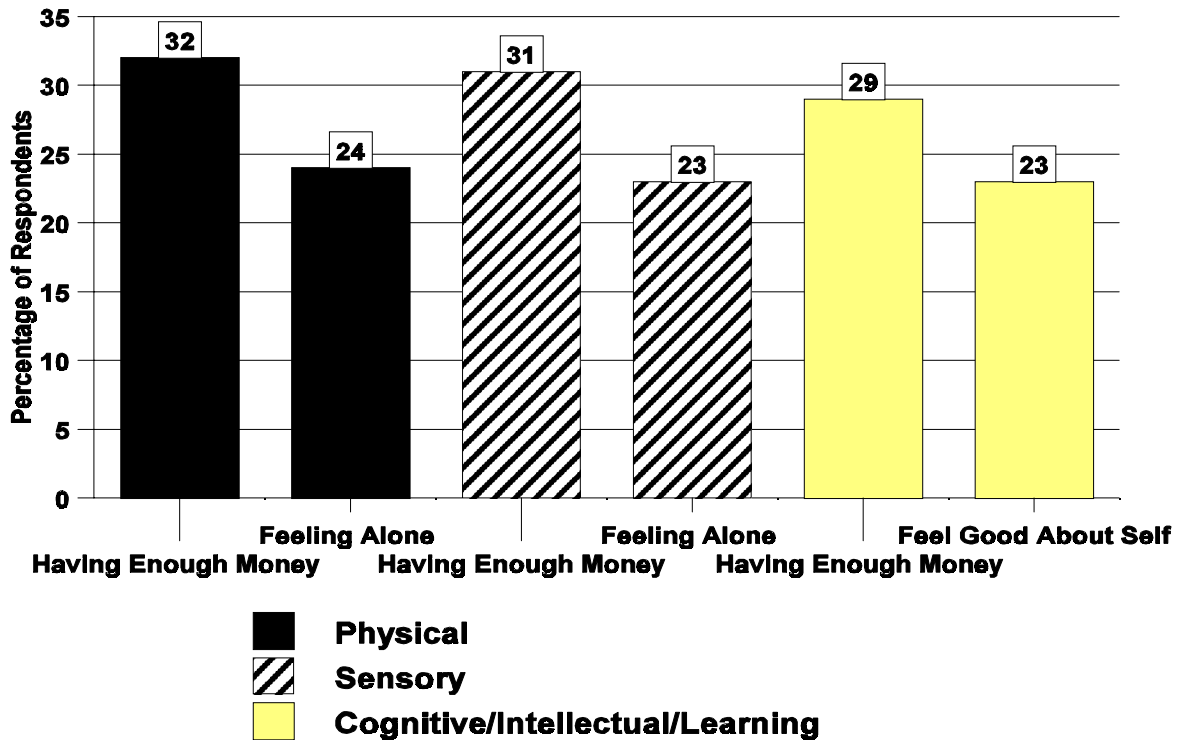
Figure 19: Main Problems Faced in Daily Living by Age and Percent, NWT Needs Assessment 2000



- Children have problems maintaining self-esteem and getting a diagnosis or assessment.
- Adults mainly encounter financial and employment problems.
- Seniors face loneliness and financial issues.

Lack of financial resources is the number one problem facing persons with disability regardless of the type of disability they have. (Figure 20) This is not surprising given that most adults participating in the Needs Assessment have personal and household incomes of less than \$20,000/year and live in

Figure 20: Main Problems Faced in Daily Living with Disability by Type and Percent, NWT Needs Assessment 2000



communities with costs of living (exclusive of shelter) that are as much as 110% higher than in Edmonton.³⁰

NWT community service providers were asked to identify the problems they believe that persons with disability face. They perceive persons with disability being challenged by:

- the lack of programs and services, (49.3%)
- getting programs/services from qualified people, (31.1%) and
- loneliness and isolation. (25.7%)

Some service providers agree that getting professional diagnosis/assessment (22.2%) and getting support from family members

³⁰GNWT Bureau of Statistics

(21.5%) also challenge persons with disability.

This Assessment did not examine in any detail, the extent to which persons with disability have quality of life. Anecdotal information provided by persons with disability suggests that while people participate in activities, the quality of this participation may be less than that enjoyed by other members of society. Loneliness, inadequate financial resources and getting help from people around them are some of the factors impacting on quality of life.

“Acute hearing loss separates one from most social activities. I go to church but miss the sermon. I go to meetings but come out uninformed. I can carry on a conversation one to one but not in a crowd.” (from Personal Questionnaire)

“Disabled people have a culture of their own, which varies somewhat according to the specific disability. Society needs to become more aware of the disability culture and the sub-cultures.... Society must also become more accepting and willing to assist whenever/however it can. Only then will people with disabilities truly feel a part of society.” (from Personal Questionnaire)

3.5 Parent/Caregiver Perspectives on Living with Disability

Unpaid caregivers/parents mainly care for children (38%) and working age adults (37%) who are immediate family members. One-quarter (25%) of parents/ caregivers care for persons 65 or more years of age. Persons cared for are more likely to be male than female.

The vast majority (86%) of parents/caregivers say the person with a disability whom they care for, lives with them all of the time. For most (79%) of these caregivers, this means 10 or more hours of care each week. Almost half of parents/caregivers (49.8%) provide constant or 24 hour care and supervision.

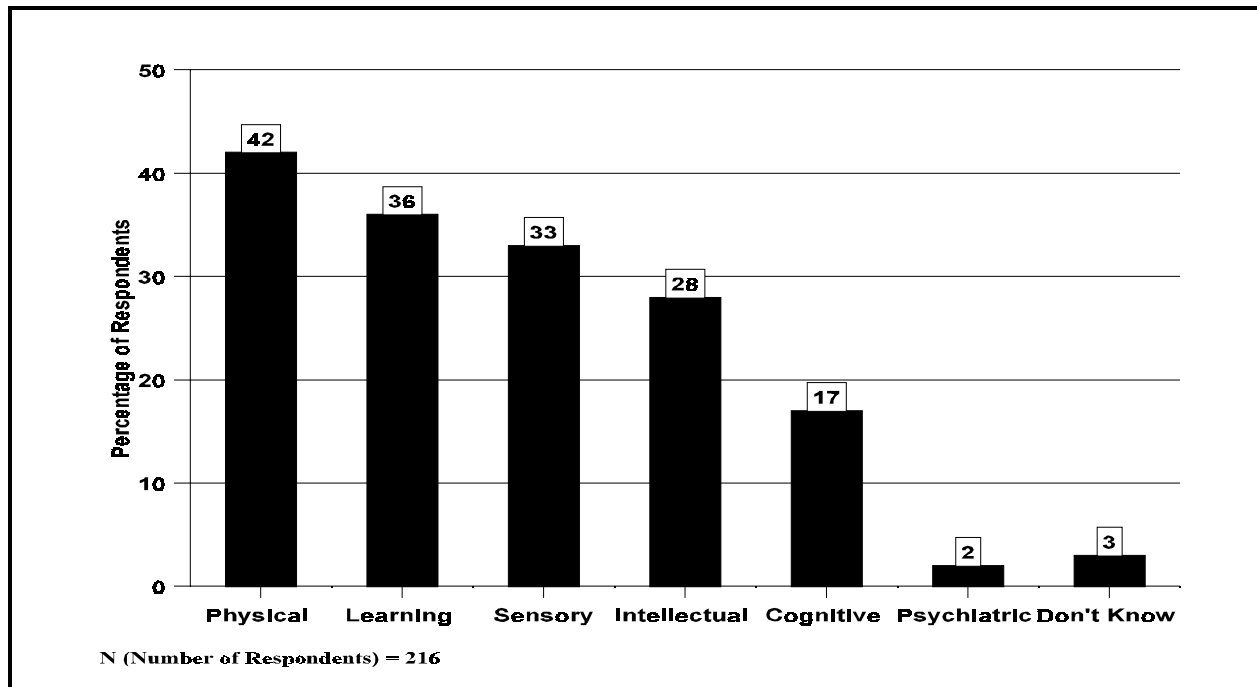
Parents/caregivers of persons with disability participating in this Assessment provide care to persons with a range of disabilities. Physical, sensory and learning disabilities are mainly found among persons cared for. (Figure 21)

Thirty-seven percent (37%) of parents/unpaid caregivers give care to persons with multiple disabilities.

Parents/caregivers described the behaviours/characteristics of disability of the person cared for. Most frequently, parents/caregivers identify delay developing, difficulty with and/or loss of:

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

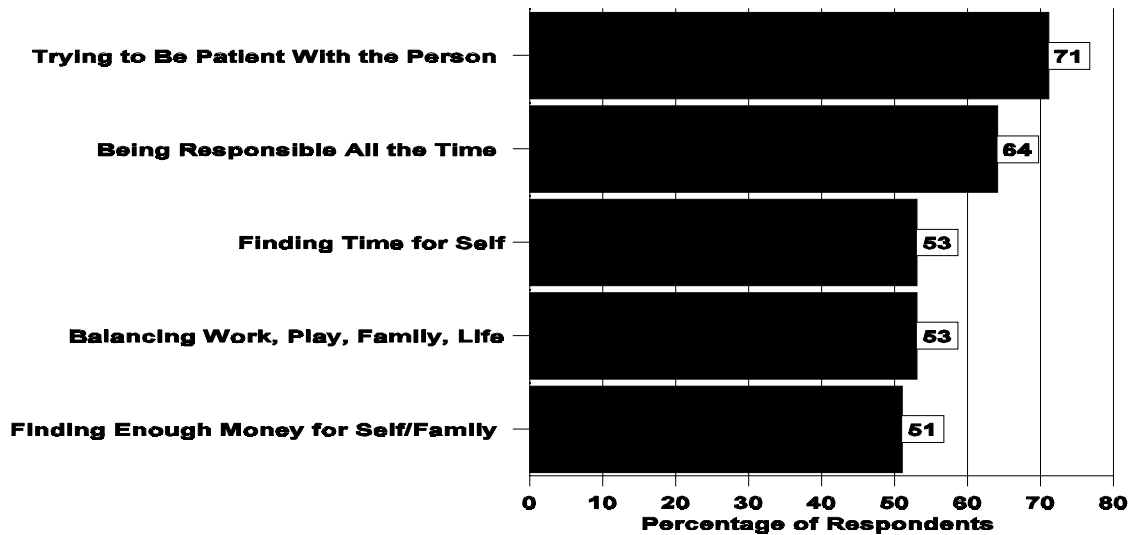
Figure 21: Type of Disability of Person Cared for by Percent of Parents/Caregivers, NWT Needs Assessment 2000



Parents/caregivers of persons with disability face a range of challenges in providing care to persons with disability. (Figures 22 and 23) Personal challenges are significant and seem not to be influenced by the age of the person cared for, the nature or severity of the disability, or the time required to give care. Parents/caregivers of persons with disability require an inordinate amount of patience and sense of responsibility to give care and to manage daily living challenges. Responding to the personal care needs, negative behaviours and poor communications of persons in their care, are difficult for many parents/caregivers. These challenges are exacerbated by difficulties finding professional and community supports/services, and having adequate financial resources. Parents/caregivers also encounter safety and attitudinal issues in their role

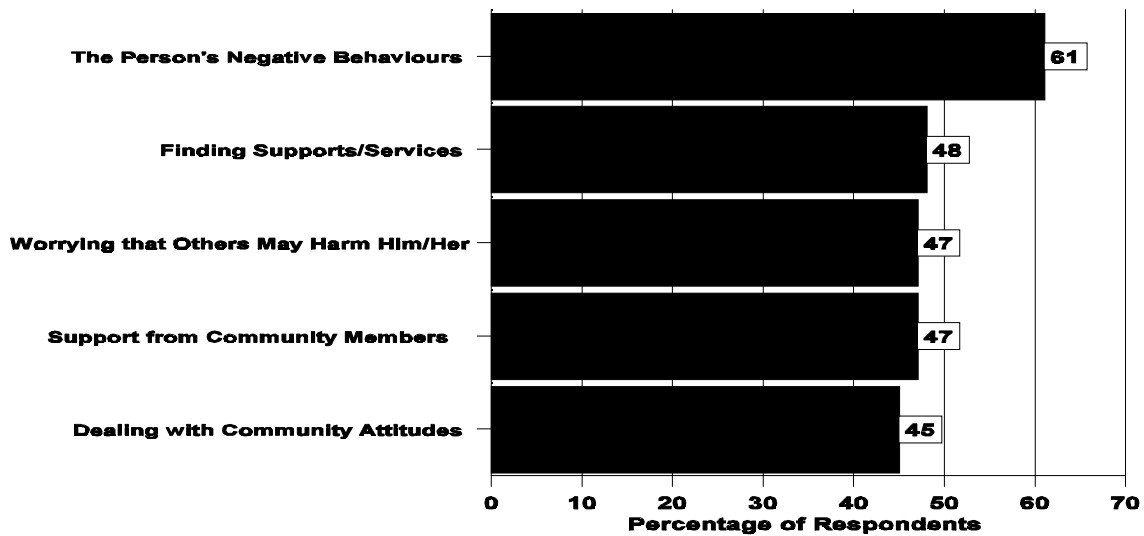
as caregivers. The challenges confronting NWT parents/caregivers of

Figure 22: Personal Challenges Faced by Parents/Caregivers of Persons with Disabilities, NWT Needs Assessment 2000



N (Number of Respondents) = 217

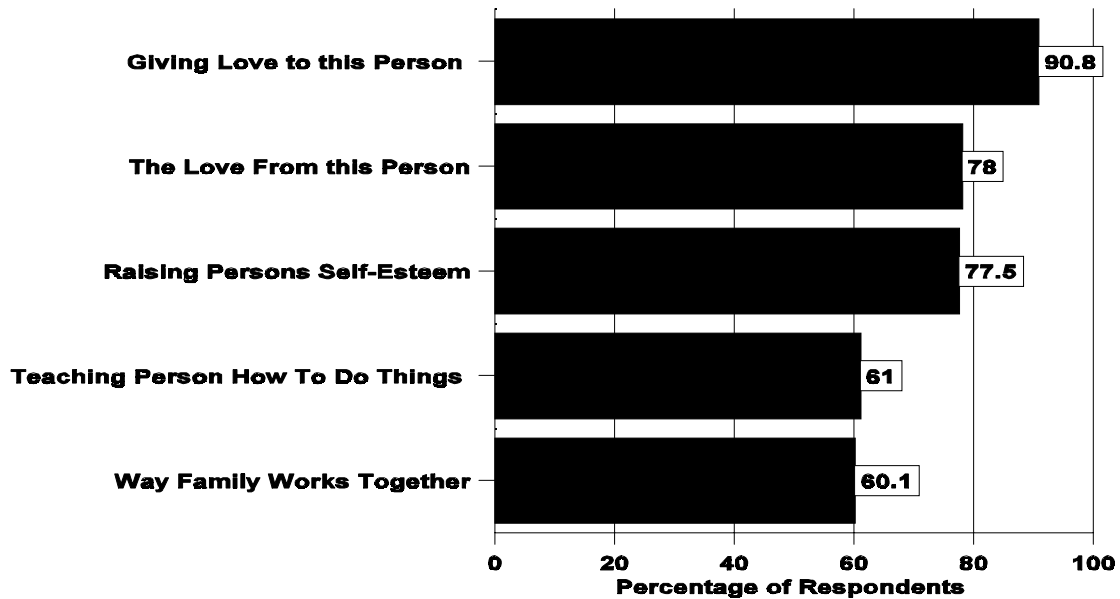
Figure 23: Other Challenges Faced by Parents/Caregivers of Persons with Disabilities, NWT Needs Assessment 2000



persons with disabilities point to the need for respite, training, support services and financial assistance.

Parents/caregivers encounter tremendous challenges in caring for persons with disability but they are clear about the rewards of giving care. Giving love to persons with disability is the greatest reward. (Figure 24)

Figure 24: “Good” Things About Caring for Persons with Disability by Percent of Parents/Caregivers, NWT Needs Assessment 2000



N (Number of Respondents) = 218

4. Programs and Services

What programs/services are used and needed now by persons with disabilities? What programs/services will be needed in the future? What concerns do persons affected by disability have with respect to programs/services? These questions are answered in this chapter. It should be kept in mind that:

- program/service needs refer to those needs of persons with moderate to severe disability.
- familiarity and access to programs and services may result in under-estimates of use and need among persons where programs/services are limited.

In 1999, an estimated 5,543 people living in NWT households had some

degree of disability. Of these people, 1780 have a moderate to severe degree of disability and 3,763 have mild disability.

- By the year 2004, there may be 5,910 persons with disability in the NWT of which 1,982 will have moderate to severe disability.

As shown in Appendix F, the population with moderate to severe disability is estimated to be 2,276 in 2009 and 2,919 by the year 2019. Persons with moderate to severe disability are more likely to use and need programs and services than persons with mild disability.

Community service providers participating in this Assessment agree that over the next five years, there will be more people in their communities with some type of disability.

- More than one-third (35%) of community service providers anticipate that the NWT population with disability will increase by 6%-10% over the next five years.
- Another third (34%) expect the population with disability to grow by 1%-5% while 31% forecast increases of 11%-15%.

Most community service providers (81%) identify the high use of alcohol, drugs and solvents as the main factor contributing to a likely increase in the population with disability. Abuse and neglect and an aging population are other factors expected to contribute to a larger population with disabilities. The program/ service needs of an increasing population of persons with disability together with the needs of caregivers will significantly impact on programs/services in the NWT.

“Our biggest challenges are and will be dealing with cognitively impaired.”
(from Community Service Provider Questionnaire)

“FAS/FAE are on the rise.” (from Community Service Provider Questionnaire)

“FAS impacts the whole community.” (from Community Service Provider Questionnaire)

4.1 Current and Future Program/Service Needs Among Persons with Disability in the NWT

Generally, programs and services are available to all NWT persons in need, at no cost to the user. Three-quarters (75%) of parents/caregivers of persons with disability say they do not pay for the services they use now. Similarly, community service providers (77%) say that no fee is charged for the programs/services they deliver to persons affected by disability. Among those providers who charge for the program/service, 5% charge the full cost of the service while the remainder levy a nominal or a fee based on income.

Persons with disabilities in the NWT currently use and need a variety of programs and services. In this Needs Assessment, programs/services were segmented into 10 main types. The Needs Assessment found that:

- the current demand exceeds the availability and/or the capacity of existing programs/services.
- there are nearly as many people who still need services as there are people receiving them now. It is interesting that roughly an equal number of Aboriginal adults with mainly mild disability enumerated in the 1991 Aboriginal Peoples Survey in the NWT/Nunavut needing help in daily living activities were getting the help they needed.
- 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 demand for programs/services among persons with moderate to severe disability in the NWT is discussed below and shown in Tables 25 to 34.³¹

Medical/Physical Health Services

Medical/physical health services are available in every community in the NWT. In smaller communities, a basic level of service is available. More complex and a greater variety of services are available in larger centres. Compared to all other types of services, medical/physical health services are the most widely used by persons with disability. General medical care/treatment, testing/diagnosis/ assessment, referral services and home/personal care are the most frequently used services. (Table 25) These and other medical/physical health programs/ services, particularly occupational therapy and physiotherapy, will be needed in the future.

“(Living with disability is)Feeling pain all the time. Feeling alone with the illness.” (from Personal Questionnaire)

Table 25: The NWT Demand for Medical/Physical Health Services in 2000, 2004 and 2009 by Number of Persons with Moderate to Severe Disability

³¹This Needs Assessment involved one-third of the estimated 1,780 persons with moderate to severe disability living in households in the NWT. To provide estimates of the total demand for programs/services by persons with moderate to severe disability living in households in the NWT, the data shown in Tables 25 to 34 are three times that reported by Needs Assessment respondents.

Program/ Service	Use Now	Need Now *	Total 2000 Demand n=1780	Total 2004 Demand n=1982	Total 2009 Demand n=2276
Testing/Diagnosis/Assessment	1026	198	1224	1368	1570
Referral Services	894	177	1071	1189	1366
General Medical Care/ Treatment	1194	141	1335	1487	1707
Occupational/Physiotherapy	534	222	756	832	956
Audiology/Ophthalmology	465	135	600	673	774
Speech/Language Pathology/ Development	210	138	348	396	455
Health Counselling or Promotion	213	198	411	456	523
Home/Personal Care	591	210	801	892	1024
Alternative Therapy/Treatment	162	189	351	396	455

Note:

**Need now" refers to services needed but not received now.

The Needs Assessment involved one-third of the estimated 1,780 persons with moderate to severe disability. The total demand for programs/services in 2000 is three times that identified in the Needs Assessment. The demand for programs/services in 2004 and 2009 assumes the same ratio of demand as in 2000.

Anecdotal information provided in Personal Questionnaires by persons with disability suggests that the need for alternative therapy/treatment is driven by high levels of chronic pain and discomfort, and lack of relief through mainstream/existing services/treatments. While alternative therapy/treatment was not defined, examples given over the course of the Assessment include traditional Aboriginal medicines and healing practices, massage therapy, acupuncture and healing/treatment approaches from other cultures such as Asian cultures.

“Doctors don’t know about Dene medication. They don’t understand us elders.” (from Personal Questionnaire)

Community service providers of mental/physical health services are concerned that there are not enough staff to serve persons with disability and/or their families who need or want occupational therapy, physiotherapy, speech/language pathology/development and alternative therapy/treatment.

“What I need is somebody to help when (I’m) in pain. Some one to help.”
(from Personal Questionnaire)

Social and Mental Health Services

Most communities in the NWT offer social services through a government agency(ies) or on a project-specific basis through First Nation or community organizations. Like other human services in the NWT, the range of social and mental health services available is proportionate to the size of the population served.

Loneliness and feeling good about themselves are among the daily living problems faced by persons with disability in the NWT. These issues are particularly critical for the young and for the old, regardless of the type of disability they have. (see Figures 19 and 20, pg. 62 and 63) The issues of loneliness, isolation and self-esteem have been raised in a wide variety of NWT research as key factors in high risk behaviours including suicide, early school leaving and violence.³²

³²Peart, M. and King, A.J.C. January 1996. Health Behaviours, Attitudes and Knowledge of Young People in the Northwest Territories. Education, Culture and Employment. GNWT

“Nobody visits me. I can’t walk very far. I feel very sad and lonely.” (from Personal Questionnaire)

To deal with social and mental health needs, persons with disability in the NWT mainly use personal supports (eg. local support groups). Special equipment/aids such as workshops and resource materials, are the greatest unmet need. (Table 26) The demand for personal supports including personal and family counselling, and special equipment/aids is expected to continue in the future.

As shown in Table 26, the need for addictions counselling and treatment services and alternative therapy is more than double the current use of these services. The demand for alternative services may be due to a lack of success using or accessing mainstream programs. In the case of addictions services, persons with disability may have difficulty accessing these programs due to the closure of treatment/rehabilitation programs in Yellowknife and Inuvik in recent years.

“There are no support groups or special programs for disabled people.” (from Personal Questionnaire)

Table 26: The NWT Demand for Social and Mental Health Services in 2000, 2004 and 2009 by Number of Persons with Moderate to Severe Disability

Program/Service	Use Now	Need Now*	Total 2000 Demand n=1780	Total 2004 Demand n=1982	Total 2009 Demand n=2276
Personal Supports	531	249	780	872	1001
Specialized Intervention/ Program	171	192	363	396	455
Special Equipment, Aids, Tools	393	303	696	773	888
Personal or Family Counselling	189	207	396	436	501
Addictions Counselling or Treatment	63	144	207	238	273
Psychological or Psychiatric Help	135	135	270	297	341
Diagnosis or Assessment	390	186	576	634	728
Referral or Information	333	177	510	535	615
Parenting Support	150	96	246	277	319
Alternative Therapy/Treatment	99	195	294	337	387

Note: *"Need now" refers to services needed but not received now.

The Needs Assessment involved one-third of the estimated 1,780 persons with moderate to severe disability. The total demand for programs/services in 2000 is three times that identified in the Needs Assessment. The demand for programs/services in 2004 and 2009 assumes the same ratio of demand as in 2000.

Community providers of social and mental health services believe that there are adequate program/service staff to provide referral services for persons with disabilities and their families who want or need these services. However, there are insufficient staff to serve those persons affected by disability who need or want other social and mental health services listed in Table 26. 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. Economies of scale limit housing options in small communities. Housing subsidies are used now and are the greatest unmet need among persons with disabilities in the NWT. Demand for accommodation subsidies are expected to continue in the future. Demand is likely due to low income levels and high unemployment among persons with disability in the NWT.

Persons with disabilities also identify a significant unmet need for help fixing or modifying the home. (Table 27) The extent of this need is almost equal to the number of persons with disability now receiving housing subsidies. This demand

Table 27: The NWT Demand for Accommodation/Housing Services in 2000, 2004 and 2009 by Number of Persons with Moderate to Severe Disability

Program/Service	Use Now	Need Now*	Total 2000 Demand n=1780	Total 2004 Demand n=1982	Total 2009 Demand n=2276
Housing Referral or Information	210	177	387	436	501
Help Fixing/Changing the Home	144	306	450	496	569

Accommodation/Housing Subsidy/Money	330	252	582	654	751
Special Accommodation/Group Home	324	126	450	496	569

Note:

*"Need now" refers to services needed but not received now.

The Needs Assessment involved one-third of the estimated 1,780 persons with moderate to severe disability. The total demand for programs/services in 2000 is three times that identified in the Needs Assessment. The demand for programs/services in 2004 and 2009 assumes the same ratio of demand as in 2000.

is consistent with the needs expressed by NWT persons with disabilities for adaptations in the home to help cope with daily living activities. (shown in Tables 15-24, pages 50-58)

Persons with disabilities also indicate a need for special accommodation/group home programs/services. This need may arise from affordability issues or from concerns about loneliness and isolation, two significant daily living problems identified throughout this Needs Assessment.

"Due to illness, I need to be around people I feel comfortable with. I need to live with people not on my own." (from Personal Questionnaire)

Community service providers of accommodation/housing services identify a shortage of staff to provide services to persons affected by disability who need or want them. Providers identify the main service shortfall as special accommodation/group home programs/services.

"I am 89 years old, who will look after my son?" (from Parent/Caregiver)

Questionnaire)

Housing for persons with disability is not an immediate concern of parents/caregivers of persons with disability.

- A significant number of parents/caregivers of persons with disability have not considered or do not know where the person they care for would live, should a change in living arrangements be required.
- One-third of parents/caregivers (33%) felt that the person with disability would be cared for by another family member.
- Another one-fifth (20%) expect that the person could move to a community facility.

Lack of contingency planning may pose risks for persons with disability given the shortage of suitable and affordable housing in most NWT communities.³³

Income

“Being blind, it’s hard because there’s not enough \$ to take care of myself. How come there’s no funding for disabled people?” (from Personal Questionnaire)

‘Having enough money’ is the main difficulty for persons with disability. Most (80%) persons with moderate to severe disability in the NWT have personal and household incomes below the national poverty level of \$20,000. (Figure 8 pg. 34) Only 16% of persons with moderate to severe disability who are 15 or more years of age are employed or run a business. Only a small number of persons with disability have income from a pension or disability benefit. (The Workers Compensation Board provides pensions

³³1999 NWT Housing Survey

to 248 persons in the NWT with permanent long term disability.)

“ One year ago I found out I have a condition called Primary Pulmonary Hypertension. I don’t know how long I’ll be able to work. Haven’t paid enough CPP for disability pension. I don’t know how I will be funded.”
(from Personal Questionnaire)

“ Because of my condition, I cannot work and the Income Support is not enough to support my children and myself.” (from Personal Questionnaire)

Next to medical/physical health and social/mental health services, income support is in greatest demand by persons with disability. About 40% of persons with disability use or need income support now. (Table 28) Over half (52%) of adults with disability use, need or will need income support. There is also an unmet need for budgeting and financial information.

Table 28: The NWT Demand for Financial Assistance in 2000, 2004 and 2009 by Number of Persons with Moderate to Severe Disability

Program/Service	Use Now	Need Now*	Total 2000 Demand n=1780	Total 2004 Demand n=1982	Total 2009 Demand n=2276
Income Support, Subsidy or Basic Needs	501	219	720	793	910
Budgeting or Money Management Help	159	186	345	377	432
Financial Info/Advice	75	204	279	317	364

Note: *" Need now" refers to services needed but not received now.

The Needs Assessment involved one-third of the estimated 1,780 persons with moderate to severe disability. The total demand for programs/services in 2000 is three times that identified in the Needs Assessment. The demand for programs/services in 2004 and 2009 assumes the same

ratio of demand as in 2000.

In some communities, the Income Support Program has placed persons with disability on a payroll system, meaning that cheques are issued regularly and sent by mail. This system streamlines services and may contribute to the view of community service providers that financial assistance programs/services listed in Table 28 have adequate staff to serve the people with disability and their families needing or wanting these services.

“Having a program set up specifically for people with disability. We don’t have to continuously go to get forms filled out every month.” (from Personal Questionnaire)

Life Skills, Employment and Residential Supports

Persons with moderate to severe disability in the NWT between the ages of 15 and 64 identify the main problems faced in daily living as having enough money and finding a job. (see Figure 19, pg. 62) With 61% of persons with moderate to severe disability having less than grade 9 education, opportunities to secure a job and have enough money to live with dignity are limited. Further, as discussed in sections 3.1 and 3.2 of this report, the unmet need for specialized aids, equipment and supports to enable persons with disabilities to participate in the work place or at school present even more challenges.

“ There is no one in the NT who can teach ASL (American Sign Language)”.
(from Personal Questionnaire)

Compared to medical/physical health and social services, fewer persons

with moderate to severe disability use life skills training or job supports. The reason for this may be limited availability of these services in communities outside of Yellowknife. The need for these services now is as great or greater than the current use. (Table 29) Information provided in Personal Questions indicates that the demand for life skills training, in-home support and job coaching will continue in the future.

Community service providers suggest that there are adequate staff to provide general personal/family/emotional help to persons with disability and their families needing or wanting this program/service. All other programs/services listed in Table 29 are understaffed to meet demand by persons affected by disability. Paid residential support is severely understaffed to meet the demand for people with disability and their families who want or need this service. The Yellowknife Association for Community Living has lent its expertise to several communities in the NWT (eg. Fort Simpson, Rae-Edzo and Inuvik) in the hope of developing a network of supports for persons with intellectual disabilities. Few of these developmental efforts have resulted in a base of life skills, employment and residential supports in communities outside of Yellowknife due to funding issues.

Table 29: The NWT Demand for Life Skills, Employment and Residential Supports in 2000, 2004 and 2009 by Number of Persons with Moderate to Severe Disability

Program/Service	Use Now	Need Now*	Total 2000 Demand n=1780	Total 2004 Demand n=1982	Total 2009 Demand n=2276
Paid Residential Support	192	105	297	337	387
Life Skills Training	99	162	261	297	341
In-Home Support/Assistance	156	159	315	357	410
Personal/Family/Emotional Support	189	159	348	396	455
Employment or Job Coaching	84	162	246	277	319
Special Equipment, Aids, Tools	135	126	261	297	341

Note:

*"Need now" refers to services needed but not received now.

The Needs Assessment involved one-third of the estimated 1,780 persons with moderate to severe disability. The total demand for programs/services in 2000 is three times that identified in the Needs Assessment. The demand for programs/services in 2004 and 2009 assumes the same ratio of demand as in 2000.

Education and Training for Adults

The demand for adult education and training programs/services among NWT adults with moderate to severe disability is similar to life skills, employment and residential supports. (Table 30) Aurora College Community Learning Centres operate in only 11 NWT communities and funding for adult literacy and basic education has significant diminished in recent years.

Table 30: The NWT Demand for Education and Training Services in 2000, 2004 and 2009 by Number of Adults with Moderate to Severe Disability

Program/Service	Use Now	Need Now*	Total 2000 Demand n=1780	Total 2004 Demand n=1982	Total 2009 Demand n=2276
Job Skill Development	96	171	267	297	341
Job Training	114	168	282	317	364
Education Program/ Academic Upgrading	126	198	324	357	410
Individualized Education/ Training Service	87	174	261	297	341
Specialized Speech or Language Services	15	114	129	139	159
Personal or Special Needs Assistance	90	138	228	258	296
Personal or Family Counselling	69	123	192	218	250
Special Equipment, Aids, Tools	87	141	228	258	296

Note:

*"Need now" refers to services needed but not received now.

The Needs Assessment involved one-third of the estimated 1,780 persons with moderate to severe disability. The total demand for programs/services in 2000 is three times that identified in the Needs Assessment. The demand for programs/services in 2004 and 2009 assumes the same ratio of demand as in 2000.

The unmet need for adult education and training services is greater than current use. Education program/academic upgrading, job training, job skill development and individualized education/training are the services most frequently used and needed now. (Table 30) According to Personal Questionnaires completed by adults with disabilities, job skill development

and job training will likely continue to be required in the future.

Adult education and training programs/services in NWT communities seem to be limited. In communities where these programs are available, waiting lists are long and persons needing basic education may be a lower priority than those with higher levels of education (eg. those who can enter a college-level program). Limited access to education and training programs was perceived by one person with disability as “*schools do not accept disabled people*”. In other cases, access is limited by the financial resources available to assist persons with disability to attend adult or post-secondary education and training programs.

“Sometimes (it is) hard for me to read and difficult to get help. Have to go to income support. Want to learn how to read and write. Frustrated about things (and) get angry.” (from Personal Questionnaire)

Community service providers believe that adult focussed education and training programs and services are severely under-staffed. Persons completing the Community Service Provider Questionnaire reported that virtually all of the services listed in Table 30 except for the provision of special equipment, aids and tools, have one-third to one-half of the staff needed to respond to the demand for adult education and training among persons affected by disability.

Education and Training for Children and Youth

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 in 2000, will provide more comprehensive information on

program and service needs among school-age children with disability.

This Needs Assessment found that the main problems faced by children (0-14 years) with moderate to severe disability are related to self-esteem/feeling good about themselves and to getting a diagnosis/assessment. (Figure 19, pg.62)

Among the small number of school aged children with moderate to severe disability who participated in this Assessment, the unmet need for education and training services is similar to current use. (Table 31) Those services used and needed now are personal help in the classroom, an individualized education plan (IEP) and/or specialized speech or language services. There is also an unmet need for personal counselling, school readiness or other preschool programs and special equipment. Information provided in Personal Questionnaires indicates that the demand for IEPs and personal counselling is expected to continue into the future.

Table 31: The NWT Demand for Education and Training Services in 2000, 2004 and 2009 by Number of Children/Youth with Moderate to Severe Disability

Program/Service	Use Now	Need Now*	Total 2000 Demand n=1780	Total 2004 Demand n=1982	Total 2009 Demand n=2276
School Readiness/Other Preschool Program	90	66	156	178	205
Individualized Education Plan	108	90	198	218	250
Specialized Speech or Language Services	102	90	192	218	250

Personal or Special Help in the Classroom	142	111	253	277	319
Personal Counselling	72	99	171	198	228
Special Equipment, Aids, Tools in School	69	99	168	178	205

Note: *"Need now" refers to services needed but not received now.

The Needs Assessment involved one-third of the estimated 1,780 persons with moderate to severe disability. The total demand for programs/services in 2000 is three times that 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 identify a severe shortage of staff to serve children/ youth with disability who need or want education and training programs. Special speech and language services are seen as severely understaffed. Speech and language difficulties are major barriers to participation in work, school, social and recreational activities.

Legal Services

This Assessment found that NWT communities are concerned about the lack of services for and/or recognition of brain-related disabilities and the impact to the individual and the legal system. Persons with these disabilities may be unable to assess the consequences of certain actions and find themselves in conflict with the law. Few persons with disability participating in this Needs Assessment use or need legal services. (Table 32)

Table 32: The Demand for Legal Services in 2000, 2004 and 2009 by Number of Persons with Moderate to Severe Disability

Program/Service	Use Now	Need Now*	Total 2000 Demand n=1780	Total 2004 Demand n=1982	Total 2009 Demand n=2276
Probation Supervision	12	9	21	20	23
Placement Services	15	30	45	59	68
Community Justice/ Local Supports	16	39	55	59	68
Legal Aid	48	48	96	99	114
Mediation, Negotiation, Advocacy	96	57	153	178	205

Note: *"Need now" refers to services needed but not received now. The Needs Assessment involved one-third of the estimated 1,780 persons with moderate to severe disability. The total demand for programs/services in 2000 is three times that identified in the Needs Assessment. The demand for programs/services in 2004 and 2009 assumes the same ratio of demand as in 2000.

Mediation/negotiation and legal aid are services most frequently used and needed now. In data collected on 'other' programs/services (Table 34), the Needs Assessment found that use of guardianship/trusteeship or supported decision-making services is also high.

In most cases, community service providers believe that legal programs/services are adequately staffed to meet the needs of persons affected by disability who need or want the services listed in Table 32. Information provided in the Community Service Provider Questionnaire indicated a shortage of staff to provide placement services to persons affected by disability.

Protection Services

In a discussion of children in care, the 1999 NWT Health Status Report states that “ *many of these children have behavioural problems which may be the result of developmental delays, FAS/FAE, poor parenting skills or general neglect. Other children may come into care because they are being abused. Others may come into care because their parents are receiving alcohol or drug treatment.*”

The Needs Assessment found that compared to other services the number of persons with disability of all ages who use or need protection services, is relatively small. (Table 33) This seems to contradict the high rates of children coming into care, many with disability, reported in the GNWT’s Health Status Report (1999). Low participation of children and youth may explain the small demand for protection services identified in this Assessment.

Mediation/negotiation and emergency care are the most frequently used protection services. Emergency care or shelter services are needed most. Community providers of protection services listed in Table 33 say that these services are understaffed to meet the demand of persons affected by disability. Victim’s services are severely understaffed.

**Table 33: The NWT Demand for Protection Services in 2000, 2004 and 2009
by Number of Persons with Moderate to Severe Disability**

Program/Service	Use Now	Need Now*	Total 2000 Demand n=1780	Total 2004 Demand n=1982	Total 2009 Demand n=2276
Emergency Care or Shelter	75	78	153	178	205
Placement Services	48	60	108	119	137
Victims' Services	21	54	75	79	91
Mediation, Negotiation, Advocacy	132	54	186	198	228

Note: *"Need now" refers to services needed but not received now.

The Needs Assessment involved one-third of the estimated 1,780 persons with moderate to severe disability. The total demand for programs/services in 2000 is three times that identified in the Needs Assessment. The demand for programs/services in 2004 and 2009 assumes the same ratio of demand as in 2000.

Other Programs and Services

"Having this disability and living in the north I feel discriminated against with very little services." (from Personal Questionnaire)

A variety of "other" programs and services targeted at persons with disability are available in larger NWT communities such as Yellowknife and Fort Smith. Few other NWT communities have programs/services for persons with disability. This is a major concern of persons with disability, as expressed by two persons with disability in Aklavik. *"There are no special needs/services for disabled in the community."* *"I have to fly out of town to get services."* (from Personal Questionnaires completed by two Aklavik residents with disability)

Holman is one small community which has given priority to persons with

disability. The municipal council in that community has purchased a handivan to assist persons with disability to live independently and to participate in the community. The Holman Community Council has also endeavoured to ensure that all public buildings in the community are wheel-chair accessible.

Among 'other' services available guardianship/trusteeship or supported decision-making, transportation services, and general information/referral/support services have the greatest use now among persons with disability. (Table 34) The greatest unmet need and expected demand in the future are for transportation (eg. handivan services), advocacy and disability awareness/education services. These

Table 34: The NWT Demand for Other Programs and Services in 2000, 2004 and 2009 by Number of Persons with Moderate to Severe Disability

Program/Service	Use Now	Need Now*	Total 2000 Demand n=1780	Total 2004 Demand n=1982	Total 2009 Demand n=2276
Disability Awareness/Education	84	255	399	436	501
Respite	75	147	222	238	273
Mobility Supports (eg.seeing eye dog)	63	60	123	139	159
Transportation Services	324	324	648	714	819
Special Parking Program	117	75	192	218	250
Equipment/Technical aids/Tools	240	195	435	476	546
Advocacy to Get Services	216	255	471	515	592

General Information/ Referral/Support	312	198	510	575	660
Recreation/Social Activities	282	213	495	555	637
Translation/Interpretation	180	147	327	357	410
Guardianship/Trusteeship/Support t Decision-Making	327	105	432	476	546

Note: **Need now** refers to services needed but not received now.

The Needs Assessment involved one-third of the estimated 1,780 persons with moderate to severe disability. The total demand for programs/services in 2000 is three times that identified in the Needs Assessment. The demand for programs/services in 2004 and 2009 assumes the same ratio of demand as in 2000.

needs are particularly great in smaller communities where there are virtually no specialized services for persons with disability. The need for disability awareness/education, respite and advocacy for services outstrips the current use.

According to community service providers, not one of the programs and services listed in Table 34 is adequately staffed to meet the demand for these services by persons affected by disability. Two programs/services which are significantly understaffed are disability awareness/education and special parking programs.

4.2 Program/Service Needs of Parents/Caregivers of Persons with Disability

Parents/caregivers of persons with disability participating in this Assessment care mainly for children (0-14 years) and adults (15-64 years of age) with known, moderate to severe disability. Over one-third care for persons with multiple disabilities and about half provide 24 hour

care/supervision. Parents/caregivers encounter significant personal and other challenges in giving care (as illustrated Figures 22 and 23, pg. 67). These challenges are exacerbated by an overall lack of program/service support for caregivers in the NWT. The lack of programs/ services and recognition of the role of parents/caregivers are major sources of frustration for caregivers. This frustration was expressed in completed Parent/caregiver Questionnaires.

“Its hard to care and help with so few services/programs.”

“There are no resources/programs for people with disability.”

“How do we as parents come to terms with what has happened to cause the disability? How do we cope with what the present and the future may bring if things stay as they presently are?”

“I really want my son to live with me at home but no resources are available in the region. At the same time I want what is best for him (I have) no options.”

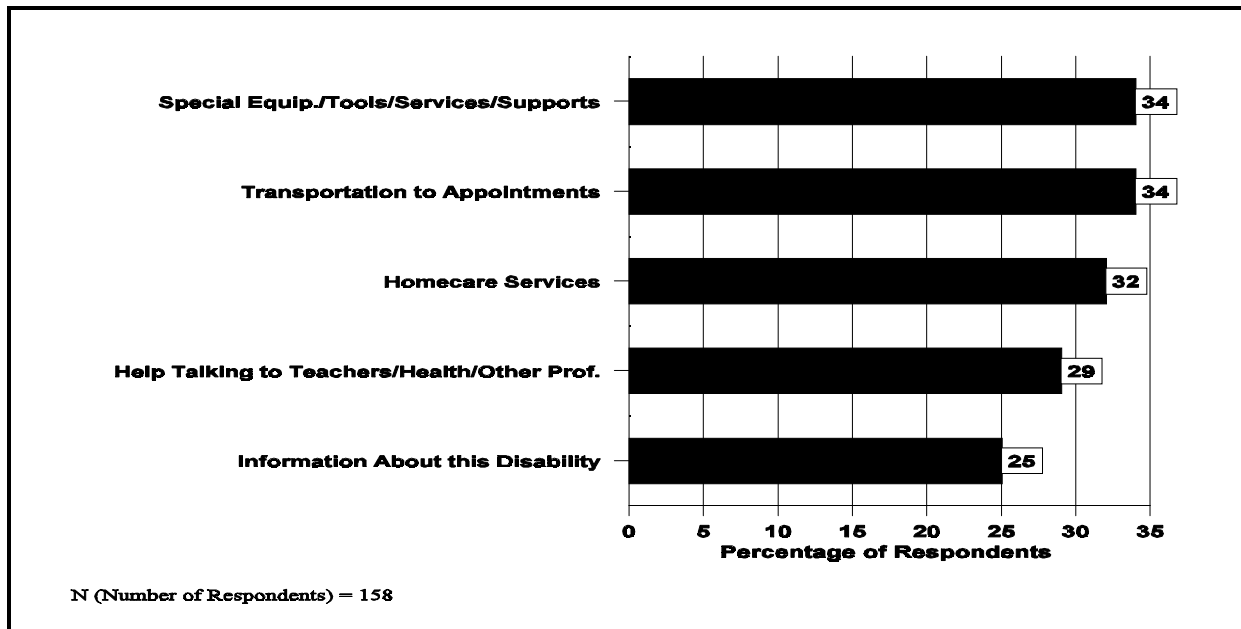
“There is no extra help for special needs children in any way, shape or form. From money to learning aids that the specialists recommend. For two years I have been fighting to get my son the learning aids he requires. I have now given up hope.”

“Do I get any money for caring for my spouse? NO”

“You need an advocate, case manager, advice on funding and procedures to procure \$\$.”

To help parents caregivers give care, special equipment/supports and transportation to get to appointments are the two programs/services most frequently used. (Figure 25) As noted elsewhere in this report, these programs/services are not widely available in NWT communities. Special equipment/supports also may not be available to persons within their own homes. *“Providing special aid/support and home caring services. Learning tools (should) be accessible to (in the) home. Training and learning tools (should be available) for home use.”* (from Parent/Caregiver Questionnaire)

Figure 25: Programs and Services Used by Parents/Caregivers of Persons with Disability, NWT Needs Assessment 2000



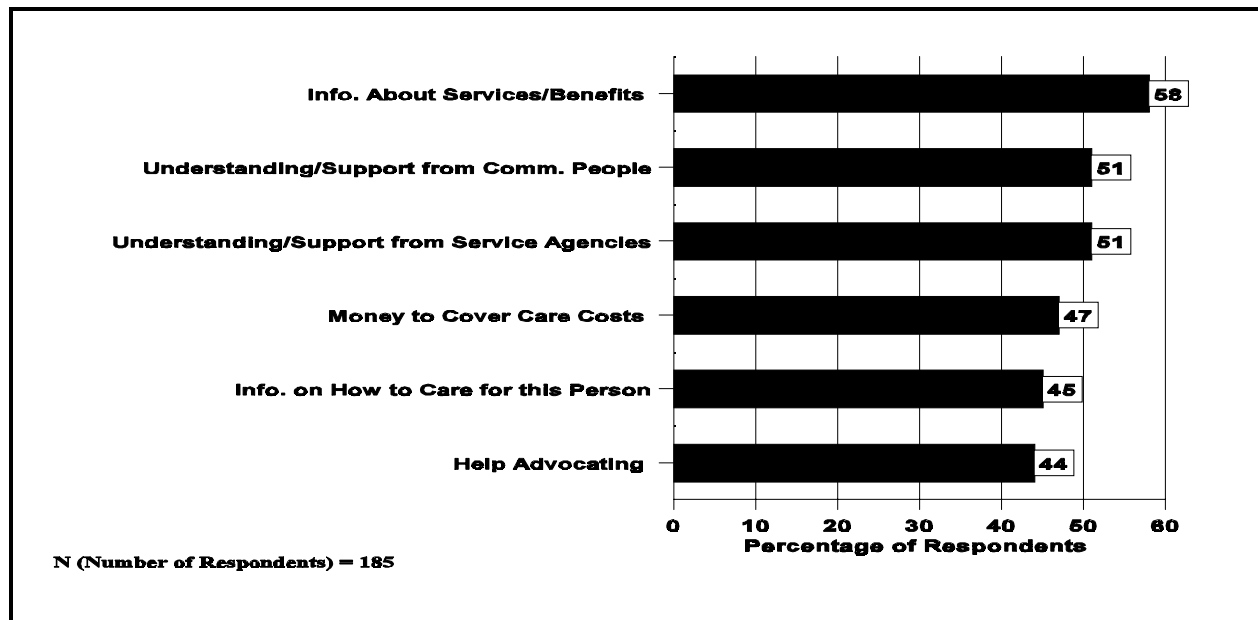
Parents/caregivers of persons with disability identify a wide range of unmet needs. Information, understanding, support and financial resources are needed most. (Figure 26)

Numerous comments were made in the Parent/Caregiver Questionnaire about programs/services to care for and offer respite to caregiver. At the same time, respite was not identified as an unmet need by parents/caregivers of persons with disability. (Figure 26) There may be many reasons for this, including an unwillingness/shyness about asking for help or a break, lack of understanding of the term, or fear for the safety and well-being of the person.

“This person should be encouraged to stay somewhere where he is cared for while I can take a break.”

“(I) Need respite care badly. I can’t leave Mom. (My) Brothers won’t help.”

Figure 26: Programs and Services Needed by Parents/Caregivers of Persons with Disability, Needs Assessment 2000



It is likely that the needs of parents/caregivers could be met through widespread respite, counselling, advocacy and caregiver benefit programs.

“No financial help or training because he is a family member. Should consider training and paying family instead of others. Could be more a part of family, culture and community this way.” (from Parent/Caregiver Questionnaire)

4.3 Delivering Appropriate Programs and Services

to Persons Affected by Disability

Community service providers in the NWT encounter a wide variety of challenges to delivering appropriate programs/services to persons with disability. These challenges are made more difficult by high staff turn-over, large caseloads, poor understanding of disability, and lack of opportunities to work and share information with other service providers. While there was little consensus on the greatest challenges faced by community service providers participating in the Needs Assessment, most frequently identified were:

- inadequate financial resources (37%).
- inadequate numbers of staff (33%).
- lack of community programs/services (32%).
- inadequately trained staff (28%).

“Burn out is a danger in this job especially considering the inability of Social Services to provide much support.” (from Community Service Provider Questionnaire)

The vast majority (79%) of persons with moderate to severe disability living in households in the NWT, have Aboriginal ancestry. About two-thirds of community service providers participating in the Needs Assessment consider their programs/ services to be culturally relevant to persons with disability in the NWT. Service providers in NWT communities must overcome tremendous barriers to deliver culturally relevant programming. The most significant of these are:

1. difficulties hiring/retaining qualified staff fluent in the Aboriginal language(s) of the community.

“(Difficult to hire) *Interpreters with sound medical knowledge and excellent grasp of both English and Native language.*” (from Community Service Provider Questionnaire)

2. access to culturally relevant materials, activities, and programs.

***“material is not culturally relevant and assessment tools (are) not made for Aboriginal people.”* (from Community Service Provider Questionnaire)**

***“Program does not consider alternative medicine.”* (from Community Service Provider Questionnaire)**

3. limited awareness or understanding of the culture and lifestyles of the community.

***“Cross cultural workshops are needed to provide non-Aboriginal people with an understanding of the people.”* (from Community Service Provider Questionnaire)**

***“Lack of knowledge of (Aboriginal) culture. Lack of normative studies of (the) northern population.”* (from Community Service Provider Questionnaire)**

4. lack of community support.

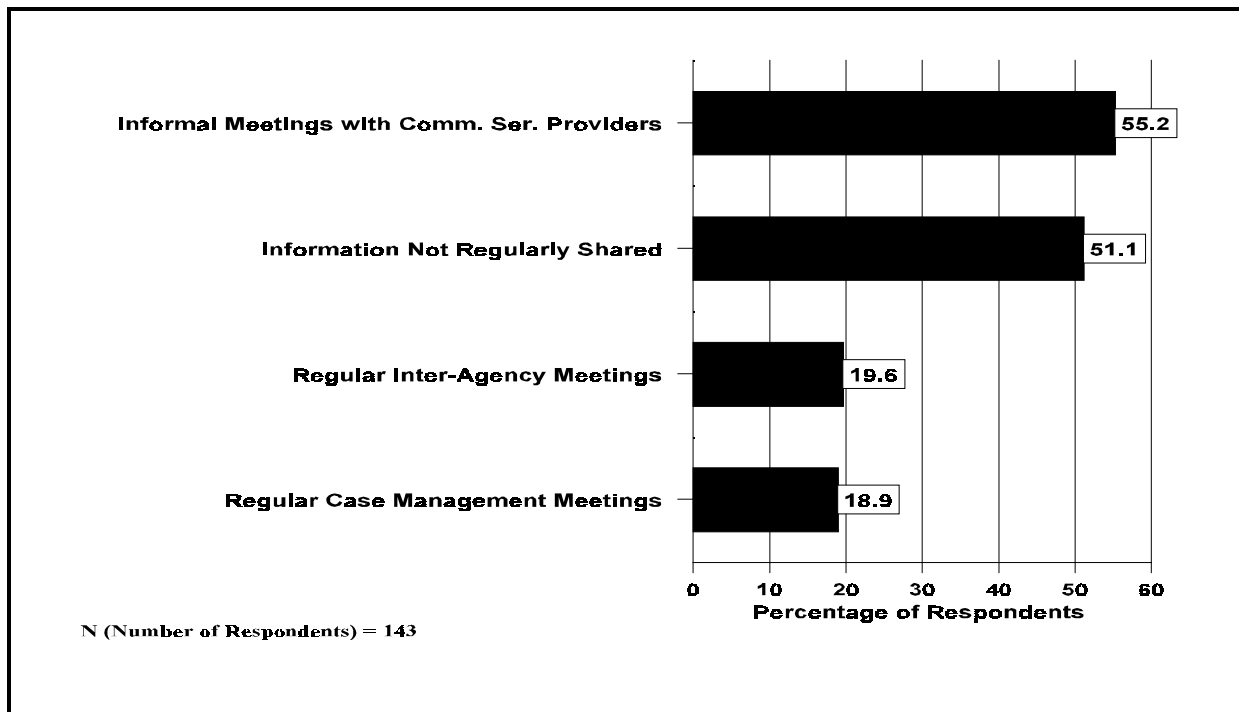
***“social-economic barriers effect service delivery.”* (from Community Service Provider Questionnaire)**

“Unrelated caregivers (are) reluctant to do personal care and client(s) (are)

reluctant to have strangers provide it.” (from Community Service Provider Questionnaire)

While inter-agency collaboration and case management are principles of many social programs in the NWT, less than one-fifth of community service providers apply these principles to addressing disability issues and needs. At best, information sharing among service providers at the community level is informal. Over half of the community service providers participating in this Assessment say that information is not regularly shared. (Figure 27).

Figure 27: Information Sharing on Disability Issues and Needs by Percent of Community Service Providers, NWT Needs Assessment 2000



In this Needs Assessment persons with disability were asked whether programs and services meet their cultural needs. Most (63%) believe that programs/ services do not meet their cultural needs or their needs in general. Anecdotal comments offered by persons with disability suggest four main reasons for this view:

1. General lack of understanding, support and recognition of disability. *“Politically no one is representing the disabled people.”* (from Personal Questionnaire)

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

2. Lack of awareness of and sensitivity toward Aboriginal languages and customs.

“ Everything is more directed at (the) non-Aboriginal way of life.” (from Personal Questionnaire)

“ I can’t trap and spend time in the bush. I would like to do that but no program allows me to.”(from Personal Questionnaire)

“ Need qualified medical interpreter/translator and more interaction with the elders and qualified staff/homecare.” (from Personal Questionnaire)

3. Lack of access to services in the (home) community.

“ We need more programs and services HERE.” (from Personal Questionnaire)

4. Lack of care and attention by community and service providers. (from Personal Questionnaire)

“ No one asks me what I need” . (from Personal Questionnaire)

“ Programs and services are kept secret -disabled people are usually the last to know.” (from Personal Questionnaire)

Persons with disability describe five main ingredients of programs/services which meet their needs, including their cultural needs.

1. A sense of peace and security within their environment.

“I am happy with this home setting and what this program has to offer me.” (from Personal Questionnaire)

2. Support to participate in community events, particularly cultural activities.

“I am encouraged to attend any cultural events whenever possible and enjoy traditional foods.” (from Personal Questionnaire)

3. Access to country foods and help with such activities as sewing, drying
meat, and getting ice.

4. The ability to receive services in one’s own community.

“The service provided by home care and by my family is all I need at this time.” (from Personal Questionnaire)

5. The availability of Aboriginal language speakers.

“Yes, I believe these services and programs meet my needs but I often am lonely.” (Personal Questionnaire)

Other elements of appropriate programs/services for persons with disability were cited as: the quality, understanding and sensitivity of caregivers and placements; and the availability of a handivan/special transportation in the community.

4.4 Programs and Services Best Practices

Community service providers offered examples of programs/services which have assisted people with disability. Many of these examples are drawn from larger communities, particularly Yellowknife, and from non-government organizations. These examples may provide some guidance for future programs and services for persons with disability.

- Programs which focus on advocacy for the person with disability and his/her parent/caregiver and collaboration among various groups. Programs/services offered by the following organizations were cited as examples: the Yellowknife Association for Community Living, the NWT Council for Disabled Persons, Chartrand Group Home, Yellowknife Womens' Centre, Tree of Peace, Project Change/Learning Centre, Salvation Army, CNIB, and Canadian Hard of Hearing Association.
- Homecare programs, in-home support, home visits, "meals on wheels" and outreach programs which provide much needed help as well as reduce the isolation and loneliness that persons with disability may feel.
- Day programs which stimulate persons with disability including literacy, adult education, fitness and healing programs, and enable participation and contribution to the community.
- Early intervention programs which enable early detection and development of skills/techniques to cope with disability.

- **Rehabilitation services including the loan of equipment/tools/aids.**
- **Respite and supports for caregivers.**
- **Transportation services and adaptations to facilitate access in the community.**

5. Recommendations to the Needs Assessment Partners

Persons with disability, parents/caregivers of persons with disability and community service providers contacted over the course of this Needs Assessment expressed a high degree of scepticism about the will of government, other organizations, communities, families and individuals to address the issues that will enable persons with disability to live with dignity. Implementing the following recommendations will demonstrate that the will is there to work toward this goal.

1. It is recommended that the partners sponsoring this Needs Assessment, use the findings to plan appropriate programs and services for persons affected by disability in the NWT.

2. It is recommended that the partnership established for this Needs Assessment continue to function, in order to ensure that appropriate programs and services for persons affected by disability are implemented throughout the NWT.

3. It is recommended that the partnership established for this Needs Assessment communicate the findings and intended actions to the general public.

4. It is recommended that the responsibility for disability within the Government of the NWT be clearly identified and communicated to the public.

5. It is recommended that those factors limiting collaboration in this Needs Assessment be addressed by the partners both in the example that they set

and the message that they send to service providers and organizations delivering programs/services/supports to persons affected by disability.

6. It is recommended that the Needs Assessment partners begin discussions with the GNWT Department of Education, Culture and Employment, Early Childhood and School Services 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 ECE's Student Needs Survey.

7. It is recommended that the lessons learned from this Assessment be applied to Phase 2 research into psychiatric disabilities.

Appendix A: Terms of Reference

TERMS OF REFERENCE

PROJECT TITLE:

Needs Assessment of Persons with Disabilities in the western Northwest Territories (NWT)

BACKGROUND:

A needs assessment of persons with disabilities in the western NWT would be valuable for future program and service planning for people with disabilities. There are many gaps in current services for people with intellectual, sensory and physical disabilities. These needs include but may not be limited to: health care, social services, education, training, employment, housing, residential support, respite care and income support.

A Project Working Group will oversee this project. It includes representatives from the Government of the Northwest Territories Departments of Health and Social Services and Education, Culture and Employment, the N.W.T. Council for Disabled Persons and the Yellowknife Association for Community Living.

PURPOSE:

The purpose of this needs assessment is to identify the numbers of persons with intellectual, sensory and physical disabilities in the western NWT, identify existing services and the need for additional services required to ensure that the needs of persons with disabilities and their families in western NWT communities are met. This will enable effective and appropriate resource planning and development of programming for this target group.

SCOPE OF THE PROJECT:

Compile existing quantitative and qualitative information on individuals with disabilities in the western NWT to: identify the number and percentage of the western territorial population with sensory, intellectual and physical disabilities; the nature and distribution of these disabilities; day to day living needs by main type of disability; existing services available in communities; issues faced by persons with these disabilities and their families; and, current and projected (5-10 years) service needs.

Develop and administer a survey instrument to capture the above information which is not already available.

Establish an information base for each western NWT community identifying the number and percentage of the western territorial population with sensory, intellectual and physical disabilities; the nature and distribution of these disabilities; day to day living needs by main type of disability; existing services; issues faced by persons with these disabilities and their families; and, the current and projected (5-10 year) service needs.

Consult with individuals with various types of disabilities and existing government and non-government service providers to assess current and projected service needs in various types of western NWT communities for various types of disabilities.

Prepare a report and data base compiling the data and other information collected for review by the project working group which includes appropriate options for meeting needs of persons with disabilities.

Persons with mental illnesses, including depression, schizophrenia, panic disorders, etc., and service gaps for this population will not be included in this needs assessment.

PROJECT OUTPUTS:

A data base which allows access to community-based information on numbers of persons with sensory, intellectual and physical disabilities, the nature of disabilities, existing services, and current and projected gaps in services. Confidentiality of individuals will be protected.

A report on findings including options for the delivery of services to persons with disabilities. Confidentiality of individuals will be protected.

All backup documentation, survey and interview results and data base gathered through the project will be the property of the working group and are to accompany the final report with anonymity of stakeholders protected.

PROJECT TIMEFRAME:

Project to be completed by March 31, 1999.

RELATIONSHIPS:

The contractor will report to the Disability Needs Assessment Project Working Group. This working group will support and provide input into the project. At the outset definitions of sensory, intellectual and physical disabilities will be provided.

The active participation of regional health and social service boards and education boards, and their respective community staff, is critical to the success of this project and will be actively advocated by the Departments of Health and Social Services and Education, Culture and Employment.

SKILLS AND EXPERIENCE REQUIRED BY THE CONTRACTOR:

research and analytical skills
survey tool development skills
organizing data into a comprehensive, readable format (report writing) and data base
related experience
sensitivity to northern issues

PROPOSAL RESPONSE GUIDELINES:

All proposals shall be received by 4 p.m. January 8, 1999 and include the following information:

1. Approach and methodology options for completing the project.
2. Proposed alteration to request time frame if unable to provide as estimated.
3. A detailed time frame for each data collection stage and the final written report.
4. Resumes of all personnel to be attached to the project, including descriptions of experience relevant to this proposal call.
5. Two references.

6. Fee and expense estimates with explanation, including person/hour estimates, per diem rates and travel and accommodation expenses where applicable.

PROPOSAL EVALUATION CRITERIA:

1. Cost within available budget range.
2. Workplan and schedule within timeframe.
3. Relevance of qualifications and past experience to this proposal.
4. Methodology demonstrates understanding of project.
5. Project team.

**Submit proposals to: N.W.T. Council for Disabled Persons
Centre One Building, 5013 48th Street
Yellowknife, NWT X1A 2P1
Fax: 867-873-4124
Phone: 867-873-8230**

Appendix B: Needs Assessment of Persons with Disability Chronology

NEEDS ASSESSMENT OF PERSONS WITH DISABILITIES - CHRONOLOGY

Background

1997	Formation of H&SS/NGO working group on disabilities
November 4, 1997	Preliminary research instrument
August 1998	Regrouping of disabilities working group. ECE joins
December 22, 1998	Call for proposals
January 8, 1999	Proposal call closes

Phase 1: Research Design

January 22, 1999	Needs Assessment Partners Meeting #1³⁴ (parameters, outcomes, information sources, partner responsibilities and regional contacts)
January 29, 1999	Needs Assessment Partners Meeting #2 (parameters, desired outcomes and communications)
February 8, 1999	Introductory letter to regional education, health and social service boards
March 1, 1999	Needs Assessment Partners Meeting #3 (parameters, definitions and instrument development)
March 8, 1999	Needs Assessment Partners Meeting #4 (instrument development)
March 14, 1999	Revised instruments for review by partners
March 17, 1999	Five test instruments sent to Bureau of Statistics for review

³⁴The average duration of each Partners Meeting was 3 hours.

March 19,1999	Needs Assessment Partners Meeting #5 (refinement of instruments with partners and H&SS statistician)
March 19 - 31,1999	Testing instruments in Rae-Edzo and Yellowknife
April 1,1999	Needs Assessment Partners Meeting #6 (review of test results with H&SS statistician)
April 9, 1999	Needs Assessment Partners Meeting #7 (involvement of schools)
April 13,1999	H&SS info and request for participation letter to Health Boards CEOs
April 19 - June23,1999	Negotiations with Early Childhood and School Services
April 22,1999	Draft final research instruments
April 28, 1999	Needs Assessment Partners Meeting #8 (address ECE-EC&SS negative reaction to Assessment)
May 18,1999	Needs Assessment Partners Meeting #9 (negotiation with EC&SS - partners rethink inclusion of psychiatric disabilities)
May 21,1999	Meeting with D. Bower of YACCS regarding proposed Cognitive Impaired Needs Assessment
June 23,1999	Needs Assessment Partners Meeting #10 (EC&SS ECE decides not to participate in the Assessment)
July 29,1999	Metis Nation -NWT advertise for Disabilities Opportunities Coordinator
August 10,1999	Needs Assessment Partners Meeting #11 (finalize newsletter and questionnaires for printing)
<u>Phase 2: Field Work</u>	
August 17,1999	Gary Bohnet, President of the Metis Nation agrees to join the partnership
August 18,1999	Needs Assessment Partners Meeting #12 (promo strategy, identification of additional funding to meet project costs)

Needs Assessment - Chronology

August 18, 1999	Partners' letter updating regional boards/agencies on status of the Assessment
September 13,1999	Questionnaires go into the field in Yellowknife and regional scoping begins
September/October	ECE's EC&SS directs Regional DEC's not to talk to the Lutra research team or participate in regional scoping
September 30,1999	Stanton Regional Hospital expresses disappointment of not participating as a partner
October 6-12,1999	Determine protocol for EC&SS involvement in Assessment
October 8,1999	H&SS HQ and Lutra teleconference with W. Drodge, CEO Hay River to address methodological issues
October 8,1999	NWTCDP seeks partners input on budget for HRDC funding
October 20, 1999	ECE EC&SS letter to all schools/principals requesting limited participation in the Council's Assessment, ignoring the multi-sector partnership
October 26,1999	Review Metis Nation field support with concerns about lack of field reports. Metis Nation wants more/higher profile in Assessment
October 31,1999	All regions involved in Assessment except Deh Cho and North Slave/Dogrib Region
November 1, 1999	Needs Assessment Partners Meeting #13 - status report
November 8,1999	Dogrib Community Services Board - understaffed and reluctant to participate
November 8,1999	Partners/HRDC Conference call to discuss resources for completing data collection
November 8,1999	First recorded incidence of front-line worker being verbally abused due to exclusion of psychiatric disability

November 9,1999	MaryAnne Duchesne submits Guest Editorial to 'News/North'
November 10,1999	H&SS contemplates sending HQ staff into the regions to promote the Assessment
November 15,1999	Meeting between Independent Clubhouse and some Needs Assessment Partners regarding exclusion of psychiatric disabilities
November 16,1999	Needs Assessment Partners Meeting #14 (data compilation logistics)
November 16,1999	H&SS proposes phase two of the Assessment to engage persons with psychiatric disabilities within a broader mental health framework
November 8-26,1999	H&SS fielding concerns from Boards regarding consistency of data, validity, resources, methodology and manner Boards have been engaged in the Assessment
November 19,1999	Project overview developed to answer H&SS Board questions
November/December	Open Houses at Baker Centre and the NWT Council for Disabled Persons
December 8,1999	Metis Nation withdraws from Needs Assessment partnership
December 9, 1999	HRDC approves funding to complete data collection
December 17, 1999	Needs Assessment Partners Meeting #15 (status report)
January/February, 2000	Open Houses at Salvation Army, Aurora College, Yellowknife Correction Centre
<u>Phase 3- Data Compilation, Analysis and Reporting</u>	
January 31,2000	Needs Assessment Partners Meeting #16 (status report and reporting framework)

March 13,2000	Yellowknife Focus Group
March 27,2000	Fort Smith Focus Group
April 17, 2000	Submission of draft methodological and findings reports
April 18, 2000	Partners and stakeholders workshop to review draft reports
April 28- May 12,2000	Partners provide feedback on draft reports
June 7,2000	Submit five community reports
June 8, 2000	Circulate popular summary for Partner's review
June 23,2000	Submit final draft methodological and findings report

A Needs Assessment of Persons with Disabilities in the NWT - Community Service Provider Questionnaire

Have you read the August News Bulletin describing the Needs Assessment?

The Community Service Provider Questionnaire is one of three questionnaires being completed as part of the Needs Assessment of Persons with Disabilities. The other two questionnaires are the Personal Questionnaire to be completed by persons with disabilities, and the Parent/Caregiver Questionnaire to be completed by those who care for people with disabilities.

A Community Service Provider *is someone who has personal contact with and delivers programs/services directly to people with disabilities and/or their families/caregivers.* In most cases, a Community Service Provider is a paid person although some volunteers may also provide programs/services to people with disabilities and/or their families. People who are employed to provide residential or employment supports to people with disabilities are also Community Service Providers.

Community Service Providers can have many different job titles but most often they are:

Alcohol and Drug Workers	Home Care Workers	Social Workers
Community Support Workers	Community Health Representatives	RCMP officers
Tenant Relations Officers	Legal Aid Workers	Nurses

• Child Care Workers	Income Support Officers
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All Community Service Providers are being asked to complete a **Community Service Provider Questionnaire**. If you share responsibilities for a particular program or service, please work with your co-workers to complete this Questionnaire. This avoids duplication and helps to collect the best possible information.

Please ensure that individuals are not identified by name and that all other information about each person with a disability is kept confidential.

The **Community Service Provider Questionnaire** collects information on each service/ program which is provided directly to people with disabilities and/or their families. As a Community Service Provider, you may deliver many services and programs. A separate **Community Service Provider Questionnaire** should be completed for each program or service delivered. For example, Income Support Officers provide financial assistance directly to people with disabilities and/or their families. They may also advocate directly on behalf of individuals who have a disability and/or their family/caregiver. The Income Support Officer would complete one questionnaire for direct financial assistance services and one questionnaire for direct advocacy services. Services that are not provided directly to individuals with disabilities/families such as policy, planning or general advocacy for all disabled persons should not be reported in a **Community Service Provider Questionnaire**.

Depending on the completeness of your own records, it should take about two hours to do the **Community Service Provider Questionnaire.**

Once the **Community Service Provider Questionnaire** is done, the next step is to invite people with disabilities to complete a **Personal Questionnaire** and to ask their families to do a **Parent/Caregiver Questionnaire**. Community Service Providers are being asked to distribute these Questionnaires and if need be, help

to complete them. By working with other Community Service Providers, we hope that people with disabilities receive only one Personal Questionnaire, and the parents or the main unpaid caregivers of people with disabilities receive only one Parent/Caregiver Questionnaire.

People with disabilities and their families/caregivers may receive services/ programs from more than one agency. Please contact colleagues in other helping agencies to look at ways to ensure that everyone affected by a disability is invited and helped to participate.

The success of this Needs Assessment of Persons with Disabilities depends on YOU, the Community Service Provider.

The Needs Assessment Partners know that Community Service Providers are very busy. We greatly appreciate your time and help. We will recognize your efforts in the final report and give you a small gift as a token of our appreciation.

Lutra Associates Ltd. has been contracted to coordinate the Needs Assessment and they will be in touch with Community Service Providers regularly to give assistance and support. Or you can contact Sandy Auchterlonie, Lois Little or Bob Stephen at Lutra at any time. Contact Sandy, Lois or Bob at Lutra at (867) 920-2177 or by fax (867) 873-8368 or via e-mail at xlutra@ssimicro.com

Please complete the Community Service Provider Questionnaire within one (1) month of receiving it. All completed questionnaires should be returned to Lutra Associates Ltd., Box 1866, Yellowknife, NT XIA 2P4.

Definitions Used in this Needs Assessment

A disability is *any degree of physical, sensory, cognitive, intellectual, learning or psychiatric limitation which causes difficulty in the usual activities of daily living*. Psychiatric disabilities/illnesses are not included in this Needs Assessment except in cases where they may be present along with another disability. Specific disabilities are defined as follows.

Physical Disability

A physical disability involves a significant loss of mobility, agility, strength, flexibility or coordination. Some conditions which involve physical disabilities are paraplegia, quadriplegia, amputation, cerebral palsy, polio, multiple sclerosis and arthritis.

Sensory Disability

A sensory disability involves the senses. Sensory disabilities include: blindness or significant vision loss, deafness or significant hearing loss, the inability to speak, and a lack of balance from disorders such as Vertigo or Meniere's Disease.

Cognitive Disability

A cognitive disability is usually a degenerative condition that affects the brain's ability to process information. It is not present from birth. Cognitive disabilities may include Alzheimer's, senility and late stage alcoholism.

Intellectual Disability

An intellectual disability impacts the rate at which a person develops, learns and/or remembers. This disability is usually present from birth. People with intellectual disabilities may have

Down's Syndrome, traumatic brain injury, fetal alcohol syndrome, alcohol-related birth defects or other undefined disabilities.

Learning Disability

A learning disability affects the way people with average or above average intelligence take in, process or express information. Learning disabilities are permanent, range from mild to severe, and encompass a group of disorders. Common learning disabilities include problems with memory, attention, reading, writing, arithmetic, reasoning, social skills, emotional maturity and coordination.

Part A: An Introduction to Your Program/Service

1. In two or three words, please describe the type of program/service you deliver.

—
Please describe one program/service only. Possible descriptions could be physical health; social or mental health; housing; educational or training; legal; protection; financial; and recreation. The program/service described is the basis for much of this Questionnaire. A separate Community Service Provider Questionnaire must be completed for each distinct program or service you provide.

2. Your Job Title:

—
More than one title may be included if co-workers providing the program/service have different job titles.

3. Name of Your Organization:

4. Name of this Community:

Part B: Number & Characteristics of People With Disabilities

5a. In a typical month, how many people are served by the program/service named

in Q1? Give the total number of individuals who usually use your program/service each month. Include people of all ages and people with and without disabilities.

5b. In the past year, how many people did your program/service serve?

Give the total number of individuals.

5c. Are the numbers provided in Q5a and 5b, the actual or estimated number of people served ? Check () one only.

5d. In the past year, how many people served by your program/service

have a disability? Give the total number of individuals served over the past year. Include people of all ages who show signs of having a disability. Please refer to the disability definitions on page 3.

5e. Is the number in Q5d an estimate or the actual number of people with disabilities served ? Check () one only.

6. How many of the people with disabilities who were served by your program/service in the past year were:

a. younger than 15 years of age?

b. 15 to 19 years of age?

c. 20 to 64 years of age?

d. 65 years of age and older?

7a. How many of the people with disabilities who were served in the past year are limited in their daily living activities due to difficulties in one of the following

areas? Please count only those people who show signs of having a single disability in each area of

difficulty. Do not include people whose single disability is psychiatric. Please refer to the disability

definitions on page 3.

7b. How many of the people served in the past year are limited in their daily living activities due to difficulties in more than one of the following areas? Some people may be counted in more than one category. For example, an individual might show signs of having a visual impairment as well as a problem processing information. This person would be counted once as having a sensory difficulty and counted again as having a learning difficulty.

AREA OF DIFFICULTY	Q7a. Number of People Limited in Their Daily Living Activities Due to a Difficulty in <u>One</u> Area Only	Q7b. Number of People Limited in Their Daily Living Activities Due to a Difficulty in <u>More than One</u> Area
Physical (eg. mobility, agility, strength, flexibility or coordination)		
Sensory (eg. seeing, hearing, speaking, or maintaining balance)		
Cognitive (eg. problem <u>not</u> present at birth related to processing information)		
Intellectual (eg. problem at birth affecting rate of development)		
Learning (eg. taking in, processing and expressing information)		
Psychiatric/Mental Health (eg. mental illnesses)		

Part C: DIRECT Services to People with Disabilities

**LOCATE THE TYPE OF PROGRAM/SERVICE YOU PROVIDE (as identified in Q1).
ANSWER THE FOLLOWING FOUR (4) QUESTIONS FOR THIS PROGRAM/
SERVICE ONLY. *Please note that:***

Q8 refers only to the number of people who use your program/service and show signs of having a disability.

Q9 refers to unpaid caregivers of people with disabilities such as parents and other family members who use your program/service.

Q10 refers to the number of staff and the skills available to deliver the program/service.

Q11 asks you to draw on your professional knowledge to identify new or additional programs/services needed by people with disabilities in the future.

Community Service Provider Questionnaire

Type of Program/Service	Q8. How many people with a disability(ies) use this program/ service?	Q9. How many families/ caregivers of people with disabilities use this program/ service?	Q10. Does this program/service have enough staff to serve the people with disabilities and/or their families who WANT OR NEED these services?		Q11. Will additional or new types of programs/ services be needed in 5 to 10 years to serve this community's population with some level of disability?	
			Yes	No	Yes	No
A. Medical/Physical Health Services						
- testing/diagnosis/assessment..... <input type="text"/> <input type="text"/>				
..... <input type="text"/> <input type="text"/>				
- referral..... <input type="text"/> <input type="text"/>				
-general medical care/treatment..... <input type="text"/> <input type="text"/>				
-occupational therapy or physiotherapy.... <input type="text"/> <input type="text"/>				
-audiology or ophthalmology <input type="text"/> <input type="text"/>				
.....						
-speech/language pathology/development.						
-home/personal care..						
.....						
-health counselling/promotion						
.....						
-alternative therapy/treatment.....						
- other_____						

Community Service Provider Questionnaire

Type of Program/Service	Q8. How many people with a disability(ies) use this program/ service?	Q9. How many families/ caregivers of people with disabilities use this program/ service?	Q10. Does this program/service have enough staff to serve the people with disabilities and/or their families who WANT OR NEED these services?		Q11. Will additional or new types of programs/ services be needed in 5 to 10 years to serve this community's population with some level of disability?	
			Yes	No	Yes	No
C. Accommodation/Housing Services -housing referral or information..... -assistance fixing/modifying home..... -accommodation/housing subsidy/money.. -special accommodation/group home..... - other _____ - other _____ <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>				

Community Service Provider Questionnaire

Type of Program/Service	Q8. How many people with a disability(ies) use this program/ service?	Q9. How many families/ caregivers of people with disabilities use this program/ service?	Q10. Does this program/service have enough staff to serve the people with disabilities and/or their families who WANT OR NEED these services?		Q11. Will additional or new types of programs/ services be needed in 5 to 10 years to serve this community's population with some level of disability?	
F. Life Skills, Employment and Residential Supports -paid residential support..... -life skills training..... -in-home support and assistance..... -general personal/family/emotional help... -employment/job coaching..... -special equipment, aids, tools..... -other _____ <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>				
G. Financial Assistance -income support/subsidy/basic needs -budgeting/money management help..... -financial information or advice..... -other _____ <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	Yes	No	Yes	No

Community Service Provider Questionnaire

Type of Program/Service	Q8. How many people with a disability(ies) use this program/ service?	Q9. How many families/ caregivers of people with disabilities use this program/ service?	Q10. Does this program/service have enough staff to serve the people with disabilities and/or their families who WANT OR NEED these services?		Q11. Will additional or new types of programs/ services be needed in 5 to 10 years to serve this community's population with some level of disability?	
H. Legal Services -probation supervision..... -placement services..... -community justice/local supports..... -legal aid..... -mediation, negotiation or advocacy..... -other _____ <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>				
I. Protection Services -emergency care or shelter..... -placement services..... -victims' services..... -mediation, negotiation or advocacy..... -other _____ <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>				

12. To use the program/service described in Q1, people with disabilities or their families/

caregivers pay: *Check () one only.*

- | | |
|----------------------|-----------------------------------|
| nothing | based on income (eg. income test) |
| a small amount | the full cost of the service |
| Other (explain)_____ | |

13a. Do you consider your program/service to be culturally relevant to the people you serve who have a disability? Yes No *Check () one only.*

13b. In a few words, please list the main barriers that you face to providing a culturally relevant program/service. _____

—

—

—

14. What are the three main challenges that you face when delivering programs/services to people with a disability(ies)? *Please check () three only.*

- | | |
|---------------------------------|-------------------------------------|
| inadequately trained staff | inadequate financial resources |
| inadequate numbers of staff | little/no training available |
| inflexible funding arrangements | no/poor facilities |
| no support from leaders | negative community attitudes |
| lack of inter-agency support | lack of community programs/services |
| lack of political will | lack of community support |
| lack of information | too much paperwork |
| client confidentiality issues | inadequate/poor standards/policies |

lack of inter-agency communication
physical access to existing facilities/programs
other (explain)

15. How is information about disability issues and needs shared among Community Service Providers in your community? Check () all that apply.

regular case management meetings
regular inter-agency meetings
informal meetings with other Community Service Providers
information is not regularly shared
other (explain)

16. Based on your front-line experience serving people with disabilities, what do you think are the three main challenges faced by people with disabilities? Please check ()

no

more than three.

- | | |
|---|--|
| meeting day-to-day shelter/food/clothing needs | getting help with daily living needs |
| lack of programs/services | having enough money |
| finding out about services/programs | finding a job |
| getting a professional diagnosis/assessment | dealing with community attitudes |
| finding out about basic rights | paying for programs/services |
| feeling safe and secure | getting support from family members |
| getting a referral | getting follow-up from service providers |
| loneliness and isolation | being understood and accepted |
| getting programs/services from qualified people | |
| getting physical access to programs/services/facilities | |
| other (explain)_____ | |

17. In a few words, please describe good examples of programs/services that have assisted people with disabilities. _____

—

—

—

—

**Part D: Future Program/Service Needs of People
with
Disabilities**

18a. In the next five years, do you think your community will have more ; less ; or the same number of people with some type of disability? *Check () one only.*

18b. How many more or less? *Check () one only.*

1% - 5% decrease

1%-5% increase

no
chan
ge

6%-10% decrease

6%-10% increase

don'
t
kno
w

11%-15% decrease

11%-15% increase

other

(explain) _____

18c. What are the two main factors leading you to expect increases OR decreases in the incidence of disability in your community?

If you said 'increase'.... (Check () only <u>two</u> .)	If you said 'decrease' (Check () only <u>two</u> .)
<p>inadequate medical care lack of pre-natal/post-natal education high use of alcohol, drugs and/or solvents high use of tobacco high rate of accidents/injuries high rate of work-related accidents/injuries poverty abuse and/or neglect family genetics aging population better/more diagnosis or assessment other (explain) _____ _____ other (explain) _____ _____</p>	<p>better medical care more pre-natal/post-natal education less use of alcohol, drugs and/or solvents less use of tobacco efforts to prevent accidents/injuries efforts to prevent work-related accidents/injuries less poverty less abuse and/or neglect genetic screening more acknowledgement of FAS/FAE better/more diagnosis or assessment other (explain) _____ other (explain) _____</p>

19. What did we forget to ask you about your work with people with disability(ies)?

Please complete the Community Service Provider Questionnaire within one (1) month of receiving it. All completed questionnaires should be returned to Lutra Associates Ltd., Box 1866, Yellowknife, NT XIA 2P4

Please attach any working papers that you may have used to complete this questionnaire, ensuring that no individuals can be identified. THANK YOU.

Appendix D: Community Team Members

**Needs Assessment of Persons with Disabilities -
Community Team Members
(including local researchers)**

BEAUFORT

Paulatuk

Sadie Ruben, Community Wellness

Adelle Dyall, NIC, Paulatuk Health Centre

Bill Kudluk, CHR, Paulatuk Health Centre

Irene Ruben, Coordinator, Paulatuk Preschool

Richard Ruben, Community Wellness Worker, Inuvialuit Regional Corp.

Annie Thrasher, Paulatuk Housing Association

Phoebe Ruben, Income Support

Trudy McClements, Community Social Services

Senior Administrative Officer, Hamlet of Paulatuk

Marlene Wolki, Researcher

Sachs Harbour

Shirley Esau, Community Health Representative

Peggy Lucas, NIC, Sachs Harbour Health Centre

Kelly Carpenter, Child Development Centre

Lorna Dillon, Community Wellness, Inuvialuit Community Corp.

Yvonne Elias, Housing Association

Joanne Carpenter, Income Support

Holman

Tony Kulbisky, Community Wellness

Linda Huchkowsky, NIC, Holman Health Centre

Alice Kimiksana, CHR, Holman Health Centre

Ron Wilson, Community Learning Centre

Rita Banksland, Coordinator, Child Development Centre

Sarah Kuptana, Community Wellness Worker, IRC
Colin Okheena, TRO, Holman Housing Association
Joyce Banksland, Income Support
Barbara Memogana, Researcher

Tuktoyaktuk

Lucy Dillon, Community Mental Health Worker
Paula Gregory, Community Social Services Worker
Shawn Hoey, Community Social Services Worker
Jenny Jacobson, Child Development Centre
Lynn Jullian, Income Support
Michelle Skanes, Community Learning Centre
Fred Kuptana, Tuk A&D Centre
Ada Cockney, Community Wellness, ICC
Reenie Palmer, NIC, Health Centre
Anita Pokiak, CHR, Health Centre
Lucille Pokiak, Tuk Housing Assoc.
Warren Schofer, Community Corrections
Recreation Coordinator, Hamlet of Tuk
Vera Ovaynak, Researcher
Shelia Taylor, Researcher

MACKENZIE DELTA

Inuvik

Wendy Mepham, Homecare Coordinator, Inuvik Regional H&SS Board
Donna Kisoun, NWT Training Centre
Arlene Jorgenson and Cathy Shortt, Inuvik Family Counselling
Dennis Inglangasuk, Turning Point
Tracy McPherson, Inuvik Probation and Parole Services
Gloria Allen, Ingamo Hall Friendship Centre
Diana Tingmiak, TRO, Inuvik Housing Authority
Cathleen Smith, Occupational Therapy, Inuvik Regional H&SS Board

Needs Assessment - Community Team Members

Amy Gordon, Physiotherapy, Inuvik Regional H&SS Board
Barb Lennie, Inuvik Public Health and Homecare
John Nash, Inuvik Justice Committee
Tracy Woodman, Student Services, Aurora College
Sharon Spangts and Sandra Suliman, Inuvik Social Services
Cathy Ross and Merrick Naporkorski, Researchers

Fort McPherson

Kim McLeod, Community Social Services Worker
Tetlit Zheh Child Centre
Abe Stewart, Income Support
Lloyd Hyatt, Community Learning Centre
Mary Ross, TI'oondih Healing Camp
Beatrice Blake, Peel River Alcohol and Drug Centre
Jackie Ryan, A/NIC, Health Centre
Winnie Greenland, CHR, Health Centre
Shirley Wilson, TRO, Ft. McPherson Housing Assoc.
Wilbert Firth, Manager, Tetlit Gwich'in Council
Edna Alexie and Karen Colin, Researchers

Tsiigehtchic

Carol Norwegian, CHR, Health Centre
Courtnae Clark, NIC, Health Centre
Linda Andre, Income Support
Elaine Blake, Recreation Coordinator
Tsiigehtchic Day Care
Olive Blake/Anna May McLeod, Alcohol and Drug
Corrine Dillon, Researcher

Aklavik

Elizabeth Kunnizi, Alcohol and Drug Program, Aklavik United Friendship Centre
Gladys Edwards, Community Social Services Workers

Eugene Pascal, Aklavik Aboriginal Committee
Terry Peterson, Joe Greenland Centre
Flora Elanik, Aklavik Housing Association
Diane Gordon, CHR, Aklavik Health Centre
Nurse in Charge, Aklavik Health Centre
Faye Gordon, Community Wellness, Aklavik Community Corp.
Eva Gordon, Coordinator, Aklavik Preschool
Mary Storr, Community Counselling Service
Cheryl Johnson, Community Learning Centre
Sandra Arey, Income Support Worker
Shauna Gordon, Researcher

SAHTU

Colville Lake

Sharon Tutcho, CHR
Marie Kotchon, A&D Worker, Behdzi Ahda First Nation
Joseph Kochon, Band Manager, Behdzi Ahda First Nation

Fort Good Hope

Karen Shublyn-Moldnar, Community Social Services Worker
Chief Delphine Pierrot, K'asho Got'ine Community Council
Florence Barnaby, Family Violence Program
Sue Morency, Fort Good Hope Daycare
Justice Coordinator, K'asho Got'ine Community Council
Chris Jackson, Seniors' Residence
Henry Tobac, CHR, Health Centre
Marilyn Lidstone, Health Centre
Wolfgang Bauman, Community learning Centre
Phoebe McNeeley, Income Support Officer
Robert Kelly, K'asho Got'ine Alcohol and Drug Program
Angela Grandjambe, Radilih Koe' Housing Association

Patricia McKeon, Family Counsellor

Darrell Cook, Employment Officer

Tulita

Bertha Lennie, Tulita Wellness Agency

Elaine Doctor, Community Social Services

Rita Doctor, Employment Officer

Andrea Dougherty, NIC, Tulita Health Centre

Joanne Fraser, CHR, Tulita Health Centre

Theresa Etchinelli, A&D Worker

Stephanie O'Brien, Community Learning Centre

Tulita Child Development Centre

Lillian Doctor, Researcher

Norman Wells

Dennis Farley, Mental Health Counsellor, Town of Norman Wells

Linda Lasch, Health Centre

Tony Harrison, Health Centre

Deline

Rosemary Elemie, A&D

Carolyn Yukon, Community Social Programs

Ann Bayha, Housing

Lori Morgan, Nurse in Charge

Betty Tetso, CHR, Deline Health Centre

Brenda Baton, Employment Officer

Jane Modeste, Income Support

Chris Courage, Community Learning Centre

Deline Preschool

Camilla Tutcho, Researcher

DEH CHO

Fort Simpson

Pearl Norwegian, Metis Local
Charles Jacobson, Career Centre
Hilda Gerlock, Housing Authority
Nicole Barrington, Melaw Child Care
Pat Swartzter, Fresh Start Addictions Program
Valerie Stark, Open Door Society
Mel Sabourin, Friendship Centre
Leah Keats, Homecare Coordinator
Barb Tsetso, Adult Educator
Debbie Antoine, Social Services
Sheila Sears, Health Clinic
Karen McCorresten, Stanley Isaiah Senior's Facility
Louisa Moreau, Researcher
Joyce Moses, Researcher
Louisa Moreau, Researcher

Fort Providence

Allan Bouvier, Housing Association
Margaret Field, Community Learning Centre
Joyce Villeneuve, Aboriginal Head Start
Allyn Rohatyn, A&D Program
Faye Stark, NIC, Health Centre
Wilma Field, Zhati Koe Friendship Centre
Albertine Nadli, Seniors' Facility
Leonie Sabourin, Researcher

Kakisa

Ruby Landry, Band Manager

Wrigley

Vicki Maloney, Lay Dispenser

Needs Assessment - Community Team Members

Jeanine Gaulin, NIC, Fort Simpson

Bill Bertrand-Williams, Justice Coordinator

Eric Menicoche, Community Wellness Coordinator

Stella Pellisey, Pehdzeh First Nation Council

Etonia Hardisty, Researcher

Peter Moses, interpreter

Jean Marie River

Lucy Simon, Lay Dispenser

Trout Lake

Ruby Jumbo, Band Manager

Brenda Jumbo, Researcher

Phoebe Punch, Researcher

Nahanni Butte

Joan Ekotla, Lay Dispenser

Pauline Campbell, Band Manager

Fort Liard

Lynn Morin, NIC, Health Centre

Judy Kotchea, Acho Dene First Nation

Bernice Hardisty, Community Health Rep.

Mike Drake, Community Social Worker

Sandy Chalifoux, A&D Worker

Albertine Bertrand, Home Care

Emma Bertrand, Home Care

Susan Kotchea, Brighter Futures

Marie Kotchea, Researcher

SOUTH SLAVE

Fort Resolution

John Young, CEO, Fort Resolution Health and Social Services

Elizabeth MacKay, Housing

Terry Larocque, Social Services

Ruthie Mandeville, Deninu First Nations

Trina Norn, Income Support

Peter McCall, Health Centre

Gail Beaulieu, Health Centre

Dolly Lafferty, Alcohol and Drug Program

Eva Villeneuve, Mgr. Seniors' Facility

Elizabeth Giroux, CHR, Health Centre

Noleen Villebrun, Researcher

Hay River

Gary MacDonald, Occupational Therapy, Hay River Community Health Board

Raafat Ramzy, Physiotherapy, Hay River Community Health Board
Karen Ennis, Woodland Manor
Marilyn Lea, Hay River Housing Authority
Betty Lyons/Angela Libby, Soaring Eagle Friendship Centre
Liz Pope, Aurora College
Sharon Sunrise, Judith Fabien Senior Centre
Rita Plunkett, Home Support Worker, Hay River Reserve
Rhonda Latimer, Hay River Playschool
Quinn Groenheyde, Dene K'onia Young Offenders Facility
Deb Beck, Dene K'onia Young Offenders Facility
Sharon Cardiff, Extended Care Unit, Hay River Community Health Board
Karen Cooper/Pam Villeneuve/Martha Lenoir, Education, Culture and Employment
Mike Morrill, Hay River Community Health Board
Joanne Connors/Wanda Budgell, Aboriginal Headstart Program
Deb Stephen, Hay River Community Health Board
Shirley LaMalice, Hay River Dene Band First Nations
Mary King, Community Advocate
Jennifer McSwain, NWT Council for Disabled Persons

Enterprise

Bonnie Kimble

Fort Smith

Pamela Bradley, Homecare, Fort Smith Health and Social Service Board
Moira Jones, Public Health, Fort Smith Health and Social Service Board
Paulette Heron, Director Patient Services, Fort Smith Health Centre
Joan Bevington, Physiotherapy, Fort Smith Health and Social Service Board
Jessica Hval, Fort Smith Community Day Care
Ruth White, Fort Smith Housing Authority
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Appendix E: Bibliography

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**Appendix F: Generalizing the Results of the
Needs Assessment to the Total NWT Population
with Disability**

Generalizing the Results of the Needs Assessment to the Total Population with Disability

The 1991 Health and Activity Limitation Survey (HALS) was used to derive an estimate of the total population with disability. The HALS is a post-censal survey that provides coverage of the entire population of the NWT and Nunavut. Wherever possible the definitions used in the Needs Assessment reflected those used in the HALS. As shown in Table 1, it is expected that 13.1% of the population living in households in the NWT in 1999 have a disability. As expected most persons that reported disabilities have mild disabilities (67%) while almost a quarter (23%) have moderate and one in ten (10%) have severe disability.

Table 1: Estimated 1999 NWT Population with Disabilities by Age and Severity based on 1991 HAL Post Censal Survey Rates

	Total Population	Persons with Disabilities Living in Households				Total
		Mild	Moderate	Severe		
Number	41,606	3,674	1,259	521	5,453	
0 - 14	11,337	763	66	27	856	
15 - 64	28,579	2,530	942	228	3,700	
65 - over	1,690	381	250	266	897	
% of Disabilities		67.4%	23.1%	9.6%	100.0%	
0 - 14		89.1%	7.7%	3.2%	100.0%	
15 - 64		68.4%	25.5%	6.2%	100.0%	
65 - over		42.4%	27.9%	29.7%	100.0%	
% of Population		8.8%	3.0%	1.3%	13.1%	
0 - 14		6.7%	0.6%	0.2%	7.6%	
15 - 64		8.9%	3.3%	0.8%	12.9%	
65 - over		22.5%	14.8%	15.7%	53.1%	

Notes: Table 1 provides an estimate of the total number of persons with disability by severity living in households based on rates derived from the HALS and the NWT population³⁵ in 1999. Rates derived from the HALS-based degree of severity for each age group were applied to the NWT population in 1999 by age. This methodology assumes that the rates have not changed since 1991 and that the degree of disability by severity and age for persons living in Nunavut and the NWT are similar.

Two questions were posed to determine whether the Needs Assessment results could be applied to estimates of the total population of persons with disability in the NWT:

1. What portion of the total population with disability did the Needs Assessment cover?
2. Are Needs Assessment respondents representative of the total population of persons with disability so that Assessment results can be generalized to the total population?

Table 2 presents the number of persons with disability living in households and participating in the Needs Assessment by age and degree of disability.

Table 2: Needs Assessment Population Living in Households with Disabilities by Age and Severity

	Total Population	Persons with Disabilities Living in Households				Total
		Mild	Moderate	Sever e		
Number	41,606	85	209	379	673	
0 - 14	11,337	14	28	56	98	
15 - 64	28,579	44	123	211	378	
65 - over	1,690	27	58	112	197	
% of Disabilities		12.6%	31.0%	56.3%	100.0%	
0 - 14		14.3%	28.6%	57.1%	100.0%	

³⁵NWT Bureau of Statistics, Population by Age for 1999

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	15 - 64	11.6%	32.5%	55.8%	100.0%
	65 - over	13.7%	29.4%	56.9%	100.0%
% of Total Population		0.2%	0.5%	0.9%	1.6%
	0 - 14	0.1%	0.2%	0.5%	0.9%
	15 - 64	0.2%	0.4%	0.7%	1.3%
	65 - over	1.6%	3.4%	6.6%	11.7%

In total the Needs Assessment involved 85 of the expected 3,674 mild disabilities (2.3%), 209 of the expected 1,259 moderate disabilities (16.6%), and 379 out of the 521 expected severe disabilities (72.7%). (Table 3)

Table 3: Needs Assessment as Proportion of Estimated Population

Number	HALS	NA	NA % HAL
Mild	3,674	85	2.3%
0 - 14	763	14	1.8%
15 - 64	2,530	44	1.7%
65 - over	381	27	7.1%
Moderate	1,259	209	16.6%
0 - 14	66	28	42.4%
15 - 64	942	123	13.1%
65 - over	250	58	23.2%
Severe	521	379	72.7%
0 - 14	27	56	207.4%
15 - 64	228	211	92.5%
65 - over	266	112	42.1%
Total	5,453	673	12.3%
0 - 14	856	98	11.4%
15 - 64	3,700	378	10.2%
65 - over	897	197	21.9%
Moderate & Severe	1,780	588	33.0%
0 - 14	93	84	90.3%
15 - 64	1,170	334	28.5%
65 - over	516	170	32.9%

This pattern was expected because the Needs Assessment was drawn from persons already seeking services due to disability, likely due to moderate to severe disability (e.g. persons with moderate to severe disability are more likely to be in the service loop than those with mild disability.) Table 3 also shows that if the moderate and severe disabilities are combined the Needs

Assessment covered one-third (33%) of the expected population with disabilities.

The high proportion of the population covered by the Needs Assessment for the moderate and severe disability groups provide an opportunity to generalize results to the total population. The much lower coverage in the mild disability group makes generalization to the total population much less reliable.

The remaining question is whether there is any significant difference in the characteristics of the population with moderate and severe disability covered by the Needs Assessment and those not covered by the Needs Assessment. If there are no basic differences, the Needs Assessment is representative of the entire expected population of persons with disability. It is the best professional judgment of the Lutra research team in consultation with Ellis Consulting Ltd. that there are no reasons to expect any differences in the populations covered by the Needs Assessment and the HALS. This means that the results of the Needs Assessment can be used to represent the entire estimated population of persons with disability.

Population Projections

The Needs Assessment represents one-third (33%) of persons with disability living in non-institutionalized settings. Based on data derived from HALS and the NWT population projection. Table 4 projects to the total number of persons with disability by severity living in households in the NWT from 1999 to 2019.³⁶ (Rates derived from HALS based on degree of severity for each age group were applied to the NWT population projections for each

³⁶Source: NWT Bureau of Statistics, Population Projections by Age to 2019

year by age. This methodology assumes that the rates have not changed since 1991 and that the degree of disability by severity and age for persons living in Nunavut and the NWT are similar.) As shown, it is expected that the population with disability will increase from 5,453 to 6,515 in 2009 to 8,883 in 2019.

Table 4: Projected Number of Persons Living in Households in the NWT with Disability by Age and Severity, 1999-2019

Number		1999	2004	2009	2014	2019
0 - 14		856	867	832	861	917
	Mild	763	772	742	767	817
	Moderate	66	67	64	66	71
	Severe	27	27	26	27	29
15 - 64		3,700	3,913	4,186	4,400	4,592
	Mild	2,530	2,676	2,862	3,008	3,140
	Moderate	942	997	1,066	1,121	1,170
	Severe	228	241	258	271	283
65 - over		897	1,130	1,497	1,980	2,373
	Mild	381	480	635	840	1,007
	Moderate	250	315	418	553	662
	Severe	266	335	444	587	704
Total		5,453	5,910	6,515	7,241	7,883
	Mild	3,674	3,928	4,239	4,616	4,964
	Moderate	1,259	1,379	1,548	1,740	1,903
	Severe	521	603	728	885	1,016
Rates		1999	2004	2009	2014	2019
Percent of Population		13.1%	13.5%	14.1%	14.7%	15.1%
	Mild	8.8%	9.0%	9.2%	9.4%	9.5%
	Moderate	3.0%	3.1%	3.4%	3.5%	3.7%
	Severe	1.3%	1.4%	1.6%	1.8%	1.9%
Percent Change			2.9%	4.6%	4.5%	2.7%
	Mild		1.5%	2.5%	2.4%	1.4%

Needs Assessment Bibliography

Modera	4.0%	6.6%	5.6%	3.1%
te				
Severe	10.0%	14.5%	14.3%	8.2%