Urban Aboriginal Families of Children with Disabilities: *Social Inclusion or Exclusion?*

Participatory Research:
Working Together for the Inclusion of
Aboriginal Families of Children with Disabilities

February, 2006

by:

NATIONAL ASSOCIATION OF FRIENDSHIP CENTRES

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Executive Summary:

Urban Aboriginal Families of Children with Disabilities

First Nations people with disabilities are severely marginalized in numerous ways: They have a disability; they are Aboriginal; they are off reserve or urban (Durst and Bluechardt, 2001). Women are even further marginalized (Lonsdale, 1990; Marshall & Juarez, 2002). The rate of disabilities among Aboriginal people (32 per cent) is twice the national average (Canada, 1995, p.5). Aboriginal people with disabilities are not living an independent lifestyle and are excluded from participating in community life. Little is known about the Aboriginal families of children with disabilities and those that leave their home reserve are lost in the urban city.

This two-year study examined the challenges identified by urban Aboriginal families of children with physical disabilities and determined practical solutions for policy makers and service providers to help eliminate or overcome these obstacles. The study has been coordinated by National Association of Friendship Centres, Ottawa and funded through the Social Development Partnership Program – Office for Disability Issues of the Government of Canada. Interviews were conducted with Aboriginal parents of children with disabilities and service providers in the social and health services across Canada. The study concentrated on Regina but site visits and interviews were conducted in Montreal, Toronto and Vancouver. Telephone interviews were completed with participants in Halifax. These site visits were very enlightening. Although, most of the issues are common across the country, there are significant issues and unique concerns in some locations.

The major over-riding issue facing all urban First Nations and Aboriginal families is the confusing jurisdictional and bureaucratic structures. Health and social services are programs fragmentation among various government levels and agencies is a major barrier to access. The situation is confusing and frustrating and many persons simply give up, and therefore are not accessing services or programs to which they are fully entitled. The first step that should begin immediately is addressing the complex jurisdictional issues of government departments.

Second, the government and non-government agencies purporting to serve persons with disabilities need to address the low participation rates of Aboriginal people. These professionals need more than cultural awareness but a sound and critical self-examination of their policies and programs, looking for forms of discrimination and racism. These agencies need to employ Aboriginal service providers and include Aboriginal persons in positions of leadership such as on their Board of Directors. These agencies need to take a hard and critical look at themselves and find ways to reach this population.

Third, Aboriginal leadership needs to take the problem seriously at the reserve, provincial and national level. There needs to be improvement in the professionalization of services provided by Aboriginal agencies. They have not been serving the urban members of their First Nation very well.

There is a need for awareness of the issue at all levels of service. Both the provincial and federal governments in conjunction with national Aboriginal leaders need to improve awareness education and sensitivity. There is a need for greater coordination of policy at the federal and provincial levels as many of these issues cross programs and are separated "ghetto-ized" in "Aboriginal" departments or divisions within government.

Finally, there is a need for continued research on a variety of topics including understanding aspects of "inclusion" for families of children with disabilities. Assumptions used in Euro-western culture about independence and self-sufficiency may not apply in the same way in Aboriginal societies. There is a need for health and social research that is more focused than this broad overview of the issues. For example, parents are desperate for help in caring and raising children with FAS/E. Other focused research should look at families of children with specific disabilities such as physical mobility or intellectually challenged.

From the literature and from the findings, this report offers four specific courses of action that are recommended for immediate implementation.

Action #1: Establish Provincial Advocate Offices

An "Ombudsperson for Aboriginal Persons with Disabilities" would offer a tangible source of support and assistance to Aboriginal persons with disabilities. An intergovernmental office should be established and include the major stakeholders: First Nations, non-government service providers, provincial and federal governments and Aboriginal persons and families with children of disabilities. This intergovernmental effort would ensure, that Aboriginal and First Nations persons with disabilities and their families, receive the basic services and programs to which they are entitled.

Action #2: Implement a National Jurisdiction Review Panel

There is an immediate need to resolve the jurisdictional problems outlined in the following report. Repeatedly, studies have identified the jurisdictional difficulties and reported that it is a major barrier for this population. An intergovernmental review team should be established which could be based on the similar partners as suggested for the ombudsman offices. This intergovernmental team would complete a comprehensive review of the jurisdictional issues and propose a realistic system to adequately resolve it.

Action #3: Create National Network of Urban Aboriginal Health and Social Services Centres

There are over-riding issues facing Aboriginal families in all of the major cities in Canada. They lose contact with their cultural and family supports; they face agencies and service providers who are intentionally and un-intentionally unwelcoming. They face administrative bureaucracy and a cold impersonal system. There is a desperate

need to take a hard and critical look at the provision of health and social services to urban First Nations/Aboriginal individuals and families. The model of the cooperation between the Vancouver Friendship Centre and Vancouver Native Health Society may be an example. However, the instability of funding continues to plague both agencies. In Montreal, English speaking Aboriginal persons regularly encounter blatant racism in their dealings with government agencies. The situation in Montreal is simply appalling and unacceptable. Steps should be taken immediately to develop an Aboriginal Health and Social Services Centre in Montreal. Every city with a significant urban population should have such a centre where a variety of health and social services can be coordinated and accessed.

Action #4: Expand Research Knowledge Base

It is recommended that the federal government departments including Human Resources Development Canada, in conjunction with relevant partners, initiate expanded and strategic research endeavours in the areas of need identified in this report. Effective and efficient policy development, both nationally and regionally, as well as programs planning and service delivery, must be based upon empirical research findings completed under the rigours of accepted systematic inquiry. The relationship between social and policy research, and sound practice has too frequently been ignored. This study has determined the need for three potential research areas:

- · disabilities among Aboriginal children, with a focus on prevention,
- · issues facing specific disabilities including strategic interventions,
- · issues regarding the family and its role, and
- · the aspirations of Aboriginal families regarding inclusion and integration.

The old man said, to have been born imperfect was a sign of specialness… as Canadians, where have we gone wrong? It is time to start to right the wrongs.

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February, 2006
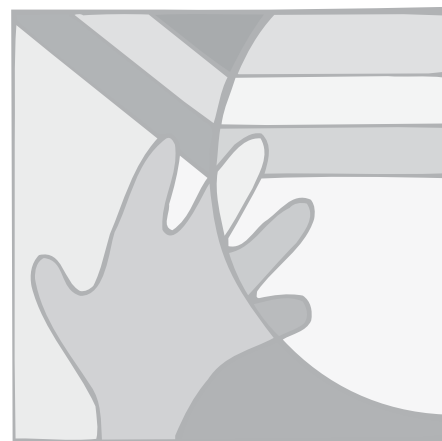
Prologue: A Case Study

Broken Eye Glasses

It was during an intermission at a classical music concert and a dear friend came up to me to chat away the few minutes, which we were enjoying. She is an elementary school teacher who works with children with learning disabilities. She has lots of experience with Aboriginal children and is very understanding and sensitive. No one would consider her "racist" in the overt sense of the word. After all, we all are "racist" in some sense or another.

She asked about my research and I told her about my work with children of Aboriginal descent who have disabilities. Immediately, she told me about a young girl with a learning disability whose glasses broke in class. "Oh it took weeks and weeks to get new glasses. I had to call the mom several times; the girl couldn't see the board she couldn't learn without them. Oh, it was so frustrating". I could feel her anguish and sensed her feelings of non-compliance from the mother. She didn't quite say it but she was implying the mom didn't really care about getting new glasses.

I could feel my face getting warm and I offered this scenario.

"Look Kathy, the mom is probably First Nation and "status" and she is probably single with a couple of kids who have some problems or another. If there is a father, most likely, he is not much help or part of her problems as well. Her main source of income is probably social assistance. The glasses broke and her daughter told her that night that you, her teacher, told her to get them fixed immediately.

Now, if this were me, I would call the optometrists and pop into his office that evening and get the glasses replaced or repaired. I would pay for it on my VISA card and submit an insurance claim the next day. My insurance, which my employer pays half of the premium, would send a cheque for 80% of the costs the next week.

However, this mom would have a different experience. She can't do anything that evening so she calls her "welfare worker" the next morning. The worker says, "Oh yeah, we pay regular clients, and this is a non-insured health benefit. But, you are a status Indian and therefore, Medical Services of the federal government covers it. Give them a call. Well, our mom looks up the number and she gets the electronic computer run-around you get when you call a federal department. After a couple tries, she finally gets to talk to a real person. After a delay, the federal bureaucrat says, "oh, yeah, you are fully entitled to the benefit but we have devolved these non-insured benefits to the Band under our new program of "self-government". Call your Band office. Have a nice day".

The next day, she calls the Band office and after several calls she discovers that the Band office is closed for a professional development workshop put on by the Federation of Saskatchewan Indian Nations. They will open next Monday. She calls at 8:30 am Monday but does not reach anyone until 11 am. She leaves a message for the worker handling these benefits and waits for her to call back. She doesn't call back and the mom tries again. Finally she reaches the worker who tells her that she is entitled to the benefit but it must be approved by her supervisor. He is on a trip to Ottawa attending a conference on non-insured health benefits. The worker reassures the mom that she will "get on it" as soon as her supervisor gets back. Since the mom is a re-instated "Indian" under Bill C-31 and living off of the reserve, she suspects that nothing will happen. Her Band has not shown much interest in helping off-reserve families. "Out of sight, out of mind".

Meanwhile, her daughter has again expressed discontent about the delay in getting the glasses repaired. The mom feels guilty. It is the end of the month and finally, her social assistance cheque arrives. She cashes it and takes her daughter to get the classes fixed. Then she drops by the Food Bank to feed her family because most of the social assistance cheque is gone. The next day, another student, big Albert, sits on and crushes the new pair of glasses."

At the end of the concert, my friend approaches me, smiles and says, "Thanks, I needed that".

Douglas Durst
January, 2002
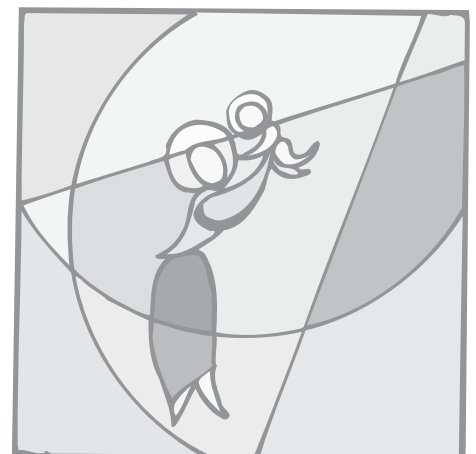
Section 1: Background to Urban Families of Children with Disabilities

1.1 Introduction[1]

Whether on reserve or in the cities, Aboriginal persons with disabilities are virtually invisible in Canada. They are a hidden and forgotten population lost in the busy-ness of people around them. Not surprisingly, few social researchers in Canada have taken an interest in these marginalized people. This writer was involved in a two-year study that produced the ***Urban Aboriginal Persons with Disabilities: Triple Jeopardy*** (Durst, D, & Bluechardt, M. 2001). This report is available from the Social Policy Research Unit, University of Regina or on the web at: **http://www.uregina.ca/spru/spruweb/durst.html** The study found that these people experience a triple jeopardy: they are Aboriginal, they have disabilities and they are urban (off-reserve). Women are even further disadvantaged.

The above research stimulated interest and raised further questions regarding urban Aboriginal families of children with disabilities. Little is known about this group and this research sets the foundation to examining in greater depth issues and barriers they face limiting their participation and integration into community life.

1.2 Objectives of this Report

The purpose of this report is to provide an overview of disability issues as they related to urban Aboriginal families of children with disabilities in Canada. From this overview, research needs and gaps in knowledge are identified and strategies of meeting these needs are presented.

The goals of this report are:

- to complete a comprehensive literature review of relevant research on disabilities and Aboriginal people in Canada,
- to explore with service providers the current issues facing urban Aboriginal families of children with disabilities,
- to interview families of children with disabilities and capture their living experiences,
- to identify and present a conceptual framework that will guide future research with these families,
- to list gaps in knowledge and generate research questions that could guide policy at the local, provincial and national levels, and
- to determine culturally-sensitive strategies in collecting data that would address the gaps in knowledge.

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[1] For the purpose of this report, the term "First Nations" is used to describe persons who are status Indians as defined by the Indian Act. The phrase "Aboriginal people" is a broader term used to define all those people who identify with being of Aboriginal ancestry and may be of mixed ancestry. The term is used to include status, non-status, Inuit and Metis persons.

This first section, Background to Families of Children with Disabilities, sets the stage for the topic. It provides some definitions of disabilities, an overview of the demographics of the people, a brief literature review and some issues they face. Section 2 reports on a brief "study" of the current situation in Regina and provides a "snap-short" of the situation that Aboriginal families of children with disabilities face in their day-to-day lives. This section represents an example of what a national Canada wide study might encounter and in a sense, it is a "pilot study". Section 3 presents a detailed description and narrative of the experiences of these families. Section 4 summarizes the site visits to Toronto, Vancouver, Montreal and Halifax. The final section summaries the issues, offers some specific actions and identifies research gaps and strategies.

1.3 Defining Aboriginal/First Nations People

In Canada, approximately one million people, or 3.3% of the total population, report some Aboriginal origin (Canada Census, 2001). The Aboriginal people of Canada comprise numerous cultural and ethnic groups; all are diverse, with unique cultural systems and historical experiences. With the enactment of the federal Indian Act (1876) and the Constitution Act (1982), categories were developed to classify Aboriginal people. As stated earlier in this report, the term "First Nations" people is used to describe persons who are status or registered Indians as defined by the Indian Act. These persons are under the fiduciary responsibility of the federal government. Status Indians are registered with the federal government and have special rights to income tax exemption, health care, housing, and education in exchange for land surrendered to the federal government. This applies when they live on reserve; however, if they move off reserve, some of their treaty entitlements are restricted.

The phrase "Aboriginal people" is a broader term used to define all those people who identify with being of Aboriginal ancestry and may be of mixed background. The Indian Act does not apply to non-status Indians (Aboriginal persons) and they must receive benefits from the province, as do all other Canadian citizens (Brizinski, 1989). Metis people are of mixed Aboriginal and European parentage. Finally, Inuit are Aboriginal peoples of the Arctic and sub-Arctic regions of the North and are under a special agreement to receive federal benefits under the Indian Act.

The federal Bill C-31 was an Act passed in 1984 to reinstate Aboriginal women, children, and others who lost their status as a result of off-reserve education, employment, and marriage. For example, prior to 1984, an Indian woman who married a non-Indian man lost her Indian status, as did any subsequent children of the marriage. However, non-Indian women who married Indian men gained status, as did any subsequent children of the marriage. Any Indian person who resided off the reserve for more than five years for reasons of education or employment lost their status (Canada, 1994b). The passing of this Bill has lead to the dramatic increase in the number of Indian people holding status in Canada.

1.4 Defining Disability

Developing a universal definition, operationalizing the term "disability", is difficult considering the array of interpretations or meanings based on medical, administrative, and self-defined concepts of disability. Historically, these definitions have been used as a means of labelling and segregating individuals and limiting their access to goods and services.

Developing a definition of disability is difficult and complex. However, in 1980, the World Health Organization (WHO) addressed the need for a more concise definition in the International Classification of Impairments, Disabilities, and Handicaps (ICIDH). ICIDH had as its principle aim to characterize three distinct dimensions of "disablement": impairment, disability, and handicap (WHO, 1980:27-29).

> **Impairment**: Any loss or abnormality of psychological, physiological or anatomical structure or function.

> **Disability:** Any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.

> **Handicap:** A disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfilment of a role that is normal, depending on age, sex, social and cultural factors, for that individual. (WHO, 1980, p. 27-29).

Boylan (1991) illustrates the WHO definition in this way.

> There is a difference between disability and handicap. Disabled persons are not handicapped in all circumstances or in everything they do. Disability should, in no way, be seen as inability. Disability may be permanent. When someone loses a leg in an accident, this disabling condition will remain throughout the person's lifetime. It may be a handicap in, for example, walking, riding a bicycle, or working as a waitress, but not while playing card games, cooking a meal, or working as a computer operator. Concentrating on ability - and not on what a person cannot do - should be the principal concern of every disabled person, and of those agencies and individuals interested in their welfare (Boylan,1991, p.viii).

According to Oliver (1990), these definitions are based upon the assumptions of able-bodied people about what is normal, and, as such, are situated within the experience of able-bodied people. He suggests that the definition of a problem influences the outcome, and that definitions such as the above continue to individualize the problem of disability. This, in turn, results in social policy, which addresses individual concerns, leaving social and economic structures intact. This serves to maintain the status quo. Oliver (1990) goes on to explain that, "If disability is defined as social oppression, then disabled people will be seen as the collective victims of an uncaring or unknowing society rather than as individual victims of circumstance. Such a view will be translated into social policies geared towards alleviating oppression rather than compensating individuals" (p. 2-3).

Oliver (1990) then proposes using the following definitions from Union of the Physically Impaired Against Segregation (UPIAS, 1976) which are situated in the reality of people with disabilities:

Impairment - lacking part or all of a limb, or having a defective limb, organism or mechanism of the body;

Disability - the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from the mainstream of social activities" (UPIAS, 1976 in Oliver 1990 p. 11).

This definition, too, has its limitations. It suggests that the only reason people with disabilities are disadvantaged is because society tends to be structured for people who are able bodied. French (1993) cautions against this view as it overlooks impairments experienced by people with disabilities such as chronic pain or severely mobility impaired people.

Most of the recent studies use the World Health Organisation's definition of disability (TPG, 1994, p. 3: SK Network, 1996; FNCCEC, 1995, p. 7-8; NAND, 1994, p. 3-4; Canada, 1981, p. 186, 1987). Different types of disability are included which are: physical, developmental, psychiatric, learning, hearing, and visual. The severity of the disability and aetiology of it - born with it, childhood onset, or the result of an accident or disease (FNCCEC, 1995, p. 8-11) – are also considered.

Joe and Miller (1987, p. 1) point out the meanings of disability from the Euro-Western definition are based upon whether or not a person can support him/herself, the degree and type of work that the individual can complete, and the degree of inability. Disability is the loss of a valued function and what is valued is different in different cultures. Differences between the Aboriginal culture and the dominant culture, and even within the Aboriginal cultures, lead to differences in what constitutes a disability, causes of disabilities, and appropriate interventions. For example, the Navajo culture emphasizes the cause of the disability, and focuses less on the symptoms influencing the choice of interventions.

Gething (1995, p. 78) notes a discrepancy in perception of disability due to culture: Aboriginal people may not see themselves as having a disability whereas the "trained professional" might. Gething (1985, p. 81) attributes the lack of accurate statistics to

variations in the personal definition of a disability between professionals and Aboriginal people. Only obvious and noticeable conditions such as an amputation or severe physical impairment are thought of as a disability. Subtle forms of foetal alcohol syndrome or mental health issues are not identified. "Disability is rarely seen as a separate issue, but is perceived as part of problems which are widespread and accepted as part of the life cycle" (Gething, 1995, p. 81).

In addition, there are cultural differences, which affect the definition, interpretation and designation of a disability. For some Aboriginal nations, there does not exist a word that can be translated from "disability." Depending on the cultural beliefs and values, conditions that are classified as disabilities by dominant ideology may not be considered in the same context in a particular First Nation. Robert Thomas stated, "the cultural conflict between Indians and non-Indians occurs because some traditional Indian cultural views do not accept secular causes but only sacred foundations as explanations for all experiences" (Thomas, 1981:97). As such, the cultural definition of disability emerges out of social relationships, not out of rigid medical or physiological criterion (Thomas, 1981). For example, the Hopi believe that a person born with a condition that inhibits mobility, but can still contribute to the functioning of the community, is not seen as being disabled (Dapcic, 1995). However, a person who consumes alcohol and is unproductive is classified as being disabled, and may be shunned from the community. In addition, that individual who acquires a condition at some point in their life that is not in their control is viewed as being disabled. Despite one's disability (with the exception of addictions), there is a place in the community for the person (Dapcic, 1995). Unfortunately, non-Aboriginal communities, as well as many Aboriginal communities, do not encourage participation of the disabled. Therefore, when examining issues pertaining to Aboriginal people and disabilities, it is necessary to consider the issues from their vantage point and not base them on non-Indian standards because, simply, they are not at all comparable.

There is also evidence that some disabilities are seen as special gifts from the Creator. Reflecting on a disfiguring disability, an old man states, "to be born imperfect was a sign of specialness" (Wiebe, 1998, p.423).

1.5 Demographics of Canadians with Physical Disabilities

Approximately 4.5 million or 12.6% of Canadians report having a physical or mental disability (Canada, 1994b). It should be noted that adults using a technical aid that effectively eliminates the limitation are not considered to have a disability (Canada, 1994b). Therefore, those who wear corrective hearing devices or lenses and report no limitation are not included in the disability statistics. According to the World Health Organization, six basic types of disability are identified: physical disabilities, developmental disabilities, psychiatric disabilities, learning disabilities, hearing disabilities, and visual disabilities. For the purpose of this study, the World Health Organisation's definition of "disability" will serve as the primary definition.

According to Statistics Canada (1994b), over two million Canadians between the ages of 15 and 64 have some form of disability. The latest statistics on Aboriginal people with disabilities is now 15 years old, the 1991 Aboriginal Peoples Survey. It found that 31.4% of the Aboriginal population reported some form of disability. The rate of disability is quite high for this population, and it increases significantly with age and gender (female). Approximately 66.5% of Aboriginal people 55 years or older live with a disability (Statistics Canada, 1994b).

1.6 Social Demographic Information

Identifying and understanding issues relevant to a designated population involves the use of statistical data. Statistical data have been used to highlight the state of economic development, health, education, housing, income, and social structure of a given population. However, prior to 1991, First Nations people were not represented by Census data. The Aboriginal Peoples Survey (APS) of 1991 was developed in an effort to address this problem (Canada, 1994b). The APS was administered to Aboriginal people across Canada, to obtain information about the Indian people, including their socio-economic conditions and cultural lifestyle. Despite the intention, First Nations participation in data gathering continues to be limited. Therefore, the statistical information included in this study is a small sample of the socio-economic conditions of Indians in Canada.

Aboriginal people constitute approximately 3.3% of Canada's total population (Canada, 1994b). In the 2001 Census, 608,850 people declared their racial origin to be Indian; 292,305 declared Metis status; and 45,075 declared Inuit status. Of Saskatchewan's total population, approximately 130,190 were people identified as being of Aboriginal ancestry, and roughly 16,000 of the City of Regina's population consist of self-identified persons of Aboriginal ancestry. According to the APS (Canada, 1994b), the Aboriginal population is increasing at twice the national rate, which may be attributed to increasing birth rates and decreasing mortality rates. In addition, with the enactment of Bill C-31 in 1984, many Aboriginal women and their children have been reinstated and regained status (Frideres and Gadacz, 2001). Given the increasing population, and relatively unchanged socio-economic conditions, the status of Aboriginal people remains in a continued state of crisis.

1.7 Aboriginal People with Disabilities

Canada has a population of 31 million people of which approximately 4.2 million have a disability; this figure represents 16% of the population (Canada, 1995, p.5). Most adults with disabilities have mild disabilities (47%), while 32% had moderate disabilities and 22% had severe disabilities. In Canada, 1.2 million adults or 4% of the total population had disabilities that were severe.

The estimated First Nations population, both on and off reserve in Canada, is 608,850 (Canada, Census 2001) and the estimated number of persons identifying themselves as "Aboriginal" is approximately one million individuals. Past research has shown that 31.4% of Aboriginal people have reported a disability (NAND, 1994, p.33). The rate of disability among Aboriginal people is approximately double the national average (NAND, 1994, p.33). Therefore, there are approximately 191,100 First Nations persons, and approximately 307,000 Aboriginal persons, with a disability in Canada.

Demas (1993) states that in some native communities it is estimated that 40% of people live with some kind of disability. Lifestyle diseases associated with socio-economic conditions are quite prevalent amongst First Nations people (Frideres and Gadacz, 2001). First Nations women are slightly more likely than men to have a disability (SK, 1999). Approximately 66.5% of First Nations people 55 years or older live with a disability (Canada, 1994b). Of those surveyed in the Aboriginal Peoples Survey, 72% classified their disability as mild, with 4% indicating a severe disability. Disabilities were most frequently caused by injuries, followed by aging and congenital factors (SK, 1999). Saskatchewan has one of the highest rates of disability in Canada: 19.2% of the total population (Canada, 1994b).

1.8 Socio-economic Status and Disability

For the majority, Aboriginal people are positioned at the lowest end of the socio-economic scale regarding education, employment, income, and health (Comeau and Santin, 1995; Frideres and Gadacz, 2001; Canada, 1994b). Housing on many remote and rural reserves is inadequate, failing to meet basic housing standards for amenities and structure, and the unemployment rate can be as high as 95% in some Indian communities (Durst, 1992). On average, Aboriginal people without disabilities have less than a grade nine education, have an unemployment rate four times the national average, have annual incomes of less than $20,000, and have higher rates of infectious diseases and disabilities (Canada, 1994b).

Seventy per cent (70%) of First Nations people with disabilities have low literacy levels (NAND, 1991; RCAP, 1996). Ninety per cent (90%) of all First Nations people with disabilities living on reserve have income levels below the poverty line (NAND, 1991). The G. Allan Roeher Institute (1989) reported that approximately 65% of adult persons with disabilities earn less than $10,000 per year, with many individuals having to rely on social assistance. If this data pertains to the Canadian population with disabilities, it is assumed then that the conditions for Aboriginal people with disabilities are even more severe, given that the rate of poverty is higher for Aboriginal people. They are clearly affected by disabilities because of poor economic, political, and social living conditions. (RCAP, 1996).

Many First Nations people with disabilities move to urban areas to obtain treatment or to be closer to services. They find that accessible housing is scarce, education and training opportunities are inadequate, as are home care services, employment opportunities, and transportation. In addition, they are isolated and have limited opportunities for social interaction. (RCAP, 1996)

Although Aboriginal people have genetic disabilities at about the same rate as the rest of Canadians, they have a higher rate of disability due to environment and trauma-related disabilities. "The disparity between Aboriginal and non-Aboriginal rates of disability corresponds to disparities in rates of injury, accident, violence, self-destructive or suicidal behaviour and illness (such as diabetes) that can result in permanent impairment" (RCAP, 1996, p.148).

Table 1 presents data comparing the breakdown of disabilities by category of disability and cultural group. Keep in mind that the rates amongst Aboriginal persons are still twice the national average.

Table 1

Percentages of Adult Persons with Physical Disabilities

	Mobility	Hearing	Seeing	Agility	Speaking	Other
	45 45 47 45 44 36	23 35 39 33 34 44	9 24 32 21 22 24	44 35 34 36 38 26	10 13 14 13 13 10	37 36 37 37 35 36

- ■ Total Population
- □ Total Aboriginal
- ■ North American Indians On-Reserve
- ■ North American Indians Non-Reserve
- ■ Metis
- ■ Inuit

(Source: Statistics Canada, 1994, #11-001E)
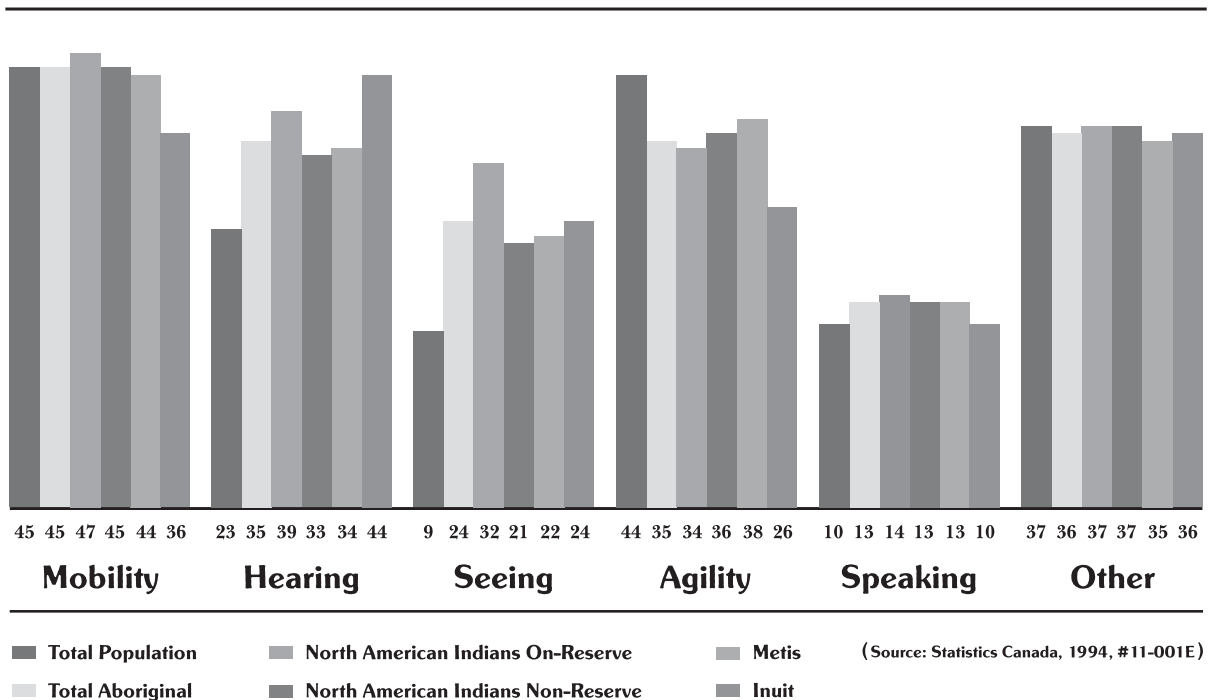
As Table 1 demonstrates, percentages of mobility disabilities tend to be approximately the same among all of the groups, with the Inuit slightly lower. A possible explanation for the mobility percentage being lower among the Inuit may be definitional. For the Inuit living in small communities, family help is available and distances are short. Everyone has trouble in the winter so it may not be reported in the same way as in the other culture groups.

The very high percentages of vision impairment can be related to the onset of diabetes, which is two to three times higher among Aboriginal peoples of all groups. Sadly, some prevention is possible. With careful insulin control and appropriate diet in the early stages, many of these impairments are preventable.

The agility category raised some definitional issues. Agility included the person's ability to complete normal personal and household activities. For example, agility may include opening a can of soup, completing personal hygiene such as toileting and cleaning teeth, making a bed, and other tasks that require some strength, flexibility and agility. The lower percentages may reflect the person's definition. With family supports, and a culture that encourages giving and receiving help (interdependency), individuals are not expected to be totally independent and self-sufficient in all aspects of their lives. As a result, one does not perceive to have a problem with agility if they need help opening a jar of strawberry jam!

In the final categories of speaking and "other", the percentages of disability are similar among all groups. Speaking disabilities would be predominately related to strokes and heart disease, which has been increasing in recent decades.

1.9 Literature's Overview of the Situation

The idea of double jeopardy was a common observation in the literature. The First Nations Confederacy of Cultural Education Centres (FNCCEC 1995, p. 13) identified the double jeopardy of discrimination and prejudice towards Aboriginal people, and the disability as barriers to employment and access to services. The Social Planning Council of Winnipeg (SPCW, 1996, p. 11) also listed the double bind of membership in two disadvantaged populations: the Aboriginal's low education, income, and employment rates, and the population of persons with disabilities who find barriers to training, education, and employment. In addition to facing barriers due to poverty and disability, Aboriginal persons face systemic discrimination, jurisdictional barriers, and lack of culturally sensitive services (SPCW, 1996, p. 37).

Everett Soop adds the urban environment as the third jeopardy. In addition to being Aboriginal and having a disability, Aboriginal people often lack the skills or knowledge to cope in an urban environment, "and the result is awesome human misery and hopelessness that takes more than a welfare cheque can alleviate", (SK Network, 1996, p. 4).

The literature makes the link between health, socio-economic, political and cultural conditions, and disability. The issues are complex and interrelated, which precludes easy solutions. Through a literature review, the Manitoba study (TPG, 1994, p.iv) found that the most frequently cited predisposing factors were diabetes combined with a general failure to access early treatment, ongoing problems with some infectious diseases such as bacterial meningitis and otitis media, especially among young children, accidents and violence, mental health problems, and substance abuse including FAS/E. These factors are related to issues facing Aboriginal communities such as poverty, geographical remoteness, lack of access to adequate health care, lack of control over resources, and cultural and economic change.

The Winnipeg study (SPCW, 1996, p.viii) also found through their literature review that "low education, poverty, cultural issues and issues related to having a disability" lead to multiple and interrelated disadvantages and barriers. RCAP (Vol. III, p. 148) reported that the differences between Aboriginal and non-Aboriginal rates of disability correspond to the differences in rates of injury, violence, accident, suicidal or self-destructive behavior, and illness (such as diabetes) that can result in permanent impairment.

According the Obstacles, the Third Report (1981),

> Native communities, and Native people living in non-Native communities suffer on a daily basis from living conditions, which other Canadians experience only rarely. These adversities – economic, political, social and cultural in nature - greatly increase the probability of being disabled at some time in a person's lifetime (cited in RCAP, Vol. III, p. 148).

The First Nations Confederacy of Cultural Education Centres (FNCCEC, 1995, p. 30) acknowledges the 1990 findings of the National Aboriginal Network on Disabilities that poor health and poverty contribute to and exacerbate incidences of preventable disabilities.

The Obstacles Report (Canada, 1981, p. 137-138) and the Follow Up Report (Canada, 1987, p. 47-48) recognize that alcohol is increasingly linked to disability among the Aboriginal population. The Obstacles Report (Canada, 1981, p. 132) quotes the National Indian Brotherhood (now called the Assembly of First Nations), which also identified alcohol abuse as the primary cause of physical and mental disabilities. They further identified the causes of many diseases and illnesses to be social, economic, occupational, environmental, nutritional, and spiritual in nature. Education was viewed as a critical preventive action.

The Follow Up Report (Canada, 1987, p. 5-6) acknowledges that "These adversities – political, economic, social and cultural" – and unemployment, poor nutrition, poverty, low education, and unhealthy lifestyles need to be addressed first, in any effort to deal with the problems of disability. Problems within government bureaucracies, poverty, unemployment, social and geographical isolation, and substandard living conditions still contribute to the incidence of disability among Aboriginal people. It also makes the process of organizing and obtaining adequate services more difficult (Canada, 1993, p. 6).

The Albert Report (p. 6) noted that it is difficult to separate the problems that face Aboriginal people with disabilities from those that face all Aboriginal people. According to the demographic data of Winnipeg, if people are both Aboriginal and have a disability, they are likely to be poor, dependent on social assistance, and suffer poor self-esteem and self-image (SPCW, 1996, p. 17). However, the connection between health indictors of Aboriginal people and disability needs more study. An illness does not necessarily mean a disability, and a disability can exist without a medical diagnosis according to the definition of a disability (TPG, 1994, p. 8).

The FNCCEC study in Saskatchewan named the needs of Aboriginal people with disabilities as a social versus a political issue because persons with disabilities are aware that they are entitled to employment, access to buildings, health care services, and transportation benefits (SK Network, 1996, p. 1-2). The National Aboriginal Network on Disability also states that disability is not necessarily a health issue as many people with disabilities are healthy (NAND, 1994, p.4). The definition of health is the absence of disease. Completing the Circle Report (Canada, 1993, p. 50) states, "It is not sufficient to equate disability issues with the provision of health care." Disability is a problem of housing, transportation, education, recreation, and home support versus a health issue (SK Network, 1996, p. 25). The BC Society (1993, p. 18) recommends that the issue be approached in a much broader context than a health care issue. The Follow Up Report states that "There is enough evidence to demonstrate the direct relationship between poor health conditions and the widespread incidence of disability among Native people" and calls for a holistic approach to health including social, economic, political, and cultural conditions (Canada, 1987). All the conditions are connected.

In order to address the disadvantaged conditions of Aboriginal people, RCAP (Vol. III p. 148-150) recommends primary prevention in the form of enhanced health and safety conditions in Aboriginal homes and communities in order to decrease injury and accident, enhance social and economic conditions to decrease violence and self-destructive behaviour, and facilitate better health promotion and disease prevention programs to decrease disabilities resulting from illness.
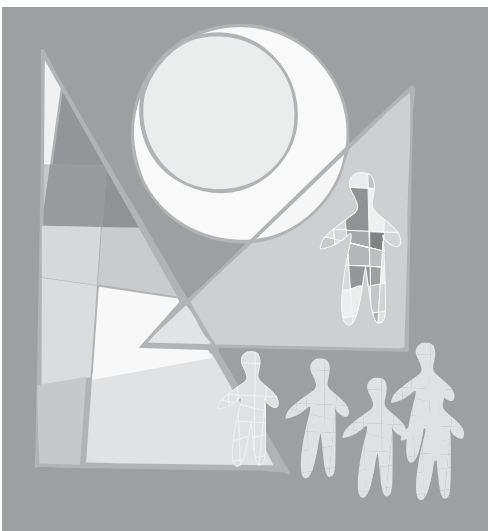
Section 2:
A "Snap-shot" of the Regina Situation

2.1 Introduction[2]

This initial research created a "snap-shot" of the current situation in Regina, Saskatchewan. These findings have national implications and it is expected that many of the issues in Regina directly relate to other cities in Canada. Twenty-five agency personnel from a variety of social agencies and ten caregivers, mostly women, were interviewed. The interviews were conducted mainly by face to face and a few by telephone to determine the major issues facing these parents. The following section highlights the key issues determined by this convenience sample.

2.2 Population Characteristics

One of the first questions asked was regarding the characteristics of the Aboriginal families with children with disabilities. General information was sought that could give a "snap-shot" of the key characteristics of this population.

The respondents, which included service providers and single mothers, highlighted a number of important characteristics and issues. There were many children in the city that have complicated intellectual and emotional problems such as Foetal Alcohol Syndrome/Effects, learning disabilities, attention deficit disorders, internalized emotional problems such as anxiety and depression. The participants reported developmental delays in speech and language as well as delayed physical development. They also reported accident related disabilities such as head and brain injuries and permanent physical injuries. There was also reported genetic or birth related disabilities such as cerebral palsy and cleft palate. Although these problems are seen in the wider population of mainstream society, it was reported that they are even more prevalent among Aboriginal families and appear more frequently among children who are in the care and custody of the provincial department of social services.

If the child is in temporary care there is often a shuffling back and forth between care and the natural mother. Either there are insufficient supports for the parent when the child is in the home or there are other problems in the home's functioning to provide the level of care the child requires. Hence the parent cannot cope and the child is returned to provincial care such as a foster home.

The participants consistently reported that most of the children are living with their single mother who lives in poverty. It is not uncommon for more that one child to have some forms of disabilities and other family issues such as alcohol and drug abuse or family violence. These families have multi-problems.

In addition, many of these families are very transient moving within the city and returning to their home reserve. The migration to and from rural reserves complicates and frustrates the delivery of services and supports.

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[2] Contributions by Kavita Ram and Karen Martens Zimmerly, Community Researchers

2.3 Family Goals and Aspirations

Agency professionals tended to find this question difficult to answer except in general terms that the parents of these Aboriginal children generally want what is "best" for their child. The parents wanted their child to grow up as normal as possible, to be accepted in school and get along with other children.

Often these children have been removed from daycare centres and schools that had difficulty coping with the child's behaviour. The mothers are keenly aware of her child's issues and desperately wanted help.

In some cases where the child's disability was related to the neglect or behaviour of the parent such as FAS/E, the mother had shame and guilt over the situation. In other cases, the professionals reported that the mother was in denial over the situation and that created a serious barrier to the provision of services.

The agency staff could offer little opinion on the goals of these single mothers. They had not determined if their goals were different or similar to other parents of children with disabilities. They did not seem to know this client population very well.

One participant, an Aboriginal mother of two children with disabilities, could offer insights to what she wanted and what she felt other families sought. She desired the family to be a complete and functioning unit in the traditional Aboriginal understanding where their physical, cultural, community and spiritual needs are met. She reported that her children are a special gift from the Creator and given to her for a special reason. She wished that other caregivers and providers of services including teachers and medical staff would operate from this perspective. She felt that professionals were to quick to focus on the behavioral problem to be controlled by Ritalin and "consequences" such as punishment. She wanted more than "survival" – the day-to-day struggle that she lives under. She wants her sons to get the help they need so they will grow up to "make this world a better place" and become an active contributor to society.

2.4 Disability Supports and Services

The city of Regina has a vast array of supports and services for persons with intellectual, emotional and physical disabilities. There are numerous agencies, which collaborate in making referrals, doing case management and providing parental support in terms of education of the needs of the child. Many of these services are designed to support the family in the home environment and avoid removing the child from his/her home. A number of agencies are able to provide workers to go into the home and give the parent guidance and services.

Whether First Nations or Aboriginal, the non-insured health benefits can provide many technical aids that a physically disabled child might need. An Aboriginal person without status can receive these benefits if they qualify for social assistance and a First Nations person can access them through the non-insured benefits program offered through their Band Council. Even though they may be eligible for the benefit, accessing a benefit may be a problem if there are communication problems with the Band personnel or if the Band workers are uncooperative. This unfortunately situation does occur and creates serious problems accessing benefits.

The city has a number of agencies, which are organized and operated by Aboriginal people specifically for Aboriginal clients. Also, some of the agencies have staff that is of Aboriginal descent. It was reported that these agencies and Aboriginal staff are more effective in delivering programs and services to Aboriginal mothers/parents. It was felt that the staff is better able to bridge the culture gap.

The funding arrangements vary widely from agency to agency. The entire spectrum of organizations is present in Regina: provincial government agencies, Band/Tribal Council agencies, non-profit charitable organizations, which receive government grants, grants from local organizations and private donations and for-profit businesses. Some of the non-profit agencies charge a modest fee for service but most of the services are available without personal cost to the mother.

2.5 Goals And Gaps

The professional members, at agencies that provide specific services to address a physical disability or a disability like speech and language, believe that they are providing an efficient and effective service. They believe that they are addressing the problem or need and see themselves as competently meeting these needs in the future.

There seems to be more supports available to help the family when the child is at home then in care of the province or in an institution. However, they report the need for expanded services and the need for Aboriginal workers. Also, there seems to be more supports and services directed at children than adolescents.

As in the literature review, there is a serious problem in accessing services because of the lack of knowledge of these services. Many services and programs are not utilized because the mother simply was unaware of their existence or how to access them. These women are just trying to *survive* and lack the knowledge and time to "track down" services.

Many services cost money and usually the money that is made available has certain qualifications that are attached. When these children do not met the exact criteria they can be denied services. Where they live, status or non-status, and category of disability can limit the availability of services. Sometimes this is called the "hardening of the categories".

When funding is a problem there is a "ping pong" effect from agency to agency; no one seems to have the mandate to cover the costs of the benefit or service. Sometimes the gap means no service, particularly as the child gets older. While a Band receives funding for the disabled child who has treaty status they may be reluctant to pay for a service when the child is off-reserve and living in the city.

In many cases these families are dealing with other issues besides a child with a disability such as poverty, isolation, family dysfunction. To address the needs of the child effectively these other issues need to be addressed as well.

Transportation was frequently cited as a barrier. Mothers asked, "Even if the service is available how do I get my child there?" Sometimes they might have a vehicle but insufficient funds to keep it operating. When other children are in the home, there are problems finding child care when pursuing services. They ask, "Who will look after the other children when I am taking my son to speech class?

In the city, there is little respite care or funding available. Some agencies will provide childcare while a parent is taking one of their educational programs; some daycares have allocated spots for respite care. But, there are no level 4 respite care places available. The researcher was told that it can take 1½ years for a respite bed to become available at Wascana Rehabilitation Centre (Provincial Health Centre in Regina).

It is difficult to get specialized equipment for a child with a physically disability or ramps or other specialized adaptations to a home; equipment is available for the needs of the child but not to make life for the family a bit easier. Even if there is funding from the Band Council, the mother will encounter difficulties in getting approval and accessing the funds.

It was identified that mental health services for Aboriginal youth is a major problem. The existing service network just is not reaching them.

Professionals seem dedicated and are genuinely concerned for the welfare of these children and their needs but the services provided tend to be based on the mainstream society. The issue is that these children and their families are Aboriginal and have a different cultural perspective. The professionals may not be aware of it but the Aboriginal family with a child with disabilities often experience racism and discrimination

There is a growing awareness among these agencies that they must do better at networking and making referrals to one another so that there are not as many "cracks to fall through" and so that the parent is not overwhelmed by so many agencies working with their child in a disjointed and fragmented fashion.

Section 3:
Research Findings: Families Speak[3]

3.1 Introduction to Social Inclusion Model

Social inclusion is what creates a community, how people are accepted, recognized and able to take part in the life of that community. According to Freiler,

> Social inclusion is how we are alike as human beings, for what binds us together as persons;… it is about participating as a valued member of society. Inclusion makes the link between the well-being of children, our common humanity, and the social, economic, political and cultural conditions that must exist in a just and compassionate society (Freiler, 2002).

Social inclusion calls for a "valuing of diversity, as well as recognition and valuing of the commonalities in people's lived experiences and aspirations for themselves and their children." (Freiler, 2002)

Hanvey (2002) states that full inclusion means that children and families are able to participate with choice and individual children are involved in activities and social structures in a way that is meaningful to their own unique experiences.

The Laidlaw Foundation has identified five critical dimensions, or cornerstones, of social inclusion:

1. **Valued recognition** - Conferring recognition and respect on individuals and groups. For example, policies and programs that recognize the differences in children's development and do not equate disability with pathology; support for community schools that are sensitive to cultural and gender differences; and public policy recognition of common worth through universal programs such as health care.

2. **Human development** - Nurturing the talents, skills, capacities and choices of children and adults to live a life they value and to make a contribution both they and others find worthwhile. For example, ensuring learning and developmental opportunities for all children and adults; community child care and recreation programs for children that are growth-promoting and challenging rather than merely custodial.

3. **Involvement and engagement** - Having the right and the necessary support to make/be involved in decisions affecting oneself, family and community, and to be engaged in community life. For example, youth engagement and control of services for youth; parental input into school curriculum or placement decisions affecting their child; citizen engagement in municipal policy decisions; and political participation.

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[3] Contributions by Pat Duggleby, Community Researcher

4. **Proximity** - Sharing physical and social spaces to provide opportunities for interactions, if desired, and to reduce social distances between people. For example, shared public spaces such as parks and libraries; mixed income neighbourhoods and housing; and integrated schools and classrooms.

5. **Material well-being** - Having the material resources to allow children and their parents to participate fully in community life. This includes being safely and securely housed and having an adequate income. (Freiler 2002)

3.2 General Information/Demographics of Regina Participants

During the period May 27 to October 15, 2004, 52 organizations and 16 individuals were contacted for possible inclusion in the study. Organizations were chosen because of the likelihood of their being in contact with the target group, families with disabled Aboriginal children. These included such diverse groups as the Salvation Army, Aboriginal associations, faith communities and special interest groups such as the Canadian National Institute for the Blind (CNIB) and the Foster Parents Association of Saskatchewan. Spokespersons for the organizations stated they have little direct contact with the target group, although most acknowledged that they were aware of Aboriginal children with disabilities in the community. Provincial and national organizations, such as the CNIB and Canadian Arthritis Society, do not track by culture or ethnicity and would know if clients are Aboriginal only if they self-declare. This "colour-blindness" was designed to ensure equal treatment but contacts within the organizations acknowledged that persons in special needs groups may not be receiving the information, treatment and care they need to be full members of the community.

- Demographics:
  - o 10 interviews – 1 male, 9 females involving 11 children
  - o profile of disabilities
    - 13 year old male – cerebral palsy, visual impairment, non-verbal
    - 11 year old male – cerebral palsy, asthma
    - 9 year old male – cerebral palsy
    - 2 ½ year old female – cerebral palsy, asthma, respiratory distress
    - 17 year old male – cerebral palsy
    - 28 year old male – cerebral palsy, epilepsy
    - 16 year old male – cerebral palsy, ADHD, OCD
    - 6 year old female – pyridoxine dependency for seizures, hypotonic muscles, lacks protective reflexes
    - 18 year old female – fused fingers, facial and body scarring as result of house fire in early childhood
    - 16 year old female – cleft palate/reconstructed pharyngeal flap, FAS
    - 22 year old male – cerebral palsy
  - o participant profile
    - 9 primary caregivers in the 50+ age group; 1 in the 40 – 49 years age group
    - 2 lone parent (f) parent with physically disabled adult children living at home
    - 3 grandmothers (2 widows, 1 unknown)
    - 1 female foster parent with partner, 1 lone female foster parent, 2 mothers with partners, 1 father with partner

o Other family members living at same address/relationship to p.d. child:
- · cousin 5
- · birth siblings 4
- · adoptive siblings 1
- · other children being fostered 3

o 1 rented house, 1 rented duplex, 1 rented fourplex, 7 owned homes

o 6 work full-time, 1 part-time worker, 2 full-time foster parents, 1 on social assistance

o participant education:
- · Grade 11 - 1
- · post-secondary certificate - 2
- · GED - 1
- · Post-secondary degrees - 6

o education level of children
- · pre-school 1
- · elementary school 3
- · high school 2
- · high school completion (1 enrolled in university in fall 2004, 1 enrolled in another post-secondary institution)
- · developmental centre 1
- · other (currently attends sheltered workshop, in developmental centre until age 22) 1
- · other (in adult day care – on waiting list for shelter workshop) 1

o Status of caregivers:
- · Status 7
- · Métis 1
- · Non-Aboriginal 2

o Status of children:
- · Status 11

Notes: _____

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1. There is a growing population of middle class Aboriginal professionals in Regina which can be explained partially by the presence of First Nations University of Canada. There are also large numbers of Aboriginal government workers due to the efforts of the provincial and federal governments to hire from this designated group.

2. None of the participants came from the stereotypical at-risk Aboriginal population. Only one person, a non-Aboriginal foster parent, did not have at least a Grade Twelve equivalency. Whether or not the children from the at-risk group were more "invisible" than non-Aboriginal children from the same group is difficult to determine.

3. Many of the participants said they did not ask for help because it was not part of their culture to do so. Part of this is the legacy from the residential schools – those who asked questions or spoke out were frequently punished so they learned not to speak. Another factor is the notion that the "government" (anyone with authority) would take away the children if questions were asked or if caregivers admitted they needed help.

4. Nine of the ten participants were in the 50+ age group, meaning that the population that is caring for children will not be able to care fully for the children in their care as they age. This will place a burden on the health care system as the adult children need placements in care homes.

5. All the caregivers commented on the lack of information on rights, responsibilities and services available to children and their caregivers. No one seems to know just who is entitled to what, or just who pays for what. There is a real need for some sort of central clearing house for information on services and benefits.

6. The "reserve system" is highly political. Some people receive funds from their reserves for improvements to their homes while others do not. Participants suggested it is a case of "not what you know, but who you know."

3.3 Findings: Inclusion or Exclusion:

3.3.1 Life with a young disabled child

A young disabled child's life is filled with medical appointments. Often, severely disabled children spend the first months or years of their lives in the hospital. One mother, whose child was hospitalized for the first two years, said their lives centred around his care, "watching his seizures and watching the breathing and just keeping an eye on things so that he didn't go back to how he started when he was born, just not being able to breathe on his own." One parent was always with him which meant 24 hour a day care.

One lone parent said her son began having seizures 10 days after he was born. By the time she got him to the doctor the child was having grand-mal seizures. The boy was admitted to hospital in both Regina and Saskatoon and was subjected to a series of tests over the next month. Initial diagnoses included hepatitis, B5 deficiency and herpes: the final diagnosis was a blocked artery at the base of his skull which prevented a normal flow of blood to the brain. While the mother was at the hospital, a social worker came to visit her and asked if she wanted to keep her son, because "normally, a lot of

people with disabled, with kids who have problems like that, they'll give them up for foster care or adoption. " The mother said she felt offended they would ask: this was her son and she was going to care for him. Over the course of the next year, it was a constant struggle to balance the medications prescribed for the seizures. Once, when the family was visiting their home reserve he began having seizures again. It was frightening time for the family because they were far from any kind of medical facility. After that episode, they experimented with different drugs until they found two that worked in tandem. He was frequently admitted to hospital during the first few years of his life. He had many surgeries in the following years to correct the positioning of his eyes, lengthening the tendons in his legs, groin and feet as well as surgery to reposition a disjointed hip. At one point he "coded" while in the hospital: another time he developed pneumonia. He also has scoliosis, which has contributed to his physical disabilities and which has prevented him from ever crawling or walking on his own. But in spite of all these medical concerns, his mother feels fortunate that he wasn't as sick as some of the other children they encountered in the hospital. He has always been non-verbal, but has learned to communicate with his eyes.

A grandmother said her grandson, who was three months premature, was a very sick little boy who spent a great deal of time in the hospital. She and the doctor sat with the child during many crises as the mother had no interest in him.

A non-Aboriginal foster parent said her 15 year old foster child was put in her care when he was six months old. His prognosis was not good – he had been born 13 weeks premature and was addicted to cocaine and heroin, and had a cerebral haemorrhage at ten days of age. The doctors predicted he would be "profoundly retarded," blind, deaf, and never walk or talk, even if he survived past one year. He had what the foster parent terms "neonatal syndrome": with the constant noise and light in the neonatal unit the child does not have a chance to "shut these things off to give his body, his mind a rest develop." While he was in the Neonatal Unit, he'd been bundled, and sat in a lounge chair or in his isolette.

> That's where he lived. He'd never been given the freedom to do these things. And the nurses – it's not the nurses' fault. It's the staffing fault, because they don't have the proper staffing in there to cover all these kids who are developing but not fast. So you can't blame the nursing staff… because they have just a caseload in there that's just pathetic. But, I mean, that's when we need to get these kids out of there a whole lot faster than they are so what chance of development they have they can do, they can use.

It wasn't until he was eight months old that he showed signs of being able to see and hear. The foster parent "pushed buttons" to get an assessment done at Wascana Rehabilitation Centre which confirmed that he had perfect hearing and sight. The caregiver took him to WRC every two weeks for several years to meet with occupational and physical therapists, psychologists and social workers. He was able to walk by himself at 17 months. Now, at the age of 15 years, he is fully mobile and is enrolled in an adapted program in a local high school.

Caregivers may spend a great deal of time with their children in acute care facilities, but once the children come home, other medical and therapy procedures take up a significant part of the day. One grandmother spends a great deal of time morning and

night with her granddaughter – sitting with her, reading to her, doing exercises, getting her dressed – because the child needs a very specific routine to cope with daily living. Since she doesn't amuse herself well, someone has to be with her helping her learn to play and finding activities appropriate to her developmental stage. Getting her to school can be a chore: she gets used to a routine during the school year and then has difficulty adjusting to not going to school during holidays and vacations.

Several of the children walked very late, up to four years of age, and then only after surgery to correct orthopaedic problems. One foster family spends a great deal of time each week doing therapy at home with their disabled child, including massage, occupational, speech and play therapy. A father described the time when his physically disabled daughters were young as

> very hectic, stressful at times. We needed to be able to be able to make sure that things at home went as smoothly as possible and sometimes it wasn't always that way. Lots of medical appointments for both of them to bring them to, what should I say, to reduce their disabilities to the lowest point possible.

Children who are born in Regina and who are diagnosed with disabilities at birth or soon after are seen at the Developmental Assessment Centre, located in the Regina General Hospital. At that point, the children come under the auspices of Wascana Rehabilitation Centre (WRC) until s/he is six years old and can attend school full-time. One caregiver said that when her granddaughter left the developmental assessment centre it wasn't an automatic move over to Wascana. They were given a very long form to fill out and submit to WRC. Someone from WRC would then call and set up an appointment. The process of registering and being scheduled for the first appointment can take several months, which she believes can be intimidating for those who are not familiar with health care system. Once registered at WRC, the family has access to all the services WRC provides, such as counselling, physical therapy, occupational therapy and advocacy. All the children in this study had received care and treatment at Wascana Rehabilitation Centre and their caregivers had praise for those who worked there and for the program. The staff give emotional support to caregivers as well as professional services. The most common concern participants had about taking children to WRC was that it was difficult to keep appointments because of transportation issues: not everyone had access to a vehicle for transporting a disabled child, although once caregiver said she was able to get WRC to pay for a taxi so she could get her disabled grandchild to appointments. One child goes to gymnastics and swimming classes at WRC, which help her develop flexibility, muscle control and balance. One young boy took part in the preschool program at WRC which was, according to his caregiver, very beneficial to his development.

General access to medical services does not appear to be an issue because the provincial health insurance system ensures all children receive emergent or other medical care as needed. One grandmother said her granddaughter experienced difficulties at birth so she was seen by the neo-natalogist immediately and was therefore able to be part of the "system" right from the beginning. She felt this was important – that children become involved with the medical profession as early as possible to ensure their medical and other care needs are met.

The participants reported occasional difficulties when dealing with emergency departments at hospitals. One caregiver said she always phones the emergency department first to let them know she was coming in with the child because otherwise she would sit in the waiting room for hours, regardless of how ill the child was. A child who had seizures was admitted to hospital, and the family was investigated by Social Services because they felt the child had been harmed in some way at home. Families occasionally had difficulty with hospital admissions, but as one mother said "You have to be really, really insistent. If you need help you let them know it. Don't be afraid to let them know."

One parent said she did everything the doctors told her to do, but she now wishes she had tried to do things she felt were best for her child.

> And I think because of not knowing, that's where we failed. And I call it a failure because we just tend to listen to everything everybody says. And I think that goes back to my, you know, my upbringing in the residential school… we were told to do this and do that and we had to listen. If we didn't listen, you know, and I swear I was one of the best behaved child[ren] because I didn't want to get the strap. I didn't want, you know, to be punished. So I learned like that and it stuck with me. And when our son was born, then I listened to whatever the doctor said. If he would have told me something I thought was so ridiculous I probably would have done it, you know. So that's what I would… that's my experience. I would say now, you know, "You go ahead and try what you think will maybe work for your child.

As one mother said "We are the best medicine that we could give these kids".

3.3.2 Inclusion in family and community life

Generally, the participants made every effort to include their disabled children in family and community activities and events and have met with varied success over the years. One parent, who also has a mentally disabled older child, could not take her younger son to activities because she did not know how the older one would respond. Other caregivers take their children everywhere, regardless of the disability, because they felt it was important for them to be included whenever and wherever possible. It was easier for these families to take their children places because they had at least one vehicle at their disposal. As the children grew older, they were able to take part in more activities as the children were more mobile. One foster parent, who has the care of other children with multiple disabilities, takes all of the children to special events and makes a point of eating in restaurants frequently. Occasionally, restaurant staff and other customers have made it difficult for her, but she feels it is important that the children are seen to be part of a family outing.

One mother is concerned that her son is not able to take part in activities outside the school. He "sits there and watch TV. That's all he does is sit in front of that TV. Or he'll be sitting playing games." He goes to a community lunch program three days a week during the school year, and is allowed to leave school a few minutes early so he can get to the facility on his crutches. At the lunch program, he is allowed to eat before the other children because it takes him longer to feed himself. He has not been away from his mother overnight since he was born: he is reluctant to spend time away from her and his

brothers. During the school year, his mother is able work part-time but she is tied to the house while he is there. Her other sons, the older of whom is 12, looks after his younger brothers while his mother goes to the store or to appointments. She rarely spends time with other adults in a social setting. Since she doesn't have access to a vehicle, she has difficulty getting her physically disabled son to appointments at Wascana Rehabilitation Centre, although her family doctor has an office close to their home. She walks everywhere with her sons. Her able-bodied children are able to take part in community sponsored events but her disabled son cannot, as the facilities are generally not accessible to persons with disabilities and the activities are not adapted to suit those who do not have a normal range of motion. One grandmother agreed with this: her grandson is often left behind because he can't get to accessible activities or the facilities aren't accessible to his wheelchair or walker. Now that he is older, his grandmother can take him for a car ride or to the store, just "to walk around – get his mind off it." If there is an elevator it is easier for them to gain access to buildings but escalators present serious barriers.

Most of the caregivers described the children as easy going and cheerful, hard-working and fun to be with. One grandmother described her grandson as occasionally "grouchy and stubborn" but generally friendly, especially if he has had a good day at school. One father said his daughters were absolutely typical teenagers, with typical behaviours, activities and dreams. One young man agreed with that, saying that he did mostly typical "teenager stuff" during the week at school and on weekends.

> I think that the only problems that I would have would probably be those that I would probably create for myself. The only problem I've ever had with my disability is a lack of courage to do things that I want to do and become what I want to become.

Another family made sure their children were included in all family gatherings and events. Their children had visible physical disabilities and the parents made sure they got them out so that other people could see them because the one girl was scarred from a fire.

> People would look at her and my comment was "Oh, I'm glad you're admiring my beautiful daughter." And they would look at me and look at her and look at me and look at her again and finally agree that she is beautiful and this, of course, adds to the self-esteem of the child. This was my goal in all of this – to get people to go away from the physical disabilities of either child.

Only one Aboriginal family maintains strong connections to their home reserve as their extended family all lives on the reserve: they spend as much time as they can with them. She said the elders told her that children like her son were gifts from the Great Spirit and as such they had a special connection with the spirits of those who had gone before – the grandmothers and grandfathers. When the family goes to pow-wows and other cultural events, the elders always come up to her son and shake his hand so they, too, can experience this connection with the spirits. The mother remembers one elder telling her that the Great Spirit only gives these children to those people who are strong enough to bear the pressures and sacrifices they require: she considers her son to be her gift from the spirits.

The other Aboriginal families did not feel connected to their home reserves, although they all considered their Aboriginal heritage to be important and were raising their children with an awareness of their culture. The non-Aboriginal foster families make an extra effort to teach their Aboriginal foster children about their culture. One foster family maintains strong ties to the child's home reserve. They attend cultural activities which highlight Aboriginal culture whenever they can. One grandparent received funding from her reserve for extra equipment for her grandson while others report they have had no help from their reserves. The same grandmother was able to call on someone from the reserve to help her get the initial support from Social Services for her grandson – she said they wouldn't listen to her, but they listened to the representative from the reserve. One foster parent stated that there is nothing for children with disabilities on the reserves, that parents and other caregivers have to move to urban centres so they would have access to the services the children need. One mother said "That is one of the reasons I left the reserve – 'cause there's nothing out there." Another woman reported that you had to live on reserve for six months to get any funding or services but she would have had to sell her house in Regina to do so. Since she had lived in Regina for more than 30 years, and her grandson had lived all his life in the city, she felt she couldn't do this.

3.3.3 Support systems

Support for caregivers and families vary with the family circumstances. One foster parent said that they were fortunate to have a good social worker and that she and her supervisor had been very supportive over the years. Another foster parent suggested that what was needed was an informal support system for families, even if it just took the form of a "coffee klatch" where people could talk about their concerns and "let off some steam." She feels this would cut down on the calls to health professionals for non-emergent assistance. Most families reported that their medical support – doctors, nurses, physiotherapists etc – were easily accessible and were of great help to them. One parent said they were able to use the medical system whenever they needed it: they had a network of medical professionals who were very supportive and helpful. They feel they were able to get the assistance they needed because they were not willing to take no for an answer – they kept pushing until they got what they felt their children needed. One grandmother didn't know what support services, other than mainstream medical care, was available for her grandson, and she didn't know who to ask. Another grandmother said that asking for help was difficult for Aboriginal people because "it relates to traditional [culture] where you're not supposed to ask for things. Just let things go and… a lot of us will just kind of just give up."

One lone parent said she remembers being tired all the time when her three children were young. The days were filled with rushing the children to day care, going to work, picking them up and trying to get them their supper and then to bed at a reasonable time. She did not qualify for subsidized home care, and because her son was severely disabled she would have had to hire two caregivers. She couldn't afford this, so she did everything herself. She still managed to find time to enrol her able-bodied children in activities, but she's not sure how she actually managed when the children were young, and how she still is able to look after her children by herself.

> We do what we have to do to survive… These were all my own decisions. I decided to have children. I decided to have a career, so these were all decisions I made on my own, and so I had to live – I had to follow through… I could've pushed harder, but this is telling me it's my responsibility. So I do it on my own without the assistance that I tried to get at the beginning.

One caregiver suggested that Aboriginal people may not get the help they need from non-Aboriginal health-care and other professionals because they're afraid. "Every time they ask for things the kid's gone – he's put into permanent care and you never see him again, or put into foster care." Often, putting the child into foster care is the first option suggested to parents when they do ask for financial or other support.

One problem identified is that even those people who are working in the health care system don't know what programs are available and who is responsible for them.

> There needs to be a nice booklet that everybody gets… maybe some team building between all the different departments so that the neonatal unit, which might pick up some of the problems, is connected to the developmental assessment centre and is knowledgeable about Wascana Rehab and then some of the community agencies so that more information is shared so that if something's picked up by public health during just a routine immunization, that they have access to the [programs]. But there has to be a way to get that information out and into the parents' hands so that they can access some of those services.
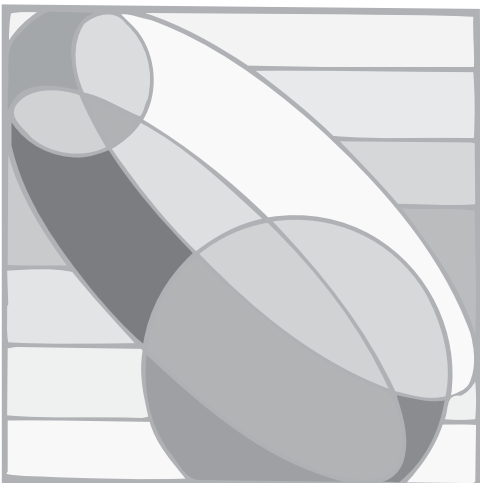
This was confirmed by a non-Aboriginal foster parent. Social workers and other professionals either do not know what services are available or do not tell the caregivers what services they're entitled to. She told of one woman with a grandchild who was not told of services such as the Para Program [a provincially-funded support program for disabled persons in Saskatchewan], what respite care she was entitled to or what recreational activities such as Camp Easter Seal [a summer camp for children with physical disabilities in Saskatchewan] the child could have been attending.

One mother was shifted from one agency to another in her search for financial support for her and her son. She contacted the Para Program, and was told she did not qualify because she was a treaty Indian: she was told to go to Indian Affairs, who then referred her to her home reserve. The Band office referred her to Indian Health: "nobody knew who was responsible for what at the time, so I was getting the run-around. So I gave up." She bought disposable diapers for her son until her childcare giver told her she could get them on prescription and have them paid for by Non-Insured Medical Benefits: she had been paying for them herself for seven years. Some equipment, such as a special car seat or ramp, is not covered by NIMB, while splints for his hands and feet, as well as wheelchairs, are covered.

One grandmother said her support comes mainly from her immediate and extended family. She frequently sends the children in her care to see their mothers, as they all live in the same neighbourhood. If the grandmother requires childcare her son, the child's uncle, is usually available to come to the house, even overnight. But only recently has the grandmother begun to spend time away from the family and making time for herself. She says she doesn't know "how many years I stayed home with that little boy, 'cause everybody was scared to baby-sit him. 'We don't want to keep him: he's too much. What if something happens?'"

Family support is also very important to one lone parent. She says she relies on her daughter to give her emotional and physical support, and even at five years old her daughter was able to change her brother's diaper and put him to bed. The mother said her other children had been very supportive over the years, although there were times when they did not want their brother to be part of their outings, but that this was all a part of growing up with a disabled child in the family. Generally they had been very tolerant of their brother. Her son currently is looked after during the day by his aunt, which has been a wonderful experience for all of them.

One parent, who has a 28-year-old disabled son living at home, began a support group for parents in similar circumstances. These parents are struggling with the care of their adult children. "I guess it's good that people come to me and we can cry together. That, you know, at the end it's a relief. It's not a sign of weakness — we're understanding one another." She told the story of a man who would like to attend the meetings:

> You know," he said, "I'd like to go but we can't even go at anywhere together. People think we're divorced 'cause I go and she stays home. She goes and I have to stay home. That kind of thing. My prayer every day is that my son will go before me, because if I have to go before, I know he would die of loneliness."

She feels people don't seem to understand what happens to families who care for their adult children.

> We're really crying for help and they don't understand. This is the bad part. You don't know the actuality of what's happening with our, you know, within our lives and how desperate we are. We are desperate. When we're looking for help we are sincerely needing that help. We are not just making up stories just to, you know, waste people's time, our time.

One lone parent has no one to help with her son. She doesn't qualify for social assistance because she is working part-time, and her home reserve has no funding for her son's special needs. She has no relatives living in the city and finds it difficult to have a life outside of her family. This lack of personal or social life is common to the participants: all reported it difficult to even visit with friends if they had to take their children with them. And finding suitable, affordable, casual childcare is trying, so they simply don't go anywhere.

According to one participant, there are many grandparents who have the care of their grandchildren. She has doubts about how well she and her husband are doing, especially since they were not expecting to have to raise a child later in their lives. It is not because "the grandparents don't love them, but because where they are in age and energy, and resources… like, what are they not getting?… presumably it's better than being in care or being with their parents but still probably not the best either."

3.3.4 Childcare, preschool and school

There are few daycare workers who have the experience and training to care for a child and the greater the disability, the more difficult it is to find suitable childcare. One family has childcare which can accommodate physical disabilities because the childcare worker has special training in caring for special needs children. She receives extra funding from the provincial government so she can give more personal attention to the special needs child by lowering the staff/child ratio in her childcare facilities. The foster parents said that it was even more difficult to find casual childcare for children with disabilities. If someone did have sufficient training to work with them, the cost would be prohibitive. Usually, one parent is home with the child, which precludes any chance of that parent working outside the home. One mother had to quit her part-time job to care for her son because he needed constant care. Another family was able to arrange for one parent to be home most of the time with their children because the father had flexible working hours. If they needed childcare, there was a group of people in the neighbourhood who looked after the children in their homes, rather than send them to a daycare centre. Other families simply stayed home: it was too difficult to find someone to look after the child. One family had sufficient financial resources to place their children in the local Montessori preschool, which they felt allowed the children the freedom to develop while learning social skills. One lone parent found a family who was willing to care for her son when he was small, and they became a great source of support for her over the years, more of a "surrogate family" than paid child care.

There are preschool programs available at various agencies in Regina, including Regina School Divisions, the Early Learning Centre and the Early Childhood Intervention Program (ECIP). The Early Learning Centre is community-based centre providing preschool programs for low income children, and is funded through the federal and provincial governments. One child was able to take part in their programs, which greatly enhanced his ability to socialize. One foster family and two other caregivers took advantage of ECIP, which they felt was beneficial to the development of their children because the staff understood the issues surrounding both the disability and the culture of the child. The staff there acted as advocates for one child, referring the family to Wascana Rehabilitation Centre and helping them get a grant for special needs daycare. One caregiver had heard about ECIP through her work; she is certain that if that hadn't been the case, she would not have known these services existed. She thinks this would be a problem for caregivers who do not work in health care. Even then, she feels there are many activities they could not take advantage of because both she and her partner work full-time during the day.

Children with multiple disabilities may be placed in developmental centres in either school division, where the learner/staff ratio is low so the learners' many needs may be met, until the age of 22. After that, the young adult can be accepted into a sheltered workshop, although there is a waiting list for the programs. One lone parent enrolled her son in one of these developmental centres when he was three years old and he remained there for 19 years. She found the class "wonderful", and over the years she was able to borrow equipment from them to help make her son's life a little easier. One grandmother said her grandson goes to a public school in another area of the city where they have a special needs classroom. The school division pays for bus transportation to the school. The family is generally happy with the arrangement; the boy will be in a developmental classroom for the first four years, then he will be integrated into a regular classroom and have a teacher's aide to help him with his schoolwork.

There are some preschools in some of the public schools in Regina that deal with special needs children. They are called integrated preschool classes and children attend half-day sessions. The advantage to these preschool classes is that all the children have special needs and the staff is able to work with the each of the children individually. One lone parent was able to take advantage of one of these preschools and found it to be a wonderfully supportive place for her child.
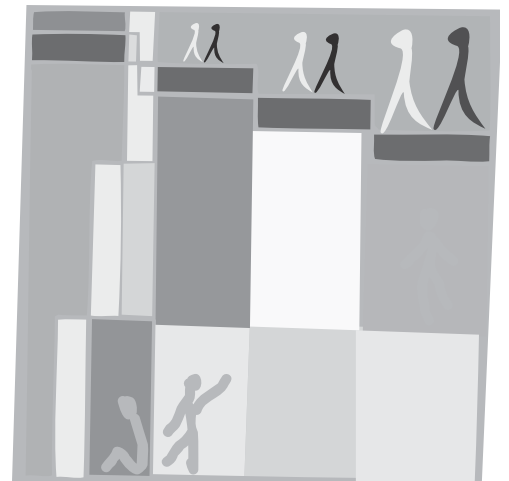
Once the child enters the school system, s/he may be seen at WRC for occupational, play or physical therapy, but it is the responsibility of the school division to provide services and support for the child during the school day. Some children may be placed in adaptive classrooms, but spend some time each day in the regular classroom with her/his peers. Most children with less severe physical disabilities are placed in regular classrooms. Some will receive help with their schoolwork from teachers' assistants or aides, but not everyone who needs a TA will be provided with one. One child had a teacher's assistant in kindergarten in a rural school, but when the family moved to the city he was not provided with one. His mother said she had been asking for help for her son every year, but he still does have an assistant to help him with his schoolwork. It was suggested that the boy use a computer to do his work because he has difficulty writing, but one has not been issued to him. One parent, who drove her son to school every day until he reached Grade 12, decided she could not physically do this any more and called the school division offices to ask for assistance in transporting her son to school. She feels that it was not suggested to her earlier because it appeared as if she was coping so well, that she didn't seem to need the help.

One parent feels they "trained the teachers in looking after children who are either mentally or physically different from other children in the school." They tried to make the school experience as normal as possible for the children, keeping them in regular classrooms instead of putting them into special classes for children with physically or mental disabilities. They provided the teachers with information about their children's disabilities, which they felt would help other parents and children in the future.

How these children are accepted in schools varies with the school, the staff and the other children. The 17 year old said the other children made fun of the casts on his feet: they thought he was some kind of monster. He said it was really

> quite sad. The kids – they really didn't know any better. They didn't know what my disability was. They were really… they were really kind of curious and harsh and mean, 'cause my disability was like a novelty to them. They'd never seen anything like it before so they were just kind of singled me out and things like that.

One 11 year old boy with cerebral palsy does not like to take his wheelchair to school because the other children tease him about it. He uses crutches most of the time, which is difficult for him as his balance is not good. They live close to the neighbourhood school where he is part of a regular classroom. There are no curricular adaptations made for him and he is expected to take part in all activities at the school. Shamefully, there is not a fully accessible washroom at the school, so he waits until he gets home at the end of the school day to go to the bathroom. In spite of these experiences, most of the participants said that the teachers had been helpful in trying to change the other students' attitudes. A non-Aboriginal foster parent said that her foster son has been to many different schools, and that some were better than others at dealing with his physical and mental disabilities. She said he has experienced some racist attitudes from school division personnel and teachers. At one point, division personnel wanted the boy to attend a school in the inner city, where "there were more native children", even though it was not at all close to his home. In another school, a teacher told the boy that if he didn't get his hair cut, she would do it for him. Intervention by the foster parent resolved these issued, but the incidents still rankle with her.

One caregiver wants her granddaughter to enjoy school and be challenged at the same time. She feels there is tremendous support for the child in her school.

> I want it to be a positive, affirming experience for her but at the same time I don't want it… her to not be challenged, you know, so that she can reach the best of her abilities. But it's a fine line between that and discouraging.

One caregiver said his children had "normal" relationships with their peers, and have made many long-term friendships. His older daughter took part in extracurricular activities, but the younger one was not as interested. She had been a participant in the Therapeutic Riding Association earlier, and was a volunteer in the program over the summer months. The 17-year-old male had received numerous academic and spirit awards in elementary and secondary school, and was elected to the Student Advisory Council several times.

3.3.5 Respite care and home care

For those caregivers who have the responsibility of a severely disabled child, respite care is important because it allows them to have a break from the intensive work of looking after their child 24 hours a day, 7 days a week, 365 days a year. It is beneficial to the child as well, because if the parent/guardian is unable to look after the child for any reason, then being away from the caregiver will be less traumatic for the child. One grandmother is grateful to Wascana Rehabilitation Centre for providing respite care; she said she feels very comfortable with leaving her grandson with them. As one parent said,

> You need to start putting him into respite as soon as you can, as often as you can you need to get that separation going as soon as possible. And then it's going to be really good for you – good for your child.

The parent of a physically disabled adult child living at home only recently began using provincially-funded respite care. When her son was younger, she relied on her husband and three daughters for respite care. Her husband has since died, her daughters have their own lives and families, and there is now no one to look after her son. She believes it is important for her son to get used to being in an institution as she believes he will live there when she is no longer able to care for him. A grandmother who named her grandson as a ward of the province receives four to five days respite care per month. Until recently, family members were allowed to be hired to fill this need, but it is her understanding that recent changes to the legislation means that the respite care has to be in an approved facility, such as WRC or a long term care home.

One grandmother said she had just learned that she was entitled to respite care, but she was having difficulty finding out any information about that would provide the care or where it would be provided. She felt it was the responsibility of the social worker to inform the caregiver about programs and services available to children. She believes no one really had a good understanding of what the children or the caregivers were entitled to receive. The foster parents agree. It is only through their many years of being foster parents that they know what is available for the children. But according to one foster parent, many of these funded programs end when the child turns 19 years of age; it is then the responsibility of the family to fund respite care.

Other families do not receive any funded respite care. If they need time away from their children, family members or friends step in to relieve them. One caregiver said her granddaughter's childcare giver has offered to take the child for respite care should it be needed. The grandparents have not done this yet; they are reluctant to put her in someone else's care overnight because the child has seizures occasionally and they do not think it is right that others have to cope with their child's seizures. One mother says her work is her respite.

One mother said she could pay for respite care at WRC, but she is reluctant to do so. She just can not see herself putting her son in an institution so she can have some free time. She says she may not be giving WRC enough credit, but she feels they would not love and care for her son the way she does.

> And everybody needs to feel that love. No matter how, how disabled, or how unaware we might be. Otherwise, if, if a person doesn't love the, the – what they're looking after, or care for what they're looking after, then they're not – they're not going to be… They might be abusive, or they might – they, they'll just do the minimum.

Home care is another issue with the caregivers, especially as their children get older and bigger. Just who gets home care is not clear. One grandmother, who has made her 11-year-old grandson a ward of the province, receives home care in the morning and evening every weekday. Another parent said she could not get home care until she gets an adjustable, hospital-style bed for her adult son, although she does have a track lift for lifting him in and out of bed. One lone parent borrowed a hospital bed from Wascana Rehabilitation so she is able to get home care, which she pays for, although because of her son's size she is required to hire two workers which means she can't afford home care very often. . Other families report that getting home care is very difficult. As one mother said "… you still have to do more than what you should do as a parent."

3.3.6 Financial issues

The grandmother who had her grandson named a ward of the province was on social assistance after the child had been apprehended by social services in another city. She was not getting any extra benefits or money for his special needs because "social services would tell me 'Well, you took him on your own. There's nothing we can do to help you.'" It was not until someone from their home reserve spoke to social services on their behalf that it was suggested more could be done for the child. She was placed on "mini foster care", and then took the foster parents course mandated by social services. But in order for her to get the extra help she needed, she was required to sign her grandson over as a ward of the province. Now she receives anything she needs for him – including home care and accessible housing. Another grandmother, who had taken the foster parent courses, has never received recognition for her training, nor had she received any extra funding for her grandson. She said she was reluctant to ask for help.

Financial worries vary with the severity of the disability and the family income. One mother spoke of not having enough money for basics, let alone extras for her disabled son. One grandmother gets a small amount of money from Social Services but she is always short of money for things like gas for her van. Recreation is especially difficult as

she tries to take her grandson places but she finds the costs prohibitive. Another grandmother had support from her reserve, social services and Kinsmen Telemiracle for a track lift. Other families report there was no help from the reserve at all. Wheelchairs for children are available either from Saskatchewan Health or Non-Insured Medical Benefits (Indian Affairs). All the families said they had no problem getting the basic equipment for their children, but if they needed specialized equipment or non-essential equipment they were responsible for all the costs. One lone parent, who is working full-time, paid for a ramp for their home: Non-Insured Medical Benefits does not pay for "extras", such as ramps for wheelchairs. Her adult son receives social assistance, which pays mainly for his daycare expenses. The same lone parent can not afford to get a van which has been adapted to accommodate a wheelchair. She currently puts the wheelchair in the back of a pickup truck, and her son is propped up in the seat beside her. This is difficult in inclement or cold weather, as the chair freezes or gets wet and is uncomfortable for her son when they reach their destination.

None of the families had received any direct funding from their reserves or other government agencies for renovations to their homes to make them accessible to their children. One woman's house was house was renovated by the housing authority from whom she rents and is now fully accessible except for the bathroom. Another parent's main floor apartment has not been adapted because the housing authority from which she rents has decided that it would be too difficult to rent it out after they leave. One grandmother said that when she moved into her house, the owners of the building, the community association, put a ramp in for her grandson at a cost of $10,000. She was grateful for it, as she could not have afforded to put it in herself.

Medications can be expensive. One child's medication is $400 per month but because the child is First Nations it is paid for by Non-Insured Medical Benefits. It can sometimes take many months for N.I.M.B. to grant approval for coverage of medical expense. One parent said it took almost six months for approval to be granted to cover her son's asthma medication. Although it was finally approved, she was not reimbursed for the months it was not covered.

Not every family has financial concerns. One parent said they always managed to get what they needed when they needed it as most of their medical needs were covered under the provincial health plan. Another parent said they just accepted the fact that they would have to spend money to make sure their child has everything she needs. The foster parents feel their remuneration is sufficient to cover all the children's needs, especially since there are extra allowances for other medical conditions which may require special foods or clothing.
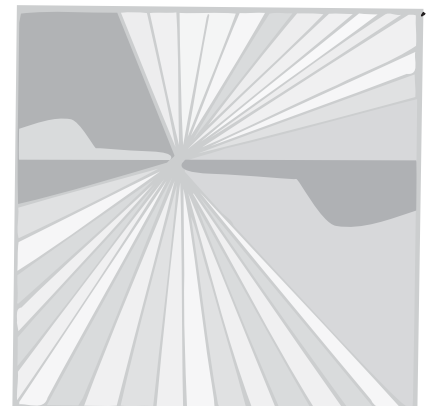
3.3.7 Future of the children

One mother felt that the more severe the disability, the more uncertain the future. The child who is a ward of the province will always be in care, but his grandmother believes that he will one day get up out of his wheelchair, walk and be able to work in a sheltered environment. One lone parent believes her son will accomplish anything he sets his mind to and will achieve his goal of becoming a doctor. One parent, whose son is just entering university, believes he will accomplish his goal of becoming a Ph.D. and a university instructor. The caregivers for the younger children have guardians in place for them, although they are uncertain as to what the future holds for the children. One grandmother did not adopt their grandchild, nor have they placed her in the care of the province. She was told that if they as persons without treaty status did adopt her, the child would lose the benefits due her as a First Nations person with treaty status. She believes her granddaughter will be able to work in a sheltered environment when she is an adult.

> I'm very scared for her, you know – very worried. It's hard enough when you have all your abilities to, to you know, take care of yourself and do okay. You may not do great but, you know, manage to take care of all the things that you need to but I just don't know if she's going to be able to do that. We want her to feel good about herself. I want her to love people and be loved. I want her to be safe and I guess if all of those things are there in some measure you're happy.

One grandmother hopes her grandson will be able to support himself when he leaves school, and is encouraging him to stay in school and to learn as much as he can about computers. She believes his future job will depend on his technological skills.

One parent has every confidence that his daughters will accomplish their goals. His elder daughter is enrolled in a postsecondary institution: his younger daughter has yet to decide what she wants to do with her life. He wants his children "to be the best that they can possibly be within the limits that's been prescribed for them, both physically and mentally." One of the foster parents agrees – she knows her foster son will have difficulties but believes there will be a job for him, one that suits his talents and abilities. To help him cope in the future, she pays him a wage for helping with the other foster children and for doing chores, such as the laundry, cooking, dishes and yard work. He is expected to budget for savings as well as everyday and extra expenses.

One lone parent is working with her reserve to establish a long-term care home for Aboriginal adults with multiple disabilities. She believes she will be able to build a multi-purpose facility which would house elderly people as well as the disabled because the elders would like giving their time to the younger people. The reserve recently purchased land close to Regina, which would be easily accessible to medical care as well as to the reserve. She believes it is important for her son to be with people from his own culture because he is aware of his surroundings. She would also feel better knowing that there were caring people looking after him when she is no longer able to.

The parent of an adult son with physical disabilities knows he will probably become a resident of Wascana Rehabilitation Centre in their long-term care facility, but she is still concerned for his future.

> If I was totally to let my son go, go into a home, and I'm not going to see him any more, he would die of loneliness. But we need to continue that contact. We need to continue being part of their lives until such time we can't do it any more.

3.3.8 Defining disability

The participants defined the word disability in different ways. One grandmother said she didn't like the word, that it reminded her of someone who is lazy so she didn't like to use the word disabled, and since she didn't think anyone was lazy she didn't use the word. She believes her grandson will not be "disabled", that he will walk and talk and be able to function in his community.

Most participants believe a disability is not being able to do something that "normal" people could do, a loss of some "normal" capabilities. "Normally you can walk … use your two legs. Normally you can make your requests or your wants and needs verbally. Normally you can, you know, use your hands to do something for yourself." One parent said, "…it's a handicap. It's a handicap that can knock the self-esteem out of someone."

One grandmother said a disability was "using walkers, wheelchairs, tubes in – like tubes on their wheelchairs when they're out, can't walk, can't talk, can't fend for themselves, can't hear." She considered her grandson to be disabled because he is not able to do what other children his age can.

One caregiver said that you "learn to live with it [the disability] every day the same as you do anything else. You know, it's very much harder on the child than probably the family that are doing the child caring. More so than the average child. Time consuming." Another parent sees a disability

> more as a limitation: it becomes a mental attitude. They may have certain disabilities but they can achieve things well beyond what others have over the years. I see people all over the place, all the time, who feel negative about, in quotations marks "disabilities", and instead of trying to achieve, put the fault outside of themselves and say, you know, "I can't. I can't. I can't." And I look upon them and say, "I can." – like the little train that could.

One grandmother, who has the care of her granddaughter, had difficulty defining the word:

> Like I know she has a couple disabilities, but they're, like I wouldn't change her … I wouldn't change anything about her because it's all part and parcel of who she is. I sometimes feel like she is an angel and we have opportunities to be better and grow and be different than we would have without her.

A non-Aboriginal foster parent defined the word disability as

> a lack of level of knowledge that he should have but he doesn't, or mobility that he should have that he doesn't – that the average person would have. But every one of us has a disability, but it's not labelled that because it's more normal for 16 people to have a short finger on one hand, which is actually a disability, than him because there's so few like him. And his level of disability is a whole lot milder than a lot of people, but yet, worse than some people. It's just the different levels of the severity of the needs that they need to adapt their lives to function in public.

It takes a lot of courage for disabled children to live in the same world as able-bodied people. The 17 year old feels the word "disability" is the biggest obstacle he has had to face:

> The biggest part about having a disability is the mental, the mental strength to have the determination, have the perseverance, have the work ethic to just, you know, surmount that, just overcome that. That's the biggest obstacle I've always faced living with a disability. And that's, that's what my disability always has been for me. And that's something that I'm still struggling with today.

His mother agrees that her son has a great deal of inner strength and courage, which have enabled her son to get where he is today.

3.3.9 Speaking to the policy-makers

The participants were asked what was needed to ensure their children would be able to become full members of society – what each of them would like to tell the policy-makers. One grandmother believes more money should be made available to families to help with the costs of recreation "to get them out there and see different, a different world from what they know."

One mother believes she falls between the cracks of the different jurisdictions, that she doesn't qualify for the policies that were made for either group – those on social assistance and those who are status. She's "borderline" and finds it very frustrating:

> I'm not the only one. But I felt like the only one. And maybe that's a good point to make there, is that with policy makers they, you know, they – they have to talk to people like me, who are falling through the cracks. Because like I said, I felt alone. I never knew that there was others who, who were in …running into the same problems that I was. So it's, it's not something that's, that's out there. That knowledge isn't out there.

One caregiver felt that there has to be more help available to families, and the policy-makers have to be aware of children with physical, intellectual and mental health disabilities.

> Somebody has to come into the home and see what the parents are going through and the kids, you know… [to understand] that they're human beings and they should be more aware and watch things more closely. I was lucky: I survived. But look what it took for me and my husband to survive. He had a heart attack. His health, my health.

The mother of an adult child with physical disabilities agrees.

> We need people that are not only going to listen but are going to really take our requests or our concerns, you know, at an understanding point. They are going to have to understand and know that we are needing help, that these things really happen… You wonder if they're even listening. Or do they think you're just making up stories? I think sometime I'm talking to some people. They … you think I'm making up a story here, uh? And I tell them "Come to my home: come and visit me. Come and meet my son. Go to Cosmo Centre there. You know, go here, you know. See my son when he's at Wascana, when he's at the hospital. Take time to do that. Go to that level.

One mother felt that her culture should not be an issue in providing care and services to her child, but there needs to be "an understanding or a mutual understanding between the caregiver and the reserve and a respect for each one, for one another's culture." Another mother stated that more Aboriginal program staff is needed to help Aboriginal clients feel more comfortable in a system geared towards non-Aboriginals. A grandmother who works within the Aboriginal community said that the system itself might be a deterrent to people needing help with their children. Some parents may be in denial when they are first informed of their child's disability so they would not be looking for those services that would be most beneficial to the child and the family.

> It's those early years that are so critical and if you are able to access and feel comfortable accessing all those services and your child has the benefit of all that, like, you know, then you have – you may still have that disability but you've done as much as you can to enhance the skills and the strengths that your children do have.

If the family is not stable they may not be as comfortable inviting people into the home for assessment, especially if it's someone from another culture. "You worry that you might be judged or that you might be found lacking in the possessions that you have or the type of home you live in." A young mother might feel that they may be there to help you but you're also worried that "they're going to judge you and find that you're, you know, maybe not doing as well as an older, more mature mom who has a husband and a job and supports."

One father said that there is a "buckskin curtain", a barrier between the Aboriginal and non-Aboriginal peoples. He believes that to break this barrier down, both "sides" have to trust the other. As well, regardless of ethnicity, people have to show that they care for what happens to their clients, students or whatever, and

> somehow maintain our humanity throughout all of this, and if we don't then we'll lose those people we're going to help, or we're attempting to work with. What has a bearing on it is our ability to communicate with a person and show that we, you know, care. They will begin to trust us. And we have to show the same trust and respect back to them. It will help.

The 17-year-old believes there has to be more support on the reserves.

> I think that Aboriginal people on reserve have it a lot worse than they do in the city. I mean, like the accessibility isn't as good, the policies aren't as good… they need strong families, they need to be able to get around, and be autonomous, and you know, live on their own, be independent. And just … give them encouragement, give them the courage, give them the determination, give them inspiration to be who they want to be and become who they want to become.

One non-Aboriginal foster parent was adamant that the policy-makers, as well as those who carry out the policies, must realize that to many Aboriginals the government signifies stolen children. Over the last hundred years, Aboriginal children have been taken from their parents, and many Aboriginal families do not want to ask for help, "to stir the waters," because they are afraid that if they ask for help their child will be taken away and placed in foster care. They simply don't have the information they need to help their children thrive. One caregiver, who over the years has taken in several of her grandchildren, says that she stepped in to take the children because once a child is in the care of social services, it is difficult to have them returned to the family. One mother said that from her experiences

> a lot of our own people, our Native people … They're afraid. They're not going to speak up … They're just going to continue listening — you do this, you do that, you do this, you know. Those things — we're still stuck in that.

One foster parent believes those with authority have not bothered to learn about Aboriginal culture.

> The government professionals have to learn the native culture. That it's not necessary that the child has to be raised up and educated like everybody else that's white. But they have to understand the native culture, the native background, the native beliefs, the native traditions.

Part of the problem is that children are sent to non-Aboriginal foster homes. "Ninety percent of native handicapped children are in white homes and those white homes, a lot of those white homes, do not maintain native culture. They do not even initiate native culture. They do not even accept native culture, which is not right."

Section 4:
Findings from Site Visits

4.1 Introduction

In the fall of 2005, the researchers made site visits to the cities of Toronto, Montreal and Vancouver. The purpose of these visits was to:

- Determine if the findings from Regina were confirmed in other major cities;
- Identify specific regional differences from the perspectives of professional service providers; and
- Identify specific regional differences from the perspectives of the mothers.

These visits were arranged and based on on-going contacts and relationships that have occurred during the history of the study and were not "in and out" visits. The actual visit was meant to involve the workers and parents in a direct and face-to-face manner. The interviews were supplemented with information from extensive telephone and email communication.

The researchers started contact with the Friendship Centres of each city and through the social service worker, development worker or other outreach worker familiar with the topic make further contacts with other agency professionals and families. These Friendship Centre workers played a critical role in making contacts and identifying critical issues facing their clients.

4.2 Toronto Site

In Toronto, services for children are not coordinated from the Native Canadian Centre of Toronto but delivered by the Native Child and Family Services of Toronto. This professional agency was created in response to the amended provincial Child and Family Services Act (1985) which recognized the special needs of children of First Nations and Aboriginal ancestry. The principles state that "all Indian and Native children and families should be provided in a manner that recognizes their culture, heritage and traditions and the concept of extended family." Opening in April, 1998, it has been "Ontario's only full service off reserve child and family welfare initiative under the direct control and management of the Native community." It receives support from numerous funding sources and provides a variety of programs that hold a culturally based service approach (**www.nativechild.org**). The centre is located in the downtown core at College and Yonge Street.

The city of Toronto is unique in Canada in several ways. There are no large Aboriginal groups in the vicinity and the Aboriginal population is approximately 0.4% of the total population. This small group is in a city and environs of about 4 million with about 50% visible minorities and foreign born residents. Aboriginal and First Nations individuals come to the city from long distances and normally, they have lost their connections to family. Those families who come from southern Ontario are more likely to access services from their own First Nations agency. Hence, it was reported to the researchers that there are very few families of children with disabilities in Toronto that seek services from Aboriginal agencies.

Our contact was the Development Services Worker who has credentials in psychology, mental health, trauma counselling, and addictions counselling. She is located at a FAS/FAE satellite clinic of the Centre where she works with parents and their children.

The worker reported that she had been seen a number of families of children with disabilities but mostly in the mental health domain. Using her knowledge of the service professions, she has connections with the Geneva Centre for Autism. It offers six week training sessions for parents to help them with their child. The Centre's program is behaviour based and quite theoretical. In the worker's assessment, most parents whom they refer to the Centre finish the course but find difficulty in applying what they have learned when they get home. She finds that the mothers need help with the daily struggles that parents share with her.

She gave some examples of her practical and applied teaching. For example, mothers get frustrated when their child does not listen and obey. She tries to help them understand that when the emotional tone of the voice changes the child picks up on that and not the words so she emphasizes the use of consistent language and a consistent tone of voice that their child can understand. On example is that autistic children can have difficulty with space issues in relationship to other people and therefore travelling on public buses where they must share a small space with a stranger can be difficult. So she works with the parents in helping them understand the personal space needs of their child.

It is this kind of practical and concrete assistance that her clients need and often do not seem to receive in the formal agencies.

The worker also reported assisting two thirteen year old youth with Down's syndrome. One lives out of the Toronto area and is quite isolated. Both are in special education classes. They are teens with special needs but like all teenagers they seek peer relationships and they need to learn acceptable social functioning skills. She has been working at bringing them together to help them deal with the isolation and social barriers they experience.

Another case is a twelve year old child who acquired a brain injury as a result of an infection as an infant. The child was in a good institution but there has been no support to help this child make the transition into a regular school. Her role is to work as an advocate for this boy.

Once again there are grants that can be applied for, through the school system to identify the needs of the child and help with placement. Once again there are challenges from worker's perspective as an advocate. For lay people, the process for successfully applying for the grant is illusive and difficulty. She also notes that the parents do not seem to take ownership for their child's education and do not seem to understand that help is available for their child.

It was reported that many children with FAS/E are in the formal care and custody of the province. The "in care" status is terminated in their late teens and they are sent home after many years of being cared for in the provincial foster homes or group homes. Little has been done to prepare the children and the families for their return. Suddenly, these adults with serious behavioural and social disabilities appear at the door of their mothers. The development worker reported that this issue as a serious neglected area of need.

She has been working with a family where the child has tumours on the peripheral nerve endings (neuro fibro mitosis) and that has meant numerous surgeries. The child is 8 years old but only in grade one and is falling behind in school work because of absences due to the surgeries and the struggles of low self-esteem, related to his condition. He needs to wear very thick glasses which make him stick out from his peers. The worker does her best in offering support and guidance.

The worker advocates for respite care and encourages the parents to make use of this service which is available to families from a number of sources. She identified the following services. The Geneva Centre for Autism provides respite homes and will waive the fee for parents who are on welfare or assistance. Bridges is a service of the Geneva Centre that will provide one day of respite on a weekend. They offer a planned day of activities that include recreational and community programs for the child. Finally, Assistance for Children with Severe Disabilities (ACSD) is a grant that will pay for 10-15 hours of respite care to care for the child in the home.

The challenge with any of these services is that there is paper work to complete in order to receive the service and this stresses the parents and often prevents them from getting the help that they and their child need.

The problem is further complicated. Not only does the child have a disability, often the parent is struggling with an addiction or multiple issues such as one parent who is bi-polar and living with the effects of polio. In these situations the parent is also in need of support services that add to the stress of trying to cope with the child's needs.

While there are programs available including respite care, the worker sees problems accessing them. In addition, she sees a major need for evening workers who are available to help parents cope with the situations that arise when they are at home. It is difficult to respond and correct the situation "after the fact" and in-home support and training would go a long way in addressing this need.

4.3 Vancouver Site

The site visit to Vancouver was extremely productive and informative. The Program Director of the Vancouver Aboriginal Friendship Centre Society coordinated the researchers visit and arranged interviews with both service providers and mothers of children with disabilities. He also arranged a visit and interviews at the Vancouver Native Health Society on East Hastings and in the centre of the "down and out" subculture (**www.vnhs.net**). His preparation was most helpful and interviews enlightening. Seven professionals and service providers and two mothers were interviewed in-depth; the content of the interviews are presented below.

The Vancouver Aboriginal Early Childhood Support is a program of the Vancouver Native Health Society. It is one program of many that are designed to assist the inner city Aboriginal population who are coping with a myriad of social and health problems from full-blown AIDS, addictions, STDs, and general poverty. The Childhood program focuses on improving the lives of Aboriginal children by addressing gaps in services and seeking culturally sensitive services. It provides peer support, advocacy, parenting skills training, life skills training and linkages for the family to community activities and services. The program has one worker who was extremely knowledgeable and experienced.

These two agencies are on the "frontline" and in the centre of a notorious neighbourhood. They are offering a vast array of social and health programs but find their worker's time is consumed with "chasing bucks". The core funding for both agencies is more or less stable but the funding arrangements for the programs are very unstable and insecure. The temporal nature of the funding means that a lot of energy is lost on re-applying, submitting funding reports and seeking funding elsewhere. Sometimes, the situation changes and complications arise that require more reports justifying minor changes. This lack of flexibility creates insecurity and stress for the staff. It is very frustrating. In addition, the provincial and federal governments are exploiting these staff with under-funded projects. There are insufficient funds to adequate pay many of these professionals who work from their hearts with low pay without employee benefits and without any real security. As a nation, Canada prides itself on fair wages and benefits for its workers and those in unionized workplaces often do quite well. Health and social service workers in these Aboriginal non-profit organizations are not working "for the money" but out of dedication and commitment to their people.

One of the unique features of Vancouver is that the workers see a lot of clients who have status under the Indian Act but not band membership. This situation creates serious problems for accessing services, supports, resources, and programs that are "devolved" to the Band governments. The various health and social programs and services administered by Band governments are not available to non-members regardless of their status. Then the workers are having serious problems accessing services such as non-insured health benefits from the federal Indian Affairs or Medical Services Branch of Health Canada.

For those clients with Band membership, accessing services such as non-insured health benefits continues to be a problem. The workers state that the social and health workers in the Band offices do not follow up with requests and approvals. They feel that there is a general lack of professionalism from Band workers. On the other hand, these workers have limited resources for their Bands and may be reluctant to give scarce resources to members no longer living on the reserve. Some mothers move to the city to access services for their children. They lose their cultural and familial supports and with difficulty accessing services in the city, they return to the Band. These mothers report that their children are not welcomed back in the community.

The common issues of accessing information, not being informed of services and even denial of services was reported as a consistent problem for their clients.
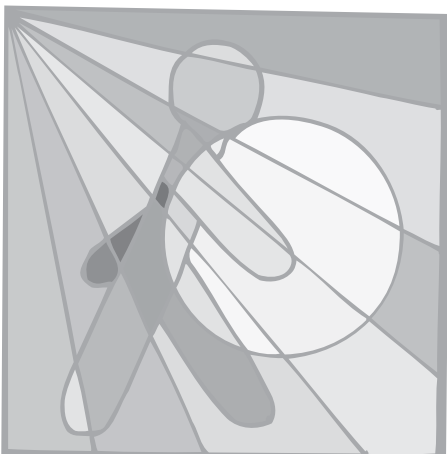
The mothers had fascinating stories and insights to their situation. The mothers have children who have intellectual disabilities, including Foetal Alcohol Syndrome, Attention Deficit, hyperactivity and behaviour control issues. One mother commented that once you get a "tag on you", services become available and professionals seem to go out of their way to make as many services available as possible. However, "no tag, no service!" They commented that there seems to be lots of services for children under 5 years of age but a lack of services for the 6-12 age bracket. They commented that day care services picked up on problems but focused on the child and not the mother. They found that there is almost "nothing for the mother" in the way of parenting help and support. They reported feeling very much "alone" and frustrating feelings of "no escape."

In the province of British Columbia, there is a two tier level of benefits for those on Disability Assistance. Once on the second tier, many additional benefits are available such as bus passes and some extra money. They appreciated the stability and security that the money offered however, it still was not sufficient for so-called "extras" like skating, swimming or club fees. These mothers are not receiving adequate money to provide their children with a more well-rounded development. The assistance is the bare minimum and is limited to basic food and shelter.

In Vancouver, housing is a real issue and concern. They talked about "couch surfing" and living from one friend's house to another. This situation is hardly the way to raise a child and even more dis-concerning for a mother of a child with disabilities. They described it as extremely difficult for the children. Stable housing helps reduce the stress and tension.

The issue of Indian status can be a problem for these Aboriginal women. At times, their children are entitled to status through the father's inheritance. However, the lack of cooperation from the father and family breakdown, they can not provide the documents to secure status. Services and benefits that these children are entitled to receive are not accessible because of the family resistance and conflict. One mother reported that her family "was against me."

On a final note, the mothers admitted to have complex health and social problems themselves. One mother has serious health limitations do to chronic conditions that limit her mobility and strength. She is inclined to "just stay home and rest." Another mother admitted to a long history of illegal drug addiction and was "clean" at this time. She had her child removed by the child welfare authorities and he had just been returned since she was free from drugs and in treatment. This issue is an important point. The Aboriginal mothers of children with disabilities are not like the assumed "white middle class" families of suburbia. These women do not have the personal and social resources of the middle class mothers who can advocate, and negotiate the labyrinth of agencies and services. They are at a disadvantage and it became evident that they themselves have disabilities! These women need help and yet, they fumble and stumble along doing the very best that they can.

It should also be noted that the B.C. Aboriginal Network on Disability Society (BCANDS) has been active in providing awareness, education, advocacy and support to Aboriginal individuals and families (**www.bcands.bc.ca**). Located in Victoria, they have been leaders in this research topic for many years and have more than 4400 members across B.C. They sponsor an annual conference and provide a clearing house of resource materials.

4.4 Montreal Site

In Montreal, the researchers made contact with program staff of the Native Friendship Centre of Montreal and also the Dis-Abled Women Network of Canada (DAWN Canada). The trip was enlightening and an "eye opener" to some unique issues facing Aboriginal people in the Province of Quebec.

The Dis-Abled Women Network has local and provincial groups across Canada with three active groups in Quebec, Ontario, PEI and B.C. They have connections with the Canadian Council for Disabled Persons. They concentrate of assisting women and the particular issues that women with disabilities face. The DAWN member reported that in Quebec, Aboriginal issues are "segregated" and that there was little "cross over" into mainstream agencies. The Aboriginal people in the city are not accessing services for which they would normally be entitled. Historically, children with disabilities would be moved to the city for programs and never returned. The DAWN worker reported a case where a young woman wanted to return to her home reserve and was rejected because she had grown up in the city. The Band refused her services citing that she had long lost her Band membership. She bluntly stated, "If we [non-Aboriginal women with disabilities] have it bad, they have it even worse!"

At the time of the site visit, the Friendship Centre was in a financial freeze and at the edge of bankruptcy. The staff members had not been paid and were waiting for federal funds to refinance the Centre. They were working on a "volunteer" basis hoping that the situation would change. The insecure funding arrangements were plaguing this centre in a deeper and more serious way than even the Vancouver Friendship Centre.

The Band action, to exclude their own members, was identified by program staff at the Friendship Centre. Repeatedly, the staff have advocated on client's behalf in attempting to re-gain status and access benefits for which they were entitled to receive.

The staff reported that they did not see many children and most of the adults have complex and cumulative disabilities relating to mental illness, psychiatric disturbances, HIV, AIDS, HepC, TB, diabetes and various infections. Most find their way to the city and do not return to their home community.

For 16 years, the Friendship Centre provided a health outreach worker to work in the hospitals for northern Aboriginal patients. As hospital liaison, the outreach worker advocated and supported the patients and maintained relationships with family members in the home community. For example, she would relay information to the family on their relative's health progress and assist in preparing for discharge. She worked steadily for the 16 years between 3 Montreal hospitals. She was not good at "paper work" and documenting her important service; hence, her funding was cut two years ago.

The social worker coordinates the Montreal Urban Aboriginal Homelessness Pilot Project and has many years experience working with families trying to adjust to the rigors of city life. He described two scenarios that seem to repeat themselves. First, on the edge of the city is the Kahnawake First Nations with very sophisticated health and social services. There are a number of other Bands within a reasonable driving distance. The First Nations people competently manage their own programs and advocate on behalf of their own people. The members maintain strong connections and the Band advocates on their behalf. These families tend to manage fine and generally do not interface with the Friendship Centre.

However, serious issues relate to those Aboriginal peoples from Inuit and First Nations communities in Quebec's isolated north. They normally are required to fly south for services and find themselves lost in the large city. With the high cost of travel, they are sometimes "trapped" in the south and susceptible to a host of health and social problems. They lose family and cultural support and often are cut from the Band or community membership. It can take 3 to 6 months to reinstate treaty or disc number and without membership many Montreal agencies refuse service. When the worker tries to contact the First Nation or community to get approvals for spending or reinstatement, he is faced with "incompetence" or sometimes just neglect. It is extremely frustrating and often of the individual just gives up and turns back into the street.

The social worker repeatedly sees mothers with children with disabilities such as the effects of foetal alcohol. The mother has found herself in this situation because of her own addiction and social problems. Like the women interviewed in Vancouver, they do not have the knowledge, skills and resources to manage their children. The worker provides support and gives a fresh start but soon the situation spirals out of control. The children find themselves getting into deeper trouble as they enter their teenage years. The cycle of poverty, drugs, prostitution and homelessness returns.

There are a few adults from northern communities who have been institutionalized since childhood and now are middle-aged. They arrived without parents and ended up in institutions or white foster homes. They have their costs covered by Indian Affairs and will never return. No one really knows how many of these Aboriginal children became lost in the system and locked into permanent care. This issue would be interesting research topic because this pattern has occurred in other regions of Canada.

There are serious and fundamental problems between the provincial services and the Aboriginal community. With illegal drugs readily available, many displaced Aboriginal people find themselves with serious problems. Many parents from the north do not speak French. With the province officially francophone, many services are available in

only French. When they seek help, they are rebuffed and encounter blatant forms of racism. Sometimes they are refused services because the provincial official claims to not understand the request. The worker recalls an incident where he was advocating for a client in attempting to get a birth certificate from a provincial office. Not realizing that the worker was fluent in French, the provincial employees were making the process difficult and were heard whispering "sauvage". To the surprise of the clerk, the Friendship worker responded in French.

In order to access disability benefits under the provincial social assistance program, the client needs a birth certificate and a doctor's signature. The application forms are complicated and authorization is required. The client needs to arrange appointments and travel to the appropriate offices. Simple mistakes stop the application and it has to be "re-started." Many urban Aboriginal persons with disabilities give up "fighting" the system.

In another incident with Vital Statistics, the worker attempted to get a birth certificate for a child with a disability. The certificate was required for disability benefits. After paying the fee and submitting the documents, they waited three hours suspecting that the clerk was delaying until closing time at 4:30. They were told that the documents would be mailed. They returned to the centre and in the pursuing days, they waited and called and called. After 3 months, the clerks claimed that they sent it to 201 St. Laurent and not the correct address of 2001 St. Laurent. The worker believes that they took the fee and never processed the application. They had to return to the office and re-apply.

The worker recalls another upsetting incident. From the high Arctic, a single mother with three children, all with minor disabilities, arrived at the Friendship Centre. She was seeking some help enrolling her children in school. She also had problems and a history of poverty and drug abuse. With the assistance of the Friendship Centre social worker, they collected the necessary documents: past report cards and birth certificates. All the documents were in order and together, they went to see the school principal. He refuses their enrolment demanding a letter from the principal of the Arctic community. Speaking in French, he turns aside and says something like, "oh, she won't stay, homeless, no point in enrolling the kids in school." It is clear that the school did not want the three children and she sent the children back to their northern home. The mother continues to live in the city.

The situation in Montreal is very different than Vancouver. The language barriers, the vast travel distances and blatant racism has created a unique situation in Canada. In Vancouver and Victoria, there is an array of First Nations/Aboriginal operated health and social services agencies. Even the non-Aboriginal service providers seemed to be more open and accepting of First Nations/Aboriginal clients. In the near future, the situation is not going to change in Montreal. The community is desperate for an Aboriginal Social and Health centre such as on the one on East Hastings St., Vancouver. Such a centre would allow the Montreal Friendship Centre to focus on recreation, education and cultural services and deliver special programs for families, youth and elders. A Social and Health Centre could focus on public health, preventive health, social services and include disability issues. The federal government is remiss in not beginning a developmental plan for First Nations/ Aboriginal community in the city of Montreal.

4.5 Halifax Site

The Mic'maq Friendship Centre of Halifax operates a Child and Family Development Centre. The contact at the Development Centre was very open to being involved in this research but said they really did not see Aboriginal children with disabilities at their Centre. Our researcher was referred to the Izaak Walton Killam Hospital for Children and contact was made with the Social Work Department. The social worker said that they did see Aboriginal children with disabilities at their hospital from different regions of the province. They run a Program Based Care model with separate departments for physiotherapy, occupational therapy and social work. The hospital employs a First Nations worker to support and advocate for the Aboriginal families and their needs. Unfortunately, our researcher was not able to actually visit the staff; however, through discussion, the issues facing the families are common to other regions of Canada.

4.6. Conclusion

There are over-riding issues facing mothers of children with disabilities in all of the cities. They lose their contact with their cultural and family supports. They face agencies and service providers who are intentionally and un-intentionally unwelcoming. They face administrative bureaucracy and a cold impersonal system. The Friendship Centres attempt to address some of their needs but with funding dependent upon multiple sources, the workers live with insecurity and instability.

There is a desperate need to take a hard and critical look at the provision of health and social services to urban First Nations/Aboriginal families. The model of the cooperation between the Vancouver Aboriginal Friendship Centre Society has some merit but again, funding prohibits any long term strategic planning. The situation in Montreal is simply appalling and unacceptable. The partnership between the urban Aboriginal communities, provincial and federal governments seems to be working in Ontario and B.C. but it is not happening in Quebec. Each of the major cities should have a professionally staff and self-governed Aboriginal Health and Social Services agency delivering a variety of health and social programs such as outpatient addictions counselling, family supports, education, public health and health prevention. Comprehensive services should be available and management/administrative systems should be developed. Secure and dependable financial arrangements should be established in the same way our provincial health and social services are.
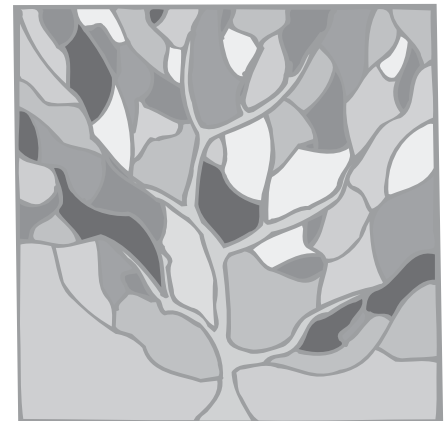
Section 5: Concluding Comments[4]

5.1 Introduction

This final section attempts to link important themes and issues, which emerged in the preceding sections. Research methodological issues are raised including the problems associated with identifying suitable participants. Suggestions for future research are indicated and the implications for service providers outlined. This chapter also includes a summary of the significant findings from the service providers and the participants themselves – Aboriginal families with disabilities. Five important recommendations are highlighted, which build upon previous research. Perhaps the most important contribution resulting from this research is the specific courses of action. These four courses of action provide policy makers and planners with concrete and realistic actions to address the issues raised in the study and the many preceding studies. They are "bold" because they challenge the existing structures –both government and non-government - to make fundamental changes to how they do their "business." Without fundamental changes, this study has the potential to do more than "collect dust" as, unfortunately, many others have.

5.2 Research Methodological Issues

Identifying and contacting potential participants was a problem. First, many service and voluntary organizations had little contact with First Nations families with disabilities, and did not have the type of relationship necessary to recommend or suggest persons meeting the research criteria. Curiously, the staff of these organizations purported to serve these individuals but had little contact with this sample of the population. The health care professionals possessed the best knowledge of this hidden population, probably because their clients had to access their services. Hence, the health professionals were the most helpful in identifying research participants. However, this situation raises questions as to how these clients are perceived. The disability is understood as a "health" issue rather than an economic or social issue. Furthermore, it creates a situation where First Nations or Aboriginal identity is second to the health or physical focus of the person.

To a non-Aboriginal person, this may not seem significant but it is a major concern for these clients who are struggling to maintain their cultural ethnic identity in a hostile urban environment, which readily expresses overt and covert racism. Identity with the reserve is a major social and psychological foundation for First Nations persons in Canada.

5.3 Directions for Further Research

There have been very few studies conducted concerning urban Aboriginal families of children with disabilities. Even more alarming, there have been even fewer studies conducted directly involving Aboriginal people with disabilities, exploring their trials, tribulations, and triumphs. Although the results of this study are limited, the qualitative method unearthed the richness of personal experiences of, first, having a disability and, second, being Aboriginal in the urban community.

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[4] See Durst and Bluechardt, 2001.

Considering the lack of research in the area of the urban Aboriginal children with disabilities and their families, it is recommended that further study be conducted involving a larger sample of this population. Studies are needed that focus on specific disabilities. Specific topics could include physical or intellectual disabilities and of particular concern is the area of alcohol related disabilities such as FAS/E. In addition, there is seems to be a growing problem of disabilities caused by the inhalant of solvents. Health and social service providers are not equipped with the empirical knowledge to know how to help these families.

This research study was able to capture only a small segment of the population of persons with disabilities, and there are certainly more personal testimonies that could shed light on an area so little understood. Taking into consideration the increasing number of Aboriginal people moving to urban centres and the increasing number of those children with disabilities, there is a need for expanding the research questions and including a larger sample.

5.4 Implications for Professional Service Providers

As previously mentioned, recent statistics have shown that the Aboriginal population is growing at twice the rate of the general population. In addition, more Aboriginal people are drifting to urban centres in search of services, resources, and opportunities that are not available on reserves. Their increased presence in the city will have profound effects on the larger community, in that they will be competing for services and opportunities. Considering the systemic barriers that have contributed to Aboriginal people being marginalized within the existing economic, political, and social institutions, there will be more pressure placed on various social agencies to assist in either maintaining or improving their current situations.

A high percentage of urban Aboriginal people rely on social assistance for their income, and the rate of disabilities among the Aboriginal population is two times the national average (Statistics Canada, 1991). Considering these statistics it is safe to assume that, at some point in their careers, all professionals will be in contact with an Aboriginal adult or child with a disability. It is extremely important for health and social service providers to have an understanding of the special circumstances of Aboriginal people. A lack of understanding may very well serve to perpetuate the barriers that continue to restrict Aboriginal children from full participation in the community. Not only is it important to have an understanding of the Aboriginal culture, it is necessary for the service providers to expand their awareness and understanding of the problems affecting this population. Since the rate of disabilities continues to rise, there is a need to understand the underlying causes of the circumstances that influence the rate of disabilities in the Aboriginal population.

With an increased presence in urban centres, there is the need to change attitudes, not only for the acceptance of Aboriginal people, but for the inclusion of Aboriginal adults and children with disabilities. Professionals are in an advantageous position and can help to facilitate this process by acting as advocates. Also, many social policy makers can influence policies that ultimately affect the lives of Aboriginal families of children with disabilities. However, they need to be more aware of the social, emotional, physical, and spiritual needs of Aboriginal people.

5.5 Summary of Findings: Service Providers and Professionals

The service providers and professionals reported that they had an "open door" and invited all groups to access their programs and services. They boasted that they attempted to reach as diverse a population as possible and that Aboriginal people were always welcomed. However, they admitted that there were few Aboriginal people accessing their services.

Some professionals frequently complained that in the past they had actively sought participation of Aboriginal persons, but none came forward. They reported that they had no Aboriginal staff, and those with a Board of Directors had no Aboriginal board members. They reported, "But, everyone is welcome!" There did not appear to be any serious efforts made to include the participation of Aboriginal people as staff, volunteers, or consumers of services.

5.6 Summary of Findings: Our Partners - The Consumers of Services

In the Canada, First Nations people strongly identify with their Bands and their respective reserve where their parents, brothers and sisters, and even their children live. Understanding this connection is critical for professionals who are providing employment, recreational, social, and health services.

This study found that First Nations parents of children with disabilities usually left their reserves in order to access health and social services. If their disability came as a result of an accident or deteriorating condition, they found that a "temporary" move to the city was necessary in order to access rehabilitation or treatment. The days evolved into months and the months into years. Without consciously thinking about it, they had developed a new life off reserve. Moving back to the reserve, where there are few services, buildings are inaccessible, transportation is impossible, and independent housing unrealistic, their dreams of permanently returning gradually faded with the rude reality. Leaving behind their families, First Nation people found loneliness and isolation. They now lived in a "foreign" and hostile urban environment.

The primary reason for moving into the city was to access services. Curiously, most of the funding for their services comes from the federal government and is dispersed through the individual Bands. So, in order to access funds for support programs, physical aids, and services, they must apply to their Bands. Since they are no longer located on the reserve, these individuals with disabilities get the "ping pong" treatment. Provincial government programs are reluctant to become involved and refer to Medical Services or Indian Affairs; Medical Services refer to the Bands; the Band administrators hold an "out of sight, out of mind" attitude, and refer to provincial programs.

The research has indicated some serious issues regarding self-government. It has been determined that the right to self-government by First Nations supersedes the rights of the First Nations person with a disability. This means that the Band and Tribal Councils determine how resources are employed and can deny individuals access to physical supports, non-insured benefits, and services if they choose to apply resources elsewhere.

There are some cultural differences in understanding disabilities and it seems that children with disabilities are accepted more readily in some First Nations communities than in mainstream Canada. So-called abnormalities are viewed as natural and normal, and little attention is paid to them. As one participant stated, a person with a disability "is a gift from the Creator" and should be cherished and respected. In some First Nations traditions, some persons with disabilities were seen as having special powers or gifts, which enabled them to communicate with the spiritual world. However, this research has also seen the opposite where the First Nations community has not been welcoming or accepting.

This view of "disability" changes the meaning of participation. The parents in this study did not necessarily want to "participate" in mainstream society as one might expect. Perhaps because of their culture, they held different views of the meaning of participating in leisure, recreation and sport activities, achieving self-sufficiency, and social and economic independence. Western Euro-Canadian cultures value independence and self-sufficiency and, curiously, value conformity. Mainstream society rejects interdependency and dependency on others. One just has to consider the RRSP advertising which promotes planning and sacrificing for future independence. First Nations cultures value interdependency, creating a belief that each individual can in some way contribute to the group as a whole. Each person has a role to play regardless of his or her physical, mental, or intellectual capacities.

Sometimes the parents were unaware that personal assistance was available from the program deliverers. They saw the need for personal assistance as a major barrier and felt that their only option would have been to provide their own personal assistant, who is frequently required to provide a variety of services already. Asking for help for a social or recreational activity seemed inappropriate after the amount of personal care provided by these helpers just to get through the day. Personal care is also "personal" and many objected to attending activities where strangers were expected to assist in feeding, moving, and more personal and private functions. Hence, the first preference for care-giving was always a member of the extended family who volunteered his/her time. The parents did not want to over-tax these helpers for less important activities, and they did not want strangers assisting them in the private and personal duties.

The costs of transportation and the amount of time involved arranging, planning, and waiting for rides created another barrier to participation. In addition, the financial costs of participation even in subsidized activities created another barrier to participation. When one is living on minimal assistance, the smallest fee is a major decision.

5.7 Recommendations

The Aboriginal families of children with disabilities are marginalized in a number of ways: they have a child with a disability, they are Aboriginal, they are off reserve, or in urban centres. Women are even further marginalized. This study reinforces the findings of previous research and highlights the following recommendations

1. Resolve the jurisdictional issues.

The first step that should begin immediately is solving the jurisdictional issues. Provincial and federal authorities and Band members need to organize themselves to ensure that services are made accessible. The ping ponging of clients must end. The jurisdictional conflicts can be solved as the federal and provincial governments have demonstrated that they can resolve jurisdictional issues as evidenced in their co-operation and co-ordination of services to refugees and immigrants. In regard to refugees and immigrants, the two levels of government with municipal governments and non-government agencies provide a comprehensive array of services even though they cross jurisdictional lines. If the will is there, it can be done. One strategy is to coordinate services from an Aboriginal governed and staff Health and Social Service Centre.

2. Mainstream agencies need to improve their outreach

The government and non-government agencies, purporting to serve children and adults with disabilities, need to address the low participation rates of Aboriginal people. They need cultural awareness including an honest self-examination of their policies and programs. They need to hire Aboriginal staff and include Aboriginal persons on their Boards of Directors. One of the key findings or lessons learned is that part of the reason for low participation in mainstream agencies and with service providers is not what they are doing but how they are doing their "business." These agencies need to take a hard and critical look at themselves and find ways to reach this population.

3. First Nations leadership needs to change

The First Nations leadership needs to take the problem seriously at the Band, provincial and national level. There needs to be an improvement of the professionalization of services at the community or Band level. Often, the workers have not been competent at simple tasks such as following up on telephone messages, keeping appointments, and completing promised tasks. They have not been serving the urban members of their First Nation very well.

4. National awareness is needed

Both the provincial and federal governments, in conjunction with national First Nations leadership, need to improve awareness education and sensitivity to these issues through supporting research and professional conferences. There is a need for awareness of the issue at all levels of service. Both the provincial and federal governments in conjunction with national Aboriginal leaders need to improve awareness education and sensitivity. There is a need for greater coordination of policy at the federal and provincial levels as many of these issues cross programs and are separated "ghetto-ized" in "Aboriginal" departments for divisions within government.

5. Issues of "inclusion" need to be understood and agreed upon

The belief that children and adults with disabilities need to be "included" in the daily life of our community is a widely held value. However, the meaning of "inclusion" may be problematic, especially for the Aboriginal person with a disability living off reserve. "Inclusion" may mean participation and social identification with other Aboriginal/First Nations families, or it may mean inclusion with other persons with disabilities, or it may mean inclusion with the dominant culture group of able-bodied citizens. At this point in the study, it is not clear what the objective of "inclusion" or integration means to Aboriginal families of children with disabilities, but it appears that inclusion may mean inclusion within sub-communities within larger communities.

This research project has indicated that many Aboriginal families of children with disabilities are not living an independent lifestyle, and the numerous barriers that inhibit independent living are deeply entrenched within society. Not all, but many parents have multiple problems and have disabilities themselves. A strong and effective voice is required to initiate change and improve the conditions for persons with disabilities. However, this will not occur until Aboriginal families participate in the decision-making processes that ultimately impact on their lives and the lives of their children.

The studies are piling up. The results are in and they are overwhelmingly identifying the issues presented in this report in the preceding pages. Now, the dust has begun to collect on many of these reports. Most of the previous studies have identified the barriers but offered little in concrete solutions. This study offers four specific courses of action to resolving these issues. Listed below, these recommendations for change can begin immediately and they need to be done in order for real, long lasting and significant change.
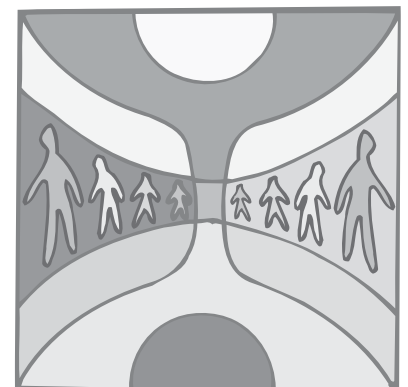
Action #1: Establish Provincial Advocate Offices:
Ombudsman for Aboriginal Families of Children with Disabilities

Accessing services and programs, which are readily available for many persons, are often inaccessible or denied to Aboriginal/First Nations persons and families with disabilities. An intergovernmental office should be established which could be based on the following partners:

- Federal/Provincial/Territorial Ministers Responsible for Social Services,
- the Department of Indian Affairs,
- the National Association of Friendship Centres,
- the Assembly of First Nations, and
- Aboriginal adults and families of children with disabilities.

This intergovernmental effort should establish Advocate Offices for each province, with a director whose primary responsibility is to ensure that Aboriginal and First Nations persons with disabilities and their families receive the basic services and programs they are entitled to receive from whatever government is responsible.

This "ombudsman" for Aboriginal persons with disabilities would facilitate the access to services and would be prepared to facilitate the client in achieving his/her rights. This may mean taking agencies, both government and non-government, to court. The position must have "teeth."

Offices should be established in every province with a sizable Aboriginal population. The office for the province of Newfoundland and Labrador should be located in Labrador. This plan would involve the establishment of nine offices across Canada: at approximately $200,000 per office it would cost about 1.8 million dollars. This action would greatly enhance the profile of Aboriginal/First Nations persons and their families with disabilities in Canada and directly improve their quality of life.

Action #2: Implement a National Jurisdictional Review Panel

There is an immediate need to resolve the jurisdictional problems outlined in the preceding pages. Repeatedly, studies have identified the jurisdictional difficulties and reported that it is a major barrier for this population. An intergovernmental review team should be established which could be based on the similar partners as suggested for the ombudsman offices. It could include the following:

- Federal/Provincial/Territorial Ministers Responsible for Social Services,
- the Department of Indian Affairs,
- the National Association of Friendship Centres,
- the Assembly of First Nations, and
- Aboriginal adults and parents of children with disabilities.

This intergovernmental team would complete a comprehensive review of the jurisdictional issues and propose a realistic system to adequately resolve it.

Action #3: Create National Network of Urban Aboriginal Health and Social Services Centres

As stated above, there are over-riding issues facing Aboriginal families in all of the major cities in Canada. They lose their contact with their cultural and family supports. They face agencies and service providers who are intentionally and un-intentionally unwelcoming. They face administrative bureaucracy and a cold impersonal system. The Friendship Centres attempt to address some of their needs but with funding dependent upon multiple sources, the workers live with insecurity and instability. However, these Friendship Centres can not do it alone.

There is a desperate need to take a hard and critical look at the provision of health and social services to urban First Nations/Aboriginal individuals and families. The model of the cooperation between the Vancouver Aboriginal Friendship Centre Society and Vancouver Native Health Society may be an example but again, funding prohibits any long term strategic planning. The situation in Montreal is simply appalling and unacceptable. The partnership between the urban Aboriginal communities, provincial and federal governments that struggles but seems to be working in Ontario, and B.C. is not happening in Quebec. Each of the major cities should have a professionally staff and self-governed Aboriginal Health and Social Services agency delivering a variety of health and social programs such as outpatient addictions counselling, family supports, education, public health and health prevention. Comprehensive services should be available and management/administrative systems should be developed. Secure and dependable financial arrangements should be established in the same way the provincial health and social services are.

It is beyond the scope of this report to recommend a structural arrangement but two models do come to mind. One model is to develop a parallel national network of First Nations/ Aboriginal Health Centres that is roughly constructed on the national model of existing Friendship Centres. The National Association of Friendship Centre is a central national body that distributes core funding to the provincial and regional centres Such an organization exists as the National Aboriginal Health Organization (**www.naho.ca**). Their mandate could be expanded to include both health and social services. The individual centres then seek additional funds from a variety of sources to provide specific programs and services. These funds are time and program limited and are used to provide site specific programs and services depending upon local needs. The other model is to expand the mandate of the existing National Association of Friendship Centres to include comprehensive health and social services. This model could create a specific "division" within the national body to create Health and Social Service centres either physically separate or within existing centres. However, it appears that many centres have limited space and would need to expand into separate or larger facilities. For large Friendship Centres such as in Victoria, some of their existing program, for example in the domain of public health, could be transferred to the new specialized health and social services centre. It is important to centralize and coordinate information and services and not exacerbate the fragmentation and over-specialization of the service delivery systems.

Action #4: Expand Research Knowledge Base

It is recommended that the federal government departments including Human Resources Development Canada, in conjunction with relevant partners, initiate expanded and strategic research endeavours in the areas of need identified in this report. Effective and efficient policy development, both nationally and regionally, as well as programs planning and service delivery, must be based upon empirical research findings completed under the rigours of accepted systematic inquiry. The relationship between social and policy research, and sound practice has too frequently been ignored. This study has determined the need for three potential research areas:

- disabilities among Aboriginal children, with a focus on prevention,
- issues facing specific disabilities including strategic interventions,
- issues regarding the family and its role, and
- the aspirations of Aboriginal families regarding inclusion and integration.

While some literature does exist regarding the adult population of persons with disabilities, little information is available on the infants, children, and adolescent Aboriginal population. Considering the increasing rate of a young Aboriginal population, an understanding of their circumstances and issues is crucial to providing proactive measures in the detection, prevention, and intervention of disabilities. Also, it would be beneficial to examine the causes and implications of potentially disabling conditions such as chronic ear infections and foetal alcohol syndrome. Insight into these conditions may identify the causes and the necessary steps for prevention.

There is a desperate need for research on the Foetal Alcohol Effects/Syndrome. There is very little information on how to help these children and the impacts of early intervention. There is little understanding of the impact of the living environment and behaviour management that will lead to successful adjustments. The mothers in this study often had serious problems themselves leaving the children to manage as best as they can. Much research is needed to find ways to help these families.

Further study is required to examine the role of the family in the care of family members with disabilities. The exploration of how Aboriginal families cope with family members who have disabilities, and how communities assist or alienate these families, needs further study. Considering the lack of support and services available to families with disabilities, it would be beneficial to examine what services and supports are available to family members both on and off reserve, and whether or not there is compensation.

There is also the need for an improved understanding of "inclusion" and "integration" from the families' perspectives. There are many assumptions of what citizenship and participation mean from different partners and these assumptions may not coincide with the aspirations and goals of this population.

The old man said, to have been born imperfect was a sign of specialness… as Canadians, where have we gone wrong? It is time to start to right the wrongs.

Douglas Durst, Ph.D.,
University of Regina.
February, 2006

Section 6:
Comprehensive Bibliography

The following is a comprehensive bibliography of the resources relating to the topic of First Nations/Aboriginal persons and disability issues. Not all of the sources were used in this report but they might be of interest to others seeking information or completing research in this area.

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Notes

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