FINAL REPORT:

SUPPORTING ABORIGINAL CHILDREN AND YOUTH

WITH

LEARNING AND/OR BEHAVIOURAL DISABILITIES IN

THE CARE OF ABORIGINAL CHILD WELFARE AGENCIES

Alex Wright, Diane Hiebert-Murphy, and Gwen Gosek

Faculty of Social Work
University of Manitoba

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I. INTRODUCTION

This report provides a comprehensive overview of a research project that began in September 2003. The project involved 124 First Nations Child and Family Services (FNCFS) agencies and communities across Canada and describes their experiences with, and perceptions of, service planning and provision for children and youth with learning and/or behavioural disabilities.

The objectives of the study were multiple. First, the study was designed to further knowledge related to the needs of Aboriginal children with learning and/or behavioural disabilities in the care of Aboriginal child welfare agencies. This included an understanding of current First Nations child welfare agencies' policies and practices involved with the planning and provision of services to these children and their families. The study also included an examination of collateral service providers and community members' perspectives and experiences with meeting the needs of this group of children. Ultimately, research goals were to identify challenges and "best practice" for addressing the needs of children with learning and/or behavioural disabilities.

This report begins with a summary of general demographic information of First Nations people living on reserves. This includes definitions of terms used to refer to Aboriginal people. Background information concerning FNCFS agencies follows with a mention of key jurisdictional issues. The report continues with a succinct review of government policy that prioritizes disability as a policy issue. A literature review then presents issues related to Aboriginal children and youth with disabilities, highlighting basic categorical data. The third section of the report presents the research design and methods, followed by an overview of survey data collection and findings. Site visit data collection methods and findings are reported in section five. Finally, the report concludes with a discussion of the findings and specific recommendations for change.

II. BACKGROUND AND LITERATURE REVIEW

Consistent with the Constitution Act, 1982 the term Aboriginal includes "the Indian, Métis and Inuit people" (Part II.35.2). The term First Nations is used throughout this report to refer to registered (sometimes referred to as "status" or "treaty") and non-status "Indians" and includes terms such as "Native". This is consistent with Statistics Canada definitions used for published data (Statistics Canada, 2003).

In 2002, 1.3 million people (or 4.4% of the total Canadian population) reported some Aboriginal ancestry (Statistics Canada, 2003). Nearly one million reported Aboriginal identity, and of those, 704,851 were considered "Registered Indians" (DIAND, 2004). Of those Aboriginal people identified as "Registered Indians", 403,337, or close to 60%, reside on reserve. The median age was 23.5 years, and 35% of the population was 14 years and under (this compares with 19% of the non-Aboriginal population) (Statistics Canada, 2003). The number of on-reserve children aged 18 years and under was 148,503. Of those children, 9,031 or 6.1% were in the care of FNCFS agencies. While there are some mandated Métis child and family services agencies in Canada (for example the Manitoba Métis Federation in Manitoba), the focus of this research project was on children and youth on reserve. As a result, only FNCFS agencies and reserve communities were included in the study. There are 614 bands across Canada (DIAND, 2004).

First Nations Child and Family Services (FNCFS) agencies reflect constitutional divides between federal and provincial responsibilities and authority. For example, Section 91(24) of the Constitution Act (1867) lists "Indians and lands reserved for Indians" as under the legislative authority of the parliament of Canada. In addition, Section 92 gives the provinces responsibility for "hospitals, asylums and charities", which are believed to include social services such as child welfare. Finally, Section 88 of the Indian Act (1985) states that "all laws of general application from time to time in force in any province are applicable to and in respect of Indians in the province, except to the extent that those laws are inconsistent with this Act". This can be interpreted to mean that provincial laws are the authority unless the *Act* specifies otherwise. As the Constitution Act of 1867 does not specifically identify child and family services, they then fall under provincial jurisdiction. A thorough review of federal, provincial/territorial jurisdiction is available in the document "Child Welfare in Canada 2000", (2002).

These constitutional divisions are evident in the FNCFS agencies which operate under a "delegated model" of service delivery (Taylor-Henley & Hudson, 1992, p. 14). In this model, agencies are authorized by the province to provide delegated services and must abide by provincial laws. While the agency retains autonomy in the staffing, planning and provision of services (based on provincial laws and standards) the province maintains the "ultimate authority" (Taylor-Henley & Hudson, 1992, p. 15) and can terminate an agency's mandate or "delegate it to another agency" (p. 15). As part of the federal responsibility, funding for FNCFS agencies on reserve is undertaken by the Indian and Northern Affairs Canada (INAC) (for a funding and related FNCFS agency review please refer to McDonald & Ladd, 2000). INAC's objective is to

> …assist First Nations in providing access to culturally sensitive child and family service in their communities, and to ensure that the services provided to First Nations children and their families on-reserve are comparable to those available to other provincial residents in similar circumstances. (INAC, 2004)

Canada's provincial and federal governments have identified early childhood development as a priority for all of Canada's children, including Aboriginal children (Health Canada, 2002). For example, in 1998 the Aboriginal Head Start programme (started in 1995) was expanded to provide on reserve services (Health Canada, 2003). Out of 6,467 children who received services, 377 were targeted as special needs.

The federal government of Canada has clearly stated its commitment to children with disabilities in various policy documents at the international and local level. Canada is a signatory to the UN Convention of Rights of the Child (1989). This Convention dictates that the rights of children with disabilities should be ensured and respected without discrimination (Article 2). Key rights include the right: to be protected from abuse, neglect, exploitation, discrimination and punishment; to be cared for by parents and to maintain family relations; to education; to enjoy his/her culture; to freedom of expression, thought and conscience; and to recreation. Of particular importance to this topic, Article 23 of the UN Convention states: "…that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community". This article also recognizes the rights of children with disabilities to assistance for the child or parents to care for the child and to ensure the child has

…effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child's achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development. (United Nations, 1989)

Federally, Article 15 of the Canadian Charter of Rights and Freedoms (1982), guarantees equality before and under the law for people with a disability. The issue of disability has become a policy priority in Canada, evident in several policy papers. For example, the federal and provincial/territorial governments (excepting Quebec) promote "full citizenship" for people with disabilities in the policy paper "In Unison: A Canadian Approach to Disability Issues" (1998). This was followed up with a report entitled "Future Directions to Address Disability Issues for the Government of Canada: Working Together for Full Citizenship" (1999) which presented a government agenda to meet the needs of this group and highlighted the "acute needs of Aboriginal people with disabilities (p. 11). One noted commitment by the Government of Canada was to "develop a longer-term action plan to identify gaps in federal programmes and services" (p. 11). The report "Advancing the Inclusion of Persons with Disabilities" (2002) was the first federal report to provide an accountability framework to assess and evaluate inclusion policy. In the past three years, the budget speeches have again highlighted the federal government's commitment to children with disabilities (2003 and 2004) and early learning and First Nations children on reserve (2005). More recently the federal government has promoted social inclusion as a policy, evident in the report "Advancing the Inclusion of Persons with Disabilities" (Social Development Canada, 2004), recognizing that poverty is more than low income. Disability can act as an obstacle to full participation and inclusion in society (Hatfield, 2004). Inclusion can be defined as: "In the broadest sense, people with disabilities are fully included when they have opportunities like those of all Canadians to participate fully in all daily activities – at home, at school, at work and in the community" (Social Development Canada, 2004, p. 2).

There is currently no systematic or comprehensive national data concerning children and youth with learning and/or behavioural disabilities. This information gap is even more evident for Aboriginal children and youth with learning and/or behavioural disabilities. Approximately 3.6 million Canadians (1 in 8) are considered to have a disability (Statistics Canada, 2002). Based on findings from the "Participation and Activity Limitation Survey" (PALS) 3.3% of children and youth aged 0-14 years were considered to have a disability in Canada

in 2001 (Statistics Canada, 2002).

It is estimated that 26.2% of Canadian children between 4 to 11 years of age suffer from emotional or behavioural problems. Approximately 10% of these children suffer from conduct disorder, 10% from hyperactivity, and 9% from an emotional disorder, while over 5% repeated a grade in school (Health Canada, 1999, p. 17). Research has found that approximately 6.5% of First Nations youth report disabilities that limit their daily functioning (McDonald & Ladd, 2000). The First Nations and Inuit Regional Health Surveys (First Nations Centre, 2004), designed and implemented provincially and nationally by First Nations and Inuit groups, included 4% of the child target population, or 4,138 children and youth. The results found that the majority of parents and youth (84% and 80%) described the youth's health as in very good or excellent health. However, 17% of the children were identified as having greater behavioural problems than other children. Ten to 15% of youth reported problems with depression and anxiety (in the Ontario and Nova Scotia sites). The Ontario region found conduct disorders (aggressive behaviour) to be almost double for First Nations children (16.1-9.6%) although hyperactivity was lower in First Nations children. In Canadian Aboriginal populations, the prevalence of FAS/FAE has been estimated by the BC FAS Resource Society to be as high as one in five (Health Canada, 1997, p. 14).

Children and youth with learning and/or behavioural disabilities appear to be at greater risk of experiencing difficulty in school, becoming involved in the criminal justice system, misusing substances, requiring greater health services, and experiencing employment difficulty as adults (McKechnie, 2000). Other noted difficulties affecting children with learning and/or behavioural disabilities include greater medical problems and difficulty with emotional bonding (Dubienski, 1996) and problems with the transition to adulthood (McKechnie, 2000).

Farris-Manning and Zandstra (2003), based on provincial and territorial figures for 2000-2002, estimate that 76,000 children and youth are in alternate care in Canada and a disproportionate number are Aboriginal (Health Canada, 2001). In a national study, Trocmé, Loo, Nutter, and Fallon (2002) identified 46% of children in care as Aboriginal. In some jurisdictions this figure is much higher. For example, in the province of Manitoba, the rate is estimated to be 72% (Government of Manitoba, 2004). Trocme, Knoke, and Blackstock (2004) found that Aboriginal children are twice as likely to be placed in foster care and there is a higher substantiation rate among Aboriginal children. As well these

families are more likely to be living in unsafe housing, and have experienced multiple moves in the prior year. McDonald and Ladd (2000) report that, based on 1996/97 data, four percent of First Nations children were in the custody of Child and Family Service agencies.

Research has found that educational outcomes for children "in care" are less favourable compared with children "not in care". As well, children in care have been found to have more negative behaviours (hyperactivity and inattention, emotional disorder and anxiety, conduct disorder and physical aggression, indirect aggression and offences against property) (Flynn & Biro, 1998).

The history of colonization has left far-reaching effects on the political, economic, and social health of Aboriginal communities (Armitage, 1993; Schmidt, 1997) (for an overview of the child welfare system and the Aboriginal community please refer to Blackstock & Trocmé, 2004). Hudson and McKenzie (1981) provide an analysis of the child welfare system within a colonial context and argue that what has occurred with reserves reflects a cultural colonization. Domination of culture with the goal of assimilation is evident in Aboriginal child welfare history. Aboriginal child welfare agencies frequently provide services in a context of community impoverishment, high suicide rates, lower life expectancy, higher rates of infant mortality, substance abuse, and family violence (McDonald & Ladd, 2000; Tikinagan Child and Family Services, 2000). There is an association between poverty and childhood disability, risk taking behaviour, problems with the law, and poor educational achievement. Aboriginal youth and children with learning difficulties have been identified as at greater risk of leaving school (Health Canada, 1999). Many of these children suffer poor outcomes, including behavioural and mental health problems, poor educational and employment performance and parenting problems (Health Canada, 2001).

Health Canada has identified key health determinants considered relevant to the development of children and youth. These health determinants include: income and social status, social support networks, education, employment and working conditions, social and physical environments, early childhood development, culture, health services, biology and genetic endowments, gender, personal health practices, individual capacity and coping skills, and health and social services (Health Canada, 1999). Social support networks are critical resources in supporting families and children and youth with learning and/or behavioural disabilities.

On an immediate caring level, children and youth with learning and/or behavioural disabilities can require specialized care. Among the many issues identified, the burnout of caregivers is a major concern (McKechnie, 2000). Research also suggests that half of children born with FAS/FAE are raised by caregivers other than their birth parents (McKechnie, 2000). While there is little evidence regarding best practices in meeting the needs of families with children or youth with learning and/or behavioural disabilities, support services, including the provision of respite, are considered a necessary resource for families caring for these children and youth. As well, education and training in the area of intervention with a family-centered approach was identified as a method to support families (McKechnie, 2000). However from an agency perspective there are limited resources to support caregivers of children and youth with learning and/or behavioural disabilities.

Other issues concern the broader service delivery system. Rural and remote communities have identified difficulty with a lack of support services available to diagnose and provide services to meet the needs of these children and youth. As well children and youth with learning and/or behavioural disabilities frequently require services from multiple settings: health, education, justice, social services, housing, and employment. However there is little evidence of multi-jurisdictional collaboration, cooperation, and partnerships across and between service providers where available (McKechnie, 2000). In most First Nations communities there is a paucity of other service providers (Tikinagan CFS, 2000). McKechnie's (2000) report also identified a need for greater involvement of First Nations people in the provision of culturally sensitive and competent intervention, highlighting the importance of the role of elders.

Related issues for Aboriginal child welfare agencies include funding arrangements and divided responsibilities between federal, provincial, and territorial governments. In some areas children with learning and/or behavioural disabilities are ineligible for provincial services as they live in a federal jurisdiction, on reserve (McKechnie, 2000). Other funding issues relate to the necessity for coordinated, planned, partnered, long-term funded programs, both on a community level and nationally (McKechnie, 2000).

In summary, the available evidence suggests that there is a disproportionate number of Aboriginal children in the care of child welfare agencies. It is also reasonable to estimate that a considerable number of these children have learning and/or behavioural disabilities and that these children are at a greater risk for negative outcomes. Currently, there is little data nationally that addresses the incidence and prevalence of

learning and/or behavioural disabilities among Aboriginal children in care, and there is little research on best practice with this population. It is clear that there is a necessity to systematically examine issues surrounding Aboriginal children and youth with learning and/or behavioural disabilities in the care of Aboriginal child welfare organizations across Canada.

III. OVERVIEW OF THE RESEARCH DESIGN AND METHODS

This project was designed to further knowledge related to (a) the needs of Aboriginal children with learning and/or behavioural disabilities in the care of Aboriginal child welfare agencies, (b) current practices of Aboriginal child welfare agencies in providing services to these children and their families; (c) challenges that are faced by child welfare agencies and communities in meeting the needs of this group of children, (d) "best practice" for addressing the needs of children with learning and/or behavioural disabilities, and (e) resources that would assist agencies, families, and communities in meeting the needs of this group of children.

In keeping with the objectives of the research project, the research focused on the following questions:

- What is the extent to which Aboriginal child welfare agencies provide services to children with learning and/or behavioural disabilities and their families?

- To what extent do agency data collection practices allow a determination of the number of Aboriginal children with learning and/or behavioural disabilities in the care of Aboriginal child welfare agencies?

- What is the process by which agencies determine whether a child has learning and/or behavioural disabilities?

- To what extent is addressing the needs of children with learning and/or behavioural disabilities perceived to be a key priority within Aboriginal child welfare agencies?

- To what extent do Aboriginal child welfare agencies think that they have knowledge of the needs of this group of children? Has the agency taken any specific action been taken to assess the needs of this group?

- Has the agency developed policies or practices specific to working with this group of children and their families/caregivers?

- Have agency staff received any training specific to working with children with learning and/or behavioural disabilities?

- What mainstream organizations does the child welfare agency partner with to meet the needs of these children and their families/caregivers?

- How do staff in Aboriginal child welfare agencies perceive the relationship between Aboriginal child welfare agencies and other organizations that provide support to children with learning and/or behavioural disabilities and their families?

- What do agency staff perceive to be the needs of Aboriginal children with learning and/or behavioural disabilities?

- What do families/caregivers identify as the needs of children with learning and/or behavioural disabilities in their communities?

- What do families/caregivers identify as their needs in caring for children with learning and/or behavioural disabilities?

- What do agency staff see as their role in responding to these needs?

- What do agency staff define as their needs in terms of providing services to children with learning and/or behavioural disabilities?

- What do families/caregivers perceive as their role in meeting the needs of their children with learning and/or behavioural disabilities?

- How do agency staff work with families/caregivers in providing for the needs of these children?

- What is the role of external agencies in meeting the needs of these children?

- What do agency staff perceive to be the challenges to meeting the needs of children with learning and/or behavioural disabilities?

- What do agency staff and families/caregivers perceive to be the strengths of the current system?

- What do agency staff and families/caregivers see as the limitations of the current service delivery system? (examples of issues explored: availability of culturally appropriate resource materials and services, availability of specialized services, available expertise, funding structures, geographic accessibility, flexibility in service systems, etc.)

- What do agency staff see as markers of "best practice" with Aboriginal children with learning and/or behavioural disabilities and their families?

- What do families/caregivers see as markers of "best practice" for agencies supporting children with learning and/or behavioural disabilities?

To answer these questions, a two-step research plan was developed that included both quantitative and qualitative methods. This project attempted to emphasize an approach to research which is sensitive and respectful of cultural contexts and practices (Burford & Pennell, 1995; Maxell & Morris, 1995; McKenzie, Seidle, & Bone, 1995), "including the use of community-based researchers with an appreciation of cultural traditions" (Hudson & Gallaway, 1995, p. xx). Additionally, as suggested by Bullock (1995) and Durst, McDonald, and Rich (1995), the project attempted to implement an inductive approach to the research process and represent accurately the participants' responses with no preconceived ideas or hypotheses. This includes a pre-dominance of qualitative data (Backe-Hansen, 1995; Bullock, 1995; Gorlick, 1995; Silva-Wayne, 1995; and flexibility within the research process (Bullock, 1995; Cameron, 1995; Jackson, 1995; Kufeldt, 1995) to allow for the pursuit of "new leads" when collecting data (Hudson & Gallaway, 1995, p. xxi). Ethics approval for the project was received from the Research Ethics Committee at the University of Manitoba.

The project was also designed to maximize opportunities for building the research capacity of individuals in the Aboriginal community. Aboriginal individuals were involved as research partners, as members of the advisory committee, as the project coordinator, and as on-site research assistants.

IV. PHASE 1

In the first phase of the research the objective was to determine on a broad level the scope of the issue and agencies' perceived needs, best practices, and challenges. The project attempted to gain information from as many Aboriginal child welfare agencies as possible. The initial work on the project involved developing and piloting a survey that could be used to obtain information from First Nations child welfare agencies that addressed the identified issues. A draft survey was initially developed by the project team. In order to ensure cultural appropriateness and relevance, the draft survey was circulated to an advisory group with representatives from the Aboriginal community as well as individuals with expertise in childhood disabilities. Feedback from this advisory committee was used to modify the survey. The final survey, which includes quantitative questions as well as open-ended questions, may be found in the Appendix.

The survey was sent to all First Nations agencies that explored (a) the number of Aboriginal children with learning and/or behavioural disabilities in the care of Aboriginal child welfare agencies and the nature of these disabilities, (b) current practice with these children within these agencies, (c) the agencies' perceptions of their needs in providing the best care for these children, (d) what agencies perceive to be the strengths and weaknesses in their current ability to meet the needs of these children, (e) what agencies see as changes that would enhance their ability to meet the needs of this population, and (f) policy related to this issue.

In order to initiate data collection for Phase 1, a database of all Aboriginal child welfare agencies was developed. While an existing database was obtained from The First Nations Child & Family Caring Society of Canada Inc.,[1] it required updating so that accurate information about contact persons was available. Telephone contact with the agencies occurred to update the database and to inform agencies about the project. Information was provided to agencies and the survey and consent forms were sent. Agency directors were asked for consent to their agency's participation in the project and to identify a contact person within the agency who would be best able to address the issues under study. The consent process emphasized the voluntary nature of the survey and the confidentiality of both the agency and respondent. Agencies were given the option of completing the written survey and returning it to the researchers or completing the survey with project staff during a telephone interview. This methodology was used as a way of addressing a poor

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1 This list was provided by M. Bennett, Director, First Nations Research Site.

response rate which is frequently experienced with mail-out surveys.

Contact was made with the 124 Aboriginal child welfare agencies in the database. Multiple contacts with these agencies occurred to inform them about the research and encourage their participation. The project received a total of 29 completed surveys. Six agency representatives stated they could not complete the survey because they had "no time" and eight stated that they do not have responsibility for children with disabilities. The distribution of respondents by province is shown in Figure 1.

Figure 1
Survey Respondents by Province[2]

Respondents, Agency, and Community Characteristics

Surveys were completed by staff with a range of positions in the child welfare agency. Fourteen respondents were in management positions, six were supervisors, four were front-line workers, and four were "other" (such as a resource services worker or support service coordinator). Five of the survey respondents were male and 24 were female. Their years of employment varied from one to six years in length.

With regards to participating agency characteristics, sixteen survey respondents reported that their agency is fully mandated or delegated. Partial delegation was identified for six agencies and three respondents stated that the agency is not mandated or delegated. With the exception of one, all respondents stated their agency provides services on reserve. The agencies serve between one and eleven reserves.

Figure 2
Number of Reserves Served
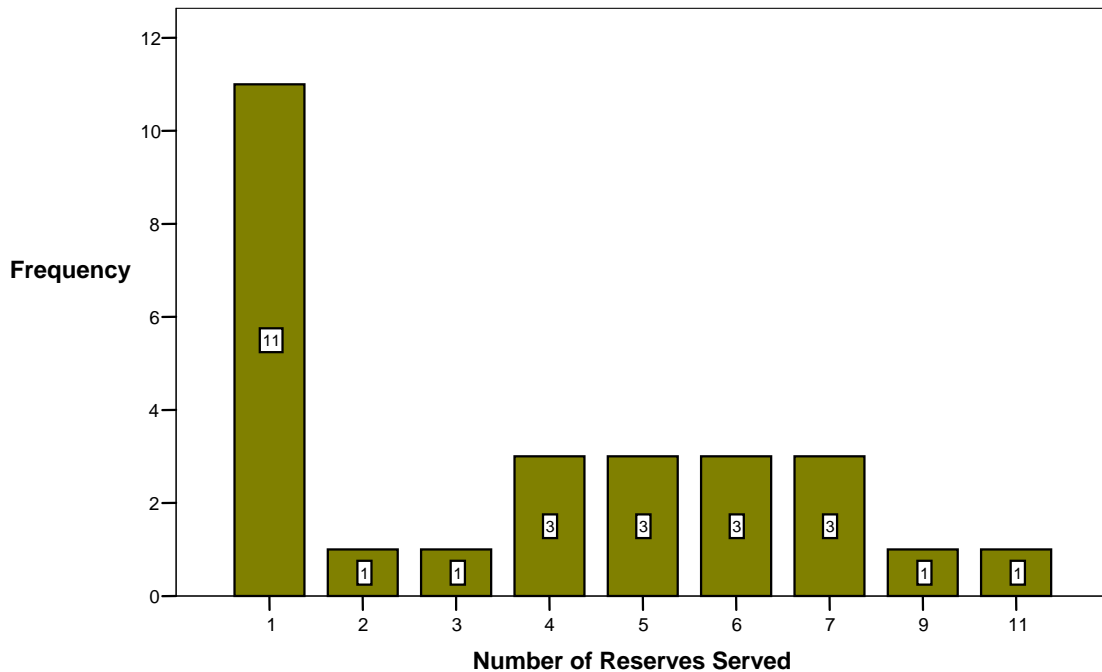
Agencies provide services in a variety of locations. Seventeen of the participating agencies provide services off-reserve, 18 of the agencies provide services in rural communities, and 12 agencies provide services in urban communities. Fifteen agencies include northern communities and ten participating agencies serve remote communities. Three of the agencies provide services in the south. Six respondents stated that their agency services Métis communities whereas 15 reported they do not provide services to Métis communities.

Agencies vary considerably in staff size and training of staff. Agencies reported having two to 500 full-time staff and between 0 and 55 part-time staff. Generally, managers were reported to have a post-secondary degree or diploma. For example, participants identified that the agency's managers have a degree in social work ($n = 15$) or an MSW ($n = 5$), a BA ($n = 2$), a Bachelor of Education, a post-secondary degree (not specified, $n = 2$), or a business diploma. As with managers, the majority of respondents identified that most supervisors have post-secondary education, whether a university degree or a college diploma. This includes a BSW ($n = 13$), an MSW ($n = 3$), a CSW ($n = 1$), degrees not specified ($n = 7$), a BA ($n = 2$), and post-secondary education such as a Social Work Diploma or a diploma not specified ($n = 2$), a number of years of college, or New Careers training. Most front-line workers were reported as having completed a BSW ($n = 16$), MSW ($n = 1$), RN ($n = 1$), CSW ($n = 1$), BA ($n = 3$), or degrees not specified ($n = 5$). Other survey respondents noted that workers have college degrees such as a Social Work Diploma ($n = 2$) or other college diplomas (not specified, $n = 4$). Less formal educational qualifications listed include a high school education ($n = 2$), some university courses, delegation training, certificates ($n = 3$), and Child Youth Worker, Behavioral Science, Law and Security, Child Development, and traditional knowledge ($n = 2$).

The survey respondents identified 31 different cultural groups within the communities served by their agencies. Cree was the most frequently reported ($n = 9$). The cultural groups include:

- Coast Salish ($n = 2$)
- Maliseet
- Cree ($n = 9$)
- Mi'k Maq/ Micmac ($n = 2$)
- Conichan Tribes
- Carrier and Sekani

- Shuswap
- Ktunaxa
- Métis
- Ojibway ($n = 5$)
- North Shuswap
- Algonquin
- Oji-Cree
- Cayaga
- Tyendinga

- Tuscurora
- Oneida
- Senea
- Shuswap - Selluncheen Band members
- Mohawks ($n = 2$)
- Onenaga
- Salteaux

- Anglican
- Catholic
- Presbyterian

- Long House
- Traditional
- Non-Believers

- Plains Cree (Willow)
- Nisga'a

Although there are 50 Aboriginal languages in Canada (Norris, 1998), respondents identified a total of 24 languages used in their communities. Twenty-two are Aboriginal languages and twelve communities were noted as including English as one of the languages of the community. One participant stated that French is a language used in the community served. Most of the communities had more than one language listed. The languages include:

- Sencoten
- English, Maliseet
- English, Cree
- Mi'k Maq, English
- Hulqum'inum
- Carrier
- Sekani
- English, Ktunaxa and Shuswap
- English, Ojibway
- Shuswap, English
- English French, Algonquin
- Ojibway, Cree, Oji-Cree, Mohawk, Cayaga, Tyendinga, Tuscurora, Oneida, Senea
- Splatsin,Shuswap
- Mohawks English
- Saulteaux
- Ojibway
- Cayuga, Mohawk, Onandaga, Seneca, Tuscarora, English
- Cree
- Plains Cree
- Cree and English ($n = 3$)
- Cree, English and Ojibway
- English and Nisga'a
- Cree and English

A total of 18 languages were identified by survey representatives as spoken by the agency, 16 of which are Aboriginal languages. This number is fewer than the number of Aboriginal languages identified as spoken in the communities ($n = 22$). Although none of the communities was described as being unilingual English speaking, seven agency respondents explained that English is the sole language spoken at the agency. Two of the representatives stated that French is also spoken in their agency. English was the most frequently listed language spoken ($n = 14$), followed by Cree ($n = 5$), Ojibway ($n = 2$), and French ($n = 2$).

Definition of Disability

Of the 29 survey respondents, the overwhelming majority reported that their agency does not have a definition of disability. One respondent wrote that the agency does not have a definition of disability, but rather *"we look at each case on an individual basis"*. Three respondents provided the agency definition:

> *With any restriction or lack of ability to perform an activity in the manner within the range considered normal for a human being*
>
> *Individuals presenting with delays in the four domains*
>
> *Children that are physically or emotionally handicapped*

A variety of terms were identified as terms that the agency uses to specifically describe children with cognitive/learning or behavioural disabilities. Thirty-five percent reported that they use the term cognitive/learning disability and 45% use the term behavioural disability. Less frequently used terms include different behavioural pattern, learning differences, therapeutic, ADHD, FASD, special needs, compromised, slow learners, delayed cognitively, and disability.

Identification of Children with Disabilities

Three agency representatives reported that the agency does not identify children with disabilities, whereas 22 respondents identified various means through which the agency identifies children with disabilities. Starting with the most frequently identified method to identify children with a disability, school ranked first, followed by formal diagnosis (not specified), the social worker, the family, medical professionals (including doctors and those not specified), psychologists, and referrals from other agencies (see Table 1).

Table 1
Process of Identification of Children with a Disability

Process	n
Social Worker	9
Family	7
Necessary for funding for special care (INAC)	3
Formal diagnosis (not specified)	10
Formal Diagnosis – Doctor	2
Formal Diagnosis - Medical professional (not specified)	5
Formal Diagnosis – Psychologist	2
School	13
Referral from other agencies (i.e. school, health care centre)	1

Some survey responses identified that different professionals provide diagnoses for different types of disability and stated that some disabilities are less easily diagnosed. For example one respondent commented that children and youth with *"FAS/E disorders most often go without diagnosis. The school identifies children with learning disabilities and physical disabilities are medically identified"*. Another participant commented that a lot of the disability identified *"is behavioral"*. One response demonstrates a conceptual differentiation based on a dichotomous *"normal/abnormal"* division of a child's health and explained that it is through a medical assessment *"that is how we know the child is not normal"*. Similarly, another respondent clarified that the use of the term "disability" is considered limiting however in order to provide services, a label can be necessary. The quotation also reflects the difficulty these service providers experience when trying to work with some of these children:

> *Identifying children with disabilities is a sensitive subject. We try not to label children. However, it gets difficult when the child experiences crisis and we're called upon to intervene. We are finding that children are affected biologically and that no matter what we try, we cannot help them. Children with behavioral difficulties are the most challenging, they have potential to do well, yet their learned behaviors impede on their development. It's quite stressful.*

Three responses highlighted that access to funding is the basis for a professional assessment of a child's disability: *"It depends upon what the identification is for. If for funding purposes, the child is assessed by a professional"*.

Identification of Children with Cognitive/Learning and/or Behavioural Disabilities

Responses regarding the process of the identification of children with

cognitive/learning and behavioral disabilities were very similar to those used to identify children with disabilities in general. Twenty-five survey respondents stated that the agency identifies children through various means. The most frequently reported method is through the school ($n = 19$) which is a higher frequency than that reported for a general disability. As with the process for identifying disability in general, the second most frequently reported process is the agency social worker ($n = 13$), and a formal diagnosis (not specified, $n = 11$). The fourth method for identification noted is via the child's family ($n = 8$). There were fewer respondents who rely on a medical diagnosis ($n = 3$), and finally through a psychologist ($n = 1$) or another child welfare agency ($n = 1$). One respondent reiterated that a formal diagnosis is necessary *"to access funds and services"*.

Fifteen survey respondents stated that the agency takes specific action to assess the needs of children and youth with learning and/or behavioural disabilities whereas eight responded that no agency action is taken to assess the needs of this group. The type of action taken to assess the needs varies considerably although they generally focus on the assessment of the individual child/youth (see Table 2). For example four staff identified that a child's referral for a professional assessment and diagnosis is the type of action used to assess needs. Other responses ($n = 11$) highlighted training, both for staff and caregivers, as the type of action taken to assess needs. Some commented on the application for targeted funds, whether for testing and assessment or service provision ($n = 4$). For some agencies this means that a referral has to be made *"for testing in order to apply for funding"*. Another respondent explained that the agency had submitted a proposal for service funding to *"assist the families with these children requiring a special needs service"* which resulted in a pilot project providing services to this group. Finally, the use of individualized care plans for children, the use of community crisis teams, meetings with the child's school, and a role for research, were all described as types of action used to assess needs. Comments made by respondents suggest that while this area is a priority *"we do not necessarily have the good resources"* and services suffer as a result.

Table 2
Action Taken to Assess the Needs of Children with Learning and/or Behavioural Disabilities

Type of Action	N
Referral of child to professional assessment and diagnosis	4
Training for staff	2
Staff member(s) trained in FASD	3
Staff member(s) trained in ADHD	2
Staff member(s) trained in Autism	1

Staff member(s) trained in Trauma and the Brain	1
Staff member(s) trained in Dual Diagnosis Mental Health Issues	1
Training for Foster Parents/Birth Parents	1
Preventative Groups	1
Specific funds directed for multi-disciplinary assessments (including testing)	2
Application for funding for services	2
Develop individualized plans of care for each child	1
Use of community crisis teams for children/youth	1
Meetings with school staff	1
Research	1

With regards to those respondents who stated that their agency does not have a specific action to assess the needs of children and youth with learning and/or behavioural
disabilities, some explanations were provided. One respondent stated that while the agency does not currently assess the needs of these children and youth it *"needs to assess the needs/services/resources development"*. Another respondent explained that the agency does not assess the needs of these children and youth as the agency's *"primary concern is protection from abuse"*. An additional explanation was *"No time to train for them to assess"*. Others explained that decisions are made on a *"case by case scenario"* or assessments completed *"as needed"*.

Distinctions among the Types of Children's Disabilities

Eighteen respondents reported that the agency uses distinctions among the types of children's disabilities (see Table 3). Four respondents stated that the agency uses no such distinctions. The most frequently reported include behavioural, physical, cognitive, developmental, and FAS. Several respondents identified that the distinctions are necessary to access funding or services: *"For funding purpose we must decide type of disability of child and level of care required by foster home so that we can bill INAC appropriately"*.

Table 3
Agency Distinctions among Types of Children's Disabilities

Distinctions	Number of Agencies Reporting this Category
Behavioural	5
Physical	4

Cognitive	3
Developmental Disability	2
FAS	2
Learning	1
Sanfilippo	1
Rhetts	1
Cerebral Palsy	1
ADHD	1
Mental	1

For respondents who stated there is no distinction made among the types of children's disabilities, one explained that it is the medical professionals who make distinctions, as opposed to the agency: *"Our agency does not make the distinctions in the types of disabilities as the children are usually referred by medical professionals. These medical distinctions are made by the medical professionals in most cases"*.

In one case, the respondent commented on the clear division between child protection services on-reserve and services provided for children with special needs. When asked whether the agency makes distinctions among the types of disabilities that children may have (for example physical disabilities, cognitive disabilities, learning disabilities, and behavioral disabilities), the respondent explained that children are provided with services off-reserve. *"All children and youth with disabilities are referred to the city hospital. Referrals to proper services such as an institution we end up sending child to the city and look for specialized medical foster home"*.

In eight cases respondents identified that agency distinctions are made for the purpose of accessing other resources, whether services or financial. Referrals to other agencies for services, foster home requirements, and accessing agency services (including protection services) are reasons noted for the distinctions. As well, billings to INAC are based on the type of disability and levels of care required of the foster home and thus necessitate distinctions. Some of these participants responded affirmatively that distinctions are made however did not define them. For example, one participant focused on the outcome of the process as a necessary means to make a referral to a program for children with special needs and stated *"Yes, what our agency is capable of handling what/when we need to make the referral to the CLS program"*. In another instance the participant explained that *"Special needs assessments are completed on each child to determine the level of care and financial support required"* however there was no specification of agency distinctions among the types of disabilities that children may have (for example physical disabilities, cognitive disabilities, learning disabilities, and behavioral disabilities).

It was difficult for respondents to report the number of children with disabilities that their agency has in care. Thirteen of the 29 respondents answered that they were able to identify these children, although this could include a manual count. Eleven respondents said that it was not possible to identify the number of children with disabilities in the care of the agency and three responded that the question was not applicable. Some commented on the difficulty in identifying a specific figure due to a lack of administrative tracking of this group. One respondent thought it would be possible to identify a number if the child or youth *"use the specialized foster home, it may be possible to determine what type"*. Another respondent wasn't sure of the number and explained *"I don't know, a lot have FAS, part is cultural, not enough nutrition"*. Others were reluctant to label the child/youth as having a disability. For example, the following respondent identified a number of children in care with behavioural problems, but did not consider them to be a disability: *"21- in care with behavioral problems, but it is usually parents not providing the supervision and guidance, so kids do not have the behavioural disabilities"*. Of the 13 respondents who identified the number of children, 15 categories were identified with a total of 90 children in care with a disability (see Table 4).

Table 4
Reported Frequency of Types of Disability of Children and Youth in the Care of 13 Responding Agencies

Type of Disability	Number of Children/Youth
Disability	3+
FAS	12+
ADHD	1
Autism	2
Cerebral Palsy	1
Mentally Challenged	1
Cognitive	28
Behaviour	25
Physical	5
Learning	1
Rhetts	1
Sanfilippo	1
Medically Fragile	2
Additional Services and Resources to Assist with Daily Life	7
Insufficient Nutrition	1+

Total	90+

Children with a Disability

Twenty-one survey respondents affirmed that there are children who come into care primarily because services and supports for children are unavailable to the child and his/her family. Three participants responded that children do not come into care due to a lack of available supports and one responded that she did not know whether or not this occurred.

There were two primary reasons for the placement of these children. The most frequent reason given was a serious medical conditions ($n = 6$) and the corresponding lack of
services within the community necessary to maintain the child either at home or in the community. This was particularly noted by northern communities where children have to be transported to the southern urban centres to access services. The parents' inability to cope with the child's needs due to his/her care requirements was also noted.

However the lack of support services available to keep the child within the parental home is not solely limited to circumstances where the child has complex medical needs. The second reason identified for the child coming into care is the behavioural problems of children and the parents' corresponding inability to deal with their needs. For example, one survey respondent wrote that the *"behavioral-needs of child exceeded the capabilities of a single parent"* and another stated in response to the question *"We do have children in care? About six with behavioral problems. They place themselves at risk: out of control behavior, don't go to school, do drugs and don't follow rules, promiscuous and alcohol"*. While both of these identified reasons are serious they are qualitatively different issues. The number of children with disabilities in care due to a lack of services and supports ranged from one to 10% of all of the agencies' children in care. These numbers add to a total of 71 divided between 13 agencies.

Fourteen survey respondents stated that there were between 0 and 37 children with disabilities within the community to whom the agency provides services. This adds to a total of 151 children from 14 agencies. Seven survey respondents stated they did not know the number of child with disabilities in the community.

Fifty-two children were identified by 12 respondents as having left the community in order to access resources. One respondent explained that she estimated a large number as *"So many children live in medical foster homes. Too many to count"*. Eight respondents stated that no children had left the community in order to access resources and three survey respondents stated they did not

know whether or not children with disabilities left the community to access resources.

Policies and Practices for Working with Children with Cognitive/Learning and/or Behavioural Disabilities

Twenty-two respondents stated that they have no specific written policies concerning children with disabilities. Three survey respondents identified that there is written policy however it was not shared with the research group. Some respondents clarified that there is a distinction between policy and practice and that certain practices are used with children and youth with learning and/or behavioural disabilities. For example when this staff person was asked whether there were policies and practices in place she explained that while the agency has no policy, the agency practices nevertheless apply: *"Not that I am aware of. It's not written. Cultural practices/mediation, we work from holistic policy."* She went on to elaborate how the agency and community intervened on behalf of a child who the Ministry wanted to take away. The agency provided mediation services for the community in order to keep the child in the community.

A second survey respondent explained that the agency has *"Practice to connect families to services and resources outside the agency"*. Another example of practice without formal policy is the development of staff resources*: "There is no specific policy, however we have two full-time workers dedicated to the developmental disability work for our clients"*. A fourth participant stated that the completion of a certain form results in specific practice for this group: *"No policies have been developed but there is a needs assessment form required to be filled out by the family - this determines the level of service, type of service, etc."*.

Several respondents commented that other existing policies, such as the "Family Services Act" or external agency policies concerning children in crisis are extended and used to apply to children with disabilities. For example one respondent said *"No specific policies presently exist. Youth centres provide youth protection policies to address children in crisis, which are most often children with disabilities"*.

Staff Training Specific to Working with Children with Cognitive/Learning and/or Behavioural Disabilities

Nineteen participants identified that the agency provided training specific to work with children and youth with cognitive/learning and/or behavioural disabilities. The most frequently reported topic of training was FAS/FAE, followed by ADHD, autism, and adolescent behaviour concerns. As displayed in Table 5,

participants noted that many other topics were the focus of staff training.

Table 5
Type of Training Identified by Respondents who Indicated that their Agency
Provides Training Specific to Children with Cognitive/Learning and/or
Behavioural Disabilities (*n* = 19)

Topics for Staff Training	Number of Agencies
FAS/FAE	10
ADHD	4
Autism	3
Youth at risk, difficult teens and defiant behaviors (behavioural)	4
Neurological	1
Attachment and bonding	1
Cognitive learning disabilities	1
Ages in Stages	1
Critical Incident	1
Group facilitation for families in crisis	1
Children who witness violence/trauma resolution	1
Cognitive impacts from abuse-neglect training	1
Trauma and the brain	1
Dual diagnosis mental health issues	1
Children with anger issues	1
How to level children	1
Using computers to communicate	1

There was a wide variation in the responses to the question concerning the breadth and depth of training for children and youth with learning and/or behavioural disabilities. For example, one agency was reported to provide staff with extensive training, evident in the participant's response:

> *Yes. Some of the training provided: Ages in Stages training which provides such training as "Nobody's Perfect", "Touching", "How to Play with Your Child", "Good Toys for Kids" and "Positive Parenting". Trainer provides training for work with children with special needs on areas of infant nutrition, parenting life skills, grief and loss issues, communication and goal setting. There is Critical Incident Training to do, group facilitation for families in crises. There is a resource list that is quite extensive where staff are listed identifying what training each has received.*

This contrasts with the following response in which agency training has not been provided: *"We have several individuals with specialized backgrounds, but NO training has been offered other than workshop style education"*. Other

respondents stated that staff receive training when it is "available" but did not elaborate on the topic or method of training.

While there was evidence of breadth in training, some of the reported training was very narrow in scope, and focused on administrative processes as opposed to specific content regarding children and youth with learning and/or behavioural disabilities. For example, one respondent explained that staff received training in how to *"Level children (assessment for any referrals) to assess needs and determination of type of foster care needed"*.

In terms of methods, staff reported workshops to be the main means of training although conferences and seminars were also identified. One participant explained that staff receive training through *"telepsychiatry seminars"*.

The six responses stating that no training was provided were generally succinct, with little explanation. However, one respondent identified that there are "*other therapists hired to work with children*" and as a result specific training about children and youth with learning and/or behavioural disabilities is unnecessary. Another staff explained that the individual decided what training she wanted to pursue due to her own interests.

Receipt of Targeted Funding to Support Children with Cognitive/Learning and/or Behavioural Disabilities

Four survey respondents stated that the agency receives targeted funding to support children with cognitive/learning and/or behavioural disabilities. They listed the provincial government, and in one case INAC, as the sources of funding. This funding was used in a variety of ways (e.g., for in-home support for children with special needs, for a "Developmental Program" that includes two full-time positions including an onsite consulting psychiatrist).

Twenty respondents stated that the agency receives no targeted funding to support children with cognitive/learning and/or behavioural disabilities. Respondents explained that the agency gets funds for children in care and is reimbursed for residential treatment, special needs, or therapeutic foster homes. Other local service providers, such as the health agency or the school, were identified as receiving targeted funds, although on a "minimal" level.

One respondent stated while the agency does not receive targeted funding to support children with cognitive/learning and/or behavioural disabilities, the agency receives *"higher levels of core funding for children with formal diagnosis"*. She explained that she believes the reason the agency doesn't receive targeted funding is *"Possibly because our numbers of children with formal*

diagnosis are quite low, INAC probably does not see a need". Several respondents stated that the agency receives core funding from INAC and at times additional funding from the province.

Cut-backs were also identified as a reason for the lack of targeted funding. For example, one survey respondent explained that *"This is why we are using community funds - government has cut these services for the north. Communities have had to pick up the costs for children with special needs"*. One respondent explained that because services to children with cognitive/learning and/or behavioural disabilities are not considered to be fully delegated or mandated services, they are not funded as core services.

Additional Services for Children with Disabilities and their Families/Caregivers

Survey responses reflect a range of options regarding partnerships with mainstream organizations. For some participating agencies, only one mainstream organization was identified whereas for one agency, twelve organizations were listed. However, on average, approximately four organizations were identified. Health services, mental health services, schools, and other mandated child welfare agencies were the most frequently identified organizations. Early intervention programs such as Head Start, Healthy Babies, and Early Years were also frequently listed ($n = 6$). Two respondents stated that there are no mainstream organizations with whom they can partner to provide services.

The majority of survey respondents identified many other services available for children and youth with learning and/or behavioural disabilities and their families in the community or an urban centre. They include medical services, educational services, speech therapy, physiotherapy, psychological services, recreation, child development counselors, and behaviour specialists. One respondent stated that there are simply no other services available in the community.

While agencies clearly identified that other services are available in the community, these services vary considerably in terms of quality and quantity. For example, one respondent noted that the local hospital provides a six week comprehensive assessment as well as medical, educational, speech therapy, physiotherapy, psychological, recreational, child development, and behaviour specialist services. In contrast, another respondent stated that basic medical, educational, speech, physiotherapy, and occupational therapy services are provided, however on a very limited basis. The agency representative explained that medical services are "basic", speech therapy is available in the community two days per week, physiotherapy and occupational therapy are available once every four months, and child development counselors (who provide services for

children at birth to age five) are available on a regular basis. Another respondent explained that speech therapy is available at a hospital in the nearest urban centre however there is a six month waiting list and no other services available in the community. Similarly one respondent stated that speech therapy at school is the only service available in the community for these children and their families. Another example of the limited availability of services is evident in one participant's response regarding an infant development worker. She explained that the worker is available to the community for: *"60 hours per month including travel"*.

Remote access to psychiatric services through telemedicine was also noted as a service available to community residents: *"We have access through telemedicine to 75 psychiatrists"*. For many respondents, the nearest urban centre provides the closest access to these services. Even though services may be available in the community area, some agencies are required to purchase specific services. For example, one respondent stated that *"We have had to contract services with our funds to meet needs in areas of speech and counseling services"*. As stated, several respondents commented that they have to access these services in the nearest urban centre. One agency participant stated that the *"goal is to have mobile medical team"* in order to provide greater accessibility to services for community members.

Twelve survey respondents identified that culturally based services are available for children with disabilities and their families. Eight respondents stated that such services do not exist. There were various explanations given for those respondents who answered that culturally based services are available for children with disabilities and their families in the community. Some clarified that the participating agency provides culturally based services. For example, one agency representative said *"We work from a holistic perspective, so it's always families/communities driven"*. Similarly another respondent stated *"Everything we do here is about culture"*. One respondent stated that social services are culturally based because the First Nation administers the services: *"Each First Nation has their own health and social service providers who provide culturally based services to all community members (i.e., mental health, educational, counselors, psychologists)"*. Some culturally based services are available to those who request it. For example, one respondent explained *"To the clients who are interested we also have a traditional program that works in conjunction with other agencies in the community"*. One survey respondent stated that *"Culturally based services are being provided as we are utilizing service providers that know the culture of the family"*.

The range of culturally based services identified by respondents include:

- Prevention groups
- Addiction recovery program for parents
- Nurse in care provides diet in which traditional foods is incorporated
- Cultural support workers provide culturally appropriate services for that area
- Patient liaison worker works in the hospital and can access the translator
- Mental health team incorporating cultural and spiritual practices
- Traditional teachings
- Traditional healing and medicine
- Ceremonies
- Children's pow-wow hosted by our agency
- Language program through daycare and school
- Drumming group
- Summer culture camp (new)
- Community activities
- Holistic health
- Child and family services
- Women's shelter
- Repatriation

Support to Care for Children with Disabilities and their Families

There were many identified needs for additional support to provide care to children with disabilities and their families. Many respondents (*n* = 17) highlighted funding as a major solution to improve the agency's ability to provide better care to children with cognitive/learning and/or behavioural disabilities and their families, including specific targeting, augmentation, and flexibility. Increased funding is considered a way to meet various needs of this target group. For example, greater funding dollars could assist in increasing the availability of alternate care treatment opportunities in the community such as substance abuse treatment. One participant noted that there are *"lots addicted to sniffing and serious mental health issues and nowhere to put them"*. Another respondent stated that increased funding is necessary to cover costs related to the remoteness of the agency and access to services. Increasing financial resources is also viewed as a means to hire more staff to provide services for these children: *"If we had access to more family support workers for children with disabilities, it would help"*. Several respondents stated that funding is needed for assessments and services. One explained that the agency requires increased funding for psycho-educational assessments, respite, intensive behavioral one-on-one work with children, and neurodevelopmental assessments for adolescents affected by FASD. Targeted funding is viewed as a means for an agency to engage in "adequate" program development, *"as opposed to trying to do with money we have - no targeted funds"*.

Flexibility with funding was also raised as a solution to provide better care to children with cognitive/learning and/or behavioural disabilities and their families. One respondent wrote that the rigidity of funding results in services being funded only when children are brought into care. She believes that *"Allowing us to re-direct our monies into supportive services instead of only providing funding when a child is brought into care"* would result in improved services for these children and families.

Staff training was noted by twelve respondents as a means to improve the care of children with disabilities and their families. Identified training needs are diverse. Some respondents listed training needs in the area of ADHD, FAS, and *"behavioural children"* and another participant commented more generally that *"More trained staff to work with special needs children"* would result in improved services. Others believe that staff should have the knowledge to provide specialized services for these children and their families.

Issues related to professional services were presented by the survey respondents as additional means to provide better care to children with cognitive/learning and/or behavioural disabilities and their families (*n* = 11). Respondents gave several examples of needs in this area including available, accessible, affordable, culturally appropriate, and effective professional services in their communities. Many respondents believe that services need to be developed at the community level as even if children with disabilities are assessed and diagnosed, there may be no services available. For example, a staff person stated that one *"Cannot expect families to leave their communities to go with the services"*. Another survey respondent stated that the agency needs professionals *"who are licensed to medically diagnose (i.e., FAS) our children in our catchment area"*. Similarly, another respondent said *"More community resources instead of having someone come in from out of town i.e., occupational therapist, child development counselor, etc."*. Other service needs identified to improve care to children with cognitive/learning and/or behavioural disabilities and their families include better screening services, culturally specific residential treatment programs and support programs, infant development programs, specialized foster homes in the north, emergency foster homes, a treatment centre for children with behavioural problems, and an increase in hours for child psychiatry services. One respondent noted that transporting children and youth to an urban centre for treatment results in the children taking on damaging behaviours:

> *There's need to have a treatment facility for behavioral problems in the community because they learn other behaviors (negative) when we send them out distances such as [large urban centre].*

Support for caregivers, including parents and foster parents, was also raised as a

means to help the agency provide better care to children with cognitive/learning and/or behavioural disabilities (*n* = 4). For example one respondent stated that support for foster parents to learn how to complete administrative procedures and understand assessments would be beneficial: *"Foster parent programs-Education/training on specific disabilities (how to fill out forms and reading assessments)"*. The same respondent noted that some disabilities are not receiving sufficient attention. She explained that there are *"Invisible disabilities like depression- that hinders their spirit. Youth suicide is a serious issue-it's a crisis"* and a need for parenting skills programs *"such as how to identify signs of depression"*.

Not all responses concentrated on changes to their agency's programs or services. For example, several survey respondents focused their comments on needed changes with the educational system and the local school. One respondent stated that she believes that changes in schools have to occur to become inclusive of children with behavioural problems because they are otherwise denied school access because of their behavior. She added that funding for teacher assistants and additional classroom resources are needed. Another response, while advocating for targeted funds, views them as necessary to improve services for children with disabilities in the school system: *"That targeted funding can be clarified so care plan be in place for school children as they go through the school system to adulthood"*. Another participant stated that increased funding is necessary to provide *"one on one support in schools"*. This staff person stated that without sufficient resources, these children suffer:

> *There are a high number of children with identified need cognitive and behavioral. Schools in area not equipped to successfully work with these children. Instead they (my impression) is that they continue "passing" them into next grade. End result: Student graduates but is not ready for University. They need to go back to upgrade or get discouraged and do not try to further education (usually the latter).*

One respondent from a northern community stated that *"resources like what is in the city"* would result in better care to children with disabilities and their children. She also noted that basic needs such as *"Better housing, more houses, running water and sewage"* would improve the condition of these children.

When survey respondents were asked what other resources are needed in the community to support families caring for children with disabilities, 22 respondents provided a wide range of responses. Many overlapped with previously identified agency needs: Seven respondents identified respite programs for both biological and foster families to be a needed resource in the community

to support these families. Staff responded that respite should be affordable, available, consistent, and culturally appropriate.

Educational training for community staff and parents including health, education, and skills to *"help parents deal with daily living issues with these children"* was identified by six survey respondents as needed community resources to support families with children with disabilities. As well, three respondents stated that support groups for families would be helpful.

Funding for various services was also identified as a necessary resource by multiple respondents. One respondent stated that *"more dollars to provide relief support to families"* are needed. Another respondent argued that funds are needed for *"houses with wheelchair accessibility and other equipment"* whereas a third comment stated that funding is needed for increased numbers of staff, day treatment programs, outreach, and respite services. The need for transportation to access services was also identified.

Other respondents identified the need for direct services for the children and youth. For example, survey respondents stated that necessary resources currently unavailable in the community are *"skill building for children with disabilities"* and that there is a lack of recreational programming for special needs children and youth.

Professional services were also identified as a need. One respondent stated that needed resources in her community include a number of professionals: occupational therapist, physical therapist, and pediatricians. She also stated that children and youth with special needs require increased follow-ups in both quantity and regularity with pediatricians. Another survey respondent commented that *"Having our own people trained to do the O/T, P/T and Speech Therapy as this is costly. Need to figure out how the agency can provide support"*. A third respondent commented that the community requires *"consistent medical personnel"*. Two respondents stated that increased coordination and *"networking with agencies who work in specialized area"*, particularly *"schools, medical and social workers"* is necessary to support these families and their children.
The need for trained social workers was also identified by some respondents. For example, two respondents stated that "specialized social workers" to work with families are needed. One participant argued that access to child/youth workers is a resource required by the community.

Racism was highlighted as a negative effect on families caring for children with disabilities and several suggestions were proffered as a means to confront its consequences. For example, culturally appropriate resources were identified as a way to combat the effects of *"racism, colonization, drug and alcohol misuse"*.

Training was also offered as one way to address racism:

> *Training specific to meet the needs of families who are caring for disabled children. There is racism in the north, and a lot of families can't speak up for themselves when they receive shabby treatment. Services are contracted out, people who provide these services don't treat Aboriginal families right. Racism is a factor.*

Finally, programs that focus on suicide prevention and intervention, particularly for youth, were identified as lacking.

V. PHASE 2

While the purpose of Phase 1 of the project was to identify common themes and issues, as well as differences among agencies, it was expected that issues would emerge that would warrant more focused study using a methodology that allows for the collection of rich data that adequately captures the context in which the issues under study are embedded. In Phase 2, a qualitative methodology was used to explore the issues in an in-depth manner. The purpose of Phase 2 was to examine in greater depth perceptions of the community (this includes Elders, agency staff, parents, siblings, extended family members, caregivers, and youth) regarding the needs of children with learning and/or behavioural disabilities, the current practice in responding to these needs, the resources that are available to support these children and their families, limitations or gaps in services to meet the needs, and perceptions of the type of resources that would assist Aboriginal families and agencies in responding to the needs of these children.

Five research sites were identified and targeted for participation in Phase 2 of the research. The goal was to select sites that represented diversity in terms of such factors as region, language, and issues emerging from the survey. Consideration was also given to selecting sites that were willing to participate and where local personnel could be located to assist in the project coordination and data collection.

The criteria for selection included the following:

(a) The Aboriginal child and family agency had participated and completed the survey in Phase 1;

(b) The Aboriginal child and family services agency's contact person in Phase 1 indicated the agency was interested in participating in a site visit during Phase 2;

(c) The selected agencies represented different regions of Canada (including the east coast, central Canada, the Prairies, the west coast, the north, and the south);

(d) The Aboriginal child and family services agency identified that it was a fully mandated agency;

(e) The agencies represented diverse experiences in dealing with the issue of disability; and

(f) Consent to complete research in the community was granted by the chief and council and by their community research committees where such committees were established.

Site visits were completed with five Aboriginal child welfare agencies across Canada. For each site visit, efforts were made to explore the issues using the following data collection methods:

1. Community focus groups (involving an open invitation to all members of the community interested in the topic area);

2. Focus groups/in-depth interviews with child welfare agency staff (including program managers, supervisors, and front line staff);

3. A review of relevant agency policy;

4. Identification of collateral agencies providing services to children and youth with learning and/or behavioural disabilities; and

5. Where available, analysis of financial data on service cost.

To facilitate Phase 2 research, on-site research assistants (individuals nominated by the participating agencies) were employed to assist in planning the visit and facilitating data collection. Their responsibilities included: advertising and preparing for the community focus group, arranging for staff focus group/interviews, assisting in the planning of the meal/feast and selection of honoraria/gifts to thank the community, and collecting all relevant policy and financial data from the agency. The field research assistants were also actively involved in the data collection process in their communities. Although the initial

intent was to have a formal training event that brought together research assistants from the various sites, this became unworkable due to the schedules of the visits, the availability of the research assistants, and the time constraints of the project. A research assistant for the first site came to the University of Manitoba for training. Training for assistants for the other community visits occurred through telephone and email contact as well as meetings during the on-site visits.

A list of questions was developed to guide the facilitators in conducting the interviews/focus groups. While the facilitators explored the issues of central interest to the study, the interviews/focus groups were open-ended and allowed participants to identify issues of importance to them. Interviews varied in length and occurred in a variety of settings within each community including, for example, the child welfare agency, the school, and a community hall. Interviews/focus groups were audiotaped and subsequently transcribed. Translation of the interviews occurred when necessary. Transcripts were reviewed by research staff against taped interviews to ensure the accuracy of transcription.

Data analysis involved coding of the transcripts, written material compiled during site visits, and field notes. Codes were organized into emerging themes.

Overview of Agency Site Visits

1. Site A

This site visit involved visiting an Aboriginal child and family services agency head office based in an urban setting as well as a community visit to a remote First Nations community. During this visit a focus group was held with eleven supervisors and one area manager. A scheduled meeting with front line staff was cancelled due to the crisis oriented nature of their work which resulted in the workers not being available to attend.

The visit to the remote First Nations community included a community focus group with nine adults in attendance, an interview with the principal of the on-reserve school, and a visit with a foster parent who was fostering several special needs children.

2. Site B

This site visit involved visiting a remote northern First Nations community. The interview schedule included opportunities for numerous interviews and focus groups which included:

- Four educational resource staff members from the on-reserve school;

- Three individuals representing community agencies supporting families;
- One individual representing a pilot project for long term support for families with children who have lifelong physical disabilities;
- Two individuals, the project coordinator and support worker, who represented the child and family agency's pilot project supporting families caring for children with special needs;
- Three professionals including a family therapist, a psychologist, and a child development specialist;
- A community occupational therapist;
- A front line worker whose responsibilities included working with families who have children in care with long term medical needs;
- An assistant director of the Aboriginal child and family services agency;
- A band councilor;
- An elder from the community; and
- A community focus group that included eight individuals representing the Aboriginal child and family services agency, an on-reserve school, and several other community based agencies.

3. Site C

The Aboriginal child and family services agency for this visit is located in a suburb of a large urban setting and provides services for six First Nations communities. Contact with agency and community members included:

- A focus group with five Aboriginal child and family services agency staff who represented three of the six First Nations communities, one representative from the local Friendship Centre, and two parents;
- Interviews with three community parents who have children with special needs;
- Interviews with seven individuals including the executive director, front line staff and a student at a neighboring Aboriginal child and family services agency which is in the process of receiving its mandate;
- A focus group with six individuals with representation from the Aboriginal child and family services and the Friendship Centre; and
- A community focus group with twenty adults.

4. Site D

The First Nations child and family services agency for this particular site visit is located in a small town and provides services to approximately 1300 residents on a nearby reserve. This visit provided an opportunity for:

- A focus group with six individuals who represented the First Nations child and family agency and collateral on-reserve agencies,
- An interview with a band councilor,
- An interview with a therapist,
- An interview with a foster parent of children with special needs,
- A community focus group with nine individuals and with representation from the child and family agency staff and community members with special needs children, and
- An interview with a school principal and school social worker.

5. Site E

The First Nations child and family agency chosen for this community visit provides services to a large number of reserves and covers a large geographical area. Interviews and focus groups were arranged in two separate communities:

- A focus group comprised of nine First Nations child and family agency supervisors and directors,
- An interview with two foster parents,
- An interview with two community health personnel,
- An interview with a children's therapist,
- A focus group with nine First Nations child and family agency front line workers,
- An interview with 2 foster parents, and
- A telephone interview with a parent with a special needs child.

Results

Themes that emerged from the analysis of data in Phase 2 of the study can be organized into 6 primary categories: (a) view of disability, (b) community context, (c) unmet needs of children with disabilities, (d) barriers to meeting needs, (e) strengths within communities, and (f) need for action.

View of Disability in Aboriginal Communities

Awareness of disability in the community. Participants in the study vary in their knowledge of, and experience with, people with disabilities. Some participants reported a lack of awareness of disability in the community. Others indicated that they had little awareness of, or experience with, disability. For example, according to one elder in a community:

> *When I was bringing up my children, I never… when I was at home all the time caring for my children, but I never noticed any disabled children.*

There appears to be more awareness of physical disabilities or disabilities resulting in complex medical needs. Other types of disability, especially "invisible" disabilities, are less recognized and understood.

> *As I see it from my point of view and when you say special needs I think the perception that's allowed here by the community members is when you say special needs, it's a health issue. Which it's more than a health issue. So I think you need to address some of these areas. You need to educate the community or the general public that it's not only a health issue, it's more than a health issue.*
>
> *I've heard comments such as, uhm, "They're scared of my kid". Uh, it's a lot of fear, and the fear comes with the unknown. They're not aware of the conditions and they're not… so they'd be scared even to babysit…. But I do know there is a lack of awareness. The whole community.*

Learning and behavioural disabilities as a meaningful distinction. While a specific focus of the research was on learning and/or behavioural disabilities among Aboriginal children, it soon became apparent that focusing on this group of disabilities was too narrow for many of the participants. The term "learning and/or behavioural disabilities" was not familiar to all participants. It seemed to resonate more with school personnel than with child welfare staff or other community members. Given the definition of disability held by participants, while

still examining learning and/or behavioural disabilities, discussion often extended to a broader range of disabilities. Discussion included, for example, concerns related to physical disabilities and children with complex medical needs. The needs related to specific types of disabilities such as fetal alcohol spectrum disorder were also discussed. A variety of specific behavioural concerns were identified as disabilities including, for example, suicidal behaviour, oppositional and aggressive behaviour, and attachment disorder. Participants acknowledged that disabilities can be readily apparent or more difficult to identify.

> *We sort of have these two groups, one with very visible disabilities, you know. We know that something is wrong and you know there's a specific cause. There's also a group of kids where you think by all accounts these kids should be doing okay, but they're really struggling in school and acting out.*

The lack of focus on learning and/or behavioural disabilities is perhaps not surprising given the challenges that participants reported their communities had in addressing the needs of children with disabilities. In some communities, for example, agencies are struggling to provide for the basic needs of children with physical disabilities.

> *I find it very hard for the special needs kids that are in wheelchairs to get around, cause I have this other young lady that's in a wheelchair that I work with and it's very hard for her to get around. Cause of the lack of transportation I guess, cause if we were to arrange transportation for her it would be, it would have to be with [the school division] cause they have a special van there to transport children in wheelchairs.*

Some members expressed concern about the high number of children with complex medical needs in their communities, noting that these children require many supports in order to be able to stay in their communities. Responsibility for meeting these needs often rests with the child welfare agency, which struggles to find the resources to meet those needs.

> *We have over twenty plus kids that we have identified that are special needs or medically challenged kids. We have that in a graph. It's a high percentage. So why is it that we're like that?*

> *The plight of families caring for children with disabilities or lifelong complex medical need had to be addressed. And this gap in service provision in this particular area, particularly in First Nations communities has become a major social issue. Most families have*

been forced to move from their community to urban centres where services are available and accessible. For those families who remain on the reserve they endure a hefty emotional and health toll by caring for their child or children by themselves without any adequate supports.

Attitudes toward disability. While exploring participants' definitions of disability, participants talked about their perceptions of attitudes towards disability within their communities. Some participants identified a traditional view of disability. This view includes seeing disability as a gift, with individuals with disabilities perceived as being special. Some members clearly identify with this view.

I read one time that children that were born different were treated as very, very special, extremely special. They were gifted. And I think that perception still exists today.

Because children born with disabilities was a rare thing and, if it did happen they were looked at as gifts from God. And were treated as such.

Let's put it this way: special needs is a white term. That's your term. Special needs, if I remember correctly, are taken care of our own way, our own herbal medicines whether they worked fully or not.

As I've understood it, any child that was born into a First Nations family you just always accept them no matter what, how they come at you. That's just their way and they'll develop into their own person.

I don't want people to see him as abnormal. I want them just, like, want them to accept him as much as I do, and I know that's the difficulty we really all face. It's like, because what is normal? And like, I think in our communities, I think my ideal First Nation ideation is that we are loving and accepting of our children in that manner, and that we embrace the differences. Because we believe the creator has gifted every child from birth, from the time of creating them in the womb, so, you know, I embrace that.

While this view contributes to valuing and respecting people with disabilities, in the view of one participant, it can also affect the way that the need for services is perceived.

But native people have the opposite view of their children that are born different. And I think, uh, even today that perception still exists

> *with, uh, within society that, uh, these people shouldn't be providing*
> *a service. You shouldn't provide the services for them, you know.*
> *That perception is still strong in a lot of people's minds.*

Some participants perceived a shift away from the traditional view of disability and the respect shown towards people with disabilities, and the negative consequences that have resulted.

> *And I think too a long time ago kids were taught to respect*
> *everything and everybody. And you don't see that now. So you see a*
> *lot of kids when they see something different about somebody they*
> *tend to say something because they haven't really been taught to*
> *respect anyone anymore.*

Some participants had experiences in which they saw people with disabilities receiving negative treatment by community members.

> *Well I remember my grandparents raising, um, a child with, um,*
> *special needs, with a disability. And, uh, I don't know how … it*
> *wasn't, um, something that was accepted readily. You know, um, and*
> *he certainly wasn't accepted readily. You know what I mean? So it*
> *was, uh, you know, the sense of devaluation. You know, he was*
> *devalued in his time. And, um, I often think about that. He's still*
> *alive. He's an adult now and, um, but he certainly was devalued by*
> *the community, you know, in the sense where ridiculed I guess. But*
> *not in a way I think that was intended to hurt him. I think it was just*
> *a way that Aboriginal people cope with things they don't fully*
> *understand.*

The issue of labeling children with a disability emerged, and with it different opinions about the value of identifying disability. Some participants raised concerns about the effects of labeling and the potential for a disability label to be inappropriately applied to Aboriginal children. Participants noted that, in some cases, parents in the community are fearful of having their children labeled as having a disability. They fear that the label will have negative consequences for the child. Some parents fear being blamed for the disability. This seems to be especially the case in a diagnosis of fetal alcohol spectrum disorder where parents fear that the diagnosis comes with the implication that they are the cause of the disability.

> *People have this idea that labeling stigmatizes kids and makes other*
> *people look down on them or treat them with contempt or whatever.*
> *And that's what they're afraid of when they're labeling.*

And even if we know of a family that has a child with a disability we can't approach them and say well these are the services we offer, come and apply… Well, some people might get offended, you know… If someone came up to me and said [name] we're offering these types of services and I'll look at them "Are you saying my child's disabled?" Like, get out of here, you're not going to come and tell me this. You know? That's how I would see somebody reacting if I were to go up to them. So it's a very sensitive, uhm, issue I think to approach people in that way.

Something else that I've come across is in regards to labeling and getting assessment done, is parents' fears around taking the child to have an assessment done and that child being labeled.

A lot of women came into the program [targeting substance abuse among pregnant women]. We had a very large number of referrals… And they did come through the program but when they did, they started going through a stigmatization, you know, and labeling and stuff like that. So they started dropping out of the program.

Some participants stated that there needs to be caution specifically around labeling children with learning disabilities. There is fear that many Aboriginal children may be labeled as having a learning disability when the difficulties may be more of a reflection of factors external to the child (e.g., unstable family situations, the failure of having basic needs met) than of a deficit on the part of an individual child.

The Community Context

In discussing disability and the communities' responses to the needs of children with disabilities and their families, it is clear that the issue of childhood disability cannot be easily separated from other social issues within the communities. Participants identified a number of issues they see as related to childhood disability including self-governance issues, poverty, the effects of residential schools, family violence, child abuse history, fear of child welfare, lack of economic opportunities, lack of recreational facilities, increase of drugs on reserve, overcrowding, lack of housing, parents with disabilities raising children with disabilities, and teen pregnancy.

I think too the overcrowding certainly adds to behaviour [problems] because there's no place to be. I think a lot of kids tend to be looked after by other children. We also have whole generation, second

generation, third generation, in some cases now, of fetal alcohol effect and [adults with] disabilities raising children [who] are also affected. That's huge. Definitely the overcrowding. The last six, eight months crack has moved into the community with a vengeance and I'm seeing eleven year olds, they're on crack. And younger and younger kids getting pregnant. I don't know what the rate of teen pregnancy is in this community, but I think it's pretty high.

What we must take into consideration in a lot of, uh, reserve communities is that unemployment is very high. The cost of living is high too. Something like buying pampers [for a child with a disability] could mean not eating for a week. That's what some people have to decide. So that's another reality that has to be taken into consideration is, uh, a lot of these families are on social assistance. And they just cannot make ends meet, you know.

Cocaine's on the rise in our community. Like we've had marijuana use, which now is just like smoking a cigarette to everybody, you know, it's not as bad as cocaine and rock. I know that rock has hit our community and we are having to deal with a lot of families that are on this. It's affecting the children.

I think that the whole drug, gang, criminal activity has gone up definitely since I've been coming in… But that definitely has a huge impact on the kids, especially the kids with behaviour problems because it's the "cool" thing. I was working with an eight year old the other day who's saving up to buy a gun. And silly me, I said, "Oh, you're going to go hunting?" He says, "No, I'm going to rob people."

And you can factor in also the housing situations and the poverty and the lack of jobs. Kind of the overall health of the community in a way and the mental well-being of the community. There's a long way to go cause if you have, uh, your adults in the community that are unhealthy and not doing well and, uh, there's, you know, sad stories for the kids, right?... I would have to say that the number one issue for the reserve is alcohol. Not that other factors are lesser, but alcohol is the problem that has a trickle effect…

I believe children have difficulties in learning because of FAS. It is hard for children to study when you are living in a crowded home. The lack of housing and overcrowding has a direct relation to poor learning ability. In this community we have a growing drug problem I sometimes see that at school, at the grade five and six level. This is

sad. I want to see something done.

These issues affect the community at large, the work of the child welfare agency, and families with children with disabilities. In some cases these issues are directly related to disability (e.g., increased substance abuse affecting the number of children diagnosed with FASD, poverty affecting the resources that families have to address disability-related needs). In a less direct way, these social issues affect the resources available to address needs related to disability. These issues all demand a response from the community and have implications for the child welfare agency. Participants pointed out that the social reality of their communities, which includes a complex range of social issues, must be understood because it creates the context in which disability-related needs are defined and prioritized.

In understanding the community context, it is important to acknowledge that child welfare agencies do not necessarily service only one community. Some large agencies serve numerous communities, each with its own culture and practices. Even within one community there may be different subgroups. For example, some communities have divisions based on the extent to which community members identify with traditional cultural beliefs and practices.

> *Every community, even parts of the community, is very different. You have to learn really fast. Have to be respectful. How to respond. And, uh, you have to know your resources, whatever's in that community.*

The location of a particular community is also important in understanding the context in which communities respond to the needs of children with disabilities. Proximity to larger centers appears to impact considerably on the services that can be accessed. Those communities that are close to urban centers have greater access to off-reserve services such as assessment services, services offered by not-for-profit agencies, and specialized intervention services. Remote communities have more limited contact with off-reserve service providers and are more limited in the extent to which they can partner with other services providers to meet the needs of the people in their communities. Members of these communities cannot access off-reserve resources unless they leave their communities.

There are also differences among First Nations child welfare agencies in their experience with being responsible for children with disabilities. Some agencies are early in the process of having responsibility for children with disabilities transferred from provincial authorities to the First Nations agency. Other agencies have been mandated for a longer period of time and have more extensive

experience, not only with child protection, but also with working with children with disabilities and their families.

These differences within and across communities are significant and must be understood in order to develop and deliver effective programs and services.

Unmet Needs of Children with Disabilities and Their Families

Participants are keenly aware of gaps in services for children with disability in their communities. These gaps include:

(a)   lack of support for families caring for children. This support includes tangible support (e.g., respite, financial assistance) and emotional support (e.g., parent support groups). The lack of support makes it extremely difficult for some families to cope with the demands of raising a child with disabilities. Family supports are seen as an important factor that contributes to keeping children out of care.

> *What happens is systemically when the parents aren't getting the support they need, it gets worse for the children and then it gets worse for them. We get the cycle going. Very often kids are put into voluntary placement simply to access services and that's really sad, you know.*

> *I think it's important that while the child with the special needs is the focus, that you can't forget about the family members or community members that are supporting the family and the child. I think it's important that they have a safe place to go to where they feel it's not judgmental, where they feel welcome to come and be honest about the things that are happening at home, to try and ensure that placement breakdown doesn't happen. And I don't know that we have a place like that actually here in [the community]. I think that's one of the, one of the big huge gaps in the service.*

The issue of family support extends to foster parents who often appear to have minimal access to support.

The importance of having these supports available within the Aboriginal community is important (even for those families who are able to access similar services offered within non-Aboriginal communities).

> *Yeah, support's really important… It's important to have that support from other parents cause the struggles, especially, uhm, I*

think it may be for women too because we carry the child, there's that little bit of blame on our part for the things that we may or may not have done during pregnancy, or things like that, you know, kinda comes back in your head and you think, oh, I shouldn't have done that or you know, you, there's a lot of blaming going on. It's important to have support... I think that I could go to an Aboriginal [parents support] group but I don't want to go outside, into a non-Aboriginal group sort of thing, and I guess maybe that's what I'm waiting for.

(b)   a lack of education and training for parents and foster parents in how to deal with the behaviour associated with learning and/or behavioural disabilities.

So we need some very special foster homes here, that are ready to take in these kids with physical disabilities or, you know, cognitive problems, especially when they have these... for instance, maybe an autistic child. The foster parent would have to be trained, informed about what that is.

They already have here a huge shortage of good First Nations foster homes period. I guess that's pretty much across Canada an issue. Imagine putting a child with very special needs into that home. Those parents need additional training, additional resources to support that child, to help that child exist in the home and feel some accomplishment.

(c)   lack of community-based services that extend beyond the educational system. Although school-based services may be very helpful, often they do not extend beyond the school. Some participants noted that the services are not accessible to the children who, for a variety of reasons, are not in school. Ironically, these children, who may be in most need of services, are not able to access school-based support services.

So the school does an awful lot. But it's outside of school where the problems are.

Don't assume that school age kids are necessarily being identified more because what percent of kids go to school? Of if they do, what percent are going regularly?... A lot of kids that we see, or I should say, many of the children I see, especially those over the age of 9, 10, they aren't necessarily in school because of behavioural issues, learning problems. Parents aren't able to get them there.

(d)   lack of recreational activities in the community that children with disabilities can access either because appropriate recreational activities do not exist or because there are insufficient supports to promote integration of children with disabilities in existing programs.

There has never been any kind of programs offered just for kids with disabilities, like arts and crafts, little activities like therapy programs, physical programs, you know, like there's lack of funding especially in the area of recreation... We put a worker at the youth centre to have all of these activities, but we don't have anyone there to do one to one work with a child with various physical disabilities that come in and do hands on activities.

(e)   lack of early diagnosis and intervention services.

Like that's really needed... more up-front when the kids are born, being able to do more healthy start things with the parents, more groups for the parents, peer run. You still need a professional or somebody else to give them support.

(f)   lack of resources to assess needs and follow through with recommendations that emerge from assessment. In some communities there is little access to assessment. In other communities there are few support services available to implement the plans recommended in the assessment. In other communities the support services available are not sufficient to meet the demand for the services.

There's a struggle just around the availability of services starting with assessments being able to, the children being able to access appropriate assessment, you know, to diagnose what the issue is. I mean that's a challenge. There's, once it's identified, to be able to offer regular and frequent services, whether it's OT, speech, psychology. I think the community relative to other communities does fairly well, but as you can see, there's huge gaps in terms of frequency and intensity of service.

Assessment is a huge [issue]. It's such a panic about assessment of the children... There's some [assessment resources], but it's overly backlogged...the schools, if they have the time and the resources to do it, like we [the child welfare agency] don't do assessments on children, we don't... If you don't get the label you don't get the service, you don't get the funds.

I would like to have more time for complete assessments instead of

just screening and follow-through service [so] the children can get their needs met. The physio, the OT, the speech, the psychology.

(g)   lack of access to professionals with specific skills to provide supportive services (e.g., speech therapists, physiotherapists, psychologists).

There's some kids that fall through the cracks, because they're not able to access like speech and language services. They're not able to access the occupational therapist. We have an occupational therapist [waiting list] this long because for many reasons because they wouldn't come to our school every two, three months. And when they cancel a trip that's six months. You know, that's almost a full school year because it's ten months. So a lot of kids don't ever get seen in their school year.

Another thing that would be nice with the number of children we have in care and the number of special needs children is to have a psychologist or some sort of clinician on staff full-time. That could help give input in our case management for these children, because we're not getting the services out there... and all the children we being in [care], if we go through this to do that, we still have to take them [out of the community]. There are no services here for them.

And sometimes it is very difficult to get an appointment with some of the professionals that come here to [the community] at the clinic, cause they're so full and backlogged. I found that very hard, even with the doctors that comes and prescribes Ritalin for my child. He comes in, I don't know, once ever 3 to 4 months and presecribes medication to last him for half a year...They [the professionals] don't really have the time to really focus on a child, cause that's what I noticed with my son and just a 5 minute checkover, you know, I didn't like that. Just looked at my son, asked a few questions, and goodbye.

(h)   lack of services for youth when they reach adulthood (i.e., 18 or 21, depending of whether or not they are in school). There is a recognition that many of the services that children receive are accessed through the school system. Once the youth leaves school there is little available in communities to support the youth and facilitate ongoing involvement and integration within the community.

That whole area of once a child leaves school, whether they're sixteen or eighteen or twenty-one, there has to be something in the community that takes over the role of the school in making sure that

kids with handicaps and disabilities are able to participate in the community still.

(i)   lack of training for professional and paraprofessional staff who provide support services.

If we had money to train people to provide the support services, that's an area that thinking with the interveners and the home support workers and stuff, there isn't a whole lot of training for them, if any.

So even medically we're at a disadvantage because our medical staff, uhm, would need specialized training, right, to accommodate all these people [with complex medical needs].

(j)   lack of coordination among existing service providers. This coordination can be a challenge in part because many of the professionals do not live in the community. In some communities it appears that there is a need for greater networking and collaboration among services on reserve in order to maximize the services that they can offer. Funding and jurisdictional issues appear to interfere with collaboration and cooperation.

There's not necessarily good coordination or follow-through, not because of lack of will, just being in a northern community and having people fly in and the doctors who do great work here aren't here all the time. They fly in.

I think there are a number of resources and natural ones, and there's a lot of churches in the community. There are respected elders and natural healers. I do not think there's a level of communication and discussion amongst these groups to begin to identify the problems and to work together on offering services both in terms of crisis prevention and being proactive. In other words, there isn't a coordinated effort occurring. I think that's the starting point – dialogue.

There seems to be for whatever reasons such a huge level of distrust. I'm not sure what would need to happen for that to dissipate before people would come to the table and actually talk about what they're doing… the ultimate wish would be trust within the community to work together more.

There's many agencies trying to get involved and there's conflict between agencies because of the funding and what not. I think that

> *the government of Canada needs to look at how they fund First Nations. They break up the funding in all these different groups and they all have their administrations and when it comes to front line, they're in poverty.*

> *One of the things that could help too is part of our fault, too, is maybe there's not enough coordination or communication between schools, social workers and band level, other parents and, like, maybe we need to coordinate a bit more because we do have some discretionary funds...*

Some participants noted a need for greater collaboration across the country so that First Nations communities could have a better sense of what other communities in other provinces are doing to meet the needs of children with disabilities.

> *I'd like to see more Aboriginal unity across Canada creating a network of people just so there is more involvement with each other, everybody has an understanding of what is happening in each province, each band.*

(k)   lack of foster homes for children with special needs. One worker, for example, explained that they have no foster homes in the community that are wheelchair accessible. If a child in a wheelchair came into care that child would have to be removed from the community. Other workers pointed out the specific challenges of having foster homes that are willing to take children with learning or behavioural disabilities.

> *If we were able to apprehend that child in a wheelchair, where would we put that child? Cause there's no homes in the community that are, where they could take this child in. They're not accessible, like the washroom would have to be renovated, hallways, things like that. If they were to do that, they would have to send these children out of the community... There's no homes that are renovated to meet their needs, like special devices, wheelchair ramps, special washrooms.*

> *We do have a high population of special needs in care with the permanent care unit. These are crown wards that we have until they're 18. It is very disheartening to put children in a hotel room, uhm, having to send out videos to different agencies begging them for placements, calling the child advocate, looking for placements, because there's just nothing out there.*

> *So we need some very special foster homes here, that are ready to*

take in these kids with physical disabilities or, you know, cognitive problems, especially when they have these…for instance maybe an autistic child. The foster parent would have to be trained, informed about what that is.

I find it's very difficult in a community to find foster homes for teenagers if they're threatening to hurt themselves, it's very hard.

Barriers to Meeting Needs

Participants strongly expressed how communities in general, and the child welfare agencies in particular, are seriously limited in how they can respond to the needs of children with disabilities because of the lack of resources. It is clear that in all communities the need for services far exceeds the resources that are available.

So the reality is there's a lot of kids and families with needs and certainly not enough services and certainly not enough services at the right time.

We go through the child advocate to explain the case and from there we go to case resolution and from there we go to [program name] which is the inter-provincial ministerial committee and we get the same answer back – "There's nothing more that we can offer you." You're doing what you can and there's no services out there for these children. And it's very frustrating sometimes.

Participants do not perceive governments and funding bodies to be understanding of, or responsive to, the needs of children with disabilities.

I wish that, uh, that we had at least government agencies [that] would look at our proposals that we give them for funding, that they meet the need, our needs, not what their policies or funding authorities dictate. I think that's where people that are doing this kind of research need to get that message back to the funding agencies that they be more of a human touch toward people, not just policy, you know, driven by policy.

Then when I submit the special ed report I am told by INAC that they don't accept that because it's attendance problems. And I said, "I'll tell you what...". INAC changes stuff to try to save money and not look at the problem.

It's easy for Health Canada to say, well we don't have a problem.

> *We don't have that many children. It's cause it's never been identified. But they conclude we don't need the funding cause there's no numbers. Well if you don't generate the numbers cause you don't put any assessments in the communities, it's pretty easy to justify the expenditures... But it is that kind of thinking that is a big frustration for the parents and caregivers of these children.*

There appears to be variability in the extent to which local bands place a priority on supporting children and families. For example, in one community, the band has given funding for a project that provides support services to children with disabilities and their families. In another community a parent expressed the wish that community leaders more clearly communicate that children and families are valued:

> *I think they [the chief and council] can go even further in regards to values of children and families. Because I know it's our culture that the children have always been really highly valued, but modern times our philosophies from leadership on down don't reflect that. They don't reflect an emphasis on children and families, and I think that's something that needs to be built in...*

Participants clearly articulated a major dilemma that directly affects the services and supports that they can provide: no one wants to take responsibility for funding supports for children with disabilities. Ongoing jurisdictional arguments around the responsibility for providing disability services are a major impediment to securing resources and providing support to these children and their families.

> *I am not really ok with it. We have to go into our [community] monies to provide services that government agencies should be responsible for... Why do we have to go to our resources to provide a program [for children with disabilities] like that? It should be there from governments to provide that service. They could build and provide it like in an urban centre... Because we're federal, responsibility would be federal. But then again, the province as well should take into account... but they always have a jurisdictional BS, the boundary line, you know.*

> *So responsibility of [the child welfare agency] would be a provincial, but medical services, as we all know, is federal. All of a sudden... already when our agency becomes involved it becomes a provincial responsibility. This is where it get real frustrating cause, uh, we should, uh, try and work as a team in providing service to the client but it's not happening. It becomes very difficult to get the family the service that they require. And it becomes a big hassle.*

> *Somebody else is responsible... And it shouldn't occur because we're supposed to be helping the people in our community but what we see is these jurisdictional issues instead of providing what the people require.*

Some concern was expressed about the transferring of responsibility for children with disabilities to local First Nations governments when the amount of funding being transferred cannot meet the needs within the community.

> *We are in a period where increasingly feds are transferring authority and transferring funding, you know, to more local self-government kinds of agencies... but part of the transfer in health dollars has also been dramatic decreases in the amount of money being transferred. That's the reality too, so. And that concerns me when we're talking about special needs children because they're going to come with a price tag... Ottawa seems to want to kind of download right now.*

Many community members, including some staff of child welfare agencies, are unclear about the complex ways in which their agencies and services are funded. The policy context in which these services are delivered is not uniformly understood by community members. While the details of the funding are not always clear, participants are painfully aware of the ways in which the funding is inadequate.

Child welfare agencies, in particular, can be caught between working within the constraints creating by their funding structure and meeting the expressed needs of community members. Strained relationships between the child welfare agency and the community can result.

> *What I see is that it [the child welfare agency] is not what [it] was designed for. It's supposed to be Native run but it is run by senior officials in Ottawa.*

> *Child welfare is one area where Native people should have control. [The child welfare agency] is another CAS. They are very bureaucratic. Having some Native people working there doesn't make any difference.*

Child welfare agencies find themselves in the position of being asked for support services but being limited in what they can provide. Agencies appear to struggle with balancing their child protection mandate with requests to provide support to

families with children with disabilities.

> *I'm aware the agency has to watch their dollars and limit, I guess, in a way, some of the services provided to families. Cause we were told to I guess watch how we assess families when it comes to family service plans*

> *Most of these families [with children with complex medical needs] had turned to the local child welfare agency for support only to be rejected because the mandate of the welfare agency is child protection. Statistics indicated that approximately 22 families had applied for services within the [child welfare] agency and they had to be turned away because there was no provision in the funding to accommodate them right now.*

In some communities, the only way to access resources to support a child with disabilities is for that child to come into care. In many communities there are few, if any, voluntary, community-based support services available to children with disabilities and their families. The way in which many child welfare agencies are funded requires the child to be in care before any resources for that child can be secured. Because of the lack of supports, some parents are not able to continue caring for the child. This is extremely difficult for the child, the parents, and child welfare staff.

> *If you're a multi-handicapped child coming from a home, your own home, so you're not in care or you've been adopted and you're not connected with the [child welfare] agency anymore then there's really nothing and if you're not treaty it's even worse.*

> *I felt like we had to take kids into care to provide services for. Not just for people who are disabled, medically complex needs but also social needs, like, uh, for treatment and all that.*

> *The only way they can provide services is if I had a child apprehended or maybe put under voluntary placement agreement. And that's the only way I would be able to access services.*

> *I don't know if it is written policy but when we have children that come into care with a complex medical need, they invite partners to the table to negotiate who's going to pay for what. And it's more or less forcing agencies, forcing parents to sign their kids over in order to access this, that. Like I feel really bad about that. It's almost like the residential school system where our parents were forced to give their children up just so they can access the service. It still happens.*

If we were able to re-look at the funding formula, you know, so we can pull resources into the family to work with the family to keep the child there. I mean our current funding formula, you know, doesn't kick in until we do an investigation and the child comes into care.

Your child shouldn't be brought into care because of their special needs, but we haven't got the same type of resources up here that they have in other parts of the province to meet those kids' needs. So they do have to come to [the child welfare agency] in order to get served.

The only way that [the child welfare agency] can ideally bring in the child for assessment is if the child's in care... We had one where we had to bring the child in care just to get an assessment done, which doesn't make sense.

The issue that the governments need to look at, why will they pay a foster parent and not the parents? Why will they pay a foster parent the needs for the child and not the parent? Like something's wrong here. Drastically wrong. And you know, there's this whole trust issue comes to the forefront and that issue has to be dealt with as far as I can see, the political machine that we have here is totally out of touch with what actually goes on the front lines. You know, it would cost about $1,000 a day to have a child in [a hospital] with all the staff and the social workers and the specialists and what not. The kid comes home, [and the family gets] nothing, not even diapers.

They don't have any resources to work with. I think that even, and I think this is the only option they have is [the child welfare agency]. Because lots of time, you know, when you bring children into care, like I always tell them, "I don't like bringing children into care or prefer taking them away or sending them off for treatment." It's a long ways for them to be away from home. I understand because I went through the residential school system and I know how it feels especially if you're away from your home, parents.

I think also the parents are disempowered, huge to think you have a special needs child, and you want the best for that child and yet are incapable. Yes we are incapable because the funding isn't there and so you have to give a child to somebody else to look after... The parent feels inadequate. The child is taken out of the home. The child doesn't feel good. The whole family's affected because they have a failure, right, and that permeates the whole community.

Given this situation, it is understandable that families are reluctant to approach the child welfare agency for support. They fear being seen as incompetent parents requiring child welfare involvement.

> *There is a stigma attached to that [the child welfare agency] and a lot of families although happy to receive the services, didn't really want that connection with [the child welfare agency], uhm, didn't want to be labeled as incompetent parent or something along those lines... There's still people out in the community that are unaware of our project and the last intake I did the family was under the impression and totally believe that once we opened a file on them it was going to be a family services file, and that they would be then showing up in the system. They were concerned about that.*

> *I think that there's a feeling of helplessness that the parents may experience. Uhm, there's the stigma as well that's attached to being involved with the child protection agency. Where they have no where to turn but to a child protection agency for service, even in spite of their best efforts to work with their child, but there's the stigma I guess, you know, because the communities are smaller, remote communities, so when something like this happens, you know, it gets around that so and so may be involved with [the child welfare agency]. And, but it's because they're trying to do what's best for the child, so there's that piece I guess and along with it then, you know, the feeling of guilt... I guess the bottom line is that this child needed some types of supports that they weren't able to access them.*

In some communities, the inability of the child welfare agency to meet the needs of children with disabilities and their families has led the agency and community partners to seek outside funding for support programs. Such projects allow children with disabilities and their families to access services without the children coming into care. These services are offered as projects; relying on project funding (as opposed to secure, ongoing funding), however, is problematic. Such projects are always vulnerable.

> *So, you have a grant and it's six months. You've got a person in there and they sort of start to set things up where they do a survey and find out how many kids there are out there between the ages of sixteen and twenty-one that have handicaps or that have disabilities of whatever variety and they get a list and everybody goes "Oh my God, that much? We have to do something for these people and then the grant's over and it just kind of disappears."*

> *When we started the program and when we thought about training the service providers, we knew that we weren't gong to be... I shouldn't say that. We knew that there was a possibility that we won't be around by 2007... And so we don't want to leave them [the children and families] with nothing.*

> *I don't know what happened to the program this year but apparently [the school division] had cut it out of their budget but I think the community was picking that one up again. Again, you see, everything is being cut away from us slowly but we always manage to squeeze it out of some other program in the community.*

The lack of resources has meant that some support programs, in order to contain costs, have to limit the services they provide. These program decisions are driven by financial considerations, not by need.

> *One thing you may have noticed when we're breaking down the various disabilities, uhm, one area that we didn't have was fetal alcohol... If we were to, uhm, open our doors to children that, uh, have specifically only fetal alcohol syndrome we wouldn't be able to handle the numbers.*

In some cases, it has been impossible to restrict services because of pressure from community members to have access to those services. For example, one child welfare agency developed a program that taught traditional activities to children who were not functioning in school. This program was perceived so positively by the community that the agency was pressured to allow children not in care to participate. While a sign of success, finding the resources to fund such programs is challenging.

> *We have to go beyond the kids in care because what's going to happen is the other ones will end up wanting to come into care because of this, and cause that issue there. And there would be an issue, like you know, parents coming up to us, "Well why can't my kid go into your program". You know, they're always questioning that because it would always have to be kids in care. So we make it open to our service, our family service files too.*

Due to the lack of resources, agency staff and other professionals often find themselves responding to crises. They recognize the importance of moving beyond a crisis orientation in order to address the broader issues but are constrained by the imbalance between current demands and existing resources.

> *As long as we're working in crisis all the time, nothing can… You're putting out the fire but everything's burnt.*
>
> *You know, if you can get through a crisis and you're intact and you're not dead, you're not crying every day, you know you've made it, but then you never get to deal with some of the longer-term underlying problems.*

Such a situation can be very stressful for program staff.

> *It's just because the needs are so large and those who are helping out, it's really hard to say no… But there's just so much going into the problems right now, there's stuff that haven't been dealt with. So it does feel very weighty.*

Strengths in Aboriginal Communities

In the face of many challenges, some participants expressed hope and identified positive changes that are occurring.

> *There's also a lot of hope, and I see hope growing. I'm really, I want us not to lose sight of that. Yes there's a huge issue and yes there's a whole bunch of things that need to be done, but we're doing a lot. We're moving a lot.*
>
> *They're our kids and we're going to pay for it one way or another. I've worked in group treatment centres and in prisons, and who do you think end up there?… We know these children [with learning and behavioural disabilities] will be disproportionately represented in the institutions. If we can intervene with some private programs, and I feel that we can, Aboriginal agencies can. Aboriginal communities can and have got a really rich history of including special children. I think that can happen, but nobody has really highlighted the difficulty and the problems that need to be addressed.*

There exists among many of the participants in the research a strong sense of commitment to the issue and a resolve to see things happen so that children with disabilities have greater opportunities for integration and an improved quality of life. In some communities concerned people have come together to identify needs and work collectively on solutions. For example, in one community a group of professionals started meeting to discuss the issue of fetal alcohol syndrome. They were able to pool financial resources to begin providing services and are now

running a project that provides support to families, works on prevention, and is increasing public awareness.

> *The school division had a committee that was looking at students at risk. And one of the things that came at risk of failing in school, one of the things that came out of that was the whole alcohol thing and young, pregnant moms, and, uh, we looked at that and that's when we first heard the term Fetal Alcohol Syndrome. Like none of us really knew anything about it prior to that... the school division approached, uhm, the [child welfare] agency and the health division and the person at that time who was the director of the health division was very, very interested. So our superintendent of schools, our director of health division, and our director of the [child welfare] agency were the three key people who came together and from there was invited input from all of the agencies that had anything to do with it and that's how we started...There is still a strong core of people who are really committed to this.*

There emerges from the research examples of creative solutions to the challenges. In one community the child welfare agency, recognizing its inability to provide adequate support for families and children with disabilities, sought and received band funding to provide services to these children and their families. The services they are able to provide now include respite, in-home support services, occupational and speech therapy, counseling and advocacy, training and education, escort services, and the purchase of non-medical supplies.

> *So with this issue [of the agency's inability to provide support to children with disabilities] resting on shoulders of [the child welfare agency]... [the executive directors] decided to do something about it. With their hard work and dedication they made this project a reality...*

In another community efforts have been taken to make facilities wheelchair accessible and to hire extra workers so that children with disabilities can participate in community activities. They have also developed an after-school homework program to assist children with learning disabilities. Other communities have developed programs that provide cultural teaching for children and youth and integrate children with disabilities. In spite of limited resources, there are many examples of positive, creative programs directed at the needs within the communities.

Participants in one community noted that there has been a shift within their provincial government towards keeping children on reserve. Although it was

acknowledged that this was in part motivated by a desire to save money, it was also identified as a positive change.

Some participants pointed out that the social workers in their agency are a strength. Their community has emphasized training which they believe has strengthened the ability of the child welfare agency to address community concerns.

> *If I look at this community overall, there's some very exciting things that are happening. The amount of adults who are in the social work program.*

> *We have the highest percentage of native educated people working in this [child welfare] agency and that's because we push that.*

Need for Action

Some of the people working within Aboriginal child welfare agencies and within the communities expressed a sense of urgency and impatience for change that will improve the lives of children with disabilities.

> *The hard work that we're putting into trying to get things going, that's the biggest strength, and being patient, waiting, you know. But the patience is running out.*

Participants expressed different views on the role of research in this process. Some participants were eager to participate in this study and appreciated the opportunity to voice their concerns. They believe that this type of research will result in change. Other participants are more skeptical about research. While they see the role for research, they realize that research, by itself, is not enough; it needs to be used to promote change.

> *It seems like there's like research on Aboriginal communities and Aboriginal people. There like… we've been researched to the max probably. It's time to do something other than research. Like what do we do with our research, our findings? Like we know that there's kids out there… things need to happen. More action than reaction I guess.*

> *We need to try and put some resources in this area for the children. So I hope with the research you are doing that Health Canada will take a look at that.*

Participants are in agreement that there is a need for action.

VI. DISCUSSION, RECOMMENDATIONS AND CONCLUSION

Key themes and issues are evident in the analysis of Phase 1 and Phase 2 data. In the following section these themes and issues are discussed, highlighting some identified strengths of FNCFS agencies and communities, but in particular emphasizing significant challenges FNCFS agencies and communities face in order to meet the needs of Aboriginal children and youth with disabilities in care.

Defining Disability: Having a Common Definition

Findings show that there is great variability in the way in which disability is defined across the participating agencies and communities. This seems to be particularly true for disabilities that are sometimes referred to as "invisible". Children with physical challenges and those who have complex medical needs are easiest to identify as children with disabilities. There is much less consistency in identifying children whose needs are less visible (as is the case for many children with learning and/or behavioural disabilities). Notwithstanding the challenge of reaching a consensus regarding what constitutes learning and/or behavioural disabilities, it would appear that some effort at developing an inclusive definition of disability that acknowledges learning and behavioural issues is needed. Such a definition must be based on an integration of knowledge about disability as well as the cultural context, and must use language that is meaningful to people within Aboriginal agencies and communities.

The controversy around labeling children as "disabled" must be acknowledged. As noted by the participants, all children have traditionally been viewed as gifts from the Creator and accepted openly by their communities. The stigma attached to labeling often negates this value and some individuals in this study presented as acutely aware of the potential for misuse of negative labels to describe Aboriginal children. These concerns are important; the application of labels to children must be done cautiously, with a full appreciation of the context in which that child lives. Furthermore, care must be exercised so that no child is ever reduced to being understood within the confines of stereotypes that frequently accompany diagnostic labels. The uniqueness of each child, and his/her needs, can never be fully captured by a label.

While being fully mindful of these issues, there are some potential benefits to having greater consistency and clarity around the definition of disability: (a)

Clearer definitions of disability would assist child welfare agencies and communities in identifying children within their communities who might benefit from support. (b) Such a definition would be a starting point for staff training in childhood disabilities. (c) A broad, inclusive definition of disability could be used within Aboriginal communities as a framework for educating community members about disability, a need that some communities clearly identified. (d) Such a definition would provide "common language" for inter-agency, intra-governmental, and inter-governmental communication. (e) Clarity around definitions would also facilitate the collection of information about the level of need among children in Aboriginal communities. It would be extremely useful if agencies used similar information systems for identifying children with disabilities and tracking service provision. Developing a national database containing information on children with disabilities is critical for advocating for resources and for increasing awareness of the importance of the issue of childhood disability in Aboriginal communities. Such a database would contribute to building knowledge that would inform policymakers, service providers, community members, and families about the needs of children with learning and/or behavioural disabilities and how to support this group of children.

Jurisdictional Tension/Division and Funding

The existence of jurisdictional tensions and divisions between federal, provincial, and band governments results in an overall lack of leadership and responsibility for children and youth with disabilities. Research participants identified this jurisdictional issue as a fundamental problem affecting service planning and provision. It results in inadequate levels of funding, limited availability and access to support services (particularly culturally appropriate services), and inequity in service provision on- and off-reserve. The issue of funding was a reoccurring theme raised by research respondents. Nearly all participants viewed funding as problematic causing severe under-resourcing of agencies and communities resulting in limited abilities to meet the needs of children and youth with disabilities and their families.

The First Nations, provincial, and federal jurisdiction divisions result in a political service tension that causes problems for meeting the needs of children with disabilities. The federal government funds FNCFS agencies (on-reserve) through grants based on the number of days a child is in care that covers child maintenance costs for children and youth. There is generally no funding for support services to families and little flexibility in the way the funds are used. One consequence, as was clearly identified by participants in this study, is that children with disabilities are coming into care, at times being removed from the community, because it is the only way to access funding and services. This reflects inadequate policy regarding children with disabilities and a lack of

commitment to provide basic support services so that children can remain with their families. The inadequacy of funding also means that children and their families on-reserve do not receive support comparable to the standard of children off-reserve. This does not comply with Article 23 of the UN Convention on the Rights of the Child.

Adequate and flexible funding is also necessary to develop preventive and supportive programs and sustainable funding is necessary for long-term benefits. As previously noted in the Joint National Policy Review, the level of funding provided to FNCFS agencies is inadequate and as much as 22% lower (per child) than provincial funding (McDonald & Ladd, 2000). This results in a crisis response approach to service planning and delivery with little emphasis on prevention. A study of FNCFS agencies across Canada examining least disruptive measures in First Nations child welfare recommended changes to DIAND's funding system to include an equal prioritization on prevention as well as flexibility with funding and sustainability of funding (Shangreaux, 2004). This study suggests that such changes are needed to address the needs of children with disabilities in care and thus supports this recommendation.

Aboriginal advocates have stated the need for a comprehensive federal/provincial/territorial approach to policy and service provision for Aboriginal people with disabilities (Demas, no date). The findings of this study highlight the need for the establishment of a national agenda and associated policy and service delivery specifically for Aboriginal children with disabilities, both on- and off-reserve. This national agenda should be comprehensive in its coverage of children. For example, services should be provided based on the child's need, regardless of why a child is in care (e.g., due to maltreatment but with a disability). Special needs services should be available to any child whether in alternate care or residing with family. The federal government should take a primary lead in setting a national policy agenda and funding primary, secondary, and tertiary levels of prevention related to disability. Provincial policy should be integrated within a national framework and provincial services should be available and accessible to children on reserve. Inter- and intra-provincial divisions and departments should have joint policy and practice which identify primary responsibility, and support an integrated approach to service provision (public health, primary health, education, rehabilitation, child welfare). Currently, health, education, and social services do not systematically coordinate services for children and youth with disabilities and their families. Disputes over funding occur between divisions and within departments as to who is responsible for funding a child with a disability in alternate care.

Findings also suggest that band council responsibility and leadership can impact on the ability of the child welfare agencies and other service providers to meet the

needs of children with disabilities. Some bands are reported to be extremely supportive of efforts to enhance services to children with disabilities and their families and have committed funds to new initiatives targeting this group of children. Some participants, however, noted that they did not perceive children with disabilities as being to be a high priority for their band councils. In some communities, increasing the awareness of the council to the issue of childhood disability may help to make services for children with disabilities a priority.

Lack of Support Services

The results of this study highlight the lack of support services that are available for children with disabilities and their families, including children with learning and/or behavioural disabilities. The services that are lacking include: (a) respite, (b) financial assistance for families caring for children with disabilities, (c) parent/foster parent training and support groups, (d) community-based therapeutic services (e.g., speech therapy, occupational therapy, physiotherapy, psychological services, child development counselors), (e) early diagnosis and intervention services, and (f) services for youth with disabilities when they reach adulthood.

The lack of support services available in the community has serious repercussions. For example, respondents identified that children with disabilities are placed in agency care due to a lack of support services in the community. This finding is consistent with other Canadian findings. The Canadian Association of Community Care (1995) found that a lack of respite and other child care services were cited by parents as the reason for alternate care by 50% of parents. There is also the concern that short-term cost savings result in longer term expenses. For example, families with few or no support services may rely on the state to care for their child:

> The stresses of multiple responsibilities, lack of adequate support, and the juggling of multiple roles take a toll on many families. In some cases, insufficient support may lead to the placement of a child in a residential setting or foster care which greatly increases the cost to society. (Hanvey, 2002, p. 13)

No child should have to be placed in care (surrender guardianship or under Voluntary Placement Agreement) in order to receive disability services. Some children may require institutional care due to their medical needs, however the parent(s) should not be expected to surrender guardianship.

While Aboriginal people have made substantial progress in pursuing education and training, there remains a great need in this area. Participants stated their

desire to have their community members educated and trained in various professions

such as psychology, occupational therapy, physiotherapy, and speech therapy. Ongoing education and training is a crucial ingredient for capacity building in Aboriginal communities and should be supported by all levels of government, federal, provincial, band, as well as by educational and training institutions.

Voluntary Sector Involvement

The analysis of the data presents an image of reserve communities as isolated from outside sources of support. Data shows that collaborative service providers are limited in availability, difficult to access, and not culturally appropriate. FNCFS agencies located far from a metropolitan area experience particular difficulty accessing additional services. Most of the participating FNCFS agencies are the only community resource for families, regardless of the needs. They are not in a position to provide all of what is needed. For example, availability and accessibility of recreational facilities for children and youth with disabilities is one type of service considered lacking in the communities. Access to recreational activities is an issue that has been previously identified in the First Nations and Inuit Regional Health Surveys (First Nations Centre, 2004) and is clearly not a need that child welfare agencies can address by themselves.

This study indicates an overwhelming need to develop the voluntary sector's provision of services to reserve communities. The findings are consistent with other reports of the limited involvement of the voluntary sector in Aboriginal communities and extends this analysis to the area of childhood disability. Nadjiwan and Blackstock (2003), for example, note that the voluntary sector receives 90 billion dollars, and has an interest in meeting the needs on reserve. There is minimal evidence, however, of service delivery by the voluntary sector on reserves. As Shangreaux (2004) documents,

> The absence of this vital sector of supports places additional stress on the already inequitable resources provided by DIAND to First Nations child and family service agencies….they complement the range of social supports provided by child protection services agencies and other government programs for children. (p. 14)

Irvine (2004) has reviewed the implications of the lack of voluntary sector involvement with on-reserve communities and argues that without their involvement, community development and capacity building will be difficult and can be viewed as "communities in crisis" (p. 21). The author notes that FNCFS agencies are often the sole resource on reserve coping with high caseloads, under-funding, large geographic service areas, and few collaborative service providers. This results in a severely limited "range, level and scope of services that FNCFS agencies provide" (Irvine, 2004, p. 30). Governments

must actively support initiatives aimed at developing relations between the voluntary sector and FNCFS agencies and First Nations communities generally, particularly for children with disabilities. An example of unsupportive policy making was INAC's decision to cut the Alberta Canadian Paraplegic Association's budget for Aboriginal people with spinal cord injuries on reserve (Taillon, 2001).

Integrated Service Coordination

The study findings also indicate the need for comprehensive, coordinated, and integrated service delivery for children with disabilities and their families. The current care system for children with disabilities is fragmented and inequitable, with provincial and national differences in funding and service provision. At a community level, greater collaboration and coordination between service providers is seen as necessary to maximize the services that can be provided.

Challenges to service coordination for children with disabilities have been well documented. More than thirty years ago, the lack of coordinated services was identified as a problem for children with special needs by a national study (Commission on Emotional and Learning Disorders in Children (CELDIC), 1971). For example, of 144 recommendations "The multiplicity of unrelated services" was the "number one problem in providing assistance to children with emotional and learning disorders" (CELDIC, 1971, p. 294). The issue of service coordination has also been identified as an issue for Aboriginal people. In 1993 the federal Standing Committee on Human Rights and Disabled Persons argued that the needs of Aboriginal people were not being met due to fragmented and inconsistent service standards. Toubbeh (1989) notes the poor interdisciplinary coordination and lack of supportive agencies available to on-reserve residents:

> Obscure jurisdictional boundaries and absence of service coordination among responsible agencies constitute one of the major factors impeding the development of viable habilitation and rehabilitation programs in the majority of reservation and urban Indian communities. In the light of the high prevalence of chronic illness and disability in these populations, it may be assumed that the disabled Indian today is not receiving an equitable share of the benefits that are available to disabled citizens. (Toubbeh, 1989, p. 7)

Comprehensive services should focus on meeting all the needs of children and youth with disabilities and their families, regardless of their developmental stage. Coordinated services should reflect a collaborative approach to service delivery, and partnership between service providers and the family to ensure all assessed needs of children and youth with disabilities are met by at least one service

partner. This can also include sharing resources, developing joint protocols and planning, and providing combined training/education for staff and families.

Noting recommendations from the Children and Youth Homecare Network, Hanvey (2002) advocates for an integrated care system:

> Children and youth requiring care in their home and community experience the best results when services and supports are integrated at every level including the overall system level. Such a system needs to encompass formal and informal services and supports, flowing from institutions to home, school, day care, and back to institutions, when appropriate. (Hanvey, 2002, p. 21)

This system should follow the individual through all developmental milestones and provide adequate and comprehensive services, regardless of his/her age. This issue overlaps with the identified issue of jurisdiction divides between provincial/territorial, federal, and band responsibilities. Integrated services can help to bridge these divides to ensure that comprehensive services are provided to children and youth with disabilities. Hanvey notes that in order for community members to fully participate, services must be accessible to all:

> At its foundation, however, the notion of a supportive community environment must provide full access and participation for all children – including those with disabilities – as well as their parents and siblings. This means offering inclusive services such as child care, health, respite services, homecare, education and recreation – that enable all families to participate as full citizens. (Hanvey, 2002, p. 26)

Cultural Context and Approaches to Helping

The responses of participants in the study made it clear that it is difficult to separate the issue of childhood disability from other social issues within their communities. They identified many issues that they see as relevant to understanding childhood disability and how to improve the lives of these children and their families. These issues include, for example, poverty, the effects of residential schools, family violence, previous history with child welfare, lack of economic opportunities, lack of housing, and substance abuse. The community context must be central in the development of policies and practices for children with disabilities. Efforts to address these broader social issues will positively impact children with disabilities and their families.

Much has been written about the importance of understanding social issues in First Nations communities within a broad social and historical context. Timpson

(1995), for example, discusses the high rates of First Nations children in care, suicide, and domestic violence and argues that these issues relate to the loss of culture and that solutions will not be found on an individual case level, but rather on a community level:

> These conditions reflect generations of cultural and spiritual destruction. These problems are not individual problems requiring individual approaches. They affect entire communities and require community healing and the prevention of further intergenerational damage. Native agencies face the challenge of providing services that treat underlying causes by community healing. (Timpson, 1995)

Furthermore, the importance of cultural identity in human development has more recently been highlighted. According to the Human Development Report (United Nations, 2004),

> Human development requires more than health, education, a decent standard of living and political freedom. People's cultural identities must be recognized and accommodated by the state, and people must be free to express these identities without being discriminated against in other aspects of their lives. In short: cultural liberty is a human right and an important aspect of human development—and thus worthy of state action and attention. (p. 6)

Such a view implies that services for First Nations children must be provided in a way that supports their cultural identity and is culturally appropriate. The findings of this study suggest that the availability of culturally appropriate services for First Nations children and youth with disabilities is very limited, particularly with collaborative service providers. The minimal integration of Aboriginal approaches to helping children and youth with disabilities and their families suggests that cultural approaches should be incorporated not only within FNCFS agencies' operations and practices, but with other service providers. This is not a simple matter. Respondents in this study spoke of the diversity within their communities and the challenges that this presents to service providers. Within this context there is a need to recognize diversity in Aboriginal culture and avoid what Gross (1995) describes as a "politically correct" approach that can overgeneralize cultural characteristics and minimize individual differences.

Strengths

This study identified examples of how some communities and agencies have creatively developed program and projects to address the needs of children with disabilities in their communities. In spite of the challenges that they face, these

communities have developed solutions to meet some of the gaps in service. There exists among many of the participants a strong commitment to improving the lives

of children with disabilities and a desire to work with others within their communities to implement positive changes. This commitment, the ability to work collaboratively with other systems, and the support of the local band has resulted in innovative and successful projects. Participants described the support of families, which includes extended family members, and their community, as key strengths in supporting children with special needs. They also noted that the vast majority of the FNCFS workers are Aboriginal individuals who understand the issues and resources available in their communities. The capacity for further development of exemplary policy and practice clearly exists in these communities. They need to be supported in their efforts.

Conclusion

This report presents findings on FNCFS agencies' and communities' experiences with, and perceptions of, service planning and provision for children and youth with learning and/or behavioural disabilities. This study is an initial attempt to explore this topic area and contributes significantly to the literature as it presents data on which little research has been published. It contributes to our understanding of the issues and challenges faced by First Nations child welfare agencies and communities in meeting the needs of children with disabilities, and in particular, the needs of children with learning and/or behavioural disabilities. The results highlight the difficulties with defining learning and/or behavioural disabilities, gaps in services, the barriers to meeting the identified needs, and strengths.

FNCFS agencies are in a unique jurisdictional context unlike any other social service agency in Canada. This political-practice environment results in a high demand for services, jurisdictional divides, broad catchment areas, remote or northern locations, under-funding, over reliance on short-term project funding, and a lack of accessible, coordinated, collaborative and culturally appropriate service providers. Findings from the study present a context of significant need for children and youth with disabilities in the care of FNCFS agencies. FNCFS agencies are often the only resource available to the children and their families on reserve. This places an inordinate amount of pressure to deal with crises with limited ability to focus on prevention. Fundamentally, there has to be a national, comprehensive strategy to address the needs of Aboriginal children with disabilities. The time is now to not only identify but proactively plan and provide services to meet the needs of these children, their families, and their communities.

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APPENDIX

TELEPHONE INTERVIEW SURVEY

</div>

Date: _____

Agency Name: _____

Agency address: _____

Telephone Number: _____

E-mail address: _____

Delegation Level: **Fully Delegated/Mandated** _____
                              Partially Delegated _____
                              Non-Mandated _____

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PARTICIPANT DATA

</div>

1.   **Participant's Name:** _____

2.   **What is your current position?** _____

3.   **Are you (circle):**   Male   Female

4.   **How long have you worked with the agency?** _____

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AGENCY DATA

</div>

In total, how many people live in the communities that you serve?
_____

How many reserves are serviced by your agency?   _____

How many Métis communities are served by your agency? _____

What are the main Aboriginal cultural groups served by your agency?
_____

What languages are spoken by the people in the communities your serve?
_____

What languages are spoken in your agency?
_____

What is the size of the geographical area you serve (square miles or km)?
_____

What year did your agency begin providing non- mandated/non-delegated services? _____

What year did your agency begin providing partially or full mandated/delegated services? _____

Does your agency provide services:(a) on reserve? Yes _____   No _____
                                    (b) off reserve? Yes _____   No _____

Would you describe any of your communities as:
(a) rural   yes _____   no _____
(b) urban   yes _____   no _____
(c) remote   yes _____   no _____
(d) North   yes _____   no _____
(e) South   yes _____   no _____

How many full-time staff are employed by the agency (all positions)? _____

How many part-time staff are employed by the agency (all positions)? _____

What is the educational/training background of your staff?

(a)   Managers? _____

(b)   Supervisors? _____

(c)   Front-line workers? _____

CHILDREN WITH DISABILITIES IN THE CARE OF THE AGENCY

1. Does your agency have a definition of disability? Yes _____   No _____

If yes, can you tell me what it is?

_____
_____

2. **Does your agency make distinctions among the types of disabilities that children may have? Do you distinguish between physical disabilities, cognitive disabilities, learning disabilities, and behavioural disabilities? Explain.**

_____
_____
_____
_____
_____
_____

Does the agency identify children with disabilities? If yes, how are these children identified (e.g., worker-identified, formal diagnosis, family-identified, school-identified)?

_____
_____
_____

Using your categories of disability, is it possible to identify how many children in each category are <u>in the care of your agency</u>?

_____
_____
_____

How many children with disabilities <u>in the community</u> (i.e., not in care) does the agency provide services to? _____

Are there any children who came into care primarily because services and supports for children with disabilities were not available to the child and his/her family? If yes, can you estimate how many and describe the circumstances.

_____
_____
_____
_____
_____
_____

Are you aware if any children with disabilities have left the community in order to access resources? If yes, can you estimate how many? _____

CHILDREN WITH COGNITIVE/LEARNING AND/OR BEHAVIOURAL DISABILITES

In the following section we are going to focus on children who have cognitive and/or learning and/or behavioural disabilities. The terminology that best fits the way your agency describes these children can be used in place of "cognitive/learning and behavioural". Please indicate the term that would be most appropriate in your agency:

_____

1. **Does the agency identify children with cognitive/learning and behavioural disabilities? If yes, how are these children identified (e.g., worker-identified, formal diagnosis, family-identified, school-identified)?**

   _____
   _____
   _____
   _____

2. **To what extent is addressing the needs of children with cognitive/learning and behavioural disabilities perceived to be a key priority by the agency?**

1	2	3	4	5
Low Priority				**High Priority**

3. **How knowledgeable do you think your agency is about the needs of this group of children?**

1	2	3	4	5
Low Level of Knowledge				**High Level of Knowledge**

4. **Has your agency taken any specific action to assess the needs of this group?**

   Yes _____   No _____

   Please explain:

   _____
   _____

_____
_____
_____

5. **Has your agency developed policies or practices specific to working with this group of children and their families/caregivers? If so, what are these policies and/or practices? May we have a copy of these policies?**

    _____
    _____
    _____

6. **Have your agency staff received any training specific to working with children with cognitive/learning and behavioural disabilities? Explain.**

    _____
    _____
    _____
    _____

7. **Does your agency receive any targeted funding to support children with cognitive/learning and/or behavioural disabilities? If so, please describe. If not, why not?**

    _____
    _____
    _____
    _____
    _____
    _____

8. **What mainstream organizations does your agency partner with to meet the needs of these children and their families/caregivers?**

    _____
    _____
    _____
    _____
    _____
    _____

    In addition to the services your agency provides, what other services are

available for these children and families in your community? (e.g., medical, educational, speech therapy, physiotherapy, occupational therapy, psychological, recreational, child development counsellors, behaviour specialists, other organizations)

_____
_____
_____
_____
_____

9. **What culturally based services for these children with disabilities and their families are available?**

_____
_____
_____
_____
_____

10. **Generally, how would you rate the services provided for children and youth with cognitive/learning and behavioural disabilities (who are in the care of your agency) by the following agencies in your community:**

   ➢ **Medical services**

1	2	3	4	5
Poor				**Excellent**

   ➢ **The schools**

1	2	3	4	5
Poor				**Excellent**

   ➢ **Other**: _____

1	2	3	4	5
Poor				**Excellent**

11. **To what extent is your agency able to meet the needs of children and youth with cognitive/learning and behavioural disabilities in the care of the agency?**

1	2	3	4	5
Not at all				**Completely**

12. Generally, how would you rate the services provided for children and youth with disabilities (who are in the care of your agency) by your agency?

1	2	3	4	5
Poor				**Excellent**

13. What degree of difficulty do you experience in the following areas?

➢ Identifying children and youth with cognitive/learning and behavioural disabilities.

1	2	3	4	5
Not at all difficult				**Very difficult**

➢ Being able to provide those children and youth with support services.

1	2	3	4	5
Not at all difficult				**Very difficult**

➢ Helping those children and youth to access recreational activities.

1	2	3	4	5

Not at all difficult   **Very difficult**

➢ Supporting the foster family care for children and youth with cognitive/learning and behavioural disabilities.

1	2	3	4	5

Not at all difficult   **Very difficult**

➢ Supporting the biological family's relationship with children and youth with cognitive/learning and behavioural disabilities.

1	2	3	4	5

Not at all difficult   **Very difficult**

14. What would help your agency provide better care to children with cognitive/learning and behavioural disabilities?

_____
_____
_____
_____
_____
_____

15. What other resources are needed in communities to support families who are caring for children with disabilities?

_____
_____
_____
_____
_____
_____
_____

16. Any other comments?

_____
_____
_____
_____
_____
_____
_____
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_____
_____
_____

Thank you very much for the time that you have taken to participate in this survey! Would you like to receive a copy of a summary report of the project?