CHAPTER 7

Supporting Aboriginal Children and Youth with Learning and Behavioural Disabilities in the Care of Aboriginal Child Welfare Agencies

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This chapter presents an overview of a two-year project entitled "Supporting Aboriginal Children and Youth with Learning and Behavioural Disabilities in the Care of Aboriginal Child Welfare Agencies." The project involved 29 First Nations child and family services agencies (FNCFCAs) and communities across Canada (the full report can be accessed at: http://www.fncfcs.com/docs/ SupportingAboriginalChildren.pdf). The need for this project emerged from three related sources of information.

First, it is estimated that 26.2% of Canadian children between 4 and 11 years of age experience emotional or behavioural problems. However, there is no systematic or comprehensive national data concerning children and youth with learning and behavioural disabilities (LBD) (Health Canada, 1999). Children and youth with LBD appear

to be at greater risk of having difficulty achieving at school, becoming involved in the criminal justice system, misusing substances, requiring greater health services, and experiencing employment difficulty as adults (McKechnie, 2000). Other difficulties affecting children with LBD include a greater number of medical problems, difficulty with emotional bonding, and problems with the transition to adulthood (Dubienski, 1996). Second, it has been noted that educational outcomes for children in care are less favourable than for children who are not in care. For example, some children recorded higher scores on negative behaviours such as hyperactivity and inattention, emotional disorder and anxiety, conduct disorder and physical aggression, indirect aggression, and offences against property (Flynn & Biro, 1998). Third, Aboriginal children and youth are over-represented in the child welfare system, with statistics ranging between 30% to 80%, depending on the province or territory represented (Gough, Trocmé, Brown, Knoke, & Blackstock, 2005; Manitoba Aboriginal and Northern Affairs, 2000).

There were several objectives of the study. Overall, it was designed to further knowledge related to the needs of Aboriginal children with LBD in the care of Aboriginal child welfare agencies. This included an understanding of current FNCFSAs' policies and service practices, and an examination of collateral service providers' and community members' perspectives and experiences. Ultimately, though, the research goals were to identify challenges and best practices for addressing the needs of these children.

The research team, composed of Aboriginal and non-Aboriginal members, determined that the study would reflect a culturally respectful and helpful approach. Accordingly, the study was designed to maximize opportunities for building research capacity within the Aboriginal communities and to ensure collaboration with community members. Maximizing opportunities for building research capacity within the Aboriginal communities included incorporating an Aboriginal research partnership, developing a national advisory committee made up of representatives from the Aboriginal community as well as individuals with expertise in childhood disabilities, and hiring and training Aboriginal research coordinators to assist with on-site community visits.

Collaboration and consultation between the researchers and com-

munities were ongoing throughout the study and were accomplished in a number of ways. For example, the research team met with the advisory committee and had ongoing contact through email and by phone. Feedback, in the form of suggested changes was incorporated into the research instruments and design. To ensure a respectful and culturally appropriate approach, planning for community site visits included obtaining permission from band councils to approach their communities, speaking to FNCFSA directors in advance, and maintaining ongoing discussions with on-site research coordinators who were appointed by the agencies' directors. At the end of the study, written reports were distributed to all First Nations communities who had been contacted about the study.

The research plan incorporated two phases that used both quantitative and qualitative methods. In the following sections, the research design, methods, and findings of Phase I and Phase II are discussed in greater detail.

PHASE I RESEARCH DESIGN, METHODS, AND FINDINGS

Phase I of the research consisted of a survey that incorporated open and close-ended questions. The survey was developed and piloted, and then distributed to 124 FNCFSAs and communities across Canada. Survey items addressed: a) the number of Aboriginal children with LBD 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) agency policies related to accepting children for service and providing services to them.

Multiple contacts were made with the agencies to familiarize staff with the research and encourage their participation. Of 124 surveys distributed to agencies, the project received a total of 29 completed surveys. Six agency representatives stated they could not complete the survey because they did not have time due to high workloads,

and eight other agencies stated that they do not currently have responsibility for children with disabilities.

Identification of Disability

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

- 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 who are physically or emotionally handicapped.

Three agency representatives reported that their agencies do not identify children with disabilities, whereas 22 respondents identified various means by which their agencies identify children with disabilities. The most frequently reported means was referral by the school, followed by social worker assessments, a formal diagnosis (not specified), referral by family and medical professionals (including doctors and those not specified), psychologists, and/or referrals from other agencies.

Reasons for Entering Care

Twenty-one of the respondents affirmed that there are children who come into care primarily because services and supports are unavailable in their communities. Two primary reasons were given for the placement of these children: serious medical conditions and the corresponding lack of services within the community, especially northern communities, to maintain the children either in the home or in the community; and behavioural problems that were putting children at risk. Thirteen respondents identified a total of 71 children who were

in care due to a lack of services and supports in their home communities.

Agency Disability Policies

Twenty-two respondents stated that they had no specific written policies concerning children with disabilities. Three survey respondents noted that they had written policy, but that this was not shared with the research group. Other respondents identified established practices based on provincial family services legislation, needs assessments, and holistic practices.

Staff Training

Nineteen participants reported that their agencies provide training to enable the workers to work effectively with children with LBD. The most frequently reported topic of training was Fetal Alcohol Spectrum Disorder and Fetal Alcohol Effects (FASD/FAE), followed by attention deficit hyperactivity disorder (ADHD), autism, and adolescent behaviour concerns. Some of the participants reported that training was narrow in scope, and focussed on administrative processes rather than specific content regarding children with LBD. The main methods of training were workshops, although conferences, seminars, and tele-psychiatry seminars were also noted.

Targeted Funding

Twenty respondents stated that their agencies receive no targeted funding to support children with LBD. Respondents explained that the agency receives 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, received targeted funding on a minimal level. Explanations for the lack of targeted funding for these families include government funding cutbacks, and difficulties in accessing formal diagnoses.

On the other hand, four survey respondents stated that their agen-

cies receive targeted funding to support children with LBD. The funding, from the provincial government and in one case, from Indian and Nothern Affairs Canada (INAC), was targeted for in-home support for children with special needs, and for a "development program" that provides for two full-time positions, including an on-site psychiatrist.

Service Partnerships

Survey responses identified a range of options regarding partnerships with mainstream organizations. Two agencies stated that there were no mainstream agencies to partner with. Other agencies identified between 1 and 12 mainstream partner organizations, with an average of four identified organizations. The most frequently mentioned organizations included health services, mental health services, schools, and other mandated child welfare agencies. Early intervention programs such as Head Start, Healthy Babies, and Early Years were also frequently listed.

Communities in, or in close proximity to, urban centres have access to comprehensive services, but rural and remote communities reported limited availability of services. For example, one agency respondent 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 counsellors (for children from birth to 5 years of age) are available on a limited basis.

Culturally-Based Services

According to 12 respondents, culturally-based services were available for children with disabilities and their families. Eight respondents stated that such services do not exist. While some respondents described the culturally-based services as being intrinsic to their agencies, others replied that the services were available from other sources in the community.

Identified Needs

The agency representatives identified a wide range of needs that, if met, would assist them and their respective communities in providing adequate supports to children with disabilities and their families. Seventeen respondents identified increased funding as a major solution to current difficulties. Other identified needs addressed quality of life issues, often related to either non-existent or difficult to access services and specialized supports. Some of the identified needs that could be met through increased funding include:

- community-based professionals;
- costs related to community remoteness;
- culturally-specific residential treatment and support programs;
- educational training for staff, community, and parents;
- emergency foster homes;
- improved living conditions;
- improved screening services;
- increased availability of alternate care treatment opportunities;
- increased child psychiatry services;
- increased staffing;
- infant development programs;
- intensive behavioural one-on-one work with children;
- neuro-developmental assessments (i.e., FASD);
- psycho-educational assessments;
- recreational programming for children and youth with disabilities;
- respite care for biological and foster families;
- specialized foster homes in the north;
- specialized social workers;
- suicide prevention and intervention;
- treatment centres for children with behavioural problems; and
- wheelchair accessibility and other equipment.

PHASE II RESEARCH DESIGN, METHODS, AND FINDINGS

The second phase of the study examined the needs and supports of children with LBD and their families in greater detail. This was done through community focus groups, interviews and focus groups with agency staff and collateral agencies, reviews of relevant agency policies, and, where available, the analysis of financial data.

Five research sites were targeted for participation in Phase II. These sites represented the diversity of issues emerging from the survey. The final selection of sites represented the west coast, central Canada, the Prairies, the northern and southern regions, and the east coast.

Consent to conduct research was obtained from the agency, chief and council, and from the research committees where such committees were established. On-site research assistants, selected by the participating agencies, were employed by the research team to assist in the planning of the visit and to facilitate data collection. Their responsibilities included: advertising and preparing for the community focus groups, the staff and collateral focus groups, and interviews; assisting in the planning of traditional community feasts and give-aways; overseeing the distribution of honoraria for Elders and helpers; and collecting relevant policy and financial data from the agencies.

Although five agency sites were selected, research was conducted in six communities in order to accommodate one agency that requested that research occur in two of their communities. Overall, 136 participants took part in 13 focus groups and 10 individual interviews.

View of Disability in Aboriginal Communities

Although a specific focus of the research was on learning and behavioural disabilities among Aboriginal children, it soon became apparent that focussing on this group of disabilities was too narrow for many of the participants. The term *learning and behavioural disabilities* was not familiar to all participants. It seemed to resonate more with school personnel than with child welfare staff or other commu-

nity members. Given the understanding of disability by participants, 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 FASD, 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. When viewed from the context of the challenges faced in many communities, it is not difficult to understand the reluctance to view disabilities from a narrow perspective. Communities and agencies are struggling to provide for the basic needs of children with disabilities.

The participants had varying perceptions of attitudes towards disability within their communities. Some participants spoke of a traditional view of disability. This view includes seeing disability as a gift, where individuals with disabilities are perceived as being special. This view can contribute to valuing and respecting people with disabilities, but it can also mean that some people do not perceive a need for services. Other participants described a shift away from the traditional view of disability, including the respect shown towards people with disabilities, and the negative consequences that have resulted.

The issue of labelling children with a disability emerged, and with it different opinions about the value of identifying disability. Some participants raised concerns about the effects of labelling and the potential for a disability label to be inappropriately applied to Aboriginal children. In other cases, parents in the community are concerned a disability label will have negative consequences for the child. The research also found that some parents fear being blamed for the disability, especially with a diagnosis of FASD.

Community Context

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. These include 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 facili-

ties, the increased use of drugs on reserve, overcrowding, lack of housing, parents with disabilities raising children with disabilities, and teen pregnancy.

Unmet Needs of Children with Disabilities and Their Families

Participants in Phase II were keenly aware of gaps in services for children with disabilities in their communities and echoed many of the same concerns as the Phase I survey respondents. They identified various unmet needs of children with disabilities that highlighted the overall lack of resources related to specialized services and supports, training of professionals and paraprofessionals, and community-based services. These are:

- access to professionals with specialized skills,
- community-based educational services outside of the regular school system,
- coordination among existing service providers,
- early diagnosis and intervention services,
- education and training for parents and foster parents,
- recreational activities for children with disabilities,
- resources to assess needs and follow through with recommendations,
- services for youth when they reach adulthood,
- specialized foster homes for children with special needs,
- tangible and emotional support for biological and foster families, and
- training for professional and paraprofessional staff.

Barriers to Meeting Needs

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

Some of the concerns identified by agency personnel and community members as barriers to supporting the needs of children with disabilities and their families include:

- lack of government and other funding bodies to understand and respond to the needs of children with LBD,
- lack of supports to maintain children with LBD in their homes and/or communities,
- ongoing jurisdictional disagreements,
- policy and financial constraints in meeting the expressed needs of the community, and
- short-term project funding.

One consequence of the lack of resources is that agency staff and other professionals often find themselves responding to crises. They recognize the importance of moving beyond working in a crisis mode and toward addressing the broader issues, but are constrained by the imbalance between current demands and existing resources. The stress of working in crisis mode is illustrated by the comments of two participants:

> 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.

Community Strengths

Overall, community members, family members, and agency people demonstrated a strong sense of commitment to supporting children with LBD and their families. They expressed determination to encourage the education and training of their own community members to provide specialized services such as occupational therapy, physical therapy, pediatric care, and speech therapy. They also expressed a determination to continue to network and lobby for pos-

itive changes for their communities. Participants were hopeful, and identified some positive progress in their communities. Some of these include:

- developing an after-school homework program specifically for children with disabilities,
- hiring extra staff so children with disabilities can participate in recreational activities,
- making facilities wheelchair accessible, and
- providing cultural teachings.

At the same time, 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. This is illustrated by the comment of one participant:

> 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.

RECOMMENDATIONS AND CONCLUSION

First Nations child and family service agencies function within a unique jurisdictional context that is unlike other social service agencies 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 shortage 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 FNCFSAs. FNCFSAs 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, and there is limited ability to focus on prevention.

In light of the study's findings, the following recommendations are made:

- Provide adequate support services within Aboriginal

communities.

- Provide culturally appropriate services that reflect the cultural aspects and social realities of Aboriginal children living with disabilities.
- Develop a common, inclusive, and meaningful definition of disability that acknowledges learning and behavioural issues.
- Develop a voluntary sector to provide services to Aboriginal communities.
- Establish a comprehensive national agenda and associated service delivery to provide systematic and integrated funding and services that include federal, provincial, and band levels of government.

AUTHORS' NOTE

The research team would like to express our deep gratitude to those First Nations agencies and communities who participated in the study. Thank you for your willingness to share your experiences so we may all learn more about meeting the needs of Aboriginal children with disabilities and their families. Your commitment to improving the lives of these children and families has greatly impressed us.

REFERENCES

Dubienski, N. (1996). *Identifying FAS/FAE: The health problems of children affected with FAS/E*. Winnipeg, MB: The Family Support Working Group of the Committee on Alcohol and Pregnancy and the Fetal Alcohol Support Network of Manitoba.

Flynn, R., & Biro, C. (1998). Comparing developmental outcomes for children in care with those for other children in Canada. *Children in Society*, *12*(3), 228-233.

Gough, P., Trocmé, N., Brown, I., Knoke, D., & Blackstock, C. (2005). *Pathways to overrepresentation of Aboriginal children in care*. CECW Information Sheet #23E. Toronto, ON: University of Toronto. Retrieved April 13, 2006, from www.cecw-cepb.ca/DocsEng/AboriginalChildren23Epdf

Health Canada. (1999). *Healthy development of children and youth: The role of the determinants of health*. Retrieved February 6, 2003, from http://www.hc-sc.gc.ca/hppb/childhood-youth/spsc/pdf/overveng.pdf

Manitoba Aboriginal and Northern Affairs. (2000). *Aboriginal people in Manitoba 2000: Children in care of CFS agencies*. Retrieved April 13, 2006, from http://www.gov.mb.ca/ana/apm2000/3/b.html

McKechnie, B. (2000, June). *FAS/FAE initiative information and feedback sessions: National Synthesis Report*. Ottawa, ON: Health Canada. Retrieved February 6, 2003, from http://www.hcsc.gc.ca/hppb/childhoodyouth/cyfh/pdf/FAS_Synthesis%20.pdf