Putting our Minds Together: Respite Care and FASD

***"Let us put our minds together
and see what life we can make for our children."***

Chief Sitting Bull

March 2007
Fort Qu'Appelle, Saskatchewan

Acknowledgements

This project is funded by First Nations and Inuit Health Branch (FNIHB) and facilitated by Karen Arnason, Health Educator for the File Hills Qu'Appelle Tribal Council (FHQTC). Marilyn Gosselin is the researcher/writer.

The project was initiated in response to the requests of several Standing Buffalo Band members who want to explore the possibility of developing community supports for the children, youth, and families affected by prenatal maternal use of alcohol. It is the determination of these community members that guided the Asset Mapping process in 2006 and motivated the development of this project. In addition, Tatanka Najin School staff acknowledged the validity of the project and encouraged it to go forward.

Standing Buffalo First Nation is a Dakota Sioux community located in the Qu'Appelle Valley, 11 kilometres from the town of Fort Qu'Appelle, Saskatchewan. Its on-reserve population is four hundred and ten. This project does not mean that Standing Buffalo feels the impact of fetal alcohol spectrum disorder (FASD) more than any other community. It means that more residents of Standing Buffalo acknowledge the problem and are willing to do something about it. FASD exists in all communities where there is a lot of alcohol use.

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Background

In January of 2006 the Asset Mapping process was completed in the community of Standing Buffalo First Nation. The following contributors participated in the process:

- Brighter Futures Coordinator
- Community Health Nurse
- Community Elders
- Corrections and Public Safety representative
- RCMP representative
- Tatanka Najin School principal
- Community Health representative
- Band Office representative
- Qu'Appelle Child & Family Services representative
- Birth mothers of children with FASD
- Other community members

These individuals adopted the following objectives for addressing FASD:

- Increase education about FASD, including support for family and prevention information
- Establish an FASD support group
- Increase access to testing with regard to funding and resources.

The following committee was struck to steer this project:

- Kim Goodfeather/Connie Wajuntah, Health Staff
- Stan Dirkson, School Principal
- Georgieann Bear, Parent
- Larry McKay, Elder
- Karen Arnason, FHQTC Health Educator

Subsequent to this, Karen Arnason met with a FNIHB representative to discuss the Asset Mapping results and determine funding options. With information gained from this discussion, Karen wrote a proposal that addressed the need for family support as identified through Asset Mapping. FNIHB accepted the proposal in terms of its goal: "Exploring successful models of respite care for youth 12 to 22 years of age with special needs, especially those with FASD"; and its objectives: to examine respite care in terms of: (1) which programs that occur regionally are specific to FASD; and (2) what do Standing Buffalo residents consider to be an optimal model for their community. Canada consists of thirteen regions: 10 provinces and three territories, so the proposal's goal led to a pan-Canadian exploration of respite care particular to FASD.

In December 2006 I was hired as the consultant to respond to the proposal's goal. On January 9 2007, I submitted to Karen Arnason an overview of the proposed phases of the project, and in February she was given the databases of on- and off-reserve contacts and their responses thus far. The report was completed and submitted by mid-March.

What is FASD and respite? Who are parents?

Fetal Alcohol Spectrum Disorder (FASD). FASD is an umbrella term that describes a spectrum of conditions that result from prenatal maternal alcohol consumption. FASD is the leading cause of developmental disability among Canadian children, and the most common form of preventable brain damage in the Western world. Although not a diagnostic term, FASD will be used in this project to describe diagnoses across the spectrum:

FASD: Fetal Alcohol Syndrome (FAS)
FASD: Partial Fetal Alcohol Syndrome (pFAS)
FASD: Alcohol Related Neurodevelopmental Disorder (ARND)

The brain function deficits in all three diagnoses may be similar. The term "partial" in partial FAS does not imply a lesser form of the disability. In March 2005, *Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis* was published, which formalizes the spectrum of disorders, and allows for reliable and consistent diagnoses. The *Guidelines* were welcomed because they acknowledge that the FAS facial features only occur if the mother drinks in one particular week in the first trimester, and that the neurological damage occurs when the mother drinks at any time in the pregnancy.

Respite. Health Canada's 1993 *Principles of Child and Youth Health* notes: "for optimal development, children need to grow up in a nurturing atmosphere of support, happiness, love and understanding. Support for the family…is the single most important way that society can optimize the development of children and youth." This principle informs the Canadian Association for Community Care's (CACC) definition of **respite care** as a "service, the main function of which is to relieve the family caregiver(s) for a period of time while facilitating a positive and rewarding experience for the child with a disability or chronic illness." This definition guided a three-part CACC study on respite for families of children with special needs. For this *Putting Our Minds Together* project, respite is seen as a caregiver break, but also as a service that meets the needs of those affected by prenatal exposure to alcohol.

This definition guides this project with the following clarification: The steering committee for this project defines **child** as someone between 12 and 22 years of age who, due to prenatal exposure to alcohol, is more functionally dependent than is typical of others his or her age. The inclusion of individuals 18 to 22 acknowledges the struggles of this age group and the developmental delays that characterize those affected by FASD. In addition, 22 represents the upper age limit for receipt of school-related educational funding from Indian and Northern Affairs Canada (INAC).

Parent. For the purposes of this project **parent** refers to anyone who provides regular care to an individual between the ages of 12 and 22 who is diagnosed or suspected of having an FASD.

How common is FASD?

It has been difficult to determine incidence and prevalence rates of FASD due to the absence, or inconsistent application, of diagnostic criteria; however, the March 2005 publication of the *Canadian guidelines for diagnosis* allows for reliable and consistent diagnoses. As yet, there are no national statistics about the rate of FASD in Canada, just vaguely framed estimates, but there are statistics on alcohol consumption.

The 2004 Canadian Addiction Survey (CAS) revealed that alcohol is the most common substance used by women and its use has been on the rise over the past decade: 17% of the surveyed women drank heavily on a monthly basis. Although heavy drinking for women was described in CAS as four or more drinks per occasion, the *Canadian FASD diagnostic guidelines* note that many researchers and physicians define heavy drinking for females as three and a half or more drinks per day. Furthermore, the guidelines refer to research that found risk-drinking during pregnancy (enough to potentially damage offspring) to be an average of more than one drink (half an ounce) per day on a single occasion, or

less if more than five drinks are consumed in a binge. Even though some children born to mothers who drank alcohol during pregnancy do not have an FASD, the research, and the varying degrees of susceptibility to alcohol of each mother and child, leads medical professionals in pediatrics, obstetrics, and gynecology to recommend abstinence from alcohol for those who may become pregnant.

Even though there are no incidence or prevalence rates for Canada, there are studies that present a snapshot of FAS in two Canadian First Nations:

- Elders from a band in Manitoba invited a team from the University of Manitoba to conduct a study in response to teachers' complaints that half of the reserve's children had severe learning problems. The results indicated that one in ten children was the victim of either fetal alcohol syndrome (FAS) or fetal alcohol effects (FAE), which was the terminology used at the time of the 1997 study. Researchers said that for every child identified with FAS/FAE there were probably two or three others with behavioural, learning, and attention problems caused by prenatal exposure to alcohol.

- A First Nation band council in British Columbia requested a study to assess the presence of FAS/FAE among children in their community. The results of the 1987 study found that 22 of 123 children met diagnostic criteria for FAS/FAE: two-thirds of these children were mentally retarded.

A historical perspective reveals that the First Nations people of Canada began abusing alcohol long after such abuse was commonplace in most other cultures, and they are among the first to acknowledge and address the damage that their children suffer from prenatal maternal use of alcohol.

What principles guided this project?

The FASD Support Network of Saskatchewan Inc., in conjunction with the Saskatchewan Prevention Institute, subscribes to five basic principles that provide a framework to guide their discussions and actions to ensure that consistent messages are portrayed. The principles and their relevance to this project are as follows:

- ***Hope***, by acknowledging that supportive interventions make a difference for all individuals with FASD

- ***Respect***, for all communities in their efforts to address FASD
- ***Understanding***, by being sensitive to the impact of a diagnosis on an individual, family, and community
- ***Compassion***, by being sensitive to the situations of individuals and families who feel the impact of FASD and being open to both their strengths and weaknesses
- ***Cooperation,*** by recognizing the importance of building partnerships within communities in addressing all aspects of FASD.

What factors influenced this project?

Although Standing Buffalo residents have moved forward in FASD education and diagnosis, they recognize that there is still much to be done and many people to be reached. They feel, however, that it is time to start responding to the needs of the young people affected by FASD, many of whom are diagnosed. The diagnosis is important only if it leads to an increase in understanding and appropriate interventions, services, and supports.

Burnout. Many parents and extended families are experiencing compassion fatigue or "burnout," as it is often called by mental health professionals. The complexity of their children's needs is unrelenting and parents are on high alert twenty-four hours a day, seven days a week. These children, for the most part, are in the school system, but their behaviours are such that they are frequently excluded from school: sent home for part of a day, suspended, or expelled. These parents always expect, and often receive, the dreaded call from school staff that confirms their expectations. The stress of raising children who are alcohol affected wears on all caregivers. These families need relaxation and personal regeneration time, thus their interest in community-based respite care.

Grandparents and kinship care. Standing Buffalo is a family-oriented community, where aunts, uncles, and grandparents assist in the kinship care of children. Across the country the numbers of grandparents raising grandchildren has increased significantly over the last decade: This is especially true in the First Nations population. This may be due in part to the mandate of First Nations Child and Family Services, which is to provide culturally appropriate care and rely on grandparents or other relatives for foster care placements. Women are over-represented among grandparent caregivers, and often it is a woman with a disability, like diabetes, who cares for multiple children with disabilities, like FASD. These women invest long hours in childcare and housekeeping, often with minimal resources, and they do so willingly as they

are well aware of the social issues that have led to their children's absence as parents: The aftermath of residential schools and trans-cultural adoptions continues to take a toll.

From a grandmother who raises grandchildren with an FASD:

> *When I was really tired, I would ask [the social service agency] for some help with the children; sometimes I got it, but eventually they said there was no money for respite care. I will take care of my grandchildren no matter what, but it is hard. Getting the FASD diagnosis helped because I got more money to get my own help. But one of the children rips her clothes apart all the time and it costs a lot of money to replace them.*

From another parent who raises a family of foster children affected by FASD:

> *Sometimes I got respite when the children were little, but as they got older, they [the social service agency] said that it was no longer necessary. It is even more important as they get older because they have to be watched all the time. If I don't take care of them who will because not many people want this many children with FASD. They are brothers and sisters and they should stay together.*

From a woman who wants to foster children with special needs like FASD:

> *The only thing that stops me from taking in foster children with FASD is that there is no guaranteed respite care.*

Over and over again, respondents in this project spoke of the uncertainty of respite care and the need for them to go "begging" when they feel overwhelmed. This response came from those parenting within, and outside of, the foster system.

School. Tatanka Najin is Standing Buffalo's school, and it educates children from preschool to Grade Nine. From Grade Ten, the students attend Bert Fox High School in Fort Qu'Appelle or Lipton School in Lipton. In addition, some parents choose to send their elementary school children to Lipton or Fort Qu'Appelle. The teachers at these three schools are aware of FASD and its impact on learning and behaviour, but there are times that their coping capacities are stretched and overwhelmed by the complex needs of the students, and it is at these times that the children get sent home. Impaired self-regulation or self-control, a primary disability in FASD, is a key contributor to the disrupted school experience of those

with FASD. Teachers feel discouraged when they exclude students, and are eager to consider alternatives in which attendance at school will be something on which parents can rely. Teachers realize that parents need this time to regenerate, and they view alternatives to exclusion as an issue of respite care for the families of those with FASD.

In 1999, in response to the urgings of First Nations leaders, DIAND implemented a Targeted Behaviour Plan to address in the schools the exceptional behaviours typically associated with emotional and neurobehavioural disorders. The plan was based on the identification of these students and the provision of specific interventions targeted at meeting their emotional and behavioural needs. The Targeted Behaviour Plan allowed for the infusion of funds into the schools, and these funds were contingent upon a team-based, culturally-oriented, social skills-focussed, Individual Education Plan-directed response to the targeted students' needs. I have been involved in the plan since its inception, either as a Special Education Coordinator and/or educational psychologist. Many students in school today would not be there without the Targeted Behaviour Plan. In Saskatchewan Region, the plan has now become the Targeted Behaviour Program, as the funds are now more program-based than individual student-based; however, students involved in the programs must still be assessed and have Individual Education Plans available for review by the Education Program Review Officer during on-site visits. See Saskatchewan Region Special Education Program Guidelines for details.

In the first six or seven years of the Targeted Behaviour Plan, schools throughout Saskatchewan opted to use the funds for various types of interventions: providing targeted students with teacher-assistants, direct social skills instruction, elder time, alternate classroom with low pupil-teacher ratio (four students to one teacher), or a combination of all these strategies. There were many creative responses throughout Saskatchewan and the other regions of Canada. INAC's focus on inclusive education discouraged the development of separate classrooms or programs where the targeted students were singled out; however, it was expected that each student's program be individualized. If a school chose to have an alternate classroom for these children where their individual academic, social, cultural, and emotional needs were acknowledged and met, there was an expectation by the Review Officer that such a placement was temporary and that plans for gradual inclusion of the child in the regular classroom must be in place. Underlying this philosophy was the notion that somehow these students could be fixed. It was an admirable goal, but unrealistic in terms of what is known about FASD being a lifelong disability.

Since 2006, when INAC moved the Plan to a Program, schools submit school-wide program plans that use the principles of the inclusive education model. In other words, programs that include alternate classrooms will not likely be approved. The school-wide inclusive approach reflects the non-categorical attitude toward special education that is advocated by

Saskatchewan Learning, and it will be what some students need. There are other students, however, most of whom are affected by FASD and its secondary disabilities, whose externalizing behaviours are such that they put other children's learning and personal security at risk. These are the students whose sensory needs are such that the hustle and bustle of a school and its classrooms can be at times overwhelming. These students are the ones of whom this project speaks. These students need their school, the Targeted Behaviour Program, and much more. The "much more" is the focus of this project.

Primary/Secondary Disabilities. Individuals with FASD often have both primary and secondary disabilities. Primary disabilities are a result of organic brain damage, cannot be undone, and often result in impaired self-control, memory, judgment, and learning. Secondary disabilities are preventable; they occur after birth, and include the following:

- fatigue, tantrums
- irritability, frustration, anger, aggression
- fear, anxiety, avoidance, withdrawal
- lying, running away
- trouble at home, school, and community
- legal trouble
- drug/alcohol abuse
- mental health problems (depression, self-injury, and suicidal tendencies)
- inappropriate sexual behaviour
- homelessness and joblessness
- alcohol-exposed pregnancies.

Protective factors such as safe, stable, structured living and learning environments free of violence; early diagnosis; and appropriate interventions can reduce the development of, or alleviate the impact of, secondary disabilities. Streissguth, a leading researcher in FASD, estimates that 60% of individuals with FASD are in trouble with the law. If this is the case, Tina Antrobus noted in a 2006 presentation that there may be an estimated 37,448 individuals (age 15-64) with FASD in trouble with the law in Saskatchewan. A 2006 Alaskan study found that due to the serious nature of the behaviours associated with FASD and the lack of local supports, many parents in the study felt that their only option was to seek residential treatment for their children. The Standing Buffalo experience has been that

involvement with the justice system, disrupted schooling, and addictions are, indeed, factors for the children of whom this project speaks. Respite services that provide breaks for families must be mindful of both the primary and secondary disabilities associated with FASD. Increased understanding of the primary factors, in addition to avoidance of, or reduction in, secondary factors will have a positive impact on the wellbeing of the affected individuals and their families.

Multiple placements. It is well known that a safe, stable home environment is critical to a successful outcome for those affected by FASD. The sad fact is that because of the stresses of caring for children with FASD they are often moved from one home to another. In response to this project, a woman living on an Ontario First Nation wrote:

> *We have fostered seven children since May 2006 and the highest number of homes these kids have been in is 44 and counting. The least number of placements was my last little angels with 11 in their four years in care. All of them had FAS or FAE.*

Another mother told of the challenges she faced raising an adopted daughter who was prenatally affected by drugs and alcohol. The child was adopted at four years of age and had suffered neglect and sexual abuse. The mother wrote that over the years all her requests for respite were denied. When her daughter was 12 years old, she was desperate for relief, but was told that turning her child over to the Children's Aid Society for a foster home placement was the only relief she could be offered. The mother's response was as follows:

> *I didn't see that as a solution. In fact I felt that would only send a negative message to my daughter as she had come out of that system and I would be consumed by guilt.*

The stress is apparent in the general population, but is particularly obvious in First Nations communities where there is an overwhelming desire to care for their own children, often in spite of poverty and poor health. When the burden of providing supervision 24 hours a day, 7 days a week to one or more children becomes emotionally and/or physically unbearable, the caregiver experiences debilitating grief and guilt over the decision to place a child in care or return a child to the foster system. This guilt and grief was expressed over and over again by biological, kinship, foster, and adoptive caregivers contacted for this project.

It is likely that a creative, flexible community-based system of respite care would reduce the number of placements and the impact of secondary disabilities for those children with FASD; thus increasing their chances of having a successful life outcome.

Successful Outcomes. Theresa Kellerman, in response to Streissguth's research, defines success for those suffering from FASD as achieving potential with decent quality of life in a healthy, safe environment, which means preventing secondary disabilities. To be successful Kellerman emphasizes the need for "systems of care." Systems include health care, child welfare, education, vocational/rehabilitation, mental health, justice, chemical dependency, and organizations working for the benefit of people with disabilities, and they would collaborate around principles that are child-centred, family-driven, strength-based, and culturally competent. In addition, Kellerman fingers respite and residential care as being among the "cracks" in the current systems. Systems of care that are strength-based will recognize a community's potential for providing support and acknowledge that it is common for those with FASD to have strengths, such as the following:

- artistic, musical, mechanical
- athletic
- friendly, outgoing, affectionate
- determined, persistent
- willing and helpful
- generous
- good with younger children.

Standing Buffalo residents who are educated about FASD urge that any respite breaks families receive be meaningful for the children, which means they be weakness-aware, but strength-based.

What underlying belief drove this project?

This project is based on the belief that respite care services for those who care for children and young people are critical to the avoidance, or alleviation, of the secondary disabilities that often accompany FASD and decrease the chances of the affected individual experiencing a successful life outcome. The problems associated with prenatal use of alcohol are

going to be with us for some time. Michael Miltenberger, the Northwest Territories Minister of Health and Social Services was quoted in a Toronto Star article:

> *If we had alcohol stopped tomorrow, it would take the next 80 to 90 years for the system to clear itself of the troubles created by everyone who's damaged by alcohol. Even if we were to do wonders tomorrow in terms of alcohol abuse, we have that segment of the population right from birth to age 80 that are damaged.*

What questions did this project ask?

This project, *Putting Our Minds Together: Respite Care and FASD,* answers the following questions:

1. What respite care services are currently available across Canada, in the general population and in First Nations communities, specifically for families affected by FASD?

2. After considering the answers to Question 1, how do Standing Buffalo residents envision respite care services for families in their community who are affected by FASD?

How were the questions answered?

Phase 1. The question about respite services specifically for those affected by FASD came from FNIHB; rather than being restrictive, it was the inspiration for a vast range of dialogue about the issue.

A letter/questionnaire (see Appendix A) was faxed or e-mailed to 66 targeted respondents who represent a cross-section of individuals active in Canada in the field of FASD or other disabilities. As a result of respondent referrals, 80 contacts were initiated. Reminder phone calls were made to increase the response rate. Responses were received from all provinces and territories. The purpose of the questionnaire was to determine if there are respite care services in Canada for those with FASD and the nature of those services. The response rate was 66.2%. Many respondents were passionate about the topic and engaged in multiple phone, e-mail, or fax exchanges with the researcher/writer. These exchanges revealed valuable information about the challenges Canadian families affected by FASD face when accessing respite care services.

To further understand these challenges a post was placed on the FASlink Discussion Forum requesting individual views on respite care availability in Canada for families struggling with FASD. The response was overwhelming and highly emotional. In addition, a search of the FASlink Archives clearly demonstrated how critical the issue of respite care is to Canadian families affected by FASD. The voices of foster, adoptive, and biological parents, as well as kinship caregivers, both on-reserve and in the mainstream were heard.

In February 2003, Bob Stephen of Lutra Associates Ltd. researched and wrote *A Report on Respite Services and Programs in Canada for Families Caring for People with Disabilities.* The research, which in part, examined models of respite services in selected Canadian jurisdictions, was done for the Yellowknife Association for Community Living and the NWT Council of Persons with Disability. The selected jurisdictions are Alberta, Ontario, British Columbia, Yukon, and Northwest Territories. Mr. Stephen's report informed this project in terms of the models of respite service he found to be available on a planned basis in these jurisdictions.

Phase 2. First Nations Child & Family Services (FNCFS) is a program funded by the Department of Indian Affairs and Northern Development (DIAND), and it is the agency that most on-reserve residents look to for respite care services. The DIAND website states that "the main objective of FNCFS is to assist First Nations in providing access to culturally sensitive child and family services 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." Though funded by DIAND, the program is designed, managed, and controlled by First Nations. It is important to note: "Since child and family services is an area of provincial jurisdiction, these First Nation agencies receive their mandate and authorities from provincial or territorial governments and function in a manner consistent with existing provincial or territorial child and family service legislation. In areas where First Nations Child & Family Services do not exist, DIAND funds service that is provided by provincial or territorial organizations or departments." The role that FNCFS plays in respite care on-reserve was queried by faxing a letter/questionnaire (see Appendix B) to 96 Child & Family Service agencies or their counterparts in all provinces and territories; reminder phone calls were made. The response rate was 24% percent.

Phase 3. Sixteen Standing Buffalo Band members with an expressed interest in FASD were presented with the findings of Phases 1 and 2. They were asked to review the project thus far and confirm that it accurately reflected their views on respite care and that it did so in a culturally sensitive manner. This third phase is intended to provide a basis for ongoing consideration of which respite care services would best meet the needs of their community.

What information was gathered in Phase 1?

The letter/questionnaire (see Appendix A) was faxed or e-mailed to 66 targeted respondents who represent those active in FASD-related issues, as well as those associated with organizations that either deliver respite care services or develop policy. In addition, a post was placed on the FASlink Discussion Forum requesting individual views on respite care availability in Canada for families struggling with FASD. A respite care service is deemed to be specifically for families affected by FASD when it accepts the diagnosis, regardless of IQ, as a disabling condition that qualifies for service and when the services provided are specialized to FASD. The search for respite care services specific to FASD was certainly not exhaustive, but it revealed the following:

- In Cold Lake, Alberta, Lakeland Centre for FASD holds a summer camp for those with an FASD between the ages of 8 and 13. The camp is held for 5 days each summer.

- Renfrew Educational Services in Calgary provides Stepping out on Saturdays (SOS), which is a full day camp for those diagnosed with an FASD. The SOS camps take place 3 Saturdays per month and are for children 3 to 10 years of age. FASD-specific strategies are integrated into the camp activities, and staff are informed about the disability. This information is from the Renfrew website.

- Yellowknife Association for Community Living (YACL) in the Northwest Territories provides respite services that are not specifically for FASD, but has services that are specific to FASD. Qualifying for YACL respite care services is disability-based, not intelligence quotient (IQ) dependent. In order to qualify for most of the Community Living services in Canada a person must have an IQ of 70 or less, as well as deficits in adaptive living skills. Those with an FASD have the adaptive skills deficits or they would not be diagnosed, but the majority of them do not meet the IQ criterion. In addition, YACL has a Coordinator of Living and Learning with FASD, and training in FASD for service providers.

- Enviros Wilderness School Association in Calgary, Alberta offers Respite Care Connections (RCC). RCC provides fee-for-service based respite care for families raising children with behaviour challenges to assist in maintaining them in their families and communities. Families are provided with a break while the children participate in small-group community-based activities or stay overnight in a family-based setting provided by foster parents. Although

not exclusively directed at FASD, it does have an FASD Support Program, which links to community resources and to Respite Care Connections. In this sense it specifically addresses respite care and FASD. This information is from the Enviros website.

- Huron Respite Network in Clinton, Ontario provides respite services to families affected by disabilities, which specifically includes FASD. Services are tailored to meet individual needs. The Network provides host families, in-home respite providers, vacation respite, and provides help finding community resources. There is a moderate cost, but subsidies are available through the Huron Respite Network.

- Catholic Social Services in Wetaskiwin, Alberta offers respite care to individuals with a disability. When the disability is FASD the respite provider is encouraged to utilize the support of the FASD Program for information and the FASD Program Coordinator is a team member for planning and advocating for the individual.

- Whitecrow Village, which operates out of Burns Lake, British Columbia, runs camps specifically designed to allow for those with FASD, parents, and professionals to learn, work, and play together in a camp setting in order to create a common language and understanding of FASD. The camp is a concept rather than a particular physical location, which makes it available to communities throughout the world. This information is from Whitecrow's website.

Incidental Phase 1 findings. So much more than simple yes/no responses came out of Phase 1. In addition to the above-mentioned providers of respite care for families affected by FASD, the following respondent/researcher observations represent recurring themes about the respite care/FASD picture in Canada:

Note: Opinions expressed on FASlink about respite care/FASD in the mainstream are incorporated in Phase 1 findings.

- Respite care services are usually embedded within government sponsored agencies, and more often than not, eligibility for support is determined by application of the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV) diagnostic criteria for mental retardation (also referred to as intellectual, cognitive, or developmental disability), including age of onset, adaptive behaviour, and intellectual functioning. Those with FASD easily meet the first two criteria, but usually do not meet the third. Streissguth's study on secondary disabilities found that 86% of those with FAS/FAE (now called FASD) had IQs over 79, and therefore did not

meet the “70 or below” IQ requirement to qualify for services. This is a critical barrier to respite care services for families affected by FASD.

Note: The medical model informs the DSM-IV. This writer prefers the terms developmental or cognitive disability, instead of mental retardation.

- There is Canada-wide unrest over the IQ criterion, unrest which is beginning to make its way into the courts. On December 15, 2006 British Columbia’s Supreme Court upheld a ruling in the Fahlman v. Community Living British Columbia (CLBC) court case, which ruled that CLBC can not determine eligibility for adult services on the basis of IQ. For this decision refer to http://www.courts.gov.bc.ca/jdb-txt/sc/06/09/2006bcsc0900.htm.

- Community Living (CL) is a government agency with regional offices in all provinces and territories, and it is responsible for some individuals who require lifelong government-funded supports. Many respondents believe that Community Living services should be available to those with severe functional deficits regardless of IQ, which requires the development of a functional assessment tool to assist in the design of appropriate supports. Furthermore, many wish that CL’s expertise would be available to First Nations communities.

- Even if the diagnostic criteria for a cognitive disability are met and respite funding is approved, it is usually up to the parents to find a service provider. In some jurisdictions when families are approved for respite services they will be given a list of profit and non-profit agencies that may be accessed; this is particularly the case in Alberta. Those who choose a private individual to provide services must set themselves up as employers according to Revenue Canada’s requirements.

- Service providers are often unprepared for and overwhelmed by the behaviours associated with FASD. There is more tolerance for the challenges of providing service to someone with a visible disability than there is for those who look normal but behave negatively. Unless well trained, service providers are inclined to regard the behaviours as willful noncompliance rather than neurologically-based and noncompetent. Aggression is particularly difficult for service providers to deal with, and it leads to many failed service provision arrangements. Parents often feel respite care is more trouble than it’s worth, since it often fails and they are called to the rescue. A parent said that if she trained the workers, it might go better, but she is too worn out to train anybody.

- Even when the respite service is not contingent on meeting the criterion for mental retardation, a disability diagnosis must be provided. As yet, diagnosis is difficult to access in Canada, especially for adults. Diagnosis is further complicated when confirmation of maternal prenatal use of alcohol is not available.

- Diagnosis is critical to stopping the damage seen in FASD because it shows a concrete connection between prenatal maternal consumption of alcohol and an affected person's struggles with living and learning. Services, however, should be available without a diagnosis if a multifaceted, multiperspective functional assessment of an individual's daily living indicates a need for support in order to have a safe, successful life.

- There is a faulty understanding of the nature of FASD that undermines lobbying efforts to establish services for those with FASD. FASD is permanent brain damage that is not going to get better. It is not a question of setting up supports from which those affected will eventually be weaned. Families are often faced with the question, "How do you expect him to become independent with all these supports?" It is about functional dependence, not independence. For information on functional dependence refer to the work of Nathan Ory.

- Respite care is not readily available for any family affected by FASD, but it is more available to foster parents than it is for birth, adoptive, or kinship parents. An adoptive father told of his attempts to get respite care for their daughter so he and his wife could go to an FASD conference and a marriage retreat; after six or seven calls the agency in question decided to pay for half of the babysitting expenses, but the family had to arrange everything themselves. He spoke fervently about "burnout."

- A foster family's access to respite care services is highly dependent on the knowledge or resourcefulness of individual social workers and the foster parent's skill as an advocate.

- Policy developers prefer to address respite care and other support services in a cross-disability, pan-Canadian context, which often excludes those affected by FASD, as they do not fit into the established categories. Typically respite care has been considered in terms of the bed-ridden or elderly, but those with FASD are "out-and-about," which their services need to acknowledge.

- "Regular" respite will be unsuccessful unless it is very individualized and tailored to the specific needs and abilities of the individual with FASD. Diverse and flexible services are needed for FASD: Respite care could mean fewer children in the home or a centralized and localized program with brief, intermittent residential care and skill-building; it may mean more in-home supports, but clearly it needs to go beyond the traditional view of respite as home care for the bedridden and elderly.

- A pan-Canadian, cross-disability view of respite care must be sure to build the capacity of all systems to serve people with FASD. It is the most common cause of disability, yet the needs of those affected by it often go unacknowledged by existing systems.

- In 1996 the Canadian Association for Community Care (CACC), recently amalgamated with the Canadian Healthcare Association (CHA), published *Best Practices in Respite Services for Children: A Guide for Families, Policymakers and Program Developers.* The *Guide* was ordered for this project, but not received due to the amalgamation process; however, the project's Executive Summary specifically addresses the following sentiments echoed in all phases of *Putting Our Minds Together*:

    - Improve services to families caring for children with special needs who also have severe behaviour problems.
    - Create a one-stop-shopping approach that provides families with services in a respectful and dignified manner.
    - Design programs that are flexible, wide-ranging, (i.e. in-home, out-of-home, after school, etc.) and individually tailored.

- Other commonly mentioned barriers to respite care service for those affected by FASD: sparse work force, no funding or inadequate funding, and lack of community awareness about how to accommodate the needs of people with FASD and other disabilities.

- One jurisdiction said that respite care for FASD is not an issue because, as yet, they are not diagnosing, in spite of having numerous suspected cases.

- Jurisdictional responses to FASD start out stronger in western Canada and diminish steadily in an eastward fashion.

Models of respite Care. As mentioned earlier, the 2003 report on *Respite Services and Programs in Canada for Families Caring for People with Disabilities* prepared by Bob Stephen of Lutra Associates Ltd. for the Yellowknife Association for Community Living and the NWT Council of Persons with Disability, identified the typical respite services available across Canada. The responses received in Phase 1 of this project found that, as described by Mr. Stephen, respite services in Canada are generally comprised of variations of the following four options:

1. **In-home**, whereby a service provider comes into the home to relieve the primary caregivers in the care of the person with a disability.
2. **Out-of-home**, whereby caregivers are relieved when the individual requiring care is removed from the home to another situation, like a host family, group home, respite home/apartment, or long-term care facility.
3. **Community activities**, whereby individuals requiring care accompanied by a respite service provider participates in supervised community activities, including recreation or social events, summer camps, or other special programming.
4. **Emergency respite**, whereby caregivers are given a break in order to avoid a crisis in the family and, presumably, is one of, or a combination of, the three types of services mentioned above.

What information was gathered in Phase 2?

People living on reserves turn to the local First Nations Child & Family Services agency for assistance when seeking respite care services. For this reason, the role that FNCFS plays in respite care on-reserve was queried in Phase 2 by faxing a letter/questionnaire (see Appendix B) to Child & Family Service agencies or their counterparts in all provinces and territories. On-reserve health home care assists those with typical physical problems, but does not accommodate those with behavioural or emotional challenges. FNCFS is the only respite care option in most cases, as very few of the existing mainstream programs are available to those living on reserve. There may be other exceptions, but Community Living British Columbia (CLBC) has, in one area at least, a support worker/service provider for adults with FASD who live either on- or off-reserve. The service, however, is available only to those who meet the criteria for an intellectual disability. Those living on reserves can access the camps and some of the other sources of respite care that are specific to FASD, but they must leave the reserves to do so.

Of 96 Child & Family Services agencies contacted, 24% responded. Phone calls were made to improve the response rate. Respondents' comments are summarized as follows:

Note: Opinions expressed on FASlink about respite care/FASD in First Nations communities are incorporated in Phase 2 findings.

- By far the most common response was that there are no respite services of any kind.
- One agency provides respite care for those with disabilities, including FASD. Further queries about the nature of the services went unanswered.
- One agency representative said their community has no problem with FASD; there is just one suspected case. If needed, home care or respite services would be provided.
- Another agency representative reported no specific respite care program is available, but funds can be accessed for severe physical and mental disabilities, and the health centre provides the services. Overcrowding and inadequate housing in the First Nations served by this agency make it difficult to find placements for children in need. It appears that there are more pressing issues than respite care services for this agency.
- One agency signs a special needs agreement with non-foster caregivers that puts the child in care for up to 14 days per month in order to receive benefits that can be used to buy respite services. Presumably, if this is done for non-foster parents, respite funding must be available for foster families.
- Another agency tries to provide respite care for caregivers of people with disabilities by using an agreement like the one mentioned above. A major barrier, however, is getting caregivers for 35 dollars per day, which is what their funding agent allows them.
- Yet another agency allows for five days of babysitting per year, but only for children in care. This agency will not use agreements (like those mentioned above) to access services for those not in the system because it is felt that such agreements are strictly for child protection, and the need for respite services is not a child protection issue.
- One agency representative said that in her area respite care services are accessed by requests to individual Band Councils, which may or may not be approved. She cited an example of an elderly mother who cares for her son

who has a mental illness: When she becomes too tired, she temporarily has her son admitted to a psychiatric facility so she can rest and regenerate.

- Child & Family Services workers sometimes minimize the child's problems, as in "He has a little FAS" or "She has accidents." One very frustrated foster parent viewed this as an attempt to "broker children." She feels it is irresponsible of the province to license Child & Family Services agencies to operate in tandem with the mainstream social service agencies without the benefit of additional strengths or supports.

- Another reserve resident speaks of CLBC reaching out to First Nations living on reserve, but she acknowledges that there is "a lot of work to be done to open some of the doors both on the side of First Nations and on the side of the government agencies." She further notes: "One of the issues with our kids not getting services on reserve is that their families don't ask CLBC for help and the kids are not assessed."

What story did the first two phases tell about respite care and FASD in Saskatchewan?

Assume that you are in Saskatchewan parenting a child diagnosed with an FASD. The child has seriously disruptive externalizing behaviours, including meltdowns characterized by verbal and physical aggression. You may be trying to hold down a job, take care of other children, or just have some time to yourself, but the school's principal calls you frequently (or infrequently) to come and get your child. This is in spite of the school individualizing programming and providing a shared teacher-assistant. If you are lucky, you have a spouse, another family member, or friend to share this responsibility, but this may not be the case. Some days you can predict this will happen: the child did not sleep well; the only clean pants he had to wear were slightly snug; his brother had worn his favourite t-shirt; and he slept in and did not eat breakfast. You go to work rigid with anticipation of what the day will bring. At school there is a substitute teacher, who does his best but does not run the classroom exactly the same way as the teacher. The teacher-assistant may recognize that the child is on edge and needs a rest, something to eat, and the lights dimmed, but she must attend to the similar needs of other children. It does not take long for the meltdown to occur, which disrupts the learning of other children and often threatens the personal safety of school staff and students. Your only option is to leave work, with all the implications that may have, pick up your child or get home so you can be there when the child is dropped off. The supervision you must provide this child is unrelenting, as he sets fires, steals, and engages in other risky behaviour if given the opportunity. He cannot be left unsupervised to play with other children because of his aggression and inappropriate

sexual behaviours. Whether you are a Saskatchewan urban, rural, or reserve resident your only option when receiving the call from the school is for you to provide the supervision at home or find someone else to do it.

Even if the school manages the child's behaviour during the school day, and he is rarely or never sent home, chances are it requires a team of people and special programming to accomplish this. You, on the other hand, are alone and responsible for other children, who may also have special needs. You cannot even sleep soundly at night for fear of the child with FASD getting up, finding a lighter and setting fire to the house. You think you could manage if only there were times that others watch over this child or children for a weekend or an evening or two, so you start looking for respite care for your handsome son, with a low average IQ, who speaks like he knows exactly what life expects of him.

You heard about the Cognitive Disabilities Strategy (CDS), so you call the Special Services Coordinator in your area, if you live in Regina, Saskatoon, Prince Albert, or La Ronge. Since you live in Regina, you are encouraged to learn that with a diagnosis a Service Provider can assist your son in dealing with his areas of difficulty, which sometimes may mean taking him out of your home and working with him in a community context. The purpose is not to offer respite for the family, but it can have this effect. If respite is your main concern, the Coordinator will refer you to the local Community Living Division (CLD), but only if the child's IQ is 70 or below. This excludes your son and most others affected by FASD. If you are fostering your child, the Department of Community Resources may provide you with funds to hire respite care, but you would be responsible for finding a service provider and likely would have to set yourself up as an employer meeting Revenue Canada's regulations.

If you lived in a First Nation community, you would be told that you are not entitled to CDS services and that CLD does not case manage on reserve. If your child is fostered and in the care of First Nations Child & Family Services, you may or may not, depending on available funding be allowed some babysitting dollars, but the onus is on you to find a service provider. If your child is not fostered, you may be given the opportunity to place the child in a special care arrangement for the purpose of receiving the babysitting allowance, but this is subject to an individual agency's interpretation of the need for protection. If you are at your wit's end and barely able to function, you can appeal to Chief and Council for respite dollars, but this is subject to their deliberation: This will take time and may or may not happen. If the child with an FASD has a co-existing physical disability that requires regular medical attention, on-reserve homecare may provide assistance, but it is restricted to medical conditions that require medical interventions in the home or school. Chances are if you are living on reserve and caring for a child with FASD, you are a grandmother with diabetes, living on a restricted

income, providing care for more than one affected child, and you may or may not have phone service with which to seek out supports.

There may be other sources of respite care, but I have not heard about them either in the course of my work or through the contacts in this project. Fax and phone messages to CLD offices in Regina and Saskatoon went unanswered, so I am assuming that qualifying for their services continues to require that the IQ criterion be met and that they do not case manage in First Nations Communities. Even if there are respite care services for families struggling with FASD, they are not widely known by those of us who seek out such services on a regular basis.

Phase 3: What is an optimal model of respite care for Standing Buffalo?

The impetus for this project comes from Standing Buffalo residents repeatedly voicing the need for follow-up supports for those with an FASD diagnosis and their families. They know with certainty that there is a need for respite care in their community and they have a vision of the form it should take. These residents are familiar with, or have been directly involved with, the Targeted Behaviour Plan/Program in the schools, but acknowledge that some students' and young people's needs will never be entirely met within the confines of a school. They want a holistic, comprehensive approach that brings all the major systems together, collaboratively responding to the particular needs of those with FASD and their families.

In this phase a few (16) Standing Buffalo residents were provided with information they can use to drive community discussions toward a specific proposal for a respite care service model that meets their needs. The 16 people were chosen because in my work on Standing Buffalo over the years they voiced interest in the topic. These Standing Buffalo residents were presented visually and verbally with a draft of this report then asked if it accurately represented their views on respite care and FASD, and if it did so in a respectful way. The conversation that ensued was entirely supportive of the contents of the report. The band's FASD support worker and mentor was provided with a two-page handout (see Appendix C) for her to distribute throughout the community in order to generate discussion and create momentum for further delineation of an optimal model of respite care for Standing Buffalo.

As described by Bob Stephen in his report, respite services in Canada are generally comprised of variations of the following four options: in-home, out-of-home, community activities, and emergency. The 16 Standing Buffalo participants were informed of these four options, as well as a fifth. This fifth option may not exist anywhere in Canada, but was

mentioned by a respondent in Phase 1 and, repeatedly, has been dreamed of by several Standing Buffalo parents. These are parents stressed by the challenges faced when their children are excluded from school for serious behavioural infractions, in spite of the advances made with the Targeted Behaviour Plan and extensive FASD education for school staffs, and depleted by the relentless supervision they are required to provide for 24 hours a day, 7 days a week, 52 weeks a year. This option is superficially described as follows:

> *The respite facility would be located on Standing Buffalo and function as a **brief, intermittent** service staffed by a qualified special education teacher and support staff that are well trained in positive behaviour interventions and guided by an awareness of the strengths and weaknesses of those with an FASD. It would be supported by the collaboration of multiple systems: health care, child welfare, education, vocational/rehabilitation, mental health, justice, chemical dependency, and organizations working for the benefit of people with disabilities.*
>
> *It would be a comprehensive service accessible during the school day, as well as evenings and weekends. The purposes of the service would be to provide:*
>
> 1. *respite for parents by ensuring that when their children are sent to school in the morning, they are safely and productively engaged until the school day is over, even if there is a breakdown in their school situation.*
> 2. *respite for parents whose children safely and productively spend their days at school, but who need time for rest and regeneration some weekends and evenings.*
> 3. *a place where the needs of those with FASD are addressed in an attempt to prevent the development of, or diminish the effects of, secondary disabilities that seriously threaten the children's wellbeing.*
> 4. *a service to assist those with FASD in their transition to adulthood.*
> 5. *an environment welcoming to individuals and organizations who can feed the artistic, musical, and mechanical aptitude of the students: Organizations like the Mackenzie Art Gallery Outreach program, First Nations University of Canada, various "trades" organizations, and individuals from the community with skills to share.*
> 6. *an environment with physical adaptations and modifications to address the many sensory issues (e.g., light, noise, textures, patterns, air quality, and spatial arrangements) characteristic of those who are alcohol-affected.*
> 7. *computer-based and teacher-guided access to academic and vocational skill development, so education is ongoing whenever possible.*

8. *a central source for the provision of FASD-related information and resources.*
9. *a sacred place for those with an FASD that embodies Dakota principles and spirituality.*

What are the next steps?

This project is limited by a low response rate in Phase 2 and by the breadth of the overall project. When reminder calls were placed, one person told me he did not respond because the answer to all the questions was "No"; perhaps others felt the same. Each of the three phases should have been a project in itself. In effect, Phase 3 sets the groundwork for the next step, which it is hoped will become its own project. Although the search for answers is not exhaustive, it clearly reveals that families affected by FASD in Canada have an overwhelming struggle to qualify for, and receive, respite care services; the situation is particularly desperate for those living in First Nations communities. Furthermore, the project found that the few respite care services specific to FASD are not models of interest to Standing Buffalo residents. The Public Health Agency of Canada's FASD National Strategic Projects Fund has as one of its goals to create new capacity where no previous capacity exists, and the results of Phases 1 and 2 demonstrate the need to create capacity in respite care services for those affected by FASD.

Phase 3 describes Standing Buffalo's plan to address gaps and provide opportunities in order to improve outcomes for individuals in their community affected by FASD. Standing Buffalo residents acknowledge the continuing need for FASD education/awareness, prevention, and diagnostic services, but respite supports are desperately needed in order to keep FASD-affected individuals in the community where they are loved and cared for by their Dakota families. The description of the Fifth Option is merely the seed of an idea yet to be developed into a full-fledged plan should further funding be provided.

This early, as yet undeveloped, plan is characterized by:

- *Collaboration* that involves the building of partnerships both on- and off-reserve.
- *Inclusion,* in that it addresses the respite care needs of foster, adoptive, birth, and kinship families.
- *Understanding compassion, and respect* (i.e., no blame, no shame).
- *Cultural sensitivity,* in that Dakota people will be guiding a Dakota response to respite care.
- *Sustainability,* in that it will be a model to inform the pan-Canadian approach to respite care and FASD.

- *Comprehensiveness,* in that the proposed project considers all the issues discussed in the ***What factors inform this project?*** section of this report.

It is recommended that the next step be as follows:

A representative of File Hills Tribal Council Health write a proposal for funds to hire a researcher to further explore with Standing Buffalo residents a specific plan that encompasses the essence the Fifth Option as described in this report. It is hoped that the resulting exploration and delineation will lead to another step: the creation of a respite care service on Standing Buffalo that meets the needs of families affected by FASD.

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APPENDIX A: Letter/Questionnaire for Cross-Canada Contacts

Dear ___________________________,

I am contracted by the File Hills Qu'Appelle Tribal Council to determine what respite care services are available in Canada for individuals with a fetal alcohol spectrum disorder (FASD). The first part of the project is to inform the second part, which is to determine the type/s of respite care services that residents of Standing Buffalo First Nation are interested in developing for individuals in their community between the ages of 12 and 22 who are prenatally affected by alcohol.

I have been involved in the assessment of FASD since 1998, and your name was selected from lists of fellow conference attendees and other FASD-related sources of information. I have targeted a cross-section of Canadians who may lead me to a valid sense of the extent to which respite care services exist in our country for those affected by an FASD. **It is just as important for you to report that you are unaware of any respite care services as it is to report their existence.**

My contact information is available at the top of this page. Please return this page to me as soon as possible and by the means that is most convenient for you. Thank you so much for your assistance.

1. Do you know of a respite care program **specifically** for anyone of any age who is affected by prenatal maternal use of alcohol?

   (circle: YES or NO)

2. If you circled **YES**, what is the name and contact information of the person who can provide me with information about the type of respite care offered?

   Name:____

   Contact information:________________________________

3. In the space below, and/or on the back, please write comments you have about respite care for those with FASD.

APPENDIX B: Letter/Questionnaire for First Nations Child & Family Services Contacts

I am contracted by the File Hills Qu'Appelle Tribal Council to determine what respite care services are available in Canada for individuals with a fetal alcohol spectrum disorder (FASD). The first part of the project is to inform the second part, which is to determine the type/s of respite care services that residents of Standing Buffalo First Nation are interested in developing for individuals in their community between 12 and 22 who are prenatally affected by alcohol. In most cases, Child & Family Services is the only source of respite care for those who live in First Nation Communities, so it is important to hear from you. I would appreciate it if you would take a moment and respond to the following questions:

1. Do you offer respite care services for those with a disabled family member?

   (circle: YES or NO)

2. If YES, do the families of those affected by FASD qualify for your respite care services?

   (circle: YES or NO)

3. If you answered YES to Question #1, please describe the types of respite care services available.

Thank you so much,

APPENDIX C: Information Sheet for Standing Buffalo Residents

For this project:

- respite care service is seen as a caregiver break, but also as a service that meets the needs of children and youth affected by prenatal exposure to alcohol.
- "child" refers to a person between the ages of 12 and 22 who are suffering the effects of prenatal exposure to alcohol.
- "parent" refers to anyone who cares for these children on a regular basis.

A 2003 report on *Respite Services and Programs in Canada for Families Caring for People with Disabilities* prepared by Bob Stephen of Lutra Associates Ltd. for the Yellowknife Association for Community Living and the NWT Council of Persons with Disability, identified the typical respite services available across Canada. The responses received in Phase 1 of this project found that respite services in Canada are comprised of variations of the following four options:

5. **In-home**, whereby a service provider comes into the home to relieve the primary caregivers in the care of the person with a disability
6. **Out-of-home**, whereby caregivers are relieved when the individual requiring care is removed from the home to another situation, like a host family, group home, respite home/apartment, or long-term care facility.
7. **Community activities**, whereby individuals requiring care accompanied by a respite service provider participates in supervised community activities, including recreation or social events, summer camps, or other special programming.
8. **Emergency respite**, whereby caregivers are given a break in order to avoid a crisis in the family and, presumably, is one of, or a combination of, the three types of services mentioned above.

The search for respite care services specific to FASD was not exhaustive, but the ones that were found roughly fall into one or more of the above options. The following respite care services are specific responses to FASD:

- Cold Lake, Alberta: Lakeland Centre for FASD Summer Camp for 8 to 13 year olds for 5 days in the summer.
- Calgary, Alberta: Enviros Wilderness School Association runs Respite Care Connections, which offers fee-for-service respite for families caring for children with behaviour challenges to assist in maintaining them in their families and communities. Families are provided with a break while the children participate in community-based activities or stay overnight in a family-based setting provided by foster parents.
- Burns Lake, B.C.: Whitecrow Village Camps are specifically designed to allow for those with FASD, parents, and professionals to learn, work, and play together in a camp setting in order to create a common language and understanding of FASD.
- Clinton, ON: Huron Respite Network provides respite services to families affected by disabilities, and FASD is included.
- Calgary, AB: Renfrew Educational Services provides Stepping out on Saturdays (SOS) a full day camp for those diagnosed with FASD – 3 Saturdays per month for children from 3 to 10. Trained staff and strategies are integrated into the camp activities.
- Yellowknife Association for Community Living's respite services are not specifically for FASD, but they do not have an IQ requirement and, if the disability is FASD, they provide training in FASD for the service providers.

Appendix C continued

None of the above services speaks to the option that has been discussed on Standing Buffalo, and it may represent a fifth option of respite care service provision that does not exist anywhere in Canada. It is an idea that is in its infancy, so this fifth model is very superficially described as follows:

Fifth Option. *The respite facility would be located on Standing Buffalo and function as a* ***brief, intermittent*** *service staffed by a qualified special education teacher and support staff that are well trained in positive behaviour interventions and guided by an awareness of the strengths and weaknesses of those with an FASD. It would be supported by the collaboration of multiple systems: health care, child welfare, education, vocational/rehabilitation, mental health, justice, chemical dependency, and organizations working for the benefit of people with disabilities.*

It would be a comprehensive service accessible during the school day, as well as evenings and weekends. The purposes of the service would be to provide:

- *respite for parents by ensuring that when their children are sent to school in the morning, they are safely and productively engaged until the school day is over, even if there is a breakdown in their school situation.*
- *respite for parents whose children safely and productively spend their days at school, but who need time for rest and regeneration some weekends and evenings.*
- *a place where the needs of those with FASD are addressed in an attempt to prevent the development of, or diminish the effects of, secondary disabilities that seriously threaten the children's wellbeing.*
- *a service to assist those with FASD in their transition to adulthood.*
- *an environment welcoming to individuals and organizations who can feed the artistic, musical, and mechanical aptitude of the students: Organizations like the Mackenzie Art Gallery Outreach program, First Nations University of Canada, various "trades" organizations, and individuals from the community with skills to share.*
- *an environment with physical adaptations and modifications to address the many sensory issues (e.g., light, noise, textures, patterns, air quality, and spatial arrangements) characteristic of those who are alcohol-affected.*
- *computer-based and teacher-guided access to academic and vocational skill development, so education is ongoing whenever possible.*
- *a central source for the provision of FASD-related information and resources.*
- *a sacred place for those with an FASD that embodies Dakota principles and spirituality.*

This is for you to think about until the next phase of this project asks you to describe the type of respite care service that you consider optimal for your community.

Questions may be directed to Zelda Bear at the Standing Buffalo Health Station.