



First Nations of Quebec and Labrador
Health and Social Services

Exploring Successful
Models of Respite Care
for First Nations
Communities
in Quebec

March 31st, 2007





Report on Successful Models of Respite Care for First Nations Communities in Quebec

Published by :

First Nations of Quebec and Labrador

Health & Social Services Commission (FNQLHSSC)

250, Place Chef Michel Laveau, Wendake, Quebec G0A 4V0

Telephone: (418) 842-1540

Fax: (418) 842-7045

Web site: www.cssspnql.com

Graphic Design:

Christiane Vincent

Acknowledgements



TABLE OF CONTENTS

FOREWORD	4
1. INTRODUCTION	5
1.1 Background.....	5
1.2 Objective	5
1.3 Methodology.....	6
2. RESPITE CARE.....	7
2.1 General	7
2.2 Types of Respite Care.....	8
2.2.1 In Home.....	8
2.2.2 Out of Home.....	9
2.3 Guiding Principles.....	11
3. EFFECTIVENESS OF RESPITE CARE PROGRAMS.....	12
4. MODELS/CASE STUDIES OF RESPITE CARE	13
4.1 In Home Models	13
4.1.1 Labrador (Labrador Grenfell Health Board)	13
4.1.2 Nunavut (Department of Health & Social Services)	14
4.1.3 Kinosao Sipi Minisowin Agency	14
4.1.4 Yukon (Yukon Territorial Government, Health & Social Services)	15
4.1.5 Self Managed Care Program - Winnipeg, Manitoba	16
4.1.6 North Okanagan Neurological Association Child Development Centre	16
4.1.7 St Mary's College and Sacred Heart Parish, Notre Dame Indiana.....	17
4.2 Out of Home Models	18
4.2.1 Lakeland Centre for Fetal Alcohol Spectrum Disorder – Cold Lake, Alberta	18
4.2.2 Ontario Ministry of Community and Social Services Guidelines (2000).....	18
4.3 Situation of Respite Care in Quebec First Nations Communities.....	19



5.	RECRUITMENT & TRAINING.....	21
5.1	General FASD Training Recommendations.....	22
6.	BEST PRACTICES.....	23
7.	FUNDING.....	25
7.1	Federally-funded Respite Programs.....	25
7.1.1	First Nations and Inuit Health Branch, Health Canada	25
7.1.2	Veterans Affairs Canada (VAC).....	26
8.	AVAILABLE INFORMATION RESOURCES.....	27
9.	SUMMARY OF IMPORTANT CONSIDERATIONS	28
10.	NEXT STEPS FOR FIRST NATIONS COMMUNITIES.....	29
	REFERENCES.....	31





FOREWORD

Health Canada, in its Principles of Child and Youth Health (1993), asserts that children must be valued and felt to be valued for their intrinsic worth, not just as a resource for the future. «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.»

In particular, among First Nations, where the effects of multi-generational trauma still continue to tear away at the traditional fabric of our communities, support is urgently needed for families who are caring for children/ youth and adults with FASD, or other special needs.



1. INTRODUCTION

1.1 Background

The Health Commission is an administrative body that oversees health and social services on behalf of the member communities of the Assembly of First Nations of Quebec and Labrador (AFNQL). The mission of the FNQLHSSC is to improve the physical, mental, emotional and spiritual well being of First Nation and Inuit individuals, families and communities in respect of their local autonomy and culture.

This report represents one of the Fetal Alcohol Spectrum Disorders (FASD) initiatives undertaken by the Health Commission to provide information to communities as a means of assisting the communities in establishing services and programs for FASD families.

1.2 Objective

The 2003 First Ministers' Accord on Health Care Renewal provides for substantial investment in home care as an increasingly important component of the health care system in Canada¹. As family caregivers play a growing role in providing care, their need for respite, or time off, is also growing. The purpose of respite is to give the caregiver a break in order to avoid burnout or crisis, to enable the caregiver to take care of necessary activities outside the home, and to support a healthy relationship between the person receiving care and the caregiver. Respite care for families of children with special needs, such as FASD, can also provide a positive and rewarding experience for the child, and strengthen the family by reducing stress.

The main goal of this project is to provide an information report on various types of successful models of respite care and support for FASD families that could be used by the First Nations communities in Quebec, contingent upon the situation and needs of the community. Therefore the objectives upon which this report is based are:

- To explore various models of respite care and services available for FASD families within the region and other provinces;
- To look at established standards for respite care and support for FASD families;
- To investigate what types of training exist or are recommended for respite care workers/providers;
- To determine the possibility of partnerships with existing agencies providing respite care and support for FASD families;
- To report on a survey of First Nations communities to determine if there are existing models of respite care already implemented for FASD families, and to examine the models, organization, support, training and standards that may exist. In addition, to highlight any specific needs which have not yet been raised in this regard.

¹ Janet Dunbrack for Health Canada (2003). *Respite for Family Caregivers: An Environmental Scan of Publicly-funded Programs in Canada*, February.



1.3 Methodology

The following sources were investigated to gather as much information as possible for this report:

- Associations; service agencies; and government reports & guidelines.
- Academic research papers using electronic databases (ERIC, MEDLINE, CINAHL, HealthStar, OVID, PAIS, and Canadian Electronic Publications Database).
- Websites (private organizations; associations; etc.).

Telephone interviews were conducted with service providers in other aboriginal jurisdictions where some form of respite care was being offered. These included Labrador, Nunavik, Nunavut, NWT, and the Yukon.

A needs assessment survey was sent out to the First Nations communities in Quebec under the Health and Social Services Commission to determine what was being done in the communities to provide this type of care, and what the needs would be.



2. RESPITE CARE

2.1 General

Today, most children with disabilities live at home with their families as opposed to being placed in institutions as they were for most of the 20th century (Valentine, 2001). Unfortunately, this notable change does not mean that disabled children are full and active members within their communities. Despite the policy attention directed to children in recent years, children with disabilities have at times been excluded and the particular needs of their parents overlooked; for First Nations children and families the situation is even more prominent (Valentine, 2001).

Access to sources of support such as disability support services, health services, equipment, homecare, education, child care and recreation are just some of the challenges faced by special needs children and their families (Hanvey, 2002). For those living in remote, poorly resourced communities the difficulties are even greater. In this sense, First Nations children on reserve are particularly vulnerable; and although there are a large number of Aboriginal children affected by disability, service delivery is consistently poor or non-existent in Aboriginal communities (Hanvey, 2002).

Brust, Leonard, & Sielaff (1997) worked with Minnesota's Services for Children with Handicaps to survey families with children with special needs. The study evaluated the time parents spend providing extra caregiving tasks for their special needs child. They found that the mothers responding to the survey averaged more than 12 hours per day caring for a child with disabilities. Fifty-four percent of this time was spent watching the child and providing emotional support. Mothers in this study cited the time demands of caring for a special needs child as contributing significantly to their psychological distress². As noted by Campanale (1997), constant caregiving is exhausting. It puts the caregiver at risk physically, emotionally, and spiritually and is considered a risk factor for abuse and neglect³.

Even though public policy has determined that the best place for special needs children is at home with their families, assistive services for these families have not consistently been put into place. Many families find themselves overwhelmed by the financial, physical, and psychological demands of caring for a child with special needs 24 hours a day, seven days a week, 52 weeks a year. Without community support, these day-to-day demands run the risk of exhausting, possibly destroying the family. Sokol (1995) found that the more severely impaired and functionally dependent the child, the higher the probability that the family will be emotionally and economically depleted as time passes. Sokol concluded that there should be support services available in each community that would enable visiting nurses, home-makers, and respite care providers to go into the home to assist families with special needs children⁴.

Children with special needs such as FASD require a variety of services to ensure their health, well-being and quality of life. Such children usually require intensive care on a continual basis. For their families or foster families, providing the level of care required can be a significant burden over time. Such families often have a great need for help with time to run errands, time to visit friends, spend time with their other children or just take a break from providing continual care to a special needs child.

² Brust, Leonard & Sielaff (1992). *Maternal time and the care of disabled children*. Public Health Nurse.

³ Campanale (1997). *Respite care: lightening the caregiver's load*. Journal of Clinical Nursing.

⁴ Sokol (1995). *Creating a community of caring for families with special needs*. Journal of Obstetrics and Gynecology. Neonatal Nurse.



However, it can be very difficult for these families to make arrangements for adequate and appropriate care for their child from within their networks of extended families or friends. They may require «respite» services, which can be defined as follows:

«the shared care of a person with an illness or disability, either at home, in the community, or in a short term residential setting, in order to give the family a break from the routine of care giving.»

Many of the papers reviewed described the need for respite care and the lack of funding or programs to meet those needs. While there are several sources describing types of respite care and exploring specific case studies, there is a general lack of information about the comparative benefits of various models.

2.2 Types of Respite Care

The various types of respite care services described in the literature were driven by consideration of four primary factors:

1. **Purpose:** Primary purpose – where the intent of the service is to provide family with respite from care giving. Secondary purpose – to meet needs of individual with disability and respite occurs as by-product (e.g. day camp or activity programs).
2. **Duration:** Short term - a few hours up to one day. Longer term - one week or more, typically facility-based out of home care.
3. **Location:** In home (either with family present or to allow family to go out). Out-of-home includes variety of options (other home, residential home, hospitalization, day/week activity camps).
4. **Provider:** May come from a variety of backgrounds such as: paid professionals; people with training in nursing, education, child care, recreation or rehabilitation; friends; students; homemakers; parent groups; or community support groups.

Generally, respite care is categorized as “in home” or “out of home”.

2.2.1 In Home

In Home Respite Care is provided for family/caregivers by an intervener coming to the home for a number of hours per week to give the caregiver time off. During the time off, the family caregiver may remain in the home or leave. The intervener is either paid for the service or functions as part of a community network. The customary amount of time for in-home respite care is usually 2 – 4 hours, once or twice a week.

The stated advantages of using in-home services are seen to be:

- Child and family routines are preserved;
- Child’s surroundings are familiar to him/her;
- Any special equipment required by child is on site;
- Transportation is not required;

- Respite care giver may be able to care for other children in the family at the same time (allowing parents to go out);
- Respite care giver may be able to assist with housekeeping chores simultaneously.

2.2.2 Out of Home

Out of Home Respite Care involves leaving the special needs child in a facility (hospice) or an activity camp for a period of one day or longer. However, First Nations and Inuit communities tend not to use facility-based respite services because such facilities are usually far from their communities and the child's health often declines when they are removed from their community and cultural context.

The perceived advantages of Out of Home services are as follows:

- The child is exposed to a new routine;
- The child has the opportunity to socialize and develop independence;
- The parents can concentrate on their other children or other activities;
- The family does not have to leave their home to experience respite.

The literature shows that there are no defined rules about what constitutes respite care. The objective is to create relief for the family while enhancing the quality of life for the special needs child. Therefore, there is a lot of room for creativity and individual ideas about what kind of services meet those needs.

The Canadian Association for Community Care offers the following list of examples of types of Respite Care⁵:

1. Matching and Brokerage Programs: Recruit volunteers/care workers from the community and match them to families. Care is offered either in the family home or the home of the volunteer/worker.
2. Parent Respite Care Cooperatives: Organized by the families themselves, and may be overseen by a coordinator. Effectively it is an exchange of direct respite care between parents with special needs children.
3. Volunteer Families: Match families of children with special needs with host families in the community. Host families commit to specific amounts of time to care for child in their home. An "agreement for service" contract is entered into between families to ensure host families follow through on their commitment and protects them from damage to their homes.
4. Buddy Programs: Recruit and train people to provide companionship to children with special needs. Activities may include sports, crafts, shopping, recreational and community events.

5. CACC (1996). *Best Practices in Respite Services for Children – A Guide for Families Policy Makers and Program Developers*, Canadian Association for Community Care, June.



5. Summer Camps: With recreational activities and medical support for special needs children.
6. Group Day Care (may include after school programs): This type of service is licensed and usually provided through an agency that offers a range of services.
7. Group Respite Facilities offer only respite care. They offer both short and long term respite services and allow the child to socialize and to develop peer relationships.
8. One Day Drop in/Parents' Day Out Programs: Usually consist of both paid workers and volunteers. Programs are recreational and siblings may participate when space allows.
9. Residential Treatment Facilities may reserve one or two spaces for respite care.
10. Community Residences sometimes reserve one or two spaces for respite care or admit children for short periods of time in emergency situations. Care is provided for both adolescents and adults. They often work with agencies who make the referrals.
11. Paediatric Nursing Homes/Hospitals/Rehab/Extended Care offer some respite care for children who have medical needs. They function primarily as long term care facilities.
12. Hospice/Palliative Care Placements offer short and long term respite for families. Comprehensive care programs are provided to address the medical and psychological needs of the child, along with play activities. Counselling and training for families learning specialized medical and care techniques is also provided. In some hospices, the entire family including pets can move in for a number of days, a number of times per year, to give parents a break from the total responsibility for care while continuing to have contact with the child, which is an effective model of service for children who are chronically or terminally ill.

2.3 Guiding Principles

The following guiding principles and values would be important to the planning and delivery of respite care services in First Nations communities:

- Each child/youth/adult is part of a family that is unique and has different needs;
- Each child, youth and adult has a right to a permanent home and stable relationships within his/her own community;
- Families of children/youth and adults with disabilities or chronic illnesses have the same needs as other families;
- Family support has a place within the network of community services which include health, education and social services;
- Providing support to families allows them to take greater control over their lives, and allows them time to take care of themselves, and other children/members of the family unit;
- The needs for support should be identified and agreed to by the family;
- Providing support services promotes the inclusiveness of all community members in the life of the community;
- Services must be flexible, accessible and comprehensive to respond to a wide array of family-identified needs;
- Responsibility and coordination for respite care should be shared by the family and community services;
- Standards of care should be developed by the community to guide the delivery of respite services;
- Respite care workers should be recruited and trained according to the standards of care developed by the community;
- Respite care should be seen as part of an overall package of support and caregiving services for families of children/youth/adults with disabilities and chronic illnesses.



3. EFFECTIVENESS OF RESPITE CARE PROGRAMS

The Canadian Association for Community Care (CACC) in studying respite care in three Ontario regions, Metropolitan Toronto, Sudbury and Ottawa-Carleton, stated that parents and professionals found that respite services are an absolutely essential aspect of home care for many children with special needs and their families⁶. In particular, respite is a quality-of-life issue in families where children have medically fragile, complex, technology-dependent conditions. It is necessary for the physical, emotional, and social health of all family members and the family as a whole.

A coordinated, comprehensive program of services for children with special needs – in which respite is an integral part – contributes to the health of the community. It does so, by assuring that families who have children with special needs at home are contributing members of their communities, and are able to prepare citizens of the future who are as capable as they can be.

Several papers reviewed in the literature examined the families' perspectives on the effectiveness of various types of respite care. Some common themes emerged:

- Parents consistently described a combination of three types of care as best meeting their needs:
 - In-home, “babysitting” style short breaks by family/friends;
 - In-home 3 – 4 hour breaks by trained care worker; and,
 - Occasional (monthly) out-of-home overnight or longer at respite facility/activity camp.
- Parents also observed that a significant challenge is that the support level (i.e. respite care from family/friend and agencies) tends to decline when child gets older yet complexity and intensity of child's need is often greater.

It is worth noting a comment made when interviewing the Director of Child, Youth and Family Services at the Labrador Grenfell Health Board. She indicated that it can be difficult for them to assess the effectiveness of respite services to families with FASD children because parents sometimes have unresolved addictions problems, and can be FASD themselves. Therefore, the child's needs are even more complicated since the families' parenting capabilities can also be impaired.

6. CACC (2002). *Best Practices in Respite Care for Families of Children with Special Needs*. Phase Three Report on 3 Ontario Communities.



4. MODELS/CASE STUDIES OF RESPITE CARE

There are various examples of respite care service models currently in place in Canada, and the U.S. However, with a few exceptions, most of these models exist in urban areas and may not be easily modified to suit the needs of remote, and/or smaller First Nations communities.

The following is a summary of the most relevant of the respite care service models that were reviewed.

4.1 In Home Models

4.1.1 Labrador (Labrador Grenfell Health Board)

- At this time, the Labrador Grenfell Health Board – a provincial Board – delivers a range of services including respite care services for special needs children/families within all Labrador Communities through 2 programs: Family Rehabilitative Services program and Supportive Services for Families.
- It is anticipated that within the Nunatsiavut settlement region these responsibilities will be transferred to the Nunatsiavut Government over the next two years.
- The entry point for the child and their family is usually either the Community Health Centre or the local Social Worker. The child is assessed by a multi-disciplinary team, which may consist of a Social Worker, Child Management Specialist, and, sometimes a medical professional.
- In their assessment of eligibility for respite care, the team uses a formalized set of criteria that focus on assessing evidence and extent of developmental disability generally. That is, the family and child's eligibility is based on the child's capacity and needs rather than a diagnosis of specific disorder (FASD, Down's Syndrome, etc). *This approach has enabled them to avoid limiting services for FASD/E children (where clear diagnosis is often difficult).*
- The assessment of eligibility and need included a determination of the number of hours per week required for respite care services.
- Funds for "x" hours of respite care services are given directly to the parents. The parents identify and make arrangements with a community Respite Care Worker. They can negotiate with the worker both the frequency and type (in-home versus out of home) based on their preferences.
- Respite Care Workers are community members, very few have training. They are chosen by the client family, and based, usually, on willingness and/or comfort with the individual. Families usually choose friends (they are not allowed to choose family members).
- Lack of training for the Respite Care Workers and the families with special needs children is a significant challenge. The Grenfell Board is presently seeking funding to provide some community based training in the coming year (2007).



4.1.2 Nunavut (Department of Health & Social Services)

- In 1999/2000, Nunavut undertook a pan-territorial consultation to determine how to administer the federal governments Home & Community Care funds. The decision was made for HCC services to be administered and delivered by the territorial health department (GN) through the existing health care system in the Nunavut communities. Respite care services were one of the communities' priorities although emphasis was placed on care for elders and disabled persons.
- The funding for respite care primarily comes through the HCC program monies plus a contribution from the GN.
- Nunavut does provide respite care for children with special needs, called "homemaking care", on ad hoc basis (i.e. not formally written in HCC service document).
- The entry point for the child, like Labrador, is through the community health and/or social services system.
- Also like Labrador, assessment of eligibility and need are based only on the extent of developmental disability, not on age or diagnosis of special needs individual.
- Local Health Centre (nurse or, if available, homemaker nurse) identifies a family with needs, make an assessment of requirements and designs a homemaker plan with family.
- In-home respite care services are provided by a Personal Care Worker (or nurse if needs are severe).
- Services provided are a) relief to allow parents to leave home for period of time; b) assist parents at home with childcare and homemaking chores.
- Personal Care Workers are community members with local training (provided by GN). They are employees of GN HSS.
- Training was identified as a significant challenge. At present training is adhoc and there are no training standards. The GN is currently working with Nunavut Arctic College and Yukon College to standardize and formalize Personal Care Worker training.
- Note: The interview emphasized the importance of including community participation in any program (e.g. forming a parent group).

4.1.3 Kinosao Sipi Minisowin Agency

- The Kinosao Sipi Minisowan Agency (KSMA) is the child & family service provision agency of the Norway House Cree Nation. Over the past several years, they have been engaged in an initiative to create community-based services for families with children with special needs.
- Unfortunately, they encountered a funding barrier caused by a mandate gap between First Nations & Inuit Health Branch (responsible for health services on-reserve) and Indian & Northern Affairs Canada (responsible for child welfare services). Effectively, neither federal department felt responsible for providing in-home services for families of children with special needs. Ultimately, KSMA secured funding that came from the Norway House Cree Nation Implementation Trust Fund.
- They were able to secure \$45,000/yr to implement a three-year, tri-level pilot program.
- The three levels of the program are: 1. Rehabilitative Therapy; 2. Case Managers; 3. In Home Services – including respite care.

- Included in their program are training workshops to educate/train parents & caregivers.
- Another important aspect of their program is a community volunteer parent committee. This committee organizes monthly activities for children & families in the program.

4.1.4 Yukon (Yukon Territorial Government, Health & Social Services)

- The Yukon Territorial Government (YTG) offers respite care services to families with special needs children through their Family & Children's Services.
- The child can be referred by local service providers (health care, social work, educators) or friends of the family in need. Once identified, the child is assessed for eligibility based on their developmental impairment, not on a specific diagnosis.
- Children are assessed based on severity of need as Level 1, 2 or 3. The needs associated with each level are defined within their Respite Care Services policy as follows:
 - Level 1: The child is fully ambulatory, independently mobile, requires no special equipment, needs assistance with activities of daily living including guidance and monitoring, requires close supervision but not specialized behavior programming or intervention.
 - Level 2: The child has: identified behavior problems requiring close supervision and intervention (such as aggressive acting out, tantrums, stealing, self-harming), requires monitoring and assistance with activities of daily life.
 - Level 3: The child is: non ambulatory requiring lifting, needs specialized medical attention, requires constant one-to-one attention and specialized behavior intervention, needs assistance dressing, feeding, bathing and toileting beyond age appropriate levels, may exhibit behaviors posing a risk to self or others.
- The number of hours of respite service and associated funding are tied to these levels as follows:
 - Level 1: 40 days per year (3.33 days per month) at up to \$30/day
 - Level 2: 56 days per year (4.66 days per month) at up to \$50/day
 - Level 3: 80 days per year (6.66 days per month) at up to \$70/day
- There are no trained community respite workers, so the caregivers are usually identified by the parents from within their community (although relatives are allowed, the caregiver may not live with the family). The YTG has a network of foster parents who can also be called upon to provide services if the parents are unable to identify a suitable caregiver.
- Funds are either paid directly to the respite caregiver or, based on the family's functionality, given to the parents to make their own payment arrangements.
- The program deliberately seeks to be non-prescriptive in terms of what kind of respite services parents choose (e.g. whether the care giver takes the child out of the family home versus caring for the child in the family home). They believe the parents' know best what form of respite they need.
- One disadvantage of the YTG program, which was pointed out by the Director who was interviewed, was that their program requires a financial contribution from parents over a certain income level. The Director was firm that this is not a desirable element of their program – she feels that the financial burdens on families with a special needs child are already excessive (and often unrecognized) and they should not be required to provide contribution funds to be eligible for services. They are presently seeking to change this aspect of their program.



4.1.5 Self Managed Care Program - Winnipeg, Manitoba

- The Self Managed Care Program (SMC) was developed in 2001 at Winnipeg Child and Family Services as an initiative designed to test an alternative model for provision of respite services.
- Client families were primarily urban (66%) with minority rural (34%)
- Similar to the Labrador approach, the SMC model of respite services provides funds to families involved with the provincial/local child welfare organization to obtain respite services.
- Parents who require respite services can select and directly compensate care providers with funds provided by the organization. Parents take an active role in determining the services they need and are responsible for identifying a care provider, scheduling respite hours and budget the allotted funds.
- Respite funding is provided for the assessed number of hours needed for the service plan, as well as up to 5 hours per week for self care.
- The hourly rate is based on Level 1 Family Support Worker scale (\$7-\$8/hr).
- Respite funds are provided in advance of the service, either 2 week or 4 week intervals, depending on the family's preference.
- Parents are encouraged to identify care providers within the family's existing social network or to develop a care provider resource in their community.
- A goal of SMC is to improve the family environments and increase the likelihood of positive outcomes for parents and children. By providing parents with respite funds that they can manage at their discretion, the SMC program is believed to empower parents through a sense of partnership and control over decisions concerning their child's care provider.
- The SMC operates on the principles that include: children belong with their families; when given the opportunity, parents will make good choices for the care of their children; relationships between families and the organization should be empowering.

4.1.6 North Okanagan Neurological Association Child Development Centre

- A non-profit society providing services including respite care for children with special needs in Vernon, B.C.
- The respite care team is a group of 19 individuals, 1 coordinator and 18 respite workers
- Respite is provided in the home of the child or in the home of the respite worker
- Spaces are limited to 30 families.
- The respite care program is funded through the B.C. Ministry of Children and Family Development. The Ministry also determines eligibility of families and children to receive the services.
- Once in the program, it is long term (birth to 18 years)
- Respite workers have experience with children or youth with special needs and perform the respite care work on a part-time basis.
- Family members are also involved in the program as volunteers.

4.1.7 St Mary's College and Sacred Heart Parish, Notre Dame Indiana

- An initiative born of collaboration between local families with special needs children and the nearby nursing college (Saint Mary's College).
- Saint Mary's College incorporated a pediatric respite program into their nursing education.
- Prior to the development of the respite program, Saint Mary's nursing students were placed in one of three sites to work with children with special needs: at a special needs classroom in the local school district, a center for developmentally challenged individuals of all ages, or a short-term respite care facility that provided respite for all ages. The pediatric respite experience provided a viable, and now preferred, alternative to these clinical experiences
- Families in need join the program (referral method unclear) and student nurses are assigned as respite care workers to specific families and are required to provide 14 hours of care per semester as part of their pediatric clinical experience.
- Both students and families report this program is a success.



4.2 Out of Home Models

4.2.1 Lakeland Centre for Fetal Alcohol Spectrum Disorder – Cold Lake, Alberta

- A diagnostic and assessment clinic for children and adults with FASD serving rural northeastern Alberta.
- A pilot project launched in 2001 with multi-source funding, the majority of which comes from Alberta Health and Wellness (Health Innovation Fund) in 2001.
- Out-of-home respite care is offered in the form of Summer Camps – 6 days/5 nights for children with FASD (8-10 years boys and 8-10 years girls; 11-13 years boy and 11-13 year girls) 6 day, 5 nights - \$500 per child (may seek assistance through Family Supports for Children with Disabilities).
- Other services provided include: Follow-up support services (including respite care); Mothers-to-be mentorship program; Community Alcohol/Drug Awareness Coordination; School Based Support; FASD workshops; Train the trainer workshops; Mentorship Program development training; and Diagnostic and Assessment Certified Team Training.

4.2.2 Ontario Ministry of Community and Social Services Guidelines (2000)

- This report was prepared in 2000 by the Ministry of Community and Social Services to facilitate the implementation of a specific program to enable out-of-home respite care service capacity in Ontario communities.
- Excerpted from the report and listed below are some of the practical suggestions for communities to increase out-of-home services:

#1 – Expand on Existing Respite Services

Add one or more spaces in an existing respite group home/facility in order to accommodate similar children for respite purposes.

It should be noted that families of children residing in a group home/facility on a full time basis may be amenable to taking their children home for the weekend at intervals of 6 weeks in order to free up their child's space for respite purposes.

#2 – Expand on Existing Residential Services

Identify an existing residential group home/facility where spaces can be added for the purpose of respite. Add one or more respite spaces, or convert existing long-term residential space(s) to respite spaces.

#3 – Create New Out of home Respite Capacity (where none exists)

- (a) Use MCSS funding to cover rental costs of a new respite care home.
- (b) Purchase a home with funding available from other sources and fund operational costs through this initiative.

#4 – Host Families/Home Share/Family Home

Recruit and train host families to provide respite for natural parents. This is a cost-effective option, which may be useful in some remote areas where there is no critical mass of children for the creation of a home/facility.

#5 – Expand the Scope of Eligible Children in a Respite Service

Approach agencies with existing respite capacity and ask what would be required to create or increase respite capacity for a given group, or groups of children with compatible needs. For example, hiring an additional staff member and/or adding new equipment could create additional respite for children in the target group. This model may offer the potential to spread funding more widely across the region and across targeted high needs groups.

4.3 Situation of Respite Care in Quebec First Nations Communities

According to the responses from the Needs Assessment Surveys, the situation in regards to Respite Care, and in particular to families of FASD and special needs children, among First Nations communities in Quebec is as follows:

- More than half (50%) of the responding communities indicated that children, youth and adults with special needs (and in particular FASD) were integrated in most social and recreational activities in the communities. 20% indicated that there was a partial integration, and 30% stated that there was no attempt at integration except at the level of the community school.
- Many of the communities cited that it was difficult to intervene with respite services because there was a lack of diagnostic and evaluative services for children/youth/adults with FASD. As such, there was a reluctance to address the issue. However some communities were able to provide varying estimates of between 5 and 18 families that would benefit from respite care, and that there were probably more that were not known.
- 80% of the communities stated that they did not have the funding to provide respite care services. One community reported that they provide a placement in a foster home as the only form of respite care available. The balance, 20% stated that they do provide services.
- Those providing respite services report the following services:
 - One weekend a month for parents coping with special needs children/youth/adults (60 hours)
 - Day programs for Special Needs children
 - Short-term stay in Foster Residence for special needs children/youth/adults
- Most communities have not developed a policy on Respite Care Services. One community has a policy in place, and another is in the process of developing a policy.
- For those few communities offering the services, the duration of hours were reported as 60 hours per month (one weekend) 4-7 hours per day in day program and one community had not clarified the number of hours as the service was based on need.
- None of the communities had provided any training for the respite care workers.



- 60% of the communities reported that children and youth with special needs such as FASD are integrated in general into summer day camp programs. However, one community reported that they also financed a specialized summer camp out of the community for children with challenging needs, but this took most of their resources to do so.
- One community reported that they did not integrate special needs children into the summer camp program as they did not have a specialist teacher to work with these children.
- The principal obstacles that were cited concerning respite care for FASD families were:
 - Lack of funding;
 - There is not easy access to diagnosis of FASD, however, it is documented that there are a number of children with lags in psychomotor development which has to be addressed;
 - Parents who are in denial over the needs of their children;
 - Lack of trained personnel;
 - Need for more diagnostic services;
 - Overprotective parents who do not want to leave their children with anyone else;
 - Lack of availability of resources and services;
 - Budget cuts in the schools which limit shared resources and support services.
- Although there is a limit in respite services among communities, some communities did provide examples that showed:
 - There was a decrease in the number of placements in foster homes due to respite services being provided;
 - Foster homes are not a good option, and the children/youth/adults with FASD are better off in their own homes with their own families.
- In summary, the communities stated that:
 - There has to be an easier access to the identification of children/youth/adults with FASD;
 - There are no targeted dollars to design programs for respite services for families who are trying to cope with these difficulties;
 - There is a need for a training program for respite workers.



5. RECRUITMENT & TRAINING

Recruitment of respite care workers or volunteers from within the community is often the first challenge faced by anyone attempting to organize respite care services. In the *Best Practices in Respite Services for Children Handbook for Parents* (published by the Canadian Association for Community Care) some very practical advice is provided to assist parents in choosing someone from their community to provide respite care.

In some cases, parents know a friend or babysitter who, preferably with some training, would be willing to provide respite care. Alternatively, parents can consider approaching: day care centre staff, public health workers, elementary or high school staff; health care providers; community associations, religious and cultural centres. The same handbook has a series of Appendices offering useful samples of forms for parents to interview potential respite care workers and provide organized information and schedules for the worker.

The lack of and need for adequate training for respite care workers was identified consistently across the literature and within the Canadian case studies examined. In addition to challenges accessing funds (either federal or provincial/territorial), training standards are inconsistent and training programs are often tied to one or two year diploma programs (not necessarily appropriate for initiatives seeking to train community members for part-time or voluntary services).

However, there are two potentially interesting courses offered by Red River College in Manitoba. These are certificate programs being offered through distance education: *Studies in Special Needs Child Care*; and *Studies in Aboriginal Child Care*. Given that they are already designed for distance education, it is possible that some of the materials or an adaptation of the courses offered in these programs may be of value to organizers of a community-based respite care program. Contact information is provided in the Resources Section of this report.

Within the literature, there were suggestions as to appropriate content and scope to consider when designing respite worker training. A good example of this are the guidelines summarized below:

Basic training for respite care workers should, at a minimum, cover the following areas:

- Overview of respite for children with emotional & developmental disabilities
- First Aid and CPR
- Defensive driving (if children need to be transported)
- Overview of medications and administration techniques
- Emergency medical procedures and emergency protocols
- Behaviour management strategies
- Non-violent physical crisis intervention (restraint certification recommended)
- Planning and providing quality activities for children
- Working with families
- Liability issues
- Burnout prevention
- Confidentiality



5.1 General FASD Training Recommendations

One interesting resource available was the *FASD Training Study: Final Report of the First Nations Child and Family Caring Society and Pauktuutit*. This study was not specifically focused on respite care, but rather on FASD services and needs within aboriginal communities. However, the Training Section of the survey addresses aspects of community training needs worth considering for training respite care workers:

1. Comprehensive and targeted FASD funding is urgently needed to ensure access to training that will enhance community capacity through culturally meaningful awareness and prevention services.
2. Ensuring the delivery of the full spectrum of FASD training in the community will raise awareness, increase competencies and provide practical skill sets for FASD interventions.
3. Without the funding that enables access to training, First Nations service providers cannot obtain the updated skills, knowledge and interventions needed to provide an adequate level of service in their communities.
4. The scarcity of FASD funding also impacts the extent of training programs offered by First Nations organizations. That is, without the funding needed to fully support the level of FASD training required in First Nations communities, key people are often not included.
5. The inadequate level of funding also prevents First Nations organizations from developing and providing FASD training information in ways that are understandable, useful and relevant to on-reserve community members.
6. There does not appear to be a system of certifying instructors for FASD training in First Nations communities. The lack of certification for trainers suggests that the quality of the training can vary significantly. Without an independent means of evaluation, there is no way to assess the efficacy of training programs.
7. There is a scarcity of FASD trainers even under the current conditions. It appears that governments may contract with one or two individuals to provide FASD training to a broad number of First Nations. Every trainer has his or her strengths and areas of growth - meaning no one person can meet the diverse training needs of First Nations. There is also no information on to what degree government involves First Nations in identifying a trainer that would best meet the unique needs in their respective communities.

6. BEST PRACTICES

Within the literature, there were several examples of organizations and associations seeking to establish best practices guidelines for respite care for families of special needs children. Most notable was the work of the Canadian Association for Community Care (CACC) undertaken between 1995 and 2002. They have published a full set of guidelines entitled: *Best Practice in Respite Services for Children* (1996).

In general, observations within the literature reviewed reflected the positions put forward by the CACC. A summary of the key points in the CACC guidelines is as follows:

- **Family-Centeredness:** Respite care is most effectively provided within a family-centered framework. Strong parental involvement in respite service development ensures the relevance of the program and a natural and essential advocacy group.
- **Flexibility:** Respite care services are flexible and responsive to the individual needs of all families, honor the ethnic, cultural and geographical differences of families and are individualized to respond to each family's changing needs.
- **Accessible and community-inclusive respite care:** Respite care programs operate in environments that are accessible and community-inclusive, with the amount of respite care services provided determined by family need.
- **Single Point of Entry:** There is a central point of access where parents can be informed about and assessed for eligibility for all available respite services.
- **Responding to Changing Needs:** Planning and funding of respite care services must consider the full range of family needs. One standard approach for all families is not appropriate.
- **Assessment/Entry Procedure:** A central intake process addresses the needs of the child and family by ensuring access to both informal and formal respite services while eliminating the need to apply to individual programs. Respite services are delivered in a proactive manner through anticipatory planning and health promotion.
- **Eligibility:** The determination of eligibility for services is based on the needs of the family, with special attention given to the needs of the child and primary caregiver.
- **Appeal Process:** All agencies/governments should have a fair appeal process in place.
- **Public Awareness:** A targeted strategy should exist to increase awareness of respite services among individuals and groups in the community who lack this information.



- **Recruitment:** Guidelines should be provided to parents to assist them in the selection of a respite worker/volunteer or to screen agency staff.
- **Training:** The respite care program should establish and maintains documented procedures for identifying training requirements and provides training for all workers/volunteers.
- **Funding to Families:** Parents are given responsibility for allocating funds approved for their child's care, or funds are given directly to the parents, allowing them to purchase the respite care services they prefer.



7. FUNDING

Throughout the Canadian literature reviewed, funding was identified as inadequate and a barrier to the provision of respite services to families with children with special needs. One document prepared by Health Canada identified the First Nations and Inuit Health Branch's Home and Community Care as the primary source of potential funding for respite services. The nature of the program entails prioritization of needs and desired services by each First Nations and Inuit community.

Practical experience with the implementation of the program (for example, Nunavut) reveals that in cases where emphasis is placed on "elder care", there are precious few resources left for other respite care clients. In many cases, provincial/territorial funding is integrated with federal funding to enable expanded respite care services to be provided (for example, Yukon and Labrador).

7.1 Federally-funded Respite Programs

7.1.1 First Nations and Inuit Health Branch, Health Canada

In-home respite is defined as an essential service element under the Home and Community Care Program. The First Nations and Inuit Health Branch (FNIHB) of Health Canada is responsible for working with communities to develop services. Once a community service plan has been approved and is implemented, the community manages the program and FNIHB plays an advisory, monitoring and funding role for the program. Facility-based respite, day programs and palliative care are designated as supportive service elements rather than essential elements. FNIHB does not currently have a mandate to provide these services.

An estimated 50% of communities offer in-home respite care, depending on local needs and conditions. Very few communities offer facility-based respite or day programs. Unless long-term care facilities are located in the community or in an Aboriginal cultural context, they are unlikely to be used for respite. Experience has shown that Aboriginal clients suffer health decline in facilities that are far from home and not culturally appropriate.

An ongoing challenge in providing care and respite is the need to train health care workers. As well, most communities find that the majority of the funding available is used to address nursing and personal care services for the general population, and in particular for the elders, and little is available for other respite services such as for families with special needs children.

In the North in particular, there is a strong degree of integration of provincial/territorial health care services and Health Canada (FNIHB) and Department of Indian and Northern Affairs health care services because of the large First Nations and Inuit populations.



7.1.2 Veterans Affairs Canada (VAC)

As reported by Jane Dunbrack (2003) Veterans Affairs Canada (VAC) is a significant provider of respite services for family caregivers of veterans and those with disability pensions. This type of funding is a good example which parallels the type of needs of families with FASD children, youth and adults. The purpose of VAC respite services is to avert caregiver burnout or crisis before it occurs. The average age of veterans is currently 79. The principal family caregiver in many cases is an elderly spouse.

Based on a needs assessment, VAC will provide time off for the family caregiver and help with household upkeep and maintenance (including outdoor maintenance). The annual maximum entitlement for all respite services is 59 days, which may be extended during palliative care. Some day programs are available, especially in cases of dementia. All services are normally provided without direct cost to the user. VAC services are intended to supplement and complement services available in the community and those provided by provincial/territorial health plans⁷.

7. Dunbrack (2003). *Respite for Family Caregivers An Environmental Scan of Publicly-funded Programs in Canada*. Health Canada.

8. AVAILABLE INFORMATION RESOURCES

Some resources that are available to the communities include:

- Canadian Association for Community Care (currently amalgamated with the Canadian Healthcare Association). Copies of the two publications used in this report are accessible to those involved in organizing or utilizing respite services. In particular, a modified version of the Handbook for Parents may be a valuable hand-out for recipients of respite care services. (contact www.cha.ca; or Chantal Easy at ceasy@cha.ca for ordering information)
- First Nations Child & Family Caring Society of Canada (www.fncfcs.com). This organization has an impressive list of research publications dealing with many relevant topics. In addition, it is possible to become a member of the FNCFCS and receive regular information bulletins as well as accessing an up to date listing of Canadian child and family service agencies and child welfare resources.
- Red River College (www.rrc.mb.ca), Distance Education: 1.800.616.1113 or 204.632.2451
- The Children's Foundation, British Columbia (http://childrens-foundation.org/website/family_support.html)
- Canadian Centre on Substance Abuse (www.ccsa.ca). Directory of FAS/FAE: Information and Support Services in Canada; FAS Community Development Toolkit.



9. SUMMARY OF IMPORTANT CONSIDERATIONS

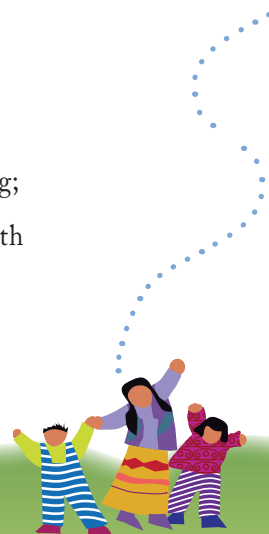
Within the literature and case studies reviewed, a set of common themes emerged that should be considered when developing an appropriate model for respite care services:

- Parents prefer a combination of in-home short breaks (3 – 4 hrs) and occasional out-of-home (i.e. camp or facility placement) longer stay services.
- With respect to in-home services: parents prefer local para-professionals whose training allows them to keep pace with the changing needs of children as they age.
- Training for local respite care workers is a significant challenge and is/has been a barrier in regions where this system is in place. Development of a training plan and identification of training funds should be developed in step with the respite care service model (i.e. not considered a separate or add-on aspect of the service).
- With respect to assessment and eligibility for respite care services: the most successful case studies focus on assessing need and extent of child's developmental disability, not diagnosis of specific disorder. This approach has enabled some initiatives to avoid funding or mandate gaps that exist within federal funding programs.
- The most successful case studies involve streamlined (single) entry points for the service with multi-disciplinary assessment and service provision teams.
- Inclusion of the parents in designing their families' respite care plan is a key factor in success.
- If possible, program services should consider occasionally allowing respite care workers to include siblings in their care, to allow parents a break from all children and to facilitate development of the relationship between the special needs child and their sibling(s) outside of the family dynamic.
- Community involvement is a key factor in success, particularly in small, remote communities.

10. NEXT STEPS FOR FIRST NATIONS COMMUNITIES

The following suggestions are made for Quebec First Nations communities to be able to put in place services for respite care, and in particular, for families with FASD:

1. Quebec First Nations Communities should further develop respite care services as a means of promoting and supporting healthier families. This can be accomplished through a networking of services from Indian and Northern Affairs Canada Social Development, Indian and Northern Affairs Education Program, FNIHB Health and Community Care, Health Canada Regional FASD Initiatives, Human Resources Development Canada Early Childhood Program and through the implication of local community programs.
2. Communities should undertake a “Health and Activity Limitations” survey of the children, youth and adults in the community to create a list of individuals and families that may be impacted by physical, social, mental and emotional limitations, and that would benefit from a respite care program.
3. The approach of health and physical limitations is a much easier means of addressing the difficulties of FASD in situations where a diagnosis is not possible or there is reluctance on the part of the health professional to do so. This is the same procedure that is used with the Grenfell Board in Labrador where the family and child’s eligibility is based on the child’s capacity and needs rather than a diagnosis of specific disorder.
4. The family-centered approach to health and social services is now a common-place philosophy for non-aboriginal agencies and governmental services, nevertheless, it is a traditional concept for all First Nations communities, and as such is not seen as an “approach” but is a way of life integral to the planning and provision of community services. Therefore, funding agencies should show more flexibility in regards to respite care in keeping with the values, beliefs and traditions of the First Nations community.
5. Communities should develop an expanded definition of respite care to include services that can support the child/youth/adult and family, and which can be supplemented through other related services in the community. Therefore respite services should be seen to include:
 - Meeting the care needs of the child;
 - Offering the child or youth or adult opportunities to develop social and recreational life skills;
 - Strengthening families by reducing stress and thereby improving the long-term functioning;
 - Maintaining and enhancing the quality of life for families of children, youth and adults with FASD, disabilities or chronic illness.



6. Families in First Nations communities are diverse so the policy for respite care should define families in an inclusive way that reflects the diversity of family structures and patterns. Examples of First Nations families include big, small, extended, nuclear, multi-generational, single parent, grandparents, two-parents, temporary for a scheduled time, adopted families, birth families, same-sex couples, the clan, the community and individuals in their own home.
7. A single point of entry should be established by the community at some point in the health and social services network. Respite services must be very flexible and fluid, culturally appropriate and based on a plan of care.
8. In addition to the services of a trained respite care worker, options for support can also include the assistance of other services which may already be provided in the First Nations community such as:
 - Child care services through the Daycare or Early Childhood Center;
 - Nursing Care through the Home and Community Care program or the CLSC;
 - Social recreational programming through community organizations;
 - Home Support through Homemaker services;
 - Personal Care through the Home and Community Care program;
 - Tutoring and educational outreach through the School or Adult Education Center;
 - Weekend foster care in a home in the same First Nations community (organized through social services);
 - Technological support such as the use of a computer at home for a disabled child through educational or social services.
9. Communities should determine the type of respite services to be provided by consulting with the concerned families in their own communities. This would inform any policy development process.
10. A centralized training should be developed and implemented regionally for Respite workers in First Nations communities with funding support from Health Canada, Regional FASD Initiatives Funding, and possibly Indian and Northern Affairs Canada which has responsibility for Social Development Programs and Education.

REFERENCES

B. Minore, M. Boone, A. Arthur, J. O'Sullivan, Canadian Health Services Research Foundation, (2005) **Managing Continuity of Care for Children with Special Needs in Rural and Remote parts of Northern Ontario.**

Brust JD, Leonard BJ, Sielaff BH. **Maternal time and the care of disabled children.** Public Health Nurse. 1992; 9 (1):177-184.

Campanale R. **Respite care: lightening the caregiver's load.** Journal of Clinical Nursing. 1997; 14(3):32-33.

Canadian Association for Community Care, (1996) **Best Practices in Respite Services for Children: A Guide for Families, Policy Makers, Program Developers.**

Canadian Association for Community Care, (1997), **Best Practices in Respite Services for Children: A Handbook for Parents.**

Canadian Association for Community Care, (2002), **Best Practices in Respite Care for Families of Children with Special Needs: Phase Three Report on 3 Ontario Communities.**

First Nations Child & Family Caring Society of Canada & Pauktuutit, Inuit Women's Association, (2006), **FASD Training Study: Final Report.**

H. MacDonald & P. Callery, School of Nursing, Midwifery and Health Visiting, University of Manchester, Manchester, UK, (2004) **Different Meanings of Respite: A study of parents, nurses and social workers caring for children with complex needs.**

Hall, S., *Journal of Advanced Nursing*, Vol. 24(3), pp 512-521, (1996), **An exploration of parental perception of the nature and level of support needed to care for their child with special needs.**

Hanvey, L. (2002) **Children with Disabilities and their Families in Canada: A Discussion Paper.** National Children's Alliance for the First National Roundtable on Children with Disabilities.

Health Canada, Janet Dunbrack, (2003), **Respite for Family Caregivers: An Environmental Scan of Publicly-funded Programs in Canada.**

Implementation Guidelines for the Ontario Ministry of Community and Social Services, (2000), **Increasing Planned Out of Home Respite for High Needs Multiple Special Needs Children with Developmental and/or Physical Disabilities Living at Home.**

Kinosao Sipi Minisowin Agency & First Nations Child & Family Caring Society of Canada, (2006), **Promising Practices in First Nations Child Welfare: Creating a Community Response for Special Needs Children.**

Lakeland Centre for Fetal Alcohol Spectrum Disorder, (2004), **Final Evaluation Report: NONA Child Development Centre (Vernon, BC).**

Nurse Educator, Kendle, J., Campanale, R, (2001) **A Pediatric Learning Experience: Respite Care for Families with Children with Special Needs.**



Pollock, N., Law, M., King, S., & Rosenbaum, P., CanChild Centre for Childhood Disability Research, (2001), **Respite Services: A Critical Review of the Literature.**

Self Managed Care: Evaluating Partnership, Social Networks and Community Capacity Building in the Provision of Respite Services.

Sokol M. **Creating a community of caring for families with special needs.** Journal of Obstetrics Gynecology Neonatal Nurse. 1995; 24(1):64-69

Streissguth, O'Malley, Centre of Excellence for ECD; Encyclopedia on Early Childhood Development, **Clinical Intervention and Support for Children Ages 0-5 with FASD and their Parents/Caregivers.**

Sturtevant, J., Elliott, S., ARCH National Resource Centre for Crisis Nurseries and Respite Care Services, Chapel Hill, NC, (1994), **Respite for Families with Children Experiencing a Serious Emotional Disturbance.**

Valentine, F. (2001). **Enabling Citizenship: Full Inclusion of Children with Disabilities and their Parents.** Canadian Policy Research Networks. Ottawa, ON.

Wright & V. Barnby (funded by the Centre of Excellence for Child Welfare and Health Canada), (2004).





www.cssspnql.com