

# Focus on Families

Community Living-Manitoba  
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February 2006

*Special Edition on Respite in Manitoba*

## Families Say Respite Promotes Well-Being

In October 2006 members of the Family Strategic Planning Group once again identified respite as still high on the list of most family agendas. On November 25th a family workshop on respite offered an opportunity for parents to look at respite—how it works and how it might be improved—in Manitoba. This newsletter is a compilation of discussions at both of these meetings. Our hope is that the contents will be useful to all families looking at how they can create balance in their lives.

Whether you're a parent of a younger child or an older child, it's important to maintain a balance in your life—between supporting and raising your children while trying to prevent

burnout and keep your sanity.

How parents find out about and access respite in Manitoba turns out to be quite different for each of us. What you know and who you know seems to determine how well respite services work, as does where you live—urban or city. Finding and keeping qualified, dedicated respite workers also is a challenge. What are the pros and cons to self-administered plans? What about other plans? What are they and how do they work?

This newsletter may not answer all these questions. Minimally it will give some history, offer some options, stimulate creative planning, and provide some resources for families to consider. So let's begin . . .

## National Respite Project Offers Local Picture

As participants of a workshop, part of a national initiative on respite, we learned preliminary research on respite tells us that . . .

Presently there is no legislation, acts or regulations that exist which govern respite funding.

However, under the Child & Family Services Act (CFS), respite support is

offered under the auspices of 'family supports.'

In 1982 Manitoba signed a Master Agreement that was part a tripartite between the three levels of government (Federal, Provincial, and First Nation). It established guiding principles for the operation of CFS on reserve and specified the way in which the agencies are funded to provide community-based First Nations Child & Family Service Program.



### Defining Respite—

- a short break or time away
- suspension: an interruption in the intensity or amount of something
- a pause from doing something
- a pause for relaxation; "people actually accomplish more when they take time for short rests"
- an interruption in the intensity or amount of something
- to relieve temporarily, esp. from anything distressing or trying; give an interval of relief from
- **Respite** care is an essential part of the overall support that families may need to fully support their child with a disability or chronic illness at home.

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In government, respite services can be accessed through **Manitoba Family Services & Housing**, which provides respite funding to children and adults living at home under the following programs —

- **Children's Special Services (CSS)**
- **Supported Living Program (SLP)**

For children with complex medical needs, **CSS and Homecare** partner where some of the respite duties are performed by medical staff.

There are varying degrees of services available for First Nations families living on and off reserve,

which can involve complicated coordination between Indian & Northern Affairs federally, Child & Family Services provincially.

CSS and SLP operate respite services on a capped budget. For individuals whose main support requirements involve a physical disability, **CSS** will assign a case worker through **SMD—Society of Manitobans with Disabilities**.

The respite policy statement and guidelines that presently exists are standard practices in both the **CSS** and **SLP** programs, and include —

- Limits on who can be hired, in that family members who are also primary caregivers, grandparents, or other immediate family do not qualify as being eligible to provide respite.
- If you live in a rural or remote area an exception to this practice can be approved by the **CSS** or **SLP** staff

If you use the services offered by **Community Respite Services** you can be accommodated in the way that fits your circumstance best, including hiring a family member.

## Eligibility: Qualifying for Respite Services

In order to be eligible for respite services a family must be referred to **CSS** through a medical professional such as a pediatrician, psychologist, or the Child Development Clinic with a diagnosis.

If you are a natural, extended or adoptive family who has a child 17 years of age and under living with

them you are eligible if your child has one or more of the following:

- a mental and/or physical disability;
- a developmental delay;
- a risk of developmental delay; a pervasive developmental disorder such as autism;

- or lifelong extreme complex medical needs which result in a dependency on medical technology.

In order to be eligible under the **SLP** program and individual must be also be eligible for community living supports as an adult and living in the family home.

## Offering Feedback

When families got together in November 2006 to look at respite in Manitoba, the first question they were asked to consider is "What needs to be in place to take time off?" Here's some of what they identified:

- > A plan that offered flexibility and a back up plan
- > Someone to help — someone who —
  - meets our standards
  - meets our son/daughter's standards
  - will care for other children too

- we can trust
- can be flexible
- is dependable
- has the skill set to handle the needs that arise
  - ... emergency ... personal care ...
- has similar value system
  - ... respectful ... age appropriate ...
- can offer appropriate amount of support
- has good judgment
- is mature and still "cool"

Each of us have different approaches. What needs to be in place for you to make respite happen successfully?



# What's Available Out There?

There are several models of funding and respite supports available in Manitoba

*An overview of what's available in Manitoba presents different options and there are many reasons families choose one option over the next.*

The **SELF-ADMINISTERED** plan offers flexibility in hours and pay although there is a recommended wage. The family is responsible for recruiting and paying the respite workers directly. Budgeted hours are within a six-month contract.

Respite workers are found through advertising — universities, colleges, schools (educational assistants) — and families conduct the interviews, approve and pay for the work of the respite worker. A completed form to CSS reimburses the expense.



On an **ASSIGNED BASIS** the CSS or SLP staff recruit and assign respite workers for a specific period of time period each week, and respite workers are usually geographically assigned.

Both of these models require that a diagnosis be made before a referral can be done, as outlined previously under "Eligibility" on page 2.



For individuals with complex medical needs, respite can be managed in coordination with **PEDIATRIC HOME CARE & CSS**. Nursing respite is offered with funding from both departments. Completion of the United Referral & Intake System (URIS) Group B application from CSS is required. It's important to note that only the

child with special needs 'qualifies.' All medical supplies are provided.



For **ADULT CHILDREN** or **TEENS** living at home respite workers can accompany individuals to social settings, summer programs/camp, or summer jobs. For teens who do not qualify for childcare any longer, respite can also be used for after school care.

There is also **EMERGENCY** support through CSS which can provide respite when exceptional care is required over a short period of time.

For **YOUNG ADULTS** qualifying under the SLP program, some residential service agencies offer respite through social and recreational activities. Transition preparation from the family home is also something which can be arranged through these agencies.



**FAMILY-BASED** respite models, such as the Cooperative Respite Program piloted through the Community Living-Winnipeg office, enabled families to pool their respite hours. Their children were paired up with other children who had similar special needs and interests. A respite worker was chosen to accompany them was on social events/outings.

This allowed families to save money

on respite while allowing their children to get to know new people and get out into the community to experience things without their immediate family.



**COMMUNITY RESPITE SERVICES (CRS)** operates in the Winnipeg and Brandon area, and offers both self-managed or assigned respite options. All aspects of payroll is managed by the CRS office.

Families wanting to explore this option must call CRS and complete a form. The CSS worker must then be notified so they can arrange the transfer of funds—CSS to CRS.

**CITY OF WINNIPEG** Community Services Department has Special Needs Services and offers leisure attendant services. This leisure attendant provides support and assistance to a person with a disability participating in a self-selected mainstream program from the City of Winnipeg's Leisure Guide.

Other sources of respite in the City of Winnipeg include **The Rady Centre**, which offers one-on-one volunteer support for clients with special needs, who need help or guidance participating in the Rady Centre's athletic and social programs. For the summer, **GROW in GIMLI** Program offers some residential life skills for youth who are 18-24 years with special needs.

The **Family Centre** offers support when a parent is needing to regain mental or physical health.



## More Feedback from Parents

**A**t the respite workshop parents, although grateful for the respite options they do have access to, felt there was room for improvement.

Of concern was the lack of qualified workers available to choose from, and the lack of information that is shared with families.

Generally, people felt is now more of a demand for respite services than ever. There was an observation that access to workers is easier in urban centres. Noted also was some recognition for more flexibility in rural and remote communities.

Over all families felt more flexibility and control was needed in obtaining and using respite services. There seems to be a lack of transparency about options. Workers could be trained and supported in ways that would recognize the value of their jobs — they are not just “baby-sitters.”

One of the ways that parents and families have gained strength in knowledge and networking is around sharing information with other parents, and collectively becoming a stronger, united voice. Outcomes seem better because of this sharing of information between parents. Identifying and addressing inconsistent standards

and expectations is what families need to do locally and provincially.

No entitlement or guarantee to respite as part of any program makes families receiving respite feel vulnerable/at risk sometimes. Cutbacks are constant threats to many families. Jurisdictional issues for families who live on First Nations land increases issues.

### ***What do families want?***

Parents and families are looking for people who want to take part in our family member's life, paid or unpaid, in a real, meaningful way. They want people who will show a genuine interest, not pity.

In supporting their family member, they would also like people to feel comfortable to ask questions and get involved.

It would be desirable if workers come up with more ideas on their own and created a relationship where the worker feels like a partner in the process. A worker who involves a child/adult with others, being a connector would be helpful.

A respite worker helps those he/she supports take small risks—not become the substitute parent. In social activities, developing more of a friendship connection was felt to be appropriate. An agreement that families wanted their loved one to be accepted for who they are was a universal expression.

### ***Hints by families for families***

Some of the places families who use a **self-administered model** say respite workers are found included

- > Faith Communities
- > Special "O" coaches/volunteers
- > Camps
- > Other programs
- > University/High School/College students
- > Common interests in the community such as cafes, library, skating rink, etc.

Of importance is the fact that families need to know they are responsible for obtaining criminal record and abuse registry checks. Liability/release form for workers is considered important.

When using **assigned respite**, remember geography is considered and could result in reduction of hours due to transportation costs related to someone doing respite.

It might be worthwhile asking **residential agencies** in your area if they would be willing to provide outreach support for activities. Doing volunteer work, attending summer day camp, “sleep-overs” in the transition apartment might be some possibilities.

Some questions to ask if you're not sure which might be the best respite model for your family. This is just a guide to help stimulate exploring your own options.

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*Dedicated to the full inclusion in the community of  
personal of all ages who live with an intellectual disability*

1. I like controlling who my children are supervised by (**self-administered**)
2. I don't have much time to interview respite workers (**assigned**)
3. I'm comfortable with someone else hiring the respite workers (**assigned or Community Respite**)
4. I need someone who is flexible (**self-administered**)
5. I want my family member to be comfortable with the person that does respite with them (**self-administered**)
6. My son/daughter is a young adult and needs to experience more independent life skills (**residential agency**)
7. There is a shortage of qualified respite workers in our area but a high need for many individuals (**family centered/co-op**)
8. My child really need social contact in the summer time. (**summer programs—self-administered, agency, or assigned**)

## More Feedback from Parents

"How would you like to get a break?" brought forward these ideas of how respite was and could be used:

- > time away overnight to return refreshed and renewed
- > spa time
- > free time to do "whatever" in the community or in the home
- > additional hours to volunteer just for a change or to make change
- > to sleep
- > not have to use respite because of work priorities
- > the freedom to decide how and when to use respite
- > time for self care
- > someone to help with housework
- > the opportunity for flexibility

In response to the question, "What can you do tomorrow to improve things?" we heard answers like:

- > talk to my CSS worker or respite coordinator (if you're thinking about getting more information or changing your respite model)
- > calling a parent you're comfortable approaching to ask what they know about respite; what model do they use?
- > approach some of the people I know in the community who might know potential respite workers
- > call an advocate for help



## WE ASK YOU

What things might you be able to do to better understand which respite model suits you, or your family member?

Sometimes it takes testing options and going from there. If you have a chance, compare the pros/cons of each type of model available to you. What works in the beginning as your son/daughter is a preschooler may not be appropriate as he/she enters school and ultimately as they mature. Everyone's skill or comfort level is different and changes along the way.

Consider your options, skills, preferences, etc. and go from there.

Call our office if you think we can help.