A Respite Guide
for Families of
Children and Youth with
Chronically High Needs in
Nova Scotia

A project of the

Nova Scotia Partnership
on Respite, Family Health
& Well-Being

respite, YOU deserve it
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*This guide is for parents and caregivers of children and youth with disabilities or chronic illnesses who are thinking about adding respite into their lives. The guide tries to provide information on respite opportunities in Nova Scotia. Not all of the information in this guide will apply to each family.*

*4th Printing—June 2013*
What is Respite?

Respite is typically defined as a *short period of rest or relief; a temporary break from continuous responsibility or activity*. But families say they want to think about respite in a new way. “Respite should be more than a *break* from life’s circumstances it should be a *change* of life’s circumstances.” (Hutchinson et al., 2010). For parents, family members, and children/youth with special needs, respite is vital and should be a regular part of the family schedule.

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**Definitions**

**Children/Adult children with disabilities or chronic illnesses**
- Refers to children, youth and adults with disabilities or chronic illnesses, including autistic spectrum disorder, Down syndrome, developmental delays, behavioural difficulties deafness, blindness, medical or technological needs or any other special challenge.

**Families**
- Inclusive of biological or adoptive parent(s) and caregivers, siblings, and extended or foster family members.

**Caregivers/Family caregivers**
- Parents or guardians who have the ongoing daily responsibility of delivering and managing the care and support provided at home and in the community.

**Respite providers/Volunteers**
- The paid or unpaid individuals who provide services to support family caregivers in taking a break from their caring role by providing support for children/adult children to engage in social, recreational, cultural or life-skill activities.
Respite is an important part of healthy family development. It allows parents to take time to recharge their energy. It allows children, youth, and adults with disability to participate in activities and make new friends outside of their family circle.

Family respite can take many forms. It can be going for a walk or meeting a friend for coffee, while your child/youth goes swimming. It can be taking a few hours to complete household tasks while your child/youth goes to a movie or social program. It can be a weekend away for your child/youth with a skilled respite provider. Or, it can be special time with older or younger siblings while your child/youth is hanging out (with support) in another part of the house. It can also be time for you and your partner to do something fun!

Respite is for the whole family!

**How can respite help my family?**

Having respite as part of family life can give family members time to do the things they want and need to do. Respite allows time for oneself and for each other. Regular respite can give family members time to take care of their health, pursue hobbies, meet up with friends, rest, or do the housework! It should be a positive time for your child/youth. It’s a chance to practice social, leisure and life skills, and do something enjoyable. It is also a positive time for other family members and
contributes to the overall well-being of the family. Respite is about choosing what is important to you and using the opportunity to participate in it.

Taking respite opportunities can strengthen your family by allowing time for doing things you want to do and need to do, to take care of yourself. Respite lowers your stress and family stress. It increases feelings of well-being, and creates more positive outlooks. Respite improves everyone’s ability to cope with the challenges of daily life.

**How do I find respite?**

Although it may feel unattainable, respite can become a regular part of your life. Learning about available respite options and which ones will work best for you and your family’s needs is a normal and healthy milestone in the lives of families of child/youth with special needs. Some families are able to find and fund respite, others recruit volunteers or join family co-operatives, but the reality is that most families struggle to fund respite and seek assistance through government programs (e.g., Direct Family Support (DFS) or Enhanced Family Support (EFS)).

Respite opportunities can be found through *formal* and *informal* means.

**Formal** respite involves hiring respite providers to work inside or outside of your home. Some families may have their own funds to purchase respite services but others may seek external funding for respite.
Nova Scotia does offer a funding program for families looking for respite. The Direct Family Support Program and the Enhanced Family Support Program, operated through the Department of Community Services, provides funds to families. The amount of funding is based on the degree to which the disability impacts the individual and the family. In some cases the funding may be prorated or reduced due to family income. It's important to note that the eligibility criteria are different for children than for adults. For a complete description of programs and criteria, please go to [http://gov.ns.ca/coms/disabilities/DirectFamilySupport.html](http://gov.ns.ca/coms/disabilities/DirectFamilySupport.html) or contact your local Community Services office.

If you meet the criteria and are approved for funding, you will receive monthly funds to be used for respite services. It is important for you to save all your receipts for the funds used, as you will have to submit receipts to your Community Services care coordinator.

If you don’t qualify for these funds, you may find alternative programs. Another option for respite is the Nova Scotia Department of Health, Continuing Care Program. This program serves people with ongoing care needs, either on a short-term or long-term basis.
For a complete description of criteria, please call your local Continuing Care Services personnel at 1-800-225-7225 or go to http://www.gov.ns.ca/health/ccs/.

Also some health care plans may provide funding for respite purposes. There are also grant opportunities through non-profit agencies. Ask your social worker or a professional involved with your child to help you find a suitable funder.

Once you have secured a funding source, you will need to find a respite provider. Nova Scotia has four Regional Respite Coordinators. Their combined services cover the entire province and they help families to find respite providers with various skills. They meet with families, talk with them about their needs and try to find suitable respite providers. There is no charge for this service. What the Respite Coordinator can do for you and the process they use is discussed in more detail in the Regional Respite Services section on page 11.

If you are not successful finding a good match through a regional respite coordinator or you prefer to conduct your own search, you can do so. This is discussed more in the Finding the Right Fit for your Family on page 10.

You might also consider community programs such as the Boys and Girls Clubs, YMCA programs or your local municipal recreation service. They may include children/youth with disabilities
into programs. For children under age 12, there are some daycares that offer after-school programs.

**Informal** respite is provided through family, friends, neighbours and others in your community. There is usually no financial compensation for this type of respite arrangement. These supports come in the form of a neighbour watching your child while you take a walk around the block or a neighbourhood play group which welcomes your family member.

Sometimes informal support can develop when parents pool their resources to create a respite solution. For example, some parents create co-operative programs (co-op) with other families. A co-op can allow one set of parents a night out while their child/youth is looked after by other parents in the co-op. It can also offer a nice support system for parents.

Don’t limit yourself by what is currently offered. Think outside the box!

**Planning respite**

Your respite choices will depend on your family’s needs as well as what is available in your community. Thinking about what your child needs and why your family needs respite may help you decide which type of respite that will work best for you. For example, if your respite goal is for your child to be
involved in the community and you to be at home then out-of-home respite might be your best choice.

The process of understanding the reasons for respite will also help you plan how to use your respite time (*Relax. Take a Break: A Family Guide to Respite for Children in Michigan*).

1. Why do you and your child or youth need respite? Many parents say that *real respite* happens when their child or youth is doing something meaningful for their development. So it’s important to not only think about your needs but also the types of activities that respite can provide for your family member too! Put all the reasons down on paper.

2. Prioritize the list. For example, which reason is number 1 for respite? You may not meet all your respite needs, but this will make sure the most important needs are handled first.

3. Try putting the needs into a table like the one on page 10. Start with a blank table and fill in your own reasons for respite in order of importance and the types of activities for your child/youth (see page 28). Determine how often you and your child/youth need respite, and the length of time required. Then add up the total amount of respite time. Don’t forget to include the type of respite that will best meet each respite need.
<table>
<thead>
<tr>
<th>Reason for Respite</th>
<th>Activity for child/ adult child with disability</th>
<th>How often?</th>
<th>Length of Time</th>
<th>Total Amount</th>
<th>Type of Respite</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spend time with partner/spouse</td>
<td>Bowling</td>
<td>Once per week</td>
<td>2 hours</td>
<td>8 hours / month</td>
<td>Out of home</td>
</tr>
<tr>
<td>One on one time with other child</td>
<td>Swim or Library</td>
<td>Twice a month</td>
<td>2 hours</td>
<td>4 hours/ month</td>
<td>No preference</td>
</tr>
<tr>
<td>Time at home</td>
<td>Go to a social group or respite providers’ home</td>
<td>Two times per week</td>
<td>2 hours</td>
<td>8 hours / month</td>
<td>Out of home</td>
</tr>
<tr>
<td>Join a support group</td>
<td>Once per week</td>
<td>1 hour</td>
<td>4 hours/ month</td>
<td>In home</td>
<td></td>
</tr>
</tbody>
</table>

Table 1 - Examples of Possible use of Respite Time

Finding the right fit for your family

Naturally, families often worry about the quality of care their child may receive while they are absent. Families may worry whether the respite provider can handle any
emergencies that come up or manage behavioural issues or other challenges that may present themselves.

These are realistic concerns. In order to take advantage of respite, you must feel comfortable and confident in your respite provider. In order to feel comfortable, it is important that the respite provider is the right fit for your family.

**Regional Respite Services**

Nova Scotia offers a respite service. The service operates in 4 regions throughout the province, and each region has a Respite Coordinator who manages the service. Province-wide, the service is funded by Community Services, with each region operated by a different non profit organization. (Please see chart Pg. 16)

The Respite Coordinator helps families plan respite care for children 18 years and under who have developmental disabilities and/or physical challenges. Respite providers are screened by the Respite Coordinator. Screening includes: an interview, police and/or RCMP criminal record check, Child Abuse Registry and three other references. Once screened, respite providers are placed on a register from where they are referred to families. Referrals are made based on consideration of both the family and respite providers needs, to help build a successful relationship.

Although the Respite Coordinator screens and refers respite providers, **parents are ultimately responsible for choosing their provider**. The parent/guardian interviews the respite provider and decides if they are the most suitable to provide
care for their child or youth. The relationship between parent and provider is that of employer and employee, with the coordinator acting as a liaison and support for both. Once a family has decided on a respite provider, it is the family’s responsibility to provide training to the respite provider on their child’s specific needs. Families are also responsible to pay their child’s respite providers directly, and to make bookings for specific times. For more detail please see *The Respite Provider* on page 16 of this booklet.

Respite can take place in the family home, in the community, in the respite provider's home or in a respite apartment. Several regions have a respite apartment available to families within the program. Availability of the apartment is on a first come, first served basis. The apartment is not staffed so the parents are expected to provide a respite provider when using the apartment. The respite provider and family must receive an orientation of the apartment before using it. The apartment is equipped with everything necessary with the exception of food. The apartment can be booked by calling the Respite Coordinator in your region. (see table on page 16).

**Emergency Respite**

In some instances, short term emergency respite care can be arranged. Emergencies may include any situation in which the primary caregiver may not be able to care for the child/youth in the family home. Please contact the Respite Coordinator in your region for more information.
If you do not use the regional respite service coordinator then you may be hiring and training your own respite provider. Included in this booklet is information on finding, hiring and training your respite provider. Please see the Appendix beginning on page 16.

**Respite Orientation**

Leaving your child with someone new can be stressful. Many families provide an orientation time for the respite provider and the child to get to know each other before they are left on their own. Begin with shorter periods of time in a place where your child/youth is most comfortable. Arrange for them to do an activity that your child/youth enjoys. It is important to share your child or youth’s communication strategies and every day routines. This is a chance to spend some time with the respite provider and guide him/her on how to interact with your child. This may help you to feel more comfortable with the respite provider’s abilities and offers an opportunity for the respite provider to learn about your child while you are nearby to offer advice and support.

**Respite follow-up**

Families should talk to both the respite provider and the child/youth to make sure everything went well. Engage the respite provider in a discussion about the respite experience and encourage him/her to ask questions if there was something they did not understand. Be sure to provide the respite provider with feedback about their work.
Take some time to talk to your child about their experience. Some questions you might ask:

- Tell me about your time with ----- 
- What did you do? 
- Did you like ----? 
- Was he/she nice to you? 
- Would you like to spend time with ----again? 
- What did you like best/least?

Some children who cannot use verbal communication express themselves with behaviour and mood changes. If your child seems unhappy or is behaving out of character, take this seriously. Be sure to discuss any concerns with the respite provider and/or the respite service coordinator.

**Respite Benefits us All!**

Don’t forget that respite has a beneficial effect for everyone. When we went across the province we asked parents about their respite experiences. The following is one parents reply to “How did you know that you needed Respite?”

“I was very tired, physically, mentally and emotionally. I knew I needed a bit of a break … I thought in the back of my mind that I don’t think anybody can give the kind of care to my son that he should have. I soon discovered that was not the truth. I was not allowing my son to expand his world. I probably thought that I was his world, and that I would always be his world. It was equally as important for him to have new experiences with other people away from me, as well as it was for me to have the same away from him.”
“Quality respite is not only required, it is a necessity for the caregiver and the person with exceptional needs.” (Hutchinson et al., 2010).

References


Canadian Association for Community Living (2008) Real respite for the whole family: a resource guide for organizing and delivering a family workshop on respite for individuals with an intellectual disability and their families, Ottawa, Ontario.


Appendices

Appendix I

Respite Providers: The Search and the Interview

How do I find a respite provider?
In a perfect world, there would be respite providers readily available to you and your family when you needed them. However, the current situation is that caregivers must be actively involved in searching for and hiring of respite providers. This article is intended to give you some tips to help you in the process.

The first source to contact is the respite coordinator in your area. Nova Scotia has four regional respite coordinators. These agencies hold a contract with the Department of Community Services to connect families in their region with respite providers. The agencies will talk with you about your family and needs, and refer a respite provider to you. There is no charge to the family for finding a respite provider.

<table>
<thead>
<tr>
<th>Region of NS</th>
<th>Respite Service</th>
<th>Contact</th>
</tr>
</thead>
<tbody>
<tr>
<td>Northern</td>
<td>Northern Region Respite Services (NRRS)</td>
<td>902-752-1755 <a href="mailto:nrrs@eastlink.ca">nrrs@eastlink.ca</a></td>
</tr>
<tr>
<td>Western</td>
<td>Yarmouth Association for Community Residential Options</td>
<td>902-742-9258 <a href="mailto:info@yacro.com">info@yacro.com</a></td>
</tr>
<tr>
<td>Central</td>
<td>New provider TBA</td>
<td>TBA</td>
</tr>
<tr>
<td>Cape Breton</td>
<td>Cape Breton Community Respite</td>
<td>902-539-6685 <a href="mailto:autismres@ns.sympatico.ca">autismres@ns.sympatico.ca</a></td>
</tr>
</tbody>
</table>
If you are not successful in finding a good match through the respite service coordinator, or you prefer to do your own search, there are several other ways to find a respite provider. First, talk to everyone you know. Word of mouth is often the best way to find possible respite providers. Post ads in community places such as: community centres, university departments (e.g., nursing, education, child studies, psychology, social work, speech language pathology, occupational therapy, physiotherapy), colleges, daycares, faith communities, libraries and schools. Some families have found respite providers using the internet (e.g., emailing their social network or Kijiji.ca). Be sure to include basic information in the ad— that they will be working with an individual with special needs, the number of hours, any special skills you are looking for, etc. Don’t forget your contact information!

**Screening and Interviewing**
What to do once you have replies to your advertisement. Start with a telephone call. The call should be a brief conversation to see if you want to have a full interview with this person. You can ask some questions to see if they might be suitable – do they have experience with special needs? How long have they worked in the field? If the telephone call goes well, ask them to come for an interview. You will probably have to interview several people to find someone to best suit your family’s needs.

Before the interview, take a moment to create a list of duties or a job description for the position. The list may include things like personal care, behaviour management plans or assisting the person with special needs at a community program.

During the interview, think about the following:
• Ask for a copy of the candidate’s resume.
• Have a friend, relative or someone you trust at the interview with you. They can act as a second pair of ears and eyes.
• Use written interview questions.
• Take notes during the interview so you can remember what was said
• Ask the candidate to describe themselves and their interests. You will get a better sense of who they are and what skills they may have which could benefit your family member.
• Ask about the candidate’s background and training. Try to use open-ended questions so they have an opportunity to talk. Avoid questions which are easily answered with a yes or no – you will get less information.
• Ask about the experience they may have that fit the needs of your family. You need to ask questions which reflect your situation. How would they handle a person having a seizure? Do they have experience with G-tubes? Try to be very clear about the expected duties in the job.
• Ask the candidate what their expectations for the job duties are.
• Ask about their ideas for activities – this can show how creative and energetic they may be.
• What is their work availability? How flexible are they? Can they be available for emergencies?
• Talk about transportation. Do they have a car or will they use the bus?
• Ask for three references. This is very important. Talk to past employers if you can and call each reference. Ask for a Criminal Records Check (the candidate can get one through the local Police station for a small fee). This
person will be working closely with your family in your home, and for safety reasons you need to be very thorough.

- Confidentiality should be a requirement of the position. Whoever you hire, have them sign an agreement about confidentiality.
- Discuss the wage you are offering for the position. At the end of the interview, ask the candidate to think about the position and call them back to confirm that they are still interested – this gives some breathing room for both you and the candidate.

If the interview goes well, and the references are good, you should schedule a trial run with the candidate. Ask them to come and spend time with both you and your family. See how well the she/he fits with your family member.

**Expectations**

Be clear from the beginning about the expectations you have for your respite provider. Think about:

- Can he/she bring anyone with them – children or anyone else?
- Cell phone use – are there restrictions?
- Personal vehicle – are you comfortable allowing your family member to be transported in the respite provider’s vehicle? Do you require the respite provider to have extra car insurance? Who will pay for the gas? Be sure there are appropriate car seats available if they are needed.
- Your house should be found as you left it but the respite provider is not there to clean house. Be clear about your house work expectations.
- Discuss any expectations around discipline. It is important to explain your discipline approach so your
respite provider can be consistent and follow existing rules.

- Make notes about routines, about medications, and about favourite things. You know the routines intimately, but your respite provider does not. They will appreciate the support.

A respite provider is usually self-employed. This means they must keep track of their earnings and report these to the Canada Revenue Agency. You would not issue a T4 to the individual.

Anyone who agrees to work with your family should have a signed agreement outlining their role, responsibilities and employment status.

**Appendix II**

**Respite Providers: Training**

The interviews are over and you have found a respite provider. Now what? Your respite provider may have some experience with your family member’s particular disability, but they will not have experience with your family member. It is important that you prepare and train the respite provider so that he/she can work effectively with your child/youth.

Introduce the respite provider to the needs of your child/youth. Set up a binder for the respite provider with information about your family member.

You might include a profile of your child/youth:

- Include a picture. List his/her name, age, siblings’ names, school attending, and any after-school care or day program your family member attends.
• Talk about your child/youth’s personality. Talk about his/her abilities and needs. This is a great way to introduce your child to the respite provider.

• List activities your child/youth enjoys. List activities they do not enjoy. What does a successful activity or day look like?

• List people your family member likes to be with. List those people he/she does not like to be with.

• Give the respite provider key strategies you use to help prevent outbursts or upsets in your child. There may be a certain toy, or words/phrases you use to calm a stressful situation. Make sure your respite provider has this information.

• Explain your child/youth’s communication system. Can they communicate verbally or do they use another communication system (e.g., sign language, Picture Exchange Communication System (PECS), visual strategies, assistive technology).

• List any medications your child/youth is taking.

• Make sure the respite provider understands where medications are kept and when they should be administered. Create a log to fill in when medications are given. This will act as a record and way to be sure medications have been given. Be sure the meds are kept in a safe place.

• List any assistive devices used

• List any personal care needed
Be very honest with your respite provider. They need good information to be a good support. Some other suggestions:

- Train the respite provider to understand your family member’s non-verbal clues – body language and facial expression – to understand when he/she might be happy, sad, or anxious. Your child/youth might not exhibit emotions in the same way as more typical people.

- What is the backup plan if a difficult situation develops? If a situation does escalate, what steps should the respite provider take? Who should he/she call, and when?

- Set up a communication page in the binder as an information path. You may not see the respite provider before or after their time with your family member. You can jot down any items you feel he/she needs to know for their shift, and they can share information about their experiences during the shift with you.

- Plan for successful outcomes! Be specific.

**Safety Considerations**

Even in the most well organized and well planned settings, safety may be an issue. Some tips to consider:

- Make sure the respite provider is aware of any allergies or special diets your family member is on.
- Make sure they are careful with hot drinks or foods. This can lower the risk of burns.
- Train respite providers to do a quick scan of any new environment to be certain it is a safe spot for your child. For example, when arriving at a playground, do a quick check of the area for glass or other dangerous objects, as well as a scan of the playground equipment. How easy is it to manipulate a wheelchair? If the child is mobile, are there objects around which might limit his/her mobility? Can these be moved?
- Sometimes there may be behaviour outbursts. It is important to stay calm in stressful situations. Often these are the situations where someone could get hurt. A good strategy to use is keeping your voice low and movements slow. If someone is agitated or upset, a loud voice or quick movements might heighten their agitation. Staying calm and slowing everything down can help to diffuse the situation. Be sure the respite provider knows the strategies used to manage an outburst, and has a backup plan.

It is important to give as much information to your respite provider as you can, but also remember that it will take some practice before the she/he will become comfortable in his/her role. Working with your respite provider to help them gradually understand your family’s routines and lifestyle will increase success!
Appendix III

Respite Providers: Developing the Relationship

The original document appears on the website
www.respitepartnership.ning.com

The respite provider is hired and trained. You hope they will work well with your family and for a long time. You will want to foster the relationship, but how do you keep it on a professional level?

The respite provider as friend
It is important to define the boundaries with your respite provider(s). They will be coming into your home and personal life to work with your child. They may share meals or other personal times with your family. As you become more familiar with your respite provider, you may start to see her/him as a member of your family. However, the respite provider is there on a professional level. They are present as a contracted employee to do a job. They may become very fond of your child and your family. You and your family may become very attached to them. Where do you draw the line?

Be friendly. It is natural to chat with people, to find out about them and their lives. Show concern and interest for their life situations, but stay away from any direct personal involvement with their problems.

As you develop a comfortable relationship with your respite provider, there may be a temptation for you to share intimate problems with them. It is wise not to follow this temptation. Share information which is important to your
child, but do not go beyond that. For example, if you and your spouse separate, you would need to share that information with your respite provider. You do not need to share any personal difficulties you may be having in dealing with your estranged spouse.

Payment
You have hired the respite provider to do a job. The respite provider has a right to expect payment on a regular basis. Arrange the payment system/schedule with the respite provider from the beginning and stick with it. If you agree to pay the him/her at the end of the shift, or on a weekly basis, be sure to pay them on time. Respite providers have their own financial commitments and will appreciate receiving payment when it is promised.

Meetings
Arrange a regular meeting time with your respite provider. This may be a check-in type of meeting to see how things are going. Review any plans you have established to see if they need to be tweaked. Talk about any ideas for new or different activities.

Give feedback to your respite provider. Talk about any issues or problems which have come up. It is better to deal with potential problems early so they do not become bigger. Be sure to highlight successes. Everyone likes to hear that things are going well. Let her/him know how much they are appreciated and what this respite time means to you and your family. Your respite provider will gain tremendous job satisfaction knowing his/her work is making a difference to your lives.
Ending the Relationship

Happy Endings:
One of the constants of life is that it will change. Eventually, your family situation or your respite provider’s situation may change, and it will be time for her/him to move on. Although saying good-bye is difficult, there may be ways to make it easier. Ask if he/she would be willing to help train the new staff person. This may make the transition easier for your family. If the respite provider is staying in your community, ask if they would be willing to fill in as an emergency caregiver, or would like to drop in for visits with your family. Here is a time to build a friendship without the restrictions of the employer/employee relationship.

You could plan a farewell party or event for the respite provider. This is an opportunity for everyone to show appreciation and to enjoy each other’s company. This also serves as a closure event for your child/youth as they move on to a new person or situation.

Not So Happy Endings:
The respite provider you carefully interviewed, screened and trained is not working out. Perhaps you have noticed problems in the way the respite provider does the job. The first approach would be to work with the staff person to try and resolve the problems.

- Arrange a private meeting with the respite provider.
- Describe the problem(s). Be clear and direct. Tell the respite provider what you have observed and why this is causing concern.
• Do you have a written job description or agreement? Discuss the problem in reference to the original job expectations.

• Be certain the respite provider understands the issues and is prepared to change his/her behaviour.

• Set a time period for the respite provider to make changes in his/her job performance.

• If necessary, have a third party help with the situation. Perhaps the respite provider needs a coach or mentor for a time, to help work effectively with your child/youth.

• If the respite provider is unable or unwilling to make the necessary changes, you should give him/her notice that he/she will be let go from the job and move on. Be honest, be clear and be firm with your worker.

If you see or are informed of dangerous behaviour on the part of your respite provider, suspend him/her immediately. If you suspect neglect or abuse, contact:

http://www.gov.ns.ca/coms/families/abuse/
or call 1-877-424-1177 between 8:30 am – 4:30 pm
(or 1-866-922-2434 between 4:30 pm – 8:30 am, on weekends and holidays).
### Appendix IV

**Blank Table—Planning Respite Time**

<table>
<thead>
<tr>
<th>Reason for Respite</th>
<th>Activity for child/adult with disability</th>
<th>How often?</th>
<th>Length of Time</th>
<th>Total Amount</th>
<th>Type of Respite (in home vs. Out of home)</th>
</tr>
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</tbody>
</table>
Appendix V

Direct Family Support criteria

The Direct Family Support Program provides funding to eligible families to help them support their family member (both children and adults) with a disability at home.

The Direct Family Support Program may also include Enhanced Family Support (EFS), which provides additional funding to assist families to support their child at home when their child’s care and support needs are considered extremely challenging and they require comprehensive, highly structured and skilled forms of support and intervention. This funding will allow families to hire support providers who have specialized training, education or experience related to the needs of the child.

Eligibility for Direct Family Support for Children

- The family and child are permanent residents of Nova Scotia.
- The child is under 19 years of age.
- The child is living in the home of a family member/guardian of the child.
- The child has been diagnosed by an approved clinician as having a mild or moderate intellectual disability with a significant behavioural challenge that has been documented within the last two years.
- The child has been diagnosed by an approved clinician as having a severe intellectual disability that has been documented within the last two years.
- The child has a significant physical disability with ongoing functional limitations that are a result of the
Direct Family Support for Children (DFSC) Program Income Guidelines

A family's size and income will determine the amount of funding they will receive. This means that the family will be expected to contribute a portion of the respite funding depending on the number of people in the family and family's annual income. The table on page 31 outlines the annual net income ranges per family size category and the family’s monthly contribution.

Eligibility for Direct Family Support for Adults

To be eligible for the Direct Family Support for Adults (DFSA) program the application and/or assessment process must identify and determine that the applicant/individual and their family meet the following criteria:

- The applicant and their family are permanent residents of Nova Scotia.
- The applicant is 19 years or over.
- The applicant is residing in the home of a family member or guardian.
- The applicant has a medical diagnosis of one or more of the following: intellectual disability, long term mental illness, or physical disability.
- The applicant and family have unmet needs as identified through the assessment process.
- The applicant meets the financial eligibility criteria as outlined in SPD policy and procedures.

The applicant and their family agree to participate in the assessment process as outlined in SPD policy and procedures.

<table>
<thead>
<tr>
<th>Family Size</th>
<th>Income From</th>
<th>To</th>
<th>Monthly Family Contribution</th>
</tr>
</thead>
<tbody>
<tr>
<td>Two-Member Family</td>
<td>$31,440</td>
<td>$36,000</td>
<td>$100</td>
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<td>$36,000</td>
<td>$40,000</td>
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<td>Three-Member Family</td>
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<td>$80,000</td>
<td>$83,808</td>
<td>$800</td>
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</tbody>
</table>

(For Five(+) Member Family, visit: http://www.gov.ns.ca/coms/disabilities/DirectFamilySupport.html)

Above criteria are subject to change without notice.
Enhanced Family Support criteria

Eligibility for Enhanced Family Support for Children

To be eligible for funding under Enhanced Family Support for Children, the application and/or assessment process must identify & determine that the child and their family meet the following criteria:

- Meet all requirements of the SPD/DFS Program
- Have extremely challenging care and support needs that are not adequately addressed through their current DFS funding
- Have care and support needs that are assessed at, or exceed an overall range of 3 or 4, as determined by the Support Assessment Tool (SAT).
- Require the involvement of healthcare practitioners from two or more disciplines
- Require one or more behavioural supports as outlined in the Enhanced Family Support for Children Policy
- Have one or more family circumstances in evidence as outlined in the Enhanced Family Support for Children Policy

Enhanced Family Support for Children funding is subject to the DFSC Income Guidelines to determine financial eligibility.

Eligibility for Enhanced Family Support for Adults

To be eligible for funding under Enhanced Family Support for Adults, the application and/or assessment process must identify and determine that the applicant/individual and their family meet the following criteria:

- Meet all requirements of the SPD/DFS Program
- Have extremely challenging care and support needs that are not adequately addressed through their current DFS funding
- Have care and support needs that are assessed at or exceed DII, DIII, ARC, RRC level of care (Level 4 or 5 equivalent) as determined by the Individual Assessment & Support Plan (ISP)
- Require the involvement of healthcare practitioners from two or more disciplines
- Require one or more behavioural supports as outlined in the Enhanced Family Support for Adults Policy
- Have one or more family circumstances in evidence as outlined in the Enhanced Family Support for Adults Policy

Contact Information for Organizations that Provide Support Services in Nova Scotia

**Alexander Society for Special Needs**
Provides art based educational programs to children and teens with special needs. Located in Wolfville, NS  
902-582-3888  
www.alexandersociety.org

**Art Gallery Nova Scotia**
902-424-5280 Information  
902-424-2197 Dale Sheppard, Curator of Education and Public Programs  

**Autism Nova Scotia**
Offers information, resources and programs to individuals and families living with autism spectrum disorder.  
1-877-544-4435  
in Halifax 446-4995  
www.autismnovascotia.ca

**Autism Society of Cape Breton**
Offers information and programs to individuals and families living with autism spectrum disorders in the Cape Breton Region  
902-567-2830 Michelle Gardiner, Executive Director  
autismcb@bellaliant.com

**Bonny Lea Farm**
Offers residential living, vocational day programs and a Greater Achievement Centre. Located near Chester, NS  
902-275-5622

**Boys and Girls Club**
Offers afterschool and summertime programming for all children. Will consider taking participants with special needs.  
902-657 9674 (Maritime Region)  
www.bgccan.com
Camp Brigadoon
A non-profit recreational facility in the Annapolis Valley. Offers camp programming to Maritime children, youth and families living with chronic illness, condition or special need.
888-471-5666
902-422-3387
www.brigadoonvillage.org

Camp Tidnish
A sleep away camp designed to support campers of all ages with special needs. Located near Amherst, NS
902-453-6000 ext. 227
camping@easterseals.ns.ca
http://www.easterseals.ns.ca/programs-and-services/camp-tidnish/

Camp Triumph
A camp experience for siblings (age 8—17) of people with special needs or chronic illness. Located in PEI.
902-542-7439
info@camptriumph
www.camptriumph.ca

Cape Breton Community Respite
Regional respite service for Cape Breton region.
902-539-6685
autismres@ns.sympatico.ca
www.nsnet.org/cbcr/

Caregivers Nova Scotia
Offers information, programs and services for families who are primary caregivers to a family member with chronic illness or special need.
877-488-7390
902-421-7390 in Halifax
www.caregiversns.org

Dept. Of Community Services – Direct Family Support
877-424-1177

Dept. Of Health – Continuing Care
800-225-7225
www.gov.ns.ca/health/ccs/
DIRECTIONS Council for Vocational Services Society
Assists and supports member organizations in delivery of services which help support people with disabilities in their communities. A complete list of vocational programs is located on this website.
www.directionscouncil.org/memberagencies

Disabled Persons Commission
A government agency which advises policy makers and program developers about issues, needs and concerns of people with disabilities.
800-565-8280
http://novascotia.ca/disap

The Epilepsy Association of Nova Scotia
Supporting through education, client based services and support of research.
866-374-5377
http://epilepsyns.com

Early Intervention NS
Provincial association representing all Early Intervention (EI) programs for preschoolers with special needs. A list of all EI programs can be found at the link below.
www.earlyintervention.net/where.cfm

Fetal Alcohol Syndrome & Effects Support Network of NS
Information on Fetal Alcohol Syndrome and Effects
902-678-0281
fasfae_ns@hotmail.com
www.nsnet.org/nsfas/index.html

Halifax Association for Community Living (HACL)
Offers information and support to people with disabilities and their families in the Halifax area.
902-463-4752
famsupporthacl@eastlink.ca
www.halifaxacl.com

Highland Community Residential Services
Offers residential living and support for persons with disabilities to live more fully in community. Located in New Glasgow, NS
902-752-1755
www.hcrsweb.ca
Kings Rehab Day Program
Located in the Annapolis Valley, affiliated with Kings Regional Rehab. 902-538-3103

IWK’s On the Move
902-470-7039
kim.clarke@iwk.nshealth.ca

IWK Recreational Therapy
Works to increase access to recreation for children with physical disabilities or acquired brain injury.
902-470-7539
www.iwk.nshealth.ca Click on Care Services, then Rec Therapy.

L’Arche Communities
An international federation of faith-based communities creating homes and day programs for people with developmental disabilities.

L’Arche Antigonish
902-863-5000
info@larcheantigonish.org
http://www.larche.ca/en/communities/antigonish

L’Arche Cape Breton
902-756-3162
office@larchecapebreton.org
www.larchecapebreton.org

L’Arche Halifax
902-407-5512
office@larchehalifax.org
www.larchehalifax.org

L’Arche Homefires
902-542-3520
office@larchehomefires.org
www.larchehomefires.org

Learning Disabilities Association of NS
Information, resources, support to people with learning disabilities and their families. 877-238-5322
902-423-2850 in Halifax
www.ldans.ca
Northern Region Respite Services for Children
Regional respite coordinator for Northern Nova Scotia
902-752-1755
nrrs@eastlink.ca
www.hcrsweb.ca

NS Association for Community Living (NSACL)
a province wide association of family members and others working
for the benefit of persons of all ages who have an intellectual disability.
902-469-1174
www.nsacl.ca

NS Community Organization Network
Links persons with disabilities and/or health challenges with resources and services.
902-678-0281
www.nsnet.org/

NS Down Syndrome Society
A non-profit organization which acts as a resource to anyone interested in
Down Syndrome in Nova Scotia.
902-538-1087
www.novascotiadowns syndromesociety.com/

Nova Scotia "211"
Dial 2-1-1 to find and connect to the community and social services you
need, anywhere in the province, regardless of location.
888-692-1382
http://ns.211.ca/

Speech and Hearing Association of Nova Scotia (SHANS)
902-835-7680
pad@eastlink.ca
www.shans.ca

SRMK/S.M.I.L.E. – Acadia University
902-585-1692 or 1477
www.familynavigator.ca/resource/acadia-university-smile-sensory-
motor-instructional-leadership-experience-program
Every child is gifted. They just unwrap their packages at different times.
-- unknown
Funders who Support Individuals with Special Needs

Jumpstart/RecKids Program ** Halifax area only
- Provides support to participate in sport, art, cultural & recreation activities.
  www/Halifax.ca/rec/JumpStartRecKids.html

Abilities Foundation
- Wheelchair seating, mobility items, hearing aids, communication devices, lifts. Maximum amount $500.00
  www.abilitiesfoundation.ns.ca

Access-A-Home, Dept. Community Services
- Modifications to make the home accessible to a resident with a disability. Maximum amount $5000.00
  www.gov.ns.ca/coms

Direct Family Support
- Must be approved client of Direct Family Support Program
- Provide some funding for respite costs
  www.gov.ns.ca/coms/department/contact/agencies.html

Local Lions Clubs
- Must apply to the club in your geographic area. Open to a variety of needs. Maximum amount $500.00

Local Rotary Clubs
- Must apply to the club in your geographic area. **Ask if they have a Disabled Childs Fund. Open to a variety of needs.

President's Choice Children's Charity
- Family must earn under $70,000/year. Variety of equipment up to $10,000. Will go up to $20,000 for van modifications and communication devices. Maximum lifetime amount $20,000.00
  www.presidentschoice.ca/ChildrensCharity

Private Health Insurance
- Know your Insurance policy and always call for clarification if there is any question of coverage.

Q104 Children's Trust Fund **Halifax area only
- One time grant per child. Variety of items funded. Maximum amount $1000.00
  www.childrenstrustfund.ca
For Further information, or to contact the NS Partnership on Respite, Family Health and Well-Being:

Thank you:

to our funders:
IWK Health Centre
Community Grants

IWK Health Centre
Research Services

To Dr. Susan Bryson for her help

To the Respite Guide Working Group
Vicki Harvey
Paula Hutchinson
Dawn LeBlanc
Anne MacRae
Sandra McFadyen

To the NS Partnership on Respite Committee
About the NS Partnership on Respite, Family Health and Well-being

With its beginnings at the IWK Health Centre and the Nova Scotia Disabled Persons Commission, the NS Partnership on Respite, Family Health and Well-Being was developed in order to raise public awareness about the respite and support issues of families who are caring for children/youth and/or adult children with disabilities.

The Respite Partnership also works in collaboration and consultation with families to educate parents and caregivers about respite, to offer parents and caregivers the opportunity to connect and network with other parents, and to identify how respite services and policies may be designed and enhanced to better address the support needs of Nova Scotia families who have children/adult children with disabilities.

The Respite Partnership includes families, community and health organizations, government policy officials, and health researchers and is comprised of the following organizations:

- Autism Nova Scotia
- Cape Breton Community Respite Program (Society for Treatment of Autism NS)
- Caregivers Nova Scotia Association
- Halifax Association for Community Living
- IWK Health Centre – Autism Research Centre
- IWK Health Centre – Primary Care
- IWK Health Centre – Social Work *
- Northern Region Respite Services (Highland Community Residential Services)
- Nova Scotia Advisory Council on the Status of Women
- Nova Scotia Association for Community Living
- Nova Scotia Department of Community Services - Services for Persons with Disabilities
- Nova Scotia Disabled Persons Commission*
- Parents Supporting Parents
- Progress Centre for Early Intervention
- Western Region Respite Program (Yarmouth Association for Community Residential Options—YACRO)
- and parents

*Co-Chairs of Partnership