

Nova Scotia Respite Guide

A Guide for Caregivers of Children
and Adults With Disabilities



*Nova Scotia
Respite Partnership*

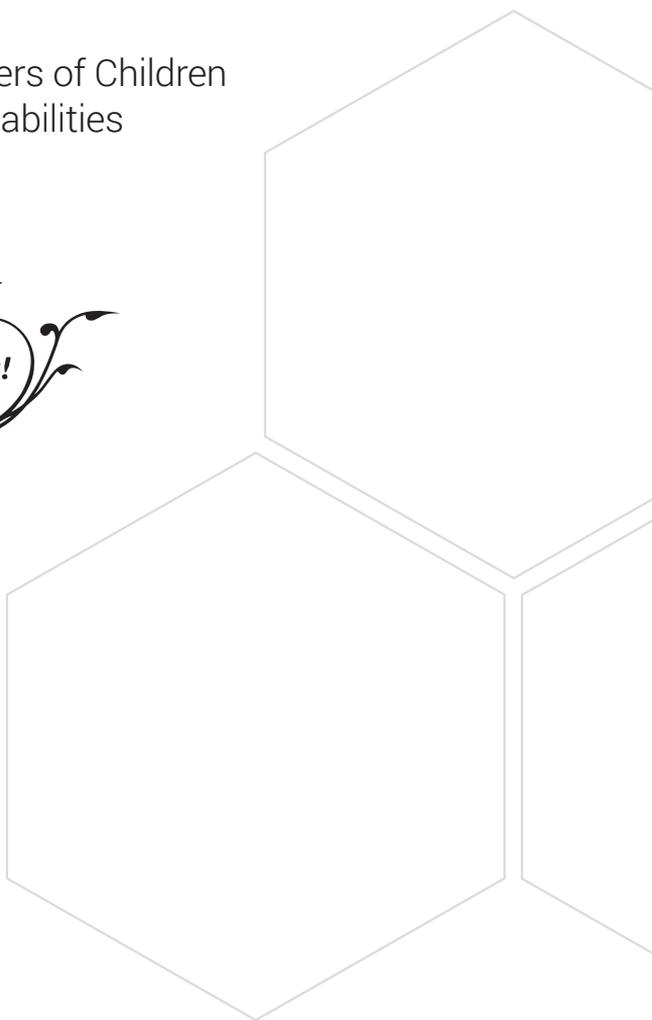
Respite, WE deserve it!



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Is This Guide for You?

This guide was developed for caregivers of children and adults who have disabilities that affect development, physical ability and/or mental health.

As a caregiver your time is valuable and limited. This guide is intended to provide an easy-to-follow map. It will guide you through the process of:

- discovering the role respite could play in your family
- how to apply for respite funding
- ways to recruit and hire respite providers
- sharing the care of your loved one

This guide will help you navigate a course towards meeting the needs of your family member.

This guide is for parents and caregivers of child and adults with disabilities who are thinking about adding respite into their lives. The guide provides information on respite opportunities in Nova Scotia. Not all of the information in this guide will apply to every family.

5th Printing – April 2017

Definitions

Children/Adults with disabilities or chronic illnesses Refers to children, youth and adults with disabilities or chronic illnesses, including but not limited to, autism 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 for 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 care giving role by providing support for children/adults to engage in social, recreational, cultural or life-skill activities.

Using This Guide

This guide is divided into four sections that will help you and your family locate the respite supports most appropriate for your situation.

1. What is respite? This section defines respite and explores how it can benefit you, your family member with a developmental disability, physical disability, and/or mental illness, and your family as a whole.
2. How do I find and fund respite support? This section explores formal and informal respite supports and provides a path to obtaining both types of respite supports.
3. Planning for respite supports.
4. Providing orientation, oversight and follow-up with the respite provider.





Role of Respite

What is Respite?

Family respite can take many forms. It can be going for a walk, meeting a friend for coffee, or taking a few hours to clean the house while the person you care for engages in a recreational or social activity. It can be a weekend away for your child/adult with a skilled respite provider.

It can help you spend time with older or younger siblings while your child/adult is hanging out (with support) in another part of the house. Or, it can also be time for you and your partner to do something fun!



Respite is support for the whole family

Having respite as part of family life gives family members (caregivers and care receivers) time to do the things they want and need to do. Respite allows caregivers to make time for themselves and for their other family members. Regular respite can give family members time to take care of their health, pursue hobbies, meet up with friends, rest, or do the housework! Respite should also be a positive time for your loved one to develop relationships and the opportunity to engage in social and leisure activities, and do something enjoyable in the community. Respite is about creating positive time for yourself, your loved one, and other family members and contributes to the overall well-being of the family.

“Respite should be more than a break from life’s circumstances, it should be a change of life’s circumstances”

(Hutchinson et al., 2010)

Learning about respite options and finding the ones that work best for you and your family’s needs are normal milestones for families caring for a loved one 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 for Children, Flex Program, and Continuing Care).

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 parent's reply to "How did you know that you needed Respite?"

"Quality respite is not only required, it is a necessity for the caregiver and the person with exceptional needs."

(Hutchinson et al., 2010)

"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."



Finding Respite Support

Finding and Funding Respite Support

Informal Respite

Informal respite is provided through family, friends, neighbours and others in your community. This is usually not paid work. These supports may be a neighbour watching your child/adult while you take a walk around the block or a neighbourhood 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-op programs with other families. A co-op can allow one set of parents a night out while their child/adults is looked after by other parents in the co-op. It can also offer a helpful support system for parents.

You might consider your local municipal recreation service or other local organization. Ask how they include children/adult with disabilities into their programs. As a start, there are a number of organizations listed at the back of this guide.



Formal Respite

Formal respite involves hiring respite providers to work inside or outside of your home. Some families may have their own funds or have health care coverage to pay for respite services but others may need to seek external funding for respite. There are also grant opportunities through charities that may be helpful.

Formal respite often has age criteria. Some programs serve children/youth under 19 years of age, others serve those over 19 years of age, and others serve all ages. Formal respite may include funding, personnel who work in your home or out-of-home respite in a facility. See below for an overview.

Name of Program	Service	Age of family member	Contact
DCS - Disability Support Program – Flex Individualized Funding & Direct Family Support for Children	Funding for respite.	All Ages	novascotia.ca/coms/disabilities/index.html
DHW Continuing Care Program: Caregiver Benefit	Funding (\$400/month)	19 years and older	novascotia.ca/dhw/ccs/caregiver-benefit.asp
Respite Coordinators	Finds Respite Support Workers for those who have funding	Under 19 years	See Respite Coordinators list provided on page 15 of this Guide.
DHW Continuing Care Program: Home Support	Respite Service	All Ages	novascotia.ca/dhw/ccs/ 1-800-225-7225
DHW Continuing Care Program: Facility Based Respite Care	Respite Service	All Ages	novascotia.ca/dhw/ccs/ 1-800-225-7225

DCS = Department of Community Services; DHW = Department of Health and Wellness

Funding for All Ages

The Direct Family Support for Children Program (DFSC) and the Flex Individualized Funding Program, are operated by the Department of Community Services (DCS). The amount of funding is based on the degree to which the disability impacts the individual and the family. The funding may be prorated or reduced based on family income. It's important to note that the eligibility criteria are different for children than for youth/adults. Please refer to eligibility criteria for these programs listed later in this guide. More information can be found on line at: novascotia.ca/coms/disabilities or by contacting your local Community Services office or by calling 211.

Funding for those aged 19 years and older

Caregiver Benefit:

The Nova Scotia Department of Health and Wellness, Continuing Care Program offers the Caregiver Benefit. The Caregiver Benefit recognizes the important role of caregivers in their efforts to assist loved ones and friends. The program is intended for caregivers of low income adults who have a high level of disability, as determined by a Home Care assessment. If the caregiver and the care recipient both qualify for the program, the caregiver will receive \$400 per month. For more information, please go to: novascotia.ca/dhw/ccs/FactSheets/Caregiver-Benefit.pdf

Finding a Respite Provider

Once you have secured funding, you will need to find a respite provider. For youth aged 19 year and under, there is a respite coordination service in all regions of the province, and each region has a Respite Coordinator who manages the service.

Respite Coordinators help families access respite providers and plan respite care for family members. They screen and refer respite providers. Screening includes: an interview, police and/or RCMP criminal record check, Child Abuse Registry check and three other references.

Several regions have a respite apartment available to families within the program. The availability of the apartment is on a first come, first served basis. The apartment is not staffed so the parents/guardians are expected to provide a respite provider when using the apartment, however, there is no cost for use of the apartment itself. The apartment can be booked by calling the Respite Coordinator in your region or for Central Region call Support Service Group (902-466-0230).

Region of NS	Respite Coordinators	Contact
Northern	Northern Region Respite Services (NRRS)	902-752-9452 info@hcrsweb.ca
Western	Yarmouth Association for Community Residential Options	902-742-9258 sitland@yacro.com or info@yacro.com
Central	Autism Nova Scotia	902-446-4995 mmyers@autismns.ca
Central	Support Services Group Cooperative (apartment)	ssgns.ca 902-466-0230
Cape Breton	Cape Breton Community Respite	902-539-6685 autismres@ns.sympatico.ca

Department of Health and Wellness (DHW), Continuing Care for All Ages

Although the Respite Coordinator screens and refers respite providers, *parents/guardians are ultimately responsible for choosing their provider*. The parent/ guardian interviews and decides if a respite provider is the most suitable to provide care. Once a family has decided, it is the family's responsibility to provide training to the respite provider on their child/ adult's specific needs. Families are also responsible to pay their respite providers directly, and to make bookings for specific times.

The Flex Program also offers up to 60 days of annual residential respite in licensed homes. See Section 12 of the DSP policy: novascotia.ca/coms/disabilities/documents/SPD_Public_Policy.pdf

Home Support:

Another option for formal respite is the DHW's, Home Care Program. This program provides personal support services to people with ongoing care needs, either on a short-term or long-term basis. A range of personal care, respite and home support services are available. Personal care services help the client with daily living tasks, such as dressing/undressing, bathing, toilet use, feeding, and help with mobility. Home Support Services also help the client with tasks, such as light housekeeping, laundry, and meal preparation. In-home respite services for caregivers are available. There may be a cost, depending on your income. For a complete description, please see novascotia.ca/dhw/ccs.

You can apply by calling toll-free 1-800-225- 7225.

Finding a Respite Provider – Conducting Your Own Search

Facility-Based Respite Care:

To support family caregivers and their families, the DHW helps caregivers by providing access to respite beds for their loved ones in licensed long-term care facilities (nursing homes) across the province. There are also options available for children.

A person may stay in a licensed respite bed for up to a total of 60 days within a calendar year. However, to ensure fair access to the beds during the high demand periods (July 1 to October 1), no more than 30 days can be scheduled. You can apply for a respite bed by calling toll-free [1-800-225-7225](tel:1-800-225-7225). A Care Coordinator will assess the applicant's care needs and eligibility. Once the applicant is confirmed to be eligible for the service, the Care Coordinator will arrange for a respite bed for the applicant on a first-come, first-served basis.

Caregivers must be actively involved in searching for and hiring respite providers.

There are several 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:

- Faith communities, libraries, and schools.
- Vocational Agencies (see directionscouncil.org/MemberAgencies),
- Residential agencies (nsraa.ca),
- Colleges (e.g., Nova Scotia Community Colleges, NSCC)
- University departments (e.g., nursing, education, child study, psychology, social work, speech language pathology, occupational therapy, or physiotherapy)

Some families have found respite providers using the internet (e.g., emailing their social network or Kijiji.ca).

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

Be sure to include basic information in the ad – that they will be working with an individual with disabilities, the number of hours, and any special skills you are looking for. A sample ad may look like this:

Job Opportunity

Peer/Support Worker

**To Provide Companionship, Support,
and Community Inclusion for a
23-year-old Man with Cerebral Palsy**

Qualifications:

An undergraduate degree in any care field, or equivalent combination of education, training, and experience in the field of disabilities. Self-motivated, excellent interpersonal skills, and good communication skills, both oral and written, are essential.

Role:

- Plan meaningful recreation and leisure opportunities.
- Provide peer and buddy support.
- Assist in planning and carrying out life skills and recreational activities
- Record keeping – daily activities and organize respite receipts.

Approximately 11 hrs/week (this is negotiable and a combination of daytime and evening hours), at \$_____/hr.

For more information regarding the position, please contact:

Your Name
Email or Phone Number

Naturally, families often worry about the quality of care their child or adult 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. For additional information, see Respite Providers: Screening and Interviewing on page 24.

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/adult in the family home. Consider contacting your Disability Support Program Care Coordinator or Continuing Care Coordinator for more information.



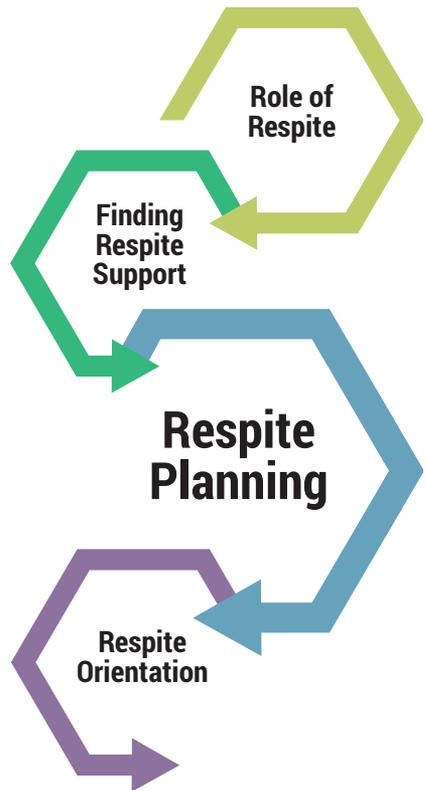
Respite Planning

Planning Respite With Your Family

Your respite plan will depend on your family's needs as well as what is available in your community. This will help you decide which type of respite will work best for you. For example, if your respite goal is for your loved one 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.

1. Start with listing the reasons why you and your child/adult need respite. You may list activities that are meaningful for them. It is also valuable to list activities that help meet your practical and emotional needs. Lastly, expand your list to various community or neighbourhood activities that respite could enable your whole family to participate in.
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 the next page. Fill in your own reasons for respite in order of importance and the types of activities that best suit your child/adult. Determine how often you and your child/adult 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.



Respite Providers: Screening and Interviewing

What do you do once you have replies to your advertisement or have received resumé's from the Service Provider? 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? How long have they worked in the field? If the telephone call goes well, ask them to come for an interview. You can meet them in your home or in a public place (e.g., coffee shop). You may have to interview several people to find someone to best suit your family member's and 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 communication skills, personal care, behaviour management plans or the amount of experience with persons with disabilities in the community.

Prior to and during the interview consider:

1. Have a family member, friend or someone you trust at the interview with you. They can act as support and a second pair of ears and eyes.
 2. Ask for a copy of the candidate's resumé.
 3. Write out interview questions before hand, for example, 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 experiences he/she may have that will fit the needs of your family. You need to ask questions which reflect your situation. How would they handle challenging behaviour? Do they have experience with personal care? 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?
4. Ask for **three references**. This is very important. Call each reference and talk to past employers. 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.

5. Confidentiality should be a requirement of the position. Whoever you hire, have them sign an agreement about confidentiality. A sample confidentiality agreement is provided on page 38.
6. Discuss the wage you are offering for the position.
7. Take notes during the interview so you can remember what was said.

At the end of the interview, ask the candidate to think about the position and call them to confirm their interest. This gives time for you and the candidate to consider the arrangement.

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 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 the respite provider bring anyone with them – their 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 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 the house. Be clear about your house work expectations.
- Discuss expectations around personal boundaries and responding to challenging behaviour. It is important to explain your approach for supporting your loved one so your respite provider can be consistent and follow existing rules.
 - Make notes about routines, medications, and favourite things to do. 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. This is not your responsibility and you would not issue a T4 to the individual.

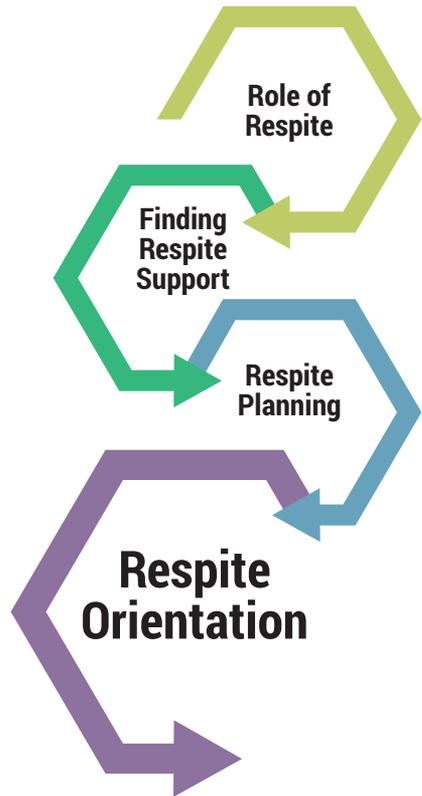


Respite Orientation

Respite Orientation and Follow-up

Orientation

Leaving your child or adult with someone new can be stressful. Many families provide an orientation time for the respite provider and the child or adult to get to know each other before they are left on their own. You may want to consider starting with shorter periods of time in a place where your child/adult is most comfortable. Arrange for them to do an activity that your family member enjoys. It is important to share their communication strategies and every day routines with the worker. This is a chance to spend some time with the respite provider and guide him/her on how to interact with your family member. 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 or adult while you are nearby to offer advice and support.



Follow-up

Families should talk to both the respite provider and the child/adult 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 prompt and regular feedback about their work.

It is also recommended that you take some time to talk to your child/adult 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 or adults who cannot use verbal communication express themselves with behaviour and mood changes. If your child or adult seems unhappy or is behaving out of character, take this seriously. Be sure to discuss any concerns with the respite provider and/or, if relevant, your care coordinator.

Respite Providers: Online Training

There are a few online training programs that your potential worker might complete while they are learning about your family member. For example:

1. respitecourse.ca
2. autismnovascotia.ca

Respite Providers: Training for your Child/Adult

The interviews are over and you have found a respite provider. Now what? Anyone who agrees to work with your family should have a signed agreement outlining their role, responsibilities and employment status. 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/adult.

Introduce the respite provider to the needs of your child/adult. You might set up a binder for the respite provider with information about your family member or you could create a one-page profile.

All About Me!

- Include a picture. List his/her name, age, siblings' names, school attending, and any programs your family member attends.
- Talk about your child/adult's personality. Talk about his/her abilities and needs. This is a great way to introduce your child or adult to the respite provider.
- List activities your child/adult enjoys and does not enjoy. What does a successful activity or day look like?
- Give the respite provider key strategies you use to help prevent outbursts or upsets in your child/adult. There may be a strategy or words/phrases you use to calm a stressful situation.
- List people your family member likes to be with. List those people he/she does not like to be with.
- Explain your child/adult'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 or adult 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 medications 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.

- Train the respite provider to understand your family member's non-verbal clues (body language & facial expression) to understand when he/she might be happy, sad, or anxious. Your youth/adult might show their emotions in different ways.
- 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 an information binder. 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.

The following website provides information on how to complete a one-page profile, which includes most of the information outlined above in a one-page format: helensandersonassociates.co.uk.

Check out samples of All About Me! guides on the Nova Scotia Respite Partnership's webpage: disability.novascotia.ca/content/respite-partnership-publications.

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 dietary requirements your family member has.
- 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/adult. For example, when arriving at a park, do a quick check of the area for glass or other dangerous objects. How easy is it to manipulate a wheelchair?

If the child or adult 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 movement may increase 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 remember that it will take some practice before the she/he will become comfortable in his/her role. Work with your respite provider to help them gradually understand your loved one, and your family's routines and lifestyle.

Respite Providers: Developing the Relationship

The respite provider is hired and trained. You hope they will work well with your family and for a long time. How will you foster a positive relationship?

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/adult. They may share meals or other personal times with 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/adult and your family and you of 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 problems with them. It is wise not to follow this temptation. Share information which is important to your child/adult, but do not go beyond that.

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 respite provider 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.

Ending the Relationship

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.

Happy Endings

One of the realities 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 goodbye 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.

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.

Here is the process you can follow to resolve problems with your respite provider:

- 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 youth/adult.
- 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:

Your local Child or Adult Protection Services (numbers are online under DCS or call 211 for assistance locating the contact information).

Sample Confidentiality Agreement

1. I understand that during the course of my duties as a respite provider with _____ I will have access to information about this person and their family.

2. I understand that any such information is strictly confidential and I agree that I will not use or share this information with anyone, at any time, from this day forward, unless:
 - a) specifically directed by this family, or
 - b) it is required for the safety of the child/adult in my care.

3. I agree to use caution and take all steps to keep the confidentiality of such information safe at any time or in any place, and in particular, when using any type of electronic device or when performing my role as a respite provider. I will use caution when using social media such as Facebook, Twitter, etc., so that this person (or family) is not identified.

Signature of Respite Provider:

Signature of Decision Maker:

Date:

Direct Family Support for Children and Flex Individualized Funding Program Criteria

Direct Family Support for Children and the Flex Programs are administered by the Disability Support Program within the NS Department of Community Services. These programs provide funding to eligible families to help them support their family member (both children and adults) with a disability at home. This funding will allow families to hire respite providers who may have specialized training, education or experience related to the needs of the youth/adult.

The Direct Family Support for Children and Flex Programs 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.

Eligibility for Direct Family Support for Children (DFSC)

- The family and child are permanent residents of Nova Scotia;
- The family and child are lawfully entitled to be in or to remain in Canada;
- The child is **under 19 years** of age.
- The child is living in the home of a family member/guardian;
- The child has been diagnosed by an approved clinician with a disability as defined as:
 - a mild or moderate intellectual disability with a significant behavioural challenge that has been documented within the last two years; or
 - a severe intellectual disability that has been documented within the last two years; or
 - a physical disability with ongoing functional limitations that are a result of the disability and which seriously limits their capacity to perform age appropriate activities of daily living; or
 - a dual diagnosis consisting of any of the above.
- The family net income meets the DFSC Program income guidelines;
- The child's family agrees to participate in the assessment process.

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. You can view the Income Guidelines here: novascotia.ca/coms/disabilities/DFSCIncomeGuidelines.html

Eligibility for Flex Individualized Funding (for Adults)

To be eligible for the Flex program the application and/or assessment process must identify and determine that the individual and their family meet the following criteria:

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

Enhanced Family Support for Children Program Criteria

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 DFSC Program
- Have extremely challenging care and support needs that are not adequately addressed through their current DFSC 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

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

For more information about the Enhanced Family Support for Children program, see: novascotia.ca/coms/disabilities/documents/Enhanced_Family_Support_for_Adults_Policy.pdf

References

Canadian Association for Community Care (1996) *Best Practices in Respite Services for Children, a Handbook for Parents*, Ottawa, Ontario.

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.

Hutchinson, Paula, with Bryson, S., Harvey, V., LeBlanc, D., MacRae, A. and McFadyen, S. (2010) *Creating Respite Solutions for Nova Scotia Families of Children and Adult Children with Chronically High Needs*. Dalhousie University, Halifax, NS.

Montana Real Choice Systems Change (RCSC) Grantee. *Relax. Take a Break: A Family Guide to Respite for Children in Michigan*.

Respite-Related Support Services in Nova Scotia

For more information, call 211

Alexander Society for Special Needs

Provides art based educational programs to children and teens with special needs. Located in Wolfville, NS.

902-582-3888
alexandersociety.org

Art Gallery of Nova Scotia

902-424-2197
Dale Sheppard, Curator of Education and Public Programs
artgalleryofnovascotia.ca

Autism Nova Scotia

Offers information, resources and programs to individuals and families living with autism spectrum disorder.

1-877-544-4495
902-446-4995 (In Halifax)
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.

Robyn Gallant, Program Coordinator
autismcb@bellaliant.com
14 Glenwood Street,
Sydney, NS B1P 7G4

Bonny Lea Farm

Offers residential living, vocational day programs and a Greater Achievement Centre. Located near Chester, NS.

902-275-5622
bonnyleafarm.ca

Boys and Girls Club

Offers afterschool and summertime programming for all children and youth.

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
brigadoonvillage.org

Camp Tidnish

A sleep away camp designed to support campers of all ages with disabilities. Located near Amherst, NS.

902-453-6000 ext. 227
camping@easterseals.ns.ca
easterseals.ns.ca

Camp Triumph

A camp experience for children who have a sibling or parent with a serious chronic illness or disability (age 8–17). Located in PEI.

902-542-7439
info@camptriumph.ca
camptriumph.ca

Cape Breton Community Respite

Care provided in the child's home or in the one bedroom respite apartment for the families of children with special needs.

902-539-6685
autismres@ns.sympatico.ca

Caregivers Nova Scotia

Offers information, support and programs to families and friends who are giving care to someone with a chronic illness or special need. All services are free.

1-877-488-7390
caregiversns.org/

**The Club Inclusion
(formerly SCRI Society)**

Offers inclusive social, cultural, and recreational programming for people aged 12 years and up.

902-478-1917
alice@theclubinclusion.com
Jackie@theclubinclusion.com
(summer camp)
theclubinclusion.com

**Department of Community Services –
Direct Family Support/Flex**

1-877-424-1177
novascotia.ca/coms/disabilites/index/html

**Department of Health and Wellness –
Continuing Care**

1-800-225-7225
novascotia.ca/dhw/ccs

**DIRECTIONS Council for
Vocational Services Society**

Assists and supports member organizations in the delivery of services that promote the abilities and inclusion of persons with disabilities in their communities. A complete list of vocational programs is located on this website.

directionscouncil.org

Disabled Persons Commission

An agency that works with government and community partners to promote programs, issues, needs and concerns of people with disabilities.

902-424-8280
1-800-565-8280
disability.novascotia.ca

Epilepsy Association of Nova Scotia

Supporting through education, client based services and support of research.

1-866-374-5377
epilepsyns.org

**Halifax Association for Community
Living (HACL)**

Offers information, support, and inclusive programs to people living with intellectual disabilities and their families in the Halifax Region.

902-463-4752
hacl@eastlink.ca
halifaxacl.com

**Halifax Recreation Programs
& Activities Catalogue**

A resource for service users and providers. Lists a variety of recreation and service options for all Nova Scotians.

halifax.ca/rec/ProgramsandActivities.php

**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
hcrsweb.ca

IWK's Village News

An electronic newsletter which provides information regarding upcoming events as well as stories to inspire participation and quality of life.

902-470-7039
kim.clarke@iwk.nshealth.ca

IWK Recreational Therapy

Works with families to increase their awareness of recreation opportunities for children/youth with a physical/developmental disability which are matched to their individual needs and abilities. Collaborates with schools and community organizations/services to enhance optimal participation of children/youth with a disability.

Through an assessment process matches children/youth to adapted recreation equipment which they can borrow to support participation in biking, swimming, skating, snow and beach activities, and school activities/class trips which require adaptation.

902-470-7539
iwk.nshealth.ca
Care Services
Rec Therapy

Kings Rehab Day Program for Youth

Located in the Annapolis Valley, affiliated with Kings Regional Rehab.

902-538-3103
krcc.ns.ca/day-program-for-youth

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
director@larcheantigonish.ca
larcheantigonish.ca

L'Arche Cape Breton

902-756-3162
larchecb@larchecapebreton.org
larchecapebreton.org

L'Arche Halifax

902-407-5512
office@larchehalifax.org
larchehalifax.org

L'Arche Homefires

902-542-3520
office@larchehomefires.org
larchehomefires.org

Northern Region Respite Services

Regional respite coordinator for Northern Nova Scotia

902-752-1755
info@hcrsweb.ca
hcrsweb.ca

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.

1-888-692-1382 (TTY services)
ns.211.ca

Nova Scotia 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.

1-844-469-1174 (Toll Free)
nsacl.wordpress.com

Nova Scotia Early Childhood Development Intervention Services

Provides specialized services to families of children between birth and school entry who are at risk, or have a diagnosis of developmental delay. Programs listed on website.

902-423-8010
nsecdis.ca

Nova Scotia Down Syndrome Society

A non-profit organization which acts as a resource to anyone interested in Down Syndrome in Nova Scotia.

902-441-3925
info@halifaxnsdss.ca
halifaxnsdss.ca

Nova Scotia Residential Agencies Association (NSRAA)

The NSRAA strengthens the ability of member agencies to focus on person-centered service delivery and pursue excellence in community-based service.

nsraa.ca

Nova Scotia Respite Partnership

The Nova Scotia Respite Partnership is a formal collaboration of parents/caregivers and professionals working in human services, health care, research and policy. The membership is comprised of individuals who have an in-depth, first-hand understanding and passion for the complex and sensitive nature of care giving. The goal of the Partnership is to develop solution-focused strategies that promote a proactive system of care for children and adults with disabilities and respite for caregivers and families.

902-424-0796
Toll-free: 1-800-565-8280
disability.novascotia.ca/content/nova-scotia-respite-partnership

Reachout Respite

902-405-3020
register@reachoutrespite.com
reachoutrespite.com

S.M.I.L.E. – Acadia University

The Acadia S.M.I.L.E. Program provides persons with varying disabilities a unique physical activity experience in order to improve their total development as individuals.

902-585-1477
smile@acadiau.ca
smile.acadiau.ca

Funders who Support Individuals with Disabilities

Society for the Treatment of Autism/ Cape Breton Community Respite

902-539-6685
autismres@ns.sympatico.ca

Special Olympics

1-866-299-2019 (Toll Free)
902-429-2266
specialolympicsns.ca

Speech and Hearing Association of Nova Scotia (SHANS)

902-423-9331
webmaster@shans.ca
shans.ca

Yarmouth Association for Community Residential Options (YACRO)

902-742-9258
info@yacro.com
yacro.com

Jumpstart/ReckKids Program ** Halifax area only

Provides support to participate in sport, art, cultural & recreation activities.

halifax.ca/rec/JumpstartReckKids.php

Easter Seals Nova Scotia

Wheelchair seating, mobility items, hearing aids, communication devices, lifts.

easterseals.ns.ca

Access-A-Home Program , Housing Nova Scotia

Modifications to make the home accessible to a resident with a disability.

housing.novascotia.ca

Disability Support Program (DSP)

Provides support for participation in a range of community-based, residential and vocational/day programs.

novascotia.ca/coms/disabilities/index.html

Local Lions Clubs

Must apply to the club in your geographic area. Open to a variety of needs. Maximum support amount of \$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

Support children with special needs by providing financial grants for essential specialized equipment and essential therapies.

presidentschoice.ca/en_CA/community/pccc.html

Private Health Insurance

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

For further information regarding the Nova Scotia Respite Partnership contact Sandra McFadyen at the Nova Scotia Disabled Persons Commission at 902-424-0796 or visit disability.novascotia.ca/content/nova-scotia-respite-partnership

Thank You

Nova Scotia Disabled Persons
Commission,
Nova Scotia Respite Partnership



*Nova Scotia
Respite Partnership*

Respite, WE deserve it!

