

Respite... YOU deserve it!

This week's article is a response to a question from a parent on the Staying Connected Group. It is not a full or final answer by any means, but we hope it will help you think about different ways to look for respite. We appreciate your questions and comments, so please keep sending them to us. We will do our best to find some answers.

Some of you may read this and realize you have different ways to find respite which are not detailed in this article. Please feel free to share – there may be some amazing ideas out there that could be shared with the group.

I did not qualify for the Direct Family Support Program. What do I do now?

1. Appeal the decision

If you do not qualify for the DFS program and you feel your family should receive the funding, you can appeal the decision. The person who did your assessment can tell you the steps to take for an appeal.

If you are appealing a decision, it is probably because you think your family life faces more challenges due to the needs of your family member with high needs. These challenges may not have been clear to the DFS staff that made the decision to disqualify your family. You will need to paint a fuller picture of your family situation so DFS can better understand what your daily life is like. You may want to describe a typical day or week to show the challenges your family faces. You may want to ask someone outside of your family (e.g. doctor or teacher) to describe your child's challenges.

It is important to remember that an appeal does not mean you will qualify for the program. Even after an appeal, your family may not meet the criteria and you will be looking for other options for respite. However, if you find yourself in an emergency situation, don't hesitate to contact Community Services again. You can always reapply if your situation changes.

2. Other Respite options

Respite options can be divided into two categories – Formal Respite and Informal Respite. The difference between these is money. Formal Respite involves dollars to pay a worker, or to pay for a program your family member can take part in. Informal Respite is unpaid respite. It is whatever support you put in place to give yourself a few moments of breathing room. These moments can be anything from having a half-hour in front of the TV to enjoy a favourite show, to walking, reading, going for coffee, listening to music, going to the gym, or chatting on the phone with family or friends.

3. Informal Support - Who can I ask to help?

The Inner Circle

You may have informal support by finding someone who can take on care giving for 30 minutes or an hour so you can have some time to do whatever you wish. You could ask a family member or a friend to give you this break. Perhaps a neighbour would be interested in helping out, or someone through your local community organization. Advertise in a local church bulletin, or at your library. Don't be afraid to ask – there may be people around you who have interest or skill and are willing to help.

It is better to be specific when asking someone to help you. Take some time to map out your daily tasks. What kind of time do you need for respite? Is it 1 hour for a walk, or do you want 3 hours for a date night with your spouse or partner? Look at your daily schedule and be sure to slot in respite – then start asking for help.

Creative Ideas

Some families have organized cooperatives for respite. Find some other families who are looking for respite options, and talk about the possibility of sharing your care giving. This may be a way for you to have an afternoon or an evening out while your family member is cared for by another family (or families), and you can offer the other families a chance for an evening out the next time.

Community Resources

Don't forget about community resources. Some communities have family programs where the family members attend together. The program may offer a time for parents to chat or hear a speaker, while the children (with disabilities or without) enjoy a different activity. Ask your local library, community centre, YMCA, family resource centre if they are know of any programs. You can also ask your social worker, Early Interventionist, or school staff – they may also have connections to family programs in your community.

Students

Think of recruiting a student to help you. Many college or university students are looking for practical experience and might be interested in volunteering with you. Speak to a professor or instructor and ask if they would allow a student's volunteer work experience with your family to count as a part of the course work. Talk to the guidance counsellor at your local high school – there may be students there looking for some volunteer experience who would be willing to work with your family.

Support Groups

Call your local support group. Sometimes the best ideas can come from other families who have faced the same issues. The Special Needs Information Service (SNIS) website www.snis.ca can connect you with many provincial and local support organizations that would be very happy to help you. The Self Help Connection (<http://www.selfhelpconnection.ca/index.htm> , 902-466-2011) has a directory which lists provincial support groups. They would also be happy to help. And don't forget the old standby - your local telephone book will have listings of different support groups in the white and the yellow pages.

4. Formal Support – in search of dollars

If you prefer to have formal supports, you will need to find funding. There are programs which provide additional funding for different family needs. Talk to a social worker – they can help you find the programs and help you in applying for available funds.

Examples of programs:

President's Choice Children's Charities

<http://www.presidentschoice.ca/ChildrensCharity/HowToApply.aspx>

Rainbow Haven Fund <http://thechronicleherald.ca/charities/rainbowhaven.html>

HRM Kids <http://www.halifax.ca/Recreation/HRMKids.html>

Recreation Programs

Have some funding but no worker to hire? Consider a recreation program for your family member with high needs. Most public recreation programs have an inclusion policy and funding dedicated to including the special needs community. Make an appointment with the Program Manager at your local Recreation Program and ask about:

- The inclusion policy. Does the program accept people with special needs? If not, how can you work with the program to change that?
- Program accessibility – what is the physical access? What is the staff capability to support your family member's needs?
- Does the program have funds set aside to hire extra support staff for people with special needs? What kind of qualifications does the program require for support staff?

The IWK Health Centre has a Recreation Therapy Department. They are an excellent resource for accessible and inclusive recreation programs around the province. For more information check their website <http://www.iwk.nshealth.ca/index.cfm?objectID=7D7C1E4D-B12C-7E9B-598F83080DEA49E2>.

Next week's article – preparing for summer!