Chapter 12
Support for Families

“I gained such strength from hearing the trials and experiences of the other parents that I feel ready to tackle the parenting tasks ahead of me with more confidence.”
CHAPTER 12
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Goal for this Chapter

- To learn about different ways in which families can get the support and help they need to raise their children who have a disability, find good information, and to deal with issues that may arise.

What You will Find in this Chapter

- Information about:
  - Respite
  - Community resource centres and provincial disability organizations
  - Public sources of advocacy support and information
  - Family networking/family to family support
- Worksheet 9 – Planning for Hiring or Selecting Support Workers for Your Child
- A List of Additional Resources
Our Journey So Far

◆ Many years ago families who had a child with a disability were often left with two choices: place their child in an institution or raise their child with little or no help or support from others.

◆ In the 1950s and 1960s, disability organizations started to form as a result of families coming together to demand better opportunities for their children.

◆ By the late 1970s and early 1980s, governments began to recognize the important roles of families in the lives of people with disabilities. Government programs were created that provided support to families and to their children within the family home.

◆ It is now widely recognized that people with disabilities belong in families and that families deserve the support they need to raise their children. There is still work to be done to ensure that families get the help and support that they need.

Introduction

Raising a child with a disability often requires additional time and energy on the part of families. You may have more meetings or appointments to attend. You may need information about your child’s disability and how it may affect his or her life. You may need to arrange for services that will provide your child with better opportunities. One parent may have to stay home or reduce work hours to provide support to your child. Your child may have challenges that other children do not have that means that you need to spend more time and attention looking after your child’s needs. You may not get the sleep and rest that you need to maintain your energy levels.
**Respate**

Respate is about getting a break or some short relief from your care giving responsibilities. However, it is also more than this. Respate is about ensuring that your child’s support needs are being met in a way that allows families to feel comfortable about taking time away from their responsibilities.

**How does Respate Happen?**

Respate can take many forms or happen in several ways. It can happen when:

- Other family members or friends offer to “look after” your child for a few hours or longer so that you can have time to yourself.
- Families who have children with disabilities decide to work together to provide a break for each other. This happens as a “trade off” when families look after each other’s children for a few hours or even longer.
- Your child is attending a day care or is in school.
- Your child is working in the community or is involved in other activities that take him or her out of the home.
- You are able to hire someone to come into your home to look after your child or when your child leaves your home for a time and lives somewhere else for a short time.

**Funding for Respate Support**

If you have to hire someone to look after your child you may be able to receive funding from the government to do this. For children under age 19 the relevant program is the *Children with Special Needs* program. This program is reviewed in Chapter 3. This program can be difficult to access as it is mainly available to children who have more significant disabilities. If you are successful having your child eligible for this program it can provide funding for someone to look after your children for a time or additional money to hire a sitter for children under the age of 12.

For adults the relevant program is the *Disability Support Program*. This program is discussed in detail in Chapter 9. If your child is eligible for this program, he or she may request funding for family respate. This will allow families to use this money to hire someone to provide respate in the family home, someone else’s home, or sometimes within a residential facility.

**Hiring a Support Worker to Support Your Child and to Provide Family Respate**

Whether you are doing this with your own money or with government funding, it is important that you find the right people for the job. Respate for families will be much easier knowing that the person supporting your child is trustworthy, qualified and the right match for your child.
At the end of this chapter we have included a worksheet to help you plan for hiring support workers or a respite provider for your child. It includes sample interview questions for when you are hiring or selecting support workers. Feel free to make copies of this worksheet to use as many times as you need to.

**Tips for Choosing a Support Worker or Respite Provider**

- If you are advertising in a local newspaper, or posting notices for the job – attempt to screen potential candidates over the telephone first. Do this by asking about their background in this work, their interest, etc. You will usually get a sense from this initial interview whether or not you wish to have a face-to-face interview with the person.
- When you are interviewing potential support workers/respite providers remember that you are the director, the “employer” of that service. Often we feel that we have to trust them because they are the “professional”. Walk through the day of the particular time period that you would like them to support your child, detailing the routine and activities. Remember you are the expert here on matters concerning your child.
- You may want to interview them in your home with your son or daughter as part of the interview. It is important to witness how your child reacts to them and vice versa.
- Use this time to point out the particular things about your child that are unique or are important in terms of support.
- Trust your gut, it is usually right! Talk with other parents about any misgivings you may have. Remember that not every support worker or respite provider is going to develop the kind of relationship you want them to have with your child. A good “out” for families is to simply say that the candidate is not a good fit.
- If you are working through an agency remember that you have a right to have a big voice in the choosing of a support worker or respite provider. If a worker that they suggest does not seem satisfactory let them know right away.

Adapted from: *Real Respite for the Whole Family*, Canadian Association for Community Living, 2008.
**Community Resource Centres**
Throughout New Brunswick there are a number of resources centres that provide information and support to families. *Family Resource Centres* offer a variety of programs and activities for parents and their children ages 0 – 6. *Community autism centres* provide people with autism spectrum disorder and their families with support and assistance. Many of these centres offer information and resources to families, sponsor workshops and other learning activities, provide a space where people can meet and share ideas, and assist families to find the support they need for their child.

Further information on these resources centres can be found in Chapter 3.

**Disability Organizations**
New Brunswick has a number of active non-profit organizations that serve people who have a variety of disabilities. Most of these organizations offer information to individuals and families and some have programs that provide services of different kinds. Many of the organizations put on education sessions on issues of interest to families. A list of provincial disability organizations, with contact information and a brief outline of their activities can be found in the Family Support section of the NBACL website.

**New Brunswick Association for Community Living**
Since we are producing this guide we will take the opportunity to tell you about some of the things that NBACL does to support people who have an intellectual disability and their families. NBACL is a charitable organization that was originally formed by families in 1957. Below is a list of our main activities – some of which have already been mentioned in other parts of this guide. If you would like further information on any of these activities, please contact the NBACL main office in Fredericton.

- **Disability Support Program**
  Independent Facilitation Services. Since April 2005, NBACL has been providing independent facilitation services to individuals under the Disability Support Program. These services are cross disability in nature and seek to assist individuals applying for disability supports to identify their goals, interests, needs for disability support and a disability support plan that will help them lead more productive and independent lives within their communities. See Chapter 9 for more information on independent facilitation.

- **Transition facilitation support for youth in high school.**
  NBACL’s Transition to Work Program assists high school youth with an intellectual disability get ready to make the transition to work or post-secondary education after they graduate. See Chapter 5 for more information.
• **The provision of education and training opportunities.**

NBACL provides education and training opportunities on a number of issues facing people with intellectual and other disabilities. Such education and training opportunities include:

- Person centered planning approaches and PATH facilitation;
- Sexuality and relationships;
- Circles of Friends;
- Transition planning from school to adult life for persons with disabilities;
- Employment for persons with intellectual disabilities – including on topics such as work customization and developing natural supports in the workplace;
- Community inclusion and developing connections to community for persons with disabilities;
- Inclusive education (for educators, Teacher Assistants, and parents);
- Quality inclusive early learning and child care;
- Futures planning (including estate planning);
- Aging parent issues; and
- Registered Disability Savings Plans (RDSPs).

Education and training workshops and presentations are also supplemented by resources that NBACL has developed in the areas of inclusive education, sexuality and relationships, employment, circles of friends, early learning and child care, transition from school to adult life, estate planning, RDSPs, community inclusion, and aging parents.

• **Circles of Friends Facilitation Training**

Circles of Friends seeks to support the development of relationships for children and youth with intellectual disabilities. This activity is typically operated within local schools and involves the facilitation of a “Circle” for the benefit of an individual with a disability. Training on Circle of Friends facilitation is offered to school personnel and volunteers. See Chapter 11 for more information.

• **Social Inclusion Program.**

This program involves the facilitation of community participation and connections to community, personal support networks and supported living arrangements for individuals with an intellectual disability. See Chapters 10 and 11 for more information.

• **Focus on Inclusion.**

This project supports early learning and childcare centres to welcome and include children with a disability or additional needs. Early Learning Inclusion Facilitators provide advice, strategies and resources to centre staff on ways to be inclusive.
Family Support.
NBACL provides support to and advocates on behalf of families across New Brunswick who are struggling with a system, finding community resources, or in need of tips and strategies on a difficult issue. Through a provincial Family Support Program, families are provided with information, resources and assistance to address issues related to supporting a child or an adult child with an intellectual disability. Areas of support often include supported living, will and estate planning, accessing disability supports, person-centered planning, PATH, sexuality and healthy relationships, and developing personal support networks, among many others. The Family Support Facilitators also oversees family workshops, events, and retreats, as well as manages the Families United Networks (FUN-NB) and the Seniors United Networks (SUN) in areas around the province. More information on both networks can be found later in this chapter.

PATH Facilitation.
PATH is an important planning process that is described in Chapter 5. NBACL offers individuals with disabilities and their families the opportunity to use the PATH process to help people identify their dreams and goals for the future and to develop a person-centered plan that will enable them to reach their goals and dreams. NBACL also trains people around the province to facilitate the PATH process.

Community College Program.
This program facilitates access to community college programs for people with an intellectual disability. This involves recruiting and preparing people for entrance into community college and providing “case management” support for students while they are attending college. See Chapter 6 for more information about accessing Community College

Assistance with Future and Estate Planning.
NBACL provides assistance to families on future and estate planning through one-on-one consultations, workshops, and the distribution of resource materials written specifically for families in New Brunswick. Information is also available to families on the new Registered Disability Savings Plan.

Social Policy Development.
For many years, NBACL has advocated for better social (government) policies that affect people with disabilities and their families. This includes work to promote progressive public policy in the areas of disability supports, income support, employment, transition from high school to adult life, affordable housing, inclusive education, early learning and child care, and aging families.

Public Sources of Advocacy Support and Information
New Brunswick Association for Community Living
There are also a number of public organizations or agencies that provide support and information in a variety of ways. Here is a brief description of some of the key organizations with their contact information.

**Office of the Ombudsman**

The Ombudsman is independent from government and has authority to conduct independent and confidential investigations into complaints from individuals regarding administrative actions or decisions made by government. The Ombudsman will investigate “complaints against administrative decisions and acts of officials of the NB government, agencies or organizations, and any of the municipalities of the province to determine if the decisions or actions were unreasonable, unjust, oppressive or discriminatory, or made under a mistake of law or fact, or contrary to law or by an abuse of discretion.”

As a result of the information gathered through the investigation, the Office of the Ombudsman will make a finding. If, on the conclusion of the investigation, the finding supports the individual’s complaint, the Ombudsman will try to facilitate a resolution, or alternatively, make a recommendation for corrective action. The Ombudsman does not have the authority to require the government to act; however, negotiation has proven to be very effective. Where there is insufficient evidence to establish that the complaint is justified, the investigation is discontinued and the individual is advised of the results in writing.

Here is the contact information for the Office of the Ombudsman:

**Office of the Ombudsman**

* Mailing Address: P.O. Box 6000, Fredericton, NB E3B 5H1
* Toll Free: 1-888-465-1100
* Website: www.ombudnb.ca

**New Brunswick Child and Youth Advocate**

This is a relatively new office created by the government of New Brunswick to be a voice for children and youth in the province. It is run out of the same office as the Ombudsman. Officially the mandate of the Child and Youth Advocate is to:

* Listen to the needs and concerns of children and youth.
* Ensure that the rights and interests of children and youth are protected.
• Make sure the views of children and youth are heard in the appropriate forums.
• Investigate complaints children and youth may have about how previous situations were handled by government agencies.
• Assure that children and youth have proper access to the appropriate services.
• Continually monitor laws and policies to make sure they are not only fair to children and youth, but that they are followed properly as well.
• Report on the availability, effectiveness, responsiveness and relevance of child and youth services.
• Act as advocate for the rights and interests of children and youth in general.
• The Child and Youth Advocate does not act as an advocate for the rights and interests of parents or adults or act as legal counsel in any fashion.

The contact information for the Child and Youth Advocate is the same as that for the Office of the Ombudsman.

New Brunswick Human Rights Commission
The Human Rights Commission is created by the Human Rights Act. This act prohibits discrimination against people with disabilities (as well as others) in the areas of employment, housing, and public services (including schools, stores, motels, hospitals, police and most government services). People who believe that they are being discriminated against can file a complaint with the Human Rights Commission. The Commission investigates and tries to settle complaints of discrimination and harassment. If a complaint cannot be settled, a human rights tribunal can hear the evidence. If it decides that there was discrimination, it can issue orders to correct it. There is no cost to filing a human rights complaint.

Here is the contact information for the Human Rights Commission:

New Brunswick Human Rights Commission
Mailing Address:
Barry House
P.O. Box 6000, Fredericton, NB E3B 5H1
Toll Free: 1-888-471-2233
Website: www.gnb.ca/hrc-cdp/index-e.asp
Premier’s Council on the Status of Disabled Persons

This provincial agency was established in the 1980s and provides advice to the government of New Brunswick on ways to improve policies and programs that affect people with disabilities. The Premier’s Council develops a comprehensive Action Plan for changes needed to government programs or policies. It also provides information and advice to people with disabilities and their families who are looking for ways to address issues and concerns. The Premier’s Council also has developed a Directory of Services Offered to Persons with Disabilities in New Brunswick. It is regularly updated. Copies of the directory are available from the Council or it can be accessed on-line through the Council’s website.

Here is the contact information for the Premier’s Council:

Premier’s Council on the Status of Disabled Persons  
Mailing Address:  
440 King Street, Suite 648  
Fredericton, NB E3B 5H8

Toll Free: 1-800-442-4412  
TTY and Voice: (506) 444-3000

Website: http://www2.gnb.ca/content/gnb/en/departments/pcsdp.html

Public Legal Education and Information Service of New Brunswick (PLEIS)

This non-profit/charitable agency develops and provides educational materials and information for the public on a variety of legal issues. Their goal is to “assist the public in identifying and understanding their legal rights and responsibilities” and to improve people’s ability to deal with legal issues. PLEIS has a number of publications that can be ordered and most of these are free to the general public. A list of these publications can be found on the organization’s website. Publications can be ordered by telephone or on-line.

Here is the contact information for PLEIS:

Public Legal Education and Information Service of New Brunswick  
Mailing Address:  
P.O. Box 6000, Fredericton, NB E3B 5H1

Telephone: (506) 453-5369  
Website: www.legal-info-legale.nb.ca/index.php
Family Networking/Family to Family Support

Families have often said that they learn a lot from spending time with other families who have a child with a disability. They have also said that being with other families provides a great sense of support from having a shared experience.

There may be opportunities in your community to get together with other families to “network” or to provide support to one another. Local chapters of disability organizations (such as the ACL, the Down Syndrome Society, local autism centres, etc.) often provide opportunities for families to meet, share information, and to support one another. Also attending workshops and conferences at which other families are present provides similar opportunities. Sometimes family networking and support activities are more formally organized as is the case with the following examples.

Families United Network-N.B. (FUN-NB)

FUN-NB is a provincial family network which promotes family connections for mutual support and information sharing.

FUN-NB members:

- Have family members with a disability
- Believe in the power and uniqueness of families across New Brunswick
- Support each other
- Offer strength, stability, confidence and knowledge
- Believe that all people should have the opportunity to lead a meaningful life

FUN-NB members are connected to information and to other families who may share similar experiences. They are also invited to participate in events such as parent retreats, family weekends and workshops. There is also a provincial Family Support Committee whose role is to find ways to promote family connections for mutual support and information sharing.

Families are invited to join FUN-NB if they would like to connect with people who share similar experiences, gain information and/or are willing to offer or receive support from other families. Network members also receive information from time to time in the form of a newsletter.

To become a member of FUN-NB, or to receive more information about the network, contact the NBACL office in Fredericton and ask for the Manager of Family Support. Families can also follow NBACL on Facebook and receive regular updates on events, news and other helpful information.
Seniors United Network (SUN)

This network of senior families is currently based in Saint John, Moncton and Fredericton. These parents are (for the most part) age 55 or over who have adult sons and daughters with a disability – many of whom still live in the family home. SUN members meet regularly to support one another and to discuss issues of common concern. One of the main issues that these senior parents address is the need to secure good futures for their children when they, as parents, are no longer able to provide care and support.

To find out more information about SUN contact the NBACL office in Fredericton and ask for the Manager of Family Support.
Worksheet 9

Planning for Hiring or Selecting Support Workers for Your Child

(Adapted from: Real Respite for the Whole Family: A Resource Guide, Canadian Association for Community Living)

1. Identify the qualifications, skills and qualities that you want support workers for your child to have.

   
   
   
   

2. Outline the support worker’s job description (include duties, hours, location of work and salary).

   
   
   
   

3. Identify ways that you want to use to find the right support worker for your child.

   
   
   
   

4. Identify the questions that you want to ask when interviewing possible support workers for your child.

   
   
   
   

   
   
   

Additional Resources

Available from NBACL (free to families)
Everyone Can… FUN-NB (brochure)

Other Resources
