Taking the JOURNEY

An Information and Advocacy Guide

for Families Supporting a Child with a Disability

InclusionNB

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Taking the JOURNEY

Part 1

Getting Started

INFORMATION IN THIS PART

- An Introduction
- An Important Note about Updates to this Guide

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Introduction to the Guide

As parents, we hope and expect that all of our children will have opportunities to learn, grow, and reach their own potential. We want our children to have the best that life can offer them, including a good education, employment, a home and opportunities to make friends and be involved in a variety of community activities.

Most parents are natural advocates for all of their children. We speak up for our children, and over time, help our children learn to speak for themselves. We help our children get the things that they may need or want from time to time. We may help our children find their first job or deal with difficult situations that they may encounter.

Raising a child with a disability often requires greater parental involvement to ensure that your child reaches his or her own potential and gets the things he or she may need. Your role as your child's advocate may require additional effort, skills and time.

This guide, *Taking the Journey*, is a comprehensive resource for families who require information and strategies to ensure that their child has the best opportunity to live a good life. It recognizes that families will be in different situations that will depend in part on the age of their child and on the circumstances or challenges that may be present from time to time. It also allows families to think and plan ahead on a variety of issues that may be on the horizon.

The guide also talks a lot about different service systems and your role as an advocate for your child within these systems. Service systems (such as education, health, etc.) can play a big role in all of our lives and are often more involved in the lives of people who have a disability. It will be important to know how these systems work and how you can help them be more effective in helping your child have the best chances at success.

Taking the Journey is divided into three main parts. This section (Part 1) provides some basic information about human rights, service systems and strategies for families to be effective advocates for their child. Part 2 addresses issues that arise from childhood to adult life in the lives of people who have a disability. Part 3 deals with issues that families often have to deal with across the life span of their child.

Please note that it is not necessary to read this guide from cover to cover (although we encourage everyone to read the chapters in Part 1). Find the chapters that will provide you with the information you most need at this time. We encourage families to add their own notes and information to the binder and to share additional information with other families. Most chapters also have a list of additional resources that you can look to if you need further information.

An Important Note about Updates to this Guide

We have put this guide in a binder format so that we can update the information on various topics as changes are made to government or other programs and services that may assist your child. Updated chapters or sections will be posted on our website from time to time so that families can download or print the new information to insert in their own copy of the guide. We will advise of new updates in our regular electronic newsletter that is also available free to families. Contact Inclusion NB if you want to be added to the e-mail list to receive the newsletter. You can also check our website for updates by visiting us at www.inclusionnb.ca

Taking the JOURNEY

An Information and Advocacy Guide
for Families Supporting a Child with a Disability

CHAPTER 1

Starting Points

"The more informed you are the better off you will be."

InclusionNB

CHAPTER 1

Starting Points

Goal for this Chapter

- To become familiar with human rights laws and the power of expectations and language.

What You will Find in this Chapter

- Information about human rights and their importance to people with disabilities.
- How expectations can help to shape your child's future.

Our Journey So Far

- Over the years, progress in supporting the inclusion of people with disabilities in our communities has been made possible because of families and others who imagined that things could be better. Just fifty years ago, people with intellectual and other disabilities were routinely institutionalized and sometimes sterilized, denied opportunities to attend school and learn, and routinely denied basic rights and freedoms. In Canada and elsewhere, people with disabilities were not really citizens at all.
- Fortunately, families had a different vision for their children and for other people with disabilities. During the 1960s and early 1970s, a new movement emerged which was led by families and people with a disability who envisioned a society in which people with disabilities would be welcomed as valued citizens. The concept of "community integration" saw the implementation of attempts to move people with disabilities out of large institutions and to provide opportunities for education and involvement in the community. Initially, this meant that people with disabilities were still grouped together in order to learn, work or otherwise participate in community.

A Reminder of Recent Progress

During the last twenty-five years the vision of citizenship and community inclusion for people with disabilities has changed dramatically. Many families and other people were not satisfied with the mere presence of people with disabilities in community. The new vision is based on the belief that all people should have real opportunities (and corresponding choices) to participate in community and to develop meaningful relationships with others. This is the vision of inclusion that sees people with and without disabilities participating together in schools, colleges, workplaces, community organizations and in recreation and leisure activities.

While much progress has been made toward achieving this vision, much also remains to be done to overcome the exclusion experienced by many citizens with disabilities. Moving forward, efforts on the part of many people, including families, are needed to continue to develop inclusive communities in which all people can fully participate.

One of the most important developments over the years has been improvements in the service systems for people with a disability. While still far from perfect, these systems today provide support for children, youth and adults with disabilities in various aspects of life. Many of these service systems will be reviewed in detail in other parts of this guide.

The Importance of Human Rights

Change and progress has been made possible in part because of the growing recognition of the rights of people with disabilities over the past few decades. To date, tremendous progress has been made to ensure that people who live with a disability have the right to be included in our public school system, to attend post-secondary education, to work and to contribute to the economic life of our communities, and to receive the support and assistance that they require in their day-to-day lives.

Families have played a major role in efforts to promote human rights. They have been assisted by various laws that have developed over the years to recognize and uphold the rights of people with disabilities and others. While you may not become a legal expert, it may be helpful to know a few things about the laws that protect people's rights. Here are three laws worth taking note of:

(i.) **The New Brunswick Human Rights Act.**
This law protects the the rights of New Brunswickers and prohibits discrimination and harassment in:

- Employment
- Housing
- Public services (for example schools, stores, motels, hospitals, police and most government services)
- Publicity, and
- Certain associations

It prohibits discrimination on the basis of many grounds including "physical and mental disability". 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. For more information, check out the Commission's website at www.gnb.ca/hrc-cdp/index-e.asp.

IMPORTANT NOTE: Sometimes going through the human rights complaint process can take several months or longer. While an important tool to safeguard the rights of your child, this may not be a quick solution.

(ii.) **The Canadian Charter of Rights and Freedoms.**
This is part of the Constitution of Canada and came into effect in 1982. It provides a constitutional protection of the rights and freedoms of all Canadians and applies to the laws, policies and actions of all levels of government. Section 15 (1) of the Charter provides that every person is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination based on race, national or ethic origin, colour, religion, sex, age or mental or physical disability. The Charter is usually enforced through the courts but it has been generally used to promote human rights and dignity of people with disabilities in many areas of life.

(iii.) **The United Nations Convention on the Rights of Persons with Disabilities.**
The Convention is an international treaty that spells out the rights of people with disabilities and the obligations of countries that ratify the convention to promote and protect those rights. The Convention came into force in 2008, and was ratified by Canada in March, 2010. The U.N. Convention is one of the most progressive human rights documents affecting the lives of people with disabilities to date. It contains 50 sections (or articles) and touches on the rights of people with disabilities in the areas of inclusive education, employment, community inclusion, and the justice system. It is worth taking a few moments to read. You can find it on the internet at www.un.org/disabilities. Inclusion NB has developed a plain language overview booklet on the U. N. Convention. Please contact Inclusion NB to obtain a copy.

The Power of Expectations and Language

People's (including your own) attitudes towards and expectations of your child can be one of the most important factors in shaping your child's future. If you or others have low expectations of your child, this can have a direct impact on his or her life. High expectations do not provide any guarantees of "success", but they will give your child a better chance of reaching his or her potential. The way you view your child can influence the way others view him or her as well.

Similarly, the way in which we talk about people with disabilities can have an impact on their lives. Some words have a negative connotation or portray people in a way that may be harmful. Other words, however, are affirming and reflect a more positive attitude about people. By using "words with dignity" you will help to promote a positive view of your child as well as other people who have a disability.

Words with Dignity

The following terms are suggested to describe people with disabilities:

Instead of disabled, handicapped,
Use person with a disability, people with disabilities.
Instead of crippled by, afflicted with, suffering from, deformed,
Use person who has… or person with…
Instead of lame,
Use person who has a mobility impairment.
Instead of confined, bound, restricted to a wheelchair,
Use person who uses a wheelchair.
Instead of deaf and dumb, deaf-mute, hearing impaired,
Use person who is Deaf; …hard of hearing.
Instead of mentally retarded, mentally challenged,
Use person with an intellectual disability.
Instead of special needs child,
Use child who has a disability.
Instead of spastic (as a noun),
Use person with cerebral palsy.
Instead of physically challenged,
Use person person with a physical disability.
Instead of mental patient, mentally ill, mental, insane,
Use person who has a mental illness, person who has schizophrenia, person with lived experience, etc.
Instead of learning disabled, learning difficulty,
Use person with a learning disability.
Instead of visually impaired, blind,
Use people who have a visual impairment.
Instead of disabled sport,
Use sport for athletes with disabilities.

**REMEMBER, APPROPRIATE TERMINOLOGY CHANGES WITH THE TIMES…
IF IN DOUBT, ASK.**

*Adapted from Active Living Alliance
– retrieved July 10/09 from www.ilrc.nf.ca/wordswithdignity.htm*

CHAPTER 2

Being an Effective Advocate for Your Child

"Remember that the person
you are annoyed and dealing with
is just another person sitting behind a desk.
For you it's your life, for this person
it's a job."

InclusionNB

CHAPTER 2

Being an Effective Advocate for Your Child

Goals for this Chapter

- To learn about advocacy
- To learn how to be a more effective advocate for your child

What You will Find in this Chapter

- Information about:
    - Why advocacy is important
    - How service systems work
    - Tips for being an effective advocate
    - Tips for working with professionals
- Checklist for Preparing for Meetings
- **Worksheet 1** – Contact List of People Willing to Help Advocate for My Child
- **Worksheet 2** – Sample Log for Recording Discussions
- A List of Additional Resources

Our Journey So Far

- Families have led the charge for change and opportunities for people with disabilities.
- Families have come together and created organizations (such as the Association for Community Living) to combine their voices. This has led to significant change in the systems that people with disabilities encounter on a regular basis.
- People with disabilities have been supported to speak up for themselves.

Introduction

This chapter reviews some of the important aspects of advocacy for families who have a son or daughter with a disability. In essence, advocacy is the process of supporting and standing up for another person. Good advocacy on behalf of a child with a disability may be necessary for a number of reasons:

- Your child may have difficulty speaking for him or herself because of communication difficulties or other reasons.
- Your child may not be afforded the same opportunities in life because of other people's attitudes, or because of physical or other barriers that may exist.
- Your child may have greater needs for support in order to enjoy life or to be involved in school or other learning opportunities, employment in the community, or other community activities.

How much and what kind of advocacy may be required will depend on each individual's or family's own circumstances and needs. Regardless, advocacy can be more effective when families learn the skills and steps that can help you get results. This chapter provides valuable information that will assist families with the advocacy process.

Advocating for What?

Advocacy can be used for many purposes. Advocating for and with a loved one with a disability may:

- Help your child stand up for his or her individual rights (for example, the right to make decisions, the right to dream and set goals, the right to have meaningful relationships, the right to be safe, etc.).
- Help your child have and maintain opportunities for meaningful involvement in the community (including school and learning, employment and recreation).
- Help your child gain access to the supports and disability related services that he or she may require to have a good life.

A good starting point for effective advocacy is to know and be clear about what you and your child want and need. It may be harder to get good results when you are unclear about what you want to see happen in your child's life. There are a few important things that you, your child, and others can do:

- You can help your child develop and tell others about his or her vision or dreams for the future. At times, especially when your child is younger, you may need to talk about your vision for your child. It is this vision that should inform and drive your efforts to achieve good things for your child.
- You can help your child develop and set some short and long term goals. Goals may involve the areas of education and learning, employment, recreation and so on. Goals should be positive but also realistic and achievable.
- You can help to identify what actions or steps need to be taken to achieve your child's goals. Knowing what needs to happen is a critical part of effective advocacy. Remember that there may be other people that need to be involved in helping to figure out what actions need to take place.

Fortunately, there are planning processes that can help you and your child identify dreams, goals and actions. Many people with disabilities have benefited from planning processes such as PATH and MAPS. For more information on these planning processes, please read Chapter 5 or contact Inclusion NB.

A Note about Service Systems

Over the course of your child's life you will encounter a number of different service systems. There are many different types of service systems including early child care, education, medical and mental health, disability services, employment, and income support. Some services are provided by government while others may be provided by community agencies (which are usually funded by government). Each of these systems is unique but most have some common features, including:

- Its own set of rules and regulations that set out what services can be provided and by whom.
- Professionals and support staff who are hired to provide services that you and your child may need. (For more about working with professionals see the information at the end of this chapter).
- A "hierarchy". This means that there are levels of authority that can range from "front line" workers to supervisors, managers, directors and often other layers of people who are in control of the organization. Working with these kind of systems can be frustrating but it is important to know the "chain of command" if you are going to be an effective advocate.

- A budget or set amount of money that someone decides will be available to provide services and supports. How this money is used is important. Service systems are often challenged by the demand for services that exceeds the money that is available.
- Sometimes (or perhaps often) service systems are disconnected from one another and work independently (some call this working in "silos"). This can cause considerable frustration for families as they often have to try and work with a number of different systems at the same time. Governments are looking for ways to better "integrate" their service systems in order to make them more effective to those they serve.

Tips for Being an Effective Advocate

Becoming an effective advocate may require learning about good advocacy practices as well as having a lot of patience and perseverance. Some people are naturally better at advocacy than others. Those who tend to be better advocates are people who are not easily intimidated by difficult people or situations and who have little difficulty in speaking up for themselves or others. Some people, however, learn to be good advocates over time (often because they feel they have to be to achieve good things for their child).

There are a number of good practices that will help you to become an effective advocate. These practices can be broken down into four main areas: preparation, communication, documentation or note taking, and follow up. It is important to remember that what you may need to do as an advocate may depend greatly on the issue or situation. Some situations will be more difficult and trying. They may require action over a period of weeks, months, or sometimes years. Other situations may be resolved more easily and therefore require less effort.
Below are a few tips that you can consider as you advocate on behalf of your child

Preparation

Good preparation is a very important aspect of effective advocacy. Here are a few tips to help you become more prepared:

- **Remember that information is power.**
  The more that you can inform yourself about a particular issue or situation the better you will be able to speak on behalf of your child. Depending on the situation, you may need to become better informed about your child's rights, how different service systems operate, how other families have achieved similar things for their child, and so on.
- **Have specific goals or things you would like to achieve for your child.**
  Sometimes goals can be broadly stated (for example, to help my child find a job) but goals may also be much more specific. Good preparation usually involves trying to be as specific as possible about what you want to achieve and, if possible, what specific actions you would like to see happen**.**

- **Identify the key issues or problems that you and your child are encountering.**
  Often, people with disabilities face barriers that may result from other people's attitudes, a lack of effective supports and services, etc. When you are able to clearly identify the problems or barriers that may exist, you can focus your advocacy on what needs to be addressed.
- **Identify some possible solutions that you see as workable.**
  Sometimes, solutions may not be easily identified or can only be identified by talking things through with others.
- **If possible, identify what you are willing to accept if you cannot get exactly what you want.**
  This will require thinking about what you may be willing to compromise with. This is not always easy but it is sometimes necessary. Having a "fall back" position will allow you to still negotiate for something that may be acceptable, even if it is not the perfect solution.
- **Identify people who may be able to help you.**
  Often, advocacy is more effective if you have allies. This may be simply someone who agrees to attend a meeting with you to support your cause or to simply take notes. It may also be someone who has some particular expertise in the issue you are dealing with or in advocating for people with disabilities (for example, a volunteer or a staff person from a disability organization). Remember, being a good advocate does not mean that you have to do everything on your own.
- **Identify the people that you need to talk with to achieve results for your child.**
  These may be people who have some authority to make some decisions or who can help make things happen. Depending on the circumstances, key people might include someone who works for government, a politician, someone from a service agency, an employer or a human resource manager in a company, and so on.

Communication

Effective advocacy also requires good communication. Communication can take many forms including phone calls, face to face meetings, group meetings, letters and emails. Here are a few tips to remember about communication:

- **Be clear and concrete.**
  This means making sure that your messages or requests are stated as clearly and briefly as possible. If your message or request sounds confused, other people may not know what it is that you want for your child. What is the most important information that you need to convey? At times, other information may be useful to support your request. Too much information, however, may get you side-tracked on other issues that may not be as important.

- **Be assertive.**
  When you communicate with others, they should understand that you have expectations that you expect to achieve. Assertive communication also means talking in a firm (but not harsh) tone of voice. In face to face meetings, try to keep your body erect but also relaxed and use eye contact. Remember that assertive communication is not aggressive.

- **Listen carefully to what other people are saying.**
  Listening is simply a respectful way to communicate. This means paying close attention to what people are trying to tell you and not interrupting when other people are talking. In addition, listening may also provide you with information or clues about how to solve a problem or to get what you want for your child.

- **Ask questions.**
  If something is not clear to you, ask for a better or clearer explanation. Asking questions is also a good way to get valuable information that may assist you in your advocacy. Asking questions may also be a useful way to have a conversation with someone who may be able to help you. A key part of effective advocacy is building good relationships with people who are in the position to make decisions or to offer help. If possible, prepare the questions you want to ask before a conversation or meeting.

> **A key part of effective advocacy is building good relationships with people who are in the position to make decisions or to offer help.**

- **Where appropriate, use stories or visual ways to communicate information.**
  Often, people remember personal or other kinds of stories more than anything else. Stories can be helpful in providing a sense of the real life issues that may be at stake. They can also be helpful by providing examples of how situations or issues may be resolved.

Documentation and Note Keeping

Keeping good notes and records can be a great aid to the advocacy process. We like to call it the "power of the paper trail". Here are some tips that may be helpful:

- **Keep a notebook, log or a diary to record your discussions.**
  Whether you have talked with someone on the telephone or in person, it is important to keep track of the name, contact information and title or position of the person with whom you spoke. Also, record the date and any responses you have received. This information will be particularly helpful to you if you need to do a follow up or talk with someone else who is higher in the "chain of command" within an organization, government or company.

- **Keep a file of written responses and other documents.**
  Sometimes you will receive written responses to requests or will want to ask for a written response. This may be in the form of letters or emails. It is important to keep track of these in case you need them in the future. Sometimes, people will say or promise things verbally but not later act upon. Having a written record of what was agreed to may be very helpful. Also, when a request is being refused, it is helpful to have the refusal (preferably with the reasons for the refusal) spelled out in writing. This may be particularly important if you are asking someone else to review the decision or have the opportunity to make an appeal.
- **Use e-mails as a follow up to meetings.**
  After meetings it may be useful to send an e-mail message to the people you met with to summarize what was agreed upon. If so, send your message as soon as possible after the meeting and print your message and any responses and keep them in your document file.

Follow Up

Often, advocacy does not provide immediate results. Some situations may require persistence and effort to achieve success or have things resolved. Often the adage "the squeaky wheel gets the grease" is very true when families are trying to accomplish things for their child with a disability. Keep the following points in mind:

- **Try not to be too frustrated or intimidated if you are not getting the response or results that you are seeking.**
  Continue to follow up until you feel that your issues have been resolved to your and your child's satisfaction.
- **Sometimes, following up your issues may require that you talk with a more senior person with the organization.**
  This person may have more authority to make decisions or may have an interest in helping you resolve your issue.
- **At some point, you may feel that you have done all you can on your own.**
  Following up your advocacy may require that you involve other people, particularly from a disability organization to assist you.
- **When dealing with government systems or agencies, you may need to contact elected officials.**
  This kind of follow up should normally be done only when you have gone through all of the regular channels in the government system.
- **Lastly, there may be times that you are not successful no matter how hard you try.**
  Remember that advocacy is about negotiation. What are the things that you are willing to compromise with or settle for if you cannot get what you want or need? Sometimes, the next best solution is better than no solution at all.

Working with Professionals

From the time of the birth of your child, you may be involved with a number of professionals. These may be medical professionals, social workers, early intervention specialists, educators, and others. Your relationships with these professionals will be important. The best kind of professional–parent relationships are those where there is trust, respect and open communication. Parents are recognized for the central role they play in the life of a child with a disability and in that child's growth, development and well being. Professionals are recognized because they have some special knowledge to contribute.

It is sometimes easy to feel that professionals know best and that parents should not challenge what professionals are saying or suggesting. At the same time, however, it is important that parents' ideas and concerns are respected. There may be times when you and professionals will not agree on important issues concerning your child. In a good parent-professional relationship, these differences are often resolved by talking openly. Sometimes, however, parent-professional relationships break down, and you may need to find other people who can help you and your child.

The best kind of professional–parent relationships are those where there is trust, respect and open communication. Parents are recognized for the central role they play in the life of a child with a disability and on that child's growth, development and well being. Professionals are recognized because they have some special knowledge to contribute.

The National Information Center for Children and Youth with Disabilities in the United States has provided a number of useful suggestions for parents on working with professionals:

- If you are looking for a professional with whom you can work well, ask other parents of children with disabilities.
- If you do not understand the words that a professional uses, be prepared to ask questions. For example, say "What do you mean by that?" or "I don't fully understand, can you please explain that again?"
- If necessary, write down what professionals are saying. This can be particularly helpful in medical situations when a medication or therapy is to be given.
- Learn as much as you can about your child's disability. This will help you to better understand what professionals are saying and to be better informed in discussions with professionals.
- Prepare for visits to professionals by writing down a list of questions or concerns you would like to discuss during the visit.

- Keep a notebook in which you write down information concerning your child's particular needs or your concerns. This can include notes about your child's medical history, results from tests that may have been given, observations you have made about your child, and so on. A loose-leaf binder is easy to maintain and add information to.
- If you do not agree with professional recommendations, say so. Be as specific as you can about why you do not agree.

Adapted from: *Parenting a Child with Special Needs: A Guide to Reading and Resources*.
Available from www.kidsource.com

It is also important to remember that as a parent you have rights. You have:

The right to be fully informed
about and involved in decisions affecting your child.

The right to ask for or seek a second opinion,
if you believe it is necessary.

The right to ask questions
and to receive accurate and timely information.

The right to have your opinions and concerns count.

The right to ask that people be held accountable
for their actions or lack of actions.

The right to have you and your child
treated with respect and dignity.

Checklist for Preparing for Meetings

Before the meeting

☐ I have identified what I am asking for

☐ I have identified the "key players" that need to be involved

☐ I have a supporter to go with me to the meeting

☐ I have written down any points I wish to discuss or questions I would like to have answered

☐ I have the following information: the day, date, time frame, and place of the meeting, who will be in attendance, and whether I must bring any materials

☐ The scheduled meeting time allows enough time to cover the issue(s) that need(s) to be addressed

☐ I have gathered and prepared any materials that I think are necessary for the meeting

During the meeting

☐ I arrive a few minutes before the meeting time

☐ I record (or have your supporter record):

- the date and place of meeting
- who is in attendance with contact information, if possible
- key points of information, decisions made
- the date and details of any future meetings

☐ I ask participants to clarify any terms or points I don't understand

After the meeting

☐ I have asked for minutes to be sent out regarding the meeting with a summary of decisions that were made and issues that were addressed

OR

☐ I have sent out an email to all participants summarizing what I understood to be the decisions made and issues that were addressed, with a request for their confirmation of my summary

Worksheet 1

Contact List of People Willing to Help Advocate for My Child

Name: ______________________________

Telephone #: ______________________________

E-mail: ______________________________

Name: ______________________________

Telephone #: ______________________________

E-mail: ______________________________

Name: ______________________________

Telephone #: ______________________________

E-mail: ______________________________

Name: ______________________________

Telephone #: ______________________________

E-mail: ______________________________

Name: ______________________________

Telephone #: ______________________________

E-mail: ______________________________

Worksheet 2

Sample Log for Recording Discussions

Date: ____

Names of people involved: ________________________________

____

____

____

Contact information for people involved: ______________________

____

____

____

Questions asked / What was discussed? ______________________

____

____

____

Result of Discussion: ______________________________

____

____

____

Follow-up steps required: ____________________________

____

____

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Additional Resources

Available from Inclusion NB (free to families)

Opportunity Link – Module 4 – Advocacy Skills for Families.
Available on-line at www.inclusionnb.ca

Other Resources

Advocacy Handbook, Fredericton Association for Community Living (1997)

Assertiveness and Effective Parent Advocacy, Marie Sherrett.
Available on-line at www.fetaweb.com/01/assert.sherrett.htm.

Introduction to Self Advocacy, Disability Rights California.
Available on-line at www.disabilityrightsca.org/pubs/507001.pdf.

Strategies: A Practical Guide for Dealing with Professionals and Human Service Systems.
Shields, Craig V. Ontario: Human Services Press (1987) (Book)

Ten Steps to Being an Effective Self Advocate, Advocacy Center for Persons with Disabilities.
Available on-line at www.advocacycenter.org/documents/Ten_Steps_Brochure.pdf.

Websites

www.childrensdisabilities.info/advocacy/index.html.
This site contains various articles on advocacy from a parent's perspective.

www.wrightslaw.com/info/advo.index.htm
Articles on advocacy and education.

Please note that this site is American and may refer to U.S. laws and policies

Taking the JOURNEY

Part 2

From Childhood to Adult Life

INFORMATION IN THIS PART

InclusionNB

Taking the JOURNEY

An Information and Advocacy Guide
for Families Supporting a Child with a Disability

CHAPTER 3

The Early Years and Supporting Children

"The early years are the
time to encourage your child
to be as independent as possible
and to learn to make
his or her own decisions."

InclusionNB

CHAPTER 3

The Early Years and Supporting Children

Goal for this Chapter

- To become familiar with the supports and services available to children with a disability and their families.

What You will Find in this Chapter

- Information about:
    - Early Intervention programs
    - Services for preschool children with Autism Spectrum Disorder
    - Other support programs for children
    - Early learning and child care laws and programs
    - Community Resources Centres
- **Worksheet 3** – Information About My Child's Disability
- A List of Additional Resources

Our Journey So Far

- Local Associations for Community Living first began Early Intervention Programs in the 1980s. These programs are now broadly available through a variety of community organizations and funded by the provincial government.
- In 1985, the government of New Brunswick closed its institution for children and invested in supporting children to live with their families or with foster families.
- Until recently, children with disabilities were routinely denied access to early child care and early child care programs.

Introduction

As with all children, the early years of life are critical for the growth and development of children who have a disability. The early years are also a time of learning and adjustment for families.

During this time, families are beginning to learn about their child and his or her disability. They are also learning about different service systems and dealing with a number of professionals – including some professionals for the first time. Families may also be dealing with medical issues facing their child. Families are also adjusting to the unique circumstances that arise from having a child with a disability in their family. This is also a time when families begin to learn about the value of advocacy and the important roles they play in ensuring that their child has opportunities for growth, learning and inclusion.

Supports and services that are available to children who have a disability and their families are often vital to the early development of children and to the ability of families to raise their children in the best way possible.

When using the information in this chapter, you should also review other information in this guide that may be helpful. In particular, Chapters 2, 12 and 13 provide important information on issues relating to advocacy, support to families and financial issues that should be considered.

Discovering That Your Child has a Disability

As families, there may be many issues that you face you when you discover that your child has a disability – whether that is at birth or later. This includes dealing with your own reactions and the reactions of others. Inclusion NB has developed a short guide called *Welcome to the Family! An Information Kit for Parents Who Learn That Their Child has a Disability.* This guide was developed because families said that they wished someone had told them a few things at the beginning – things that they felt would have made a difference to them. This guide is free to families and can be obtained by calling Inclusion NB office in Fredericton.

Services for Children with a Disability

The government of New Brunswick funds a number of important services aimed at children who have a disability. Many of these programs provide services to children up to school age, while others offer services up to age 18. Below is a description of the main programs available. Either within or at the end of this chapter we include contact information for the various agencies and organizations that provide these services.

Family and Early Childhood Program (formerly Early Intervention)

This program offers screening, assessment and intervention services for children 0 to 8. Services are delivered by 7 Family and Early Childhood agencies which are aligned with the school district boundaries throughout New Brunswick. For a list of Family and Early Childhood agencies and their contact information, see the Family Support section of Inclusion NB website at www.inclusionnb.ca.

Entry into the Family and Early Childhood program happens through a referral that can be made by:

- A parent
- Family doctor
- Pediatrician
- Speech and language therapist
- Occupational therapist
- Autism clinical supervisor
- Child protection social worker, or
- Public Health nurse

Children can be referred at any time up to age 8. There are no financial eligibility criteria so a family's income has no effect on who is eligible. Family and Early Childhood services are targeted to children who have a developmental delay or who have been identified to be at risk of having a developmental delay.

Family and Early Childhood agencies can provide a variety of services, including:

- ***In-Home Visitation services***. These are usually for children up to age 3 but they can also be provided on a more limited basis for children ages 4 to 8. These are visits by Family and Early Childhood staff to the family home to help families meet the needs of their child as they develop. They also help families to develop appropriate expectations for their child's development. The visits usually last for an hour and require that the child and at least one parent be present.

- ***Infant-Parent Attachment Program***. This program is available to parents and guardians who have an infant less than 12 months of age who is at risk of developing "disorganized detachment" (that is, problems in forming attachment with parents). In this program, parents and guardians learn to identify and respond to their infant's cues and signals, especially when the infant is in distress. They also learn how to understand and respond to their infant's behavior and how to have fun with their baby. The program provides information to strengthen the parent child relationship and to build self esteem in babies. It also helps parents and guardians learn about the different roles they have in meeting their child's needs.

- ***Group Based Parent Support***. This is a form of group support that requires at least 3 families involved with the Family and Early Childhood program who can benefit from participation in a group based intervention.

- ***Creative Outreach***. This is used to connect with families that may be difficult to engage and families that are not available for home visits. Outreach activities may involve telephone calls, receiving newsletters, invitations to take part in parent support activities and educational activities (for example, information sessions).

- ***Transition to School Activities***. Family and Early Childhood agencies administer the Early Years Evaluation – Direct Assessment (for children registered for kindergarten) which measures a child's development in four areas: awareness of self and environment, cognitive development, language and communication, and physical development. This will identify each child's developmental strengths and weaknesses and provide parents with the opportunity to address areas of potential difficulty prior to their child entering school. Family and Early Childhood agencies will offer follow-up with all children identified as having difficulty in one or more developmental areas. This may involve a referral to other early childhood services in their communities to provide a variety of supports and learning opportunities that will help provide a more smooth the transition to school. For children who are considered as having a more difficult time with the transition to school, Family and Early Childhood agencies will provide direct intervention up to age 8.

- ***Developmental Child Care Services***. For more information, please refer to the section on Developmental Child Care Services later in this chapter.

Intervention Services for Preschool Children with Autism Spectrum Disorder

Recently, the government of New Brunswick has developed and funded specific intervention programs for preschool aged children with Autism Spectrum Disorder. These services are provided by agencies located in various communities across the province.

To be eligible for these services your child must be of preschool age, have a formal diagnosis of ASD from a doctor or psychologist, and be a resident of New Brunswick (including children in First Nations communities). A child will be eligible until the beginning of the school year in which he or she turns five. If your child receives a formal diagnosis of ASD, you will receive a Confirmation of Diagnosis form from the doctor or psychologist. This form must be sent to the Department of Social Development in Fredericton. You will be given the name of the agency in your area that is authorized to provide the services.

With your involvement, the community agency will be responsible for developing an intervention program for your child. This program will be based on your child's strengths and needs. It may also include one-on-one instruction from an autism support worker and may also include referrals to therapy services such as speech and language therapy, occupational therapy, and physiotherapy. The plan will include a transition to school plan that should be developed with your involvement as well as the involvement of your child's school.

Talk with Me/Parle-Moi: Early Language Services

This program is a provincial, community-based program funded by the Departments of Social Development and Health. It is administered by a team of speech-language pathologists and rehabilitation assistants. The program provides information and education in all areas of preschool communication development and promotes the prevention and early identification of communication delays from birth to school entry.

- Talk with Me/Parle-Moi offers information about:
- language and learning; demonstration of techniques that help language grow;
- workshops, training, and education regarding all aspects of communication development; and
- referrals to regional speech and language services if assessment and treatment are required.

The program is available in French and English to all families and caregivers of children aged 0-5. No referral is necessary and programs are provided at no cost to families. Families and caregivers can access the programs through their Regional Health Authority.

Family Supports for Children with Disabilities Program (formerly Children with Special Needs Program)

On April 1, 2014 a new Family Supports for Children with Disabilities Program came into effect. This Department of Social Development program replaces the Community Based Services for Children with Special Needs Program. The new program name reflects the intention to provide services to support the entire family that is raising the child with a disability. The program provides both social work support and financial aid to families to assist with the care and support required to address the developmental and other needs of a child with a disability.

To be eligible for the program, a family must have a child with a disability under the age of 19 and have unmet needs related to raising their child. In addition, the child with a disability must:

- have an impairment, activity limitation or participation restriction that significantly limits the child's ability to function in one or more area of daily living and/or has a significant impact on the family and the parents' ability to manage their care.
- have a letter of support from a professional that speaks to the child's limited ability to function in normal daily living. (For the purpose of the program, examples of professional who may verify a child's limited ability to function in normal daily living include: physician/surgeon/nurse practitioner, optometrist, occupational therapist, physiotherapist, school psychologist, speech language pathologist or social worker)
- be a resident of New Brunswick for the past three months; and
- have a valid New Brunswick Medicare card.

It is important to note that your child does not require a formal diagnosis to be eligible for the program.

To apply for the program, you must contact the Department of Social Development in the region in which you live. This is done by calling the Department's general toll-free telephone number (a list of contact numbers for the various Social Development regions can be found at the end of this chapter). A pre-application assessment will be done to determine if some basic eligibility requirements are met. If so, you will be contacted by a social worker to make arrangements to complete the application process. The program will have a new "streamlined" application process and an application form.

After the application process is completed, a "Family Support Plan" is developed. This will be based on your child's developmental needs, your child's and family's strengths, and identified unmet needs for support. A variety of service options may be available, including:

- relief care funding,
- a baby sitting supplement for children over the age of 12,
- assistance with medical transportation, and
- medical and rehabilitation equipment

Under the new program, "enhanced" service options are also available to families who are raising a child with significant unmet needs. These options include:

- participation in specialized or intensive interventions,
- parent training, or
- other applicable education programs for families raising children with disabilities

The new program will provide families with more flexibility when using approved funding. Depending on your family's income, you may have to contribute to the cost of the services that you are going to receive. The income limit for contributing to the cost of services has been increased to $39,000 per year (from $20,000 under the old program).

Once a Family Support Plan is developed, families will have the choice of using a social worker to help with the on-going management of their plan (this will involve regular contact and support from the social worker). Families will also have the choice of "self-managing" their plan without the regular involvement of a social worker.

Early Learning and Child Care

Early learning and child care is important to all families who need to work or attend school. It is also important for early learning for children to learn social and other skills to prepare them for school. Finding quality inclusive early learning and child care is important to families who have a child with a disability.

The government of New Brunswick has programs that help families pay for child care and for providing support for children who have a disability within early learning and child care settings.

Day Care Assistance Program

The Day Care Assistance Program provides financial assistance to assist families with accessing affordable quality childcare at a licensed daycare facility. If you are working, attending school or undergoing medical treatment, you may be eligible for assistance. Eligibility (and the amount you may receive) is based on your family's net income. Parents who do not have access to a licensed facility may be eligible for assistance under the Alternative Childcare Program. For more information about the rates of assistance and how to apply, contact the Department of Education and Early Childhood Development.

Developmental Childcare Services

This program provides for a developmental plan for children who are at a 'medium to high' risk of having a developmental delay (the plan must be designed with the involvement of parents or guardians). The program also provides for participation in an approved early learning and child care facility for children who require involvement in a child care setting for their personal development (in other words, the child's development would benefit from being around other children in an early learning setting). The Department of Education and Early Childhood Development will fund up to 12 hours per week in a child care facility if the child:

- Is between age 3 and school entry;
- Has one or more of the following types of "functional challenges": cognitive, emotional/behavioural, physical, sensory, and communication (as determined by a Family and Early Childhood agency or by a medical professional);
- Shows that he or she is a moderate to high risk for a developmental delay in the assessment done by a Family and Early Childhood agency; and
- Shows that his or her social development would benefit by participating in an approved early learning and child care environment.

To be eligible, the child's parent or guardian must be a client of the Family and Early Childhood program (formerly Early Intervention) and have an active plan. The local Family and Early Childhood agency must recommend that a child be eligible for Developmental Child Care services and the services must be a part of the child's developmental plan.

If parents or guardians are not working, the Department of Education and Early Childhood Development may also provide funding for transportation to child care (in limited circumstances) or for a support worker while the child is attending the child care setting.

Enhanced Support Worker Program

This program provides funding for an early learning and child care facility to pay for a support worker for children (with disabilities or additional needs) who require a support worker to participate in the activities of the child care facility. The program is intended to support families to be active in the labour force. As such, parents must be employed or attending a training program. Funding is available for infants and children up to 12 years old to help with the costs of a support worker. Parental income is not considered when determining eligibility for the program. The amount of funding available will depend on the support needs of the child.

New Early Learning and Child Care Law

In 2010, the government of New Brunswick made a new law called the *Early Learning and Childcare Act*. This law is part of the government's new "early learning and child care strategy" that seeks to create a system that supports the early development of young children "so that they have a strong start in life." It also is aimed at supporting families so that parents can work while knowing that their children are being well cared for in early learning and child care facilities.

The new law requires early learning and child care centres to use new early learning and child care curricula. These were developed by New Brunswick universities and will be used by licensed early learning and child care centres that offer programs for preschool children.

Having fully inclusive early learning and child care centres is crucial to children with disabilities and their families. As with all children, early learning and development is of primary importance to children who have a disability. Having opportunities to learn skills (including academic and socialization skills) help to prepare all young children for school and participation in society. The new early learning curricula that are intended to apply to all children are an important step in ensuring that we are taking full advantage of the early years of children's lives to help them learn and develop their potential.

Having opportunities to learn skills (including academic and socialization skills) help to prepare all young children for school and participation in society.

Yet, too many children with disabilities are missing out on early learning and child care opportunities. There are several reasons for this including the refusal of some early learning and child care facilities to accept children with a disability, particularly children with more significant disabilities. There are also issues that relate to the lack of access to the additional support that children may need to participate and be included. Families and organizations with an interest in early learning and child care will need to continue to advocate for full early learning and child care opportunities.

Quality Inclusive Early Learning and Child Care

Inclusion in early learning and child care settings means:

- ***Educating*** all children who require extra support in regular child care settings regardless of the degree of their needs
- ***Providing*** special services and support within the regular child care setting
- ***Supporting*** child care educators/caregivers
- Having children with diverse abilities follow the same child care routines/activities and ***adapting*** routines/activities where necessary
- ***Teaching*** all children to understand and accept human differences
- Placing children with a disability in the same child care settings they would attend if they did not have a disability, and making sure it is the ***best environment*** to experience success
- Taking families' ***concerns seriously***
- ***Providing*** an appropriate individualized program
- ***Welcoming***, supporting and valuing children with diverse abilities.
- ***Encouraging*** friendships and social relationships between and among all children

Inclusion in early learning and child care settings does NOT mean:

- Placing children with a disability into regular child care settings without preparation or supports
- “Pull out” therapy sessions in separate areas of the setting
- Grouping children with support needs together
- Ignoring children’s individual needs
- Exposing children to unnecessary hazards or risks
- Placing unreasonable demands on child care educators/caregivers
- Ignoring, condescending, or disrespecting families’ concerns
- Placing older children with developmental delays with younger children or in other non-age appropriate settings/groups
- Children with a disability being physically present only

Community Resource Centres for Families and Their Children

Family Resource Centres

Thirteen non-profit Family Resource Centres, funded through the Community Action Program for Children (CAPC), operate in New Brunswick. The Centre’s programs cover the province through a network of about 82 sites, many in isolated rural areas. These centres are not focused solely on families who have a child with a disability, but are inclusive of all families who wish to take part in the activities and programs offered.

Family Resource Centres offer a variety of programs and activities for parents and their children ages 0 – 6. This includes drop-ins, parent education and support groups, collective kitchens, toy and resource-lending libraries and programs to promote parent-child communication and bonding, family literacy and child development and safety.

The Centres work with several partners including New Brunswick’s Healthy Baby and Me, literacy, education and health organizations.

For a list of Family Resource Centres in New Brunswick (and their contact information) visit the Family Resource Centre website at www.frc-crf.com.

Community Centres for Persons with Autism Spectrum Disorder and Their Families

In New Brunswick there are a number of community autism centres that provide people with a condition on the autism spectrum 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. These centres are funded by the New Brunswick Department of Health and from private fundraising activities. For a list of community autism centres in New Brunswick (and their contact information) visit the Family Support section of Inclusion NB website at www.inclusionnb.ca.

Contact Information for Department of Social Development Regional Offices

Region 1 (Moncton) 1-866-426-5191
Region 2 (Saint John/Fundy) 1-866-441-4340
Region 3 (Fredericton / Woodstock/ Perth) 1-866-444-8838
Region 4 (Edmundston / Grand Falls) 1-866-441-4249
Region 5 (Restigouche) 1-866-441-4245
Region 6 (Chaleur) 1-866-441-4341
Region 7 (Miramichi) 1-866-441-4246
Region 8 (Péninsule Acadienne) 1-866-441-4149

Worksheet 3

Information About My Child's Disability

Type and nature of my child's disability:________________________________

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Health and other professionals involved with my child:____________________

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Medications my child takes:_______________________________________

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Therapies my child receives:______________________________________

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Support programs my child is involved with: ___________________________

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Additional Resources

Available from Inclusion NB (free to families)

Welcome to the Family: An Information Kit for Parents Who Learn That Their Child has a Disability (2006)

Taking the JOURNEY

An Information and Advocacy Guide
for Families Supporting a Child with a Disability

CHAPTER 4

Going to School

(Inclusive Education)

"Inclusive education is the foundation
for an inclusive community.
If your child is well included in school
and receives a quality education
he or she will have a much greater chance
of being included in the
community as an adult."

InclusionNB

CHAPTER 4

Going to School (Inclusive Education)

Goals for this Chapter

- To learn about the importance of inclusive education and legal rights of students.
- To learn about ways that families can participate in their child's education, including the development of a Personalized Learning Plan (PLP).
- To learn about ways in which students can be included in the regular education system and how this can be supported.

What You will Find in this Chapter

- Information about:
    - The key features of inclusive education
    - Legal rights and issues
    - A checklist for preparing for your child to start school
    - The PLP process and family involvement
    - Support for inclusive education
    - Ways to address problems and concerns
- **Worksheet 4** – Preparing For My Child's PLP
- A List of Additional Resources

Our Journey So Far

- Sixty years ago many children were prohibited from attending school because they had a disability.
- From the late 1950s to mid 1980s, students with disabilities were educated in separate schools and separate classrooms within schools.
- In 1986, the law in New Brunswick changed and provided a right for children with disabilities to be educated in regular schools and learning environments (classrooms). Since then, significant progress has been made in developing an inclusive education system for all children.

Introduction

This chapter aims to assist families who want to ensure that their children receive a high quality education. It is based on the belief that a high quality education can best be achieved in an inclusive setting where children with disabilities spend their days in neighbourhood schools and in regular classes with students their own age. It is also based on years of experience that shows that inclusive education, when done well, enables children and youth to gain self confidence, a positive self image, and social behaviours, as well as the academic and other skills necessary to feel valued and to be included in our communities.

Primarily, this chapter is about helping families understand what inclusive education is about and how they can play important roles in helping their children have a quality inclusive education. It also addresses legal issues, ways to think about and provide support for inclusion, and offers suggestions to deal with problems and concerns that may arise from time to time.

New Brunswick's Inclusive Education System

New Brunswick has an inclusive public education system. Inclusive education is about looking at the ways our schools, classrooms, programs and lessons are designed so that all students can participate and learn. Inclusion is also about finding different ways of teaching so that classrooms actively involve all students. It also means finding ways to develop friendships, relationships and mutual respect between all students, and between students and teachers in the school.

Inclusive education is not just for some students. Being included is not something that a child must be ready for. All students are at all times ready to attend regular schools and classrooms. Their participation is not something that must be earned.

Inclusive education is about looking at the ways our schools, classrooms, programs and lessons are designed so that all students can participate and learn. Inclusion is also about finding different ways of teaching so that classrooms actively involve all students.

Inclusive education is a way of thinking about how to be creative to make our schools a place where all students can participate. Creativity may mean teachers learning to teach in different ways or designing their lessons so that all students can be involved.

As a value, inclusive education reflects the expectation that we want all of our children to be appreciated and accepted throughout life.

Key Features of Successful Inclusive Education

Generally, inclusive education will be successful if these important features and practices are followed:

- Accepting unconditionally all students into regular classes and the life of the school.
- Providing as much support to students, teachers and classrooms as necessary to ensure that all students can participate in their schools and classes.
- Looking at all students at what they can do rather then what they cannot do.
- Teachers and parents have high expectations of all students.
- Developing education goals according to each child's abilities. This means that students do not need to have the same education goals in order to learn together in regular classes.

IMPORTANT NOTE: Some teachers, principals, schools and districts do a better job than others in making their schools and classrooms truly inclusive. In some areas, students who have certain types of disabilities are still segregated in separate rooms, have different lunch periods, and are generally not included with the school community.

- Designing schools and classes in ways that help students learn and achieve to their fullest potential (for example, by developing class time tables for allowing more individual attention for all students).
- Having strong leadership for inclusion from school principals and other administrators.
- Having teachers who have knowledge about different ways of teaching so that students with various abilities and strengths can learn together.
- Having principals, teachers, parents and others work together to determine the most affective ways of providing a quality education in an inclusive environment.

Does Inclusive Education Mean That All Students Should Never Leave Their Regular Classrooms?

Inclusive education means that all students are educated in regular classrooms. It does not, however, mean that individual students cannot leave the classroom for specific reasons. For example, a child may require one-on-one assistance in a particular subject. This may or may not be happening during regular class time. Some students may need to be outside of the regular classroom for longer periods. Once schools are inclusive, serious thought is given to how often a student may be out of regular classrooms and the reasons that this may be happening. It does not mean that students with certain characteristics (for example, those who have disabilities) are grouped together in separate classrooms for all or part of the school day.

Inclusive education means that all students are educated in regular classrooms. It does not, however, mean that individual students cannot leave the classroom for specific reasons.

For more information see the section below entitled "The Right to be Educated in Regular Classrooms".

Legal Rights and Issues

There have been recent changes to the Education Act and provincial education policy that affects inclusive education and the education of students with a disability. In September 2013, the New Brunswick government introduced a new Policy on Inclusive Education (Policy 322). The purpose of this policy is to "ensure that New Brunswick public schools are inclusive". It applies to all schools and school districts within the public education system (private schools are not affected by this policy).

Policy 322 covers a broad range of issues. It defines inclusive education as a philosophy that when combined with education practices "allows each student to feel respected, confident and safe so that he or she can participate in the common learning environment and learn and develop to his or her full potential". "Common learning environment" is new language that the policy defines as "an inclusive environment where instruction is designed to be delivered to students of mixed ability and of the same age in their neighbourhood school, while being responsive to their individual needs as a learner, and used for the majority of the students' regular instruction hours". This definition recognizes that the traditional classroom may be one of several types of learning environments that exist in the schools of today and tomorrow.

Policy 322 is not a policy that deals only with students who have a disability. While the inclusion of students with a disability is important, inclusive education is about having an education system that includes all students regardless of their background and characteristics. Inclusive education respects diversity and seeks to ensure that all students are welcomed and learn to their potential.

Students Requiring a 'Personalized Learning Plan'

The New Brunswick Education Act states that a Personalized Learning Plan (PLP) shall be developed for a student if the district superintendent determines that a plan is required as a result of a student's physical, sensory, cognitive, socio-emotional or other needs. It is defined as a "personalized plan for a pupil that specifically and individually identifies practical strategies, goals, outcomes, targets and educational supports and designed to ensure the pupil experiences success in learning that is meaningful and appropriate".

Decisions about whether your child requires a PLP should not be taken lightly. Under the law, the school district must consult with parents when deciding whether a child requires a PLP. This does not mean that you have a right to decide that your child does or does not require a PLP but you should be very involved in the decision. Policy 322 notes that students must receive a Personalized Learning Plan when teaching strategies "beyond robust instruction are required", behavioural supports are required, or the student's common learning environment is varied (see below).

The Right to Be Educated in the Common Learning Environment

Under the Education Act, school districts are required to educate students who require a PLP in the common learning environment (regular classroom) to the fullest extent considered practicable. The law directs that the district superintendent is to have regard for the student's rights and needs and the needs of other students when making these decisions.

The effect of the law is that students who require a PLP have a strong qualified right to be educated in common learning environments (regular classrooms) with their peers. If the school district believes or decides that your child should not be in a regular class, it has the duty to show why this is not possible.

Policy 322 outlines in more detail the right to be included in the common learning environment and when a student can receive their education outside the common learning environment.

- The policy expects that all students will be educated in the common learning environment. The common learning environment must be appropriate for the student's age and grade.
- The policy does, however, provide that under specific conditions, a "variation" of the common learning environment may be necessary to meet the needs of a student. A "variation" is a situation where a student is removed from the common learning environment for more than one period daily or more that 25% of the regular instructional time, whichever is greater. This means that short term "pull-outs" (that last no longer than one class period or 25% of instructional time) can happen without need to say that the common learning environment is being "varied". Such pull-outs should still be justified and tied to a student's education plan.
- Prior to removing a student from the common learning environment for more that one period (or 25% of instructional time), a school must demonstrate that its ability to meet the needs of a student (even when supported by the district and the Department) is not sufficient. In these situations, schools must keep a record of student progress and the results of any supports or accommodations provided. Schools must also have a plan for the student's return to the common learning environment when they are removed for more than one period. A student whose learning environment is "varied" shall be provided with a "personalized learning environment" where the student receives "individualized instruction in the neighbourhood school".

Other Important Provisions of Policy 322

There are other issues that are covered by Policy 322 that may affect the education of your child.

- The policy obliges school principals to ensure that a student's instruction is primarily provided by a classroom or subject teacher and that the grouping of students based on their ability is "flexible and temporary".
- Principals must also ensure that all students have access to co-curricular and school-sponsored activities, including access to transportation in school vehicles when it is provided to other students.
- The policy prohibits the creation of "segregated, self contained programs or classes for students with learning or behavioural challenges".

- Students in kindergarten to grade 8 must not be placed in "alternative education" programs (these are programs that are provided in a different location than the regular education system).
- Teachers must ensure that their lesson plans and teaching strategies are consistent with what is required in a student's PLP. Teachers must also provide formal progress reports for students on a PLP "on the same document (report card) and at the same time as this is done for all other students".
- When a student has a behavioural crisis, any removal from the common learning environment must only be temporary and never used as a punishment.
- A school must only use a single version of the High School Diploma and any graduation ceremony must be inclusive and distribute diplomas without dividing students based on their performance.
- The policy contains many other provisions. Families are encouraged to become familiar with the policy. You can read the full policy on-line at http://www.gnb.ca/0000/policies.asp or contact Inclusion NB for a copy.

Appealing Placement Decisions

The Education Act also states that parents of students under the age of 19 can appeal "placement" decisions of the school district regarding their child. Decisions about placement can mean decisions about classes, programs, services, and schools. Appeals provide an important way to challenge decisions that deny opportunities for a child to be educated in regular classes.

It is extremely important to remember that the physical presence of your child in a regular class does not necessarily mean that they are included. Your school district and local school may be following the law by allowing your child to be in a regular class. They may not, however, be doing more to ensure that your child actively participates in the classroom, is learning appropriate material, and has opportunities to be involved with other students. Having rights and being educated in regular classrooms is only the beginning. Ensuring that all students are active members of their classrooms and schools, and are learning, will require personal commitment and effort of the part of many people.

The Guideline on Accommodating Students with a Disability

In 2007, the New Brunswick Human Rights Commission issued an extensive *Guideline on Accommodating Students with a Disability*. This Guideline was updated in 2017.

This Guideline offers a detailed discussion on the "duty to accommodate" and what it means for the school system. The duty to accommodate is a legal principle that requires the school system to provide "reasonable accommodations for students with disabilities." Reasonable accommodations may involve making changes to the school environment, making changes to a student's education program, or providing various types of support to a student.

According to the Human Rights Commission:

> *The goal of accommodating students with a disability is to ensure their fullest possible participation in a timely manner and to the same extent as non-disabled students, not only in classrooms, but in all aspects of the educational experience, and to ensure that they have the opportunity to reach their individual potential.*

The right to have reasonable accommodations does have some limits. This is usually defined in terms of providing accommodations that would cause "undue hardship" on the school system. For more detailed information on the duty to accommodate and "undue hardship" you can access the Guideline on-line at www.gnb.ca/hrc-cdp/index-e.asp - just click on "Guidelines" under the "resources" section of the Commission's home-page.

Getting Ready for School

Checklist for Getting Ready for School

☐ Set up a meeting with the school principal (and possibly some of the teachers from the grade that your child will be entering) a few months before your child enters the school. You may also want to meet with the Resource teacher who may be helping to develop an education plan for your child.

☐ Before your child starts school, you may be asked to attend a meeting with the school about transportation and the support your child may need. If so, think about whom else should attend (including someone from your child's pre-school, other professionals who have been involved with your child such as an Occupational Therapist or Speech Therapist, or the school district person responsible for transition to school).

☐ Talk with the principal and teachers about some of the expectations you have for your child (you may want to make a few notes before the meeting).

☐ Identify some of the support that your child may need to learn and to be included in their school and classroom.

☐ Make an appointment for when your child can visit the school for a tour before he or she starts school.

☐ If your child has difficulty communicating, or uses a different way of communicating, talk about how school staff and other students will be encouraged to communicate with your child.

☐ Talk about your child's routines while at school. This could include making sure they enter and leave school at the same time as other students, take lunch recess or breaks at the same time, etc.

☐ If your child will have a PLP, find out about the school's process for developing the plan. You may want to emphasize your expectations about being involved and that the plan is completed early in the school year.

If your child is entering school for the first time (or moving to a new school) there are a number of things that you can do to prepare for the successful transition to school. Consider the steps and actions in the checklist below:

The PLP Process: Families Being Involved in Planning for Their Child's Education

Personalized Learning Plans

A Personalized Learning Plan (PLP) will vary depending on the circumstances of each child. Plans may talk about extensive changes or modifications to the regular school program and curriculum as well as a need for on-going support.

Planning should take place every school year prior to the beginning of the school year (sometimes it does not happen until the school year has begun). The development of a PLP usually involves parents, regular classroom teachers responsible for your child, Education Support Teacher - Resource (EST-Resource) and sometimes other professionals. Students should also be involved, although this may depend on the student's age and abilities to make decisions for themselves.

By law, the school district must consult with the parents of a child when decisions are being made to determine if a child requires a Personalized Learning Plan (PLP) and during the process of developing a PLP. This means that you have a direct say in any decisions being made about your child's PLP. You should never be asked to sign a PLP for your child without having been given a real chance to be involved in its development.

A PLP can be very important as a way to plan for your child's inclusion within regular classes and other school activities. The PLP can set the tone for the expectations for your child throughout the year. While goals and needs for support should be identified, planning sessions should also consider your child's strengths and the ways that your child can be better included within the activities of the regular classes and school. A PLP will only be as good as the commitment of the people involved to make sure that the plan becomes implemented. As parents, it will be important for you to regularly find out if the plans are being put into place and if your child is achieving the objectives that you have set out.

Focus on Strengths and Capacities

All children have strengths and capacities. These are the positive qualities that are often recognized by others. Sometimes, however, people (including people with disabilities) get to be known by the things that are wrong with them. When this happens, children are often seen to have very little potential.

While goals and needs for support should be identified, planning sessions should also consider your child's strengths and the ways that your child can be better included within the activities of the regular classes and school.

Focusing on your child's strengths, gifts and interests will be an important part of trying to plan for the day to day inclusion of your child in regular classrooms and other school activities. As parents, you will likely be able to identify many of your child's strengths and gifts. Sometimes, though, other people are able to see things in your child that you may not. Ask others who know your child well to help you identify things that make your child a unique and interesting person.

Take some time to note some things about your child's strengths, capacities and interests.

My Child's Strengths, Capacities and Interests

Preparing for Planning Meetings

If you have already thought carefully about what you want your child to achieve from school, and about your child's dreams, capacities, and interests you have done a lot of preparation for a PLP meeting. All of your ideas should be written down. It may also be important for you to get to know other key people. This may include the school principal and the teacher who will be responsible for your child. Ask for information about the subjects that are taught at your child's grade level. Ask also for the daily schedules of other students that are your child's age.

You will find it very helpful if you are well organized before a meeting. Prepare an outline of the things you wish to say. Have your goals clearly written down so you can refer to them during the meeting.

Many parents find it helpful if someone attends the meeting with them. This may be another family member, parent, or representative from an advocacy organization. If you have difficulties speaking during meetings, another person may be able to speak on your behalf. They can help to take notes of the meeting so that you can review what was said afterward.

Using the PLP as a Basis for Inclusion and a Quality Education

Going into a PLP meeting, you should have three main objectives:

- To clearly identify what you want your child to learn during the school year (for example, specific lessons or skills). This should be fairly consistent with the goals that you have already set for your child.
- To identify ways in which your child can be included in the activities of the classroom as well as other school activities.
- To identify the kind of support your child will need to learn and to participate and how that support will be provided.

Begin planning meetings by stating or re-stating your vision for your child (or better still, have your child talk about their own dreams, particularly if he or she is a teenager). Make your goals and your child's strengths and interests the focus of the meetings.

An important part of the PLP will be to decide how your child's goals and strengths will be met within the overall objectives of the regular classes in which they will participate. For example, if one of the goals for your child is to improve communication skills, how will those skills be worked on during regular class times? What different ways of teaching will be needed to ensure that everything can happen in the regular classroom?

The PLP should also address the goals you have set for your child to develop friendships and relationships with other children. This will include ways in which your child can participate in activities such as field trips, school fundraisers and other events. It may also involve identifying other children who can be role models for your child so they can learn social skills or develop good language skills.

The plan that comes out of the PLP meeting should include clear expectations for your child. This will give you something valuable to use when you want to find out whether the goals you have set are being achieved.

Tips for Parents Attending PLP Meetings

- Expect to be a full and equal partner in the planning process.
- Tell the other people at the meeting your dreams for your child.
- Have an outline of what you want to get out of the meeting.
- Keep in mind the strengths and needs of your child.
- Refer frequently to the short and long term goals you have prepared.
- Be aware of any situation that you would like to change and raise it during the meeting.
- Be courteous and positive.
- Listen carefully.
- State your case simply and directly.
- Be assertive without being aggressive.
- If someone disagrees with your plan for your child, be persistent and provide them with any additional information you may have.
- Ask questions when you need to.
- Take notes or bring someone with you to assist you. If you become too emotional or feel that the meeting is breaking down, reserve the right to postpone the meeting until another time.
- Summarize the meeting from your perspective and ask for feedback.
- Know the follow up steps and when the next meeting will be held.

Support for Inclusive Education

Support for inclusive education can involve many things, including:

- The help your child receives for personal needs they have;
- Various "accommodations" children with disabilities may need to participate in regular school and classroom activities;
- The overall support from the school including the leadership and commitment necessary to include all children;
- Different ways of thinking about what and how children are taught so that all children can participate in regular classrooms and school activities.

Personal Support and Accommodations

Different children will require different kinds of support to participate fully in school. Some children need physical supports such as help with personal care, changes in seating arrangements, alternate forms of communication (for children who do not speak), and extra help to participate in activities which would not otherwise be possible.

It is important for you to know the specific support or accommodation needs for your child. Make sure you write down the things that your child will need help with. These needs should be addressed fully during the PLP process and other meetings with your child throughout the year. Be careful not to assume that there is only one way of doing things. Also, make sure that the support that is provided allows your child to participate in activities in the classroom and school as well as to develop friendships with other children.

Adjusted Curriculum

Many educators now realize that children who are learning the same subjects can have different educational goals. Going to school does not require that every child learn the same thing. In fact, children can be working on different things and skills during the same lesson. The secret is to find out how the subject being taught in the regular classroom can be used to benefit a particular child.

Many educators now realize that children who are learning the same subjects can have different educational goals. Going to school does not require that every child learn the same thing.

It is important not to assume too quickly that your child cannot learn the same things that other children are learning. The question that you need to ask first is: Can your child participate just as other children are? Also, your child may only require small changes like different expectations (for example, fewer math problems) or different class materials. Try to find out if your child can learn or handle the regular curriculum with some accommodations. You may not want to assume or want others to assume that your child is not capable.

In school terms, adjusting curriculum means significantly simplifying the content and concepts of a program or course. This usually happens when a child is having a lot of difficulty that cannot be dealt with in other ways (for example, by providing accommodations or changing teaching techniques). Remember that making accommodations for your child does not mean that their curriculum is being adjusted.

Decisions to adjust subjects should only happen after discussions with parents (and sometimes students) have occurred and after you have agreed to it. When a decision is made to modify curriculum, people involved in planning for your child's inclusion in regular classrooms should look at each subject to see what information, concept or skills may be relevant for your child. For example, during an English class, your child may be learning words from a story while other children are learning how to analyze the story.

Key Roles of Principals and Regular Classroom Teachers

Leadership from principals and teachers is often crucial to creating an inclusive school. If principals and teachers have a commitment to meeting the needs of all children, the inclusion of children with disabilities in the school and in regular classrooms will likely happen. Your child's school principal has the overall responsibility for running the school.

They must make sure that teachers and other school staff are doing their jobs and that the programs and services are working smoothly. More importantly, the principal is responsible for guiding the school's approach in a way that supports the inclusion of all children. Principals can support inclusion by taking a real interest in making sure that children with disabilities are part of the school. Principals can also support teachers and other staff by helping to find ways to make inclusion happen (for example, by providing teachers with opportunities to learn to take time away from their classrooms to meet with parents).

Get to know the principal of your child's school. Try to find out what they think about inclusive education. How does the principal provide leadership to make inclusion happen?

Regular classroom and subject teachers are also the key for setting the tone for inclusion in the regular classroom. Inclusion will be successful when regular class teachers know how to:

- Create a feeling that everyone belongs regardless of ability.
- Change and adapt the teaching styles, activities and curriculum to ensure the success of all children.
- Help the children in the class accept each other.
- Help children find ways of supporting other children who may need help.
- Take full responsibility for the education of all children in their classroom.

Taking responsibility for teaching all children does not always happen. Sometimes, teachers believe that others (for example, Education Support Teacher - Resource or educational assistants) should have the main responsibility for teaching children with disabilities. However, taking responsibility for teaching all children does not mean that teachers must do it alone.

Ways to Support Teachers and Your Child in Regular Classrooms

Within the school, there may be various sources of support for teachers and children. Three of the main ways to provide support are through Education Support Teacher - Resource (EST - Resource), educational assistants, and other children.

Education Support Teacher - Resource (EST - Resource)

Most schools have specialist teachers who are not responsible for a classroom but who provide valuable support for classroom teachers. These are called Education Support Teacher - Resource (EST - Resource). They may have some special training or experience for them to provide help to regular classroom teachers and students.

Education Support Teacher - Resource (EST - Resource) provide support for inclusive education in a number of ways:

- They provide direct assistance to classroom teachers on ways to use the lessons to achieve education goals that have been set for children with disabilities.
- They can assist teachers by substituting for teachers so that they can meet with parents or others about your child's inclusion.
- They can identify ways to give children with disabilities opportunities to make friends or to be supported by other children.
- They have a responsibility to coordinate PLPs and the services and supports some children will receive.

The Education Support Teacher - Resource (EST - Resource) is someone that you should get to know quite well. Your knowledge and expertise about your child will be helpful to the Education Support Teacher - Resource (EST - Resource) in working out ways your child can be fully included in the school. Be aware that the Education Support Teacher - Resource (EST - Resource) should not be seen to be your child's teacher. Unfortunately, in some schools, students with disabilities are grouped together and taught by Education Support Teacher - Resource (EST - Resource) in what are sometimes called "resource rooms". This is something that should not be happening within an inclusive education system.

Educational Assistants (EA)

Educational assistants also play an important role in supporting inclusive education. These are people who provide assistance to teachers in the classroom, library, shop or laboratory and who fulfill a number of duties, including:

- Assist with the physical needs of a child with a disability
- Ensuring the safety and supervision of children
- Classroom observation
- Assist with the preparation of teaching aids and the assembly of materials as directed by the teacher
- Assist individual students or small groups in performing activities in the school
- Follow and implement therapy programs set out by therapists (for example, a speech therapist)
- Assist with maintaining records and notes that can be used by regular classroom teachers to inform you of your child's activities and progress

Many people, including some parents, assume that every child with a disability in a regular classroom needs an educational assistant. There is often the belief that if a student has some additional needs, these needs can only be met by another adult person in the classroom. These beliefs have led parents, teachers and other people in the school system to depend too much on educational assistants to include students with disabilities. This can cause a few problems of which you should be aware.

One problem is when the regular classroom teacher feels that they have little or no responsibility to educate a student with a disability because the educational assistant is there to do that. This leads to the educational assistant being seen as the primary teacher of the student, often finding themselves working at the student's side and often at the back of the class so as not to disturb other children. Other problems are created outside the regular classroom. For example, an educational assistant may be the only person who helps a student with a disability to eat, play, or do other things in the school. Other students may not approach a fellow student when an adult is present. Students may end up being segregated by a person who is supposed to help with inclusion.

Some students may require regular help from an educational assistant. Most often, it will be students with significant physical needs that require ongoing attention. For most students with disabilities, however, having a "full time EA" can cause problems. As parents, you will need to be aware of the "danger signals" that will tell you if your child is depending too much on an educational assistant. If this is happening, it will be time to start to think about other ways your child can be supported.

Danger Signals!

You know your child's school may be depending too much on an Educational Assistant when:

- ☐ At a meeting, it is the Educational Assistant who knows the most about what and how your child is doing rather then the regular classroom teacher.
- ☐ The Educational Assistant is the only person who sends a message to you in your child's communication book.
- ☐ The Educational Assistant is always seen by your child's side, both inside and outside the classroom.
- ☐ Your child will mainly seek out the Educational Assistant when in need of help.
- ☐ Other students in the class call upon the Educational Assistant when they notice that your child needs help rather then notifying the teacher or offering to help your child themselves.
- ☐ Other students and school staff will talk to your child through the Educational Assistant rather than directly to your child.
- ☐ The Educational Assistant is often working alone with your child at the back or the side of the class, frequently doing something different from the rest of the class.
- ☐ Whenever a problem arises or a question is asked concerning your child, the Educational Assistant is called upon as the "expert" in the school.
- ☐ Your child spends their recesses, breaks, and lunch times with the Educational Assistant rather than other children.
- ☐ When the Educational Assistant is ill, it is suggested your child stay home from school.

Support from Other Children

When children are part of a regular classroom, it becomes natural for other children to get to know them as a classmate. This is more likely to happen if the educational assistant learns to keep their distance and help other students learn how to support your child. When children support children, it brings them closer together.

When you are planning for and discussing your child's education, think about ways they can receive support from their classmates. Make it one of your goals that your child will receive help from other children. This does not mean that adults with special training are not necessary. There are some things (for example, assistance with toileting) that may not be appropriate for classmates to provide.

When you are planning for and discussing your child's education, think about ways he or she can receive support from his or her classmates. Make it one of your goals that your child will receive help from other children.

Family Advocacy in Action: Addressing Problems and Concerns

Achieving true inclusion may at times be difficult. From time to time, problems may arise that will require you to take action. Problems may occur when decisions are made about your child with which you do not agree. For example, you may disagree with the goals established in your child's PLP. Your child may not be getting the proper support they need to be included in the regular classroom and school activities.

The way that you respond to problems will likely be determined by the kind of problem that arises. For example, the decision to keep your child out of a regular class can be appealed under the Education Act. Most often, however, problems can be dealt with within the school or the school district level. Problems may be resolved simply by talking with the teacher in person or on the telephone. Sometimes, you may need to meet with the teacher and others who are involved in the education of your child.

Suggestions for Dealing with Problems

When problems arise concerning your child's education, you may need to take action quickly and sometimes forcefully. If necessary be sure to ask for the help of others as you deal with the school system. You may want to involve people who can give you advice and, if necessary, attend meetings with you, take notes, or speak on your behalf. It is important to remember that you do not need to be liked or popular, but you do need to be respected.

Below are some steps to deal with problems that may arise:

- Write the problem down. Describe the nature of the problem and be sure to record the date that you are writing. If you use a book, you can make regular entries about phone calls, letters, discussions, feelings that relate to the problem.
- Talk within your family or to a friend about the problem and about how it might be resolved.
- Decide what action you need to take. Ask yourself whether the problem needs to be addressed immediately and who you need to talk with. Think about whether the problem could wait until your child's next PLP meeting.
- If the problem concerns something that is happening with your child in the classroom or in the school, and requires immediate action, set up a meeting with your child's teacher and other people who may be involved in your child's education.
    - Make sure you go to the meeting with some ideas of what actions you would like to take. If you are unsure, make sure the meeting is used to discuss ways to address the problem.
    - At the meeting, be sure to take notes or have someone go with you who can take notes.
    - If you are satisfied with the results of the meeting, you may wish to put down in writing what was decided and send a copy to everyone who attended the meeting.
    - Think about whether a follow up meeting is required to review the progress that has been made to address the problem you have raised.
- If you have been unable to resolve the problem by meeting with the teacher (and others involved in your child's education), request a meeting with the school principal. Again, it is very important that you say very clearly why you think that there is a problem and what you think should be done about it. After the meeting, you may want to send a letter to the principal confirming the action that was agreed to.
- If the problem is not resolved within your child's school, you may have to take it up with the school district. At this level, you may be meeting with people with whom you are not familiar. At the school district level, you should first try to meet with the Education Support Services Coordinator or the director of schools. Again, make sure that you are well prepared for the meeting and that you take good notes. If you are unable to resolve the problem, request a meeting with the school district superintendent.
- If your meetings with the employees of the school district are not successful, you may wish to ask to meet with the members of the District Education Council. Alternatively, you may want to ask the Department of Education to get involved to help resolve the issue.

> At this level, you may want to meet with the person responsible for student services, the assistant deputy or deputy minister, or even the Minister of Education and Early Childhood Development.

If you need to go through this process, make sure that the time it takes does not create more problems for your child. You may wish to skip one or two steps if you feel that a decision at a higher level needs to be made more quickly.

Please also refer to the tips for being an effective advocate that are provided in Chapter 2.

If you are appealing decisions made by the school or school district, familiarize yourself with the education appeal process. The Department of Education has a guide entitled *A User's Guide for the Appeal Process* that can be found on-line at https://www2.gnb.ca/content/dam/gnb/Departments/ed/pdf/K12/UsersGuideForTheAppealProcess.pdf .

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Worksheet 4

Preparing for My Child's PLP

My goals for my child's academic learning (reading, writing, math, etc.) for this school year:

My goals for enhancing my child's personal abilities (communication, socializing, etc.) for this school year:

My goals for my child's participation in extracurricular activities for this school year:

My expectations for my child's inclusion in school and in the classroom:

Supports my child will need to reach these goals:

Additional Resources

Available from Inclusion NB (free to families)

Achieving Inclusion: A Parent Guide to Inclusive Education in New Brunswick (2000)

Achieving Inclusion: A Collection of Resources for Families on Inclusive Education (Binder)

Other Resources (Available On-Line)

A User's Guide to the Appeal Process. New Brunswick Department of Education. Available at https://www2.gnb.ca/content/dam/gnb/Departments/ed/pdf/K12/UsersGuideForTheAppealProcess.pdf

Canadian Association for Community Living national website on inclusive education – www.inclusiveeducation.ca

Guidelines and Standards: Educational Planning for Students With Diverse Learning Needs New Brunswick Department of Education.
Available at https://www2.gnb.ca/content/dam/gnb/Departments/ed/pdf/K12/curric/Resource/GuidelinesStandardsEducationalPlanningStudentsWithExceptionalities.pdf

Inclusion Press – www.inclusion.com/inclusiveschools.html

Inclusive Education Resources. J. P. Das Developmental Disabilities Centre – University of Alberta. Available at www.ualberta.ca/~jpdasddc/inclusion/index.html

New Brunswick Education Act.
Available at https://www.gnb.ca/0062/acts/BBR-2001/2001-49.pdf

Autism Training Framework. Available at https://www2.gnb.ca/content/dam/gnb/Departments/ed/pdf/K12/autisme/EECD_Provincial_Autism_Training_Framework.pdf

Whole Schooling Consortium. Wayne State University. Resources on inclusive education available at www.wholeschooling.net/

Taking the JOURNEY

An Information and Advocacy Guide
for Families Supporting a Child with a Disability

CHAPTER 5

Transition from High School to Adult Life

"We tend to live day-to-day
with our children who have disabilities,
instead of planning for the future
like we do with our other children.
But if we plan now,
there will be a lot fewer
boxes to tick later on."

InclusionNB

CHAPTER 5

Transition from High School to Adult Life

Goal for this Chapter

- To help families understand the roles they can play in helping their child make a successful transition from being a student to being an adult.

What You will Find in this Chapter

- Information about:
    - The activities that will make transition from high school more successful
    - The importance of transition planning and the roles that families can have in planning for the future
    - The planning process, including who should be involved, setting goals, and identifying activities that will help prepare your child for life after high school
- A Transition Planning Checklist
- **Worksheet 5** – Planning for Transition from High School
- A List of Additional Resources

Our Journey So Far

- For many years families and others have known that preparing for the transition from high school to adult life is crucial for youth with disabilities.
- The Department of Education has developed resources to help with transition planning, but in many areas of the province not enough attention is paid to planning and preparing youth for life after school.
- There is a real need for improvements in the ways in which schools and others assist students with disabilities to prepare for work and other aspects of adult living. Inclusion NB is promoting some new ways of doing things and will continue to make successful transition from high school a priority.

Introduction

All parents wonder what their child's life will look like after school is finished. We all ask: What will my child do? Where will he or she live? What kind of friends will be a part of his or her life? What kind of person will he or she be?

For at least 13 years, parents are reassured by the regularity and structure of a school that fills a child's day with classes and activities. Making that transition from school to either the work place or further study is both exciting and challenging. We all share the same goals for our children – with or without disabilities. We want them to have a job, a good home and friends and opportunities to be involved in their community.

What is Transition from High School?

Transition is about change. For young people who attend school, it is a change from their role as students to being adults and doing things other adults do in the community. This may include getting a job, going to college or university, getting a place to live, developing personal and social relationships with other adults, and being involved in the community.

All young people who attend and eventually leave school go through some kind of transition. For many people, the transition from school to adult life is smooth. They go to college, get a job and an apartment, and so on. Some people find the transition more difficult. Young people with disabilities are at greater risk of being unable to attend college or university and of being unemployed or uninvolved in the life of their communities. Figuring out how to make this transition smooth and successful is crucial. The steps that are taken to prepare for adult life while people are still in school can make a positive and lasting difference.

At the school level much more work needs to be done to ensure that youth with disabilities can make successful transitions from school to work and adult life. As a result, you may need to be a strong advocate for your child to ensure that planning and other activities take place that will prepare your child for life after school. You may also need to ask other people to get involved to help you and your child to achieve your goals.

TRANSITION FROM SCHOOL

There are many possibilities, including:

- **College or university**
- **Other employment training**
- **A job in the community**
- **Involvement in the community (recreation, leisure or volunteering)**
- **A home of one's own**

What Can Make Transition More Successful?

Achieving successful transitions from school to work and adult life starts with all children receiving a good education. There are a number of other factors that have been identified as important to the successful transition of youth with disabilities (and all youth). These include:

- Schools provide youth with disabilities with a quality inclusive education. This means that youth with disabilities learn in regular classrooms and actively participate in classroom and school activities. Having a quality education means that youth with disabilities learn subjects and skills that will prepare them for work and adult life after high school.
- People with disabilities learn to make decisions for themselves about their futures. Youth with disabilities learn to speak for themselves, set their own goals and be active participants in planning for ways to achieve those goals.
- Family and friends of youth with disabilities play an important role in planning for the transition from school to work and life in the community.
- Transition planning takes place long before an individual graduates from high school. Transition planning is well facilitated and coordinated and based on achieving specific goals for youth with disabilities.

- Youth with disabilities have useful work experience during the high school years.
- Since some youth with disabilities may need ongoing supports and services to work in the community, steps are taken during the school years to make sure these supports and services are available.

Transition planning can help young people with disabilities learn to make decisions and take responsibility for themselves. With the goals that are established through planning, youth with disabilities, families, and people working in the school system will have a clear direction on what is important.

Transition Planning

Transition planning is an activity that helps to prepare youth for adulthood. It is important because it helps to get the most of our school experience. Transition planning can help young people with disabilities learn to make decisions and take responsibility for themselves. With the goals that are established through planning, youth with disabilities, families, and people working in the school system will have a clear direction on what is important. Transition planning will also provide opportunities for meaningful experiences, both inside and outside school.

There are a number of key elements to successful transition planning. These include:

- Transition planning is usually a process that evolves over a number of years (and should start by grade 9 at the latest).
- Transition planning usually involves the student and his or her family, teachers, guidance counselors, individuals who may be involved in providing services to the student either during or after high school, other family members, friends and people from the community. Planning is more effective when a "team" of people are involved.
- Transition planning is also a process that respects student choice. The process itself should actually help a student gain a sense of control over his or her plan and decisions.
- Transition planning is a process that takes a broad view of a person's life. Planning can involve areas such as work, leisure activities, relationships, confidence building, and living in the community.
- Transition planning attempts to identify the goals the person wants to achieve in his or her life once he or she leaves school. For most people, getting a job will be a main goal.
- Transition planning involves the selection of school and work activities and experiences that will help achieve goals. As much as possible, these experiences should be selected by the individual student.
- Transition planning, to be successful, also must coordinate school learning, work experiences, and potential services prior to the student leaving school. Bringing the different pieces together before the student leaves school will help to ensure that there is continuity between the school years and life once school is finished.

Roles for Families

Families should be active participants in planning for the successful transition from school to work for their child. Sometimes families have to be responsible for making sure things happen within the school if transition planning is not happening. Families, therefore, should be prepared to make sure that transition planning happens, and to be actively involved in the planning process.

There are a number of ways that families can be involved in transition planning, including:

- Be aware of what happens within the school system regarding how decisions are made for your child. For example, some students with disabilities are required to have an education plan (in New Brunswick called a PLP) that sets out goals and objectives. If your child's school or school district does not have a separate transition planning process, it may be necessary to ensure that transition goals become part of your child's PLP.
- Follow up with your child's school regularly to ensure that transition goals and plans that are developed are being implemented. The best way to get plans implemented may be to develop ongoing and positive communication with the teachers and other professionals who are responsible for implementing the plans.
- Monitor and evaluate the plans to ensure that they are working and results are being achieved. Sometimes goals that are set are not achieved even though the people responsible have made their best efforts. At other times, not enough effort has been made. Monitoring transition plans may also involve making changes to plans as they are implemented because your child's wishes have changed or the plan was not fully appropriate.

Focus Primarily on Your Child's Strengths and Interests

Achieving successful transitions from school to work and adult life will be more likely if plans, goals and actions are based on a person's strengths and interests. Sometimes, people with disabilities get to be known by the things that are "wrong" with them. When this happens, people are often seen to have very little potential. Others tend to make plans to "fix" those things seen to be wrong.

Achieving successful transitions from school to work and adult life will be more likely if plans, goals and actions are based on a person's strengths and interests.

When you focus on your child's strengths and interests, very different information about your child is often revealed. This information is important when determining what motivates your child.

Focusing on strengths and interests does not mean that specific needs or limitations of your child are ignored. Nor does it mean that the goals you set for your child should be unrealistic. You need to be honest about things that may limit your child's ability to move forward. At the same time, be prepared to think about how these limitations can be faced and possibly overcome.

It often helps to write down the things that you know or discover about your child's strengths and interests. Share this information with other people who will be involved in the planning process.

Encouraging Your Child to be Active in the Transition Process

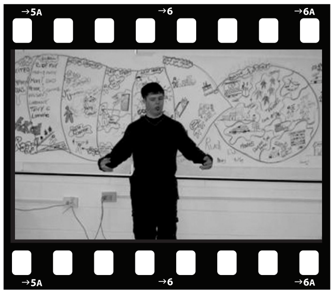
There are several ways to encourage your child to be active in the transition planning process:

- As families, you can help build confidence in your child by having positive attitudes and expectations about his or her life and future. Remind or help your child to talk about or express his or her desires and wishes. Talk to your child about his or her future after high school. Learning to make decisions and speaking for him or herself can be one of your child's education goals. Encourage your child's school to help your child develop these skills.
- During meetings to discuss transition planning, make sure your child is present and sitting at a place that makes him or her the focal point of the discussion. Make sure questions concerning your child's wishes, fears or other matters are addressed to your child. Give your child a chance to respond in a way that he or she finds comfortable. Before and after meetings, talk with your child about the meeting.
- Encourage your child to talk with people his or own age about the future. Sometimes, people find it easier to relate to others who are in similar situations.

The Transition Planning Process

There are various parts to the transition planning process that will need to be considered. The planning process will involve identifying specific goals for your child's future as well as action steps to achieve those goals. It will require the involvement of different people as well as meetings, follow up discussions, monitoring and evaluation. There are specific planning tools available that will help make the planning process more successful. One planning tool is called PATH. It has proven very effective in helping youth with disabilities to plan for their futures.

PATH



PATH is a planning process designed by Jack Pearpoint and Marsha Forest. It is described in great detail in the publication ***All My Life's a Circle***. PATH is an eight step planning exercise in thinking backwards from a person's dreams for his or her ideal future. A PATH is facilitated by two trained people who are not part of the person's life. The facilitators use a large sheet of paper with pictures and words to show the plan as it is developed.

No limits or constraints are placed on the dreams or the ideal future that they illuminate, so that a person can indicate what matters most to him or her. Then, on the basis of the person's dreams and ideal future, specific goals that are both positive and possible are identified. The complete eight steps are as follows:

1. Identifying the dream or vision of the future.
2. Establishing goals that are both positive and possible over a short period (for example, one or two years).
3. Identifying what is happening now.
4. Identifying other people to enroll to help reach the goals.
5. Finding ways to build strength to accomplish the goals (for example, what skills need to be developed or what relationships maintained).
6. Charting actions and goals for the mid-way point of the plan.
7. Charting actions and goals for three to six months from the day of the PATH.
8. Identifying the first steps to take.

A key to this planning process is identifying who will be responsible to do what to help achieve a person's goals. This is a way in which the person him or herself, family members, other community members, and service agencies can make specific commitments to take action. Usually, opportunities to review the pathfinders' goals and update actions are provided.

Who Should Participate in Transition Planning?

Planning for transition usually involves people from within and outside the school system. There may be people involved in your child's life or in your community that will have valuable information and advice to offer. Since transition planning should take place over a number of years, there may be different people who are called upon, as they are needed. You may want to start the planning with a small group of people and add others over time. This will give you and your child a chance to become familiar and comfortable with the planning process.

There are no rules regarding who should be involved and how many people should be involved in transition planning. As a general guideline, transition planning should include your child and yourself, a teacher who is working closely with your child, the school guidance counsellor, and other individuals who may be able to assist with future educational or employment opportunities.

Transition Planning Meetings

If transition planning starts early enough, there will be a few key meetings during your child's secondary school years (grades 6-12). The initial planning meeting will be crucial since it will be an opportunity to discuss the vision you have for your child and set some important long term goals. Other meetings will likely be required to review those goals and to identify a plan of action for the current school year. It will be important that you remind other people about the vision for your child as you go through this process.

Effective planning usually requires someone who is able to run the planning meetings. This person guides the meeting to ensure the purpose of the meeting is achieved and that you and your child are encouraged to talk and present your ideas. The person who runs the meeting should:

- Be objective and not too closely involved with your child;
- Be open minded;
- Not have strong views on what your child should be planning for once he or she finishes school;
- Be able to guide the discussion about the vision of your child's future, the specific goals that are set, and what actions need to take place to achieve the goals; and
- Be skilled in involving everybody present at meetings.

If such a person is difficult to find where you live, you will need to rely on someone within the school system or another individual you know who may be able to help.

Identifying a Vision and Goals for the Future

Planning usually starts with a vision. This means being able to imagine what your child's life could look like as an adult. Identifying a vision gives you, your child and others a clear idea how you see the future and what you want to accomplish. It helps create some positive expectations about your child. Identifying a vision of the future requires the active involvement of your child. Your child must be allowed and encouraged to express his or her ideas, hopes and dreams for him or herself.

Setting goals for your child is the most important aspect of transition planning. Goals will help decide what kind of experiences and skills your child should have and learn during his or her last few years of school. Setting goals will also help to clarify the vision of your child's life as an adult. Use the Worksheet at the end of the chapter to write down some of your child's goals for life after high school.

Identifying a vision gives you, your child and others a clear idea how you see the future and what you want to accomplish. It helps create some positive expectations about your child. Identifying a vision of the future requires the active involvement of your child.

Below are some guidelines you may wish to consider when setting transition goals with your child:

- Goals should be reasonably possible to achieve.
- As much as possible, goals should be specific about what you and your child would like to achieve in the areas of employment, community participation, etc. Specific goals may be easier to set as your child moves closer to completion of high school. In the beginning of transition planning, goals may sound more general. For example, in grade 9, a transition goal may be that after graduation, your child will be working in the community for real wages. By grade 11 or 12, the goal may be that your child is working in a specific occupation for at least a certain number of hours per week.
- Consider setting both long term and short term goals. Long term goals may be the ones you wish your child to achieve when he or she leaves school. Short-term goals may identify things you may want your child to learn or experience during a school year.
- Set goals that you are able to measure. In other words, will you be able to determine whether or not your child has achieved the goal.
- When setting goals, consider fears that you or your child have about the future. Be prepared to talk about these fears with the group of people who will be meeting to assist with transition planning.
- When you have set transition goals for your child, consider where he or she is now in relation to where he or she would like to be in the future. What has to happen while your child is in school to make sure that the goals are realized?

Agreeing On an Action Plan

Before you leave a transition planning meeting, make sure the goals you have set have an action plan. The action plan should identify what specific steps will be taken to help your child achieve his or her goals.

The action plan can be based on what should happen during the entire school year, or even a shorter period. The planning meeting should identify someone who will be responsible for ensuring the action plan is carried out. This does not mean that only one person is responsible to do everything. It means that one person is responsible for making sure that everyone involved does what they have agreed. The goals, action plans and people responsible should all be written down in a document identified as your child's transition plan.

Monitoring and Follow up Meetings

Well-prepared transition plans will be of little value unless there is commitment to act upon the plans and to determine whether the goals are being achieved.

Monitoring means making sure that the things which are supposed to be done actually get done. It means staying on top of what is happening so that problems can be solved as they arise. Monitoring provides opportunities to fine tune the action plans in between planning meetings.

Follow up meetings are an important part of monitoring and evaluation. After each transition planning meeting, make sure you set a date for the follow up meeting. Follow up meetings will allow you to bring your full group to:

- Review your vision and goals and to find out what has happened for your child since the last meeting;
- Discuss goals that have been met or goals that may need to be changed;
- Solve problems that may have arisen; and
- Set out the next steps for achieving the goals for your child and getting commitments from people in the group for further action.

The Transition from School to Work in the Community

One of the most important areas for transition planning is employment in the community after high school is finished. There is a lot to think about and plan for in the area of work. Please see ***Chapter 7: Going to Work*** for information and strategies for helping your child make a successful transition to work as an adult.

Transition Planning Checklist

☐ We have started to plan for life after high school with our child no later than grade 9.

☐ Our child's school is committed to transition planning and has identified a key person who will be responsible for coordinating transition planning meetings and discussions on an on-going basis.

☐ Our child is involved in transition planning and is being supported to participate to the best of his or her ability.

☐ With the help or our child's school, we have identified the people or organizations that need to be involved in transition planning with our child and these people have been invited to participate.

☐ We have explored the use of "person centred" planning processes such as PATH and MAPS and have used these tools when needed.

☐ For each year of high school transition goals are established as part of our child's transition plan.

☐ For each year of high school transition activities are identified as part of our child's transition plan and these activities are taking place.

☐ Our child's transition plan is updated regularly and there are discussions taking place about our child's progress in achieving his or her transition goals.

☐ Work experience in the community with regular employers is part of our child's transition plan in grades 11 and 12.

☐ We have explored summer employment opportunities with our child and have encouraged our child to find summer employment.

☐ We are taking steps at home to encourage our child to make his or her own decisions and to become as independent as possible. We are supporting the transition plan with activities at home that will help our child learn new skills.

Worksheet 5

Planning for Transition from High School

My child's goals for life after high school: ______________________________

People who need to be involved in transition planning: ______________________________

Key activities (including school and community activities) that will help my child be ready for adult life: ______________________________

What we have done so far to achieve our child's goals for the future: ______________________________

Additional Resources

Available from Inclusion NB (free to families)

Building Bridges: A Parent Guide on Transition from School to Work, Adult Life and Community Participation for Youth with Disabilities, Second Edition (2002).

Opportunity Link – Module 1 – Transition from School to Employment and Community Participation. Available on-line at www.inclusionnb.ca.

Other Resources

Below are some additional resources on the topic of transition from school to work and adult life. Some of these resources require *Adobe Reader*. If you do not have this program you can obtain it free at www.adobe.com

Person-Centered Planning: A Tool for Transition (Parent Brief).
National Center on Secondary Education and Transition (2004).
Available at www.ncset.org/publications/viewdesc.asp?id=1431.

Planning for Real Life After School: Ways for Families and Teachers to Plan for Students Experiencing Significant Challenge. Inclusion Press (2009).
Available for order at www.inclusion.com.

Resource for the Transition of Students with Exceptionalities from School to Work or Post- Secondary Education and Adult Life. New Brunswick Department of Education (2002). Available at www.gnb.ca/0000/publications/ss/life.pdf.

School to Life Transition Handbook: Five Steps to Successful Planning. Saskatchewan Association for Community Living (1999).
Available at www.sacl.org/file/admin/user_upload/content/sacl/docs/school_to_life_transition_handbook.pdf.

Transition Planning: A Resource Guide. Ontario Ministry of Education (2002).
Available at www.edu.gov.on.ca/eng/general/elemsec/speced/transiti/transition.html.

CHAPTER 6

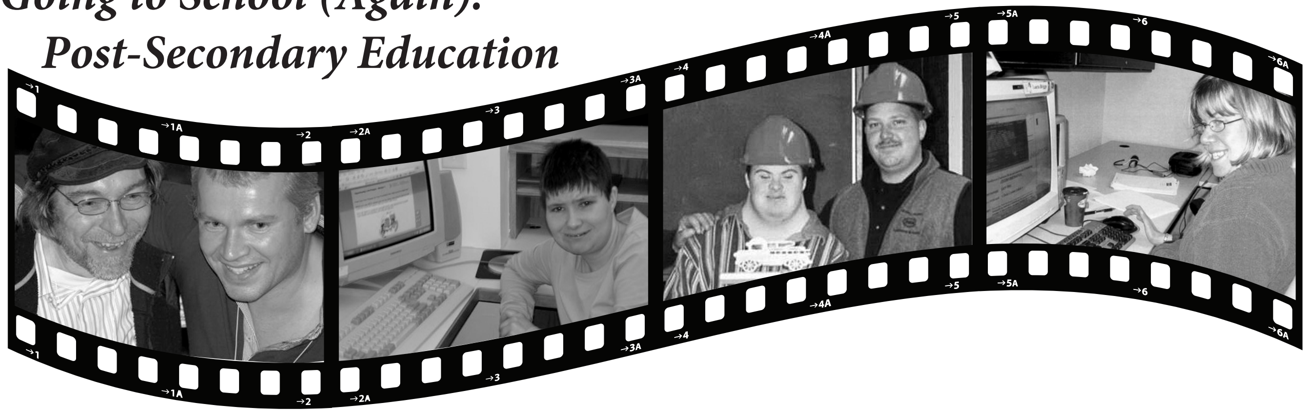
Going to School (Again): Post-Secondary Education

"Christine has learned more than just skills.
She has learned social skills and independence.
Christine has acquired many work skills
and shows much more social confidence.
I see her more able to have an independent life
with some support from an agency.
It seems realistic now."

(Comments from a parent
about her daughter's college experience)

CHAPTER 6

Going to School (Again): Post-Secondary Education



Goal for this Chapter

- ◆ To learn about opportunities for your child to attend community college

What You Will Find in this Chapter

- ◆ Information about:
    - How your child can apply to attend community college
    - How your child can get financial assistance to attend college
    - The benefits of going to college
- ◆ A Checklist for planning for your child to apply to and attend college
- ◆ A List of Additional Resources

Our Journey So Far

- ◆ Until recently, students with disabilities (particularly intellectual disabilities) were not supported to attend college after they finished high school.
- ◆ New Brunswick’s community colleges have become much more inclusive over the past 10 years. The government has a formal policy that supports the inclusion of students with disabilities.
- ◆ For New Brunswick’s community colleges, a process has been established to assist people with intellectual or significant learning disabilities to apply even if they do not meet the regular criteria for getting into college.

Introduction

Many young people leave high school with plans to attend university or community college in order to further their education and pursue a career goal. Increasingly, people are realizing that finding a job requires skills in specific occupations or careers.   In recent years people with all types of disabilities have been given greater opportunities to attend post-secondary education institutions to pursue their goals for higher education.

This chapter will review options for post-secondary education for your child with a focus on community college. This is not to deny that there are also opportunities within universities. Many universities today are more willing and able to support students with disabilities in their programs. If your child is thinking about university you may want to check out the "track record" for including students with a disability before your child makes a selection about which university to attend. Also, the information in this chapter on financial assistance and supports for students with a disability will apply to universities as well as community college.

Accessing New Brunswick Community College Programs

Recently, the New Brunswick Community College/Collège communautaire du Nouveau-Brunswick (NBCC/CCNB) has increased its efforts to provide post-secondary education and job training to people with disabilities, including people who have an intellectual disability. This includes people who would not meet the regular college entrance criteria because they graduated from high school on a modified education plan. This has happened because governments and, to some extent, businesses are recognizing that people with disabilities are a largely untapped source of workers for many types of occupations.

What does NBCC/CCNB offer?

NBCC/CCNB offers a number of job training programs throughout its eleven provincial campuses. Each college campus offers programs in a number of trades or occupations. Some programs are offered in more than one college campus, but usually individual colleges have a limited number of programs that may not be offered by other colleges. Please review the most recent NBCC/CCNB Calendar to review the programs that are offered at each individual college. You can get a copy of the Calendar at your local community college.

How can people with a disability apply to attend community college?

Students who wish to attend a French community college (CCNB) can apply through the ***Service de l'admission collégiale (SAC).*** If a student does not meet the regular criteria and will likely need a modified college program, he or she He or she can complete the questionnaire that comes with the fee application form. This process is primarily for students with an intellectual or significant learning disability. The college admission service will determine if a student is eligible and refer the student to Inclusion NB for support.

Any person who wishes to attend an ***English*** community college (NBCC) must apply through the College Admissions Service (CAS). There are two ways to apply:

1. People who meet the regular entrance criteria for community college will use the regular admission process and application.
2. People who do not meet the regular entrance requirements for community college (because they had a modified high school program) will use the ***Special Admissions Process***. This process is primarily for students with an intellectual or significant learning disability. Students must complete the regular application form on-line or by mail (at a cost of $25). Once it is received by CAS the student's high school transcript will be reviewed to identify if the student had a modified school program. If so, the application will be referred to Special Admissions.

What are the criteria for selection of students with a disability who do not meet the regular entrance criteria for community college?

People with a disability who followed a modified program at high school will still need to meet some selection criteria. These include the following:

- The student has completed high school (or is in the final year of high school)
- The student has followed a modified program in high school
- The student demonstrates a strong desire to attend community college
- The student has identified a specific career goal that matches the community college program that he or she wishes to take
- With support from the student's family and others, the student is likely to complete his or her chosen college program

For people considering community college, it is suggested that they participate in the "Test Drive" Program. This provides individuals a full day experience on campus in the desired programs.

How will students be selected?

There are a limited number of seats available for students with a disability who do not meet the regular entrance criteria and who will take a modified college program. When a student applies, he or she will be invited to participate in an *interview* that will take place at the community college. This interview will help to determine if the student meets the selection criteria listed above. The interview will also help to determine if there is a "good fit" between the student and the program that he or she has selected. The interview will also help to determine the student's needs for accommodations and support if he or she is selected to attend.

Given the limit on the number of seats available for students taking modified programs, some students may not be selected to attend community college. Students who are not selected can re-apply for another school year.

How will a modified college program be possible?

Prior to the beginning of the college school year, an *Individual Learning Plan* will be developed for the student. This plan will set out the specific learning goals for the student within their identified program. This may involve the student taking some (but not all) of the courses within the program. In addition, the course learning objectives may be modified for the student so that specific skills can be developed. Students will be evaluated on the basis of the skills that they learn and the goals that have been achieved (or partially achieved) as identified in the Individual Learning Plan.

What will students receive if they complete their college program?

Students who complete a regular college program will receive a diploma in the area of their studies. Students who complete a modified college program will receive a *Certificate of Participation* from NBCC/CCNB. In addition, students will receive a "Skills Profile" that identifies the skills that have been learned within the program area selected by the student.

How will students with disabilities be supported to achieve their college goals?

While attending community college, students with disabilities will be supported in a number of ways:

- Students who are on a modified program will have an *Individual Learning Plan* developed that will match their abilities and interests. This plan will include reasonable goals for the student that will be monitored during the college school year.
- Students with an intellectual disability will be managed by a Inclusion NB facilitator. The facilitator will be responsible for assisting students and monitoring (in collaboration with college instructors) a student's Individual Learning Plan.
- Students may also apply to receive extra assistance from tutors. Tutors can provide one-on-one help to students to review specific course material and to assist with the learning of information and skills.
- Students may also receive a number of "accommodations" that will help them have a positive college experience. Accommodations may include note-takers, mentors, extra time for or different methods of testing, etc. Also, all college campuses are equipped with up to date technology to assist students with disabilities in a variety of ways.

Unlike high school, community college will not provide a "EA" (educational assistant) to attend classes with the student. Students will be expected to attend classes on their own but will be supported as required in the ways outlined above.

Paying for Post-Secondary Education

Post-secondary education can be expensive. In terms of tuition cost a one or two year community college program will cost significantly less than a four year university degree program. There are a number of ways to pay for a post-secondary education.

Student Loans

Student loans can help with the cost of tuition, books and materials, and living expenses while attending college or university. There are some restrictions on who may be eligible for a student loan based on family income. To find out more about student loans contact:

Department of Post-Secondary Education, Training and Labour
Student Financial Services
77 Westmorland Street, Suite 500
P.O. Box 6000
Fredericton, NB E3B 6Z3

Toll Fee: 1-800-667-5626
Fax: (506) 444-4333
Website: www.studentaid.gnb.ca

If your child is receiving income support benefits (social assistance) and is eligible for a student loan, he or she must use student aid for education expenses. If he or she is also single, student aid must also be used for living expenses (for example, food and shelter). This will mean that your child's monthly cheque will be reduced or terminated while he or she is receiving a student loan to attend a university or college program.

IMPORTANT NOTE:
If your child is taking a modified program at community college or university, and will NOT receive a regular degree or diploma, he or she will not be eligible to receive a student loan. If this is the case, other financial support (in the form of grant) may be available through the provincial TESS program to cover the cost of tuition, books and materials. Also, if your child is receiving income support benefits, he or she will be able to keep receiving the monthly income support cheque.

Canada Access Grant for Students with Permanent Disabilities

These federal grants are available to students with disabilities who are eligible to receive a student loan. Students may be eligible to receive up to $2000 per loan year to help with the costs of tuition, books, accommodation and other education related expenses. To apply, your child must first apply for a student loan. Students who are eligible will have to have a permanent disability, have a financial need, and be eligible to receive student loans. If your child is eligible for a Canada Access Grant, the first $2000 of assessed financial need (for a student loan) will be paid for by way of the Grant.

Financial Assistance Available Through the Provincial Income Support (Social Assistance) Program

If your child receives income support benefits (see Chapter 9 for further information) and has developed a plan to go back to school, he or she may be eligible to receive financial help for items such as clothing needed for training, school supplies, special equipment requested by the training facility, student fees, textbooks, or transportation. To investigate financial assistance through the income support system, talk with your child's income support case manager.

Paying for Disability Support Costs for Attending Post-Secondary Education

There are a number of possible avenues to access disability supports for attending a post-secondary education program.

Canada Study Grants

These grants are available to students who are eligible to receive a student loan. Students with disabilities may be eligible to receive up to $8000 a year from the federal government to cover "exceptional education related costs associated with certain permanent disabilities." To apply, your child must first apply to the provincial student financial services office (see information table) for a full or part time student loan. Your child must then submit a separate application form for the Canada Study Grant.

Training and Employment Support Services (TESS) Program

This program is operated by the Department of Post-Secondary Education, Training and Labour. This Department has offices in every region of New Brunswick. It provides funding for people with disabilities for a variety of items, including support necessary for a person to participate in a post-secondary education or training program. This may include funding for a tutor, special equipment, etc. In circumstances where a student is not eligible for a student loan because he or she is on a modified program, TESS will cover the cost of tuition, books and materials. See Chapter 9 for further information on the TESS program.

Disability Support Program

The provincial Disability Support Program may also be available to provide funding for disability supports that may be required while your child is attending a post-secondary program. These would have to be supports that are not covered under another program such as TESS. See Chapter 9 for more information on the Disability Support Program.

Benefits of Considering Post-Secondary Education for Your Child

There are a number of potential benefits of considering post-secondary education as an option for your child. Post-secondary education can:

- Provide access to valuable job training;
- Expand opportunities for your child to gain more independence;
- Significantly increase employment opportunities for your child;
- Increase your child's connections to people in your community;
- Increase your child's confidence and self esteem.

> *Participating in challenging and interesting experiences*
> *and being accepted by peers*
> *enhances self-esteem and confidence*
> *both at school and in the community.*
> *Students now "know what they want to do*
> *and say what they want to do" and*
> *"achieve things their parents and others never thought possible".*
> *They have shared experiences with others*
> *that provide connections*
> *that would not otherwise be possible.*
>
> *– (Wienkauf, 2002)*

Checklist for Planning for Your Child to Apply to and Attend College

- ☐ My child has completed high school (or is in the final year of high school)
- ☐ We have explored the use of “person centred” planning processes such as PATH and MAPS and have used these tools if necessary
- ☐ I have discussed post-secondary education with my child
- ☐ We have discussed my child’s strengths and abilities and what he or she is interested in studying
- ☐ We have discussed what my child is not interested in studying
- ☐ We have explored the courses and programs offered at NBCC/CCNB
- ☐ My child has identified an employment goal and this goal matches the community college program that he or she wishes to take
- ☐ We have thought about what supports my child would need while attending college
- ☐ I have the information concerning my child’s modified education program while in high school and have taken this into account
- ☐ We have noted the deadlines to apply for college and have submitted the application prior to the deadline
- ☐ We have explored possible funding options
- ☐ We have explored travel and arrangements for getting to/from college
- ☐ We have explored possible living arrangements if moving is necessary to attend a program offered in another area
- ☐ My child has practiced interview skills
- ☐ We have toured the college and met with appropriate personnel

Additional Resources

Building Bridges: Inclusive Post-Secondary Education for People with Intellectual Disabilities, The Roeher Institute (1996).

Think College! Postsecondary Education Options for Students with Intellectual Disabilities, Meg Grigal & Debra Hart, Brookes Publishing (2010).
Available to order from www.brookespublishing.com.

The Power to Spring Up: Postsecondary Education Opportunities for Students with Significant Disabilities, Diana M. Katovitch (2009).
Available to order from www.amazon.ca

Impact: Feature Issue on Postsecondary Education and Students with Intellectual, Developmental and Other Disabilities (2010/2011)
Available online at https://ici.umn.edu/products../impact/233/default.html

Taking the JOURNEY

An Information and Advocacy Guide
for Families Supporting a Child with a Disability

CHAPTER 7

Going to Work

> *"Having a job*
> *is good for my son's self-confidence.*
> *It gave him independence*
> *and a chance to*
> *explore things he can do."*

InclusionNB

CHAPTER 7

Going to Work

Goal for this Chapter

- ◆ To learn about opportunities for your child to work in the community

What You will Find in this Chapter

- ◆ Information about:
  - Why employment is an important aspect of your child's life
  - The steps that can be taken to prepare your child while he or she is still in school
  - Strategies that families can use to help their child think about work possibilities
  - Programs and services that may be available to help your child find and keep employment
- ◆ A Checklist for planning for your child to go to work
- ◆ **Worksheet 6** – Planning for Employment
- ◆ A List of Additional Resources

Our Journey So Far

- ◆ There are many examples of people with disabilities who are successfully employed.
- ◆ For people with an intellectual disability the employment situation is bleaker.
- ◆ Access to long term on-the-job support for people who require it is limited. Disability organizations in New Brunswick are working to convince government that improvements in employment support programs must be made.

Introduction

What does work bring to our lives? Work is obviously important for the money we earn so that we can buy the things we need to live. If we earn enough money we may be able to do more than look after our basic needs – such as take a vacation, save for the things we would like to own, enjoy entertainment, and save for our futures (including retirement). But while work is often thought about in terms of "earning a living" it is actually much more than that. Work can bring many other things to our lives, such as:

- Giving us a sense of self worth. When we enjoy our work and feel we are productive by contributing something to society, we gain a sense of pride in ourselves.
- Providing us with a sense of identity. Think of the first questions that someone will ask you when you meet them for the first time. One is what kind of work do you do? Through our work we are known by what we do: teacher, cleaner, store clerk, office worker, and so on.
- Connecting us with other people in our community. Our workplaces are where we meet and get to know people. We will have co-workers and often contact with others who use the business we are working for. For many of us, our contact with other people is what makes work enjoyable.

Breaking Down Barriers to Employment for People with Disabilities

People with disabilities still face significant barriers to becoming employed. There are several reasons for this – including employer beliefs and attitudes, poor preparation and planning for employment during high school, lack of access to job training, and programs and policies that limit the support that people can get while on the job (particularly for people who have more significant disabilities).

Yet the employment prospects for people with disabilities have improved over the years. More people are now employed in a variety of occupations and efforts by government and community organizations to promote workforce participation are beginning to have an impact.

Going forward, we know that currently there are trends that strongly suggest that as our workforce ages and more people retire, we will be facing labour shortages in a number of areas (this is already happening in some industries). These trends and challenges provide for unprecedented opportunities for people with disabilities and other segments of the labour force that have been traditionally excluded. Already, governments and businesses are placing significant emphasis on importing labour and, to a lesser degree, encouraging older workers to remain in the labour force.

We are now at a point in our history where we can reasonably and strongly argue that there is an ‘economic imperative’ to including people with disabilities in the labour force. The potential is to achieve employment parity – something that was not even thinkable 5 to 10 years ago.

Thinking About Work if Your Child is Still in School

The school years are an important time for preparing all young people for work. They may be more important for youth with disabilities who may not go onto college or university after they graduate. There are a number of actions that should be taking place to prepare your child for work.

Good Planning

Employment should be a key part of transition planning that was discussed in detail in Chapter 5. Inclusion NB has a Transition to Work Program that assists students grades 10 to 12 with an intellectual disability to plan and prepare for work after they leave school. Contact Inclusion NB to check if this program is available in your area.

Career Education and Identifying Your Child’s Employment Interests

Career education simply means learning about work, different types of jobs and the skills necessary to be a part of the everyday work force. Career education involves learning about different occupations, various roles of workers, the importance of work and having a good attitude toward work. Career education will also involve your child learning more about him or herself and about his or her interests in future work.

Career education should begin during the elementary and middle school years. If this has not happened for your child by the time you start planning, you will need to seriously think about providing opportunities for career education as soon as possible.

Career education is also about starting to match your child's interest about potential careers or jobs. Use the questions below to help your child identify his or her interests with potential work:

- What jobs do you think you might enjoy doing?
- What jobs have you held in the past?
- Where do your parents work and what do they do in their jobs?
- What do your brothers, sisters or other relatives do in their jobs?
- What do you like to do in your spare time?
- What subjects do you like best in school?
- What subject do you like least in school?
- What subjects would you like to try that you haven't taken yet?
- What responsibilities do you have at home? What responsibilities do you like best and least?
- What accomplishments or achievements have you had outside of school?

Work Experience and Exploration

Work experience means having opportunities to actually experience different kinds of jobs and one's own role as an employee. Sometimes, work experiences are simulated within your child's school. Most often, however, work experience should and will mean that your child actually performs a job at a regular workplace in your community. Work experiences can either be for a very short time or last several months, and are unpaid when they take place during school hours. In high school, work experience is usually called Cooperative Education or a "Co-op placement". For some people, a Co-op placement can take place for two years if it is believed that a student will benefit from more work experience. It must be noted, however, that Co-op placements do not necessarily lead to meaningful employment after high school.

Sometimes, work experiences are simulated within your child's school. Most often, however, work experience should and will mean that your child actually performs a job at a regular workplace in your community.

Work experience and exploration should build on what your child will have learned about work through career awareness activities. Work experience and exploration is important because it will:

- Help your child identify his or her interests;
- Allow your child to explore a range of different jobs or occupations through hands on experience;

- Allow your child to become familiar with a variety of work settings; and
- Assist your child in developing skills that may be required for employment.

Work experience and exploration activities can begin as early as middle school. For most students, work experience and exploration will happen during high school. For work experience and exploration activities to be useful keep the following in mind:

- Activities should provide hands on experience at worksites within your community (with the provision of whatever help your child may require).
- Activities should be linked to the transition goals you and your child have set.
- Activities should be decided on the basis of your child's interests and abilities.
- Activities should start with short-term work experience in a variety of regular workplaces and work toward longer-term experiences.

Making decisions about the best possible work experience and exploration activities should be part of transition planning. Any specific activities that are identified should become part of the action plan for your child.

Evaluating Work Experiences

You and your child's transition planning group should be prepared to evaluate the quality of the work experience for your child. This means that people have to take the time to determine the effectiveness of the work experience. Here are some general questions you may wish to consider:

- Was the work experience desired by your child and supported by yourself and the transition-planning group?
- Has the work experience been consistent with the goals set out as part of your child's transition plan?
- If your child required help on the job site, was it adequately provided?
- How much responsibility has the employer or your child's co-workers taken to provide this support?
- Has the workplace generally been a positive experience for your child? If so, why? If not, why not?
- Has the work experience provided your child an opportunity to practice skills he or she has learned while in school?
- Has the work experience helped your child to develop new social and work related skills and to develop a positive attitude towards work?

Work Preparation Activities

School can also provide a number of other activities that will help your child become better prepared for work. These can be built into your child's transition plan or SEP. In some areas, schools are now involving community employment agencies to help with these activities for high school students who have a disability. Work preparation activities can involve:

- Developing resumes
- Practicing for job interviews (using community employers)
- Learning about the expectations of employers
- Learning about workplace dress codes
- Learning to use a public transit system
- Opportunities to do "job shadowing" (going into a workplace to observe different types of jobs)
- Learning CPR

Summer and Part-time Employment

A summer job can provide opportunities to have a real work experience – one in which your child is paid for the work he or she does. This is also the case with a part time job that your child has during the high school years. Experience has shown that a paid work experience before the completion of high school is an important step in preparing youth with disabilities for employment after they graduate.

Experience has shown that a paid work experience before the completion of high school is an important step in preparing youth with disabilities for employment after they graduate.

A provincial government program that provides job support is now available to students 16 years of age or older for summer employment (see the information on the TESS program later in this chapter). Also, community employment agencies serving people with disabilities are now able to work with high school students to assist them with the transition to employment after high school. This includes assisting students with summer and part time employment (see the information on EAS agencies under Employment Support Programs later in this chapter).

Helping Your Child Think About Work Possibilities

Inclusion NB has developed an Employment Module in an on-line resource (called Opportunity Link) that is designed for people who have a disability who are interested in finding a job. It is a voice and print based program that reviews a number of aspects of employment and looking for a job, including:

- Why work is important
- Learning about different kinds of Jobs
- Finding the right job
- Going for a job interview
- Being a good employee

This program is designed for people with disabilities to use on their own or with some help, if necessary. It prompts people to think about various aspects of looking for work such as identifying their skills and interests in different types of work. Families are encouraged to use this program with their own child or to ask someone else (such as an employment counsellor or someone from your child's school) to assist your child to use the program.

You can find the module by going to Inclusion NB website: www.inclusionnb.ca. Click on "Opportunity Link" on the right hand side of the home page and go to Module 2 – plain language version with audio.

**Your advocacy will be greatly strengthened if you have a good understanding of the opportunities and services that exist in your community.
In some communities, help may be limited and you may need to assume a more direct role to advocate to your child's employment opportunities.**

Strategies for Developing Work Opportunities for Your Child

As families, you can play an important role in assisting your child to find a job (or other meaningful activities) in the community. As an advocate, your expectations for your child's opportunities for employment will be important. There may be a number of challenges that you will have to deal with, including:

- Other people's attitudes and beliefs that your child cannot work.
- Finding the right match between your child's interests and skills and jobs available in the community.
- Finding the right supports or services that your child may require to find and keep a job, or to do other things in the community that will make his or her life meaningful.

There are a number of actions that you may be able to take to advocate for your child's right to work in the community. One of the key things to remember is that there may be organizations or other people in your community who can assist your child with these issues. For example, there are government programs that specifically assist people with disabilities to find employment (see the information on EAS agencies found under Employment Support Programs in this chapter).

Your advocacy will be greatly strengthened if you have a good understanding of the opportunities and services that exist in your community. In some communities, help may be limited and you may need to assume a more direct role to advocate to your child's employment opportunities. Below are a few ideas and suggestions about the roles that families, community organizations and others may play.

Advocacy Roles for Families

When families are supportive of their child's goals for work, success is more likely to occur. As you would for any of your children, you will likely want to take whatever steps possible to help your child with a disability obtain and keep a job. Here a few practical suggestions you may consider:

- **Use your own contacts with family members and friends.**
  Let them know that your son or daughter is looking for work and ask them to talk with their friends about possible job opportunities.
- **Encourage your son or daughter to think about work and work opportunities.**
  Talk with him or her early about what work means and what he or she might like to do. Start with encouraging your child to work in part-time or summer jobs as early as possible.
- **If necessary, meet with employers who are willing to give your son or daughter an opportunity to work.**
  This may involve you planning schedules or addressing problems that may occur. For example, if particular routines or habits are important, employers should know about these and how to accommodate them.
- **If necessary help your son or daughter get to and from work.**
  You will want your child to do this for him or herself but this may not always be practical or possible.
- **Get in touch with local agencies that may be able to help your child find and keep a job.**
  You may have to put pressure on an agency to help in ways you feel are important. Be respectful, but also be determined.

Developing a "Customized" Employment Opportunity for Your Child

Some people with disabilities may need to have a job that is designed specifically around their skills and needs. "Customized" employment opportunities are those that match a person's skills to jobs but usually involve a set of tasks that differ from standard job descriptions. A customized job is one that is designed to fit the person looking for work and may involve:

- Specifically identified job duties and responsibilities;
- Work expectations that are individualized; and
- Flexibility with hours and with where work can be performed.

Customized employment opportunities are often developed through a three step process that involves:

1. Helping people explore their employment options;
2. Developing an employment plan for a person that builds on his or her strengths and interests; and
3. Negotiating employment opportunities with employers that have specific labour needs to be addressed.

In many communities, employment specialists are available to help develop these opportunities. They can help match people with disabilities with employers by using a variety of work customization strategies. See the information found later in this chapter on Employment Assistance Services (EAS).

Example of Customized Employment

A local discount department store was having difficulty with its shoe department - shoes were not getting on the shelves on time and the shelves were constantly disorganized and messy. Shoe sales were poor. The store manager realized it was an area that needed improvement, but other employees were either too busy or not interested in the tasks associated with the shoe section.

A local employment agency introduced the store manager to Michelle, a young woman with an intellectual disability who wanted to work in a retail store. While Michelle could not do all the tasks associated with working in retail sales, she was very capable of stocking the shoe shelves and keeping them maintained. Moreover, it was a job she enjoyed. The employer agreed to hire Michelle to do this customized part-time job that matched her skills and interests.

Shortly after Michelle was hired, shoe sales increased.

Employment Support Programs

There are a number of government funded programs that may help your child prepare for employment and find and keep work. Some of these programs have restrictions and further work needs to be done to improve the support available to people with disabilities who want to be gainfully employed.

Training and Employment Support Services (TESS)

This program is operated by the Department of Post-Secondary Education Training and Labour. This Department has offices in every region of New Brunswick. It provides funding for people with disabilities for a variety of items, including:

- **Employment training** – includes tuition, books, tutors, living expenses, and training supplies (some of these items are only covered to the extent of making them usable be people who have a disability – for example, converting text to Braille).
- **Employment support** – includes job search and coaching, counselling, entrepreneurial planning, and work-site modifications.
- **Adaptive and assistive** – includes technologies, tools and equipment, ergonomic aids, specialized transportation, and assessment.
- **Job crisis** – includes various job crisis intervention services.

To be eligible for this program an individual must be 16 or over and have a permanent or long term physical, intellectual, psychiatric, or cognitive disability. They must also have an employment action plan developed. A recent change has seen the program expand to include youth with disabilities who are 16 or over and still attending high school.

The funding available under the TESS program is time limited. For example, a person who requires on the job support (for example, a job coach) can usually receive up to 1200 hours of support that can be used over a 52-week period. There is no ability to have on-going job support funded under this program should this be required.

Employment Assistance Services (EAS)

This program provides funding to non-profit community agencies who assist people with disabilities (and sometimes other people who face barriers to finding employment) in a number of ways. These agencies provide a variety of services including:

- One on one employment counselling
- Job search assistance
- Resume writing

- Assessments for work accommodations
- Information and support to employers who hire people with a disability

There are several EAS agencies across New Brunswick. A list of agencies and their contact information can be found in the Family Support section of Inclusion NB website, www.inclusionnb.ca.

Work Ability Wage Subsidy Program

This program (also operated by the Department of Post-Secondary Education, Training and Labour) provides a short term wage subsidy to employers to allow people to explore employment options, gain work experience and/or develop work skills. Eligible individuals are people who have been out of an education institution for at least six months and who have developed an employment action plan. (This program is not available to students who are seeking a summer work experience). A wage subsidy can be paid for up to 40 hours of work per week.

An employer must agree to participate in the wage subsidy program. Employers are responsible for paying worker's compensation premiums and must agree to complete an employee evaluation.

ADAPT Program

This program is operated by the Department of Social Development. ADAPT stands for Adult Developmental Activities, Programs and Training. This program is provided through 38 community agencies which are funded by the Department of Social Development. Each agency is provided an annual grant for a specific number of "seats", which varies from agency to agency (from as low as 8 to as high as 127).

The ADAPT program is technically not an employment program but some agencies are supporting people to work in the community. Under the ADAPT standards established by government, agencies can provide day services in a "centre or a community based setting". Many agencies provide services in sheltered centres where people spend part or all of their days. These are usually program based activities in which people are engaged in routines in groups of people who have a disability. The routines vary from learning activities, recreation activities, and "work" related activities in which a product is often produced or a service provided. Some agencies operate "social enterprises" through which they sell their products (or services) in the local community. Some agencies also pay their participants a small stipend for the tasks that they perform (although a small number of people who are seen as being more productive are paid minimum wage).

Some agencies support people with more individualized community activities such as work, volunteer or recreation pursuits. These agencies have evolved from sheltered based centres or are in the process or attempting to support the people they serve to be more involved in the community in activities that they choose.

If you are interested in the services of an ADAPT agency to assist your child with employment in the community, you may need to encourage the agency to offer employment services. Under the Disability Support Program (see Chapter 9), employment supports can be provided by ADAPT agencies. This means that your child may qualify for funding for employment supports (including on-the-job support) that are provided by an ADAPT agency. Unlike the TESS program reviewed earlier, these supports may be available for a longer period.

Supports for Pre-Employment Activities

Adults with disabilities who are 19 years of age or over may also be eligible for funding under the Disability Support Program for certain pre-employment supports and activities that are designed to help people become better prepared for employment. Supports and activities may include:

- *Job/career exploration assistance* (for example, learning about different types of work, job shadowing experiences, volunteer work experiences, etc.)
- *Transition to independence skills assistance* (for example, using public transportation, decision making, etc.)
- *Social skills assistance* (for example, learning about social boundaries and healthy relationships, personal hygiene, manners, grooming and appropriate dress for work, etc.)
- *CPR training*

Information about applying for services under the Disability Support Program can be found in Chapter 9.

Literacy Programs

The Community Adult Learning Program (CALP) provides adults with basic skills and knowledge to help them strengthen their literacy level. CALP programs are available in all regions of New Brunswick and further information can be found on-line at www.cnbb.nb.ca. As this is a general program available to any adult, there may be some issues with people with disabilities being able to access and use this program due to a lack of support and accommodations. Families who want to pursue this program on behalf of their adult child may need to advocate for inclusion and supports and accommodations.

What to Expect From an Employment Program

Employment programs and services for people with disabilities have been around for many years. Some agencies have learned what it takes to support people in real paid employment. When your child is considering an employment program, or is already using a program, there are some things that you may want to watch for to find out if he or she is being well supported. A list of "quality indicators" and examples of those indicators that you may want to think about can be found here. This is adapted from a resource from a group called T-Tap (Training and Technical Assistance for Providers) and can be found on the internet at www.t-tap.org/strategies/se/qualityindicators.html

Quality Indicator	Example of Things that Should be Happening for Indicator
Meaningful Competitive Employment in Integrated Work Settings	*Employee with a disability is hired, supervised, and paid directly by business where job setting is located; receives wages/benefits at the same level as non-disabled co-workers.*
Informed Choice, Control, and Satisfaction	*Employee selects own service provider and job coach; selects job and work conditions; is satisfied with job and supports.*
Employment Supports	*Program is skilled in identifying and developing workplace support options.*
Employment of Individuals with Truly Significant Disabilities	*Program is serving individuals whose disability and barriers to employment are truly reflective of people who need ongoing supports to keep their job.*
Amount of Hours Worked Weekly	*Program is achieving employment outcomes at 20-30 or more hours per week consistently. Individuals are satisfied with their hours of employment.*
Number of Persons from Program Working Regularly	*Program currently has a majority of its participants working in competitive employment.*
Well Coordinated Job Retention System	*Program maintains regular contact with its employed customers to monitor job stability and can respond effectively to job retention support needs.*
Employment Outcome Monitoring and Tracking System	*Program maintains an information system that provides information readily to its customers on employment status, longevity, wages, benefits, hours of employment, and jobs.*
Maximizing Integration and Community Participation	*Employees with a disability work in jobs where the work environment facilitates physical and social interaction with co-workers.*
Employer Satisfaction	*Program viewed as an employment service agency rather than a human service provider. Employers are seen as a customer of the service, and the program designs policies and procedures that are responsive to the business community.*

Checklist for Planning for Work

- ☐ I have talked to my son or daughter about work and the kind of work he/she would like to do
- ☐ We have discussed what my child is not interested in doing
- ☐ We have discussed on-the-job fears, triggers, annoyances that may have to be acknowledged in the workplace
- ☐ We have explored if he/she is interested in volunteer work
- ☐ My child has been part of a school co-op program
- ☐ My child has a resume
- ☐ My child has a Social Insurance Number
- ☐ My child has appropriate work clothes
- ☐ We have had a conversation about work with his/her case manager
- ☐ We have explored how my child's income benefits will be affected by his/her wages
- ☐ We have identified my child's abilities and strengths and thought about possible job opportunities
- ☐ I have the information concerning my child's school co-op experience and have taken this into account
- ☐ We have had a discussion on workplace boundaries and relationships
- ☐ We have explored job readiness programs (if required)
- ☐ My child has practiced interview skills
- ☐ We have found an employment agency in our region/we know that there is no employment agency in our region
- ☐ We have used our networks to explore possible work opportunities
- ☐ We have determined whether or not my child would need a support person
- ☐ We have got referrals to appropriate agencies for on the job employment supports
- ☐ If necessary, we have discussed job customization with his/her employment agencies/ employers (for example, if there is a part of a job that my child could do)
- ☐ We have informed his/her employer of their specific workplace needs
- ☐ We have secured transportation to/from work
- ☐ We have role played his/her work day routine

Worksheet 6

Planning for Employment

1. Identify your child's skills and qualities.
    a) Identify skills demonstrated at home, school and community (including previous work or volunteer experiences.)

    b) Identify important personal qualities (for example, good around people, caring, humorous, etc.).

    c) Identify skills that may need improvement

2. Identify your child's work related interests and likes/dislikes (for example, working in a store, working outside, working with people, etc.).

3. Identify possible jobs that might match your child's skills and interests.

4. Identify people, agencies, and employers who may be available to help your child find and keep a job. ____

____

____

5. Identify the support needed (if any) by your child to:

   a) Find a job ____

   ____

   ____

   b) Learn a job ____

   ____

   ____

   c) Keep a job ____

   ____

   ____

Additional Resources

Available from Inclusion NB (free to families)

Employ Ability: An Employer's Guide to Hiring and Training Workers with an Intellectual Disability

Getting the Job Done: Fostering Business Involvement and Leadership in Providing Employment Opportunities for People with a Disability (2008)

Work Customization: Creating Employment Opportunities For People with a Disability in Today's Workforce (2008)

Other Resources

Job Accommodation Network (JAN). Available at askjan.org

Recruiting and Retaining Persons with Disabilities in British Columbia: An Employer Handbook, Work Able Solutions. Available at
www.eia.gov.bc.ca/epwd/docs/handbook.pdf

Tapping the Talents of People with Disabilities, The Conference Board of Canada. Available at www.conferenceboard.ca (go into the e-Library – you will need to input your information to access this- then search by title).

Taking the JOURNEY

An Information and Advocacy Guide
for Families Supporting a Child with a Disability

CHAPTER 8

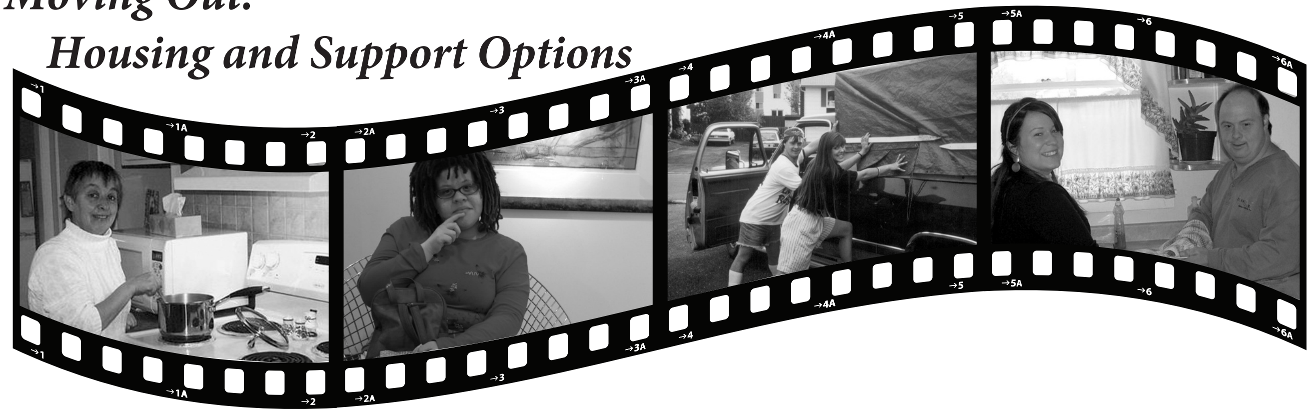
Moving Out:
Housing and Support Options

"It is getting close to time to be
talking more to my son about his own place.
I am excited and nervous.
For me it is about putting arrangements
in place, letting go and
stepping back…
easy to say."

InclusionNB

CHAPTER 8

Moving Out: Housing and Support Options



Goal for this Chapter

- To learn about different housing and support options for your child.

What You will Find in this Chapter

- Information about:
    - The importance of home and what it provides
    - An overview of a variety of housing and support options
    - Issues to think about when planning for your child to live in his or her own home
    - Housing programs
- A Checklist for Planning for Your Child to Leave the Family Home
- **Worksheet 7** – Planning for a Home and Support
- A List of Additional Resources

Our Journey So Far

- Many years ago people with disabilities were routinely placed in large institutions. By the 1980s many institutions were downsized or closed. They were replaced with community based group living settings often referred to as “group homes”.
- Many group living arrangements still exist. In New Brunswick, most group living arrangements are operated by for-profit “Special Care Home” operators.
- Today, individualized funding and the new Disability Support Program provides greater opportunities for people with disabilities to live in their own homes and to choose with whom they live.

Introduction

Planning for a future home for your child is one of the most important aspects of planning for the time that you, as parents, will not be the main support providers in your adult child's life. Over the years, your son or daughter has known the comfort and security that comes from living in your family home. The family home has provided a sense of belonging and security that your son or daughter will want in any future home that they may have.

Planning for a future home for your child is one of the most important aspects of planning for the time that you, as parents, will not be the main support providers in your adult child's life.

Before reviewing some possible future home options, it is important to think more carefully about what home provides to all of us. For most of us, home is a place:

- Where people exercise control over their daily routines, including who enters to visit and stay;
- That is private and which matches each person's chosen lifestyle;
- Where people who share a home live in some kind of chosen and mutual relationship with each other;
- Where people have a connection to their communities;
- That provides some type of legal right to belong (for example, as a home owner or a tenant in a leased apartment).

When thinking about a future home for your child, try to keep these important points in mind. The other key point for your adult child is support and assistance that he or she may need to be able to live in his or her home. The type and amount of support will vary from person to person.

Thinking about your child moving out is a big deal. It is often the issue that is the most emotional for families and that evokes a lot of fears. When is the right time to have your child move out? What needs to happen to make this as positive and smooth as possible for everyone? How can you prepare your child for this well in advance of it happening? These are all questions that you will need to think about at some point, and the sooner you do so, the better.

Family Tip:

Living with and supporting your child can have many rewards and challenges. There may be a time when either you or your child decides that it is the right time to live apart.

What are Some Possible Options for a Future Home?

There are a number of possible options to consider. Below is a brief description of these options. Later in this part, we explore in more detail the option of planning for your son or daughter to have a home of his or her own.

- **Living with Another Family Member.**
  Some families will consider having your son or daughter with a disability move into the home of another family member (such as a brother or sister). This option can provide a home in a place that is usually familiar to your son or daughter. There are, however, a number of questions to consider before choosing this option:
    - Is this where your son or daughter wants to live?
    - Is the other family member committed for the long term? Is there a backup plan if the living arrangement does not work out?
    - Is the location of the family member's home suitable? Is there space available for another person to live comfortably?
    - Will there be extra cost to the family member? How will these costs be covered?
    - Will your son or daughter with a disability have opportunities to be involved in his or her community?
    - Will services be required (for example, relief support, support during the day, etc.)?
    - Is the family member, his or her spouse and children, fully aware of the wishes and needs of your son or daughter with a disability?
- **Living with an "Alternate Family".**
  Under this option, your son or daughter would go and live with another family. This option is part of a government program called an Alternate Family Living Arrangement (AFLA). The provincial government provides funding for alternate families who provide a home and support to people with a disability. In these arrangements, an alternate family is not permitted to have more than two individuals with disabilities living in their home. This option can provide your son or daughter with a home environment as he or she would live in a typical home in a neighbourhood or community. The questions listed above for living with another family member are also relevant to this option.
- **Living in a Residential Facility.**
  Residential facilities are government licensed buildings that provide housing and support to groups of people with disabilities who are usually unrelated. In New Brunswick, there are three main types of facilities for adults: group homes (or community residences) that are operated by non-profit organizations; special care homes that are for-profit operations, and nursing homes. These facilities are subject to rules that are established by the government of New Brunswick. The most widely used facilities are the for-profit special care homes. If you are considering a residential facility as an option, it is

important that you (and your son or daughter with a disability) find out as much about the facility as possible. There are also a number of potential drawbacks of residential facilities that you need to consider, including:

- The facility may not have the look and feel of a home or at least the kind of home that your son or daughter is used to.
- Facilities can have six or more people living together with different personalities, wishes and needs. Also, people may be different ages (for example, some may be seniors while others are younger adults).
- The "rules" of the facility are usually set by the people that operate the facility. This may place some restrictions on your son or daughter's ability to make choices about his or her daily activities, and whom she or he wishes to spend time with.
- The facility may be in a neighbourhood or community that is not familiar to your son or daughter. Sometimes, people are "placed" in a facility in another community.

A Moving Out Check-In

Deciding the right time to have your child move out of your family home can be very difficult. Here are some questions to consider when deciding if the time is getting close:

☐ Am I getting older or less able to support my child at home?
☐ Am I able to care for my own needs (do I need support for myself to stay in my home)?
☐ Does my child want to move out?
☐ Do I want to be able to monitor my child's new living arrangement after it is first set up?
☐ Is there a good opportunity to have my child set up in another living arrangement that I don't want to miss?
☐ Do I want more time for myself and to have the chance to do things while I am still able or before I get too old?

How Can My Son or Daughter Have His or Her Own Home?

The first three options noted above all involve your family member with a disability living in someone else's home or facility. Increasingly, adults with disabilities (and their families) are interested in exploring the possibility of establishing their own homes in the community. This could involve your son or daughter living in his or her own house, apartment, condominium, town-house or "granny suite."

This option provides more flexibility and opportunity to design a living arrangement that suits the wishes and needs of your adult child. Also, it allows for the strong possibility of creating a home that provides the kinds of things that we value in a home.

Increasingly, adults with disabilities (and their families) are interested in exploring the possibility of establishing their own homes in the community. This could involve your son or daughter living in his or her own house, apartment, condominium, town-house or "granny suite."

How Can We Make This Option Happen?

The own home option will likely require some detailed planning in order to develop the best possible living arrangement for your son or daughter. You will benefit greatly from some help in developing a good plan and then putting that plan into effect.

A "network of support" can provide this help. This is a small group of people who agree to support your son or daughter to achieve his or her goals. Members of a network can help in many ways. They can help find affordable housing, plan for and arrange the support your son or daughter will need in the home, manage money for housing and support services, and help monitor the living arrangement. For more information about networks of support, see Chapter 11.

You may also get help from an agency in your area that helps people with disabilities live in their own homes. Unfortunately, not every area has an agency that provides this kind of service. Inclusion NB has a program called the *Social Inclusion Program* that will assist people with an intellectual disability and their families to facilitate "supported living" arrangements so that people are able to live in their own homes. This program is currently active in the following areas: Saint John, Moncton, Fredericton, Bathurst, and Grand Falls/Edmunston. Inclusion NB will work to make this program available in other areas of New Brunswick in future years.

You may also want to *check out some living arrangements that have been developed* for people to live in their own home with support. Inclusion NB can put you in touch with other families or people who have already made this happen.

Planning for Affordable and Adequate Housing

One key part of your son or daughter having a home of his or her own is affordable and suitable housing. Many people with disabilities live on fixed (and often low) incomes and may need assistance with housing costs. Here are some ways to plan for affordable housing:

- Apply for Government Housing Programs.
  The government of New Brunswick has programs that assist people who are in need of affordable or accessible housing. Here are some of the programs available:
  - **SUBSIDIZED HOUSING UNITS.**
    This involves accessing housing units that are owned directly by the province or by non-profit housing organizations in local communities. People who qualify pay 30% of their total income towards rent. Eligibility is based on the person's income and their level of priority as determined by government.
  - **RENT SUPPLEMENT PROGRAM.**
    This program involves 'rent supplements' that are paid to landlords for people who cannot afford regular 'market' rents. People who qualify pay 30% of their total income towards rent. Eligibility is based on the person's income and their level of priority as determined by government. Some rent supplements for people with a disability are "portable". These supplements provide people with more choice about where to live.
  - **REPAIR PROGRAM FOR PERSONS WITH DISABILITIES.**
    This program provides funding to do work to make accessibility changes to a home that will be occupied by someone with a disability. Changes or repairs can include ramps, chairlifts, wheel-in showers and wider doors. Government can provide a grant (which does not have to be re-paid) or a repayable loan up to $10,000.
  - **SECONDARY/GARDEN SUITE PROGRAM.**
    This program offers funding for modifications to residential homes to create a secondary or garden suite for an adult with a disability. It will also provide funding to place a mini-home on a residential property. It will provide up to $24,000 in grant funding. On top of this grant, you may be able to access the Repair Program for Persons with Disabilities for accessibility modifications.
  - **EMERGENCY REPAIR PROGRAM.**
    This program provides funding for urgent repairs to housing that is a threat to a person's health and safety. Emergency situations can include heating and electrical fire hazards, lack of water, and roof damage.

These programs may have financial eligibility requirements and a waiting list. For more information about these programs, contact your regional office of the Department of Social Development (see Chapter 3 for telephone contact information).

◆ **Use Family Assets.**

Some families may want to use their own assets to provide a home for their adult child. This can involve leaving the family home to be used by the family member with a disability or using some family assets to purchase or finance a home. There are many types of housing options to consider including a single family dwelling, townhouse, condominium, duplex, and so on. This approach will be much more affordable if the home is mortgage free or has only a small mortgage to re-pay. Planning options include:

- Transferring the ownership of a home to a family member with a disability.
- Making your family member a joint owner of a home with another person.
- Providing for a "life estate" (the right to own and use of property for a person's lifetime).
- Creating a housing trust. A housing trust provides a legal right for the beneficiary of the trust to occupy the home while leaving the management responsibilities in the hands of trustees. Trustees can also be given the authority to collect "rent" from the beneficiary or possibly other occupants of the home. Trustees can also be given some discretion to change the housing arrangement if the beneficiary's needs or circumstances change.

◆ **Supplement Your Adult Child's Income.**

You may also use your own assets to supplement your son or daughter's income. If he or she is **not** receiving provincial income support benefits you can supplement income at any time and in any way you wish. If he or she is receiving income support benefits as a person who has been certified "disabled", deaf or blind, you can supplement income by using a financial trust or a Registered Disability Savings Plan (RDSP). Provincial rules allow money from a trust (up to $200,000 in value) or an RDSP to be used to supplement the income of a person with a disability (up to $800 per month and other payments that may be approved by the Government). A trust or RDSP can be used to pay for housing expenses beyond what the person is able to afford from his or her own income. This can be done without affecting the person's monthly cheque.

◆ **Share the Home to Share Living Expenses.**

Some people may want to share their home with another person and share the cost of housing. People with disabilities can share a home with another person with a disability or with someone who is providing support without having provincial income support benefits affected. It is important to make sure that people are compatible and able to live with one another before considering this option.

Jessica's Story:

At the age of 31 Jessica informed her mother she wanted a place of her own, a place that offered her independence. Jessica and her mother began to talk about this new idea and all that it involved. First was the question of where she would live – there were many factors to consider when choosing the right place. It had to be close to a bus stop so she could get to and from her work at a local child care centre, enjoy the shopping malls, and be able to visit family and friends. It had to be in a good neighbourhood and in a secure building to ensure her personal safety, as Jessica planned to live alone.

Jessica and her family set out to find a subsidized apartment that met all of her needs. Moving out on her own was exciting, and she enjoyed hours of shopping - picking out furniture, towels, dishes and lamps. Jessica had waited a long time for a place to call her own and she wanted everything to be perfect.

Planning for the supports to ensure Jessica was successful in living on her own was critical; Inclusion NB helped Jessica and her family consider these needs as she prepared to move. Although Jessica was moving out on her own, she would need some support with household duties and someone who would call her daily to check in and ensure she was safe, in addition to the informal visits of friends and family.

With the necessary supports in place, Jessica moved into her new apartment, decorated with family photos, homemade quilts and colourful flowers. With the help of a life skills coach, Jessica continues to work on her housekeeping skills and has the new goal of baking a lemon pie!

Planning for Support in the Home

Ensuring that your son or daughter will have adequate and appropriate support in his or her home is crucial. Some people will require very little support while others may require much more. Good planning about how support in the home will be provided will be necessary. It will also likely require an application for funding from the government to pay for the supports (see the information in the next chapter about the Disability Support Program).

There are a variety of support options which include:

- **On-demand support.**
  This involves establishing some system to allow the person to obtain support only when needed. For example, this could be accomplished through a beeper, an intercom, or a call button. It may also be accomplished by a person telephoning or visiting another person who is available to help.
- **Scheduled assistance or support.**
  In this option, people simply obtain the support they need on an agreed upon schedule. For example, an attendant may arrive at 6:00 a.m. to assist someone to get out of bed.
- **Immediately accessible support.**
  Much like "on-demand" support, the person obtains his or her assistance when needed; however, immediately accessible support is always available within minutes. For example, in case of an emergency, someone living across the hall in an apartment complex could be available to help.
- **Roommate support.**
  A number of own home living situations use roommates as a method of providing supports. Roommates may be paid or unpaid, or may receive free room or board (or both) in exchange for supporting an individual. Roommates are frequently offered the opportunity to have time away from the home. In some situations, where support needs are greater, individuals may have two roommates who perform different support functions. Having roommates also helps to avoid isolation and loneliness for the person with the disability. Roommate situations may be short-term, but may also last for years, during which the individuals who share the home often develop a strong relationship. There is no one "model" for arranging roommate supports. It is individualized and may change as the individual decides upon different things or as different needs for support arise.

Having roommates also helps to avoid isolation and loneliness for the person with the disability. Roommate situations may be short-term, but may also last for years, during which the individuals who share the home often develop a strong relationship.

Family Tip:

Make sure that you have everything worked out as much as possible to help make the transition to a new home successful. Do your homework.

Planning for On-Going Monitoring

Setting your son or daughter up in his or her own home offers many potential benefits for a good life in the community. It will, however, be important to monitor the living situation carefully. When planning to establish a home, give consideration to who will be responsible for checking in on your son or daughter on a regular basis and for resolving issues that may arise from time to time. Here are some options to consider:

- **Family.**
  Family members may be willing to take on this responsibility. This may include other members of your immediate family or people from 'extended' family. They will need to be committed to taking on this role.
- **A network of support.**
  Networks are discussed in greater detail in Chapter 11. Network members can include family members, friends and others (such as your child's social worker) who are committed to ensuring that your son or daughter has the support he or she needs to live in the community. One or more of the network members can assume responsibility for monitoring your adult child's living arrangement. Issues can be addressed with the help of the entire network.
- **A community agency.**
  Some agencies will assume responsibility for helping to establish and monitor supported living arrangements for people with disabilities. These agencies will likely receive some funding for their services (this can be built into your son or daughter's support plan that is submitted to government). When using an agency, make sure to clearly spell out their responsibility for monitoring the living arrangement and for addressing issues that arise. Even with agency involvement, it will be important to have other family or a network of support members involved in making sure your son or daughter is safe and happy in his or her home.

Ralph’s Story:

Living at home with mom and dad, Ralph had his own space, followed his own schedule and had lots of natural support from his family, good friends and coworkers. Living in the family home ensured Ralph’s safety overnight and in case of emergency and allowed Ralph to have the support he needed when it came to preparing meals, daily household duties, and making good decisions.

Ralph’s parents spend the winter months in Florida, and each year a friend would come to stay with him during this time to maintain his daily routine and support. One year this arrangement broke down while Ralph’s parents were away, requiring quick emergency planning by his family and friends. Ralph’s parents began to wonder if it was time Ralph moved out of the family home to a living arrangement that would be safe and secure in the future, when they were no longer able to care for him. Ralph’s parents are aging and have health issues, and saw the benefit of planning for Ralph to move out before a crisis occurred. It was time to help Ralph get a home of his own.

Although 40 years old, Ralph had never lived on his own and he and his family had many questions. Where will he live? Who will he live with? What happens if things go wrong? Ralph does most things for himself but needs some prompting and support with others. Ralph has also been employed with the same company for 14 years. Getting to and from work from his new home would have to be considered.

Ralph and his family received assistance from Inclusion NB to ensure Ralph’s successful transition from the family home to a home of his own. An apartment was found that was within walking distance to the grocery store and other amenities, and was on the bike path to Ralph’s work. A life-sharing roommate was found that would live with Ralph and support him in his daily routine. And funding was secured through the Disability Support Program to allow Ralph the supports he required to maintain his new ‘supported living arrangement’.

Ralph now lives with his roommate on a tree-lined side street, close to many of his friends. He bikes to work, meets friends at Tim Horton’s, and can often be found sitting with his neighbour on the back porch. There have been ups and downs in his new living arrangement; however, every year Ralph, his friends and family celebrate his “home of my own” anniversary. It is a celebration of independence: making his own choices, living where he wants and with whom he wants. If you ask Ralph what all of this means, he’ll smile and say “219. My home.”

Checklist for Planning a Home and Support

- ☐ I have talked about moving out with my child
- ☐ I would like my child to have a home:
    - ☐ right away
    - ☐ within a year
    - ☐ within 2 years
    - ☐ later
- ☐ I am emotionally prepared for my child to leave
- ☐ I have taught independent living skills to my child

AND/OR

- ☐ I have thought about what home supports my child would need
- ☐ We have discussed ideas about where they would live
- ☐ We have discussed whether they would live independently or with a roommate(s)
- ☐ I have thought about what the accommodation would need (ramps, close to amenities, on the bus route, etc.)
- ☐ We have gotten information about funding available
- ☐ We have worked out a budget
- ☐ We have identified a support system/network of support
- ☐ I have explored the housing options that exist in our community
- ☐ We have applied to NB Housing (if necessary)
- ☐ We have applied for necessary disability supports (if necessary)
- ☐ We have found a roommate(s), a support roommate
- ☐ Have created roommate agreement between child and support roommate(s)
- ☐ Determined if respite is needed/secured respite
- ☐ Determined transportation
    - ☐ Bus
    - ☐ Cab allowance
    - ☐ On bike/walking trails
    - ☐ Network members that will drive
- ☐ We have made an emergency back up plan
- ☐ We have put safety mechanisms in place
- ☐ We are meeting regularly with our support network to monitor the arrangement (if applicable)

Worksheet 7

Planning for a Home and Support

1. Identify the things that must be present in your child's future home that will make it a warm and welcoming place for him or her.__________________________________

____

____

____

2. Is it important where your child's home is located? If yes, please indicate what you believe is the ideal location. ____

____

____

____

3. How important is it that your child and your family choose with whom your child will live? ____

4. If your child prefers to share his or her home with another person(s), identify who this will be. ____

5. Does your child prefer to live in one of the types of homes listed below?

☐ Apartment
☐ Single Dwelling
☐ Townhouse
☐ Condo
☐ Duplex
☐ Mobile Home

6. If your child will live in his or her own home, what can be done to ensure that the home is affordable? ____

____

7. When do you anticipate that your child will move out of the family home and into another home? ____

8. What are the things that your child is able to do for him or herself (consider personal care, preparing meals, household duties, shopping for groceries, clothes and personal items, managing money, etc.)? ____________________

____

____

____

9. What are the things that your child is able to do with some assistance (consider the list in question 8 above)? ____________________

____

____

____

10. What are the things that your child is unable to do now but could probably learn if he or she had help? ____________________

____

____

11. How much support or supervision will your child need in his or her future home (all the time, during the time he or she is awake, a few hours a day, occasionally – someone to check in every now and then, etc.)? ____________________

____

____

____

12. What is your preference for how this support should happen (from a family member, live-in support room-mate, homemaker, alternate family, hourly paid support workers, etc.)? ____________________

____

____

13. What expectations do you have for the people who will provide the care and support to your child in his or her future home? What qualities should these people have?

____

____

____

14. What continuing roles will family members and friends have in supporting your child in his or her future home? ______________________________________

____

____

____

15. Who will monitor your child’s future living arrangement?____________________

____

____

____

Additional Resources

Available from Inclusion NB (free to families)

A Time of Change: An Information Guide for Senior Parents Supporting an Adult son or Daughter with a Disability (2008)

Other Resources (available for borrowing from Inclusion NB)

A Good Life, by Al Etmanski, Planned Lifetime Advocacy Network.

Finding a Place: An Individualized Approach to Support (DVD), Kerry's Place Autism Services.

My Life, My Choice: Personal Stories, Struggles, and Success with Person Directed Living (DVD), Inclusion Press.

Safe and Secure: Six Steps to Creating A Good Life for People with Disabilities, by Al Etmanski, Planned Lifetime Advocacy Network.

The Ties That Bind (DVD), Planned Lifetime Advocacy Network.

Taking the JOURNEY

An Information and Advocacy Guide
for Families Supporting a Child with a Disability

CHAPTER 9

Disability and Income Supports for Adults

> *"Disability Supports are tools for inclusion. They are critical if people with disabilities are going to lead fulfilling lives and participate fully in their communities ."*
>
> *In Unison 2000:*
> *Persons with Disabilities in Canada*

InclusionNB

CHAPTER 9

Disability and Income Supports for Adults

Goal for this Chapter

- To learn about different support programs available to adults with disabilities in New Brunswick.

What You will Find in this Chapter

- Information about:
  - The new Disability Support Program for adults ages 19 to 64
  - Other support programs including the Vehicle Retrofit Program, the Health Services Program, and the Prescription Drug Program
  - Income support benefits for people with disabilities, including the assets and other income that people can have and still keep their benefits
- A List of Additional Resources

Our Journey So Far

- In the past, access to disability supports was limited to specific programs (such as residential or day programs) that people were required to access if they wanted help.
- Recently, there have been changes to support programs that have been aimed at improving the lives of adults with disabilities.
- One significant change has been the development of more opportunities to have "individualized" disability supports. This means that supports can be designed (and funded) so that they help to meet the specific goals and needs of people with disabilities.
- Improvements to income support programs have also been made. For example, people are now allowed to have more money in trust funds and Registered Disability Savings Plans while being able to keep their income support benefits. Also, people with a disability can keep more of the money they earn from employment before their income support cheque is reduced.

The New Brunswick Disability Support Program (DSP)

This is a new program that was piloted from 2005-2008 and was fully implemented throughout New Brunswick in July, 2010. This program replaced the Long Term Care Program for adults ages 19 to 64 (the Long Term Care program will still apply to seniors age 65 and over).

The DSP program aims to provide disability supports to adults who are eligible for the program in order to facilitate their personal development and their participation and inclusion in their communities. The program represents a significant shift in thinking about people with disabilities and the way in which disability supports are provided. It is designed to provide more control to people with disabilities (and those close to them) and to allow for the development of support plans that are "individualized".

The DSP program provides funding to adults with disabilities (who are eligible) for personalized and flexible disability supports. This means that supports will be tailor made for each individual based on his or her wishes, goals, and needs.

The program also is designed to ensure that people with disabilities and those close to them have the right to make decisions about the supports that will be provided (what, when, how and by whom).

The DSP program operates on the following core principles:

- **Empowerment and Self-determination.**
  Persons with disabilities require the means to maximize their independence and enhance their well being. Individuals must have control over their own lives; support mechanisms must recognize and encourage each individual's freedom of choice.
- **Rights and Responsibilities.**
  People with disabilities have the same rights and the same responsibilities as other Canadians. They are entitled, as others are, to the equal protection and equal benefit of the law and require measures for achieving equality.
- **Participation.**
  New Brunswickers with disabilities have the right to participate, and to be invited to participate, in all aspects of the economic, social and cultural life of New Brunswick.
- **Individualization.**
  Government policies and programs will be based on determining and enhancing individual strengths and capacities as well as individual approaches which seek to maximize an individual's potential and opportunities to participate in society. Programs and service will be flexible so as to provide for individually focused and personalized supports.
- **Respect.**
  New Brunswickers with disabilities have the right to have their abilities, right of choice and dignity respected in all stages of their lives.

- **Access.**
  New Brunswickers with disabilities have the right to places, events, services and functions that are generally available in the community.
- **Equality.**
  New Brunswickers with disabilities have access to disability supports which are goods and services that will provide individuals with disabilities equality of opportunity and outcome.

How is a Person Considered Eligible to Receive Government Funding Under the DSP Program

There are two aspects to determining a person's eligibility to receive government funding for services:

- A person must demonstrate sufficient need for supports and services. This need is related to a person having a disability of a long term nature that "substantially limits his or her ability to carry out regular daily activities". Also, a person must also demonstrate an "unmet need" in either personal care (for example, dressing, feeding, etc.) or enhancing his or her independence or community involvement. The need for family relief or respite can be a need under this second category. There are some circumstances that may exclude a person from being eligible from the program.
- A person must also demonstrate that he or she has a financial need for government assistance. A person who applies for government funded supports and services must go through a financial assessment process that looks at his or her net income. For adults with disabilities who live with their parents, government will only look at the adult child's own income to determine if he or she is eligible for government funding for services (the family's income is not considered).

How Can My Child Develop a Plan for His or Her Supports?

Planning is an important part of providing the right disability supports. Families can greatly assist their adult child to develop a disability support plan. You may, however, want to find someone to help with this planning.

Under the Disability Support Program, there are a number of people who can help to develop a support plan. These include social workers or mental health counsellors who are employed by government. People can also ask for an "independent facilitator" to help with this process. Other disability organizations, such as Ability New Brunswick, are also available to provide planning support.

There are also some planning processes that can assist your child to develop a support plan. See the information on the PATH planning process found in Chapter 5.

What is "Independent Facilitation?"

Independent Facilitation is a special service available through the DSP program. It provides a way for people with disabilities to get information, advice and help to:

- Identify goals, needs for disability supports and services, and different ways to have supports and services provided; and
- Develop a disability support plan and, if necessary, negotiate with government ways to use individualized funding to receive disability supports and services.

Inclusion NB currently has an agreement with the government of New Brunswick to provide Independent Facilitation to people who request it. The advantage of using Independent Facilitation is that Inclusion NB is not an agency that is involved in:

- Funding disability supports and services (that is the government's job); or
- Providing disability supports and services (that is usually done by individuals or agencies working in your community).

An independent facilitator works directly for and on behalf of a person with a disability (and his or her family). The facilitator is a "neutral" helper who can represent the person with a disability in discussions with government, professionals, service providers and others in the community.

What Does an Independent Facilitator do Exactly?

An independent facilitator can help in several ways including:

- Assist people with disabilities and their families to develop a vision for their future;
- Help people to identify their needs for support as well as possible options for meeting those needs using both unpaid and paid sources of support;
- Help people make informed choices based on all options available in their community;
- Help people prepare an application for disability supports and with the presentation of their individual support plan for consideration for funding by the government;
- Help people to access other kinds of services that may be required.

What Kinds of Supports Are Available Through the DSP Program?

As much as possible, support for each person who is eligible is to be "individualized". This means that the support will be based on each person's own goals and needs. Some types of support that may be available include:

- Personal care assistance within or outside your home (such as help with dressing, bathing, grooming and toileting);
- Support for community involvement and participation;
- Personal skills training (including pre-employment skills training);
- Home support (including cleaning, laundry, meal preparation and other household tasks);
- Assistance with transportation (under limited circumstances);
- Technical supports and assistive devices that are not covered under other programs; and
- Respite support for families and caregivers (see Chapter 12 for more information).

How Will Disability Supports Be Paid For?

Under the DSP Program, government funded disability supports will be paid for using "individualized funding". This means that:

- Funding is provided in a way that meets some or all of the person's specific needs for support that are identified in his or her disability support plan; and
- The person (and his or her family/support network) will identify how money for approved disability supports should be spent.

For people who are eligible to receive government funds for disability supports, monthly payments can be made directly to the person or to a trustee on the person's behalf. Payments can also be made directly to a service provider that is selected by the person with a disability.

If My Child Is Eligible to Receive Government Funding for Services in the Home or Community, How Can I find People to Provide These Services?

There are a couple of ways to find people to provide services for your son or daughter with a disability.

- **Using a Community Service Agency.**
  In many communities, there are a number of service agencies that hire 'support workers' to provide services that may be required. These agencies look after the scheduling and paying of support workers. Government will pay the agency directly to provide services to your son or daughter. There are typically more agencies in urban areas. In some rural communities access to agencies may be limited.

- **Hiring People Privately.**
  You can also hire support workers privately. This usually requires paying the worker and then submitting receipts to get reimbursed by government. This allows you to hire the people you want to support your son or daughter, but it means that you have to pay the worker, keep records, and sometimes make regular payments to the federal government for tax and other contributions as an employer. Please note that the government provides a different funding rate for hiring privately than it does for using a community agency. This is because agencies are given extra money for "overhead" and other expenses.

  Hiring privately allows you to hire people you know to provide support. There are, however, some restrictions on the hiring of relatives (such as parents and brothers and sisters). When it is very difficult to find support workers for your son or daughter (such as in rural areas), the provincial government can provide permission to hire close relatives.

Hiring privately allows you to hire people you know to provide support. There are, however, some restrictions on the hiring of relatives (such as parents and brothers and sisters). When it is very difficult to find support workers for your son or daughter (such as in rural areas), the provincial government can provide permission to hire close relatives.

Other Programs that Provide Disability Related Services and Supports

Housing Programs

The Government of New Brunswick offers programs that provide funding for affordable or subsidized housing and to make repairs or modifications to your home in order to make it more accessible. These programs are reviewed in brief in Chapter 8. For more information about these programs, contact your regional office of the Department of Social Development (see Chapter 3 for telephone contact information).

Vehicle Retrofit Program

This program is operated by the New Brunswick Department of Transportation. It is designed to increase the mobility of people with disabilities by providing funding to help pay for the cost of supplying and installing "eligible retrofitting and accessibility features for vehicles."

The program provides grants that are available to individuals, organizations, municipalities or private companies that live in or are based in the province. Grants are provided in the amount of 80% of the cost of eligible accessibility features (for a new or assisting vehicle) up to a maximum of $8000.

The grants are renewable every 8 years for individuals and every 5 years for organizations. Grants are provided for eligible accessibility features such as:

- Wheelchair lifts and ramps
- Hand controls, steering devices and left foot gas pedals
- Wheelchair restraint systems
- Special seating
- Roof, floor and door alterations
- Scooter lifts
- And other possible features

To be eligible, a vehicle must have a valid Safety Inspection Sticker.

For more information about the Vehicle Retrofit Program, and for a copy of the application form, visit the Government of New Brunswick's website at www.gnb.ca. Do a search of the home page for a "vehicle retrofit program"

ADAPT Program

This program is operated by the Department of Social Development. ADAPT stands for Adult Developmental Activities, Programs and Training. This program is provided through 39 community agencies which are funded by the Department of Social Development. To access support through these agencies, a person will need to apply through the Disability Support program (DSP). For more information on this program, please see Chapter 7, Going to Work.

Health Services Program (Health Card Services)

This program offers significant benefits for persons with disabilities (and others). Under this program a number of benefits and services are available for people who are eligible. Health Services are typically provided to people who qualify for a Health Card from the government of New Brunswick. A provincial Health Card can provide coverage for people in different circumstances, including:

- People who qualify for social assistance (these individuals automatically qualify for a Health Card).
- People who qualify because of financial need (but who are not on social assistance).
- Children who are eligible for the Children with Special Needs Program (see Chapter 3) whose families can demonstrate financial need.
- Adults who reside in a residential facility (Community Residence, Special Care Home, etc.).

Health Cards can be obtained from the regional offices of the Department of Social Development.

Health Cards may provide different benefits depending on the person's situation and needs. Most provide for prescription drug coverage, as well as dental and vision coverage. There are many other types of benefits that can be provided. A brief description of the available benefits is provided below. If your child is in need of any of these benefits you should contact his or her case manager from the Department of Social Development.

- **Dental Program.**
  The Dental program has been improved in recent years. It now provides a range of dental services including diagnostic (x-rays and exams), extractions, dentures and repairs, fillings and some emergency services. For children 18 and under it also covers cleaning and root canals. For certain types of services, a person may have to pay some of the cost. Health Cards must indicate "Dental" coverage. Also, the program is only available to people who do not have other dental coverage.
- **Enhanced Dental Program.**
  This program will help people with additional coverage for specific dental services which are not covered under Medicare or private health insurance. It will cover the cost of exams, cleanings and root canal (for certain teeth). To be eligible, a person must be between the ages of 20 and 63 and be in need of additional dental treatment to support their employment or educational goals.
- **Vision Program.**
  The Vision program covers the cost of major eye exams and eye glasses (including frames, corrective lenses, and cases). Adults are eligible for vision benefits once every 2 years and children 18 and under are eligible once every year.
- **Hearing Aid Program.**
  This program covers the cost of hearing aids and any necessary repairs.
- **Wheelchair/Seating Program.**
  The Wheelchair/Seating program assists with the provision and maintenance of wheelchairs, seating components and accessories, as well as provides any modifications and repairs necessary for eligible equipment. Equipment may be provided from the Recycling Program, operated jointly by Easter Seals New Brunswick and the Health Services Program or provided new, when recycled equipment is not available. Under the program, funding is provided for manual wheelchairs, power wheelchairs, four wheeled scooters, rehabilitation strollers, simple and modified simple seating components, custom ordered and custom made seating components, and rentals. Wheelchairs will be considered every five years and seating and accessories are eligible every two years.

- **Orthopedic Program.**
  This program helps with the cost of orthopedic devices and services to help individuals meet a basic need (defined as a need that occurs on a regular or daily basis). The program provides funding for non-custom supports and braces, custom orthoses, orthopedic and therapeutic footwear, custom footwear, repairs, and modifications.
- **Convalescent/Rehabilitation Program.**
  This program helps with the cost of providing and maintaining convalescent and rehabilitation items and services which help individuals to meet a basic need. Equipment may be provided from the Recycling Program, operated jointly by Easter Seals New Brunswick and the Health Services Program, or may be provided new, when recycled equipment is not available. The program provides funding for bathroom aids, mobility aids, stability aids, transfer aids, pain management equipment and supplies, emergency response systems, and other related benefits.
- **Ostomy/Incontinence Program.**
  This program helps with the purchase of supplies required for the direct management of ostomies (colostomy, Ileostomy, urostomy) and catheterization. Incontinence supplies can also be provided for these individuals as well as for people who utilize a wheelchair on a full time basis. The program provides funding for ostomy supplies, in-dwelling catheters and related supplies, external catheters and related supplies, intermittent catheters, incontinence supplies, etc.
- **Oxygen and Breathing Aids Program.**
  This program assists with costs relating to the provision of home oxygen and specific breathing aids. It provides funding for oxygen therapy, breathing aids, CPAP/BiPAP, ventilation equipment, and related supplies.
- **Out of Province Medical/Hospital Program.**
  This program provides assistance with covering the cost of specific medical and hospital services that are provided outside of New Brunswick and which are not covered or completely covered by Medicare.
- **Hyperalimentation (Tube Feeding) Program.**
  This program assists with the cost of tube feeding. It provides funding for TPN (Total Parenteral Nutrition) and related supplies and enteral feeding and related supplies.

Prescription Drug Program

The Prescription Drug Program provides drug coverage for people who are eligible. There are various pieces to this program that allow people who are in different situations to become eligible. For example, any person who has a Health Card from the government of New Brunswick is eligible for the program. People in special circumstances, such as people who have Multiple

Sclerosis and Cystic Fibrosis, or people who live in residential facilities, may also be eligible. There is also coverage for “special needs children”. In some circumstances, individuals may have a co-pay fee for their prescription drugs.

New Brunswick Drug Plan

Any person who does not have private or work related prescription drug coverage is able to join the NB Prescription Drug Program. This program will cover a number of medications – including “catastrophic” drugs. People will be required to pay premium based on their individual or family incomes. Lower income New Brunswickers will have premium subsidized at 100%. People covered under the Prescription Drug Program (See Page 9.12) will continue to be covered under that program.

Income Support Programs (Social Assistance)

Not every person with a disability is entitled to receive income support benefits under the Extended Benefits Program. This is because they are not seen to meet the criteria of being ‘disabled’, blind, or deaf. Generally, people with disabilities who are not eligible for Extended Benefits, will receive income support benefits under the Transitional Assistance Program.

What are Income Support Benefits?

Income support (also known as income assistance or social assistance) is a provincial government program that provides monthly income benefits to people who are in financial need. Financial need is determined by the amount of income and assets that a person has (or sometimes the income and assets of people who live together).

What are the Different Categories of Income Support?

There are two main categories of income support benefits:

- Benefits under the Transitional Assistance Program are designed for people that are considered to have some training and employment potential.
- Benefits under the Extended Benefits Program are designed for people who are considered to be disabled, blind or deaf. “Disabled” is a status that must be verified by a medical advisory board. A disability must be likely to continue indefinitely without substantial improvement and cause a person to be severely limited in his or her activities of daily living. A person with a disability who qualifies for this program can start to receive benefits at age 18 while he or she is living in the family home (benefits may be reduced by up to $100 per month if your income as parents is over $50,000 per year). People who receive income support benefits under this category receive the highest amount of income support per month.

Not every person with a disability is entitled to receive income support benefits under the Extended Benefits Program. This is because they are not seen to meet the criteria of being ‘disabled’, blind, or deaf. Generally, people with disabilities who are not eligible for Extended Benefits, will receive income support benefits under the Transitional Assistance Program.

IMPORTANT NOTE: Current rules in New Brunswick allow people with disabilities (who are certified as being ‘disabled’, deaf or blind by the provincial government) to have assets in an RSDP AND a trust fund up to $200,000 without having income support benefits affected. In addition, the rules allow for the person to receive up to $800 per month from the RDSP and/or trust fund without affecting the monthly cheque from the province. Other payments from an RDSP and/or trust may also be received if they are first approved by the government of New Brunswick.

What Kind of Benefits are Available?

Based on a person’s other sources and amounts of income and assets, he or she can receive a monthly income support cheque, a health card (to help pay for the cost of prescription drugs, basic dental and eye care, and other health needs - see the information on the Health Services Program provided earlier in this chapter), emergency benefits, and assistance with funeral expenses.

What Income or Assets can a Person Have and Still be Eligible for Income Support Benefits?

Generally, government considers all income and assets that a person may have when determining eligibility for income support benefits. However, the government does allow people to earn some income and keep some assets and still receive benefits. These include the following:

- Income from employment up to $500 per month plus 30% of income above $500 for people receiving Extended Benefits and $150 per month plus 30% of income above $150 for people receiving Transitional Assistance Benefits.
- Up to $1,000 in “liquid assets” for a single person receiving Transitional Assistance Benefits and up to $10,000 in liquid assets for a single person or family unit receiving Extended Benefits (that is, people who are certified disabled, deaf or blind). “Liquid assets” are assets such as money, bank accounts, assets that can be sold or other investments (for example, Canada Savings Bonds, and interest accounts).
- The cash surrender value of the life insurance policy.
- A person’s home that is used as a principal residence and the property on which the home is located.
- A motor vehicle that is used for routine transportation, work, medical reasons, etc.
- Property which is necessary for a person to earn a living (for example, equipment, tools, etc.).

- A Registered Disability Savings Plan (RDSP).
- A pre-paid funeral
- The principal and the accumulated interest of a documented trust fund up to $200,000 established for the person receiving Extended Benefits (certified disabled, deaf or blind) to help that person live in his or her home or community.
- Up to $800 per month from a trust fund and/or an RDSP.
- Additional amounts from an RDSP or trust fund that are approved by the Department of Social Development and that are intended to assist in maintaining a person to live in his or her home or community.
- Up to $50000 in RRSP assets (for people receiving Extended Benefits only)

Heating Allowance and Fuel Supplement Programs

The **Heating Allowance Program** provides assistance with heating costs for people living in rental housing that is owned by the government or by non-profit or co-op housing organizations. The heating allowance reduces the monthly rent payment of these individuals. To be eligible to receive the allowance people must pay their own heating bills. The amount of the allowance will depend on the type of rental unit, the number of bedrooms or the location of the unit.

The **Fuel Supplement Program** helps people with the cost of heating their home in winter. It is generally available from November to April each year. It applies mostly to people who receive Social Assistance benefits. Some people are not eligible to receive the supplement, including people who:

- Have accommodation costs of less than $100 per month;
- Are receiving an Income Supplement of $100 per month through the heating season;
- Are in subsidized housing where heating is included in the monthly rent;
- Live with their parents or who live in a boarding situation.

For people on Social Assistance there are a few different supplements including the Electric Fuel supplement, Non-electric Fuel Supplement, and the Bulk Fuel Supplement (for the purchase of wood or oil). The amounts that people can receive for these may differ (but are currently around $145 to $150 per month).

For people on Social Assistance and those who do not receive Social Assistance, an Emergency Fuel Benefit may be available if people experience a winter heating hardship or emergency situation. Currently this benefit can be up to $550 in each calendar year.

To apply for these programs people must contact their regional office of the Department of Social Development. Please see the end of Chapter 3 for telephone contact information.

Additional Resources

Available from Inclusion NB (free to families)

Disability Support Program: Independent Facilitation Services, brochure.

Fact Sheet: Income Support Benefits in New Brunswick

Fact Sheet: Accessing Disability Related Services in New Brunswick

Position Statement on Disability Supports.
Available on-line at www.inclusionnb.ca (see the "Defending Rights" section of the website).

Other Resources

Creating a Good Life in Community: A Guide on Person Directed Planning,
Individualized Funding Coalition for Ontario, 2006.
Available on-line at www.individualizedfunding.ca.

Impact: Feature Issue on Consumer-Controlled Budgets and People with Disabilities,
University of Minnesota, Institute on Community Integration, 2004.
Available on-line at www.ici.umn.edu/products/impact/171/default.html.

In-Control U.K. website – www.in-control.org.uk.

Moving Toward Citizenship: A Study of Individualized Funding in Ontario,
Individualized Funding Coalition for Ontario, 2006.
Available on-line at www.individualizedfunding.ca.

New Brunswick Department of Social Development website – www.2.gnb.ca/content/gnb/en/departments/social_development_sociale.html

Part 3

Issues Through the Life Span

INFORMATION IN THIS PART

InclusionNB

Taking the JOURNEY

An Information and Advocacy Guide
for Families Supporting a Child with a Disability

CHAPTER 10

Community Involvement and Recreation

> *"It is good to have an end*
> *to journey towards,*
> *but it is the journey*
> *that matters in the end."*
>
> *– Ursula LeGuin*

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CHAPTER 10

Community Involvement and Recreation

Goal for this Chapter

- To learn about ways to help your child to become involved in his or her community and in recreation activities.

What You will Find in this Chapter

- Information about:
    - General suggestions for thinking about community involvement
    - Encouraging the community involvement of children, youth, and adults with an intellectual disability
    - Sources of support for community involvement
- **Worksheet 8** – Planning for Community Involvement and Recreation Opportunities
- A List of Additional Resources

Our Journey So Far

- Like many aspects of life (such as school and employment) people with disabilities were excluded from participating in community recreation, leisure and volunteer activities.
- Recreation and community involvement plays an important role in the lives of most people. It provides us with opportunities to be with other people, learn new skills, develop friendships, have fun, and do things that will improve our health and well-being.
- Over the years, "special" community activities developed for people with disabilities. While some of these still exist, community organizations are now doing a much better job at including people with disabilities within regular reaction and other activities. There are, however, barriers that must be addressed to ensure that people have full opportunities for community involvement.

Introduction

Participation in community offers a variety of rich experiences for all of us. We are often known and valued by the things we do and the contributions we make in our communities. Participation also offers opportunities to develop friendships and relationships with others. This provides us with a sense of belonging and a source of support and caring.

Families can play important roles in ensuring that your child with a disability has opportunities to enjoy an active life in his or her community. As parents, you typically do this for any of your children. You host birthday parties, encourage your children to invite friends over, sign your children up for groups and activities, and so on. For your child with a disability, however, participation may happen less "naturally" than for others. Specific actions may be necessary to help bring about real community involvement.

General Suggestions for Thinking about Community Involvement

Start Community Involvement Early

If you are a parent of a young child, try to get him or her involved in community activities at an early age. This will involve your child in activities that other children of the same age are doing. This will help your child have experiences with other children and ensure that other children get to know your child from an early age.

Know and Believe in Your Child's Interests and Strengths

It is important to recognize that your child is unique and has his or her own interests and strengths. What are the things that capture his or her attention? What are the activities that he or she does well? What shows your child's unique strengths? (For example, a desire or love of being around other people is a strength that could be useful in encouraging community involvement).

Know Your Community

Every community has groups, activities, programs, events that are available. Community newspapers, event calendars, bulletin boards, etc. are a useful way to find out what's going on in your community and what your child might enjoy being involved with.

Encourage Your Child

You may want to actively encourage your child to get involved in the community (for example, doing things at school, or becoming involved in community groups and activities). Part of this encouragement will be to help your child make decisions. Encouraging the ability of your child to make decisions will mean that he or she will be encouraged to think about involvement in the community.

Help Your Child Develop Personal and Social Skills

Developing skills may be important for a number of reasons. First, acquiring skills means that your child will be better able to do things that will make it easier to participate in the community. For example, learning a hobby or how to play a sport will make it easier for your child to be involved in groups that promote these activities. Likewise, learning how to ride a bus may make participation easier. While your child may always have some limitations, he or she will also have the ability to learn and grow.

Think About Involving Others in Planning for Community Involvement

Sometimes, other people can help think about how your child can become involved in his or her community. Other family members, friends, neighbours, teachers, people from religious communities, etc. may have ideas to offer on how participation may happen. There are also some specific planning processes that may be helpful. For example, Inclusion NB offers individuals with disabilities and their families access to people who can do a planning process called PATH. These processes help to set some positive goals and ways to achieve those goals with the involvement of others.

Be Careful of Overprotection but Be Mindful of Safety

It is not unusual for parents of children with disabilities to want to be protective. This may result in a reluctance to expose your child to people or activities in the community. This may result in your child having a very narrow social network (for example, he or she may do everything with family). Overprotection may deny your child the opportunity for involvement in the community and for developing other relationships. At the same time, however, it is important to understand why your family member may be at greater risk of being harmed than others. Think about ways of providing safeguards that will allow your child to participate in community life while remaining safe from harm.

Overprotection may deny your child the opportunity for involvement in the community and for developing other relationships. At the same time, however, it is important to understand why your family member may be at greater risk of being harmed than others. Think about ways of providing safeguards that will allow your child to participate in community life while remaining safe from harm.

Encouraging the Community Involvement of Children and Youth

There are a number of steps that families can take to help young children and youth become involved in their communities:

Create a Welcoming Environment for Other Children

Community involvement for children often means spending time with other children. You can make this happen by attracting other kids to your home. Events such as birthday parties or having activities going on that your child and other children will enjoy will help bring people together.

Sign Your Child up for Community Groups and Activities

There are several opportunities for involving your child in group activities. Groups such as Brownies, Cubs, Scouts and activities such as soccer, swimming lessons, dancing, etc. provide opportunities in many communities.

Try to look for organizations that have embraced the inclusion of all children. If you're feeling uncertain about your child's involvement, many groups encourage parents to be involved as well. For example, parent volunteers are always welcome in local Brownie groups. This may help address some of the fears you may have about your child's safety or his or her acceptance into the group.

If you are able, take on the responsibilities that other parents do for their children – sign them up, carpool, take turns bringing snacks, and so on. Over time, you may feel confident in the group's ability to include your child and you may be able to limit your involvement.

Look for Opportunities for Summer Camps

There are a variety of types of summer camps which children attend. These may include outdoors adventure, sports camps, theatre camps, music camps, etc. Again, you may want to look for signs that the camp will willingly accept all children. For example, is the camp willing to look for ways to provide support to your child if this is required?

It may be helpful to look at the types of camps that other neighbourhood children are attending. In this way, relationships between children or youth can be deepened. If the summer camp requires the children spend time away from home, it may be necessary for you to explore the camp's ability to adequately support your child and his or her involvement.

Promote Your Child's Involvement in School Groups and Activities

As with community groups, school groups and activities provide excellent opportunities for involvement. Planning to have your child included in these groups and activities can be a part of your child's education plan (should he or she have one). This will help to place expectations on teachers and others in the school that your child's participation is important.

Show Your Child's Friends and Acquaintances Ways to Involve Your Child

Sometimes other children may be uncertain about how to involve your child, particularly if he or she has difficulty in doing certain activities. You may be able to help by showing ways that your child can be involved in games or activities or ways that your child will feel more comfortable in group settings.

Identify the Places where Children and Youth Gather

There may be places that are regularly used by children and youth to do activities. Many communities have Boys and Girls clubs, community centres, teen centres, and so on. Talk to the organizers of these places to see if they will help to include your child. If necessary, you can become a volunteer if you have concerns about your child's safety or acceptance. There are also helpful resources on inclusion that will offer suggestions on ways to involve all children.

Minimize the Presence of Adults

We have suggested it may be appropriate for you to be involved in groups or activities with your child. Sometimes, though, the presence of an adult makes it difficult for your child to be accepted by other children. Think about when it is appropriate to pull yourself back or remove yourself from activities involving children or youth.

Encouraging the Community Involvement of Adults

Many of the suggestions offered for involving children and youth in community life may also work for adults with disabilities.

Young adults with disabilities may be more likely to continue living with their parents than with other children. Adults with disabilities may also face fewer opportunities after they graduate from high school. As a result, they may become more dependent on parents and other family members for social opportunities when school is over.

Whether your family member is a younger or older adult he or she can have opportunities to participate meaningfully in the community. Apart from paid work as an option, adults can be involved in volunteer activities, recreation and leisure activities (for example, art classes, sporting activities, and social clubs) and in religious activities (for example, by joining the choir or assisting with religious services).

As families you can take steps to assist your adult child to become actively involved in his or her community. Here are a few suggestions:

- If your son or daughter is approaching graduation from high school, let your child's school know that you are interested in planning for community involvement (and other goals such as employment) after school is finished. This could be built into your child's transition plan (see Chapter 7).
- Look for places that will welcome new people. Some groups or associations may be promoting the inclusion of people with disabilities.
- Use your own contacts. Who do you know or know of in a group or organization that could be approached to help involve your child?
- Help prepare the ground. If your child is beginning involvement in a new activity, it may be helpful for you or someone else to take him or her to the location ahead of time to become familiar with it.
- Be active in introducing your child to other people in a group or organization. It may be better to do this one person at a time.
- If necessary, talk with other members of the group. Try to address any concerns or misconceptions that people may have. Help others realize that your family member can make a contribution.

- Assist your child to have regular contact or involvement with the group or activity. If necessary, help him or her remember names of other people.
- It may be necessary for you or someone else to accompany your child to the group or activity until he or she begins to develop good connections. Try not to get in the way of your child getting to know other people. It may be necessary or helpful to make some suggestions to the group of how your child can be included in activities.
- If transportation is a problem, be available to provide transportation yourself or look for other opportunities. Is there someone in the group who can provide transportation?
- Don't be afraid to ask people to become involved. Experience shows that when asked, most people will say yes. If you find it difficult to ask on behalf of your family member, try to find someone else who can help.

Support for Community Involvement

There may be a number of sources of support available to assist your child to be involved in community activities. Here are some suggestions:

Government Support Progams for People with Disabilities

Government programs for children and adults with disabilities may be available to provide community support workers who can help your child to be involved in the community. These support workers can attend activities with your child if he or she is unable to participate without additional support. Before involving a disability support worker it may be important to find out if the group or organization is able to provide support on its own. Sometimes, this is a better way to ensure that your child will be fully included in the group and its activities.

Information on government support programs can be found in Chapter 3 (for children up to age 18) and Chapter 9 (for adults).

Inclusion NB's Social Inclusion Program

This program supports youth 17 and older and adults with an intellectual disability to develop connections in their communities in order to participate in community life. As of November 2014, the program operates in a few regions of the province including Saint John, Moncton, Grand Falls/ Edmundston, Fredericton and Bathurst. The program provides for Social Inclusion Facilitators who identify ways for people to become involved in their communities (such as recreation groups and activities, sports clubs, faith groups, or volunteerism). The facilitators do this by:

- Learning about the interests and goals of the person;
- Introducing the person to an individual, group or organization that suits his or her interests; and

- Providing information and support to groups and organizations to ensure that the person feels welcome and encouraged to fully participate.

Social Inclusion Facilitators are not disability support workers but they are available to help people with an intellectual disability to become established in a group or activity. If additional support is required to ensure your child's involvement, this will need to be provided by the group itself (and often is) or by a disability support worker.

For more information about this program please contact Inclusion NB through our toll free line 1-866-622-2548.

Support for Community Organizations to Learn How to be More Inclusive

Sometimes groups or organizations are not sure how they can include people with disabilities in their activities. These groups may need some help in learning about inclusion and the steps they need to take to open their doors to everyone.

There are options available to provide information and training to community groups who want (or need) to learn how they can better include people who have a disability. Inclusion NB has a new on-line learning module on inclusive recreation. This module contains information and strategies for recreation organizations so that they can better include people who have a disability. You can access this module through Inclusion NB website, www.inclusionnb.ca. Just click on "Inclusive Recreation Learning Module" on the "quick links" located on the right hand side of the home page. Training may also be available through Recreation New Brunswick. Information about Recreation New Brunswick can be found at their website www.recreationnb.ca.

* * *

Worksheet 8

Planning for Community Involvement and Recreation Opportunities

1. Identify your child's previous or current involvement in recreation and leisure activities.

   ____

   ____

   ____

2. Identify your child's interests in recreation or leisure activities. ______________

   ____

   ____

   ____

3. Identify your child's likes and dislikes (including things to avoid when planning for recreation or leisure activities). ______________

   ____

   ____

4. Identify recreation or leisure opportunities in your community that may match your child's interests and personality. ______________

   ____

   ____

5. What support will your child need (if any) to participate (include both financial and personal support)? ______________

   ____

   ____

6. Identify ways that your child can get to and from recreation activities (include family, public transportation, car-pooling with others, etc.) ______________

   ____

   ____

Additional Resources

Available from Inclusion NB (free to families)

*Agents of Opportunity: Facilitating Community Participation for People with Disabilities – A Guide for Agencies (*2005).

*Changing Lives … Changing Communities: Reflections on Inclusion (*2005).

*Developing Inclusive Communities: Learning From Our Experiences (*2005).

*Social Inclusion Through Recreation: A Learning Module on Inclusive Recreation (*2010). Available on-line at www.inclusionnb.ca.

Social Inclusion Tool-Kit

*Tips for Families: Encouraging the Involvement of Your Sons and Daughters with Disabilities in Community Life (*2004).

*Tips for Faith Communities for the Inclusion of Persons with Disabilities within Their Congregations (*2004).

Other Resources

Impact: Feature Issues on Volunteerism by Persons with Developmental Disabilities.
Institute on Community Integration (2001), University of Minnesota.
Available on line at http://ici.umn.edu/products/impact/142.

Impact: Feature Issue on Social Inclusion Through Recreation for Persons with Disabilities.
Institute on Community Integration (2003), University of Minnesota.
Available on line at http://ici.umn.edu/products/impact/162

Taking the JOURNEY

An Information and Advocacy Guide
for Families Supporting a Child with a Disability

CHAPTER 11

Healthy Relationships and Sexuality

"Healthy relationships and sexuality
involves having a strong sense
of who we are as individuals,
identifying and acting on
our feelings positively,
and having the skills and confidence
to have and enjoy
good relationships."

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CHAPTER 11

Healthy Relationships and Sexuality

Goal for this Chapter

◆ To learn about healthy relationships for your child with a disability.

What You will Find in this Chapter

◆ Information about:

- Helping your child understand different types of relationships
- Learning more about social and relationship "boundaries"
- Ways to help your child understand puberty
- Activities to help your child prevent abuse and exploitation
- Ideas for helping your child to develop relationships and friendships

◆ A List of Additional Resources

Our Journey So Far

◆ In the past, many people with disabilities were denied opportunities to learn about healthy relationships and sexuality. People with disabilities were seen as being asexual and some people were routinely sterilized.

◆ It is now recognized that people with disabilities have the same desires and feelings as do other people.

◆ People with disabilities are more likely to be abused than people who do not have a disability. Sexuality and abuse prevention education is one important way to help keep people safe.

◆ More information is now available to assist families and others to teach people who have a disability about healthy relationships and sexuality.

Introduction

Building healthy relationships is important for all of us. Our relationships give our lives meaning and provide us a sense of belonging and connection. Our lives are enriched when we develop a number of types of relationships, and in particular, close relationships with people we love and care about.

Your child will hopefully have an opportunity to develop many different types of relationships. This includes relationships with family members, friends, romantic partners, acquaintances, and so on. Each of these relationships will bring your child different experiences.

The relationships your child has will change from time to time. He or she will get to know different people in a variety of circumstances. Relationships will change when your child changes and as he or she learns more about other people.

This is a complex issue that involves many different considerations including ensuring that your child's relationships are healthy, identifying ways that your child can learn about "social boundaries" and what is or is not acceptable in relationships, and finding ways to help your child develop friendships in a world that still sees differences between people with and without disabilities.

Inclusion NB has developed an extensive guide called *Friendships, Feelings, Futures: Relating to Myself and Others* that explores these and many other issues relating to relationships (including sexuality). This guide contains many learning activities that may be helpful to your child. A few of these activities are reviewed in this chapter. If you would like more information about this issue please contact Inclusion NB.

* * *

Helping Your Child Understand Different Types of Relationships

Relationships are about the kinds of connections we have with other people. For most of us, our connections with others involve a range of relationships and interactions. With some people, our connection is very strong. Our bonds with these people often involve love and affection, and sometimes intimacy. At the other end of the spectrum are people with whom we have no personal connection. These are people we do not know. In between the two are people with whom we have some connection and with whom we may share common interests, goals or activities.

Within our range of relationships, the ways in which we interact with people will differ. What we say to other people, how we touch one another, and how much we trust others will vary greatly depending on the kinds of relationships we have.

It will be important that your child learns and understands as much as possible about different types of relationships. For example, if your child is quick to hug people he or she does not know well, then he or she will need to learn about “social boundaries” and what actions are appropriate in different types of relationships.

It will be important that your child learns and understands as much as possible about different types of relationships. For example, if your child is quick to hug people he or she does not know well, then he or she will need to learn about “social boundaries” and what actions are appropriate in different types of relationships.

Activities for Exploring Different Types of Relationships

Circles Training

This activity uses the Circles I: Intimacy and Relationships training program published by the James Stanfield Publishing Company in the United States. Circles is an easy-to-follow and engaging learning program. The Circles program comes with training videos and a manual as well as a large floor or wall mat that depicts the spectrum of relationships using coloured spaces on concentric circles. Unfortunately, the training videos and manual are available only in English. The floor mat and the instruction activities can be used with other languages once a trainer understands the learning concepts and activities.

The Circles program was designed to offer relationship education to people who have difficulties learning or who learn best through interactive learning opportunities. The Circles training program is, however, useful for all learners, particularly pre-teen and adolescent learners. In addition, the Circles program is flexible. People who use it can personalize lessons to address the specific learning requirements of an individual.

The Circles Concept

The Circles program teaches about personal space and boundaries within different types of relationships. It uses a series of different coloured circles that represent people with whom we have either a close relationship (such as family or a romantic partner) or a more distant relationship (such as acquaintances or strangers). A sample Circle reference can be found at the end of this chapter.

The centre circle represents the self (private purple circle) and each new coloured circle "represents behaviours, feelings and actions appropriate to the distance from the centre or self" (Champagne and Walker-Hirsch, 1993). For the various phases of the Circles program, learners are introduced to a variety of relationships that are depicted as people who can be located within one of the coloured circles. Within the range of relationships, those with whom we have the closest connection are in the circles close to us. People with whom we have little or no connection are located in the circles that are farther away. Thus, close family members and romantic partners are in our closest circle from the centre and extended family members, friends, acquaintances, helpers and strangers can be found in the circles that move further away from us.

In addition, the circles concept offers the following principles of autonomy and action as we relate to people with whom we have a variety of types of relationships:

- You are the most important person in your world.
- No one touches you unless you want to be touched.
- You do not touch anyone unless they want to be touched.
- There are very few people who hug you and who you hug-your mother or father, girlfriend or boyfriend (sweetheart).
- There are a few more people you give far away hugs to (that is, a friendly but not intimate hug) such as your friend on a special occasion.
- You shake hands with acquaintances when you are introduced to someone.
- You wave to children and nod to people with familiar faces.
- You have business touch with community helpers (such as doctors and dentists).
- You do not touch strangers.
- Strangers do not touch you.
- You decide who can touch you – you decide when to say "STOP" and when to walk away. (Champagne and Walker-Hirsch, 1993)

Touch, Talk and Trust

One of the most important aspects of the Circles program involves the outline of the nature of what we say, how we touch one another and how much we trust others (talk, touch and trust) within the context of different types of relationships. For example, close family members that are within our “blue hug” circle are people we touch in a loving but non-romantic way; people we can talk to about personal topics and people we usually trust fully. Conversely, someone who is a stranger to us would not be a person with whom we would talk, touch or trust (unless the stranger is an identified “helper” and was providing us some type of assistance).

Finding Circles

Some schools or school districts have the Circles program and are willing to use it to help teach children with disabilities about relationships. If your child is still in school, check to see if Circles is available in your district. Alternatively, Inclusion NB has a copy and can arrange to provide training. If you cannot find a copy, you may be able to teach the ideas and concepts by drawing ever-widening circles on a large piece of paper.

Learning More about Social and Relationship “Boundaries”

Understanding social and relationship boundaries is crucial for many reasons:

- It provides the basis for acting in ways that are considered socially appropriate. In this sense, social and relationship boundaries provide us with guidelines for talking and acting in ways that will encourage other people to accept us as part of the community.
- It is important for developing and maintaining healthy relationships. People are more likely willing to get to know and spend time with us if we act in ways that are respectful. This means knowing what we can and cannot do in the context of our relationships.
- It informs us of our own rights to be treated respectfully and with dignity. This means that we have a strong sense of our personal space and the right to control our own bodies.

Activities for Learning about Privacy and Distinguishing Between Public and Private Activities, Places, and Body Parts

Another key part of learning about social and relationship boundaries is developing an understanding of privacy and learning the difference between public and private activities, places and body parts. On the following pages there are a few activities that you or others (such as a teacher) can use with your child.

1. **Reviewing Public and Private Places**
   The activities can be used to help your child understand the difference between public and private places. These activities can be used at home or as part of your child's learning plan at school:
   - **Defining Public and Private Places.**
     Talk about public and private places as follows:
       - Public places are places in which we are likely to be with or see other people;
       - Private places are places in which we are usually by ourselves or alone.
   - **Charting Public and Private Places.**
     Ask your child to think about places that are usually public and places that are usually private. On a large sheet of paper, make a chart with two columns, one labeled "Public Places" and another labeled "Private Places." Ask your child to give examples of places under each column. If your child is unsure if a place is public or private (or if it could be both) make a third column for these examples. For individuals who have difficulty reading, use drawings, pictures or other symbols.
   - **Picture Sorting Activity.**
       - Collect magazine pictures of places (both indoors and outdoors, both with people in them and without people in them. A good source for room pictures is furniture store advertising).
       - Ask your child to look at the pictures and label them as public, private or sometimes public and sometimes private places. Pictures can be sorted into piles or taped to two ends on a wall or on a large sheet of paper with unclear pictures in the middle.
       - For greater clarity and comprehension, use the picture sorting activity to talk about public and private places within your home. Normally, our own homes would be considered to be private places, but when we live with other people, some of the rooms may be public places and others may be private places. Using pictures of different rooms in a home, ask your child to identify which rooms are private places and which rooms are public places. Point out that in most homes, the private places are the bathrooms and bedrooms. We make these places private when we close the door. We respect people's privacy when we knock on closed doors and are invited to come in (or told not to come in).

2. **Reviewing Public and Private Activities**
   - **Defining Public and Private Places.**
     Talk about public and private places as follows:
     - Public activities are things we usually do with other people or when other people are around us or can see us.
     - Private activities are things we usually do by ourselves (when we are alone). Sometimes, we do private activities with another person.
   - **Charting Public and Private Activities.**
     Ask your child to think about activities that are usually public and activities that are usually private. On a large sheet of paper, make a chart with two columns, one to list "public activities" and one to list "private activities." Ask your child to give examples of activities under each column. Examples of private activities can include going to the bathroom, taking a bath or shower, taking all our clothes off, adjusting our underwear and so on. Depending on your child's age, you may also wish to include masturbation or touching our genitals and sexual activity with another person (including touching another person's genitals, sexual intercourse or passionate kissing).
3. **Reviewing Private Body Parts**
   - **Define Private Body Parts.**
     Describe private body parts as the parts of our bodies that are covered by our underwear or bathing suits. These parts are the breasts, vulva and buttocks on females, and the penis, testicles and buttocks on males. For further clarification, provide your child with the following information:
     - When we are in public places, we wear clothing that covers our bodies. Usually, most of our bodies are covered in public places, but our private body parts are always kept covered. The one exception is changing rooms and showers at public gyms and swimming pools (where private changing areas are not available).
     - As people get older, expectations about covering body parts change. For example, little girls may not consider breasts to be a private body part, but older girls and women do consider these to be private body parts and keep this area covered when in public places. Also, babies and toddlers may be seen without clothes on in public places (for example, at a beach) but this is not considered appropriate for older children and adults.
     - When people get older (usually when they are adults) they may decide to share a private part of their body with a romantic partner. This should only happen when both people agree to share and if they are in a private place.

- **Identification and Brainstorming Activity.**
  Present your child with a list of different places and ask him or her to identify what parts of the body should be covered when we are in these places. For further clarification, ask your child to identify what kind of clothing we would normally wear in these places. Note that when we are in a public place such as a school or movie theatre, we wear more clothing over our underwear (even though underwear covers our private parts, it is not enough in many public places).

  The list should involve some discussion about confusing places such as a public changing room that does not have private cubicles and a doctor's office. Have your child discuss and brainstorm covering our bodies in the following places (you may wish to add others):
    - Shopping mall
    - At the beach
    - At school
    - In a movie theatre
    - At a party (or perhaps a pool party)
    - At a public changing room at a gymnasium or swimming pool
    - At a doctor's office (in the waiting room and on the examining table)
    - At home, while in the bathroom
    - At home, while standing in front of a window from which people who are outside can see you
- **Brainstorming Activity.**
  Discuss with your child when it is okay for someone to see your private parts. The answers may differ, depending on the age of the learners. Some answers may include:
    - When our parents helped us bathe or get dressed when we were younger.
    - When we are having a physical exam by a doctor (sometimes a nurse is also present).
    - When we are having a gynaecological exam by a doctor (sometimes a nurse is also present).
    - When we are in a public changing area (at a swimming pool or gymnasium) and there are no private places for changing or showering.
    - When we are with a romantic partner as an adult and we both agree to share our private parts with each other.

- **Dressing a Doll Activity.**
  This activity is recommended by Schwier and Hingsburger (see the Additional Resource list at the end of the chapter). This is an excellent activity that parents can do with their young children. For this activity, you will need male and female dolls with removable clothing. It is recommended that you use anatomically realistic dolls (such as Teach-A-Bodies) and use the following steps:
    - ▶ Ask your child to determine if the doll is a boy or girl (or man or woman). If your child does not know, show him or her how you can tell. Pretend with your child that the doll wants to go shopping. To make it interactive, have your child decide what the doll would like to buy. When the doll is naked, ask if the doll can go to the store. Explain that the doll, like people, must wear clothes because other people will see her in the store as a public place.
    - ▶ Put on the doll's underwear. Ask if she is now ready to go to the store. Why not? Although she has covered up her private parts with clothes, these underclothes are private clothes and not for everyone to see.
    - ▶ Put "outside" clothes on the doll, such as shirts, pants, dresses, hats and shoes. Explain to your child that these are the kind of clothes we wear in public places. You may wish to extend the learning by teaching your child what kind of clothes should be worn for different seasons, different temperatures, weather conditions and different social events.

- **At-Home Learning Activity.**
  This is another activity recommended by Schwier and Hingsburger to teach the concepts of public and private. For early learners or for individuals who have difficulty understanding concepts, the authors recommend simplifying the concepts and using visual cues so as to remind the learner of "privacy rules." Families can use the following steps:
    - ▶ Separate your child's clothing into public and private drawers. Mark each with a symbol – for example a picture of an open door for public and a closed door for private. Another symbol is the use of red tape for private and green tape for public. It is recommended that families not use a happy face for public and a sad face for private because their child may assume that private means sad or mad.

- Next, on the doors of the public rooms of the home, place the public symbol. On the private rooms, place the private symbol. Explain to your child that in public rooms, we wear public clothing. When we are in private rooms, it is okay just to have our underwear on, or no clothing at all. When we are doing private things like getting dressed, using the toilet, taking a bath, we usually close the door to our private rooms.

SEXCESS

Inclusion NB supports individuals with an intellectual disability in achieving healthy sexuality and in developing positive relationships. Inclusion NB staff are trained in "Sexcess" facilitation. Inclusion NB facilitators can help parents who are struggling with a particular challenges related to sexuality and healthy relationships by providing one-on-one support with your son or daughter. This includes coaching on issues such as self-esteem, basic sexuality, boundaries, healthy vs unhealthy relationships and abuse prevention. Inclusion NB may also be able to connect families to other resources that may help address these and other issues. To learn more about Sexcess facilitation for your son or daughter, please contact Inclusion NB main office at 1-866-622-2548.

Inclusion NB also delivers Sexcess workshops at various times throughout the year. This three day workshop gives participants the tools necessary to support an individual with or without an intellectual disability in understanding boundaries and healthy relationships, self-esteem, puberty, dating and romantic relationships, recognizing sexual exploitation and abuse and much more. The training is based on Inclusion NB's publication *Friendships, Feelings and Futures: Relating to Myself and Others*. Upcoming workshops will be announced in the events section of Inclusion NB website: www.inclusionnb.ca.

Helping Your Child Understand Puberty

Puberty is an important time of transition and change for everyone. Being aware of these changes and what they mean can help make puberty a positive time rather than a confusing one. Here is some information and activities that you can use with your child to help him or her to better understand puberty.

- Using pictures or illustrations that show people in different life stages, talk about puberty being a time of change for all people. Puberty means that we are "growing up" and are changing from a child into an adult. (Inclusion NB has illustrations that can help with this discussion. If you would like to get copies of these illustrations contact Inclusion NB office).
- Note that the changes we experience during puberty are gradual – that is, they happen over a period of 4 to 5 years.
- Note that people can begin puberty at different ages, and that girls usually begin puberty earlier than boys. For girls puberty usually begins between the ages of 9 and 11. For boys,

puberty usually begins between the ages of 10 and 12. Some people may begin puberty at a later age, which is normal.

- As an activity, ask your child to identify some of the main changes that occur during puberty for boys and girls. Assist your child to identify which changes happen only to girls, only to boys, and to both boys and girls. Write two lists on a large sheet of paper with the headings "Male/Boy" and "Female/Girl." After the brainstorming exercise, assist your child to identify any missing information or any incorrect information. Make sure you stress that these changes are normal for everyone.
- Use pictures or illustrations which show some of the physical changes that happen from childhood to adulthood. These physical changes include:
    - Increases in height (males and females)
    - Broadening of shoulders (usually more in males)
    - Broadening of hips (usually more in females)
    - Development of pubic hair (males and females)
    - Development of facial hair (males)
    - Development of larger breasts (females and, to some extent, males)
    - Development of larger genitals (males and females)

  Stress again that all of these changes are normal and may take four to five years to complete.

Reviewing Menstruation

For females, the beginning of menstruation is a major event in puberty. Learning about menstruation involves having information about internal parts of the body and the words used to describe these parts. Some people with disabilities may have a difficult time understanding the words or the concepts. It may be necessary, therefore, to simplify the information. It is important that people be assisted to understand that the monthly discharge of blood that begins during puberty is a normal activity for females and is not dangerous. On the next few pages are some activities that you may want to use with your child.

It is important that people be assisted to understand that the monthly discharge of blood that begins during puberty is a normal activity for females and is not dangerous.

- **Introducing the Vocabularly**

  Introduce your child to the following words and their meanings:
    - Ovary: a storing place for human eggs
    - Human eggs: very tiny cells or things that the female body uses to make babies during reproduction. The size of the egg is about size of a dot on a piece of paper made by a pencil or pen.

  - ▶ Uterus: the place inside a female's body in which a baby can develop or grow from an egg.

- **What Happens During Menstruation**
  Using an illustration, review what happens inside a female's body during menstruation. (Inclusion NB can provide a copy of an illustration – please contact Inclusion NB office if you would like a copy). Depending on your child's level of understanding, review the following information:
  - ▶ Point out the ovaries and uterus, noting to your child that these parts of the body are inside the female's body and cannot be seen.
  - ▶ Inform your child that each female is born with many eggs that are stored or kept inside the ovaries. At the time of puberty, the ovaries begin to release or let go of the eggs, one at a time. This happens once each month.
  - ▶ The ovaries can begin release or let go of the eggs any time between the ages of 9 and 15 or 16. For many girls, this begins to happen around the ages of 11 or 12.
  - ▶ Each month, an egg travels or moves down a tube (Fallopian tube) and into the uterus. The uterus has a lining or wall that gets thicker and fills with blood. This happens to help a baby (called a foetus) grow inside the uterus.
  - ▶ If there is no baby (or foetus) growing, the lining with the blood is not needed. About once a month, it comes out through the vagina. This is called "having a period" or menstruation. This process repeats itself about once each month when there is no baby growing in the uterus.
  - ▶ Most females stop menstruating or having periods between the ages of 45 and 60. This is because the ovaries stop releasing eggs into the uterus. Some females stop menstruating earlier than age 45. If this happens, a female should talk to her doctor.

- **Reinforcement Activity**
  Give your child a copy of the illustration showing the female internal reproductive parts. Ask or assist your child to circle the ovary and draw a line with a pencil to show how the egg moves from the ovary into the uterus. Next, ask her to colour the lining of the uterus with a red pen or a fine tipped red marker. Next, ask or assist your child to draw a red line that shows where the lining comes out. Also ask or assist her to retrace the red line with a pencil, showing that the egg also comes out with the lining.

- **How Does Menstruation Make Me Feel?**
  Point out to your child that menstruation or having your period is a very normal process. Females may, however, experience:

    - An ache or cramps in the area of the uterus before menstruation starts and also during menstruation;
    - A feeling of being tired or more easily upset (grouchy) when menstruation is happening.

Stress to your child that they should talk with you, another trusted adult or their doctor if they think that there is something wrong with their menstruation.

- **Menstrual Hygiene**

  This learning activity should be conducted with your child on a one-on-one basis or in a group with no males present. Emphasize the private nature of menstrual hygiene. Display and discuss menstrual supplies. Note the following information:

    - Menstrual supplies are purchased in a drugstore, grocery store and some department stores.
    - One type of supply is called a sanitary napkin. This is worn outside the body, but inside the female's underwear or other undergarments. The napkin catches the blood from the vagina. It is worn when the person is having her period.
    - Another type of supply is called a tampon. This is inserted into the vagina to absorb or catch the blood before it comes out. A tampon should be changed when they are full of fluid or every 4 to 6 hours. Most girls or women use sanitary napkins or pads when sleeping at night.
    - Review when to use supplies. Note that some people use the supplies when they think they might start their periods. Show your child that using a calendar can be helpful in predicting when a period will start. If supplies are not being used before a period starts, it is important to recognize when it has started (by noticing red or blood in underwear). When this happens, start to use supplies as soon as possible.
    - Model and practise disposal of menstrual supplies. Using red food colouring and actual supplies, demonstrate the proper way to dispose of used supplies by folding and wrapping the supplies with toilet paper. Also demonstrate where the wrapped used supplies should be discarded. Have or assist your child practise proper disposal. Make sure you include washing hands.
    - Review the private nature of good menstrual hygiene. Menstrual care should be done in a bathroom (or a cubicle of a public bathroom), with the door closed.

- ▶ Stress the fact that menstruation is a normal activity for females.

Helping Your Child to Prevent Abuse and Exploitation

It is a well established fact that people with disabilities are at a greater risk of being abused (both sexually and otherwise) than are people who do not have a disability. This is a major issue that is beyond the scope of this guide to fully address. Families have a clear role to play in helping to prevent the abuse and exploitation of their child. This section offers a few activities that will get you started. Inclusion NB has other information that may be helpful to families. We encourage you to do all that you can to equip your child as best as possible to keep safe.

It is a well established fact that people with disabilities are at a greater risk of being abused (both sexually and otherwise) than are people who do not have a disability.

Exploring Different Types of Touch and Touching Rights: A Discussion and Brainstorming Activity

To the fullest extent possible your child should understand when it is okay to be touched and when it is not. Use some or all of the activities below to help your child learn about touching. You may have to modify the activities based on your child's age and ability to understand information.

- Talk with your child about touching and how it is a very important part of our relationship with other people. This is particularly true in our relationships with people to whom we are close (such as close family members, good friends and romantic partners). Touch can also be important with community helpers (such as doctors and dentists) when they do things to help look after us.
- Review with your child the three different types of touch: fair, never fair, and confusing. As you talk about each one, write the word on a large piece of paper. You may wish to use the colours green (for okay), red (for never okay) and yellow (for confusing) to help learners who will benefit from additional visual cues.
    - ▶ **Okay touch:**
      This is touch that you allow to happen and which makes you feel good and happy.
    - ▶ **Never okay touch:**
      This is touch that you do not give your permission to happen and that might or might not hurt your body, or make you feel sad or ashamed. Many times, people who do *never okay touch* will want to keep it a secret (not tell anyone else)

  - **Confusing touch:**
    This is touch that you are not sure about or that makes you feel worried or uncertain. Sometimes, confusing touch can seem to feel different or wrong.

Sometimes, a touch may be *okay* or *never okay*, depending on who does it and how it happens. Often, this will depend on whether we give our permission for the touch to happen. For example, if a doctor touches our private parts as part of a medical examination, this would be okay touch if we gave our permission to the doctor. However, if a stranger or acquaintance touches our private parts without our permission, this would not be an okay touch.

- Remind your child that different types of touching may be fair or okay in certain relationships or with certain people. Ask your child to brainstorm about different types of touching. Write the word "touch" on a large sheet of paper and ask for ideas about different types of touches. You may wish to have pictures of various types of touches on hand to use as they are mentioned or to add to the list if they are not mentioned. Alternatively, you may wish to model some of the suggestions. Below are some touch examples that may be helpful:
  - Shaking hands
  - Kissing
  - Holding hands
  - Hugging
  - Doctor's exam
  - Slap on the face
  - Punch
  - Touching private parts of the body
  - Tickling
  - Forcing someone to have sexual intercourse
  - Agreeing to have sexual intercourse with someone whom you know well and love
  - No touch
- Next, talk about how to describe each of the types of touch that are identified. Are they okay, never okay, confusing? Place an "x" through the ones that are identified as *never okay.*
- Remind your child that every person has rights and responsibilities when it comes to touching. Our rights include:
  - To be touched only in ways that are okay and respectful
  - To be touched in a sexual or affectionate way only with your permission
  - Never to be touched in a violent way, except by choice (like when playing a "contact sport" such as football or hockey) and never to be touched in a way that is not okay

Ask your child to repeat the statements of touching rights out loud (you may want to do this several times over a period of time). Remind your child that if someone touches them in a way that is not okay, it is not your fault but the fault of the other person.

Explain that just as we have touching rights, we are also responsible for the way we touch others.

Helping Your Child Learn the Importance of Saying "No" and Getting Away

The activities below explore the protection strategies of saying no and getting away. It also encourages people to role play these two steps in order to practice self-protection skills.

- Explain to your child that saying "no" to something we do not want is very important. Saying "no" means that we are not giving our permission for something to happen. When we say no clearly and assertively, there should be no confusion about what we want. Often, when we say no, another person will stop what they are doing. Saying no is important when:
    - ▶ Someone is trying to touch you and you do not want to be touched;
    - ▶ Someone is trying get you to do something you do not want to do (or you are not sure you want to do);
    - ▶ Someone is asking you personal questions.

  When we say "no," we can also use other words such as "Stop bothering me." "Don't touch me," and "Leave me alone."
- Stress the importance of saying "no" like you mean it. This means you are being assertive. When we say "no" like we mean it, we:
    - ▶ Sit or stand up straight;
    - ▶ Look the other person in the eye;
    - ▶ Say it in a clear and loud voice.

  Ask your child to practise saying "no" in a clear, loud voice and then in a soft voice. Ask them to compare the two ways to say no. You may want to use a recorder and play back the examples of saying no assertively and not assertively.
- Next, talk about "getting away" as the next step in protecting ourselves. Note that this means leaving the place where we are to get away from the person who is bothering us. Sometimes, this is not possible. If you cannot get away, and someone hurts you, this is not your fault. If you can get away, keep the following in mind:
    - ▶ Get away as quickly as possible (run if you can).

    - Go to a safe place (where there are other people around who can help you, for example, Block Parents, police station, friends house, grandparents house).

- As an optional discussion, you may wish to help your child think about situations in which it may be unnecessary to get away. Some people may have great difficulty in distinguishing when getting away is or is not necessary, so it may be best to leave out this discussion. Getting away may not be necessary when:
    - The person stops bothering you after you say, “no”.
    - You do not feel you are in any danger after you have said no.

  Ask your child to think about some examples of when getting away may not be necessary (for example, when a girlfriend or boyfriend tries to hug you, and they respect your wishes after you have said no). Remember to stress that if you feel unsafe in any situation try to get away as quickly as possible.

- Ask your child to role play saying “no” assertively and getting away. You may use a variety of role play situations that best suit the age or other circumstances of your child. You may wish to model the role play situations with another person before asking your child to do it him or herself. Below are a few suggestions for “say no, get away” role plays:
    - Your next door neighbour offers to give you $20 if you will take off your clothes.
    - Someone has just asked you to put your hands down his pants in exchange for a present that he has bought for you.
    - A stranger driving a car stops and asks you if you want to go for a drive.
    - A stranger sitting beside you on a bus puts his or her hand on your leg.

Ideas for Helping Your Child to Develop Relationships and Friendships

Having friends and caring relationships is important for all of us. From an early age most people learn the skills they need to develop and nurture friendships and other relationships. These skills involve learning how to initiate contact with others, learning to play together and keep the relationship going, and learning to resolve conflicts that may arise.

For some people with disabilities making friends and developing relationships outside of the home can be more difficult. This may be due to various reasons, including some difficulties that people may have in relating to a person who has a disability. Whatever the reason, it is sometimes necessary to find ways to help your child to develop relationships with others. Below are some ways to make this happen.

Create or Look for Opportunities for Community Involvement for Your Child

Being involved in groups and activities is a great way for your child to get to know people and make friends. Many people also develop relationships from their involvement in faith communities. For further information, review the ideas provided in Chapter 12.

While Circles are developed with one person in mind who may be isolated, they are usually developed without putting too much emphasis on the individual. In this way the person is not "singled out" as being different. Emphasis is placed on the group and what the group does with some thought given to how the person is being well connected in the group.

Establish a Circle of Friends for Your Child in School or in the Community

Circles of Friends is a program of Inclusion NB. This is different from the Circles program discussed earlier in this chapter. In the context of developing relationships, a Circle of Friends is a way to bring a group of people together who provide opportunities for people with a disability to make friends and do activities with.

Circles of Friends are usually developed for children and youth in elementary and middle school (high school is more difficult for various reasons). Circles can also be created in other contexts such as community groups such as Scouts or Boys and Girls Clubs. Circles are started with the help of a facilitator who meets with the person who may be isolated, his or her family, and the school or group that will be used to create the Circle. The facilitator also helps to recruit members of the Circle (other children) and helps the group to plan activities that usually occur at least weekly, but sometimes more often.

While Circles are developed with one person in mind who may be isolated, they are usually developed without putting too much emphasis on the individual. In this way the person is not "singled out" as being different. Emphasis is placed on the group and what the group does with some thought given to how the person is being well connected in the group. In fact, Circles are often beneficial for many other students, particularly those who may also be having some difficulty "fitting in".

Inclusion NB is available to help train people to facilitate such as a staff person in a school or group or another volunteer.

One note of caution is important. If your child uses the services of an Educational Assistant in school it is important that the EA give your child some space to develop relationships with other students. While a EA could facilitate a Circle he or she needs to be aware of how best to encourage inclusion in the Circle and learn how to step back so relationships can develop and hopefully flourish.

For further information about Circles of Friends please contact Inclusion NB and review the information in the Additional Resources section of this chapter.

The Best Cupcake I Ever Ate

There are not too many things I enjoy more than a good cupcake. But a good success story gets me every time.

I meet with my grade four Circle of Friends group once a week. These students simply know the Circle as a group they joined to make new friends. This particular group is a lively bunch made up of nine girls and one boy. In the weeks since we have started the Circle, I have witnessed some pretty amazing changes in the students. Initially the girls would ask me to ask Josh a question, as they were not accustomed to speaking directly to him, even though they were in the same classroom with him all day.

Getting to the cupcake. I had to miss one week of Circle of Friends when I took a week's vacation. When I returned the following week I asked the students if they continued with their activities while I was away. They told me it had been Josh's birthday and that they had a little party and ate cupcakes together. When Josh arrived I wished him a happy birthday and told him I was sorry to have missed the party and the cupcakes. The group went on to plan their activities for the next week and then went on to dance, which oddly enough is how they choose to spend the remainder of our time together. Josh stayed for a while but then he began to leave. Circle of Friends is voluntary and we do not make students stay if they do not want to. I hoped nothing was wrong but I let Josh leave and we continued with our Circle. A few minutes later a little girl came to the door and asked for me by name. She had blue frosting smudged all over her lips as she handed me a cupcake. She said today was her birthday so it was her turn to get cupcakes. She had one left over and she was giving it to me. Josh had left early to find a teacher and tell her I didn't get a cupcake for his birthday and he wanted me to have one. He felt bad I hadn't been part of the group.

A Circle of Friends meet for less than an hour once a week, the only resource needed is a calendar and the planned activities are simple. The results, however, are incredible. In a few short months of our Circle of Friends, Josh has gone from being outside of the group and not always being included, to now being a full member of a group of close-knit friends. It has evolved from me wanting to ensure Josh belonged and was never left out, to him worrying about me being left out. Circle of Friends benefits everyone involved, in this case even the adult who facilitates the Circle. I left my Circle of Friends that day feeling accepted and part of the group. I drove away with tears of happiness in my eyes and blue frosting smudged over my lips.

Best Buddies

Best Buddies is a national program that is dedicated to creating one-to-one friendships between student volunteers and people who have an intellectual disability. This program "gives people with intellectual disabilities the chance to have experiences which most people take for granted - going for coffee, out to a movie, or simply enjoying the company of a good friend."

With the assistance of organizations such as Inclusion NB, Best Buddies Canada establishes chapters at universities, colleges and high schools across the country. There are currently 175 chapters across Canada. At each chapter students are matched with people with an intellectual disability (usually young adults) who share similar interests. The "Buddy Pairs" call each other weekly and get together approximately twice a month. During the school year, Buddy Pairs at a chapter hold group activities.

In New Brunswick, Best Buddies chapters are in place in the following locations:

- Chapters in Universities
- High Schools
- Best Buddies Canada http://bestbuddies.ca/

For more information about *Best Buddies*, visit the organization's website at www.bestbuddies.ca or contact Inclusion NB.

Establish a Network of Support for Your Child

Personal support networks/Networks of support are an important aspect of planning for a safe and secure future for people with disabilities. A network is a group of people who care about a person to the extent that they will commit to being involved in the person's life on a regular basis. Networks of support usually involve the individual with a disability, family members, friends and other community members. They can also involve service providers and support workers.

Networks of support can play many different roles depending on the circumstances and needs of the person who is at the center of the process. This can include the following:

- Help the person and the family to make decisions
- Help the person and the family make plans for the future
- Make sure that the person's voice is heard
- Make a commitment to the person's future and security
- Provide companionship, enter into a relationship and have fun
- Provide practical support
- Help manage supports and money
- Advocate with service systems and address issues that may arise (Bruce Kappel, *Stronger Together: Ideas, Reflections and Suggestions About Networks of Support*, 1998)

A full list of possible roles is available from Inclusion NB. For each individual, the actual activities of the network may change from time to time. This may depend on the needs of the individual and any issues that may need to be addressed. Likewise, the membership in the network may also change. People may move away or take on other commitments. If people leave the network, it is important to find others who will take their place. Parents may also decide to fade out of being the most active members of the network to allow other people to assume more responsibility.

Getting a network started and then maintaining it can involve some time and effort. Parents can get things started by thinking about who should be initially invited. A first gathering of the network can talk about why the network is necessary and then what needs to be done to support the individual and the family.

Parents may want to find an outside facilitator who can help establish a network of support. A facilitator can help:

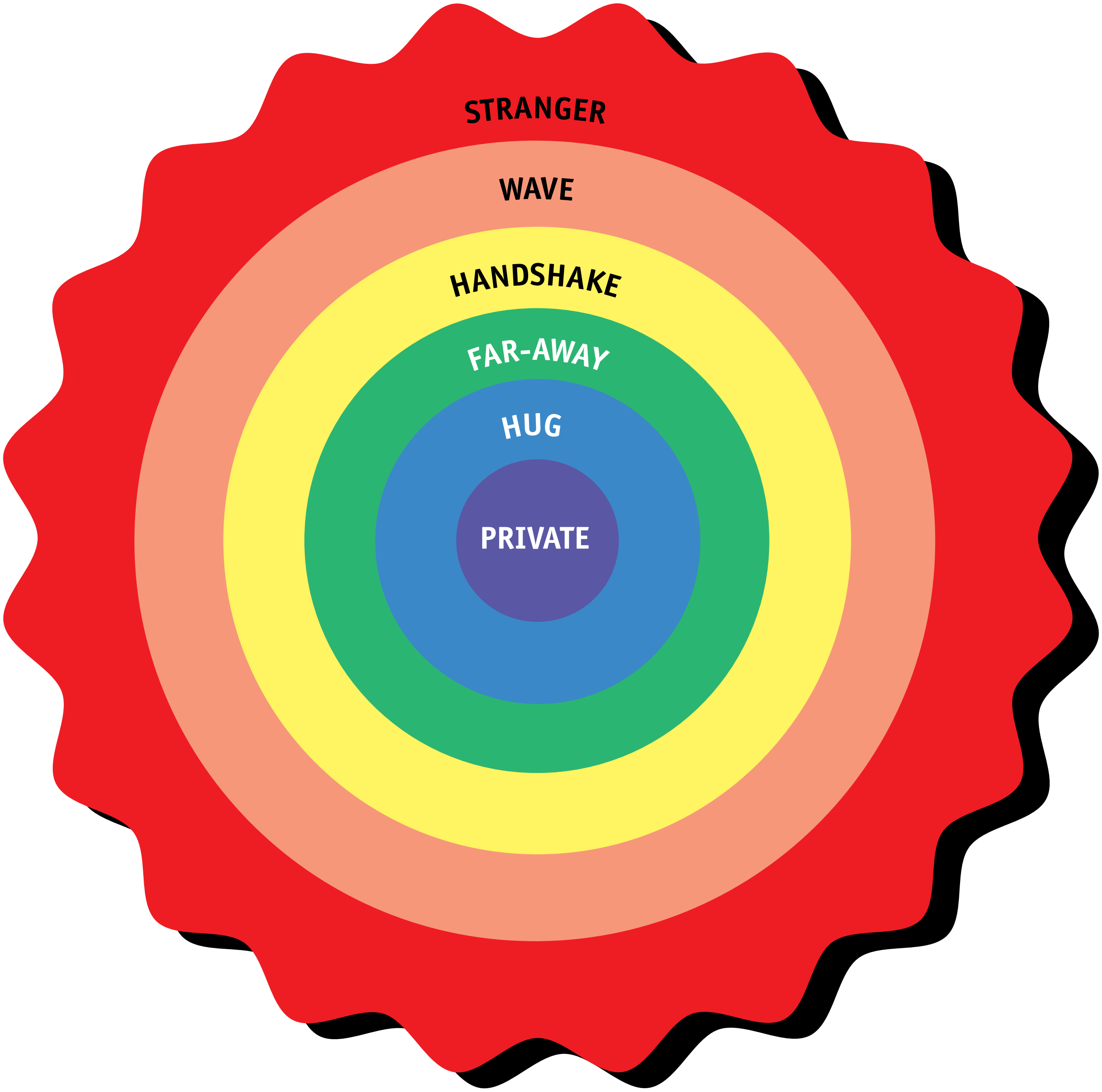
- with invitations to prospective network members;
- run network meetings;
- identify roles for people in the network; and

- keep the network going well into the future.

Inclusion NB will facilitate networks of support through its *Social Inclusion Program*. The program operates in a few regions of the province including Saint John, Moncton, Grand Falls/ Edmundston, Fredericton and Bathurst. The program will facilitate a network for adults with an intellectual disability who are living with a senior parent and/or adults with an intellectual disability who are moving from the family home into a home of their own.

For more information about networks of support, contact Inclusion NB or visit the website of the Planned Lifetime Advocacy Network at www.plan.ca.

"CIRCLES" Reference



Champagne, Merklyn and Walker-Hirsch, Leslie (1993).
Circles 1: Intimacy and Relationships. Santa Barbara, CA: James Stanfield Publishing Company.
Tel (800) 421-6543. Web address: www.stanfield.com

Additional Resources

Available from Inclusion NB

Circles of Friends: An Instruction Manual for Facilitating Support Circles (2002).

Friendships, Feelings, Futures: Relating to Myself and Others: Facilitation Guide (2004).

Other Resources

Circles I: Intimacy & Relationships; Marklyn Champagne & Leslie Walker-Hirsch; James Stanfield Publishing Company (1993). www.stanfield.com

Circles II: Stop Abuse; Marklyn P. Champagne and Leslie Walker-Hirsch; James Stanfield Publishing Company (1986).

Just Say Know: Understanding and Reducing the Risk of Sexual Victimization of People with Developmental Disabilities, Dave Hingsburger, Diverse City Press (1995).

Making Sense of Sex: A Forthright Guide to Puberty, Sex and Relationships for People with Asperger's Syndrome (2008)

LifeFacts: Sexuality; Toolkit. James Stanfield Publishing Company. www.stanfield.com

Sexuality: Your Sons and Daughters with Intellectual Disabilities, Karin Melberg Schwier and Dave Hingsburger. Paul H. Brookes Publishing Co. (2000).

Stronger together: Ideas, Reflections, and Suggestions about Networks of Support, Bruce Kappel, Support and Trustee Advisory Services of Brampton Caledon (1998).

The Secret of the Silver Horse.
Pdf availible online at www.crcvc.ca/docs/The_secret_of_the_silver_horse.pdf

The Ties That Bind, DVD. Planned Lifetime Advocacy Network (PLAN). www.plan.ca.

What's the Big Secret?: Talking about Sex with Girls and Boys (1997)
by Laurene Krasny Brown, Marc Brown (Illustrator)
Published by Little, Brown Books for Young Readers

Taking the JOURNEY

An Information and Advocacy Guide
for Families Supporting a Child with a Disability

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."

InclusionNB

CHAPTER 12

Support for Families

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.

Respite

Respite is about getting a break or some short relief from your care giving responsibilities. However, it is also more than this. Respite 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 Respite Happen?

Respite 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 Respite 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 respite. This will allow families to use this money to hire someone to provide respite 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 Respite

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. Respite 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 Inclusion NB website.

Inclusion NB

Since we are producing this guide we will take the opportunity to tell you about some of the things that Inclusion NB does to support people who have an intellectual disability and their families. Inclusion NB 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 Inclusion NB main office in Fredericton.

- **Disability Support Program**
  Independent Facilitation Services. Since April 2005, Inclusion NB 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.**
  Inclusion NB'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.**
  Inclusion NB 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 Inclusion NB 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.**
  Inclusion NB 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. Inclusion NB 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. Inclusion NB 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.**
  Inclusion NB 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, Inclusion NB 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

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.

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.

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

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

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:

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.

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

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

Public Legal Education and Information Service of New Brunswick

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

(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.

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.

Here is the contact information for PLEIS:

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 Inclusion NB office in Fredericton and ask for the Manager of Family Support. Families can also follow Inclusion NB 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 Inclusion NB 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. ______________________________

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____

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

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

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

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Additional Resources

Available from Inclusion NB (free to families)

Everyone Can… FUN-NB (brochure)

Other Resources

It Matters: Lessons from my son. Janice Fialka. Inclusion Press, www.inclusion.com

In the Company of Others: Stories of belonging. Sandra Shields and David Campion, Plan Institute for Caring Citizenship, 2005. www.plan.ca

Taking the JOURNEY

An Information and Advocacy Guide
for Families Supporting a Child with a Disability

CHAPTER 13

Financial Issues and Estate Planning

"Planning is what we do
so that we are approximately right
instead of exactly wrong."

InclusionNB

CHAPTER 13

Financial Issues and Estate Planning

Goal for this Chapter

- To learn about a number of important financial related issues and ways to plan to provide for your child now and in the future.

What You will Find in this Chapter

- Information about:
  - Financial help available through the tax system
  - Financial planning and the new Registered Disability Savings Plans (RDSPs)
  - Estate Planning
  - Considerations when planning financially for a family member with a disability
  - Creating wills and trusts
- **Worksheet 10** – Estate Planning for a Child with a Disability
- A List of Additional Resources

Our Journey So Far

- Many people with disabilities live in poverty or live on fixed incomes.
- While more people with disabilities are finding jobs, many still rely on government programs for their income.
- In recent years the laws have improved so that people with disabilities can have more assets and other sources of income and still receive provincial income support benefits. As a result, the laws are clearer about what families are able to do to support their family member who has a disability.
- Families now have different options for dealing with financial issues and for planning for the future. These include using the tax system, establishing a Registered Disability Savings Plan, leaving a home or setting up a trust.

Introduction

Now we come to the exciting part of the guide (okay, so we exaggerate a bit).

While maybe not terribly exciting, financial issues and estate planning are obviously important for families and their children with a disability. Families can have additional expenses when raising a child with a disability and, sometimes, face financial pressures if one parent stays home rather than goes to work. In addition, families want to make sure that their child will have enough money to have a good life now and in the future.

Information regarding income support benefits for people with disabilities was reviewed in Chapter 9 and will not be covered in this chapter.

Financial Help Available Through the Tax System

The Canadian Income Tax System provides for a number of important benefits and deductions for people with disabilities and their families. Over the past several years, the federal government has made improvements to the tax system.

Each year, the Canada Revenue Agency produces and updates a guide entitled Medical and Disability Related Information (CRA document number RC 4064). People can usually get this guide at their local Canada Revenue Agency Office or from the agency's Internet site – www.cra-arc.gc.ca (click on "Forms and Publications" on the left margin, then select "Client Group" under "Listed By" and then on "Persons with Disabilities"). The guide is also available in alternate formats for people who require Braille, large print, e-text, or audiocassette.

The benefits, tax credits and deductions include a number of important features that primarily help to reduce the amount of income tax paid by persons with disabilities and/or their families. Some of the current benefits, credits and deductions include:

Tax Credits and Deductions

- **Disability Tax Credit** *(line 316 of Schedule 1 of your federal income tax and benefit return and line 5844 of your New Brunswick return)*

  This is a "non-refundable" tax credit that helps to reduce the amount of tax paid by people who have a disability. Non-refundable means that it only has value if it is able to reduce the taxes a person owes. The DTC is available for a person of any age who meets the eligibility criteria. A person is eligible for the Disability Tax Credit (DTC) if they have a "severe and prolonged physical or mental impairment" that causes the person to be "markedly restricted" in a basic activity of daily living. A Disability Tax Credit must be applied for using the T2201 application form (available on line at www.cra.gc.ca/forms or by calling 1-800-959-2221). The DTC application form has 2 parts:

  - Part A is personal information that is filled out by the applicant or his or her representative;
  - Part B must be filled out by a "qualified practitioner" (medical doctor, optometrist, audiologist, psychologist, etc.) who certifies the effects of the person's disability.

  Not every person with a disability will be eligible to receive the DTC. It will depend on the nature of the person's disability and sometimes on the quality of the information provided by medical people who are asked to certify the person's disability. Some people who have been denied the DTC have had success when they have reapplied using a different doctor to fill out Part B of the form.

NOTE: Some doctors or other medical professionals may not be willing to sign the application form for the DTC. In this case, you may need to ask for a second opinion to have the application form completed.

Once the Disability Certificate is obtained from the Canada Revenue Agency, it continues to be valid for subsequent tax years until the person's condition changes. It is not necessary to obtain a new DTC each year, unless the CRA requests this.

HELPFUL TIP:
If your child is eligible for the Disability Tax Credit but does not have enough income to use it, a parent or caregiver may be able to claim it instead to reduce his or her income.

- **Disability Tax Credit Supplement for Children** *(line 316 of Schedule 1 of your federal income tax and benefit return and line 5848 of your New Brunswick return).*
  If your child is under 18 at the end of the year and qualifies for the Disability Tax Credit, you can claim an additional amount for the tax credit. This credit "supplement" may be reduced if someone claims child care expenses or attendant care expenses (as a medical expense – see below, or as a deduction on line 215).

- **Transfer of the Disability Tax Credit** *(line 318 Schedule 1 of your federal income tax and benefit return and line 5844 of your New Brunswick return).*
  If your child is eligible for the DTC but does not have enough income to use it, the credit can be transferred to you as a caregiver. When you can claim an amount for a dependent adult or child on lines 305, 306 or 315 of the federal tax form, then your child can transfer the DTC to you. This includes any *DTC Supplement for Children* as discussed above. This can result is significant tax savings for families.

- **Medical Expense Tax Credit**
  This also a non-refundable credit that you are able to claim for medical expenses that you have paid for your child or another relative who is dependent on you for support. You are able to claim for the full amount of medical expenses you paid less any amount for which have been reimbursed (for example from a private insurance company).
  This credit covers a variety of expenses that people with disabilities or their families may incur, including attendant care expenses, voice recognition software, food for special diets, sign language interpreters, payments for vehicle adaptations, special equipment, and travel costs to access specialized medical care. For a full list of eligible medical expenses see the *Medical and Disability Related Information* guide available from the Canada Revenue Agency.

- **Infirm Dependent Tax Credit** *(line 306 Schedule 1 of your federal income tax and benefit return and line 5820 of your New Brunswick return).*
  This is another non-refundable tax credit. It applies if your adult child with a disability (18 or over) is living in your home and is dependent on you for support. If you or another person is claiming the Caregiver Tax Credit for your child (line 315) then you will not be able to claim this credit.

- **Caregiver Tax Credit** *(line 315 of Schedule 1 of your federal income tax and benefit return and line 5840 of your New Brunswick return).*
  You can claim this non-refundable tax credit if your child is 18 or over and you are his or her primary care giver. Your tax package contains federal and provincial "worksheets" that you can use to find out how much you can claim.

- **Child Care Expenses Deduction** *(line 214 of your T1 general income tax and benefits return).*
  This is a deduction rather than a credit meaning that whatever you can claim reduces the amount of income on which you have to pay tax. You can claim expenses for child care you paid to work, go to school, run a business or do research. There are special provisions for child care expenses for children who have a disability. You need to calculate your amount using the federal form T778.

- **Disability Supports Deduction** *(line 215 of your T1 general income tax and benefits return).*
  This deduction allows people with disabilities to claim expenses for personal attendant care and other disability supports expenses that were used to go to school or work. However, the person cannot claim this deduction if he or she or someone else (such as a parent) claims these expenses as medical expenses for the Medical Expense Tax Credit.

Tax Benefits

Tax Benefits provide direct payments from the federal government to families who have children who are younger. They generally are given to people who apply and qualify and who have filled out their income tax forms.

The income tax system can be complicated. If you are unsure of what kind of benefits, credits, or deductions that you or your child may qualify for, talk to a counsellor at the Canada Revenue Agency or an accountant who assists people in the preparation of income tax returns.

- **Universal Child Care Benefit**
  This is a "universal" benefit which means that your eligibility to receive it does not depend on how much money you earn. It pays $100 per month for every child you have under the age of 6. You do not to apply for the benefit if you are already receive the Canada Child Tax Benefit or have already applied for the Canada Child Tax Benefit. Otherwise you have to apply to receive using the federal government form RC66.

- **Canada Child Tax Benefit**
  This benefit provides a monthly cheque to families who have children under 18 years of age. The amount that you receive will depend on your family's net income from the previous year. In order to receive this benefit you and your spouse have to file an income tax return. To apply for this benefit you need to fill out form RC66 that you can get by calling the Canada Revenue Agency or from the CRA website www.cra.gc.ca/forms.

- **Child Disability Benefit**
  In addition to the Canada Child Tax Benefit (CCTB) you may also be able to receive the Child Disability Benefit. This will be paid as a supplement to the CCTB if your child who has a disability is eligible to receive the *Disability Tax Credit*.

Registered Disability Savings Plans

In 2008, the government of Canada established a new tax deferred savings plan for people with disabilities. Registered Disability Savings Plans (RDSPs) provide opportunities for parents and others to make contributions and for people with disabilities to receive government grants and bonds. Inclusion NB has a detailed resource booklet for families who are interested in using an RDSP to plan for their child's future security. Contact Inclusion NB office in Fredericton to obtain a free copy.

Who is Eligible?

A person can be a "beneficiary" of an RDSP if they are:

- A resident of Canada; and
- Eligible to receive the federal Disability Tax Credit (DTC) – see the information above under tax credits and deductions.

Who Can Open an RDSP?

If the beneficiary is a minor, a parent or legal guardian can open an RDSP and become the 'holder' of the plan. If the beneficiary is an adult, he or she can open an RDSP and

Note: An important principle of law is that people who are adults (age 19 or older in New Brunswick) are presumed to be competent until proven otherwise. If you believe that your child is able to sign an agreement to open an RDSP you may have to remind people that he or she is presumed to be competent to do so.

become the holder of the plan. If, however, the beneficiary is an adult but not considered 'competent' to enter into a contract then:

- A person who is a legal representative of the beneficiary (for example, the beneficiary's Power of Attorney or court appointed guardian) can open the RDSP and be the plan's holder; or
- Until the end of 2016, the parent(s), spouse or common-law partner of an adult who is unable to enter into a contract are be able to open and become the holder of an RDSP (this temporary measure has been put in place to allow each province to make its own laws on opening RDSPs for adults who cannot do this for themselves).

Contributions to RDSPs

Each RDSP will have a $200,000 lifetime contribution limit. With the holder's written consent, anyone can make a contribution for a beneficiary under an RDSP. There is no annual limit on contributions and contributions can be made until the year in which the beneficiary turns 59.

Canada Disability Savings Grant

The Canada Disability Savings Grant will provide a federal contribution to assist families and individuals to save for the future. Grants will be greater for families or individuals in the lower and middle-income categories. For plan beneficiaries who are 19 and over, the relevant income will be that of the beneficiary and his/her spouse or common law partner. This means that the income of parents will not be considered when deciding the amount of the grant.

Here are some rules about the Disability Savings Grant:

- The Grant can be received until the year the plan beneficiary turns 49;
- The maximum federal lifetime Grant contribution will be $70,000;
- Grants will not be considered part of the $200,000 contribution limit;
- Beneficiaries must wait 10 years after the last Grant is received to avoid repayment rules (see the section below on withdrawals and payments).

Canada Disability Savings Bond

The Canada Disability Savings Bond is an amount of money that the federal government will pay into an RDSP that will not require any contributions. All that will be necessary is to have an RDSP in place and a yearly application to receive the bond. It will provide a federal contribution of $1000 to an RDSP when family or individual yearly income falls under a certain amount that is established each year. The Bond will be phased out gradually for families or individuals whose income is above the yearly limit. As with the Disability Savings Grants, when the plan beneficiary is 19 or older, it is his or her yearly income and not the parent's income that will be considered.

Here are some rules about the Disability Savings Bond:

- The Bond will have a $20,000 lifetime limit and can be received until the year the beneficiary turns 49;
- Bonds will not be considered part of the $200,000 contribution limit;
- Beneficiaries must wait 10 years after the last Bond is received to avoid repayment rules.

Withdrawals/Payments from an RDSP

There are two types of payments that can be made from an RDSP:

- **Disability Assistance Payments** (DAPs). These are discretionary withdrawals from the RDSP to the beneficiary, which can be made at any time.
- **Lifetime Disability Assistance Payments** (LDAPs). These are annual withdrawals that must begin by the age 60 (but you can choose to begin these payments earlier). Once started, LDAPs must continue to be paid at least once per year until the beneficiary passes away or the plan is closed.

Payments from an RDSP are also affected by the following situations:

- If the RDSP has no government contributions (from grants and bonds);
- If there are more personal contributions than government contributions; and
- If there are more government contributions (from grants and bonds) than personal contributions.

Refer to Inclusion NB resource booklet for further details on these payment rules.

In addition, the following rules and conditions apply to payments from RDSPs:

- The money in an RDSP can be used for any purpose.
- Only the beneficiary (or a person who is a legal representative of the beneficiary) will be permitted to receive payments from the plan.
- Withdrawals from an RDSP does not affect a person's eligibility for federal benefits such as the Canada Child Tax Benefit, the Goods and Services Tax credit, Old Age Security, or Employment Insurance.
- Earnings accumulate tax-free until you take money out of your RDSP.
- The grant, bond and investment income earned in the RDSP will be included in the beneficiary's income for tax purposes when paid out of the RDSP. Original contributions to the RDSP will not be included in the beneficiary's income for tax purposes when paid out of the RDSP.

Repayment Rules

The grants and bonds are intended to encourage savings and must remain in an RDSP for at least 10 years to avoid repayment rules. Currently, whenever money is withdrawn from an RDSP, or if the beneficiary dies or loses his or her entitlement for the Disability Tax Credit, all grants and bonds paid into the RDSP during the previous 10 years must be repaid to the Government.

In 2014, a new ‘proportional repayment’ rule came into effect for ***withdrawals*** from an RDSP. This rule requires that $3 be repaid to the Government of Canada for every $1 that is withdrawn, up to the maximum ‘Assistance Holdback Amount’ (the total of all grants and bonds paid into the RDSP within the last 10 years). Private contributions and investment income earned are not affected by the repayment rules.

The original repayment rule (all grants and bonds paid in to the RDSP within the past 10 years) will still apply if the beneficiary dies or if the beneficiary loses his or her eligibility for the Disability Tax Credit.

Impact on Provincial Programs

The government of New Brunswick has exempted the RDSP as an asset for adults with disabilities who receive provincial income support benefits. This means that the RDSP can grow in value over time without affecting the amount of the monthly cheque a person can receive. Once payments are made from the RDSP, the person receiving income support benefits will be able to withdraw $800 per month from the plan without having his or her cheque affected. Lump sum payments will also be exempt if they are approved by the government prior to the withdrawal. If more than $800 per month is withdrawn then the person’s cheque will be reduced dollar for dollar for any amount above $800.

The government of New Brunswick has exempted the RDSP as an asset for adults with disabilities who receive provincial income support benefits. This means that the RDSP can grow in value over time without affecting the amount of the monthly cheque a person can receive.

Estate Planning

Estate planning is an important aspect of family financial and future planning. Overall, financial planning is about reviewing your family’s financial situation, determining your financial needs and goals, and deciding how you are going to achieve your goals. When you have a family member with a disability, financial planning tends to address the goal of providing for your family member today and in the future.

Estate planning is about deciding how you distribute your assets and provide for the people who you care about. There are a number of important things to consider when preparing an estate plan, especially if you are intending to support a loved one with a disability. Worksheet 10 at the end of this chapter will help you record some important information.

Estate Planning Considerations and Options

You have several options for deciding how and when to distribute your assets:

- The most commonly known option is through a Will. A Will distributes your assets only upon your death and has no impact on your estate until you die. Spouses should each have their own Will.
- You can also distribute assets at the time of your death but outside of your Will. This happens when you own assets jointly with another person who has a "right of survivorship". This can include assets such as a home, other real property, or a bank account. Upon your death, the other person who has the "right of survivorship" will automatically own the jointly owned asset. Your Will has no effect on the distribution of the asset.
- Another way of distributing assets upon your death (but outside your Will) is through a beneficiary designation. This usually happens with assets such as RRSPs, RRIFs, insurance policies or pension plans. A person who is named as a beneficiary will be entitled to receive the asset upon your death.
- You may need to think about the consequences (e.g., the effect on government benefits and the person's ability to manage money) of leaving assets directly to a family member with a disability using these estate planning options.
- A third estate planning option is the distribution of assets while you are still alive. This can be done by giving "gifts" of money or other property to others before your death. It can also involve establishing a trust for a loved one while you are still alive.
- Keep in mind that estate planning is a process rather than a one time event. You may use a combination of the options discussed above. You should also be prepared to review your estate plans regularly (for example, every 2 years) to determine if changes need to be made.

Additional Considerations when Planning for a Family Member with a Disability

When preparing an estate plan to provide for a family member with a disability, there may be some important issues to consider, including:

- How can an estate plan help to provide a good standard of living for a family member with a disability?
- Will your family member with a disability have opportunities to earn an income and to support him or herself?
- Will your family member be able to manage money or other property that he or she may inherit?
- Will your family member need to maintain his or her eligibility for government income benefits or other services? If so, how can your estate plan most effectively maintain and supplement these benefits and services?

- Will your family member need help with housing or maintaining a home?

Creating a Will

A Will is an important component of an estate plan. It is a legal document that only takes effect at the time of your death. You can make or change your Will up until the time you die so long as you are able to understand what assets you own and what you are doing with a Will (that is, signing a legal document to distribute your assets).

Remember, a Will deals only with estate assets that have not been distributed through other means. A Will allows you to appoint an executor who will look after your assets upon your death and to give directions to your executor on how those assets should be distributed.

Before you use the services of estate planners/lawyers there are a number of things you can do to be better prepared:

- ***Prepare a list of your assets and liabilities.***
  For any family assets, you should record who owns them and how they are owned. Also, make a list of assets or insurance policies for which you have already selected beneficiaries. Your lawyer will need to know if you have named your family member with a disability as a beneficiary of assets (such as an RRSP or an insurance policy).
- ***If possible, identify your executors and trustees.***
  You may wish to get some more advice on how best to select people for these roles and whether it makes sense to use financial institutions, family members or friends, or a combination of these possibilities.
- ***Identify how you would like to distribute your estate assets.***
  There may be a lot involved with these decisions and you may need professional help to work out the details. You may want to give people (or charities) specific amounts of money or other property you own or decide who should get a share of your estate.

Creating a Financial Trust

A trust is a legal arrangement whereby a person gives assets (that he or she owns) to a trustee to manage and use for the benefit of another person or a group of people (known as "beneficiaries"). The trustees of a trust have strict legal responsibilities to hold and administer trust assets, to follow the terms of the trust and to act in the best interest of the beneficiary or beneficiaries. Trustees cannot use trust assets for their own purposes and must keep trust assets separate from their own assets.

There are a number of important decisions that must be made when establishing a trust as part of your estate plan.

- ***When to establish the trust?***
  There are two basic types of trusts that differ on when they are established. A living trust is established while you are alive. To become effective, this type of trust requires

creating a legal document and the transfer of assets to trustees. The benefit of this type of trust is that it sets aside assets for a beneficiary at an earlier time. It also will allow families to oversee the administration of the trust or even be a trustee of the trust. There are tax issues to be considered when setting up a living trust. Income earned within these types of trusts is taxed at the highest federal tax rate. There may be ways to limit the amount of tax that will have to be paid. When setting up this kind of trust, make sure you obtain good advice from an expert in tax issues (for example, an accountant or lawyer who specializes in tax law).

The second main type of trust is called a testamentary trust. This is a trust that is established through your Will and only takes effect upon your death. This means that you can change the terms of the trust while you are still alive. This type of trust also allows you to continue to use your assets while you are alive. Currently, testamentary trusts are taxed in the same way as individuals. This means that tax rates will depend on the amount of income that the trust earns each year from investments. For most modest sized trusts, the lowest tax rate will be used.

Beginning in 2016, new tax rules will take effect. Most testamentary trusts will be taxed in the same ways as living trusts (at the highest tax rates). However, the current "graduated "rates (that depend on how much income is earned) will continue to apply to trusts if the beneficiary is eligible for the Disability Tax Credit.

- ***Who will be the trustees?***

  Choosing a trustee or trustees is a very important estate planning decision. Your trustee will decide when and how to use the money or other property you have put in trust for the benefit of your family member. There are a variety of options for choosing trustees. You can rely on other family members or friends or you can appoint a financial institution to fulfill this role. You might have one trustee or two or more trustees. When you have two or more trustees (called co-trustees) they must usually decide jointly about how to manage and administer the trust properly. You can also appoint alternate trustees who will take the place of a trustee who may be unwilling or unable to continue to act as a trustee.

  There are a number of important considerations when choosing trustees:

  - Your trustee's willingness and desire to take on this responsibility.
  - The trustee's relationship with your family member with a disability. Generally, the trustee should be someone who knows and cares about your family member.
  - The trustee's ability to manage and invest assets.
  - The trustee's knowledge and understanding of rules regarding government benefits and services (particularly if your trust is intended to supplement these sources of support).
  - Your trustee's age in relation to the age of your family member with a disability.

Choosing a trustee or trustees is a very important estate planning decision. Your trustee will decide when and how to use the money or other property you have put in trust for the benefit of your family member.

- ***What assets will be put in trust?***
  Again, there are a variety of options that you can consider for establishing a trust. A trust can receive a specific sum of money, a share of your estate, proceeds from a life insurance policy, or real property such as a home. A living trust will usually be established with a specific sum of money or an identified asset. Testamentary trusts can be set up to receive a share of your estate or the proceeds of a life insurance policy.
- ***What kind of trust will be created?***
  This issue requires careful consideration if you are planning for a family member with a disability. Make sure you get good legal advice before you decide on how to establish a financial trust. There are provincial rules that you may need to consider (for example, the provincial government now allows people with disabilities who receive income support benefits under the Extended Benefits Program to have up to $200,000 in a financial trust, as well as some monthly income (up to $800 per month) from the trust, without affecting their monthly cheque).

  Generally, there are three kinds of trust options to consider:

  - ▶ ***An income trust.***
    This type of trust is designed to pay the beneficiary a regular income from a trust. This kind of trust can be a useful way to supplement the income of a family member with a disability. Depending on how much income is paid each month (or otherwise), an income trust may affect the amount of money the person can receive from government programs that provide income support benefits and disability related services.
  - ▶ ***A support trust.***
    In this type of trust, trustees are given some specific direction to use the trust to support and maintain the beneficiary. Trustees can be given some discretion about how the support should be provided and how much money is paid from a trust either monthly or more or less frequently.
  - ▶ ***An absolute discretionary trust.***
    An absolute discretionary trust (sometimes referred to as a “Henson” trust) is a trust that gives trustees full and complete discretion to decide if, when and how to use the trust for the beneficiary. Under this kind of trust, trustees have no specific obligations and cannot be forced to pay the income or capital to the beneficiary. A potential drawback of this type of trust is that the trustees may, in their discretion, decide not to use the trust for the beneficiary with a disability.
- ***Who will receive trust assets following the death of the beneficiary?***
  In the event that the trust has assets remaining at the time of the beneficiary’s death, your estate plan must indicate who will receive trust assets. Normally, the trust will be terminated at this time and the assets will be distributed according to your wishes.

DID YOU KNOW?

Current rules in New Brunswick allow people with disabilities (who are certified as being "disabled", deaf or blind by the provincial government) to have assets in an RSDP and a trust fund up to $200,000 without having income support benefits affected. In addition, the rules allow for the person to receive up to $800 per month from the RDSP and/or trust fund without affecting the monthly cheque from the province. Other payments from an RDSP and/or trust may also be received if they are first approved by the government of New Brunswick.

How this Helps People with Disabilities

If, in 2014 a person with a disability had $800 per month in income from a trust and/or an RDSP and received the maximum amount under the Extended Benefits (Including the Disability Supplement, he or she would have the following monthly income:

$763 – Income from Extended Benefits
$800 – Income from a Trust and/or RDSP
$1563 – Total Monthly Income

Under this scenario, a person would have a yearly income of $18,756.

In addition, under current rules a person receiving Extended Benefits can also earn up to $500 per month from employment without having his or her government benefits affected (plus 30% of income above $500 (month)). Added to the income he or she could have from a trust and/or RDSP and government benefits, this would mean:

$763 – Income from Extended Benefits
$800 – Income from a Trust and/or RDSP
$500 – Income from Employment
$2063 – Total Monthly Income

Under this scenario, a person would have a yearly income of $24,756.

Worksheet 10

Estate Planning for a Child with a Disability

1. If you were to die today, what would be the value of your estate? Include all assets and life insurance less any debts that would have to be repaid.

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2. Will you put any of your estate plans into effect before your death? ☐ Yes ☐ No

If so, what will you do?______________________________

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3. Have or will you set up a Registered Disability Savings Plan for your child? ☐ Yes ☐ No
If so, what do you believe that this plan will be worth when your child starts to receive regular payments from it?

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4. Are you aware of your assets that will pass outside of your Will when you die? ☐ Yes ☐ No
   a. Have you provided a designation of a named beneficiary with financial institutions for your RRSP, RRIF, TFSA, pension plan or life insurance policies? (If yes, these assets will pass outside your Will). ☐ Yes ☐ No
   b. Do you own assets jointly with another person (for example, property or bank accounts)? ☐ Yes ☐ No
   (If yes, these assets will pass outside your Will if you are the first to die).

5. Who do you want to be the executor of your estate when you die?

____

6. What assets do you wish to leave to your child who has a disability (specific assets, a share of your estate, etc.)?

____

____

____

7. Will you be setting up a trust for your child with a disability? ☐ Yes ☐ No
   If so, answer the following questions:
   a. When will the trust be established (while you are alive or when you die)?

   ____

   b. Who will be the trustees of the trust?

   ____

   c. What do you intend to put in trust for your child?

   ____

   d. What kind of trust will you use? You may require legal advice to decide this.

   ____

   e. Will the trust be designed to supplement government income benefits that your child receives or may receive in the future? ☐ Yes ☐ No
   f. If there are assets left in the trust when your child dies, do you want the trust to pay for funeral and burial expenses for your child? ☐ Yes ☐ No
   g. If there are assets left in the trust when your child dies, who do you want to receive the remaining trust assets?

   ____

   ____

   ____

8. Do you want to use your assets to provide a home for your child with a disability? ☐ Yes ☐ No
   If so, who will own the home and how will it be managed?

____

____

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Additional Resources

Available from Inclusion NB (free to families)

Estate Planning for Families who Have a Family Member with a Disability: an Information Kit for Families

Estate Planning for Families who Have a Family Member with a Disability: an Information Kit for Planning Professionals

The Registered Disability Savings Plan: Information for Families (2014)

Other Resources

Medical and Disability Related Information, Canada Revenue Agency.
Available on-line at www.cra.gc.ca.

Taking the JOURNEY

An Information and Advocacy Guide
for Families Supporting a Child with a Disability

CHAPTER 14

Decision Making and Your Child

"One of the greatest gifts
that you can give your child is to
encourage him or her
to be as
independent as possible."

InclusionNB

CHAPTER 14

Decision Making and Your Child

Goal for this Chapter

- To learn about ways you can help your child to learn to make decisions.

What You will Find in this Chapter

- Information about:
  - Encouraging your child to make decisions
  - Decision making rights and "Supported Decision Making"
  - Appointing guardians for your minor children
  - Substitute decision making for adults
- A List of Additional Resources

Our Journey So Far

- Parents have said that they are sometimes the biggest barriers to their children learning to make their own decisions. It is easier and often quicker to make decisions for your child.
- Parents have also noted that they have a lot of anxiety about their children making the wrong choices.
- More and more, however, parents of children with disabilities are learning that it is important that their children learn to make their own decisions. They know that this can be a life long process and that starting as early as possible is important.

Introduction

Making choices and decisions for ourselves is an important part of who we are. Learning to make good decisions often takes a lot of practice during the time that we are children, teenagers and even adults. We are all capable of making choices that may not be good for us. Often times, we learn important lessons from making poor choices. Developing the ability to make good decisions is important for a number of reasons:

- It helps us develop a sense of control over our own lives.
- It teaches us that we are responsible for ourselves and that we often have a responsibility to others.
- It helps us become more assertive and, therefore, less vulnerable to exploitation.
- It helps us develop positive and healthy relationships with others.

Encouraging Your Child to Make Decisions

One of the best things that you can do for your child is to encourage him or her to make decisions. Often, parents of children with disabilities are tempted to make all decisions for their child. Encouraging your child to make decisions (and to develop decision making skills) will mean that your child will have better opportunities, as they grow older. In considering your child's ability or potential ability to make decisions, remember the following:

Often, parents of children with disabilities are tempted to make all decisions for their child. Encouraging your child to make decisions (and to develop decision making skills) will mean that your child will have better opportunities, as they grow older.

- ***Your child may be able to make more decisions then you presume.***
  Ask yourself how you will help to encourage your child to make his or her own decisions now and in the future. Most people develop their decision-making barriers by making small decisions first.
- ***People with disabilities sometimes communicate in different ways (for example, sign language, other gestures, picture boards, etc.).***
  Decisions are often expressed in ways people may not understand. Listen to your own child's choices and help others understand the way in which he or she communicates. The way in which you communicate with your child will be an important lesson for others.
- ***Making decisions sometimes involves taking risks.***
  Allow your child the chance to make decisions even if some risk is involved.
- ***It is typical for all of us to ask others for help and opinions when we make decisions.***
  Your child can also benefit from the help and support from other people in the same way.
- ***Do not expect perfection from your child when he or she is making decisions or choices.***
  We all make mistakes from time to time. Remember, every decision or choice has consequences, some good and some bad. Everyone, whether or not they have a disability, has to learn this.

There are some activities and actions that you can do to help your child develop the ability to make choices for him or her self.

Choosing Activity

The following activity is from Inclusion NB publication, Friendships, Feelings and Futures: Relating to Myself and Others. This book contains a module designed to help people with disabilities learn to make decisions.

This activity is designed for younger people. It may, however, also be useful for others. The purpose of the activity is to help your child become aware of the fact that we make decisions about a lot of different things. It is also designed to have your child think about what is involved in making decisions.

- Present the activity as a "choosing game." Your child will be presented with two items or activities between which he or she is asked to choose. For individuals who do not speak, the game will need to be set up to allow individuals to point to a choice or to use a communication device with which they are familiar (for example, a picture board). Remember that some people may require more time to make a choice.
- Set up the activity with various items or activities that provide choices for your child. You can modify the game to make it more relevant to your child's age. Some suggestions for choices include:
    - ▶ Choosing between an apple and an orange for a snack;
    - ▶ Choosing between an apple and a chocolate bar for a snack;
    - ▶ Choosing between two movies to watch;
    - ▶ Choosing between wearing a red shirt or a blue shirt;
    - ▶ Choosing between going to a park or a playground or to a museum
- Following the activity, ask your child about the decisions he or she made. Were they easy ones to make or were they more difficult to make? Why do they think they made these choices?
- This activity can be modified to involve role-playing of situations that require a "yes" or "no" answer. For example, your child could be asked to decide to accept or refuse an invitation to go swimming with a friend. This activity can invite your child to practise ways of saying yes or no in ways that are respectful of other people's feelings.
- Families can offer opportunities for choosing at home or in other environments. For example, when an individual asks for a drink, a choice of water, juice or milk may be offered.

Other Activities that Promote Decision Making

In addition to the above activities, here are a few more for you to consider:

- Use laminated pictures for various situations that will require your child to make decisions. For example, a number of pictures can be used to help your child to decide what he or she needs when going outside. This could include pictures of a coat, shoes, backpack, hat, mitts or gloves, etc. Depending on the time of year or where your child may be going, the choosing activity can allow your child to make decisions in various situations. It may be helpful to put Velcro on the back of the pictures and put them on a mini-board so that they are always in the same place and easy to keep track of.

- A variation on the above activity is to use pictures of food that have magnets attached so that they can be placed on the refrigerator. Your child can choose from the various pictures and tell you what he or she has chosen to eat or drink.
- To encourage decision making about money, give your child an allowance so that he or she can choose how to spend it. You can also set up a joint bank account that provides your child with some say over how much money is deposited or withdrawn and for what purpose.
- Many people with an intellectual disability have difficulty learning money concepts (and thereby have trouble making decisions about spending money). If your child has this kind of difficulty, explore using a simple program called "prudent payment" that helps people learn to count money. It is based on a person being able to count to ten. You can find information about prudent payment in the Family Support section of Inclusion NB website.

Provide Your Child with Opportunities to Practice Making Decisions

Encouraging the development of decision making skills also means that your child will need to practice speaking up for him or herself. This will obviously be more of a challenge if your child does not communicate with words. Your child's ability to speak for him or herself will be particularly important during times that you and your child are engaged in planning for the future and setting goals.

As much as possible, your child should be present and participating in meetings or discussions that involve making decisions or plans about his or her future. In addition, try to use opportunities to encourage your child to speak up for him or herself. There may be many different opportunities for this to happen (for example, while shopping, signing up for or becoming involved in community activities, social gatherings, and so on.

As much as possible, your child should be present and participating in meetings or discussions that involve making decisions or plans about his or her future.

Use the On-Line Resource on Self Advocacy with Your Child

Inclusion NB has developed a self advocacy on-line resource (called Opportunity Link) that is designed for people who have a disability who want to learn about making decisions and speaking up for themselves. It is a voice and print based program that reviews a number of aspects of decision making and self advocacy, including:

- What self advocacy is all about and why it is important
- What it means to make decisions for ourselves
- The different types of decisions we make
- What rights we have (particularly as adults)
- Ways that people can speak up for themselves

This program is designed for people with disabilities to use on their own or with some help, if necessary. It prompts people to think about various aspects of making decisions and understanding their rights. Families are encouraged to use this program with their own child or to ask someone else (such as an employment counsellor or someone from your child's school) to assist your child to use the program.

You can find the program on Inclusion NB website, www.inclusionnb.ca. Just use the "Opportunity Link" quick-link on the right hand side of the home page and go to Module 4: Advocacy Skills for Families (plain language version).

Decision Making Rights and Supported Decision Making

When we become adults (in New Brunswick this legally happens when we turn 19) the law recognizes that we have the right to make our own decisions – regardless of who we are. This is an important part of our law as it recognizes that when we become adults we acquire rights (and responsibilities) that are valued in our society. The law presumes that we are all "competent" to make our own choices. This right to choose allows us to control our own lives and decide what we believe is best for us.

This right to make decisions can be affected in a number of ways. People who break the law and end up in jail lose the right to decide many things – particularly where they will live. Our rights can also be given to another person voluntarily (such as through a Power of Attorney). Or they can also be taken away from us by the appointment of a legal guardian by a court (this is discussed below).

There is something important that parents of children with disabilities need to understand. When your children are minors (under age 19) you have the right to make decisions for them based on what you feel is in their best interests. Your rights can be challenged if your decisions are seen to put your children at risk of harm (this is what the child protection system is about). When your children turn 19, however, you lose the legal right to make decisions for them because they are presumed to be competent to make their own decisions.

When your child with a disability turns 19 there may not be much fanfare or change in the way decisions are made within your family. You are likely still going to be greatly involved in helping your child make decisions. Or, you may still be making decisions on his or her behalf that you feel are best.

Supported Decision Making

Supported decision making is a fairly new legal idea that is based on the rights of people to make their own decisions when they become adults. This idea has developed as a way to recognize the rights of people with disabilities to make their own decisions and choices. It provides an alternative to the laws that exist that remove people's rights because they are not considered to be "competent".

Supported decision making is now recognized in law at the international level. The new *U. N. Convention on the Rights of Persons with Disabilities* provides that countries must take "appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity" (Article 12). "Legal capacity" is a phrase that means one's right to make decisions.

The new U. N. Convention on the Rights of Persons with Disabilities provides that countries must take "appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity" (Article 12). "Legal capacity" is a phrase that means one's right to make decisions.

Some provinces in Canada (but not New Brunswick as yet) have also passed laws that recognize supported decision making as a valid way to help people to make decisions when they may have difficulty doing this on their own.

While the laws around supported decision making are still being developed there are many things that families can be doing to support their children to make decisions. The following suggestions are adapted from a draft new resource from the Canadian Association for Community Living called *Decision Making and Intellectual Disability: Supporting People to Make their Own Decisions.*

Supported Decision Making: Suggestions for Families

- **Help explain what decision needs to be made.**
  If your child is not used to making decisions he or she may benefit from having you explain what decision has to be made and why it is important. Depending on the decision, it may also be helpful to explain how the decision affects your child's future.
- **Get and provide useful information about the decision.**
  Without prior experience or knowledge, your child may need some additional information in order to make a decision.
- **Provide information in plain language**.
  Language can sometimes exclude people from participating in decisions that are going to affect them. By making language plain, you can help your child understand more about the issue or topic. You can use plain language by:
    - ▶ Using smaller words that are easier to understand
    - ▶ Breaking down ideas so that too many things are not presented at once

  - Using shorter sentences
  - Avoiding jargon or medical or legal language
  - Using direct language that describes things clearly

- **Provide your child the opportunity to ask questions and take time to listen to concerns.**
  Listening can also mean observing and interpreting things like your child's "body language" or responses.
- **Provide time to make decisions.**
  It may not be helpful to always expect that a decision be made right away. Your child may need some time to think about what he or she is being asked to decide. Ask yourself if this is a decision that needs to be made now or can it wait for a while.
- **Discuss the pros and cons of decisions that may need to be made.**
  One of the most difficult aspects of making decisions is understanding the consequences of the choices we make. Help your child as much as possible understand what different decisions might mean so that he or she has a better appreciation for what may happen.
- **Understand what your child is communicating and help others to understand what he or she is "saying".**
  Sometimes your child may have difficulty communicating or may not communicate by using words. As a parent, you will likely be best in tune with your child's way of communicating. This will be important for identifying your child's wishes or decisions about a number of things. It may also be crucial for interpreting what your child is saying and letting other people know what choices he or she is making. Informing other people about your child's way of communicating will help others learn how best to listen to your child and to respect his or her decisions.

Another key aspect of supported decision making is ensuring that there are people in your child's life who are committed to making sure that he or she has a good life (including having the right to make decisions and choices). In ***Chapter 11, Healthy Relationships and Sexuality***, we reviewed the idea of developing a "network of support" for your child. Such a network may be an important way of ensuring that there will also be people available who are willing to support your child with making decisions that will affect his or her life.

Another key aspect of supported decision making is ensuring that there are people in your child's life who are committed to making sure that he or she has a good life (including having the right to make decisions and choices).

Appointing Guardians for Your Minor Children

If your children are under age 19, you have the legal right to make decisions for them. You also have the right to appoint other guardians for your children should something happen to you. The Guardianship of Children Act allows parents to use their Wills to appoint a guardian of their minor children. This could allow another person to be a guardian either jointly with a surviving parent should you die or upon the death of the surviving parent.

This law can be an important planning tool for families. It gives you the right to decide who will look after your child (and possibly other minor children) should you and your spouse die before he or she reaches 19. If you have a potential future guardian in mind it is important that you have a conversation with that person to make sure that they are in agreement with your wishes. Then you must make sure that the right wording is placed in your Will to make it effective should you die. This should be done along with other plans that you have made to leave your money and other assets to benefit your children (see Chapter 13 for more information about estate planning).

Substitute Decision Making for Adults

There are two main ways to have a substitute decision maker appointed for someone who is an adult:

- **By using a Power of Attorney.**
  This is a legal document that allows a person to appoint someone else to make decisions on his or her behalf. A Power of Attorney is usually done up by a lawyer and can affect decisions of a financial nature and/or decisions about your personal care (for example, medical treatment). In order to have a valid Power of Attorney a person must be able to understand what he or she is signing and what it means for them (that someone else will be making decisions and managing his or her affairs). If a person is not able to understand what the Power of Attorney is about then he or she by law will not be able to make one. Also, one person cannot create a Power of Attorney for another person. A Power of Attorney ends when it is either revoked by the person who made it or when he or she dies.
- **By having a substitute decision maker appointed by a court.**
  This requires a formal court application that usually involves lawyers. The law for this in New Brunswick is called the Infirm Persons Act and it requires that a judge decide that someone is "incompetent" to make decisions or manage his or her financial or personal affairs, or is incapable of doing so. It also requires medical and other evidence from professionals who can talk about a person's abilities to make decisions. If a court makes an order to appoint a substitute decision maker then this effectively removes the right of the person to make decisions for him or herself. This process is usually quite expensive and can cost several thousands of dollars for legal and court fees.

Alternatives to Appointing Substitute Decision Maker for Adults

There are important alternatives to having someone declared incompetent and removing their rights that need to be considered. If you are considering this for your adult child keep the following in mind:

- There are ways to support your child to make decisions (see the information earlier in this chapter on supported decision making). Having a support network set up for your child can ensure that people will be available to help your child make decisions even when you are not around.
- Even if you (or someone else in your family) need to make a decision for your adult child this can still happen in an informal way. Oftentimes, doctors and other people will accept the decision of a parent because of the relationship that you have with your child.
- In the event of a medical emergency, medical professionals do not need a person's consent in order to provide medical treatment.
- If your child has difficulty managing money (or other property) you can set up a trust that provides for trustees to make decisions about how money or property is managed and used. This can be done while you are alive or through your Will. See the information on estate planning in Chapter 13 for further details.
- If your child is receiving government income support benefits, the provincial government can appoint you or someone else to act as a trustee for these benefits.
- You can establish a joint bank account with your child to help him or her manage money and make decisions about how to spend it wisely.

Additional Resources

Available from Inclusion NB

Friendships, Feelings, Futures: Relating to Myself and Others, 2004.
See Module 6: Making Choices for Myself and My Future

Opportunity Link: Module 4 – Self Advocacy. This is an on-line module designed for people with disabilities. It uses pictures and voice-over format to make it easier for people to use. It contains information about making decisions. To access, go to www.inclusionnb.ca and click on the "Opportunity Link" quick link on the right hand side of the home page.

Taking the JOURNEY

An Information and Advocacy Guide
for Families Supporting a Child with a Disability

CHAPTER 15

Dealing with the Medical System

"As a parent of a child with a disability you may find that the medical system can be one of the toughest systems to advocate in… and the most confusing"

Navigating the System,
Saskatchewan Association for Community Living, 2004

InclusionNB

CHAPTER 15

Dealing With the Medical System

Goal for this Chapter

- To learn about being an effective advocate for your child when dealing with the medical system.

What You will Find in this Chapter

- Information about:
  - Ideas and strategies for being an effective advocate with the medical system
  - Creating a good working relationship with your child's doctor(s)
  - Addressing issues and concerns
  - Financial consideration
- A List of Additional Resources

Our Journey So Far

- At times, people with disabilities have faced discrimination in the medical system. In part, this has stemmed from medical professionals lacking knowledge of people with disabilities and human rights laws.
- While medical professionals are getting better at serving people with disabilities, families often must be vigilant in advocating for their child when he or she is involved with the medical system.

Introduction

Dealing with the medical system can be challenging for families who have a child with a disability. This can be particularly true if your child's disability or condition involves one or more serious medical issues. But it can also be true for people with disabilities who are otherwise healthy.

New Brunswick's medical system has many wonderful people doing great work and who serve people well. But like all systems, the medical system has its challenges. These challenges include funding limitations, doctor shortages, lack of access in rural areas, lack of expertise in some medical areas, waiting lists for tests and treatment, and so on. Some of the challenges involved in pediatric care are addressed more than adequately by having access to out of province institutions such as the IWK Children's Hospital in Nova Scotia.

There may also be challenges related to the lack of knowledge and understanding amongst medical professionals about people who have disabilities. Many medical professionals (including doctors) are not adequately trained in disability issues and human rights. In the past (and to some extent presently) this has led to discrimination against people with disabilities in the area of medical care and treatment. For some families, this has meant being told that their concerns about their child's health are unfounded. For other families, it has meant their child being denied basic medical treatment because he or she has a significant disability (this is sometimes based on beliefs that people who have significant disabilities have no quality of life – which is a very dangerous and false viewpoint).

Ideas and Strategies for Being an Effective Advocate with the Medical System

There are a number of steps you can take to become an effective advocate for your child when dealing with the medical system. Here are a few ideas:

Know Your Child's Rights

Under federal law all Canadians have the right to universal health care services. Every province also has the obligation to provide equal access to public health care to all citizens. In addition, the *Charter of Rights and Freedoms* (part of our constitution) and the New Brunswick *Human Rights Act* prohibit discrimination on the basis of disability. Governments and health care providers have a duty to provide "reasonable accommodations" to people with disabilities so that they can equally participate in the health care system. For more information on human rights laws please see the information in Chapter 1.

Inform Yourself about Your Child's Disability and Medical Issues

You may receive a lot of information from medical professionals about your child's medical issues. There are, however, many other sources of information on specific medical diagnoses or issues, medications, other treatments, etc. that you may want to review. Your child's doctor(s) may offer this information or you may find it on the internet, from diagnosis specific organizations, through other families, and through published books. You may also want to share information that you find with your child's doctors or other medical professionals and find out how this may apply to your child's situation.

Choosing a Good Doctor

Given current problems with doctor shortages (many doctors state that they are not taking new patients) you may feel that you do not have much choice when it comes to selecting a doctor for your child. In some areas, the choice of specialists may even seem more restrictive.

Even if choice seems limited, finding a good doctor is still an important goal for you and your child. The following advice comes from families in Saskatchewan:

> *The most important advocacy tool is knowing someone in the medical system. If you have a committed doctor who is willing to do the research and make sure your child receives the best medical treatment, you will be miles ahead. Many parents expressed their gratitude for having a doctor who would listen to their concerns and get things done. Doctors are paid for the time they see you and are accountable to you. Find a doctor who respects your child. You need a doctor who truly believes that your child is not a "burden". . . . Also, a good doctor will be able to explain things in words you can understand, not technical jargon.*
>
> *You will need to get your doctor to fill out forms for your child, such as tax forms. It is important to note that this service is not covered by Medicare which means you might have to pay the doctor a small fee. Many parents explained that their doctor never charged them, yet had filled out many forms.*
>
> *Since children with disabilities sometimes face complicated medical challenges, it is a good idea to have a pediatrician as your child's regular doctor. . . . A general practitioner (GP) who is willing to do the research and advocate for your child can be just as effective as a pediatrician. However, many GPs do not have the knowledge base to deal with developmental issues.*
>
> (From: *Navigating the System: An Advocacy Handbook for Parents of Children with Intellectual Disabilities,* Saskatchewan Association for Community Living, 2004).

With any doctor who is serving your child you may want to find out his or her level of knowledge of your child's particular disability or condition. If limited, you may need to look for other sources of good information or find out if a referral to a specialist might be possible.

Beyond a doctor's knowledge and expertise, you will want to have a doctor who is approachable and who has positive interactions with your child. The way in which any medical professional treats your child may be a good indication of that person's commitment to your child and the way in which he or she values people who have a disability.

Create a Positive Relationship with Your Child's Doctor

Having a positive relationship with your child's doctor will be important. A positive relationship will be one in which:

- You feel comfortable asking questions and providing your thoughts and ideas
- Both you and your doctor are "good listeners"

- Your doctor takes time to consider and address your concerns
- You show your doctor the way you want your child to be treated
- You share information about the good things going on in your child's life and the doctor is interested in your child as a person
- You express your gratitude for your doctor's help and understanding

(Adapted from: *Building Early Intervention Partnerships with Your Child's Doctor: Tips from and for Parents,* Washington State, Department of Social and Health Services)

Create and Maintain a Medical Journal

Having your own medical journal can be an invaluable way to keep track of information that will be vital to your child's health care. A medical journal can include a number of things, including:

- A record of doctor's visits/appointments and what was discussed
- A record of your child's medications (including doses) and other treatments and how your child responds to these treatments
- Information about allergies to foods and medications
- Information about your child's symptoms and how these symptoms change over time
- Contact information for your child's doctors or other medical professionals

Trust Your Instincts

You know your child better than anyone else. This knowledge gives you the ability to sense when something is not right with your child's health. It also gives you an important role in your child's care or treatment. Do not hesitate to speak up when you have concerns or when you have information that you know is important for others to hear.

Get the Most out of Medical Appointments

Sometimes it can be difficult to get appointments with doctors (especially specialists). Here are some suggestions for getting good value from the time you are able to spend with doctors or other medical professionals:

- Try to schedule an appointment at the beginning of the day or right after lunch if you want to reduce waiting time. This may be important for your child if he or she has difficulty "sitting still".
- If you have questions or concerns that may take more time to discuss, ask for a longer appointment or alternatively, book two appointments at the same time.
- Prepare yourself ahead of time. Make a list of the questions or concerns you want to talk about or what information you want to share with your doctor. Find out if your doctor is

open to you sending a list of things to discuss ahead of time. You may need to decide what issues are most important if you think that you will run out of time. Or, you may tell your doctor what you want to talk about and decide together what you will cover during the appointment and what may need to be discussed at a later time.

- If possible take notes. It is often difficult to remember everything you discussed after the appointment is over. Taking notes will be much easier if you have another person with you (perhaps your spouse) and one of you is responsible for writing things down.
- If the doctor provides you with information that you find difficult to understand, ask if you can call her or him later to ask questions you may have after the appointment.

(Adapted from: Building Early Intervention Partnerships with Your Child's Doctor: Tips from and for Parents, Washington State, Department of Social and Health Services)

Ask for a Second Opinion and Referrals When Needed

Having a second opinion or a referral to a specialist can be important if you are unsure of your doctor's diagnosis or advice for treatment. Do not be hesitant to ask for another doctor's opinion or advice as many medical professionals will be prepared to make referrals if you feel that this is necessary.

Consider a Nutritionist

Sometimes medical and other problems (including challenging behaviours) can be caused by reactions to food or from having the wrong diet. Sometimes doctors will only be interested in dealing with your child's medical symptoms – and will provide treatment (usually medications) that seeks to reduce these symptoms. Problems can also arise if a person lacks important vitamins and minerals – which is not uncommon for some people with a disability. It may be important (if not crucial) to find out if something in your child's eating habits or vitamin/mineral deficiencies is causing physical problems and reactions. A nutritionist may have special knowledge about how changing your child's diet can help his or her situation. Other families may also have information on things that they have tried that have helped their children.

Tips for Safeguarding Your Child During Hospital Stays

Being in hospital can be challenging for any person but there may be additional concerns when the patient has a disability. Families can play important roles in making sure that their child receives the best possible health care when in hospital. Here are some tips that other families have offered:

- When your child is required to go to hospital, bring your medical information with you to make sure that the hospital staff have the right information.
- Be available to help interpret your child's medical symptoms (especially if your child does not communicate well on his or her own).
- Help hospital staff know or understand how to identify that your child is in pain.
- To ease your child's anxiety, arrange to do a hospital tour with your child before he or she is admitted.
- As much as possible have a parent or other advocate at the hospital to support your child and to deal with doctors and other medical staff. Find out if you or someone else can stay overnight (on a cot). The less time that your child is at the hospital by him or herself the safer he or she will be.
- If you have concerns, be direct with doctors and other medical staff. If necessary, use the hospital patient advocate or social worker to help you address issues that may arise.

Financial Considerations

Addressing your child's medical concerns can be costly. Here are a few suggestions to help families deal with the financial aspects of dealing with the medical system:

- Keep track of all of your medical expenses as you may be able to use them to reduce the amount of income tax that you are required to pay. This includes expenses for travel if you have to take your child outside of your community to see specialists, etc. For more information see the section on the Medical Expense Tax Credit in Chapter 13.
- If your child has a health card he or she may be eligible for financial assistance to travel out of the province for medical treatment. For more information, see the section on the Health Services Program in Chapter 9.
- Families may also be able to get financial assistance to cover the cost of parking passes while your child is in hospital. If this is a concern, speak with the hospital social worker to find out if you are eligible.

Medical professionals are also very important in helping people with disabilities to become eligible for the Disability Tax Credit. If your child cannot use this credit (because his or her income is too low) then it can be transferred to a parent so that his or her income tax can be reduced. For more information, see the section on Tax Credits and Deductions in Chapter 13.

Additional Resources

Building Early Intervention Partnerships with Your Child's Doctor: Tips from and for Parents, Washington Department of Social and Health Services.
Available on-line at www.del.wa.gov/publications/esit/docs/FamilyGuide_English.pdf

Families Partnering with Providers: Tips to Help Families Build Effective Partnerships with their Child's Health Care Providers, Family Voices, 2007.
Available on-line at
www.familyvoices.org/admin/work_caring/files/partnering_providers.pdf

Family Voices: Keeping Families at the Center of Children's Health,
website – www.familyvoices.org.

Nutritional Needs in Autism, Slides from a presentation by Dr. Joan Jory (2010). Available from Inclusion NB.

Nutritional Needs in Down's Syndrome, Slides from a presentation by Dr. Joan Jory (2010). Available from Inclusion NB.

Final Remarks

A Journey Worth Taking

This guide has covered many important topics that families face as they raise and support their children who have a disability. It may be necessary for you to read and work through this guide several times to fully digest the information presented.

We called this guide *Taking the Journey* because we believe that supporting a child with a disability to grow, learn and reach his or her potential is a life long journey of discovery for parents and their children. Along the way there will be successes and failures, as well as smooth sailing and rough seas. There will be issues that challenge families to be strong advocates for their children. There will be many stories to tell as children grow and change.

As many families know, the journey may not always be easy but having good and current information will help to ensure that your loved ones who have a disability will have a better chance to have a good life. Families are encouraged to share this information with others who are dealing with some of the same issues. We also encourage you to check Inclusion NB website for updates to this guide so that you can be kept informed of new developments as they occur. Finally, we sincerely hope that the information that is offered in this guide will help make your journey an easier one.