

WELCOME

TO THE FAMILY



New Brunswick
Association For
Community Living

Association du
Nouveau-Brunswick
pour l'intégration
communautaire





Welcome to the Family is an information package for parents who have just found out that their child has a disability. We know that this will not answer all of your questions or concerns. We sincerely hope that it will give you the information that will send you on the right path to helping you get the information that you need.

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Project Coordinator, Danny Soucy

Our children are our most precious gifts. Having a child or children changes our lives forever. Children are a source of great joy and provide us with opportunities to learn more about ourselves and about what it means to deeply love and care for another person.



All children are unique – each with his or her own abilities, qualities, characteristics and life challenges. If you are reading this information kit, you have recently learned that your child has a disability. This may mean that you and your child will face more challenges. At the same time, however, your child is a person first who will want to live, play and learn as other children do. As a parent, you will want your child to have the best opportunities in life to live and grow and reach his or her own potential.

This information kit is presented to you by other parents who also have children with a disability. The New Brunswick Association for Community Living (NBACL) was founded in the 1950s by parents of children with an intellectual disability who wanted their children to go to school and have opportunities to learn and develop. The Families United Network of New Brunswick (FUN-NB) was created in 2003 with the support of NBACL to provide ways for families with children with disabilities to get together to share information, learn from each other and to support one another. These parents said that they had wished they had known some important things about having and raising a child with a disability earlier. They noted that having better information and a better understanding of their role as parents after learning that their child had a disability would have made an important difference in their lives and in the life of their child. This information kit is intended to provide you with some valuable information to support you on your journey as a parent of a child with a disability. While this kit covers a number of topics, it will not provide all of the information that you may need. We hope, however, that you will find it helpful to your family.

We wish you the very best.

Congratulations!

I was congratulated when my son was almost one year old. His disability was diagnosed when he was two months old. So I want to be one of the first to say **“Congratulations!”**

I can tell you that it only gets better with time. The acceptance of this news comes in different stages. For me the first year was the hardest. But everyone heals differently and at their own pace. You do mourn for the child that you thought you were going to have. But it does get better with time.



The first year was the hardest because we were left to deal with this alone. Having family and friends to support you is very important. Sometimes family members are waiting to be asked to help.



Meeting with other families dealing with similar situations earlier on would have helped speed up the process.

I know personally that when we finally did connect with other families, the loneliness in our hearts disappeared.

For the first time we felt a sense of belonging and a sense of calm. This is what we needed to be able to feel that life will go on and that life is still the same and is wonderful. Life was still there waiting for us to enjoy.

At the beginning, the Doctor's congratulations would have been reassuring and his taking the time to answer our questions would have eased a lot of our anxiety. But today I can proudly say that I am honoured to have my child with all his qualities and his advanced soul.

***The love that our family now shares is enriched.
Having our child did change our life – for the better!***



Welcome to Holland

By Emily Perl Kingsley

I'm often asked to describe the experience of raising a child with a disability – to try to help people who have not shared that unique experience to understand it, to imagine how it would feel.

It's like this...

When you're going to have a baby, it's like planning a fabulous vacation trip – to Italy. You buy a bunch of guidebooks and make wonderful plans. The Coliseum. The Michelangelo David. The Gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes and says, ***“Welcome to Holland”***.

“Holland?!?” you say. “What do you mean Holland? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy.”

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

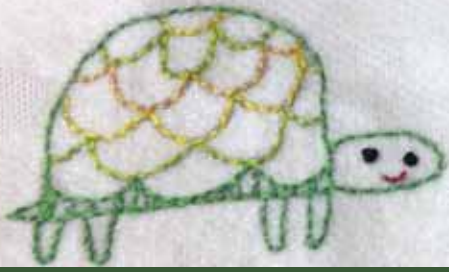
The important thing is that they haven't taken you to a horrible, disgusting, filthy place full of pestilent, famine and disease. It's just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would have never met. It's just a different place. It's a slower pace than Italy, less flashy than Italy. But after you've been there for awhile and you catch your breath, you look around... and you begin to notice Holland has windmills... and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy... and they are all bragging about what a wonderful time they had there. And for the rest of your life you will say “Yes, that's where I was supposed to go. That's what I had planned”. And the pain of that will never, ever, ever go away... because the loss of that dream is a very, significant loss.

But... if you spend your life mourning the fact that you didn't get to go to Italy, you may never be free to enjoy the very special, the very lovely things...about Holland.

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Learning That Your Child Has a Disability

Learning that your child has a disability, can cause a variety of emotions for parents. Not every parent will react in the same way, but it is completely normal to have some or all of the following emotions:

- Fear of the unknown as it relates to your child's disability or what that might mean for your child today and in the future. It is very normal to wonder what will happen in the future. What kind of life will my child have? Will I be able to handle this situation?
- Disappointment and grief are also normal emotions. Every parent wants and expects their child to be healthy and "normal". As noted in Emily Kingsley's story "A trip to Holland", you are in a totally different place than you expected to be. Initial feelings of disappointment or shock that you didn't get what you expected are quite common.
- Sometimes parents feel powerless because they would like to change what has happened but obviously cannot. Some parents may not have the first idea of what raising a child with a disability may be like. They may doubt their own abilities to be a good parent.
- Parents are also often confused about what is happening. Initially, they may not have much information about their child's disability. This, along with other feelings, can lead to a lot of anxiety (and sometimes sleepless nights) for parents.



You may or may not experience these or other feelings and emotions.

What you go through as a family may depend on your individual circumstances, prior knowledge about people with disabilities, and the information and help that you may or may not receive.

Having feelings and emotions about your situation is a normal part of adjusting to your situation.

This adjustment period may take more time for some people, but parents usually find that a sense of stability does return to their lives.

Over time, families usually find the strength within themselves (and with the support of others) to handle what they are facing. Most parents turn their attention and energy to finding out what they must do to be good parents for their child.

Some Things to Remember If You Are Still in the Hospital

Most families learn that their child has a disability soon after birth. These first few days while you and your child are still in the hospital can be challenging. Below are some lessons learned by other parents that you may find useful:

- If possible, ask for a private hospital room. This may be a helpful way to give you some privacy to deal with your feelings and to spend some quiet time with your child or with other loved ones.
- It is not unusual that some babies with disabilities may have difficulty with nursing. There are usually people who can guide you through this problem. It will be very important that you have patience with yourself and your baby.
- Sometimes, doctors or other health professionals may not know a lot about your child's disability. In the past, many doctors have tended to down play expectations and hopes that parents should have for children with disabilities. Fortunately, this is happening less and less. There are now many doctors and nurses who take a more positive view of people with disabilities. If a health professional does tell you not to expect too much from your child, know that these opinions may well be inaccurate or untrue for your child. Many people with disabilities have shown that they have far more potential than some people believe.
- While you are in the hospital, you will likely receive visits from other professionals. This may include a social worker or others who will provide you with some information and help you to get connected to various services that may exist in your community (such as Early Intervention). These professionals may also be able to provide you with some more information concerning your child's disability.
- Sometimes, children with disabilities have medical problems that may need to be addressed. For example, young children with Down Syndrome may have a heart condition that will require surgery to correct. As much as possible, make sure you have information on any potential medical problems that may arise or may be already happening for your child.



Delays in Diagnosing Your Child's Disability

Sometimes, finding out your child has a disability can take time – even months or years.

This is particularly true with some types of disabilities such as autism spectrum disorder, certain intellectual disabilities, muscular dystrophy or learning disabilities. In these circumstances, parents usually have a sense that something isn't quite right with their child. Depending on the circumstances, the diagnosis of your child's disability may happen quickly. At other times, however, parents may face a longer struggle to find out what is happening. In these circumstances, parents may encounter medical professionals or others who will tell them that nothing is the matter. Instinctively, parents know that this isn't the case. It may take a lot of persistence before you can get an accurate diagnosis.

This can be very frustrating for families. Eventually, however, appropriate experts are able to accurately diagnose your child's disability. When this happens, parents often feel a sense of relief because they finally know what they are dealing with. They may also experience some of the same feelings or emotions discussed earlier. At this time, parents will need information, support, and possibly other kinds of services that will help them adjust to the situation.



Dealing With Other People's Reactions

While some people may react positively when they learn that your child has a disability, others may react awkwardly. Worse still, some people may react with a sense of pity. Other people may not know what to say or how to react to you.

It is important to keep in mind that other people's reactions often stem from a lack of understanding. Often, people still feel awkward around people with disabilities. Remember that as people with disabilities become more involved in our communities, other people's reactions will become more positive. Here are a few suggestions on how to deal with people's reactions:

- Let people know that you do not want to be pitied nor do you want your child to be pitied.
- Respond to inappropriate reactions with something positive. Portray your child in a positive light and remind people that your child is a child first – a person to be loved and cherished.
- Remember that some people have no experience with people with disabilities. You may have to be patient and use these opportunities to educate people about the value of people with disabilities – including your child. Try your best not to respond with anger. Rather, show people in a positive way how you feel about your child.

Do not spend too much time worrying about other people's reactions.

Sometimes, other people's reactions can be positive and helpful. One parent who was feeling discouraged after the birth of her child (and after receiving condolences from others) met an acquaintance on the street a couple of weeks after her child was born. The acquaintance offered a hearty "Congratulations! You had a baby!" From that moment, she realized she had received a wonderful gift.



Telling Other People About Your Child

When you have learned that your child has a disability, it is generally not a good idea to wait too long to tell family members and friends about your child. If you learn about your child's disability while still in the hospital, close family and friends will likely visit with you and can be informed. Family and friends will "follow your lead" and will often offer you encouragement and support.

When talking to family, friends, and others about your child and his or her disability, here are a few suggestions to keep in mind:

- Give people information and offer to explain what you know.
- Be open to other people's questions, as this might be a good opportunity to dispel some myths about people with disabilities.
- Tell and show other people that you love your child.
- With some people, don't be afraid to show and share some of the feelings and emotions that you are experiencing. While you don't want people's sympathy, it may be helpful for them to understand what you are experiencing.
- Sometimes, close family members or friends will tell others about your child. This may help avoid repeating the same information to many people.



Talking With Your Other Children

Having a child with a disability may affect everyone in the family. This includes other children that you may have. It will be important for you to talk to your other children about their brother or sister with a disability. Your other children's ability to understand information will obviously depend on their age and level of development. Try to provide information in ways that they can appreciate and understand.



Your other children may have children with disabilities in their playgroups or school classrooms. They may be able to relate the information that you give them to other children they know.

For many siblings, having a brother or sister with a disability is often a positive experience. It can teach them to accept people who may be different and to accept people for who they are. Other children can also learn about family responsibility by helping around the house or by helping their brother or sister in small or large ways.

Be aware that sometimes other children may react negatively. This may particularly be the case if they feel that their brother or sister with a disability is receiving all of your

energy and attention. You may need to find ways to ensure that your other children still feel appreciated and loved.

Raising a child with a disability will likely require that you obtain information on a variety of topics or issues. It may also require that you access some services that may be available in your community. You will likely have more contact with professionals and other service providers from time to time.

While additional information and accessing services may be very helpful, it is important that you remember that your child is a child first, and deserves a normal childhood. To the fullest extent possible, life at home and in the community for your child should be the same as for any other child.

Getting More Information

Getting good information can help you become a more effective parent and advocate for your child. You may want to find out about:

- Your child's disability and how it may affect his or her life.
- How you can assist your child to develop and grow.
- How you can best support your child to be involved in the community.
- What services may be available to assist your child or your family.



There are a variety of sources of good information that you can explore. One is talking with other parents who have had similar experiences in raising a child with a disability.

There are a number of organizations (such as the Association for Community Living) that are parent based and that have information packages available for families, often at no cost. There are also many books that have been written for families who have a child with a disability. Lastly, there is a wealth of information on a variety of Internet sites that you can access very quickly.

As a note of caution, some information may be inaccurate or outdated. Some may also use old language to describe your child with a disability that is no longer considered appropriate. Lastly, be careful about becoming too overloaded with information – especially all at once.

To get started on accessing your own information, please see the suggested resources and contact information section of this information kit.

Accessing Services

Over the years, a number of programs and services have been developed to assist children and adults with disabilities and to help families. Readily accessing these programs and services may depend to some degree where you live. Typically, programs and services are more accessible in urban areas.

If you live in a rural area, you still may be able to access different services, but you may have to be prepared to travel to do so.



Provincial government departments usually fund some programs and services for people with disabilities and families. Government may provide these services directly, or they may be provided by community agencies that receive government and other funding. In New Brunswick, the Premier's Council on the Status of Disabled Persons has prepared a directory of services that can be accessed via the Internet at www2.gnb.ca/content/dam/gnb/Departments/pcsdp-cpmcph/pdf/directories/DS-person-withDisabilities2015.pdf.



There may be services that you need that government does not currently fund or for which funding is very limited or not available. In these situations, parents should continue to ask for what they need. Often, families can influence what government provides by advocating for their child.

Below are short descriptions of some of the programs and services that you may want to access, particularly if you have a young child. Please see the section on suggested resources for further information on how to contact these services.

- **Extra Mural Program** – This program offers a wide variety of health-care services to people in their homes and communities. Professionals who work for this program may include nurses, registered dietitians, respiratory therapists, occupational therapists, physiotherapists, speech language pathologists and possibly social workers.
- **Early Intervention Program** – This program is a home based support and teaching program that is designed to give young children a good start in life. Parents may be offered information and help on child development and parenting skills. The program is designed to help children develop as much as possible and to become ready for school. An extensive resource library is also available for families. For more information visit [www.gnb.ca/0048/pcsdp/directoriesfor persons/Education-e.asp](http://www.gnb.ca/0048/pcsdp/directoriesforpersons/Education-e.asp))
- **Family Supports for Children with Disabilities (FSCD)** – This program provides services to children with disabilities up to the age of 19. If a child is eligible under the program, an individual service plan is developed that will be based on the child's strengths, needs and the services that are available. The program may provide services or items to assist the family in providing the care and support the child requires. This may include respite care, parent aides, medical and rehabilitation transportation, recreational opportunities and home support services. In addition, children whose families do not have private health insurance may be eligible for a "health card" that covers items such as prescription drugs, dental care, eye care, medical and rehabilitation equipment. (For more information contact Social Development.



To locate your local office visit http://www2.gnb.ca/content/gnb/en/departments/social_development/about_us/regional_offices.html.

Early Childcare Services – There are a variety of early childcare services that may be available to families of children with disabilities. These include early intervention services, child day care services, the Day Care Assistance Program, Alternative Child Care Program, Services for Pre-School Children with Autism, early childhood social worker services, home economics services, and others. (For more information visit www2.gnb.ca/content/gnb/en/departments/education/elcc.html).

- **Support and Services in the School System** – Children with disabilities in the school system (kindergarten to grade 12) may be eligible to receive a variety of supports and services. This may include accommodations (such as audio FM systems, memory devices, large print, tutorial assistance, and many others), a modified curriculum, help from a Resource Teacher or help from a Teacher Assistant. For many students with disabilities, these supports and services are identified in the child's Personal Learning Plan (PLP). (For more information, contact the Department of Education or your local school district office).

Working With Professionals

From the time of the birth of your child, you may have involvement 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 on 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 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 <http://www.kidsource.com/NICHCY/parenting.disab.all.4.2.html>).

Personal sources of support and assistance can be very valuable for parents of children with disabilities. This kind of support can come from many different people and in many forms. Sometimes it is offered freely by people you are close to, while at other times you may have to seek it out. Here are a few suggestions to consider:

- Look at your own support network. These will be people that you have some kind of close relationship with, perhaps as family members or good friends. Sometimes these people will automatically offer assistance, but you may need to be prepared to make people aware of how they can support you (for example, by helping with child care, having someone to talk with, moral support and so on). Remember that sometimes people may be hesitant in offering help to you because they feel that you may be offended.



- Seek the support and assistance of another parent in a similar situation. This may be a parent whose child is older than yours and who has already gone through some of the same challenges and struggles. Other parents can help bring some perspective to what you are dealing with. They can provide information on various programs, services, or simply offer suggestions on how to deal with situations in your own family. There are a variety of different organizations representing people with disabilities that may be able to help you find another parent who is willing to support you.

- Many parents have found that parent networking groups are a valuable source of support. Parent networking groups offer opportunities to share information, ideas and experiences with other families. Often, parents form new friendships with other parents who are experiencing similar circumstances in their life.



These relationships can expand beyond the networking group itself, so that parents have regular contact with other individuals. Again, there are a variety of disability organizations that offer to bring parents together from time to time. In New Brunswick, the Association for Community Living has spearheaded the creation of the Families United Network of New Brunswick (FUN-NB) that seeks to provide families with opportunities to come together and to network with one another.

Do not overlook the support that spouses or partners can provide one another.

Sometimes, spouses forget to take the time to communicate with one another and express their feelings and concerns.

When you are able to openly communicate with your spouse or partner, you will add strength to each other and to your family.

Your expectations for your child can be one of the most important factors in shaping his or her future. For some parents, having positive attitudes and expectations can be difficult, especially when parents are reminded by others of all the things that may be “wrong” with their child. There was a time when many parents were told not to expect very much from a child with a disability.

Fortunately, these attitudes are changing. There is now a better understanding that all children are capable of growing and developing.

While positive expectations for your child will not provide any guarantee of “success” they will give your child a better chance of reaching his or her own potential. The way you view your child is likely to have a great influence on the way that others view him or her as well.

This does not deny that your child may have limitations (and sometimes significant limitations). Rather, limitations should be viewed as barriers that need to be overcome while helping your child develop his or her own potential.

Every person has strengths and interests from which realistic expectations can be built.





Also, be aware of the impact of talking about your child in ways that highlight his or her limitations. Sometimes, words such as “special needs child” or “handicapped child” place too much emphasis on the person’s disability or needs. Try to talk about your child in ways that will portray your child in a positive way.

Lastly, as your child grows, be aware of ways that you and others can encourage your child to learn and develop his or her abilities. One of your goals as a parent is to have your child do as much for him or herself as possible. As the years go by, you will want your child to become as independent as possible. This also means encouraging your child to make decisions for him or herself.

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 Information Concerning People with Disabilities. People can usually get this guide at their local Canada Revenue Agency Office or from the agency’s Internet site at www.cra-arc.gc.ca/E/pub/tg/rc4064/rc4064-15e.pdf. 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:

- Child Disability Benefit
- Disability Supports Deduction
- Disability Amount (a non-refundable tax credit that reduces the amount of income tax that people with disabilities may have to pay)
- Medical Expenses (this 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)
- Child Care Expenses
- Amounts for eligible dependents and amounts for infirm dependents 18 or older
- Amounts for caregivers
- The transfer of the Disability Amount from a dependent who has a disability

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.

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Supporting Children and Adults with an Intellectual Disability Since 1957

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