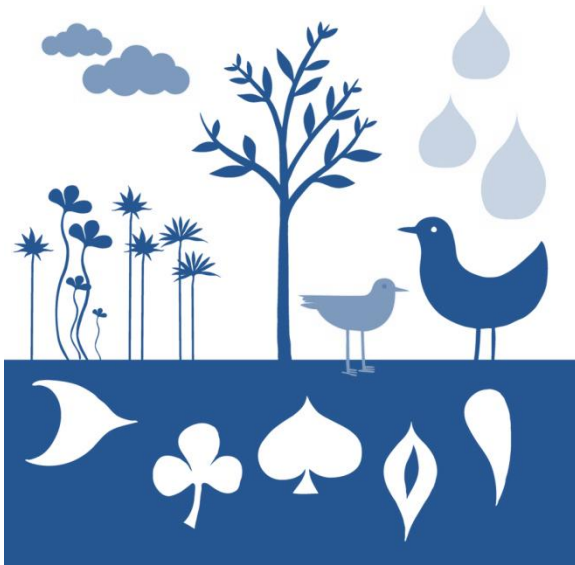


# A FAMILY GUIDE TO OPTIONS

## Learning your child has a disability – Messages *from families to families*



*This guide conveys the voices of experienced parents to assist new parents just beginning their journey. Intended to help families get informed quickly, it provides many helpful suggestions.*

*Call it a clan, call it a network, call it a tribe, call it a family.  
Whatever you call it, whoever you are, you need one.*

– Jane Howard, Author

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## 1-INTRODUCTION

As parents, we see our children as treasures and are often amazed by their creation. Every parent will tell you that having children will alter your life. They will also say there are no specific “how-to” references for every situation. Our children are a source of joy and present opportunities to learn about their development, ourselves, and how all emotions are experienced in the raising of a child.

We know that all children offer their unique stamp on the earth, demonstrating their gifts, virtues, purpose and challenges along the way. If you are reading this, you might suspect or have been given a diagnosis that indicates your child has a disability. Like many parents before you, there are likely a number of feelings you are experiencing. You may be coming to the realization that this means additional challenges for you as a family. All of these emotions are valid. The suggestions in this guide may help you deal with those emotions more effectively.

What all parents need to learn along the way is that every child is a “child/person” first; they are not the label they are given. Our children play and learn as do other children, although they may not always learn in the same way. To reach their own potential, they require love, appreciation, valuing, and an opportunity to learn and contribute with all their uniqueness.

This guide was created to answer a need voiced by countless parents and professionals in

*Just when you think you have learned what you need to know in life someone truly special comes into it and shows you just how much more there is . . .*

*– Author unknown*

Manitoba. Many people expressed the desire to have a guide to resources and options – a road map that would reduce the number of wrong turns and detours that families of children with disabilities might encounter. It is a challenge for parents to find answers and opportunities that will enhance their lives. It isn't always easy for professionals either.

Experienced parents and their support networks want to offer their understanding, wisdom, and support through this resource. There will be suggestions, ideas, or references that appear more than once. This means it's important. Many of us have learned it takes more than once and in different ways to "get the message."

The collection of parents who had input and offered feedback in the development of this guide represents various disabilities, ages, and experiences. While this book offers valuable information, it cannot provide all of what you'll need to know. It is only the beginning. The organizations, agencies, and societies in the community that parents belong and contribute to, offer a diverse understanding, views, and options.

Before determining which step to take next, consider connecting with one or more of the resources offered at the back of this guide. Whether you take that step immediately or not, we hope that this guide is helpful. We wish you the very best and welcome you to the "family of families."



*Life's not always fair.  
Sometimes you can get a  
splinter even sliding  
down a rainbow.*

**~ Cherralea Morgen**

## 2-LEARNING YOUR CHILD HAS A DISABILITY

### Welcome to Holland

"I am 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 guide books and make your wonderful plans: the Coliseum, the Michelangelo David, the gondolas in Venice. You may even 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 in 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 pestilence, famine and disease. It's just a different place.

So you must go out and buy new guidebooks. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around.... and you begin to notice that Holland has windmills....and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy... and they're 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, ever go away... because the loss of that dream is a very, very significant loss.

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

*Copyright 1987 Emily Perl Kingsley*



## After you receive the news

When parents hear that their child has a disability, the waves of emotions they experience can be unexpected and overwhelming. None of us react in the same way or even how we might have anticipated. It is usual to experience some or all of the following five emotional stages of grieving at different times, ways and intensities.

The following examples represent some thoughts you may be having.

- ... 1 **Denial** – *“Everything is fine. This isn’t happening to me/to us; There’s nothing wrong with the baby.”*
- ... 2 **Anger** – *“This isn’t fair! Why did this happen to me/us? It’s his/her fault. They don’t know what they’re talking about.”*
- ... 3 **Bargaining** – *“I’ll do anything if you can change this, cure this, fix this...”*
- ... 4 **Depression** – *“I’m so sad, why bother with anything? What’s the point, it won’t help anyway.”*
- ... 5 **Acceptance** – *“It’s going to be okay. We can’t change this. Let’s see what we can do about this. Let’s learn more.”*

These five stages do not necessarily come in the order noted above, nor are all steps experienced by all people. However, Dr. Kubler-Ross stated a person experiencing a loss will always experience at least two.<sup>1</sup>

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<sup>1</sup> Kubler-Ross, E (1973) *On Death and Dying*, Routledge, ISBN 0415040159

There are other emotions you may experience. Here are some others you may feel or have felt:

- Shock is a common emotion after a diagnosis is given. How intense it feels combined with how prepared you are to deal with that intensity makes this experience feel traumatic.
- Fear surfaces frequently. It might be fear of the disability, of the unknown, or the future. This experience can bring forward all kinds of questions about how this will affect your child, your family, and your lives. Your confidence about parenting may be totally shaken. Where do you begin this journey?
- Grief for the loss of the child you thought you were going to have is also common for many parents. The feelings of sorrow and disappointment that your child may not be healthy or “normal” are usual. No matter how old your child is when you hear this news, you will feel some of this.
- Overwhelmed feelings, similar to grief are common. You will have these feelings as your child grows and ages, especially when milestones are missed or delayed.
- Frustration is often described as a feeling we have when we know something is possible and it’s just not happening fast enough. It also arises when we feel deprived of the ability to stand up for ourselves and no immediate solution is obvious.
- Guilt, shame and anger often tag-team. First you might feel like it’s your fault and

you have not lived up to expectations. Then you might worry how others interpret your situation. This could be closely followed by anger over all of it and your sense of helplessness.

Experiencing all these emotions can be draining and leave you feeling powerless. You may feel you have little control over the circumstances or your life, and feel weighed down by your responsibilities.

What next? Everyone offers advice, consolations, and ideas that can lead to confusion. There is lots of information to suddenly absorb. This may add to anxiety or stress which leads to sleepless nights, poor health and general reduced well-being.

Whether you have experienced all or some of these emotions depends on your past experiences, beliefs and attitudes and on how you approach challenges. Everyone's circumstance is individual. If you as a family have prior experiences or some knowledge about people with disabilities, this may or may not be helpful in dealing with the information you receive and the help you request.

Experiencing any or all of these emotions is a common part of the adjustment period. Adjusting to the situation is different for everyone and the time it takes to find a sense of stability after the chaos varies too. Over time, families find their own strength. With support from others, they manage to handle whatever they are facing. Most parents focus their intention, attention, and energy in finding out what they need, to feel they are doing their best as parents for their child.

### **How science says we experience emotions:**

*Although there are certain emotional systems that can be triggered automatically, it takes less than 90 seconds for one of these programs to be triggered, surge through the body and then be completely flushed out of our blood system. If the emotion remains then it is a chosen circuit we continue to run.*

*– Jill Bolte Taylor, Ph.D.  
Neuroscientist and Author*





## Before Birth

Most parents receive this diagnosis after their child is born. If you are a parent who has been given a diagnosis “in utero” (before your child is born) you are facing a bigger unknown since you do not have your child in your arms yet to love and appreciate.



If you have received your diagnosis in utero, you might find it helpful to actually hold a baby or talk with a family of a child that has that disability. Connecting with the appropriate disability-specific organization could be beneficial too. There are no easy answers or suggestions to help you move through this experience. Again, everyone responds differently, in their own way, and in their own time.

## While you’re in the hospital

Learning that your child has a disability is often experienced shortly after birth, while mother and baby are still in the hospital. Dealing with these circumstances in a hospital environment can be stressful. Based on experience, we offer some thoughts and suggestions that may be useful:

-  Consider the most private setting you can manage in the hospital. The more privacy you can arrange the more beneficial the quiet time. Spending time with minimal distractions will benefit you and your child/other loved ones.
-  Nursing a baby with a disability can be more difficult for some. Do not be discouraged.

Enlist the assistance of others who can guide you through this challenge. Establishing this delicate relationship with your baby will be well worth the effort and patience.

-  It is uncommon for doctors or other health professionals to have extensive knowledge of your child’s disability/condition. How they present expectations of your child’s potential can vary. You may receive a positive, hopeful prognosis or you could hear something more negative. Professionals of many disciplines can only offer their opinion or best guess based on their knowledge and experience.
-  During your stay in the hospital there may be other professionals who come to visit. You could have visits from a hospital social worker, a physician specialist, a psychologist or psychiatrist, clergy or spiritual advisor. Many of them can provide links to community connections or supports.

## The first few weeks at home

Once you return home from the hospital you may want to consider meeting with one or more of the following people:

- ▶ A public health nurse from your regional health authority will pay you a visit.
- ▶ You could be contacted by someone from an early intervention child development program.
- ▶ You may receive information while still in the hospital that is disability-specific and have an opportunity to talk with another parent if you choose.



- ▶ These professionals and others may be able to offer the resources and information about your child’s disability.

Sometimes additional medical problems will need to be addressed. These will vary. There are common conditions that arise with certain disabilities. If your child has, or could experience additional medical circumstances, obtain any information about your child’s needs so you can address them. Ask the professionals you encounter questions if you are not clear. You might find it helpful to ask family and friends to be present when you attend appointments. If you need to have additional moral support, ask your family and friends for that too.

Many of the organizations involved in the development of this guide have peer support options available. At no time do you need to go through this alone. When you are ready, other parents will be there if you need them, for information or additional support.



**At no time do you need to go through this alone.**

*People with disabilities have surprised and inspired many people by their potential and successes. They have and continue to shatter all kinds of illusions people hold of them by demonstrating what’s possible when we change our focus. Not everyone has this awareness or experience.*

## Receiving a diagnosis later

Although receiving an early diagnosis is fairly common, there can be delays in finding out whether your child has a disability. This can occur months, sometimes even years later. There are different conditions and disabilities which do not present at birth. Conditions found within the autism spectrum, some global developmental delays or intellectual disabilities, muscular dystrophy, or general learning disabilities are not always apparent in the very early stages of development.

Parents, other family members or friends often identify or sense that “something isn’t quite right.” Following through on these concerns with a medical professional is the first step. Receiving a diagnosis for your child may occur quickly, or, depending on the circumstances, it could take longer.

It is possible you could encounter medical professionals or others who don’t support your concerns. As a parent you may hear that “nothing is the matter.” If your intuition tells

you otherwise, you may need to be persistent in order to obtain an accurate diagnosis. Although it may feel frustrating because you're not able to get definitive answers, keep asking questions. Eventually you will be led to the appropriate experts. There might be a feeling of relief once your worries are verified and/or your concerns are addressed.

No matter when a diagnosis is received, there will be emotions to deal with. It's a good idea at this stage to begin gathering information, support, and exploring what options and services are available . . . not just for your child, but also for yourselves as parents, and for other members of your family.

Find ways and make attempts to stay positive. Connect with people who enable and inspire you. There's a lot of information "out there" and some of it isn't encouraging or hopeful. There are many parent support groups that meet on a regular basis to learn about their child's disability and to find strength to face the challenges.

If you feel comfortable you can connect to the Internet and interact through parent chat rooms, web casts, or web logs (blogs). Keeping on top of helpful information needs to be balanced and comfortable however you choose to collect it.

You should track how much time you spend collecting information from various sources. Be certain that the information is useful in some practical manner. This will help you realize what information sources are useful to you.

Ask yourself some questions:

- ▶ Who do you trust to get information from?
- ▶ What criteria will you set in order to measure that trustworthiness, from a professional, another parent, or an organization?
- ▶ What exactly are you searching for? Are you looking for – hands on help, emotional support, inspiring stories, research material, opportunities for networking, or workshops – all of this information cannot be found and understood in one day.

What other questions could you ask yourself? If you don't know, consider talking with someone who could help you identify some good questions.

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### 3-HOW TO USE THIS GUIDE

We would encourage you to use this guide as you need to. You may choose to review it a bit at a time, or immediately read it from cover to cover. Everyone handles unexpected news in their own manner. Either way, we suggest you keep this guide handy for your reference.

Let your extended family, friends, and close colleagues know that you have some information that offers ideas and resources. The more everyone learns about the possibilities and various disabilities, the better children and families are supported, remain strong, and grow within their communities.

Record keeping, paper trails, storytelling and history documenting is the art of keeping track of what happens as a child grows. This is likely to become a big part of your life when you have a child with a disability. Being organized has helped many families stay on top of what they need to know.

We encourage you to consider trying these ideas:

-  Set up a portion of a room that is dedicated to your child's development. Desk and storage space will be needed.
-  Include items such as a binder or files for medical appointments, therapy sessions, childcare or school meetings.
-  Dedicate a photo album to keep track of special events and accomplishments.
-  Consider scrapbooking as a way to add value to the memories of your family member's life experiences.
-  Use a calendar that meets your needs and serves the family's lifestyle – a personal pocket calendar, a large one in the kitchen, or electronic, etc.
-  Dedicate a spot for resources – books, pamphlets, guides, CDs, DVDs, downloads, etc. that you have gathered or purchased and keep them within easy reach.

We hope this guide will be the beginning of your resource gathering on this new journey.

## 4-TALKING TO OTHERS ABOUT YOUR CHILD

### Telling Others about Your Child

Sharing the news is the first step. Recognizing and acknowledging that this experience will affect the entire family follows. Truthfully, it can impact your entire life in ways you haven't yet imagined. Learning about and using inclusive language early on will role model for others acceptance of diversity and respectfulness.

Telling your family and friends generally needs to occur soon after you have received a diagnosis. If you are still in the hospital and friends or family visit, they will receive the information then. They will want to stay connected and learn more about how things are going for you and your baby after you leave the hospital.

Other families have found these tips helpful:

- Offer people the information you have and explain things the best you can based on what you know. Let people know that this is all new to you and there is a learning curve to cover.
- Answer people's questions the best you are able. Family and friends will follow your lead. Answering their questions in ways that dispels some myths and brings value to people with disabilities is a good thing.
- Let people know that your child is a child first and not the disability. Expressing and showing people that you love your child sends a clear message too.
- Sharing emotions with people who you feel safe with also works. Most parents don't

want sympathy. It might be useful to explain your situation to help others understand more fully what you are experiencing.

#### *Inclusive language:*

- Does not infer that people with disabilities are abnormal by referring to people without disabilities as being "normal".
- Portrays people with disabilities as active participants in society. *"Mike volunteers as a greeter in church every other Sunday."*
- Defines people in terms of their interests and other characteristics rather than by their disability. **For example:** *"My daughter is a brown haired, brown-eyed child who loves dolls and horses. She has cerebral palsy and uses a wheelchair" rather than "My daughter is a wheelchair-bound CP child who..."*

For more information on how to use language that portrays people with disabilities in a dignified and respectful fashion, you can visit the Human Resources and Skills Development Canada website at [www.hrds.gc.ca](http://www.hrds.gc.ca) and search for *A Way with Words and Images*.

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***Society must do everything in its power to eliminate remaining prejudices and stereotypes. Choosing words and images that help shape positive attitudes will promote the person rather than the disability.***

– Excerpt from *A Way with Words & Images*

## Telling Your Other Children

It is important for you to talk with your other children about their sibling. There are many resources that address this subject at different age levels. This will be ongoing as your child goes through different stages of development and helping your other children understand will create strong bonds and advocates as they grow older. Your other children may also have classmates or playmates who have disabilities. This will help them apply information you give them to other children they know.

Siblings who have a brother or sister with a disability often find their experiences to be very positive. It has the ability to teach acceptance of difference and diversity. Learning about family responsibility, helpfulness and many other virtues will assist siblings in a variety of ways as they grow up. It is not uncommon for siblings to choose careers based on their experiences with their sister or brother with a disability.

It's also important to be aware that your other children may react negatively, particularly if they feel the child with the disability is receiving more attention. There are ways to ensure that all children feel appreciated and loved. Learning how to be a whole and healthy family inside your home and being part of the community happens in all kinds of ways. Exploring different resources to assist you in making that possible can help.

## Responding to people's reactions

When you tell people – your family, friends, colleagues, neighbours, even strangers – that your child has a disability you will receive mixed reactions. Some people will be supportive and

respond in a positive way while others will display discomfort or react awkwardly. Others may show pity while some find it difficult to say anything.



As hard as it might be, it helps to remember that people react in these ways due to lack of understanding. If people have had no exposure to people with disabilities, they can feel awkward and may act differently. Acceptance is common in communities where people with disabilities are involved.

Here are some ways other parents and families have dealt with people's responses:

- Respond to inappropriate reactions as positively as you can. Unexpected experiences will always surface. You can only do your best in each circumstance and learn from it.
- Present your child positively. Talk about their "giftedness" and what they *can* do instead of dwelling on what they cannot do (yet). You need not buy into the limitations of the label. People respond with understanding when they recognize a child is first a child – someone to be loved and cherished.
- Refuse to accept pity as a valid reaction and let others know this is something you neither need, nor want.
- Everyone you tell will handle the news differently. Occasionally people will deny

that your child could have a disability and try to calm your anxieties as a result.

- It's okay to experience the emotions we have mentioned. You may feel safe and comfortable enough with some people to authentically share your experiences. It can help them further understand what you're going through.
- Let go of worrying about other people's reactions. It's okay to be different. This country is built on diversity and disability is part of that.

When you hear "congratulations" from someone, embrace this positive experience wholeheartedly. You will receive this kind of feedback along with the less positive. Keeping things balanced and in perspective means becoming aware that your child is a wonderful gift.



## 5-LIFE GOES ON – Home & Community

### Getting More Information

You are the expert and your child's best advocate. It is important that you become informed. As you begin this unknown parenting journey, you will likely find it necessary to gather more information on a variety of topics and issues. You may also want to access services that are available in your community, some of which you may have heard of, others you may need to research further. There will be increased contact with a variety of professionals and other service providers as your child matures.

Although we encourage you to seek helpful information, we also caution you to keep things in balance. Your son/daughter is a child first. Medical appointments and therapy sessions need to be tempered with playgroups, community recreation and leisure activities. Whether in your home or community, it is important that your child experiences the same things as other children as much as possible.

Other parents have found it invaluable to be informed on a variety of topics. Being informed will enable you as a parent to be a better advocate for your child. Here are some things you might want to get more information on:

- Anything related to your child's disability and how it might affect his/her life. Consider different sources to gain a wide perspective.
- Ways that you can effectively assist your child to develop and grow.

- Ways to support your child to be involved in the community will help build natural friendships and support.
- Services and supports through government or non-government agencies are available to assist your child and family.

More resources to try include:

- Talking to other parents who have had similar experiences in raising a child with a disability.
- Many of the organizations listed at the end of this book are parent-based with access to information, often at no cost.
- Books are available for families who are raising a child with a disability.
- There are also DVDs or VHS tapes that can be accessed through these organizations or parent resource libraries.
- Internet sites offer quick, easy availability in written and visual content.

We find it necessary to add another word of caution here. Much of the material you will come across contains outdated terms/language that is no longer appropriate to describe your child's condition. Some of what you come across may produce uncomfortable emotions and more confusion. Overloading on information is not something we recommend. Try to keep things in balance, researching a bit at a time, digesting carefully all that you find.

Please consider the suggested resources at the end of this guide as a starting point in accessing information and developing contacts.



## Locating & Accessing Services

There are programs and services that have been developed to assist children and adults with disabilities, and their families. How readily accessible these services and programs are may depend on where you live. Urban settings tend to have more accessible services whereas people living in rural areas may find themselves having to travel further.

Provincial government departments often fund some support services or programs which specifically addresses people with disabilities of all ages and their families. Sometimes community agencies/organizations that receive government funding offer the services or government may provide the services directly.

In this province there are several departments which work collaboratively in supporting children and families. In supporting your child you could learn more about the following:

Manitoba Family Services & Housing

- > *Children Special Services*
- > *Child & Family Services*
- > *Healthy Child Manitoba*
- > *Supported Living Program (for adults)*
- > *Employment & Income Assistance*
- > *Vocational Rehabilitation*

Manitoba Health

- > *Regional Health Authorities*

Manitoba Education Citizenship & Youth

- > *School divisions*

Periodically, time limited options are offered by community agencies/organizations. An opportunity to participate in new initiatives may be something you may want to consider if you find it's a "fit" for your family.

There may be services that you believe would be helpful, however, the service doesn't presently exist. Because a service is not available does not mean families cannot request it from government. Families have been, and continue to be "change agents" by informing government and community of their issues and needs, along with possible solutions.

The programs and services that follow may be some you want to consider. The brief descriptions will help you identify what is age appropriate for your child. Please refer to the resources page for contact information.

Once you begin getting more referrals and contacts to help you in finding the appropriate support or service that meet your family's needs, remember to keep track. Know who you are calling (or who is contacting you) and why.





## Contact Information Example

Contact Person	<i>Nancy Campbell</i>
Position	<i>Children Special Services (CSS) Worker</i>
Place	<i>Manitoba Family Services &amp; Housing (MFSH)</i>
Address	<i>123 Main Street, Steinbach, MB</i>
Phone	<i>333-5555</i>
Fax	<i>333-7777</i>
Email	<i><u>Nancy.Campbell@gov.mb.ca</u></i>
Reason	<i>Helps with resources, referrals, getting information</i>

## Who's on your list?

Manitoba Family Services & Housing	
Medical	
Respite	
Community Organization	
Therapist	
Support Group	
Child Care Centre	
Education	
Other	

## CHILDREN'S SPECIAL SERVICES

Manitoba Family Services & Housing under the Children's Special Services program provides support to families to care for children who have physical and/or mental disabilities.

### *Who is eligible?*

Natural, extended or adoptive families who have a child 17 years of age and under living with them are eligible if a child has one or more of the following:

- a mental and/or physical disability;
- a developmental delay;
- a risk of developmental delay;
- a pervasive developmental disorder such as autism; or
- life-long extreme complex medical needs which result in a dependency on medical technology.

The process involves calling the local/regional Manitoba Family Services & Housing office. A Family Services Worker will contact you and arrange a convenient time to meet with you and your family. Initially you will be asked some basic questions such as your name, address, and other contact information. You will be asked what type of assistance you are looking for, so do give this some thought.

During such a meeting you will be provided with counselling, information, and/or referral to other services, if necessary. The worker will tell you about the supports available. They recognize that each child and family has unique needs.

### *The Types of Supports Available*

Besides counselling, information and referral, support for families with children who have disabilities depends on the individual family circumstance, the needs of the child, what support extended family provides along with any neighbourhood supports. You can let your Family Services Worker know what your needs are. In turn, they will outline what services might be available in your region.

Family support reduces stress encountered by families and helps them maintain their children with disabilities in their own homes to the greatest extent possible.

It is the intention of Family Services staff responsible for the Children's Special Services Program to work as partners in developing a family support plan that addresses each family's individual needs.

The types of service and the level of supports you are able to access is dependent on the needs of your child with a disability along with your family's circumstances. These supports and services can change when your family circumstances change. This change occurs naturally and/or in unexpected ways. Your Family Services Worker will be available to discuss the needs of your family and the availability of support.



Family supports may include:

- **General Support** – This includes things like counselling, information and referral.
- **Respite Care** – A short-term, regular period for parents to take a break from caring for a child with disabilities. There are several options that you can inquire about.
- **Child development** – An early intervention program done by trained child development counsellors to help children reach average development stages. Families are offered opportunities to develop skills to care for their children in their home and community. Counsellors usually offer this service in the child's home. It can also be done in other settings such as the child care centre or nursery school.
- **Therapy services** – These consist of speech and language therapy, physiotherapy, occupational therapy and behavioural or developmental therapy for preschool children with lifelong disabilities.
- **Supplies and equipment** – Special supplies can cover items such as formula and diapers that go beyond the usual costs of raising a child and because a child has a disability. Strollers and adaptations to equipment plus one-time purchases for items like seizure helmets, bath lifts, or lifts for vans are included in this category.
- **Home modifications** – This is for when your child needs a ramp, your home needs to accommodate a wheel chair, or if other modifications are required, related to your child's disability.
- **Transportation** – There is assistance available for families who are faced with extraordinary costs associated with transportation to medical appointments, mostly for people who live in rural and northern Manitoba.
- **Training** – There may be opportunities for you to attend special training with regard to medical practices your child needs, educational, or therapy training. Offered at no charge, these sessions will assist you in your parenting skills.



***“What is Inclusion?”***

*Inclusion is about ALL of us*

*Inclusion is about living full lives - about learning to live together.*

*Inclusion makes the world our classroom for a full life.*

*Inclusion treasures diversity and builds community.*

*Inclusion is about our 'abilities' - our gifts and how to share them.*

*Inclusion is NOT just a 'disability' issue.*

**Inclusion.com creates & shares tools, resources, capacities, so all can live full lives.**

**Inclusion.com is for citizens: educators, families, individuals, organizations—all of us.**

Source: [www.inclusion.com](http://www.inclusion.com)

## **Appropriate Educational Programming**

### **What is Manitoba's philosophy of Inclusion?**

- Inclusion is a way of thinking and acting that allows every individual to feel accepted, valued, and safe. An inclusive community consciously evolves to meet the changing needs of its members.
- Through recognition and support, an inclusive community provides meaningful involvement and equal access to the benefits of citizenship.
- In Manitoba, we embrace inclusion as a means of enhancing the well-being of every member of the community. By working together, we strengthen our capacity to provide the foundation for a richer future for all of us.
- The philosophy of inclusion goes beyond the idea of physical location and incorporates basic values and a belief system that promotes the participation, belonging and interaction.

Source: [www.educ.gov.mb.ca](http://www.educ.gov.mb.ca)

## Inclusive Child Care in Manitoba

Government funding is available to licensed, non-profit child care centres, nursery schools and licensed family child care homes. Staffing grants are the main grant support at facilities caring for children with special needs and can cover the entire cost of the special needs worker's salaries and employer contributions. Parents do not pay additional fees for their children, other than the cost of daily care which is the same for all children. Financial assistance may be available through the provincial government for lower income families.

For children, inclusion means to be meaningfully involved with families, friends and neighbours and to have opportunities to learn, play and recreate with other children and community members. The fact that at times some children may need extra support must never be used as an excuse to exclude a child from participating and contributing. The truth is that ALL children, youth and adults need 'special supports' from time to time. So, please know that your young child CAN access full time, part time, or before and after school care in a community program close to your home, work, or school.

What can you expect when you get there? Every children's program is a bit different, and you will want to find one with a good fit for your family's needs. In the highest quality centres we expect to see:

- A range of children with special needs are meaningfully included in ALL aspects of the child care day

*Early childhood supports such as daycare and other services must be available to all children. Programs such as early childhood interventions must include the entire family, wherever possible, as the primary teachers of their children. As children grow, supports and services must be provided in an inclusive environment. We must respect individuality and offer all children the opportunity to learn from each other's differences.*

Source: Community Living-Manitoba

- All staff at the centre feel equally comfortable in working with children with special needs
- Child care facilities make the best use of available funding and multi-disciplinary consultants to support your child's full inclusion
- Parents are key partners in all decisions being made about their children
- Staff and parents act as advocates for the entitlement of children with special needs for high quality child care services

The Canadian Association for Community Living recommends that measures of inclusion must be built in alongside other elements that are considered to be a part of 'high quality' early learning and care. High quality childcare **IS** inclusive child care.

For help finding an appropriate placement for your child, please contact the Manitoba Child Care Program at 945-0776 or toll free at 1-888-213-4754, or check out the government website at [www.gov.mb.ca/childcare](http://www.gov.mb.ca/childcare)

**Parents contribute to a child's growth, development and well-being. Professionals contribute special knowledge or expertise.**

## **Working with Professionals**

There are different times and different ways of working with professionals. Whether you give birth, foster, or adopt – if your child has a disability, the odds are pretty good that a variety of professionals will enter you and your child's life. These could include:

- ... medical professionals
- ... social workers
- ... child development specialists
- ... educators
- ... therapists, or others

The relationship you establish with them is important. The ideal situation is one in which the professional and you have respectful, trustworthy, open communication. Parents contribute to a child's growth, development and well-being. Professionals contribute special knowledge or expertise.

No child comes with a parent manual, least of all a child with a disability. There is uncertainty for all parents and many parents remain hopeful and optimistic. There will be times when as a parent, you might feel challenged or defensive. It is easy for parents to think professionals know best and to feel inadequate. You may think that you don't have the right to ask questions when you don't understand, or

you may feel unable to challenge what professionals say or do. It is important that your views and ideas are heard and respected.

There will be times when you and the professional may not agree on important issues concerning your child. This is not unusual or uncommon. In a balanced parent-professional relationship, differences are resolved with open communication. Being able to find common interests and having a willingness to resolve any differences in a respectful manner enables both you and the professional to appropriately support your child.

Even with the best efforts, the communication between parent and professional can break down. Working through your differences may require time or another person's involvement. This may not always be possible if they are not a regular member of your child's team. There may be a variety of different professionals in your child's life, and, they will change as your child develops/matures. Getting to know the professionals at those different stages will provide you with a diverse view. This offers you something on which to base your decisions regarding how to parent and support your child.

Connecting with family networks provides an opportunity to talk with other parents and family members about your concerns or intentions. Members of family networks can encourage you to ask questions, offer examples of good questions, and provide suggestions. Remember, no one knows everything. Such networks can also provide opportunities to locate experienced and empathetic/supportive professionals.

If you are dealing with people within an unfamiliar system, such as medicine or education, here are some helpful suggestions:

- Take notes or bring someone along who will take notes for you.
- Prepare your questions or your concerns prior to your appointments with professionals.
- Establish a record keeping system.  
Keep records of your child's:
  - medical history,
  - milestones, or delays, and
  - notes relevant to his/her development which provide clarity and help keep you organized.

There may be times when you do not agree with what a professional suggests or states. It is appropriate to say so, along with the reasons why you don't agree. If you keep yourself informed on your child's disability, their way of learning, and their communication style you will be able to speak with conviction and knowledge based on experience. Maintaining good records will help transition new professionals when there is a change, or additional people become involved.

Some parents have found it helpful to ask the professional to review the chart or file before they attend a meeting. If it helps and you are able to do so, creating an abridged version (a one page outline, for example) can assist in helping a new professional understand your child more quickly. Of course, building a relationship wherever possible with professionals will enable your child's needs to be met in a way that is congenial and supportive of everyone concerned.

## **ASK YOURSELF . . .**

**What skills do I have when it comes to dealing with professionals?**

**How can I use those skills to advocate and support?**

**What additional skills would be helpful to me?**

**Who do I know who might help me gain more skills?**

**What can we as a family do to prepare for meetings?**

**Am I clear about what I want to happen for my child?**

**Are there any examples from other parents that I can model or use?**

**What other resources can I tap into to help me gain more information?**



## 6-FINDING SUPPORT

### Respite and self-care

Finding and accepting personal supports or help can be valuable for parents who have children with disabilities. This can occur by connecting with various people in different ways. Friends and family that are close to you may offer their support willingly. Sometimes others may not know how to approach you with their offer of help and it may be necessary to ask. You might want to consider the following suggestions to help you in this process.



Consider who you already know and who you feel comfortable with. These are the folks who you have close relationships with and who might offer their help freely. Even when close friends and family are willing, you need to be prepared. What kind of support do you think would be helpful? Can they assist with child care, offer to listen, be there for general moral support, or help in some other way that would be of great benefit to you? Sometimes people hesitate to offer their help because they think you might be offended. Make it easy for them if that's what you need and want.



Find another parent with a similar experience or situation. This may be most valuable. A parent who has a child that is older can offer their knowledge from experiences that include challenges, struggles, and successes. Other parents can provide a perspective that is similar to what you are dealing with, along with information about programs, services or suggestions on how to handle your own family situations. There are various organizations and groups which represent people with disabilities who may help you connect with a parent who can provide this

kind of support. Please refer to the resource page in this guide for some of those contacts.



Join a parent networking group. Many parents have found support groups to be very helpful. Lifelong friendships have developed as a result of this kind of networking and sharing of common life experiences.



Communicate with your partner. The support we receive from our spouse or partner should not be overlooked. The ability to communicate with each other in a safe environment, sharing feelings, concerns, hopes and dreams strengthens your relationship and ultimately your family. Keeping your relationship strong and healthy is crucial while trying to support your child with a disability. **Do not underestimate the value of this.**



Utilize respite services in the best way possible. There are lots of stories about families who found themselves in crisis, unable to cope, and we strongly recommend you don't let yourself get there. Respite can offer all kinds of opportunities for the entire family. There are a variety of models available. Check with your family services worker about options. Accept support from your family and friends if they offer you support in this way. If you have not yet secured access to any government services, you may want to ask family or close friends to help you with respite. Respite is one of the outcomes that contribute to a balanced life. Any efforts to make that possible will pay off in the long-run.



### **Respite: A Definition**

*Defined as “relief from duties of care,” respite is a funded service available to families eligible for Children’s Special Services.*

*It is intended to provide families with a short-term break.*

*Families can choose from a number of options:*

- *Office-administered respite, where a respite agency hires staff and matches available staff to family needs;*
- *Self-administered respite, where families receive funding and hire their own respite staff;*
- *Facility-based respite, where families can choose a location outside the home as a temporary respite provider, such as
  - *a designated respite apartment or room in a community agency,*
  - *a hospital or a personal care home, based on availability.**

*For detailed information about respite, find Children’s Special Services on the Manitoba Family Services & Housing website at [www.gov.mb.ca/fs/](http://www.gov.mb.ca/fs/). There you will find links to a government of Manitoba web page detailing a variety of respite options.*

*In Winnipeg, Community Respite Services also offer a variety of options including a respite apartment, which can be booked for your eligible family member and his/her respite staff, or a family member who will provide support. Refer to the resources pages for contact information.*

### **A WHALE OF A TIME**

On one of their many visits to Children’s Rehab with their son Tyler\*, who has complex medical needs, Jane and Laurence noticed a flyer on the bulletin board; it was information about a fund established to enable children of low income families to attend summer camp.

“Both of us had the same idea at the same time”, Laurence recalled later. “We thought about Tyler’s love of dolphins and whales, and decided to apply.”

The result was a subsidized trip to BC to go whale-watching. Tyler, his parents and foster siblings, along with Tyler’s support staff enjoyed the vacation immensely.

“It was an amazing experience for all of us,” remembers Jane. “There is so much available out there; although your dreams may look different than what a fund is usually designated for, it never hurts to apply. You just might have the experience of a lifetime as a result!”

*\*Names and some details changed to protect identity.*

## Reframing Circumstances

Children come into our lives in a variety of ways

- by natural birth
- by adoption
- through fostering
- in grand parenting
- through relationship/marriage
- through an unexpected circumstance

Everyone handles unforeseen situations differently. Dwelling only on the negative has been proven to produce more of the same. Every family experiences the “disability factor” in their lives differently. There are many ways of looking at a circumstance. Reframing what appears to be a negative into a positive is not an automatic process. It is, however, a necessary step for moving forward.

Finding ways to remain strong and supported in a positive ways takes practice. People who inspire and help you recognize your own possibilities are beneficial to be around. Resources such as books, websites, DVDs, offer many different exposures that can help identify ways of reframing.

**If we perceive something as a liability, that's the message we deliver to our brain. Then the brain produces states that make it a reality. If we change our frame of reference by looking at the same situation from a different point of view, we can change the way we respond in life. We can change our representation or perceptions about anything and in a moment change our states and behaviours. This is what reframing is all about.<sup>2</sup>**

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<sup>2</sup> Anthony Robbins, *Unlimited Power* (New York: Ballantine, 1987) 291

***TO REFRAME:* To frame again or anew; to look at something from a different perspective; to take an undesirable behaviour or trait and transform it into a positive intention.**

Reframing how you perceive things means learning to be in tune with your child in ways you might not have thought of before. Your intuitive side offers ways of stretching how you may have seen and done things in the past. It means being more mindful of how you live your life, which also takes practice. Clarity around what questions you need answered or problems you need resolved often produces results that appear as “coincidence” – moments of just the right person, book, meeting, etc. coming along when you need it.

On the following pages we offer some examples of how others reframed their experiences.



## **The Power of Language — A Tool to Shift Our Perception**

**Story #1 . . . A woman who had recently given birth to a baby with complex medical needs was talking with her mother about the sacrifices her older children would be making in order for her to take care of their baby brother. She was concerned that they would become jealous of all the attention he would need from her. “You hoped your children could learn to be ambassadors for diversity and inclusion,” her mother said. “Now it is something we can all learn together. And your youngest will be our teacher.”**



**Story #2 . . . A new mother was bringing her baby, who had Down syndrome, home from the hospital for the first time. She was feeling over-whelmed by the challenges she, her husband and their child would face together.**

**“You always wanted to be a teacher,” her husband reminded her. “Here’s your chance.”**

Our use of words says a lot about how we perceive a person or situation. We can change our perceptions and role model a new way of looking at things for others by being conscious of the language we use. The Virtues Project offers one way of becoming more aware of how we see ourselves and others. Virtues are the positive qualities of the human spirit, such as kindness, compassion, integrity and justice. Each and every one of us has core virtues that are well established. Virtues that we need to develop would be our “challenge” virtues. Review the list of virtues on the next page. The ones you feel drawn to are your core virtues, while the ones you are less familiar with are likely your challenge virtues.

To consider how powerful our language can be, think of a situation where someone was not backing down from getting their needs addressed. They could be described as being “demanding” or “assertive”. These two words have very different connotations and present different perceptions of the person. Being demanding may suggest that the person is being unrealistic in their request, while being assertive suggests strength and confidence in their right to make a request.

When we consider the number of labels that may be applied to a person who has a disability, it is obvious how one’s life could be enhanced by a positive shift in perception. As parents, we can use virtues to role model a more honest and positive perception of our children.

Here is a quick exercise that you can do at any time in any situation when you think a shift in language and perception is in order:

*What is the “put down” or negative perception?*

**Example response — demanding**

*How it feels to be described in that way?*

**Example response — creates a feeling of being unworthy/expecting too much**

*Why someone would give that “put down”?*

**Example response — to silence requests**

*How we could view the same behaviour using virtues?*

**Example response — assertive**

*How it feels to have a virtue acknowledged?*

**Example response — powerful, confident, worthy**

For further information on The Virtues Project visit their website at [www.virtuesproject.com](http://www.virtuesproject.com)

## The Virtues

Assertiveness	Integrity
Caring	Joyfulness
Cleanliness	Justice
Commitment	Kindness
Compassion	Love
Confidence	Loyalty
Consideration	Moderation
Cooperation	Modesty
Courage	Orderliness
Courtesy	Patience
Creativity	Peacefulness
Detachment	Perseverance
Determination	Purposefulness
Diligence	Reliability
Enthusiasm	Respect
Excellence	Responsibility
Flexibility	Self-discipline
Forgiveness	Service
Friendliness	Tact
Generosity	Thankfulness
Gentleness	Tolerance
Helpfulness	Trust
Honesty	Trustworthiness
Honour	Truthfulness
Humility	Understanding
Idealism	Unity

## Asking Good Questions

Along the way there will be situations which will seem foreign, not feel right, or simply seem puzzling. Asking questions is the only way we learn and stretch ourselves. Pretending to understand may have detrimental outcomes or create additional unexpected situations. There is no such thing as a “stupid question.” It’s okay to say you don’t understand an answer or to ask someone to repeat their answer. Asking someone to repeat their question or answer using “plain language” sometimes helps.

No one knows everything, so questions are good. Keep your communication clear and respectful. Here are some questions of different professionals and other community representatives that might be helpful to keep in mind.

**Medical Professional** – If you have received a prescription or regime to follow, ask about time lines, side effects, or next steps if appropriate. Examples might include . . .

- What signs or symptoms should I be aware of?
- How will this treatment affect my child’s development?
- Are there other therapies/medications to consider?

**Educational Professional** – It is helpful to get a sense of how the child care centre, school division or school works with students. In order for your child to fully participate, questions about inclusion will help you determine involvement. You might find these questions as a good starter . . .

- What has been your experience in working with children who have disabilities like those of my child?
- What is your philosophy about the degree of interaction that my child will have with their same-aged, typically developing peers?
- What supports can be put in place to allow my child to have an appropriate education?

**Recreational Coordinator** – Wanting your child to experience his/her community will require getting a sense of what kind of supports or accommodations your neighbourhood or local children’s programming offers. Here are a few tips to find out what the practices of your local club or leisure centre might be . . .

- What has been your experience in working with children with disabilities?
- How do you see my child participating in your program?
- What kind of supports can you put into place that will allow my child to participate fully in your program?

The following abridged version of *The Family Lens: A Tool for Family Advocacy*<sup>3</sup> is designed to give you an overview of the type of questions that can help you evaluate various policies against what fits for your family. All or parts of this “tool” may be useful.

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<sup>3</sup> Canadian Association for Community Living 2004 Child & Family Task Force with assistance from Provincial & Territorial Association across Canada. Visit [www.aclmb.ca](http://www.aclmb.ca) for full version.

# A FAMILY LENS:

## *A Tool for Family Advocacy*

*Condensed from CACL revised 2004 version*

The family lens is a tool to enable families to more effectively and readily participate in the development, implementation and evaluation of policies that affect their lives and those of their family members with intellectual or developmental disabilities. The family lens can assist families and advocates in developing a better understanding of policies and how to improve them.

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### **How to use *the Lens***

The questions are designed to assist you in understanding the policy which you are going to review. As you go through the policy using the questions, you should get a clearer picture about the policy. Try not to focus on the detail or terminology used in the policy, focus more on the key policy implications, and their relationship to community inclusion and family support principles.

Public policies are written for professionals by professionals and serve the best interest of human service systems. Policies ensure program efficiencies, sets standards, manage eligibility, serve political agenda, and create monitoring mechanism. It is important that families are involved in those processes and have input in the development of those policies. There is a growing recognition of the importance and value of family involvement.

### **Guiding Principles**

- Families are the corner stone to inclusive community life and inclusive communities
- Children should grow up in families and all families are entitled to the necessary supports to raise their children at home
- Supporting/strengthening family life contributes to community well-being
- Families provide the greatest degree of continuity in the life of their child with an intellectual disability and that connection should be honoured and supported
- Policies should be designed to strengthen all families, respect and honour all families and facilitate inclusion in all aspects of family and community life.
- Supports for families should not be provided in place of, or to replace, the supports which children, youth or adults with disabilities require.

These questions the first time around may seem a bit overwhelming. You can work on this a bit at a time, or get together with a few friends. Grab a pen and paper. Use the questions to guide you as you review the policy. Just get started! Remember, if you want to do a more detailed lens exploration you can access the full version.

### GETTING THE BIGGER PICTURE

1. Who is the author of this policy?
2. What are the important points in the policy?
3. What issues are covered in the policies?
4. Who would be interested in those issues?
5. Who stands to gain the most?
6. Who are the key players/what are the points of influence?
7. Does the policy or language reflect our voice and dreams?
8. Do I know what existing policies/standards are?
9. What is the real meaning of the words used, are they code words for something else
  - ▶ reduced duplication= limit eligibility
  - ▶ Sustainability=cutting costs
  - ▶ Cost containment=waiting lists
10. What is the history behind the policy?
11. When does feedback have to be in, to whom and how?
12. When does this come into effect?
13. Who is responsible for implementing and interpreting the policy?
14. Is the policy respectful to family, child?
15. How does it affect the development of relationships/friendships?
16. Will this policy:
  - ▶ Strengthen your family?
  - ▶ Change family roles?
  - ▶ Keep or bring families together?
  - ▶ Threaten your child's ability to grow up in your family?
  - ▶ Support your child's participation in family life?
  - ▶ Give you more or less control over decisions which concern your child's life?
  - ▶ Enhance the community's perception of your child?

### COSTS

1. How much will this cost our family?
2. Is there a limit on the amount of funding? How is it limited? More/ less than before?
3. How hard will it be to get funding?
4. How complex will it be to report and account for the funding?
5. Is quality & safety important?
6. Will the quality of support/service be improved?
7. How will this affect my child's future?
8. Is the policy sensitive to the concept of individual/ family needs?
9. Is the policy fair, flexible?
10. To whom will the family be accountable?
11. Does it affect our eligibility for other services/supports?
12. What about appeals?
13. What are the timeframes around the appeal process?
14. Who hears the appeal?
15. Is it fair? Can advocates assist?
16. What's the overall view?
17. Is the policy a step forward or backwards?
18. What are the long-term implications?
19. Does it impact on other initiatives, policies; if so, in what way?

## 7-SEEING POSSIBILITIES

### Supporting Your Child

A parent's vision and belief of what their child is capable of is one of the most important factors in shaping their child's future. On a regular basis parents face labels that have been given their child. Over time this can make having a positive attitude difficult. No one likes to be reminded about all the things they cannot do.

Most of us try to present ourselves in a positive light by stating what we "can do." We learn quickly that as our children grow they can do many things with practice, praise, and encouragement. Many things have changed over time, including attitudes. People's understanding has been stretched into recognizing that all children and individuals are capable of growing and developing.

Accepting and creating a positive approach to your child's development requires letting go of limited preconceived thinking at times. It means accepting that children are children first, unique and special in all aspects with things to contribute as both the learner and the teacher. At times you may find that although you are the parent, you are also very much the learner, and your child, the teacher. Many parents have shared stories filled with wisdom taught to them by their children who have a developmental or intellectual disability.


If we as parents, view our children from what gifts, skills, and potential they bring to the world, the world will also view our children in that light. Applying this method of thinking does not mean that parents are in denial. Instead, it indicates they want their children to be seen in a contributing light. The limitations placed upon our children can be seen as barriers needing to be overcome while helping him/her blossom into their own potential. Each of us wants to contribute and be recognized for our skills or talents. Finding ways to recognize those abilities in our children will make that possible for them.

Language has a great deal of influence on how we perceive, accept and respond to people. When we as parents make our language respectful when speaking about our children, others will follow.

Talking about our children means using words of ability, not words of dis-ability. Introducing children by their disability or limitation, saying they have a "special need" or have a "handicap" may take away from the child or person they are first and foremost. Your child has a name first and the disability label comes after that; it does not define him/her.

In using "Person First" language remember that your family member is a child/person **who** enjoys . . . or is good at . . . He/she is a child or person **with** a diagnosis of . . . (insert appropriate responses in the blanks).






Sally is a student who enjoys music, reading and spending time with friends. She has Down syndrome.

or

Peter likes to talk about dinosaurs, loves counting, and game shows. He experiences behaviours known within the autism spectrum.



Building relationships with and for your child will help them learn about being a friend. Taking photos, scrap-booking memories, and making videos are ways to help track your child's growth, achievements, and interests. These are tools for relationship building and will help your son/daughter establish ways of expressing their interests, experiences, and abilities. It will make him or her look interesting and friendships can result.

As a long-term benefit, keeping track of your child's time lines by recording events with pictures and brief descriptions will help down the road when they're in school. You might be surprised to find that much of this personal history you are developing can come in very handy for some, yet unknown future classroom assignments, or help new teachers/staff learn about your child's interests and abilities.

## Developing Decision-Making & Self-Determination

Our sense of self begins with how others describe us as children; how people and situations are presented. Some thoughts to consider here include –

- ▶ Talk to, and about your children, in ways that emphasizes their abilities
- ▶ Encourage your children to learn and develop their abilities
- ▶ Ask your child's support staff to do the same
- ▶ Acknowledge that everyone needs help along the way; we live inter-dependently more than independently
- ▶ Encourage your children to make choices however small or limited, find ways to offer options
- ▶ Accept this will take practise

For many reasons it is important to foster self-determination in our children if they have disabilities. There are legislations and other documents which clearly state self-determination as an outcome to accept and strive for.

The next section of this guide is about legislation and human rights. It may seem too early to be thinking about this when your child is newly born, in child care, or in the early years of school. However, being aware has its advantages. Knowing early on that it's important to teach children how to make decisions helps us raise more competent adults. Working with support staff and educators in child care centres and schools will support this.

This is not saying our children won't need supports and assistance along the way. All of us will need some manner of supports and services

at one time or another in our lifetimes. No one lives his/her life as an island.

Some of the legislation you will read about may seem confusing. You might need resources that go beyond the immediate supportive relationships you have now. Reaching out and connecting with community organizations in ways that fit your needs will provide the chance to talk to other parents, learn what worked for them, and hear about services, policies, or other changes. Making the effort to connect in these ways will help you personally and it will of course help your child.



## 8-LEGISLATION & TAXES

### Voluntary Placement Orders

Since this is a book that presents options, we felt it was important to include information about voluntary placement orders. This is because we know there are times that it is the only way a child with a disability can receive specific services.

The majority of parents do not make this their first choice. Most families will have tried to advocate to access appropriate and necessary supports for their children with great effort before exhausting all possibilities.

In times of crisis, enormous stress, or heavy demand on resources – time, money, people and energy – sometimes discussing this option with your Family Services Worker becomes necessary. Taking this step does not prevent you from remaining involved in your child’s life. It does change your involvement however.

The following is an excerpt from the Manitoba Family Services & Housing information.

#### ***The Child and Family Services Act***

provides services to protect children and help parents care for their children. These services include counselling, education, financial assistance, homemaker and day care services.

#### ***Authorities***

When it came into force on November 24, 2003, *The Child and Family Services*

*Authorities Act* created a new child welfare system in Manitoba. This law allows authorities for the Northern and Southern First Nations and a Metis authority to develop and deliver Aboriginal child welfare services for their own people. A general authority was also created for all others.

Child and family services agencies provide services throughout Manitoba under the authority of their respective authorities. The four authorities must designate agencies to provide joint intake and emergency services in certain geographic areas of the province. A family’s first contact with the child welfare system will usually be through one of these designated intake agencies.

However, there is a process that allows adult family members to choose either the authority that is culturally appropriate or another authority as a service provider. All child and family services agencies and their primary addresses and telephone numbers are listed in the resources page.

#### ***Voluntary Services***

A parent who wishes to temporarily place a child in agency care or permanently surrender guardianship of a child may ask a child and family services agency to enter into a written agreement to do so.

#### **Voluntary Placement**

Parents who are unable to care for their child may enter into a written agreement with a child and family services agency to have their child placed in care for a period of time (*voluntary placement agreement*). Such agreements allow the agency to care for the child for up to 12 months. The parents must give the agency financial information and may

have to contribute all or part of the costs of caring for the child.

A voluntary placement agreement can be renewed until the child reaches age 18 or if the child:

- has a mental disability defined in *The Vulnerable Persons Living with a Mental Disability Act*
- is suffering from a chronic medical disability requiring treatment that cannot be given if the child remains at home
- is 14 years of age or older and beyond the control of the parent or guardian entering into the agreement

When an agreement is in place because of a temporary illness or misfortune, the agreement and any renewals cannot last for more than 24 months in total.

The parents or the agency may cancel a voluntary placement agreement at any time by signing the required form.

### **Voluntary Surrender of Guardianship**

A parent may agree to give up care and custody of his or her child permanently by signing a written *voluntary surrender of guardianship agreement* with a child and family services agency.

Once such an agreement is signed, the agency becomes the legal guardian of the child. That means the agency takes the place of the child's parents and makes decisions about the child's care, including placing the child for adoption. A parent can withdraw from this agreement within 21 days of signing it, but only if written notice is given to the agency. If the parents of a child are married or are

common-law partners, both must sign the agreement. If the parents are not married and are not common-law partners, the mother alone may sign it. To qualify as common-law partners under this law, the couple needn't have lived together for any particular length of time, but need only have cohabited in a conjugal relationship of some permanence. Where the mother alone signs a voluntary surrender of guardianship agreement, the agency cannot place the child for adoption if the father has applied to court for an order that he be declared the father of the child.

A decision to enter into a voluntary surrender of guardianship agreement is very serious and should be made only with professional assistance and careful consideration of all other options. Such help is available from the child and family services agencies listed in the resources section. It is also wise to seek legal advice about such an important decision.

For more information on the resources noted in the excerpt please visit [www.gov.mb.ca/fs/](http://www.gov.mb.ca/fs/)

## **UN Convention on the Rights of Persons with Disabilities (CRPD)**

Coming into force in April 2008, the purpose of the Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities. It also includes the intention to promote respect for their inherent dignity.

Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments, which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others.

Canada has signed the Convention and is developing ways to ratify and implement the articles outlined in it. With 50 Articles contained in the UN CRPD there is still much work to be done on this. Some areas of importance include . . .

### **Article 7 – Children with Disabilities**

States Parties\* shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children.

1. In all actions concerning children with disabilities, the best interests of the child shall be a primary consideration.
2. States Parties\* shall ensure that children with disabilities have the right to express

*\*The term “states parties” refers to all countries that ratified the convention, each of which is responsible for implementation.*

their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right.

### **The Guiding Principles of the Convention**

There are eight guiding principles that underlie the Convention and each one of its specific articles:

1. Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons
2. Non-discrimination
3. Full and effective participation and inclusion in society
4. Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity
5. Equality of opportunity
6. Accessibility
7. Equality between men and women
8. Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities

### **What is the Convention on the Rights of Persons with Disabilities?**

The Convention on the Rights of Persons with Disabilities is an international treaty that identifies the rights of persons with disabilities as well as the obligations on States Parties to the Convention to promote, protect and ensure those rights. The Convention also establishes two implementation mechanisms: the Committee on the Rights of Persons with

Disabilities, established to monitor implementation, and the Conference of States Parties, established to consider matters regarding implementation.

States negotiated the Convention with the participation of civil society organizations, national human rights institutions and inter-governmental organizations. The United Nations General Assembly adopted the Convention on 13 December 2006 and it was opened for signature on 30 March 2007. States that ratify the Convention are legally bound to respect the standards in the Convention. For other States, the Convention represents an international standard that they should endeavour to respect.

Please note that at the time of this writing Canada still needs to ratify this convention.

Further details can be obtained by searching the website at [www.un.org](http://www.un.org)

## **UN Convention on the Rights of the Child (UNCRC)**

The United Nations Convention on the Rights of the Child (UNCRC) is an international human rights treaty that grants all children and young people (aged 17 and under) a comprehensive set of rights. Canada was a leader in developing the UNCRC, and one of the first signatories. Canada ratified the UNCRC in 1991. When a country ratifies the convention it agrees to do everything it can to implement it.

The convention gives children and young people over 40 substantive rights. These include the right to:

- Special protection measures and assistance
- Access to services such as education and health care
- Develop their personalities, abilities and talents to the fullest potential
- Grow up in an environment of happiness, love and understanding
- Be informed about and participate in achieving their rights in an accessible and active manner

All of the rights in the convention apply to all children and young people without discrimination.

Further details can be obtained by searching the website at [www.un.org](http://www.un.org)

## Canadian Charter of Rights & Freedoms

This *Charter* guarantees some fundamental rights and freedoms for all persons living in Canada. It contains the principles that we recognize as overriding law governing Canadians and outlines rights and freedoms regarding democracy, mobility, legality, equality, languages, enforcements plus some general areas.

Section 15(1) under Equality Rights is the one that draws attention to disability. It states, *“Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability.”*

It needs to be noted here that although this is the ideal we strive for in this country, the reality for persons with disabilities is such that not all the rights are experienced in a full citizenship capacity. A variety of equality seeking groups and organizations continue to work towards making the principles in the Canadian Charter of Rights & Freedoms attainable in a practical and measurable way. Although there are barriers to overcome, many benefits have been gained as a result of this Charter.

For more information on the *Canadian Charter of Rights & Freedoms* please visit [www.gc.ca](http://www.gc.ca) and check the index under human rights.

## Vulnerable Persons Living with a Mental Disability Act (VPA)

In October 1996, The Vulnerable Persons Living with a Mental Disability Act was passed. According to this legislation a “vulnerable person” is someone defined as . . .

- ▶ An **adult** over 18 years of age
- ▶ Who has a **mental disability** that manifested prior to age 18 with a lower IQ needing help in daily living
- ▶ And who **needs help** making decisions around personal care or property and money management.

All three of these scenarios must be present in order for someone to be deemed as falling under this Act.

There are five guiding principles that set the “tone” of the legislation. In plain language these are:

1. Vulnerable persons are presumed able to make their own decisions.
2. Individuals are encouraged to make their own choices.
3. If someone needs help to make a choice the legislation encourages friends, family, and service providers to help someone understand the choices to make an informed decision.
4. Any help provided must be respectful of an individual’s privacy and dignity as an adult.
5. As a last resort, a substitute decision-maker can be identified if there is a decision that a person is unable to make, even with help.

For further information contact the VPA Commissioner’s Office at (204) 945-5039 – if outside of Winnipeg call 1-800-757-9857 or visit the website [www.gov.mb.ca/fs/](http://www.gov.mb.ca/fs/)

## Human Rights in Manitoba

The Manitoba Human Rights Commission attempts to uphold a Universal Declaration of Human Rights that declares, "All human beings are born free and equal in dignity and rights." Translated into law in Manitoba as *The Human Rights Code*, this provincial statute prohibits discrimination on the basis of ancestry, religion, nationality, sex, age, disability, or other group stereotypes. The Manitoba Human Rights Commission (MHRC) is the agency responsible for overseeing the laws. The MHRC enforces provisions of *The Code* plus is authorized to mediate and investigate complaints of discrimination, refer matters to adjudication, educate the public and promote human rights.

The Commission offers all of its services to the public without charge. *The Human Rights Code* disallows unreasonable discrimination on characteristics that apply to a group such as – ancestry, nationality, ethnic origin, religion, age, sex, pregnancy and other gender determined characteristics, sexual orientation, marital or family status, source of income, political belief and physical or mental disability.

The Human Rights Commission can only deal with matters that apply to provincial matters. Most activities carried on in Manitoba are within the provincial jurisdiction. Anything federally regulated such as airlines, railways and federal civil service are filed with the Canadian Human Rights Commission. The staff of either commission will answer any questions regarding the appropriate jurisdiction to deal with a particular complaint.

To learn more about the Human Rights Code, find publications, links or other related information go to [www.gov.mb.ca/hrc/](http://www.gov.mb.ca/hrc/)



You are a human being. You have rights inherent in that reality. You have dignity and worth that exists prior to law.

– Lyn Beth Neylon,  
Human Rights Activist



## Disability Tax Credit (DTC)

The federal income tax system in Canada offers a number of important benefits and deductions for people with disabilities and their families. Canada Revenue Agency produces updates to a guide called “Information Concerning People with Disabilities.” You can pick up this guide at your local Canada Revenue Agency office or from their website. If you need an alternate format to understand the document there are Braille, large print, e-text and audio options available.

There are a number of important features that can help reduce the amount of income tax a person with a disability pays through benefits, tax credits and deductions. Currently some options 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 be required to pay)
- Medical Expenses – a variety of expenses incurred by people with disabilities or their families are covered
  - attendant care expenses
  - voice recognition software
  - food for special diets
  - sign language interpreters
  - payments for vehicle adaptations
  - special equipment
  - travel costs to access specialized medical care
- Child Care Expenses
- Amounts for eligible dependants and amounts for dependents 18 or older having special support needs
- Amounts for caregivers

- Transfer of the Disability Amount from a dependent who has a disability

The income tax system is always changing and can be complicated. In order to be sure what kind of benefits, credits, or deductions that your child or you may be eligible for, contact a counsellor at the Canada Revenue Agency. You may also consult with an accountant that prepares incomes tax returns. Be sure to inquire about any retroactive benefits if there are some years for which you may have been eligible and the appropriate documents haven't been submitted.

To read up on the latest information on the DTC eligibility and other relevant information visit the Canada Revenue Agency website at [www.cra-arc.gc.ca/disability/](http://www.cra-arc.gc.ca/disability/)

## Registered Disability Savings Plan (RDSP)

Declared officially by Parliament as legislation on December 2007, the RDSP presents an opportunity for persons with disabilities to participate with financial investments to build a secure future. It also enables families who have a child with a disability to invest in their child's future. As their children reach adulthood they can invest their own money, plus families can also continue to contribute to the plan over their adult child's lifetime. The investment cannot exceed \$200,000. There are provincial options for additional investments available.

The legislation allows an individual with a disability to register the program or a family member can invest indicating the child/person with the disability as beneficiary.

There are two ways to invest –

1. Disability Savings Bond or
2. Disability Savings Grant.

Both plans contain contributions that are matched in some manner by the Canadian government depending on your family income. You qualify for the RDSP if you have completed a T2201 Form, received the Disability Tax Credit and filed an income tax return with Canada Revenue Agency.

You can find the most recent information on the Registered Disability Savings Plan at [www.rdsp.com](http://www.rdsp.com)

## Manitoba Trust Funds

### *Disability Trusts*

In April 2003, the provincial government announced, "*Manitobans with disabilities living in the community can use certain lump-sum payments to improve their quality of life, without affecting their Employment and Income Assistance (EIA) benefits.*"

People with disabilities can obtain enhanced disability supports if there is a trust fund set up for them. Now people can access other sources of income to purchase disability-related supports that will bring them a better quality of life without affecting their EIA benefits.

This means an inheritance or life insurance policy can be set up as a trust fund in which it stipulates the funds are to apply specifically toward purchases of equipment or services to improve an individual's quality of life. **There is a lifetime limit of \$100,000 per person that can accumulate.**

There are various sources the fund can come from, including:

- proceeds from an estate (inheritance) or life insurance policy;
- compensation payments, except for loss of income;
- gifts from family, guardians or friends;
- proceeds from the sale of a home or land; or,
- investment growth from the trust.

Some of the disability-specific goods and services people may pay for include:

- technical equipment, such as upgraded hearing aids;
- extended homemaker services;
- increased rent, for disability reasons;
- the purchase of a primary residence or a vehicle, for disability reasons; or
- modifications to their primary home, workplace or vehicle.

Also good to know for planning purposes is:

- this type of trust can be set up by an adult who has a disability and can manage it themselves or with support
- the trust can be in the individual's name without impacting any EIA benefits
- it can be as simple as setting up a designated daily savings account or some other separate account at your bank or credit union
- talk to the EIA worker to see what the best way might be to set this up and how to report on the funds

### ***Discretionary Trust***

A discretionary trust is a trust set up by a parent or other family member in their will. Also referred to as a "Henson Trust," this trust allows an investment to be used in any way which enables improved quality of life without restrictions. For example, this might make it possible for someone to live in a better home, have nicer furniture, take some vacations, participate in additional recreational/leisure or continuing education opportunities, etc.

There are some important things to note here:

- There is no set limit on how much money can be put into this type of trust.
- This trust must be held in someone else's name and is not considered an asset of the individual.
- It does not negate or disallow someone's eligibility to receive EIA.
- Someone must be appointed to administer the trust.
- The investment is held in trust by a trustee(s) that can be one or more individuals or a corporate trustee such as a trust company.
- How the money is spent is determined by the discretion of the trustee(s) not the beneficiary.

The wording of the trust agreement is important. Make a will and estate plan. To be fully effective we recommend talking to a solicitor, and accountant or financial advisor who has experience and expertise in this area.

To obtain more information on trust funds check with a financial advisor or lawyer that specialize in this area. Your Family Services Worker may be able to refer you to someone who can supply more specific information, depending on your questions or circumstance.



***The future is always beginning now.***

– Mark Strand, *Reasons for Moving*

## 9-SUGGESTED RESOURCES & CONTACT INFORMATION

### Community Organizations:

#### **ASPERGER'S MANITOBA INC. \***

**Telephone:** (204)-947-944

**Email:** [info@asperger-manitoba.ca](mailto:info@asperger-manitoba.ca)

**Website:** [www.asperger-manitoba.ca](http://www.asperger-manitoba.ca)

#### **AUTISM SOCIETY MANITOBA (ASM) \***

**Address:** 825 Sherbrook Street  
Winnipeg, MB R3A 1M5

**Telephone:** (204)-783-9563

**Website:** [www.autismmanitoba.com](http://www.autismmanitoba.com)

#### **CEREBRAL PALSY ASSOCIATION OF MANITOBA \***

**Address:** 105 - 500 Portage Ave.  
Winnipeg, MB R3C 3X1

**Telephone:** (204)-982-4842

**Toll Free:** 1-800-982-4842 (Within Manitoba Only)

**Fax:** (204)-982-4844

**Email:** [office@cerebralpalsy.mb.ca](mailto:office@cerebralpalsy.mb.ca)

#### **COMMUNITY LIVING-MANITOBA \***

**Address:** #6 - 120 Maryland Street  
Winnipeg, MB R3G 1L

**Telephone:** (204)-786-1607

**Fax:** (204)-789-9850

**Email:** [aclmb@mts.net](mailto:aclmb@mts.net)

**Website:** [www.aclmb.ca](http://www.aclmb.ca)

#### **COMMUNITY LIVING-WINNIPEG \***

**Address:** 120 Maryland Street  
Winnipeg, MB R3G 1L1

**Telephone:** (204)-786-1414

**Website:** [www.communitylivingwinnipeg.com](http://www.communitylivingwinnipeg.com)

**Community Organizations Continued:**

**COMMUNITY RESPITE SERVICES \***

**In Winnipeg:**

**Address:** 825 Sherbrook Street  
Winnipeg, MB R3A 1M5  
**Telephone:** (204)-953-2400  
**Fax:** (204)-775-6214  
**Email:** [comresp@mts.net](mailto:comresp@mts.net)

**In Brandon:**

**Address:** 710- 3rd Street,  
Brandon, MB R7A 3C8  
**Telephone:** (204)-727-4910  
**Fax:** (204)-728-3305  
**Email:** [crsbdn@mts.net](mailto:crsbdn@mts.net)

**CONTINUITY CARE**

**Address:** #2-120 Maryland St.  
Winnipeg, MB R3G 1L1  
**Telephone:** (204)-779-1679  
**Email:** [contcare@mts.net](mailto:contcare@mts.net)  
**Website:** [www.continuitycare.ca](http://www.continuitycare.ca)

**DOWN SYNDROME SOCIETY (MANITOBA) \***

**Address:** 825 Sherbrook Street  
Winnipeg, MB R3A 1M5  
**Telephone:** (204)-992-2731  
**Fax:** (204)-975 -3027  
**Website:** [www.manitobadownsyndromesociety.com](http://www.manitobadownsyndromesociety.com)

**EPILEPSY MANTIOBA \***

**Address:** #4-1805 Main Street  
Winnipeg, Mb R2V 2A2  
**Phone:** (204)-783-0466  
**Fax:** (204)-784-9689  
**Toll Free:** 1-866-374-5377  
**Website:** [www.manitobaepilepsy.org](http://www.manitobaepilepsy.org)

**Community Organizations Continued:**

**THE FAMILY CENTRE**

**Address:** 401-393 Portage Avenue (Portage Place)  
Winnipeg, MB R3B 3H6  
**Telephone:** (204)-947-1401  
**Fax:** (204)-947-2128  
**Email:** [staff@familycentre.mb.ca](mailto:staff@familycentre.mb.ca)

**MANITOBA FOSTER FAMILY NETWORK \***

**Address:** 3rd floor 555 Broadway Avenue  
Winnipeg, MB R3C 0W4  
**Telephone:** (204)-940-1280  
**Toll-Free:** 1-866-458-5650  
**Website:** [www.mffn.ca](http://www.mffn.ca)

**MANITOBA FAMILIES FOR EFFECTIVE AUTISM TREATMENT**

**Address:** Suite 129, 162-2025 Corydon Avenue  
Winnipeg, MB R3P 0N5  
**Telephone:** (204)-487-1685  
**Email:** [info@mfeat.ca](mailto:info@mfeat.ca)  
**Website:** [www.mfeat.ca](http://www.mfeat.ca)

**OPEN ACCESS RESOURCE CENTRE**

Communication Devices  
**Address:** #3-120 Maryland  
Winnipeg, MB R3G 1L1  
**Telephone:** (204)-949-2430  
**Website:** [www.oarc.ca](http://www.oarc.ca)

**REHABILITATION CENTRE FOR CHILDREN FOUNDATION**

**Address:** 633 Wellington Crescent  
Winnipeg, MB R3M 0A8  
**Telephone:** (204)-475-5073  
**Fax:** (204)-453-5182  
**Email:** [rccf@mts.net](mailto:rccf@mts.net)

## **ST AMANT FAMILY CARE PROGRAM (Children) \***

**Address:** 440 River Road  
Winnipeg MB R2M 3Z9  
**Telephone:** (204)-256-4301  
**Fax:** (204)-257-4349  
**Email:** [inquiries@stamant.mb.ca](mailto:inquiries@stamant.mb.ca)  
**Website:** [www.stamant.mb.ca](http://www.stamant.mb.ca)

## **SOCIETY FOR MANITOBANS WITH DISABILITIES**

**Address:** 825 Sherbrook Street  
Winnipeg, Mb R3A 1M5  
**Phone:** (204)-975-3010  
**Fax:** (204)-975-3073  
**Toll Free:** 1-866-282-8041  
**Email:** [info@smd.mb.ca](mailto:info@smd.mb.ca)  
**Website:** [www.smd.mb.ca](http://www.smd.mb.ca)

## **SPECIALINK**

The National Centre for Childcare Inclusion

**Address:** University of Winnipeg  
2E22-515 Portage Avenue  
Winnipeg, MB R3B 3H6  
**Telephone:** (204)-258-2901  
**Toll-Free:** 1-866-902-6333  
**Fax:** (204)-786-7803  
**Email:** [info@specialinkcanada.org](mailto:info@specialinkcanada.org)  
**Website:** [www.specialinkcanada.org](http://www.specialinkcanada.org)

### **\* Denotes Children's Coalition Member –**

*Committed to working with communities, service agencies, and government to achieve a coordinated network that supports children with disabilities and their families and promotes full participation in all aspects of community life.*



**Government Contacts:**

**MANITOBA FAMILY SERVICES & HOUSING**

**Address:** 305 - 114 Garry Street  
Winnipeg, MB R3C 4V7  
**Website:** <http://www.gov.mb.ca/fs/>  
**Telephone:** (204)-945-3744 (Manitoba General Inquiry)  
**Fax:** (204)-945-4261  
**Toll-Free:** 1-866-626-4862 **TTY:** (204)-945-4796  
**E-mail:** [mgi@gov.mb.ca](mailto:mgi@gov.mb.ca)

**Regional offices also have information on:**

- Children Special Services
- Child Care
- Child & Family Services
- Supported Living Program
- Disability Trust Information
- Income Assistance
- Vulnerable Persons Living with a Mental Disability Act

<b>Winnipeg</b>	3-139 Tuxedo Avenue	(204) 945-8137
	2-189 Evanson Street	945-6333
	1021 Court Avenue	945-8333
	2015 Portage Avenue	945-8911
	233 Provencher Boulevard	945-8966

<b>Brandon</b>	340-9th Street	726-6173
<b>Beausejour</b>	20-1st Street, South	268-6025
<b>Morden</b>	63B Stephen Street	822-2861
<b>Portage la Prairie</b>	25 Tupper Street, North	239-3092
<b>Selkirk</b>	825 Manitoba Avenue	785-5100
<b>Dauphin</b>	27-2nd Avenue SW	622-2035
<b>Flin Flon</b>	143 Main Street	687-1700
<b>The Pas</b>	Box 2550	627-8240
<b>Thompson</b>	59 Elizabeth Drive	677-6570

<b>Vulnerable Persons Commissioner's Office</b>	(204) 945-5039
Outside Winnipeg:	1-800-757-9857

**MANITOBA EDUCATION CITIZENSHIP & YOUTH**

<b>Special Education</b>	(204) 945-7933
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## **Medical/Health Contacts:**

### **CHILD DEVELOPMENT CLINIC**

*Located in Children's Hospital at Health Sciences Centre*

**Address:** 820 Sherbrook,  
Winnipeg MB R3A 1R9  
**Telephone:** (204)-787-2595  
**Website:** [www.hsc.mb.ca](http://www.hsc.mb.ca)

### **PUBLIC HEALTH NURSE**

*Refer to the Regional Health Authority (RHA) nearest you:*

#### ***Assiniboine RHA***

**Address:** 192-1st Avenue West  
Souris MB R0K 2C0  
**Telephone:** (204)-483-5000  
**Toll-Free:** 1-888-682-2253  
**Website:** [www.assiniboine-rha.ca](http://www.assiniboine-rha.ca)

#### ***Brandon RHA***

**Address:** 150A - 7th St. **Address:**  
Brandon MB R7A 7M2  
**Telephone:** (204)-571-8400  
**Website:** [www.brandonrha.mb.ca](http://www.brandonrha.mb.ca)

#### ***Burntwood RHA***

**Address:** 867 Thompson Drive S.  
Thompson MB R8N 1Z4  
**Telephone:** (204)-677-5353  
**Website:** [www.thompson.ca/dbs/brha/](http://www.thompson.ca/dbs/brha/)

#### ***Churchill RHA***

**Address:** Churchill Health Centre  
Churchill MB R0B 0E0  
**Telephone:** (204)-675-8318  
**Website:** [www.churchillrha.mb.ca](http://www.churchillrha.mb.ca)

#### ***Interlake RHA***

**Address:** 589-3rd Avenue South  
Stonewall MB R0C 2Z0  
**Telephone:** (204)-467-4742  
**Toll-Free:** 1-888-488-2299  
**Website:** [www.irha.mb.ca](http://www.irha.mb.ca)

#### ***Nor-Man RHA***

**Address:** 84 Church Street  
Flin Flon MB R8A 1M7  
**Telephone:** (204)-687-1300  
**Website:** [www.norman-rha.mb.ca](http://www.norman-rha.mb.ca)

#### ***North Eastman RHA***

**Address:** 24 Aberdeen Avenue  
Pinawa MB R0E 1L0  
**Telephone:** (204)-753-3101  
**Toll-Free:** 1-877-753-2012  
**Website:** [www.neha.mb.ca](http://www.neha.mb.ca)

#### ***Parkland RHA***

**Address:** 25 Third Street SW  
Dauphin, MB R7N 1R7  
**Telephone:** (204)-638-2118  
**Toll-Free:** 1-800-259-7541  
**Website:** [www.prha.mb.ca](http://www.prha.mb.ca)

### ***Central RHA***

**Address:** 180 Centenaire Drive  
Southport MB R0H 1N0  
**Telephone:** (204)-428-2000  
**Toll-Free:** 1-800-742-6509  
**Website:** [www.rha-central.mb.ca](http://www.rha-central.mb.ca)

### ***South Eastman RHA***

**Address:** Box 470  
La Broquerie MB R0A 0W0  
**Telephone:** (204)-424-5880  
**Toll-Free:** 1-866-716-5633  
**Website:** [www.sehealth.mb.ca](http://www.sehealth.mb.ca)

### ***Winnipeg RHA***

**Address:** 1800 - 155 Carlton Street  
Winnipeg MB R3C 4Y1  
**Telephone:** (204)-926-7000  
**Website:** [www.wrha.mb.ca](http://www.wrha.mb.ca)

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## **Updates and comments:**

We have included some basic contact information that might be helpful depending on what questions you need answers to. At the time of the last printing to the best of our knowledge the information contained in this guide is accurate.

Community and government offices do change location periodically. This could impact the contact information outlined here. To review any additions or amendments to this guide please visit [www.aclmb.ca](http://www.aclmb.ca)

Your comments and feedback are always welcome. Let us know if you found this guide helpful or if there is something you would like to see updated.

To advise of an update or offer your comments please contact us at [aclmb@mts.net](mailto:aclmb@mts.net) or phone (204) 786-1607

## GLOSSARY OF TERMS

- Advocate:** (verb): To speak, plead or argue in favour of.  
(noun): One who pleads on another's behalf.
- Autonomy:** Self-government, self-determination, independence.
- Early intervention:** Refers to the provision of services to school age or younger children who either have, or are at risk of having, disabilities. Early intervention either works to keep existing conditions from getting worse, or works to prevent disabling conditions from developing.
- Family network:** A family system including immediate and extended family.
- Full citizenship:** Full access to every relevant community, provincial and federal resource; opportunity to participate in every possible way as a citizen; enjoying all rights and privileges that come with citizenship.
- Learning disabilities:** Difficulties with academic progress; discrepancies between a person's potential for learning and what he actually learns; uneven pattern of development (language, physical, academic, and/or perceptual development).
- Global developmental delay:** Delays in all areas of development.
- Inherent:** Existing as an essential characteristic.
- Intellectual disability:** Intellectual development; not seen as typical, usually caused by congenital causes, brain injury or disease; formerly known as "mental retardation" (a term still used in USA).
- Muscular dystrophy:** Any of several progressive muscular disorders caused by a defect in one or more genes that control muscular function. It is characterized by gradual irreversible wasting of skeletal muscle.
- Pervasive developmental disorder:** Any of several developmental disorders, such as Autism Spectrum Disorder or Asperger's syndrome, characterized by severe deficits in social interaction and communication or by the presence of repetitive, stereotyped behaviours. Many of these disorders are evident in the first years of life.

- Psychiatrist:** A physician who specializes in psychiatry, with emphasis on medications. A psychiatrist is a medical doctor.
- Psychologist:** A person educated and trained to perform psychological research, testing and therapy. A psychologist holds a PhD, and can specialize in research and testing as well as psychotherapy.
- Prognosis:** A prediction of the probable course and outcome of a disease; a forecast or prediction.
- Regime:** A regulated system, as of diet, exercise and therapy; a regimen.
- Support network:** A group consisting of family and friends who are available for a variety of support roles, ranging from friendship to practical assistance with any of a number of daily life issues.
- Transition planning:** Refers to planning for the change-over periods of a child/individual's life –home or child care to kindergarten and from school life to adult life are considered major transitions. This type of planning occurs also when children move from early years to middle school and then to high school.

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Finally, you the parent/family member and the child or children you support were the inspiration. We all acknowledge your journey – your struggles, your joys – and the lessons learned along the way. I leave you with this thought attributed to Helen Keller, *“When one door of happiness closes, another opens; but often we look so long at the closed door that we do not see the one which has been opened for us.”* May you find your new opening, your “Holland.”



**COMMUNITY LIVING - MANITOBA**

*Diversity Includes.*