

NAVIGATING THE SYSTEM

A GUIDE FOR FAMILY MEMBERS OF
PEOPLE WITH INTELLECTUAL DISABILITIES

FOURTH EDITION



**INCLUSION
SASKATCHEWAN**
supporting individuals with intellectual disabilities

NAVIGATING THE SYSTEM

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PEOPLE WITH INTELLECTUAL DISABILITIES**

FOURTH EDITION



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Inclusion Saskatchewan
3031 Louise Street
Saskatoon, Saskatchewan
S7J 3L1

Phone (306) 955-3344 Fax (306) 373-3070
Website: www.inclusionsk.com
E-mail: info@inclusionsk.com

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Dear Readers,

It is more than likely that you have cracked the cover of this book because you are looking for answers. This is not the type of book that you pick up for a bit of light reading. This is however, the type of book that can change your life and that of your family. It can empower you to make better decisions and help alleviate at least some of the stress you may be experiencing. Now that I have your attention: Welcome to Navigating the System!

If, like me, you have a child with an intellectual disability, you may have already recognized that doing what is best for that child can be very challenging. There are so many unanswered questions, uncertainties and multiple perceptions on what is best for the child. Within the pages of this edition of Navigating the System, you will find the most truthful statement a parent will ever hear: "You are your child's best advocate." These words alone can boost the confidence in us as parents and lead us in the right direction for helping our child reach their greatest potential.

After receiving and coming to terms with a diagnosis for our children, we are faced with a steep learning curve. One of the first things we must learn about is the extensive system of organizations and services available, or in many cases, the unavailability in our community. As in life, there are no textbooks to tell you exactly what you need to know to be successful however, now there is an updated handbook to assist you in the learning process thanks to Inclusion Saskatchewan. They have recognized the value of the experience of parents who have come face-to-face with these same challenges before us and compiled this information into a user-friendly format.

Whether you read it in one sitting or one paragraph at a time, the content that will benefit you the most will stand out above the rest. If you find it overwhelming or difficult to understand, invite a friend or another parent to read and discuss it with you. It will take time but having a clear picture of how things work will make it easier for you and your family in the long run.

If there is only one take away from reading this book right now, let it be: Your energy to be an advocate will ebb and flow and that's ok! Your love for your child and your desire to help them reach their potential never will! Take a breath, drop your shoulders. You got this!

We can navigate this together.

Sincerely and most compassionately yours,

A handwritten signature in black ink, appearing to read 'Bluesette Campbell', with a stylized, flowing script.

Bluesette Campbell
Parent/Vice President, Inclusion SK
Meadow Lake, SK

Introduction

When you become the parent of a child with an intellectual disability, you start on a journey that you may not feel prepared for, as there are often increased challenges that parents experience when they have a child with an intellectual disability. Many parents have found that it can often be difficult to find a doctor who is patient and understanding; a dentist who is able to come up with creative solutions when your child is struggling in the dental chair; or a qualified care provider who you trust with your child's needs. If your child has more intensive support needs, you may spend a lot of your time managing medical, educational, and/or recreational challenges that may not exist for other children.

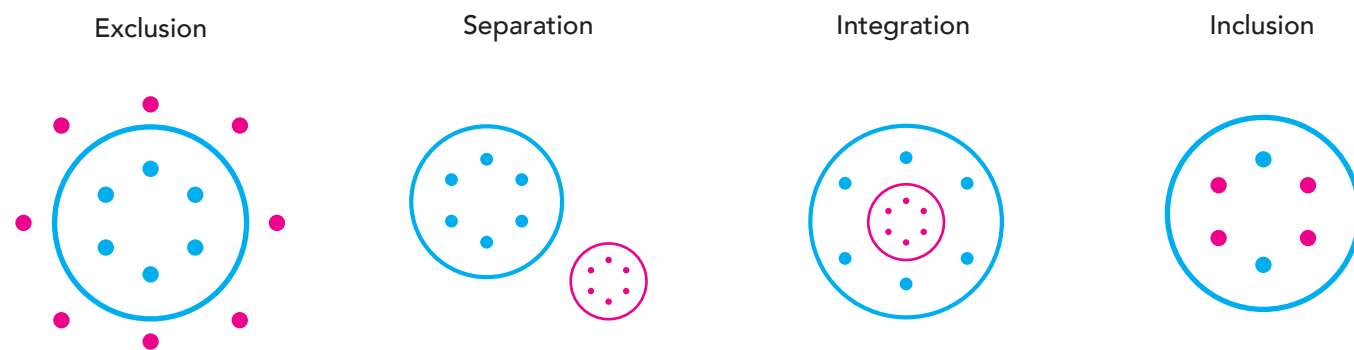
In order to ensure that your child has the best quality of life possible, you will become involved, in ways you never dreamed of, with the doctors, educators, social workers and therapists that make up the human service system. This can be physically and emotionally draining and leave less time and energy for the rest of your family. It may feel impossible and overwhelming. This is why we created this guide.

Navigating The System is a guide to finding solutions in systems that are often complicated, restrictive, under-funded and confusing. This book will provide you with the tools and information you need to find support for your family and your child throughout childhood and into adulthood. In these pages, you will find tips from parents and professionals about how to advocate for your child. You will also find explanations of some of the bureaucracies and policies that you will encounter on your journey.

Understanding Inclusion

When we are included in all aspects of life, we are connected, we have purpose, and have meaningful relationships. We feel like we belong to something larger than ourselves and feel the joy of community. This is true for everyone, especially those with intellectual disabilities. This is why our mission is to ensure that citizens of Saskatchewan who have intellectual disabilities are valued, supported and included members of society and have opportunities and choices in all aspects of life.

As you move forward in your journey, ensure that you understand the differences between programs and services that offer separation, integration, and inclusion (see diagram below). While we always strive for inclusion over separation and integration, the reality is that some individuals prefer to have separate or integrated programming, as they feel it suits their sensory/emotional needs.



Using Respect-First Language

Language continually evolves when it comes to speaking about or speaking with people who have intellectual disabilities. Some people prefer to use identity-first language, in which the identifying word comes first in the sentence and highlights the person embracing their identity. For example, members of the autism community prefer to be referred to as “autistic” rather than, “a person who has autism.” Other people prefer to use people-first language, which avoids using labels or adjectives to define someone. For example, instead of saying, that a person is disabled, we might say the person has a disability. We believe that respect-first language is best: how an individual prefers to be addressed is the important thing. If you don’t know how an individual prefers to be acknowledged, simply ask them if the context deems it appropriate.

Becoming An Advocate

You are your child’s best advocate. From birth, you have been the person who makes sure your child’s needs are met. You know your child better than anyone else does and you are the person who cares the most about making sure your child succeeds. When your child is sick, lonely, uncomfortable, excluded, or not reaching their full potential, you are the one supporting them through it.

Advocating for your child comes naturally, but working with schools, the medical system, social workers, and other professionals can be challenging. Effective advocacy can require skills; however, these are often skills that people do not learn until they have to and they learn them through experience. Teachers, doctors, and social workers are trained to work with you, but being successful requires some preparation on your part. Here is some advice to help you become an effective advocate.

- **Be Informed**

Know your rights and what to expect from the services your child receives. Know the facts of your child’s situation, including strengths and challenges. It may be important to hear what those who are working with your child are experiencing. Get to know the people who support your child in schools, hospitals, etc. Know who they are, what their role is, and ask them what they can do to support your child as well as what their strengths/limitations are.

- **Keep Records**

Keep copies of everything you receive/send in a file system or a binder to keep everything organized so you can find it when you need it. Make all requests in writing. When you speak to someone on the phone or in person, make notes of the conversation (date, time, name, person’s position, requests, and decisions made). It is also a good idea to send a copy of your notes to the person you talked to, so be sure you write your notes with the expectation that others will see them. Always ask for written confirmation of what you were promised.

- **Encourage Self-Advocacy**

Support people to dream and to carve out their own place in the world. Learn from self-advocates and follow self-advocacy movements to understand how to be a good ally for your child, as they are the ones who should guide each step they take in life. Encourage them to speak up for themselves as often as possible, and assist them to find other self-advocates who may become members of their personal networks.

- **Advocate With Others**

Develop a support network of friends, family, other parents, etc., who know you, know your child, and are willing to help you advocate. When you go to meetings, try to take a support person with you. This person can take notes for you (even if someone is already the official note taker). Your support person is another set of eyes and ears.

- **Prepare For Meetings**

When you are invited to a meeting, ask for an agenda that includes the topics for discussion, the reason for the meeting, and who will be attending. If you asked for the meeting, provide the agenda prior to the meeting. Call to confirm the meeting the day before, find out who will be attending, and ask or mention that you will be bringing a note taker with you so that you can fully participate in the meeting. This eliminates any surprises or tensions created when you show up with your own support. Take time in advance to think of questions and collect any documents or information that will help you at the meeting. Also, clarify how your loved one may be involved in the meeting so that you can hear how they will be included in the process.

- **Run An Effective Meeting (See Meeting Checklist and Meeting Log Sample)**

At the beginning of the meeting, ask who will be taking notes and request a copy of the notes. Acknowledge when good things have happened and special efforts have been made. Sit across from the decision makers and keep eye contact and be as clear and concise as possible. If you do not understand something, ask questions. Do not feel pressured to discuss something if you are not prepared. Do not feel that you must make a decision immediately. If you need time to process, request a break. At the end of each meeting, repeat back what you heard and ask if that is correct.

Inclusion Saskatchewan

Our mission is to ensure that people with intellectual disabilities in Saskatchewan are valued, supported and included members of society and have opportunities and choices in all aspects of life. We believe in citizenship. This means that people with disabilities have their rights and freedoms respected and protected. We believe in membership. People with disabilities are a part of every community, and have the same right to access school, work and community as everyone else. We believe that people with disabilities have the right to self-determination. They deserve to play an active role in making decisions that affect their lives. No matter which system you're trying to navigate, Inclusion Saskatchewan can support you on your journey. The work we do for people with intellectual disabilities and their families is based on the principle that any support offered must respect and defend the value, dignity and choices of each person.

Inclusion Saskatchewan's Family Network

Inclusion Saskatchewan facilitates a Family Network consisting of parents and siblings of persons with intellectual disabilities. The network connects parents and siblings through a Facebook group and variety of workshops and retreats held throughout the year. At each workshop, attendees build relationships through fun activities and presentations. If you're looking to connect with other families that are just like yours, our events will offer you the chance to meet others, share knowledge, and share stories in a supporting and understanding environment.

Meeting Checklist

Before the Meeting

- ☐ I know what I am asking for.
- ☐ I have identified the key players that need to be involved.
- ☐ I have a supporter to go with me to the meeting.
- ☐ I have written down my questions or points I wish to discuss.
- ☐ I have prepared any materials that I think are necessary for the meeting.
- ☐ I have a meeting agenda that shows the day, date, time frame, and place of the meeting, who will be in attendance, and any materials needed.

During the Meeting

- ☐ I arrive a few minutes before the meeting time.
- ☐ I record (or have your supporter record): date and place of meeting; who is in attendance; key points of information and decisions made; the date and details of any future meetings.
- ☐ I ask participants to clarify any terms or points I don't understand.

After the Meeting

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

Meeting Log Sample

Date: _____

People Attending (Positions, Contact Info): _____

What Was Discussed: _____

Results Of Discussion: _____

Next Steps (Include Who Is Doing What): _____





Chapter One

Dealing With The Diagnosis

Learning that your child has a disability can cause a variety of emotions. You may fear the unknown as it relates to your child's disability. You may feel powerless because you do not have control over your child being born with a disability. You may also feel scared and doubt your ability to raise a child with a disability. You may feel confused about what is happening and you may not have much information about your child's disability. The initial shock may cause feelings such as disappointment and grief. You may need time to process and come to terms with the unexpected.

What you go through as a family may depend on your individual circumstances, prior knowledge about people with disabilities, and the information and help that you may or may not receive. The adjustment period may take more time for some, but parents usually find that a sense of stability does return to their lives. Over time, families have found the strength within themselves (and with the support of others) to support their family member and manage situations related to their disability.

1.1 Getting The Diagnosis

Doctors or other health professionals may not have a lot of knowledge about your child's disability. In the past, many doctors would minimize the expectations and hopes that parents should have for children with disabilities. Fortunately, this is happening less and less. There are now many doctors and health care professionals who rightfully take a more positive view of people with disabilities. If a health professional tells you not to expect too much from your child, know that these opinions may well be inaccurate or untrue for your child. People with disabilities can and do live enriching lives full of opportunity when they have access to the right supports.

Sometimes, children with disabilities have medical issues that may need to be addressed. For example, young children with Down syndrome may have a heart condition that requires surgery. Make sure you ask questions and request information on any potential medical problems that may arise or may already be occurring.

Tip: If you learn that your child has a disability soon after birth, ask for a private hospital room. This may be a helpful way to give you some privacy to address your feelings and to spend some quiet time with your child or with other loved ones.

1.2 Delayed Diagnosis

Sometimes, finding out that your child has a disability can take time – even months or years. This is particularly true with some types of disabilities such as Autism Spectrum Disorder, certain intellectual disabilities, muscular dystrophy or learning disabilities. Depending on the circumstances, the diagnosis of your child's disability may happen quickly. At other times however, parents may face a longer journey to receive a diagnosis. In these circumstances, parents may encounter medical professionals or others who discount your child's experience. It may take a lot of persistence before you receive an accurate diagnosis for your child. When this happens, people often feel a sense of validation because they finally have answers and can seek out the necessary information, services and supports.



1.3 Dealing With People's Reactions

While some people may react positively when they learn that your child has a disability, others may not know what to say and some may even react with a sense of pity. It is important to keep in mind that other people's reactions often stem from a lack of understanding. Remember that as people with disabilities become more involved in our communities, other people's reactions will become more positive.

1.4 Talking With Your Other Children

Having a child with a disability will affect everyone in the family. This includes other children that you may have. It will be important for you to talk to your other children about their sibling and their disability. For many children, having a sibling with a disability can be a positive experience. It can teach them to accept people for who they are. Children can also learn about family responsibility by helping around the house or by helping their sibling in various ways. Be aware that sometimes other children may react negatively. This may be the case if they feel that their sibling with a disability is receiving all of your energy and attention. You may need to find ways to ensure that your other children are feeling appreciated and loved.





Chapter Two

Programs & Services For Children

To be included and happy, your child needs what every other child needs: acceptance in the group, support, individual attention, and respect for their learning style. Children thrive in environments where they feel accepted for who they are. Just like other kids, children with disabilities do not need labels, separate activities or sympathy. They need to have the same opportunities that other children have to explore, learn and make friends in a safe environment.

2.1 The Early Childhood Intervention Program (ECIP)

The Early Childhood Intervention Program (ECIP) is a program for families with children 6 and under who have a disability or who are at risk of having a developmental delay. ECIP assists families in three key ways: child development, parental support, and community support. ECIP is family-centered, making sure that parents are included in all aspects of their child's program.

Eligibility: Children do not require any diagnosis. Eligibility is determined through a screening process that includes a home visit. If your child is eligible, you will have access to early intervention support with a trained Early Childhood Consultant (ECC) who will help to identify and to implement goals, as well as inform you about other services available for your child. You can obtain program services by direct referral, by contacting the local ECIP office yourself, or through a referral by a doctor, nurse, psychologist, therapist, social worker, or community agency. Since there is often a waitlist, ECIP advises families to connect with them as soon as possible.

- **Child Development Services:** ECIP provides each child a fun, unique program that encourages development and learning. Your family and the ECC assess your child's abilities and determine which skills to work on. Together, you set developmental goals and plan strategies to help your child succeed. There are typically two home-based visits per month in order to work on the identified goals and monitor progress. Between ECIP sessions, parents work with their child on specific tasks.
- **Parental Support Services:** ECIP workers use their experience to work with children with disabilities and enhance the natural skills that each parent has. There are educational and networking opportunities offered through ECIP. As a family-friendly program, ECIP works to adapt to each family's needs, resources, cultural values, schedules and responsibilities. The ECC can also refer you to other services and help to develop a team of service providers to assist in maximizing your child's development. In addition, when your child is going through a transition such as starting in a center-based program, the consultant can help you plan the process and share important information so that the transition goes smoothly.
- **Community Support Services:** ECC's are advocates in the communities they work in, bringing awareness about inclusion and gaps in services for children with disabilities. Many workers have helped to develop better early childhood services, especially in rural areas, by increasing public access to disability-related materials and offering training sessions to early childhood workers.



2.2 KidsFirst

KidsFirst is an early intervention program that is available in targeted communities. This federally funded and provincially run program gives vulnerable families in Saskatchewan the knowledge and tools needed to support the development of their child. While KidsFirst does not specialize in early intervention for children with disabilities, it offers home visits, early-learning opportunities, parenting courses, referrals to various supports in your community, as well as mental health and addiction services. Contact the Ministry of Education Early Years branch to learn more about the program.

Eligibility: You must be pregnant or have a child under 24 months and live off-reserve.

Services:

- Support from a home visitor who assists child development, parenting, and connecting to the community.
- Help to access services such as childcare and parent support groups.
- Early learning opportunities for children.
- Help regarding literacy, nutrition, transportation and specialized counseling services.

2.3 Preschool

Preschool, nursery school and playschool all refer to daytime programs that allow children to learn while they play. Preschool can be a great experience for your child if you prepare yourself and prepare the people who will be working with your child. When you are looking for a preschool, you may want to ask about their experience with children with disabilities. If they have no experience working with a child with an intellectual disability, you can help them understand the benefits of inclusion not only for your child, but also for the other children in the preschool.

If there is any hesitancy from the preschool director, do not be discouraged. They may be concerned that there are not enough staff to support your child's needs. It helps to have funding in place to ensure that your child receives the necessary support. If an assistant is required, you can reach out to your local school division to request funding.

2.4 Daycare

Finding a suitable daycare provider that suits your family's needs and provides the necessary supports for your child can be challenging. It is important to be as proactive as possible; many daycare providers have waitlists so you may want to begin inquiring early. Some parents find a good fit in a private caregiver and do not use a licensed daycare. Other parents have found a licensed daycare that understands inclusion and is willing to accommodate their child.

Choosing The Right Daycare

If you have an ECIP consultant, they will find programs and advise you on which ones might be best for your child. If you do not have an ECIP consultant, asking other parents or early childhood workers will allow you to find the best possible program for your child. The Licensed Child Care program of the Ministry of Education sets minimum standards and provides a yearly list of licensed daycare centres on their website. If you want to ask which daycares

are open to accepting children with disabilities, you can call a local child daycare branch (contact information is at the end of the chapter). They have information about which daycares have spots specifically for children with disabilities.

Child Care Subsidy

Daycare is a huge expense for many families. The Ministry of Social Services offers a Child Care Subsidy through the Child Care Subsidy Office. A Child Care Subsidy is a monthly subsidy that helps Saskatchewan families meet the costs of licensed childcare. Subsidies are provided directly to childcare facilities to reduce the fees charged to eligible parents. Subsidies vary on a sliding scale with income - the lower the income, the higher the subsidy. Childcare subsidies are only available for services provided in childcare facilities licensed by the Early Learning and Childcare Branch of the Ministry of Education. The subsidies are only available if you use licensed childcare 36 hours or more per month for a child who is not in school, or 20 hours or more for a child in grade one or higher.

Eligibility:

- Have lawful custody of a child under the age of 13 years or a child who have a disability under the age of 15. Children with disabilities can be in a licensed daycare and are eligible to receive childcare subsidies until they reach their 15th birthday.
- Use a licensed childcare facility.
- Be residents of Saskatchewan.
- Have a valid reason for care such as employment, education, or special health needs.

Child Care Inclusion Program

If you have found a good daycare, but the daycare feels that they are unable to provide additional supports for your child, you can apply for funding through the Child Care Inclusion Program. An early childhood professional such as an ECIP consultant or a child psychologist can make the referral for the funding. They need to assess your child and determine that there is a need for additional supervision, guidance, or assistance.

Eligibility: The daycare must be licensed and your child must attend at least 20 hours a month.

- **Individual Inclusion Grants:** these assist with the additional cost of supporting a child with diverse needs, to a maximum of \$300 per month.
- **Enhanced Accessibility Grants:** these assist with the additional cost of supporting a child with exceptionally high and diverse needs who requires extensive or one-on-one care beyond that which can be provided through an Individual Inclusion Grant. The level of funding must reflect the actual cost of the additional supports required, to a maximum of \$1,500 per month, as determined by the referring professional, the parents, and the childcare facility. To be eligible, the parent/guardian(s) of the child must be employed or enrolled in a recognized education program.
- **Adapted Equipment Grants:** these assist a childcare facility with the cost of adapted or specialized equipment necessary for the inclusion of a child with diverse needs. The maximum is \$600 per year or, in exceptional circumstances, \$1,200 per year.



- **Training and Resource Grants:** these assist a childcare facility with the cost of training and the resources necessary for the inclusion of a child with diverse needs, as determined by the referring professionals, the parents, and the childcare facility. Maximum is \$100 per year or, for enhanced accessibility, \$200 per year.

Troubleshooting

When a child has complex needs, it can be difficult to find a placement in a regular daycare. Some daycares in Saskatchewan have reserved spaces and specially trained staff who work with children with various disabilities. ECIP consultants generally help parents find daycare placements if they are having trouble, and will often have knowledge about what is available in your area. You can also call a program consultant at the Child Day Care program directly and ask if there are any reserved daycare spaces in your area. Part of their role is to be a resource for parents who are trying to find a placement for their child.

Government of Saskatchewan Child Day Care Regional Offices

Regina	(306) 787-4980	Saskatoon	(306) 933-6071
Moose Jaw	(306) 694-3644	Meadow Lake	(306) 236-7692
Swift Current	(306) 778-8531	North Battleford	(306) 446-7574
Weyburn	(306) 848-2497	Prince Albert	(306) 953-3612
Yorkton	(306) 786-5770	LaRonge	1-800-667-4380

2.5 Pre-Kindergarten Programs

The Ministry of Education funds educational programs for children with disabilities before they enter kindergarten. The educational goals of pre-kindergarten are to foster social, educational and language development through an experiential, child-centered program. Like early intervention, the goal is to focus on all aspects of development and offer the specialized supports that are necessary. There are limited numbers of Early Learning Intensive Support spaces available for children with complex needs. Contact your local school division to find pre-kindergarten programs. If you have an ECIP consultant, they can help your family with the transition into a pre-kindergarten, preschool or kindergarten setting.

2.6 Assessments

Before the school division provides funding, they may request to test your child in order to determine what their needs are. Since this is the first assessment in the school system, it is important that the assessment focus on strengths as well as needs, as it should provide a full and balanced picture of your child. Pre-K documents are now required to be placed in your child's official file, known as a cumulative file, under a Ministry of Education assigned student identification number. This assessment can also be used to determine if your child is eligible for support from Community Living Service Delivery (CLSD). If so, your family can request funding for respite and your child will be eligible for other types of support at age 18. If your child was already assessed, either with a private psychologist/psychiatrist, or at an assessment and service centre, such as the Alvin Buckwold Child Development Program in Saskatoon or the Wascana Rehabilitation Centre in Regina, then this assessment could also be used.





Chapter Three

Inclusive Education

Inclusive education means that all students are welcomed into age-appropriate, regular classes and are supported to learn, contribute and participate in all aspects of school. Inclusive education is very important because it allows all children to be part of their community and develop a sense of belonging. They are able to take part in all activities and build relationships with their peers. Inclusion, not just in the schools but also in life, is incredibly important as it allows for the practice of acceptance of everyone. When inclusive classrooms are filled with diverse learners, children can explore how everyone learns in different ways and find that they have more in common with each other than they realized.

Becoming An Inclusive Education Advocate

Parents have been successful in working with schools to ensure their children have a fully inclusive education. They advocate within the education system for provincial and local policies that respect and promote inclusion. As a parent, you have the right to be included in the decisions that are made about your child's education.

3.1 Inclusive Curriculum

The goals of education should not be different for a child with an intellectual disability. The teaching method or pace may need to change, but the subjects should be the same. For most children, school is a place where they can learn and interact with other children and this should be no different for your child with an intellectual disability.

Tip: Sexuality and sexual development is another area that is essential to the education plan for children with disabilities. The more your child knows about relationships and their sexuality, the more likely they are to make good decisions. A lack of knowledge can leave adults with intellectual disabilities vulnerable to mistreatment and abuse. Knowing that they deserve to be respected in their social and sexual relationships will give them the power of knowledge and self-expression.

3.2 Inclusion And Intervention Plan

Students with disabilities in Saskatchewan are required to have a school-based team develop an annual individual instruction plan -- the schools call this plan an Inclusion and Intervention Plan (IIP). Parents should always be involved in developing the IIP for their child. If you are given an IIP to sign that you have not been involved in developing, you can tell them that you would like to be involved in the process. It is essential that parents be involved in the planning process since the IIP will have great impact on the student's success.

IIP Meetings

Think and talk to your child about what would be helpful for your child before you go into an IIP meeting. The IIP should focus on your child's strengths, goals and inclusion. Everyone there has the same goal: for your child to be successful and happy. The more you collaborate with the professionals at the table, the more beneficial the plan will be. Among other things, the IIP should include a plan for classroom participation and adaptations as well as identify who will carry out the tasks for the plan. Ensure the plan includes progress reports, as this will help you identify if something is not working and if adjustments are necessary. What works best for your child should always be the focus. Inclusion and Intervention Plan Guidelines are available from the Ministry of Education's website.

3.3 Challenging Behaviour

Every behaviour is a form of communication. Unique and/or challenging behaviours are reduced when your child has the opportunity to make choices, make friends, be a leader, be responsible for themselves, be respected, have their feelings respected, and have their frustrations heard.

If a child presents as having behaviours that are challenging to support, it is important to take time to determine what the child is trying to express and to develop a proper support plan. The child may be lonely and want attention from other children. They might be uncomfortable and may need to move around. They might be sad because they were not able to participate in an activity that all the other children were doing or it may not have been modified appropriately. They may not understand the task they were given or they may be bored and are simply tired of doing it. Feelings or events trigger behaviour. The behaviour may be a characteristic of the disability and is, therefore, part of who the child is and how they communicate. If this is the case, the child needs to be accepted as they are and not punished for how they exist in the environments where they are supported. They should feel a sense of contribution and be embraced for the value they add to the culture of their classroom.

Accommodations

If your child has a behaviour that is seen as challenging, work on a plan with the school. Ask if they have been able to identify your child's triggers (what is causing their behavior). Once triggers are identified, accommodations can be made in collaboration with parents such as modifying the environment, better adapting their work or changing the approach when working with the child. It's important to recognize that the child does not need to change but rather, adjustments may need to be made or approaches may need to change in order to meet the child's needs.

3.4 Educational Assistants

Some classrooms may have Educational Assistants (EA's) assigned to them. The teacher and the EA work together to ensure that the needs of the children in the classroom are being met. EA's are not able to educate in the same way as a teacher; however, they are able to provide support, helping children with disabilities to be included in the classroom and make connections with their peers. Often, an EA is assigned to a classroom because there is a pupil with a disability enrolled in the class, but the EA actually supports the entire class and assists as required. EA's also model how to interact with your child and demonstrate inclusion to other children in the classroom.

Tip: The EA's role is to support your child in the classroom but if the EA never leaves your child's side, then it can discourage other students and staff from getting to know them. When the only person that a child spends time with is the EA, the child may have a harder time making friends.

3.5 Addressing Problems

When navigating through the education system, there is a general procedure that must be followed when consulting with education professionals. The type of consultation and communication that occurs is largely dependent on the specific scenario and situation. If the situation or scenario is relatively minor (amounted to a misunderstanding) a simple phone call may be sufficient to resolve the issue. If the situation or scenario is seemingly more intense it might be more appropriate to request a meeting with the education professional.

There is a general order of operations when consulting with various levels of the education system. Typically, if a matter is not resolved at the lower level, consultation with a higher-level education professional may be necessary. The following provides a general guideline of the order in which these professionals should be contacted:

1. Teacher
2. Learning Resource Teacher / Student Support Teacher or other supports in the school
3. Principal of the School
4. The Superintendent for the school division

Tip: If you have done everything you can to work with the people most directly responsible for your child's education, and you still feel that your child's needs are not being met, reach out to Inclusion Saskatchewan for help with developing another strategy.

3.6 The School System

Schools, like any other bureaucracy, have a complicated structure and rules. Each school belongs to a school division and all school divisions receive funding and direction from the Ministry of Education. School divisions are still independent and each division attempts to deliver programs that reflect the needs of the people in its area.

School Boards

Each school division has an elected board of community members that make the decisions. The Board of Education (also known as a school board) makes all of the big financial and policy decisions for the schools in its division. Many board members are not professional educators so it is a good idea to get to know the board members for your school division and share your dreams and concerns with them. You could even become a school board member yourself and have direct influence. The school board's meetings are usually open to the public, unless there is a special issue. You can also receive a copy of the minutes from your school board's meetings. *The Education Act, 1995* section 85 describes the school board's duties as:

- To decide what school any child will attend in the division.
- To provide transportation to students.
- To pay for and provide education for children living in the school division.
- To suspend and expel students.
- To oversee home-schooling.
- To employ all the staff necessary to make sure the programs run smoothly.

Additionally, *The Education Act, 1995* section 103 requires that the school board prepare a manual that describes the program policies, educational goals and proper organization of the school division. Parents can ask to see both the school division's policy manual, and their child's official file (a cumulative file). It is a good idea to become familiar with the school board's policies on students with disabilities, discipline and behaviour management.

3.7 Provincial Education Law & Policies

The law that controls education is *The Education Act, 1995*. The Ministry of Education is the government ministry that develops education policy and guidelines, which are available on the Saskatchewan government website under Education. The Ministry of Education supports the vision of inclusive education in its policies and other documents. There is still work to be done to ensure that this vision is transferred to every school in Saskatchewan, but it is in the process of happening.

The Saskatchewan Human Rights Code

All provincial laws are subject to the provisions of the *Saskatchewan Human Rights Code* which protects your child's right to an education. The Code states that access to a school cannot be restricted on any of the "prohibited grounds" which include, among other things, race, color, religion, and disability. Section 13(2) of the Code says that exceptions are made for specialized schools that enroll only students with a certain gender, belief system, religion, or disability. This allows segregated schools that are only for children with disabilities still to exist. However, according to the Code, a regular school in Saskatchewan is not allowed to refuse a child because they have a disability.

The Education Act, 1995, also allows a school board to remove a child from the classroom if the board feels that the child is not able to learn in a regular classroom setting or is disruptive to other students. Of course, this is a subjective judgment and could be challenged in court with a human rights complaint.

The Education Act and Education Regulations

While *The Education Act, 1995* is the law that defines what school boards can and cannot do, *The Education Regulations, 2019* (the Regulations) is the tool that interprets and more carefully defines what the Act means. We encourage you to look at the Act for yourself. If you do not have experience looking at legislation, it is helpful to begin with the table of contents and look for sections that seem relevant to your situation, and then look through those sections. If you are looking at the legislation online, use the search function to find key words that relate to your questions and interests.

The Right To An Education: Section 142 (1) of *The Education Act, 1995* says that "every person who has attained the age of six years but has not yet attained the age of 22 years has the right: (a) to attend school in the school division where that person or that person's parents or guardians reside; and (b) to receive instruction appropriate to that person's age and level of education achievement."

The Act also notes that this shall be provided at no cost to the student for tuition, transportation, etc. Under the regulations (s. 48(10)) of the Act, a student with a disability can begin school at age three upon the parents request. It is common for students with intellectual disabilities to stay in high school until they turn 22 to access transition planning and job readiness training. It is noteworthy that the right to an education includes the right to attend an education program offered by a board of education in the French language.

Assessment: Either the principal or the parents can request that an evaluation be done to see if a child needs a special program (s.178 (5), *The Education Act, 1995* and s.48 (3) *Regulations*).

Pupils With Intensive needs: The Act refers to students who have an intellectual disability as part of the larger classification of “Pupils with intensive needs” under section 178 (1). This section provides a definition of a “pupil with intensive needs” and talks about assessment and procedures for placement. On the topic of placement, section 178 (9) of the Act states: *“A board of education or the conseil scolaire, as the case may be, shall take steps to reasonably accommodate a pupil with intensive needs in the regular program of instruction.”*

However, section 178 (10) says: *“If, after taking the factors listed in subsection (11) into consideration, a board of education or the conseil scolaire determines that the learning needs of a pupil with intensive needs cannot be reasonably accommodated in the regular program of instruction, the board of education or conseil scolaire shall ensure the provision of educational services by means of a special program to meet the learning needs of the pupil.”*

The factors listed in section 11 are:

- Whether or not the pupil is medically fragile
- Whether or not the pupil poses a risk of harm to himself or herself or to others.
- The educational needs of all pupils.
- Cost of providing special educational services to accommodate the pupil in the regular program of instruction.

Section 10 has the potential to make inclusion difficult if the school does not feel that a child’s needs can be met within the classroom. In these situations, it is important to be clear that you would like to come up with a plan to ensure your child is reintegrated back into the classroom with their peers. These can often be challenging situations to navigate so you can reach out to INSK if you feel you need additional support.

Right of Appeal: Section 178.1 establishes the right of parents or guardians to appeal decisions made by the school board and explains in some detail how this can be done. Parents can ask for a review only about the results of their child’s assessment, about a lack of assessment, or about the services provided to their child as a pupil with intensive needs. Parents must first ask their principal to review the issue. If the issue is not resolved, then parents can request that the board of education review the issue. An impartial person acceptable to both the parents and board of education will review the issue and issue a written report. If there is still disagreement, parents can appeal. Involving a third party like Inclusion Saskatchewan can help here. Your school board’s review policy can provide some direction in this matter, so consult a copy of the local policy.

Other Ministry of Education Publications

The Ministry of Education has created a number of publications that modernize educational practices to focus on the needs of students experiencing disability rather than on their medical diagnoses, and to prioritize inclusive education. These documents, which include resources designed for teachers to help them make adaptations to the learning environment, are available on the Ministry of Education’s website under the heading, “Supporting Students with Additional Needs.” Parents are also encouraged to explore the Supporting All Learners online library of resources for supporting students using a needs-based approach. A link is available from the Ministry of Education’s website page.

3.8 Funding For Children With Disabilities

When a child with an intellectual disability is not included or accommodated in the schools, a common explanation that families hear is that there is a lack of funding. While this may be true in some cases, parents should not feel guilty asking the school to pay for a support that their child needs. School divisions receive funding intended to address the needs of students who require additional supports. It is up to the school board to worry about the funding and it is important that parents continue advocating for their child's needs, even if they are told there is a lack of funding.

A problem that is common to all school divisions is that they do not have access to enough occupational, physical, and speech/language therapists. Once children reach school age, the Health Authority will no longer provide these therapies, so the responsibility lies with the school. Sometimes there are not enough therapists, or sometimes the division feels it will not have the funding for that school year. It is important that parents continue advocating and reminding the Ministry of Education that these resources are important for their children.

3.9 Planning For Graduation And Life After High School

Most people with an intellectual disability can stay in school until they are 22 years old, but we recommend that you connect with resources and start planning for your child's future as early as possible. It is important to connect to services and resources and have a system of support to help create the life beyond high school that fits for your child.

Community Living Service Delivery and Assessments

Community Living Service Delivery (CLSD) is a part of the Ministry of Social Services that helps people with intellectual disabilities and their family to access necessary and person-centred services. Most CLSD services, except respite and case management, cannot be accessed until age 18, but it is important to connect with CLSD as soon as you are able. Getting an assessment done while your child is still school aged will ensure they have access to these essential services over their adult lifetime.

CLSD staff work to ensure that the physical, emotional and social needs of people experiencing intellectual disabilities are met and that they are able to live as independently as possible within their own communities. CLSD does not deliver programs themselves; rather, they fund a system of social, residential, and vocational programs and help individuals find the programs that are the best fit for them. CLSD offers case management, program development, individual support, crisis intervention, assessment of individual and family needs, family support services such as funding for respite, providing information and referrals, and working with service providers to ensure individuals' needs are being met. The CLSD Community Services Workers (CSWs) work with families directly as case managers and program development consultants.

If your child is eligible for support through CLSD, they will be assigned a CSW who can work on a transition plan with you while your child is still in high school. Since it can take time to set up residential support and community inclusion programs, we recommend that parents start these conversations with a CSW when the child is around the age of 15 in order to plan for the future. To qualify for CLSD's services, a person must have a formal psychological assessment completed with results that meet these criteria:

- The person has an intellectual disability, defined as approximately an IQ of 70 or below on standardized measures of intelligence. This upper limit is intended as a guideline; CLSD may support an individual with an IQ of 75 or more, depending on the reliability of the intelligence test used.
- The person has impairments in adaptive behavior, defined as significant limitations in an individual's effectiveness in meeting the standards of maturation, learning, personal independence, or social responsibility that are expected for his or her age level and cultural group.
- The person's disability manifested during the developmental period - between conception and the 18th birthday.
- The person is a resident of Saskatchewan.

It is common that children are not diagnosed formally until they reach school age, as psychologists want to be sure they are diagnosing appropriately. If the school does not suggest having an assessment completed, it is important for parents to know that they can request an assessment be done for their child. According to the Regulations, if parents believe that their child needs accommodations, they can ask the principal for an assessment, and that request should move forward to the director of the board of education and an assessment should be conducted. In the case of a student graduating without an assessment being completed, it can be very difficult to access services. If your child is still in the education system, the school should provide an assessment and should prioritize the student accordingly if they are almost out of school. Schools will shred files after a student has been out of school for 7 years so it is recommended that parents request a copy of this assessment and keep it somewhere safe.

If, for whatever reason, a former assessment can no longer be obtained or if someone never received an assessment in the education system, then CLSD may provide funding for an assessment. This process requires a written application, with documentation to substantiate that no assessment exists and it would be a financial hardship to pay for one. The individual or their circle of support would be responsible for finding a qualified practitioner to complete the assessment. If CLSD will not pay for the assessment, it is possible to apply to the Cognitive Disability Strategy for funding.

Tip: If you encounter difficulty getting an assessment done for your child as a minor or as an adult, contact Inclusion Saskatchewan

Person Centered Planning

Person-centered planning is a creative approach to the transition process. It is based on the principle that the student is central and the most important person in the process so their input is crucial. The focus of a person-centered planning meeting is on the goals, abilities and interests of your child. The process involves your child and those who care about them. The planning team explores your child's experiences, goals, gifts and abilities. Your child's goals and self-determination will determine the approach to planning, rather than being defined by available services and programs. The meeting promotes listening and valuing your child's dreams for their future and results in plans of action that are required to help make those dreams come true. There are a number of person-centered planning processes:



- **McGill Action Planning System (MAPS):** MAPS starts by looking at a person's hopes and dreams. Dreams motivate us and tell others who we are. A MAPS session has a trained facilitator who focuses on the gifts and strengths of your child. The people who are most important to them are invited to participate in the session and make up a circle of support. To ensure that dreams come true, the team makes specific plans and goals.
- **Planning Alternative Tomorrows with Hope (PATH):** Planning Alternative Tomorrows with Hope is similar to MAPS but has some important differences. PATH is a more personal process than MAPS because the person with the disability (often called the pathfinder) will speak for themselves. Your child will invite the people to the meeting and start it off by telling attendees about their dreams. This process can be much more intense and emotional than doing a MAP because it asks the hard questions about how the team will commit to the dream. It must be done in a safe environment, facilitated by individuals who have been trained in it. Assisted by the facilitators, your child will develop a plan that takes them from their dreams to very real actions that they can do to step toward those dreams.
- **Person-Centred Toolkit:** As a result of government and communities working together in Saskatchewan, a Person-Centred Toolkit has been developed to make available a variety of resources to offer choice in the planning process, each of which reflect the principles of the Comprehensive Planning and Support Policy (CPP&SP) — a policy framework that guides the work of service providers across Saskatchewan. You can access the Person-Centred Toolkit at www.personcentredsk.ca
- **Helen Sanderson & Associates:** This is a consulting group based in the United Kingdom but with Canadian associates, offers a variety of person-centred tools and practices available for download at <http://helensandersonassociates.co.uk/ca/>. Associates can also offer training to help organizations and teams achieve better outcomes for people in our communities.

Transition Planning Handbook

This handbook was developed in response to concerns of parents and educators about the lack of options open to young people with intellectual disabilities leaving the educational system. It is a useful guide for students and families as they move through school and into the adult world. Find the handbook on the Inclusion Saskatchewan website at www.inclusionsk.com/resources.



PATRICK

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Chapter Four

Meaningful Employment

When persons with intellectual disabilities are looking for employment, they may need to try different options until they find what best suits them. The challenge may be helping others to see that they need time and the permission to change their mind. Another challenge may be getting the proper supports in place so they can do what they enjoy. In this section, we will look at some of the options and supports available for employment and daily activities.

Today, doors are opening for people with disabilities to receive the necessary support to find meaningful work and activities in their communities. Regardless of the options you and your child are considering, make sure that your child's personality, interests and happiness are front and center. INSK's Employment and Transition Facilitators can answer your questions about meaningful employment in the community.

4.1 High School Work Experience Programs

The lack of paid experience is one of the biggest barriers to employment for people with intellectual disabilities. In order to move into regular employment after high school, it is very important that young adults with disabilities have the opportunity to experience paid employment before they finish school. A great way for young adults to gain paid experience is through school work-experience programs.

Tip: Work with teachers to ensure that the work experience reflects the reality of being in the workforce. Occasionally, young adults are given the least demanding and least relevant jobs. You need to be aware that this could lead to unrealistic perceptions of employment once individuals start working. Also, suggest to the teacher that they ask the employer to view the student as a potential employee. If this request is made, the employer is more likely to challenge and evaluate the student like a real employee. This approach can change everything; it will allow the student will come away from the experience with a clearer idea of what the employer expects and be more prepared to work in the community.

4.2 Job Creation

Job creation means working with an employer to create a new position that makes use of the skills of a person with a disability, while also benefiting the business owner. In most workplaces, these jobs will focus on handling routine and frequently unfinished tasks that are time consuming (e.g. light administrative duties like filing paperwork or office cleaning). The goal is to create a long-term, sustainable job that fits the person and benefits the business.

4.3 Job Coaches

Job coaches provide one-on-one support that helps persons with intellectual disabilities learn the tasks of a job and help foster a supportive and inclusive environment with other employees in the workplace. As the individual becomes more and more comfortable and capable in their workplace, the job coach is slowly phased out. A job coach will help to:

- Identify tasks pertaining to the position.



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- Sort tasks in priority.
- Identify areas for accommodation.
- Orient the individual to the workplace (with the employer if possible) including: the physical layout (bathroom, lunchroom, employer's office, etc.); introduction to co-workers, customers, and employers; review of the safety rules; review of the company rules/consequences.

For more information on job coaching, contact an INSK Employment and Transitions Facilitator.

4.4 Self-Employment

Self-employment can be very successful for people with intellectual disabilities. It allows them to discover the freedom, flexibility and independence that comes from running their own business. You can help your child gain employment and build it around their needs by creating the business yourselves. Doing something they love can be empowering, rather than being placed in a job that does not work for them.

Entrepreneurs with Disabilities Program

The Entrepreneurs with Disabilities Program (EDP) helps people with disabilities start and grow their own businesses. They provide one-to-one business consultation, so if you are planning to start a business or already have one, they will meet with you to discuss your business's needs. They can assist you with creating your business plan and direct you to available resources and business training in your community. They even help you with the process of accessing business loans. There are three offices that you can contact: North Saskatchewan Independent Living Centre (NSILC) in Saskatoon, South Saskatchewan Independent Living Centre (SSILC) in Regina and Community Futures which has 13 branches in rural Saskatchewan areas.





Chapter Five

Supported Housing Options

An important milestone for everyone is becoming an adult and leaving the family home. Planning for a young adult to move out of the home can take some time, as it is important to find a home and supports that are the best fit. Having a good place to call home means having choices and control over the home environment, making sure the home reflects your family member's personality, and ensuring your family member chooses who they live with and who supports them.

When it's time to begin the planning process, the first thing you need to talk about is where they would like to live. Next, discuss what their needs will be. They may need a full-time support worker, or someone to check in on them every so often to assist them with tasks and ensure their needs are being met. Some people with intellectual disabilities have found a roommate who does not have a disability and who can provide support. If your housing option will involve sharing your home with others including support staff or roommates, you should consider compatibility. Even good friends can have disagreements when living together. Listing what is important to you in a roommate or support staff, and discussing your values and preferences with those who might share the home is a good way to start.

Tip: Since moving involves a big change in routine, many people have found that gradual transitions are better, especially if their new living arrangement looks quite a bit different from their living arrangement in the family home.

5.1 CLSD Supported Housing Options

If you are looking for supported housing options, first contact your Community Living Service Delivery (CLSD) Community Service Worker (CSW) to see what is available in the area your young adult wishes to live. CLSD funds agencies to provide housing with supports for people with intellectual disabilities. It is a good idea to tour some agencies to gain an understanding about the type of residential support they can provide. This allows you and your young adult to express your wishes to the CSW who can put forward an application to your desired agency. Since it can take some time for a placement to become available at your desired agency, it is important to begin the process well in advance. Keep in contact with the CSW to ensure they are well aware of you and your young adult's wishes and notify them if any needs have changed. Note that most adults who qualify for CLSD residential supports live in group homes or approved private service homes.

CLSD partnerships with service providers across the province offer an array of housing and day program options:

- **Approved Private Service Homes:** these homes provide a supportive family-living environment in a community setting. Residents have the opportunity to develop social and life skills.
- **Group Homes:** these homes are staffed to provide personal care, supervision, and support for adults. They are located in residential neighbourhoods throughout the province.
- **Group Living Homes:** these are shared homes where individuals are responsible for paying basic shelter costs. CLSD provides funding for support staff as needed.



- **Supported Living Programs:** these programs provide adults living in their own homes with limited support and supervision so they can live as independently as possible.
- **Day Programs:** these programs support people to participate in work and leisure activities and develop life skills. Programs include job training, supported employment opportunities, life skills development, socialization and recreation.

These residential supports are funded by CLSD, but are not operated by CLSD. Autonomous agencies run group homes and supported living homes. In their funding agreements with CLSD, they agree to operate within provincial policies such as the Comprehensive Personal Planning and Support Policy.

5.2 Non-CLSD Supported Housing Options

INSK meets many individuals who do not meet CLSD's mandate to qualify for services and yet, have an intellectual or developmental disability. These individuals may qualify for supports through the Cognitive Disability Strategy (CDS) or other community programming.

Finding A Home

Increasingly, adults with disabilities (and their families) are interested in exploring the possibility of establishing their own homes in the community. This could involve living in their own house, apartment, condominium, town house or "granny suite." This option provides more flexibility and opportunity to design a living arrangement that suits their wishes and needs. In addition, it allows for the possibility of creating a home that provides the kinds of things that we value in a home. The home ownership option will likely require some detailed planning in order to develop the best possible living arrangement. A circle of support (a small group of people who agree to support a person to achieve their goals) can help in many ways. They can help find affordable housing, plan for and arrange the support that will be needed in the home, manage money for housing and support services, and help monitor the living arrangement.

Some families may want to use their own assets to provide a home. This can involve bequeathing the family home to the family member with a disability or using some family assets to purchase or finance a home. A few options to do this include transferring the ownership of a home to a family member with a disability or creating a housing trust. A housing trust provides a legal right for the beneficiary of the trust to occupy the home while leaving the management responsibilities in the hands of trustees.

Finding Funding - Saskatchewan Assured Income For Disability & SK Social Housing Program

Many people with disabilities live on fixed (and often low) incomes and may need assistance with housing costs. Applying for provincial government assistance, such as the Saskatchewan Assured Income for Disability (SAID) Program, is one option. The SK Social Housing Program subsidizes rent according to the degree of financial need for families and seniors with low incomes and people with disabilities. The program sets rent at 30 percent of the household's income. Individuals living in social housing must be able to live independently. This independence may include support from family, the community, or other agencies. Local housing authorities administer the Social Housing Program on behalf of the Saskatchewan Housing Corporation. To apply, complete the Housing Application available on the Government of Saskatchewan website and submit it to your local housing authority.

Planning A Home Checklist

- ☐ We have listed important values for a home – likes and dislikes.
- ☐ We have a timeline in mind for a move to a new home.
- ☐ We have discussed what independent living skills and/or home supports are needed.
- ☐ We have discussed whether independent living or with a roommate is best.
- ☐ We have thought about what accommodations are needed for community living, such as ramps or access to amenities or the bus.
- ☐ We have information about available funding.
- ☐ We have worked out a budget.
- ☐ We have identified a support system: CLSD and/or circle of support.
- ☐ We have explored the housing options that exist in our community.
- ☐ We have applied for available disability supports, like SAID.
- ☐ We have found a roommate(s), or a support worker.
- ☐ We have created roommate agreement between family member and support roommate(s).
- ☐ We have determined if respite is needed.
- ☐ We have arranged for transportation.
- ☐ We are meeting regularly with our support network to monitor the arrangement.





Chapter Six

Financial Assistance

6.1 Tax Credits & Deductions

Much of the financial assistance from the government for people with intellectual disabilities and their families is distributed through the tax system. Depending on your situation, when you file your income tax return, you may be eligible for some tax credits. The credits come in two forms: the most common is the *non-refundable tax credit* that can enable you, in some instances, to reduce the amount of tax you pay to \$0; the other kind is the less common *refundable tax credit*, which can reduce your taxes below \$0 and entitle you to a payment from the government.

Tip: It is possible to transfer unused, non-refundable tax credits from a child or a dependent adult. If you are married or have a common-law partner, typically the person with the lowest income claims these credits first, and the balance is transferred to a spouse on line 326 of your federal tax form.

Disability Tax Credit

The Disability Tax Credit (DTC) is a non-refundable tax credit that was created to reduce the amount of tax paid by adults with disabilities. The DTC is on line 316 of your Schedule 1 tax form. Because it is non-refundable, it does not help the many people who live in poverty and already do not pay taxes. If your child is eligible for this credit but their income is too low to use it, it could be transferred to you as a caregiver on line 318 of the tax form. When you have claimed an amount for a dependent adult or child on lines 305, 307, or 315, then your child can transfer their credit to you.

The DTC is a federal credit, but for those who qualify, Saskatchewan has the same credit available for provincial income tax. It is the same amount and it is on line 5844 of your Saskatchewan T1 general form. It can be transferred from your child to you on line 5848.

Eligibility: The person applying for the DTC qualifies if they have a prolonged “impairment,” meaning that the impairment has lasted, or is expected to last for a continuous period of at least 12 months; and their impairment must be present at least 90% of the time. The person must also must meet one of the following criteria:

- Be blind.
- Be markedly restricted in at least one of the basic activities of daily living.
- Be significantly restricted in two or more basic activities of daily living (can include a vision impairment).
- Need life-sustaining therapy.

“Markedly restricted” means that you cannot do or it takes you a long time to see, walk, speak, perceive, think, remember, hear, eat, dress, eliminate waste (even with therapy, devices, and medication).

A person also qualifies for DTC if they dedicate at least 14 hours a week to “life-sustaining” therapy that is needed to support a vital function. Additional details about the applications and the eligibility criteria for the DTC can be found on the Canada Revenue Agency website.

How to Apply: To determine if a person is eligible for the DTC, you must fill out and submit Form T2201, also called the Disability Tax Credit Certificate. You can find it on the Canada Revenue Agency website. This certificate has very specific, narrow criteria for the definition of a disability. We recommend that you make sure you have a good family doctor who knows your child well and will fill out Form T2201 in your child's best interest. Family members can help doctors with applications by providing detail about the areas in which a person is experiencing significant impairments in the functions of daily living. Be sure to provide the form to the CRA yourself, so that you can review it and make sure that it truly reflects your child's experience of disability. Periodically, you may be asked to reapply for the DTC.

If your child is denied the DTC, you still have options:

- The first option is to reapply. You may get a different CRA adjudicator who will approve the application. In addition, disabilities change with time. If your child has lost certain functions of daily living over time, there may be a stronger case now for the Disability Tax Credit. You can also apply again with a different medical practitioner, who may be better able to supply a complete picture of your child's disability.
- You can call the CRA at 1-800-959-8281 to ask questions or discuss the application that was denied.
- You can request a review of your application by contacting CRA in writing. Your request must include any relevant medical information that you have not already sent, such as new or updated medical reports, or a letter from a medical practitioner who is most familiar with your situation.
- Within 90 days, you can formally object to the decision of the CRA by filing an appeal. Once you file the appeal, the CRA will assign you an appeals officer. (It can take up to nine months for you to receive an officer.) This officer will review your file and make a decision about your case. In these situations, an Inclusion SK consultant can help.

It is a good idea to get the Form T2201 filled out before tax time and send it in. Canada Revenue Agency suggests this as a tax tip in order to get your claim processed faster. The certificate that a doctor or another qualified person fills out is the same form that you need to have filled out in order to receive the Child Disability Benefit or the Disability Supplement. Your local tax office has copies.

Medical Expense Tax Credit

The Medical Expense Tax Credit is a non-refundable tax credit you can claim for medical expenses you paid for on behalf of a child or a relative who is dependent on you for support. You can claim the full amount unless you have already been reimbursed by private insurance. You can calculate the expenses for any 12-month period that ends within that tax year. You must keep your receipts for all medical expenses that you plan to claim under this credit. On line 330 of your federal tax form (line 5868 on your Saskatchewan form), you will enter the total amount that you spent on medical expenses. You then calculate the amount you can claim on line 332 of your federal form by following their calculation formula. A full and detailed list of the medical expenses you are able to claim can be found on the Government of Canada's website.

Canada Caregiver Credit

The Canada Caregiver Credit (CCC) helps caregivers with expenses involved in caring for a family member who has a physical or mental impairment. An individual is considered to be dependent on you for support if they regularly rely on you to provide them with some or all of the necessities of life such as food, shelter and clothing. You can claim the CCC on different lines of your tax return depending for whom you are claiming an amount. The amount you can claim will also depend on your relationship to the person for whom you are claiming the CCC, your circumstances, the person's net income, and whether you claim other credits for that person. CRA may ask for a signed statement from a medical practitioner showing when the impairment began and what the duration of the impairment is expected to be.

Refundable Medical Expense Supplement

The Medical Expense Supplement is a refundable tax credit that is for working people with low incomes and high medical expenses. You can claim all amounts paid, even if they were not paid in Canada. This supplement is only federal, so there is no provincial refund. You can only claim this supplement if you have not claimed the medical expenses anywhere else.

Disability Support Deduction

If your adult child paid for personal care support, they can deduct that amount from their taxes if they hired the support so that they could work or go to school. The person claiming this deduction must fill out the federal Form T929 to figure out the deduction, and then enter that amount on line 215 of their federal tax form.

Canada Child Benefit

The Canada Child Benefit (CCB) is a tax-free monthly payment made to eligible families to help with the cost of raising children under 18 years of age. Benefits are paid over a 12-month period from July of one year until June of the following year. Your benefit payment will be recalculated every July based on information from you and, if applicable, your spouse's, income tax and benefit returns from the previous year. The CRA uses information from your income tax and benefit return to calculate how much your CCB payments will be. To get the CCB, you have to file your return every year, even if you did not have income in the year.

Child Disability Benefit

The Child Disability Benefit is a tax-free monthly payment made to families who care for a child under the age of 18 with a severe and prolonged impairment in physical or mental function. In order to be eligible for the child disability benefit, you must be eligible for the Canada Child Benefit and your child must qualify for the Disability Tax Credit. If you are already receiving the Canada Child Benefit for your child who is eligible for the disability tax credit, you do not need to apply for the Child Disability Benefit, as you will receive it automatically.

Children's Special Allowance

The Children's Special Allowance (CSA) is a tax-free monthly payment for a child who is maintained by a government department and living in a group or foster home. Foster parents can receive this benefit, along with the CCTB cheque. If you are fostering a child with a disability, it is important to know that you are entitled to receive these benefits. Child and Family Services can redirect the Children's Special Allowance cheque to the foster parent with Form RC64, which can be found on the Government of Canada's website.

6.2 Income Support & Financial Programs

Saskatchewan Assured Income for Disability (SAID)

The Saskatchewan Assured Income for Disability is an income support program intended to provide long-term income support to Saskatchewan residents, 18 years of age or older, who:

- Have disabilities that are significant and enduring, irrespective of whether the disabilities are physical, psychiatric, cognitive, or intellectual in nature.
- Have insufficient income from employment or other sources to permit self-sufficiency.
- Are not expected to attain long-term financial self-sufficiency through employment or self-employment given available treatments or supports.

SAID benefits include three main components:

1. **The Living Income:** individuals will receive a fixed amount of monthly income which allows them opportunity to make decisions to have more control over how the person is spending their income.
2. **The Disability Income:** income that is designed to help with costs related to the impact of disability.
3. **The Exceptional Need Income:** income that helps individuals with a number of special circumstances. For example, additional income is available for clothing recommended by a health professional, special food items, food and grooming costs associated with service animals, and homecare.

Individualized Funding for Home Care

The Saskatchewan Health Authority provides individualized funding in cases where people need acute, palliative, and supportive care in order to stay independent at home, based on the assessed need. If you are eligible and choose the individualized funding option, you are responsible for arranging, managing, and accounting for your child's support services. To learn more and to apply, contact the Saskatchewan Health Authority in your community. They will assess your child's level of care and determine eligibility.

Autism Spectrum Disorder Individualized Funding

The Saskatchewan Government has introduced individualized funding for parents of a child diagnosed with Autism Spectrum Disorder (ASD) who is under the age of twelve. Parents can use the funding to pay for services that best suit the needs of the child. This provides parents with the flexibility and freedom to choose from a range of therapeutic interventions and supports that will most benefit their child.

Families will receive their first benefit once their application has been approved and future benefits will be paid to them each year in the month of the original application date, until your child is over the age of twelve. You can find more information about this benefit and the application process on the Government of Saskatchewan's website.

Self-Directed Funding

Self-Directed Funding (SDF) is a funding option where funding is provided directly to adults who have intellectual disabilities. This gives them choice and control over their supports and services so they can live an inclusive life in their community and achieve their own personal goals. In order to be eligible for SDF, the individual must qualify for Community Living Service Delivery (CLSD) support. With SDF, a person-centered plan is developed for the individual, reflecting the individual's needs and goals. If the individual's plan is approved, the funding is given directly to the individual to implement the plan. The individual and their chosen representatives then manage the funding by selecting the supports that best suit their needs. SDF funding can only be used to hire staff that provide residential support and/or community inclusion/day programming.

If you chose a self-directed option, you need to understand that it is a lot of work. You will need to learn about being an employer and administering the funds for the services. Some families choose to take on the responsibility and manage the funds themselves. Other families decide to hire a third party, such as an accountant, to do the administration and provisions of the services.

Process: When a family is interested in SDF, the first step is to get into contact with us at Inclusion Saskatchewan so that we can set up an orientation meeting. If you decide to pursue SDF, one of our Inclusion Consultants will guide you through the application process (note: Inclusion Consultants do not make decisions about whether or not you are approved for funding). Once you have completed your application and submitted it to your CLSD worker, the next step is to wait until CLSD contacts you to say whether you have been prioritized for funding.

Funding: The funding amount is based on CLSD's funding guidelines. You will not receive any more funding than if you were accessing funding through a traditional service, such as a group home or a day program. The amount of funding you could receive is based on assessment scores. One assessment is called the Daily Living Skills Assessment (DSLA), which is for residential, and the other is called Day Program Skills Assessment (DPSA). The more support you need, the more funding you will need.

6.3 Saving For The Future

Registered Disability Savings Plan

A Registered Disability Savings Plan (RDSP) is a savings plan intended to help individuals save for their long-term financial security. You must be eligible for the Disability Tax Credit (DTC) in order to open and benefit from an RDSP. The RDSP is a registered saving plan for people with disabilities where the government can match your dollars, depending on income.

The Holder of the RDSP (the person who manages the plan and makes decisions around investments and payment options) can be the same person who benefits from the RDSP if he or she can enter into contracts. A parent, spouse, common-law partner or other legal representative can also help by becoming the Holder of the RDSP. Anyone can contribute to an RDSP (family members, friends, individuals themselves) up to a maximum of \$200,000 total in a lifetime. For every \$1 put in an RDSP, the federal government could match up to \$3 depending on income. The Holder can invest the money in any way an individual or Holder chooses. Having a RDSP does not impact SAID benefits.



Saskatchewan Pension Plan

The SPP has been designed as a pension plan for individuals who do not have a way of contributing to other pension plans because they are self-employed, unemployed, living on social assistance, etc. Membership in SPP is open to anyone between 18 and 71 years of age. It doesn't matter where you live in Saskatchewan, what your income is, or whether or not you have a job.

Contributing to the plan is on your terms. You can contribute what you want when you want. When you have extra money you can contribute to the SPP or you can contribute a few dollars every month. If an SPP member is receiving social assistance or benefits from the Saskatchewan Assured Income for Disability program, the money in the plan is not considered an asset until they reach 65. According to the Saskatchewan Assistance Plan Policy Manual:

The SPP is not considered a financial resource to clients until age 65. Clients are required to explore other early retirement options (e.g. CPP, early retirement benefits). Adult clients may contribute up to \$50 per month to a maximum of \$600 per year of nonexempt wages or other earned income to the SPP. In two adult families, the maximum contribution is \$100 per month (\$1,200 per year) even if only one adult has earnings. Funds withdrawn from the SPP are exempt as long as they are retained for retirement purposes (e.g. placed in another long-term investment).

For more information about SPP, go to the Saskatchewan Pension Plan website.

6.4 Road Map To The Future

If you are looking for more in depth information on any of the topics in this chapter, please refer to INSK's financial planning guide, *Road Map to the Future*. This guide puts complex situations and terms into easy-to-grasp language, providing background information for those who must plan for individuals with a disability. Now in its second edition, this guide includes what to consider when preparing a will, how to choose executors and trustees, how to make the most of RDSPs and the SAID income program, and information about guardianship and co-decision making. Road Map to the Future is available for download via www.inclusionsk.com/resources.





Chapter Seven

The Medical System

When advocating for your child with a disability in the medical system, the first thing to remember is not to be intimidated by professionals. You know your child better than anyone else. At the same time, doctors are professionals in their fields so collaborating effectively with doctors is the most beneficial way to make sure that your child receives the best care possible. Make sure that all medical professionals provide you with the information you need and the time to ask questions. If you do not feel right about what one doctor has said, seek a second opinion.

Choosing a Good Doctor

The most important thing you can do is to choose a good doctor. If you have a committed doctor who is willing to do the research and make sure that your child receives the best medical treatment, you will feel more at ease with the options and recommendations. Beyond this, you will need a doctor in order to fill out forms for your child, such as for the Disability Tax Credit (note: there may be a fee for this).

Tip: Since children with intellectual disabilities sometimes face complicated medical challenges, it may be helpful to have a pediatrician as your child's regular doctor. You can phone the health region to see if there are local pediatricians accepting patients. Be aware that this can be a difficult process, but keep checking in as patient caseloads can change. A general practitioner can be effective as a pediatrician, however, many GP's do not have the in-depth experience needed to deal with developmental issues.

Keeping a Medical Journal

A journal of every step in your medical journey will help you to keep track of essential information produced out of visits with health professionals. A journal can also help you advocate for your child later down the road and help new doctors understand your perspective of your child's history. The doctor will be able to assess the information and make a more accurate diagnosis. It will also help doctors to understand the struggles you have gone through. Sometimes people with intellectual disabilities have their symptoms minimized or overlooked. A documented history may help your doctor recognize certain symptoms and that your child needs and deserves thorough, respectful medical treatment.

Tip: Do not assume that a doctor or nurse will know how to support or accommodate your child during an examination, especially if it is a first visit. Ask for extra time when you book the appointment. They may have textbook knowledge of your child's disability, but they do not yet know your child. If your child is sensitive to sounds, touch, new people or new environments, let the medical staff know and inquire about accommodations that can be made to ensure your child is as comfortable as possible.

7.1 Alvin Buckwold Child Development Program & Wascana Rehabilitation Centre

If you have a child with an intellectual disability, you will most likely be referred to early intervention services at one of these central rehabilitation centres in the province: The Alvin Buckwold Child Development Program (ABCDP) or The Wascana Rehabilitation Centre (WRC). The Buckwold program is located in Saskatoon and serves the northern half of Saskatchewan whereas the Wascana Centre is in Regina and serves the southern half of Saskatchewan.



Alvin Buckwold Child Development Program

The Buckwold Program offers assessments, diagnoses, consultation, and treatment for children with intellectual disabilities. The staff includes medical specialists, clinical dietitians, nurses, pediatric occupational therapists, pediatric physiotherapists, psychologists, social workers, speech-language pathologists, and therapy attendants. Sometimes, Buckwold staff travel to northern and rural communities, so it is possible that you could be served at home. Contact Buckwold to find out.

Wascana Rehabilitation Centre

The Wascana Centre facilitates diagnoses and offers clinics, consultation, therapy and information. The staff includes medical specialist, clinical dietitians, nurses, pediatric occupational therapists, pediatric physiotherapists, psychologists, social workers, speech-language pathologists, and a music therapist. There are also seating and equipment technicians to fit children with assisted-living devices. For parents of children with disabilities, they offer a family resource centre and parent support services.

Entering this system and receiving a diagnosis for your child can be intimidating and overwhelming so we suggest that you take someone with you. It may take a number of appointments before your child's assessment is complete. Once the assessment is done, you will work with the staff to develop goals and a plan for your child. The staff will also refer you to programs in your area. Before each visit, we recommend you:

- Write down your questions before you go to your child's appointment.
- Always let the staff know what your concerns are.
- If you do not understand the doctor's or therapist's explanation, ask them to explain it again.
- Give the doctor all the information you have. This will help the staff do a proper assessment.
- Fill out all the information on the forms you are given; it makes the process faster.
- Make sure that all information on forms, including addresses and phone numbers are up to date.
- If you are expecting to hear from the center and have not, call and ask what is happening.
- If there has been a miscommunication of any kind, do not hesitate to ask questions.
- If you are travelling for more than 40 km to get to an appointment, ask for a letter from center staff stating your appointment date. This will help you claim your travel expenses under the Medical Expense Tax Credit

7.2 Therapeutic Integrated Pediatric Services

For those living in the northwest region, the Saskatchewan Health Authority provides a coordinated team approach for identifying developmental concerns in children from birth until they go to school. A Therapeutic Integrated Pediatric Services (TIPS) team may be composed of physiotherapists, occupational therapists, speech language pathologists, early childhood psychologists, KidsFirst, early childhood services, the school division, and public health nurses. First Nation Services provides TIPS services in Meadow Lake, Lloydminster, and North Battleford. More information about TIPS can be found on the Saskatchewan Health Authority's website.

7.3 Telehealth

Telehealth is a tool provided by the Saskatchewan Health Authority to improve access to health services. Parents can talk with their child's specialists using video conferencing links instead of traveling back for extra meetings. Doctors can use Telehealth for appointments, consultations, follow-ups, meetings, and educational sessions. If it will make your life easier to not have to travel, ask your doctor about Telehealth.

7.4 Employment Insurance Compassionate Care Benefits

One of the most difficult times for anyone is when a loved one is dying or at risk of death. By applying for Employment Insurance (EI), you can take up to a six-week leave of absence from work, to take care of a loved one that is ill. The EI benefit is called Compassionate Care Benefits. You are eligible if your relative is gravely ill and at risk of dying in the next six months and you have not claimed EI in the last year. A family member can share the leave of absence with you. This means that your mother, husband, wife, etcetera could each take off two weeks and you could take off two weeks to care for your child, but the total must be no more than six weeks. You can spread the six-week leave of absence over six months.

When you apply, you will need a medical certificate signed by a doctor as proof that your family member is gravely ill and needs your care and support (a nurse can sign the form if you are in a northern community where a doctor is not available). Then you must submit the form and proof of recent or current employment (pay stubs, or a record of employment) to your local EI office. You will also need your social insurance number, personal identification, and information about your family member and an explanation of the situation if you were laid off.

7.5 Jordan's Principle

Jordan's Principle is intended to prevent First Nations children from being denied essential services or experiencing delays in receiving them. Jordan's Principle applies to all First Nations children, status or non-status; involves all jurisdictional disputes, between federal departments or between federal and provincial governments; and provides payment for necessary services by the government or department that first receives the request. A parent or guardian of a First Nations child can make a request for services by contacting the Jordan's Principle toll free 24 hour line at 1-855-572-4453 to get more information and an application form.

7.6 Prescription Drugs

It can be a difficult decision to explore using drug therapy for your child. Prescription drugs can balance a person's system or ease some of the physical discomfort that comes along with certain disabilities. Drug therapy can sometimes be non-health related and end up as a way of helping to manage a child who has challenging behaviours. Using drug therapy to help manage behaviour is not necessarily wrong, but parents need to be cautious with any drug. It is important to ask questions about why the particular drug is being prescribed, and the side effects.

Ask Questions

Always ask questions about any newly prescribed medication. Consider asking the following:



- **Why do you want to give my child this particular drug?** Ask the doctor if they have prescribed this drug to other patients and how it worked.
- **What are the benefits of the drug?** Ask the doctor about this drug's effectiveness and why it will benefit your child.
- **Could this drug interact badly with other medications or therapies my child takes?** Giving full disclosure about any medications, herbal remedies and therapies your child receives will help the doctor to assess any potential interactions. You can also double check drug interactions with a pharmacist. Pharmacists know the details about drugs that are on the market.
- **What are the possible side effects that my child could have while taking this drug?** Ask about short term and long term effects. You can also ask if a drug affects behavior, eating habits, sleep patterns, weight gain or thought processing.
- **Does this prescription's dosage match my child's weight?** Sometimes children with disabilities weigh less than other children the same age do, and they may be prescribed too high a dosage.
- **How much does the drug cost?** Under the Saskatchewan Children's Drug Plan, families pay a maximum of \$25 for prescription drugs if their children are 14 and under. But for older children and adults, not all costs are covered by the Saskatchewan Drug Plan. Sometimes there is a generic equivalent drug, at a much lower cost.

7.7 Prescription Drug Plans

The Saskatchewan Drug Plan

Saskatchewan residents with valid Saskatchewan health coverage may be eligible for drug plan benefits. Costs of prescriptions vary depending on the type of benefits individuals receive. The pharmacist will submit prescription drug claim information to the Drug Plan claims system online at point of purchase to determine eligibility and whether or not it can be approved for payment or partial payment.

Children's Drug Plan

The program allows families with children 14 years and under to pay \$25 per prescription for drugs listed on the Saskatchewan Formulary and those approved under Exception Drug Status. Ask your physician or pharmacist if any of your child's medications qualify for Exception Drug Status. If you already pay less than \$25 per prescription for your child, you will continue to do so.

7.8 Additional Programs to Assist with Coverage

Supplementary Health Benefits

If people with intellectual disabilities qualify for Income Assistance or SAID benefits (they can apply when they turn 18), the Income Assistance Worker or Assured Income Specialist will nominate them for Supplementary Health Coverage and the Ministry of Health will send a letter once they have been approved. Once approved, their Health

Card will identify that they have Supplementary Benefits when they access health related services such as the pharmacy, doctor, dentist, eye doctor, etc. If there are any questions about benefits, call the Supplementary Health Program directly at 1-800-266-0695.

Tip: If a person is a member of a First Nations and holds a Treaty Card, all of their health needs will be covered by their band/reserve, and they will not receive Supplementary Health Coverage.

Family Health Benefits

These benefits are for low-income working families who meet an income test

Palliative Care Drug Coverage

This program helps cover the costs of prescription drugs for palliative care patients.

Special Support Program

This is an income tested program helping low-income people with the high cost of drugs.

7.9 Medical Decision-Making For Self-Advocates

Inclusion Saskatchewan has created a series of plain language guides to help adults with disabilities with medical decision-making in clinical settings. One example is the Health Passport in which the essentials about an individual's medical background, care preferences, and ability to consent to health care treatment can be recorded ahead of time and provided to health care professionals when needed. These documents are available on the Inclusion Saskatchewan website at: www.inclusionsk.com/resources

7.10 Assisted Living Devices

In order to participate in daily activities, some people with disabilities use assisted living devices and aids. These devices help with communication, mobility and agility, hearing, seeing, eating, breathing, accessing buildings, and personal care. Many assisted living devices and aids are available and paid for through the Ministry of Health.

Saskatchewan Aids to Independent Living

The Saskatchewan Aids to Independent Living (SAIL) program provides medical equipment, supplies and services that help people with long-term disabilities be more independent and active. SAIL covers a wide variety of assistive devices such as wheelchairs, walkers, specialized crutches, toileting equipment, transfer tub seats, commodes, bathtub lifts, hydraulic lifts and swings, orthopedic equipment, respiratory equipment, and feeding pumps. Eligibility is based on assessed long-term need. Most items are loaned, not sold, and must be returned to an authorized service provider for maintenance or when no longer needed. For more information, call toll free at 1-888-787-8996.

SAIL also provides special benefits for people with certain disabilities. The Paraplegia program covers additional drugs, incontinence supplies and specialized equipment for people with cerebral palsy, muscular dystrophy or spinal cord injury or disease. These patients are also eligible for home access and vehicle modification grants to facilitate community living. The Ostomy program covers ostomy supplies for those who have a urinary or bowel appliance and who have been referred by an enterostomal therapist. The Aids to the Blind program loans equip-



ment for people who are legally blind, such as magnification aids, low-vision glasses, brailers, and white canes. The program also provides some assistance with the purchase of talking or braille watches, talking scales, large button or talking phones, talking labelers, digital playback units and multifunctional electronic devices. The Canadian National Institute for the Blind (CNIB) registers clients who are eligible for the Aids to the Blind Program.

SaskAbilities & The Wascana Rehabilitation Centre

If a doctor prescribes a certain type of device for your child, take the requisition to an authorized service provider to get the item. The two most common providers are SaskAbilities and the Wascana Rehabilitation Centre (WRC). Both SaskAbilities and WRC also provide orthopaedic services, including specialized seating for wheelchairs, custom-built footwear, splints and artificial limbs.

Respiratory Equipment

Respiratory equipment is centralized at the Respiratory Benefits Depot at the Saskatoon City Hospital. You can order the equipment at the hospital or by mail to the Respiratory Benefits Depot with approval from the prescribing physician. Most items that are issued by the Depot will be maintained, repaired and replaced by them; this is all covered under the SAIL program. If your child needs a respiratory aid, you should expect help from your doctor and respiratory specialist in the hospital to find community resources in your area and to teach you how to use the equipment properly. BREATHE, the Lung Association, also has qualified personnel to answer questions you may have about respiratory issues.

Feeding Pumps

Under the Children's Enteral Feeding Pump Program, SAIL also pays for feeding pumps and associated supplies for children under age 18; however, nutritional products, nasogastric tubes and gravity feeding bags are not covered. The Therapeutic Nutritional Products Program provides assistance towards the cost of specialized nutritional products for people with complex medical conditions, on a sliding scale based on a number of factors including family income. A physician can order the equipment and forward the request to SaskAbilities (Saskatoon Special Needs Equipment Depot). The feeding pump, feeding bags and an information sheet are sent to you. You can expect that a hospital employee will help you to learn how to use the equipment before you go home with your child. Because the patient is registered on the SAIL Supply System, this allows medical suppliers to invoice SAIL directly for feeding tubes, adapter/extension sets and syringes. If child ages out of the program but still needs a feeding pump, either the Paraplegia program or the Supplementary Health Program may pick up coverage, but coverage will not cease.

Adaptive Technology

Adaptive technology from voice-activated software to eye gaze controlled technology provides a level of autonomy and self-reliance that has a life-changing effect on the lives of people with disabilities. If your child is non-verbal or has other communication issues, your child's education may be enhanced by this technology, and the school may suggest an assessment for adaptive technology. The Ministry of Education may provide a grant for these aids to the school division if they assess the need for this technology for your student. Assessments can be done at SaskAbilities. To apply for coverage for the cost of the device, the school division must demonstrate that the aid must help your child learn in a way that is not possible without the aid. This equipment is on loan for your student, and not owned by the child. SaskAbilities also works on behalf of individuals of all ages to find the adaptive technology that works for them. Saskatchewan residents can access their Adaptive Technology Services on a fee-for-service basis.

7.11 INSK Health Passport

The Inclusion Saskatchewan Health Passport is a plain language health care tool for use within Saskatchewan. Developed with the assistance of Inclusion Saskatchewan's ICAN Self-Advocates, the passport is a 4-page fillable form (with accompanying guide) that outlines the essentials about an individual's medical background, care preferences, and ability to consent to health care treatment. The passport can be given to health professionals in both emergency and non-emergency situations. The Health Passport is available via www.inclusionsk.com/resources.

Medical Journal Sample

Date:	Doctor/Specialty:
Office Phone:	Clinic Phone:
Email:	Contact Person:

Reason For Visit: _____

Symptoms: _____

Advice Given: _____

Tests/Medications Prescribed: _____





Chapter Eight

Inclusive Recreation

Recreation is an important piece of living a full life for anyone of any age. Ensuring that your family member takes part in inclusive recreation is key to their quality of life, self-esteem, and self-confidence. By participating in recreation activities, your family member will also naturally build friendships and develop their co-operation, communication, and social skills.

Fostering Independence

You may feel the need to protect your child from all the risks in everyday life. The tendency to overprotect will be strong, however, there is much value in allowing your family member the opportunity for involvement in the community and for developing other relationships. We advise that you be aware and realistic about the safety of recreational activities, but make an effort to take part in recreation wherever possible.

Making Recreation Inclusive

People who coordinate recreational activities may not know how to adapt activities for persons with intellectual or other disabilities. The first thing to remember is, adapt only when necessary. There are many great books and websites on adapting equipment and activities for people with disabilities. Here are a few general tips that could help your child's coaches to make recreation inclusive:

- Ask the person what they need in order to participate.
- Use plain language.
- Use verbal prompts, pictures, videos, visual aids, or demonstrations.
- Teach only one skill at a time.
- Use physical guidance.
- Use positive reinforcement and feedback often.
- Encourage teamwork.
- Build in routines and repetition (but make sure that it is not boring).
- If a participant communicates differently, help the others understand how to communicate with them.

8.1 Special Olympics

Special Olympics (SO) is the world's largest sports organization for people of all ages with intellectual disabilities. It provides people with access to a variety of different individual and team sports. Each community program is run by volunteer coaches, who organize and run their team's practices and are overseen by SO Saskatchewan. The programs can range from competitive teams to play-based programs and typically practice more than once a week and travel to other communities to engage in competitions.

SO also has an inclusive program called Special Olympics Unified Sport, where athletes with and without disabilities compete on the same teams. This program allows athletes from different backgrounds to compete together, gain valuable competition experience and make new friends. If you are looking for a list of all current SO sports offered in the province, head to SO Saskatchewan's website at: www.specialolympics.ca/saskatchewan.

8.2 Summer Camps

Attending camp allows children a chance to get away from their routine for a week, meet new friends and spend time outdoors. Each summer, many children with intellectual disabilities attend regular summer camps. Most camps are happy to include all children and some parents have found that their child does not need extra support beyond what the camp offers. To find a good summer camp in your area, start with the Saskatchewan Camps Association website at www.saskcamps.ca. Most camps have said they would include a child with an intellectual disability, although some may require additional supports to be in place. If your child needs additional support, a camp companion or support worker could be the solution. Some parents have used CLSD respite dollars towards a camp companion. Some INSK branches and other disability groups offer inclusive summer programs.

Camp Easter Seal is a barrier-free camp at Manitou Beach. This camp is only for children and adults experiencing complex physical and intellectual disabilities. Space is extremely limited. Some campers like to mix it up and try both Camp Easter Seal and a regular camp.

8.3 Summer Day Programs

If your child is not ready for a week away from home at camp, there are summer day programs. SaskAbilities offers a Summer Fun Program in four major Saskatchewan centres all summer long. Participants meet for a minimum of two activities per week for each camper. Other similar day programs are offered by some of the INSK branches as well.

8.4 Volunteer Opportunities

There are lots of places where young adults can volunteer, such as at the animal shelter, a retirement home, winter games, summer festivals, a church, or a non-profit organization. This will give your child an opportunity to be involved in the community, gain work experience, or just have fun meeting new people and making a difference. Volunteering is even something you can do as a family. One family of a child with an intellectual disability volunteered together at the SPCA, helping take care of the animals. Becoming a volunteer will create new friends and new experiences, as well as help the community at the same time.

8.5 Access 2 Pass

Access 2 is a program created by Easter Seals Canada to alleviate some of the financial burden that some people with intellectual disabilities face. When someone with a disability requires a support person to accompany them in the community, they are still required to pay admission fees for that support. However, with the creation of Access 2, individuals can bring a support at no extra cost. The Access 2 Pass encourages everyone to live a healthy and active lifestyle, while also taking part in multi-cultural experiences.

The Access 2 Pass is for people of all ages and types of disabilities who require support and assistance. There are hundreds of participating entertainment, cultural, and recreational venues across Canada. Once the Pass is obtained, you can take it to partnered venues with the Access 2 program, and with the price of one general admission, you will receive a second admission pass for your support aide at no extra cost. More information along with application forms is available online on Access 2's website.

8.6 Leisure Access Programs

Many cities have community leisure facilities and programs that run throughout the year. There can be drop-in programs at leisure centres along with different activities offered depending on which city you live in and what they offer. For example; public skating, workout facilities, drop-in classes, and access to swimming pools. Sometimes the fees for these passes can be a little costly; however, some cities offer programs where eligible low-income residents are able to participate in the leisure facilities and programs at a discounted rate. Check with your city to see if they offer discounted passes and if you qualify.

8.7 Discounted Bus Pass Program

The Discounted Bus Pass Program allows people with lower incomes to access public transportation. Discounted bus passes are available to people who are currently receiving benefits from at least one of the following programs:

- Saskatchewan Employment Supplement (SES).
- Saskatchewan Income Support (SIS).
- Saskatchewan Assured Income for Disability Program (SAID)

8.8 Driving Assessment

Some individuals with intellectual disabilities have received their license and have their own vehicles. If this is one of your child's goals, there is support available. The Driver Evaluation Program offered by Kinetik, a SK Health Region program at the Saskatoon City Hospital, provides a standardized objective assessment to determine a person's ability to operate a motor vehicle safely. A driver evaluation may benefit any person with cognitive, perceptual, physical, or medical limitations that may impact their functional ability to drive. It may also be useful for individuals who have never driven before and have significant disabilities that may require special adaptations to the vehicle.

8.9 Community Inclusion Programs

As your child grows into adulthood, community inclusion programs (also known as day programs) may be a fit for your child depending on their wishes and goals. Most community inclusion programs are available through Community Living Service Delivery (CLSD) so if this is something your family member is interested in, connect with your child's Community Support Worker (CSW) and ask about the options. The CSW can provide ideas and set up tours to find a community inclusion program that is the best fit for your child. For example, some community inclusion programs take place in the community, some at an agency, and some have a combination of both. This process can take some time so if this is something your child may be interested in, tell the CSW well in advance.





Chapter Nine

Complex Situations

When you have a child with a disability, complex situations may arise. It is helpful to be proactive by surrounding yourself with a support network and finding out what supports exist before a crisis happens. Parents and advocates have suggested the following resources that may help you plan for a crisis.

9.1 Support Networks

Building a support network for yourself and your family is the best way that you can prepare for a crisis. Parents who have gone through a crisis often say they would not have made it without their friends and family. Your network does not need to be large - even three or four supportive people can make a big difference when challenges arise. A network can begin with your immediate family and include friends and neighbors you trust and who understand your family. Let people know that you see them as part of your network and that you are grateful for their support. Keep them up to date on what is happening with your family.

Find Other Parents Of Children With Disabilities

It is helpful to include other parents who have a child with a disability in your support network. Other parents often have experience, knowledge, and information that you may find helpful. The Family Network at Inclusion Saskatchewan can connect you with other families in your area who can offer support and share information. The members depend on each other for friendship and support when they are experiencing a challenging situation but also with the regular challenges that parents experience in everyday life.

Consider Bringing Someone That Supports You To Your Meetings

When attending meetings with professionals about your child, consider taking someone from your network or a person you trust with you. This means that if two parents are at the meeting, you may wish to take a third person who is not directly involved. This is especially true during a crisis. An extra person who supports you, who is not as emotionally involved, can listen, take notes, ask questions, and confirm or clarify what is said.

9.2 Cognitive Disability Strategy

The Cognitive Disability Strategy (CDS) is a program where ministries and service providers work together to support people with cognitive disabilities who have a need that is not being met. CDS provides services, supports and funding. It is important to ensure that the person with the cognitive disability is at the center of all planning so the impact of disability and the unmet need is addressed. Benefits of CDS include having access to Cognitive Disability Consultants and flexible funding. Consultants are available to support individuals and families with service coordination and development of behavioral support plans. Funding may be used to address unmet needs that cannot be met through existing services or programs. CDS flexible funding limits are based on assessed need and income.

Eligibility:

- You have a cognitive disability with limitations and impairments that are present from an early age, except in the case of an Acquired Brain Injury.



- You have an unmet need related to your cognitive disability that cannot be met by another service.
- You are a Canadian citizen or a permanent resident of Canada.
- You are not a resident on a reserve as defined in the Indian Act (Canada). If you ordinarily reside on a reserve as defined in the Indian Act (Canada), you may be eligible to access similar benefits provided by the federal government. If you are eligible to receive benefits provided by the federal government, then you are not eligible for CDS.

To apply for CDS, be prepared to provide your child's Daily Living Support Assessment (DLSA) score. There are three ways to apply:

- An individual or family member can fill out the application form (available online).
- An individual or family member can ask someone they are currently working with, such as a caseworker or social worker, to help them complete the application form.
- If individuals or family members cannot complete the application forms themselves, and they do not have a caseworker, the Cognitive Disability Consultant can provide assistance.

9.3 Comprehensive Behaviour Support Plans

Challenging behaviours need to be taken seriously, but people should look beyond the behaviour to the bigger picture. The goal of a Comprehensive Behaviour Support Plan (CBSP) is to be proactive and create a safe environment where the individual feels safe and accepted. Building a meaningful life and reducing stress, fear, and loneliness will affect the person's behaviour and allow them to express themselves in ways that are more positive.

Often psychologists, behaviour consultants, and psychiatrists will be involved when a support plan is being developed (note: schools have professionals available to develop support plans for students). Your ECIP worker can access a behaviour consultant for your child up until the age of six, or within the school system. The consultant will meet with parents and ask you questions. Sometimes they may observe your child or ask you to keep a record for a short period. The consultant will look at events that occurred before the behaviour, the resulting behaviour, and the outcomes. Understanding the environment helps them to develop a suitable behaviour support plan. Consultants may use assessment tools, such as developmental assessments, depending on the child. They will help you understand, implement, and evaluate the strategies in the support plan. The consultants can also set up structured learning programs and do assessments, program consultations, and evaluations.

There are four parts in the CBSP that make up a support plan: ecological changes, positive programming, focused support, and responsive strategies. These areas can help you think about the kind of support that would have the most positive impact on your child.

Ecological Changes: this part is a shift in a person's environment, an event leading up to or a trigger for behavior. Listening to a person and finding the trigger enables you to adapt the environment to make a better fit. Changing

the activities, the setting, the quality of interactions, or the support methods, or limiting noise or crowding are effective strategies to adapt a person's environment.

Positive Programming: Learning to substitute a challenging behaviour for a more positive one can help an individual socially. Understanding the meaning of the behaviour will help people respond to the person's needs.

Focused Support: this part involves a careful assessment of everything that affects the person. With a deep understanding of the individual, modeling and reinforcing good behaviour can be respectful. It is important to watch for any stimulants or situations that may trigger the person and attempt to change the situation before the behaviour occurs. Removing objects, people, demands, and requests are immediate responses. Responding in a new way to the person's actions may also help. The activity, environment, or events can be changed to support the person. An individual can learn to help manage their own behaviour and work out new solutions.

Responsive Strategy: A strategy keeps people safe when behaviours do occur. An intervention should never be more restrictive or intrusive than necessary. Respect for the person and their dignity is always critical. To keep the behaviour from intensifying, it may be helpful to ask what's wrong, get closer to the person, use humour, ask them to stop, help them relax, or change the focus. If the behaviour is already intense, they might need space. They must never be punished, made to feel embarrassed, or feel pain of any kind as a response.

9.4 Inclusion Consultants

If your family is in crisis, or just needs advice, Inclusion Saskatchewan employs experienced advocates called Inclusion Consultants, to support individuals and their families. Inclusion Consultants focus on a person-centred approach and work to uphold the rights of all people with an intellectual disability in Saskatchewan. They work to ensure that people with intellectual disabilities have their rights to citizenship, membership, and self-determination respected. Inclusion Consultants can help your family member with a disability to navigate these areas:

- Financial Issues, SAID, Self-Directed Funding
- Respite
- Education
- Human Rights
- Abuse
- Physical and Mental health
- Technical Aids and Supports
- Human Rights
- Residential Options
- Transition Planning
- Recreational and Leisure Activities
- Life Skills
- Supported Decision Making
- Legal Issues including Guardianships, Trusts, and Wills
- Self-Advocacy

9.5 Emergency Intervention through CLSD

If your family is in crisis and your child has a CSW through CLSD, the CSW can set up an emergency contract that will allow them to put the necessary services in place. Funding is available for emergencies, or when a family is in

crisis and needs extended respite, a day program, or a residential placement for their child. CLSD prefers that families plan ahead with their CSW however, some situations cannot be foreseen and the CSW can make the necessary requests for support in these situations. Give the CSW as much information about the situation as you can, such as what has been tried and what did and did not work. You may be asked to sign an agreement to open a file with Child and Family Services. This is only because the legislation that allows CLSD to give you extra support requires a file to be opened.

9.6 Dual Diagnosis

Dual diagnosis is not a medical term. It is a term that refers to individuals who have an intellectual disability as well as a mental illness. Autism Spectrum Disorder is also a common developmental disability among people with a dual diagnosis. Most professionals estimate that the prevalence of mental illness for people living with an intellectual disability is twice as high as in the general population. Yet serious mental health concerns are overlooked and under diagnosed among this population.

There are several reasons for this gap in support. First, it is not always easy to recognize when the distress experienced by a person with an intellectual disability is actually a symptom of mental illness. Additionally, there is still a stigma associated with mental illness, which makes many people reluctant to talk about their experiences.

Second, there are jurisdictional hurdles. Responsibility to meet the needs of people living with an intellectual disability typically exists between two service jurisdictions within Saskatchewan: Community Living Service Delivery and the Saskatchewan Health Authority. Generic mental health care services do not always have the appropriate structures in place to serve this population. They may deny service, claiming that the issue is related to the individual's intellectual disability and believe that CLSD should be the provider of service.

The situation is improving slightly, in that the problem is being recognized and discussed. The Health Authority recognizes that more training and resources are needed, since there are not enough psychiatrists who also have training in working with people who have intellectual disabilities. The most difficult situations are for people who have not had a formal assessment for intellectual disability; these are often the individuals who we describe as falling through the gaps in the system. It is important to advocate for your child to receive mental health support if they need it, as methods can be adapted to support people with intellectual disabilities. Positive Interactive-Behavioral Therapy, which relies on drama to aid in communication, is one positive therapeutic method that has shown promise.

9.7 Sexuality

Tell It Like It Is

Self-Advocates, adults with intellectual disabilities who advocate for themselves, have asked for better information about sex to support their own decision-making. Inclusion Saskatchewan has collaborated with Creative Options Regina and Saskatoon Sexual Health to create Tell It Like It Is, an adult sexual educational program that respects the self-determination of individuals with intellectual disabilities. Each 10 week program provides accurate plain language information to facilitate healthy choices, combat the effects of exclusion, and reduce the risk of coercion and abuse. Tell It Like It Is participants explore sexual wellness topics such as physiology, desire, personal hygiene,

safe internet navigation, boundaries, consent, how to cope with rejection, and how to create meaningful friendships. The program also provides participants' parents with their own guidebook, to support the students as they learn about their sexuality.

Abuse or Assault

For people with intellectual disabilities, the risk of abuse is far higher than the general population. If your loved one has been abused, here are steps you can take to get help and promote healing:

- Offer emotional support, without any judgment.
- Support the person to describe clearly what has occurred. Be mindful to not ask leading questions and allow them to go at their own pace. Document information received.
- Call 211 to find the nearest sexual assault, suicide prevention, or child abuse prevention support services in Saskatchewan, for specialized support.
- Discuss the options of reporting or not reporting the incident to the police, and the likely course of events associated with each option, such as testifying in court. Adult survivors get to decide whether they want to report a sexual assault to the police, but we all have a duty to report sexual assault against minors to the police.

Remain supportive and caring, and realize that it is normal for people to take time before they reach out for support and counselling. Counselling assures victims of crime that they are not to blame, and they are not alone. For more information regarding how to navigate the justice system, see section 11.5.

9.8 Last Resorts

Some parents of children with disabilities have found themselves without options. Services are inadequate and there may be times that you think you cannot get through another day. If you find yourself in that place, there are some "last resorts." These options are not family-friendly or ideal and can involve your child being placed outside your home. Talk to your CLSD worker about all the options for your family.

Child and Family Services

If you are feeling like you can no longer safely look after your child, you can call Child and Family Services at the Ministry of Social Services and they will take your child into care. Section 9 of the Child and Family Services Act allows Social Services to place the child temporarily in care. If the child is placed in foster care, the parent(s) remain the child's guardian unless there are unusual circumstances. However, you need to be aware that if your child has been taken into care, the social worker does have the authority to keep them in care. If you do need to have your child taken into care, there are special foster homes that care for children with disabilities. Some parents have gone this route when they were not able to find support for their child elsewhere. If the child is 12 or older, the social worker may ask the child's opinion. It is suggested that parents seek third-party advice if they are considering placing their child in care. Inclusion Consultants may have some alternative ideas to help you keep your child at home.



Families Experiencing Exceptional Loss

While medical advancements have meant that children with intellectual disabilities can live for a long time, the reality remains that some parents of a child with an intellectual disability outlive their child. Families Experiencing Exceptional Loss (FEEL) is an Inclusion Saskatchewan program for families who experience the death of a family member with a disability. Through FEEL, families gather to share their sorrow, remembrances and love for their family member with a disability who has died. By sharing their common experiences around the death of their loved one, they develop friendships and form a community of mutual support.

FEEL also hosts an annual workshop where families can get together and interact with different supports such as grief counsellors and various professionals. The weekend away provides the families with the opportunity to bond with other people who truly understand what they are going through in their grief. You can reach out to the FEEL coordinator at FEEL@inclusionsk.com.





Chapter Ten

Respite

Respite supports families by providing temporary care for a loved one who needs individualized care and assistance. Respite relieves the caregiver of their duties for a period of time, so that they can take a well-deserved break and time for themselves. Respite can last anywhere from an hour to a couple weeks and allows the caregiver to refresh and restore their energy. Not only is it beneficial for a caregiver, there are benefits for your child as well. It allows your child the opportunity to form new relationships with people outside of their everyday routines. It allows them to grow and develop in many ways.

10.1 Respite Funding

Community Living Service Delivery (CLSD) provides respite funding to families who are eligible through the Family Respite Benefit -- an income-tested, monthly financial benefit for parents or guardians of a child with an intellectual disability. In order to access this benefit, you will need to speak with a Community Services Worker (CSW) through CLSD about the needs of your child and family.

If a Daily Living Support Assessment (DLSA) has not yet been completed, the CSW will need to complete one for your child in order to determine what level of support they need. The CSW will also have to complete a Family Impact of Disability Assessment (FIDA) for your family. The amount of funding a family receives will depend on their financial need and the assessed level of disability impact, meaning that funding depends on how much support your child will need from a caregiver. The funding that families receive is a subsidy, so although the program is very helpful, it may not cover the full cost of the respite you are seeking.

Tip: If you are not able to get the support your family needs through the respite program or your child does not meet the Community Living Service Delivery mandate, you may want to consider making a request through the Cognitive Disability Strategy (CDS).

10.2 Finding A Respite Provider

If you have funding from CLSD, but no respite worker, start by thinking about how you will advertise. Think of your child's needs and then think of some of the people who may be able to meet their needs. Sometimes educational assistants, home care workers, and day care workers would like extra work in their spare time. These people probably have CPR and other skills that would help ease your mind. You can put up posters in places where people will take notice (e.g. university bulletin boards). You can advertise on an online classifieds website or with local work placement agencies that include human service workers.

Choosing The Right Person

When you are interviewing and hiring a caregiver for respite, be sure to discuss expectations. First, talk about and agree on wages. If you want your other children to be cared for as well, ask if they are comfortable with that. Let the caregiver know your expectations about eating habits, routines, toileting procedures, discipline, personal care needs, napping, bedtime routines, therapies, recreation, and guidelines for outings.

Respite Registries

A respite registry is a list of people who have expressed interest in being a respite provider. Information is captured within the registry such as availability and interests. It is then up to parents to interview, hire and train the respite provider. If you live in a larger centre such as Saskatoon or Yorkton, you may be able to find a caregiver on a respite registry. Some Inclusion Saskatchewan branches such as CLASI in Saskatoon create respite registries. Some agencies assist with this as well such as Yorkton's SaskAbilities branch.

Saskatoon Respite Registry (306) 652-9111

Yorkton Respite Registry (833) 444-4126

10.3 Summer and Holiday Respite Programs

When asked about summer activities, many parents said that they enrolled their children with disabilities in summer programs. Sometimes the only reason that children with disabilities have not been included in programs is because it has not yet been tried. Various accommodations can be made for children to attend summer programs. Libraries, schools, community centres, the health regions, the YMCA, and recreational centres put on a variety of programs.

Summer camps are another possibility for children with intellectual disabilities. If your child needs more support than these programs can offer, you may be able to use some respite funding to send a support worker with your child to the summer program or camp. Several Inclusion Saskatchewan branches offer summer programs for children and young adults.

10.4 Funding For Respite Projects

If you have a great idea for a respite space, an after-school care program or other programs that could benefit your child, put together a project proposal and seek out funding. Funding for these types of projects can be found via:

- The Government of Saskatchewan (Ministries of Education, Health, or Social Services, or SaskCulture)
- City or Town Council
- Local Rotary Clubs
- Local Foundations such as the Kinsmen Foundation and Community Initiative Fund.
- Province-wide businesses such as Crown Corporations, large banks, credit unions, and grocery chains

Tip: If you are having trouble figuring out funding proposals, or just need some advice, ask a fundraising person at a non-profit organization. People who work in fundraising know how to locate funding for projects, and have experience with writing proposals.





Chapter Eleven

Justice, Rights, & Legal Issues

We do not “earn” our rights; we have them because we are human beings. Knowing your legal rights is a powerful advocacy tool. Legally, people cannot be discriminated against because of their disabilities. As a parent, it is important to know how legislation supports your child’s rights and inclusion within society. If a policy or the way it has been interpreted discriminates against your child, it is good to know that there are places you can reach out to advocacy help or advice. There are organizations that exist to help people who are facing injustice or discrimination.

11.1 United Nations Conventions On The Rights Of Persons With Disabilities

The Convention on the Rights of Persons with Disabilities is an international human rights treaty that was created with the intention of protecting the rights and dignity of people with disabilities. In March 2010, the Government of Canada ratified the Convention.

There are eight guiding principles within the Convention:

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 different 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

11.2 The Canadian Charter Of Rights And Freedoms

The *Canadian Charter of Rights and Freedoms* is the cornerstone of our human rights as citizens of Canada. The Charter is historically significant for people with a disability: it was the first time Canadian law specifically included people who have a disability. The inclusion of persons with mental and physical disabilities came about because of the strong advocacy of people who have a disability and other allies.

Section 15(1) of the Charter 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.”



While Section 15(1) establishes the broad principle of our right to live without discrimination, Section 15(2) recognizes that because of centuries of discrimination, we still need laws that give people equity as well as equality under the law. Section 15 (2) of the Charter states: "Subsection (1) does not preclude any law, program or activity that has as its object the amelioration of conditions of disadvantaged individuals or groups including those that are disadvantaged because of race, national or ethnic origin, colour, religion, sex, age or mental or physical disability."

Based on Section 15 we have the right to live free from discrimination. According to the Government of Canada, "Discrimination occurs where, for example, a person, because of a personal characteristic, suffers disadvantages or is denied opportunities available to other members of society." The Supreme Court of Canada states that this section is meant to protect groups that are disadvantaged in Canada.

All people have equal protection and equal benefits under the law. Equal protection means that a law (including regulation and policy) must apply equally to all Canadians. Beyond that, we are entitled to the equal benefit of the law. The outcome of a law, the benefit provided by the law, and the way it affects an individual, must be the same for all. For example, a law that says everyone has the right to go to school provides for equal protection, but unless the law also recognizes individual difference it will not ensure equal benefit of the law. It is not only the right of the individual to benefit from attending school, there is also a corresponding responsibility of educators to ensure that you benefit from attending school.

It is important to recognize that the *Canadian Charter of Rights and Freedoms* is meant to protect us from discrimination as a result of an act of government (federal, provincial and municipal) but does not protect us from discrimination by other citizens or businesses. Also the Charter, while providing the basis for our protection against discrimination, puts the onus on a citizen who believes they have been discriminated against, to prove their case.

11.3 The Saskatchewan Human Rights Code

As with the Charter of Rights and Freedoms, the *Saskatchewan Human Rights Code* specifically mentions people who have a disability as a protected group. People with disabilities are a protected group in the Code because they have been targets of discrimination in the past. However, it is important for parents to know that children are not protected from discrimination because of their age. The Code prohibits discrimination based on age but then limits that by defining age to mean "any age of eighteen years or more."

Two areas of the Code that may be important for parents of children with disabilities are sections 12 (public services) and 13 (education). Being part of the community means having access to the same activities and services as everyone else. In section (12:1-a) of the Code, your child is entitled to have the same accommodations, services and facilities as other people. Your child cannot be discriminated against by any service that is offered to the public (13:1-b). This means that public education, health care, dental care, parks, pools, buildings, washrooms, restaurants, stores, hotels and government services must be accessible and available. It is important for parents to stand up for their child's right to the same services as every other child. If your child is denied first-rate health care, dental care, counseling, mental health services, education or any other service, involve a human rights advocate.

11.4 Defending Your Child's Rights: Where To Go For Help

Discrimination or injustice comes in many forms. It can include not allowing a child to learn in a regular classroom, not having an accessible playground or denying someone the financial support they are entitled to from the government. When your family feels there has been discrimination, it is easy to get frustrated or angry, and feel that there is nothing you can do. However, in many situations, it is possible to challenge the system. Here is a list of both non-profit and government organizations that help citizens uphold their rights.

- **Inclusion Saskatchewan**

We are often involved in cases in which individuals believe their human rights as a Saskatchewan citizen are being neglected or ignored. Our website is www.inclusionsk.com and our phone number is (306) 955-3344.

- **The Saskatchewan Human Rights Commission**

If you think your child's rights have been violated, you can call the Saskatchewan Human Rights Commission for advice. It is a government-funded commission with offices in Regina and Saskatoon. The website is www.saskatchewanhumanrights.ca. By investigating complaints of discrimination, the Commission makes sure that the *Saskatchewan Human Rights Code* is followed and enforced.

- **The Ombudsman**

When people have problems with a provincial government department they can call the Ombudsman's office. The Ombudsman can investigate complaints if you feel that a government program or service has treated you or your family unfairly. They can review any decision made by a provincial government worker, department, branch, board, agency, or commission. The Ombudsman's office is independent from any government department, reporting directly to the Legislature. This allows them to make an independent decision. The website is www.ombudsman.sk.ca.

- **The Saskatchewan Advocate for Children & Youth**

The Advocate for Children and Youth is a provincial office, independent from other government departments, that investigates complaints on behalf of children. The Advocate for Children and Youth will intervene if a child or a parent makes a complaint. They will attempt to resolve the dispute or do an independent investigation. They cannot intervene in a complaint against the court, the federal government, the police, or a municipal body or school board. They can be contacted through the website www.saskadvocate.ca.

- **Anti-Poverty Advocates**

If an adult is having problems with a government income support program, there are anti-poverty advocates who can help by advocating with any government system such as Social Services. The following are anti-poverty groups in Saskatchewan:

- The Regina Anti-Poverty Ministry (Regina)
- The Saskatoon Anti-Poverty Coalition (Saskatoon)
- Poverty Free Saskatchewan



- **Saskatchewan Voice of People with Disabilities**

The Saskatchewan Voice of People with Disabilities advocates for people with disabilities and their families. The Voice was a founding member of the Council of Canadians with Disabilities. The Voice advocates in the areas of citizenship, accessibility, employment, housing, human rights, health, income support, individualized funding, organizational development, public education, social policy and transportation. The Voice also offers a newsletter and other publications.

11.5 The Court System

Victims of a Crime

If your child is a victim of a crime, knowing what to expect in the justice system can be very helpful. Victim's Services is a Branch of the Ministry of Justice whose job it is to help the justice system better understand the needs of victims. Victim's Services can help your family make a decision about reporting the crime and give you information about the process you will need to go through to press charges and during court proceedings. The best way to advocate is to make sure that the police, the prosecutor (lawyer) and Victim's Services understand that your child has an intellectual disability and outline the supports they will need.

The Public Prosecutor's Division of the Department of Justice will assign your child a lawyer to represent their interests. You can speak with the lawyer assigned to the case and ask if your child will need to testify. It is important to let the lawyer know about your child's strengths, limitations, and if your child needs support in some way. The victim can have an advocate with them in court if it makes them more comfortable.

People Accused of a Crime

When a person is accused of a crime, it is important to get a lawyer. Low-income adults should qualify for a lawyer from the Saskatchewan Legal Aid Commission. If a person does not qualify, they can apply to the court to have a lawyer appointed. Interview potential lawyers to make sure they understand disability issues, or at least have a willingness to learn. It is best to have a lawyer who has some experience with people with disabilities.

Alternative Measures & Extrajudicial Sanctions Programs

Alternative measures/extrajudicial sanctions programs might be a good option for an accused individual, depending on the circumstances. These programs offer accused persons a chance to take responsibility for their behaviour and address the harm they have committed. They take a problem-solving approach to crime that emphasizes healing while helping repair relationships between the victim, the accused and the community as much as possible.

Alternative measures/extrajudicial sanctions programs frequently use restorative justice -- an approach that focuses on addressing the harm caused by crime while holding the offender responsible for his or her actions, by providing an opportunity for the parties directly affected by crime – victim(s), offender and community – to identify and address their needs in the aftermath of a crime. It supports healing, reintegration, the prevention of future harm and reparation, if possible.

Mental Health Strategy Court

Mental Health Strategy (MHS) Court is a collaborative model to coordinate treatment needs and criminal justice needs for individuals with mental health, Fetal Alcohol Syndrome Disorder (FASD), or cognitive issues who have

been charged with a crime. The Saskatoon Mental Health Strategy Court brings together the knowledge of health, social services and criminal justice professionals. It is designed to improve the Court's access to information in order to support and supervise offenders safely in the community.

Adults accused of a crime may be referred to the MHS Court through the Crown Prosecutor if the accused appears to have issues related to mental health, such as cognitive disability, FASD, brain damage, or psychiatric disorder. The mental health issue must be related to the criminal behaviour. Legal aid, defense counsel, social agencies, and individuals can contact the Crown Prosecutor and ask that the accused person be considered for this court.

Finding Legal Help

When a person with an intellectual disability enters the justice system, often the supports they need are simply not there. They will need you as their advocate more than ever. If there are any supports they need to have a fair trial, demand them. Help is available at the following places:

- [Legal Aid Saskatchewan](#)
Legal Aid Saskatchewan provides accessible and professional legal services in criminal and family law to eligible people. They provide legal services to people and organizations who are financially unable to secure services on their own. More information, including eligibility criteria, can be found on their website.
- [Lawyer Referral Service](#)
The Law Society of Saskatchewan helps people contact lawyers in their community who are interested in a particular area of law such as criminal, estates, wills and trusts, human rights, landlord and tenant, medical malpractice, and taxations. It allows you to search lawyers who are members of the Law Society of Saskatchewan.
- [Pro Bono Law Saskatchewan \(PBLs\)](#)
PBLs is a non-profit that improves access to justice in Saskatchewan by creating, facilitating, and promoting opportunities for lawyers to provide high-quality pro bono (free) legal services to persons of limited means.
- [The John Howard Society](#)
The John Howard Society of Saskatchewan offers advocacy, referrals, mediation, anger management, and counselling to youth and adult males in Saskatchewan. All programs are aimed at helping those affected by the criminal justice system to reintegrate into the community.
- [The Elizabeth Fry Society of Saskatchewan](#)
The Elizabeth Fry Society offers support to youth and adult women affected by the criminal justice system. The society offers information about court proceedings, resources, counselling, and reintegration programs.
- [Community Legal Assistance Services for Saskatoon Inner City \(CLASSIC\)](#)
CLASSIC is a non-profit and charitable organization that provides free, professional and confidential legal services for low-income members of Saskatoon who cannot otherwise afford legal advice or representation.



Chapter Eleven

Justice, Rights, & Legal Issues

- **ARCH: A Legal Resource Centre for Persons with Disabilities**

ARCH is a non-profit legal aid clinic in Ontario that provides free, confidential, basic legal information as it relates to disabilities. ARCH has a mandate to serve the citizens of Ontario, but you can phone for advice if you have had a hard time finding disability-related legal advice. Also, there are publications on the ARCH website that are written for lawyers explaining how to respect and support a person with a disability.

11.6 Planning For Your Child's Financial Future

To ensure that your child with an intellectual disability has a good quality of life, for their whole life, you need to plan ahead. It can be helpful to seek the advice of a lawyer in addition to a financial planner and/or accountant to help make your plan sustainable long term. More information can be found in our publication *Road Map to the Future: A Financial Planning Guide for Families of People with Disabilities*.

The Planned Lifetime Advocacy Network

A good way to make sure your child has a secure future is to check out the resources of the Planned Lifetime Advocacy Network (PLAN). PLAN is a non-profit organization created by and for families with children who have a disability. The organization offers books and online supports with excellent advice on building a safe and secure future for a person with an intellectual disability. You can learn about PLAN by accessing their website at www.plan.ca.

The Dependents Relief Act

When you are preparing your will, it is important to find out about current legislation that could affect how your estate is distributed. In Saskatchewan, the Dependents' Relief Act requires you to make "reasonable and adequate" provisions for your dependent child, regardless of their age. A "dependent" can be "a child of the deceased who is 18 years or older at the time of the deceased's death and who alleges or on whose behalf it is alleged that: (a) by reason of mental or physical disability, he or she is unable to earn a livelihood."

If your will does not adequately provide for your child with a disability, the Public Guardian and Trustee of Saskatchewan can ask the court for a maintenance payment from your estate. This means they will rewrite your will to allow financial support for your dependent child. If your adult child receives SAID or other social assistance and inherits money from your estate, this may mean forfeiting public assistance until all the inheritance money is used up.

Discretionary Trusts

We recommend that parents find a good financial planner and a lawyer who understands disability issues and consider setting up a third-party discretionary trust. A discretionary trust gives the trustee or trustees full discretion as to how and when to provide for the beneficiary. The trustee(s) will be able to spend your child's inheritance on improving your child's quality of life. They will be able to purchase those extra items that social assistance does not provide. If the money is in your child's name instead of a discretionary trust, Social Services can deny them assistance until the money is spent at a government rate on their basic needs. It has become a common practice in Saskatchewan to set up a discretionary trust under a will as means for providing for a dependent child.

11.7 Supported Decision Making & Guardianship

Supported Decision Making

Supported Decision Making (SDM) is a process of supporting a person's right to make informed choices about their life. SDM includes the person's support network as it recognizes the importance of meaningful, supportive relationships. The supporters (the person's circle of supports) work to empower the person to be the leader of their own life while ensuring they feel supported, respected and heard.

SDM requires established relationships between a person and their support network, an understanding of the underlying principles, and a respectful process for making decisions. SDM should be transparent, team-oriented, and focused on identifying the wishes and goals of the person. The best course of action should also be determined, including what decisions require support, the specific roles of each supporter, and how differences of opinion will be handled. SDM is intended to be carried out with the least restrictive measures possible. The success of SDM is not measured by outcomes; it is measured by how well a person is empowered to have choice in their life.

Principles of Supported Decision Making:

- Recognize that everyone has an inner drive to choose how they want to live.
- The person making the decision is at the center of the decision-making process.
- Every person has the right to self-determination -- making decisions is not limited or removed by disability.
- The right to make decisions includes the right to have the support needed to make decisions. This includes respecting the choices other people make and helping them achieve their goals.
- Decision making is a human right that is guaranteed in the *Canadian Charter of Rights and Freedoms* and in Canadian and provincial/territorial human rights laws.

The Supported Decision Making Process:

1. Determine what decision needs to be made. What does the person want? Do they need/want support to make a decision? What are their strengths? What areas may they need support with?
2. Include preferred supporters who understand what is important (both short term and long term) to the person. The supporter must work with integrity to support the person with an unbiased approach and awareness of a person's goals and wellbeing.
3. Present the options in a way that works best for the person. There may be many ways for the person to achieve what they want. This includes considering when is the best time for the person to make a decision, adapting to how the person likes to receive information, and including others who should be enlisted as a support.
4. Gather the person and their supporters to identify any additional information needed to make the decision. Map out who makes the final decision and be clear about who will be doing what. Make sure all information is shared, that the steps to the desired outcome are discussed and that everyone understands the options.



Consider the advantages and disadvantages of each option, and outline challenges. Take as much time as is required, and do not try to accomplish too much at one single meeting. Consider how the person likes to receive information and go at their pace.

5. The person makes a decision and the supporters ensure they fully understand their decision. The outcome should be the most appropriate option for the person.
6. Check in with the person and evaluate the outcome. How do they feel? What did they learn? Was it what the person was hoping for? Why or why not? If new information comes forward, or the situation changes, continue communicating, as required.
7. What is the next decision the person would like support with? Every decision is an opportunity for people to exercise their autonomy. Begin the process again, but remember to begin at step one each time, as every decision is different and may require different supporters, sharing updated information, etc.

Co-Decision Making, Guardianship, and Power of Attorney

Many parents who have a child with an intellectual disability assume that once their child turns 18, the next step is to get guardianship. Guardianship, however, is only needed and is only effective in certain situations.

Guardianship: Guardians make decisions for an adult that takes away the adult's right to self-determination. The guardian manages main areas of the adult's life, depending on the type of guardianship that is obtained (personal, property, or both). The guardian is supposed to take the wishes of the adult into consideration when making decisions. A personal guardian makes decisions about an adult's personal welfare and a property guardian makes decisions about an adult's finances and property. Guardianship applications require two assessments from professionals (such as a doctor) who know the individual well and can assess the adult's capacity to make decisions. Once the application is complete, it is sent to the Court of Queen's Bench.

Co-Decision Making: Co-Decision Makers assist the adult with making choices about their lives. They ensure that the adult is well informed about their choices, that they understand the information to the best of their ability, and that they are made aware of the possible consequences of a decision. However, the vulnerable adult has the final say about what they would like to do. A personal co-decision maker makes decisions with the adult about personal matters and a property co-decision maker makes decisions with the adult about finances and property. Co-decision making is a formal type of supported decision-making tool that enables the person who is being supported to take more control over their own life. It allows for growth and learning in decision making through practice. An application to the Court of Queen's Bench is still required for formal co-decision making.

Power of Attorney: A power of attorney is a written document that grants the ability for an adult to help another adult make decisions on their behalf. A person may use an enduring power of attorney to appoint a personal attorney, a property attorney, or both a personal and property attorney. An adult may appoint the same person to be both their personal and property attorney, or can appoint different people to fulfill each role. An individual who has an intellectual disability but who has decision-making capacity can use this tool if they would like decision making support from someone they trust. An enduring power of attorney continues during the grantor's lifetime until death, but the grantor can also get rid of their Power of Attorney at any time, assuming mental capacity to do so exists. All the necessary forms are available for download at the Saskatchewan Justice website.

In Closing

As a parent, you are your child's best advocate. Parents advocate for inclusion and meaningful participation for their children because they want a rich, full, interesting life for each of them. Parents encourage their children to dream and to carve out their own place in the world. We believe that supporting a child with a disability to grow, learn and reach his or her potential is a lifelong journey of discovery for parents and their children.

Inclusion Saskatchewan is privileged to walk with families and self-advocates on this journey. We think of Navigating the System as having Inclusion Saskatchewan in your back pocket, as you encounter new forks in the road ahead. This guide is a compass: a navigational tool designed to point your searches in the right direction. We hope this book can help you navigate the systems of support currently in place, while helping you and your child to develop the self-advocacy skills necessary to help those systems evolve.

Navigating the System is a companion for the journey. There will be successes and failures, smooth highways and winding paths along the way. There will be issues that challenge families to be strong advocates for their children, and many stories to tell as children grow and change. As many families know, the journey may not always be easy but having current information and necessary resources will help to ensure that your loved ones are well supported and lead meaningful lives in their community. Families are encouraged to share this information with others who are experiencing some of the same challenges. We also encourage you to continue checking our website for downloadable updates to this guide.

Your child is a person with unique gifts and talents. Your community is a better place because your child is part of it. We sincerely hope that the information in this guide will help make your journey an easier one.

RESOURCES: ACRONYM LIST

ABCDP	Alvin Buckwold Child Development Program	PBLC	Pro Bono Law Society
ACL	Association For Community Living	PCP	Person Centred Plan
APSH	Approved Private Service Home	PLAN	Planned Lifetime Advocacy Network
ARC	Autism Resource Centre	PLEA	Public Legal Education
ASD	Autism Spectrum Disorder	PPP	Personal Program Plan
CBO	Community Based Organization	PTA	Provincial Training Allowance
CBSB	Comprehensive Behavior Support Plan	RDSP	Registered Disability Savings Plan
CCB	Canada Child Benefit	SAID	Saskatchewan Assured Income for Disability
CCC	Canada Caregiver Credit	SAI	Saskatchewan Alternatives Institute
CDS	Cognitive Disability Strategy	SAIL	Saskatchewan Aids to Independent Living Program
CDSB	Canada Disability Savings Bond/Grant	SARC	Saskatchewan Association of Rehabilitation Centers
CIW	Community Intervention Worker	SPCA	Saskatchewan Cerebral Palsy Association
CLASI	Community Living Association Saskatoon Inc	SDF	Self Directed Funding
CLSD	Community Living Service Delivery	SDM	Supported Decision Making
CMHA	Canadian Mental Health Association	SETI	Supported Employment Transition Initiative
CNIB	Canadian National Institute for the Blind	SILP	Supported Independent Living Program
COR	Creative Options Regina	SIS	Saskatchewan Income Support
CPP&SP	Comprehensive Personal Planning and Support Policy	SO	Special Olympics
CRA	Canada Revenue Agency	SPP	Saskatchewan Pension Plan
CSA	Children's Special Allowance	SSILC	South Saskatchewan Independent Living Centre
CSW	Community Services Worker	TIPS	Therapeutic Integrated Pediatric Services
DISC	Disability Income Support Coalition	WRC	Wascana Rehabilitation Centre
DLSA	Daily Living Support Assessment		
DPSA	Day Program Skills Assessment		
DTC	Disability Tax Credit		
EA	Educational Assistant		
ECC	Early Childhood Consultant		
ECIP	Early Childhood Intervention Program		
EDP	Entrepreneurs with Disabilities Program		
EI	Employment Insurance		
FASD	Fetal Alcohol Spectrum Disorder		
FEEL	Families Experiencing Exceptional Loss		
FIDA	Family Impact of Disability Assessment		
GIS	Guaranteed Income Supplement		
GP	General Practitioner		
INAC	Indigenous and Northern Affairs Canada		
IEP	Individual Education Plan		
IIP	Inclusion and Interventions Plan		
INSK	Inclusion Saskatchewan		
KFN	Kids First North		
MAPS	McGill Action Planning System		
MSS	Ministry of Social Service		
NESI	New and/or Expanded Service Initiative		
NSILC	North Saskatchewan Independent Living Centre		
NSN	North Sask Special Needs		
PART	Professional Assault Response Training		
PATH	Planning Alternative Tomorrows with Hope		

RESOURCES: ESSENTIAL ORGANIZATIONS

Autism Resource Centre

Phone: (306) 569-0858
www.autismresourcecentre.com
info@autismresourcecentre.com

Autism Services of Saskatoon

(306) 665-7013
www.autismservices.ca

Canadian Down Syndrome Society

Phone: (403) 270-8500, 1-800-883-5608
www.cdss.ca

Canadian National Institute for the Blind

1-800-563-2642
Regina: 306-525-2571
Saskatoon: 306-374-4545
www.cnib.ca/

Community Living Service Delivery (CLSD)

Ministry of Social Services

CLSD Central Office (Regina)
Phone: (306) 787-7803
Fax: (306) 798-4450
www.saskatchewan.ca/government
clsd.info@gov.sk.ca

CLSD Regional Offices:

Estevan: 306-637-4550
La Ronge: 306-425-4552
Lloydminster: 306-825-6410
Melfort: 306-752-6100
Moose Jaw: 306-694-3800
Nipawin: 306-862-1704
North Battleford: 306-446-7705
Prince Albert: 306-953-2668
Regina: 306-787-3848
Saskatoon: 306-933-6300
Swift Current: 306-778-8219
Weyburn: 306-848-2404
Yorkton: 306-786-1300

Council of Canadians with Disabilities

Phone/TTY: 204-947-0303
www.ccdonline.ca
ccd@ccdonline.ca

Epilepsy Saskatoon Inc.

Phone: (306) 665-1939
www.epilepsysaskatoon.com
epilepsysaskatoon@sasktel.net

Inclusion Canada

Phone: (416) 661-9611
Fax: (416) 661-5701
Help Line: 1-800-856-2207
www.inclusioncanada.ca

Inclusion Saskatchewan

3031 Louise St. Saskatoon, SK S7J 3L1
Phone: (306) 955-3344
Fax: (306) 373-3070
www.inclusionsk.com
info@inclusionsk.com

Learning Disabilities Association of Saskatchewan

(306) 652-4114
www.ldas.org
reception@ldas.org

Office of Disability Issues

Phone/TTY: (306) 787-7283
odi@gov.sk.ca

Saskatchewan Advocate for Children & Youth

Toll Free: 1-800-322-7221
Phone: 1.306.933.6700
www.saskadvocate.ca
contact@saskadvocate.ca

Saskatchewan Association of Rehabilitation Centres (SARC)

Phone: (306) 933-0616
www.sarcsaran.ca
contact@sarcan.sk.ca

RESOURCES: ESSENTIAL ORGANIZATIONS

Saskatchewan Brain Injury Association

Phone: (306) 373-1555, 1-888-373-1555

www.sbia.ca

Saskatchewan Cerebral Palsy Association

Phone: (306) 955-7272, 1-800-925-4524

cpsk.ca

saskcpa@shaw.ca

Saskatchewan Deaf and Hard of Hearing Services (SDHHS)

Regina Phone/TTY: (306) 352-3323,

1-800-565-3323

regina@sdhhs.com

Saskatoon Phone/TTY: (306) 655-6575,

1-800-667-6575; text 306-229-2010

sdhhs.com

saskatoon@sdhhs.com

Saskatchewan Down Syndrome Association

Phone: (306) 545-7038

www.skdownsyndrome.ca

skdownsyndromesociety@gmail.com

Saskatchewan Epilepsy

Phone: 306-359-0905

www.skepilepsyinc.com

skepilepsy@sasktel.net

Saskatchewan Voice of People with Disabilities

Phone: 1-877-569-3111

www.saskvoice.com

Spina Bifida and Hydrocephalus Association of Saskatchewan

Regina 306-537-1372

sbhac.ca/regional

Saskatoon 306-249-1362

www.sbhasn.ca

Spinal Cord Injury Saskatchewan

(306) 584-0101, 1-877-582-4483

scisask.ca

sciinfo@scisask.ca

