

NAVIGATING THE SYSTEM



Saskatchewan Association for
Community Living

**THIS BOOK IS PROVIDED COMPLIMENTARY TO FAMILIES BY
THE SASKATCHEWAN ASSOCIATION FOR COMMUNITY LIVING**

Navigating the System

**An Advocacy Handbook for Parents of
Children with Intellectual Disabilities**

Third Edition



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Editor's Notes

He/She Gender References and This Handbook

Language is confusing sometimes. We try to use language that is easy to understand. Because of this, we are not using he/she, even though it is an appropriate way to refer to both genders. Throughout the handbook, we will use either “he” or “she” in a sentence, but for us it means both genders. We think it is just a little easier to read.

Children and Adults with Disabilities

Because this book was originally intended for parents with young or school-aged children, we use the term “child with an intellectual disability” in most chapters of the book. Many of the topics covered include issues that parents will face as their child grows into adulthood. When we say “child with an intellectual disability,” we do not want you to think that this is irrelevant for your son on the day he turns 18. We hope that you will make use of this information any way you need to, throughout his life, no matter the age of your son.

What do those letters stand for?

Many of the terms in this handbook have long titles. When you have long titles, it is easy to get lost in all of the words, and it is hard to read. So we use acronyms; for example, the Saskatchewan Association for Community Living is referred to as the SA CL. If you are having trouble figuring out what an acronym means, all of the acronyms and the meanings are listed at the back of the handbook.

Help us keep up to date.

If you find any information, addresses, phone numbers, program names, etc. that are wrong or have changed, please let us know. Also, if you find new programs or ideas that have worked for you and you want to share them with other families, let us know that, too.

You can contact our office in Saskatoon

by mail:

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sacl@sacl.org

Welcome to Navigating the System

Dear Readers,

It is more than likely the reason you have cracked the cover of this book is because you are looking for answers. This is not the type of book that one picks 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 our confidence as parents and lead us in the right direction to helping our children reach their greatest potential.

After receiving and coming to terms with a diagnosis of intellectual disability 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, unavailable, 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 the Grassroots Alliance and the SACL. 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 an understandable and user-friendly format.

Whether you read this book cover to cover 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 thing you can retain right now because you are overwhelmed by everything else that is going on,



let it be this fact: You will **always** make the right decision for your child based on where you are at the time. There are no wrong decisions for you as a parent. Have faith and confidence that you know your child better than anyone else!

Sincerely and most compassionately
yours,

Bluesette Campbell
Parent/Advocate
Meadow Lake, SK

Foreword

All parents want the best for their children. They want to their children to be happy and accepted citizens who are fully included in the community.

The parents of children with disabilities are no different. They want their children to make friends, attend their neighbourhood schools with their peers, engage in meaningful activities, and live in the community of their choice.

Navigating the System offers valuable information for parents of children with disabilities. If your child has a disability, ensuring your son or daughter's needs are met can be an ongoing challenge. This handbook was created to help parents as they confront that challenge.

The Saskatchewan Association for Community Living (SACL) works to ensure that individuals with intellectual disabilities are fully included, involved, and valued members of our society. Our organization believes in full inclusion in every aspect of life and community.

The SACL is about families. Fifty-five years ago, families began to work to make life in the community a reality for their sons and daughters with disabilities. They knew that their children had gifts to give to their communities and that they should have the same opportunities as other children. Today, that vision continues to guide our work.

One of the first areas to be identified as needing change was education. In the 1950s, there was no right of education for students with intellectual disabilities. Families of these children got together, raised money, and ensured that their children would be educated – at first in a separate environment, and eventually in regular schools and classrooms.

The SACL believes that parents of children with intellectual disabilities know their children best and have valuable insight and information to share. *Navigating the System* was created for parents with the assistance of parents. We are indebted to the Saskatchewan families who have shared their experiences in an effort to aid other families.

Parents, SACL employees, and other stakeholders provided input for *Navigating the System*. We would like to express our appreciation to all who offered valuable input and information throughout the process of updating this handbook.

If you are a parent or relative of a child with a disability, or if you are a caregiver, teacher, physician, social worker, or someone else who works in the human services field, we hope this handbook is useful to you.

If you would like more information about *Navigating the System* or about the SACL, please let us know. If you would like to share your thoughts on the handbook, or if you would like to share your experiences with navigating the human services system, please contact us at our provincial office in Saskatoon at (306) 955-3344 or at sacl@sacl.org.

We look forward to hearing from you.

Sincerely,

Kevin McTavish
SACL Executive Director



Introduction

The United Nations Convention on the Rights of Persons with Disabilities says:

States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community...

From Article 19

For most of us, our experiences of being a parent are of joy, pride, and hope, but are not without challenges. When you become the parent of a child who has an intellectual disability, or any disability for that matter, you are taken on a journey that your

experience with your other children did not prepare you for. While there is joy and pride, the increased challenges of parenting a child with a disability should never be underestimated.

As a parent of a child with a disability, you are more likely to struggle for all the things that other parents take for granted. Even when your child does not need a lot of intensive support, it is often harder to find a doctor or a dentist, or even to find a sitter when you go out for the evening. If your child has more intensive support needs, you spend your time managing medical, sleeping, eating, education, social, and recreation issues that do not exist for other families.

In order to ensure that your child has a good life you become involved, in ways you never dreamed of, with the doctors, special education professionals, social workers, and therapists that make up the human service system. It can be physically and emotionally draining, leaving less time for nurturing, teaching, and playing and less time for the rest of your family.



It seems like an impossible process, ***but you can learn how to navigate the system.***

This advocacy handbook is about finding solutions, and figuring out how to work with systems that are complicated, restrictive, underfunded, and confusing. This handbook will give you 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 as you face “systems.” You will also find explanations of some of the bureaucracies and policies that you will encounter on your journey.

Why is it an ‘advocacy’ handbook? Because parents have the right and responsibility to advocate for their children and parents who have been through it know that you need the information and support to do so. This is how the idea for this handbook came about.

We began by asking parents of the Saskatchewan Association for Community Living (SACL) to share their experiences. The pages of this handbook are alive with wisdom from these parents who want you to have the information they wish they had a long time ago. While the parents we talked to have children with intellectual disabilities, their experi-

ence and their wisdom can benefit all parents who have a child with any disability.

Through this handbook, we want to offer more than a list of resources and information. We understand that getting your child’s basic needs met can feel like begging and it shouldn’t. We understand that sometimes it feels like wherever you turn, there are huge walls to climb and no one to help you.

This handbook does not have an answer for every problem. We know there are huge gaps in services. The Saskatchewan Association for Community Living is working to fill those gaps for people with intellectual disabilities and their families through advocacy, lobbying, and education.

If you feel there is an area missing in this advocacy guide, or if you have experiences that are significantly different from what you read, please contact us.

WHAT IS ADVOCACY?

In the context of this handbook, we think of advocacy as a concerted effort to fight for your child’s and your family’s right to support. An advocate is someone who speaks for another. When you are an advocate, you stand beside someone, providing support,



questioning the system, challenging the status quo, and using your knowledge to ensure fair treatment.

Sometimes people's needs are ignored, their rights are taken away, or they fall through the cracks, and no one listens when they ask for help. Children and young adults with intellectual disabilities are especially vulnerable to this kind of discrimination. Parent advocates may need to challenge a school, a hospital, a community service, a business, a landlord, or a recreational facility to be sure that the person they love is treated fairly. As an advocate you will tell others about your child's strengths and the supports your child requires. Your goal as an advocate is to make sure your child is respected and accepted, and has the necessary supports.

Sometimes, there are injustices built right into the fabric of our society. Often people with intellectual disabilities, in fact all disabilities, are not given the same opportunities as everyone else because organizations and rules were created without them in mind. Advocates may challenge the laws, rules, and policies that control our communities and organizations. In a democratic country, this may mean getting a group of advocates together and demanding change.

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 does and you are the person who cares the most about making sure your child succeeds. When she is sick, lonely, uncomfortable, excluded, or not reaching her full potential, you do something about it. This makes you a natural advocate.

The great thing is that by advocating for your child you make things better for all children with disabilities. Think about how things have changed in the nearly 60 years that the SACL has been around. Children with intellectual disabilities are no longer separated from their families and placed in institutions. They attend school, many of them in regular classrooms. Many participate in regular recreational activities in the community. Adults with intellec-



tual disabilities are finding opportunities to work in regular jobs. There are human rights laws to protect people with all disabilities from discrimination. **Parents and people with intellectual disabilities accomplished all of these things.**

Opportunities are still not available for all people with intellectual disabilities. So today, we continue to advocate alongside our children and friends to make sure that they have all the opportunities and supports they need to live a full life in the community. With the combined energy and vision of people with intellectual disabilities and their families, it will happen.

Being an Advocate

Advocating for your child comes naturally, but working with schools, the medical system, social workers, and other professionals does not. These are learned skills. Remember that 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 be a better advocate.

Be informed:

- Know your rights and what you can expect from the services your child is receiving.
- Know the facts of your child's situation, including strengths and challenges. Also, you need to try to understand what the professionals you are working with think about your child.
- Get to know the people your child depends on for support in schools, hospitals, etc. Know who they are and what their role is, understand their situation, and ask them what they can do and can't do to help your family.

Keep records:

- Keep copies of **everything** you get or send. You will need a file system or a binder to keep everything organized so you can find it when you need it.
- Make all requests in writing. Don't rely on phone calls or casual conversations. When these happen, make notes of the conversations (date, time, name and position of the person you talked to, and any decisions reached.) You may want 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. If someone will not give you written confirmation, put in writing what you believe was promised and send your interpretation to him or her.

Never advocate alone:

- You need to 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, take someone with you. Recruit a person(s), in addition to your spouse, who can attend meetings with you. At the meeting they can take notes for you (even if someone is the official note taker for the meeting you should make your own notes). Your support person is another set of eyes and ears. They are someone you can talk to after the meeting to

help you understand what went on.

- You can give your support person(s) copies of important documents so that if you can't find your copy you have a backup.

Before meetings:

- When you are invited to a meeting, ask for an agenda (the things that will be talked about), the reason for the meeting, and with whom you can expect to meet.
- If you asked for the meeting, make an appointment, give them your agenda (the things you want to talk about), and who will attend with you. Call to confirm the meeting the day before and find out who will be there.
- Take time in advance to collect any documents or information that will help you at the meeting.
- Make a list of questions you would like to ask.

At meetings:

- Be polite and courteous at all meetings.
- At the beginning of the meeting ask who is taking notes and ask to receive a written summary of what was agreed to and who was present.
- Acknowledge when good things have happened and special efforts have been made.
- Sit across from decision makers. Keep eye contact.
- Say what you want in your own words. Be clear and concise.
- Repeat what they say to make sure you understand. If you don't understand, ask questions and make sure you get answers.
- Don't feel pressured to discuss something if you are not prepared.
- Don't feel that you must make a decision immediately. If you need time to think, take the time.
- Take breaks when needed to cool off, consult, or cry.
- At the end of the meetings make sure you know the next steps.

Remember:

- Know what is truly important to you and your child and advocate for it!
- Focus on the issues, not the people.



- Focus on the present and the future, not the past.
- **There may be more than one way to get what your child needs.** Work toward mutually agreeable solutions. Be flexible and creative. Problem solve! Problem solve! Problem solve!

MYTHS ABOUT SEGREGATION

At the SACL, we truly believe in community living, meaning that everyone belongs and must be included in all aspects of their community. In the past, people who had intellectual disabilities were segregated because of fear and rejection. As a society, we have begun to understand how cruel and unjust it is to deny people their rights by keeping them isolated. But segregation still exists in many forms. Even when segregation is not official, as in an institution, many people with intellectual disabilities are isolated and marginalized in our communities. It is helpful for all of us to understand what segregation is and how segregation has been justified. Hutchison and McGill list some myths that allow society to justify segregating people with disabilities:²

■ **MYTH: She needs to be “ready” before she can live in the community.**

FACT: Some of the skills that people are expected to learn before they are allowed to be in the community are not necessary, useful, or even possible. It is not possible for a person to “get ready” to live or work in the community by being isolated. To live and work in their community, what people need is support, not training.

■ **MYTH: Integration is not for everyone.**

FACT: Some people still believe that the only option for certain people with intellectual disabilities is segregation, and that segregation is appropriate and necessary. This is a myth. We know that no person has needs so great that she cannot be supported in her own community. Many people with complex care needs already live in and contribute to their communities.

■ **MYTH: People should have the right to choose segregation.**

FACT: Segregation is often to do with a lack of options. We think there need to be more options.

MYTH: Complex support is better provided in a segregated setting.

FACT: This myth has nothing to do with what is best for a person, but a lot to do with efficiency. The truth is that a segregated arrangement is better for administrators and staff, not for the person with a disability.

MYTH: Segregated services are a safeguard.

FACT: This myth is based on the argument that if inclusion doesn't work, then we will need a place for "them." Those who argue this believe that they need something to fall back on while trying out inclusion. But we cannot afford to maintain the expensive segregated services and integrated services at the same time.

As advocates, we need to say loud and clear that we want inclusion. Segregated services are not good enough for the children and adults with disabilities we love and support. They teach us and give us so much and they deserve respect, acceptance, support, and full inclusion.

THE SASKATCHEWAN ASSOCIATION FOR COMMUNITY LIVING (SACL)

Our History

In the past, professionals told parents that their children with intellectual disabilities would be better off if they did not stay at home and did not stay in the community, and that they did not belong with their family. The children were put in institutions, and grew up there, without the experiences of childhood that most of us had. They grew up without family, school, and community.

Many courageous parents stood up and said, "NO." Parents wanted more than institutions for their children. All over Canada, parents knew that their children, no matter what it was that made them 'different,' needed the same experiences as other children. They decided that their children deserved to live in a loving home rather than in an institution, make



friends, go to school, and plan their future. Out of this, the parents' movement began in church basements and meeting halls, in large and small towns across Canada and the world, as families got together to make their dreams for their children come true. The Saskatchewan Association for Community Living (SACL) was formed by families in 1955 to help families make their dreams a reality.

The SACL continues to speak out for individuals with intellectual disabilities and their families. We advocate for the supports and services that families and individuals need to stay in their own homes and to enjoy and participate in their communities.

What We Believe

Our mission is to make sure that all people with intellectual disabilities in Saskatchewan are full, active, and valued members of society, with worthwhile opportunities and a range of choices in all aspects of life. Each person must be provided with all the supports they need to be included and participate in their community.

We believe in *citizenship*. This means that the rights and freedoms of people with disabilities are respected and protected.

We believe in *membership*. People with disabilities are part of every community, and have the same right to access school, work, and community life as everyone else.

We believe in the right to *self-determination*. People with disabilities need to be active in making the decisions that affect their lives.

These beliefs guide our daily actions and work. 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.

THE WAYS WE CAN OFFER SUPPORT

The SACL was started by and for families who have a member with an intellectual disability in order to ensure that all people who have an intellectual disability have the support needed to be full, active, and valued members of our shared community. All the work we do, including this handbook, is done in support of this vision. While the SACL has a mandate to support individuals who have an intellectual disability, we believe that everyone deserves to be welcomed and included in the community. For this reason we do not turn away anyone with a disability who comes to us for help.

We are here to help you reach your goals for your child whenever help is needed. Our members, board of directors, and staff at the SACL can offer you help in a variety of different ways.

The SACL has active local branches in communities around Saskatchewan, including Biggar, Esterhazy, Humboldt, Kindersley, Lloydminster, Moose Jaw, Outlook, Prince Albert, Regina, Saskatoon, and Swift Current, as well as the Valley View Parents Group. The Regina, Saskatoon, and Lloydminster branches have paid staff that can offer assistance. Other branches have committed volunteers that can offer friendship, support, and advocacy.

If you are looking for support from a parent/family group and there is no SACL branch close by, you may want to talk to your early childhood interventionist or your social worker from Community Living Services Delivery (CLSD – formerly Community Living Division). Or you can call the SACL at (306) 955-3344 and we will attempt to connect you with a parent/family group close to you.

The Saskatchewan Family Network (SFN)

The Saskatchewan Family Network (SFN), which runs with the continuing support of the SACL, is a group of families who have a family member with

a disability. The network's main purpose is to connect families who will offer support and share information with each other. SFN members know from experience how valuable it is to have friendship and support from other families. They believe in inclusion and the importance of diversity. They have published a series of books telling the personal stories of families in Saskatchewan called *Life Landscapes*. For more information you can contact the network's coordinator at (306) 955-3344.

Self-Advocacy Action Group (SAAG)

The Self-Advocacy Action Group (SAAG), developed by the SACL Grassroots Alliance, is an action-oriented group of self-advocates from across the province who speak about the rights of individuals with intellectual disabilities and what it means to live with an intellectual disability. The group's goal is to stand beside self-advocates as they find their voices and achieve their rights as self-determining people. SAAG members decide for themselves what the focus of the group will be and then pursue their goals with the help of a coordinator. SAAG travels across Saskatchewan educating people about the rights of people with disabilities through stories, skits, a facilitated discussion, and a video presentation. SAAG has a variety of presentations and participatory workshops that can be tailored to suit any audience. For more information about SAAG, call the SACL at (306) 955-3344.

Fusion Inclusion Youth Group

Fusion Inclusion is the SACL's provincial youth program. It was founded on the belief that differences should be celebrated and should not prevent anyone from being included at school and in a community. There are youth members with and without disabilities. Everyone is equal and appreciated. The group has discussions on creating positive change, they share experiences, they support each other, and most importantly, THEY HAVE FUN! There have been various activities over the years – sleep-overs, swimming, go-karting, bowling, mini-golf, etc. The great part is that your voice is heard! If you have an

idea for an activity, we can certainly try it out. Youth aged 14 -19 are welcome to join Fusion Inclusion for some fun times and to find out that we are all more the same than we are different. For details, or if you would like to have a presentation about the concept of inclusion in your classroom, school, or community event, contact the SACL youth coordinator at (306) 955-3344.

The Saskatchewan Association for Community Living – Provincial Office

The SACL has a provincial office in Saskatoon and we offer support to families anywhere in the province. Our staff is committed to building an inclusive community. We offer family and individual advocacy and employment assistance. We focus on community development, education, and training. As well, we conduct organizational advocacy with policy makers. We promote policies that support full inclusion for people with intellectual disabilities.

In order to help families and individuals, we have advocates located in Regina (306-790-5684), Saskatoon (306-955-3344), and Prince Albert (306-763-5605). The advocates serve people throughout the province and are available to help individuals access quality education, employment, housing, social services, and health and medical services. They also advocate for justice and human rights issues. Please contact them at any time for help or advice.

The SACL also has employment consultants who bring employers and job seekers together. The offices are located in Regina (306-790-5685), Saskatoon (306-955-3344), and Prince Albert (306-763-5606). When you are thinking about your child's future and the transition from high school to the adult world, consider calling our employment consultants for advice or help with a transition plan. The consultants can help you access programs and act as a liaison. They can offer sensitivity training to prospective employers or help resolve employment concerns. It always helps to plan early for major transitions.

Workshops and Conferences

The SACL offers participatory workshops, conferences, and other training events on various topics, designed with families in mind. For example, the Supported Decision Making workshop, which discusses how an individual who has an intellectual disability can be supported when making decisions, is available to parents as well as service providers or community members. A facilitator will help participants understand supported decision making and will offer a practical framework for developing a supported decision making process.

Each spring at our annual general meeting we present speakers who provide information about education, residential support, and many other topics of interest to families and individuals who have an intellectual disability. We also support the development of a wide variety of other community workshops and training events. Call (306) 955-3344.

The Kids on the Block Puppet Troupe (KOTB)

The Kids on the Block (KOTB) puppet troupe is an educational awareness program that uses life-sized puppets and theatre to educate children about disabilities. Through factual information and a fun presentation, KOTB fosters positive attitudes about people with disabilities. The KOTB performances replace myths and stereotypes by focusing on what individuals can do rather than what they can't do. KOTB performs for schools, recreation programs, clubs, day care centres, or special events. Call (306) 955-3344.

The John Dolan/SACL Collection

The John Dolan Resource Centre was a library specializing in information about a wide range of issues related to people who have intellectual disabilities. In 2008, a large part of this collection was donated to the Stewart Resources Centre (SRC) at the Saskatchewan Teachers' Federation (STF), which con-



tinues to make this unique collection available to parents and professionals. Materials continue to be added to the collection.

The STF's website provides the following direction on how to access the material of the John Dolan/SACL Collection.

Contact the Stewart Resources Centre (SRC) at the Saskatchewan Teachers' Federation (STF) in Saskatoon at 373-1660, ext. 6323, with the name(s) of the item(s) you would like to borrow or with a topic for which you would like to find resources. Most items have a four-week lending period.

- *If you would prefer to search the SRC catalogue yourself, you may do so by:*
 - *Visiting the STF website at **www.stf.sk.ca***
 - *Choosing the link for the Stewart Resources Centre*
 - *Clicking on the option for the Online Catalogue*
 - *Clicking on the link in the first paragraph that reads **click here***
 - *Choosing the Expert tab when LibraryNet opens*
 - *Typing John Dolan in the empty field to the right of the Keyword title, and then pressing ENTER*
- *All of the items that were donated to the STF from the John Dolan Collection will appear in lists of 10 items at a time. You may click on individual titles to see more details, such as kit contents, book authors, and whether a particular item is in the library or out on loan.*
- *We will mail all books and large audiovisual kits with multiple videos/DVDs to you free of charge. We will include a postage-paid return label for you to use to mail the items back to us. You will need to pay the return postage to return single videos, however, or single videos with an accompanying guide.*
- *Remember that only a portion of the John Dolan/SACL Collection was donated to the SRC. Some items may not be available, but often we can suggest a suitable substitute.*

Dialect Magazine

The SACL publishes an award-winning magazine called *Dialect*. It has stories about individuals and families, news, innovative strategies, training and conferences, information, resources, and updates on what is happening around the world. It can be ordered from the SACL office or read on our website.

SACL Publications

The SACL publishes books on many different topics that parents may find helpful. Just call the office. Below is a list of our current publications:

- *Inclusion is More than 9 to 3 (video)*
- *The Road Map to the Future: A Financial Planning Guide for Families of People with Disabilities (limited copies)*
- *A Parent's Guide to Inclusive Education*
- *Life Landscapes: Parents talk about raising children with disabilities*
- *Life Landscapes: Saskatchewan Advocate stories of success*
- *Life Landscapes: Siblings share their experiences of living with brothers and sisters with disabilities*
- *The Right Stuff: A Plain Language Book About Human Rights (currently being updated)*
- *School to Life Transition Handbook: Five steps to successful planning (book can be downloaded at: <https://www.sacl.org/support.php?p=handbooks>)*

ORGANIZATIONS YOU NEED TO KNOW ABOUT

Throughout this handbook, there are references to two organizations that will be important to you as the parent of a child with an intellectual disability: Community Living Service Delivery (CLSD) of the Ministry of Social Services and the Saskatchewan Association of Rehabilitation Centres (SARC). It is also important to know about People First of Saskatchewan, a self-advocacy organization whose members are people who have been labelled as

having an intellectual disability. Here is a quick run-down about who these organizations are and what they do. Contact information is in the resource section at the end of the book.

Community Living Service Delivery (CLSD)

Community Living Service Delivery (CLSD) is part of the Ministry of Social Services' Income Assistance and Disability Services Division. Community Living was formed to help people with intellectual disabilities and their families access services. CLSD Community Service Workers do not deliver programs themselves, but fund and facilitate programs. They also fund and regulate a system of social, residential, and vocational organizations. The CLSD Community Service Workers work with families directly as case managers and program development consultants.

The main objective of Community Living Service Delivery is to ensure physical, emotional, and social needs are met and that people with intellectual disabilities live and function as independently as possible within their own communities.

The services that CLSD offers include case management; program development; individual support, counselling and crisis intervention; assessment of individual and family needs; planning; family support services, such as respite planning and funding, information, and referrals; development, licensing, and support of Approved Private-Service Homes (APSH); and working together with service providers to ensure individuals' needs are being met.³

You can learn more by going to <http://www.socialservices.gov.sk.ca/community-living/>. Other contact information is listed at the end of the handbook.

The Saskatchewan Association of Rehabilitation Centres

The SARC website states:

Established in 1968, the Saskatchewan Association of Rehabilitation Centres (SARC) is a non-profit association representing community-based organizations that provide residential, developmental, and employment supports/services to thousands of individuals with disabilities. SARC Members are located in every corner of this province and employ more than 2,000 people. SARC provides a variety of supports to its Members so that they can provide a quality service to persons with disabilities.

VISION

Persons with disabilities enjoying full citizenship.

MISSION

To provide vision, leadership, and support to agencies through advocacy, education, and provision and development of employment opportunities.

VALUES

SARC believes in respect, honesty, and integrity at all levels of the operation.

MEMBERS/BOARD STATEMENT

- *Being accountable to its members and stakeholders*
- *Functioning in a framework of co-operation and teamwork*
- *Conducting all affairs with respect, honesty, and integrity*
- *Empowering individuals with disabilities to achieve full citizenship*

SARC member agencies offer services to individuals in a variety of areas, including developmental activities, life skills, work experience programs, residential services (group homes and supported independent living), and supported employment to enable people to work in their own communities. Also, if you live in Saskatchewan, you have probably heard of SARCAN Recycling. SARCAN is the business arm of SARC, dedicated to employing people with disabilities.

As your child becomes an adult, services from SARC member agencies may become an option. There is a comprehensive list of member agencies on the SARC website. To learn more about the organization, the work it does, and the availability of services in your area of the province, you can go online to <http://www.sarcsarcan.ca/> or call them at (306) 933-0616.

People First of Saskatchewan

The self-advocacy movement developed when people with intellectual disabilities began to demand better lives for themselves. As with every other marginalized group, the time came for them to begin telling their own stories. Instead of having their parents advocate for them, they became their own advocates. Parents and advocates need to stay informed about the self-advocacy movement and what self-advocates are saying. When your child becomes an adult, she may want to become active in a local advocacy group, and begin speaking out on behalf of people with intellectual disabilities.

People First is an international movement that has been crucial in lobbying for rights and services for people with intellectual disabilities. Saskatchewan People First developed in the 1980s with the message that people with intellectual disabilities must be treated as **people first** and foremost, not as second-class citizens. There are local People First chapters around Saskatchewan. For more information about self-advocacy, check the People First website at <http://www.peoplefirstofcanada.ca/> or the Community Inclusion Project website at www.communityinclusion.ca.

The main goals of People First of Canada are to

- promote equality for all people who have been labelled,
- speak for ourselves and make our own decisions, and
- teach the community about our movement and our issues.

People First exists to

- support people who have been labelled to speak for themselves and to help each other, and
- help make sure that what people who have been labelled have to say is heard.

Some of the things that People First does is to

- protect the voice of the people,
- act on what people say,
- identify issues about which people can speak,
- bring people together so they can help each other,
- support members helping each other,
- create opportunities and events for people to speak up and be heard,
- provide encouragement and models for action, and develop information about issues and action.

People First of Canada must be an organization directed and controlled by people who have been labelled.



Chapter 1: Respite

When you have a child with an intellectual disability, you may not remember what it means to rest. You use every bit of your energy to make sure that he is happy and he has what he needs. It would be wonderful if someone could just step in for a few hours – or a whole day – to give you a break away from the house or to get a good night's sleep. It would make all the difference in the world. The respite program can do this.

Respite means a short time of rest or relief. It could be provided by a family member, a paid worker, or a friend. It must be someone you trust. Good respite is a dream for most parents, but a reality for only a few. This section will let you know about respite funding, policy and legislation, registries, summer and holiday programs, and innovative options.

RESPITE FUNDING

Parents refer to respite funding as “the best kept secret in Saskatchewan.” Many families, especially those with young children, do not know it is

available. **We need to spread the word.** Currently, there is funding available to provide some respite for families who have a child who meets certain criteria. The funding comes from Community Living Service Delivery Division of the Saskatchewan Ministry of Social Services. One of the jobs of Social Services is to assist people with intellectual disabilities and their families.

As described in the Respite Program Manual used by CLSD:

Respite provides parents and guardians of children with intellectual disabilities with a break from the daily responsibility of caregiving. It is a vital need for families as they respond to, what is for many children with disabilities, intense and complex care needs. The desired outcome of respite is to contribute to the rejuvenation of physical, emotional, and spiritual health of the caregiver. The nature and form of respite can vary from family to family in pursuit of this desired outcome; however, for the majority of families, respite is achieved by accessing alternative or additional supervision.



As a family support, respite has been shown to

- *maintain the health and well-being of the family and individual with a disability,*
- *provide emotional relief to parents,*
- *improve family functioning,*
- *avoid early out-of-home placement, and*
- *reduce the likelihood of later more costly services.⁴*

Do We Need Respite? A Parent's Experience

In the beginning my husband and I felt as though we *had* to be solely responsible for our child because **we** made the decision to have him. Applying for respite dollars seemed to us to mean that we were failing as parents and that we should be able to do it all on our own just as any other family. Perhaps we were too proud to accept any financial help from the government. After much thought, however, we came to our senses. What was most important to us was to have a healthy family unit. We did not realize the impact of having a child with disabilities. We were accumulating stress. Perhaps it was only a matter of time before we would begin to see the signs of a deteriorating marriage. We immediately began to see the value in taking time away from our son that we were so reluctant to do from birth. The burden that we were unwilling to admit to was lifted each occasion we spent time on ourselves and our marriage. An evening at the movies or coffee at the neighbours' house was all it took.

Many parents are thrilled when they first hear about the respite program. Don't get too excited yet! The money that you get is a subsidy. This means that it is not intended to cover the full cost of all the respite you may need. The amount of the subsidy is based on the support your child needs. In addition, the program is income tested. That is, the amount of subsidy you receive is determined by your family's income and does not take into account a number of other expenses you will have because your child has an intellectual disability. In short, the program will help you pay for respite but you may find it is not enough.

Once you are accepted into the program, your respite benefit will be paid monthly.

Parents should also know that the home care services of your local health authority are another good way to access respite. See Chapter 5 on the medical system.

How do I get respite funding?

The respite program is administered through Community Living Service Delivery (CLSD), Ministry of Social Services, and is available to the families and guardians of individuals who meet the eligibility requirements for their services. If your child is not on their caseload, you will need to apply for services. The local numbers are listed at the end of the handbook.

When you call, a CLSD community service worker will explain the respite program and send you an application form. The following topics are covered in the application process:

- your child's needs
- your family's ability to provide support
- support available from your community
- funding available
- your respite needs

Most importantly, they will need 'proof' that your child has an intellectual disability. While the process of moving to a needs-based system has begun, CLSD uses the criteria of an IQ level as the basis for eligibility for their services. (To qualify, a person must have an IQ score of 70, plus or minus five, or less). So make sure you bring the relevant papers and reports with you, such as psychometric tests. CLSD also incorporates a needs test, especially for children who are too young for an IQ test.

When you apply for respite services you will be asked to complete a respite application form. The form will ask for basic information, including the name of your child, your community service worker with CLSD, your name and your marital status, etc.

Tips for Talking to a CLSD Community Service Worker

Parents and respite coordinators have some tips for you when you are going to talk to a CLSD community service worker.

1. Take someone with you (another parent, an advocate, a respite coordinator) for support and to help you recall what was discussed.
2. Figure out what you want before you go. (What would help? One day off a week, a vacation, a weekend off?)
3. Ask about respite options and what you can do with your funding.
4. Ask the CLSD community service worker to go with you to see a respite space or resource home.
5. If you are not comfortable going to his/her office, ask the CLSD community service worker to come to your home and visit there. They may get a better sense of what your needs are.

When asked what advice they would give to parents, some CLSD community service workers said, "Please don't think of CLSD the same way you think of child protection. We really are here to work co-operatively with you, not to judge your family situation or parenting skills."

In addition, when you sign the form you agree to the following:

Parent(s) Responsibilities and Consents:

I/we agree to:

1. Report any change in circumstances that may affect my/our eligibility for the respite benefit.
2. Direct (use) the respite benefit for the payment of caregivers who provide alternate or additional supervision and care for my child(ren) with an intellectual disability.
3. Not pay myself/ourselves with this funding.
4. Not use the benefit for the payment of employment-related child care expenses.

5. Consent to initial and ongoing assessments as required for benefit determination.
6. Participate in an annual meeting with the Community Living Service Delivery worker to review my/our respite plan and how I/we have used the benefit over the past year.

You also consent to "Authorize the Canada Revenue Agency to release information from my/our income tax returns and other required taxpayer information, if applicable, to the Community Living Service Delivery."

Also, if it has not happened already, you are required to take part in the Daily Living Support Assessment (DLSA), which is intended to determine what help your child needs on a daily basis. You will be required to have a Family Impact of Disability Assessment (FIDA) done. Based on these, CLSD decides how much your subsidy will be per day of respite. You will be informed by mail of their decision.

If you are not able to get the support you need through the respite program, you may want to consider the Cognitive Disability Strategy (CDS). You can learn more about CDS in Chapter 8.



How can I use respite funding?

At some point, the community service worker will explain the basic rules. Here is a brief explanation of the rules from the policy guidelines:

- You are in charge of finding and paying a respite provider.
- You can use the money for a designated respite space in a group home or resource home.
- If you are a foster parent or an approved private home operator you do not qualify for respite funding.
- You are not supposed to use respite funding for child care while you are at work.

RESPITE LEGISLATION

Legislation guides what the government departments do. The *Child and Family Services Act* is the legislation that gives CLSD its mandate to assist parents of children with intellectual disabilities. There are sections of the *Child and Family Services Act* that allow the Ministry to give financial assistance to parents. For adult sons and daughters with intellectual

disabilities (ages 16 and older), the *Saskatchewan Rehabilitation Regulations* give CLSD the mandate to give support to families through designated respite spaces. Below are the important sections of these two documents and a brief explanation.

The Child and Family Services Act⁵

The *Child and Family Services Act* provides the broad legal guidelines for all of the government services for children, including the services provided through the Community Living Service Delivery (CLSD). The *Child and Family Services Act* aims

“to promote the well-being of children in need of protection by offering, wherever appropriate, services that are designed to maintain, support and preserve the family in the least disruptive manner.”⁶

The important piece for families of children with disabilities is Section 5 (b).⁷ According to this section, support can be provided to a parent or child when those services are essential to the care of the child. Parents know what they need. Respite is only the beginning.



With the current respite program, CLSD reports they no longer use Section 5 to fund support. However, to fully support the well-being of children with intellectual disabilities and their families, the Ministry of Social Services could offer more substantial and individualized support to parents. Section 5 (b) allows them to do whatever is necessary to keep the child in the family home and support his well-being.

When parents feel they can no longer take care of their child, Section 9 of the *Child and Family Services Act* allows Social Services to temporar-

ily place the child in care. If the child is placed in foster care, the parent(s) remains the child's guardian (s.9-2) unless there are unusual circumstances. The child should not spend more than two years in a row in foster care (s.9-5) but the agreement can be renewed (s.9-4). If the child is 12 or older, the social worker may ask his opinion and take that into consideration (s.9-6). It is suggested that the parents could seek third-party advice if they are considering placing their child in care (s.9-3). The SACL advocates can help you work your way through the system and help you keep your child at home.

Family Services

Sec 5. Subject to this Act and the regulations, the minister may:

- (a) establish, operate, and maintain family services;
- (b) provide family services to or for the benefit of a parent or a child where the minister considers them essential to enable the parent to care for the child;**
- (c) enter into agreements with any person providing family services by which the minister is obliged to make payments for the provision of family services pursuant to this section.

A Section 9 agreement is voluntary. It can give parents flexible, individualized options. We believe that this is a tool that can be a proactive way to keep a family together and it does not need to be considered a negative step.

Agreements for Residential Services

- Sec 9(1)** Subject to subsection 68(2), a parent who:
- (a) through special circumstances is unable to care for his or her child; or
 - (b) because of the special needs of his or her child is unable to provide the services required by the child; may enter into an agreement with the director for a term not exceeding one year for the purpose of providing residential services for the child.

The Saskatchewan Rehabilitation (Mentally Retarded Persons) Regulations⁸

Please note that the title of these regulations still includes a label that is derogatory for people with intellectual disabilities. Out of respect for adults with intellectual disabilities using CLSD's services, we want it removed. However, there are many sections in these regulations that will become relevant as your child becomes an adult and applies for social assistance. The section that applies to respite is Section 4. It does not specify that the minister can give respite funding to parents, but it allows the minister to supply "any item of assistance he deems advisable."⁹ Parents cannot receive respite funding for adult children living at home but they can use, at a cost, a resource home or respite spaces in a group home.

You can see the regulation for yourself at <http://www.qp.gov.sk.ca/documents/English/Regulations/Regulations/SR265-72.pdf>.

FINDING A RESPITE PROVIDER AND RESPITE REGISTRIES

It is tough when parents need to find their own respite providers. When you need a rest, the last thing you want is to worry about whether your child is safe. How do you find the right person?

Finding a Respite Provider

If you have funding from CLSD, but no respite worker, start by thinking how you will advertise. Think of your child's needs and then think of some of the people who may be good at meeting those 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 they will take notice. You can advertise in the local paper

or with local work placement agencies that include human service workers.

The Saskatoon and Regina Associations for Community Living have a respite coordinator who can assist you in your search. One resource they have that will help you is a list of good questions to ask when you are interviewing a potential caregiver.

I like that idea!

Elmwood Residential Services saw a dilemma and created its own solution. Parents were asking for respite that provided a camp-like atmosphere with recreation options. A new respite home for Saskatoon was needed, a place for children and adults with disabilities to take a break. With some innovative renovations, Elmwood created two respite homes in one, with a shared kitchen but separate living spaces for children and adults. They also recognized the need for a person with a disability to have their privacy respected, so they created a respite home with single-occupancy bedrooms. Elmwood is providing a wheelchair bus to this home to allow respite users to enjoy recreational opportunities within the community. The result of their efforts is a fun environment that parents can trust.

Expectations and Things to Think About

When you are interviewing and hiring a caregiver for respite, be sure to discuss expectations. First of all, 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 and bedtime, therapies, recreation, and guidelines for outings.

Before you leave, make sure that the respite caregiver has contact numbers, the doctor's and hospital's phone number, the child's Saskatchewan health card number, and information on allergies, medica-

tions, seizures, and anything else applicable to your child. Be sure to let your caregiver know how your child communicates.

Don't forget to let the caregiver know ahead of time some of the things to expect in terms of challenging behaviours, and what to do about them. Challenging behaviours can sometimes make it hard to find, or keep, respite workers. The better prepared that your caregiver is and the more strategies that are available to work with challenging behaviours, the greater the chance your respite worker will respect your child and also provide respite again.

When a parent cannot find a respite provider, the respite coordinators with the Saskatoon and Regina branches of the SACL try to find out what the problem is. Is there another place the parent could advertise? Does the child need very specialized care? Is the parent not able to supplement the subsidy from CLSD? Challenging behaviours and wages were mentioned as the biggest barriers to finding a respite provider. It is likely that parents will need to pay extra money for a good caregiver. One of the best ways to find and keep a good caregiver is to pay well.

Respite Registries

You may be one of the lucky families who live in Swift Current, Saskatoon, Regina, or Prince Albert where there are respite registries (contact information is at the end of this chapter). A respite registry is a list of people who have expressed an interest in being a respite provider, have completed a criminal record check, and have provided information about their availability and interests. It is up to parents to interview, hire, and train the respite provider. Respite registries provide a place to start. Saskatoon and Regina also have respite coordinators who can help a family find the right caregiver for their needs.

Respite registries have been started by parents and community workers who were frustrated with the lack of reliable caregivers. If you would like to start a respite registry in your area, here are some tips from respite coordinators:

- Talk to others who have developed registries, and use the successes and learn from the failures of others.
- Make sure that parents are involved in the whole process, from formulating questions to advertising.
- Be selective about the people on the registry. The quality of care providers will make or break the project.
- Once you have some people on your registry, hold a “meet and greet” event to allow caregivers and families to get to know each other even if only slightly. This makes everyone more comfortable and is a good starting point for families.
- Create an information package for parents and have it available around the community.
- Hold an information night to explain respite funding to new parents who are interested.
- Advertise in key spots where those interested in providing care are likely to see it (e.g. hospital, doctor’s office, community centre, schools, schools’ or educational assistants’ newsletters, universities and colleges).
- If you are having trouble keeping a respite registry updated, try approaching the health region, CLSD, and members of the community to fund a respite coordinator.



Respite Spaces

Regina Residential Resource Centre (RRRC) and Elmwood Residences Inc. both have respite homes. Respite spaces, for overnight or short-term stays, are sometimes available in group homes. If you are having difficulty finding a respite space, talk to your CLSD community service worker who should have a list of potential respite spaces in your area, or may be able to find a space outside your area.

SUMMER AND HOLIDAY RESPITE PROGRAMS

Holidays. Suddenly your child is out of school and you have to be there 24 hours a day without any rest. Or, if you are working, you need to figure out some kind of reliable child care. Most parents would love to have the opportunity to enroll their child in summer and holiday programs to keep them occupied and happy during school breaks. But are there any opportunities like this for children with intellectual disabilities? The answer for many communities is yes.

Regular Community Programs and Camps

When asked about summer activities, many parents said that they enrolled their children with disabilities in regular summer programs. Sometimes the only reason that children with disabilities have not been included in regular programs is because it just hasn’t been tried. One parent said that no one has ever questioned her child going into regular programs. Another parent’s child, who has a gastrointestinal tube, has also been accommodated in a regular summer program. Libraries, schools, community centres, the health regions, the YMCA, and recreational centres put on a variety of programs that you can look into.

Of course, not all parents have good experiences trying to get their child into regular community programs. If you meet with resistance, it can’t hurt to ask why. The people running the program may need

to know specifically what support your child needs and that their program can accommodate those needs. Alternatively, they may need prompting from a supervisor or additional staffing. You may need to offer some training. Give some examples of regular activities that your child participates in at home or at school. If they know that your child is included in regular activities, they may be more open to enrollment in their program.

Regular summer camps are another possibility for children with intellectual disabilities. Many camps can accommodate different needs. Sometimes a child with an intellectual disability might need a little more one-on-one time with a counsellor than other children. If the camp or summer program is well staffed, that should not be difficult. If your child needs more support than these programs can offer, ask about using some respite money to send a support worker with your child to the summer program or camp. Parents have used respite money for activities like this in the past. There is also “Camp Companion” funding that has been offered through the Regina and District Association for Community Living and the Community Living Association Saskatoon, Inc. For more information about choosing a camp, see Chapter 7 on Recreation.

Organizations that support people with particular disabilities may also have funding available to send your child to camp or summer programs. If your child has an identifiable intellectual disability, check with the corresponding provincial organization to see what your options are.

The SACL also supplies grants for summer programs. If people in your community or members from your local ACL have a good idea for an inclusive summer program, give the SACL a call.

Homegrown, Parent-led, Holiday Respite Programs

Some parents have done the really hard work of developing their own solutions for summer and holiday programs. Setting up a respite program takes

time, money, staff, and volunteers. Giving up the very little time you have is a sacrifice. It takes a passionate, determined person to set up a respite program. Most parents probably got involved through sheer frustration with the lack of services to address their child’s needs. When you are getting started, go to CLSD first. Let them know what you want to do and build a partnership. Parents have received funding for summer and holiday respite programs from CLSD in the past. Your local CLSD social worker may be able to help you in many ways. Also, try to hold a community meeting. The more community people are involved, the more community support you will have to run your program.

I like that idea!

The Prince Albert Association for Community Living developed a program where youth with disabilities could access existing community activities during the February school break. This program was person centred and was directed by the youth themselves. Using family-trained support workers, “Winter Break” gave youth the opportunity to participate in regular activities with their peers. Parents also benefited from a week of respite.

Locating Funding for Projects

You may have a great idea for a respite space, an after-school care program or other programs that could benefit your child. And you may have determination, community support, and volunteers. But there is still one thing you need – a good source of funding.

How do you find the money? The SACL fundraising coordinator offers this advice: if you are starting any project that you want funded, make sure you know exactly what you want funding for. Think about who will benefit from the respite program, how much money you need, the goals you want to accomplish, standards, activities, and how you will advertise for staff and participants.

There are LOTS of grants and subsidies out there. The most important thing you have to do to get that money is to know exactly what you want to do with the funding. Figuring out what type of program you want, who it will benefit, why it is necessary, who the stakeholders will be, how the program will be managed, and what the philosophy and goals will be are important details in making a coherent plan. Once you have a plan, look for a grant with guidelines that match your project. Then you need to write the funding proposal. If you have never done it before, the idea of writing a proposal may be scary. Here are some tips and facts about writing a funding proposal in order to receive a grant:

- When you find a foundation or business that gives out grants, visit their company website and read their mission statement.
- See if they have a list of other projects they have funded. This will help you figure out if your project fits.
- Do your research. Find out what their guidelines are and make sure your project falls within those guidelines.
- Be clear and concise.
- Always focus on the outcome of the project and who it will benefit.
- Have an outcome that can be measured. They will want to know that you can give them numbers at the end of the year about how well the project has worked.
- Some grant proposals will specifically ask where you have already sought funding and if you have been approved.
- Always cover the basics: who, what, why, where, when, and how.

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 are often very good at writing proposals.

The next question is: Where do you look for funding? The answers include the following:

- Contact the SACL provincial office. We may have grant money available, or we may know of new sources of funding that you can apply for.
- Ask your local branch of the SACL if it has grant money available.
- Approach the Government of Saskatchewan (Ministries of Education, Health, or Social Services). If they do not have funding for projects, they may have funding available (especially in the summer) to hire students.
- Ask your city or town council. Often they have funding available for summer programs and youth initiatives.
- Ask the local Rotary clubs and other service clubs.
- Phone the Kinsmen Foundation. They give grants for programs that assist children with disabilities.
- Look into applying for funding from other foundations. The Saskatchewan Lottery Foundation may supply a grant.
- Check on the Internet for other sources, at <http://www.charityvillage.com/>. Look under *resources* and then *funding sources* on the webpage.
- Approach businesses that operate province-wide, such as the crown corporations, large banks, credit unions, or large grocery chains.

You want the staff and volunteers for a summer/holiday respite program to be caring, competent, and enthusiastic. Here are some ideas of places to look and people to talk to:

- Regional colleges in your area that teach programs for child care or youth workers
- SIAST
- Church youth groups
- Social work students

Another thing to consider is building partnerships with other local groups who may want to start a summer program. If you can work together, you can offer a summer program that is inclusive of all children, and offers support for children with different needs.

I like that idea!

In one community where parents were struggling to find consistent, good respite, they created their own solution. They created a respite apartment. They decided that the best model to serve all families would be to rent a space and find regular respite workers to create a respite service. They did fundraising, and were shocked at the amazing response and support from the community. For these families it meant many of hours of work, but the benefit is that they are able to depend on having planned and emergency respite, with competent workers who listen and respect each child.

WHAT PARENTS REALLY WANT

The SACL has asked parents what their dreams are for respite. We were told parents need a respite program that is well-funded, easy to access, flexible, and responsive to their individual needs. They said it is best for families when children are cared for in the family home and parents have the financial support they need. Respite is a truly proactive and preventative support that we can offer families – and because of this, it is cost effective. A good respite program is:

- driven by the individual needs identified by families – not by a diagnosis
- supportive of universal access regardless of where you live
- responsive and unique to each family
- flexible
- available regardless of age
- facilitated, not dictated

It is important to let the government know what your needs are. If respite is an area of concern, you may not have the energy or time to get involved in a formal group to lobby for change. But maybe you can send an e-mail to your MLA, or a letter explaining how respite will make your family stronger. It is possible to have your voice heard. If you do write your MLA, you may wish to copy the SACL and other organizations you think need to know and may be able to help. You can e-mail us at sacl@sacl.org. Our mailing address is listed in the back of the book.

RESPIRE RESOURCES

Community Living Service Delivery

See complete list of CLSD offices at back of book

Elmwood Respite Home

Phone: (306) 374-5151

Prince Albert Respite Registry

Phone: (306) 922-3230

Fax: (306) 922-3457

Regina Respite Registry

Phone: (306) 790-5680

Regina Residential Resource Centre

Phone: (306) 352-3223

Saskatoon Respite Registry

Phone: (306) 652-9111

Swift Current Respite Registry

Phone: (306) 778-4619

Help us keep up to date. If there are any changes or additions we need to make to *Navigating the System*, please let us know. Phone (306) 955-3344 or e-mail sacl@sacl.org.

Chapter 2: Early Childhood Intervention, Preschool Programs, and Day Care

For children with intellectual disabilities and their families, early intervention and preschool programs are essential. These programs help parents and children develop the skills they need in order to get the most out of learning opportunities. Parents who have witnessed their child's growth through early intervention or preschool programs know how powerful that experience was as their child began kindergarten.

There are some intervention services that extend beyond early childhood. One of these services is sometimes recommended through school personnel or health professionals. This could be a great opportunity and help your child develop important skills. However, ongoing intervention is often only recommended for children who have challenging behaviours.

If someone recommends a specific intervention, make sure to ask questions about the program, and its goals and philosophy before you sign up your

child. Ask other parents who have used the program how it benefited their child.

Be aware that some program staff may still believe in behaviour modification techniques that punish the child in order to stop "inappropriate" behaviours. This ignores what the child, particularly a non-verbal child, is trying to communicate through that behaviour. They may be trying to change something that is simply part of who your child is. Your child deserves to learn and grow in a respectful environment.

THE SASKATCHEWAN EARLY CHILDHOOD INTERVENTION PROGRAM (ECIP)

Families who receive early intervention support will work with a trained early interventionist who will



help them identify and implement goals and can inform them about the services available for their child. The parents we talked to for this handbook believe that the Saskatchewan Early Childhood Intervention Program (ECIP) gave their child a head start and connected their families with valuable resources. It also helped parents prepare to advocate within the systems that provide services for their children.

Funded through the Ministry of Education, the Saskatchewan Early Childhood Intervention Program offers support to families with young children (birth to school age) who have a disability or who are at risk of having a developmental delay. ECIP was started as a way to offer home-based support to preschool children and their families. Today, ECIP offers free, home-based services to families anywhere in the province. If you are a parent of a child with an intellectual disability, living in a rural area, this is good news. It is one less appointment you will need to travel for.

ECIP is family-centred, making sure that parents are included in all aspects of their child's program, from birth until school age. There are three ways that ECIP workers provide assistance to families: child development, parental support, and community support.

Child development is a key part of what ECIP does. Each child has a fun, unique program that will encourage development and learning. Your family and the ECIP worker look at your child's abilities and decide what skills to work on. Together you set developmental goals and plan strategies to help your child succeed. There are two home-based visits per month in order to work on the goals and monitor progress. Parents are involved in setting the time when the home-based visits will take place. Between ECIP sessions you work with your child on specific tasks.

ECIP offers you support as you begin the journey of advocating for your child. You can learn more about your child's disability, plan the program, and

learn how to foster development and learning. ECIP workers use their experience with children with disabilities to enhance the natural skills that each parent has. There are educational and networking opportunities offered through the program. ECIP workers will also accompany (or even drive) your family to appointments and meetings if you request advocacy and support. ECIP provides resources and educational toys through lending libraries. As a family-friendly program, ECIP works to adapt to each family's needs, resources, cultural values, schedules, and responsibilities.

The ECIP worker will refer you to other services and help develop a team of service providers to assist in maximizing your child's development. Also, when your child is going through a transition, for example starting in a centre-based program, the worker can help you plan the process and make sure important information is shared so that the transition will work smoothly.

Building community support is another way that ECIP serves families. Parents often say that ECIP was their first introduction to parent and disability groups. ECIP workers are advocates in the communities they work in, bringing awareness about inclusion and gaps in services for children with disabilities. Many workers have successfully worked to develop better early childhood services, especially in rural areas. They have increased public access to disability-related materials through the toy-lending library and offered training sessions to early childhood workers.

ECIP can help you feel better prepared to face the meetings and obstacles ahead. Most importantly, it gives your child a better chance of succeeding in all the challenges that life will bring. Program services can be obtained by direct referral, contacting the local ECIP office yourself, or through a referral by a doctor, nurse, psychologist, therapist, social worker, or community agency.

However, there is a waiting list for many ECIPs. This has been a barrier to many parents who have tried to

get early intervention services for their child. Don't let the waiting list discourage you: keep advocating! For the many families who have accessed ECIP services, the success of the program is obvious. Their children are better prepared for school and for everything that life throws at them. As advocates, we need to take the success stories to politicians to make sure this program is well funded and universal. No child should have to wait for early intervention services.

KIDSFIRST

KidsFirst is an early intervention program that is available in targeted communities. (KidsFirst sites are listed at the end of this chapter.) While KidsFirst does not specialize in early intervention for children with disabilities, it offers home visiting, early-learning opportunities, and referrals to various supports in your community.

KidsFirst is a voluntary program that helps vulnerable families to become the best parents they can be and to have the healthiest children possible. The program enhances knowledge, provides support, and builds on family strengths.

The KidsFirst program is not designed to replace existing services, but to enhance existing programs in the community.

KidsFirst families receive:

- *Support from a home visitor who provides assistance regarding child development, parenting and connecting to the community;*
- *Help to access services such as childcare and parent support groups;*
- *Early learning opportunities for children; and*
- *Help regarding literacy, nutrition, transportation and specialized counselling services.*¹⁰

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-centred program.¹¹ Like early intervention, the goal is to focus on all aspects of development and offer any specialized supports that are necessary. There is a yearly directory of pre-kindergarten programs in Saskatchewan on the following website: <http://www.education.gov.sk.ca/adx/asp/adxGetMedia.aspx?DocID=441,213,136,107,81,1,Documents&MediaID=8270&Filename=2008-09+PreK+Directory.pdf>.

You can call your school division to find out what is available for preschool children with disabilities. If you have an ECIP worker, she will help your family with this transition into a pre-kindergarten, preschool, or kindergarten setting. If the school division does not have a program that fits for your family, the funding it receives can be used to provide an aide and tuition in a community preschool. Before the school division funds anything, they may request your child be tested in order to determine what his needs are. Since this is a first "assessment" in the school system, make sure that any conclusions focus on strengths as well as needs. The labels your child gets as a result of assessments will follow him through school, so it is important that they always show a balanced picture of the whole child. Remember that Pre-K documents are now required to be placed in your child's official file, known as a cum file or cumulative file, under a Ministry of Education assigned student identification number.

Regular Preschool and Day Care Programs

You may think your child cannot go to a regular preschool or a day care program because of an intellectual disability. We have good news! Children with all types of disabilities have been successfully included in regular preschool and day care programs. We believe that every child has the right to participate in

all the normal activities of childhood. Your child has a right to learn and socialize with other children of the same age.

Your child already lives in a home with non-disabled people. She shares the grocery store, the swimming pool, the park, and the hospital with non-disabled people. She is not defined by her intellectual disability.

Some people may suggest that it is better socially for your child to be around “others like him.” Your child already lives in a home with people without intellectual disabilities. She shares the grocery store, the swimming pool, the park, and the hospital with non-disabled people. She is not defined by her intellectual disability. Many parents have broken down prejudices as they enrolled their preschool children with disabilities in regular programs and activities. This opens the door, and helps people see that chil-

dren with intellectual disabilities have gifts just like every other child. The reality is, a child is never too “challenged” to be included, accepted, and respected and to learn new things alongside non-disabled peers. If non-disabled children play and learn alongside a child with an intellectual disability starting in preschool, as adults they will appreciate the gifts that people with disabilities have.

Preschool

Preschool, nursery school, and playschool all refer to daytime programs that allow children to learn while they play. By playing with teachers and other children, a child may be exposed to learning the alphabet and numbers, following rules, and sharing toys. Above all, children have fun at preschool. A few hours at preschool may be just the transition that your child needs before beginning kindergarten.



Included from the Beginning

We started planning right after our son's second birthday by initiating discussions with the school board and the Ministry of Education. Our son set a precedent when he attended the same nursery school as his siblings, a community co-operative with a child-centred, play-centred philosophy, rather than attending the special preschool setting provided in Regina at that time. The school board paid his tuition and provided a grant for the salary of an assistant. We know of at least two other children with intellectual disabilities who have benefited since.

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 past experiences with children with disabilities. If they have had no experience working with a child with an intellectual disability, you can help them understand the benefits of inclusion for your child and for the other children in the preschool. Ask about the rules and expectations in the preschool. If any of the preschool's rules and expectations need to be adapted for your child, help the staff create a respectful support plan. The more information and support people have when working with your child, the less likely it is that they will react inappropriately if something goes wrong.

Not every preschool director will be open and accepting of your child right away and you may encounter obstacles to enrollment. Don't be discouraged. Keep advocating. The director's hesitancy could be due to under-funding or the feeling there is not have enough staff to support your child. It helps to have funding in place to make sure that your child gets the extra support necessary. If an assistant is required, the funding can come from your local school division (which they get from the Ministry of Education). Below is a short explanation of the Ministry of Education's policies that relate to funding for preschool and early intervention.

- *Transportation for Students with Disabilities* (4.7): The board of education will pay for transportation for students with disabilities to participate in educational programs. There is no additional cost to parents.
- *Prevention and Early Intervention* (5.1): The school division will provide prevention and early intervention programs to promote an inclusive and challenging environment and the success of the student.
- *Early Childhood Education for Children with Disabilities* (5.3): Preschool programs will be provided for children with disabilities either through the school or a community-based program.

You can read the actual policies in the **Children's Services Policy Framework** at <http://www.education.gov.sk.ca/adx/asp/adxGetMedia.aspx?DocID=190,211,107,81,1,Documents&MediaID=1371&Filename=CS-PolicyFramework.pdf>.

If you have any questions, talk to your school division. It is good to talk to them ahead of time since they will be a big part of your child's education from kindergarten on.

DAY CARE

You need to get back to work, but if your child has an intellectual disability, it may be even harder than usual to find a day care that will meet your family's needs. Some parents find a good fit in a private caregiver and do not use licensed day care. Other parents have found a licensed day care that understands inclusion and is willing to accommodate children with intellectual disabilities.

For your child, day care can be a wonderful opportunity to make friends and learn new skills from peers. As part of a child's early intervention plan, some parents enroll their children with intellectual disabilities part-time in day care because of the benefits of being with the other children. Below are some questions that you might have about day care and your child with an intellectual disability.

What would an inclusive program look like?

To be included and happy in day care or preschool, your child needs what every other child needs – acceptance into the group, support, individual attention, respect for her learning style, and someone who will truly listen. She may need extra help, but she will only be happy when she is accepted for who she is. She does not need labels, separate activities, or sympathy. She needs to have the same opportunities that other children have to explore, learn, and make friends in a safe environment.

Here are some tips on what an inclusive day care or preschool program would look like:

- All children are seen as children first, and are accepted and valued for who they are.
- Behaviour is seen as a form of communication and efforts are focused on listening and adapting the environment to meet the child's needs.
- Parents are welcomed as partners and are taken seriously. Communication between the program staff and parents is open, honest, and regular.
- Children are encouraged and supported to build friendships.
- The director and program staff has a positive attitude toward inclusion. Successful inclusion will happen when they are committed to making it work.¹²
- Funding is appropriate, sufficient, and stable in order to develop a well-designed curriculum and an accessible environment.¹³
- Training, resources, and support are available to the staff.¹⁴
- Professionals from the community are involved in developing every child's potential.¹⁵

A few resources on inclusion and day care are available on loan from the John Dolan/SACL Collection at the Stewart Resource Centre at the STF offices in Saskatoon. Phone (306) 373-1660 or go online at <https://www.stf.sk.ca/portal.jsp?Sy3uQUnbK9L2RmSZs02CjVy0w7ZkI/ks6g2u00gzAtsk=F>. Resources can be sent anywhere in the province.

The Child Care Act

The *Child Care Act*, the legislation that governs the provision of child care, including day care, defines a child as:

- 2(a) "child" means a person under the age of:
- (i) 15 years if, in the opinion of the minister, the person has special needs;
 - (ii) 13 years in any case other than that described in subclause (i)

This means that children who have a disability can be in licensed day care and are eligible to receive child care subsidies until they reach their 15th birthday.

Be aware that the Ministries of Education and Social Services share responsibility for the *Child Care Act* and that this may create some confusion for you.

How do I choose a day care that will fit my child's need?

If you have an ECIP worker, that is a good place to start. Early interventionists often help families find programs and can advise you on which ones might be best for your child. The ECIP staff may know other parents in your area who have had the same questions and struggles. If you do not have an ECIP worker, asking other parents or early childhood workers will allow you to find the best possible program for your child.

ADVICE

FROM A DAY CARE PROFESSIONAL

"When you are searching for a daycare for your child, be truthful about your child's needs, but always emphasize her strengths."

The Child Day Care program of the Ministry of Education sets minimum standards and monitors child care centres in Saskatchewan. The Ministry provides a yearly list of licensed day care centres on its website at <http://www.education.gov.sk.ca/>

Child-Care-Listings. If you want to ask which day cares are open to accepting children with disabilities, you can call a local child day care branch (contact information is at the end of the chapter). They have information about which day cares have spots specifically for children with disabilities. They also have *A Parents Guide to Choosing a Child Care Service* that offers some advice on what to look for in a day care. You can find it on their website at <http://www.education.gov.sk.ca/Default.aspx?DN=d21b9e96-b0e4-445b-9d8e-d5d7fb9f13b2>.

What if I cannot afford day care?

Day care is a huge expense that many families struggle with. The Ministry of Social Services offers a Child Care Subsidy (CCS) through the Child Care Subsidy Office. According to the Ministry's website (<http://www.socialservices.gov.sk.ca/childcare-subsidies.pdf>),

“a Child Care Subsidy is a monthly subsidy that helps Saskatchewan families meet the costs of licensed child care. Subsidies are provided directly to child care 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.”

Child care subsidies are only available for services provided in child care facilities licensed by the Early Learning and Child Care Branch of the Ministry of Education. The subsidies are available only if you use licensed child care 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. According to the Ministry of Social Services pamphlet *Child Care Subsidies*:

To be eligible for a child care subsidy, individuals must:

- *have lawful custody of a child or children under the age of 13 years who receive care in a licensed facility,*
- *be Canadian citizens or permanent residents of Canada,*
- *be residents of Saskatchewan, and*
- *have a valid reason for care.*

The *Child Care Act* applies to qualifying children who have a disability until their 15th birthday.

According to the Child Care Subsidies program description, valid reasons for care include:

- *employment or self-employment,*
- *attendance at an educational institution,*
- *looking for work,*
- *involvement in an approved pre-employment program, or*
- *special medical or social needs.*¹⁶

What happens if you are not working, but the ECIP worker said it would be beneficial for your child to attend day care? If an early childhood professional believes that your child with an intellectual disability will benefit from day care, you may qualify for a subsidy. This is good news for families that have one parent staying at home in a community where there are no early childhood services.



The subsidies are income tested, which means you will need to report your family income when applying, and your level of income will determine if you can receive a subsidy and how much you can receive. The program description says,

“Subsidy amounts are determined using a calculation that takes into account gross family income, family size, the age of a child, the location of a child care facility, and the actual fee charged. Families with incomes below the thresholds described below may qualify for maximum subsidies, but families with incomes above these thresholds may still qualify for a reduced subsidy. Families receiving income assistance through the Social Assistance Program or Transitional Employment Allowance may be eligible for subsidies sufficient to cover the entire fee.”

The levels of subsidies are even more complicated than the rules to qualify. If you are interested, we encourage you to talk to the Child Care Subsidy Office. For more information on the child day care subsidy program call 1-800-667-7155.

What if my child needs support that the day care feels it cannot provide?

If you have found a good day care, but the day care manager feels unable to support your child properly, there is a way to get the extra support your child needs. You can apply for funding through the Child Day Care Inclusion Program (Ministry of Education). For more information go online to <http://www.education.gov.sk.ca/ELCC/inclusion-program/>. To qualify for a grant, the day care must be licensed and your child must attend at least 20 hours a month. There are four grants available:

1. **Individual Inclusion Grants** to assist with the additional cost of supporting a child with diverse needs, to a maximum of \$300 per month.
2. **Enhanced Accessibility Grants** to assist with the additional cost of supporting a child with exceptionally high 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 costs of the additional supports required, to a maximum of \$1,500 per month, as determined by the referring professional, the parents, and the child care facility. To be eligible, the parent/guardian(s) of the child must be employed or enrolled in a recognized education program.

3. **Adapted Equipment Grants** to assist a child care facility with the cost of adapted or specialized equipment necessary for the inclusion of a child with diverse needs, as determined by the referring professionals, the parents, and the child care facility. The maximum is \$600 per year or, in exceptional circumstances, \$1,200 in a year.
4. **Training and Resource Grants** to assist a child care 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 child care facility. Maximum is \$100 per year or, for enhanced accessibility, \$200 in a year.¹⁷

An early childhood professional such as an ECIP worker or a child psychologist can make the referral in order to get the funding. They need to assess your child and determine that need for additional supervision, guidance, or assistance.

When your child’s needs have been identified, the day care staff, the referring professional, and a program consultant will have a meeting with you to decide what supports are needed. In the meeting the group will discuss your child’s needs and goals, the roles of each group member, ongoing communication, and the level of funding. You will need to fill out forms and the referring professional will need to supply an assessment and possibly a letter of support. The day care needs to submit an attendance report in order to get the funding each month.

For further information you can contact the Early Learning and Child Care Branch office nearest you. These are listed at the end of this chapter.

EARLY CHILDHOOD RESOURCES

Useful Websites

<http://www.circleofinclusion.org/>
<http://www.closingthegap.com/index.lasso>
<http://www.familyvillage.wisc.edu/index.htmlx>
<http://www.hanen.org>
<http://www.inclusion.com/>
<http://www.specialinkcanada.org/>

Canadian Pediatric Society

<http://www.cps.ca/>
 Phone: (613) 526-9397
 Fax: (613) 526-3332

Early Childhood Intervention Programs

<http://www.education.gov.sk.ca/ECIP>
 Ile a la Crosse (306) 833-2595
 Kindersley (306) 463-6822
 La Ronge (306) 425-6600
 Lloydminster (306) 825-5911
 Meadow Lake (306) 236-4247
 Moose Jaw (306) 694-9200
 North Battleford (306) 446-4545
 Prince Albert (306) 922-3247
 Redvers (306) 452-3730
 Regina (306) 347-5021
 Saskatoon (306) 655-1083
 Swift Current (306) 773-3600
 Tisdale (306) 873-3411
 Weyburn (306) 842-2686
 Yorkton (306) 786-6988

KidsFirst Sites

<http://www.education.gov.sk.ca/KidsFirst>
 Meadow Lake (306) 236-6441
 Moose Jaw* (306) 692-1204 or
 (306) 694-8336
 Nipawin (306) 862-6222
 North Battleford (306) 446-6012
 Northern Sask. (306) 235-5436 or
 (306) 425-8033

Prince Albert* (306) 765-6656
 Regina* (306) 766-6796
 Saskatoon* (306) 655-5399
 Yorkton (306) 783-1946 or
 (306) 783-0383

*selected neighbourhoods in these communities

Parent and Preschool Education Program, Esterhazy

Phone: (306) 745-6641
 Fax: (306) 745-6549

Saskatchewan Early Childhood Association

510 Cynthia Street
 Saskatoon, SK S7L 7K7
 Phone: (306) 975-0875
 Toll Free: 1-888-658-4408
 Fax: (306) 975-0877
 E-mail: saskcare@sasktel.net

Superintendent of Children's Services

phone numbers: see the Education Resources in the next chapter

Government of Saskatchewan

Child Day Care Regional Branches

Regional Offices

Regina (306) 787-4980
 Saskatoon (306) 933-6071
 Prince Albert (306) 953-3612
 Moose Jaw (306) 694-3644
 Weyburn (306) 848-2497
 Meadow Lake (306) 236-7692
 Swift Current (306) 778-8531
 Melfort (306) 752-6164

Help us keep up to date. If there are any changes or additions we need to make to *Navigating the System*, please let us know. Phone (306) 955-3344 or e-mail sacl@sacl.org.

Chapter 3: Education

The United Nations Convention on the Rights of Persons with Disabilities says:

States Parties recognize the right of persons with disabilities to education. With a view to realizing this right without discrimination and on the basis of equal opportunity, States Parties shall ensure an inclusive education system at all levels and lifelong learning...

From Article 24

When any child goes to school for the first time, it is a scary experience for the parents. If you have a child with an intellectual disability, there are many more fears and unanswered questions – not just in the first year, but every year of school. Will the teacher include him in everything the other kids are doing? What will her educational assistant (EA) be like? Will she even have an EA? Will they teach

him in a way that he will learn? Will other children accept and play with her? There may be many questions running through your mind.

About 50 years ago, children with intellectual disabilities were not allowed to go to school. They were sent to institutions far away from their families and were excluded from all the normal experiences of childhood. Many people in institutions were never taught to read, write, or do math, even though they were able to learn. They also missed out on all of the life lessons about relationships that children learn on the playground and in school. Through the work of committed parents, children with intellectual disabilities were brought home from institutions. These parents demanded an education for their children. Since the doors of the regular schools were closed for children with intellectual disabilities, segregated schools were built.

In Saskatchewan we have learned our lesson and moved away from segregated education. Today, most children with disabilities attend a neighbourhood school. But even in regular schools or class-



rooms, children are not always fully included. Many children remain segregated in time-out rooms, “special” resource rooms, or alone with an EA. We believe that all children have a right to an education in a classroom of children their age and in their neighbourhood school. Children who need additional supports should have an individualized plan designed to meet their educational and social needs. We believe that schools must actively involve the student’s parents and recognize their role as team members in their child’s education.

What can you do to ensure that your child is secure, accepted, engaged, learning, and happy in school? A lot. Parents have been successful in working with schools to ensure their children have a fully inclusive education. They continue to advocate within the education system for provincial and local policies that respect and promote inclusion. This chapter has the basic information you need to advocate for an inclusive education for your child. To learn



more about inclusive education and advocating in the school system, parents can receive a copy of the SACL’s book, *A Parents’ Guide to Inclusive Education*, free of charge, by calling (306) 955-3344.

The first and most important thing to remember is that your child has the right to be in a regular classroom, in your neighbourhood school, and the right to the supports needed to succeed. It is important to remember that rights are not favours. The school is not doing something extra by supporting your child; they are simply doing their job. As a parent, you have the right to be included in the decisions that are made about your child’s education. If you are left out of the decision-making process, stand up for your right to be involved. You are the expert on your child.

Inclusion is more than 9 to 3

This is a 15-minute video made by students, for students, on the topic of inclusion. It is a teaching tool to spread the message that inclusion is good for everyone. Developed by the SACL Fusion Inclusion Youth Group and the Self-Advocacy Action Group in partnership with the University of Saskatchewan, this insightful video visits the true meaning of inclusion in our schools, at work, at home, and in all our daily activities.

The video serves to dispel myths as students both with and without disabilities speak out about what true inclusion means to them. The students, friends, and family interviewed speak openly about their experiences. This video is an opportunity for educators to teach that inclusion is simple: it’s just acceptance. To order a copy, contact Media Access and Production, Room 25, Education Building, 28 Campus Drive, Saskatoon, Saskatchewan, S7N 0X1.

Phone 306-966-2500 or
e-mail Media.access@usask.ca.

EDUCATION LAWS AND POLICIES

There are laws and policies that control your child's education in Saskatchewan. These laws and policies set out guidelines for the education of students with disabilities. The law (legislation) that controls education is the *Education Act, 1995*. The Government also establishes regulations and policies that direct how the *Education Act* will be made to work. Regulations and policy do not have the same force as laws; they are guidelines that the school divisions are expected to follow. The Ministry of Education is the government ministry that develops education policy and guidelines.

The *Saskatchewan Human Rights Code* is also important because it protects your child's right to education.

The Ministry of Education supports the vision of inclusive education in its policies and other documents. That vision has not transferred to every school in Saskatchewan, but we believe it will happen. If you have trouble finding any of these documents, phone the Student Support Services of the Ministry of Education at (306) 787-1183 or go on the website at <http://www.education.gov.sk.ca/> and follow the links to Student Support Services, publications.

Each school division makes policies about students with disabilities. As a parent advocate it is important for you to understand the provincial rules, but you also need to become familiar with your school division's policies. Knowledge is power. The more you understand the education system and its disability policy, the more likely it is your child will fully benefit from time in school. It doesn't always work, but many parents feel that knowing what their child is entitled to is the first step toward a better education.

In this chapter we will talk about provincial legislation and policy related to inclusive education. For local policy and practices you will need to talk

to your school division. We will talk more about this later in the chapter under the heading of "The School System."

The Saskatchewan Human Rights Code

It seems odd to look at the *Saskatchewan Human Rights Code* (we'll call it the Code) when talking about education laws and policies. However, this law protects your child's right to an education, so this is a good place to start.

The Code says

13(1) Every person and every class of persons shall enjoy the right to education in any school, college, university or other institution or place of learning, vocational training or apprenticeship without discrimination on the basis of a prohibited ground other than age.

(2) Nothing in subsection (1) prevents a school, college, university or other institution or place of learning from following a restrictive policy with respect to enrolment on the basis of sex, creed, religion, or disability, where it enrolls persons of a particular sex, creed or religion exclusively, or is conducted by a religious order or society, or where it enrolls persons who are disabled.

This means access to a school cannot be restricted on any of the "prohibited grounds"¹⁸ which include, among other things, race, colour, religion, and disability.

Section 13(2) of the Code means 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 to still exist. However, according to the Code, a regular school in Saskatchewan is not allowed to refuse a child because he has a disability.



The *Education Act, 1995*, allows a school board to discriminate against a child if it feels that the child is not able to learn in the regular 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 Emily Eaton case was a famous test case where the Supreme Court of Canada established that every reasonable accommodation must be tried before the school board refuses to include a child in a regular classroom. (Please refer to *A Parents' Guide to Inclusive Education* for a complete explanation of the Eaton case. *A Parents' Guide to Inclusive Education* is available from the SACL.)

If you think that your child's right to go to your neighbourhood school has been violated, you can call the Human Rights Commission for advice. Be ready! If you file a human rights complaint it can often be a long battle.

The Commission has offices in Regina and Saskatoon and its contact information is at the end of the chapter.

Also, you can read the Code online at <http://www.gov.sk.ca/shrc/>.

The Education Act and Education Regulations

The *Education Act, 1995* (hereafter referred to as the Act), is the law that defines what school boards can and cannot do. The *Education Regulations, 1986*¹⁹ (the Regulations) is a tool that interprets and more carefully defines what the Act means. All school boards and schools in Saskatchewan are required to follow these laws. Below we refer to some of the more significant parts of the Act and Regulations but our summary is in no way extensive and even within the sections we refer to here we only touch the surface. We encourage you to look at the Act for yourself. Here is a bit of advice for the novice legislation reader. If you do not have experience looking at legislation it may be intimidating the first time, but with experience it will be clearer. Begin with the table of contents and look for sections that seem relevant to your situation, then go to those sections and follow along. If you are looking at the legislation

online use the search function to find key words that relate to your questions and interests.

The *Education Act* and *Education Regulations* are available at <http://www.qp.gov.sk.ca/>.

The right to an education: The *Education Act* says in section 142(1):

Subject to the other provisions of this Act, 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 educational achievement.*

The Act also notes that this shall be provided at no cost to the student for tuition, transportation, etc. Under the regulations (s. 50(10)) to the Act, if parents request, a student with a disability can begin school at age three. Often students with intellectual disabilities stay in high school until they are 22 and are able 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. This has been done! A SACL member successfully advocated to have her child with an intellectual disability enroll in French immersion.

Assessment: Either the principal or the parents can ask for an evaluation to see if a child needs a special program (s.178(5), *Education Act* and s.50(3) *Regulations*). Most often, children with disabilities are assessed and have a personal program plan before they enter kindergarten.

Pupils with intensive needs: The *Education Act* refers to students who have an intellectual disability as part of the larger classification of “Pupils with intensive needs” and talks about them in 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, the Act says at section 178(9),

“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 subsection 11 are

- (a) whether or not the pupil is medically fragile;*
- (b) whether or not the pupil poses a risk of harm to himself or herself or to others;*
- (c) the educational needs of all pupils;*
- (d) the cost of providing special educational services to accommodate the pupil in the regular program of instruction.*

If your goal for your child is inclusive education, subsection 10 can make it difficult. It clearly puts the principle of inclusive education at risk.



Right of Appeal: Section 178.1 establishes the right of parents or guardians to appeal decisions of a board of education and explains in some detail how this can be done. However, in section 178.1(1), it limits the issues that can be appealed to the following:

- (a) the results of an assessment conducted pursuant to subsection 178(5);*
- (b) a failure to conduct an assessment of a pupil to determine if the pupil is a pupil with intensive needs;*
- (c) the educational services provided pursuant to section 178 to a pupil with intensive needs.*

And, specifically, the regulations in section 50.1 state:

For the purposes of section 178.1 of the Act, the right to a review does not apply where the disagreement with respect to the placement of the child is based on:

- (a) parental preference as to the location of the delivery of the program;*
- (b) parental convenience;*
- (c) other factors unrelated to the impact of the location of the educational instruction on the child's education and development;*
- (d) location within an educational institution;*
- (e) any other reason that relates to or is similar in nature to those listed in clauses (a) to (d); or*
- (f) an allegation of discrimination pursuant to The Saskatchewan Human Rights Code or the Canadian Charter of Rights and Freedoms.*

One of the implications of these sections from the Act and the Regulations is that parents are not able to appeal where their child goes to school. You may want your child to go to the neighbourhood school and be in a class of other students his age, but if that does not happen you have no right of appeal. However, you can appeal the result of the assessment or the failure to assess and you can appeal “the educational services that may be required to meet the learning needs of the pupil.”²⁰

Also of concern is that the Act and its Regulations give no direction on how the report of the review shall be dealt with. It must be delivered to the people involved, but no one has to read it or respond to it. This does not mean, of course, that your board of education's review policy does not provide some direction in this matter, so it is important to obtain a copy of the local policy.

OTHER MINISTRY OF EDUCATION PUBLICATIONS

The *Education Act* does not stand alone and the Ministry of Education has a number of publications that help to understand the programs and policies that arise from the Act. The following are some that we believe are important for families who have a child with an intellectual disability in school. These and others are available by contacting the Ministry of Education, Student Support Services, at the address at the end of this chapter. They are also available online at <http://www.education.gov.sk.ca/Student-SupportServices>. Follow the links for publications.

Creating Opportunities for Students with Intellectual or Multiple Disabilities

Creating Opportunities is a resource document that promotes inclusive education and suggests effective methods for teaching children with disabilities. School divisions are not required to follow it because it is a resource document, not a policy. However, it could be very helpful to you as a parent if you are involved in developing the plan for your child's program. Like the SACL, *Creating Opportunities* defines inclusion as more than physical placement in a regular classroom; it is participation, friendship, interaction, and good teaching. Two attitude adjustments are suggested in this document: that we need to stop looking at a child's weaknesses and focus instead on strengths and abilities, and that we need to give teachers support so that all children can do well in regular classrooms.

The topics covered in *Creating Opportunities* are:

- The philosophy and benefits of inclusive education
- The characteristics of disabilities and working with students with disabilities
- Effective practices that make a school inclusive
- Working together and team building
- Developing curriculum, Personal Program Plans, and classroom plans
- Developing communication and social skills
- Teaching about sexuality
- Preventing abuse
- Promoting positive behaviour
- Transition planning

The Children's Services Policy Framework

The school divisions should be following the plans and suggestions in the *Children's Services Policy Framework* because it is government policy. Even though the framework supports inclusion, many school boards will interpret the policies to mean different things. Challenge them. The definition of inclusion varies from family to family. Regardless, inclusion in school, no matter how you define it, will build a society where people with disabilities are fully accepted as contributing members. The framework supports the idea that all children belong in the school because they can all learn and contribute. Children have different needs, therefore special supports are required to make sure students benefit equally. The vision is that schools are "caring, respectful and inclusive learning communities."²¹

Here is a brief explanation and interpretation of the most important policies that affect children with disabilities:

- *School Culture and Climate* (2.1): The school will be a respectful and responsive environment for children and parents. The board and the school need to respect parents as partners in their children's education. Special programs and practices will be offered for students with different needs.



- *School-wide Discipline (2.2)*: The goal of this policy is prevention. The board and the school need to set positive standards for behaviour and support students with challenging behaviours and intensive needs.
- *Assessment of Student Strengths and Needs (3.1)*: Parents are supposed to be involved in interpreting assessments. Parents need to be involved in all assessments that have anything to do with making decisions about a child. Personal Program Plans need to be based on current assessments.
- *Personal Program Plans (PPP) (4.1)*: A PPP will be developed for every student who needs special education or personal supports. Parents should always be included in this planning process. (It is very important for parents to be involved, since the PPP is the master plan for your child's school year. Never sign a PPP that you were not part of developing. You have a right to be involved.)
- *Early Childhood Education for Children with Disabilities (5.3)*: Preschool programs will be provided for children with disabilities either through the school or a community-based program.
- *Access to Student Information (7.2)*: The school division must have policies in place concerning access to student information. A student's files can be seen by the student, his parents, authorized staff, or a youth worker. For anyone else to see the student's files, there must be consent by the parents or the student. (You can ask to see your child's files. The *Canadian Charter of Rights and Freedoms*, *Saskatchewan Human Rights Code* and the *Freedom of Information and Protection of Privacy Act* uphold parents' rights.)
- *Health-Related Services (7.7)*: The school division will work with the health region to provide health-related services to students. These services include responding to urgent situations, therapy, counselling, and personal care. Parents will help create a plan and monitor the success of health care supports for their child. There must be written consent from the parents to give the child any medication or services. Health care support should be as minimally intrusive to the student and the class as possible. (School staff

may feel that it is intrusive to perform any kind of health-related services in the classroom. If this is used as an excuse for frequent pull-outs, ask them to prove that the services are intrusive to the class through documentation.)

- *Parent and Community Partnerships* (7.12): The framework quotes research that says parent involvement leads to greater success for students. They promote an increase in parent involvement in the schools. The schools should work toward better communication with parents and the involvement of all families in the school.

School^{Plus}

School^{Plus} is the Ministry of Education's plan to create a better environment for children and strong partnerships with parents and communities. Schools are meant to have two functions in the *School^{Plus}* vision: to educate all children and to work with other agencies to provide a place where children have better access to support and services. Schools are already starting to integrate supports such as health services, social work, recreation, cultural programs, and justice.

The government commits to *School^{Plus}* in the *Securing Saskatchewan's Future* document. One goal that the government has for implementing *School^{Plus}* is to ensure that students “all receive the developmental and learning supports needed to achieve their full potential and become caring and contributing citizens.”²² Children with disabilities have often been denied what they need to reach their full potential. *Securing Saskatchewan's Futures* also explains that supports mean “schools will be *student-ready* rather than requiring students to be *school-ready*.”²³ The end result should be that schools will “be able and expected to meet the learning needs of every child...”²⁴ As parents and advocates for children with disabilities, we need to hold the government and school divisions accountable to this vision for each child.

You can read all of the policies on the Ministry of Education website at <http://www.education.gov.sk.ca/StudentSupportServicesPublications>.

THE SCHOOL SYSTEM

Schools, like any other bureaucracy, have a complicated system of structure and rules. Each school belongs to a school division. All of the school divisions receive funding and direction from the Ministry of Education. However, school divisions are still fairly independent and each division attempts to deliver programs that reflect the needs and wants of the people in its area of the province. Divisions are supposed to follow provincial policies made by the Ministry of Education, but interpretation of these policies is very broad. Some school divisions are progressive and others are not. For these reasons it is important that you understand your school division, its policies and its practices.

All school divisions are divided into school districts that have a board of trustees to carry out the everyday tasks. This will only be relevant to you if you are having trouble with the school. After you have talked to the teacher and the principal, the board of trustees will be the next group you talk to before you get to take your concerns to the board of education.

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

- 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

Also, section 103 requires that the board prepare a manual that describes the program policies, educational goals, and proper organization of the school division.

Parents are allowed to see the school division's policy manual. Your child's school should have a copy. It would be good to become familiar with the school board's policies on students with disabilities, discipline, and behaviour management. If you have questions about your school division, the staff at your child's school should be able to answer them.

Many people within the school system make decisions about placements and programs for students with disabilities: the school board members, the director of education, the school superintendent, the principal, and the special education consultant. You need to find out who these people are and what their role is. Find out who has influence and try to meet them before any problems come up. It might help to introduce them to your child. Let them know what your dreams and expectations are for your child's education and life after school is finished.

You may also be interested in looking at the *Student Support Service, Service Delivery Model Rubric*. The document, subtitled *Facilitating and Monitoring Effective Practice*, is a tool that the Ministry of Education can use to support school divisions to provide better support to your child. It deals with effective practices in the areas of inclusionary philosophy and beliefs, intervention plans, and staffing. Each parent should know how their division rates in these areas. You can find the document at <http://www.education.gov.sk.ca/StudentSupportServices>.

WHAT SHOULD MY CHILD BE LEARNING IN SCHOOL?

MYTH: *Your child does not need to learn academics. For children like yours, it is better to just concentrate on life skills.*

Remember that it is easier to teach cooking than it is to teach math skills. Just like every other child, a child with an intellectual disability should learn life skills like cooking, self-care, making a bed, and social skills, at home or out in the community. If your child is learning too many "life skills" at school, he may not be learning some of the academic lessons that will be harder to learn later on in life. The goals of education should not be changed for a child with an intellectual disability. The teaching method or pace might need to change, but the subjects should be the same. School for most kids means academics and social interaction. This is what school should mean for your child as well.

Think about the skills you learned in school that you use every day. Those skills include reading, writing, math, and maybe computer skills. Now, imagine trying to function in your everyday life without these skills. It may take longer to teach a child with an intellectual disability these subjects, but these skills will add to your child's quality of life and ability to be independent. If someone tells you it is not worth teaching your child these skills, do not accept it.

Sexuality and sexual development is another area that is often left out of the education plan for children with disabilities. The more your child knows about relationships and his sexuality, the more likely he will make good decisions. Lack of knowledge has left adults with 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. If the teacher is hesitant about teaching sexuality to your child, explain that there are training kits and resources available through the John Dolan/SACL Collection at the Stewart Resource



Centre at the Saskatchewan Teachers' Federation offices in Saskatoon. Phone (306) 373-1660 or go online to www.stf.sk.ca.

Personal Program Plans

■ **MYTH: Your child is better off in a class with other special children where a teacher can focus on his needs.**

Research tells us that all children are better off academically and socially when they are supported in an inclusive classroom. Students with disabilities in Saskatchewan are required to have a school-based team develop an individual plan for what they will be taught throughout the year. The team must decide what teaching methods and resources will be used, as well as what the specific objectives will be. This is your chance to make sure that your child has all the supports necessary and that he is not segregated from other students. The school system calls this plan a Personal Program Plan (PPP).

Parents should always be involved in developing the PPP for their child. We have seen parents handed a PPP to sign without having been involved in the development. If that happens to you, do not sign it! Leaving parents out of this important process is disrespectful, and it is also a violation of the Ministry of Education guidelines. The guidelines for school divisions state:

“School division personnel collaborate with parents in the development, implementation, evaluation and revision of the Personal Program Plan.”²⁵

It is essential to know what you want and to have your own plan before you go into a PPP meeting. Make sure that the PPP focuses on your child's strengths and inclusion. Do not be intimidated by professionals at the table. No one knows your child or cares about his education as much as you do. You are the expert. Among many other things, the PPP should include a plan for classroom participation and adaptations. As well, make sure it is clear who will carry out the tasks for the plan; this is not your responsibility. You are the adviser (and some-

times the watchdog). Keep monitoring the PPP and make sure you get progress reports. The plan can be changed if it is not working. Your child's best interest must always be the focus. No one should forget that.

A Parent's Advice

Always try to make it apparent that you are planning for a child, not a student ID number. Have your child present for the PPP if you want him there. This places a face to the process. I always let the school know that my son will be there for the introductions and give him a chance to make an impression upon the planning team. We, my son and I, also designed a quick PowerPoint presentation showing a brief history of how we got to where we are today. The slides describe how amazing he is and the potential we see in him. Each slide has a picture. No one has ever told me this had no value and it has set a positive and solution mind-set for the meeting every time.

For more information about Personal Program Plans, see the Ministry of Education publication *Personal Program Plans (PPP) Smart Outcomes And Student Outcome Rubric*, June 2008. It can be found online at <http://www.education.gov.sk.ca/adx/asp/adxGetMedia.aspx?DocID=2005,211,107,81,1,Documents&MediaID=3808&Filename=Personal+Program+Plans+%26+Student+Outcome+Rubrics+June+2008.pdf>.

Funding for Children with Disabilities

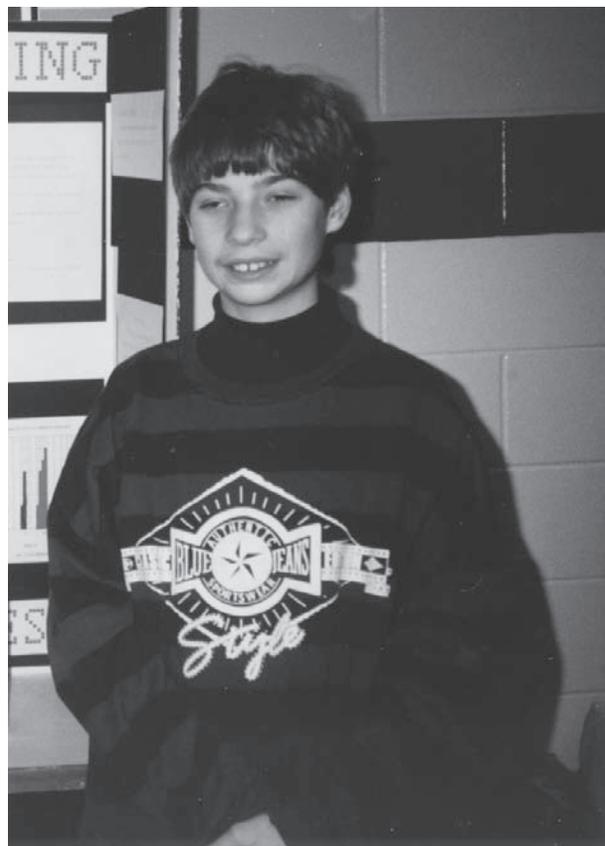
■ **MYTH:** “We just do not have the money available for your child to be fully included in a regular class.”

The most popular excuse for not including or accommodating a student with an intellectual disability is, “We don't have the money.” Parents are made to feel guilty for asking when the school doesn't

want to pay for a support that your child needs. Do not feel guilty! You already pay taxes to fund the education system. Beyond that, the school board's budget is not your problem. It is their responsibility to worry about money. You only need to advocate for your child.

The school division receives extra funding for students with disabilities. According to the Ministry of Education's *2008–09 Funding Policy Manual*,²⁶

*“Intensive supports funding recognition is provided to school divisions for learners requiring intensive supports as identified through a **Provincial Impact Process**. These learners have learning needs that impact on numerous areas of performance and require intense and frequent supports as documented in their Personal Program Plan. In addition, intensive supports funding recognition provides assistive technology that allows students identified as requiring intense and frequent supports to access educational programs and instructional services.”* (E p.2)



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 hit school age, the health region will no longer provide these therapies, so the responsibility lies with the school. This is agony for many parents of children with disabilities who have seen their children progress when they had regular therapy. Sometimes it is the problem of “not enough therapists,” or sometimes the division feels it will not have the funding for that school year. Regardless, it is always a **funding choice**. Therapists are not available because they are not being paid as much as they could get in other places. Enough funding is not available because the political will is not there. We need to continue to be assertive in advocating for continued and better therapy services for children with disabilities (also see the section on therapy in Chapter 5).

Some parents have stopped advocating because they feel like their child is a financial burden on the school. Even if your child needs extra support, the school will benefit from his presence and gifts. Your child has a right to be there and be supported, just like any other child.

Communicating through Behaviour

■ **MYTH: Your child will not be accepted by others in the class. He is just not ready to be included.**

Children with intellectual disabilities sometimes react differently than other children in certain situations. People often misunderstand and judge their behaviour. Strong reactions can be damaging to a child and can make real inclusion difficult. Unique and/or challenging behaviours are reduced when your child has the opportunity to make choices, make friends, be a leader, be responsible for himself, be respected, have his feelings respected, and have his frustrations listened to. If a child has behaviours that are challenging to some people, a respectful support plan is needed, not segregation.

Your child cannot “get ready” to be in a regular classroom by being segregated from it. A child may never, nor should he have to, reach the “level” of skill, or behave the way that the administration deems as good enough. A child should not be discriminated against for not being the same as another child. Keep fighting for an inclusive placement. Your child has the right to be there.

All behaviour is communication. The child may be lonely and want attention from other children. He might be uncomfortable and may need to move around. He might be angry because he was left out of an activity that all the other children are doing or it might not be modified appropriately. The task he was given might be boring and he is simply sick of doing it. There is always a feeling or event that triggered the behaviour. The behaviour may be a characteristic of the disability and is, therefore, part of who the child is and how he communicates. This child needs to be accepted as he is and not punished for his behaviour.

Watch out for labels. The labels that people use to explain behaviour often ignore what children are trying to say.²⁷ One harmful term is “attention seeking” behaviour. Saying that a child is only “trying to get attention” could be dismissing the real reason the child wants attention. We need to listen and observe first and find out. Some children are labelled as violent or aggressive, terms that ignore what he is communicating. Other labels are non-compliant, defiant, or oppositional. As adults, we never do things we are told to do without knowing why we have to do them. We should not expect children to do things without giving them a good reason. If the child is not listening to instructions, maybe he does not understand and needs a better explanation. Avoidant is another common label. If no one looks more deeply into why he is unhappy and avoiding an activity or a person, the problem will not be solved.

As a parent, you would never want your child punished for trying to communicate. If your child has a behaviour that others do not understand, work on a plan with the teachers. Ask them to listen first



and find out what went wrong. It is better to find out what is behind the behaviour than to continually isolate or punish the child. A teacher can change the environment for the child instead of moving him out of the classroom. A good rule to follow is to change the environment first, then change your own approach, but never to try to change the child. Labelling and punishing behaviour are ways of ignoring the real issues and devaluing the person. We need to listen, watch, and learn.

For additional help with developing a behaviour support plan, contact CLSD and ask for assistance from a program development consultant. There are also some very effective private behaviour consultants. Call the SACL for more information at (306) 955-3344.

Teachers and Educational Assistants

In the classroom the teacher and educational assistant (EA), working together, are key to your child's education. They set the tone of the classroom; the teacher and the EA are the people who can make or break inclusion.

The EA is often assigned to a classroom because there is a pupil with a disability enrolled in the class but he or she is, in theory, not there only to support the pupil with a disability. The classroom teacher is in charge of the classroom and the EA is there to assist as required. This could mean working with the pupil with a disability or it could mean working with the rest of the class when the classroom teacher is working with the pupil with a disability.

The way that the EA assists your child is important. 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 him. When the only person that the child hangs out with or plays with is the EA, the child is not going to make friends. When this happens it means that the child is still segregated in an "inclusive" classroom.

Sometimes parents have said that the EA became their child's teacher. The teacher is in charge of assigning duties to the EA. If a teacher transfers all the responsibility for teaching the child with a disability to the EA, the teacher is not fulfilling his or her duty. The teacher is paid to teach all the children in his class.

The EA's role should be to work on making the child a part of the class. They can do this by

- helping the child work on the same activities as the rest of the class
- helping other students in the class understand how to relate to the child

- getting the child involved in group work
- giving the child opportunities to be independent
- helping the child make friends
- helping other students in the class with activities so that the EA is seen as the teacher's assistant, not the child's assistant

If the teacher and the EA are committed to inclusion, then they will be aware of the potential dangers posed by a child having a 'personal assistant.' A truly inclusive classroom is one where all students are taught by the teacher, and assisted by the EA. The teacher may need to give help to one child more than others, but everyone is a participating member of the class.

You can let teachers know what your desires are for your child's classroom participation. If you think a certain role is harmful to the goal of inclusion, let them know and provide your ideas about promoting inclusion.



EDUCATION RESOURCES

Canadian Association for Community Living Inclusive Education Resources

<http://www.cacl.ca/english/priorityresources/incedu/resources.html>
www.inclusiveeducation.ca

Department of Education for Exceptional Children

College of Education, University of Saskatchewan
<http://www.education.gov.sk.ca/>
 Phone: (306) 966-5253

Inclusion Press International

Jack Pearpoint
 Website: www.inclusion.com
 Phone: (416) 658-5363
 Fax: (416) 658-5067

IRIS

4700 Keele St. North York, Ontario M3J 1P3
 Phone (416) 661-9611
 Fax: (416) 661-5701
 TTY: (416) 661-2023
 1-800-856-2207

Learning Disabilities Association of Saskatchewan (LDAS)

www.ldas.org
 Saskatoon (306) 652-4114
 Regina (306) 352-5327
 Prince Albert (306) 922-1071

Regional Superintendents of Children's Services

Region One (Weyburn) (306) 848-2429
 Region Two (Swift Current) (306) 778-8251
 Region Three (Regina) (306) 787-6073
 Region Four (Saskatoon) (306) 933-5033
 Region Five (Melfort) (306) 752-6166
 Region Six (North Battleford) (306) 446-7436
 N. Education Office (La Ronge) (306) 425-4307

Saskatchewan Teachers' Federation (STF)

www.stf.sk.ca/
 Phone: (306) 373-1660
 Fax: 374-1122

Services for Students with Disabilities

University of Saskatchewan
<http://www.usask.ca/>
 Phone: (306) 966-5673
 Fax: (306) 966-5081

Student Support Services, Ministry of Education

1st Floor, 2220 College Avenue, Regina, SK S4P
 4V9
[http://www.education.gov.sk.ca/
 StudentSupportServices](http://www.education.gov.sk.ca/StudentSupportServices)
 Phone: (306) 787-1183
 Fax: (306) 787-2265

University of Regina

<http://www.uregina.ca/>
 Phone: (306) 585-4631
 Fax: (306) 585-5650

Help us keep up to date. If there are any changes or additions we need to make to Navigating the System, please let us know. Phone (306) 955-3344 or e-mail sacl@sacl.org.

Chapter 4: Prescription Drugs and Drug Plans

For some children with intellectual disabilities prescription drugs are a daily reality, so we asked parents about what they have experienced. They told us how difficult it can be to make a decision about a prescription drug for their child. Sometimes the side effects of drugs can outweigh the benefits. And who can you trust to give you information and advice about drugs? They told us that when new drugs come onto the market, it is hard to know where to get accurate information. Sometimes it is easy to fall into the trap of following the latest craze to find a 'cure.' Parents may be told that the doctor knows best, but this is your child, and a doctor will never know her like you do. It is your responsibility and right to ask questions and receive helpful answers.

ASKING YOUR CHILD'S DOCTOR THE RIGHT QUESTIONS

No parent makes the decision about a drug therapy lightly. 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 'fixing' a child who has challenging behaviours. Using drug therapy to control behaviour is not necessarily wrong, but parents need to be cautious with any drug, ask why the particular drug is being prescribed, and ask about the possible side effects.



People have different reactions to prescription drugs. Some people have an allergy or an intolerance to a certain drug. Drugs can cause adverse reactions when they are taken with over-the-counter or other kinds of medications. All drugs need to be monitored carefully to make sure the drug is working and the dosage is right. Parents have told us that some doctors prescribe drugs but do not do careful follow-up. No one likes to take their child back to the doctor again and again to get a prescription right. Asking lots of questions and giving the doctor the right information will make it more likely that the first prescription works.

What does the doctor need to know from you?

It is a good idea to make notes ahead of time so that you remember everything when you arrive.

- Tell the doctor what has been tried before, and what has worked or failed and why.
- Tell the doctor what alternative therapies and over-the-counter drugs your child takes, and about any prescriptions from another doctor.
- Tell the doctor what allergies or intolerances your child has.

What do you need to ask the doctor?

Parents often only find out from experience what they should have asked the doctor. Here are a few questions that other parents and medical professionals have suggested to ask the doctor before a child starts taking a new drug.

Why do you want to give my child this particular drug? You have a right to understand the doctor's reasons for prescribing a drug. Find out if the doctor has prescribed this drug to other patients and how it worked. Ask the doctor what he or she believes the drug will do to benefit your child.

Parents Be Aware

Always ask questions when a doctor prescribes a drug for your child, but especially if your child has behaviour challenges. The drug group benzodiazepines are used for sedation. Ativan is one of them. In many situations, this drug has been used on people with intellectual disabilities as an oral restraint to keep them under control. While benzodiazepines may have some valid usages, controlling your child is not one of them.

What are the benefits of the drug? As a parent, you need to know what the drug is supposed to do for your child. This is not an experiment. There should be concrete scientific evidence that it has been successful in improving the symptoms that your child is having. Also, find out what your doctor's experience has been with this drug's effectiveness.

Could this drug interact badly with any of the prescriptions, alternative medications, or non-prescription drugs (e.g. allergy medicine) that your child takes? The doctor might not know off-hand if there are any negative interactions with the drug being prescribed. You could ask the doctor to research and make sure that there are no problems with the drug before you fill the prescription. Possible drug interactions are something to double check with a pharmacist, who will have access to pharmaceutical books and be able to cross-check with the other medication your child is taking.

Parents Be Aware

One parent told us that her son with a disability had been given a drug to help with his behaviour. While the drug was successful, it caused her son to continually gain weight, a side effect that she wasn't anticipating. She found out later that this was a common side effect that the doctor knew about, but she wasn't told that could happen.

What are all the possible side effects that my child could have while taking this drug? I want to know what to expect. If you ask this, the doctor most likely will tell you about any risks involved in taking the drug. Ask about short-term and long-term effects. Sometimes a drug can cause a terrible reaction if it is taken over a long period of time and builds up in the body. As with antibiotics, people can build up immunity to a drug if they take it too often or for too long. If your child will need this drug for the rest of her life, this is a concern. You can also ask more specific questions. Some drugs make a person tired all the time. You could ask if this drug affects behaviour, eating habits, sleep patterns, or thought processing.

How does the body absorb and store the drug?

This is an important question because a drug can cause damage to organs and cells depending on how the body stores it. One parent told us she found out that drugs sometimes leave long-term deposits in the body. As a parent, the more you know about how the body uses the drug, the easier it will be to spot or predict problems.

What is the cost of the drug? All of us have probably been surprised when we went to fill a prescription and found out how much it cost. It doesn't hurt to ask how much the drug will cost, if there is a generic equivalent, or if the doctor has samples you could be given.

If your doctor is trying to end the conversation and get to the next appointment, stress how important it is for you to have your questions answered. Don't back down.

CHECKING IN WITH THE PHARMACIST

The best advice that parents gave when asked about prescription drugs was to get to know a good pharmacist. Doctors do not always spend the time to give you all the information you need to know about the drug they are prescribing. It is the phar-

macist's job to know the details about drugs that are on the market. They will know where you can find additional, reliable research and information about drugs. Pharmacists are more than happy to help and have studied drug interactions in depth.

Ask your pharmacist the same questions about the drug that you asked the doctor. Your pharmacist will double check to see if there are any drug interactions you should know about. Checking the pharmaceutical interactions index is a good place to start, but pharmacists often also hear the complaints about and side effects of drugs as they fill and refill prescriptions for families. Pharmacists see customers every time they fill their prescription, which is usually more often than a doctor sees them.

There are additional questions that you can ask a pharmacist. One pharmacist suggested that parents ask whether or not the dosage matches the child's weight. She explained that prescription dosages are



decided by the child's age for which there is an average weight. Sometimes children with disabilities weigh less than the average and are given too high a dosage for their size.

The pharmacist will tell you what time of day or with what meal your child should take the drug. If your child's sleep schedule is irregular or unusual, the pharmacist may take that into consideration when she tells you what time the drug should be taken. If there are going to be side effects, the pharmacist will know from experience what works to minimize those effects.



NEW DRUG THERAPY

There is always a buzz about a new drug or therapy to help or even “cure” a child with an intellectual disability. Drugs and therapies can certainly help to eliminate some of the uncomfortable effects of certain health conditions, but some doctors spend too much time trying to cure people of being different. In the past the medical model saw people with intellectual disabilities as diseased and in need of fixing. This attitude did a lot of emotional and physical damage to people. People with intellectual disabilities do not have a disease that needs to be cured.

Responsible parents want to do everything they can to make life comfortable for their child with an intellectual disability. With this in mind, parents who have accessed various new therapies give this advice: do not jump on the bandwagon without doing your homework. New drug therapies can be risky and very expensive. If you are considering a new type of drug therapy, get lots of information from reputable sources before you decide.

Organizations that are disability specific will know about the new therapy and should be able to tell you if any of their members have tried it. They should know what people who support or criticize the therapy are saying about it. Some of these local organizations include the Saskatchewan Cerebral Palsy Association, Epilepsy Regina/Epilepsy Saskatoon Inc., Autism Treatment Services of Saskatchewan, the Autism Resource Centre, and the Saskatchewan Down Syndrome Association (contacts at the end of the book). If there is no local group,

there might be a national group such as the Canadian Down Syndrome Association. *Disability* magazine often covers the topic of innovative drug therapies.

For more information about prescription drugs you can call the University of Saskatchewan Drug Information Services hotline at (306) 975-3784.

PRESCRIPTION DRUG PLANS

The comment we heard most often from parents is that the cost of drugs prescribed to children with intellectual disabilities is incredibly high and is often not covered under drug plans because their child was born with a disability. There are a few programs that you should know about that may help with the high cost. Chapter 11 also contains information on tax credits and benefits as a reimbursement for drug costs.

We researched to see if it was possible to purchase private health insurance once you know that you have a child with an intellectual disability. The answer was usually no, or dependent on the disabil-

ity. Many parents have a drug plan through their workplace. This is the best option because children cannot be made ineligible for being born with or developing an intellectual disability. Generally, the parents that did not have trouble with drug costs were the ones who had insurance through work.

If you decide to look for a private insurance plan, here are some questions to ask yourself:²⁸

- How affordable is the insurance?
- What will it insure for my child?
- Is there any deductible that I will need to pay?
- What percentage of my costs will be covered by the plan?
- Are there limits to how much I can claim?
- Have other parents been successful with this plan?

Private insurance companies try not to insure people who have any risk of needing insurance. Children who have an intellectual disability could cost the insurance company a lot of money and, therefore, may not be covered for everything. There is an exception, although it is likely too late for parents who are reading this book. A well-known private health insurance provider in Saskatchewan has a clause that they will insure all children under their parents' plan, **no questions asked and no medical needed**, as long as it is within 30 days of the child's birth. This means that they cannot exclude a child from the plan, even if they are already diagnosed with an intellectual disability. It is likely that most insurance providers have a similar clause. If your child is older than 30 days, you can still pass this valuable information on to other new parents.

GOVERNMENT DRUG PLANS

The government has additional assistance for families who have high drug costs. Because these programs are income-tested, not all families will be able to access them. Only families that have very high drug costs **or** a low income will benefit. If you qualify, the financial support could alleviate the monthly stress of buying prescriptions for your child.

The Special Support Program

The Government of Saskatchewan, through the Ministry of Health, has established a drug plan for people whose drug costs are high in relation to their income. This is called the Special Support Program. You qualify based on your "annual adjusted income" compared to your drug costs. If you have already received money back on your family's prescriptions through a drug plan, you may not qualify.

Take your family's gross income and subtract \$3,500 for each child you have (under 18) and this will give you your adjusted income. Then multiply your adjusted income by 3.4%. If you spend more on prescription drugs than the final calculation, you qualify for financial assistance.

Example \$27,000 (Dad's gross income) + \$27,000 (Mom's gross income) = \$54,000

$$\begin{aligned} \$54,000 - \$7,000 (2 \text{ children}) &= \$47,000 \\ \$47,000 \times 3.4\% &= \$1,598 \end{aligned}$$

In this example, if the family spends more than \$1,598 on prescription drugs, they are eligible for support. Once you are considered eligible, you will receive an immediate reduction in your drug costs. It is not a reimbursement, but an immediate reduction at the pharmacy counter. For once it is convenient! You will only have to pay 50% of your drug costs when you go to the pharmacy. If your drug costs remain really high, it is possible to get your payments down to 35% of the cost.

Families with a deductible due to receiving the Guaranteed Income Supplement (GIS), Saskatchewan Income Plan (SIP), or Family Health Benefits (FHB) may be eligible for further benefits under the Special Support Program.

It is important to remember that you will be required to fill out forms in order to access these benefits. You can ask for the forms at your local pharmacy. On the forms you must give your consent so that the Ministry of Health can verify your income

information through Revenue Canada. You will need to include a photocopy of page 1 and 2 of your last year's tax return, including both your own and your spouse's income. You will also need receipts or a printout from the pharmacist stating the cost of your prescriptions. If you need help or an explanation, phone the Ministry of Health Drug Plan at 306-787-3420 in Regina or at 1-800-667-7581 or go online to <http://www.health.gov.sk.ca/special-support-program>.

Emergency Prescription Drug Assistance

If you have trouble making ends meet at the end of the month and your child needs expensive prescriptions, Emergency Prescription Drug Assistance could be an important program to know about. The amount of assistance you get will depend on your ability to pay. You apply for emergency assistance through your pharmacist. The pharmacist calls the Ministry of Health (only during regular office hours) and gives them your health number, the name and the cost of the drugs, and the reason why you cannot pay for them. To receive any future assistance, you will need to submit a "Special Support Application" to the Ministry of Health. For more information, go to <http://www.health.gov.sk.ca/emergency-drug-assistance>.

Supplementary Health Program

If your adult daughter is on social assistance, she will have access to Supplementary Health coverage. She will have to pay \$2 for each prescription, but the rest of the cost of the majority of prescriptions will be covered. The drugs that the Ministry of Health covers for people on assistance are called "formulary drugs," which includes most drugs. Many non-formulary drugs can also be covered if they are essential to your daughter's health. If she lives in a group home or a special care facility, the whole cost of any drug will be covered. You can find this information at <http://www.health.gov.sk.ca/supplementary-health>.

Family Health Benefits

If your family receives the Saskatchewan Child Benefit or the Saskatchewan Employment Supplement, your children's drug costs can be covered under the Family Health Benefits plan. The plan covers basic dental, drug, optometry, chiropractic, and ambulance services and medical supplies. You can call the Ministry of Health at 1-800-266-0695 to apply.

PRESCRIPTION DRUGS AND DRUG PLAN RESOURCES

Ministry of Health-Family Health Benefits

<http://www.health.gov.sk.ca/family-health-benefits>
Phone: 1-800-266-0695

Ministry of Health-Special Support Program

<http://www.health.gov.sk.ca/special-support-program>
Phone: (306) 787-3420 (in Regina) or toll-free at 1-800-667-7581

Saskatchewan Drug Information Services (SDIS)

<http://druginfo.usask.ca/>
Phone: (306) 966-6378 [Saskatoon] or 1-800-665-DRUG (3784)
Fax: (306) 966-2286

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Chapter 5: The Medical System

The United Nations Convention on the Right of Persons with Disabilities says

States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation.

From Article 25

Some parents of a child with an intellectual disability have told us the medical system can be one of the toughest systems to advocate in and the most confusing. Services are not the same in every part of the province. Money for health services is always an issue. Often children with an intellectual disability

have complex medical needs and this makes it more difficult to get the treatment and therapy services they need. Children need to fit a certain criteria to get services, and even then there are wait lists.

Some parents report having had a doctor refuse to properly look into a medical concern, suggesting that the child's symptoms are simply related to his disability. Many times people with intellectual disabilities are discriminated against and do not receive first-rate services. As a parent, this can leave you feeling that your child's worth as a human being is questioned.²⁹

In this chapter we will look at the good and bad news about the medical system and how it affects children with intellectual disabilities. Included are some specific problem areas where parents have faced barriers to services or outright discrimination. There is also hope. While there is nothing you can do that will absolutely guarantee that your child will get the best medical services, there are actions you can take to inform yourself, educate medical professionals, and prepare your child.



For this handbook, parents offered their advice about working with an imperfect medical system. Never allow yourself to be intimidated by medical professionals. Keep a journal of everything that happens. Never stop advocating. You are the only one who intimately knows your child and sees the changes in health every day. Trust your instincts.

A COMPLICATED SYSTEM

In Saskatchewan, the health care system is broken down into 12 health regions and the Athabasca Health Authority. Each region does things differently. This means you can be confronted with different policies and practices if you are required to use a service in another health region. Wait lists can be shorter for a treatment or service in rural areas, but many treatments are simply not available unless you travel to the cities. Parents have had such different experiences within the same health region that sometimes accessing services is simply luck.

As your child's advocate, you will probably need to 'push the system' a lot in order to have your child's needs met. Phoning the 1-800 number for your health region may not be the best avenue for finding out what is available or how far the boundaries can be pushed. Some parents are getting more hours of home care or therapy than other families because they kept advocating until someone listened. Others have not been so lucky despite their effort, or they haven't talked to the right person yet.

From experience, parents have told us that the best way to find information is from inside the system. You will need someone on your side: another parent who has been successful, a nurse who knows your child well, a therapist who sees your child's potential, or a doctor who will work to make sure things get done. Often the medical professionals who work in this complicated system will sacrifice and advocate on your child's behalf. Developing relationships with compassionate medical staff can be an avenue for advocacy. There are ways to get things done.

KNOW YOUR RIGHTS

As a parent struggling to obtain medical treatment for your child with an intellectual disability, it is important to know your rights and the legal avenues that people have taken to uphold their rights.

"What a sad statement that is about the value that a society places on those most vulnerable – that the only way to effect change and enable the provision of effective treatment, required health care, and supports for people with disabilities is through pursuit of one's rights through legal actions."

Parent, Health Care Forum

The intent of medicare, as stated in the *Canada Health Act*, is that every person has equal access to medical care, regardless of need or resources. *"It is hereby declared,"* the Act proclaims,

*"that the primary objective of Canadian health care policy is to protect, promote and restore the physical and mental well-being of residents of Canada and to facilitate reasonable access to health services without financial or other barriers."*³⁰

Under the Act, Canadians have the right to **universal** health care services. All the provinces must provide equal access to public health care to all their citizens. Your child has the right to access the same insured health services and treatments as every other person in Canada. He cannot be discriminated against because of his disability.

In the *Regional Health Services Act*, it states that health regions are

"responsible for the planning, organization, delivery and evaluation of health services it is to provide" (c. R-8.2, 27 (1)).

The following are the major services that health regions are responsible for:

- Hospitals;
- Health centres, wellness centres, and social centres;
- Emergency response services, including first re-

- sponders, and ambulance;
- Supportive care, such as long-term care, day programs, respite, palliative care and programs for patients with multiple disabilities;
- Home care;
- Community health services, such as public health nursing, public health inspection, dental health, vaccinations, and speech pathology;
- Mental health services; and
- Rehabilitation services.

If your health region is not providing a necessary service for your child, you have the right to question that. Some parents have talked to their local MLA or the Ministry of Health about their struggles. The Minister of Health has the power to ask the health regions to take action and to cut funding if they don't (c. R-8.2, 7(1) & 8(3)).

Human rights legislation and the *Canadian Charter of Rights and Freedoms* have been used to fight discrimination and the lack of services in the health care system. Research sponsored by the Canadian Policy Research Network on “Accountability in Health Care and Legal Approaches” looked at how citizens have made the health care system accountable by using the legal system. Parents of a child with autism in Newfoundland went to the Supreme Court on behalf of their child and won, using provincial human rights legislation. The Supreme Court upheld the human rights tribunal decisions that the boy was treated differently than children with other medical conditions, such as cancer. The court decided that he deserved effective and timely treatment and had been put at risk by not having that treatment.

The Supreme Court of Canada has emphasized that governments cannot defend their choices with arbitrary assumptions. The Court has noted that “*It is all too easy to cite increased cost as a reason for refusing to accord ... equal treatment. ... I do not assert that cost is always irrelevant.... I do assert, however, that impressionistic evidence of increased expense will not generally suffice.*”

(Ries and Caulfield, 2004)

We know that not every parent will go to court when the health care system fails but those who do help us all. Ries and Caulfield³¹ suggest that these cases “may have the effect of enhancing accountability in health care” by making governments justify how they are distributing resources. If the government says it cannot provide a particular service, then it will need to justify and supply evidence as to why it can't provide the services. Parents should never have to go to this extent to access services for their children, but it is still good to know that parents have won. If you are interested in reading this paper, you can find it online at http://www.cprn.org/documents/28717_en.pdf.

REMEMBER: YOU ARE THE CONSUMER

Health literature has started using the word “consumer” to describe those who use health services. Your taxes are paying health workers and, as a consumer, you should be receiving high-quality, respectful services. If you are not happy with the services you have received from the health care system, write down your experiences. Each health care professional belongs to a professional organization whose job, in part, is to monitor their members. If you have a problem with any of the medical staff who has worked with your child, you can file a complaint with their professional organization and it will be investigated. At the end of this chapter is a list of professional organizations you can call.

SEXUAL HEALTH

In the past, people with intellectual disabilities were often portrayed as non-sexual beings. This is, of course, false. Sexual maturation, relationships, sex, and even babies do happen for people with intellectual disabilities and are a normal part of life. In Chapter 3 we talked about sexuality and sexual development as something your child should be learning in school. Parents often teach their children about sexual development and values at home

from an early age as well. Some training kits and resources designed to help at every step of the way by addressing the needs and issues regarding sexuality and people with intellectual disabilities are available in the John Dolan/SACL Collection at the Stewart Resource Centre at the STF offices in Saskatoon. Phone (306) 373-1660 or go online to www.stf.sk.ca.

Children with intellectual disabilities should be learning the same age-appropriate lessons about sexual development and sexuality as their peers without disabilities. Children need to learn about body parts, male and female maturation, and creating relationship boundaries to reduce the risk of abuse. They also need to learn about privacy awareness, assertion, masturbation, homosexuality, birth control, sexually transmitted diseases, building emotional relationships, marriage, and becoming parents (just to name a few!). By the time your child becomes an adult (at the very latest), you want to make sure he knows the basics about sex and sexual decision



making. Healthy sexuality is part of being healthy as a person.

Dave Hingsburger and Karin Melberg Schwier have written an informative book called ***Sexuality: Your Sons and Daughters with Intellectual Disabilities*** that covers sexuality, and also deals with love, trust, relationships, self-esteem, and the stages that parents go through as their children grow up. It outlines the things you need to consider and the real-life emotions and experiences of people with intellectual disabilities and their parents as they embraced their independence and sexuality. Hingsburger and Melberg Schwier begin with self-love and self-acceptance as the basis of a healthy sexual identity. They explain how lessons of touch, boundaries, trust, and verbal encouragement shape how we see ourselves and relate to others.

IDEAS FOR ADVOCACY

How do you advocate in a system that is only beginning to value people with intellectual disabilities? Again, the first thing to remember when you are involved with the medical system is not to be intimidated by medical professionals. Doctors are human, just like everyone else. You know more about your child than any doctor does; you are the expert. Make sure that all medical professionals give you the information you need and the time to ask questions. If you don't understand, keep asking. If you don't feel good about what one doctor has said, seek a second opinion.

Here are some of the advocacy tips from parents who have accessed the medical system.

FIND A GOOD DOCTOR

The most important advocacy tool is knowing someone within the medical system. If you have a committed doctor who is willing to do the research and make sure your child receives the best medical treatment, you will be miles ahead. Many parents expressed their gratitude for having a doctor who

would listen to their concerns and get things done. Find a doctor who respects you and, most importantly, respects your child. You need a doctor who truly believes that your child is not a “burden,” but that it is the barriers created by the medical system that are burdensome. Also, a good doctor will be able to explain things in words you can understand, not technical jargon.

You will need to get your doctor to fill out forms for your child, such as for the disability tax credit. It is important to note that this service is not covered by medicare, which means you might have to pay the doctor a small fee.

Since children with intellectual disabilities sometimes face complicated medical challenges, it is good to have a pediatrician as your child’s regular doctor. It may be hard to find a pediatrician who is taking patients. You can phone your health region to see if there are local pediatricians. If none are taking new patients, keep checking in since patient loads can change. A general practitioner (GP) who is willing to do the research and advocate for your child can be just as effective as a pediatrician. However, many GPs do not have the in-depth experience needed to deal with developmental issues.

Keep a Medical Journal

A parent who was preparing to go on vacation wrote a journal that included all of her child’s medical treatments and interventions, the results, suggestions, and where things are at now. She wished she had done this earlier! A journal of medical interventions and advice, especially when you are heavily involved with the medical system, will help you to remember important details about every visit.

The journal does not need to be complicated. You can get a notebook and use it to keep a brief record of when your child has been to the doctor or received other medical treatment.

- Start with the date.
- You can write down your child’s symptoms or

the reason for getting medical help.

- Make a note of where you went; for example, the hospital, clinic, or doctor’s office.
- Record who you saw and what advice you were given.
- Make a note about how the hospital/clinic staff treated your child.
- What medications, if any, were prescribed, what you were told they should do for your child, and what were the side effects you should look for?
- Were there other tests, such as blood tests, etc.?
- Did the doctor ask you to bring your child back? If so, when?
- If medications were given, note what they were and how your child reacted to them. Did the drugs help? Were there side effects?

These notes can help you advocate for your child later down the road, especially if problems arise. You have a historical record of what was said and the circumstances around it (see next page for a sample journal page).

A journal can also help a new doctor 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. Perhaps this history will convince your doctor of the symptoms and that your child needs and deserves thorough, respectful medical treatment.

Preparing the Medical Staff for Your Child’s Visit

Never 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. Always be prepared. If it is your 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 know the person. They need you to help them understand who your child is.

Sample Journal Page

Doctor: _____

Date: _____

Reason for Appointment: Regular checkup
 Immediate health concern

Symptoms, if any:

Questions for the doctor:

Doctor's responses:

Medications, if needed: _____

Dose: _____

Possible side effects/Recommendations:

Follow up appointment: I need to call for appointment
 Doctor's office will call with date

If your child is sensitive to sounds, touch, new people, or new environments, let the medical staff know what they can do to make this visit more comfortable. These accommodations will help your child feel comfortable and give the medical staff a chance to see the person, not the condition.

You should always take your medical journal with you to let the doctor or nurse know about your child's medical history.

Prepare Yourself

When a child is receiving medical treatment, it can be a very unsettling time for parents. Make sure that you have the support of other parents and friends who will encourage you and stand beside you as you make medical decisions. The SACL Family Network

and advocates can help you when you need support. Knowledge is power. It is important that you prepare yourself by finding out about your child's disability as well as any treatments that are recommended. Ask the doctor about his or her experiences treating other children. Ask questions about your child's disability. New research is coming out all the time. Ask your doctor to check into the current research. Also check with disability-specific organizations, since they often know what new information is available about each disability. The Kinsmen Children's Centre in Saskatoon is a good place to find out what treatments and therapies are available. The University of Saskatchewan College of Medicine also has current medical journals on treatments for many disabilities.

Medical treatment should never be about curing a child's intellectual disability. It should be about making your child healthier and improving his quality of life. This is why it is important, especially in the midst of medical treatment, to help the medical staff keep your child at the centre of all interventions. Let the medical staff know who he is and what he needs.

A Parent's Advice

Do your own research! With many disabilities, new research studies and medical treatments are available. Through their own research, some parents have found treatments for medical conditions that were associated with their child's disability. Doctors are not always up to date on current research. Parents do not need to give in to hopelessness, nor do they need to look for a magic cure. There is a middle ground. There is information out there, mostly on the Internet, but also in very good books on the subject. It can be a little tricky to find because there is also a lot of misinformation on the Internet as well. Be careful, but stay open to new ideas.

QUALITY OF CARE COORDINATORS/PATIENT ADVOCATES

Recognizing that people could not always get their questions answered, the Ministry of Health recommended that the health regions create positions for patient advocates, also known as quality of care coordinators. These advocates help patients understand their rights and options, get patients' questions answered, and recommend changes and improvements in the health region. If you are having any problems with your health region, call and ask for the quality of care coordinator. You can find a listing of quality of care coordinators on the Ministry of Health website at http://www.health.gov.sk.ca/ph_br_ae_qual_of_care.html. There is also a provincial quality of care coordinator who can help if you have concerns about the services being offered by the Ministry of Health (787-6992).

"The medical community has been throwing around a catch phrase now called "quality of life" for a number of years. Their definition of quality of life and our definition of quality of life are two different things because they don't see us, the disabled community, as a priority."

Parent, Health Care Forum

The Children's Advocate (see Chapter 9) and the SACL advocates also frequently intervene when parents are struggling to get appropriate services for their child. If the issue involves your child's health or well-being, and the quality of care coordinator cannot help, do not hesitate to talk to an SACL advocate.

SPECIAL SERVICES FOR CHILDREN WITH DISABILITIES

There are specialized medical services and treatments for children with disabilities in Saskatchewan. The services available may help improve your child's or your family's quality of life. However, some parents have found it a struggle to access these services. For each service, you need to be referred by a doctor or another professional, so it is that much more important to have a good family doctor or a pediatrician who will refer your child.

The Kinsmen Children's Centre and Wascana Rehabilitation Centre

If you have a child with an intellectual disability, it is almost inevitable that you will end up receiving early intervention services at one of the central rehabilitation centres in the province. The Kinsmen Children's Centre (KCC) is located in Saskatoon and serves the northern half of Saskatchewan. The Wascana Rehabilitation Centre (WRC) is in Regina and serves the southern half of the province. If your child was born with an intellectual disability, then you may be referred to KCC or WRH from the hos-

pital. In any case, you need a doctor's referral in order to access these services.

Parents Take Note

Even though KCC and WRC are mandated to serve children up to age 18, usually it is the younger children that are able to access the majority of services. A coordinator explained that the younger your child is when referred, the better your chance is of getting in for therapy.

KCC, also known as the Alvin Buckwold Child Development Program, offers assessments, diagnosis, 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. They also have a resource centre where you can find information about disabilities and disability-related programs. Sometimes, KCC staff travel to northern and rural communities, so it is possible that you could be served at home. Contact your health region to find out.

WRC facilitates diagnosis and offers clinics, consultation, therapy, and information. The staff includes medical specialists, 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 diagnoses can be intimidating and overwhelming. The SACL advocates 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, the staff will send you a written report and ask you who else should receive it. 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. It is overwhelming once you are in the midst of these assessments and treatments. However, these centres are safe places to ask questions. KCC and WRC staff offered this advice about preparing for your visit:

- Write down your questions before you go to your child's appointment.
- Always let the staff know what your concerns are.
- If you don't 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.
- Use the services available, such as the social worker and the resource library.
- Fill out all the information on the forms you are given; it makes the process faster.
- If you are expecting to hear from us and have not, call and ask what is happening.
- If there has been a miscommunication of any kind, don't hesitate to ask questions.
- If you have to leave work to take your child to KCC appointments, talk to your employer about arranging for family time off (hopefully with pay).
- If you are travelling more than 40 km to get to an appointment, ask for a letter from our staff stating your appointment date. This will help you claim your travel expenses under the Medical Expense Tax Credit (see Chapter 11).

For those living in the northwest region, the Prairie North Regional Health Authority provides a coordinated team approach for identifying developmental concerns in children from birth until they go to school. A Therapeutic Integrated Pediatrics Services (TIPS) team may be composed of physiotherapists, occupational therapists, speech language pathologists, early childhood psychologists, KidsFirst, early childhood intervention program/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 is available on the website http://www.pnrha.ca/bins/content_page.asp?cid=21-127-7788&lang=1 or by contacting the main office for Primary Health Services at (306) 446-6400.

Complex Needs Case Management

If you are having trouble with the school because home care won't come in when it is convenient for the teacher or because the school board won't fund it properly, then it is definitely time for complex needs case management. Read the section on complex needs case management in Chapter 8 to see how you can get involved.

At the SACL we believe that case management should be available to families not only in times of crisis, but at all times. If case management services were available to everyone, many crises could be avoided.

HOME CARE AND INDIVIDUALIZED FUNDING

Some children require personal care support with things like toileting, eating, or suctioning. Home care is a program offered by the Ministry of Health to allow people with disabilities (both children and adults) to live more independently with the supports they need. You should be able to access respite support through home care to give you a rest.

To access home care you need to call your health region and ask for the home care program. Your child does not need a referral, but his needs will have to be assessed in order to access home care. The home care coordinator will look at your child's strengths and needs using a functional assessment, talk with you about the services, and then figure out how best to help. If you are turned down, there is an appeal process. You can call the quality of care coordinator (patient advocate) in your health region for more information.



The good news is that home care is the one area where parents have some options. Once your child has been assessed and approved for home care, you can access individualized funding (see <http://www.health.gov.sk.ca/individualized-funding>) and hire your own home care worker. This allows parents the freedom to employ whomever they want for approved support services, personal care, and home management. You will be responsible for recruiting, hiring, payroll, paying out worker's compensation, following the relevant legislation, reporting, and paying a home care fee. This sounds complicated, but parents who have used individualized funding say it is very simple once you get started, and it means one less system to deal with.

There is a free handbook about individualized funding at <http://www.saskvoice.com/SIFI%20Handbook%20June03.pdf>. If you have any questions about individualized funding you can call the SACL.

Nurses and therapists cannot be funded through individualized funding even though they are funded through the home care program. Do not be surprised if you are told that a home care worker cannot perform some of the tasks that you do for your child on a daily basis. They may insist that a nurse do certain things, even if it seems routine to you. There are guidelines in the health system about what a nurse can do and what a home care worker can do. What this means is that if your child needs a certain type of care, and a nurse is not available, you may lose your respite time. So far parents have not found a way around this inconvenience. Let us know if you do.

TELEHEALTH

Getting to Saskatoon or Regina to have meetings with medical specialists is often not ideal for parents. The Ministry of Health came up with a solution – Telehealth. With the goal of improving access to health care services, parents can talk with their child's specialist using video conference links instead of travelling back for extra meetings. Doctors

can use Telehealth for appointments, consultations, follow-ups, meetings, and education sessions. If it will make your life easier not to travel, ask your doctor about Telehealth.

EMPLOYMENT INSURANCE – COMPASSIONATE CARE BENEFITS

Filling out forms is not what you want to do when your child or relative is very ill, but if you apply for Employment Insurance (EI), you can take up to a six-week leave of absence. The EI benefit is called the Compassionate Care Benefits. You are eligible if your relative is gravely ill and at risk of dying in the next six and a half 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 and your husband 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 and a half months.

When you apply, you will need a medical certificate signed by a doctor as proof that your child 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. You can find the form on the EI website at http://www.servicecanada.gc.ca/eng/ei/types/compassionate_care.shtml#Sharing.

The doctor may charge you a fee to fill out the form. Then you must submit the form and proof of recent or current employment (pay stubs, or a record of employment) to the local office (information at the end of the chapter). If you have trouble with your employer, the local EI office can help. You will also need your social insurance number, personal identification, and information about your child and an explanation of the situation if you were laid off.

It takes about two weeks to process the claim. You do not need to submit monthly reports when you

are receiving Compassionate Care Benefits from EI. To be exempt, you need to fill out a declaration of exemption when you apply. With this form you are agreeing to notify EI if you start working again, receive money or if there is any other situation that affects your benefits. EI will provide details on what income you need to declare.

You will receive 55% of your earnings. If you receive the Canada Child Tax Benefit (CCTB), then you can also receive the Family Supplement. If you receive the CCTB and are not getting the Family Supplement, talk to an EI representative to find out why. If you do not agree with a decision that EI has made, you can appeal. For more information, check the EI website at <http://www.ei-ae.gc.ca/en/home.shtml>.

PROBLEM AREAS

At the SACL we have seen children with intellectual disabilities denied access to health care in specific areas. Sometimes you are told there is a waiting list, or your child does not fit the program's mandate. Keep advocating. These issues have more to do with political will and myths about people with intellectual disabilities than they have to do with waiting lists and criteria. We believe that the time is coming when all people with intellectual disabilities will be able to access the services they need, without question. Every parent who advocates for his child today is moving us closer to that goal. We will keep working together to make sure all people with disabilities get the services they deserve.

Dentistry

Finding a dentist for your child should be easy, and for most people it is. However, because of a lack of understanding about intellectual disabilities and the cost of special supports, many dentists are reluctant to have children who need accommodations during their dental visits.

Parents told us they have been denied services as soon as the dentist found out their child had an intellectual disability. In some cases, the dentist would

not even try to work on the child's teeth; he referred them to the hospital, where there is a three or four year waiting list. Most children with intellectual disabilities can and should be served in a regular dental office. Some will need extra time with the dentist and some will need things explained slowly. The dentist may have to be more creative about how he approaches his work. One dentist, who himself has a child with an intellectual disability, explained that the sooner you start bringing your child to the dentist, the more relaxed your child will be as he gets older. Through serving people with intellectual disabilities, he knows how simple accommodations can be.

Dental Lobby

When the Dental Residency Program at the University of Saskatchewan was scheduled for closure due to funding cuts, the SACL pulled together a coalition of stakeholders. The stakeholders urged the Ministry of Health to provide more funding to the program because it served so many children and adults with disabilities who are not able to get dental care anywhere else in the province. While the coalition was successful in keeping the doors open, there are still long waiting lists. We aren't satisfied. We will keep working with the Ministry of Health and the Saskatoon Health Region to reduce wait times.

For those who do need additional accommodations, such as general anesthetic, services are limited. The hospitals that do provide dentistry with general anesthetic have long waiting lists and are sometimes only able to serve patients who are in pain. Parents don't want to wait until their child is in pain to receive services. One parent whose child was in pain was still not able to access services.

Many parents would find this whole situation frustrating and give up, considering all the other pressing demands. However, if you know your child will be afraid of the dentist and will not allow dental work to be done, it is even more important to access

dental care at a young age. Whatever accommodations your child needs, dental services should be available.

Meet with the dentist ahead of your visit and explain to him or her who your child is and what she will need. Together you can have a plan in place.

Drugs as an Intervention

When your child receives a prescription from the doctor, you assume that the dosage is safe and that the drug is necessary. In our experience, we have seen children and adults with intellectual disabilities given drugs they don't need. Some drugs, known as anti-psychotic or anti-anxiety drugs, are only given to people as an easy way of restraining them. These types of drugs are referred to as PRN medication, prescribed to be taken "as needed." "PRN" stands for *Pro Re Nata*, which is Latin literally meaning "for the thing born." In medicine, it means, "as needed" or "as the situation arises." It means that using the drug is up to the caregiver or the patient as the need warrants. Because giving a medication PRN depends on a person's understanding of the situation, it is important that careful records are kept of when a drug is given and behaviours that lead to it being given.

When a doctor prescribes a drug, ask about the side effects. New information about the dangerous effects of drugs is not always made public right away, so it is good to check with other parents as well.

Always ask why the drug is being prescribed. Usually there is a very good reason. However, no one should have to take a drug simply to make the service provider or health care worker more comfortable. An adult with an intellectual disability explained that every time he went to the hospital for asthma treatments, the emergency staff gave him an Ativan, a drug used to treat anxiety, and sent him home.

One parent expressed her dismay at finding out that her adult son was regularly given mood-controlling drugs. She learned this only when he suddenly

stopped talking to her. Another parent explained that after many bad experiences at the hospital, her daughter became afraid whenever they went there. The medical staffs' response was to recommend a mood-controlling medication. The parents explained that their daughter did not need any medication like that, and that she was simply afraid (like anyone else would be who had undergone intolerable treatment in the past). Medication must never be about changing the person.

Medication at School?

For this handbook, parents warned that school personnel might ask that children with disabilities be medicated. Many parents have been told by schools that their children "must" be medicated in order to be at school. School personnel are NOT medical professionals. Do not let them force you into medicating your child!

The best advice from our parents is to keep asking questions until you get the answers you need. Make sure that the drugs and the dosages are necessary and appropriate for your child.

Do Not Resuscitate Orders (DNR)

A "do not resuscitate" order, sometimes referred to as a "Resuscitation Care Plan," is a way a person can let the hospital staff and emergency medical workers know what he wants them to do if his heart fails or if there is some other medical crisis. Without knowing the wishes of the patient, it is usually expected that medical workers will do what they can to resuscitate him.

This is not an easy issue for any of us to talk about, but it is necessary. If you feel uncomfortable with this topic even now as you are reading this, you may want to find a family member, friend, or a support worker with whom you can discuss the issue. We do recommend that you and your family spend some time talking about what you want if you are asked to consider a DNR. At the hospital with a sick child,

the most fragile time a family can face, the doctor may ask you to consider a DNR order.

First of all, when the doctor asks about it, they are doing so because they need to know what you want. Also, it means that your child is seriously ill and his life is in danger.

If you consent to the DNR order, it means if there is a crisis the medical staff will not intervene with CPR (cardiopulmonary resuscitation). Patients who do not want the doctors and nurses to use artificial means to keep them alive often give DNR orders. DNRs only can be placed on a person's charts if the individual or their parent/guardian consent.

How do you respond if you are asked about a DNR? Take your time. Find out why the medical staff are asking. If you are in doubt about what to do, find someone you trust to help you make the decision. Once you have decided, it may help to put your feelings in writing and have that letter attached to your child's file.

Mental Health Services

When a child has a dual diagnosis (an intellectual disability and a mental health disability), parents find it very hard to access adequate mental health treatments. Some doctors will think that every problem a child has is linked to his disability, and will refuse access to mental health services. Others will say that their programs are not effective for children with intellectual disabilities, so they will not treat him at all. This is simply a denial of access to health care. Under the *Canadian Charter of Rights and Freedoms* no one can be discriminated against because of their disability, yet this is a clear example of just that. And under the *Canada Health Act*, all services should be universally available and accessible to all people.

Your health region has no right to deny your child mental health treatment if he has been diagnosed with mental health problems. Accommodations may need to be made so that he can benefit from

the program, but he has the right to access. If you have been denied service, involve the quality of care coordinator for your area, or get a second opinion. You can also use the Canadian Mental Health Association (CMHA), which has locations around the province. CMHA is a non-profit organization and is not the same as mental health services through the health region. When asked about their services, they responded that they can and do serve people with intellectual disabilities.

“When I phoned mental health services (to request counselling for my daughter), they told me that they have never been required to provide mental health services for someone who has an intellectual disability. When they did respond, they wanted to perform a full psychological assessment to establish whether ‘counselling would even be of any benefit to her.’ I didn’t take that comment very well. It was minimizing, labelling, saying it can’t be effective.”

Parent, Health Care Forum

By advocating, parents have been successful in accessing wonderful, comprehensive mental health services for their children with intellectual disabilities. If you are told no, keep advocating.

Access to Therapy

When your child is young, it may be easier to access therapies. The health region provides speech and language pathology, physiotherapy, and occupational therapy. It gets harder to access therapy the older your child gets. The therapy services available when your child is young are still under-funded, but they are at least accessible. Once your child is of school age, the health region no longer funds therapies. What is considered a “medical” service becomes an “educational” service after the child reaches school age. This means it is up to the schools to provide therapy. Some will provide it, while others will only provide the bare minimum, or will not be able to find a therapist who will work for them. Parents often need to purchase therapy services privately. See

Chapter 11 on the Medical Expense Tax Credit to see how you can write off these expenses.

Something to think about – A Case Coordinator

A doctor experienced in working with children who have disabilities suggested that the biggest problem parents face is the lack of case management. Parents spend a huge amount of time chasing down solutions to each medical problem. Doctors often work in isolation with no one coordinating the child's care.

One health region addressed the problem: they hired a coordinator. Heartland Health Region employs a program manager who is responsible for what is called the CARRE Program. CARRE stands for Community Approached Rehabilitation, Respite and Education/Employment. Part of the responsibility of this program is to help families find their way through the service system maze. Families of children with disabilities in the region had identified that they needed a facilitator. There were too many gaps in the system and they needed someone to help them access the appropriate services for their children. The CARRE program manager is able to inform them about the services that exist, connect families with services, and also advocate for them.

The government has long been looking for ways to help families bridge the gap between departments and services. In the past, the Complex Needs Case Management Unit was working on this. This effort continues in 2010 through the Regional Intersectorial Committees. To find out more read the section on Complex Needs Case Management in Chapter 8.

We need to continue to advocate for more and better services in this area. Parents have enough on their plates. They do not need to be chasing down doctors and therapists. If you can access the Complex Needs Case Management services, then the health regions will begin to get the picture.

GRIEVING

One area of support where more work needs to be done for families of children who have an intellectual disability is the area of understanding grief. Grieving is a significant emotional process in the lives of parents who have a child with an intellectual disability. Research and experience show that parents can undergo grief twice during the lifetime of their child who has an intellectual disability. For some parents the first experience of grief is when their child is born or when they first learn of the disability. This is a real and valid experience of loss.³²

The other experience of grief can occur if a child dies before his parents. While medical advancements have meant that children with intellectual disabilities live for a long time, the reality remains that the parents of a child with an intellectual disability are more likely to outlive their child. So what help is there?

In *'When Your Child Dies You Don't Belong in That World Any More' – Experiences of Mothers Whose Child with an Intellectual Disability has Died*,³³ Deidre Reilly and her colleagues in Great Britain provide some insight on this topic. In the article they say research has discovered that the grief experienced by a mother of a child with an intellectual disability is more complex than for other parents. The explanation for this seems to arise from what is referred to as the disenfranchisement of grief. These mothers often feel the people around them undervalue their child as well as their loss.

This is not surprising in a society that has not yet learned to fully value individuals who have an intellectual disability. Friends, neighbours, and even extended family can feel, and sometimes express, that a burden has been lifted from parents when their child dies. When others undervalue your loss it means you have fewer people to turn to for support to help you cope with your grief.

MEDICAL RESOURCES

Quality of Care Coordinators

| Health Region | No Charge | Phone | Fax |
|---|-----------------------|--|--|
| Cypress | 1-888-461-7443 | In Swift Current call (306) 778-5115 | (306) 778-5108 |
| Five Hills | 1-888-425-1111 | In Moose Jaw call (306) 694-0294 | (306) 694-0282 |
| Heartland | 1-800-631-7686 | In Saskatoon call (306) 882-4111 (ext 239) | (306) 882-1389 |
| Keewatin Yatthé | 1-866-274-8506 | | (306) 235-4604 |
| Kelsey Trail | 1-877-573-6601 | (306) 752-8808 | (306) 752-2276 |
| Mamawetan Churchill River | | (306) 425-4823 | (306) 425-3298 |
| Prairie North in N. Battleford call in Lloydminster call in Meadow Lake call in rural areas call | 1-888-274-8506 | (306) 446-6587 (306) 446-6054 (780) 871-7921 (306) 236-1550 (306) 893-2622 (ext 7860) | (306) 446-6810 (306) 446-4114 (780) 875-3505 (306) 236-5801 (306) 893-2213 |
| Prince Albert Parkland | | (306) 765-6415 | (306) 765-6401 |
| Regina Qu'Appelle | 1-866-411-7272 | In Regina call (306) 766-7272 | (306) 766-7152 |
| Saskatoon | 1-866-655-5066 | In Saskatoon call (306) 655-1026 | (306) 655-1037 |
| Sun Country | 1-800-696-1622 | In Estevan call (306) 637-3642 | (306) 637-2494 |
| Sunrise | 1-800-505-9220 | In Yorkton call (306) 786-0735 | (306) 786-0422 |
| | | | |
| Saskatchewan Cancer Agency | 1-866-577-6489 | (306) 791-2767 | (306) 584-2733 |
| Provincial Quality of Care Coordinators | | (306) 787-2718 | (306) 787-6113 |

Regional Health Authorities

<http://www.health.gov.sk.ca/health-region-list>

| | |
|--|---|
| Cypress (Swift Current) | (306) 778-9531 |
| Five Hills (Moose Jaw) | (306) 691-6500 Toll-Free: 1-800-205-2273 |
| Heartland (Kindersley) | (306) 882-4111 |
| Keewatin Yatthé (Buffalo Narrows) | (306) 235-2220 Toll-Free 1-866-274-8506 |
| Kelsey Trail (Tisdale) | (306) 873-6600 |
| Mamawetan Churchill River (La Ronge) | (306) 425-2422 |
| Prairie North (North Battleford) | (306) 446-6622 |
| Prince Albert Parkland (Prince Albert) | (306) 765-6405 Toll Free: 1-800-922-1834 |
| Regina Qu'Appelle (Regina) | (306) 766-5279 Toll Free: 1-888-354-8111 |
| Saskatoon | (306) 655-3300 |
| Sun County (Weyburn) | (306) 842-8718 |
| Sun Rise (Yorkton) | (306) 786-0103 |
| Athabasca Health Authority (Black Lake) | (306) 439-2200 |

Canadian Mental Health Association

<http://www.cmhask.com/>

Phone: 1-800-461-5483

(Ask for your local branch phone number.)

Children's Advocate Office

www.saskcao.ca

Phone: (306) 933-6700 or 1-800-322-7221

Complex Needs Case Management, Regional Intersectoral Committees

<http://www.sasked.gov.sk.ca/hsif/rics.shtml>

Phone: (306) 787-5592.

College of Physicians and Surgeons

<http://www.quadrant.net/cpss/>

Phone: 1-800-667-1668

Families Experiencing Exceptional Loss (FEEL)

Phone (306) 244-5125

Kinsmen Children's Centre (KCC) Alvin Buckwold Child Development Program

http://www.saskatoonhealthregion.ca/your_health/facilities_kinsmen_about.htm

Phone: (306) 655-1070

Saskatchewan Association of Speech-Language Pathologists and Audiologists

<http://www.saspla.ca/careers.html>

Phone: (306) 757-3990

Saskatchewan Physiotherapy Association

<http://www.saskphysio.org/>

Phone: (306) 955-7265

Saskatchewan Registered Nurses Association

<http://www.srna.org/>

Phone: (306) 358-4200

Saskatchewan Society of Occupational Therapists

<http://www.ssot.sk.ca/>

Phone: (306) 956-7768

Saskatchewan Voice of People with Disabilities

<http://www.saskvoice.com/>

Phone: 1-877-569-3111

Wascana Rehabilitation Centre

http://www.rqhealth.ca/finding/long_term/wascana/wascana_rehab_hospital.shtml

Phone: (306) 766-5100

Help us keep up to date. If there are any changes or additions we need to make to Navigating the System, please let us know. Phone (306) 955-3344 or e-mail sacl@sacl.org.

Chapter 6: Assisted Living Devices

The United Nations Convention on the Rights of Persons with Disabilities says

States Parties shall promote the availability, knowledge and use of assistive devices and technologies, designed for persons with disabilities, as they relate to habilitation and rehabilitation.

From Article 26

In order to participate in daily activities, some children with disabilities use assisted living devices and aids. These devices and aids help with communication, getting around, agility, hearing, seeing, eating, accessing buildings, and personal care. If your child needs to use this type of equipment, we hope you have worked your way through the system and your child has the necessary supports.

However, some parents have missed out on opportunities to access certain assisted living devices

simply because they do not know that equipment is available. In a Statistics Canada study, 39% of people had unmet needs for specialized equipment.³⁵ Where that number includes our children, as parents and advocates, we need to access what we can and work to ensure that additional equipment and aids become available.

LEARNING MORE ABOUT ASSISTED LIVING DEVICES

Finding a comprehensive list of all assisted living technologies, aids, and devices is difficult. A good place to start is a website that Canadian teachers use as a resource for kids from kindergarten to grade 12. It covers a list of websites that have information about different devices, from special pencils to computers. It lists website links to find devices that will assist children with particular disabilities. You can read this resource book for free at <http://www.curriculum.org/tcf/teachers/projects/assistive.shtml> – look at “teacher-developed resources.”



WHERE TO FIND EQUIPMENT AND AIDS

There are two publicly funded depots in Saskatchewan that distribute and maintain many of the assisted living devices that your child might need. If a doctor prescribes a certain type of device for your child, you take the requisition to one of these places to be filled, just like taking a prescription to a pharmacy. There are also private companies and some disability-specific, non-profit agencies that provide equipment.

A Piece of Advice from Equipment Providers

The Saskatchewan Abilities Council explained that sometimes the fittings are hard on children. They try to make sure that a child sees the same staff person each time. In recognizing that you know your child better than anyone, they suggested that you call ahead if there are any specific things they can do to make the visit easier for your child. Good advice! You can call ahead and make sure that the staff at any organization know your child's needs before you even arrive.

The Saskatchewan Abilities Council (SAC) provides a variety of services for people with disabilities. It was formed in 1950 by parents who needed to access equipment and services for their children with cerebral palsy. Most likely when your child needs special equipment, you will go to SAC in Saskatoon to have it fitted and pick it up. However, there are also equipment depots in Regina, Yorkton, Swift Current, and Prince Albert.

The Wascana Rehabilitation Centre (WRC) in Regina also supplies and maintains orthotics and prosthetics that are paid for by the Ministry of Health. WRC is a long-term care facility and a hospital where children with disabilities can be tested, diagnosed, and given therapy. If you live in the southern part of the province, you may be accessing the Wascana Rehabilitation Centre for your child's therapy.

Contact information for all the service agencies mentioned is at the end of the chapter.

Equipment and Aids Available through the Ministry of Health

Many assisted living devices and aids are available and paid for through the Ministry of Health. 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. As with most government programs, there are always eligibility criteria, which means that your child will need an authorized health care professional to refer her for this service. The health care professional will likely be a doctor, a specialist, an occupational therapist, or a physical therapist.

Most of the time, people are able to access the assisted living devices and aids they need. If your child chooses a different type of product that is more expensive, the Ministry of Health may not cover it. One woman from Regina was denied any reimbursement when she chose a more expensive type of orthopaedic footwear. It is always best to check and see exactly what is covered before you make a decision.

It is also important to remember that there have been exceptions where people have received funding for things that are not officially covered. If your child needs equipment or aids that should be covered by health care, keep asking. Extra funding is available for children with complex care needs.

The following are the regular services offered by the SAIL program.

Special Needs Equipment Program

Mobility aids and assistive devices such as wheelchairs, walkers, specialized crutches, toileting equipment, transfer tub seats, commodes, bathtub lifts, hydraulic lifts and slings, hospital beds, alternating pressure point mattresses, and lymphedema equipment are available through the special needs

equipment program. This program is operated by SAC and funded by SAIL. Your eligibility is based on assessed long-term need. All items are loaned, not sold, and SAC does maintenance. Since it is on loan, you need to return the equipment if your child has outgrown it or no longer uses it. There may be a delivery charge if you are unable to pick up items

at one of the depots. You will need the requisition from the doctor/therapist and your child's valid health card.

Certain lower-cost items like raised toilet seats, grab bars, canes, and standard crutches are not covered by SAIL and must be purchased by parents.



There will likely be a wait of several months for certain items, such as powered or ultralight wheelchairs, due to the application process. To get these wheelchairs, you need a requisition from a physiatrist. A physiatrist is a doctor who specializes in physical medicine and long-term rehabilitation. If your child has not seen a physiatrist, ask your family doctor for a referral to make sure that you are receiving the best equipment that your child can get. If you are told no, keep advocating, maybe with a different doctor. You know what your child needs to lead to an inclusive and active life.

Orthopaedic Services

Prosthetic and orthotic appliances are available at SAC and WRC when you bring a requisition. These aids include specialized seating for wheelchairs, custom-built footwear, pressure garments, high-cost back and knee braces, splints, and artificial limbs. Your child will need to be fitted for these aids periodically as she grows. All of the aids are supplied, fitted, adjusted, and repaired at no cost through SAC and WRC as long as you have a requisition from a health professional. There should be no problem getting your child's orthopaedic devices, but there will be a wait while they are being moulded.

Respiratory Equipment

When children need respiratory equipment at home, SAIL funds it, but it may be complicated to access it. We have been told that respiratory services in Saskatchewan are inconsistent because there is no provincial program. Rural families and home care workers get frustrated because there is no reliable, easy way to set up respiratory equipment in the home.

If your child is leaving the hospital and needs a supply of oxygen, a respiratory specialist will prescribe a home oxygen therapy system. Your child may need a respiratory aid such as a suction machine, tracheostomy pack, ventilator, or CPAP (continuous positive airway pressure) machine. If the specialist prescribes this type of aid, you should expect help from the hospital to find community resources

in your area and to teach you how to properly use the equipment. The equipment (paid for by SAIL) might be ordered at the hospital, through home care, or picked up at a private medical oxygen supplier. There is no province-wide system for ordering this equipment, so you need to ask the hospital about the process for your area. Make sure to advocate for very close follow-up from medical professionals until everything is going well.

Parents should shop around to find a supplier that has a good service record in their community. The supplier should help them learn to use the equipment, be available to answer questions on the phone, and come to the home to help with troubleshooting.

Parents should have a back-up plan because equipment can fail. Inform your local hospital about your child's disability and the type of equipment she uses. It is good to have identified a back-up oxygen source. For families whose child needs suctioning, it is suggested they learn how to do it manually, just in case. No parent wants to think of equipment failing, but it is always best to be prepared.

All equipment will be given to you on loan, which means you need to return it when your child no longer requires it. The companies will also repair the equipment at no charge to you. The one piece of respiratory equipment that is only partially paid for by SAIL is an aerosol therapy compressor. Families are responsible for part of the cost as well as maintenance and repairs.

The Lung Association has qualified personnel to answer any questions you have about respiratory issues. SAIL suggests contacting the association for more information and advice. (Contact information for the Lung Association and SAIL is listed at the end of this chapter.)

Children's Enteral Feeding Pumps and Supplies

Feeding pumps and supplies are paid for by SAIL when your child has a gastrostomy operation, or uses a nasogastric or naso-jejunal feeding tube. One parent explained that the hospital released her child without teaching her how to use the feeding equipment or even where to get it. Don't let this happen to you. You can **expect that a hospital employee will help you** learn how to use the equipment and tell you where to order equipment.

You should not have to pay for the feeding pumps, bottles, tubes, or any other similar device. The hospital can send in a requisition to SAIL for the equipment and it will be sent directly to you. Even if you need extra equipment from private suppliers, such as syringes, SAIL can be billed directly if your child qualifies. One parent found out the hard way what SAIL actually pays for. After learning to use feeding tubes manually (a gravity feed), she found out that the only way the tubing is paid for is if you order a feeding pump as well. Parents who have been through the experience of receiving equipment from the government know how small loopholes can cause big problems. Make sure you know what you are entitled to.

Parents Be Aware

If you live in a small community, don't assume that your local doctor will know how to reinsert tubes or how to run equipment. We ended up teaching our doctors how to do it. I suggest having your specialists send your child's file directly to your doctor to pass any information along before a problem arises. That way you give your doctor time to do some research and be well prepared before you come in.

Special Benefit Programs

Children with certain disabilities receive extra coverage from SAIL. The Paraplegia Program covers extra services for people with paraplegic disabilities. Additional drug coverage, incontinence supplies (diapers), and specialized rehabilitation equipment is covered under this program. Financial assistance is also available to buy hand controls, ramps, and wheelchair lifts. This is important! If a hand control, ramp, or lift will make your child's life better, apply for the grant. There is more information on funding for home modifications in Chapter 11.

Parents Take Note!

If you have a child who DOES NOT have a physical disability, but who still requires incontinence supplies, they are not covered by the Ministry of Health. This is a huge expense for families, and something we need to advocate to change.

There is an Ostomy Program for those who need ostomy supplies and appliances. (An ostomy is a surgically created opening in the body for the discharge of body wastes.) Your child must be referred to the Ostomy Program by an enterostomal therapist. Make sure the therapist tells you everything you need to know about ordering and using the supplies. These items are reimbursed when you send your receipts to SAIL.

The Aids to the Blind Program covers the cost of equipment for people who are legally blind. Services are provided through the Canadian National Institute for the Blind (CNIB), Saskatchewan Division, in Regina and Saskatoon. The Saskatchewan Association of Optometrists is also involved in providing low-vision clinics. You can borrow magnification aids, low-vision glasses, braille, talking book machines, and talking calculators. (Contact information for CNIB and the Association of Optometrists can be found at the end of this chapter.)

Car Seat Loaner Program

The Saskatchewan Cerebral Palsy Association (SCPA) has a Car Seat Loaner Program for children who have outgrown regular car seats, but require head/trunk support to sit independently when using a seat belt. They offer a number of options to suit each child with a disability. Seats are loaned to SCPA members in Saskatchewan using manufacturers' criteria regarding height and weight guidelines. Parents will be asked for a \$50 deposit, refundable if the seat is returned in good condition. If parents want to buy one of these seats, the cost is around \$1,000. SCPA suggests that if you have had the same seat for longer than 10 years, it should be exchanged and that even a slight accident could cause structural damage to the seat. For more information call the SCPA (contact information is at the end of this chapter).

ADAPTIVE TECHNOLOGY AVAILABLE THROUGH THE MINISTRY OF EDUCATION

Your child's education may be enhanced by adaptive technology to help her communicate, read, write, or do math. Computer technology can help some children increase their independence in the classroom and their learning opportunities. This isn't just about school; it is about your child's ability to communicate with and understand the world around her. This type of technology has opened doors for people and allowed many people with disabilities to work at regular jobs.

If your child uses non-verbal communication, or if it is hard for many people to understand her speech or writing, the school may have already suggested an assessment for adaptive technology.

Some parents seemingly need to fight for everything in the school system, while others have support offered to them. If the school is not doing everything it can to enhance your child's learning, keep advocating. The school might tell you that it cannot af-

ford adaptive technology. As a parent, you need to know that school divisions can receive grants for approved technical aids. This means that if they get your child assessed, and it is established there will be a benefit from the aids, the Ministry of Education will give the school division a grant to pay for the equipment. Here are the steps, as outlined in the *Children's Service Policy Framework*, the school must go through to get your child adaptive technology.³⁶

- Your child must be designated as a student with a disability. This is described in section 50 of the Education Regulations, 1986. A designation means that the school receives extra funding for your child's education and will facilitate a Personal Program Plan (PPP) to accommodate learning needs and set educational goals. The use of any technical aid must be written in your child's PPP.
- A professional who has expertise in technology and children with disabilities must do an assessment. In order to get the technical aid paid for, the school division must use a professional in the assessment, set-up, maintenance, and ongoing support to the child. Usually the schools go to SAC for assessments, since they have an adaptive technology department that supports people with disabilities. You can call SAC if you have any questions about adaptive technology.
- The technical aid must be approved. The aid must help your child learn in a way that is not possible without the aid. The school division fills out a Technical Aids Cost Recognition Form and a Technology Implementation Plan and submits them to the regional Superintendent of Children's Services. The superintendent gives prior (written) approval and then the school division is allowed to buy the technical aid.
- The school division must return the equipment if the "designated student" is not using it anymore. For more information contact the office of Student Support Services of the Ministry of Education.
- The school division is responsible for the cost of maintenance, repairs, and insurance for the technical aid.

When your child is finished high school, she may still need a technical aid for communication or learning. If she goes on to post-secondary education, she is allowed to keep the technical aid or equipment she was using in high school. If the Ministry of Education does not let her keep the equipment, SAC supplies technical aids to adults with disabilities. An electronic technologist at SAC explained that for individuals to receive technical aids, funding has come from service groups such as the Kinsmen Telemiracle, the Lions Club, and the Legion. He also said that Social Services has occasionally provided minimum funding for equipment, but not usually more than \$500. Some groups only fund children, so if your child needs a technical aid that you cannot afford, it would be best to access funding opportunities before she reaches adulthood.

ASSISTED LIVING RESOURCES

Canadian National Institute for the Blind (CNIB) Saskatchewan Branch

<http://www.cnib.ca/en/mb-sk>
 Regina (306) 525-2571
 Saskatoon (306) 374-4545

Canadian Paraplegic Association (Saskatchewan) Inc.

<http://www.canparaplegic.org/en/>
 Phone: (306) 652-9644

Lung Association of Saskatchewan

<http://www.sk.lung.ca/>
 Phone: 1-888-566-5864
 E-mail: info@sk.lung.ca

Saskatchewan Abilities Council (SAC)

<http://www.abilitiescouncil.sk.ca/>
 Regina (306) 569-9048
 Provincial Services (306) 374-4448
 Saskatoon (306) 653-1694
 Swift Current (306) 773-2076
 Yorkton (306) 782-2463
 Prince Albert (306) 922-0225

Saskatchewan Aids to Independent Living Program (SAIL)

<http://www.health.gov.sk.ca/aids-independent-living>
 Phone: (306) 787-7121

Saskatchewan Association of Optometrists

<http://www.optometrists.sk.ca>
 Phone: 1-877-660-3967

Saskatchewan Cerebral Palsy Association

<http://www.skcerebralpalsy.ca/>
 Phone: 1-800-925-4524 or (306) 955-7272

The Tetra Society (a non-profit organization offering free, customized assistive devices)

<http://www.tetrasociety.org/>

Wascana Rehabilitation Centre

http://www.rqhealth.ca/finding/long_term/wascana/wascana_rehab_hospital.shtml
 Phone: (306) 766-5100

Help us keep up to date. If there are any changes or additions we need to make to Navigating the System, please let us know. Phone (306) 955-3344 or e-mail sacl@sacl.org.

Chapter 7: Inclusive Recreation & Sport

The United Nations Convention of the Rights of Persons with Disabilities says

States Parties shall take appropriate measures: To ensure that persons with disabilities have access to services from those involved in the organization of recreational, tourism, leisure and sporting activities.

From Article 30

What activities are suitable for children with disabilities? The answer is all activities. Anything that your child is interested in should be open to him. This chapter can help you think about what a full life in the community will look like for your child.

A Vision for Inclusive Recreation

- Recreation is fun and voluntary.
- Regular recreation programs will take responsibility to address the leisure needs of all citizens, even if they happen to have a disability.
- Support is available if it is needed to facilitate participation in any activity.

Ski trips, swimming, water fights, baseball, skating, craft days, horseback riding, camp fires, and playing in the park – these are the memories of childhood. No child should be denied these opportunities. Your child loves to have fun and enjoys the same recreational activities as every other child. And you know that he has no trouble having fun when he is accepted, supported, and included. As your child's advocate, you may need to teach recreation staff how to include him. For some people the idea of inclusive recreation may take some thinking outside the box. Recreation staff may lack the experience to make inclusion work. Helping people overcome



their prejudices about your child's abilities is part of being an advocate.³⁷

BEYOND SEGREGATED RECREATION

People with intellectual disabilities are often limited to segregated recreational activities where they do the same things over and over again. Parents are demanding more for their family members with intellectual disabilities. These parents want their children in regular activities. Their children belong there, but it is a lack of awareness and a lack of information that keeps them out. The current generation of children with intellectual disabilities joins girl guides and boy scouts, goes on class field trips, takes art, dance and music classes, and attends regular summer recreation programs and camps with their peers who do not have intellectual disabilities.

For these boys and girls, the benefits of inclusive recreation will be huge, both now and throughout their lives. Here are a few benefits for those who need some convincing:³⁸

Real Inclusion

*The video **Over Land, Over Water: A Costa Rican Adventure** demonstrates true inclusion. A high school class taking a trip to the Costa Rican jungle included a young man with cerebral palsy. Adam Zimpel defied everyone's expectations and joined his class of 22 students through muddy mountain hikes, a waterfall, horseback riding, and boating. Members of his class developed a harness to carry him on the long hikes in order to make sure he didn't miss anything. Inclusion was part of the adventure for this class. Every class should have this kind of opportunity and challenge.*

- **Quality of Life** — We all need leisure to make our life satisfying and fun. Children with intellectual disabilities are no different. Recreation is not about keeping children busy; it is about enjoying life.
- **Self-Esteem and Self-Confidence** — Children with intellectual disabilities participating in activities with their same-age peers helps all children to see that differences are normal and that everyone can participate. This raises all children's self-esteem and self-confidence.



- **A Stepping Stone to Community Living** — All children naturally build co-operation, communication, and social skills when they are involved in structured recreation activities. Every child will grow up knowing that children with intellectual disabilities belong in the community, just like everyone else.
- **Numerous Health Benefits** — Recreation reduces stress and social isolation while improving both physical and mental health.
- **Friendship** — Children are together where they belong and where they can develop new friendships. These friendships are based on the connections that are built while children participate in community recreation activities and programs. When they are participating together, it is natural that friendships occur between children who are diverse.
- **Self-Discovery** — When people are involved in recreational activities, they find out new things about themselves. Through recreation, your child can find out that he has talents and gifts, enjoys adventure, has a lot to teach others, can master certain skills, and can express himself in a creative way. He will develop a sense of belonging and a feeling of accomplishment.³⁹

Everybody's Playground

A completely accessible playground is possible. All you need is a few determined, visionary parents. Believing that no child should be left out, a motivated group of parents in Saskatoon formed a committee to build a barrier-free playground so that all children could play. The Everybody's Playground Committee of the Erindale/Arbor Creek Community Association raised funds and saw its dream become a reality. Now all children are included.

Not every type of recreation is available to children with disabilities...yet. We have some work to

do. Some of the barriers to inclusive recreation are a lack of transportation, information, or funding; inaccessibility; and, of course, that sometimes children with disabilities are simply not welcomed.⁴⁰ We know that if the determination is there, ANY activity can be adapted to be inclusive, even for children who need to participate in a modified way. If your child has a physical disability as well, it might take some more creativity, but it can be done. This chapter includes ideas about adapting activities and finding the support you need to make inclusive recreation work for your child.

HOW TO MAKE RECREATION INCLUSIVE

People who coordinate recreational activities may not know how to adapt activities for children with intellectual or other disabilities. The first thing to remember is, **adapt only when necessary!** Children with intellectual disabilities are more similar to their peers than they are different. There are lots of great books on adapting equipment and activities for people with disabilities. Here are a few general tips to help make recreation inclusive:⁴¹

- Make instructions specific, precise, and brief
- Use plain language
- Check to see if the children understood clearly
- 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
- Teach the children how they can encourage each other; positive reinforcement is more meaningful coming from another child
- Use co-operative learning
- Don't rush the children
- Build in routines and repetition (but make sure it is not boring)
- Use a buddy system so that all children are engaged
- If a child communicates differently, help the other children understand how to communicate with him

- Work with the parents to set short-term and long-term goals for a child with a disability and write them down

Adapt only when necessary!

One parent explained that her best advice is to start with the attitude that any child can be included, and add support only when it is necessary. Parents of children with intellectual disabilities have sometimes been surprised at how well their child did in a regular recreation setting without any plan or extra support in place. Inclusion sometimes works best for children when there is minimal intervention. Of course, in many other cases, there are barriers that get in the way of inclusion that require some facilitation and a plan to be in place. You know what is best for your child.

RECREATIONAL CLUBS AND CLASSES

There are endless clubs and classes for children, from 4-H clubs to computer classes, from modern dance to interpretive nature walks. Communities often publish a leisure activity guide every year explaining what is available for children. Community-based leisure activities are not expensive and are well attended, giving children lots of opportunities to make friends. The good news is that many children with disabilities are already included in regular activities.

Parents may be reluctant to sign their child up for regular programs because his participation will require extra supports or planning. A SACL advocate suggests that you visit the program coordinator and inquire about including a child with an intellectual disability. Talk to the coordinator about your child's abilities and how he is integrated in other recreational activities like school field trips, gym, and art classes. Ask to watch the activities in action so you can see for yourself what could be a barrier to your child's inclusion. The main reason why inclusive rec-

reation may fail is because of structural and attitudinal barriers. Parents can challenge the recreation coordinator to think strategically about the barriers that prevent some children from participating. You can help the coordinator by letting him know how to support your child.

Recreation centres and organizations are often run by local boards. They may already have a policy about inclusion, or they may be open to putting a policy in place. If you see barriers that are not easy to overcome, request a meeting with the board or the management of the program. Some activities may not be inclusive yet because no one ever asked to enroll a child with an intellectual disability. Offer to be an advisor or be involved in planning to make the program more accessible to everyone.

Remember that you can use respite money to hire a companion or support person.

Sports and Physical Activities

Sports and other physical activities are a great way to have fun and stay fit. Some parents would rule out this option, thinking that their child would not feel accepted or be able to participate like other children. However, many children with intellectual disabilities have excelled at sports and found a place where their disability goes unnoticed. They are part of a team that relies on everybody's best effort in order to finish well.

Developing a Healthy Lifestyle

Some adults with intellectual disabilities struggle to stay physically fit. When they were young they were left out of physical activities, so they haven't made fitness part of their lifestyle. Poverty and some types of medication only make it harder to maintain a healthy weight. Everyone needs to make physical activities part of their lifestyle for fun and fitness. Developing a healthy lifestyle starts in childhood.

Other people are simply not athletic or do not participate in the typical way. There are lots of ways of

adapting sports and other activities to make them accessible for children with physical challenges. It is good to remember that not every sport or every physical activity is about being the best. There are plenty of physical activities like walking, swimming, golf, and aerobics that do not need to be competitive, but are still physically beneficial. Being active with others and having fun should be the primary goals.

When your child is young, it will probably be easier to integrate him into regular physical activities. He should be learning about sports in gym class at school and discovering activities he likes. As he gets older, and some sports teams become more competitive, it may be more difficult. If it is something your child loves, keep looking, and keep advocating. Not every team is competitive. Some community groups offer recreational sports that allow people at different levels to get involved.

Summer Camps

Children love going to camp. They get away from their routine for a week, stay up late, sing songs around the campfire, meet new friends, eat camp food, and spend their days outdoors. If you have

not sent your child to camp before, you are missing a great opportunity. Every summer many children with intellectual disabilities have attended regular camps. Most camps are happy to include all children. Some parents have even found that their child does not need extra support beyond what the camp offers.

Start with the Saskatchewan Camping Association website at <http://www.saskcamping.ca/>. You can find out which camps are in your area. Most camps questioned said they would include a child with an intellectual disability, although some required additional supports to be in place. Some regular camps made additional arrangements when parents requested it to make sure a child's needs were met.

If your child does need additional support, a camp companion or home care worker could be the solution. Some parents have used CLSD respite dollars to pay for a camp companion. Also, some local branches of the SACL and other disability groups offer Camp Companion programs each summer. As well, some parent advocates received funding from local service groups. If your family's income is low, there is a financial program to send kids to camp through the Saskatchewan Camping Association.





Volunteering Opportunities

With a busy schedule and family life, you may not have thought at all about volunteer work. As your child grows up, this can be a good way to get him involved in the community. 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 almost any 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 something you could do as a family even with younger children. One family of a child with an intellectual disability all volunteered together at the SPCA, helping take care of and selling the pets at a shopping mall location. Becoming a volunteer will create new friends and new experiences, and help the community at the same time.

RECREATION RESOURCES

John Dolan/SACL Collection at the Stewart Resource Centre at the STF Saskatoon
www.stf.sk.ca

Phone: (306) 373-1660

Ministry of Tourism, Parks, Culture and Sport

<http://www.tpcs.gov.sk.ca/>

Phone: (306) 787-5729

Saskatchewan Camping Association

<http://www.saskcamping.ca/>

Phone: (306) 586-4026

Saskatchewan Parks and Recreation Association

www.spra.sk.ca

Phone: 1-800-563-2555

Help us keep up to date. If there are any changes or additions we need to make to *Navigating the System*, please let us know. Phone (306) 955-3344 or e-mail sacl@sacl.org.

Chapter 8: Planning for the Unexpected

When you have a child with a disability, there are emergencies that cannot wait for the process and paperwork. You need immediate support, whether it is respite or financial or emotional support. The best plan is to build a support network and find out what is available before a crisis happens. Parents and advocates have suggested a few tips and resources that may help you plan ahead for a crisis.

SURROUND YOUR FAMILY WITH SUPPORT

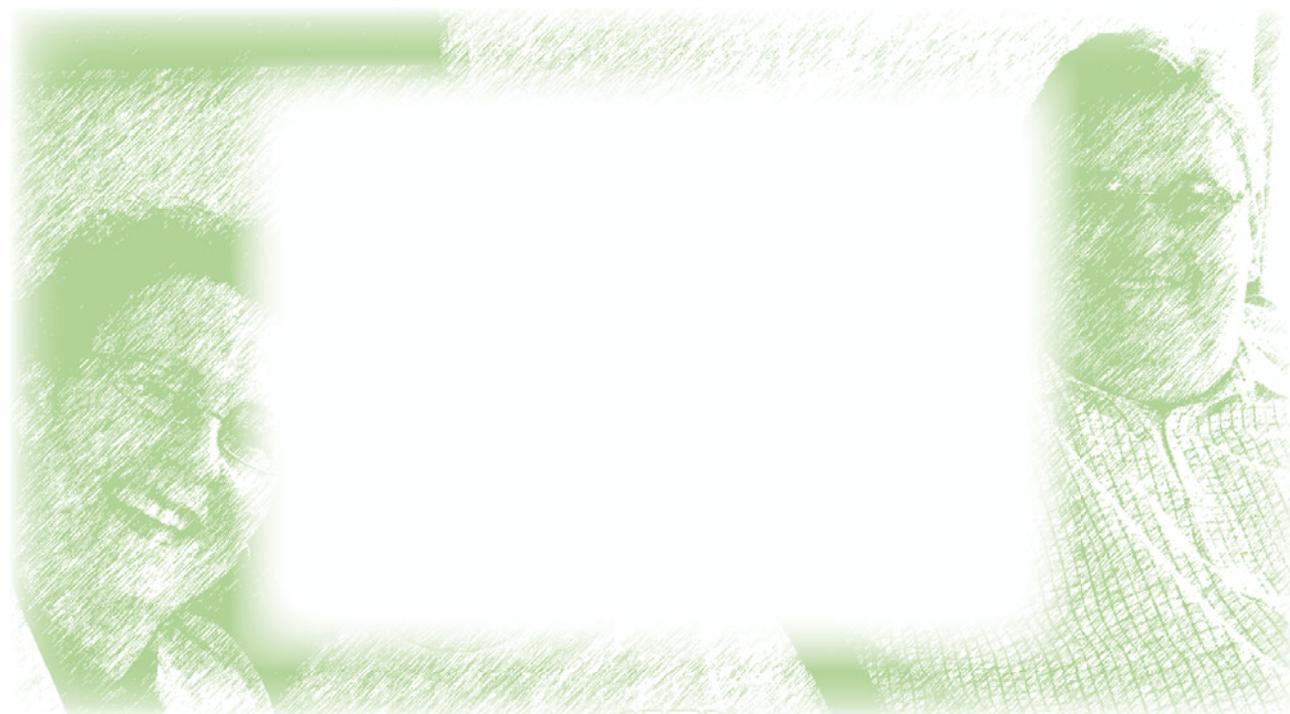
Building a support network for yourself and your family is the best way that you can prepare for a crisis. Parents who have gone through a crisis often say they couldn't have made it without their friends and family. Don't wait until the crisis to build the network: start now.

Your network does not need to be a large group – three or four people is likely enough. A network can begin with your immediate family and include

friends and neighbours you trust and who understand your family. Let people know that you see them as part of your network and that you rely upon their support and advice. Keep them up to date on what is happening with your family.

If possible, it is good to include other parents who have a child with a disability and who have the experience, knowledge, and information to help you make it through. Other families who have a child with a disability are an incredible support when you feel like no one else is listening. If you don't know other families, the Saskatchewan Family Network at the SACL can connect you to other families in your area who can offer support and share information. The members depend on each other for friendship and support when they have a crisis happening, but also with the regular struggles of daily life.

It is advisable to go to meetings with someone from your network or a person(s) you trust. To be clear, this means if both mom and dad are at the meeting, take a third person. This is especially true during a



crisis: it is important to have an extra person who supports you; who is not as emotionally involved; and who can listen, take notes, ask questions, and confirm or clarify what is said. If you would like the support of a SACL advocate, call us at (306) 955-3344 to get the name of the advocate in your region. Your Social Services worker or your CLSD case manager may be a support person for your family at any important meetings.

Confidentiality?

Be assertive with your choice to bring part of your network to meetings. It is up to you as the parents to include or not include an advocate in a meeting about your child. You can sign a release form to allow your advocate to attend. Don't let anyone tell you any different.

Make sure you take well-deserved breaks where someone else can take care of your children. Using formal or informal respite will give you a chance to collect your thoughts and rest. Without regular periods of rest, a crisis will only become more difficult to manage.

Friends cannot guarantee that a crisis will not happen. However, the more people your family has in their circle of support, the better chance you will have of finding the solutions and immediate support you need.

Remember to surround your family with information. It is best not to wait until there is a crisis to learn about the supports that are available. Ask questions about programs that you think you might need one day. Ask your CLSD worker to tell you about programs and supports that could assist you in a crisis. Take the time to learn. The following are some of the programs and supports that you might need in a crisis.

THE COGNITIVE DISABILITY STRATEGY

The Cognitive Disability Strategy (CDS) began in 2005. The primary focus is for people who are 6 to 24 years old, however, requests from all ages may be considered. It is a concept of planning, not an agency someone is referred to. It is a partnership between all Government systems to support individuals who meet the five criteria with the goal of meeting unmet needs.

The Cognitive Disability Strategy's criteria are:

1. Significant limitations in learning and processing information. Individuals are limited in retaining knowledge, learning skills, making decisions, and communicating with others, and
2. Behaviour challenges which result in limited inter-personal, social, and emotional functioning, and
3. Developmental challenges which limit capacity to adapt to daily living in areas such as self-care or independence at home, in the community, at work, or at leisure, and
4. Limitations and impairments that are persistent and long-term, and
5. Have an unmet need

The Cognitive Disability Strategy is meant to

- Improve the availability of assessment and diagnostic services
- Provide services to address the unmet needs of people with cognitive disabilities and their families
- Provide training opportunities to enhance the knowledge and skills of people who provide services to individuals with cognitive disabilities
- Enhance Fetal Alcohol Spectrum Disorder prevention and intervention initiatives throughout the province
(Priorities may vary depending on the region you are in)

The CDS has offices and consultants throughout the province. (See the contact list at the end of this

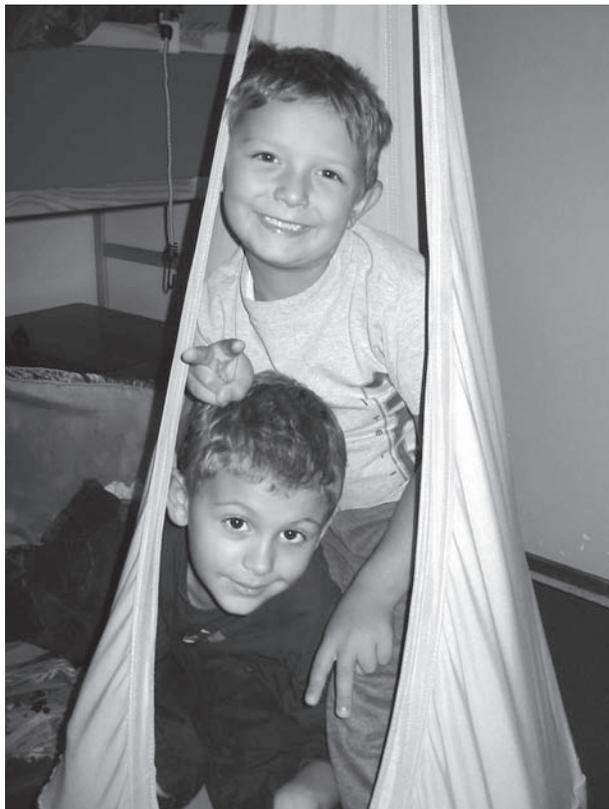
chapter.) The consultants offer assistance to families in finding services and support within their community. The consultant has 4 roles:

1. Training (Community Capacity Building)
2. Increased Awareness of Cognitive Disability Strategy
3. Enhanced Consultation to Planning
4. Behavioural Support/Consultation

If you believe that you have unmet needs, you should contact a staff person within one of the organizations (government, education, or health for example) that you are already involved with. The worker will help you see if there are any existing agencies that can provide supports and services to meet the unmet need. If there is no one that can meet the unmet need then you may want to apply for Cognitive Disability Benefits.

Eligibility for Cognitive Disability Benefits is based on the following pieces of information:

1. That there is an unmet need that no existing system or service can meet.
2. Income testing, meaning it is based on com-



bined family income or the individual income (over 18 years of age) from line 236 of the most recent Income Tax Return.

3. The Daily Living Support Assessment (DLSA). The DLSA will be completed by a trained person. The assessment is done by interviewing the primary caregiver of the person being assessed. The areas covered are dependence, behavioural, health, and educational/vocational. When the assessment is scored, a level between 1 and 5 will be identified to determine your child's level of care needs.

Once an application has been made for funding, the application is reviewed by a regional committee. This committee will forward their recommendations to a provincial coordinator. The provincial coordinator will send a letter letting you know if the request has been approved.

The process to apply for benefits will vary from region to region. Use the contact list at the end of this chapter to get more information about the process for applying for benefits in the area where you live.

For more information and background on the Cognitive Disability Strategy, read the action plan online at http://www.health.gov.sk.ca/fs_cognitive_disabilities.pdf.

BEHAVIOURAL SUPPORT PLANS

A crisis may happen simply because someone has misunderstood your child. If your child has behaviours that people find challenging, a behavioural support plan can prevent this kind of “meltdown” from happening. A behaviour support plan can be built into your routines at home and any activity your child is involved in. All behaviour is communication. Preventing a crisis starts with learning about your child's reactions to his environment and how you can support him. You can help others learn how to respectfully support your child before a crisis happens.

There are people who develop behaviour support plans for children and adults with challenging behaviours. Often psychologists, behaviour consultants, and psychiatrists will be involved when a support plan is being developed. Schools have professionals available to develop support plans for students. If your child has behaviours that school staff find challenging, they may encourage the development of this kind of plan. Also, CLSD has program development consultants who can help parents, educators, and support workers develop a support plan and implementation strategies for both adults and children with disabilities. The consultants can also set up structured learning programs and do assessments, program consultations, and evaluations.

Your CLSD worker can refer your family for an assessment with a program development consultant. The consultant will come to your home and ask you questions. Sometimes they may observe your child or ask you to keep a record for a short period of time. Some of the information the consultant is looking

for are 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. Collaboration with parents is essential to create a plan that works.

Challenging behaviours need to be taken seriously, but people need to look beyond the behaviour to the bigger picture. The goal of Comprehensive Behaviour Support (CBS) plans is to be proactive and create a safe environment where the individual feels accepted. Building a meaningful life and reducing stress, fear, and loneliness will affect the person's behaviour.

There are four parts in the CBS that make up a support plan: ecological changes, positive programming, focused support, and responsive strategies.



These ideas can help you think about the kind of support you want for your child.

There is always a reason, an event leading up to or a trigger for behaviour (an “ecological” change). Listening to a person and finding the trigger can support him as you 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 can be an important tool for empowering people. Teaching assertiveness can help a person communicate better. Learning to substitute a challenging behaviour for a more positive one can help an individual socially. Understanding the meaning of the behaviour will help the workers/teachers respond to the person’s needs.

Focused support must be done with a careful assessment of everything that affects the person. With a deep understanding of an individual, modelling and reinforcing good behaviour can be respectful. Watch for red flags and 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 his own behaviour and work out new solutions.

A responsive strategy is something that keeps people safe when behaviours do occur. An intervention should never be more restrictive or intrusive than is necessary. Respect for the person and their dignity is always critical. To keep the behaviour from intensifying, ask what is wrong, get closer to the person, use humour, ask him to stop, help him relax, or change the focus. If the behaviour is already intense, he might need space. He must never be punished, embarrassed, or feel pain of any kind as a response.

EMERGENCY INTERVENTION THROUGH COMMUNITY LIVING SERVICE DELIVERY

Some families may be reluctant to get involved with government programs, especially if it means filling out forms and going through intrusive interviews. One benefit of having a CLSD case manager is that if a crisis were to happen, it is far easier to access the support you need if they know your family already. Do not wait until the crisis happens; it will be harder to access help.

If you are in crisis and have a CLSD worker, what happens then? CLSD case managers can step in and set up services if your family is in crisis. You will have a meeting to set up an emergency contract that will allow them to put services in place. There is always extra funding available for emergencies, or when a family is in crisis and needs extended respite, a day program, or a residential placement for their child.

If you are setting up an emergency contract with a CLSD worker, take a friend or an advocate with you who can help you testify to what you have been experiencing. It helps to give the CLSD worker more information about the situation – what has been tried and how it failed. If you have no energy to explain the situation, your support person can speak on your behalf. Setting up an emergency contract can feel stigmatizing, but it can provide the services your family needs to get through the crisis. 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.

SACL ADVOCATES

If your family is in crisis, or just needs advice, the SACL employs experienced advocates to support individuals and families and to 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.

Often when there is a family crisis, the stress could be reduced if appropriate, flexible supports were in place. Many systems are still rigid and leave families vulnerable at the times they need the most help. The SACL advocates will help you find the right people in the system to talk to and bring them to the table so that a solution is found.

The SACL advocates can help your family member with a disability in the areas of

- financial issues, SAP, SAID
- respite
- education
- human rights
- abuse
- physical and mental health
- technical aids and supports
- where to live (supported living, approved private service homes, group homes)
- transition planning (MAPS, PATH, supported decision making)
- employment
- recreation and leisure
- life skills
- legal issues, including co-decision making, guardianship/trusts/wills and estates, justice, legal aid, or issues with police or with regard to access to/custody of children.

The goals of the SACL advocates are:

- to provide a voice
- to work with people, not for people
- to bring about awareness and change
- to empower people

- to provide hopeful strategies
- to listen⁴²

Some local branches of the SACL have staff and volunteer advocates who can also help you find solutions and support. They have experience in your community, and know what is available. The Prince Albert and Lloydminster branches of the SACL have volunteer advocates who have developed a significant number of services and promoted real inclusion in their areas. The Regina and District and Saskatoon branches of the SACL have paid staff who can advocate for families. They have also been successful in working for changed attitudes and better supports in their communities.

DUAL DIAGNOSIS

Families are sometimes left in limbo when they are told that their child has a dual diagnosis. Service providers are reluctant to deal with a child they have determined does not fit their mandate.

Advice from an Advocate

The mental health worker may tell you that he or she cannot serve your child because his intellectual disability prevents him from understanding the methods they use. Methods can be adapted! Don't take no for an answer.

The child psychiatrist that diagnoses your child can recommend services. If you are told no at mental health, insist that they find a way. Go higher up. Involve an advocate. Just because your child has an intellectual disability does not mean that he cannot receive services like every other child. It is discrimination to deny him necessary services. You may need to suggest an outside facilitator who can come in and help modify the program to fit your child.

SEXUAL OR PHYSICAL ABUSE OR ASSAULT

No one likes to think of abuse, but for many people with intellectual disabilities, abuse is a horrifying reality. Abuse can happen anywhere. If your child or adult son or daughter has been abused, involve a SACL advocate. An advocate can step in and make sure that a proper investigation is done and that your child is respected and supported.

For your child's healing, she will need support and counselling. In every town and city in Saskatchewan there are crisis centres and hotlines for people who have been abused or assaulted. Involving your child in regular counselling will allow her to know that she is not to blame and that she is not alone. If the crisis centre feels it needs additional support to adapt the counselling, your CLSD worker should provide the additional support. These crisis numbers are always available at the front of your phone book.

The best way to prevent this type of crisis is to teach

your daughter or son about their sexuality and about abuse. The more they know, the better they will understand their personal desires, boundaries, and how to say no. They will also know what to do if they are attacked. The John Dolan/SACL Collection at the Stewart Resource Centre at the STF offices in Saskatoon (Phone (306) 373-1660 or go online to www.stf.sk.ca) offers a variety of resources and kits developed for people with intellectual disabilities.

COMPLEX NEEDS CASE MANAGEMENT

When children have complex care needs, including challenging behaviours or health concerns, it is difficult to coordinate services and get government departments and community services to work together. Crisis can be a regular experience for families with these challenges. They hope that services will fall into place and what they find are wait lists, rules, and criteria that shut out their children. Service providers can be very good at telling parents what they cannot do for them. Parents spoke out about the



lack of coordinated services for their children with complex care needs and their voice was heard.

The Human Services Integration Forum started because there was a need to develop holistic, integrated human services. The ministries involved in the forum are Health, Education, Social Services, Corrections, Justice, Indian Affairs, Culture, and the Executive Council. The forum works to bring everyone to the table to talk. Once the process is started, there will be meetings to make sure that all the problems are addressed. Conflicts have been resolved between families and schools, hospitals, and home care services, just to name a few.

The hope is that the forum will be able to support interagency planning and service delivery, reduce barriers, offer education and policy support, and use resources effectively. For parents of children with complex care needs, this means that there are people who can actually help you get a plan in place

so that your child has the necessary services. Unfortunately, the forum does not have the authority to make all the departments comply or participate with the plan, but it can get the process going and keep communication from breaking down. Parents of children who have benefited from complex case management are amazed by the difference. With all parties at the table, things get done.

A Parent's Experience

"Complex case planning made a tremendous difference. There was no more blaming or fighting once everyone was at the table. We began dealing with issues together and everyone took responsibility and kept on communicating."

For more information about Complex Needs Case Management or the criteria, call the Human Services Integration Forum at (306) 787-5592.



PLANNING AND INTERVENTION RESOURCES

Client Patient Access Services (CPAS)

Phone: (306) 665-4346

Cognitive Disabilities Strategy Consultants

| | |
|----------------------------|----------------|
| Athabasca Health Authority | (306) 439-2200 |
| Cypress | (306) 778-8476 |
| Five Hills | (306) 691-1569 |
| Heartland | (306) 778-8476 |
| Keewatin Yatthe | (306) 833-3383 |
| Kelsey Trail | (306) 752-8767 |
| Mamawetan Churchill River | (306) 425-6671 |
| Prairie North | (306) 875-3363 |
| Prince Albert Parkland | (306) 765-6055 |
| Regina Qu'Appelle | (306) 751-5659 |
| Saskatoon | (306) 955-3344 |
| Sun Country | (306) 786-1384 |
| Sunrise | (306) 786-1384 |

Community Living Association Saskatoon

<http://www.clasaskatoon.org/>

Phone: (306) 652-9111

Complex Needs Case Management, Regional Intersectoral Committees

<http://www.sasked.gov.sk.ca/hsif/rics.shtml>

Phone: (306) 787-5592

Ministry of Social Services Income Assistance and Disability Support Community Living Service Delivery (see the main resources at the end of the book)

<http://www.socialservices.gov.sk.ca/community-living/>

Moose Jaw Families for Change

<http://www.mjffc.com/>

Phone: (306) 693-2271

Provincial Cognitive Disabilities Strategy Interdepartmental Working Group

Saskatchewan Ministry of Health

<http://www.health.gov.sk.ca/cognitive-disabilities-strategy>

Phone: (306) 787-3862

Fax: (306) 787-7095

Regina and District Association for Community Living

<http://www.rdacl.ca/>

Phone: (306) 790-5680

Regina Mobile Crisis Services

Phone: (306) 757-0127

Saskatchewan Family Network- Saskatchewan Association for Community Living

<http://www.sacl.org/programs.php?p=sacl-family-network>

Phone: (306) 955-3344

Saskatoon Mobile Crisis Intervention

Phone: (306) 933-6200

Sexual Assault Services of Saskatchewan

<http://www.casac.ca/node/48>

Phone: (306) 783-7500

System Wide Admissions & Discharge Department (SWADD)

Phone: (306) 766-7200

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Chapter 9: Justice, Rights, and Legal Issues

The United Nations Convention on the Rights of Persons with Disabilities says

States Parties shall ensure effective access to justice for persons with disabilities on an equal basis with others, including through the provision of procedural and age-appropriate accommodations, in order to facilitate their effective role as direct and indirect participants, including as witnesses, in all legal proceedings, including at investigative and other preliminary stages.

From Article 13

In the past, people with intellectual disabilities were not always treated fairly under the law. Since the middle of the last century, people with intellectual disabilities and their families have fought

to ensure that the laws in Saskatchewan recognize and accommodate all people who have a disability. In this struggle, laws have been amended to ensure that people with intellectual disabilities have the right to marry, are entitled to the same right to education as other children, are included in the human rights code and the *Canadian Charter of Rights and Freedoms*, and receive fairer treatment in the justice system.

This chapter will focus on three legal issues: human rights, criminal justice, and financial planning.

HUMAN RIGHTS AND PEOPLE WITH DISABILITIES

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. 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 call for advocacy help or advice. Organizations exist to help people who are facing injustice or discrimination.

"All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood."

Article 1 of the Universal Declaration of Human Rights, December 10, 1948

United Nations Convention on the Rights of Persons with Disabilities

On December 13, 2006, the General Assembly of the United Nations adopted the *Convention on the Rights of Persons with Disabilities* and the *Optional Protocol*. The convention and protocol entered into force on May 3, 2008, after 20 countries had ratified it. In March 2010, the Government of Canada ratified the Convention.

The stated purpose of the Convention is

"...to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity."

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

- a. Respect for inherent dignity, individual autonomy, including the freedom to make one's own choices, and independence of persons
- b. Non-discrimination
- c. Full and effective participation and inclusion in society
- d. Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity
- e. Equality of opportunity
- f. Accessibility

- g. Equality between men and women
- h. Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities

The Optional Protocol is a document that, when adopted by a country, allows the United Nations' Committee on the Rights of Persons with Disabilities

*"to receive and consider communications from or on behalf of individuals or groups of individuals subject to its jurisdiction who claim to be victims of a violation by that State Party of the provisions of the Convention."*⁴³

In short, the Optional Protocol allows the UN the right to hear complaints of discrimination. It is called the Optional Protocol because countries can ratify the Convention without ratifying the Protocol. Canada has not yet ratified the Optional Protocol.

For more information, go to <http://www.un.org/disabilities/index.asp>.

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 as a stated protected class of Canadians came about because of the strong advocacy of people who have a disability and other activists.

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."⁴⁴

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 some people a equal opportunity:

“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.”⁴⁵

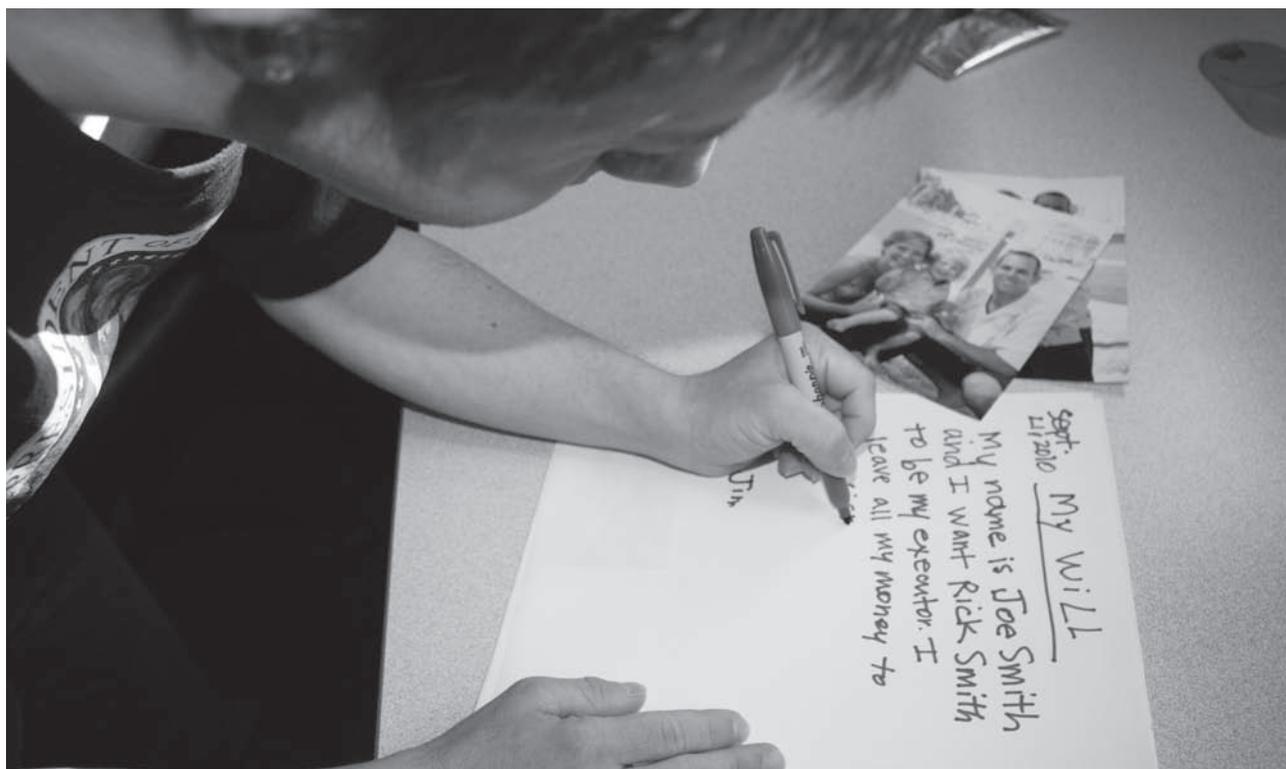
Based on Section 15 we have the right to live free from discrimination. Discrimination is explained by the Government of Canada:

“Discrimination occurs where, for example, a person, because of a personal characteristic, suffers disadvantages or is denied opportunities available to other members of society.”⁴⁶

The Supreme Court of Canada states that this section is meant to protect groups that are disadvantaged in Canada.

All individuals 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. In other words, the outcome of a law, the benefit that is given 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 responsibility of the individual to benefit from attending school, there is also a responsibility of educators to ensure that a child benefits 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 it does not protect us from discrimination by other citizens or businesses. 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.



The Saskatchewan Human Rights Code

The objects of the *Saskatchewan Human Rights Code*, as stated in Section 3 of the code, are:

- (a) to promote recognition of the inherent dignity and the equal inalienable rights of all members of the human family; and
- (b) to further public policy in Saskatchewan that every person is free and equal in dignity and rights and to discourage and eliminate discrimination.

As with the *Charter of Rights and Freedoms*, the Human Rights Code specifically mentions people who have a disability as a protected group. The reason that people with disabilities are identified in the Code is 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) of the Code, your child is entitled to have the same accommodations, services, and facilities as other people and cannot be discriminated against by any service that is offered to the public. This means that public education, health care, dental care, parks, pools, buildings, washrooms, restaurants, stores, hotels, and government services must be accessible and available to him

Parents need 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, counselling, mental health services, education, or any other service, involve a human rights advocate. Your child should never have to settle for second best: the law is behind you.



Parents Be Aware

Sometimes children with disabilities are denied access to universal services when a professional feels he or she cannot serve them. Remember that your child has the same rights to services as other children and to be denied services on the basis of a disability is discrimination. Your child's rights to access and accommodations are both protected under the Charter and the Human Rights Code.

Section 13(1) of the Code explains that everyone has a right to education in any school, unless there are age limitations. We believe this means that your child has the right to attend his neighbourhood school.

Section 13(2) of the Code explains that exceptions are made for specialized schools that enroll only students with a certain gender, belief, religion, or disability. This means that, for example, a religious school could refuse someone who does not believe in their religion. Still, no school can refuse a child because they have an intellectual disability.

Like the Charter, the *Saskatchewan Human Rights Code* is a way that a citizen of Saskatchewan, who believes he has been discriminated against, can do something to correct the situation. Unlike the Charter, the Code provides, through the Saskatchewan Human Rights Commission, a complaint process to assist an individual who believes he is a victim of discrimination. If the Commission agrees with the individual, it will assist in finding a remedy to the discrimination.

Defending Your Child's Rights: Places to Call

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 fam-

ily feels there has been discrimination, it is easy to get frustrated or angry and feel that there is nothing you can do. But in many situations it is possible to challenge the system. (Advocating for your child at this point most likely won't mean going to court, but there is information and resources in the next section if it comes to that.) Here is a list of both non-profit and government organizations that help citizens uphold their rights.

- **The Saskatchewan Association for Community Living:** We are often involved in cases where individuals believe their human rights as a Saskatchewan citizen are being neglected or ignored. You can call the SACL and our advocates will support you in having your voice heard and in finding a solution. Our web address is <http://www.sacl.org/> 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.shrc.gov.sk.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 child 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 Children's Advocate:** Like the Ombudsman, the Children's Advocate is a provincial office, independent from other government departments, that investigates complaints on behalf of children. The Children's Advocate 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. The Children's Advocate can be contacted through the website www.saskcao.ca.
- **Anti-Poverty Advocates:** If your adult son is having problems with a government income-support program, there are anti-poverty advocates that can help. They can advocate on his behalf with any government system, such as the Rentalsman or Social Services. The following are anti-poverty groups in Saskatchewan:
 - The Regina Anti-Poverty Ministry (Regina)
 - Equal Justice for All (Saskatoon)
 - Voice of the Blue Rose (North Battleford)
 - Saskatchewan Anti-Poverty Coalition (see below)
- **Saskatchewan Voice of People with Disabilities:** Like the SACL, 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.
- **Rentalsman:** Your adult child may run into trouble with a landlord. The Office of Residential Tenancies is a government organization that provides advice to landlords and tenants about their rights and obligations. Landlords and tenants may apply for a hearing to resolve a dispute that cannot be settled. Fees may apply for some

applications. (Fees will be higher if the claim exceeds \$5000.00.) The purpose of the Office of Residential Tenancies is to uphold the standards and obligations in the *Residential Tenancy Act*. The Rentalsman can be contacted at 1-888-215-2222 (toll free). The web address is <http://www.justice.gov.sk.ca/officeofresidentialtenancies>.

- **The Saskatoon Anti-Poverty Coalition** is a group of concerned citizens and organizations who are dedicated to addressing the causes and effects of poverty. The goal is to reduce and eliminate poverty, and the effects of poverty, among residents of Saskatoon, by increasing community involvement and input into the development of a long-term, integrated, anti-poverty strategy. Contact the Coalition by phone at (306) 653-2662.
- **Welfare Rights:** The Welfare Rights Centre in Regina has a full-time advocate who works with people receiving assistance who are having problems with the welfare system. The centre provides advocacy, counselling services, and money management advice. For more information go to <http://www.povnet.org/node/2845> or call (306) 757-3521.

ADVICE AND RESOURCES IF YOUR CHILD IS GOING TO COURT

Your child may end up in court someday for any number of reasons. He may be the victim of a crime and may be called to testify. It could be a human rights complaint hearing. He may end up with a criminal charge and, warranted or not, end up going through the criminal justice system. Any of these situations would be intimidating. Many people do not know where to start. Human rights lawyer Catherine Knox, who regularly represents people with disabilities, and the Public Prosecutions Division of the Ministry of Justice shared the following information for parents whose child is going to court.

Victims of Crime

No one wants their child to be the victim of a crime, but if it happens, knowing what to expect in the justice system can be very helpful. If your son is a victim and is unsure about reporting it, Victim Services can help your family make a decision and give you information about the process you will need to go through to press charges. Victim Services is a branch of the Ministry of Justice that helps the justice system better understand the needs of victims of crime. The best way to advocate is to make sure that the police, the prosecutor (lawyer), and Victim Services understand that your child has an intellectual disability and the supports he will need. Always make sure you know what is going on with the case. Once a charge is laid, you may not be told right away if the accused is going to court. Tell the police officer that you want to know when the case is going to trial to give your son time to prepare.

Whether going to court as the victim or as a witness, your son will be assigned a lawyer from the Public Prosecution Division of the Ministry of Justice. When you know that the case is going to court, phone the Public Prosecution Division and ask to speak to the prosecutor assigned to the case. Ask if your son will need to testify and let the prosecutor know about his strengths and where he might need support. The prosecutor will have a meeting to talk to your son about the process and to try to make the experience less stressful. Advocates are allowed in court if it makes the witness more comfortable.

It is likely that Victim Services will become involved through its Victim/Witness program and you will need to inform them about your son's needs as well. They can help walk you through the process and get the necessary supports in place. They will assess your son's needs before court and during court proceedings. An orientation will be done so that he knows what to expect, who everyone is, what his role is, and that it is ok to take a break or to say, "I don't understand."

If you know that your son will not be comfortable testifying in front of the court, arrangements can be made so that he can testify behind a screen or outside the courtroom. Section 486 (2.1) of the Criminal Code of Canada permits these arrangements at the judge's discretion.⁴⁷ Don't wait until the court date to ask for this support. The judge will need to see evidence ahead of time that special supports are necessary. This process is fairly similar if your son is the witness to a crime, even if he is not the victim.

People Accused of a Crime

When a person is accused of a crime, he needs to get a lawyer. If your son is an adult and has a low income, he will qualify for a lawyer from the Saskatchewan Legal Aid Commission. For an adult, it is his income that determines eligibility, not yours. If he does not qualify, he 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. You can also call the Lawyer Referral Service through the Law Society of Saskatchewan. Phone: (306) 569-8242.

Once a defence lawyer is found, you can advocate by informing the lawyer about your son's needs. A person accused of a crime needs to understand what he is being accused of in order to enter a plea of guilty or not guilty. If your son truly does not understand the charges against him, he may be deemed "unfit to stand trial" or that he did not have "criminal intent." He may still be held in custody if there is evidence against him, but he will not be convicted. See Section 672 of the Criminal Code of Canada, which is about the general issue of "Mental Disorder" and talks, among other things, about the issues and process of court-ordered assessments and fitness to stand trial.

Parents Take Note!

The proper legal procedure for police to follow, if a person under 18 is accused of a crime, is to inform the parents. One parent of a 12-year-old with a disability was not informed that there was a charge against her son and that the police were investigating. A Saskatchewan Justice official commented that, legally speaking, the parents should have been informed immediately after the police were contacted.

A general red flag to watch for is that the courts are still not well equipped to assess and respond to people with intellectual disabilities. They will require some significant involvement from a parent or an advocate to ensure a proper assessment is done and accommodations are in place. A good front-end assessment may identify a solution that means your son will not end up in court or in jail, but will receive the support he needs.

Finding Legal Help

When a person with an intellectual disability enters the justice system, often the supports he needs are simply not there. He will need you as his advocate more than ever. People may need to be taught how to communicate effectively with him. Assume nothing. Make sure people working with your son have a clear picture of who he is and what his strengths and needs are. If there are any supports he needs to have a fair trial, demand them. The results of going to court always have a huge impact on the people involved. Help is available at the following places:

- **The Saskatchewan Legal Aid Commission:** The Saskatchewan Legal Aid Commission provides legal services to people for criminal and certain civil cases when they are financially unable to hire a lawyer. Not everybody qualifies, but it is good to know that services are available. More information can be found on the Commission's website at <http://69.27.116.234/>.



Relevant Parts of Section 486 of the Criminal Code of Canada

(1.2) In proceedings referred to in subsection (1.1), the presiding judge, provincial court judge or justice may, on application of the prosecutor or a witness who, at the time of the trial or preliminary hearing, is under the age of fourteen years or who has a mental or physical disability, order that a support person of the witness' choice be permitted to be present and to be close to the witness while testifying.

(2.1) Despite section 650, if an accused is charged with an offence under section ... and the complainant or any witness, at the time of the trial or preliminary inquiry, is under the age of eighteen years or is able to communicate evidence but may have difficulty doing so by reason of a mental or physical disability, the presiding judge or justice, as the case may be, may order that the complainant or witness testify outside the court room or behind a screen or other device that would allow the complainant or witness not to see the accused, if the judge or justice is of the opinion that the exclusion is necessary to obtain a full and candid account of the acts complained of from the complainant or witness.

(2.101) Notwithstanding section 650 ... the presiding judge or justice, as the case may be, may order that any witness testify

(a) outside the court room, if the judge or justice is of the opinion that the order is necessary to protect the safety of the witness; and

(b) outside the court room or behind a screen or other device that would allow the witness not to see the accused, if the judge or justice is of the opinion that the order is necessary to obtain a full and candid account from the witness.

- 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 taxation. The web address is <https://www.can-law.com/secure/sslreferrals/referralsk.htm>.
- Pro Bono Law Saskatchewan (PBLs)** is a non-profit corporation 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 web address is: <http://www.pblsask.ca/>.
- 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. Talk to the John Howard Society by calling 1-877-584-2115 toll free or going online to <http://www.sk.johnhoward.ca/>.
- 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. The society can be reached at 1-888-934-4606 or online at <http://www.elizabethfrysask.org/>.
- Community Legal Assistance Services for Saskatoon Inner City (CLASSIC):** as stated on their website,

“CLASSIC is a non-profit and charitable organization which provides free, professional and confidential legal services for low-income members of our community who cannot otherwise afford legal advice or representation.”

Phone (306) 657-6100 or go online to <http://www.classiclaw.ca/> for more information.
- 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 (www.archlegalclinic.ca/).

PROVIDING FOR YOUR CHILD'S FINANCIAL FUTURE: LEGAL ISSUES

For people with intellectual disabilities, whose adult lives are often dependent on government workers and funding, proactive financial and legal planning can reduce the number of problems that arise while parents are alive and after they die. Understanding how laws and policies can work against your child is important. The following is a brief introduction to some key legal issues that can affect your child's quality of life.

To ensure that your child with an intellectual disability has a good quality of life, for his whole life, you need to plan ahead. You most likely will need the advice of a lawyer in addition to a financial planner and/or an accountant to help make your plan work. Often the professionals you hire will not have experience working with families who have a child with an intellectual disability, so you need to know what questions to ask. You need to be able to guide them. To this end, the SACL produced *A Roadmap to the Future: A Financial Planning Guide for Families of People with Disabilities*. For information about how to get a copy, call the SACL at (306) 955-3344.

The following topics are covered in the guide: creating a vision, developing a comprehensive plan, preparing the financial future, wills, trusts, legislation, power of attorney, enduring power of attorney, health care directives, guardianship of minor children, and adult guardianship and alternatives. It concentrates on the process of financial planning, but also on how to create and ensure a full and active life in the community.

Another good way to make sure your child has a secure future is to talk to the experts. The Planned Lifetime Advocacy Network (PLAN) is a non-profit organization created by and for families of individuals with disabilities.⁴⁸ The organization offers books with excellent advice on building a safe and secure future for a person with an intellectual disability (*A Good Life—For You and Your Relative with a Disability* and *Safe and Secure*). You can also learn about PLAN by contacting the Regina and District Association for Community Living at (306) 790-5680 or by going online to <http://www.rdacl.ca/>.

Importance of the Dependent 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 his 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."⁴⁹

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 he is on social assistance and inherits money from your estate, he will be taken off assistance until all the money is used up. This means that he will not benefit from the money at all. Find out how to protect your son's inheritance in the next section on discretionary trusts.

Discretionary Trusts

Parents frequently worry about what will happen after they are gone. We recommend that parents find a good financial planner and a lawyer who understand disability issues and set up a third-party discretionary trust. This type of trust allows a trustee, whom

you choose, to spend your son's inheritance on his quality of life. They will be able to purchase those extra items that social assistance does not provide, and if your son wants to go on a vacation, he can! If the money is in his name instead of a discretionary trust, Social Services can deny him assistance until the money is spent at a government rate on his basic needs. Basically, he will be told that he must use his inheritance up to pay for his basic needs, instead of receiving social assistance. We cannot emphasize enough how important discretionary trusts are! Currently there is no legal way for your son to hold liquid assets, bank accounts, RSPs, bonds, or investment certificates over \$1,500 in his own name and still receive assistance (owning a house can be an exception). It is important to know how social assistance works before you set up your will or make any financial arrangements for your son.

Read the section on Income in Chapter 10 and the section on Social Assistance in Chapter 11 for more information on income assistance and asset limitations. For more information about discretionary trusts, read *A Road Map to the Future: A Financial Planning Guide for Families of People with Disabilities*.

Supported Decision Making and Adult Guardianship

Adult guardianship is something that was never questioned in the past. People with intellectual disabilities were assumed to be unable to make decisions for themselves and someone had to be their legal guardian. Guardianships gave another adult legal authority over a person, taking away his right to decide where to live, how to spend his money, and what to do in his spare time.

Self-advocates have told us this is unfair and said they want to have more control over their own lives. If they had someone who could help them, and explain things in plain language, they could make decisions for themselves. We must start listening to people with intellectual disabilities and allow them to speak for themselves. We know that people with intellectual disabilities have a lot to say about how they want to live their lives and they must have that opportunity.

Every person has the right to self-determination. Adult guardianship should only be pursued in ex-



LEGAL AND JUSTICE RESOURCES

ARCH: A Legal Resource Centre for Persons with Disabilities

<http://www.archdisabilitylaw.ca/>
Phone: (416) 482-8255

Community Legal Assistance Services for Saskatoon Inner City Inc. (CLASSIC)

<http://www.classiclaw.ca/>
Phone: (306) 657-6100

Elizabeth Fry Society

<http://www.elizabethfrysask.org/>
Phone: (306) 934-4606

Equal Justice For All (Saskatoon)

<http://www.povnet.org/node/2842>
Phone: (306) 653-6260

John Howard Society

<http://www.sk.johnhoward.ca/>
Moose Jaw (306) 693-0777
Regina (306) 757-6657
Saskatoon (306) 244-8347

Law Society of Saskatchewan (Lawyer Referral Service)

<http://www.lawsociety.sk.ca/>
Phone: (306) 569-8242

Office of the Ombudsman

www.ombudsman.sk.ca/
Regina (306) 787-6211, or 1-800-667-7180
Saskatoon (306) 933-5500, or 1-800-667-9787

Planned Lifetime Advocacy Network

<http://www.plan.ca/>
Phone: (604) 439-9566

PLEA (Public Legal Education)

<http://www.plea.org/contact/>
Phone: (306) 653-1868

Pro Bona Law Saskatchewan

<http://www.pblsask.ca/>
Phone: (306) 569-3098

Public Prosecution Division—Saskatchewan Department of Justice

<http://www.justice.gov.sk.ca/publicprosecutionsdivision>
Phone: (306) 787-5490

The Regina Anti-Poverty Ministry

<http://www.angelfire.com/sk3/rapm/>
Phone (306) 352-6386

Rentalsman—Saskatchewan Department of Justice

<http://www.justice.gov.sk.ca/officeofresidentialtenancies>
Regina (306) 787-2699
Saskatoon (306) 933-5680

Saskatchewan Children's Advocate

<http://www.saskcao.ca/>
Regina (306) 787-6850
Saskatoon (306) 933-6700, or 1-800-322-7221

Saskatchewan Human Rights Commission

<http://www.shrc.gov.sk.ca/>
Regina (306) 787-2530, or 1-800-667-8577
Saskatoon (306) 933-5952, or 1-800-667-9249

Saskatchewan Legal Aid Commission

<http://69.27.116.234/>
Phone: 1-800-667-3764

Saskatchewan Voice of People with Disabilities

<http://www.saskvoice.com/>
Phone: 1-877-569-3111

Victim Services

<http://www.justice.gov.sk.ca/victimsservices>
Phone: 1-888-286-6664

Voice of the Blue Rose (North Battleford)

Phone: (306) 445-7673

Welfare Rights Centre (Regina)

<http://www.povnet.org/node/2845>
Phone: (306) 757-3521

Help us keep up to date. If there are any changes or additions we need to make to *Navigating the System*, please let us know. Phone (306) 955-3344 or e-mail sacl@sacl.org.

Chapter 10: Adulthood – Planning for Change

The time will come when your child will finish school and make choices for adult life. For most parents this is a time of mixed emotions, a time when they are forced to let go, but also a time of graduation and growth. If your child has a disability, letting go is even more frightening as you recognize the uncertain future your child faces. Even so, parents have succeeded in helping their adult children create satisfying lives of their own through planning and hard work.

There are many new experiences and unanswered questions when a person with a disability moves into adulthood. Parents and young adults find the adjustment easier when they have information about the various options and a plan. This chapter is about knowing what is available, what is possible, and how you can help your adult child to create his own life in the community. The end result will be a meaningful, satisfying, and self-determined adult life.

PLANNING FOR CHANGE

Change will happen – we know that. Sometimes we even know when it will happen. We know with a high degree of certainty when we will graduate from school. Most people with an intellectual disability know that they can stay in school until they are 22 years old. Graduation day will only come as a surprise if you fail to plan. When we fail to take the scary step of looking into the future and preparing to meet it, we can fail before we start. Of course, things don't always go as planned.

In preparing to plan for change one of the key steps is to never do it alone. We have said this before in the handbook, but it is important to repeat it here. If you, your spouse or partner, child or children plan without outside support, your chances of success may well be reduced. You need the support, encouragement, ideas, and questions of others to help create the change you want.



If you have a support network, invite them to be involved in planning for change. If you haven't already created a network, it is time to do so.

The next step is to identify a person-centred planning process that makes sense to your family.

Person-centred Planning

The idea of person-centred planning grew out of the experience of many individuals with disabilities and their families who were dealing with health, school, and social service systems. They found that the planning directed by systems is sometimes about what is good for the system and not what is good for the person. The interests of the person with a disability can be overshadowed by the needs of the system.

In response to this, the idea of person-centred planning grew based on very different principles.

- Person-centred planning looks at things first and last from the individual's point of view.

- Person-centred planning comes from respect for the person, is about creating positive change, focuses on the person, and assists the person in defining a more desirable future.
- In person-centred planning, personal commitment to, and knowledge of, the person is the basis of involvement and authority, rather than someone's professional role.
- Meetings happen when and where it is most comfortable for the person and her family.

There are a number of person-centred planning processes. Three that we can recommend are MAPS, PATHS, and *School to Life Transition Handbook*.

McGill Action Planning System (MAPS)

MAPS also means Making Action Plans and was first used by schools for many years before it became more widely used. Like any good planning system, MAPS sets out to help an individual get from where she is today to where she wants to go



in the future. Unlike other management by objective planning processes, which often emphasize that things should be measurable and controllable, MAPS starts from a person's hopes and dreams. It begins with dreams because they are what move us to change. They motivate us and tell others who we are. They are a reflection of our deepest, most personal desires and there is no better place to start a personal plan. Beginning with a dream, MAPS takes you toward a plan that is action oriented.

MAPS begins with the person's history. This is the opportunity for the person who is the focus of the MAPS to tell her story so that those gathered with her learn more about her and who she is. The next step is for her to share her dreams and from there the process moves through a number of steps to an action plan. If the person is not able to do this herself, then someone close to her, usually a parent, will tell the story.

MAPS allows time for the group to get to know the person. In addition to the history and dreams, it also asks the group gathered to talk, very briefly, about how they see the person who is the focus of the MAPS.

Doing MAPS is a group process and usually takes about two hours. Two people with training in facilitating MAPS must lead the process. One person, the process facilitator, leads the individual through the steps and the other, the graphics facilitator, makes a record of the process. It helps to have facilitators whom you choose and who you know understand the principles of person-centred planning and MAPS. It is also important to invite the right people to share this process with you. When we get personal we become vulnerable, so MAPS needs to be done in a safe environment.

Planning Alternative Tomorrows with Hope (PATH)

Planning Alternative Tomorrows with Hope is very similar to MAPS but has some important differences.

PATH assumes that those gathered already know the person who is the focus of the PATH (often called the pathfinder) and usually the pathfinder speaks for herself. PATH is in many ways a more personal process than MAPS. If Judy is the pathfinder the PATH is called Judy's PATH. She invites people to attend and it begins with telling those she invited about her dreams. From this beginning, assisted by the facilitators, Judy will develop a plan that takes her from her dreams to very real actions that she can do as her first steps toward reaching her dreams.

If a pathfinder is unable to speak for herself, then the group will do their PATH for Judy: it is not her PATH but the group's PATH for Judy.

The PATH process will take about two hours, but is much more intense and often very emotional. It must be done in a safe environment facilitated by individuals who have been trained.

You can find more information about MAPS, PATH, and person-centred planning online from Inclusion Press at www.inclusion.com/. There are trained facilitators in Saskatchewan for both MAPS and PATH. Contact the SACL at (306) 955-3344 for more information.

School to Life Transition Handbook

The *School to Life Transition Handbook: Five Steps to Successful Planning*, by Rita McLeod, outlines a five-step process to planning a transition. The five steps to successful transitions are: getting ready (a first step in getting ready may be MAPS); deciding who should be on the transition-planning team; suggestions for team meetings; carrying out the plan; and checking to see if the plan is working.⁵¹ The handbook includes stories of successful transitions, resources, websites, and agencies and organizations that are helpful with transitions. You can use the handbook to learn more about the important questions that need to be asked before your young adult leaves high school. If you would like a copy of the handbook contact the SACL at (306) 955-3344 or email sacl@sacl.org. You can also find the handbook

online at www.sacl.org. Look under “Need Support?” for Handbooks.

The handbook uses person-centred planning principles in that it focuses on the young adult’s dreams and goals as central to the planning process. This process will help the young adult and her family decide on goals and find ways to reach those goals. As it says in its introduction,

This Handbook is designed to help students who are in the process of transition out of school to adult life. It provides information for them, their families and teachers about transition planning, giving an overview of:

- *When to begin planning for transition.*
- *What areas of adult living to plan for.*
- *How the meetings should go.*
- *Who should be part of the planning team and what are their jobs?*
- *How to carry through with the transition plan.*
- *Where to get more information about resources and materials.*⁵²

Here are some tips from the handbook for parents who are planning a transition.⁵³

- *Getting involved in your child’s transition planning is one of the ways in which you can feel good about preparing for her or his future. Other members of the transition team should be there to offer you support and information.*
- *Being involved also means being informed. You have to learn about transition planning, about work experience courses offered by schools and options in supported employment. You have to learn more about your local community. Who are the employers and what kinds of jobs are available? What are the opportunities for summer and after-school jobs? Does your local regional college offer any programs that might interest your child? What programs and services in your community might help your child achieve her or his goals? What opportunities are there for recreation and social activities?*

- *And, finally, don’t give up! Things can get discouraging, but it is important to remember that you are doing all this so that your son or daughter can have a full life in the community, doing what they want to do and meeting people they want to meet.*

A final note: Planning takes time and the process outlined in the *Transition Handbook* involves the participation of a number of people in your son’s network and beyond. For these reasons the process should start when he begins high school, not when he is finishing. Beginning early also has the advantage of assisting the school to design an education program plan that is based on his dreams for his life after high school. The plan may need to be adjusted annually, but it will give the direction needed so the school can best help him get to where he wants to go.

CREATING A HOME

Article 19 of the United Nations Convention of the Rights of Persons with Disabilities says,

“Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement.”

One of the important milestones in becoming an adult is leaving the family home. There is probably more stress over this issue than any other challenge facing parents of young adults with disabilities. The stress is not only about having to let go but also about finding a home and the support needed for your child to have a life of her own. Historically there were very few options. In the last few years some progress has been made. In the fall of 2008, the Government of Saskatchewan made a commitment to respond to the long waiting list for residential supports for adults who have intellectual disabilities.

When you and your daughter decide that it is time she moved out of your home, the first thing she needs to figure out is where she might want to live. If this has not been identified in her transition plan, it may be a good time to do a PATH. She may want her own apartment, or to live in a city where there are a lot of activities. Help her to dream and let her know that if she tries something and doesn't like it, she can try something else.

Next, help her figure out what her needs will be. She may need a full-time support worker, or someone to check in on her twice a day, perhaps a roommate who does not have a disability and who can provide some support. Will she need assistance with cooking, cleaning, or personal care? Since you know her the best, you are the right person to sit down with her and figure out what supports will make her housing choice successful. It is useful to put in writing your ideas regarding where, with whom, and how your daughter will live so when she, with your support, talks to others it will be easier for her to share her ideas about what she wants.

A gradual transition is very important when your daughter moves into her new home. Many people have found that slow transitions are better, especially if the person with an intellectual disability is going to have roommates in her new home. Don't let administrative or funding pressures rush the transition. You know your daughter better than anyone else and you will know when she is comfortable in her new home.

If you are looking for supported housing options, contact your CLSD community service worker to see what is available in your area. CLSD gives block funding to organizations that provide housing with supports for people with intellectual disabilities and they know where there are openings. The CLSD community service worker will tell you about your daughter's options. Most adults who qualify for CLSD residential supports live in group homes or approved private service homes. The Ministry of Social Services website says the following:⁵⁴



The Community Living Service Delivery (CLSD) funds approximately 100 community-based organizations which provide residential services to the public in the following areas:

Group homes - homes which are staffed to provide personal care, supervision and support to usually three to six adults with intellectual disabilities. They are located in residential neighbourhoods throughout Saskatchewan.

Supportive independent living programs - provide adults living in their own apartments with the limited support and supervision they may require to live as independently as possible.

Supported apartment living programs - provide an alternative for individuals who do not require the extensive supports of the group home program, but require more support than the supportive independent living program.

Group living homes - individuals who share a group living home are responsible for paying their basic shelter costs. Community Living Division provides funds for the support staff that may be required.

Valley View Centre - Valley View Centre in Moose Jaw provides accredited care for individuals with intellectual disabilities who live at the Centre.

Approved Private-service Homes are private homes that provide a family atmosphere for people with intellectual and/or physical disabilities

These residential supports are funded by CLSD, but with the exception of Valley View Centre are not operated by CLSD. Group homes and supported living homes are run by non-profit corporations that are autonomous organizations. In their funding agreements with CLSD they agree to operate within provincial policies such as the Comprehensive Per-

sonal Program and Support Policy (CPP&SP). As they are autonomous organizations, it is important that you and your daughter learn about an organization's unique way of operating to be sure that it is right for her.

Approved private-service homes are private homes that are licensed by CLSD to provide a residence for adults who have intellectual disabilities. Each is quite unique and it is important to meet with the home operator and learn what life might be like in that home.

Even with the 2008 provincial government initiative to address the wait list, there are still wait times associated with residential options, or the options available may not be the best fit for your child. You can consider asking about openings in other communities. There may be nothing available that suits your daughter right now. This does not mean that you need to settle for an inappropriate option! Keep advocating for her. If your daughter's housing needs are not being met, contact an SACL advocate. We can help you find out where to go from here. For example, we have seen parents get together with other parents and community members to lobby for a new housing development when there was nothing available in their community.

MEANINGFUL EMPLOYMENT AND DAILY ACTIVITIES

We all want to find fulfillment and to make a contribution to our community. People with intellectual disabilities are no different. Today doors are opening for some people with disabilities to get the support needed to find meaningful work and activities in their communities. Regardless of the options you are considering, make sure that your child's personality, interests, and happiness are front and centre. The SACL's Employment Opportunities Consultants can answer your questions about meaningful employment in the community.

Your adult daughter should be comfortable and find satisfaction and fulfillment in her daily activities. As her advocate, you can work with her to make sure she is doing something she likes. Whether she is looking for employment or another activity, she may need to try different ones until she finds something that suits her. The challenge may be getting others to see that she needs time and the permission to change her mind. Another challenge may be getting the supports in place so she can do what she enjoys. In this section we'll look at some of the options and supports available for employment and daily activities.

Vocational Programs

Article 27 of the United Nations Convention on the Rights of Persons with Disabilities recognizes

“the right of persons with disabilities to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive, and accessible to persons with disabilities.”

There are a number of options for vocational services funded through Community Living Service Delivery of the Ministry of Social Services and provided, for the most part, by non-profit corporations. According to the Ministry of Social Services website (<http://www.socialservices.gov.sk.ca/Default.aspx?DN=207512e5-2e34-463f-964b-cfef59f47b00>), there are a variety of vocational services offered.

- **Activity Centres** are facilities designed for individuals who have limited motor and sensory development. Programming emphasizes basic living skills, socialization, and recreation. Although some activities may be of a productive nature, they are secondary to the primary goal of maximizing an individual's potential in the community setting.
- **Sheltered workshops** focus on training and production. Clients develop work and social skills until they are able either to reach their potential level of independence or obtain com-

petitive employment. A portion of the profit realized by workshops is returned to clients.

- A number of day **Activity Programs** provide activities that range from full-time, centre-based activities to integration of seniors into existing programs.
- **Long-term Employment Programs** ensure ongoing employment for persons with disabilities by providing support services such as job coaching or wage subsidy initiatives.

The Ministry of Social Services is currently developing new funding standards for day programs. The news release announcing this new approach said,

“the new funding standard matches day program funding with the assessed needs of people with intellectual disabilities. The old funding model was based on cost-per-space, which did not take into account individual differences in the support needs of clients.”⁵⁵



It is not clear how these new standards will affect individuals who are in a vocational program or who are seeking a vocational support. The Ministry and a number of the Saskatchewan Association of Rehabilitation Centres (SARC) member agencies are piloting this approach in a number of communities. The pilots should be complete by the spring of 2011.

Many Saskatchewan towns and cities have an organization offering these services. If you cannot find one in your community, you can get more information through the SARC website: <http://www.sarc-sarcan.ca/>.

Like residential support, workshops and activity centres are operated by autonomous non-profit corporations, which operate in a way to balance the unique needs and wants of the individuals they support and their community. You should get to know the organizations to determine their fit for your daughter.

Activity centres and workshops have evolved over the last half century. Today they provide more options for the men and women who attend each day. We need to continue to advocate to ensure that the vocational supports offered are individualized and support inclusion.

The reality is that everyone who has an intellectual disability is an individual and deserves the opportunity to decide how to live her life. We need to ensure that people with intellectual disabilities have real options. A job may not be the best fit for every person. Some people do not thrive working at the same task every day. There are many ways that adults can find fulfillment and make a contribution. Individualized, community-based vocational programs are one way that people with intellectual disabilities can find fulfillment and make a contribution to their community.

The Saskatchewan Institute of Applied Science and Technology (SIAST) offers, as part of its Basic Education Program, Employment Readiness and Bridging to Employment, which help individuals develop

job readiness skills as required by the labour market. The programs offered include:

Living Skills

A work preparation program that helps adults with diagnosed disabilities who are eligible for funding achieve non-sheltered, gainful employment in the community.

Transition to Work

An individualized continuous-intake course that covers basic academic and employability skills. You will strengthen your reading, writing, and mathematics skills while practicing behaviours that will contribute to your employability. One or more work placements is a recommended option.

Way to Work

An employment readiness training project for adults who have an intellectual disability. It provides pre-employment and employment skills, on-site training experiences and opportunities that may lead to competitive community employment. It consists of life and living skills training, workplace literacy training, job readiness, and work placements.

Not all programs are offered at each SIAST campus. You can get more information online at http://www.siastr.sk.ca/programs/basic_education/readiness_bridging.shtml or by phoning SIAST at 1-866-467-4278.

There are other options, too. People with intellectual disabilities have attended post-secondary schools, gone travelling, and helped out with community development projects and other activities that young adults do. Just like other young people, they could get grants or loans from the government or a grant from a community organization or a service club. Help your daughter be creative when figuring out how to live her life and be part of her community.

Each individual needs to have access to a support system that will help them find the way they can

contribute to the life of their community. It may be through work, or it may be through volunteering. Each of us makes a contribution in our own way. This is something each individual needs to discover.

Preparing For and Finding Paid Employment

If your daughter's first choice is regular, paid employment, here are some things to think about. It might seem impossible at first, but don't rule this out right away. There are many people with intellectual disabilities who hold regular full or part-time jobs in the community. Either on their own, or with the support of a job coach, they have learned the job and proven their abilities in regular employment settings.

Setting the Stage: Getting Work Experience Before Finishing High School

We all remember our first job: how scary it was, how much we learned and how good it felt to put something on our resumes for the next time. The lack of paid work 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 critical that young adults with disabilities have paid work experience before they finish school. Look for opportunities through summer jobs or working part-time after school. One program that can help is the Student Summer Works program. A description of the program can be found later in this chapter.

Young adults do gain skills from school work-experience programs, but often they do not really see what real work is like. If in work experience positions young adults are given the least demanding, least relevant and least threatening jobs, you need to pay attention to what they are learning. When a work experience offers low expectations, it can lead to unrealistic perceptions of "work" once individuals start working. For example, your daughter may not have experienced the same rules as paid staff

with regards to coffee breaks and the need to do a job quickly. When an employer is paying someone to do a job, there are expectations that need to be met. This is why it is so important to have experience in paid employment before high school is completed.

Teachers can help, too. A school can shape the work experience program so that it is more realistic and reflects real life. In the first years of high school less structured and less demanding work experiences can be opportunities for career exploration. However, during the last few years of high school, programs should help young adults build up their real life experience in the workplace. Instead of treating work experience like volunteering, teachers can challenge employers to view the student as a potential employee. With this mindset, the employer is more likely to challenge and evaluate the student like a real employee. This approach changes everything. 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.



Parents can help their young adult prepare for the workforce by giving them responsibilities at home. Doing chores around the house is a good way to teach young adults about expectations in the real world.

If the young adult's goal is to work in paid employment after high school, then she should try to get the experience that will give her the greatest chance of reaching her goal. For example, she should aim at working a full three-hour shift as often as possible. If she cannot work for three hours at a time, there will need to be more planning and support in place to help her find work after high school.

Finding Work

There are many challenges to finding employment when you have an intellectual disability. Some employers may discriminate because they have stereotypical preconceptions about people with disabilities. Other employers expect new employees to come in with work experience. Some will not want to pay for extra training time or supports. To help overcome these barriers, the SACL, and many other agencies, have Employment Opportunities Consultants who assist adults with intellectual disabilities in finding employment.

Doing a Good Job

Francis Schaan was proof that paid employment is a real option for people with intellectual disabilities. At the time of his death, he had been a valued employee at McDonald's for more than 25 years. He always hoped that other people with disabilities could have the same opportunity he had to serve the community. Francis used every chance he had to tell others about his success and encourage them to find paid employment in their community.

The SACL's Employment Opportunities Consultants can give you information about the options for support. They can travel anywhere in Saskatchewan to help begin the process of finding employment for

a young adult. They can do training with employers or staff, or set up a job coach to help ensure that your daughter has the skills she needs to succeed. Your CLSD community service worker can also help with transition planning and finding resources for your young adult. Talk to them about what is available in your area.

Your young adult may have untapped talents that could lead to an exciting career path owning her own business. People with intellectual disabilities have been successful in starting a variety of businesses, such as pet grooming, growing bean sprouts, grocery pick-up, and lawn care. Self-employment is a way to find independence, serve the community, and get out of the minimum wage rut. There is funding available for people with disabilities to start their own business. With a plan, some start-up funding, and a committed circle of support, self-employment is a real option for many people with intellectual disabilities. Call the South/North Saskatchewan Independent Living Centres for more information on start-up loans. You can also check the John Dolan Collection at the Stewart Resource Centre at the STF offices in Saskatoon. Phone (306) 373-1660 or go online to www.stf.sk.ca.

Supported Employment Transition Initiative (SETI)

There are new opportunities for people with disabilities who are looking for work. Employment agencies, especially those that are specifically mandated to help people with intellectual disabilities, can be a great resource for a young adult who is looking for work. The Supported Employment Transition Initiative (SETI) works to develop new ways to assist people to make the transition to employment. The goals of SETI initiatives are to

- Assist individuals with intellectual and/or developmental disabilities who are currently in a vocational program to find sustainable employment in their communities;
- Demonstrate how labour market attachment will be addressed; and
- Develop processes/procedures to support,

extend or enhance the capacity of supported employment in your community.

Questions to Ask an Employment Counsellor

Here are some good questions to ask if you are helping your son or daughter interview potential employment counsellors. These questions are not intended to put the counsellor on the spot, but to help you find the right person.

1. Do you have any experience finding employment for people with intellectual disabilities?
2. What is the program's philosophy about securing and creating employment opportunities?
3. Is job carving a possibility for my son? What other methods do you use?
4. How will my son's participation be encouraged in the job placement process?
5. How do you present a person with a disability to the business world?
6. How will my son be represented during a meeting with an employer?
7. What services are offered?
8. What is your success rate for placement? How many people that you have placed are still working?

For information about a SETI pilot project in your area, contact the SETI coordinator by phoning the Saskatchewan Association of Rehabilitation Centres (SARC) in Saskatoon at (306) 933-0616.

You can also look in the phone book for regular career and employment services in your area. They may offer assistance to people with disabilities or a referral to another organization. However, it is best to be cautious. Some employment counsellors who do assessments may say your child is "not employable." At the SACL, we believe that everyone has something to contribute. If you need help from our Employment Opportunities Consultants, you can contact the SACL office at (306) 955-3344.

Often young adults find jobs through their parents' personal contacts or workplaces. Many entry-level jobs do not make it to a public job board. Check around at local community message boards. Ask friends at your workplace, professional organizations, clubs or churches if they know of any potential employers. With the help of personal networks, some parents have been very successful in creating a tailor-made job for their child.

SUPPORTED EMPLOYMENT: JOB CARVING, FINANCIAL INCENTIVES, AND JOB COACHES

Supported employment is when a person with a disability is able to receive personal assistance to help her find and keep a job. Workplace supports can take many forms. The three most common are job carving, training allowances, and job coaches.

Job Carving

Job carving⁵⁶ is a way to create a new position that makes use of the skills of a person with a disability and benefits the business owner. The process begins by understanding the skills and abilities of the person with a disability and matching this with tasks in the workplace that other, often highly paid, workers are doing. In most workplaces a worker will spend part of her day doing tasks that she is over qualified to do. For example, in an office, there can be an administrative assistant who is in charge of managing the office, an accounting clerk, a payroll clerk, etc. Each of them will spend hours a week doing filing. This is an opportunity to carve off the filing task and allow the other workers to focus on other parts of their jobs.

Job carving can also result in unfinished tasks getting done, e.g. the pile of documents to be shredded that is accumulating in the corner of the office. By showing the employer which tasks could be included in a new position, he or she may see the benefits

to the business. The goal is to create a job that fits the person and benefits the business.

Training Allowances

Since Statistics Canada (1990) studied the disadvantages that people with disabilities face in finding permanent employment, more financial supports have become available. **Training allowances** are available to pay a person with a disability for any additional training time she needs to learn the tasks. The federal government has developed the Opportunities Fund for people with disabilities. Provincially, through the Ministry of Advanced Education, Employment and Immigration, there is funding available through Employability Assistance for People with Disabilities (EAPD). Also, the Ministry offers the Enhanced Access for Students with Disabilities program. This program makes limited funding available specifically to students still in school who need employment supports. Information is available by calling the SACL Employment Opportunities Consultants at (306) 955-3344 or by going online to <https://www.sacl.org/programs.php?p=employment-opportunities-program>.

Training allowances need to be presented carefully to employers. A contract should be set up so that everyone involved understands the goal: the young adult will work toward receiving a full wage without a subsidy. This option allows students with disabilities the extra time required to learn the job well – time that might not be offered (or paid for) by the employer.

Job Coaches

Job coaches can bridge the gap between training for a job and being comfortable with a job. Aside from providing one-to-one support to assist a young person to learn the tasks, job coaches can help other people in the workplace become natural supports. These natural supports (co-workers) will be critical to the long-term success of the young adult when she is on her own in the workplace.

You can expect a job coach to:

- Identify tasks pertaining to the position
- Sort tasks in priority
- Identify areas for accommodation
- Assist only when needed and begin training task-by-task
- 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 the SACL Employment Opportunities Consultants, SARC member agencies or other agencies that are listed at the end of this chapter.

There are also other helpful websites that offer advice on how to accommodate people with disabilities in the workplace. Below are some programs that fund employment assistance for individuals with disabilities.

SUPPORTED EMPLOYMENT FUNDING

Student Summer Works (SSW)

The SSW program was introduced in 2010 to replace Student Employment Experience. The Ministry of Advanced Education, Employment and Immigration (AEEI) describes the SSW program on its website at <http://www.aeei.gov.sk.ca/ssw>. It says SSW

“is a summer program designed to connect students to quality part-time and full-time employment. SSW strives to:

- *improve students' ability to pay for continued education;*
- *provide students with work experience to develop practical work skills;*

- link future graduates to potential long-term employers in Saskatchewan; and
- create employment opportunities that strengthen organizational capacity and support succession planning.

Ensuring students with employment barriers can gain work experience to build their employment capacity is a key priority for AEEI. As a result, the SSW program will continue to be focused on students with disabilities and Aboriginal students who continue to be under-represented in our growing workforce.”

SSW will focus on employment in the sport and recreation, culture, and environmental sectors.

Although the SACL does not administer SSW funds, the SACL’s Employment Opportunities Program will continue to support students who have a disability in finding summer employment. If you are interested, contact the SACL’s Employment Opportunities Coordinator by phone at (306) 790-5685.

Opportunities Fund for People with Disabilities

The Opportunities Fund for People with Disabilities is money set aside by the federal government to help people with disabilities train for work and find work. The goal of the Opportunities Fund is to assist people with disabilities to prepare for work, develop skills, and find employment. A person can request individual assistance from this fund. The federal government also finances special employment services for people with disabilities through this fund. Some financial support is available to people who are not on social assistance when they are going through training. The activities that can be funded are

- supporting employers to provide jobs and experiences to people with disabilities
- helping someone start a business
- providing work experience
- training to increase skills
- providing services for special needs to help a person integrate into a workplace

- providing personal supports to help a person seeking employment

To apply, you can call your local Human Resource Centre (listed at the end of the chapter).

Employability Assistance for People with Disabilities (EAPD)

Employability Assistance for People with Disabilities (EAPD) has assisted many people with disabilities to train, find, and keep a job. The program has also funded employment projects for people with disabilities. The goal of EAPD is to provide training and remove the barriers that prevent adults with disabilities from finding secure employment. The program also supports employers to hire people with disabilities. You may want your daughter to apply for EAPD to access the following supports that could increase her chances of finding employment:

- training on the job
- vocational, work, or educational assessments
- job coaching
- employer support to cover disability-related costs

Contact the SACL Employment Opportunities Consultants to find out how to apply for EAPD (contacts are at the end of the chapter).

PROVINCIAL TRAINING ALLOWANCE (PTA)

The Provincial Training Allowance (PTA) is short-term funding that people can receive while they are taking a training program, such as basic education, work readiness programs, or short-term educational programs. The rates are similar to social assistance, but the administration is different. The student will receive a monthly cheque and will be responsible for paying rent, utilities, and expenses. Many students with intellectual disabilities who access the Way to Work program receive the PTA. The PTA is a grant, not a loan, so if a person receives the PTA, they are not expected to pay it back. However, parents may be expected to contribute a portion.

Eligibility

You are eligible to apply for financial assistance if

- You are a Saskatchewan resident. You are considered a Saskatchewan resident if you are registered with the Ministry of Health.
- You are a Canadian citizen, Permanent Resident, or designated as a Protected Person;
- You are enrolled in an approved program at an approved training centre;
- You have financial need according to program criteria; and
- You are not in default on a previous Provincial Training Allowance (i.e. you have failed to repay past PTA overpayments).

*Landed immigrants who are sponsored by individuals or organizations are not eligible for financial assistance for the term of the sponsorship. Sponsors are responsible for supporting the landed immigrant financially when he or she arrives for the term of the sponsorship. You should not apply for PTA during the term of the sponsorship.*⁵⁷

If you are a student with a permanent disability, you will be provided with PTA to assist with living costs. EAPD funding may be provided to assist with disability related costs.

You are not eligible for student loans for the same period you are receiving the PTA.

If you are enrolled in a PTA-eligible course, you will not be denied funding if you have defaulted on federal or provincial student loans or are restricted from receiving loans for any other reason.

Eligible Programs

The PTA provides income support to low-income students enrolled in approved post-secondary education and adult training programs. There are some restrictions with respect to the programs that are eligible for funding and to program length. For example, programs that are less than 20 days in a four-week period are not eligible and some post-secondary programs of 12 weeks or more are not eligible for PTA.

For anyone interested in a training program for which they need the PTA, contact the Ministry of Advanced Education, Employment and Immigration. For more information, go to <http://www.aeei.gov.sk.ca/pta/> or phone 1-800-597-8278 toll-free or (306) 787-0923 in the Regina area.

SELF-DIRECTED FUNDING – THE WAY OF THE FUTURE?

The Principles of Self-directed Funding

All funding mechanisms for people with disability should be based on the following principles. This requires a funding support system that provides a range of supports and options for management of funding, planning, and purchasing of services.

1. **Independent Living** - I can get the support I need to be an independent citizen.
2. **Individual Budget** - I know how much money I can use for my support.
3. **Self-determination** - I have the authority, support or representation to make my own decisions.
4. **Accessibility** - I can understand the rules and systems and am able to get help easily.
5. **Flexible Funding** - I can use my money flexibly and creatively.
6. **Accountability** - I will tell people how I used my money and anything I've learnt.
7. **Capacity** - My capacity is assumed, and I can also get information and support to build my vision of what is possible in my life.

from In-Control Australia, http://www.in-control.org.au/about_sdfunding.asp

Definition of Self-directed Funding

Currently, services and supports for adults with intellectual disabilities are primarily delivered in group or congregated settings such as group homes and vocational programs. Financial support is given to agencies by the provincial government to provide

a set number of spaces for services and supports for people with intellectual disabilities. This way of providing supports is called the Block Funding model (BF). (Also see page 117 for information on the new day program funding standards that are being piloted in some communities.)

While Self-directed Funding (SDF) is not commonly available in Saskatchewan for persons with intellectual disabilities, we do know that there are a very small number of SDF projects that are operating successfully in the province. We believe that these projects set a precedent for a move to make SDF a true option for everyone.

Self-directed Funding is a way some governments provide financial support to people with intellectual disabilities. Under SDF, a person-centred plan is developed for the individual. This plan reflects the individual's needs and goals. The person with a disability can, if they wish, receive money directly from the government to purchase the supports and services they choose, instead of using the services that are currently provided for them. Funding can be sent directly to the individual, or a parent, support person or team acting on the individual's behalf, and that money can be used to buy the services and supports the individual needs. Self-directed Funding has been used successfully in many other parts of Canada for more than 25 years.

If you chose a self-directed option, you will need to learn about being an employer and administering the funds. Some families and individuals do not want to take on this extra work. If the individual and her family/support team do not want to manage the funds, a third party, such as a service provider, can do the administration and provision of the services. This means the individual's personal plan is still at the centre of all planning.

With SDF, if the person with a disability or her family decides that her needs can be better met through another service provider, they can choose, with appropriate planning and notice, to have her funding moved to another agency or to hire new support

staff. The funding is portable; in other words it "follows" the person when they move to another service provider or another community.

At this time, there are a very limited number of SDF plans in Saskatchewan. We believe that all people with intellectual disabilities should have the right to choose SDF if they want it.

Benefits of Self-directed Funding

People who have been able to access SDF say that controlling their own funding helps them get the kind of supports and services they want. They report that their life is better when they have choices and control. They can explore supported employment opportunities, daytime activities and housing options that were not available before. Some people have been able to own their own homes, hire staff and get out in the community more often. They tell us that Self-directed Funding has changed their lives.

People who have access to SDF, with management support, negotiate directly with their service provider as they need to. They can change which service provider they use if they find their needs are not being met. Their funding follows them.

SUPPORTED EMPLOYMENT RESOURCES

Canadian Mental Health Association Provincial Office

Phone: (306) 525-5601

Canadian National Institute for the Blind

Phone: (306) 525-2571

Canadian Paraplegic Association

Phone: (306) 652-9644 in Saskatoon

Phone: (306) 584-0101 in Regina

Career Headways Inc.

Phone: (306) 352-8768

Community Advocates for Employment (CAFÉ)

Phone: (306) 634-9554

Employment Assistance for People with Disabilities

<http://www.aeel.gov.sk.ca/eapd/>

Phone: (306) 787 – 5602

Employment Opportunities Program-Saskatchewan Association for Community Living

<http://www.sacl.org/>

North Saskatchewan (306) 763-5606

Central Saskatchewan (306) 955-3344

South Saskatchewan (306) 790-5685

Rotary Partnership (306) 955-3344

Neil Squire Foundation

Phone: (306) 781-6023

Northern Saskatchewan Independent Living Inc.

Phone: (306) 665-5508

Opportunities Fund for People With Disabilities — Human Resource & Skills Development Canada (HRSDC) <http://www.hrsdc.gc.ca>

-Regina Human Resource Centre of Canada (Call for a satellite office in your area)

Phone: 1-800-206-7218

-Saskatoon Human Resource Centre of Canada (Call for a satellite office in your area)

Phone: 1-800-206- 7218

Partners in Employment – Saskatchewan Abilities Council

http://www.abilitiescouncil.sk.ca/main/html/services/supported_empl/partners_in_employment.shtml

Phone: (306) 374-4448

Partners for Workplace Inclusion Program (PWIP)

<http://www.ccrw.org/en/pwip.html>

Phone: (306) 651-7177

Portage Vocational Society

Phone: (306) 445-3752

Regina Work Preparation Centre

Phone: (306) 757-9096

Saskatchewan Association of Rehabilitation Centres (SARC) (for a listing of member agencies providing supported employment services in your area)

<http://www.sarcsarcan.ca/>

Phone: (306) 933-0616

Supported Employment Transition Initiative (SETI)

Coordinator

111 Cardinal Crescent

Saskatoon, SK S7L 6H5

Phone: (306) 933-0616

South Saskatchewan Independent Living Centre

Phone: (306) 757-7452

The Way to Work Program, SIAST

http://www.siastr.sk.ca/programs/basic_education/readiness_bridging.shtml

Chapter 11: Financial Assistance

The United Nations Convention on the Rights of Persons with Disabilities says

States Parties recognize the right of persons with disabilities to an adequate standard of living for themselves and their families, including adequate food, clothing and housing, and to the continuous improvement of living conditions, and shall take appropriate steps to safeguard and promote the realization of this right without discrimination on the basis of disability.

From Article 28

This chapter is about understanding and accessing the available financial assistance, benefits, and opportunities for people with intellectual disabilities and their families.

The financial supports listed here will only begin to help with the financial stresses faced by people with intellectual disabilities. When you have a child with an intellectual disability, you know the expense of extra programs and supports. As your child becomes an adult, you will quickly find that there are few opportunities for adults with intellectual disabilities to have financial security. Adults with disabilities have limited access to work opportunities and in the past have been forced to rely on social assistance. The good news is that some of this is changing due to the work of parent advocates, such as those involved with the SACL. The SACL believes that to promote equal opportunity in Saskatchewan, there must be more financial support for people with intellectual disabilities and families who have a member with an intellectual disability.



FINANCIAL ASSISTANCE THROUGH THE TAX SYSTEM

Much of the financial assistance from the government for people with disabilities and their families is distributed through the tax system. Anyone who does his own taxes knows this is a complicated section and you need to understand tax credits and tax benefits.

The actual dollar amount of the tax credits and benefits are increased each year. This is known as “indexing to inflation.” What it means is that the value of the tax credits and benefits will stay consistent with the rising cost of living (inflation). Since the values change each year, the actual dollar amounts of the tax credits will not be included in the explanations below. This information is updated every year in the General Income Tax and Benefit Guide.

Tax Credits and Deductions

When you file your income tax return you may be eligible for some credits. A tax credit is a tool that governments use to encourage economic behaviour, as with the 2009 Home Renovation Tax Credit. Credits are also used to provide a tax break or a benefit to taxpayers. The tax credit has the effect of reducing your taxable income and thus reducing the amount of tax you will pay. The credits come in two forms. The most common is the non-refundable tax credit, which can enable you, in some instances, to reduce the amount of tax you pay to \$0.00. The other kind is the less common refundable tax credit, which can reduce your taxes below \$0.00 and entitle you to a payment from the government.

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, usually 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.



The following is a list of the tax credits and deductions that might apply to you if you have a child with an intellectual disability.

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 with disabilities who live in poverty and already do not pay taxes. If your child with an intellectual disability is eligible for this credit but his 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, 306 or 315, then your child can transfer his 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, also indexed to inflation, and it is on line 5844 of your Saskatchewan T1 general form. It can be transferred from your child to you on line 5848.

For a person to be eligible for the DTC, he must fill out and submit Form T2201, also called the *Disability Tax Credit Certificate*. You can find it on the Canada Revenue Agency website at <http://www.ccca-adrc.gc.ca/E/pbg/tf/t2201/README.html> or by phoning 1-800-959-8281. This certificate has very specific, narrow criteria for the definition of “a disability.” Your son may not fit this strict definition. If you are wondering if your child is eligible, there is no quick answer. From the experiences of people who have applied, we know that some people with intellectual disabilities do not qualify. The first thing you could do as an advocate is make sure that you have a good family doctor who knows your family and will fill out Form T2201 in your family’s best interest. If your child is turned down, **get a second opinion** from a different doctor and appeal the first decision. Some parents have had success when they reapplied with a different doctor filling out Form

T2201. For more information, read about appeals at the end of this section. It is also important for you to know that you may be asked to reapply for the DTC every year.

The person applying qualifies if he has a **prolonged “impairment”** that has lasted or is expected to last at least a year. He must have an impairment that causes him to be **“markedly restricted”** in a basic activity of daily living. “Markedly restricted” means that you cannot do, or it takes you a long time to do, one of the following basic activities even with therapy, devices, and medication. The basic activities are

- seeing (you are blind even with corrective lenses or medication)
- walking
- speaking
- perceiving, thinking, and remembering
- hearing
- feeding and dressing
- eliminating bodily waste

A person also qualifies for the DTC if they dedicate time to “life-sustaining” therapy for an average of 14 hours a week. Again, it is very hard to qualify as someone who needs life-sustaining therapy.

It is possible (and a good idea) to get the Form T2201 filled out ahead of time during the year and send it in. Revenue Canada suggests this as a tax tip 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 to receive the Child Disability Benefit or the Intellectual Disability Supplement. Your local tax office has copies.

Disability Tax Credit Supplement for Children

There is a Disability Tax Credit Supplement available for children with disabilities who qualify through the Disability Tax Credit Certificate. If your child qualifies, you can claim the disability supplement amount as a non-refundable tax credit on line 316 of your federal tax form and line 5844 of your



Saskatchewan form. If you claim child care expenses (line 214) or attendant care expenses (line 215 or 330), then your child's Disability Supplement will be clawed back dollar-for-dollar. The Disability Supplement can also be transferred from your child to you on line 318 of your federal form and line 5448 of your Saskatchewan form.

Medical Expense Tax Credit

The Medical Expense Tax Credit is a non-refundable 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 for medical expenses you paid, unless you have already been reimbursed for what you spent. You are allowed to calculate the expenses for any 12-month period that ends within that tax year.

You need to 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. Then you calculate the amount you can claim on line 332 of your federal form by following their calculation formula.

The medical expenses that you can claim for are

- payments to medical professionals or facilities (this includes speech and language pathologists, occupational therapists, and physiotherapists)
- payments for health care premiums
- payments for wheelchairs, crutches, hearing aids, prescription eyeglasses and contact lenses, pacemakers, and prescription drugs and medical devices
- payments for guide and hearing-ear dogs
- payments for caregivers or care in an institution (your child may lose his disability tax credit if you claim this)
- payments for professional captioning, sign language interpreting, or note-taking
- payments for voice-recognition software
- the cost of adapting a vehicle or the cost of a device to help a person with a disability operate a vehicle
- 20% of the cost to buy a van that was already adapted
- payments for altering a driveway
- travel expenses if travelling for treatment (only if it is not available where you live)
- moving expenses to more accessible housing
- fees paid to a group home

- payments for therapy (only for a person over 18 who qualifies)
- the cost of tutoring or a talking textbook
- the cost of building or renovating a building for a person with a disability⁵⁸

Tax Tip

If you are doing major home renovations for a child with a disability, break down the cost and claim it over two tax years, since the medical expense tax credit allows you to set the 12 months for which you will claim expenses.

Dependent Child Tax Credit

Saskatchewan has a tax credit for parents with dependent children. The non-refundable Dependent Child Tax Credit is found on line 5821 of your Saskatchewan tax form. Your child must be living with you at the end of the year when you file, and you can only claim for your child if no one else has (such as your spouse or foster care). The spouse with the lowest income must claim this credit first, then the balance can be transferred on Schedule SK (S2). To receive this credit, you need to fill out Form SK428 from your tax package. This gives the government details about your dependent children.

Eligible Dependent Tax Credit

If your child has lived in your home at any time in the last year, and is dependent on you for support, then you can claim the non-refundable Eligible Dependent Tax Credit. This credit can also be claimed for adults with disabilities who are dependent on their family. This credit is on line 305 of your federal tax form and 5816 of your Saskatchewan tax form.

Infirm Dependent Tax Credit

If your adult son or daughter with a disability is living in your home, and is dependent on you for support, then you can claim the non-refundable Infirm Dependent Tax Credit. It is on line 306 of your federal tax form and line 5820 of your Saskatchewan tax form. If another person is claiming on line 315 as

a caregiver for your child, then you will not be able to claim this amount.

Caregiver Tax Credit

If your child is an adult, and you are his primary caregiver, then you can claim the non-refundable Caregiver Tax Credit on your tax form. You will find this tax credit on line 315 of your federal tax form and line 5840 of your Saskatchewan tax form. There is a federal and a Saskatchewan worksheet included in your tax package to figure out how much you can claim.

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. In 2009 you could claim a refund of up to \$1,067 if you have an amount entered on line 332 of your federal tax form. Your family's net income must be at least \$3,116 but not more than \$44,972. There is a separate federal worksheet for you to determine your family net income and your refund. This supplement is only federal, so there is no provincial refund.

Disability Support Deduction

If your adult son paid for a personal care attendant, he can deduct that amount from his taxes if the attendant was hired so that he 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 it on line 215 of his federal tax form.

Child Care Expenses Deduction

Often parents of children with intellectual disabilities have higher child care expenses, so pay attention to this deduction. If you paid for child care so that you could work, go to school, run a business or do research, then you can deduct that amount from your taxes. You need to calculate your amount with the federal Form T778 and enter the final amount on line 214 of your federal tax form.

Tax Benefits

Tax benefits are given to people who apply, qualify and who have filed their income tax return. These benefits are income-tested, which means that as you make more money, your benefit will gradually shrink, and people with high incomes are not eligible to receive a benefit. These benefits are indexed to inflation (see the introduction in this chapter) so that the actual cheque you get in the mail does not lose value as the cost of living rises.

Canada Child Tax Benefit

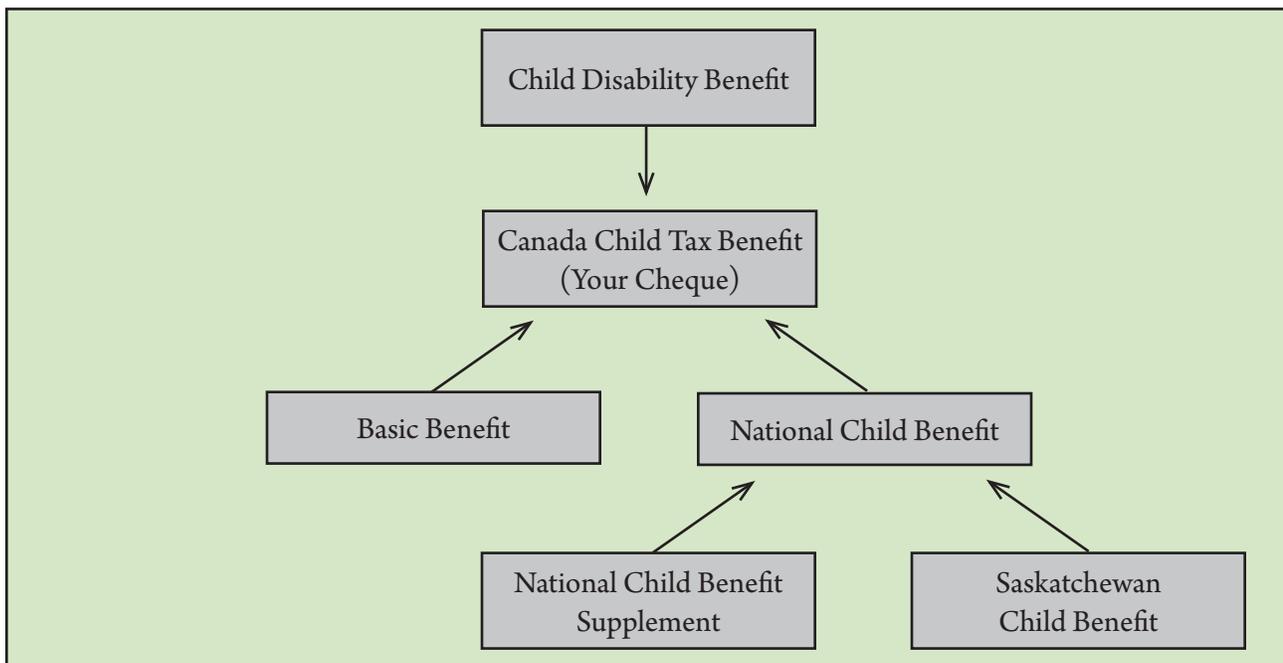
If you have children, you may already receive the Canada Child Tax Benefit (CCTB). It is a monthly cheque that is meant to help with the costs of raising children. Every year in July the amount you get is calculated based on your family's net income from the previous year. You and your spouse both need to file an income tax return in order to get the CCTB. You can figure out how much your cheque will be with the online calculator on the Canada Revenue Agency (CRA) website at: <http://www.cra-arc.gc.ca/bnfts/clcltr/menu-eng.html>. CRA deducts a certain amount from your benefit if you have claimed child care costs on your tax form.

To apply for the CCTB, you fill out Form RC66, the *Canada Child Tax Benefit Application*, that you can get by calling 1-800-387-1193 or from the CRA

website at <http://www.ccra-adrc.gc.ca/E/pbg/tf/rc66/README.html>. If you are applying for the first time, the government can make retroactive payments for the previous 11 months. You might be asked for a copy of your child's birth certificate. From experience, it may take three months to process the form (CRA says two months).

If your situation changes, then you should contact CRA and let them know. Contact CRA when your child turns 18, the number of children who live with you changes, your marital status changes, or you move.

Even though you only get one cheque, the CCTB is divided into different parts. You do not need to know all of these details, but you may be interested to know of all the different programs involved in the one cheque you receive. There are two parts to the CCTB – the Basic Benefit, which is based on your income, and the cost-shared National Child Benefit (NCB). Since the NCB part is cost-shared with the provinces, it is made up of two parts: the National Child Benefit Supplement (NCBS) and the Saskatchewan Child Benefit (SCB). These are income-tested benefits that are calculated individually and then included in one cheque, so you may receive one portion and not another. Below is a diagram of the CCTB.



Child Disability Benefit

The Child Disability Benefit is a supplement to the CCTB, specifically for children with disabilities. To receive this benefit, you need to fill out Form T2201, the Disability Tax Credit Certificate (please refer to the Disability Tax Credit section of this chapter). This benefit is income-tested, so it is reduced as your income increases. If you want to find out how much you will receive, you can use the CRA online calculator at <http://www.cra-arc.gc.ca/bnfts/clcltr/menu-eng.html>.

Children's Special Allowance

The Children's Special Allowance (CSA) is a monthly benefit for a child who is maintained by a government department and living in an institution, group home or foster home. This is a benefit that foster parents receive, along with the CCTB cheque. If you are fostering a child with a disability, it is important to know that you receive these benefits. Child and Family Services can redirect the Children's Special Allowance cheque to the foster parent with Form RC64. This form is online at <http://www.ccra-adrc.gc.ca/E/pbg/tf/rc64/README.html> or by call Canada Revenue Agency (CRA) at 1-800-387-1193.

APPEALS

If you do not agree with an assessment of your income tax, you can appeal the decision. The first step is to contact the tax centre that processed your return in writing, or visit your local tax office. You have 90 days, after Canada Revenue Agency mailed your Notice of Assessment, to file an objection. If you have a good reason for not getting the appeal in on time, then you can write and ask for an extension. To appeal, you need to write a letter to the Chief of Appeals at the tax office or centre for your area (Saskatoon and Regina have tax offices). You should include

- Your name, address, social insurance number, and daytime contact information
- The date of your Notice of Assessment and the taxation year

- The facts and reasons for your objection
- Any documents that support your objection

After you have sent in your appeal, the office will send you any information it has on the issues you are disputing. It will also let you know what has been discussed with your local tax office.

If you lose this appeal, you can ask for information about appealing to the Tax Court of Canada. For more information, check the website at <http://www.ccra-adrc.gc.ca/tax/individuals/resourcekit2003/fs-appeals-e.html>.

REGISTERED DISABILITY SAVINGS PLAN

A Registered Disability Savings Plan (RDSP) is a savings plan that is intended to help parents and others save for the long-term financial security of a person who has an intellectual disability. The program grew out of the effort of parents involved with the Planned Lifetime Advocacy Network (PLAN) in Vancouver, who worked for many years with the Government of Canada to develop the RDSP. It is another tool that families can use in planning a good life for their family member who has an intellectual disability. It is something that every family who has a member with an intellectual disability should consider when planning for their future.

To be eligible for the Registered Disability Savings Plan, you must:

1. Make sure you or your relative qualify for the Disability Tax Credit,
2. Be a Canadian resident and have a valid Social Insurance Number,
3. Be under 60 years of age, and
4. File a tax return for two years prior (to receive the Grant and Bond).

Contributions to an RDSP are not tax deductible and can be made until the end of the year in which the beneficiary (the person who has a disability) turns 59. There is no annual limit to the contribution, but there is a lifetime limit of \$200,000.

The Government of Canada, in announcing the RDSP, also announced two separate programs to assist families and individuals with disabilities to save for the future. These are the Canada Disability Savings Grant (CDSG) and the Canada Disability Savings Bond (CDSB).

To qualify for the Canada Disability Savings Grant (CDSG) you must establish and make a contribution to an RDSP. As of 2010, if your family income is less than \$78,130, the CDSG will match your contribution with \$3 for every \$1 you contribute on the first \$500 and \$2 for every \$1 of the next \$1,000 to a maximum of \$3,500. In short, if you contribute \$1,500 you receive a grant of \$3,500. If your family income is greater than \$78,130, the program will match you dollar for dollar to a maximum of \$1,000.

The Canada Disability Savings Bond (CDSB) was established to assist families who have a low income and who might not be able to make a contribution. For 2010, if your family income is less than \$21,947, you can receive a bond of \$1,000 even if you made no contribution. Of course you have to establish an RDSP. If your income is more than 21,947 and less than 39,065, your bond will be prorated, e.g. if your family income is \$25,500 your bond would be approximately \$500.

Grants and bonds are payable until the end of the year in which the beneficiary turns 49. This means contributions made after that time will not be eligible for a grant or a bond.

When the beneficiary is under 18 years of age, it is his parents' income that is considered when calculating the amount of the grant or bond. Once he turns 18, family income will be defined as his income only.

When the beneficiary begins to make withdrawals from the RDSP, only the money received through the Canada Disability Savings Grant (CDSG) or Canada Disability Savings Bond (CDSB) and investment income earned in the plan will be considered income for the purpose of taxes. In other

words, the portion of the contributions made by the beneficiary, family and friends will not be taxable when withdrawn.

The beneficiary of a plan can receive Disability Assistance Payments as soon as the RDSP is established. The Disability Assistance Payments must begin when the beneficiary turns 60. There are no restrictions until age 60 on when the funds can be withdrawn or for what purpose, but any grant or bond (does not include interest earned on the grant or bond) received within 10 years prior to the withdrawal must be repaid. In short, to get the greatest impact out of the grant or bond, withdrawals should not be made until 10 years after the last grant or bond is received.

The Government of Saskatchewan's policy is that the assets of an RDSP or income from an RDSP will be exempt from calculation related to social assistance. This is money that will allow people to get ahead.

RDSP are not as complicated as they may appear at first glance. For more information you can go to the Canada Revenue Agency website at <http://www.cra-arc.gc.ca/tx/ndvdl/tpcs/rdsp-reei/menu-eng.html> or to the PLAN website at <http://www.rdsp.com/>.

Saskatchewan Pension Plan (SPP)

Another tool to help your child build a more secure financial future is the Saskatchewan Pension Plan (SPP). 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, what your income is, or if you have a job or not.

Making contributions 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. It is up to you. If you don't make a payment, that does not matter.

If a SPP member is receiving social assistance or payments from the Saskatchewan Assured Income for Disability program, the money he has in the plan is not considered an asset until he reaches 65. Section 18.3.1 of the *Saskatchewan Assistance Plan Policy Manual* says:

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).⁵⁹

For more information about SPP, see contact information at the end of this chapter or go to the website <http://www.saskpension.com/index.php>.

INCOME SUPPORT AND FINANCIAL PROGRAMS

As your child becomes an adult, there is a good chance that he will be accessing government programs. If your adult son is on social assistance, it is beneficial to know the rules for that program. Rent supplements and home modifications are available for people with disabilities. Parents also need to know there is a new provision in the Employment Insurance program that allows parents to take compassionate leave when a child or family member is facing a life-threatening situation.

Saskatchewan Assured Income for Disability (SAID)

In 2009, the Government of Saskatchewan began a new era in income support for people who have a disability when it announced the Saskatchewan Assured Income for Disability program. SAID, as described in the *SAID Policy Manual*, 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; and*
- *have insufficient income from employment or other sources to permit self-sufficiency; and*
- *are not expected to attain long-term financial self-sufficiency through employment or self-employment given available treatments or supports.⁶⁰*

See <http://www.socialservices.gov.sk.ca/SAID-policy-manual.pdf>.

The development of SAID has been an example of cooperation and collaboration unique in the development of human service programs and policy in Saskatchewan. The program began with a small coalition of disability advocates, consumers and organizations who were committed to advocating for a respectful, dignified and adequate income support system. Their efforts grew into the Disability Income Support Coalition (DISC) with a membership of more than 38 disability organizations as well as a large number of disability advocates and self-advocates.

DISC's vision is,

"[an] income system that offers both an adequate baseline income for people with disabilities and a user-friendly mechanism to address individual financial needs based on the impact of disability."

In support of its vision, DISC has also set out a number of principles for an improved income support system. These are:

Adequacy - People with disabilities should have an adequate income that truly meets their needs without the indignity of having to justify their needs. Lifelong disability and subsequent economic insecurity needs to be a consideration. What does DISC consider adequate? A disability income should be enough financial support to meet individual needs, not just basic needs. Our primary aim is to see an income system that offers both an adequate baseline income for people with disabilities and a user-friendly mechanism to address individual financial needs based on the impact of disability.

Hope and Security - People with disabilities must have financial accommodations so that they can live their lives with hope, respect and dignity instead of a system of disincentives.

Person-Centred and User Friendly - People with disabilities should be able to expect a dignified service that focuses on their individual financial needs as its reason for being. Financial accommodation should be easily accessible with consistent, respectful income workers who have the mandate and power to respond quickly to individual discretionary needs.

Higher Income Exemptions - People with disabilities need to be adequately accommodated as they move into training or employment. Income exemptions need to be increased to eliminate disincentives to employment and independence. Rapid reinstatement needs to be a working principle that allows people with disabilities to feel secure as they move in and out of employment opportunities.

Consistent Implementation - People with disabilities should be able to expect a portable and flexible income system that meets their individual needs no matter where they choose to live in the province.

DISC met with government officials to explain its vision and principles. In the fall of 2008, Social Services Minister Donna Harpauer announced the

government's intention to develop a new income support system for people with disabilities. In December 2008, the minister invited DISC and other community agencies to join the Ministry in designing the new income program. To do this, Minister Harpauer struck a task team of disability community advocates and organizations and senior Ministry officials. In May 2009, the task teams presented 50 recommendations⁶¹ for the new program, all of which were adopted by the minister. To see the report, go to <http://www.socialservices.gov.sk.ca/Backgrounder-ODI.pdf>.

The Saskatchewan Assured Income for Disability (SAID) program began in the fall and early winter of 2009. In announcing the start of the program, the Ministry said:

The new program, which will be separate from the existing Saskatchewan Assistance Program, will be based on the goals and principles recommended by the task team, including:

- *To assure a socially acceptable income for people with disabilities - recognizing the range of additional costs associated with disability; and*
- *To encourage and empower people with disabilities to participate as fully as possible in community life.*

In the fall of 2009, only individuals living in group homes, approved private service homes, and some family homes were accepted into the program. We expect that in a few years the number of individuals eligible for SAID will grow. As it begins, SAID looks a lot like the Saskatchewan Assistance Program it is intended to replace. There are some initial changes in the reporting requirement so that individuals will not need to affirm annually that they have a disability. But in the beginning, levels of support are the same and the policies and rules from the Saskatchewan Assistance Plan are being used to administer SAID.

DISC is committed to working with the government to ensure the program becomes more separate and distinct. There is a great deal of work that remains to

be done on the implementation of SAID and the 50 task team recommendations. DISC will continue to work toward a “socially acceptable level of income” for all who have a disability.

Saskatchewan Assistance Program – Social Assistance

In the past, many adults who have an intellectual disability have needed to apply to the Saskatchewan Assistance Program (SAP) for income support. With the introduction of SAID, this will change and most will be eligible for the new program. However, as this handbook goes to press, SAID is not fully implemented and it is important for you to understand how the SAP works. The Ministry of Social Services will keep the public informed as SAID evolves and the SACL will help you keep up with these changes.

Most people will know social assistance as “welfare.” If you have not had any experience with social assistance, it may be shocking to see how little money single adults receive to live on, even adults with disabilities. Often people with intellectual disabilities in Saskatchewan will access government-funded placements in group homes. While their basic needs are covered, they receive only \$160 a month as spending money for personal items, recreation, clothing, and transportation. They are just as restricted in their personal life choices as other low-income people. Even when someone on assistance works in regular jobs, the majority of what he earns is clawed back; that is, his assistance payment is reduced because of it. There is really no way for him to ever improve his situation.

Many of the adults with intellectual disabilities who choose to live in the community, and not in a group home, live on social assistance and have no other option for financial support. Social assistance was not designed for people with disabilities and it really is not enough to live on long-term. This is why the SACL continues to provide leadership to the Disability Income Support Coalition. We are hopeful that over time SAID will give people who have a disability the opportunity to live a better life.

Before anything else, parents need to know that people with intellectual disabilities who live on social assistance are allowed only \$1,500 in savings and assets before their assistance payments are reduced. (There are some exceptions to this rule; for example, a person on assistance can own a house and a car without it affecting the level of assistance he receives. See the *Saskatchewan Assistance Plan Manual*, Chapter 20 – Assets). If any of your son’s assets are ‘available’ (in his name), Social Services will deny him assistance until the money is spent at a government rate, which is at a subsistence level. Social Services may also check your son’s financial history as far back as two years before his application for assistance is approved. If money was moved out of his account in the previous two years, and it cannot be accounted for to pay bills or rent, then Social Services will take a portion of his cheque every month until they are satisfied that the money is paid off. For example, if your son went to Hawaii on his own savings before applying for assistance, he would be expected to pay that money back. Their reasoning is that if he didn’t go to Hawaii, that money would be available for his needs. (Read more about this in Chapter 9 on discretionary trusts.)

Dependent’s Relief Act

“The capital of and income from a trust is not to be considered as an asset or income of the dependent for the purpose of determining the dependent’s eligibility for assistance pursuant to *The Saskatchewan Assistance Act* or any other similar program funded by the Government of Saskatchewan.”

Section 9(4) of *The Dependent’s Relief Act, 1996*

As your son’s advocate, you’ll want to make sure that he keeps the same quality of life after he moves out of your home as he has now. For your son to be able to use his money to keep or improve his quality of life, it is important to legally protect that money before he goes on assistance. While you are alive, you can keep his additional savings and assets (anything over \$1,500) under your name, and pay for things

he needs as they come up. This way, you can purchase items as gifts for him without jeopardizing his assistance.

For people with intellectual disabilities, the Government of Saskatchewan has provided a way that they can keep their financial savings after their parents die (but not in their own name). Section 9 (2) of the *Dependent's Relief Act 1996* says that the court can let an individual with an intellectual disability have a trust fund set up to help him achieve independence, meet his special needs, or provide special gifts for him.

As a parent helping your son apply for social assistance, whether or not it is through a CLSD worker, make sure you have him sign a Release of Information form so that you can talk about his income security file with the worker. This way you can get updates on the phone.

To set up a trust properly, you need to go through the proper legal process. After you die, this will allow your son, with the support of a trustee, to keep his savings and use them without risking his social assistance benefits. There is more information about discretionary trusts in Chapter 9. For a comprehensive overview of how to set up a trust, read *The Roadmap to the Future: A Financial Planning Guide for Families of People with Disabilities*.

However, as soon as your son is 18, he is eligible to receive assistance (even if he is living with you), although it will not be much. He will probably have a Community Living Service Delivery (CLSD) community service worker already who can help him apply for assistance. If not, contact CLSD and ask for a community service worker to guide you through the process. The reason for involving the CLSD community service worker is that it will save you time and grief. Getting on social assistance is not an easy process. Without someone to intervene, people with intellectual disabilities have the same starting point and undergo the same intrusive questioning that other people have if they apply for assistance.

The CLSD staff have experience with the process of getting people with disabilities on assistance and can work with the social workers in the Income Security Division to make the process easier.

You can also help him apply by going through the Income Security call centre at 1-866-221-5200. Applying through the call centre requires a person to answer a lot of personal questions. It is meant to filter out those who are not eligible. For a person on assistance, the amount they will receive as of April 2010 (<http://www.socialservices.gov.sk.ca/SAP-rate-card.pdf>) is as follows:

| | Adult Living Allowance - includes food, clothing, travel, personal and household items | Adult Shelter Allowance (maximum) - rate depends on where you live |
|--------------------------------|---|---|
| Adult | \$255 | \$225 - \$328 |
| Adult with a Disability | \$305 | \$307 - \$459 (if unemployable) |

Aside from what is on this chart, single adults on assistance can receive money for the following items:

- basic utilities paid in the client's name (phone, power, heat, and water)
- utility deposits and connection fees (including back bill payments when you apply)
- laundry allowance
- damage deposits and moving expenses
- special diet allowances
- special clothing or clothing to start a new job
- training allowance for employment
- household equipment (when you first apply)
- repairs to property
- basic funeral expenses
- payments for home care services
- prescription drugs, basic dental services, optical services, and incontinence supplies are covered
- a special care allowance to help people with disabilities buy services necessary for outside work (example: snow removal)

| | Combined Room and Board Allowance (living at home) |
|--------------------------------|--|
| Adult | \$330 |
| Adult with a Disability | \$350 |

If your son with an intellectual disability is living at home, as of April 2010, he will receive \$350 a month for his social assistance cheque, and will not receive the cost of utilities. (This information is available online at <http://www.socialservices.gov.sk.ca/SAP-rate-card.pdf> or from your worker.) You may receive more if he goes through a level of care assessment. Your son's level of care is determined through the Daily Living Skills Assessment that can be done by CLSD. There are nine levels of care from Level 1, the lowest, increasing in increments of half (1.5, 2, 2.5, etc.) to Level 5, the highest. Read the following section on level of care funding.

Parents Be Aware

If your adult son or daughter with a disability is on assistance and needs expensive dental work, such as a root canal, it is not covered. They are only entitled to the cheapest option (in this case, having the tooth pulled instead of a root canal).

These rates can be found in the *Saskatchewan Assistance Plan Policy Manual*, which is available online at <http://www.socialservices.gov.sk.ca/SAP-policy-manual.pdf/>. These rates change from time to time, so we recommend that you consult the manual (and be sure to check the date on the manual to see if it is current) or the Income Security Call Centre to be certain you have the current rates.

If your son works and is on assistance, then he will be allowed to keep a portion of his earnings before the rest is clawed back from the assistance cheque. He can earn \$100 plus 25% of the next \$500 to a maximum earnings exemption of \$225 a month.

It is important to report any income changes to Income Security because they will often alter the amount your son receives. If he receives a cheque

that is more than what he is entitled to (an overpayment), he will need to pay it back. To pay off this debt, Income Security will take an amount off his monthly allowance until it is paid. Also, your son is entitled to receive an "advance" from his monthly cheque, but \$40 a month will be taken off his regular cheque after the advance until the debt is paid off. Your son has the right to appeal if he was denied assistance, if his benefits are changed, or if the amount of assistance he receives does not meet his basic needs. Your son is permitted to have an advocate go through the whole appeal process with him. You could also arrange for support through the appeal process from the SACL or from anti-poverty advocates (there is information at the end of this chapter).

To appeal, he first must send a letter to the Director of Income Security stating the reasons for the appeal. The appeal board is a group of community members who make up a volunteer board that re-evaluates Income Security decisions and upholds the policies and legislation. You will need to present a strong argument in order for them to overturn a Department decision. Therefore, you will need to develop your son's argument based on Income Security policies and legislation. When you are looking at the policies, it is important to note that the appeal board may rule only on decisions that the "unit administrator" is responsible for. We believe the "unit administrator," who is frequently referred to in the appeal process in both the SAP Manual and Handbook, but not defined, is the person in charge of a regional office of the Ministry of Social Services, the Regional Director. The *Saskatchewan Assistance Act* refers to the unit administrator as "a person designated or appointed by the minister as a unit administrator."

The appeal will be heard in front of a local appeal board. The decision of the local appeal board can be appealed to the provincial appeal board. Be prepared, because an appeal ends up at the provincial appeal board either because you take it there or the Ministry does. If your son is asking for something that will set a precedent for people with disabilities,

then it will be harder to win an appeal. If you are your son's advocate, make sure that the Ministry knows you are willing to take the case to appeal.

Sometimes you can get things done without a formal appeal. If there is a problem with an Income Security worker getting back to you or giving your son what he is entitled to receive, call his or her supervisor to ask your question.

Parents Be Aware

All parents want to rate their child's abilities high, but that may prevent you from accessing the funding your child justifiably needs. If your daughter is being assessed by a doctor for "level of care" funding, make sure the doctor knows her needs and challenges. The rating is a stigmatizing label, but one that will pay the bills.

Social Assistance and CLSD Group Homes/Approved Private Service Homes

There is a whole different set of rules if your son is living in a group home or an approved home and receiving social assistance. Income Security pays a room and board rate of \$410 to the group home/approved home and \$115 for a personal living allowance.⁶²

CLSD pays the balance of the cost of any Approved Private-Service Home (APSH). The amount that CLSD will pay is based on an assessment called a Daily Living Support Assessment form, filled out by a CLSD community service worker or another person such as a mental health worker. The assessment will place him in a "level-of-care" category from 1.0 to 5.0. The top-up that CLSD provides for each person (depending on level-of-care) for an APSH is between \$687 to \$1,926/month.

If your son starts working, then the amount that Income Security pays will go down, and he will be expected to pay some of his living expenses out of

his wages. He is still entitled to receive the personal living and quality of life allowances.

Level of Care Funding for Personal Care and Family Homes

For people with disabilities who are living in a home licensed under the Personal Care Home Act, the amount of money that the home operator gets is based on a level of care assessment. The full amount that Income Security offers a private home for support is listed below:

- Level 1 - \$736 per month
- Level 2 - \$909 per month
- Level 3 - \$1,134 per month

When an adult with an intellectual disability lives with a relative, he can be assessed to receive a higher rate of funding. A relative could be a son, daughter, sister, brother, parent, aunt, uncle, great aunt, great uncle, grandparent, great-grandparent, cousin, nephew, or niece. It is interesting that the amount a family receives for a level of care payment is less than if the person was in a group home or a private care home.

- Level 1 - \$616 per month
- Level 2 - \$770 per month
- Level 3 - \$983 per month

It is obvious that families are expected to carry a portion of the financial cost of an adult family member with an intellectual disability living with them.

To receive a level of care rate, a medical report and Assessment of Level of Care (form 1093) must be completed by a doctor within 60 days of application. For people with a permanent disability who have a file with the Ministry of Social Services, they may not need to have another assessment done if there already is a medical report (form 1092) on file. If you do not agree with the assessment made, you can get a second opinion and appeal. If you ask to appeal, the social worker must inform you of your rights and the appeal process.

Disability Rental Housing Supplement (DRHS)

The Disability Rental Housing Supplement (DRHS) is a monthly benefit for adults with disabilities who have an income under \$2,200 a month. The supplement is open to families, single individuals, and couples. The supplement is conditional upon one family member having a disability that produces a recognized effect on his housing. Supports that address the housing impact of the disability must be in place at the time of application.

Recognized disability-related housing supports include

- **Accessibility/location supports**, including elevators, widened doorways, and ramps or required supportive services such as living close to a supportive neighbour, family member, or transportation/shopping services.
- **Other physical supports/features** such as audio or visual alarms, intercoms, grab bars, bath lifts, lowered counters, enhanced ventilation, lighting, security or reduced noise/soundproofing.

For more information, call 1-888-488-6385 or (306) 787-4723 in Regina or go online to <http://www.socialservices.gov.sk.ca/programs-services/housing/>.

Rent Supplement Program

There is some subsidized housing available for people with disabilities through the Saskatchewan Housing Corporation (1-800-667-7567) or Northern Administration District (NAD). Call 1-800-667-9656 toll free or go online to <http://www.socialservices.gov.sk.ca/programs-services/housing/>.

The Rent Supplement Program gives grants to building owners, who in turn subsidize their rental spaces for low-income people. The rental unit is available to the person in the greatest need. The things they look at are the condition and cost of their housing and social and health factors. Subsidized housing through this program is available in 20 towns and

cities in Saskatchewan, not only in Regina and Saskatoon.

Saskatchewan Home Adaptations for Independence Program (SHAIP)

This program is income tested and offers a forgivable loan of up to \$3,500 for a person with a disability to modify their home. The person must live in a permanent residence and the change must relate to his disability. The things that the Home Modifications for the Disabled program can cover are wheelchair ramps and lifts, air purifiers, widening doorways, remodelling bathrooms, and modifying lighting. The Saskatchewan Housing Corporation can approve other repairs or modifications as well. For more information phone 1-800-667-7567 or go online to <http://www.socialservices.gov.sk.ca/programs-services/housing/>

Residential Rehabilitation Assistance Program for Persons with Disabilities

As a parent and a homeowner, you can apply for a loan to modify your home for a child with a disability, if your income is low for the area you live in or your house is modest in value. This is a loan, but parents can receive the total cost of the modifications, up to the maximum loan amount of \$16,000-\$19,000, depending on where they live. For more information, contact ⁶³

- Your local housing authority in Moose Jaw, Prince Albert, Regina, or Saskatoon. If you live in a northern community, call the Prince Albert office toll-free at 1-800-667-9656. Or go online to <http://www.socialservices.gov.sk.ca/programs-services/housing/>
- If you live in another location, call toll-free 1-800-814-8688 to be referred to the nearest Territory Operations office.

In Conclusion

A few parents who believed life could be better for families who have a child with an intellectual disability founded the Saskatchewan Association for Community Living in 1955. They began the long fight to secure rights for people with intellectual disabilities. The parents of today can reach higher and see further because of this foundation.

We are called the Saskatchewan Association for Community Living because we believe that all people have a right to be full members of the community. Parents advocate for inclusion and meaningful participation for their children because they want a rich, full, interesting life for each of them. There is no disability that should exclude someone from a life of learning, companionship, and contribution. We believe your child must be treated as a regular citizen, appreciated for his unique gifts and talents. Your community is a better place because your child is part of it.

As a parent, we know that you are your child's best advocate. By advocating for him, you will teach people about inclusion and break down the myths that have kept people with disabilities segregated. As he grows up, people will know him for who he is, not his intellectual disability.

Together, we are making community living a reality.



Acronyms and Short Forms

ACL- Association for Community Living

AEEI- Advanced Education, Employment and Immigration

APSH- Approved Private Service Home

ARCH- A Legal Resource Centre for Persons with Disabilities

CAFÉ- Community Advocates for Employment

CARRE- Community Approached Rehabilitation, Respite and Education/Employment

CBS- Comprehensive Behaviour Support

CCS- Child Care Subsidy

CCTB- Canada Child Tax Benefit

CDS- Cognitive Disability Strategy

CDSB/ CDSG- Canada Disability Savings Bond/ Grant

CLASSIC- Community Legal Assistance Services for Saskatoon Inner City

CLSD- Community Living Service Delivery

CMHA- Canadian Mental Health Association

CNIB- Canadian National Institute for the Blind

CPAS- Client Patient Access Services

CPP&SP- Comprehensive Personal Program and Support Policy

CRA- Canada Revenue Agency

CSA- Children's Special Allowance

CSEP- Centennial Student Employment Program

DISC- Disability Income Support Coalition

DLSA- Daily Living Skills Assessment

DNR- Do Not Resuscitate

DRHS- Disability Rental Housing Supplement

DTC- Disability Tax Credit

EA- Educational Assistant

EAPD- Employability Assistance for People with Disabilities

ECIP- Early Childhood Intervention Program

EO- Employment Opportunities

Family Network- The Saskatchewan Family Network

FEEL- Families Experiencing Exceptional Loss

FIDA- Family Impact of Disability Assessment

GIS- Guaranteed Income Supplement

KCC- Kinsmen Children's Centre

KOTB- Kids on the Block puppet troupe

MAPS- McGill Action Planning System

MLA- Member of the Legislative Assembly

NCB- National Child Benefit

NCBS- National Child Benefit Supplement

PATH- Planning Alternative Tomorrows with Hope

PBLS- Pro Bono Law Saskatchewan

PLAN- Planned Lifetime Advocacy Network

PLEA- Public Legal Education

PPP- Personal Program Plan

PTA- Provincial Training Allowance

PWIP- Partners for Workplace Inclusion Program

RDSP- Registered Disability Savings Plan

RICs- Regional Intersectoral Committees

RRRC- Regina Residential Resource Centre

SAAG- The Self-Advocacy Action Group

SAC- Saskatchewan Abilities Council

SACL- The Saskatchewan Association for Community Living

SAID- Saskatchewan Assured Income for Disability

SAIL- Saskatchewan Aids to Independent Living

SARC- Saskatchewan Association of Rehabilitation Centres

SETI- Supported Employment Transition Initiative

SCB- Saskatchewan Child Benefit

SCPA- Saskatchewan Cerebral Palsy Association

SDF- Self-directed Funding

SDIS- Saskatchewan Drug Information Service

SDM- Supported Decision Making

SETI- Supported Employment Transition Initiative

SFN- Saskatchewan Family Network

SHAIP- Saskatchewan Home Adaptations for Independence Program

SIAS- Saskatchewan Institute of Applied Science and Technology

SIP- Saskatchewan Income Plan

SPP- Saskatchewan Pension Plan

SRC- Stewart Resources Centre

SSW- Student Summer Works

STF- Saskatchewan Teachers Federation

SWADD- System Wide Admissions & Discharge Department

TIPS- Therapeutic Integrated Pediatrics Services

WRC- Wascana Rehabilitation Centre

Important Resources for Every Chapter

Saskatchewan Association for Community

Living

3031 Louise St.
Saskatoon, SK
S7J 3L1
Phone: (306) 955-3344
Fax: (306) 373-3070
www.sacl.org
e-mail: sacl@sacl.org

The Canadian Association for Community

Living

Phone: (416) 661-9611, Fax: (416) 661-5701
TTY: (416) 661-2023, Help Line: 1-800-856-2207
<http://www.cacl.ca/>

Community Living Service Delivery (CLSD)-

Ministry of Social Services-

CLSD Central Office (Moose Jaw)

Phone: (306) 694 – 3565
<http://www.socialservices.gov.sk.ca/community-living/>

Community Living Service Delivery Offices:

| | |
|-------------------|----------------|
| Estevan | (306) 637-4550 |
| La Ronge | (306) 425-4357 |
| Lloydminster | (306) 825-6468 |
| Meadow Lake | (306) 236-7501 |
| Melfort | (306) 752-6288 |
| Moose Jaw | (306) 694-3800 |
| Nipawin | (306) 862-1704 |
| North Battleford | (306) 446-7535 |
| North East Region | (306) 953-2668 |
| Regina | (306) 787-3848 |
| Rosetown | (306) 882-5400 |
| Saskatoon | (306) 933-6300 |
| South West Region | (306) 694-3800 |
| Swift Current | (306) 778-8219 |
| Weyburn | (306) 848-2421 |
| Yorkton | (306) 786-1300 |

NORTHEAST REGION

8th Floor, 800 Central Avenue
Prince Albert, SK S6V 6G1
Telephone: (306) 953-2668

Sub-offices:

| | |
|----------|----------------|
| Melfort | (306) 752-6288 |
| Nipawin | (306) 862-1704 |
| La Ronge | (306) 425-4357 |

NORTHWEST REGION

405-1146 102nd Street
North Battleford, SK S9A 1E9
Phone: (306) 446-7535

Sub-offices:

| | |
|--------------|----------------|
| Meadow Lake | (306) 236-7500 |
| Lloydminster | (306) 825-6468 |

REGINA REGION

6th Floor, 2045 Broad Street
Regina, SK S4P 3V6
Phone: (306) 787-3848

SOUTHWEST REGION

118 - 110 Ominica Street West
Moose Jaw, SK S6H 6V2
Phone: (306) 694-3800

Sub-offices:

| | |
|---------------|----------------|
| Swift Current | (306) 778-8219 |
| Rosetown | (306) 882-5400 |

SASKATOON REGION

122 3rd Avenue North
Saskatoon, SK S7K 2H6
Phone: (306) 933-6300

SOUTHEAST REGION

72 Smith Street East
Yorkton, SK S3N 2Y4
Phone: (306) 786-1359

Sub-offices:

| | |
|---------|----------------|
| Estevan | (306) 637-4568 |
| Weyburn | (306) 848-2421 |

Saskatchewan Association of Rehabilitation Centres (SARC)
 Phone: (306) 933-0616
www.sarcsaran.ca

Council of Canadians with Disabilities
 Phone/TTY: 204-947-0303
<http://www.ccdonline.ca/>

The Office of Disability Issues
 Phone/TTY: (306) 787-7283
<http://www.socialservices.gov.sk.ca/office-disability>

Saskatchewan Voice of People with Disabilities
 Phone: 1-877-569-3111
<http://www.saskvoice.com/>

Saskatchewan Children's Advocate
 Regina (306) 787-6850
 Saskatoon (306) 933-6700,
 1-800-322-7221
<http://www.saskcao.ca/>

Saskatchewan First Nations Network on Disabilities
 Saskatoon (306) 665-1215,
 Fax: (306) 244-4413
 Pelican Narrows (306) 632-2253

DISABILITY-SPECIFIC ORGANIZATIONS

Autism Treatment Services of Saskatchewan
 (306) 665-7013
<http://www.autismservices.ca/>

Autism Resource Centre
 Phone: (306) 569-0858
<http://www.autismresourcecentre.com/>

Canadian Down Syndrome Society
 Phone: (403) 270-8500, 1-800-883-5608
<http://www.cdss.ca/>

Canadian Paraplegic Association
 Saskatoon (306) 652-9644
 Regina (306) 584-0101
<http://www.canparaplegic.org/en/>

Epilepsy Regina
 Phone: (306) 565-0009

Epilepsy Saskatoon Inc.
 Phone: (306) 665-1939

(H.O.P.E.) for Autism Saskatoon Society
 Phone: (306) 665-7013

Saskatchewan Brain Injury Association
 Phone: (306) 373-1555
<http://www.sbia.ca/>

Saskatchewan Cerebral Palsy Association
 Phone: (306) 955-7272, 1-800-925-4524
<http://www.skcerebralpalsy.ca/>

Saskatchewan Deaf and Hard of Hearing Services Inc. (SDHHS)
 Regina Phone/TTY: (306) 352-3323,
 1-800-565-3323
 Saskatoon Phone/TTY: (306) 655-6575,
 1-800-667-6575
<http://www.sdhhs.com/>

Saskatchewan Down Syndrome Association
 Phone: (306) 545-7038
<http://www.skdownsyndrome.ca/>

Saskatchewan Foundation for Attention Deficit/Hyperactivity Disorder
 Regina (306) 352-2343

Spina Bifida Association of Saskatchewan
 Regina (306) 924-2100
 Saskatoon (306) 373-5199
http://www.sbhasn.ca/Spina_Bifida.htm

Endnotes

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