

## Introduction

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

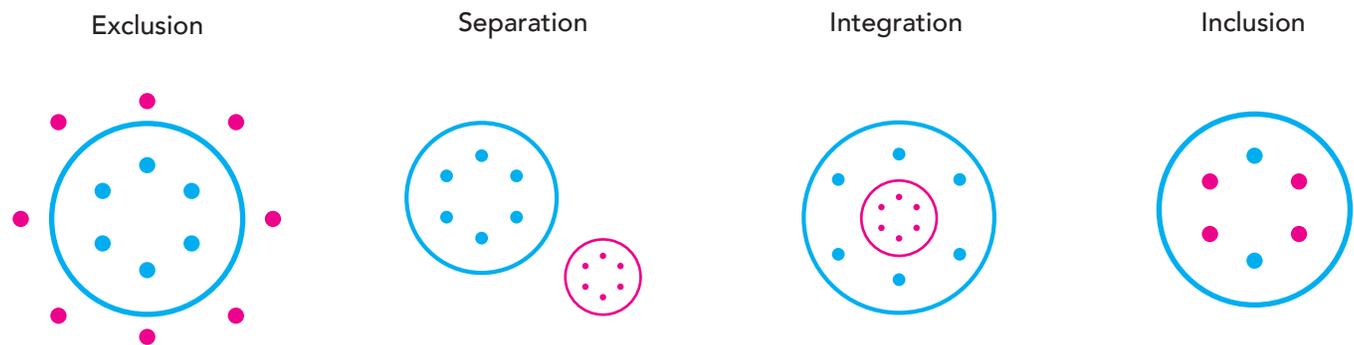
In order to ensure that your child has the best quality of life possible, you will become involved, in ways you never dreamed of, with the doctors, educators, social workers and therapists that make up the human service system. This can be physically and emotionally draining and leave less time and energy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

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

## Understanding Inclusion

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

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



## Using Respect-First Language

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

## Becoming An Advocate

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

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

- **Be Informed**

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

- **Keep Records**

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

- **Encourage Self-Advocacy**

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

- **Advocate With Others**

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

- **Prepare For Meetings**

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

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

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

## **Inclusion Saskatchewan**

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

### **Inclusion Saskatchewan's Family Network**

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

# Meeting Checklist

## Before the Meeting

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

## During the Meeting

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

## After the Meeting

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

# Meeting Log Sample

Date: \_\_\_\_\_

People Attending (Positions, Contact Info): \_\_\_\_\_

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What Was Discussed: \_\_\_\_\_

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Results Of Discussion: \_\_\_\_\_

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Next Steps (Include Who Is Doing What): \_\_\_\_\_

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