



## Chapter Nine Complex Situations

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

### 9.1 Support Networks

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

#### **Find Other Parents Of Children With Disabilities**

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

#### **Consider Bringing Someone That Supports You To Your Meetings**

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

### 9.2 Cognitive Disability Strategy

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

#### **Eligibility:**

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



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

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

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

## 9.3 Comprehensive Behaviour Support Plans

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

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

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

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

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

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

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

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

## 9.4 Inclusion Consultants

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

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

## 9.5 Emergency Intervention through CLSD

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



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

## 9.6 Dual Diagnosis

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

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

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

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

## 9.7 Sexuality

### **Tell It Like It Is**

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

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

### Abuse or Assault

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

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

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

## 9.8 Last Resorts

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

### Child and Family Services

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



### **Families Experiencing Exceptional Loss**

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

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