



Supported Decision Making For Supporters

Inclusion Saskatchewan's Supported Decision Making Series





INCLUSION SASKATCHEWAN

supporting individuals with intellectual disabilities

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TABLE OF CONTENTS

Understanding Supported Decision Making	1
Key Principles of Supported Decision Making	2
The Person is the Expert in Their Life	2
The Right Supported Decision	3
Personalizing the Process	3
Dispelling Myths about Supported Decision Making	4
The Supported Decision Making Process	5
Things to Keep in Mind	6
Acknowledging Caregivers, Navigating Challenges, and Paving the Way Forward	6
Support For Caregivers	7
Forms of Communication	7
Best Interests Decisions	7
Substitute Decision Making for Medical Decisions	8
Your Role in the Supported Decision Making Process	8
Appendix	
My Commitment as a Supporter Contract	
Resources	

Understanding Supported Decision Making

Historically, people with intellectual disabilities have not always had the right to exercise autonomy over their own lives and many have expressed that their quality of life is negatively impacted when decisions are made for them rather than with them. This is why the process of Supported Decision Making is critical. Not only does it rightfully give individuals autonomy and centre them in their own lives, but it profoundly increases their quality of life.

As a process, Supported Decision Making (SDM) is a method of decision making where a person makes their own decisions, supported by people they trust. It's a process that relies on trust and meaningful, supportive relationships in order to work because the person being supported needs to feel empowered to express their opinions and wishes. For this reason, the people involved in the SDM process are all chosen by the person and often include family, friends, and members of the community.

It is essential to understand that SDM is an entire way of living and a lifelong process. Over time, the decision-making process itself can change, evolve, and look different. It can also involve different people each time, depending on the relationships the person has with their supporters, the decision being made, and how options are presented. It's flexible, team oriented, and focused solely on identifying the wishes and goals of the person.

Most importantly, SDM is a person-centred and person-directed process for making decisions. It's about empowering the person to be the leader of their own life while ensuring they feel supported, respected, and heard. For this reason, SDM is not measured by outcomes, but whether a person feels empowered to have choice in all aspects of their life.



Read the Supported Decision Making Workbook

It is very important that supporters are well-informed about the SDM process, and for this reason, we highly recommend reviewing the *Supported Decision Making Workbook* prior to assisting someone with the process. This workbook was written for and by Self-Advocates as a guide to making a supported decision and includes information on rights and freedoms, having a guardian or co-decision maker, as well as quotes from those with lived experience. You can find it on our website at: www.inclusionsk.com/sdm

Key Principles of Supported Decision Making

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

The Person is The Expert in Their Life

As a supporter, it can be challenging to allow someone to make a decision that you would not choose for the person, but it is important to allow the person to express their autonomy. Everyone's experiences, thoughts, and opinions are valid, but the person being supported is the expert in their life. If you override or make a decision that the person you support does not agree with, you will create a negative experience for the person.

Here is what a Self-Advocate said when a family member made a decision without consulting them: *"I felt like my world turned upside down and I was powerless. It took me a long time to even open up about how that made me feel. It made me feel like I couldn't trust my family. I shut down and did what people told me to do, but it made me feel sick when I did that."*



Understand and Respect The Person You Support

Supporters must commit to understanding a person's values, culture, experiences, relationships, abilities and areas required for support. Supporters must also demonstrate respect for them when attending meetings and appointments with other members of the person's community.

The Right Supported Decision

The right supported decision is always the decision made by the person at the centre of the decision making process. As a supporter, your role is to help the person understand the context and outcomes of the decision, including the risks and benefits, and then make sure that the decision is in alignment with the values and the goals of the person.

With that said, there may be limitations to consider and you may have to engage in challenging conversations as a supporter. SDM is not intended to support decisions that are illegal or high risk, or decisions that don't take into account the influences surrounding the person, the person's financial situation, as well as the person's previous experiences.

As a Supporter, You Should:	As a Supporter, You Should Not:
Help the person understand choices and decisions they are making.	Make choices or decisions without the person.
Remember that the person you are supporting is the expert of their own life.	Share your views, opinions, and thoughts unless asked to do so.
Help the person gather and understand the information they receive.	Support dangerous or illegal choices (you must help the person understand alternative options).
Help the person tell their decisions to other people.	Tell others about decisions the person makes without their permission.

Personalizing the Process

Some people prefer a formal process and others do not. Who the person is and what their preferences are will help guide what a process may look like. For example, some people feel very overwhelmed when they are the centre of attention in a room full of people, but others thrive in that environment. Prior to beginning the process, it is important to ask questions like: *Who will be in charge of meetings? Who will decide when the team meets? Do meetings need to be recorded? How will problems or disagreements be solved? Who will make the final decision*?*

**Note: In most cases, it would be the individual themselves, but there may be instances in which the individual would like support. In these cases, they should assist in identifying who will make the final decision. A guardianship order may also impact this, in which case, the individual should still be actively involved in the process and included as much as possible.*

Dispelling Myths about Supported Decision Making

Myth: “SDM may work for some but will not work for...”

Reality: Anyone can have their supports personalized to maintain choice and control in their life. If an SDM process has been tried in the past and been unsuccessful, it is important to reflect on this. Did the person feel empowered? Was the person receiving an adequate amount of support? Was the process tailored to meet their needs?

Myth: “SDM is not necessary when someone has a guardianship order.”

Reality: It is important to note that all guardianship orders can look different and while a guardian may be able to have the final say in some areas of a person’s life, they may not in other areas. However, even if a guardian has the final say in a particular area of that person’s life, the SDM process still can and should be utilized. Including people in the decisions that directly impact them is not only the right thing to do, but it also allows people to build confidence, learn, and grow.

Myth: “It’s just easier if I make the decision for the person”

Reality: While this may be easier for the supporter, this is not easier for the person the decision is impacting. When people are actively involved in the decisions that impact their life, they feel empowered and are able to establish their independence.



Read Alternatives To Guardianship

We recognize that the system can be challenging to navigate and that can be tiring for caregivers and supporters. While it may feel like more work, supported decision making can greatly improve a person’s quality of life when the process is tailored to meet the person’s needs. Our *Alternatives to Guardianship* resource may be helpful in finding alternative ways to support someone in navigating through various systems. You can find it on the publications and resources page of our website: www.inclusionsk.com/resources

The Supported Decision Making Process

Follow these steps to support someone to make a decision:

1. Determine what decision needs to be made.

What does the person want? Do they need or want support to make a decision, or can they do so independently? What are their strengths? What areas may they need support with?

2. Remember that the person chooses which supporters they want to support them.

The person may choose different supporters depending on the decision they are making. The supporter must work with integrity to support the person with an unbiased approach and awareness of a person's goals and wellbeing.

3. Present the options in a way that works best for the person.

There may be many ways for the person to achieve what they want. This includes considering when the best time is for the person to make a decision, adapting to how the person likes to receive information, and including others who should be enlisted as a support.

4. Identify any additional information needed to make the decision.

Be clear about who will be helping with what. Make sure all information is shared, that the steps to achieve the desired outcome are discussed and that everyone understands the possible options. Consider the advantages and disadvantages of each option, and outline challenges. Take as much time as is required - this may mean multiple meetings need to occur. Consider how the person likes to receive information and go at their pace.

5. Ensure the person fully understands the decision.

The outcome should be the most appropriate option or the option that is focused on the person's wishes and goals.

6. Check in with the person.

How do they feel? What did you learn while supporting them with the process? What did they learn? Evaluate the outcome. Was it what the person was hoping for? Why or why not? If new information comes forward, or the situation changes, continue communicating.

7. What is the next decision the person would like support with?

Every decision is an opportunity for people to exercise their autonomy. Begin the process again, but remember to begin at step one each time, as every decision is different and may require different supporters and a different process.

Things to Keep in Mind

Acknowledging Caregivers, Navigating Challenges, and Paving the Way Forward

Supporters often feel that supporting people through the Supported Decision Making process can take extra time and sometimes feels like extra work. While this may be true, it is so important that people with disabilities have opportunities to actively participate in decision making as much as possible. This allows people to feel empowered and supported rather than controlled.

It is also important to acknowledge family members/caregivers. It can sometimes be challenging to transition from providing the majority of support to trusting other supporters and encouraging independence. Additionally, it is common for families to have one or two members providing support beyond their capacity, which leads to burnout and possibly even trauma. Expanding the person's support network and including other preferred supporters to make sure no one person has too many responsibilities can encourage balance. Our communities thrive when all members are included, and while we sometimes feel that we are far away from where we would like to be, it is important to remember that we are paving new ways forward.

Caregivers also express how they worry that the person they care about may get hurt, or that their needs may not be met by others. If an individual and their support team are planning for a particularly big change, such as moving out of a family home, it is helpful to establish and communicate everyone's needs. As a caregiver's role changes, there are often mixed feelings that arise, so being flexible and allowing the caregiver time to process is important. Things may be done differently for the person when they experience support from others, and sometimes taking a step back to see the bigger picture is helpful. Supported Decision Making thrives when there is flexibility within both supporters and systems which allows individuals to live a life they choose.

There may be times when a supporter cannot support a decision or might need to declare a conflict of interest or bias. In such instances, they should be encouraged to abstain from being a support for those decisions. If a supporter observes others being coercive or using tactics that are not in the individual's best interests, they should discuss and problem solve. Being proactive and deciding ahead of time what roles and responsibilities each member of the person's team should play will help set the tone, but adjustments should be made throughout. Sometimes bringing in a third party to facilitate a discussion is helpful to get members back on track. This should be done with the consent of the individual when possible, unless there is a pronounced risk to the individual's wellbeing.

Support for Caregivers

Saskatchewan has an incredible array of agencies that offer respite services, personal care services, and person-centred programming and support. These support agencies focus on building community engagement and acknowledging that all members of society are interdependent.

At Inclusion Saskatchewan, we have a Family Network that connects family members of an individual with an intellectual disability with other families through networking opportunities and a series of workshops held throughout the year. At each workshop, attendees build relationships through fun activities and presentations. Members are offered the chance to meet others, share knowledge, and share stories in a supportive and understanding environment. For more information, please go to: www.inclusionsk.com/familynetwork

Forms of Communication

It is important to value all forms of communication and to provide the necessary support to allow someone to communicate in the ways that work for them. People may not speak by saying words out loud, but may use other ways to communicate, including:

Sign language

Communication boards

Tablets or similar technology

Speech-generating devices

Gestures

Writing or typing

Stimming (hand flapping, repeating noises)

Art

Interacting with objects

Showing or sharing things with others

Movement or a lack of movement

Grunting or other vocalizations

Silence or withdrawing from a conversation

Facial expressions



Representation Matters

We highly recommend listening, following, and celebrating Self-Advocates in Saskatchewan and other jurisdictions who are creating their own content and sharing their thoughts, ideas, and opinions on social media. By listening to those with lived experience, you can better understand the perspective of Self-Advocates as well as the person you are supporting.

Be aware that there are a variety of ways to describe people who use these types of communication methods, for example: people who do not speak verbally, or with their mouths, sometimes prefer to be described as non-speaking people while others prefer to be called non-verbal or “person who speaks with their hands.” Some people can say some words with their mouths and still call themselves non-speaking because they feel it is right for them. If a supporter is unsure how a person prefers to be described, they should ask them directly.

Best Interests Decisions

Supporters should make every reasonable effort to engage the person in making decisions, no matter how they communicate or what their perceived capacity may be. If a person’s comprehension, health, comfort, or the way they communicate makes their decisions difficult to interpret, decisions can be based on the supporters’ understanding of what they want and what is in their best interests.

That said, making a decision in someone’s best interests requires safeguards and a comprehensive understanding of Supported Decision Making. Here are some recommendations for making a best interests decision.

- Be aware that there are laws and formal processes for people who need support to make decisions regarding health, justice, and other matters. In Saskatchewan, there is legislation that guides substitute decision making. If a supporter is unsure of their role, they should seek further information.
- While it can sometimes be challenging to interpret a person’s wishes, supporters must work with the person to the best of their ability to understand what the person is communicating. Information about how a person communicates should be documented to inform new members of the person’s team.
- People who know the person best should observe the impact of a decision on the person. This is especially important for people who are nonspeaking or nonverbal.
- Include at least 3 supporters in the decision making process (people who know the person well and can share information that will help the team reach consensus).
- Consider the personal history and life story of the supported person to understand how they may feel about the decision being made.

- If a decision is likely to be overwhelming or harmful for the person you are supporting, explore as many options as possible to preserve or enhance their quality of life.

People with disabilities may have a personal history of not being listened to and past feelings or trauma that may impact their ability to trust supporters. If the person you support shows signs of stress as a result of a decision that you made in their best interests, you should try to repair any harm done to your relationship. When the time is right, ask the person about their experience, including how they felt, and try to create understanding to address how all parties may heal and move forward.

Substitute Decision Making for Medical Decisions

When a person is not able to consent to a medical procedure and their nearest relative is their substitute decision maker, the substitute decision maker must act in the person's best interests. Before making any medical decision, the substitute decision maker should first consult with the person to understand their goals then consult with other supports, such as medical professionals, to understand the risks and benefits of the procedure. Doing this will ensure that the substitute decision maker is making a decision in the person's best interests.

Your Role in the Supported Decision Making Process

The success of the Supported Decision Making process requires you to evaluate and reflect on your role as a supporter and your relationship with the person you're supporting. It's important to do this before you start supporting someone, and continually evaluate as your relationship grows. Think about what you like or admire about the person, what made you want to become their supporter, and what qualities you bring to the relationship between you and this person. Consider things you have a hard time dealing with or are not comfortable assisting with and how you can ensure that the person you're supporting remains at the centre of decision making.

My Commitment as a Supporter Contract

I, _____ agree to act as _____'s supporter.

I know that I may not make decisions for this person. As a supporter, I will:

- Honor the comfort, values, interests, talents, gifts, and goals of the person I am supporting and be understanding if/when these change.
- Support the person how they want to be supported.
- Respect the person's boundaries if they say they do not want my help with something.
- Respect the person's right to self-determination and recognize their equality, dignity, and human rights.
- Commit to keeping the person's needs, interests, likes, and dreams at the centre of the decision making process.
- Work towards the personal empowerment of the person.
- Remember that everyone communicates in different ways; I will provide information in a way the person can understand when asked to do so.
- Support the person to communicate their decision(s).

I agree to support this person's decisions to the best of my ability, and in good faith.

Signature of Supporter

Printed Name

Signature of Decision Maker

Printed Name

Date: _____

Resources

Comprehensive Personal Planning and Support Policy (CPP&SP)

The CPP&SP establishes policies that guide Community Living Service Delivery (CLSD) staff and third-party service providers who are contracted, licensed, or certified by the Ministry, in the provision of effective and ethical supports to individuals with intellectual disabilities in Saskatchewan. Services and Supports for individuals experiencing intellectual disability are guided by this policy.

The Saskatchewan Disability Strategy

The Saskatchewan Government committed to developing a disability strategy in consultation with the disability community. It is a 10-year comprehensive strategy that articulates the vision and actions needed to move our disability service system forward to better serve people who experience disability to live the life they choose.

Saskatchewan Person-Centred Framework

The framework aims to support the disability community in becoming more person-centred through the development of an understanding of how person-centred culture could be experienced from the point of view of the individual, their family, and other stakeholders.

The Rights of People with Disabilities are upheld in the following documents:

- Canadian Charter of Rights and Freedoms
- The Canadian Human Rights Act
- The United Nations Convention on the Rights of Person with Disabilities
- The Saskatchewan Human Rights Code