The Right to Decide.

Supported Decision-Making in Action

This document offers an in-depth look at how five Ontario developmental service organizations support people to take control of their lives and make decisions.

COMMUNITY LIVING
Ontario

INTÉGRATION COMMUNAUTAIRE
Ontario

The Right to Decide Project – Overview

'Legal capacity' refers to people's experience of being recognized as persons before the law, exercising rights, accessing the civil and judicial system, entering into contracts, making decisions about their own life and property, and communicating on their own behalf.

In many situations (for example, in the case of guardianship) substitute decision-making removes people's legal capacity, i.e., the right to direct their own lives, including managing their money, making health-related decisions, and deciding where and with whom they live.

From 2018 to 2023, Community Living Ontario worked with five front line service organizations to understand how people who have an intellectual disability exercise their right to legal capacity – that is, how they make choices and decisions, and the barriers they face in doing so.

Our collaborative work uncovered many enablers of legal capacity, as well as many barriers. This resource is part of a series of documents that address this important issue.

Our local partners in the project were Community Living Dryden & Sioux Lookout, Brockville & District Association for Community Involvement, Durham Family Resources, and Community Living Windsor in partnership with Windsor Essex Brokerage for Personal Supports.

Special thanks to the Institute for Research and Development on Inclusion and Society (IRIS), PooranLaw, and Inclusion Canada.

For more information and resources related to this project, please visit our Right to Decide resource page.

The Right to Decide.

COMMUNITY LIVING Ontario

Executive Summary

This document offers an in-depth look at how five Ontario developmental service organizations support people to take control of their lives and make decisions. The approaches described in the document are particularly relevant for people whose mental capacity might be in question, and who face barriers to exercising their right to legal capacity.

> *Legal capacity* refers to the experience of being recognized as a person before the law, exercising rights, accessing the civil and judicial system, entering into contracts, making decisions about one's own life, and communicating on one's own behalf.

The organizations profiled in this document:

- Always presume that the people they support have the capacity to understand information, express their will and preferences, and make decisions.

- Consistently tailor their communications to people's needs.

- Engage in extensive relationship-building in an effort to understand how people communicate their will and preferences.

- Assist people to grow their ability to understand information and gain confidence in making decisions.

- Advocate within the community to address biases and stereotypes about people they support.

While these actions fit under the umbrella of supported decision-making, this document does not offer a specific program or template that other organizations can use to implement this approach in their work.

Rather, it describes a philosophy, approaches, and initiatives that these organizations have found to be effective in growing people's ability to control their lives and make decisions.
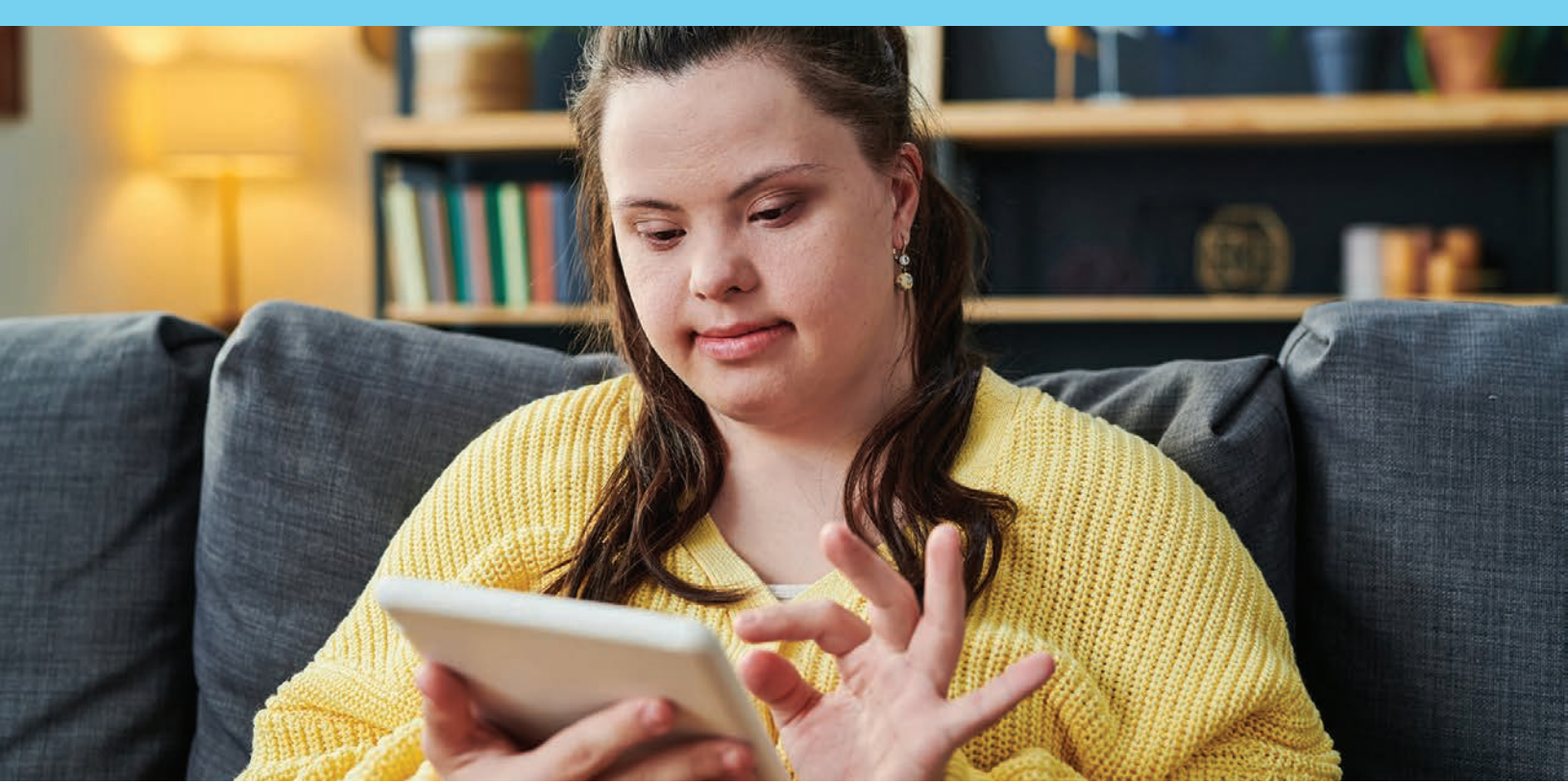
What is Supported Decision-Making?

While 'supported decision-making' is often seen as applying only to people who have an intellectual disability, it is really just another way of describing how we all make decisions. For example, when we fill in our tax returns, get our car fixed, or choose to undergo a health procedure, we turn to experts and the people around us to help make informed decisions.

When used with people who have cognitive impairments, supported decision-making generally involves assistance with the following key steps:

1. Gathering and understanding information related to a particular decision.

2. Weighing different choices and understanding the consequences of those choices.

3. Communicating the decision that has been made.

4. Carrying out the decision, including steps to put it into action.

1. Why Supported Decision-Making is Needed in Ontario

The population of people labelled as having an intellectual disability, developmental disability, cognitive impairment, etc., is incredibly diverse. Every person has a unique history, experiences, perspectives, desires, gifts, will and preferences.

> (Please see Appendix A for definitions of key terms used in this document, including "will and preference.")

Across this diversity, everyone has the right to exercise legal capacity. In simpler terms, this means that everyone has the right to control their lives and make decisions – what we are calling The Right to Decide.

For people with disabilities in Canada, the right to exercise legal capacity is guaranteed by a series of legislative and judicial frameworks, including:

- The Convention on the Rights of Persons with Disabilities, particularly Article 12, "Equal recognition before the law."

- Section 15 of the Canadian Charter of Rights and Freedoms, which states that "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."

- Decisions of the Supreme Court of Canada, which has used section 15 of the Charter to emphasize the central role of dignity in Canadian law. For example, the Court has stated that the purpose of the Charter is to "… promote a society in which all persons enjoy equal recognition at law as human beings or as members of Canadian society, equally capable and

equally deserving of concern, respect and consideration."[1]

- The Accessible Canada Act, which states that "All persons must have meaningful options and be free to make their own choices, with support if they desire, regardless of their disabilities."*

Despite this progress, unfortunately the Right to Decide is not a reality for far too many people with intellectual disabilities in Ontario.

The organizations that collaborated in the Right to Decide project believe that guardianship and other forms of substitute decision-making are in conflict with the above-mentioned legislative and judicial frameworks. Perhaps just as importantly, they understand that increasing control and decision-making power leads to better health and quality of life among people they support. As a result, they have developed approaches to support that emphasize person-directedness, individualization, capacity-building, accommodation, and personal control.

2. Supported Decision-Making in Practice: A Brief Overview

The American Civil Liberties Union[2] provides a simple and relatively straightforward overview of actions that service providers can take to support decision-making among people who have an intellectual disability:

- Plain language information.

- Information in pictures or explained in language a person understands.

- Research on the internet, at the library, or from a trusted person, so that a person can understand the things that they like or don't like, or learn more about choices.

- Help in knowing what choices a person has in a given situation.

- Extra time to think about choices.

- Trying out different choices (including visits to accommodations, programs, etc.) to see how they feel and deciding which one a person prefers.

- Reminders about important dates and times.

- Help in thinking about pros and cons, e.g., making lists of the good and bad parts of different choices.

- Having a supporter attend meetings and appointments with a person.

- Talking to experts who know a lot about a given choice. Experts can also help with pros and cons about choices.

- Reminding a person of their values, and what is most important to a person.

- Classes to learn about healthy choices.

- Help communicating a choice so that others understand which choice has been made.

- Technological support, e.g., using a phone, tablet, computer, etc.

- Advice and opinions from supporters, with the understanding that the person remains the ultimate decider.

- Interpretive Support, i.e., from trusted people who bring the best interpretation

- of a person's will and preferences to guide decision making in particular circumstances.

To a large extent, this list accurately reflects the work of the five local Right to Decide project partners. It also reflects the view that supported decision-making is just another way of describing how everyone makes decisions:

> "We all engage in Supported Decision-Making. We consult with family or friends, colleagues or classmates, mechanics or mentors before we make decisions. We may seek support to decide whether to go on a blind date, buy a used car, change jobs, renew a lease, or undergo cataract surgery. We confer and consult with others, and then we decide on our own."[3]

It is important to note that supported decision-making alone is not enough. Even when people have trusted decision supports in place, the ongoing existence of disability-related biases and stereotypes means that they will face many barriers to exercising control and decision-making power in their lives. Thus, supporters must also be active in educating others about people's right to exercise legal capacity.

3. Decision-Making Supports in Action

The forms of support outlined in the above list from the American Civil Liberties Union play out directly in the work of all five local organizations that partnered in the Right to Decide project. Over the course of several interviews, one project partner offered insights into how they put these types of supports into action:

- The organization's approach is about "walking with the person" and being led by them, which means the process is different for every person.

- Each time a staff member meets with a person they are supporting, that person has their own agenda for what they want to talk about. Staff don't guide them through a prescribed process or format, because they want people to be in control, and comfort is a big part of control. Getting to the important things often requires patience and usually comes with time:

  > "The work that I do is based on what you [as the person supported] are looking for, and the information you're looking for, and the connections you're looking for. If I suggest something, I wait until you say, 'yeah, okay, I think I'm ready to do that.' We'll put things on the table and we talk about, 'these are your choices to make. We can't make choices for you. I'm not going to tell you to go to that day program. I'm not going to tell you to take that support worker, but I'm going to help you develop some skills so you can ask good questions and maybe build some healthier relationships.'"

  > "You capture bits and pieces of their story, and they'll start talking and telling you about something, and then you just kind of live in that moment and say, okay, so why are you talking about that now? Why is this important today? And it helps that person kind of sort out that direction in that moment. You just kind of help them get there by asking really simple, really open questions."

  > "For example, I've been meeting with this woman, and she tells me bits and pieces of her story every time we're together, but this one day, I said, 'So what's new?' And she started talking about a necklace that belonged to her mother and given to her by an aunt. And she just kept coming back to this and giving bits and pieces of the story."

  > "I asked, 'Why are you talking about this right now? What's the importance here?' And it all led back to people understanding what's important to her. When she was taken into the child welfare system, a lot of things were lost or left behind. The story is that her mom pawned this necklace because she needed to make rent. When she told the story, it was about, 'I don't want to ever be in that place. I want to be able to keep my things and respect my things, and have others respect my things.'"

- According to this project participant, supported decision-making includes introducing and using forms of communication that a particular person can understand so they can make decisions:

  > "So, for [name omitted], it's visual. It's going out there and seeing things or getting pictures and going through some of those exercises with people she trusts."

  > "Sometimes it can be as simple as cutting up pieces of paper to represent money, where one pile of paper represents all of a person's money. If they want to buy a house, it will take about *this much* of the pile,

leaving them with *that much* left over. If they rent instead, it will take less of the pile, leaving them with more to spend on other things. It's up to them to place value on each of those decisions, but the supporter helps them conceptualize it and think it through."

"Or she would talk about her depression, so we talked about different places she could go to talk to people. She reached out over the phone and found somebody she was comfortable talking to. Or when she needed to hire support workers, she went out and met different people and sat down through that process, part of the interview process, so she could tell them what was important to her and then ultimately have that decision on whether that person was going to come work for her."

- For staff members in this organization, interpersonal patience and comfort with giving up control is a central part of the job description:

  "We talk about decision-making a lot, and [name omitted] made decisions that haven't gone well for her. And she does feel the consequences… We are still working through these pieces because it can't be me to initiate, it has to be her. She called me up really upset, and we are still having conversations about this, about where you can go get assistance and who are the people that you can get help from. I've tried to initiate these connections but she prefers to do it on her own – although

she will come back and ask me for referrals and advice on who to talk to, which is how she connected with an Adult Protective Services Worker as well as with legal services."

"She's definitely a person that, because of her lived experience, has to feel she's in total control of a situation because of trauma she's experienced with family."

- This approach can present difficulties for staff who develop strong relationships with the people they support:

  "Just because I support them to make their choices doesn't mean that their choices don't emotionally impact me. I'd be lying to you if I said they didn't. I just have to compartmentalize that by understanding that this isn't my life. I don't have to like everything they do – that's not my job. My job is to be patient, be with them, and to help them make that next step when they're ready. And to help them find out where and how they can do it. I can't do it for them, but I can help them figure it out."

Interpreting and Supporting People's Will and Preference

As described above, a major part of 'walking alongside' people consists of spending time with them, exercising patience, listening deeply, and engaging in conversation adapted to the person's needs to make sure supporters truly understand what that person is trying to communicate to them. It is only through deep reciprocal engagement that supporters can

begin to help a person communicate their will and preference (as opposed to, for example, communicating what a person thinks their supporters want to hear), and to interpret and fully understand their will and preference.

Any truly inclusive approach to legal capacity and decision-making needs to grapple with the issue of interpreting will and preference, particularly (but not only) among people who do not use words to communicate. The following section offers information and context on such an approach, informed by actions taken by the project's five local partner organizations.

a. Before and beyond interpretation – Building people's capacity to direct their own life

In many cases, supporters (including families, friends, allies, and staff) assume incapacity, and people themselves can come to believe they are incapable. Many people with disabilities who face biases and stereotypes about their mental capacity will need to be supported to recognize their own will and preference, and to understand that will and preference can change over time. They are also likely to need support to gain confidence and the ability to communicate what they really want in their lives.

For organizations engaging in this work, the basic framework can be relatively straightforward:

- Start with the assumption that all people have the capacity to understand information, weigh risks, and make and communicate decisions. Following this assumption, work to surround people with the expectation that capacity is present.

- Actively demonstrate what it means to be open to getting to know people deeply,

understand the goals they have for their lives, and take direction from them.

- Work to enhance people's opportunities to understand, learn about, and communicate their own will and preference by connecting them to experiences that help them learn and grow, gain confidence, and exert their will on the world.

In other words, this work is not only about interpreting. It requires a clear approach and mindset within organizations, as well as active steps to create a context where people are directing their lives and being supported to express their will and preference. It requires constant vigilance and self-reflection to ensure that an organization's leadership, staff team, and other connected stakeholders avoid imposing an alternate vision on someone based on a 'best interest of the person' approach.

Things can get more complex when people do not have family members or other natural supports in their lives. Responsibility often falls to paid supporters to fill gaps where natural networks are missing, or while natural supports are developing and being nurtured. This can be a difficult balance to maintain, and requires work to ensure that knowledge about a person isn't lost as a result of staff turnover.

As an example of this type of work, Community Living Dryden-Sioux Lookout (CLDSL) creates a communication profile for each person they support (Windsor Essex Brokerage for Personal Supports uses the term 'social dictionary'). This document explains the meanings behind the words, actions and behaviours that people use to communicate. This is important, in part, because of the possibility of a conflict of interest or disagreements among supporters.

The more that people add to the profile over time, the less likely it is that there will be disagreements about what a person is communicating.

CLDSL works with many people whose families are deeply affected by the trauma of racism, discrimination, and the horrors of the residential school system. Many have become separated or estranged from their families, and do not have connections to people who know them deeply. The organization assists people in these situations to build natural supports, including reconnecting with family members, which helps increase the number of people who are able to interpret and support their will and preference.

Many stakeholders believe that unencumbered planning/independent facilitation is crucial if a person's true will and preferences are to be uncovered and honoured. The belief is that as long as planning and interpretation supports are offered by service providers, there will always be a tendency or pressure to steer people toward the programs of those service providers.

Unfortunately, not every community has readily-available independent facilitation resources. Some organizations have taken the step of creating person-directed planning divisions that are hived off from the rest of the organization, i.e., they have no connection to services, and no oversight over direct service staff. While some doubt the effectiveness of this approach, it can be a stop-gap where truly independent resources are lacking.

b. How people express will and preference

People often express will and preference in response to things: for example, things that they like or don't like, situations that make them happy or upset, or items/activities that bring up good or bad memories (including past traumas).

This may be particularly true for people who do not use words to communicate and/or who have limited capacity to physically engage with the world (e.g., people with cerebral palsy and other physical disabilities).

There is increasing understanding across the sector that behaviour is communication. However, it is still common for behaviours that may be unpleasant for others (e.g., yelling, crying, disengagement, self-harm, property destruction, physical violence) to be attributed to a person's disability rather than being interpreted as a communication of unhappiness, fear, pain, displeasure, frustration, or trauma. It is important to recognize that people who have intellectual and developmental disabilities have the capacity to communicate complex thoughts and ideas, even when they don't use words to communicate. We heard a number of examples of this over the course of the project,. For example:

- During a meeting with a person's support network, a worker was talking about the prospect of the person leaving their parents' home and living on their own. In response, the person (who rarely uses verbal language) got up, took the worker by the arm, and led them out the door. At a future meeting, the same worker talked about finding a way for the person to live separately but in the same building as their parents. The person then got up, sat beside the worker, and put his head on their shoulder.

- We heard several stories about people gathering up the belongings of workers they weren't happy with and putting them

by the door, as a way of communicating "you're fired."

It can be difficult to predict how a person who doesn't use words to communicate might be affected by novel situations. However, people in close, trusting relationships who are continually attentive and responsive to feedback are more likely to be able to safely introduce new things into people's lives because they have learned what a person likes, what they want from life, and how they want to contribute to their community. For example:

- A mom enrolled her daughter (who doesn't use words to communicate) in a medical study that included multiple blood draws and physical examinations by medical professionals. While this is something that would be unappealing to many people, participation in the study put her daughter in the type of situation where she had consistently demonstrated happiness and enjoyment: going on long drives (in this case, to the hospital), being the centre of attention, helping others, and making a positive contribution to the community.

c. *Understanding a person's whole communication and the context of that communication*

While it is crucial to get to know a person well, and to understand their body language and behaviour in addition to oral language, this is still not enough to be able to interpret what a person is truly communicating. A person may indicate that they are okay with something when they are in fact not okay with it, because they feel pressured to go along with what is being suggested, they don't want to 'rock the boat,' they want to keep someone happy, etc. People who lack confidence and experience in making decisions are always at risk of going along with things even if it's not what they want.

To counter this, supporters who know a person well sometimes need to step in and revisit decisions, based on how a person looks when communicating, how they acted in the hours and days after the decision was made, and other cues.

Sometimes people will make decisions in front of certain people in a particular way, and these decisions might not conform to their will and preference because of the influence involved. It is important for supporters to attend to what a person says, and also what's going on around them and the relationships that are present when decisions are made.

It is also important to provide interpretive support for people who use more advanced oral communication. There is often a need for interpretation, even for people who use oral language to communicate.

This topic was discussed in detail by local project partners:

"[As a team] we talk about, what does the person think about that? If we don't know, how do we figure that out and how do we listen? How do we think about how they approach other things in their lives and what they care about the most? We tie some of that together and then check in and say, is this what you think? Is this how you feel about that? Given what we know about you, this is how we're kind of drawing these conclusions. Are we on point or are we way off and finding ways to check in…"

"It's always about picking up the conversation to figure out what are people thinking, what are people feeling, and how do I help you make the decisions that you want to make? What rocks do I need to move off that path? … In all those different conversations, we (don't) use the language of supported decision-making and we don't think of it as a thing that we're implementing. It's a way of being in the conversation with people."

"If we're working with a family that's up north, they might say one thing to someone who is not Indigenous. And then to someone who they feel close to, who knows the language and the nuances of that, they will say something different. Because they feel that they could be honest, because they're scared about how they'll be viewed. And we're running into that too – to be very careful that you make it culturally safe for people to be their whole selves, including people you support, but also families."

"In order to truly understand someone's will and preference, to be committed to that, you need the time… to reach out to, maybe, the person that's known them for 30 years, and all the people that are important in their life to really kind of bring together this idea of, 'when she does this, this is what I've noticed it means.'"

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d. *Orienting staff to the organization's mindset*

The COVID-19 pandemic led to a hyper-focus on keeping people safe. As a result, orienting new staff to organizational values and principles may have fallen by the wayside.

In response, Community Living Windsor has developed a new orientation process to ensure that the organization's history, values, and approaches (including how to listen, understand and communicate to people supported) are made clear and accessible to all staff.

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As part of this process, newer staff work alongside mentors who have strong relationships with people supported and who are skilled at interpreting will and preference. As much as possible, there is one mentor at each residential location, and another mentor not at the residence, which adds impartiality and objectivity.

> "We have staff who have supported a person for thirty years, who know that person and just from the blink of their eye what they would like to say to you at that point in time. It's about working with people and learning from them. It's about sharing the knowledge and we evaluate it all the time."

> "We ask people all the time how it's working out. We've moved staff out of locations because of the fact that they haven't been honoring the way someone communicates. If someone feels like this staff is really not listening, we've removed the staff person from those locations and sat down and talked to them and said, what's going on? Why are you struggling with this piece? Sometimes we find they're just not a good fit for our agency. Other times we find that they struggle trying to understand certain pieces, and we get them more training, more time, more orientation, and more shifts where they're not working alone, so that they always have someone with them to ensure the person is being heard."

Similarly, Brockville & District Association for Community Involvement is constantly working on ways to help staff understand their approach:

> "It's not that we're teaching a thing as much as we are asking people to consider how they are with people. It's not that there's a module that we do on supported decision-making or supports for decisions, it's more of a way of being with people."

> "The conversations happen naturally when you start with the expectation that people have a will and preference. My job and my role is to figure out what that is. I need to be paying attention and discovering how you express that and then I need to create opportunities for you to grow that way of expressing. It's really about how you are with people and what you believe about the capacity of people."

e. *Supporting and responding to a person engaging in risky actions*

As of September 2023, the Ontario Ministry of Children, Community and Social Services (MCCSS) is prioritizing funding and residential placements for youth who have a developmental disability and/or significant support needs who are exiting the child welfare system (including foster care and youth group homes). These young people often bring experiences of impermanence, dislocation, trauma, and neglect with them into the adult system. Many have been diagnosed with mild intellectual disability in combination with Fetal Alcohol Syndrome, mental health issues, and/or learning disabilities. Many have not had the opportunity to experience life without supervision, or to take risks and learn from mistakes.

As one organizational leader noted:

> "To be honest, the big challenge we have is people who are very verbal and very able to say what they like and don't like, but they will choose things that are risky."

In Ontario's developmental service sector currently, two prominent topics of conversation are (a) alcohol and substance use among youth being supported, and (b) a feeling among youth that they do not want to be forced into group residential living, with the supervision and (often) control that entails. They want to live typical lives in community with friends and family, and they want control over their own lives.

There remains a significant focus in developmental services on the protection and care of people who often need pervasive support with all activities of daily living. The sector (which is also managing the growing needs of people with intellectual disabilities over age 50) struggles to balance more traditional ways of working on one hand, and new approaches that are necessary to work with youth entering the system on the other.

Influenced by their work with youth, staff at one of the local project partners have developed the approach that risky and potentially unsafe behaviour (including substance use, theft, sex work, etc.) is, in one sense, communicating something about what a person really wants in life. The question for the organization then becomes, how can staff help them get what they want in life in a way that moves them toward greater safety and security, and how can the organization help to keep them well in the meantime?

Building on accepted principles of harm reduction, the organization understands and is accepting of the fact that people they support may be using substances and engaging in behaviour that puts their lives at risk and that brings them into contact with the justice system. Staff also understand that people still have hopes and dreams, want to have a say in their lives, and want to contribute to their community. Thus, when supporting them, staff are always in conversation with people about what they want in the long term, as compared to what they may be drawn toward in the short term.

Many organizations have direct experience with the opposite approach: attempting to prevent people they support from using substances and alcohol, from engaging in potentially risky sexual relationships, from going into the community without support, etc. Several of the project partners have seen first-hand what can result from this approach: reduced communication between staff and people supported, increased aggression toward staff, and decreases in physical and mental health and quality of life.

Following their experiences, all project participants have a strong belief that (a) our legislative and human rights commitments to people with disabilities, and (b) the practical realities of trying to prevent people from actioning their will, even when this leads to increased risk, dictate a forward-thinking approach, even if that approach might create worry among people looking in from the outside.

f. Substance use as it relates to will and preference

When supporting people who engage in risky behaviours, substance use can present a particularly difficult challenge. Some substances alter your will and preference, and can lead to a person prioritizing short term need over long term health.

Harm reduction models of support are designed to respect the person and offer hope in the middle of an addiction. A person using substances can still grow in areas of their life and have hope that things can change. This approach acknowledges that people need to know where they are on the spectrum of change, and they need to have things of value in their life (including housing and appropriate support), so they are motivated to want to change.

Developmental service leaders often face pressure from community stakeholders to restrict, protect and control people who are engaging in substance use and other risky behaviours. However, a mindset that starts with an understanding of the right to exercise legal capacity does not support these kinds of attempts to remove control. Rather, the goal is to create a supportive environment that someone will keep coming back to. The punitive and controlling approach has been clearly shown to not work; when someone's ability to make choices is taken away, in many cases this will increase the likelihood that risky activities will happen.

For service providers, a harm reduction approach requires a delicate balance of respecting a person and their ability to choose, while at the same time talking to them (often on a daily basis) about the consequences of choices, and about their safety plan, which the person directs and is in control of.

This approach also requires training staff and other supporters to understand that a person will talk to you (and tell you what they really want for their life) in a calm state of mind when they're not triggered, and when they're not under the influence of substances.

In a state of inebriation, heightened stress, or dysregulation, they will say and do things that are not in line with their will and preference for their lives.

Perhaps most importantly, this work involves supporting the development of a safety net around people, to get them to the place where they will talk, accept help to remember what they want for their life, and accept help to move toward that vision, even when they are under the influence of substances.°

Changing mindset

From...	To:
Deficit-based / presumption of incapacity	Strength-based / presumption of capacity
Protection and care	Support and skill building
Capacity is present, or it isn't	Capacity varies over time and across decision areas
Guardianship seen as a positive option	Guardianship seen as a loss of human rights
Service orientation	Support to achieve a typical life
Judgement re: risky activities (e.g., substances, spending, sex, etc.)	Offering safety and support even when (or especially when) risky choices are being made
Special supports for decision-making	We all need support in decision-making

What does a change in mindset look like for developmental service organizations?

- Look beyond the provision of services and a service mindset. Of course, people need services, however first and foremost they need support to build a life for themselves.

- Understand that many people have trauma, including negative experiences with service providers and service systems.

- Listen deeply with extreme patience, and work to truly hear people.

- Listen to and work to amplify a person's voice, and support them to have their own voice.

- Take the time to build trust, foster attachment, and allow for people to grow and mature on their own schedule.

- Understand that without a relationship of trust, planning and change won't happen (or is unlikely to last).

- Be flexible and allow for plans to change.

- Understand that confidence in decision-making emerges over time.

- Invest in learning and understanding across the whole organization.

4. Overcoming barriers and changing mindset in the community

Despite decades of advocacy with respect to increasing human rights, choice, and control for people who have an intellectual disability, it can still be very difficult for people to make decisions and control their own lives. When it comes to accessing developmental supports, the health care system, financial services, and government services (to name just a few), a range of biases and stereotypes raise barriers to the Right to Decide at every turn.

In the previous section, we looked at some of the actions the five partner organizations have taken to orient and train their own staff on the approach that infuses this document. Next, we will provide an overview of actions the agencies are taking to orient other community partners and stakeholders to an approach based in respect for people's right to exercise legal capacity. Without engagement and participation from other sectors, people will continue to face barriers to making decisions and controlling their own lives.

a. *Maintain a seat and influence mindset at key community decision-making tables*

There is a pervasive shortage of knowledge and understanding of the capabilities and needs of people who have an intellectual disability in and outside of the developmental service sector. Organizations that take legal capacity and decision-making seriously face significant barriers to implementing a forward-thinking approach. To address this, the lead organizations place a high importance on engagement in a variety of stakeholder forums, including:

- Developmental service regional planning tables

- Regional clinical & behavioural support services

- Mental health and harm reduction planning forums

- Ontario Health Teams

- The court system, including mental health and developmental disability court diversion programs

- Police, paramedic, and fire services

- Supportive housing planning tables

When participating in planning and decision-making tables, organizations have an opportunity to push forward the work of changing people's mindset about capacity and decision-making. This includes:

- Adding value by being part of the team and part of the solution to real or perceived issues in the community, especially as they relate to people who have an intellectual disability.

- Identifying and cultivating insiders and other allies to get access to information and influence discussions where staff can't always be present.

- Consistently demonstrating practice and mindset that presumes capacity and acknowledges and supports the right to exercise legal capacity.

In the project partners' experience, there continues to be a broad expectation that people with intellectual disabilities will live in group homes, be supervised around the clock, and have key decisions made for them. There is a need for constant messaging about evolving practice within developmental services, respect for human rights, and the importance of control and decision-making power.

b. Work to change practice within systems

Over the course of the project, and in their work more generally, the five local partner agencies reported a number of barriers that prevent positive outcomes and deny the legal capacity of people they support. They must work consistently, following the life objectives and wishes of people supported, to find ways over, under, and around these barriers, and to remove barriers where possible. This includes:

- Changing clinical supports to incorporate dignity, control, and decision-making within the values and philosophical frameworks of physicians, psychiatrists, nurses, behaviour analysts, and system administrators.

- Training new entrants to the health and social service system in a forward-thinking approach, including how to understand and interpret legislation in a way that recognizes legal capacity.

- Addressing misconceptions about guardianship, e.g., the belief that it is easy to remove.

- Pushing back and providing breathing room for people supported when system actors try to move too fast toward a

traditional solution (e.g., 24 hour residential care, guardianship, trusteeship, etc.).

- Addressing stereotypes within the child welfare system with respect to parents who have an intellectual disability, Fetal Alcohol Syndrome, brain injury, etc., in order to prevent children from being unnecessarily removed from households.

- Bringing attention to contradictions and practical failures in the system, for example cases where guardianship has led to increased isolation and reduced safety for a person.

- In the event of legal proceedings, ensuring that attorneys understand that they represent people, not the legal system, and they have a responsibility to act on the direction and in the interests of a client who has an intellectual disability (whereas often they will act in what they believe to be the best interest of the client or system).

c. Influence the application of law and policy

Within the five local partner organizations, there is a conscious ongoing effort to understand where it is possible to work within the law (including the *Substitute Decisions Act* and *Health Care Consent Act*) in a way that supports the exercise of legal capacity, and where the limit points are – in other words, where it isn't possible to interpret legislation or policy in a way that supports the presumption of mental capacity and the right to exercise legal capacity.

The organizations play this balancing act with respect to money management, health and medical decisions, legal matters, and a range of other areas. For example:

- Some community stakeholders (e.g., family service associations, child welfare agencies, First Nations governments, etc.) are open to supporting people with intellectual disabilities to avoid substitute decision-making with respect to significant life, health, and financial decisions, while others are not (though they may be open to change). The cultivation of relationships within organizations and institutions can often make the difference between the exercise of legal capacity and a loss of control.

- Engaging with financial institutions alongside people with intellectual disabilities requires a delicate balancing act. Finding the right bank, as well as the right people at the bank, can make all the difference.˘

- The outcomes of capacity assessments can vary depending on the approach and knowledge of the person performing the assessment. Some assessors appear to be more influenced by bias, stereotyping, and a lack of knowledge than others. Finding an informed and attentive capacity assessor who understands the official assessment guidelines can make a decisive difference in whether a person is found to be capable or incapable.

- Some developmental service organizations in the province avoid capacity assessments because of the high risk of a finding of incapacity.

When a capacity assessment is pushed on a person, these organizations are aware that a person has a right to independent counsel, and can refuse to participate in the assessment.

There are many gray areas where systems can be bent to support the presumption of capacity, and sometimes the system can be bent toward official recognition of capacity. As one example, in 2022 the Ministry of Health changed its Family Managed Home Care program so that people who have an intellectual disability can now access direct funding for home care without being under guardianship, when they have appropriate decision and financial supports in place.

At the same time, it must be acknowledged that, as long as we continue under current legislation including the *Substitute Decisions Act* and *Health Care Consent Act*, there will always be limit points to influencing the application of law and policy. This includes important areas such as transfers of property, allocations of pension benefits, and medical decisions, where institutions including financial institutions and hospitals are forced to anticipate and manage legal and reputational risk.

d. *Build the support and advocacy capacity of family members and other supporters*

Many people supported by developmental service organizations do not have strong social networks or family members to support them, a fact that is particularly true for youth leaving the child welfare system. And while parents have always been at the vanguard of the fight for rights and access to community-based services for people who have an intellectual disability, many family members continue to have limiting perspectives on the capacity of their loved ones.

For people who have family to support them, it can also be the case that supporters who are themselves marginalized are at risk of being overwhelmed by systems. Organizations can work with families to increase their capacity to engage with and advocate within systems, develop new ways of offering support, and change their expectations of people who have an intellectual disability.

A major goal of each of the five lead organizations is to help create systems of natural support that allow paid services to recede over time. This approach is based in the view that everyone is a decision-maker, and it is meant to spur supporters to respond to and support a person's will and preference, while also addressing the need for risk management and protection where needed.

To learn more about how people who have an intellectual disability can be supported to have greater choice and control in their lives, please see our Right to Decide resource page.

The Right to Decide.

COMMUNITY LIVING Ontario

Appendix A

Definitions: Understanding the Language of 'legal capacity,' 'mental capacity,' 'will and preference,' and 'supports for decision-making'

Discussions about decision-making and control among people who have an intellectual disability can be complex and sometimes confusing. It is important to define a few key words and phrases that are commonly used: 'legal capacity,' 'mental capacity,' 'will and preference,' and 'supports for decision-making.'

What is 'legal capacity'?

'Legal capacity' refers to people's right to be recognized as persons before the law, exercise rights, access the civil and judicial system, enter contracts, make decisions about their own life, and speak on their own behalf.[4 & 5]

In many situations (e.g., in the case of guardianship), substitute decision-making removes people's legal capacity, i.e., the right to direct their own lives, including managing their money, making medical decisions, and deciding where and with whom they live.

What is 'mental capacity'?

In Ontario's *Substitute Decisions Act*, 'mental capacity' is defined as the ability to understand information that is relevant to making a decision, and the ability to appreciate the reasonably foreseeable consequences of a decision or lack of a decision.

What is 'will and preference'?

Article 12 of the CRPD refers to the "rights, will and preferences of the person." While a broad range of articles have been written about the definition of 'will and preference,' Community Living Ontario is informed by the realities of the past in thinking about these concepts. For example:

- People with disabilities have an overwhelming *preference* not to be sterilized against their *will.*

- People with disabilities have an overwhelming *preference* not to be forced into large, controlled-access facilities against their *will.*

- People with disabilities have an overwhelming *preference* to not be physically touched, abused, or restrained against their *will.*

We know this because people with disabilities are people, and no person wants these things. All people, including disabled people, have an overwhelming *preference* to control their own lives and make their own decisions.

As we know, disabled people have been sterilized against their will, forced into locked residential wards, and physically and sexually abused on a disturbingly massive scale. These experiences inform the way we currently approach decisions about related things like sexual and reproductive health, housing, and medical care. They translate into how we understand people's desire to control and manage their own money, who they choose to provide support and care, who they choose to hang out with, which foods they like to eat, and what substances they want to put into their body.

Decades of experience have taught us that all people can express will and preference, even if they don't use spoken, written, or signed language to communicate. Therefore – and this is a central tenet of the CRPD – all people are presumed to be capable of exercising their legal capacity.

What is 'supported decision-making'?

In much of the literature about legal capacity, there is a close connection between mental capacity and the idea of 'supports for decision-making,' or 'supported decision-making' (as opposed to substitute decision-making) – where people with intellectual disabilities get help with understanding information, weighing options, considering benefits and risks, thinking through consequences, and communicating decisions.

While the idea is often seen as applying only to people who have an intellectual disability, supported decision-making is just another way of describing how we all make decisions. For example, when we fill in our tax returns, get our car fixed, or choose to undergo a health procedure, we turn to experts and the people around us to help make informed decisions.

Recently, the Institute for Research and Development on Inclusion and Society (IRIS) has put forward the decision-making capability approach to legal capacity, which is instructive:

> "Unlike the usual approaches to recognizing the right to decide, which require that a person must demonstrate a certain level of ability to understand information about a decision and appreciate the consequences of a decision or non-decision, the decision-making capability approach recognizes that we all need support to make decisions.
>
> "The foundational, and universal, decision-making ability in this approach is that a person manifests an intention and expresses their will and preference to achieve it. This is the basis for decision-making in a particular circumstance. As needed, others can, to a lesser or greater extent, bring the understanding and appreciation needed to interpret a person's intentions, will, and preferences and apply them to a decision at hand.
>
> "There are two main ways a person's decision-making capability can be constituted:
>
> - Independent decision-making capability – a person can carry out the understanding and appreciation needed for a valid decision, with only minimal support from others.
>
> - Interdependent decision-making capability – a person requires significant or total support of others in interpreting and translating their will and preferences into a particular decision."

Decades of experience have taught us that all people can express will and preference, even if they don't use spoken, written, or signed language to communicate. Therefore – and this is a central tenet of the CRPD – all people are presumed to be capable of exercising their legal capacity.

In simpler terms, this approach revolves around the idea that disabled and non-disabled people alike are able to understand information, and are able to think about the consequences of decisions, with assistance from people that they know and trust, and who know them well. Further, the argument is that this approach is safer for people who have an intellectual disability, and produces greater health and well-being, than substitute decision-making arrangements like guardianship.

Notes

1. Law v Canada (Minister of Employment and Immigration) [1999] 1 SCR 497.

2. Supported Decision-making: *A guide for people with disabilities and their families.*
    ACLU-Supported-Decision-Making-Guide.pdf.

3. Centre for Public Representation. *About supported decision-making.*
    https://supporteddecisions.org/about-supported-decision-making.

4. https://www.un.org/esa/socdev/enable/rights/ahc8docs/ahc8idc1218ex.doc.

5. https://inclusioncanada.ca/2017/11/15/what-is-legal-capacity/.