



**Community-led Initiatives
for SUPPORTING
THE RIGHT TO DECIDE**



A READINESS ASSESSMENT TOOL

from IRIS – Institute for Research and Development on Inclusion and Society

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Title: *Community-led Initiatives for Supporting the Right to Decide: A Readiness Assessment Tool*

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About IRIS

Informed by the systemic exclusion that people with intellectual disabilities and other marginalized groups face, IRIS' mission is to seed and support transformative social development. Guided by principles of full inclusion and human rights, we carry out research to identify issues and policy options. We foster social innovation to re- imagine inclusion and design new ways to meet unmet needs. Through capacity- building we strengthen leadership and constituencies for transformative change. For more information: visit us as at www.irisinstitute.ca or email contact@irisinstitute.ca.



Introduction

Every person has the capacity and right to make and guide decisions about their lives. However, people with intellectual, developmental, or cognitive disabilities, or living with mental health issues are often denied this right because their capacity is not seen or recognized. As a result, others are given the authority – through guardianship or other types of substitute decision making – to make financial, health, personal care, and life decisions (e.g., relationships, where to live, etc.) for that person. The person is left without a voice of their own.

The equal right to decide, or to exercise “legal capacity” without discrimination based on disability, is recognized in the UN Convention on the Rights of Persons with Disabilities (CRPD). Under the CRPD, governments must take steps to ensure this right is realized in people’s lives. This includes ensuring that people have access to the supports they may require for this purpose. One way to do this is by investing in community initiatives to arrange and deliver decision-making supports.

This tool is part of a series of resources IRIS is developing to help create communities where all people can be supported to exercise their right to decide. It is designed to assist community organizations assess their readiness to implement the “core functions” associated with supporting people in decision making. See IRIS’ related resource, *Community-led Initiatives for Supporting the Right to Decide: A Framework for Design and Implementation*, which describes these functions in arranging and delivering community-based supports for decision making.

What is a supported approach to decision making?

A supported approach to decision making ensures that:

- A person's expression of their will, preferences and contributions are acknowledged, noticed, recognized, and respected.
- People have relationships of value and respect that enable their voice to be expressed and heard, and they have choice, power, and control in their lives.
- People have access to the range of decision-making supports they may need. These supports could include: communication assistance; independent advocacy; a trusted supported decision-making network of family, friends, or other supporters; adapted decision-making processes which provide more time for a person, like in a doctor's appointment; or other assistance in planning for and making person-directed decisions.

'Core functions' in community-led initiatives for a supported approach to decision making

Successful community-led initiatives for supporting decision making tend to carry out eight core functions:

1. **Change community norms** – about the place and rights of people with intellectual/developmental, cognitive, psychosocial and communication disabilities – through community forums, awareness raising, the sharing of personal experience and community planning.
2. **Explore a person's current situation and aspirations** – through the provision of planning facilitators who assist a person to begin planning for their future and identifying who they would like to assist them.
3. **Identify needed supports and accommodations** – with the assistance of a planning facilitator who helps the person identify what would be of most assistance.
4. **Arrange needed supports for decision making** – whether this be one-time supports, an individual advocate, or a supported decision-making arrangement where the person has designated decision-making supporters to assist them.
5. **Support real life opportunities to make decisions** – by a planning facilitator and support network assisting the person to take decisions, encountering others in their community, as they seek to put their plans into action.
6. **Arrange accommodations as needed** – as issues or difficulties may be raised with other parties as a person seeks to make decisions in health care or with a bank, for example, assist the person and the other party to adapt the decision-making process to be more inclusive and responsive to the person.
7. **Legally challenge obstacles as needed** – sometimes if accommodations and supports cannot be arranged, legal avenues may be available to challenge the lack of decision-making rights and supports.



8. **Safeguard a person's autonomy** – recognizing that a person may be vulnerable to harm, neglect, abuse, or undue influence, take steps to make sure the oversight is in place to protect the person and their interest, while continuing to support their right to decide.

To implement these core functions, actions are taken at three levels:

- By the individual being supported
- At the 'interpersonal' level, including a person's supporters and those they interact with – like banks, health care, etc.
- Community agencies and partners

For a full discussion of these core functions see the IRIS guide, *Community-led Initiatives for Supporting the Right to Decide: A Framework for Design and Implementation*. It lays out steps that individuals, supporters, and community organizations can take to implement each of the core functions for supporting decision making.

Who Should Complete the Readiness Assessment Tool?

The *Readiness Assessment Tool* is to be used by community organizations which host some aspect of a community-led initiative to arrange and deliver supports for decision making. Host organizations could be a local agency providing disability supports and services, a disability advocacy organization, or an agency providing more generic education, health, and social supports in the community.

The tool guides a team from the host organization in reflecting on each of the core functions for arranging and delivering supports, their current capacities to carry out these functions, barriers they may face, and strategies they could use to enhance their capacity.

Delivering Supports for Decision Making: Readiness Assessment Tool

The purpose of this tool is to gather information about which core functions related to supporting decision making an organization is already doing, and not doing, but considering implementing. The tool is meant to help a team reflect on the specific actions taking place at their organization and in their community. It can also guide collection of 'baseline' information that could be used in an evaluation of an initiative on supporting decision making. It provides information about the 'starting point' for the initiative. The tool can also be used to track progress in strengthening capacities to deliver the eight core functions.



There are two key parts of this readiness assessment tool:

- **Part 1: Demographic/Community information**
- **Part 2: Readiness to deliver core functions**

Please complete this readiness assessment to the best of your ability. You can complete it individually or as a team – whatever works best for you.

Part 1: Key demographic information about community goals, challenges, and target population for pilot project

Community:

Partners:

Community-specific goals:

Targeted population (i.e., who will be supported in the pilot). Please specify selection criteria (if applicable):

Part 2: Key information about specific core functions practices/being adopted

Please use the tables on the following pages to respond to these questions.

1. How are you currently supporting decision making for those you support? Select the core function(s) that you are currently practicing, as well as the level(s) (individual, interpersonal, community) at which actions are currently being taken. If the actions described in the table match what you are doing, simply place a checkmark beside the action. If it does not match what you are currently doing, please describe what action looks like at your site.
2. Which functions/actions do you want to adopt (if you are currently not doing them)? Please indicate in the table below with a checkmark which ones your site is planning to adopt (if any), and use the space provided to elaborate on any actions that you will be taking to perform that core function that are not already described in the table.

Core function 1: Change community norms about the capacity of all people to govern their lives and to contribute and belong on an equal basis with others - for example, people living with an intellectual or cognitive disability, or mental health issues.

Doing before April 1, 2019	Currently doing/ underway (April 1 2019 to now)	Want to adopt	Actions	Description	Details – i.e.,what this looks like at your agency/ in your community; alternate actions	What challenges do you anticipate in sustaining or adopting this practice (e.g. lack of resources, lack of skilled human resources, community attitudes, legal barriers)	What strategies would be helpful in overcoming these challenges?
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Individual-level actions	Share with community members personal experience of barriers and opportunities to exercise choice and control in making personal, health care, and financial decisions.			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Interpersonal-level actions	Share experience of how the core values, policies and programs of community systems and human service agencies can directly and immediately shape opportunity for people to exercise choice and control in their lives.			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Community-level actions	Convene community conversations to: a) share stories and experience of people seeking personal choice and control in their lives, and ways in which they are excluded from doing so;			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		b) build community awareness, networks, goodwill and enthusiasm for a community where everyone is included and able to govern their own lives;			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		c) explore how current governmental and non- governmental systems operate in the community to influence, restrict and enable people’s choice, power and control in their lives;			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		d) design community responses to address barriers and build on opportunities to achieve the objectives;			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		e) to build awareness about the right to decide on an equal basis, and the recognition in the UN CRPD and the Canadian Charter of Rights and Freedoms.			



Core function 2: Explore with the person and supporters the person’s current situation, their circumstances, and their concerns, fears, hopes and aspirations in making decisions and planning for the future.

Doing before April 1, 2019	Currently doing/underway (April 1 2019 to now)	Want to adopt	Actions	Description	Details – i.e.,what this looks like at your agency/ in your community; alternate actions	What challenges do you anticipate in sustaining or adopting this practice (e.g. lack of resources, lack of skilled human resources, community attitudes, legal barriers)	What strategies would be helpful in overcoming these challenges?
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Individual-level actions	Person identifies who they want to support them in exploring plans for the future and in decision making, and participates in initial conversation about what is important to the person right now.			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Interpersonal-level actions	Planning facilitator reaches out to the person and people the person identifies, and through an evolving and multi- layered process helps to:			
				a) develop a relationship of mutual trust and openness;			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		b) identify and invite potential supporters, where a person is socially isolated and/or wishes others to become involved in building relationships of personal knowledge, trust and commitment;			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		c) discover and capture how the person communicates, what is important to them including others in their life (i.e. their will and preferences), their character and personality, and their communication support and other needs;			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		d) sensitively learn about what the person and/or supporters are saying and not saying, what avenues there might be for exploration, and what is happening ‘behind the scenes’ in the person’s ‘backstory’			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		e) understand the typical decisions afforded most people at this life stage; and,			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		f) identify what is most important to the person and their priorities.			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Community-level actions	Learning about and gauging the receptivity and capacity of the community to universally welcome, support and include people in all of the places, health care and other services, labour and housing markets, social networks and opportunities the community has to offer.			



Core function 3: Identify the supports and accommodations a person needs to make plans and decisions about what is important to them and their priorities

Doing before April 1, 2019	Currently doing/underway (April 1 2019 to now)	Want to adopt	Actions	Description	Details – i.e., what this looks like at your agency/ in your community; alternate actions	What challenges do you anticipate in sustaining or adopting this practice (e.g. lack of resources, lack of skilled human resources, community attitudes, legal barriers)	What strategies would be helpful in overcoming these challenges?
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Individual-level actions	The person communicates to a planning facilitator and support persons what kinds of supports they want in decision making			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Interpersonal-level actions	a) Explore the decision-making supports a person needs to make decisions in their lives, for example: (i) personal visioning and planning assistance; (ii) interpretive assistance; (iii) communication support; (iv) opportunity support; (v) building/strengthening personal relationships (e.g. with unpaid people, ‘unencumbered’ and not in a conflict of interest with the person); (vi) administrative support; and/or, (vii) other decision-making supports as identified.			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		b) Develop plans and action steps for achieving what is most important to the person, and revisiting these as the person’s priorities and circumstances evolve.			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Community-level actions	Continue work with community systems and agencies to better understand what types of decision-making supports and accommodations will allow all people to make decisions in their community.			



Core function 4: Arrange needed decision-making supports that are tailored to and welcomed by the person and are robust, viable, reliable and sustainable for all parties.

Doing before April 1, 2019	Currently doing/ underway (April 1 2019 to now)	Want to adopt	Actions	Description	Details – i.e., what this looks like at your agency/ in your community; alternate actions	What challenges do you anticipate in sustaining or adopting this practice (e.g. lack of resources, lack of skilled human resources, community attitudes, legal barriers)	What strategies would be helpful in overcoming these challenges?
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Individual-level actions	Where possible, the person identifies who will provide what types of decision-making supports and arrangements.			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Interpersonal-level actions	Arrange who will provide what types of decision-making supports for the person and for what purpose, and put the arrangements into place, which may involve:			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		a) appointing decision-making supporters;			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		b) taking steps to further, develop personal relationships with potential supporters;			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		c) arranging needed communication supports;			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		d) formalizing a supported decision-making agreement; and/or,			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		e) other arrangements as needed.			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Community-level actions	Identify which community actors/agencies are best positioned to develop and deliver decision-making supports and work to develop resources for this purpose			



Core function 5: Support real life opportunities for the person to exercise choice, power and control (including in legal relationships) in all aspects of their life.

Doing before April 1, 2019	Currently doing/ underway (April 1 2019 to now)	Want to adopt	Actions	Description	Details – i.e.,what this looks like at your agency/ in your community; alternate actions	What challenges do you anticipate in sustaining or adopting this practice (e.g. lack of resources, lack of skilled human resources, community attitudes, legal barriers)	What strategies would be helpful in overcoming these challenges?
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Individual-level actions	Person directs decision making in all aspects of their life, based on their will and preferences.			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Interpersonal-level actions	Assist the person, decision-making supporters and third parties to create decision-making processes that enable the person to exercise legal capacity, through steps such as:			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		a) role modelling how to assist the person to exercise their capacity;			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		b) problem-solving as issues arise, so as to avoid substitute decision making;			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		c) showing how to adapt and accommodate the decision-making process as needed;			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		d) raising awareness of those involved about why it is important to maintain a person's capacity; and,			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		e) other steps as needed.			



Core function 5 (continued): Support real life opportunities for the person to exercise choice, power and control (including in legal relationships) in all aspects of their life.

Doing before April 1, 2019	Currently doing/ underway (April 1 2019 to now)	Want to adopt	Actions	Description	Details – i.e.,what this looks like at your agency/ in your community; alternate actions	What challenges do you anticipate in sustaining or adopting this practice (e.g. lack of resources, lack of skilled human resources, community attitudes, legal barriers)	What strategies would be helpful in overcoming these challenges?
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Community-level actions	Identify obstacles people face to exercising legal capacity and take steps to address them, which could include:			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		a) reforming policies and programs operating in the community;			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		b) developing public awareness;			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		b) problem-solving as issues arise, so as to avoid substitute decision making;			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		c) training and information resources in key sectors/systems - e.g., banking, housing, health care, justice, education, municipal services, citizenship, and employment; and,			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		d) other steps as identified.			



Core function 6: Arrange accommodations in decision-making processes as needed.

Doing before April 1, 2019	Currently doing/ underway (April 1 2019 to now)	Want to adopt	Actions	Description	Details – i.e.,what this looks like at your agency/ in your community; alternate actions	What challenges do you anticipate in sustaining or adopting this practice (e.g. lack of resources, lack of skilled human resources, community attitudes, legal barriers)	What strategies would be helpful in overcoming these challenges?
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Individual-level actions	Person seeks to resolve obstacles encountered in making personal life, health care and/or financial decision.			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Interpersonal-level actions	Identify and implement needed decision-making accommodations to assist a person in exercising legal capacity.			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Community- level actions	Take steps to ensure the training, information and other resources are in place to assist parties to effectively carry out their duty to accommodate in decision making.			



Core function 7: As needed, legally challenge obstacles to exercising legal capacity.

Doing before April 1, 2019	Currently doing/ underway (April 1 2019 to now)	Want to adopt	Actions	Description	Details – i.e.,what this looks like at your agency/ in your community; alternate actions	What challenges do you anticipate in sustaining or adopting this practice (e.g. lack of resources, lack of skilled human resources, community attitudes, legal barriers)	What strategies would be helpful in overcoming these challenges?
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Individual-level actions	Person, or supporters on their behalf, seek legal support to challenge obstacles to making personal life,health care, and/or financial decisions on an equal basis with others.			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Interpersonal-level actions	Consider legal options available to the person to challenge barriers encountered and provide legal support as needed to launch challenges.			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Community- level actions	Review legal issues being identified by parties to decision making processes, and consider law, policy and program reform options to address them.			



Core function 8: Safeguard a person’s autonomy and protecting from harm.

Doing before April 1, 2019	Currently doing/ underway (April 1 2019 to now)	Want to adopt	Actions	Description	Details – i.e.,what this looks like at your agency/ in your community; alternate actions	What challenges do you anticipate in sustaining or adopting this practice (e.g. lack of resources, lack of skilled human resources, community attitudes, legal barriers)	What strategies would be helpful in overcoming these challenges?
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Individual-level actions	Identify areas and relationships where a person is or may be vulnerable to harm or to harming others, and strategies to address.			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Interpersonal-level actions	Identify areas where a person is or may be vulnerable, and steps to be taken to safeguard and maximize the person’s autonomy while protecting from harm (e.g. increasing disability supports, appointing monitors of a supported decision-making arrangement, expanding the circle of personal relationships and decision-making supporters).			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Community- level actions	Explore ways that people with disabilities are vulnerable to losing autonomy and to harm in the community, examine available supports and services to address this issue, and identify how gaps can be filled.			



Next Steps

Once the host organization has completed the readiness assessment tool, it is time to sit with other partners in the community who are part of the initiative. Partners can review the results of each other's readiness assessments, and consider questions like:

- What strengths do we have in arranging and delivering the core functions for supporting decision making in our community?
- What gaps exist?
- What is the range of tools we are using for delivering each of the core functions? Do we need to revise, or add to our toolbox, to achieve our objectives for supporting decision making in our community?
- What barriers do we face in implementing a community-led initiative?
- What strategies could best strengthen our capacity to implement the core functions for supporting people in our community to exercise their right to decide?

Conclusion

Community leaders and organizations are wanting to take action to support people in exercising their right to decide, or what is referred to in law as 'legal capacity.' A helpful place to start is IRIS' *Community-led Initiatives Supporting the Right to Decide: A Framework for Design and Implementation*. The *Framework* identifies eight core functions that local communities can put into place to support people in exercising the right to decide in their communities. '

The *Readiness Assessment Tool* complements the *Framework*. It is designed to assist community agencies and organizations who lead on implementing these core functions, in identifying their "readiness" to do so. By assessing capacity to fulfill these functions, and identifying barriers to implementing them, the assessment tool invites community actors to identify strategies to overcome these barriers.

The right to decide is a basic human right. Changes in laws are needed to ensure that people who live with intellectual, cognitive or communication disabilities, or mental health issues are not discriminated against in exercising this right and have the decision-making supports needed to do so. But law reform can take time. In the meantime, local communities can take action. They can look at their own community practices, organize decision-making supports for people and raise awareness about this fundamental human right. The *Readiness Assessment Tool* should help community organizations and agencies in taking this step on the path to full inclusion and participation.

Good luck on the journey to supporting people in your community to exercise the equal right to decide. For more information, visit us at www.irisinstitute.ca or reach out at contact@irisinstitute.ca.

