



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



**A FRAMEWORK FOR
DESIGN AND IMPLEMENTATION**

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

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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 learn about the “core functions” associated with supporting people in decision making. See IRIS’ related resource, *Community-led Initiatives for Supporting the Right to Decide: A Readiness Assessment Tool* to assist community organizations in assessing their readiness to deliver these functions and develop strategies to strengthen their capacity.



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.

Who may need intentional support in their decision making?

We all encounter situations where we seek or require support to make decisions in our lives. Many of us are able to find the people and ways to gain this support. However, people with intellectual, developmental cognitive and other disabilities, or living with mental health issues, often face communication, mobility, opportunity, and structural societal barriers to getting the support they need. Providing intentional supports for decision making in ways that uniquely respond to a person's situation, can ensure they have the means to express their will and preferences, and to make and guide their own decision making.

What kinds of decisions may need to be supported?

The decisions that may need to be supported are the ones that all of us face – the everyday, ordinary and extraordinary decisions that we encounter in our lives. They can range from opening an account at a bank, getting a cell phone from a retailer, or making a treatment decision at the hospital. While we all face the same types of decisions, the supports for these decisions may look different for different people. Because a person with a cognitive disability or mental health issue will likely have to interact with others to make these decisions (e.g., the bank teller, the phone retailer, the nurses and physicians), it is important that people who need decision-making support have the arrangements in place and that all community members recognize and respect the right of a person to decide.

What does support for decision making look like?

Our long-term vision of supporting decision making in all communities is that supports will become less formalized and professionalized; and that supports and accommodations will become widely known, respected, valued and legally recognized. Community members – bank tellers, landlords, hospital personnel, lawyers, neighbors, friends and others – will be able to recognize and engage in supporting decision making to ensure that the voice, will and preferences of the person is heard. In a society that currently doubts the capacity of many people to make their own decisions, dedicated efforts are required to achieve this vision and more formal supports may be warranted in the interim.

Community-led initiatives are usually organized to connect a person who needs additional support for decision making with what we might call a ‘planning facilitator’ who is attached to a partner organization in their community. This is a more formal type of support. The person and the planning facilitator work together to identify who will be involved in assisting the person to plan for their lives and support decision making. Together, with the person and supporters, they develop a plan for how decision making will take place in different situations that the person needs support with. The long-term goal is to move towards less formal kinds of support that can be identified and delivered effectively by family members, other members of a person’s support network, and the various community actors a person interacts with in decision making (i.e., doctors, banks, shopkeepers, etc.).

In addition, these initiatives aim to foster community dialogue and awareness about the importance of recognizing and respecting a person’s equal right to decide, and to stimulate a shift in how community organizations and services respond to a person who needs assistance with decision making.

What are the core functions of community-based initiatives to support decision making?

Based on research and experience in implementing community-based initiatives in many different jurisdictions, there appear to be eight core functions that enable provision of decision-making supports (see Figure 1). We call these “core functions” because they are the foundational activities that constitute best practices in supporting decision making for people who are traditionally stripped of this right. They are not steps, or stages of a process, or a prescriptive guideline. The core functions that each partner organization adopts and the way they perform that function might vary depending on the person involved and the community context. However, they are core functions because the purpose of doing these activities in each community remains the same, even if the activities look slightly different.

In summary, the eight core functions of successful community-led initiatives for supporting decision making are:

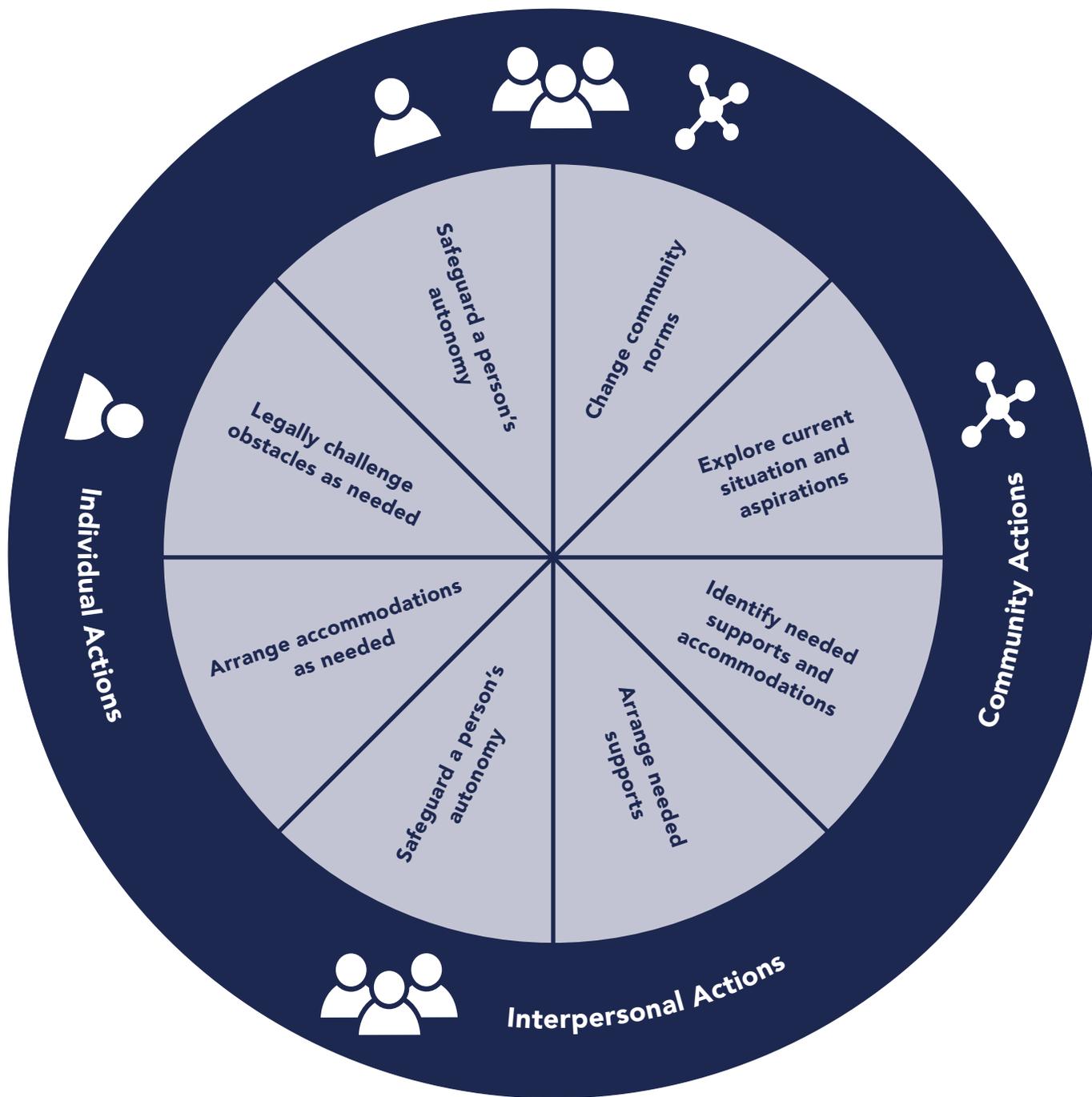
- 1. Change community norms** – about the place and rights of people with intellectual/developmental, cognitive, psychosocial and communication disabilities – through community forums, awareness raising, the sharing of personal experience and community planning.
- 2. Explore a person’s current situation 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

Steps that individuals, supporters, and community organizations can take to implement each of these core functions are presented below.

Figure 1. Core functions for supporting decision making in communities. These core functions are actioned at the individual (person making decision), interpersonal (planning facilitator and supporters), and community levels. Each of the core functions is described in more detail below.



CORE FUNCTION 1: Change community norms

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.



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.



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.



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
- (b) build community awareness, networks, goodwill and enthusiasm for a community where everyone is included and able to govern their own lives.
- (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
- (d) design community responses to address barriers and build on opportunities to achieve the objectives.
- (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 current situation and aspirations

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.

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.

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;
- (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;
- (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;
- (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';
- (e) understand the typical decisions afforded most people at this life stage; and,
- (f) identify what is most important to the person and their priorities

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 needed supports and accommodations

Identify the supports and accommodations a person needs to make plans and decisions about what is important to them and their priorities.



Individual-level actions

The person communicates to a planning facilitator and support persons what kinds of supports they want in decision making.



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.

(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.



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

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



Individual-level actions

Where possible, the person identifies who will provide what types of decision-making supports and arrangements.



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:

- (a) appointing decision-making supporters;
- (b) taking steps to further, develop personal relationships with potential supporters;
- (c) arranging needed communication supports;
- (d) formalizing a supported decision-making agreement; and/or,
- (e) other arrangements as needed.



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 3: Support real-life opportunities to make decisions

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



Individual-level actions

Person directs decision making in all aspects of their life, based on their will and preferences.



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:

- (a) role modelling how to assist the person to exercise their capacity;
- (b) problem-solving as issues arise, so as to avoid substitute decision making;
- (c) showing how to adapt and accommodate the decision-making process as needed;
- (d) raising awareness of those involved about why it is important to maintain a person's capacity; and,
- (e) other steps as needed.



Community-level actions

Identify obstacles people face to exercising legal capacity and take steps to address them, which could include:

- (a) reforming policies and programs operating in the community;
- (b) developing public awareness;
- (c) training and information resources in key sectors/systems - e.g., banking, housing, health care, justice, education, municipal services, citizenship, and employment; and,
- (d) other steps as identified.

CORE FUNCTION 6: Arrange accommodations as needed

Arrange accommodations in decision-making processes as needed.



Individual-level actions

Person seeks to resolve obstacles encountered in making personal life, health care and/or financial decision.



Interpersonal-level actions

Identify and implement needed decision-making accommodations to assist a person in exercising legal capacity



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: Arrange accommodations as needed

As needed, legally challenge obstacles to exercising legal capacity



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.



Interpersonal-level actions

Consider legal options available to the person to challenge barriers encountered and provide legal support as needed to launch challenges.



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

Safeguard a person's autonomy and protecting from harm.



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.



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).



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.

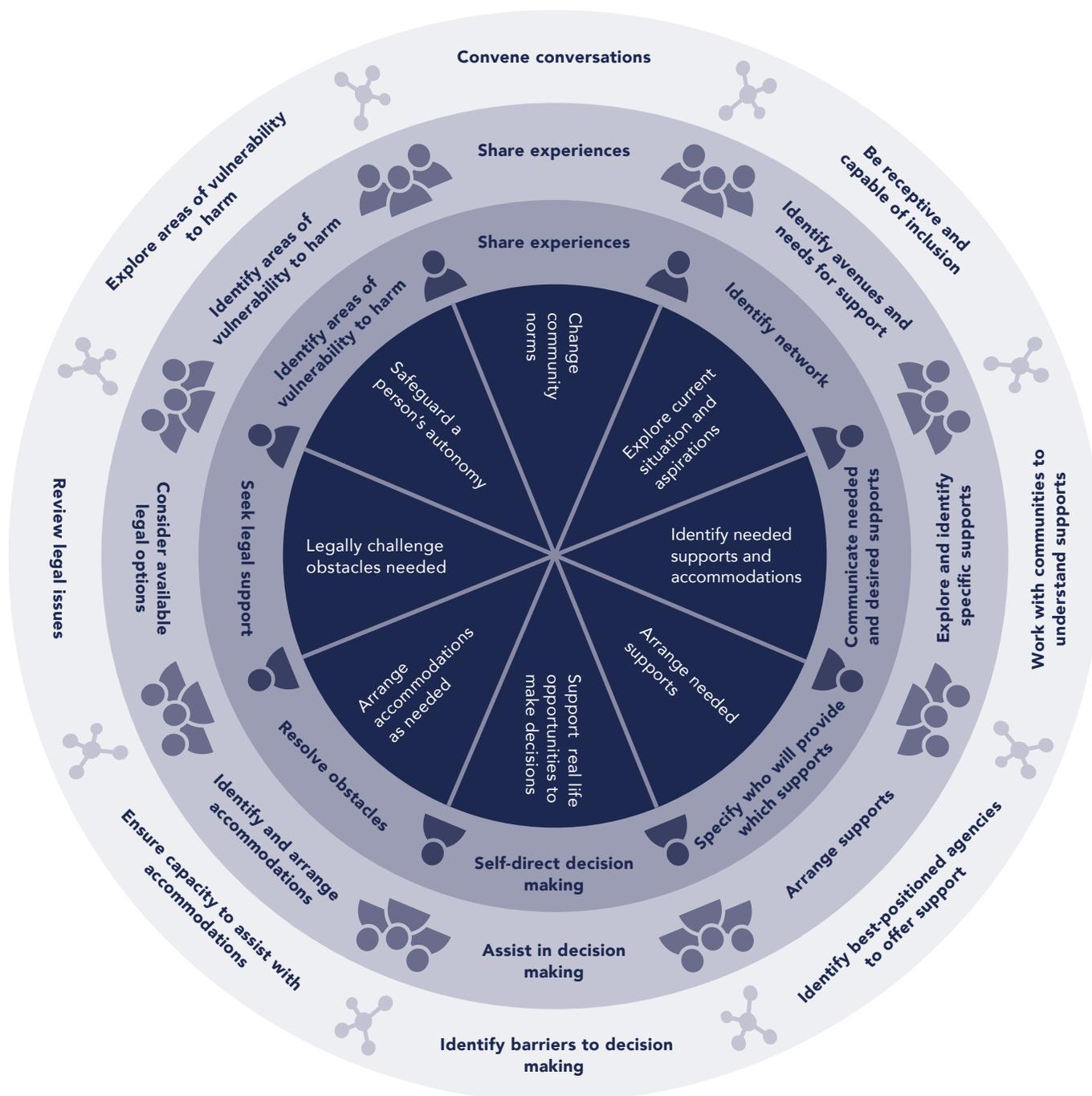
How will core functions for supporting decision making be implemented?

Many community-based organizations are already performing these core functions, at least to some extent. The process of piloting community-based initiatives to support decision making begins with partners:

- Understanding which core functions are already being used in practice
- Identifying which additional core functions may/will be adopted
- Exploring what it looks like to “do” each of these core functions in their community

As part of designing community-based initiatives, change strategies are identified (e.g., tools, resources, trainings, champions and opinion leaders, etc.) which can be used to help facilitate the adoption and uptake of the core functions for supporting decision making and the equal right to decide.

Figure 2. Summary of the core functions for supporting decision making in communities, and related actions at the individual, interpersonal and community levels.



Next Steps and Conclusion

The right to decide is a basic human right, denied to a growing group of people who live with intellectual, cognitive or communication disabilities, or mental health issues. Changes are needed at many levels to recognize, promote and protect the right to decide, or to exercise legal capacity:

- Changing laws that restrict or deny the right to decide to some groups
- Changing policies and programs that deny support that people need to make and guide their own decision making
- Investing in community capacity to change attitudes and provide the support people may need to exercise their right to decide.

The core functions of community-based initiatives to support people in making decisions, presented in this document, provides a helpful framework to begin the dialogue in your community. The first step is to convene community organizations and advocates who want to partner in launching a local initiative for the right to decide. Once you have taken this step, you can use another resource from IRIS – *Community-led Initiatives for Supporting the Right to Decide – A Readiness Assessment Tool*. This tool assists community organizations in reviewing their capacity to deliver the core functions presented in this resource guide.

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.

