



# MY LIFE, MY DECISIONS

Supporting the **EQUAL RIGHT TO  
DECIDE** for People with Disabilities



**A COURSE OVERVIEW  
- FOR COMMUNITY ACTORS**

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

Institute for Research and Development on Inclusion and Society (IRIS), Oshawa.  
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20-850 King Street West Oshawa, Ontario, Canada L1J 8N5

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Title: *My Life, My Decisions: Supporting the Equal Right to Decide for People with Disabilities – A Course for Community Actors*

Author: Institute for Research and Development on Inclusion and Society

Course Design: Michael Bach, Managing Director, IRIS

Publication Design: Chloe Ings

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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](http://www.irisinstitute.ca) or email [contact@irisinstitute.ca](mailto:contact@irisinstitute.ca).



# Purpose and Overview of this Course

This course introduces concepts and strategies to assist community actors in designing and implementing community-based initiatives to support people with disabilities to have power, choice and control in their lives. The right to make decisions about one's own life is recognized in the United Nations Convention on the Rights of Persons with Disabilities (CRPD), which states that persons with disabilities enjoy this right on an equal basis without discrimination based on disability, and must have access to the support they may require for this purpose.

However, making sure people with disabilities can enjoy and exercise the right to decide on an equal basis with others requires change at many levels. Laws, government policies, community programs and services, and attitudes and practices of family, friends and community members often create barriers to people having the support they need to make decisions about their own lives. As a result, many people with disabilities – especially those with intellectual, cognitive, psychosocial or communication disabilities – are denied the right to make decisions about where they will live, with whom, about their education, social and personal life, jobs, their finances and health care.

While change is needed at many levels, this guide focuses on community-level practice: what steps community actors can take to assist people with disabilities in exercising decision-making power in their lives and communities.

## Who is this Course for?

This course is intended for three main audiences:

- People with disabilities, their families and supporters, and Disabled Persons Organizations (DPOs) working for inclusion and human rights
- Providers of Supports and Services to persons with disabilities
- Allied community-based organizations and service providers.

## Learning Objectives

This course aims to assist these audiences to:

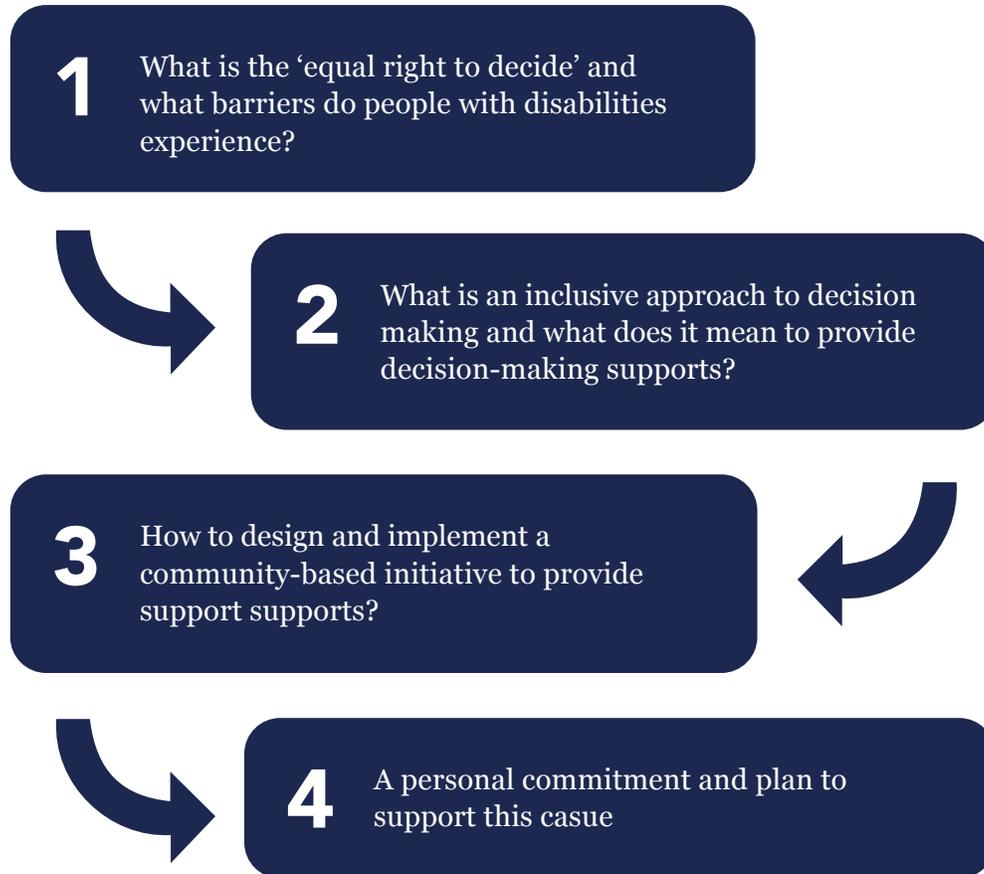
- Increase their understanding about what it means to make personal decisions and exercise the right to decide, and how to support people with disabilities to do so.
- Learn about how to design and implement a community-based initiative to develop and provide decision-making supports.
- Develop personal commitment and a plan to contribute to this agenda.

## The Learning Journey

The course will take you through a learning journey with four main steps:

1. It begins with what the ***'equal right to decide'*** is, why it matters, how people with disabilities are often denied enjoyment of this right, and why it is a driving world-wide issue for people with disabilities and their advocates.
2. We then turn to the ***'micro' or 'personal' level of decision making*** – what it actually means to make personal decisions, what the principle of respecting autonomous decisions requires, and the various ways to support a person in this process.
3. The journey travels from there to the ***'mezzo' or 'community' level of providing decision making support*** – how community stakeholders can organize to provide people with disabilities decision-making support in their lives. The guide introduces the core functions of a community-based initiative for providing decision-making support and the roles that are needed to implement these functions.
4. Finally, the guide invites you to ***imagine and plan for continuing your own learning journey*** by identifying ways they will participate in supporting people to exercise power over personal life decisions.

## The Equal Right to Decide: A Learning Journey



### Topics

Through this learning journey, we will cover the following topics:

1. The 'equal right to decide' – What does it mean, why does it matter and how is it violated?
2. Denying people with disabilities the right to decide – why does it happen, what are the barriers, and what are the consequences?
3. An inclusive approach to respecting autonomy and the right to decide: the 'decision-making capabilities approach'
4. "Supports" for decision making, "supported decision making" and the duty to accommodate a person in decision making.
5. Designing a community-based initiative to support people with disabilities in exercising the right to decide.
6. Where you fit in the process – identifying personal goals and roles in supporting people to exercise their equal right to decide.

## Format

The course can be divided into three on-line or in-person sessions. Session materials and instruction include:

- Background information on each topic;
- Learning exercises;
- Some tips and tools to help take each step of the learning journey
- Summaries for each topic.

# Summary of Topics Covered

## Topic 1: The 'equal right to decide'

- The 'equal right to decide' is the recognition that all persons can make decisions about their lives, and that they must be accorded the power and support to do so.
- Recognition and enjoyment of this right is fundamental to being recognized and included as a full citizen and to developing your potential as a human being.
- The right to decide applies to legal decisions, those with legal consequences – like entering a contract, making a health care decision, or any personal decision that imposes rights and responsibilities on yourself and others. These legal decisions help us to fulfill our everyday decisions about what matters to us and what we care about.
- The right to decide is recognized at five main levels:
  - International law
  - Domestic law
  - Government policies
  - Community services and practice
  - Inter-personal relationships
- Your right to decide may be recognized at one of these levels – like in international law – but denied at other levels. This means you will face restrictions or be denied your right to make decisions on an equal basis with others.

## Topic 2: Being denied the equal right to decide

- People with intellectual, developmental, cognitive, psychosocial and communication disabilities are often denied the right to make decisions in their lives.
- Some people say that people with these kinds of disabilities *should* be denied the right to decide because their disability means they do not have the ability to make decisions on their own. This is the 'bio-medical' model of disability – it assumes that the problem lies in the person rather than in their environment and society.



- The bio-medical model informs the three main approaches to defining who has the right to make decisions:
  - status approach – if people are diagnosed with a “mental disorder” of some kind, they are denied the right to decide);
  - outcome approach – if people are considered a danger to themselves or others, they are denied; and,
  - cognitive/functional approach – if a person is unable to demonstrate they have the cognitive and communication abilities to make a decision on their own, they can be denied the right to decide.
- One or more of these approaches are usually reflected in the ways the right to decide is recognized – whether in international law, a domestic law, a government policy, a community program, or attitudes of a group of families or community members about the right of a person with a disability to decide.
- The ‘social and human rights’ model of disability challenges these ideas. The UN *Convention on the Rights of Persons with Disabilities* is based on the social and human rights model. It recognizes that disability results from attitudinal, environmental, physical, social and legal barriers.
- Barriers to exercising the right to decide, which people with disabilities commonly face include, for example:
  - Legal barriers – like guardianship and mental health laws which remove a person’s right to decide based on disability and perceptions of risk;
  - Policy barriers – which limit resources for access to community-based mental health and supports for decision making
  - Community program barriers – like a disempowering service culture; and,
  - Interpersonal barriers – which leave so many people with disabilities isolated, excluded and without people in their lives who can assist in decision making.
- These barriers to the right to decide cause significant harm to people with disabilities, including a negative impact on their functional abilities, social isolation, low self-esteem feelings of hopelessness, being demeaned and socially stigmatized, and being victimized by guardians and substitute decision making.

### **Topic 3: An inclusive approach to respecting autonomy and the right to decide: the ‘decision-making capabilities approach’**

- If the mainstream approaches to the right to decide discriminate against and disadvantage large groups of people with disabilities, what does a more inclusive approach look like?
- It starts with the accepted principle of respecting autonomous decisions of others, which are defined as decisions a person makes (1) intentionally, (2) with understanding, and (3) voluntarily, without coercion or undue influence by others.



- Applied in law, policy, programs and practice, this principle usually means that a person must do all these steps by themselves.
  - All persons can do step 1 – we all have intentions, preferences and a will
  - However, many persons with more significant intellectual, developmental or cognitive disabilities are unable to demonstrate they understand all the steps needed to put their intentions into action.
- However, no person does step 2 by themselves. We all rely on support from others to make and coordinate plans so that we can fulfil our will and preferences. A more inclusive account of autonomous actions and decision making recognizes that people may need extensive support to help them make decisions and act voluntarily.
- A ‘decision-making capability approach’ to the right to decide is based on this more inclusive account of autonomy. It addresses the limitations of the discriminatory status, outcome and cognitive approaches. It recognizes that people can make decisions either ‘independently,’ without much assistance in demonstrating understanding, or ‘interdependently’ with support from others. Both ways of making decisions are valid, and both protect a person’s right to decide.
- A decision-making capability approach must also include safeguards, recognizing that some people with disabilities are particularly vulnerable to coercion, undue influence and other factors which may make it difficult to recognize their true intentions and free will. This group will need others to act on their ‘best interpretation of the person’s will and preferences’ and make sure some oversight and protections are in place, without taking away the person’s autonomy and right to decide.

## **Topic 4: “Supports” for decision making, “supported decision making” and the duty to accommodate a person in decision making**

- Putting a decision-making capability approach into law, policy, programs and practice requires making available to people: 1) supports for decision making, 2) supported decision making, and 3) accommodations in decision making.
- ‘Supports for decision making’ is a broad term and means any type of assistance a person may need to make decisions and put them into action. Supports for decision making can include:
  - personal planning and navigation support
  - individual advocacy
  - interpretive assistance
  - communication assistance
  - opportunity support
  - relationship building
  - administrative support
  - representation support.



- ‘Supported decision making’ is one arrangement for putting supports for decision making into place. It is usually established for people who need support to make decisions interdependently. It involves one or more people who have a relationship of personal knowledge, trust and commitment being designated or appointed to support a person in all the ways listed above.
- Supported decision making should not be confused with ‘supports’ for decision making. Many people with disabilities can act legally independently with one-time support, like communication assistance, planning support or independent advocacy. It would restrict their right to decide if they had supported decision making, as defined above, imposed upon them.
- The duty to accommodate in decision making is the duty of other parties in a decision-making process – doctors, banks, community and government services. It refers to their duty to adjust their decision-making processes to ensure people with disabilities have the support and adaptations they need so they can enter legal agreements with these other parties and use their services.

## Topic 5: Designing a community-based initiative to support people with disabilities in exercising the right to decide

- The equal right to decide without discrimination based on disability is most clearly recognized in international law, the UN CRPD. For people with disabilities to truly exercise and enjoy this right it must also be recognized in domestic law, government policy, community practice and interpersonal relationships.
- Even if currently there is little or no support for domestic law and policy reform, community actors can stake steps to bring about change in their own communities.
- Community-based initiatives to support people in exercising the right to decide tend to provide 8 main functions:
  1. Change community norms
  2. Explore a person’s current situation and aspirations
  3. Identify needed supports and accommodations
  4. Arrange needed supports for decision making
  5. Support real life opportunities to make decisions
  6. Arrange accommodations as needed
  7. Legally challenge obstacles as needed
  8. Safeguard a person’s autonomy
- Implementing these core functions in a community can take some time. A good place to start is to design pilot project to begin testing out these functions and engaging community actors in the process. Steps in that process include:
  1. Convene an Organizing Committee (months 1-2)
  2. Host a Community Forum (month 3)
  3. Establish a Design Committee for a Pilot Initiative (month 4)



4. Identify Focus of the Pilot Initiative – based on experiences of people (month 4-5)
5. Identify which community organizations will deliver the pilot projects (month 5)
6. Create information (months 5-6)
7. Put the project into action (months 7-18)
8. Engage the broader community (months 12-36)
9. Document learning (ongoing)
10. Grow the project and agenda for change (months 30-36)

## **Topic 6: Your personal goals and roles in supporting people to exercise their equal right to decide**

- It will take change at many levels to ensure that people with disabilities can enjoy and exercise their equal right to decide.
- Making change happen in law, policy, community programs and personal relationships can take significant time and resources. The process can seem overwhelming.
- We can all take steps, from wherever we are located to contribute to the change process, even if it is learning more and shifting our own perceptions.
- It is helpful to think about your own commitment and intention to contribute to the change process and how you can best do that.

### **Next Steps**

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 ‘My Life, My Decisions’ course introduces the main principles of the equal right to decide and how to put them into practice. It can assist those who want to make change happen at any level – in law, policies, programs or community practice – so that all people can take their rightful place as full and participating members of the community.

Good luck on the journey to supporting people in your community to exercise the equal right to decide. For more information or if you are interested in participating or hosting this course, visit us at [www.irisinstitute.ca](http://www.irisinstitute.ca) or reach out at [contact@irisinstitute.ca](mailto:contact@irisinstitute.ca).

