

THE EQUAL RIGHT TO DECIDE

Designing a Pilot Project Initiative to support people with intellectual and other disabilities to gain choice and control over their lives.



IRIS facilitates design of a supports for decision making pilot initiative with community partners in Dryden, Ontario

People with intellectual, cognitive and psychosocial or mental health disabilities often face barriers to the equal right to 'legal capacity'. Legal capacity is the power to make and direct your own decisions about your personal life, health care, and money.

WHY START A PILOT PROJECT

People with intellectual and other disabilities face barriers to exercising choice and control in their lives.

THERE ARE BARRIERS:

IN PRACTICE

(relationships with family, doctors, banks, government and community services)

- People's voice and decisions are sometimes not respected by others.
- People don't have information or support to make their own decisions.
- Often families are told they should become legal guardians.

IN PROGRAMS

- Many community support programs are not "person-directed."
- Many people are poor and without affordable housing, which takes away choices.
- Many communities don't have resources to support people in decision making.

IN GOVERNMENT POLICIES

- People are not able to get individualized funding and planning support.
- For most, there are no options but guardians and substitute decision makers.
- Doctors, banks and others need more help to accommodate people in decision making.

IN LAWS

- Many laws that regulate legal capacity discriminate based on disability – they require that people have certain cognitive abilities to maintain power over their lives.
- They take away people's "liberty" – or right to control their own life – on this basis.
- Most laws don't allow for supports, or supported decision making.

A community-based pilot project works on addressing the barriers at the first two levels – practice and community services and programs. These can include disability-related services, health care and hospitals, banks, businesses, police and the justice system, and government services.



WHAT A PILOT PROJECT CAN DO

It can support people in two main ways:

Provide decision-making assistance:

Many people can make most or all their decisions by themselves, if they have support or decision-making assistance they need to do this – like plain language, or an advocate, or a communication aid, like a communication board. The project will help people get this assistance.

Arrange supported decision-making:

Some people are not able to make decisions by themselves. But they know what they want and what matters to them. In these situations, supporters help the person make a plan for their lives and put it into action. They also interpret the person's will and preferences to others. This approach is called 'supported decision making.' The project will help set this up, so people can have power over decisions in their lives.



Zambia Federation of Disability Organizations hosts training for local pilot teams in Zambia, with training and technical support from IRIS.

HOW THE PROJECT CAN WORK:

Design the project (months 1-4)

In each community, design the project to support 8-10 participants with intellectual disabilities, and possibly another 8-10 with mental health, and 8-10 with cognitive disabilities. Or, the project could focus on intellectual disability.

Create information (months 3-6)

Create information about decision-making assistance and supported decision making, and agreements for people to participate in the project.

Put the project into action (months 7-36)

Support individual participants in the project, promote the project in local communities, and carry out research about how it is working.

Engage the broader community (months 25-30)

Outreach to local community partners to share lessons learned and help change community practice.

Document learning (ongoing)

Design and activate an ongoing learning strategy - for example, through photo stories, video, focus groups, and interviews with participants, families, and community partners.

Grow the project and agenda for change (months 30-36)

Look at how to expand the pilot project. Explore with elected representatives and governments how laws and policies must change so all people can have power over their own lives.

TO LEARN MORE

IRIS is supporting the development of pilot initiatives in communities in Canada and internationally. To learn about developing a community-based pilot initiative to support people in your community gain greater choice and control in their lives, please visit us at www.irisinstitute.ca, or contact:



Michael Bach, Managing Director,
 IRIS at mbach@irisinstitute.ca.

