The Right to Decide: Background Information on Decision Making

What is the right to decide?
The legal term for being able to make decisions is “legal capacity”. All countries have laws and practices that relate to legal capacity. These laws apply to all people and have been used to determine who can make decisions and what kinds of decisions they can make. These laws can be used to take away the “legal capacity” of people with intellectual disabilities. We know that many countries have laws that prevent people with intellectual disabilities from making decisions because they are perceived by others to be “incompetent” or “incapable”.

Article 12 UN CRPD
Article 12 of the UN Convention on the Rights of Persons with Disabilities (CRPD) focuses on legal capacity. It guarantees that all people with disabilities “enjoy legal capacity on an equal basis with others in all aspects of life.” This means that ALL people with disabilities have the right to make decisions.

Article 12 also recognizes that some people may need support to make decisions (to exercise their legal capacity) and requires that governments “take appropriate measures to provide access... to the support...” a person needs to make decisions. This means that no one should be denied the right to decide just because they need help to make decisions.

Article 12 CRPD:
1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.
2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.
3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.
4. States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.
5. Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.
Il believes that, with support, all people with intellectual disabilities are able to make decisions and have control in their lives.

**What types of decisions do we mean?**

Having the right to decide means being able to make decisions in all aspects of our lives. This includes:

- **Personal life decisions** – the day to day decisions like personal care, what we wear, where we shop, what we eat, and what we do for fun. The right to make these day to day decisions is also very important to people with intellectual disabilities. Also the more substantive personal decisions like having a boyfriend or girlfriend, getting married, taking post secondary schooling or training, where they want to live or the kind of work that they might like to do.

- **Health care decisions** – People want to be able to understand and learn more about their health issues and proposed medical interventions, so that they can make informed decisions around their health care. As well they may have to give consent for certain medical procedures.

- **Financial and property decisions** – It is important that people can decide where they want to live and who they want to live with. They want to be able to have control over their own money and be the ones who decide how to spend it. Have access to pensions, inheritance and to manage other financial affairs. Be able to sign contracts such as leases or employment contracts. They may want to apply for a credit card, or purchase bigger items like cell phones, a computer, or a new television.

**SUPPORTED DECISION MAKING**

**What is it?**

Supported decision-making recognizes we all make decisions with support from others – we talk with family and trusted friends; we get additional information to understand the implications of decisions etc. Supported decision-making is an individual-specific, life-long process that grows and changes as the person does. It gives legal status to the process of using support to make decisions. The support provided through supported decision-making models can take many forms. It could include: the provision of information in plain language; support to understand the options and consequences of decisions; or, extra time to make decisions. For people with more significant support needs and/or difficulties in communicating, support could be a network of people who express and articulate a decisions based on the will and intent of the individual and the knowledge they have of the individual as a result of a trusting relationship.

**Substitute Decision Making vs Supported Decision Making**

Historically, if someone has not been seen by others as being able to make their own decisions independently, their right to decide has been limited or completely removed. This is sometimes done formally – through the appointment of a guardian; it can also be an informal practice where third parties (like lawyers, bankers, doctors, service providers or other professionals) do not accept or expect – the individual with a disability to make their own decision and relies on the parent to be the decision maker. Examples of this include: a bank refusing to open a bank account for a person with an intellectual disability without the primary account holder being the parent; or, a doctor who only speaks and listens to the parents of a person with an intellectual disability; or, a family member making decisions for an individual about day-to-day things like what to wear, what to eat and bigger things like where and with whom to live.

In substitute decision making, decision making authority is granted to someone else – usually a family member – to act as “guardian” or “substitute decision maker”. In these systems, decisions are made for the person. The system removes the individual’s right to have control and voice in their own lives. For a long time, substitute decision making systems were seen as a way of protecting people. We now know this is not true. People are safest when they have a voice that is respected and heard. Substitute decision making takes away power and makes people weaker and more vulnerable. The key difference between guardianship and supported decision-making is that through supported decision-making, the individual remains the decision-maker.