The Right to Decide: Why Does it Matter?

Adults who have an intellectual disability wherever they live in the world continue to be isolated, excluded and often vulnerable in their communities. They continue to be denied the right to control their own lives and make decisions about how they want to live their lives. While families represent the main source of support for people with intellectual disabilities they worry about what will happen to their family member when they are gone or when they are no longer able to care for their family member. Strategies to build networks of support for people with intellectual disabilities enable a person to direct their own lives and be supported to make decisions for themselves (supported decision making). Having these supports to make decisions means that people who have an intellectual disability are less vulnerable, less isolated and less dependent on their families to live the lives they choose.

Why does this right matter to families?

Families are the first and main source of support for people with intellectual disabilities. Because of this and the lack of other supports or services, families assume larger responsibility in the lives of their adult children with disabilities than their children without disabilities. Families have told us they are:

- Fearful for the future and often ask “What will happen when I’m gone?”
- Concerned about the safety of their sons and daughters in communities that have not demonstrated acceptance and inclusion.
- Blamed if their son or daughter makes a poor decision or a mistake.
- Lacking the skills and tools to understand how to support their sons and daughters to make their own decisions.
- Required (as a result of legal practices and/or a lack of community awareness) to assume formal decision-making roles.

These factors have contributed to an over-reliance on families to be decision-makers and the notion that substituted decisions are a form of protection.

We know now that guardianship and substitute decision-making are not the answer. Adults who are not allowed to make their own decisions are more vulnerable. To ensure a safe and secure future, people with intellectual disabilities need to be supported to make their own decisions.

A growing voice

Over the past few decades, the direct engagement of people with intellectual disabilities and the development of a self-advocacy movement have provided adults with intellectual disabilities a platform to express their priorities. Consistently, adults with intellectual disabilities have told us that having a voice and control in their lives is a top priority; that the right to make decisions is essential for being seen and treated equally in community. Increasingly, we have heard that having the right to decide is important for securing all other rights. The development of a UN Convention on the Rights of Persons with Disabilities (CRPD) represented an

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1 More detail on decision making and supported decision making can be found in The Right to Decide: Background information on decision making.
opportunity to secure this right in international law. This campaign looks at how we make this right real for people with intellectual disabilities.

**Why do people need support?**
Some people may have difficulty making decisions independently – it may be that they don’t understand what they are being asked or the implications of their decisions.

Some people may have a hard time making their wishes or choices understood by others if they don’t communicate in traditional ways. Some people don’t use words to communicate – they may use gestures or certain behaviours.

Families and others may have concerns about the decisions an individual is making; they may not understand how to support an individual to make decisions.

People with intellectual disabilities tell us that they need support to develop decision making skills and support to make decisions; they express fear that if they make a “bad” decision no one will let them make their own decisions again.

**How we make decisions**
For everyone, our decisions are shaped and influenced by many factors. Decisions are made in a context and reflect an individual’s reality. Individuals and families have told us that while certain cultures recognize decision-making in terms of individual autonomy, many others emphasize group and mutual responsibilities. When we live as a family unit our decisions have impact on others and often family members are mutually dependent on one another.

Supported decision-making does not mean ANY and ALL decisions are possible. All of our decisions are determined by our financial realities, our relationships, and our support needs.

**Decision making in a world with few options**
Inclusion International’s global report on living and being included in the community documented that, around the world, the vast majority of adults with intellectual disabilities live at home because there are no other options available to them. Most individuals are not getting the supports and services they need to live and be included in their communities – often because these services do not exist.

A lack of options restricts choice – it does not restrict voice. Limited options may require creativity to respect the wishes of an individual. For example, an adult with intellectual disability may want to decide to live away from the family home – this may not be possible for a number of reasons (cultural, availability of adequate housing, lack of services, financial etc.) How then can the persons wish to live independently be respected? Individuals and families have told us about innovative solutions to respect a person’s wishes within the realities of their lives. This could include ensuring the individual has an equal measure of control in the house over household decisions about activities, meals etc.

Limited options should not restrict goal setting. Just because something isn’t possible today doesn’t mean we can’t aim to make it a reality. We may decide on a goal that we want to reach (about where to live, go to school, or work; what we want; how we want to spend our time etc) but reaching that goal may take time and require many decisions along the way.

**What does this mean for families?**
For many, particularly those with more significant support needs and those living in countries with few resources and services, it is their families that facilitate their inclusion in community and the expression of their
wishes. In advancing the right to decide, what is the role of families? What can they do to support their sons and daughters with intellectual disabilities to have voice and control in their lives?

Families have to believe that their sons and daughter have a voice and are able to express their own decisions. To support this, families can:

- Learn more about how people are supported to make their own decisions
- Encourage their sons and daughters to develop decision-making skills as they grow and develop
- Provide information in plain language and help identify implications/consequences of decisions
- Expect their sons and daughters to have opinions
- Rely on behaviours and other forms of communication as an expression of will and intent and use that to guide decision-making
- Acknowledge that mistakes will happen and that we all learn from making mistakes
- Commit to supported decision-making
- Establish a support network/circle
- Reject pressure to seek guardianship orders