The Right to Decide: Why it is important?

www.inclusion-international.org

People with Intellectual Disabilities have said...

- Adults who have an intellectual disability wherever they live in the world continue to be isolated, excluded and often vulnerable in their communities.
- They do not control their own lives and are not able to make decisions about how they want to live their lives.
- Too often their voice is restricted because they are denied the right to make decisions in their lives.
- Informally or formally they are deemed “incapable” or “incompetent”;
- They are penalized if they need support to make decisions.
Families have said...

- Their sons and daughters with a disability live with them until their adult years and the majority for life in a disproportionate way when compared with their other children who do not have a disability.

- They fear for the safety of their sons and daughters. They are afraid of them being abused and mistreated.

- They also feel excluded and lonely and do not have the supports they need because of the challenges they face related to the disability of their family member.

- They spend close to 30% to 60% more resources than other families that do not have a child with a disability.

- They need respite.

Raising Concerns

- Families are the greatest support and advocate for their family member with a disability to achieve inclusion and at the same time their fears, beliefs and attitudes are the biggest obstacles for their sons and daughters to achieve independence and self-determination.

- 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 them.
Networks of support

- 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.

Everyone Benefits

- For Families
  - finding ways to support their family member to express their opinions and make decisions is a critical factor in planning for the future and ensuring that their family member is included in the community
  - peoples reliance only on their families is reduced and families fear of what will happen when they are gone get addressed.

- For people with intellectual disability
  - realizing their right to make decisions is essential for being seen and treated equally in community.
  - Having voice and control is a priority for them.
The Right to Decide:

What does it mean for people with intellectual disabilities?

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.
A Growing Voice

• 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 opportunity to secure this right in international law.

There is a need to look at how we make this right real for ALL people with intellectual disabilities.

Self Advocate Paradigm Shift

• Self Advocate Presentation
The Right to Decide:

Why should this 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 paradigm shift

Family presentation: