

# This is our Convention too!

## People with intellectual disabilities & the right to make decisions

Many people who have an intellectual disability cannot speak or communicate. The challenge of the new UN Convention (A Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities) will be to ensure that even those who have no voice are heard!

### Inclusion International

With its member societies, Inclusion International acts as an agent for change on the basis of four main principles affecting the lives of people with an intellectual disability and their families:

- *Inclusion in all aspects of everyday society;*
- *Full citizenship which respects individual human rights responsibilities;*
- *Self-determination in order to have control over the decisions affecting one's life*
- *Family support through adequate services and support networks to families with a disabled member*


### Our Vision

*is of a world where people with intellectual disabilities and their families can equally participate and be valued in all aspects of community life.*

For people with intellectual disabilities, the new UN Convention is an important tool for realizing our vision of full inclusion in society.

All of the human rights that will be outlined in the new Convention apply equally to people with intellectual disabilities. However, to exercise these rights and have them realized, people with intellectual disabilities must be recognized as full citizens with the right and capacity to make decisions on their own behalf (self-determination). The right to make decisions and have those decisions respected underpins all other rights in this convention; without it people with intellectual disabilities will be denied the right to live in the community; to go to school, to participate in their communities as equal citizens.

The following is intended to inform the discussions about *legal capacity* by providing information about the way that people who have intellectual disabilities make choices and decisions.



*"Rebecca does not speak, so those around her ensure that she has many other ways to express her feelings and desires. Her family, friends and support*

*circle try to be very attentive to her cues which indicate what she likes to do and what she definitely does not like to do."*

*- Susan Beayni*

## WHAT IS SUPPORTED DECISION MAKING?



Robert Martin, Haydee Beckles  
and Karen Spence at the UN

*“I want to talk for a moment about how it really feels when no one listens to you. When others make your decisions for you. For many years I was ignored. I was in the room but it was like I was not really there. No-one bothered to ask me what I wanted. Really important decisions were made about things like where I would live, what school I would go to and who I would live with in the other room. The other room that I was never part of.”*

– Robert Martin

All people must have control over their own lives. We all make choices in our everyday life; what to eat, what to wear, where we live, who we have relationships with. We rarely make decisions alone, in isolation. We talk things over with people we love and trust. Those people are usually members of our family or our closest friends. These decisions do not have to be recognized in any legal way but they are choices we make that reflect our fundamental freedoms.

For many people who have an intellectual disability these basic choices are denied or questioned simply because of their disability.

Other people (doctors, teachers, caregivers even family members) sometimes question if these choices are in the person’s “best interest”.

People with intellectual disabilities who cannot speak,; who have difficulty communicating or understanding, need support to make decisions and to have their ‘will’ understood by others.

Supported decision-making depends on *trusting relationships* between a person giving support and a person receiving support. If a person is isolated and does not have these relationships, they may need help to build them.

*No one really lives on their own. We all have support from others who do not always live with us. Many of us with a disability require specialised support to meet the needs of our disability. Unfortunately this support often takes over other parts of our lives and we lose our ability to make our own choices and decisions.”*

– Robert Martin

## LEGAL CAPACITY & THE UN CONVENTION

The new UN Convention for people with disabilities will include the right to make decisions in an article called “Legal Capacity”. This article will say that every person including people who cannot speak or make themselves understood in traditional ways has the right to make their own decisions. It also will give people the right to have support to make those decisions.

No one can make decisions for a person with a disability but the

person can have help in making decisions from people we know and trust. All of us need support. All of us need personal advice and people whom we can trust and whom we can ask for help. We talk things over with people we love and trust. This is called “supported decision-making”.

It takes time to build love and trust with other people. Sometimes those relationships don’t work out. If a person does not have friends and family who

they trust, governments will be asked to help build those relationships. People should also be protected in serious situations when they need help to make decisions right away.

People with intellectual disabilities need a convention that secures legal capacity and recognizes supported decision-making as a legitimate form of decision-making.

## KEY TERMS

**Self-determination** is based on two defining ideas:

- Every person has a will and is capable of making choices; and
- Autonomy and interdependence are not mutually exclusive ideas. No one makes choices in a vacuum; self-determination respects a person's right to make choices concerning his or her own life with the support, affection and assistance of family and friends.

**Person or Personhood:** Those individuals accorded legal capacity to act and recognition to exercise the right of self-determination — and recognized to have:

- Decision-making capacity
- Reflective Capacity
- Personal identity

**Decision-making; capacity to act — give consent, contract**

- Understanding relevant information
- Appreciating consequences of a decision
- Acting voluntarily, autonomously
- Communicating decisions

**Legal Capacity:** The recognized capacity of persons to make binding legal arrangements, enter contracts, sue and be sued, marry, and make other decisions of a legal nature. (Some distinguish legal capacity from personhood, others see it as integral to the notion of persons before the law.)

## The *Voices* of Self-Advocates

People with intellectual disabilities explain what legal capacity means to them.

*“The term living independently needs to be explained. It does not mean that we have to live on our own. We can live with others who may or may not have a disability. Living independently is about being able to make our own decisions as to where and with whom we live. It is about not having your life controlled by others or a service such as an institution.*

*We all need the support of family and friends who understand us and we understand them. It is about helping each other and working together. We may choose to live with some of our family or friends but that must be our right to choose.*

– Robert Martin



*“Even with all the tools available, Charlie still can't express his choices independently. We don't always know what he wants, decisions aren't always perfect, but together we can support him to make decisions about where he wants to live or what he wants to do.”*

– Susan Swensen (mother)

## Promoting the Value of All People as Equals

*All people are people first and must be treated with  
dignity and respect and be accepted.*

*Each person must be recognised as the person they are.*

*All individuals must have the right to make their own decisions  
and to have these decisions respected.*

*From birth, every human has the same worth.*

*All people have the right to be valued as an equal  
in their own community.*

From, *"The Beliefs, Values and Principles of Self-Advocacy"* (ILSMH 1994)



**Inclusion International** is an assembly of the voices of persons with intellectual disabilities and their families that promotes shared values of respect, diversity, human rights, solidarity and inclusion. Inclusion International represents over 200 member federations in 115 countries throughout five regions Middle East and North Africa, Europe, Africa and the Indian Ocean, the Americas, and Asia Pacific. For over forty years Inclusion International has been committed to promoting the human rights of people with intellectual disabilities and their families.

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