

Priorities for People with Intellectual Disabilities in Implementing the United Nations Convention on the Rights of People with Disabilities: The Road Ahead



About the United Nations

The United Nations is an international organization in which 191 countries are members.

It has 2 main ways of making them agree:

- A Resolution or Declaration shows what the member countries think about a subject. Governments do not have to follow a Declaration.
- A Convention or a Treaty is a kind of international law. When a member country has agreed to a Convention, it has to follow it. The UN checks if member countries follow a Convention.



The United Nations supports human rights through its Conventions.

- It encourages countries to include the Conventions in their national laws.
- It helps countries in their efforts to support human rights and social justice.
- It monitors what countries achieve when they agree to support the Convention.



United Nations Meeting

Raising awareness

This booklet is intended to raise awareness about key issues affecting the lives of people with intellectual disabilities and their families.

It outlines how the *United Nations Convention on the Rights of Persons with Disabilities* can be used to address those issues.

The Convention is important because:

- People with intellectual disabilities and their families are among the most marginalized groups in society.
- Achieving their inclusion depends on the transformation of segregated communities to inclusive communities for all.
- The Convention recognises that the making of accommodations and providing services will not achieve the human rights of persons with disabilities.

The *Convention on the Rights of Persons with Disabilities* is not the end of our journey – it is the beginning.

Self Advocates at the United Nations



Barb Goode, first self advocate to speak at the United Nations.

Never before in the history of the UN have people affected by a Convention been so involved in writing it.

What does the Convention offer?

The Convention on the Rights of Persons with Disabilities (CRPD):

- Says the rights of persons with disabilities have not been respected or protected in the same way as for those without a disability.
- Does not give people with disability new rights but explains how their existing rights must be promoted and protected.
- Tells governments how they should promote and support the rights of their citizens with disabilities.
- Says that once a government signs the Convention they must respect these rights in their laws and the United Nations will monitor them to make sure they are doing what the Convention says.



“We have been working on this for about 5 years. We have joined with other people representing those of us with a disability to have our say. The governments have listened to what we have said”

– Robert Martin,
Council Member



Supporting people to have a voice

The main issues for people with intellectual disabilities and their families:

- Families have an important role to play in helping people with disabilities to achieve their rights. (Preamble)
- Equality and non-discrimination – before the law and under the law. (Articles 5, 12 and 13)
- Right to life – the inherent right to life of a human being. (Article 10)
- Equal recognition before the law – being able to make own decisions and have them respected. (Article 12)
- Freedom from exploitation, violence and abuse. (Article 16)
- Living independently and being included in the community – we say no to institutions. (Article 19)
- Education – the right to an inclusive education. (Article 24)
- Work and employment – freedom from discrimination and the right to seek paid employment. (Article 27)
- Adequate standard of living and social protection – we say no to poverty. (Article 28)

**Our voice: Every person has the right to have their voice respected
– then by working together we can achieve anything.**





The Role of Families

(Preamble)

The main issues of people with intellectual disabilities and their families:

- The Convention recognizes that families play an important role in the lives of children and adults who have a disability and that they need support.
- For children, families are the link to all aspects of the community, school, recreation, social networks, health etc.
- For adults who have an intellectual disability, families play the role of building supports in the community and enabling inclusion.

The challenge for this Convention is to protect the rights of people who cannot always speak for themselves

What Self-advocates say

Having this recognition in the Convention means that :

- *Even those who have difficulty being understood or speaking for themselves can have all the rights that are listed in the Convention protected.*
- *Children should grow up in families and all families should have the supports they need to raise their children at home.*
- *Families should be given the supports they need.*





Right to equal treatment before the law

Articles 5, 12 and 13

The Convention will ensure that:

- The legal rights of persons with intellectual disabilities will be protected in the same way as others.
- They will have the right to be a witness when crimes are committed against them.
- They will be person before the law and under the law in the same way as others.

Equal under the law: We are entitled to the same rights as others and the protection of our rights in the way as others.

What self advocates say

Many of us are not seen as full citizens in our own country.

- *Our birth has not always been registered and therefore we are not protected by our laws.*
- *When others commit crimes against us they often get away with it because we are not seen as having the ability to be a witness.*
- *This often leads to others believing that they can commit crimes against us and they will not be punished.*
- *This is why so many of us are abused and ill treated by others.*



There are no half rights – only equal rights for all.



Right to life

Article 10

- The Convention says the lives of people with intellectual disability must be valued in the same way as others.
- People with intellectual disabilities wanted the right to be born to be included in the Convention. This is not addressed because the Convention can only address the rights of a person once they have been born.
- People with intellectual disabilities are concerned that prenatal screening and genetic testing are being used to eliminate people with disabilities. This worries us because it sends a message that our lives are not worth living.

Right to Life: If we lose the right to be born, our right to live on an equal basis with others is meaningless.

What self advocates say

Our right to be born

- *Some scientists are trying to eliminate intellectual disability by preventing people with an intellectual disability from being born.*
- *This is already happening with people with Down Syndrome and soon it will be others.*
- *We don't want to be "prevented". We want to be included.*
- *We as people with intellectual disabilities will no longer exist.*
- *This devalues all of us who have an intellectual disability.*





Equal recognition before the law

Article 12

- This is about the legal capacity of people as citizen of their own country.
- This is about the right of people with intellectual disabilities to make their own decisions and to act on these.
- Many do not have the right to make decisions even when they are adults. Someone else is given this authority.
- Decisions are often made about their lives without the person even being in the room.
- They have been expected to agree to these decisions regardless as to what they really want.

**Equal Recognition: We must be part of the
decision making that affects our life.**

What self advocates say

On our legal capacity

Having legal capacity means we can make our own decisions and have these respected.

- *We can act on our decisions – we can do the things we decide to do.*
- *Other people will no longer have the power to make our decisions*
 - *to decide where we live and who we will live with*
 - *to sign contracts*
 - *to have control over our finances.*

On our right to support

Supported decision making is being introduced by the Convention. This means:

- *The support we need to make our own decisions will be provided.*
- *Support provided in a way that respects our wishes.*
- *Support will be available if we are at risk due to our disability.*
- *There will be rules as to how and when the support will be provided.*
- *There will be no more full and/or plenary guardianship.*



We may need support to make our decisions but we do not want others to decide for us.



Freedom from exploitation, violence and abuse

Article 16

The Convention will require governments to:

- Provide information and education that will help people with intellectual disability to avoid, recognise and report exploitation, violence and abuse.
- Monitor all the services provided for them to prevent exploitation, violence and abuse.
- Help them to recover when they have suffered exploitation, violence and abuse.
- Ensure that instances of exploitation, violence and abuse are investigated and, where appropriate, prosecuted.

Exploitation, violence and abuse: We are more likely to suffer exploitation, violence and abuse when we have a disability.

What self advocates say

Sadly exploitation, violence and abuse is very much part of many of the lives of people with an intellectual disability.

- ***We often face exploitation, violence and abuse when we live in an institution.***
- ***We often face exploitation, violence and abuse when we live in the community.***
- ***We may also face exploitation, violence and abuse when we live with our family.***





Living in the Community

Article 19

- The Convention secures the right to choose to live in the community.
- For years, people with disabilities have been saying that they want to live in the community.
- They will be able to choose where and with whom they wish to live.
- This will mean that all institutions will close but this may take some time.
- The discussion is no longer should institutions close but when they will close.

What self advocates say

Closing of institutions

- *Living in an institution is not a human way of life.*
- *We must stop any more of our friends being placed in the institutions.*
- *We must help those who are still in the institutions to leave.*
- *We need to start planning for the closing of the last institution.*
- *The Convention can help the thousands of people still living in institutions to leave and live in the community.*
- *We must make sure that people get the supports they need when they move.*
- *Those of us who have already left must help those who leave the institutions to adjust to life in the community.*





Right to education

Article 24

- The convention gives persons with intellectual disabilities the same right to education as all other children, teenagers and adults.
- The education system of each country must be inclusive.
- This means there is one system of education that meets the needs of all.
- People with disabilities must be able to participate in education alongside others – no more segregation!

**To have knowledge is everything. We must be included
– we all have an equal right to education.**

What self advocates say

Our lack of education

Our lack of formal education is the extra handicap we are all forced to carry.

- *Through out the world, as children with an intellectual disability, there are more of us out of school.*
- *Very few of us who live in less developed countries get the chance to go to school.*
- *The situation is even worse for those of us who are girls.*





Work and employment

Article 27

The convention requires governments to:

- Prohibit discrimination on the basis of disability.
- Give persons with intellectual disability access to vocational training.
- Promote their right to seek employment in both the government and private sectors.
- Promote opportunities for self employment.
- Provide the support that they need to participate in paid work.

Work and employment: We need equal opportunity to seek training and employment in our community.

What self advocates say

- *Most of us with an intellectual disability have been excluded from the paid workforce.*
- *Some of us have been placed in workshops where at best we get very little pay.*
- *This has reinforced the negative attitudes, as to our value, in the minds of others. This breaks our spirit.*
- *Our lack of opportunity to get paid work has locked many of us into poverty.*





Adequate standard of living

Article 28

The Convention recognises the right of persons with intellectual disabilities and their families to have:

- An adequate standard of living including adequate food, clothing and housing.
- Access to the affordable aids they need due to their disability.
- Access to social protection programmes and poverty reduction programmes when they are living in poverty.

‘People don’t see us because we are poor.’

– From the *Poverty Report in the Americas*

Understanding poverty: All too often poverty is a situation that we are forced to endure.

What self advocates say

Those of us with an intellectual disability and our families are most at risk when it comes to poverty.

- *Most of us live in developing countries where poverty is often a major problem.*
- *Poverty is not just about money – it is also about our lack of opportunity.*
- *It limits our opportunity to live like others and to meet our own needs.*



Who is covered by the Convention

The United Nations has adopted the Convention.

- The Convention only applies when our country signs and ratifies (says they will implement) the Convention.
- Many countries have ratified the Convention. Until a country ratifies, their citizens' rights are not protected by the Convention.
- We hope all countries will agree to implement the Convention as soon as possible. Implementation will change our lives.



What you can do

You can learn about the Convention and what it means for all of us with a disability.

- Talk to your friends about how, by working together, you can make a difference.
- Share your ideas with others – we all need to know what we want changed.



By working together we can make a difference.

Want to learn more?

Here are some ways you can learn more about the Convention.

- Get a copy of the Convention on the Rights of Persons with Disabilities by visiting **www.unenable.org** or ask your local disability support organisation if they can get a copy for you.
- Visit **www.Inclusion-International.org** to learn about the work of self advocates and others who helped write the Convention.
- Ask if your government has signed and ratified the Convention as it cannot come into force in your country until they do.



We, as people with disabilities, must take the convention to our communities, to our governments, and to the world.

About Inclusion International

Inclusion International supports:

- Families in their effort to obtain the help they need to assist their family member with a disability.
- Families to champion the rights of their family member with a disability.
- Persons with an intellectual disability in their fight for social justice and the recognition of their rights.
- Persons with an intellectual disability to have their own voice, to become self advocates.
- Persons with an intellectual disability to achieve their dream of full inclusion in family life and the life of the wider community.



Inclusion International
www.inclusion-international.org
The Rix Centre,
University of East London,
Docklands Campus,
4-6 University Way,
London E16 2RD,
United Kingdom
Tel: (+ 44) 208 223 7709
Fax: (+ 44) 208 223 7411
Email: info@inclusion-international.org

*Thanks to Robert Martin,
Desmond Corrigan, the Inclusion
International Self Advocacy Task
Force for the development and
consultation of this document.*

Photos on cover and pages 7 to 29
copyright © Carlos Reyes-Manzo

Carlos Reyes-Manzo
Andes Press Agency
26 Padbury Court
London E2 7EH
tel. 020 7613 5417
www.andespressagency.com