

Hear our Voices

Priority Issues for People with Intellectual Disabilities
and their Families in the Implementation of the
**United Nations Convention on the Rights
of Persons with Disabilities (CRPD)**

This brochure provides some background on key issues affecting the lives of people with intellectual disabilities and their families and how the Convention recognizes those issues. It also outlines how the Convention can be used as a tool for social and economic development. We hope that this will provide self-advocates and families with a tool for advocacy in promoting the rights protected in the Convention.

Inclusion
International





In 50 articles, the CRPD clearly articulates what existing human rights mean within a disability context and establishes reporting and monitoring procedures for States Parties. The Optional Protocol on Communications provides for a complaints mechanism wherein groups and individuals, after having exhausted all national resources, can have the Committee on the Rights of Persons with Disabilities consider a claim that a State Party has violated the provisions in the CRPD. The CRPD marks a paradigm shift by addressing the human rights of persons with disabilities from a progressive social model approach to disability. In many instances, this new approach requires a new way of understanding the exercise of key human rights.

An important instrument for inclusion

On December 13, 2006, the United Nations General Assembly formally adopted the Convention on the Rights of Persons with Disabilities (CRPD). The Convention is unique for three reasons

1. The way it was developed

- Never before in the history of the United Nations have people affected by a Convention been so intimately involved in drafting it.
- The disability community influenced not only the text itself, but also influenced the level of awareness among member states of the challenges faced by people with disabilities and their families.

2. The way it understands human rights

- Shifts the understanding of disability from a medical to a social model. Disability is not seen as a problem, but as a set of barriers. The CRPD is designed to be a tool to drive this shift.
- Shifts the understanding of human rights in isolation to seeing their realization within a context of development and cooperation. It links policy and investments in poverty reduction to a human rights framework.
- Explicitly includes articles that will require state parties to develop social policies and practices over time.
- Provides a blueprint for human rights driven development.

3. The way it will be supported

- This Convention will be the first core human rights Convention to have links to both the United Nations Office of the High Commissioner on Human Rights and the United Nations Department of Economic and Social Affairs.
- This Convention helps move the UN towards a new way of working by recognizing the need for cooperation and collaboration.



*“We have been working on this for about five 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 II

People with intellectual disabilities and their families identified a number of priorities during the negotiations on the Convention:

Inclusion International's Position	What's in the Convention
Education:	
<p>Inclusion International promotes the right to inclusive education as the basis for the full development of the person and as a means to enable the person to participate effectively in society and believes that all persons with disability should be able to choose inclusive education in their own community.</p>	<p>Article 24 recognizes: “the right of persons with disabilities to education. With a view to realizing this right without discrimination and on the basis of equal opportunity, States Parties shall ensure an inclusive, education system at all levels, and life-long learning(…)”</p>
Legal Capacity:	
<p>People with Intellectual disabilities (all people) should have the right to make decisions for themselves; the state must ensure that they have support to make those decisions</p>	<p>Article 12 recognizes:</p> <ul style="list-style-type: none"> • that persons with disabilities have the right to recognition everywhere as persons before the law; • that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life; • that States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.
Families:	
<p>Inclusion International believes that families play a critical role in the promotion of human rights and the inclusion of people with intellectual disabilities and that they require supports to fulfill this role.</p>	<p>The Preamble to the Convention recognizes the role of families: “Convinced that the family is the natural and fundamental group unit of society and is entitled to protection by society and the state, and that persons with disabilities and their family members should receive the necessary protection and assistance to enable families to contribute towards the full and equal enjoyment of the rights of persons with disabilities”</p>
The Right to live in the Community:	
<p>Inclusion International promotes the right of all people with intellectual disabilities to decide where and with whom they live and to receive the supports they require in the community. Specifically promoting:</p> <ul style="list-style-type: none"> • the right of persons with disabilities to live in the community; • that persons with disabilities are not be obliged to live in institutions; and • that persons with disabilities should have the opportunity to live in the location and type of living arrangement of their choice and that such choices must be supported by a range of support and community services. 	<p>Article 19 “the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community...”</p>
<h3>Other important articles in the Convention for people with intellectual disabilities and families</h3>	
<ul style="list-style-type: none"> • Right to an adequate standard of living (Article 28) • International Cooperation (Article 32) • Recognition of Children (Article 7) • Recognition of Women (Article 6) • Protection from exploitation, violence and abuse (Article 16) • Right to Employment (Article 27) 	

"As children and adults with intellectual disabilities we have the right to:

- Live with our families.
- Participate in all aspects of family life including sexual relationships, marriage, and parenthood.
- Grow up in an environment made up of happiness, love, and understanding."



The Role of Families – Preamble

Throughout the world it is families who are responsible for providing the bulk of supports to persons with disabilities, often with minimal or no financial compensation. Further, they provide an essential bridge to the realization of citizenship in the daily lives of children, youth and often adults, with disabilities.

Financial challenges, isolation and exclusion are too often the shared experience of families. The impact on the family unit is undeniable. Family members who provide significant levels of unpaid caring tend to experience higher rates of ill health, stress, and poverty than those who do not make such commitments. The impact of these stresses can be seen by the over-representation of children with disabilities in child welfare systems. Children who are part of strong supported families are more likely to realize their right to a healthy family life.

Families caring and supporting a family member with a disability require legal and policy recognition of the role they play in advancing the well being and citizenship of their family members. They want to continue to provide supports to a family member with disability-related needs but require some economic contribution and support for this purpose. Policies aimed at addressing issues facing families must ensure that the unique needs of families caring for a family member with a disability are taken in to account. Measures to ensure economic security and to foster supportive communities are essential to address the financial challenges and the social exclusion of families of persons with disabilities.

- It is estimated that 30 – 40% of households worldwide and that at least 25% of the world population is directly affected by the presence of disability.
- Family members provide the bulk of disability-related supports for everyday activities.
- Women are more likely to be involved than men in providing caregiving
- Households with children with disabilities are likely to have a lower household income than households with children without disabilities.
- Families require community supports and systems – childcare, health and social services, physical and social infrastructure in the cities and communities in which they live, access to transportation and a wider network of social relationships and social capital they can draw upon for support.
- Families provide an essential bridge to the realization of citizenship in the daily lives of children, youth and often adults with disabilities.
- Children with disabilities and their families require fuller supports that reflect the real needs of families and provide the necessary supports to raise children at home.

Guiding Principles for Policy Development

- Families are the cornerstone to inclusive community life and inclusive communities.
- Families come in all “shapes and sizes”.
- Children should grow up in families and all families are entitled to the necessary supports to raise their children at home.
- It is normal for all families to need different forms of support at different times.
- Supporting/strengthening families contributes to community well-being.
- Families provide the greatest degree of continuity in the lives of their sons and daughters with intellectual disabilities and that connection should be honoured and supported.
- For families, inclusion is naturally rooted in their love for their sons and daughters.
- Policies should be designed to strengthen all families, respect and honour all families and facilitate inclusion in all aspects of family and community life.

Recognition of Family in International documents

While there is no UN Convention specific to families, all states parties have recognized the important role of families in various conventions. These include:

- **International Covenant on Civil and Political Rights (1966)**

Art.26 “The family is the natural and fundamental group unit of society and is entitled to protection by society and the state.”

- **Convention on the Rights of the Child (1989)**

Convinced that the family, as the fundamental group of society and the natural environment for the growth and well-being of all its members and particularly children, should be afforded the necessary protection and assistance so that it can fully assume its responsibilities within the community,

Recognizing that the child, for the full and harmonious development of his or her personality, should grow up in a family environment, in an atmosphere of happiness, love and understanding.

- **Vienna Declaration, adopted by the World Conference on Human Rights (1993)**

The World Conference on Human Rights also stresses that the child for the full and harmonious development of his or her personality should grow up in a family environment which accordingly merits broader protection.

- **The Standard Rules for the Equalization of Opportunity for Persons with Disabilities (1993)**

Rule 9. Family life and personal integrity: States should promote the full participation of persons with disabilities in family life. They should promote their right to personal integrity and ensure that laws do not discriminate against persons with disabilities with respect to sexual relationships, marriage and parenthood.

- **Copenhagen Declaration, World Summit for Social Development (1995)**

(h) Recognize the family as the basic unit of society, and acknowledge that it plays a key role in social development and as such should be strengthened, with attention to the rights, capabilities and responsibilities of its members. In different cultural, political and social systems various forms of family exist. It is entitled to receive comprehensive protection and support.

- **World Fit for Children (2002)**

III A.15:

The family is the basic unit of society and as such should be strengthened. It is entitled to receive comprehensive protection and support. The primary responsibility for the protection, upbringing and development of children rests with the family. All institutions of society should respect children’s rights and secure their well-being and render appropriate assistance to parents, families, legal guardians and other caregivers so that children can grow and develop in a safe and stable environment and in an atmosphere of happiness, love and understanding, bearing in mind that in different cultural, social and political systems, various forms of the family exist.

"As a person with an intellectual disability I have the right to:

- Equal access to all kinds of learning and education.
- Participate in education alongside other people that may not have disabilities – no more separation!"



Education is recognized as a universal human right. Access to education largely determines long-term prospects for children and youth. It is essential to their growth and to the social, cultural, economic and political development of the countries in which they live. Countries with more highly education populations are more prosperous and democratic. Education can make the difference between a life of poverty and a life of prosperity. Education determines the conditions of people's lives. The extreme and immediate impact of education systems has contributed to keeping education in the international spotlight. International efforts and initiatives have resulted in improvement.

For children with intellectual disabilities lasting patterns of inclusion begin at school. Social inclusion in schools is foundational for social inclusion in society. Inclusive education plays a role in providing shared public spaces for children with disabilities to grow and develop alongside their non-disabled peers. It is essential in realizing the educational rights of all children and in fostering values of diversity, dignity, citizenship and inclusion. Research supports that inclusive education is better for all children.

We know that:

- The number of children in school rose significantly in the past decade, from 599 million in 1990 to 681 million in 1998.
- Since 1990, some 10 million more children go to school every year, which is nearly double the 1980-90 average.
- The number of out-of-school children decreased from 127 million in 1990 to 115 million in 1998.

However, for children with disabilities, the numbers show that this improvement is uneven. Exclusion continues to be the norm.

We know that:

- There are 120-150 million children with disabilities in the world;
- 80% live in developing countries;
- Only 5% in developing countries have access to support services of any kind;
- Less than 2% attend school;
- An estimated one-third of the 115 million children not in school have a disability (The World Bank);
- Disability may be the single most important factor in the exclusion of a child from schooling;
- For the majority of these children it is a lack of schooling and the structural barriers in society that cause dependency.



Legal Capacity – Article 12

For people with intellectual disabilities self-determination and full citizenship are fundamental principles that underlie the potential enjoyment of human rights. It is the presumption of legal capacity that makes it possible to exercise self-determination and full-citizenship.

Guardianship laws assume that some people do not have the capacity to make legally binding decisions.

Supported Decision-Making means a person may accept help in making decisions without relinquishing the right to make decisions. Supported Decision-Making helps a person to understand information and make decisions based on his or her own preferences. A person with a learning disability might need help with reading, or may need support in focusing attention to make a decision. A person who has no verbal communication might have a trusted family member who interprets their non-verbal communications, such as positive or negative physical reactions, or uses Alternative and Augmentative Communication.

Inclusion international promotes the exercise of legal capacity by advocating:

- Development of models of supported decision making; and
- Development of safeguards that ensure that the persons with a disability are protected. These safeguards should be consistent with Article 6 of the Montréal Declaration, October 2004 developed by the Pan-American Health Organization and the World Health Organization.

Living in the Community – Article 19

The experience of institutionalization over the past several centuries has in many countries resulted in exclusion from economic, social and political participation. Frequently, the need for support or assistance is used to argue that placement in an institution is necessary, or that the person is ineligible to live in the community in the living arrangement of their choice. We know from the experiences of people with intellectual disabilities that it is not the level of disability or ability that determines whether a person can live in the community but rather the key determinant is the supports to which they have access.

Inclusion International promotes the right of people with intellectual disabilities to live in the community by advocating for:

- appropriate supports in the community including in-home, residential and other community support services;
- supports to families;
- access to regular mainstream services and support in the community.

“As a person with an intellectual disability I have the right to:

- *Make my own decisions.*
- *Act on my own decisions.*
- *Have the support I need to make my own decisions.*
- *Be protected in the same ways as others.*
- *Be a witness when crimes are committed against me.*
- *Be person before the law and under the law in the same way as others.”*

“As a person with an intellectual disability I have the right to:

- *Choose where I will live.*
- *Choose who I will live with.*
- *Have the support I need provided where I live.*
- *Have support provided in the way that best meets my individual needs.*

The Convention also affirms my right to choose to live in the community. As a result, institutions that once separated me from the community will need to close.”

Next Steps in Implementing the UN Convention

As countries ratify the Convention and process are put in place for implementation, family organizations and self-advocacy groups should be ensuring that governments comply with the Convention by establish mechanisms for:

Dialogue – dialogue with family organizations, self-advocates and the disability community is necessary in order to develop a shared understanding of the Convention

Consultation Mechanism and Focal Point

– Governments are required to establish a focal point in Government and a consultation mechanism to implement the Convention. Such a mechanism should include cross-departmental representation and community participation.

Plan for Implementation – To effectively implement the Convention governments should commit to appropriately resourced action plans.

For more Information on the United Nations Convention on the Rights of Persons with Disabilities visit the UN Enable Website: www.un.org/disabilities/



Inclusion International is a global federation of family-based organizations advocating for the human rights of people with intellectual disabilities worldwide. For over forty years Inclusion International has been committed to the promotion of these human rights and our organization now represents over 200 member federations in 115 countries throughout five regions including the Middle East and North Africa, Europe, Africa and the Indian Ocean, the Americas, and Asia Pacific.

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.

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