

## **Inclusion International's Position on the**

### ***Draft Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities***

**April 2004**

The member societies and leaders of Inclusion International have identified several priority issues for a new Convention and we want to ensure that these issues are understood and highlighted by the Ad Hoc Working Group.

#### **Inclusion**

*'Inclusion refers to the opportunity for persons with disabilities to participate fully in all of the educational, employment, consumer, recreational, community and domestic activities that typify everyday society' (Inclusion International)*

We note with satisfaction that the concept of inclusion was regarded as an essential part of the underlying principles of the Convention. The wording used is "Full inclusion of persons with disabilities as equal citizens and participants in all aspects of life".

Inclusion requires a paradigm shift in society's current view of people with a disability as people who require special conditions to people who must be enabled to fully participate in society with their disability being accepted as part of their unique humanity. In other words a person with a disability has the right to fully participate in the life of their community and to be treated with dignity and respect regardless of any disability they may or may not have.

#### **Self Determination**

The principle of self-determination is critically important to people with intellectual disabilities. The failure to recognize the fundamental right to make decisions (if necessary with support) has resulted in institutionalization, forced sterilization and countless human rights infractions for people with intellectual disabilities all over the world. The term individual autonomy, including the right to make ones own choices, was agreed upon to replace the principle of self-determination. Inclusion International wants to ensure that the underlying concept be understood by state parties and this principle is paramount in consideration of all articles in the proposed convention.

#### **Institutionalisation**

On the issue of institutionalization, Inclusion International is unequivocal. This Convention must express the right for persons with a disability to live in the community where and with whom they choose. We must be sure that a new Convention does not

put people with disabilities at risk of institutionalization and that State parties do not interpret the Convention to justify the need for institutions.

## **Right to be Different**

Inclusion International's position is that the acceptance of difference is a key factor in the acceptance of all people's right to live in the community. Disability must be seen as part of the natural human condition and of ones humanity. Non-disabled people still need to recognise the importance of this issue for those of us with a disability as acceptance of our disability leads to acceptance of who we are as a person.

## **Guardianship**

This was a topic of utmost importance to Inclusion International. It is the view of our community that traditional guardianship laws are used to control people's lives and to deny people the right to make decisions on their own behalf. This runs counter to the principle of self-determination. What is needed is legal recognition of the legitimacy of supported decision making. That is, a recognition that all people require supports in order to make choices and decisions.

There are many jurisdictions that have adopted more progressive ways to support people with disabilities to make decisions and receive legal support and recognition of those decisions. Inclusion International's position is that if people have access to legal assistance when this support is required then the old guardianship laws will not be needed. This is a crosscutting issue for consideration in all aspects of the proposed Convention as guardianship legislation has often been used to limit a persons right to make decisions about their own health, whether they can marry, where they choose to live and even whether they choose to live or die. It is of particular importance however in Article 7 (Equal Recognition before the Law). Again, a new Convention must provide a basis for progressive state policies and not act as an incentive for states to recreate legal and legislative mechanisms that retract the rights and progress already made.

## **Inclusive Education**

Inclusion International will only support a Convention that uses the Salamanca Statement as a basis for the right to education for children with disabilities.

The fundamental principle of the inclusive school is that all children should learn together, where ever possible, regardless of any difficulties or differences they may have. Inclusive schools must recognize and respond to the diverse needs of their students, accommodating styles and rates of learning and ensuring quality education to all through appropriate curricula, organizational arrangements, teaching strategies, resource use and partnerships with communities. There should be a continuum of support and services to match the continuum of special needs encountered in every school. (Salamanca Framework for Action, Article 7)

As with many groups in society, some groups of people with disabilities share a common culture and issues. While education systems have a responsibility to provide education to all learners, school systems must also provide special education which recognises the development of social and functional skills as equally important to the development as of academic skills.

*Deaf, Blind and Deafblind learners often require special education because of their specific communication needs, such as sign language, tactile sign language and Braille. Like all children, Deaf, Blind and Deafblind children must have access to equal and quality education. They can and should reach their full potential with appropriate, visual or tactile, quality educational programmes and support. (Salamanca Framework)*

The current article on education does not adequately establish that States will take as part of their responsibility for educating all children the inclusion of children with disabilities and it does not make clear that children with disabilities and others who have been marginalized are best educated in the regular school system with appropriate supports.

## **Personal Security**

Due to their disability many people with a disability are subjected to cruel and inhuman treatment. This not only a problem for those with a disability who live in institutions. The risk of those who are vulnerable to physical, sexual, psychological, emotional and all the other forms of abuse must be recognised and acted on.

## **Poverty**

The United Nations estimates that 600 million people worldwide have a disability of which 30% are believed to reside in an industrialized country and 70% are believed to live in a developing country. However even in the wealthy countries people with a disability usually belong to the poorest socio-economic group as they are usually the last to get paid work and they often have high costs associated with their disability.

A convention must support the development of strategies to ensure that state policies and international cooperation for poverty reduction take into account people who have a disability. This means examining not only economic and labour market issues but also social policy issues such as child care for women who have children with disabilities, nutrition, access to education etc.

## **Right to Life-Valuing the life of all people and their right to be different.**

Inclusion International holds an unequivocal position on the valuing of the life of all people and their right to be different. First, issues regarding developments in bio-ethics must be considered. This includes development in gene technology that may enable

the genetic makeup of a person to be changed so that less favoured characteristics are eliminated and more favoured characteristics promoted.

Given the current general perception of the value of a person with an intellectual disability (they are amongst the most marginalised people in society) the implication for them is obvious. If society accepts that the characteristics of a child not yet born should be changed, then what does that say about the value of the life of all people with an intellectual disability? It also is a denial of the concept of the natural diversity of life and the value that a civil society places on this concept.

The lives of future people with a disability are also at risk from developments in prenatal tests that test for the presence of a disability. Most people with a disability are born in developing countries and the result of a positive test is perhaps obvious. In the more affluent countries parents do come under pressure to terminate the pregnancy after a positive test. This decision is reinforced by the assumption that such a person being born will lead to greater social, health and care needs. While this may be true it denies the richness through diversity that a person with a disability can bring to the life of their family and community.

This is not an argument about a woman's right to choice. It is about the value society puts on diversity and the value of the lives of those labelled disabled.

Is society going to distinguish between lives worth living and those not worth living? If the answer is yes then we believe it will not be people with a disability who make this decision.

Therefore we believe all people, regardless of any disability they may or may not have, must have the same right to life and disability must not become a justification for the termination of life.

## **Reasonable Accommodation**

This concept has been used in USA and Canada mainly in anti-discrimination employment law. It requires the employer to take reasonable steps to accommodate the needs of the individual, in particular those necessary due to a disability. This obligation can be tested in law to determine what is reasonable. Examples include making employment information more accessible and changing work practices to accommodate a person's disability. However the employer does not have to make changes that will be detrimental to work output. The employer must discuss with the employee the options available and to get their input but the employer retains the right to decide which option will be offered to achieve reasonable accommodation. From the experience of states with reasonable accommodation clauses and legislation, we know that many states are reluctant to place the full responsibility of accommodation on the employer and 'reasonable accommodation' has been used to significantly limit the accommodation provided in the workplace. There are some jurisdictions where the state has shared through employment support the responsibility for accommodation in the

workplace. Considering these experiences we encourage the Ad Hoc Committee to consider ***that a more detailed paragraph on reasonable accommodation should be elaborated under the right to work, in addition to any draft article on reasonable accommodation elsewhere in the Convention.***

### **Main Issues of Concern for Inclusion International**

In addition to the principles outlined above and their implications for a new Convention, Inclusion International is concerned with four specific issues in the draft text:

- 1) A new Convention must not put people with disabilities at risk of being institutionalized. Any reference to the need for institutions would be regressive and any interpretation of the responsibility of the state to provide support as justification for institutionalization must be eliminated.
- 2) Article 16 is much too closely based on out of date models for supports and contains totally unacceptable references to 'subject to existing resources'. Such a qualification would never be considered in relation to girls or members of minorities. This article as it is currently drafted would be regressive for many people who have a disability and in many jurisdictions.
- 2) Article 17 on education does not provide a strong basis for inclusive education with recognition of the needs of individual groups. The Salamanca Statement must be the baseline for a new Convention.
- 3) Monitoring – The issue of monitoring is critical to the usefulness of a new Convention. Many human rights commitments exist for people with disabilities but the lack of mechanism for monitoring their implementation has resulted in poor progress towards their realization. The fact that the working group could not agree on monitoring is symptomatic of the problem of implementation.

### **Conclusion**

Given the very different legal, cultural, political and economic context of our member societies, the challenge is to create a tool which can be used anywhere in the world to promote inclusion. To be effective in advancing Inclusion International's vision, a UN Convention must recognize that inclusion is the means to achieving human rights. A new Convention has the potential to increase awareness of governments, international agencies and the UN system of their responsibility to include people with disabilities in all of their programmes, policies and financing.

We urge the ad hoc committee to consider the proposed Convention as a tool for future generations, one that will stand the test of time and point the way toward progress, not one that will inadvertently institutionalize the status quo.



