



Children with Intellectual Disabilities and their Families

Position Paper

A Position Paper of Inclusion Europe

- Adopted at the General Assembly 2008 -

Children with intellectual disabilities have the same needs and wishes as any other children: they want to interact with their peers, play and laugh, learn and develop into a respected adult member of society. As with other children, this development process can be challenging for the child and its family, but is an intrinsic part of growing up.

Even more than for other children, the development phase of a child with intellectual disability determines its abilities and capacities later in life. Support, teaching and therapies can reduce the impact of a disability and contacts with other children in all areas of life create necessary friendships and abilities for a life fully included in society.

However, children with disabilities in all European countries are more likely than other children to be denied equal opportunities for their development. They are more often abandoned by their families and put in institutional care. They are more often victims of violence, harassment, bullying or sexual abuse than other children. They are denied education on an equal level to others, and have less access to healthy living conditions and health care. They are also often excluded from leisure, cultural or sports activities, which are crucial for their personal development and for finding their place in the society. Due to their need for additional support, poverty of their families has a very negative effect on the development chances of children with intellectual disabilities.

Article 7 of the UN Convention on the Rights of Persons with Disabilities addresses these situations by placing a clear obligation on governments:

States Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children.

It also stipulates that in all actions the best interests of the child shall be a primary consideration and that the views of the child shall be given due weight in accordance with their age and maturity. These core principles, also enshrined and monitored by the Convention on the Rights of the Child, constitute an important heritage for the fulfillment of the rights of children with intellectual disabilities and their full participation in society.

For children with intellectual disabilities, the following rights are of paramount importance as a precondition to make the most of their lives on an equal basis with other children:

- Respect for the home and the family
- Access to health care, rehabilitation and habilitation
- Access to inclusive mainstream education with the necessary support

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- Protection from violence, harassment, bullying or sexual abuse
- Participation in political and public life
- Full participation in the cultural life, leisure, recreation and sports
- Living included in the community

Inclusion Europe and its members demand from all States Parties that have ratified the UN Convention clear and decisive action in the following priority areas:

Respect for the home and the family

The Preamble of the UN Convention on the Rights of Persons with Disabilities states that “the family is the natural and fundamental group unit of society” and therefore the Convention recognizes the family as a primary place for a child and underlines the importance of growing up in a family setting. Families include not only the traditional family model, but all existing forms of family life.

The birth of a child with an intellectual disability changes the plans that families have for their lives and places additional demands on all family members. To maintain the capacity of families to meet these additional demands, governments should develop and implement comprehensive policies for supporting all families with disabled children. The policies should not only ensure respite for the parents when this is required, but also consider the support necessary to brothers and sisters, ways of enhancing employment opportunities for the primary caretaker (most often the mother), and the financial situation of the family as a whole. The Convention clearly stipulates that where the immediate family is unable to care for a child with disabilities, governments should undertake **every effort** to provide alternative care in the wider family and failing that, within the community in a family setting. The family continues also to be an important resource of help and support for adult persons with intellectual disabilities.

Children with intellectual disabilities should be effectively protected against discrimination in all areas of life, as stated in the Convention. Families of children with disabilities should also be protected from discrimination by association.

States Parties should include in their legislation specific provisions for the prohibition of discrimination by association.

Access to health care, rehabilitation and habilitation¹

Children with intellectual disabilities benefit much from early intervention services that start at birth and aim at minimizing the impact of an intellectual impairment. Governments should ensure access to free and comprehensive early identification and early intervention services for all children at risk of intellectual disability. These services should be available, accessible and affordable for all families in the whole territory of a country and should be delivered in an inclusive way without requiring the child to be placed in an institution.

Equal access to mainstream health care and dental care is a prerequisite for a good development of a child. Governments should ensure that medical professionals are able and willing to care for children with disabilities without discrimination. Medical professionals should inform all children by appropriate means about planned medical interventions.

Some disabled children need specialized rehabilitation services. Governments should ensure that this need for special services never leads to the exclusion of children from their families and from their social environment. Especially, it should be recognized as discrimination if the need for specific rehabilitation services leads to the placement of children in residential institutions.

Access to inclusive education²

It is important for children with intellectual disabilities to have equal access to all types of mainstream pre-school and school education as well as to vocational training and informal learning opportunities. Governments should ensure that all existing mainstream pre-school services and schools cater for all children of appropriate age from their catchment area, including those with different levels of intellectual disabilities. Governments should provide a range of support that meets the needs of all students to the greatest possible extent.

¹ “**Habilitation**” refers to a process aimed at helping people gain certain new skills, abilities, and knowledge. “**Rehabilitation**” refers to re-gaining skills, abilities or knowledge that may have been lost or compromised as a result of acquiring a disability, or due to a change in one’s disability or circumstances. The goals of habilitation and rehabilitation as defined in the Convention on the Rights of Persons with Disabilities (CRPD) are to “enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life.”

² See also Inclusion Europe’s Position Paper on “Education for all: Diversity as an opportunity for school education”

Protection from violence, harassment, bullying or sexual abuse

Children with intellectual disabilities are vulnerable to abuse and harassment from other children, family members, professional carers, teachers and other people. Governments should ensure that adequate and effective reporting and control mechanisms exist, that all children know about them and that children can report easily any incidents. Governments should provide professional support to victims.

A specific issue is the protection of the personal integrity of a child with disabilities from medical interventions that have no positive effect on the health status of a child. Governments should ensure that children with disabilities retain their fertility on an equal basis with others and that children are not subjected to inhuman medical interventions that serve the interests of carers rather than of the child.

Participation in Political and Public Life

Children with intellectual disabilities are equal citizens of their country and will have all associated public rights once they come of age. Furthermore, the UN Convention stipulates that the views of children shall be taken into account in all decisions that affect their lives. Therefore, Governments

should promote and support the movement of self-advocacy of people with intellectual disabilities and provide relevant information to their citizens in a format accessible to children with intellectual disabilities.

Full participation in cultural life, leisure, recreation and sports

Cultural and leisure time activities have an enormous potential for inclusive activities with non-disabled children and adults. Governments should ensure that all those activities are accessible and affordable for children with intellectual disabilities.

Living included in the community

In many European countries, children with intellectual disabilities are still forced to live in residential institutions instead of in family-type settings. Governments should ensure that families with disabled children receive all necessary support and that disabled children who are not cared for by their original families have priority access to foster family care. To prevent concealment, abandonment, neglect and segregation of children with disabilities, governments should undertake to provide early and comprehensive information, services and support to children with disabilities and their families.