



People with Severe Disabilities and/or Complex Needs and the UN Convention

Position Paper

Position Paper of Inclusion Europe

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The United Nations Convention on the Rights of People with Disabilities mentions people with severe disabilities and/or complex needs only once. It recognizes “the need to promote and protect the human rights of all persons with disabilities, including those who require more intensive support” in recital j) of the Preamble. Considering the high risk of discrimination and social exclusion of this group and their strong need for positive action, this is very limited. However, from this recital it can be concluded that all rights enshrined in the Convention apply equally also to people with severe disabilities and/or complex needs who require more intensive support.

A recent study¹ implemented by Inclusion Europe demonstrates that people with severe disabilities and/or complex needs are one of the most excluded groups of citizens. Due to the lack of adequate inclusive service systems, they often spend their lives with little support at home with their families or being confined to residential services. As underlying reasons for the widespread discrimination of this group of European citizens, the comparative research identified the values as well as the general market dynamics of modern European societies.

Furthermore, the research showed that another risk stems from the perception of a person with severe disabilities or complex needs as being incapable of taking on socially accepted mainstream roles in life. This perception goes hand in hand with prejudices and negative attitudes against this group of people and their families, who thus often experience discrimination by association. The Study clarifies that the basis for action against discrimination of people with severe disabilities must be their full inclusion as citizens with full human rights and equal opportunities in all European and national policies.

This Position Paper thus sets out to examine specific actions to be taken to ensure that people with severe disabilities and/or complex needs can fully enjoy the most important articles enshrined in the Convention. As for many other groups of people with disabilities these are:

- Accessibility (Article 9)
- Right to Life (Article 10)
- Equal Recognition before the law (Article 12)
- Protection from exploitation, violence and abuse (Article 16)
- Protecting the integrity of the person (Article 17)
- Living independently and being included in the community (Article 19)
- Education (Article 24)
- Health (Article 25), rehabilitation and habilitation (Article 26)
- Participation in cultural life, leisure, recreation and sports (Article 30)

Inclusion Europe

Galleries de la Toison d'Or
29 Chaussée d'Ixelles #393/32
B-1050 Bruxelles
Tel.: +32-2-502.28.15
Fax.: +32-2-502.80.10
secretariat@inclusion-europe.org
www.inclusion-europe.org



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¹ In 2007, the European Union commissioned a Study to identify the specific risks of discrimination faced by people with severe disabilities and/or complex needs. Extensive research and analysis was carried out in Germany, France, the United Kingdom, Italy, Spain, Poland, Lithuania, the Czech Republic, the Netherlands, Belgium, Sweden and Romania. The comparative analysis of the twelve National Reports demonstrates that people with severe disabilities and/or complex needs and their families are at a high risk of being discriminated against in all Member States and in all aspects of their lives.

Accessibility (Article 9)

People with severe disabilities and/or complex needs often have problems articulating their wishes due to communication problems. The UN Convention defines communication as including “languages, [...] tactile communication, [...] audio, [...] human-reader and augmentative and alternative modes, means and formats of communication”. Article 9 of the Convention obliges State Parties to take appropriate measures to ensure that persons with disabilities have access to information and communications.

Inclusion Europe and its members call upon all States Parties to develop training for contact people on communication methods and specific advocacy provisions so that the voices of people with severe disabilities and/or complex needs can be heard.

Right to Life (Article 10)

For people with severe disabilities and complex needs, the “inherent right to life” of every human being enshrined in the Convention has a special significance. Not only discussions about euthanasia threaten this group of citizens, but also everyday neglect and lack of support can have life-threatening consequences. It is therefore of the utmost importance that States Parties take all necessary measures to ensure the effective enjoyment of the right to life by all persons with disabilities, also by those with severe disabilities or complex needs.

Equal recognition before the law (Article 12)

People with severe disabilities and/or complex needs are most often subject to guardianship arrangements which deny them their full legal capacity. They also need specific protection and safeguards. Therefore it is for them of specific importance that the demands formulated in Inclusion Europe’s Position Paper on “Key elements of a system for supported decision-making” are fully implemented and equally accessible for this group of people.

Protection from exploitation, violence and abuse (Article 16)

People with severe disabilities and/or complex needs are especially vulnerable to many forms of exploitation, violence and abuse. Because they often cannot defend themselves, specific attention is required by family members, supporters and service staff to ensure effective protection. States Parties should thus especially ensure the provision of information and education on how to avoid, recognize and report instances of exploitation, violence and abuse to all people involved.

Protecting the integrity of the person (Article 17)

This article has core relevance for people with severe disabilities and/or complex needs. It stipulates that “every person with disabilities has a right to respect for his or her physical and mental integrity”. This article thus rules out medical experiments as well as interventions which are not of direct benefit for the person. Inclusion Europe and its members therefore call upon all States Parties to ensure that the personal integrity of all persons, and especially of persons with severe disabilities and/or complex needs is protected..

Living independently and being included in the community (Article 19)

Because of the sometimes specific needs of people with severe disabilities and/or complex needs, their choices for living are often limited and may lead to placements far away from their families. The UN Convention, however, stipulates the “equal right of all persons with disabilities to live in the community, with choices equal to others”. It obliges States Parties to “take effective and appropriate measures to facilitate full enjoyment [...] of this right and their full inclusion and participation in the community”.

Inclusion Europe and its members therefore call upon States Parties to ensure that the opportunity to choose the place of residence and where and with whom a person lives is not limited by the specific service needs of persons with severe disabilities and/or complex needs. Governments must provide also for this group of disabled citizens the necessary community support services and personal assistance to support living and inclusion in the community, and to prevent isolation or segregation from the community.

Education (Article 24)

Article 24 of the UN Convention on the primacy of inclusive education should be implemented without discrimination for all people with disabilities in all EU Member States. States must ensure that children with severe disabilities and/or complex needs have equal access to this option.

Member States should aim to develop a comprehensive education system that is able to provide inclusive education for all children within their community. All children with severe disabilities and/or complex needs should have the right and possibility to attend inclusive mainstream education and schools. It is absolutely necessary that Member States provide adequate support for these children, including training for staff of mainstream schools, individualized curricula, barrier-free environments and professional support. Schools need enough resources to educate all children with different needs in heterogeneous classes. Special schools should be the exception in duly justified cases and home schooling must be reduced.

Health (Article 25)

Equal and non-discriminatory access to health care is crucial for persons with severe disabilities and/or complex needs. The UN Convention obliges States Parties to provide “health services needed by persons with disabilities specifically because of their disabilities [...] and services designed to minimize and prevent further disabilities”. The Convention especially stipulates that States must “provide these health services as close as possible to people’s own communities, including in rural areas”.

For people with severe disabilities and/or complex needs, the specific health services needed because of their disabilities might be unique and in some cases costly. Inclusion Europe and its members request all European governments to ensure that these services are available to all persons with severe disabilities and/or complex needs within reasonable proximity to their own communities. We also demand that no such person is denied necessary health care or health services because of the severe or complex degree of their disability.

Discrimination in access to health and/or life insurances is also a common experience for people with severe disabilities and/or complex needs. Inclusion Europe and its members therefore demand that all States Parties provide special regulations for the insurance sector which do not allow exclusion from these basic insurances on the basis of any degree of disability.

Rehabilitation and habilitation (Article 26)

For people with severe disabilities and/or complex needs, it is crucial to “attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life”.

Inclusion Europe and its members therefore call upon all States Parties to ensure equal access for people with severe disabilities and/or complex needs to the comprehensive habilitation and rehabilitation services and programmes provided for by the Convention, particularly in the areas of health, employment, education and social services.

Full participation in cultural life, leisure, recreation and sports (Article 30)

Because of the often multi-dimensional needs of persons with severe disabilities and/or complex needs, full access to mainstream cultural, leisure, recreational and sports activities is sometimes difficult to organize. Therefore, specific attention is needed in the implementation of Article 30 to ensure the accessibility of places for cultural performances or services, such as theatres, museums, cinemas, libraries and tourism services, as well as places for sporting events, leisure and recreation for people with severe disabilities and/or complex needs. Physical accessibility and the availability of necessary support are the key elements for their inclusion in these areas.

A specific aspect is also the support for people with severe disabilities and/or complex needs to “develop and utilize their creative, artistic and intellectual potential, not only for their own benefit, but also for the enrichment of society”. States Parties must ensure that the necessary possibilities and supports are available.