The UN Convention on the Rights of persons with disabilities: a milestone

Instead of holding a traditional view identifying persons with disabilities as passive recipients of welfare and medical assistance, the UN Convention on the Rights of Persons with Disabilities (CRPD) describes disability as an evolving concept of a ‘social’ nature and identifies persons with disabilities as holders. The document is a milestone for the promotion of human rights and equal treatment in Europe and worldwide.

The Convention is also innovatory in that several articles deal, directly or indirectly, with issues pertaining to the rights and wellbeing of family members of persons with disabilities. This explicit reference stems from the view that persons with disabilities do not live in a social vacuum. Just as every other human being, they have family bounds and more than every one else, they can require assistance as a consequence of physical, mental, intellectual or sensory impairments. Family members of persons with disabilities are therefore very likely to undertake a caring role, be it because they willingly want to do so or because of the lack of public support available to them.

In addition, families remain the first and most immediate environment where children with disabilities can develop their potential and enjoy a fulfilling life.

A comprehensive realisation of the rights of persons with disabilities is unavoidably linked with the quality of life of their families. The circumstances affecting parents, children and siblings can have a strong impact on the wellbeing of persons with support needs living with them.

To address these challenges, various obligations arising from the CRPD – implicitly or explicitly – call on public authorities to engage into a wide range of measures to put families in the conditions of contributing to the full and equal realisation of the rights of persons with disabilities.

The family dimension of the Convention

COFACE-Disability believes that the following articles making explicit reference to the role of families are very important and recall the obligation of all the countries that ratified the text to comply with their commitment:

- Preamble (“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”);
- **Article 8** (awareness-raising, “throughout society, including at the family level, regarding persons with disabilities”)
- **Article 16** (“prevent all forms of exploitation, violence and abuse by ensuring, inter-alia, appropriate forms of gender- and age-sensitive assistance and support for persons with disabilities and their families and caregivers”);
- **Article 22** (respect for privacy, including protection against unlawful interferences with privacy, family, home or correspondence);
- **Article 23** (respect for home and the family, intended as the right of children to family life, but also as the right of adults with disabilities to found a family);
- **Article 28** (adequate standard of living and social protection, in particular “access by persons with disabilities and their families living in situations of poverty to assistance from the State with disability-related expenses, including adequate training, counselling, financial assistance and respite care”).

For the other articles that do not explicitly mention families as beneficiaries of State policies, COFACE-Disability would require the mainstreaming of the family dimension across all concrete measures adopted for the implementation of the UN CRPD:

- **Article 5** (equality and non-discrimination: State Parties “shall prohibit all discrimination on the basis of disability”);
- **Article 6** (women with disabilities, since “women and girls with disabilities are subject to multiple discrimination”);
- **Article 7** (rights of children with disabilities, given the fundamental role of families for the development and well-being of the child);
- **Article 9** (accessibility, to avoid the risk of isolation and withdrawal of the family as a whole);
- **Article 12** (equal recognition before the law, with “appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity”);
- **Article 18** (freedom of movement and nationality - which should concern measures directed not only at persons with disabilities, but also their families; right of children with disabilities to know and - as far as possible- be cared for by their parents);
- **Article 19** (living independently and inclusion in the community, since persons with disabilities shall have “the opportunity to choose their place of residence and where and with whom they live on an equal basis with others”);
- **Article 24** (education, through the provision of inclusive education policies including a number of measures directed at parents);
- **Article 25** (health – need to integrate family carers in the debate on healthcare workers);
- **Article 30** (participation in cultural life, recreation, leisure and sport, which will benefit not only the person with disabilities, but also his/her family);
- **Article 33** (national implementation and monitoring, since “civil society, in particular persons with disabilities and their representative organisations, shall be involved and participate fully in the monitoring process”).

**At Member States level**

All Member States of the European Union signed the Convention, and some of them signed also the Optional Protocol. However, several Member States have not yet ratified the CRPD.

COFACE-Disability urges all EU countries to complete the international procedure of ratification for both the Convention and the Optional Protocol, and to put in place the necessary steps to include the text within their national legislations.

In the implementation of the obligations foreseen by the Convention, EU Member States must also take into account the family dimension and provide concrete measures in order to put families in the conditions of contributing to the full and equal realisation of the rights enshrined in the text.
What role for the EU?

COFACE-Disability addresses the following recommendations to the European Union, in line with the action plan of the European Disability Strategy 2010-2020:

- Ensure accessibility to goods, services - including public services - and assistive devices for people with disabilities and their families;
- Ensure an adequate standard of living for all persons with disabilities and their families;
- Promote autonomy of living and inclusion in the society for all (including persons with disabilities and their families) and support Member States’ efforts towards deinstitutionalisation;
- Enable family carers to better balance their work and family responsibilities, in the framework of the Strategy for Equality between Women and Men 2010-2015; ensure recognition of skills and promote training of family carers;
- Take the special needs of children with disabilities and their families into account in the EU Strategy on the Rights of the Child, in order to prevent all forms of mistreatment or violence and promote inclusive education for students with disabilities;
- Ensure better access to health care systems and that persons with disabilities and their families are informed about their rights, by promoting information and awareness raising campaigns;
- Address problems of mobility within the EU for persons with disabilities and their families and ensure their full participation in cultural life, recreation, leisure and sport;
- Legislate further on non-discrimination; including discrimination by association;
- Make best use of EU funding instruments for accessibility and non-discrimination for persons with disabilities and their families;
- Integrate the family dimension of disability among the indicators and statistics used for monitoring the situation of persons with disabilities with reference to key Europe 2020 targets.

What is COFACE-Disability?

COFACE-Disability was founded by the Confederation of Family Organisations in the EU (COFACE) in 1998 in order to better represent the people with disabilities and their families. COFACE-Disability's mandate is to help people with disabilities achieve fulfilment throughout their entire lives, in particular within the family context. Its member organisations actively work together to see that a policy for family carers is mainstreamed across all EU policy spheres. COFACE-Disability advocates that families are given a central place in policy on disability.

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