



Working Group Inclusive Policies for Disabled and Other Dependent Persons and their Families (COFACE-Handicap)

The Family Dimension of the United Nations Convention on the Rights of Persons with Disabilities

Approved by COFACE Administrative Council on 18 February 2011

Executive summary

By introducing an innovative understanding of the issue of disability, the UN Convention on the Rights of Persons with Disabilities (CRPD) represents a milestone for the promotion of human rights and equal treatment in Europe and worldwide. The Convention defines disability as the product of interaction between long-term physical, mental, intellectual or sensory impairments and the physical/attitudinal barriers present in the environment: disability is therefore recognised as a *social issue*, rather than a sole individual characteristic, whose roots are ultimately residing in society.

The CRPD explicitly acknowledges the critical role played by families for the promotion of human rights and the inclusion of persons with disabilities in society. By voluntary will or because of lack of public support, families are particularly likely to undertake a caring role and remain the first and most immediate environment where children with disabilities can develop their potential and enjoy a fulfilling life. The concrete realization of the rights of persons with disabilities is strictly interdependent with the quality of life of their family members, and can be very much influenced by the circumstances affecting parents, partners, children and siblings living with them.

To address these challenges, various obligations arising under the CRPD implicitly or explicitly commit public authorities to put families in the conditions of contributing to the full and equal realisation of the rights enshrined in the text. Some articles make *explicit reference* to measures to sustain families, while other provisions *implicitly* require a mainstreaming of the family dimension in order to ensure an effective implementation.

The first aim of this paper is to illustrate the main implications of the CRPD for the improvement of the rights and wellbeing of persons with disabilities and their families, recalling Member States' and EU's role in this regard. Moreover, this position intends to raise awareness on the scope and relevance of the Convention among family organisations, policy makers and other representatives of civil society, in order to promote advocacy activities and facilitate the dissemination of the CRPD at national and European levels.

PREFACE

By Yannis Vardakastanis, President of the European Disability Forum

With or without disability, a family network is something that few of us can do without. Family encourages and motivates us for big endeavours, while serving as a safety net when things get rough and acting as a voice of reason in times of doubt and big decisions.

The United Nations Convention on the Rights of Persons with Disabilities, formally concluded by the European Union on 23 December 2010, has firmly established the human rights-based approach to disability, reconfirming persons with disabilities as full citizens with the same rights and obligations as their non-disabled peers.

Living up to the Convention standards is unthinkable without reflecting on the involvement of all those who count and who are equipped to make the difference. The role of families of persons with disabilities is hard to overestimate – in today's far from perfect society, when the obstacles preventing disabled people from being fully included in the community life are vast and the economic crisis is hitting hard, it is the families that often serve as educators, service providers and carers (often, regrettably, without any compensation from the state). It is the families that stand by the person's dignity and help maximise their independence. The Convention recognises the precious role of families in affirming the rights of persons with disabilities. Families themselves are right-holders as well, and it is up to us to ensure that this is recognised at all levels of policy making.

It is a multifaceted instrument, and opening up its full meaning from different perspectives is an invaluable exercise that will help build bridges between those whose job it is to fulfil its standards. It gives me an enormous pleasure and comfort to witness the profound involvement of the European Confederation of Family Organisations in the process of making real the rights of 80 million Europeans with disabilities and their families. We don't expect this journey to be short or entirely smooth, and uniting the forces is the way forward!

A. The UN Convention: a milestone for the realisation of the rights of persons with disabilities and their families

The UN Convention on the Rights of Persons with Disabilities (CRPD) represents a milestone for the promotion of human rights and equal treatment in Europe and worldwide. The CRPD recognises that "*disability is an evolving concept*", resulting from "*the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society*". Above all, it identifies persons with disabilities as *right-holders* rather than *passive beneficiaries* of welfare and medical assistance: this paradigm shift in the understanding of disability - from a medical to a social and human rights model - remains one of the Convention's most innovative aspects.

By addressing *de iure* and *de facto* discrimination, the CRPD introduces an unprecedented level of protection and foresees several measures for translating the entitlements of persons with disabilities into effective rights.

Several articles in the CRPD also affect, directly or indirectly, the rights and wellbeing of family members of persons with disabilities. The Preamble states 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*". This reference departs from an important recognition: 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 can require assistance as a consequence of physical, mental, intellectual or sensory impairments. Family members of persons with disabilities are particularly likely to undertake a caring role, for voluntary will or lack of public support, and families remain the first and most immediate environment where children with disabilities can develop their potential and enjoy a fulfilling life.

A comprehensive realization of the rights of persons with disabilities, therefore, 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 care needs living with them: the psychological and physical exhaustion of family carers, for instance, might increase the risk of neglect and abuse, while the absence of preventing measures targeting poverty and social exclusion can be detrimental for the entire household. The quality of life of each family member is essential, and must be preserved - inter alia - by ensuring a good level of physical and psychological health, the maintenance of normal family bonds (between parents and children or between partners) and an adequate standard of living.

To address these challenges, various obligations arising from the CRPD - implicitly or explicitly - require public authorities to undertake 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 following articles make *explicit reference* to the role of families and recall the obligation of all contracting parties to provide them with help and support:

- 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*”).

Other provisions, although not explicitly mentioning families as beneficiaries of State policies, 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 by 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 (**liberty of movement and nationality** - which should concern measures directed not solely 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 being included 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 encompassing a number of measures directed at parents);
- Article 25 (**health** – need to integrate family carers in the debate on the 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 organizations, shall be involved and participate fully in the monitoring process*”).

B. From rights to policies: recommendations for a family approach in the implementation of the CRPD

Since the wellbeing and empowerment of family members of persons with disabilities is an important pre-requisite for the full realisation of the rights enshrined in the text, family policies must form an integral part of the States’ obligation to fulfil their human rights commitments: families must receive

support, information and advice in order to be able to accomplish their fundamental role. In particular, the rights of family members of persons with disabilities shall be appropriately taken into account in all measures relating to the concrete implementation of the CRPD, with special focus on the following areas:

Equality and non-discrimination (art. 5)

Fight against discrimination by association

Family members of persons with disabilities are particularly at risk of ‘discrimination by association’, i.e. to be detrimentally treated by reason of their connection with a person with disabilities¹. Discrimination may arise in a wide variety of fields, from education to employment, from freedom of movement to access to goods and services, from health to cultural life: in all these circumstances parents, partners, children and siblings of persons with disabilities risk to be excluded from the enjoyment of human rights and fundamental freedoms protected under the Convention by reason of their family bound.

Discrimination by association is likely also to cause a double-harm to the person with disabilities or multiple disabilities: some families might be pushed, or forced, to the extreme of hiding the presence of the person by keeping him/her at home, or even ask for institutionalization. A family victim of discrimination might feel unable to keep ensuring an adequate quality of life for the person with disabilities and/or other members of the family, it can suffer, isolate itself and eventually not be able to provide an adequate support.

To avoid discrimination and achieve *de facto* equality, specific measures - including positive actions - should be implemented to the benefit of persons with disabilities and their families alike. Discrimination between different forms of disability should also be prevented.

Women with disabilities (art. 6)

Disability and the family: recognise the gender dimension

Several significant links can be established between gender and disability: the Convention recognises that women and girls are often subject to multiple discrimination by reason of gender *and* disability, to the detriment of their rights and fundamental freedoms. According to UN sources, “women with disabilities face significantly more difficulties - in both public and private spheres - in attaining access to adequate housing, health, education, vocational training and employment, and are more likely to be institutionalized”².

Families have an essential role to play for the education, development and empowerment of girls with disabilities. States must encourage and assist families in order to combat gender discrimination and promote active inclusion, inter-alia by involving parents and siblings of girls with disabilities in programmes and policies promoting gender equality and empowerment of women.

According to recent studies, women with disabilities do not yet “fully enjoy the right to marry and form a family, decide freely on the number and spacing of their children, have access to family

¹ The discrimination by association of family carers has been recognised by the Court of Justice in the “Coleman” judgement of 17 July 2008:

<http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=CELEX:62006J0303:EN:HTML>.

² United Nations, ‘Gender perspectives on disability and the disability perspective on the situation of women and girls with disabilities’, at: <http://www.un.org/disabilities/default.asp?navid=13&pid=1514#footnote 1>.

planning information and retain their fertility on an equal basis with others”³. All contracting parties to the Convention must ensure that women with disabilities are protected against discrimination in all matters relating to the right to marriage, family, parenthood and relationship. All persons with disabilities must have access to age-appropriate education on sexual and reproductive health and rights.

Finally, the issue of family care and disability has an evident gender dimension due to the predominance of women among informal carers. The realisation of appropriate work/life balance represents a key challenge for the attainment of wider gender equality, and acquires even stronger importance for women providing care to dependent family members. State policies must encourage the equal sharing of private and family responsibilities between women and men, introduce effective mechanisms for the reconciliation of work, private and family life (leave schemes, flexible working time arrangements and services), and protect the rights of all family members taking care of persons with disabilities by ensuring, *inter alia*, official recognition of their carer status.

The access of children with disabilities to inclusive childcare services, in a larger framework of early childhood intervention, is also essential to allow women to maintain a professional activity or continue their education⁴.

Children with disabilities (art. 7)

The right of children with disabilities to family life

The UNCRPD commits all States Parties to “ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children”⁵, and explicitly recognised the right of children with disabilities “to know and be cared for by their parents”⁶. The Preamble of the United Nations Convention on the Rights of the Child recognises, moreover, 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”⁷.

States must ensure that the family - one of the first and best places in which children with disabilities can be assured personal growth, well-being and self-fulfilment- is given a central place in all policies regarding disability and childhood. Families may be encouraged to take an active role and provide a bridge towards the full realization of the right of children with disabilities to active citizenship, thus contributing to their involvement in the society.

Obviously, one of the first and foremost obligations of contracting parties to this regard is to ensure that all children with disabilities have equal rights with respect to family life. The mainstreaming of the family dimension of disability, however, includes several other aspects where the participation of – and support to – the family is fundamental for the realisation of the rights of children with disabilities, such as health care, education, inclusion in the society or fight against poverty and social exclusion. In relation to all actions concerning children with disabilities, the Convention clearly states

³ Study on the situation of women with disabilities in light of the UN Convention for the Rights of Persons with Disabilities (VC/2007/317), A Final Report for the DG Employment, Social Affairs and Equal Opportunities of the European Commission, p. 10.

⁴ Idem.

⁵ UNCRPD, art. 7.1.

⁶ Ibid, art. 18.2.

⁷ United Nations Convention on the Rights of the Child, Preamble.

that “*the best interests of the child shall be a primary consideration*”⁸.

Awareness-raising (art. 8)

Information and training

Awareness on the special needs of persons with disabilities must be raised first and foremost at the family level, in order to foster a culture of respect for their rights starting from the inner circle.

Parents must receive professional counselling as to how to address the multiple aspects of a child’s disability, and be helped to familiarise with the new circumstances and settings required by their caring role. Such information and counselling shall be provided to parents since the very moment of the announcement of the child’s disability, a very delicate step that must be object of particular regard.

The brothers and sisters of a disabled child must also benefit of information and training, adapted to their age and maturity⁹.

Accessibility (art. 9)

Prevention of isolation and withdrawal by the family as a whole

Persons with disabilities, independently from the type of disability (intellectual, sensorial, physical, poly-handicap...) have the right to access, on an equal basis with others, to the physical environment, transportation, information and communication technologies and to other facilities and services open or provided to the public.

Clearly, access to goods and services concerns not only the inclusion in society of persons with disabilities, but also their relatives. When a disabled child faces exclusion, his/her parents and siblings are also affected and the inaccessibility of places, transport, cultural events etc. may lead to the withdrawal from society of the family as a whole.

Equal recognition before the law (art. 12)

The role of families in supported decision-making

The Convention reaffirms the right of all persons with disabilities to recognition everywhere as persons before the law and to enjoy legal capacity on an equal basis with others in all aspects of life. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they require in exercising their legal capacity.

Parents and siblings may be requested to undertake this role: this may often be an onerous and difficult duty, giving rise to concerns, dilemmas and tensions, for which families require assistance and specific preparation.

An initial stage of information, before taking any decision concerning supported decision-making, is essential so that families fully understand the interests of the person with disabilities. The person with disabilities shall remain as much as possible free to question the choice and to choose his/her

⁸ UNCRPD, art. 7. 2.

⁹ See COFACE position « Siblings and persons with care needs”:

<http://coface-eu.org/en/upload/WG%20HANDICAP/2009-Fratrie-en.pdf>.

support person- who could also not be a member of the family. A third party could intervene to accompany the person and his/her family in this choice, also to understand the mechanisms and implications of different forms of support. It is essential, therefore, to develop forms of training for families in supported decision-making, for instance through specialised networks or services.

Prevention of all forms of exploitation, violence and abuse (art. 16)

Prevention of exhaustion of family carers

The prevention of psychological and physical exhaustion of families is key to avoid extreme circumstances such as neglect or violence. The wellbeing of persons with disabilities and their carers are in fact strictly interdependent: appropriate preventive policies must focus on avoiding all those negative factors (such as illness, weariness, excess work load, exhaustion, etc.) that would make it impossible for the family carer to fully meet the needs of the assisted person or - even worse - lead to abuse.

To this purpose, both the carer and the person with disabilities must benefit from the support of approved and quality community-based infrastructures and community-based services, while appropriate supporting measures must provide family carers with the concrete possibility to reconcile work and private/family life.

The *right to respite* must be recognised for all family members taking care of persons with disabilities and implemented through the provision of support, occasional and/or emergency assistance, substitution services and/or top-quality temporary care centres in case of particular circumstances (holiday, rest, health problems, etc.)¹⁰.

Liberty of movement and nationality (art. 18)

Harmonisation of legislations

In order for the right to free movement to be effective, harmonisation and coordination should not concern solely measures directed at persons with disabilities, but be directed also at their families, for instance by ensuring a harmonisation of work/life balance legislation between EU Member States.

Living independently and being included in the community (art. 19)

Community-based services and support for carers

Persons with disabilities and their families have the right to live in society: they must have the freedom to choose their place of residence and where and with whom to live, and not be forced to live in a particular setting. They also must have access to “a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community”¹¹.

¹⁰ See COFACE position « Respite: a need and a right for family carers”, at: <http://coface-eu.org/en/upload/WG%20HANDICAP/COFACEPosition-Respite-en.pdf>.

¹¹ CRPD, art. 19, b).

In no case the process of transition from institutional to community-based care¹² should lead to the overburdening of families: family solidarity cannot absolve States or public authorities of their duty to provide the necessary appropriate help for people with care needs.

The process of de-institutionalisation must entail first of all the development of a wide net of specialised facilities and community-base services, as well as global policies to support family carers¹³. Among these, States should make progress on the recognition of a statute of family carers and the deployment of quality support services (ranging from information and training to respite opportunities).

Respect for privacy (art. 22)

Privacy in family life

Persons with disabilities and their families must be protected against any arbitrary or unlawful interference with their privacy and family life, home and correspondence. This includes also all personal, health and rehabilitation information (e.g. personal medical dossier).

Respect for home and the family (art. 23)

Right to found a family and right of children to family life

The Convention clearly provides for the right of persons with disabilities to found a family and decide freely on the number and spacing of their children. Persons with disability must have access to education and age-appropriate reproductive and family planning information, and be informed about their rights.

All persons with disabilities and their partners/spouses must be able to maintain their full roles as sexual partners. National policies have to set up the necessary psychological, social and medical measures to preserve a relationship which must not be distorted by the disability. A place must be given to sexual and emotional life of persons with disabilities in the sexual education of children and young people, in order to counter ignorance and taboos.

Children with disabilities have the right “to know and be cared for by their parents”¹⁴. The right of children with disabilities to family life shall always be protected, with the aim of obtaining the maximum quality of life and wellbeing. The CRPD explicitly foresees the provision of comprehensive information, services and support to children with disabilities and their families in order to prevent concealment, abandonment, neglect and segregation. In no case, according to the CRPD, shall a child be separated from parents on the basis of a disability of either the child or of one or both of the parents.

¹² See Report of the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care, which defines institutional care as “any residential care where users are isolated from the broader community and/or compelled to live together; these users do not have sufficient control over their lives and over decisions which affect them; and the requirements of the organisation itself tend to take precedence over the users' individualised needs”. Also, care institutions are not defined by their size, but by the characteristics of the “institutional culture” they display (depersonalisation, rigidity of routine, group treatment, social distance and paternalism), from the perspective of the human rights and dignity of the users, their quality of life and health, their autonomy and social inclusion.

¹³ See COFACE-Handicap, European Charter for Family Carers:
<http://coface-eu.org/en/upload/WG%20HANDICAP/CharteCOFACEHandicapEN.pdf>.

¹⁴ CRPD, art. 18.2.

Education (art. 24)

The role of families in inclusive education

The CRPD clearly states the right of persons with disabilities to inclusive education and life-long learning at all levels. Not only does inclusive education contribute to the self-actualisation and development of children with disabilities, by maximising their inclusion into society: it is fundamental also for the quality of life of the family as a whole. By giving the right to raise a child “like other children”, in the same places and same way as other families, inclusive education helps parents to be involved in the social network and to engage more with the educational aspect of their child, working in partnership with professionals. By dispelling the marginalising effect of disability, it also contributes to its acceptance by siblings and the extended family, establishing a culture of inclusion.

Inclusive education policies must allow the right for children with disabilities to express their own wishes and choices concerning study options. Parents should be fully involved in the drawing of the individual educational plan of their child in partnership with education, medical and welfare professionals so as to offer the most appropriate and efficient responses for an inclusive study option. In this perspective, associations representing parents should actively participate in the elaboration of new legislation, policies and measures in the field of inclusive education.

It is unacceptable that the choice between specialised and ordinary education systems for a child with a disability is determined by financial reasons or the parent’s educational background. Inclusive education in ordinary schools must provide for the same care that children with a disability would benefit from in the specialized education system. Today, those parents who wish for their child to grow up in an ordinary schooling environment have to pay too high a price to obtain the necessary adapted responses to their child’s needs. Ensuring access to a high quality education system for all children shall always remain a primary concern.

Health (art. 25)

Recognition of the role of family carers in the health systems

The Convention recognizes that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability.

It is essential to recognize the role played by family carers in the health system, and to take it into account for all policies concerning health and long-term care - including those relating to health personnel. There is a need both for harmonisation of conditions between family carers and the professional workforce and for increased and better cooperation and coordination between them, in particular through awareness raising and training of professionals.

The harmonisation of conditions is needed in terms of continuous training (e.g. as regards the use of new technologies), periodical free medical check ups, psychological support, and right to respite, but also in terms of assessment of the quality of care.

Adequate standard of living and social protection (art. 28)

Support to families to prevent poverty and social exclusion

Families of persons with disabilities (in particular, children with disabilities) face a higher risk of poverty compared with other households. Social protection systems must aim at ensuring an adequate standard of living and the continuous improvement of living conditions of persons with

disabilities and their families, taking into account their fundamental needs in terms of resources, time and services.

Anti-poverty strategies directed at families of persons with disability may encompass a wide variety of measures, including:

- compensation of the expenses related to the handicap of a child;
- support for the access to housing;
- provision of care services financially accessible;
- favourable tax policy;
- increase in the number and quality of jobs;
- close-to-home workplaces and flexible working hours;
- systems of leave for care provision (splittable on different periods according to carer's specific requirements, and maintaining rights to social security);
- recognition of the status of carer in the pensions systems¹⁵;
- protection against discrimination at work and arbitrary dismissal;
- free movement within the EU with preservation of the right to personal assistance;
- EU-level harmonization and convergence to improve services and help achieve balance between professional and caring role.

Participation in cultural life, recreation, leisure and sport (art. 30)

Promote the inclusion in society of the family as a whole

The Convention specifically recognises the right of persons with disabilities to take part in cultural life and recreational, leisure and sporting activities. This will benefit not only the person with a disability, but also his/her family as a whole, helping to avoid segregation and fostering inclusion in society.

Public authorities must provide for the necessary conditions to concretely implement this right, by ensuring not only access to leisure facilities, cultural and sporting events, but also their economical affordability. For example, it is important to access to holidays for persons with disabilities and their families through accessible amenities and touristic venues and income-related financial allocations.

National implementation and monitoring (art. 33)

Involvement of organisations representing families of persons with disabilities in the monitoring mechanisms

One of the Convention's overarching aims is to achieve the empowerment of people with disabilities and their representative organisations, as a fundamental step for ensuring full enjoyment of the rights enshrined in the text.

Family organisations shall be involved and participate in the awareness-raising, policy planning and decision-making processes relating to the implementation of the UNCRPD: specific measures shall be dedicated to their empowerment, with particular emphasis on families of children with disabilities or families of persons with disabilities who might require assistance in representing themselves.

¹⁵ See COFACE Response to the European Commission Consultation on the Green Paper on Pensions, October 2010.

In particular, the organisations representing persons with disabilities and their families must take full part in the monitoring process foreseen by the Convention in article 33.3, and actively contribute in the elaboration of the reports submitted by State Parties to the Committee on the Rights of Persons with Disabilities¹⁶.

The organisations representing family carers can also play a fundamental role for elaborating communications under art. 1 of the Optional Protocol (“from or on behalf of individuals or groups of individuals subject to [the State] jurisdiction who claim to be victims of a violation by that State Party of the provisions of the Convention”)¹⁷.

C. Ratification by EU Member States

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 urges all EU countries to complete as soon as possible the international procedure of ratification for both the Convention and the Optional Protocol, and to put in place the necessary steps for the incorporation of the text within their national legislations.

In the implementation of the obligations foreseen by the Convention, EU Member States must 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.

D. The European Union’s role

The European Union, following its formal ratification of the Convention on the 23 December 2010, has the same responsibility as the Member States to promote the measures outlined above. These lie within the ambit of many of the European Union’s policy spheres - social affairs and equal opportunities, public health, education and training, transport, new technologies, standardization, etc. - where it either has specific competence or just a facilitating role. The domains of actions identified by the European Disability Strategy 2010-2020 can also all be put in correlation with the articles of the United Nations Convention recalled above.

In addition, in many of the fields at stake, several important disparities remain among national situations, and in particular between ‘old’ Member States and ‘new’ Member States. The EU’s role is therefore to help Member States where support to families is scarcely developed to implement such measures, taking inspiration from best practices existing in other Member States.

Finally, the EU shall mainstream the issues affecting persons with disabilities and their families in all EU initiatives on disability (in particular, in the implementation of the EU Disability Strategy 2010-2020), but also beyond that, in all initiatives relating to the **EU-2020 Strategy**.

COFACE addresses therefore the following **recommendations** to the European Union, in line with the areas for action identified by the European Disability Strategy 2010-2020:

Accessibility

- **Ensure accessibility to goods, services - including public services - and assistive devices** for people with disabilities and their families, independently from the type of disability (intellectual, sensorial, physical, poly-handicap,...), including through a ‘European Accessibility Act’; make use of the relevant Europe 2020 Flagship initiatives, such as

¹⁶ UNCRPD, art. 34.

¹⁷ Optional Protocol to the Convention on the Rights of Persons with Disabilities, art. 1.

“Innovation Union”, “A Digital Agenda for Europe” and “An Industrial Policy for the Globalisation Era”.

Participation

- Promote **autonomy of living and inclusion in society** for all persons with disabilities and their families, particularly through relevant Europe 2020 Flagship initiatives such as “Innovation Union” and “An agenda for new skills and new jobs”;
- **Support Member States' efforts towards deinstitutionalisation** by making efficient use of the Structural Funds, and foster the development of a quality framework for community-based services for persons with disabilities and their families;
- Enable family carers, in the framework of the Strategy for Equality between Women and Men 2010-2015, to better balance their work and family responsibilities, in particular by proposing a **EU directive introducing a leave to care for a dependent family member**, and by developing EU targets for availability of quality long-term care (building up on the model of the Barcelona targets for childcare);
- Address the persisting problems of **intra-EU mobility** for persons with disabilities and their families, also in view of the full right to free movement foreseen by the Stockholm Programme, in particular by exploring the possibility of a mutual recognition of disability cards and related entitlements and the portability of rights such as the right to personal assistance;
- Ensure **participation in cultural life, recreation, leisure and sport**, by addressing the issue of accessibility of sports, leisure, cultural and recreation organisations, activities, events and venues - also in the framework of the European Platform against poverty - in order to fight social exclusion;
- Take into account the special needs of **children with disabilities and their families** in the EU Strategy on the Rights of the Child, also in view of preventing all forms of mistreatment or violence.

Equality

- Legislate further on **non-discrimination**, including discrimination by association, by adopting the directive proposal on equal treatment beyond the workplace;
- Encourage Member States to promote the conformity of their legislation on legal capacity with the UN Convention, and sustain families in their role of assistance to the exercise of legal capacity by persons with disabilities, encouraging the exchange of good practices and training for family carers.

Education and Training

- Promote **inclusive education** for students with disabilities within the strategic framework for European cooperation in education and training, focusing more on disabled children's inclusive education within the **Open Method of Coordination (OMC) in education and training**; make use of EU 2020 Flagship initiatives such as “Youth on the move” and “An agenda for new skills and jobs” to develop partnerships between the worlds of education/training and work; support the work of the European Agency for Development in Special Needs Education;

- Promote **training for family carers** through the European Commission’s Lifelong Learning Programme and **validation of non-formal learning** (European Qualifications Framework).

Social Protection

- Ensure an **adequate standard of living** for all persons with disabilities and their families, by mainstreaming the issue of disability within the relevant Europe 2020 Flagship initiatives such as the “Platform against poverty”; promote social inclusion of persons with disabilities and complex needs through EU programmes;
- Enhance the exchange of good practices and the promotion of policies on assistance to family carers within the **OMC on social protection and social inclusion** (OMC SP/SI).

Health

- Ensure better access to **health care systems**, in particular within the framework of the flagship initiative “Platform against poverty”; promote harmonisation, cooperation and coordination between family carers and the professional workforce.

Awareness Raising

- Ensure that persons with disabilities and their families are informed about their rights and of relevant Commission activities, by promoting **information and awareness raising** campaigns;

Financial Support

- Optimise use of EU funding instruments for accessibility and non-discrimination for persons with disabilities and their families ;
- In particular, make use of the **Structural Funds** and the **Rural Development Fund** for ensuring availability of quality community-based services and for offering support to families and informal carers, in the framework of the process of de-institutionalisation; reinforce the targeted support of the **European Social Fund** for promoting training and social inclusion for family carers, as well as harmonisation, cooperation and coordination between family carers and professional workforce.

Statistic and data collection and monitoring


- Integrate the family dimension of disability among the indicators and statistics used to monitoring the situation of persons with disabilities with reference to key Europe 2020 targets.

Mechanisms required by the UN Convention

- Encourage participation of organisations representing persons with disabilities and their families in the monitoring process foreseen by the Convention in article 33.3.

Optional Protocol

- Ratify the Optional Protocol to the Convention on the Rights of Persons with Disabilities.

 <p>EUROPEAN COMMISSION DG Employment, Social Affairs and Inclusion</p>	<p>COFACE is supported under the European Union Programme for Employment and Social Solidarity – PROGRESS (2007-2013). http://ec.europa.eu/progress</p>
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