



Confédération des Organisations Familiales de l'Union européenne
Confederation of Family Organisations in the European Union

COFACE Position on siblings and persons with care needs

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Executive summary

The issue of siblings and dependency is a complex quality-of-life issue for persons with care needs and their families. This first stands true during childhood, as, whether all come to terms with it easily, or some less easily, a child's disability dramatically changes a family's life, and has a profound effect on the development of the sib group members. Then, in adult life, the brothers and sisters of a person with care needs (whether due to disability or to another cause) may very often have caring demands placed on them, often because of the lack of public solidarity, whereas this is not in the nature of things for siblings.

This issue is taken up by the UN Convention on the Rights of Persons with Disabilities. Many of its provisions requires measures to be taken concerning siblings to contribute towards the full and equal enjoyment of their rights by persons with disabilities. With this legal framework, public authorities should take a wide range of measures to support siblings, thus contributing to improve the wellbeing and quality of life of all family members (person with care needs, siblings, parents).

These measures differ according to whether the person with care needs is a disabled child/teenager or an adult with care needs. In any case, all measures should be accessible and affordable for all families.

During childhood and adolescence, key measures to support siblings are :

- information and awareness building of siblings ;
- dialogue and counselling for siblings ;
- help to family carers to preserve good parent-child relationships ;
- achievement of an accessible and inclusive society for people with disabilities, which will promote social inclusion for all siblings.

In adult life, any person with a disability and/or special needs must be able to choose their place of residence and living arrangement, and if they cannot live a fully independent life, the type of care. When care is provided by siblings, they should be supported thanks to the following measures:

- support to siblings in their caring role;
- help to siblings for supporting the person with care needs in exercising his/her legal capacity;
- appropriate care provision for ageing people, meeting the needs of ageing persons with a disability on the one hand, and those of other elderly with care needs on the other hand.

Siblings facing the risk of an inherited disorder should also have access to genetic counselling, if they wish so, after having received all necessary information.

The European Union's role in the provision of support measures for siblings is important, in the framework of the implementation of the UN Convention on the Rights of Persons with Disabilities, and because the measures outlined 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, standardisation, etc.). It also the role of the EU to held reducing disparities between Member States, which remain important in this field. European initiatives on disability, ageing and health should "mainstream" issues that affect families since they are central to the quality-of-life of persons with care needs. The Open Method of Coordination on social protection and social inclusion, initiatives in the field of education and training, and EU structural funds are also essential tools to support siblings of persons with care needs. The designation of 2012 as European Year for Active Ageing and Intergenerational Solidarity would contribute to emphasise the role of siblings in respect with persons with care needs.

A. Siblings and dependency: a complex quality-of-life issue for persons with care needs and their families

The quality of life and wellbeing of persons with disabilities, persons with other special needs and their families is necessarily bound up with the circumstances of their parents, children and partners. The brothers and sisters of persons with care needs get less attention, even though a disability or other form of care needs may affect them to a large degree.

This is relatively obvious in childhood. A child's disability dramatically changes a family's life, upsetting the roles and places within it. The quality of life of a disabled child (and subsequently adult) depends among other things on his/her family's quality of life, and especially the wellbeing of the sib group generally, as well as the disabled child's relationships with his/her siblings and feelings of being a full member of the group. But whether all come to terms with it easily, or some less easily, a child's disability will always have a profound effect on the selfhood, emotional development and social identity of other sib group members, since the sibling relationship is one sphere in which social identity is constructed. The brothers and sisters of a disabled child can feel "left out of the loop" of a daily life where everything revolves around the disability. Prey to a host of conflicting feelings, they cannot always handle jealousy, guilt, frustration, fear, loneliness or having adult responsibilities before their time. They can be at a loss when facing their parents' upheaval and sadness. But these general issues aside, each person lives the situation in their own way, even often drawing increased human value from it.

The brothers and sisters of an adult disabled person with care needs who has no partner or children, and ageing or deceased parents, may very frequently have caring demands placed on them, often because of the lack of public solidarity. This is not in the nature of things, as siblings have neither the professional skills, nor a maintenance obligation, nor the kind of personal life experience that necessarily fits them to be a carer. Likewise the brothers and sisters of someone who develops care needs later in life (Alzheimer's, etc). These care-giving demands are also in too many cases placed on siblings without the care-needer being consulted or given an opportunity to state his/her desires and choose with whom and where he/she wishes to live.

Finally, when a sibling has progressive disability and/or dies during his/her childhood, this can seriously affect the brothers and sisters. This can also be true during adulthood.

B. Siblings and care needs: a challenge taken up by the UN Convention on the Rights of Persons with Disabilities

The Preamble to the United Nations Convention on the Rights of Persons with Disabilities 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” (point x).

Various obligations arising under the Convention reflect this affirmation and require direct measures to be taken concerning siblings to contribute towards the full and equal enjoyment of their rights by persons with disabilities:

- article 8 (awareness-raising, “throughout society, including at the family level, regarding persons with disabilities”);
- 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 19 (living independently and being included in the community, and in particular “the opportunity to choose their place of residence and where and with whom they live on an equal basis with others”)
- article 23 (respect for home and the family, in pursuance of which “States Parties shall ensure that children with disabilities have equal rights with respect to family life. With a view to realizing these rights, and to prevent concealment, abandonment, neglect and segregation of children with disabilities, States Parties shall undertake to provide early and comprehensive information, services and support to children with disabilities and their families”).
- article 28 (adequate standard of living and social protection for persons with disabilities and their families, and in particular “to ensure 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 obligations arising under the UN Convention will also benefit siblings, albeit more indirectly:

- article 9 (accessibility, avoiding the risk of isolation and withdrawal by the family as a whole)
- article 24 (education, especially inclusion in mainstream education to temper feelings of difference between children)
- article 30 (participation in cultural life, recreation, leisure and sport, which will benefit not only the person with a disability, but also his/her family, and especially his/her siblings).

This legal framework requires public authorities to take a wide range of measures that will improve the wellbeing and quality of life of all family members: persons with care needs, their siblings, and parents. The measures differ according to whether the person is a disabled child/teenager or an adult with care needs.

C. Measures to support siblings during childhood and adolescence

As a prerequisite, all measures detailed below should be accessible and affordable for all families.

1/ Information and awareness building of siblings

First of all, parents should receive advice and support on how to announce the disability of the child to his/her brothers and sisters, in conditions making it less alarming.

Then, as soon as they are old enough, both the disabled child and their siblings need to understand about the disability and its well-known and predictable consequences, including in daily life at home.

It is important for early support services to provide specific information and appropriate programmes and learning activities according to the age and understanding of siblings (e.g., using children's literature, games, ...).

Professionals should be trained to talk about the disability not just with parents but siblings, too. Brothers and sisters should be able to visit their disabled sibling's care facility from time to time when advisable, to familiarise themselves with his/her setting, strengthen sibling ties and their understanding of the situation.

2/ Dialogue and counselling for siblings

It is important to create specific counselling provision where brothers and sisters can talk about their concerns, as they may be reluctant to confess their problems to their parents so as not to burden them further. Family organizations do extensive work on this, and their schemes should be supported.

It is also important to get parents and siblings talking openly to one another and between themselves – something parents rarely seem to find easy. Professionals have an important enabling role here, but too few are yet aware of what they could be doing. Professionals should also be given training in this, therefore. Family therapies are also useful.

Early support services should also be encouraged to develop specific programmes for siblings, like meeting and discussion days, one-to-one attention and conferences on sibling issues.

Such programmes should also be provided in and even beyond later childhood and adolescence, at the onset of adult life (the independence of non-disabled children, for example, needs to be extensively discussed in the family for it not to be resented by the disabled child, and be assumed by their siblings).

In some cases (including in the event of the death of their sibling), brothers and sisters may need counselling, as parents do. Counselling provision should be made available for the immediate family – which therefore includes siblings.

Activities for children should be appropriate for their age and understanding and be based as far as possible on play.

Best practice in Luxembourg:

Luxembourg's early support services provide specific sibling support programmes including meeting and discussion days, information and awareness building programmes, one-to-one attention and conferences.

The long-term care insurance scheme offers family counselling services to support immediate family members, and therefore siblings also.

3/ Helping family carers to preserve good parent-child relationships

Some children with a disabled brother or sister display evidence of considerable emotional and behavioural disturbance that are significantly linked to the parents' stress levels.

Supporting parents in their family carer role¹ can only be of all-round benefit to siblings (parents in better health, less stressed, more time/energy to spare).

Respite and home-based care provision is particularly important for brothers and sisters, as it allows parents who are normally "monopolized" by the disabled child to spend time on the siblings.

Information of parents is also crucial, including to provide them with guidance in their relationship with siblings as soon as the disability has been diagnosed.

Other forms of support to family carers (services like transport, work-life balance measures, training, health surveillance/screening and counselling, etc.) will also help improve the quality of family life in terms of wellbeing, but also, as far as they enable the continuation of a professional career, in financial terms.

4/ An accessible and inclusive society for people with disabilities: promote social inclusion for all siblings

There is much still to do for our societies to become really inclusive for people with disabilities, and for full accessibility to be achieved. Where a disabled child faces exclusion, the entire family will very often withdraw from society: curtailing social life for fear of others' judgemental attitudes, foregoing leisure activities and holidays due to the inaccessibility of places, transport, cultural events, etc. When the disabled child is being left alone on the sidelines, it deals a severe blow to his/her development and inclusion, and undermines the bonds between siblings.

Measures like raising awareness on disability as from an early age and as a compulsory part of the school curriculum, inclusive education, accessible sporting and leisure amenities and activities, and more generally promoting inclusion and access throughout society, are essential to inclusion for disabled people, their family, and the wellbeing of their siblings.

Best practice in Italy:

Brothers and sisters of a disabled child benefit from priority allocation of places in childcare services, full-time schools, holiday centres, etc..

D. Measures to support siblings in adult life

Any adult with a disability and/or special needs must be able to choose their place of residence and living arrangement, and if they cannot live a fully independent life, the type of care (article 19 of the

¹ For more information, please see COFACE-Handicap's European Charter for Family Carers, supported by COFACE: <http://www.coface-eu.org/en/basic435.html>

UN Convention on the Rights of Persons with Disabilities). In many cases, that care is provided by their parents or partner.

But if they have died or have become unable to care for their now-adult disabled child, the caring role often falls to a sibling, whether through supporting the disabled person in exercising their legal capacity, supportive care to enable them to remain living at home for example, supervising care-giving by others, or as a personal attendant on holidays. But it is essential that this arrangement should be what the disabled person chooses and wants. It should also respect the choice and will of the brother or sister concerned.

The care of an ageing person with complex dependency needs other than disability (e.g., Alzheimer's disease) may also entail demands on brothers and sisters.

This exercise of solidarity within the family - often made necessary by the lack of public solidarity - should necessarily be supported by a network of professionals and types of provision, while there should be more help for those needing care (appropriate services, resources, housing, ...).

Finally, siblings facing the risk of an inherited disorder should have access to genetic counselling.

Again, as a prerequisite, all measures detailed below should be accessible and affordable for all families.

1/ Help for supporting decision-making

One demand often made on brothers/sisters is to support their sibling with a disability and/or care needs in exercising their legal capacity.

Article 12 of the UN Convention on the Rights of Persons with Disabilities requires the States Parties to take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity. Provided it is what the person with a disability wants, such support for decision-making is most often provided within the family, as the person's immediate circle are often best-placed to know and understand their wants and choices.

However, brothers/sisters who with their disabled sibling's consent take up the parents' role of providing such support often find it an onerous and difficult duty that may give rise to concern, agonising choices, and strains with other siblings. So training and help in supporting the exercise of legal capacity needs to be provided, such as by developing specialized networks.

Best practice in Italy:

The role of the supporting administrator (*"amministratore di sostegno"*) has been developed since 2005 into providing support to parents or siblings responsible for supporting the care-needer's decision-making by helping them navigate through the various administrative, legal, and other procedures.

2/ Appropriate care provision for ageing people

The care needs of a dependent person, whether due to ageing with a disability or being elderly, may be such that their immediate family cannot provide them with a good quality of care. Relatives should also be given the choice to be the care-giver or not – and sometimes there are no relatives left.

It is therefore essential to develop community-based long-term care services that meet the needs of ageing persons with disabilities on the one hand, and those of other elderly care-needers on the other hand.

Care staff should be trained to discuss with siblings, and accept that they have a legitimate right to be present in the care facility, thereby enabling sibling attachments to be preserved.

3/ Supporting siblings in their caring role²

The demands placed on siblings who become primary carers can severely disrupt their lives. Like their parents, and perhaps more so for not having been continuously involved with the development of their sibling's disability/illness in the same way, they need information and training. They need to be able to balance what may be a well-established career with this new responsibility that suddenly claims a place in their life. They need support services, especially respite provision, to recharge their batteries but also to continue looking after the family they may already have. They also obviously need health surveillance/screening and counselling, including in the event of the death of the brother or sister they were caring for (frequent occurrence of depression). The above-mentioned measures are also essential to prevent abuse and neglect.

Best practice in Italy:

Workers caring for a disabled brother or sister are entitled to the same rights in terms of work/life balance (leave, ...) than parents with a disabled child.

4/ Access to genetic counselling

Siblings facing the risk of an inherited disorder should have access to genetic counselling, if they wish so, after having received all necessary information. They should be advised of the consequences and nature of the disorder, the probability of developing or transmitting it, and the options open to them in management and family planning in order to prevent, avoid or ameliorate it.

E. The European Union's role in the provision of support measures for siblings

The issue of siblings and care needs as described above falls fully within the scope of implementation of the UN Convention on the Rights of Persons with Disabilities. The European Community, owing to its conclusion of the Convention, 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.

Besides, in many of the fields at stake, many 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

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Member States where so far little is done to support siblings to implement such measures, taking inspiration from best practices existing in other Member States.

European initiatives on disability (EU Disability Strategy 2010-2020), ageing and health should “mainstream” issues that affect families, including siblings, of persons with care needs, since they are central to their quality-of-life.

More specifically, the Open Method of Coordination on social protection and social inclusion (OMC SP/SI) should provide a platform for sharing good practices and promoting policies on assistance to family carers, as proposed by the European Commission Communication of 22 July 2009 on a European initiative on Alzheimer’s disease and other dementias. An EU directive introducing a leave to care for a dependent family member would also be a crucial means to enable family carers, parents, partners and siblings to balance their work and family responsibilities.

The OMC SP/SI should also provide a platform for promoting policies on accessible and affordable quality long-term care services and other community-based social services, including through the adoption of quantified targets similar to the Barcelona targets for childcare, and of a voluntary EU quality framework for social services. The European Social Fund should target funding on innovative early support services that cater to siblings, community-based services that meet the needs of elderly people in need of care, respite provision, etc.

The OMC in education and training should focus more on disabled children's inclusive education. The Community Lifelong Learning Programme and EU structural funds should promote training for family carers, including help in supporting the exercise of legal capacity, as well as training to help professionals working with disability and special needs to focus more on the problems of siblings.

The European Union should also legislate further on accessibility and non-discrimination.

Finally, the European Alliance for Families and the designation of 2012 as European Year for Active Ageing and Intergenerational Solidarity should contribute to emphasise the situation of siblings of person with care needs.

For more information, please contact the COFACE Secretariat:

+ 32 2 511 41 79

secretariat@coface-eu.org



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