**Submission to the UN Committee on the Rights of Persons with Disabilities on the draft General Comment on the**

**right to live independently and be included in the community (Article 19 CRPD)**

# Introduction

1. COFACE Families Europe very much welcomes the draft General Comment (GC) on Article 19 of the UN Convention on the Rights of Persons with Disabilities (CRPD). COFACE Families Europe is a pluralistic network of civil society organisations representing the interests of all families. With 59 member organisations in 23 Member States of the EU, COFACE Families Europe represents more than 25 million families. We appreciate the opportunity to share the views and remarks of COFACE Families Europe and its COFACE Disability branch on the right to live independently and be included in the community.
2. COFACE Families Europe advocates for policies of non-discrimination and equal opportunities between persons and between family forms, and specifically supports policies aimed at increasing equality between women and men, with a special focus on reconciliation between work, care and family life. COFACE’s focus is essentially on policies and legislation that impact the lives of children and families, in particular in the fields of social protection and inclusion, safeguarding the rights of persons with disabilities and persons with support needs, prevention and fighting child poverty, reconciling family and work life, migration, inclusive education and early childhood education and care, parenting support services to families, information and communications technologies, health and consumer policies. More information is available at: <http://www.coface-eu.org/>

# General comments

1. COFACE Families Europe compliments the CRPD Committee for including a detailed explanation about the right to independent living, however the text uses **institutional and residential care** interchangeably, without making a clear distinction and without describing **‘institutional culture’**. We suggest to rely on the [Common European Guidelines on the Transition from Institutional to Community-based Care](http://www.deinstitutionalisationguide.eu/wp-content/uploads/2016/04/GUIDELINES-Final-English.pdf) (page 25) which define an institution as any residential care where:
* residents are isolated from the broader community and/or compelled to live together;
* residents 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 residents’ individual needs.
1. **Prevention of institutionalisation of children and providing support to families** is an integral part of the process of transition from institutional to community-based care. We suggest that the General Comment put more emphasis on the need to provide children with disabilities with accessible, high quality, community-based early childhood education and care services, and access to inclusive education, as well as on the support to families in forms of a wide range of community-based support services and work-life balance measures (page 27 of the  [Common European Guidelines on the Transition from Institutional to Community-based Care](http://www.deinstitutionalisationguide.eu/wp-content/uploads/2016/04/GUIDELINES-Final-English.pdf)).
2. We find that the draft General Comment does not reflect sufficiently the **rights and needs of children with disabilities**, thus we suggest to include references to the UN Convention on the Rights of the Child, with special regard to Article 7 on ‘the right to know and be cared for by his or her parents’, Article 18 concerning the State’s duty to provide support to the parents to assist them in their parental responsibilities and Article 20 on the right of the child to substitute family care, if parents are unable to look after them. Furthermore, children with disabilities also have a right to “effective access to and receive education, training, health care services, rehabilitation services, preparation for employment” (Article 23).
3. The draft General Comment should discuss **‘Alternative care’ for children** who are deprived of parental care. It is important to ensure that children with disabilities without parental care have access to **family-based care**, or **family-like care** in the community on an equal basis with others and are not placed in institutional care, because it is sometimes easier or cheaper, especially when the home of the host family needs to be adapted. This includes informal fostering by family or non-relatives, formal foster care placements, other forms of family-based or family-like care placements, places of safety for emergency child care, transit centres in emergency situations, other short and long term residential care facilities including group homes and supervised independent living arrangements for children.
4. **Access to employment and to the open labour market** is a key issue to ensure the full participation of persons with disabilities in society. Without **adequate income**, persons with disabilities will have no options to choose where and with whom to live and would more likely be obliged to live in a particular living arrangement. The General Comment lacks linking employment with the right to independent living, so we suggest to include more references throughout the document. People who are leaving institutions must be provided with vocational education and training as well as employment opportunities to **avoid re-institutionalisation**, or social deprivation. For persons with intellectual disabilities and persons with complex support needs, the ‘benefit trap’ presents a huge barrier to enter the labour market, thus States Parties should make it a priority to resolve. There is a need for specialised employment services and vocational education and training which should be accessible for those who need them, without discrimination.
5. It would be useful if, beyond describing the principles of Article 19 in detail, the GC provided **more concrete guidance** to States Parties on how to implement the provisions of Article 19 in a CRPD compliant way and where should they put their **funding priorities** when it comes to the social and health sector to ensure the transition from traditional to 21st century, person centred services (e.g. integrated care, in-home solutions, work-life balance measures to support families, prevention of institutionalisation etc.).

# Substantive comments

1. In **Para 5**,we suggest to include ‘States parties recognised that the majority of persons with disabilities and their familieslive in conditions of poverty’. COFACE Families Europe is taking a life-cycle approach towards disability, therefore it is important for us to consider the needs and rights of persons with disabilities both when they are young to have a family life (Article 7 CRPD), but also the right of adults with disabilities to found a family (Article 23 CRPD). The lack of independent living and community-based services do not only impact negatively the person with a disability, but their family and immediate circle too, including their parents, siblings, or their own children. The life-cycle approach should be mainstreamed throughout the General Comment, because persons with disabilities do not live in isolation, but with their parents, partners, spouses, children, or other relatives, just like anyone else.
2. **Para 14** should comprise a reference to the lack of access to employment with particular regard to the open labour market and adequate income.
3. **Para 15** should alsoinclude the definition of **community support services**, as it is a core part of Article 19 CRPD. The [Common European Guidelines on the Transition from Institutional to Community-based Care](http://www.deinstitutionalisationguide.eu/wp-content/uploads/2016/04/GUIDELINES-Final-English.pdf) define community-based services’, or ‘community-based care’, as a ‘spectrum of services that enable individuals to live in the community and, in the case of children, to grow up in a family environment as opposed to an institution. It encompasses mainstream services, such as housing, healthcare, education, employment, culture and leisure, which should be accessible to everyone regardless of the nature of their impairment or the required level of support. It also refers to specialised services, such as personal assistance for persons with disabilities, respite care and others. In addition, the term includes family-based and family-like care for children, including substitute family care and preventative measures for early intervention and family support’. This definition should be directly included in the text of the General Comment.
4. **Para 15 (a)** on **‘Independent living’** should include the recognition of and support for family carers, including the need to help maintaining or improving their quality of life, in line with the [Common European Guidelines on the Transition from Institutional to Community-based Care](http://www.deinstitutionalisationguide.eu/wp-content/uploads/2016/04/GUIDELINES-Final-English.pdf) and the [European Charter for Family Carers](http://www.coface-eu.org/resources/publications/charter-for-family-carers/). Furthermore, we suggest adding a more precise list of areas, including
* accessibility of the built environment;
* accessible transport;
* availability of technical aids;
* accessibility of information and communication;
* access to personal assistance, as well as life and job coaching; and
* access to community-based services.
1. In **Para 15 (c)** we suggest taking out ‘including large and smaller group homes’ in the first sentence. We also find problematic the sentence ‘therefore, neither large scale institutions with more than hundred residents nor smaller groups homes with five to eight individuals can be called independent living or community living arrangements’, as it gives the impression that numbers are the only, most important indicators of institutionalisation. As we explained earlier, rather than defining an institution by the size, or the number of the residents, the concept of ‘institutional culture’ is more suitable to identify the difference between ‘institutions’ and ‘independent living’. A small group home, located in the community can provide independent living if people have full choice and control over their life. It is the institutional culture that would characterize it as an institution. Having said that, institutional care could take place in even smaller settings, e.g. in a flat where two individuals live, or in cases where individuals live alone, but left without adequate support.
2. In our view, **Para 15 (d)** neglects the perspective of children with disabilities and persons with complex support needs. In their case, parents, relatives, or their immediate circle must play a role in contracting personal assistance services either as the guardian of children, or as supporters for those who do not have mental capacity in the supported decision-making process. It is important to provide personal assistance schemes to children with disabilities in order to avoid overburdening family carers, but good practices (e.g. from Norway, Flanders) show that it is the parents, or immediate relatives, who sign the contract and manage the budget for personal assistance. Undoubtedly, all persons with disabilities, regardless of their impairment, as well as children should be fully included in the process of choosing personal assistance services, and in the evaluation of such services.
3. **Para 16** should provide more clarity on the distinction between residential and institutional support services, specify what are residential support services and clarify that institutional support services are not in line with Article 19 CRPD.
4. In **Para 19**, we ask the Committee to use a more precise definition of the full and partial deprivation of legal capacity, instead of ‘legal capacity issues’.
5. The scope of **Para 20** should also refer to the fact that many people with high support needs are institutionalised due to the lack of accessible, affordable and good quality community-based services and family support. **Family support** is key to allow persons with severe, complex disabilities to live in the community through introducing a broad range of work-life balance measures (adequate resources, time arrangements and services) for family members and a flexible system in which persons with high support needs can use a combination of community-based professional and family care. The paragraph should also refer to persons with psychosocial disabilities, and persons with multiple disabilities.
6. **Para 23** should be more precise and describe that the implementation of Article 19 requires that migrants, refugees, asylum-seekers with disabilities and their families should not be detained. The right to family life is recognised in International and European human rights instruments and therefore, families should be supported and facilitated in the fulfilment of this right, with no discrimination of individuals or of family form. **Family reunification** is a vector of inclusion therefore no family should be discriminated and prevented from the enjoyment of this right.
7. In **Para 25**, the Committee rightly points out that in many cases, informal support by the family is the only available option, especially for people with disabilities in rural areas. Family members, mostly women take up the role of the family carer in order to fill the gap in public service provision and to avoid institutionalisation of their relatives. This leads to their fall out of the labour market and lack of income, access to social benefits, health care and pension. The paragraph should mention that this situation places the whole family in the risk of poverty and put high pressure on especially vulnerable and single parent families. **Inter-generational poverty** affects greatly persons with disabilities and their families. We suggest removing the sentence ‘Even if no formal laws are in place, others, like families or caregivers, sometimes exercise control and restrict an individual’s choices by acting as substitute decision-makers.’ and replace it with ‘Family members should receive adequate support to be able to promote the rights of persons with disabilities and support them in their decision-making in line with Article 12 of the CRPD’. In some cases, despite the obvious challenges and long-term disadvantages, persons with disabilities and their family members might prefer that care or support is provided at home by family members and professional carers. Their choice should be respected by providing logistical support and in-home services to persons with disabilities and their family members to ensure better reconciliation of care, work and private life. Last, but not least, families also need support if their relative with a disability lives and receives support far away from them, in order to be able to maintain family relations and avoid isolation.
8. Under **Para 29**, the draft GC describes the list of individualised services that are necessary to support living and inclusion in the community. We would like to highlight that **digitalisation** can play an immense role in improving the autonomy and independence of persons with disabilities, including older persons with disabilities, therefore public investment in ICT development and robotics should be considered as a priority.
9. It is very positive that **Para 30** of the draft GC particularly refers to respite services, supported parenting or parent’s night out services, which have a key importance for persons with disabilities and their family members.
10. In **Para 33**, it is necessary to add ‘employment’ in the first sentence. Furthermore, we suggest to take out the word ‘residential’ from the sentence ‘Various de-institutionalisation programs have shown that the closure of ~~residential~~ institutions’.
11. **Para 34** does not sufficiently reflect on the ever-changing nature of communities. Persons with disabilities and their families ideally can enjoy their right to move freely to another country, or community, therefore all communities should provide accessible community-based services to all persons with disabilities, regardless of their impairment, age, or support needs.
12. Without **adequate income**, or **personal budget**, persons with disabilities will not be able to have a real choice regarding their housing. Therefore, it is necessary to include a direct reference to ensure access to adequate income and personal budget under **Para 40 (b)**.
13. **Para 40 (c)** should additionally include ‘the development of a strategy with allocation of resources to support to families and people with care responsibilities for persons with disabilities, as to ensure that the right to live independently does not entail dependence on informal support from family and friends’. In no case the process of transition from institutional to community-based care 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, or support needs. The process of deinstitutionalisation must entail the development of a wide net of specialised facilities and community-based services, as well as global policies to support family carers. 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).
14. It would be necessary to clarify what ‘basic’ means in **Para 40 (e)** regarding mainstream community-based services to avoid that States Parties fail to provide some essential services if they don’t consider it as basic.

1. **Para 42** should be more concrete and include direct reference to ‘a realistic and short time frame’ for implementing the deinstitutionalisation process and the transition from institutional to community-based care. Studies show that deinstitutionalisation should take place within about six years’ timeframe and be started with moving out people who have the most complex needs.
2. We suggest taking out **Para 47** regarding the choice of individuals to live in institutional settings. The draft GC rightly considers institutional care as a human rights violation (see Para 65 of the draft GC), as it limits the individual’s choice and control over their life, as well as isolates the person from its community. Persons with disabilities who prefer institutional settings do so, because there is no alternative in the community and very often they would face homelessness and a socially deprived situation. We believe that the GC should focus on how to provide persons with choices that are in line with human rights standards, instead of implicitly supporting public and private investment in institutional care.
3. Families should not be considered as third parties, listed in **Para 50** alongside ‘service-providers, landlords or providers of general community services’, which people with disabilities deserve protection from. While recognising there is a case for more independence from families in adulthood, the current wording of the draft GC may be interpreted in a negative way towards families, enhancing some of the prejudices and discrimination they are subjected to. In line with the Preamble of the CRPD, family members should be empowered and supported to become facilitators of the social inclusion and development of their relatives with disabilities.
4. In **Para 51**, we agree that monitoring mechanisms should be introduced in order to protect persons with disabilities from violation, or abuse, but we would add ‘adopt measures which protect persons with disabilities from being hidden in the family, including measures to empower family members to protect the human rights of their relatives - or isolated in institutions’.
5. **Para 71** highlights a very important link between Articles 19 and 6 regarding the multiple and intersectional discrimination, institutionalisation, violence and abuse women and girls with disabilities face. The paragraph should also call States Parties to provide affordable, or free legal remedy and **support services for victims of violence and abuse**.
6. COFACE Families Europe finds it very positive that **Para 72** of the draft GC includes a particular reference to the situation of **women with disabilities** caused by gender stereotypical attitudes in society. We find it extremely important that States Parties adopt adequate **work-life balance measures** (resources, time, services) that support women with disabilities in **(re-)entering the open labour market** and facilitate the better share of parental duties between men and women.
7. We completely agree with the scope of **Para 73** and would further mention the need to introduce **adequate work-life balance measures** in order to prevent the institutionalisation of children with disabilities.
8. COFACE Families Europe compliments the CRPD Committee for including a detailed paragraph on the link between Articles 19 and 23 of the CRPD. We agree with the scope of **Para 84** and would only add that the mention of ‘adequate work-life balance measures’ would help States Parties to better understand what kind of support families need to avoid the institutionalisation of children.
9. Under **Para 94**, the draft GC should call States Parties to develop as part of the national implementation of Article 19 CRPD, measures that prevent the institutionalisation of persons with disabilities, with special regard to children and persons with intellectual, psychosocial disabilities and complex support needs, who are not yet in institutional care, but at risk due to the lack of community-based services, adequate income, or support network.

# Conclusions

1. Once again, we would like to thank the Committee for drafting the General Comment on Article 19 CRPD and hopefully the Committee will find our comments and feedback useful. We are looking forward to reading and using the final version of the General Comment.

For more information, please do not hesitate to contact Dr. Magdi Birtha, Policy and Advocacy Officer at mbirtha@coface-eu.org