**English**

**Questionnaire on** **the provision of support to persons with disabilities**

1. Please provide information on the following services that are available for persons with disabilities in your country, including data on their coverage, geographic distribution and delivery arrangements, funding and sustainability, challenges and shortcoming in their implementation:
2. Personal assistance;
3. In-home, residential and community support;

COFACE Families Europe[[1]](#footnote-1) brings together a large number of civil society organisations with the aim of giving a voice to all families and representing the issues most important to them at the European level. A lot of our members are fulfilling caring and supporting roles for their relatives with complex needs and profound disability.

COFACE Families Europe takes a life course approach towards disability and calls for the development of high-quality community-based support services for those needing care, or support. Persons with disabilities should have the opportunity to choose the form of care, or support they want. We also want family carers, who give their time and help free of charge, to be recognised through a certain number of rights, social and other benefits. These rights should also enable them to make an informed choice on caring arrangements, in agreement with their relative who has support needs and still preserve the quality of family life. Inadequate social protection floor, the lack of access of persons with disabilities to the mainstream school system, open labour market, support services, or health system leaves a lot of families at risk of poverty and may lead to human rights violations and institutionalisation of persons with disabilities. Unfortunately, in many European countries institutional care is still the only alternative for persons with disabilities, especially those living in rural areas. This practice must be stopped by investing in accessible, affordable, high-quality and person-centred community-based services.

1. Support in decision-making, including peer support; and
2. Communication support, including support for augmentative and alternative communication.
3. Please explain how persons with disabilities can access information about the existing services referred to in question one, including referral procedures, eligibility criteria and application requirements.
4. Please elaborate on how these services respond to the specific needs of persons with disabilities throughout their life cycle (infancy, childhood, adolescence, adulthood and older age) and how is service delivery ensured in the transition periods between life cycle stages.
5. Please provide information on the number of certified sign language interpreters and deafblind interpreters available in your country.
6. Please provide information on the existence of any partnership between State institutions and private service providers (e.g., non-governmental organizations, for-profit service providers) for the provision of support to persons with disabilities.

The European Expert Group on the Transition from Institutional to Community-based Care (EEG)[[2]](#footnote-2) is a broad coalition gathering stakeholders representing people with care or support needs and their families, including children, people with disabilities, homeless people, people experiencing mental health problems; as well as service providers, public authorities and intergovernmental organisations.

The Group has as its mission the promotion of person-centred, quality and empowering models of services and formal and informal care that fully respect the human rights of all people with care or support needs. The Group supports national efforts to implement the necessary reforms, in compliance with the United Nations Convention on the Rights of Persons with Disabilities (in particular with Article 19), the United Nations Convention on the Rights of the Child and the European Fundamental Rights Charter.

The Group provides expert support on EU policy, legislation and funding. All members of the Group provide a link to operational expertise at national, regional and local level through their direct involvement and the empowerment of their member organisations.

1. Please describe to what extent and how are persons with disabilities and their representative organizations involved in the design, planning, implementation and evaluation of support services.
2. Please provide any other relevant information and statistics (including surveys, censuses, administrative data, reports, and studies) related to the provision of support to persons with disabilities in your country.

Members of COFACE Families Europe are greatly affected by current social and demographical changes, such as the growing ageing population, changing family structures, the situation of intergenerational families, or women’s increased participation in the labour market. Leaving family carers to provide all the care for elderly people, or support to their relatives with disability, undermines the social inclusion (poverty risk), health (physical and/or mental exhaustion) and gender equality (most family carers are still women) of these families. However, we find the persistent existence of institutional care another threat, as they violate human rights and isolate people with care and support needs from their families and communities.

Please find more information about the situation of carers in the relevant chapter of the European Reconciliation Package:

<http://www.coface-eu.org/en/upload/ERP/ERP_2015-carers.pdf>

As co-chairs of the European Expert Group on the Transition from Institutional to Community-based Care, COFACE Families Europe is advocating for the investment in community-based services that would provide person-centered support, instead of maintaining institutional care. We would like to highlight that long-term care should never take place in institutional settings, but in the form of home-based care, or community-based care. People with care and support needs should be provided with a flexible system in which they can use a combination of informal and formal care, and have access among other measures to a personal budget and personal assistance system. COFACE Disability published the European Charter for Family Carers[[3]](#footnote-3), a reference tool that contributes to reconciling family and working life by allowing an informed choice by the person with care needs and the carer too and provide them with adequate financial compensation, as well as social rights and benefits (pension, respite care etc.).

1. <http://www.coface-eu.org/en/> [↑](#footnote-ref-1)
2. <https://deinstitutionalisation.com/> [↑](#footnote-ref-2)
3. <http://coface-eu.org/en/upload/07_Publications/COFACE-Disability%20CharterEN.pdf> [↑](#footnote-ref-3)