



S.H.I.F.T.

Support - Human rights - Independence - Families - Transition

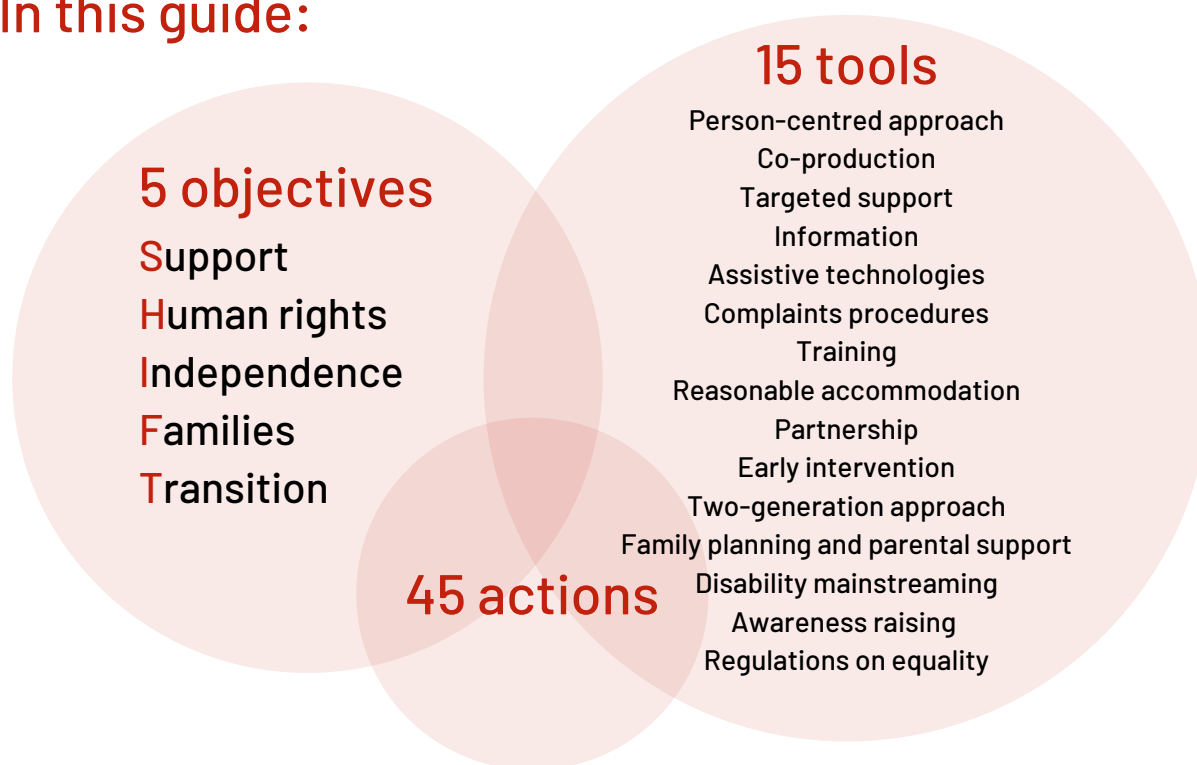
A GUIDE TO SHIFT TOWARDS
MEANINGFUL INCLUSION OF
PERSONS WITH DISABILITIES
AND THEIR FAMILIES



For further information about this paper and on COFACE Families Europe's stance on disability please contact:

Irene Bertana, Policy and Advocacy Officer, COFACE Families Europe
ibertana@coface-eu.org

In this guide:



towards meaningful inclusion of persons with disabilities and their families

Using the UN Convention on the Rights of Persons with Disabilities (UNCRPD) and the 2030 Sustainable Development Goals as the guiding vision, the COFACE Disability Guide highlights **5 objectives**, **15 tools**, and **45 actions** that different actors in society can use to contribute to a human rights-based and sustainable shift towards meaningful inclusion of persons with disabilities and their families.

Deinstitutionalisation is not only about closing down large-scale residential institutions, but refers to the whole process of putting inclusion and respect of human rights at the centre of all policy actions towards persons with disabilities, from birth to old age.

This means developing a range of person-centred support services in the community, having efficient ways to monitor the respect of human rights, making the mainstream sector inclusive and accessible, empowering the families of persons with disabilities, and driving a cultural shift to embrace inclusion as an overarching value in society.

OBJECTIVES

setting our vision for the future



SUPPORT

The disability sector is structured in order to achieve the full inclusion of persons with disabilities in society, avoiding segregated settings in all areas of life and offering needs-based and evidence based options.



HUMAN RIGHTS

Persons with disabilities are aware of their rights and they exercise them, by deciding for themselves in every area of life.



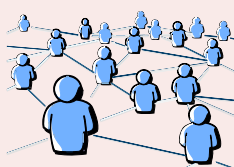
INDEPENDENCE

The mainstream sector is re-shaped to be inclusive in all its services that are available to the general public, the persons with disabilities can choose between different options, according to their needs and wishes.



FAMILIES

Families where a member has disabilities are empowered, enjoy a stronger social protection, and are fully included in society. Persons with disabilities enjoy their right to found their own family.



TRANSITION

The whole society embraces the value of inclusion, persons with disabilities and their families participate actively in every area of life as their equal opportunities are promoted and respected.

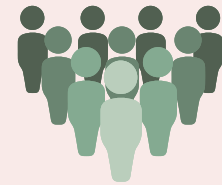
TOOLS

for achieving inclusion

Person-centred approach in social, educational, employment, housing and health sectors.

Co-production: full inclusion of persons with disabilities and key stakeholders in the design, implementation and evaluation of services.

Targeted support on independent living and autonomy.



SUPPORT

Information to persons with disabilities and their families about their rights.

Easy-to-read, technical aids and assistive technologies to facilitate communication.

Complaints procedures and involvement of independent bodies to monitor the respect of human rights of persons with disabilities-



HUMAN RIGHTS

Training on inclusion to mainstream sector professionals and **reasonable accommodation** in the fields of education, health care, housing, employment, public transport, leisure and sport.

Cross-sectoral and multi-level partnerships building bridges between disability-specific and mainstream sectors and professionals.



INDEPENDENCE

Identify and provide effective **early intervention and support** to children and their families.

Two-generation approach in the assessment of needs and support, including of family carers.

Family planning and parental support for persons with disabilities.

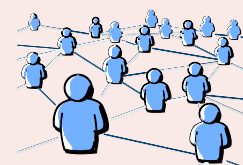


FAMILIES

Mainstream disability issues across all policy areas.

Information and awareness raising on the benefits of inclusion of all people in society.

Regulations on equal participation of persons with disabilities in all areas of life.



TRANSITION

ACTIONS

to transform the disability sector



SUPPORT

TOOLS:

- PERSON-CENTRED APPROACH
- CO-PRODUCTION
- TARGETED SUPPORT

ACTIONS:

- Reform the disability sector, providing a spectrum of inclusion-oriented and community-based support services looking at the specific needs persons with disabilities (including physical, sensorial, intellectual, psychosocial and severe disabilities) and of their families.
- Use the "European Quality Framework for Social Services" in the development and evaluation of services, including the respect of the users' rights, participation and empowerment.
- Invest in services innovation fostering a person-centred approach, and the co-production methodology involving persons with disabilities and their families as experts by experience.
- Require day care centres to structure their activities in inclusive community settings.
- Deliver housing services according to the persons' needs and wishes, with specific schemes to provide adequate housing support for persons with severe disabilities.
- Create employment support services for persons with disabilities recognising and enhancing their skills, and based on their choice and wishes.
- Give persons with severe disabilities the opportunity to take part in meaningful activities outside the home, including work, education and leisure.
- Support the transition out of care by offering special trainings on independent living and autonomy to adults, and youngsters reaching 18 years of age.
- Establish and support national and International partnerships to innovate the sector.

ACTIONS

to increase the respect of human rights of persons with disabilities



HUMAN RIGHTS

TOOLS:

- INFORMATION
- ASSISTIVE TECHNOLOGIES
- COMPLAINT PROCEDURES

ACTIONS:

- Adopt a definition of disability in line with the human rights model, as a function of the interaction of the person with the social and physical environments and work on its harmonisation at international level.
- Establish the respect of human rights and the well-being of people as policy objectives.
- Ensure a meaningful involvement of persons with disabilities, their representatives and their families in all decision making processes.
- Ensure the right to live and grow up in a family for children with special needs (providing adequate family support) and that children without parental care can grow up in a family setting (providing extended kinship care, foster care, or adoption).
- Include the principles of the UNCRPD in the curricula of professional and retraining of staff providing services to persons with disabilities.
- Provide training on the UNCRPD to persons with disabilities and their families.
- Support and establish self-advocacy movements.
- Monitor the respect of human rights in services for persons with disabilities, create user councils to give a voice to persons with disabilities, ensure that complaint procedures are provided, and complaints are responded to appropriately.
- Promote and fund the use of technology to increase the choice and control by the persons with disabilities, including of those with severe and multiple disabilities.

ACTIONS

to improve the independence of persons with disabilities



TOOLS:

- TRAINING ON INCLUSION
- REASONABLE ACCOMMODATION
- NATIONAL, CROSS-SECTOR AND MULTI-LEVEL PARTNERSHIPS

INDEPENDENCE

ACTIONS:

- Improve the accessibility of the built environment and mainstream services such as schooling, health care, social housing, public transport, leisure and sport.
- Ensure the availability and reasonable accommodation of mainstream day-care, early childhood education and care, schools, out-of-school care and after-school activities for children with disabilities.
- Support to the transition of students with special educational needs towards the labour market or towards higher education.
- Foster the participation of persons with disabilities in the open labour market, including instruments such as quota in the public sector, and incentives or awareness raising in the private sector.
- Ensure the implementation of correct procedures in the health and hospital sector to respond to the needs of persons with disabilities and of those with high support needs including cooperation with their families to facilitate communication and identification of needs.
- Create legislative frameworks to provide personal assistance to persons with disabilities.
- Develop personal care budget schemes.
- Include disability awareness in the trainings of the public sector workers.
- Foster local partnerships of the different stakeholders working with persons with disabilities.

ACTIONS

to empower families with members with disabilities



FAMILIES

TOOLS:

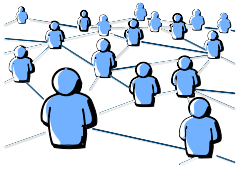
- EARLY INTERVENTION
- TWO-GENERATION APPROACH
- PARENTAL SUPPORT TO PERSONS WITH DISABILITIES

ACTIONS:

- Create legislative frameworks to recognise and support family carers, inspired by the COFACE Disability "European Charter for Family Carers" in the areas of choice, peer support, respite services, reconciliation measures, counselling and psychological support.
- Ensure an early and transdisciplinary assessment of child conditions and of family needs, including siblings.
- Support financially persons with disabilities and their families with all the disability-related expenses.
- Commission a range of respite services that provide staff with sufficient skills, expertise, equipment and facilities to meet the needs of families supporting persons with profound intellectual and multiple disabilities.
- Increase the use of participatory and empowering methodologies to solve family conflicts and plan support
- Offer subsidised or free training to family members providing care and/or support to persons with disabilities, especially to those with severe disabilities.
- Strengthen work-life balance measures for parents or spouses of persons with disabilities, with special leaves and financial support in case of high support needs.
- Provide sexuality education and parenting support to persons with disabilities.
- Strengthen family, parents' / family carers' networks, and foster peer support.

ACTIONS

to shift societies towards full inclusion of persons with disabilities



TOOLS:

- **DISABILITY MAINSTREAMING**
- **AWARENESS RAISING**
- **REGULATIONS ON EQUAL PARTICIPATION**

TRANSITION

ACTIONS:

- **Mainstream disability across all policy areas and consolidate policy frameworks based on the promotion and protection of human rights, non-discrimination, tolerance, respect for diversity, equality of opportunity, solidarity, security, and participation of all.**
- **Create awareness-raising campaigns and programmes promoting greater social awareness towards persons with disabilities, informing on their different needs and abilities in society, and affirming their dignity as human beings.**
- **Foster an attitude of respect for the rights of persons with disabilities at all levels of the education system, including in all children from an early age.**
- **Encourage the media to increase the representation of persons with disabilities, in movies, series, TV shows, and advertising, portraying them in a positive way.**
- **Incentivise the toy industry to represent disability and to create toys adapted to children with different kinds of disabilities.**
- **Include human rights education in school curricula.**
- **Implement Universal Design principles into new developments in the areas of ICT, transport, the built environment and product development.**
- **Reinforce anti-discrimination law at all levels.**
- **Involve persons with disabilities and their caregivers in consultations to understand their safety and dignity concerns, the barriers they face, and how to overcome these.**

USEFUL RESOURCES:

A Voluntary European Quality Framework for Social Services, Social Protection Committee, SPC/2010/10/8 final, 2010

Online: <https://ec.europa.eu/social/BlobServlet?docId=6140&langId=en>

Common European Guidelines on the Transition from Institutional to Community-based Care, European Expert Group on the Transition from Institutional to Community-based Care, 2012

Online: <https://deinstitutionalisationdotcom.files.wordpress.com/2017/07/guidelines-final-english.pdf>

Convention on the Rights of Persons with Disabilities and its Optional Protocol, United Nations, 2006

Online: <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html#Fulltext>

European Charter for Family Carers, COFACE Families Europe, 2017

Online: <http://www.coface-eu.org/wp-content/uploads/2016/12/European-Charter-for-Family-Carers.pdf>

European Pillar of Social Rights, European Parliament, Council and Commission, 2017

Online: https://ec.europa.eu/commission/sites/beta-political/files/social-summit-european-pillar-social-rights-booklet_en.pdf

From Institutions to Community Living: key Findings and FRA Opinions, Fundamental Rights Agency, 2018

Online: https://fra.europa.eu/sites/default/files/fra_uploads/fra-2018-independent-living-summary_en.pdf



USEFUL RESOURCES:

General comment No. 5 on living independently and being included in the community, Committee on the Rights of Persons with Disabilities, 2017

Online: <https://www.ohchr.org/en/hrbodies/crpd/pages/gc.aspx>

Guidelines for the Alternative care of Children, Resolution adopted by the General Assembly, United Nations, 2010

Online: https://www.unicef.org/protection/alternative_care_Guidelines-English.pdf

The Family Dimension of the United Nations Convention on the Rights of Persons with Disabilities, COFACE Families Europe, 2012

Online: <http://www.coface-eu.org/wp-content/uploads/2017/01/COFACE-DISABILITY-UNCRPD-BOOK.pdf>

The right to live independently and to be included in the community in the European States: ANED synthesis report, Neil Crowther, on behalf of the Academic network of European disability experts (ANED), with contributions from the ANED country experts, 2019

Online: <https://www.disability-europe.net/downloads/1040-task-year-4-2018-19-policy-theme-il-synthesis-report>

Toolkit on the Use of European Union Funds for the Transition from Institutional to Community-based Care, European Expert Group on the Transition from Institutional to Community-based Care, June 2014

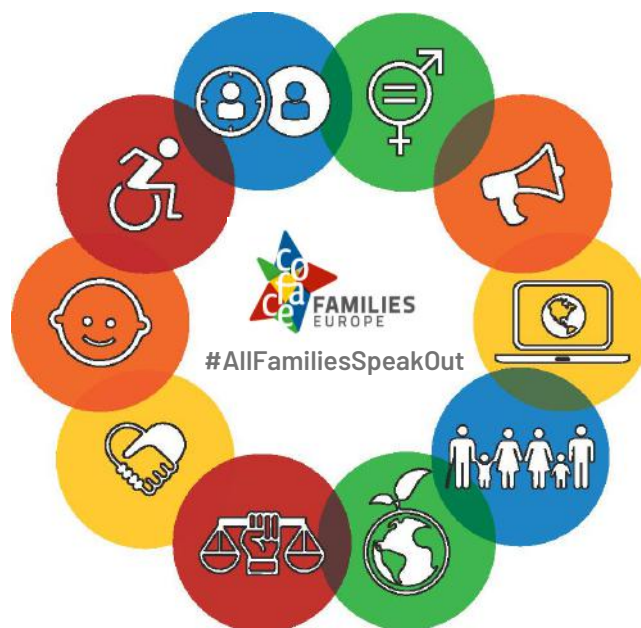
Online: <https://deinstitutionalisationdotcom.files.wordpress.com/2017/07/toolkit-10-22-2014-update-web.pdf>

Transforming our World: The 2030 Agenda for Sustainable Development, United Nations, 2015

Online:

<https://sustainabledevelopment.un.org/content/documents/21252030%20Agenda%20for%20Sustainable%20Development%20web.pdf>





About COFACE Families Europe

COFACE Families Europe has been involved for 60 years in building a strong social, family friendly Europe. It brings forward the voice of millions of families, gathering 60 organisations from all over Europe. COFACE Families Europe advocates for strong social policies that take into consideration family needs and guarantee equal opportunities for all families.

About COFACE Disability Platform for the rights of persons with disabilities and their families

COFACE-Disability was founded by COFACE Families Europe in 1998 to better represent persons with disabilities and their families. COFACE Disability's mission is to promote the interests of persons with disabilities, their families and caregivers and to support the enjoyment of their rights throughout their lives.



For more information please contact

COFACE Families Europe

Rue de Londres 17, 1050 Brussels

Tel: +322.511.41.79

Email: secretariat@coface-eu.org

Website: coface-eu.org

Facebook /COFACE.EU

Twitter @COFACE_EU



This publication has received financial support from the European Union Programme for Employment and Social Innovation «EaSi» (2014-2020)

For further information please consult: <http://ec.europa.eu/social/easi>

This document is produced with the support of the European Commission but does not necessarily express its views. Copyright © 2019 COFACE, All rights reserved.