



The right to independent living and to be included in the community

Art. 19 being a core element of the UNCRPD because:

- It emphasizes persons with disabilities rights and choices equal to others as right bearing individuals and not recipients of welfare or charity,
- It aims to prevent social exclusion, segregation and institutionalization,
- It encourages inclusive environments and participation in all aspects of life,
- It rejects policies and practices that deprive people of autonomy and choice,

Implementing Art. 19 is about fostering and empowering personal competence, identity and persons with disabilities potential

The duties of the European Union as party to the UNCRPD

Respect

- The EU must refrain from engaging in any act or practice that is inconsistent with the UNCRPD and ensure that EU institutions act in conformity with the Convention.
- The EU must repeal all existing discriminatory EU laws, regulations, and practices.

Protect

- The EU must adopt all appropriate legislative, administrative and other measures where needed for the implementation of the UNCPD.
- The EU must take all appropriate measures to eliminate discrimination on the basis of disability by any person, organization or private enterprise.

Facilitate

- The EU must take into account the protection and promotion of the rights of persons with disabilities in all its policies and programmes.
- The EU must undertake or promote research and development initiatives aiming at improving the rights of persons with disabilities .





Union of Equality: Strategy for the Rights of Persons with Disabilities 2021-2030

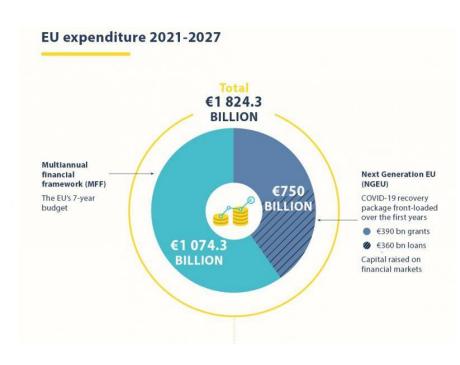
Developing independent living and reinforcing community-based services



Union of Equality
Strategy for the Rights
of Persons with Disabilities
2021-2030

- Supporting national, regional and local authorities in their efforts for deinstitutionalisation and independent living, through EU funding
- Issuing guidance to Member States on independent living and inclusion in the community, in order to enable persons with disabilities to live in accessible, supported housing in the community, or to continue living at home (including personal assistance schemes).
- Presenting a specific framework for Social Services of Excellence for persons with disabilities, to improve service delivery for persons with disabilities
- Implementing good practices of deinstitutionalisation in the area of mental health and in respect of all persons with disabilities, including children, to strengthen the transition from institutional care to services providing support in the community;

Supporting the implementation of the disability strategy through EU funding



The European Structural and Investment Funds (ESIF) set out so-called 'enabling conditions' for funding to MS to ensure that the investment environment for EU support is well prepared upfront. One enabling condition requires that a national framework to ensure implementation of the UNCRPD is in place.

The ESIF support areas such as deinstitutionalisation, community care, socioeconomic inclusion of persons with disabilities, access to services, inclusive education and healthcare, making cultural heritage more inclusive and ensuring accessibility.

Given the heavy reliance by a number of EU Member States on the ESIF to support the process of deinstitutionalisation, they have a huge potential to play a pivotal role in advancing the rights of persons with disabilities to live independently and to be included in the community.

The use of ESI Funds in facilitating the transition from institutional care to community living for people with disabilities during 2014 – 2020

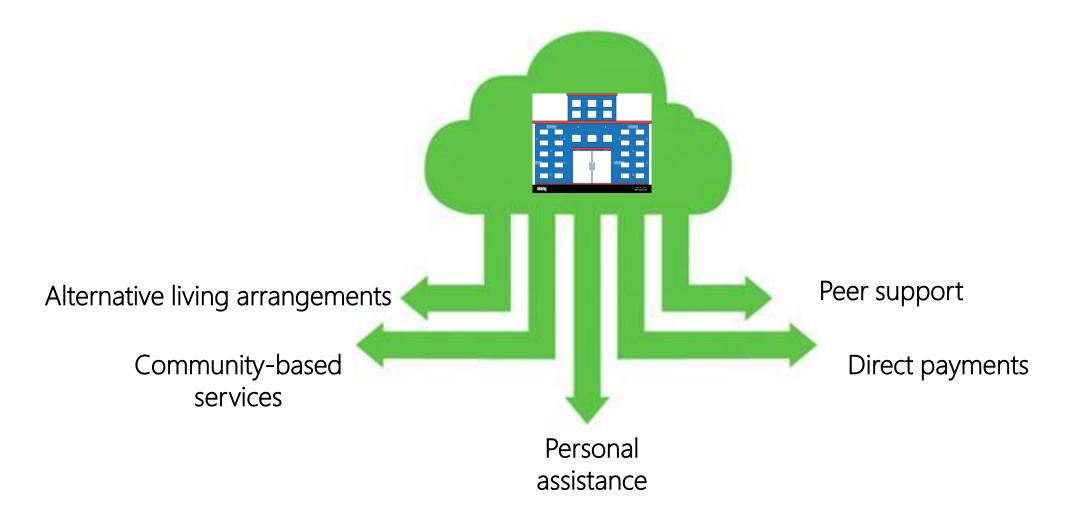


Report on the Transition from Institutional Care to Community-Based Services in 27 EU Member States. The European Expert Group on the transition from institutional to community-based care, 2020

The right to live independently and to be included in the community in the European States. Academic Network of European Disability Experts (ANED), 2019.

Inclusion for all: achievements and challenges in using EU funds to support community living. Community Living Europe - Structural Funds Watch (2018)

Approaches of the use of the ESI funding for deinstitutionalisation by the Member States





Alternative living arrangements

Resettling the current residents of institutional care facilities into smaller-scale modes of congregate living and support (CZ, EL, HU, LT, PL, SI, LT)

Setting caps on the numbers of persons with disabilities that can reside in the same setting - ranging from 4 to 50 persons (HU, PO, CZ, SK, IE, SE)

Diversifying the range of housing and support options available to persons with disabilities (IE, FI, NL)

Developing Community-based services

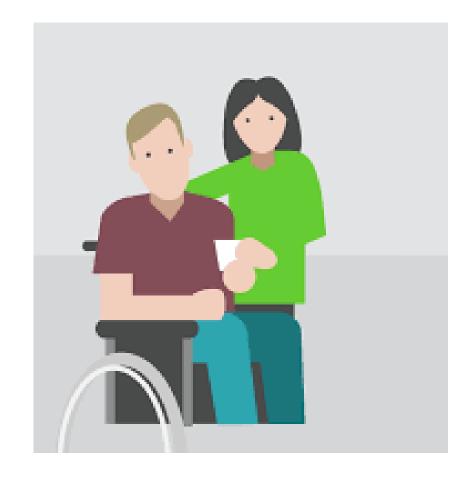


Delivering of person-centred care in the home and community. to enable people to stay in their homes, rather than moving to a facility for care, both generally, as well as specifically towards the goal of deinstitutionalisation (LV, LT, MT, CZ)

Shifting gradually the balance of spending from institutional modes of care to day care, domiciliary care and personal assistance (SK, SL, EE, BG)

Introducing schemes for personal assistance

Providing persons with disabilities with their own personal assistant, empowering them to be in control of how support is provided in their day-to-day lives (MT, PT, SK)



Implementing personal budgets and direct payments

Funding persons with disabilities to enable them to buy in support that is assessed as being needed, instead of providing that support through local public services or through service providers (IT).



Implementing peer support schemes

Developing programmes aiming at providing mutual, one-to-one relationships between more experienced and less experienced persons with for the purpose of personal and professional development.

In the Structural Funds Watch report (2018), it was noted that in 2017, there were <u>no mention</u> of fostering peer support networks, or organisations of ex-users and survivors of mental health services.



Issues and concerns in the use of ESI Funds for people with disabilities during 2014 – 2020

The number of people in institutions has not "substantially changed" over the past 10 years. Despite a gradual shift away from institutions, progress in many countries has slowed down in the last 7 years.

Access to the ESI Funds including for the transition from institutional care to community-based services, has failed to substantially decrease the number of people in institutions and to significantly improve opportunities for children and adults with disabilities to grow up in families and to live independently in the community.



In May 2020, the Special Rapporteur on the rights of persons with disabilities and the Special Rapporteur on adequate housing sent a 'communication to the European Commission raising concerns about the "inappropriate use of European Structural and Investment Funds (ESIFs) to maintain institutional care, including by replacing large institutions for persons with disabilities with smaller institutions in several countries of the European Union"



Important Steps to be taken in the use of ESI Funds in facilitating the transition from institutional care to community living

Giving prominence to the concept of independent living rather than 'community-based care

Providing clearer guidelines about the meaning of deinstitutionalisation drawing upon General Comment 5 of the CRPD

Establishing closer coordination among ESI funding sources

Ensuring closer consultation and involvement of persons with disabilities in all stages of the ESI funding

Introducing closer monitoring and sanctions for non compliance with the principles of article 19

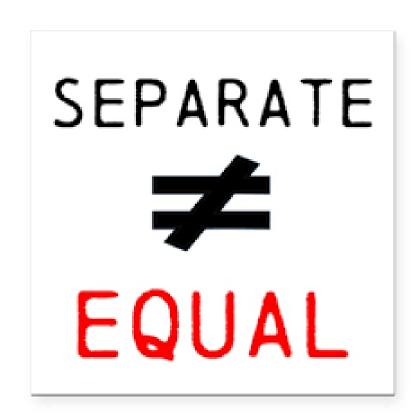
Encouraging MS to take measures, including support for innovation, increased investment and regulatory measures, to diversify housing and support options

Why the implementation of article 19 is so difficult?



It is about new ideas and beliefs

- Introducing new and innovative policies and practices are problematic if the basic underlying ideologies and system are not compatible with the proposed innovations.
- New policies and practices have to come to be embedded in operations and everyday actions of various actors in the society and at various levels

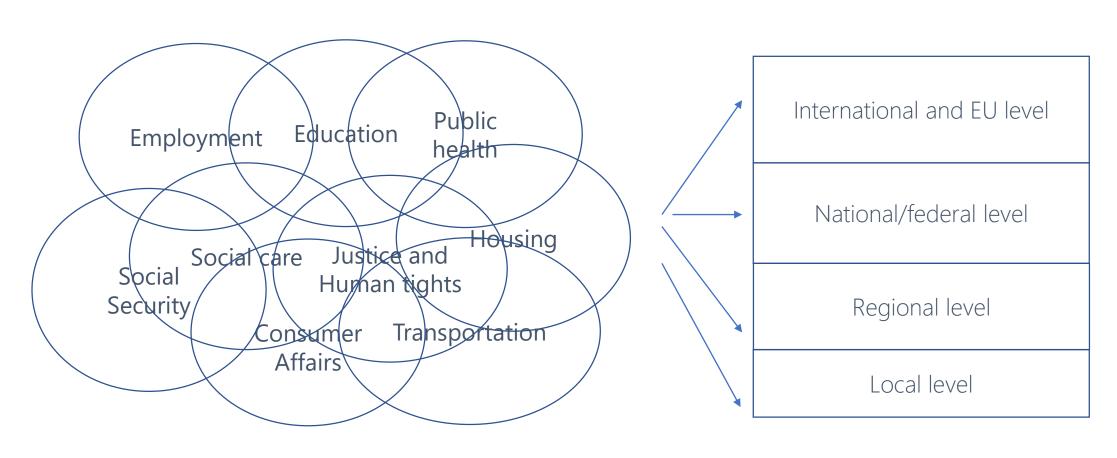


It is about complex problems

Goals such as the right to community living require complex changes in personal, and institutions behavior and practices to attain.



It is a multi-sectoral and multi-institutional issue



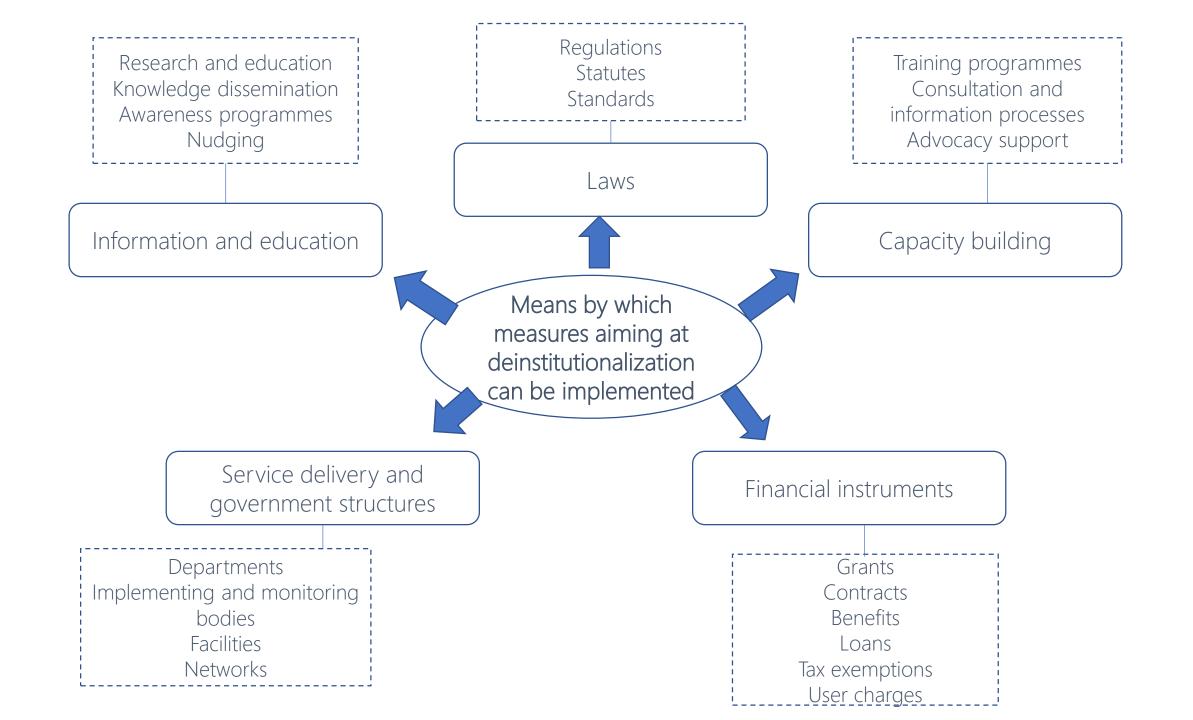
Sectoral policies

Institutional levels

It requires the right combination of different policy instruments

Issues such as deinstitutionalisation come in complex matrixes, and policy responses usually must consist of a matrix of instruments.





It is about choosing adequately between competing and complementary strategies

	Formal	Informal
Sustaining	Improve	Supplement
	System	Change
Disruptive	Reinvent	Transform

Formal

Informal

Sustaining

Fostering better practices in the existing social care programmes for people with disabilities

Combining different types of services, programmes and policies for persons with disabilities

Disruptive

Creating radically different kinds of services for persons with disabilities

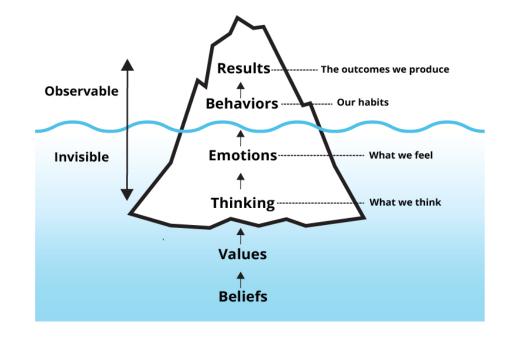
Doing new things in new ways in new settings...often without experts, guidelines and rules (pull/not push)

To make our disability system more resilient, capable, adaptive, we need more transformative innovation



Transformation within our organization began with 'hanging our culture. We decided to challenge our own restrictive assumptions and practices, and to explore successful strategies for seizing opportunities and building new relationships with other people and places in our community to facilitate social change and full citizenship

Realizing the program-based supports we were offering were the problem, we began to look for solutions. We reached out to other organizations in the sector who had successfully transformed their support services."



A final thought

Knowledge dissemination is far more than the simple distribution of information or good practices.

it is a process requiring a careful match among the creation of new knowledge, and the context of that creation, the needs, contexts, prior experiences, values, and beliefs of the target audiences, and the channels used in getting the outcomes into the hands, minds, and activities of those target audiences.

