

# Plenary 1: Community Care in Europe

## Where do we stand?



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# State of Play in Deinstitutionalisation Social Services Leading Care in the Community 9 -10 October, 2023 Barcelona, Spain

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The logo grid includes the following organizations and forums:

- unicef
- LUMOS
- inclusion europe
- ECCL European Coalition for Community Living
- MHE Mental Health Europe
- European Social Network
- EUROPEAN DISABILITY FORUM
- FEANTSA
- Autism Europe aisbl
- Eurochild Putting children at the heart of Europe
- GO TO FAMILIES EUROPE
- EASPD

**EUROPEAN EXPERT GROUP ON THE TRANSITION  
FROM INSTITUTIONAL TO COMMUNITY-BASED CARE**

# Outline

1. Definition of institutions and institutional culture
2. Current situation in terms of Deinstitutionalisation and the development of community care in Europe – Comparison 2007 to 2020
3. Has progress varied by population groups?
4. What if anything has changed?
5. What is still needed to move forward?

# Definition of institution and institutional culture

- “Users are isolated from the broader community and/or compelled to live together;
- these users do not have sufficient control over their lives and over decisions which affect them;
- the requirements of the organisation itself tend to take precedence over the users' individualised needs.” (The EC Adhoc expert group, 2009)
- Institution is not defined by its size

*To allow comparisons, in our study we used the same definitions as Mansell et al had used in DECLOC study in 2007 – large residential services = 30 or more places. Institutional setting = more than 6 people living together.*

“It is more helpful to focus on the definition of community living

- living in ordinary housing – same range of housing options available to those without disabilities
- participation in community
- choice and control, and equal rights and access

# Community Living definitions over time....

Kings Fund Centre (1980) defined community living as:

- Local housing with support for people of all levels of disability
- Work and work experience as an alternative to day care
- Widening participation of people with all levels of disability in community life

*“The aim of community living ... is to enable people with ....disabilities to use the same range of accommodation, living arrangements and patterns of living that are available to the rest of the population, and to have a good quality of life, participating as full citizens in social, cultural and economic activities to the extent and in the ways the individual chooses” (Mansell and Beadle-Brown et al. 2010, page p. 106).*

**UNCRPD Article 19, 2006** community living = having a home in the community like everyone else with choice over where and with whom they live AND support for full inclusion and participation in the community. ...

# Current situation

- Are Large Residential settings (Institutions) still being used?
  - YES
    - in 26/27 countries large residential settings were still used for adults with disabilities, adults with mental health conditions and older adults.
    - In 25/27 countries large residential settings were still used for children with disabilities.
    - In 19/27 countries large residential settings were still used for unaccompanied and migrant children
    - For some countries no data was available for one or more groups.
    - Very limited data on those who are homeless – where data was available (4 countries) larger residential settings still used.

## Current situation cont.

- How many people still live in institutions
  - Lots of missing data
  - Estimated at 1,321,927 people who live in residential care in a setting of more than six people with a disability or mental health needs.
  - Very few countries were providing small residential settings (i.e. six or fewer).
- Are people living in their homes with support to be active members of their community?
  - Limited data
  - Personal assistance or equivalent available at least as a pilot for some populations in 17/27 countries
  - In five other countries personal assistance was part of the plan



# Has the situation changed since 2007?

- Calculated estimates for number of people living in residential care with more six or more other people to compare with the figures from the DECLOC study in 2007.
- No data available for some countries and some population groups – likely to be an underestimate.
  - In 2019 estimate was: 1,294,253 ; In 2007 estimate had been: 1,286,059
- Most progress made for children.
- Adults with intellectual disabilities still most likely to be in institutions
- Growth in aging population makes it difficult to draw conclusions for older adults. Deinstitutionalisation in Central and Eastern Europe - structural funds. Lack of change in western European countries - reinstitutionalisation.



# Some key conclusions

- In many countries still seen as a project, conducted with **external funding**. Driven by **external expectations** rather than internal motivation?
- Policies and plans do not include **how progress will be continued** or maintained without EU or other external funds
- Lack of **affordable and suitable housing** is key barrier to people moving out of institutions or not going into them.
- Very little data to show that people are actually experiencing community living. Almost no data to show if UN CRPD is being implemented. Focus is still on people NOT living in institutions rather than on people Living and participating **in the community**.
- Possible to collect and collate data that would enable this – some potential models found – e.g. Unicef TransmonEE dashboard; research on homelessness that prompted understanding of risk factors and outcomes.
- Need clear and agreed **definitions** to allow accurate monitoring.

# What is needed to move forward

- Take a **rights-based approach** centred on giving effect to Article 19 of the CRPD\* & on transforming the lived experience of people with disabilities
- Ensuring **consistency of definitions**, concepts across policy, regulation and data collection;
- Speaking about community care and not closing institutions, address fragmentation of services, and promote better care integration (transition child protection – adulthood, hospital-home care etc.)
- **Housing** is key but not everything – must have the **support structures** in place to ensure people can live and be included in the community – not matter what their level of disability.



\*CRPD = UN Convention on the Rights of Persons with Disabilities

## Do's and don'ts (some...)

Do	Don't
<p>Employ partnering people with disabilities and their representative organisations in formulating goals, plans and actions in their implementation</p>	<p>Allow providers of institutional care to lead deinstitutionalisation strategies and processes</p>
<p>In consultation with people with disabilities, and researchers, develop progress measures that centre on the lived experience of living independently and being included in the community as compared with non-disabled people</p>	<p>Rely on proxy process measures concerning where people with disabilities are residing, how many people access particular services.</p>

**Thank you**

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