Independent living in Europe

Irene Bertana
Policy and Advocacy Officer
COFACE Families Europe

Round Table on the Implementation of the UNCRPD article 19 on independent living
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In the last 20-30 years disability and disability-related policies have been at the centre of an important evolution, or revolution, based on a paradigm shift from a medical to a social approach to disability, where the focus moves from treating the medical conditions to the social barriers to a substantive equality of persons with disabilities.
Erving Goffman 1922-1982

• One of the most influential sociologists of last century
• Theatre metaphor: humans as social actors in a social representation
• The self is determined by society
• The ‘institutions’ are places that are segregated from society through permanent barriers which don’t allow the outside perception, with different roles and clear distinction between who is part and who is not part of the institution. They are functional to the social representation,
• He writes ‘Asylums: Essays on the Conditions of the Social Situation of Mental Patients and Other Inmates’ in 1961
Goffman’s ‘total institutions’

- Different kind (shelters, orphanages, prisons, psychiatric hospitals, rehabilitation centres..)
- Large number of people
- Separation from wider society by distance, laws, protections
- All aspects of life happen in the same place and are regulated by the same single authority
- Strict norms, rules, schedules
- Those who live within them tend to be similar to each other in some way
- Deprivation of the old identity, for a new one
- Involuntary treatment: new identity is a stigmatized one, lowering the person’s status
- Deprivation of autonomy
- Limited or prohibited communication with the outside world
Consequences of institutionalisation

• Goffman adaptation alignments: withdrawal, rebellion, colonisation, conversion

• Many people end up homeless or in jail after leaving institutions: institutional syndrome after the deinstitutionalisation

• In children: risk of behavioural, communication problems, to symptoms of autistic behaviour

• In adults: deficit in social and life skills, loss of autonomy, higher risk of psychosis

• Stigma, negative social label
Social model of disability

- UK 1975, Union of the Physically Impaired Against Segregation
  «in our view it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecassarily isolated and excluded from full participation in society»

- 1983, Mike Oliver «social model of disability»
- Then, inclusion of persons with intellectual disabilities, and persons with mental health problems
- Focus: struggle for equality, empowerment, self-determination
- «Nothing about us without us»
- Disability vs. impairment
The social model in International law

- UN Convention on the Rights of Persons with Disabilities (UNCPRD), 2006
- First human rights treaty of the XXI century
- First HR convention open for signature by regional integration organisations
- Broad definition of disability
- Choice
- Legal capacity
- Independent living
- Inclusive education
- Reasonable accommodation
- Right to family life

- The European Union ratifies it in 2010
- European Disability Strategy 2010-2020
- European Pillar of Social Rights 2017
- European Accessibility Act 2019
European Actions

• Social Rights
• Legislation
• European Funds
• Advocacy
• European Alliances
Deinstitutionalisation

EU Fundamental Rights Agency– Report 2017 - definitions

An institution is 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;
• The requirements of the organisation itself tend to take precedence over the residents’ needs

Community-based services: spectrum of services that enable individuals to live in the community including mainstream services (housing, healthcare, education, employment, culture and leisure) and specialised services (e.g. supported living, personal assistance)
Community-based services

- Personal assistance
- Support for enhancing life skills and autonomy
- Day care
- Technical aids and assistive technologies
- Non-segregated social housing within the community
- Accessibility of services and built environments, (transport, housing, public buildings...)
- Supported housing

- Inclusive education (ECEC, day-care, out-of-school care and after-school activities)
- Employment-related measures, vocational and skills training
- Parental and carer support
- Strengthening of foster carers/parents networks
- Crisis intervention and emergency services
- Social work, including counselling and advice services
- Respite care services
Keywords for an inclusive transition

- Prevention
- Choice
- Autonomy
- Lyfe-cycle approach
- Tailor-made support
- Person-centred approach
- Co-production
What makes DI successful?

- **Commitment** to deinstitutionalisation
- **Change in attitude** towards persons with disabilities
- **Active cooperation** between the people involved in DI
- **Availability of guide and support**
- **Practical organisation**

FRA, 2018
What key barriers?

- Insufficient funding
- Resistance from service providers
- Institutional model of care persisting
- Learned dependence from PWD
- Family resistance
- Insufficient information to families and PWD
- Lack of cross-sector cooperation
- Insufficient national guidance
- Lack of specialised support in the community
- Lack of employment opportunities for PWD
- Inaccessible general services

FRA, 2018
Family members are providing the 80% of long-term care in Europe and their support must be part of the transition to community-based support for persons with disabilities.
RECOMMENDATIONS AT NATIONAL LEVEL
1. Develop community-based services
2. Right to choice
3. Health prevention
4. Legal recognition and social security for family carers
5. Work-life balance policies to address care penalty
6. Improve the working conditions of the long-term care sector
7. Administrative changes to improve access to informations and support
8. Involvement, inclusion and awareness-raising

RECOMMENDATIONS AT EUROPEAN LEVEL
1. Driving policy reform towards a more holistic long-term care
2. Adopt and consolidate legal measures to improve the social protection of family carers and of persons in need of care
3. Research and innovation
4. Legal recognition and social security
5. Monitoring and evaluation of national reforms
6. Transformative EU funding investments
THANK YOU