



# **“De-institutionalization” in international context: A Human Rights perspective**

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# Human rights of people in the context of institutional care

- Universality of human rights – all human rights apply equally to all human beings, including persons with disabilities and to children.
- Human rights are indivisible and interdependent – violations of rights in one area often lead to violations of rights in other areas
- Four distinct “emancipation narratives”: children, persons with disabilities, persons with mental health problems and older persons.
- Common denominators of human rights challenges posed by “institutional culture”: e.g., impersonal character of care, lack of stimulating activities, rigidity of routines, isolation from community etc.

# Key human rights instruments

- UN Convention on the Rights of the Child (1989)  
Ratified by all EU Member States
- UN Guidelines for the Alternative Care of Children  
Resolution adopted by the UN General Assembly in 2009
- UN Convention on the Rights of Persons with Disabilities  
(2006)  
Ratified by the European Union and 25 EU Member States

# The right to living independently and being included in the community (CRPD art. 19)

- [...] **opportunity to choose** their place of residence and with whom they live
- [...] access to a range of in-residential and other **community support services**, including personal assistance necessary to support living and inclusion in the community
- [...] Community services and facilities for the general population are available **on an equal basis**

**Key to the realization of other rights!**

# UN Guidelines for the Alternative Care of Children

- Institutionalization should not be a response to material poverty (or conditions directly imputable to material poverty)
- Placement in residential institutions should be only the last resort, after all possibilities of family-type care have been exhausted
- Children aged 0-3 should not be placed in residential institutional care at all
- Where large institutions exist, States should create a program for their replacement (de-institutionalization).

# Institutional care as an expression of a mid-20<sup>th</sup> century modernist paradigm of progress

The institutional model of care is based on:

- the recognition of **everyone's material needs** (food, clothing, shelter, security)
- on the recognition of **responsibility of public authorities** for preventing hunger, homelessness and misery
- the belief in **supremacy of science** and rationalism
- the trust in the **capacity of modern organizations** to identify, diagnose and solve problems

# Institutional care as an inherent human rights challenge

- Denial of the right to family life, the right to found a family and the right to independent living
- Denial of the right to privacy and the right to own property
- Lack of access to services, including adequate health care and education
- Lack of autonomy - one's personal will and preferences are not taken into account
- Not taking into account the best interest of the child

# Risk factors for abuse in institutional care for children and adults with disabilities

## SYSTEMIC:

- Staff shortages or lack of appropriate qualification of staff
- Lack of meaningful activities (“warehousing” – use of physical and pharmacological restraints)
- Rigid institutional culture
- Broader cultural patterns in given society
- Lack or inconsistency of control mechanisms
- Isolation from outside world, remote location

INDIVIDUAL: authoritarian personalities, persons with abusive tendencies (and history) etc.

# Where are our societies coming from - and where are they going?

- FROM “OBJECTIVE NEEDS” TO SUBJECTIVE RIGHTS
- FROM PATERNALISTIC TO INTERACTIVE ETHICS
- BEYOND MATERIAL CONDITIONS ALSO TO NON-MATERIAL ASPECTS

# Which way ahead from the classical modernist paradigm?

**Let's not throw out the baby with the bathwater!**

- States must continue providing for material needs, but we need to see them truly as **rights of individuals**, not just as society's "management of poverty"
- States should maintain responsibility of public authorities while **empowering service users themselves, their families and communities and working closely with civil society**
- Societies should continue developing scientific knowledge while acknowledging that it is never absolute and that it must always remain **subordinated to humanistic principles.**

# What are the opportunities?

- Availability of European Structural and Investment Funds (ESIF) as bridging funds for implementing reform
- Commitment and support of the European Commission
- Existing reform processes in EU Member States are an opportunity for shared learning
- Ratification of the CRPD by the EU and 25 EU Member States – opportunity for synergies and harmonized implementation

# What are the risks? (I)

Risk No 1: Investing into alternatives that are themselves too institutional – replacing huge institutions by middle-sized or small ones, without sufficient change to institutional culture. Reforms driven by needs of service providers more than those of rights-holders. Minor improvements with large costs may mean a lost opportunity.

Warning: Size matters – research shows that facilities larger than a normal family (4-6 persons) are unlikely to provide a non-institutional culture, ...though even individual services can remain top-down and “institutional” if they don’t take their users as rights-holders and as active subjects.

# What are the risks? (II)

Risk No 2: Bureaucratically or economically driven reforms with excessive focus on meeting deadlines, on reaching quantitative targets, on savings. Failure to create robust, high-quality services in the community to replace institutions. Shifting of burden to families (often women). Risk of homelessness, destitution.

Warning: The aim is not (in itself) to “close” institutions – it is to replace them by something better, more individualized, more humane. It is not about returning to a pre-modern approach!!!

# What are the risks? (III)

Risk No 3: Privatization, introduction of fully commercial logic, lack of oversight.

Risk No 4: Economic crisis, austerity-driven cuts in social, overall decrease of funding for care.

# Recommendations I

- Use EU Structural Funds as bridging fund for implementing reform
- Reform should be holistic and ambitious (but realistic)
- Bridge-building between human rights expertise and social and health policies
- Involve all groups of rights-holders (persons with disabilities, children and their families)
- Cooperation across sectors

# Recommendations II

- Implementing recommendations by international human rights mechanisms (including Treaty Bodies, Special Procedures and UPR)
- Use the Toolkit and the Guidelines on the Transition from Institutional to Community-Based Care to promote independent living and inclusion in the community

<http://deinstitutionalisationguide.eu/>

# Thanks

Thanks to the Latvian Presidency for choosing this theme and to all of you for your kind attention!