



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

EU Presidency Conference, Riga, 15 June 2015

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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-20th 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!