

Online Annual Conference on the Rights of Persons with Disabilities 2021
ERA Academy of European Law
18 November 2021

Ending institutionalization of persons with disabilities

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Aim of my presentation

**To discuss the concept of INDEPENDENT LIVING as a fundamental
human right that concerns persons with disabilities in light of:**

- Convention on the Rights of Persons with Disabilities of the United Nations (CRPD)
- Patterns and practice of institutionalization of person with disabilities
- Work and jurisprudence of the CRPD Committee



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Structure of my presentation

- The human rights model of disability
- Institutionalization as violation of human rights of persons with disabilities
- The ways of perpetuating the institutionalization
- Principles and practice of independent living
- Necessary actions for deinstitutionalization



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The human rights model of disability

The CRPD as paradigm shift from discriminatory concepts of disability such as:

- Charity model treats persons with disabilities as passive objects of kind acts, not able to live independently, to be carried in specialized settings
- Medical model focuses on the impairment of an individual, who is conceived as lacking capacities, abnormal, defective, to be "fixed", normalized through medical interventions to get back to society

To the human rights model of disability (including the social model of disability)



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The human rights model of disability

Through the CRPD, all persons with disabilities are recognized as subject of all human rights and rights' holders

The purpose of the CRPD:

- to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.
- Persons with disabilities include those who have long-term physical, mental (psychosocial), intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.



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The human rights model of disability

The social model sees disability as a form of socially created oppression

The human rights model of disability values impairment as part of human diversity, it encompasses both sets of human rights,

Degener describes the CRPD as a codification of the human rights model of disability, which is build on, develops, moved beyond and develops the social model of disability.

Anna Lawson & Angharad E. Beckett discuss the social model as descriptive and heuristic model of disability, and the human rights model as prescriptive model of disability policy.



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The human rights model of disability

Article 3 General principles

Respect for inherent **dignity**, individual autonomy including the **freedom** to make one's own **choices**, and **independence** of persons

Non-discrimination

Full and effective **participation** and inclusion in society

Respect for **difference** and acceptance of persons with disabilities as part of human **diversity** and humanity

Equality of opportunity

Accessibility

Equality between men and women

Respect for the evolving capacities of **children** with disabilities and respect for the right of children with disabilities to preserve their identities.



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The human rights model of disability

As explained by the CRPD Committee in its General Comment No 6 on the article 5 Equality and non-discrimination (chapter III):

The human rights model of disability recognizes that disability is a **social construct** and **impairments** must not be taken as a legitimate ground for the denial or restriction of human rights.

It acknowledges that disability is one of several layers of **identity**.

Hence, disability laws and policies must take the **diversity** of persons with disabilities into account.

It also recognizes that **human rights** are interdependent, interrelated and indivisible (par. 9).



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Institutionalization as violation of human rights of persons with disabilities

Deprivation of dignity of persons with disabilities through the denial of substantive human rights such as freedom and equality to them (charity and medical models)

Historically denied their personal and individual choice and control across all areas of their lives.

Persons with disabilities presumed to be unable to live independently in their self-chosen communities

Presumed as lacking capacities to live independently

Capacity assessment procedures

Legal restrictions that do not allow persons with disabilities to exercise their legal capacity

Guardianship / Substitute decision making regimes



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Institutionalization as violation of human rights of persons with disabilities

Institutionalization as the denial of freedom & independence on the grounds of person's impairment

Some typical cases

In Poland around 80 thousand persons are placed in residential institutions and around 70 thousand are under substitute decision making regimes.

In Hungary, 28 thousand, out of 57 thousand of persons under guardianship regime, are institutionalized.

In France, approximately 100,000 children and 200,000 adults with disabilities reside in a broad range of institutionalized settings, more than 700 thousand persons with disabilities are placed under substitute decision making regimes in France.



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Institutionalization as violation of human rights of persons with disabilities

Institutionalization as the denial of freedom & independence on the grounds of person's impairment

Legal provisions, allowing involuntary or non-consensual commitment in mental health institutions and non-consensual treatment during the deprivation of liberty

Practices of physical restraints and solitary confinement

In France: placement in close units without consent, on the grounds of psychosocial disability, including hospitalizations and other inpatient treatment not subject to judicial review,



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Institutionalization as violation of human rights of persons with disabilities

Institutionalization as a vehicle of inequality of persons with disabilities

Resources are invested in institutions instead of in developing possibilities for persons with disabilities to live independently in the community.

Support is either unavailable or tied to particular living arrangements, and community infrastructure is not universally designed.

Lack of access to justice, including through the substitute decision making regimes and lack of support and accommodations

This has led to abandonment, dependence on family, institutionalization, isolation and segregation.

Institutions, hotspots of COVID-19



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Institutionalization as a violation of human rights of persons with disabilities

CRPD's Concluding observations on the initial reports of the States Parties

France, 2021: Regulations, structures and budgets that promote placement of children and adults with disabilities in segregated settings, including 'medico-social institutions' and specialized services, including in small-size residential care institutions so-called "*l'habitat inclusive*" or "*l'habitat partagé*", particularly impacting persons requiring higher levels of support

Estonia, 2021: Institutionalization on the basis of disability persists in the form of alternative care homes and new small-scale "family type" or "special care villages" and that such forms of institutionalization affect particularly persons with intellectual disabilities, persons with psychosocial disabilities and persons with autism;



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Institutionalization as a violation of human rights of persons with disabilities

CRPD's Concluding observations on the reports of the States Parties

Spain, 2021: Continuing investment of public funds in the construction of new residential institutions for persons with disabilities

Bulgaria, 2018: the National Long-term Care Strategy envisages transfer of residents from large institutions to small group homes as the DI measure



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Institutionalization as a violation of human rights of persons with disabilities

Children and women and other persons with disabilities, critically vulnerable to discrimination and abuse of rights

Institutions, including small size residential care “family-like” institutions for **children with disabilities**, may be still considered as appropriate alternative care

Forced sterilization of **girls and women** with psychosocial and intellectual disabilities and autistic women in institutions

Persons with **intellectual or psychosocial disabilities, or autistic** persons as well as persons with high support requirements are particularly affected by institutionalization



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Ways of perpetuating institutionalization of persons with disabilities

Through the lack of arrangements for independent living

France, 2021: The lack of arrangements for living independently and in the community, including the lack of independent accessible and affordable housing, individualized support, and lack of equal access to services in the community

Spain, 2019: The limited access to personal assistance, despite positive developments in some autonomous communities, due to non-personalized eligibility criteria and the lack of a human rights-based approach to individualized support;

Bulgaria, 2018: persons with psychosocial disabilities are hospitalised in psychiatric hospital wards due to lack of recovery oriented rehabilitation, adequate individualized services and accommodation within the community



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Ways of perpetuating institutionalization of persons with disabilities

Through the lack of arrangements for independent living

Estonia, 2021: The absence of a system to provide individualized support and personal assistance for living independently and in the community,

The limited accessibility for persons with disabilities of mainstream services and facilities for the general population, including education and health.

Poland, 2018: Lack of access to community-based services, especially in villages, and the continuation of sheltered housing programmes, including the establishment of group homes.



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Ways of perpetuating institutionalization of persons with disabilities

Through the lack of awareness and action plans

Spain, 2019: The lack of a deinstitutionalization strategy and action plan to promote independent living for all persons with disabilities within their community.

Estonia, 2021: The lack of awareness in society and among public authorities of the right of persons with disabilities to live independently and be included in the community, the right to choose where and with whom to live and the right not to be obliged to live in a particular living arrangement

France, 2021: The lack of awareness of public authorities, professionals and social servants about the negative impacts of institutionalization on persons with disabilities, and the absence of strategies and action plans to end institutionalization



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Ways of perpetuating institutionalization of persons with disabilities

Through funding institutions using EU funds

Investments into refurbishment of institutions including through building new ones, group homes.

Group homes reiterate the features of institution.

Investments into group homes doesn't take into account the access of persons with disabilities to open labour market, to mainstream education, health facilities and community-based service.

Social inclusion of persons with disabilities, and their deinstitutionalization has yet to be included among priorities in international investment programmes (EU Funds)

This is not a form of progressive realisation of the social inclusion of persons with disabilities.



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Ways of perpetuating institutionalization of persons with disabilities

Group homes usually are built at the edge of villages, in remote areas, in the same area as institution.

Shelter workshops that are built within the same particular setting as group home.

No usual work contract

People remain under control of the institutions and the staff.

No way to move in any other place at their choice, if they do so, they would lose any support from their governments.

It is believed to be the deinstitutionalization and community-based service and is being perpetuated.



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Ways of perpetuating institutionalization of persons with disabilities

Through the medical and charity models of disability

Persons with disabilities are considered as objects of care and cure through the relevant social and professional mindsets, laws, policies, including but not limited to patronizing concept of protection (France, Poland etc), substitute decision making, capacity assessments, disability certification, etc

Focus on impairments and control rather on human rights, including respect of freedom, support and accessible environments.



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Ways of perpetuating institutionalization of persons with disabilities

The case of Hungary, CRPD inquiry under art 6 Optional Protocol 2017 – 2019

The Committee finds:

grave - the systems of guardianship and institutionalization profoundly affect the lives of a substantial number of persons with disabilities)

and systematic violations patterns of structural discrimination entrenched in legislation, policies, plans and practices, including resource allocation.



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Principles and practice of independent living

The case of Hungary, CRPD inquiry under art 6 Optional Protocol 2017 – 2019

The Committee recommends to:

Abolish the provisions of the Civil Code providing for the full or partial restriction of the capacity to act of persons with disabilities;

Restore the capacity to act of all persons with disabilities, including those in any form of institutional setting;

Move expeditiously to adopt a system of supported decision-making

Ensure equal right to live in the community, with choices equal to others, access to support

Ensure access to community services and facilities for the general population

Ending institutionalization



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Principles and practice of independent living

CRPD Article 19 Living independently and being included in the community and the CRPD Committee's General Comment No 5 on art 19

Recognition of equal right of all persons with disabilities to live in the community, with choices equal to others, full inclusion and participation in the community:

- (a) opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement,
- (b) access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
- (c) Community services and facilities for the general population available on an equal basis to persons with disabilities and are responsive to their needs



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Principles and practice of independent living

CRPD Committee's General Comment No5 on art 19

Main concepts

Independent living. **Independent living**, individuals with disabilities are provided with all necessary means to enable them to exercise choice and control over their lives and make all decisions concerning their lives.

Being included in the community relates to the principle of full and effective inclusion and participation in society

Independent living arrangements refer to life settings outside residential institutions of all kinds.

Personal assistance refers to person-directed/"user"-led human support available to a person with disability and is a tool for independent living.



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Necessary actions for deinstitutionalization

CRPD Committee's Guidelines on Deinstitutionalization of Persons with Disabilities, including in emergency situations

Origin and process

COVID-19 Disability Rights Monitoring about worldwide survey on human rights violations during the COVID 19 pandemic

CRPD Working Group with a support of Secretariat

Outcomes of 7 regional consultations with persons with disabilities

In cooperation with Global Coalition on Deinstitutionalization and consultants

Annotated outline of the Guidelines

Purpose

Supplement the GC No. 5 by providing concrete guidance to States parties and other actors on how to carry out deinstitutionalization processes, including in emergency situations.



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Necessary actions for deinstitutionalization

CRPD Committee's Guidelines on Deinstitutionalization of Persons with Disabilities, including in emergency situation

Annotated outline

Obligations of the States Parties to recognise the discriminatory pattern of institutionalization and end it in law and practice

Deinstitutionalization principles and process, to shift from the outdated charity, paternalistic and medical models of disability to the human rights model of disability

Address structural patterns, including through the reform of legal and policy frameworks, and practices perpetuating institutionalization

Ensure implementation in line with the Convention through ensuring the free choice of persons with disabilities, and respect their will and preferences, restoring their legal capacity, providing individualized support and access to information in accessible formats.



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References and documentation

1. CRPD Committee's Concluding observations: https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/TBSearch.aspx?Lang=en&TreatyID=4&DocTypeID=5
2. CRPD Committee's General Comment No 5. **Article 5: Equality and non-discrimination** (Adopted 9 March 2018) <https://www.ohchr.org/EN/HRBodies/CRPD/Pages/GC.aspx>
3. CRPD Committee's Guidelines on Deinstitutionalization of Persons with Disabilities, including in emergency situations. Living independently and being included in the community: Guidelines on deinstitutionalization of persons with disabilities, including in emergency situations. Annotated outline. CRPD webpage: <https://www.ohchr.org/EN/HRBodies/CRPD/Pages/CRPDIndex.aspx>
4. Degener T. (2016). Disability in a Human Rights Context, Laws, 5, 35
5. Degener, Teresia. (2017). A Human Rights Model of Disability, in Routledge Handbook on Disability Law and Human Rights, eds. P. Blanck and E. Flynn, 31
6. Inquiry concerning Hungary carried out by the Committee under article 6 of the Optional Protocol to the Convention and Observations from the State party. CRPD webpage: <https://www.ohchr.org/EN/HRBodies/CRPD/Pages/CRPDIndex.aspx>
7. Lawson, Anna & Beckett, Angharad E. (2021) The social and human rights models of disability: towards a complementarity thesis, The International Journal of Human Rights, 25:2, 348-379
8. Living independently and being included in the community: Guidelines on deinstitutionalization of persons with disabilities, including in emergency situations. Annotated outline. CRPD webpage <https://www.ohchr.org/EN/HRBodies/CRPD/Pages/CRPDIndex.aspx>
9. The Convention on the Rights of Persons with Disabilities of the United Nations <https://www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx>



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