

Organized by:  
**Japan Society for Disability Studies**



Institute of  
Ars Vivendi,  
Ritsumeikan University

# **Deinstitutionalization and persons with intellectual disabilities: towards equality and non-discrimination**

Lecture given at Doshisha University in Kyoto on 17 September 2022

by Jonas Ruškus

Expert-member, Vice-chair of the Committee on the Rights of Persons with Disabilities of the United Nations

Professor at the Department of Social Work, Vytautas Magnus University, Lithuania

Visiting researcher at Institute Ars Vivendi Ritsumeikan University

# My background and experience

- Studies on defectology – medical model of disability
- L'Arche experience in France <https://www.larche.org/about-larche/>
- Experiences in residential institutions in Lithuania
- PhD in Education on the impact of teacher's attitudes on classroom interaction and socialization of a child with intellectual disability
- L'Arche experience in Kaunas, Lithuania <https://www.kaunoarka.lt/>



# My background and experience

- Board member of Lithuanian Human Rights Centre, Lithuanian Association for Independent Living, Teach for All
- Professor at Vytautas Magnus University, Lithuania
- Nominated for Award „Year’s Person of Tolerance“ by Chiune Sugihara Foundation in Kaunas „Diplomats For Lives“ in 2007

[www.sugiharahouse.com/#/](http://www.sugiharahouse.com/#/)

*“For a noble work by humanizing intellectual and moral vocabulary, related to the others’ pain, disability and social exclusion, for the protection of dignity and pride of a diverse person by joining scientific language, moral sensitivity and awareness raising.*

*Your work remind us that without research and awareness on social exclusion and disability, we will stay with the abstract sentiments on and without understanding of the object of moral sensitivity, when without humanistic view on humanity we dehumanize knowledge”*





# My background and experience

Member of the CRPD Committee, elected in 2014 and reelected in 2018, since then its vice-chair

Rapporteur for the reports of the States Parties, including Japan

Member of working groups of the Committee



# Work of the UN CRPD Committee

- The review and consideration of the reports of the States Parties
- Providing States Parties with the Concluding observations
- Developing of the jurisprudence of the Convention – General Comments, Statements
- Review and consideration of individual communications through Optional Protocol
- Cooperation with other human rights bodies of the United Nations
- Annual conferences of the States Parties at the UN in New York
- Elections of the members of the Committee



# The Convention on the Rights of Persons with Disabilities of the United Nations

- Adopted in 2006
- Arisen from and rooted in international human rights law
- Promoted by disability-advocacy movements
- Encompasses the set of all kind of human rights (civil, political, economic, social, cultural)
- Specifying rights of persons with disabilities
- Establishes international standards for the rights of persons with disabilities
- Aimed at abolishing all forms of inequality and discrimination on the basis of impairment, including the medical model of disability, discriminatory legislation, regulations, policies, negative stereotypes and attitudes, etc
- Aimed at the human rights model of disability



# The Human Right model of Disability (HRMD)

(ref. 1)

**Dignity, freedom and equality** - Purpose of the Convention (art 1)

Principles of the Convention (art 3):

- Respect for inherent dignity, individual **autonomy** including the freedom to make one's own choices, and independence of persons (*vs substitute decision making*)
- Non-discrimination (*on the basis of impairment, i.e. involuntary treatment & confinement*)
- **Full and effective** participation and inclusion in society
- Respect for **difference and acceptance** of persons with disabilities **as part** of human **diversity and humanity** (*recognition of disability, anti-eugenic*)
- Equality of opportunity (reasonable accommodation vs barriers, denials)
- Accessibility
- Equality between men and women (*intersectionality*)
- Respect for the **evolving capacities** of children with disabilities and respect for the right of children with disabilities to preserve their **identities** (*attitudes and aspirations*)



# Living independently and being included in the community - at the hearth of international human rights' framework

The Universal Declaration of Human Rights, art 29 (1) “Everyone has duties to the community in which alone the free and full development of his personality is possible”.

The International Covenant on Civil and Political Rights, art 12 of “Everyone <...> have the right to liberty of movement and freedom to choose one’s residence”.

The International Covenant on Economic, Social and Cultural Rights, art 11 “Everyone <...> have the right to an adequate standard of living, including adequate clothing, food and housing”.

Sustainable Development Goals:

Reducing inequalities, Target 10.2, empowerment and promotion of social, economic and political inclusion for all

Make cities and human settlements inclusive, safe, resilient and sustainable, Target 11.1, ensuring access to adequate, safe and affordable housing and affordable services for all





# Living independently and being included in the community, article 19 of the CRPD

(ref. 1)

States Parties to this Convention recognize the **equal right** of **all** persons with disabilities to **live in the community, with choices equal to others**, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

- a. Persons with disabilities have the **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. Persons with disabilities have **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 **are available on an equal basis to** persons with disabilities and are responsive to their needs.



# Institutionalization is a grave and systematic discrimination of persons with disabilities (1)

(ref. 2, par. 106-109).

The Committee considers violations to be **grave** if they are likely to produce **substantial harm to victims leading to further segregation, isolation and impoverishment**. A determination regarding the gravity of violations must take into account the scale, prevalence, nature and impact of the violations.

The term **systematic** refers to the **organized nature of the acts leading to the violations** and improbability of their random occurrence. The existence of a **legislative framework, policies and practices** that, by intent or through impact, **adversely or disproportionately affect** persons with disabilities constitute systematic violations of the Convention. Discriminatory or structural patterns against persons with disabilities based on impairment constitute systematic violations.



# Institutionalization is a grave and systematic discrimination of persons with disabilities (2)

(ref. 3)

Massive institutionalization of persons with intellectual disabilities, persons with psychosocial disabilities, persons requiring more intense support are the most affected.

Some typical cases (approximative numbers):

France: 100.000 of children, 200.000 adults with disabilities in live residential institutions, more than 700.000 - under substitute decision making regime

Poland: 80.000 in residential institutions, 70.000 - under substitute decision making regime.

Hungary, 28.000 in residential institutions, 57.000 - under substitute decision making regime, are institutionalized

Republic of Korea: 29.000 in residential institutions, 8.800 at nursing homes for persons “with mental disabilities”

Japan: 120.000 persons with intellectual disabilities and 73.000 persons with physical disabilities in residential institutions, 172,000 persons with psychosocial disabilities - hospitalization of one year or longer



# Grave and systemic discrimination, resulting in institutionalization (1)

Discrimination on the basis of impairment, non provision of individual / reasonable accommodation (art 5)

Stigma, negative stereotypes, eugenic mindset (art 8)

Deprivation of legal capacity and substitute-decision making (SbDM) (art 12)

Lack of access to justice due to SbDM, lack of means of communication (art 13)

Deprivation of liberty and security through non-consensual treatment and confinement, hospitalization, ECT (art 14, 15)

Violence against woman and girls with disabilities, eugenic practices (arts 6, 16, 17)

Lack of access to information and shelters in situations or risk and humanitarian emergencies (art 11)

Lack of access to information and communication (arts 9, 21)





# Grave and systemic discrimination, resulting within institutionalization (2)

Separation from family, lack of support for family (art 23)

Segregated special education, boarding schools (art 24)

Work in segregated areas outside mainstream market, low wage, no usual work contracts (art 27)

Group homes, including for children, reiterate features of institutions (art 19)



# Defining elements of institutionalization

(ref. 4, par. 13)

Placement of persons with disabilities in particular living arrangements, outside regular living places, usually in remote areas

Disproportionate number of persons with disabilities in the same environment

Obligatory sharing of assistants with others

Isolation and segregation from independent life in the community

Lack of control over day-to-day decisions

Lack of choice for the individuals concerned over with whom they live

Rigidity of routine irrespective of personal will and preferences

Identical activities in the same place for a group of individuals under a certain authority

Paternalistic approach in service provision

Control of living arrangements



# Defining elements of institutionalization

(ref. 4. par. 14)

Any detention based on disability alone or in conjunction with other grounds such as “care” or “treatment”.

Disability-specific detention typically occurs in institutions that include, but are not limited to, social care institutions, psychiatric institutions, long-stay hospitals, nursing homes, secure dementia wards, special boarding schools, rehabilitation centres, half-way homes, group homes, family-type homes for children, sheltered or protected living homes, forensic psychiatric settings, transit homes, albinism hostels, leprosy colonies and other congregate settings.

Mental health settings where a person can be deprived of their liberty for purposes such as observation, care or treatment and/or preventive detention are a form of institutionalization.



# Obligations to respect, protect and fulfill By becoming parties to international treaties

Viena Convention on the Law of Treaties, 1969, Article 26 “*Pacta sunt servanda*”: every treaty in force is binding upon the parties to it and must be performed by them in good faith (*bona fides*).

The obligation to respect means that States must refrain from interfering with or curtailing the enjoyment of human rights.

The obligation to protect requires States to protect individuals and groups against human rights abuses.

The obligation to fulfil means that States must take positive action to facilitate the enjoyment of basic human rights.

Governments undertake to put into place domestic measures and legislation compatible with their treaty obligations and duties.





# Measures to be taken for deinstitutionalization: protection of dignity, freedom and equality

States parties should recognize institutionalization in all its forms as a multiple violation of the rights enshrined in the Convention (ref 5, par 114)

Prohibition of discrimination based on impairment, discrimination, reasonable accommodations, as equality measure, provided (art 5)

Right to legal capacity, abolishment of substitute-decision making mechanisms and establishing supported decision-making mechanisms (art 12)

Right to liberty and security of person: Abolishment non-consensual treatment/confinement on any impairment-bases grounds (art 14)

Protection of woman and girls with disabilities against violence (art 6)

Recognize and consider intersectionality of persons with disabilities (ref. 5, section A)



# Measures to be taken: elimination of barriers

Right to access to justice: Establishing procedural accommodations at justice (art 13)

During emergency situations, such as pandemics, natural disasters or conflicts, States parties should continue and accelerate efforts to close institutions. (art 11)

Right to communication: alternative and augmentative means and modes (arts 9 and 21)



# Measures to be taken: service provision in the community

(ref. 4 and 5)

All persons with disabilities have the support, based on their own choices, that they may require to carry out daily activities and participate in society.

Assessment of capacities for independent living based on impairment are discriminatory and should shift to assessments of individualized requirements and barriers for independent living in the community.

Support should be individualized, personalized and offered through a variety of options.

Personal assistance services must be individualized, funded based on individual needs, and controlled by the user

Support encompasses a wide range of formal assistance, as well as informal community-based networks: peer support, supportive caregivers for children in family settings, crisis support, support for communication, support for mobility, provision of assistive technology, support in securing housing and household help, and other community-based services

Support and services for family (art 26)

Assessible housing (art 28)



# Measures to be taken: access to mainstream services on an equal basis with others

(ref. 4 and 5)

Inclusive education for children (art 24)

Access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation (art 24):

Work and employment in an open labor market (art 27)





# Process of deinstitutionalization

(ref. 4 and 5)

Deinstitutionalization strategies and action plans

collect appropriate and ethically disaggregated statistical, research and administrative data, and use these to inform decision-making. (ref 5, par 123)

Should be led by persons with disabilities, including those affected by institutionalization, and not by those involved in managing or perpetuating institutions.

Prevent the emergence of new segregated services., group housing – including ‘small group homes’ – sheltered workshops, institutions for the provision of ‘respite care’, transit homes, day-care centres, or coercive measures such as community treatment orders are not community-based services.

Investments in institutions, including renovation, should be prohibited. Investments should be directed towards the immediate release of residents and the provision of all necessary and appropriate support for living independently.

There is no such a right to choose to live in institutions, that is to say to choose discrimination and social segregation

Monitoring deinstitutionalization processes (ref 5, section XI)



# Right to family life for children with disabilities

States Parties shall respect the right to family life for children with disabilities on an equal basis with other children. The Committees agree that all children, for the full and harmonious development of their personalities should grow up in a family, in an atmosphere of happiness, love and understanding. <...> The Committees call on States parties to provide inclusive and supportive services for children with disabilities and their families in the community <...>. (ref. 3)

Even short-term placement outside a family can cause great suffering, trauma and emotional and physical impairments. Preventing the placement of children in institutions must be a priority. Opportunities for family-based placements, with financial and other forms of support, should be created for all children with disabilities (ref 5, par 45)



# UN CRPD Committee on deinstitutionalization in Japan (Concluding Observations, 2022,41&42,a)

(ref. 7)

**Concern:** Perpetuation of institutionalization of persons with intellectual disabilities, persons with psychosocial disabilities, elderly persons with disabilities, persons with physical disabilities and those who require more intense support, *in particular living arrangements* outside community, and of children with disabilities, particularly, children with intellectual, psychosocial or sensory disabilities and those who require more intense support, through the Child Welfare Act, in various types of facilities, depriving them family and community life;

**Recommendation:** Take expedited measures to end the institutionalization of persons with disabilities, including children with disabilities, by *redirecting its budgets allocations* from the placement of persons with disabilities in residential institutions *towards arrangements and supports for persons with disabilities for living independently in the community* on an equal bases with others;



# UN CRPD Committee on deinstitutionalization in Japan (Concluding Observations, 2022,41&42,b)

(ref. 7)

**Concern:** Promotion of institutionalization of persons with psychosocial disabilities and persons with dementia in *psychiatric hospitals*, both public and private, particularly, the continuance of indefinite hospitalizations of persons with psychosocial disabilities in them;

**Recommendation:** Review all cases of persons with disabilities hospitalized in psychiatric hospitals to *cease any indefinite hospitalization*, ensure their informed consent and foster their independent living along with the required *mental health support in the community*;





# UN CRPD Committee on deinstitutionalization in Japan (Concluding Observations, 2022,41&42,c)

(ref. 7)

**Concern:** *Lack of a national strategy and legal framework* for the deinstitutionalization of persons with disabilities residing in residential institutions and psychiatric hospitals, and their independent living in the community on an equal basis with others, including the ***recognition of their right*** to autonomy and full social inclusion

**Recommendation:** *Launch*, in consultation with organizations of persons with disabilities, a ***legal framework and national strategy*** with time-bound benchmarks, human, technical and financial resources, aiming at the effective transition of persons with disabilities from institutions into independent living in the community on an equal basis with others, including the recognition of their right to autonomy and full social inclusion, and obligations for prefectures to ensure its implementation;



# UN CRPD Committee on deinstitutionalization in Japan (Concluding Observations, 2022,41&42,d)

(ref. 7)

**Concern:** *Limited opportunities* for persons with disabilities **to choose their place of residence** and where and with whom to live, including for those, dependent on parents and living in their homes, and those, placed in particular arrangements such as group homes under the Act on the Comprehensive Support for the Daily and Social Life of Persons with Disabilities;

**Recommendation:** Ensure that persons with disabilities have opportunity to choose their place of residence and where and with whom they live in the community and are **not obliged to live in a particular living arrangement**, including group homes, and enable persons with disabilities to exercise choice and control over their lives;



# UN CRPD Committee on deinstitutionalization in Japan (Concluding Observations, 2022,41&42,e)

(ref. 7)

**Concern:** *Insufficient support arrangements* for persons with disabilities for living independently in the community, including accessible and affordable housing, in-home service, personal assistance and access to services in the community;

**Recommendation:** *Strengthen support arrangements* for persons with disabilities for their living independently in the community, including the independent, accessible and affordable housing outside any type of congregated premises, personal assistance, user-led budget, and access to services in the community;



# UN CRPD Committee on deinstitutionalization in Japan (Concluding Observations, 09/2022,41,42,f)

(ref. 7)

**Concern:** *Assessment* schemes for granting support and services in the community that are based on *medical model of disability*;

**Recommendation:** Revise existing schemes of *assessment* for granting support and services in the community for ensuring that they are *based on human right model of disability*, including the assessments of barriers in society for persons with disabilities and their required support for their social participation and inclusion.



# References

1. The Convention on the Rights of Persons with Disabilities of the United Nations (2006)

<https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-persons-disabilities>

2. Inquiry concerning Hungary carried out by the Committee under article 6 of the Optional Protocol to the Convention, Committee on the Rights of Persons with Disabilities, CRPD/C/HUN/IR/1

[https://tbinternet.ohchr.org/\\_layouts/15/treatybodyexternal/TBSearch.aspx?Lang=en&TreatyID=4&DocTypeCategoryID=7](https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/TBSearch.aspx?Lang=en&TreatyID=4&DocTypeCategoryID=7)

3. Official and alternative reports to the UN CRPD Committee

[https://tbinternet.ohchr.org/\\_layouts/15/TreatyBodyExternal/SessionsList.aspx?Treaty=CRPD](https://tbinternet.ohchr.org/_layouts/15/TreatyBodyExternal/SessionsList.aspx?Treaty=CRPD)

4. Guidelines on Deinstitutionalization, including in Emergencies (2022)

<https://www.ohchr.org/en/documents/legal-standards-and-guidelines/crpd273-guidelines-deinstitutionalization-including> CRPD/C/27/3

5. General Comment No 5 on the right to live independently, Article 19 (2017)

<https://www.ohchr.org/en/treaty-bodies/crpd/general-comments>

6. Joint Statement on The rights of children with disabilities by the Committee on the Rights of the Child and the Committee on the Rights of Children with Disabilities (2022)

<https://www.ohchr.org/en/treaty-bodies/crpd>

7. Concluding observations on the initial report of Japan. United Nations, Committee on the Rights of Persons with Disabilities CRPD/C/JPN/CO/1

[https://tbinternet.ohchr.org/\\_layouts/15/treatybodyexternal/Download.aspx?symbolNo=CRPD%2fC%2fJPN%2fCO%2f1&Lang=en](https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolNo=CRPD%2fC%2fJPN%2fCO%2f1&Lang=en)





*Arigato Gozaimasu*

