

2019

Good practices

**GOOD PRACTICES TO PROMOTE THE RIGHT TO
LIBERTY OF PERSONS WITH DISABILITIES**
PROF. EILIONÓIR FLYNN AND MARÍA GÓMEZ-CARRILLO



NUI Galway

CENTRE *for* DISABILITY
LAW & POLICY



**Institute for
Lifecourse and Society**

This collection of good practice has been prepared by Centre for Disability Law and Policy NUI Galway as part of a wider research project on deprivation of liberty in collaboration with the office of the Special Rapporteur on the Rights of Persons with Disabilities. The mandate of the Special Rapporteur is to recall the universality, indivisibility, interdependence and interrelatedness of all human rights and fundamental freedoms and the need for persons with disabilities to be guaranteed the full enjoyment of these rights and freedoms without discrimination. The information and views contained in this research are not intended as a statement of the Special Rapporteur for Disability, and do not necessarily, or at all, reflect the views held by the Special Rapporteur.

Table of Contents

INTRODUCTION	5
SUMMARY OF FINDINGS OF THE RESEARCH ON DISABILITY-SPECIFIC FORMS OF DEPRIVATION OF LIBERTY	6
DATA COLLECTION	8
DEINSTITUTIONALIZATION	11
ALTERNATIVES TO INVOLUNTARY PSYCHIATRIC HOSPITALIZATION	23
MONITORING SYSTEMS AND STRONG ETHICAL STANDARDS	28
STIGMA	31
MAINSTREAMING SERVICES	37
CONCLUSIONS	38

Introduction

The research on disability-specific forms of deprivation of liberty conducted by the Centre for Disability Law and Policy revealed different forms of deprivation of liberty and barriers to the full enjoyment of the right to liberty but also positive experiences and practices designed to avoid deprivation of liberty that may serve as guidance for future reforms. These are the practices this publication will highlight, with the hope it serves to inform new policies and steps towards full enjoyment of the right to liberty for persons with disabilities.

The research project reviewed legislation and policies on deprivation of liberty based on an actual or perceived impairment¹, as well as the barriers to full enjoyment of the right to liberty of persons with disabilities, and alternative options to involuntary hospitalization, institutionalization or other discriminatory practices. It also conducted qualitative research on the underlying causes of deprivation of liberty. The results were published in March 2019.² This publication cannot provide a detailed analysis of each good practice due to the broadness of the topic covered. Instead, it aims to stimulate the imagination of the different stakeholders to see what can be done and where to start asking for information. A word of caution must be issued at this stage – the practices listed here may not be 100% compliant with the CRPD and should be used as examples of steps towards change, not as perfect models. Replication of positive practices always require taking into account the context in which they are to be implemented and with the participation of all stakeholders, particularly persons with disabilities. Promising practices refer to initiatives that pursue the fulfilment of the CRPD or tackle specific barriers to the right to liberty. Some of these practices are at an initial stage of development. For others, the researchers were not able to find enough evidence of the practice's implementation to support final conclusions. Other practices included may have some aspects that may not be fully CRPD compliant – for example where they operate in jurisdictions which maintain substituted decision-making regimes.

¹ Following the UN Convention on the Rights of Persons with Disabilities Committee's wording used in the Guidelines on Article 14 (2015).

² See the Centre for Disability Law and Policy's website.

Summary of findings of the research on disability-specific forms of deprivation of liberty

The research was conducted over two years on deprivation of liberty explored human right standards, available data and legislation on deprivation of liberty of persons with disabilities. It also included field work with the help of local research teams in five countries: [France](#), [Ghana](#), [Jordan](#), [Indonesia](#) and [Peru](#) to further explore why persons with disabilities are being deprived of liberty.

The Convention on the Rights of Persons with Disabilities (CRPD) introduced a social and human rights model of disability, parting from the medical model, and understand persons with disabilities as *“those who have long-term physical, mental, 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.”*³

The CRPD Committee considers all deprivation based on an actual or perceived impairment as discriminatory and contrary to the CRPD.⁴ The Guidelines explain that this excludes any exception to the right to liberty based on the criteria of dangerousness and risk to self or others. This interpretation has been embraced by many international treaty bodies and some regional courts and treaty bodies.⁵ The interpretation has not yet trickled down to countries, where the research team found exceptions to the right to liberty in the form of mental health laws or civil commitment or social protection laws, which allowed for hospitalization, internment in asylums or institutionalization. Further, there seems to be a confusion around the definition of institution and the right to independent living. In this sense, residential settings were often not considered institutions, or residential forms were included in independent living policies. This has been criticized by the CRPD Committee in General Comment no. 5 on the right of persons with disabilities to live independently and be included in the community (article 19).⁶

³ Article 1 CRPD.

⁴ CRPD/C/12/2 Annex IV.

⁵ Working Group on Arbitrary Detention (WGAD Report A/HRC/36/37, para. 55), Committee on the Elimination of All Forms of Discrimination against Women (CEDAW/C/IND/CO/4-5, para.37), African Commission on Human and Peoples' Rights in its protocol on the rights of persons with disabilities, the Special Rapporteur on the rights of persons with disabilities and the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.

⁶ CPRD/C/GC/5, para16 (c).

Despite the major importance of the right to liberty and its connectedness to all other rights (education, health, etc.), many of the researched countries did not have data⁷ on this issue. States may not intervene to stop deprivation as it brings up other duties states may have towards the person or her family, such as provision of support, education, appropriate health care packages, etc. Moreover, hospitalization and institutionalization are often understood by states as a means of guaranteeing other rights. This publication includes practices that guarantee those other rights (right to support, education, health, housing) without violating the right to liberty.

The review of the available data during phase I showed that while efforts are being placed on meeting the CRPD requirements, the legal structures remain largely unchanged, and that both legal capacity and the right to liberty are often still limited on the basis of medical model of disability.

When examining the underlying causes during phase II, several themes emerged from the interviews. Firstly, many situations that potentially qualify as deprivation of liberty under the CRPD are not recognized as such, and the research team found resistance to this description. Secondly, stakeholders described how in situations of urgency, acute need for support, distress or exhaustion of a person's social network, professionals' most common response (due to a duty under the law or because no other option was imagined or available) was to deprive the person of liberty to provide 'care', education or to subject them forcefully to treatment. The interviews revealed a lack of information and of imagination on how things could be done differently. Stigma was a recurrent theme in all countries.

This publication wishes to underline the necessity to create space for alternatives to flourish and grow, and that other ways of providing support are possible.

⁷ See the full report for the sought indicators.

Data collection

During phase I, the research team developed a set of indicators which was designed to guide the research and help to scale the issue. Unfortunately, despite the efforts to collect this data through a questionnaire, contacting ministries or through reports, this data was not available in most instances.

Often, the reasons for this lack of data were:

- a) The data is not collected by administrations or is not shared with the administration;
- b) The data was not collected routinely or systematically;
- c) This information belongs to the private or charity run sector;
- d) The data is within the system but it is not possible to collect it (especially with legal sentences or guardianship);
- e) This is a decentralized competence and thus, there is no centralized data collection;
- f) No unified data collection: Data on institutions or restraint can be limited by different definitions and understandings of these terms.

While private or NGO run networks or local administration such as social work departments may have part of these data, this may not be publicly available, or it was not possible to distinguish the different type of services offered for persons with disabilities. The research team did find information on existing services for persons with disabilities, but it was not possible to filter which services provided housing, residential accommodation or independent living services. The naming of services was very diverse and often induced to confusion, as the CRPD Committee has also highlighted.⁸

Properly documenting involuntary hospitalization, coercive measures and institutionalization is essential to tackle these human rights violations and develop appropriate policies.⁹

One of the main barriers to a proper analysis was the lack of available data on persons with disabilities deprived of liberty. Routine data collection on a local

⁸ CRPD/C/GC/5.

⁹ CRPD Committee, CPRD/C/HTI/CO/1, para 56.

level is extremely important to analyse different policy schemes.¹⁰ The call for data is present in many studies on disability rights,¹¹ and is reiterated in the recommendations and conclusion of the study on disability specific forms of deprivation of liberty.

The importance of data collection is highlighted in the Convention on the Rights of Persons with Disabilities, in its article 31:

'Article 31 - Statistics and data collection:

1. States Parties undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention. The process of collecting and maintaining this information shall:

a) Comply with legally established safeguards, including legislation on data protection, to ensure confidentiality and respect for the privacy of persons with disabilities;

b) Comply with internationally accepted norms to protect human rights and fundamental freedoms and ethical principles in the collection and use of statistics.

2. The information collected in accordance with this article shall be disaggregated, as appropriate, and used to help assess the implementation of States Parties' obligations under the present Convention and to identify and address the barriers faced by persons with disabilities in exercising their rights.

3. States Parties shall assume responsibility for the dissemination of these statistics and ensure their accessibility to persons with disabilities and others.'

The importance of proper data collection has been consistently highlighted by the CRPD Committee in numerous State reports.¹² The CRPD Committee has recommended countries to use the Washington Group Set of Questions¹³ in

¹⁰ Sheila Riddell et al, 'The development of direct payments in the UK: implications for social justice' (2005) 4(1) Social Policy and Society 75-85.

¹¹ She Peiyun et al, 'Research Brief: A Review of Disability Data for the Institutional Population' (2006) Cornell University Institute for Policy Research; Jim Mansell et al, 'Deinstitutionalisation and community living – outcomes and costs: report of a European Study' (2007) Volume 2: Main Report. Canterbury: Tizard Centre, University of Kent.

¹² CRPD/C/LVA/CO/1, CRPD/C/MNE/CO/1, CRPD/C/GBR/CO/1, CRPD/C/HND/CO/1.

¹³ See more information under <<http://www.washingtongroup-disability.com>> accessed 11 April 2019.

future census¹⁴ and to actively collaborate with Disabled Persons Organisations and with their representative organisations in the design and collection of data.¹⁵ Persons living in institutions or hospitals (or homeless) will not appear in household census, becoming invisible to statistics. Some countries may hold data on institutional households, but it is not as common or up-to-date.¹⁶

Lastly, some countries have also adopted their own Guidelines on data collection based on international standards¹⁷, and the team also found local regional administrations that created maps with public services.¹⁸ The Sustainable Development Goals (SDG) are monitored through data, and the inclusion of data on disabilities has been reinforced by UN's expert group on SDG indicators (Inter-agency and Expert Group on SDG Indicators¹⁹) in its latest report, which included a priority list of data that should be disaggregated by disability.²⁰

Within phase I, Australia was one of the countries with the most available data. The Australian Bureau of Statistics and the states and territories of Australia maintained updated data on disability and deprivation of liberty on a variety of indicators. This includes statistics on intersecting identities, carers and their relationship, the use of disability services, access to mainstream services (e.g. health) and geographic distribution of individuals and services, among others.

A good practice from Cambodia includes training elected disabled people's representatives from villages and communes on disability rights, advocacy and meeting facilitation. This training is conducted by an international development organisation to enable local representatives to organize meetings of persons with disabilities, collect data and then represent them at local district meetings, to implement policy changes.²¹

¹⁴ CRPD/C/NPL/CO/1, para 46.

¹⁵ CRPD/C/OMN/CO/1, para 56.

¹⁶ One country that does include statistics on institutional households is India, see <<https://data.gov.in/catalog/institutional-households-household-size-census-2001-india-and-states>>, accessed 11 April 2019.

¹⁷ Ethiopian National Disability Action Network (ENDAN) Comitato Collaborazione Medica (CCM).

¹⁸ E.g. Andalucía, Spain: <<https://www.serviciossocialesandalucia.es/mapa-servicios-sociales>> or Valencia, Spain: <<http://www.inclusio.gva.es/estatico/mapificacion/es/index.html>> accessed 11 April 2019.

¹⁹ More information available at: <<https://unstats.un.org/sdgs/iaeg-sdgs/>> accessed 11 April 2019.

²⁰ More information available at: <<http://www.internationaldisabilityalliance.org/prioritylist-ofindicators>> accessed 11 April 2019.

²¹ More information available at: <<https://zeroproject.org/practice/pr191231kkm-factsheet/>> accessed 11 April 2019.

Deinstitutionalization

One of the areas included in the study referred to institutions as potential places of deprivation of liberty. While not all persons living in institutions are deprived of liberty, these settings often do constitute places of deprivation of liberty, whenever the person cannot leave this setting (e.g. under guardianship or has not consented to this placement or under a court order). In this sense, the right to liberty is intimately connected to the right to live independently and being included in the community.

Deinstitutionalization processes are complex, and require systemic transformation.²² The research on deprivation of liberty showed that countries have different understandings of what independent living and deinstitutionalization engrained in their policies and laws.²³ Under terms like ‘independent living’ or deinstitutionalization’, the laws and policies often still included congregated care or living places as an option. The study also found that it was difficult to tackle the question around institutions due to the variety of names the different settings received. This may be interpreted as an intention to break away from institutions without having tackled the underlying nature of how the setting is structured. This has also been identified by the CRPD Committee, which called upon States in its General Comment no.5 to “*ensure that private institutions are not established in the guise of “community living”.*”²⁴

Deinstitutionalization requires two main actions: closing down existing institutions and setting up a comprehensive strategy including things like supporting the transition and setting up community based services. This entails a cross-government approach, with a focus on many sectors, including childhood and adoption, mainstream services, housing policies, social care and employment. It

²² CRPD/C/GC/5, para 58.

²³ Republic of Moldova, Government Decision no. 784 of 9 July 2007 on approval of the National Strategy and Action Plan for the reform of the residential care system for children for the period 2007-2012, Law no. 60 of 30.03.2012 on the social inclusion of people with disabilities. Order of 3 March 2016 regarding the approval of members of the Council of coordination and of plan of actions to implement reforms in the field of de-institutionalization (Ordin cu privire la apro-barea componentei nominale a Consiliului de coordonare si a planului de actiuni pentru implemen-tarea reformelor in domeniul deinstitutionalizarii); Qatar’s National Mental Health Strategy 2013–2018 aims to support a shift “from the model of patient hospitalized in psychiatric departments to the model of attention in community services.” – not mentioning deprivation of liberty outside of hospitals; Spain - Ley 39/2006, de 14 de diciembre, de Promoción de la Autonomía Personal y Atención a las personas en situación de dependencia, includes residential care as part of an independent living scheme.

²⁴ CRPD/C/GC/5, para 51.

needs to ensure “*reforms, budget and attitude on all levels and sectors of government, including local authorities.*”²⁵

Cross sectorial working groups are recommended to lead and coordinate deinstitutionalization efforts. In Ireland, the Working group on Congregated settings produced a report “*Time to Move on from Congregated settings*”, which set out recommendations and a plan to move persons with disabilities back into the community.²⁶ The report discusses different housing options, funding and support schemes, and reports the actions taken by the Working Group (surveys, mapping, etc.). It also states specific recommendations to the different government authorities on what steps to take towards moving persons into the community. “A new way home” by Frances Brown and John Dalrymple²⁷ is another example which includes a proposal on how to lead the transition into community based independent living.

Deinstitutionalization must combine the closure of institutions with the creation of alternatives, as well as with a strategy for Community inclusion.²⁸ A participatory research project conducted in New Zealand describes how spatial presence of persons with disabilities in the community has dominated as an indicator of inclusion, which does not necessarily guarantee actual belonging and a sense of membership.²⁹ Access to the community must be guaranteed, but confrontation of the wider social construction of impairment is also necessary.³⁰ This particular piece of research also notes that persons with disabilities may be exposed to psychological and physical risk when taking part of activities in the community.³¹ This must be addressed and access to justice needs to be guaranteed, providing reasonable accommodation wherever necessary. The research also highlights

²⁵ *ibid*, para 58.

²⁶ Report of the Working Group on Congregated Settings, Health Service Executive, June 2011. More information at: <<https://www.hse.ie/eng/services/list/4/disability/congregatedsettings/>> accessed 11 April 2019.

²⁷ published by the Centre for Welfare Reform, available at: <<https://www.centreforwelfarereform.org/library/by-az/a-new-way-home.html>> accessed 11 April 2019.

²⁸ Examples include Change (DPO) initiative Inclusion in the Community, <<https://www.changepeople.org/projects/inclusion-in-the-community>> accessed 11 April 2019, the Community Inclusion Initiative <https://www.nds.org.au/images/resources/resource-files/What_Does_Community_Inclusion_Look_Like.pdf> accessed 11 April 2019, 19 stories <<https://www.19stories.org>> accessed 11 April 2019.

²⁹ Paul Milner et al, ‘Community participation and inclusion: people with disabilities defining their place’ (2009) 24(1) Disability & Society 47.

³⁰ Johnson, Traustadotir 2005 and Hall 2004 in Paul Milner et al, ‘Community participation and inclusion: people with disabilities defining their place’ (2009) 24(1) Disability & Society 47.

³¹ Reid and Bray 1998 in Paul Milner et al, ‘Community participation and inclusion: people with disabilities defining their place’ (2009) 24(1) Disability & Society 47.

the importance of how the person participates, rather than where, as well as “*being able to decide where, when and with whom they were in public settings*”. The American Disability Integration Act³² which has not yet been passed, would require states to ensure that people with all types of disabilities have a choice to live in the community and lead independent lives. It would extend the applicability of antidiscrimination law to all types of disabilities whenever services within the community are denied. The Act addresses housing issues, framing the lack of public housing to allow a person to live in the community and not in an institution as discriminatory.

Jim Mansell et al. published a frequently cited report on deinstitutionalization,³³ which concluded that most support “*comes from families, friends and neighbours, but the inputs, responsibilities and burdens of family and other unpaid carers often go unrecognised and unsupported.*”³⁴ It highlights the need for coordination and planning, and warns against expectation of generalized lower costs, as good support will cost money. Community based care may not be less expensive, but does provide better outcomes. People’s preferences vary, and this must be taken into account when designing services. It also suggests that families can be supported “*through direct or indirect financial support, employment-friendly policies, educational programmes, counselling and respite services.*”³⁵ The report also proposes having practical examples of how things could be better and creating incentives for change. Lastly, it sets out a plan toward deinstitutionalization, including legal reform, policy adoption, strengthening the voice of persons with disabilities and their networks, making professionals adapt their working methods to support inclusion, encourage media, feed the dissatisfaction with the current system (transparency), learn from other countries, create monitoring bodies, encourage comparison of quality of life, give practical examples of how things could be done better, include everybody from the very beginning, introduce new funding schemes that promote change and remove obstacles to develop community services.³⁶

³² More information available at: <<http://www.disabilityintegrationact.org/>> accessed 11 April 2019.

³³ Jim Mansell et al, ‘Deinstitutionalisation and community living – outcomes and costs: report of a European Study’ (2007) Volume 2: Main Report. Canterbury: Tizard Centre, University of Kent.

³⁴ Ibid, p 96.

³⁵ Ibid, p 99.

³⁶ Ibid, pp 102- 104.

The European Fundamental Rights Agency published a comprehensive report on the right to independent living³⁷ (“FRA report”), which highlights the need for commitment to deinstitutionalization and a shift in attitudes. The report includes the findings of the fieldwork conducted in Bulgaria, Finland, Ireland, Italy and Slovakia on the progress on the deinstitutionalization process. Shifts in attitude require tackling stigma, which is explored further below. It also involves specific training to all policy makers and stakeholders to understand the principles of the CRPD.

The FRA report notes the importance of a change in culture on how support services are provided and how support is given to persons with disabilities. It aims at an empowering approach, focusing on trainings on article 12 on legal capacity and decision making, developing support materials on how to prepare persons with disabilities for independent living and how to transform support services.

It also highlights the need for coordination efforts (national, regional local level) and cross-sectors. A coordinating figure is recommended to work together with public and private services, users, staff, families and NGOs, and ensure that all groups are involved and on track. It is important to involve all stakeholders during the entire process, as the process depends on all stakeholders.

One of the key element of any deinstitutionalization strategy is involvement of all stakeholders, specially Disabled People Organizations.³⁸ The participants with disabilities and NGOs in the research on disability-specific forms of deprivation of liberty also demanded to be involved and consulted more frequently. Participation was one of the common themes in all countries.

The Zero project mentions an example of involvement of persons with disabilities on local policy making in Ecuador.³⁹ *Fundación Discapacidad y Desarrollo* invited local DPOs to identify urgent issues and propose solutions to their local councils and followed up through permanent monitoring.

An example of participatory decision-making relating to housing and independent living is highlighted in the TOPHOUSE report⁴⁰ and comes from Austria, called

³⁷ Fundamental Rights Agency, ‘From institutions to community living. Part I-III’ (2017).
Fundamental Rights Agency ‘From institutions to community living for persons with disabilities – perspectives from the ground’ (2018).

³⁸ See recommendation by Mental Health Europe Report p.13.

³⁹ Zero Project report p. 34.

⁴⁰ More information at: <http://www.easpd.eu/sites/default/files/sites/default/files/io_january_2019- final-compressed_version.pdf> accessed 11 April 2019.

“*Wiener Wege zur Inklusion*”.⁴¹ This project is based on the principle that persons with disabilities are experts by experience. Persons with disabilities were invited to identify current issues, discuss possible solutions, prototype them and try them out. The project is supported by different organizations and the city council.

The TOPHOUSE report identified a peer review system in Finland, whereby persons with disabilities assess the housing quality through interviews with the users. Their findings are then presented to service providers and are often combined with a training session.⁴²

Living Lab provides co-design and has been implemented in independent living and health initiatives in France.⁴³ This initiative has explored different tools to support independent living, with a strong focus on technologies and using user-centered methodologies.

A Disabled Persons’ Organisation from Lebanon leads several independent living centres and provides home alterations, accessible transportation, assistive equipment, and training.⁴⁴

Lastly, deinstitutionalization strategies must avoid any new admissions to institutions, as moving somebody back into the community will cost more than if she is already living in the community.⁴⁵ Further, it must consider and carefully plan relocation of existing residents, as well as the development of support for peer support and user groups. Specialized community-based supported accommodation services are also a good option to tackle institutionalization practices, e.g. acute therapeutical services,⁴⁶ crisis homes,⁴⁷ homes for women with psychosocial disabilities victims of sexual abuse,⁴⁸ home care support.

⁴¹ More information at: <<http://www.wiener-wege-zur-inklusion.at>> accessed 11 April 2019.

⁴² More information at: >https://www.esn-eu.org/sites/default/files/practices/DP_FI ASPA Dispersed Community Living Model.pdf> accessed 11 April 2019.

⁴³ Robert Picard, ‘*Co-design in living labs for healthcare and independent living concepts, methods and tools*’ (2017) Health Engineering and Society Series.

⁴⁴ More information available at: ><https://zeroproject.org/practice/pr191358lbn-factsheet/>> accessed 11 April 2019.

⁴⁵ Jim Mansell et al, ‘Deinstitutionalisation and community living – outcomes and costs: report of a European Study’ (2007) Volume 2: Main Report. Canterbury: Tizard Centre, University of Kent.

⁴⁶ More information at: <<http://positivepracticemhdirectory.org/adults/acute-therapy-service-ats-lancashire-care/>> accessed 11 April 2019.

⁴⁷ An example from UK <<https://www.islcs.org.uk>>, and more information at: <<https://www.icpmh.info/commissioning-tools/cases-for-change/crisis/what-works/crisis-houses/>> accessed 11 April 2019.

⁴⁸ Good practice identified through the Zero project and Ashoka at: <<http://impact-transfer.org/zero/enosh-seeds-of-wellness/>> and ENOSH’ website: <<https://www.enosh.org.il/en/service/enosh-the-israeli-mental-health-association/>>, Drayton Park Women’s Crisis House, more information at: <<https://www.candi.nhs.uk/services/drayton-park-womens-crisis-house-and-resource-centre>>, all accessed 11 April 2019.

Participation in policy and decision-making

Deinstitutionalization requires coordination and policy-making with strong involvement of all stakeholders. The CRPD reinforces participation of persons with disabilities on all levels of decision-making and policy design (see article 29 CRPD).

The National Service for Persons with Disabilities of the Chilean Government (*Servicio Nacional de la Discapacidad - Gobierno de Chile*) published a collection of good practices⁴⁹ including a framework of data and legislation applicable to independent living. Further, it highlights good practices in education and transition from institutions to community living, and how it promotes public institutions to promote inclusive policies through competitions and funding calls.

Housing policies

The UN Special Rapporteur on Housing published a “report on adequate housing as a component of the right to an adequate standard of living, and on the right to non-discrimination in this context”.⁵⁰ The report highlights the importance of adequate housing with access to support in the community as the difference “*between life and death, security and abuse, and belonging and isolation.*”⁵¹ The report reminds the reader that the right to housing, included in article 11 of the International Covenant on Economic, Social and Cultural Rights, is much more than just “*a physical shelter*”.⁵² The report also recognizes the discrimination persons with disabilities face when seeking private and public housing.⁵³ It establishes a link between inadequate housing or lack of support, homelessness and incarceration.⁵⁴ Further, the lack of affordable housing may render other efforts like protection of supported decision making and legal capacity ineffective.⁵⁵ It also finds a high percentage of persons with disabilities among homeless people.⁵⁶ Housing and development do not take persons with

⁴⁹ Available at: <<https://www.senadis.gob.cl/areas/autonomia/documentos>> accessed 11 April 2019.

⁵⁰ UN Special Rapporteur on Housing, ‘Report of the Special Rapporteur on adequate housing as a component of the right to an adequate standard of living, and on the right to non-discrimination in this context’ (2017) A/72/128.

⁵¹ *ibid*, para.1.

⁵² *ibid*, para. 2.

⁵³ *ibid*, para. 13.

⁵⁴ *ibid*, para. 14.

⁵⁵ *ibid*, para. 17.

⁵⁶ *ibid*, para.22.

disabilities into account, and urban planning is rarely monitored on barrier-free design, despite that designing barrier-free houses reduces the cost of reasonable accommodation.⁵⁷ The respect for inherent dignity and choice must be fundamental in any housing policy, as well as the right non discrimination, which includes reasonable accommodation as a component of this right.⁵⁸

The report identifies the key components to adequate housing:

1. Secure tenure: within the community, and with access to services and support. States must protect from forced eviction or provide alternative housing that meets the accessibility requirements and ensures access to community.
2. Affordability
3. Availability of services
4. Habitability: which includes the physical and social dimension of housing, e.g. protection against violence, soundproof apartments for persons with autism.
5. Location: within the community.
6. Cultural adequacy.

The report recommends States to adopt a holistic and system approach, to move away from charitable models and include all persons with disabilities.

The TOPHOUSE report⁵⁹ explores housing policies in Austria, Ireland, Spain and Finland, including supporting housing and non-accommodation providing support. In its review of the Austrian situation, it warns against the trend of believing that non-discrimination is met by pre CRPD legislation when the paradigm shift to the human rights model has not taken place, and it explains how many people are still constrained to live in residential care, and that care packages to be provided at home are based purely on medical criteria, e.g. hygiene.⁶⁰ However, it also notes slow implementation of the individualized support model through individual support contracts. The report highlights the

⁵⁷ *ibid*, para 28.

⁵⁸ *ibid*, para 37.

⁵⁹ Available at: <http://www.easpd.eu/sites/default/files/sites/default/files/io_january_2019- final-compressed_version.pdf> accessed 11 April 2019.

⁶⁰ *ibid*.

example of Jugend am Werk in Styria⁶¹, where 11 persons with disabilities were supported to transition from institutions to supported housing. The organization offers different intensity of support. Another identified initiative is the inclusive living home,⁶² which offers sharing a home without preselecting criteria such as disabilities, but simply a commitment to live for at least a couple of months or alternatively a whole year. The Finnish legislative framework and services are described as CRPD supportive, including social housing services and community based supported services. Persons living in institutions have been reduced by 50 % in 10 years. The KEHAS programme is a government led project to provide individual housing options to persons with intellectual disabilities, which included a consultative period where persons with intellectual disabilities defined their housing wishes and assigned a clear responsibility to local governments. The ASPA Foundation runs the dispersed community living model and different housing options (renting apartments for clients, two doors – one to apartment one to a shared area, providing in home support).⁶³ On the whole, personal support is central within the Finnish system.⁶⁴

In Ireland, there are voluntary housing associations that tackle housing issues for different collectives. There is a national social housing federation which works on expanding social housing to include “*various groups of the population such as the elderly, homeless, people with disabilities or families on low incomes.*”⁶⁵ It includes services such as aid to facilitate renting processes, maps housing initiatives and projects to reduce living costs, e.g. prepay electricity bills (to avoid estimates). An example includes HAIL (Housing Association for Integrated Living) which manages over 300 housing units and support during the moving in phase and tenancy issues. It uses a floating support approach⁶⁶ rather than permanent provision of support. Another highlighted approach is the principles of Self-Directed living.⁶⁷

⁶¹ More information at: <<https://jaw.or.at/unterstuetzung-angebote/menschen-mit-behinderung/wohnen/>>

⁶² <http://lebebunt.strikingly.com>> accessed 11 April 2019.

⁶³ More information at: <https://www.esn-eu.org/sites/default/files/practices/DP_FI_ASPA_Dispersed_Community_Living_Model.pdf> accessed 11 April 2019.

⁶⁴ This information could not be contrasted with CRPD Committee country reports as none have been submitted yet.

⁶⁵ See more at: ‘About ICSH’ <<https://www.icsh.ie>> accessed 11 April 2019.

⁶⁶ Floating support approach provides support only when support is needed, rather than creating a permanent support structure that may impose support or decisions on the person.

⁶⁷ More information at: <<http://sunbeam.ie/self-directed-living>> accessed 11 April 2019.

Housing First⁶⁸ approach provides long term homeless persons with an apartment and the necessary support, taking into account possible accommodation needs and on a non-discrimination basis.

The need to develop alternative child care within families has been highlighted by many, including the CRPD Committee in its the General Comment no.5 of the CRPD Committee. The Committee insists that *“policies of de-institutionalization therefore require implementation of structural reforms, which go beyond the closure of institutional settings. Large or small group homes are especially dangerous for children, for whom there is no substitute for the need to grow up with a family. “Family-like” institutions are still institutions and are no substitute for care by a family.”*⁶⁹ The Annie Casey foundation includes resources on how to transform foster care⁷⁰, and the Better Care Network also includes resources on alternatives to residential care, such as kinship care.⁷¹

While the research on independent living initiatives is vast, this project aimed to highlight some possibilities and some of the needs. Deinstitutionalization requires creating space for opportunities to collaborate with persons with disabilities, which includes supporting empowerment initiatives, allowing for uncertainty and pilot programmes, and including disability perspectives in other policies. During our qualitative research on the causes of deprivation of liberty, one of the policy makers highlighted that it is a common practice of treating disability as a separate issue, which makes inclusive perspectives practically impossible.

The Japan Council on Independent living works through independent living centers, in which it offers advocacy services, information, personal assistant referral, peer counseling, housing services and independent living skills training.⁷²

⁶⁸ UN Special Rapporteur on Housing, Report of the Special Rapporteur on adequate housing as a component of the right to an adequate standard of living, and on the right to non-discrimination in this context (2017), A/72/128.

⁶⁹ CRPD/C/GC/5, para 16(c).

⁷⁰ Annie E Casey Foundation, 'A Movement to Transform Foster Parenting. 2016' available at: <https://bettercarenetwork.org/sites/default/files/aecf-TransformFosterParenting-2016.pdf> accessed 11 April 2019.

⁷¹ More information at: <https://bettercarenetwork.org/library/the-continuum-of-care/kinship-care> accessed 11 April 2019.

⁷² For more information at: <http://www.j-il.jp/jil.files/english/aboutjil.html> accessed 11 April 2019.

Individual funding schemes

Individual funding schemes are often related to independent living plans and have been implemented in several countries.⁷³ In some cases, this involves transferring money to the individual, in others, it may be managed by the State.⁷⁴ Direct payments have been found to increase the choice and control of recipients, as well as an increase of self-esteem. Moreover, direct funding schemes may be 30% to 40 % less expensive than service provision⁷⁵. Persons may receive support from the government to deal with the administrative side of the applications, or with process of the hiring of a support person.

Personal assistance

In Sweden, persons with disabilities are entitled by law to a Personal Assistant. Further, assessment of needs for a personal assistant is not based on medical criteria, but on the support needs of the person.⁷⁶ The personal assistant introduced the element of individualization, where the user decides who to hire and where the money is spent, rather than service providers. In 1987, a pilot project was run under the Stockholm Cooperative for Independent Living (STIL), whereby persons who requested support became members of the cooperative, and were responsible for the recruitment of assistants, wage negotiation, training, scheduling and supervising their respective personal assistants, while the cooperative assumed the legal tasks. The cooperative has since become a service provider to the municipality of Stockholm, without increasing costs for the municipality, but changing the way services are provided and promoting the self-determination of the former recipients of personal assistance services. This developed into formal legislation, the Swedish Personal Assistance Act 1993, recognizing the right to personal assistance to all persons with disabilities, including those with higher support needs. A research project exploring how personal assistance was provided in decentralized governments found that this

⁷³ E.g. Canada, Australia, New Zealand, the USA, the Netherlands, Germany, Sweden, England and Scotland as seen in the report by Keogh S., Quinn G., see following footnote.

⁷⁴ Sinéad Keogh et al, 'Report: Independent Living: An Evaluation of The Áiseanna Tacaíochta Model of Direct Payments' (February 2018).

⁷⁵ Nadash and Zarb (1994), Jones et al (2011) and Stainton et al (2009) in Sinéad Keogh et al, 'Report: Independent Living: An Evaluation of The Áiseanna Tacaíochta Model of Direct Payments' (February 2018).

⁷⁶ Sinéad Keogh et al, 'Report: Independent Living: An Evaluation of The Áiseanna Tacaíochta Model of Direct Payments' (February 2018).

model has been impacted in recent years by austerity measures and cuts to Personal Assistant Budgets.⁷⁷

Support schemes

The Special Rapporteur on the Rights of Persons with Disabilities published a report on Support Services to ensure the inclusion of persons with disabilities⁷⁸. In the TOPHOUSE report some examples of supported decision making around housing and support needs are listed, e.g. ZIELWÄRTS includes a phase where the desired support is fleshed out collaboratively with the person, relatives and support workers, a plan is established and a tool called "Personal Future Planning" states how the person wants to be supported around the living plans in the future.

KeyRing⁷⁹ in the UK has developed a system of network supports whereby disabled people who need support live in their own homes but within the same neighbourhood where they can provide peer support to each other. This model has also been used in Ireland by StepIn, which creates networks of up to 10 members, 9 of which have support needs and 1 who is a community volunteer. Members live close by (not together) and are willing to support one another. The networks are supported by a network coordinator. While the network does not provide for paid support, it focuses on "*supporting individuals with their housing needs (managing their tenancy, bills and so forth) and with being an active member of the network.*"⁸⁰

Curtin University in Australia has produced a manual on Independent Supported Living that provides examples of what independent supported living may look like and how to implement it. It reviews different forms of arranging individualized support (through NGOs, direct employment, etc.) and how this works in combination with other services.⁸¹ The proposed framework can also be used to review existing arrangements. The manual provides a description of "home" and

⁷⁷ Ciara Brennan et al, 'How can states ensure access to personal assistance when service delivery is decentralized? A multi-level analysis of Iceland, Norway and Sweden (2017) 19(4) Scandinavian Journal of Disability Research 334.

⁷⁸ Report of the Special Rapporteur on the rights of persons with disabilities, 20 December 2016, A/HRC/34/58.

⁷⁹ More information at: <<http://www.keyring.org>> accessed 11 April 2019.

⁸⁰ More information at: <<http://www.stepin.ie/what-we-do/>> accessed 11 April 2019.

⁸¹ Errol Cocks et al, 'Individual Supported Living Manual' (2017) Second edition. School of Occupational Therapy and Social Work. Curtin University.

attributes for different aspects of independent living, with various indicators to see if all aspects of home and independent living are being respected.

Alternatives to involuntary psychiatric hospitalization

The objective of the study on deprivation of liberty was not coercion, but the subject is deeply connected to the different forms of deprivation of liberty and consent. It often came up during the interviews with family members and persons with lived experience and some of the indicators developed in phase I included coercive measures, e.g. restraint. We therefore strongly recommend reading a recent report on alternative to coercion was published by the University of Melbourne,⁸² which reviews the term of coercion and how it comes into play within mental health settings. It includes an extensive literature review and a list of alternatives. Within its findings, it highlights the need of coordination of local and central (top and down governments), similarly to deinstitutionalization policies. It further runs through the different alternatives depending on their leadership and place of occurrence as in within the family or wider network, hospital based or community based proposals.

The ‘Six Core Strategies to Reduce the Use of Seclusion and Restraint’, extensively described within the report on alternatives to coercion, has proven to be effective to reduce the use of restraints, as well as adopting a ‘trauma-informed approach’.⁸³

Within the research conducted by this research team, powerlessness was described by family members (France and Ghana), who also felt coerced into giving up their relative to involuntary admission or institutionalization. The stakeholders identified small initiatives as good practices, that could prevent further deprivation of liberty:

- General access to mental health services, especially in Indonesia, Ghana and Jordan, ideally in community based mental health services;
- Peer support groups for persons with lived experience and for families (mixed and separate): Participants from Ghana spoke about peer support groups where they discussed ongoing issues which also helps overcoming stigma, according to participants.

⁸² Piers Gooding et al, ‘Alternatives to Coercion in Mental Health Settings: A Literature Review’ (2018) Melbourne: Melbourne Social Equity Institute, University of Melbourne.

⁸³ *ibid.*

- The “Collective 39”⁸⁴ in France, a group of psychiatrists who oppose the use of coercion and forced psychiatry which was founded as a response to a law reform initiated at the end of December. The group calls for an “open door policy” and for the provision of care rather than turning persons into object of monitoring and psychiatrists into guardians. As a response to the State’s violence, each of them will resist within their workplace.
- Basic Needs in Ghana: This NGO provides free medication and organizes peer support groups within Ghana, and was cited by many participants as a good practice.

Further, the research team included following good practices:

Open dialogue initiative

The Open dialogue initiative was developed in Finland to work with persons experiencing a mental health crisis and their networks. It is embedded within psychiatric services and it proposes the use of psychotherapeutic treatment within the natural environment of the person. In this model, a crisis intervention team facilitates a dialogue with the person and the person’s social network. It embraces three principles: tolerance for uncertainty, dialogism, polyphony in social networks.⁸⁵ It provides immediate help upon contact from the patient, a relative or a referral service. From the beginning, the patient, the family and people from its network are invited to participate in the meetings, which take place at the person’s home with the individual and the family’s consent. The team remains mobile and flexible to changes and continues supporting the person throughout the treatment. Within this practice, tolerance for uncertainty is combined with building up trust. This model has been proven to reduce hospitalization, the rate of recidivism and the use of medication.⁸⁶ The Open Dialogue model is now also been taught in the UK.⁸⁷

⁸⁴ More information at: <<https://www.collectifpsychiatrie.fr>> accessed 11 April 2019.

⁸⁵ Jaako Seikkula et al, ‘Open dialogue in psychosis I: An introduction and case illustration’ (2001) 14(4) *Journal of Constructivist Psychology* 247.

⁸⁶ Jaako Seikkula et al, ‘The Open Dialogue Approach to Acute Psychosis: Its Poetics and Micropolitics’ 42(3) *Family Process* 403.

⁸⁷ More information at: <<http://opendialogueapproach.co.uk>> accessed 11 April 2019.

Advanced directives

Advanced directives are laid out instructions by the person with disabilities for situations in which the person will be deemed unable to make choices.⁸⁸ The advanced directives include treatment preferences and who can make decisions on their behalf. The use of advanced directives is not very common, but research found that it promotes the consumer's autonomy and provides better care.⁸⁹ Barriers included lack of training and resources (e.g., overworked staff, lack of facilitation services), as well as lack of information for consumers and lack of trust if the advanced directives can be overridden.

Family Group Conferencing

This concept emerged from Maori practice and was first recognized as part of child welfare policy and legislation in New Zealand.⁹⁰ It has more recently been successfully used in the context of psychosocial disability as a voluntary consultation process in which the person invites family members, friends and whoever she chooses to discuss a certain issue and help finding solutions.⁹¹ The group designs a plan foreseeing formal and informal support. This approach recognizes the person as an expert on her own life and provides for supported decision making in critical situations.⁹² According to Ma Mawi Wi Chi Itata Centre, three principles reign the process:⁹³

- Persons are gathered as problem solvers and have an equal right to participate;
- The aim is to talk through the issues and seek to understand what is going on, not to ascribe blame;
- Search consensus among participants.

Applied in the context of persons with disabilities, it essential that the will and preferences of the person are respected and their decision-making supported.

⁸⁸ Heather Zelle et al, 'Advance directives in mental health care: evidence, challenges and promise' (2015) 14(3) World Psychiatry 278.

⁸⁹ Ibid.

⁹⁰ David Hayes et al, 'Lifeworld', 'System' and Family Group Conferences: Habermas's Contribution to Discourse in Child Protection' (2007) 37(6) The British Journal of Social Work 987; Judge Andrew Becroft, 'Family Group Conferences: Still New Zealand's gift to the world?' Children's Commissioner (December 2017).

⁹¹ More information on the Eindhoven model available at: <www.Mindrights.nl> accessed 11 April 2019.

⁹² Summary on Family Group Conferencing by PERSON Project, available at: <http://righttoactcampaign.com/family-group-conferencing-a-new-tool-for-responding-to-psychosocial-crises-with-respect/>

⁹³ More information at: <<http://www.mamawi.com/family-group-conferencing/>> accessed 11 April 2019.

The meetings follow a structure and have a plan as an outcome, which is regularly revisited.⁹⁴ Further, it is voluntary and, according to the Eindhoven Model, it must be coordinated by an independent coordinator.⁹⁵

More initiatives can be found on any MIA website (or its regional partners)⁹⁶ and in the research on alternatives to coercion.⁹⁷ The alternatives listed have in common that they are led, directed or designed by persons with lived experience, they respect the person's will and preference, including on the person's understanding and identification of the distress or actual or perceived impairment and cultural or social belief. Guidance on how to establish these practices can be found in the Special Rapporteur on the Right to Health's report on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health⁹⁸ and in the WHO Quality Care toolkit⁹⁹ and training.¹⁰⁰ We also found online manuals and guidance on how to set up a peer led crisis homes¹⁰¹ and peer support groups.¹⁰² Online peer support through social media has also been explored and described as a successful tool to provide support, advice and sharing experiences, as well as to combat stigma and common misperceptions.¹⁰³

Intentional Peer Support (IPS), founded by Sherry Mead, provides a methodology to co-create through dialogue, relationships and learning to see things from different angles.¹⁰⁴ It provides a new framework to design relationships and support, including within human services. IPS is described as

⁹⁴ Chantal Hillebregt et al, 'Effects of family group conferences among high-risk patients of chronic disability and their significant others: study protocol for a multicentre controlled trial' (2018) 8(3) BMJ e018883.

⁹⁵ More information at: <<https://punkertje.waarbenijj.nu/reisverslag/4567654/presentation-text-on-eindhoven-model-cosp>> accessed 11 April 2019.

⁹⁶ More information at: <<https://www.madinamerica.com/initiatives/>> accessed 11 April 2019.

⁹⁷ Piers Gooding et al, 'Alternatives to Coercion in Mental Health Settings: A Literature Review' (2018) Melbourne: Melbourne Social Equity Institute, University of Melbourne.

⁹⁸ Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, A/HRC/35/21

⁹⁹ WHO 'QualityRights tool kit to assess and improve quality and human rights in mental health and social care facilities' (2012).

¹⁰⁰ Available under https://www.who.int/mental_health/policy/quality_rights/en/

¹⁰¹ National Center for Empowerment, more information under <https://power2u.org/resources-for-starting-a-peer-run-crisis-alternative-in-your-area/>

¹⁰² An Australian example: <https://www.peerconnect.org.au/setting-and-running-peer-networks/background/peer-networks-what-they-are-and-how-they-can-help/>, a Spanish example Federación andaluza de asociaciones de usuarios/as de salud mental "En Primera Persona", available under: <https://consaludmental.org/publicaciones/Recuperacionayudamutua.pdf>

¹⁰³ John A Naslund et al, 'The future of mental health care: peer-to-peer support and social media' (2016) 25(2) Epidemiology and psychiatric sciences 113.

¹⁰⁴ More information at: <<https://www.intentionalpeersupport.org>> accessed 11 April 2019.

a tool for community development. The website includes a handbook on how to set up peer respite, which frames peer support as an opportunity to learn from crisis, an alternative to hospital providing a non-medical alternative and ultimately, an opportunity to address social justice.¹⁰⁵ The emphasis is on self-determination, autonomy and personal responsibility rather than on risk assessment, and all healing options are explored.

Peer support

Peer support groups exist around the globe.¹⁰⁶ These are built on relationships of reciprocity and respect, promoting recovery focusing on strength and learning.¹⁰⁷ Within the project on deprivation of liberty, a peer support initiative in Ghana was highlighted.¹⁰⁸ Another example from Kenya¹⁰⁹ shows that these groups may come in different sizes, and have different purposes: providing psychosocial support for persons with disabilities and their families, building self-advocacy capacity, empower and involve in decision-making processes within their country, act as social change enabler and fighting stigma and defending the human rights model within their local community.

The Personal Ombudsman (PO) from Sweden¹¹⁰ is a nationwide system in which independent individual ombudsman provides support in decision-making for persons with psychosocial disabilities. The PO works on building a relationship of trust with the supported person and identifies the needs and resources of the person. This network actively reaches out to people to offer support. They work on an individual basis and do not make any decisions on behalf of authorities or the person. There is no formal bureaucratic application procedure and works with the person at the person's home or a neutral space, not an office (symbol of power) nor keeps records, which belong to the client.

¹⁰⁵ Sera Davidow, 'Peer Respite Handbook: A Guide to Understanding, Developing and Supporting Peer Respites. Western Mass Recovery Learning community' Denver: Outskirts Press, 2017. Available under <https://static1.squarespace.com/static/5630e573e4b0efc185471156/t/5abd7a9b70a6ad798f81aa55/1522367180975/Peer+Respite+Final+2017.pdf>

¹⁰⁶ Julie Repper et al, 'A review of the literature on peer support in mental health services' (2011) 20(4) Journal of Mental Health 392.

¹⁰⁷ Ibid.

¹⁰⁸ GH_G6_P5; GH_G6_P3. The initiative is facilitated by Basic Needs Ghana.

¹⁰⁹ More information under <http://www.uspkenya.org/peer-support-groups/>

¹¹⁰ More information available here: <http://po-skane.org> and here: <https://zeroproject.org/policy/sweden-2/>

Monitoring systems and strong ethical standards

Regulating civil commitment does not automatically lead to a reduction of its use.¹¹¹ Monitoring systems have not yet impacted significantly on reduction of the use of deprivation of liberty or coercion. Thus, implementation of monitoring systems or rules are intended to address lack of data and non-recognition of deprivation of liberty as a human rights violation, and are only one step of the entire process. Even where monitoring or data collection on types of disability-specific deprivation of liberty exists, it is often flawed data, as it only focuses on specific settings (e.g. psychiatric hospitals) failing to recognize that liberty is deprived in the community and private settings as well. Most of the data available is not complete because it only counts involuntary hospitalisations as deprivations of liberty, even though many of those admitted ‘voluntarily’ may not have given their free and informed consent.¹¹²

The report on disability specific forms of deprivation of liberty found that despite an increase of regulation and partial awareness of this human rights violation, it has not ceased to occur. This is not to say that law and monitoring are not useful, but that they need to be accompanied by other policies and conducted in a manner that is socially and culturally conscious. Data collection is not only for monitoring nor punitive purposes, but also to inform policy and to understand and frame issues.

As identified in the report on Alternatives to Coercion¹¹³, coercion may occur in nominally ‘voluntary’ settings, which means that services have to become especially aware of their actions. Similarly, coercion or former relationships of dependency may reemerge within the new forms of supported living¹¹⁴ and independent living schemes.¹¹⁵ This needs to be taken into account when setting up alternative services.

¹¹¹ Hans Joachim Salize et al, ‘Compulsory Admission and Involuntary Treatment of Mentally Ill Patients – Legislation and Practice in EU-Member States’ (2002).

¹¹² Mark Roberts et al, ‘The mental health system in Ghana’ (2013) The Kintampo Project. Available at: <<https://www.mhinnovation.net/sites/default/files/downloads/innovation/research/The-Mental-Health-System-in-Ghana-Report.pdf>> accessed 11 April 2019.

¹¹³ Piers Gooding et al, ‘Alternatives to Coercion in Mental Health Settings: A Literature Review,’ (2018) Melbourne: Melbourne Social Equity Institute, University of Melbourne.

¹¹⁴ Jim Mansell et al, ‘Deinstitutionalisation and community living – outcomes and costs: report of a European Study’ (2007) Volume 2: Main Report. Canterbury: Tizard Centre, University of Kent.

¹¹⁵ Sheila Riddell et al, ‘The development of direct payments in the UK: implications for social justice’ (2005) 4 (1) Social Policy and Society 75.

Forms of addressing this include inviting persons with disabilities to lead services or have representatives in leading positions, continuous training of staff, having ethics and/or human rights committees within organizations to address complex situations, creating effective complaint systems, having peer advocates to support persons subject to coercion and guaranteeing access to justice of persons with disabilities.

Monitoring practices include incorporating developing feedback schemes from users of services.¹¹⁶

Litigation is essential to monitor not only the respect of human rights but also to enforce new legislation that may find resistances. Access to justice for persons with disabilities has been weak in challenging detention as explored in the study.¹¹⁷ Moreover, all areas referred to above require reinforcement of the right to access to justice.

The French Observer on Deprivation of Liberty (*Contrôleur général des lieux de privation de liberté*) was established by Law of 30 October 2007 as an independent body to monitor establishments that deprive persons of liberty, including hospitals, and to ensure that the person in detention's rights are respected. The Observer is protected from interference as no authority can issue instructions to the Observer, nor can the appointed person be removed from office until the end of a six year appointment. The Observer cannot be legally prosecuted for his or her opinions and actions carried out under his duties. S/he can conduct unexpected visits and receive complaints from individuals, organisations and the Government. In 2016, the Observer issued a report on restraint and isolation,¹¹⁸ which included a recommendation to register and collect data on these practices, which has now become a duty by law.

The Association for the Prevention of Torture (APT) organised a global symposium on monitoring psychiatric facilities, during which participants identified a lack of training on disability rights within national monitoring bodies. The symposium adopted a wide understanding of psychiatric institutions (including nursing homes) and reviewed different aspects of involuntary

¹¹⁶ E.g. Sunbeam feedback system highlighted in TOPHOUSE report.

¹¹⁷ Data on number of complaints filed by persons with disabilities was low or non-existent in many cases and one of the participant explained that he had difficulties finding a lawyer who would agree to take his case forward. See report on disability specific forms of deprivation of liberty for more details.

¹¹⁸ *Contrôleur général des lieux de privation de liberté, Isolement et contention dans les établissements de santé mentale* (2016).

hospitalization or institutionalization, such as restraint practices, overmedication and the fluidity of the voluntary and involuntary status.¹¹⁹

The National Preventive Mechanisms (NPMs) which monitor the implementation of the Convention Against Torture in individual countries have recommended different strategies of relevance to disability-specific deprivation of liberty, such as including ex users of psychiatric services within their national monitoring teams.¹²⁰

Funding practices must also be monitored, as organisations may seek to fund rehabilitation of their premises, or stretch certain parameters to meet the requirements. Clear terms and clear understanding of the CRPD is required (including funding of other activities in segregated settings). The Structural Funds Watch report¹²¹ monitored funding streams within the European Union, and included following recommendations: include clear language in any call for funds to promote deinstitutionalization, to avoid refurbishing of existing or establishing smaller institutions, target consistency in all funding calls to promote deinstitutionalization and to be aligned with the CRPD and to “*develop long-term strategies to support the transition from institutional to community-based living.*”

¹¹⁹ Association for the Prevention of Torture, ‘Monitoring psychiatric institutions – Outcome report of 2016 Jean-Jacques Gautier NPM Symposium’ (2016) Available at: <https://apt.ch/content/files_res/report-jjg-symposium-2016-en.pdf> accessed 11 April 2019.

¹²⁰ *ibid.*

¹²¹ Neil Crowther et al, ‘Opening up communities, closing down institutions: Harnessing the European Structural and Investment Funds’ (2017) Community Living for Europe: Structural Funds Watch.

Stigma

The study found stigma was one of the main causes identified as a contributing factor to deprivation of liberty, and so does the FRA report. Stigma has vast impact, not only on rejection, but also on the way of providing care, support or guaranteeing access to services and community. Destigmatization must not only address prejudices, but also target any paternalism that may be present in the style of providing support of different organizations.

Stigma includes the idea that persons with disabilities need to be looked after or cared for¹²². These attitudes hinder inclusion in community, leaving residential care and assuming direction over one's life. It affects the opportunities people get and people seize, and was described as pervasive and very painful by the participants in the research study. Participants from all countries agreed that stigma was a major barrier to full enjoyment of rights and a source of distress. It affects primarily the person with disabilities, but also families and one of the policy makers mentioned that his fellow colleagues were not interested in working with him because of his area of work (rights of persons with disabilities).¹²³

Combatting stigma

Countries have set up campaigns to eliminate stigma through advertisement and information campaigns. Disabled People Organisations have started advocacy campaigns and actively participating in politics. Working on stigma requires combinations of nationwide campaigns but also locally very targeted work, e.g. with a group of doctors to become aware of stigmatizing behaviours, which has been considered more effective.¹²⁴ The Global Anti-Stigma Alliance was founded to share learning on how to address stigma around "*persons with mental health issues*". It includes a list of resources, partners and campaigns.¹²⁵

¹²² FRA report.

¹²³ GH_G1_P14. Disability-specific forms of deprivation of liberty. 2019.

¹²⁴ Norman Sartorius, 'Fighting stigma: theory and practice' (2002) (1) World psychiatry 26.

¹²⁵ More information at: <<https://www.time-to-change.org.uk/about-us/what-we-do/global-anti-stigma-alliance/research-resources>> accessed 11 April 2019.

Using personal stories

Personal experiences of persons with disabilities are powerful and compelling.¹²⁶ The FRA report found that “*positive stories of people with disabilities living ordinary lives in the community help to reshape perceptions of disability and counter the ‘fear of the unknown’*”,¹²⁷ and that these had a positive impact on societal attitudes towards persons with disabilities. Personal stories of persons with disabilities are being used more and more in art, research and advocacy to support the demands under the CRPD. Examples of this can be found in 19 stories, and the ERC Voices project¹²⁸. The 19stories project shows *lived inclusion*, as a response to the questions around what does social inclusion mean. In this context, it includes a story of Dee, a person with learning disabilities, who fought to live in an apartment, not in congregated care, and lives independently.¹²⁹ The ERC Voices project (The Voices of Individuals: Collectively Exploring Self-determination) explored personal narratives in relation to legal capacity to promote legal change. The project explores the intersection of legal capacity and deprivation of liberty in its different forms – involuntary hospitalization and institutionalization, among other themes. One of the participants was Rusi Kosev Stanev, who fought for his freedom and brought forward a landmark case against institutions and deprivation of legal capacity.¹³⁰ Paul Alford’s story includes his moving out of a large institution back into the community,¹³¹ Claire Hendrick’s story also embodies an example of independent living,¹³² while Cath Roper’s story explores involuntary psychiatric hospitalization.¹³³ The stories include a shared analysis in which non-coercive alternatives are proposed.

Inclusive education has been promoted by the UNESCO since 1994, and there is evidence that considers inclusive education the most effective way of combating discriminatory attitudes, building an inclusive society and achieving

¹²⁶ Kay Schaffer et al, *Human rights and narrated lives: the ethics of recognition*. Palgrave Macmillan, 2004.

¹²⁷ FRA report, p10.

¹²⁸ More information at: <zeroproject.org>, <19stories.org>, <ercvoices.com> accessed 11 April 2019.

¹²⁹ Read the full story: <<https://www.19stories.org/story-2>> accessed 11 April 2019.

¹³⁰ More information at: <<https://ercvoices.com/participants/rusi-and-sheila/>> accessed 11 April 2019.

¹³¹ Find Paul’s story at: <<https://ercvoices.com/participants/paul-michelle/>> accessed 11 April 2019.

¹³² Find Claire’s story at: <<https://ercvoices.com/participants/claire-donna/>> accessed 11 April 2019.

¹³³ Find Cath’s story at: <<https://ercvoices.com/participants/cath-piers/>> accessed 11 April 2019.

education for all.¹³⁴ The CRPD has enforced this mandate and excludes any exception to inclusive education.¹³⁵ Inclusive education is a right of persons with disabilities, regardless of antistigma policies. The Atlas on disabilities from 2007, found that *91.3% of countries have special schools for children with intellectual disabilities*.¹³⁶ This needs to be addressed as part of wider policy against discrimination of persons with disabilities. Boarding schools are potential sites of deprivation of liberty, and within the research project participants explained that children with disabilities are often abandoned at boarding schools or sent there for longer periods without alternative within the community, with limited contact with their parents.¹³⁷

Legal reform

The CRPD Committee calls upon States to abolish any legislation providing for disability-specific deprivation of liberty and to refrain from directly or indirectly from limiting the individual exercise of the right to live independently and in the community.¹³⁸ The FRA report highlights that while legislation and policies can be very advanced and positive, implementation remains challenging.¹³⁹ This may be due to funding or lack of political will, inclusion of all stakeholders in the decision making processes, and the weakness or absence of a rights-based approach to disability and deinstitutionalization.

Italy is often quoted as an example of deinstitutionalization legislation.¹⁴⁰ The Basaglia Law, which was key to closing down psychiatric institutions, and Law No. 122 of 22 June 2016 guarantees the right to independent living of persons with disabilities. However, this law allows for settings with up to 10 persons with disabilities to be living together that may be run by disability services.¹⁴¹ Institutional culture is not linked to size, but to the way a place is designed and

¹³⁴ WHO Atlas on intellectual disabilities (2007); Eleweke C.J. & Rodda M., 'The challenge of enhancing inclusive education in developing countries' (2002) *International Journal of Inclusive Education*, 6:2, pp. 113-126.

¹³⁵ Article 24 CRPD.

¹³⁶ WHO Atlas on intellectual disabilities (2007), available at: <https://www.who.int/mental_health/evidence/atlas_id_2007.pdf> accessed 11 April 2019.

¹³⁷ GH_G1_P14, Flynn E., Gomez-Carrillo M., Disability specific deprivation of liberty project. 2019.

¹³⁸ CRPD/C/GC/5, para 47.

¹³⁹ FRA report, p 22.

¹⁴⁰ Michele Tansella, 'Community-based psychiatric care without back-up from the mental hospital: a long-term experience' (1996) 11(4) *European Psychiatry* 189.

¹⁴¹ This definition would not meet the threshold of UN CRPD General Comment no.5. In Ireland, the Working Group recommended a maximum size of 4 persons.

works, and whether the person has control over her day-to-day choices and life.¹⁴²

This law provides for specific assistance for people with severe disabilities who do not have family support, including the creation of innovative housing solutions. In addition, a wide range of national funds, some directed towards specific impairments and some for specific purposes, fund different aspects of deinstitutionalisation.

Recognition of full legal capacity

A recent law reform in Peru has recognized full legal capacity to persons with disabilities. The new law sets out a mandate to provide supports according to the person's wishes, and does not allow for imposition of support. Civil society led this legislative change by promoting a citizen initiative recognizing the rights of persons with disabilities, which included the creation of a multi-stakeholder commission to reform the civil code. This example represents a rare effort in which a law reform had both grassroots support from disabled peoples' organizations and broader civil society, as well as the political will to enact legislative reform. While it is too early to assess the impact of this new law on the lived experience of persons with disabilities in Peru, including those who have experienced deprivation of liberty, the existence of both grassroots and political support for the initiative means that there is a significant prospect of success.

Anti-discrimination laws and policies

Anti-discrimination laws and policies support a new understanding of disability, which will influence all interpretation of rights. Article 14 of the CRPD has been classified as an essentially anti-discrimination article.¹⁴³ A report on the implementation of non-discrimination within Europe reviewed non-discrimination legislation and initiatives in the context of employment and education, which recommends focusing on removal of barriers and tackling deep-rooted inequalities, rather than on welfare and rehabilitation.¹⁴⁴ Employment and housing was combined in a good practice from Kazakhstan, where a training café

¹⁴² CRPD/C/GC/5 Committee, para 16c).

¹⁴³ CPRD/C/12/2 Annex IV.

¹⁴⁴ Lisa Waddington et al, 'Promoting equality and non-discrimination for persons with disabilities.' Council of Europe (March 2017).

was set up as a part of an independent living programme, whose employees now live on their own.¹⁴⁵

The need to address deep-rooted inequalities is shared by all rights included in the CRPD. The Olmstead decision in the United States of America found that the applicant was entitled to receive state funded support in the community rather than in an institution, applying antidiscrimination law. The US Supreme Court found that “*unjustified segregation of persons with disabilities constitutes discrimination in violation of the title II of the Americans with Disabilities Act.*”¹⁴⁶ The American Disability Integration Act¹⁴⁷ extends this non-discrimination approach to all persons with disabilities and services in the community. It also frames unavailability of public housing and consequent institutionalization as discriminatory.

Anti-discrimination laws and policies require the provision of reasonable accommodation. According to the Council of Europe report, “[the] *reasonable accommodation duty is an individualised response to the particular needs of an individual with disabilities to ensure equal opportunities.*” The OHCHR has listed examples of reasonable accommodations, which include adapting to the person’s communication style, schedule and allowing access to support persons.¹⁴⁸ The report further highlights legislation from Norway, which contains a duty to universal design and to provide individual accommodation. Any breach of this duty is considered a discrimination.¹⁴⁹ Another example of good practice found in this report refers to The Protection Against Discrimination Act in Bulgaria, which tackles multiple discrimination.¹⁵⁰

¹⁴⁵ More information available at: <<https://zeroproject.org/practice/pr191224kaz-factsheet/>> accessed 11 April 2019.

¹⁴⁶ Olmstead v. L.C., 527 U.S. 581 (1999).

¹⁴⁷ More information available at: <<http://www.disabilityintegrationact.org/>> accessed 11 April 2019.

¹⁴⁸ Office of the United Nations High Commissioner for Human Rights, ‘Equality and non-discrimination under article 5 of the Convention on the Rights of Persons with Disabilities’ (December 2010) A/HRC/34/26, para 28.

¹⁴⁹ Norway, Act relating to equality and a prohibition against discrimination (Equality and Anti-Discrimination Act) (2018), available at: <<https://lovdata.no/dokument/NLE/lov/2017-06-16-51>> accessed 11 April 2019.

¹⁵⁰ Bulgaria, Protection Against Discrimination Act, September 2003, unofficial translation available at: <<https://ec.europa.eu/migrant-integration/?action=media.download&uuid=29F795FE-B5DA-74ED-B8BD4F1ED7856576>> accessed 11 April 2019.

The recognition of the right to adequate housing in legislation

The report by the UN Special Rapporteur on Housing mentions the Mexican Federal Law for the Inclusion of Persons with Disabilities of 2011 and its regulation of 2012, which includes the right to adequate housing, Constitution of Kenya of 2010 which prohibits discrimination of persons with disabilities, including in housing, in combination with national disability policy, which recognizes the fundamental nature of the right of housing, and proposes a minimum of 5% of accessible houses in all housing schemes. The right to housing is recognized in the South African Constitution, requiring progressive realization of this right through legislative and other measures. The South African Constitutional Court ruled that the State had a duty to provide temporary shelter whenever a person is at risk of being evicted and cannot find an alternative place to live.¹⁵¹ While this ruling was not specific to persons with disabilities, it extends to them and provision of this housing support could help to avoid situations where individuals are deprived of liberty due to a combination of disability and poverty.

¹⁵¹ Residents of Joe Slovo Community v Thubelisha Home (CCT 22/08) ZACC 16; 2009 (9) BCLR 847.

Mainstreaming services

The lack of accessibility and participation in the community and in mainstream services was denounced by many participants. During the interviews, participants with lived experience or family members explained that one of the reasons why their family member or themselves were institutionalized, hospitalized involuntarily or kept at home was due to the lack of accessibility, accommodation and acceptance in mainstream education (primary, secondary and university).

The right to liberty is thus compromised in order to access other rights (e.g. right to health or a right to education), which stresses the importance of a joint effort of different government agencies and legislation pieces to guarantee the right to liberty and lead deinstitutionalization processes successfully. Institutions and segregation are not to be defined simply by the description of a building, but also looking at how a person is supported, whether she can develop social relationships and a sense of belonging.¹⁵²

Experiences of inclusion can be found,¹⁵³ although they are often not reported or known. There are also initiatives by persons with disabilities who conduct training to mainstream services, to ensure these services are available for persons with disabilities. Access to cultural life is essential, not just as a consumer, but also as a participant.¹⁵⁴

¹⁵² FRA report.

¹⁵³ <<https://www.19stories.org>> accessed 11 April 2019.

¹⁵⁴ There are many more examples, but we chose to include the Blue Teapot is a multi-award winning Theatre Company, Performing Arts School & Outreach programme for people with intellectual disabilities at the forefront of arts & disability in Ireland, more information at: <<http://blueteapot.ie>> accessed 11 April 2019.

Conclusions

Good practices often come in the shape of grass root initiatives, rather than large processes. This gives a clear hint that space needs to be created for these initiatives to grow and be replicated on a larger scale. Creating space may mean abolishing legislation, providing funds, not interfering or promoting different practices, such as supporting the person's family and environment to support the person and making communities inclusive. Legislation was a major barrier identified by professionals and policy makers during the interviews, and by other reports and guidelines on deinstitutionalization. However, legal reforms alone are not enough and must come with a change in mindset and positive actions to create opportunities within the community. Will and compromise is essential to create change. It will also help during times of uncertainties and fear. Change is never easy, and all stakeholders need to be supported directly and indirectly to face this change (e.g. strengthen the person's network or show support and tolerance for slow results or error).

The call for inclusion of persons with disabilities is consistent across all sectors and topics. Persons with disabilities need to be consulted to inform policies and to design and lead support services. Consultation should not be symbolic, but be done consistently. The outcome, when consultation and participation is done properly, is very different. Strategies on consultation and participation of persons with disabilities can be found in the Special Rapporteur on the rights of persons with disabilities' report on Participation of Persons with Disabilities.¹⁵⁵ The Kenyan Disabled Person's Organisation United Disabled People Kenya constitute a good example of participation and coordinated efforts to drive change, with several published policy briefs and strategies.¹⁵⁶

¹⁵⁵ Special Rapporteur on the rights of persons with disabilities' report on Participation of Persons with Disabilities, A/HRC/31/62.

¹⁵⁶ More information at: <<http://www.udpkenya.or.ke/publications/>> accessed 11 April 2019.

Glossary

<i>Deinstitutionalization</i>	a process that provides for a shift in living arrangements for persons with disabilities, from institutional and other segregating settings to a system enabling social participation where services are provided in the community according to individual will and preference. ¹⁵⁷
<i>Institutional households</i>	A legal body for the purpose of long-term inhabitation and provision of institutionalised care given to a group of persons. ¹⁵⁸
<i>Persons with disabilities</i>	Persons with disabilities include those who have long-term physical, mental, 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.
<i>Supported decision-making</i>	the process whereby a person with a disability is enabled to make and communicate decisions with respect to personal or legal matters. ¹⁵⁹
<i>Pilot projects</i>	Projects that are run on a small scale to evaluate effectiveness and costs and, if considered successful, to be implemented on a wider scale
<i>Social model</i>	The social model of disability was proposed by Mike Oliver, which explains disability as a social construct, and locates the disability within society. It calls for a removal of all barriers. ¹⁶⁰
<i>Human rights model</i>	This model has been described by Theresa Degener as contained within the CRPD. It rejects the idea that any impairment may hinder human rights capacity, and adopts the anti-discrimination approach. ¹⁶¹
<i>DPO</i>	Disabled Persons Organization
<i>Community-based care</i>	The term 'community-based care', refers to the spectrum of services that enable individuals to live in the community and, in the case of children, to grow up in a family or family-like environment. It encompasses mainstream services, such as

¹⁵⁷ UN General Assembly (2014), Thematic study on the right of persons with disabilities to live independently and be included in the community, A/HRC/28/37, 12 December 2014, para. 25

¹⁵⁸ Economic Commission for Europe / Eurostat

¹⁵⁹ UN Office of the High Commissioner for Human Rights, Annual Report of the United Nations High Commissioner for Human Rights and Reports of the Office of the High Commissioner and the Secretary-General: Thematic Study by the Office of the United Nations High Commissioner for Human Rights on Enhancing Awareness and Understanding of the Convention on the Rights of Persons with Disabilities, UN Doc A/HRC/10/48 (26 January 2009), para. 45

¹⁶⁰ Mike Oliver. *The Politics of Disablement* (1990) Basingstoke: Macmillan

¹⁶¹ Theresa Degener, 'A New Human Rights Model of Disability' (2017) In: Della Fina V., Cera R., Palmisano G. (eds) *The United Nations Convention on the Rights of Persons with Disabilities*. Springer, Cham

housing, health care, education, employment, culture and leisure, which are accessible to everyone regardless of the nature of their impairment or the required level of support. It also refers to specialised services, such as personal assistance for persons with disabilities, respite care and others. In addition, the term includes family-based and family-like care for children, including substitute family care and preventative measures for early intervention and family support.¹⁶²

¹⁶² European Expert Group on the Transition from Institutional to Community-based Care “The Common European Guidelines on the Transition from Institutional to Community-based Care”. November 2012 available at: < www.deinstitutionalisationguide.eu > accessed 11 April 2019.

This collection is part of a research project conducted by the Centre for Disability Law and Policy which is part of the Institute for Lifecourse and Society at NUI Galway.



This work was supported by the Department for International Development (DFID) and Disability Rights Fund (DRF).

