

# Disability-specific forms of deprivation of liberty

REPORT ON A TWO-YEAR PROJECT



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**Report on disability-specific forms of deprivation of liberty  
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## Foreword

It is hard to exaggerate the importance of this work. Although grounded on disability it speaks to a long evolutive process in the law - including international law.

It is hard at this remove to fathom just how novel the general idea of liberty is in the tangled skein of world history. Sir Henry Maine posited that the history of law over the past three centuries or so can be characterized as a steady movement from 'status to contract.' Instead of a defined set of rights and obligations tied to one's status, persons now have a general right to liberty that manifests itself in ever expanding specific liberties.

In this long process the general idea of human liberty has been, in Maine's evocative language, working itself pure from case to case - and one might say from treaty to treaty. Implicit in this is an assumption that the general right bumps up against islands where liberty is simply assumed to yield to countervailing considerations. Put another way, the open-ended ambit of a general right to liberty is naturally truncated when it touches on other consideration which are viewed as important. These implicit limits do not necessarily reside within the law - they are super-imposed from without.

So it is with disability. As this report highlights, the truly fascinating thing about Article 9 of the UN ICCPR is that, while it provides for a right to liberty with broad amplitude, its does not specifically mention disability as a ground for the deprivation of liberty. Rather, it prohibits the 'arbitrary' deprivation of liberty - a concept that has substantive as well as procedural connotations. What informs an analysis of arbitrariness is not something contained within legal doctrine - it has to do with contemporary practices and cultural acceptance of the same. At the time of the drafting of the ICCPR it may well have been culturally acceptable to call out disability and to carve an exception to the right to liberty based on disability.

Not anymore. The turn taken in the UN CRPD provides a corrective to that cultural temptation. This isn't a question of prioritizing one treaty over another. This is more a question of the UN CRPD marking the ending of one set of long-standing cultural assumptions that are not in fact engraved in the text of the UN ICCPR. It restores the generality to the right of liberty to enable an interrogation of accumulated assumptions on the ground of disability. Dissolving these cultural assumptions enables one to 'see' deprivations of liberty on the ground of disability when previously they would not register as such. The ability to 'see' the world differently was precisely what Thomas S. Kuhn meant by a 'paradigm shift.' The authors have done us a great service by expanding our vision of liberty on the ground of disability.

Gerard Quinn  
February 2018

## Executive summary

This report summarizes research conducted by the Centre for Disability Law and Policy, National University of Ireland Galway on disability specific forms of deprivation of liberty. Persons with disabilities are often hospitalized, institutionalized or diverted into other forms of detention from the criminal justice system without their consent, on the grounds of an actual or perceived impairment. These different forms of detention violate the right to liberty set out in article 14 of the Convention on the Rights of Persons with Disabilities, but are largely unrecognized as human rights violations by the general public and by many states.

The research team designed a set of indicators to collect data on this issue in fifteen and subsequently conducted fieldwork through local research teams to understand the underlying causes and triggers that result in these disability-specific deprivations of liberty in five countries: France, Ghana, Jordan, Indonesia and Peru.

The lack of data available is alarming. Most states have no data on the number of persons deprived of liberty detained in psychiatric facilities and institutions. Very often, the number of institutions is also not available. Neither is the number of persons deprived of legal capacity (which often results in subsequent deprivations of liberty). Further, deprivation of liberty on the basis of an actual or perceived impairment is permitted in all countries included in this study. Institutionalization beyond psychiatric facilities (for example in social care institutions, group homes or nursing homes) is not typically recognized as a deprivation of liberty in most national legal frameworks. Many persons with disabilities are also deprived of liberty within their family homes and in other community settings, including in prayer camps, with no recourse to justice or ability to challenge their detention. The development of mental health legislation is on the rise, including more procedural rules to regulate, rather than abolish, disability-specific deprivations of liberty. These practices of deprivation of liberty were found to exist in all countries included in the study, regardless of socio-economic development and legal tradition.

The interviews of different stakeholders reveal that the different situations (involuntary psychiatric hospitalization, institutionalization, diversion from the criminal justice system and home confinement) are often not perceived as human rights violations. Some defended that procedural safeguards were sufficient to guarantee the right to liberty and justify disability-based detention. A number of stakeholders, particularly family members, thought it was not a matter of rights or law but a very difficult and complex situation which caused pain to all involved. Further, the lack of access to mainstream services such as housing, education, community services, employment and support services was also identified as a major contributor to deprivation of liberty by stakeholders. Stigma was cited as an underlying cause of deprivation of liberty by many stakeholders, along with a lack of knowledge on how to respond to distress. These factors, in combination with societal pressure to hospitalize or institutionalize persons with disabilities, were reported to contribute to deprivation of liberty, particularly in crisis situations or where the person had high support needs.

Lastly, the research project searched for good practices to avoid or provide redress for disability-specific deprivations of liberty, finding that there is a need to provide space for more practices to develop. Many of the positive examples identified by stakeholders in this respect included pilot projects, local efforts and underfunded projects led by individuals or initiatives that experienced many barriers imposed by mainstream services and existing legislation. Therefore, this research finds that in order to fully realize article 14 of the Convention on the Rights of Persons with Disabilities, it not sufficient to simply abolish the legal frameworks which permit disability-specific deprivations of liberty. To truly realize the vision of the Convention, the right to liberty must be made effective in practice, including through the availability of practical supports and freedom from coercion in the communities in which persons with disabilities live around the world.

## 1. Background

It has long been acknowledged that persons with disabilities are at heightened risk of unique forms of deprivation of liberty – including detention in psychiatric hospitals, nursing homes and other institutional settings, forced treatment in prayer camps to ‘cure’ disability, and being subject to physical, mechanical and chemical restraint in the community.<sup>1</sup> All these practices share characteristics, philosophies, and rationalities that relate to protection and social control. Although this issue is recognised as one that is in need of urgent attention by different stakeholders,<sup>2</sup> limited data is available on the wide range of disability-specific forms of deprivation of liberty occurring across the globe.

Censuses and surveys provide only limited information about institutionalized populations, and most of the available information comes from administrative data and grey literature. For example, one major study that included twenty-five European countries estimated nearly 1.2 million people with disabilities are living in institutions, most of them without their consent and without opportunities to challenge their placement.<sup>3</sup> In 2002, UNICEF found that 317,000 children with disabilities were living in residential care in Europe and Central Asia.<sup>4</sup>

Deprivation of liberty of persons with disabilities is clearly a global human rights concern.<sup>5</sup> Several cases before human rights treaty bodies and international courts have addressed this issue,<sup>6</sup> but there is a lack of knowledge and of

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<sup>1</sup> Human Rights Watch, ‘Like a Death Sentence’. Abuses Against Persons with Mental Disabilities in Ghana’ (2012); Human Rights Watch, ‘Living in Hell. Abuses against People with Psychosocial Disabilities in Indonesia’ (2016); Disability Rights International Report, ‘No Justice’ Torture, Trafficking and Segregation in Mexico’ (2015); MDAC report, “They don’t consider me as a person” Mental health and human rights in Ugandan communities’ (2014).

<sup>2</sup> Most notably, the Office of the High Commissioner for Human Rights (OHCHR) hosted an expert meeting on disability specific deprivation of liberty (September 2015).

<sup>3</sup> 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.

<sup>4</sup> UNICEF, ‘Children and Disability in Transition in CEE/CIS’, Innocenti Research Centre, data obtained from UNICEF website, available at: <[https://www.unicef.org/protection/57929\\_28534.html](https://www.unicef.org/protection/57929_28534.html)> accessed 11 April 2019.

<sup>5</sup> Inter-American Commission on Human Rights, Principles and Best Practices on The Protection of Persons Deprived of Liberty in the Americas, OEA/Ser/L/V/II.131 doc. 26; Office of the High Commissioner for Human Rights, ‘Background note for the Expert meeting on deprivation of liberty of persons with disabilities’ (2015), para 9; European Union Fundamental Rights Agency (FRA), ‘Involuntary placement and involuntary treatment of persons with mental health problems’ (2012); Human Rights Watch, ‘Children with disabilities: Deprivation of liberty in the name of care and treatment’ (2017).

<sup>6</sup> Inter alia, UN, Human Rights Committee, *A. v. New Zealand*, Communication No. 754/1997 of 3 August 1999; *The Gambia: Purohit and Another v The Gambia* (2003) AHRLR 96 (ACHPR 2003); *H.L. v U.K.* [2004] ECHR 471, *Storck v Germany* [2005] ECHR 406.

understanding of how to secure this right for all persons with disabilities. This gives rise to the need for the present report, which brings attention to the human rights violations occurring in disability specific deprivations of liberty around the globe.

The study looks at the different forms of deprivation of liberty based on a perceived or actual impairment<sup>7</sup>, namely: involuntary hospitalization, institutionalization, diversion from the criminal justice system and home confinement. These different forms of deprivation of liberty often include subjecting a person also to a high degree of control and coercion and may happen consecutively to a person.<sup>8</sup> Deprivation of liberty crystalizes a continuum of segregation, laws and policies based on the medical model of disability, as well as engaging a number of related human rights concerns, including the right to equal recognition before the law, the right to access justice (particularly to challenge deprivations of liberty), the right to live independently and be included in the community, and rights to freedom from torture, cruel, inhuman and degrading treatment.

Previous research on deprivation of liberty has often focused on denouncing conditions of detention, estimating the numbers of persons affected in a specific setting and determining what procedural guarantees are most suitable. This research is unique in the sense that it explores the global picture on deprivation of liberty, under the hypothesis that persons with disabilities are targeted in numerous ways. This two-year study aimed to undertake innovative research, documenting the various forms of deprivation of liberty experienced specifically by persons with disabilities. In doing so, this research intends to reduce the existing data gap and to explore the causes of and alternatives to deprivation of liberty for persons with disabilities.

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<sup>7</sup> The CRPD Committee clarified in its Guidelines on article 14 that article 14(1)(b) prohibits the deprivation of liberty on the basis of actual or perceived impairment. This study adheres to the terminology and criteria laid down in the Guidelines.

<sup>8</sup> Linda Steele, 'Disabling forensic mental health detention: The carcerality of the disabled body.' (2017) 19(3) Punishment & Society 327.

## 1.1. Structure of this report

This report includes eight sections. Section one which provides background information on the topic and the objectives and research questions. Section two discusses how this research was structured and the methodology used to gather data on aspects related to deprivation of liberty on the basis of disability. Here, the literature review and the country selection is presented, followed by a description of the different research tools used for the phases I and II of this research and of the different sources of data used for this report.

Section three presents the theoretical framework of this research. It explores human rights treaties and their interpretative guidelines in order to understand the substantive content of the right to liberty, the tensions within the international human rights system and what situations qualify as a deprivation of liberty. Based on this legal framework, the report provides a working definition to describe the substantive content of what constitutes deprivation of liberty. Section four presents the findings from a literature review conducted for this research and the data collection undertaken in phase I of the project on the existing practices of deprivation of liberty at a global level. Section five explores the findings of the qualitative fieldwork conducted in five specific countries undertaken in phase II of this research, including steps towards human rights compliance. Lastly, Section six ends with the conclusions.

## 1.2. Definitions

For the purposes of this report, *persons with disabilities* are understood to include persons with long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers, affects the full enjoyment of their human rights and their equal participation in society.<sup>9</sup>

Deprivation of liberty based on an actual or perceived impairment and deprivation of liberty based on a disability is used interchangeably, following the CRPD

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<sup>9</sup> We adhere to the CRPD understanding of disability within article 1: '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.' While we acknowledge the different meanings of impairment and disability, in this report we use disability to refer indistinctively to a perceived or actual impairment or disability (Mike Oliver, 'Defining impairment and disability' in Emens and Stein (eds) '*Disability and Equality Law*' (Routledge, 2016)).

Committee's Guidelines on Article 14. Exceptions identified in laws, literature or during the qualitative research based on risk to self or others in combination with an actual or perceived impairment are included in this definition.

The working definition for deprivation of liberty used as basis of this report is *an individual is deprived of their liberty when s/he is: confined to a restricted space or placed in an institution or setting; or under continuous supervision and control; not free to leave; and the person has not provided free and informed consent.*

Further, this report explores institutions as settings for deprivation of liberty and adopts the ENIL definition for institutions as follows: '*any place in which people who have been labelled as having a disability are isolated, segregated and/or compelled to live together. An institution is also any place in which people do not have, or are not allowed to exercise control over their lives and their day-to-day decisions. An institution is not defined merely by its size.*'<sup>10</sup> It includes, among others: nursing homes, residences, group homes, orphanages and disability-specific boarding schools.

The report explores independent living as a positive expression of the right to liberty. Independent living is defined as '*situations in which individuals with disabilities are provided with all necessary means enabling them to exercise choice and control over their lives and make all decisions concerning their lives*'.<sup>11</sup>

Involuntary hospitalization in a disability-specific context is understood as an admission into psychiatric services without the person's consent.<sup>12</sup> Finally, diversion from the criminal justice system is defined as rules '*seeking to avoid the formal processing of an offender by the criminal justice system*'<sup>13</sup> and an exemption from criminal responsibility on the basis of a disability (*inimputability*) which is used as a basis to impose security measures.

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<sup>10</sup> Definition given by European Network on Independent Living, available at under point 8: <<http://enil.eu/independent-living/il-fact-sheet/>> accessed 11 April 2019.

<sup>11</sup> For full definition see CRPD Committee General Comment No.5 on living independently and being included in the community (2017), CRPD/C/GC/5, para 16.

<sup>12</sup> Encyclopedia of Mental Disorders, Forum, Involuntary Hospitalization, available at: <http://www.minddisorders.com/Flu-Inv/Involuntary-hospitalization.html> accessed 11 April 2019.

<sup>13</sup> Definition given by Encyclopedia Britannica, available at <https://www.britannica.com/topic/diversion> accessed 11 April 2019.

### 1.3. Objectives

This two-year study aimed to undertake innovative research, documenting the various forms of deprivation of liberty experienced exclusively by persons with disabilities. In doing so, this research intended to reduce the existing data gap and to explore the causes of and alternatives to deprivation of liberty for persons with disabilities.

The study firstly explored the legal norms around deprivation of liberty and the available data, which served as basis to explore the underlying causes and good practices. Fifteen countries<sup>14</sup> across the globe were selected as sample to obtain available data. In this sense, the objectives included:

- To systematize existing international human rights norms related to disability-specific deprivations of liberty, and to analyse their application to regional and domestic laws and policies.
- To investigate the different laws and policy frameworks that allow for disability-specific forms of deprivation of liberty.
- To summarise the available statistical information related to disability-specific forms of deprivation of liberty from fifteen countries.
- To identify the drivers and underlying causes for the existence of disability-specific forms of deprivations of liberty.
- To identify good practices in relation to the right to liberty and security of persons with disabilities.

It is herein acknowledged that persons with disabilities are often disproportionately represented in other situations of deprivation of liberty such as migrant related detention and the criminal justice system.<sup>15</sup> While it may be considered indirect discrimination, this study focused on direct discrimination

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<sup>14</sup> Ghana, Senegal, Rwanda, Kenya, Indonesia, Philippines, Australia, France, Spain, Moldova, Jordan, Qatar, Argentina, Costa Rica, Peru.

<sup>15</sup> Persons with intellectual disabilities are overrepresented in remand in prison (UK) in Afia Ali et al, 'Prisoners with intellectual disabilities and detention status. Findings from a UK cross sectional study of prisons.' (2016) 53-54 *Research in Developmental Disabilities* 189; Susan Hayes, '*Ability Screening Index (HASI) manual*' (2000) Sydney; Jennifer M Reingle Gonzalez, et al, 'Disproportionate Prevalence Rate of Prisoners with Disabilities: Evidence From a Nationally Representative Sample' (2015) 27(2) *Journal of Disability Policy Studies* 106.

against persons with disabilities with regards to the right to liberty, and therefore focused on disability-specific forms of deprivation of liberty.

## 2. Methodology

This study used an exploratory research method to examine disability-specific forms of deprivation of liberty. It used mixed research methods (qualitative and quantitative) and divided the research in two phases. The first phase systematized the international norms regarding deprivation of liberty and explored the existing data on persons with disabilities, while the second one was devoted to identifying the underlying causes of deprivation of liberty and good practices. The methods were adjusted to the objectives of each phase.

During phase I, the research team conducted a literature review and some quantitative research to set the legal framework around deprivation of liberty and persons with disabilities. The explored question was the conception of deprivation of liberty of persons with disabilities, with a focus on the areas where the deprivation of liberty is based on a disability. Four areas were identified in which persons with disabilities are deprived of liberty on the basis of a disability: involuntary psychiatric hospitalization, diversion from the criminal justice system, institutionalization and deprivation of liberty at home. A fifth area was identified as transversal to the other four areas: legal capacity. Based on these areas, the research team developed a set of quantitative indicators following the the model proposed by United Nations Human Rights Office of the High Commissioner (2012).<sup>16</sup> These indicators were divided into three main categories: legal,<sup>17</sup> process and outcome indicators. The quantitative data collected for these indicators will be discussed in section 4 of this report.

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<sup>16</sup> United Nations Human Rights Office of the High Commissioner, 'Human Rights Indicators. A guide to measurement and implementation' (2012).

<sup>17</sup> OHCHR proposes three types of levels of indicators: structural, process and outcome indicators: Structural indicators aim to measure the level of commitment a country has for the fulfilment of a human right; process indicators assess the state's efforts to implement programmes, or to transform situations to guarantee the fulfilment of a human right; and outcome indicators assess the results of the implementation of strategies and the actual enjoyment of the right.

## 2.1. Country selection

The selection of the countries for collection of quantitative and qualitative data was the result of discussion and deliberation with the project's Advisory Board<sup>18</sup> and all members of the research team. Fifteen countries from the five regions of the world were selected for Phase I based on four main criteria:

1. Countries should have signed and ratified the Convention on the Rights of Persons with Disabilities.
2. Within each region, selected countries should have different levels of socioeconomic and human development.
3. Countries should have previous research or statistical data on topics related to deprivation of liberty.
4. Countries should be ones where international agencies hold an office or where the research team has local contacts and who can facilitate the process of data collection.

At the end of the process, fifteen countries were selected<sup>19</sup>: Argentina, Costa Rica, Peru, France, Spain, Moldova, Australia, Indonesia, the Philippines, Jordan, Qatar, Kenya, Ghana, Rwanda and Senegal. Table A1 in the Annex I presents a summary of the main characteristics of each country. At the beginning of phase II, five countries were selected out of these fifteen countries to conduct more in-depth qualitative fieldwork: France, Ghana, Jordan, Indonesia and Peru. These countries were chosen during the second Advisory Board meeting in Geneva, where the initial findings of phase I were presented.

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<sup>18</sup> Members of the Advisory Board are: Dainius Pūras, Nils Melzer, Amita Dhanda, Theresia Degener, Marta Santos, Catalina Devandas, Manfred Novak.

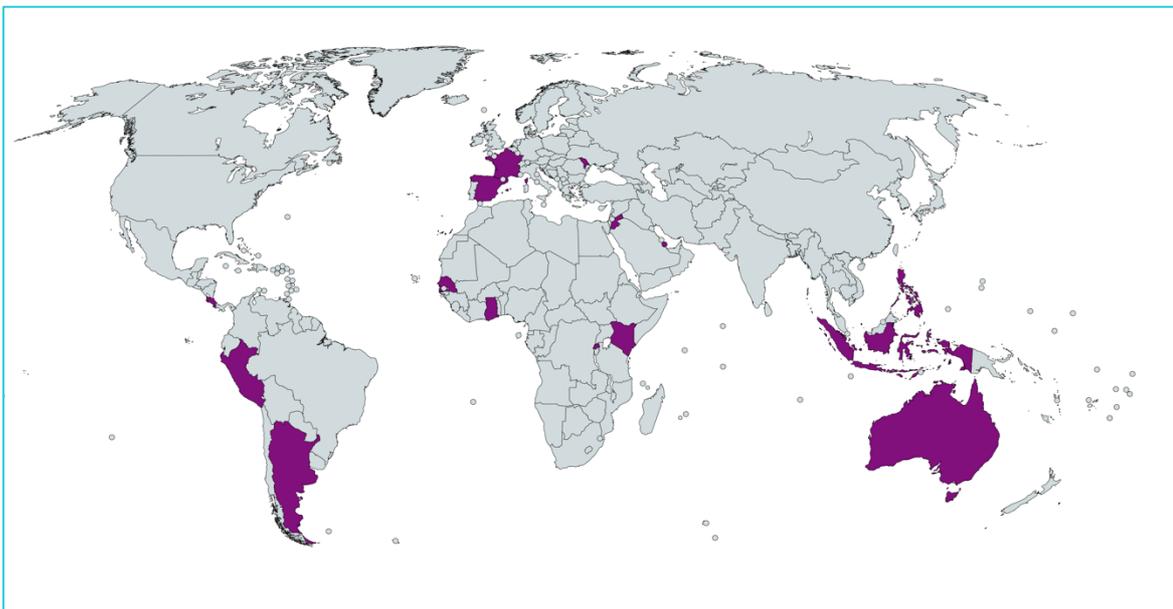
Other stakeholders included: Gerard Quinn, Tina Minkowitz, Facundo Chavez-Pinillas, Victoria Lee, Michelle Funk (among others).

<sup>19</sup> Yemen was included in the analysis, however, given the current situation of conflict in the country it was not possible to gather any type of data.

The selection criteria for the phase II countries were as follows:

1. One country from each geographic region would be selected.
2. Selected countries needed to have some data on disability-specific deprivation of liberty available as evidenced from phase I (countries where no data was found, e.g. Qatar were automatically excluded).
3. Selected countries needed to have a baseline of relative political stability (e.g. Philippines was excluded).
4. Selected countries must have some recent legislative or policy initiatives around the subject or specific phenomena of relevance to this topic e.g. faith based healing camps and/or their approach was viewed as influential on other countries (e.g. France).

The selection was proposed by the research team and approved by the Advisory Board.



### **Data collection**

The sources of data used in phase I included the responses received by the research team to a questionnaire developed for this purpose and distributed by the Office of the United Nations Special Rapporteur on the Rights of Persons with Disabilities (see Annex II), as well primary and secondary documents for the legal indicators. In the case of process and outcome indicators, official secondary

sources of data were found and analyzed by the research team. The consulted sources included national statistics offices or their equivalents, the ministry of justice, prosecution services and penitentiary authorities, the ministry of health, social services or any equivalent institution and disability specific institutions or national focal points or observatories on disabilities. After revising all possible available official sources of information, the team decided that, given the lack of information, recourse was required to other sources of information. Those included published reports from Disabled People's Organizations (DPOs), Non-Governmental Organizations (NGOs), Ombudsman offices and Law Clinics on topics related to deprivation of liberty. In cases where the reports based conclusions on other sources, those were also researched and included in the analysis. The information used in phase II included the available data from phase I on the country profiles, as well as the literature produced during the literature review and the findings from the field work conducted during this phase.

## 2.2. Literature review

A literature review of scholarly research and grey literature on the subject of disability-specific deprivation of liberty was conducted on an ongoing basis throughout the project. In phase I, the literature review explored the international and regional framework around the question of deprivation of liberty of persons with disabilities. Phase II of the project began with an extensive literature review on literature on the different disability-specific forms of deprivation of liberty, with a focus on causes and the current approaches.

The literature review sought to address following questions:

- What triggers deprivation of liberty of persons with disabilities?
- What are the pathways into a placement of deprivation of liberty?
- How does a placement in a hospital or an institution constitute a deprivation of liberty?
- What are the barriers to full enjoyment of liberty?
- How are children with disabilities affected by out-of-home care?
- What are the good practices in the different areas?

The literature review was approached with following search terms: “persons with disabilities”, “disability”, “impairment”, “intellectual OR learning”, “autism OR autistic”, “retardation”, “mental”, “mental disorder”, “mental health”, “psychiatric”, “involuntary admission”, “involuntary commitment”, “institution\*”, “institutionalization”, “home”, “care home”, “nursing home”, “orphanage”, “out-of-home”, “prayer camp”, “deprivation AND deprived of liberty”, “civil OR administrative commitment”.<sup>20</sup>

The literature review conducted throughout the project revealed that persons with disabilities receive different terms throughout the literature. Children with disabilities were often not disaggregated in the studies, but could be found under “vulnerable children”, children with “developmental issues”, “retardation”, “behavioral issues” or similar terminology. For instance, the literature review highlighted that the figures around children with disabilities vary due to the different understandings of children with disabilities, as some studies include children with emotional and behavior challenges within the population of children with disabilities, while others follow a more restrictive definition of disability.<sup>21</sup> In a similar sense, the terms to describe institutions vary enormously, e.g. alternative care<sup>22</sup>, nursing homes, residential care, small group homes, boarding schools, orphanages, children’s homes, family based care<sup>23</sup>, out of home care, etc. This variety of naming and types of institution is also reflected in similar research undertaken by the European Union’s Fundamental Rights Agency.<sup>24</sup>

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<sup>20</sup> Search terms in French and Spanish included: ‘*psychiatrique*’, ‘*hospitalisation sans consentement*’, ‘*maison d’accueil*’, ‘*ingreso involuntario*’, ‘*psiquiátrico*’.

<sup>21</sup> Bernadette Kelly et al, ‘Disabled Children and Young People who are Looked After: A Literature Review.’ (2012) Belfast: Queen’s University Belfast.

<sup>22</sup> Alternative care refers to care for orphans and other vulnerable children who are not under the custody of their biological parents. It includes adoption, foster families, guardianship, kinship care, residential care and other community-based arrangements to care for children in need of special protection, particularly children without primary caregivers (UNICEF, ‘Alternative Care for Children Without Primary Caregivers in Tsunami-Affected Countries Indonesia, Malaysia, Myanmar and Thailand’ July 2006).

<sup>23</sup> Family based care has been used at times to designate small group homes with home mothers or similar, eg Cathleen A Lewandowski et al, ‘Assessing the Effect of Family-Centered Out-of-Home Care on Reunification Outcomes’ (2002) 12 (2) Research on Social Work Practice 205. Another example small group homes are sometimes called family based care if there is a ‘home mother’ see <<http://www.sos-botswana.org/family-based-care>> accessed 11 April 2019. In the USA foster care can also refer to group homes see <http://www.cdss.ca.gov/inforesources/Foster-Care/Group-Homes>> accessed 11 April 2019.

<sup>24</sup> Fundamental Rights Agency, ‘Summary overview of types and characteristics of institutional and community-based services for persons with disabilities available across the EU’ (November 2017).

The databases that were searched during phase II included legal databases (Westlaw IE, JustisOne, Westlaw (UK & International, Lexis Butterworths, Hein-On-Line, Oxford bibliographies International law), sociology (SocINDEX), psychology (Scopus), nursing and healthcare sciences (PubMed). Findings that were not specific to persons with disabilities were excluded, as well as studies which exclusively focused on treatment, therapies and other intervention methods within the different settings, rather than the process or outcomes of depriving individuals of liberty.

### 2.3. Qualitative research

Phase II included a piece of qualitative research conducted in five countries selected from the previous phase. Local researchers were selected on the basis of prior experience on qualitative research and conducting interviews, expertise in social and disability issues. Up to twenty individuals per country were interviewed, which were selected on the basis of their experience, expertise or work related to deprivation of liberty.<sup>25</sup> A non-probability sample based on the accessibility of the interviewees or by the purposive personal judgment of the researcher (convenience sampling) was used. This sample is not intended to be representative of the entire population. Therefore, the results of the research cannot be used in generalizations pertaining to the entire population; however, the results can be illustrative of some of the barriers and opportunities encountered in each of the specific countries relating to disability-specific deprivation of liberty.

The research team overviewed the preselection of interviewees to guarantee a variety of participants. The stakeholder categories included: policy makers, directors of healthcare institutions and social services, Non-Governmental Organizations (NGOs) working with persons with disabilities, health and social care professionals, family members and persons with lived experience of deprivation of liberty based on a disability. See Annex III for a more detailed definition of the stakeholder categories. All interviews were audio-recorded and transcribed verbatim and then translated into English. The team also provided an open set of codes that was widened if any of the researchers felt the need to add

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<sup>25</sup> The interviews were not completed in Indonesia, where only 16 interviews were conducted.

codes to it (See Annex IV). The local research team provided their analysis and the research team in Galway read and coded all interviews. The identification of emerging themes was discussed over skype with local researchers and internally by the research team.

### **Ethics**

Ethical approval for phase II was granted by the National University of Ireland Galway. All participants in interviews were provided with a written information sheet and consent form which was translated into the relevant local language, which explained the purpose of the study and the possibility of withdrawing from the process at any time. Participants were asked to sign consent forms or to record their consent in the audio recording of the interview for those with limited literacy for whom signing a form would not represent meaningful consent. Local researchers were required to prepare for distress and possible support options if necessary. In situations in which the participant required legal advice or advice on treatment options, the local researchers facilitated contact with local authorities, social services or NGOs.

In this section, the background, objectives and methodology of the research project has been set out in brief, to provide context for the research which was conducted during this project. The following section explains the main findings of the research in terms of the international legal framework concerning the right to liberty for persons with disabilities, and the notion of disability-based exceptions to the universal right to liberty.

### 3. The right to personal liberty of persons with disabilities

#### 3.1. International legal framework on deprivation of liberty

In order to understand how disability-based exceptions to the right to liberty emerged at regional and national levels, the research team first explored the international legal framework on the right to liberty. The right to liberty and security of person is recognized by core international human rights instruments, from the Universal Declaration of Human Rights, to the recently adopted UN human rights treaty, the CRPD.<sup>26</sup>

In addition, in the context of the United Nations, there are several non-binding international instruments that provide guidance in relation to the rights of persons deprived of their liberty. They include, *inter alia*, the Body of Principles for the Protection of all Persons under any form of Detention or Imprisonment<sup>27</sup>, the revisited Standard Minimum Rules for the Treatment of Prisoners (the ‘Mandela Rules’)<sup>28</sup>, the UN Rules for the Treatment of Women Prisoners and Non-custodial Measures for Women Offenders (the Bangkok Rules)<sup>29</sup>, UN Economic and Social Commission on Human Rights Study (1961),<sup>30</sup> the Working Group on Arbitrary Detention (WGAD) Guidelines,<sup>31</sup> the UN Rules for the Protection of Juveniles Deprived of their Liberty<sup>32</sup> and the United Nations Model Strategies and Practical Measures on the Elimination of Violence against Children in the Field of Crime Prevention and Criminal Justice.<sup>33</sup> At a regional level, the African Charter on

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<sup>26</sup> Including the Universal Declaration of Human Rights (article 3), the International Covenant on Civil and Political Rights (article 9), the Convention on the Rights of the Child (article 37(b)), the International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families (article 16), the International Convention on the Elimination of All Forms of Racial Discrimination (article 5(b)), the Convention on the Rights of Persons with Disabilities (article 14), Optional Protocol to the Convention Against Torture (Article 4(2)) and covered in the report by the Working Group on Arbitrary Detention (WGAD) in A/HRC/22/44 paras 52-54.

<sup>27</sup> A/RES/43/173.

<sup>28</sup> A/R/70/175.

<sup>29</sup> A/RES/ 65/229.

<sup>30</sup> UN Economic and Social Council, Commission on Human Rights, ‘Study of the right of everyone to be free from arbitrary arrest, detention and exile’ (9 January 1961) E/CN.4/813. The WGAD has confirmed this in its previous deliberations on house arrest, rehabilitation through labour, retention in non-recognized centres for migrants or asylum seekers, psychiatric facilities and so-called international or transit zones in ports or international airports, gathering centres or hospitals; A/HRC/22/44, para 59; A/RES/45/113 para 11(b).

<sup>31</sup> Working Group on Arbitrary Detention. Basic Principles and Guidelines on Remedies and Procedures on the Right of Anyone Deprived of His or Her Liberty by Arrest or Detention to Bring Proceedings Before Court (2015), A/HRC/30/37.

<sup>32</sup> A/RES/45/113.

<sup>33</sup> A/C.3/69/L.5.

Human and Peoples' Rights, the American Convention on Human Rights, and the European Convention on Human Rights also recognize this right.<sup>34</sup>

Across all these varied instruments, the research team found a number of common elements related to the right to liberty. These include the notion that the right to liberty can be restricted by the State or its agents in accordance with law, but that deprivations of liberty which are unlawful or arbitrary in nature, violate human rights norms. The absence of free and informed consent to be in a particular setting means that a situation constitutes a deprivation of liberty under human rights standards, which links the right to liberty to the right to legal capacity. Finally, while there is little clarity on a universal definition of the concept of liberty, there is a growing recognition of a wide range of locations and facilities where deprivations of liberty occur in violation of human rights norms. These issues will be addressed in turn in the remainder of this section.

It is clear that the right to liberty is not an absolute right, but one which can be restricted in accordance with law, for example, in the interests of public health or public safety. However, all these instruments required that any restriction of the right to liberty must be justified, necessary or proportionate,<sup>35</sup> otherwise it will be considered unlawful. The requirement of necessity and proportionality means that where detention imposed in a manner that is inappropriate, unjust, unpredictable, discriminatory or without due process it is considered unlawful.<sup>36</sup> A finding of arbitrariness may also be made when there is no connection between the grounds of detention and the place and conditions of detention.<sup>37</sup> Some examples of arbitrariness in the context of disability-specific detention can include the imposition of labels of 'mental disorder',<sup>38</sup> which are inherently subjective and

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<sup>34</sup> The African Charter on Human and Peoples' Rights (article 6), the American Convention on Human Rights (article 7) and the European Convention on Human Rights (article 5).

<sup>35</sup> IACHR, *López Alvarez v Honduras*, 1 February 2006 para 67.

<sup>36</sup> OHCHR, 'Background note for the Expert meeting on deprivation of liberty of persons with disabilities' (2014) para 14.

<sup>37</sup> ECHR, 'Guide on Article 5 of the European Convention on Human Rights 5' updated in 2018 para 39.

<sup>38</sup> WGAD Opinion no. 68/2017 concerning Zaheer Seepersad (Trinidad and Tobago) A/HRC/WGAD/2017/68.

value laden,<sup>39</sup> or the determination that a person poses a risk of harm to himself or others.<sup>40</sup>

According to these human rights norms, a lawful deprivation of liberty may be done by State actors (e.g. police and courts) or by third parties authorised by the State. Any detention or deprivation of liberty that does not follow the procedures established by domestic law is considered unlawful.<sup>41</sup> Deprivation of liberty with no effective remedies available to the victim are also considered unlawful.<sup>42</sup> Any detained person has a right to be brought before a judicial authority without exception to ensure that all detentions are subject to judicial control. The requirement from these norms that the State authorise the detention is sometimes problematic in the context of disability, where individuals might be deprived of liberty at the request of family members in private institutions not regulated or controlled by the state.<sup>43</sup> The WGAD reiterates “*that a State retains a positive duty of care in relation to those on its territory and under its jurisdiction and that a State cannot absolve itself of this responsibility in relation to those in privately run institutions.*”<sup>44</sup>

In international human rights law, the regulation of the right to liberty of a person has been construed in terms of physical liberty.<sup>45</sup> However, there is no universally adopted definition of what constitutes a deprivation of liberty *per se*.<sup>46</sup> The international and regional human rights mechanisms have focused on the

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<sup>39</sup> KWM Fulford et al, ‘Looking with both eyes open: fact and value in psychiatric diagnosis?’ (2005) 4(2) World Psychiatry 78.

<sup>40</sup> UN High Commissioner for Human Rights, Annual Report ‘Mental health and human rights’ A/HRC/34/32 (31 January 2017) para 22.

<sup>41</sup> IACHR, López Alvarez v Honduras, 1 February 2006, para 67; WGAD Opinion No. 68/2017 concerning Zaheer Seepersad (Trinidad and Tobago), A/HRC/WGAD/2017/68 para 3.

<sup>42</sup> CCPR/C/GC/35 para 44.

<sup>43</sup> WGAD Report of the Working Group on Arbitrary Detention, A/HRC/36/37 (19 July 2017) para 55.

<sup>44</sup> Ibid.

<sup>45</sup> Niels Petersen, ‘Right to Liberty, International Protection’ (2012) Max Planck Encyclopaedia of Public International Law, para 4.

<sup>46</sup> While there is an approach to defining deprivation of liberty, it does not give a full account of situations of deprivation of liberty persons with disabilities encounter such as deprivation of liberty at home, nor does it describe deprivation of liberty, eg The Optional Protocol to the UN Convention against Torture, Article 4(2) (similar to Article 11(b) in the United Nations Rules for the Protection of Juveniles Deprived of their Liberty), defines deprivation of liberty as “any form of detention or imprisonment or the placement of a person in a public or private custodial setting which that person is not permitted to leave at will by order of any judicial, administrative or other authority”. It is equally important to take into consideration the UN Body of Principles for the Protection of All Persons under Any Form of Detention or Imprisonment, adopted by the General Assembly Resolution A/RES/43/173 in 1988. Similar finding in European Fundamental Rights Agency, ‘Involuntary placement and involuntary treatment of persons with mental health problems’ (2012).

prohibition of arbitrary or unlawful deprivations of liberty in their respective jurisprudence. The Human Rights Committee broadly describes liberty as ‘freedom from confinement of the body’ and distinguishes deprivation of liberty from mere interference with liberty of movement, with the former being considered a more severe restriction.<sup>47</sup>

The requirement of the absence of consent for deprivation of liberty to exist is undisputed. HRC Comment no.35 affirms that ‘*deprivation of personal liberty is without free consent*’.<sup>48</sup> The WGAD considers a person deprived of liberty when she cannot leave at will.<sup>49</sup> The ECtHR requires consent to be on-going, as the right to liberty is ‘*too important in a democratic society for a person to lose the benefit of Convention protection for the single reason that he may have given himself up to be taken into detention*’.<sup>50</sup> In *Storck v. Germany* the ECtHR affirmed that the person must ‘*validly consent to the confinement in question*’<sup>51</sup> and that the applicant was deprived of liberty where the applicant had initially consented to her admission to a clinic but had subsequently attempted to escape. Further, the court recognized that where the person is perceived to lack capacity to consent to a placement, she may well subsequently be deprived of liberty. In *H.L. v UK*<sup>52</sup> the court found that the applicant, an adult considered incapable of consenting to admission to a psychiatric institution under domestic law, was deprived of his liberty even though he had never tried to escape. In this same case, the Court considered irrelevant the question of whether the space was locked or lockable.<sup>53</sup> In *Guzzardi v Italy* (1980)<sup>54</sup>, in which a person was subjected to compulsory residence on part of an island, the Court concluded that close confinement or the reduction of the living space, and being subject to continuous control and limited social contact, amounted to a deprivation of liberty.

In its General Comment No. 35 on Article 9 (Liberty and security of person), the Human Rights Committee mentions as examples of deprivation of liberty: *police*

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<sup>47</sup> CCPR/C/GC/35, paras 3-5.

<sup>48</sup> *ibid*, para 6.

<sup>49</sup> WGAD Report of the Working Group on Arbitrary Detention, A/HRC/36/37 (19 July 2017) para 52.

<sup>50</sup> *De Wilde, Ooms and Versyp v Belgium* [1971] ECHR 1, *Storck v Germany* [2005] ECHR 406.

<sup>51</sup> *Storck v Germany* [2005] ECHR 406, para 74.

<sup>52</sup> *H.L. v U.K.* [2004] ECHR 471.

<sup>53</sup> *H.L. v U.K.* [2004] ECHR 471, para 92, *Ashingdane v. U.K.* [1985] ECHR 8, para 42.

<sup>54</sup> *Guzzardi v Italy* ECHR 6 Nov 1980 [1980] ECHR 5.

*custody, arraigo,<sup>55</sup> remand detention, imprisonment after conviction, house arrest,<sup>56</sup> administrative detention, involuntary hospitalisation,<sup>57</sup> institutional custody of children and confinement to a restricted area of an airport,<sup>58</sup> as well as being involuntarily transported.<sup>59</sup> The HRC Committee also include certain further restrictions on a person who is already detained, for example, solitary confinement or the use of physical restraining devices.<sup>60</sup> Regional human rights mechanisms have provided further clarity on the kinds of settings in which deprivation of liberty may occur. For example, the Inter-American Commission on Human Rights<sup>61</sup> has recognised an extensive list of institutions that may become places of detention, including ‘(...) *psychiatric hospitals and other establishments for persons with physical, mental or sensory disabilities; institutions for children and the elderly; (...); and any other similar institution the purpose of which is to deprive persons of their liberty.*’<sup>62</sup> In its report, the WGAD noted the increase of regimes and places “*which an individual is not free to leave at will and which raise a question of de facto deprivation of liberty.*”<sup>63</sup> This increasing recognition of the wide range of locations and facilities and methods of deprivation of liberty is particularly relevant in the context of disability as will be discussed in further detail in section 4 below.*

The Special Rapporteur on Torture has recognised psychiatric facilities, social care centres, orphanages or similar facilities as especially prone to corruption and torture or ill-treatment,<sup>64</sup> following suit of the previous Special Rapporteur Juan Mendez.<sup>65</sup> The former also called for an absolute ban on forced treatment,

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<sup>55</sup> Short-term detention in the context of organized crime, which allows detention up to 80 days, see Concluding Observations, Mexico, CCPR/C/MEX/CO/5 (2010) para 15.

<sup>56</sup> *Gorji-Dinka v Cameroon*, Communication No 1134/2002 (2005) 12 IHRR 628, para 5.4; see also Concluding Observations, United Kingdom, CCPR/C/GBR/CO/6 (2008) para 17 (control orders including curfews of up to 16 hours).

<sup>57</sup> 754/1997, *A. v. New Zealand*, para 7.2 (mental health); see Concluding Observations, Republic of Moldova, CCPR/C/MDA/CO/2 (2009) para 13 (contagious disease).

<sup>58</sup> Concluding Observations, Belgium, CCPR/CO/81/BEL (2004) para.17 (detention of migrants pending expulsion).

<sup>59</sup> R.12/52, *Saldías de López v. Uruguay*, para 13.

<sup>60</sup> See Concluding Observations, Czech Republic, CCPR/C/CZE/CO/2 (2007) para 13; and Republic of Korea, CCPR/C/KOR/CO/3 (2006) para 13.

<sup>61</sup> IACHR ‘Resolution 1/08, Principles and Best Practices on the Protection of Persons Deprived of Liberty in the Americas’ (13 March 2008).

<sup>62</sup> *Ibid*, General Provision.

<sup>63</sup> WGAD Report of the Working Group on Arbitrary Detention, A/HRC/36/37 (19 July 2017) para 52.

<sup>64</sup> Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, A/HRC/40/59 (2019).

<sup>65</sup> Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, A/HRC/22/53 (2013).

considering “*involuntary treatment and other psychiatric interventions in health-care facilities are forms of torture and ill-treatment.*”<sup>66</sup>

### 3.2. Working definition of deprivation of liberty

Based on the international and regional human framework, this research understands that *an individual is deprived of their liberty when s/he is: confined to a restricted space or placed in an institution or setting; or under continuous supervision and control; not free to leave; and the person has not provided free and informed consent.* In this context, the right of liberty interacts directly with the rights to equal recognition before the law, access to justice, freedom from torture, the right to health and the right to live independently and be included in the community.<sup>67</sup> The inclusion of the criteria of ‘*under continuous supervision and control*’ is especially relevant to monitoring practices which are often presented as alternatives to hospitalization and institutionalization, e.g. Community Treatment Orders or similar structures which include movement restriction or regular checking in with a specific authority, or constant monitoring of a person. As described above, deprivation of liberty is not a question of nature or substance, but a matter of degree and intensity.<sup>68</sup>

### 3.3. Deprivation of liberty on the basis of disability

The universal nature of the right to liberty in the international human rights norms discussed above means that while the right to liberty may be restricted for reasons of safety, no international human rights treaty states in its text that disability or impairment (including actual or perceived impairment) can be used as a ground to justify restriction of the right to liberty. Public health has been also alleged by member states.<sup>69</sup> In fact, the CRPD requires that no person may be deprived of liberty on the grounds of a disability (art. 14)<sup>70</sup>. The CRPD Committee has clarified that the CRPD requires an absolute prohibition on disability-specific deprivation of liberty in its Concluding Observations, General Comments and

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<sup>66</sup> Ibid, para 64.

<sup>67</sup> See final section of this report on Discussion for an analysis of the interaction between areas.

<sup>68</sup> ECHR Guide on Article 5 of the European Convention on Human Rights, para 2; *De Tommaso v Italy* ECHR 23 Feb 2017 [2017] ECHR 205, para 80; *Guzzardi v Italy* ECHR 6 Nov 1980 [1980] ECHR 5, para 93; *Rantsev v Cyprus and Russia* ECHR 10 October 2010 Application no. 25965/04, para 314; *Stanev v Bulgaria* ECHR (2012) 55 EHRR 22, para 115.

<sup>69</sup> Eg Philippines Rule 101 Proceedings for Hospitalization of Insane Persons.

<sup>70</sup> Disability has been interpreted as “perceived and actual impairment” in the Guidelines on article 14 by the CRPD Committee (2014) CRPD/C/12/2, Annex IV, para 7.

Guidelines on Article 14.<sup>71</sup> The Special Rapporteur on the right to health has called for States to stop using “*detention and confinement as a preferred tool to promote public safety, “morals” and public health.*”<sup>72</sup>

Nevertheless, this position is not always consistently addressed in the interpretations of the right to liberty provided by the various international and regional human rights bodies. This section will address some of the competing statements on the application of the right to liberty to persons with disabilities. The text of the ICCPR does not include any disability-based exception to the right to liberty, but the HRC, in its General Comment no.35, interprets article 9 to mean that admission to a psychiatric institution against the will of the patient constitutes a form of deprivation of liberty that is compatible with human rights norms, under certain conditions. According to General Comment no.35, involuntary admission to psychiatric institutions must be ‘*for the purpose of protecting the individual in question from serious harm or preventing injury to others*’,<sup>73</sup> not simply based on the existence of a disability. This interpretation stands in clear contrast to the CRPD Committee’s position that disability together with other criteria, including risk, cannot be used as the basis for deprivation of liberty.<sup>74</sup>

The ECHR<sup>75</sup> is the only regional human rights treaty to include an exception to the right to liberty based on a disability in the text of the treaty. Despite not having any exception in the American Convention on Human Rights, the Inter-American Commission on Human Rights (IACHR) has, in the past, also accepted the exception to the right to liberty based on disability, if an additional criterion<sup>76</sup> is met. However, the IACHR has recently moved towards a CRPD understanding of the right to liberty. Similarly, the Inter-American Court of Human Rights also has embraced article 14.2 CRPD in a case arguing for accessibility measures for a person with a disability within a prison.<sup>77</sup> The Inter-American Commission on

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<sup>71</sup> CRPD/C/GC/1, para 40; CRPD/C/GC/5, para 48; CRPD/C/GC/6, para 48.

<sup>72</sup> A/HRC/38/36, para 96.

<sup>73</sup> CCPR/C/GC/35 para 19.

<sup>74</sup> CRPD/C/12/2, Annex IV.

<sup>75</sup> Except European Convention on Human Rights in article 5.1(e).

<sup>76</sup> IACHR Principles and Best Practices on the Protection of Persons Deprived of Liberty in the Americas, principle III, 3.

<sup>77</sup> IACHR *Chinchilla Sandoval v Guatemala* (2016) para 209 ff.

Human Rights held similar views in precautionary measures,<sup>78</sup> where it held that an impairment cannot be the grounds for deprivation of liberty.<sup>79</sup> In a recent report on Guatemala, the IACHR builds on the CRPD Committee's recommendation with regards to the right to liberty, explicitly recognizing the power imbalance between persons with disabilities and hospital authorities and recalling the state's duty to monitor the situation of persons in confinement.<sup>80</sup> Further, this judgment finds that institutionalization exists due to a lack of community services, and that this constitutes a human rights violation.<sup>81</sup>

The African Commission on Human and People's Rights held in one of its cases that the right to liberty is not applicable to persons in need of medical assistance who are institutionalized,<sup>82</sup> but has now published an Optional Protocol on the Rights of Persons with Disabilities, including similar language as contained in the CRPD.<sup>83</sup> Further, the European Network of National Human Rights Institutions has recently issued a public statement<sup>84</sup> on the Draft Additional Protocol to the Oviedo Convention (which included forced treatment and deprivation of liberty based on a perceived or actual impairment) calling Member States to work on more CRPD compliant regulations and place their efforts on finding alternatives to involuntary treatment.

In the case of children with disabilities, the CRC Committee has accepted the use of small group homes to provide care and rehabilitation to children with disabilities, even though it rejects institutions.<sup>85</sup> It should however be noted that the General Comment on children with disabilities was written before the CRPD was adopted. As discussed below, the CRPD recognises the right to liberty for all persons with disabilities and the right to family life (article 23 CRPD) for children

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<sup>78</sup> IACHR Precautionary measure No. 440-16, Zaheer Seepersad regarding Trinidad and Tobago (4 August 2017).

<sup>79</sup> *Ibid.*, para 21.

<sup>80</sup> IACHR Situation of Human Rights in Guatemala, OEA/Ser.LV/II, Doc. 208/17 (2017).

<sup>81</sup> *Ibid.*, para 465.

<sup>82</sup> *The Gambia: Purohit and Another v The Gambia* (2003) AHRLR 96 (ACHPR 2003) para 68.

<sup>83</sup> Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa, article 8.5: The existence of a disability or perceived disability shall in no case justify deprivation of liberty.

<sup>84</sup> Available at:

[http://ennhri.org/IMG/pdf/ennhri\\_statement\\_on\\_the\\_draft\\_additional\\_protocol\\_to\\_the\\_oviedo\\_convention.pdf](http://ennhri.org/IMG/pdf/ennhri_statement_on_the_draft_additional_protocol_to_the_oviedo_convention.pdf) accessed 11 April 2019.

<sup>85</sup> CRC Committee General Comment No 9 (2007) on children with disabilities, CRC/C/GC/9, para 47.

with disabilities. Within the right to independent living, it firmly rejects any justification for institutional care of disabled children or adults. General Comment no. 5 CRPD has highlighted the dangerousness of small group homes, especially for children.<sup>86</sup> The Convention on the Rights of the Child recognizes in article 41 that it shall not affect any provisions that are more conducive to the realisation of the rights of the child. In the report on Guatemala cited above, the IACHR endorses the CRPD Committee's request to abolish "*all placements at institutions for all children of all ages, with or without disability, due to the abuse that occurs within these settings.*"<sup>87</sup>

### 3.4. Discriminatory deprivation of liberty for people with disabilities

The CRPD Committee upholds a universalist perspective on the right to liberty and security of the person that supersedes previous soft law standards and interpretations.<sup>88</sup> In its Guidelines on the interpretation of Article 14, the Committee has recalled that during the negotiations of the CRPD there were extensive discussions on the need to include a qualifier, such as 'solely' or 'exclusively', in the prohibition of deprivation of liberty due to the existence of an actual or perceived impairment in the draft text of Article 14(1)(b). However, many states and civil society organizations opposed this, arguing that it could lead to misinterpretation and allow deprivation of liberty based on actual or perceived impairment in conjunction with other conditions, like danger to self or others.<sup>89</sup>

Furthermore, the Committee recalled that discussions were held on whether to include a provision for periodic review of the deprivation of liberty in the text of draft article 14(2). This suggestion was also rejected by states, as reflected in the summaries of the drafting sessions.<sup>90</sup> Consequently, in the view of the Committee, Article 14(1)(b) prohibits the deprivation of liberty based on actual or perceived impairment even if additional factors or criteria are also used to justify the deprivation of liberty. Drawing on the right to equality and non-discrimination

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<sup>86</sup> CRPD/C/GC/5, para 16 (c).

<sup>87</sup> IACHR Situation of Human Rights in Guatemala, OEA/Ser.LV/II, Doc. 208/17 (2017), para 433.

<sup>88</sup> *Lex specialis derogat legi generali* – Martti Koskenniemi, 'Fragmentation of international law: difficulties arising from the diversification and expansion of international law: Report of the study group of the international law commission' (2006) A/CN.4/L.682.

<sup>89</sup> CRPD/C/12/2, Annex IV, para 7.

<sup>90</sup> Office of the High Commissioner for Human Rights 'Thematic Study on Legal Measures for Ratification and Implementation of CRPD' (2009) A/HRC/10/48, paras 48-49; Ad Hoc Committee, Fifth Session, Daily summary of discussions (27 January 2005).

(art. 5), and the right to equal recognition before the law (art. 12) and reading these in conjunction with the right to liberty the Committee describes detention of persons with disabilities against their will in institutions, either without their consent or with the consent of a substitute decision-maker, as arbitrary<sup>91</sup> and therefore incompatible with human rights norms.<sup>92</sup>

Different international actors have gradually endorsed this shift of interpretation of the right to liberty. Specifically, the Working Group on Arbitrary Detention (WGAD) has recently endorsed the interpretation of the right to liberty in accordance with the CRPD in its latest report from July 2017.<sup>93</sup> The WGAD's Basic Principles and Guidelines on the right of anyone deprived of their liberty to bring proceedings before a court include the prohibition on '*involuntary committal or internment on grounds of the existence of an impairment or perceived impairment*'.<sup>94</sup>

In a recent case of Mr. N,<sup>95</sup> the WGAD affirmed that Mr. N's involuntary hospitalisation constitutes a deprivation of liberty and that "*it is contrary to the provisions of article 14 of the Convention to deprive a person of his or her liberty on the basis of disability*" (para. 45). It also affirms that the existence of national legal provision cannot be invoked if it was not followed in the first place to justify any detention. WGAD found that the Japanese government had not followed the procedural rules established in its mental health law. Further, it found that Mr. N was deprived of liberty in a discriminatory manner, as he was firstly arrested for a minor criminal offence but then placed in a psychiatric hospital against his will, and the detention continued based purely on the basis of his psychiatric disorder.<sup>96</sup>

The Committee on the Elimination of All Forms of Discrimination against Women (CEDAW) has also adhered to the CRPD standards<sup>97</sup> in its Concluding

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<sup>91</sup> CRPD/C/GC/1, para 40.

<sup>92</sup> CRPD/C/12/2, Annex IV.

<sup>93</sup> WGAD Report, A/HRC/36/37, para. 55.

<sup>94</sup> WGAD Basic Principles and Guidelines on the right of anyone deprived of their liberty to bring proceedings before a court (2015) WGAD/CRP.1/2015, guideline 20.

<sup>95</sup> WGAD, Opinion No. 8/2018, A/HRC/WGAD/2018/8.

<sup>96</sup> Ibid, para 46.

<sup>97</sup> CEDAW/C/IND/CO/4-5, para 37. Recommendation "to repeal laws and prohibit disability-based detention of women, including involuntary hospitalization and forced institutionalization".

Observations on India from 2014. The World Health Organisation (WHO) has withdrawn its 'Resource Book on Mental Health, Human Rights and Legislation' because it was drafted prior to the CRPD and was not in accordance with its standards. The WHO has recently affirmed that its work will be informed by CRPD and calls for training and creating human rights respectful mechanisms to support persons with disabilities.<sup>98</sup> Coupled with this, it has launched the Quality Rights Initiative,<sup>99</sup> highlighting the unequal power structures within mental health services and including a module on strategies to end the use of seclusion, restraint and other coercive practices.<sup>100</sup>

Within the framework of the African Decade of Persons with Disability 2009-2019, the African Commission on Human and Peoples' Rights adopted a protocol on the rights of persons with disabilities prohibiting disability-specific deprivation of liberty<sup>101</sup> in order to close the interpretative gap. While this protocol is yet to be ratified by the African states, it constitutes a recognition without reservation of the human rights of persons with disabilities.<sup>102</sup>

The CRPD has fundamentally challenged the understanding of the right to liberty, provoking different reactions. While some treaty bodies' and member states' efforts are still focused on reducing the number of disability-specific detentions through improved procedural rules and criteria (e.g. last possible resort), other international actors such as WGAD, CEDAW, WHO, 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 have embraced the ban on disability-specific forms of deprivation of liberty completely, fully embracing the human rights model of disability.

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<sup>98</sup> See WHO website, available at: <[http://www.who.int/mental\\_health/policy/legislation/en/](http://www.who.int/mental_health/policy/legislation/en/)> accessed 11 April 2019.

<sup>99</sup> See WHO website, available at: <[http://www.who.int/mental\\_health/policy/quality\\_rights/guidance\\_training\\_tools/en/](http://www.who.int/mental_health/policy/quality_rights/guidance_training_tools/en/)> accessed 11 April 2019.

<sup>100</sup> The full module is available at: <<http://apps.who.int/iris/bitstream/10665/254809/1/WHO-MSD-MHP-17.9-eng.pdf?ua=1>> accessed 11 April 2019.

<sup>101</sup> Protocol to the African Charter on Human and People's Rights on the Rights of Persons with Disabilities in Africa.

<sup>102</sup> See OHCHR website announcing its adoption: <<https://www.ohchr.org/en/NewsEvents/Pages/DisplayNews.aspx?NewsID=22661&LangID=E>> accessed 11 April 2019; Laura-Stella Enonchong, 'Mental disability and the right to personal liberty in Africa' (2017) 21(9) The International Journal of Human Rights 1351.

#### 4. Mapping disability-specific forms of deprivation of liberty

This section covers the first phase of the research, explaining the human rights standards around deprivation of liberty, the available data on the different settings and highlights the different country findings per researched area.<sup>103</sup> This helped to frame the existing legal barriers and to review available data in a selection of fifteen countries.

In the first phase of this research, the research team focused on the interpretation of the right to liberty in relation to persons with disabilities. This interpretation has been evolving since the adoption of the CRPD. As explored above, some treaties and interpretative bodies have not yet embraced the CRPD paradigm that rejects discrimination on the basis of disabilities, but here is a growing level of adherence to this standard.<sup>104</sup>

Secondly, the team explored different indicators within the initial data collection in Phase I for fifteen countries, finding a general commitment to the rights of persons with disabilities including liberty yet establishing that all countries have legislation in place that includes an exception to the right to liberty based on risk of harm to self or others, need for care or disability diagnosis. Anti-discrimination laws and provisions coexist with exceptions to the right to liberty and, in some instances, are not being applied to persons with disabilities with regards to the right to liberty.<sup>105</sup>

The tendency to increase regulation of deprivation of liberty, rather than to prohibit disability-specific deprivations of liberty is widespread at national level in all of the countries included in this research. The exception to criminal responsibility is also widely accepted, as well as guardianship or substituted decision-making in different forms. Lastly, independent living initiatives coexist alongside contradicting norms which promote institutionalization with the latter sometimes even forming part of the independent living policy.

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<sup>103</sup> Involuntary hospitalization, diversion from the criminal justice system, institutionalization and home confinement.

<sup>104</sup> CPRD/C/12/2, Annex IV.

<sup>105</sup> Purohit and Moore v The Gambia (2003) AHLR 96 (ACHPR 2003).

#### 4.1. Regulation not abolition

While many international human rights actors are moving towards an understanding of deprivation of liberty as discriminatory whenever it is based on a disability, the framework has not shifted for all treaty bodies nor for all states. As explained above, the HRC still includes an exception to the right to liberty in its interpretation of the treaty text, and so does the ECHR within its normative text. However, all supervisory bodies have increased the emphasis on procedural rights. While the awareness that these situations constitute a deprivation of liberty has increased, it is not always understood as a discriminatory or unlawful deprivation of liberty. This has had an effect of increasing procedural regulations in member states and stricter monitoring before regional human rights courts, instead of a prohibition of discriminatory deprivation of liberty. Procedural guarantees as a safeguard against unlawful deprivation of liberty have occupied much of the debate and case law in regional courts and international treaty bodies.<sup>106</sup> The right to liberty is one of the few rights which includes procedural protection rules in its wording in most human rights treaties.<sup>107</sup>

The inclusion of regional treaties has provided an interesting insight into the right to liberty when applied in different contexts. The resulting case law often has a direct impact on the state parties, especially regarding procedural guarantees. For example, the decision of the European Court of Human Rights in *H.L. v U.K.*, where it found that a voluntary patient in a psychiatric hospital was deprived of his liberty, led to legislative reform in the United Kingdom via an amendment to the Mental Capacity Act<sup>108</sup> creating the Deprivation of Liberty Safeguards<sup>109</sup>. Most of the recent domestic reforms concerning deprivation of liberty of persons with disabilities concern the strengthening of procedural safeguards, rather than any acknowledgment of the discriminatory nature of this deprivation of liberty.<sup>110</sup>

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<sup>106</sup> See Chapter 5 of OHCHR Training book 'Human Rights in the Administration of Justice: A Manual on Human Rights for Judges, Prosecutors and Lawyers'; IACHR Case compilation on article 7 available at: <<http://www.corteidh.or.cr/tablas/26393.pdf>> accessed 11 April 2019.

<sup>107</sup> See article 9 ICCPR, article 5 ECHR, article 7 American Convention on Human Rights, article 8 Arab Charter on Human Rights.

<sup>108</sup> Legal reform in UK – see Law Commission report 'Mental Capacity and Deprivation of Liberty' (March 2017) Law Com No 372, section 4.2.

<sup>109</sup> Available at: <<https://www.gov.uk/government/publications/deprivation-of-liberty-safeguards-forms-and-guidance>> accessed 11 April 2019.

<sup>110</sup> Ghana's new mental health law (Mental Health Act 2012), which was endorsed as a good practice by WHO. France introduced procedural regulation of civil detention in its public health code through Loi

In contrast, the African Commission on Human and Peoples' Rights has adopted a protocol<sup>111</sup> to protect the right to liberty in accordance with the CRPD and the IACHR has embraced a closer approach to the CRPD in its interpretation of the right to liberty, reiterating or adopting the CRPD Committee's requests to countries or within their resolutions.<sup>112</sup>

During phase I of this research, 9 out of 15 countries examined were found to have specific mental health laws in place which allowed for a specific form of deprivation of liberty, and other countries included provisions on involuntary hospitalization in general health laws<sup>113</sup> or in civil procedural codes.<sup>114</sup> The regulation of other disability-specific forms of deprivations of liberty including placement in institutional settings is usually not included in procedural legislation and is often not considered a deprivation of liberty at a national level.<sup>115</sup> These pieces of legislation or policies usually frame the placement as a form of 'care' or even as independent living arrangements.<sup>116</sup> The CRPD Committee has already raised the issue of misunderstanding of independent living in States Parties, whereby smaller residences or group homes have been created as a purported part of deinstitutionalization programs.<sup>117</sup> Countries that do recognize this practice as a deprivation of liberty, such as the UK, do not consider the placement unlawful if it is based on a lack of capacity to consent and a need for care, as long as the placement complies with set out safeguards in the Deprivation of Liberty Safeguards.<sup>118</sup>

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n° 2011-803 du 5 juillet 2011 relative aux droits et à la protection des personnes faisant l'objet de soins psychiatriques et aux modalités de leur prise en charge.

<sup>111</sup> Protocol to the African Charter on Human and People's Rights on the Rights of Persons with Disabilities in Africa.

<sup>112</sup> IACHR Precautionary measure No. 440-16, Zaheer Seepersad regarding Trinidad and Tobago (4 August 2017); IACHR 'Situation of Human Rights in Guatemala' OEA/Ser.L/V/II, Doc. 208/17 (2017).

<sup>113</sup> Eg Costa Rica, Jordan and France, although they have a developed mental health scheme for involuntary admissions.

<sup>114</sup> Eg Spain and Philippines.

<sup>115</sup> Deprivation of liberty of older persons in institutions was not included in the research. The research team acknowledges that these practices happen and that are often based on age-related impairments/disabilities.

<sup>116</sup> Senegal : Loi d'orientation sociale relative à la promotion et à la protection des droits des personnes handicapées. Spain: Ley 39/2006, de 14 de diciembre, de Promoción de la Autonomía Personal y Atención a las personas en situación de dependencia.

<sup>117</sup> CRPD/C/GC/5 para 15.

<sup>118</sup> The Deprivation of Liberty Safeguards are an amendment to the Mental Capacity Act 2005. They apply in England and Wales only. In July 2018, the government published a bill that will replace the Deprivation of Liberty Safeguards with the Liberty Protection Safeguards, which follow the same logic to ensure procedural rights.

## 4.2. Scarce availability of data

Despite the importance of the right to liberty in all international human rights law and most national legal systems, accurate data and information on disability-specific forms of deprivation of liberty is scarce.<sup>119</sup> National censuses do not collect data on persons who are not living in households, leaving out persons living in shelters, hostels, residential care, institutions or hospitals. Within the national statistics on legal or administrative decision-making, placements in the different settings (e.g. hospitals, institutions, nursing homes) is collected by different authorities (health, criminal justice, social welfare) and no aggregated data which covers all settings is usually available.<sup>120</sup>

During phase I, the research team sought to find data on how many persons with disabilities are deprived of liberty on the basis of a disability, but this information was not available for a wide range of reasons, e.g. the information was not systematized or disaggregated or the register could not retrieve this information from its database (regarding legal capacity and guardianship). Decentralized countries in which decision making on disability and data gathering is at a local level such as Indonesia have an additional barrier to data collection, as well as various competing responsible branches of the administration (social services, health, child welfare, etc.).

Most available data are qualitative in nature, describing situations of deprivation of liberty and other human rights violations such as inhuman treatment, violence, abuse, forced sterilization or long term deprivation of liberty, without any register of duration or locus of detention. While it was possible to obtain some quantitative data on diversion from the criminal justice system or systems of involuntary psychiatric hospitalization, there was almost no data available for institutionalization (neither number of existing institutions or persons living in

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<sup>119</sup> CRPD Committee Concluding Observations on Panama CRPD/C/PAN/CO/1, para 34; Concluding Observation on Colombia CRPD/C/COL/CO/1, para 36; UNICEF press release (2017), available at: <[https://www.unicef.org/media/media\\_96099.html](https://www.unicef.org/media/media_96099.html)> accessed 11 April 2019.

<sup>120</sup> Data on diversion from criminal justice was usually obtained from justice statistics, while involuntary hospitalization data was often not available, aggregated on a regional or local level or within public prosecution offices statistics or mental health courts. Data on persons living in institutions was not available or only available in some regions. UK is probably the only country holding data on all settings due to the Deprivation of Liberty Safeguards.

institutions) in any of the 15 countries studied.<sup>121</sup> In the researched countries, no register of the number of existing institutions nor any official sources of statistical data on how many persons with disabilities live in institutions was found. The regulation of institutions was scarce or non-existent and at times operated by a mix of private, public and charitable organizations, that are not always licensed by the state.<sup>122</sup>

#### 4.3. General context: national legal frameworks on disability and liberty

All countries reviewed for Phase I of this research protect the right to liberty in general terms within their legal framework. The right to liberty is usually protected in general terms at the highest level (e.g. the constitution) within the states' legal framework. However, the extent of this protection is unclear, as it is often in contradiction with other rules which allow for disability-specific deprivation of liberty. For example, Ghana includes an exception to the right to liberty in its constitution if the person *'is suffering from an infectious or contagious disease, a person of unsound mind, a person addicted to drugs or alcohol or a vagrant, for the purpose of his care or treatment or the protection of the community'*.<sup>123</sup>

In the same context, the right to non-discrimination is protected in all fifteen countries included in Phase I, but only eight anti-discrimination laws expressly include the right to non-discrimination for persons with disabilities (Costa Rica, Ghana, Peru, France, Jordan, Indonesia, Kenya and Rwanda), most usually in specific disability laws, not in general antidiscrimination laws.<sup>124</sup> States demonstrate rhetorical commitment to right to liberty for all and non-discrimination for persons with disabilities, but see no contradiction between this position and the existence of laws which facilitate disability-specific deprivation of liberty.

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<sup>121</sup> The only country with information on this indicator was Moldova.

<sup>122</sup> Lawrence O Gostin, 'Old' and 'new' institutions for persons with mental illness: Treatment, punishment or preventive confinement?' 122 (2008) *Journal of the Royal Institute of Public Health* 906.

<sup>123</sup> Ghanaian Constitution, article 14 (d).

<sup>124</sup> Costa Rica: Ley N° 7600 (1996) sobre la Igualdad de Oportunidades para las Personas con Discapacidad y su reglamento (paras 20 y 235); Peru: Ley 29973 article 8 (ley general de la persona con discapacidad); France: loi n° 2008-496 du 27 mai 2008; Jordan: Law No. (20) for the Year 2017; Indonesia: Law 39/1999 on Human Rights; Kenya: Constitution of Kenya, 2010. Senegal has a law that stands against all acts of discrimination but considers guaranteeing access to treatment as not discriminatory. Ghana follows a similar wording to the Senegalese provision. Australian, Philippines and Spain's non-discrimination clauses refer to specific areas within the laws and Philippines recent mental health act excludes discrimination prohibition when "advancing persons with decision-making impairment capacity".

The extent of the complaints taken concerning the right to liberty in states is unknown. Argentina, Australia, Indonesia, Kenya, Peru and Spain have jurisprudence related to deprivation of liberty for persons with disabilities. Some cases identified affected persons considered unfit to plead or criminally not responsible,<sup>125</sup> others on accommodation within prison,<sup>126</sup> legal capacity,<sup>127</sup> or the applicability of the procedure of involuntary admission to persons lacking legal capacity.<sup>128</sup> The Philippines was the only country in this study for which the number of complaints of people with disabilities adjudicated by human rights institutions was available. Nevertheless, this number is often not disaggregated by topic of complaint, making it impossible to know how many claims related to the right to liberty specifically. For the Philippines, this figure included a high volume of complaints related to other rights, such as discrimination and access to social services.<sup>129</sup> In the case of Peru, the Ombudsman had information relating to different complaints of people with disabilities. However, it was not possible to know the total number and whether some were related to the right of liberty.<sup>130</sup>

Only Costa Rica and Kenya have policy frameworks which include actions related to disability-specific deprivation of liberty. In the case of Costa Rica, the National Policy on Disability aims to protect all human rights of persons with disabilities, including the right to liberty. Kenya has a National Plan of Action 2015-2022 which includes the protection against deprivation of liberty of persons with disabilities as one of the proposed action items.<sup>131</sup>

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<sup>125</sup> Australia, Argentina and Peru.

<sup>126</sup> Argentina.

<sup>127</sup> Kenya.

<sup>128</sup> Spain and Peru.

<sup>129</sup> Philippine Coalition on the U.N. Convention on the Rights of Persons with Disabilities, Parallel Report submitted to the Committee on the Rights of Persons with Disabilities on the implementation of the Convention in the Republic of the Philippines from 2008-2013; Philippine Deaf Resource Centre, Case Monitoring Report (2006-2012).

<sup>130</sup> Defensoría del Pueblo, Vigésimo Informe Annual (2016) Lima –Perú.

<sup>131</sup> Ministry of East African Community, Labour and Social Protection, National Plan of Action on implementation of recommendations made by the Committee on the Rights of Persons with Disabilities in relation with the initial report of the Republic of Kenya (September 2015 - June 2022).

#### 4.4. Deprivation of liberty as a result of involuntary hospitalization

Involuntary psychiatric hospitalization is the most recognised form of deprivation of liberty on the basis of a disability. Of all the countries studied in Phase I, only Peru has legislation forbidding psychiatric involuntary admission, although in practice, involuntary admission is permitted within an exception in a section for mental health in the general health law.<sup>132</sup> All other countries permit involuntary hospitalisation of persons with disabilities and regulate this through mental health laws or civil detention procedures. Nine countries have mental health laws in place. Likewise, the Philippines recently passed its mental health act (RA 11036). A wide range of persons can initiate involuntary admissions of persons with disabilities in the countries included in this research, including family members, guardians, doctors or directors of mental health facilities, police or third parties. Finally, all countries except Rwanda have regulations to review cases of involuntary admission.<sup>133</sup>

Seven of the fifteen countries have information related to involuntary admission. In the case of Australia, it was reported that 30.8% of the admissions in 2015 were involuntary.<sup>134</sup> France and Spain have also published data on the number of involuntary admissions: Spain had 51,320 applications processed by the Public Prosecutor in 2015 and in France 24% of inpatient admissions were declared as involuntary in 2015.<sup>135</sup> In Ghana, 2-8% of in-patients were detained on a legal order in 2011, and a study of the situation in Rwanda affirms that 70.3% of the admissions in Ndera Hospital (the only psychiatric hospital in the country) were involuntary.<sup>136</sup>

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<sup>132</sup> Article 16(c) of the Peruvian General Health Law states that in the case of a psychiatric emergency, in cases where the patient cannot consent, his/her family can consent to the admission. In cases where no family member is available the prosecution unit should be contacted in order to admit the patient without his/her consent.

<sup>133</sup> Eg In Spain only persons with full legal capacity are considered involuntary patients, persons deprived of legal capacity are considered incapable of not consenting. In Peru, a government official affirmed there are no involuntary hospitalizations as it is considered against human rights, but it is still done under the need for care and with the consent of families or public prosecutors.

<sup>134</sup> Australian Council for Healthcare Standards 'Australasian Clinical Indicator Report 2008-2015' (2016) 6 Mental Health Inpatient.

<sup>135</sup> Magali Coldefy et al, 'Compulsory Psychiatric Treatment: An Assessment of the Situation Four Years After the Implementation of the Act of 5 July 2011' (2017) 222(0) Questions d'économie de la Santé.

<sup>136</sup> Charles Mudenge, 'Patterns of psychiatric morbidity among patients in Ndera neuropsychiatry hospital Kigali -Rwanda. Master thesis.' (2009) University of Nairobi.

All countries have information on the number of residential psychiatric hospitals or mental health units. Most of the data on this indicator was collected through the World Health Organization Mental Health Atlas 2014 and 2017.<sup>137</sup> The total number of mental health facilities and psychiatric hospitals varies from country to country. For example, Rwanda was reported to have six mental health residential units. Similar numbers were found in Jordan, Senegal, and Qatar. Australia was the country reporting the largest number of residential mental health facilities with 1,607 in total.<sup>138</sup> All countries included in the analysis have information on the total number of mental health beds in psychiatric hospitals and general hospitals. As in the previous case, numbers vary between countries. On the one hand, France was reported to have 38,614 beds for mental health in 2016. On the other hand, in Ghana, 600 mental health beds were reported, all of which are located in the main psychiatric hospital.

Finally, the average number of days an individual spends under involuntary admission at mental health facilities was only available in France. In this country, the average number of days was 40 in cases where a third person requested the admission. For persons declared not criminally responsible this number increased to 162 days.<sup>139</sup>

Involuntary hospitalization of persons with disabilities (especially in psychiatric units) is still considered necessary by many scholars and the mainstream public.<sup>140</sup> It is understood as a way of caring or healing the person. The literature reviewed for this research often focuses on assessing the effects of forced hospitalization or the profile of coerced patients. Patients in hospital care have expressed their discomfort with being simply told what to do, without further

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<sup>137</sup> See WHO website, available at: <[http://www.who.int/mental\\_health/evidence/atlas/profiles-2014/en/](http://www.who.int/mental_health/evidence/atlas/profiles-2014/en/)> accessed 11 April 2019.

<sup>138</sup> Australia had 1607 residential mental health facilities in 2018, for latest update see <<https://www.aihw.gov.au/reports/mental-health-services/mental-health-services-in-australia/report-contents/summary-of-mental-health-services-in-australia>> accessed 11 April 2019.

<sup>139</sup> Questions d'économie de la santé n° 205 - janvier 2015, Irdes.

<sup>140</sup> Marisha Wickremesinhe, 'Emergency involuntary treatment law for people with mental disorders: A comparative analysis of legislation in LMICs.' (2018) 56 International Journal of Law and Psychiatry 1.

<sup>140</sup> Ivana Stašević Karličić et al, 'Predictors of involuntary hospitalisation of patients suffering from schizophrenia.' (2017) 8(2) Open Journal of Psychiatry & Allied Sciences 124; Myriam Guedj et al, 'French lay people's views regarding the acceptability of involuntary hospitalization of patients suffering from psychiatric illness' (2012) 35(1) International Journal of Law and Psychiatry 50.

explanation or choice in which treatment to pursue.<sup>141</sup> In literature on the experiences of involuntarily detained individuals, many described the distress which they experienced as a result of the detention, its impact on their relationship with clinicians, and the frustration and resistance they experienced during detention. Further research on this experience has included reflections from individuals detained on the processes of ‘losing control’, ‘regaining control’ and ‘maintaining control’ over their emotional, personal and social lives during the involuntary hospitalization.<sup>142</sup> Persons with disabilities are portrayed as a heterogeneous group in much of this literature<sup>143</sup> and the measures of deprivation of liberty are supposed to be reduced to those “who need it”, “who lack capacity” or those who are “dangerous”, even if there is no evidence that persons with disabilities are more violent or dangerous than other populations.<sup>144</sup> In turn, there are studies that show that coercion does not lead to improved outcomes and has a negative impact.<sup>145</sup> Voluntary community based services have been found to be just as or more effective than hospitalization.<sup>146</sup>

The literature review reflects a generally accepted shift towards a right based language and that much more needs to be done to prevent involuntary hospitalization. However, the prohibition of involuntary treatment and detention is still hotly discussed. Some authors argue that the CRPD Committee’s interpretation of article 12 (General Comment no.1) undermines other fundamental rights such as the enjoyment of the highest attainable standard of health, access to justice, the right to liberty, and the right to life.<sup>147</sup> There are scholars who hold the idea that deprivation of liberty is necessary to protect the

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<sup>141</sup> Christina Katsakou et al, ‘Why do some voluntary patients feel coerced into hospitalisation? A mixed-methods study’ (2011) 187 *Psychiatry Research* 275.

<sup>142</sup> David McGuinness et al, ‘Individuals’ experiences of involuntary admissions and preserving control: Qualitative study’ (2018) 4(6) *BJPsych Open* 501.

<sup>143</sup> Vicki Welch et al, ‘Permanence for disabled children and young people through foster care and adoption: A selective review of international literature’ (2015) 53 *Children and Youth Services Review* 137.

<sup>144</sup> Lawrence O Gostin, ‘Old’ and ‘new’ institutions for persons with mental illness: Treatment, punishment or preventive confinement?’ (2008) 122 *Journal of the Royal Institute of Public Health* 906.

<sup>145</sup> Tom Burns et al, ‘Community treatment orders for patients with psychosis: a randomised controlled trial’ (2013) 381 *Lancet* 1627; Andrew Molodynski et al, ‘Coercion in mental healthcare: time for a change in direction’ (2016) 13(1) *BJPsych international* 1.

<sup>146</sup> See studies cited in Agnes Turnpenny et al ‘Mapping and understanding exclusion: institutional, coercive and community-based services and practices across Europe’ (2017) *Mental Health Europe*.

<sup>147</sup> Melvyn Colin Freeman et al, ‘Reversing hard won victories in the name of human rights: a critique of the General Comment on Article 12 of the UN Convention on the Rights of Persons with Disabilities’ (2015) 2 *Lancet Psychiatry* 844.

right to life and health or out of ethical reasons.<sup>148</sup> Others propose increasing the procedural safety guarantees but still allowing for substitute decision making (meaning forced hospitalization and treatment) for situations in which the person is considered 'lacking mental capacity'.<sup>149</sup> Security as a form of protection of persons is also alleged to justify deprivation of liberty.<sup>150</sup>

Coercion was further described as being pushed towards accepting hospitalization by family members or staff, under the threat of otherwise being involuntarily admitted and deciding under fear. Hospital was described by some authors as a place of confinement, not one of treatment and care, in line with previous studies.<sup>151</sup> Monahan et al's research found that many of the individuals in psychiatric hospitals on a 'voluntary' basis stated that they were coerced into admission, in accordance with previous investigations. An Irish study on this topic found that voluntary patients experienced similar levels of coercion compared with involuntary admitted individuals.<sup>152</sup> The coercion exercised on patients has been interpreted as the clinician's belief of pursuing the best interest of the patient<sup>153</sup> or as part of the culture of the profession.<sup>154</sup>

One of the reviewed studies which was conducted in Ireland (n=161) found that the experiences that led to coercion in psychiatric hospitalization included the perception that an alternative treatments would have been more appropriate and that the hospital treatment was not effective, the insufficient involvement in the admission and treatment process and lastly not feeling respected and cared for by professionals.<sup>155</sup> This was also concluded by another literature review on

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<sup>148</sup> Hanna Pickard, 'Choice, deliberation, violence: Mental capacity and criminal responsibility in personality disorder' (2015) 40 *International Journal of Law and Psychiatry* 15.

<sup>149</sup> John Dawson, 'A realistic approach to assessing mental health laws' compliance with the UNCRPD' (2015) 40 *International Journal of Law and Psychiatry* 70; Sascha Callaghan, 'Risk of suicide is insufficient warrant for coercive treatment for mental illness' (2013) 36(5-6) *International Journal of Law and Psychiatry* 374.

<sup>150</sup> John Petrila et al, 'Legal Issues in Maximum Security Institutions for People with Mental Illness: Liberty, Security, and Administrative Discretion' (2002) 20 *Behavioral Sciences & the Law* 463.

<sup>151</sup> John Monahan et al, 'Coercion and Commitment: Understanding Involuntary Mental Hospital Admission' (1995) 18(3) *International Journal of Law and Psychiatry* 249.

<sup>152</sup> Brian O'Donoghue et al, 'Service users' perspective of their admission: a report of study findings' (2017) 34 *Irish Journal of Psychological Medicine* 251.

<sup>153</sup> Clive Seale et al, 'Sharing decisions in consultations involving anti-psychotic medication: a qualitative study of psychiatrists' experiences' (2006) 62 *Social Science & Medicine* 2861.

<sup>154</sup> Rigmor R Diseth et al, 'Potential legal protection problems in the use of compulsory commitment in mental health care in Norway' (2011) 34 *International Journal of Law and Psychiatry* 393.

<sup>155</sup> Brian O'Donoghue et al, 'Perceived coercion in voluntary hospital admission' (2014) 215 *Psychiatry Research* 120.

voluntary and involuntary hospitalization.<sup>156</sup> Another study on perceived coercion (n=446) conducted in London (UK) found that individuals who said they were coerced at admission also were coerced into treatment a month later. Individuals in this study described three major issues with psychiatric hospitalization: feeling that the treatment was not effective, not participating in the admission process and a lack of respect on behalf of professionals.<sup>157</sup> Forced treatment has also been described as a form of indefinite incarceration.<sup>158</sup> In the context of the present study, the research team acknowledges that the framing of research as being about how people ‘feel’ undermines the validity of persons with psychosocial disabilities as reporters of their own circumstances, which in turn reinforces discrimination.

#### 4.5. Deprivation of liberty in residential institutions

All countries included in Phase I of this research allow institutionalization of persons with disabilities in specific situations. Institutionalization is distinguished from hospitalization because it occurs in different settings (outside of hospital or strictly medical facilities) and because the confinements within institutions are invisibilized, as there is frequently no legal or formal procedure to institutionalize a person. The regulation on this topic is diverse and less developed than in the cases of involuntary hospitalisation. In certain cases, the same regulation is used as in cases of involuntary hospitalisation, in others, guardianship measures are the trigger for deprivation of liberty in institutions. Some countries have a legal provision on the right to shelter,<sup>159</sup> which is used to justify the placement of persons with disabilities in institutions. Other countries require court supervision in the case of persons deprived of legal capacity, without specifying how such supervision must take place.<sup>160</sup> Eight countries<sup>161</sup> have legislation promoting deinstitutionalization of persons with disabilities. However, in all of these

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<sup>156</sup> Thomas Kallert et al, ‘Involuntary vs. voluntary hospital admission. A systematic literature review on outcome diversity’ (2008) 258 *European Archives of Psychiatry and Clinical Neuroscience* 195.

<sup>157</sup> Christina Katsakou et al, ‘Why do some voluntary patients feel coerced into hospitalisation? A mixed-methods study’ (2011) 187 *Psychiatry Research* 275.

<sup>158</sup> Erick Fabris E et al, ‘Chemical Constraint: Experiences of Psychiatric Coercion, Restraint, and Detention as Carceratory Techniques’ In: Liat Ben-Moshe L et al (eds), *Disability Incarcerated* (2014) Palgrave Macmillan, New York.

<sup>159</sup> Some countries include within their legislation a specific right for persons with disabilities as a right to shelter, eg Senegal: *Loi d’orientation social*, n. 2010-15 du 6 juillet 2010, article 9; Spain: *Ley 39/2006*, article 15.

<sup>160</sup> Article 578 Peruvian Civil Code.

<sup>161</sup> Costa Rica, Peru, Australia, Ghana, Rwanda, Jordan, Moldova and Qatar.

countries, legislation permitting the admission of persons with disabilities to institutions is also in place.

Indonesia,<sup>162</sup> the Philippines, Australia, Kenya, Ghana, France and Qatar have legislation or protocols regulating the use of restraints. The use of restraints was included within institutions to show the lack of consent, as very often, persons with disabilities within institutions are not asked whether they want to be there nor do they have a legal remedy to challenge their detention. The research team acknowledges that restraint and isolation is also used within psychiatric hospitalization, despite the call to end this practice from several human rights bodies.<sup>163</sup> France has recently introduced a duty to register the use of isolation and mechanical restraints following the recommendation of the *Contrôleur général des lieux de privation de liberté*.<sup>164</sup> However, no data from this register is available at the time of writing. No information was found on the use of chemical restraint in any of the countries included in this study except for Spain,<sup>165</sup> where one study analysed the general health of persons with disabilities. The research found a high use of medication and a high use of neuroleptic and anti-seizure medication to control behaviour.<sup>166</sup>

Costa Rica, Argentina, Australia, Senegal, Spain, Jordan and Moldova have regulations on the provision of residential services. However, regulation on this topic mainly only included aspects related to the minimum standards for the provision of services in institutions, but it did not consider aspects related to the

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<sup>162</sup> Indonesia has a law prohibiting shackling and a policy to end shackling by 2020 (e.g. Indonesia Free from Shackling). Under this program, 8,690 persons were found shackled in 19 provinces. In 2015, 7,961 were freed and given medical treatment. Despite these efforts, not all provinces include regional regulation that prohibits shackling. According to Human Rights Watch, the community mental health teams (Tim Penggerak Kesehatan Jiwa Masyarakat (TPKJM)), which coordinate all mental health related departments and facilitate release, lack resources and are not present in all provinces. Moreover, there is no follow up of the released individuals and often persons are shackled again. Approximately 57,000 persons with disabilities have experienced being shackled in Indonesia (Human Rights Watch. Living in Hell. Abuses against People with Psychosocial Disabilities in Indonesia (2016)).

<sup>163</sup> CRPD/C/12/2, Annex IV; Special Rapporteur on Torture in his report A/HRC/22/53 (2013).

<sup>164</sup> *Contrôleur général des lieux de privation de liberté, Isolement et contention dans les établissements de santé mentale* (2016).

<sup>165</sup> Only one study in the case of Spain – Pomona. Available at: <<http://www.proyectopomona.com>> accessed 11 April 2019.

<sup>166</sup> 84% of the participants took daily medication and 19 % of the participants had a daily intake of 7 or more medications. Estudio POMONA. Laura Letrán et al, 'Polimedicación e interacciones medicamentosas: Un estudio poblacional en adultos con discapacidad intelectual en España' (2017) XXXIV Congreso Nacional De Enfermería De Salud Mental 607.

quality of care.<sup>167</sup> Regular monitoring seems to be part of private initiatives. International monitoring bodies such as the Subcommittee on Prevention of Torture and other Cruel, Inhuman or Degrading Treatment or Punishment ('SPT') do access some institutions but they cannot visit all of them and visits are not regular.<sup>168</sup> This does not exclude the fact that NHRIs may visit institutions from time to time if required to do so but, again, this is not done on a regular basis<sup>169</sup>.

The number of institutions for persons with disabilities is only available in Peru (public), the Philippines (public and private accredited centres), Rwanda (only for children with disabilities) and France (public). In the case of Rwanda, only information related to the number of institutions for children with disabilities was available, including residential and mixed centres.<sup>170</sup> France was reported to have 8,500 centres for persons with disabilities, with 3,000 for children and 5,000 for adults.<sup>171</sup> However, this figure includes both residential and non-residential centres, so it is difficult to ascertain where deprivations of liberty might occur. When information related to residential or inpatient institutions for persons with disabilities was sought, official sources indicated that of the 8,500 centres mentioned, 1,574 institutions provided residential services in 2010.<sup>172</sup>

Information on the total number of persons with disabilities living in institutions was available in Argentina, Moldova and Spain. France has a related number, but it does not disaggregate which persons are at a day care centre or school

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<sup>167</sup> The minimum standards are usually related to the number of doctors, nurses or other medical staff that should be present. However, it does not establish aspects related to quality of provision of services aiming to improve the health status or quality of life of patients.

<sup>168</sup> Argentina ratified the OPCAT in 2004 and had a country visit in 2012; Peru ratified in 2006 and has had one country visit in 2013; Costa Rica ratified the OPCAT and has had no country visit; Philippines ratified in 2012 and had one country visit in 2015 but the report has not released yet; Australia signed in 2009 but has not ratified yet; France ratified in 2008 and had a visit by the European Committee against Torture (CPT) 2015 which includes long term placements in hospitals; Spain ratified in 2006 and the CPT visited Spain in 2014 and 2016; Ghana ratified 2016 and has had no country visit; Rwanda ratified in 2015 and had country visit in 2017 which had to be suspended due to lack of cooperation; Senegal ratified in 2006 and had one country visit in 2012.

<sup>169</sup> Angela Ofori-Atta et al, 'MHaPP Research Programme Consortium. A situation analysis of mental health services and legislation in Ghana: challenges for transformation' (2010) 13(2) African Journal of Psychiatry 99.

<sup>170</sup> 'Mixed centre' refers to residential and daily care centres, see National Council of Persons with Disabilities & National Commission for Children, Report on national assessment of centres caring for children with disabilities in Rwanda (2016).

<sup>171</sup> See Sanitaire-social.com: Centre pour handicapés, available at: <<https://www.sanitaire-social.com/annuaire/centre-pour-handicapes/25>> accessed 11 April 2019.

<sup>172</sup> This information was collected in l'enquête ES 2010 and included Maison d'accueil spécialisé (MAS), Foyer d'accueil médicalisé (FAM), Établissement expérimental, Foyer d'accueil polyvalent and Établissement d'accueil temporaire.

and how many in residential services.<sup>173</sup> In the case of Argentina, only information related to the number of persons with psychosocial disabilities was available (50,000).<sup>174</sup> In Spain, data collected showed that 269,139 persons with disabilities were living in institutions for older people, institutions for persons with disabilities 65 years or younger, psychiatric hospitals and geriatric hospitals in 2008.<sup>175</sup> Nine countries<sup>176</sup> have some information related to the use of seclusion and restraints. In most countries, only information related to their possible use was captured with no specific estimate of the use of seclusion or restraints. Specific data on this point was only available in the case of Australia where official sources report that in 2015-16 seclusion rates were 8.1 events per 1,000 bed days.<sup>177</sup> Finally, no information was available in any country on the budget for institutions or for independent living. Most countries have budget information aggregated by sectors (e.g. health care, social services provision, social care), but no country in the study has publicly available information related to budget allocation for these two areas.

The findings from phase I show that institutionalization is often provided for by law and policies for persons with disabilities and their families, sometimes as part of services to promote autonomy<sup>178</sup>, for public health<sup>179</sup> or as part of the right to health, social rehabilitation.<sup>180</sup> The common causes referred to in the literature for institutionalization of persons with disabilities are paternalism,<sup>181</sup> the perceived need for care, the lack of alternatives within the community<sup>182</sup> or of an

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<sup>173</sup> 490,000 is the total number of persons with disabilities in institutions in 2015. Of those, 155,00 are children and 335,000 are adults, see Caisse Nationale de Solidarite pour l'autonomie, Les chiffres clés de l'aide à l'autonomie (2016).

<sup>174</sup> Centro de Estudios Legales y Sociales (CELS) Argentina.

<sup>175</sup> Ministry of Labour, Social Protection and Family, Annual Social Report 2011 (2012).

<sup>176</sup> Costa Rica, Peru, Argentina, Indonesia, Australia, Ghana, Spain, Jordan, Moldova and Qatar.

<sup>177</sup> Australian Institute of Health and Welfare.

<sup>178</sup> Spain: Ley 39/2006, de 14 de diciembre, de Promoción de la Autonomía Personal y Atención a las personas en situación de dependencia.

<sup>179</sup> Senegal Loi 76-03 du 25 mars 1976 relative au traitement de la lèpre et au reclassement social des lépreux guéris et mutilés; Gerald N Grob, 'Mental Health Policies in America: Myths and Realities' Fall 1992. on <HealthAffairs.org> accessed 27 March 2018.

<sup>180</sup> Anthony Stratford et al, 'Introducing recovery-oriented practice in Indonesia: the Sukabumi project – an innovative mental health programme' (2014) 24(1-2) Asia Pacific Journal of Social Work and Development 71.

<sup>181</sup> Walter Boente, 'Some continental European Perspectives on safeguards in the case of deprivation of liberty in health and social care settings' (2017) 23 International Journal of Mental Health and Capacity Law 69; Winnie S Chow et al, 'Understanding psychiatric institutionalization: a conceptual review' (2013) 13 BMC Psychiatry 169.

<sup>182</sup> Inclusion Europe's analysis of the EU Council conclusions on Independent living, available at: <<http://inclusion-europe.eu/wp-content/uploads/2018/02/Position-paper-Inclusion-Europe-EU-Council-conclusions-on-Independent-living.pdf>> accessed 11 April 2019.

organization which can provide an appropriate care package, the hope for better opportunities<sup>183</sup>, behavioral symptoms<sup>184</sup>, crisis situations<sup>185</sup>, to control persons with disabilities, stigma<sup>186</sup>, beliefs<sup>187</sup>, policy and cultural structures including around parenting identities<sup>188</sup> and colonization.<sup>189</sup> Persons with high support needs or so-called challenging behavior are at a higher risk of being institutionalized or reinstitutionalized.<sup>190</sup> The lack of proper community facilities may also push former patients into non-psychiatrically oriented institutions.<sup>191</sup>

Institutionalization has been known to be used to ensure access to care and health services.<sup>192</sup> Several reports acknowledge that persons 'with severe mental disorders' are found to be more likely to be poor and at risk of being homeless.<sup>193</sup> This risk is often used to justify the need for shelter<sup>194</sup> which can result in deprivation of liberty. As an example of addressing these, NGOs run rehabilitation centers and shelters for the homeless in Nigeria in partnership with the Government Primary Healthcare Departments for a community psychiatry program.<sup>195</sup>

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<sup>183</sup> Claire O'Kane C et al, 'Alternative Child Care and Deinstitutionalisation' (2016), available at: <<https://www.sos-childrensvillages.org/getmedia/1764d663-1b65-40c3-8288-882afa94b4f1/Indonesia-Alternative-Child-Care-and-Deinstitutionalisation-Report.pdf>> accessed 11 April 2019.

<sup>184</sup> David W Gilley et al, 'Influence of behavioral symptoms on rates of institutionalization for persons with Alzheimer's disease' (2004) 34(6) Psychological Medicine 1129.

<sup>185</sup> Angela Cretteden et al, 'Supporting families: Outcomes of placement in voluntary out-of-home care for children and young people with disabilities and their families' (2014) 39 Children and Youth Services Review 57.

<sup>186</sup> Human Rights Watch, 'Once you enter, you never leave. Deinstitutionalization of Persons with Intellectual or Mental Disabilities in Croatia' (2010).

<sup>187</sup> Jacqueline Slikker, 'Attitudes towards Persons with Disabilities in Ghana' (May 2009) VSO Sharing skills/sharing lives.

<sup>188</sup> Elena Iarskaia-Smirnova et al, 'Parenting Children with Disabilities in Russia: Institutions, Discourses and Identities' (2015) 67(10) Europe-Asia Studies 1606.

<sup>189</sup> Laurence Kirmayer et al, 'Mental Health of Aboriginal Peoples: Transformation of Identity and Community' (2000) 45(7) Canadian Journal of Psychiatry 607.

<sup>190</sup> Julie Beadle-Brown et al, 'Deinstitutionalization in intellectual disabilities' (2007) 20(5) Current Opinion in Psychiatry 437.

<sup>191</sup> Erica Irene Daes, Special Rapporteur of the Sub-Commission on Prevention of Discrimination and Protection of Minorities, Principles, Guidelines and Guarantees for the protection of persons detained on grounds of mental ill-health or suffering from mental disorder, UN Document E/CN.4/Sub.2/1983/17/Rev.1, para 48.

<sup>192</sup> Anne Penneau et al, 'Institutionalisation Favours Access to Health Care for Disabled Persons Aged under 60 in France' (2015) 207 *Question de l'économie de la Santé* 1.

<sup>193</sup> Nancy H Liu et al, 'Excess mortality in persons with severe mental disorders: a multilevel intervention framework and priorities for clinical practice, policy and research agendas' (2017) 16(1) *World Psychiatry* 30.

<sup>194</sup> Ursula M Read et al, 'Local suffering and the global discourse of mental health and human rights: An ethnographic study of responses to mental illness in rural Ghana' (2009) 5:13 *Globalization and Health*.

<sup>195</sup> Julian Eaton et al, 'Developing mental health services in Nigeria: the impact of a community-based mental health awareness programme' (2008) 43 *Social Psychiatry and Psychiatric Epidemiology* 552.

Lack of public housing has also been identified as a possible cause for psychiatric institutionalization.<sup>196</sup> Institutions have often served to provide basic shelter and food for persons and may be the only resource available for the person. Community reentry interventions often fail because they do not take into account other factors such as social disadvantage and poverty, failing to provide support in other basic needs the persons may have, e.g. housing or identification.<sup>197</sup> Research has supported the call for better supported housing policies and supporting families who wish to care and support family members with a disability.<sup>198</sup>

While institutionalization is currently most associated with persons with intellectual and psychosocial disabilities, persons with physical disabilities are still experiencing institutionalization to access care.<sup>199</sup> For example, placement in nursing homes has often been initiated due to the acquisition of a physical or mobility impairment,<sup>200</sup> with the inability to continue living at home without support and the need for end-of-life care needs.<sup>201</sup> The inability of families to continue providing support due to age and stress of carers has also been identified as a cause of institutionalization.<sup>202</sup> Other identified causes of institutionalization from the literature review included a lack of community nurses and social workers, a lack of home-based assessments of children in need and their families, a lack of free universal prevention or targeted intervention services to reduce child abuse, neglect, and abandonment.<sup>203</sup>

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<sup>196</sup> Care Quality Commission. Mental Health Act: The rise in the use of the MHA to detain people in England (January 2018).

<sup>197</sup> Stacey Barrenger, 'You Don't Get No Help': The Role of Community Context in Effectiveness of Evidence-Based Treatments for People with Mental Illness Leaving Prison for High Risk Environments' (2013) 16 *American Journal of Psychiatric Rehabilitation* 154.

<sup>198</sup> Thomas Kallert et al, 'Comparing the effectiveness of different types of supported housing for patients with chronic schizophrenia' (2007) 15 *Journal of Public Health* 29.

<sup>199</sup> World Health Organization World Report on Disability WHO/NMH/VIP/11.01 (2011); Bonnie Pape, 'Finding my place: Age appropriate housing for younger adults with multiple sclerosis' (2006) Toronto: Multiple Sclerosis Society of Canada, Toronto Division.

<sup>200</sup> Marlene Fransen et al, 'Excess Mortality or Institutionalization After Hip Fracture: Men Are at Greater Risk Than Women' (2002) 50 (4) *Journal of the American Geriatric Society* 685.

<sup>201</sup> Miharū Nakanishi et al, 'Processes of decision making and end-of-life care for patients with dementia in group homes in Japan' (2009) 48(3) *Archives of Gerontology and Geriatrics* 296.

<sup>202</sup> World Health Organization (WHO) World Report on Disability WHO/NMH/VIP/11.01 (2011).

<sup>203</sup> 'The Effects of Institutionalization and Living Outside of Family Care on Children's Early Development' in National Academies of Sciences, Engineering, and Medicine 'Forum on Investing in Young Children Globally: A Synthesis of Nine Global Workshops Exploring Evidence-Based, Strategic Investments in Young Children' (2017) Washington, DC: The National Academies Press.; Kevin Browne, 'The risk of harm to young children in institutional care.' (2009) Save the Children UK & the Better Care Network; Catherine Hamilton-Giachritsis et al, 'Forgotten children? An update on young children in institutions across Europe' (2012) 88(12) *Early Human Development* 911.

As this research and the literature review demonstrates, deinstitutionalization initiatives are complex. In some instances, national deinstitutionalization policies simply relocate individuals in a smaller institution or different congregated setting, rather than ensuring true inclusion in the community.<sup>204</sup> Deinstitutionalization initiatives have often been said to fail due to a lack of planning before and during the deinstitutionalization, and because not enough resources were allocated to community services.<sup>205</sup> Rushed and ill-planned deinstitutionalization policies have also ended in deaths.<sup>206</sup> Children leaving care were also often found to end up homeless, due to poor education or acquisition of life skills during institutionalization and ill prepared deinstitutionalization.<sup>207</sup>

The CRPD Committee has found that states which have DI plans have not implemented their deinstitutionalization plan<sup>208</sup> and urges others to adopt deinstitutionalization plans.<sup>209</sup> Often, deinstitutionalization or independent living strategies, policies and laws include the provision of care and support in segregated residential facilities.<sup>210</sup> This misinterpretation has also been highlighted by the CRPD Committee. In this sense, the destruction of “total institutions” does not guarantee that the underlying social processes, values and assumptions are changed.<sup>211</sup>

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<sup>204</sup> Michael Donnelly et al, 'A three- to six-year follow-up of former long-stay residents of mental handicap hospitals in Northern Ireland' (1997) 36 *British Journal of clinical Psychology* 585; Roy McConkey et al, 'A longitudinal study of the intra-country variations in the provision of residential care for adult persons with an intellectual disability' (2013) 57(10) *Journal of Intellectual Disability Research* 969; Lawrence O Gostin, 'Old' and 'new' institutions for persons with mental illness: Treatment, punishment or preventive confinement?' (2008) 122 *Journal of the Royal Institute of Public Health* 906.

<sup>205</sup> Harry Richard Lamb et al, 'Understanding and Treating Offenders with Serious Mental Illness in Public Sector Mental Health' (2017) 35(4) *Behavioural Sciences and the Law* 303; John A Talbott, 'Deinstitutionalization: Avoiding the Disasters of the Past' (2004) 55(10) *Psychiatric Services* 1112.

<sup>206</sup> Melvyn Colin Freeman, 'Global lessons for deinstitutionalisation from the ill-fated transfer of mental health-care users in Gauteng, South Africa' (2018) 5(9) *The Lancet Psychiatry* 765.

<sup>207</sup> World Health Organization (WHO), 'World Report on Disability' (2011) WHO/NMH/VIP/11.01; Georgette Mulheir, 'Deinstitutionalisation – A Human Rights Priority for Children with Disabilities' (2012) 9 *The Equal Rights Review* 117; Philip Mendes et al, 'The needs and experiences of young people with a disability transitioning from out-of-home care: The views of practitioners in Victoria, Australia. *Children and Youth*' (2014) 36 *Services Review* 115.

<sup>208</sup> CRPD Committee, Concluding Observations on Haiti, CRPD/C/HTI/CO/1, paras 26 and 27.

<sup>209</sup> CRPD Committee, Concluding Observations on Bolivia, CRPD/C/BOL/CO/1, para 38.

<sup>210</sup> In Spain Ley 39/2006, de 14 de diciembre, de Promoción de la Autonomía Personal y Atención a las personas en situación de dependencia. In Argentina Ley 2243 Sistema de protección integral de las personas discapacitadas.

<sup>211</sup> Benny Goodman, 'Erving Goffman and the total institution' (2013) 33 *Nurse Education Today* 81.

#### 4.6. Deprivation of liberty as a result of diversion from the criminal justice system

Diversion from the criminal justice system results in the person being deemed unfit to stand trial or not responsible for her criminally relevant actions. Criminal legislation which creates disability-based categories such as unfit to plead or not criminally responsible thus justifies an intervention on the basis of disability and links diversion from the criminal justice system to involuntary hospitalisation and institutionalization.

All reviewed countries in Phase I of this research had laws providing for exceptions to criminal responsibility based on a disability. Indonesia, Australia, Kenya, Ghana, Jordan, Moldova and Qatar included an exception to criminal responsibility based on an assessment of ability to participate in a trial (unfitness to plead),<sup>212</sup> whereas other countries<sup>213</sup> included an exemption from criminal responsibility based on a lack of ability to understand the unlawfulness of the act, the consequences of an individual's actions or the purpose of the sanction. The application of these exceptions usually trigger the imposition of security measures or hospitalisation of the defendant, which imply deprivation of liberty based on the finding of a disability, not based on the commission of a crime. Frequently, persons who are diverted from the criminal justice system are subject to mental health legislation and may be treated in a similar manner to involuntary patients, experiencing forced treatment and deprivation of liberty. In the cases of Ghana, Kenya, Rwanda and Qatar, the mental health law regulates security measures, which are applied instead of a criminal sentence. Australia has specialised courts to manage diverted defendants.<sup>214</sup>

The criterion of dangerousness is usually used to assess the need for imposition of a security measure. Fourteen out of fifteen countries include an explicit rule within their legislation that allows police or social services to arrest persons with disabilities based on risk to self or others. This provision may be found in civil codes, under anti-begging laws, mental health laws or criminal codes. In some

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<sup>212</sup> Eg Australia, Kenya.

<sup>213</sup> Costa Rica, Peru, Argentina, The Philippines, Rwanda, Senegal, France and Spain.

<sup>214</sup> Fiona Davidson, *'Mental Health Liaison and Diversion. Court Liaison Services and Mental Health Court Programs in Australia'* (2015) The Australian Centre for Research Excellence in Offender Health.

countries, this provision is part of criminal procedures while in others it is an aspect of involuntary hospitalisation or institutionalization standards.<sup>215</sup> In some cases, the general duty to bring a person to hospital is within civil codes as an adult protection measure (e.g. Argentina).<sup>216</sup>

Five of the fifteen countries reviewed in Phase I of this research have data related to the number of persons with disabilities declared unfit to plead or not criminally responsible.<sup>217</sup> Australia is the only country with data available on the number of persons with disabilities declared unfit to plead: 43,862<sup>218</sup> individuals were declared unfit to plead in 2016. In the cases of Costa Rica and Argentina, the total number of persons with disabilities declared not criminally responsible was 44<sup>219</sup> and 131,<sup>220</sup> respectively. France reported a total of 4,025 individuals not criminally responsible and in Moldova 307 persons were included in the reference of other measures. No information on this indicator was available in the African or Middle East countries.

Eleven countries had information on the number of institutions which hold persons with disabilities declared unfit to plead or not criminally responsible. All countries with this information were reported to have less than twenty institutions. However, in some countries, such as Rwanda, no specific units exist, and the main mental health hospital is also the institution where this population is detained.

Three of the fifteen countries have information on the number of security measures in force: 796 cases in Argentina, 28 in Peru and 532 in Spain. The available information is limited as the category of 'security measures' or

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<sup>215</sup> In Argentina, its civil code says in article 482 'autoridades publicas'; In Indonesia this may be found under provincial anti-begging laws according to HRW report; in Australia there is an example VA MH Act 1986 section 10; In Kenya, Senegal and Ghana this provision can be found in the respective Mental Health Acts; in Jordan within article 7 of the Crimes Prevention Act; in Moldova within the Moldovan Criminal Procedure Code and in Qatar within the Criminal Procedural Standards.

<sup>216</sup> Article 482.

<sup>217</sup> Costa Rica, Argentina, Australia, France and Moldova.

<sup>218</sup> This number includes defendants with cases withdrawn by prosecution and other non-adjudicated finalizations.

<sup>219</sup> Information for the second trimester of 2016 "Informe población en condición de vulnerabilidad" available at <[http://www.mjp.go.cr/Documento/Catalogo\\_DOCU/66](http://www.mjp.go.cr/Documento/Catalogo_DOCU/66)> accessed 11 April 2019.

<sup>220</sup> Servicio Penitenciario Federal, Sintesis Diaria, available at <<http://www.spf.gob.ar/www/estadisticas-indicadores-mapa/catcms/91/Mapa-Indicadores>> accessed 11 April 2019.

‘diversion’ is not disaggregated by disability and may include other categories such as deceased defendants, minors diverted into juvenile justice systems or other forms of diversion unrelated to disability. It was not possible to identify which diversion measures include internment and which ones result in forced treatment under the threat of incarceration if the person does not comply. Diversion may also be in the form of diversion into a ‘mental health court’ that focuses on getting the person into treatment and usually there is some element of coercion involved, either by way of a guilty plea that allows state to require the person to serve a prison sentence if he or she does not comply with a prescribed treatment plan or other forms of incentives such as the threat of criminal charges, making the consent to treatment not free. This is the case in Australia where diversion may occur at different procedural moments depending on the state legislation: charge, prosecution, bail, plea, trial and sentence.<sup>221</sup>

All countries in this study except Qatar<sup>222</sup> include some form of reasonable accommodation measures in their justice system legislation for persons with disabilities as defendants.<sup>223</sup> The most common measures are sign language interpreters and physical access to the courtroom. This means that in fourteen countries consideration for some needs of persons with disabilities was given to some extent. However, this does not guarantee that the process inside the criminal justice is fair or that persons with disabilities are not diverted from the criminal justice system because of their disabilities. In addition, this does not address the accessibility needs of persons with cognitive or psychosocial disabilities.

In conclusion, all countries have exceptions to criminal legislation based on disabilities which often rely on medical assessments to trigger diversion. There is no common single stage where diversion is triggered. Fourteen countries have legislation on security measures and all, with the exception of Spain, have established a legal basis for police or social services to arrest based on risk to

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<sup>221</sup> Fiona Davidson, *Mental Health Liaison and Diversion. Court Liaison Services and Mental Health Court Programs in Australia* (2015) The Australian Centre for Research Excellence in Offender Health.

<sup>222</sup> The research team has not been able to identify accommodation measures in Qatar.

<sup>223</sup> The research team is aware that victims with disabilities are often entitled to more support measures but in this context the aim was to understand how a defendant with disabilities could access justice without discrimination.

self or others. Police and social services may also act as diversion agents and are in many cases entitled to initiate involuntary hospitalisation. Australia has information related to the number of persons declared unfit to plead and Costa Rica, Argentina, France and Moldova are the only countries with information on the number of persons declared not criminally responsible. Data on the number of institutions for persons declared unfit to plead or not criminally responsible was available in eleven countries, however in most cases the total number of institutions underestimates the real number of institutions. In addition, data on the number of available security measures was only available in Peru, Argentina and Spain. No other information related to this topic was found in other countries. The criminal justice system relies on medical criteria to determine whether a person is considered unfit to plead or criminally not responsible. The person will undergo medical examination to determine their ability to participate in a trial or whether the person can be deemed responsible.<sup>224</sup> The imposition of security measures often results in placements in psychiatric hospitals or in long-term institutions. While a criminal sentence is limited in time, a security measure may be justified as long as the risk to self or others is deemed to persist.<sup>225</sup>

Despite research findings that persons with disabilities or persons with psychosocial disabilities are not more dangerous than other populations,<sup>226</sup> most mental health legislation still includes “dangerousness” as a criterion for deprivation of liberty and forced psychiatric treatment. It is this idea of dangerousness that feeds into diversion from the criminal justice system, where different treatments are applied, without consent or as a condition of probation or in order to access other benefits.<sup>227</sup> The mental health system is expected to assume prisoners with psychosocial disabilities and persons with disabilities who have been diverted from the criminal justice system.<sup>228</sup> Clinicians may feel

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<sup>224</sup> Article 34 Argentinian Criminal Code; article 741 Ley Enjuiciamiento Criminal (Spain); article 44 (2) Indonesian Criminal Code; Samuel Adjorlolo et al, ‘Criminal Responsibility and the Insanity Defence in Ghana: The Examination of Legal Standards and Assessment Issues’ (2016) 23(5) *Psychiatry, Psychology and Law* 684.

<sup>225</sup> Special Rapporteur on the Prevention on Torture Report on Peru (2013), CAT/OP/PER/1, para103.

<sup>226</sup> Lawrence O Gostin, ‘Old’ and ‘new’ institutions for persons with mental illness: Treatment, punishment or preventive confinement?’ (2008) 122 *Journal of the Royal Institute of Public Health* 906.

<sup>227</sup> Claire Spivakovsky, ‘From punishment to protection: Containing and controlling the lives of people with disabilities in human rights’ (2014) 16(5) *Punishment & Society* 560.

<sup>228</sup> Harry Richard Lamb et al, ‘Understanding and Treating Offenders with Serious Mental Illness in Public Sector Mental Health’ (2017) 35(4) *Behavioural Sciences and the Law* 303.

unprepared or that the system does not have enough resources to offer appropriate support for persons with psychosocial disabilities coming from the criminal justice system.<sup>229</sup>

The subject of insanity, dangerousness and possible treatment also occupies part of the literature around diversion<sup>230</sup>, as well as the relationship between criminal justice and psychiatric hospitals and which placement is more adequate, prison or general mental health systems.<sup>231</sup> Some studies have reported the discriminatory nature of forensic facilities, where persons with disabilities are subject to stricter regimes, and have less access to recreational, educational and therapeutic services than those available in mainstream prisons, as well as fewer procedural guarantees.<sup>232</sup> Having an intellectual disability has been found as an independent variable to be on remand<sup>233</sup>, resulting in overrepresentation of persons with disabilities in remand in prison.

A paper exploring the experience of persons with intellectual disabilities in the criminal justice system in the UK revealed that support in the criminal justice system is inconsistent, and that professionals were perceived as “*uncaring, disrespectful and lacking disability awareness*”.<sup>234</sup> Participants in this study also expressed a preference to be diverted into a healthcare system, because of the “*safer environment, beneficial activities, skilled staff, and increased support provision.*” A research study exploring the experience of persons with intellectual disabilities within forensic community rehabilitation services, found five emerging

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<sup>229</sup> Ibid.

<sup>230</sup> Piers Gooding et al, ‘Unfitness to stand trial and the indefinite detention of persons with cognitive disabilities in Australia: human rights challenges and proposals for change’ (2017) 40(3) Melbourne University Law Review 816; Annete Opitz-Welke et al, ‘Inpatient treatment in the psychiatric department of a German prison hospital’ (2012) 35(3) International Journal of Law and Psychiatry 240.

<sup>231</sup> Victor Blüml et al, ‘Psychiatric Hospital Bed Numbers and Prison Population Sizes in 26 European Countries: A Critical Reconsideration of the Penrose Hypothesis’ (2015) 10(11) PLoS ONE e0142163.

<sup>232</sup> María Florencia Heggin, ‘Las medidas de seguridad en el Sistema penal argentino: su contradicción con principios fundamentales del Derecho penal y de la Convención sobre los Derechos de las Personas con Discapacidad’ (2017) in Documenta, *Inimputabilidad y medidas de seguridad a debate: Reflexiones en torno a los derechos de las personas con discapacidad*, Documenta Mexico.

<sup>233</sup> Afia Ali et al, ‘Prisoners with intellectual disabilities and detention status. Findings from a UK cross sectional study of prisons.’ (2016) 53-54 Research in Developmental Disabilities 189.

<sup>234</sup> Ruth Howard et al, ‘I’d trust them if they understood learning disabilities” support needs of people with learning disabilities in the Criminal Justice System’ (2015) 6(1) Journal of Intellectual Disabilities and Offending Behavior 4.

themes: “A taste of freedom; Having no control and the interconnected theme of Getting control back; Loneliness; and Feeling like a service user.”<sup>235</sup>

In summary, diversion from the criminal justice system into forensic facilities is a common practice all over the world, but so is the finding of prisoners with disabilities, whose disability was not taken into consideration during trial.<sup>236</sup> Persons with disabilities have been said to be disproportionately represented in the criminal justice system<sup>237</sup>, and if the person is not in the prison, deprivation of liberty may take the shape of a forensic institutions or care home. Scholars do not agree on whether the deinstitutionalization and closing of mental health hospitals has resulted an increase of persons with disabilities in the criminal justice system.<sup>238</sup> A study conducted in the UK found that “*prisoners with intellectual disabilities were more likely to have lived in institutions or taken into local authority care and more likely to live in temporary accommodation.*”<sup>239</sup> However, it is clear that the overcrowding of prisons, combined with the belief that prison is not adequate for persons with psychosocial disabilities has led to the promotion of diversion alternatives, including mental health courts and placement in forensic facilities.<sup>240</sup>

#### 4.7. Deprivation of liberty in the community and home confinement

In many contexts, despite the absence or limited use of institutions and involuntary hospitalisation, many people with disabilities remain deprived of liberty in their communities, including through home confinement. For the purpose of this research, in phase I, the research team sought quantitative data on the kinds of measures that might support persons with disabilities to live

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<sup>235</sup> Alana Davis et al, ‘I Am I there yet? The views of people with learning disability on forensic community rehabilitation’ (2015) 6(1) Journal of Intellectual Disabilities and Offending Behavior 148.

<sup>236</sup> Jonathan Beebee, ‘People with learning disabilities in the criminal justice system’ (2010) 24,38 Nursing Standard 35.

<sup>237</sup> Afia Ali et al, ‘Prisoners with intellectual disabilities and detention status. Findings from a UK cross sectional study of prisons’ (2016) 53-54 Research in Developmental Disabilities 189; Glynis Murphy et al, ‘Screening prisoners with intellectual disabilities in three English prisons’ (2015) 30(1) Journal of Applied Research in Intellectual Disabilities 198.

<sup>238</sup> Seth J. Prins, ‘Does Transinstitutionalization Explain the Overrepresentation of People with Serious Mental Illnesses in the Criminal Justice System?’ (2011) 47(6) Community Mental Health Journal 716; Harry Richard Lamb et al, ‘Understanding and Treating Offenders with Serious Mental Illness in Public Sector Mental Health’ (2017) 35 Behavioural Sciences and the Law 303.

<sup>239</sup> Afia Ali et al, ‘Prisoners with intellectual disabilities and detention status. Findings from a UK cross sectional study of prisons.’ (2016) 53-54 Research in Developmental Disabilities 189.

<sup>240</sup> Harry Richard Lamb et al, ‘Understanding and Treating Offenders with Serious Mental Illness in Public Sector Mental Health’ (2017) 35 Behavioural Sciences and the Law 303.

independently and be included in their communities and to avoid home confinement.

Independent living arrangements are supported in twelve of the fifteen countries included in the analysis. This support is mainly given by way of action plans or national policies on disability. All countries have legislation on social benefits for persons with disabilities, which in some cases might be used to facilitate independent living. Nevertheless, the provision of the benefits varies in each country. Information related to the number of persons with disabilities receiving social benefits was found in nine countries.<sup>241</sup> In the case of Argentina, more than 800,000 persons with disabilities receive disability pensions and in France more than 220,000 persons with disabilities obtain a benefit for their disability.<sup>242</sup>

Of the countries studied none had information exclusively related to the number of persons with disabilities benefiting from independent living programmes. In specific countries, it was possible to identify the existence of programmes promoting independent living or better living conditions for homeless people and persons who have been abandoned. Two examples are France<sup>243</sup> and Costa Rica,<sup>244</sup> whose programmes aim to provide housing arrangements to the vulnerable population living in the streets, including people with disabilities. Australia has information related to the number of persons benefiting from disability support services. In this country, 333,795 persons with disabilities received this type of support in 2014-2015.<sup>245</sup> Of those, 134,391 (42.35%) had intellectual/learning disabilities, 90,257 (28.4%) were living with a physical/diverse disability, 63,510 (20%) had a psychiatric disability and 29,465 (9.3%) had a sensorial disability. This information comprises a large number of

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<sup>241</sup> Costa Rica, Peru, Argentina, Indonesia, Australia, Kenya, France, Spain and Moldova.

<sup>242</sup> Prestation de compensation du handicap. Ministère des Solidarités et de la Santé (2016), available at: <<http://www.data.drees.sante.gouv.fr/ReportFolders/reportFolders.aspx>> accessed 11 April 2019.

<sup>243</sup> Housing First 'Un chez-soi d'abord', available at: <http://housingfirst.wp.tri.haus/assets/files/2016/04/un-chez-soi-dabord-EN.pdf> accessed 11 April 2019.

<sup>244</sup> Política Nacional para la atención integral a las personas en situación de abandono y personas en situación de calle. Ministerio de Desarrollo Humano e Inclusión.

<sup>245</sup> Australian Institute of Health and Welfare (2016), available at: <<https://www.aihw.gov.au/reports/disability-services/disability-support-services-services-provided-under-the-national-disability-agreement-2014-15/formats>> accessed 11 April 2019.

support services, including accommodation support, community support and community access.

Finally, only Spain, Jordan and Indonesia have information on reported cases of persons with disabilities abused at home. In Spain, 'Fundación A la Par, NGO', who specialise in survivors with disabilities who have experienced sexual and other types of violence, provided information on this topic. According to this source, they worked on 597 cases of abuse of persons with disabilities at home between 2010 and 2016.<sup>246</sup> The National Team for Family Protection against Violence in Jordan reported 214 cases of sexual abuse and 351 cases of physical abuse from 2012 to 2016.<sup>247</sup> Indonesia has acknowledged home-based deprivation of liberty within its state report<sup>248</sup> where it describes the practice of shackling. The National Basic Health Riskesdas Survey (2013) reports that 14% of households who have a member with a 'severe' mental health condition have used *pasung*,<sup>249</sup> with a higher rate in rural areas of 18%. Indonesia has attempted to address this issue through a program called 'Indonesia free from Shackling' and reports that in 2015, 7,961 cases of shackling were addressed. Human Rights Watch has considered this to be insufficient, as no follow-up measures are in place and often the person is subsequently shackled again.<sup>250</sup>

The literature review undertaken for this research found that community treatment orders have been criticised by several scholars for leading to deprivation of liberty in the community. Community treatment orders have been one of the responses to deinstitutionalization initiatives and exist in 75 jurisdictions worldwide.<sup>251</sup> Community treatment orders force treatment onto persons under the threat of hospitalization. The review conducted by Jorun Rugkåsa concluded that there is no evidence for the hypothesis that they have

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<sup>246</sup> Fundación A la Par, 'Dossier Unidad Atención a Víctimas con Discapacidad Intelectual' (October 2017).

<sup>247</sup> Joint submission of Shadow Report on the Status of Implementation of the Convention on the Rights of Persons with Disabilities in Jordan INT/CRPD/CSS/JOR/27000 (February 2017).

<sup>248</sup> CRPD Committee, Concluding Observations on Indonesia, CRPD/C/IDN/2?6963/E, para 51.

<sup>249</sup> '*Pasung*' is the practice of families detaining family members and shackling them in sheds or yards for a long period.

<sup>250</sup> Human Rights Watch, 'Living in Hell. Abuses against people with psychosocial disabilities in Indonesia' (2016).

<sup>251</sup> Jorun Rugkåsa, 'Effectiveness of Community Treatment Orders: The International Evidence' (2016) 61(1) Canadian Journal of Psychiatry. *Revue canadienne de psychiatrie* 15.

the desired results, whereas other academic publications support the use of community treatment order as a way of reducing involuntary hospitalization.<sup>252</sup>

Throughout the research, different settings for disability-specific deprivations of liberty emerged according to the predominant cultural, family and social model and the conception of disability applicable in each country's context. Even though residential settings operated by traditional faith healers are recognised as possible places of detention for persons with disabilities,<sup>253</sup> traditional faith healers are present in Senegal, Rwanda, Indonesia, Philippines and Ghana as an alternative to mainstream health services, including psychiatric services.<sup>254</sup> It is estimated that more than 700 prayer camps led by traditional and faith healers exist in Ghana.<sup>255</sup> In this country, the Mental Health Act 2012 includes the duty for psychiatrists and other mental health staff to collaborate with traditional healers, who must register with the state to be recognised.<sup>256</sup>

Disability-specific deprivation of liberty also occurs within the community or at home for persons with leprosy and albinism. In Senegal, Indonesia and Philippines, persons living with leprosy are subject to discrimination and segregation.<sup>257</sup> In Tanzania, persons with albinism are also subject to segregation. Several schools have been transformed into temporary shelters for persons with albinism, as this group has been subject to attacks and cases of body part trafficking have also been reported.<sup>258</sup> In this context, persons with

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<sup>252</sup> Steven P Segal et al, 'The Utility of Outpatient Commitment: I. A Need for Treatment and a Least Restrictive Alternative to Psychiatric Hospitalization' (2017) 68(12) *Psychiatric Services* 1247; John Monahan et al, 'Coercion and Commitment: Understanding Involuntary Mental Hospital Admission' (1995) 18(3) *International Journal of Law and Psychiatry*, 249.

<sup>253</sup> Human Rights Watch, 'Like a Death Sentence'. Abuses Against Persons with Mental Disabilities in Ghana' (2012); Human Rights Watch, 'Living in Hell. Abuses against People with Psychosocial Disabilities in Indonesia' (2016).

<sup>254</sup> Daniel Arias et al, 'Prayer Camps and Biomedical Care in Ghana: Is Collaboration in Mental Health Care Possible?', (2016) 11(9) *PLoS ONE* e0162305.

<sup>255</sup> Human Rights Watch, 'Like a Death Sentence'. Abuses Against Persons with Mental Disabilities in Ghana' (2012).

<sup>256</sup> Ghana: Traditional Medicine Practice Act, 2000.

<sup>257</sup> In Senegal 'Loi no 76-03 du 25 mars 1976 relative au traitement de la lèpre et au reclassement social des lépreux guéris et mutilés' calls for the segregation of persons with leprosy and creates special living settings for them. In Indonesia, a specific rule prohibits access to public spaces to persons 'who suffers any disease which causes a worry among the community', including persons with leprosy. Finally, in the case of Philippines, Culione has been established as an island for persons with leprosy. It still hosts hospices for persons with leprosy despite having been declared free of leprosy.

<sup>258</sup> Statement by the United Nations Independent Expert on the enjoyment of human rights by persons with albinism, Ms. Ikponwosa Ero, upon conclusion of her official visit to the United Republic of Tanzania on July 2017 available at <<http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=21915&LangID=E>> accessed 11 April 2019.

leprosy and albinism may be deprived of their liberty in special schools and segregated in their own communities.

#### 4.8. Deprivation of liberty and denial of legal capacity

Throughout this research, denial or restriction of legal capacity emerged as a transversal factor connected with disability-specific deprivation of liberty. The denial of legal capacity can be used as a trigger for institutionalization or involuntary hospitalization, and is deeply connected with diversion from the criminal justice systems into forensic services. Informal denials of legal capacity are also imposed through home confinement of persons with disabilities. Therefore, in phase I, the research team sought data on deprivation of legal capacity in the 15 countries included in this study, to better understand how this mechanism links with and is used to justify deprivation of liberty on the basis of disability.

Legislation in thirteen countries allows for restrictions of legal capacity, regulating it in different degrees.<sup>259</sup> Costa Rica enacted a law in 2016<sup>260</sup> with the aim of guaranteeing the autonomy of persons with disabilities. This law establishes a supported decision-making scheme and promotes independent living. The law has also included the appointment of a 'safeguard', which only affects persons with psychosocial or intellectual disabilities,<sup>261</sup> and there still is a regulatory gap (in the form of a *regulation*) on how persons with disabilities will be supported, and what the safeguards imply. The impact and development of this law remain to be seen. Peru has recently reformed its civil code and notary act to abolish substituted decision-making, recognising full legal capacity to persons with disabilities.<sup>262</sup> This initiative was started by civil society and provides for reasonable and procedural accommodation in courts and notary offices.

While laws limiting legal capacity mostly affect persons with cognitive or psychosocial disabilities, countries such as Qatar and Jordan include persons

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<sup>259</sup> As of 2018, Peru has recently enacted a new law that abolishes guardianship and substituted decision-making.

<sup>260</sup> Costa Rica Ley 9379.

<sup>261</sup> The guarantor of autonomy can only be appointed by a court and there is no provision for the person affected to refuse this appointment. The law provides for this guarantor for persons with intellectual, mental or psychosocial disabilities (see article 2 I).

<sup>262</sup> Legislative Decree No 1384.

with sensorial disabilities (blind, deaf, or 'mute' persons) as subjects of restriction of legal capacity. Similarly, the Philippines Rules of Court include persons with leprosy under the definition of legally 'incompetent'<sup>263</sup> persons. Thirteen of fifteen countries have expressly included review mechanisms for restrictions of legal capacity. Those were often only accessible if the individual's 'inability to decide' was no longer present, usually on the basis of a medical expert opinion<sup>264</sup> or a review of the person's capacity by a medical board.

The total number of persons under guardianship was found in six of the fifteen countries (Peru, Australia, Kenya, France, Spain and Moldova).<sup>265</sup> The number varies between countries, an aspect related to the available data and how the authorities register information on this topic. It is important to highlight that data from this indicator should not be compared between countries and, in some cases, the common practice of informal deprivation of legal capacity (e.g. Kenya<sup>266</sup>) may lead to underrepresentation of the magnitude of the problem. In the case of France, around of 700,000 persons with disabilities are under guardianship,<sup>267</sup> according to national reports.<sup>268</sup>

Finally, in four countries (Australia, Argentina, Senegal, France and Spain) public or private organisations may be appointed as guardians of persons with disabilities. In these countries, the total number of persons with disabilities under guardianship per public guardians has increased in the last five years.<sup>269</sup> This finding highlights the state's growing role in deprivation of legal capacity, which can often result in a deprivation of liberty.

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<sup>263</sup> Rules 92.2 of the Rules of Court.

<sup>264</sup> Eg Private law in Indonesia, Ghana, Senegal, Moldova, Spain.

<sup>265</sup> In the case of Costa Rica, information related to the number of persons under guardianship before the law 9379 2016 was enacted, was not found.

<sup>266</sup> MDAC, 'The right to Legal Capacity in Kenya' (March 2014). In addition, the National Human Rights Institute in Kenya produced a report on legal capacity revealing the widespread use of informal deprivation of legal capacity (The Kenya National Commission on Human Rights, 'A briefing paper on implementation of article 12 of the Convention on the Rights of Persons with Disabilities regarding legal capacity in Kenya' (2016)).

<sup>267</sup> This includes both legal figures '*tutelle*' and '*curatelle*'.

<sup>268</sup> This number includes individuals under *curatelle* and *tutelle* in the country in 2014.

<sup>269</sup> Office of the Public Guardian- Department of Justice (2016), 'The Public Guardian Annual Report 2015-2016' Tasmanian Government; Office of the Public Advocate, 'Decision making support and Queensland's guardianship system. A systemic advocacy report' (2016) Queensland Government; Public Guardian, 'Public Guardian Advocacy Report' (2016) Government of NWS; Asociación Española de Fundaciones Tutelares, 'Estudio sobre la situación de la tutela de las personas adultas con discapacidad intelectual en España. Servicios de apoyo al ejercicio de la capacidad jurídica' (2015).

Legal capacity is, to a certain extent, traceable, whereas other practices, such as coercing persons into consent, are harder to prove. Persons with disabilities may be coerced into giving consent by or are under pressure to comply with the institutions or persons placing them in the relevant facilities. In this sense, the distinction between voluntary and involuntary patient has been contested, challenging the assumption that many of the voluntary patients in psychiatric care willingly participate and are under no pressure to comply with treatment.<sup>270</sup> A study conducted in Sweden in 2004 found that coercion is not always legally based and that “*many of the patients reported they felt violated during the admission process.*”<sup>271</sup> The voluntariness of admission does not guarantee involvement in further decisions such as treatment or discharge.<sup>272</sup> Moreover, patients initially labelled as involuntary may then be re-categorized as voluntary<sup>273</sup>, making it difficult to analyze how many persons are *de facto* hospitalized against their will. Persons placed under guardianship are in many countries not counted as involuntary patients, as the admission to psychiatric hospital can be consented to by the guardian.<sup>274</sup>

In certain cases, being placed in an institution leads automatically to deprivation of legal capacity.<sup>275</sup> In others, restriction of legal capacity and the imposition of guardianship on a person are considered alternatives to undertaking involuntary admission procedures.<sup>276</sup> Both scenarios allow for the subsequent institutionalization of the person without her consent. In addition, restriction of legal capacity may be stipulated by law as a requirement to access social benefits

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<sup>270</sup> Christina Katsakou et al, ‘Why do some voluntary patients feel coerced into hospitalisation? A mixed-methods study’ (2011) 187 *Psychiatry Research* 275; Brian O’Donoghue et al, ‘Perceived coercion in voluntary hospital admission’ (2014) 215 *Psychiatry Research* 120; John Monahan et al, ‘Coercion and Commitment: Understanding Involuntary Mental Hospital Admission’ (1995) 18(3) *International Journal of Law and Psychiatry* 249.

<sup>271</sup> Lars Kjellin et al, ‘Coercion in psychiatric care: patients’and relatives’ experiences from four Swedish psychiatric services’ (2004) 58 *Nordic Journal of Psychiatry* 153.

<sup>272</sup> Christina Katsakou et al, ‘Why do some voluntary patients feel coerced into hospitalisation? A mixed-methods study’ (2011) 187 *Psychiatry Research* 275.

<sup>273</sup> Brian O’Donoghue et al, ‘Perceived coercion in voluntary hospital admission’ (2014) 215 *Psychiatry Research* 120.

<sup>274</sup> John Monahan J et al, ‘Coercion and Commitment: Understanding Involuntary Mental Hospital Admission’ (1995) 18(3) *International Journal of Law and Psychiatry* 249.

<sup>275</sup> Senegal: Article 345 of Family Code provides for guardianship for people who are admitted to psychiatric facilities.

<sup>276</sup> Spanish public prosecutor official instruction Circular 02/2017 recommends initiating guardianship procedures instead of involuntary admission procedures in cases where the requirements for involuntary admissions are not met.

for persons with disabilities,<sup>277</sup> which may lead to the imposition of guardianship. A person deprived of legal capacity has more difficulties challenging her placement or involuntary admission, as her capacity to be party to a court procedure may be questioned<sup>278</sup> or because no due process guarantees are in place.

#### 4.9. Children

While this study in general focuses on adults with disabilities, it is important to acknowledge some specific concerns of children with disabilities in the context of deprivation of liberty. Children with disabilities are widely acknowledged to be overrepresented in the care protection and care system.<sup>279</sup> Residential care for children has increased substantially across the globe.<sup>280</sup> There is an estimate of 2 million children living in institutions, but this number is highly question due to underreporting.<sup>281</sup>

Very often, children are placed in institutions, especially if the child is older or has “*behavioral problems*”, where social services may prefer more “*restrictive environments*”.<sup>282</sup> In some instances, this has become routine practice.<sup>283</sup> In USA, the statistics in 2011 showed that 15% of the 408,425 children in out-of-home care were in institutions (6% in group homes – with a maximum of 6 children - and 9% in residential care).<sup>284</sup> While the number of children in out of home care in the USA has dropped according to the National Statistics Office, “*states continue to be less successful in finding permanent homes for children*

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<sup>277</sup> This has recently been contested in a court case in Peru through the decision Exp. N° 01305-2012-0-1001-JR-FC-03.

<sup>278</sup> CRPD/C/GC/1, paras. 31 and 38.

<sup>279</sup> Bernadette Kelly et al, ‘Disabled Children and Young People who are Looked After: A Literature Review’ (2012) Queen's University Belfast; Steven A Rosenberg et al, ‘Out-of-home placement for young children with developmental and medical conditions’ (2004) 26 Children and Youth Services Review 711.

<sup>280</sup> See Cambodian Children’s Trust Factsheet available at: <<https://cambodianchildrenstrust.org/wp-content/uploads/2017/10/Countries-Residential-Care.pdf>> accessed 11 April 2019.

<sup>281</sup> UNICEF’s press release available at: <[https://www.unicef.org/media/media\\_96099.html](https://www.unicef.org/media/media_96099.html)> accessed 10 September 2018.

<sup>282</sup> Harmke Leloux-Opmeer et al, ‘Children referred to foster care, family-style group care, and residential care: (How) do they differ?’ (2017) 77 Children and Youth Services Review 1.

<sup>283</sup> See US case Brian A. v. Sundquist in Lily T Alpert et al, ‘Moving away from congregate care: One state’s path to reform and lessons for the field’ (2012) 34(8) Children and Youth Services Review 1519.

<sup>284</sup> Lily T Alpert et al, ‘Moving away from congregate care: One state’s path to reform and lessons for the field’ (2012) 34(8) Children and Youth Services Review 1519.

*with disabilities and for children who entered foster care when they were older than age 12, as compared to the general foster care population.”<sup>285</sup>*

Statistics from Northern Ireland found that “14% of the children and young people in public care in Northern Ireland are disabled”,<sup>286</sup> while a UK study found that 34% of the children who had spent more than four years in out of home care were disabled.<sup>287</sup> While family care is undisputedly preferred, exceptions based on the child’s additional support needs are widely accepted.<sup>288</sup> Another study found that children with disabilities were “approximately 1.5 times more likely to have “no plan identified” as their primary placement plan, than to have reunification or relative care identified as their primary plan.”<sup>289</sup>

Group care is considered “*inevitably necessary to treat children with serious physical, behavioral, and mental health issues who cannot be served appropriately in a family setting.*”<sup>290</sup> Services may believe it will be more difficult to place a child with a disability, that the child will not receive appropriate support nor access to a good education.<sup>291</sup> In Latvia, the municipalities prefer placing children with disabilities in institutions to avoid assuming the costs of allocating additional support, as institutions are covered by other authorities.<sup>292</sup> Other research studies focused on comparing foster or family care to care within institutions conclude that “*group home placement does not universally adversely affect a child wellbeing.*”<sup>293</sup>

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<sup>285</sup> USA. Children’s Bureau (ACYF, ACF) of the U.S. Department of Health and Human Services. Child Welfare Outcomes 2015. Report to Congress. Available at: <https://www.acf.hhs.gov/sites/default/files/cb/cwo2015.pdf#page=7> accessed 11 April 2019.

<sup>286</sup> Bernadette Kelly et al, ‘Disabled Children and Young People who are Looked After: A Literature Review’ (2012) Belfast: Queen’s University Belfast.

<sup>287</sup> Schofield et al. (2007) quoted Bernadette Kelly et al, ‘Disabled Children and Young People who are Looked After: A Literature Review’ (2012) Belfast: Queen’s University Belfast.

<sup>288</sup> UN General Assembly, Guidelines for the Alternative Care of Children (2010), A/RES/64/142.

<sup>289</sup> Katherine Hill, ‘Permanency and placement planning for older youth with disabilities in out-of-home placement’ (2012) 34 Children and Youth Services Review 1418.

<sup>290</sup> Lily T Alpert et al, ‘Moving away from congregate care: One state’s path to reform and lessons for the field’ (2012) 34(8) Children and Youth Services Review 1519.

<sup>291</sup> Lily T Alpert et al, ‘Moving away from congregate care: One state’s path to reform and lessons for the field’ (2012) 34(8) Children and Youth Services Review 1519; Bernadette Kelly et al, Disabled Children and Young People who are Looked After: A Literature Review (2012) Belfast: Queen’s University Belfast.

<sup>292</sup> Eurochild Secretariat. Children in alternative care. January 2010 – 2nd Edition.

<sup>293</sup> Kathryn Whetten et al, ‘Three-Year Change in the Wellbeing of Orphaned and Separated Children in Institutional and Family-Based Care Settings in Five Low- and Middle-Income Countries’ (2014) 9(8) PLoS ONE e104872.

A study analyzing permanency and placement planning for older youth with disabilities, concluded that “*older youth with disabilities were more likely to experience longer time in out-of-home placement, and higher rates of placement instability than their peers without disabilities. Additionally, analysis found that only 60% of the youth in the sample had a concurrent plan on file, and that youth with disabilities have different placement plans than their peers without disabilities.*”<sup>294</sup>

The causes of child out-of-home care identified in research commonly include family stress, material problems, the ability of families to meet their child’s needs (e.g. poor parental skills), a parental illness (including mental health), housing problems or a distressing event (e.g. sudden death, unemployment).<sup>295</sup> A literature review on out-of-home care revealed that children with disabilities were less likely to return home, to be reunified with their biological family or with extended family.<sup>296</sup>

A study on children with autism in out-of-home care found that “*the estimated median length of stay for children with ASD is 1.6 times longer than the length of stay of children without ASD (1,506 days as compared to 924 days).*”<sup>297</sup> Children with intellectual disability were also found to have the longest permanency in out-of-home care compared to all disabilities.<sup>298</sup> Further, children with disabilities are more likely to be placed in residential care instead of foster care.<sup>299</sup> The research on children in out-of-home care seems to have focused on the child’s characteristics in determining the outcome of the placement (breakdown, etc.) instead of on the environment where this occurs. A literature review by V. Welch

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<sup>294</sup> Katherine Hill, ‘Permanency and placement planning for older youth with disabilities in out-of-home placement’ (2012) 34 Children and Youth Services Review 1418.

<sup>295</sup> Bernadette Kelly et al, ‘Disabled Children and Young People who are Looked After: A Literature Review’ (2012) Belfast: Queen’s University Belfast; Harmke Leloux-Opmeer et al, ‘Children referred to foster care, family-style group care, and residential care: (How) do they differ?’ (2017) 77 Children and Youth Services Review 1.

<sup>296</sup> Vicki Welch et al, ‘Permanence for disabled children and young people through foster care and adoption: A selective review of international literature’ (2015) 53 Children and Youth Services Review 137.

<sup>297</sup> Lucy A Bilaver et al, ‘Foster Children with Autism Spectrum Disorder: Prevalence, Length of Stay, and Placement Patterns’ (2013) 7(5) Journal of Public Child Welfare 496.

<sup>298</sup> Katherine Hill, ‘Permanency and placement planning for older youth with disabilities in out-of-home placement’ (2012) 34 Children and Youth Services Review 1418.

<sup>299</sup> Lily T Alpert et al, ‘Moving away from congregate care: One state’s path to reform and lessons for the field’ (2012) 34(8) Children and Youth Services Review 1519.

et al. found that children with disabilities are underrepresented in research studies including the child's views on permanence and barriers.<sup>300</sup>

In some countries, e.g. Bulgaria, children with disabilities have been specifically excluded from deinstitutionalization efforts which have been instigated for adults with disabilities.<sup>301</sup> Another phenomenon specific to children with disabilities is the recommendation of psychiatric residences or disability institutions as a better option for their development to parents or to give up the custody over the child to access (treatment) services.<sup>302</sup> Several reports acknowledge that children are often denied the opportunity to be heard before their placement in these kinds of institutions.<sup>303</sup>

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<sup>300</sup> Quotes from Vicki Welch et al (2015): Pamela Clark et al, 'Integrating the older/special needs adoptive child into the family' (2006) 32(2) *Journal of Marital and Family Therapy* 181; Elizabeth Lightfoot et al, 'Prevalence of children with disabilities in the child welfare system and out of home placement: An examination of administrative records' (2011) 33(11) *Children and Youth Services Review* 2069; John G Orme et al, 'Measuring willingness to foster children with disabilities and special medical conditions' (2013a) 37(3) *Social Work Research* 169; John G Orme et al, 'Who is willing to foster children with disabilities?' (2013b) 7(5) *Journal of Public Child Welfare* 566; Ada Schmidt-Tieszien et al, 'Children who wait: Long term foster care or adoption?' (1998) 20(1-2) *Children and Youth Services Review* 13.

<sup>301</sup> 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*.

<sup>302</sup> Barbara J Friesen et al, 'Research in the service of policy change: The "custody problem"' (2003) 11(1) *Journal of Emotional and Behavioral Disorders* 39; Eileen Prescott, 'Russia's Disabled "Orphans": Suggestions for Institutional Change' (2017) 58 *International Immersion Program Papers*; Katherine Hill, 'Prevalence, experiences, and characteristics of children and youth who enter foster care through voluntary placement agreements' (2017) 74 *Children and Youth Services Review* 62.

<sup>303</sup> Bernard Perlmutter et al, 'Please Let Me Be Heard: The Right of a Florida Foster Child to Due Process Prior to Being Committed to a Long-Term, Locked Psychiatric Institution' (2001) 25(7) *Nova Law Review* 725.

## **5. Main findings from phase II: stakeholders' views**

The results of the questionnaire and the analysis of documents from phase I of this research, along with the literature review reveal that deprivation of liberty based on disability is a common phenomenon. Factors related to levels of economic and human development appear not to affect the existence of processes facilitating deprivation of liberty for persons with disabilities. Indeed, the analysis of documents shows that in all fifteen countries included in this study persons with disabilities are subjected to multiple forms of deprivation of liberty, such as restriction of legal capacity, being involuntarily hospitalised and being subjected to long term institutionalisation.

Disability-specific deprivation of liberty occurs in different areas and cannot be pinned down to a single rule or setting. As seen above, the applicable legal and policy frameworks of the five explored areas interact at various levels, which allows for the existence of multifarious means of depriving persons with disabilities of their liberty. There is a contradiction between the understanding of the right of liberty and the accepted exceptions based on disabilities which exist, as well as antidiscrimination law which is often not understood as applicable to persons with disabilities in all spheres, including liberty. Allowing for disability-specific forms of deprivation of liberty is discriminatory, harmful and reduces the person's possibilities to engage meaningfully in society and develop themselves fully. Despite the importance of the right in question, there is an acute lack of data which hinders any in-depth analysis and assessment of the situations of uncountable persons with disabilities across the globe.

The review of the literature around the underlying causes of these practices revealed that deprivation of liberty seems to be most clearly recognized in the psychiatric context. Much of the literature describes the necessity to deprive a person of liberty based on dangerousness, risk to self or to others, profiling

patients<sup>304</sup> or predicting involuntary hospitalization.<sup>305</sup> Other research papers argue about the nature or effectiveness of deprivation of liberty, the challenges to measure involuntary commitment and coercion<sup>306</sup> and describe how psychiatric hospitalization is experienced.<sup>307</sup> Procedural rules are also widely discussed<sup>308</sup> as well as the alignment of national legislation and policies to the CRPD or WHO standards.<sup>309</sup> Given the scarcity of data as revealed by phase I of this research, and the focus in the global literature review on conditions of detention, rather than underlying causes and possible solutions, the following

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<sup>304</sup> Paul F Tremblay et al, 'Clinical and Demographic Characteristics of Voluntary and Involuntary Psychiatric inpatients' (1994) 39(5) *The Canadian Journal of Psychiatry* 297; Tonje Lossius Husum et al, 'A cross-sectional prospective study of seclusion, restraint and involuntary medication in acute psychiatric wards: patient, staff and ward characteristics' (2010) 10:89 *BMC Health Services Research*; Tomasz Pawlowski et al, 'How patients' characteristics influence the use of coercive measures' (2017) 59 *Indian Journal of Psychiatry* 429; Thomas Kallert et al, 'Involuntary vs. voluntary hospital admission. A systematic literature review on outcome diversity' (2008) 258 *European Archives of Psychiatry and Clinical Neuroscience* 195; Genevieve Santillanes et al, 'Involuntary Psychiatric Holds in Preadolescent Children' (2017) 18(6) *Western Journal of Emergency Medicine* 1159.

<sup>305</sup> Ivana Stašević Karličić et al, 'Predictors of involuntary hospitalisation of patients suffering from schizophrenia.' (2017) 8(2) *Open Journal of Psychiatry & Allied Sciences* 124; Shmuel Fennig et al, 'Involuntary first admission of patients with schizophrenia as a predictor of future admissions' (1999) 50 *Psychiatric Services* 1049; Povl Munk-Jørgensen et al, 'Hospitalization patterns in schizophrenia. A 13-year follow-up' (1991) 4 *Schizophrenia Research* 1.

<sup>306</sup> Hermann-Alexander Jungfer et al, 'Reduction of seclusion on a hospital-wide level: Successful implementation of a less restrictive policy' (2014) 54 *Journal of Psychiatric Research* 94; Kjetil Hustoft et al, 'Voluntary or involuntary acute psychiatric hospitalization in Norway: A 24 h follow up study' (2018) 56 *International Journal of Law and Psychiatry* 27; Lars Kjellin et al, 'Differences in perceived coercion at admission to psychiatric hospitals in the Nordic countries' (2006) 41(3) *Social Psychiatry and Psychiatric Epidemiology* 241; Jane Gilhooley et al, 'Voluntary and involuntary psychiatric admissions in a suburban area: Comparison with national rates, diagnosis and other correlates of involuntary admission status' (2017) 34(4) *Irish Journal of Psychological Medicine* 243; Klaus Seigel, 'Perception of coercion: a pilot study using the Swedish version of the Admission Experience Scale' (1997) 51(1) *Nordic Journal of Psychiatry* 49; Jason Craw et al, 'Characteristics associated with involuntary versus voluntary legal status at admission and discharge among psychiatric inpatients' (2006) 41 *Social Psychiatry and Psychiatric Epidemiology* 981.

<sup>307</sup> Carlos de las Cuevas et al, 'Psychiatric patients' preferences and experiences in clinical decision-making: Examining concordance and correlates of patients' preferences' (2014) 96 *Patient Education and Counseling* 222; Lauri Kuosmanen et al, 'Deprivation of liberty in psychiatric hospital care: the patient's perspective' (2007) 14(5) *Nursing Ethics* 597; Diana Rose et al, 'Service user perspectives on coercion and restraint in mental health' (2017) 14(3) *BJPsych International* 59; Lars Kjellin et al, 'Coercion in psychiatric care: patients'and relatives' experiences from four Swedish psychiatric services' (2004) 58 *Nordic Journal of Psychiatry* 153.

<sup>308</sup> Rigmor R Diseth et al, 'Potential legal protection problems in the use of compulsory commitment in mental health care in Norway' (2011) 34 *International Journal of Law and Psychiatr.* 393; Fundamental Rights Agency, 'Involuntary placement and involuntary treatment of persons with mental health problems' (2012); Simei Zhang et al, 'Involuntary admission and treatment of patients with mental disorder' (2015) 31(1) *Neuroscience Bulletin* 99; Maritta Välimäki et al, 'Deprivation of liberty in psychiatric treatment: a Finnish perspective' (2001) 8(6) *Nursing Ethics* 522-532; Marisha N. Wickremsinhe, 'Emergency involuntary treatment law for people with mental disorders: A comparative analysis of legislation in LMICs.' (2018) 56 *International Journal of Law and Psychiatry* 1.

<sup>309</sup> Peter Bartlett, 'The United Nations Convention on the Rights of Persons with Disabilities and the future of mental health law' (2012) 75(5) *The Modern Law Review* 752; George Szmukler et al, 'Mental Health Law and the UN Convention on the Rights of Persons with Disabilities' (2014) 37(3) *International Journal of Law and Psychiatry* 245; Juan Antonio Donoso et al, 'Internación psiquiátrica involuntaria. Antecedentes, reflexiones y desafíos' (2018) 146 *Revista Med Chile* 511; Francisca Figueroa San Martín, 'Internamientos involuntarios y tratamientos forzados en psiquiatría: Autonomía y no discriminación como estándar de derechos humanos' (2017) 13 *Anuario de Derechos Humanos* 111; Brendan Kelly, 'Mental health legislation and human rights in England, Wales and the Republic of Ireland' (2011) 34 *International Journal of Law and Psychiatry* 439.

section will now turn to discuss in detail the findings of phase II of this study, in which qualitative research was undertaken with persons with disabilities, family members, health and social care professionals and policy-makers in five specific countries, to get a better sense of the triggers of deprivation of liberty at the grassroots level, and possible alternatives and good practices which might emerge.

### 5.1. Overall findings

The data collected in this research gives rise to three overarching and interconnected findings. First, the analysis of the data collected in both phases of this research showed that the participants identify the same causes of deprivation of liberty across different settings in all the relevant countries. For example, a perceived need for care and treatment, was identified by many participants as the cause of deprivation of liberty, regardless of the country, and regardless of the location (hospital, institution, prayer camp) in which the deprivation of liberty occurred. Secondly, the research showed that many persons with disabilities experienced more than one type of deprivation of liberty, e.g. forensic confinement and psychiatric hospitalization, or psychiatric hospitalization and institutionalization/home confinement. Finally, many persons with disabilities experience deprivation more than once and in more than one kind of setting, so persons who have been involuntarily hospitalized once are more likely to be readmitted as an involuntary patient again, and also more likely to experience other forms of deprivation of liberty, e.g. in social care institutions. Many participants had visited different hospitals or hospitals and prayer camps, in a constant search for a “definitive” cure or searching for appropriate care or support.<sup>310</sup>

*“There are some whom we have already seen them over and over. Like recidivist, who have been committing crime (laughs) so the moment they see them, then they say, you, the last time I gave you 2 weeks so now, go for six months....”<sup>311</sup>*

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<sup>310</sup> GH\_G6\_P5, JO\_G5\_P9, ID\_G6\_P11.

<sup>311</sup> GH\_G4\_P16.

The underlying causes or triggers of deprivation of liberty, and the perspectives of different stakeholders (health and social care professionals, policy makers, persons with disabilities and family members) are discussed in detail below. However, prior to entering this discussion it is worth noting some common concerns about the concept of deprivation of liberty in the context of disability which emerged from this research.

The notion that a setting which a person with disability cannot leave is a place of deprivation of liberty was generally rejected by professionals, directors of healthcare services and some family members who participated in phase II of this research project. These settings were understood as places where care is provided and which save persons from homelessness, risking their lives or ending up in prison. Psychiatric hospitalization was more likely to be recognized by participants in this research as a form of deprivation of liberty, but was often justified by participants on the basis of the persons “lack of capacity or insight” and was therefore not recognized as unlawful or arbitrary deprivation of liberty resulting in a violation of human rights.

Individuals and families reported being coerced into placing themselves or the individual in settings where they were deprived of liberty, by their neighbors, professionals or relatives. Consent is thus often given under the threat of involuntary admission. Some of the participants (family members and persons with disabilities) experienced being tricked into admission or being taken there while asleep. Persons and families expressed a lack of information regarding the procedures, length of stay, treatment and release procedure. Lastly, this research found that while socio-economic factors may aggravate factors that trigger deprivation of liberty; poverty itself does not trigger deprivation of liberty. Interestingly, the research also revealed that financial resources do not protect against deprivation of liberty in specific settings such as involuntary admission to psychiatric hospitals.

In general terms, policy makers, directors and healthcare professionals interviewed for this research spoke about the law and its requirements, while families and persons with lived experience focused instead on lack of resources,

of information and stigma. Healthcare professionals and NGOs also spoke about the central role of families. Guilt, shame and in some cases assumption of responsibility related to deprivation of liberty was clearly in the discourse of family members and persons with disabilities interviewed for this research.

While this research did not focus on the conditions of detention, this issue came up in most of the interviews, especially in the interviews with persons with disabilities and family members. Persons with disabilities were mainly concerned by the treatment experience and its impact on their lives, such as isolation and lack of opportunities, e.g. to find a job or have social relationships (e.g. marriage) and sexual development. Where individuals did not have strong natural support networks, such as among their families and friends, and where societies did not provide any kind of social safety net in the form of income support, social housing or other welfare provisions, then persons with disabilities were more likely to end up deprived of liberty in one or more settings.

The emerging themes from the interviews include: lack of support, perceived need for treatment, care and protection linked to a perceived lack of capacity, a culture of locking away, lack of individual or family support, stigma and a narrow mindset. The following sections elaborate on the different causes and themes separately, but they must be understood as inter-connected and interdependent.

## **5.2. Stakeholders' perspectives on the causes of deprivation of liberty**

This section covers the second phase of the research, in which different stakeholders were questioned on deprivation of liberty of persons with disabilities. It covers the findings in these interviews and is followed by an analysis by the research team. The situations described by the research as deprivation of liberty were not perceived as such by many prospective and actual participants. These views are incompatible with the human rights standards, and are not shared by the research team. It is important to bear in mind that the right to liberty is a civil and political right of immediate application, that cannot be subject to progressive realization.<sup>312</sup> The right to live in the community in article 19 of the Convention on

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<sup>312</sup> CRPD/C/12/2, Annex IV.

the Rights of Persons with Disabilities also contains elements of immediate application.<sup>313</sup> Nonetheless, the research team identified a gap between the stakeholders' views and human rights standards, which will be tackled at the end of this section.

The research found three different narratives which were analyzed as part of the underlying causes or triggers of deprivation of liberty on individual instances: a specific moment, crisis or breakdown, a search for support or help without there necessarily being a critical situation, and a continued experience of exclusion and isolation that results in deprivation of liberty within one of the settings described above.

For some participants, a specific personal or family crisis was identified as a trigger that eventually led to deprivation of liberty on the basis of disability. These events could be related to emotional or behavioral issues, family or relationship breakdown, loss of employment or accommodation, or allegation of criminal activity. As a result of this crisis the individual and/or family's inability to cope intensified, and ultimately this resulted in a deprivation of liberty. A few participants mentioned traumatic events in their childhood, including sexual abuse, as something that had followed them to this day, making it difficult to cope with certain situations.<sup>314</sup> Many participants recalled stressful situations at university or their workplace, which at some point they did not know how to handle.<sup>315</sup>

Many of the participants with disabilities identified external factors (e.g. loss of employment or breakdown in family relationships) as the source of a crisis they experienced which resulted in the deprivation of liberty. However, healthcare professionals interviewed for this research were more likely to locate the cause of the crisis within the person, for example, failure to comply with medication; or the emergence of violent behavior, as a trigger for deprivation of liberty.<sup>316</sup> The use of non-compliance with medication as a basis for deprivation of liberty was

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<sup>313</sup> CRPD/C/GC/5.

<sup>314</sup> JO\_G6\_18.

<sup>315</sup> GH\_G6\_P3, JO\_G6\_20, ID\_G6\_P10.

<sup>316</sup> FR\_G4\_P8.

confirmed by participants who had experienced involuntary hospitalization in the psychiatric system.

*“I didn’t want to go see the psychiatrist any more. But they caught up with me. I refused to take medication and see the doctor because I didn’t feel ill at that time...”<sup>317</sup>*

Violent behavior was also considered a trigger by family members, NGOs, policy makers, healthcare workers and directors in all five countries and one person with psychosocial disabilities. In one of the countries, family members spoke about fearing for their lives.<sup>318</sup>

*“Families accept for their children to be placed in a forensic ward because of the violence. Usually their children are adults with a psychiatric history whose violence they do not know how to control.”<sup>319</sup>*

*“The factor that triggers (involuntary) hospitalisations is violent behaviour: kicking, slapping or hitting someone... but it stops there at a low level of aggressiveness. Often this is a reaction because we didn’t know how to reassure them (autistic persons) at a certain point in time. So, we scream at them, we generate anxiety because we didn’t know how to do things differently. Then they are aggressive as a response. And that is what triggers involuntary hospitalisation...”<sup>320</sup>*

By contrast, in other cases, the trigger was when the individual or family asked for support or care from the state or private bodies and involuntary hospitalization or institutionalization was all that was offered.

*“We were told there is no other option”.<sup>321</sup>*

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<sup>317</sup> FR\_G6\_P15.

<sup>318</sup> PE\_G5\_P9, PE\_G5\_P10.

<sup>319</sup>FR\_G3\_P6.

<sup>320</sup> FR\_G5\_P12.

<sup>321</sup> FR\_G5\_P10.

*“I took him to a medical appointment and the doctor proceeded to an involuntary admission”<sup>322</sup>*

Family members interviewed for this research also reported that the lack of sufficient information in a crisis situation also led them to give up and have their family member hospitalized involuntarily. In certain cases, the family was not informed of the procedure or even wrongly informed or “manipulated” by professionals in the health, social and judicial sectors.

*“[The doctor] tricked us too, we thought it was simply an appointment...”<sup>323</sup>*

These findings are supported in the literature on deprivation of liberty which was reviewed for this research. One study found that “the families felt that they would not be able to care for their child in the long term, primarily because they perceived that the community-based service system could not meet their needs.”<sup>324</sup> A separate study on voluntary placement of children with disabilities in out-of-home care found that “when the demands of care exceed the capacity of parents to cope and service responses fail to adequately relieve these stresses, some families may decide to relinquish the care of their child to statutory child protection services (child services or child welfare services).”<sup>325</sup>

The second narrative uncovered by this research was that deprivation of liberty occurred where individuals or their families asked for support – and all that was offered was an institutional placement or involuntary hospitalization. Individuals and families interviewed for this research also reported that services that admit or support persons with disabilities beyond an institution or a hospital are scarce or non-existent in their communities.

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<sup>322</sup> FR\_G5\_P10.

<sup>323</sup> FR\_G5\_P10.

<sup>324</sup> Brigit Mirfin-Veitch et al, “It was the hardest and most painful decision of my life!”: seeking permanent out-of-home placement for sons and daughters with intellectual disabilities’ (2003) 28(2) Journal of Intellectual & Developmental Disability 99.

<sup>325</sup> Kathleen Ellem et al, ‘When Families Relinquish Care of a Child with a Disability: Perceptions from Birthmothers’ (2016) 69(1) Australian Social Work 39.

*“No, there is none of that [referring to assistance to leave psychiatric care] – that’s the problem. One keeps on seeing the doctor.”<sup>326</sup>*

The services provided by the state and very often, private initiatives are not usually provided in ways that would fully respect the individual’s human rights or ensure that the person had a good life in their community. One family member expressed concern at the knowledge that placing a relative in an institution would lead to human rights violations:

*“...there is nothing more difficult to leave the person that you love the most under the care of people that you do not know if they are going to respect his most basic human rights.”<sup>327</sup>*

Moreover, in interviews conducted for this research, the choice of institutions was found to be forced upon persons with disabilities and families are often portrayed by health and social care professionals as the last resort before institutionalization.<sup>328</sup>

In many cases, when health and social care professionals interviewed for this research were approached by individuals or families seeking support, their response was to recommend or initiate hospitalization.

Some families were also told that deprivation of liberty was the only option to ensure the person with disabilities would get access to the support or treatment they needed:

*“They do it because it’s a matter of access to treatment once again, primarily access to treatment. The distance is too great, cost issues.”<sup>329</sup>*

Critical situations such as economic burden, the need to work or the lack of accessible transport was often cited to explain institutionalization.

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<sup>326</sup> FR\_G6\_P15.

<sup>327</sup> PE\_G5\_P9.

<sup>328</sup> FR\_G4\_P9.

<sup>329</sup> ID\_G1\_P1.

*“They have a one room where the grandmother is living in, the mother is there, the grandchildren are there, all living in one room, and you become a psychotic and living together. It is impossible. So, the best way is to get you out, so they push the patients unto admission ward.”<sup>330</sup>*

Nonetheless, the socio-economic position of the family did not guarantee not being deprived of liberty. Families with more economic resources in Jordan, for instance, managed to access a private hospital with better conditions, but the situation of deprivation of liberty occurs nonetheless. Lack of economic resources was a driver when opting for faith based healing centers, together with the expectation of total healing or lack of information, as psychiatric care is expensive in countries like Ghana, Jordan and Indonesia. In Ghana, a deposit is requested from hospitals before treating the person<sup>331</sup>, which was problematic for some of the participants, due to the high prices, which led to exploring other options or deferring consulting doctors.

Refusal of enrollment by schools, including special education schools, and the parents' need to work was cited as the cause to confine the person at home by one of the participants in Ghana. In this research, two participants expressed regretting not having taken their child to school or insisting on their right to be admitted.<sup>332</sup> In one case, the mother was too exhausted to argue with the school while in the second case, the father did not believe his son could learn anything.

*“Yes. I thought being there means he will be trained to change because people have been there, and they are better now. I was called one day and told that the boy is causing problems in the school. He defecated in the school's kitchen. The school authorities told me that if that is how my son behaves then it won't be possible. I was tired, so I said okay, thank you.”<sup>333</sup>*

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<sup>330</sup> GH\_G4\_P16.

<sup>331</sup> GH\_G5\_P21.

<sup>332</sup> GH\_G5\_P19, GH\_G5\_P21.

<sup>333</sup> GH\_G5\_P11.

Furthermore, this research found that many family members were subsequently unable to visit the person in the institution due to a wide range of factors, including the internal rules of the institution, a lack of public transport, and inability to take time off from their jobs to visit the person. A policy maker in France described this as part of the institutional culture, where “the staff knows best” and described how family relations may be cut off for therapeutic reasons.<sup>334</sup>

These findings are also reflected in literature review, which found that in many cases persons are deprived of liberty in order to guarantee their access to certain services.<sup>335</sup> Services may feel they are the only option, believing that the persons will not get help anywhere else but there or that the person needs to be detained in order to access a bed in a particular facility.<sup>336</sup> The literature review conducted for this research also found that uncertainty about the availability of good community services to continue living at home if the individual’s support needs increased or the inability to afford a support worker often led to an admission into residential care.<sup>337</sup>

The third narrative concerning deprivation of liberty uncovered by this research was that in some situations there was no specific moment which triggered the deprivation of liberty, but the deprivation rather occurred as a result of the long-term and cumulative impact of exclusion from participation in society, including through denial of access to education, employment, housing, transport and other public services.

*“[t]hey are isolated perhaps even abandoned. There are also many persons with autism who are homeless or in prison. (...)”<sup>338</sup>*

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<sup>334</sup> FR\_G0\_P1.

<sup>335</sup> Taylor (Steven J Taylor, ‘Caught in the Continuum: A Critical Analysis of the Principle of the Least Restrictive Environment’ (2004) 29(4) *Research and Practice for Persons with Severe Disabilities* 218) argued, the construct of a continuum has four major flaws: (1) The construct of a continuum conflates segregation with services, implying that **one must be in a segregated environment to obtain the most intensive services** (2) The continuum sanctions infringement of basic human rights (3) The continuum is based on a readiness model and (4) The continuum directs attention to physical settings rather than service and supports.

<sup>336</sup> Care Quality Commission, ‘Mental Health Act. The rise in the use of the MHA to detain people in England’ (January 2018).

<sup>337</sup> Caroline Ellison et al, ‘Avoiding institutional outcomes for older adults living with disability: The use of community-based aged care supports’ (2011) 36(3) *Journal of Intellectual and Developmental Disability* 175.

<sup>338</sup> FR\_G3\_P6.

Involuntary hospitalization and institutionalization were also related to homelessness and abandonment. Some of the NGOs, healthcare professionals, family members and persons with lived experience also spoke about “dumping a person” or “abandoning them” at institutions or hospitals. Further, many highlighted that in occasions, persons were abandoned in institutions or never picked up from psychiatric hospitals.<sup>339</sup>

*“The person cannot go home he might not be able to go straight home because the family can’t be contacted or the family refuses or the family is not ready.”<sup>340</sup>*

This isolation, segregation and exclusion applied not just to the person with disability but to their families, who often lacked information on options and alternatives, and would therefore be more likely to accept advice of professionals to institutionalize the family member.

*“Looking back [to the involuntary psychiatric admission], we realize how completely ignorant we were ...”<sup>341</sup>*

All participants felt that stigma about persons with disabilities, discrimination, and exclusion from participation in mainstream society were contributing factors that ultimately caused a deprivation of liberty to occur. One participant (a mother of a person with epilepsy) recalled how their family would not touch whatever she had touched because they thought it was contagious. This type of behavior was also mentioned by persons with leprosy from Indonesia in this study. Another participant from France described how their wider family has abandoned them because of the persons with disabilities and that families experienced isolation due to their child or sibling’s disability.<sup>342</sup> A participant with disability from Ghana said she kept hiding because she thought she was the only disabled person in the world:

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<sup>339</sup> PE\_G2\_P4, JO\_G2\_P4.

<sup>340</sup> ID\_G2\_P2.

<sup>341</sup> FR\_G5\_P10.

<sup>342</sup> FR\_G5\_P12.

*“...before I joined the association I was thinking I am the only disable[d] person in the world so I kept hiding myself, I didn’t want to go to certain places (...)”<sup>343</sup>*

A mother of a man with epilepsy explains that her son *“feels shy to go public places (..)Maybe he feels because of his illness people may stigmatize against him.”*<sup>344</sup>

Discrimination within community settings was frequently mentioned by many participants with disabilities in this research as a contributing factor to deprivation of liberty. One participant recounts people throwing money at her while waiting on the street.<sup>345</sup> A Ghanaian participant recalls seeing people in the community mistreating other children with disabilities, especially an incident including caning and putting a hot iron on a boy. Another participant recalls being discouraged from accessing to church or any opportunity to participate or help with community and faith-based roles due to lack of physical accessibility and stigma.<sup>346</sup> Even her appearance at the beach would be frowned upon.

Marriage was highlighted as very important for many of the participants, especially for the participants from Ghana<sup>347</sup> and Jordan, where the desire to marriage was impeded because of the stigma attached to their disability. Many family members, NGOs’ representatives, policy makers and health care workers interviewed for this research also explained the need to hide the family member with disability to ensure that other family members could get married.

*“This issue would negatively impact my daughters and sons because nobody would marry them for example.”<sup>348</sup>*

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<sup>343</sup> GH\_G6\_P20.

<sup>344</sup> GH\_G5\_P2.

<sup>345</sup> GH\_G6\_P20.

<sup>346</sup> GH\_G6\_P18, GH\_G6\_P20.

<sup>347</sup> GH\_G6\_P20.

<sup>348</sup> JO\_G6\_P17.

In France, one participant complained about not being able to access mainstream social activities and being offered options to form social relationships only with other persons with disabilities or healthcare professionals.

*“At a social level, there are the GEM [Groupes d'Entraide Mutuelle], and there are therapeutic clubs but I don't go there because people are too old there...”<sup>349</sup>*

Similarly, where the person with disability was excluded from education or left education early or without completing qualifications, and was often unemployed, in societies with no welfare system had no means of accessing housing, and financial support to live on, and therefore ended up institutionalized.

*“[talking about where the problem lies] So they can, if we have social networks, like social workers who probably could assess and know what are the social problems of each client, they could suggest what remedies, or they can now identify, there is always a diagnosis, that this man in his social upbringing, there was some kind of deficit, he could not complete school because he was living 40 miles away from the school. It is not that he was not intelligent. And now he finds himself in Accra, he looks back and says, eei, what have I lost? He walks with people, she is a lady and she see herself and she is like, why didn't I get married? Probably, I live in an area I couldn't find one. All these can affect the person psychologically. And if you don't have people to work, I mean, to give you some kind of relief, the other symptoms, which we always think is medical, we could handle.”<sup>350</sup>*

*“A majority of those we see [as psychiatrists] tend to have a financial challenge.”<sup>351</sup>*

*“There are children exiting welfare services that (...) At the age of 20, one finds that there is not always a shelter or housing infrastructure to accommodate*

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<sup>351</sup> GH\_G4\_P6.

*them. Secondly, support programs might not have a residency and these young people end up on the street. [...] These people are often with a mild disability, who have developed mental health problems, and who are on the streets, since everybody has given up on them.”<sup>352</sup>*

*“...when a person with a psychiatric disorder is not exempted from criminal liability by the judge and receives a prison sentence, they will serve their entire sentence or even more, with no adjustment or reduction of the sentence. This is because the person will not be capable of reaching the objectives laid down in the prison, of working and will often commit violent acts against the prison guards because they are not well. The person will be unable to develop a plan for the future, has a psychiatric disorder and no one cares for them. The person may have no family, and without a promise of housing or employment, it is impossible for them to petition the judge to suspend their prison sentence. These people are penalised and there are a lot of people with stories like that in French prisons.”<sup>353</sup>*

Participants in this research described how institutionalization in boarding schools of persons with sensory disabilities was caused by lack of education alternatives in the home town of the participant, as well as a refusal of mainstream schools to accept children with these disabilities. A mother recalls her son being bullied by a teacher and that when her child was at school other parents withdrew their children from that school<sup>354</sup>. A similar case was described in France, where parents filed a petition to expel a participant’s son from the school.<sup>355</sup> Parents and persons with disabilities interviewed for this research regretted not having accessed or completed education, as this was now perceived as a barrier to live more independently or get a job.

Practical job and skills training specifically for persons with disabilities was described in this study as deficient, archaic and useless by some participants,

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<sup>352</sup> FR\_G3\_P7.

<sup>353</sup> FR\_G4\_P8.

<sup>354</sup> GH\_G5\_P2.

<sup>355</sup> FR\_G5\_P12.

who acquire skills that are out of date in the market.<sup>356</sup> Further, many participants with psychosocial disabilities explained that disclosing a disability would prevent them from accessing a job.<sup>357</sup> One participant explained that could not identify as a person with disability because he felt it was incompatible with providing for his family and having a job:

*“...to me, I don’t classify myself as an ‘ill’ person, I have my family and I want to secure them their living requirements, I was taking salary from the ministry of social development then it was cut off.”<sup>358</sup>*

Many participants with disabilities interviewed for this research who managed to have a job were denied reasonable accommodation or were dismissed when asking for it.<sup>359</sup>

Healthcare professionals recognized the impact of events on persons, and mentioned the need to provide jobs (and income sources) for persons with disabilities:

*“...if the person’s symptom is probably exacerbated by loss of job, what do you think should be? It would be to ameliorate that symptom, which is loss of job.”<sup>360</sup>*

Denial of education and employment opportunities is perceived by participants as both a cause and a consequence of deprivation of liberty becoming a self-perpetuating cycle.

These findings were also reflected in the literature review conducted as part of this research. At a global level, persons with disabilities have been known to have lower access to education<sup>361</sup> and employment, especially if there are pension schemes that prohibit persons with disabilities from entering employment, or if family members are encouraged to stay home to become the carer of a person

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<sup>356</sup> GH\_G1\_P14.

<sup>357</sup> JO\_G6\_P17, ID\_G4\_P6.

<sup>358</sup> JO\_G6\_P17.

<sup>359</sup> ID\_G6\_P10, JO\_G6\_P17.

<sup>360</sup> GH\_G4\_P16.

with disabilities. A study in the UK found that persons with disabilities in prison were less likely to have had a paid job prior to being admitted to prison or to have ever had a paid job in the past compared to non-disabled peers, and that they lacked social support.<sup>362</sup> The same study also pointed to other studies that identified the early drop out from education as a risk factor.<sup>363</sup>

Lack of reliable, accessible and affordable transport systems was highlighted during the interviews in Ghana by participants with disabilities, family members and NGOs as a relevant factor which ultimately led to a deprivation of liberty.<sup>364</sup> Access to transport was described as critical for participants to access appropriate healthcare and education services, especially if they did not live in major cities. Lack of inclusive and accessible housing was also mentioned by most participants with lived experience and health care workers, which often led to tense family situations in crowded living spaces.<sup>365</sup>

Community is also one of the major carriers of stigma. Most participants describe the expectation that persons with disabilities should be locked away, or somewhere else.

*“Q: Why does shackling occur? A: Because people do not know, they do not understand. The stigma is also still strong. Or there is a trauma when patients become violent. People think they will be like that all the time. Whereas, when mentally healthy people are angry, they also can do violence.”<sup>366</sup>*

All participants with disabilities from the five countries of this study described how the community marked and avoided them. Two participants from Ghana had experienced discrimination in church. One of the example from France shows how a neighbor had a person involuntarily admitted by telling the police he is

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<sup>362</sup> Afia Ali et al, 'Prisoners with intellectual disabilities and detention status. Findings from a UK cross sectional study of prisons.' (2016) 53-54 *Research in Developmental Disabilities* 189.

<sup>363</sup> Tomer Einat et al, 'Learning disabilities and delinquency: A study of Israeli prison inmates' (2008) 52(4) *International Journal of Offender Therapy and Comparative Criminology* 416.

<sup>364</sup> GH\_G6\_P20.

<sup>365</sup> GH\_G4\_P16.

<sup>366</sup> ID\_G4\_P5.

schizophrenic, and that this diagnosis alone was enough to initiate the involuntary hospitalization.<sup>367</sup> According to the participant, the police knew about his diagnosis due to prior search when the person escaped the psychiatric hospital, but they do not question the hospitalization, they simply said “*Him again?*”

Very often, deprivation of liberty was masked behind a no alternative narrative, describing the person’s behavior as unmanageable or unacceptable in any other context.

*“[Nowadays] to avoid stigmatization, we prefer getting people away from looks, from the world. Lock them up, going back to the asylum practices...”<sup>368</sup>*

Several participants described how the medical or rehabilitative model continues to prevail with respect to deprivation of liberty, in the response to persons with disabilities is to “lock them up” or treat only the symptom:

*“I feel that it is not correct most of the time, many of these services are still in a medical model, in correcting the person rather than correcting society and in segregating, (...).”<sup>369</sup>*

*“Their mind is: if he is not admitted to a psychiatric hospital because there is no hospital or does not receive it, I will lock him up [at home], so I prefer to avoid him going around the street suddenly having some irregular behaviour and I’m ashamed (...).”<sup>370</sup>*

*“(...) So, the public objects to that person wandering around, must be shackled. That’s all, really.”<sup>371</sup>*

Family reliance on hospitals and institutions was a concern expressed by persons with lived experience and a director of a healthcare institution,<sup>372</sup> possibly mixed

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<sup>367</sup> FR\_G6\_P14.

<sup>368</sup> FR\_G1\_P3.

<sup>369</sup> PE\_G3\_P6.

<sup>370</sup> PE\_G1\_P1.

<sup>371</sup> ID\_G1\_P1.

<sup>372</sup> JO\_G2\_P4.

with a lack of confidence in parenting skills, the belief it is best for the person to be isolated and segregated. Participants described stigma and discrimination:

*“People feel that when you have a disability you need specialized care, you need specialized attention, you need people who have been trained to manage your situation very specially.”<sup>373</sup>*

These findings are supported by studies included in the literature review for this research, which analyzed the public perception of involuntary hospitalization and residential care for persons with disabilities and found that the public largely supports practices regarding involuntary hospitalization and compulsory treatment.<sup>374</sup> In a study conducted in Norway, caregivers were found to be strongly supporting coercion. Other sources in the literature showed that persons with disabilities may be deemed unsuitable to live in the community<sup>375</sup> or persons with high support needs or persons under acute distress are often not deemed suitable for community based services.<sup>376</sup> Notwithstanding these views, deprivation of liberty was also considered to lead to more rights violations and deprivation of liberty by a policy maker in France and many participants spoke about negative effects and experiences around involuntary hospitalization and institutionalization, such as abuse from staff, social isolation, feelings of helplessness, guilt and abandonment.

The findings show that deprivation of liberty is used to address many situations or demands of persons with disabilities or their families, whether it is to provide education, training for employment, information on how to handle certain situations as parents, care, support during personal or family crisis or housing. Any attempt to establish the underlying causes leads to a complex and interrelated picture of structural conditions such as permanent exclusion from mainstream services, a heavy reliance on family to prevent institutionalization or

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<sup>373</sup> GH\_G3\_P17.

<sup>374</sup> Inge Joa et al, 'Public attitudes towards involuntary admission and treatment by mental health services in Norway' (2017) 55 International Journal of Law and Psychiatry 1.

<sup>375</sup> Arlene S Kanter, 'There's No Place Like Home: The Right to Live in the Community for People with Disabilities, under International Law and the Domestic Laws of the United States and Israel' (2012) 45(2) Israel Law Review 181.

<sup>376</sup> Winnie S Chow et al, 'Understanding psychiatric institutionalization: a conceptual review' (2013) 13 BMC Psychiatry 169.

hospitalization, while providing hardly any tools beyond deprivation of liberty to the family or individual to support themselves or their family members. There is a lack of knowledge on how to support persons and to respond to situations of distress (e.g. a person with autism during a meltdown), as well as a lack of information among persons with disabilities and families on what options and rights they have and regarding the disability itself, which may lead to a never-ending search for a final cure and acceptance of hospitalization or institutionalization as the only solution possible.

### 5.3. Perspectives on deprivation of liberty

This research adheres to the CRPD and its interpretation of the right to liberty. The right to liberty is of political and civil nature with immediate effect, similarly as the right to choose where and with whom to live (article 19). The findings within the interviews reflect the views of the different stakeholders contacted in each country. The research team acknowledges that the is not representative of all views on these issues and that some were not familiar with the CRPD and its interpretation by the UN Committee.

During the interviews, different views on deprivation of liberty, the definition of this study and whether situations could qualify as such emerged. These have been classified into four different positions, although participants are sometimes between these positions. The first position was that the situations covered by this research (involuntary hospitalisation, institutionalisation, home confinement and diversion from the criminal justice system) did not amount to a violation of human rights, especially in the context of institutions and persons with intellectual disabilities.<sup>377</sup> The second position was that while deprivations of liberty might occur in these settings, they did not automatically amount to human rights violations if certain safeguards or conditions were met. The third position was that disability-specific deprivations of liberty were clearly human rights violations where individuals were subject to constant supervision and control and were not free to leave (either by law or in practice).

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<sup>377</sup> All local research teams struggled to include persons with intellectual disabilities as participants, because of the organizations that denied the qualification of deprivation of liberty or because of guardianship laws.

Finally, many participants expressed the view that deprivation of liberty had nothing to do with human rights at all, but was rather simply an unfortunate reality facing persons with disabilities in their context. For some participants, especially family members and a few persons with disabilities, the situation was beyond a debate around rights, but was a result of dramatic and painful experiences, such as loneliness, rejection, not knowing what to do and a strong desire to care and get their sibling, son or daughter better, into a better place. Resignation and feeling abandoned by the state or even the wider family and community was also expressed.

### *Failure to Recognise Deprivation of Liberty as a Human Rights Violation*

With respect to the first position, several participants (especially health and social care professionals) expressed the view that no violation of rights occurred in these settings. In fact, they argued that these settings take care of persons with disabilities, and one participant (a family member) raised the point to the research team that framing it as a deprivation of liberty was wrong and that it had been a very painful process. Many potential participants with disabilities declined to participate in the study because they felt they did have experience of deprivation of liberty, even in cases of involuntary hospitalization. There is a resistance to accept these situations as deprivation of liberty.

Adherents to this first position denied that any rights were being restricted via the process of detention and placed special emphasis on the necessity of detention to safeguard the right to life, health, shelter and care for persons with disabilities. Within the context of psychiatric involuntary hospitalization, the need for care and protection was highlighted across all stakeholder groups and countries.

*“It doesn’t mean we restrict their rights, but we need to look from their condition. We don’t limit their rights, in here we still give them food, we give them life, and we serve appropriately.”<sup>378</sup>*

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<sup>378</sup> ID\_G2\_P3.

The participating policy makers and psychiatrists often pointed to legislation to justify involuntary psychiatric hospitalization, as well to the duty of doctors to provide for the highest standard of health and to protect the person's life.

*"In my opinion, a person that dies "free" next to the road because she did not want to be treated, is no progress for that person..."<sup>379</sup>*

Human rights were explicitly described as something dispensable on a few occasions, as something that one as a doctor could take from the person to ensure the right to health and life.<sup>380</sup>

*"I also disagree that if he gets placed in a mental hospital there is a potential for a human rights violation."<sup>381</sup>*

*"Now, in reference to all those human rights things that goes around place to place, it depends on which extent you value those claims. I am not the one to say that, there are some countries they conform strictly to what let's say the UN will say or what the country's law states about what are your rights. I think all should be taken with a pinch of salt because it is a situational decision. If the situation demands that you should take away the person's human right, you should."<sup>382</sup>*

The right to health and to protection of the person themselves and the community was presented as conflicting with the right to liberty. While very few participants spoke explicitly about risk and responsibility, participants in all five countries expressed a general feeling that families and the healthcare system, specifically, doctors and judges when consulted, have a duty to prevent the person from harming themselves or others.<sup>383</sup> In Peru,<sup>384</sup> participants described judges not lifting the deprivation of liberty order out of fear that something would then happen

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<sup>379</sup> FR\_G2\_P4.

<sup>380</sup> GH\_G4\_P16.

<sup>381</sup> ID\_G1\_P1.

<sup>382</sup> GH\_G4\_P16.

<sup>383</sup> ID\_G1\_P1.

<sup>384</sup> PE\_G1\_P2.

which they could have prevented and that if something did happen, it would lead to an investigation against them.

This idea of necessity of detention and dangerousness of persons with disabilities is also present in legislation around the criminal justice system. In France, for example, this is reflected in the law *loi de 2008 créant « la rétention de sûreté »*: a person who just finished a prison sentence of 15 years (crime) and who is considered dangerous or at risk of reoffending may be detained in a security center at the prison hospital for one-year periods which may be indefinitely extended. One of the participants highlights that in this case, the notion of dangerousness prevails over the notion of responsibility and is contrary to the principle of criminal responsibility and sentencing.<sup>385</sup>

Participants who expressed the view that deprivation of liberty was not a human rights violation in these settings, often referred to two inter-linked justifications: the perceived need for care and the perception that the person is unable to look after themselves. In this sense, deprivation of liberty in psychiatric hospitals, institutions and at home was framed mainly as an unavoidable consequence in the attempt to care and protect persons with disabilities.

*“They are deprived of liberty at home. Because sometimes it’s protection; people fear that some of these persons will be abused when they go out, generally. So, it’s about protecting them from public abuse, sometimes it’s about that...Yes, and sometimes it also turns to draw them from ridicule, or extension ridicule to the family...Ridicule because that is the general societal response to people with disability out there in the society. Again, these people do not understand so that is how they will respond. But more so I think that, apart from protection, I think that people are used also to getting complaints of how maybe they are not taking good care of such a family member (...).”<sup>386</sup>*

Institutionalization was conceived as perfect solution by directors and some healthcare workers – as a place of support and care for persons with disabilities,

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<sup>385</sup> FR\_G0\_P1.

<sup>386</sup> GH\_G3\_P17.

which is conceived as a burden from which family is entitled to be relieved. Not having family, needing support and being perceived as unable to take care of oneself was also considered a reason to justify deprivation of liberty and not view it as a rights violation.

### *Conditional Recognition of Deprivation of Liberty as a Violation of Human Rights*

The second position admits that it is a violation of human rights to place persons with disabilities in settings where there is no legal regulation or safeguards for the placement and no monitoring of the conditions of detention. Several respondents, including directors, health and social care professionals and family members justified deprivation of liberty via involuntary psychiatric hospitalization based on the criteria laid down in the law. This viewpoint was also shared by one of the policy makers. He stated that the causes of deprivation of liberty in a psychiatric hospital were related to an illness that required care which the person refused to consent to;<sup>387</sup> disturbance of the peace; behavior which puts the person or others in danger or finally, in cases of exemption of criminal liability.

This is also linked with an understanding of deinstitutionalization, especially among policy makers, who envision residential care and small group homes as an integral part of deinstitutionalization strategies, as the concerns lie within the conditions of detention, not the detention *per se*. Deinstitutionalization was deemed impossible in many cases and residential care is part of its design or the good practices mentioned by participants. When asked about institutions, one of the policy makers affirmed that deinstitutionalization in the sense of the CRPD was not possible, and that one could only aim for change within services improving conditions within these services, but not full deinstitutionalization.<sup>388</sup>

The research shows that there is a widespread belief among all stakeholder categories of this study, including persons with lived experience, that deinstitutionalization is only possible for some people and that one should focus on closing the old-style institutions. Many participants expressed the view that institutions are necessary for people with high support needs or those who have

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<sup>387</sup> FR\_G1\_P3.

<sup>388</sup> FR\_G1\_P2.

been abandoned by their families. Policy makers often understood institutions as old fashioned places determined by *brick and mortar*, even though the CRPD Committee has been very clear on the definition of institution and the universality of the right to live in community, without exception.

### *Recognition of Deprivation of Liberty as a Human Rights Violation*

The third position considers that disability-specific deprivation of liberty is discriminatory. This was recognized by a policy maker in France, who talked about the life expectancy in nursing homes for older people as sinister: *“So they find a solution to remedy the loss of autonomy that actually kills the person”*. He goes on saying that people will tell him that one can leave a home for persons with disabilities or who have lost their autonomy: *“Sure, people will tell me that everybody’s free to leave a [nursing home] - that’s utter hogwash! We need to think about this today too, because we currently deny the fact that certain places really are places of deprivation of liberty. To me, this should be even more of a priority since the number of people concerned is automatically going to increase considering our longer life span.”*<sup>389</sup>

Other participants also acknowledged the disability-based discrimination inherent in these deprivations of liberty but explained it with the ignorance of persons, stigma or lack of alternatives.

*“This comes back to our first discussion that we had that people just feel helpless, feel afraid, they don’t know what else to do so in order that he does not become a danger to himself and to others and also does not expose the family to a certain level of public embarrassment, the best is to confine and deprive him of his liberty. But these are all untenable. That is no reason why you should do that, but unfortunately people do it because they will tell you we don’t know what else to do. We took him to this facility, to this healer he got better, we went to the psychiatric hospital they gave medicine, it got better and recently it’s this and even he wandered away in the night, we heard of him in the next town and we brought him back and because of*

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<sup>389</sup> FR\_G1\_P2.

*that we don't feel that it is safe to allow him. They give certain levels of reason that seem genuine but again it is not an excuse. But then again is the fact that "so where else?"*<sup>390</sup>

### *Failure to Link Deprivation of Liberty to Human Rights Framework*

The fourth position does not look upon this issue as a matter of rights, but rather a traumatic and unavoidable experience. Many participants with disabilities and family members interviewed for this research felt invisible to their governments and as if rights were nothing tangible and far away from their reality.<sup>391</sup>

The narratives of families in this study reflect that the hospitalization or institutionalization always responded to a last resort from their personal perspective. Fear of being hurt was expressed by a minority of families, as well as not knowing how to help their relative and feelings of guilt and distress.<sup>392</sup> A commonly shared motivation in all five countries was the strong desire for the person to get better and exhaustion<sup>393</sup> from caring for the person. Families, NGOs, healthcare workers and a few of the participants with lived experience felt that often there was no other option or that it was the best care the person could be offered.

*"Among the worst, the best for him."*<sup>394</sup>

A final finding of interest to the recognition or failure to recognise deprivation of liberty as a human rights violation from this research is the discussion on consent. Participants often expressed views that either the absence of consent was evidence that a deprivation of liberty had occurred, or on the contrary, that because an individual was not capable of providing consent, that she should not be regarded as deprived of her liberty. These perspectives were usually informed by national legislation, especially the laws on involuntary hospitalisation. In this study, the differentiation between voluntary and involuntary admission was

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<sup>390</sup> GH\_G3\_P10.

<sup>391</sup> GH\_G6\_P18.

<sup>392</sup> JO\_G5\_P9, JO\_G5\_P12, GH\_G5\_P19.

<sup>393</sup> JO\_G5\_P9.

<sup>394</sup> PE\_G5\_P11.

several times dismissed because “the person lacks capacity” and thus consent cannot be sought.<sup>395</sup> Some professionals interviewed expressed the view that it is impossible for certain people to give consent the way it is recognized in the CRPD.

*“What does consent in this context [institutionalization] mean? We don’t know what it means, even if it is in the UN Convention. A person with autism does not know where she is going and does not know what consent means. For 30% of persons with autism who are nearly multi-disabled, they can’t give consent.”<sup>396</sup>*

The perspectives on deprivation of liberty show a tolerance or resignation around the practice of deprivation of liberty based on a disability. Some of the views denying or justifying deprivation of liberty may point towards a medical model of disability. Further, the legalities around deprivation of liberty are perceived as sufficient guarantee to prevent discriminatory detention, and often intended to reduce the number of involuntary detention, even though the contrary has happened.<sup>397</sup> Diversion was especially complex for most participants, who in many instances skipped the topic or merely described the theoretical and legal process, in some occasions pointing out the arbitrariness of identifying who needs to be diverted<sup>398</sup> or that prisons are not an adequate solution either.<sup>399</sup> Participants seemed overwhelmed by the complexity of the issue and found it difficult to tackle, even in those cases where the discriminatory nature of these practices was recognized, as no alternatives to provide to criminal justice proceedings, e.g. restorative justice, nor supports during trial are available.

#### 5.4. Alternatives to deprivation of liberty

Participants in this research suggested a number of important inter-related solutions and alternatives to enable individuals to avoid or to leave settings where they were deprived of liberty on the basis of disability. Most participants did not discuss major systemic necessary changes (abolishing all legal grounds for

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<sup>395</sup> PE\_G5\_P9.

<sup>396</sup> FR\_G3\_P6.

<sup>397</sup> FR\_G0\_P1.

<sup>398</sup> GH\_G4\_P16.

<sup>399</sup> FR\_G4\_P8.

disability-specific deprivation of liberty), possibly due to the framing of the study, which supports the CRPD standpoint and identified the described practices as discriminatory. This section will analyze the alternatives for individuals and families which were suggested by participants in this research, and discuss how these relate to alternatives to deprivation of liberty found in the literature review for this research.

### *Supports for Individuals and Families*

One of the most significant findings of this research was that support for individuals and supports for families is necessary to end disability-specific deprivations of liberty. This is partly because, as described in the section on underlying causes of deprivation of liberty above, families often initiate the process by which the person is deprived of liberty (either directly or indirectly) and families are also often the best protection individuals have against becoming deprived of liberty, or challenging their placement in an institutional setting, and getting support to leave the situation of detention.

Alternatives to detention and segregation found in this research relied on strong family and community networks.<sup>400</sup> Often, one specific family members' strong commitment to the person's rights was crucial to keep the person out of an institutional setting. One of the family members in France whose son was deprived of liberty described how he fought to ensure his son's return to his community and to get him a job. The father described the neighborhood as a place where friends ask about his son's wellbeing. These community members and neighbors shared the family's feeling of disbelief when the son experienced the deprivation of liberty. The father found that "*society was much more tolerant than the treatment staff with regards to his son*".<sup>401</sup>

The different stakeholders interviewed for this research identified the need for information on disability and the rights of persons with disabilities, for their families and wider society, in order to end deprivations of liberty.<sup>402</sup> The role of

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<sup>400</sup> FR\_G0\_P1, GH\_G6\_P20, ID\_G3\_P4, ID\_G4\_P6.

<sup>401</sup> FR\_G5\_P11.

<sup>402</sup> PE\_G1\_P1, GH\_G6\_P1.

families was described in two main ways by stakeholders. Many participants acknowledged that processes which resulted in deprivations of liberty were often initiated by families and at the same time, for many people who had been deprived of their liberty, their families played a vital role in challenging these deprivations and ultimately ensuring the person's release from confinement.<sup>403</sup> Therefore, education and support to families is important, to ensure that the family context is supportive, bearing in mind that this should be to the benefit of the person's will and preferences and respecting his or her rights.

*"...the environment is at its end, completely isolated and families don't know their rights, so they can't defend their family member, and the person themselves even less. We have a big deficit of directly accessible information to persons with disabilities."*<sup>404</sup>

A practice which could contribute to empowering individuals and families which emerged from the literature review is known as Family Group Conferencing. This concept emerged from Maori practice and was first recognized as part of child welfare policy and legislation in New Zealand.<sup>405</sup> 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.<sup>406</sup> 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.<sup>407</sup>

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<sup>403</sup> FR\_G3\_P6.

<sup>404</sup> FR\_G3\_P7.

<sup>405</sup> 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).

<sup>406</sup> The Eindhoven model available at: <[www.Mindrights.nl](http://www.Mindrights.nl)> accessed 11 April 2019.

<sup>407</sup> 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/>> accessed 11 April 2019.

### *Knowledge of Rights and Access to Justice to Challenge Detention*

There is a low awareness of rights within psychiatric hospitals<sup>408</sup> and institutions are considered traditionally considered places of care, not places of detention.

*“Actually, there are two issues, first, the patient sometimes isn’t aware of his options, or doesn’t complain, or isn’t aware that he can complain.”<sup>409</sup> [referring to an individual within a psychiatric hospital]*

Persons with disabilities interviewed for this research also emphasized the need to be aware their rights at the time they experienced deprivation of liberty:

*“I want to reaffirm that I didn’t know during my life in this school that my rights were violated because I didn’t know that I have rights in the first place, there was no liberty in this school...”<sup>410</sup>*

Some participants also identified the need for the support of lawyers who understood disability rights in order to challenge deprivation of liberty and end disability-specific deprivations of liberty. One participant with disability in France described lawyers’ prejudice against persons with psychosocial disabilities:

*“[They] take us for nut cases, we are discredited. I’ve seen what their opinions are and they think we are dangerous so they’re not the ones who are going to defend our rights. Duty lawyers know even less than ordinary lawyers and just say ‘amen’ to whatever the psychiatrists say as the specialists.”<sup>411</sup>*

This view was shared by a participant in Jordan who was unable to find legal assistance to challenge his deprivation of liberty, and ended up representing himself in court:

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<sup>408</sup> Mahbobeh Yaghobian et al, ‘Association between Awareness of Patient Rights and Patient’s Education, Seeing Bill, and Age: A Cross-Sectional Study’ (2014) 6(3) Global Journal of Health Science 55.

<sup>409</sup> ID\_G2\_P2.

<sup>410</sup> JO\_G6\_P19.

<sup>411</sup> FR\_G6\_P14.

*“I tried to find a lawyer to file a lawsuit to have judicial decision that I have no mental health problem but all lawyers I met refused to help me. I began to read and study the laws and the legal references, there was a lawyer she was supportive but she refused to take the lawsuit because it has something related to psychiatric problems.”<sup>412</sup>*

Another interviewee, a policy maker who was also a lawyer himself stated:

*“When I saw the documentary [referring to 12 Jours by Raymond Depardon on involuntary psychiatric hospitalisation], I wasn’t proud of the [barrister] gown (...) If we really want to do something about this judicial control, it is essential that lawyers start getting involved, because otherwise we’ll find ourselves with mere ratifications like shown on Depardon’s film.”<sup>413</sup>*

Persons with disabilities face many barriers when trying to access justice, disbelief of police or other relevant actors,<sup>414</sup> such a lack of awareness of entitlement, fear of reprisals or withdrawal of care, fear of negative consequences, financial cost as well as lack of accessibility and quality of lawyers.<sup>415</sup> During proceedings, lack of procedural accommodation is also a barrier.<sup>416</sup> Some examples of positive initiatives found through the literature review included guidelines and recommendations published by the UK and Costa Rica, among other countries, to guarantee the access to justice.<sup>417</sup> Mexico has introduced a support person during criminal proceedings (“*facilitador*”)<sup>418</sup> to support victims, witnesses and defendants. The figure has been defined as neutral and aims to make sure the person is heard.

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<sup>412</sup> JO\_G6\_P15.

<sup>413</sup> FR\_G1\_P3.

<sup>414</sup> Peter Bartlett et al, ‘Urgently awaiting implementation: The right to be free from exploitation, violence and abuse in Article 16 of the Convention on the Rights of Persons with Disabilities (CRPD)’ (2017) 53 International Journal of Law and Psychiatry 2.

<sup>415</sup> Anna Lawson, ‘Disabled people and access to justice. From disablement to enablement?’ in Blanck, P. (Ed.), Flynn, E. (Ed.). (2017). Routledge Handbook of Disability Law and Human Rights. London: Routledge.

<sup>416</sup> Ibid.

<sup>417</sup> Costa Rica’s protocol available at: <<https://www.consaludmental.org/publicaciones/Protocolo-justicia-discapacidad-psicosocial.pdf>> accessed 11 April 2019. UK Equal treatment bench book available at <<https://www.judiciary.uk/wp-content/uploads/2018/02/equal-treatment-bench-book-february-v6-2018.pdf>> accessed 11 April 2019.

<sup>418</sup> More information available at: <<https://documenta.org.mx/blog-documenta/2018/01/29/facilitadores-opportunidades-de-acceso-a-la-justicia-para-personas-con-discapacidad/>> accessed 11 April 2019.

Restorative justice and diversion programs not based on a person's disability can also be very effective to avoid disability-specific deprivations of liberty. Restorative justice is flexible and allows the process to be adapted to the person with disabilities' needs, while shifting away from analyzing the guilt or capability of guilt, concentrating on the harm done and possible reparations. The literature review conducted for this research also found a number of different initiatives to make these programs accessible to persons with disabilities, e.g. British Columbia Association for Community Living.<sup>419</sup>

The area of diversion from the criminal justice system into forensic facilities or other forms of detention received less attention in phase II of this research because many participants knew very little about it and perceived it as something very technical. It seems to be an area and population routinely ignored by mainstream disability policies and actors. Yet this issue is also ignored in much of the mainstream literature on mainstream criminal justice and prison reform. Further research is therefore clearly required in this area.

### *Role of Families in Challenging Detention*

Families played a critical role in challenging disability-specific deprivations of liberty and in advocating and raising awareness with other families about the need to do the same. For example, one family who challenged the doctor's decision of placing their son with autism in a unit "for difficult patients", stated that they were privileged to have a good level of education and the capacity to face all stakeholders (doctors, justice system, prosecutors, police prefects, CGLPL, etc.), but that this was an exception: "*1% of families that have the possibility of moving heaven and earth.*"<sup>420</sup>

In Jordan, a father who had experienced himself deprivation of liberty now advocates for inclusive education, especially for his own children. He warned

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<sup>419</sup> Available at: <<http://www.inclusionbc.org/resources/restorative-justice-and-people-developmental-disabilities-booklet-family-members-advocates>> accessed 11 April 2019.

<sup>420</sup> FR\_G5\_P11.

against segregated educational and social care institutions because families become dependent on them and do not learn how to communicate with their child:

*“I’m telling them: don’t go... pay attention... Don’t go to boarding schools... If you go to such schools your families will become dependent and they will not communicate with you. Very few families pay attention and give security to their deaf kids. I want to say that I’m trying to avoid my deaf son everything I encountered during my life in that school, so I enrolled my son in inclusive school and I’m providing him with everything he needs to live properly.”<sup>421</sup>*

Regardless of the family efforts to challenge detention, states have a duty to eliminate detentions based on disabilities and to facilitate direct access to justice of persons with disabilities.

### *Empowerment and peer support*

The theme of empowering and educating individuals on the rights of persons with disabilities as well as educating society to end disability-specific deprivation of liberty is also reflected in the literature review undertaken for this research. Creating safe spaces where persons with disabilities may speak up freely (self-advocacy groups, peer support organizations, and DPOs) emerged as important opportunities to enhance political participation and awareness of rights, to build confidence to challenge discriminatory practices, including deprivation of liberty.

The literature review demonstrated that peer support has proven to be a good tool for sharing information, experiences and insights and empower persons with disabilities, by making them aware of their rights and the ongoing human rights violations. This was also the case in Ghana, where most participants highlighted peer support initiatives.<sup>422</sup> Peer support has been described as *“a system of giving and receiving help founded on key principles of respect, shared responsibility and agreement of what is helpful. Peer support is not based on*

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<sup>421</sup> JO\_G6\_P19.

<sup>422</sup> E.g. peer support groups facilitated by Basic Needs Ghana.

*psychiatric models and diagnostic criteria*".<sup>423</sup> According to ENIL, peer support is essential to bridge dependency and independent living, as it empowers individuals to recognize barriers and tackle them.<sup>424</sup> Community-care networks have shown to be successful and include linkage to peer support groups, access to education and awareness training.<sup>425</sup>

### *Living Independently and Being Included in the Community*

Deinstitutionalization strategies are essential in ending disability-specific deprivation of liberty, but these alternative approaches must be supported by adequate funding so that resources are shifted from the institution into the community.<sup>426</sup> This study revealed that many participants felt community based initiatives were not (sufficiently) funded and that the money invested in hospitals could have had a wider impact if used in community based care.<sup>427</sup> Community based models of support and independent living are not more expensive than traditional residential care. The evidence around this varies due to multiple factors such as previous expenditures on institutions, wages, public or private services and funding mechanisms.<sup>428</sup> In some countries, the evidence shows that community based services are less expensive, while in others it varies. There is a common conclusion within the literature that overall, community services provide for a better quality of life than institutional care. Another review on the cost savings of individual funding schemes found that direct payments are more effective than conventional service provision.<sup>429</sup>

The literature review conducted for this research therefore showed that deinstitutionalization efforts must be accompanied by a sufficient increase in

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<sup>423</sup> Shery Mead et al, 'Peer support: A Theoretical Perspective' (2001) 25(2) *Psychiatric Rehabilitation Journal* 134; ENIL's manual on peer support, available at: <[http://www.enil.eu/wp-content/uploads/2012/06/Peer-Support-Training-Manual-Final\\_281014.pdf](http://www.enil.eu/wp-content/uploads/2012/06/Peer-Support-Training-Manual-Final_281014.pdf)> accessed 11 April 2019.

<sup>424</sup> ENIL's manual on peer support, p. 10.

<sup>425</sup> André I Wierdsma et al, 'Effects of community-care networks on psychiatric emergency contacts, hospitalisation and involuntary admission' (2007) 61(7) *Journal of Epidemiology and Community Health* 613; Sudipto Chatterjee et al, 'Collaborative community based care for people and their families living with schizophrenia in India: protocol for a randomised controlled trial' (2011) 12(12) *Trials*.

<sup>426</sup> WHO and the Calouste Gulbenkian Foundation, 'Innovation in deinstitutionalization: a WHO expert survey' World Health Organization, Geneva (2014).

<sup>427</sup> GH\_G3\_P10.

<sup>428</sup> David Falce D, 'Community Living for Adults with Intellectual Disabilities: Unravelling the Cost Effectiveness Discourse' (2017) 14(3) *Journal of Policy and Practice in Intellectual Disabilities* 187.

<sup>429</sup> Gerry Zarb et al, 'Cashing in on Independence: Comparing the Costs and Benefits of Cash and Services' (1994) London: BCODP, referenced in Sinéad Keogh et al, 'Independent living: an evaluation of the Áiseanna Tacaíochta model of direct payments' (2018).

more and affordable home care and community-care provision.<sup>430</sup> There are several paths to successful deinstitutionalization.<sup>431</sup> Moldova has been highlighted as an example of a deinstitutionalization process as well as Sweden. In Sweden, one of the key points was shifting responsibility to local governments as well as changing general services to serve a wider range of people.<sup>432</sup> Further, institutions lost support from the wider society as families' views changed. The housing conditions improved and despite the general improvement, Sweden still has a long way to go to challenge institution-like practices and segregation in day to day activities, including the termination of detention within psychiatric facilities. Therefore, to end disability-specific deprivations of liberty, it is important that these changes come along with an empowering approach to the individual and individual support for decision making processes.

The establishment of a right to community care and recognition of personal assistance (including during crisis situations), have also been recognized in the literature as essential components of deinstitutionalization strategies that comply with human rights norms.<sup>433</sup> For example, Swedish law recognizes the individual right to a personal assistance for all persons with disabilities, including persons with intellectual disabilities. Co-operatives of persons with disabilities who use personal assistance, such as the organization known as JAG, whose members all have intellectual disabilities and limited autonomy, emerged from the literature review as an example of good practice in supporting the right to live independently and be included in the community for persons with high support needs.<sup>434</sup> Another good practice from Sweden for people with psychosocial disabilities is the personal ombuds, which provides assistance during crisis

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<sup>430</sup> Slavina Spasova et al, 'Challenges in long-term care in Europe. A study of national policies' (2018) European Commission.

<sup>431</sup> WHO and the Calouste Gulbenkian Foundation 'Innovation in deinstitutionalization: a WHO expert survey' World Health Organization, Geneva (2014).

<sup>432</sup> Jan Tøssebro, 'Scandinavian disability policy: From deinstitutionalisation to non-discrimination and beyond' (2016) ALTER, 10 European Journal of Disability Research 111.

<sup>433</sup> Available at: <<https://www.independentliving.org/docs5/jag.html>> accessed 11 April 2019.

<sup>434</sup> JAG Manual on the European Network for Independent Living available at: <[http://enil.eu/wp-content/uploads/2012/02/Pa-manual\\_ENG.pdf](http://enil.eu/wp-content/uploads/2012/02/Pa-manual_ENG.pdf)> accessed 11 April 2019.

situations and only responds to the person with disabilities wishes, and is independent of any governmental authorities or social or health services.<sup>435</sup>

Deinstitutionalization initiatives need to be comprehensive and adequately funded, following the standards set out in the CRPD Committee's General Comment on independent living<sup>436</sup>. Further, capacity building and awareness raising initiatives need to be done simultaneously, closely consulting persons with disabilities seeking out their leadership and expertise for the process.

On a related note, there many strategies are required to end child institutionalization, including the deprivation of liberty of children with disabilities. The literature review conducted for this research demonstrates that efforts are required to build up family support, foster care and adoption, in order to avoid deprivation of liberty of children with disabilities. Services for the child need to be provided within the community, to facilitate the parent's caring role. In Ghana, a small organization ran a program to bring children with disabilities back into the community, which was considered a good practice by the UN.<sup>437</sup> The NGO arranged for mediators to identify children with disabilities living at home hidden away from the community and work with them and the family to access services. The literature review conducted for this research revealed that foster and adoptive parents also need support from the community to avoid deprivation of liberty of children. In one example, therapeutic foster care used specially trained foster parents to provide active and structured treatment in the context of the family setting, in addition to any interventions the child or youth may receive outside of the home.<sup>438</sup>

### *Supporting persons with disabilities in crisis situations*

Participants in this research acknowledged that the existence of a trusted network of supporters who would not resort to institutionalizing the person (including family and peers) around the person is particularly important in situations of crisis.

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<sup>435</sup> More information under <<http://po-skane.org/in-foreign-languages/>> accessed 11 April 2019.

<sup>436</sup> CRPD/C/GC/5.

<sup>437</sup> United Nations. Best practices for including persons with disabilities in all aspects of development efforts (2011), ST/ESA/346, available at:

<[http://www.un.org/disabilities/documents/best\\_practices\\_publication\\_2011.pdf](http://www.un.org/disabilities/documents/best_practices_publication_2011.pdf)> accessed 11 April 2019.

<sup>438</sup> Lily T Alpert et al, 'Moving away from congregate care: One state's path to reform and lessons for the field' (2012) 34 Children and Youth Services Review 1519.

Crisis situations can be defined in multiple ways. A review of the literature around the definition of crisis in dementia found multiple definitions, which shared the presence of stressors the need for immediate decision, the view of crisis as a process and the resolution.<sup>439</sup> In this study, crisis situations were understood to refer to multiple scenarios, as covered in the definitions identified in the literature review. Further, these situations (e.g. family conflict, emotional distress) are not limited to persons with psychosocial disabilities, but may occur to anybody.

Crisis situations can be very frightening for all involved. The most commonly suggested services in the literature and from participants in this research include crisis houses (safe, non-medicalized places for people to go in distress),<sup>440</sup> inclusive and accessible women's shelters,<sup>441</sup> and non-coercive sources of information such as hotlines or drop-in cafés.<sup>442</sup> The availability of these kinds of alternatives have also been shown to reduce instances of involuntary hospitalization<sup>443</sup> and higher satisfaction rates.<sup>444</sup> However, in order to make these services more available and ensure that people feel safe in accessing them, discriminatory deprivations of liberty based on disability need to be abolished, in line with the requirements of the CRPD.

Housing initiatives such as Housing First<sup>445</sup> or Transitional Housing Program for Forensic Patients Discharged into the Community were identified in the literature review<sup>446</sup> which assist persons leaving forensic facilities, constitute an opportunity for persons with disabilities who have experienced deprivation of liberty to access housing. However, such initiatives must respect the person's will and preferences and cannot require adherence to psychiatric medication or impose curfews or

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<sup>439</sup> Janet MacNeil Vroomen et al, 'Reviewing the definition of crisis in dementia care' (2013) 13(1) BMC Geriatrics 10.

<sup>440</sup> Jørgen Aagaard et al, 'Crisis homes for adult psychiatric patients' (2008) 43(5) Social Psychiatry and Psychiatric Epidemiology 403.

<sup>441</sup> E.g. Drayton Park women's crisis house in North London, more information available at: <<https://www.candi.nhs.uk/services/drayton-park-womens-crisis-house-and-resource-centre>> accessed 11 April 2019.

<sup>442</sup> Community Access houses, available at: <<http://www.communityaccess.org>> accessed 11 April 2019, Runaway House, available at: <<https://www.weglaufhaus.de>> accessed 11 April 2019, or the Windhorse community, available at: <<https://windhorsecommunityservices.com>> accessed 11 April 2019.

<sup>443</sup> Jørgen Aagaard et al, 'Crisis homes for adult psychiatric patients' (2008) 43(5) Social Psychiatry and Psychiatric Epidemiology 403.

<sup>444</sup> Chiedu Obuaya et al, 'Is there a crisis about crisis houses?' (2013) 106(8) Journal of the Royal Society of Medicine 300.

<sup>445</sup> More information available at: <<https://raisfundacion.org/housing-first-europe-final-report-and-local-evaluation-reports-for-amsterdam-budapest-copenhagen-glasgow-and-lisbon/>> accessed 11 April 2019.

<sup>446</sup> Rebecca Cherner et al, 'Findings of a Formative Evaluation of a Transitional Housing Program for Forensic Patients Discharged into the Community' (2013) 52(3) Journal of Offender Rehabilitation 157.

other coercive conditions in order to ensure human rights compliance. Further, to ensure the full abolition of deprivation of liberty, access to mainstream social housing options is required, as will be discussed in further detail in the steps for human rights compliance section below.

The literature review conducted for this research revealed that advance directives which allow patients to set out their will and preferences on how they wish to be treated in the event of a crisis can be a useful tool to avoid deprivation of liberty.<sup>447</sup> They may include advance refusals of certain treatments (e.g. ECT) and/or advance requests for particular options the person has found helpful in the past. Similar initiatives can be found in crisis cards, which focus on broader support needs prior to medical intervention, in contrast to advance directives, that may only focus on the admission to hospital.

*“Advance directives might be good, but I don’t believe they will really work. They will still give you drugs. Will it force them to talk to you? I went to go see what they are doing in Marseille at the Respite House where I heard about methods like WRAP (...).”<sup>448</sup>*

However, with all these advance planning tools, it is critical to ensure that they are freely chosen by the person, and in order to ensure compliance with the CRPD, the individual should have full control to determine when the advance directive or crisis card should take effect. This means that discriminatory approaches, whereby advance directives can only take effect once the individual is deemed by medical professionals or others to ‘lack mental capacity’ are not compatible with the human rights standards set out in the CRPD. Advanced planning should not undermine the right to exercise legal capacity and are binding for service providers, but not so for the person, who is entitled to decide otherwise.

Further good practices identified within phase II were psychiatrists and hospitals that do not believe in deprivation of liberty and want to work only on the basis of informed consent, e.g. “the open door policy” in France. Policy makers described

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<sup>447</sup> Yasser Khazaal et al, ‘Advance directives based on cognitive therapy: A way to overcome coercion related problems’ (2009) 74(1) Patient Education and Counseling 35.

<sup>448</sup> FR\_G6\_P15.

how some psychiatrists have an open regime, in their hospitals and have reduced involuntary hospitalization as a result. The emergence of “Collective 39” in France, a group of 39 psychiatrists who oppose the use of coercion and forced psychiatry, was also mentioned by participants as an example of good practice which avoids deprivation of liberty.<sup>449</sup> The refusal to use force or restraint can also be seen in many campaigns around the world calling to end coercion and restraint in psychiatric care and any other spaces.<sup>450</sup> From the literature review conducted for this research, examples were found of social care organizations<sup>451</sup> and psychiatric hospitals were found to run services without restraining persons.<sup>452</sup>

This approach can also be found in the literature review with examples such as the open dialogue model<sup>453</sup> which 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.<sup>454</sup> It provides immediate help upon contact from the patient, a relative or a referral service. From the beginning, the person, 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.<sup>455</sup>

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<sup>449</sup> Available at: <<http://www.collectifpsychiatrie.fr/?cat=13>> accessed 11 April 2019.

<sup>450</sup> Regarding psychiatric spaces: platforms such as Mindfreedom.org or ><https://0contenciones.org>> accessed 11 April 2019; Within institutions: Fundación Cuidados Dignos, Manual sobre eliminación sujeciones or e.g. Indonesia started an anti-pasung campaign, available at: <<https://jakartaglobe.id/opinion/commentary-break-the-chains-of-mental-health-stigma/>> accessed 11 April 2019, “Collectif des 39”, available at: <<http://www.collectifpsychiatrie.fr/>> accessed 11 April 2019.

<sup>451</sup> Programa Desatar, available at: <<http://ceoma.org/desatar/>> accessed 11 April 2019.

<sup>452</sup> Wilma Di Napoli et al, ‘A “no-restraint” psychiatric department: operative protocols and outcome data from the “opened-doors experience” in Trento’ (2014) 26(1) *Psichiatria Danubina* 138.

<sup>453</sup> Jaako Seikkula et al, ‘Five-year experience of first-episode nonaffective psychosis in open-dialogue approach: Treatment principles, follow-up outcomes, and two case studies’ (2006) 16(2) *Psychotherapy Research* 214. More information available at: <<http://open-dialogue.net>> accessed 11 April 2019.

<sup>454</sup> Jaako Seikkula et al, ‘Open dialogue in psychosis I: An introduction and case illustration’ (2001) 14(4) *Journal of Constructivist Psychology* 247.

<sup>455</sup> Jaako Seikkula et al, ‘The Open Dialogue Approach to Acute Psychosis: Its Poetics and Micropolitics’ (2003) 42(3) *Family Process* 403.

### *Supported Decision-Making as a Tool to End Deprivation of Liberty*

Abolition of coercion and disability-specific forms of deprivation of liberty are essential to end human rights violations against persons with disabilities. However, structural changes also need to happen, as well as the recognition of different forms of decision-making. Supported decision-making practices include assisting a person to execute their preferences, provide information or, provide a more intensive support. It may be framed as a collaborative interdependent initiative,<sup>456</sup> with a specific set values<sup>457</sup> to ensure respect for the person's will and preferences, avoiding power imbalances and remaining CRPD compliant. Supported decision making includes accepting nonverbal communication together with its interpretation by a trusted person or group and the uses of alternative and augmentative communication. The support style may vary depending on each person and the type of relationship (formal, informal, partners, friends, professionals, volunteers, etc.). Supported Decision-making must be understood as a tool to live within the community and develop meaningful relationships. A project from Australia retelling stories of success of social inclusion can also help to guide future initiatives<sup>458</sup> around inclusion and support. One globally acknowledged good practice in the field of supported decision-making which can support individuals to avoid deprivation of liberty is the Personal Ombudsman in Sweden.<sup>459</sup> This approach which supports persons with psychosocial disabilities with whatever decisions they choose and only works the person concerned, not for family or other actors. Self-advocacy platforms have published their recommendation on support<sup>460</sup> and the CRPD General Comment no.1 can also serve as guiding principles<sup>461</sup>, as well as the Special Rapporteur

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<sup>456</sup> Joanne Watson, 'Supported decision making for people with severe or profound intellectual disability: 'We're all in this together, aren't we?' (2012) Paper presented at the 6th Roundtable on Intellectual Disability Policy 'Services and Families Working Together', Bundoora: LaTrobe University.

<sup>457</sup> Anna Arstein-Kerslake et al, 'Future Directions in Supported Decision-Making' (2017) 37(1) Disability Studies Quarterly 1041.

<sup>458</sup> 19 stories, more information available at: <<https://www.19stories.org/research>> accessed 11 April 2019.

<sup>459</sup> More information available at: <<https://europe.ohchr.org/EN/Stories/Documents/MathsJesperson.pdf>> accessed 11 April 2019.

<sup>460</sup> See Empower Us: good support, available at:

<<https://static1.squarespace.com/static/5aa6b00caf20961b4b2283d2/t/5b336e7d88251b930fe2805e/1530097281353/Empower+Us+Good+support+Guide.2018.pdf>> accessed 11 April 2019.

<sup>461</sup> CRPD/C/GC/1.

on the Rights of Persons with Disabilities' report on article 12, which includes good practices.<sup>462</sup>

Supported decision making will inevitably take different shapes for each person and community. However, supported decision making initiatives must be embedded within the community and respect the person's will and preferences at all times. Persons do not 'belong' to services and this requires a change within the mindset of support staff and the wider community.

### 5.5. Steps towards human rights compliance

This research has revealed some important findings about the nature and causes of disability-specific deprivations of liberty, possible alternatives and ways forward to ensure compliance with the human rights norms enshrined in the CRPD. This final section of the report will address the steps needed for human rights compliance at global, regional, national and local levels, to ensure that persons with disabilities are no longer arbitrary or unlawfully deprived of liberty on the basis of disability.

The first issue which needs to be addressed in order to achieve human rights compliance is a shift away from the medical, individualistic and charitable models of disability. These models sustain legal and social regimes of segregation and violence, which must be ended to comply with the CRPD. The qualitative research and the global literature review undertaken for this study reveal that the responses to persons with disabilities have resulted in segregation, isolation, marginalization, and ultimately in deprivations of liberty. The next, and related issue, is the need to recognize the segregation of persons with disabilities in settings which they are not free to leave, and where they have not consented to be, as deprivations of liberty that violate human rights norms. While there is a growing recognition of this position in the international human rights sphere,<sup>463</sup> this realization has often, in the experience of participants in this research, not filtered down to national laws, policies and practices – and a recognition of this approach is particularly missing at regional and local levels within countries,

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<sup>462</sup> Special Rapporteur on the Rights of Persons with Disabilities. Report to the Human Rights Council, 37<sup>th</sup> session (December 2017), A/HRC/37/56.

<sup>463</sup> CRPD/C/12/2 Annex IV; WGAD Report A/HRC/36/37, para. 55, CEDAW/C/IND/CO/4-5, para 37.

where traditional practices based on segregation and institutionalization remain prevalent.

Once these settings and placements begin to be recognized as disability-specific deprivations of liberty, then the argument for abolishing the legal and other regulatory frameworks (including the allocation of funding) which underpin these discriminatory systems becomes clearer. These include specific mental health laws or other provisions within civil or public health codes which allow for involuntary hospitalization, laws creating exemptions from criminal responsibility on the basis of disability which nonetheless require detention in forensic or purportedly therapeutic settings, and laws on adult guardianship or other substituted decision-making regimes which are often used as a mechanism to involuntarily detain or otherwise institutionalize persons with disabilities. However, as emphasized by an overwhelming majority of participants in this research, changes to laws alone are not sufficient, unless they are accompanied by a major culture change and shift in the societal perception of persons with disabilities.<sup>464</sup> For both legal and social change to occur, there is a need to develop widespread grassroots support for such initiatives, as well as a political willingness to pursue change.

One positive example in this respect is Peru, where a recent law reform has abolished guardianship, and substituted decision-making almost entirely.<sup>465</sup> 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.

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<sup>464</sup> Fleur Baupert et al, 'Questioning Law's Capacity' (2015) 40(3) *Alternative Law Journal* 161.

<sup>465</sup> Persons with addictions, "bad administrators", "prodigals", people criminally convicted, and people in a coma without a designated support person

These aspects were identified by participants in all countries of this research as critical, and often missing elements, without which, individuals and organizations were unable to progress change.

An example of law reform which has not yet translated to sufficient change at the grassroots level, is Indonesia's effort to tackle shackling practices through a prohibition within the law and a program lead by the local government aimed at freeing persons that had been shackled.<sup>466</sup> While it was important that the law was accompanied by leadership at the local government level, some participants in this research felt that without educating individuals and families on the rights of persons with disabilities, and without providing alternative solutions to respond to people in crisis, distressed, or lacking social support, the law was often not enforced in practice. This viewpoint is reflected in the reports from several participants, that the discrimination and segregation they experienced, or which they witnessed persons with disabilities experiencing, seemed very far removed from discussions of 'human rights.' It is important to reiterate that while supports must be provided to respond to those who wish to use them, it is not acceptable from the standpoint of the CRPD for states to refuse to abolish discriminatory practices because support services have not yet been sufficiently developed.

Monitoring of implementation and of the impact a certain law reform or program is also essential to guarantee the implementation of policies. For instance, while laws may prohibit cruel treatment, shackling practices or restraint practices may continue despite the government's prohibition.<sup>467</sup> The understanding of hospitalization and institutionalization as situations of deprivation of liberty is essential for existing monitoring bodies such as Ombudsman to assume an active monitoring role.

One example of monitoring which emerged from this research is the Contrôleur général des lieux de privation de liberté (CGLPL) in France, who is entitled to access and control the management and situations of persons deprived of liberty,

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<sup>466</sup> HRW has documented the progress of this: <https://www.hrw.org/news/2018/10/02/indonesia-shackling-reduced-persists> accessed 11 April 2019.

<sup>467</sup> See recent example from Ghana: <https://www.hrw.org/news/2018/10/09/ghana-oversight-needed-enforce-shackling-ban> accessed 11 April 2019.

without needing to be granted access by the authorities or courts. The CGLPL is an independent public monitoring entity and is responsible for checking that the fundamental rights of persons deprived of liberty are respected. As an independent body, the CDLPL may not receive instructions from anybody and cannot be prosecuted during the execution of her duty.<sup>468</sup> As a result of one of her visits to psychiatric hospitals, she recently recommended the imposition of a duty to register the use of isolation and mechanical restraints, which was then adopted as law.<sup>469</sup> While this example shows how powerful monitoring might be, it is also important to emphasize that monitoring places of deprivation of liberty is not a replacement for abolition of these settings entirely – but rather, when used well, from a human rights-standpoint, and when applied to all settings where deprivation of liberty might occur, can help to advance efforts for abolishing these discriminatory settings.

In addition to the need for legal, social and cultural change regarding the rights of persons with disabilities, most participants focused on the need for accessible, affordable, and effective mainstream public services and supports, for example in the fields of employment, education, health, housing and transport, which could be relied upon by persons with disabilities and their families in order to avoid deprivations of liberty. Further, the need for a social safety net, and a societal commitment to ensure that individuals' basic needs for food, warmth, shelter and income support, were viewed as critical – and the absence of ways to meet these basic needs in individuals' communities were often cited as reasons for institutionalization and other forms of deprivation of liberty. More broadly, the need to embrace diversity in society, in particular, the acceptance of diverse forms of communication and behaviors which some may find challenging, was noted as an important dimension of ensuring that persons with disabilities could be respected and fully included within their communities and society as a whole.

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<sup>468</sup> More information available at: <<http://www.cglpl.fr/en/>> accessed 11 April 2019.

<sup>469</sup> Contrôleur général des lieux de privation de liberté, 'Isolement et contention dans les établissements de santé mentale' (2016).

## 6. Conclusions

This research has documented how deprivation of liberty of persons with disabilities is routinely practiced across the globe. Persons with disabilities are at risk of being deprived of liberty throughout their lives, as the provision of support, care and treatment is frequently made contingent to being hospitalized or institutionalized. Persons with disabilities are subject to constant control and supervision over their lives.<sup>470</sup> The individual has to meet to a certain expected behavior and is the target of rehabilitation programs, but not the community around him. In many instances, persons with disabilities will experience more than one of these forms of deprivation of liberty. This research has further demonstrated that closing disability-specific settings or prohibiting disability based deprivation of liberty is not enough to prevent discrimination and human rights violations. Clear laws and policies targeted at ending disability-specific practices of detention must be in place, as general recognition of the right to liberty or non-discrimination has not been effective enough to achieve this right in practice to date. An active counter policy of support in the community, of provision basic services such as access to health and education in the community and active monitoring is required.

The law in all reviewed countries allows for deprivation of liberty in one form or another, very often with limited access to review of the decision or no practical chances of accessing justice, often due to lack of recognition of the discriminatory nature of these spaces of detention. In many instances, persons who are deemed to lack capacity or under guardianship are not considered deprived of liberty but 'cared for'.<sup>471</sup> Further, while psychiatric hospitals and forensic facilities are generally recognized as potential places of detention in national legal frameworks, social care institutions, nursing homes, group homes, prayer camps and home confinement are often not recognized as settings in which deprivation of liberty occurs. Legislation, policies and even governmental structures on these areas are often separate bodies.

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<sup>470</sup> CRPD/C/GC/5; Alana Davis et al, 'Am I there yet? The views of people with learning disability on forensic community rehabilitation' (2015) 6(3/4) *Journal of Intellectual Disabilities and Offending Behaviour* 148.

<sup>471</sup> Lawrence O Gostin, 'Old' and 'new' institutions for persons with mental illness: Treatment, punishment or preventive confinement?' (2008) 122 *Journal of the Royal Institute of Public Health* 906.

The lack of data and of national monitoring of institutions together with the fact that procedural regulation applies mainly to involuntary psychiatric hospitalization may be interpreted as a lack of awareness that institutionalization is a form of deprivation of liberty. In many cases, placing persons under guardianship puts them at higher risk of being deprived of liberty and they also become invisible to data collection on the specific issue of deprivation of liberty, as most institutional settings do not keep disaggregated data on individuals admitted by guardians without the person's consent. Further, this research found that some deinstitutionalization strategies often include smaller institutions as part of independent living or better options than institutions, where the underlying framework picturing persons with disabilities as objects of care and the culture of locking away remains the same.

The increasing awareness of human rights violations within psychiatric facilities and other institutions (particularly with exposures of violence and abuse) has put pressure on states, which consequently have increased procedural regulation, rather than attempting to abolish these settings entirely. As described in this research, procedural rules are insufficient because they very often simply verify the technicalities of the detention (bureaucracy) while not addressing the underlying substantive discriminatory reason to detain the person, nor do they address discrimination (especially where persons with disabilities are deemed to lack capacity to consent to the placement). Further, the interviews conducted for this research revealed that persons with disabilities often do not know their rights, that the procedural safeguards or monitoring provisions are weak and that the medical and legal systems reinforce each other to justify the continued use of detention. This increased attention to due process reaffirms the belief that mental health laws are necessary and that persons with disabilities need security, protection and care above all.<sup>472</sup>

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<sup>472</sup> Lance Gable et al, 'Mental health and due process in the Americas: protecting the human rights of persons involuntarily admitted to and detained in psychiatric institutions' (2005) 18(4/5) *Revista Panamericana de Salud Pública* 366.

This research has also found that a key factor in the continued existence of disability-specific deprivation of liberty is the lack of alternatives and support in the community and lack of inclusion in mainstream education, employment and community. Housing is, in many cases, not accessible nor affordable. Participants in this research who experienced institutionalization were isolated from mainstream society, and often found the process of returning to mainstream spaces and communities much more difficult than the deprivation of liberty itself. Social housing must therefore be further developed,<sup>473</sup> and welfare safety nets must avoid creating or feeding into structures of dependency and vulnerability, and instead focus on supporting individuals to live full lives in their communities.

Families were identified throughout this research as playing a major role to prevent or to trigger deprivation of liberty of the person, particularly in communities and cultures where the person is dependent on the family's care and support. This puts a lot of pressure on families, who may struggle to cope with their relatives' needs for care and support. The alternative offered by states is usually an institution, instead of finding ways to support the family and the individual within the family. In most contexts, care is still assigned to families as a lifelong responsibility. The alternative for persons with disabilities without families or whose family can no longer support or care for her, is usually hospitalization or institutionalization, if available. Policies need to start recognizing families and communities as actors and subject of support needs, not only persons with disabilities.<sup>474</sup>

Persons with disabilities are not involved in decision-making processes nor in research on disability-specific deprivations of liberty. Many of the participants in this study called for a more active involvement of persons with disabilities in decision making processes, especially about issues that affected their lives directly. This finding is also reflected in the literature review, which shows that most research projects do not include persons with disabilities, or does not look

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<sup>473</sup> 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, Raquel Rolnik, 30 December 2013, A/HRC/25/54/Add.2.

<sup>474</sup> Vicki Welch et al, 'Permanence for disabled children and young people through foster care and adoption: A selective review of international literature' (2015) 53 Children and Youth Services Review 137.

at other factors within the community. While studies on deinstitutionalization or institutions often do take into account the views of family members, studies on involuntary psychiatric hospitalization focus more on the profiles of detained persons rather than the needs and desires that patient may have. Research on children and disabilities is still particularly marginalized and needs to be expanded.<sup>475</sup>

Lastly, disability-based discrimination in mainstream public services and supports such as transport, education, employment, social welfare, housing, and health needs to be addressed to start building a more inclusive society, supporting both individuals and families and to reverse the trend of pushing people into institutions and hospitals. This research has therefore starkly demonstrated that disability-specific deprivation of liberty crystalizes the continuum of social, segregation and violence exercised over persons with disabilities, and must be addressed comprehensively.

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<sup>475</sup> Nick Watson, 'Theorising the lives of disabled children: How can disability theory help?' (2012) 26(3) *Children and Society* 192.

### Annex I: Characteristics of the selected countries

Table A 1. Socioeconomic characteristics selected countries

Country	Region	CRPD	World Bank classification	GNI per capita (current USD 2015)	GINI (2014)	HDI (2015)	MPI (2015)	Public health expenditure (%GDP)	Share of the regional population (2015)	Type of welfare state	Availability of information
Costa Rica	Latin America	Ratified Convention and protocol	Upper-middle	10.400	48.5	0.776	No information	6.8	1%	Pioneer	Limited information
Peru	Latin America	Ratified Convention and protocol	Upper-middle	6.130	44.1	0.740	0.043	3.3	4.7%	Middle comer	Limited information
Argentina	Latin America	Ratified Convention and protocol	Upper-middle	12.460	42.7	0.827	0.015	2.7	6.4%	Pioneer	Limited information
Indonesia	East Asia and Pacific	Ratified Convention	Lower-middle	3.440		0.689	0.024	1.1	5.6%	Limited	Limited information
Philippines	East Asia	Ratified Convention	Lower-middle	3.550		0.682	0.033	1.6	2.2%	Limited	Limited information

	and Pacific										
<i>Australia</i>	East Asia and Pacific	Ratified Convention and protocol	High-income	60.070	31.3 (1981)	0.939	No information	6.3	57.1%	Liberal	Good source of data
<i>Kenya</i>	Africa	Ratified Convention	Lower-middle	1.340		0.555	0.166	3.5	3.6%	Limited	Limited information
<i>Ghana</i>	Africa	Ratified Convention and protocol	Lower-middle	1.480		0.579	0.147	2.1	20.8%	Limited	Limited Information
<i>Rwanda</i>	Africa	Ratified Convention and protocol	Low	700		0.498	0.254	2.9	1%	Limited	Limited information
<i>Senegal</i>	Africa	Ratified Convention and protocol	Low	980	40.3	0.494	0.439	4.7		Limited	Limited information
<i>France</i>	Europe and Central Asia	Ratified Convention and protocol	High-income	40.540		0.897	No information	9.0	8.9%	Conservative	Influence over former colonies
<i>Spain</i>	Europe and Central Asia	Ratified Convention and protocol	High-income	28.530		0.884	No information	6.4	6.3%	Conservative	Influence over former colonies

<i>Moldova</i>	Europe and Central Asia	Ratified Convention	Lower-middle	2.240	26.8	0.699	0.04	5.3	0.5%	Limited	Moderate sources of information
<i>Qatar</i>	Middle East	Ratified Convention	High income	75.660		0.856	No information	2.2		Limited	Limited information
<i>Jordan</i>	Middle East	Ratified Convention	Upper-middle	4.680		0.742	0.04	5.2	0.14%	Limited	Limited information

## Annex II: Questionnaire

### Questionnaire: The right to liberty and security of persons with disabilities

#### I. Context

For her report to the Human Rights Council, 40th session, the Special Rapporteur on the rights of persons with disabilities, Ms. Catalina Devandas Aguilar, intends to focus on the right to liberty and security of persons with disabilities.

The Special Rapporteur intends to undertake an innovative research on the various forms of deprivation of liberty experienced exclusively by persons with disabilities across the globe. In her report, she aims to examine the global challenges in relation to securing enjoyment of the right to liberty and security of person by persons with disabilities on an equal basis with others, identify disability-specific forms of deprivation of liberty and scrutinize them through the lens of human rights, as well as to present emerging trends and good practices related to securing implementation of this right.

The Special Rapporteur hopes to further develop the understanding of the scope of the right to liberty and security of the person in relation to persons with disabilities and to provide a clear guiding framework aimed at assisting governments in the implementation of rights as set under the article 9 of the International Covenant on Civil and Political Rights, article 37(b) of the Convention on the Rights of the Child, and article 14 of the Convention on the Rights of Persons with Disabilities.

The following questionnaire will assist the Special Rapporteur to identify instances in which persons may be deprived of their liberty for reasons tied to their actual or perceived disabilities and to better grasp the current situation when it comes to the enjoyment of the right to liberty and security by persons with disabilities.

#### II. Questionnaire

1. Please provide information in relation to the existence of legislation and policies that are intended to ensure and protect the right to liberty and security of persons with disabilities.
2. Please provide information on relevant legislation and policies related to:
  - 2.1. exercise of legal capacity;
  - 2.2. the rights of persons with disabilities in institutions<sup>476</sup> including processes of deinstitutionalization;

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<sup>476</sup> For the purposes of this questionnaire, institutions include all facilities that are aimed to provide shelter, care or a living arrangement **for persons with disabilities** such as residences, nursing homes,

- 2.3. involuntary admission to mental health services or other institutions;
  - 2.4. criteria to be found not criminally responsible (insanity defence, *inimputabilidad*, etc.);
  - 2.5. unfitness to stand trial or unfitness to plead;
  - 2.6. security measures and diversion programmes.
3. Please provide the most recently available data, disaggregated by sex and age if possible, on the number of:
    - 3.1. persons under guardianship;
    - 3.2. cases where the state or an organization has been appointed guardian;
    - 3.3. institutions for persons with disabilities;
    - 3.4. persons with disabilities placed in institutions;
    - 3.5. persons in institutions under guardianship;
    - 3.6. registers of the use of seclusion and restraints and its frequency;
    - 3.7. involuntary admissions to mental health services or other social care facilities;
    - 3.8. existing inpatient mental health facilities;
    - 3.9. beds for mental health inpatients in psychiatric hospitals and general hospitals;
    - 3.10. average days a person spends under involuntary admission at mental health facilities;
    - 3.11. persons who have been declared unfit to stand trial or unfit to plead;
    - 3.12. persons who have been found not to be criminally responsible;
    - 3.13. institutions where persons who have been declared unfit to plead, stand trial or found to be not criminally responsible are placed and number of inmates;
    - 3.14. security or preventive measures applied in the criminal justice context.
  4. Please provide information on jurisprudence, complaints or investigations in relation to abuses and violence against persons with disabilities at home.
  5. Please provide any other relevant information (including information from surveys, censuses, administrative data, reports, studies, and case law) in relation to the right to liberty and security of persons with disabilities in your country. Please also refer to any innovative initiatives that have been taken at

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orphanages, homes for the elderly, community homes, tutorised homes, farms, faith based institutions, boarding schools, prayer camps, or others.

the local, regional or national level to promote and ensure the right to liberty and security of persons with disabilities and identify lessons learned from these.

Thank you for your responses and contributions.

### **III. Submission of responses**

Due to limited capacity for translation, we kindly request that you submit your answers, if possible, in **English, Spanish or French** and, no later than **30 May 2017**. Kindly identify links or provide copies of any laws, documents or cases, related to your answers. All responses will be posted in the official web page of the Rapporteur unless you indicate otherwise at:

<http://www.ohchr.org/EN/Issues/Disability/SRDisabilities>

Kindly be concise in your responses and them preferably via email to: [sr.disability@ohchr.org](mailto:sr.disability@ohchr.org), copying [registry@ohchr.org](mailto:registry@ohchr.org).

For any question, please contact the Special Rapporteur through Ms. Alina Grigoras, human rights officer at Special Procedures Branch- OHCHR: email: [agrigoaras@ohchr.org](mailto:agrigoaras@ohchr.org); phone: +41 22 917 92 89; or Ms. Cristina Michels, human rights officer at Special Procedures Branch- OHCHR: email: [cmichels@ohchr.org](mailto:cmichels@ohchr.org), phone +41 22 928 9866.

### Annex III: Stakeholder categories

<b>Group</b>	<b>Requirements</b>	<b>Justification</b>	<b>Min. Number</b>
<b>Policy maker</b>	A person who is part of the National Council for Persons with Disabilities or who has been involved in recent policymaking.	Policy makers are often identified as key stakeholders for change, without understanding what pressures or reasons they may be exposed to.	1
<b>Directors of healthcare institutions &amp; social services</b>	At least one from psychiatric (mental health) services and one General Practitioner.	Directors of healthcare institutions and social services have been chosen in an effort to identify the role of the services, the demands and the limitations of services.	2
<b>Non-Governmental Organizations working with persons with disabilities</b>	Disabled Persons Organizations run for and by persons with disabilities for the provision of services for persons with disabilities.	Local NGOs provide a critical voice. These interviews will give us an understanding of what NGOs identify as the needs of persons with disabilities and to identify changes and good practices.	2
<b>Health and social care professionals</b>	A psychiatrist, a doctor or a health care professional who evaluates persons with disabilities going through a legal process.	Health and social care professionals are often a gateway to the admission of or institutionalization of persons with disabilities. This group will help us to understand the reasons why persons with disabilities are admitted to institutions, the options available and to examine what structures and policies are needed to ensure full enjoyment of the right to liberty for persons with disabilities.	2
<b>Family member</b>	Family members include grandparents, parents and siblings. They do not have to be related to the interviewed persons with disabilities, but it is ok they if they are – please mark it in the questionnaire if this is the case.	Family members will paint a picture of the situations of disability-specific deprivation of liberty. Family members will be asked their opinion on what supports are available and what supports are missing and it is hoped that family members will be able to identify the triggers or causes of an admission or institutionalization	5

		or the factors that prevented an admission or institutionalization.	
<b><i>Person with Disabilities</i></b>	Please include at least one person who identifies with a psychosocial disability and one who identifies with a physical disability. Persons identifying with intellectual disabilities are highly desirable.	Persons with disabilities with lived experience of deprivation of liberty to provide personal insights into this experience.	8
<i>Total</i>			<b>20</b>

## Annex IV: Codes

### CODING

Storyline: Persons with disabilities are deprived of liberty on the basis of disability because of a lack of opportunities, the dominating conceptual model of disability, stigma and the organization of services.

Please code your notes too.

#### Codes:

Open List: We will use inductive and deductive analysis, with an open set of preset codes which may be enlarged with emerging codes. Further, we have identified overarching categories for the different codes.<sup>477</sup>

#### Category: Lack of opportunities

Code	Rule of inclusion - Example
<i>Relational conflicts</i>	There is a conflict between the person with disabilities and their environment and family. For e.g. Participant says a relative placed them in an institution/hospital against their will after a conflict, e.g. parents died, inheritance, partner divorce.
<i>Frustration, tiredness, burden - Family can no longer support</i>	Participant expresses that the family could no longer support the person because of the stress it is for the family, or the participant expresses the need to work and impossibility to support their family member. Monoparental family, out of wedlock child, Parents with disabilities
<i>Lack of knowing how to support</i>	The family did not know how to communicate or support the person
<i>Lack of community services or family support</i>	Participant says there is no other option or that the only option was the institution, there is no support for families
<i>No available resources</i>	Participant mentions the cost or burden of reaching services or support.

#### Category: Views and models of disability

Code	Rule of inclusion - Example
<i>Stigma</i>	Participant expresses negative feelings in relation to persons with disabilities such shame, disgrace, dishonor, tragedy, bad luck
<i>Discrimination</i>	Participants express discriminatory practices based on gender, ethnic minority, faith, sexual orientation, or the fact that a certain service or place is not suitable for

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<sup>477</sup> Lewins & Silver, 2007

	the person due to her disability or because of high support needs.
<i>Security - Avoid uncertainty</i>	Participant expresses the wish to guarantee a living or security for the person with disabilities.
<i>Control persons</i>	Participant expresses that there is a need to control the person or this type of population, to avoid or control aggressive behavior, public security
<i>Need for protection, fear and concern, overprotection</i>	Participant expresses fear and concern about the person's wellbeing or future. Participants expresses that the persons need to be kept safe, expresses pity, sympathy, "the person is fragile, cannot do anything" – no plans for the future.

**Category: Structural causes**

<b>Code</b>	<b>Rule of inclusion - Example</b>
<i>Responsibilities / liability issues / Fear of losing job</i>	Participant expresses diminished capability of responsibility of persons with disabilities or duty of care over the person: "He could hurt someone", "he does not know what he is doing", "We have a duty of care over him", "We cannot let a person leave just like that", "If something happens, they will blame us". "I have to do it, otherwise I would lose my job".
<i>Legal requirement</i>	Participant identifies a mandatory rule to justify the action or the fact that the person lacks legal capacity.
<i>Design of services</i>	Participants identifies organizational issues, e.g. "all persons we assist have to be institutionalized", "we cannot let people leave because we do not have persons to support them", "we do not provide assistance if we cannot control all risks", this risk assessments requires us to hospitalize the person", lack of staff.
<i>Only option to get services or resources</i>	Participants identify that it is the sole resource to obtain support or services, e.g. mandatory institutionalization or hospitalization to access a specialist or care services.
<i>Cultural and social pressure</i>	Participants identify social expectations, habits and traditions

### **Emerging codes:**

If you identify any ideas, concepts, actions, relationships, meanings, etc. that come up in the data and are different than the pre-set codes, please report them to us and we can code them and communicate them to the rest of the team.

The interview transcripts and notes will be explored for patterns<sup>478</sup> as stable regularities but also as varying forms, noting that the patterns can be characterized by:

- similarity (things happen the same way)
- difference (they happen in predictably different ways)
- frequency (they happen often or seldom)
- sequence (they happen in a certain order)
- correspondence (they happen in relation to other activities or events)
- causation (one appears to cause another)

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<sup>478</sup> Hatch (2002)

## Annex V: Topic guides

### Topic guide for semi-structured interviews – stakeholder groups 1- 4

Introduction: I am \_\_\_\_\_ from  
\_\_\_\_\_

- ✓ **General purpose of the project**
- ✓ **Aims of the interview and expected duration**
- ✓ **Who is involved in the process (other participants)**
- ✓ **Why the participant's involvement is important**
- ✓ **What will happen with the collected information and how the participant will benefit**
- ✓ **Any questions?**
- ✓ **Consent to participate and for interview to be recorded**

Today, I would like to ask you some questions about your experiences of working as a [policy maker] on matters around persons with disabilities. We are especially interested in the areas where persons with disabilities are at risk of being deprived of liberty or are deprived of liberty. These areas are: involuntary admission to a psychiatric hospital, diversion from the criminal justice system, institutionalization and home deprivation of liberty.

These areas were identified through a review of international and regional human rights law.

The interview has been designed to better understand the responses to persons with disabilities, what services are available to them and what barriers persons with disabilities, families or professionals encounter.

The interview will include all types of disabilities. Children with disabilities are also included.

Diversion from the criminal justice system means any referral of a person with disability who has been accused of committing a crime into a separate branch such as a forensic mental health facility avoiding prosecution and trial.

Institutionalization refers to any person placed to live in an institution. Following the European Network for Independent Living's definition of institution: '*any place in which people who have been labelled as having a disability are isolated, segregated and/or compelled to live together. An institution is also any place in which people do not have, or are not allowed to exercise control over their lives and their day-to-day decisions. An institution is not defined merely by its size.*' Examples of institutions include: residences, boarding schools, community residences, nursing or collective homes.

A person living in an institution that cannot leave is considered to be deprived of liberty.

Home deprivation of liberty means a person who is locked up at home and cannot leave.

This interview will be recorded. Please make sure to sign the consent form. You may stop the interview at any point if you feel uncomfortable or tired. Your participation is voluntary and you may withdraw from it at any point. We are very grateful for your time and involvement in this research.

Topic	Questions and Probes
<p><b><u>Involuntary hospitalisation</u></b></p>	<ol style="list-style-type: none"> <li>1. Why are persons admitted involuntarily? What triggers the admission?           <p><i>Probes:</i></p> <ol style="list-style-type: none"> <li>a. What is the concern of doctors, judges, families or police when admitting or retaining a person against her will on the basis of a disability?</li> <li>b. What happened before the admission into a hospital?</li> <li>c. What do you think the role of family or community is with regards to involuntary hospitalisation? And the state's role?</li> <li>d. Is the discharge of a person planned? Is there support available?</li> </ol> </li>   <li>2. Some persons accept to be admitted to a psychiatric hospital voluntarily because they know they will be otherwise admitted involuntarily. Why do you think this happens?           <p><i>Probes:</i></p> <ol style="list-style-type: none"> <li>a. Can you think of other reasons why persons go to a psychiatric hospital under coercion? E.g. Or be maltreated in the house or in prayer camps or other unwanted alternative treatment?</li> <li>b. How does psychiatric admission work?</li> <li>c. What rights and support does a person get within the psychiatric facility?</li> <li>d. What are the rules to convert a patient from voluntary to involuntary status?</li> <li>e. Is the consent of a guardian considered to be voluntary or involuntary admission?</li> <li>f. Do you think there is any type of overrepresentation of some part of society (e.g. lower social classes, migrants, gender, etc.)?</li> </ol> </li>   <li>3. Do you know of any alternatives to involuntary psychiatric hospitalisation? (If yes, what made these alternatives possible? What is the background?)           <p><i>Probes:</i></p> </li> </ol>

	<ul style="list-style-type: none"> <li>a. What is, in your opinion, needed to avoid involuntary hospitalization?</li> <li>b. What are the barriers to the use of alternatives to psychiatric hospitalisation?</li> <li>c. In your own work, to what extent would you say that a human rights-based approach to mental health is a priority?</li> <li>d.</li> </ul>
<p><b><u>Diversion from the criminal justice system</u></b></p>	<p><b>I would now like to discuss different aspects on diversion from the criminal justice system. As you may know, persons with disabilities may be put onto a parallel track to the criminal justice system like a forensic or psychiatric hospital, a special prison, etc.</b></p> <ul style="list-style-type: none"> <li>a. Why do you think this happens?</li> </ul> <p><u>Probes:</u></p> <ul style="list-style-type: none"> <li>b. What are the concerns when assessing somebody for a diversion measures?</li> <li>c. Why can a person with disability not participate in a trial?</li> <li>d. Do you think the family can avoid or promote diversion?</li> <li>e. Do you think there is any type of overrepresentation of some part of society (e.g. lower social classes, migrants, men, etc.)?</li> <li>f. Are there any diversion options that are not based on mental capacity or disability, e.g. for young offenders or from ethnic or cultural minorities? Or any restorative justice initiatives? Are they suitable for persons with disabilities?</li> <li>g. Are there any support measures available if a person has difficulties participating in trial?</li> </ul> <p><u>Probes:</u></p> <ul style="list-style-type: none"> <li>h. Are there any support services available during trial?</li> <li>i. Are there any resources to support persons with disabilities in prisons?</li> <li>j. Are there any barriers to using support measures during trial?</li> <li>k. Can you think of any good practices in relation with supporting persons with disabilities through a criminal justice procedure? (If yes, what made these good practices possible? What is the background?)</li> </ul> <p><u>Probes:</u></p> <ul style="list-style-type: none"> <li>l. How does the police work? Do they have any awareness training?</li> <li>m. Are judges aware of the support needs or barriers persons with disabilities encounter?</li> <li>n. Is there any training or support service available?</li> </ul>

## Institutionalization

**I would now like to move to discussing the placement of persons with disabilities within institutions such as care homes, residences, special homes, or other alternative practices such as faith based camps.**

- a. Why are persons with disabilities brought to institutions?

Probes:

- b. What do you think the role of the family and the community is in placing or avoiding the placement of persons with disabilities in institutions or alternative settings?
- c. And the state's role in institutionalization?
- d. To what extent do you face attitudinal barriers towards persons with disabilities living independently?

Consider: political commitment; coordination between different actors/levels of government; adequate resources; societal attitudes; established models of service provision.

- e. Why are children placed in institutions?

- f. What happens when the person expresses discontent or the wish to leave?

Probes:

- g. Are there transition support services to leave out-of-home care/institutions?
- h. What is the costliest part of supporting a person with disabilities?
- i. Are there alternatives available to support persons with disabilities living independently?
- j. Do you know of any good practices in deinstitutionalization?

(If yes, what made these good practices possible? What is the background?)

Probes:

- k. What do you think is needed to make deinstitutionalization a reality in [COUNTRY]?
- l. Have deinstitutionalization processes just created mini institutions in the community (e.g. smaller group homes where the person still lacks choice and control) or has it been a real effort to promote independent living?
- m. Consider: political commitment; coordination between different actors/levels of government; adequate resources; societal attitudes; established models of service provision.
- n. What services are needed?
- o. Who opposes deinstitutionalization?

<p><b><u>Home deprivation of liberty</u></b></p>	<p><b>I would now like to move to discussing situations where the person with disability is locked up or isolated at home.</b></p> <ol style="list-style-type: none"> <li>1. Why do you think persons with disabilities are deprived of liberty at home? <i>Probes:</i> <ol style="list-style-type: none"> <li>a. Have you ever heard of persons with disabilities being detained at home? Could you imagine that this happens here? Why?</li> <li>b. What do you think the role of family or community is? And the state's role?</li> <li>c. What hinders the inclusion of persons with disabilities?</li> </ol> </li> <li>2. What support is available for the person and her environment to overcome difficult situations, e.g. unemployment, abandonment, distress within the family such as death, divorce, domestic violence, etc.? <i>Probes:</i> <ol style="list-style-type: none"> <li>a. Do you think persons with disabilities living at home have opportunities within the community? If not, what is missing?</li> <li>b. Why does abuse or exploitation of persons with disabilities within the family occur?</li> <li>c. Is a disability certificate or a specific percentage of disability a trigger to obtain support?</li> </ol> </li> <li>3. Are you aware of any good practices in this area, that support persons with disabilities living at home in their communities? (If yes, what made these good practices possible? What is the background?) <i>Probes:</i> <ol style="list-style-type: none"> <li>a. Are carers or informal support persons eligible for support programmes or trainings?</li> <li>b. Do you know of any services that support persons at home?</li> <li>c. Do persons with disabilities have opportunities to participate in the community?</li> </ol> </li> </ol>
<p><b><u>Final questions on deprivation of liberty</u></b></p>	<p><b>Lastly, I want to ask you a few questions on the general perception of persons with disabilities, the available resources and services for persons with disabilities.</b></p> <ol style="list-style-type: none"> <li>1. Do you think that there is a stigma attached to the notion of a disability? If yes, what is it? <i>Probes:</i> <ol style="list-style-type: none"> <li>a. What ideas are associated with persons with disabilities?</li> <li>b. Are there disability positive messages in society in general?</li> </ol> </li> </ol>

	<p>c. Do general policies and laws acknowledge persons with disabilities? d. How does stigma affect families?</p> <p>2. How are service providers organized? What is their main concern? <i>Probes:</i></p> <p>a. Do you think that responsibility or liability is an issue for service providers? b. Do you think services are centered on the person or on their organizational needs? What is the service's priority? c. Where does the funding for disability services come from? Do you think disability-specific services get more funding than services to support or include persons with disabilities in the community?</p> <p>3. Are general population or mainstream public services accessible for persons with disabilities? <i>(If you can think of a good example please name it. What made this possible? What is the background?)</i></p> <p><i>Probes:</i></p> <p>a. Is support, reasonable accommodation or accessibility measures available to participate in mainstream events and services? b. Do you think mainstream services would reject a person with disabilities? Why? c. What do you think is most difficult for mainstream services to support persons with disabilities?</p>
<p>Closing – Is there anything else you think is important that we have not talked about that you would like to mention?</p> <ul style="list-style-type: none"> <li>✓ <b>Summarize</b></li> <li>✓ <b>Thank participant</b></li> <li>✓ <b>Inform participant of possibility to contact CDLP with any further questions on the research or the project, or anything they would like to add</b></li> <li>✓ <b>Ask if there are other people the participant considers important to contact/interview as part of the research.</b></li> </ul>	

**Topic guide for semi-structured interviews – stakeholder groups 5 - 6**  
**Interview for persons with lived experience**

Purpose: Our objective is to find out what underlying causes trigger deprivation of liberty of persons with disabilities and what can be done differently to avoid deprivation of liberty.

Please do not read out the parts in brackets.

**Introduction:** I am \_\_\_\_\_ from  
\_\_\_\_\_

- ✓ General purpose of the project
- ✓ Aims of the interview and expected duration
- ✓ Who is involved in the process (other participants)
- ✓ Why the participant's involvement is important
- ✓ What will happen with the collected information and how the participant will benefit
- ✓ Any questions?
- ✓ Consent to participate and for interview to be recorded

**Today, I would like to ask you some questions about your experiences in \_\_\_\_\_ . We are interested in finding out why persons with disabilities are put into psychiatric hospitals or institutions. Your experience is very valuable to us.**

**This interview will be recorded. Please make sure to sign the consent form. You may stop the interview at any point if you feel uncomfortable or tired. Your participation is voluntary and you may withdraw from it at any point. We are very grateful for your time and involvement in this research.**

Warming up questions:

1. Tell us a bit about yourself.
2. Where do you currently live?
3. Do you identify as a person with disabilities or do you prefer a different concept?
4. What does society think about persons with disabilities?

We are interested in your experience during your hospitalization/institutionalization.

1. Can you tell us how you got there?
  - a. Who took you there? Why? [Let the person tell the story in depth/ possible causes – lack of opportunities, stigma, etc.]
  - b. What was going on in your life?
  - c. How was it?
  - d. What happened after your admission?
  - e. How did you feel?
  - f. When did you leave? Who decided that?
2. What is different now from the situation when you were institutionalized?
  - a. What has been helpful to change that situation?
  - b. What type of support do you like?
  - c. What would you tell other persons who are institutionalized?
3. What needs to change to avoid these practices of institutionalization?
  - a. What services do you think will help to avoid hospitalization / institutionalization?
  - b. What do you think needs to change in your community?
  - c. Can you tell us of any good practices? How do they work? [find out about the context]

## Interview with family members

**Introduction:** I am \_\_\_\_\_ from  
\_\_\_\_\_

- ✓ General purpose of the project
- ✓ Aims of the interview and expected duration
- ✓ Who is involved in the process (other participants)
- ✓ Why the participant's involvement is important
- ✓ What will happen with the collected information and how the participant will benefit
- ✓ Any questions?
- ✓ Consent to participate and for interview to be recorded

**Today, I would like to ask you some questions about your experiences as family of a person that has been in**

\_\_\_\_\_. **We are interested in finding out why persons with disabilities are put into psychiatric hospitals or institutions and how this can be avoided. Your perspective is very valuable to us.**

**This interview will be recorded. Please make sure to sign the consent form. You may stop the interview at any point if you feel uncomfortable or tired. Your participation is voluntary and you may withdraw from it at any point. We are very grateful for your time and involvement in this research.**

Please substitute "relative" by the kinship with the person with disabilities.

Please note whether the family member still is institutionalized or not.

Warming up questions:

1. Tell us a bit about your family life.
2. Has your (relative) with disabilities influenced your family life? If yes, how?
3. Are there prejudices or stigma around disabilities? How do they affect institutions and services for persons with disabilities?

We are interested in understanding what triggered the hospitalization/ institutionalization of your (relative).

1. Can you tell us when was your relative admitted?
2. How did it happen? [Let the person tell the story in depth/ possible causes – lack of opportunities, stigma, etc.]
3. Was there anything of particular that triggered the decision?
4. Were you concerned with being held responsible for your relative's actions?
5. How did you feel during that period of hospitalization / institutionalization?

If the person is no longer institutionalized,

1. Please tell us how the deinstitutionalization or release from hospital happened.
2. What was helpful?
3. What changed during that period?
4. How has the situation changed from before being institutionalized to now?

We now want to talk about what do you think is needed to support persons with disabilities in your community.

1. Can you tell us what you think must change to support persons with disabilities in your community?
2. What type of support do you think families could need?
3. Can you tell us of any good practices for families and for persons with disabilities? How do they work? [find out about the context]

### **Annex VI: Good practices' criteria**

The determination of good practices will be based on the CRPD, especially the respect of inherent dignity, the will and preferences of the person and life within the community.

For this research study, the good practices sought shall focus on respecting the right to liberty, such as the existence of peer support or crisis homes to avoid involuntary psychiatric hospitalization, or a non-discriminatory alternative to diversion from the criminal justice system such as support during criminal procedures, reasonable accommodation, non-discriminatory diversion measures or restorative justice initiatives. Accommodation within mainstream services are especially welcome, as well as practices that addressed intersectional or multilayered discrimination (e.g. women with disabilities) and initiatives to redesign or rethink housing to be all inclusive. Activities that promote social inclusion, combatting stigma, access to justice initiatives are also relevant to tackle the causes and consequences of disability-specific forms of deprivation of liberty. Good practices may also include the development of ethics of care, the reduction or elimination of restraint mechanisms, independent living initiatives, data collecting, monitoring initiatives. Lastly, the acceptance of service user without requiring a certificate, the provision of support without the need of a diagnosis or label is also considered a good practice to reduce the stigmatization of the person and the postponement of provision of support, especially in the case of children. The examples identified are subject to further exploration to ensure adherence to the CRPD.

Good practices shall not include any activity that uses or promotes:

- Any form of forced treatment (such as Community Treatment Orders);
- Any form of coercion or threat to deprive a person of liberty or legal capacity;
- Control or security mechanisms over persons with disabilities;
- Provision of guardianship;
- Substituted decision-making;
- Lack of respect of the person's will and preferences;
- Segregation of persons with disabilities.

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