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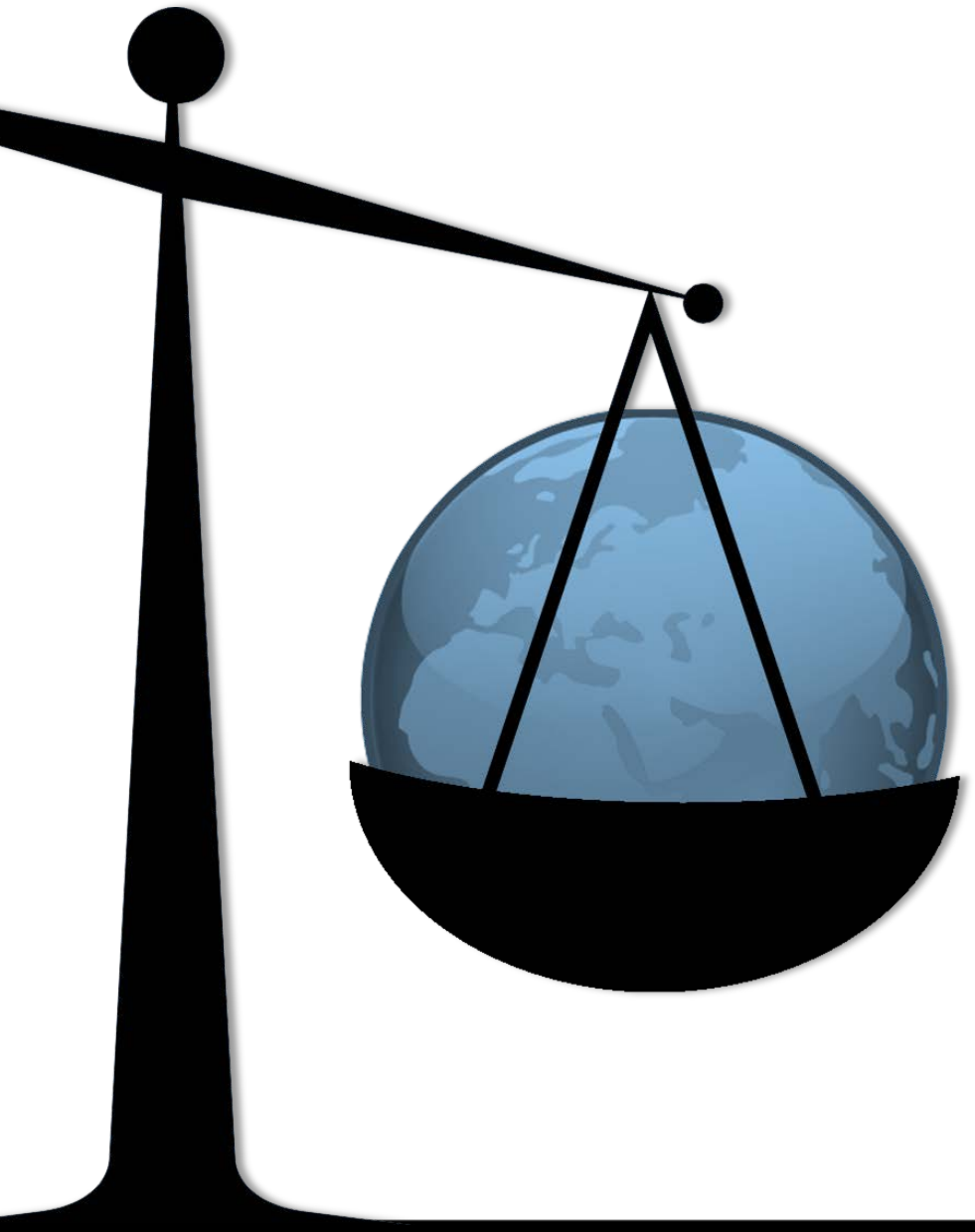
Right of a Child with disabilities to NOT be institutionalized



International Human Rights Internships Program - Working Paper Series

McGill Centre for Human Rights and Legal Pluralism
Centre sur les droits de la personne et le pluralisme juridique de McGill
McGill Faculty of Law Faculté de Droit

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Abstract

Despite the adoption of the Convention on the Rights of Persons with Disabilities, which offers the most comprehensive set of standards on the rights of persons with disabilities, in the context of health care, children with disabilities all around the world are still marginalized from society and permanently referred to institutions by medical doctors based on their supposed "best interest." These institutions are inherently dangerous where serious violations, discrimination and torture against children with disabilities may be masked as "good intentions" of health professionals. In this essay, I will argue that institutionalization of children with disabilities is a clear violation of their right to health and such practice should no longer be an option.

In the first part, I will display how the CRPD embodies a paradigm shift in the way disability is viewed. In part II, I will set the context of massive institutionalization and violations of the rights of children with disabilities in Guatemala. In part III, I will demonstrate how institutionalization is a violation of the right to health of children with disabilities. Finally, in part IV, I will elaborate on the implications of article 19 of CRPD, the right to live in community, and how it can be implemented to achieve deinstitutionalization and to enforce the right to health of children with disabilities.

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Introduction

More than one billion people around the world, of whom nearly 150 million are children, live with some form of disability. [1] Most of the children with disabilities around the world live in poverty or are isolated in mental institutions or orphanages. More than 80 % live in developing countries with little or no access to services.[2] Due to society's misconceptions and stigma, children with disabilities experience multiple forms of discrimination and inequalities in their daily lives and are at greater risk of neglect, institutionalization, and even death.

People with disabilities have historically been arbitrarily and unnecessarily segregated from society in institutions where they are abandoned for life and are subject to cruel, degrading treatment or torture. Over 80% of institutionalized children have a living parent and could be reunited with their families given the right support.[3] Even when institutions are well-resourced with dedicated staff, they cannot replace the care provided by a family and are inherently dangerous for the life and development of children with disabilities. The quality of care provided, whether educational, medical or rehabilitative, is often inferior to the standards necessary for the care of children with disabilities either because of a lack of identified standards or lack of implementation and monitoring of these standards. Children in institutions are also more vulnerable to mental, physical, sexual and other forms of abuse as well as neglect and negligent treatment.

Although earlier international human rights treaties applied to everybody, the specific situation of people with disabilities has been invisible in these instruments.[4] The right to "not be institutionalized" is not protected in any existing international human rights instruments, largely because it is assumed to be unproblematic in the case of persons without disabilities.[5]

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[1] UN World Health Organization, *World Report on Disability: Summary*, WHO, 2011, 43rd session, WHO/NMH/VIP/11.01, at para 1.

[2] UN Committee on the Rights of the Child (CRC), *General comment No. 9 (2006): The rights of children with disabilities*, 27 February 2007, CRC/C/GC/9, p.1.

[3] Csáky, C., *Keeping children out of harmful institutions: why we should be investing in family-based care*, Save the Children, London, 2009, p 3.

[4] Frédéric Mégret, "The Disabilities Convention: Human Rights of Persons with Disabilities or Disability Rights?", 2008 *Human Rights Quarterly* 30:2, 494-516. [*Mégret*]

[5] *ibid*, at p.510.

However, with the adoption of the United Nations *Convention on the Rights of Persons with Disabilities*[6] (CRPD) in 2006, there have been some positive developments on the rights of persons with disabilities, who are unique in their vulnerability to both exploitation and denial of participation.

Nevertheless, despite the CRPD receiving the highest number of signatures in history for a UN Convention on its opening day, discrimination and exclusion related to disabilities occur globally in all sectors of society. This is due mainly because disability has been viewed under the medical lens rather than the human rights framework for centuries and separation of children with disabilities from society have been justified as the best interest for their health and development. Even today, despite more than eighty years of research showing the negative impact of institutionalisation on children's health, development and life chances,[7] a high number of children with disabilities are still placed in institutions and institutionalization is still the preferred placement option in many countries around the world.

In this essay, I will argue that institutionalization of children with disabilities, despite the emphasis of the right to live in the community in the CRPD (article 19)[8], is a violation of their right to health. For far too long, children with disabilities have been permanently referred to institutions by medical doctors as their supposed best interest. It is time to break those barriers and recognize that **institutionalization is a clear violation of the right to health of children with disabilities.**

In the first part, I will display how the CRPD embodies a paradigm shift in the way disability is viewed. In part II, I will set the context of massive institutionalization and violations of the rights of children with disabilities in Guatemala. In part III, I will demonstrate how institutionalization is a violation of the right to health of children with disabilities. Finally, in part IV, I will elaborate on the implications of article 19 of CRPD, the right to live in

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[6] International Convention of the Rights of Persons with Disabilities and its Optional Protocol, U.N. GAOR, 61st Sess., Item 67(b), U.N. Doc. A/61/611 (Dec. 6, 2006) [CRPD].

[7] Berens, A., Nelson, C., *The science of early adversity: is there a role for large institutions in the care of vulnerable children?*, The Lancet, 2015, p.1.

[8] CRPD, *supra* note 6, art 19.

community, and how it can be implemented to achieve deinstitutionalization and to enforce the right to health of children with disabilities.

I. CRPD and the Paradigm shift

Although International Human Rights treaties, such as the *Universal Declaration on Human Rights* and the *International Covenant on Civil and Political Rights*, apply to everybody, people with disabilities have been forgotten in most treaties. Historically, disability has been treated within a medical model, where the person's incapability was seen as the problem that had to be "fixed." This model encouraged segregation and institutionalization of people with disabilities into lifetime mental facilities, because they were seen as a burden to society.

The charity model was the prevailing approach for dealing with social problems, in which people with disabilities were seen as objects of pity. It was assumed that philanthropists (donors) knew the needs of the "disabled" and would satisfy those needs through generosity, without their participation. Without identifying the root causes of disability, this model did not make any systemic changes.

Increased advocacy for human rights at the United Nations sessions with the effect of globalization and several political changes around the world, lead to the adoption of the *Declaration on the Right to Development* by the United Nations General Assembly:

"The right to development is an inalienable human right by virtue of which every human person and all peoples are entitled to participate in, contribute to, and enjoy economic, social, cultural and political development, in which all human rights and fundamental freedoms can be fully realised."[9]

This declaration highlighted the Rights-Based Approach to human rights and marked a new era in social development. "Nothing about us without us" is the new maxim, which establishes that the participation of the members of the group is necessary in policy making.

[9] UN General Assembly, *Declaration on the Right to Development : resolution / adopted by the General Assembly*, 4 December 1986, A/RES/41/128, art. 1.

This movement lead to the adoption of the CRPD, which embodies a paradigm shift in the approach to disability from a medical to a social model and identifies people with disabilities as right holders, celebrating human diversity and dignity. [10] The social model underlines that the problem lies in attitudinal and environmental barriers that prevent people with disabilities from participating fully and effectively in society on an equal basis with others.[11] In the Human Rights-based approach, the disability therefore arises from the interaction of an individual's 'impairment' with wider social and environmental barriers.[12] People with disabilities who were considered objects of pity are now regarded as subjects with equal rights, capable of taking their own decisions and contributing to society.

The Convention aims to empower people with disabilities by granting them a number of civil, political, economic, social, and cultural rights.[13] It claims that persons with disabilities are entitled to the full enjoyment of human rights and fundamental freedoms without discrimination,[14] reflected in its preamble and articles. The definition of disability now inherently includes the lack of participation in society.[15]

Furthermore, the CRPD and its Optional Protocol challenges customs and behavior based on stereotypes, prejudices, harmful practices and stigma by establishing the obligation, not only on states but also on society, to promote positive perceptions and greater social awareness towards persons with disabilities. Since all the rights are inter-related, the respect of all rights and full participation of people with disabilities are necessary for the respect of human dignity.

As human rights is a project in progress, in majority of the human rights conventions the rights are proclaimed as goals imposing obligations on the state but the implementation is left to the discretion of the states. The CRPD goes further with very detailed implementation

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[10] Caroline Harnacke, "Disability and Capability: Exploring the Usefulness of Martha Nussbaum's Capabilities Approach for the UN Disability Rights Convention", (2013) *Journal of Law, Medicine and Ethics* 41:4, p. 774

[11] UN General Assembly, Convention on the Rights of Persons with Disabilities, 13 December 2006, A/RES/61/106, Annex I, Section E.

[12] CRPD, *supra* note *6,* art 1.

[13] Supra note 10, at 768.

[14] United Nations Human Rights Office of High Commissioner, *The Convention on the Rights of Persons with Disabilities Training Guide Professional Training Series No. 19,* 2014, UNITED NATIONS PUBLICATION.

[15] *Mégret*, *supra* note 4 at 509.

articles, which include "negative" and "positive" obligations, explaining how states should ensure the respect of the rights of persons with disabilities.[16] The process of implementing international human rights treaties at national level often leads to changes in the law.[17]

a. Positive obligations

Negative rights require from the right-granter simply non-interference, whereas positive rights require active measurements from the state. The distinction is not always clear, so they are better seen as interrelated. Unlike most international human rights instruments which focus on negative obligations of the state, the CRPD also adds positive obligations on states to ensure the full and equal enjoyment of all human rights and fundamental freedoms by persons with disabilities, and to promote respect for their inherent dignity.[18] Article 2(4) of the CRPD defines discrimination as "any distinction, exclusion or restriction on the basis of disability which has the **purpose or effect** of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. **It includes all forms of discrimination, including denial of reasonable accommodation,"**[19] which is defined in article 2(5) as necessary and appropriate modification and adjustments, that do not impose a disproportionate or undue burden, where needed in a particular case.[20] Thus framing the concept of discrimination in terms of a denial of reasonable accommodation with reference to individual cases clearly establishes an individual right to reasonable accommodation. Further, article 5(3) stipulates that in order to promote equality and eliminate discrimination States Parties shall take all appropriate steps to ensure that reasonable accommodation is provided. The CRPD is the first convention that elaborates, in a legally binding international human rights instrument, the concept of reasonable accommodation, explicitly linking it to the realization of all human rights – civil,

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[16] *Ibid* at 504.

[17] Audrey Osler and Juanjuan Zhu, "Narratives in Teaching and Research for Justice and Human Rights" (2011) 6:3 *Education, Citizenship and Social Justice,* p.226.

[18] CRPD, *supra* note 6, art. 1.

[19] CEPD, *ibid* at art 2(4).

[20] CRPD, *ibid* at art 2(5).

political, economic, social, and cultural – and embedding it within the non-discrimination mandate.

The notion of negative and positive obligations comes from the negative and positive liberty approaches to autonomy. Negative liberty is the principle used to claim protection against unnecessary state intrusion on freedom.[21] In the positive liberty approach, self-determination and the capabilities for autonomy are interdependent and achievable through social, economic and political conditions that make it possible. The state has a positive obligation to maximize the exercise and enjoyment of autonomy by providing individuals with the goods and services necessary for developing their own capabilities.[22]

Actually, the CRPD highlights the interconnectedness of all human rights and re-conceptualize and unite negative and positive rights in the realization of equality for persons with disabilities by requiring reasonable accommodation through positive measures in all areas of life.[23]

i. Implementation and Optional protocol

By ratifying the different United Nations human rights treaties, states automatically assume the principal roles of guaranteeing these rights.[24] The CRPD is a legally binding treaty that requires signatories to implement strategies to promote and protect the rights of people with disabilities, including adopting legislation and administrative measures to promote the human rights of people with disabilities and abolish discrimination. Under the CRPD, states must also ensure that the public sector, private sector and individuals respect the rights of people with disabilities.[25] All States parties are obliged to submit regular reports to the Committee on how the rights are being implemented. Additionally, the *Optional Protocol* allows individuals or civil

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[21] Martha Fineman, The Autonomy Myth (New York: New Press, 2004) at 9.

[22] Catriona MacKenzie & Natalie Stoljar, "Introduction: Autonomy Reconfigured" in Catriona MacKenzie & Natalie Stoljar, eds., Relational Autonomy: Feminist Perspectives on Autonomy, Agency, and the Social Self (New York: Oxford University Press) at 4.

[23] Porter, B., "Rreasonableness of articles 8(4) – Adjudicating claims from the margins." 2009, Nordic Journal of Human Rights, 39–53, at 42.

[24] Ljungman, Cecilia M., COWI. *Applying a Rights-Based Approach to Development: Concepts and Principles,Conference Paper: The Winners and Losers from Rights-Based Approaches to Development.* November 2004, p.6.

[25] CRPD, *supranote 6,* art. 4(e).

societies to also submit complaints, which allows the most marginalized members of the disability community to advocate for their rights.[26] The CRPD inquiry procedure has the potential to advance the advocacy of organizations, such as Disability Rights International, that have exposed institutionalization and serious abuses against children and the absence of community living arrangements through monitoring and reporting these practices hidden from the public.[27]

The CRPD is the first human rights convention that has such holistic scope and its implementation that assures the respect and full enjoyment of all, socioeconomic, political and cultural rights of persons with disabilities. As a result, governments must take measures to create inclusive societies in which people with disabilities are welcomed, accommodated, and enabled to live as full citizens.[28] The CRPD sets the international standards and offers opportunities for regional human rights systems in Europe, Africa and the Americas to increase their disability rights considerations under their regional human rights treaties as well as change in the domestic level reform in law, policy and practice.[29]

II. Institutionalization in Guatemala

Guatemala has signed a number of international conventions, including the Inter-American Convention on the Elimination of All Forms of Discrimination against persons with Disabilities (ratified 2003) and is also a signatory to the CRPD and signed its Optional Protocol on March 2007. Guatemala was the last Central American country to ratify it (7 April 2009), mainly due to changes in government and lack of political will, interest and commitment to disability.[30]

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[26] UN General Assembly, *Optional Protocol to the Convention on the Rights of Persons with Disabilities*, 13 December 2006, A/RES/61/106, Annex II.

[27] Mental Disability Rights International, *Human Rights & Mental Health: Mexico (2000, Children in Russia's Institutions: Human Rights and Opportunities for Reform (1999), Human Rights & Mental Health: Hungary (1997); (2003); Human Rights & Mental Health: Uruguay (1995).*

[28] Marcia Rioux and Anne Carbert, "Human Rights and Disability: The International Context" (2003) 10:2 Journal on Developmental Disabilities 1 at 11.

[29] Janet E. Lord and Rebecca Brown, "The Role Of Reasonable Accommodation In Securing Substantive Equality For Persons With Disabilities: The UN Convention On The Rights Of Persons With Disabilities" Critical Perspectives on Human Rights and Disability Law, pp. 273-308, at p.307.

[30] Shaun Grech, "Disability and Poverty in the Global South: Renegotiating Development in Guatemala", Palgrave Studies in Disability and International Development, PALGRAVE MACMILLAN, 2015, at p.48.

Guatemala have enacted a number of legislation for disabilities, however implementation of standards as required by the international treaties have not been respected in practice.[31]

In Guatemala over two million people live with some kind of disability, equivalent to around 13% of the population.[32] The Guatemalan system forces a large number of children to live in institutions perpetuating the cycle of institutionalization.[33]

Children with disabilities are among the most marginalized and vulnerable populations in rural Guatemala, with many families living below the poverty line being unable to pay for specialized care. 50-60 percent of the population is composed of Indigenous Mayan people; most are among the poorest[34] and are further vulnerable to discrimination. The majority of children with disabilities does not attend school and are least likely to have access to medical services. Inaccessible public infrastructure, cultural attitudes towards those with disabilities, and a lack of financial assistance from the government all contribute to their exclusion.

Despite, international movement and focus on de-institutionalization of persons with disabilities and their integration within community, especially with the adoption of article 19 of CRPD, which stipulates the right to live independently and be included in the community, and article 14, which states that "the existence of a disability shall in no case justify a deprivation of liberty,"[35] international cooperation and governmental help is still directed towards institutions in Guatemala. The violation of the right to live in the community is particularly serious and one of the most severe forms of discrimination given that, by being segregated from society, a person loses all ability to exercise the other rights recognized in the Convention, including the right to health, education, a decent job, and family, among others. Further, permanent detention

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[31] *Ibid.*

[32] Swedish International Development Agency, *Disability Rights in Guatemala,* November 2014, at p.1, available at: http://www.sida.se/globalassets/sida/eng/partners/human-rights-based-approach/disability/rights-of-persons-with-disabilities-guatemala.pdf [last viewed Dec 17 2016]

[33] Méndez Pérez, Lucrecia, *SITUATION FACED BY INSTITUTIONALIZED CHILDREN AND ADOLESCENTS IN SHELTERS IN GUATEMALA,* SBS, La Secretaría de Bienestar Social de la Presidencia de la República, 2008 Guatemala, at p.14

[34] *Supra* note 52 at 29.

[35]CRPD, *supra* note 6, art.19, 14.

of children is a violation of Article 37 (b) of the Convention on the Rights of the Child (CRC).[36] The UN Special Rapporteur on Torture has also particularly noted that the deprivation of liberty of a child should be a last resort measure used only for the shortest possible period of time.[37]

The situation of people with disabilities in Guatemala is in extreme crisis and abandonment. In their concluding observations for Guatemala in 2010, the CRC Committee was concerned at the large number of children in institutions, as well as at the insufficient implementation of minimum care standards and monitoring systems for these institutions.[38] The Committee recommended that the "State party guarantee the rights of all children with disabilities in order to prevent them from becoming victims of abuse, exclusion and discrimination and to give them the necessary support to enable them to exercise their rights as active members of their communities."[39]

Furthermore, the CRPD Committee, in its latest concluding observations to Guatemala (2016), noted that children with disabilities living in poverty are at greater risk of abandonment and institutionalization.[40] The Committee recommended that the State replace measures to institutionalize all abandoned children with disabilities with measures to promote their adoption or placement in foster care and ensure that foster families receive the requisite support for their care. The Committee also urged Guatemala to urgently draw up a strategy for the deinstitutionalization of persons with disabilities; to allocate sufficient resources to the development of local community support services; to provide support to families of children with disabilities to prevent family breakdown and institutionalization of the children; and, to abolish the institutionalization of children of any age.[41]

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[36] Guatemala ratified the CRC in 1990.

[37] *Report of the Special Rapporteur on Torture and Cruel, Inhuman or Degrading Treatment or Punishment, General Assembly*,A/HRC/28/68(March 5, 2015), Juan Méndez, para. 72.

[38] UN Committee on the Rights of the Child (CRC), *Consideration of reports submitted by States parties under article 44 of the Convention : Convention on the Rights of the Child : concluding observations : Guatemala*, 25 October 2010, CRC/C/GTM/CO/3-4, para 58.

[39] *Ibid* at para 69.

[40] UN Committee on the Rights of Persons with Disabilities (CRPD), *Concluding observations on the initial report of Guatemala* , 30 September 2016, CRPD/ C/GTM/CO/1, para 57.

[41] *Ibid* at para 60.

The Committee also expressed their concerns at the high rate of maltreatment, abuse, corporal punishment, abandonment and institutionalization of children with disabilities; at the prevalence of the welfare and charity-based approach to their care; and at the limited scope of specific measures taken on their behalf in rural areas and indigenous communities.[42] One of the most concerning situation in Guatemala is the placement of people with disabilities in the Federico Mora National Mental Hospital, which is the only public psychiatric facility for adults in Guatemala.[43] The facility is intended for adults, but children as young as fifteen are mixed in with the adult population, and face physical, mental and sexual abuse and torture on a daily basis. Given the lack of alternatives or community-based supports, any person in Guatemala who has a psychiatric breakdown or an intellectual disability is at risk of being detained at this hospital.[44] According to the hospital's director, Romeo Minera, only a minority of the patients has serious mental health problems; most arrive to the hospital in need of some attention and care and should have stayed in their community.[45]

The lack of political will to provide equal services for people with disabilities steams from the fact that Guatemala, like many other countries, still follow the medical/charity model and there is a lack of education, training and awareness among the government and community towards the rights and dignity of people with disabilities, usually facing stereotypes and discrimination. Most adults and children with disabilities are arbitrary sent to institutions by doctors for their "treatment."[46] Guatemala allocates only 1% of its healthcare budget to mental health, from which 94% goes to maintain its national psychiatric center, Federico Mora, which is described as the most dangerous facility in the Americas by DRI.[47] In order to break through

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[42] *Ibid* at para 23.

[43] Disability Ombudsman, *Informe de Monitoreo al Hospital Nacional de Salud Mental* [Monitoring Report on the National Mental Health Hospital] (July, 2007), p.1; Report on the Visit to Guatemala by the UN Special Rapporteur on Disability, Hissa Al Thani (2004), p.6; Information provided to DRI by a former psychiatrist at the hospital in August, 2011.

[44] Disability Rights International, "Precautionary Measures Petition in fabor of 34 patients in Guatemala, [2012], p.3.

[45] Denis Calnan, "Human waste, sedated patients and regular rape: Inside the most dangerous mental health hospital in the world", News Americas, 5 December 2014, available on: http://www.independent.ie/world-news/americas/human-waste-sedated-patients-and-regular-rape-inside-the-most-dangerous-mental-health-hospital-in-the-world-30801932.html [last viewed: Dec 16 2016]

[46] *Supra* note 44.

[47] *ibid*

this medical and political barrier, it is important to recognize that institutionalisation is a direct violation of people with disabilities' right to health (CRPD article 25) and institutionalization cannot be justified as "treatment", especially when children with disabilities face multiple forms of abuse, violence and torture in inherently dangerous institutions.

III. Institutionalization violates the Right to health

The right to health is a fundamental part of our human rights and of our understanding of a life in dignity. Many international treaties have recognized the right to health. WHO's constitution defines health as *"a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity."*[48] The Universal Declaration of Human Rights[49] and International Covenant on Economic, Social and Cultural Rights also "*recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*." [50]

Article 25 of the CRPD reinforces the right of persons with disabilities, who are particularly vulnerable to deficiencies in health care, to attain the highest standard of health care without discrimination. Unfortunately, in reality, most medical practitioners treat people with disabilities as objects of treatment rather than rights-holders and do not always seek their free and informed consent. Challenging behavior, such as aggressive, destructive, attention seeking, self-injurious behavior, displayed by 45% of children with intellectual disability are the most common reason for referral to long stay institutions.[51] Such unethical practices violate the Convention.[52] Children with disabilities face higher risks of neglect; violence; and, physical, sexual,

[48] Preamble to the Constitution of WHO as adopted by the International Health Conference, New York, 19 June - 22 July 1946; signed on 22 July 1946 by the representatives of 61 States (Official Records of WHO, no. 2, p. 100) and entered into force on 7 April 1948. The definition has not been amended since 1948.

[49] UN General Assembly, *Universal Declaration of Human Rights*, 10 December 1948, 217 A (III), article 25.

[50] UN General Assembly, *International Covenant on Economic, Social and Cultural Rights*, 16 December 1966, United Nations, Treaty Series, vol. 993, article 12.

[51] Dr. Veronika Ispanovic Radojkovic, *Deinstitutionalization and independent living of persons with disabilities,* TAIEX Workshop on Rights of Persons with Disabilities In Health Settings Skopje, 27-28 September 2012, p.15.

[52] CRPD, *supra* note6, art 3.

psychological and emotional abuse. Women and girls with disabilities are in particular exposed to forced sterilization and sexual violence.[53]

Adequate policies, programmes, laws and resources are lacking; for instance, in 2001, most middle- and low-income countries devoted less than 1% of their health expenditures to mental health, including Guatemala.[54] As a result, mental health care, including essential medication such as psychotropic drugs, is inaccessible or unaffordable to many, which forces people into institutions for life as the only alternative. Access is also more challenging due to stigma and discrimination and a lack of community alternatives, contrary to the obligation on States to provide access to health care on an equal basis.

Institutions are inherently detrimental

There is a growing research based consensus that institutionalization is an active source of harm and simply do not provide a suitable environment for any child to grow up, as they foster inhumane, dehumanizing, coercive and abusive forms of experience that systematically harm physical and mental health and can result in reduced life expectancy, or in the worst cases, in early death.[55]

Long-term placement in institutions can further aggravate intellectual disability or result in serious developmental delays among children who were not intellectually disabled at first. With a lack of education, rehabilitative activities, physical therapy and nursing care in institutions, children spend most of the day in bed, which frequently causes atrophy of the limbs, contractures, spine deformities and breathing disorders. Also, the lack of sufficient number of nurse-caregivers makes it impossible for children in institutions to get the individual stimulation or emotional contact they need. Overuse of medication and abuse of restraints, including the use of cage beds may amount to torture.[56]

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[53] Office of the United Nations High Commissioner for Human Rights, WHO, *The Right to Health,* Printed at United Nations, Geneva, June 2008.

[54] World Health Organization, *Mental Health Atlas:* 2005 (Geneva, 2005).

[55] WHO, *Better health, better lives: children and young people with intellectual disabilities and their families,* EUR/51298/17/5, 6 September 2010, p.2.

[56] During my visit to monitor Hogar Infantil San Luis Gonzaga I.A.P, June 15 2016, Mexico City. Also see: *Cage beds: inhuman and degrading treatment in four EU accession countries.* Budapest, Mental Disability Advocacy Centre, 2003.

Another problem is lack of access to health care when an institutionalized child has an episode of serious or acute illness requiring hospitalization. Neglect, physical distance from hospitals as well as negative responses and discrimination from hospital personnel towards institutionalized children, especially those with severe intellectual disability, all contribute to institutionalized children having untreated hydrocephalus, untreated congenital heart disorders, cleft palates, dental problems and other major health problems. Additionally, other factors include lack of financial resources to provide appropriate stimulation, therapy, nutritional and hygienic standards; uniform treatment for all children that do not account for individualized needs of privacy and self-determination; and an absence of legislation regulating the use of restraints on children with developmental disabilities.[57]

Children placed in institutions are separated from their parents, their siblings, friends and community, which gravely affect their development. They may exhibit mental disturbances and an inability to feel empathy for others; they have difficulty developing trust; and face difficulty in becoming integrated members of society in adulthood, and this may result in their continuing to live in institutions as adults.

Right to Health

The *Committee on Economic, Social and Cultural Rights* (CESCR) general comments no.14 specifies that the right to health is not limited to hospitals and access to health care, it extends to include a wide range of factors that allow a healthy living, such as safe drinking water and adequate sanitation; safe food; adequate nutrition and housing; healthy working and environmental conditions; health-related education and information; gender equality.[58]

The right to health contains freedoms, such as the right to be free from non-consensual medical treatment, and to be free from torture and other cruel, inhuman or degrading treatment or punishment. The right to health also comprises entitlements, such as the right to a system of

[57] Who, *supra* note 58 at 11.

[58] UN Committee on Economic, Social and Cultural Rights (CESCR), *General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12 of the Covenant)*, 11 August 2000, E/C.12/2000/4,

health protection providing equality of opportunity for everyone to enjoy the highest attainable level of health; to prevention, treatment and control of diseases; and, access to essential medicines. All services, goods and facilities must be available, accessible, acceptable and of good quality to all without discrimination.[59]

The right to health of persons with disabilities cannot be achieved in isolation. It is closely linked to non-discrimination and other principles of individual autonomy, participation and social inclusion, respect for difference, accessibility, as well as equality of opportunity and respect for the evolving capacities of children.[60]Thus, institutionalization on the basis of disability, instead of providing access to health resources to persons with disabilities on the same basis and quality like other members of society is a clear demonstration of discrimination and segregation.

State Obligation

The CRPD states measures States should take to ensure people with disabilities' right to health, including early identification and intervention, services designed to minimize and prevent further disabilities as well rehabilitation services, which enable them to become independent, prevent further disabilities and support their social integration.[61] Similarly, States must provide health services and centres as close as possible to people's own communities, including in rural areas and with similar quality and standard of free or affordable health care and programmes as provided to other persons, including on the basis of free and informed consent. States should "prevent discriminatory denial of health care or health services or food or fluids on the basis of disability,"[62] To this end, States are required to train health professionals and to set ethical standards for public and private health care. The Convention on the Rights of

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[59] Office of the United Nations High Commissioner for Human Rights, WHO, *The Right to Health,* Printed at United Nations, Geneva, June 2008, p.3.

[60] These and other principles are reflected in art. 3 of the Convention on the Rights of Persons with Disabilities, which was adopted by the United Nations General Assembly in its resolution 61/106 of 13 December 2006.

[61] Committee on Economic, Social and Cultural Rights, general comment N° 5 (1994) on people with disabilities, and arts. 25 (*b*) and 26 of the Convention on the Rights of Persons with Disabilities.

[62] CRPD, *supra* note 6, art 25, 26.

the Child recognizes the right of children with disabilities to special care and to effective access to health-care and rehabilitation services.[63]

However, even though most states are parties to most international treaties protecting the right to health, enforcement has been ineffective, mainly because the right to health, with other social and economic rights, is subject to progressive realization obligation, which takes into account the availabilities of resources that countries have to supply goods and services and practically excuses inaction. The International standard set by the CRC, general comments #9, is that children should only be put in an institution as a last resort, only when a service system lacks any other better placement for the best interest of the child. However, there is a difference between necessity and interest, if institutions are inherently dangerous, placement in an institution can never be for his/her best interest.[64] Countries should strive to provide community-based services and deinstitutionalize children with disabilities.

States have the obligations to respect, meaning to ensure access to health-care services without discrimination; to protect, meaning to ensure that private actors conform to human rights standards when providing health care services; and to fulfill, meaning to adopt appropriate legislative, administrative, budgetary, judicial, promotional and other measures to fully realize the right to health.[65] In case of failure, they could be held accountable for failing to respect and enforce the right to health of people with disabilities through international bodies or courts.

Duty to enforce right to health in the Inter-American Court of Human Rights

Most cases in the Inter-American Court of Human Rights, regarding disability, deals with negligent treatment or inaccessibility to healthcare services. The Inter-American Court of Human Rights is beginning to bridge the enforcement gap between negative and positive rights with regards to the right to health. The court confirmed in *Street Children (Villagrdn-Morales et al.) v. Guatemala* that "the fundamental right to life includes not only the right of every human being not to be deprived of his life arbitrarily, but also the right that he will not be prevented from

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[63] *Ibid* at art 23.

[64] *Supra* note 2 at para 47.

[65] WHO, *supra* note 53 at 25.

having access to the conditions that guarantee a dignified existence."[66] The Inter-American Court is expanding the right to life to the right to health in the protection of a "dignified life." The court recognized the right to health as a positive right that the government is under the duty to enforce.

In *Sawhoyamaxa*, the State's failure to recognize the Sawhoyamaxa's title and possession of their lands had negative implications on their nutrition and health, and thus threatened their survival and integrity. The court set out a test for a right to life violation which involved (1) knowledge of a threat to right to life; (2) inaction in the state's scope of authority.[67] This test was further refined in the case of *Ximenes-Lopes v. Brazil,* in which Ximenes a person with mental illness was hospitalized for psychiatric treatment at a private psychiatric clinic that operated within Brazil's public health system, where he was subject to various inhumane treatment and died under violent circumstances in the hands of hospital staff.[68] The court concluded that the "scope of state authority" involves an affirmative duty to supervise and regulate healthcare systems, both public and private, so that they could deter any threat to the right to health and life. The court also emphasized the special care owed to individuals with mental disabilities due to their vulnerability[69] and ordered the implementation of institutional reform, such as training programs for all staff and a duty to provide decent health treatment. The court in these cases expanded the right to life to enforce the right to health and established that the right to life requires not only some food, water and health services, but enough of them to ensure a dignified existence. Thus the right to health requires adequate quality and governments are not excused from failure to act when they have knowledge of life-threatening conditions so that the conditions necessary for a dignified life are not denied to any individual.

Institutions not only represent life-threatening conditions due to abuse, neglect and torture, but it can never be treated as the adequate quality of treatment for children with disabilities, who are denied a life in community or in family, essential for proper development. It is the

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[66] "*Street Children" (Villagrdn-Morales et al.) v. Guatemala,* 1999 Inter-Am. Ct. H.R. (ser. C) No. 63, 144 (Nov. 19, 1999); *cf.* Hum. Rts. Comm., *General Comment 6, Art. 6, The Right to Life,* 5, U.N. Doc. HRI/GEN/1 - Five youths, three of whom were minors, were "street children" abducted, tortured, and killed by State security agents.

[67] *Sawhoyamaxa Indigenous Community v. Paraguay*, 2006 Inter-Am. Ct. H.R. (ser. C) No. 146, J 178 (Mar. 29, 2006).

[68] 2006 Inter-Am. Ct. H.R. (ser. C) No. 149 (July 4, 2006).

[69] *Ibid,* at 101-1

State's responsibility to ensure that children with disabilities are provided all the services they need to live a dignified life without discrimination. The main objective of international development should thus be to minimise the number of children placed in institutions by giving families the kind of support that enables them to meet children's needs. Most institutions for children should thus be abolished*;* however, there must be parallel emergence of alternative forms of community-based care. This is the necessary first step and has proved, in combination with deinstitutionalization, capable of acting as a forceful stimulus for developing modern and effective care services for children and families in the community.[70]

IV. The Right to NOT be institutionalized

"Under the human rights approach, persons with disabilities have the right to liberty on an equal basis with others, and deprivation of liberty cannot be justified on the basis of disability. Forced institutionalization or hospitalization on the basis of disability is prohibited."[71] Deinstitutionlization and respect for the right to health of children with disabilities can only be achieved through implementation of the right to live in the community and independently. The CRPD establishes the right to live in community as a distinct right (article 19), particular to the unique experiences of people with disabilities with institutionalization.

a) CRPD Article 19

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

[70] *Supra* note2.

[71] *Supra* note 14 at 12.

(a) Persons with disabilities have the opportunity to **choose** their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;

(b) Persons with disabilities have access to a range of in-home, residential and other community support services, including **personal** assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;

(c) Community services and facilities for the general population are available on an **equal** basis to persons with disabilities and are responsive to their needs." [72]

It is focused on three main elements: choice; individualized support that promotes inclusion and prevents isolation; and making services for the general public accessible to people with disabilities.[73]

Choice[74]

Choice is the fundamental element for the implementation of article 19. Institutions do not allow people with disabilities to exercise a choice equal to others. Lack of alternative supports or community-based services does not give real choices to people with disabilities. The need for support should not justify depriving people with disabilities from their liberty and choice of living. This kind of regulation would not be imposed on people without disability and represents discrimination and marginalization based on disability. In most countries, including Guatemala, some drug therapies are only available in institutions placed away from communities where people with disabilities end up for life due to lack of resources and out of necessity. Deinstitutionalisation must therefore be accompanied by measures to augment a person's decision-making capacity.

[72] CRPD, *supra* note 6, art 19.

[73] Council of Europe Commissioner for Human Rights, *The right of people with disabilities to live independently and be included in the community*, 2012, France, p.31.

[74] CRPD, *supra* note 6, art 19(a)

Individualized support[75]

People with disabilities need individualized support and access to various services to allow their full inclusion in community, be it "in-home, residential, community-based or personal assistance."[76] Support must be tailored to individual needs to allow the person with disabilities with the same choices provided for persons without disabilities. The person with disabilities 'choice and control over the kind of support needed is also an important element of the service.[77]

Moreover, the right to inclusion and to live in the community is deeply linked to socioeconomic rights. States often justify the lack of such services and support over the lack of resources. Unfortunately, even the CRPD does not impose the immediate obligation of the state to offer these must needed resources to people with disabilities. Article 4(2) states that these rights should be implemented progressively, meaning every year the situation must get better.

Studies have shown that it is less costly to provide services and support in the community than in institutions.[78] However additional resources need to be allocated to transition from institutions to community based services. There is also a caveat in the implementation because deinstitutionalization without the alternative community support is also not desirable and does not amount to inclusion. Eventually, costs will be lower when services for the general population are also available to people with disabilities with available support systems to individuals.

Inclusive communities[79]

States also need to ensure the inclusiveness and availability on an equal basis of already existing services for the general population, such as health, education, housing, employment,

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[75] *Ibid*, art 19(b).

[76] *Ibid.*

[77] *Supra* note 73.

[78] James W. Conroy, "The Costs of Supporting People with Developmental Disabilities in Institutional Versus Community Settings" (revised June 2004), Center for Outcome Analysis, US. See also: Jones, P., Conroy, J., Feinstein, C., & Lemanowicz, J. (1984). "A Matched Comparison Study Of Cost Effectiveness: Institutionalized And Deinstitutionalized People", Journal of the Association for Persons with Severe Handicaps, 9, 304-313; and Stancliffe, R.J. & Lakin, C. (2004) "Costs and outcomes of community services for persons with intellectual and developmental disabilities", Policy Research Brief 14(1), Minneapolis, University of Minnesota, Research and Training Center on Community Living.

[79] CRPD, *supra* note 6, article 19(c).

etc. The more inclusive community services are, there will be less need for individualized support as every service will already account for the needs of people with disabilities.

In countries like Guatemala where institutions is the dominant response of the state for people needing intensive support, implementing the right to live in the community is of outmost importance and need. Policies and funding schemes in support of institutionalization should be denounced and resources allocated to community-based services to allow quality living for people with disabilities and the respect of their inherent dignity. Challenges include segregation of people with disability in community as well if there are no institutions, this is also undesirable outcome. Effective community-based support is necessary to achieve deinstitutionalization.

Violation of right to live in community

The right to live in community is the right to deinstitutionalization! However, the right to independent living does not simply mean getting people with disabilities out of institution and then abandoning them on the streets or where there are no alternative community-based supports; institutions should not be replaced by other forms of segregation. States must offer reasonable alternatives and support so that people with disabilities can effectively live in the community. The right to live in the community applies to all people with disabilities. Programs from around the world demonstrate that no matter the severity of the disability, individuals are better in community settings which allow for expression of individuality and closer scrutiny to prevent abuse.[80]

The right to live independently is of fundamental importance for the whole of the CRPD. The philosophy is in line with the preamble of the convention, which lays the "respect for the inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons "(Article 3(a) of the CRPD).[81] The "independent living" movement has come to mean a demand for personal autonomy and control over one's life, as well as

[80] *Supra* note 73 at .9.

[81] CRPD, *supra* note6, article 3(a).

demanding that the State provide effective services to enable people to live independently in the community.[82]

The right to live in the community enshrined in article 19, in fact goes beyond the right to not be institutionalized. Community living may be compromised even where no institutions exist. People with disabilities may be isolated in various ways even when physically present in the community, if they are not provided with sufficient supports to ensure their participation and inclusion in the community or are subject to models of support that perpetuate loss of control, impose restrictions on choice, and provide limited or no meaningful access to the community. Article 19 of the UN Convention on the Rights of Persons with Disabilities (CRPD) provides the most developed articulation of the right to live in the community of any international human rights instrument to date and imposes clear obligations on state parties on how to implement these rights through legal reform, policy changes or reallocation of resources.

b) Other Human Rights Instruments

The CRC, the ICESCR, the CAT also recognize the importance of living in community and denounce institutionalization. The CRC general comments no.9 on the rights of children with disabilities also recognizes the right to live in the community and fully enjoy all other rights.[83] The Committee has advocated for anti-discrimination laws to provide protection from discrimination in the areas of social security, healthcare, education and provision of goods and services, and has noted the multiple forms of discrimination experienced by children living in poverty, including children with disabilities.[84] The Committee states:

In addressing institutionalization, States parties are therefore urged to set up programmes for de-institutionalization of children with disabilities, re-placing them with their families, extended families or foster care system. Parents and other extended family members should be

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[82] *Supra* note 73 at 16.

[83] *Supra* note 2.

[84] UN Committee on the Rights of the Child, *Concluding observations: the Slovak Republic*, 10 July 2007, CRC/C/SVK/CO/2, para. 39.

provided with the necessary and systematic support/training for including their child back into their home environment. [85]

The UN convention against torture (CAT) has established that "each State party should prohibit, prevent and redress torture and ill-treatment in all contexts of custody or control, for example, in prisons, hospitals, schools, institutions that engage in the care of children, the aged, the mentally ill or disabled, in military service, and other institutions as well as contexts where the failure of the State to intervene encourages and enhances the danger of privately inflicted harm.[86]

c) Jurisprudence

Though the CRPD is probably the most complete and overreaching international instruments recognizing the rights of people with disabilities, every nation or regional courts also have established and elaborated their own disability rights laws and declarations, such as several provisions in the European Convention on Human Rights (ECHR)[87] are relevant to establishing the right to live in the community; the European charter[88] also have a provision specific to the rights of people with disabilities; the Inter-American Convention have the Inter-American Convention on the Elimination of Discrimination Against Persons with Disabilities[89] that is binding over the State Parties; US have the Americans with Disability Act[90]; Canadian Charter[91] equality provisions also apply to people with disabilities. No matter what the extent of these regional bodies, the CRPD still serves in setting the international standard and as a guide for the interpretation and application of these requirements.

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[85] *Ibid,* para 49.

[86] UN Committee Against Torture (CAT), *General Comment No. 2: Implementation of Article 2 by States Parties*, 24 January 2008, CAT/C/GC/2, para. 15.

[87] Council of Europe, *European Convention for the Protection of Human Rights and Fundamental Freedoms, as amended by Protocols Nos. 11 and 14*, 4 November 1950, ETS 5.

[88] Article 15 of the European Social Charter (Revised), Strasbourg, 3 May 1996.

[89] OAS, *Inter-American Convention on the Elimination of All Forms of Discrimination against Persons with Disabilities*, 7 June 1999, AG/RES. 1608 (XXIX-O/99).

[90] 42 U.S.C. § 12101 *et seq.* (2001).

[91] *Canadian Charter of Rights and Freedoms*, Part I of the *Constitution Act, 1982*, being Schedule B to the *Canada Act 1982*(UK), 1982, c 11, article 15.

European jurisprudence

The Grand Chamber of the European Court of Human Rights has recently, and for the first time, found a violation of Article 5 of the ECHR (which sets out the parameters of the right to liberty) in relation to someone living in a social care institution. In *Stanev v. Bulgaria*, the applicant, Rusi Stanev, had been institutionalised for nine years. The distance and isolation from the community he experienced, the institution's regimented daily schedule, the rules on leave of absence, the lack of choice in everyday matters, and the lack of opportunity to develop meaningful relationships, as well as the fact that Mr Stanev had been deprived of legal capacity, were all factors that led the Court to find a violation of the right to liberty within the meaning of Article 5 of the ECHR.[92]

Some other important cases such as *Autism Europe v. France and MDAC v. Bulgaria* have furthered the right of people with disabilities, especially children with disabilities and their right to education on an equal basis to others under the European Social Charter's provision that apply specifically to people with disabilities. According to the provision States must promote "full social integration and participation in the life of the community in particular through measures, including and enabling access to transport, housing, cultural activities and leisure."[93]

US

In ***Olmstead v. L.C. ex rel. Zimring,***[94] the United States Supreme Court held that it is discrimination to deny people with disabilities services in the most integrated setting appropriate. Accordingly, the Court found that individuals with mental disabilities are entitled to live in the community, whenever appropriate, and to receive treatment there, rather than in institutions.[95]

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[92] *Stanev v. Bulgaria,* Application No. 36760/06, judgment 17 January 2012.

[93] Article 15 of the European Social Charter (Revised), Strasbourg, 3 May 1996.

[94] 527 U.S. 581 (1999).

[95] Eric Rosenthal and Arlene Kanter *, The Right to Community Integration for People with Disabilities Under United States and International Law, https://dredf.org/news/publications/disability-rights-law-and-policy/the-right-to-community-integration-for-people-with-disabilities-under-united-states-and-international-law/#sdfootnote1sym*

Inter-American Court of Human Rights

The Inter-American Convention on the Elimination of Discrimination Against Persons with Disabilities article IV b) states: "the development of means and resources designed to facilitate or promote the independence, self-sufficiency, and total integration into society of persons with disabilities, under conditions of equality" [96]

The Inter-American Human Rights System began to address the rights of persons with disabilities prior to the entry into force of the Inter-American Convention on the Elimination of All Forms of Discrimination against Persons with Disabilities (IACEDPD), the first international human rights instrument specifically about persons with disabilities.[97]The Inter-American Commission on Human Rights (IACHR) has handled this issue through its various human rights protection and promotion mechanisms, in particular through its petition and case system, precautionary measures, general hearings and country reports. In addition, the Inter-American Court of Human Rights has handed down three judgments in cases relating to persons with disabilities.

The first judgment, handed down in the Case *of Ximenes Lopes v. Brazil* as described above, is an exemplary decision on this issue.[98] The case addressed the inhumane and degrading conditions of the hospitalization of Mr. Ximenes Lopes, a person with a mental disability, in a private psychiatric institution, the inhumane treatment he experienced at the hands of the staff, his death while undergoing psychiatric treatment, and the impunity with which those acts were met.

In 2012, the Court ruled in the Case of *Furlan and Family v. Argentina*, concerning the excessive delay in the adjudication of a civil action against the State, on which the medical

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[96] The Inter-American Convention on the Elimination of Discrimination Against Persons with Disabilities requires states parties "[t]o adopt the legislative, social, educational, labor-related, or any other measures needed to eliminate discrimination against persons with disabilities and to promote their full integration into society." *opened for signature* June 7, 1999, *entered into force* Sept. 14, 2001.

[97] The Inter-American Convention on the Elimination of All Forms of Discrimination against Persons with Disabilities was adopted on June 7, 1999, and entered into force on September 14, 2001. To date, this Convention has been ratified by 18 States.

[98] See: I/A Court H.R., Case of Ximenes Lopes v. Brazil. Merits, Reparations and Costs. Judgment of July 4, 2006. Series C No. 149.

treatment of a boy with physical and intellectual disabilities depended.[99] In the same year, the Court handed down a judgment in the *Case of Artavia Murillo et al. (in vitro fertilization) v. Costa Rica* on the general prohibition against the practice of in vitro fertilization, in which it approached infertility as a disability.[100] In both judgments, the Inter-American Court examined the rights enshrined in the American Convention in light of the Convention on the Rights of Persons with Disabilities (CRPD).

Also through its precautionary measures mechanism, the Inter-American Commission has protected persons with disabilities in serious and urgent situations. In 2012, the IACHR issued precautionary measures on behalf of the patients of the Federico Mora Hospital in Guatemala.[101]

Implications on Guatemala

The Inter-American Convention limits the Court's jurisdiction to states' parties that have accepted the Court's jurisdiction, such as Guatemala.[102] Thus an action can be brought to the Inter-American Commission of Human Rights against Guatemala to advocate for the rights of children with disabilities to not be institutionalized and deinstitutionalized paralleled with alternative community-based support.

According to the latest jurisprudence and the model of the Inter-American Convention and its convention on disability rights, and the CRPD setting the international standards, it is likely that an obligation to provide services for people with disabilities to promote their right to health and full integration to society will be recognized. Guatemala owns a duty to provide for inclusive community and deinstitutionalize children with disabilities to respect their right to

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[99] I/A Court H.R., Case *of Furlan and Family v. Argentina*. Preliminary Objections, Merits, Reparations and Costs. Judgment of August 31, 2012. Series C No. 246.

[100] I/A Court H.R., Case of *Artavia Murillo et al. (in vitro fertilization) v. Costa Rica*. Preliminary Objections, Merits, Reparations and Costs. Judgment of November 28, 2012. Series C No. 257.

[101] IACHR, PM 370/12 – 334 Patients of the Federico Mora Hospital, Guatemala, November 20, 2012. For more information, see: Disability Rights International, Precautionary Measures Petition, October 2012. Available at: http://www.disabilityrightsintl.org/media-gallery/our-reports-publications/

[102] Shelton, Dinah. "The Jurisprudence of the Inter-American Court of Human Rights." American University International Law Review 10, no. 1 (1996): 333-372.

health. Yet again, the emphasis is on an equality argument of non-discrimination, rather than recognition of their rights as fundamentally essential and standing alone.

The greatest barrier to achieving de-institutionalization of children with disabilities, in countries such as Guatemala, is still the "best interest of child" argument used by medical doctors or psychiatrics to justify why the child should be institutionalized and segregated from society which leads to a political unwillingness and societal unawareness of their human rights. Institutionalization is the still the predominant response to treatment. Studies have shown that no matter the conditions in the institution, they are still inherently dangerous as children and adults are more at risk of negligence and abuse. As seen in the jurisprudence, most cases regarding disability at the Inter-American Court deal with inappropriate treatment or negligence offered to people with disability. It is time to break these barriers and recognize that institutionalization is a violation of the right to health of people with disabilities. Instead of providing treatment services and support on an equal basis with others in the community, Guatemala among many other countries, puts children with disabilities in institutions where their conditions worsen and they face torture and abuse.

V. Recommendations

Institutions are inherently detrimental settings for children with disabilities and a clear violation of their right to health. The state of most children with disabilities around the world is in great crisis in emergency. State inaction based on discriminatory "best interest" of the child justifications and lack of resources justification should be inacceptable. States must immediately implement a national deinstitutionalization strategy, with the participation of people with disability, by allocating more funds to provide community-based services, help to families, and education to healthcare providers, nurses, home caregivers as well as awareness in the society. In order for an abolition of children's institutions to be realised, measures at several different levels are required. There must be a conscious national plan, containing clear and scheduled targets, and with top-level political support.[103]

[103] *Infra* note 105.

In Guatemala, there is barely government support or service for children with disabilities or their families. Institutions are dangerous places of abuse, neglect and torture. Key barriers to accessing appropriate health care are poor knowledge and training of health professionals on disability issues; poor patterns of communication or requirements of consent with people with disabilities; negative attitudes of health professionals; poor intersectoral collaboration; lack of reliable health monitoring data or supervision of services; lack of community-based services.

1. Adopt rights-based approach in health care

Adequate awareness and training should be provided to all existing hospitals and psychiatric institutions in Guatemala to regard people with disabilities as subjects of rights and respect their personal choices and dignity.

2. National campaign and awareness in society

Stereotypes and stigmatization in society of persons with disabilities is a great barrier for achieving full inclusion and access to health. Government should provide more space and internalize advocacy for the rights of persons with disabilities at a national level.

3. Allocate funds to implement community-based services

Deinstitutionalization cannot be achieved without paralleled alternative care in the community. The participation of people with disabilities in deciding and establishing these services are essential. Examples of such services are day care and home-based care (family outreach services), psychosocial support for children and/or parents, legal aid, respite care and others. Providing early psychological support to parents after a child with disability is born is especially important. It can be a decisive factor that will influence the decision of parents to keep the child in the family rather than place him or her in an institution. The transition phase from an institution to community-based services might require more funds and commitment from the state, however in the long-term it is more sustainable and less costly in an all-inclusive society.

4. Stop sending children to institutions

As a first step to deinstitutionalization all new admissions of children with disabilities should be denied and support send directly to families or to close by community-based alternative supports. Most importantly, stop sending adults and children to the National Psychiatric Hospital, Federico Mora, where people with disabilities are subject to extreme violations of human rights, sexual abuse, torture and violence.

5. Psychotropic medication and health services should be available in community

Most people with disability are well capable of living within the community and their families with the help of some medication to control their crisis and symptoms. Unfortunately, most such medications are only available in isolated institution, that make it impossible for children and their poor families to afford the transport or care and thus leading to a life stay of children in those facilities.

6. Implement monitoring and supervising policy to ensure proper care in institutions and hospitals

National policy should determine the standard of care and service required in public and private institutions with details on monitoring strategy and accountability. This may also include changes in legislation, recognition of legal capacity of people with disability as well as a complaint system to process individual complaints.

7. Detailed strategy to achieve deinstitutionalization and abolishment of institutions within a 5year plan

Implement a national strategy with detailed steps and time frames with the participation of people with disabilities to close institutions, including Federico Mora, and transition children to community based services.

Even if the Guatemala is faced with extreme poverty with majority of the population living in rural regions and more than 60percent are from indigenous origins, these goals are achievable with proper national planning and political commitment. Disability is a source of

impoverishment both to the persons with disabilities and their families. Within its strategy to fight poverty, the government should include allocating more funds to implement community-based services for people with disabilities and ensure that existing services for non-disabled are also accessible to people with disabilities. The transition phase would require a greater allocation of funds by the government. There is no evidence that community-based models of care are inherently more costly than institutions, though community-based systems of independent and supported living, when properly set up and managed, should deliver better outcomes than institutions.[104] Currently, only 1% of national budget is allocated to mental health, from which 94% goes to the national psychiatric institution. Additionally, most international funds are allocated to institutional care, for 88% of institutions; the main source of funding came from private donations from international NGOs.[105] Also, many programs are scattered with no collaboration and strategy to improve access. By implementation a national strategy to coordinate and reallocate the funds in the right services, the government can achieve an all-inclusive society that will be economically more beneficial and productive in the long-term and fulfill the state's international obligations towards people with disabilities.

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[104] Mansell J, Knapp M, Beadle-Brown J and Beecham J (2007) Deinstitutionalisation and community living – outcomes and costs: report of a European Study. Volume 1: Executive Summary. Canterbury: Tizard Centre, University of Kent, at p.7

[105] Swedish International Development Agency, "*Adoption law reduces child trafficking",* Published 13 November 2012, available at: http://www.sida.se/English/where-we-work/Latin-America/Guatemala/examples-of-results/Angel-found-a-new-family-thanks-to-new-legislation/Facts-New-law-reduces-child-trafficking/ [last visited: 27 July 2016].