Convention on the Rights of Persons with Disabilities (CRPD)

I. Introduction

In 2009, Agusta Ingadottir was one of the three children born with Down's Syndrome in the Icelandic nation.[1] Her mother, Thordis, is now an activist for the rights of those afflicted with the chromosomal disorder. She claims that Iceland's near termination of Down's over the past decade ignores the possibility for diagnosed individuals to lead full and productive lives within contemporary society—with the proper medical and social assistance. Ingadottir is not questioning the rights of Icelandic women to terminate unwanted or high-risk pregnancies, even on the basis of disability; rather, she questions the recent government push for nuchal translucency (NT) screenings between the first and second trimesters. NT screenings can pinpoint the statistical likelihood for various birth defects; in cases where their results lead to confirmed cases of Down's Syndrome, the nation's abortion rate nears virtually 100%[2].

In Thordis' case, the test was faulty, resulting in Agusta's birth and the realization that NT screening may exert unwarranted pressure on expecting parents, as it is framed in public healthcare as standard practice—couples are compelled to factor in their potential child's neurotypicality in deciding whether to carry to term, before the implications of the screening are fully discussed. The validity of this argument depends on whether Iceland may be withholding information from its citizens regarding the capabilities and the dignities of the Down's Syndrome population.

The **Convention on the Rights of Persons with Disabilities** (CRPD) was developed in 2006 to address these types of questions, that feel at once practical and ethical. It is intended to

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[1] Quinones, Julian, and Arijeta Lajka. "'What Kind of Society Do You Want to Live in?": Inside the Country Where Down Syndrome Is Disappearing." *CBS News*, CBS Interactive, 14 Aug. 2017, www.cbsnews.com/news/down-syndrome-iceland/.

[2] World Health Organization Regional Office for Europe. (2018). Births with Down's syndrome per 100,000 live births.

ensure the freedoms and rights of mentally and physically disabled persons, and has been signed by 187 states since its completion; 119 have signed an additional optional protocol (including Iceland) and 91 have ratified the document, rendering it legally binding.[3] As a convention, the CRPD holds considerable weight among United Nation member-states. The question lies in whether the document is actually effective in achieving its stated purposes, and is upholding the tenets enumerated in its 50 articles. This paper will provide further information regarding the CRPD's contents and history, in an attempt to assess its usefulness in an applied context.

II. Background

The United Nations was founded after World War II with the intention of ensuring international peace and security, and promoting the equal protection of human rights for all people.[4] But it was not until the late 60's and early 70's that attention was attuned to the unique challenges and barriers to societal participation faced by those with physical and mental disabilities. The first instruments that specifically addressed these issues were the **Declaration on the Rights of Mentally Retarded Persons** (1971), and the **Declaration on the Rights of Disabled Persons** (1975). Prior to these documents, the UN's approach to disability was welfare-based: it concentrated on prevention and rehabilitation. Most resources were directed toward the "education, treatment, training, and placement," that might allow disabled persons to *overcome* their conditions and *assimilate* within an able-bodied society.[5] But by the 70's, the international community had moved away from the goal of assimilation, seeking integration instead. The aforementioned two documents, while nonbinding in a legal sense, were the first to

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[3] "Has Your Country Accepted the CRPD?" *European Union Agency for Fundamental Rights*, Fundamental Rights Agency, fra.europa.eu/en/theme/people-disabilities/ratified-crpd.

[4] "What We Do." *United Nations*, United Nations, www.un.org/en/sections/what-we-do/.

[5] "The United Nations and Disabled Persons - The First Fifty Years." *United Nations Enable*, United Nations, www.un.org/esa/socdev/enable/dis50y20.htm.

truly prioritize the self-sufficiency of disabled persons, and the fullest assumption of their civil and political rights.[6]

This change in approach proved pivotal in 1981, named the **International Year of Disabled Persons**, and again in 1982, which began the **United Nations Decade of Disabled Persons**.[7] Various research and programs were conducted to isolate which societal factors particularly impacted "handicapped" individuals, and the General Assembly added another major focus to their former two (prevention and rehabilitation): the equalization of opportunities. It was recognized on a global scale that many of the barriers facing the disabled community were actually externally imposed, and could potentially be overcome with public reeducation and restructuring. The **World Programme of Action concerning Disabled Persons** created long-term goals and specific techniques to overcome these barriers, and encouraged the cooperation of governments—both domestically and internationally—as well as non-governmental organizations like Inclusion International and the Christian Blind Mission.[8]

The 1990's saw the tangible results of such a shift in mindset, with the implementation of the **Standard Rules on the Equalization of Opportunities for Persons with Disabilities**. The document was intended to create clear standards for policy makers who intend to form "technical and human rights cooperation within and among states," and was the first to include a monitoring mechanism. Swedish politician, Bengt Lindqvist, was named Special Rapporteur on Disability of the Commission for Social Development by the Secretary-General in 1994.[9]

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[6] "A Human Rights Approach: the 1970s." *United Nations Enable*, United Nations, www.un.org/esa/socdev/enable/dis50y40.htm.

[7] "United Nations and Disability: 70 Years." *United Nations Enable*, United Nations, www.un.org/disabilities/documents/historyinfographic.pdf.

[8] Egüez, Maria Isabel. "NGOs and UN Agencies Assisting Persons with Disabilities." *Community Development, Gender Equality and Children Section* , United Nations High Commissioner for Refugees, 2008, www.unhcr.org/4ec3c78c6.pdf.

[9] "The Standard Rules on Equalization of Opportunities for Persons with Disabilities: 1993." *United Nations Enable*, United Nations, www.un.org/esa/socdev/enable/dis50y70.htm.

All of these individual declarations and programs were necessary steps that culminated in the 2006 Convention on the Rights of Persons with Disabilities. Five years prior, Mexico proposed the creation of an Ad Hoc committee that would draft a document which would utilize the research compiled over the past several decades, and "promote and protect the rights and dignity of persons with disabilities," basing decisions "on the holistic approach in the work done in the fields of social development, human rights and non-discrimination."[10] The finished product was adopted by the General Assembly on the 13th of December, with the stated purpose of "[promoting], [protecting] and [ensuring] the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and [of promoting] respect for their inherent dignity."[11] Whether the convention has actually achieved these goals is a complicated debate, especially when analyzed in the context of more specific case-studies. Before further analysis, however, it is necessary to provide, in greater detail, the contents of the document itself.

III. Contents

The CRPD is comprised of a preamble, and 50 articles which state its purpose, define its terms, and detail a comprehensive collection of tenets concerning the rights of disabled persons. Specific attention is initially given to the concepts of *communication*, *language*, *discrimination on the basis of disability*, *reasonable accommodation*, and *universal design*, which all have unique meanings inside the context of this document, and are necessary for its fullest comprehension. Communication, for instance, includes Braille, accessible multimedia, and tactile languages. Universal design goes beyond wheelchair ramps and bus lifts, clarifying that

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[10] "Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities." *United Nations Enable*, United Nations, www.un.org/esa/socdev/enable/rights/adhoccom.htm.

[11] "Article 1 - Purpose." *United Nations Department of Economic and Social Affairs*, United Nations, 2006, www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-1-purpose.html.

assistive devices should be available wherever they are required, without the "need for adaptation or specialized design." [12] These may appear to be unattainable goals, especially considering the developing status of many of the nations who have signed and ratified the convention. The **General obligations** article, however, clarifies that 'progressive realization' is the primary goal of the United Nations. States are expected to take all appropriate legislative, monetary, and intellectual measures to eliminate discrimination against disabled persons—with regard to the maximum level of resources they are able to allocate to these means.[13] Simply stated, the objectives of the CRPD are pressing, but cannot be expected to take form immediately on an international stage.

After stating its general purpose, the convention's first 30 articles respond to specific challenges faced by disabled persons, and detail their entitlements and freedoms. A brief synopsis of the contents of these articles are as follows.[14] The CRPD begins by identifying two populations with whose identities render them particularly vulnerable when combined with disability status—women and children. In the case of the former, **Article 6** establishes that women are subject to multiple discrimination on the basis of gender, which may necessitate further measures when it comes to securing their rights. Children, on the other hand, warrant special attention to assure that they have the opportunity to voice opinions on any matter that concerns their physical and mental wellbeing; while the need for guardians to act in a child's best

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[12] "Article 3 - Definitions." *United Nations Department of Economic and Social Affairs*, United Nations, 2006, www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-4-general-obligations.html.

[13] "What Are the Obligations of States on Economic, Social and Cultural Rights?" *Key Concepts on ESCRs*, OHCHR, www.ohchr.org/en/issues/escr/pages/whataretheobligationsofstatesonescr.aspx.

[14] "Convention on the Rights of Persons with Disabilities ." *United Nations Department of Economic and Social Affairs*, United Nations, 2006, www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html.

interest is an overarching belief within the United Nations, disabled minors have at least as much autonomy as any neurotypical or able-bodied peer.

The convention goes on to recognize entitlements that all disabled persons should theoretically have access to. This begins with the basic right to life, and goes on to include the equal recognition before the law, access to justice, security and integrity of person, liberty of movement and nationality, independent living, community involvement, privacy, access to information, freedom of expression, education, work, and health in a broad sense. Many of these rights overlap and encompass one another, but when considered as a complete unit, they are meant to ensure disabled persons equal integration and comparable accommodations to any other citizen of their respective states. The same goes for the aspects of society disabled persons are guaranteed freedom from: torture, degrading punishment or treatment, violence, abuse, and exploitation. All of the aforementioned rights and protections are contained within articles that go into greater detail about the exact expectations placed upon each state. For instance, the right to education explained in **Article 24** goes beyond the assurance that disabled persons shall not be excluded from acceptable public education; it further establishes the need for schools to provide lessons in sign language and Braille to the deafblind community.

IV. Implementation

In the remaining articles 31 through 50, the CRPD goes into the more technical details of the convention's monitoring and implementation, and provides statistical and legal information. This includes instruction on how best to establish and maintain compliance with earlier articles by ethically collecting data, cooperating internationally and with the UN Committee on the Rights of Persons with Disabilities, regularly submitting comprehensive reports, attending conferences with other state parties, and deferring to the authority of the UN's Secretary-

General. It further establishes the binding nature of the CRPD upon signature and ratification, and, in **Article 48**, the possibility of denunciation if a state no longer wishes to support the document.

The convention also contains an **optional protocol** (OP) that creates the ability to file claims in cases where a disabled community believes its rights have been violated. Once all attempts at national and internal remedies have failed, individuals, groups, or third-party representatives can build cases against states who have ratified both the CRPD and the OP.[15] They should include various information, including the identities of those impacted by a potential human rights abuse, factual accounts of the abuse in chronological order, which judicial steps were taken domestically, and all legal documents relevant in prior proceedings. If the Committee finds an abuse has taken place, it will provide recommendations to the state that are meant to be completed and reevaluated over the following six months.

The United Nations is not a judicial court, however, and the main means for enforcement of the CRPD is the trust that state parties will fulfill their responsibilities to create internal regulations within their domestic legal and administrative systems.[16] This, combined with the dissemination of information regarding the dignities of disabled persons, theoretically should ensure their protections within civil society.

V. Case Study: Iceland

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[15] "IDA Factsheet on the Optional Protocol to the CRPD." *International Disability Alliance*, 2017, www.internationaldisabilityalliance.org/resources/ida-factsheet-optional-protocol-crpd.

[16] "Frequently Asked Questions Regarding the Convention on the Rights of Persons with Disabilities Enable." *United Nations Department of Economic and Social Affairs*, United Nations, www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/frequently-asked-questions-regarding-the-convention-on-the-rights-of-persons-with-disabilities.html#sqc6.

Returning to the case of Iceland, however, proves that such remedies are often more complicated than they appear in print. About 85% of the country's pregnant women opt for NT screening to learn the statistical likelihood that their fetus has a chromosomal disorder, among other health complications. The procedure is non-invasive and relatively safe, but it has a large rate of false positives and negatives; typically, once high-risk pregnancies are identified, diagnoses are confirmed by more-dangerous amniocentesis.[17] Outside of Iceland, many couples reject the latter test on the basis that Down's Syndrome would not compel them to abort a fetus. There is no logical reason, then, to expose the mother or child to an unnecessary procedure.[18] The question lies in why Icelandic women are more likely to respond to NT screenings and amniocentesis with the termination of a pregnancy: is it because of cultural norms specific to the country? Or is the national government pushing its public healthcare providers to administer the initial test (and, in the case of positive diagnoses, 'nondirective' counseling) to cultivate a disability-free population?

In the case of the latter, **Article 8** of the CRPD suggests that Iceland could be violating the terms of the CRPD.[19] The section focuses on awareness-raising, stating that it is the responsibility of state parties to foster respect for persons with disabilities, by communicating their value in all facets of society. This is expected to be accomplished via public awareness campaigns, as well as within the public education system at all levels. According to reports in a study conducted by the University of Iceland, recurring sentiments about the nature of NT screenings communicated possible coercion, or at least incomplete information regarding the fact

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[17] World Health Organization Regional Office for Europe. (2018). Births with Down's syndrome per 100,000 live births.

[18] Halle, K. F., & Fjose, M. (2016). Early prenatal screening in Norway and Iceland. Norwegian University of Science and Technology, 3-49.

[19] "Article 8 - Awareness-raising.." *United Nations Department of Economic and Social Affairs*, United Nations, 2006, https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-8-awareness-raising.html

that it is entirely optional. In an interview, one mother stated that "the doctor felt it was somehow a self--evident act… I just thought, well, this is just something you do when you are pregnant."[20]

Iceland has both ratified the CRPD and its optional protocol, and it has faced negative attention among activist communities for disabled persons because of the Down's Syndrome controversy. While no formal complaints have been filed to the Committee regarding this specific potential abuse, the country does seem to have reacted from this media and NGO scrutiny. Recently, Iceland's national parliament enacted a new strategy and action plan for the years 2017-2021, with the intention of "[respecting] people with disabilities as part of human diversity."[21]In this sense, the CRPD does appear to have been effective in preventing the continuation of a human rights abuse before all of the monitoring bodies were forced to be utilized.

As a relatively new document, only time will tell whether the CRPD will achieve its goal of protecting and ensuring the rights of disabled persons. Iceland is only one nation in the global organization that is the UN. But in analyzing this single case, the convention appears to be off to a promising start.

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[20] Gottfredsdóttir, H., Sandall, J., & Björnsdóttir, K. (2009). 'This is just what you do when you are pregnant': A qualitative study of prospective parents in Iceland who accept nuchal translucency screening. Midwifery, 25 , 711-720.

[21] "Facts about Down Syndrome and Pre-Natal Screening in Iceland." *Ministry of Health*, Government of Iceland, 2017, www.government.is/news/article/2017/12/11/Facts-about-Down-syndrome-and-pre-natal-screening-in-Iceland/.