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ICELAND

The Center for Family and Human Rights (C-Fam) is a nongovernmental organization which was founded in 1997 and has held Special Consultative Status with the UN Economic and Social Council since 2014. We are headquartered in New York and Washington, D.C. and are a nonprofit, nonpartisan research and advocacy organization that is dedicated to reestablishing a proper understanding of international law, protecting national sovereignty and the dignity of the human person.

The Jerome Lejeune Foundation USA centers its activities on Research, Care, and Advocacy for people with Down Syndrome. Its mission is to raise and disburse funds in order to provide research, care, and advocacy to benefit those with genetic intellectual disabilities in accordance with the medical and ethical standards of Dr. Jerome Lejeune, the father of modern genetics. This is carried out by conducting, promoting, and funding in the United States therapeutically oriented research, by assisting in the development of healthcare services for these individuals, and by serving as their advocate in a spirit of respect for the dignity of all human persons.

INTRODUCTION

1. This report focuses on the protection of the right to life and the rights of persons with disabilities, in particular those individuals affected by Trisomy 21, otherwise known as Down syndrome, and other conditions that are the subject of prenatal screening and, to an increasing extent, “selective reproduction.”

RIGHTS OF PERSONS WITH DISABILITIES

2. Iceland ratified the Convention on the Rights of Persons with Disabilities (CRPD) on September 23, 2016, and has yet to be reviewed by the Committee on the Rights of Persons with Disabilities. In the previous cycles of the Universal Periodic Review (UPR), Iceland received several recommendations, most of which it supported, to ensure social protection for persons with disabilities, to ratify the Convention, and to ensure its laws and policies were aligned to the spirit of the Convention.
3. During the second cycle of the UPR, the Icelandic disability rights organization Throskahjalp National submitted a civil society report noted that “during the period from 2007 to 2012, [...] 38 cases of Downs syndrome were detected through pregnancy screenings after 12 weeks of pregnancy and all those pregnancies ended with abortion.”¹ Throskahjalp National questioned “how abortions on the basis of a Downs syndrome fulfill the strong conditions provided in the law.” They further cited concluding observations by the Committee on the Rights of Persons with Disabilities to several States party to the treaty condemning exceptions to abortion laws permitting abortions—particularly late-term abortions—solely on the basis of disability.
4. In 2019, Iceland changed its abortion law to allow for abortions until the 22nd week of pregnancy. It was reported that the original bill proposed an 18-week limit, which was changed due to recommendations by “numerous health care professionals”² Advocates for the rights of persons with disabilities were critical of the new law, pointing out that while women were not required to provide a reason for seeking an abortion, the obvious reason for the extended gestational limit was to make it possible to “end the life of fetuses with a deviation or disability.”³
5. Under Iceland’s previous law, gestational limits on abortion were relaxed in cases of suspected fetal malformation, a legal standard criticized in other countries by the Committee on the Rights of Persons with Disabilities as being discriminatory and leading to the selective abortion of persons with disabilities, including Down syndrome.⁴
6. Although Iceland’s new abortion law does not explicitly allow for selective abortions of those deemed likely to have disabilities based on prenatal screenings, the inherent result of the law upon application is *de facto* discriminatory against those with disabilities. As

disability rights advocates point out, the impact on persons with disabilities will not be lessened by the change, and will almost certainly be increased by the gestational limit of 22 weeks rather than 18.

ERADICATION OF DOWN SYNDROME

7. In recent years, news reports focused international attention on Iceland as “the country where Down syndrome is disappearing.”⁵ While some raised concerns about eugenic practices and likened the trend to a coordinated campaign of eradication, others pointed out that women are not required to undergo prenatal screening, and 15-20% choose not to. It is true that given the fact that Iceland is a small country with a small population, so individual births of children with Down syndrome have an outsized impact on national statistics, especially given their rarity—only a few per year, and, in some years, zero. What is not disputed is that the vast majority of unborn children diagnosed with Down syndrome are aborted: estimates have put the figure at nearly 100% in Iceland, 98% in Denmark, and 90% or more in Britain and Germany.⁶
8. Iceland is not as much of an outlier as some reports would suggest. It is often compared with fellow Nordic or Western European countries, most of which have comparably low rates of Down syndrome children born annually, relative to their population size. Nevertheless, the near-eradication of Down syndrome, which to date can only be achieved by the eradication of persons with the condition, is all the more troubling for being widespread across the region. While this may not be the result of a coordinated national policy, it remains the case that Iceland’s abortion law from 1975 to 2019 contained an exception to allow for selective abortion in case of congenital defects, and the new law contains a gestational limit that was adjusted at the request of health professionals—which becomes all the more troubling in light of allegations of “heavy-handed genetic counseling” given to women whose screening results suggested the possibility of a Down syndrome diagnosis.⁷

EMERGENCE OF A WIDESPREAD DISCRIMINATORY NORM

9. Down syndrome is a condition that a) can be diagnosed before birth, b) has no known cure, and c) is frequently compatible with having a high degree of quality of life, often for many decades. In countries with robust social services and relatively high per capita wealth, prospects are high for people with Down syndrome to receive the health care they need and find ways to meaningfully contribute to their societies, including through participation in the workforce. Their families likewise could receive support both from assistance from the government and from support groups of other families that have members with Down syndrome.
10. Tragically, children with Down syndrome are becoming more and more rare due to selective abortion in the very countries best equipped to foster support and inclusion to them and their families. In Denmark, a fellow Nordic country with a similarly high rate of selective abortion in response to a Down syndrome diagnosis, researcher Laura Louise

Heinsen characterizes women who unquestioningly opt for prenatal screenings and subsequently choose to abort as “moral adherers”: they “perceive fetal quality control to be the recommended reproductive path.”⁸

11. For those parents who do have children with Down syndrome, their scarcity in countries like Iceland and Denmark make it difficult to form supportive networks. This, in turn, is perceived by parents as additional pressure to abort, as one of Heinsen’s interviewees reveals: “So few are born with Down’s syndrome today, so a child like that is going to have a hard time getting a social network, whereas 10 or 15 years ago, they had plenty of options [...] So, in reality, my choice is a consequence of the opportunity of choosing... and the choices made by all the others.”⁹
12. While Iceland does not have an official policy to eliminate Down syndrome by the selective abortion of affected individuals, it had an explicitly discriminatory abortion law in effect for over four decades, and there is significant evidence that among health professionals, who operate within a state-run health system, a discriminatory norm has become widespread. This, in turn, is perpetuated at the societal level to the point of being perceived as a moral imperative. In order to fulfill the human rights of all its citizens, including those with disabilities, the government of Iceland should take concrete steps to reverse this harmful norm.
13. To provide examples of some best practices, the Jérôme Lejeune Foundation, named for the scientist who identified Trisomy 21, conducts advocacy work to protect and promote the rights of those with Down syndrome and their families, while also supporting research to find treatments for the health problems associated with the condition. In the United States, a family with two children with Down syndrome started a business employing workers with intellectual disabilities, providing a model for how they could live productive and meaningful lives as well as normalizing their presence within their local community.¹⁰ Sigga Ella, an Icelandic photographer, was inspired by her aunt with Down syndrome to create portraits of people of all ages affected by the condition, showcasing their diversity and shared humanity.¹¹

PROTECTING THE RIGHT TO LIFE OF PERSONS WITH DISABILITIES

14. Legal and policy interventions will also assist in ending the climate of lethal discrimination against persons with Down syndrome. The practice of selective abortion requires two preconditions: the use of prenatal tests that specifically screen for this condition and the availability of abortion, particularly later in gestation. In response to the widespread use of prenatal sex determination followed by sex-selective abortion in India, the government of India outlawed prenatal sex determination as a way to discourage this discriminatory practice and human rights violation. Iceland should consider a similar ban on specific prenatal tests that are clearly causally linked to selective abortions that are a form of discrimination on the basis of disability. Similarly, the revised law that sets the gestational limit on abortion to halfway through a pregnancy

should be scrutinized inasmuch as this change is intended to facilitate the screening and elimination of persons with Down syndrome and other disabilities, which comprise a large percentage of late-term abortions.

15. It is useful to consider a) which conditions are the subject of prenatal testing, b) the extent to which these tests are used to identify therapeutic interventions that will help ensure healthy outcomes for both mother and child, and c) the broader social context, including the pressures that may face expectant parents from family, peers, the media, and, in particular, the health professionals that provide counseling as well as health care services. Some conditions, when identified early, can be treated or managed before birth, whether by medication, surgery, or changes to the mother's diet. Other conditions can be identified *in utero* but have no associated treatment or cure, such as Down syndrome. It may be true that a prenatal diagnosis of Down syndrome would help parents adjust to the potential special needs of their child after birth. However, in contexts where prenatal diagnosis leads to selective abortion in nearly all instances, such benefits are overwhelmingly outweighed by the harms associated with testing.

PROTECTING THE RIGHT TO LIFE OF ALL

16. Alongside the pervasive discriminatory practices against persons diagnosed with Down syndrome in the womb, Iceland is also notable for having a high level of social acceptance for abortion, even later in gestation. In advance of the 2019 abortion law going into effect, a poll found that over 50% of voters in Iceland approved of the 22-week gestational limit, and among women, support was 58%. Support for abortion earlier in pregnancy is presumably significantly higher.
17. UN expert human rights bodies, including treaty monitoring bodies and special procedures operating under the Office of the High Commissioner for Human Rights (OHCHR) have expressed concern about the use of selective abortion in the context of discrimination on the basis of disability (as referenced above) or its use for sex selection. However, when it is not targeted at a class of people protected by accepted standards for nondiscrimination in international human rights law, these expert bodies have increasingly pressured UN member states to liberalize their abortion laws, decriminalize the practice, and remove practical barriers to accessing abortion, including by curtailing the conscience rights of health care providers.¹²
18. It is essential to note in this context, that the views and recommendations of experts within the UN human rights system are neither binding nor authoritative interpretations of human rights treaties. Such views and recommendations have been widely recognized as often failing to follow rigorous legal interpretative methods and have been described as becoming politicized. Report of the Commission on Unalienable Rights (2021), at 48, <https://www.state.gov/wp-content/uploads/2020/07/Draft-Report-of-the-Commission-on-Unalienable-Rights.pdf>. Any action taken by states following such views and recommendations may not be considered as based on *opinio juris* but should only be seen

as an independent effort of a states to implement their human rights obligations.

19. Nevertheless, it is true that no international human right to abortion exists, whether in binding UN human rights treaties or in nonbinding agreements adopted by consensus and accepted by the General Assembly. As outlined in the *San Jose Articles* drafted by internationally-renowned scholars, human life begins at conception and “all human beings, as members of the human family, are entitled to recognition of their inherent dignity and to protection of their inalienable human rights. This is recognized in the Universal Declaration of Human Rights, the International Covenant on Civil and Political Rights, and other international instruments.”¹³ To the extent that UN human rights experts on treaty monitoring bodies assert abortion as a right, they exceed their mandates and move well beyond the boundaries of the texts of the treaties they monitor.
20. Despite these facts, Iceland has been singularly aggressive in urging its fellow member states to liberalize their abortion laws in the context of the UPR. During the ongoing third session of the UPR, as of July 2021, Iceland has issued 38 recommendations explicitly promoting abortion, more than any other member state. In contrast, over 160 of 193 countries have not made such recommendations, in keeping with the consensus reached in 1994 at the International Conference on Population and Development that abortion laws are a matter for national governments to determine without external pressure.

CONCLUDING RECOMMENDATIONS

21. In conclusion, we recommend that Iceland take immediate and effective steps to counteract the longstanding atmosphere of discrimination against persons with disabilities, particularly those with Down syndrome, that has led to their near-elimination from the Icelandic population. Components of this effort might include limits on prenatal testing that is not intended to result in nonlethal therapeutic interventions, reduced gestational limits in the abortion law so as not to maintain a *de facto* discriminatory standard, training and sensitization for health care providers and those providing genetic counseling, and public awareness-raising campaigns that promote the rights of those with disabilities, including those with Down syndrome, and showcase their unique contributions to their families, communities, and countries. Information about persons with intellectual disabilities and the importance of their full inclusion in society should also be a component of curricula in schools.
22. We further recommend that Iceland commit to protecting human life at all stages, including the lives of children in the womb, and in particular children with Down syndrome, and ensure that women who find themselves pregnant in adverse circumstances have access to the services and support they need to live a healthy and productive life without sacrificing the life of their children.

23. Finally, we recommend that Iceland refrain from using the UPR to pressure its fellow member states to liberalize their abortion laws, as abortion is not an internationally agreed human right and no consensus exists that it should be.

¹ Throskahjalp National. Submission to the Universal Periodic Review of Iceland. March 2016. Accessible at <https://uprdoc.ohchr.org/uprweb/downloadfile.aspx?filename=2862&file=CoverPage>

² Fontaine, Andie Sophia. "Iceland's New Abortion Law Goes Into Effect Today." *The Reykjavik Grapevine*. September 2, 2019. Accessible at <https://grapevine.is/news/2019/09/02/icelands-new-abortion-law-goes-into-effect-today/>

³ Erlendsdóttir, Dagný Hulda. "Gagnrýnir frumvarp um þungunarrof." *RÚV*. October 25, 2018. Accessible at <https://www.ruv.is/frett/gagnrýnir-frumvarp-um-thungunarrof>

⁴ See Concluding Observations of the Committee on the Rights of Persons with Disabilities following reviews of Spain (2011, paragraphs 17-18), Hungary (2012, paragraphs 17-18), Austria (2013, paragraphs 14-15), and the United Kingdom (2017, paragraphs 12 and 13).

⁵ Quinones, Julian and Lajka, Arijeta. "'What kind of society do you want to live in?': Inside the country where Down syndrome is disappearing" *CBS News*. August 14, 2017. Accessible at <https://www.cbsnews.com/news/down-syndrome-iceland/>

⁶ <https://thelifeinstitute.net/info/down-syndrome-and-abortion-the-facts>

⁷ Quinones and Laika, *ibid*.

⁸ Wahlberg, A. and Gammeltoft, T. (eds) *Selective Reproduction in the 21st Century*. Basingstoke: Palgrave Macmillan. 2018.

⁹ Wahlberg and Gammeltoft, *ibid*.

¹⁰ <https://www.bittyandbeauscoffee.com/>

¹¹ <https://www.siggaella.com/First-and-foremost-i-am/>

¹² https://www.ohchr.org/Documents/Issues/Women/WRGS/SexualHealth/INFO_Abortion_WEB.pdf

¹³ <https://sanjosearticles.com/>