

Iceland's Abortion Policy concerning Children with Down Syndrome: An Ethical Analysis

SARAH KLUCZNIK¹ AND HOLLY SLEPIAN²

skluczni@villanova.edu¹ hslepian@villanova.edu²

^{1, 2} Department of Chemical Engineering, Villanova University, Villanova, Pennsylvania, U.S.A.

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I. INTRODUCTION

Iceland is known to have the most liberal abortion policy in the world. Abortion became legal in Iceland in 1975 with the law that permits a woman to abort the fetus up until 16 weeks of pregnancy. However, when pregnancy is past 16 weeks, the fetus may be legally aborted if the mother's life or health is seriously compromised or if the fetus is expected to be born deformed or with a serious genetic disease. In the early 2000s, prenatal diagnostic screening to confirm the presence of chromosomal abnormalities, like Down syndrome, was introduced in Iceland. Since then, approximately 85% of women chose to utilize the optional test to see the likelihood that their child may be born with genetic defects like Down syndrome, and almost every woman whose fetus was tested positive for Down syndrome has ended her pregnancy. As a result, only one or two children are born each year with Down Syndrome out of the country's entire population. That is, practically, children with Down syndrome do not exist. Is what is happening in Iceland a pathway to an ideal society or a sign of social sickness where people trade what is deeply human for material comfort and convenience? We diagnose that it is the latter. We are opposed to the policy, for the policy violates the cultural and social nonmaleficence as well as motivates the Icelandic mothers to abort their fetuses with Down syndrome.

II. CASE

Iceland has the universal healthcare system that the Ministry of Welfare, the governmental agency, operates based on tax revenues. Due to the highly efficient healthcare outcome of the system that its small population (only 330,000) enjoys, there is almost no private health insurance and no private hospitals.¹

¹ Gunnar H. Gunnlaugsson, Margret Oddsdottir, Jonas Magnusson, "Surgery in Iceland" *Journal of American Medical Association Surgery*, 2006; 141(2):199-203. doi:10.1001/archsurg.141.2.199.

*Address correspondence to: Sarah Klucznik and Holly Slepian, Villanova University, 800 Lancaster Ave, Villanova, PA 19085, U.S.A. E-mail: skluczni@villanova.edu and hslepian@villanova.edu

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Under the Iceland healthcare, the advance in medical technology has allowed citizens to access the information which sequence one's entire DNA for under \$100 USD, which would have costed one thousand dollars not too long ago. Mothers in Iceland can also have the genetic prescreening called the "combination test" which includes the ultrasound, a blood test, and amniotic fluid test, to determine the likelihood that the fetus will have a genetic disorder like Down syndrome. The test is not mandatory; however, the government requires that all pregnant women are informed that they can access the combination test for a cheap price.

Around 80-85% of women in Iceland decide to take the test and close to 100% of women who were detected to have positive results for babies with Down syndrome decided to terminate the pregnancy. Abortion is legal in Iceland at any stage of pregnancy when the fetus tests positive for Down syndrome. The result is that, compared to 6,000 babies born with Down's annually in the US, 1 or 2 babies born with Down syndrome a year in Iceland are typically because of inaccurate test results, which makes the children with Down syndrome look like the creatures of a mistake.

The combination test is only 85% accurate. Some Icelandic women, though extremely small in number, choose not to have the test. And some parents with a child with Down syndrome have become activists for the rights of people with disabilities. Kári Stefánsson, the Icelandic neurologist and geneticist, says that the issue here is more of a moral dilemma than a medical one because it depends on how to perceive Down syndrome since people with the disease can live a full life. The advocates also criticize that the government indirectly pushes the mothers toward the decision to terminate the fetus by allowing the combination test and the free counseling. For example, the Landspítali University Hospital in Iceland provides counselors allegedly advocating for women's right to choose what to do with their body. For example, the counselor, Helga Sol Olafsdóttir, says, "This is your life - you have the right to choose how your life will look like." Meanwhile, most Icelandic citizens seem to side with their government. It is believed that the policy eliminates the lifetime of medical problems and suffering that the child with Down syndrome may face. Because the Icelandic population is racially homogenous, the children with Down syndrome tend to be born with other medical defects as well. Thus, eliminating the Down syndrome is highly important, the proponents of the policy argue.

III. ETHICAL ANALYSIS

Iceland has a very liberal, secular culture, and is arguably the most sexually liberated country in Europe. This way of life dates back to the 1700s when smallpox spread and depopulated the country. In an attempt to rebuild the country, the Icelandic King declared it lawful for every woman to give birth to six children, regardless of their marital status. Since then, the culture of dating and marriage in Iceland has changed. Icelanders are less likely to have high expectations about a relationship-forming after a casual sex encounter, while women express their sexuality without the fear of being ashamed. Iceland has also maintained a top ranking for the smallest gender gap for eight years in a row, making it one of the most feminist countries in the world. Women are highly represented in universities, parliament, and business. In 2010, Iceland became the world's first country to ban lap dancing, stripping, and prostitution, to send the message that women's sexuality is not for sale. All this has led to the current liberal culture of Iceland where women live an independent lifestyle with the belief that they do have autonomous rights when it comes to many social issues, including the rights to abortion.

Icelandic women, in general, seem to believe that a fetus with an abnormality is one that is going to suffer, and a life with a disability is not worth living. Although some people born with Down syndrome grow up to have an independent lifestyle, many others are never able to live independently by becoming permanent burdens on their parents. And, due to the homogenous population, children with Down syndrome especially may be born with other medical complications. Thus, many women believe that abortion is the way of preventing suffering of the child and family. In the end, the abortion policy particularly targeting children with Down syndrome is said justifiable by reference to respect for the mother's autonomy as well as to nonmaleficence/beneficence for the child and the family.

However, we, the authors of this paper, want to address the problem of nonmaleficence from a cultural/societal perspective, as we are opposed to the policy. First, it can be argued that the policy sets a dangerous legal and moral

precedent. As technology is rapidly advancing, the amount of information we are going to be able to find within a DNA sequence is just going to get more extensive and in depth. Maybe one day our technology will be able to point out the markers that show diabetes, obesity, Alzheimer's, ADHD, and epilepsy in a DNA sequence, as these disease types appear 60% genetic. They could easily become part of the prenatal screening, and the babies labeled with the "impurities" will become the candidates for abortion. The truth is that many people in the world live with one of these conditions and live a successful life with great quality while managing symptoms. We have never thought that their life is not worth living because they are "impure" or "imperfect." Thus, the policy holds the danger of promoting the idea of eugenics as it eradicates the members of society who may otherwise live and enjoy ordinary life.

Second and related to the first point, the policy that promotes aborting the fetuses that people find "imperfect" creates the culture of non-maleficence in the form of discrimination. The plain message that the policy gives to society is that those who have disabilities and defects are burdens to the society and thus better not to be born, the idea of which is fundamentally in conformity with the Nazi ideology which had once led to the mass extermination of the group of people who they thought to be burdensome. Due to this, this type of reasoning can easily extend to neglect of care for the elderly and mentally-ill people, for these population groups can be seen as burdens on society because they do not contribute much and instead require constant, expensive care. Already in Iceland, children with Down syndrome experience great disadvantages because it is extremely difficult for the parents to find any support for the children.

Third, together with the voice from the activists, we argue that the policy manipulates the mothers' autonomy in the guise that it allows women to exercise autonomy. There are many treatments for the possible medical issues the child may have and also many support groups that help families manage living with their disabled children. Thousands of people with Down syndrome live independently. However, the policy first instills a false hope in the mothers that aborting fetuses with Down syndrome will advance society. In addition, there is no doubt that the combination test and the free counseling that emphasize the mother's right to abort children with Down syndrome does motivate the mothers to abort their fetuses. Thus, the mother's autonomy is greatly compromised.

We acknowledge that, due to the homogenous Icelandic population, people with Down syndrome are more susceptible to other diseases including increased risk for heart problems, respiratory problems, Alzheimer's, and leukemia. However, most of these conditions, when found early, are treatable today and thus people with Down syndrome can live healthy lives. Currently, life expectancy of people with the disease is about 60 years old.² Thus, we do not find strong the argument that the genetic challenge in the Icelandic population is the reason to eradicate the birth of children with Down syndrome.

IV. ETHICAL VERDICT AND PRACTICAL SUGGESTION

A woman's autonomous right to control her own body is important, and nonmaleficent/beneficent concern for the child and the family is understandable. However, we find it greatly problematic that the policy violates the cultural and social nonmaleficence and influences the mothers to abort their fetuses with Down syndrome.

Iceland holds the abortion law which allows the mothers to end pregnancy within 16 weeks, though aborting the fetuses with abnormalities is legal in any stage. Given that Iceland is a greatly secular country, we suggest that the abortion for fetuses with Down syndrome should be limited within 16 weeks and that the way of informing mothers of the prescreening genetic test and providing the counseling should be readdressed and rectified so that they can exercise their autonomy in a rightful way.

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