



2018

Banning Abortion in Cases of Down Syndrome: Important Lessons for Advances in Genetic Diagnosis

Rebecca Reingold

Georgetown University Law Center, rr951@law.georgetown.edu

Lawrence O. Gostin

Georgetown University, gostin@law.georgetown.edu


This paper can be downloaded free of charge from:

<https://scholarship.law.georgetown.edu/facpub/2068>

<https://ssrn.com/abstract=3184834>

Rebecca B. Reingold & Lawrence O. Gostin, *Banning Abortion in Cases of Down Syndrome: Important Lessons for Advances in Genetic Diagnosis*, 319 JAMA 2375-2376 (2018)

This open-access article is brought to you by the Georgetown Law Library. Posted with permission of the author. Follow this and additional works at: <https://scholarship.law.georgetown.edu/facpub>

 Part of the [Health Law and Policy Commons](#), [Medical Genetics Commons](#), and the [Obstetrics and Gynecology Commons](#)

VIEWPOINT

Banning Abortion in Cases of Down Syndrome

Important Lessons for Advances in Genetic Diagnosis

Rebecca B. Reingold, JD

Georgetown University Law Center, O'Neill Institute for National and Global Health Law, Washington, DC.

Lawrence O. Gostin, JD

Georgetown University Law Center, O'Neill Institute for National and Global Health Law, Washington, DC.

In December 2017, Ohio passed into law legislation that prohibited physicians from performing abortions if the pregnant woman's decision was influenced by her belief that the fetus has Down syndrome. Physicians who perform abortions in these cases would face fourth-degree felony charges and revocation of their medical license. No other state bans abortion specifically for Down syndrome, but several ban abortions in cases of genetic diseases. Lower courts have struck down most such laws, holding they violate the constitutional rights of women. In February 2018, a federal district court judge blocked enforcement of Ohio's law pending a final determination.

The Ohio statute raises compelling legal and ethical issues: Will it interfere with the patient-physician relationship and, in turn, the health outcomes of pregnant women and their children? Should women have to justify their reasons for terminating a pregnancy? The disability rights movement has challenged prevailing stereotypes and advocated for greater integration of

Disability rights advocates often object to genetic screening, arguing it "reflects and reinforces societal assumptions that disability is always harmful and should be prevented, eliminated, or mitigated."² Even "neutral" information offered by genetic counselors trained to be nondirective may be problematic because that information could unduly influence a woman's decision.³ Moreover, advocates are concerned that prenatal screening will reduce the number of children born with disabilities, resulting in reduced funding for programs and services.² Noting that 67% of pregnancies with prenatally diagnosed Down syndrome are terminated, a parent recently said, "acceptance in our communities seems scarcely possible without acceptance into our families."⁴

Legislative Landscape

Ohio is the only state that bans abortion solely for Down syndrome, prohibiting physicians from performing an abortion if the pregnant woman bases her decision on the belief that the fetus has Down syndrome. The ban applies to all abortions and requires physicians to submit a report to the Department of Health for every abortion, stating the patient did not terminate her pregnancy for this reason.

Some other states prohibit abortions with respect to a variety of genetic diseases. Indiana, Louisiana, and North Dakota ban abortions if the fetus has been diagnosed with, or has a potential for, a genetic impairment, explicitly including Down syndrome. In 2016, a federal judge struck down Indiana's law as unconstitutional; Louisiana's law has not been implemented pending ongoing litigation. This leaves North Dakota as the only state with a ban in effect. Oklahoma and Arizona require women to undergo special counseling if an abortion is sought because of a fetal diagnosis of genetic disability.

Several states require health professionals to provide specific information to pregnant women who have a positive test result for certain fetal genetic conditions.⁵ These statutes—known as "proinformation" laws—typically require genetic counselors to provide information about pregnancy options, developmental disabilities, and available resources or services.⁵ The aim is to ensure unbiased information about genetic disabilities and to diminish social pressures to terminate the pregnancy.⁵

Reproductive Freedoms

Roe v Wade (1973) declared a constitutional right to terminate pregnancy for any reason before fetal viability. Two decades later, in *Planned Parenthood of Southeastern Pennsylvania v Casey* (1992), the Supreme Court adopted

The decision to have a child with Down syndrome, like all reproductive choices, is deeply consequential.

persons with disabilities into society. Do these kinds of laws promote support for or detract from more inclusive, nondiscriminatory environments?

Down Syndrome: Current State of Knowledge

In the United States, Down syndrome occurs in 1 of every 700 births, and an estimated 6000 children with Down syndrome are born annually.¹ The risk of Down syndrome increases with the age of a woman.¹ Although individuals with Down syndrome experience cognitive delays, the effects are usually mild to moderate. Consequently, most individuals with Down syndrome lead healthy lives, and their life expectancy has increased substantially, from 25 years in 1983 to 60 years today.¹ Education, health care, and social services enable individuals with Down syndrome to work, have meaningful relationships, make life decisions, and contribute richly to society.

Physicians typically offer pregnant women voluntary testing for Down syndrome. Prenatal screenings performed in the first 2 trimesters usually involve blood tests and ultrasounds.¹ Physicians use screening results, together with the woman's age, to estimate her chances of having a child with Down syndrome.¹ Diagnostic procedures such as chorionic villus sampling and amniocentesis are nearly 100% accurate, performed in the first and second trimesters, respectively.¹

Corresponding

Author: Lawrence O. Gostin, JD, Georgetown University Law Center, O'Neill Institute for National and Global Health Law, 600 New Jersey Ave NW, Washington, DC 20001 (gostin@law.georgetown.edu).

an “undue burden” test for previability abortion restrictions: states may not impose substantial obstacles in the path of women seeking previability abortions. For postviability (defined as when the fetus has the capability of meaningful life outside the womb [24–28 weeks]), states may restrict or even ban abortions unless the pregnant woman’s life or health is endangered. Ohio’s law targets abortions prior to viability. Ohio has another law in effect that bans nearly all abortions after viability.

Courts have stressed a woman’s absolute right to choose prior to viability: states “may not prohibit any woman from making the ultimate decision to terminate her pregnancy before viability.”⁶ The government cannot question a woman’s reasons for choosing to terminate a pregnancy because it is “inconsistent with the notion of a right rooted in privacy concerns and a liberty right to make independent decisions.”⁶ The federal district court judge that blocked enforcement of Ohio’s ban on abortion solely for Down syndrome ruled that the law “violates the right to privacy of every woman in Ohio and is unconstitutional on its face.”⁷

Women, Families, and Physicians

The decision to have a child with Down syndrome, like all reproductive choices, is deeply consequential. Raising a child with Down syndrome requires medical care, support services, and resources.⁸ A variety of factors, such as values, finances, and social circumstances, influence women’s decisions.³ Ohio’s law, and similar statutes, undermine the autonomy of women and families to make fully informed decisions.

Mandating reporting of abortion decisions can interfere with the confidential patient-physician relationship. Physicians may be reluctant to offer genetic testing or to talk openly about the likely health status of the fetus. The law also places physicians in jeopardy of criminal sanctions for allowing the patient to make her own reproductive choice. The law, therefore, could discourage open and honest

communication, undermining the trust so important to the patient-physician relationship. Coercive laws could also drive pregnant women away from prenatal health services, which would be harmful to the woman and the fetus.

Persons With Disabilities

Genetic technologies could significantly reduce the number of persons with disabilities in society, changing public perceptions and reducing funding.² Disability advocates express “pride in their disabilities and the diversity that disability brings to the world, which would be lost if genetic technologies achieve their promise of eliminating disability.”² Advocates do not believe society would benefit from having fewer individuals with disabilities. Rather, they want more inclusive and accessible social and built environments.² No national disability rights organization, however, has endorsed laws that ban abortion in cases of genetic disability. These laws do not promote respect for persons—both women’s autonomy and the rights of persons with disabilities.⁵

Laws that criminalize the informed decisions of physicians and patients cannot reduce stigma and discrimination; promote social inclusion; or improve access to education, rehabilitative services, and employment opportunities. Criminal laws neither increase awareness about disabilities nor do they alter social and economic conditions that influence abortion decisions.

The reproductive rights and disability rights movements are both grounded in values of bodily autonomy, self-determination, equality, and inclusion, thereby sharing a vision by which every person has the rights, resources, and opportunities to achieve their full life’s potential.⁵ Policy makers committed to advancing disability rights should enhance autonomous choices, while ensuring services, inclusive education, and built environments conducive to thriving integrated communities with the strength that comes from diversity.

ARTICLE INFORMATION

Published Online: May 18, 2018.
doi:10.1001/jama.2018.6118

Conflict of Interest Disclosures: Both authors have completed and submitted the ICMJE Form for Disclosure of Potential Conflicts of Interest and none were reported.

REFERENCES

1. National Down Syndrome Society. Down syndrome. <https://www.ndss.org/about-down-syndrome/down-syndrome/>. Accessed April 2, 2018.
2. Generations Ahead. A disability rights analysis of genetic technologies. [http://www.generations-ahead](http://www.generations-ahead.org/files-for-download/articles/GenerationsAhead_DisabilityRightsConveningReport.pdf)

[.org/files-for-download/articles/GenerationsAhead_DisabilityRightsConveningReport.pdf](http://www.generations-ahead.org/files-for-download/articles/GenerationsAhead_DisabilityRightsConveningReport.pdf). Accessed April 2, 2018.

3. Girc S. Strange bedfellows: anti-abortion and disability rights advocacy. *J Law Biosci*. 2016;3(3):736–742.
4. Kaposy C. The ethical case for having a baby with Down syndrome. <https://www.nytimes.com/2018/04/16/opinion/down-syndrome-abortion.html>. Accessed May 1, 2018.
5. Center for Reproductive Rights. Shifting the frame on disability rights for the US Reproductive Rights Movement. <https://www.reproductiverights.org/sites/crr.civicactions.net/files/documents/Disability-Briefing-Paper-FINAL.pdf>. Accessed April 2, 2018.

6. *Planned Parenthood of Indiana and Kentucky v Commissioner of Indiana State Department of Health et al*, SD Ind (2017). <https://www.courthousenews.com/wp-content/uploads/2017/09/IndianaAbortion.pdf>. Accessed May 1, 2018.

7. *Preterm-Cleveland, et al v Himes et al*, SD Ohio (2018). <https://www.courthousenews.com/wp-content/uploads/2018/03/preterm-cleveland.pdf>. Accessed May 1, 2018.

8. Centers for Disease Control and Prevention. Data and statistics: occurrence of Down syndrome in the United States. <https://www.cdc.gov/ncbddd/birthdefects/downsyndrome/data.html>. Accessed April 2, 2018.