

Genetics at the Intersection of Reproductive Justice and Disability Rights: Rhetoric and Practice

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Outline

1. Advent of prenatal genetic testing and abortion bans
2. Using disability rights to support genetic-selective abortion bans
3. Rhetorical and practical issues
4. Implications for disability rights

Prenatal genetic testing and abortion bans

Genetic-selective abortion bans

- Prohibit abortions sought because of a prenatal diagnosis of disability or genetic abnormality
- Criminal, civil, and professional sanctions for physicians
- 30 bills introduced, 6 bills passed

Evolution of prenatal testing and genetic-selective abortion bans

- 1970s** First prenatal diagnostic testing
- 2007** ACOG recommends all women be offered prenatal screening
- 2011** Noninvasive prenatal testing available to screen for chromosomal conditions and other diseases
- 2016** ACOG and ACMG recommend NIPT for all pregnant women

Defining a genetic-selective abortion

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“‘any other disability’ means **any disease, defect, or disorder** that is **genetically inherited.**”

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“‘potential diagnosis’ refers to the **presence of some risk factors** that indicate that a health problem may occur.”

**Using disability rights to
support genetic-selective
abortion bans**

Discrimination

- Each genetic-selective abortion is harmful to the individual fetus
- Bans are an extension of existing anti-discrimination law
- Stems from the claim that a fetus has a right to be born that is being denied on the basis of disability

Expressivist harm

- Genetic-selective abortions send the message that the lives of disabled individuals are less valuable than lives of those without disabilities
- The practice of selective abortions and state endorsement of them harms the existing disability community

Eugenics

- Widespread occurrence of genetic-selective abortions harm the prospective disability community and society
- Selective abortions will lead to few or no births of disabled babies
- The state has an interest in preserving the disability community
- First step toward “designer babies”

Rhetorical issues

Defining fetal rights

- The allegation is that genetic-selective abortions prevent a fetus from being born on the basis of disability
- A fetus does not have a protected right to be born when abortion is pursued on other grounds
- Liability based on motivation is analogous to hate crime laws, which require underlying criminal conduct

Exacerbation of expressivist concerns

- The expressive function of genetic-selective abortion results in part from the perceived motivations
- Rhetoric decontextualizes the decision to terminate, which is influenced by social, political, economic, and personal circumstances
- Overstates the extent to which ableist attitudes and negative views of disability motivate selective abortions

Conflation with 20th century eugenics

- Genetic-selective abortions are a matter of individual choice, not centralized planning
- Laws are not concerned with prenatal testing and counseling that precede termination decisions
- Proponents stress importance of treatments and cures that would similarly eliminate disability

Erasure of differences among disabilities and genetic abnormalities

- Disabilities are not defined by genetics
- Disability is not distinguished from the increasing number of identifiable genetic abnormalities
- Genetic conditions have widely varying prognoses
- Rhetoric focuses on Down syndrome and presents an idealized picture of raising a child with disabilities

Focus on heritability

- Most bills limit bans to genetically inherited disabilities while making reference to non-heritable conditions
- Tension between discrimination and expressivist arguments, which apply to all disabilities, and the eugenics argument, which is most forceful with respect to heritable traits

Practical implications for reproductive care

Disruption of the doctor patient relationship

“‘Reason bans’ represent gross interference in the patient-physician relationship, creating a system in which patients and physicians are forced to withhold information or outright lie”

– American College of
Obstetricians & Gynecologists

Disruption of the doctor patient relationship

- It will be harder to access abortion care
- Women will have less reliable information about testing, diagnoses, and disability
- Counseling associated with lower termination rates

Restrictions on other reproductive care

- State interest in preventing discrimination and eugenics applies at all stages of pregnancy, justifying pre-viability abortion restrictions
- Arguments do not draw a clear line between abortion and other reproductive decision-making like contraceptive use and preimplantation embryo screening

Implications for disability rights

Advocates' concerns

- Routinization of prenatal testing
- Lack of patient-centered counseling
- Stigmatization of decision not to test or not to abort
- Tension between disability community and genetic counseling profession
- Focus on a biomedical model of disability

Reception of abortion bans

- No uniform view within the disability community
- The academic disability rights community has forcefully rejected GSA bans
- Advocates have expressed a broader range of views

Politicizing disability rights

- Tying embrace of disability right to rejection of abortion rights
- Arguments in favor of genetic-selective abortion bans rest on a politicized ideas of reproduction and family
- Rather than focus on support for disability rights in the public sphere, putting onus on private action

Focus on abortion restrictions diverts focus from consensus policies

- Increased access to high quality genetic counseling
- Training for counselors that includes the disability community and emphasizes the lived experiences of those with disabilities
- Reorientation of counseling to prioritize families' values and deemphasize biomedical models of disability
- Greater support for families of those with disabilities

Conclusion

Genetic-selective abortion bans do not advance disability rights

- Arguments are inconsistent and do not align with a disability rights agenda
- The effect is to reduce abortion access
- Genetic-selective abortion bans inhibit coalition building and set back the disability rights movement
- Coming advances in genetic testing will exacerbate these dynamics

Thank you

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