

PASSING THE TEST: PERCEPTIONS OF DISABILITY IN PRENATAL GENETIC COUNSELING GUIDANCE AND PRACTICE

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INTRODUCTION

Prenatal genetic screening and selective abortion have become ubiquitous in obstetrics care in the United States. Emerging alongside these technologies are ethical entanglements between disability activists, researchers, and practitioners regarding who decides - and by what measure - "who should and should not inhabit the world" (Hubbard, 2013, p. 81).

The nature of disability itself serves as a central tension, with the language deployed to endorse or critique screenings, their use in clinical settings, and design of the technologies themselves revealing conflicting orientations toward disability.

BACKGROUND AND JUSTIFICATION

Prenatal Genetic Screening as a Site of Controversy

- Genetic technology development and deployment may be guided by a "curative imaginary" (Kafer, 2013), and contribute to the production of a "genetic underclass" (Jasanoff, 2011).

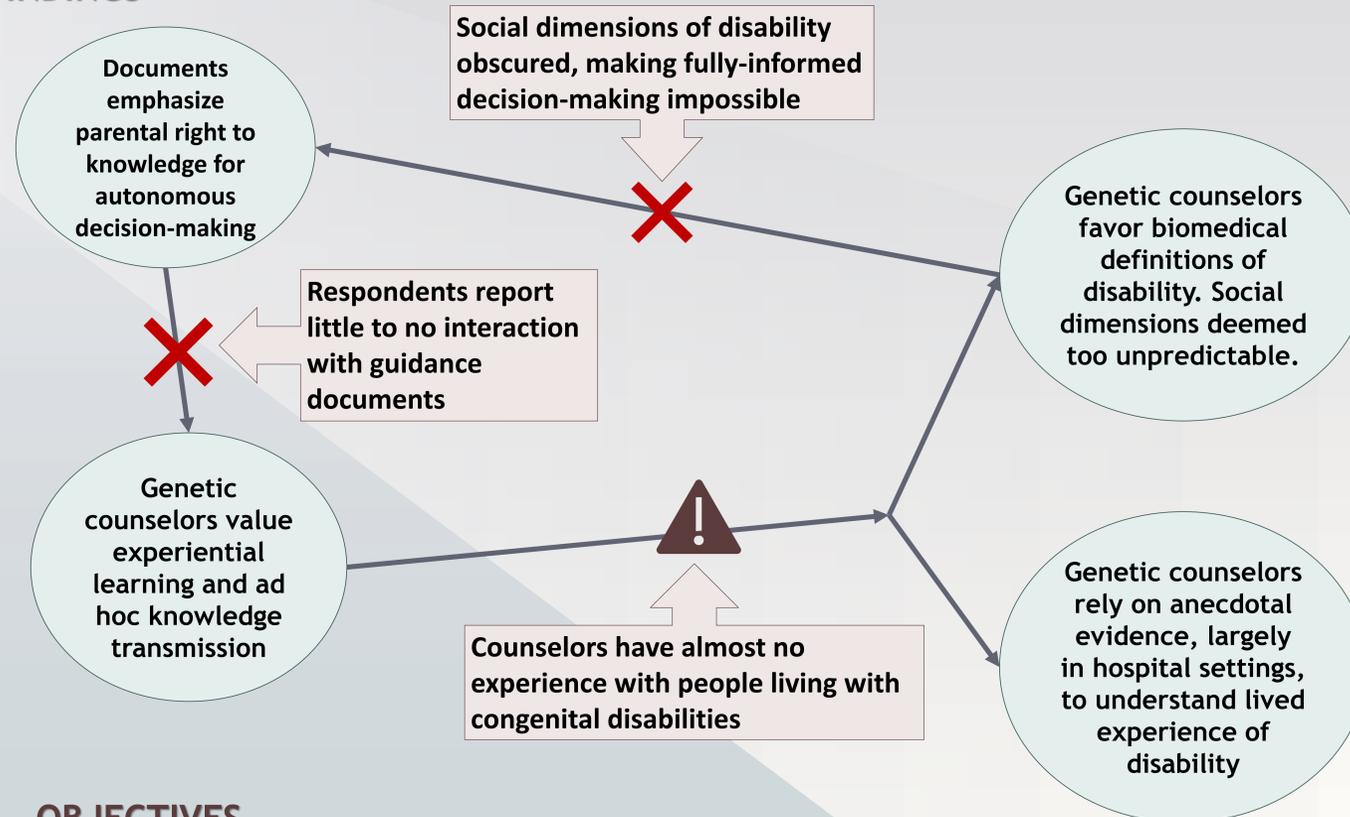
Problem-Framing

- Prenatal screening is leveraged to reinforce the stark biological line between ability and disability. The attribution of disability to purely detectable and quantifiable biological characteristics "misrecognizes and thus masks the effects of social practices and hierarchy" (Carrier, 1983) as quoted in Conrad, 1992, p. 224).

Medicalization as Social Control

- The medicalization of certain characteristics, particularly with the aid of technologies whose measurements are trusted as objective, provides a powerful foundation for legitimizing forms of social control based on those characteristics (Conrad, 1992).

FINDINGS

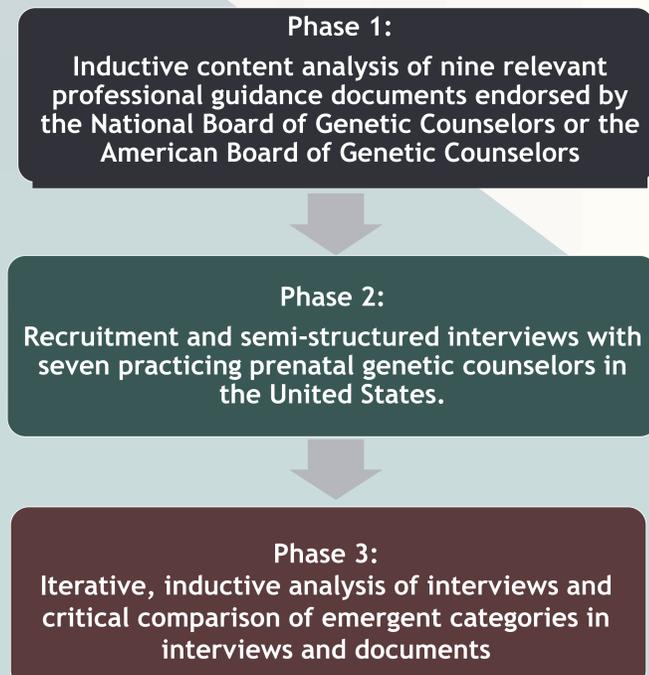


OBJECTIVES

This project sought to determine:

- The roles prescribed to clinicians, fetuses, and parents at both the institutional and the individual level.
- The rhetoric included and excluded in professional and personal discussions about congenital disability and prenatal genetic testing.
- The extent to which guidance and practice support or suppress opportunities for choice and autonomy in lay patients.
- The relationship between professional guidance and individual perception and practice.

METHODS



CONCLUSION

- Genetic counselors view prenatal genetic screening as integral to empowering "potential parents...to make fully informed and autonomous decisions about reproductive options and pregnancy management" (Hercher et al., 2016), but reliance on purely biomedical conceptualizations of disability obscure the social dimensions of disability which may impact decision-making.
- It is necessary to provide genetic counselors insight into a holistic view of disability that does not rely on a medicalized model. However, there is a question around implementation, as it is clear that guidance documents are not a sufficient means of knowledge transmission.
- Genetic counselors are not the only clinicians entrenched in the prenatal genetic testing apparatus, and it is not immediately clear how many alternative pathways to genetic testing exist and who acts as gatekeepers and educators on these pathways.
- As prenatal genetic testing becomes less invasive and more ubiquitous, the context in which it is executed will become increasingly important to shaping biological, social, and political conceptualizations of disability.

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