“If Your Genetics Aren’t as Good as the Next Person’s Genetics”

Prenatal Genetic Counseling as a Site of Controversy

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Overview

• What is Prenatal Genetic Screening/Testing?

• Who are Genetic Counselors?

• Why is PGS Controversial?
Theoretical Foundations

• Critical Disability Studies
  - Curative Imaginaries
  - Geneticization

• Science and Technology Studies
  - Controversy as site for inquiry
  - Medicalization
Research Objectives

• Determine the roles prescribed to various actors at both the institutional and individual level. (ontology and medical classification)

• Illuminate rhetoric included and excluded in professional and personal discussions of congenital disability (problem-framing)

• Understand the relationship between guidance, practice, and patient autonomy (expertise and authority)
Methods

• Phase I: Textual Analysis of genetic counseling guidance documents

• Phase II: Semi-structured interviews with practicing genetic counselors

• Phase III: Inductive analysis and integration
Selected Findings

• Value of Experiential Learning

Anton: Yeah, I mean, most of these guidelines are trying to say “Here are things you need – you should be talking about. Here is what we think is appropriate.” But none of those documents are very good at explaining “how do you talk about Trisomy 18 with the person in such a way that they understand what that means for them.” That’s a really difficult thing to write and put in a guideline or put in a reference. Like, you know, the whole discussion about eyes being open, things like that, that’s only come from my experience with patients. (2, 449-454)
Carmen: Um, you know, probably the best experience I had with people with some kind of disability was actually when I was in grad school. Um, for genetic counseling. Because we had a required rotation, you know, to go to one of the day programs that they have for people with severe mental and physical disabilities. Um, so you know, I met people there [laughs] that I just wouldn’t have ever expected to see someone alive with that condition. Or this or that condition, I suppose. So, I mean that would probably be the best experience that I had. Or the most extensive any way (4, 301-306)
Pauline: But, you know, some of the feedback I get as well, particularly with Down Syndrome is, “It was all doom and gloom. And nobody told me how wonderful it could be to raise a child that has Down Syndrome”. And while I am empathetic to that, my professional opinion is if I don’t tell you the worst of it, I have not done my job, and from a litigation perspective, it would be particularly dangerous for me. So, I try not to be all doom and gloom, I try to be balanced, but it is my personal and professional opinion that we’ve got to get some of the bad news out there in addition to some of the, you know, “families can be happy with kids with this condition stuff out there as well (1, 214-220)
Selected Findings

• The “Non-Directive” Counselor

Marcie: You know, you can never – we do this sort of nonsense of “be a non-directive counselor”, yeah, yeah, yeah, you know? [Laughs] And we strive for that, and it’s good to do that, but yes there’s a piece of yourself that has to go into this, otherwise, you’re a robot. (3, 309-311)
Marcie: Oh, absolutely. Absolutely. It’s coercive. “Have this blood test done and it will tell you if your baby’s okay. Absolutely! They’re not given a choice. No, that’s not true, they do say, “You can.” But without the explanation, it’s your doctor saying, it’s the authority saying. Why would you say no to your doctor? (3, 156-158)
Discussion

• Tenuous connections to disability communities

• “Fully-informed autonomous decision-making”
  - Shifting of accountability
  - Knowledge as empowerment

• Future Work
  - Identifying alternative gatekeepers
  - Parental experience with attention to race, ethnicity, region, sexual orientation and ability
Recommendations

• Introduce a holistic view of disability that doesn’t rely on medicalized, deficit-based models

• Identify implementation strategies that move away from underutilized guidance documents

• Provide greater access to non-clinician experts on disability, including self-advocates with experiential expertise
THANK YOU!

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