

The explicit attitudes of genetic counselors towards individuals with disabilities: A survey

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Background

Historical Tension

- The disability and genetics communities have a long and complex history, fueled by the eugenics movement and continuing as genetic technology improves the ability to prenatally diagnose disabling genetic conditions.¹

Genetic Counselors (GCs) & Disability

- GCs play a seemingly contradictory role in their interactions with patients, offering opportunities for avoidance of disabling genetic conditions in a prenatal setting while also advocating for individuals with disabilities in pediatric and adult contexts.⁶
- It is important to understand GCs explicit attitudes on disability which are currently not well-documented. Attitudes of healthcare providers can influence clinical decision making, which can contribute to inequitable care.²

Research Questions & Study Significance

- What are GCs' explicit attitudes on disability as well as
 - Their views on nondirective counseling in the context of disability due to repeated questioning of this technique's attainability?^{9,10}
 - Their awareness of health inequities faced by those with a disability?
 - Their endorsement of various disability models?
- This study sought to:
 - Provide a better understanding of the attitudes of genetic counselors towards disability
 - Determine whether there is a need to increase GC awareness of the lived experience of individuals with a disability.

Methods

Participants

- GCs in the U.S. and Canada who had graduated from a U.S. or Canadian accredited genetic counseling graduate program
- NSGC Student Research Survey Program

Survey Components

- Demographics
- Researcher-created questions addressing:
 - GC views on nondirective counseling in general and in the context of disability
 - GC awareness of several disability health inequities
 - GC endorsement of various disability models
- Attitudes Toward Disabled Persons (ATDP) scale, Form O

Data Analysis

- Descriptive statistics
- One-sample t-tests for ATDP score comparisons
- Spearman correlations
- A p-value threshold ($p < .05$) was applied for significance.

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Results

Demographics

- All study participants identified as female
- Other characteristics were representative of the field
- 10.0% had been LEND (Leadership Education in Neurodevelopmental and Related Disabilities) trainees
- 6.7% self-identified as having a disability
- 38.9% reported that they had a close friend or family member with a disability
- 41.1% reported occasional interactions with individuals with disabilities.

Non-directiveness & Disability

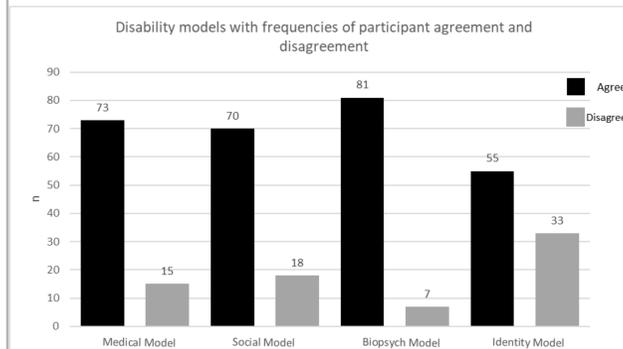
- >90% reported that they would adhere to a nondirective approach when presented with prenatal counseling scenarios, regardless of disability status of the mother or the condition of interest.
- ~ 1/3 reported that they use a combination of both directive and nondirective counseling in most counseling situations.
- Participants who self-identified as having a disability were more likely to be nondirective when discussing medical referrals ($p = 0.27$, $p=0.009$).
- Many participants identified situations where non-directiveness would be difficult to achieve, including when the patient has an intellectual disability.

Inequity & Disability

Question	Response	n (%)
Do you believe the existence of prenatal testing further stigmatizes disability?	Yes	32 (36.0)
	No	40 (44.9)
	Don't know	17 (19.1)
In your experience as a genetic counselor, have patients with disabilities been treated differently by healthcare providers based on disability status alone?	Yes	51 (57.3)
	No	17 (19.1)
	Don't know	21 (23.6)
Patients with disabilities have equal access to genetic counseling services in a prenatal setting compared to patients without disabilities.	Strongly agree	5 (5.6)
	Agree	33 (37.1)
	Neutral	26 (29.2)
	Disagree	24 (27.0)
	Strongly disagree	1 (1.1)
Patients with disabilities have equal access to genetic counseling services in a pediatric setting compared to patients without disabilities.	Strongly agree	11 (12.4)
	Agree	44 (49.4)
	Neutral	22 (24.7)
	Disagree	10 (11.2)
	Strongly disagree	2 (2.2)
Do you believe that pregnant women with disabilities are treated differently by healthcare providers in a prenatal setting?	Yes	63 (70.8)
	No	5 (5.6)
	Don't know	21 (23.6)

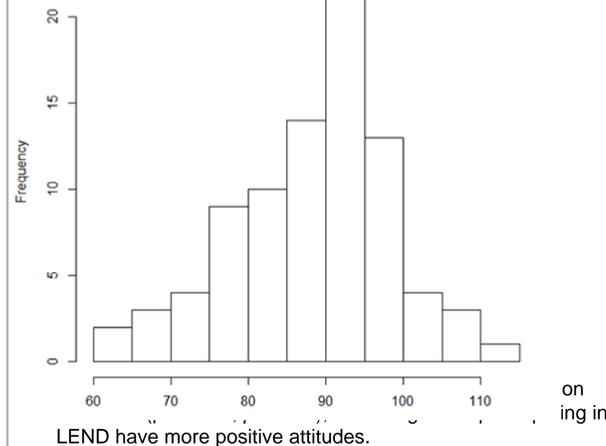
Results Cont.

Models of Disability



Model	Definition
Medical Model	An individual's limitations based on symptoms of their diagnosis.
Social Model	Society's failure to provide services and support to meet the needs of people with disabilities.
Biopsychosocial Model	An interaction between biological, social, and environmental factors related to disability.
Identity Model	A cultural identity of a minority group of society

Explicit Attitudes on Disability



- Having more frequent interactions with individuals with disabilities was associated with higher scores and more positive attitudes ($p = -0.27$; $p = 0.01$).

Discussion

Non-directiveness & Disability

- While GCs recognize that nondirective counseling is not always attainable in situations where patients have an intellectual disability, they still value this tenet in sessions that discuss disability.
- A continuum of nondirective counseling
- As a profession, we should continue to have frequent discussions about its dynamic nature and encourage debate and reflection on its use.¹⁰

Inequity & Disability

- We know patients with disabilities report inequity.⁷
- It is important to recognize the need to educate GCs on the health inequities that people with disabilities face.

Models of Disability

- Most GCs endorsed all four models, with most participants expressing the greatest agreement with the biopsychosocial model of disability.
 - Consistent with GCs roles and training

Explicit Attitudes on Disability

- GCs have an implicit bias toward ability.³
 - Disparity in GCs' explicit and implicit attitudes
 - By being self-aware of this difference in attitudes, GCs can reflect on how subconscious biases may be influencing a session even if they believe they are being outwardly positive towards individuals with disabilities.
- Importance of disability education and exposure in creating positive attitudes.
- GCs' ATDP score was significantly higher than: ($p < 0.0001$)
 - Undergraduate students with prior experience working with individuals with disabilities and completion of a service-learning course.⁵
 - Healthcare providers (doctors, allied health professionals, nurses).⁴
 - First-year medical students.⁸

Conclusions

Results suggest that while holding positive attitudes, GCs can improve their knowledge of the disability lived experience through increased exposure and interactions with disability in graduate training programs.

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