

DISABILITY COMMUNITY ENGAGEMENT

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NASEM Roundtable

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HISTORICAL TRAUMA

“The tension between the disability and genetic communities is largely rooted in a history of eugenics. Eugenics hinged on improving society as a whole by eliminating and preventing those who were thought to be genetically deficient and thus burdensome.”

(Roadhouse et al., 2018, 1361)

HISTORICAL TRAUMA

“Genetic counselors adopt seemingly contradictory roles: advocating for individuals with genetic conditions while offering prenatal diagnosis and the option of selective termination to prevent the birth of a child with a disability. This duality contributes to the tension between the disability and clinical genetics communities.”

(Roadhouse et al., 2018, 1360)

DISABILITY DEFINED

Oxford Dictionary: a physical or mental condition that limits a person's movements, senses, or activities.

A disadvantage or handicap, especially one imposed or recognized by the law.

ADA: A legal term. A person who has a physical or mental impairment that substantially limits one or more major life activity.

Disability activists:

“Disability is not just a physical diagnosis, but a lived experience in which parameters and barriers are placed upon our lives because of that diagnosis”
(Imani Barbarin)

“Once upon a time, disability was just a diagnosis. Thankfully, through time, the notion has evolved to embrace broader concepts, like constituency, identity and culture.” (Lawrence Carter-Long)

EXETER REPORT - NSGC



National Society of Genetic
Counselors Diversity, Equity, and
Inclusion Assessment

Executive Summary

Developed for The National Society of Genetic Counselors
by The Exeter Group
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7.89% of respondents
identified as having a
disability

DISABILITY RIGHTS CRITIQUE OF PRENATAL GENETIC SCREENING

- Screening may obstruct social acceptance and material support for disabled individuals, leading to discrimination of individuals living with such conditions.
- Screening sends the message that a single trait defines the whole (potential) person.
- Misunderstandings of what life is like for children with a disability and their families often exist.

Better health for people with disabilities

People with disabilities have the same general health care needs as others

But they are:

2x

more likely to find health care providers' skills and facilities **inadequate**

3x

more likely to be **denied** health care

4x

more likely to be treated **badly** in the health care system



Having a disability is not synonymous with poor health.

Although some disabling conditions do inevitably lead to poorer health, regardless of circumstance, poorer health may be attributable to economic and social inequities such as barriers to healthcare access.

(Mitra et al., 2022)

ABLEISM

- Discrimination or prejudice against disabled individuals.
- "Social habits, practices, regulations, laws, and institutions that operate under the assumption that disabled people are inherently less capable overall, less valuable in society, and/or should have less personal autonomy than is ordinarily granted to people of the same age."



(www.portland.gov)

DISABILITY PARADOX

- Many with disabilities adapt to their circumstances and experience relatively high levels of mood and QoL.
- Paradox is the discrepancy between self-reports of QoL and estimates from non-disabled outsider views including healthcare providers, parents, etc.

(Albrecht and Devlieger, 1999; Ubel et al, 2005)

"There's a general discomfort about disability. It's almost like if we don't say the word, we don't have to acknowledge it."

Ing Wong-Ward, associate director of the
Centre for Independent Living in Toronto

The Current

RESHAPING WHAT WE'VE LEARNED

Disability is a natural and neutral part of human diversity.

“**Disability Pride** is the idea that people with disabilities should be proud of their disabled identity. People with disabilities are the largest and most diverse minority within the population, representing all abilities, ages, races, ethnicities, religions and socio-economic backgrounds.”

It connects individuals to a larger community

