

Disabling Structural Ableism in Genomics and Precision Medicine Research

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Plan of Action

1. Disability constructs & representation
2. Genomic messages and application in non-clinical settings and precision medicine research
3. Key gatekeepers for inclusion
4. Pathways forward



IRB member of the *All of Us Research Program*

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Disability Constructs and Representation



Genomics Messages



- Genetic essentialism & meliorism expand to behavioral traits & outcomes
- Strategic essentialists --- along with other “isms” (e.g., racism, sexism)



Disability, Competency and Psychiatric Genetic Essentialism

- A vignettes study, non-clinical settings
- Genetic essentialism and genetic meliorism
- Strategic ableists
 - Presumption of psychiatric condition associated with low capabilities in daily life activities unrelated to the vignette

Journal of Law and the Biosciences, 1–22
<https://doi.org/10.1093/jlb/lsab026>
Original Article

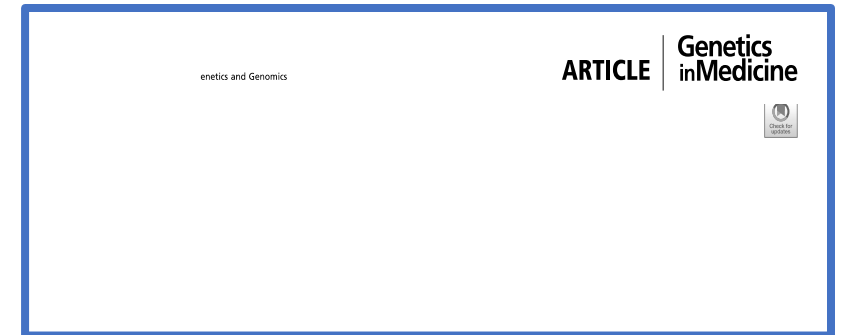


Psychiatric genetic essentialism and
stigma in child custody proceedings:
public views

Maya Sabatello^{†,*}, Audrey Chao[†], Beverly J. Insel^{**},
Thomas Corbeil^{††}, Bruce G. Link[§] and Paul S. Appelbaum[§]

Disability Inclusion in Precision Medicine Research

- ~1300 participants with diverse disabilities (national study)
- High interest in participation & willing to provide biological & lifestyle data
- Want medical and genetic results returned to them



Structural Ableism

A system that places value on people's bodies and minds based on societally constructed ideas of normalcy, intelligence, excellence and productivity. These constructed ideas are deeply rooted in anti-Blackness, eugenics, colonialism and capitalism. This form of systemic oppression leads to people and society determining who is valuable and worthy based on a person's appearance and/or their ability to satisfactorily [re]produce, excel and "behave."



Genomic agenda

Research institutions

IRBs

Medical journals

Genomic Agenda:

Mainstream research is exclusionary

- Progress but still limited racial and ethnic diversity
- Direct and indirect exclusionary criteria are pervasive
- Inclusive practices are sparse
- Health equity unlikely



Numerous Barriers for Participation

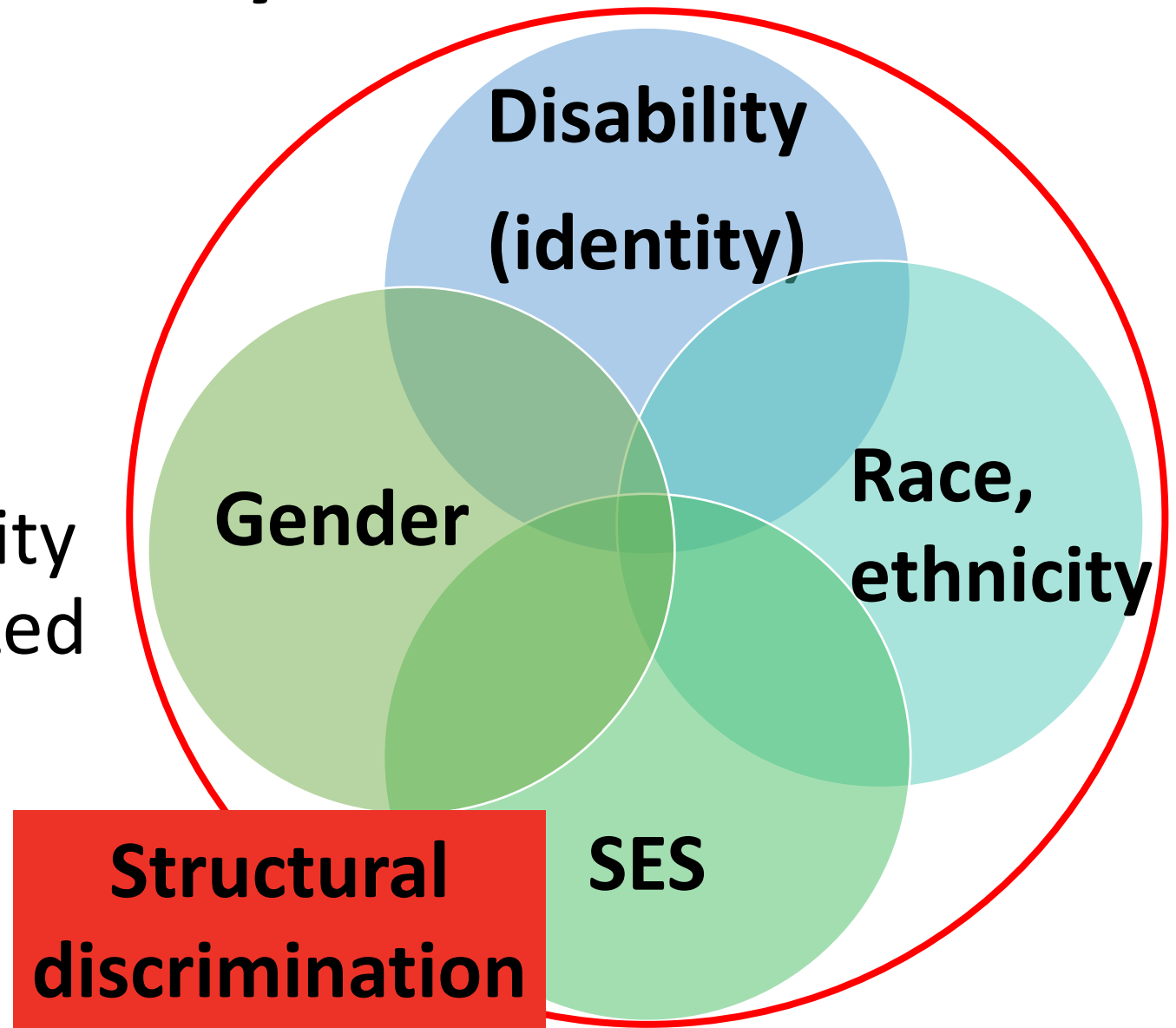


- 76% of participants have 3-8 accessibility, communication, attitudinal and other barriers to participation in precision medicine research

“They [i.e., PM researchers] won't want to include people with disabilities”

Intersectionality Matters

- More barriers among participants with low socioeconomic status
- Views differed by disability subgroup and marginalized gender, racial & ethnic communities



Genomic Agenda: Separate and Unequal

- Disability-specific cohorts may help drawing attention to needs & disease prevention strategies
- Genetic essentialism and meliorism, not person-centered
- Deprives health equity opportunities and reinforce the construct of one-dimensional victims

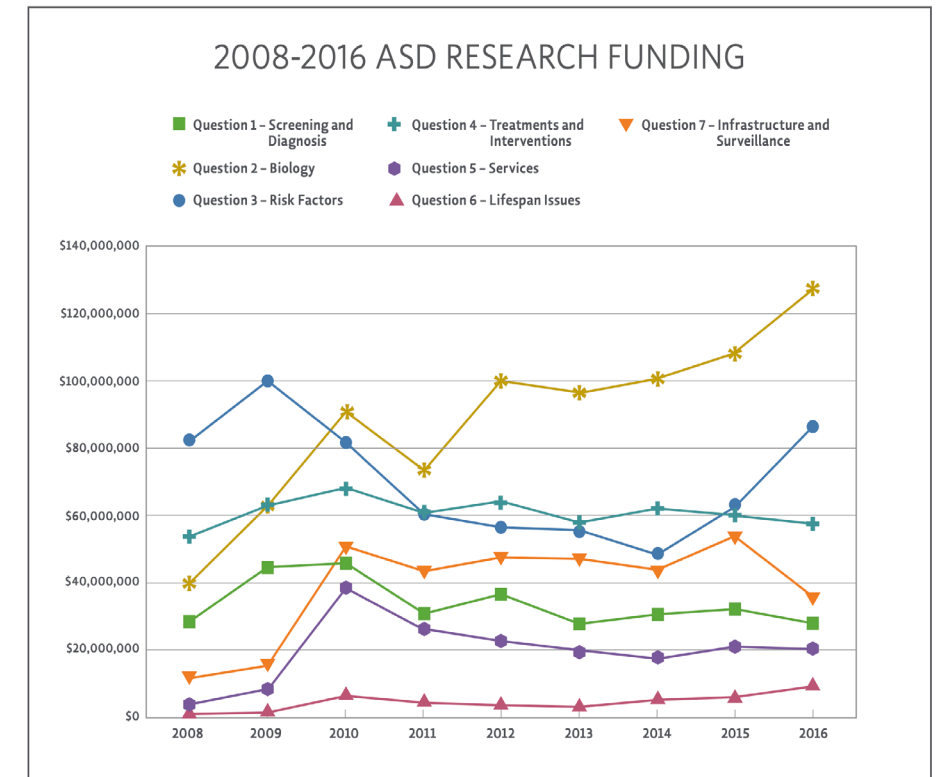
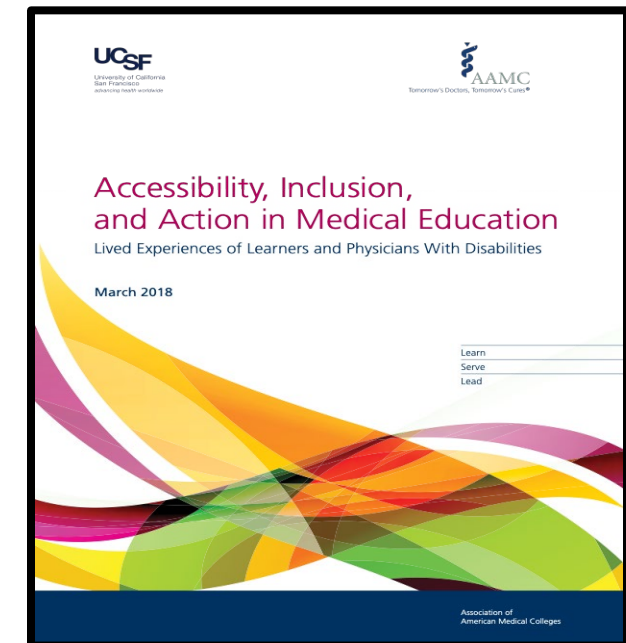
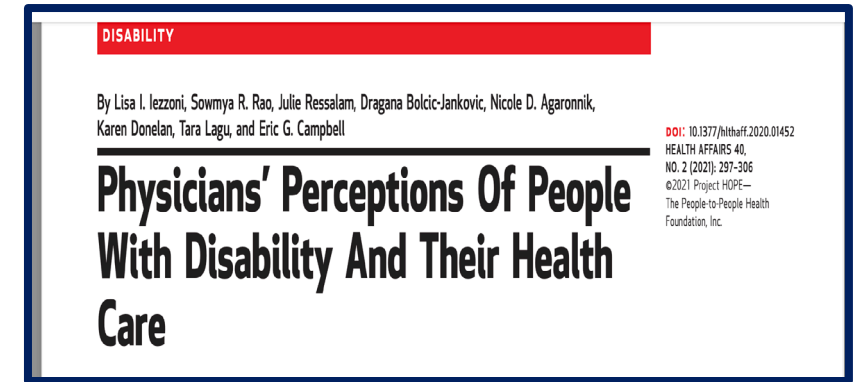


Figure 6. Trends in ASD funding for each Strategic Plan Question over the nine-year period of reporting (2008-2016).

Medical Institutions

- Primary precision medicine research sites (medical schools) are inaccessible, have limited knowledge of accommodations, and are underrepresented by colleagues with disability
- Reinforce the “Other”, innocent fool and one-dimensional victims



IRBs: Presumption of incompetency and Guardianship

“Would it make more sense to include guardians or family members from the beginning, ..., particularly since the guardians may have more pertinent information about precision medicine research in individuals with disabilities?”

IRBs: Over-protectionism = Exclusion

“... Ultimately recommended that individuals with intellectual disabilities and autism spectrum disorder not be included in the populations of interest for this protocol”

Medical Journals: Out of Mind, Out of Sight

“After considering [your abstract’s] focus, content, and interest, we made the editorial decision not to consider your proposal further.”

Abstract, pre-submission inquiry: “... The manuscript [on the needs of people with disabilities in the COVID-19 pandemic] would not have sufficient priority for [our journal]”

Medical Journals: The Power of Language

- Language reinforces disability stereotypes, power hierarchies and disability oppression



Paths Forward

Disability competency curriculum

Community engagement

Researchers with disability

Universal design studies

Research ethics & regulations

Data sharing

Disability Competency Curriculum

“[I would participate in precision medicine research] if the researchers had an understanding of the social model of disability and understood that many disabled people with non-painful disabilities aren’t interested in a cure.”

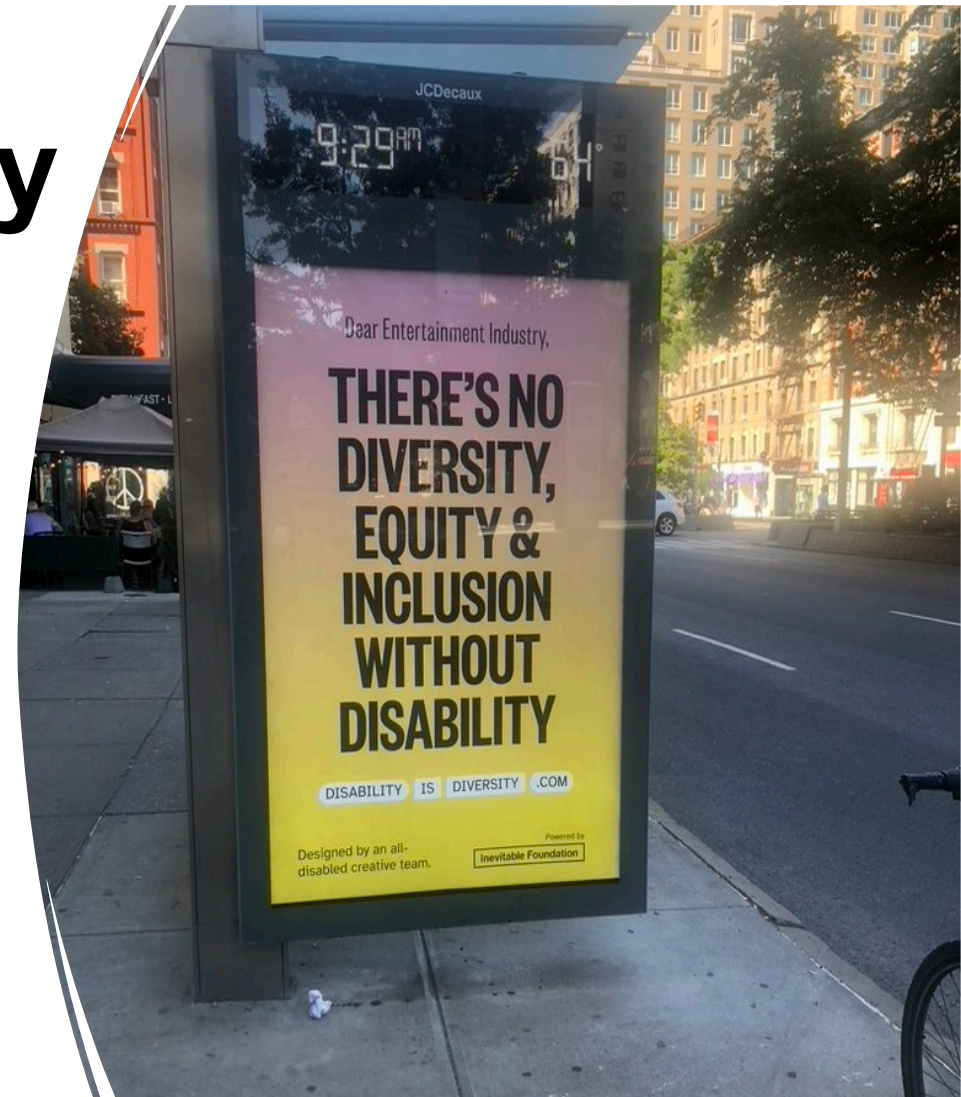
> [PLoS One](#). 2021 Aug 5;16(8):e0255722. doi: 10.1371/journal.pone.0255722. eCollection 2021.

Project Inclusive Genetics: Exploring the impact of patient-centered counseling training on physical disability bias in the prenatal setting

Emma Vaimberg ¹, Lindsay Demers ², Eric Ford ³, Maya Sabatello ^{4 5}, Blair Stevens ⁶, Shoumita Dasgupta ⁷

Building community of researchers with disability

“If the researchers had extensive knowledge and experience in disability social justice history and issues, and **WERE** disabled themselves, it would be better.”



Community Engagement

- Considered best practice but limited implementation with disability communities
- Twin-track approach is needed



Universal Design -- From the Get Go

“We're a marginalized group. If we're talking racially, if we're talking socioeconomic, rural areas, different things, the only way [precision medicine research] is going to be different is if people make it different from the beginning.”

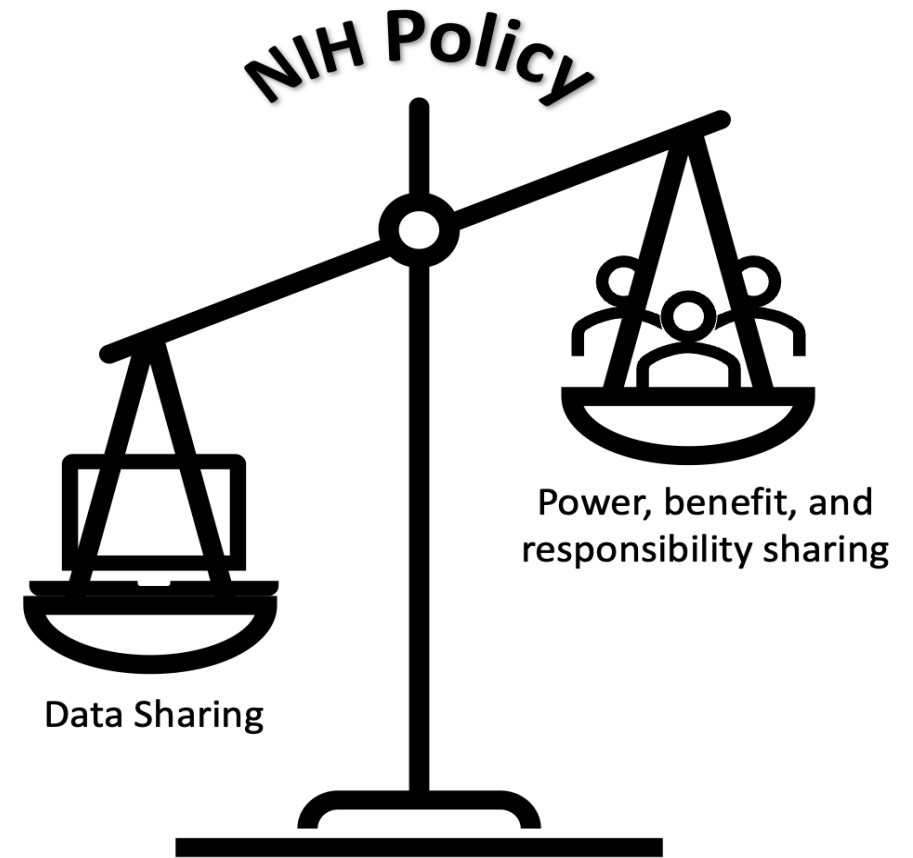
Research Policies & Regulations

- Shift from protectionism and exclusion to empowerment, equity, and benefits sharing

“[M]aybe right out of the gate, we decide to put in the work to make sure this is not just going to be available to, to rich white men, ... but for everyone”

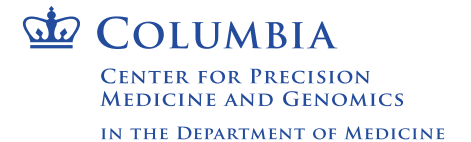
Data Sharing

- Data sharing must be accompanied by responsibility sharing to disable structural ableism





- Research participants
- Community partners
- Advisory Board/self-advocates
- Research staff & collaborators
- Funders: NHGRI K01HG008653; NHGRI/NIH's OD grant R01HG010868; NHGRI/AoU 3P50HG007257-05S1; NICHD/NHGRI R01HD108701; SU CUSE Grant



Questions?

Looking forward to the Discussion!

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