Disabling Structural Ableism in Genomics and Precision Medicine Research

Maya Sabatello, LLB, PhD
Associate Professor
CPMG & Division of Ethics
Columbia University
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*

Presentation in personal capacity

Please do not use without permission
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
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
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.”
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
“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!
Sources

• https://theday.co.uk/debate-rages-as-first-designer-babies-born/
• https://iacc.hhs.gov/publications/strategic-plan/2019/
• Sins Invalid, Skin, tooth, and bone: the basis of movement is our people: a disability justice primer (2nd ed., 2019; Sins Invalid publication)
Sources


• Rachel Adams, Disability and the Circus, in The American Circus, Susan Weber, Kenneth L. Ames, and Matthew Wittmann (eds), 2012