Project Inclusive Genetics:
Developing a Patient-Centered Counseling Approach

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Explicit vs. Implicit Bias

- **Explicit bias** – have awareness of this attitude

- **Implicit (Unconscious) bias** – no awareness of this attitude and may be opposed to declared views

We all have implicit biases. Healthcare providers manifest implicit biases to a similar degree as the general population.
Implicit Bias in Medicine

Racial bias in pain assessment and treatment recommendations, and false beliefs about biological differences between blacks and whites

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Genetics and Disability

Tay-Sachs Disease
Spinal muscular atrophy
Cri-du-Chat
Down Syndrome
Rett Syndrome
Deafness
Charcot-Marie-Tooth Disease
Huntington’s Disease
Fragile X Syndrome
Achondroplasia
Muscular Dystrophy

Many genetic diagnoses include physical or intellectual disabilities.
Evidence for Explicit Bias Against Disability in Genetics

“Seeing the bright side of being handicapped is like praising the virtues of extreme poverty.”
- James Watson
Does providing prenatal testing and opportunities for pregnancy termination for certain genetic conditions imply a belief that individuals with disabilities are defective?
ISCC Project Inclusive Genetics

Disability Implicit Bias in Medicine
- Measure implicit biases for physical and intellectual disabilities
- Implicit Association Test (IAT)

Bias and Counseling
- Examine potential correlation between IAT results and responses to prenatal counseling scenarios
- Utilize cases where child is at risk for physical or intellectual disability

Non-directive counseling
- Developed a module to describe principles of patient-centered counseling

Impact on hypothetical counseling
- After completing non-directive counseling module, assess potential impact on counseling recommendations in hypothetical cases
Clinical Decision-Making in the Prenatal Setting

Pre-module clinical scenarios:
- Becker Muscular Dystrophy
- Fragile X

Demographics:
- Includes questions on explicit biases

Implicit Association Tests:
- Physical Disability IAT
- Intellectual Disability IAT

Patient-centered counseling module:
- Down Syndrome
- Achondroplasia
- Fragile X

Post-module clinical scenarios:
- Ataxia Telangiectasia
- Down Syndrome
Clinical Decision-Making in the Prenatal Setting

Enter Module
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Does implicit bias for both physical and intellectual disability exist among healthcare providers?

- Does it vary by physical vs. intellectual disability?
- Does it vary by demographics of provider?
- Does it vary by specialty of provider or stage of training?

See evidence for bias:
PD > ID
Implicit Bias Study design

Does implicit bias for both physical and intellectual disability exist among healthcare providers?
• Does it vary by demographics of provider?

Data from 2/12/2021
n = 584

Medical students (preclinical)
Medical students (clinical)
Genetic counselors
GC students
MD (medical geneticists)
MD (other)
Resident
Nurses
Educators
Other allied health professional
Other

Pie chart showing the distribution of respondents across different categories.
Study cohort

Who is underrepresented?
- Physicians (medical geneticists and other specialties)
- Genetic counseling students
- Medical students (clinical years)
- Allied health professionals

Action items and help with dissemination:
ACOG
ACMG
ISONG
NCEMNA
PAEA
AAPA
SMFM
etc.

n = 584
Data from 2/12/2021
Implicit Bias Study design

Is there a correlation between implicit bias against disabled community and hypothetical prenatal genetic counseling of patients?
• Does it vary by physical vs. intellectual disability?
• Does it vary by demographics of provider?
• Does it vary by specialty of provider or stage of training?

See evidence for influence of implicit bias and personal preferences on testing/termination on counseling recommendations.

Personal experience with disability community also reduces likelihood of recommending testing.
Implicit Bias Study design

Are providers able to appropriately apply principles of non-directive counseling to hypothetical prenatal clinical scenarios?

- Does it vary by physical vs. intellectual disability?
- Does it vary by demographics of provider?
- Does it vary by specialty of provider or stage of training?
- Is the educational module effective at mitigating any potential deficiencies in this skill?

Evidence suggests individuals with bias perform better on counseling recommendations after completing the module.
Implicit Bias Study design

Does implicit bias impact healthcare providers’ ability to appropriately counsel patients in a prenatal setting, and can this be improved by training in non-directive counseling?

Future directions:
Evaluate intellectual disability biases as well.
Your Participation is Important!

Thank you again for participating in this research study!
We have learned so much from people like you taking the time to be part of our work.

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Sessions include:

• Cognitive science of retrieval processes
• Curricular transformation, innovation, and scholarly teaching
• Gaming strategies for genetics education
• A path from burnout to wellness
• Clinical utility of exome sequencing in under-represented populations
• Inclusivity in medical genetics education