

Project Inclusive Genetics: Developing a Patient-Centered Counseling Approach

ISCC Virtual Meeting February 16, 2021

Shoumita Dasgupta, PhD



• Explicit bias – have awareness of this attitude

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

Explicit vs. Implicit Bias

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."

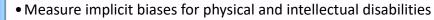
- James Watson

Prenatal Testing and Disability



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



Implicit Association Test (IAT)

Disability Implicit Bias in Medicine

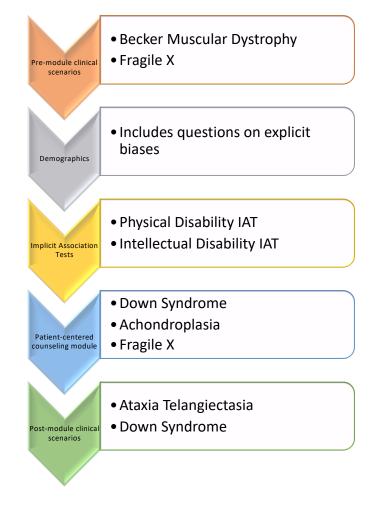
- Examine potential correlation between IAT results and responses to prenatal counseling scenarios
- Bias and Counseling Utilize cases where child is at risk for physical or intellectual disability

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





Clinical Decision-Making in the Prenatal Setting

Enter Module https://storystreetconsulting.com/projectinclusive/

Implicit Bias Study design



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?

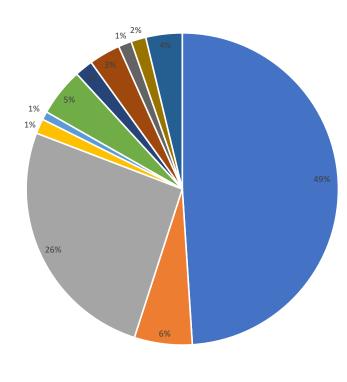
See evidence for bias: PD > ID

Implicit Bias Study design



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

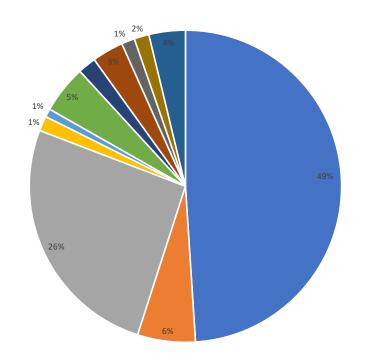
• Does it vary by demographics of provider?



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

n = 584 Data from 2/12/2021

Study cohort



 Medical students (preclinical)
 Medical students (clinical)
Genetic counselors
GC students
 MD (medical genetic ists)
MD (other)
Resident
Nurses
E du ca tors
 Other allied health professional
 Other

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.

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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.

Disability Implicit Bias in Medicine **Bias and Counseling** Non-directive counseling Impact on hypothetical counseling

Disability Implicit Bias in Medicine **Bias and Counseling** Non-directive counseling Impact on hypothetical counseling

Implicit Bias Study design

Are providers able to appropriately apply principles of nondirective 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.

Disability Implicit Bias in Medicine Bias and Counseling Non-directive counseling Impact on hypothetical counseling

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.

Implicit Bias Study design



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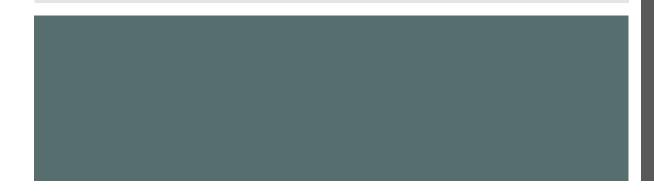
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National Human Genome Research Institute

ABE / APHMG 2021 JOINT VIRTUAL MEETING MAY 3-7



aphmg.org

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