

#### 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

Kelly M. Hoffman<sup>a,1</sup>, Sophie Trawalter<sup>a</sup>, Jordan R. Axt<sup>a</sup>, and M. Norman Oliver<sup>b,c</sup>

<sup>a</sup>Department of Psychology, University of Virginia, Charlottesville, VA 22904; <sup>b</sup>Department of Family Medicine, University of Virginia, Charlottesville, VA 22908; and <sup>c</sup>Department of Public Health Sciences, University of Virginia, Charlottesville, VA 22908

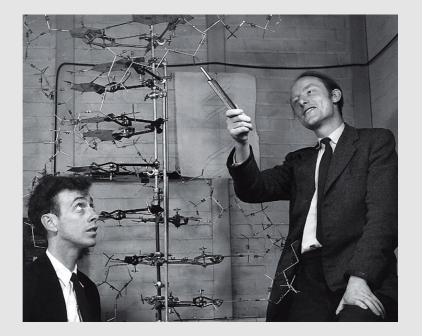
### Genetics and Disability

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."

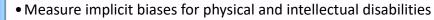
- James Watson

# 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

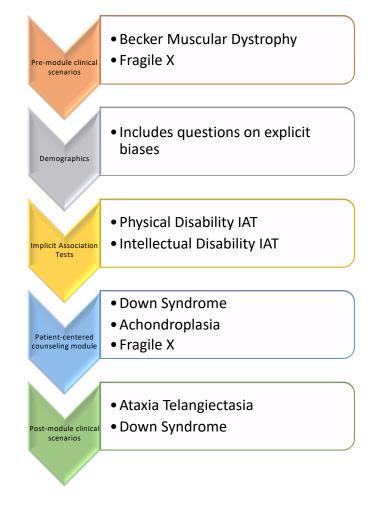
- Examine potential correlation between IAT results and responses to prenatal counseling scenarios
- Bias and Counseling Utilize cases where child is at risk for physical or intellectual disability

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?

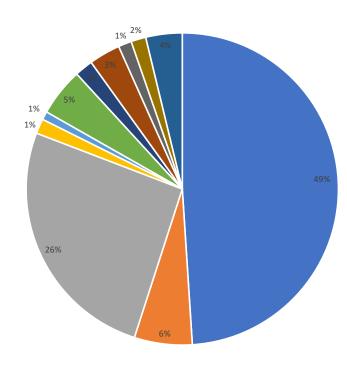
See evidence for bias: PD > ID

### Implicit Bias Study design



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

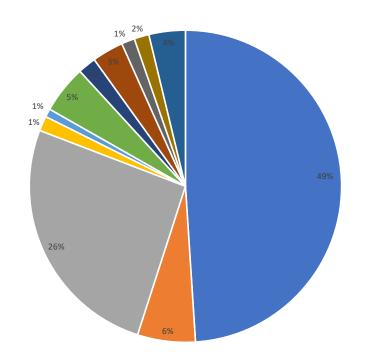
• Does it vary by demographics of provider?



- 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



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

#### 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.

**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



https://storystreetconsulting.com/projectinclusive/



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- Pilot testers and You!

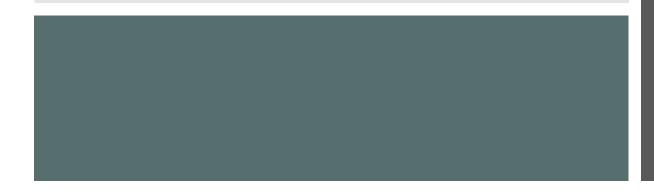
#### https://storystreetconsulting.com/project-inclusive/





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