Project Inclusive Genetics: Developing a Patient-Centered Counseling Approach
Explicit vs. Implicit Bias

Explicit bias – have awareness of this attitude

Implicit 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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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?
Evidence for Implicit Bias Against Disability in Healthcare

- Disconnect between personal views and understanding of role of physician in providing guidance to patients
- Misunderstanding of elements of patient-centered counseling

- Patients not receiving balanced information from counselors

- PA students demonstrate preference for abled individuals

Bouchard et al, 1995; Roberts et al, 2002; Archambault et al, 2008
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 non-directive 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
Enter Module
https://www.bucme.org/activity/8001

Patient-Centered Prenatal Genetic Counseling

Project Inclusive
An initiative to improve cultural competency in medicine

Faculty
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Accreditation
CME

Boston University School of Medicine is accredited by the Accreditation Council for Continuing Medical Education (ACCME) to provide continuing medical education for physicians.

ACGME Competencies
- Patient care
- Practice-based learning and improvement
- Interpersonal and communication skills
- Professionalism

Acknowledgement
In collaboration with Biomedical Genetics Section, Boston Medical Center.
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?
Implicit Bias Study design

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

- Does it vary by demographics of provider?

![Pie chart showing distribution of healthcare providers by role: 55% Medical students (preclinical), 32% Genetic Counselors, 3% MD (medical geneticists), 3% MD (other), 3% Nurses, 2% Educators, 1% Other allied health professional, 1% Other.]

n = 232
Data from 2/14/2020
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.
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?
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?
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?
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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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AAMC
Association of American Medical Colleges

NIH
National Human Genome Research Institute

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https://www.bucme.org/activity/8001
Sessions include:

• “Scientific” racism and citizen science
• Prenatal and pediatric exome seq in underrepresented populations
• Wellness and burnout
• Course Directors, Lab Directors, and Residency Directors Group Meetings
  - Gamification of genetics concepts
  - Workshop creating polygenic risk score curricula