Implementing implicit bias exercises for study staff working with African American caregivers of children with autism

A Case Study from Augusta University*, developed with the* MRCT Center

AUGUSTA UNIVERSITY

MULTI-REGIONAL CLINICAL TRIALS

THE MRCT CENTER of BRIGHAM AND WOMEN'S HOSPITAL and HARVARD

The Opportunity:

Caregivers of children with autism from diverse (non-white) racial and ethnic backgrounds are frequently unable to In order to understand theiaccess health and education services as readily as caregivers of white children, and how best to address this need was not clear.

r experiences, African American caregivers of children with autism were interviewed to explore their history with seeking services for their children and identify what has helped and might help them access services.

Since implicit biases could impact study conversations, it was considered important for study staff to minimize any underlying biases that might negatively impact participant interactions and influence data collection.

How this case is an example of health literacy in clinical research

1) Health literacy is a two-way street. It involves both the research participant, and the study team

- Prior to engaging with study participants, the study team must:
  - understand the study population;
  - be aware of their own underlying, unconscious biases about the study population;
  - mitigate the potential impact of those biases on the study.
- Addressing implicit biases is a health literacy best practice.

2) To determine whether biases affected data integrity, the accuracy of qualitative data was confirmed with the study population

- Maintaining participant engagement by confirming the accuracy of the collected data is also a health literacy best practice.
- This ensures that what information was communicated to the research team by the participant was understood correctly.

What Augusta University did:

1. Assembled a study team with diverse backgrounds
2. Guided study team members through implicit bias exercises
3. Formalized a process of checking what was heard.
   - Using a focus group, participants were involved in interpreting findings and developing next steps.

1. Assembled a study team with diverse backgrounds

- Included diverse individuals (race and gender) with varied professional training as well as graduate students from diverse backgrounds.
- Included an African-American caregiver of a child with autism as a one-time advisor
  - Having a person with the lived experience contribute to development of the study helped ensure study materials were effective for the target population.
  - This caregiver agreed to review consent materials, participate in a test interview, and share study information with other parents.
  - As part of best practices, the caregiver was offered to be paid for her time, but declined.

2. Completed implicit bias exercises prior to gathering data

The study team completed two of the Harvard Implicit Bias Tests* about race and disability. They then completed **exercises that specifically asked them to reflect upon their experiences.**

It was important to raise awareness and increase sensitivity to **biases** in order not to impact study procedures and results.

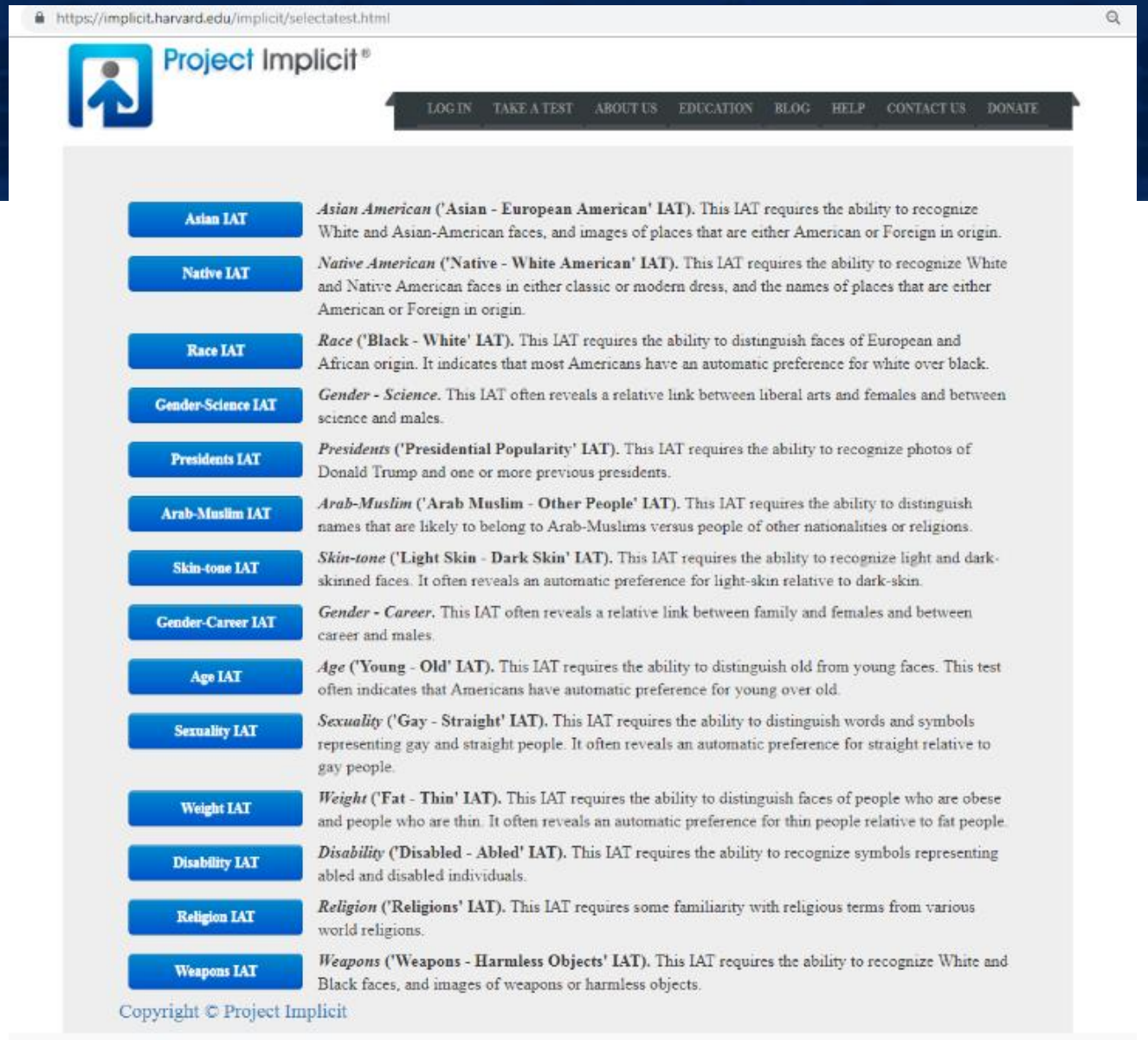
Biases are always present in research, and doing these exercises helped the study team reduce the potential impact that some biases might have on data collection and interpretation.

More information on the implicit bias training follows

* https://implicit.harvard.edu/implicit/takeatest.html

Harvard Implicit Bias Tests

Study team members were first instructed to complete the Race and Disability Implicit Bias tests offered by Harvard University (Project Implicit).



Project Implicit®

https://implicit.harvard.edu/implicit/

Investigator Developed Implicit Bias Questions

As part of the debrief from the Project Implicit test, the study team was asked to complete a set of questions developed by the Principal Investigator.

Instructions:

We all have implicit biases. The point of this exercise is to not reveal these to the research leaders (you do not need to share results with [PIs]), but to have you explore this concept in a safe manner. You may have questions about your results after you finish that might not be explored well in the group setting. If you wish to talk with [the PIs] about your results, we are happy to discuss. We have also taken these, and have reflected on their results. Your reflection below will not be made available to your peers, however, we will discuss strategies for managing implicit bias as it impacts the study.

Investigator Developed Implicit Bias Questions

As part of the debrief from the Project Implicit test, the study team was asked to complete a set of questions developed by the Principal Investigator.

Investigator Developed Implicit Bias Exercises

Study team members then answered the following questions:

1. Reflect on the result of your test. Were you surprised by the result? Why or why not?
2. The reason they are implicit is that we do not recognize that they are there. What have you learned about your implicit biases that influence your role as an practitioner and researcher?
3. Prejudice comes from knowing and approving of behaviors that reflect negative behaviors towards certain groups. Knowing something about yourself that you do not approve of or is possibly contradictory to what you consciously believe is not prejudice. **However, the implicit preference for one group over another still can influence behavior. Considering what you know about the results of your implicit bias test, what steps will you take to minimize the influence of these on the study that we will be embarking on? How will you concretely change your behavior to ensure that the results of the test do not influence the research?**

Investigator Developed Implicit Bias Exercises

The study team also completed the following questions:

1. Describe what 'autism' is to you. Whether you have a personal experience with autism or not, what does it mean to 'have autism'?
2. What do you believe are treatments that caregivers should seek out?
3. What actions should a caregiver take in order to get the treatments that you think are important?
4. Your beliefs about autism and treatment may not be the same as the caregivers you meet.
   - How will you prevent your own beliefs about 'autism' and 'treatment' from influencing the interview process?
   - How will you adapt your facial expressions, body language, tone of voice, and other ways of facilitating the conversation?

3. After gathering data, engaged participants in focus group to check what was heard

As a way to minimize biases, the team returned data results and findings to a focus group comprised of participants from the community.

The focus group participants were asked to confirm that the information collected reflected the intended messages gathered during interviews.

In qualitative research, this process is known as “member checking”: giving informants an opportunity to review and revise findings in the process of the data analysis.

Successes

- Bringing together a diverse study team with varied perspectives allowed for the successful recruitment and enrollment of African American caregivers as well as the collection of meaningful data that could be used to inform caregivers' help seeking activities moving forward.

- The team learned that implicit biases can impact study data collection, and used that awareness to manage their study-related interactions.

Challenges

- Due to the sensitive nature of implicit biases, it was challenging to discuss the results of these as a team.
  - In some cases, team members were surprised by results, which created a personal conflict between expressed personal values and implicit biases.
  - Team members were hesitant to discuss results with persons that they knew and/or with whom they work.
  - Consideration of a neutral third party (e.g. Diversity Officer) available to ‘debrief’ might have been helpful.

Feedback from Caregivers and Study Team

One caregiver's response when asked whether they would want to be involved in future research grant:

> Shoot yeah... Whatever it takes …. 'Cause, even though my kids are on the...on the other end [older children on the spectrum]…. I still want to make life better for those kids behind them

One co-investigator's response when asked about use of implicit bias tests during training:

> It can be very challenging to reflect on our own implicit biases because we often don't see ourselves as having these biases. I think this is especially true for those of us who are concerned about the healthcare experiences of underserved populations. But it is such important work to engage in, so that we can all do a better job at providing care and at meeting the needs of those we work with

Lessons Learned

- Some individuals on the study team did not think that they had any implicit biases.
- Testing for implicit bias raises awareness but does not address whether those biases will impact the study; individuals then chose whether, when, and how to address implicit bias.
- The discovery of implicit bias was difficult; engaging a knowledgeable, independent neutral third party, not involved on the study team, would have been helpful for the debrief.
- While the Principal Investigator did not evaluate the timing of training, implementation in advance of the interviews provided sufficient time to complete and process the findings.
- The study team embodied cultural humility and learned that all people have biases.

Recommendations

1. Identify and examine your target audience: could potential biases impact outreach recruitment, consent, or on-study conduct?
2. Allow sufficient time to explore implicit biases.

   - Implicit bias is challenging to recognize; its identification is most effective and impactful before the study starts.

3. Engage a non-study person (e.g. diversity officer) who can help discuss challenging results that arise as a result of testing for implicit bias.
4. Identify and disseminate resources to explain cultural considerations, microaggressions, and methods by which implicit bias is perpetuated.

Resources

MRCT Center Health Literacy in Clinical Research "Tools" – cultural considerations

https://mrctcenter.org/health-literacy/tools/overview/cultural-considerations/