

Inaugural Round Table Discussion on DEI in IDD Research at the 55th Gatlinburg Conference, Kansas City, MO

Tuesday, April 11, 2023 | Moderated by Lauren M. Schmitt, PhD (CCHMC), Brian Boyd, PhD (UNC), Leonard Abbeduto, PhD (UC Davis / MIND), and Tracy King, MD, MPH (NICHD)

SUMMARY REPORT

Prepared by [Lauren Schmitt, PhD](#) (CCHMC), [Brian Boyd, PhD](#) (UNC), [Rodney Samaco, PhD](#) (BCM) & [John Colombo, PhD](#) (KU-LSI)

During the 55th Gatlinburg Conference on Research and Theory in Intellectual and Developmental Disabilities (IDD) held in Kansas City, MO from April 10-13, 2023, [Lauren Schmitt, PhD](#) of the Cincinnati Children's Hospital Medical Center, [Brian Boyd, PhD](#) of the University of North Carolina Frank Porter Graham Child Development Institute, [Leonard Abbeduto, PhD](#) of the UC Davis MIND Institute, and [Tracy King, MD, MPH](#) (NIH NICHD IDDB) with assistance from the [Gatlinburg Conference Kansas University Life Span Institute](#) Planning Committee, coordinated an informal round table discussion on the current state of Diversity, Equity and Inclusion (DEI) in Intellectual and Developmental Disabilities (IDD) research. This was an opportunity for conference attendees, comprised of researchers, staff and other learner groups representing a wide range of experiences, career stages and disciplines, to share and discuss **(1)** barriers in enhancing DEI in IDD research, and **(2)** strategies and perspectives that have been implemented to successfully overcome challenges or reduce barriers to advance DEI in IDD research. Given the Gatlinburg Conference theme – “Rare Genetic/Monogenic Disorders & Co-Occurring Conditions in IDD” – a notable focus of the discussion was the state of DEI specifically within monogenic neurodevelopmental disabilities (NDD) and IDD research spaces.

To ensure that the discussion was productive and solution-oriented, the group opted for an informal convening to share experiences through collaborative discussion and in the spirit of Chatham House Rules. The organizers intentionally made the session open to all conference attendees given that individuals may vary in their level of activity and engagement with DEI-related efforts. Approximately 30 individuals including members of the NIH NICHD IDD Branch contributed to the lively and productive discussion.



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The following key points summarize the group's discussion regarding barriers to the common goal of increasing DEI across the IDD research enterprise and workforce, and outline possible solutions to overcome challenges, many of which are well-aligned with the core features of community engaged research principles. Based on the success of the inaugural meeting, future Gatlinburg Conferences will continue the dialogue on strategies and exemplars of success in enhancing DEI in IDD across the research enterprise, and explore sessions comprised of a mix of informal discussion and formal presentation components.

Part 1: What Barriers As Researchers Do We Experience?

1. General Barriers

- Language barriers: often an exclusion criteria in research studies due to lack of measures in specific language and/or lack of staff
- Logistical barriers: families not able to travel to research (or clinical) appointments
- Intersectionality: linguistic + cultural
- IRB: red tape in certain recruitment efforts
- Rely on samples of convenience that tend not to be diverse racially, ethnically, linguistically, etc.
- Larger systemic barriers in inequities in receiving diagnostic and intervention services within certain communities, populations

2. Mistrust with the Research Community

- Historical challenges related to mistrust of research within disadvantaged, under-represented and/or minorized communities
- Difficulty in establishing trust and building those initial community connections
 - i. "How do we get into that space?"
 - ii. "How as a scientist do you work as a team to bridge into the community that is not part of your identity?"
 - iii. Offering what you think is help, but may actually be additional burden or stress; "Yes, I'm helping but at what burden or cost"
- Racism within science "really baked in"
- The time and effort to establish and maintain community partnerships is not supported by grant funding, FTE, etc. and so difficult to balance with career, other responsibilities



3. Barriers to Working With Specific Genetic Conditions

- Reduced access to genetic testing
 - i. Larger issue within NDD/IDD community that likely starts with changing professional recommendations and guidelines for when/how/why genetic testing occurs
 - ii. NIH itself cannot drive that process, has to come from professional guidelines
- Scalability of research projects due to lower prevalence rates (compared to autism)
- Often siloed communities based on how families/individuals identify
 - i. Rare disorder community vs. autism community
 - ii. Patient advocacy groups often do not represent everyone – a genetic diagnosis may unite two families, but not united on other important socio-cultural factors

4. Lack of Available Funding to Support DEI, Community Engagement Research and/or Inclusive Research Models

- NIH supports hypothesis-driven research, so funding to support increased access to genetic testing likely has to come from elsewhere
- Difficulty to establish and maintain community partnerships
- The objective of creating inclusive research teams (e.g. comprised of individuals with diverse/neurodiverse perspectives, levels of training/career stages, socioeconomic backgrounds) does not necessarily fit into NIH's view of the traditional research model.

Part 2: What Strategies Have Worked to Reduce Barriers?

1. General Barriers → Solution: Increasing Diversity Among Staff and Participant Sample

- Hiring diverse research staff
- Working with IRB to modify recruitment strategies
- High school internship program within certain institutions that are funded through larger cooperations to increase diversity of research staff
- Use interpreter services for research
 - i. Translate consent form (usually short form only that highlights main points) – the interpreter and family sign short form, and the interpreter and research staff sign long form
- Provide compensation for transportation, provide free childcare
- Alternatives to traditional lab visits: home visits vs. research visits within community (e.g., schools, YMCA, library) – “Bring the science to the people”
- Involve community members as part of research team to bring in expertise
- Idea of “family navigator” – someone with lived experience who can walk families through the procedure – they don’t have to be expert in the science, but they can be expert in the study



2. Mistrust with the Research Community → Solution: Building and Maintaining Co-Equal Partners

- Establishing relationships with churches through participation at health fairs, getting buy in with active pastors, volunteering at church events to provide childcare/behavior support
- “Showing up consistently” and spending time with community
- Establishing team of key stakeholders
- Providing compensation to community partners
- Important to recognize partnerships are about the partnerships and supporting the community, not about advancing your own career
- Community partnerships are about empowering and uplifting the community partners
- Asking the community what they are doing that is working, what they need support in, and shifting our research questions to best serve the community
- Developing co-equal partnerships
- Importance of conducting needs assessments vs. generic focus groups
- Whatever you are working on should be disseminated back into the community
- Importance of relationship development with key community partners and having perseverance, authenticity, and intention within those relationships
 - i. Example: Color of Autism reached out to an investigator/PI, they have invested time facilitating support groups for black dads of autistic individuals, they did this for one year, followed by discussing research partnerships and working on grant funding
 - ii. Example: Administration for Community Living for Employment that has 7 demonstration projects, the first phase was establishing the community collaborative.

3. Barriers to Working With Specific Genetic Conditions → Solution: Cross-Syndrome Unification

- Conducting studies cross-syndrome versus specific genetic syndromes based on symptomatology versus diagnosis
- Connecting researchers, families through Rare Disease Diversity Coalition (RDDC) network or EveryLife Foundation

4. Lack of Available Funding to Support DEI, Community Engagement Research and/or Inclusive Research Models → Solution: Looking Outside Traditional Funding Mechanisms

- Accessing local champions who work within the government or are involved in policy making
 - i. Example: Researcher receiving seed funding received through Philadelphia city council; research is then disseminated back into the community
 - ii. Engage policy makers using dissemination strategies that include plain language, accessible reports and infographics
- PCORI as possible funding mechanism to support this type of work

