



Participatory Research in Action: Tailoring an Ableism Scale with Intellectually Developmentally Disabled Youth

Chris Danguilan, Iulia Mihaila, Helene Gussin,
Chengshi Shiu, Shanna Kattari, & Kristin Berg

American Public Health Association Conference

Tuesday, October 29th, 2024



Tailoring an Ableism Scale with Intellectually Developmentally Disabled Youth



- Background
- Ableist Microaggression Inventory
- Adaptation Process
- Preliminary Data
- Implications

AGENDA	
1. _____	
2. _____	
3. _____	

BACKGROUND

ABLEISM



Ableism is the belief that disabled people are inferior to the non-disabled, leading to systemic discrimination and social exclusion.

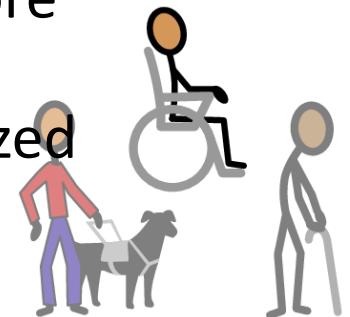
- Judith Heumann, Disability Rights Advocate

Ableism is intertwined with other systems of oppression that create disparities in health, economic stability, and mental well-being for disabled people. The constant exclusion and barriers we face aren't just physical; they take a toll on our mental health and reinforce a sense of being 'less than' in society

- Alice Wong, Disability Rights Advocate

One way in which ableism is perpetuated is through microaggressions, at the more interpersonal, or micro level. Microaggressions are everyday interactions that perpetuate inequalities and stereotypes against people who belong to marginalized communities.

- Shanna Kattari, Disability Justice Activist



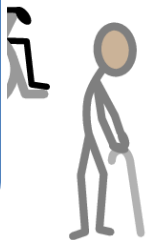
Mental Health in Disabled Youth



Youth with disabilities face a
2-3x higher risk of mental health issues. (Glasson & Hussein, 2008)

Youth with disabilities are
3-4x more likely to attempt suicide. (CDC, 2023)

Untreated mental health conditions in disabled youth lead to increased social isolation, academic decline, suicidal risk, and poor adult outcomes. (USDHHS, 2020)



ABLEISM CONTINUED



Presentation AIM



1. To describe the community-engaged research process utilized to adapt an existing ableism measure for use with youth with IDD in a large-scale clinical trial
2. Share preliminary data on the experience of ableist microaggressions in the B.E.S.T. study

ABLEIST MICROAGGRESSION INVENTORY

EXISTING MEASURE



- Ableist Microaggression Inventory
- Developed by Shanna Kattari
- 65-item scale validated using a sample of 984 participants aged 18-70 years ($M = 36.1$, $SD = 10.6$), who identified largely as women (71.2%), white (82.6%), and disabled (63.2%)
- Among those identifying as disabled, type of disability included: intellectual/developmental (2.1%), learning (2.4%), physical (including pain/illness, 31.5%), psychiatric/socio-emotional (20.9%), and multiple types (43.1%)

EXISTING MEASURE

- Need to adapt the existing measure to be culturally responsive and relevant to the experiences of youth in our existing study sample:

Youth aged 13-20 years with a diverse range of intellectual and developmental disabilities



ADAPTATION PROCESS

ADVISORY COMMITTEES



- Community Advisory Committee (CAC) and Youth Advisory Committee (YAC) provided high-level and item-level feedback on the original scale
- 4 youth with IDD (cerebral palsy, autism, Down syndrome, and intellectual disability) from the YAC reviewed the scale 1-1 with a study staff member
- Individual accommodations were put in place to support feedback



YOUTH FEEDBACK



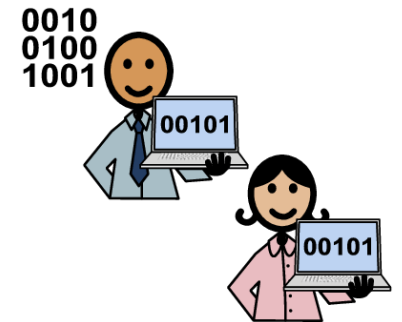
- Youth provided feedback on how to make language more relevant to teens and young adults
- Revisions were made to improve cultural responsiveness for the IDD population, specifically, and for transition-aged youth

Original Item	YAC Revision
I was given unsolicited encouragement based on my disability.	I was given encouragement because of my disability when I did not want it.
Someone spoke to my companions instead of me, based on my disability.	Someone spoke to the people around me, instead of me, because of my disability.
My opinion was overlooked in a group discussion based on my disability.	My opinion was not treated with respect in a group discussion because of my disability.

SUPPORT FROM STATISTICS TEAM



- Staff statisticians conducted an exploratory factor analysis using data from participants in the original study aged 18-25 years (subsample of 111 participants)
- This enabled us to identify key factors that could be utilized to reduce measure length and response burden
- 3 factors were identified with high Cronbach's alphas, indicating internal consistency
- Retaining these 3 factors, the number of items was reduced from 65 to 43



NEXT STEPS

- After staff review of the remaining items, the 43 items were reduced to 23
- Staff included subject matter experts, disability researchers, disabled persons, and family members of disabled persons
- We then completed one final review with the CAC and YAC and incorporated final feedback on language revisions



EXAMPLE ADAPTED SCALE ITEMS



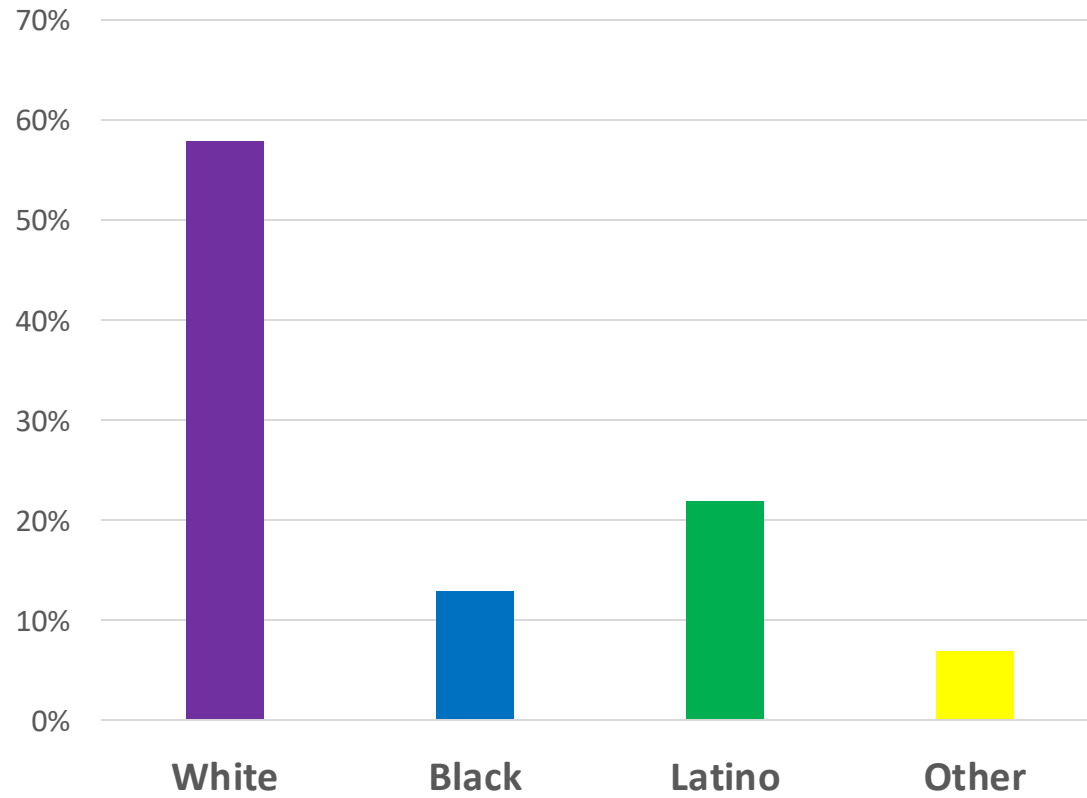
- Someone spoke to the people around me, instead of me, because of my disability
- Someone assumed I cannot learn new things because of my disability
- Someone assumed I would be ashamed of my disability
- I hear people say that having a disability is bad or a problem
- I was left out because of my disability
- I was told I talk about my disability too much

PRELIMINARY DATA

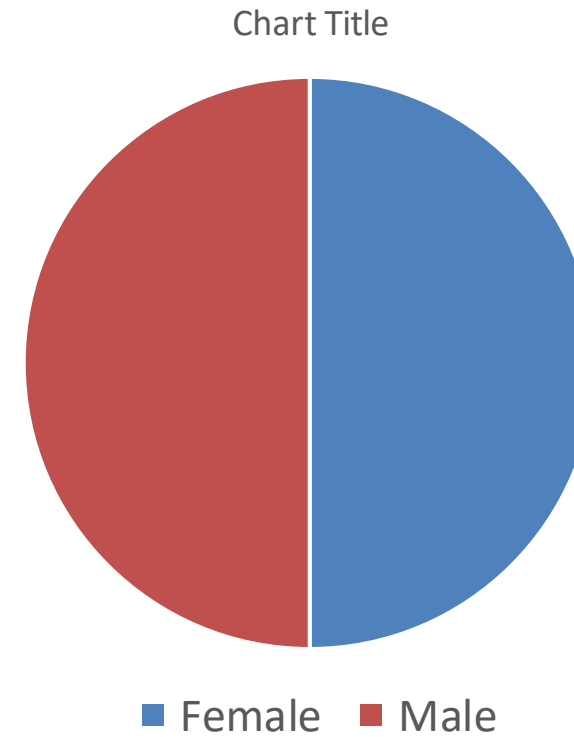
Study Sample

N=32; aged 13.22-21.13 years ($M = 16.60$, $SD = 2.51$)

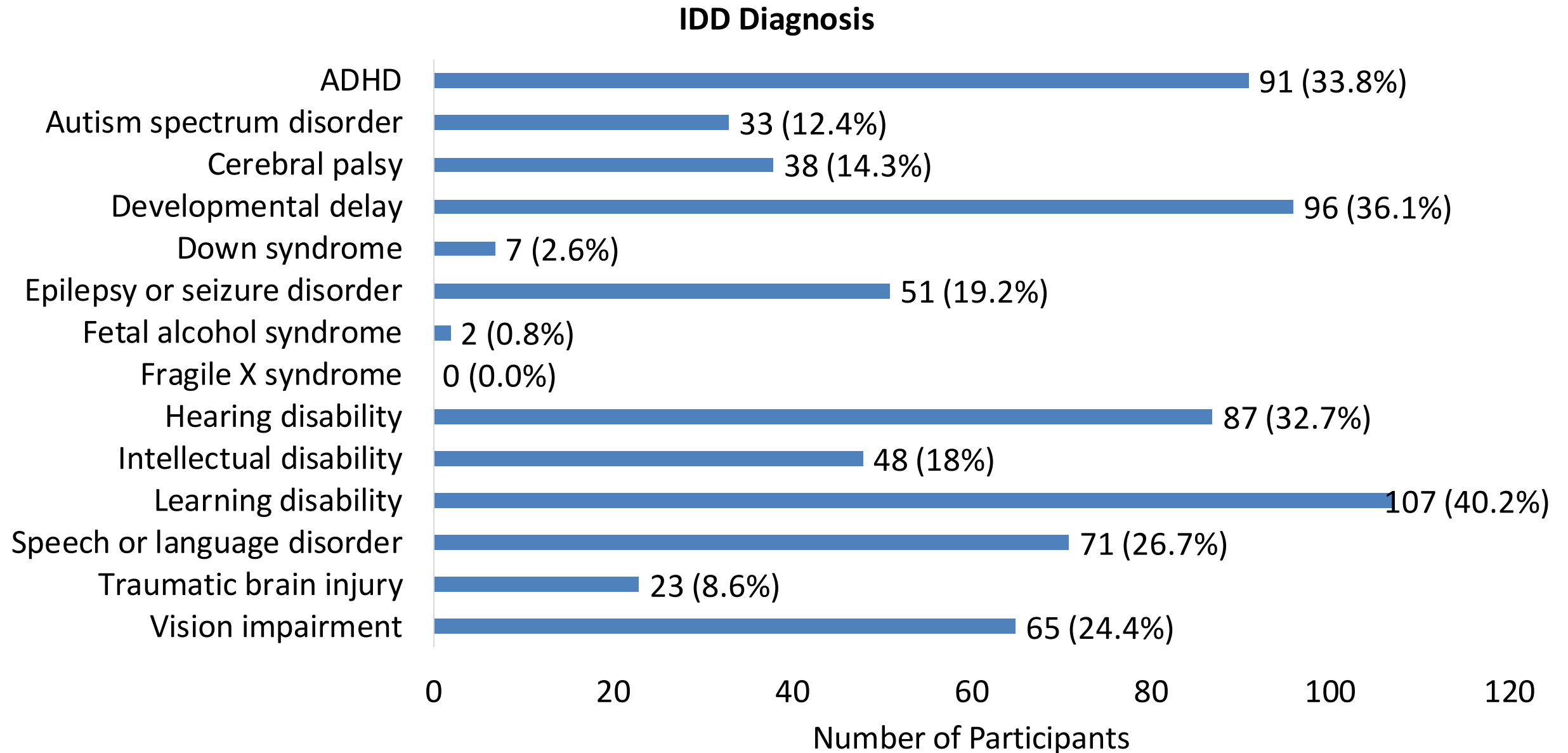
Racial Distribution



Gender



STUDY SAMPLE CONTINUED



ABLEIST MICROAGGRESSIONS DATA



Adapted Ableist Microaggression Inventory

- $n=32$
- Items rated from 1 = “Never” to 5 = “All of the time”
- Total average score range 1.00 – 2.87 ($M = 1.57$, $SD = .55$) with higher scores indicating more ableist microaggressions
- **Highest** (2.44) Someone praised a family member for taking care of me.
Lowest (1.16) Someone told me I should stop talking about or stop making a big deal about my disability.

IMPLICATIONS

IMPLICATIONS



- Involving YIDD and community stakeholders in shaping adaptations promotes study and scale accessibility and cultural responsiveness
- Stakeholder participation contributes to making research tools more accessible and relevant to the population of interest

B.E.S.T. PARTNERS



BROWN UNIVERSITY



WELLESLEY CENTERS
FOR WOMEN



THE ARC ILLINOIS



THE UNIVERSITY
OF CHICAGO



UNIVERSITY OF ILLINOIS
AT CHICAGO / UI HEALTH



THE UNIVERSITY OF
CALIFORNIA



UIC DEPARTMENT OF
SPECIALIZED CARE FOR CHILDREN



SERVICE, INC. OF ILLINOIS

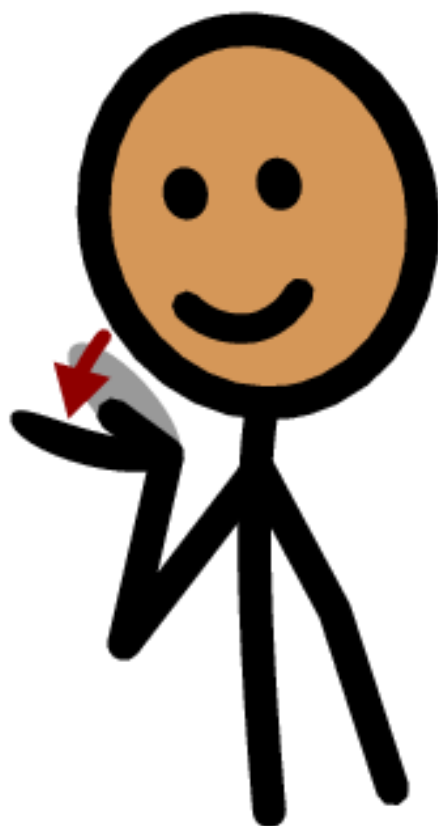


CHILDREN'S HOSPITAL
OF PHILADELPHIA



ARIZONA STATE UNIVERSITY





Thank You!

To learn more about the B.E.S.T. study,
please contact us by:

EMAIL ADDRESS

beststudy@uic.edu

PHONE NUMBER

1-833-732-5778

WEBSITE

www.beststudy.info

