TRANSFORMING MENTAL HEALTH CARE: EMBRACING A COORDINATED, ANTI-ABLEIST YOUTH-CENTERED APPROACH

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MY STORY

AGENDA

- Understanding Ableism
- Ableism in the Mental Health Field
- BEST Project: Strategies for Inclusive Care
- Youth/Parent Voices
- Experience of Ableism in B.E.S.T. – Preliminary Data

UNDERSTANDING ABLEISM

- 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

- 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 IN THE MENTAL HEALTH FIELD

01

Historic failure to recognize the mental health needs of disabled people

02

Systemic prejudice and exclusion from mental health services and interventions

THE OVERLOOKED EPIDEMIC: MENTAL HEALTH IN DISABLED YOUTH

1

Disabled youth face **2-3x higher** risk of mental health issues compared to non-disabled peers.[1]

2

Disabled youth are **3-4x more likely to attempt suicide** in comparison to non-disabled peers.[2]

3

Untreated mental health conditions in disabled youth lead to **increased social isolation, academic decline, suicidal risk and poor adult outcomes**[2]

[1](Glasson & Hussain, 2008; CDC, 2023)
[2](U.S. Department of Health and Human Services, 2020)

BEHIND THE NUMBERS: REAL LIVES

ABLEISM: GAPS IN PROVIDER TRAINING

1

Mental health training

- lacks the necessary competencies
- **lacks clinical experience related to treating disabled people**

2

Graduate social work programs, disability topics are addressed in only 6% of courses, and practicum experiences with the disabled population are not mandatory.

3

Inadequate training leaves clinicians unprepared to recognize and treat the mental health needs of disabled youth, **reinforcing documented reluctance to provide care** to this population

ABLEISM: HISTORIC EXCLUSION FROM CLINICAL TRIAL RESEARCH

75% of clinical trials either explicitly or implicitly excluded disabled people

Results in significant gaps in knowledge about medications and interventions for disabled youth

CONSEQUENCES OF INACCESSIBLE, FRAGMENTED MENTAL HEALTH CARE

- **Unmet Needs**: 40% of disabled youth go without supports/services.
- **Higher Emergency Room Visits**: Psychiatric conditions are the most common reason for inpatient admissions, with higher utilization rates compared to the general population.
- **Negative Health and Life Outcomes**: Suicide, overreliance on antipsychotic medications, recurrent hospitalizations, criminal legal system involvement, and premature death.
- **Family Impact**: Increased distress and financial strain.

Real People:
The Stories
Behind the
Data

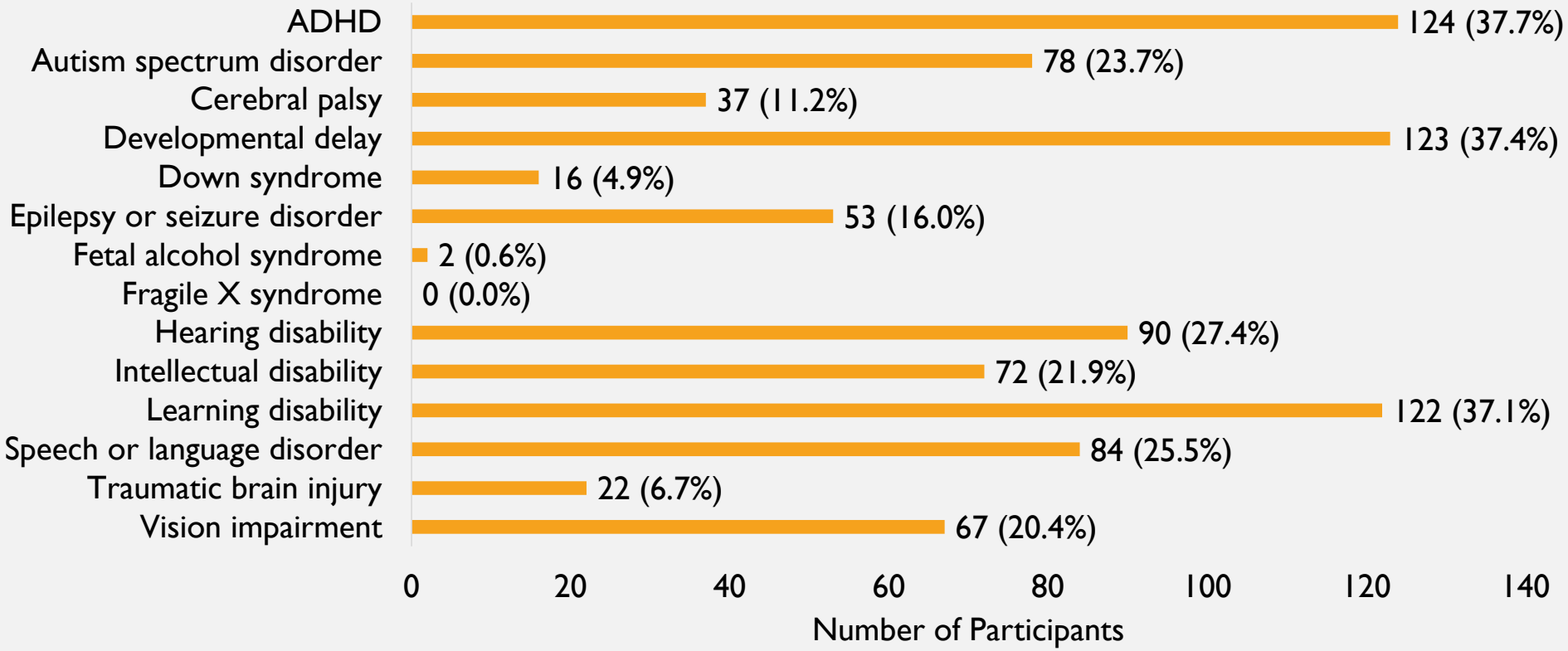
"WE DON'T TREAT AUTISM HERE."

TRANSFORMING MENTAL HEALTH THROUGH B.E.S.T.

OUR PROGRAM IS INNOVATIVE

1. Inclusive of **Diverse IDD**
2. Community Driven, Grounded in **Anti-Ableism**
3. **Leveraging Existing Care** Coordination Infrastructure
4. Tiered Screening & **Preventative** Intervention
5. **Universal Design**

1: INCLUSIVE OF DIVERSE IDD

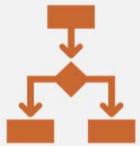


2A: COMMUNITY DRIVEN

Partnership with Community Organizations

Youth Advisory Committee

Summer Scholars Program



Shared Decision-Making

and Accountability Protocols

2B. GROUNDED IN ANTI-ABLEISM

Anti-Ableism Training

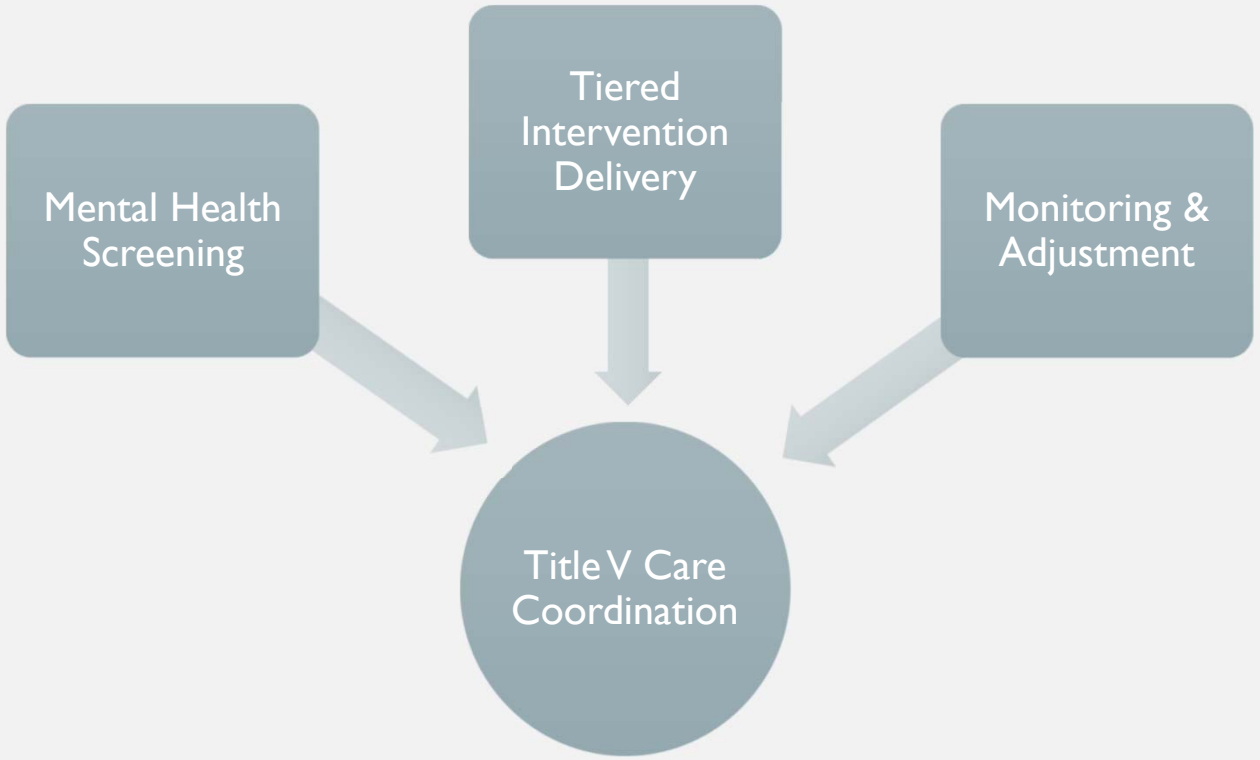
Inclusive Practices

Continuous Improvement and Feedback

ANTI-ABLEISM TRAINING & EDUCATION

- Training clinicians and research on anti-ableism and cultural competency is essential.
- Incorporating lived experience into educational curriculum enhances understanding and improves the quality of care provided.

3: LEVERAGING EXISTING CARE COORDINATION INFRASTRUCTURE



4. TIERED SCREENING AND INTERVENTION

- Online self-directed depression and anxiety prevention program for youth
- Workshops for youth and caregivers

- Level 1 programming
- Online psychoeducational group for youth (1x/week for 10 weeks + 1x/month for 6 months)

- Level 1 programming
- Online psychoeducational group for youth (1x/week for 10 weeks + 1x/month for 6 months) + 2 group sessions for caregivers

5. UNIVERSAL DESIGN

Technology-based Approach

Screening

Intervention and Delivery

UNIVERSAL DESIGN: TECHNOLOGY BASED APPROACH

WEB-BASED (PEAR DECK), ACCESSIBLE FROM A SMARTPHONE OR TABLET

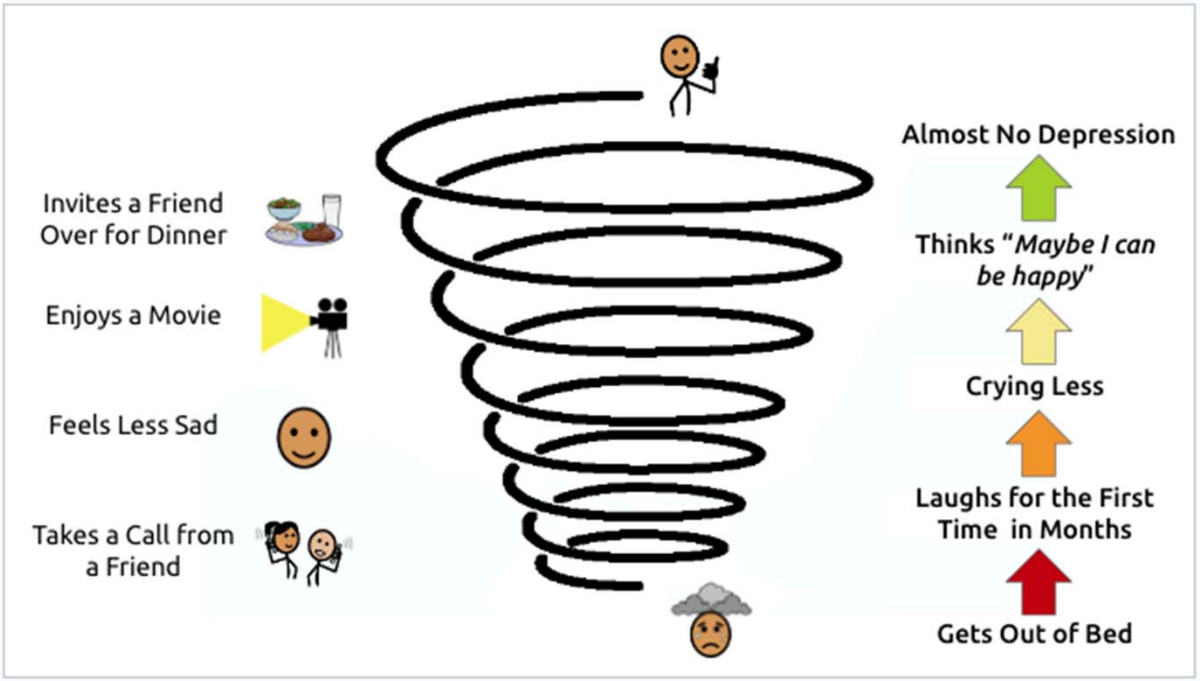
GAMIFICATION OF PREVENTION AND INTERVENTION COMPONENTS

UNIVERSAL DESIGN IN SCREENING

- Shorter sentences using plain language
- Speak in present tense; past tense anchored in personal events
- Visual imagery

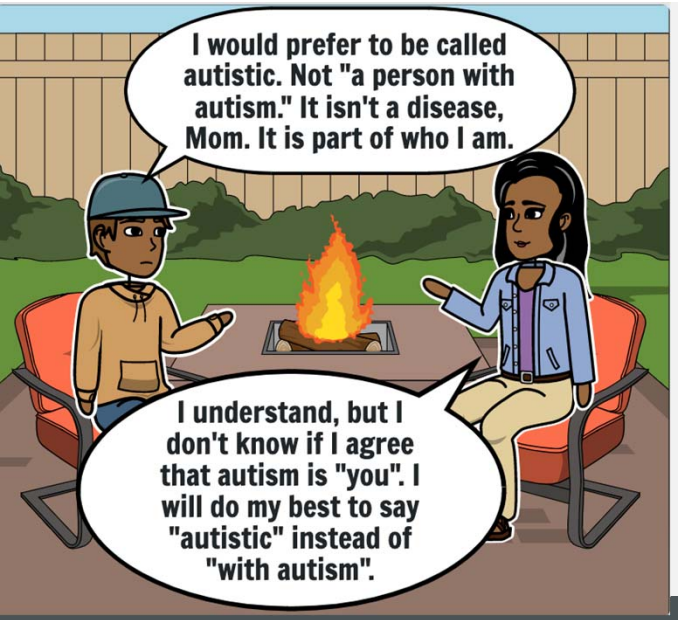
UNIVERSAL DESIGN IN INTERVENTION DESIGN AND DELIVERY

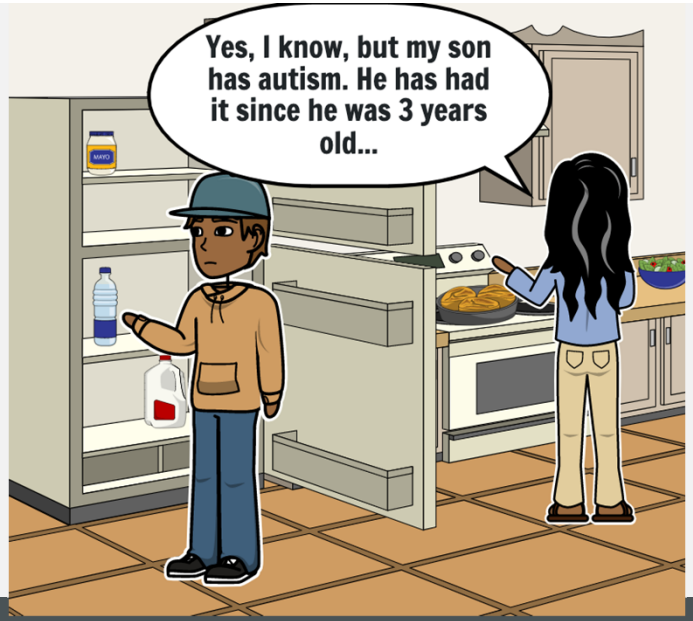
- Agendas listed between each section
- Use of visuals (SymbolStix)
- Adapted themes and context for comics/clinical scenarios
- Flexibility in delivery



Agenda

To-Do	Time	Completed
1. Check-In 	10 minutes	✓
2. Reviewing Skills 	30 minutes	✓
3. Learning New Skills: Problem Solving 	35 minutes	





CLINICAL SCENARIO

Son: **I would prefer to be called autistic. Not "a person with autism." It isn't a disease, Mom. It is part of who I am.**

Mom: **I understand, but I don't know if I agree that is "you." I will do my best to say autistic instead of "with autism"**

Later…

Mom on the phone: **Yes, I know, but my son has autism. He has had it since he was three years old.**

Son overhears mother and thinks..: **I JUST told her I want to be called autistic. No one ever listens to me! Nobody cares what I think.**

SYSTEM IMPACTS

State Care Coordination has changed their protocols to enhance mental health screening and safety protocols and procedures to reflect the B.E.S.T. Project

Care Coordinator Voices

- "She's been actively using the strategies recommended to her."
- My client acknowledges it's challenging to attend, but says she always feels better afterward.
- She is consistently taking her medication and reports feeling in a much better place than she was last year.
- **"Thanks for all your work in helping my client!"**

REAL VOICES

REAL IMPACT

- "I think a lot of people don't connect anxiety or depression to having a disability. The B.E.S.T. study has helped me talk about these things. We all have bad days, but depression is worse. Understanding how disability and mental health are tied together and having strategies to use to help me cope has really helped me."

  - Teen Participant

- "I've seen a positive difference in [participant] since she started with the B.E.S.T Study. She's using the skills she's learned, and you can really see the improvement in her attitude and overall mental health."

  - Parent of Participant

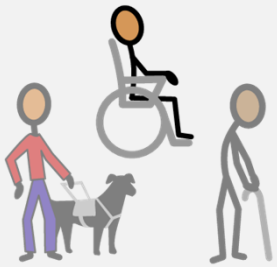
EXAMINING THE EXPERIENCE OF ABLEISM IN B.E.S.T. – A PRELIMINARY EXAMPLE

ABLEISM MICROAGRESSION INVENTORY

- 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 tyles (43.1%)

NEED FOR ADAPTATION

- Need to adapt the existing measure to be culturally responsive and relevant to the experiences of youth in B.E.S.T.: youth aged 13-20 with a diverse range of intellectual and developmental disabilities



COLLABORATIVE FEEDBACK PROCESS

- 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
- Staff statisticians conducted exploratory factor analyses using data from participants in the original study aged 18-25 years (n = 111)

YOUTH FEEDBACK

- Youth provided critical feedback on how to make language more accessible and relevant to teens and young adults
- Revisions were made to improve cultural responsivity for the IDD population, and specifically, 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.

ADAPTED ABLEISM MICROAGRESSION INVENTORY

- 23-items on a 5-point Likert scale (1 = never, 2 = rarely, 3 = some of the time, 4 = most of the time, 5 = always)
- Example 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 was left out because of my disability
  - I was told I talk about my disability too much

SAMPLE – 62 YOUTH WITH IDD

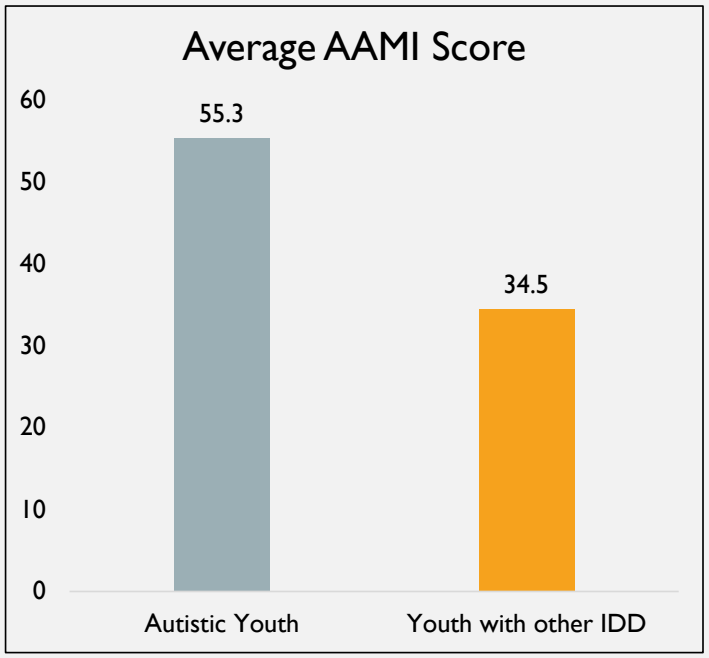
10 autistic youth

- Aged 13-20 years (*M* = 15.9, *SD* = 2.8)
- 4 male (40%), 6 female (60%)

52 youth with other IDD

- Aged 13-21 years (*M* = 16.1, *SD* = 2.5)
- 28 male (54%), 23 female (44%), 1 non-binary (2%)

AVERAGE SCORES



- Autistic youth experienced significantly more ableist microaggressions compared to youth with other IDD
- t (60) = -4.5, p < .001

EXAMPLE ITEMS

- Across all 23-items in the AAMI, autistic youth reported greater frequency of each ableist microaggression, on average
- Notable items:
  - Someone ignored me because of my disability (2.56 vs. 1.6)
  - Someone praised a family member for taking care of me (3.9 vs. 2.0)
  - Someone went out of their way to avoid me because of my disability (2.4 vs. 1.3)
  - My opinion was not treated with respect in a group discussion because of my disability (2.9 vs. 1.5)
  - I was left out because of my disability (2.7 vs. 1.5)

IMPLICATIONS

- Involving youth with IDD and community stakeholders in shaping research is feasible and leads to more accessible, culturally responsive, and relevant research and measurement tools
- There is a lot to explore as we continue to collect data about the experience of ableism in our study – however, preliminary evidence indicates that autistic youth may be at risk for experiencing increased ableist microaggressions compared to youth with other IDD

CONCLUSION: A PATH FORWARD FOR ANTI-ABLEIST MENTAL HEALTH CARE

- **Inclusive Practices**: Integrate anti-ableism at every level of mental health care design and delivery to ensure that services are accessible and equitable for all
- **Centering Disabled Voices**: Engage disabled people as active partners in care design and evaluation, ensuring their experiences and needs are reflected
- **Commitment to Continuous Learning**: Embrace anti-ableism as a continual process, focused on learning, adapting, and improving care to dismantle barriers and ableist assumptions
- **Universal Design**: Apply universal design principles to make interventions accessible, effective, and inclusive for people with all types of disabilities

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