

Engaging Transition-Age Youth/Adults with IDD and Other Stakeholders:

Identifying Health Outcomes, Creating Research Teams, and Building Equitable Partnerships

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Patient-Centered Outcomes Research Institute (PCORI) Funded Projects

- ▶ Congress included research on intellectual and developmental disabilities as a priority topic for PCORI in 2019.
- ▶ The three projects in this panel were funded through the Eugene Washington PCORI Engagement Award mechanism to meaningfully involve, support, and engage people with IDD and other stakeholders in research.
 - ▶ EASC-IDD-00241 (Benevides & Pham)
 - ▶ EU-7718435 and EA-12563 (Brasher)
 - ▶ EASC-IDD-00233 (Malow, Brasher, Coleman, McMillan)
- ▶ This work is solely the responsibility of the project leads and does not necessarily represent the views of the Patient-Centered Outcomes Research Institute® (PCORI®), its Board of Governors or Methodology Committee.
- ▶ <https://www.pcori.org/collection/intellectual-andor-developmental-disabilities>

A Note About Language

- ▶ Known differences in language use exist between autistic adults and caregivers (Kenny et al., 2016).
- ▶ It is appropriate to ask what a person prefers, but not to assume.
- ▶ Since we cannot ask all audience members, we will use a mix of person-first (e.g. individual on the autism spectrum) and identity-first (e.g. autistic adult) language.

Resources on language:

1. Gernsbacher MA (2017). Editorial Perspective: The use of person-first language in scholarly writing may accentuate stigma. *Journal of Child Psychology and Psychiatry*, 58(7), 859-861.
2. Kenny L, Hattersley C, Molins B, Buckley C, Povey C, Pellicano E. (2016). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism*, 20(4), 442-462.
3. Sinclair J. (1999). Why I dislike "person first" language.
http://web.archive.org/web/20080616063934/http://web.syr.edu/~jisincla/person_first.htm
4. *Autism in Adulthood* author guidelines require identity-first

Our three presentations will focus on:

- ▶ (1) Identifying Health Outcomes
- ▶ (2) Addressing Challenges of Transition to Adulthood
- ▶ (3) Creating Inclusive Research Teams

Followed by a facilitated discussion with Q&A about meaningful engagement and application of the content to AUCD attendees.



Individuals with Intellectual or Developmental
Disabilities Engaged, Aligned, and Leading
Consensus on Priority Health Outcomes

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IIDDEAL is a Multi-Institution Partnership



AUGUSTA
UNIVERSITY

institute for **excəptional** care

Brandeis

THE HELLER SCHOOL
FOR SOCIAL POLICY
AND MANAGEMENT
Institute for
Behavioral Health

Ethical Review

This project's activities were reviewed by Augusta University's Institutional Review Board protocol 1830929-1 and were identified as "Not Research."



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This work is a collective body of activities through which many people contributed to major project activities and products, including:

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A Note About the Presentation

- We share illustrations of priority topics.
- For people with screen readers or other devices, the slide following the illustration has written words in Plain Language summarizing the illustration.
- In our presentation, we will talk only on the illustration slides but include the slides with words for accessibility.



Learning Objectives:

At the conclusion of this presentation, you will:

- **Identify** preliminary priorities from three stakeholder groups informing “outcomes that matter”:
 - People with IDD
 - Care partners of people with IDD
 - Clinicians supporting health care for people with IDD and their care partners



IIDDEAL's Mission

- Our mission is to fix problems with health care delivery and access for individuals with IDD through **aligning outcomes that matter** across stakeholders who are empowered to change research and practice.

How will we accomplish this? We are:

- *Identifying* consensus on outcomes that matter across people with IDD, care partners, clinicians, and payers.
- *Developing* a Health Outcomes Framework to guide research & practice.
- *Engaging* stakeholders who are empowered to act.



Who Talked With Us About Priorities?

- **15 people with IDD**

- *May 2022:* 1-on-1 meetings to identify personal health stories and priorities
- *June 2022:* Group Zoom meeting to review summary of positive and negative health experiences and to discuss health priorities they felt were most important
- *July 2022:* Email and 1-on-1 review of final health priority outcomes for feedback

- **15 care partners of people with IDD**

- *July 2022:* Group Zoom meetings to discuss priorities of people with IDD and to identify priorities of care partners.
- *August 2022:* Care partners reviewed illustrations and provided input on summary

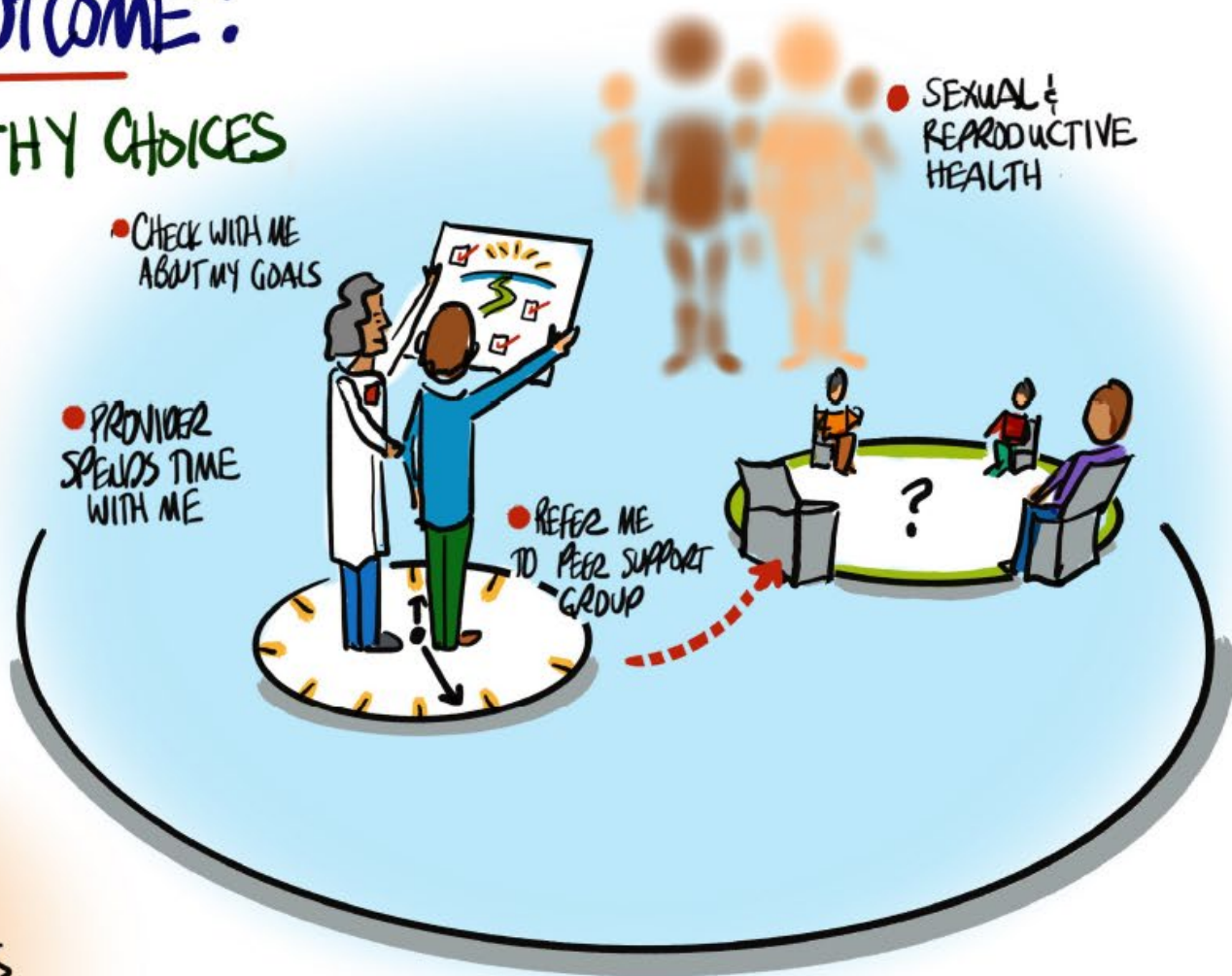
- **8 clinicians scheduled, 20 on waiting list**

- *October 2022:* Group Zoom meetings with clinicians with and without IDD experience



PRIORITY HEALTH OUTCOME :

MAKING HEALTHY CHOICES



Important Things to People with IDD and Care Partners related to ***Making Healthy Choices***

Healthcare providers who:

1. Spend time with me and support me
2. Check with me about my goals
3. Refer me to peer supports or peer groups
4. Address sexual and reproductive health
5. Support my care providers
6. Consider lifespan supports



PRIORITY HEALTH OUTCOME:

EMOTIONAL or MENTAL HEALTH

- LEARNING MINDFULNESS APPROACHES



- SELF-ADVOCACY SELF DETERMINATION and ACCOMMODATIONS



- REFERRAL TO COUNSELOR WHO KNOWS ABOUT IDD



- ADAPTED and TAILORED MENTAL HEALTH INTERVENTIONS



- PEER MENTORING



Important Things to People with IDD and Care Partners related to ***Good Mental Health:***

1. Referral to appropriate mental health care services.
2. Support for self-managed mindfulness and meditation.
3. Support for peer mentoring so I can learn from others with IDD.
4. Self-advocacy and self-determination that support mental health
5. Adapted and tailored mental health approaches





PRIORITY HEALTH OUTCOME:

PHYSICAL HEALTH,
PAIN, and ENERGY

• COMMUNITY-AVAILABLE RESOURCES FOR PHYSICAL HEALTH



• SCHOOLS AS SUPPORTERS OF PHYSICAL HEALTH



• DENTAL CARE



• PROVIDER SPENDS TIME WITH ME



• CARE COORDINATION

• SHARED DECISION MAKING



• CLINICAL ENVIRONMENT THAT SUPPORTS HEALTH



• TRAINING IN HOW PAIN IS EXPRESSED BEHAVIORALLY TO COMMUNICATE



• UNDERSTANDING and MEASURING PAIN and ENERGY WHEN COMMUNICATION IS LIMITED



Important Things to People with IDD related to ***Physical Health, Reduced Pain, Improved Energy***

1. My provider spends time with me and supports my decision-making.
2. Provide good care coordination within my care team.
3. Use shared or supported decision-making with me.
4. Support my health in the clinical healthcare environment.



Care partner priorities related to good physical health, reduced pain and improved energy:

- Understanding and **measuring pain and energy** when communication is limited.
- **Training for providers** in how pain is expressed and how thresholds may be different in people with IDD.
- **Community-available approaches** for physical health.
- **Schools** as supporters of physical health.
- **Dental** care.



PRIORITY HEALTH OUTCOME:

DOING THE THINGS I LOVE or NEED TO DO

LIVING IN A CARING and INCLUSIVE COMMUNITY

- PERSON-CENTEREDNESS and PRESUMING COMPETENCE

- RELIABLE TRANSPORTATION

- SUPPORTING PHYSICAL AND EMOTIONAL SAFETY

- RESOURCES TO LIVE SOMEWHERE SAFE AND ACCESSIBLE



Important Things to People with IDD related to
Doing the Things I Love or Need To Do:

1. Reliable **transportation** helps me do the things I love and need to do.
2. Having **resources to live** somewhere safe, accessible, caring, and inclusive.



PRIORITY HEALTH OUTCOME :

FAMILY CARE PARTNER
WELLNESS and SUPPORT



- MENTAL and PHYSICAL HEALTH

- LONG-TERM PLANNING



- RESPIRE CARE SERVICES



- CARE PARTNER RESOURCES



- CARE PARTNER PERSPECTIVES



- DOCTORS UNDERSTANDING CARE PARTNER STRUGGLES

Priorities for Care Partner Wellness & Support Should Include:

1. Mental and physical health of care partners.
2. Long-term planning.
3. Respite care services.
4. Valuing caregiver perspectives.
5. Doctors who understand a care partner's struggle.
6. Care partner resources.



PRIORITY HEALTH OUTCOME: SYSTEM SUPPORTS

- PAYMENT FOR PRIORITY OUTCOMES and DESIRED APPROACHES



- ADDRESSING DISTRUST, RACISM, SOCIAL DETERMINANTS OF HEALTH AT SYSTEM LEVEL



- BENEFITS THAT RECOGNIZE UNPAID LABOR OF CARE PARTNERS



- NAVIGATION SUPPORTS BETWEEN MULTIPLE SECTORS OF CARE and SERVICES



- PUBLIC AWARENESS and POSITIVE MESSAGING ABOUT DISABILITY

Priorities for Systemic Supports Should Include:

1. Payment for priority outcomes and desired approaches.
2. Addressing distrust, racism, and social determinants of health at a system level.
3. System navigation supports between multiple sectors.
4. Public awareness and positive messaging about disability.
5. Benefits that recognize unpaid labor of care partners.
6. Developing pipeline of healthcare providers.



OTHER PRIORITIES

CLINICIANS



Summary

- We learned from 5 Core Team, 15 Advisory Council members, almost 40 stakeholders with IDD, care partners, and clinicians at this time.
- **Empowerment of people with IDD, self-determination within health, and supports for decision-making** are overwhelmingly seen as important drivers of physical, emotional, social, and community health.
- **System barriers** are seen by all stakeholders as inhibiting health
- **Opportunities** exist to:
 - Improve communication between stakeholders,
 - Increase evidence and payment for specific health priorities, and
 - Ensure training of healthcare providers includes information about healthy aging across the lifespan for people with IDD



Next Steps for IIDDEAL

- This week, we are meeting with **payers and regulators** to discuss priority outcomes.
- We will be hosting additional opportunities to engage **people with IDD in January-March 2023**.
- In **June 2023**, we will host an in-person workshop to discuss a Health Outcomes Framework.
- A public comment period in **Fall 2023** will be made available for all interested individuals.
- To be involved, please visit: <https://www.ie-care.org/iiddeal>
- Contact us:
 - Mai Pham mai.pham@ie-care.org
 - Teal Benevides tbenevides@augusta.edu

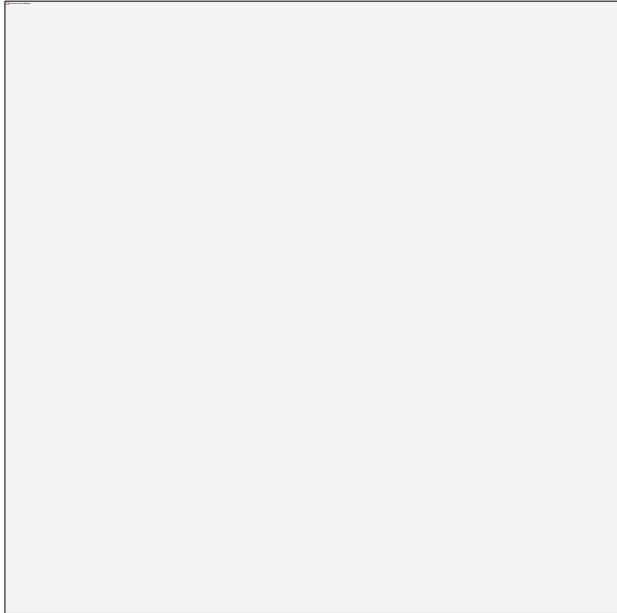


NURTURING ENGAGEMENT OF STAKEHOLDERS ON TRANSITIONING TO ADULTHOOD IN AUTISM SPECTRUM DISORDER (NEST)

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DR. MATTHEW SEGALL, PHD



EMORY

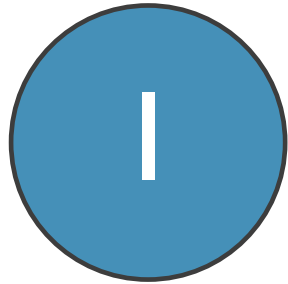
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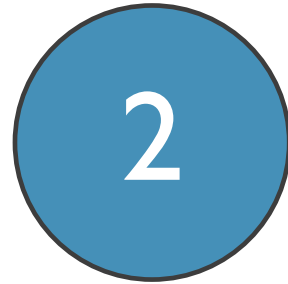
EMORY
UNIVERSITY

Emory Autism Center

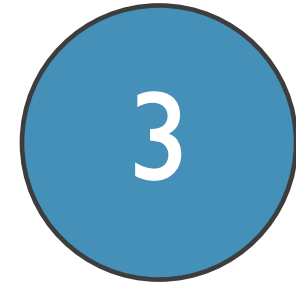
OBJECTIVES



Provide an
overview of
our project



Describe
engagement
activities



Outline next
steps

BACKGROUND

- Because symptoms of ASD present in the first 2 years of life, the majority of research and medical education focuses on the pediatric side
 - Early diagnosis
 - Early intervention
- Yet autistic youth do grow up to become autistic adults
- Each year, 70,000 youth on the autism spectrum transition to adulthood

TRANSITION CHALLENGES



- Autistic youth have poorer transition outcomes than their peers with other disabilities and those without disabilities (Sosnowy et al., 2018)
- Large datasets, but what do the people say?!

OBJECTIVE

To form equitable partnerships with key stakeholders to gain meaningful insight into challenges encountered during transition to adulthood in ASD, as well as ways to address these challenges through PCOR/CER.

PATIENT-CENTERED ENGAGEMENT

- Patients and stakeholders met monthly within their respective communities
- Groups were led by patients and stakeholders themselves
- Co-learning conferences and workshops
- One overarching Autism Advisory Board (AAB)



PATIENTS AND STAKEHOLDERS

- ASD adolescents and young adults (ages 14-36)
- Caregivers
- Psychologists
- Healthcare providers
- Legislative experts
- Previous PCORI awardees
- Directors of medical and adult ASD services
- ASD researchers
- Self advocates
- Disability lawyers
- Educators
- Independent living facility directors



Two PCORIs

Three Years of Funding

**Five Plus Years of
Engagement**

**EMORY PCORI
EUGENE WASHINGTON ENGAGEMENT AWARD AND P2P**

RACIAL AND GENDER DIFFERENCES INFLUENCED OUTCOMES

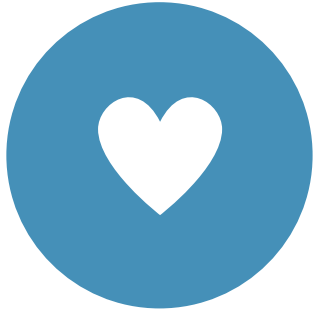


EXAMPLES OF CO-LEARNING

- Co-learning conferences
 - Tapestry and Georgia State University hosted transition consortium
 - Safety workshop (law enforcement, patients, caregivers)
 - Autistic Black Lives Matter conference
 - Atlanta Autism Consortium hosted employment conference
 - SOJOURN hosted an intersectionality conference (gender, sexuality, disability)
 - Atlanta Autistic Self-Advocacy Association hosted self-advocacy conference
 - AAP Georgia Chapter hosted a healthcare transition conference
 - Vanderbilt, Interactive Autism Network, PCORnet, and GA research meeting

OUTCOMES

- Identified seven key areas of transitioning
- Disparities identified in these areas for autistic young women and black autistic young adults
- Identified 30 PCOR/CER research questions across 7 transition areas
- Leveraged knowledge gained to query databases on PCOR
- Leveraged relationships to secure additional PCORI funding (PCORI IDD)
- Ongoing engagement of autistic women support group co-led by autistic women



Authentic, sustained engagement fosters equitable and inclusive participation



Meeting people where they are on their terms enhances sustained partnerships



Partner with individuals and strive towards meaningful goals together



Incentives never hurt, but what is it **THEY** want?! Hearing their voices are key

KEY LESSONS LEARNED ON BUILDING TRUST

WHERE DO WE GO FROM HERE

- Continue to build capacity with patients and stakeholders
- Future research and interventions responsive to their needs
- Virtual simulations and trainings
 - Law enforcement and first responders
 - Healthcare providers
 - Autistic individuals (Healthcare transition)

ADDITIONAL NEXT STEPS

- Transition readiness tools
- Mental health interventions
- Peer Navigators (Autism Inclusive Mentoring program)
- Broader capacity efforts with individuals with IDD (PCORI)



NOTHING ABOUT US
WITHOUT US

*“THE PERSON CLOSEST
TO THE PROBLEM
OFTEN KNOWS THE
SOLUTION”*

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ASSERT ECHO:

All StakeholderS Engaged in Research Together

Beth Malow, Susan Brasher, and Laura Coleman

Vanderbilt University Medical Center, Emory University
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Coordinators:
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Kasey Fitzpatrick
Sally Furukawa

Purpose and Goal of ASSERT Project

- People with IDD are not always included in research, and are rarely included as research partners
- To build capacity within the IDD community that will enhance knowledge on research among...

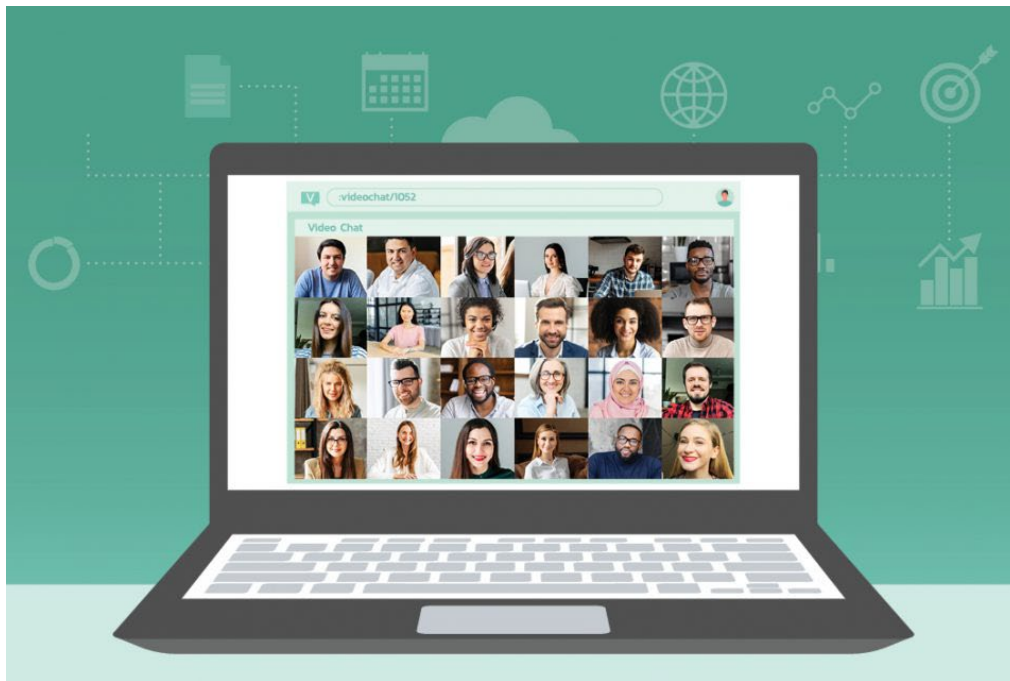
Self Advocates
Clinicians

Family Advocates
Researchers

The ECHO Model



Extension for Community Healthcare Outcomes



12 sessions

75-90 minutes each

Twice-monthly

Accessible

Structure of ECHO Sessions

- Introductions by Participants (~15 minutes)
- Topic Introduction (~15 minutes)
- Breakout Groups with Questions (20 minutes)
- Regroup for General Discussion (~20 minutes)
- Lightbulb Moments (~10 minutes)
- REDCap Evaluation after each session

First Six ECHO Topics

Introduction to
ECHO

Informed
Consent

Types of
Research

Sharing
Research
Results

What is
Patient-
Centered
Research?

Co-Creating
Research

Second Six ECHO Topics

What Do We
Call
Ourselves?

Building Trust

Consuming
Research- ABA

Creating
Research
Together- Idea
Generation

Creating
Research
Together-
Mindfulness

Creating
Research
Together-
Inclusion

SESSION 6: Co-Creating Research Together

Discussed: How Researchers and Stakeholders Can Work Alongside One Another in All Aspects of Research, with Equitable and Shared Decision-Making.

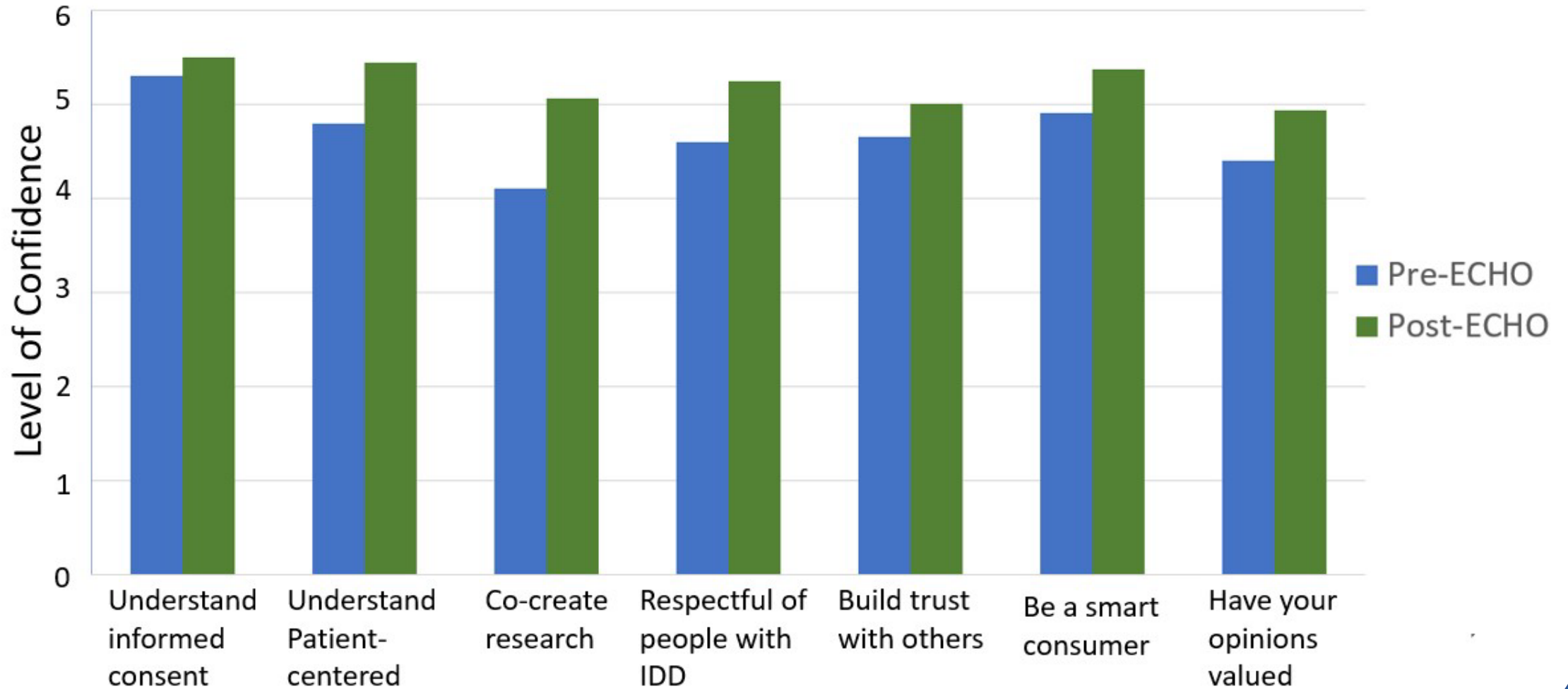
- What does meaningful stakeholder participation look like to you?
- How do you get people engaged?
- What ways foster co-creation?

SESSION 6: Co-Creating Research Together

What We Learned:

- “It must be bi-directional. If you want people to be truly engaged, it must go both ways. You need to listen to feedback and then the researchers can make changes.”
- “Equitable balance of power, everyone’s input is as valuable as anyone else’s.”
- “We sometimes save all of our excitement for our grant proposals and don’t share with the stakeholders. We should try to keep that energy and passion coming through when we engage others, including during recruitment of participants and dissemination of knowledge.”

Pre versus Post ASSERT ECHO Survey Data



End of ECHO Comment Thematic Analysis

- “What have you enjoyed most about working on this project?”
 - Collaborative nature, voices being heard, co-learning, a community of people
- “What additional resources do you need?”
 - List of community organizations, handouts, success stories, IRB resources

End of ECHO Comment Thematic Analysis

- “What are your suggestions for enhancing the ECHO program?”
 - Session on refining the process, clarity on end result, more diverse stakeholders with IDD, keeping in touch, desire for end product
- “Please share any other comments”
 - Enjoyment, gratitude, respected, addressing self-advocate attendance, partnership examples in the community.

Comments

It is exciting to see the "ah-ha" look come over many of our participant's faces when they hear a perspective they have never considered before

The group came to the discussion being our authentic selves. Everyone shared openly and honestly and as always, it was great to hear different perspectives.

Next Steps

- Work on research projects together
- Continue to build capacity for research, including among minimal verbal individuals and those with ID

Next Steps

Do you know a self-advocate, caregiver, clinician or researcher interested in participating in our next cohort in January 2023?

Contact us at
assert@vumc.org



Please scan to learn more
and sign up to be
contacted by our team