

ASSERT ECHO:

All StakeholderS Engaged in Research Together

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Acknowledgements- ASSERT Advisory Council

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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...

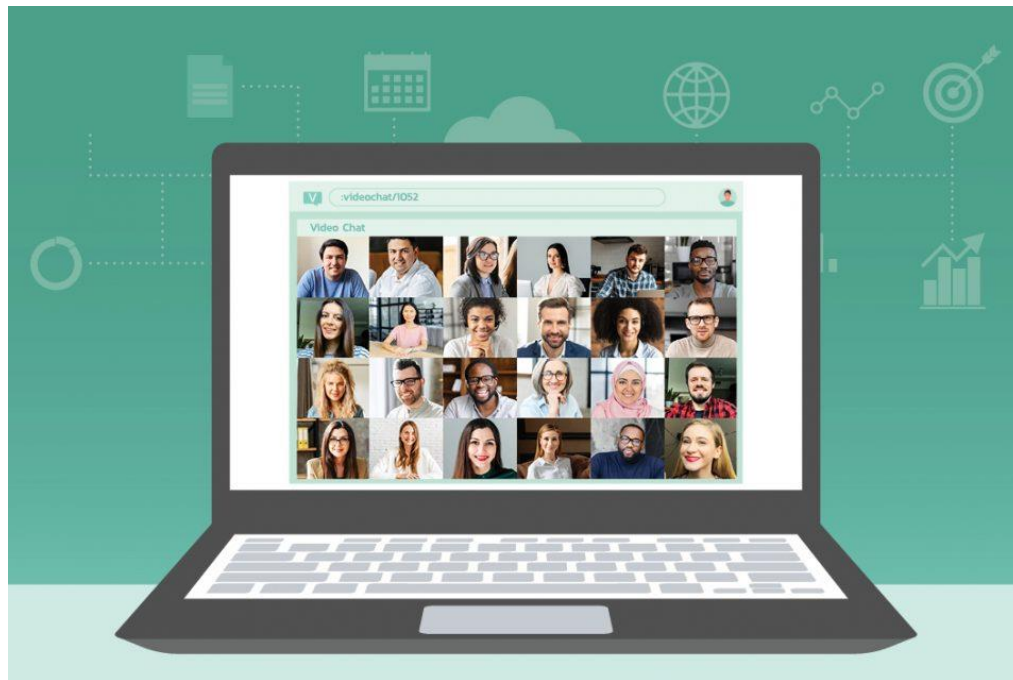
Self Advocates
Clinicians

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.

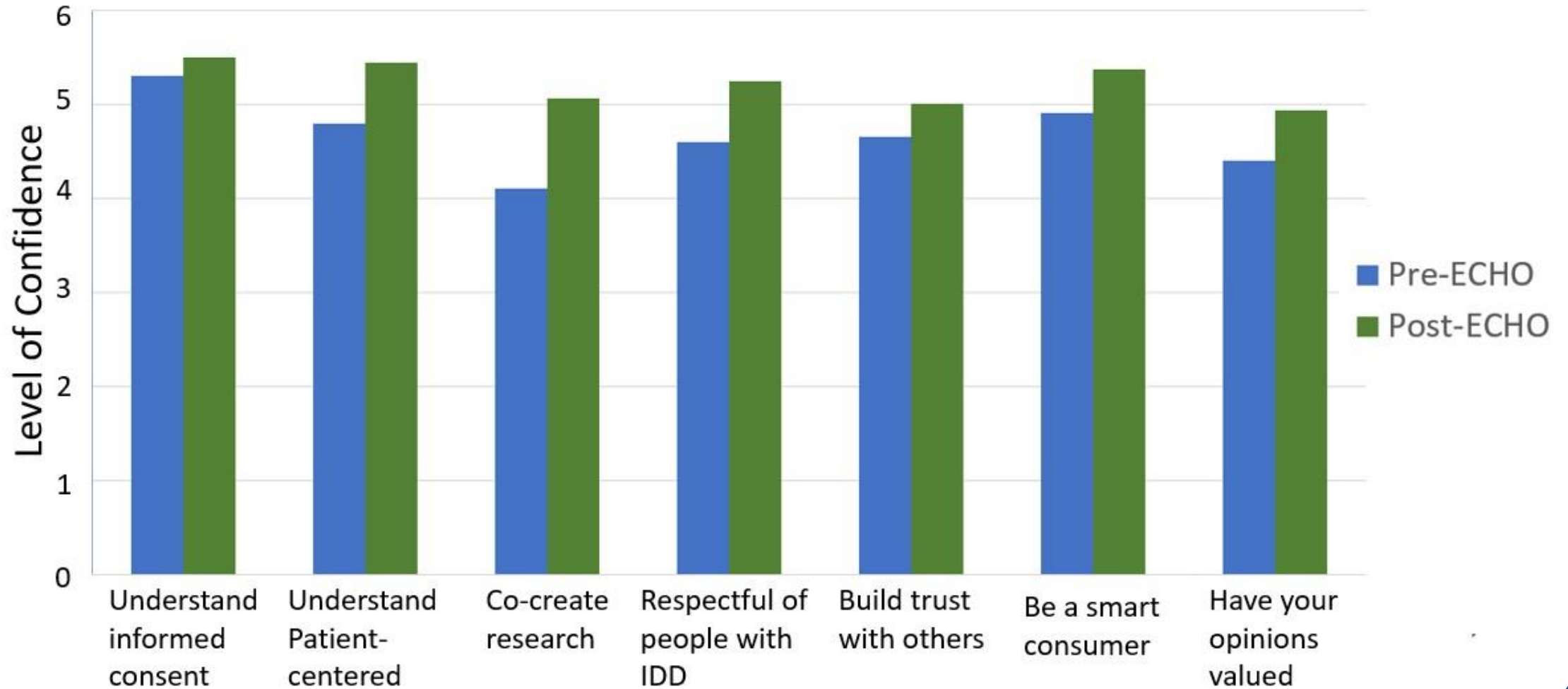
- What does meaningful stakeholder participation look like to you?
- How do you get people engaged?
- What ways foster co-creation?

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