Panel 4: Navigating Challenges to Increase Data Use and Dissemination

September 22, 2026

Tia Nelis, Moderator

I/DD Counts Summit


Enhance Partnerships
Improve Survey Data
Strengthen Administrative Data
Support Research Capacity
Increase Data Use and Dissemination

Increase Data Use and Dissemination

- "Data use" means how we use data.
- "Dissemination" means giving out or sharing information. This can be with other people or organizations who need to know about the topic.

Panelists

- **Katherine McDonald**, Syracuse University
- **Teresa Moore**, Self Advocates Becoming Empowered, Self Advocacy Resource & Technical Assistance Center Project
- **Shea Tanis**, University of Kansas
- **Jules Good**, Autistic Self Advocacy Network (ASAN)

- Moderated discussion and audience Q&A

Research Partnerships with People with Intellectual and Developmental Disabilities

Katherine McDonald and Ariel Schwartz

September 2026

Syracuse University

University of New Hampshire
Institute on Disability

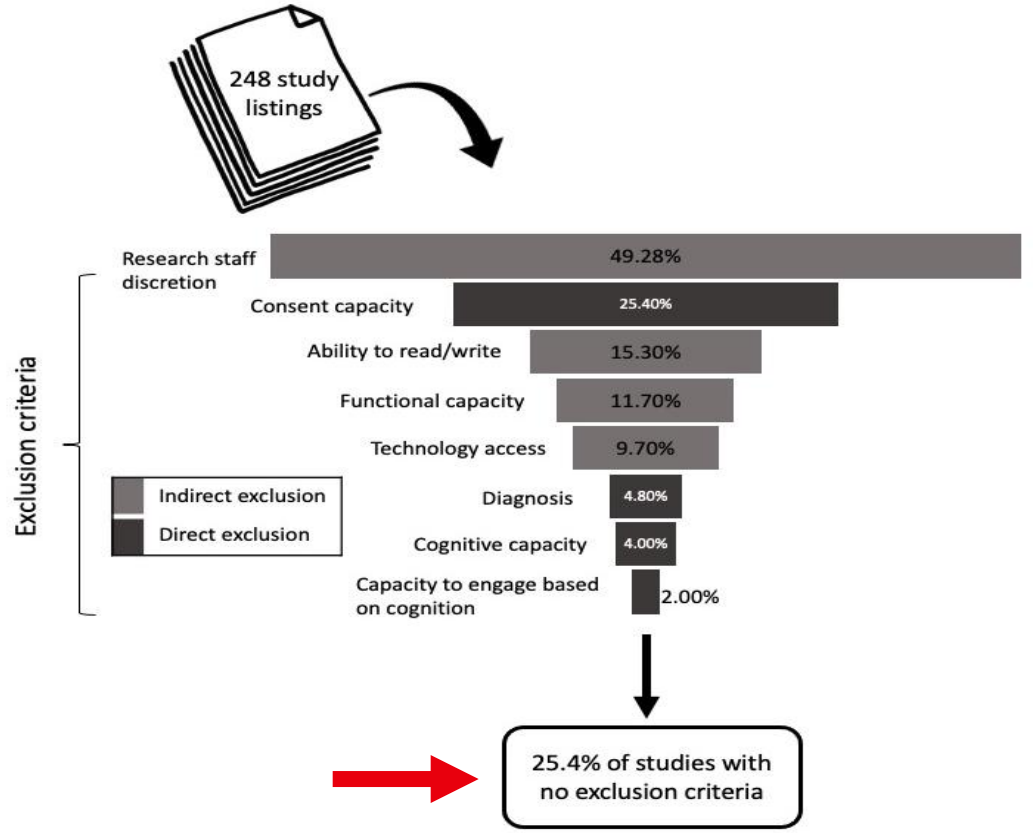

Respect us!

Including People in Research

- Research can improve people's health

- Barriers to including people and to people making their own decisions about being in research:
  - Assumptions that they can't make decisions
  - Not understanding guardianship
  - Not knowing about disability-accommodations

- Want to be in research and can make decisions



I'm not only a person with a disability but I have a brain, I have a mind, and I can think for myself. Don't look at me as a piece of furniture.

McDonald, K. E., Banzer, E., Cooley, M., Singhal, R., Goode, T. D., Kiryluk, K., & Sabatello, M. (2026) "I Make My Own Decisions": Views on Precision Medicine Research Participation Decisions from Adults with Intellectual Disability. Human Genetics and Genomics Advances, 7(3), 100589.

McDonald, K., Schwartz, A. & Sabatello, M. (2022). Eligibility criteria in clinical trials funded by the National Institutes of Health: Can adults with intellectual disability get in? *Disability and Health Journal, 15 (4)*, 101368

Research Partnerships

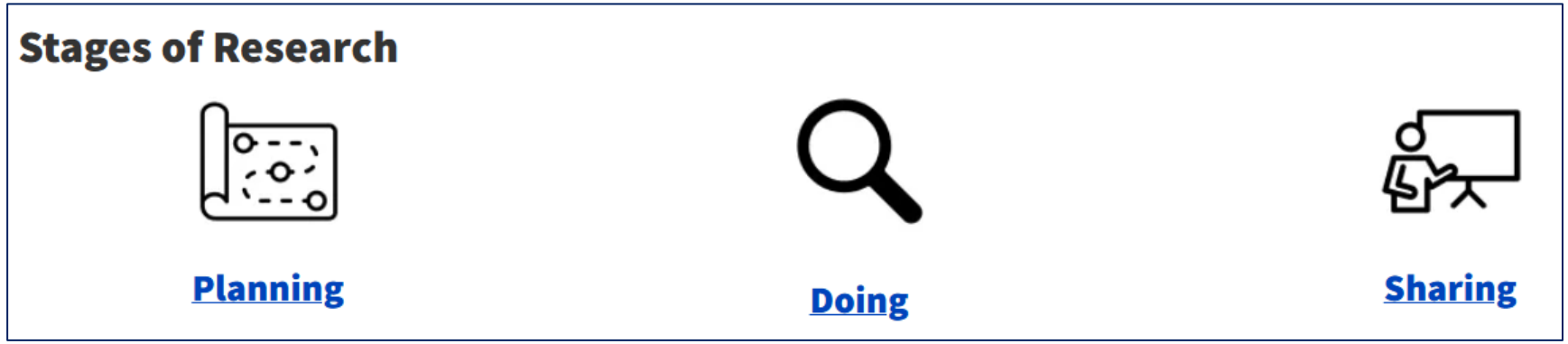
- Putting together scientific and lived experience expertise
- Improves **trust**, research samples that include people and all backgrounds, and **knowledge-to-implementation (data use)**
- We need **accessible ways** to work with research partners with intellectual and developmental disabilities

Equipped to Engage Toolkit

RE4ALL

The Equipped to Engage Toolkit

- Tools so that researchers with and without intellectual disability can work together on research
- Created with people with intellectual disability

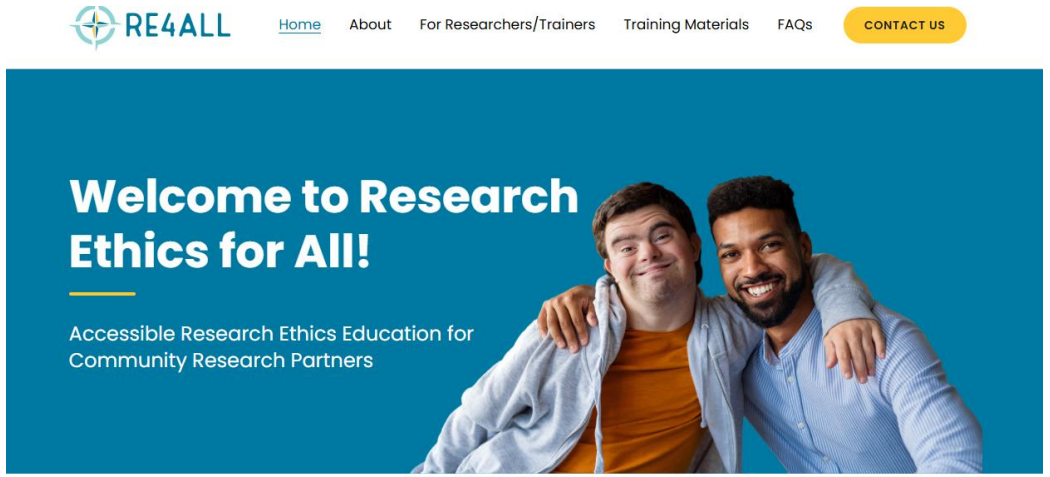


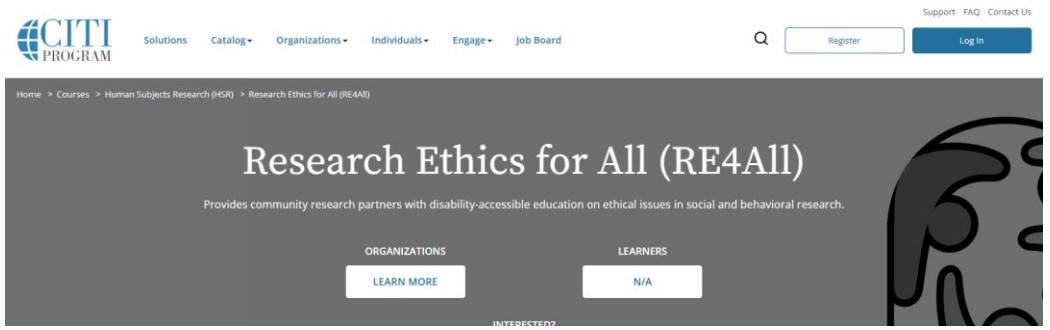
https://iod.unh.edu/equipped-engage

Eugene Washington PCORI Engagement Award EACB 29073A

Research Ethics for All

- Disability-accessible, disability-rights informed education in ethical issues in research
- Created with people with developmental disabilities
- Also available via the CITI Program
- Eugene Washington PCORI Engagement Awards EASC-IDD-00301 and EACB-38863



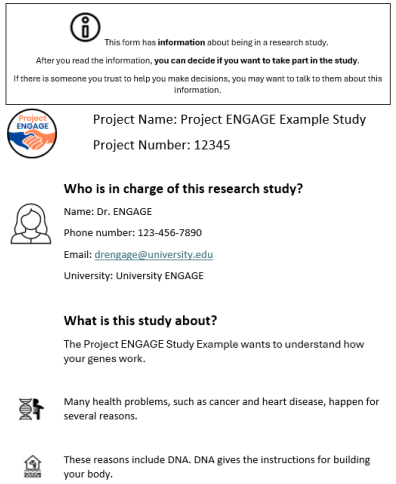


Schwartz, A., McDonald, K. and The Research Ethics for All Consortium. (2025). Research Ethics for All: Development of a social-behavioral research ethics education program for community research partners with developmental disabilities. *Disability and Health Journal, 18(1),* 10resu1675.

The ENGAGE Toolkit

https://engage-toolkit.org/

- Including adults with intellectual disability as research participants.
- Resources for making decisions about being in research that:
  - ✓ Responds to researchers' specific study
  - ✓ Maximize first-person consent and agency when consent capacity is limited
  - ✓ Enhance understandability of consent disclosures and free choice
  - ✓ Enhance researchers’ capacity



This form has **information** about being in a research study.

After you read the information, **you can decide if you want to take part in the study.**

If there is someone you trust to help you make decisions, you may want to talk to them about this information.

Project Name: Project ENGAGE Example Study

Project Number: 12345

Who is in charge of this research study?

Name: Dr. ENGAGE

Phone number: 123-456-7890

Email: drengage@university.edu

University: University ENGAGE

What is this study about?

The Project ENGAGE Study Example wants to understand how your genes work.

Many health problems, such as cancer and heart disease, happen for several reasons.

These reasons include DNA. DNA gives the instructions for building your body.

ENGAGE Supported Decision-Making Agreement:

Deciding Whether to be in a Research Study

Study Title: Project ENGAGE Interview

People leading the study (Principal Investigators): Katie McDonald, PhD, and Maya Sabatello, LLB, PhD.

Katie Maya

This form is for if you want to **use supported decision-making**:

- to decide whether you will be in this study
- for decisions you may need to make about being in the study later on

Supported decision-making is when you **choose someone you trust like a friend or family member to help you**:

- ✓ **understand information** and
- ✓ **make a decision**

When you use supported decision-making, **you make the decision**

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Research Partnerships: Lessons Learned and Challenges in Need of Solutions

- The value of long-term relationships
- The importance of disability-accessibility for research partnerships

- Presuming competence
- Understanding health needs
- The need to enhance inclusion in:
  - research teams
  - research, both general population, health-condition specific, and disability research
- Compensation of research partners

Navigating Challenges to Increase Data Use and Dissemination

Self Advocates Becoming Empowered

Self Advocacy Research & Technical Assistance Center

Presenter: Teresa Moore

SABE SARTAC Project Partners

1. ASAN or Autistic Self Advocacy Network
2. GMSA or Green Mountain Self Advocates
3. NACDD or National Association of Councils on Developmental Disabilities
4. SWI or Southwest Institute for Children and Families
5. SLN or Sibling Leadership Network
6. TASH
7. UMKC IHD or University of Missouri Kansas City Institute on Human Development

SARTAC

My Goal for the presentation:

- SARTAC is about Self Advocacy and Beyond
- SARTAC supports self advocates to grow their own center resources for leadership and research.

SARTAC is stronger because:

- It is run by and for self advocates
- People with disabilities take a lead in creating and presenting resources

Self Advocates Share Their Thoughts on Partners and Members Working Together

- Those who were driving it were open to new ideas.
- We understood and respected what we found in common.
- Took back ideas to our communities across different disabilities.
- Different cultures came together on issues and learned from each other.
- We all have problems in our states, but we came together.

Self Advocates Share Their Thoughts on Partners and Members Working Together

- There was a mixture of new and experienced members.
- Every person's ideas matter.
- We all found some level of agreement.
- No matter what administration we were under, we were always able to find common ideas.
- Everybody's culture belongs.

Stronger Employment Connections

- Members of the SARTAC Community of self advocates said that finding work was easier because they have insider knowledge of grant and funding systems.
- Self advocates believe it is important to have community, allies, and political leaders who promote professional opportunities for future advocates.

SARTAC Professional Experience

- SARTAC is a standout experience on bios and on resumes.
  - Helps build their professional credibility, resulting in more speaking engagements.

Team Development

SARTAC asks:

- How are the individuals we each serve impacted by this project?
  - Paying committee members makes them aware they are valued for their professional expertise.
  - The realization of the value of their education and lived experience was a highlight as they thought about expanding employment into the larger job market, for example, leadership roles such as manager or director.

SARTAC Resources

- SARTAC's Resource Center is developed by:
  - Members of The National Self Advocacy Zoom Weekly Meetings
  - SARTAC Advisory Committee
  - SARTAC Fellows
  - Project Partners

SARTAC Fellowship

- Self Advocates and People with Disabilities learned advanced skills related to plain language.
  - Fellows must have a host from their Community or Volunteer Organization.
  - Many Project Partners served as Expert Trainers and Mentors
  - Fellowship Projects helped Fellows to have increased employment opportunities.

Things We Need to Think About As We Shift Toward Paid Opportunities

- Pay for self-advocates needs to be expanded to include all people in the disability community.
- Need to challenge agencies to hire people with disabilities for professional roles, noting that some individuals are held back by fears regarding the impact of employment on their benefits.
- Caution against using the term "lived experience" in place of "professional" to avoid paying them well for their work.

Presentations Available on SARTAC

- How Do We Measure Who's in Control presentation about the importance of the right questions to ask

- www.selfadvocacyinfo.org
- www.sabeusa.com

State of the States in Intellectual and Developmental Disabilities Ongoing Longitudinal Data Project of National Significance

State of the States
In Intellectual and Developmental Disabilities

KU CENTER ON DISABILITIES

State of the States Data Ambassadors

DATA AMBASSADORS

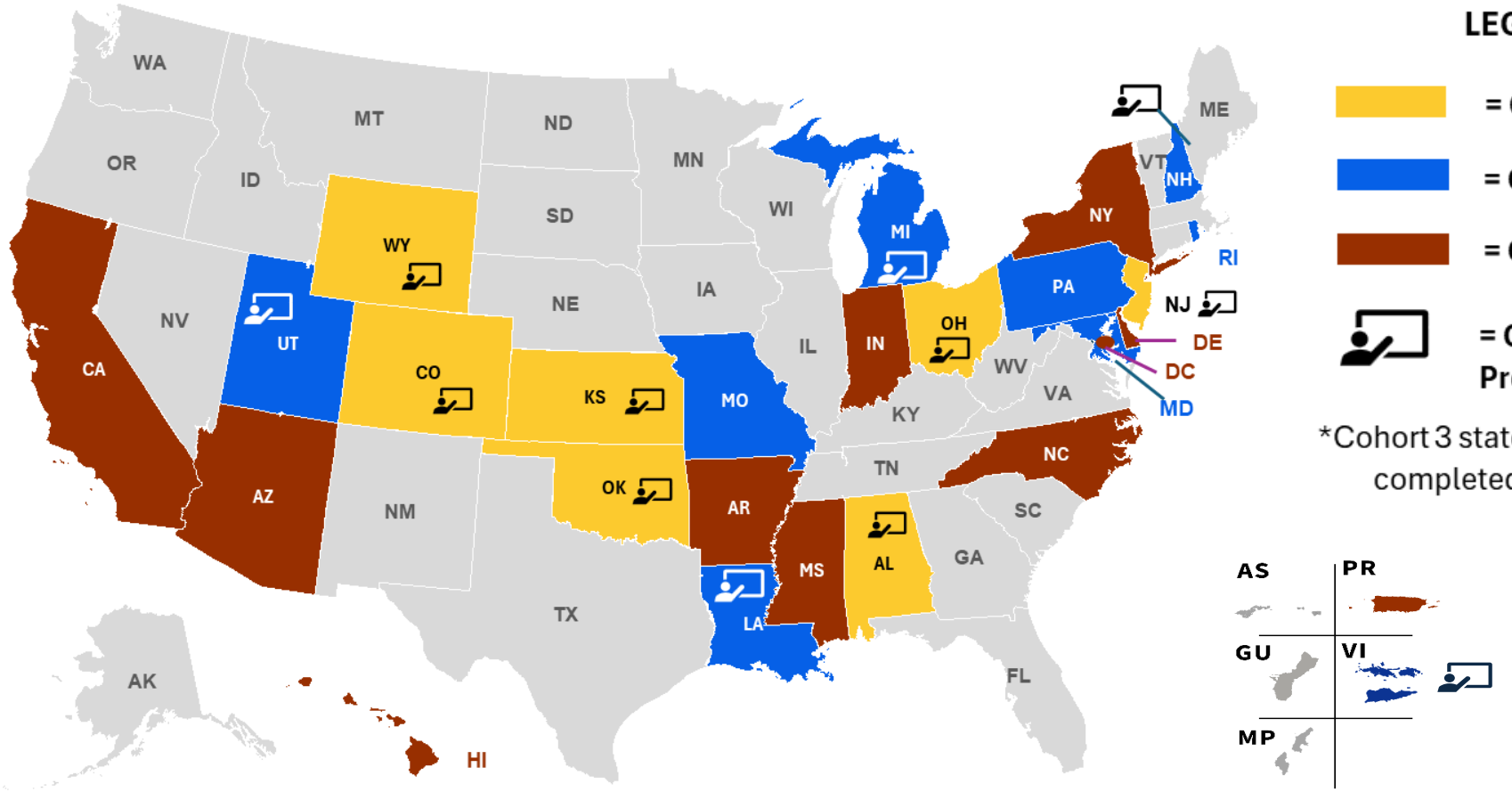
State of the States
In Intellectual and Developmental Disabilities

AUCD
Association of University Centers on Disabilities

Partnership with the Association of University Centers on Disability (AUCD) network to establish groups of people who live in certain areas of the country to be Trainee Data Ambassadors who are knowledgeable about programmatic and national intellectual and developmental disabilities (I/DD) data and data accessibility to advance leadership in policy, education, and practice.

National Activation

Data Ambassadors sweeping the nation



Inclusive by Design

35 YEARS OF COMMUNITY LIVING

"There is a difference between being asked to share and being allowed to shape outcomes."

- Advisor

"From my perspective, 'authority' for people with lived experience would mean more than advisory input, it would mean shared decision-making power that cannot be bypassed or symbolized."

- Advisor

New Frontier - Data Agency

Data agency is a form of self-determination where an individual understands, takes ownership of, and is empowered by applying their data across different settings.

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State of the States
In Intellectual and Developmental Disabilities

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How do we use plain language resources to connect with other self-advocates?

Jules Good, State Advocacy Manager, ASAN

ASAN
AUTISTIC SELF ADVOCACY NETWORK

What is plain language?

- Plain language is a way you can write.
- Plain language makes your writing more accessible to many people.
- **Accessible** means that more people can understand your writing.

What is plain language?

- Plain language is not just about swapping out big words for small words. Plain language documents have to follow rules about:
  - Formatting. **Formatting** is how writing is laid out on a page.
  - Structure. We might put the same information in a different order in a PL document.
  - Tone and style.

ASAN does not use AI to write in PL. Ever. Why?

- **Artificial intelligence** is when a computer program does things that normally need to be done by humans. We call artificial intelligence “AI” for short. There are lots of different kinds of AI.
- AI can not turn formal language into true PL. It gets facts wrong and changes the meaning of things. We tested MANY AI models to write this resource.
- **Read our PL resource about this!**

How does ASAN use plain language?

- We make PL resources about:
  - Government policy choices that affect autistic people
  - Ways that people can take action on advocacy issues
  - Systems and rules that affect autistic people
- We are working on making more of our emails and social media posts PL

How do we find out if our PL is really accessible?

- We have done focus groups about our PL resources with people with IDD. **Focus groups** are a way for people with IDD to give ASAN feedback on our PL resources.
- When people ask us questions about our PL resources, we check to make sure our PL resources can clearly answer those questions.

It’s about more than language.

PL helps us connect. How else do we connect?

- Treat people with IDD like **people, not projects.**
- Make language access consistent. **Consistent** means making sure that language in many different places is accessible.
  - Example: Our emails about PL resources are written in PL, too!
- Nothing about us, without us!
  - People with IDD should be in every room where people are making choices about our lives.
  - **No one** is “too disabled” to have the rights to information.

What does this look like in real life?

- Example: ASAN's IACCtion Page walkthrough

Thanks for listening! Any questions?

The Autistic Self Advocacy Network
http://autisticadvocacy.org/
Twitter: @autselfadvocacy Facebook: /AutisticAdvocacy/