Panel 3: Merge Ahead? Opportunities to Enhance Research Capacity

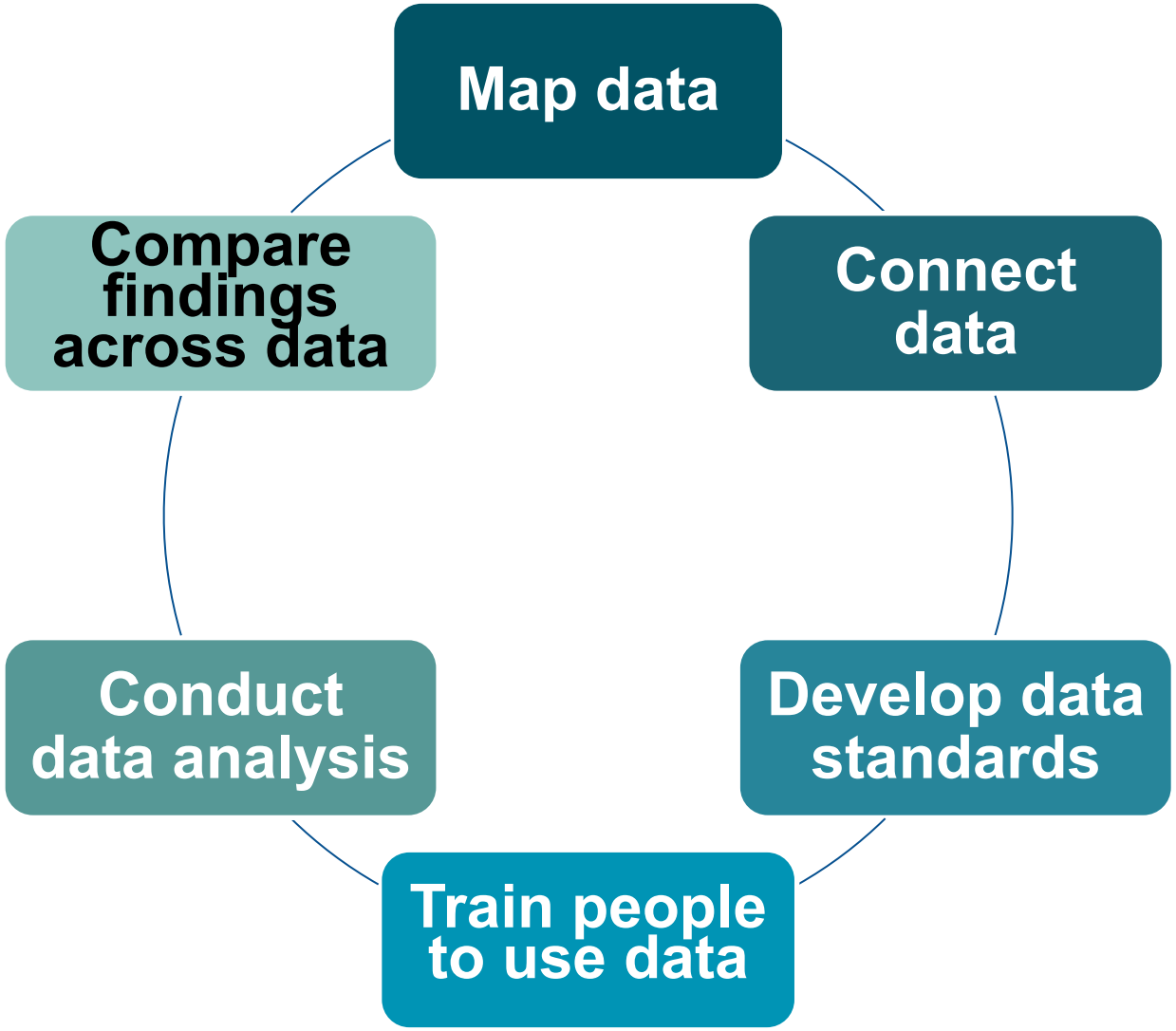
September 21, 2026

Moderator: Richard Chapman, PhD LMHC

I/DD Counts Summit


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

A roadmap to supporting research and capacity for analysis



Panelists

- **Sherri Larson** – Research Manager, University of Minnesota Institute on Community Integration
- **Susan Havercamp** – Professor, The Ohio State University Nisonger Center
- **Kayte Barton** – Special Olympics Health Messenger and Inclusive Researcher
- **Maggie Nilz** – Senior Analyst, Association of State and Territorial Health Officials
- **Lindsay DuBois** – Research Association, Human Services Research Institute

INSTITUTE on COMMUNITY INTEGRATION

UNIVERSITY OF MINNESOTA

Merge Ahead: Enhancing Research Capacity

IDD Counts Summit 2026

Sherri Larson

Research Manager

September 21, 2026

RISP

Using Administrative Data for Prevalence

Data Sources

- **Federal – RESDAC Chronic Conditions Warehouse**
  - Medicaid
  - Medicare (fee-for-service, Medicare Advantage)
- **Private Insurance**
  - Health Care Cost Institute (HCCI)
  - 40% of all privately insured
- **11% of US population not included**
  - Uninsured
  - Military insurance

Prevalence per 10,000 people in 2019

Insurance Type	Spina Bifida	Muscular Dystrophy
Medicaid	7.03	3.54
Medicare	5.03	6.54
Private	1.72	1.49
Overall	3.20	2.85

Bershadsky et al., 2026, Bershadsky et al., in clearance

Issue – Data quality, data missing, for race and ethnicity

National Surveys

- 1994/1995 National Health Interview Survey-Disability Supplement
  - DD Act definition of developmental disabilities (3 severe functional limitations, age at onset, duration)
  - Intellectual disabilities defined by ICD code
  - Operational definitions differed by age because the survey questions differed 0-5, 6-17, 18+
  - Estimated prevalence, described service use, functional needs, characteristics and factors associated with health outcomes

National Surveys

- NHIS
  - Children's survey –Parent report on ID, ASD, Developmental Delay available annually
  - Adult survey:
    - Does not ask if anyone in the household has ID or ASD, does not include ICD codes causing limitations.
    - NCHS work by Julie Weeks showed asking if an adult had ID was not a good survey question

National Surveys

- American Community Survey
  - Cognitive limitation (difficulty concentrating or remembering) is not the same as intellectual disability
    - The questions are not sensitive nor specific enough to identify adults with intellectual disability
  - Many people with ID did not say yes to the item
  - More than 90% of the people endorsing item have needs related to mental health, medication side effects, Alzheimer's, or conditions other than ID
  - Asking about difficulties with decision making improved sensitivity

The Residential Information Systems Project

Administration on Community Living Longitudinal Data Project of National Significance

Annual Surveys of
- State IDD Agencies and
- Large State-Run IDD Institutions

RISP.umn.edu

How many people have IDD?

How many people with IDD get paid supports?

Where do people who get supports live?

How do the places people live differ by age and by state?

How have the places people with IDD live changed?

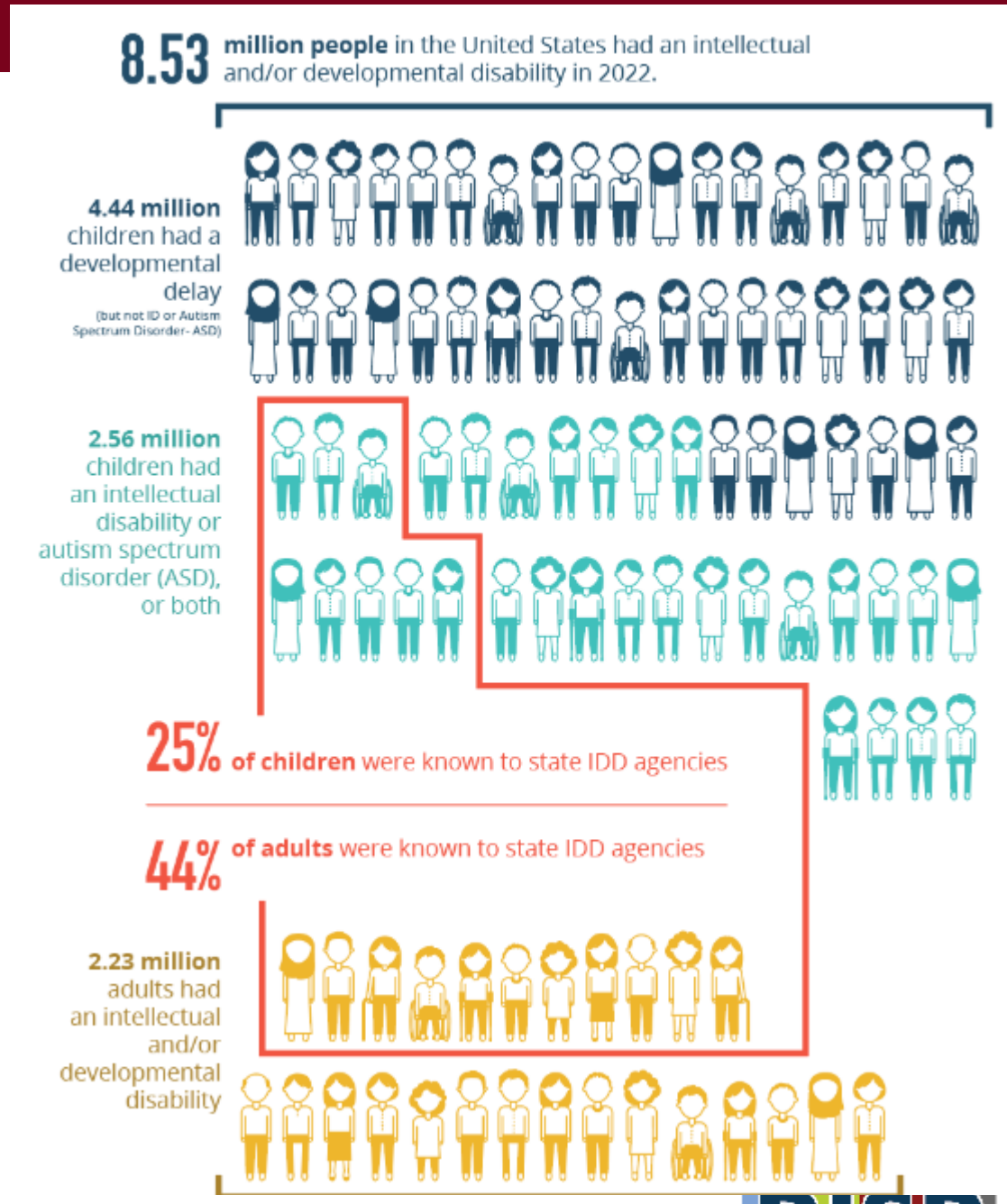
IDD Prevalence 2022

Prevalence 8.53 million people

- 4.44 million children with developmental delay (1 limitation)
- 2.56 million children have ASD or ID
- 2.23 million adults have ID or DD (94/95 NHIS-D .78 per 1,000)

Known to state IDD agencies

- 25% of children with ASD or ID
- 44% of adults with IDD



Data sources: NHIS-D, NHIS for children, RISP

RISP Improving State Data Capacity

- Annual webinar for state directors and data providers
- User guide for each survey year
- Recording of webinar available throughout data collection year
- Online or telephone assistance provided to individual states
- Targeted technical assistance to states developing new data collection and management tools
- 5 years to get stable responses and high response rates to new questions (age, number of deaths by age, race and ethnicity by age)

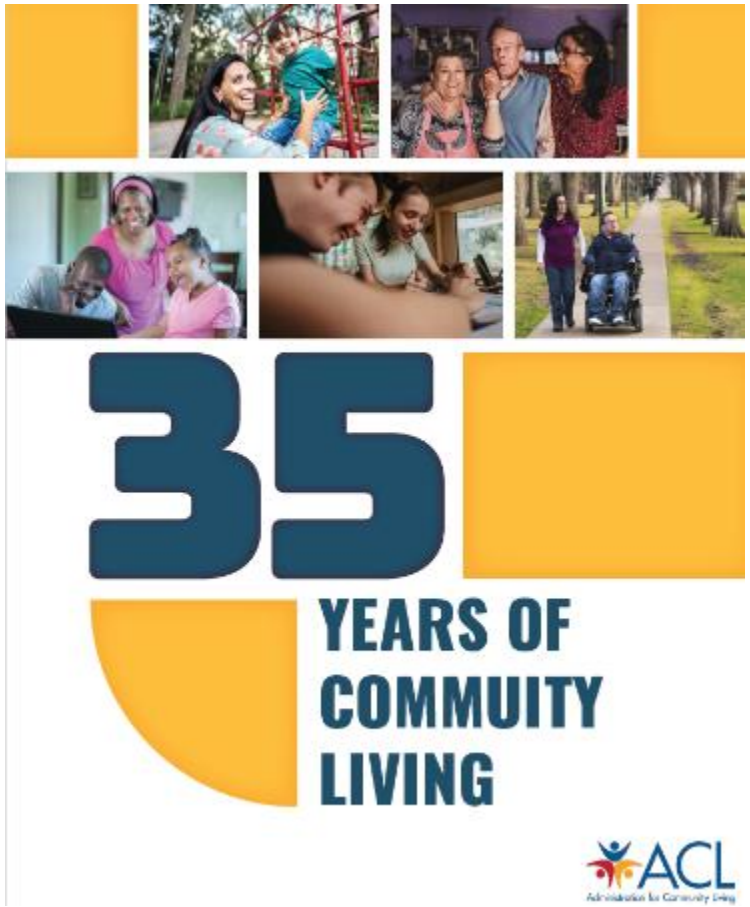
Eligibility for IDD Services Project

- Collaboration between RISP and the National Association of State Directors of Developmental Disabilities Services
- **Goal**
  - Clarify who is included when we collect information about people on the caseload of state IDD agencies
  - Who is eligible for any service offered by or through the state IDD agency

- Sample frame is used for ACL's Longitudinal Data Projects of National Significance
  - RISP
  - State of the States
  - Access to Integrated Employment
- Eligibility Criteria
  - Diagnosis
  - Functional Limitations
  - Both
  - Other

35 Years of Community Living

www.acl.gov/35years



- How many people have IDD?
- How many people get supports and services through state IDD agencies?
- Where do people with IDD live and work?
- How much does it cost?
- How can technology solutions increase access to community living

References

- Bershadsky, J., Paramothy, P. Pettingell, S.L., Larson, S.A., Street, N., Hall-Lande, J., Hallas, L., Reefhuis, J. , Reily, C. (In clearance). Prevalence of Muscular Dystrophy across the lifespan in the U.S.
- Bershadsky, J., Riley, C., Pettingell, S. L., Larson, S. A., Hall-Lande, J., Hallas, L., ... & Reefhuis, J. (2026). Prevalence of spina bifida across the lifespan in the USA. *Developmental Medicine & Child Neurology*.
- Larson, S. A., Lakin, K. C., Anderson, L., Kwak, N., Lee, J. H., & Anderson, D. (2001). Prevalence of mental retardation and developmental disabilities: estimates from the 1994/1995 National Health Interview Survey Disability Supplements. *American Journal on Mental Retardation*, *106*(3), 231-252. Integration.
- Larson, S.A., Neidorf, J., & Pettingell, S. (2026). Long-term supports and services for persons with intellectual or developmental disabilities: Status and trends through 2022. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community

RISP Acknowledgements

This presentation uses data and analyses from the Residential Information Systems Project at the University of Minnesota, Dr. Sheryl A Larson, Director. RISP.UMN.EDU

The RISP project is funded through a cooperative agreement from the Administration on Community Living, U.S. Department of Health and Human Services, Cooperative Agreement #90DNPA0001 with supplemental funding from the National Institutes on Disability, Independent Living and Rehabilitation Research Grant # 90RTCP0011.

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Institute on Community Integration (UCEDD)
University of Minnesota, Twin Cities

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Consultant: Amie Lulinski

Blueprint: Designing a data system on IDD well-being over time and across the lifespan

Susan M. Havercamp, PhD

The Ohio State University Nisonger Center

- on behalf of the Blueprint team

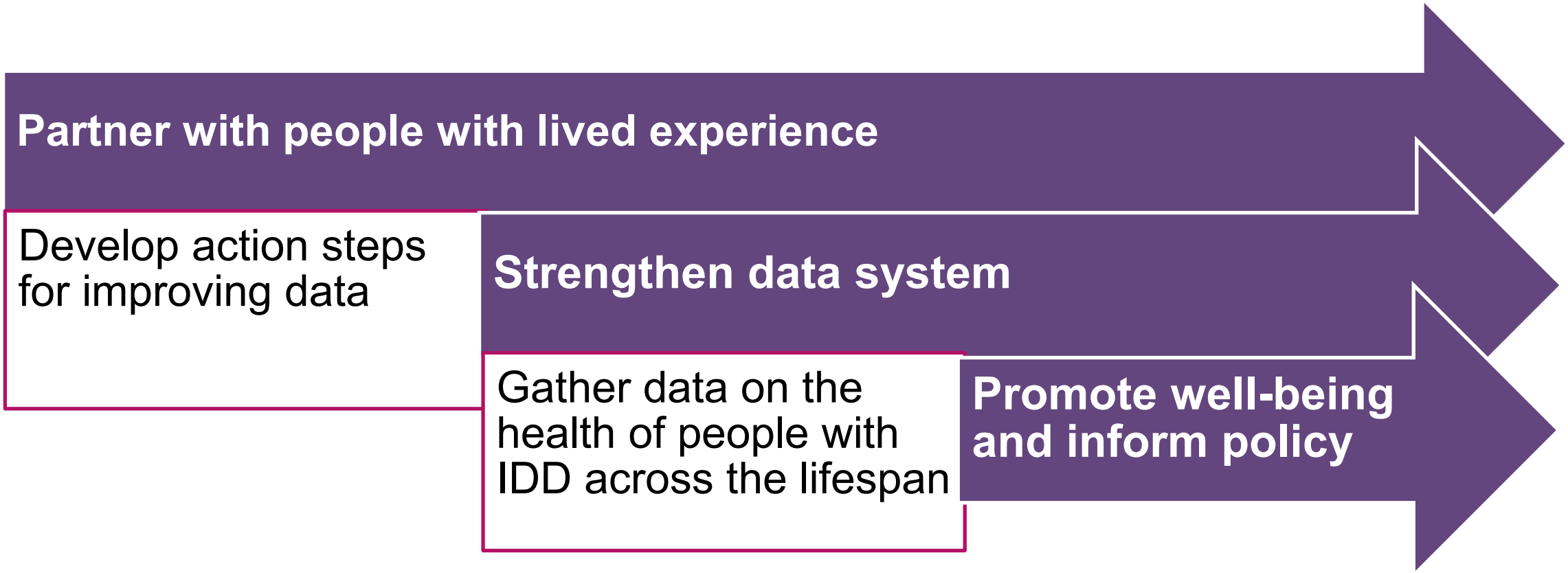
Longitudinal data can answer important policy questions

- What is the natural history of the lives of people with IDD
- What factors early in life predict later life outcomes?
- What supports and interventions impact long-term well-being?
- What negative life events impact long-term well-being?
- What factors act as barriers or facilitators to these impacts?

"Work closely with NIDILRR and ACL to develop plans and infrastructure for a sustainable long-term effort to collect longitudinal health and community living data from people with IDD."

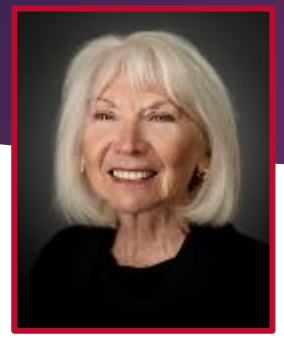
RRTC FUNDING OPPORTUNITY ANNOUNCEMENT MAY 15 2023

Blueprint Project Purpose



3 RRTCs Collaborate

Susan Havercamp
OSU RRTC PI



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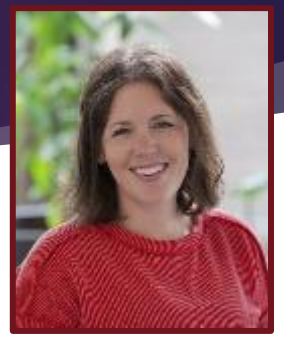

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UMN RRTC

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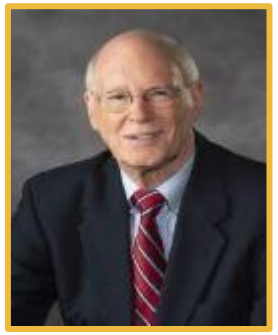

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VCU RRTC CO-PI

Parthy Dinora
VCU RRTC CO-PI

Carol Schall
VCU RRTC Director

Lived Experience Groups

Age	Functioning level	Race	Ethnicity	DD system involvement	Rurality	Living Situation

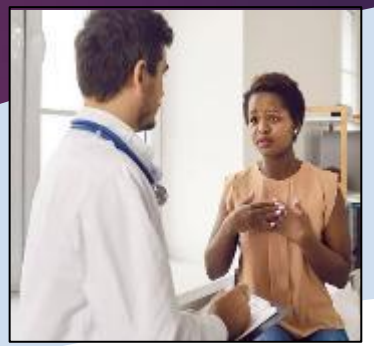
8 adults with IDD

8 family members of children or adults with IDD

In total, our team includes

- 3 RRTCs
- Lived experience experts
- Research experts
- Federal leadership

Health, Employment, and Community Living



2-Year Work Plan
September 2025 to August 2027

Data Scan What data exists and what is missing?	**July 2026**
Methods What strategies will work to track across lifespan?	**January 2027**
Framework What should the data system look like?	**April 2027**
Requirements What measures and data standards are needed?	**April 2027**
Action Steps to Build the System Concrete, feasible next steps for federal agencies	**August 2027**

Toward a clearer understanding of how **policies, services, and life experiences shape outcomes** for people with IDD across the lifespan

Special Olympics Inclusive Research

Kayte Barton

Special Olympics Health

MADE POSSIBLE BY Golisano FOUNDATION

Kayte Barton

Special Olympics Health
MADE POSSIBLE BY Golisano FOUNDATION

- Special Olympics athlete with 30+ years of experience. Played multiple sports favorites were Poly Hockey and Swimming
- High Functioning Autistic, cerebral palsy
- Inclusive Health Research and Care Advocate
- Athlete leader and health messenger

My role as a Health Messenger

I have been trained by Special Olympics to be a leader in Health advocacy.

I advocate for the following:

- Educating health care professionals about the importance of working with people with IDD
- Inclusive Healthcare training for medical students in med schools: want to make it a requirement for healthcare professionals
- Inclusive Health care, including health and fitness programs for people with IDD
- Inclusive research: including people with IDD in research both as participants and as research partners

Health Disparities for Adults with IDD

Special Olympics Health
MADE POSSIBLE BY Golisano FOUNDATION

- People IDD are more likely to experience health disparities than the general public
  - 2x more likely to die prematurely then their peers a full 20 years earlier
  - High rates of co-occurring health conditions, like obesity and mental health
- Physicians and nurses aren't trained in disability, and as result, people with IDD face gaps in care.
- People with IDD are more likely to receive medication for mental health which can cause side effects
- More likely to report being unable to access mental health care services, medication management, and therapy

Why Inclusive Research Matters

You can’t understand health if you leave a big group out

People with lived experience can help:

- Ask the right questions
- Design better research
- Help implement interventions
- Understand what we see in the data
- Find participants
- In literally every stop of the process

HEALTH 4 ME Overview

Special Olympics Health
MADE POSSIBLE BY Golisano FOUNDATION

Collaboration between Special Olympics and University of Southern California

Research team includes people with disabilities, community members, staff from Special Olympics, and university researchers

Community members included at points in the research process

Intervention project Length: 9/1/2025 - 8/30/2030

What We're Working On: HEALTH 4 ME

- HEALTH 4 ME is a comparative effectiveness research (CER) project funded by a Patient-Centered Outcomes Research Institute (PCORI) Award (IDD-2024C1-37360) to Karla Ausderau
- HEALTH 4 ME will be a way to help people with IDD advocate for their own health and for changes in healthcare
- We will do a clinical trial to see if health education and coaching improves:
  - People's abilities to reach individual health goals
  - Health outcomes
  - Healthcare access
  - Health advocacy skills

What Will HEALTH 4 ME Look Like?

Athletes in Colorado, Minnesota, New Mexico, and Wisconsin will participate as part of their team.

Half of participants will get the HEALTH 4 ME training. The other half will do Special Olympics as usual.

For those who get the training, it will include:

- 8 weeks of health education classes
- 3 booster classes
- Ongoing health coaching for 9 months after the training

Health coaches will be Special Olympics coaches and people with intellectual and developmental disabilities.

Timeline of HEALTH 4 ME

Special Olympics Health
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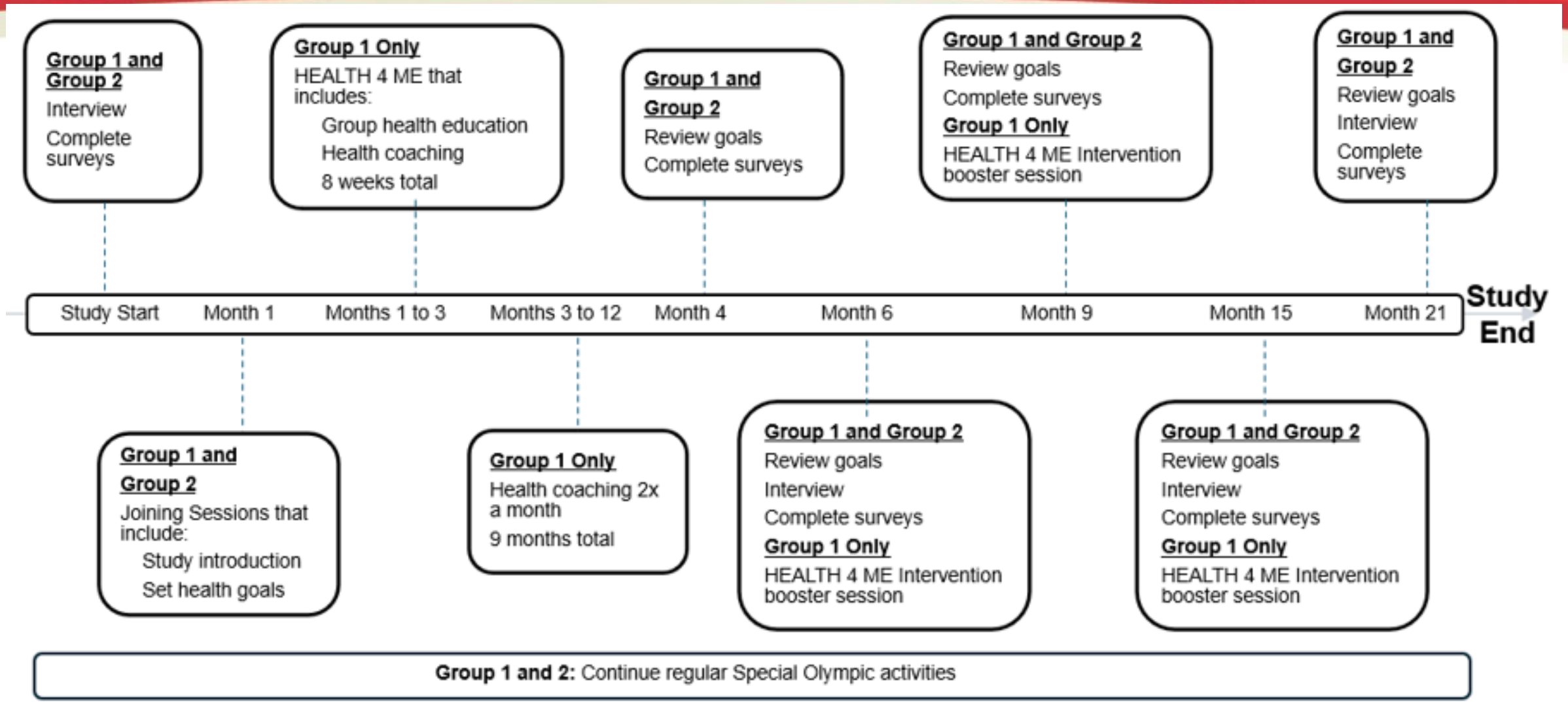


How We Built an Inclusive Research Team

- Conversations with community partners started from the beginning, with funding applications
- Community partners with lived experience involved in multiple roles, including on the leadership team
- Co-created guidelines for working together: the Expectations 4 Engagement

Expectations 4 Engagement

Expectations 4 Engagement: A Co-Design Journey for Inclusive Research

Context Summary: Bridging the Gap to Meaningful Partnership

Traditional research often excludes individuals with IDD or relegates them to symbolic roles. To bridge this gap, the "Expectations 4 Engagement" (E4E) framework—a living charter for equitable collaboration—was developed through a rigorous 4-step co-design process, moving from "designing for" to "designing with" the community.

Traditional Exclusion

Exclusion & Symbolic Roles

Inclusive Co-Design

Meaningful Research Partnership

1 Idea Generation & Foundational Questions

Core team defined identity, identified what "safety" feels like in research, and chose a name for the initiative.

2 Iterative Drafting & Glossary Development

Held six group meetings to revise the draft and created a plain-language glossary for complex terms like "confidentiality" and "IRB".

3 Broader Research Team Review

Presented to the larger Engagement Team and Special Olympics partners to ensure alignment across different community partner groups.

4 Usability Testing with Lived Experience Experts

Working group of individuals with IDD reviewed the document for clarity, meaningfulness, and effective promotion of respect and inclusion.

Key Shifts in Thinking

From "Accommodations" to "Access Needs"
Replaced "accommodations" with "access needs" to normalize supports for everyone.

"Nothing About Us, Without Us"
Shifted research agenda toward neurodiversity justice, ensuring community partners are authoritative experts.

Moving Beyond the "Charter" Label
Based on feedback, replaced "charter" with "Expectations 4 Engagement" for transparency and accessibility.

Practical Tools for Inclusive Meetings

The "Fist to Five" Voting Scale
Quick consensus-building to gauge support quality and identify objections beyond yes/no.

Inclusive Hybrid Meeting Checklist
Strategies including early tech testing, active chat for engagement, and a dedicated moderator.

Predictable Material Templates
Standardized templates with E4E norms renunders create a predictable environment for easier participation.

Impact & Future

The E4E framework empowers every team member—regardless of disability status—to contribute to their full potential, fostering a culture of respect and inclusion in research.

READI: Research Education and Advocacy for Diverse Individuals

Special Olympics Health
MADE POSSIBLE BY Golisano FOUNDATION

- Karla Ausderau: kinesiology/occupational therapist professor at University of Southern California
- Designed READI to help people with IDD to better understand what research is, how it works, and how to work with researchers
- Can be flipped: to teach researchers how to work with people with disabilities on research projects.
- I have used it as an advocacy tool to advocate for inclusive healthcare, and research

READI QR Code

My research and projects

- I researched obesity and IDD, and found that there was not good data, or research.
- This lead to crafting legislation in Minnesota to help people with IDD access obesity care that's designed for them - it never passed!
- I am thinking of reintroducing it this year

Resources to Help With Inclusive Research or how to become involved with Special Olympics

- READI – Research Engagement and Advocacy for Diverse Individuals
- RE4All - Research Ethics 4 All
- Equipped to Engage
- IIDDEAL – Individuals With IDD Engaged, Aligned, and Leading
- https://inclusivehealth.specialolympics.org/
- somn.org

My Research articles, and publications

- https://www.futureofpersonalhealth.com/mental-health/closing-the-mental-health-gap-for-people-with-intellectual-disabilities/
- https://www.specialolympics.org/stories/athletes/athlete-perspective-the-importance-of-inclusive-research-and-evaluation
- https://podcasts.apple.com/us/podcast/1026-a-mental-health-crisis-for-adults-with-idds/id1501336958?i=1000756739446
- https://www.revisor.mn.gov/bills/93/2023/0/HF/2542/versions/0/pdf/
- https://www.instagram.com/reel/DbDrhymDait/?igsi=MXVyaDF1cHowOGprMw==

Thank You!

Special Olympics Health
MADE POSSIBLE BY Golisano FOUNDATION

- Any questions?

- Contact Info: littlebarty9@gmail.com

Beyond the Dataset: Building Better Disability Health Research

Lessons from ASTHO's National Disability Data Initiative

September 2026

ASTHO

The Association of State and Territorial Health Officials (ASTHO) is a nonpartisan organization that represents the nation's state and territorial health officials.

ASTHO supports state and territorial health agencies to:

- Develop public health policies.
- Promote best practices in public health.
- Provide expertise in public health to their elected officials.
- Advance health equity and optimal health for all.

ASTHO staff provide expertise across public health topics, including preparedness and disability inclusion.

Disability Integration Work

- Evaluated costs and benefits of analyzing **Medicaid data for disaster preparedness**
- **Developed a way to identify disability in emergency health data** to understand the health of people with disabilities during emergencies.
- Hired 18 full-time **disability and preparedness specialists** in health agencies to ensure inclusive approach to disaster preparedness
  - Evaluated program's **impact and sustainability**.
- Partnered with researchers to **better understand disability and health**
- Examined how existing data can—and can't—help us **understand disability and health.**

ASTHO's Disability and Data Research Work

Oct. 2024 – May 2025

Conducted a landscape assessment of disability data

Spring 2025

Published a blog series on inclusive data structure and engaging people with disabilities in data projects

May 2025

CSTE Annual Meeting presentation

Oct. 2025 – May 2026

Developed a toolkit for using data linkage to understand disability and health

May 2026

First ever CSTE Annual Meeting Disability Health Surveillance Workshop

Sep. 2026

Publication of the Disability and Health Data Linkage Toolkit

Lessons from National Data Efforts

Lesson 1: There is no single "best" disability dataset. Different data systems answer different questions.

Lesson 2: Data linkage can improve understanding—but researchers need to be clear about how disability is defined and what the data cannot tell us.

Lesson 3: Research improves when disability communities help shape the questions, interpret the findings, and decide how results are shared.

The Disability Data Landscape

Disability Data Challenges

- No consistent **definition** of disability across data systems
- Disability is **not consistently collected** as a demographic characteristic
- Disability is often examined only as a **negative health outcome**
- **Lack of disability inclusion** in research and data project teams

How Disability Exists Within Data

Data Type	What it Tells Us	What it Misses
Self-reported (e.g., surveys)	People's experiences and disability prevalence	Detailed health information
Administrative/ program	Services and program use	People outside those systems
Clinical/claims	Health conditions and care	How disability affects daily life
Linked data	A broader picture across systems	Requires planning and oversight

Each data source answers a different research question.

Let’s Talk

When you begin a new disability research project, what is the first question you ask about the data?

Evaluating Data Systems for IDD Research

Can we identify people with IDD accurately?

- How is disability defined
- Who is included

Can the data answer the research question?

- Health and Services
- Social and environmental factors

Can researchers use it confidently?

- Data Quality
- Documentation
- Ability to link with other data

Will the findings be equitable and actionable?

- Accessibility
- Representation
- Community partnership

Linked Data

Opportunities and Responsibilities

Data linkage can help researchers:

- Better identify people with IDD across systems
- Understand health outcomes in context
- Understand how people use services across different systems
- Identify gaps and disparities that individual datasets cannot reveal

Responsible data linkage requires:

- Clear definitions
- Clear rules for how data can be accessed and used
- Community partnership
- Responsible and ethical use of data

Key Takeaways for Research

Let's Talk

What makes disability data trustworthy?

Stakeholder Engagement

- **Trust, Ethics, and Privacy**
- **Lived Experience and Decision-Making**
- **Building Bridges**

Engagement Improves Research

Build the Right Expertise

- Scientific Advisory Panel
- Technical Advisory Group
- Researcher Workgroup

Reduce Barriers to Participation

- Participant compensation
- Accessible meetings and materials

Include Diverse Perspectives

- Representation across disability, public health, and research communities

Thank you to our Disability Health Data Workgroup members!

Contact Us

Want to talk more?

Need technical assistance related to disability data?

Stay in touch!

Email mnilz@astho.org

I/DD Counts Planning Study

2026 I/DD Counts Data Summit

HSRI

Background for the I/DD Counts Planning Study

The **Roadmap to Improve IDD Health Data** was developed after the 2019 Summit and updated again after the 2022 Summit

One of the key activities to improve IDD health data was to consider a "**Center of Excellence in IDD Health Data**"

In 2024, HSRI worked with ACL and the CDC to develop a plan for a **"One Stop Shop" in IDD health data.** This became known as **"The I/DD Counts Planning Study."**

What is a “Coordinating Center of Excellence”?

- There are many IDD Centers of Excellence that provide leadership, research, and training on IDD. Examples:
  - University Centers of Excellence in Developmental Disabilities (UCEDDs)
  - ACL Projects of National Significance (PNS)
- Although some UCEDDs and PNS sites focus on health for people with IDD, there is no **“One Stop Shop” in IDD health data**

The Goals of the I/DD Counts Planning Study

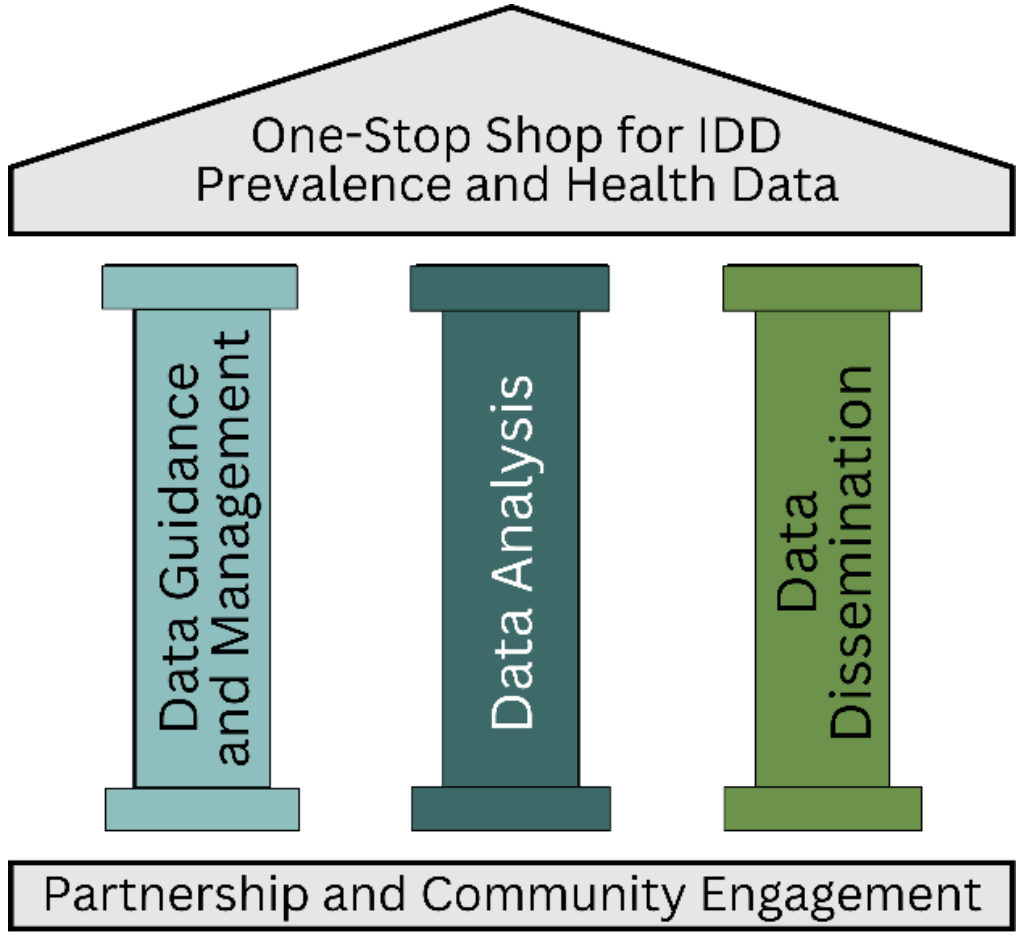
For the rest of this presentation, I'll call the proposed coordinating center of excellence on IDD health data: **"The Center"**

- Think about **what work or activities** the Center would do to improve IDD health data
- Think about **how to organize the work and activities** of the Center
- Think about **how much money** would be needed to support the Center

Methods for the I/DD Counts Planning Study

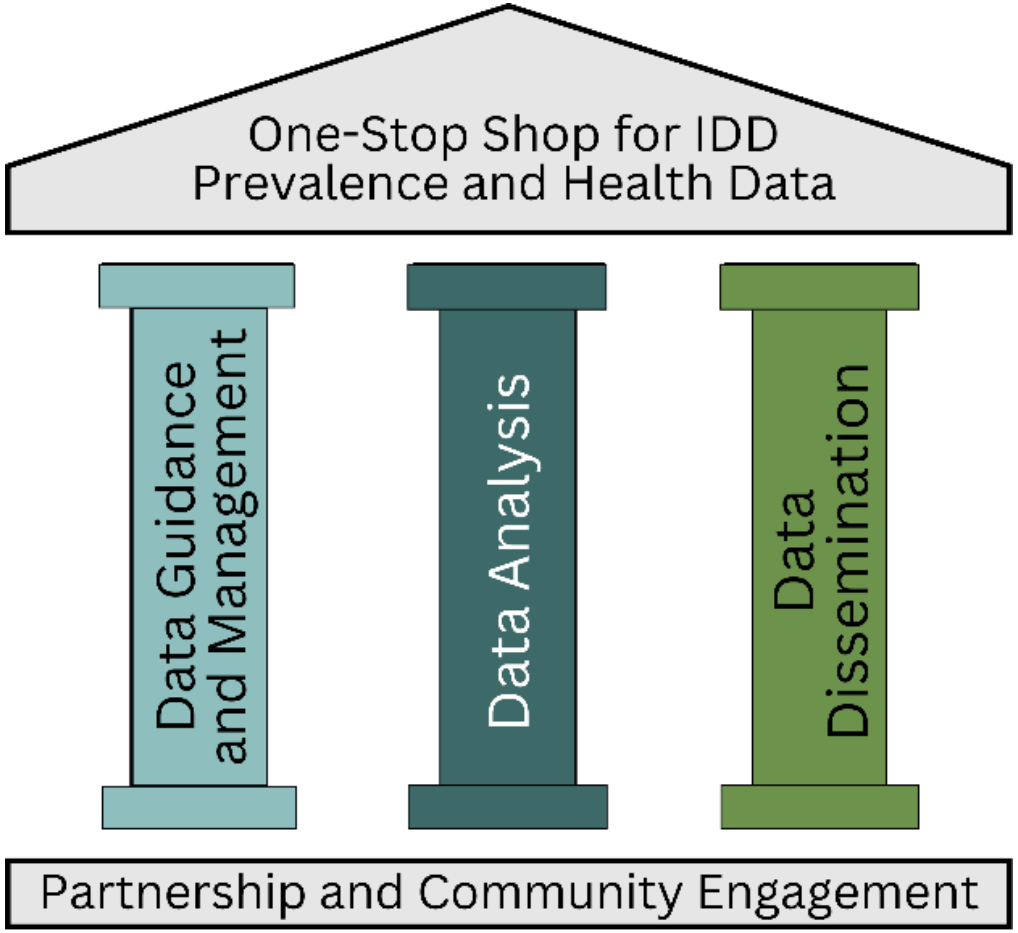
- **Review information** about the activities of other Coordinating Centers of Excellence
- **Talk to subject matter experts**, especially people with IDD, about the priorities for the Center
- **Learn from international examples** to improve IDD data collection

Results from I/DD Counts Planning Study



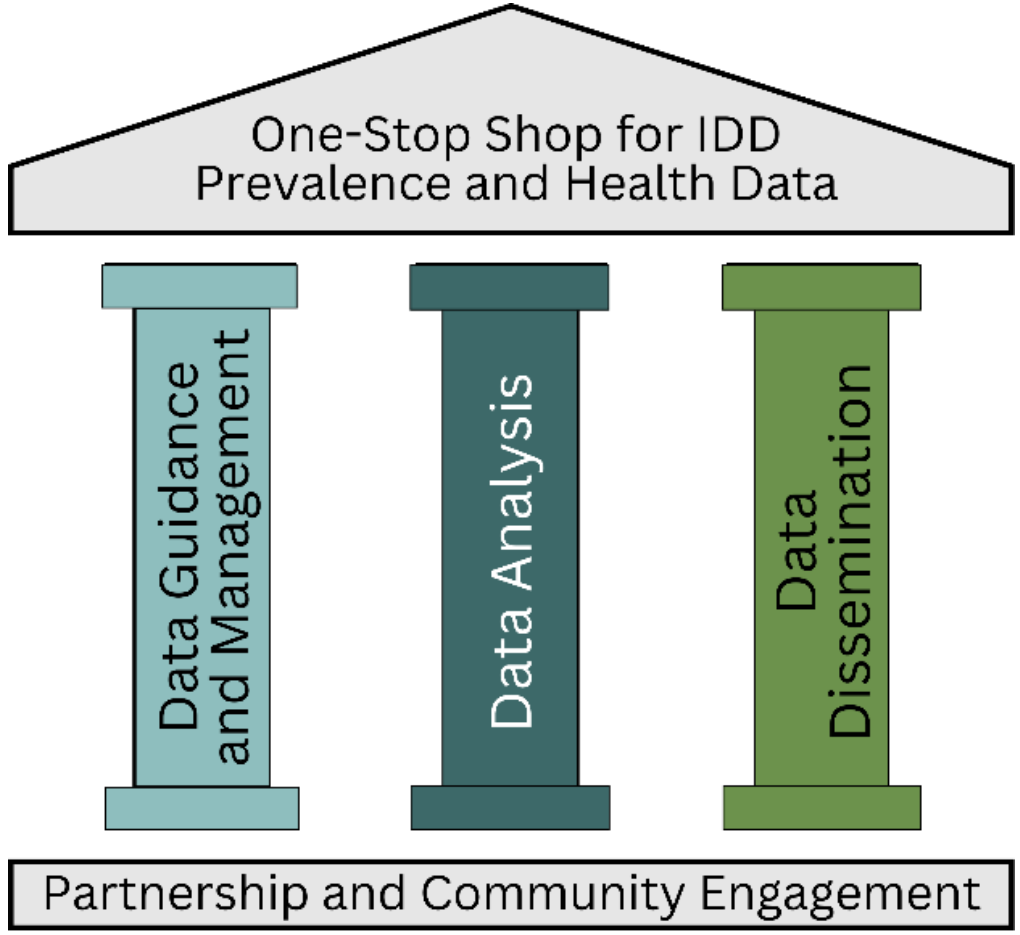
- This structure is designed for flexibility.
- Activities could be expanded over time with additional funding.
- Activities could also be adjusted as new priorities develop (ex: COVID-19).

Partnership and Community Engagement



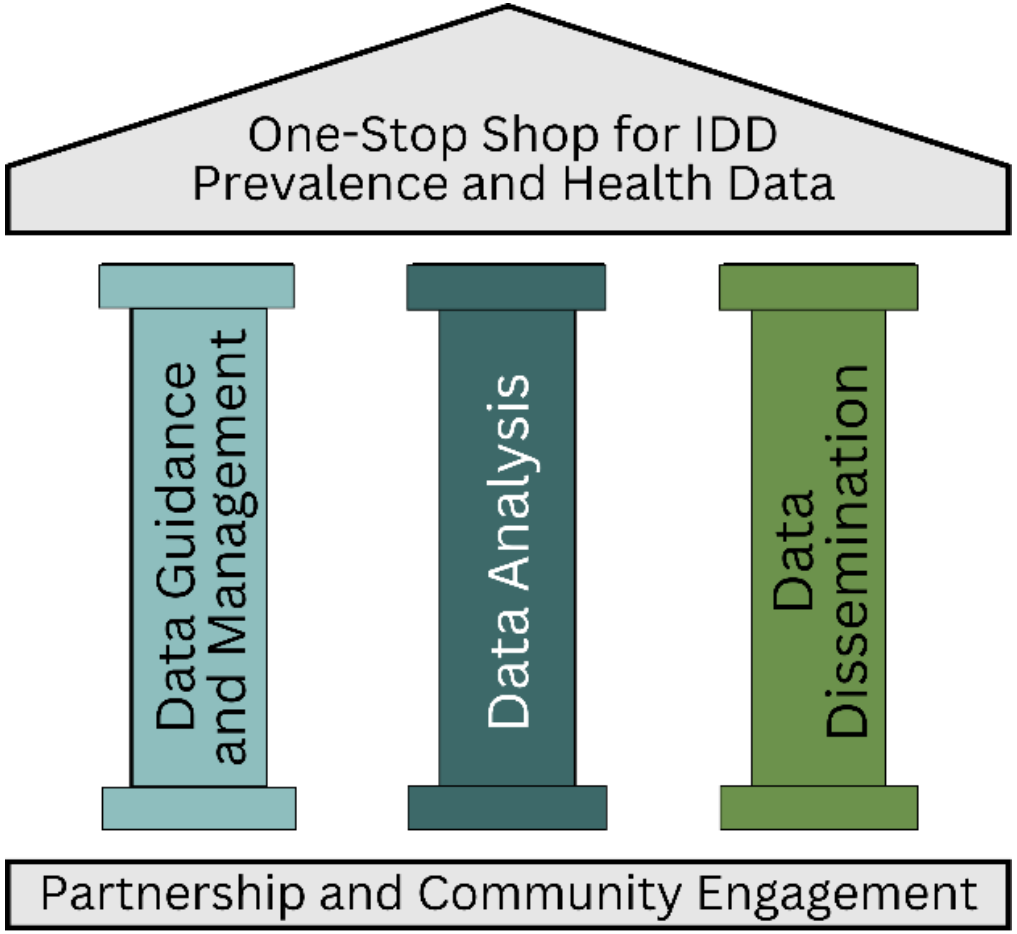
- The foundation of the Center is partnership and community engagement.
- Key activities include:
  - Having people with IDD help lead work
  - Sharing updates with community partners
  - Organizing meetings for partners to talk about data
  - Providing training to help partners improve data collection

Data Guidance and Management



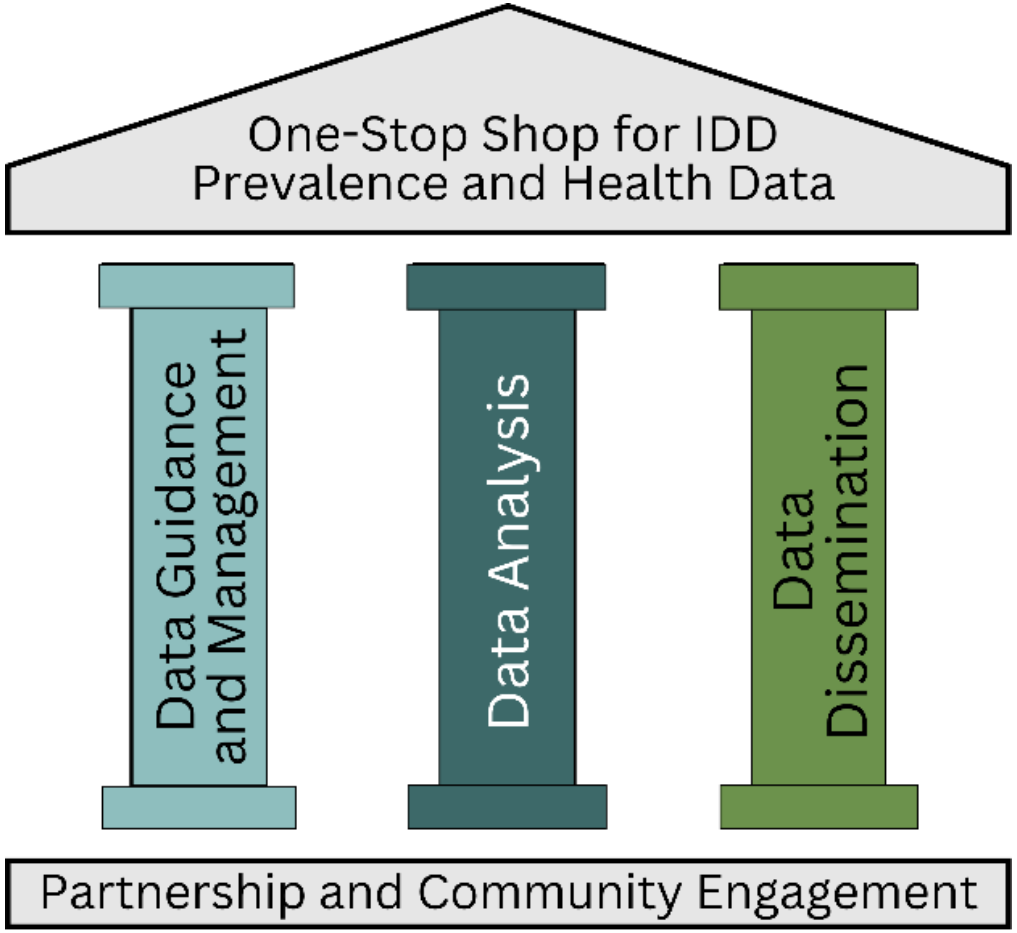
- The Center should provide clear instruction on how to collect, organize, and use IDD health data.
- Key activities include:
  - Deciding how to identify or define IDD in different data sets. This means having common definitions across studies.
  - Sharing steps and training partners to link IDD data

Data Analysis



- The Center should conduct data analysis, or look at and study data, from people with IDD.
- Key activities include:
  - Working with partners to learn how many people have IDD
  - Creating reports about the health of people with IDD
  - Provide grants to collect new data

Data Dissemination



- The Center needs to share information in ways that people can understand.
- Key activities include:
  - Improving the I/DD Counts website to include many resources about IDD and health. This is sometimes called a “Clearinghouse”
  - Creating plain language reports
  - Offering training to researchers and advocates to develop accessible resources

Other keys to success for The Center

- The Center will need support and partnership with several different government agencies to keep leading activities over time.
  - This is another way of saying that the Center needs support and partnership to be sustainable
- It will be important for the Center to have a clear mission that lays out priority activities but also room for growth
- **The Center must have leadership by and with people with IDD**

Thank you!

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