Integrated Dataset on Intellectual and Developmental Disabilities (iDIDD)

Virtual Stakeholder Meeting

November 7, 2022

1–2:30 p.m. EST

Introductions

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Meeting Introduction

- This is a listening session to learn about the project.
- We will talk about our project to create a dataset for research about people with intellectual and developmental disabilities (ID/DD).
- We will have two 10-minute breaks.
- We will hold three question and answer (Q&A) sessions over the next two days.
- Questions submitted in the chat or by e-mail will be answered during the Q&A sessions later this week.
- This meeting is being recorded.

Meeting Agenda (times are EST)

1:00–1:10 p.m.	Introductions, Background, and Objectives
1:10–1:25 p.m.	Dataset Description and Uses
1:25–1:35 p.m.	***Break***
1:35–2:00 p.m.	Stakeholder Engagement
2:00–2:10 p.m.	***Break***
2:10–2:15 p.m.	Data Privacy and Access
2:15–2:25 p.m.	State Participation
2:25–2:30 p.m.	Wrap-Up and Next Steps

Welcome Remarks

Project Description

What is the problem?

- Right now, we have data in many different places. This makes it hard to learn about the supports and services people with ID/DD use and their outcomes.

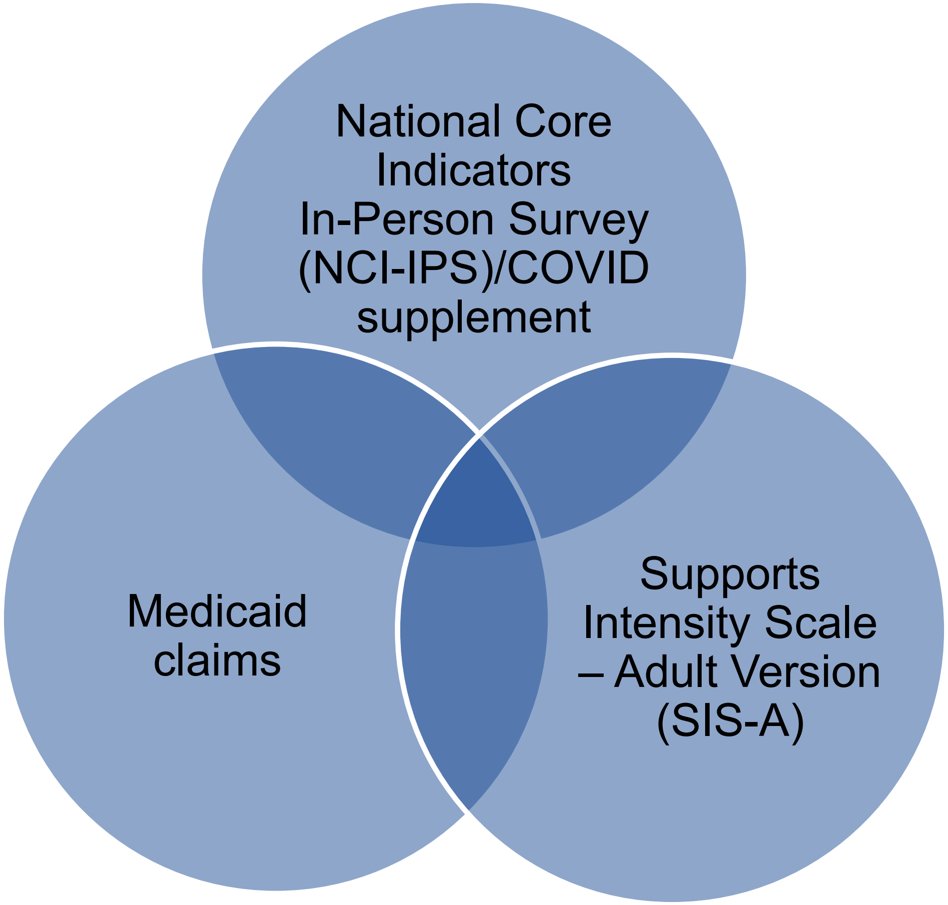
What is the goal of this project?

- We will combine data from three datasets from up to four states into one new dataset.
- The new dataset will:
  - Be available to anyone who gets permission
  - Allow users to look at outcomes over time
  - Not include names, social security numbers, phone numbers, addresses, or other identifying information
- We will provide instructions on how to use the data.
- We will show other states how to combine their data.

Dataset Description and Uses

Dataset Description

We will combine data from three datasets into one dataset:



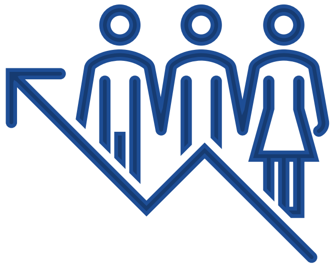
National Core Indicators In-Person Survey (NCI-IPS)/COVID supplement

Medicaid claims

Supports Intensity Scale – Adult Version (SIS-A)

Dataset Description, cont.

- We will not collect new information; these datasets already exist.
- We will not talk to people receiving services, their doctors, service providers, or direct support professionals.
- The dataset will not include any information that can be used to identify people, such as names, Social Security numbers, phone numbers, or addresses.



Dataset Description: National Core Indicators

- NCI is a survey that asks people with ID/DD about services that they receive and their life experiences.
- It asks what they think about where they live, their relationships, their ability to make choices and participate in the community, and more.
- NCI surveys are conducted in person.
- The goal of NCI is to measure and track performance of ID/DD agencies nationally.
- The dataset includes standard measures to assess outcomes of services provided.
- For example, NCI reports show the percentage of people who have input in choosing where they live.

Dataset Description: Supports Intensity Scale – Adult Version

- SIS-A is a tool that evaluates the support needs a person requires to achieve their goals.
- It measures support needs in the areas of home and community living, employment, social activities, and more.
- It is an interview with the individual receiving services and those who know them well.
- Trained interviewers conduct the interview.

Dataset Description: Medicaid Claims

- These data include information about individuals enrolled in Medicaid.
  - Medicaid provides health coverage to people with disabilities and low-income individuals.
- The information is collected by a state's Medicaid agency.
- Information includes:
  - Number and types of visits to the doctor, hospital, or emergency room
  - Reasons for visits
  - What was done during the visits
  - How much was paid for the visit

How the New Dataset Might be Used

- The new dataset can be used to answer many research questions.
- Examples include:
  - Is there a connection between an individual’s home and community-based services (HCBS) needs, their Medicaid HCBS spending, and their ability to participate in community living activities?
  - How do self-directed HCBS impact the independence, well-being, and health of people with ID/DD and their families?
  - Is there a connection between an individual’s HCBS needs, where they live, and COVID-19 infection?
  - How often do people with ID/DD use health care?
  - What are the medical costs of ID/DD patients?

Break—Please return in 10 minutes!

Stakeholder Engagement

The Quest for Truly Engaged Research—The Virginia Costs and Outcomes Project

Plan for the Presentation

- Background on our project
- Why engagement is fundamental to our work
- How we are working to achieve our goals (specific strategies)

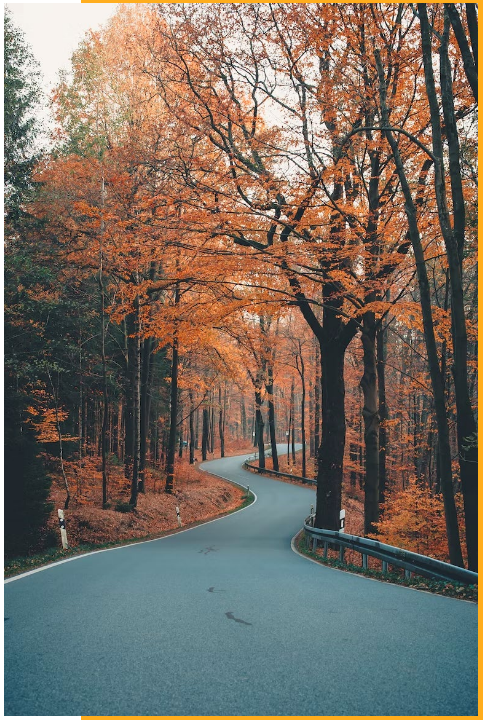
Quotation—Louis Braille

“We must be treated as equals—and communication is the way we can bring this about.”

– Louis Braille

Project Background

- The start….system change and mentorship
- Collaborations and partnership
- Pilot then applied for funding (two NIDILRR field-initiated grants)
- First stage of the project was focused on efficacy



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Key Audiences

- State agency partners
- People with ID/DD and families
- Academic audience
  - Example: Machine learning

How Do We Make This Project Truly Engaging?

- We engaged the academic audience.
- We made some good headway with the state audience (still need to do more!).
- We have made a dedicated effort toward the engagement of people with IDD & families (still need to do more!).

Some Strategies That Have Helped

- Hiring an engagement specialist

- Embracing social media as a legitimate form of information dissemination
  - Facebook Live
  - TikTok

- It is sometimes slow work getting to know people and fitting yourself into their rhythms: see how research fits into their lives

Understanding the WHY of Engagement

- Mining for lived experiences
- Grounding our work in lived experiences

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Mining for Lived Experiences

- Understanding what is important *to* people with disabilities
- Understanding what is important *for* people with disabilities

Grounding Our Work

Ensuring lived experiences are where we begin

Making findings accessible

So What Do We Do?

- Slow down
- Establish shared language
- Listen

Slow Down

- Plan for a longer research timeline to allow time for building trust and needed research knowledge
- During meetings, be aware of different ways of communicating

Language

- Avoid jargon
- Explain key terms:
  - Research
  - Data
  - Methods—especially for the project

Quotation—ALLY Alliance Member

“

> “Listen hard and listen good.”
>
> –ALLY Alliance Member

- Balance meeting agenda with members’ interests
- Prepare to adapt research agenda based on feedback

Break—Please return in 10 minutes!

Data Privacy and Access

Data Privacy

- States will link the three datasets.

- Any personal information that can be used to identify a person will be removed.

- We will make sure that individuals cannot be identified in the final dataset.

Data Access

- The final dataset will be available from a data library.
- To use the data, users will have to get permission.
- Getting permission will require users to:
  - obtain approval from an Institutional Review Board;
  - prepare a research plan;
  - submit a data protection plan; and
  - agree that attempting to identify participants is a crime.

State Participation

Why Should States Participate?

- Learn more about the health care needs, use, and outcomes of persons with an ID/DD in your state.
- Reduce gaps in needed services, improve health outcomes, address unmet health care needs.
- Use various data sources to help decide what the top care priorities for this population are.
- Play a part in improving technical skills of states to analyze data from multiple sources.
- Help state agencies collaborate with each other.
- Establish collaborations with other states.

State Selection Criteria

Criteria for selecting states to participate in the project

#	Criteria	Importance	Required?
1	Participation in 2018–2019 NCI-IPS	High	Yes
2	Use of SIS-A	High	Yes
3	Requirements and protocols in place to obtain NCI participant consent to link NCI data to other data	High	No
4	Participation in NCI COVID-19 supplement	Medium	Yes
5	Other experience with administrative data linkages	Low	No

State Selection Criteria, cont.

Additional criteria recommended by our experts

#	Criteria	Importance	Required?
6	Quality of Medicaid data	Medium	No
7	Racial and geographic diversity	Medium	No
8	Ability to access Medicaid data	Medium	No
9	Organizational structure and departmental relationships	Medium	No

Participation Requirements for States

- Contribute to the creation of datasets with content common across all the states.
- Provide feedback on what should be included in the dataset.
- Establish collaboration agreements between RTI and the state.
- Combine the data from various sources together.
- Create final anonymous dataset.
- Attend regular meetings with RTI or other participating states.

Some funding is available to support this work.
RTI will be available to help states.

Wrap-up and Next Steps

Thank you for joining us today! You can e-mail us your feedback at IDIDD_project@rti.org or ask questions and provide feedback during one of our Q&A sessions.

Q&A Sessions

Topic	Date	Time (EST)	Registration Link
1. State participation	November 7	3:00–3:45 p.m.	https://rtiorg.zoom.us/meeting/register/tJYudeGpqDkjGtEpuupQldjsn3Tq-rMh07ld
2. People with lived experience, family members, and care providers	November 8	1:00–1:45 p.m.	https://rtiorg.zoom.us/meeting/register/tJApceqrpzojHNxamHS5FafimCZPitBDlLc9
3. Data and privacy	November 9	1:00–1:45 p.m.	https://rtiorg.zoom.us/meeting/register/tJAlduygrTsvHNcUsEmok69AizTZMMTaisUs

Thank you!

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