2026

I/DD COUNTS

DATA SUMMIT NOTEBOOK

A Roadmap for Better IDD Data

September 21–22, 2026

Holiday Inn Washington Capitol – National Mall
550 C Street SW • Washington, DC 20024

Full Agenda: Monday, September 21

Breakfast served 8:00-9:00am

Day 1: 9:00am - 4:15pm (Zoom link)

Time	Agenda Topic	Speakers
9:00 - 9:30am	**Opening Plenary: Are We There Yet?** The History of I/DD Counts, Major Milestones, and Remaining Questions	*Rebecca Hines* *Jennifer Johnson* *Kathy Cargill-Willis*
9:30 - 10:45am	**Panel 1: IDD Survey Data at a Crossroads** The goal of this panel is to describe national-level survey data. We want to learn more about how many people have IDD and how healthy they are. The panel will talk about how survey data at the state and federal level can be used for these goals.	**Moderator:** *Colleen Roche* **Panelists:** *Alixe Bonardi* *Julie Weeks* *Alicia Dixon-Ibarra* *Ari Ne'eman*
10:45 - 11:00am: Break		

Time	Agenda Topic	Speakers
11:00 - 12:15pm	**Panel 2: Maintaining Momentum with Administrative Data** The goal of this panel is to describe ways to better detect people with IDD and their health outcomes. We do this using administrative data. The panel will talk about recent work using administrative data.	**Moderator:** *Jennifer Kucera* **Panelists:** *Jeffrey Galecki* *Chip Haltermann* *Rhonda Eppelsheimer* *Eric Rubenstein* *Leanne Candura*
12:15 - 2:00pm: The Rest Stop - Lunch and Networking		
2:00 - 3:15pm	**Panel 3: Merge Ahead? Opportunities to Enhance Research Capacity** The goal of this panel is to describe efforts to grow research capacity. This can include working with state public health leaders to understand IDD health data. It can also include new studies to collect data across the lifespan.	**Moderator:** *Richard Chapman* **Panelists:** *Sherri Larson* *Susan Havercamp* *Kayte Barton* *Maggie Nilz* *Lindsay DuBois*
3:15 - 3:30pm: Break		
3:30 - 4:15pm	**Reflection Time and Day 1 Wrap Up**	*Alixe Bonardi* *Gloria Krahn*

Full Agenda: Tuesday, September 22

Breakfast served 8:00-9:00am

Day 2: 9:00am - 12:30pm (Zoom link)

Time	Session	Speakers
9:00 - 9:15am	**Back on the Road: Day 2 Welcome**	*Alixe Bonardi* *Gloria Krahn*
9:15 - 10:30am	**Panel 4: Navigating Challenges to Increase Data Use and Dissemination** The goal of this panel is to describe recent efforts to use IDD data. This includes training people with and without IDD on data and sharing data in more accessible ways.	**Moderator:** *Tia Nelis* **Panelists:** *Katie McDonald* *Teresa Moore* *Shea Tanis* *Jules Good*
10:30 - 10:45am	**Break**	

Time	Session	Speakers
10:45 - 12:00pm	**Panel 5: Accelerating Improvements in IDD Data to Inform System Change Efforts** The goal of this panel is to describe creative efforts happening to improve IDD data at the federal, state and local level. The panel will also explore ways to better use data for good policies.	**Moderator:** *Christine Brown* **Panelists:** *Nassira Nicola* *Nik Koscielniak* *Mai Pham* *Melissa Parisi*
12:00 - 12:30pm	**Closing Plenary: The Next Leg of the Journey** The closing plenary will summarize themes from the Summit and the most immediate next steps needed to improve IDD data.	**Moderators:** *Nicole LeBlanc and Heather Young* **Panelists:** *Rebecca Hines* *Gloria Krahn* *Alixe Bonardi*

Summit Purpose and Goals

The purpose of the Summit is to strengthen national health data on people with intellectual and developmental disabilities (IDD). The Summit brings together people with IDD, researchers, federal agency staff, and others who work with IDD health data.

Summit participants will:

- Learn about updates to IDD health data since the last Summit in 2022.
- Develop connections and support partnerships among the disability community, agencies, and researchers.
- Create opportunities and action steps to improve IDD health data.

This notebook is designed to help you participate, reflect, and keep track of ideas throughout the Summit. Use it in whatever way works best for you.

Community Agreements

These agreements were developed by the Summit's planning committee.

- ✓ We will create space for reflection and different ways of participating.
- ✓ Ask someone to repeat or explain something in a different way when needed.
- ✓ Use plain language and define complex words and ideas.
- ✓ Speak from your own experience and make room for others.
- ✓ Respect privacy when people share personal experiences.
- ✓ Focus on learning, partnership, and practical next steps.

Notes for Summit Participation

You can use this page to write down ideas about:

- What you want to understand better
- Questions you want answered before the Summit ends
- What you want to contribute to the Summit
- Accessibility or participation notes for yourself

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You can use it for additional notes if needed.

Opening Plenary: Are We There Yet?

Use this QR code if you want to submit your responses to the questions below.

The History of I/DD Counts, Major Milestones, and Remaining Questions

Speakers: Rebecca Hines, Jennifer Johnson, Kathy Cargill-Willis

Listen for:

- What has gotten better? What still needs to improve?
- Examples of work that is going well.
- What are the gaps? What important things are still not answered?
- Ideas that can help us decide what to do next.

Use the box below for notes. You may want to reflect on:

- What was the most important idea from this panel? What stood out to you?
- What would you like to learn more about?
- Any questions you still have?

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Panel 1: IDD Survey Data at a Crossroads

The goal of this panel is to describe national-level survey data. We want to learn more about **how many people have IDD** and how **healthy they are**. The panel will talk about how survey data at the state and federal level can be used for these goals.

Moderator: Colleen Roche

Panelists: Alixe Bonardi, Julie Weeks, Alicia Dixon-Ibarra, Ari Ne'eman

Listen for:

- What should improve in survey definitions, questions, sampling, and participation?
- Examples of work that is going well.
- What are the gaps? What important things are still not answered?
- Ideas that can help us decide what to do next.

Use the box below for notes. You may want to reflect on:

- What was the most important idea from this panel? What stood out to you?
- What would you like to learn more about?
- Any questions you still have?

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Panel 2: Maintaining Momentum with Administrative Data

The goal of this panel is to describe ways to better detect people with IDD and their health outcomes. We do this using administrative data. **Administrative data is sometimes called program data.** The panel will talk about recent work related to using administrative data.

Moderator: Jennifer Kucera

Panelists: Jeffrey Galecki, Chip Haltermann, Rhonda Eppelsheimer, Eric Rubenstein, Leanne Candura

Listen for:

- How can program and system data identify people with IDD more accurately and responsibly?
- Examples of work that is going well.
- What are the gaps? What important things are still not answered?
- Ideas that can help us decide what to do next.

Use the box below for notes. You may want to reflect on:

- What was the most important idea from this panel? What stood out to you?
- What would you like to learn more about?
- Any questions you still have?

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Panel 3: Merge Ahead? Opportunities to Enhance Research Capacity

The goal of this panel is to describe efforts to grow research capacity. This means we want people to have **skills and tools they need to do research with IDD data**. This can include working with state public health leaders to understand IDD health data. It can also include new studies to collect data across the lifespan.

Moderator: Richard Chapman

Panelists: Sherri Larson, Susan Havercamp, Kayte Barton, Maggie Nilz, Lindsay DuBois

Listen for:

- What partnerships and methods could strengthen IDD data environments and research capacity?
- Examples of work that is going well.
- What are the gaps? What important things are still not answered?
- Ideas that can help us decide what to do next.

Use the box below for notes. You may want to reflect on:

- What was the most important idea from this panel? What stood out to you?
- What would you like to learn more about?
- What questions do you have that better research capacity can address?

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Panel 4: Navigating Challenges to Increase Data Use and Dissemination

The goal of this panel is to describe recent efforts to use IDD data. This includes **training people with and without IDD on data** and sharing data in more accessible ways.

Moderator: Tia Nelis

Panelists: Shea Tanis, Jules Good, Teresa Moore, Katie McDonald

Listen for:

- How can better data reach communities, decision-makers, and people with IDD?
- Examples of work that is going well.
- What are the gaps? What important things are still not answered?
- Ideas that can help us decide what to do next.

Use the box below for notes. You may want to reflect on:

- What was the most important idea from this panel? What stood out to you?
- What would you like to learn more about?
- Any questions you still have?

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Panel 5: Accelerating Improvements in IDD Data to Inform System Change Efforts

The goal of this panel is to describe creative efforts happening to improve IDD data at the federal, state and local level. The panel will also explore ways to better use data for good policies.

Moderator: Christine Brown

Panelists: Nassira Nicola, Nik Koscielniak, Mai Pham, Melissa Parisi

Listen for:

- How can innovation at federal, state, and local levels improve policy, programs, and funding decisions?
- Examples of work that is going well.
- What are the gaps? What important things are still not answered?
- Ideas that can help us decide what to do next.

Use the box below for notes. You may want to reflect on:

- What was the most important idea from this panel? What stood out to you?
- What would you like to learn more about?
- Any questions you still have?

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Closing Plenary: The Next Leg of the Journey

The closing plenary will summarize themes from the Summit and the most immediate next steps needed to improve IDD data.

Moderators: Nicole LeBlanc and Heather Young

Panelists: Rebecca Hines, Gloria Krahn, Alixe Bonardi

Listen for:

- What should happen next, and who needs to be involved?
- What are the gaps? What important things are still not answered?

Use the box below for notes. You may want to reflect on:

- What was the most important idea from this panel? What stood out to you?
- What would you like to learn more about?
- Any questions you still have?

Click or tap here to enter text.

What I Am Hearing Across Sessions

Ideas that are showing up more than once

Click or tap here to enter text.

Important differences or tensions

Click or tap here to enter text.

Whose perspective may still be missing?

Click or tap here to enter text.

People and Connections

Name	Organization	What we discussed	Follow-up

Resources to Revisit

Reports, articles, data sources, tools, or examples

Click or tap here to enter text.

Stay Connected

Use these links after the Summit to share feedback and return to the materials.

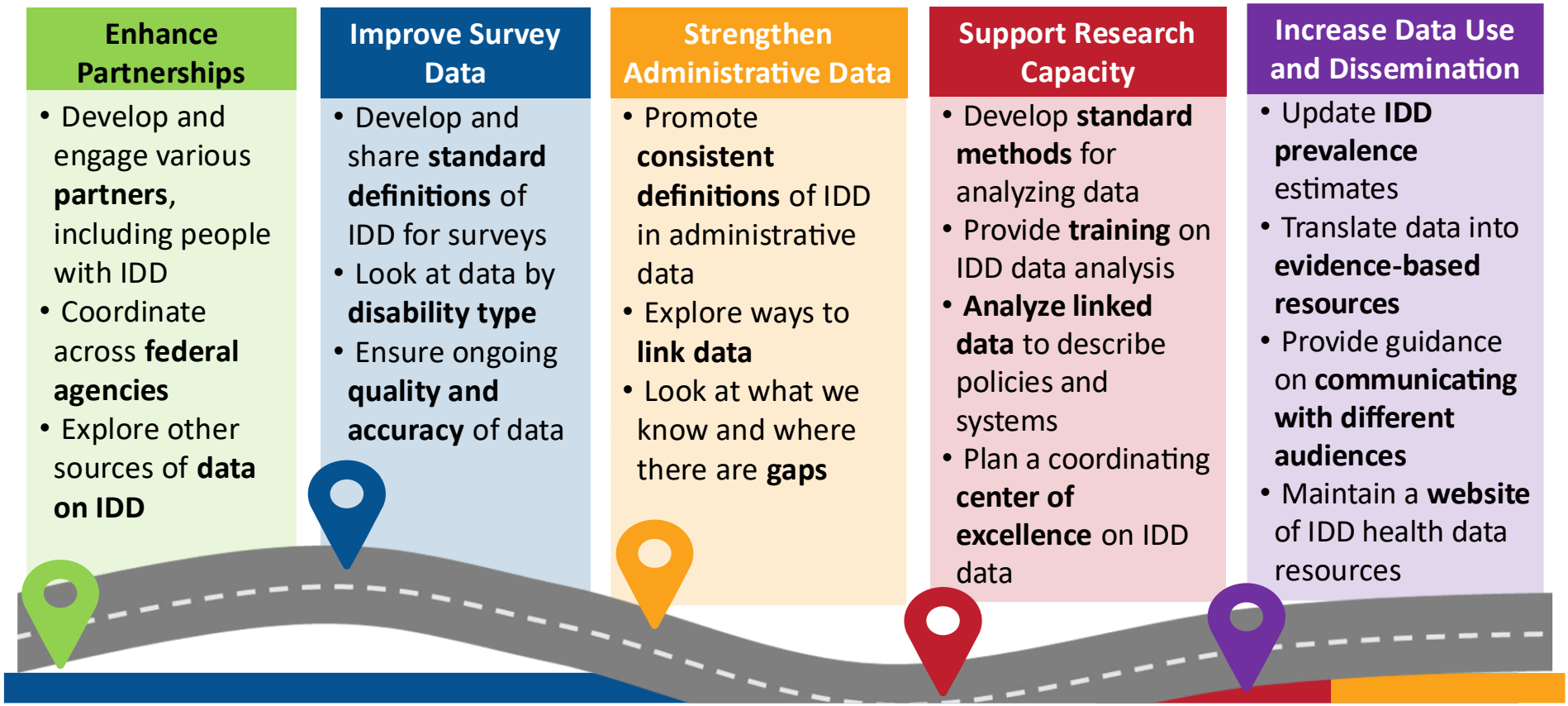
SUMMIT SURVEY	SUMMIT RESOURCES
Tell us what worked and what should happen next.	Find slides, tools, references, and other materials on the HSRI website.

Thank you for helping improve data about people with IDD.

This material describes work supported by the Administration for Community Living. Its contents are the responsibility of the presenters and do not necessarily represent official views.

I/DD Counts: A Roadmap for Better IDD Data

The Roadmap for Better IDD Data was developed after the 2019 I/DD Counts Summit and revised after the 2022 Summit.



A video explaining the roadmap in more detail can be found here or by using the QR code: https://canva.link/gc5iyhffdnqj55h