

2026 NCI-IDD ANNUAL MEETING Day 1

September 23, 2026

Welcome

Mary Sowers, Executive Director – NASDDDS

NASDDDS team

HSRI NCI team

Washington Welcome

Introductions

- Name
- Role
- State
- Connection with NCI-IDD (What do you do, related to NCI-IDD?)
- One of the following (optional)
 - If you had to come up with a book title to best describe NCI in your state, what would it be?
 - Example: “The Long and Winding Road” or “Raise Every Voice”
 - Using one sentence, what is a plot twist your team has navigated this year?

What Topics Would You Like to Discuss at NCI Meeting?



Federal Policy Update

NCI-IDD IPS Implementation Challenges

Increasing Participation in Family Surveys

Use of NCI Data

Surveyor Hiring and Retention

Meeting Agenda - September 23

- Federal Updates
- One Slide Challenge, Part 1
- Getting NCI-IDD data to CMS for HCBS QMS on behalf of states.
- Setting and fulfilling outcome goals based on NCI
- Community Café
- NCI State of the Workforce Cross Population Survey
- California: A Statewide Partnership
- AI and Technology Discussion
- One Slide Challenge, Part 2
- Dinner

Meeting Agenda -September 24

- Day 2 overview/instructions
- Response Rates: Getting to Yes
- Surveyor Recruitment and Retention
- ODESA 2.0: Update and Feedback
- Improving the Survey Experience for All Respondents
- Wrap Up

NCI-IDD Next Steps: How to Move Forward

NCI-IDD Annual Meeting September 23-24, 2026

Cool ideas to take back to my state Innovations or Approaches to Adapt	Questions/More Information Needed Topics, Tools or Data to learn more about
People in my state to talk to	People in other states to talk to

NCI in Action

Advancing Quality, Accountability & Innovation



SUPPORTING FEDERAL QUALITY REPORTING

Working closely with CMS to enable states to report NCI-IDD In-Person Survey measures included in the HCBS Quality Measure Set (HCBS QMS) for Money Follows the Person (MFP) grantee states.

1



MODERNIZING WORKFORCE MEASUREMENT

Developing a consolidated, cross-population State of the Workforce (SoTW) tool for IDD and Aging, including a new component to support HCBS Access Rule Payment Adequacy Reporting requirements.

2



STRENGTHENING THE NCI VALUE PROPOSITION

Communicating the return on investment (ROI) of NCI and equipping states with information to support quality improvement, accountability, performance management, and policy development.

3



DEMONSTRATING THE VALUE OF HCBS

Leveraging NCI data to demonstrate outcomes and the impact of home and community-based services to inform policy decisions and advance investments in systems that promote choice, inclusion, and well-being.

4



TURNING DATA INTO ACTION

Developing data briefs, dashboards, and resources, and providing technical assistance that help states translate NCI findings into meaningful quality improvement and system change.

5



DELIVERING MEMBER SERVICES

Providing ongoing support to member states through:

- Office hours for SoTW changes
- Federal updates that impact NCI
- TA on survey implementation
- TA on data use and quality improvement

6



NCI continues to evolve alongside the changing HCBS landscape—helping states meet emerging federal requirements while advancing person-centered quality improvement through trusted, actionable data.

Federal Updates



Federal Updates

Ensuring Access to Medicaid Services
Final Rule

H.R.1, One Big Beautiful Bill Act

Federal Policy Update

NCI-IDD Annual Meeting

September 2026

Access Rule

Implementation in progress

- HCBS QMS Reporting in 2028 – including select NCI-IDD IPS measures
- 2028 HCBS QMS 12/31/26
- Interested Parties Advisory Council (IPAG) is on hold from an enforcement standpoint while CMS reconsiders how it should work
- Exercise of Enforcement Discretion for Requirements for a Medicaid Fee-For-Service (FFS) Grievance System for Home and Community-Based Services Until December 2027

More to come on Payment Adequacy Reporting and State of the Workforce

Access Rule cont.

- Anticipating Notice of Public Rule Making (NPRM) very soon.
 - Aligning all incident management component dates with due date of incident management system – 2029
 - Removing requirement for Payment Adequacy 80/20 compliance

More to come on Payment Adequacy Reporting and State of the Workforce

One Big Beautiful Bill Act (H.R. 1 / P.L. 119-21)

Things to know

One Big Beautiful Bill Act (H.R. 1 / P.L. 119-21)

CMS refers to Public Law 119-21 as the Working Families Tax Cut Legislation

The law includes

- Community Engagement
- 1915(c)(11) waiver option
- Program Integrity

Community Engagement

Beginning January 1, 2027, states must condition eligibility for applicable individuals on demonstrating community engagement unless the state implements sooner.

Who the Rule Applies To

- **Age group:** Adults between 19 and 64 years old.
- **Coverage group:** Individuals in the Medicaid adult expansion group or specific section 1115 demonstration waivers.
- **Requirement:** Must complete at least 80 hours per month of qualifying activities (such as work, community service, education, or work programs) or earn an equivalent income
- **Qualifying pathways:** Include work, community service, participation in a work program, education at least half-time, combinations of activities, and specified income-based pathways.

Exclusions

Medically Frail Exclusion:

Individuals with specified physical, mental, behavioral health, or disability-related conditions are excluded when the **condition significantly impairs their ability to comply with the community engagement requirement.**

Caregiver exemption: Under H.R. 1/P.L. 119-21, a person is excluded from the Medicaid community-engagement requirement if they are the: parent, guardian, caretaker relative, or family caregiver of a dependent child age 13 or younger
OR a disabled individual.

New 1915(c) Waiver Option

- Enacted July 4, 2025, Section 71121 of the Working Families Tax Cut Legislation (WFTCL) added paragraph (11) to Section 1915(c) of the Social Security Act, and it:
- Authorizes a new 1915(c) HCBS waiver option, referred to by CMS as 1915(c)(11), created to provide HCBS to individuals who do not meet the traditional institutional level of care (LOC) requirement under Section 1915(c)
- Provides \$100 million to states to support state systems to deliver HCBS under Section 1915(c) or under Section 1115

1915 (c)(11): Things to Know

- States establish needs-based eligibility criteria; institutional level-of-care criteria must remain more stringent.
- The new waiver may not increase wait times for individuals who meet institutional level of care to receive HCBS waiver services.
- States must meet cost, service-availability, and data-reporting requirements.
- The authority creates a new opportunity to support people before their needs rise to an institutional level of care and meet the needs of people who do not meet ILOC.
- For IDD systems: key design questions include who should qualify, what services should be available, how c(11) interacts with existing waivers and waiting lists, and how states will measure outcomes.

WHY NOW

Federal oversight of HCBS is escalating

Over the past several months, a coordinated federal response across CMS, Congress, HHS-OIG, and the Department of Justice has emerged around Fraud, Waste and Abuse (FWA). HCBS and personal care programs are named repeatedly as the highest-risk category.



14 states

RECEIVED LETTERS OF INQUIRY

CMS letters to 4 states and House Energy & Commerce letters to 10 states requested program integrity documentation.



HCBS first

HIGHEST-RISK CATEGORY

Spending growth in personal care and waiver services drew the high levels of scrutiny.



Multi-branch

COORDINATED POSTURE

A DOJ National Fraud Enforcement Division, a White House task force, and HHS-OIG reviews now operate in parallel.

What the state inquiries focus on

Common themes cited across CMS and Congressional letters to 14 states.



HCBS & personal care

Self-attestation, fictitious caregivers, and billing for people deceased, hospitalized, or out of state.



NEMT

"Ghost rides," mileage and toll inflation, and rapid spending growth.



ABA services

Fast-growing autism services flagged as high-risk for undetected fraud, waste, and abuse.



Behavioral health & SUD

Upcoding, services not rendered, unlicensed clinicians, fabricated records.



Eligibility & enrollment

Broad eligibility, weak fiscal intermediary oversight, infrequent provider site visits.



EVV Gaps & spending growth

Electronic visit verification gaps; spending outpacing enrollment.

WHAT IT MEANS

Implications for I/DD, Aging, and Physical Disability systems

1

Waivers are squarely in scope

Personal care, supported living, and home health waivers match the highest-risk profiles named in every letter.

2

Self-direction draws focus

Fiscal intermediary oversight in self-directed programs is a specific Congressional area of inquiry.

3

ABA is named explicitly

States not actively monitoring ABA are warned they are likely missing fraud, waste, and abuse.

4

Screening rigor matters

Site-visit frequency by risk tier, revalidation timelines, and exemptions will be examined.

5

Growth must be explainable

Per-capita cost growth outpacing enrollment is a flag; be ready to explain the drivers.

6

EVV is implicit throughout

Demonstrating EVV implementation and data use is central wherever ghost-billing is raised.

Where NCI Can Add a Different Lens

CLAIMS / ENCOUNTERS

What was billed or paid?

CASE MANAGEMENT / PROGRAM RECORDS

What was authorized or
documented?

NCI

What does the person say
actually happened?

- NCI experience data can provide an additional signal for quality assurance and program integrity.
- Triangulating person-reported experience with plans, authorizations, claims, incident data, and provider records can help states identify patterns that warrant a closer look.

Triangulating Data for Program Integrity

No single data source tells the whole story. Looking across policy, administrative data, NCI, and workforce data helps states see where experience may not align with intent.



The value is in the pattern: gaps across these sources can signal where deeper review, quality improvement, contract monitoring, or targeted oversight may be needed.

BREAK

One Slide Challenge

One Slide Challenge

- 1) What is one exciting way you've used NCI-IDD data this year?
- 2) Share one product/resource your team has created using NCI-IDD data
- 3) How is your state using NCI-IDD State of the Workforce Data?
- 4) In your state, are there any efforts underway or planned to address racial/ethnic disparities (in outcomes, access, service utilization, etc) using NCI-IDD data?
- 5) What's your greatest accomplishment with NCI-IDD this year?

Connecticut Distributed NCI Participant Certificates



Created certificates to thank and recognize survey participants for sharing their time and experiences.



Collaborated with interns from Project SEARCH, a national job training program for people with IDD, to design, print, and mail certificates to NCI survey participants.



Many survey participants were excited to be recognized for their contribution.





How do we
inform the
community on
what NCI IPS is?

MICHIGAN DATA SPOTLIGHTS



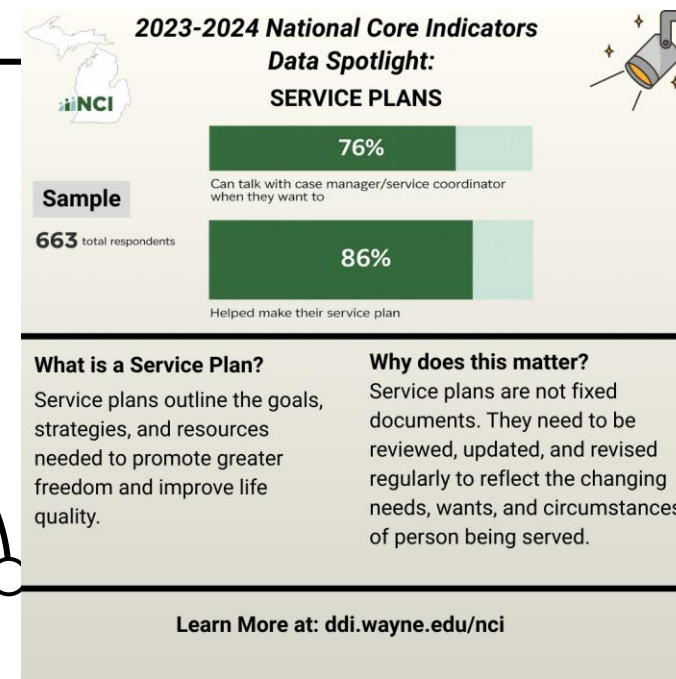
What resources do we
already have available to
us?



Where is the report
being posted & How
can we better reach
people?

What if we broke
down Data At-A-
Glance?

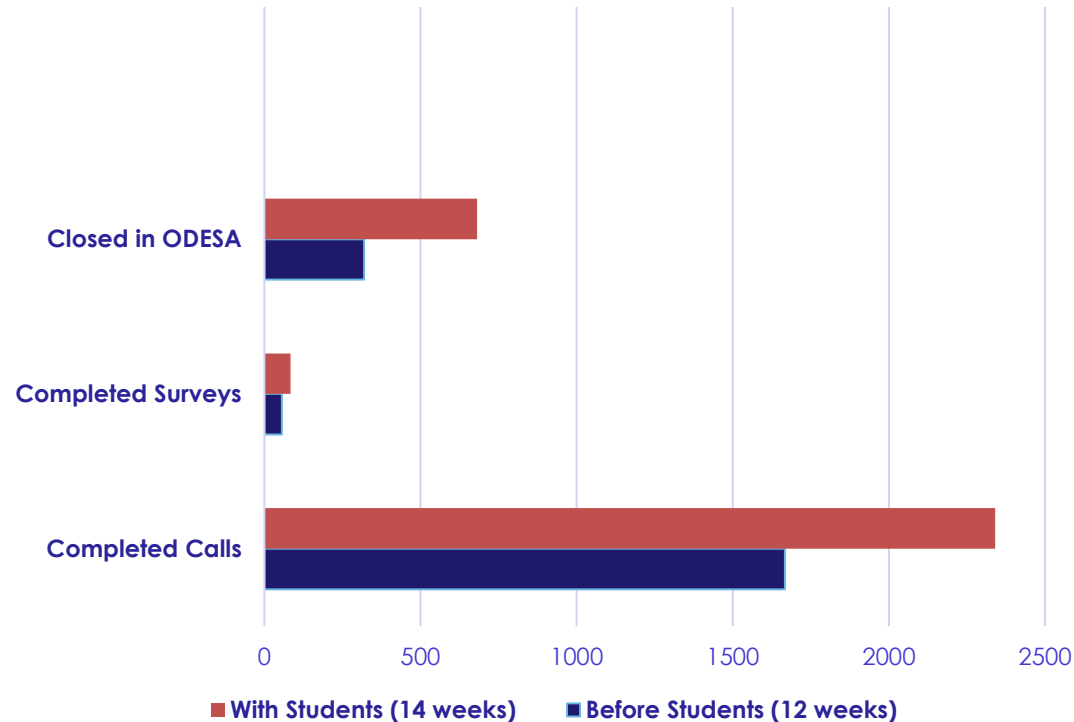
Who can help us
have a bigger reach?



Rhode Island: Student Surveyors



Progress



Highlights

- 5 student surveyors (2 bilingual)
- Enthusiastic, reliable
- Flexible work schedules
- Connection with fields of study
- Strengthen relationship with RIC
- Student experience with group homes

How Pennsylvania Will Use and Share NCI-IDD Data

New Use of Family Survey Data

- Began analysis of family survey reports to propose suggestions for system improvements to the Information Sharing Advisory Committee (ISAC)



- Made decision to administer CFS for the first time in 2026-2027
 - Will then incorporate this data into recommendations as well

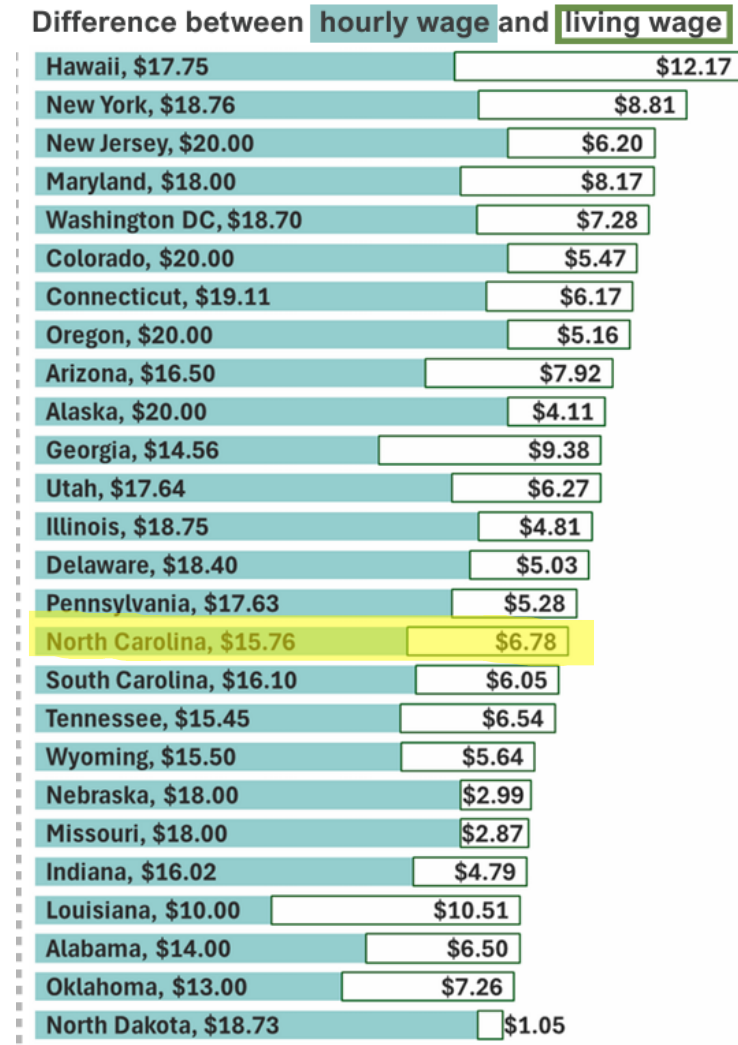
Sharing Information

- Began using the customizable template to share information
- Asked self-advocates how they want to receive data to be meaningful and useful to them
- Asked provider associations what types of reports would be useful
- Will work on combined strategies to make stakeholders more familiar with the IM4Q/NCI process



North Carolina: IDD SOTW Survey & DSP Workforce Initiatives

- NC has been actively working to improve DSP workforce to provide IDD services.
 - Initiatives include retention bonuses, competency trainings, & creating a career ladder for DSPs.
- IDD SOTW Survey serves as one of the few available datapoints to help determine efficacy of initiatives.
- Results of SOTW survey highlight different work that can be done to help improve efforts.
 - SOTW report highlighting difference between hourly wage and living wage has helped to put a new lens on current deep dive into salaries of DSPs.



New York: Increasing the State of the Workforce Response Rate

Survey Year	Response Rate	Completed / Total	Office for People With Developmental Disabilities Engagement Strategies
2023	77%	253 / 330	• Notifications of project launch • Pre-launch email for provider verification • Notifications the project is ongoing • 3 rounds of provider phone calls and reminder emails • Raising awareness • Tabling at provider and self-advocacy events • Partnering with Regional Centers for Workforce Transformation • Partnership with Division of Administration • State-specific questions focus on strategic priorities
2024	79%	258 / 327	
2025	82%	268 / 327	

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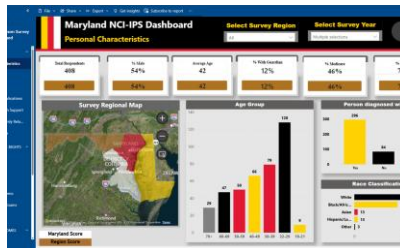
Maryland NCI Survey Dashboard



dashboard What We Built

- Public-facing dashboard
- Easy access to survey findings
- Interactive exploration

Interactive NCI-IPS Dashboard Visualization



How We'll Promote It

- Newsletters
- Coalition demos
- Social media
- Dashboard links

Expected Impact

- More data use
- Faster insights
- Better planning
- Stronger collaboration

Dashboard → Many Users → Statewide Impact

Delaware State of the Workforce

Project Lead – John McDermott

Informing Rate and Wage Decisions

Demonstrating the Impact of
Investment

Moving Towards Quality Measures

Analysis and Future State

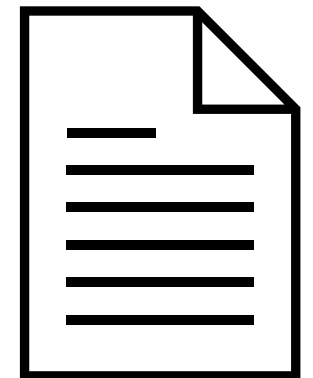
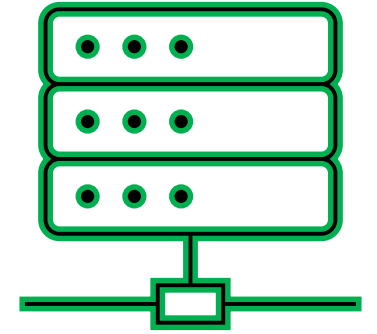
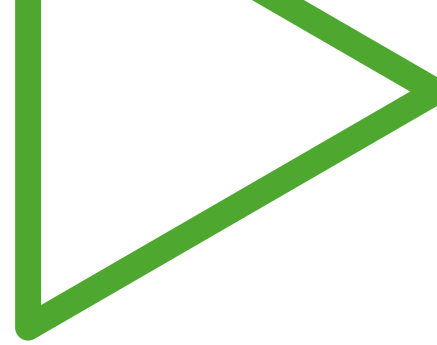


One Slide Challenge Discussion

- Do you have any questions for the states?
- What interested you specifically?
- What can you see replicating in your state?
- What barriers might you encounter?

Reporting HCBS QMS Measures to CMS for NCI States

NCI-IDD Annual Meeting
September 2026



Access Rule Refresh

Implementation in progress

- HCBS QMS Reporting in 2028 – including select NCI measures
- 2028 HCBS QMS 12/31/26
- Interested Parties Advisory Council (IPAG) is on hold from an enforcement standpoint while CMS reconsiders how it should work
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- Anticipating Notice of Public Rule Making (NPRM) very soon.
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 - Removing requirement for Payment Adequacy 80/20 compliance

More to come on Payment Adequacy Reporting and State of the Workforce

Access Rule Quality Section Overview

- States must establish performance targets, reviewed and approved by CMS, of each mandatory measure.
- The state must establish performance targets, approved by CMS, for each measure in the HCBS Quality Measure Set that are identified as mandatory, and describe the state's quality improvement (QI) strategies they will pursue to achieve performance of those measures.
 - The state may establish performance targets and QI strategies for measures that are not yet required but will be, and on populations for whom reporting is not yet required but will be.

Access Rule

Reporting on the HCBS Quality Measure Set

- Replace the minimum 86% performance level for states performance measures described in 2014 guidance
- States report every other year on all measures in the HCBS Quality Measure Set that are identified by the Secretary (following phased in approach)
- CMS will report on a subset of the measures

MFP Grantee States and Territories – HCBS Quality Measure Set Implementation

- MFP grant recipients are required to report in Fall 2026 on the HCBS Quality Measure Set every other year for their section 1915(c), (i), (j), and (k) programs and section 1115 demonstrations that include HCBS.
- For the initial implementation of the measure set, MFP grant recipients can opt to, but are not required to, stratify data for MFP participants and by demographic or other characteristics of their HCBS participants.



MFP Reporting

- **Planned Reporting Timeline**
 - NCI-IDD currently plans to transmit the applicable state level NCI-IDD IPS measure results to CMS according to the following schedule:
 - 2024–2025 NCI-IDD data: March 2027
 - 2025–2026 NCI-IDD data: June 2027
 - We will continue coordinating with CMS as these reporting dates approach and will communicate with MFP grantee states regarding any information, authorization, or other action needed to support the transmission of their data.
- 



Looking Ahead to HCBS Access Rule Reporting

- NCI-IDD also plans to use a similar approach to support states with the HCBS Quality Measure Set reporting required under the Medicaid Access Rule. As those reporting requirements are implemented, we intend to work with CMS to facilitate reporting of applicable NCI-IDD derived measures on behalf of participating states.
-
- Our goal is to continue leveraging NCI data and infrastructure to streamline federal quality reporting and reduce reporting burden for states. We will share additional information with states as the Access Rule reporting process(es) are finalized.

NCI Measures Included in the Required MFP HCBS Quality Measure Set Subset

The required MFP subset of the HCBS Quality Measure Set includes the following NCI-IDD measures:

NCI-IDD PCP-5: Satisfaction with Community Inclusion Scale

- The scale includes whether the person is satisfied with:
- How often they went shopping in the past month;
- How often they went out for entertainment in the past month;
- How often they went to a restaurant or coffee shop in the past month;
- How often they went to a religious service or participated in a spiritual practice in the past month; and
- Their level of community group participation.

NCI-IDD CI-1: Social Connectedness

- The proportion of people reporting that they do not often feel lonely.

NCI-IDD HLR-1: Respect for Personal Space Scale

- The proportion of people who report that their personal space is respected in their home.

NCI-IDD CI-1: Transportation Availability Scale

- The proportion of people who report adequate transportation, including:
- Having transportation when wanted; and
- Having transportation when needed.

As your state works with CMS on its broader MFP HCBS QMS reporting requirements, please make sure your state Medicaid office and MFP program officers are aware that NCI is working directly with CMS to report these NCI-IDD derived measures on behalf of MFP grantee states.

NCI will continue working closely with CMS and MFP grantee states to make this reporting process as streamlined as possible.

Please send us any questions

Setting and fulfilling outcome goals based on NCI

Maryland



Maryland DDA's Decision to Use NCI In-Person Survey Measures as HCBS Waiver Performance Measures

National Core Indicators 2026 Annual Meeting



The Opportunity: Timing

CMS HCBS Quality Measure Set

CMS established a standardized HCBS quality framework that included approved NCI indicators.

Maryland Waiver Amendment

Maryland already had a waiver amendment underway before the federal implementation date. DDA used that amendment cycle to revisit selected performance measures.

Opportunity to Align Early

Rather than wait for a future amendment, Maryland proposed incorporating NCI indicators into selected waiver performance measures where the measures aligned.

How Maryland Made the Decision

Review

Reviewed the CMS HCBS Quality Measure Set alongside Maryland's existing waiver performance measures.

Crosswalk

Identified where existing Maryland measures aligned with available NCI questions/indicators.

Internal Decision

DDA reviewed the opportunity, with program input and leadership decision-making.

Public Review

The proposal was included in the waiver amendment and went through the federally required 30-day public notice.

Why NCI Was a Good Fit

Participant Voice

NCI captures the lived experience of people receiving services—information that claims, authorizations, and administrative records cannot provide alone.

Existing Infrastructure

Maryland already participates in NCI and had an established survey process. Using it avoided creating a new provider-reported data collection process.

CMS Alignment

Selected NCI indicators were recognized within the CMS HCBS Quality Measure Set, providing a direct connection between participant experience and waiver quality reporting.

How We Identified the Measures: Crosswalking Maryland Measures to NCI Questions

We looked for a logical connection between the existing Maryland performance measure and an NCI indicator.

CMS DOMAIN	MARYLAND PERFORMANCE MEASURE	NCI INDICATOR UTILIZED
Service Planning	% of participants whose service plan addresses their personal goals	→ % of people who report their service plan includes things important to them
Community Inclusion	% of participants who regularly participate in community activities	→ % of people who went out for entertainment or errands in the past month
Health & Welfare	% of participants who had an annual preventative physical exam	→ % of people who report having a primary care doctor and recent visit
Rights & Respect	% of participants whose rights are protected and respected	→ % of people who report that staff treat them with respect

Where We Are Now: From Amendment to First Results

The measures have moved from proposal to implementation; Maryland is waiting for the NCI report.

The first report will establish the performance result Maryland can use for reporting, stakeholder discussion, and quality enhancement planning.



What Now? Turning Data into State Strategies

The data will identify where improvement may be needed; the strategy will follow the evidence.

- **Establish Baselines:** Use the first NCI-based performance report to establish the result..
- **Analyze:** Review the measure and available data to identify gaps, patterns, or areas needing attention.
- **Engage:** Share results with the WAC and consider stakeholder perspective on what the data may be telling us.
- **Develop Quality Enhancement Plan:** Identify targeted actions, responsible parties, timelines, and performance targets.
- **Monitor:** Use future results to assess progress and adjust strategies as needed.

A Second Opportunity: Make NCI Data Easier to Use

New Opportunities

University of Maryland Partnership

A master's-level MPH intern supported development and testing of the Maryland NCI dashboard.

Public Access

The dashboard is intended for posting on the DDA website so users can explore survey findings more easily.

Data-Informed Action

Broader access can support stakeholder questions, quality discussions, planning, and future improvement work.

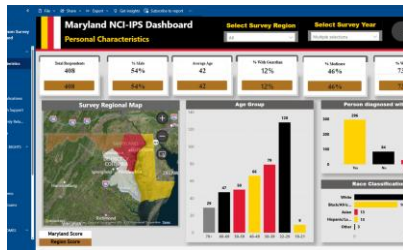
Maryland NCI Survey Dashboard



What We Built

- Public-facing dashboard
- Easy access to survey findings
- Interactive exploration

Interactive NCI-IPS Dashboard Visualization



How We'll Promote It

- Newsletters
- Coalition demos
- Social media
- Dashboard links

Expected Impact

- More data use
- Faster insights
- Better planning
- Stronger collaboration

1 Dashboard → Many Users → Statewide Impact

NCI Survey Dashboard: The Process

Step 1: In-Person Survey Interviews

First, we connect directly with people across Maryland through comfortable, in-person conversations to see how they are doing.

- **Asking Questions:** Our partner, Liberty Healthcare, conducts personal interviews to gather authentic, direct feedback.
- **Why We Do It:** Hearing straight from participants helps us learn what people truly need and how we can support them better.



NCI Survey Dashboard: The Process

Step 2: Assembling the Team

We needed a way to easily show our numbers, but we didn't have the staff to build it.



The Intern

A University of Maryland intern joined our team to build the dashboard using PowerBI.

Clean Data

The intern used clean, ready-to-use survey data provided by HSRI.

Expert Help

The Liberty team gave computer support and shared what they know from doing the surveys.

Great Ideas

The intern looked at dashboards from California and other states to find the best design ideas.

NCI Survey Dashboard: The Process

Step 3: Making the Dashboard

We wanted to make sure the survey answers were easy for anyone to read and use

One Neat Place

We put all the survey answers into one neat place. This makes sure the dashboard runs fast and doesn't get stuck.

Clear Charts

We decided which charts and graphs would show the answers best. We used clear pictures so you don't need to be a math expert.

Double Checked

We clicked all the buttons to make sure they worked right. We checked everything twice so all the charts show the correct facts.

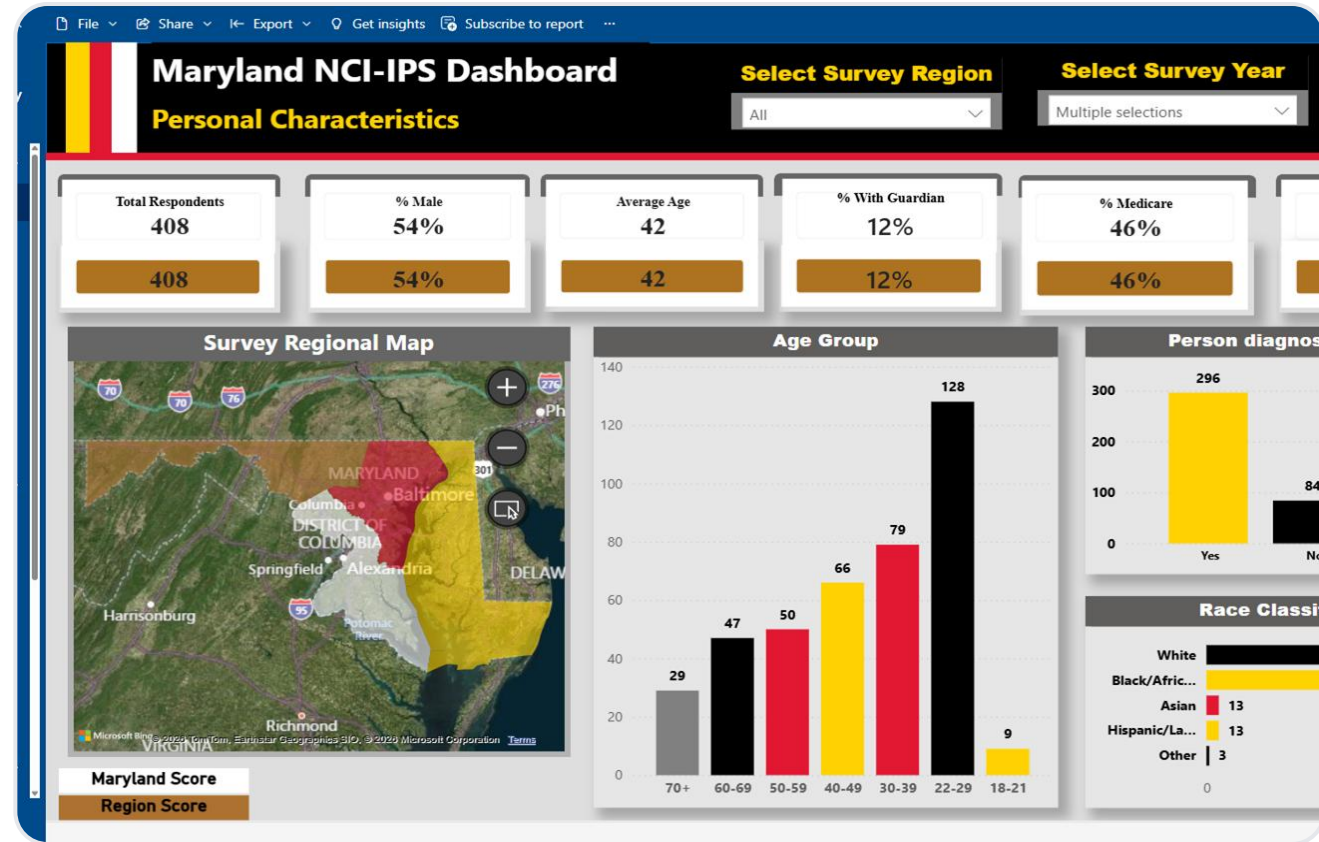
NCI Survey Dashboard: The Process

Step 4: The Public Dashboard

What We Built

We made a dashboard where anyone can see the survey answers anytime they want.

The public can click on the buttons to change the charts themselves. Once it is on the website, the public and stakeholders will not have to wait for us to send them a special report.



NCI Survey Dashboard: The Process

Step 5: Interactive Filter Controls

The dashboard features specialized buttons called "filters" to help you quickly locate the precise information you need.

Region and Age Group

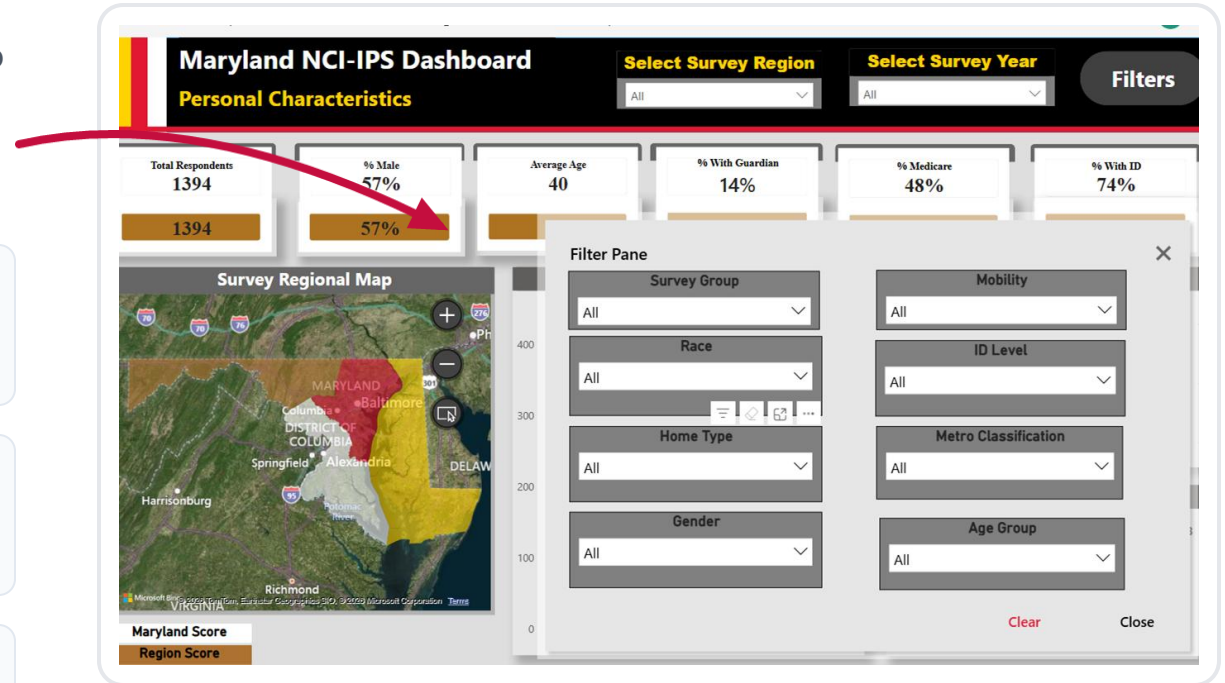
Filter results by geographical region or specific age brackets.

Race and Gender

Analyze demographic answers from specific cultural or gender groups.

Mobility and Level of Diagnosis

Narrow down by physical mobility and clinical support needs.



NCI Survey Dashboard: The Process

Step 6: Sharing with Partners

We want to make sure everyone knows this dashboard exists and how to use it.

Emails and Newsletters

We will send out an email whenever there are new numbers to look at.

Group Meetings

We will show people exactly how to click around the dashboard during our meetings.

Online Links

We will share links on social media and put it on our main website so it is easy to find.

Summary of Maryland's Experience

The strongest opportunity was connecting compliance, participant voice, transparency, and improvement.

Use the amendment opportunity

Do not wait for the deadline when an existing waiver action provides a path to align early.

Start with the outcome

Crosswalk the state performance measure to the NCI question that best represents the outcome.

Use existing infrastructure

Build from an established NCI process rather than creating duplicative reporting.

Include stakeholders

Use the waiver public notice process and continue the feedback loop by sharing results with the WAC.

Let data drive QE

Establish the baseline first, then determine targeted quality enhancement strategies.

Make the data usable

Public dashboards can extend NCI beyond reporting and into everyday quality conversations.

Questions and Contact

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QI with a *Twist*

From NCI Data to Real-World Solutions



SAME DATA.
REAL CONVERSATIONS.
SURPRISING INSIGHTS.



Discuss

What might
be behind it?



Plan

What could
we try?



Reality Arrives
Open your envelope!



Adjust
Now what?

*Same Questions.
A New Perspective.*

Better
Lives.
Brighter
Insights.

From NCI-IDD Data to Action

A 15-minute quality improvement challenge



Each table gets one NCI-IDD IPS finding.

Your challenge: figure out what you need to understand before deciding what to do.

There is no single “right” answer.

Work Through 4 Questions

You have 15 minutes.



1. WHAT DO WE KNOW?

What does the NCI result tell us? What doesn't it tell us?

3 min

2. WHAT MIGHT BE BEHIND IT?

Identify 2–3 possible reasons for the result.

4 min

3. WHAT WOULD WE TRY?

Choose one possible reason and one realistic change to test.

4 min

4. HOW WOULD WE KNOW?

What could we look at to see whether the change is helping?

4 min

Plot Twist!

Reality has arrived.



OPEN YOUR ENVELOPE

You just learned something new.

Does it change what you think is happening—or what you would try?

Adjust your plan if you need to. That's the point.

One Important Rule

Don't jump from the number straight to the solution.



“The number is low. Everybody needs training!”

Maybe. But first ask: Do we know WHY the number is low?

The goal is a thoughtful next step — not a perfect QI plan.

60-Second Report Out



Tell us your thinking, not your whole conversation.

Our NCI finding was _____.

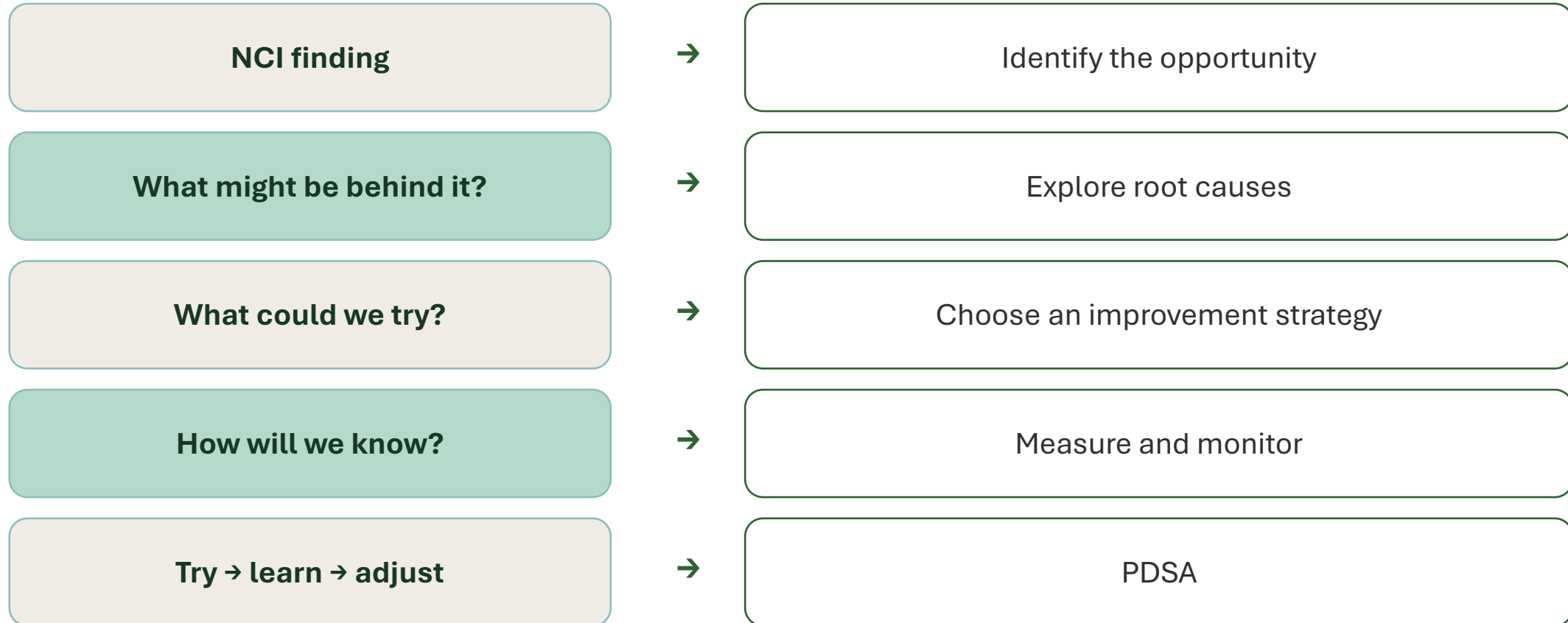
We think one possible reason is _____.

We would try _____.

We would know it was helping if _____.

Keep the test small enough that you could actually learn something from it.

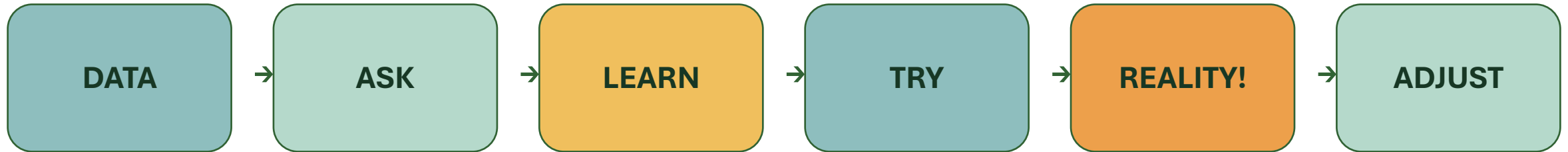
You Just Started a Quality Improvement Plan



NCI tells us where to look. QI helps us decide what to do next.

What Did the Plot Twist Teach Us?

Quality improvement is rarely a straight line.



New information is not a problem with the plan.

It is information you use to make the next test better.

LUNCH



Are there things you want to connect with other states about?

- Background Information data collection?
- Getting provider agencies on board with NCI survey administration?
- Using data for quality improvement?

Raise your hand and let everyone know and connect over LUNCH!



Community Café

Tables

- Increasing participation rates in family surveys (Cheryl)
- NCI State of the Workforce Cross Population Survey (Rosa)
- Strategies for collecting background information (BI) for the IPS (Steph)
- Access Rule (Laura)
- Virtual room (TBD)





National Core Indicators®

**NCI State of the Workforce®, CROSS POPULATION
TOOL**



Agenda

- **What is the NCI State of the Workforce Cross Population Survey**
 - Why?
 - How?
 - Who?
- **How will it work?**
- **How to prepare**

Historically, the NCI-IDD and NCI-AD SoTW have been separate surveys with separate survey cycles, separate reporting

- 1) Started with the NCI-IDD survey before NCI-AD was rolled out
- 2) Why?
 - 1) Wanted to parse out differences by population/system
 - 2) State systems are sometimes separate/"siloed"
 - 3) Terminology/service definitions/models can differ by population

REMINDER: The NCI State of the Workforce for AD is still operating in fall, 2026 to collect data on the AD workforce from 2025.



What is the Cross Population Survey?

NCI developed a single tool to be used by providers who support the IDD and/or the AD population.

What does this tool need to be able to do:

- 1) Simplify survey administration and data collection for states with providers that provide supports to various populations
- 2) Collect data needed for Access Rule Payment Reporting compliance
- 3) Retain the collection of some data by population to provide data for population specific quality improvement and program- and policy-making



DD or AD systems
can also
participate
independently.

How does it work?

- IDD state systems indicate interest to NASDDDS (done—but there’s still time!)
- AD state systems indicate interest to ADS (in progress)
- If both AD and IDD are using the State of the Workforce
 - State IDD and AD systems work together to raise awareness of the survey among providers in the state to increase buy in
 - Collaborate to create workplan. NCI sends a template to fill out which includes questions about survey administration process, responsibilities, data use, and more.
 - State IDD and AD systems together send to NCI one provider list:
 - All eligible provider agencies
 - One email address per provider agency
- State IDD and AD systems together fill out and send to NCI the list of customized language
- NCI sets each state up with a unique Verity portal. Through the Verity portal, the state sends survey invitation and monitors participation.

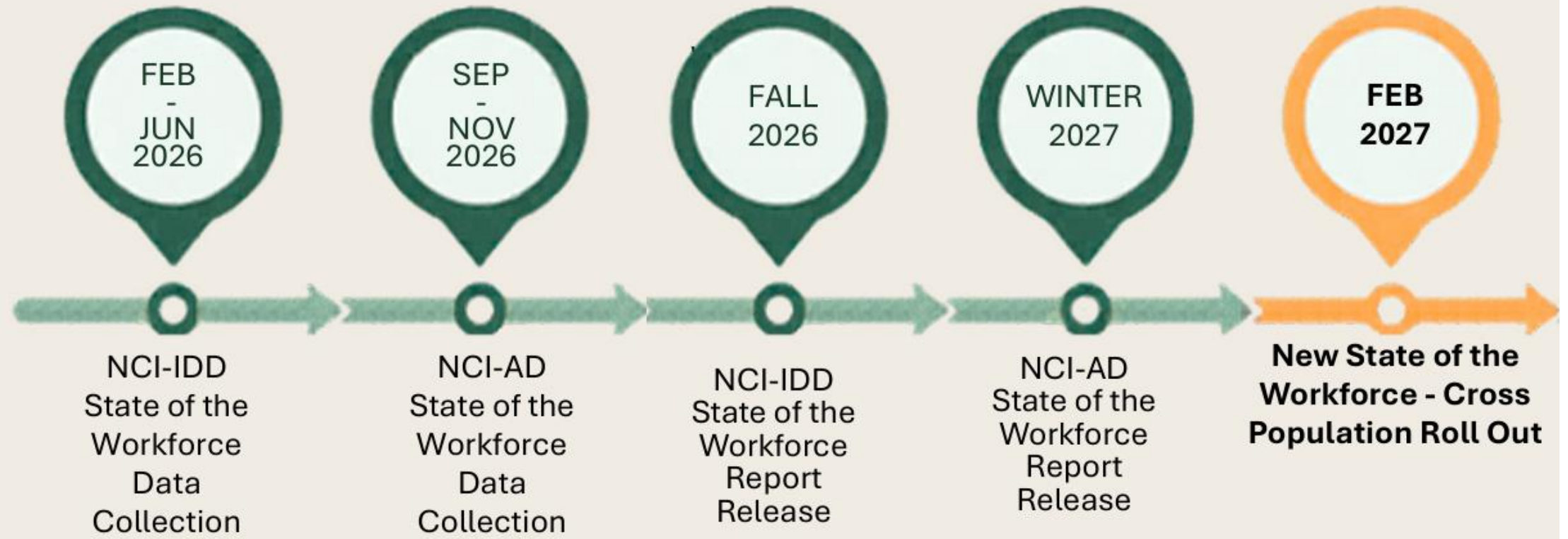


How will invoicing/payment work?

- Generally, all invoices will be sent to state IDD agencies from NASDDDS.
- States IDD agencies should have received invoices, unless other arrangements have been made with NASDDDS and/or ADvancing States. Invoices sent to IDD Directors and cc'd NCI-IDD contact
- State IDD and AD agencies should collaborate internally on sharing the costs of the SoTW membership if using across both IDD and AD
- Don't forget 50% Medicaid Administrative match
- If you need help connecting across state agencies, let us know and we can help connect!

Timeline

Now through 2026: Current IDD and AD surveys continue unchanged.



Survey administration

Which providers will take the survey?

Which providers should be part of the “list”

REMINDER: Not just HCBS – States may include other payor sources

- Medicaid Home and Community Based Services (HCBS) funding
 - 1915(c) Home and Community-Based Waivers,
 - 1915(i) State Plan Home and Community-Based Services,
 - 1915(j) Self-Directed Personal Assistance Services Under State Plan,
 - 1915(k) Community First Choice, and/or
 - 1115 Demonstration Waivers that includes HCBS)
- Medicaid ICF-ID funding
- Medicaid state plan program funding
- State-funded program funding
- Older Americans Act funding



Provider agencies should have the following type of worker on payroll:

- Any paid staff for whom the agency defines wages and benefits and who spends at least 50% of their hours doing LTSS Direct Care and Support Tasks with adults/children receiving LTSS.
- **LTSS Direct Care and Support Tasks:**
 - Support to maintain independence
 - Personal Assistance
 - Basic clinical tasks
 - Basic behavioral supports
 - Assistance with housekeeping
 - Companionship
 - Job/employment support
 - Support in the community
 - Day centers or other day activity support
 - Respite



Survey questions: PART I

- **Gathers similar information to the previous surveys.**
- **Some questions are broken out by IDD DCWs, AD DCWs or OTHER/CROSS POPULATION DCW**
 - To allow for differential reporting for continuity (somewhat)
 - Turnover,
 - Wages (starting and average)
- **Will allow for state-specific terminology**



PART II

All those who reported providing HCBS funded supports in PART I are brought to this section.

Questions related to ACCESS RULE Payment Reporting compliance

Compensation and Medicaid Payments for the following services:

- HCBS funded Homemaker Services
- HCBS funded Home Health Aide Services
- HCBS funded Personal Care Services
- HCBS funded Habilitation Services

Will allow for state-specific terminology

This section WILL include contract workers (1099, etc)



How to prepare?

- **Get the world out! State IDD and AD agencies collaborate to develop a provider outreach strategy to raise awareness and increase buy-in**
- **State AD and DD teams work together to determine how you will pull your provider list**
 - Provider agencies will be eligible if they had Direct Care Workers (DCWs) on payroll as of 12/31/2026.
 - For this survey, a DCW is defined as a paid worker who:
 - Is employed by a provider agency that defines their wages and benefits, and
 - Has a primary responsibility to provide direct care and support to the LTSS population.
- **To prepare for part II: Access Rule Payment Reporting Requirements**
 - Determine which HCBS Services fall into the four required reporting categories (personal assistance, home health aide, home maker and habilitation)
 - Develop plan to communicate with and train providers so they will be prepared to respond in 2027

More info: <https://tinyurl.com/SOTWCP>



Examples of Terminology to Customize for Provider Accessibility

(NCI will provide a template)

- HCBS waiver types: 1915(c), 1915(i), 1915(j), 1915(k), and 1115 Demonstration Waivers
- Homemaker Services
- Home Health Aide Services
- Personal Care Services
- Habilitation Services (including personal/social skill development, daily living skills, community integration, prevocational support, and behavioral habilitation)
- Self-Directed Services
- Medicaid funding types: ICF-ID, state plan programs, state-funded programs, and Older Americans Act funding



Questions?



Please contact for more information

dhiersteiner@hsri.org

lvegas@nasddds.org

rplasencia@advancingstates.org



Break

California: A Model for Partnerships

September 23, 2026

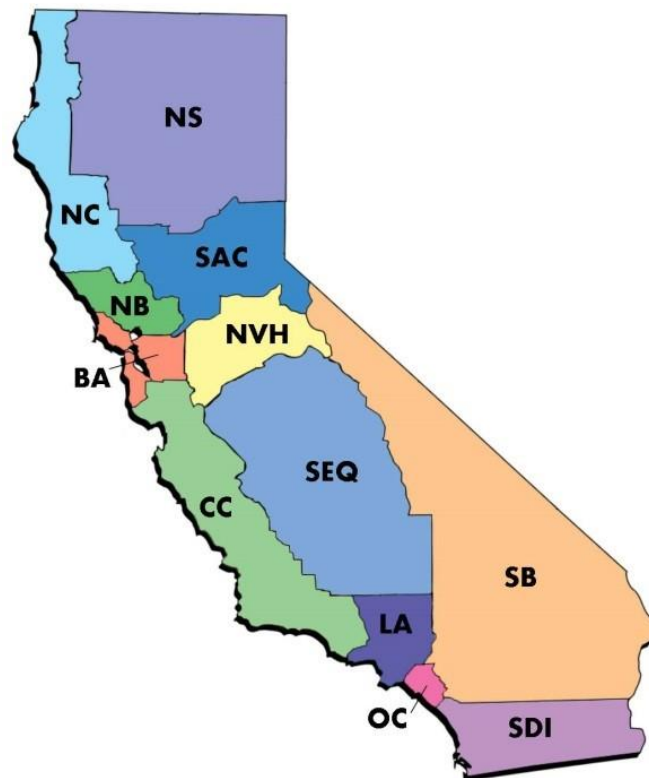


Photo by [Chona Kasinger](#),
from [Disabled and Here](#)

Partnering with State Council on Developmental Disabilities (SCDD)



- Bringing the perspective of individuals with IDD and their families into state level planning and decision making



Partnership established through statute

Welfare & Institutions Code § 4540

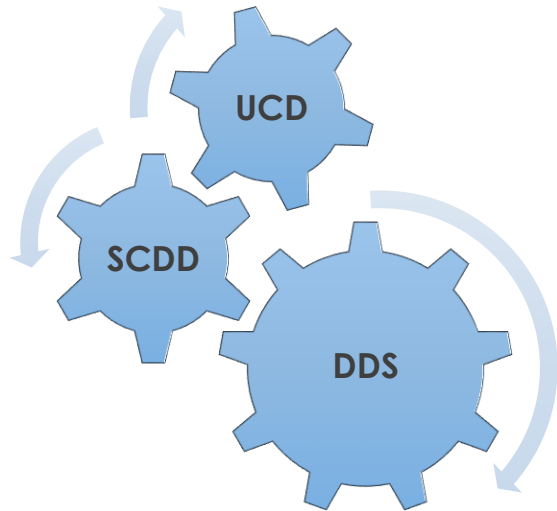
Requires State Council to:

- Develop and implement the state plan
- Monitor and evaluate implementation
- Review and comment on state programs affecting people with developmental disabilities
- Promote “interagency collaboration and coordination”
- Coordination with related councils, committees, and programs



Administration and NCI Survey Logistics

Example: Tool Development

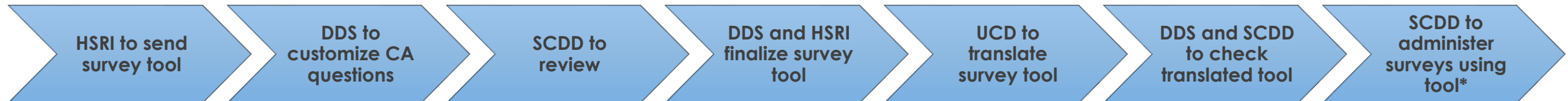


*SCDD partners with self-advocates to administer surveys



National Core Indicators®
Intellectual and Developmental
Disabilities

In-Person Survey



Development of Promotional Material

NCI Family Survey

Dear Parent/Guardian:

The California Department of Developmental Services (DDS) wants to hear from families to find out if they are satisfied with regional center services. We are contacting you because we understand that your family member receives services from a regional center. Your response will help the state and your regional center improve services and supports for families like yours.

The State Council on Developmental Disabilities has been contracted by DDS to collect this information. We know your time is valuable, but please take a moment to complete the enclosed survey and return it in the enclosed postage-paid envelope within 10 days or as soon as possible.

Your participation is voluntary. Your family will not be identified in any way.

Your answers will be used to improve services throughout the State.

You may also complete
the survey online at:

To access the online survey, please use the access code located on the top right-hand corner of your survey. Currently, the online survey is only available in English. DDS plans to add additional languages in the future.

If you are interested in receiving information on the results of the survey, issues impacting California, or events in your local community please join our mailing list by going to https://scdd.ca.gov/mail_list_signup/

If you have any questions, please email us at QAPROJECT@scdd.ca.gov or call your regional center.



DDS Department of
Developmental
Services

CALIFORNIA
SCDD
State Council on Developmental Disabilities

UC DAVIS
UNIVERSITY OF CALIFORNIA

Let your voice be heard!



IN-PERSON SURVEYS

NATIONAL CORE INDICATORS (NCI)

Evaluate the services and
supports you receive through
your regional center and
service providers!

The survey is **confidential** and
voluntary, and helps inform
key stakeholders throughout the
state of California.

The State Council on Devel-
opmental Disabilities (SCDD)
will contact you to schedule the
in-person survey at a time that
works best for you!

Email QAPROJECT@SCDD.ca.gov to participate in the survey.
Email NCIHelp@dds.ca.gov for general questions about NCI.

DDS Department of
Developmental
Services

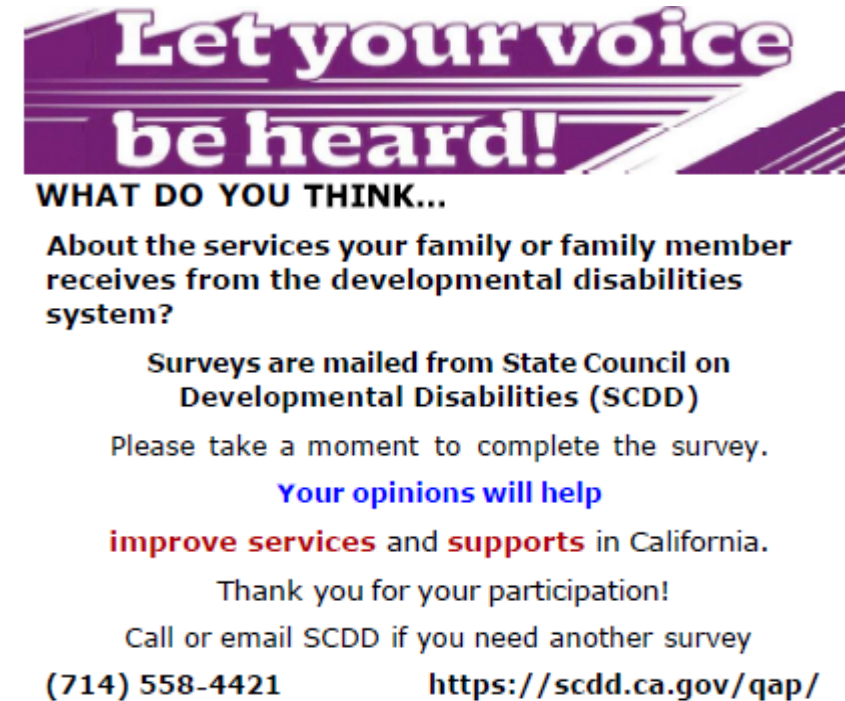
CALIFORNIA
SCDD
State Council on Developmental Disabilities

UC DAVIS
UNIVERSITY OF CALIFORNIA

Coordinating with Regional Centers

Outreach Assistance

- Collaboration between SCDD and Regional Center liaisons to
 - Inform consumers/families, provider networks and regional center staff about NCI surveys
 - Assist with distribution of promotional materials
 - Provide plain language explanations about NCI so participants feel comfortable
- Attending local Self Advocacy meetings to share info about NCI opportunities in a targeted outreach to partner with self-advocates



Parallel Outreach Efforts: Bridges Newsletter



Official website of the State of California

Select Language ▼

Powered by Google Translate



Department of
Developmental
Services

Search



Individuals & Families ▼

Services ▼

Regional Centers ▼

Vendors ▼

Initiatives ▼

Transparency ▼

About ▼

[Home](#) / [Bridges Newsletter](#) / [Complete Your NCI Survey...](#)

Complete Your NCI Surveys by July 15

June 24, 2026



Sign Up for Bridges
Newsletter

* Email

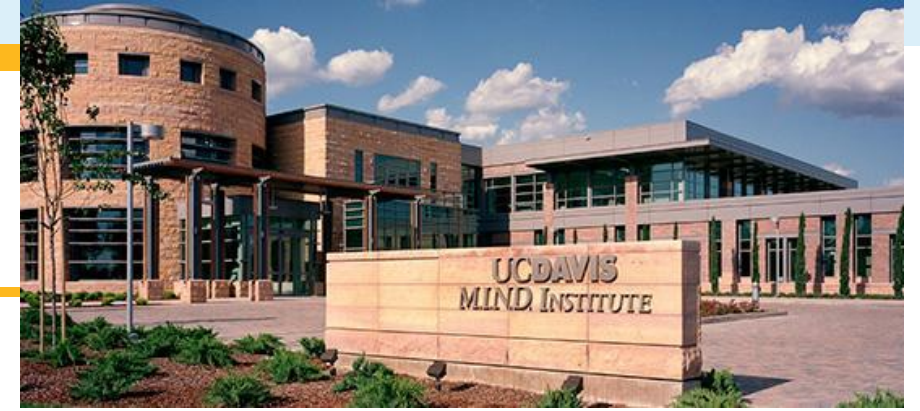
Did you receive a National Core Indicators (NCI) survey in the mail? Please complete and return it by July 15, 2026. Let your voice be heard!

Your feedback helps California understand what's working for you and what can be improved.

[Learn more about the NCI surveys](#), and see information from prior surveys!

Establishing Partnership

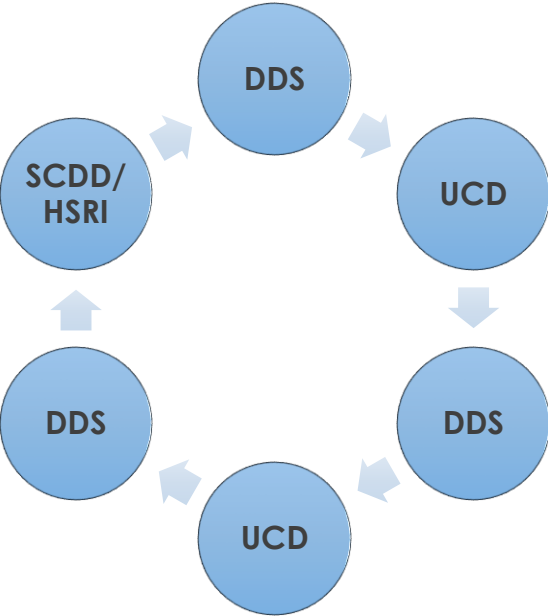
The UC Davis' MIND Institute



- Establishment of the MIND Institute in the late 1990s
 - Collaboration among families, scientists, clinicians, educators, and state agencies for a new kind of research and treatment center for autism and other developmental disabilities
- Funding through California Legislature in 2000
- While overseeing California's developmental disability service system, DDS became a natural partner in research, data-sharing, service development and policy research

Administration of Surveys

Example: Sample Methodology



Regional Center	Asian Sample	Black Sample	Hispanic Sample	White Sample	Other Sample	Total RC Sample
ACRC	46	46	83	187	38	400
CVRC	31	20	250	84	15	400
ELARC	56	4	299	31	10	400
FDLRC	57	27	201	108	7	400
FNRC	14	10	67	290	19	400
GGRC	147	26	107	94	26	400
HRC	60	40	186	76	38	400
IRC	20	47	219	89	25	400
KRC	13	31	231	106	19	400
NBRC	35	44	118	161	42	400
NLACRC	30	42	201	116	11	400
RCEB	94	73	103	104	26	400
RCOC	81	9	147	118	45	400
RCRC	10	12	76	274	28	400
SARC	109	9	165	89	28	400
SCLARC	4	81	302	5	8	400
SDRC	38	25	189	116	32	400
SGPRC	63	18	249	50	20	400
TCRC	20	7	187	167	19	400
VMRC	42	33	174	124	27	400
WRC	20	105	156	82	37	400
Total Statewide Sample	990	709	3710	2471	520	8400



Translations

العَرَبِيَّة

English

កម្ពុជា

فارسی

հայերեն

中国人

हिंदी

UCD receives
final version of
survey tool
from DDS

UCD reviews
survey tool and
sends to UCD
Health Medical
Interpreting
Services team

Translation
team
translates tools
into requested
languages and
sends to UCD

UCD conducts
QC analysis on
translated
materials and
sends to DDS

DDS conducts
QC analysis on
received
materials

Finalized
versions are
sent to SCDD

Tiếng Việt

日本語

한국어

ພາສາລາວ

русский

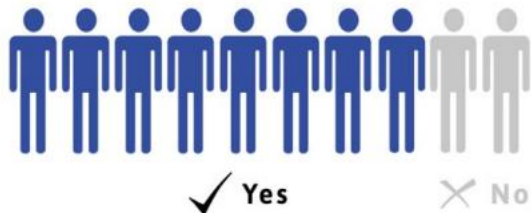
ਪੰਜਾਬੀ

User-Friendly Reports

Case Management and Support Staff



8 out of **10** families said **they were able to contact support workers when they wanted.**

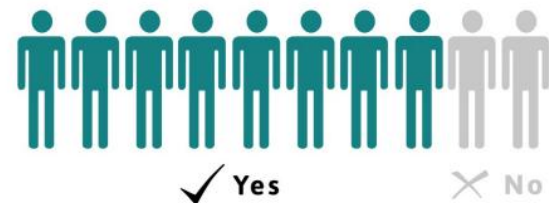


Going Out

People go out in their community to do many things. You may like to go to the movies, concerts, or play sports. When we ask about community, we mean the places close to home where you and other people go out.



8 out of **10** families said that **individuals like you took part in activities in the community.**



Challenges to Community Involvement

Although most individuals participated in community activities, some still found challenges to community involvement. Some challenges were:



Stigma
1 out of 10



Cost
2 out of 10



Lack of Transportation
2 out of 10



Lack of Support Staff
2 out of 10

Overall, challenges were not preventing most individuals from participating in the community.

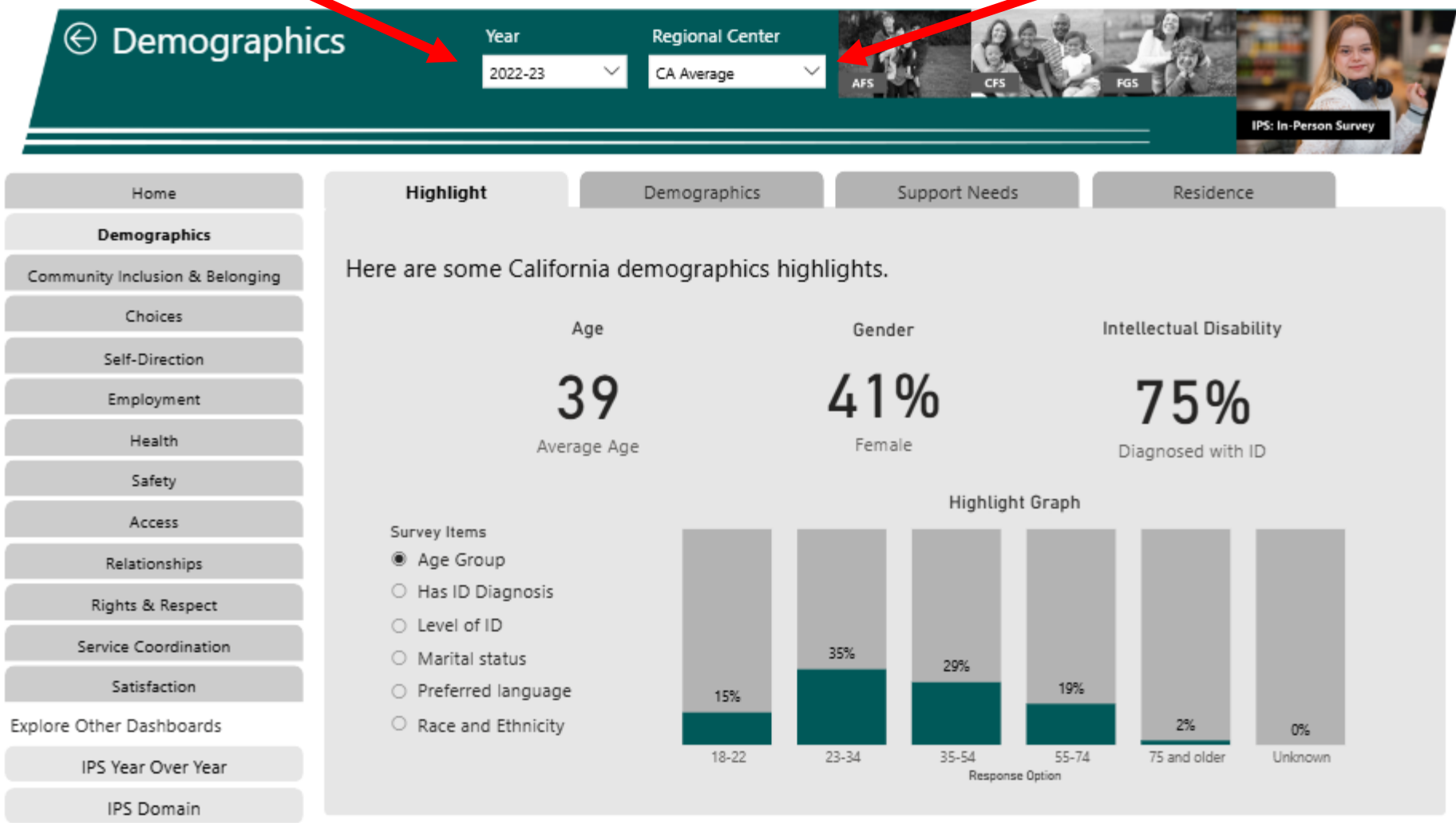
Interactive Dashboards: Comprehensive Dashboard

Comprehensive Dashboards

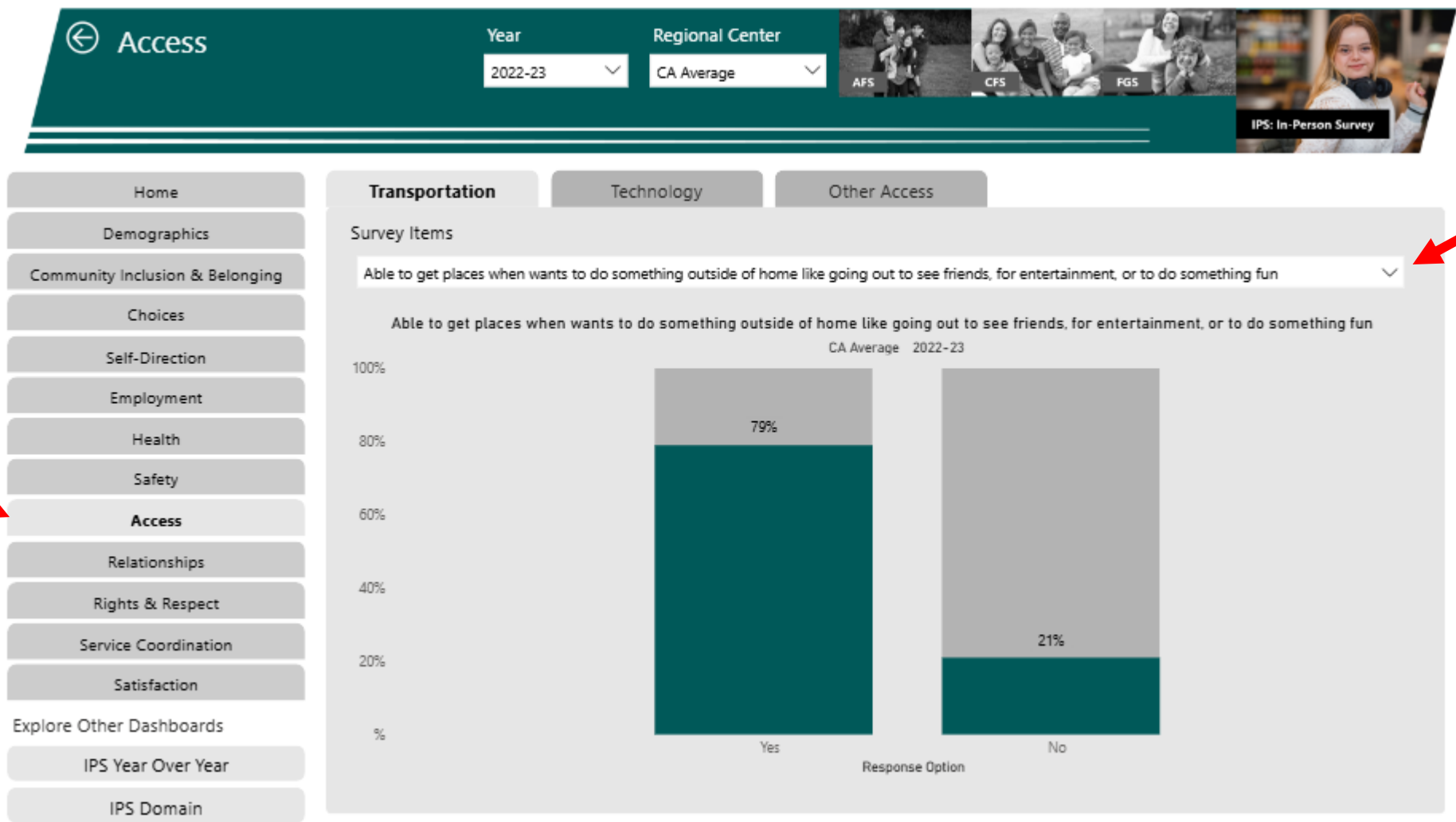




Product Development – IPS Example



Product Development – IPS Example



Partnering with California Regional Centers



Far Northern
Regional Center



Lanternman & Friends

"Lanternman and Friends is a collaborative effort by the California Department of Developmental Services (DDS) and the Regional Center system to make complex information simple, engaging, and accessible."

- Lanternman and Friends



"The Lanterman Act guarantees important rights and services for people with developmental disabilities in California. But the rules, regulations, and programs can often feel overwhelming. Lanternman and Friends delivers entertaining, easy-to-understand animated and live-action videos and resources that explain how the system works and what supports are available."

- Lanternman and Friends

Benefits of Partnerships

Working in Collaboration to
Positively Impact the Individuals
We Serve



Benefits

- **Improved project quality**
 - Quality problems identified through reviews allow for improved quality overall
- **Greater efficiency and innovation**
 - Contractor expertise allows for improvements in processes and solutions through innovative problem-solving
- **Better communication and collaboration**
 - Over time, partnerships allow for better communication and collaboration as contractors better understand the needs of the client and clients provide clearer feedback

Closing Remarks

- **NCI is more than a survey** — it's a collaborative effort
- **Strong partnerships drive success**
 - State Council → Individual, family & self-advocate voices
 - UC Davis → Technical expertise, data & innovation
 - Regional Centers → Community connections & engagement
- **Collaboration creates better outcomes**
 - Diverse perspectives
 - Earlier identification of challenges
 - New opportunities to use data
- **The goal is meaningful improvement**
 - Turn individual experiences into actionable information
 - Identify opportunities to strengthen the service system
- **It takes partnership to turn data into change**



E-mail questions about NCI: NCIhelp@dds.ca.gov

Thank you for attending!

NCI and the Ethical Use of Artificial Intelligence

What is “technology”

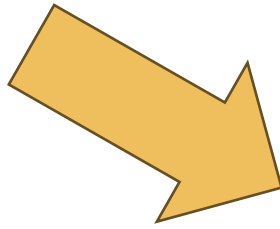
“Technology” is tools and devices that help us do things, such as learn, communicate, work, travel, or have fun.

Technology is growing quickly, creating new opportunities for connection, learning, and participation.

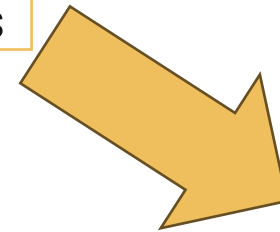
Technology can expand access—for example, through communication tools, assistive technology, and remote supports.

It is important to consider how new technology can also leave people behind and further marginalize vulnerable populations

Efficiency &
Automation



Data Extraction &
Algorithmic Bias



Surveillance &
Gatekeeping

Technology can affect people's privacy, how they are treated, and how decisions are made about them.

Harnessing Technology Innovation in Research, Evaluation and Knowledge Translation



Artificial intelligence (AI) is technology that allows computers to learn, make decisions, solve problems, and do things that people usually do.

Generative AI is technology that can create new things, like words, pictures, music, or videos, based on what a person asks it to do.

AI and Generative AI (genAI) is becoming a more regular tool in the research toolbox.

Tradeoffs are important to consider, including:

- Speed, quality, accuracy
- Privacy
- Environmental harms
- Others?

How likely is it for AI promote bias?
What is the impact on NCI?

- [Upturn report on LTSS eligibility determinations](#)

NCI data reflects real people's lived experiences and outcomes

AI tools (e.g., predictive analytics, natural language processing, automated reporting) are increasingly used to:

- Analyze trends
- Identify disparities
- Inform policy decisions

Ethical use is critical because:

- Data often involves **vulnerable populations**
- Misuse could reinforce inequities or misrepresent lived experiences
- Respondents may not have consented to having their data used with AI and all that entails

When you hear ‘AI and NCI data’:

What excites you?

What concerns you?

Scenario A:

A researcher uses AI on NCI data to predict which individuals are at risk of poor outcomes (e.g., loneliness, unemployment).

Discussion Questions:

- What are the potential benefits?
- What could go wrong?
- How might this affect how individuals are treated?
- What safeguards are needed?

Scenario B:

A researcher uses AI tools to generate automated state rankings based on NCI indicators.

Discussion Questions:

- **How might rankings misrepresent system performance?**
- **Could this penalize states serving higher-need populations?**
- **What transparency is necessary?**

Scenario C

A researcher uses AI to analyze open-ended NCI survey responses and determine themes

Discussion Questions:

- **What might be lost from the original voices of respondents?**
- **How do we validate accuracy? Who is at fault if the voice of respondents is misrepresented?**
- **Should direct quotes still be prioritized?**

Group discussion

As stewards of NCI data, when giving researchers access to NCI data, should the NCI team “manage” the risks of using NCI with AI?

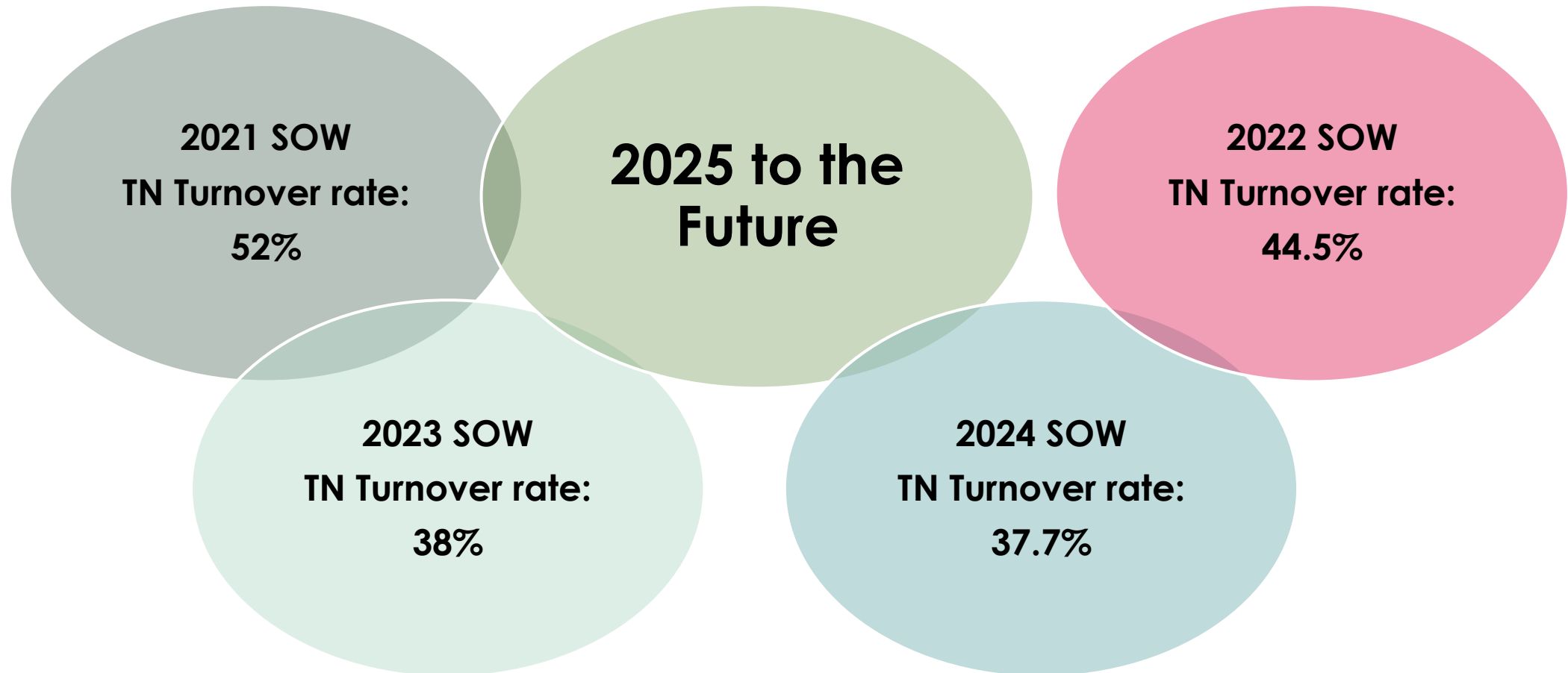
If yes, how?

NCI and the Ethical Use of Technology

- What uses of LLMs with NCI data feel clearly acceptable? Which feel questionable or off-limits and why?
- Is existing consent sufficient for how we are currently using NCI data? Does the same hold if we start using more generative AI for producing NCI related materials?
- In what ways could LLMs unintentionally reinforce stereotypes about people with IDD when summarizing NCI data?
- How comfortable are we relying on LLM-generated summaries to inform decisions about services or policy? What level of human review is necessary before using LLM outputs in reports or presentations?
- What does “person-centered” mean in an environment where AI is used to interpret data about people?
- **What is one ethical risk we are not fully addressing—and what is one concrete step we could take to mitigate it?**

One Slide Challenge

How supports are improving in Tennessee-Data works





Kentucky's Goal: Getting Data off the Shelf

Turning the data we collect into data people use

- Quality Improvement Committee
Recommendation reports in a variety of formats.
 - Input provided by members of a disability-led organization.
- Sharing reports and data points of interest with specific projects, staff, facility, organizations, etc.
- Data dashboard
 - Internal use only now; soon expanding
 - Looking to incorporate other datasets

Nebraska...Key Wins

*Our First Year
Administering National
Core Indicator Surveys
In-House*

Achievements

- ↪ Integrated NCI data directly into the Quality Improvement Committee Plan—
 - Faster insights, better alignment with improvement efforts
- ↪ Built an in-house performance review for Service Coordination Leadership—
 - More accurate, timely, and tailored evaluations
- ↪ Shared real-time insights with providers—
 - Stronger partnerships and more responsive collaboration
- ↪ Expanded and modernized the public dashboard—
 - Clear, accessible data for participants, families, and providers

Next-Cycle Goals

- ↪ Enhance participant services
- ↪ Deepen provider collaboration
- ↪ Add Nebraska-specific survey questions
- ↪ Advance quality outcomes and measures

OHIO: NCI DATA IN ACTION: DODD & OSU

- **Spark conversations:** Share “Data Bytes” that connect NCI findings to awareness campaigns and community priorities.
- **Shape policy:** Use findings to inform rule reviews, revisions, and agency initiatives.
- **Drive improvement:** Apply data throughout planning, monitoring, and reporting.
- **Guide action:** A planned NCI data council will review trends and recommend improvements to leadership.
- **Advance research:** OSU uses NCI data to support studies, publications, and learning.

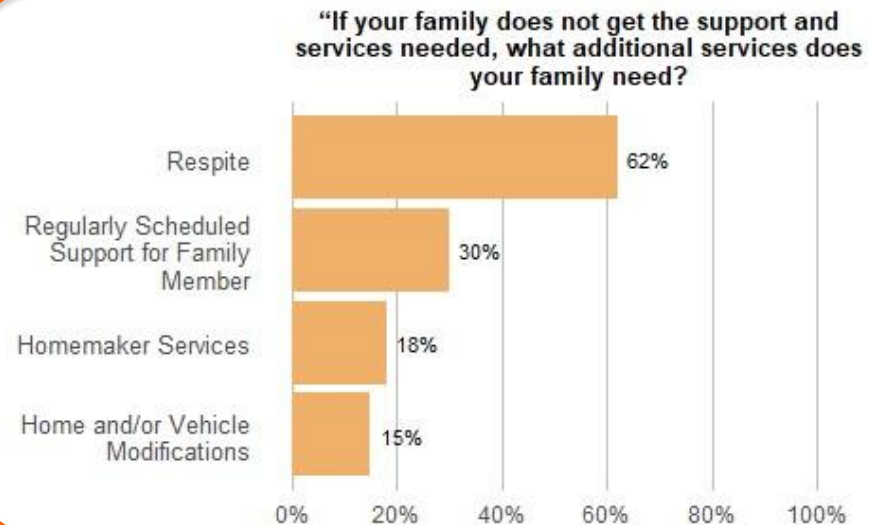
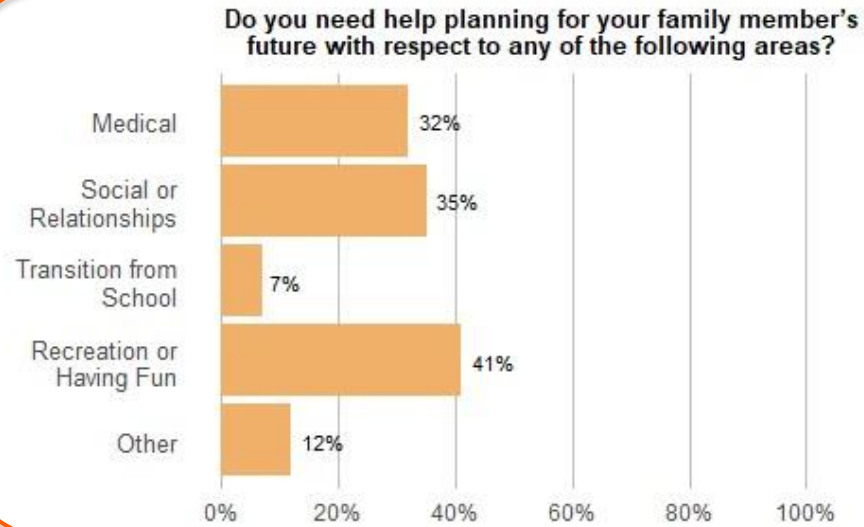
Family Caregivers Are Clear: Respite and Recreation Matter



CENTER FOR
DEVELOPMENTAL
DISABILITIES

OKLAHOMA
Human Services

WHAT FAMILY CAREGIVERS NEED

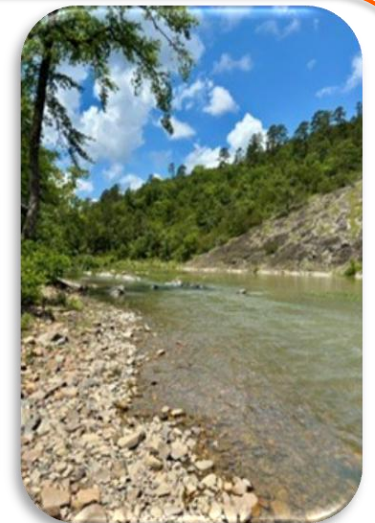


HOW WE ARE RESPONDING

OKLAHOMA STATE UNIVERSITY
UNIFIED



OSUCDD
RESPITE CONCIERGE





How do we
inform the
community on
what NCI IPS is?

MICHIGAN DATA SPOTLIGHTS



What resources do we
already have available to
us?

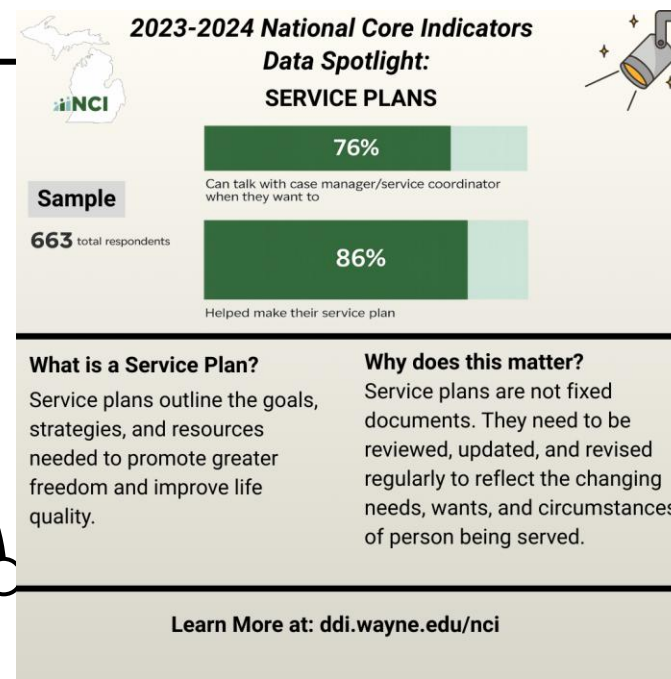


Where is the report
being posted & How
can we better reach
people?



What if we broke
down Data At-A-
Glance?

Who can help us
have a bigger reach?



Montana NCI-IDD

1) What is one exciting way you've used NCI-IDD data this year?

- a. Montana is building the infrastructure to use NCI-IDD outcomes data to identify system strengths, gaps, and opportunities for meaningful quality improvement.

2) Share one product/resource your team has created using NCI-IDD data

- a. Montana is developing accessible tools and processes to translate NCI-IDD findings into meaningful quality improvement activities, policy decisions, and stakeholder communication.

3) How is your state using NCI-IDD State of the Workforce Data?

- a. Montana has not utilized the NCI-IDD State of the Workforce survey. Our state has been conducting rate studies and workforce stability projects that directly survey our provider network. To minimize duplicative requests and provider burden, we have not added the NCI-IDD workforce survey to those efforts.

4) In your state, are there any efforts underway or planned to address racial/ ethnic disparities (in outcomes, access, service utilization, etc) using NCI-IDD data?

- a. Once Montana's NCI-IDD results are available, the state plans on examining outcomes by race and ethnicity, where sample sizes of data quality allow, to identify potential disparities and inform targeted quality improvement strategies.

5) What's your greatest accomplishment with NCI-IDD this year?

- a. Montana developed statewide sampling procedures and methodology and state staff are trained to administer the NCI-IDD survey, establishing the infrastructure needed for ongoing data collection and quality improvement.

6) How are you sharing your NCI-IDD data with interested parties? (DD agency, legislators, advocates, families, etc).?

- a. Results will be shared through stakeholder presentations, reports/data summaries, policy discussions with legislators, and engagement with people with disabilities, families, providers, advocates, and other partners.





California

Using NCI to Understand & Improve Service Delivery

- **Regional Center–Level Data**

California's 21 nonprofit Regional Centers serve distinct catchment areas; NCI results are reported at the Regional Center level to identify regional strengths and challenges.

- **Measuring Individual & Family Satisfaction**

NCI indicators—such as service access, staff availability, autonomy, and choice—inform satisfaction and Regional Center performance measurement.

- **Examining Subpopulations**

Family survey indicators are stratified by race and ethnicity to examine differences in satisfaction and whether service needs are being met across racial groups in our State.

- **NCI Dashboards**

CA is committed to making NCI data available to its stakeholders across the State

Questions? NCIhelp@dds.ca.gov

One Slide Challenge Discussion

- Do you have any questions for the states?
- What interested you specifically?
- What can you see replicating in your state?
- What barriers might you encounter?

Wrap up and housekeeping

2026 NCI-IDD ANNUAL MEETING Day 2

September 24, 2026

Introductions and Reflections

- If you are here in-person and were not here yesterday, please say your
 - Name
 - Where you work
 - The state(s) for which you work on NCI-IDD
- Any reflections on Day 1?



VCU Partnership for People
with Disabilities
School of Education

Getting the Yes! & Provider Engagement

Presenters:

Patrice Beard

Darlene Tyktor



<https://nci.partnership.vcu.edu/nci---idd-project/>



diggskg@vcu.edu

Overview

- Schedule
- Stay positive!
- Get to know the person...before you call
- Act like you like your job :)
- Explain the “why”
- Accommodations
- Prove you’re NOT a scammer
- Training & Resources
- State & Provider engagement

Schedule

- Before making calls, know when you're available & have your schedule open and ready
- Be flexible with your scheduling
- Acknowledge & validate that everyone is busy
- Think about when you're calling people
 - Different types of contacts are typically available during different times of the week (e.g. Group Homes, Day Support, Parents, etc.)
 - Avoid Friday afternoons for Group Home Supervisors

Stay Positive!

Getting the Yes Mantra:

Don't get discouraged. Don't waste energy on a no. Don't let declines get you down!



Not every call will become a yes, you will not have 100% success rate



You may not get a call back, don't get discouraged by that either



Don't be discouraged if someone is mean and disrespectful to you



Be mindful of how much time passes between an initial "yes"/ "maybe" and following up



Don't get frustrated if someone hangs up on you



Calling more people results in higher completion numbers not repetitive calls to the same person

Get to know the person...before you call

Review contact information of the person and create a summary

Provides connectivity with the person about their life

Sharing a few details further validates who you are and why you're calling

Create notecards/notes with key information*

Populate with contact information and other pertinent info like names of case manager, parents, legal guardians, provider contacts

Use to establish rapport and keep information handy while calling

**Must keep in a secure location*



Act like you like your job :)

- Have enthusiasm when calling people
- Be excited about the opportunity for participants to share their perspectives
- Balance a professional demeanor with friendliness
- Explain why the survey is important

Explain the “why”

- Take some time to understand why the survey & the data is collected in your State
 - How is your State using the data? Have they used the data?
 - What initiatives have been born out of results from the survey?
 - Are there any reports that can be shared with participants?
- Assume potential participants know nothing about NCI
 - Be aware that you are most likely going to be making a cold call
 - Don't be too formal when calling
 - Make the ask conversational rather than scripted/robotic
- Tell participants:
 - that the survey is not mandatory but their perspective is appreciated
 - the State wants to improve service delivery
 - the State wants data from real life people

Accommodations

You may often be told by parents, guardians and provider staff that the participant is unable to communicate or is too limited to participate. Here are some ways to explain participation is possible for all:



There are two parts to the survey, encourage the person to participate as much as they can and/or use a proxy if needed in Section 2



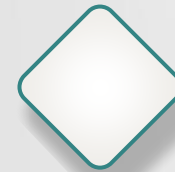
Can accommodate communication needs using Language Line, ASL interpreters, interpreters on staff, communication boards, etc.



We value whatever kind of participation the participant is able to do



Participants can answer when they want, they can skip questions



Break up interview into multiple sessions if necessary



Consider the survey method options in your State: virtual vs. in-person



Prove you're NOT a scammer



Validate their concerns

Offer to mail or e-mail participant information to further validate the initiative

If your State sends letters, ask if participant received letter

Mention they can contact SC before participating to validate information

Provide NCI website information (HSRI & your State's)

Consider adding photographs of interviewers to your NCI website

Always leave a voicemail

Customize your email signature and include logos for your institution/place of employment and NCI-IDD

Training & Resources

Training

- Mock phone calls - Practice getting the yes with other interviewers
- Mock interviews with other interviewers or co-workers with disabilities
- Shadow interviews with project staff well versed in protocol and survey
- Before doing interviews - read over the survey, all information not just questions, along with the IPS surveyor handbook
 - Understand why you are asking the questions
- Quality Assurance Look Alongs/Shadow Interviews

Resources

- Script for initial phone calls
- Interviewer mentors
- Provide 1:1 support when needed
- Monthly supervisor check-ins
- Group Chats
- Google folder with resources

State & Provider Engagement

- If a Provider says they don't have time:
 - Protocol states we need to talk with participant in order to decline
 - Ask Provider to facilitate a phone call with the participant to discuss the survey and obtain consent
- Decline Log
 - name of person who declined
 - type of person who declined (LG, Provider, Participant, etc.)
 - If a Provider declines:
 - name of provider organization
 - reason for decline
- Provider decline reports provided to State
- Conversations with State Office of Quality Management and Office of Human Rights

Now that you have the YES!

Don't forget to send reminders about a scheduled interview.

Many people appreciate a call/text/email the day before a scheduled interview.



Thank You!



Wyoming HCBS: Getting to the Yes for NCI Surveys

Dillion Johnson

Considerations

State Consent Requirements

Only applicable to states that require consents for the survey.

800

Surveys / Year

Wyoming requires 400 surveys per waiver (800 total annually).

~5,000

Waiver Participants

Approximate total participant population across waivers.

Geographic Distribution

“One city with long roads”

Institutional Review Board

IRB compliance and approval process required for survey protocol oversight.

Pre-Survey Work



Team Notification

All HCBS teams are notified of this work.

Outreach

Getting the word out.

1,200

**Participants
Randomly Selected**

This data includes all active addresses.

Pre-Consent Process: How it worked



Staff Assembly

HCBS staff would get together in one afternoon and stuff letters notifying participants they were selected and include a written consent form.

Direct Contact

Letters included my direct work number and email.

Vital Research

Letters included information about Vital Research.

Mail Return

Participants and guardians mail signed consents back to the Wyoming Department of Health.

After Letters Are Mailed

Inbound Calls

Calls from participants, guardians, and case managers.

Support & Reassurance

Alleviating concerns about the survey.

~**115**

Pre-Consents / Year

Wyoming has averaged approximately 115 pre-consents per year before surveying officially began.

How it Works Now

Vital Research

Vital Research will send out the letters.

State Envelopes

Letters are mailed out in envelopes supplied by Wyoming Department of Health.

Prepaid Envelope

The letters still include a prepaid envelope to the Wyoming Department of Health.

Direct Contact

Letters still include my direct contact information.

Recruitment and Retention of Surveyors

The Surveyor Hiring Playbook: What We Can Learn From Each Other

Station 1: Finding the right candidates

- What recruitment strategies have worked?
- Where do you advertise?
- What can you include in job postings?
- What are your pre-requisites?
- What are challenges you've encountered?

Station 2: Onboarding

- How do you onboard your surveyors?
- How do you make surveyors interested in the work?
- What resources do/can you create?
- What are challenges you've encountered?

Station 3: Retention

- What keeps good surveyors coming back?
- How do you recognize their work?
- How do you make sure surveyors stay interested in the work?
- What are challenges you've encountered?

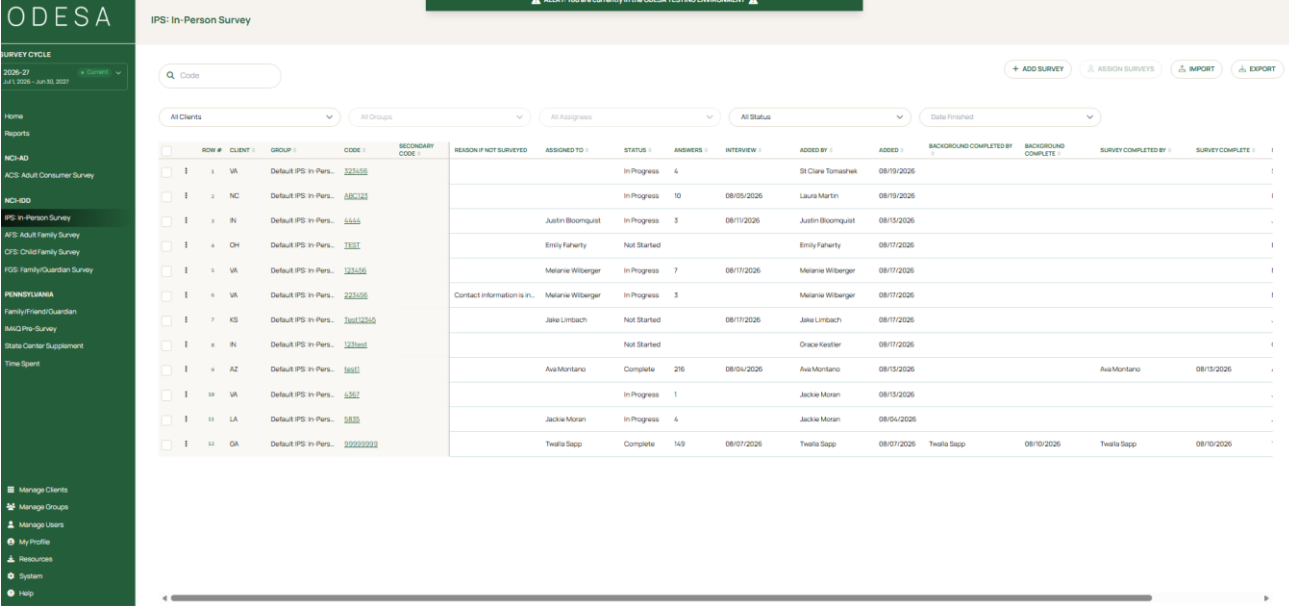
Break



ODESA 2.0

ODESA 2.0: What did you think?

- What worked well?
- What features were you most excited about?
- Any anecdotes to share?



ODESA 2.0: In-Person Survey

2026-27
Jul 1, 2026 - Jun 30, 2027

Home
Reports

NCHAD
ACE Adult Consumer Survey

NCHDD
IPS In-Person Survey
AFS Adult Family Survey
OFS Child Family Survey
FGS Family/Guardian Survey

PENNSYLVANIA
Family/Friend/Guardian
MAG Prep Survey
State Center Supplement
Time Spent

Manage Clients
Manage Groups
Manage Users
My Profile
Resources
System
Help

Code

+ ADD SURVEY
ASSIGN SURVEYS
IMPORT
EXPORT

All Clients
All Groups
All Assignments
All Status
Data Finished

	ROW #	CLIENT	GROUP	CODE	SECONDARY CODE	REASON IF NOT SURVEYED	ASSIGNED TO	STATUS	ANSWERS	INTERVIEW	ADDED BY	ADDED	BACKGROUND COMPLETED BY	BACKGROUND COMPLETE	SURVEY COMPLETED BY	SURVEY COMPLETE
	1	VA	Default IPS In-Pers...	221106				In Progress	4		St Clara Tomlinson	08/19/2026				
	2	NC	Default IPS In-Pers...	68C242				In Progress	10	08/05/2026	Laura Martin	08/19/2026				
	3	IN	Default IPS In-Pers...	6665			Justin Bloomquist	In Progress	3	08/11/2026	Justin Bloomquist	08/13/2026				
	4	OH	Default IPS In-Pers...	7331			Emily Faherty	Not Started			Emily Faherty	08/17/2026				
	5	VA	Default IPS In-Pers...	221106			Melanie Wilberger	In Progress	7	08/11/2026	Melanie Wilberger	08/17/2026				
	6	VA	Default IPS In-Pers...	221106		Contact information is in...	Melanie Wilberger	In Progress	3		Melanie Wilberger	08/17/2026				
	7	KS	Default IPS In-Pers...	70412210			Jane Limbach	Not Started		08/11/2026	Jane Limbach	08/17/2026				
	8	IN	Default IPS In-Pers...	221106				Not Started			Orace Kestler	08/17/2026				
	9	AZ	Default IPS In-Pers...	30811			Ava Montano	Complete	216	08/04/2026	Ava Montano	08/13/2026			Ava Montano	08/13/2026
	10	VA	Default IPS In-Pers...	6387				In Progress	1		Jackie Moran	08/13/2026				
	11	LA	Default IPS In-Pers...	5835			Jackie Moran	In Progress	4		Jackie Moran	08/04/2026				
	12	GA	Default IPS In-Pers...	22222222			Twila Sapp	Complete	149	08/07/2026	Twila Sapp	08/07/2026	Twila Sapp	08/10/2026	Twila Sapp	08/10/2026

Overview

- ODESA 2.0 represents a significant step forward in our technology strategy.
- The journey began in **October 2024** with a clear objective: to develop a new version of the data capture application used by NCI IDD and NCI AD that is
 - cloud-based, mobile-friendly, secure, and designed to enhance ease of administration and improve the user experience.
- Since then, our teams, partners, and clients have dedicated countless hours to the design, build, and rigorous testing required to bring this next-generation system to life.

EXCITING new features



Offline mode



NCI-IDD and NCI-AD all under one “roof”



New user interface—new look and feel!



Enhanced security features—MFA via email **or text**

Responding to state needs

- Added features to the survey grid
- Added reports
- Survey cycle selector
- Enhanced functioning of ODESA
- MFA via text
- PA and CA have gone through separate development processes

Questions and thoughts

- Have you used the ODESA 2.0?
- Any advice for new users?
- Is there any training support that could be useful?



**Office for People With
Developmental Disabilities**

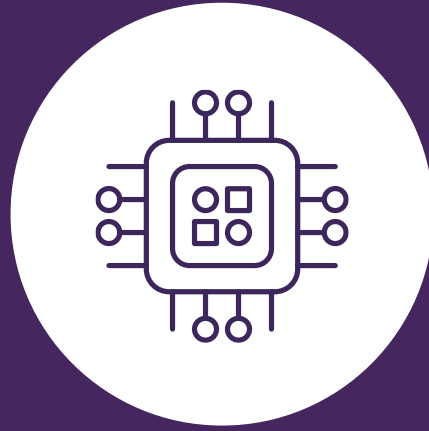
National Core Indicators – Intellectual and Developmental Disabilities (NCI-IDD) Annual Meeting

Division of Data Strategy and Technology Management
& Vital Research, LLC

SEPTEMBER 24, 2026

Agenda

- Introduction
- Relationship with Vital Research
- National Core Indicators In-Person Survey (NCI IPS) Survey Modality – Remote (Zoom) First
- Technology Barriers
- Linguistic Competence
- Engagement of People with Limited or No Spoken Communication



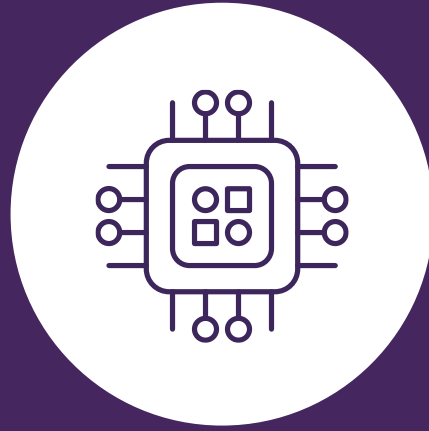
Introduction

Introduction

- New York State has a long history with National Core Indicators In-Person Survey (NCI IPS)
 - Participating annually since 2007-2008 Survey Cycle
 - Focus on public awareness of NCI IPS purpose and goals
 - Strategies: provider presentations; listserv announcements; state website announcements; outreach to advocacy groups (e.g., Self-Advocacy Association of New York State, NY Alliance)
 - Listen to concerns raised by people, their families, and providers and worked to address them to build trust
 - Strategies: interviewer email, phone numbers, and website biographies; website frequently asked questions (FAQ)
- Minimal refusals and no shows
 - Strategies: resending notification letters; communication training for interviewers; flexible scheduling

Introduction (2)

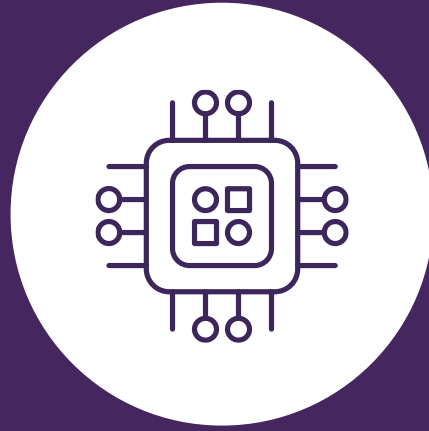
- New York State has applied several strategies to optimize National Core Indicators (NCI) survey participation for all eligible people
 - Built on shared goals and working relationship with Vital Research
 - Adapted survey modality and monitored change to maximize participation
 - Focus on linguistic competence
 - Improved access for people with limited or no spoken communication



Relationship with Vital Research

Relationship with Vital Research

- Ten years of engagement between Office for People With Developmental Disabilities (OPWDD) and Vital to administer National Core Indicators In-Person Survey (NCI IPS)
- Expanded scope – added Child Family Survey (CFS) in 2025-26 Survey Cycle
- Open line of communication and role clarity
 - Weekly check-in meetings
 - Project dashboards and regular reporting
 - Interviewer debriefing session
- Close working relationship has been essential for project success
 - Supporting project legitimacy among participants and providers
 - Access to NCI Coordinator via phone and email
 - Timely response to challenges



National Core Indicator In-Person Survey

Modality – Remote (Zoom) First

National Core Indicators In-Person Survey (NCI IPS)

Survey Modality Timeline

Prior to 2020-2021 cycle

NYS Surveying only with face-to-face interview

2020-2021

NYS Pilot of remote videoconference surveying via Zoom

"We have inserted ourselves into the lives of [survey participants]. We are a bright spot. Even if it is a challenge, it is not a bad thing."

2021-2022 & 2023-2024

Conducted survey fully via Zoom

2023-Present

Implemented a remote-first survey modality

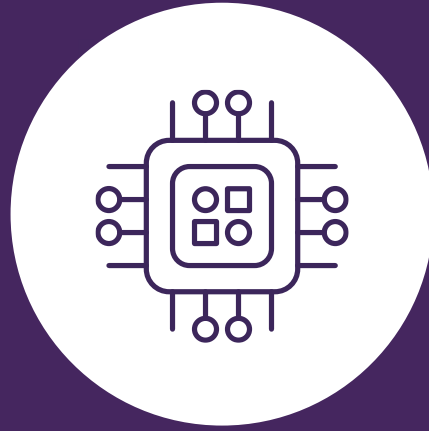
Face-to-face option available for those unable or uninterested in Zoom interviews

National Core Indicators In-Person Survey (NCI IPS)Survey

Modality – Remote First

- Lessons Learned from 2020-2021 Survey Cycle Pilot
 - Most survey respondents were familiar with Zoom and were positively engaged during the remote interview
 - The remote survey administration allowed for non-local guardians to be involved in the process
- In 2025-2026, 98.3% of surveys were conducted via Zoom
 - Interviewers are trained to troubleshoot issues
 - Allows experienced interviewers from other states
 - Allows people to participate who may not want strangers in their homes

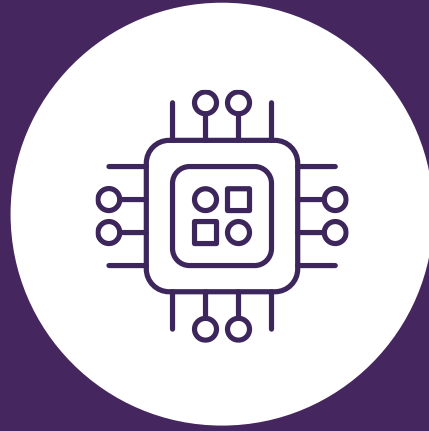
Survey Year	Completed Surveys	Zoom interviews	Face-to-face interviews
2023-2024	1,703	1,689 (99.2%)	14 (0.8%)
2024-2025	1,751	1,715 (97.9%)	36 (2.1%)
2025-2026	2,005	1,970 (98.3%)	35 (1.7%)



Technology Barriers

Technology Barriers

- With change in survey modality to remote-first, prioritized monitoring technology-related barriers to participation
- Goal is to identify “true technology barriers” and work to facilitate face-to-face participation
- “True technology barriers” include:
 - Not having a camera or computer
 - Not having internet
 - Not having support to use Zoom
 - Cases where American Sign Language (ASL) is preferred in person
- Of the 53 cases where “true technology barriers” were identified in the 2025-2026 Cycle, 35 became face-to-face interviews



Linguistic Competence

Linguistic Competence

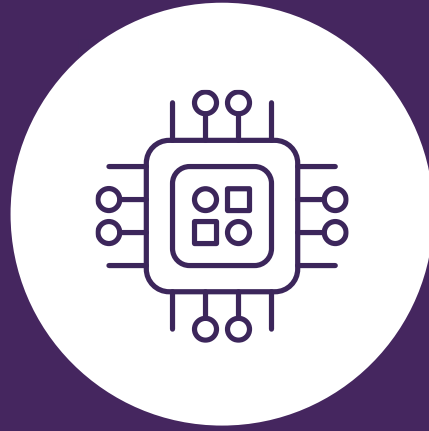
NYS Language Access Law

- This law requires State Agencies to develop Language Access Plans
- Translation of project documents into the 12 most spoken non-English languages
 - In 2026 this includes: Spanish, Chinese, Russian, Yiddish, Bengali, Korean, Haitian Creole, Italian, Arabic, Polish, French, and Urdu
- Presurvey data collection enabled identification of additional languages spoken by people sampled
- Access to remote interpretation

Linguistic Competence (2)



- Identification of non-English speaking families & participants prior to outreach
- Translation of notification letters
 - Use of Quick Response (QR) codes
 - Posting QR codes on project website
- Translation of paper Child Family Survey (CFS)
 - Lesson learned: Send out translated survey for anyone with language preference (instead of English-language survey)
- Use of language access line and translation services
- Bilingual interviewers and bilingual staff supporting project phone line
- Video interpretation makes American Sign Language (ASL) interpretation possible

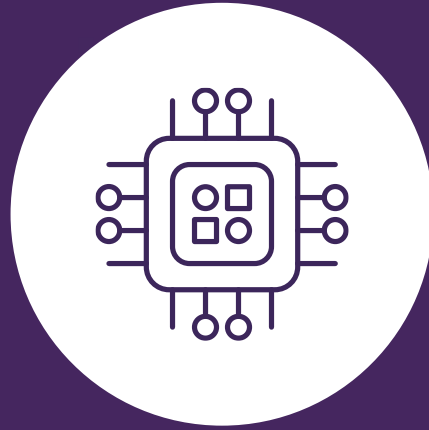


Engagement of People with Limited or No Spoken Communication

Engagement of People with Limited or No Communication

- Training field interviewers on how to engage participants who communicate without speech
- Communication cards and use
 - Practice mapping a participant's words to the standardized response options using the synonym list
 - Use processing time and alternative communication without assuming what the participant means

Winter	Spring	Summer	Fall
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Thank you!

Contact Info & Questions

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Office for People With Developmental Disabilities

WRAP UP

- Please take this quick evaluation!

<https://tinyurl.com/NCIAnnMeet>

