

# 2025 NCI-IDD ANNUAL MEETING Day 1

September 24, 2025

# Welcome

Mary Sowers, Executive Director – NASDDDS

Alixé Bonardi, Vice President Intellectual & Developmental  
Disabilities, Aging & Disability - HSRI

# NASDDDS team

# HSRI NCI team



# Georgia Welcome

# What Topics Would You Like to Discuss at NCI Meeting?



Federal Policy / Access Update

NCI Implementation Challenges

Increasing Participation

Use of NCI Data

Operations and Tools

Peer Learning and Collaboration

# Meeting Agenda - Wednesday September 24

- Federal Updates
- One Slide Challenge, Part 1
- Getting to Yes
- State Specific Questions – To add or not to add
- Sharing data with advocates – User Friendly Reporting
- Communicating NCI Data with All
- One Slide Challenge, Part 2
- Dinner - Riverscape Room

# Meeting Agenda -Thursday, September 25

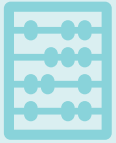
## Day 2 overview/instructions

- ODESA 2.0
- Training Updates
- Training Surveyors to Encourage Participation without Proxy
- Community Café
- Wrap Up

**NCI-IDD Next Steps: How to Move Forward**  
**NCI-IDD Annual Meeting September 24-25, 2025**

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

# What have we been up to? NCI-IDD in 2024-25



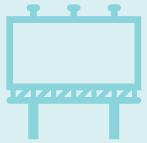
IPS: 40 states

AFS: 10 states

FGS: 6 states

CFS: 12 states

NCI SoTW-IDD: 27 States



NCI-IDD related **presentations at conferences** such as AAIDD, USAging, HCBS, ANCOR, TASH, and more



Several **webinars and resources** highlighting NCI-IDD data such as the ANCOR, AAIDD webinar series, NADSP member webinars, SciTube video, and more

# NCI-IDD 2024-2025 (cont.)



Development of ODESA 2.0



Working closely with CMS to ensure alignment with Access Rule Provisions – QMS and Payment Adequacy



Office Hours to Update States with HCBS QMS and Federal Happenings



Technical Assistance for HCBS QMS



NCI Briefing with CMS, ACL and office of federal lawmakers

# Still to come from NCI-IDD in 2025-26

Presentations at  
Six-State Summit  
and TASH

Webinars with  
the Arc

New brief on  
employment and  
other  
publications

PQM process to  
maintain  
endorsement of  
14 NCI-IDD IPS  
measures

NCI Revisions  
cycles

NCI State of the  
Workforce cross  
population tool



# Ice Breaker

# Introductions

- Name
- Role
- State
- Connection with NCI-IDD (What do you do, related to NCI-IDD?)
- One of the following (optional)
  - What's the best vacation you've ever been on?
  - What is your favorite way to eat potatoes?
  - What is the best advice you've ever received?
  - If you could turn any activity into an Olympic sport, what would you win a gold medal in?

# Federal Updates



# Federal Updates

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Ensuring Access to Medicaid Services  
Final Rule

H.R.1, One Big Beautiful Bill Act

# Ensuring Access to Medicaid Services

## Final Rule (CMS-2442-F)

- No changes in the provisions and time frames in Access Rule
- CMS was on communication pause to allow new administration to get acclimated.
- CMS monthly meetings with national membership associations - NASDDDS, ADvancing States, NAMD, NASHIA, and NASMHPD resuming
- CMS developing sub regulatory guidance.

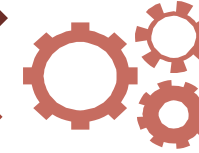
By July 9, 2025



Medicaid Advisory Committee (MAC)  
Beneficiary Advisory Council (BAC)

By July 9, 2027

Incident Management Systems Assessment  
Incident Management Compliance Reporting  
Person Centered Planning Compliance Reporting  
Wait List Reporting  
Website Transparency



By July 9, 2029

Electronic Incident Management System



By July 9, 2026



Grievance System  
Publish FFS Payment Rates \*July 1st  
First MAC Report

By July 9, 2028

Payment Adequacy Reporting for Personal Care, Home Health Aide, and Home Maker Services  
Quality Measure Set



By July 9, 2030



Payment Adequacy Minimum Performance Standard (80/20 rule)



# Home and Community Based Services Quality Measure Set (HCBS QMS)



# Background: HCBS Quality Measure Set



- **Medicaid HCBS provide individuals who need help with everyday activities the opportunity to receive services in their homes and communities as opposed to institutional settings.**
- **In 2022, the Centers for Medicare & Medicaid Services (CMS) released the first official version of the HCBS Quality Measure Set for voluntary use.**
- **The HCBS Quality Measure Set is a set of nationally standardized quality measures for Medicaid-covered HCBS that:**
  - **Promotes common and consistent use of nationally standardized measures within and across states.**
  - **Creates opportunities for CMS and states to have comparative quality data on HCBS programs.**
  - **Drives improvement in quality of care and outcomes for people receiving HCBS.**
  - **Supports states' efforts to promote equity in their HCBS programs.**



# HCBS QMS



- **CMS published an updated 2024 HCBS Quality Measure Set on April 11, 2024, that includes 65 nationally standardized quality measures for Medicaid-funded HCBS.**
  - CMS also released a CMCS Informational Bulletin (CIB) that requires states and territories with Money Follows the Person (MFP) Demonstration grants to report on a subset of mandatory measures from the HCBS Quality Measure Set beginning in the fall of 2026.
- **The HCBS Quality Measure Set includes the following experience of care (EOC) surveys to assess the EOC of all the major population groups receiving Medicaid-covered HCBS:**
  - HCBS Consumer Assessment of Healthcare Providers and Systems (CAHPS®);
  - National Core Indicators®-Intellectual and Developmental Disabilities (NCI®-IDD);
  - National Core Indicators-Aging and Disability (NCI-AD)
  - Personal Outcome Measures (POM).

CBE #	Measure Steward	Measure Name	Data Source/Data Collection Method
2967	CMS	HCBS CAHPS: Choosing the services that matter to you (Q 56, 57)	Survey
2967	CMS	HCBS CAHPS: Community Inclusion and Empowerment Composite Measure (Q 75, 77, 78, 79, 80, 81)	Survey
2967	CMS	HCBS CAHPS: Personal Safety & Respect Composite Measure (Q 64, 65, 68)	Survey
2967	CMS	HCBS CAHPS: Physical Safety Single-Item Measure (Q 71)	Survey
2967	CMS	HCBS CAHPS: Staff Are Reliable and Helpful Composite Measure (Q 13, 14, 15, 19, 37, 38)	Survey
2967	CMS	HCBS CAHPS: Staff Listen and Communicate Well Composite Measure (Q 28, 29, 30, 31, 32, 33, 41, 42, 43, 44, 45)	Survey
2967	CMS	HCBS CAHPS: Transportation to Medical Appointments Composite Measure (Q 59, 61, 62)	Survey
2967	CMS	HCBS CAHPS: Unmet Needs Single-Item Measures (Q 18, 22, 25, 27, 40)	Survey
3593	CMS	FASI-1: Identification of Person-Centered Priorities	Case Management Record
3594	CMS	FASI-2: Documentation of a Person-Centered Service Plan	Case Management Record
NA	CMS	HCBS-10: Self-direction of services and supports among Medicaid beneficiaries receiving LTSS through managed care organizations	Case Management Record
NA	CMS	MLTSS-1 and FFS LTSS-1: Comprehensive Assessment and Update	Case Management Record
NA	CMS	MLTSS-2 and FFS LTSS-2: Comprehensive Person-Centered Plan and Update	Case Management Record
NA	CMS	MLTSS-3 and FFS LTSS-3: Shared Person-Centered Plan with Primary Care Provider	Case Management Record
NA	CMS	MLTSS-4 and FFS LTSS-4: Reassessment and Person-Centered Plan Update after Inpatient Discharge	Case Management Record
NA	CMS	MLTSS-5: Screening, Risk Assessment, and Plan of Care to Prevent Future Falls	Case Management Record
NA	CMS	MLTSS-6 and FFS LTSS-6: Admission to a Facility from the Community	Administrative
3457	CMS	MLTSS-7 and FFS LTSS-7: Minimizing Facility Length of Stay	Administrative
NA	CMS	MLTSS-8 and FFS LTSS-8: Successful Transition after Long-Term Facility Stay	Administrative
NA	NCQA	MLTSS: Plan All-Cause Readmission (HEDIS)	Administrative

CBE = consensus-based entity; CMS = Centers for Medicare & Medicaid Services; FASI = Functional Assessment Standardized Items; FFS = fee-for-service; HCBS = Home and Community-Based Services; HCBS CAHPS = HCBS Consumer Assessment of Healthcare Providers and Systems; HEDIS = Healthcare Effectiveness Data and Information Set; MLTSS = Managed Long-Term Services and Supports; NA = Not endorsed by CBE; NCQA = National Committee for Quality Assurance.

CBE #	Measure Steward	Measure Name	Data Source/Data Collection Method
NA	ADvancing States, HSRI	NCI-AD: Percentage of non-English speaking participants who receive information about their services in the language they prefer	Survey
NA	ADvancing States, HSRI	NCI-AD: Percentage of people in group settings who have enough privacy where they live	Survey
NA	ADvancing States, HSRI	NCI-AD: Percentage of people who are able to see or talk to their friends and family when they want to	Survey
NA	ADvancing States, HSRI	NCI-AD: Percentage of people who are as active in their community as they would like to be	Survey
NA	ADvancing States, HSRI	NCI-AD: Percentage of people who are ever worried for the security of their personal belongings	Survey
NA	ADvancing States, HSRI	NCI-AD: Percentage of people who can choose or change their support staff	Survey
NA	ADvancing States, HSRI	NCI-AD: Percentage of people who can choose or change what kind of services they get	Survey
NA	ADvancing States, HSRI	NCI-AD: Percentage of people who can choose or change when and how often they get their services	Survey
NA	ADvancing States, HSRI	NCI-AD: Percentage of people who feel safe around their support staff	Survey
NA	ADvancing States, HSRI	NCI-AD: Percentage of people who had adequate follow-up after being discharged from a hospital or rehabilitation/nursing facility	Survey
NA	ADvancing States, HSRI	NCI-AD: Percentage of people who had somebody talk or work with them to reduce their risk of falling or being unstable	Survey
NA	ADvancing States, HSRI	NCI-AD: Percentage of people who have transportation to get to medical appointments when they need to	Survey
NA	ADvancing States, HSRI	NCI-AD: Percentage of people who have transportation when they want to do things outside of their home	Survey
NA	ADvancing States, HSRI	NCI-AD: Percentage of people who know how to manage their chronic conditions	Survey
NA	ADvancing States, HSRI	NCI-AD: Percentage of people whose money was taken or used without their permission in the last 12 months	Survey
NA	ADvancing States, HSRI	NCI-AD: Percentage of people whose service plan reflects their preferences and choices	Survey
NA	ADvancing States, HSRI	NCI-AD: Percentage of people whose support staff do things the way they want them done	Survey
NA	ADvancing States, HSRI	NCI-AD: Percentage of people whose support staff show up and leave when they are supposed to	Survey
3622	NASDDDS, HSRI	NCI-IDD CC-3: Can Stay Home When Others Leave (The proportion of people who live with others who report they can stay home if they choose when others in their house/home go somewhere)	Survey

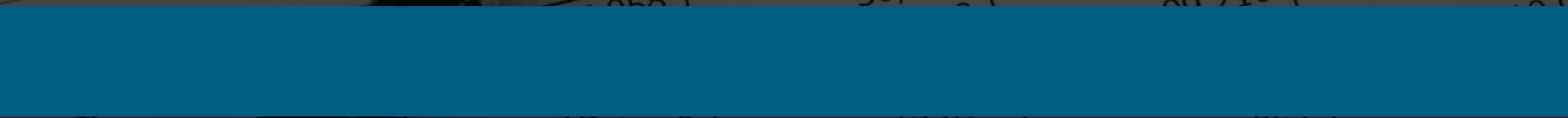
CBE = consensus-based entity; CC = Choice and Control; HSRI = Human Services Research Institute; MLTSS = Managed Long-Term Services and Supports; NA = Not endorsed by CBE; NASDDDS = National Association of State Directors of Developmental Disability Services; NCI-AD = National Core Indicators–Aging and Disabilities; NCI-IDD = National Core Indicators-Intellectual and Developmental Disabilities.

CBE #	Measure Steward	Measure Name	Data Source/Data Collection Method
3622	NASDDDS, HSRI	NCI-IDD CC-4: Life Decision Composite Measure (The proportion of people who report making choices (independently or with help) in life decisions)	Survey
3622	NASDDDS, HSRI	NCI-IDD CI-1: Social Connectedness (The proportion of people who report that they do not feel lonely)	Survey
3622	NASDDDS, HSRI	NCI-IDD CI-3: Transportation Availability Scale (The proportion of people who report adequate transportation)	Survey
3622	NASDDDS, HSRI	NCI-IDD HLR-1: Respect for Personal Space Scale (The proportion of people who report that their personal space is respected in the home)	Survey
3622	NASDDDS, HSRI	NCI-IDD PCP-2: Person-Centered Goals (The proportion of people who report their service plan includes things that are important to them)	Survey
3622	NASDDDS, HSRI	NCI-IDD PCP-5: Satisfaction with Community Inclusion Scale (The proportion of people who report satisfaction with the level of participation in community inclusion activities)	Survey
NA	NASDDDS, HSRI	NCI-IDD preventive screening single-item measures: Percentage of people who are reported to have received preventive health screenings within recommended time frames (physical exam, routine dental exam, vision screening, hearing test, mammogram, pap test, colorectal cancer screening)	Survey
NA	NASDDDS, HSRI	NCI-IDD: Percentage of people who report their staff come and leave when they are supposed to	Survey
NA	NASDDDS, HSRI	NCI-IDD: Percentage of people who report that they helped make their service plan	Survey
NA	CQL	POM: People are free from abuse and neglect	Survey
NA	CQL	POM: People choose services	Survey
NA	CQL	POM: People have the best possible health	Survey
NA	CQL	POM: People interact with other members of the community	Survey
NA	CQL	POM: People live in integrated environments	Survey
NA	CQL	POM: People participate in the life of the community	Survey
NA	CQL	POM: People realize personal goals	Survey

CBE = consensus-based entity; CC = Choice and Control; CI = Community Inclusion; CQL = The Council on Quality and Leadership; HLR = Human and Legal Rights; HSRI = Human Services Research Institute; NA = Not endorsed by CBE; NASDDDS = National Association of State Directors of Developmental Disability Services; NCI-IDD = National Core Indicators-Intellectual and Developmental Disabilities; PCP = Person-Centered Planning; POM = Personal Outcome Measures.



# Money Follows the Person Grantee States HCBS Quality Measure Set





- As required by the MFP Terms and Conditions (PTC) 43, MFP grant recipients are to implement the HCBS Quality Measure Set
- MFP grant recipients are required to report on the HCBS Quality Measure Set every other year for their Section 1915(c), 1915(i), 1915(j), and 1915(k) programs and any 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

# Reporting Requirements for MFP Grant Recipients (cont.)

- The first year of reporting will be 2026, using performance data for 2025
  - CMS expects that reporting in 2026 will be no earlier than September 1, 2026
  - New reporting forms in the Medicaid Data Collection Tool are under development
- For the initial implementation of the HCBS Quality Measure Set, MFP grant recipients will be expected to report on a subset of the measures in the measure set and to develop a quality improvement plan related to two measures of their choice

1. Conduct experience of care survey(s) for each of the major population groups included in the state or territory HCBS programs

- States and territories that conduct the HCBS CAHPS survey can report results to the database managed by the Agency for Healthcare Research and Quality (AHRQ); states and territories allowing sharing of survey results with CMS will meet its mandatory reporting requirement
- For states and territories that conduct NCI-AD, CMS plans to work with ADvancing States and HSRI to set up a process to obtain the survey results and avoid separate reporting to CMS
- For states and territories that conduct NCI-IDD, CMS plans to work with NASDDDS and HSRI to set up a process to obtain the survey results and avoid separate reporting to CMS



# CY 2026 Initial Implementation of the HCBS Quality Measure Set (cont.)

2. Mandatory reporting of two assessment/case management record measures (LTSS-1 and LTSS-2)
  - Reporting on four assessment/case management record measures (LTSS-3, LTSS-4, MLTSS-5, HCBS 10) is voluntary
3. Mandatory reporting of three claims/encounter data rebalancing measures (LTSS-6 [formerly, MLTSS-6 and HCBS-1], LTSS-7, and LTSS-8)
  - At the state or territory's option, CMS will report on the measures using Transformed Medicaid Statistical Information System (T-MSIS) data
  - Reporting on one claims/encounter data measure (all-cause readmissions) is voluntary

<b>Mandatory/ Voluntary</b>	<b>Measure</b>	<b>Data Source/Data Collection Method</b>	<b>Delivery System</b>
Mandatory	Experience of care survey(s) for each of the major population groups included in the state's or territory's HCBS programs (specific measures to be determined)	Survey	FFS/MLTSS
Mandatory	LTSS-1: LTSS Comprehensive Assessment and Update	Assessment/Case Management Record	FFS/MLTSS
Mandatory	LTSS-2: LTSS Comprehensive Care Plan and Update	Case Management Record	FFS/MLTSS
Voluntary	LTSS-3: LTSS Shared Care Plan with Primary Care Practitioner	Case Management Record	FFS/MLTSS
Voluntary	LTSS-4: LTSS Reassessment/Care Plan Update after Inpatient Discharge	Assessment/Case Management Record	FFS/MLTSS
Voluntary	MLTSS-5: Screening, Risk Assessment, and Plan of Care to Prevent Future Falls	Case Management Record	MLTSS
Mandatory	LTSS-6: LTSS Admission to a Facility from the Community	Claims/Encounter Data	FFS/MLTSS
Mandatory	LTSS-7: LTSS Minimizing Facility Length of Stay	Claims/Encounter Data	FFS/MLTSS
Mandatory	LTSS-8: LTSS Successful Transition After Long-Term Facility Stay	Claims/Encounter Data	FFS/MLTSS
Voluntary	HCBS-10: Self-direction of services and supports among Medicaid beneficiaries receiving LTSS through managed care organizations	Case Management Record	MLTSS
Voluntary	MLTSS: Plan All-Cause Readmission (HEDIS)	Claims/Encounter Data	MLTSS

- States and territories can include the costs associated with planning, implementation, and ongoing use of the HCBS Quality Measure Set in their MFP budgets
- Allowable costs include (but are not limited to):
  - Developing a quality management strategy and plan
  - Conducting experience of care surveys
  - Collecting and analyzing data for measures constructed from claims and/or encounter data and assessment/case management records

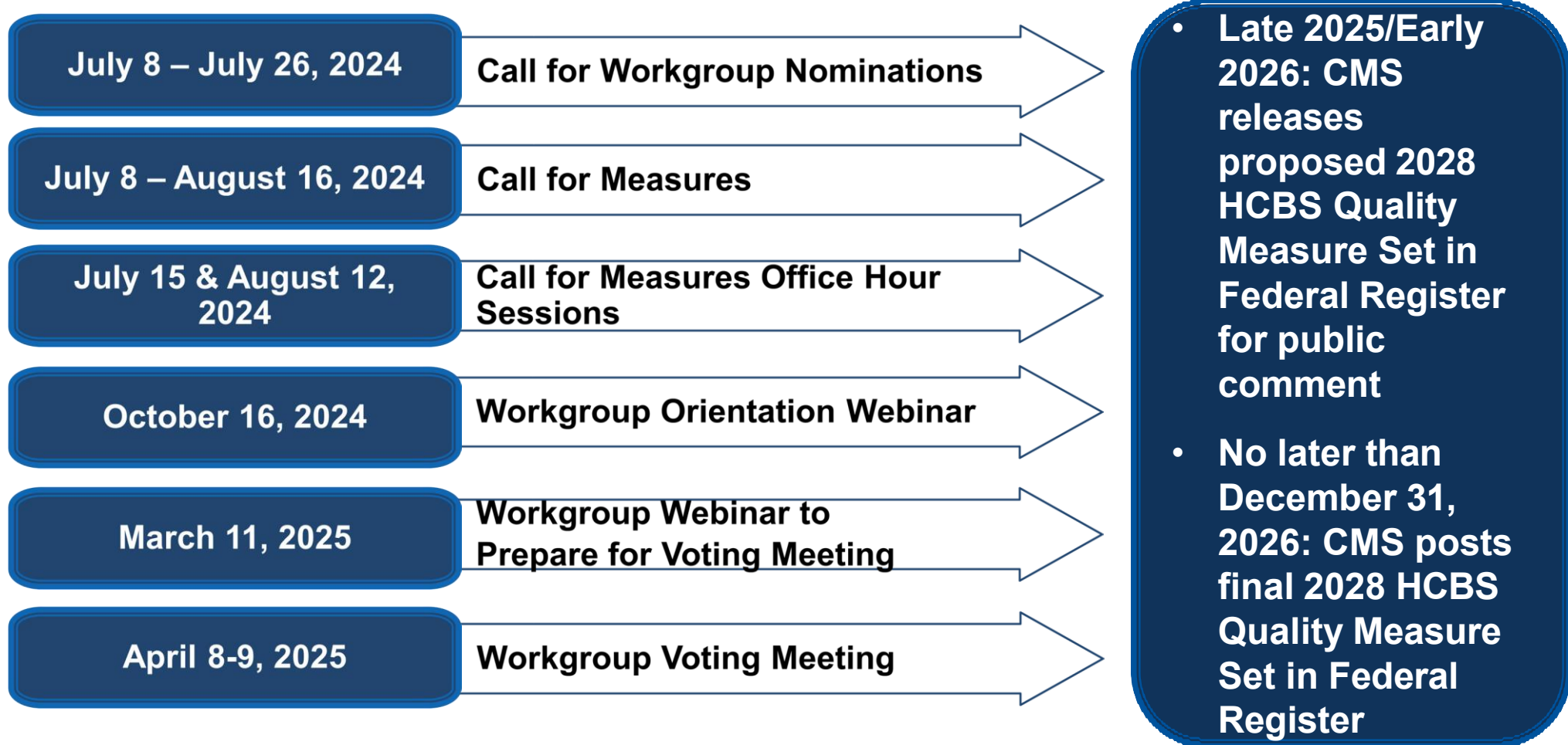
**\*As of August, CMS reports that only 50% of MFP states have requested the administrative match for HCBS QMS implementation**



# **2028 Home and Community-Based Services (HCBS) Quality Measure Set Review Workgroup**

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# 2028 HCBS Quality Measure Set Review Milestones



All webinars and workgroup meetings are held virtually and are open to the public.

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## **Measures Suggested for Removal from or Addition to the HCBS Quality Measure Set**

# Results of the Public Call for Measures

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- **For the 2028 HCBS Quality Measure Set review, members of the public were invited to suggest measures to add to or remove from the HCBS Quality Measure Set.**
  - The call for measures was open from July 8 to August 16, 2024.
- **A total of 45 measures were suggested for addition to or removal from the 2028 HCBS Quality Measure Set.**
  - **30 measures suggested for addition**
    - 6 of the 30 suggested measures for addition did not meet the criteria for workgroup discussion due to incomplete submissions and/or failing to meet the technical feasibility criteria.
  - **15 measures suggested for removal**

Domain <sup>1</sup>	Current Measures	Suggested for Removal	Suggested for Addition
Choice and Control	9	0	9
Consumer Leadership and Development	0	0	1
System Performance and Accountability <sup>2</sup>	3	1	1
Service Delivery and Effectiveness <sup>3</sup>	11	2	1
Person-Centered Planning and Coordination	9	3	0
Community Inclusion <sup>4</sup>	10	1	5
Access and Resource Allocation	3	2	0
Holistic Health and Functioning	12	3	3
Human and Legal Rights	8	3	4

<sup>1</sup> These domains were adapted from the National Quality Forum HCBS Quality Measure Framework. One domain in that framework (Caregiver Support) is not included in this list, as there are no measures currently in the HCBS Quality Measure Set, suggested for addition, or suggested for removal that fall into that domain.

<sup>2</sup> System Performance and Accountability includes rebalancing measures.

<sup>3</sup> Service Delivery and Effectiveness includes workforce measures.

<sup>4</sup> Community Inclusion includes measures of employment, non-medical transportation, social connectedness and relationships, and community participation.



**Budget Reconciliation:  
Highlights from H.R. 1, the  
*One Big Beautiful Bill Act***

# Rural Health Transformation Fund

RHT Program funding is \$50 billion

- Allocated to approved States
- \$10 billion of funding each fiscal year, beginning in fiscal year 2026 and ending in fiscal year 2030.
- 50% to be distributed equally amongst all approved States
- 50% will be allocated by CMS based on a variety of factors including rural population, the proportion of rural health facilities in the State, the situation of certain hospitals in the State, and other factors to be specified by CMS in the NOFO

# Rural Health Transformation Fund

States must use RHT Program funds for three or more of the approved uses of funds (non-exhaustive):

- Promoting evidence-based, measurable interventions to improve prevention and chronic disease management.
- Providing payments to health care providers for the provision of health care items or services, as specified by the Administrator.
- Promoting consumer-facing, technology-driven solutions for the prevention and management of chronic diseases.
- Assisting rural communities to right size their health care delivery systems by identifying needed preventative, ambulatory, pre-hospital, emergency, acute inpatient care, outpatient care, and post-acute care service lines.
- Supporting access to opioid use disorder treatment services (as defined in section 1861(jjj)(1)), other substance use disorder treatment services, and mental health services.
- Developing projects that support innovative models of care that include value-based care arrangements and alternative payment models, as appropriate.

# Rural Health Transformation Fund

## How to Apply for RHT Program Funding

- Application instructions will be included in NOFO released on September 15, 2025
- CMS will engage with States in the open application period to answer questions
- Application submissions will close in early November
- Awards will be decided by December 31, 2025

***CMS is working through governors' offices to distribute these funds—this is your point of contact***

# Community Engagement Requirements

Figure 2

## Proposed Qualifying Activities and Exemptions

Qualifying Activities	Mandatory Exemptions	Optional Hardship Exceptions
<ul style="list-style-type: none"><li>80 hours per month of work, community service, and/or “work program” participation</li><li>Enrolled in education at least half time</li><li>Any combination of the above totaling 80 hours per month</li><li>Monthly income of minimum wage multiplied by 80 hours</li><li>Seasonal workers with an average monthly income over 6 months of minimum wage multiplied by 80 hours</li></ul>	<ul style="list-style-type: none"><li>Parent/guardian/caretakers of dependent children under age 13 or disabled individuals</li><li>Pregnant or receiving postpartum coverage</li><li>Foster youth/former foster youth under age 26</li><li>Medically frail</li><li>Participating in SUD program</li><li>Meeting SNAP/TANF work requirements</li><li>American Indians and Alaska Natives</li><li>Disabled veterans</li><li>Incarcerated or released from incarceration within 90 days</li><li>Entitled to Medicare Part A/enrolled in Medicare Part B</li></ul>	<p>State option to allow short-term hardship exceptions, for an individual who...</p> <ul style="list-style-type: none"><li>was in an inpatient hospital, nursing facility, intermediate care facility, or inpatient psychiatric hospital</li><li>resided in a county with a federally-declared emergency or disaster</li><li>resided in a county with a high unemployment rate (above 8% or 1.5x the national unemployment rate), subject to a request from the state to the Secretary</li><li>traveled outside of the individual’s community for an extended period for medical care for themselves or for their dependent</li></ul>

# Community Engagement Requirements

— • The law requires HHS to release an interim final rule by June 2026 leaving states with limited time to develop or change implementation plans, protocols, and systems (and to test systems changes) before the January 2027 work requirement implementation deadline. The law allows the Secretary to exempt states from compliance with the new requirements until no later than December 31, 2028, if the state is demonstrating a “good faith” effort to comply.

***Unknowns include criteria for verifying compliance; standards for data matching; definition of “medically frail”***

# New HCBS Waiver Option

## Section 71171: Making certain adjustments to coverage of HCBS under Medicaid

- Permits the State to establish a standalone 1915(c) waiver that does not require participants to meet a nursing facility or ICF/IID level of care.
- All other 1915(c) waivers in the State must meet all statutory requirements.
- The State must demonstrate that approval of the standalone waiver will not increase average wait time to receive HCBS under any other approved waiver.
- The State must establish needs-based criteria to determine eligibility.
- The State must attest to the cost neutrality of the standalone waiver as compared to the average per capita cost of individuals receiving institutional care.
- The State must agree to submit annual reports detailing:
  - Cost of services provided under the waiver and duration of services, broken out by service type;
  - Comparison of these two data points with equivalent data on other 1915(c) waivers; and
  - The total number of participants during the preceding year.
- ***Effective July 1, 2028***

# Provider Taxes

- Freezes provider taxes at current levels for both expansion and non-expansion states.
- In expansion states, reduces hold harmless threshold for expansion states by 0.5% every year beginning in 2028 until it reaches 3.5%
- In non-expansion states, caps hold harmless threshold at 6%.
- Taxes on NF and ICF services that are in effect on May 1, 2025 are exempt from the lower hold harmless threshold, as long as the tax is not modified.



# Other Provisions

- Retroactive coverage limited to 2 months (1 month for expansion population)
- Requires HHS to certify budget neutrality for Section 1115 demonstration projects.
- Cap on State directed payments
- Establishes a lower cap of \$1,000,000 on home equity for LTSS recipients that is not waivable through asset disregards.
- Effective October 1, 2026, amends the definition of “qualified alien” to only include an alien lawfully admitted for permanent residence
  - Excludes alien visitors, tourists, diplomats, and students who enter the U.S. temporarily, certain Cuban and Haitian immigrants, and Compact of Free Association (COFA) migrants, refugees, humanitarian parolees, asylum grantees, certain abused spouses and children, trafficking victims, and other non-citizens.



# Questions?

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For More Information Please Contact:

Laura Vegas  
[lvegas@nasddds.org](mailto:lvegas@nasddds.org)

# 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?

# Georgia: How we used NCI-IDD SoTW Data to Raise the Bar

## Effective Retention Strategies & Key Accomplishments



**Significant Decrease in Employee Turnover:** Substantial reduction in turnover rates, dropping from 47% in 2020 to 32% in 2023—demonstrating a 15-percentage point decrease over four years.



**Historic Wage Increases:** The average hourly wage increased by \$2.50 between 2020 and 2023, representing a 22% relative increase.



**Investing in Our Workforce:** Georgia DBHDD established a dedicated workgroup focused on improving retention, wages, benefits, and career advancement. As a result, we developed a pilot program offering three pathways for several hundred DSPs to earn a competency-based certification (DSP Certification Pilot Program)

# CT Partners with Project SEARCH to Increase Participation of People with IDD in the NCI Project

- The Arc Favarh's Project SEARCH at the University of Connecticut (UConn) Health Center is a one-year program dedicated to building a workforce that includes people with disabilities.
- A Project SEARCH intern worked on the National Core Indicators project:



January - March



Entered  
background  
information



Shadowed  
surveys



Created a  
certificate for NCI  
survey participants



**Connecticut's NCI team plans to host more Project SEARCH interns and expand opportunities for people with IDD to be involved in the National Core Indicators project.**



Scan the QR code  
to access Project  
SEARCH at UConn  
Health Video



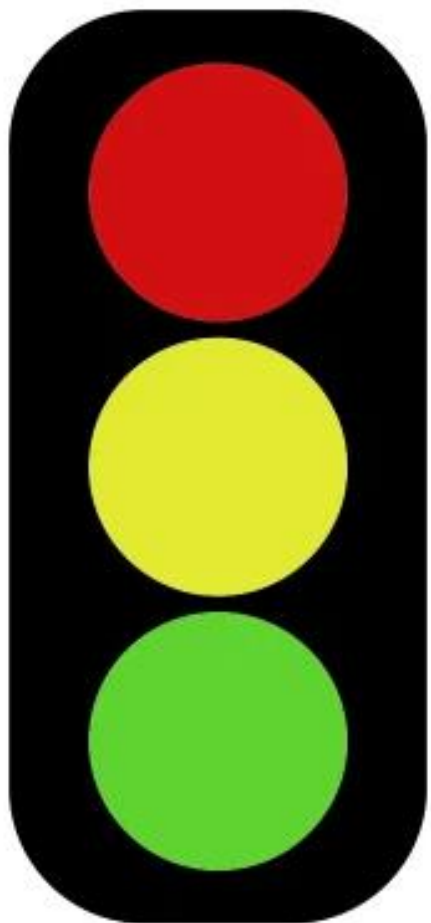




What's your greatest accomplishment with NCI-IDD this year?

- Highest ever completion rate for State of the Workforce Survey
- Received funding to conduct the In-Person Surveys

# Analyzing NCI Data Using a “Traffic Light Method” of Organization



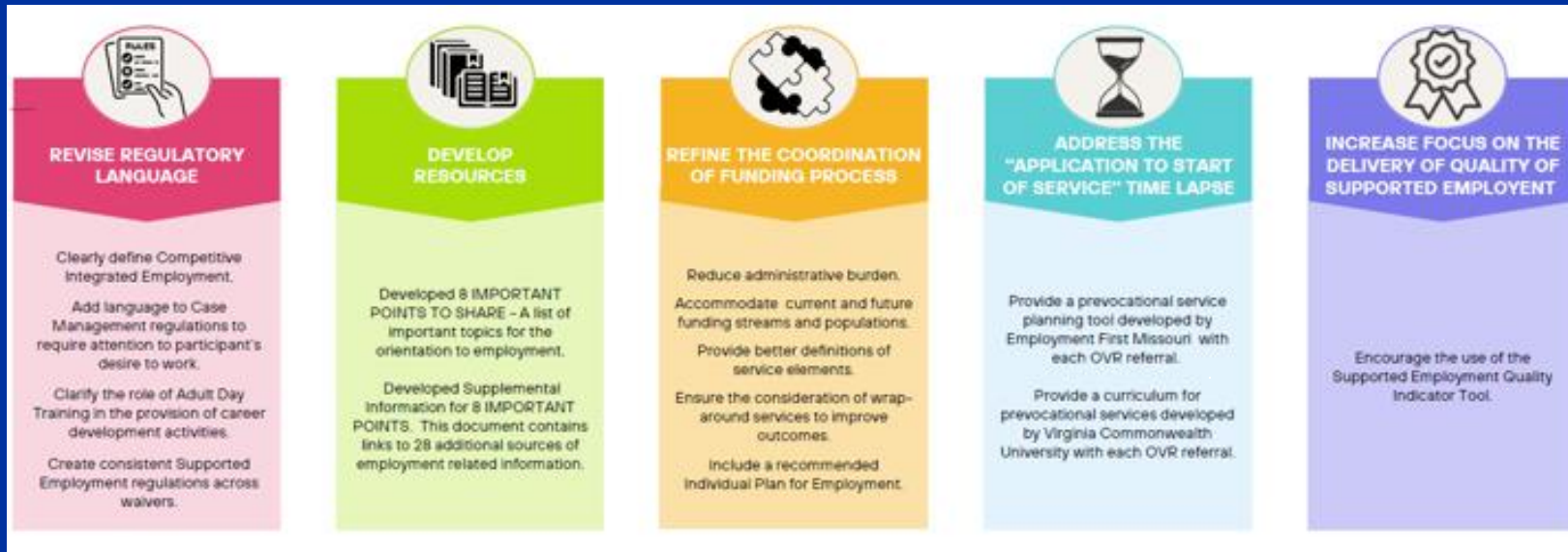
Action	Item	Ohio (n = 549)	National 30 States (n = 17,486)	% Difference
Below average, potential opportunities for improvement	Sufficient access to non-medical transportation	74%	80%	-6% Ohio
	Medicare/Medicaid dual enrollment	29%	50%	-21% Ohio
	Using a self-directed supports option	4%	21%	-17% Ohio
At or above national average, but still has growth potential	Choice of staff or were aware they could request to change staff	64%	60%	+4% Ohio
	Case manager/service coordinator has talked to them about technology that may help them in their everyday life	48%	32%	+16% Ohio
	Staff change too often	40%	42%	+2% Ohio (lower is better)
	Uses technology in everyday life to help them do things on their own	34%	30%	+4% Ohio
	Has a paid community job	22%	17%	+5% Ohio
At or above national average, sustain	Autonomy over discretionary spending	93%	90%	+3% Ohio
	Choice of regular day activities	89%	85%	+4% Ohio
	Choice of home	76%	57%	+19% Ohio
	Choice of roommates	72%	43%	+29% Ohio
	Choice of day program/vocational habilitation	71%	63%	+8% Ohio





# Kentucky Quality Improvement Committee Recommendations

## NCI Employment Recommendations

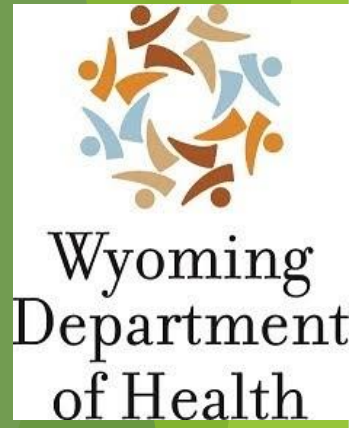


The Kentucky Division of Developmental and Intellectual Disabilities (DDID), University of Kentucky Human Development Institute (HDI), and other partners as appropriate develop an outline of items to include in the employment and community involvement informational sessions, tips for including employment goals in person-centered services plans, and information regarding transportation options.

## 8 IMPORTANT POINTS TO SHARE...

...When assisting individuals interested in competitive integrated employment.

- 1. MANY PEOPLE JUST LIKE YOU ARE WORKING AND EARNING MONEY!**  
Stay connected with the individual throughout their job search and employment journey offering encouragement, guidance, and wrap-around supports as needed. Whenever possible, share examples of other program participants who are successfully employed.
- 2. YOU HAVE TALENTS AND ABILITIES EMPLOYERS WANT AND NEED!**  
Assist individuals in recognizing their strengths, abilities, and skills, along with any necessary accommodations that might be needed for effective job performance. This process may include self-assessment and collaborating with others.
- 3. THERE ARE PEOPLE AVAILABLE TO HELP YOU FIND THE RIGHT JOB.**  
Link individuals to tailored employment services and support programs created for those with disabilities. This includes vocational rehabilitation services, job coaching, job placement aid, and skills training initiatives.
- 4. YOU CAN WORK, EARN MONEY, AND STILL KEEP YOUR WAIVER!**  
Inform the individual about their disability benefits, which include income support, healthcare coverage, and extra assistance programs. Discuss how their work earnings could affect these benefits and the eligibility criteria involved.
- 5. HELP IS AVAILABLE TO ASSIST WITH UNDERSTANDING BENEFITS.**  
Educate on government work incentive programs like the U.S. Social Security Administration's Ticket to Work and Work Incentives Planning and Assistance Programs, which can help individuals with disabilities keep benefits while being employed.
- 6. YOU CAN SAVE YOUR MONEY AND KEEP YOUR BENEFITS!**  
Assist the person to develop a plan that takes into account the use of available tools to manage resources in a manner that does not impact benefits, report income as required, and track expenses associated with employment to ensure they are appropriately utilized.
- 7. YOUR RIGHT TO WORK IS PROTECTED BY LAW.**  
Educate individuals on their rights protected by disability discrimination laws such as the Americans with Disabilities Act (ADA). These laws ensure protection against discrimination in hiring, promotions, and workplace practices.
- 8. YOU CAN GET HELP IF YOU HAVE PROBLEMS WITH YOUR JOB.**  
Provide encouragement and support to help individuals boost their confidence in handling the challenges that may arise during job hunting and employment. Stress that you and others will be available to provide assistance with challenges they may encounter.

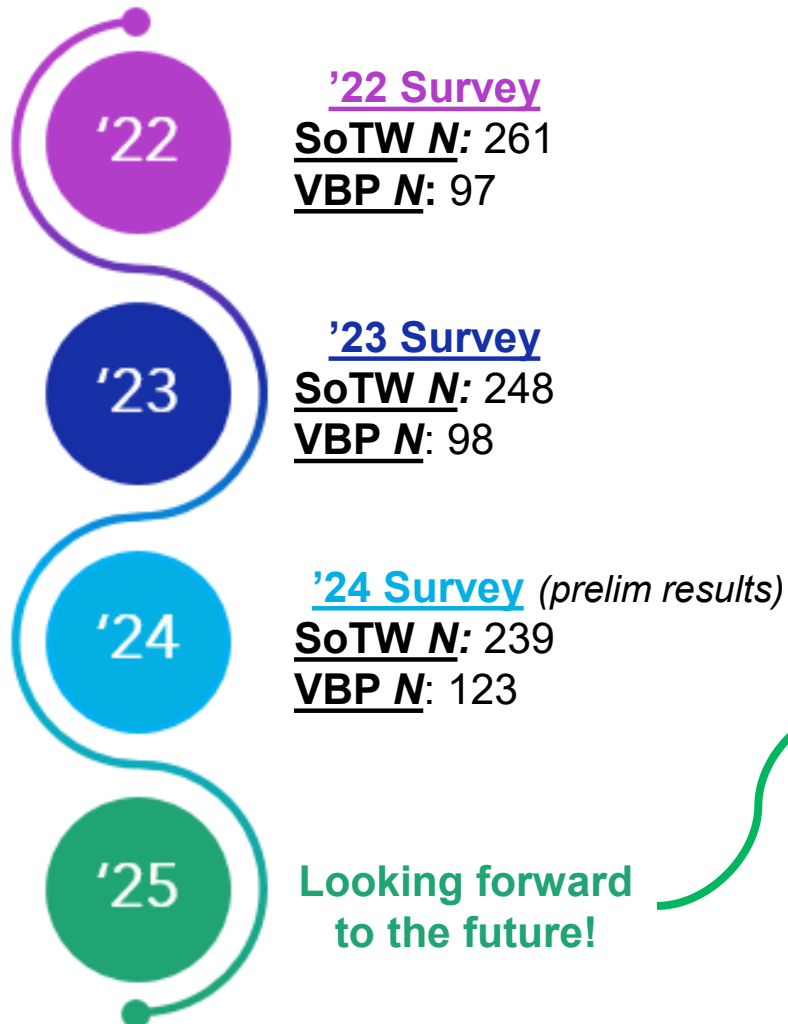


# Wyoming

## Home and Community Based Services

- What is one exciting way you've used NCI-IDD Data this year?
- NCI-IDD data is now a part of our strategic planning measures.
  - These measures are used to verify if changes are successful.

# MO One Slide Challenge: Incentivizing Participation in the NCI State of the Workforce for IDD Survey



**What:** a **\$2,000 incentive** for providers who complete the SoTW (including wages, turnover and vacancy).

**How:** providers complete the survey, then attest to it in REDCap.

Once the survey data is available, the providers that met the criteria is validated against those who submitted a survey attestation. Then, payments are processed for providers that met the initiative criteria.

**Looking forward:** as more data is collected, we will be watching to see if...

- the number of VBP participants continues to increase.
- data trends exist among providers who also participate in other VBP initiatives.

**Want to Know More?** <https://dmh.mo.gov/dev-disabilities/vbp>

# 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?

# BREAK

# Getting the “Yes”: Encouraging participation in the NCI-IDD Surveys

# Virginia



**VCU** Partnership for People  
with Disabilities  
School of Education

# Getting the Yes! & Provider Engagement

**Presenters:**

**Kayla Diggs Brody**

**Darlene Tyktor**

*with input from Leann Nussberger*



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



[diggskg@vcu.edu](mailto: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



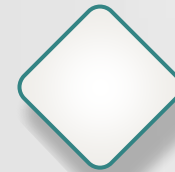
Can accommodate communication needs using Language Line, ASL interpreters, interpreters on staff, communication boards, etc.



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!

# Examples of resources to help “get to yes”

# NCI-IDD Data Spotlights



[Idd.nationalcoreindicators.org](https://idd.nationalcoreindicators.org)  
Go to Survey Reports & Insights  
Click on Data Briefs, Highlights and Spotlights.

## — Data Spotlight: Supported-decision making



Among more than 13,000 people with IDD receiving services across 26 states:

- 1 out of every 2 people have a partial or full guardian



SUPPORTED DECISION-  
MAKING

DATA SPOTLIGHT

For more information, see: [idd.nationalcoreindicators.org](https://idd.nationalcoreindicators.org)

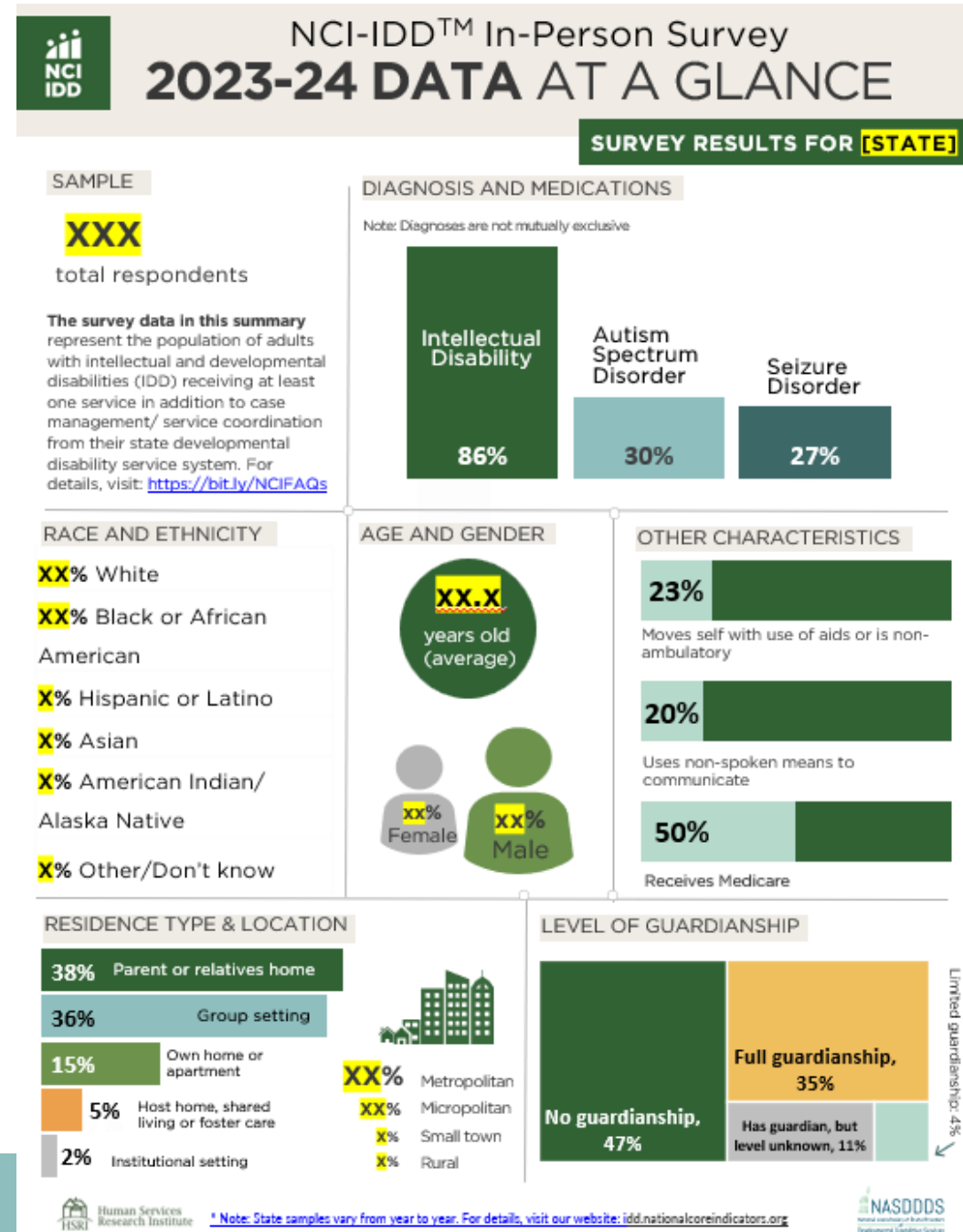
Did you know that the majority of people with intellectual and developmental disabilities who receive state DD system services have a conservatorship or guardianship in place? Across the National Core Indicators IDD surveys from 2021-22, **1 out of every 2 respondents have a partial or full guardian.**

So why does this matter? A guardianship, or conservatorship as it is sometimes called, is a legal contact that gives decision-making rights over a person to another individual. This can include decisions about finances and health care, as well as whether to marry and raise a family. In other words, people under guardianship do not have the right to make their own decisions about important matters. Because many people with disabilities have guardians, many people with disability do not have the right to make many of their own decisions.

Customizable At a Glances:

IPS and Family Surveys and  
State of the Workforce

Email [dhiersteiner@hsri.org](mailto:dhiersteiner@hsri.org)  
to request





# Videos and other resources

**Video vignette about what it is like to participate in the NCI-IDD IPS survey.**

This video is intended to be shared directly with people with IDD and their families as a **consent and decision aid**.

The video describes the

- purpose of the survey,
- rights and risks of participation,
- how we protect privacy, and
- how we use data from the survey.

SPANISH: <https://www.youtube.com/watch?v=mvlqL5PTFYU>

ENGLISH: <https://www.youtube.com/watch?v=GAs-wyoxHDs>





# I'm Going to Do An NCI Survey!

## I AM GOING TO DO AN NCI-IDD SURVEY!

A surveyor is going to ask me questions about

- What I think about things in my life,
- What I like,
- My friends,
- The services and supports I use.



I can have someone like a parent, sibling, or a staff person with me during the survey, if that makes me feel more comfortable.

That person can also help me answer **some** of the questions in the survey.



## I AM HELPING BY DOING THE NCI-IDD SURVEY

I am letting my state know:

- HOW people with disabilities are doing and
- HOW the supports they get are helping them.

I am also teaching my state about the best ways to ask questions and talk to people over the computer.

PDF:

<https://idd.nationalcoreindicators.org/wp-content/uploads/2024/05/Im-going-to-do-an-NCI-IDD-survey.pdf>

PPT for customization:

[https://idd.nationalcoreindicators.org/wp-content/uploads/2024/05/Im-going-to-do-an-NCI-IDD-survey\\_For-customization.pptx](https://idd.nationalcoreindicators.org/wp-content/uploads/2024/05/Im-going-to-do-an-NCI-IDD-survey_For-customization.pptx)

# Other resources

- Email and text templates to send remote survey appointments
- “how to access zoom”
- Zoom FAQs



## Remote Survey Meeting Appointment

EMAIL:

Dear [name],

It was great to meet you today!

Thank you for agreeing to take part in the National Core Indicators Intellectual and Developmental Disabilities® (NCI-IDD) survey over [Zoom/video conference] to learn about your life and your experiences with services from [State Agency].

We will have the survey, on: \_\_\_\_\_

At that time, please click this [link](#): \_\_\_\_\_

To learn more about NCI, visit: [www.nationalcoreindicators.org](http://www.nationalcoreindicators.org).

If you have questions or concerns about your services, please contact [contact name and info].

Thank you!

Text:

- 1) Hi [Name] this is [surveyor name]. I am looking forward to talking to you about your life and services from [agency] on \_\_\_\_\_. Are you planning to use [device] you used today?
  - a. (If phone) Great! On [date and time], open this link: \_\_\_\_\_. Sound good?
  - b. (If computer) Great! Can you tell me your email address so I can email you the video conference link on your computer?
- 2) Will you want anyone else with you for the survey? / Will [person who was present for System Check] also be with you for the survey?
  - a. (If yes) Do you have that person's phone number or email address?
  - b. Great! I'll send a reminder a few days before. Talk to you then!

Logging into a Zoom meeting using a personal computer or laptop	<a href="https://idd.nationalcoreindicators.org/wp-content/uploads/2024/05/Logging-into-a-Zoom-Meeting-using-a-personal-computer-or-laptop.pdf">https://idd.nationalcoreindicators.org/wp-content/uploads/2024/05/Logging-into-a-Zoom-Meeting-using-a-personal-computer-or-laptop.pdf</a>
Logging into Zoom meeting using iPhone or iPad	<a href="https://idd.nationalcoreindicators.org/wp-content/uploads/2024/05/Logging-into-Zoom-Meeting-Using-an-iPhone-or-iPad.pdf">https://idd.nationalcoreindicators.org/wp-content/uploads/2024/05/Logging-into-Zoom-Meeting-Using-an-iPhone-or-iPad.pdf</a>
Logging into a Zoom meeting using an Android device	<a href="https://idd.nationalcoreindicators.org/wp-content/uploads/2024/05/Logging-into-a-Zoom-Meeting-using-an-Android-device.pdf">https://idd.nationalcoreindicators.org/wp-content/uploads/2024/05/Logging-into-a-Zoom-Meeting-using-an-Android-device.pdf</a>

# Additional resources

<b>Join a Zoom Meeting from an Email Message</b>	<a href="https://idd.nationalcoreindicators.org/wp-content/uploads/2024/05/Join-a-Zoom-Meeting-from-an-Email-Message.pdf">https://idd.nationalcoreindicators.org/wp-content/uploads/2024/05/Join-a-Zoom-Meeting-from-an-Email-Message.pdf</a>
<b>Set Up Sound and Video in a Zoom Meeting</b>	<a href="https://idd.nationalcoreindicators.org/wp-content/uploads/2024/05/Set-Up-Sound-and-Video-in-a-Zoom-Meeting.pdf">https://idd.nationalcoreindicators.org/wp-content/uploads/2024/05/Set-Up-Sound-and-Video-in-a-Zoom-Meeting.pdf</a>
<b>Zoom Meeting Controls (Buttons)</b>	<a href="https://idd.nationalcoreindicators.org/wp-content/uploads/2024/05/Zoom-Meeting-Controls-Buttons.pdf">https://idd.nationalcoreindicators.org/wp-content/uploads/2024/05/Zoom-Meeting-Controls-Buttons.pdf</a>
<b>Zoom instructions</b>	<a href="https://idd.nationalcoreindicators.org/wp-content/uploads/2024/05/Zoom-instructions.pdf">https://idd.nationalcoreindicators.org/wp-content/uploads/2024/05/Zoom-instructions.pdf</a>

<b>Survey Meeting Appointment</b>	<a href="https://idd.nationalcoreindicators.org/wp-content/uploads/2024/05/TEMPLATE-Remote-Survey-Meeting-Appointment.docx">https://idd.nationalcoreindicators.org/wp-content/uploads/2024/05/TEMPLATE-Remote-Survey-Meeting-Appointment.docx</a>
<b>Survey Meeting Reminder</b>	<a href="https://idd.nationalcoreindicators.org/wp-content/uploads/2024/05/TEMPLATE-Remote-Survey-Meeting-Reminder.docx">https://idd.nationalcoreindicators.org/wp-content/uploads/2024/05/TEMPLATE-Remote-Survey-Meeting-Reminder.docx</a>
<b>‘Thank you’ message (to send after survey meeting)</b>	<a href="https://idd.nationalcoreindicators.org/wp-content/uploads/2024/05/TEMPLATE-Thank-you-message.docx">https://idd.nationalcoreindicators.org/wp-content/uploads/2024/05/TEMPLATE-Thank-you-message.docx</a>

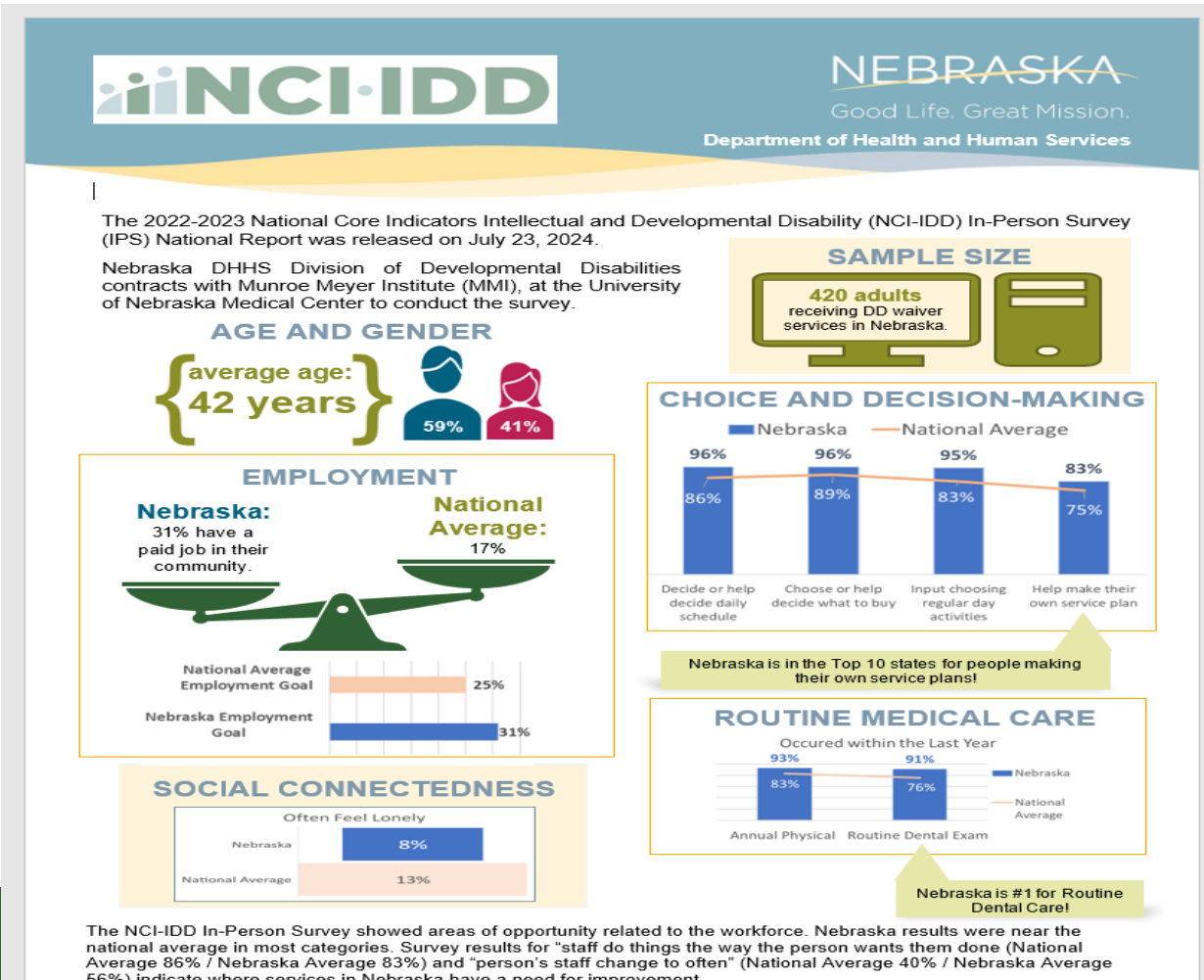
<b>Proxy/Interpreter flier</b>	<a href="https://idd.nationalcoreindicators.org/wp-content/uploads/2024/05/Proxy-and-interpreter-flier.pdf">https://idd.nationalcoreindicators.org/wp-content/uploads/2024/05/Proxy-and-interpreter-flier.pdf</a>
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# State Examples: Old and New

**Ways to share data and/or advertise the NCI-IDD surveys to encourage participation**

# Nebraska – One page at-a-glance social media campaign to share data

- Each “One Page at a Glance” permits individuals to **explore the questions answered by survey respondents in a straightforward and uncomplicated fashion.**
- A **social media campaign** is developed around each “One Page at a Glance” to disseminate the information and direct the recipients to additional resources at DHHS and other supportive entities across the State of Nebraska



# Michigan

# Sharing data



## National Core Indicators

The National Core Indicators (NCI) is a national survey used by developmental disabilities agencies to evaluate the outcomes of services provided to individuals and families. It is used in 45 states including Michigan.

### Key Areas of Concern

- Employment
- Rights
- Service planning
- Community inclusion
- Choice
- Health

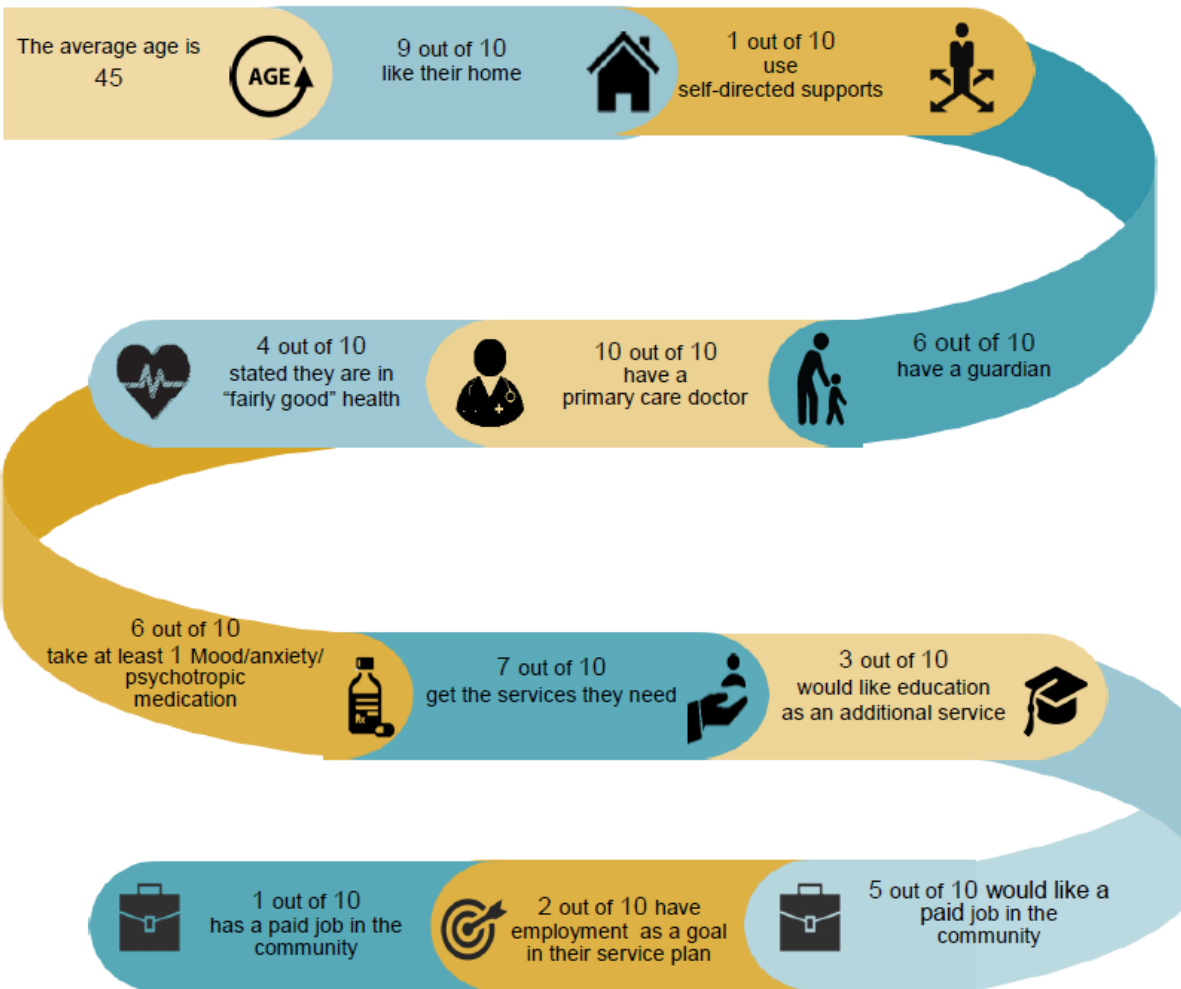
### Michigan

40,000 individual's with Intellectual and/or developmental disabilities receive services from the Michigan Department of Health and Human Services (MDHHS).

In 2015, 410 of those individuals were randomly selected to complete the NCI survey.

For the full report:  
[www.nationalcoreindicators.org/  
upload/state-reports/2014-  
15\\_ACS\\_Michigan\\_Report.pdf](http://www.nationalcoreindicators.org/upload/state-reports/2014-15_ACS_Michigan_Report.pdf)

## Michigan Report: National Core Indicators (NCI) Adult Consumer Survey Outcomes 2015



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# Arkansas: IPS Info

ONE OF THE FOLLOWING DDS QUALITY ASSURANCE/NCI STAFF MEMBERS WILL BE CONTACTING YOU SOON.

- Lynn Davenport (NCI Manager)  
870-261-6668
- Dianna Fowler (NCI Unit)  
501-541-3284
- Cory Jackson (NCI Unit)  
501-339-7624
- John "Buddy" Rhodes (NCI Unit)  
501-413-6145
- Dominique Sanders (NCI Unit)  
501-563-2963
- Earsley Winford (NCI Unit)  
501-852-8421
- Jodi Woodberg (NCI Unit)  
870-910-8557

To learn more about the project, go to:  
<http://www.nationalcoreindicators.org/states/AR/>



## The NCI Coordinator Is:

Louella "Lynn" Davenport

## Developmental Disabilities Services

PO Box 899

Forrest City, AR 72335

Phone 870-261-6668

[Louella.Davenport@DHS.Arkansas.Gov](mailto:Louella.Davenport@DHS.Arkansas.Gov)



## NATIONAL COR INDICATORS

### NATIONAL CORE INDICATORS SURVEY

### WHAT DO YOU THINK ABOUT YOUR SERVICES?



**A Quality Assurance Staff Member from the Division of Developmental Disabilities, NCI Unit will be contacting you soon!**

## WE WANT TO KNOW WHAT YOU THINK ABOUT YOUR SERVICES



We are visiting some DDS clients who receive services through CES Waiver; Home and Community Based Services (HCBS) Waivers

Your name has been randomly chosen to participate in the face to face survey. We hope you will be willing to help us.

A DDS/NCI Staff member will ask permission to come to your home for about one hour. He/she will ask you when is the best time to visit.

He/she may also ask to bring a volunteer to help with the interview.



We will talk with you and your family or support staff about your services.

We will ask if we're doing a good job of providing the services on your plan.

The information we gather will be used to make our services better for everyone.



Arkansas is one of 48 states and Washington D.C. that participate in the National Core Indicators (NCI).

It is a survey used by states to measure how an individual state is performing and compare that information with other states.

States use these survey responses to make changes in the way they do business, to improve services, and to meet federal requirements.

Reports of survey results are kept confidential and do not include names or other information that might identify you.

For more information about the National Core Indicator, visit:

[www.nationalcoreindicators.org](http://www.nationalcoreindicators.org)



## NATIONAL CORE INDICATORS



# Alabama: IPS info

The graphic features a purple background with a white grid pattern and stylized white clouds. At the top, the text 'NCI SURVEY' is in large white letters, with 'COMPLETED BY QLARANT QUALITY SOLUTIONS' in smaller white letters below it. In the center, there are three overlapping paper-like shapes: a pink one with 'YOUR' in white, a teal one with 'VOICE' in black, and a red one with 'MATTERS!' in white. A small yellow folder icon is at the bottom right of these shapes. Below the shapes, a blue box contains text about the survey. At the bottom, an orange box contains contact information.

**NCI SURVEY**  
COMPLETED BY QLARANT QUALITY SOLUTIONS

**YOUR VOICE MATTERS!**

THE ADULT IN-PERSON SURVEY IS A FACE-TO-FACE INTERVIEW WITH INDIVIDUALS WHO RECEIVE SERVICES AND USES STANDARD QUESTIONS DESIGNED TO MEASURE KEY AREAS SUCH AS:

- INDIVIDUAL OUTCOMES RELATED TO WORK, COMMUNITY ACTIVITIES, CHOICE AND DECISION MAKING, RELATIONSHIPS AND SATISFACTION.
- HEALTH, WELFARE AND RIGHTS INCLUDING SAFETY, WELLNESS AND RESPECT.
- SYSTEM PERFORMANCE SUCH AS ACCESS TO SERVICES AND PLANNING.

**QUESTIONS?**  
IF YOU HAVE ANY QUESTIONS ABOUT THE NCI ADULT IN-PERSON SURVEY OR THE PROCESS, PLEASE CONTACT QLARANT QUALITY SOLUTIONS AT 866-755-3506 OR EMAIL THE PROJECT COORDINATOR JESSY JUSTMAN AT [JUSTMANJ@QLARANT.COM](mailto:JUSTMANJ@QLARANT.COM).

## WHAT IS NCI?

NATIONAL CORE INDICATORS (NCI) IS A JOINT EFFORT BETWEEN THE NATIONAL ASSOCIATION OF STATE DIRECTORS OF DEVELOPMENTAL DISABILITIES SERVICES (NASDDDS) AND THE HUMAN SERVICES RESEARCH INSTITUTE (HSRI). THE PURPOSE OF THE PROGRAM IS TO GATHER INFORMATION ABOUT SATISFACTION OF SERVICES RECEIVED FROM PEOPLE WHO HAVE AN INTELLECTUAL OR DEVELOPMENTAL DISABILITY. THE DATA COLLECTED IS USED BY THE ALABAMA DIVISION OF DEVELOPMENTAL DISABILITIES (DDD) TO TRACK PERFORMANCE AND OUTCOMES OVER TIME AND COMPARE RESULTS FROM OTHER PARTICIPATING STATES. NCI IS A VOLUNTARY ACTIVITY AND IS A UNIQUELY VALUABLE SOURCE OF INFORMATION USED TO HELP DDD IDENTIFY POSSIBLE IMPROVEMENTS NEEDED TO THE SERVICE SYSTEM IN ALABAMA.

## WHAT IS THE ADULT IN-PERSON SURVEY?

NATIONAL CORE INDICATORS (NCI) IS AN ANNUAL PROJECT ALABAMA USES TO MEASURE OUTCOMES FOR DEVELOPMENTAL DISABILITIES SERVICES. DDD HAS CONTRACTED WITH QLARANT QUALITY SOLUTIONS TO CONDUCT THE SURVEY THIS YEAR AND INTERVIEWS WILL BE CONDUCTED THROUGH TO THE END OF JUNE.

## WHO PARTICIPATES?

EACH YEAR WE INVITE A RANDOM SAMPLE OF PEOPLE SUPPORTED AND THEIR FAMILY MEMBERS AND GUARDIANS TO COMPLETE IN-PERSON INTERVIEWS ABOUT THE SERVICES THEY HAVE RECEIVED. THE SURVEY IS COMPLETELY VOLUNTARY. ARRANGEMENTS CAN BE MADE FOR PEOPLE WHO NEED A COMMUNICATION DEVICE, INTERPRETER OR OTHER SUPPORTS. THE INTERVIEW CAN BE CONDUCTED AT THE PERSON'S HOME OR DAY PROGRAM. GUARDIANS OR CAREGIVERS CAN BE PRESENT IF THE PERSON OR GUARDIAN WANTS. ONCE THE SURVEY STARTS, THE PERSON OR GUARDIAN CAN DECIDE TO STOP AT ANY TIME. THE RESULTS OF THE PERSON'S SURVEY ANSWERS ARE KEPT PRIVATE.



# South Dakota:

## Data and survey info

### NATIONAL CORE INDICATORS

#### 2021 Adult In-Person Surveys

#### What are NCI In-Person Surveys?


South Dakota DDD contracts with the Center for Disabilities to administer NCI surveys and collect data.

The NCI In-Person Survey is a casual face-to-face interview by a NCI surveyor with a participant.

It is used to assess the quality and outcomes experienced by adults with IDD receiving publicly funded DD supports.


The participant can have a support person or proxy present, if needed.


All participant info and responses are confidential.



#### Due To Covid...

Interviews will be done remotely via Zoom.







Has Helped 93%    Has Not Helped 7%

Satisfaction

93% of participants in the 2018-19 Adult In-Person Survey stated the services and supports they receive have helped them live a good life.




Interview data is beneficial to providers, case management agencies, people receiving support, families, and the State. It can determine where improvements should be made to increase the quality of services.




NCI will work with each potential participant's Conflict Free Case Manager to gather consent to participate.

NCI and Community Support Providers will work together to schedule interviews. If the person is independent, lives at home or receives Family Support, NCI will contact the participant or their parent/guardian directly.



Questions?  
Lenora Heckel, NCI Coordinator  
Center for Disabilities  
(605) 357-1451



UNIVERSITY OF  
SOUTH DAKOTA  
SANFORD SCHOOL OF MEDICINE  
Center for Disabilities

# Wisconsin: Family Survey Info

## CHILD FAMILY SURVEY



### You can help us!

The Wisconsin Department of Health Services is surveying families of children with intellectual and developmental disabilities or delays about their child's quality of life.

By taking this survey, you are helping us understand and improve the services your child is getting.



### QUESTIONS

#### We will ask about:

- Your child's health.
- Your child's safety.
- Your child's transportation.
- Your child's supports and services.
- People paid to help your child.
- Your child's case manager.
- The things your child does in the community.

Answers are



private.



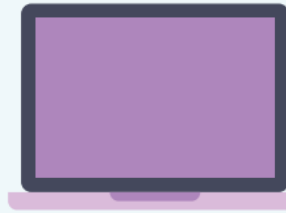
25 minutes  
to complete.



Please complete the survey as soon as you can.



### HOW TO COMPLETE THE SURVEY



#### Online

You will receive a letter with your access code.

- 1 Go to [ncifamilysurveys2024.com](https://ncifamilysurveys2024.com)
- 2 Enter the access code from your letter. Then, select "Wisconsin."
- 3 Complete the survey.



### FOR YOUR INFORMATION

#### A case manager is a:

- Support and services coordinator
- Service coordinator



#### Support workers and a care team are:

The paid staff that directly helps with your child's current services and supports.



#### A service plan is an:

- Individual service plan
- Individualized family service plan
- Individualized program plan



#### If you have questions:



You can call the NCI Coordinator at 608-471-3901.



WISCONSIN DEPARTMENT  
of HEALTH SERVICES




P-01778 | (03/2025)

# Missouri: Family Survey info and data

## We need your feedback!

The Missouri Division of Developmental Disabilities invites you to participate in the National Core Indicators (NCI) project.

Information such as what is shown below is gathered through the **Adult Family Survey**. Your responses are used to assess the quality of services and help the Division make improvements.




**The average age of family members for whom the 2014-15 survey was completed was 34.7 years old; the majority in all states were male (58% nationally).**

Most respondents of the 2014-15 Survey indicated services and supports have reduced their family's out-of-pocket expenses related to their family member's care (85%).

Nearly all respondents felt services and supports made a positive difference in their family's life (96%).

More than half of respondents reported that they or their family member were always able to contact support workers (58%) and the service coordinator (56%) when needed.

To see all the data from the NCI Adult Family Survey 2014-15, please visit [www.nationalcoreindicators.org](http://www.nationalcoreindicators.org)



# Louisiana: Family Survey Info and Data



OFFICE FOR CITIZENS WITH DEVELOPMENTAL DISABILITIES (OCDD) WOULD LIKE YOU TO PARTICIPATE IN THE NATIONAL CORE INDICATOR (NCI) PROJECT.

## NCI FAMILY SURVEY

CHECK YOUR MAIL IN FEBRUARY FOR THE SURVEY PACKET!

6 out of every 10 people (60%) surveyed across the state reported their family member with a developmental disability has friends other than paid staff or family.  
(2017 NCI Family Guardian Survey)

2 out of every 10 people with a developmental disability (20%) surveyed reported having a paid job in the community. Nine out of every ten of the people with a job (90%) said they like where they work.  
(2017 NCI Adult Consumer Survey)

7 out of every 10 people (70%) state reported across the information they get about services is always or usually easy to understand.  
(2017 NCI Adult Family Survey)

At least 90% of families with children receiving services reported that services & supports through OCDD were helping their child to live a good life.  
(2017 NCI Child Family Survey)

Would you like to add your views and experiences?

NCI SURVEY RESULTS ARE AN IMPORTANT SOURCE OF CITIZEN FEEDBACK FOR OCDD, LOUISIANA DEPARTMENT OF HEALTH, AND STATE LEGISLATORS

SOME OF THE PREVIOUS SURVEY RESULTS



HELP ENSURE THAT LOUISIANA CONTINUES TO STRENGTHEN SERVICES

NO COST TO YOU

NO INDIVIDUAL OR FAMILY NAMES ARE REPORTED

PLEASE TAKE A LOOK AT OUR SURVEY RESULTS FROM PREVIOUS YEARS BY VISITING

THE WEBSITE AT:  
[HTTPS://WWW.NATIONALCOREINDICATORS.ORG/RESOURCES/REPORTS/](https://www.nationalcoreindicators.org/resources/reports/)



This public document was published at a total cost of \$864.35. Six thousand (6,000) copies of this public document were published in this first printing at a cost of \$864.35. The total cost of all printings of this document, including reprints is \$864.35. This document was published by OTS-Production Support Services, 627 North 4<sup>th</sup> Street, Baton Rouge, LA 70802 for the Office for Citizens with Developmental Disabilities for the purpose of obtaining information about quality of life and quality of services from families of people receiving developmental disabilities services under the authority of the Louisiana Department of Health. This material was printed in accordance with standards for printing by state agencies established pursuant to R.S. 43:31. Printing of this material was purchased in accordance with the provisions of Title 43 of the Louisiana Revised



# Hemingway! First draft...

The screenshot shows the Hemingway Editor web application in a browser. The address bar displays 'hemingwayapp.com'. The interface includes a top navigation bar with the Hemingway Editor logo and a menu with options like 'File', 'Fix Grammar', 'Rewrite', and 'Paragraph'. A central text area contains a paragraph of text about NCI-IDD and NCI-AD surveys, with several sentences highlighted in red. On the left, there is a sidebar with a 'Try Free' button and a description of the 'Hemingway Editor Plus' features. On the right, a sidebar provides readability feedback, stating 'Post-graduate' readability and 'Poor. Aim for 9.' It also shows 'Words: 113' and a list of sentences that are 'very hard to read' or 'hard to read'. A bottom sidebar offers a link to 'Find grammar and spelling issues with Editor Plus'.

Hemingway's classic desktop app. Save/load files and work offline. No AI. [Learn more](#)

**Hemingway Editor**

File **Plus** ✎ Fix Grammar **Plus** ✎ Rewrite **Plus** Paragraph ▾ B I ↺

How to use Hemingway Menu ▾

Write Edit Feedback

**Readability** ⓘ ⓘ  
**Post-graduate**  
Poor. Aim for 9.

**Words: 113**  
Show more stats ▾

5 of 5 sentences are very hard to read.

0 of 5 sentences are hard to read.

Find grammar and spelling issues with Editor Plus.

**AI Tools - Try Free**

**Hemingway Editor Plus**  
Fix highlighted issues, check grammar, and adjust tone.  
Free 2-week trial.

Want to learn how to use Hemingway Editor?  
[Open Tutorial](#)

This brief examines data from NCI-IDD In-Person Survey (IPS) and NCI-AD) Adult Consumer Survey (ACS to shed light on the populations of people self-directing their supports and their experience of self-direction. These two self-direction data sets show that there are notable differences both among each survey population and between NCI-AD and NCI-IDD respondents. These include differences in demographics (e.g., diagnosis, race and ethnicity, level of disability) of those who use self-direction and differences in their experience of self-direction. The experiential differences also vary by personal characteristics, such as mode of communication and age. This brief concludes with recommendations for public managers as they consider how to expand service users' access to self-direction.

# Hemingway! Second draft...

The screenshot shows the Hemingway Editor Plus web interface. The browser address bar displays "hemingwayapp.com". The interface includes a top navigation bar with the Hemingway logo and a toolbar with options like "File", "Fix Grammar", "Rewrite", "Paragraph", "B", "I", and "Q". A sidebar on the left promotes "AI Tools - Try Free" and "Hemingway Editor Plus". The main text area contains a document draft with yellow highlights. The right sidebar provides readability metrics and feedback.

Hemingway's classic desktop app. Save/load files and work offline. No AI. [Learn more](#)

**Hemingway Editor**

File **Plus** Fix Grammar **Plus** Rewrite **Plus** Paragraph B I Q

How to use Hemingway Menu

Write Edit Feedback

**Readability** ⓘ ⓘ  
Grade 7  
Good.

Words: 120  
Show more stats ▾

0 of 15 sentences are very hard to read. ⓘ

2 of 15 sentences are hard to read. ⓘ

Find grammar and spelling issues with Editor Plus.  
**Upgrade**

0 weakeners. Nice work. ⓘ  
[View details](#)

0 words with simpler alternatives. ⓘ

**AI Tools - Try Free**

**Hemingway Editor Plus**  
Fix highlighted issues, check grammar, and adjust tone.  
Free 2-week trial.

Want to learn how to use Hemingway Editor?  
[Open Tutorial](#)

This brief looks at data from two surveys to learn about people who self-direct their supports.

The surveys are:

1. NCI-IDD In-Person Survey (IPS). This is a survey of people with intellectual and developmental disabilities.
2. NCI-AD Adult Consumer Survey (ACS). This is a survey of people with physical disabilities and older adults.

We wanted to know more about the experience of people who use self-direction. The data show that there are key differences between NCI-AD and NCI-IDD respondents. There are also key differences in experiences by personal factors. We found differences based on:

- How people communicate
- Race and ethnicity
- Level of disability
- Age.

This brief shares ideas for public managers as they try to improve access to and quality of self-direction.

# State specific questions

To add or not to add?

# Indiana





September 2025



# ***VALIDATING AND CONTEXTUALIZING SELF-REPORTED OUTCOMES IN INDIVIDUALS WITH IDD***

*A MIXED-METHODS EXAMINATION USING THE NCI IN-PERSON SURVEY*

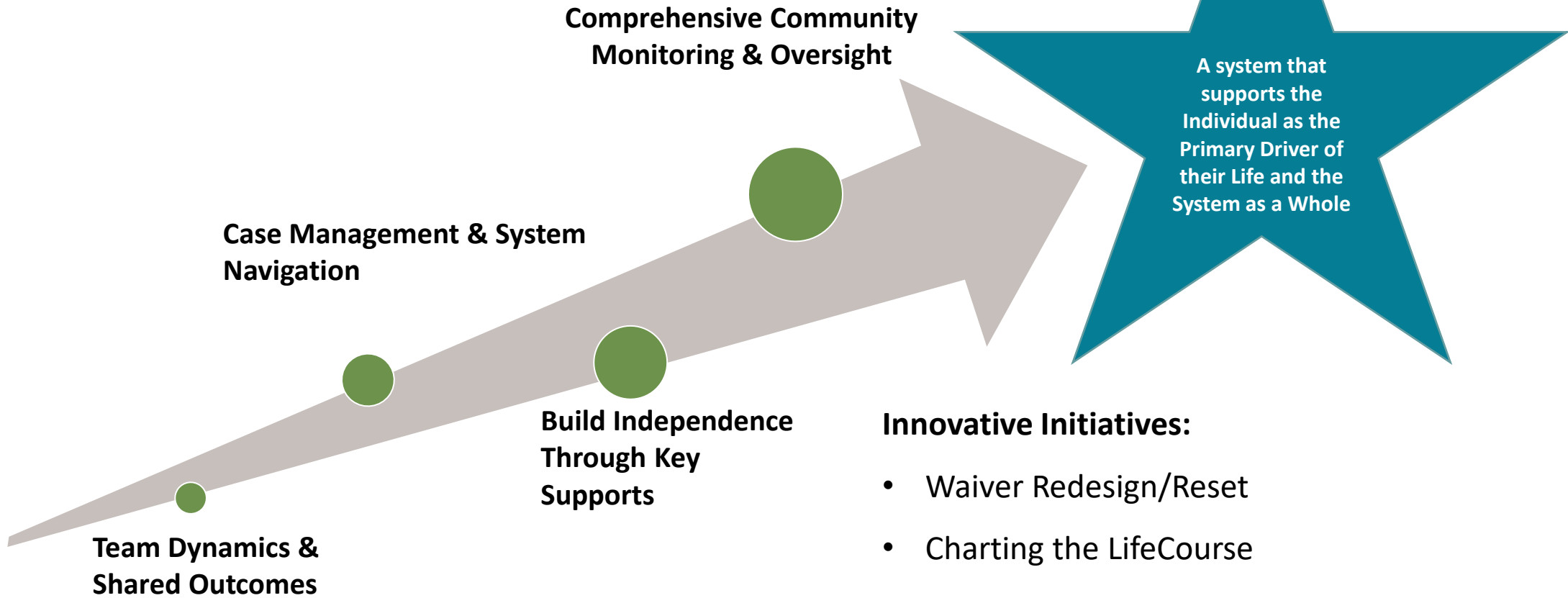
DR. ALLISON HOWLAND

GRACE KESTLER

INDIANA INSTITUTE ON DISABILITY & COMMUNITY



# A Trajectory Toward Transformation



## Innovative Initiatives:

- Waiver Redesign/Reset
- Charting the LifeCourse
- Case Management Innovation
- Competitive Integrated Employment



# IN NCI-IDD Portfolio

## Family Surveys

### Family Guardian

~ 7,000 total population  
1,500 randomly sampled bi-annually  
~28% response rate

### Adult Family

~ 15,000 total population  
1,500 randomly sampled bi-annually  
~28% response rate

### Child Family

~ 10,000 total population  
1,500 randomly sampled bi-annually  
~ 18% response rate

## State of the Workforce

120 providers

92% response rate 2022

## In-Person Survey

26,000 (CIH, FS, SGL)

~850 interviewed annually

# State-Added Question Development

## What to ask, analyzing & results

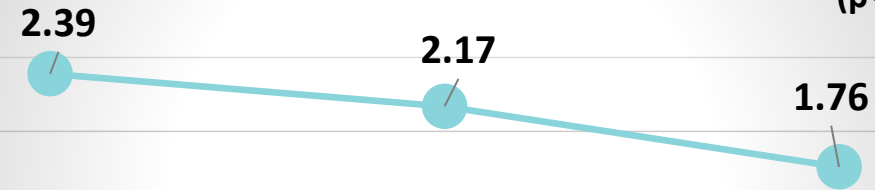


- How we decide – wanted more nuanced information on state priorities:
  - Individual Choice
  - Case Management
  - Service planning,
  - Employment
- Confirm/Question/Extend Quantitative Data
- Built on Objective State-Added Questions
- Rational – avoiding leading questions, offering various answers for context, opportunity to capture more details
  - Allowing for authentic responses

### Choice by Level IDD

N=1064

(p<.001)



MILD

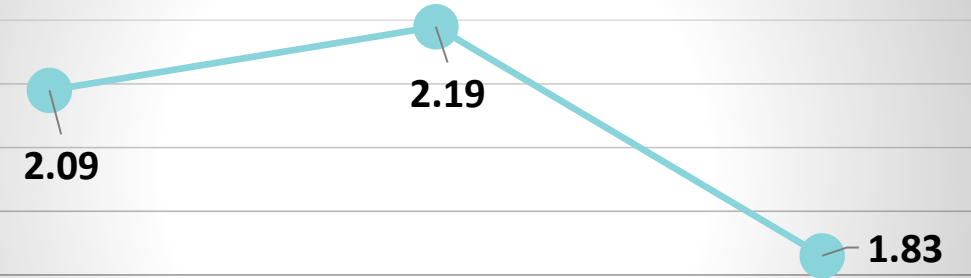
MODERATE

SEV/PROFOUND

### Choice by Program

N=1033

(p<.001)



CIH

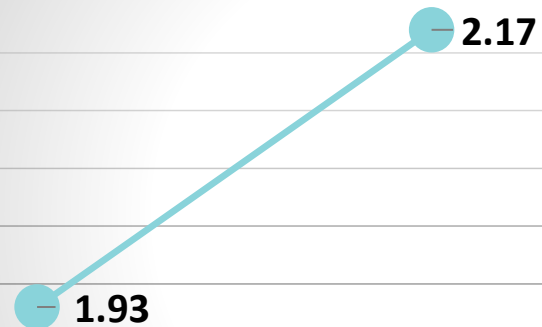
FS

SGL

### Choice by Guardianship

N=1015

(p<.001)



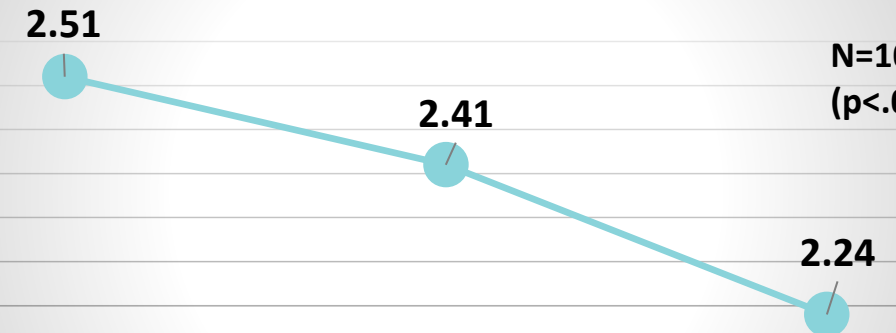
YES

NO

### Choice by Paid Employment

N=1014

(p<.001)



COMM

COMM & FACILITY

FACILITY



# NCI 23-24 Sample (n = 698)

## RACE & ETHNICITY

82.4%	White
13.9%	Black or African American
3.4%	Hispanic or Latino
.3%	Other

## AGE

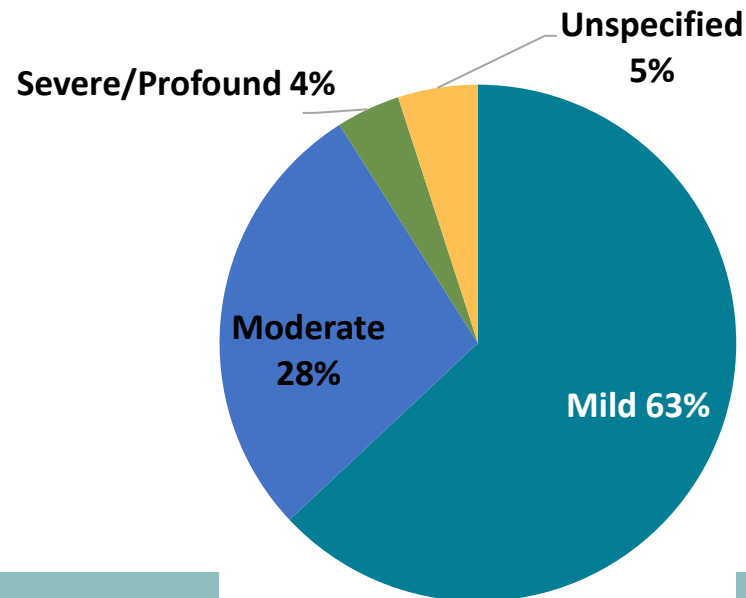
Male  
59%

18-24 years: 13%  
25-39 years: 35%  
40-59 years: 32%  
60+ years: 20%

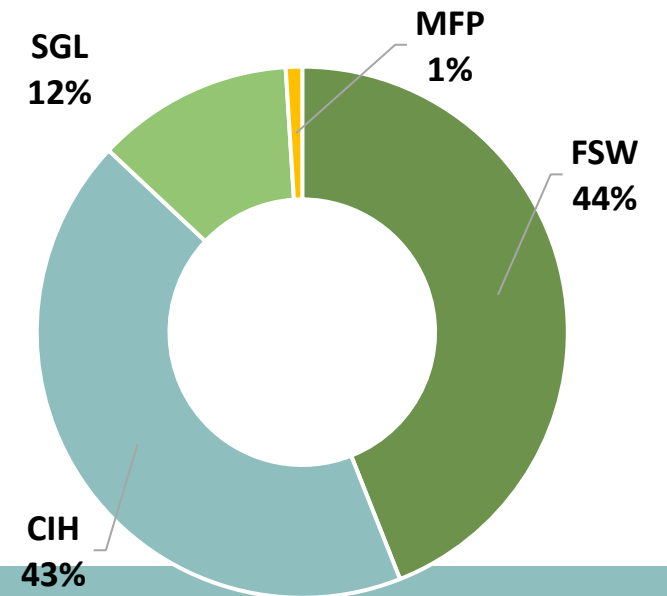
Female  
41%

**43.3**  
years old  
(average)

## LEVEL OF IDD



## PROGRAM





## Indiana DDRS Definition of ‘Choice’

Choice is when anyone has **ownership and control** in their **daily life and decisions**, with **opportunity to seek information, explore and consider a variety of available possibilities**, and **request guidance, advice, and other supports**. Choice includes the **ability to take risks, to succeed, to fail, to try again, and to change one’s mind**, as well as the **assurance of respect for decisions and support to “follow through.”**

# NCI IPS Choice Scale

## Life Choices

- Employment
- Where you live
- Who you live with

## Everyday Choices

- Daily Schedule
- Spending Money
- Activities

## Example Question

**Who chose (or picked) the place you work?**

Respondent: 1 ☐ Person 2 ☐ Family/Friend 3 ☐ Staff 4 ☐ Other

98 ☐ Not applicable – no paid community job

2 ☐ **Person made the choice**

3 ☐ **Person had help making the choice**

1 ☐ **Someone else made the choice**

99 ☐ Don't know, no response, unclear response

## Scoring (Recorded)

3 = Made choice by themselves

2 = Had help making choice

1 = Someone else made choice for them







# IN State-Added Choice Questions

**What decisions (choices) do make on your own/by yourself?** *Check all that apply. Read each response option.*

98 ☐ N/A ( Consumer does not make any choices)

1 ☐ Financial (how you spend your money)

2 ☐ Healthcare (the kind of healthcare/appointments you go to and when; taking medication)

3 ☐ Meals (the kind of food you eat and when)

4 ☐ Housing (where you live)

5 ☐ Employment (your job)

6 ☐ Daily Schedule (when to go to bed or get up)

7 ☐ What you do in your free time

8 ☐ Having visitors or friends over

9 ☐ Using the phone or internet

10 ☐ Other: Click or tap here to enter text.

For the decisions you don't make on your own, how are they decided?

99 ☐ Don't know, no response, unclear response



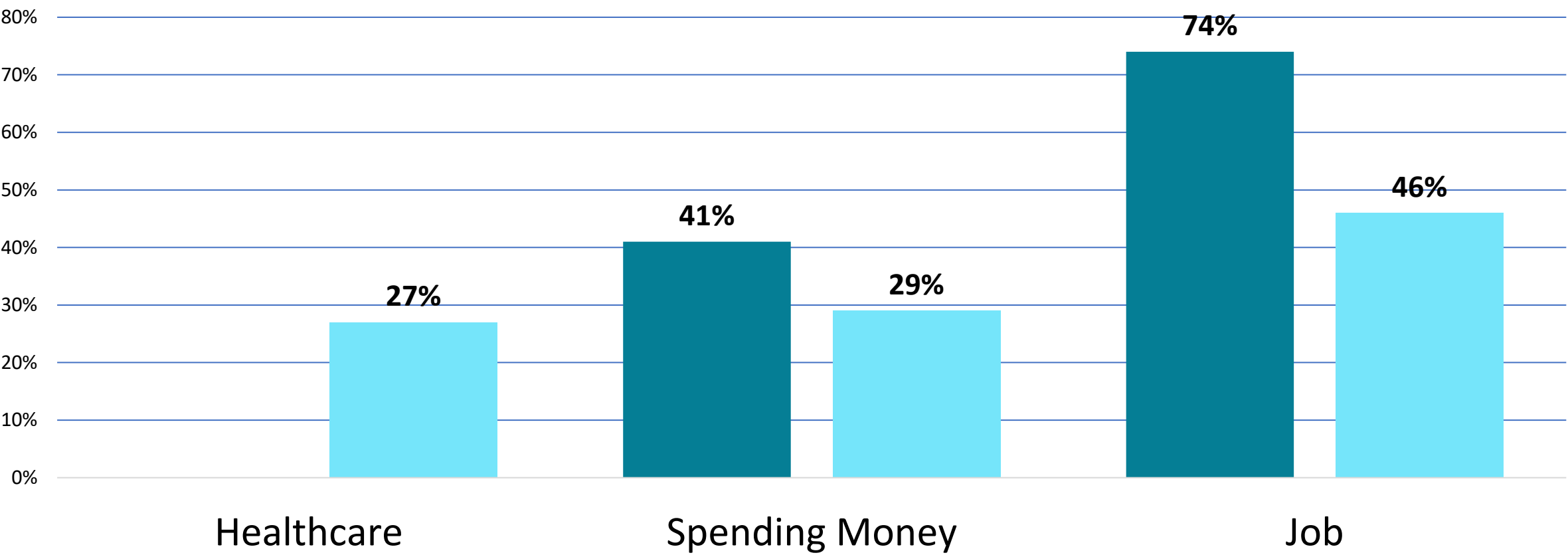
# NCI 23-24 Choice (n = 698)

What decisions (choices) do make on your own/by yourself?

Choice	Response	%
Finances	217	31.1%
Healthcare	205	29.4%
Meals	320	45.8%
Housing	282	40.4%
Employment	332	47.6%
Daily Schedule	608	87.1%
Free Time	622	89.1%
Visitor or Friends	590	84.5%
Phone/Internet	572	81.9%
Other	7	1.0%
N/A no choices	52	7%



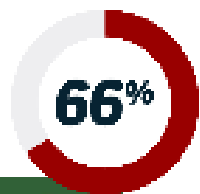
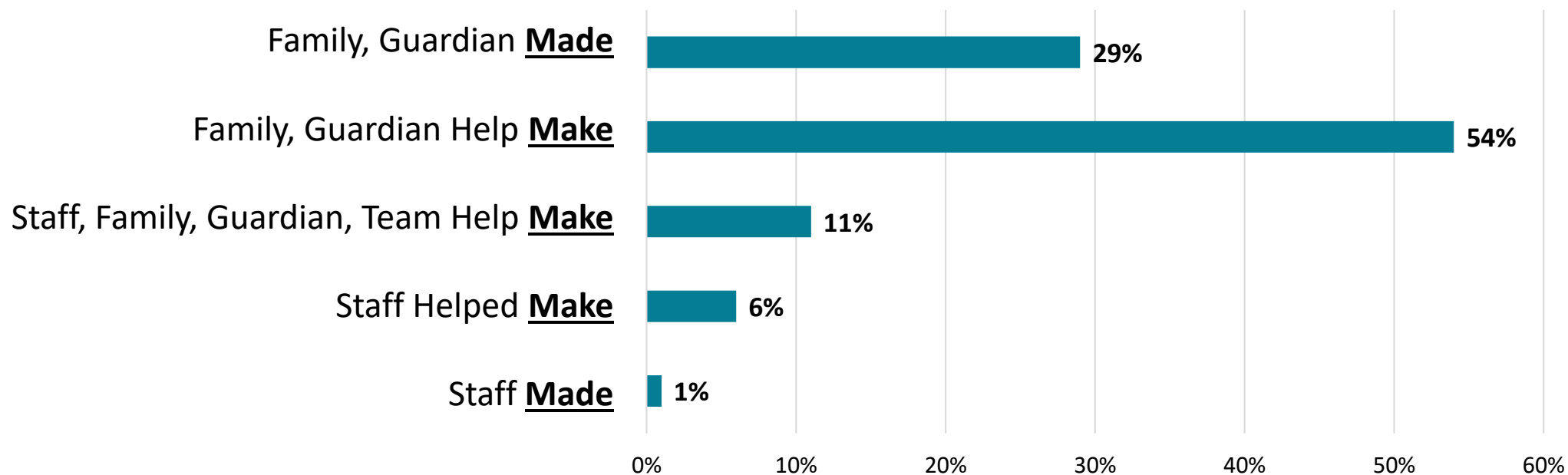
# Choice Question Comparisons



■ **NCI: Who chose...(job, schedule, etc.)**  
■ **State Added: What choices do you make by yourself (on your own)?**



For the decisions you don't make on your own, how are they decided?



**Emancipated**




Specifically Referred to Guardians Making the Decisions (e.g. believed they were under guardianship)



# Paid Community Job Comparisons (N=156)

## NCI standard question: Do you like working there?

- *PS-6*  Do you like working at *Click or tap here to enter text.*?
- 98 ☐ Not applicable – no paid job in the community
- 2 ☐ Yes
- 3 ☐ In-between
- 1 ☐ No
- 99 ☐ Don't know, no response, unclear response



**Yes**



**No**

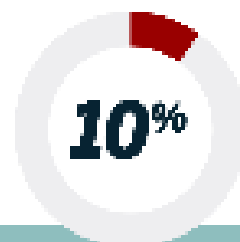


**In-between**

### State added open-ended question:

Is your current job the right job for you?

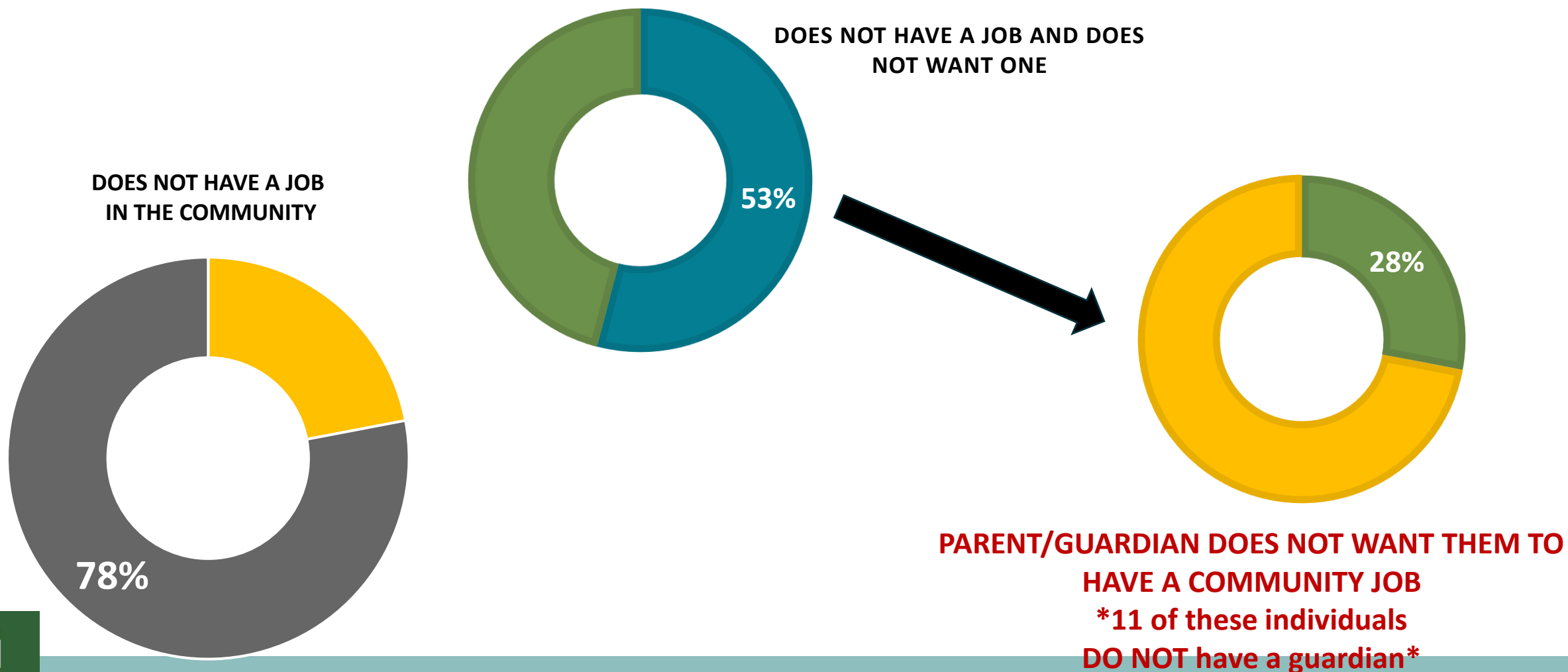
- How do you know?
- Suggested reword: Why or why not?



**Want a different job** (% who said "yes" to do you like working there)

# Open-ended State Question:

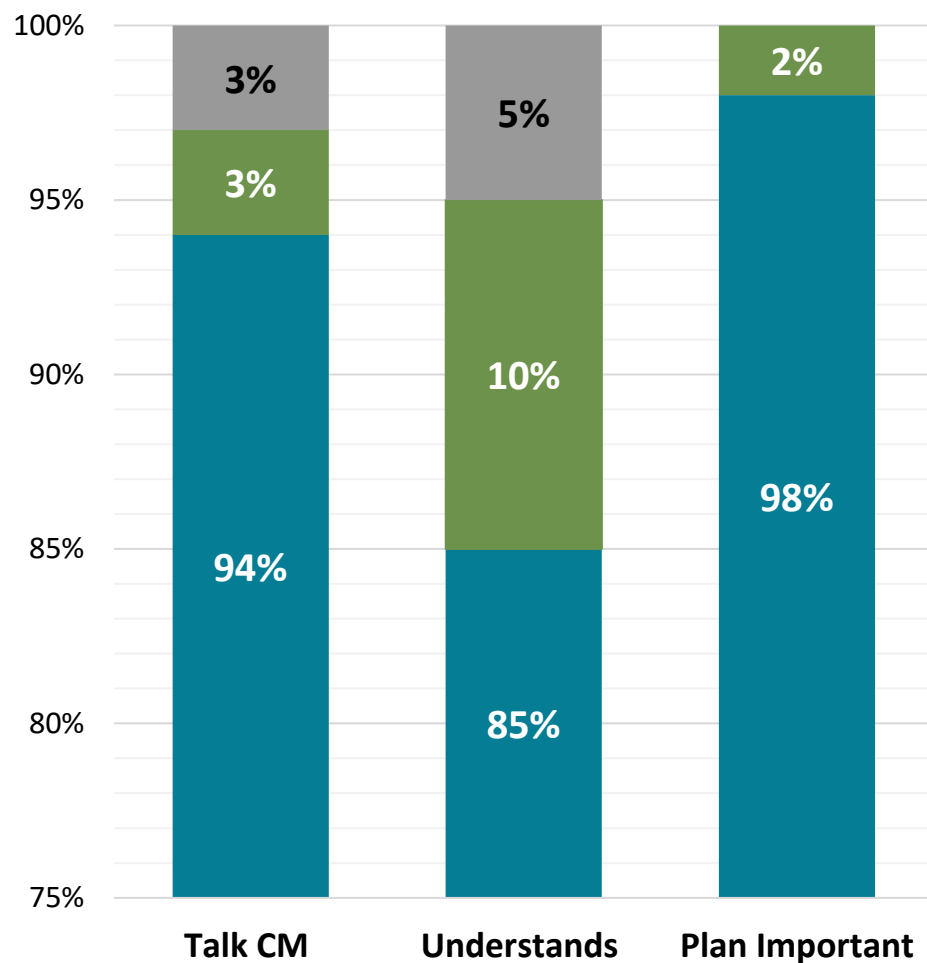
Why don't you want a paid job in the community?





# Case Management & Service Planning

## How did you participate in SPM?



■ No  
■ Some/Sometimes  
■ Yes



Engaged (asks/answers/tells what they want)



Leads/decides (sets goals, makes own decisions)



Mostly listens / minimal input



Guardian-led decisions



# Thank you!

Allison Howland - NCI Co-PI In-Person Surveys

ahowland@iu.edu

Grace Kestler – Project Coordinator

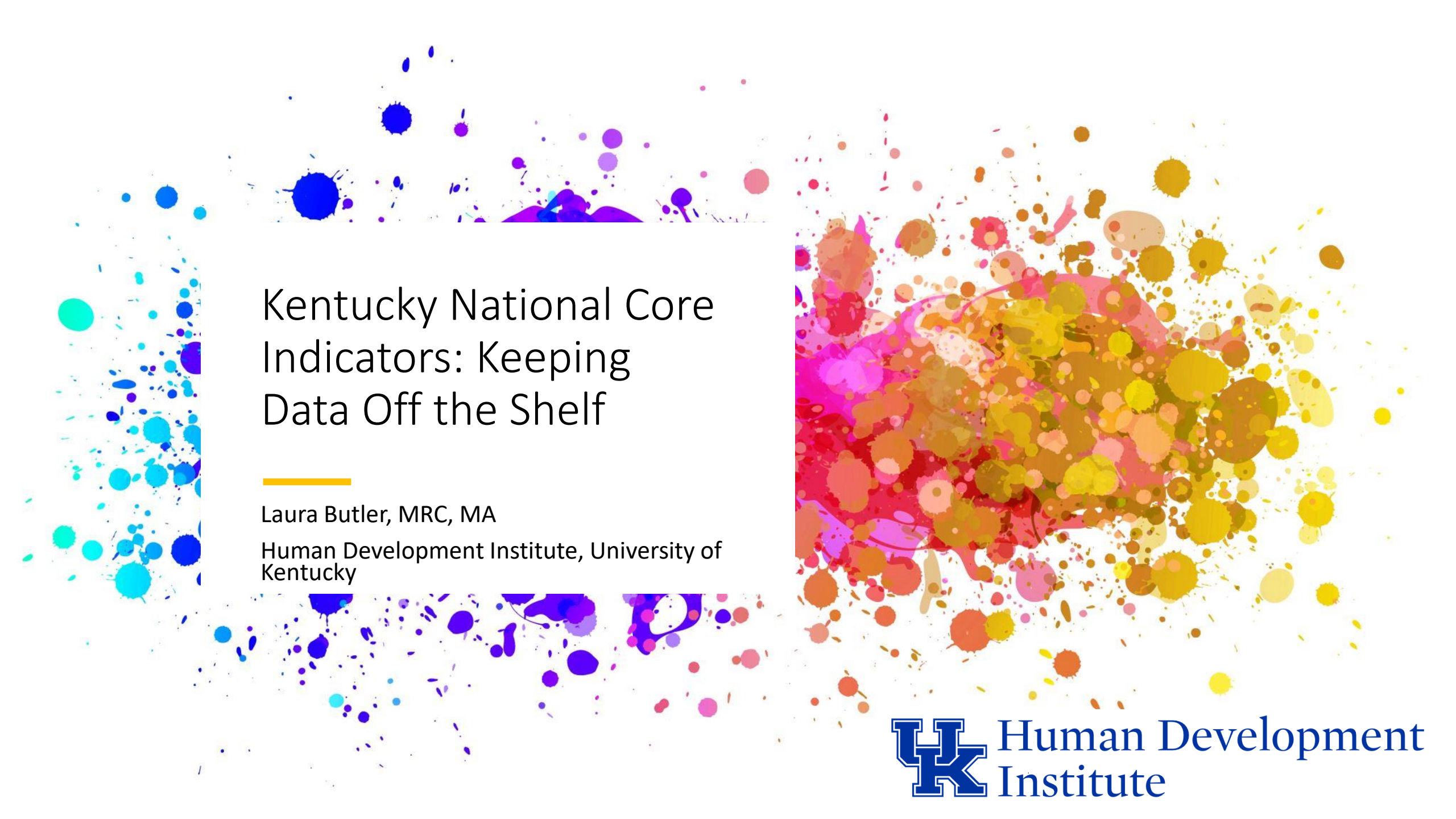
gkestler@iu.edu



**THE INDIANA INSTITUTE ON  
DISABILITY AND COMMUNITY**



# Kentucky



# Kentucky National Core Indicators: Keeping Data Off the Shelf

---

Laura Butler, MRC, MA

Human Development Institute, University of Kentucky

# What is the Secret Sauce?

- Relatable
- Trust is earned
- Provides value to provider agencies
- Captures experiences of those who are often overlooked
- Builds evidence for decision-making
- Stays current
- Participatory Action approach
- Translational research is powerful





# KY NCI Quality Improvement Committee Members

- Individuals with Disabilities
- Researchers
- KY NCI staff
- Interviewers
- State Division of Developmental & Intellectual Disabilities agency staff
- Family members
- Rehabilitation professionals



# NCI Quality Improvement Committee Reports

## Kentucky National Core Indicators Recommendations Report

Submitted by the NCI  
Quality Improvement  
Committee



2024

## 2024 QUALITY IMPROVEMENT COMMITTEE RECOMMENDATIONS

- Each year we survey at least 400 people who are receiving either the Supports for Community Living waiver (SCL) or the Michele P (MPW) waiver.
- A group of people meets to look at the information from these surveys and make suggestions for making people's lives better.
- These suggestions are called recommendations.
- Suggestions are made in four different areas:

### Employment



### Relationships & Community Inclusion



### Health & Wellness

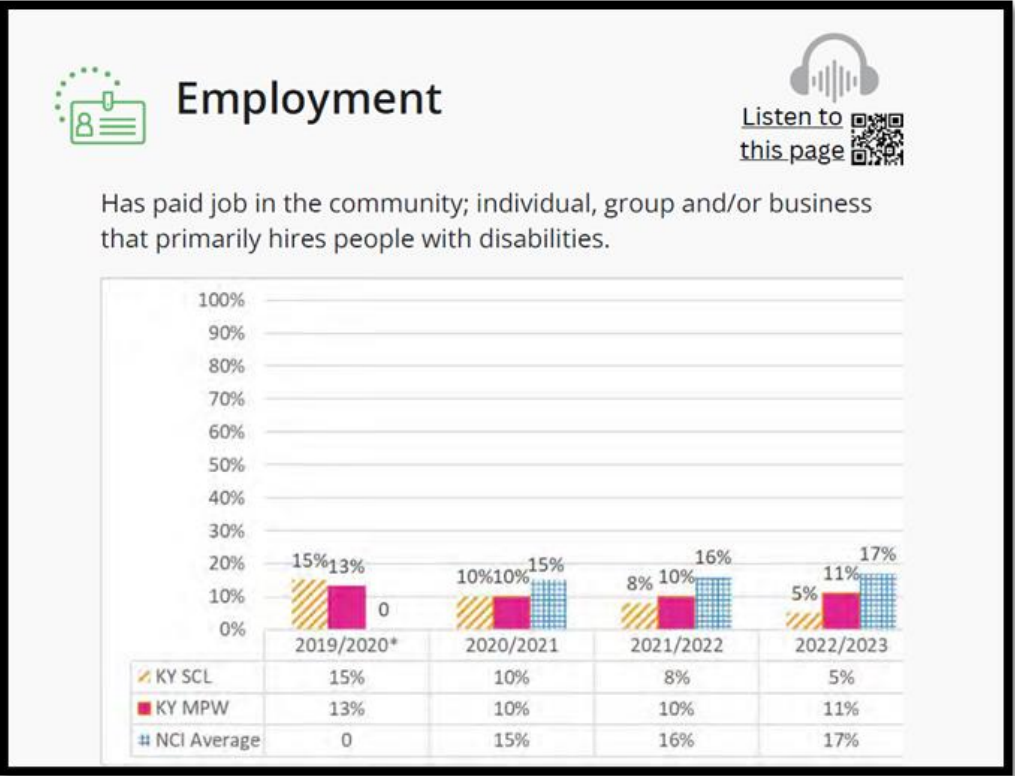


### Rights & Respect



- Some suggestions are for the people who provide services such as case managers, direct support professionals, and the people who are in charge of agencies.
- Other suggestions are for people who work for the state or other groups such as Protection and Advocacy or the Human Development Institute.

# NCI Quality Improvement Committee Reports, Continued



## 2024 Quality Improvement Committee Recommendations

- The committee made recommendations in five main areas:

  - employment
  - health and wellness
  - relationships and community inclusion
  - psychotropic medication usage
  - rights and respect
- Rights and respect

  - The area of rights and respect was added last year by the committee after reviewing the related items in the full 2022-2023 data report as well as preliminary Kentucky data from the 2023-2024 survey cycle.
- Providers vs. partners

  - Most recommendation areas include separate recommendations for providers and organizational partners.
  - The recommendations for providers are meant to promote individual-level change and the organizational partners' recommendations are meant to promote systems-level change.
- Resources

  - The committee also suggested resources to assist individuals and organizations who implement changes based on the recommendations.
  - This report details each recommendation and accompanying resources as well as items from the In-Person Survey that will be used to measure changes in each of the areas.
- Data

  - The data used to inform the committee's recommendations can be found in Appendix B.



# Adding Questions

- Added questions have changed significantly over the years
- Questions are added to:
  - Track outcomes due to new initiatives
  - Dig into concerning data trends
  - Address state-specific issues or concerns
- Most questions come from the QIC members
- HDI works with HSRI to develop question wording and response options.

# Background Question

**BI-KY1 What is the person's highest completed level of education?**

- ☐ 1. No School
- ☐ 2. Grade School
- ☐ 3. Some High School
- ☐ 4. High School Diploma/GED
- ☐ 5. High School Certificate
- ☐ 6. Some College
- ☐ 7. Some Vocational/Technical School
- ☐ 8. College Degree
- ☐ 9. Other \_\_\_\_\_
- ☐ 99. Don't know



# Employment Questions

**KY 5 *If not working, ask:* You said that you do not have a job, has your Case Manager or service provider talked with you about finding a job? (For example, has your Case Manager talked to you about what you might want to do, observe at different businesses, how to apply for a job, going to job fairs, getting information about VR, etc.)**

- ☐ **98 Not Applicable – person is working**
- ☐ **2 Yes**
- ☐ **3 In-between/maybe**
- ☐ **1 No**
- ☐ **99 Don't know, no response, unclear response**

**KY 6. *If person has a job, ask:* Thinking about the amount of hours you work each week, would you like to work more hours?**

- ☐ **98 NOT Applicable- does not work**
- ☐ **2 Yes**
- ☐ **3 In-between/ maybe**
- ☐ **1 No**
- ☐ **99 Don't know, no response, unclear response**



# Employment Questions (cont)

*KY7 If person is not taking classes, training, or skills building to help get a job/get a different job (refer to Question 10), ask: **You said that you are not taking any classes, training, or skills building right now, would you like to do any of these to help you get a job/get a different job?***

- ☐ 98 Not Applicable – taking classes, training, or skills building to help get a job/get a different job
- ☐ 2 Yes
- ☐ 3 In-between/maybe
- ☐ 1 No
- ☐ 99 Don't know, no response, unclear response





# Medication/Healthcare Questions

**KY-1 If you take medication, do you know what it's for/why you take it?**

- ☐ 98 NOT Applicable, does not take medication
- ☐ 2 Yes
- ☐ 3 In-between/ maybe
- ☐ 1 No
- ☐ 99 Don't know, no response, unclear response

**KY-4 Do your doctors talk to you about your healthcare and medicine in a way that is easy for you to understand?**

- ☐ 2 Yes
- ☐ 3 Sometimes or some providers
- ☐ 1 No
- ☐ 99 Don't know, no response, unclear







## “Healthy” Things Questions

**KY-2 Do you get to do the type of healthy things you like to do? This can include things like taking walks, exercising, playing sports, gardening, making or eating healthy food, or anything else that makes you feel healthier.**

- ☐ 2 Yes
- ☐ 3 Sometimes
- ☐ 1 No
- ☐ 99 Don't know, no response, unclear response

**KY 3. Do you get to do those healthy things as often you like?**

- ☐ 98 NA, does not get to do healthy things
- ☐ 2 Yes
- ☐ 3 Sometimes
- ☐ 1 No
- ☐ 99 Don't know, no response, unclear response

# Communication Question

**KY-8. *If person does have a cell phone or smartphone, ask:* How do you use your phone? Select all that apply. (read responses)**

- ☐ 1 Talk or text with family
- ☐ 2 Talk or text with friends
- ☐ 3 Meet with your case manager, or other people who help you
- ☐ 4 Meet with your doctor, nurse, or dentist (include speech, physical, or occupational therapists)
- ☐ 5 Video chat
- ☐ 6 Access the internet
- ☐ 7 Call for assistance/help
- ☐ 99 Don't know, no response, unclear response





# Self-Advocacy Question

**KY 10. Do you know about any self-advocacy groups in your area?**

- ☐ 2 Yes
- ☐ 3 In-between/ maybe
- ☐ 1 No
- ☐ 99 Don't know, no response, unclear response



# Required by State Agency for Reporting

**KY 9. Do you receive information about how to identify and report abuse, neglect, and/or exploitation?**

- ☐ 2 Yes
- ☐ 3 In-between/ maybe
- ☐ 1 No
- ☐ 99 Don't know, no response, unclear response

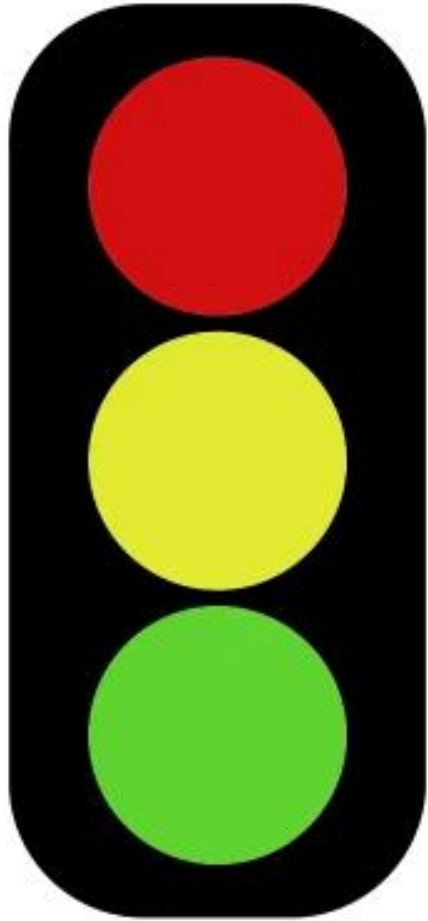


# Contact

- Laura Butler
  - [laura.smith2@uky.edu](mailto:laura.smith2@uky.edu)
- Links:
  - <https://hdi.uky.edu/>
  - <https://www.kentuckycq.org/>
  - <https://idd.nationalcoreindicators.org/>

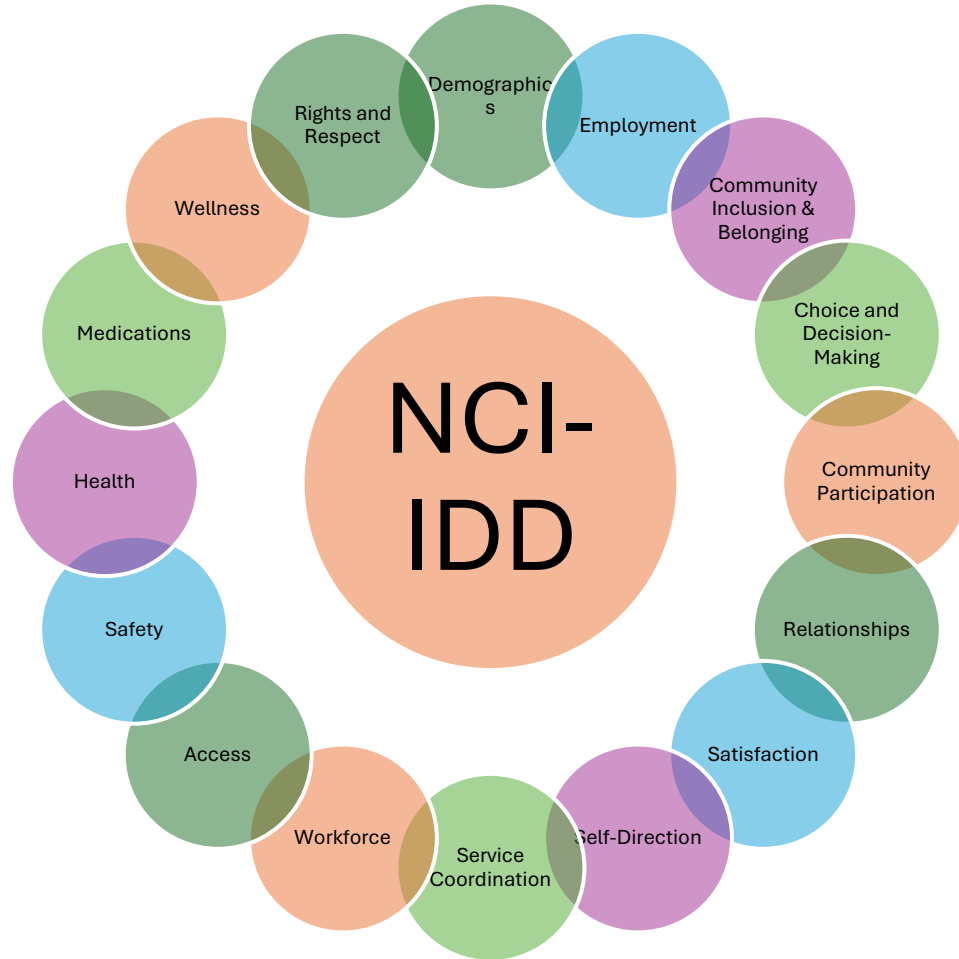


# Ohio

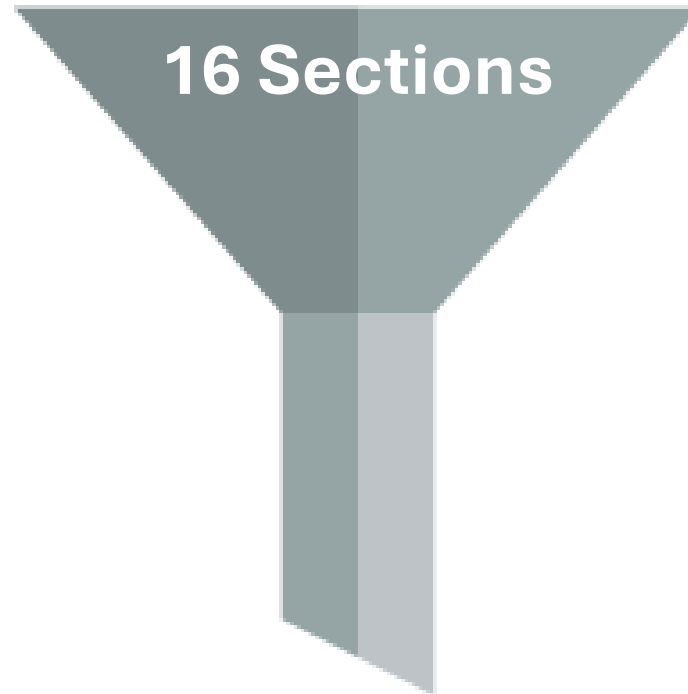


# **Analyzing NCI Data Using the “Traffic Light Method” of Organization To Monitor Quality and Progress**

# Challenge: Making Sense of Lots of Data

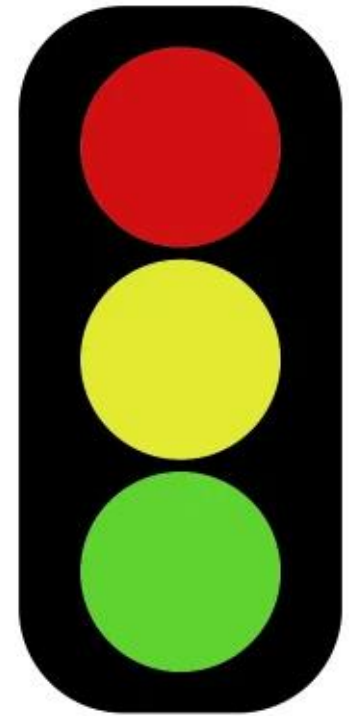
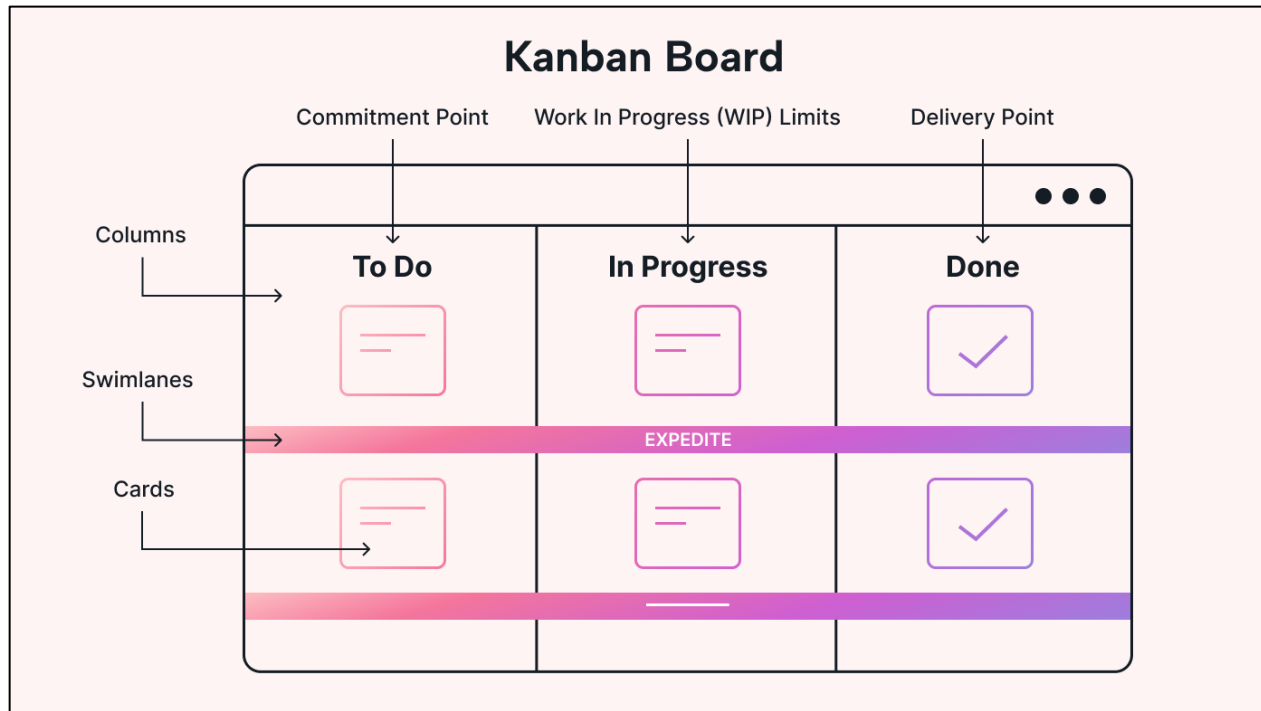


# Challenge: Identifying Opportunities for Quality Improvement Projects



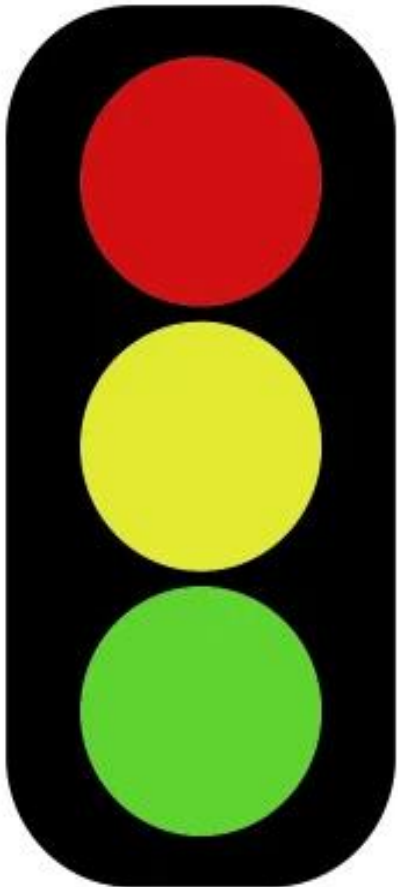
**Identifying a few opportunities for  
process improvement**

# Solution: Organizing Data Using a “Traffic Light Method” Inspired by Lean Six Sigma Kanban Board





# Analyzing NCI Data Using a “Traffic Light Method” of Organization



Action	Item
<b>Below average, potential opportunities for improvement</b>	1.) Your state is performing below national average <u>AND/OR</u> 2.) Only a minority and/or or an unacceptable amount of people report a “positive outcome” 3.) Quality improvement is based on state’s strategic plan, priorities, feasibility, demand, etc.
<b>At or above national average, but still has growth potential</b>	1.) Your state is performing at or above national average <u>BUT</u> 2.) Only a minority and/or or an unacceptable amount of people report a “positive outcome” 3.) Quality improvement is based on state’s strategic plan, priorities, feasibility, demand, etc.
<b>At or above national average, sustain</b>	1.) Your state is performing at or above national average 2.) A majority and/or acceptable amount of people report a “positive” outcome 3.) No need to work on improvement, but work to sustain this outcome

# Step 1: Create a Spreadsheet of State Data vs National Data

<b>Table 34. Has a paid community job; individual, group, and/or in a business that primarily hires people with disabilities”</b>		
<i>Also known as “competitive employment”. Information may have been obtained through state records.</i>		
State	Average within State	N
OH ↑	22%	507
NCI-IDD Average	17%	14736

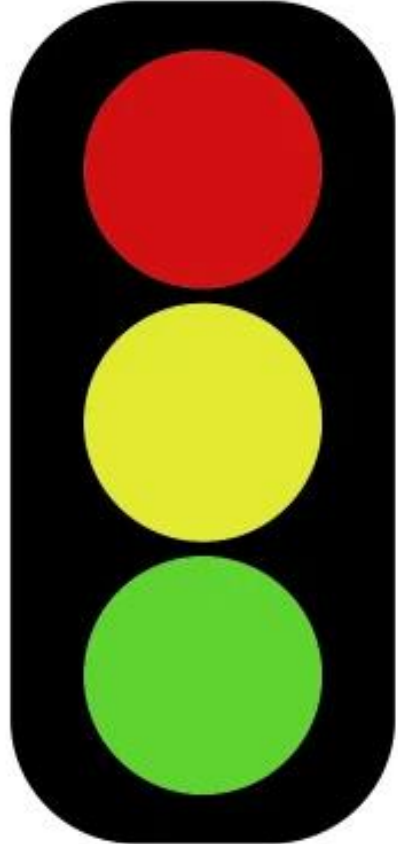
Item	Ohio	National 30 States	% Difference
Has a paid community job	22%	17%	+5% Ohio



## Step 2: Categorize Data by Traffic Light Color and Theme

- 1.) Flag items below, at, or above national average
- 2.) Flag items above or below 50% positive responses (or another threshold)
- 3.) Using this information code each item as:
  - Below average, potential opportunities for improvement
  - At or above national average, but still has growth potential
  - At or above national average, sustain
- 4.) Further organize metrics by theme to help further classify, if needed

# Step 3: Example



Action	Item	Ohio (n = 549)	National 30 States (n = 17,486)	% Difference
Below average, potential opportunities for improvement	Sufficient access to non-medical transportation	74%	80%	-6% Ohio
	Medicare/Medicaid dual enrollment	29%	50%	-21% Ohio
	Using a self-directed supports option	4%	21%	-17% Ohio
At or above national average, but still has growth potential	Choice of staff or were aware they could request to change staff	64%	60%	+4% Ohio
	Case manager/service coordinator has talked to them about technology that may help them in their everyday life	48%	32%	+16% Ohio
	Staff change too often	40%	42%	+2% Ohio (lower is better)
	Uses technology in everyday life to help them do things on their own	34%	30%	+4% Ohio
	Has a paid community job	22%	17%	+5% Ohio
At or above national average, sustain	Autonomy over discretionary spending	93%	90%	+3% Ohio
	Choice of regular day activities	89%	85%	+4% Ohio
	Choice of home	76%	57%	+19% Ohio
	Choice of roommates	72%	43%	+29% Ohio
	Choice of day program/vocational habilitation	71%	63%	+8% Ohio

# Step 4: Further Investigate and Prioritize

## Identify Risk Factors Through Assessing Results by Demographics and Other Survey Items

- Many of Ohio's findings differed by behavioral health challenges, communication abilities, level of intellectual disability, and residential setting

## Prioritize Quality Improvement Strategies

- What is **modifiable** through intervention at the state-level (example: policy, programmatic, and budgetary changes)?
- What is **feasible** to change with given constraints?
- What is **valued, needed, preferred**, and **prioritized** by stakeholders? (Can create state-specific questions or a separate survey to deep-dive into these items)



# Example of Quality Improvement Project



## Improving Oral Health of Ohioans with Developmental Disabilities

### Need Identification



- NCI dental data prompted DODD to assess Medicaid claims:
  - 67% of people served did not have a dental claim within the last year
- Data also indicated a lack of Medicaid dental providers and waitlists approaching 2 years for services

### Strategy



- Data-driven advocacy led to the inclusion of I/DD considerations in The **State of Ohio's Oral Health Plan**:
  - Funding for Ohio State's Developmental and Intellectual Disabilities Dental Certificate Program for Community Providers
  - Enhanced Medicaid reimbursement, including a behavior management code for dentists
  - Working towards permitting Ohio's primary care providers to use silver diamine fluoride for cavity management

# Activity

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- Go to <https://idd.nationalcoreindicators.org/survey-reports-insights-2/> → see QR code
- Choose a report for a survey your state participated in in 2023-24
  - IPS
  - Family Surveys
- Choose a chapter/section
- Use the stoplight for your state's outcomes
- What area(s) deserves further investigation?
- **Can you think of some topics/wordings for supplemental questions to get at this area?**



# Stoplight Template



Action	Item
<b>Below average, potential opportunities for improvement</b>	
<b>At or above national average, but still has growth potential</b>	
<b>At or above national average, sustain</b>	



# LUNCH





# Sharing Data with Advocates



# Agenda

1. User-friendly reports in the past
2. What we heard from people with lived experience
3. Creating resources and gathering meaningful input
4. Paying people with lived experience for their participation
5. Small table activity



# Engaging with people with lived experience

Do you meet with advocates to discuss NCI data?

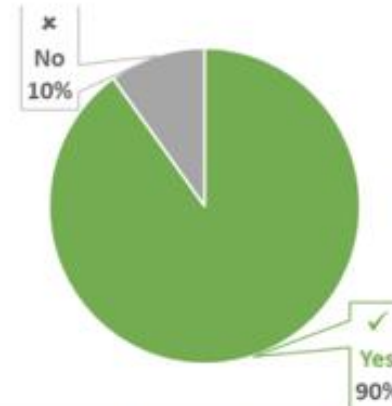
- Annually? Quarterly? Monthly?



# User-friendly reports used previously

If you have a paid community job, do you like working there?

9 out of 10



NCI-IDD tells us **9** out of every **10** people who have a paid community job said **they** like where **they** work.

# Summary at the end of each report

## What Did We Learn?

NCI-IDD tell us about people:

**20%** Have a paid community job

**50%** Who don't have a paid community job want one

**30%** Have community employment as a goal in the service plan

**20%** Take classes, training, or do something to get a job or do better at the job they have now

**30%** Volunteer



# Meetings held with people with lived experience

We wanted to learn from others, what works for them and suggestions they had.

## What we heard

- Use more visuals – less language
- Consider other ways to share data – videos, voice dictated reports, etc.





# What works well

- Showing one data point at a time
- Using “yes” and “no” when explaining data
- Percentages with bar graphs

78%

Have friends who are not staff or family

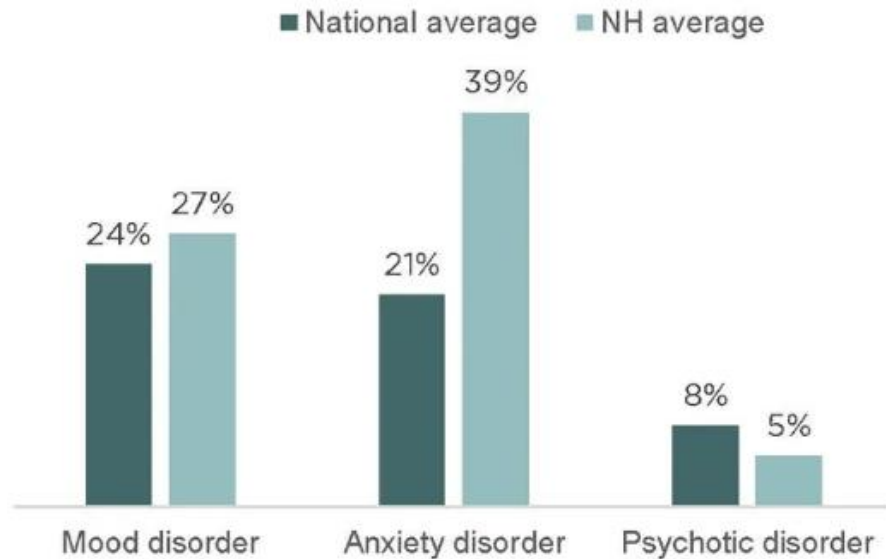


About 3 out of every 5 families (57%) say case manager/ service coordinator **always** listens to family's choices and opinions



# What doesn't work

- Pie charts are hard to understand
- Comparing two different data points in one chart can be hard to understand
- Long reports (suggestions of 2-3 pages max)



IPS respondents who had at least some input into key life decisions:



# Example of video resources

We worked with SciTube to turn our recent publication on employment among people with IDD into an accessible video.

Check it out and share with your networks!



# Creating user-friendly resources – helpful tips!

- Have a “words to know” section at the beginning of written reports or resources
- Tooltips in PDF to serve as a reminder of the definitions from “words to know”

## Why Is This Important?

People with IDD are not usually included in national data. That means decisions are made without good information about how to improve health for people with IDD. Improving the data we collect on the health of people with IDD is important to many groups. [ACL](#) and CDC provided funding for HSRI to conduct a planning study for the Center.

The goal of the Center is to create a “[On](#) Administration for Community Living – this is a federal government agency. information for these groups on:

- How many people have IDD.
- What is the health of people with IDD.



# Using AI for Plain Language

- Lots of people are turning to AI to make things plain language
- AI is a good place to start but shouldn't replace actual humans working on materials!
- Sometimes, the result of AI “plain language” prompts gives you something that is still not at the **6-8<sup>th</sup> grade reading level**
- Are you trying to make a “**plain language translation**” or a “**plain language version**”?



# Gathering meaningful input when creating materials

- Meet with people with lived experience throughout the process
  - Face to face conversations – not just through email
  - Send a draft for them to review before the meeting
- Have questions available to ask during the meeting
  - What does this information tell you, in your own words?
  - What information is not clear or hard to read?
  - What is missing? (Don't ask "If anything is missing"?)



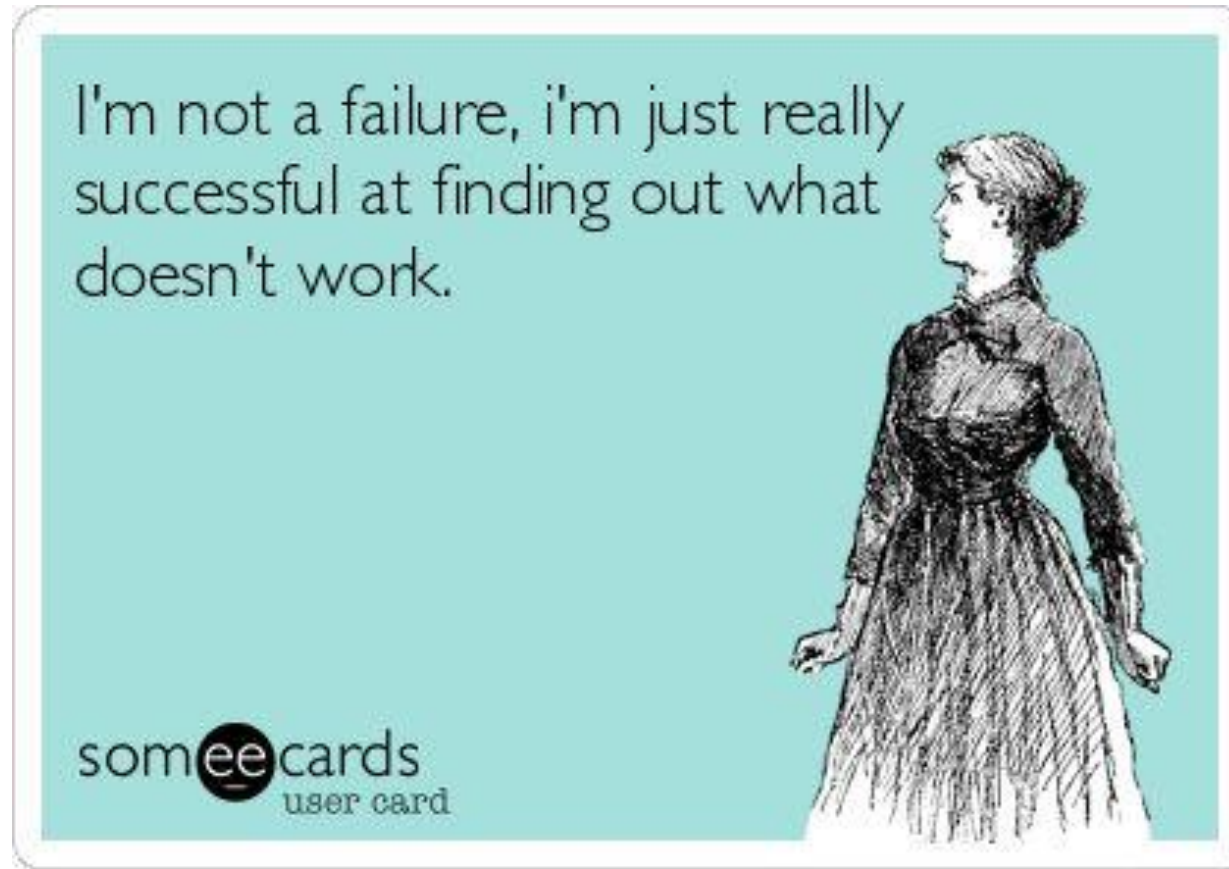
# Paying people for their time

- It is important to pay people with lived experience for their time when they participate in a work group or when reviewing content.
- Ensure that the pay is equitable.
- Work with the individual to learn the best way for them to be paid.
  - Is it through a check? Gift card? To their place of employment to be used towards work hours?





# Final words of advice: Prepare for lots of trial and error



# Small Group Activity

- **What are you doing to share data with advocates?**
  - What programs are you using?
  - Making things in plain language?
  - Certain visualization?
- **What is one thing from this conversation you want to try?**
- **How can HSRI/NASDDDS best support you?**



# Thank you!

Lindsay DuBois, [ldubois@hsri.org](mailto:ldubois@hsri.org)

Heather Young, [hyoung@hsri.org](mailto:hyoung@hsri.org)

# Communicating NCI survey results to interested parties

# Oregon



OREGON DEPARTMENT OF  
**Human Services**

September 2025

# **National Core Indicators (NCI) and Oregon's Office of Developmental Disabilities Services (ODDS)**

# National Core Indicators (NCI) and Oregon's Office of Developmental Disabilities Services (ODDS)

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## Why does the NCI Survey matter?

- ODDS values choice and strives to aid those we serve through self-determined goals and person-centered practices for individuals accessing supports and their families to ensure values are met through systemic changes within our processes.

## Quarterly Target Reviews and ODDS initiatives:

- Quarterly Target Reviews (QTR) are the measurable initiatives our agency tracks to shape our service outcomes. QTR metrics align with our core initiative supporting documents.
- National Core Indicators give ODDS a timely feedback loop for the services offered and the satisfaction of those receiving them.
- Customer satisfaction provides opportunities to identify what is working and what within our business processes' need to change.



# National Core Indicators (NCI) and Oregon's Office of Developmental Disabilities Services (ODDS)

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## What ODDS efforts does NCI inform?

We're currently using NCI data to inform and shape the following projects:

- Medicaid Provider agency rule updates
- ODDS Quality Assurance Reviews
- ISP Redesign
- Direct Support providers unionizing
- Employment

# NCI Survey – Data Brief

## Questions for CMEs to ask:



What can we do to ensure people and families are empowered to direct their annual ISP?



What are the barriers that prevent this from happening?



Are we connected with local family and self-advocacy groups?



Do we have resources around planning and do people know how to find and use them?

- Discussions around sharing with providers, self advocates, individuals, and families
- ODDS is expanding awareness of NCI data and looking to implement new forums to survey questions specific to Oregon to gather meaningful feedback for future surveys

How many people did participate in making their own service plans?



7.2 out of 10 Oregonians

# Georgia

# Georgia NCI-IDD Presentation

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**BE D·B·H·D·D**

Georgia Department of Behavioral Health & Developmental Disabilities

**Latonya E. Williams, Health System Innovation Analyst,**  
Office of Medicaid Coordination and Health System  
Innovation, DBHDD

**Krystal Hershberger, Director,** Office of Performance  
Analysis and Quality Improvement, DBHDD

**Twalla Sapp, Quality Assurance Manager,** Qlarant



# Who We Are

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**Georgia DBHDD** is the designated Operating Authority for two Medicaid Wavier programs (NOW and COMP) serving individuals with intellectual and developmental disabilities. As the operating agency, we are responsible for the day-to-day operations and oversight of the waiver programs.

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**Qlarant** is the ERQO that conducts quality reviews on DBHDD's behalf. Reviews and subsequent trainings focus on the expectations set forth in the waivers and as described in policy and provider manuals. Qlarant conducts these reviews in their role as a part of the Georgia Collaborative Administrative Services Organization.

# NCI Data Sharing Opportunities



ANNUAL PROVIDER  
NETWORK WEBINARS  
(24)



I/DD QUARTERLY  
QUALITY COUNCIL



QUALITY  
IMPROVEMENT  
MONTHLY MEETINGS



CONFERENCES

# Training Initiatives and Collaboration



## **DBHDD and Qlarant Collaboration**

Annually, 24 trainings are developed by Qlarant and DBHDD's subject matter experts (SMEs)

Training is typically web-based and in-person when requested by DBHDD



## **Qlarant and HSRI Partnership**

Spans over 17 years in Georgia

As a subcontractor, HSRI supports Qlarant with the development of specific webinars that incorporate NCI data results, including an annual NCI presentation

# Training Development

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I/DD leadership priorities and initiatives

Trends identified from the Qlarant I/DD quality reviews

NCI data results

Feedback from individuals, families, and providers



# Training Audience

Provider  
Network

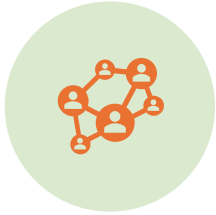
Community  
Partners

State  
Personnel

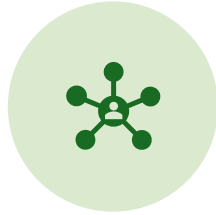
Support  
Coordination  
Services

Individuals  
and Families

# Fiscal Year 2026 Training Topics



CHOICE AND SELF-  
DETERMINATION



PERSON-CENTERED  
PRACTICES TO  
SERVICE DELIVERY



COMMUNITY  
ENGAGEMENT,  
DEVELOPMENT OF  
SOCIAL ROLES



DSP RETENTION AND  
RECRUITMENT  
STRATEGIES



HOME AND  
COMMUNITY BASED  
SERVICES (HCBS)  
SETTINGS RULE  
EXPECTATIONS



DIGNITY OF RISK



WHOLE HEALTH AND  
WELLBEING



ADVOCACY

# Georgia: NCI-IDD SoTW Data

## Effective Retention Strategies & Key Accomplishments



**Significant Decrease in Employee Turnover:** Substantial reduction in turnover rates, dropping from **47% in 2020 to 32% in 2023—a 15 percentage point decrease** over four years.

- Benefits include a more stable workforce with a more experienced and skilled DSP workforce; reduction of costs from provider recruitment and training



## Investing in Our Workforce: DSP Certification Pilot Program

- **Workforce Development Workgroup** - Established a dedicated workgroup focused on improving retention, wages, benefits, and career advancement.
- **DSP Certification Program** - Developed a pilot program offering three pathways for DSPs to earn a competency-based certification.

# Georgia: NCI-IDD SoTW Data

## Effective Retention Strategies & Key Accomplishments



**Historic Wage Increases:** Successfully implemented as a direct result of advocacy, rate study, and SoTW survey data to inform key stakeholders

- NCI-IDD data showed the **average hourly wage increased by \$2.50** between 2020 and 2023, representing a **22% relative increase**.
- Georgia's historic NOW/COMP rate increase was made possible by the **\$107 million allocated in the state budget** during the 2024 legislative session. Beginning July 1st 2024, new rate increases afford \$16.70 per hour as the median wage plus a substantial benefits package. For more about the rate increase [Georgia Waiver Rates - Health Management Associates](#)
- Amendments to the NOW and COMP waivers were approved by CMS on July 11, 2024- retroactive to July 1 2024- allowed for these historic Medicaid provider rate increases, which directly benefited Direct Support Professionals (DSPs).

# California

# California NCI-IDD Annual Meeting

September 24 & 25, 2025



# Overview of CA Service System

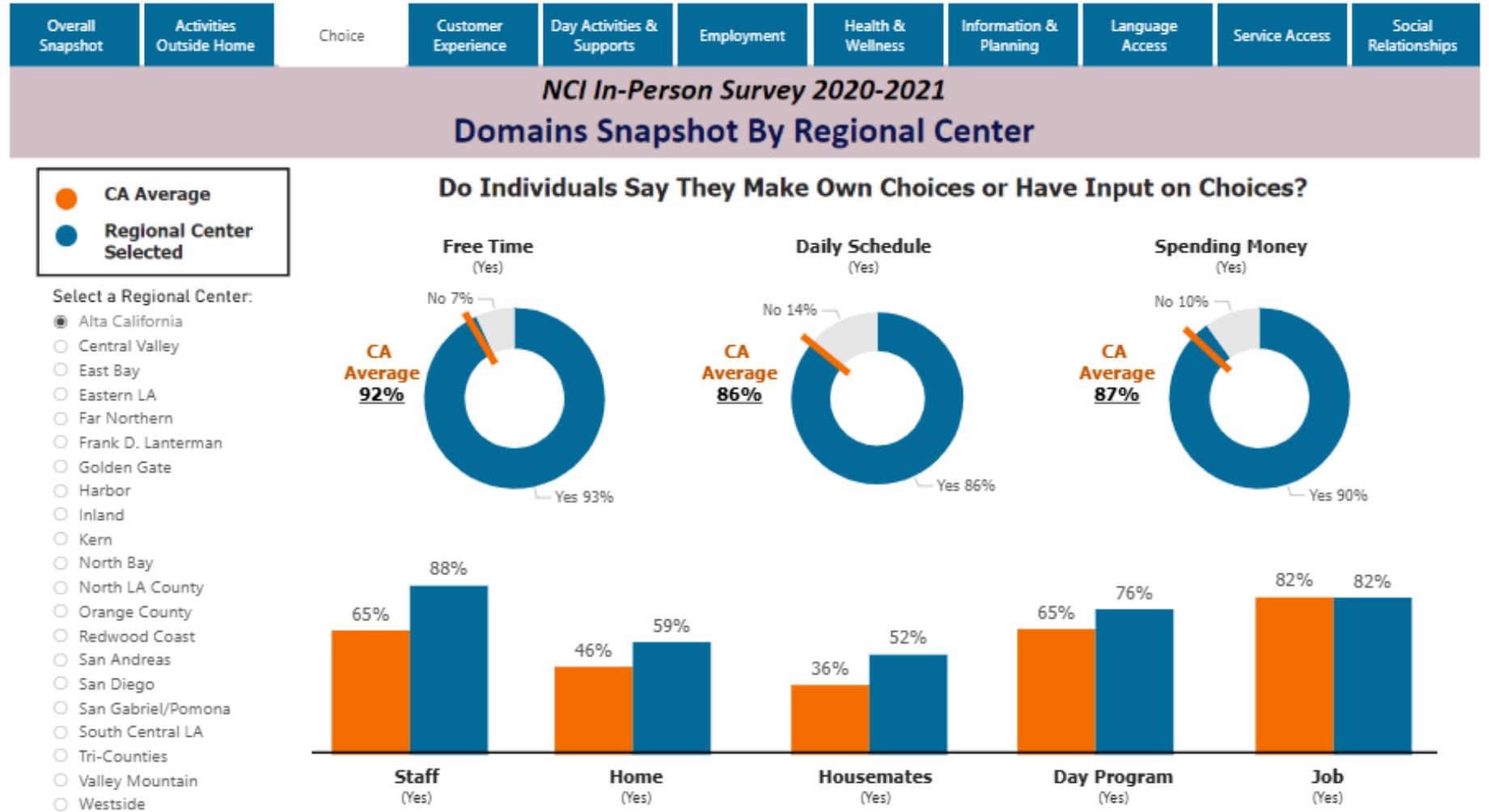
- CA Department of Developmental Services (DDS) oversees the coordination and delivery of services to over 450,000 individuals.
- The Lanterman Act – State Law originally passed in 1969.
- 21 community-based non-profit agencies coordinating services and supports for individuals with I/DD.
- Recent Initiatives:
  - Self-Determination Program
  - Standardizing Regional Center Procedures, including person-centered service planning
  - Regional Center Performance Measures
  - Enhanced Service Coordination
  - Service Provider Rate Reform
  - Workforce Initiatives
  - Employment Grants
  - Quality Incentive Program
- NCI is a data set we use to further develop quality standards throughout the state.





# Community Engagement

- Quarterly Quality Incentive Program Workgroup
  - Focus Groups for each area
- Quarterly Quality Assessment Advisory Group (QAAG)
- Monthly Progress Reports
- Regional Center Performance Measure Workgroup
- Innovative data dashboards





# NCI Snapshot



Department of  
Developmental Services

Dear Regional Center Executive Directors and NCI Liaisons,

Thank you for encouraging individuals served by your regional center to participate in the NCI In-Person surveys.

The NCI In-Person data collection concludes on June 30, 2025. A minimum of **400 surveys** per regional center is needed to achieve a statistically reliable, representative sample. The bar graph below shows interviews conducted for each regional center in January as of February 3, 2025.

Regional centers are encouraged to promote the NCI surveys to both individuals served and to their families by engaging service coordinators and family resource networks to promote participation.

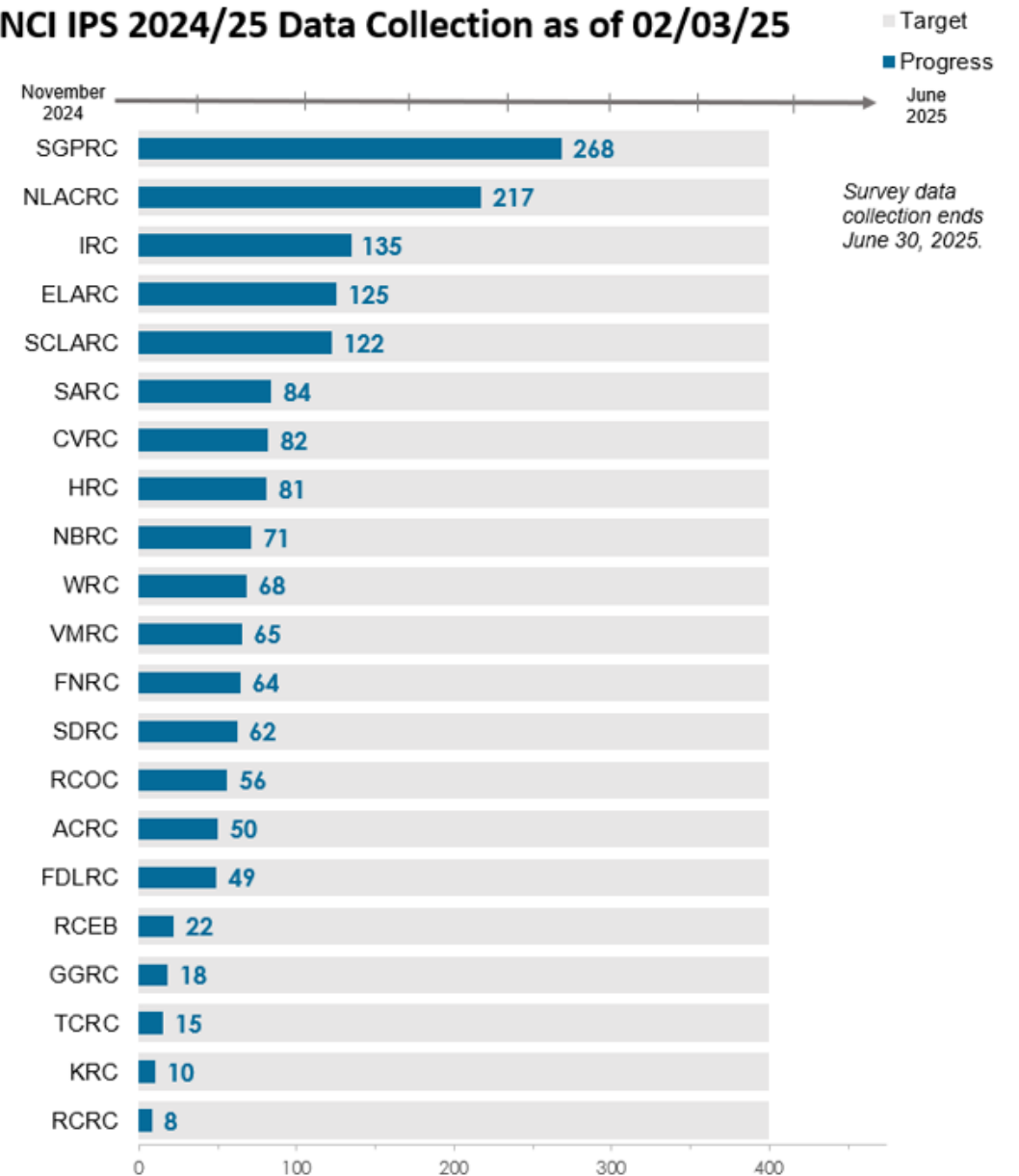
The NCI In-Person Survey (IPS) is an opportunity for adult individuals to share their experiences with services and supports through interviews from the State Council on Developmental Disabilities (SCDD) staff, a DDS contractor assisting with this data collection effort.

Additional NCI resources and information are listed at the bottom of this email.

Thank you for your continued support and for encouraging individuals served by your regional centers to participate in the NCI surveys.

## Progress Report

### NCI IPS 2024/25 Data Collection as of 02/03/25



# Quarterly Stakeholder Engagement Meetings (QAAG)

Example of questions used to guide stakeholder discussions on NCI data points

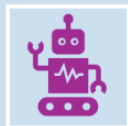
## Breakout Group Activity



What do these data findings mean to you? Does it match your experience or what you've heard?



Does this data analysis help you understand where the areas for improvement are?

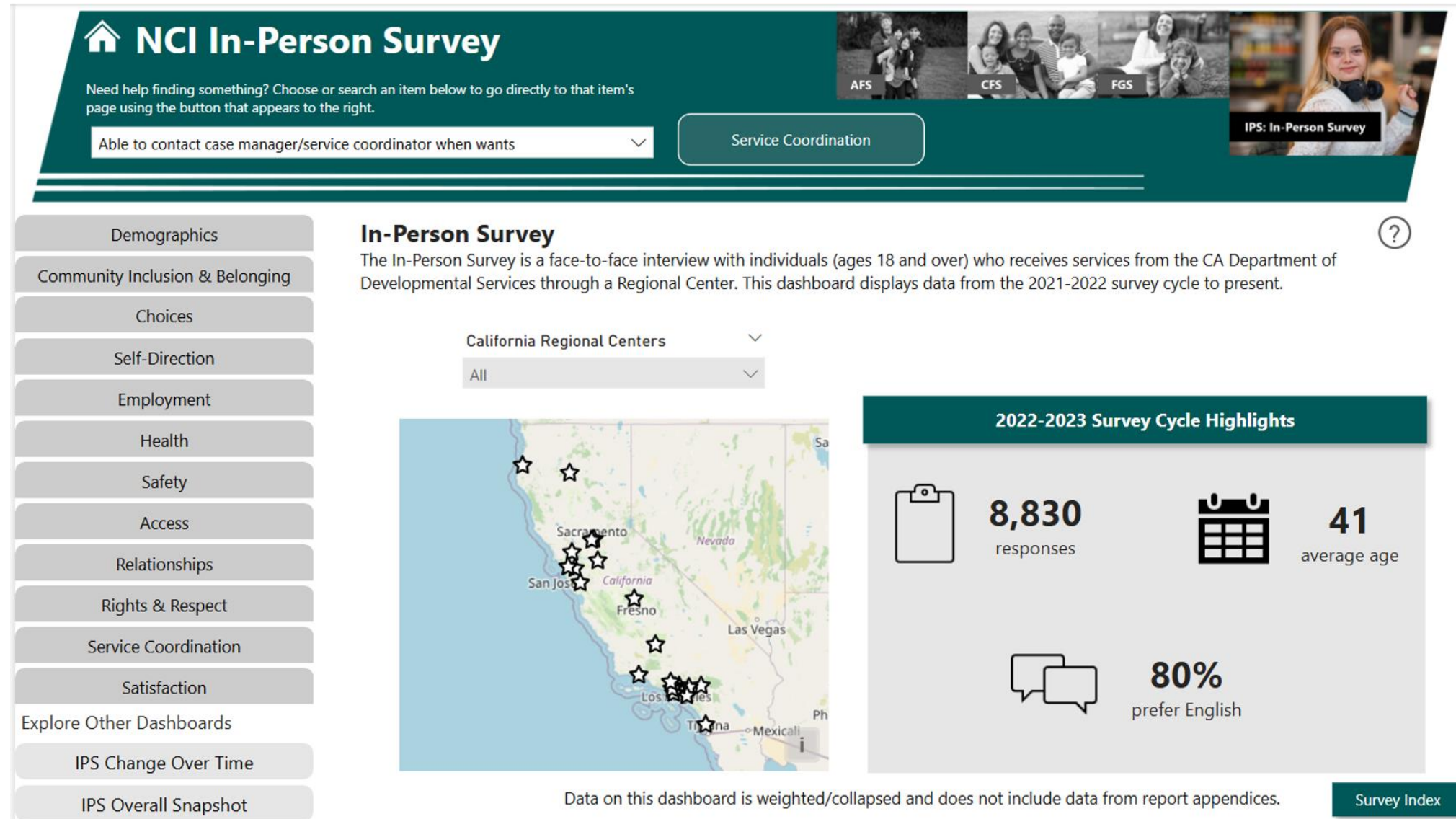


How does this data help you understand how to use NCI at your level in your system? What actions can you take?

# NCI Dashboard Redesign

CA is redesigning public NCI Dashboards:

- Single point-of-entry
- Multi-year data displays
- Organized by domains
- Filter by Regional Center



# Quality Incentive Program (QIP)



- Built upon Service Provider Rate Reform
- Designed to improve individual outcomes, service provider performance, and the overall quality of services.
- QIP Stakeholder Workgroup
- Focus Areas:
  - Prevention and Wellness
  - Employment
  - Early Intervention
  - Workforce Capacity
  - Service Access
  - Informed Choice
  - Provider Directory
- Provider Capacity Survey



# Looking Ahead...

NCI Data can be the building blocks to support so many efforts!



# BREAK

# Let's have some fun! Sharing NCI Data

1

Groups will receive various NCI data

2

Groups will be assigned an audience

3

Groups will develop a communication strategy based on the data and audience

# Instructions



1. Pick 2-3 data points/indicators that you think are the most important



2. Address the assigned audience (families, people with lived experience, lawmakers, policy makers)



3. Develop your message (summary of the information in plain language)



4. Pick the method you would use to share the information with that audience (flyer, social media, blog, etc.)



5. Include a call to action. What do you want the audience to do because of this communication?



6. Any follow up needed?



7. Report back from your group





# One Slide Challenge

# California



## Provider Characteristics

Population Served  
Support Type  
Service Type



## Race

DSP Staff  
Supervisors  
Individuals Supported



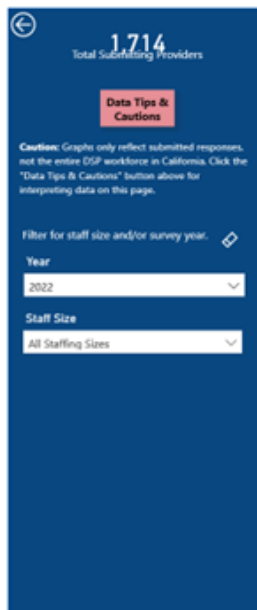
## Languages

DSP Staff  
Individuals Supported

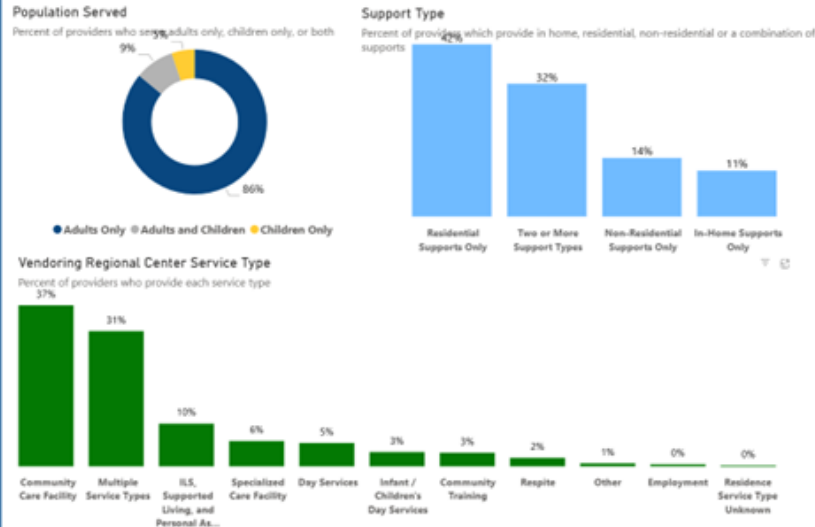


## Workforce Statistics

Turnover  
Tenure  
Vacancy Rate



## Characteristics of Responding Providers



## Using NCI data to better understand workforce capacity

- Providers received a one-time incentive to voluntarily complete the NCI State of the Workforce Survey
- CA DDS customized the survey for application in a value-based payment model – now the Provider Capacity Survey
- Data collected used as crosswalk for other data initiatives
- Provider Capacity Survey is now required for providers to receive their full Quality Incentive Program (QIP) rate (90% for service provision, 10% QIP)

## WHAT YOU NEED TO KNOW BEFORE VOTING

ELECTION DAY IS NOVEMBER 5



To vote, you need to be registered!

Apply online  
[elections.virginia.gov/citizen-portal](https://elections.virginia.gov/citizen-portal)  
OR  
fill out a registration form and turn it into  
your state or local government office.  
The final day to register is November 4th

\*Based on National Core Indicator data from 2017-2023

### WHAT YOU NEED TO VOTE

#### An Acceptable ID

- Examples include:
- Virginia DMV-issued driver's license or ID card
  - United States Passport
  - Student or Employer ID
  - Voter Confirmation Documents

For more examples visit [elections.virginia.gov/VoterID](https://elections.virginia.gov/VoterID)

### WAYS TO VOTE

#### By Mail:

Request ballot by October 25, 2024  
[elections.virginia.gov/absentee](https://elections.virginia.gov/absentee)

**In Person before Election Day:**  
Vote early at your local registration office  
September 20 - November 2, 2024

**In Person on Election Day:**  
Vote at your local polling place on  
Tuesday, November 5, 2024  
Find your polling place  
[elections.virginia.gov/VoterInfo](https://elections.virginia.gov/VoterInfo)



### ACCOMMODATIONS

You have the right to accommodations to help you vote. Examples include:

- Magnifiers for reading ballots
  - Accessible parking and entrances
  - Accessible voting booths
  - Voting from your car
  - Talking ballots or electronic ballots
  - Help reading or marking your ballot
- You can bring someone to help you!

For more information on accommodations  
[elections.virginia.gov/casting-a-ballot/accessible-voting/](https://elections.virginia.gov/casting-a-ballot/accessible-voting/)



# Virginia



**VCU** Partnership for People  
with Disabilities  
School of Education

### MENTAL HEALTH TREATMENT FOR PEOPLE WITH IDD

People with intellectual and developmental disabilities (IDD) have higher rates of mental health conditions than people without disabilities, but may face challenges in getting treatment.

**Treatment for mental health conditions may include:**

- Medication
- Talking with a therapist, counselor, or social worker
- Talking with a group of people
- Animal-assisted therapy (horse riding, therapy dogs, etc.)

**Challenges include:**

- Finding providers who take insurance
- Finding medications that are covered by insurance
- Providers who aren't comfortable working with people with IDD
- Delays in care
- Difficulty communicating

**Advice from people with disabilities**

**For people with disabilities:** don't be afraid to ask for help! Your primary care provider is a great place to start. Look for peer mentorship opportunities where you can meet with another person with a disability and mental health condition to help you figure everything out.

**For providers:** treat everyone as an individual, regardless of their disability. Understand that disabilities may affect how someone experiences a mental health condition, but don't assume that everything is because of a disability.

**Learn More:**  
National Alliance on Mental Illness  
[nami.org](https://nami.org)  
The Arc of Virginia  
<https://www.thearcva.org>

**988**  
24-hour crisis hotline  
[988lifeline.org](https://988lifeline.org)

**ALLY** Created for people with disabilities by people with disabilities  
This work was supported by the National Institute on Disability, Independent Living, and Rehabilitation Research [grant #90IRRE0047]

**VCU**

### Mental Health Matters

**By the Numbers\***

- ✓ People with intellectual and developmental disabilities (IDD) are more likely than people without IDD to have a mental health condition.
- ✓ Between 33% and 50% of adults with IDD have a mental health condition.
- ✓ Between 40-50% of adults with IDD take medication for mental health.

**Common Mental Health Conditions\***

- Mood Disorders
- Anxiety Disorders
- Behavioral Condition
- Psychotic Disorders

**What does Mental Health mean to you?**

Prevention and self-care

Good days and bad days

Education for people and their doctors

Support

Being seen as more than just a diagnosis

\*Based on data from the Virginia National Core Indicators Intellectual and Developmental Disability Survey

Spanish speaking  
interviewers

Exploring Spanish  
language resources

Implemented a new internal  
data management site using  
REDCap

Reports on Mental Health and  
Voting Rights generated by  
people with IDD using NCI data

# PA Office of Developmental Programs (ODP) – Performance-Based Contracting (PBC)

## PBC Measures

**Residential Providers:** required to participate in **NCI's State of the Workforce Survey** to validate turnover and other workforce data for those in advanced tiers

- ✓ Select and Clinically Enhanced tiers = higher rates

**SCOs:** required to support ODP data collection via survey and encourage individual and family participation to inform individual SCO performance in:

- ✓ **PCP-2: Proportion of people who report their service plan includes things that are important to them**
- ✓ **PCP-5: Community Inclusion Scale**

Successful QI Planning  
must be data driven and  
person-centered!



## PBC Continuous Quality Improvement Phased-in Measure Design



**Build Capacity**  
support survey  
completion/**data** collection

**Scale Capacity**  
meet or exceed target or  
submit **QI plan**

**Perform to Statewide**  
**Benchmarks**

## One Slide Challenge:

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

- South Dakota NCI team achieved over the minimum NCI-IDD completed state survey goal (**350; minimum of 341**) in extremely condensed timeframe (appx. 3 months)
  - Very late sample name pull due to restructuring of positions at SD Division of DD
  - Started to pull names in March of 2025
  - Effectively scheduled and completed survey meetings with consenting participants via zoom & in-person
  - Completed 350 surveys with consenting participants by June 30<sup>th</sup>, 2025
  - Also coincided with successful NCI-AD survey completion & participation during the same 24-25 survey cycle

# South Carolina NCI - IPS



Thank You

*Nothing About Us Without Us.* Your voice matters! Thank you for volunteering to participate in the NCI- IDD In-Person Survey!

Every year, National Core Indicators creates reports to share what we found. These reports share data at the state level. These data are used by states to improve services and supports. For more information about state and national data please visit [www.hsri.org](http://www.hsri.org).

~The NCI Team at CDR

Center for  
**Disability Resources**  
SCHOOL OF MEDICINE  
UNIVERSITY OF SOUTH CAROLINA



Thank You  
Card



## CERTIFICATE

OF APPRECIATION

Thank you for your participation in the  
2025-2026 National Core Indicators NCI-IDD In-  
Person Survey

*Nothing about us without us.*  
Your voice matters!

Doreen Chapel  
NCI Program Director  
Center for Disability Resources

Center for  
**Disability Resources**  
SCHOOL OF MEDICINE  
UNIVERSITY OF SOUTH CAROLINA

Ann Dalton  
Director Quality  
Management, OIDD



Certificate of  
Completion



# Nebraska DHHS

## How We Brought NCI Administration In-House in 2025

### Why Bring In-House?

- Cost savings
- Quicker data access
- Rapport with providers and participants

### Infrastructure Considerations

- Staffing Capacity
  - Program Accuracy Specialists (PAS) – Assigned a team lead
  - Statistical Analyst – Development of sample list, high level project management
  - Data Team – Provide available background data
- Technical Capacity
  - Data Team – Development of dashboard for public display of data

### Administration of Survey

- Survey Responsibilities Across Team of 7 PAS
- Use of Online Work Management System
  - Scheduling coordination
  - Communication plan
  - Change management

**NEBRASKA**

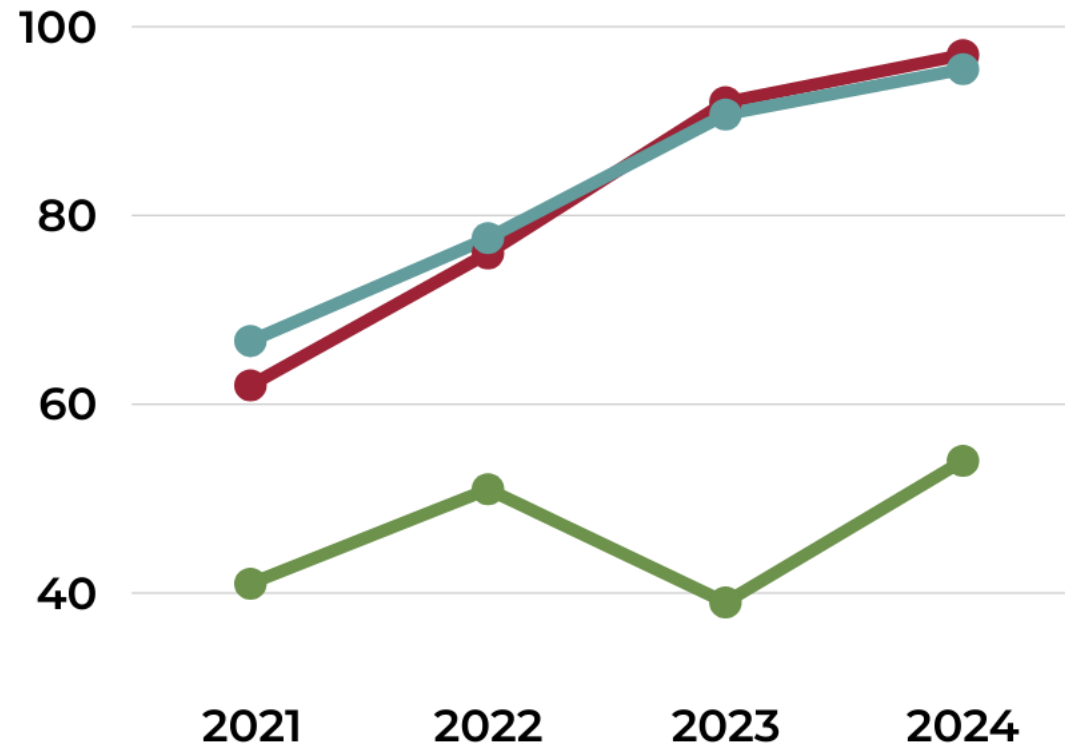
Good Life. Great Mission.

DEPT. OF HEALTH AND HUMAN SERVICES

*Helping People Live Better Lives.*

### PCISP GOALS

● Friendship ● Community ● Employment





# Use of In Person Survey Data in New York State:

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

### What is NCI-IDD?

National Core Indicators (NCI-IDD) uses standardized surveys to track performance and compare results across state developmental disability agencies. This is coordinated by the Human Services Research Institute (HSRI) and the National Association of State Directors of Developmental Disabilities Services (NASDDDS).

### About the NCI In-Person Survey

The NCI-IDD In-Person Survey (NCI-IPS) is a face-to-face or virtual meeting conducted with a person (or authorized proxy) receiving OPWDD services and supports. In New York, OPWDD randomly selects a certain number of eligible adults to participate each year based on their enrollment in one of the seven statewide Care Coordination Organizations (CCOs) or the Managed Care Organization (MCO), Partners Health Plan. Individuals are randomly selected in order to ensure survey responses accurately reflect the opinions of the entire population of individuals enrolled in OPWDD services. CCOs coordinate the health care, behavioral health, and developmental services for OPWDD participants under a fee-for-service model. The MCO is a managed care plan that partners with OPWDD and Medicaid to cover and coordinate a comprehensive array of services for people with Intellectual and Developmental Disabilities who are dual Medicaid/Medicare eligible.

Select a button below to explore findings from New York's 2023-2024 NCI-IPS.

CCO/MCO Participants & County Map	Demographics
Service Coordination	Health, Wellness, & Medications
NCI-IPS Measures for HCBS Waiver	



Office for People With  
Developmental Disabilities



### NCI IDD State Contacts:

Olivia Popiel (*presenting*)  
[Olivia.G.Popiel@opwdd.ny.gov](mailto:Olivia.G.Popiel@opwdd.ny.gov)

Samantha Gerken  
[Samantha.J.Gerken@opwdd.ny.gov](mailto:Samantha.J.Gerken@opwdd.ny.gov)

Project Mailbox:  
[NCIAdultInPerson@opwdd.ny.gov](mailto:NCIAdultInPerson@opwdd.ny.gov)

User-friendly Tableau dashboards  
NCI Easy Read document  
Presentations to CCO/MCO  
leadership and internal partners  
CMS Waiver Reporting, Access  
Rule

# 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

# 2025 NCI-IDD ANNUAL MEETING Day 2

September 25, 2025

# 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?

# ODESA 2.0 Introduction

# 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, 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.

# ODESA Team



**Tania DiCostanzo** >  
Director of Innovation and  
Technology



**Karen Gruber** >  
Business Systems Analyst



**Jared Lestik** >  
Requirements Analyst



**Brandy Richbourg** >  
Agile Team Lead

Not pictured:

Dave Vaccaro  
Wesley Oliviera



# EXCITING new features



Offline mode



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



New user interface—new look and feel!



Enhanced security features

# ROLES: Client (State) Administrator

- A Client Administrator has access to their state's information, including group/user account maintenance and the survey types to which they have been given access.
- A Client Administrator also has access to all survey data for assigned groups, which may be all groups in the state, and
- Client Administrators may add, edit, delete, and track the progress of surveys completed throughout the year.
- Any Client Administrator can perform the following functions:
  - add and edit users, transfer surveys, mark (or unmark) surveys as completed, and download survey data directly from ODESA.

# ROLES: Group Administrator

- A Group Administrator has access to users and surveys within one or more groups.
- A group is a subset of users and surveys within a state. (States are also known as a “clients” in ODESA).
  - Groups may be used to delineate users/surveys by certain criteria, such as particular regions of a state, for example.
- The use of Groups and Group Administrators is optional.

## ROLES: User

- A User has access to basic data entry functions.
- Users may be assigned to one or more groups, and users are only able to view survey information they have entered.
- Certain survey sections may be hidden from users based on permissions set by a Client Admin.
- There is a separate ODESA guide for Users

# Questions and thoughts

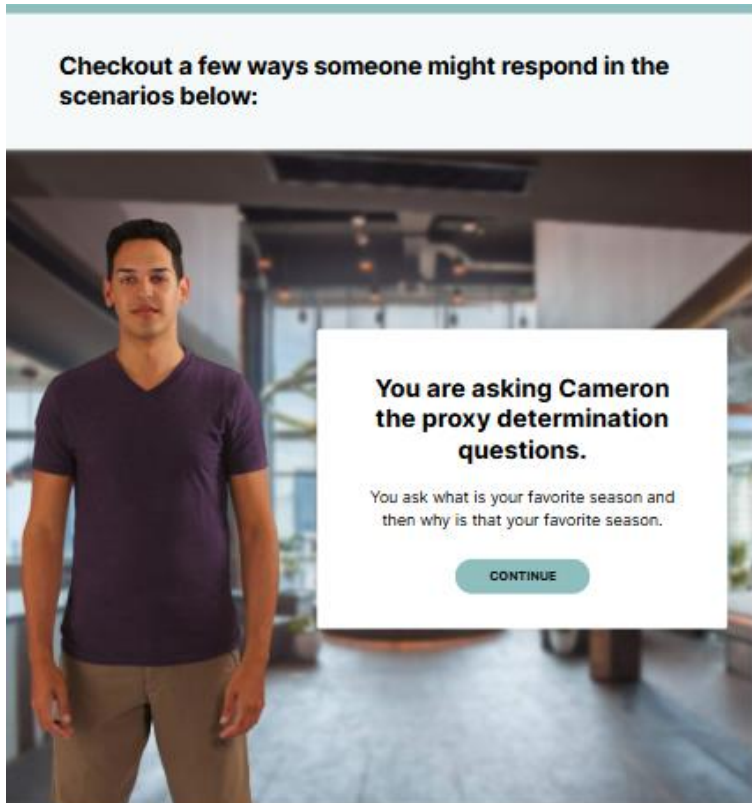
- Have you used the ODESA 2.0?
- What do you think?
- Any advice for new users?

# Training Updates



New Training for NCI Surveyors  
NCI-IDD Annual Meeting  
September 24, 2025

# Overview of the New Surveyor Training



**Purpose: Provide surveyors a comprehensive training including the knowledge and tools necessary for success**

**New this year:**

- Progress and completion tracking
- Microlearnings
- Interactive lessons
- Completion required to move on to next lesson
- Best practice tips throughout



# Why Update the Training?

Moved to new platform last year

- Unable to change or edit

Accessibility

- Captioning, audio, plain language

Feedback received about the trainings

- Too long, not engaging, hard to follow

Time to update

- Keeping trainings current ensures best practices

# Improved Breakdown of Lessons

After this section, you will be able to:

- 1 explain your role as a surveyor and why you are calling.
- 2 describe the survey and why it is important that the person participate.
- 3 be ready with some nudges if the person initially declines participation.

Check your learning:

Who does NCI want to hear from?

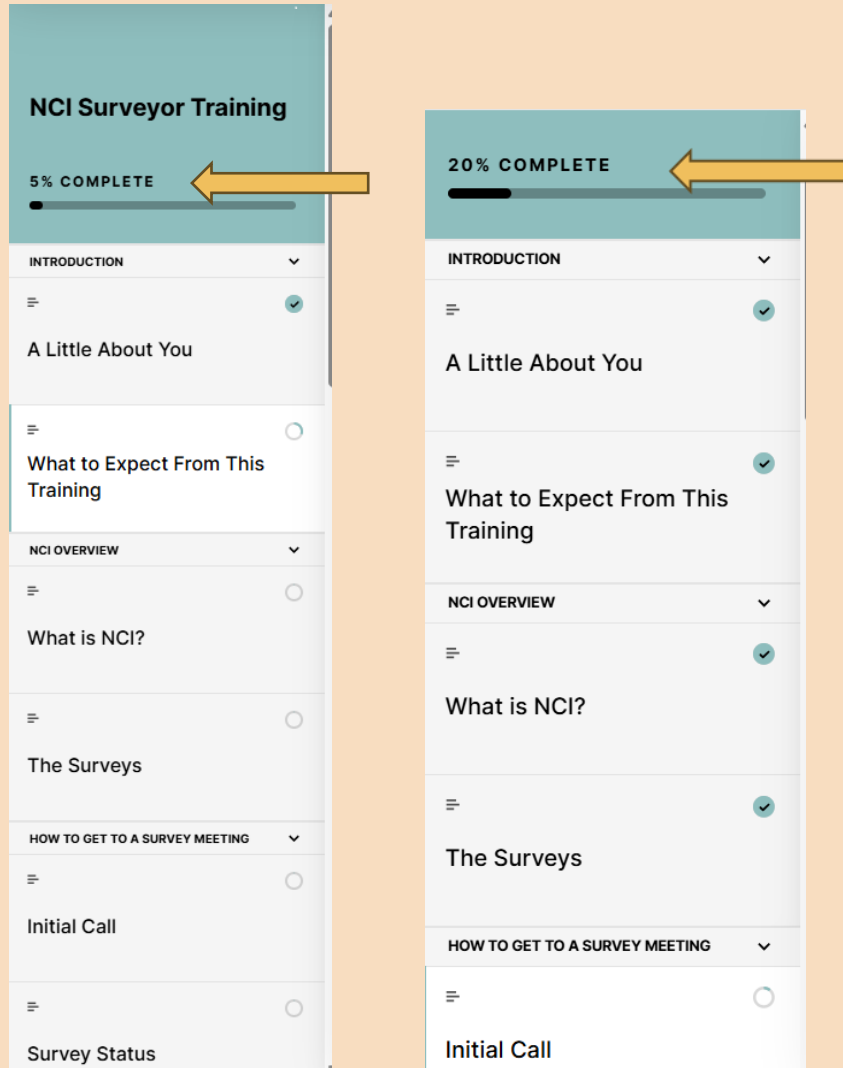
- ☐ State providers
- ☐ People receiving services
- ☐ Case managers/service coordinators

SUBMIT

## Streamlined Lesson Flow

- Bite-sized modules, shorter sessions to prevent fatigue
- Clear learning objectives at the start of each lesson
- Learning checks within lessons

# Progress Bar



## Tracking and Progress Monitoring

- Real-time progress monitoring
  - Learners can see as they move through the training
- Managers can monitor surveyors' progress
  - Number of lessons, amount of time spent

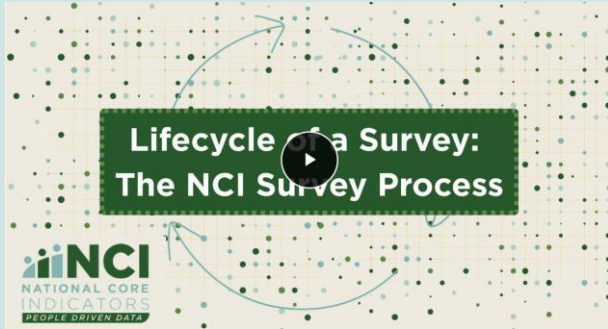
# Activity

Spend a few minutes talking to the people at your table about learning styles.

- What type of learner are you?



# Adult Learning: Multi-Modal Approach



Check your learning:

Who does NCI want to hear from?

Requires a correct answer to continue

- ☐ State providers
- ☐ People receiving services
- ☐ Case managers/service coordinators

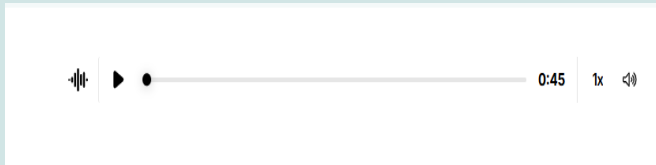
SUBMIT

Audio, Text, and Video Materials

Learning checks, scenario-based exercises, and activities

Practice scenarios to strengthen learning

Immediate feedback to reinforce learning



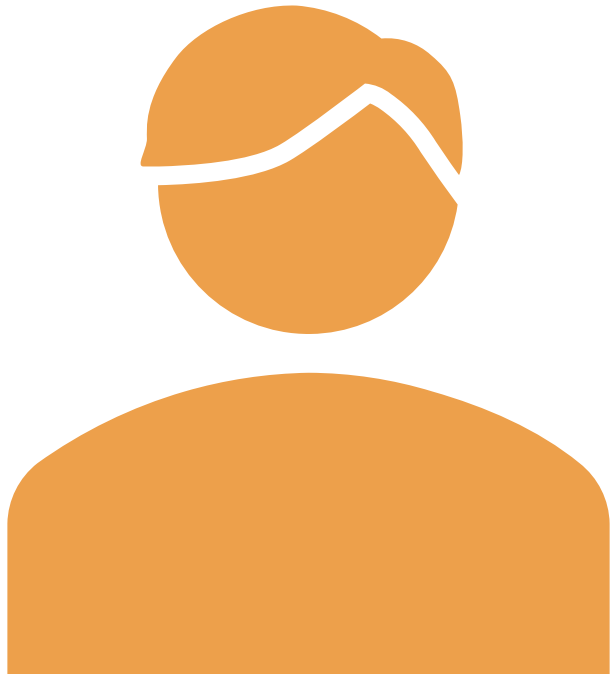
Who does NCI want to hear from?

- ☒ State providers
- ☒ People receiving services
- ☒ Case managers/service coordinators

Correct

NCI believes people receiving services are the most important people to hear from related to how things are going for them. It is okay for family or someone who knows the person well, to help with some questions.

# Benefits for Surveyors



- Self-paced learning- training does not have to be completed in one session
- Training is online and can be completed when and where the surveyor wants
- Improves understanding of NCI and how to conduct surveys
- Updates on NCI protocols
- Interactive modules that keep learners engaged

# Benefits for NCI Coordinators

- Reduces amount of information lead trainers must provide
- Focus of live training can be more state specific
- Ability to assign trainings, track progress, and send reminders



# Surveyor Training Requirements



**New surveyors** must complete the online asynchronous training as well as the live training with the lead trainer in their state.

**Returning surveyors** who have not completed the training in the past 2 survey cycles must complete the online training as well as the live training.





# Questions?

Cheryl Sartori

[csartori@hsri.org](mailto:csartori@hsri.org)



# BREAK/CHECK OUT

It's your right!: Making sure surveyors encourage people to participate and share their own perspectives without proxies

# Pennsylvania and Proxy Procedure

NCI Annual Meeting 2025

Pennsylvania Team:

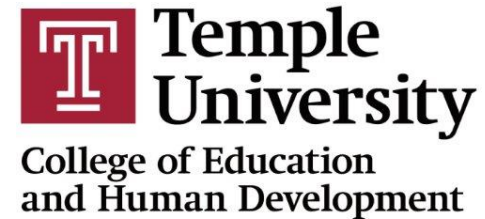
Lee Stephens – State

PA UCEDD – Institute on Disabilities at  
Temple University

Mary Kay Cunningham

Sally Gould Taylor

Guy Caruso



Institute on Disabilities

# Overview of Pennsylvania's Program 2024-2025

- 19 individual programs for the 67 counties in PA.
- Number of monitors (surveyors)- 210
- Number of monitors with disabilities - 80
- Number of monitors who are family members – 82
- People with Disabilities and family members = 77 % of monitors (surveyors)
- We do 4091 interviews
- 882 NCI ISP specific interviews
- Another 3209 interviews using NCI ISP, as well as our own PA State Supplement.

# 2024-2025 Proxy Determination Questions

- D-3. Were Proxy Determination questions answered validly?
- 2 ☐ Yes, both questions GO TO D-5
- 3 ☐ Yes, only one
- 1 ☐ No

D-3		Frequency		Valid Percent		
No		261		37.8		
Yes, both questions GO TO D-5		396		57.4		
Yes, only one		33		4.8		
Total		690				

# 2024-2025 Proxy Determination Questions

- D-4. If Proxy Determination questions were not answered validly, why not?
- 1 ☐ Person did not respond
- 2 ☐ Person did not understand question
- 3 ☐ Could not understand communication and interpreter was not available
- 4 ☐ Other

D-4		Frequency		Valid Percent
Could not understand communication and interpreter was not available		12		4.6
Other		21		8.0
Person did not respond		173		66.3
Person did not understand question		55		21.1
Total		261		

# 2024-2025 Proxy Determination Questions

- D-5. Will you conduct the Section I with person receiving services? REMINDER: Section I may be completed with the support of an interpreter. The person is not required to answer all Section I questions.
- 2 ☐ Yes, will conduct Section I
- 1 ☐ No, Section I will not be conducted (only Section II will be completed with a proxy respondent)

D-5		Frequency		Valid Percent
No, Section I will not be conducted (only Section II will be completed with a proxy respondent)		278		39.6
Yes, will conduct Section I		424		60.4
Total		702		



# Questions Asked of us in PA State Workplan:

- What Procedures are in Place to Ensure the Proxy Determination is not Overused?
- For example, will the state monitor the percentage of surveys using proxy responses, and intervene if it looks like proxy is being overused?”
- PA responded: “All monitoring teams are trained to focus on interviewees providing their own responses if at all possible.”

# Proxy Training Beyond NCI Training

- The PA training focused on the proxy determination process, supporting surveyors to understand whether a proxy is needed, working towards assuring that the maximum number of interviewees provide their own responses.



# Local Program Responses to Proxy Training

- We do cover that some consumers utilize Augmented and Alternative Communication devices and or low-tech options such as picture boards.
  - We stress that we want to hear from the consumers first regardless of communication style or needs.
  - We go through the entire survey starting at the beginning and give samples of things that may come up and we also give ample time for monitors to ask questions about scenarios about the determination process.
-



# Local Program Responses to Proxy Training

- Work directly with the lead monitors on the best way to ask/receive responses to the proxy questions.
  - Additionally, have monthly staff meetings, where I review specific topics with the monitors.
  - In our annual training, I discuss the importance of hearing from people- having their voice be heard, and then ways we can redirect other respondents to allow the individual to answer on their own behalf.
  - When we get into a section where a respondent can provide assistance, our monitors are trained to take the response of the individual.
  - We have found that if people have a way to communicate, we have had success with them answering the questions.
-



# Local Program Responses to Proxy Training

- I provide our own training in addition to the virtual NCI training, use examples, scenarios and role play to demonstrate the different situations they might encounter.
  - I also provide tools ( picture cards, yes/no, thumbs up/down, basic sign language ) for them to help with communication if needed.
  - I also stress that the “proxy” needs reminded that they are answering on the individual’s behalf and continuing to use the individuals name in the questions.
  - We have not had an overuse of Proxys, so I believe the monitors I have are doing a pretty good job with involving the individual.
-

# Why Ensuring that Interviewees Provide their Own Responses is a Value for PA

- People first that receive services we want to hear from.
- We want the “consumers” view, we utilize the FFG section for others who are permitted by the consumer to answer their own set of questions.
- We always start with a privacy statement asking if a consumer would like to have privacy to speak with the monitoring team alone or if they would like someone else present.
- Monitors are trained that if a consumer wants someone present that does not mean that their responses override the consumers.

# Why Ensuring that Interviewees Provide their Own Responses is a Value for PA

- I believe the survey is a direct way for people's voices to be heard by our state and include this in our script when scheduling surveys, and even at the beginning of the survey meeting.
- We want to hear directly from the person receiving services and how being a part of the service system has impacted their life.
- We also reinforce that they, as a participant, can impact change, because everyone should be able to live a good life!

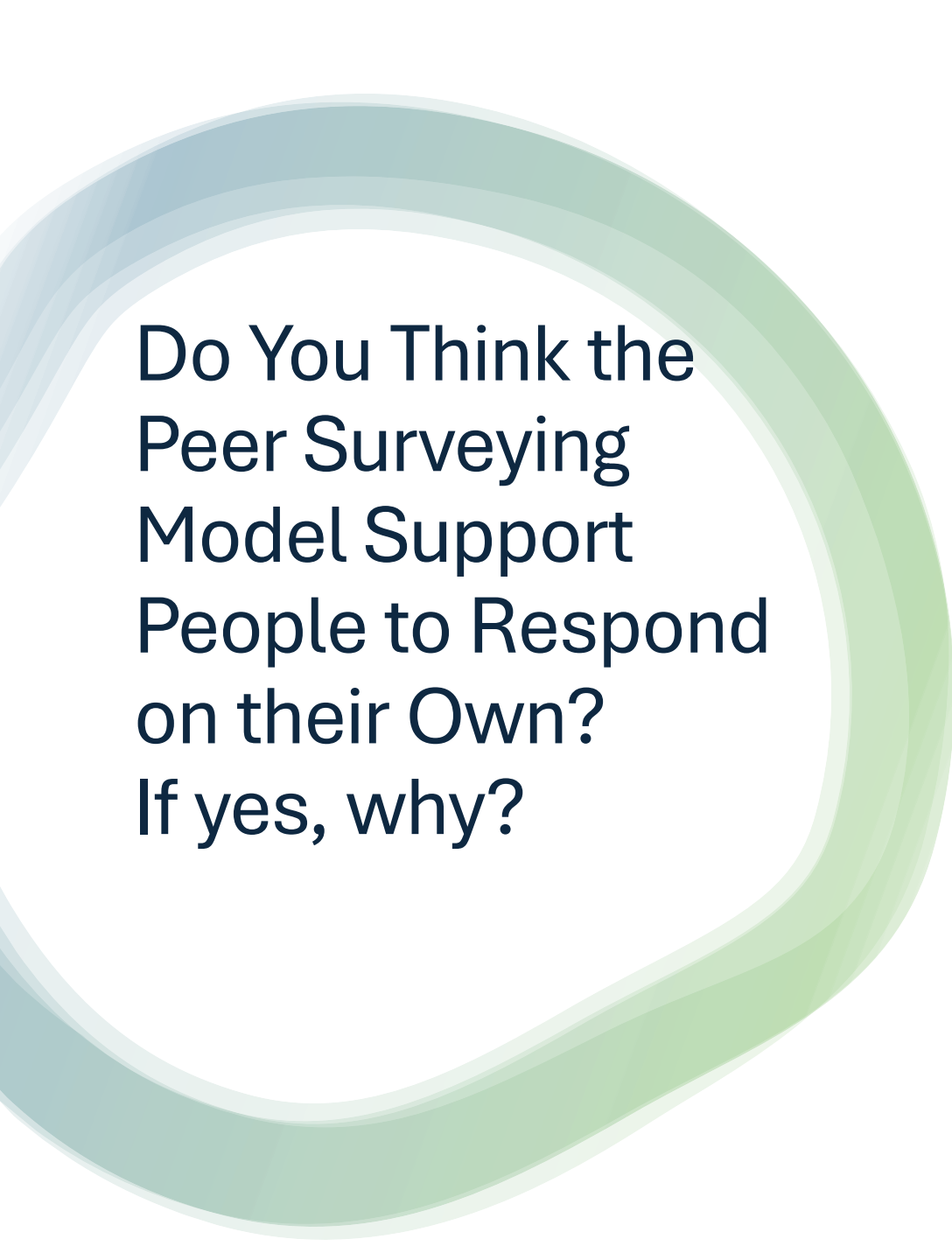
# Why Ensuring that Interviewees Provide their Own Responses is a Value for PA

- I don't think its just part of the IM4Q/NCI program, I stress that it is the reason we do these surveys.
- We need to give the individuals the opportunity to answer questions that are for them and that they have probably never been asked before.
- I discuss this with SCO's, Staff, monitors, and family members when I talk to them about IM4Q.
- The statements that frustrate me the most are “ they won't be able to answer your questions” or “ they won't understand”.
- I thank them for their opinions, but we ALWAYS try to speak with the individual and provide them the opportunity to answer themselves. I feel that doesn't happen enough in their lives and if we can provide that opportunity, we will do it.



# For 25 Years: PA's Use Peer Monitors – People with Disabilities and Family Members

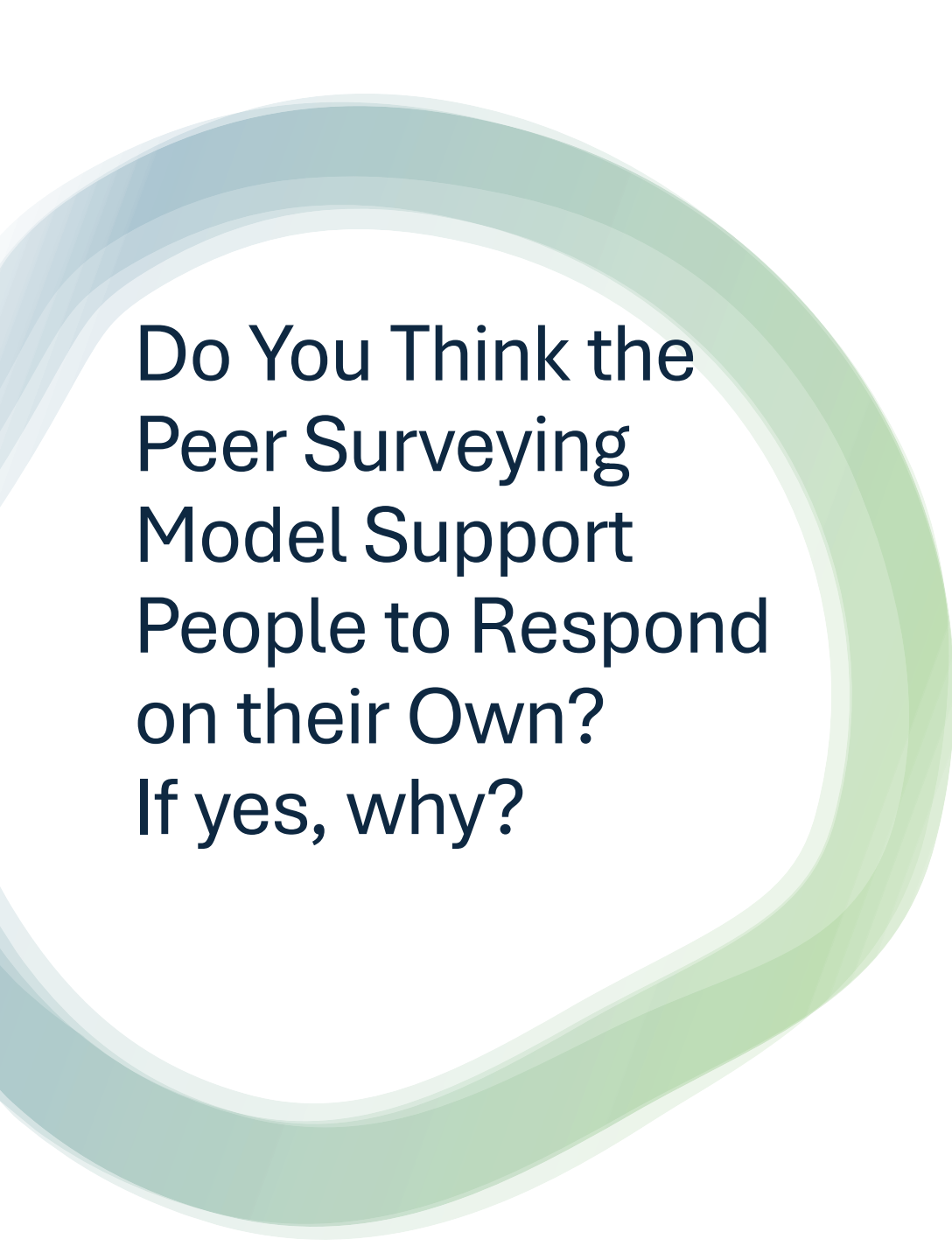
- State wanted independent interviewers who experience services.
- Believed in “Nothing about us without us.”
- Strong self-advocacy and family movement in PA influenced and supported this decision.
- Learned even virtual interviewing was possible using the peer model.
- High versus low expectations of people.
- Number of people with disabilities in 2024/2025 as monitors – 80
- Number of family members in 2024-2025 as monitors - 82



## Do You Think the Peer Surveying Model Support People to Respond on their Own? If yes, why?

First- the family member perspective:

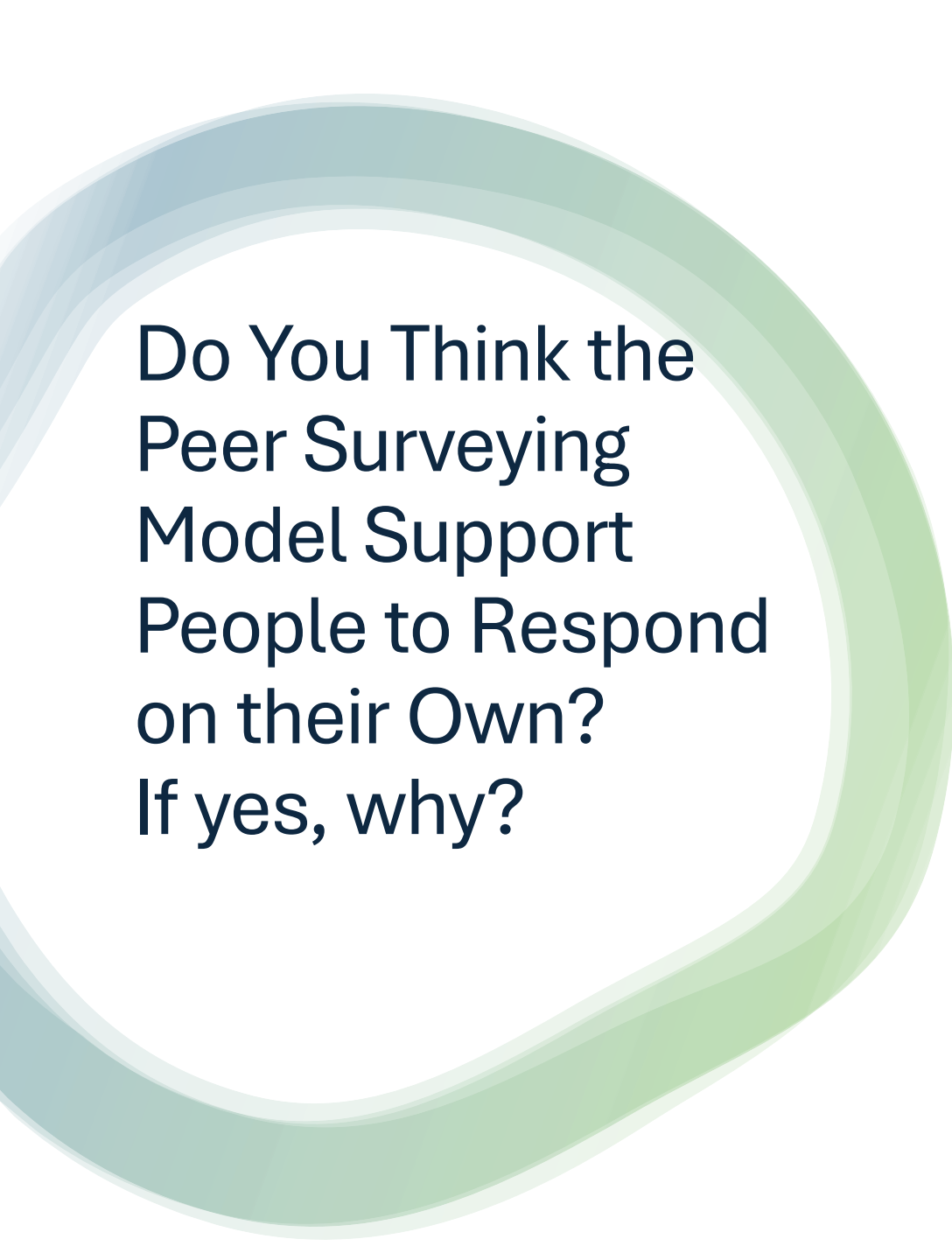
- I have found it extremely helpful to have a family member assist with scheduling surveys for people who live at home with their family. It's helpful in this situation for peer-to-peer interaction/encouragement to participate.
- Also, during survey meetings, it's a way for family members to connect with each other.
- The family participating feels they are being heard, because they are talking to another family member going through similar circumstances. Additionally, the family member is a role model for their co-workers.
- Family members can help monitors understand the service system from their perspective.



# Do You Think the Peer Surveying Model Support People to Respond on their Own? If yes, why?

## Monitors with Disabilities:

- I cannot make enough positive comments about using people with disabilities to ask their peers questions.
- We encourage our monitors with disabilities to ask questions, as they are comfortable, and assist with clarifying questions for their peers.
- I believe it can be easier for people to talk to people like themselves. It can bring about a feeling of comfortableness or knowing he/she can relate to situations.
- Not only do I believe in the importance of having monitors with disabilities as part of our teams to assist with facilitation, but I have also seen monitors gain valuable job skills.
- They have learned how to better advocate for themselves.
- They are taking on greater roles in their community (participating on MH/ID boards, self-advocacy groups, etc.).
- I also believe it's important to remember that they don't always need to be able to read or write. In the beginning, just like any other monitor, they are learning about the process. Even if they cannot read or write, but can recognize numbers to code the survey, folks with disabilities are valuable to help explain/re-word questions to their peers.



## Do You Think the Peer Surveying Model Support People to Respond on their Own? If yes, why?

- I have found it to be extremely important, not only to the individuals we interview and their families but also to the monitors with disabilities or families with a loved one that has a disability.
- When a monitor is a self-advocate, it often makes the individual feel more comfortable, lets them see that they could possibly do the same thing, shows staff and families that having a meaningful job is possible and everyone is more understanding.
- The self-advocates that are monitors really enjoy all parts of the job, they attend the trainings, take pride in participating in everything we do as a team and have a sense of purpose in helping give other individuals with disabilities a voice.

# Any Follow up with Surveyors if Proxy Overuse is Seen?

- When completed surveys are turned in, we do scan to see if there is a correlation between pre-survey and the flow of the answers from the start of the proxy section to the end and to check for any side bar notes that were written for any insight for any areas that came up during the interview as we rely on monitors to convey to the local program their input.
- If we have any questions we communicate with the monitors who completed the interview.
- Are the proxy questions relatable to all persons being interviewed? Are there a different set of questions that could be asked to get more consumers involved if proxy overuse is seen?
- We have not seen an overuse in proxies. Typically, proxies are only used if a person cannot communicate on their own behalf or they refuse but will allow someone to speak on their behalf.
- We have not seen an overuse of proxy's but If we would be seeing them more often, my monitors have continuous support and trainings if needed so it would be a topic that we would cover.

# Any Monitoring of Proxy Usage that is Done by the State/Contractor?

We do not do this at the  
state level or by the contractor.

Do you?

# Community Café

# Groups:

1. Increasing participation rates in family surveys (Cheryl)
  2. How to get provider agency/case manager buy-in for supporting people to participate in the IPS (Steph Giordano)
  3. NCI State of the Workforce survey – increasing participation and using data to inform policy, quality improvement (Dorothy)
  4. Strategies for collecting background information (BI) for the IPS (Alixé)
  5. Ensuring Access to Medicaid Services Final Rule (Laura)
- Virtual Room (Stephanie Mote)



# WRAP UP

- Please take this quick evaluation!

<https://tinyurl.com/mtmx5ks4>

