



Priority Measures of Quality in LTSS: NCI™ & NCI-AD™

Valerie Bradley, HSRI

Mary Lou Bourne, NASDDDS

Julie Bershadsky, HSRI

April Young, NASUAD

HCBS Waiver Conference 2017

Aug 30, 2017

NASDDDS

National Association of State Directors of Developmental Disabilities Services



Human Services
Research Institute



Agenda

- NCI and NCI-AD: The Basics
- Why measure and report?
- NCI and NCI-AD: Measure Properties
- NCI and NCI-AD: Feasibility and Implementation
- NCI and NCI-AD: Usability and Use
- Other Measures

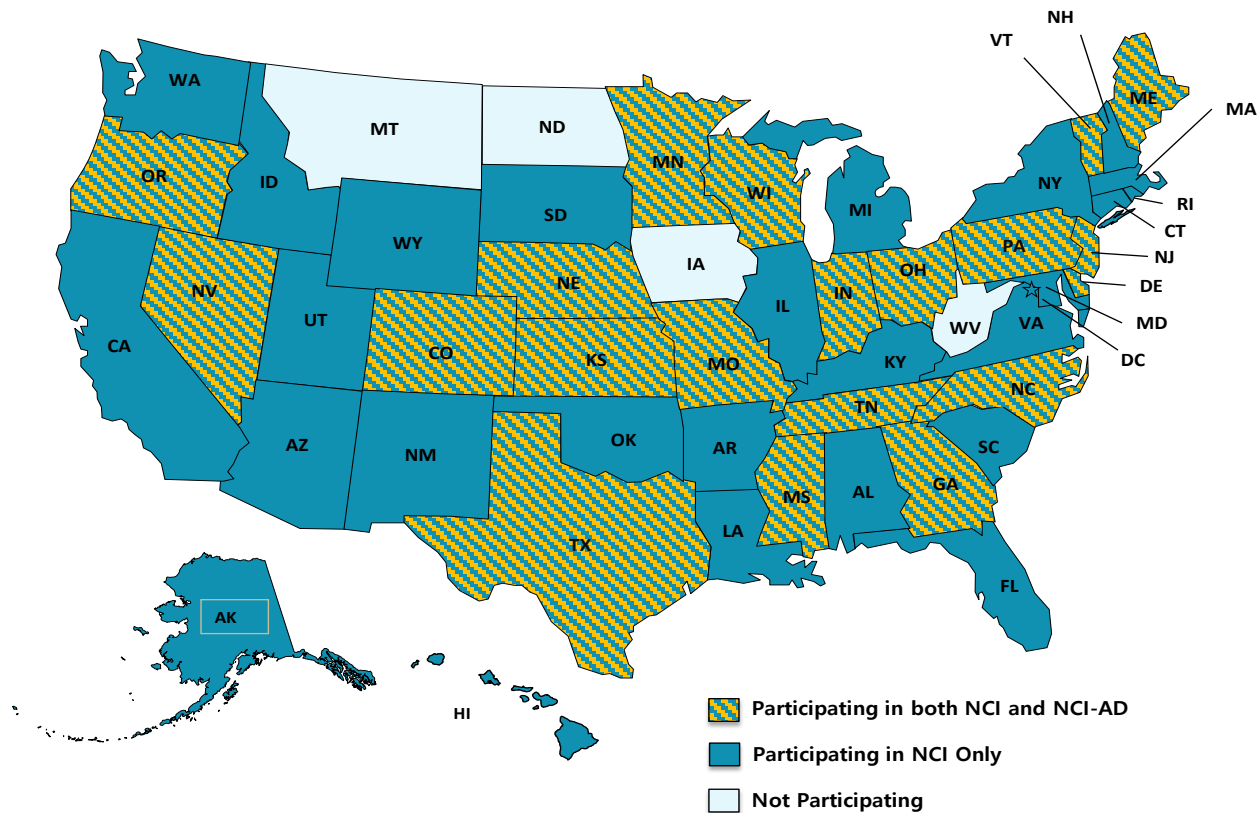
NCI & NCI-AD: Intro 101

- National Core Indicators (for Intellectual and Developmental Disabilities) (**NCI**)
- National Core Indicators for Aging and Disabilities (**NCI-AD**)
 - Two distinct but related sets of survey instruments
 - Both designed to assess state systems performance along a number of key indicators related to community living for various populations
 - Both are quality of life and outcomes surveys
 - Both are state-developed initiatives

- Focus population: **Adults with I/DD** who receive at least one service in addition to case management from state IDD systems:
 - Most participants are receiving services under an HCBS Waiver
 - A small % are either state only, or ICF/ID
- Began in 1997
- Collaboration between NASDDDS and HSRI
- Suite of surveys
 - Adult Consumer (in-person)
 - Family (mail-in)
 - Staff Stability
- Current participation: 46 states and DC
- Funded by state membership fees with ACL support for specific expansion activities

- Focus population: **Older adults and adults with physical disabilities** accessing publicly funded services in:
 - Medicaid Waivers
 - Medicaid State Plan
 - PACE
 - Skilled Nursing Facilities
 - MLTSS
 - State Funded Programs
 - Older Americans Act Programs
- Development began in 2012; Implementation began in 2015
- Collaboration between NASUAD and HSRI
- Adult in-person survey only
- Current participation: 20 states
- Funded by state membership fees

The Map



NCI & NCI-AD Adult Consumer Surveys: Survey Structure

Both measure *service outcomes* of individuals receiving services

- **In-person interview** with trained surveyors (*Person-Reported Outcomes*)
 - Protocols allow for proxy response if person unable or unwilling to respond
 - States may opt to add questions to core set
 - Questions developed and tested through pilot phases
 - Standardized training materials and protocols
- **Background Information** Section:
 - Data from administrative sources and service coordination/case management records
 - Demographic information, personal characteristics, supports needs, services received
 - Provides service system context
 - Can be used to “slice and dice” data (sub-group comparisons)

- ACL currently supporting NCI and NCI-AD to carry out further measure development
- Includes development and submission of selected measures as 'Patient-Reported Outcome Performance Measures' (PRO-PMs) to the National Quality Forum (NQF).
- NQF works to endorse measures for use in reporting on quality and efficiency of healthcare in the US
- Recently started looking at measures in LTSS



NQF Criteria For Endorsement

- 1) Importance to measure and report
- 2) Scientific acceptability of measure properties
- 3) Feasibility
- 4) Usability and use
- 5) Related and competing measures

1. Importance To Measure And Report

Setting Priorities: How Do States Decide What To Measure And How To Measure It?



- How do States determine if it is important to measure something?
 - Requirements - Federal and State Regulations/ Compliance
 - Recommendations - Stakeholders, Evidence Based and Best Practice
 - Risk - Experience

NCI As a Tool To Support Federal Or State Regulatory Compliance Efforts

- NCI – the proverbial “early warning”
 - Many states that have identified NCI as a tool for transition and ongoing compliance note that NCI is a strong starting place to identify structural or programmatic barriers to compliance and can provide ongoing data to check whether improvement strategies have had desired outcomes.
- NCI-AD – newer project; also used to demonstrate compliance

Tools To Ensure Regulatory Compliance, Continued

A number of NCI and NCI-AD indicators can help inform how well the state's system is doing on issues related to

- community integration,
- choice/ control,
- ensuring health and welfare
- employment

.....all elements contained in the final rule.

NCI & NCI-AD As Tools To Support Evidence-Based And Best Practice Recommendations

- Demonstrate Best Practices in States
 - As national data sets, NCI and NCI-AD allow for benchmarking
 - State Agencies contribute to the development of measures and indicators, based on their knowledge of best practices occurring in the field
 - National quality organizations using Expert Panels recommend measures often already existing within NCI & NCI-AD

Recommendations Example: National Quality Forum Measure Recommendations

NATIONAL QUALITY FORUM

REPORT ON HCBS MEASUREMENT GAPS

SEPT. 2016

Quality in Home and Community-Based Services to Support Community Living:

Addressing Gaps in Performance Measurement

FINAL REPORT
SEPTEMBER 2016



NATIONAL QUALITY FORUM

This report is funded by the Department of Health and Human Services under contract HHSM-500-2012-00009I, Task Order HHSM-500-T0014.

Example: NQF Domains For Home And Community-Based Services

NQF HCBS Recommended Domains

- Service Delivery and Effectiveness
- Person-Centered Planning and Coordination
- Choice and Control
- Community Inclusion
- Caregiver Support
- Workforce
- Human and Legal Rights
- Equity
- Holistic Health and functioning
- System Performance and Accountability
- Consumer Leadership in System Development

NCI & NCI-AD Domains Cross-Over With NQF Domains From HCBS Report

NCI

- ❖ Community Inclusion
- ❖ Choice and Decision Making
- ❖ Relationships
- ❖ Satisfaction
- ❖ Service Coordination
- ❖ Work
- ❖ Self-Determination
- ❖ Access
- ❖ Health
- ❖ Medications
- ❖ Wellness
- ❖ Respect and Rights
- ❖ Safety
- ❖ Family outcomes
- ❖ Staff Stability

NCI-AD

- ❖ Community Participation
- ❖ Choice and Decision Making
- ❖ Relationships
- ❖ Satisfaction
- ❖ Service Coordination
- ❖ Care Coordination
- ❖ Work
- ❖ Self-Direction
- ❖ Access
- ❖ Health Care
- ❖ Medications
- ❖ Wellness
- ❖ Rights and Respect
- ❖ Safety
- ❖ Everyday Living
- ❖ Affordability
- ❖ Future Planning
- ❖ Control

Benchmarking

- Provides comparison to other states with similar/same design of service systems
- Provides comparison year over year to your own performance
- Provides context for understanding the full picture – so what?
- Removes the competitive nature of comparison, focuses on best practice and learning
- Takes into consideration the full range - and where you fall within it
- Allows you to see gaps in your performance within generally accepted data elements

<https://www.isixsigma.com/methodology/benchmarking/understanding-purpose-and-use-benchmarking/>

Example: Paid Job In the Community

17%

Has paid
**community
job**

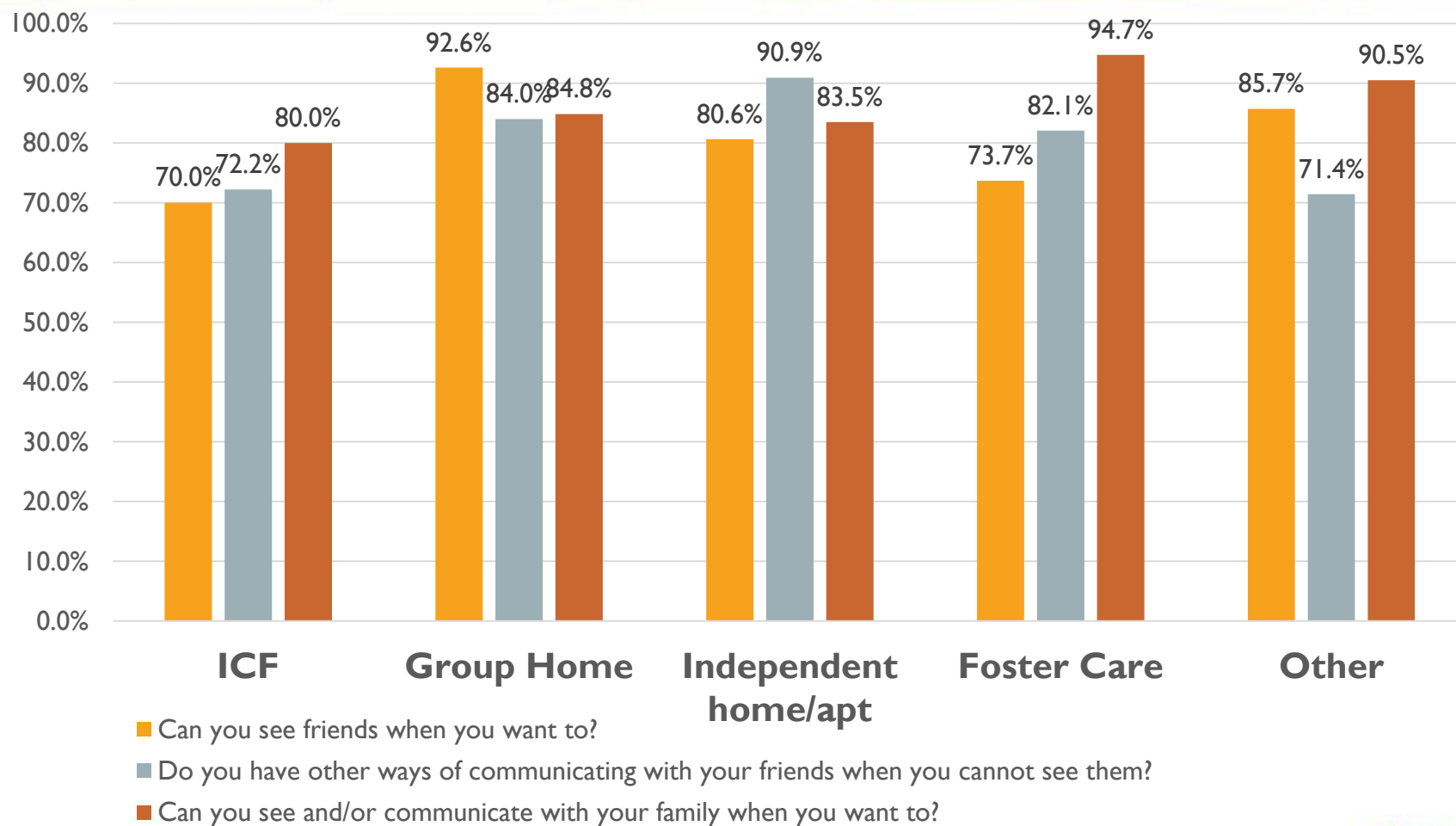
50%

Not working,
but **wants a
job**

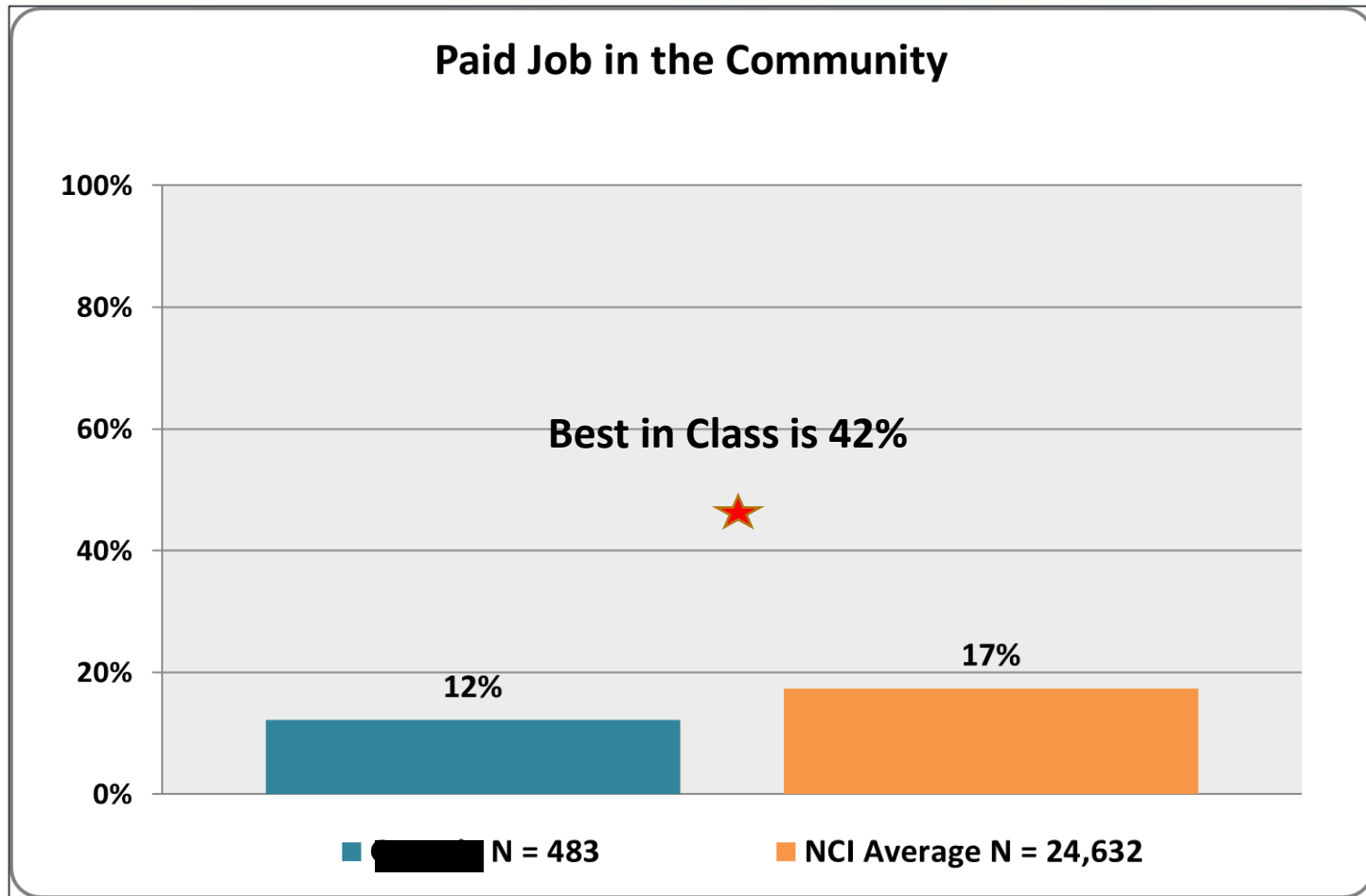
56%

Not working,
wants a job,
and has
employment
as a **goal in
service
plan**

Example: Relationships

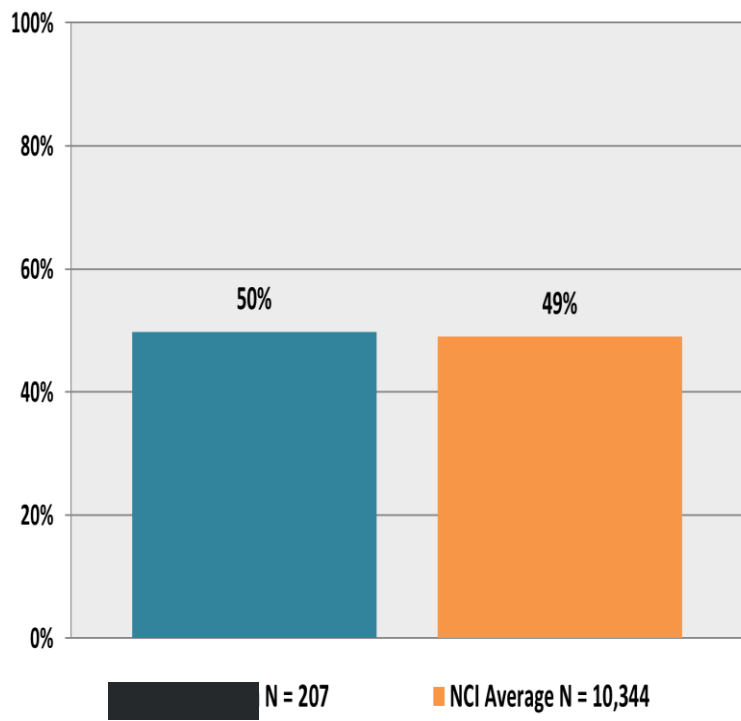


Example 1: Paid Work From State's 2014-15 NCI

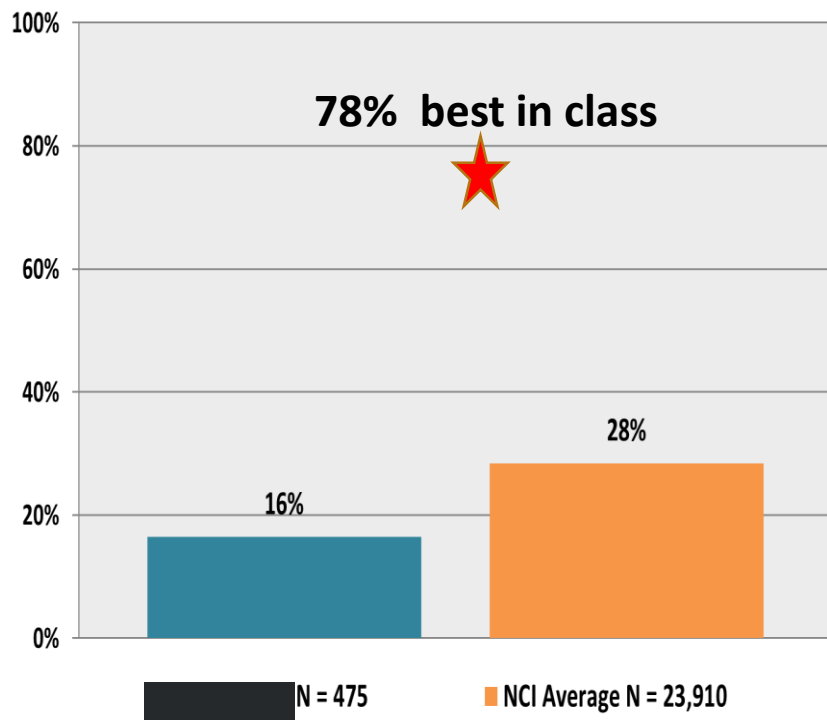


Example 1: People who currently don't have a job, who said they want a job, and have a goal in their ISP; State's 2014-15 NCI

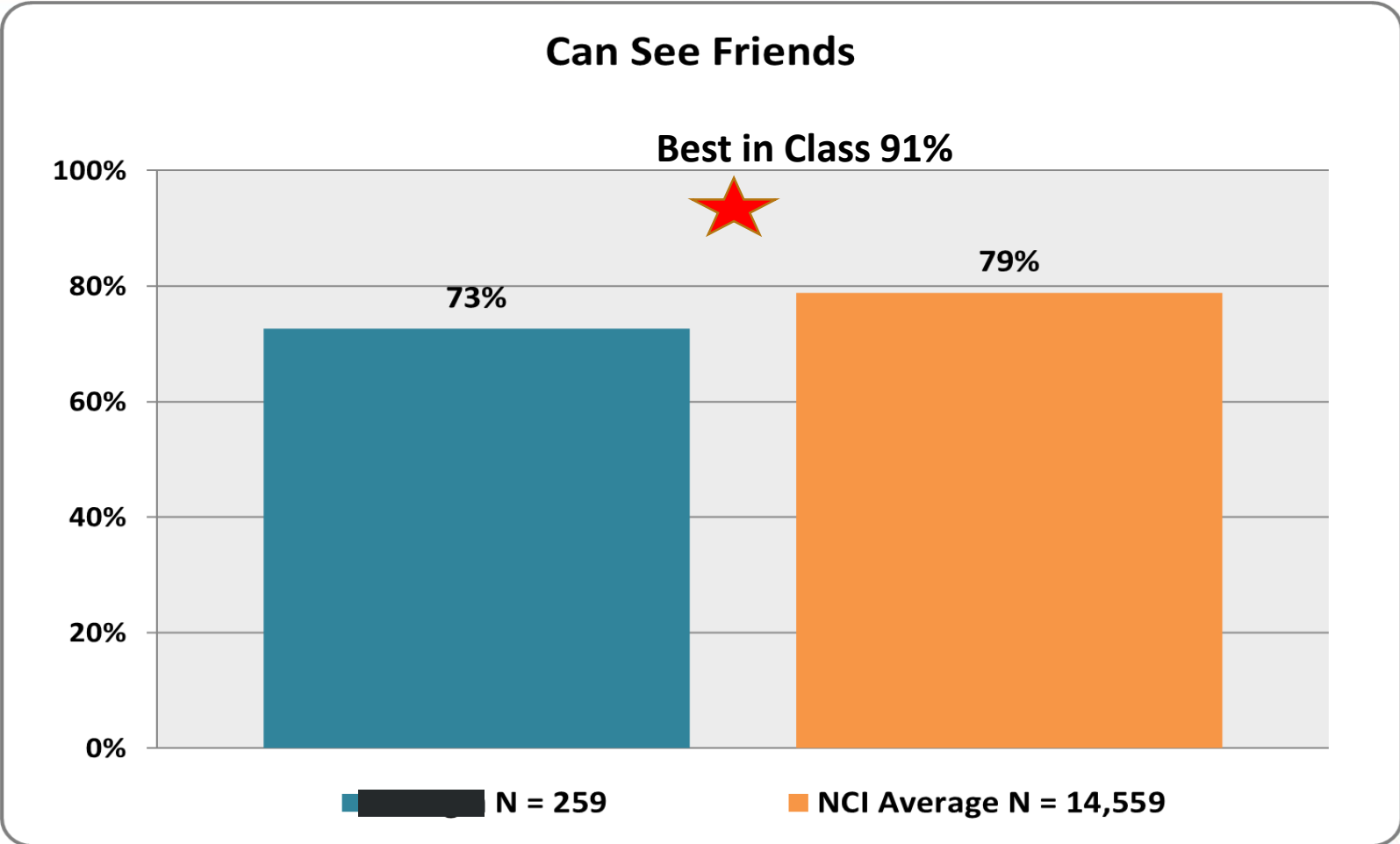
Wants a Paid Job in the Community



Has Community Employment as a Goal in Service Plan



Example 2: People who report they can see their friends when they want; State A 2014-15 NCI



Reporting

- Reports publicly available: www.nci-ad.org & www.nationalcoreindicators.org
- Reports included in the membership dues:
 - Annual National reports (NCI and NCI-AD)
 - Annual State reports (NCI and NCI-AD)
 - Annual User-Friendly State and National Reports (NCI)
 - Annual Staff Stability Survey National Report (NCI)
 - Annual At-A-Glance report of selected national results (NCI)
 - Regular data briefs on topics of interest
- Optional: additional analysis and reports as requested by states (not covered by dues)
 - E.g. Reports comparing outcomes by MCO
 - E.g. Reports comparing outcomes by region/regional center
- States have access to their own data for internal analysis and report generation

Examples: State-Generated Reports

Massachusetts DDS Quality Assurance Brief

People with intellectual and developmental disabilities are supported to:
Develop and Maintain Relationships with Family and Friends

People receive the support they need to visit family and friends FY14

Family	MA	78%
	Nat Avg	80%
Friends	MA	78%
	Nat Avg	78%

Source: National Core Indicators (NCI)

8 out of 10 people have a best friend
(Source: NCI FY14)

■ Has a best friend ■ Does not have a best friend

4 out of 10 people feel lonely at least half of the time
(Source: NCI FY14)

■ Feels lonely ■ Does not feel lonely

People can go on a date, or can date with some restrictions, if they want (NCI, FY14)

MA	88%
Nat Avg	83%

Providers support people to explore, define, and express their need for intimacy (L&C data)

FY14	91%
FY15	82%

Most Recent Licensure and Certification Data FY15
Providers support people to:

- Get together with family and friends when appropriate: 2% (98% do not)
- Develop appropriate social skills: 100%
- Develop and/or increase personal relationships and social contacts: 3% (97% do not)

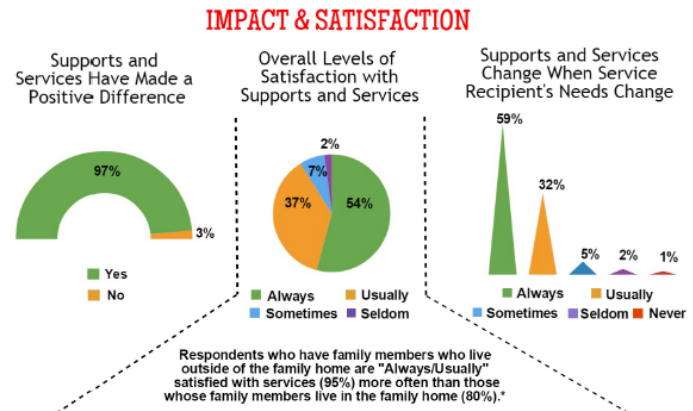
No significant changes FY12 – FY15

Licensure and certification (L&C) data include community-based homes with staff support, individualized home supports, placement services and day programs. **NCI data** include these populations, as well as people living independently or with their parents. The NCI survey asks about **people's satisfaction** with specific outcomes. Licensure and certification assesses whether **people are supported** by staff to achieve personal outcomes.

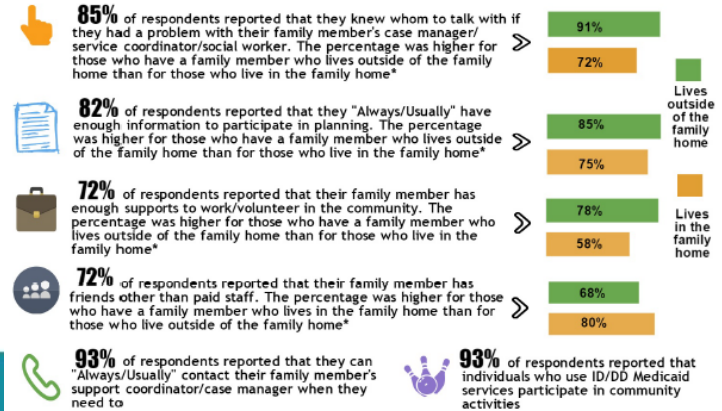
Jan 2016

VIRGINIA

NCI Family Experiences with Supports and Services



ASSISTANCE, INVOLVEMENT, & FRIENDSHIP



* Indicates statistically significant differences between groups

2. Scientific Acceptability of Measure Properties

Psychometric Properties: NCI & NCI-AD

- Both tools have been psychometrically tested
 - Evidence of validity:
 - Face validity
 - Content validity
 - Expert validation, focus groups, cognitive testing
 - Evidence of reliability:
 - Inter-rater reliability
 - Internal consistency
- Extensive field-testing during development and pilot stages
- Periodic updates to ensure ongoing validity

NCI & NCI-AD: Documenting Measure Properties

- In progress: summarizing and documenting existing evidence of measure properties (NCI and NCI-AD)
 - Psychometric properties, evidence of validity and reliability
 - Implementation protocols
 - Training procedures, requirements and protocols
 - Sampling procedures and requirements
 - Interviewing protocols
 - Implementation consistency & validity across states
- Goal: publicly available peer-reviewed published documentation
- Concurrent external validation study by University of Minnesota (UMN Background Information Study, NCI)
 - The study purpose is to:
 - Establish the reliability and validity of 31 background questions (and related sub-questions) from the NCI Adult Consumer Survey (NCI-ACS)
 - Working with three participating states: **Oklahoma, Georgia** and Washington state
 - Evaluate the different approaches and rigor to background data collection across states

NCI & NCI-AD: More In the Works

- Additional testing and analysis planned as part of ACL funded project (2016 – 2021):
 - *“Developing HCBS Quality Measures from NCI and NCI-AD”*
- Goal: to add to existing evidence of good psychometric properties
 - Confirmatory cognitive testing
 - Analysis of responders vs. non-responders
 - Inter-rater reliability testing
- Results to be peer-reviewed, published and made publicly available

Proxies: NCI & NCI-AD

- Proxies are permitted when individual is unable or unwilling to respond
- Standardized proxy protocol
- Proxies allowed for subset of more objective questions only
 - NCI-AD: separate proxy version containing only proxy-allowed questions, rephrased for the proxy
 - NCI: proxies allowed only for Part II of the Survey
- Individual response vs. proxy response tracked for each question
- Also tracked: type of proxy

NCI & NCI-AD: Sampling Frame

- Sampling design is flexible (state to state and year to year), BUT:
 - Sampling strategy is documented
 - Random sampling is required
 - Minimum sample size is required (400)
 - Project teams assist states with sampling strategy and design, including:
 - Programs and populations to be included
 - Stratification
 - Power and sample size calculations
 - Disproportionate representation
- States can choose to:
 - draw a simple random sample
 - stratify their sample proportionally (e.g. to ensure regional representativeness)
 - oversample certain entities or sub-populations (e.g. to focus on a region or a program)

NCI & NCI-AD: Risk-Adjustment

- Risk-adjustment employed for some of the outcomes in order to “level the playing field”
 - when comparing states (NCI and NCI-AD), and
 - types of funding sources (NCI-AD)
- Risk-adjusters include demographic (e.g. age, gender) and functional (e.g. mobility, level of assistance needed) factors
- Proxy response included as a risk-adjustment variable (NCI-AD)
- Different type of risk-adjustment: reporting by type of residence (NCI) and type of funding sources (NCI-AD) for each state

3. Feasibility

NCI & NCI-AD: Evidence Of Feasibility

- NCI:
 - 20 years of implementation
 - Currently in 46 states
- NCI-AD:
 - Third year of implementation
 - Currently in ~20 states
- Undoubtedly - feasible and sustainable

NCI & NCI-AD: Ensuring Feasibility And Fidelity

- Work plan (NCI and NCI-AD)
 - Planning and documenting implementation in each state
 - Surveyors, timelines, populations, etc.
 - Sampling
 - Used in concert with planning calls between national project teams and state/contractor teams
- Background Information Crosswalk
 - Used to identify and document sources of administrative data used in each state
 - Used to document how admin data elements are cross-walked and coded into survey BI elements (NCI-AD)

NCI & NCI-AD: Ensuring Feasibility And Fidelity

- Training
 - Initial standardized on-site training of interviewers by the national project teams
 - Standardized yearly refresher training webinars
 - Standardized training materials for all interviewers and state staff
 - Periodic shadow observations by the national project teams, as needed
 - Optional: periodic on-site in-person re-training as needed and if requested by state
- ODESA for standardized data entry
- NEW: NCI Handbook:
 - Administration protocols, state/NCI responsibilities, ODESA guidelines, etc.

NCI & NCI-AD: Ensuring Feasibility And Fidelity

- Extensive and ongoing Technical Assistance to participating states, including assistance with:
 - Stakeholder engagement and education
 - Sampling strategy
 - Planning and implementing the survey
 - Interpreting results
 - Publicizing and presenting data to stakeholders
 - Using the data
 - Any other issues that may arise during the surveying and reporting cycle
- Access to education and best practices webinars and presentations
- Opportunities to learn from other states, communities of practice

4. Usability And Use

NCI: An Important Element Of an Integrated Data Strategy



- When used as a complement to other data sources used by states (administrative data, record reviews and others), NCI can provide high level indicators of strong system performance.

NCI Data Informs System Change



Conflict-Free Case Management



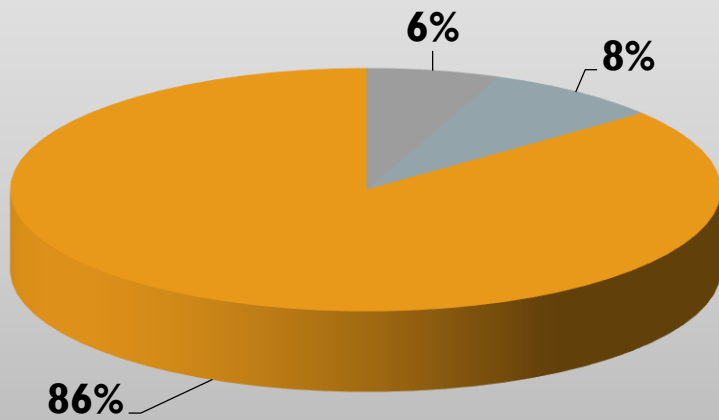
Community Conversations



NCI Data Informs System Change

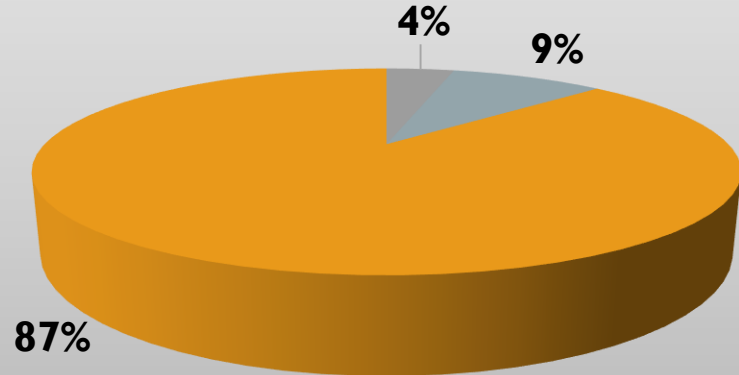
Did you help make your service plan? (N=249)

■ No ■ Maybe, not sure ■ Yes



Does your case manager/service coordinator ask you what you want? (N=264)

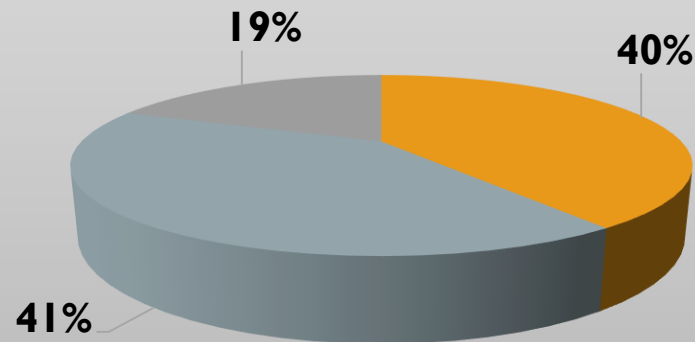
■ No ■ Sometimes ■ Yes



South Dakota: NCI Data Informs System Change

Did you choose or pick your case manager/service coordinator? (N=271)

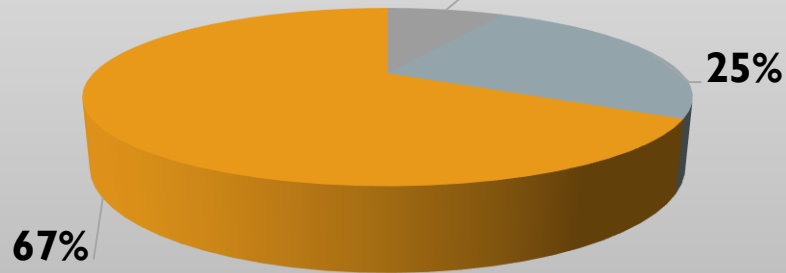
- No, Someone else chose
- Case manager/service coordinator was assigned but s/he can request a change
- Yes, chose



South Dakota: NCI Data Informs System Change

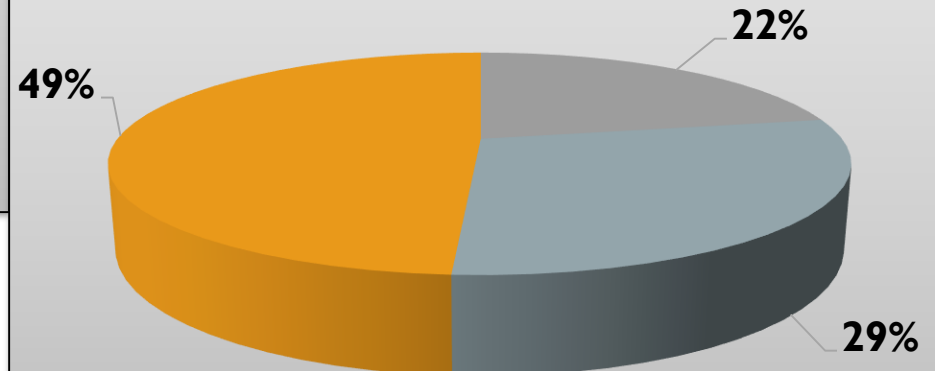
If you call and leave a message, does your case manager/service coordinator take a long time to call you back, or does s/he call back right away? (N=210)

■ Takes a long time to call back ■ In-between 8% ■ Calls back right away



Who chose (or picked) the place where you work? (N=160)

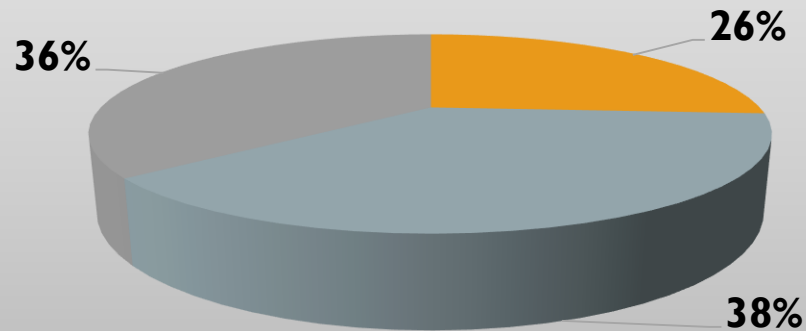
■ Someone else chose ■ Person had some input ■ Person made the choice



South Dakota: NCI Data Informs System Change

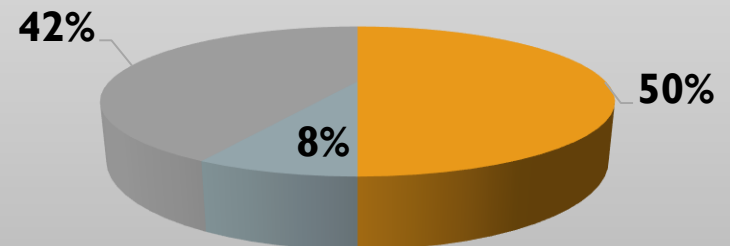
Who chose (or picked) the place where you live? (N=255)

Someone else chose Person had some input Person made the choice



Did you choose (or pick) the people you live with (or did you choose to live by yourself)? (N=246)

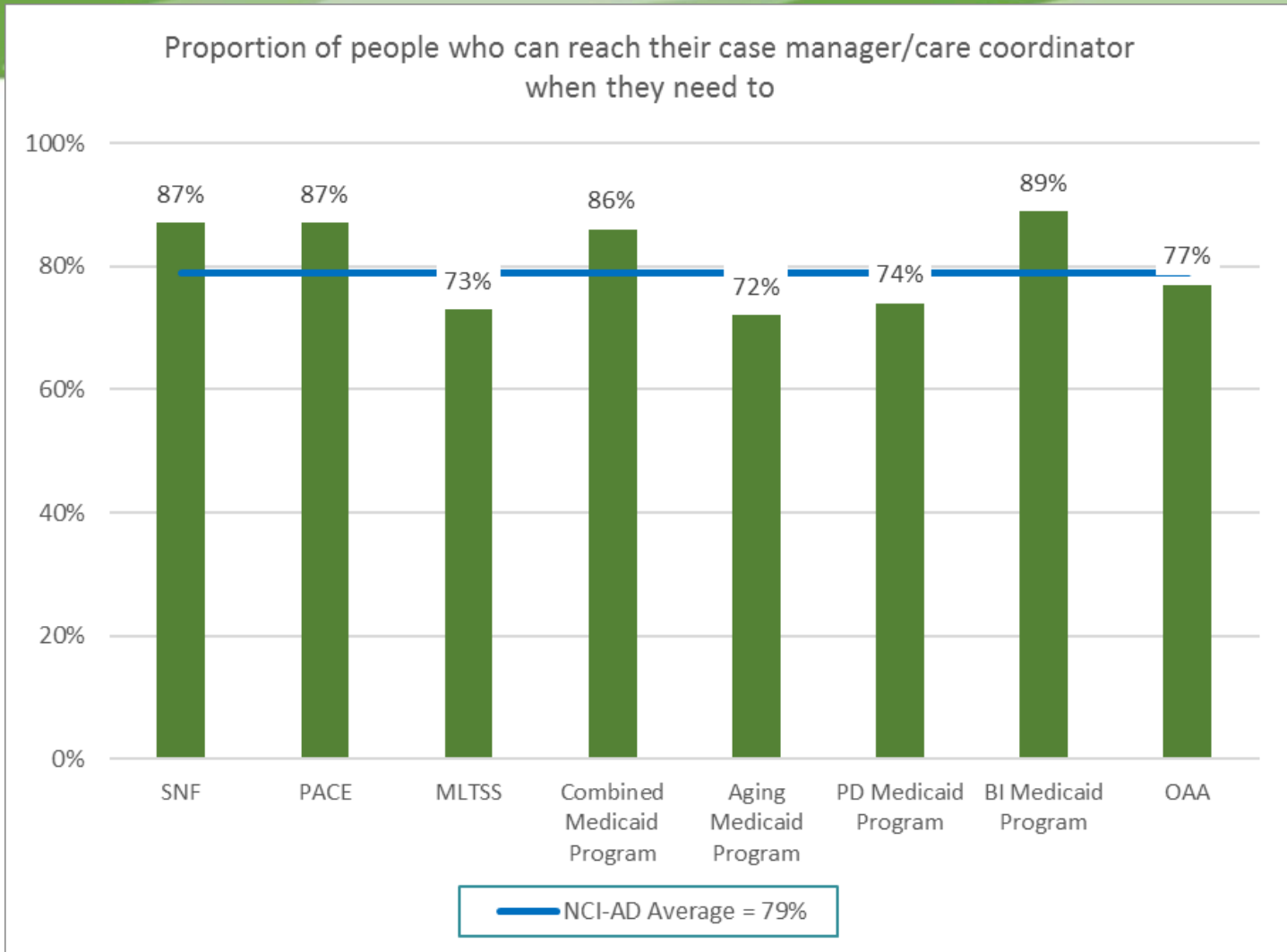
No, Someone else chose
Person chose some people or had some input



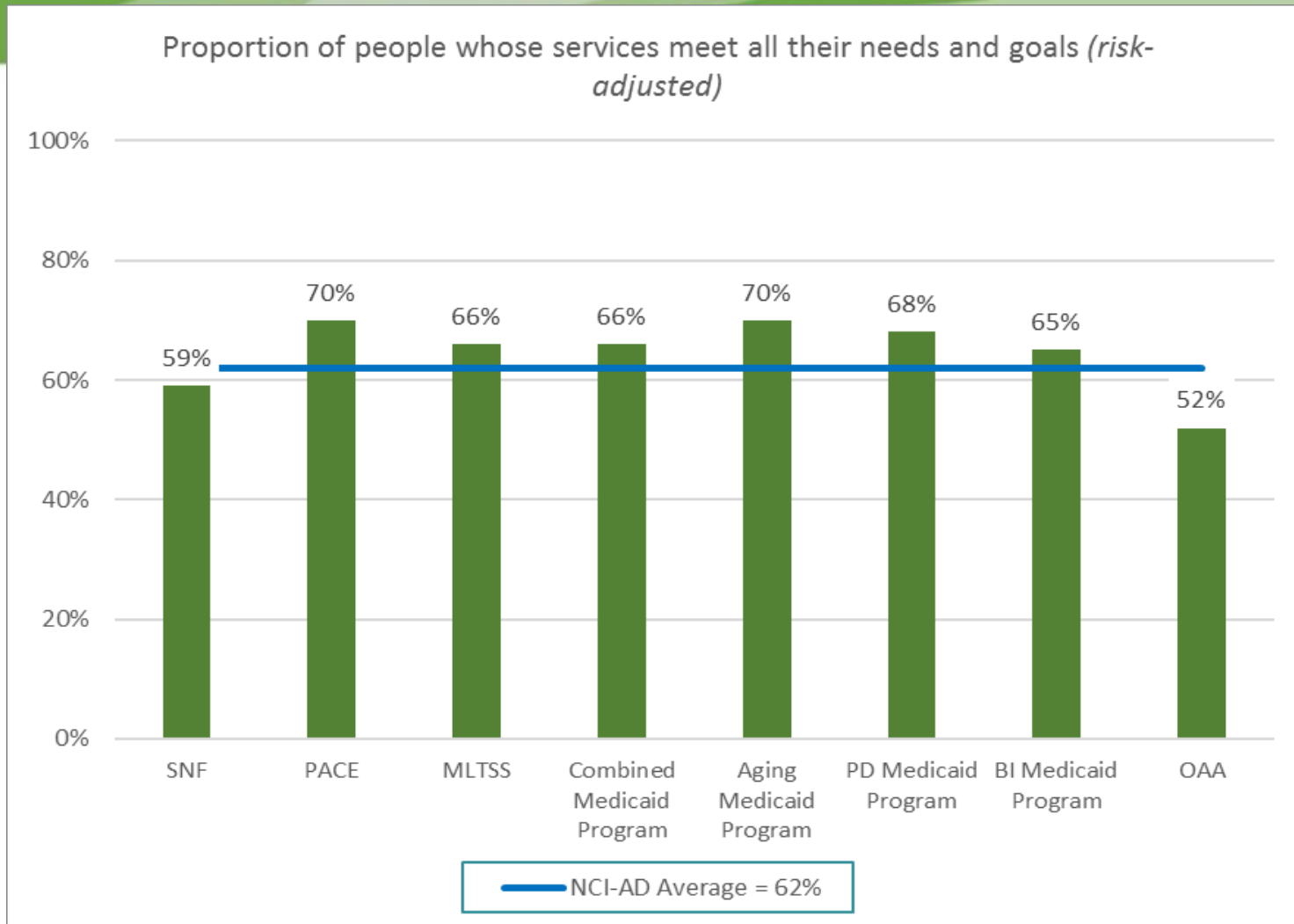
NCI-AD: Using the Data

- Can be used across settings and funding sources
- Can provide state, program, and regional comparisons
 - Crosswalks to NCI (ID/DD) measures
- Focuses on how consumers experience services and how services impact their quality of life
 - Goes beyond service satisfaction
- Provides transparency and accountability
 - State and National reports are publicly available online
- Provides timely and actionable data over time

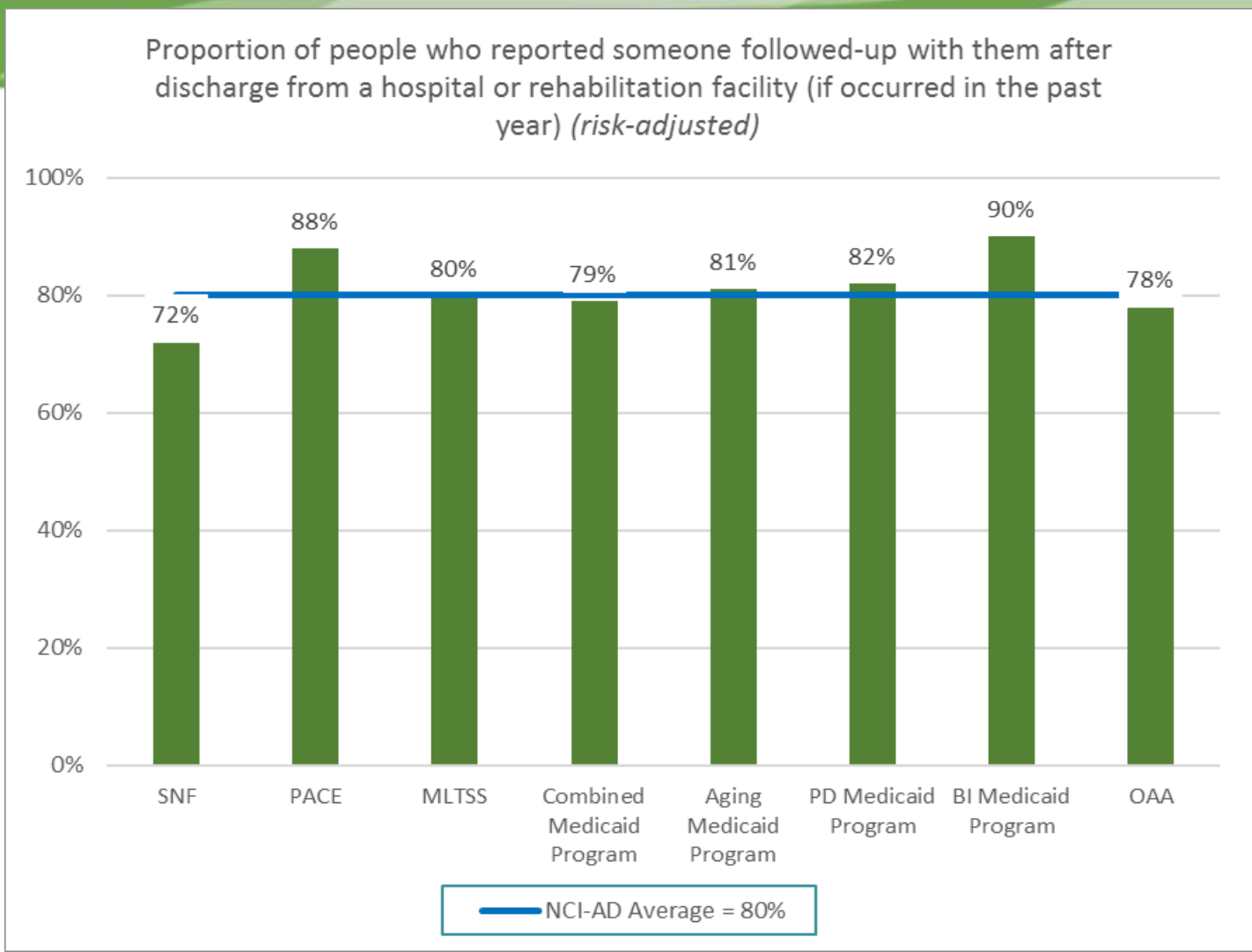
NCI-AD: Service Coordination



NCI-AD: Service Coordination



NCI-AD: Care Coordination

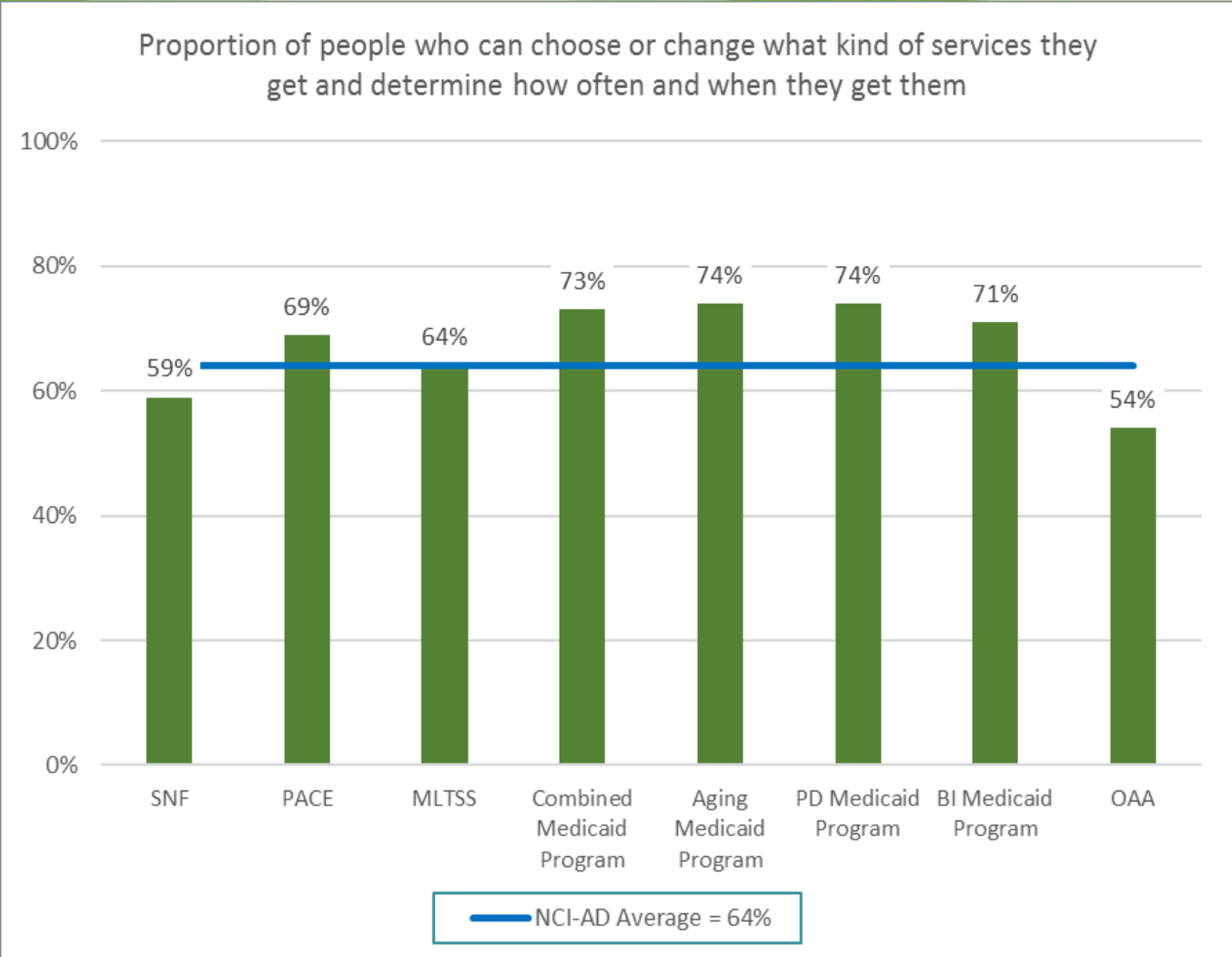


NCI-AD: What Does This Mean To States?

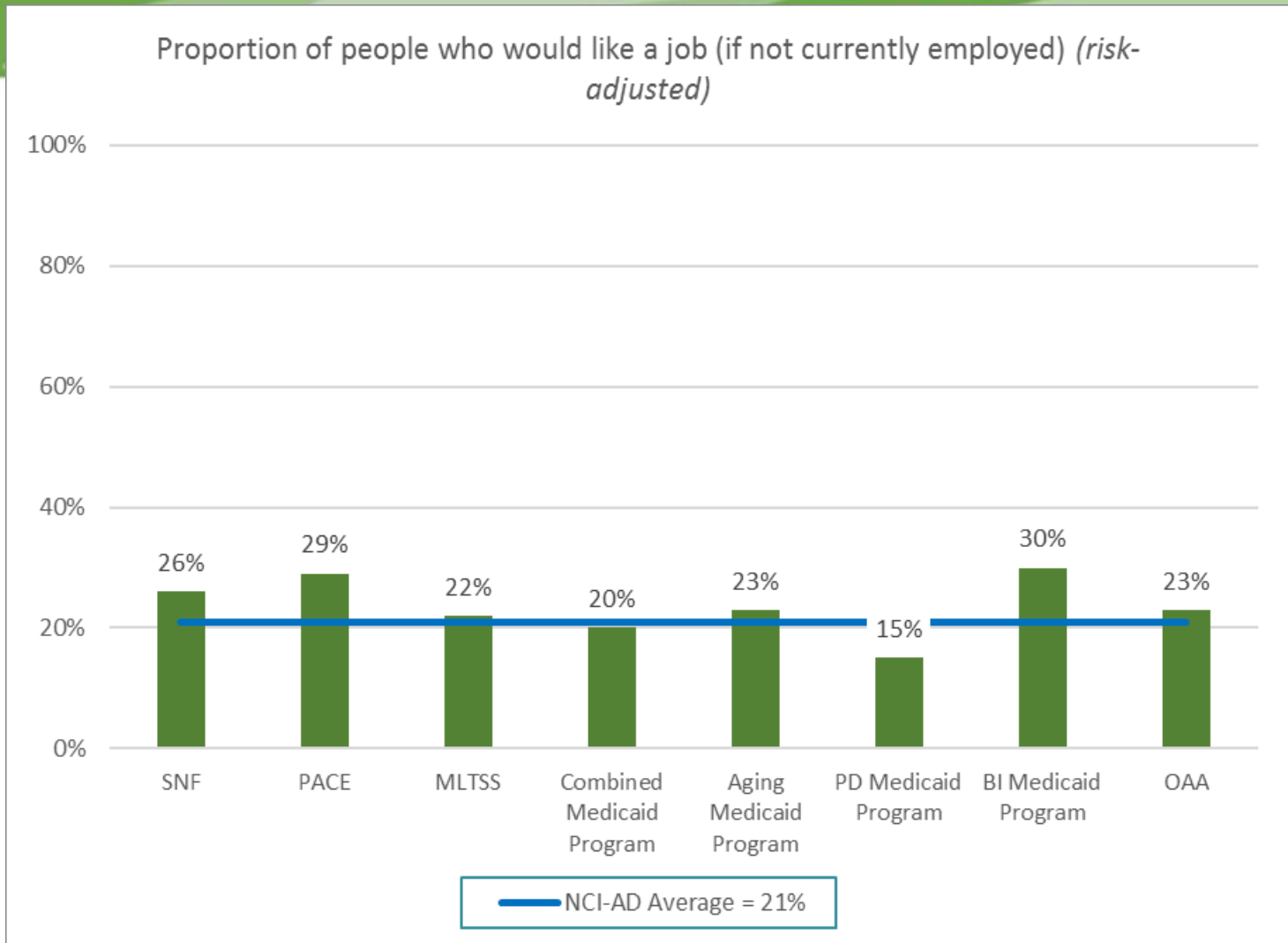
How states
can turn
survey
outcomes
into action

- Set goals to increase the number of people who can reach their care coordinator.
- Use areas with poor results to demonstrate need for additional funding because goals are not being met.
- See if the benchmarks prior to moving to MLTSS move upward after implementation.

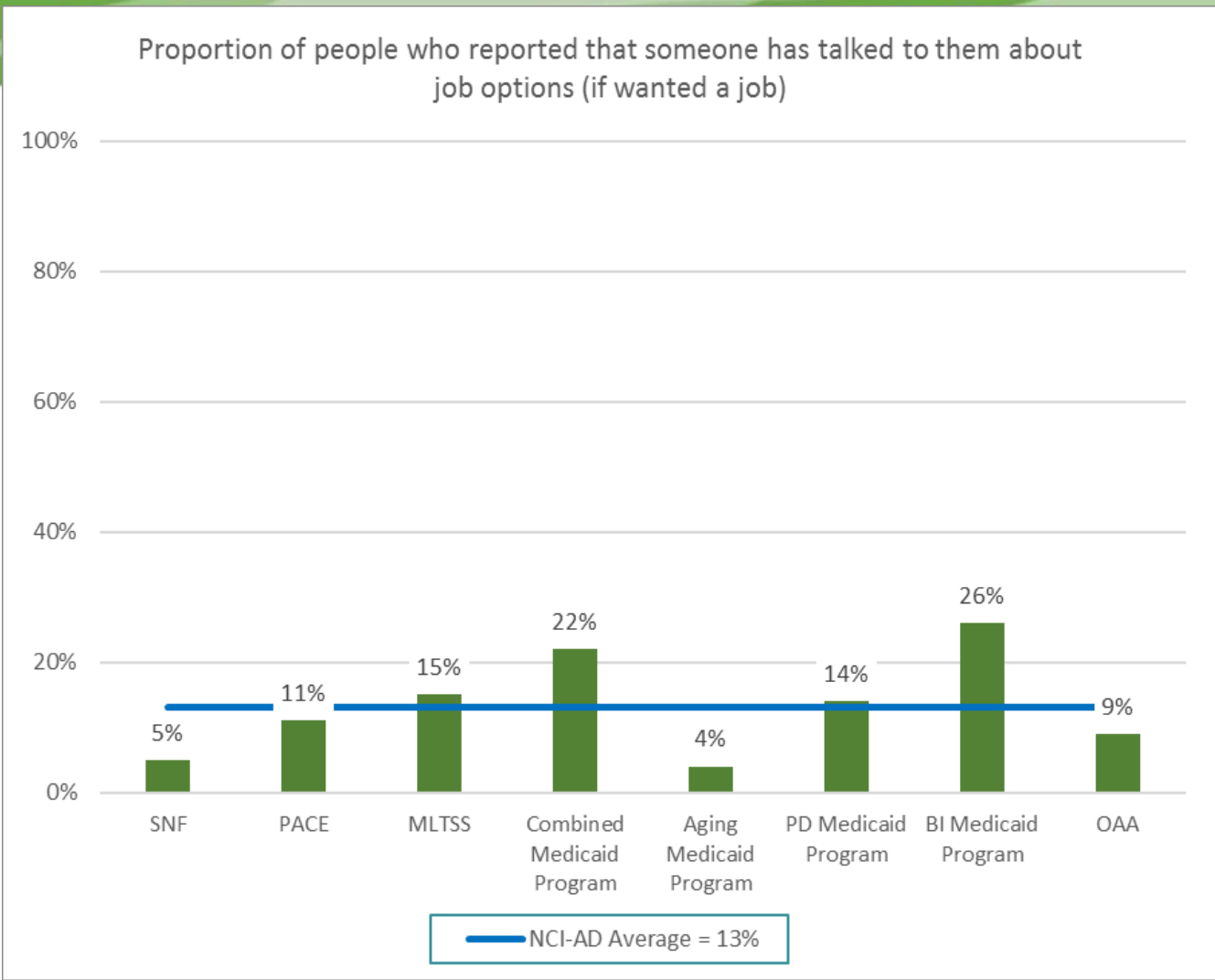
NCI-AD: Self-Direction



NCI-AD: Employment



NCI-AD: Employment



NCI-AD: What Does This Mean To States?

How states
can turn
survey
outcomes
into action

- Taking a fresh look at self-direction; using data to inspire new initiatives
- The fact that older people are stating they want employment at such high rates should be investigated.
 - ▣ States could use this data as justification to review and/or explore employment first policies

Crosswalks To HCBS Regs



A Collaboration of
The National Association of State Directors of Developmental Disabilities Services
and the Human Services Research Institute

NCI Performance Indicators: Evidence for HCBS Requirements and Revised HCBS Assurances

Practical Tools for States
REVISED 2015
For Use With 2015-16 NCI Surveys

Prepared by
Erica Hendricks, JD
Elizabeth Pell, MSW, LICSW

Human Services Research Institute

National Core Indicators Publication

www.nationalcoreindicators.org



NCI-AD Performance Indicators: A Quality Improvement Tool for Person-Centered Service Planning

Updated for the 2016-2017 Survey Year

Second in a Series of Technical Assistance Tools for States

www.nci-ad.org

Updated 10/13/2016



NCI-AD Performance Indicators: Crosswalk to HCBS Settings Requirements

First in a Series of Technical Assistance Tools for States

August 2015

www.nci-ad.org

Updated 10/13/2016



Crosswalk of NCI to NCI-AD

Section I - Crosswalk of matching NCI and NCI-AD Indicators

NCI		NCI-AD	
Q#	Question	Q#	Question
	<i>The proportion of people who have a paid job in the</i>		<i>Proportion of people who have a paid job.</i>

Section I - Crosswalk of matching NCI and NCI-AD Indicators

	NCI Indicator	NCI-AD Indicator
Work and Non-work activities	<i>The proportion of people who have a paid job in the community.</i>	<i>Proportion of people who have a paid job.</i>
	<i>The proportion of people who do not have a job in the community, but would like to have one.</i>	<i>Proportion of people who would like a job.</i>
	<i>The proportion of people who do volunteer work.</i>	<i>Proportion of people who volunteer or would like to volunteer.</i>
Community Inclusion, Participation and Leisure	<i>The proportion of people who regularly participate in everyday integrated activities in their communities.</i>	<i>Proportion of people who are able to participate in preferred activities outside of home when and with whom they want.</i>
	<i>The proportion of people who do things in their communities that they like to do, as often as they want.</i>	
Choice and Decision-Making	<i>The proportion of people who make choices about their everyday lives, including: housing, roommates, daily routines, jobs, support staff or providers, what to spend money on, and social activities.</i>	<i>Proportion of people who are involved in making decisions about their everyday lives including where they live, what they do during the day, the staff that supports them and with whom they spend time.</i>
Self-Direction of Care	<i>The proportion of people who are currently using a self-directed supports option.</i>	<i>Proportion of people self-directing.</i>
	<i>Of those using a self- or participant-directed option, the proportion of people who take part in self-directed activities (such as hiring or firing staff).</i>	<i>Proportion of people who can choose or change the kind of services they receive and who provides them.</i>

<i>o you have a paying job in the community?</i>
<i>f people who would like a job.</i>
<i>ould you like a job?</i>
<i>f people who volunteer or would like to</i>
<i>o you do any volunteer work?</i>
<i>ould you like to do any volunteer work?</i>
<i>f people who are able to participate in their is much as they like.</i>

NCI & NCI-AD: Data At the Intersect

SERVICE COORDINATION

Example: Can reach case manager

	NCI-AD	NCI
State A	82%	90%
State B	78%	61%
State C	92%	87%
State D	86%	96%
State E	71%	86%
State F	77%	90%
State G	85%	87%
State H	88%	88%
State I	90%	87%
State J	76%	91%
State K	81%	97%
Average	79%	87%

NCI & NCI-AD: Data At the Intersect

WORK

Example: Would like a job

	NCI-AD	NCI
State A	19%	40%
State B	32%	73%
State C	10%	49%
State D	20%	40%
State E	12%	39%
State F	26%	61%
State G	21%	52%
State H	20%	50%
State I	22%	59%
State J	20%	42%
State K	28%	36%
Average	21%	47%

NCI & NCI-AD: Data At the Intersect

RELATIONSHIPS

Example: Feels lonely (sometimes or often)

	NCI-AD	NCI
State A	48%	51%
State B	58%	51%
State C	37%	48%
State D	52%	36%
State E	56%	55%
State F	64%	45%
State G	54%	42%
State H	57%	56%
State I	55%	47%
State J	53%	41%
State K	50%	34%
Average	54%	45%

NCI & NCI-AD: Data At the Intersect

RIGHTS AND RESPECT

Example: Can lock door to room/bedroom

	NCI-AD (in group setting)	NCI
State A	87%	44%
State B	59%	42%
State C	88%	76%
State D	94%	45%
State E	86%	47%
State F	42%	38%
State G	76%	42%
State H	82%	62%
State I	27%	46%
State J	94%	44%
State K	28%	53%
Average	68%	46%

NCI & NCI-AD: Data At the Intersect

RIGHTS AND RESPECT Example: Staff/support people treat with respect

	NCI-AD	NCI
State A	93%	90%
State B	93%	79%
State C	96%	95%
State D	92%	97%
State E	95%	91%
State F	93%	90%
State G	93%	92%
State H	97%	87%
State I	89%	93%
State J	90%	93%
State K	91%	99%
Average	92%	92%

5. Other Measures

We Are Not Alone

Medicaid Innovation Accelerator Project (IAP): supports states' ongoing efforts related to payment and delivery system reforms

NQF and IAP: *identify and recommend measure sets for the IAP in four program areas:*

- Reducing Substance Use Disorders,
- Improving Care for Medicaid Beneficiaries with Complex Care Needs and High Costs,
- Supporting Physical and Mental Health Integration,
- *Promoting Community Integration through Community-Based Long-Term Services and Supports*

Draft report published 7/21; comment period closed 8/21

Final report coming soon



QUESTIONS?