

*What do we
want? Data!
When do we
want it? Now*

Lindsay DuBois, HSRI

Stephanie Giordano, HSRI

Rosa Plasencia, ADvancing States



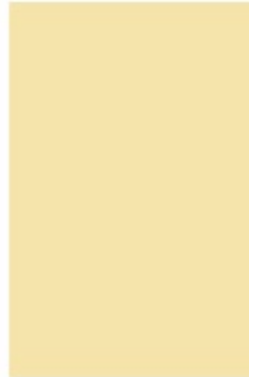


Agenda

1. Overview of National Core Indicators
2. Community participation and inclusion among older adults
3. Unmet needs among older adults
4. Future directions

National Core Indicators Initiative

About NCI



National Core Indicators: People Driven Data

National Core Indicators is an initiative designed to **benchmark and track** performance that support **quality improvement efforts** in state systems supporting people with intellectual and developmental disabilities (NCI-IDD) and older adults and people with physical disabilities (NCI-AD).

Our goal is to **support states in their quality improvement** efforts using valid and reliable data collection efforts that hear directly from the people using and supporting systems.



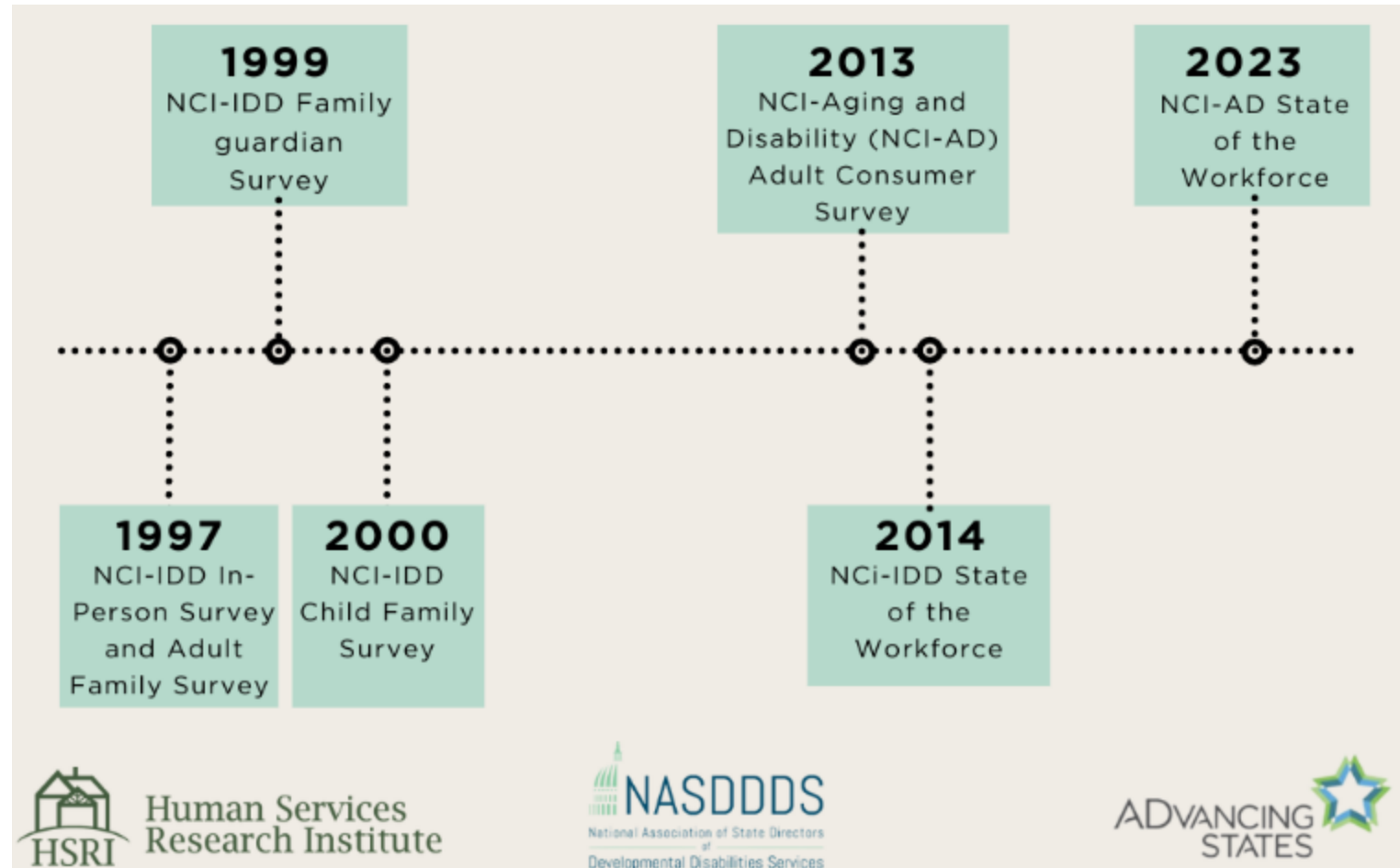
National Core Indicators Timeline

NCI tools collect data on performance and quality of life indicators directly from:

- (1) people who use disability and/or aging services systems;
- (2) families; and
- (3) those who deliver services

Participating states:

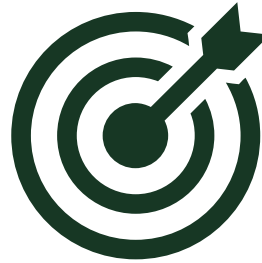
- NCI-IDD IPS and Family Surveys: 48
- NCI-AD: 26
- State of the Workforce: 30 states for the NCI-IDD SoTW, and 6 states for NCI-AD SoTW



Goals of NCI



Establish a nationally recognized set of performance and outcome indicators for aging & disability (including IDD) service systems



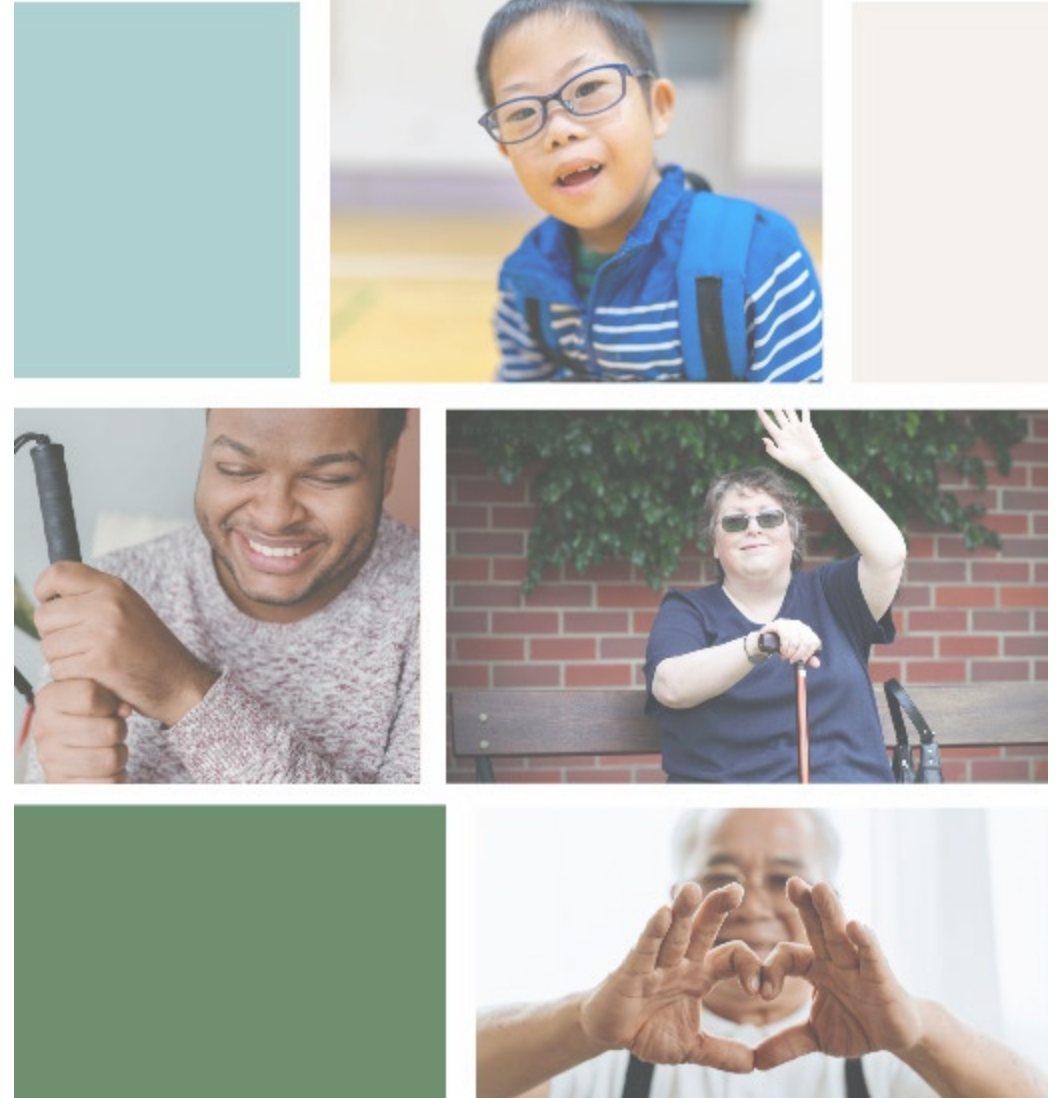
Use valid and reliable data collection methods & statistical techniques to capture information directly for people who use services



Report individual state results and national benchmarks of indicators of system-level performance

NCI Survey Overview

The Data We Collect



NCI-IDD In-Person Survey (IPS) and NCI-AD Adult Consumer Survey



- **Sampling:** States design their samples with guidance from HSRI. Final samples must reach threshold of 95% confidence level and 5% margin of error based on sample frame.
- **Inclusion criteria:**
 - AD: Person receiving one “active service” at least twice a week
 - IDD: Person receiving at least one service in addition to case management
- **Consent:** Surveyors follow state specific consent requirements
 - Those who are surveyed are informed that their services will not be impacted directly by their responses
- **Surveyor training:** All surveyors complete standardized training. IPS uses peer-surveyors as well.
- **Survey features:**
 - May be conducted in-person or remotely
 - Includes detailed Background Information section that primarily comes from existing records
 - Surveys are available in multiple languages
 - Questions may be rephrased or reworded
 - Allows for use of proxy for select questions

Measuring Quality



Process measures: *the process has led to improved outcomes.*

- Example: The percentage of support recipients who had an Individual Service Planning meeting in the past year.

Outcome measures: *the impact of supports on a participant's life*

- Example: The percentage of support recipients who have a paid community job.

Personal experience measures: *whether people are satisfied with their experiences with the service system.*

- Example: The percentage of support recipients who like where they live.

Access measures: *how hard/easy is it to access needed services.*

- Example: The percentage of support recipients who have transportation to get where they want to go.

NCI Data Elements

Background information

- *Demographic factors & residential info*
- *Service plan goals*
- *Funding sources and amount of supports*
- *Diagnoses and conditions noted in records*

Individual outcomes

- Employment
- Community inclusion and belonging
- Community participation
- Choice and decision-making
- Relationships
- Satisfaction
- Affordability

System performance

- Self-direction
- Service and care coordination
- Workforce
- Access to community, needed equipment, and technology

Health, wellness, and rights

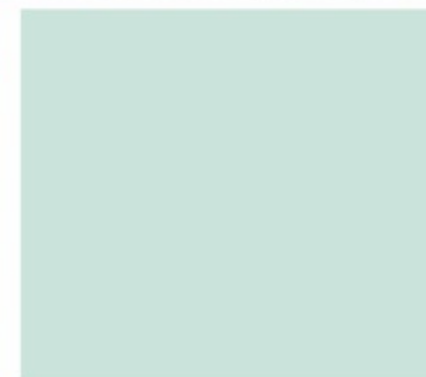
- Safety
- Health and health care
- Medication
- Wellness
- Rights and respect

NCI in National Quality Monitoring

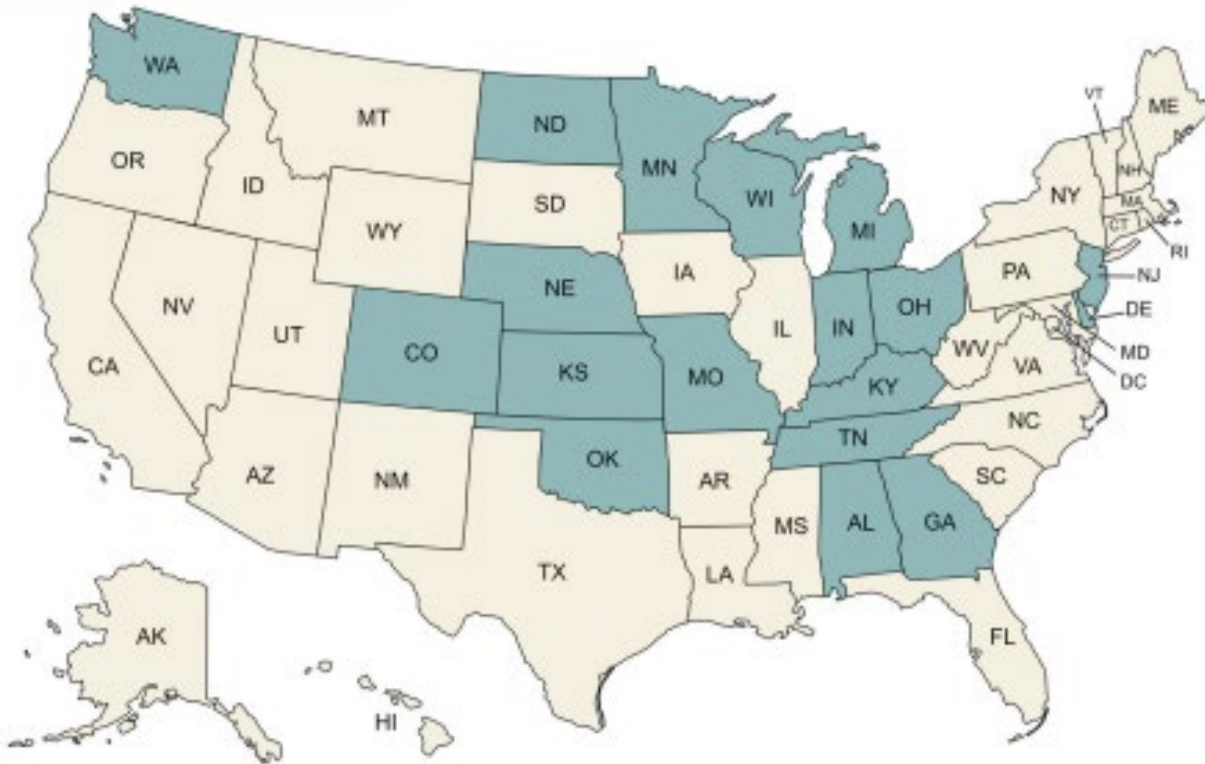
- NCI included in HCBS Quality Measure Set put forward by CMS in Access Rule (NCI-AD 18 measures, NCI-IDD 16 measures)
- NCI measures endorsed by CMS Consensus Based Entity National Quality Forum, now managed by Batelle Partnership for Quality Monitoring.
- NCI-IDD IPS measures included in the CMCS Adult Core Set
- NCI-IDD IPS and NCI-AD ACS included in the Medicaid and CHIP Scorecard
- NCI-AD participation included in AARP LTSS State Scorecard

Select NCI Outcomes

Data from 2023-24 Reporting



2023-2024 Sample – NCI-AD

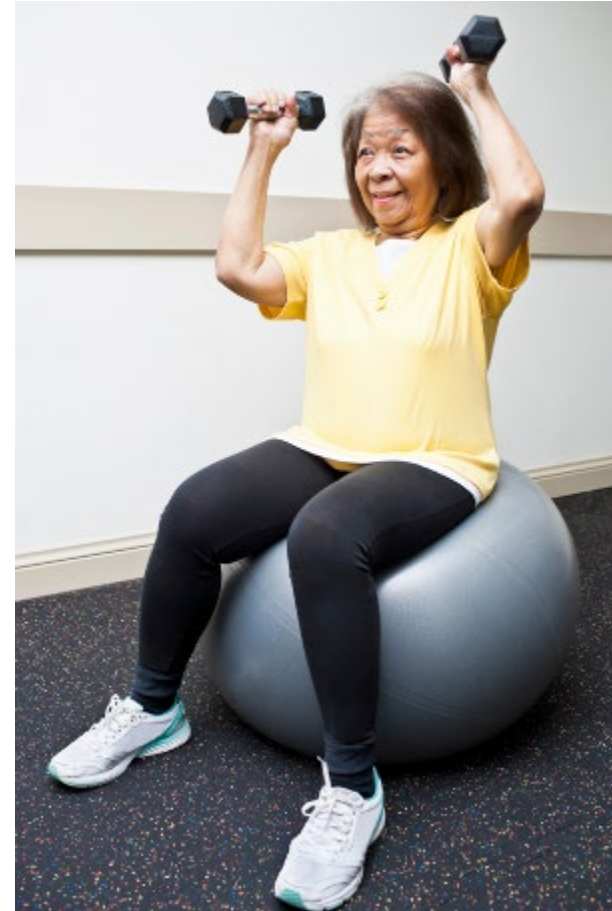


15,455 total respondents

- 18 states
- 34% male
- Race/ethnicity
 - 65% *White*; 24% *Black*; 4% *Latino*
- Diagnosis
 - 63% *Physical Disability*
 - 14% *Alzheimer's/Dementia*
 - 6% *ID*
 - 11% *TBI*

Sample characteristics: NCI-AD

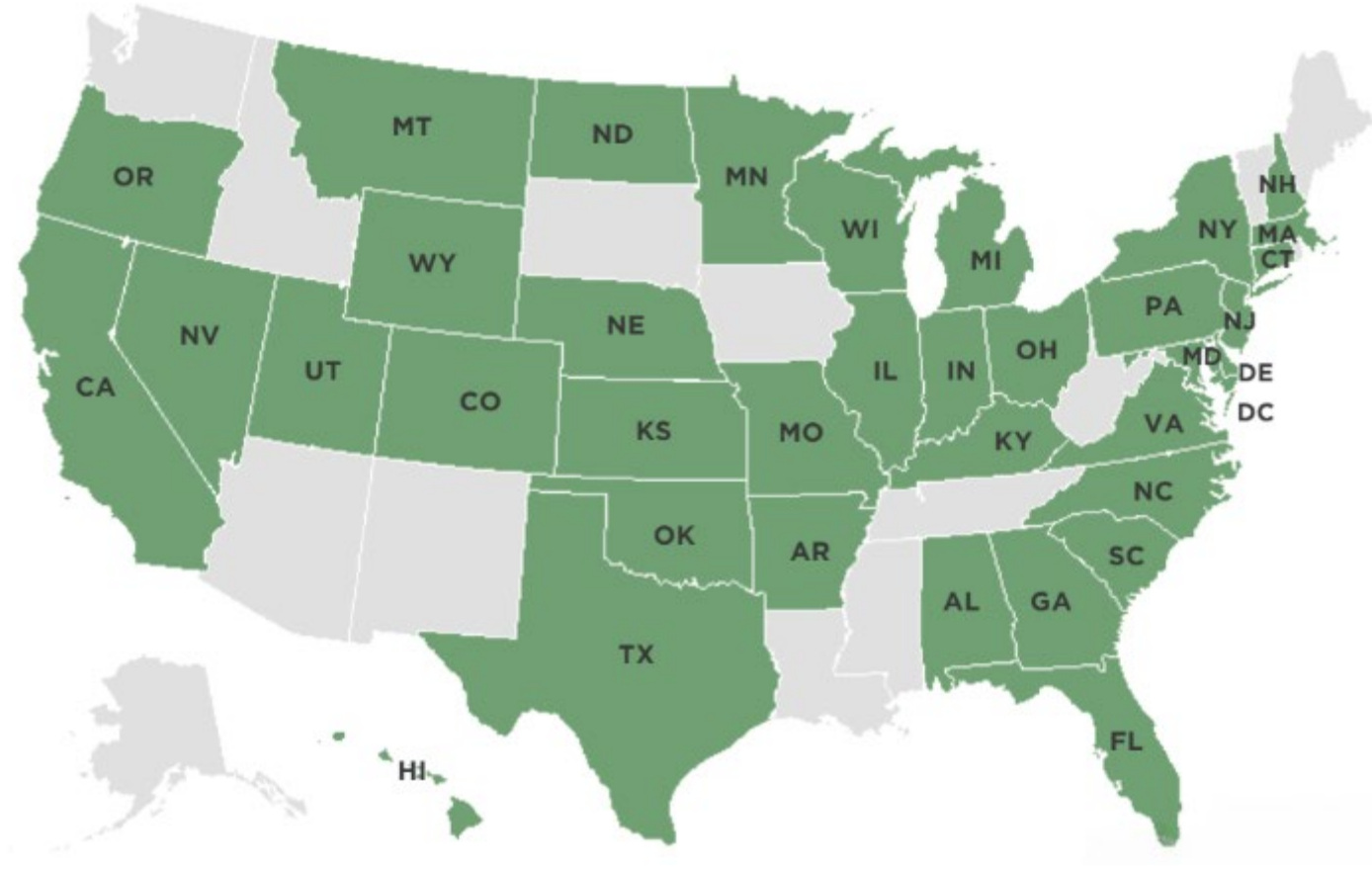
- Age
 - Under 65: 8,873 (42%)
 - 65 and older: 12,089 (58%)
- Lives in rural area: 13%
- Lives alone: 44%
- Residence
 - Institutional setting: 18%
 - Group home: 8%
 - Own home or family home: 74%



2022-2024 Sample – NCI-IDD IPS

42,537 total respondents

- 37 states
- 60% male
- Race/ethnicity
 - 65% *White*; 18% *Black*; 12% *Latino*
- Diagnosis
 - 84% *ID*; 30% *ASD*

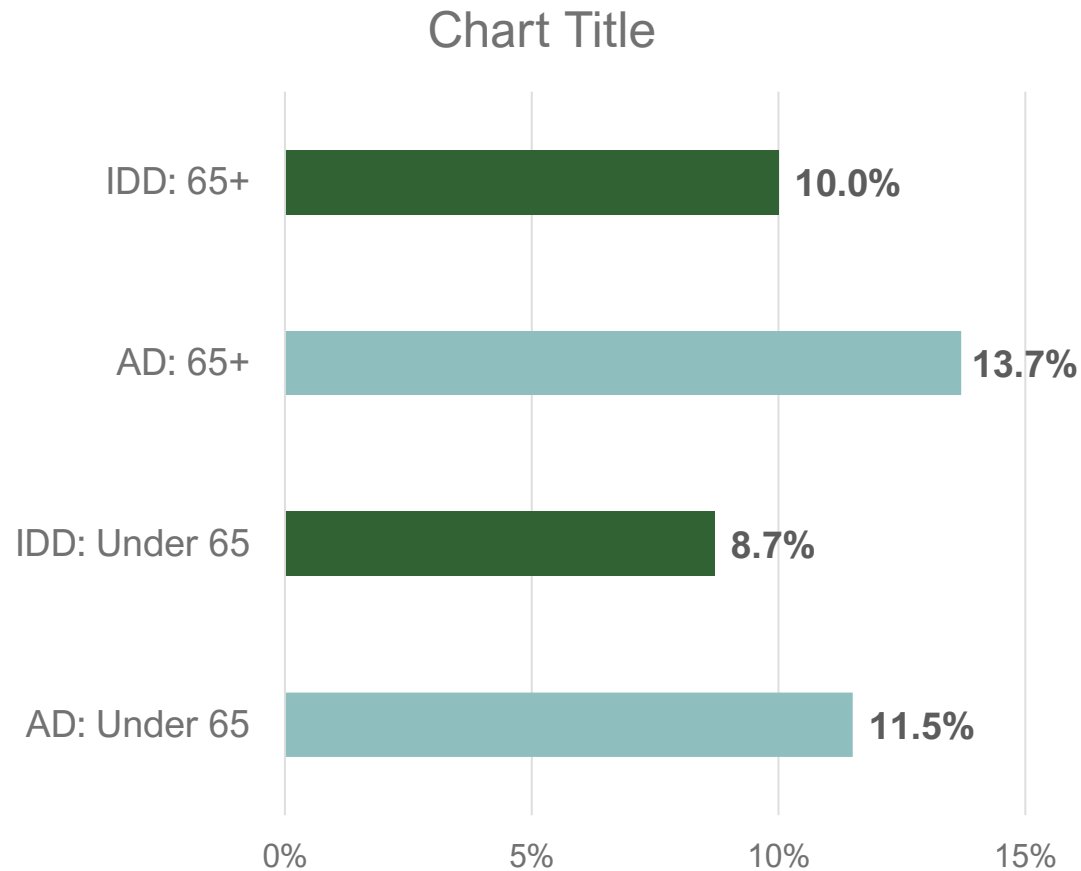


Sample characteristics: NCI-IDD

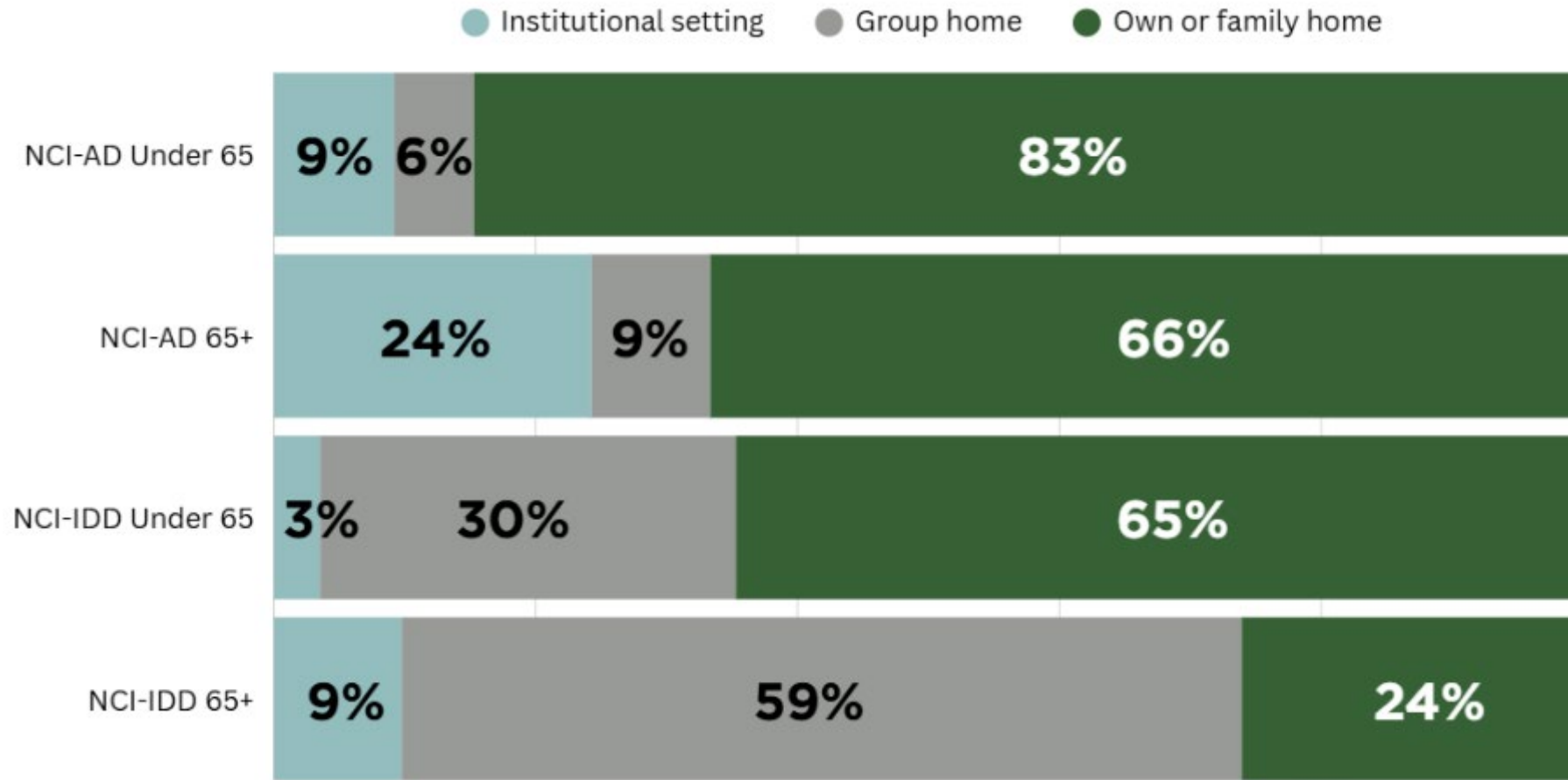


- Age
 - Under 65: 38,117 (90%)
 - 65 and older: 4,420 (10%)
- Lives in rural area: 9%
- Has guardian: 50%
- Residence
 - Institutional setting: 4%
 - Group home: 33%
 - Own home: 15%
 - Parent/relatives home: 43%

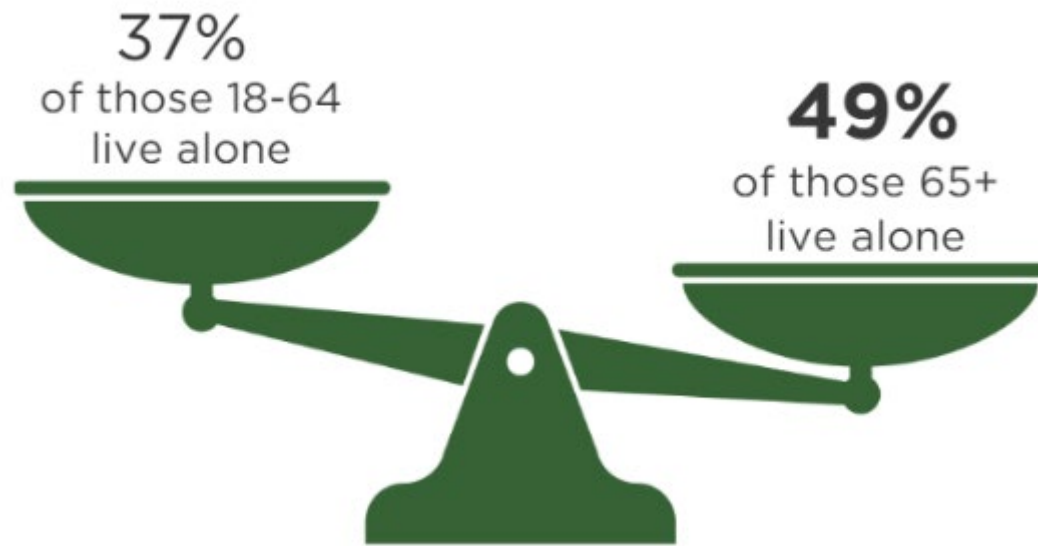
Older adults are more likely to live in rural communities



Older adults are more likely to live in institutional and group settings

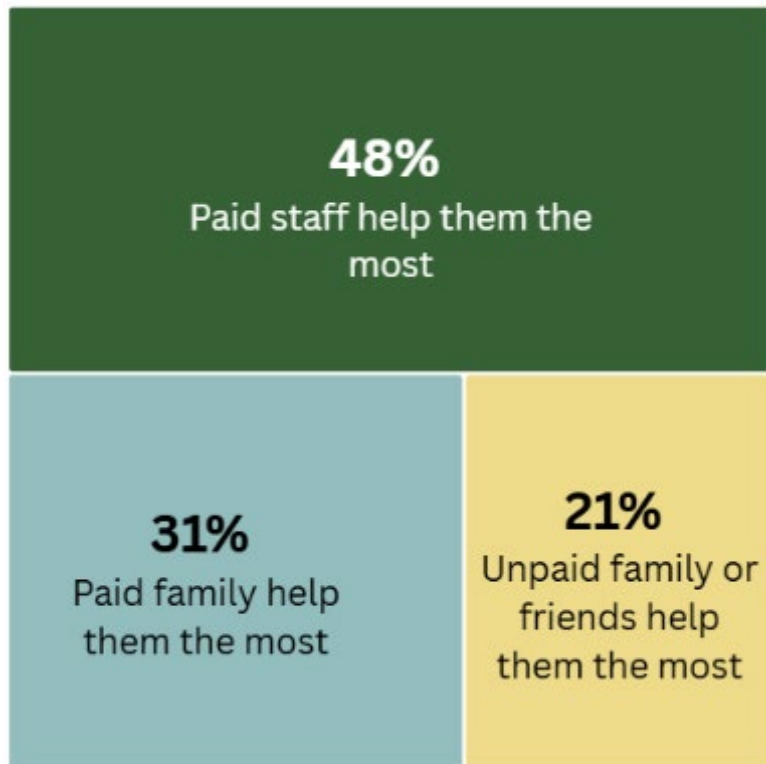


NCI-AD Older adults are more likely to live alone



NCI-AD Older adults are more likely to report paid staff help them most

18-64 year olds



65 and older



NCI-AD OAA respondents...

had **lower rates of reporting they have someone who helps** them on a regular basis (at least once a week)**

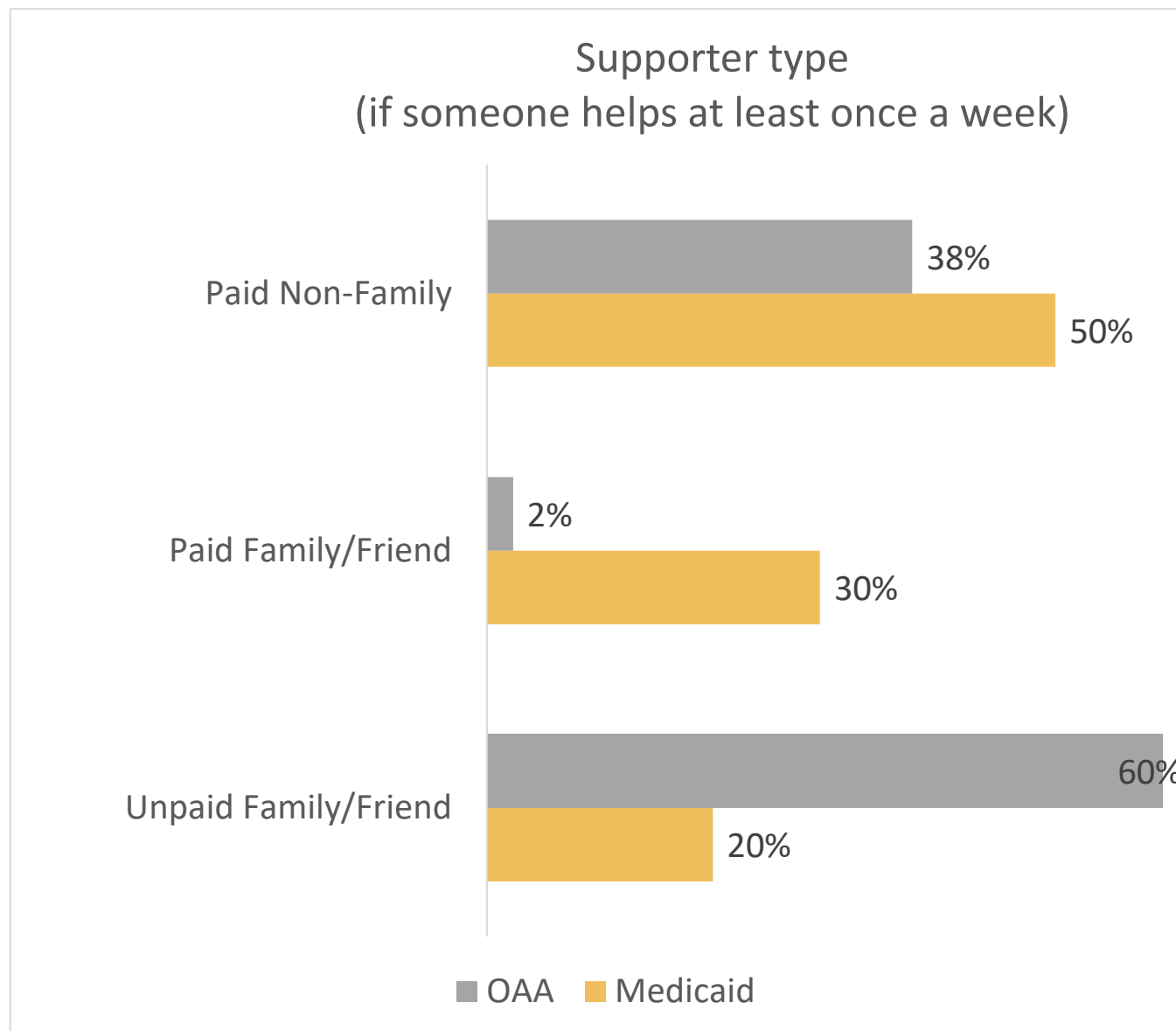
- 64% OAA
- 89% Medicaid

And OAA respondents were more than **three times as likely to rely on unpaid family/friends** as their primary supporter**

They were also less likely to **have back up plan** if their paid support did not show up**

- 57% OAA
- 69% Medicaid

**Sig. at .01 all respondents 60 and older and living in a community setting



Community participation and inclusion among older adults



More than 3 out of 5 older adults can do things in the community and be with the people that want

NCI-AD



66% of respondents can do they things they like to do in the community **as much as they want**



64% of respondents can do they things they like to do in the community **with the people they want**

NCI-IDD



69% of respondents can do they things they like to do in the community **as much as they want**



79% of respondents can do they things they like to do in the community **with the people they want**

Older adults are less likely to have friends than younger peers

NCI-AD

Has friends or family who are part of life

93.4%



Adults 18-64

91.9%



Adults 65+

NCI-IDD

Has friends other than staff or family

77.8%



Adults 18-64

70.4%



Adults 65+

Older adults with IDD have lower rates of saying they can see friends/family when they want

NCI-AD



Can see friends/family when they want

NCI-IDD



Can see friends when they want



Can see family when they want

Older adults with IDD have higher rates of having transportation for leisure activities

NCI-AD

67%

Has transportation to do the things they want outside of home

92%

Has transportation to get to medical appointments

NCI-IDD

80%

Able to get places when wants to do something outside of home

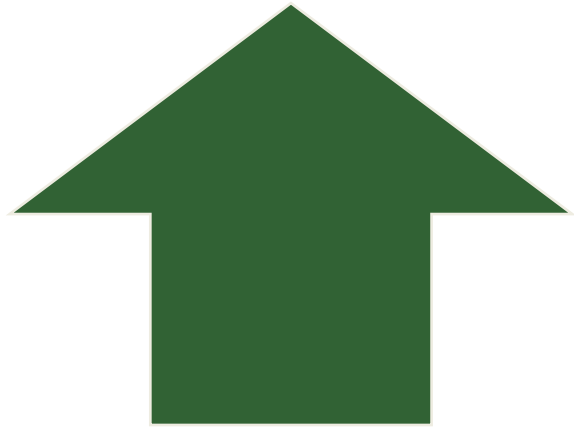
93%

Has a way to get places needs to go (like work, appointments, etc.)

Unmet needs among older adults



Older adults from NCI-AD survey also report lower rates of unmet needs than younger peers



Among those 65+, **75% say services and supports always meet their needs**



Among those 18-64, 72% say services and supports always meet their needs

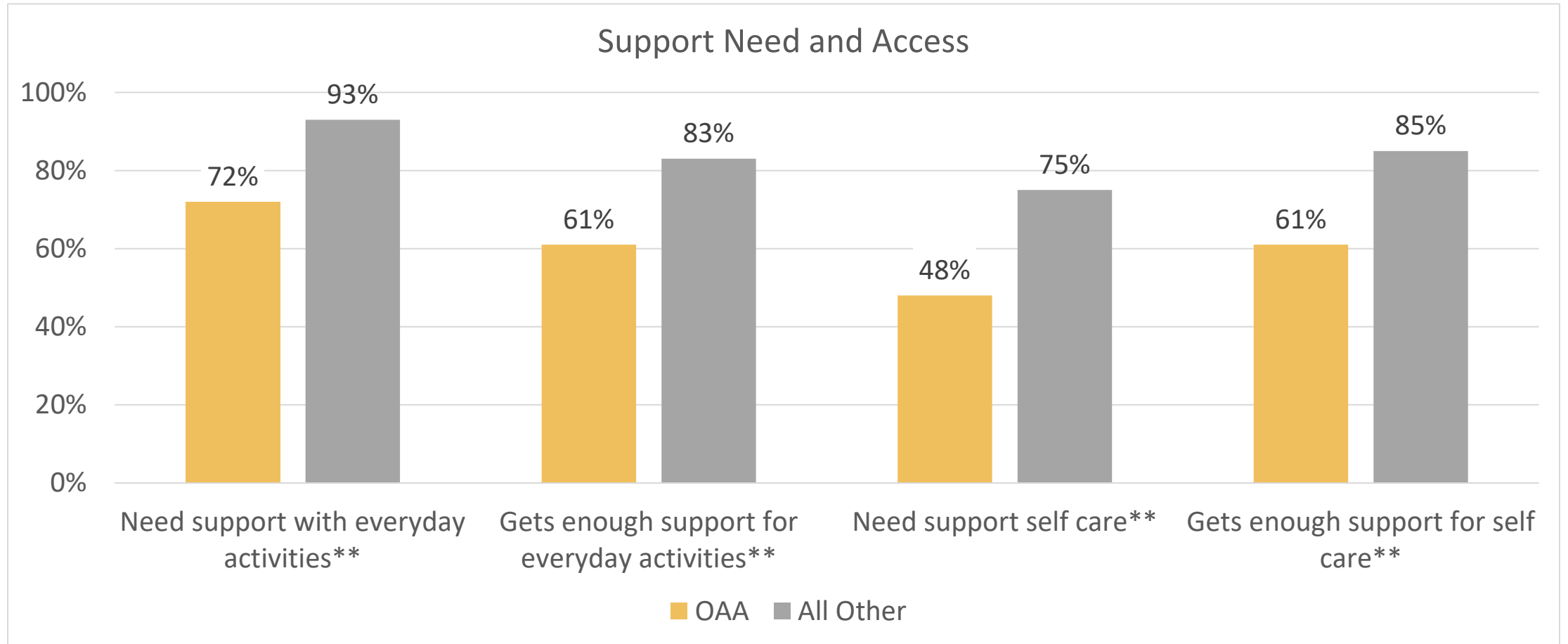
Most NCI-AD respondents get enough help with ADLs and self-care

Among those 65+:

- 91% need at least some help with activities of daily living
 - 83% always get enough help with ADLs
- 72% need at least some help with self-care activities
 - 84% always get enough help with self-care



OAA respondents reported lower ADL/IADL support need but also had lower rates of getting the support they need.



**Sig. at .01 all respondents 60 and older and living in a community setting

Older adults with IDD report lower rates of unmet needs than their younger peers



Among those 65+, **62% say they do not need any additional services**



Among those 18-64, 44% say they do not need any additional services

Most common areas of unmet need for older adults with IDD



Among those 65+:

- 12% need help finding something different to do during the day
- 10% need help finding staff to support them at home
- 9% need help with technology

Fewer NCI-AD OAA respondents reported services meet their needs and goals**

- **63% OAA**
- **75% Medicaid**

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Most common additional services needed for NCI-AD OAA respondents



Homemaker/Chore Services**

45% OAA

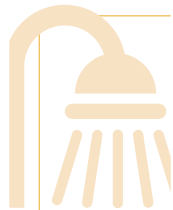
27% Medicaid



Transportation**

- 32% OAA

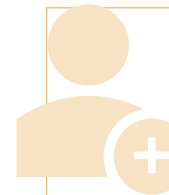
- 23% Medicaid



Personal Care Assistance, Personal Care Services

- 31% OAA

- 27% Medicaid



Companion Services**

- 22% OAA

- 12% Medicaid



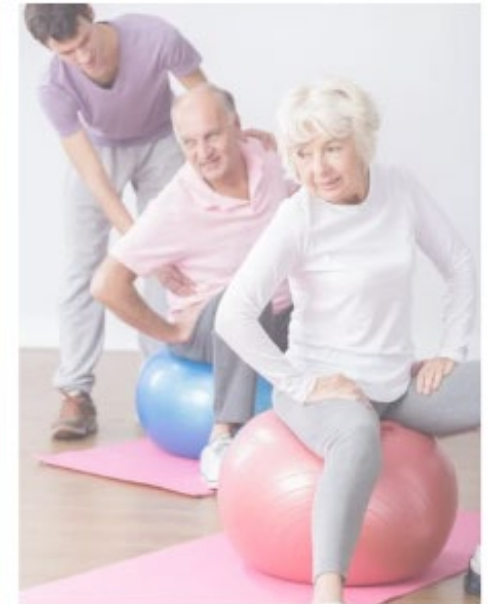
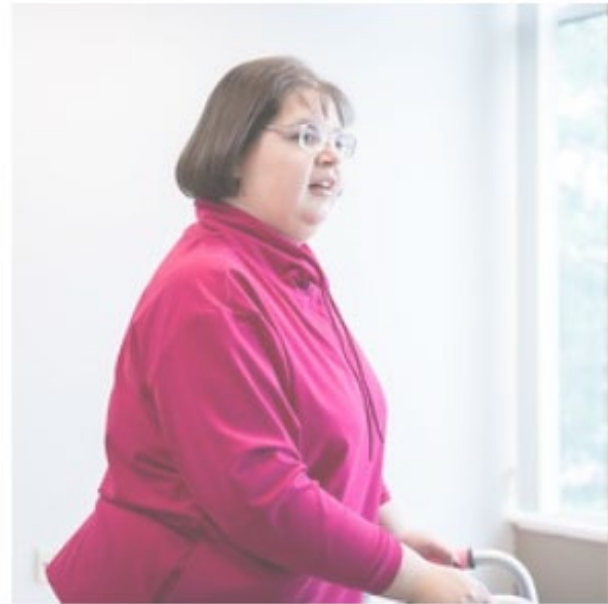
Dental Care**

- 18% OAA

- 12% Medicaid

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What Next?




Conclusions and future directions

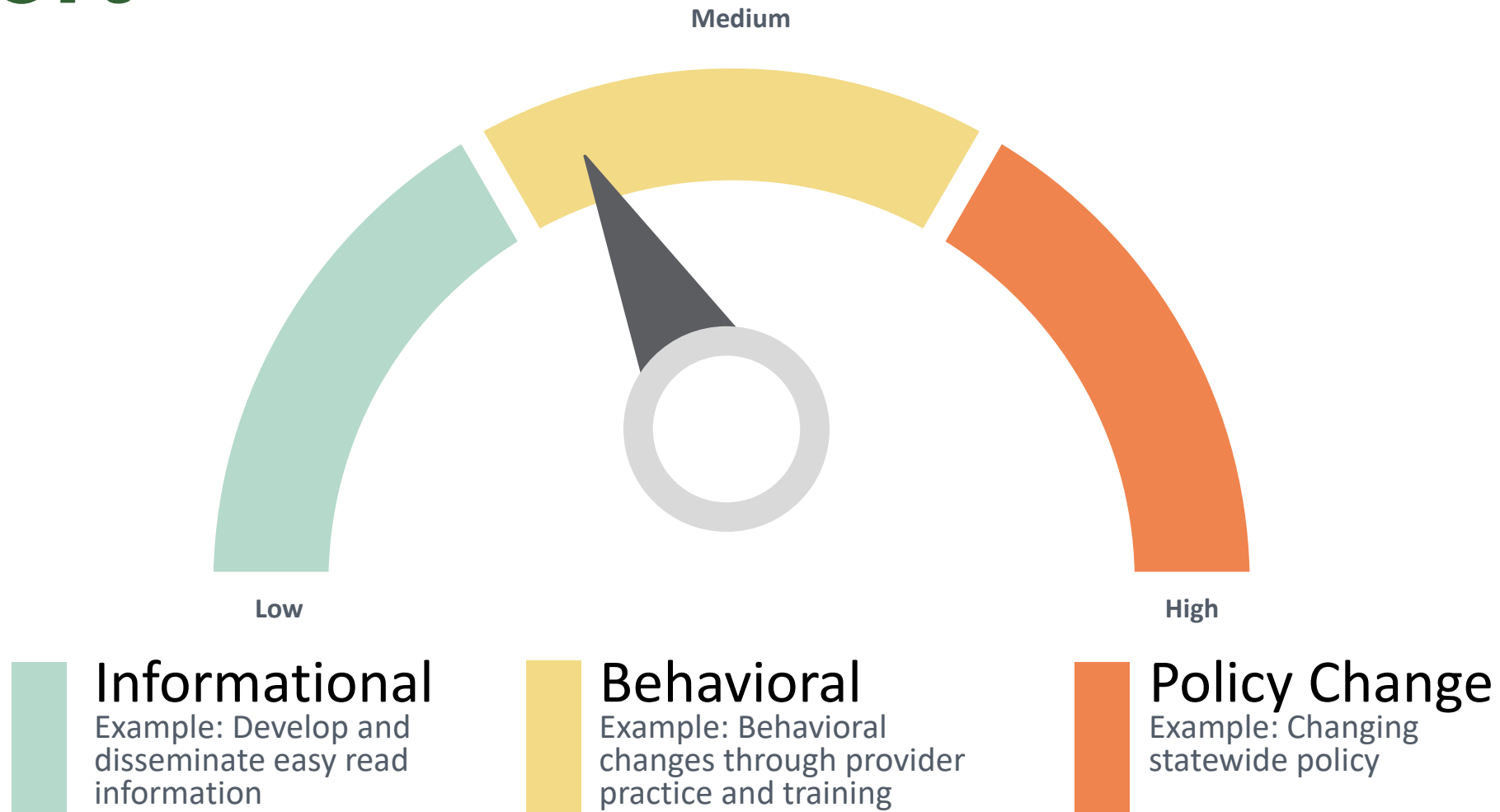
- Encourage use of NCI with various populations and programs (PACE, SNFs, OAA)
- Use data for Older Americans Act participants in State Plans on Aging and Multisector plans on aging
- Hold conversations with people using services, families, and providers to share data and reflect on experiences



Take action with the data

				
Talk with leadership <ul style="list-style-type: none">•Identify NCI measures related to strategic plans, state or federal requirements•Bring in other relevant departments and agencies (like DD and Medicaid)	Engage with Your Communities <ul style="list-style-type: none">•Bring together a coalition of people to provide insights, develop plans, provide feedback.•Be sure to include people who use, provide, and interact with services.	Review NCI Data with Coalition <ul style="list-style-type: none">•Discuss relevant outcomes and be clear about limitations of the NCI data.•Remember to look at multiple measures•Ask questions and get feedback about the outcomes you are seeing	Decide on an Area for Improvement <ul style="list-style-type: none">•Is there a strategic plan or set of priorities in place?•Are there state or federal regulations that must be met?•Are there efforts underway in other state agencies that would allow for shared learning?•Is there an area where the state is consistently under-performing?	Take action <ul style="list-style-type: none">•Set small and specific goals•Decide on interventions•Evaluate along the way•Don't be afraid to pivot

Intervention Types and Level of Effort



Sample Progress Tracker

Community Access						
Indicator	Y1 BASELINE	5 Year GOAL	Y2	Y3	Y4	Y5
As active in the community as they want to be	63%	80%	60% <i>(-20% to goal)</i>	65% <i>(-15% to goal)</i>	70% <i>(-10% to goal)</i>	75% <i>(-5% to goal)</i>
Has transportation to get places they want to go	73%	90%	70% <i>(-20% to goal)</i>	75% <i>(-15% to goal)</i>	80% <i>(-10% to goal)</i>	85% <i>(-5% to goal)</i>

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NCI updates newsletter



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www.nationalcoreindicators.org

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ldubois@hsri.org