Matters of Experience – State Perspectives in Implementing Experience of Care Surveys

HCBS CONFERENCE
Home & Community-Based Services

2025 Home and Community-Based Services Conference

Speakers

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Agenda

What is NCI?

Data from the 2023-2024 NCI-AD Survey

- Older Americans Act Outcomes

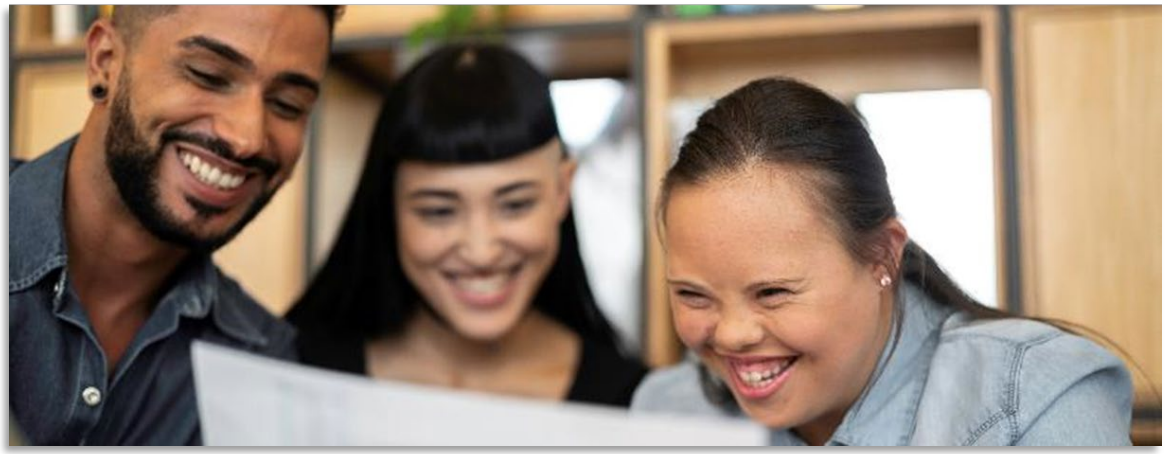
State Spotlights

- New York
- California
- Georgia

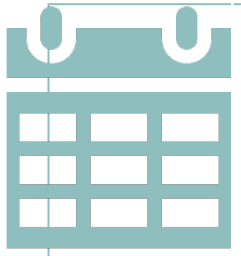
National Core Indicators: People Driven Data

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-Aging and Disabilities: An Overview

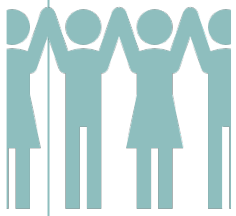


Established

- 2015
- Grew out of NCI-IDD

Participating states

- 30
- 35+ throughout project



Population addressed

- Older adults and people with physical disabilities

Covers multiple domains

- AD domains and indicators
- **New** State of the Workforce Survey – Aging and Disabilities

Adult Consumer Survey (ACS) A Person-Centered Approach

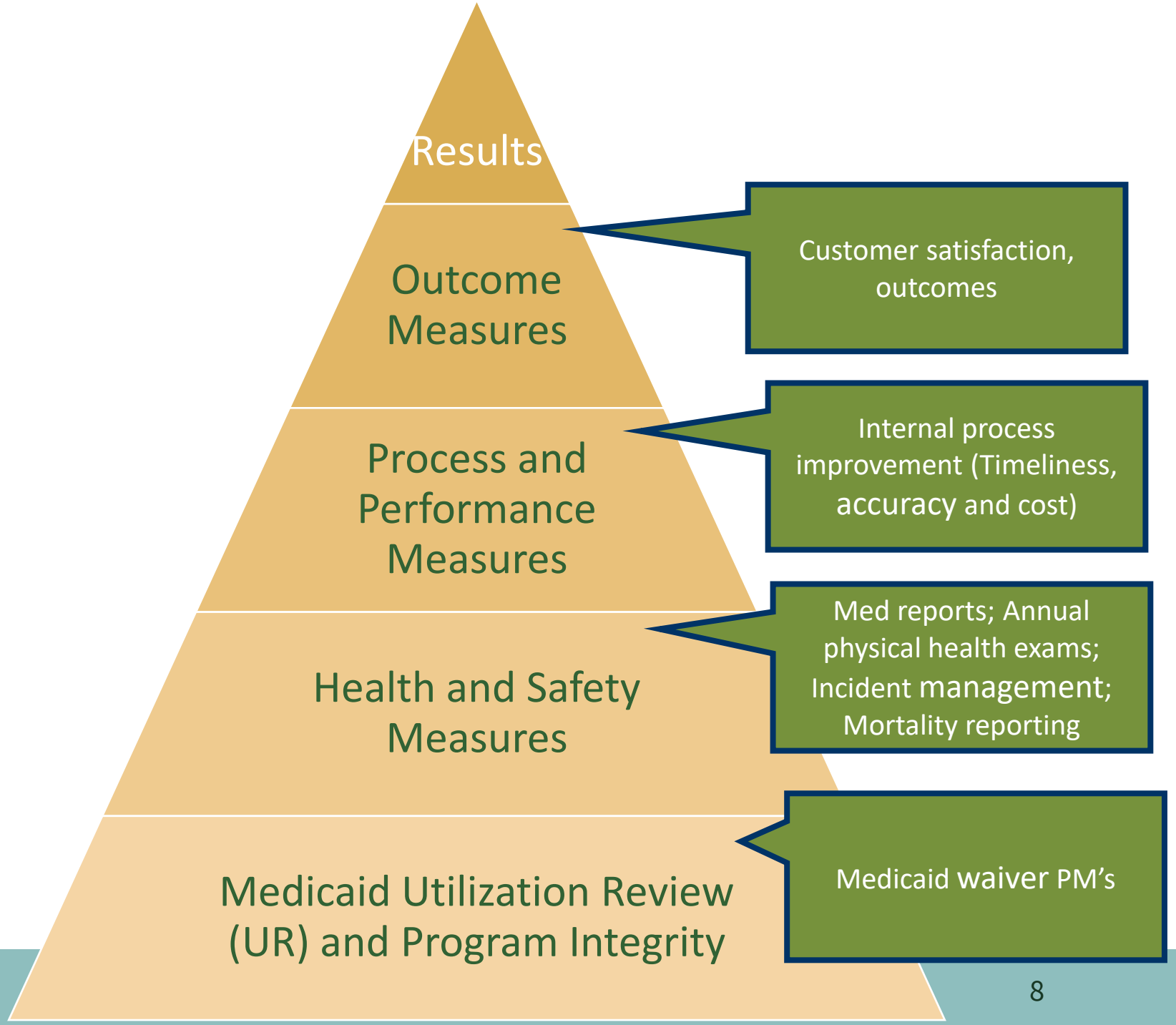
- **Standardized survey with a sample of individuals receiving services**
  - No pre-screening procedures
- **Survey includes:**
  - Demographic and service-related characteristics typically from existing records
  - Main survey section conducted with person receiving services
  - Some questions may be answered by a proxy respondent
- **Survey conducted in-person, via video conference, over the phone**
- **Standardized surveyor training**
- **Allows questions to be reworded or rephrased using familiar names and terms**
- **Survey portions take 50 minutes on average**

Using ACS data to understand experience

Individual characteristics of people receiving services	Where people live
	Gender
	Race/Ethnicity
	Disability
	Type of services people are receiving
The nature of their experiences with services	Interaction with staff and case managers
	Self-direction
	Choice and Control
The context of their live	Involvement with family and friends
	Access to community involvement
	Safety
Health and well-being	Utilization of health services
	Ability to manage chronic conditions
	Mental healthcare

Each Quality Strategy Requires Data

From the base to the top- all measures matter



Federal Focus on Outcome Measures and Person-Reported Data

ACL

OAA Guidance

CMS

Access Regulation

HCBS Quality Measure Set

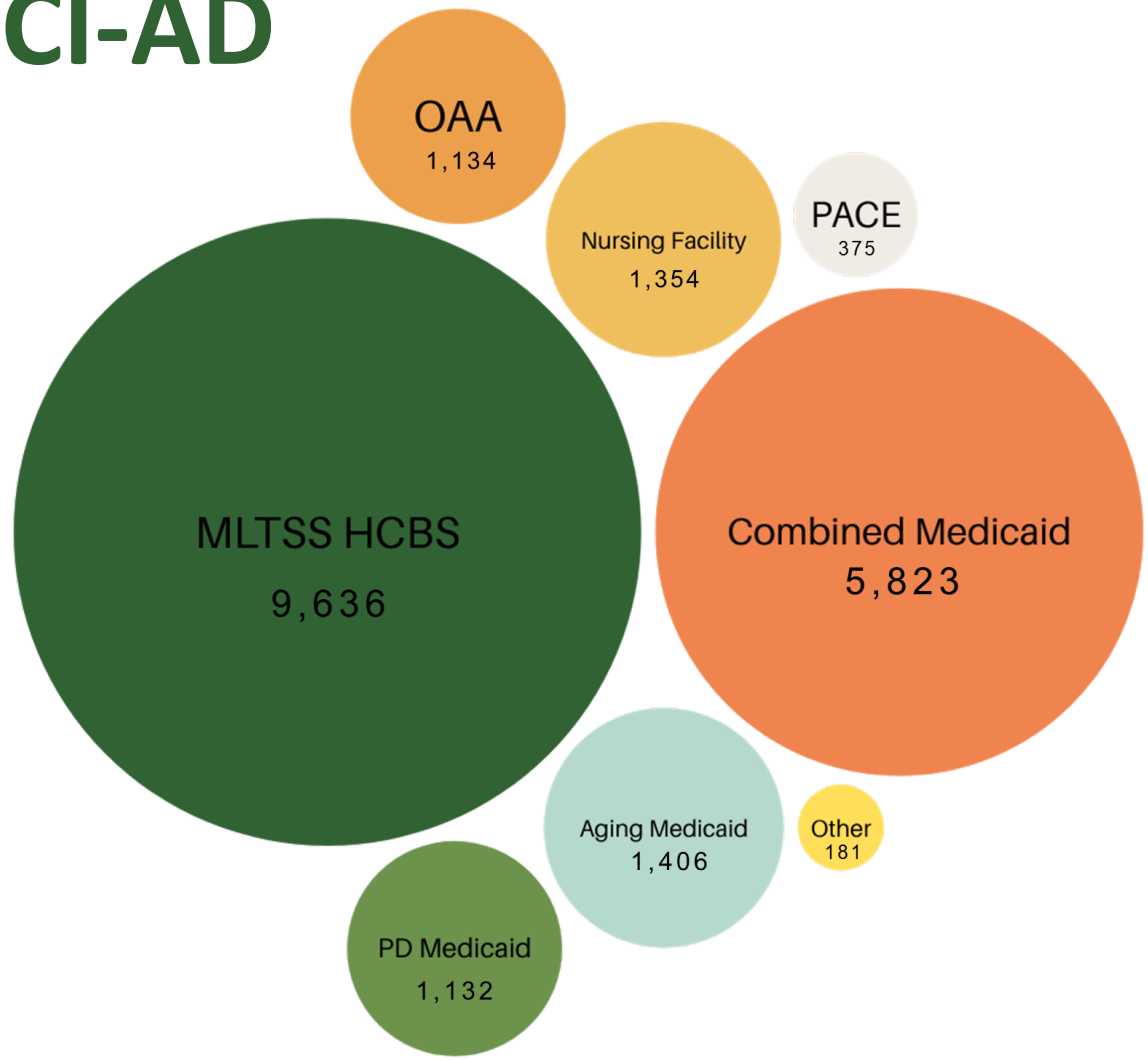
NCI-AD Data Snapshot

Select NCI-AD Adult Consumer Outcomes 2023-24

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* ACS Questions by Common State Plan and MPA Goals

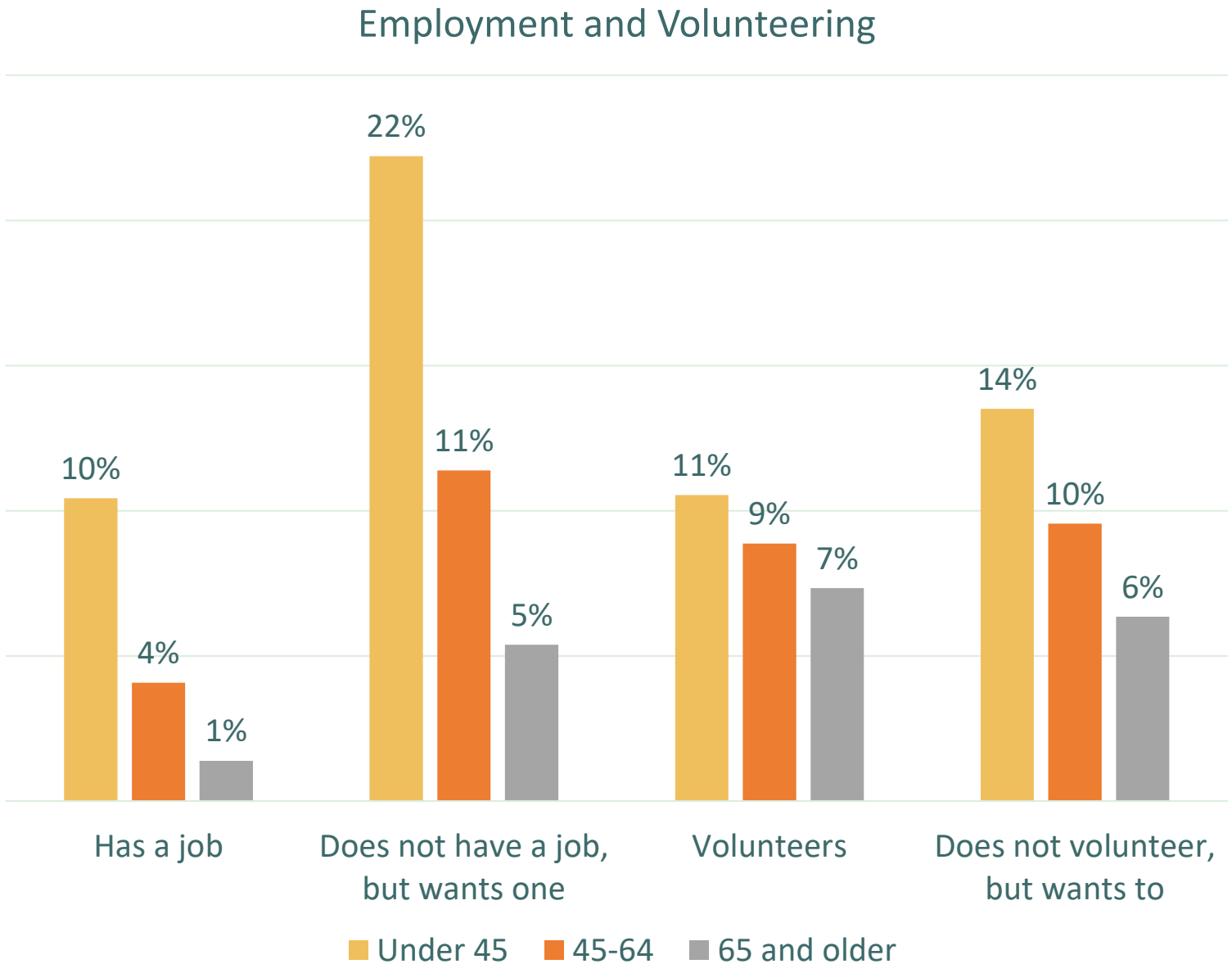
Access to Services and Supports	Gets enough support for everyday activities (if needs at least some assistance)	62% OAA 82% NCI-AD
	Services and supports help them live the life they want	88% OAA 88% NCI-AD
Health, Wellness, and Nutrition	Has worked with someone to reduce risk of falls (if someone has concerns about them falling or being unstable)	74% OAA 81% NCI-AD
	Ever has to skip meals due to financial worries	13% OAA 13% NCI-AD
Emergency Preparedness and Safety	Has an emergency plan in place in case of widescale emergency	76% OAA 79% NCI-AD
	Knows who to talk to if they are mistreated, hurt, disrespected by others	79% OAA 81% NCI-AD
Workforce and Caregiving	Paid support staff change too often*	27% OAA 28% NCI-AD
	Has a backup plan if people who are paid to help them do not show up	63% OAA 73% NCI-AD
Community Access & Participation	Takes part in activities with others as much as they want to (in-person or virtually)	71% OAA 66% NCI-AD
	Has transportation to do the things they want outside of home	76% OAA 72% NCI-AD

**This is <u>not</u> exhaustive, Rosa and Steph can work with states to align with State Plans and MPAs ☺*

Daily life

Enjoys how they typically spend the day:

- 70% 18-45
- 62% 45-64
- 65% 65 and older



Those with transportation to the community were more likely to…

- SEE FRIENDS
- SEE FAMILY
- ACCESS THEIR COMMUNITY
- FEEL LONELY LESS OFTEN

Has transportation to do things in the community

NCI-AD: 72%

NCI-IDD: 80%

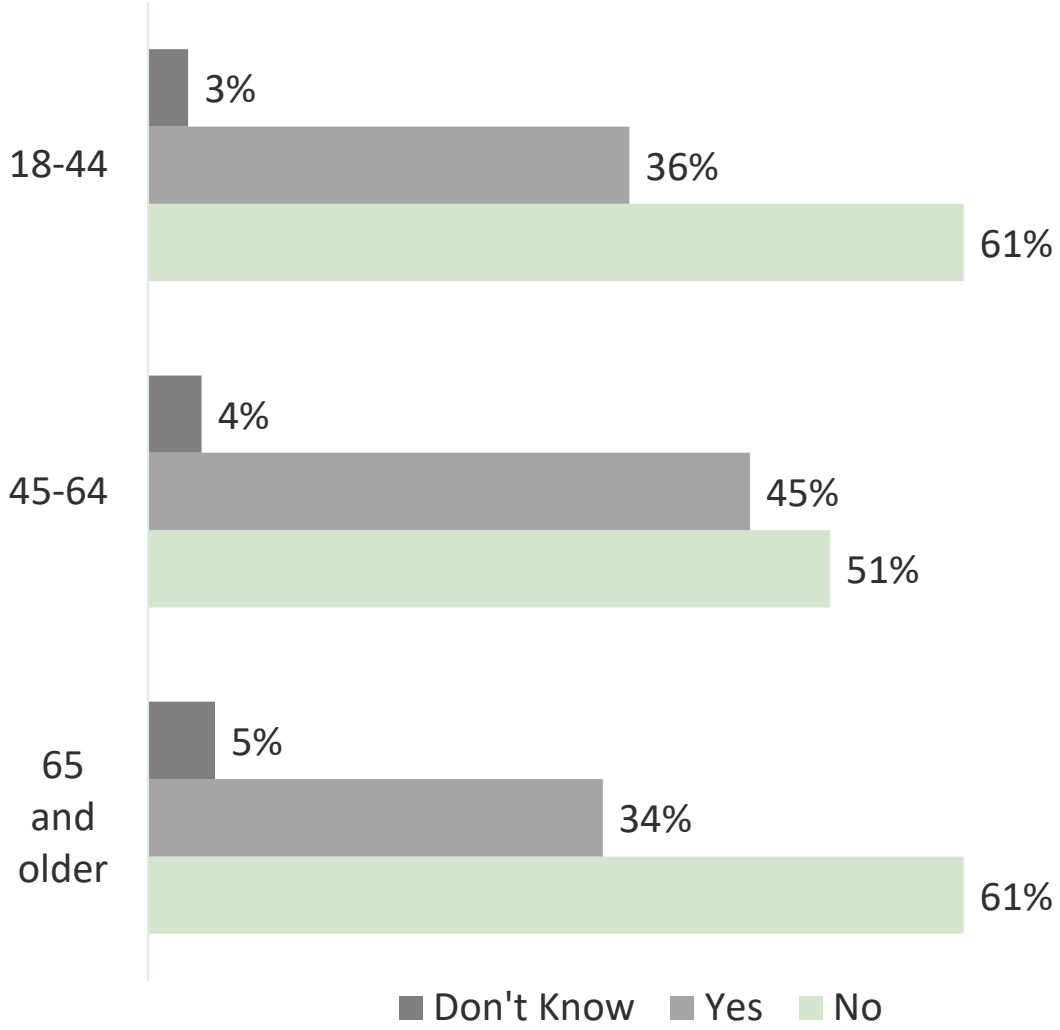
Highlighting Mental Health

28% **have a mental health diagnosis**

89% **reported they have access to mental health services if they want to use it**

9% **reported needing access to mental health services**

Mental Health Diagnosis by Age Group:
45-64 years olds have a higher rate of people with diagnosis than without



28% of respondents reported the people who are paid to help them change too often

- 60% Nursing Facility
- 35% PACE
- 32% PD Medicaid
- 30% Aging Medicaid
- 27% OAA
- 26% MLTSS HCBS
- 24% Combined Medicaid

New York

NEW YORK STATE | Department of Health

New York's experience with the NCI-AD survey, 2024-2025

Raina E. Josberger, MS
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HCBS Conference

Considerations

- Budget
  - Identify your funding source early: Though a sample of just 400 members is required for the NCI-AD, the cost per survey can be high - - much higher than the mail surveys the Department typically conducts.
  - Think about your stratifications: Do you want to look at results stratified by health plan, waiver type, program, or just statewide? These decisions will have a significant impact on budget.

Considerations

- Selecting a vendor
  - Request quotes from several vendors. There is variation in price.
  - Ask for references and call them up. We found colleagues from other states willing to share their experiences. This was very helpful in the selection process.
- Identifying your population
  - In New York State Medicaid, members receive their HCBS services through nine different programs, in different offices and different agencies. Identifying the comprehensive list of procedure, eligibility, and rate codes was time intensive and required teamwork.
  - Consult with your IRB as needed and determine what your consent procedures will be.

Considerations

- Population, continued
  - Work with your vendor to determine what data they need to conduct the survey.
  - We didn't have reliable information on members' legal guardians and, as a result, are building this into our data system.
  - Members' contact information often changes: consider pulling addresses and phone numbers from multiple data sources.
  - Oversample: survey response rates are falling. We pulled a sample of 2000 and met our goal of 400 responses.

Considerations

- Communication
  - Develop a robust communication plan so that all stakeholders are aware of the survey and when it will be in the field. For us, this was across different office and agencies.
  - Develop a member-facing communication plan. Members can be skeptical of mailings regarding the survey. Provide information on your website with contact information (we used a project-specific email address) so members can have confidence the survey is legitimate.
  - In collaboration with our survey vendor, we also developed a visually stimulating, easy-to-read infographic for members which was included in mailings and our website, as well as an FAQ document.
  - Have regular meetings with your vendor to track progress.

Partners

- NYS leveraged our External Quality Review Organization (EQRO).
  - Required partner as a Managed Care state
- Partner in reviewing potential vendors, contracting with the vendor, and engaging in data review.
- Department lead the identification of the survey sample.

NEW YORK STATE | Department of Health

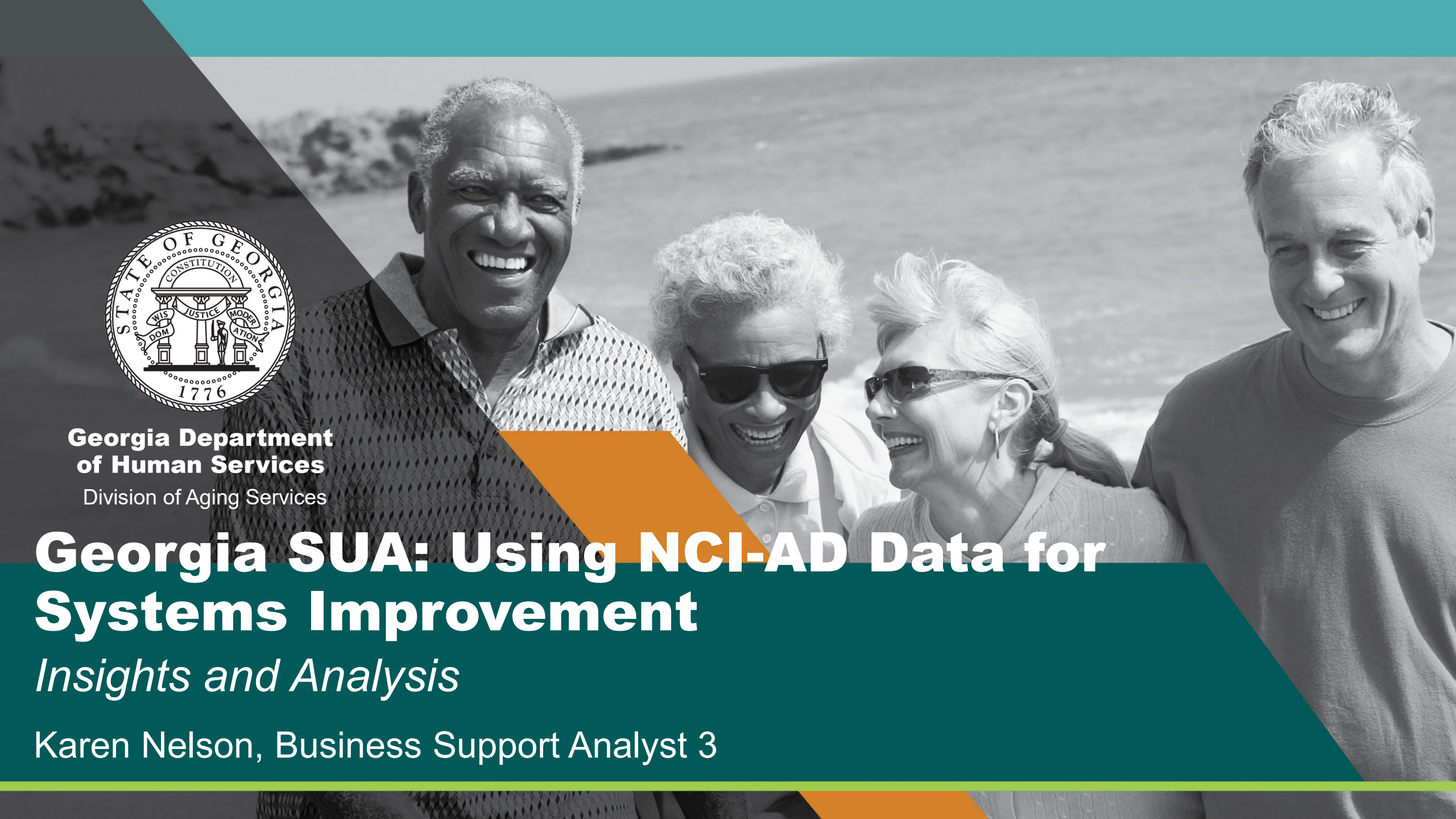
Future Plans

- We have our response set, our next step is to analyze it
  - Working through staffing constraints
  - Applied for a SUNY Albany School of Public Health student graduate intern for the fall semester.

Department of Health

California

Georgia



Georgia Department of Human Services
Division of Aging Services

Georgia SUA: Using NCI-AD Data for Systems Improvement

Insights and Analysis

Karen Nelson, Business Support Analyst 3


stronger families
FOR A STRONGER GEORGIA

Division Vision and Mission

Vision

Living longer, Living safely, Living well

Mission

The Georgia Department of Human Services (DHS) Division of Aging Services (DAS) supports the larger goals of DHS by assisting older individuals, at-risk adults, persons with disabilities and their families and caregivers to achieve safe, healthy, independent and self-reliant lives

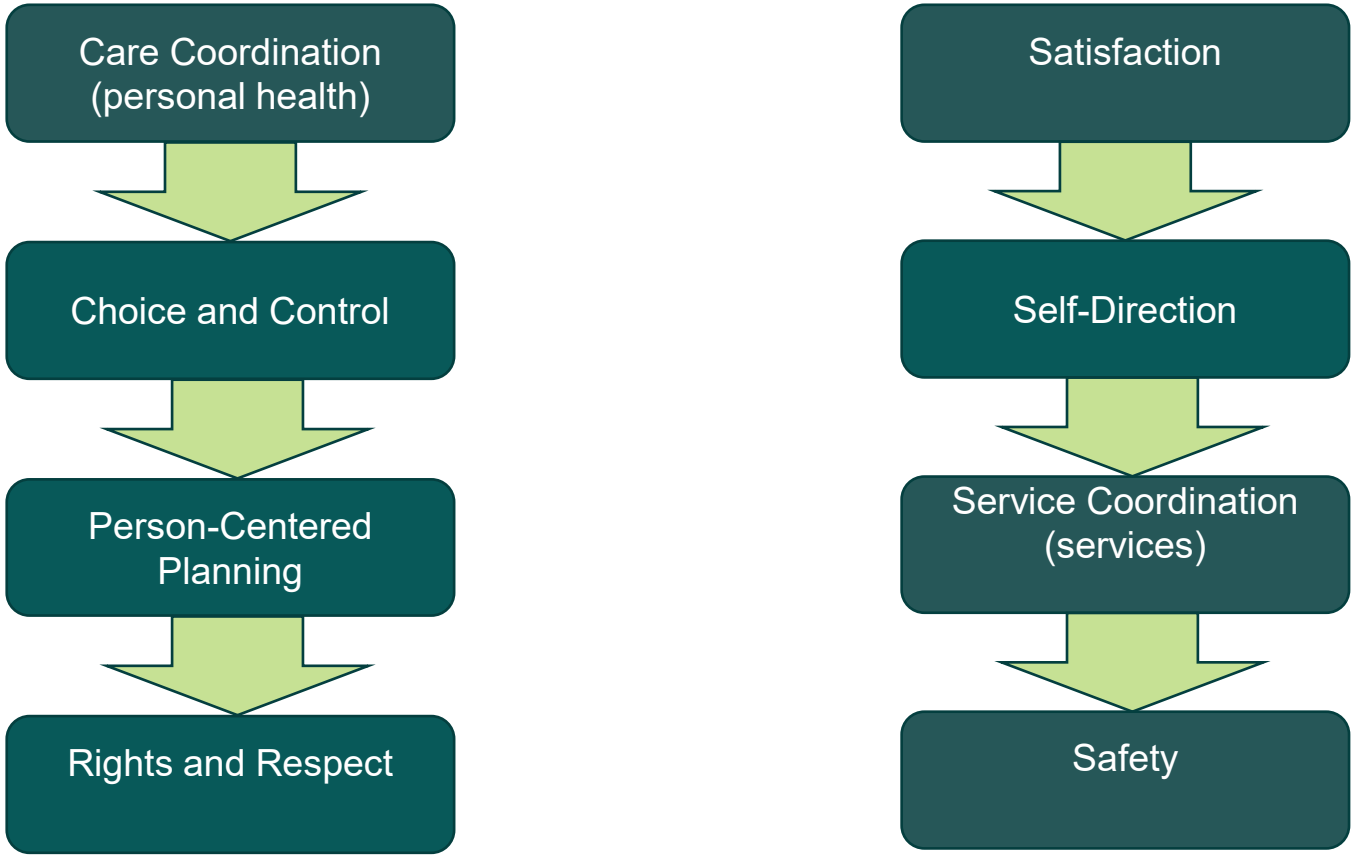
NCIAD Participation

- Georgia has participated in NCI-AD surveys since 2014
  - We did not participate during COVID (2020 and 2021)

- NCI-AD survey provides a lot of data
    - Focus on most informative domains
    - Using it for identification of service specific deficiencies by AAA
    - Using it for research activity
      - State specific questions added

Early Focus on Person-Centeredness

Using 8 of 18 domains to inform Person Centeredness



Early Person Centeredness Results

Satisfaction Domain – 76% believed paid support staff do things the way they want them done

Service Coordination Domain - 67% know who to contact to make changes to service

Care Coordination Domain - 88% with chronic conditions know how to manage them

Rights and Respect Domain - 94% feel paid support staff treat them with respect

Service Specific Deficiencies

Responses especially within the 8 Domains Georgia has selected to focus on that are below 80% are shared with the AAAs to follow up on.

Examples

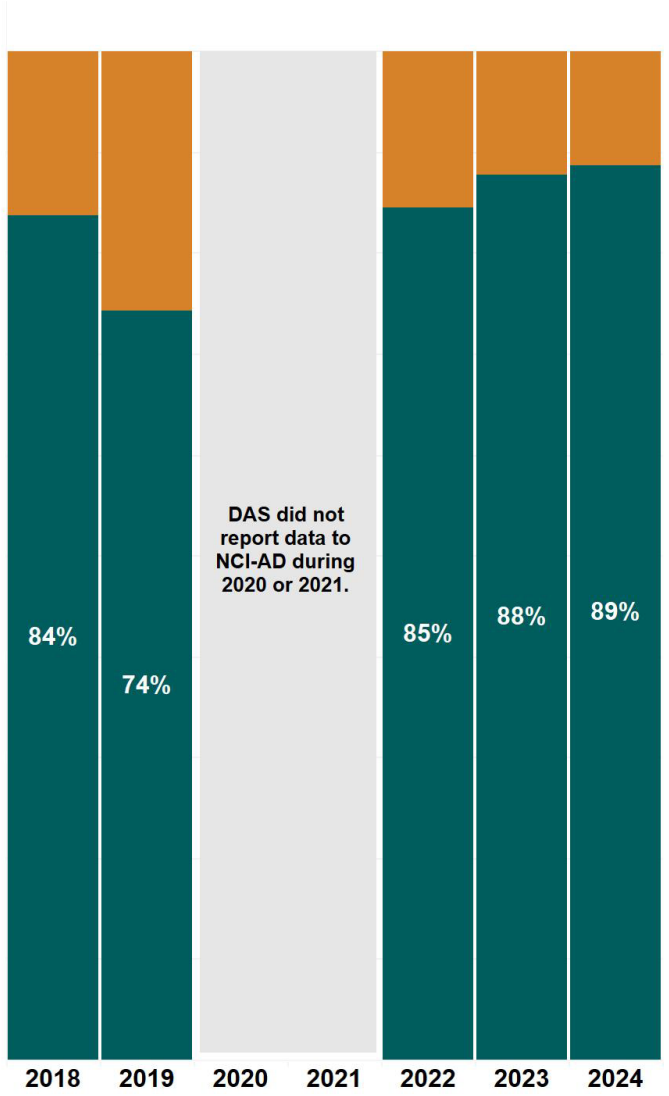
Satisfaction Domain: 23% support staff changes too much

Safety Domain: 43% had concerns about falling or being unstable

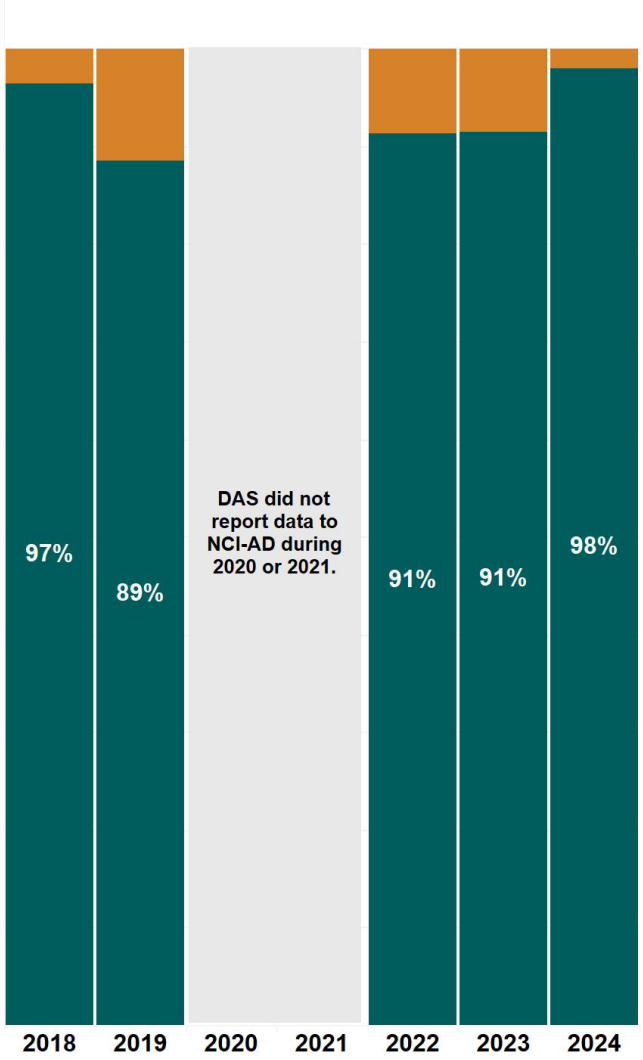
Longitudinal Analysis

- A good result in one year may just be an anomaly
- Trends
- Continuous Quality Improvement

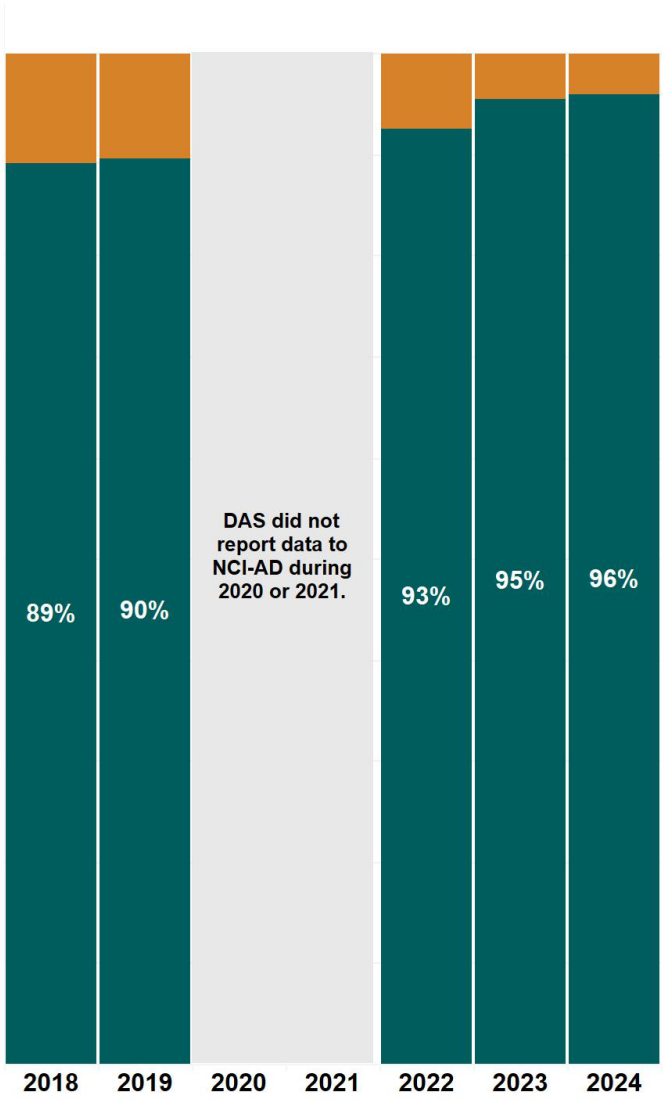
Do the people who are paid to help you do things the way you want them done?: % of NCI-AD survey clients who said 'yes'



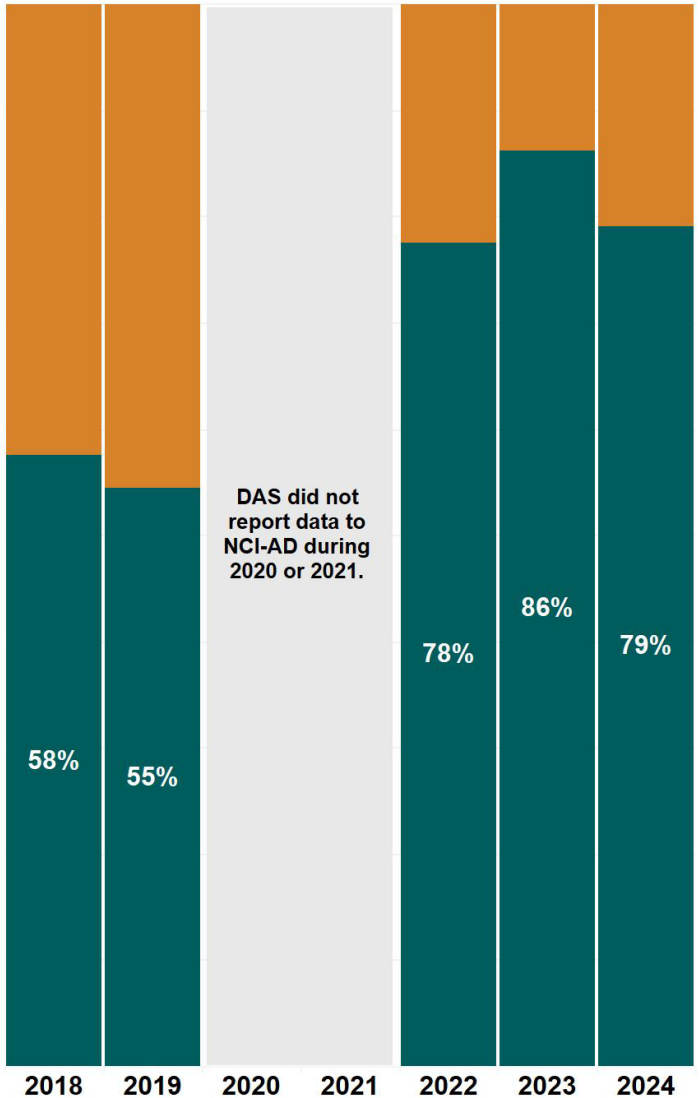
Do you feel that the people who are paid to help you treat you with respect?: % of NCI-AD survey clients who said 'yes'



Do you know how to manage your chronic condition(s)?: % of NCI-AD survey clients who said 'yes'



If you want to make changes to your services, do you know whom to contact?
% of NCI-AD survey clients who said 'yes'



Research and State Specific Questions

Working with partners to

- Identify patterns
- Strengthen strategic partnerships
- Create innovative solutions
- Inform public policy development

Some topics we've explored

- Oral health
- Dementia

2024 NCI-AD Survey Report: GA State Specific Questions

GA Q1 - Have you discussed forgetting things with your doctor, nurse, or other healthcare professional?

GA Q3 - Would you reach out to your local area agency on aging to find resources related to memory loss or brain health?

GA Q5 - Are you aware of the potential role that managing chronic conditions (e.g., diabetes, heart disease, blood pressure) and practicing healthy habits (e.g., smoking cessation, nutrition, sleep) plays in risk of developing dementia?

GA Q6 - Do you provide unpaid care for a family member or friend that has significant memory loss or a dementia diagnosis?

Questions or Comments?

Karen Nelson
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Join Our NCI-AD State of the Workforce Presentation!

AGENCY CHARACTERISTICS

68%
Provide in-home supports

84%
Private for-profit businesses

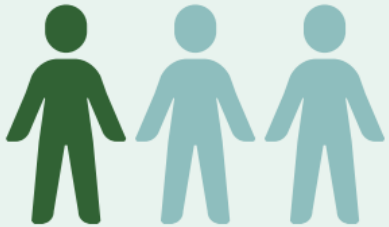
32% Report a **more than 10% increase in the number of members of the AD population enrolled** in or approved for services

29% Report they **turned away or stopped accepting referrals due to staffing issues**.

TURNOVER AND TENURE

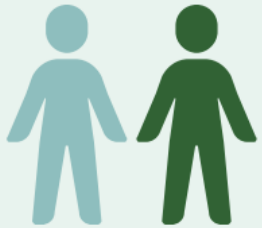
48%

Average **turnover ratio** across states



Just over **1 out of every 3 DSWs (37%)** employed as of Dec 31, 2023 had been working at their provider agency for **2 or more years.**

In contrast, almost **1 out of every 2 DSWs (47%)** who *left* their employer in 2023 had been on staff for **less than 6 months.**



Questions?

ADVANCING STATES