



Does it Make a Difference?

Understanding the Experiences of Individuals Receiving Services

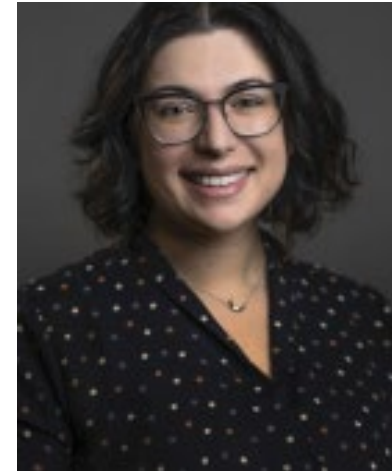


National I&R Support Center

January 19, 2023
3:00 p.m. to 4:00 p.m. ET.



Hello!



Stephanie Giordano, MEEP, DLP (she/her)

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Agenda



Overview and background

Data findings

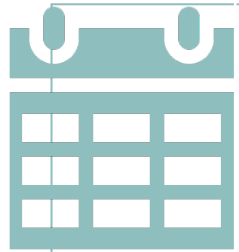
Select findings from recent presentations

Preview of 2021-2022 Data

Data for Quality Improvement

Wrap Up/Questions

NCI-AD: An Overview



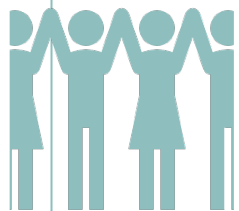
Established

- 2015



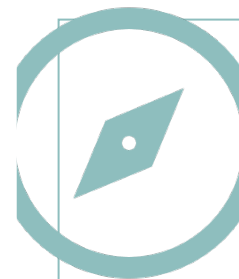
Participating states

- 23



Population addressed

- Older adults and people with physical disabilities



Covers multiple domains

- AD domains and indicators:
<https://nci-ad.org/resources/the-survey/>



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**

Domains (Area of Interest)

Community Participation Access to Community Work Everyday Living Relationships	Safety Satisfaction Service Coordination Rights and Respect	Care Coordination Access to Technology Access to Needed Equipment Health Care	Medications Wellness Affordability Choice and Control
Self-Direction (Optional) Service Planning (Optional)			



Data can help measure disparities

Individual characteristics of people receiving services

Where people live

Gender

Race/Ethnicity

Disability

The nature of their experiences with services

Interaction with staff and case managers

Self-direction

Choice and Control

The context of their life

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



Data are used to...



Compare outcomes to other states



Compare specific groups or geographic regions within states



Identify areas for quality improvement



Share outcomes with stakeholders and advocates for feedback and strategic planning



Benchmark and track progress toward quality improvement goals over time



Researchers also use data to look more closely at specific topics

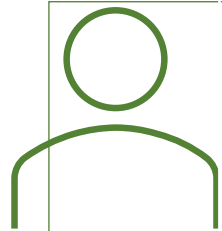


Select findings from recent presentations

Data from 2018-19

1:4 older adults (65+) who self-reported a mental health diagnosis

Those with a mental health diagnosis, compared to those without were:



4 times for likely to often feel sad or lonely



Had poorer community access and relationship outcomes, and were more likely to want to work or volunteer



More likely to live in a group setting, and less likely to like where they live



Had poorer staffing outcomes

10% of older adults reported they have to skip meals due to financial concerns

Older adults who reported they have to skip meals were more likely than those who did not to experience other measures of isolation, including being:

- **Less likely to have close relationships with friends and family**
- **More likely to live alone**
- **More likely to be in poor health**
- **More likely to report often feeling sad or depressed**

11% of ACS respondents were reported to have an ID diagnosis

The gender gap in respondents closes in older cohorts for NCI-IDD, yet increases NCI-AD

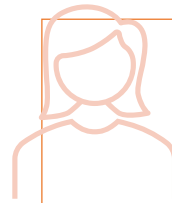
Self-reported mental health diagnosis is nearly 3.5x higher for 55-64 year olds compared to those 75 and older

Loneliness decreased with age by half

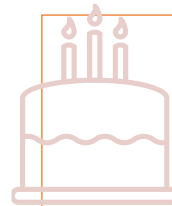
Overall, less than half of survey participants reported there are services they want that they are not currently receiving

People with an Alzheimer's or dementia diagnosis were more likely to report that services meet their needs and more likely to have ADL and IADLs met

Demographic factors associated with wanting additional services...



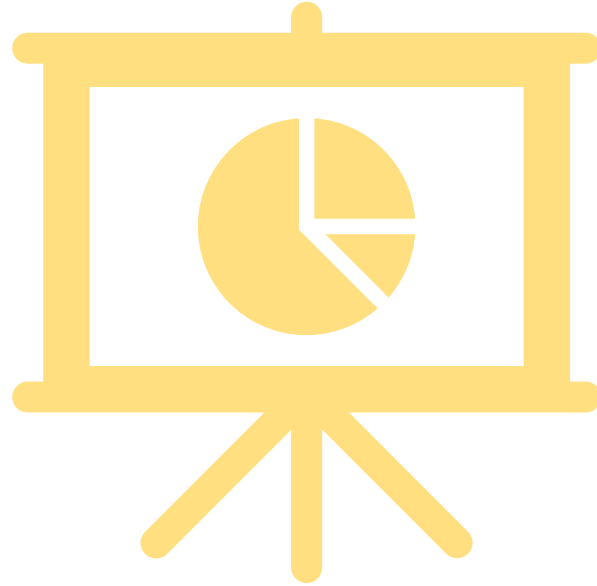
Identifying as a woman



Being 65 years and older



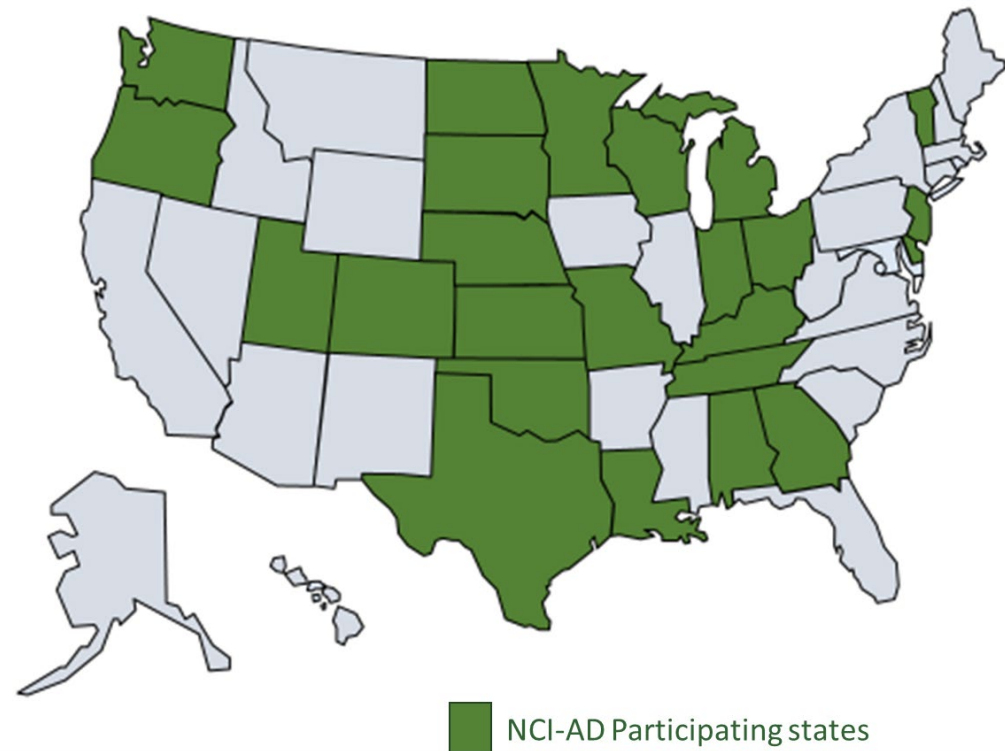
Living alone



Preview of 2021-2022 Data

*unweighted and may vary when published in national or state reports

2021 – 2022 Preview



19 States Included

- Programs Represented
 - Managed Long-Term Services and Supports (MLTSS)
 - Fee-for-service (FFS)
 - PACE
 - Older Americans Act (OAA)
 - Money Follows the Person (MFP)
 - Others

13,594 respondents

- 34% Male, 66% Female
- Age range: 18 – 99 (64 average)

Person's Race and Ethnicity

2021 – 2022 Preview

AMERICAN INDIAN OR ALASKA NATIVE	2%
ASIAN	3%
BLACK OR AFRICAN-AMERICAN	24%
PACIFIC ISLANDER	0.4%
WHITE	59%
HISPANIC OR LATINO	10%
OTHER	2%



Where Does the Person Live

2021 – 2022 Preview

Own or family house or apartment (owned or rented)	74%
Senior living apartment or complex	6%
Group home, adult family home, foster home, host home	2%
Assisted living facility, residential care facility	8%
Nursing facility, nursing home	8%
Homeless or temporary shelter	0.2%
Other	1%



Wellness Considerations



12%

- Diagnosis of Alzheimer's disease or other dementia

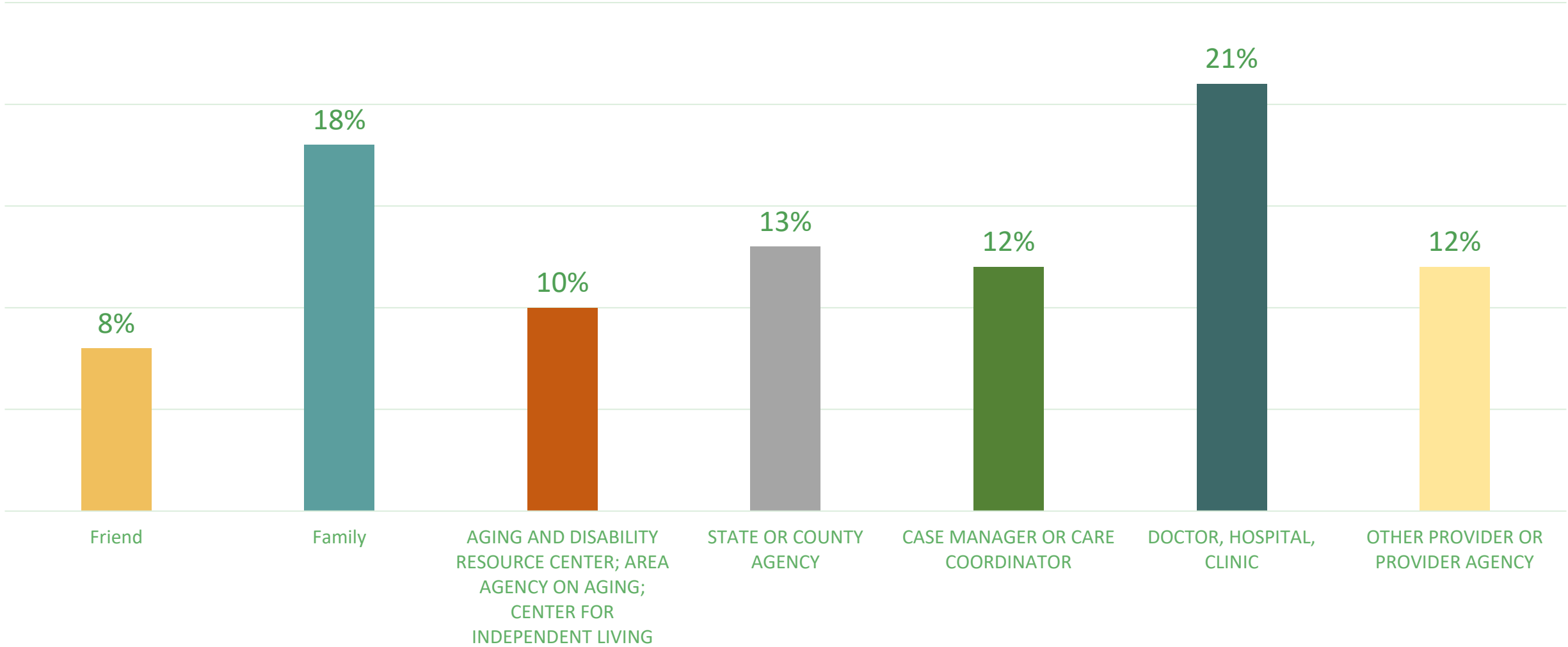
40%

- Chronic psychiatric or mental health diagnosis

4%

- Report they often skipping meals due to financial worries (6% sometimes do)

How the Person First Found Out About Services





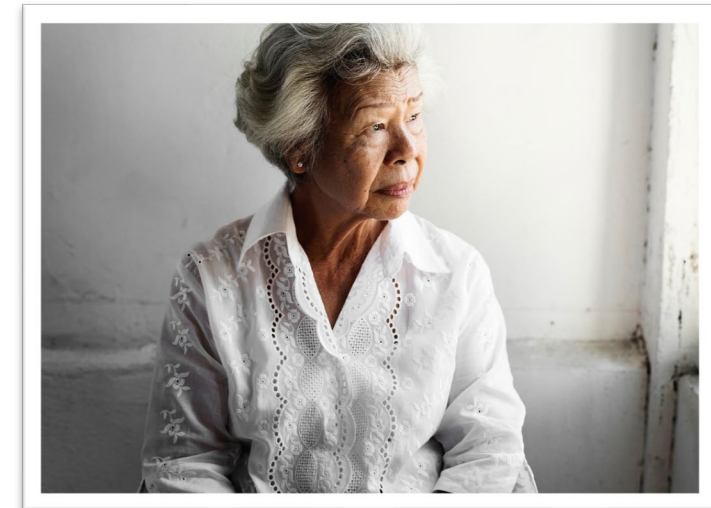
Almost 9 of 10 respondents state that the supports and services they receive help them to live a better life.

Older adults (60+) are more likely than those under 60 to report that all of their needs and goals are met by their long-term services and supports.

Social Isolation and Loneliness

4% reported they often feel lonely

- People under 60 were more likely to report often feeling lonely
- People who often feel lonely were more likely to report having to skip meals



Social Isolation and Loneliness

Over 9 in 10 respondents noted that they had friends or family, who did not live with them, who are a part of their life.

Hispanic respondents were...

- More likely to report having friends or family in their life, but
- Most likely to report often feeling lonely.



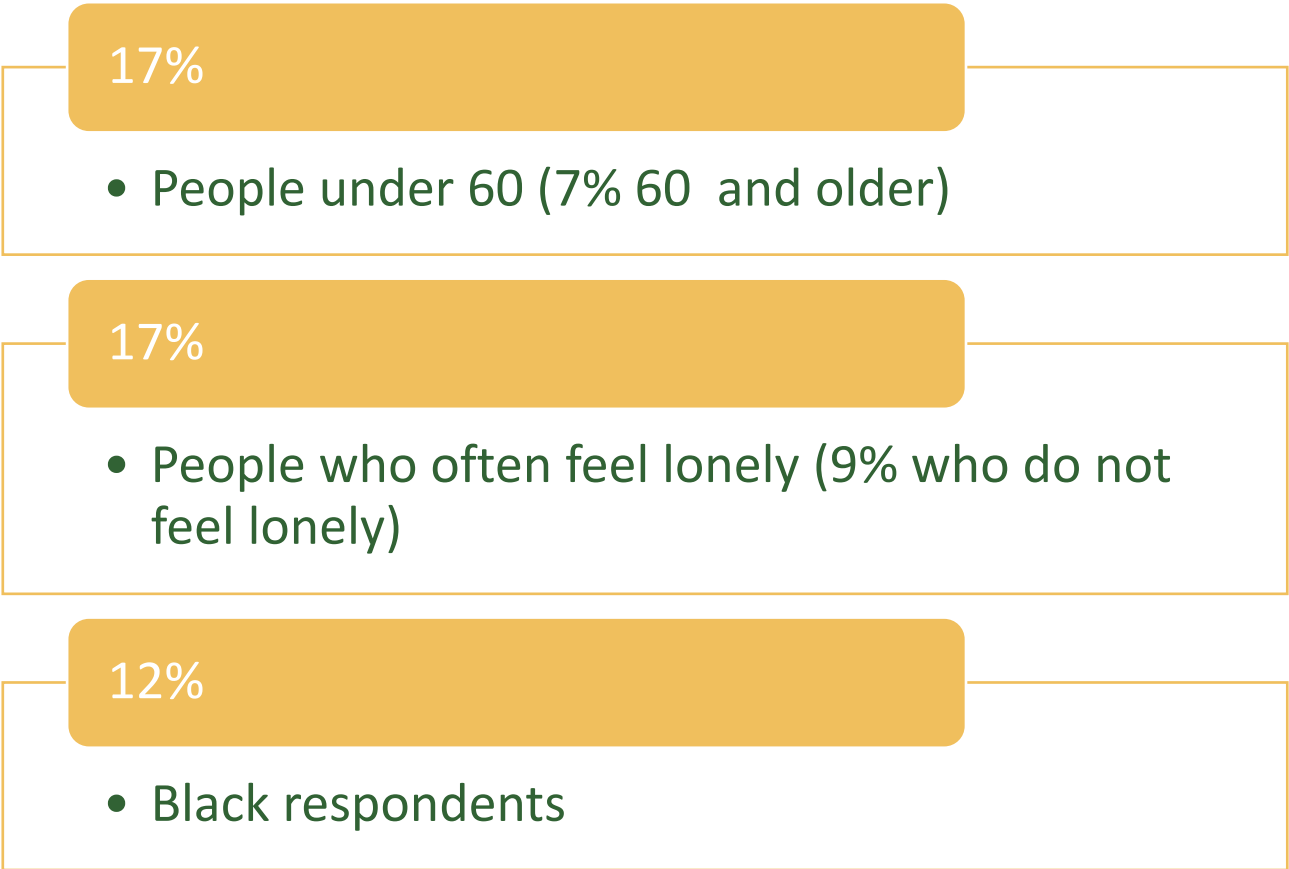
Working



3% have a job

10% reported they want a job

Who wants a job...



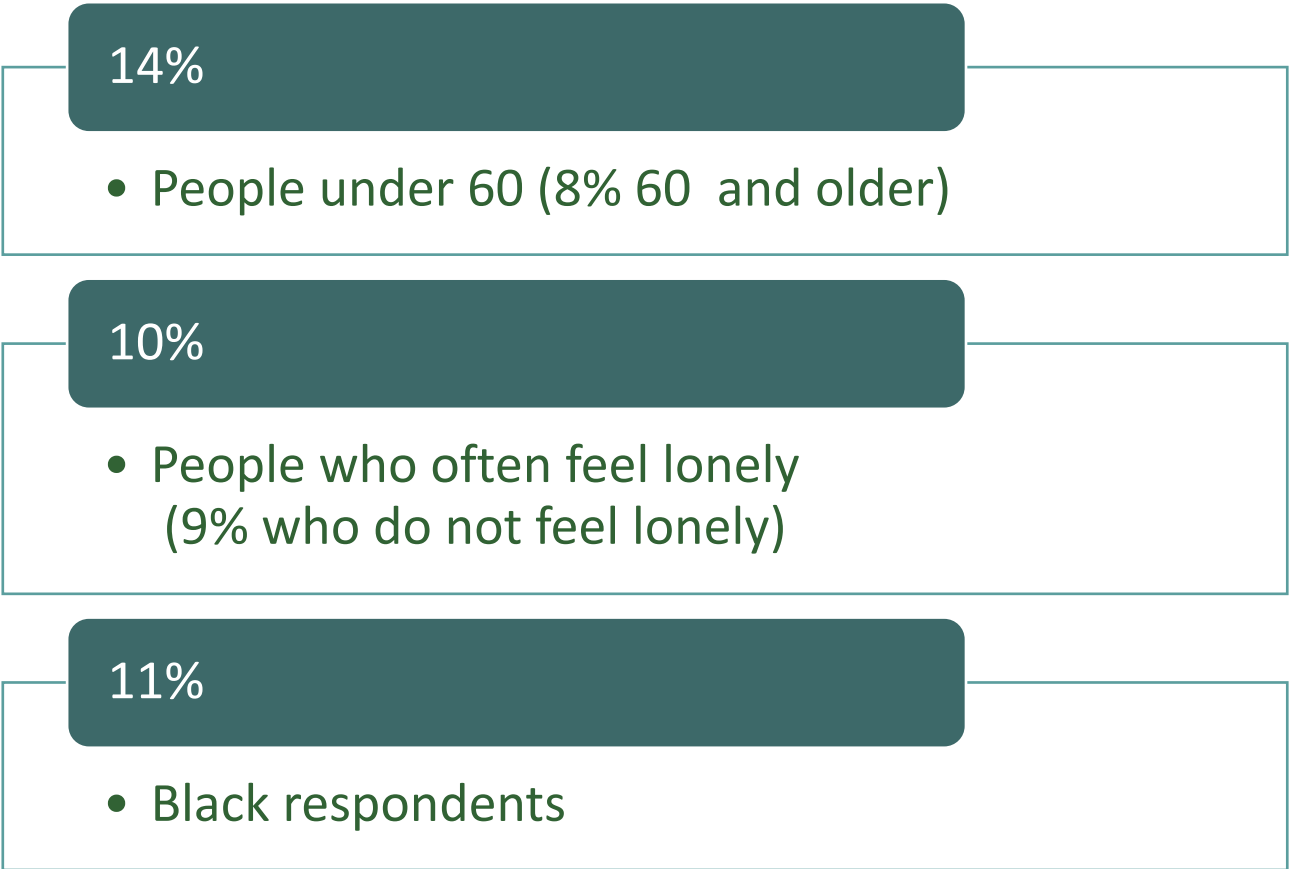
Volunteering



7% volunteer

10% reported they want to volunteer

Who wants to volunteer...



Where People Live



Those **60 and older** were more likely to **like where they are living**, and **less likely to report wanting to live somewhere else**.

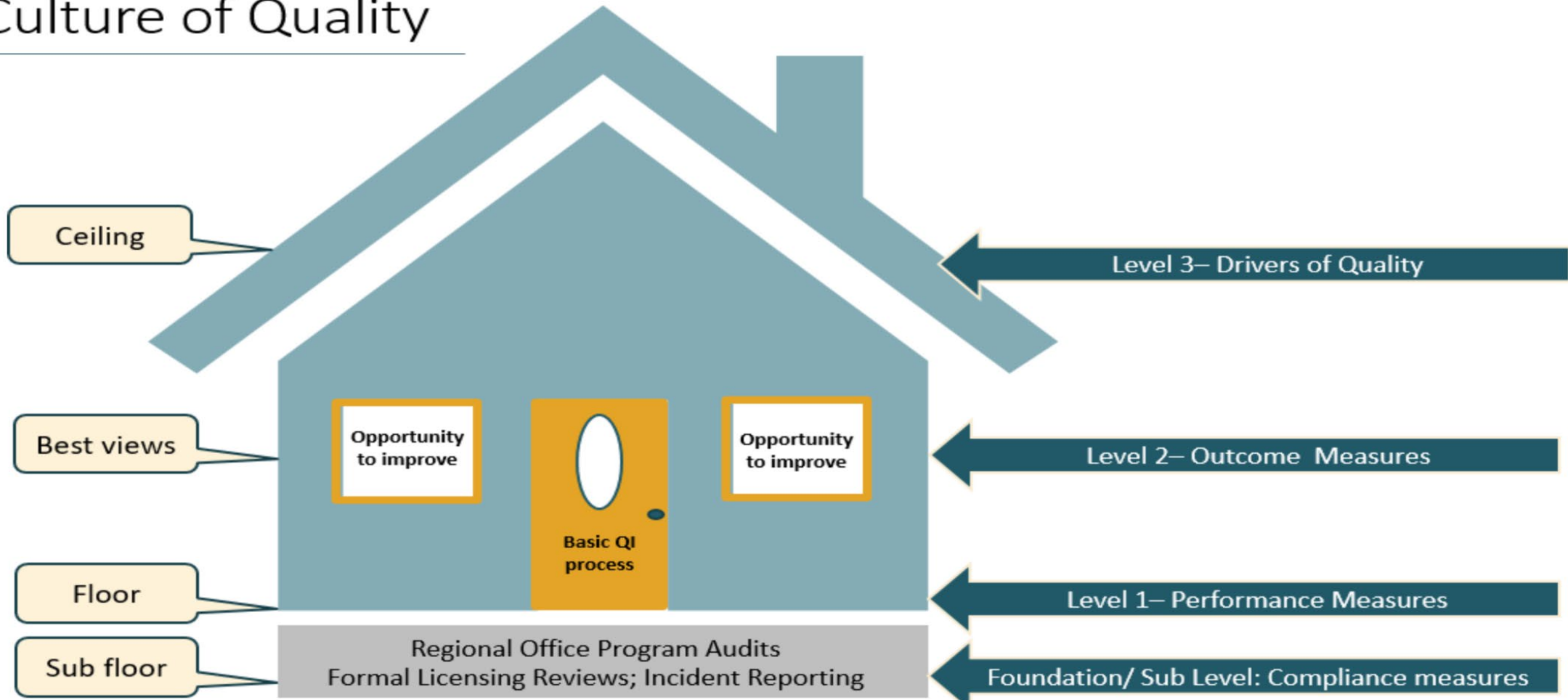
Within the same data:

Hispanic respondents were the most satisfied with where they live, followed by White respondents in satisfaction.

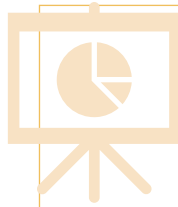
Black respondents were the least likely to like where they live, and most likely to report wanting to move somewhere else.

Data for Quality Improvement

Culture of Quality



Data for Quality Improvement: Considerations

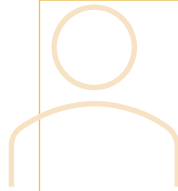


Transparency

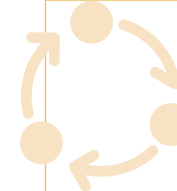


Sources of information

- Completeness of data

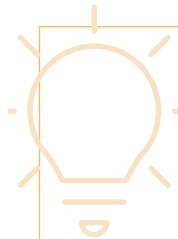


Person-centered outcomes



Methodology

- Uniform training and collection processes
- Sources of data



Relevance and impact

- Stakeholder use
- Uncover disparities



Statistically valid

HCBS Quality Measure Set: SMDL 22-003



July 21, 2022:

SMDL 22-003 was released, detailing first-ever HCBS Quality Measure Set

- 1st of 2 guidance documents from CMS
- Intended for use in all HCBS programs
- Intended to apply to both FFS and managed care

<https://www.medicaid.gov/federal-policy-guidance/downloads/smd22003.pdf>

Source

Vast majority of measures are drawn from consumer surveys

Flexibility

CMS permits states flexibility to determine which survey tool they implement:

NCI[®]-IDD

NCI-AD[™]

HCBS CAHPS[®] and

POM[®]

NCI-AD Resources





Please Note: We have a newly-refreshed design. Style options available at the bottom of the page. X

National Core Indicators – Aging and Disabilities (NCI-AD™)

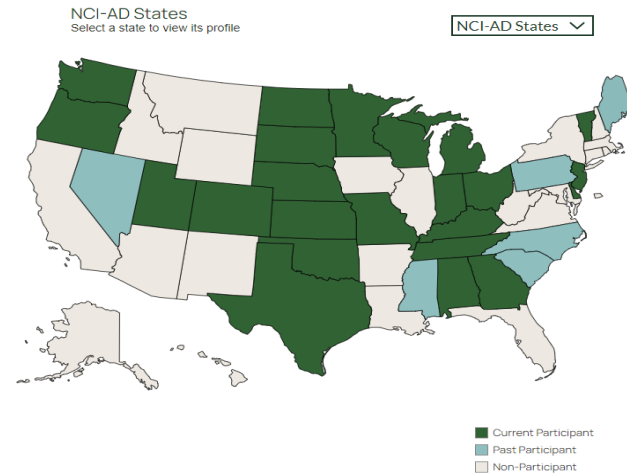
NCI-AD™ is a voluntary effort by State Medicaid, aging, and disability agencies to measure and track their own performance.

The core indicators are standard measures used across states to assess the outcomes of services provided to individuals and families. Indicators address key areas of concern including service planning, rights, community inclusion, choice, health and care coordination, safety and relationships.

NCI-AD™ is a collaboration of participating states, [Advancing States](#) (formerly NASUAD), and [HSRI](#)

[Read More](#)

[How to Participate](#)



Recent Updates

NCI-AD Webinar: Spotlight on Social Connectedness

NCI-AD hosted a webinar on social connectedness among older adults and people with physical disabilities on February 3, 2021.

[Read More](#)

New Reports Available: 2019-20 NCI-AD State Reports

Please check out the reports page for the latest updates.

[Read More](#)

Released! NCI-AD Spotlight: Social Connections Among Older Adults and People With Disabilities

NCI-AD is excited to announce the release of our first NCI-AD Data Spotlight on Social Connections Among Older Adults and People With Disabilities! The Spotlight highlights responses from the more than 14,000 older adults and people with disabilities across 16 states who took part in the 2018-19 Adult Consumer Survey (ACS). Follow the link below to check it out.

[Read More](#)

nci-ad.org



Data Spotlights



[https://
nci-ad.org/
resources/
data-
spotlight/](https://nci-ad.org/resources/data-spotlight/)

Older Adults and Mental Health

Health Care Access and Preventive Services

Alzheimer's and Related Dementias

LTSS Experiences of Black and White Respondents

Social Connections Among Older Adults and People with Disabilities

Alzheimer's and Related Dementias

Using NCI-AD Data as Context for Better Understanding

NCI-AD DATA SPOTLIGHT

Did you know June is Alzheimer's & Brain Awareness month?

Alzheimer's disease is the most common type of dementia that begins with mild memory loss but can eventually affect a person's ability to perform daily functions. Alzheimer's is more prevalent than some might think; more than 1 in 9 people aged 65 and older have Alzheimer's dementia¹. It is also the sixth leading cause of death in the US for the 65 and older population².

Age is the most important known risk factor for dementia⁴. Recent research suggests addressing certain lifestyle factors can help to mitigate the risk of Alzheimer's disease, including quitting smoking, diet and blood pressure management, increased physical activity, and staying socially and mentally active⁵.

In 2018-19, 15% of people surveyed by NCI-AD had an Alzheimer's Disease or related dementia (AD/RD) diagnosis. The information below, derived from NCI-AD data, can help provide context on the complexities of this population.



Average age of people with Alzheimer's Disease or related dementia:
72

Data are from the 2018–2019 NCI-AD Adult Consumer Surveys and are collected directly from people receiving services. For this Spotlight we limited the sample to those with a diagnosis of Alzheimer's disease or other dementia, for a total of 2,107 people.

NCI-AD Data Spotlight on Older Adults and Mental Health

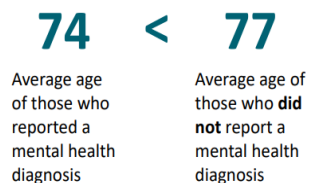
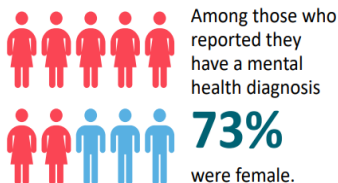


NCI-AD DATA SPOTLIGHT

May is Older Americans Month and Mental Health Awareness Month. This NCI-AD Spotlight sheds light on the impact of mental health on older adults. Older adults experience greater inequality related to social and economic factors, that in turn can affect mental health.¹ About 12% of adults aged 65 or older report that they "rarely" or "never" receive the social and emotional support they needed.²

Note: These data were collected before COVID-19.

In 2018 - 2019, what did National Core Indicators - Aging and Disabilities Tell Us?³



A higher proportion of white respondents reported having a mental health diagnosis, while a lower proportion of black respondents reported a diagnosis.



³These data come from the 16 states that participated in the 2018–19 NCI-AD™ Adult Consumer Survey. Analysis includes people 65 and older who responded to the question "Do you have a chronic psychiatric or a mental health diagnosis, such as bipolar disorder, schizophrenia, or major depressive disorder?" Data include a total of 6,639 respondents. Comparisons are significant at .01.

NCI-AD and Health Care

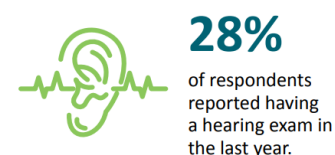
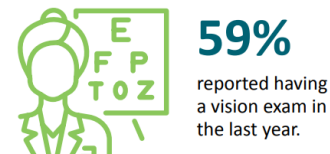
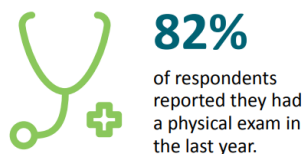
A Closer Look at Health Care Access and Preventive Services*



NCI-AD DATA SPOTLIGHT

Access to health care can impact a person's physical, social, and mental health status and quality of life.¹ Older adults and people with physical disabilities should have access to health care and preventive services to avert health crises, improve health outcomes, and live healthy lives. However, information collected by NCI-AD in 2018–19 reveals that nearly 1 out of every 5 respondents *did not* have a regular physical exam in the past year. Moreover, fewer than half had a dental exam in the past year, and only a quarter of respondents had a hearing exam. This is concerning given the impact hearing and oral health can have on quality of life.

Preventive Health Care Services:



*Information in this document comes from the more than 14,000 older adults and people with disabilities across 16 states who took part in the 2018–19 NCI-AD™ Adult Consumer Survey.

Thank you!

Questions?

Comments?

Reactions?