





# Quality of Life Data on Older Adults and People with Disabilities

Examine the Latest Findings from the National Core Indicators – Aging and Disabilities (NCI-AD)

WellSky

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# Hello!





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# Agenda

### Overview and background

#### **Data findings**

Select findings from recent presentations

Preview of 2021-2022 Data Findings

NCI-AD Resources

Wrap Up/Questions



## **NCI-AD: An Overview**



#### Established

- 2015
- Grew out of NCI-IDD



#### Participating states

• 23



#### Population addressed

 Older adults and people with physical disabilities



#### Covers multiple domains

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





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)



# **Background Information (BI)**

# **Key demographic characteristics:**



Age

Gender

Race/Ethnicity

**Martial Status** 

Preferred Language

Zip Code

Type of Residential Setting

Who Lives with Person

Guardian Status

Mobility

Falls

LTSS Services including SDS

Medicare Status

Conditions

Deaf/Hard of Hearing

Blind/Visually Impaired



# Social Deprivation Index (SDI)

"SDI is a composite measure of area level deprivation based on seven demographic characteristics collected in the American Community Survey and used to quantify the socio-economic variation in health outcomes."

— Robert Graham Center



Beginning with 2022-23 data, ACS links to area measures of SDI (based on zip code), allowing for further analysis.



# 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 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



# 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

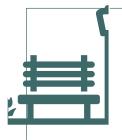


# 1:4 older adults (65+) who self-reported a mental health diagnosis

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



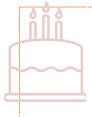
Overall, less than half of survey participants reported there are services they want that they are not currently receiving

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

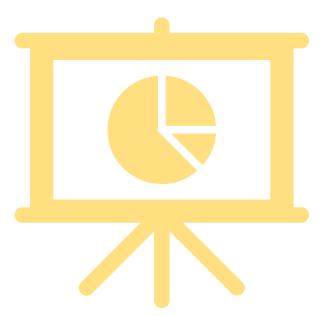


Being 65 years and older



Living alone



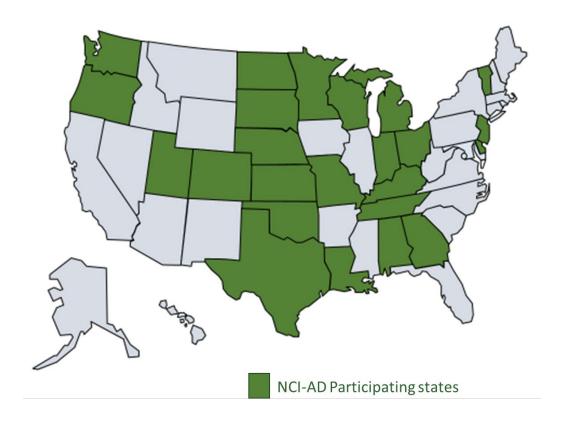


# Preview of 2021-2022 Data

\*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)



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%



Own or family house or apartment (owned or rented)	<b>74</b> %
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%

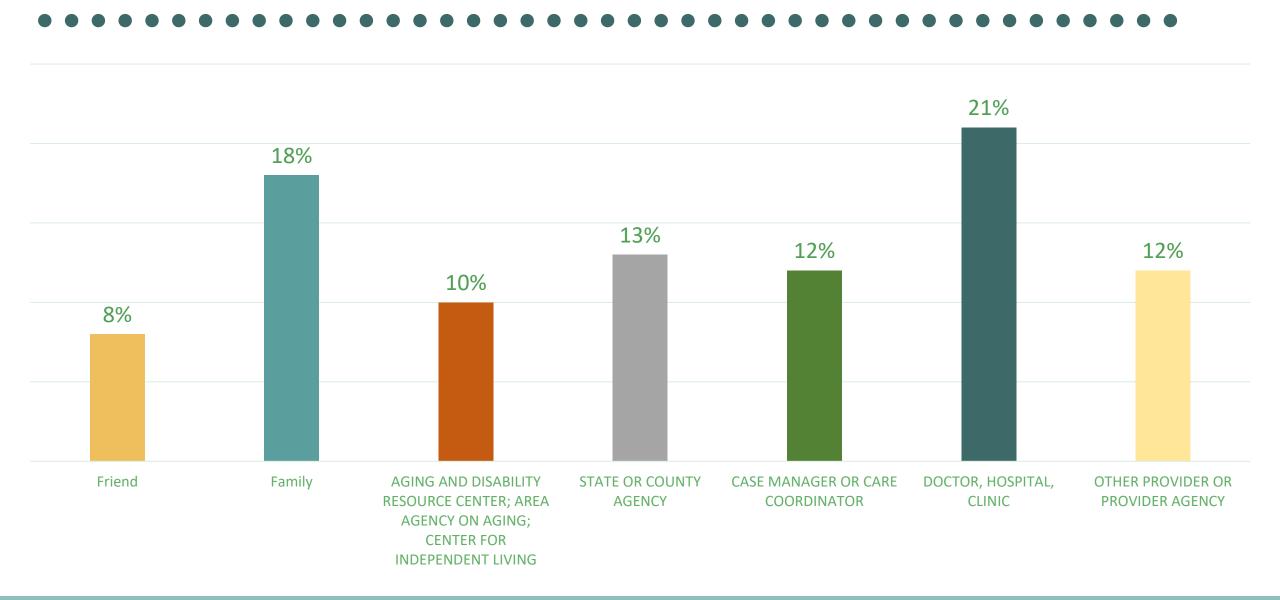
 Diagnosis of Alzheimer's disease or other dementia 40%

 Chronic psychiatric or mental health diagnosis 4%

Report they <u>often</u>
 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...

17%

People under 60 (7% 60 and older)

17%

• People who often feel lonely (9% who do not feel lonely)

12%

Black respondents



## Volunteering



7% volunteer

10% reported they want to volunteer

#### Who wants to volunteer...

14%

People under 60 (8% 60 and older)

10%

• People who often feel lonely (9% who do not feel lonely)

11%

Black respondents



### **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.

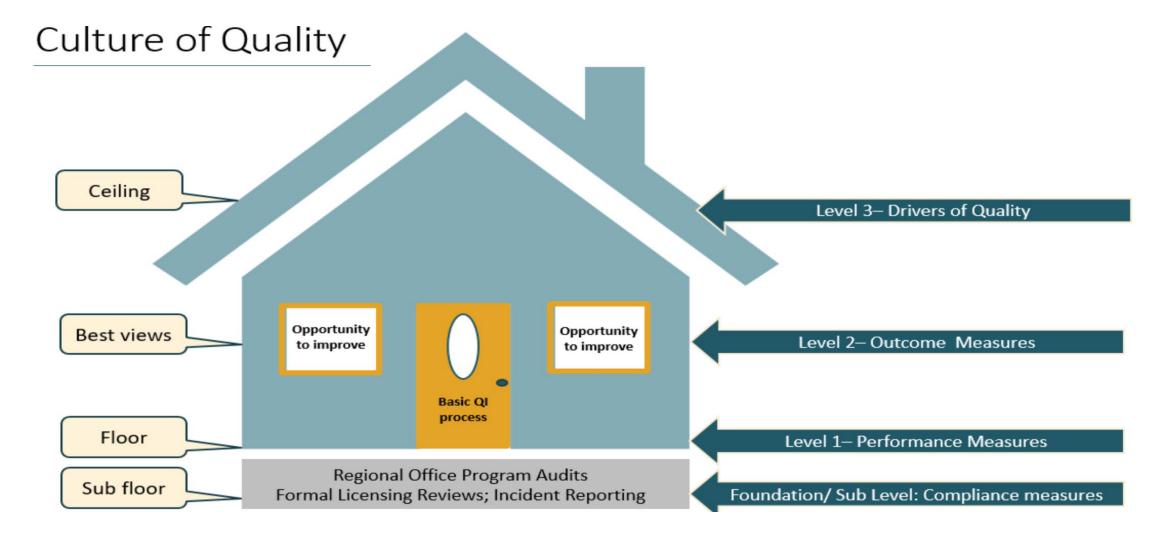
Black respondents were the least likely to like where they live, and most likely to report wanting to move somewhere else.



# **Collecting Quality Data**

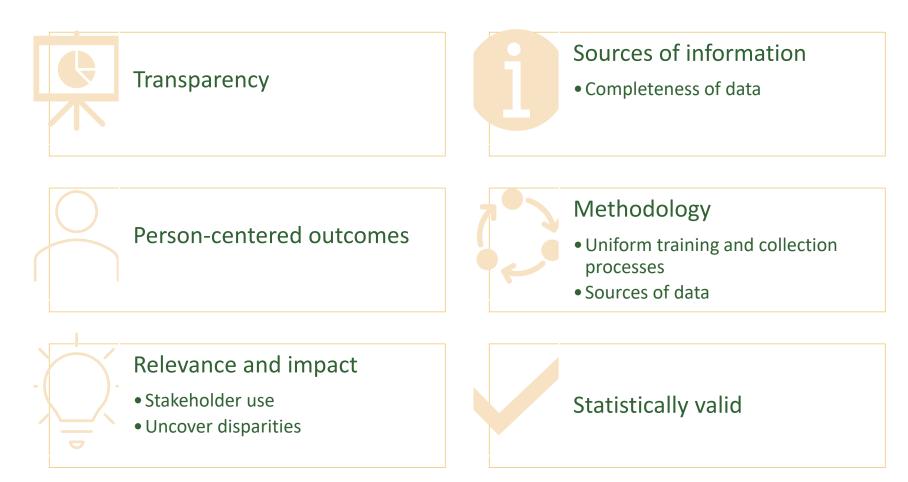


# **Data for Quality Improvement**





### **Data for Quality Improvement: Considerations**





## **HCBS Quality Measure Set: SMDL 22-003**



### July 21, 2022:

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

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

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



#### **HCBS Quality Measure Set Organization**

#### 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**





STATE LOGIN



About NCI-AD States Reports Resources News Join NCI-AD

National Core Indicators - Aging

and Disabilities (NCI-AD™)

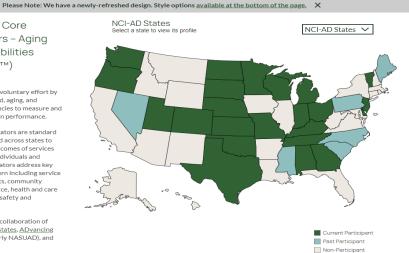
NCI-AD™ is a voluntary effort by State Medicaid, aging, and disability agencies to measure and track their own performance.

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

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

Read More

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

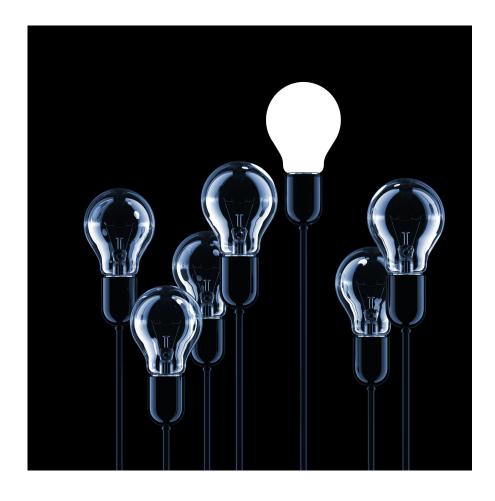
NCI-AD is excited to announce the release of our first NCI-AD Data Spotlight on Social Connections Among Older Adults and People With Disabilities! The Spotlight highlights responses from the more than 14,000 older adults and people with disabilities across 16 states who took part in the 2018-19 Adult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

Read More

nci-ad.org



### **Data Spotlights**



https:// nci-ad.org/ resources/ dataspotlight/

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



#### 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.<sup>1</sup> About 12% of adults aged 65 or older report that they "rarely" or "never" receive the social and emotional support they needed.<sup>2</sup>

Note: These data were collected before COVID-19.

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



Among those who reported they have a mental health diagnosis

Average age of those who reported a mental health diagnosis

Average age of those who did not report a mental health diagnosis

77

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



\*These 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. 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:**



**82%** 

of respondents reported they had a physical exam in the last year.



**59%** 

reported having a vision exam in the last year.



40%

of respondents reported having a dental exam in the last year.



**28%** 

of respondents reported having a hearing exam in the last year.

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.

#### 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 dementia<sup>1</sup>. It is also the sixth leading cause of death in the US for the 65 and older population<sup>2</sup>.

Age is the most important known risk factor for dementia<sup>4</sup>. 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:

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.



# Thank you!

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# Questions?

# Comments?

# Reactions?

