

2021-22 DATA AT A GLANCE

DESCRIPTION OF SAMPLE

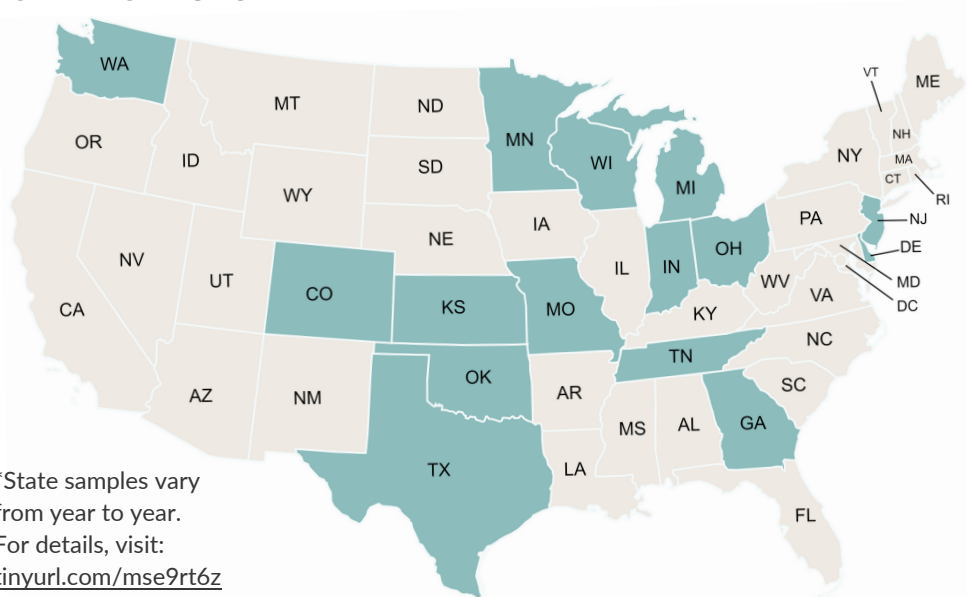
INTRODUCTION

The survey data in this summary represent the population of older adults and people with physical disabilities receiving publicly funded long-term services and supports programs—known as LTSS. For more information, visit: tinyurl.com/2dyk34rw

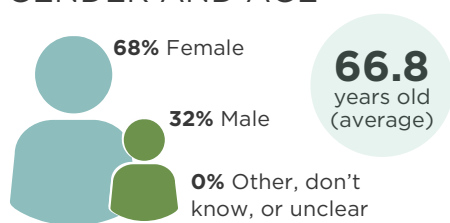
SAMPLE SIZE

13,663 total respondents

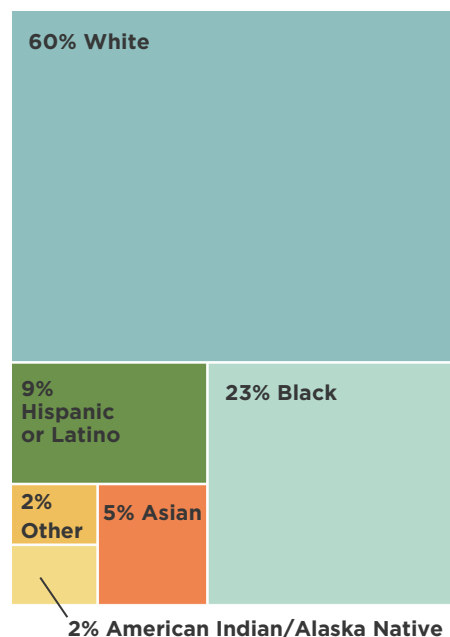
STATES INCLUDED*



GENDER AND AGE



RACE AND ETHNICITY



RESIDENCE TYPE

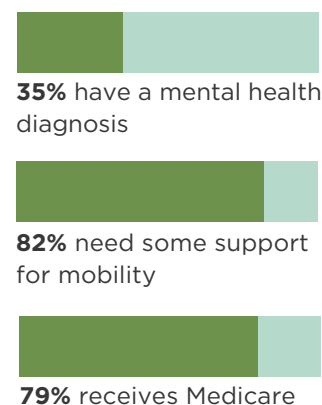
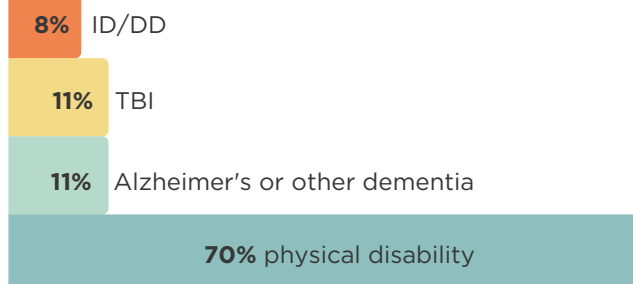


RESIDENCE LOCATION

72% Metropolitan, 14% Micropolitan, 9% Small town, 6% Rural

MEDICAL BACKGROUND

DIAGNOSIS*



*Note: Diagnoses are not mutually exclusive

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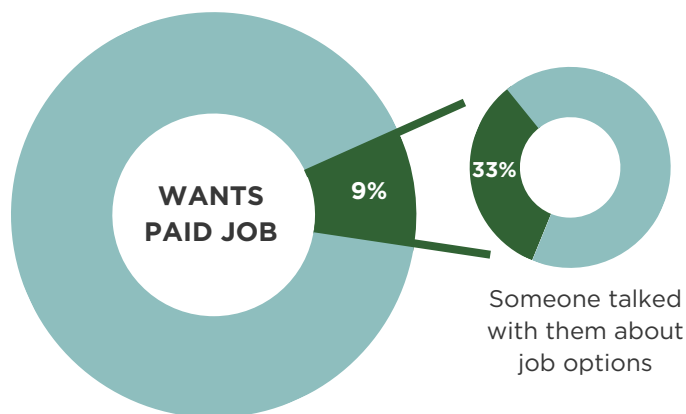
OUTCOMES

NOTE ON OUTCOMES

NCI includes data on a variety of outcomes of service users. Data from key outcomes are presented here.

EMPLOYMENT

Employment is important at any age and impacts not only a person's financial resources, but access to their community. Across all ages and states, **8% of respondents say they want to volunteer and nearly one in 10 people want a job.** However, among those who say they want to work, **just 33% report that someone has talked with them about job options.** Person-centered systems should ensure these conversations happen, help people think about the employment and activities suitable for them, and consider supports that will help people reach their goals.



RESPECT AND PRIVACY



96% say services and supports are delivered in a way that is **respectful of their culture**



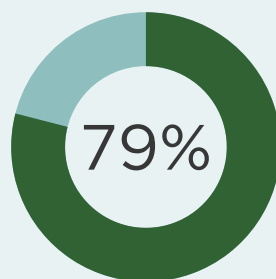
74% say they have **enough privacy where they live** (if in a group setting)



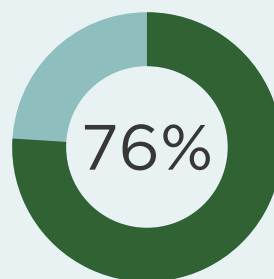
70% say others **ask before coming in** their home/room (if living in a group setting)

CHOICE AND CONTROL

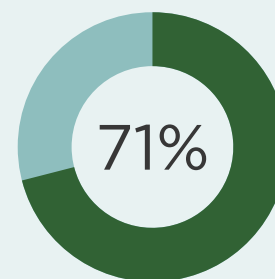
72% of respondents say they feel in control of their life



The percent of respondents who can choose/change the people who provide paid supports

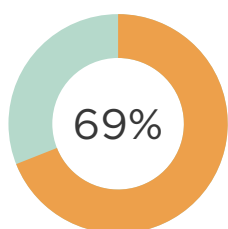


The percent of respondents who can choose/change their services and supports

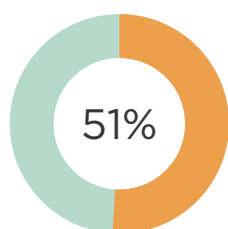


The percent of respondents who can choose/change when/how often they receive services

SERVICES AND UNMET NEEDS



The percent of people who say **services meet all their current goals**



The percent of people whose **case manager talked to them about services** to help with unmet needs (among people with case manager and whose needs/goals are not met)

STAFF LONGEVITY AND TURNOVER

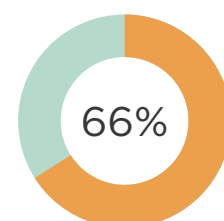


25% say paid staff changes too often



31% say case manager changes too often

SERVICE COORDINATION



The percent of people who **have a backup plan** if their paid support staff does not show up

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OUTCOMES

HEALTH AND HEALTH CARE



89% have **access to mental health services** if they wanted



84% can **get an appointment** to see or talk to their primary care doctor when needed



43% have talked to health professionals using **video conference/telehealth**



39% were **sent to the emergency room** for any reason in the past 12 months



13% self-reported **health is excellent or very good**

SUPPORT ACCESS TO COMMUNITY



85%

can see/talk to family/friends they do not live with when they want



77%

have enough help with everyday activities



74%

always have a way to get where they want to go

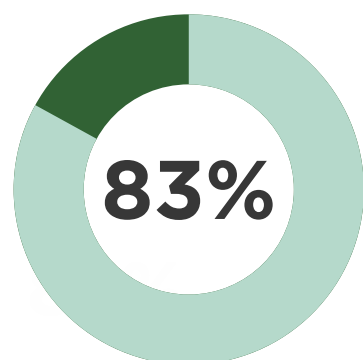


58%

can take part in activities with others as much as they want

Generally, people say they can see or talk to family and/or friends who do not live with them. However, **fewer say they can participate in activities as much as they want**, with states ranging 49% to 75% (an average of 58%). These data emphasize that although service users can usually see or talk to family and/or friends when they want, there is ample room for improvement in how systems support service users to take part in activities with others. LTSS systems can help support people to have more equitable access through conversations about how people want to be engaged and what supports they need (e.g., using tech, transportation) to achieve that.

COVID-19 RESPONSE



The percent of people who say they were **satisfied with the response of all service providers** during COVID-19

BARRIERS TO COMMUNITY PARTICIPATION

42%

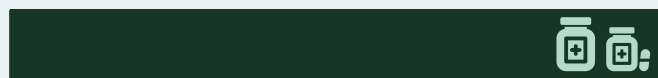
of people cannot participate in activities as often as they want due to ...



Cost, **12%**



Transportation, **29%**



Health limitations, **51%**

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OUTCOMES: HCBS FINAL SETTINGS RULE

NOTE ON HCBS FINAL SETTINGS RULE

The HCBS Final Settings Rule establishes basic requirements around community integration, choice and control, autonomy, and person-centered planning for settings providing home and community-based services (HCBS). The data on this page showcase just a few of the NCI outcomes that can be used to look at compliance with the HCBS Final Settings Rule.

PERSON-CENTERED PLANNING



79%

of respondents say they are very/fully **involved in making decisions** about what is in the service plan

Person-centered planning identifies personal goals and the supports a person needs to achieve their goals. While most respondents say they feel fully involved with planning their services, about **3 out of 10 people surveyed say they were not fully listened to** during the last planning meeting. Further, about **one-quarter report their current plan does not fully reflect their choices and preferences**. This demonstrates that methods LTSS systems use for person-centered planning can still be strengthened and more driven by service users.

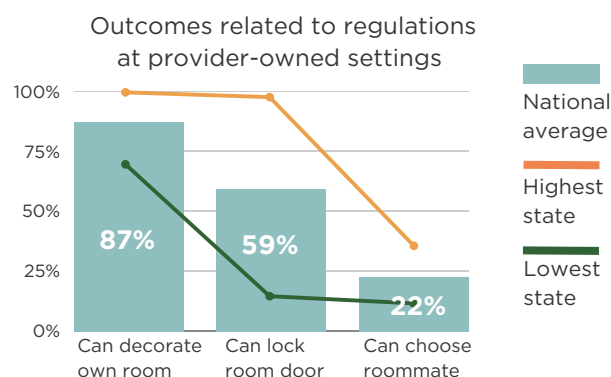
People at planning meeting listened to needs and preferences:

- **72% responded 'Yes'**
- 26% responded 'Somewhat'
- 1% responded 'No'

Choices/preferences are reflected in their current service plan:

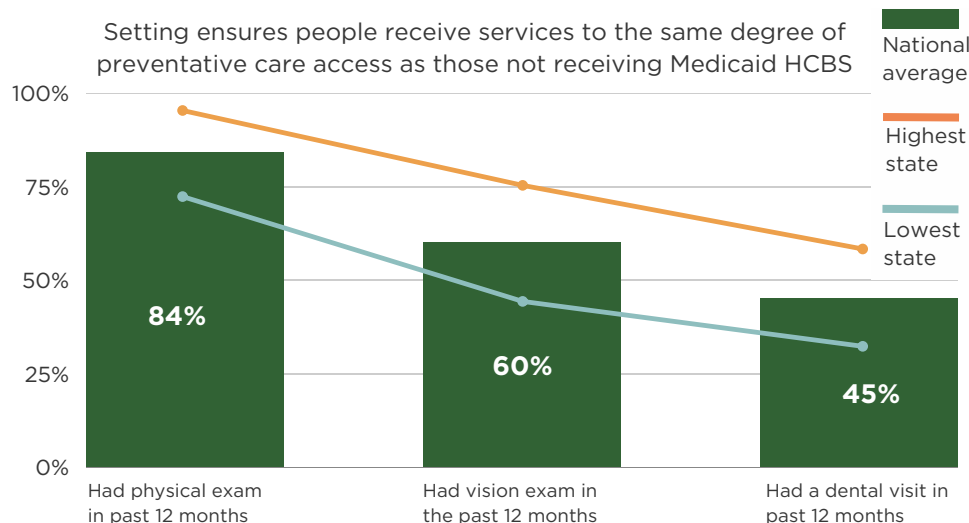
- **78% responded 'Yes'**
- 20% responded 'Somewhat'
- 2% responded 'No'

PROVIDER-OWNED SETTINGS



The above graph shows responses to three NCI-AD Adult Consumer Survey questions that look at outcomes related to the HCBS Final Settings Rule regulations for provider-owned settings. The **vertical bars display the national average percent** of respondents who have each of the outcomes in 2021-22, while the **two lines show the range of state average percentage**. The highest percent was for "can decorate own room" at 87%, while the lowest was "can choose roommate" at 22%. These data show that although users report having control over some things about their home, long-term services and supports (LTSS) can better support people in having choice in their roommates.

ACCESS TO PREVENTATIVE HEALTH CARE



This graph shows responses to three NCI-AD Adult Consumer Survey questions that can be used to examine access to preventative care. These indicators relate to the HCBS Final Settings Rule requirements that people have full access to the greater community.

Outcomes displayed focus on whether people accessed preventative health services in the past year. The **vertical bars display the national average percent** of respondents who have each of the outcomes in 2021-22; the **two lines show the range of state average percent**. Depending on the outcome, **rates of access vary between 45% and 84% nationally**. These data show that there is room to improve how systems support people to access all forms of preventative health care, especially dental visits.