2021-22 DATA AT A GLANCE

DESCRIPTION OF THE SAMPLE

INTRODUCTION

The survey data in this summary represent the population of adults receiving at least one service in addition to case management/ service coordination from their state developmental disability service system. For details, visit: tinyurl.com/22w9wpm9
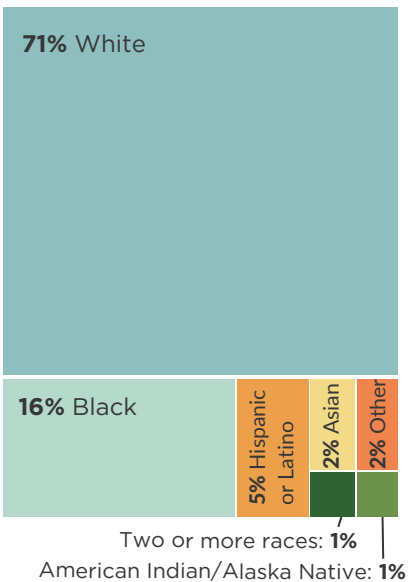
SAMPLE SIZE

13,559 total respondents

STATES INCLUDED*

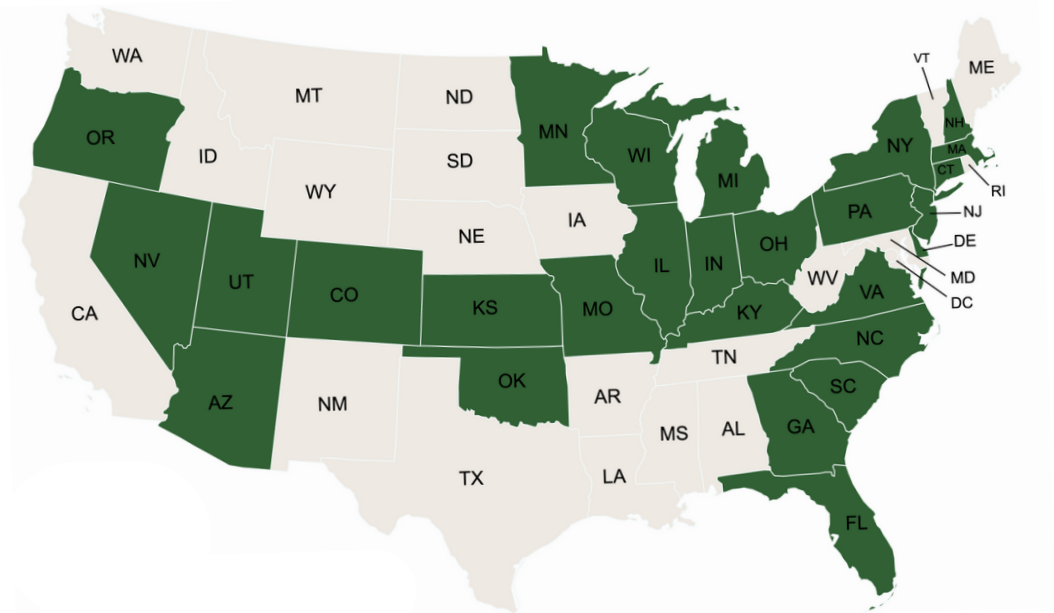## AGE AND GENDER

42 years old (average)

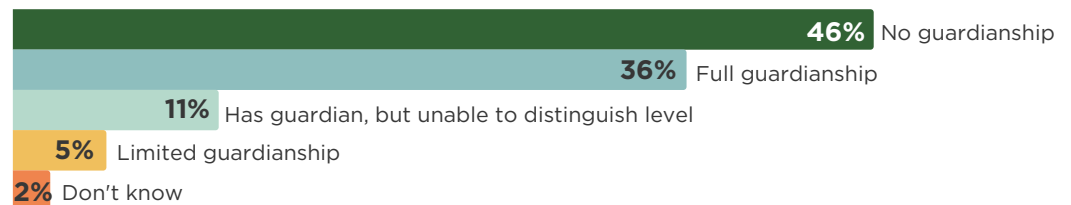40% Female

60% Male
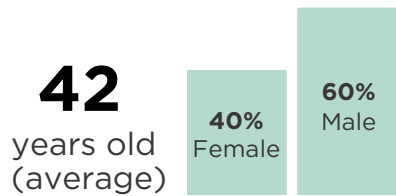
RESIDENCE TYPE

40% Family home/own home
36% Community-based group residential
15% Own home/apartment
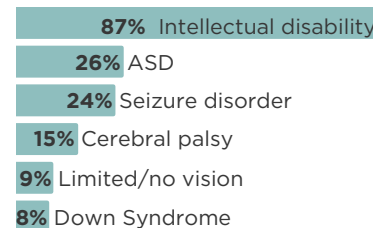**5%** Foster/host home
4% Institutional setting

RESIDENCE LOCATION

78% Metropolitan
13% Micropolitan
7% Small town
3% Rural

RACE AND ETHNICITY

71% White

16% Black

5% Hispanic or Latino

2% Asian

2% Other

Two or more races: **1%**

American Indian/Alaska Native: **1%**

LEVEL OF GUARDIANSHIP

46% No guardianship
36% Full guardianship
11% Has guardian, but unable to distinguish level
5% Limited guardianship
2% Don't know

DIAGNOSIS

87% Intellectual disability
26% ASD
24% Seizure disorder
15% Cerebral palsy
9% Limited/no vision
8% Down Syndrome

Note: Diagnoses are not mutually exclusive

RECEIVES MEDICARE

42%

MOBILITY

Moves self without aids **75%**

Moves self with aids **16%**

Always needs help to move **8%**

*State samples vary from year to year. For details, visit: tinyurl.com/mpdnze5n
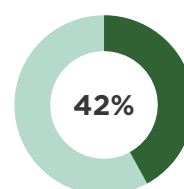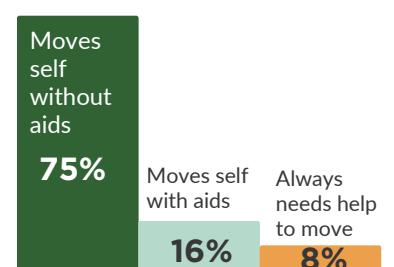
2021-22 DATA AT A GLANCE

NOTE ON OUTCOMES

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

EMPLOYMENT

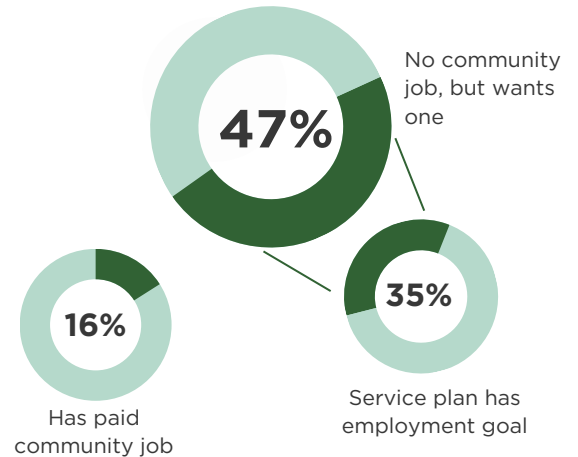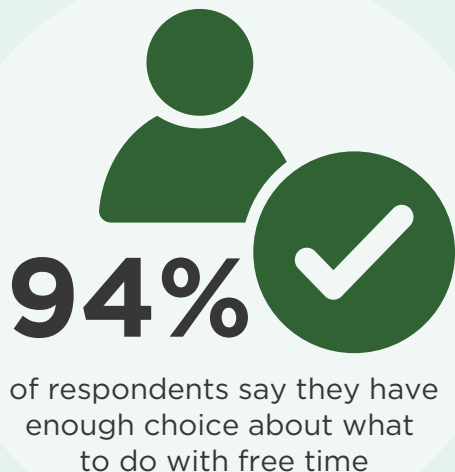**Employment is an important outcome** for many services users, and a key indicator of how well systems support people to have full access to their communities. Nationally, **just 16% of respondents have a paid job** in the community, with rates of community employment at state levels ranging from 8% to 41%. **Among those who do not have a paid community job, almost half want a job.** However, about one-third of those who want a job have an employment-related goal in their service plan, with state rates ranging from 6% to 66%. These data show there is significant room for improvement for systems to support service users in obtaining employment and ensuring person-centered plans reflect people's desires and goals.

47% No community job, but wants one

16% Has paid community job

35% Service plan has employment goal

CHOICE AND DECISION-MAKING

94% of respondents say they have enough choice about what to do with free time

90% say they can choose, have help deciding, or have set limits on what to buy with spending money

74% report they can change case manager or service coordinator if they want

63% say they chose staff or are aware they can request staff change
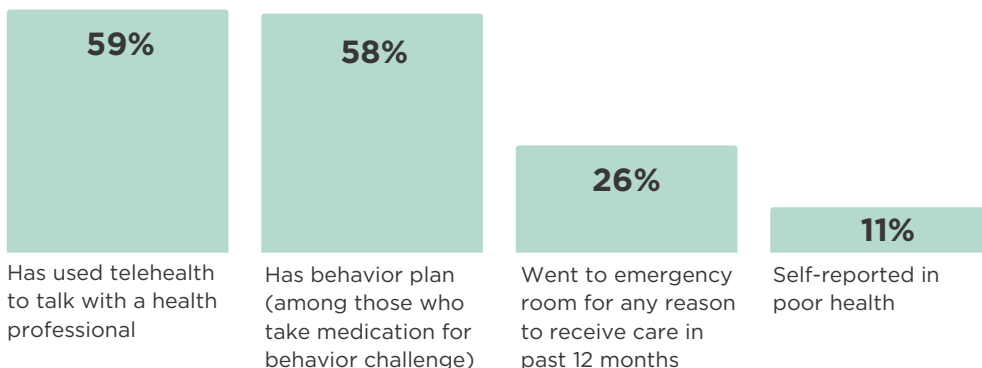
RIGHTS AND RESPECT

74% Report that staff are respectful of person's culture

40% Report that their staff changes too often

82% Report that others ask before coming in their bedroom

48% Report they can stay home if others go out (for those not living in own home or apartment)

HEALTH AND HEALTH CARE

59% Has used telehealth to talk with a health professional

58% Has behavior plan (among those who take medication for behavior challenge)

26% Went to emergency room for any reason to receive care in past 12 months

11% Self-reported in poor health

SATISFACTION

81% The percent of respondents who like how they usually spend their time during the day

INCLUSION AND ACCESS TO COMMUNITY

78%
are able to get places when they want to do something fun outside the home

69%
get to do things they like to do in the community as often as they want

68%
has friends (may be staff or family) and can see their friends in person when they want

26%
participate in groups, organizations, or communities (in-person or virtually)

90% say others include them as part of the group (among people who participate in groups organizations, or communities)

Community inclusion and belonging means that people can do things in their communities that they want to do and they feel like they belong to the communities of their choosing. The ability to do this is greatly impacted by access, and specifically whether services and support are available, accessible, and responsive to people's needs.

Looking at NCI-IDD outcomes related to access to and participation in communities, more than three-quarters report they have transportation to get places they want to go, and more than two-thirds are able to do things they like in the community as much as they want and see their friends when they want. However, **fewer people report taking part in groups, organizations, or communities**—states' rates range from 10% to 43%, with a national average of 26%. **Among those who did take part in groups, 90% felt included by others.**

These data suggest that although service users feel included by others, there is still room for improvement in how systems support service users to have more equitable opportunities for community engagement. It is important for LTSS systems to identify barriers to community access and participation.

PERSON-CENTERED PLANNING

People who use Medicaid funded HCBS have a right to a person-centered service plan. Several NCI-IDD outcomes examine person-centered planning and service coordination.

Across participating states, data from these outcomes show that 75% of users helped make their service plan and 95% report their service plan includes things that are important to them. However, about **1 out of every 5 people do not know who to talk to** if they want to change something about their services.

Together, these data underscore the importance of strengthening methods for person-centered planning.

95% say their service plan includes things that are important to them

91% say case manager/service coordinator knows what is important to them

86% say staff do things the way they want them done

82% say they know who to ask if they want to make changes to services

75% say they helped make their own service plan
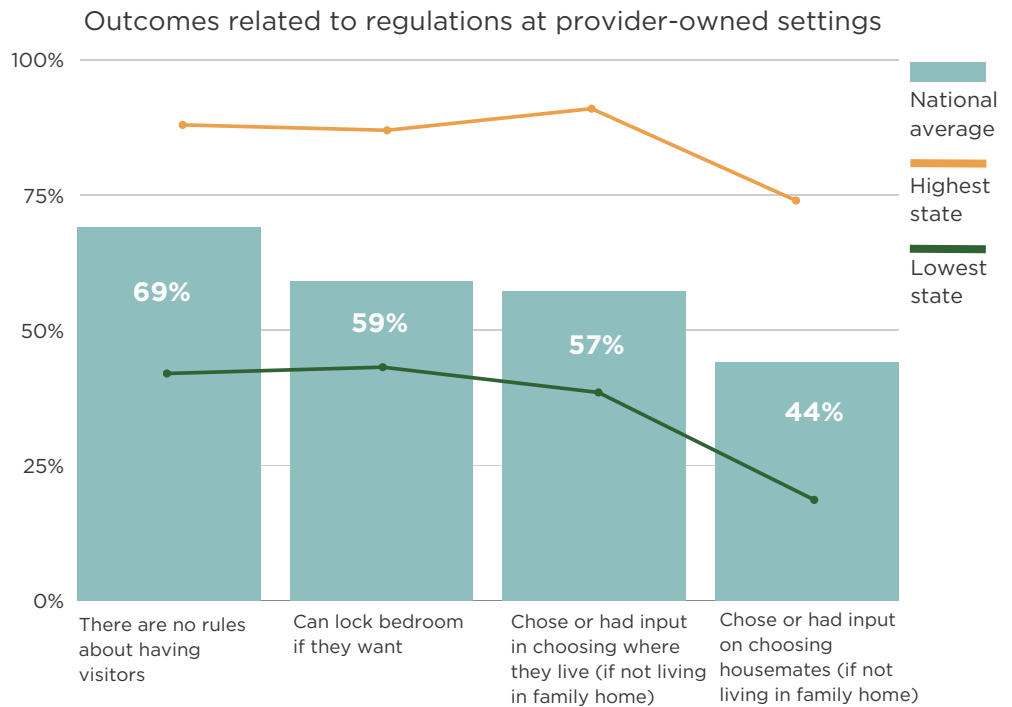
NCI IDD

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.

PROVIDER-OWNED SETTINGS

This graph shows responses to four NCI-IDD questions and reflect outcomes that are closely aligned with the HCBS Final Settings Rule regulations for provider-owned settings.
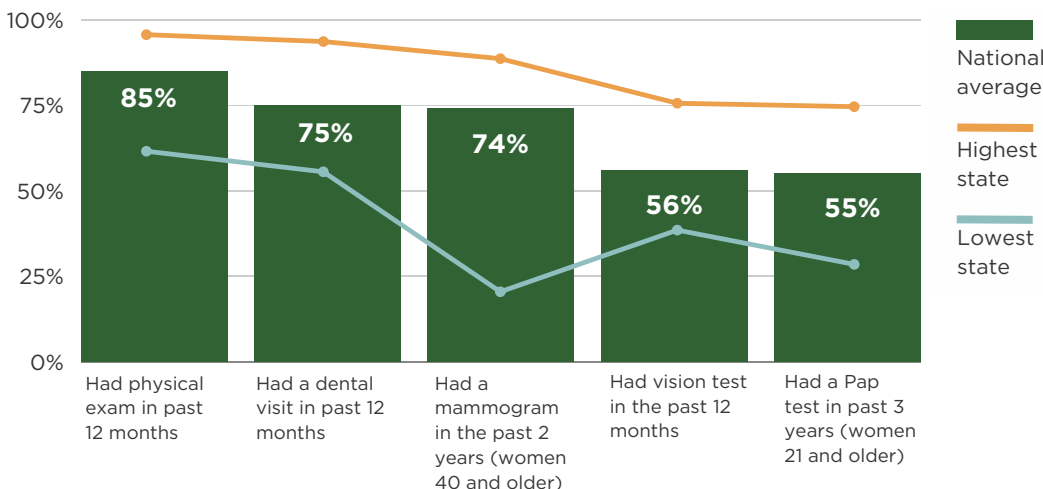
The **vertical bars show the national average for each outcome**; the two lines show the range of state average. These data indicate that while two-thirds of respondents report there are no rules about having friends or visitors in their home, just over half of respondents can lock their bedroom if they want. Further, **just 44% were able to choose or have input regarding who they live with**.

These data emphasize the importance of looking at a variety of indicators to understand systems performance towards HCBS Final Settings Rules, and where there are opportunities for performance improvement; in this case, there appears to be significant opportunity to improve choice and decision-making as it pertains to living environments.

Outcomes related to regulations at provider-owned settings

Legend:
- National average (teal bar)
- Highest state (orange line)
- Lowest state (dark green line)

Bar values: 69% (There are no rules about having visitors); 59% (Can lock bedroom if they want); 57% (Chose or had input in choosing where they live (if not living in family home)); 44% (Chose or had input on choosing housemates (if not living in family home))

ACCESS TO PREVENTATIVE HEALTH CARE

Setting ensures people receive services to the same degree of preventative care access as those not receiving Medicaid HCBS

Legend:
- National average (dark green bar)
- Highest state (orange line)
- Lowest state (light blue line)

Bar values: 85% (Had physical exam in past 12 months); 75% (Had a dental visit in past 12 months); 74% (Had a mammogram in the past 2 years (women 40 and older)); 56% (Had vision test in the past 12 months); 55% (Had a Pap test in past 3 years (women 21 and older))

In the graph at left, the vertical bars display the national average percent for each outcome, while **the lines show the highest and lowest state percent**.

The outcomes displayed here all focus on access to preventive health services in a recommended time frame (1 to 3 years, depending on the outcome). The percent reporting each outcome ranged between 55% and 85%, with wide spread across states, especially among women over 40 who had a mammogram in the past two years.

These data underscore that although systems are supporting the majority of service users to access annual physicals, nearly 1 in 2 people are not getting recommended vision and pap test screenings.