**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

**AGE AND GENDER**

42 years old (average)  
40% Female  
60% Male

**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%

**STATES INCLUDED**

*Note: Diagnoses are not mutually exclusive

**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

**RECEIVES MEDICARE**

42%

**MOBILITY**

75%

**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

*State samples vary from year to year. For details, visit: tinyurl.com/mpdnze5n*
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.

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.

HEALTH AND HEALTH CARE

- 59% have used telehealth to talk with a health professional.
- 58% have a 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.

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).

SATISFACTION

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

- 81%
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.
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.

ACCESS TO PREVENTATIVE HEALTH CARE

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

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.