

## DESCRIPTION OF THE SAMPLE

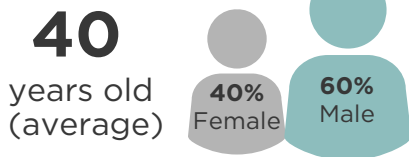
### INTRODUCTION

The survey data in this summary represent the population of adults with intellectual and developmental disabilities (IDD) receiving at least one service in addition to case management/ service coordination from their state developmental disability service system. For details, visit: <https://bit.ly/NCIFAQs>

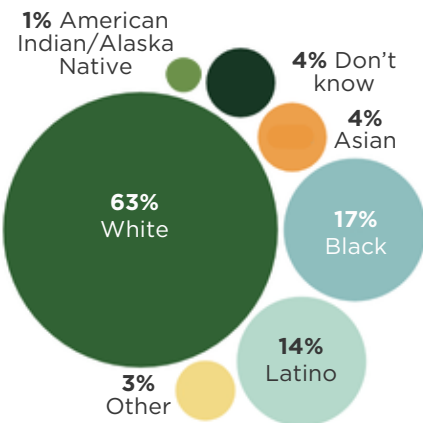
### SAMPLE SIZE

**25,424** total respondents

### AGE AND GENDER



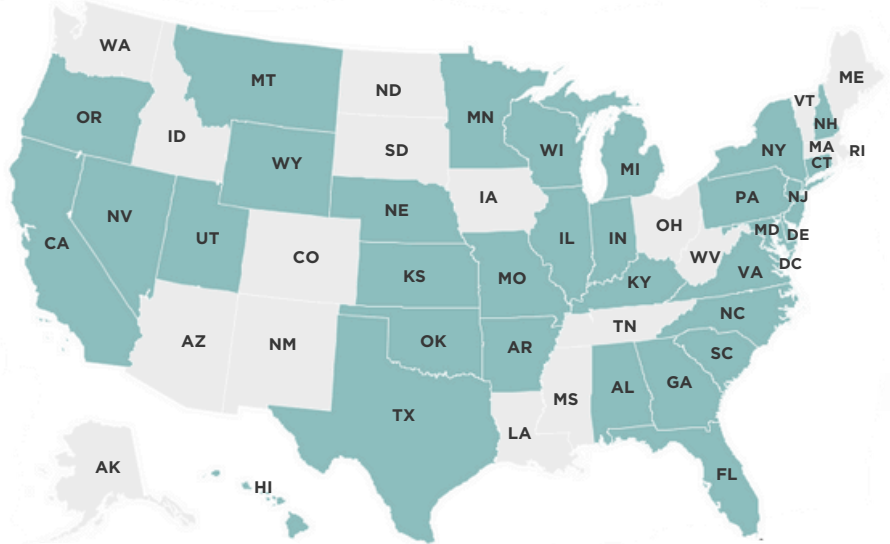
### RACE AND ETHNICITY



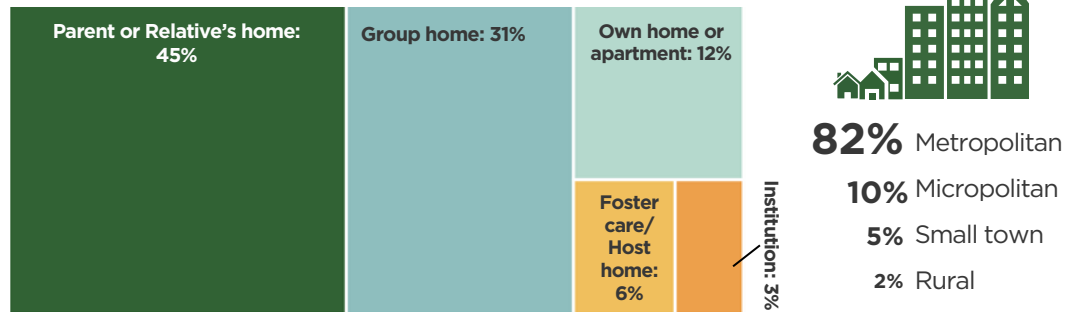
### RECEIVES MEDICARE



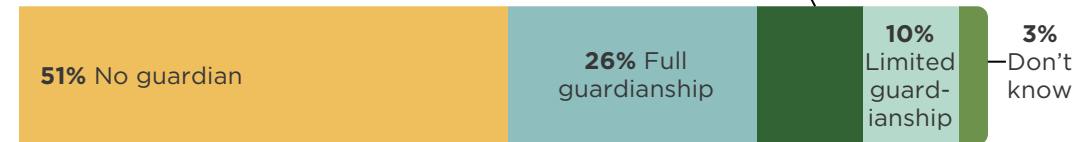
### STATES INCLUDED\*



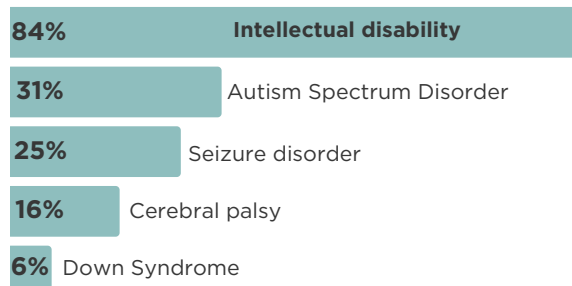
### RESIDENCE TYPE & LOCATION



### LEVEL OF GUARDIANSHIP

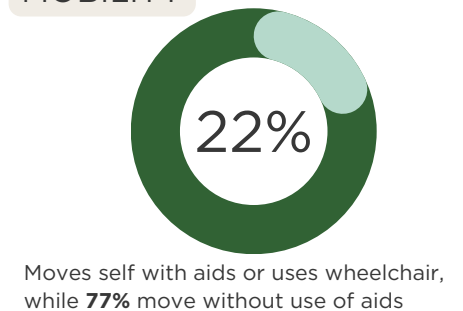


### DIAGNOSIS



Note: Diagnoses are not mutually exclusive

### MOBILITY



# 2022-23 DATA AT A GLANCE

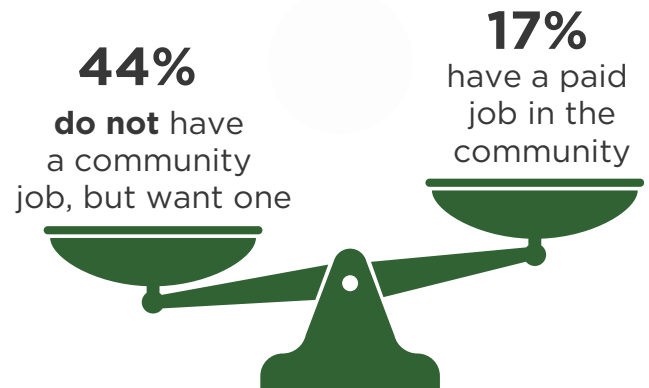
## OUTCOMES\*

### EMPLOYMENT

**Employment is an important outcome** for many services users, and a key signal of how well systems support people to have full access to their communities.

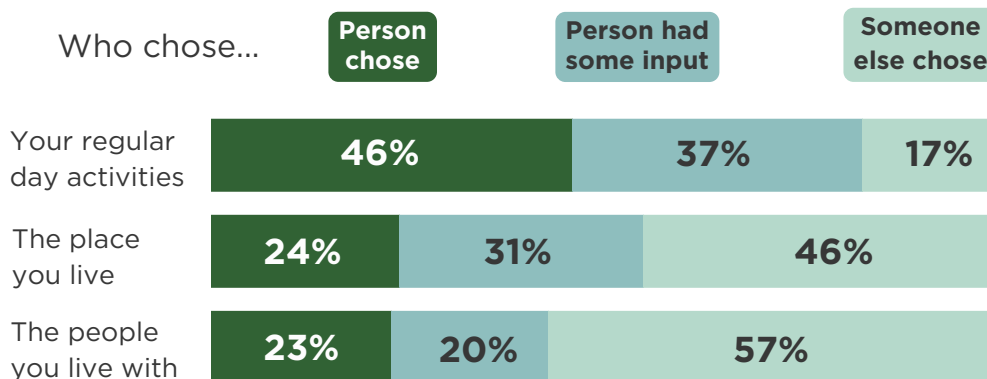
Nationally, **just 17% of respondents have a paid job** in the community. This ranges both across states *and* settings, with people who live on their own working in paid community jobs at **3 times higher** the rate of those who live in group homes. Those who work in paid community jobs spend, on average, **less than 15 hours per week** in those jobs.

Among those who do not have a paid community job, **almost half want a job**. However, just **25% of all respondents have a goal for employment in their service plan**. These data show systems can make lots of improvements to support service users in obtaining employment and ensuring person-centered plans reflect people's goals.



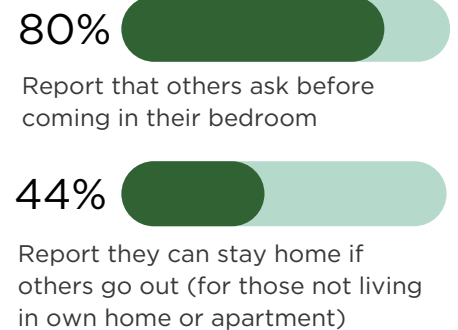
**\$10.42 to \$12.68:**  
average hourly wages (depending on setting)

### CHOICE AND DECISION-MAKING

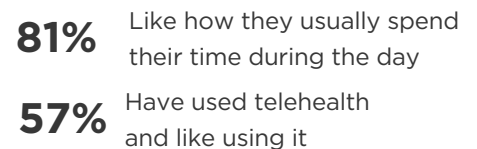


**18%** of respondents chose their staff, and **41%** had their staff assigned but can request a change

### RIGHTS AND RESPECT

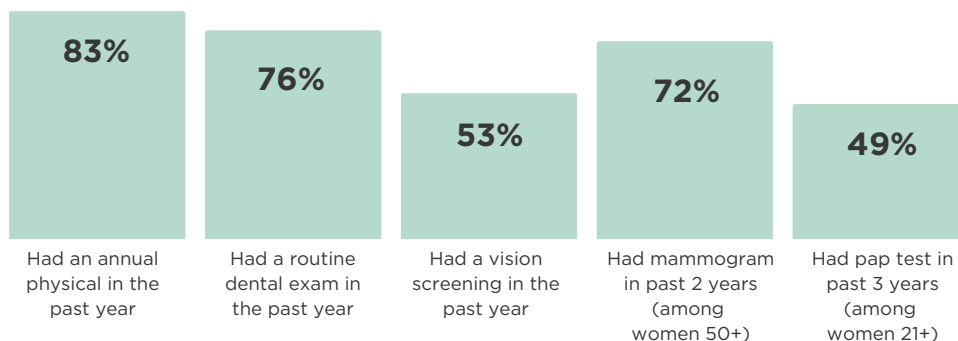


### SATISFACTION



The average respondent says they are **satisfied with their level of participation in at least 3 out of 5 community activities** (e.g., go shopping, go out for entertainment).

### ACCESS TO HEALTH CARE



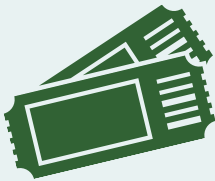
\* Note: NCI includes data on a variety of outcomes of service users. Data from key outcomes are presented here.

### INCLUSION AND ACCESS TO COMMUNITY



**80%**

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



**71%**

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 meet with their friends in person when they want



**37%**

want to be a part of more groups in their community

**Access to the community is considered a key feature of home and community-based services.** It is also connected to inclusion and belonging for people who use services.

Looking at NCI-IDD outcomes related to access to community and broader feelings of inclusion, more than **2 out of every 3 respondents** say they have transportation, can do things in the community as often as they want, and have friends they can meet with. However, there are **large differences between states** in these measures. For example, there are states in which fewer than 1 out of every 2 people can do things they like in the community as often as they want. Further, there often **differences in access to community and inclusion outcomes by residence type.**

These data suggest that there is still room to **improve community engagement.** It is important for LTSS systems to identify barriers to community access and participation.

### SERVICE COORDINATION & SELF-DIRECTION

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. These data highlight areas of opportunity to **strengthen methods for person-centered planning and enhancing opportunities for self-direction.**

**93%**

say their service plan includes things that are important to the person

**75%**

say they helped make their service plan

**86%**

say staff do things the way the person wants them done

**40%**

say their staff change too often

**17%**

use a self-directed supports option

**Who makes decisions about the services that are self-directed?**



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

# 2022-23 DATA AT A GLANCE

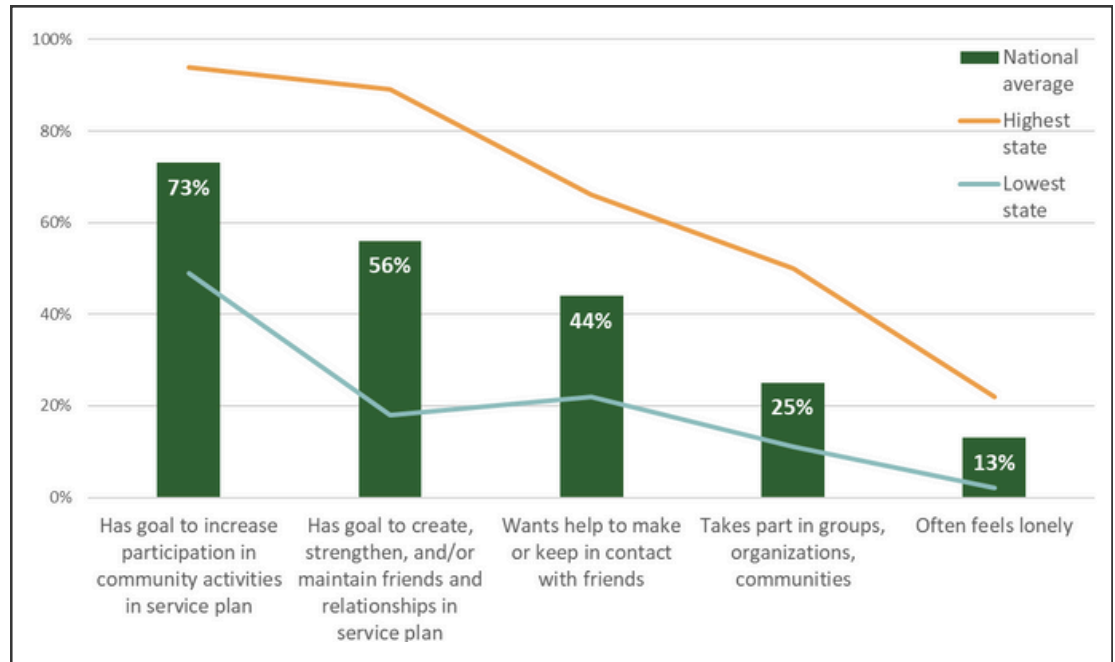
## OUTCOMES: MENTAL HEALTH AND SOCIAL CONNECTION

### SOCIAL CONNECTION

While the HCBS Settings Final Rule may specify rules around access to community, the long-term goal is to ensure that all people have **social connections that are rewarding and meaningful** to them.

Several NCI-IDD measures can be used to explore the **goals for social connection** among people who use services, and to what extent those **goals are met**.

The graph at right shows the national average and the spread between states in several NCI-IDD measures of social connection:



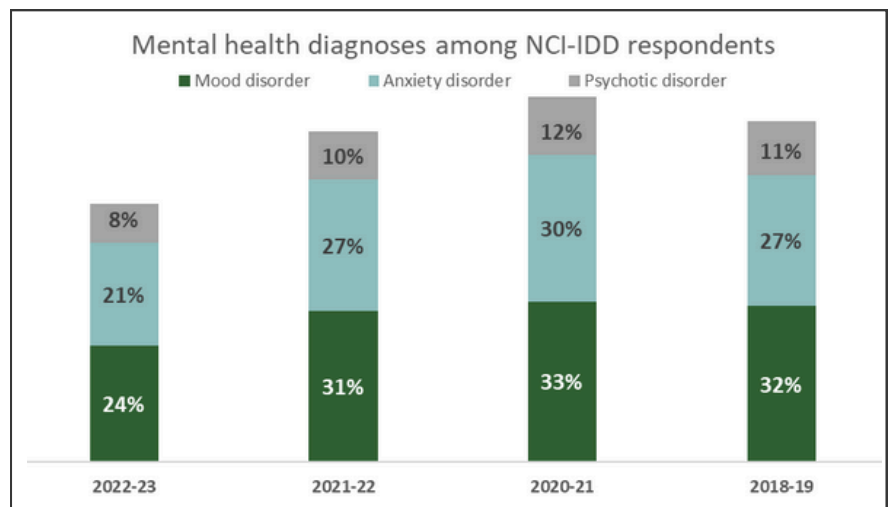
- **3 out of every 4 participants have a goal to increase participation** in their community, but just **1 out of every 4 participants take part in groups, organizations or communities**.
- Just over **half of participants (56%) have a goal related to relationships**, and nearly **half of participants (44%) want help making or keeping in contact with friends**.

Most notably, among those who want to be a part of more groups in their community, just 2 out of 3 have a goal in their service plan to increase community participation. These data emphasize the importance of **ensuring that service plans reflect the goals related to social connection among people who use services, and that services are provided to support meaningful social connections**.

### MENTAL HEALTH

**Social connection has strong ties to mental health.** NCI-IDD data confirms research that finds **high rates of co-occurring mental health conditions among people with IDD**. The graph to the right shows the rates of mood disorder, anxiety disorder, and psychotic disorder among NCI-IDD respondents.

The data show there may be a slight trend in decreasing rates of co-occurring mental health conditions since 2018-2019. Of note, the percent of respondents **taking at least one medication** for mood, anxiety, and/or psychotic disorders has remained relatively consistent at around **50% of all NCI-IDD participants since 2018-2019**.



Altogether, these data highlight the need for **better supports for people with IDD and co-occurring mental health conditions**.

Since 2022, the LINK Center has been working to bridge IDD and Mental Health Systems. To learn more, go to: <https://acl.gov/TheLinkCenter>