2022-23 DATA AT A GLANCE
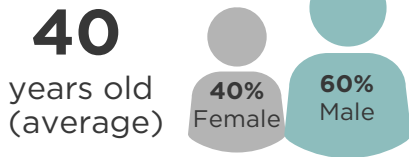
DESCRIPTION OF THE SAMPLE

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
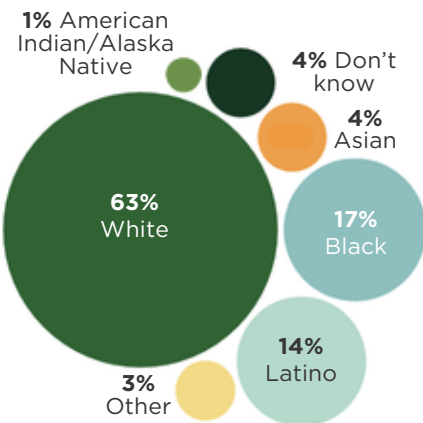
SAMPLE SIZE

25,424 total respondents

AGE AND GENDER

40 years old (average)

40% Female
60% Male

RACE AND ETHNICITY

1% American Indian/Alaska Native
4% Don't know
4% Asian
63% White
17% Black
3% Other
14% Latino

RECEIVES MEDICARE

47%

STATES INCLUDED*

WA, MT, ND, MN, ME, OR, ID, SD, WI, MI, VT, NH, NY, MA, CT, RI, WY, IA, PA, NJ, CA, NV, UT, NE, IL, IN, OH, MD, DE, CO, KS, MO, KY, WV, VA, DC, AZ, NM, OK, AR, TN, NC, SC, MS, AL, GA, TX, LA, AK, HI, FL
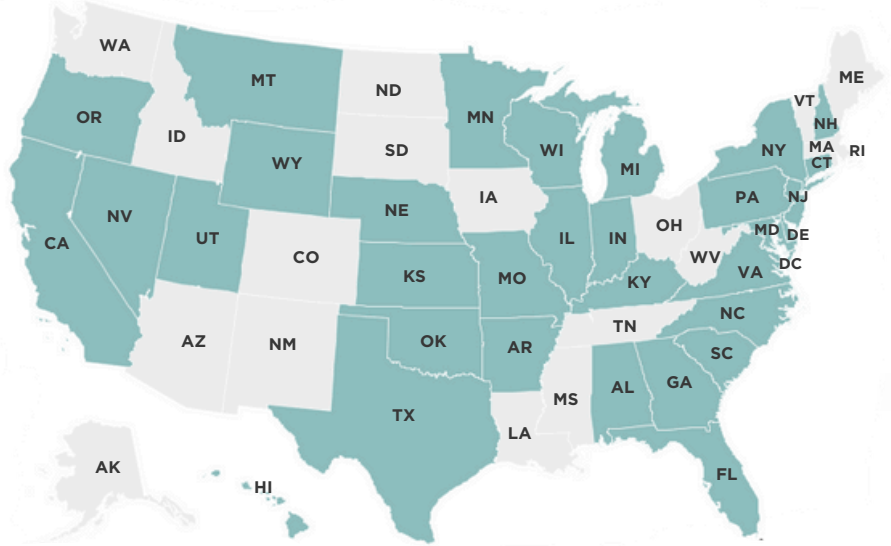
RESIDENCE TYPE & LOCATION

Parent or Relative's home: 45%
Group home: 31%
Own home or apartment: 12%
Foster care/ Host home: 6%
Institution: 3%

82% Metropolitan
10% Micropolitan
5% Small town
2% Rural

LEVEL OF GUARDIANSHIP

11% Has guardian but level unknown

51% No guardian
26% Full guardianship
10% Limited guardianship
3% Don't know

DIAGNOSIS

84% Intellectual disability
31% Autism Spectrum Disorder
25% Seizure disorder
16% Cerebral palsy
6% Down Syndrome
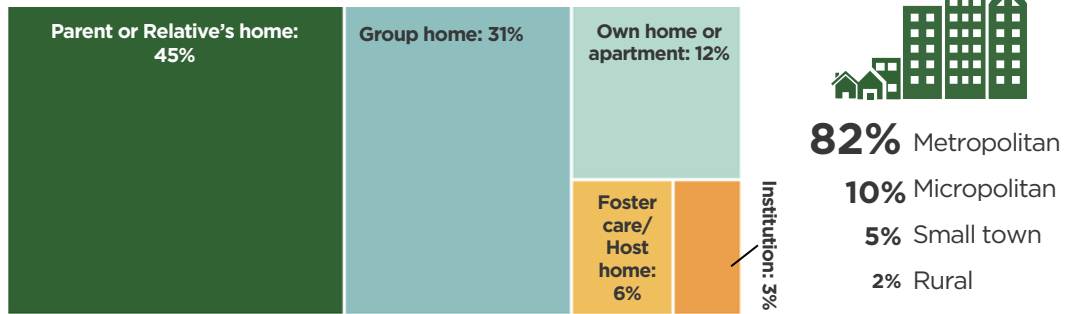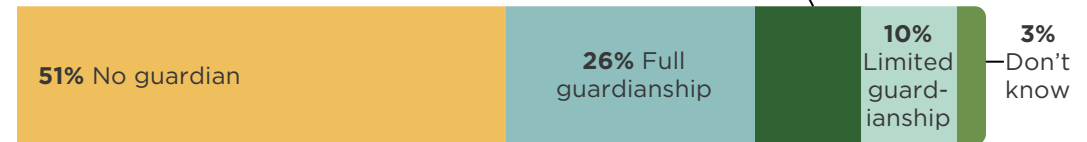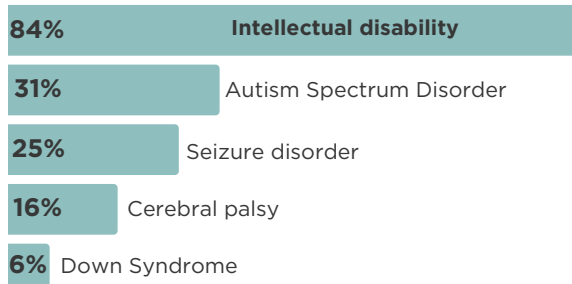
Note: Diagnoses are not mutually exclusive

MOBILITY

22%

Moves self with aids or uses wheelchair, while **77%** move without use of aids
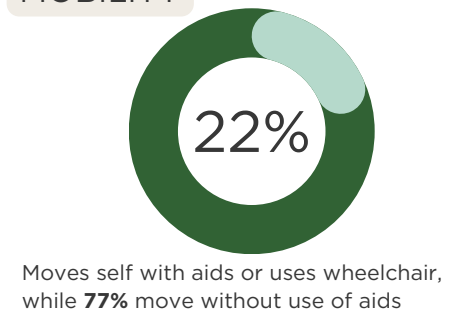
* Note: State samples vary from year to year. For details, visit: https://bit.ly/IPS2223StateSample
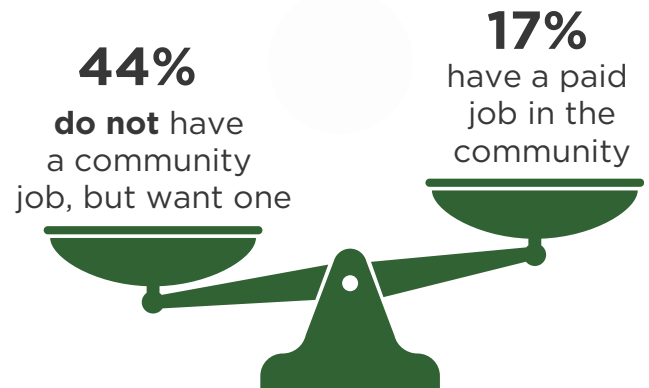
2022-23 DATA AT A GLANCE

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.
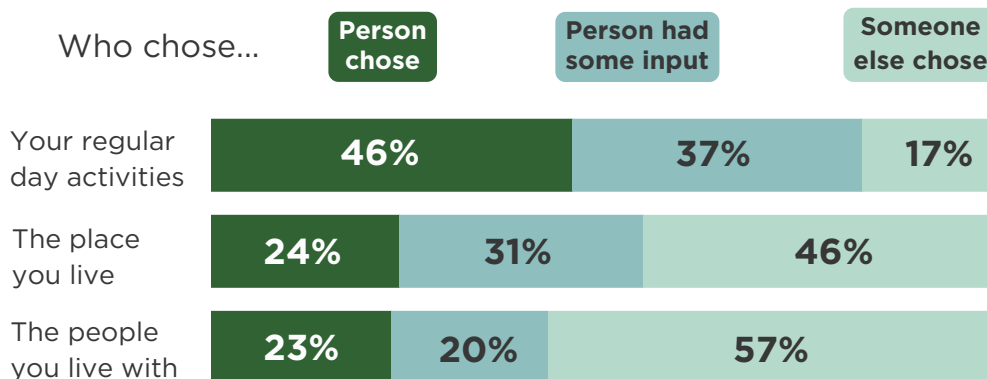
Nationally, **just 17% of respondents have a paid job** in the community. This ranges both across states *and* settings, with people who live on their own working in paid community jobs at **3 times higher** the rate of those who live in group homes. Those who work in paid community jobs spend, on average, **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.
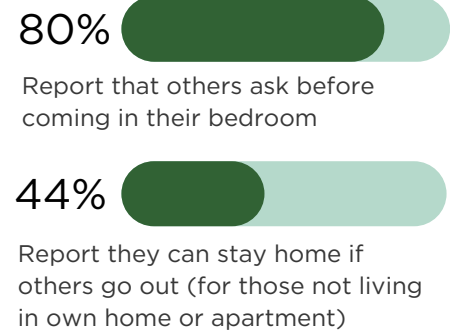
44% **do not** have a community job, but want one

17% have a paid job in the community

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

CHOICE AND DECISION-MAKING

Who chose...

	Person chose	Person had some input	Someone else chose
Your regular day activities	46%	37%	17%
The place you live	24%	31%	46%
The people you live with	23%	20%	57%

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

ACCESS TO HEALTH CARE

83%	76%	53%	72%	49%
Had an annual physical in the past year	Had a routine dental exam in the past year	Had a vision screening in the past year	Had mammogram in past 2 years (among women 50+)	Had pap test in past 3 years (among women 21+)

RIGHTS AND RESPECT

80% Report that others ask before coming in their bedroom

44% Report they can stay home if others go out (for those not living in own home or apartment)

SATISFACTION

81% Like how they usually spend their time during the day

57% Have used telehealth and like using it
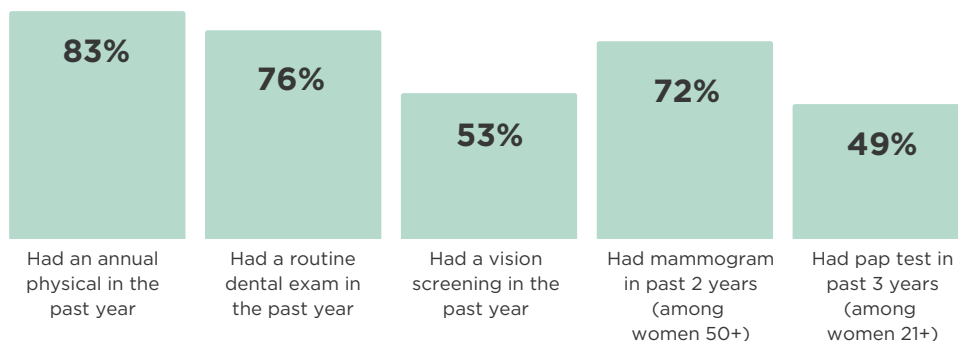
The average respondent says they are **satisfied with their level of participation in at least 3 out of 5 community activities** (e.g., go shopping, go out for entertainment).

* 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

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?

Someone else decides, 45%

Person has input, 40%

Person mostly decides, 15%

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

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:
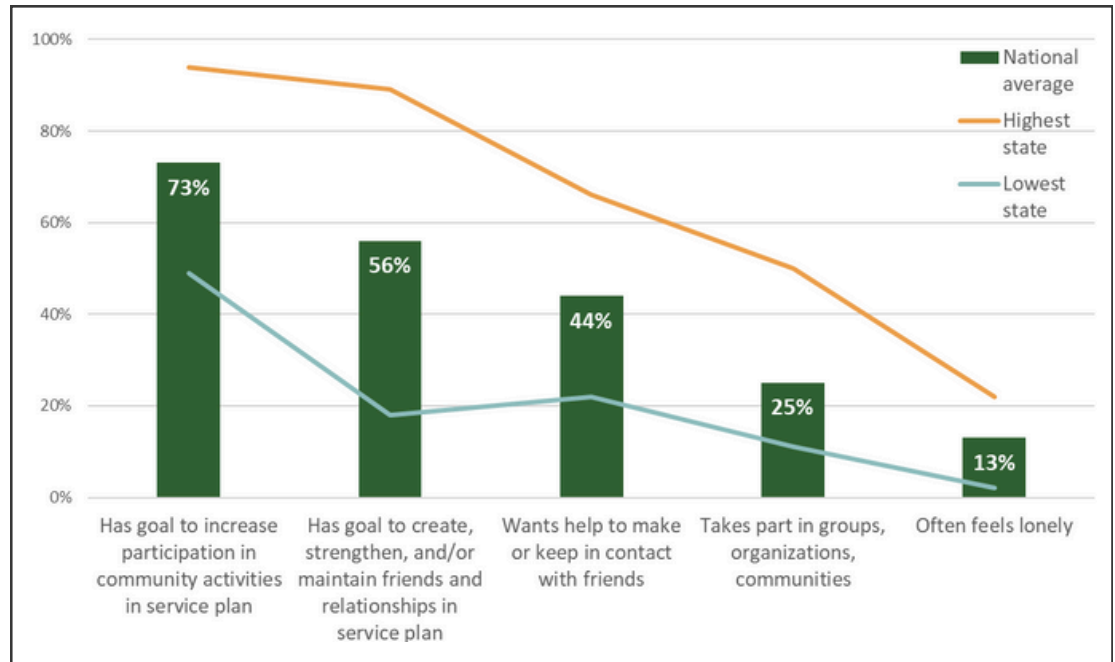

- **3 out of every 4 participants have a goal to increase participation** in their community, but just **1 out of every 4 participants take part in groups, organizations or communities**.
- Just over **half of participants (56%) have a goal related to relationships**, and nearly **half of participants (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.**
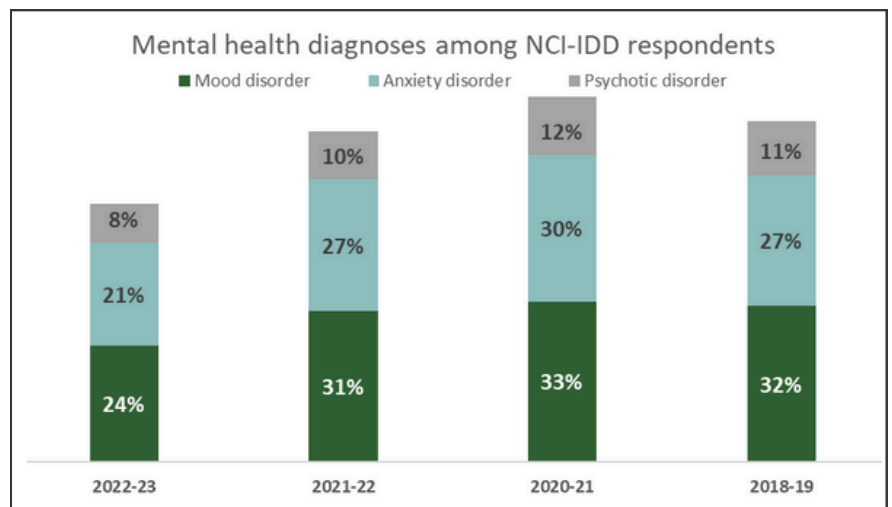
Altogether, these data highlight the need for **better supports for people with IDD and co-occurring mental health conditions.**

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