



NCI-IDD™ In-Person Survey

2023-24 DATA AT A GLANCE

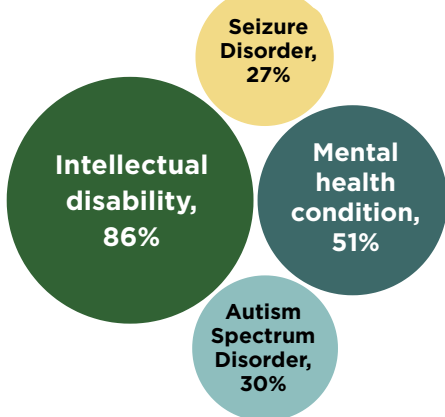
DESCRIPTION OF THE SAMPLE

INTRODUCTION

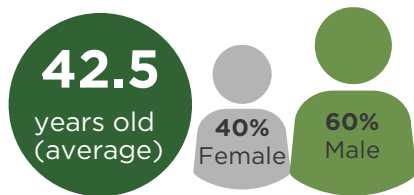
The survey data in this summary represent the population of adults with intellectual and developmental disabilities (IDD) receiving at least one service in addition to case management/ service coordination from their state developmental disability service system. For details, visit: <https://bit.ly/NCIFAQs>

DIAGNOSIS

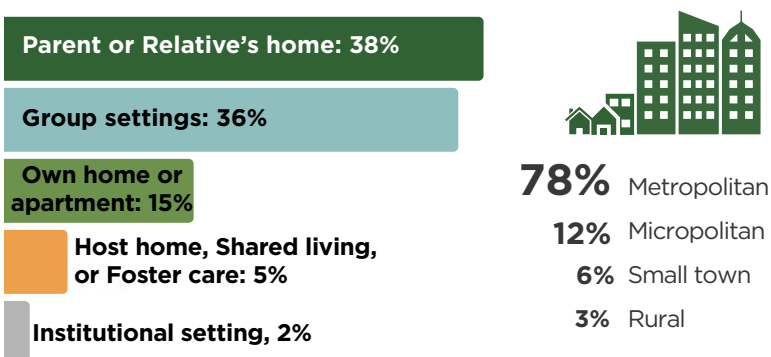
Note: Diagnoses are not mutually exclusive



AGE AND GENDER

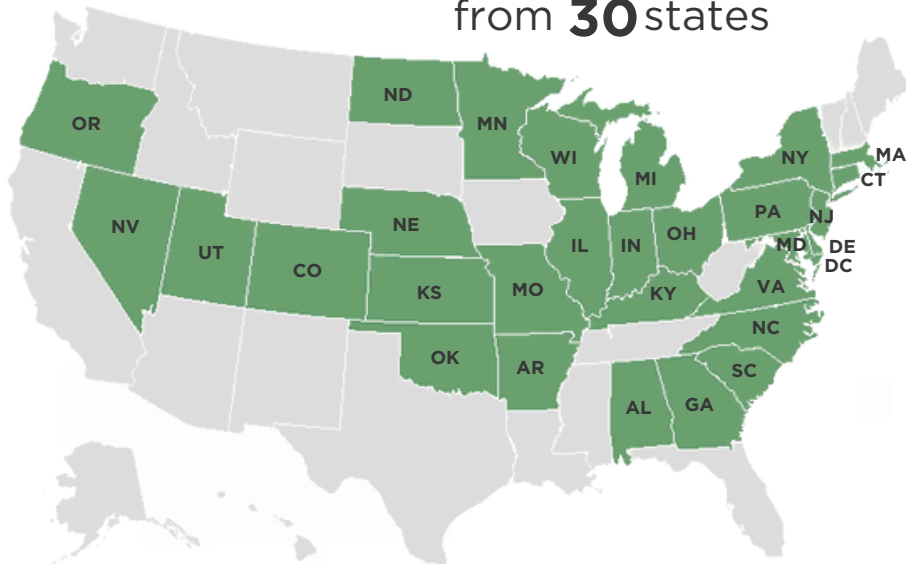


RESIDENCE TYPE & LOCATION



SAMPLE

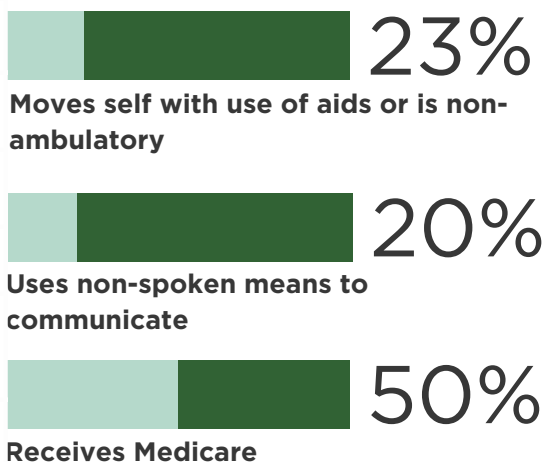
17,585 total respondents from **30** states



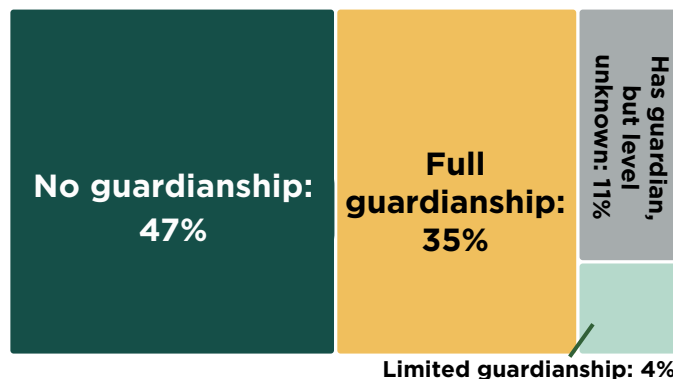
RACE AND ETHNICITY

72% White
19% Black or African American
6% Hispanic or Latino
2% Asian
1% American Indian/Alaska Native
3% Other/Don't know

OTHER CHARACTERISTICS



LEVEL OF GUARDIANSHIP



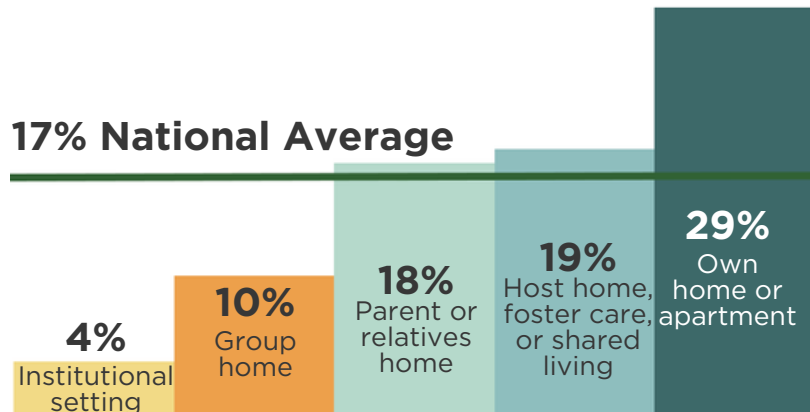
2023-24 DATA AT A GLANCE

OUTCOMES

EMPLOYMENT

17% of respondents have a paid job in the community.

The figure below shows the percent of people with paid jobs by type of residence. Those who live on their own work at rates **3 times higher** than those who live in group homes.



Biweekly hours and wages vary by type of paid community job. Those working individual jobs with publicly funded supports:



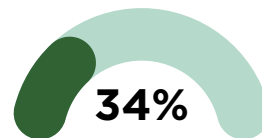
29.2 hours
worked over 2 weeks



\$16.01:
average hourly wages

42% Of those who do not have a paid community job want one

Among those who want to work and do not currently have a job, **34% have a goal for employment in their service plan.**



INCLUSION AND ACCESS TO COMMUNITY



71% can do things in the community as much as they want to



81% can do things in the community with the people they want



28% take part in groups, organizations, or communities



35% want to be part of more groups in their community



80% are able to get places when they want to do something outside their home



94% have a way to get places they need to go (like work, appointments)

RELATIONSHIPS

78%

Have friends who are not staff or family

69%

Can meet with their friends in person when they want

55%

Want help to make new friends or keep in contact with friends

12%

Often feel lonely

DATA SUMMARY



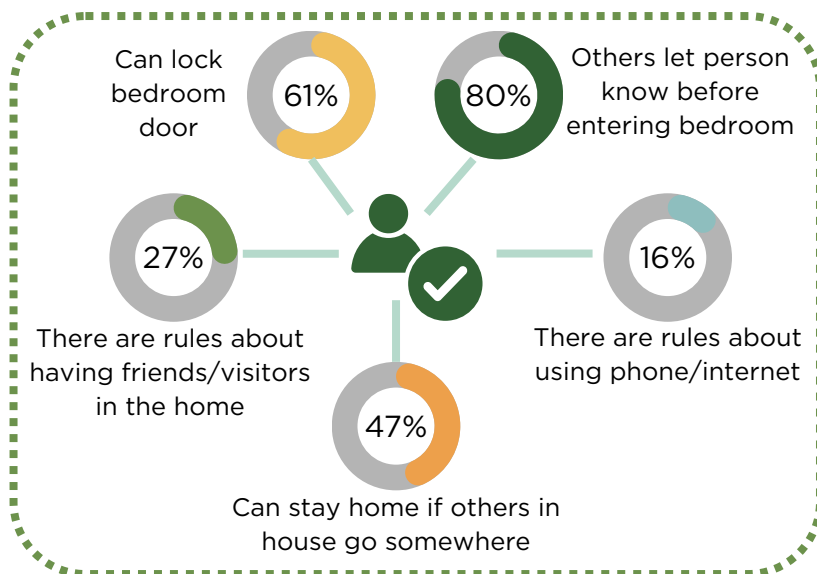
Access to the community is considered a key feature of home and community-based services. Many of these outcomes vary widely across states, as well as by residence type (e.g., group homes or with family). Overall, the majority of IPS respondents indicate they have transportation, relationships, and access to the community. However, few people with IDD work in paid community jobs and take part in community groups. *In fact, for every 1 IPS respondent who works, there are nearly 3 respondents who are unemployed but wish to work.* **These data suggest that systems can better identify barriers to community participation, and leverage person-centered planning to support people with IDD to engage in communities in the ways they want.**

2023-24 DATA AT A GLANCE

OUTCOMES

CHOICE, RIGHTS AND RESPECT

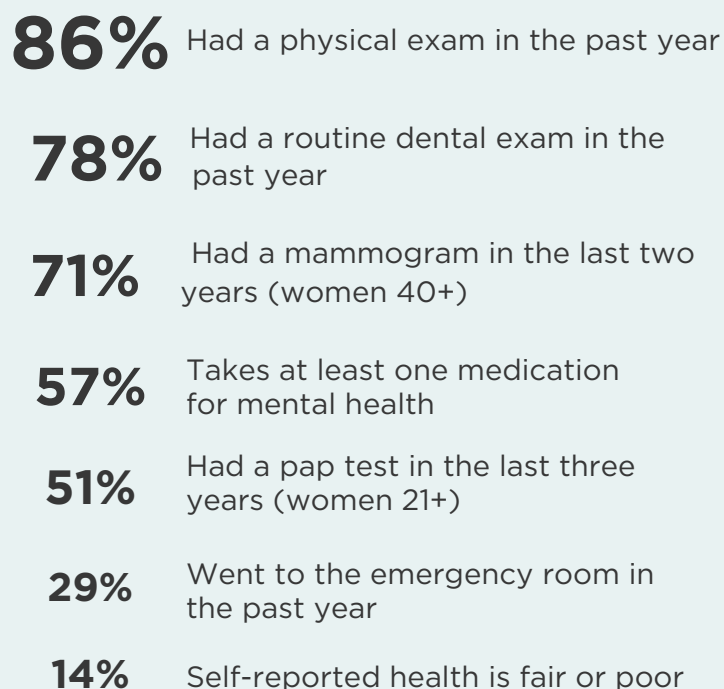
IPS respondents who had at least some input into key life decisions:



SERVICE COORDINATION AND WORKFORCE



HEALTH AND ACCESS TO HEALTHCARE



DATA SUMMARY



Services provided through state DD systems must be person-centered. The majority of IPS respondents helped make their service plan, and an average of 3 in 5 respondents have at least some input in choices about key aspects of their services, like the place they live, the people they live with, and the day programs they attend. In addition, IPS respondents have relatively high levels of preventive healthcare use, but nearly 1 in 3 respondents went to the ER in the past year and more than 1 in 10 describe their health as fair or poor. **These data highlight areas of opportunity to strengthen person-centered care, enhance opportunities for choice and control over services, and enable service providers to support wellbeing of people with IDD.**

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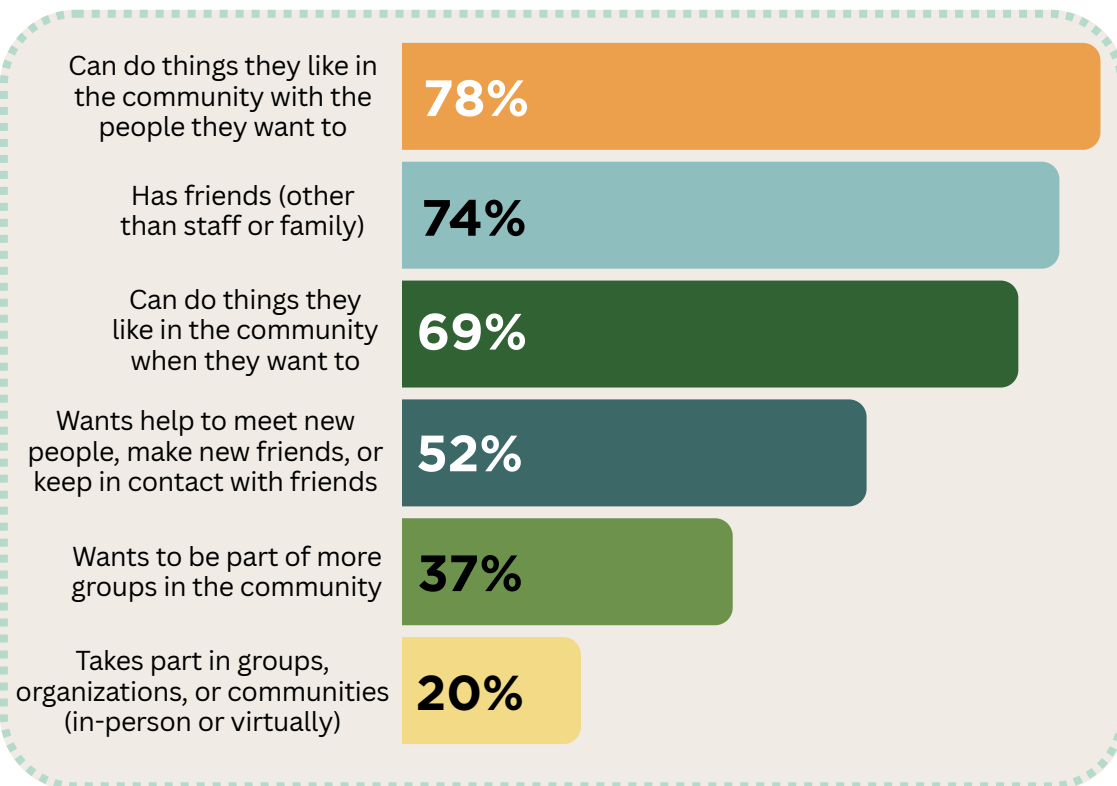
OUTCOMES: OLDER ADULTS WITH IDD

COMMUNITY LIVING

People with IDD are living longer than ever before, and they may require additional supports to equitably participate in their communities. The graph to the right shows several indicators of **community participation and relationships among adults with IDD age 65+.**

The majority of older adults do the community activities they enjoy when they want and with the people they want. **However, just 1 in 5 older adults take part in groups in the communities, and 1 in 3 want to take part in more groups in their community.**

Community participation and relationships among adults with IDD age 65+



Compared to adults with IDD 18-64, older adults with IDD have much lower rates of taking part in groups in the community and having friends other than staff or family. It is important for service providers and states to understand what **barriers older adults experience to having meaningful engagement in their communities, and the supports they need to sustain friendships and participation as they age.**

HEALTH AND HEALTHCARE USE



Among people with IDD age 65 and older:

- Nearly 1 in 10 have **Alzheimer's or dementia (9%)**
- 6 in 10 have at least one **mental health condition (60%)** such as anxiety or depression
- Almost 2 in 10 say their **health is fair or poor (17%)**

These data show the elevated risk for long-term poor health outcomes, and highlights areas that **older adults with IDD may need additional supports to promote wellbeing.**

Compared to adults with IDD 18-64, older adults with IDD have similar or higher rates of preventive healthcare use. At the same time, **older adults with IDD have much higher rates of ER visits and falls,** which can pose challenges for community living.

