

Sarah Taub Memorial Webinar



What did we learn from National Core Indicators® about the demographics and outcomes of LTSS users in 2021-22?

Human Services Research Institute

Dorothy Hiersteiner (dhiersteiner@hsri.org)

Stephanie Giordano (sgiordano@hsri.org)

NASDDDS

Laura Vegas (LVegas@nasddds.org)

ADvancing States

Rosa Plasencia (rplasencia@advancingstates.org)

Webinar logistics

- **All participants are muted. You can use the Q&A to communicate with hosts, or post questions in the Q&A.**
- **We are recording this webinar and will share the recording and slides after the webinar.**
- **This webinar will be live captioned in English and live interpreted in Spanish.**
 - Live English captions can be accessed by clicking the “CC” button at the bottom of your zoom screen.
 - Live Spanish interpretation can be accessed by clicking the “interpretation” button at the bottom of your Zoom screen (world icon). Once in the Spanish channel, please silence the original audio.
 - Se puede acceder a la interpretación en español en vivo haciendo clic en el botón "interpretation" en la parte inferior de la pantalla de Zoom (icono del mundo). Una vez en el canal español, por favor silencie el audio original.

Agenda

Welcome and tribute to Sarah Taub

Introduction to National Core Indicators

Characteristics of NCI samples

2021-2022 In Review:

- Person-centered planning
- Community Participation and Employment
- Healthcare
- HCBS Settings Rule
- Staffing

Implications and future directions

Sarah Taub

- Sarah Taub was the National Core Indicators Director until 2013 when her life was cut short by an aggressive cancer.
- Her sense of mission and purpose was an essential part of the growth of NCI to the prominence it has today.
- She was a fierce advocate for people with disabilities, and for their representation at all levels in the work we do. She never let us forget the people behind the numbers.



Presenters



Val Bradley



Stephanie Giordano



Dorothy Hiersteiner



Rosa Plasencia



Laura Vegas

Special thanks to Lindsay DuBois, the driving force behind this webinar and to Saska Rajcevic for assisting with logistics.

National Core Indicators®

Helping states examine the outcomes of human service systems since 1997



National Core Indicators



Established

- 1997 NCI-IDD
- 2015 NCI-AD



Participating states

- 48 NCI-IDD
- 23 NCI-AD



Population addressed




- People with IDD
- Older adults
- People with physical disabilities
- Workforce



Covers multiple domains

- Hears directly from people receiving services
- State of the Workforce Survey

Goals of NCI

		
<p>Establish a nationally recognized set of performance and outcome indicators for aging & disability (including IDD) service systems</p>	<p>Use valid and reliable data collection methods & statistical techniques to capture information directly for people who use services</p>	<p>Report individual state results and national benchmarks of indicators of system-level performance</p>

NCI-IDD In-Person Survey (IPS) & NCI-AD Adult Consumer Survey (ACS)



Sampling: States design their samples with guidance from HSRI. Final samples must reach threshold of 95% confidence level and 5% margin of error based on sample frame.

Inclusion criteria:

- IDD: Person receiving at least one service in addition to case management
- AD: Person receiving one “active service” at least twice a week

Consent: Surveyors follow state specific consent requirements

- Those who are surveyed are informed that their services will not be impacted directly by their responses

Surveyor training: All surveyors complete standardized training. IPS uses peer-surveyors as well.

Survey features:

- May be conducted in-person or remotely
- Includes detailed Background Information section that primarily comes from existing records
- Surveys are available in multiple languages
- Questions may be rephrased or reworded
- Allows for use of proxy for select questions

NCI-IDD Family Surveys



Mail out surveys designed to understand the experience of families of people receiving DD system services

Information is answered by the **family or guardian** of the person receiving at least **one service in addition to case management**

Three surveys:

- Adult Family Survey (AFS) – sent to families who *live with* the person with IDD
- Family Guardian Survey (FGS) – sent to families who *do not live with* the person with IDD
- Child Family Survey (CFS) – sent to families who *live with* a child with IDD

NCI Reporting



Data collected through NCI are reported annually through national and state reports

National reports show state outcomes compared to national norms

- IPS report also breaks out data by residence setting
- ACS report also breaks out data by program

NCI also produces supplemental reports to dig deeper into specific topic areas

NCI-IDD IPS Sample

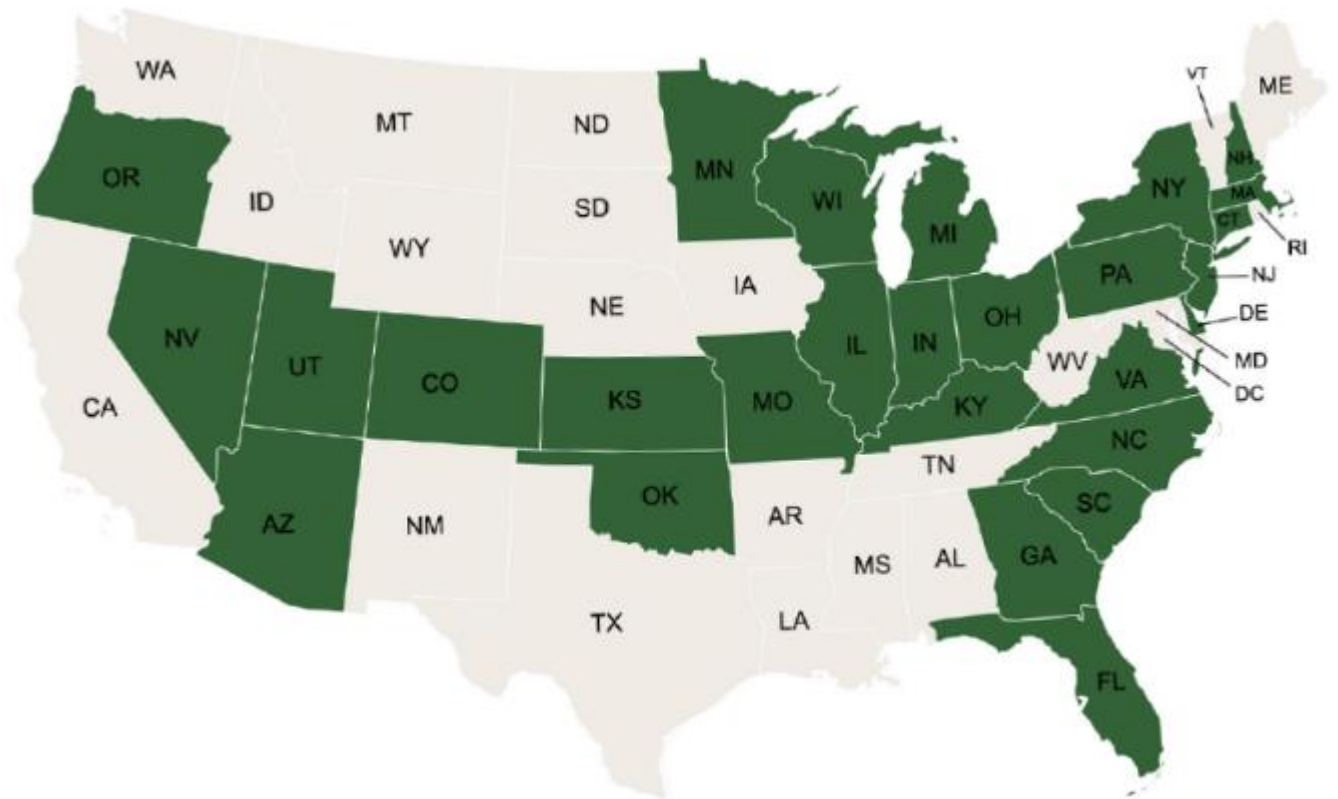
25 states represented

13,559 total respondents

42 Average Age

60% Male

87% Have IDD Diagnosis



NCI-IDD Family Survey Samples



Adult Family Survey

- **12** states
- **11,989** respondents
- Family member with IDD:
 - **35** average age
 - **59%** male
 - **66%** have ID diagnosis



Family/Guardian Survey

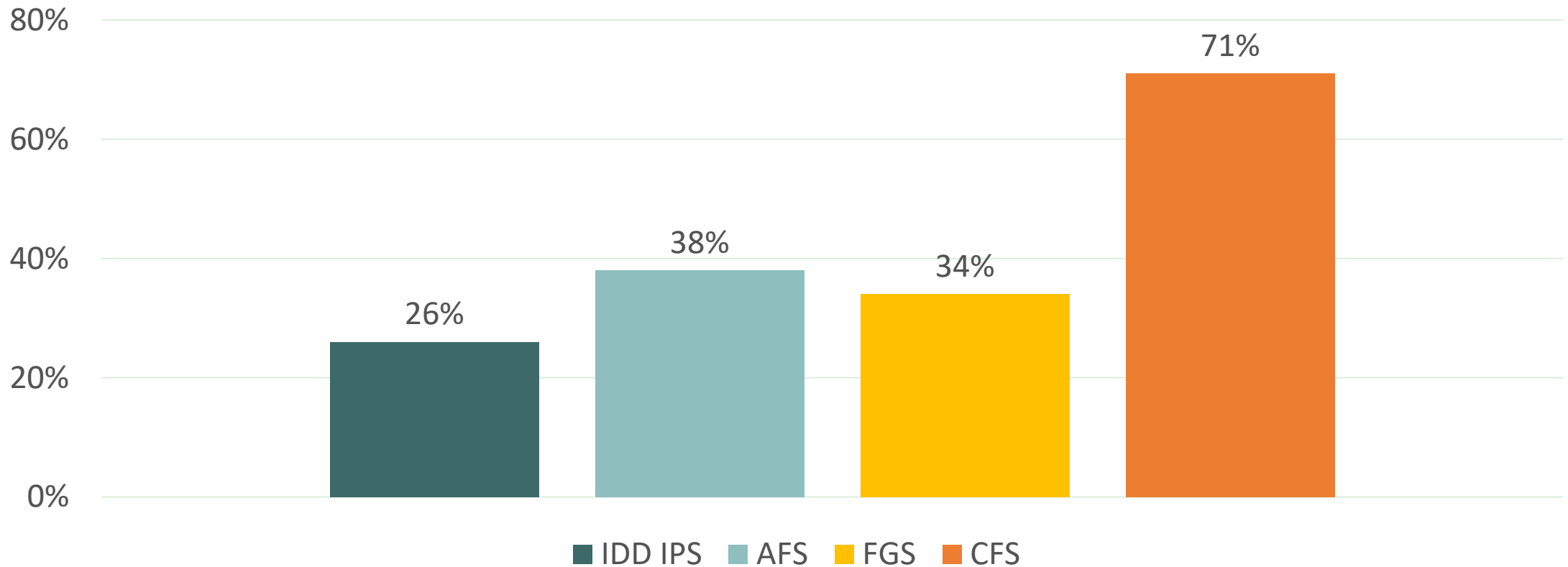
- **10** states
- **8,050** respondents
- Family member with IDD:
 - **45** average age
 - **60%** male
 - **74%** have ID diagnosis



Child Family Survey

- **8** states represented
- **7,902** respondents
- Child member with IDD:
 - **11** average age
 - **71%** male
 - **34%** have ID diagnosis

Has ASD diagnosis by IDD Survey



**IPS data are from person's records; AFS, FGS, and CFS are self-reported by the respondent about their family member receiving services*

NCI-AD ACS Sample

15 states represented

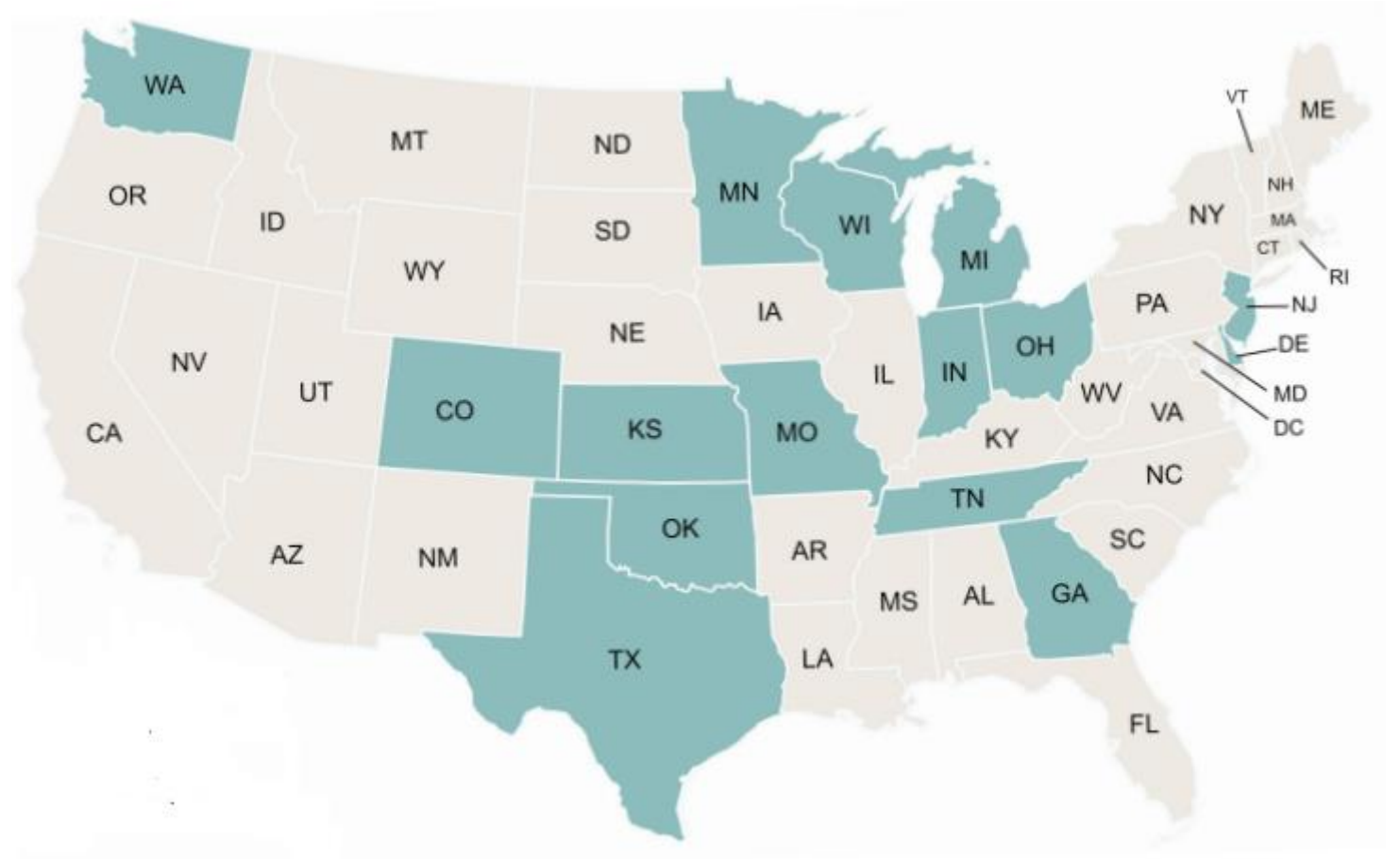
13,663 total respondents

67 Average Age

32% Male

69% 60 and older

70% Have physical disability



The majority of NCI-IDD IPS and NCI-AD ACS respondents are White. At about one-fifth of respondents, the next highest proportion are Black.

Hispanic or Latino
5% IPS
9% ACS

Asian
2% IPS
5% ACS

American Indian or Alaskan Native
1% IPS
2% ACS

Other
2% IPS
2% ACS

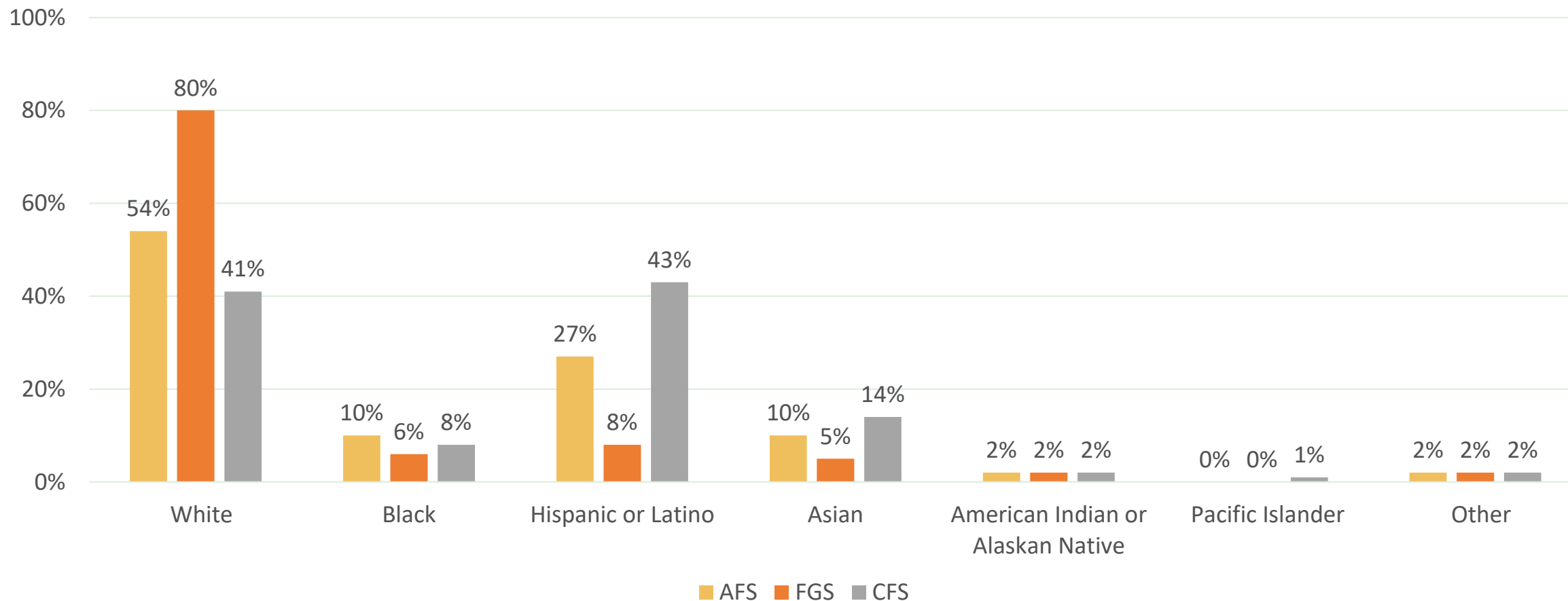
Black
16% IPS
23% ACS

White
71% IPS
60% ACS



Respondents to the AFS and CFS reported greater diversity among their family members with DD compared to FGS

NCI-IDD Family Surveys: Race and Ethnicity of Family Members with DD (Reported by Respondent)

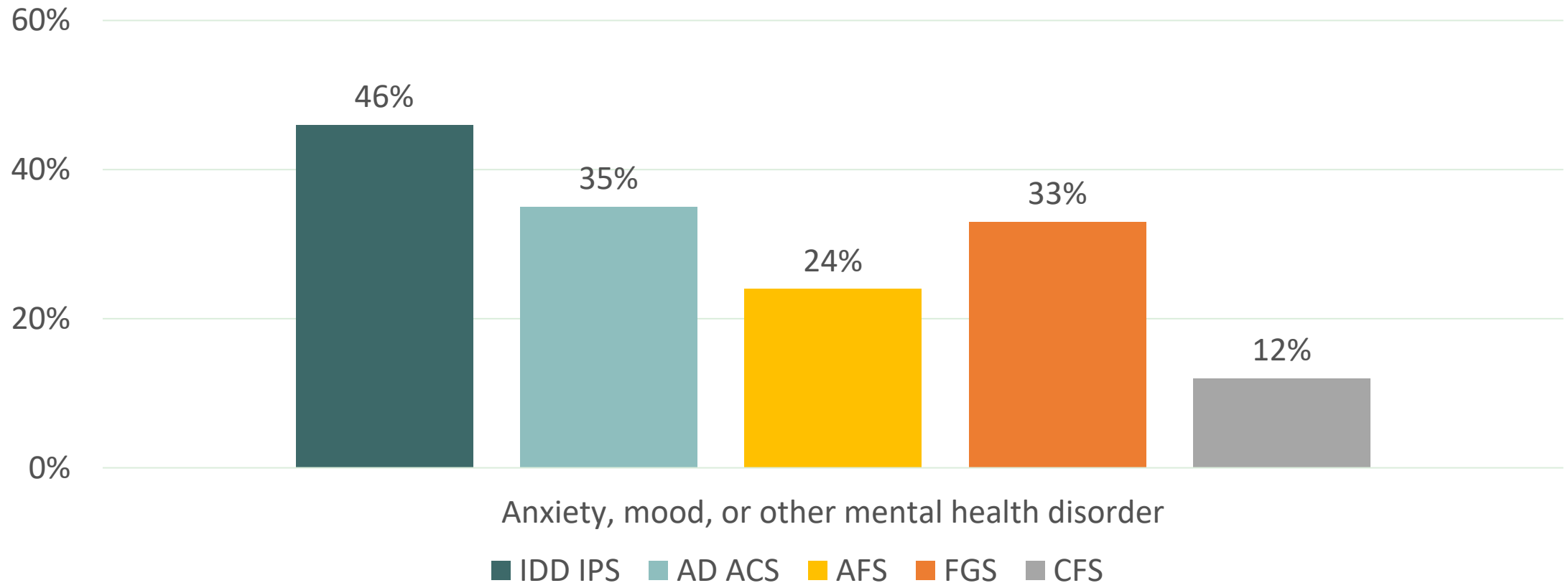


Most respondents lived in an urban or suburban area*

	IDD	IPS	AD	ACS	AFS	FGS	CFS
Urban or Suburban	91%		86%		78%	87%	84%
Rural and small towns	10%		15%		22%	13%	16%

**IPS and ACS data are from RUCA codes based on the person's zip code; AFS, FGS, and CFS are self-reported by the respondent*

Co-occurring mental health disorder by survey*



**IPS and ACS data are from person's records; AFS, FGS, and CFS are self-reported by the respondent about their family member receiving series*



The majority of respondents with IDD have a guardian

IPS

- 52%

AFS

- 65%

FGS

- 71%

ACS

- 15%

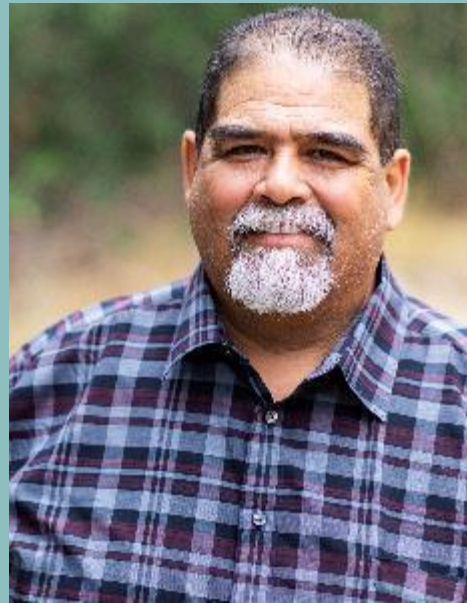
A higher rate of ACS respondents were using a self-direction option

- 19% IPS
- 33% ACS





58% of IPS respondents who used a self-direction option reported they make decisions or have input in making self-direction decisions



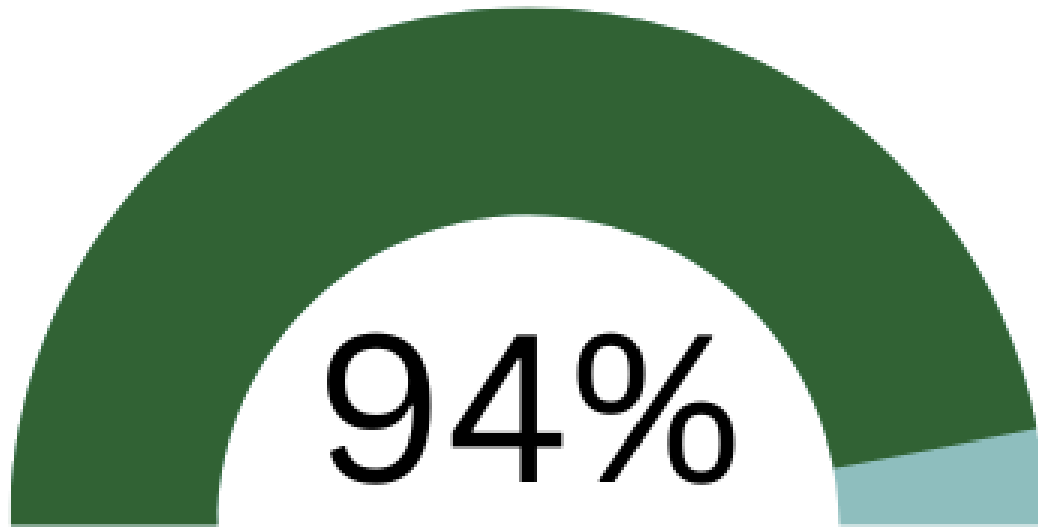
A Year in Review

What we learned from NCI in 2021-22

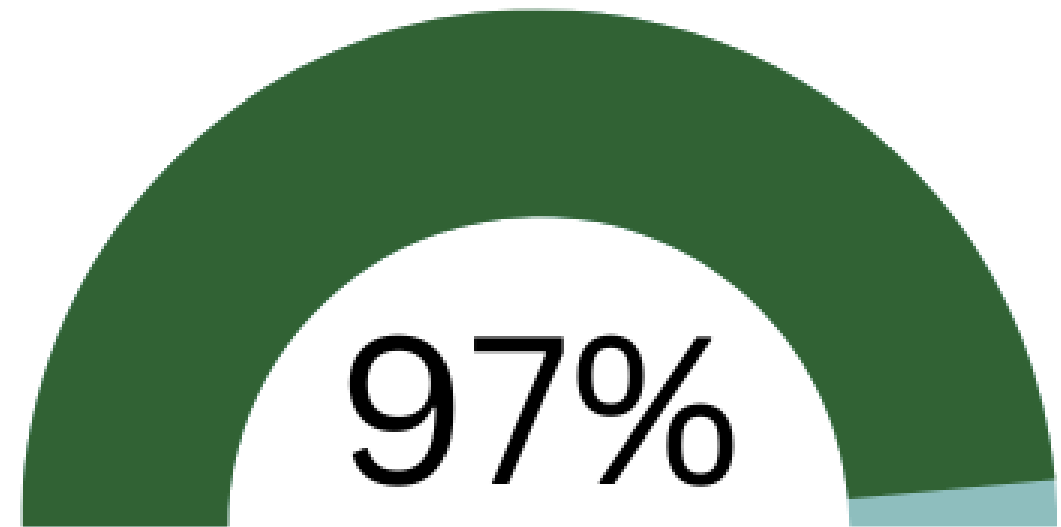


Person-Centered Planning

Nearly all respondents reported the service planning meeting *included the people the person wanted to be there*

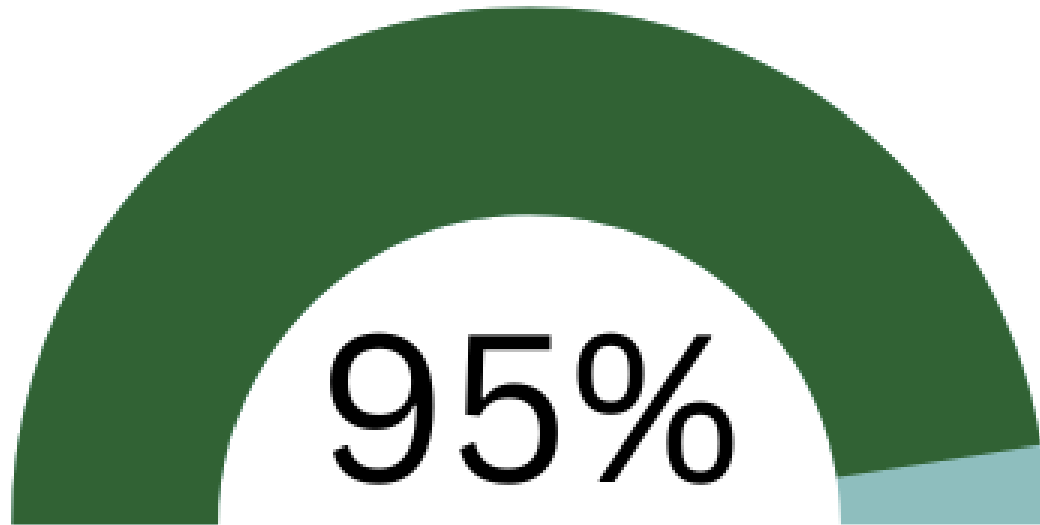


IDD IPS Respondents

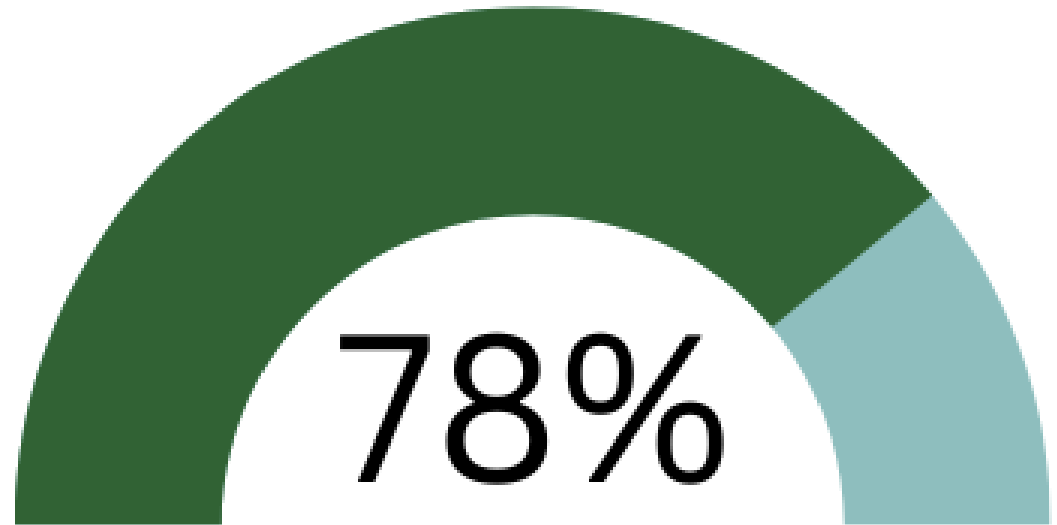


AD ACS Respondents

Fewer ACS respondents reported the *service plan includes things that are important to them*



IDD IPS Respondents



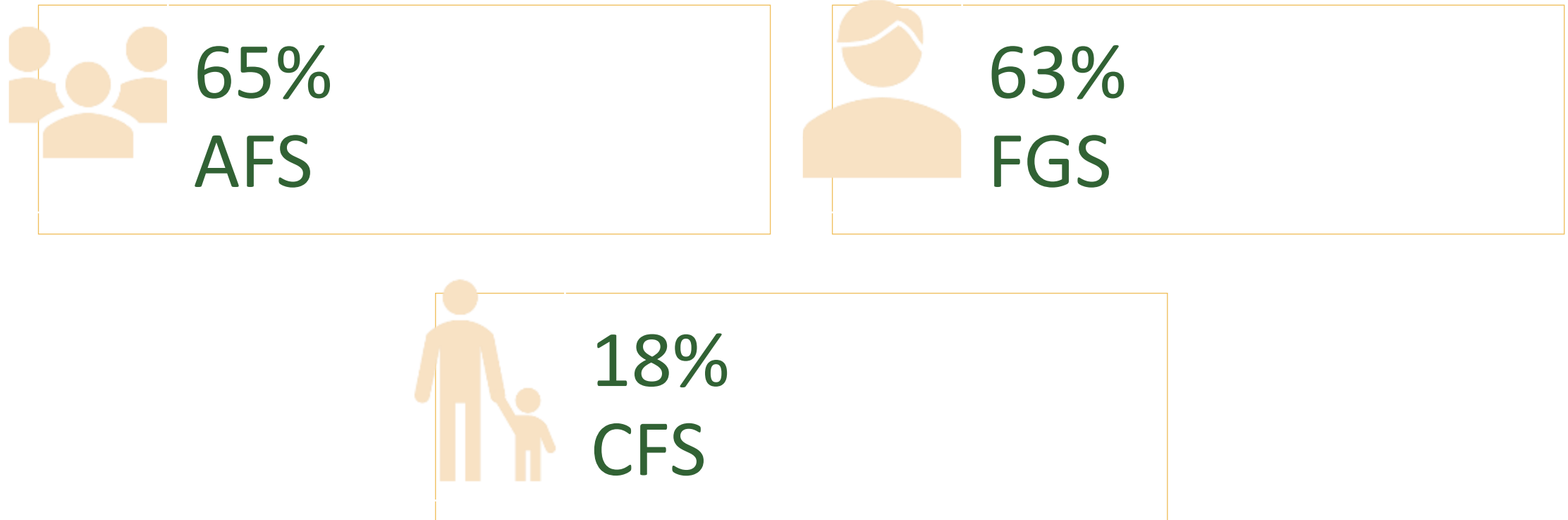
AD ACS Respondents

About 3 in 4 respondents to the IPS and ACS helped make their service plan. That means nearly 1 in 4 respondents to the IPS *did not* help make their plan.

- 25% IPS
- 21% ACS



...and even fewer family member with DD helped make their service plan according to Family Survey respondents





Community Participation and Employment



Around two-thirds of IPS and ACS respondents could do things in the community as much as they want to

- **69% IPS**
- **62% ACS**

About 9 out of every 10 people have *transportation for work or medical appointments*, but fewer have *transportation for leisure*.

Has a way to get places they need to go (like work, medical appointments)

- IPS: 93%
- ACS: 90%

Able to get places when they want to do something outside of the home for fun

- IPS: 78%
- ACS: 74%

Around 8 out of 10 people are able to see and/or communicate with their families when they want

- IPS: 83%
- ACS: 85%



The rate of community employment among IPS respondents dropped slightly since COVID, while the rate of people wanting to work increased

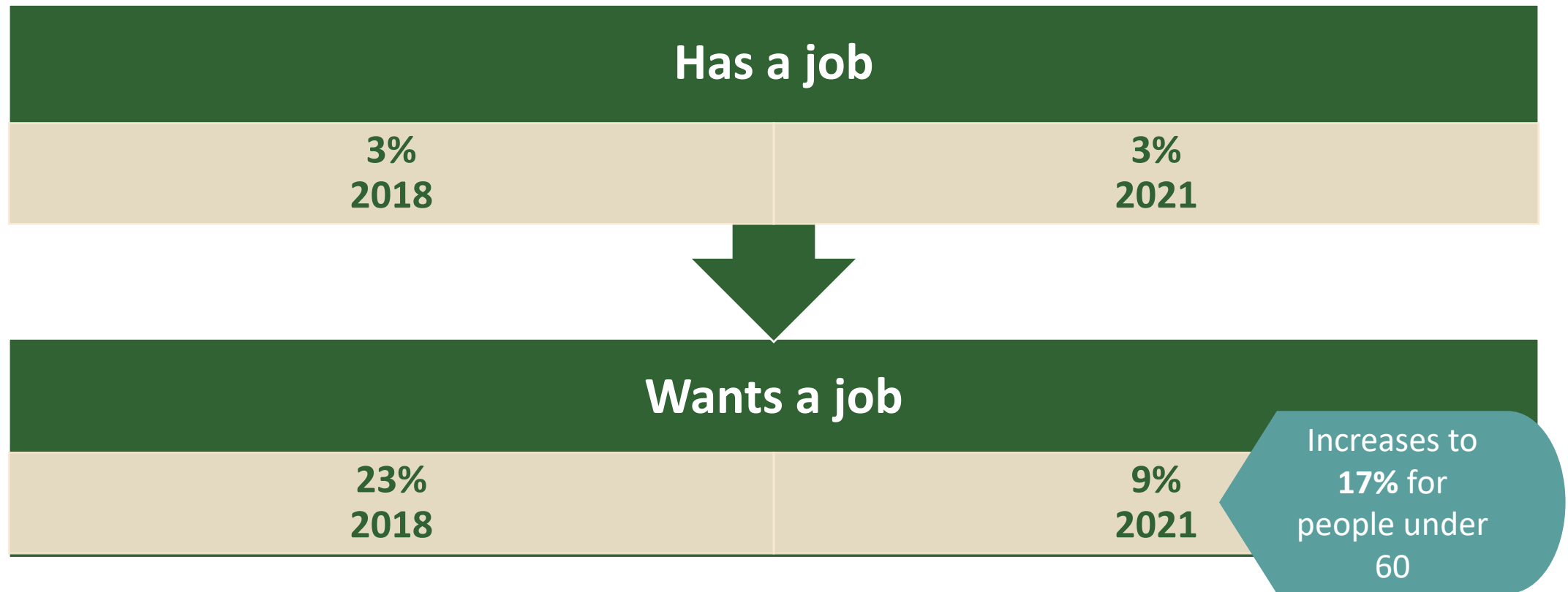
Has a paid community job

- 19% 2018
- 16% 2021

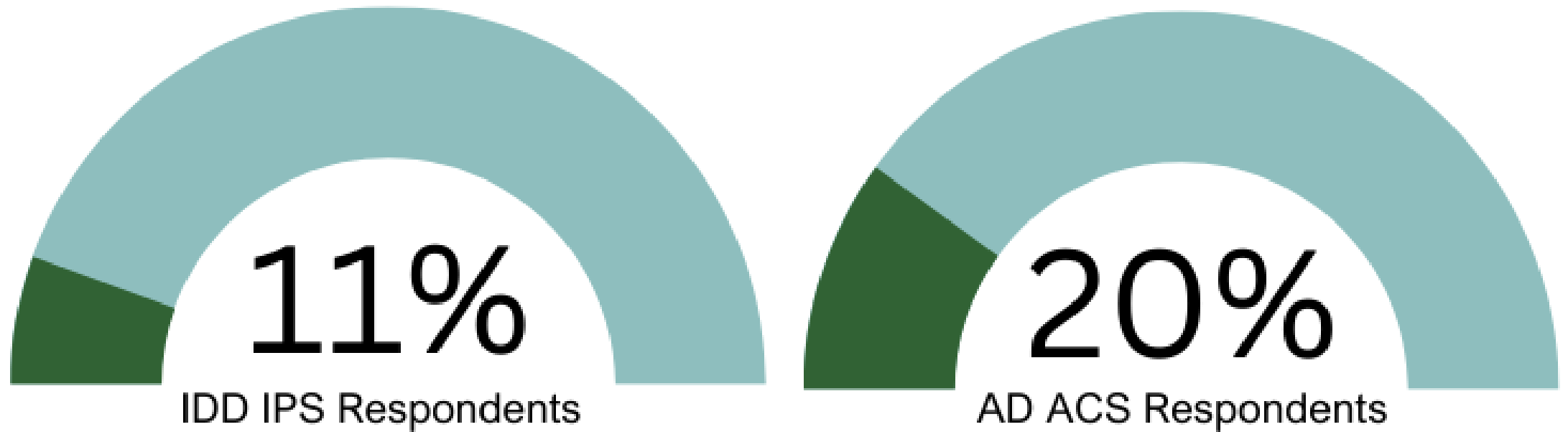
Wants a paid job

- 44% 2018
- 49% 2021

Employment among ACS respondents remained at 3% since COVID, interest in working dropped two and a half times



One in five ACS respondents reported they often felt lonely. That's twice as many as IPS respondents.





Healthcare

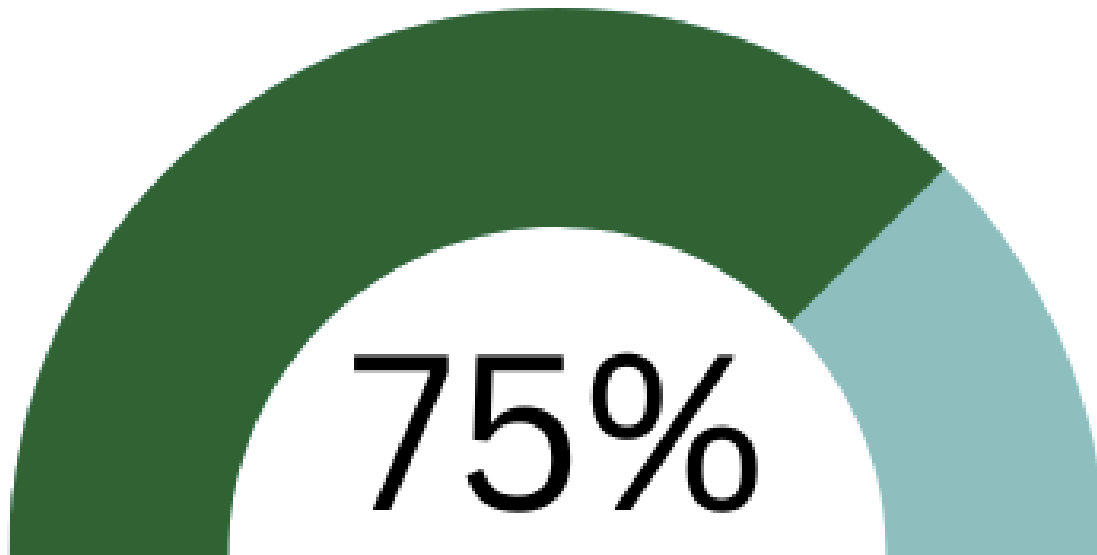


Has Medicare Coverage

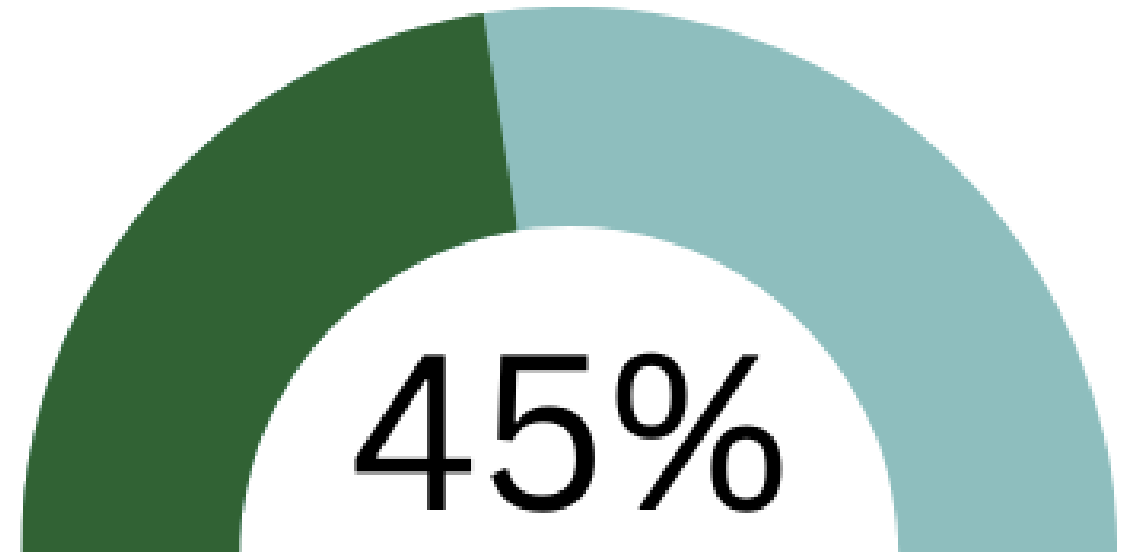
IPS: 42%

ACS: 79%

IPS respondents were more likely than ACS respondents to have had a *dental exam in the past year*

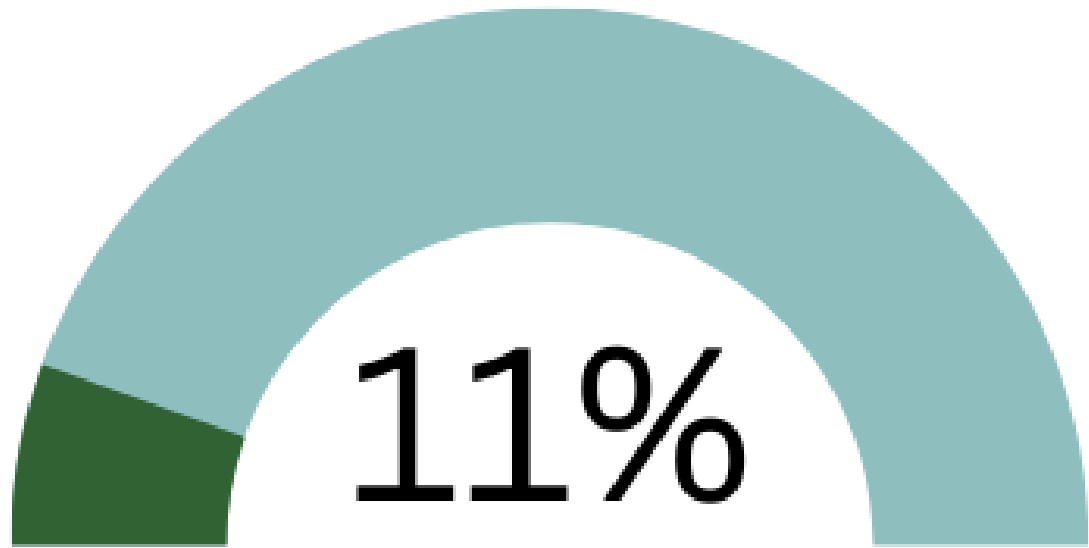


IDD IPS Respondents

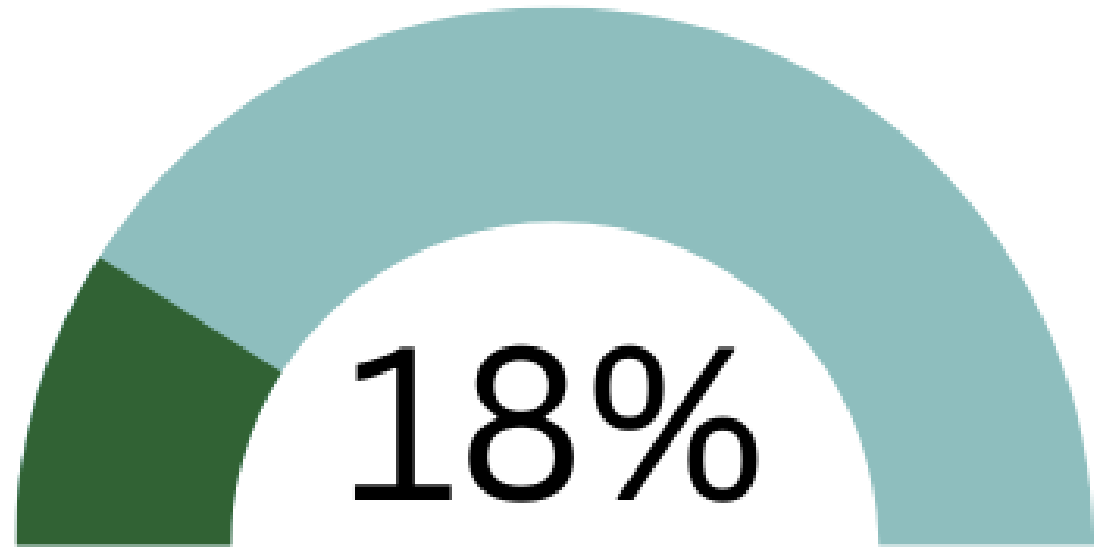


AD ACS Respondents

1 out of 10 IPS respondents describe their health as poor, while almost 1 out of 5 ACS respondents describe their health as poor

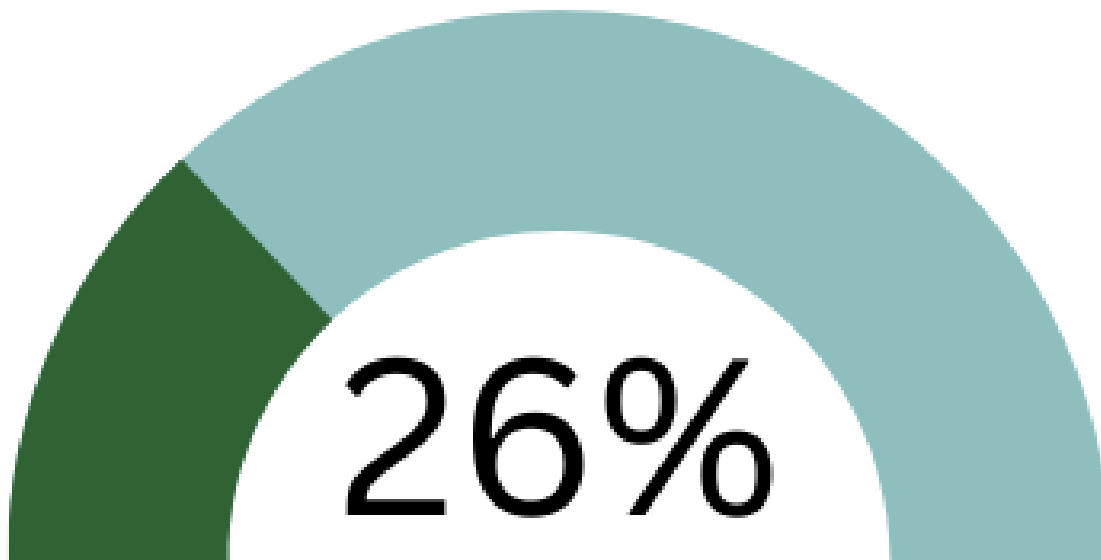


IDD IPS Respondents

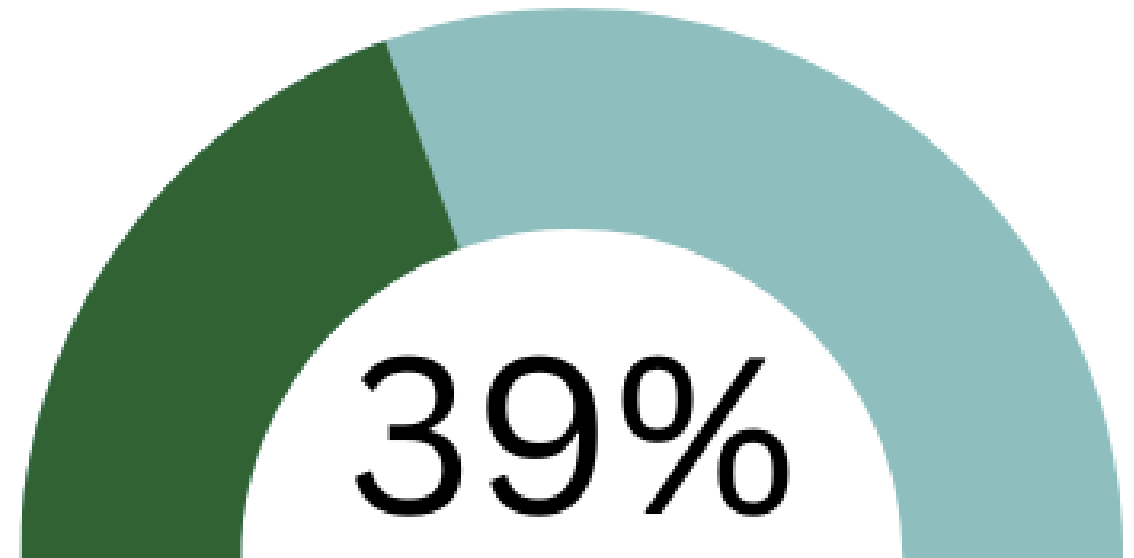


AD ACS Respondents

A quarter of IPS respondents went to the ER to get care for themselves in the past twelve months. A higher rate of NCI-AD respondents went to the ER.



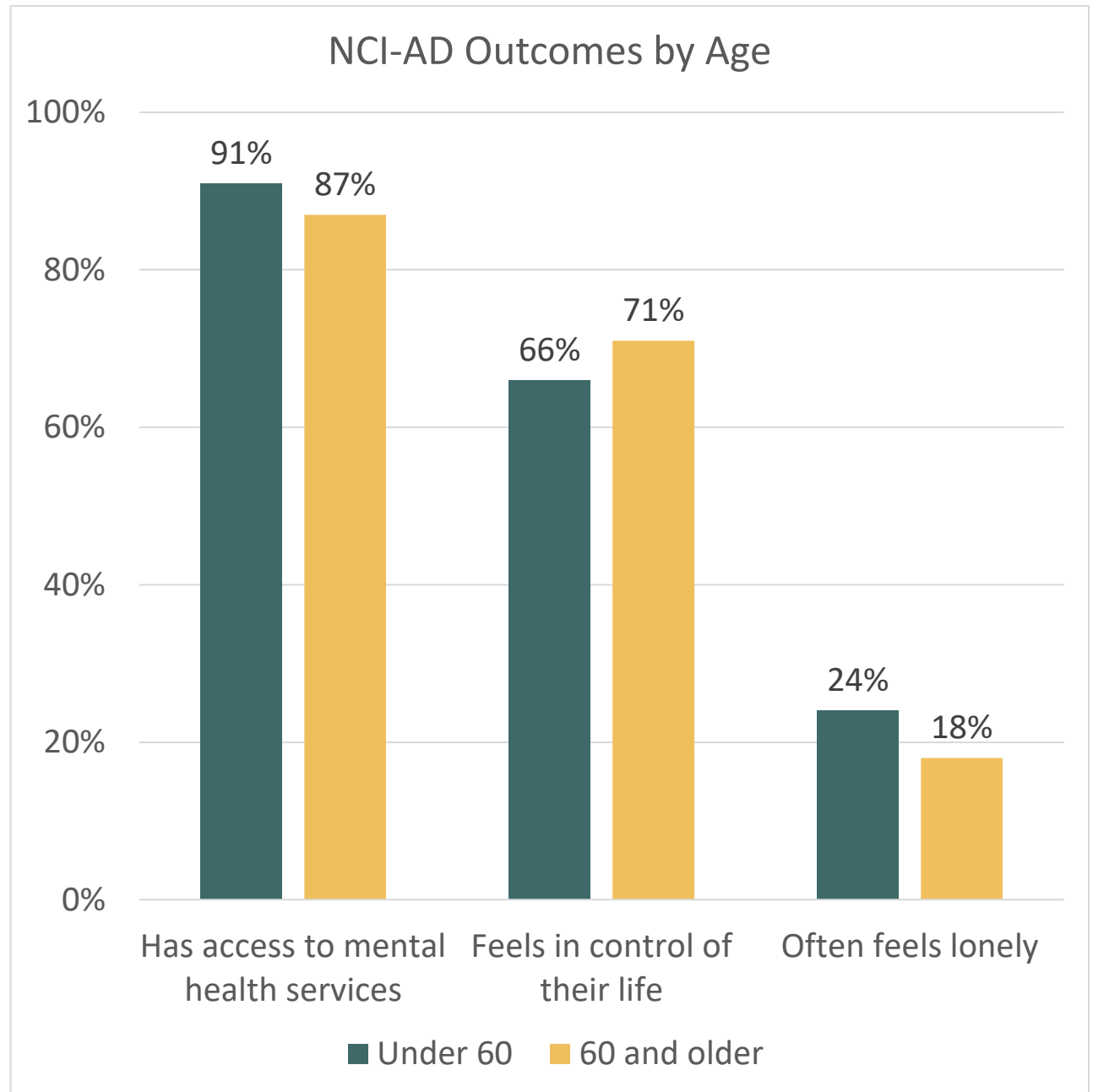
IDD IPS Respondents



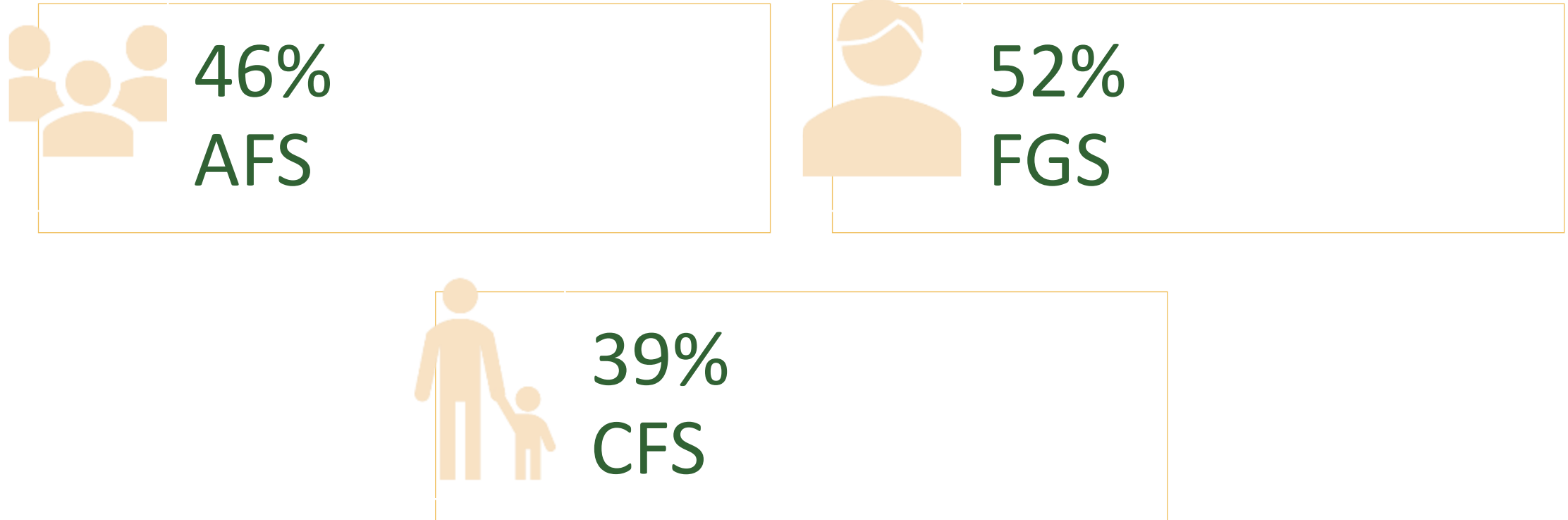
AD ACS Respondents

NCI-AD respondents under 60 were more likely to have access to mental health services, but less likely to feel in control of their life and more likely to often feel lonely*

*All significant at .01



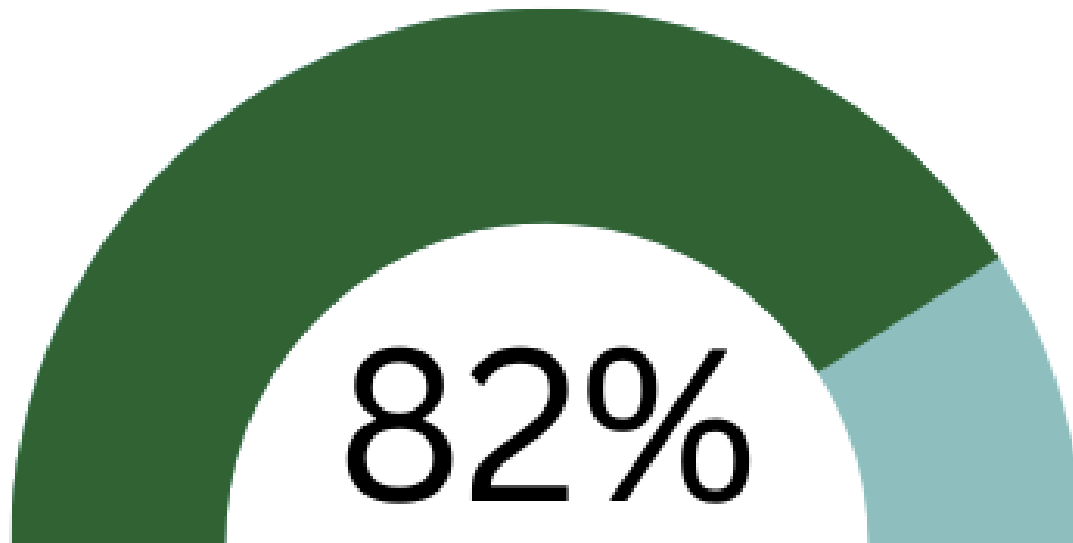
Only half or fewer of Family Survey respondents reported their family member with DD can always get mental or behavioral health supports when needed



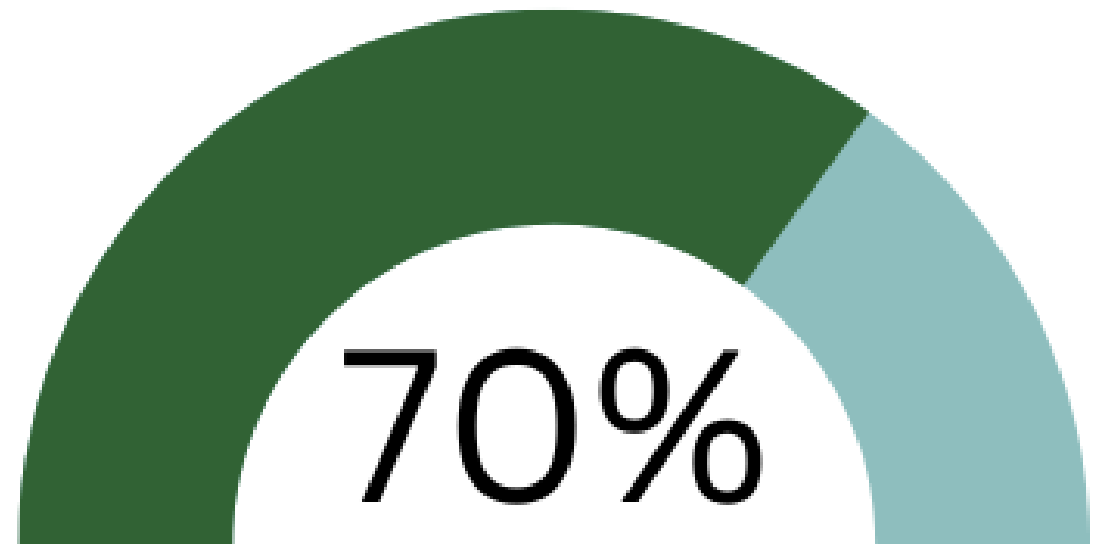


Measuring HCBS Settings Rule

A higher rate of IPS respondents reported that others ask before entering their home

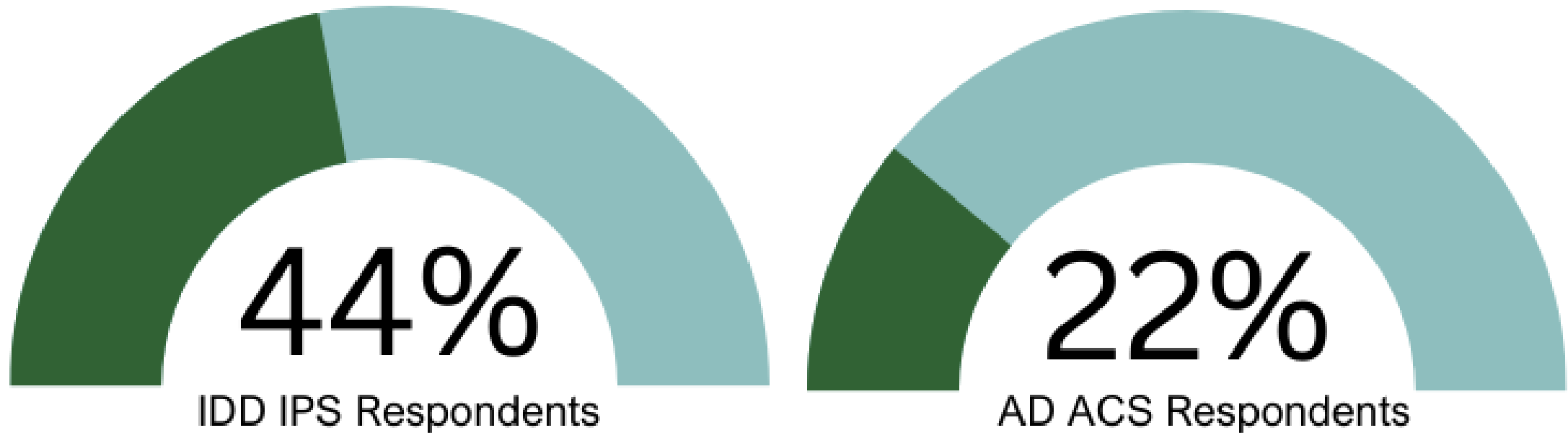


IDD IPS Respondents



AD ACS Respondents

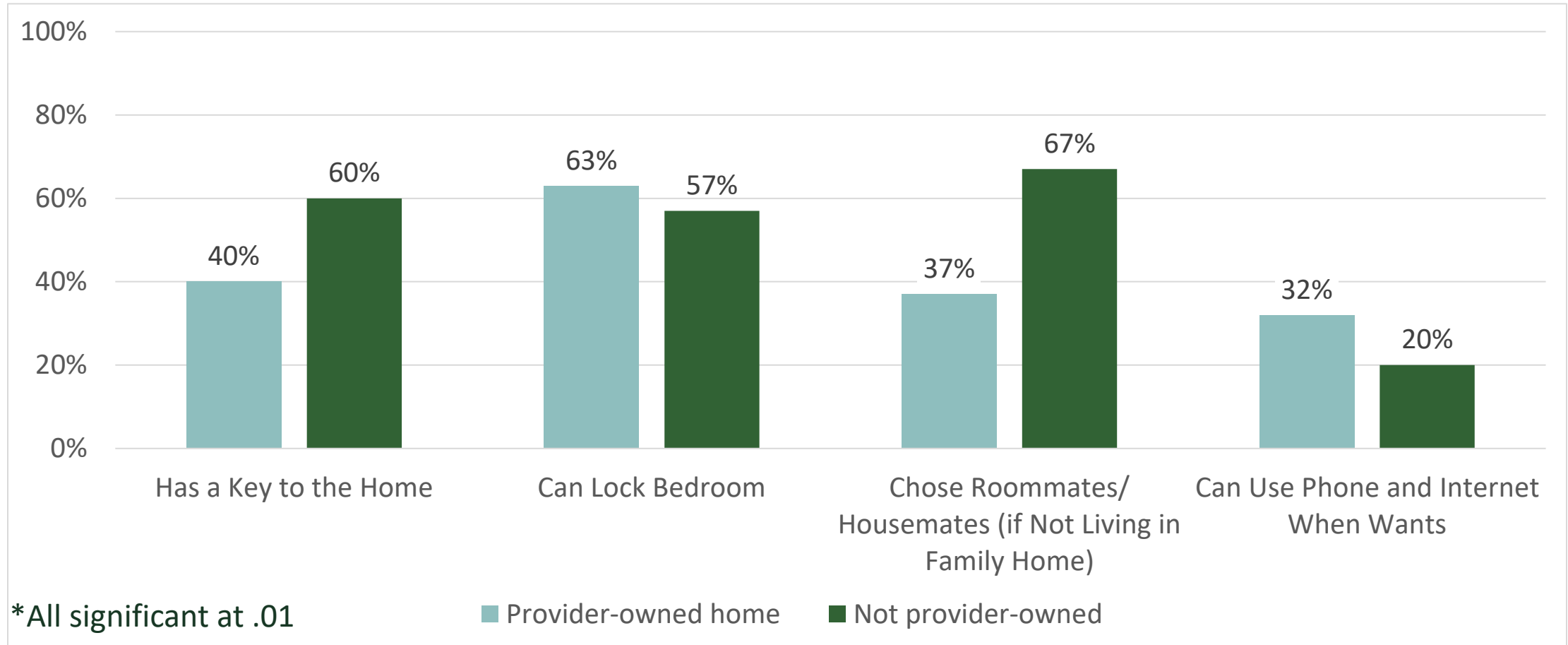
Twice as many IPS respondents compared to ACS chose or could change their roommate



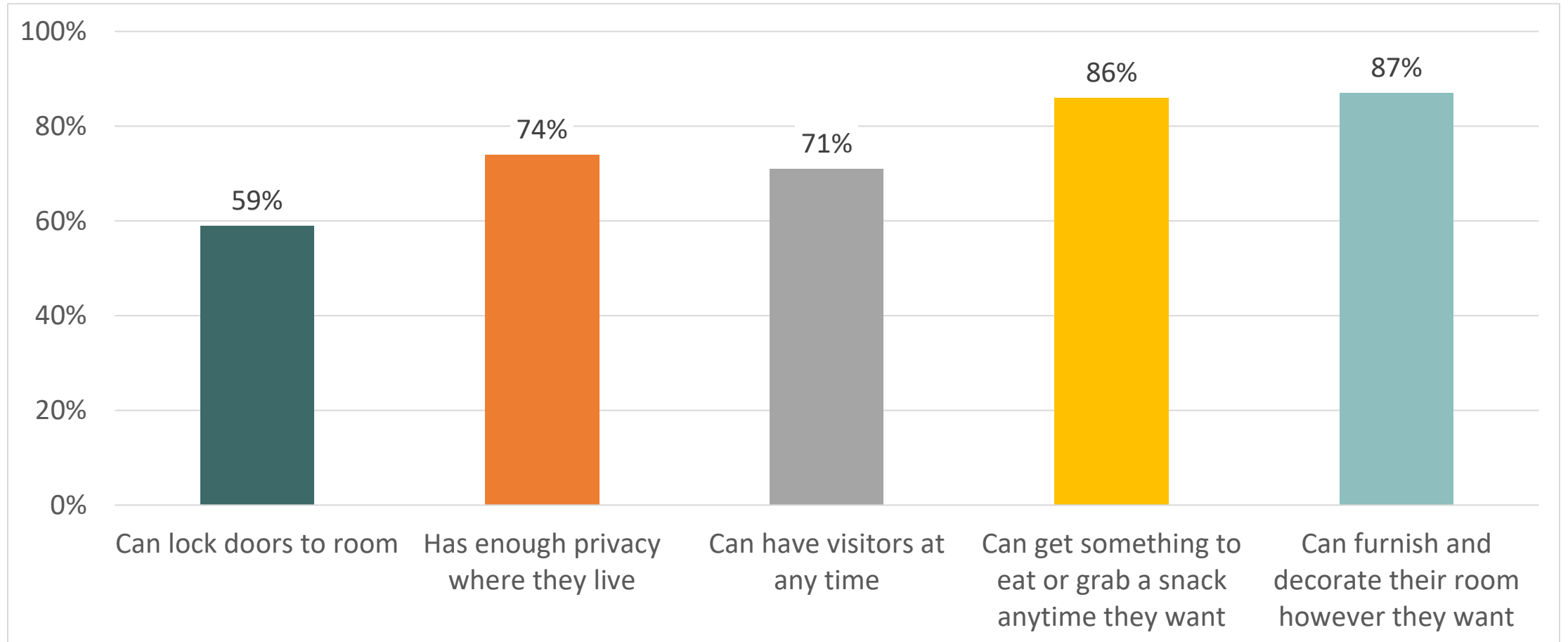
**IPS percent is out of those who do not live with family*

**ACS percent is out of those who live in group residential settings*

NCI-IDD Outcomes by Provider-Owned Settings



NCI-AD Outcomes Among People Living in Group Settings





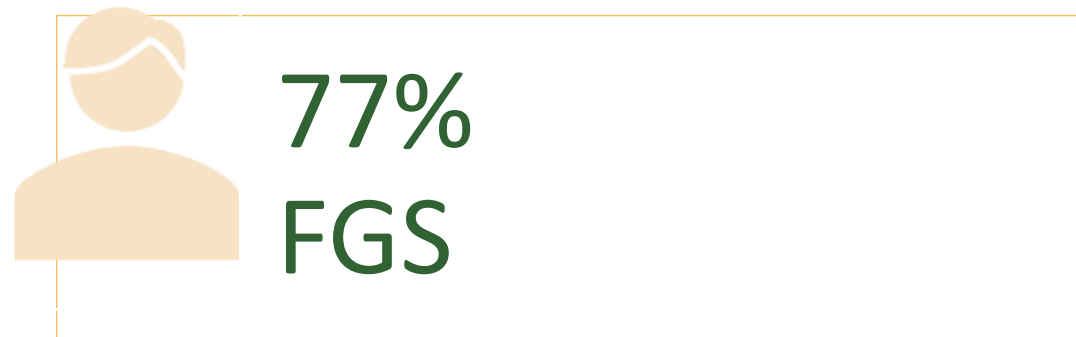
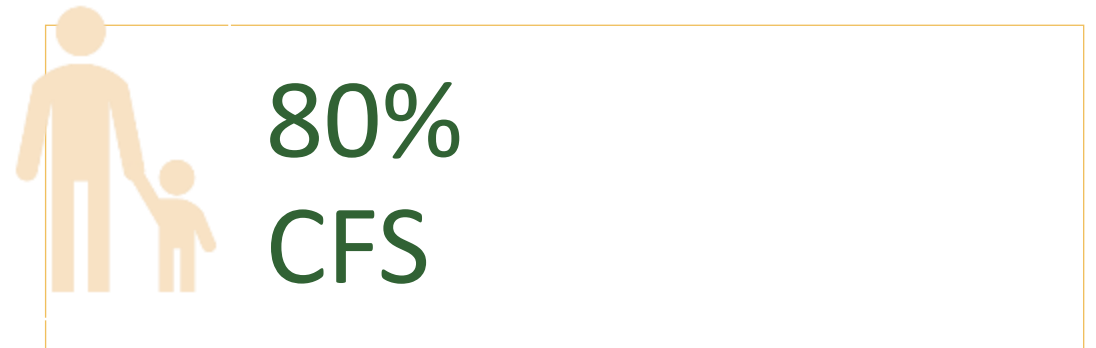
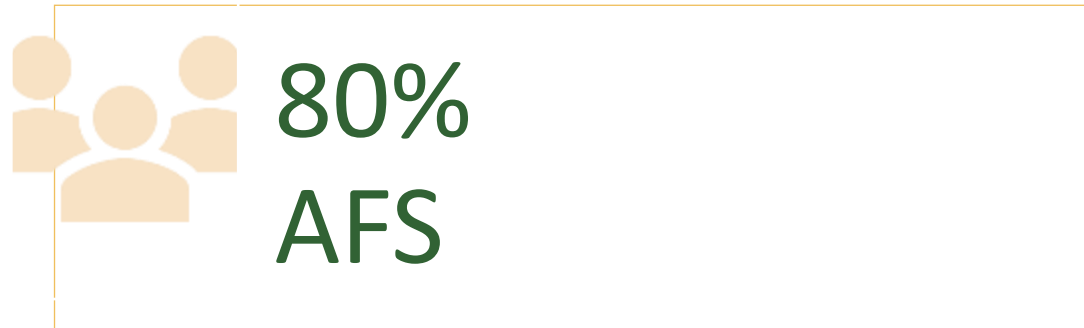
Staffing

Nearly all IPS and ACS respondents reported *staff are respectful of their culture*

- 95% IPS
- 92% ACS



Fewer respondents to the NCI-IDD Family Surveys report staff are respectful of their family's culture



**A higher rate of NCI-AD ACS respondents could
choose or change their staff if they wanted**



79% ACS



63% IPS

NCI-IDD IPS respondents were more likely to report staff change too often

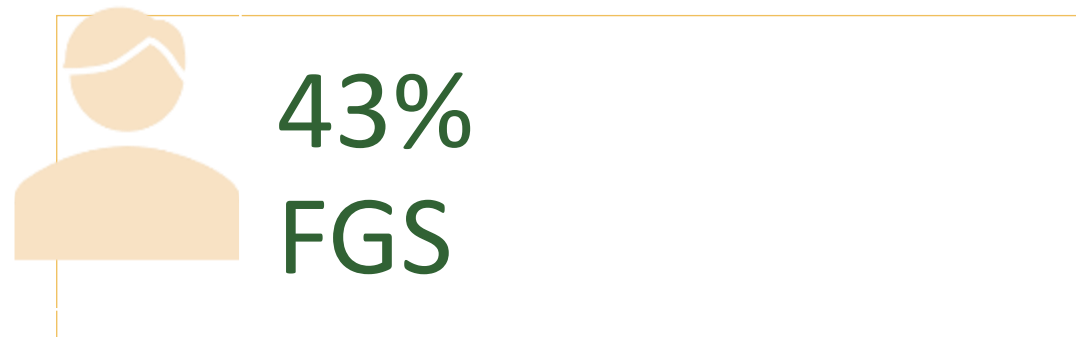
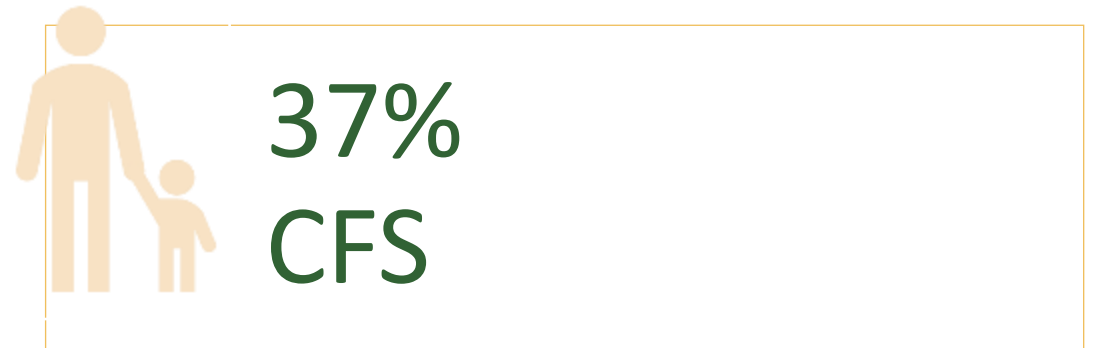
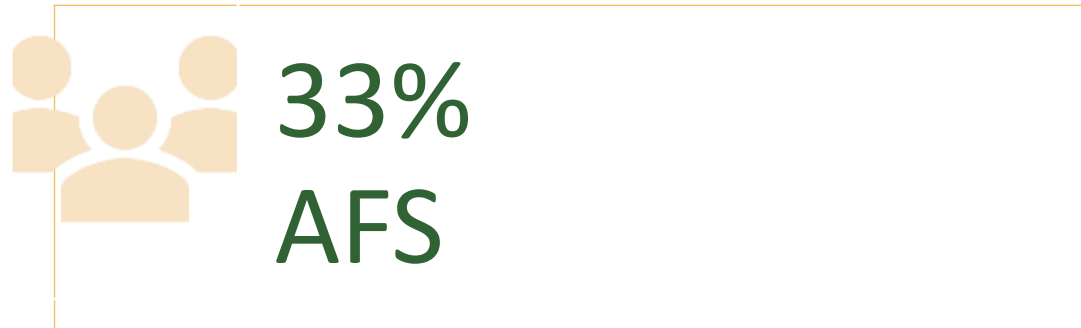


40% IPS



25% ACS

Family Survey respondents whose family member *did not live in the family home* were most likely to report *staff change too often*



Impact of Staff Turnover

Those who reported staff change too often tended to report lower outcomes in several areas. Some examples include:



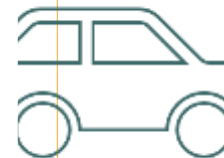
Always having enough help with self-care and everyday activities



Satisfaction with staff



Community inclusion



Transportation

What are the takeaways and what do we do next?

Recapping themes across NCI Surveys



What's going well and where is the room for improvement?

Staffing: High rates of feeling respected by staff, but turnover is related to poorer outcomes

Person-centered planning: High rates of service plans including what matters to people, but improvements needed to ensure person-centered process of developing plans

Community inclusion and employment: Impacts of COVID on lower community participation may be persisting, more supports for people who desire employment are needed

Healthcare: Access to some preventive health services, but access to mental health and dental is lacking for some populations and ER utilization is high

HCBS Settings Rule: Privacy, visitors, and rules show good progress towards compliance, but choosing roommates, locking doors show significant room for improvement in supporting choices

Implications and Future Directions

In some cases, we see *stark differences across the populations* that suggest further research is needed to understand what contributes to differences and how to *ensure all populations have equitable and positive outcomes.*

We encourage states to *collaborate with partners* to look at *who is included in their samples* and who they are not hearing from.



What Next?



State Administrators

- Look at where your state is compared to the national norm and other similarly situated states
- Have conversations with communities about their experiences and barriers to access



Providers

- Have conversations with staff and people being served about their experiences
- Use data to inform areas for improvements



Advocates and Quality Councils

- Use reports to support conversations with states and policy makers about needed changes
- Reach out to us with any additional suggestions for how we can look at data



Policy makers

- Look at national and state trends to identify how policies may be impacting outcomes
- Work with community members to develop innovative approaches to improve quality

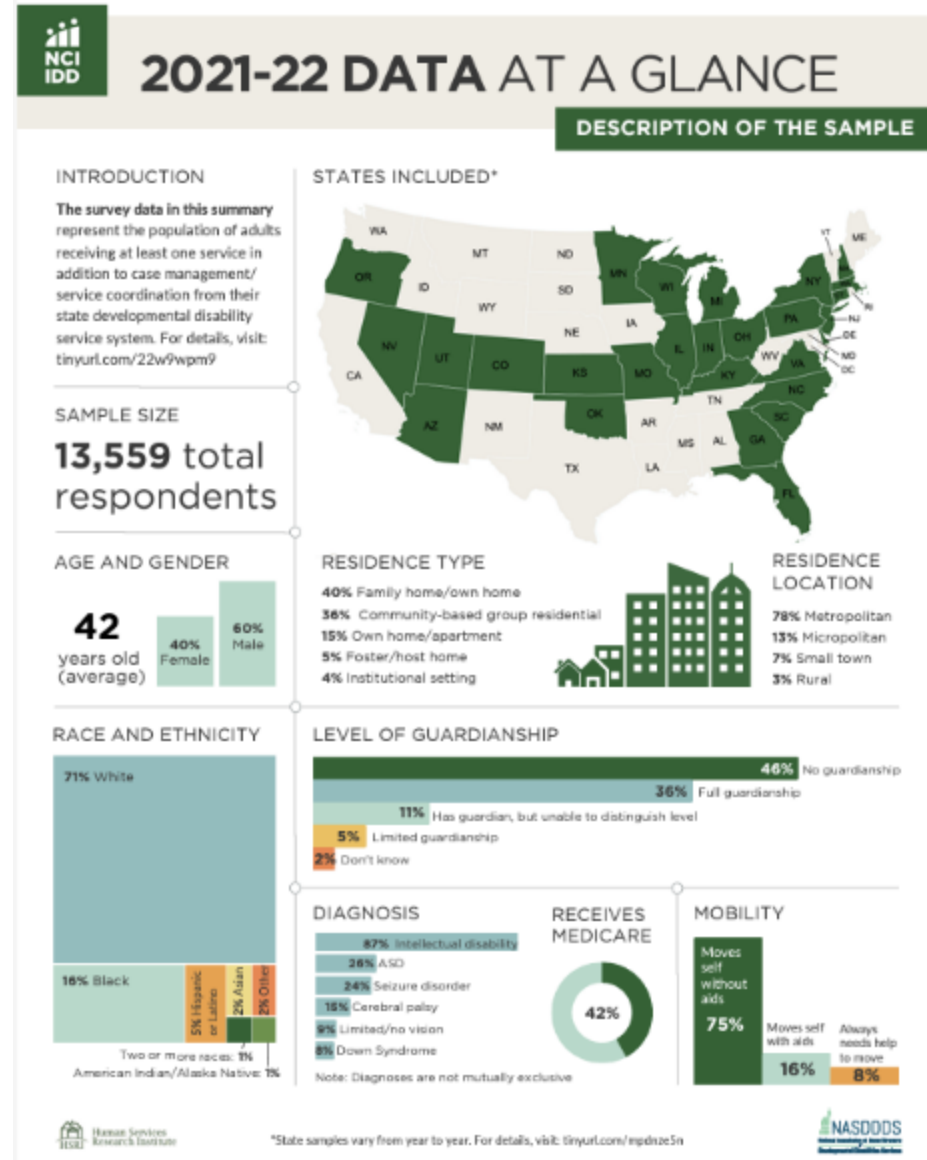
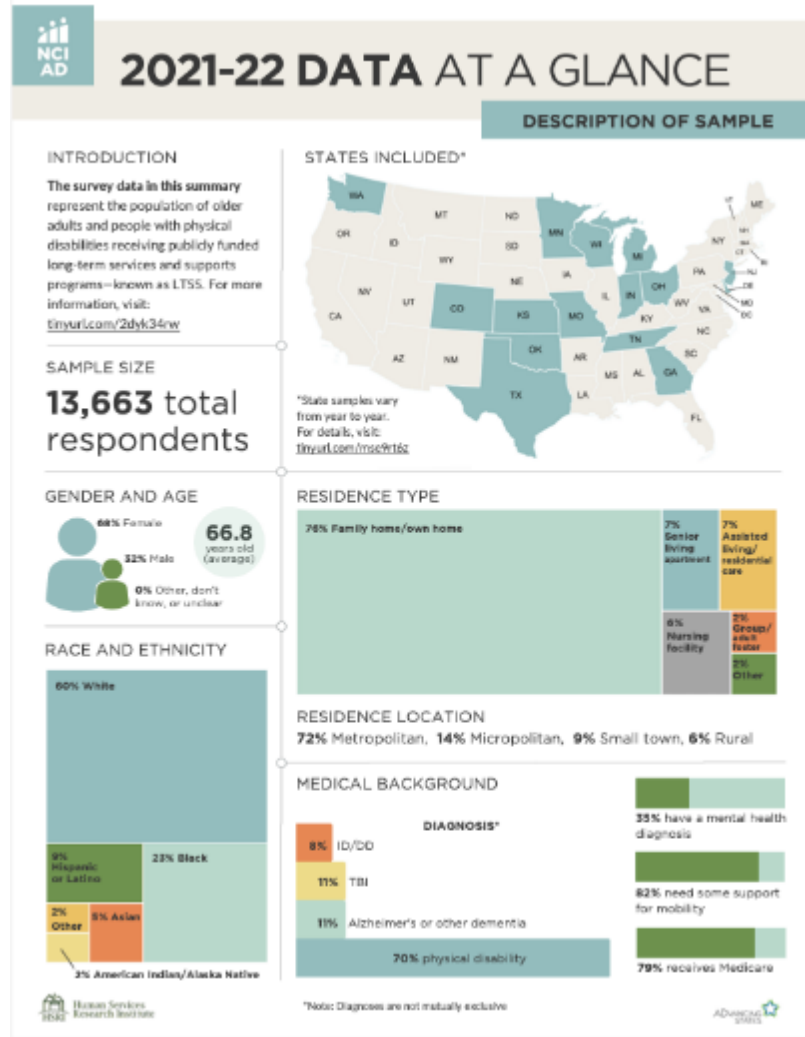
Ways to get involved with NCI

Want to help us improve our surveys? Contact us about participating in a survey revisions workgroup

Want to help collect the data? Contact us about how to become a surveyor or find out whether your state uses peer surveyors

Have a burning research question or hypothesis you want to test? Contact us to learn about how to request access to de-identified data

Results At-A-Glance



NCI-AD reports, and AD SoTW Pilot Technical Report:
<https://nci-ad.org/reports/>

NCI-IDD IPS and Family Survey reports, and IDD State of the Workforce:
<https://idd.nationalcoreindicators.org/survey-reports-insights/>

Recent NCI presentations and publications

IDD Data briefs and highlights:

- Person-centered practices and outcomes of people with I/DD
- Paid Family Caregivers
- College and university enrollment

AD Spotlights on Facebook and LinkedIn:

- Older Americans and Mental Health
- Americans with Disabilities Act

Subscribe to the [NCI Updates newsletter](#) and check out our website to stay up to date: nationalcoreindicators.org

More Info: Person-Centered Planning



[HOME](#) [ABOUT NCAPPS](#) [TECHNICAL ASSISTANCE](#) [RESOURCES](#) [LEARNING COLLABORATIVES](#) [WEBINARS](#) [NCAPPS SHORTS](#)

National Center on Advancing Person-Centered Practices and Systems



Transforming how we think, plan, and practice