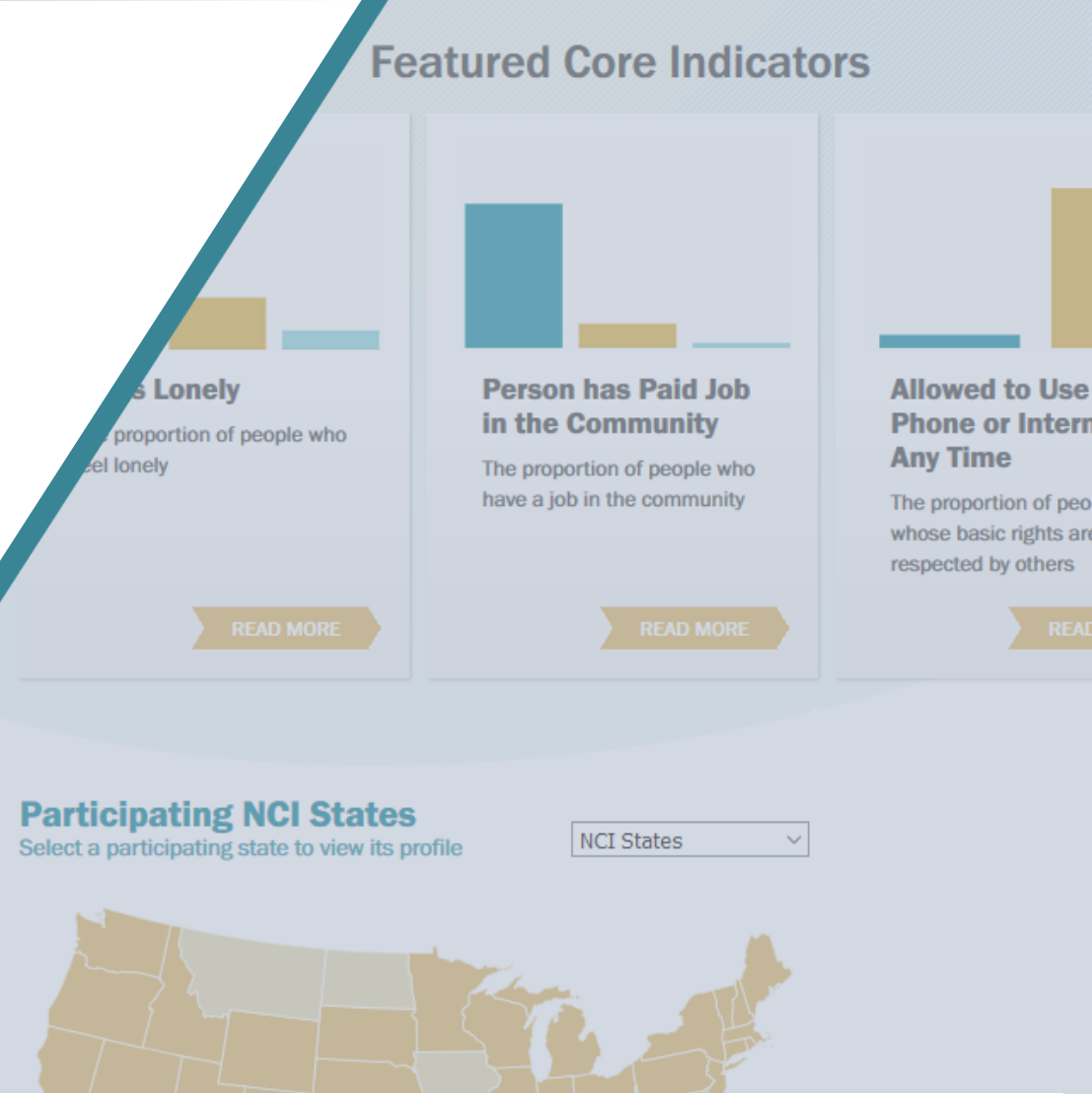


# What Do National Core Indicators™ Data Tell Us About Cultural, Racial and Ethnic Differences in Civic and Community Involvement



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# LEARNING OBJECTIVES

01



## Data Source

Describe National Core Indicators™ as a dataset that can be used to assess disparities in outcomes

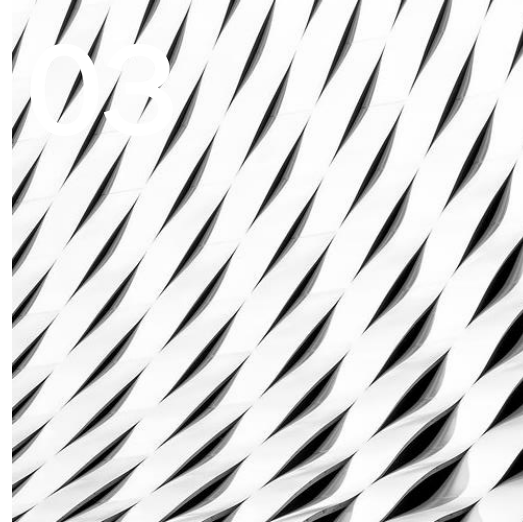
02



## Findings

Look at NCI data on civic and community engagement by race/ethnicity

03





# Evolution of a National Survey of Quality of Life Outcomes

# What is NATIONAL CORE INDICATORS™ (NCI)?

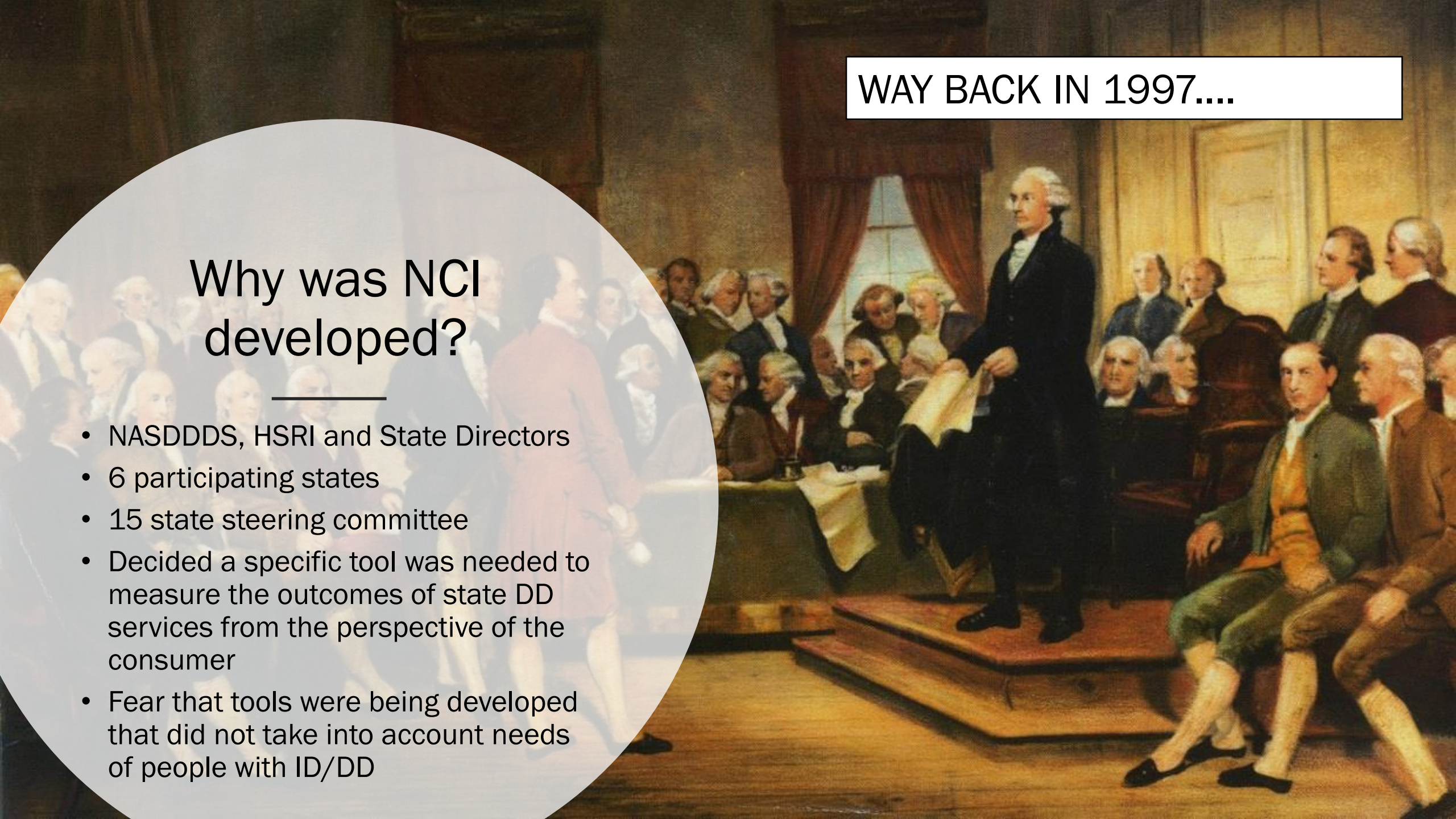
- NASDDDS, HSRI & State DD Directors
  - Multi-state collaboration
    - Launched in 1997 in 13 participating states – now in 45 states (including DC) and 22 sub-state areas
- Goal: Measure performance of public systems for people with intellectual and developmental disabilities by looking at **outcomes**
  - What are outcomes?
  - Instead of measuring the number of people in a program/receiving funding, measuring the consequences/results of that program.
  - DOMAINS: employment, community inclusion, choice, rights, health, safety, relationships, service satisfaction etc.

WAY BACK IN 1997....

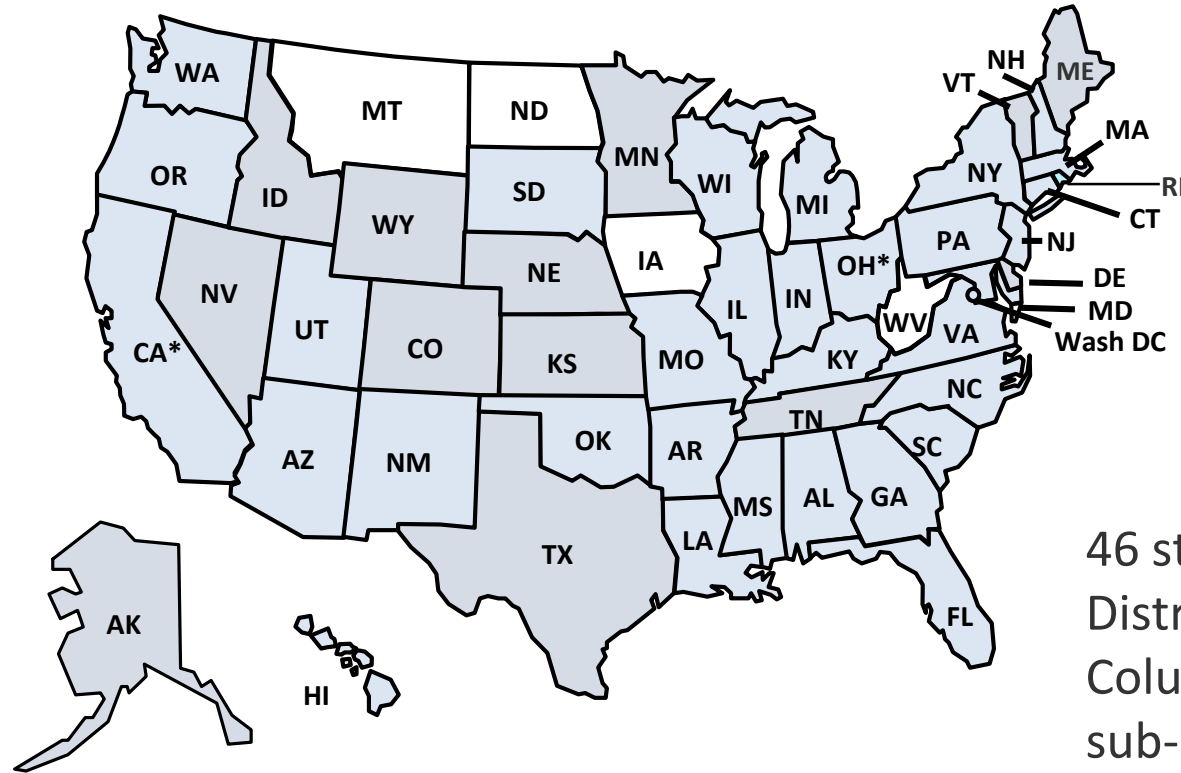
## Why was NCI developed?

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- NASDDDS, HSRI and State Directors
- 6 participating states
- 15 state steering committee
- Decided a specific tool was needed to measure the outcomes of state DD services from the perspective of the consumer
- Fear that tools were being developed that did not take into account needs of people with ID/DD



# National Core Indicators<sup>TM</sup> State Participation 2016-2017



46 states, the  
District of  
Columbia and 22  
sub-state regions

**Please note:** not all NCI participating states participate in all NCI surveys each year.



How are NCI data collected?

## Adult Consumer Survey (ACS\*)

### Family Surveys

- (Adult Family Survey, Family Guardian Survey, Child Family Survey)
- (mail/direct entry)

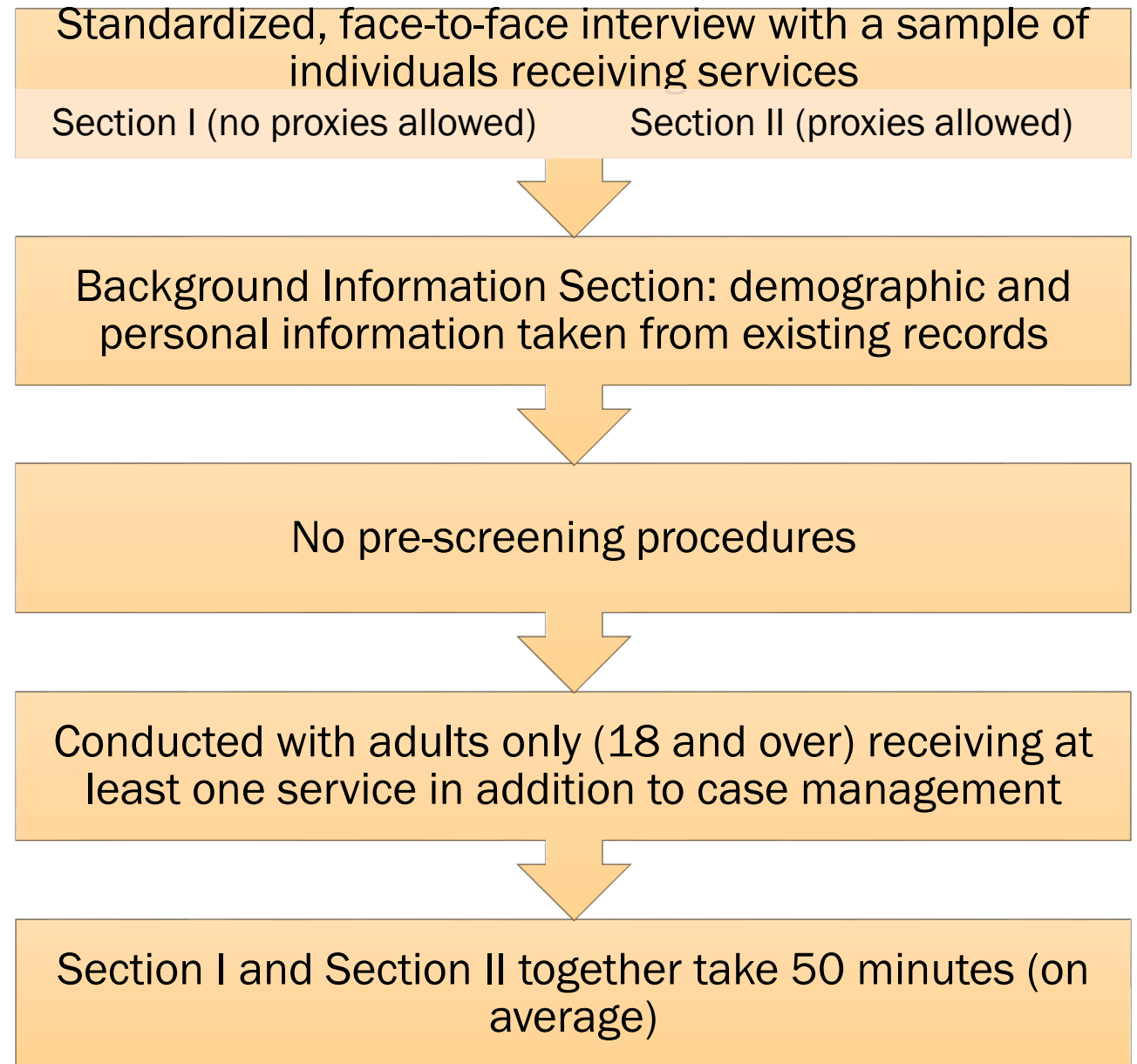
### Staff Stability Survey

- Respondents are provider agencies providing info on the stability and quality of the DSP workforce working with adults with IDD

\*In 2017-18, survey name changed to the In-Person Survey (IPS)

# How is the Adult Consumer Survey\* Conducted?

(\*In Person Survey)





# National Core Indicators offer a unique view

- Person-centered
- Individual characteristics of people receiving services
- The locations where people live
- The activities they engage in during the day including whether they are working
- The nature of their experiences with the supports that they receive (e.g., with case managers, ability to make choices, self-direction)
- The context of their lives – friends, community involvement, safety
- Health and well-being, access to healthcare

NCI can be used to look at disparities in personal characteristics and outcomes of people with IDD.....





# Race/ethnicity and Community Inclusion and Engagement

# STUDY OF STATE SERVICE RECIPIENTS

- 1) Do White, non-Hispanic adults with IDD, Black/African American, Non-Hispanic adults with IDD and adults with IDD who identify as Hispanic experience disparities in outcomes regarding community inclusion and engagement?
- 2) Do the families of individuals with IDD report disparities in outcomes?

# Data and sample for the ACS

Data from 2016-17; 36 states

Only included respondents that were identified as one of the three race/ethnic categories.  
N: 19,786

Race information is collected in BI section, from existing system records

	Number of respondents	Percent of total
White, non-Hispanic	15,235	77.0%
Black/African American, Non-Hispanic	3,542	17.9%
Hispanic	1,009	5.1%
	19,786	

The rest of this presentation will refer to:

- White, non-Hispanic as “White”
- Black/African-American, Non-Hispanic as “Black”
- Hispanic as “Hispanic”

# Sample characteristics

	White	Black	Hispanic	P-value
Age	42.9	41.4	37.4	<.001
Gender=Male	57.2%	60.2%	58.5%	<.05
Guardianship=No	40.4%	58.4%	51.7%	<.001
ID level Severe or Profound (of those with ID level reported)	23.5%	29.5%	30.2%	<.001
DX Psychotic disorder	10.0%	19.8%	13.1%	<.001
DX Down Syndrome	10.2%	5.8%	10.2%	<.001
DX High Blood Pressure	20.5%	31.4%	14.1%	<.001
Primary Language=English	99.2%	98.9%	73.3%	<.001
Preferred means of communication=Spoken	80.2%	78.0%	72.2%	<.001
Has paid community job	21.9%	14.6%	12.4%	<.001
Self-Directed Supports Option	10.8%	6.2%	13.5%	<.001

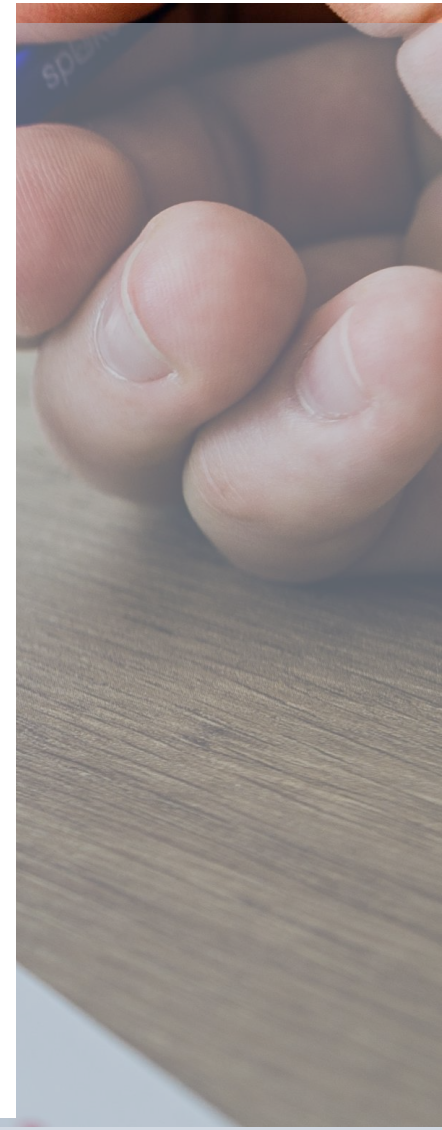
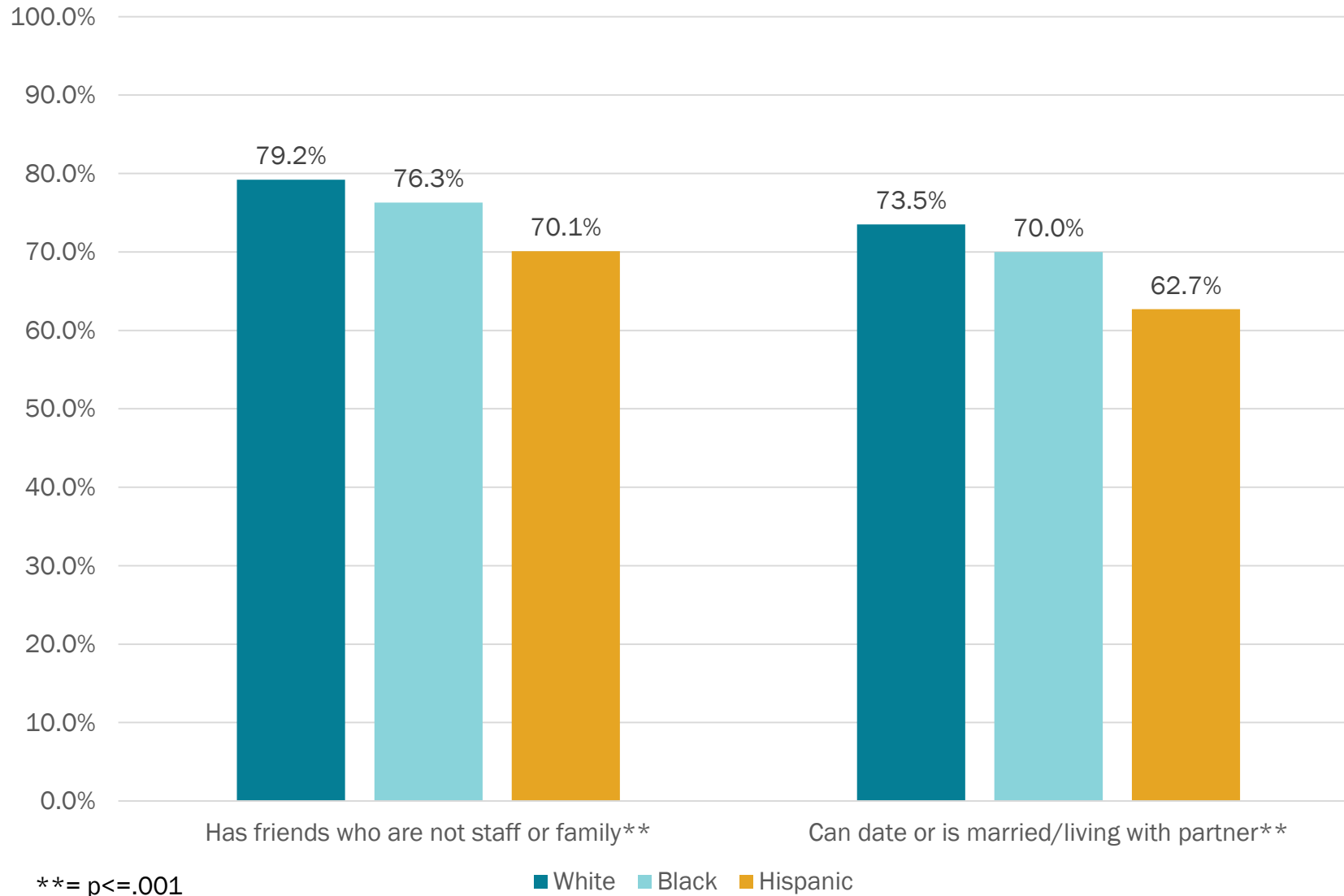
P value: Anova for age, chi square tests for the rest of the table

# Sample characteristics

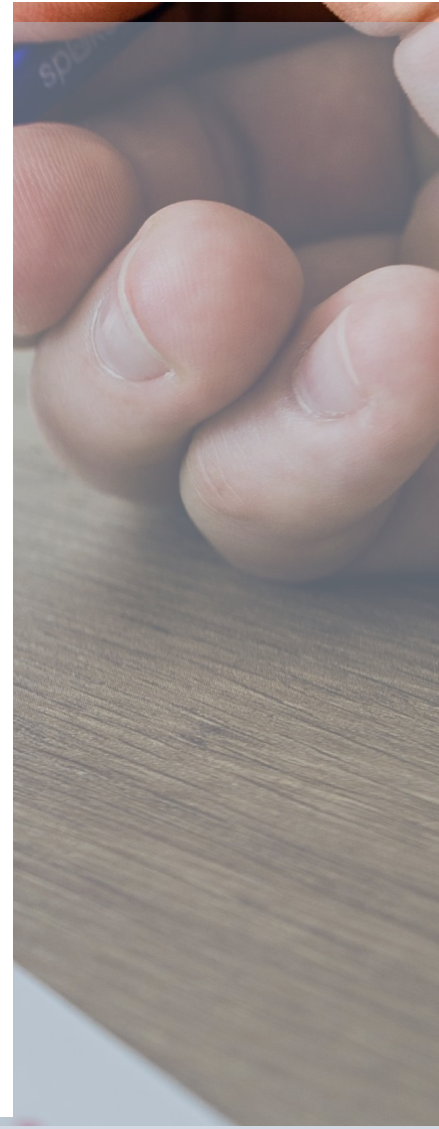
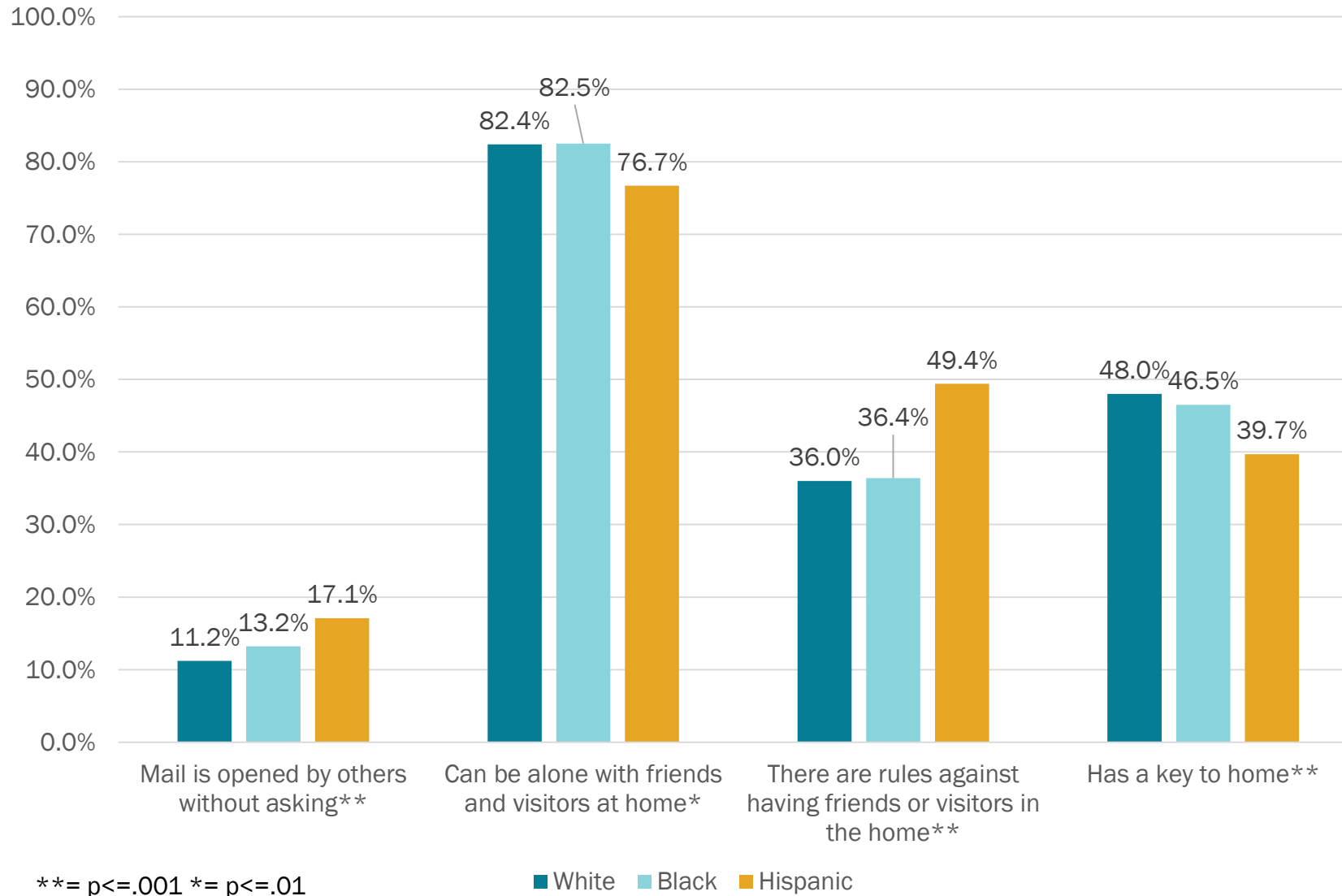
	White	Black	Hispanic
Residence type (p<.001)			
Intermediate Care Facilities	8.1%	9.3%	15.2%
Group residential settings	32.7%	29.4%	18.8%
Own home or apartment	18.9%	16.9%	10.2%
Parent/relative's home	33.5%	39.7%	53.5%
Foster care/host home	6.8%	4.7%	2.3%

P value: Chi square test

# Relationships

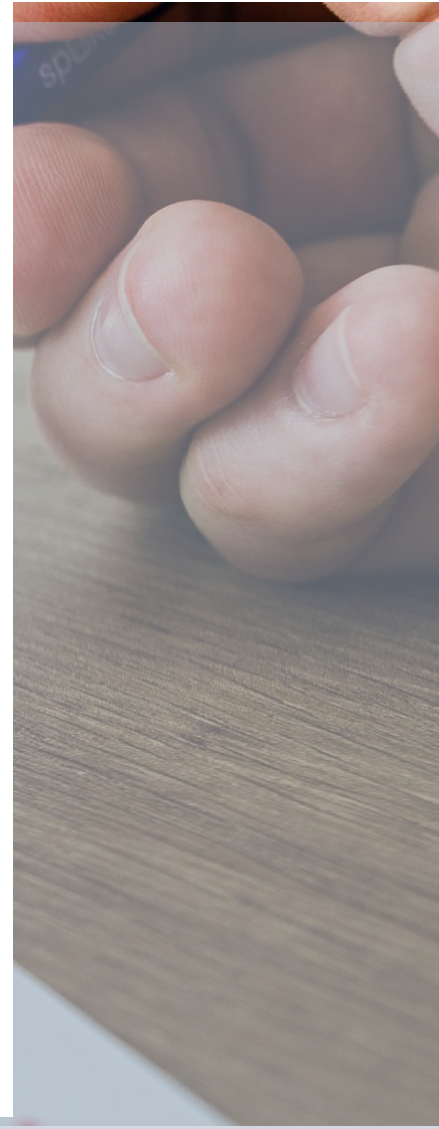
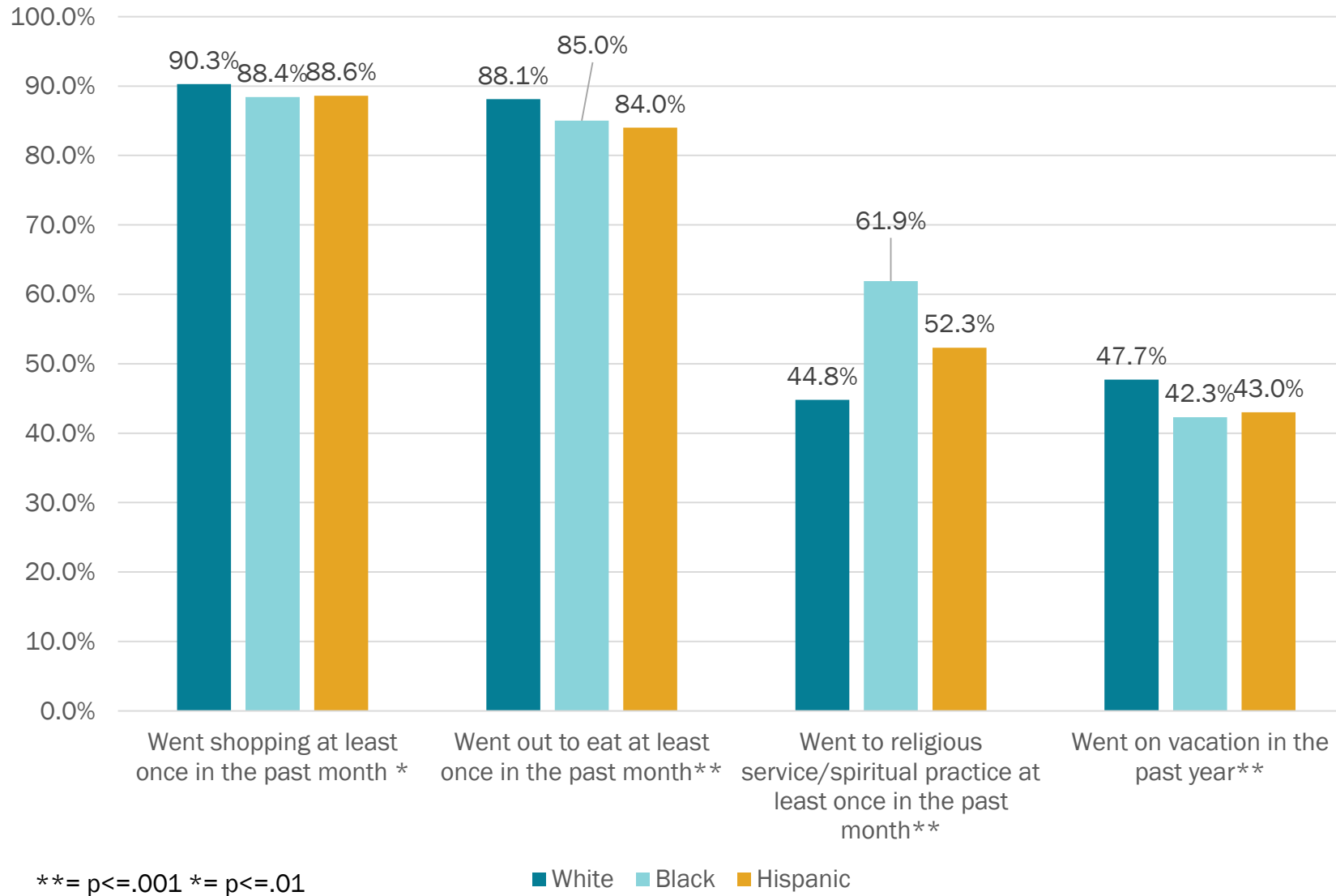


# Rights and respect





# Community inclusion



# NCI Family Surveys 2016-17

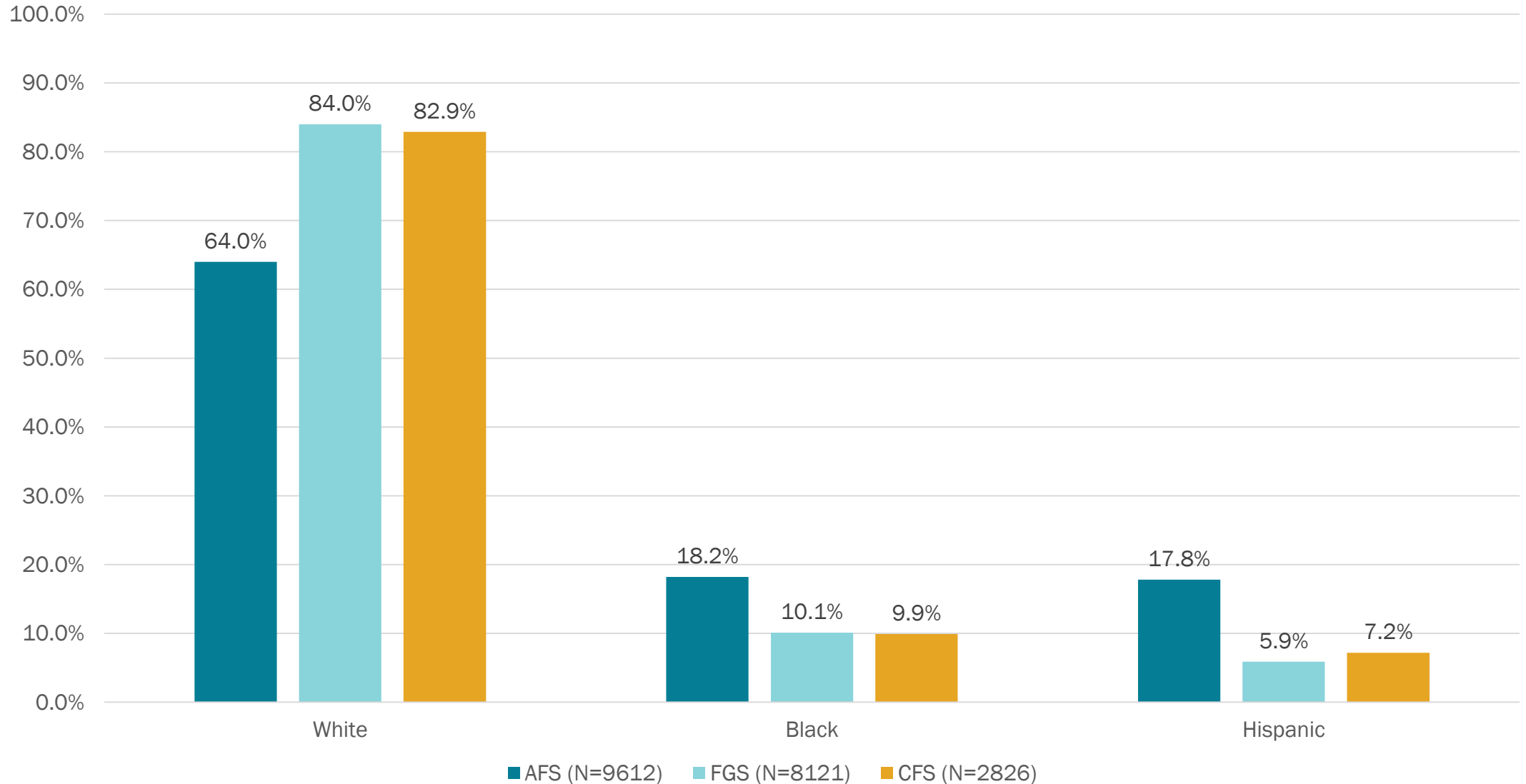
- Adult Family Survey: Respondents are families of adults with IDD living in family home. (N=11419; 16 States)
- Family Guardian Survey: Respondents are families/guardians of adults with IDD not living in family home. (N=9194; 12 States)
- Child Family Survey: Respondents are families of children with IDD living in family home. (N=3352; 9 States)

All family members with IDD are receiving at least one service from the state in addition to case management,

# Racial/Ethnic Composition of Family Survey Samples

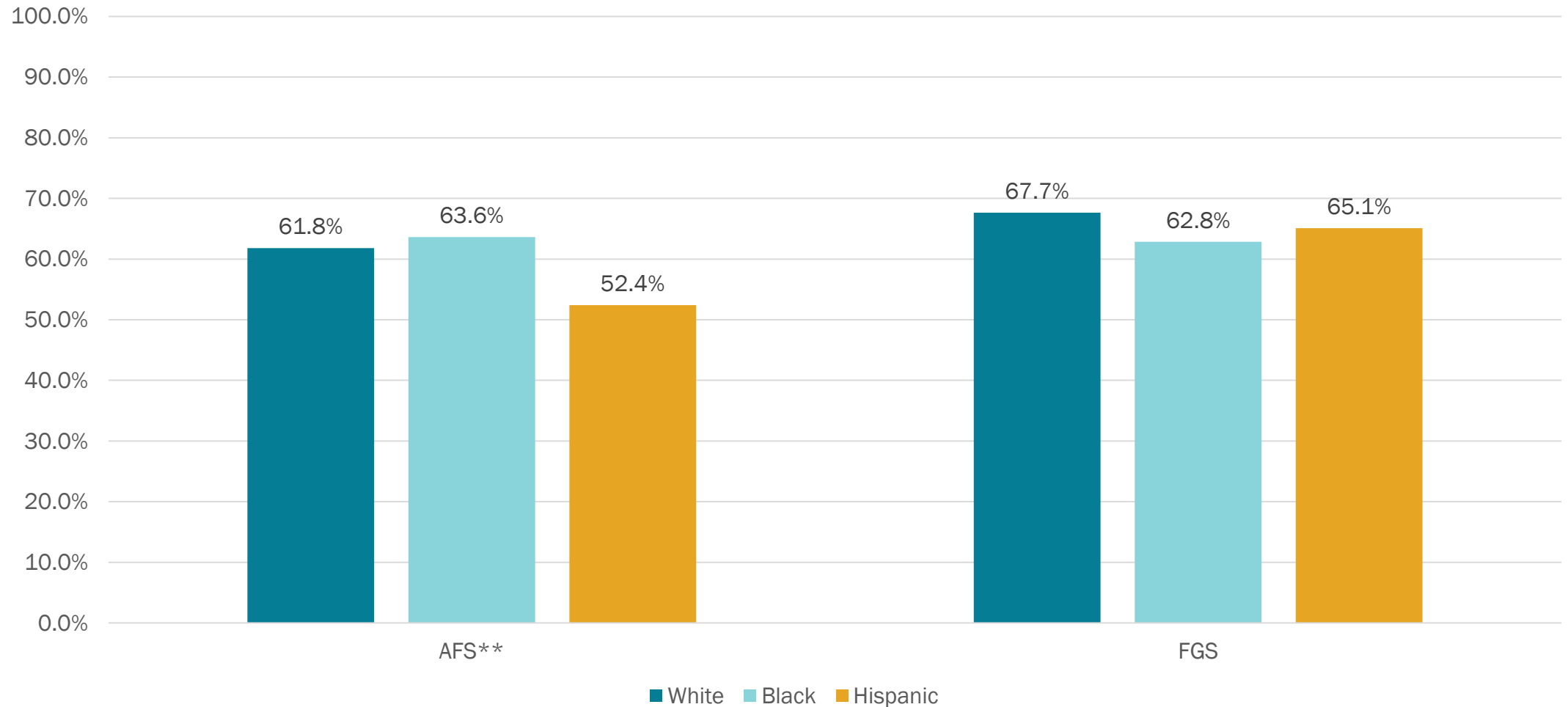
Respondents reported the race/ethnicity of their family member with IDD.

The percentages demonstrate the percentage of those reporting to be one of the three categories.



# Community Engagement in the AFS and FGS

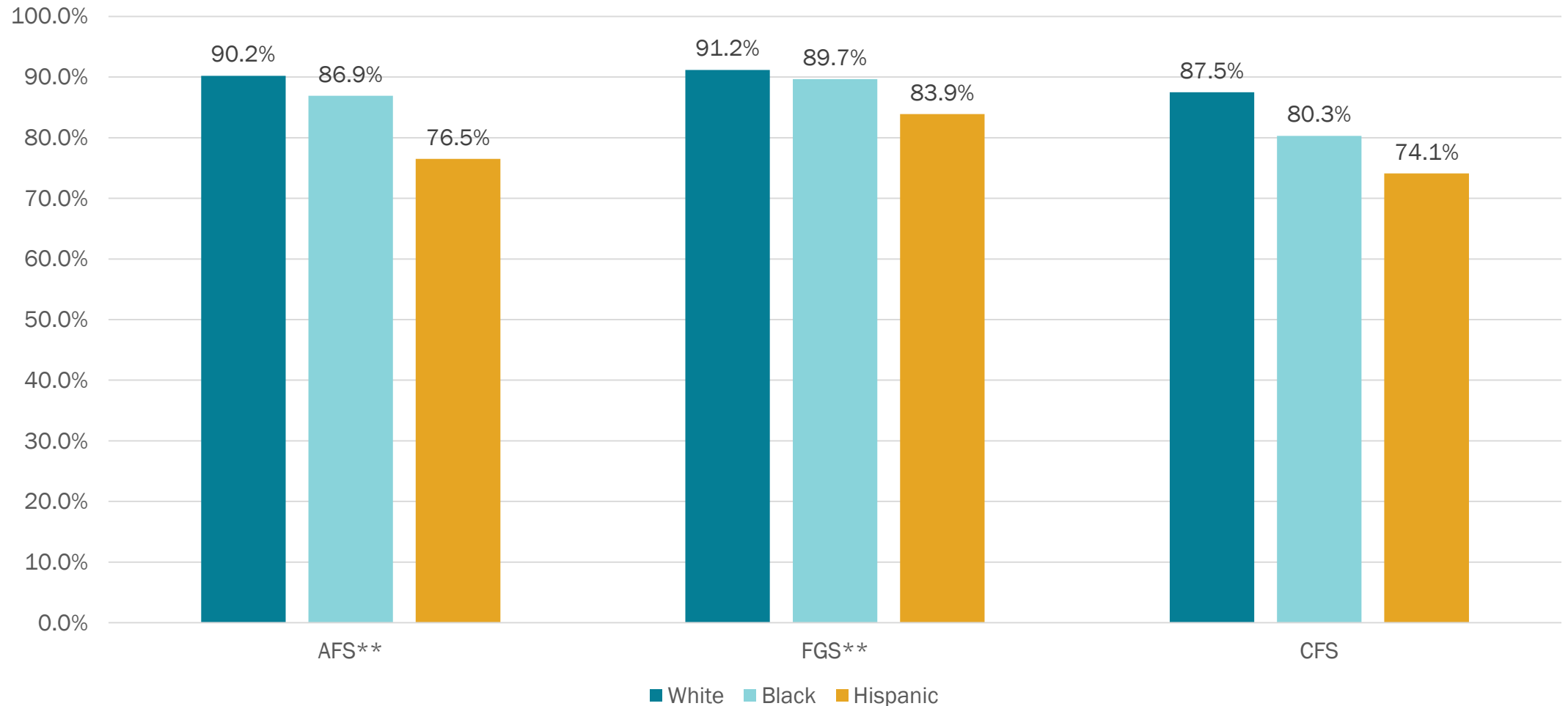
Family member with ID has enough supports (for example, support workers, community resources) to work or volunteer in the community



\*\* =  $p \leq .001$  \* =  $p \leq .01$

# Community Engagement in the Family Surveys

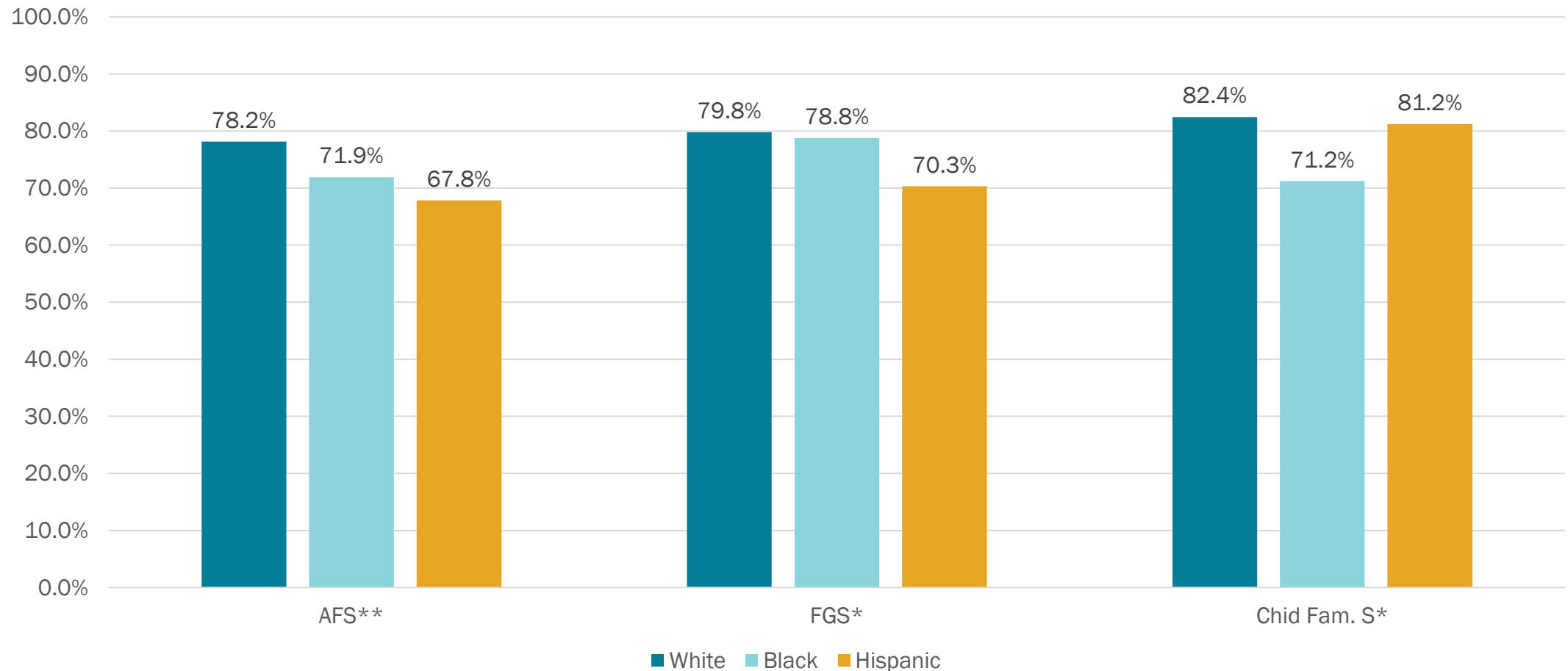
Family member takes part in activities in the community (For example, going to a restaurant, movie or sporting event)



\*\*=  $p \leq .001$  \*=  $p \leq .01$

# Community Engagement in the Family Surveys

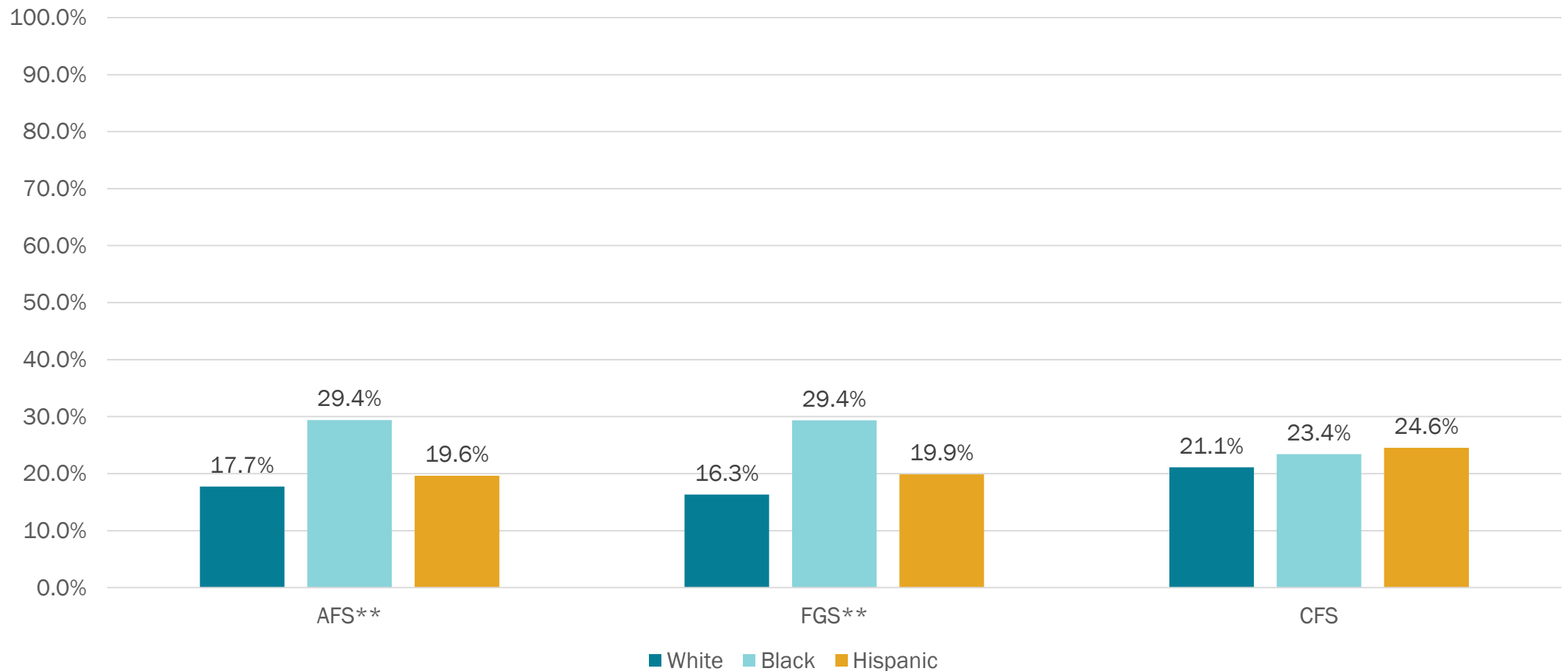
Are there resources that family can use that are not provided by the I/DD agency?  
(For example, recreational programs, community housing, library programs, religious groups, etc.)



\*\*=  $p \leq .001$  \*=  $p \leq .01$

# Community Engagement in the Family Surveys

Does your family take part in any family-to-family networks in your community? (For example, Parent to Parent, sibling networks, etc.)



\*\*=  $p \leq .001$  \*=  $p \leq .01$

# Adult Consumer Survey Results Summary

Black and Hispanic respondents more likely to be in guardianship

Black respondents more likely to be diagnosed with psychotic disorder

Hispanic respondents less likely to speak English as the preferred language and less likely to use spoken communication

White respondents are more likely to have a paid job in the community

Hispanic respondents more likely to use a self directed supports option.



# Adult Consumer Survey Results Summary (contd.)



Hispanic respondents less likely to have friends that are not staff or family and less likely to be able to date without restrictions



Hispanic respondents are less likely to have their rights respected

- Have their mail read without permission
- Can't be alone with visitors
- There are rules about visitors



African American respondents more likely to have gone to a religious service/spiritual practice in the past month



White respondents are more likely to have gone on vacation in the past year

# Family Survey Results Summary

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Families of Hispanic service recipients **less likely** to report that their family member has enough support to work or volunteer in the community. (AFS)

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Families of Hispanic service recipients **less likely** to report that their family member participates in activities in the community (all Family Surveys)

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Families of Hispanic service recipients **less likely** to report that their family has access to community resources that are not provided by the DD agency.(AFS & FGS)

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Families of Black service recipients **less likely** to report that their family has access to community resources that are not provided by the DD agency. (CFS)

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Families of Black service recipients **less likely** to report that their family participates in Family-to-Family networks. (AFS & FGS)



# Limitations

- Results are simple correlations, not controlling for other characteristics by which respondents may differ
  - For example, residence, state of residence, mobility, language, etc.
  - Further research is needed into the cultural factors that may contribute to these differences.
- Respondents to NCI surveys reflect those receiving supports from the state agency. Results cannot be generalized to the IDD population as a whole.



# Future Research

- Expanded analyses controlling for factors by which the three racial groups differ (residence, state, etc.)
- Include qualitative study to enhance understand of the reasons behind the disparities.
- Expand analyses in the context of social determinants of health context and frameworks.

# CONTACT US



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Thank You.

