

National Core Indicators™

Using data to examine systems-level
cultural competence



AGENDA

01



What can the data tell us?

- Examples of how NCI can be used to explore questions cultural competency in support systems

03



The Basics

- Quality measurement in NCI
- What is NCI
- How does it work?
- What questions can NCI answer?

02



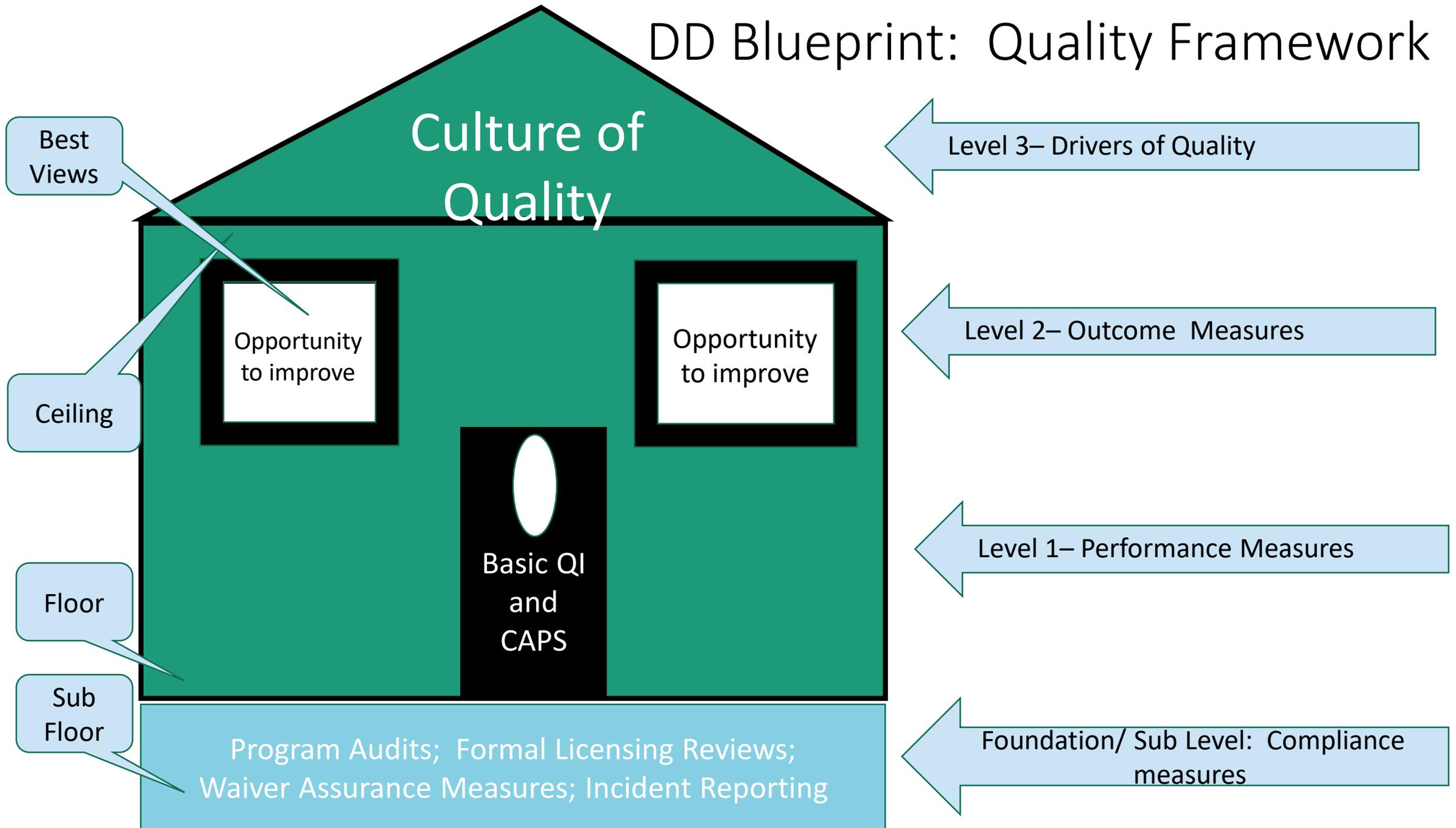
Looking ahead

- Current limitations
- Future opportunities



THE BASICS

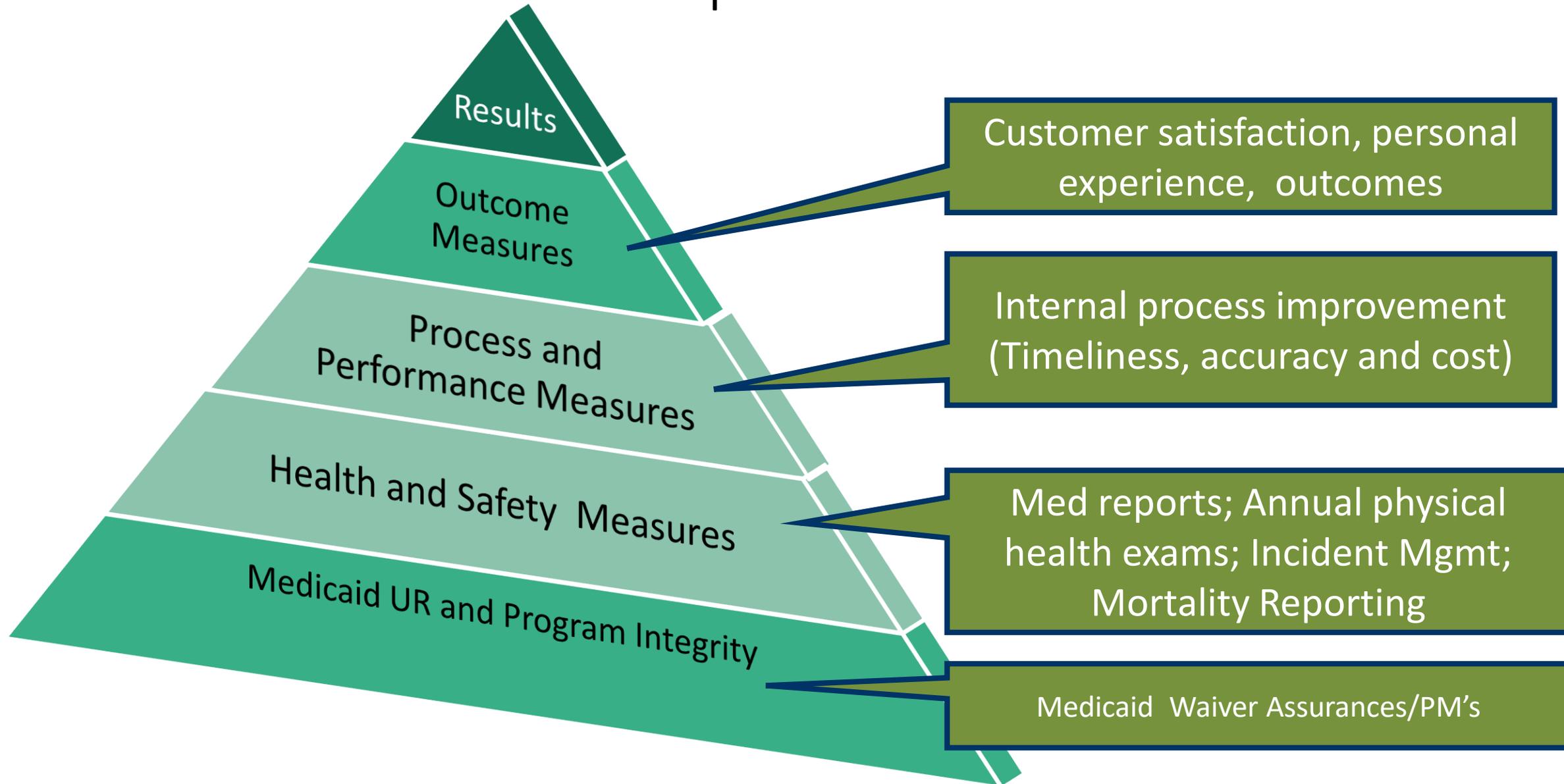
DD Blueprint: Quality Framework



- Compliance with minimum standards gets your blueprints approved, but does not make the house a home
 - Meeting these standards is the *floor*, not the *ceiling*
 - Go beyond for systemic improvement
-



From the base to the top- all measures matter



Key Components of All Quality Systems:

- Quality by Perception
- Quality by Fact



Quality by Fact / Quality by Perception

Quality by Fact-

- evidentiary, indisputable, tend to be binary, can be “proven”

Quality by Perception-

- opinion, impression, influenced by values, senses, emotions, but nonetheless present

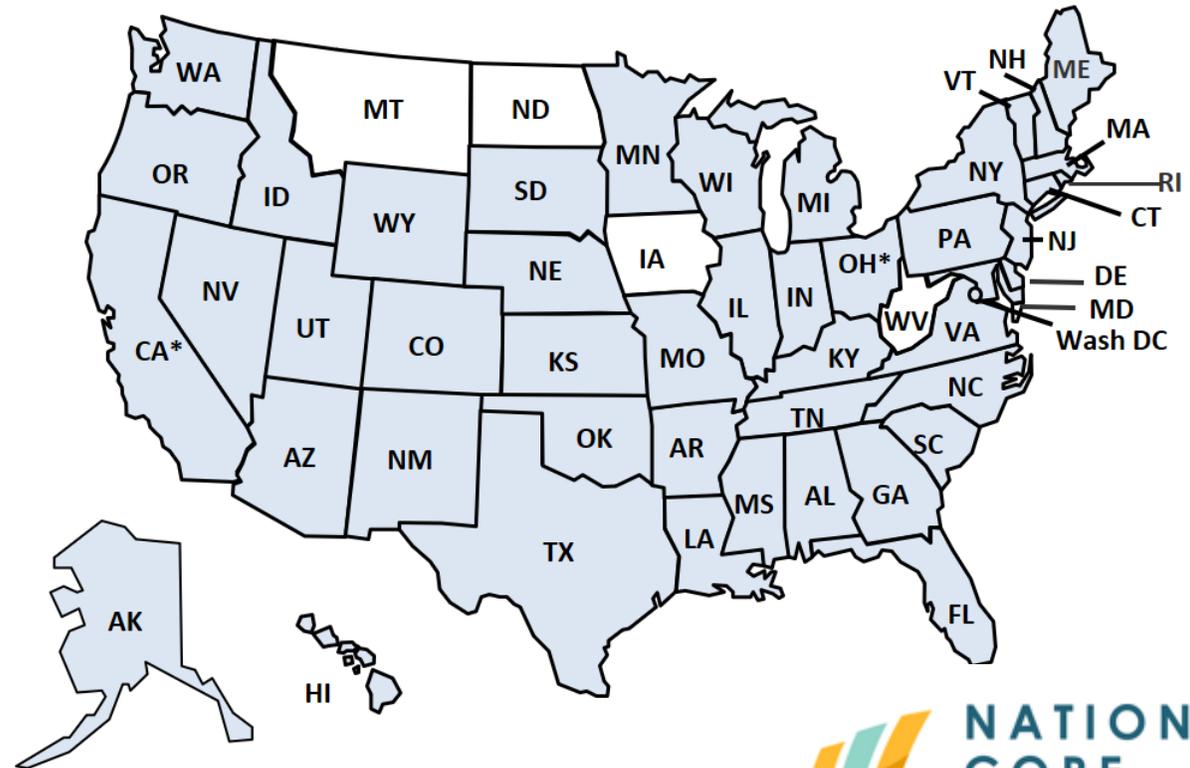
PRO PM's tend to fall into this category



Quality Management Systems take a **both/and** approach, rather than **either/or** approach to these measure types

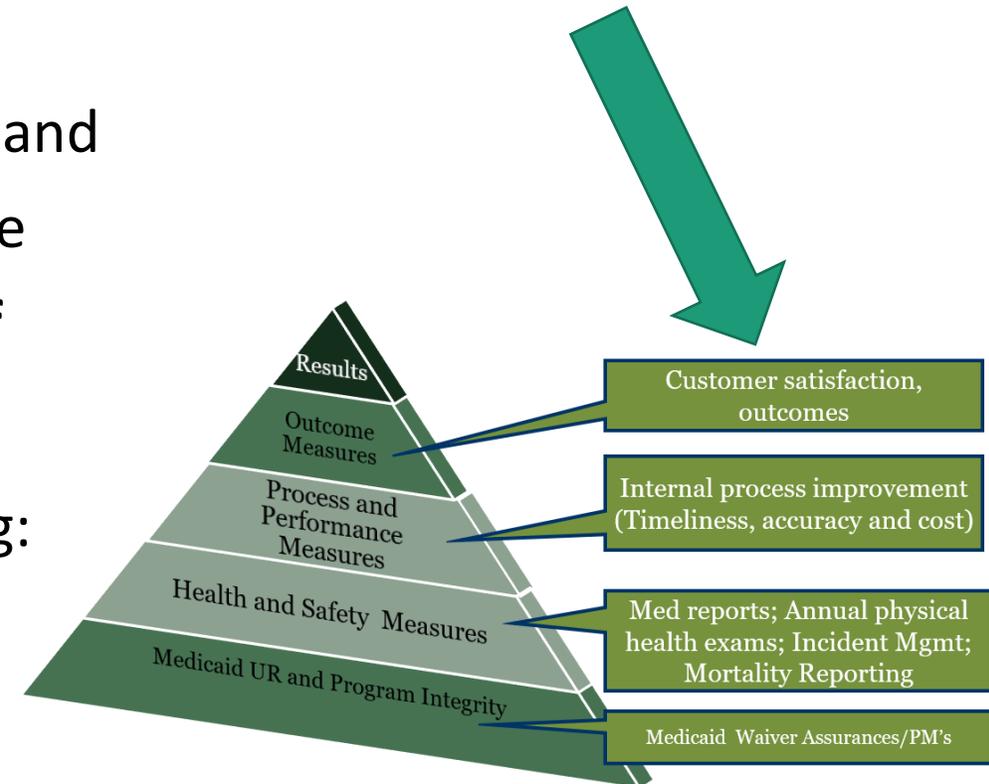
National Core Indicators™

- Provides both perception (people's expectations and insight) and fact (actual services, dx, dates, etc.)
- Provides all three Voices:
 - Customer
 - Workforce
 - Process or operations



What is National Core Indicators™?

- 1997: NASDDDS, HSRI and State DD Agencies came together with a common goal
 - **Look at system performance related to outcomes**
 - Besides looking at numbers such as people served, and types of services being received, they wanted to see **how services affected people's lives and quality of life** → **customer satisfaction & outcomes**
 - NCI looks at performance in several areas, including: employment, community inclusion, choice, rights, satisfaction and health and safety



How Does NCI Collect Data?

In-Person Survey

- Background Information Section
 - Data collected from existing systems data.
 - Age, gender, has a job, preventive care, etc.
- Section I: Subjective, opinion-based questions only answered by person receiving services in face-to-face conversation
- Section II: Fact-based questions. How many times...? Proxy can participate.

Adult Family, Child Family, and Family/Guardian Surveys >> mail surveys – separate sample In Person Survey

Staff Stability Survey >> sent directly to providers – gaining information about turnover rates, wages, benefits.



National Core Indicators offers a unique view

- Individual characteristics of people receiving services
- Outcomes sorted by where people live (residence type)
- Activities people engage in during the day including work outcomes
- 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



Photo credit:

<https://www.thinkculturalhealth.hhs.gov/clas>

NCI surveys provide valuable information from people who are receiving supports and their families and is well situated to examine the cultural and linguistic competence of systems.

Examining NCI data in the 10 NCCC states

2017-18 NCI In-Person Survey

AZ	493
CA	8280
CO	405
DC	416
IN	739
MI	650
NY	515
UT	401
VT	331
WI	987
Total	13217

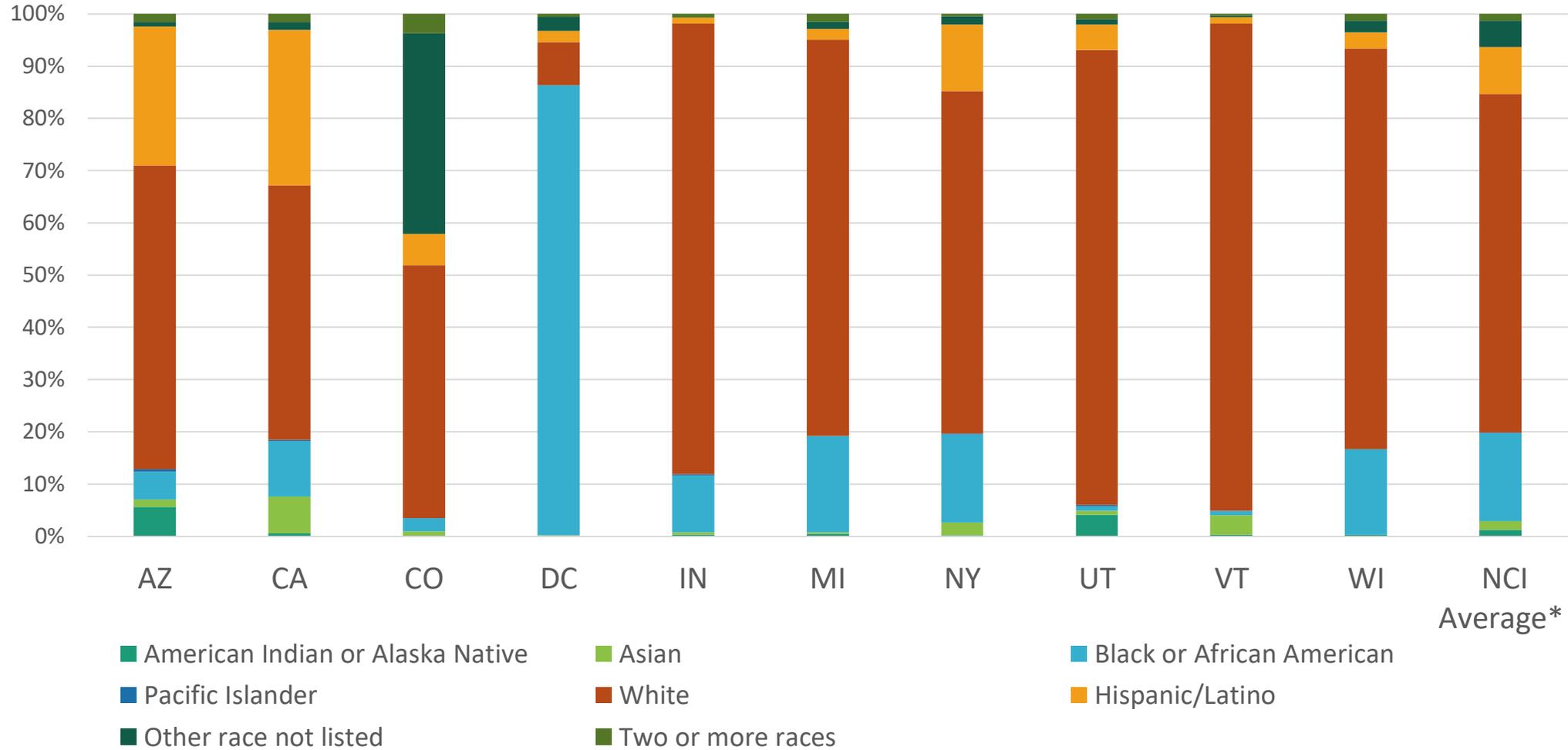


GEORGETOWN UNIVERSITY NATIONAL CENTER FOR CULTURAL COMPETENCE

Community of Practice

on Cultural and Linguistic Competence in Developmental Disabilities

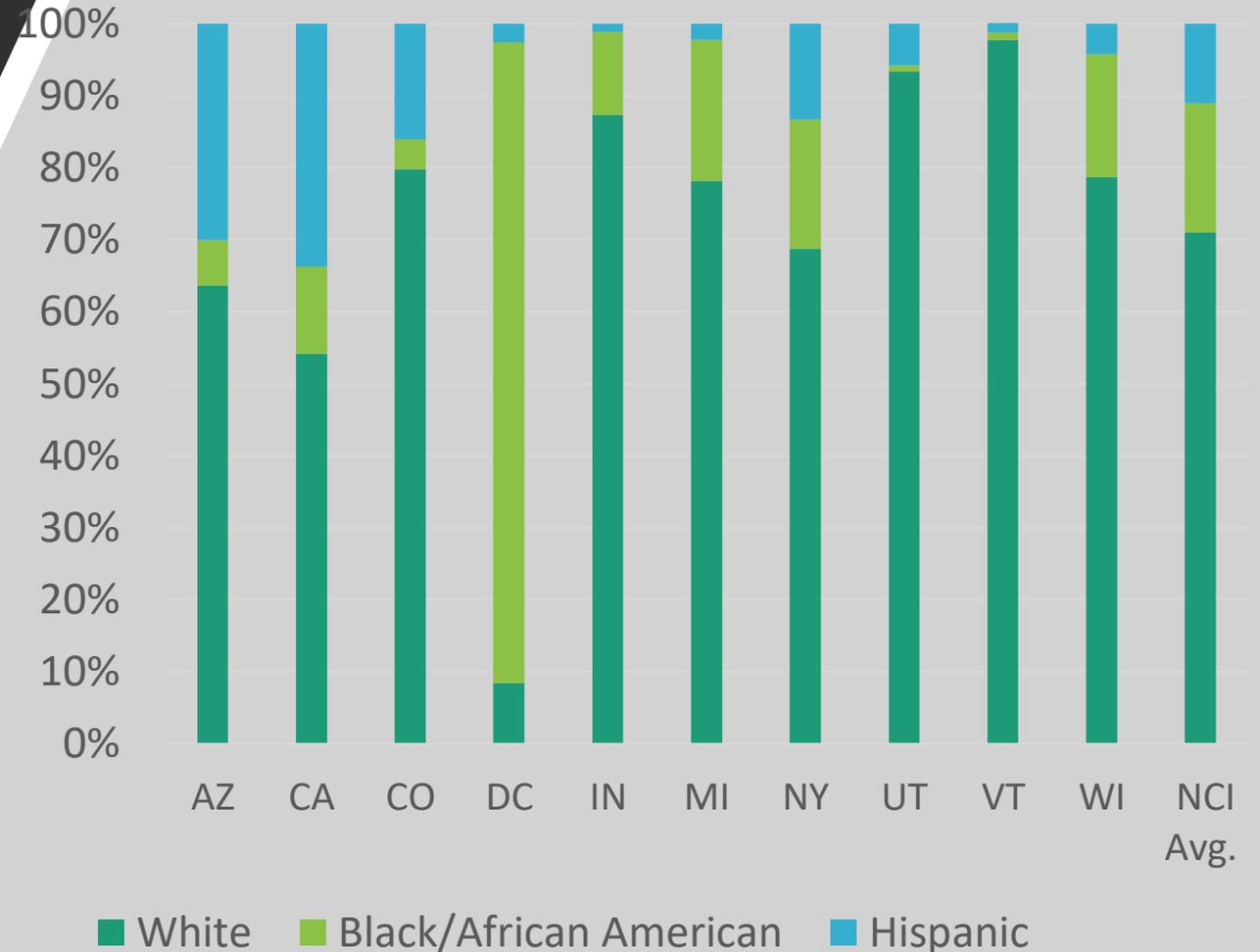
What is this person's race and ethnicity? (reported from existing records)



* Average of state averages

Race/ethnicity vary significantly by state

- For this presentation, using three race/ethnicities to demonstrate capacity of NCI data to look at racial/ethnic differences
- Racial/ethnic composition of states vary significantly
 - Differences in outcomes by race/ethnicity could be based on state differences, rather than actual race/ethnic disparity.
 - Further, deeper analysis is needed understand those differences



What is this person's primary language? (Reported from existing records)

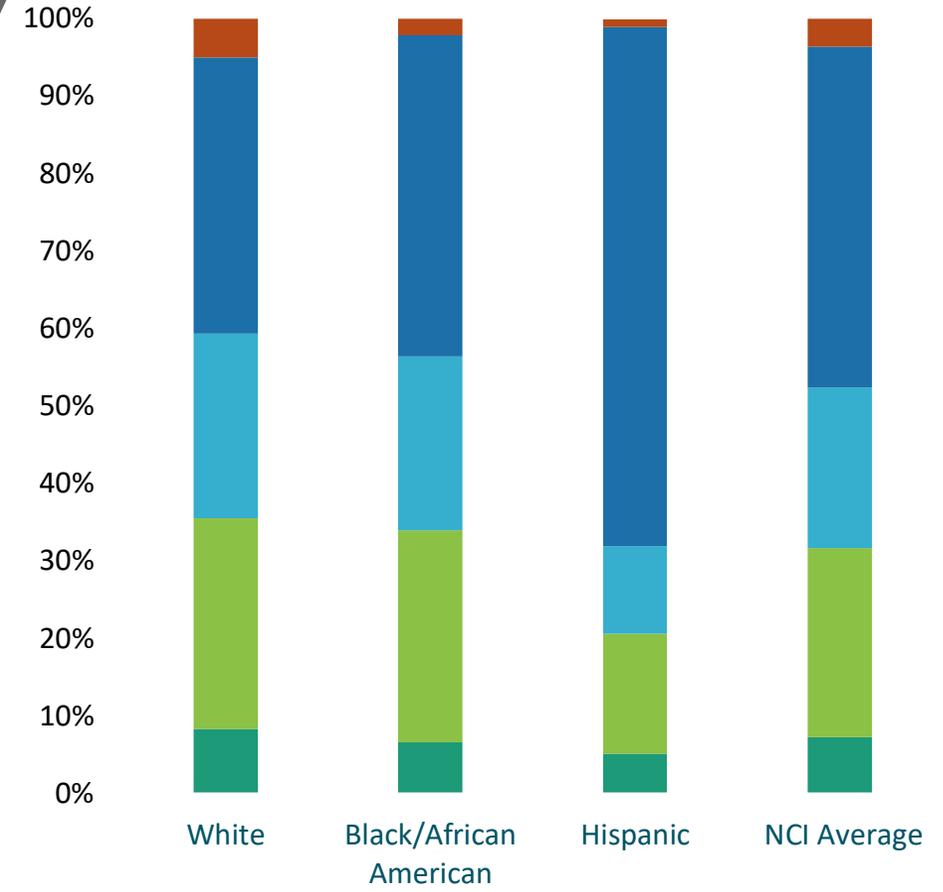
	English	Other
AZ	92.9%	7.1%
CA	81.7%	
CO	98.0%	2.0%
DC	99.0%	1.0%
IN	99.7%	0.3%
MI	97.4%	2.6%
NY	94.1%	5.9%
UT	97.2%	2.8%
VT	94.9%	5.1%
WI	96.8%	3.2%
NCI Average*	95.2%	3.3%

CA additional response options:

- Spanish
- Mandarin
- Tagalog
- Vietnamese
- Korean
- Arabic
- Armenian
- Farsi

* Average of state averages

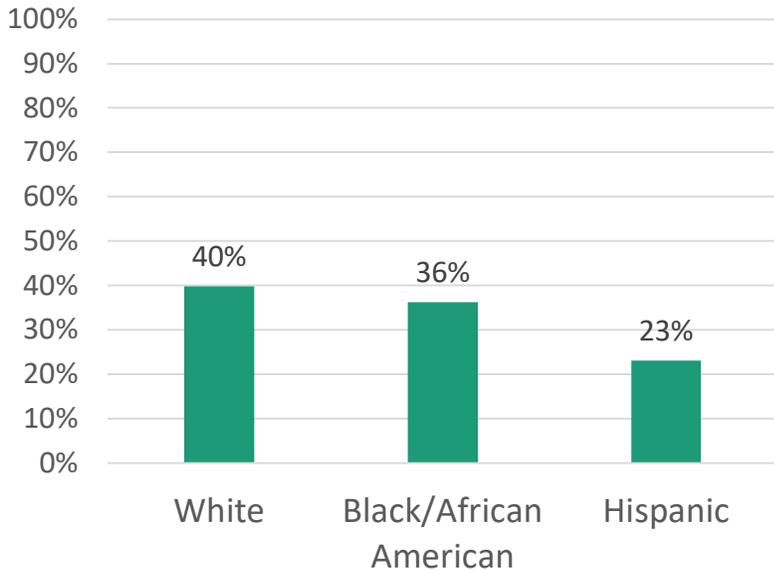
- People of different race/ethnicities live in different residence types
 - Differences in outcomes by race/ethnicity could be based on state differences, rather than actual race/ethnic disparity.
 - Further, deeper analysis is needed to understand those differences



- Foster care or host home
- Parents/relative's home
- Own home or apartment
- Group residential setting (e.g., group home)
- ICF/IID, nursing facility or other institutional setting

Other demographic/personal characteristics

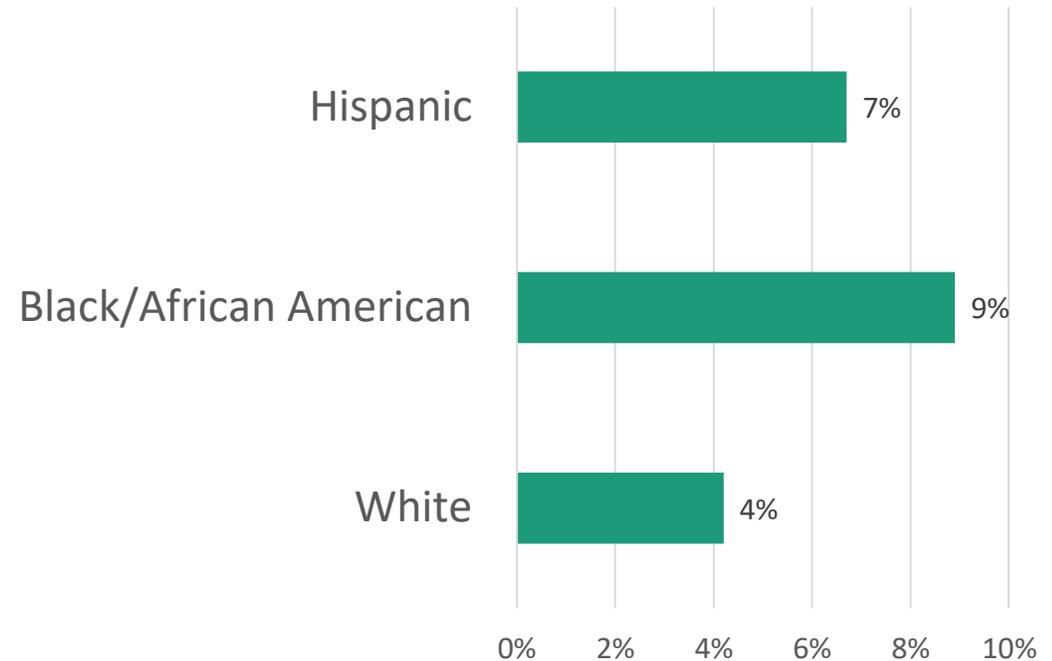
Guardianship



■ Yes, in guardianship relationship. Full, limited, or level can't be distinguished.

Hispanic respondents significantly less likely to be in guardianship relationship

Is this person a parent?



■ Yes, is a parent to at least one child/adult child

Black/African American respondents significantly more likely to be a parent

Examples of differences by race/ethnicity that NCI can show

White respondents significantly more likely to be reported to have a diagnosis of mood, anxiety, psychotic and/or other mental illness.

White: 48.7%	Black/AA 40.5%	Hispanic: 38.5%
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Hispanic respondents significantly less likely to take at least one medication to treat mood, anxiety, psychotic disorders

White: 49.8%	Black/AA 42.7%	Hispanic: 29.3%
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Hispanic respondents significantly less likely to speak as their preferred means of communication

White: 77.6%	Black/AA 78.5%	Hispanic: 69.5%
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NCI allows one to look at differences by race/ethnicity in the following:

- Diagnosis (for example, ASD, CP, Down, FSD, etc.)
- Health conditions (for example: Cardiovascular disease, diabetes, high blood pressure, Alzheimer or other dementia, etc.)

Relationships

1

Do you have friends that you like to talk to or do things with?

No, does not have friends:

White: 11.2%

Black/AA: 11.5%

Hispanic: 18.1%

2

Can you see your friends when you want to?

Yes:

White: 80.1%

Black/AA: 83.5%

Hispanic: 76.9%

3

Do you ever feel lonely?

No, not often:

White: 53.7%

Black/AA: 56.7%

Hispanic: 59.9%

4

Can you go on a date if you want to?

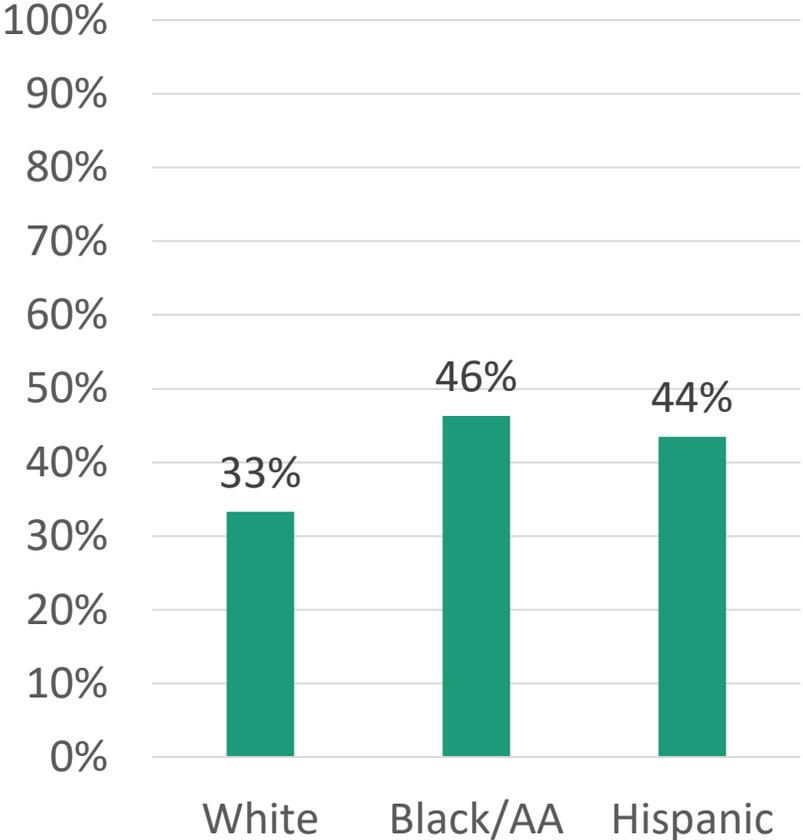
Yes, can date or is living with partner:

White: 77.6%

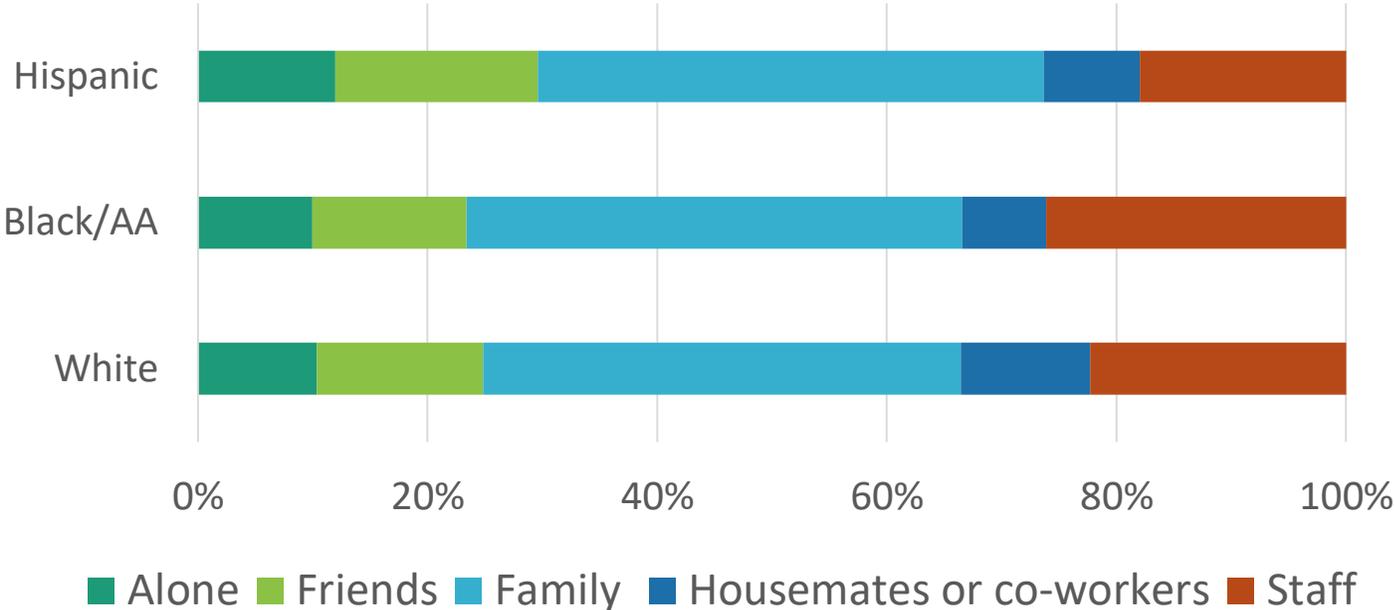
Black/AA: 73.2%

Hispanic: 71.8%

Religious/spiritual practice in the past month

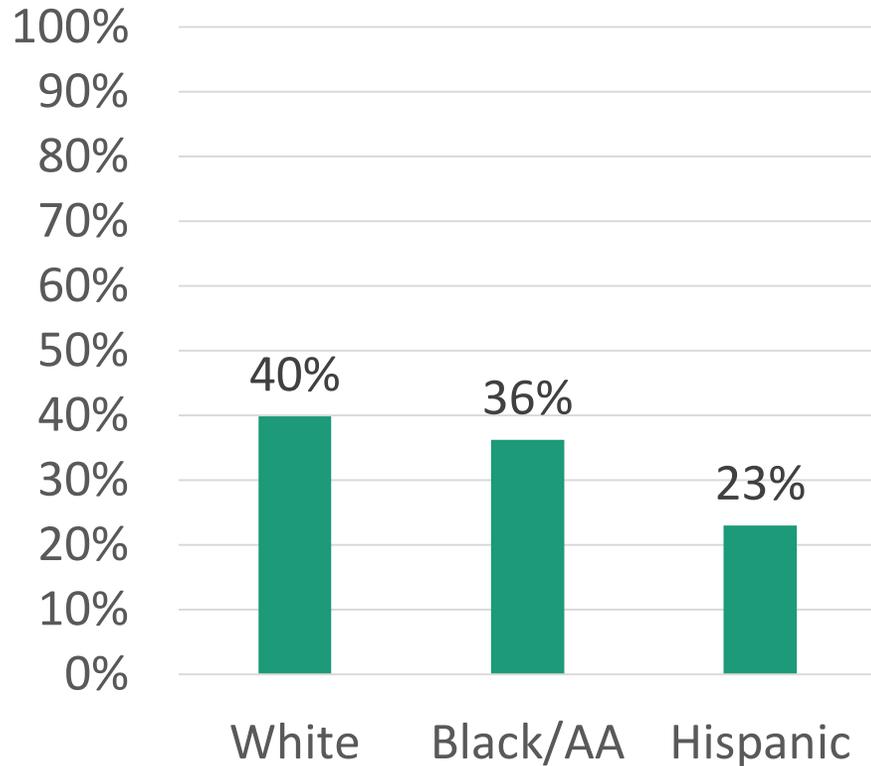


Who did you usually go with?

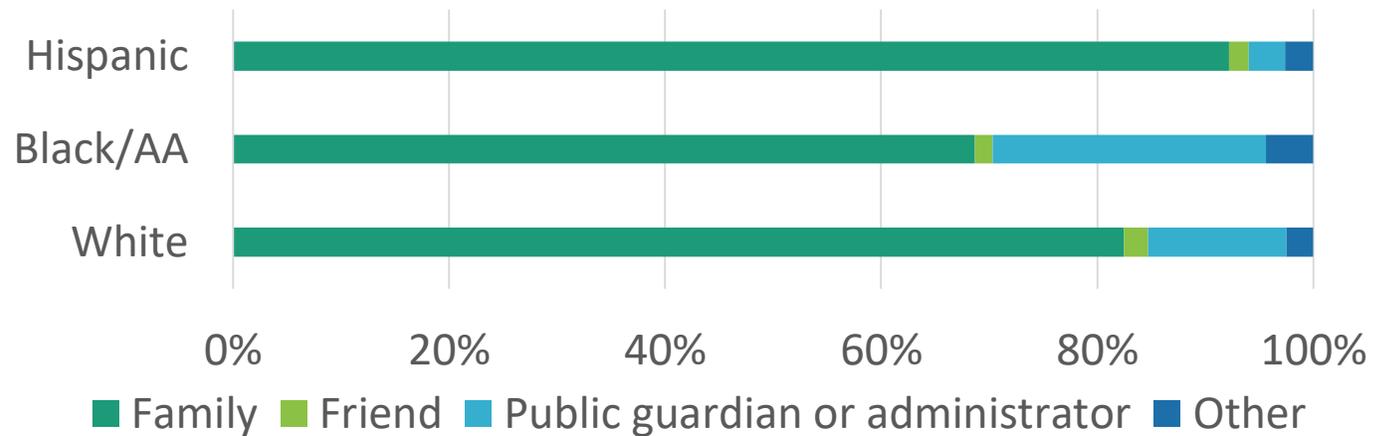


Guardianship

Has guardianship—
limited, full, or unknown
level

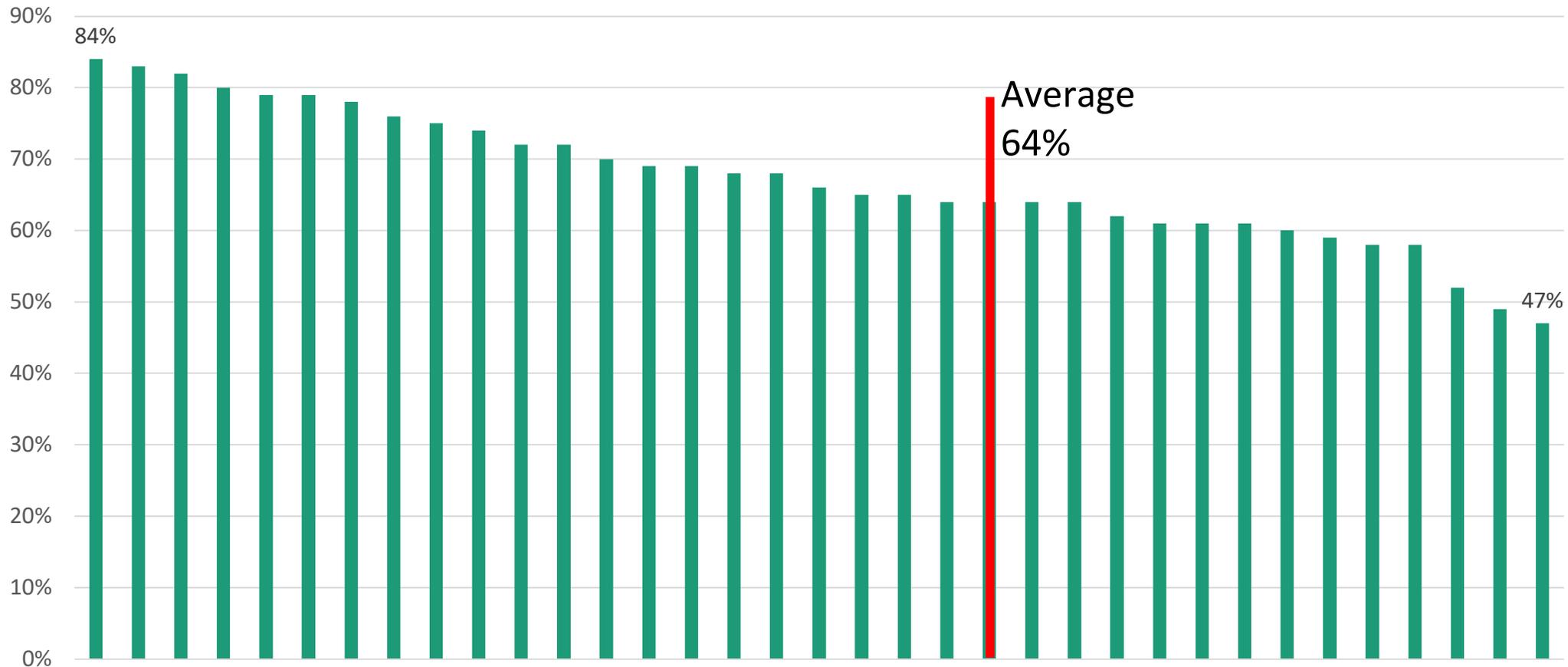


Of those with guardianship, Hispanic respondents are significantly more likely to have a guardian that is a family member, and significantly less likely to have a public guardian or public administrator.



Benchmarking with the Life decisions scale

Includes choice of: residence, roommates, work, day activity, and staff



Results of this scale are risk adjusted. Variables used as risk adjusters are: level of mobility, support needed for behavior, level of ID, and age.

Family Surveys

- Mail-out/internet surveys
 - Adult Family Survey
 - Respondents are families living with adult with disabilities (who receives at least one service in addition to case management)
 - Family Guardian Survey
 - Respondents are families/guardians NOT living with adult with disabilities (who receives at least one service in addition to case management)
 - Child Family Survey
 - Respondents are families living with child with disabilities (who receives at least one service in addition to case management)

Family Surveys (continued)

- Aimed at collecting information about the family experience within service system
- Collect demographic information about family member with disability
 - Age, gender, race, language, daily activity, etc.
- Collects demographic information about respondent and family.
 - Health, age, family income, respondent education level,

For this presentation, we'll look at the

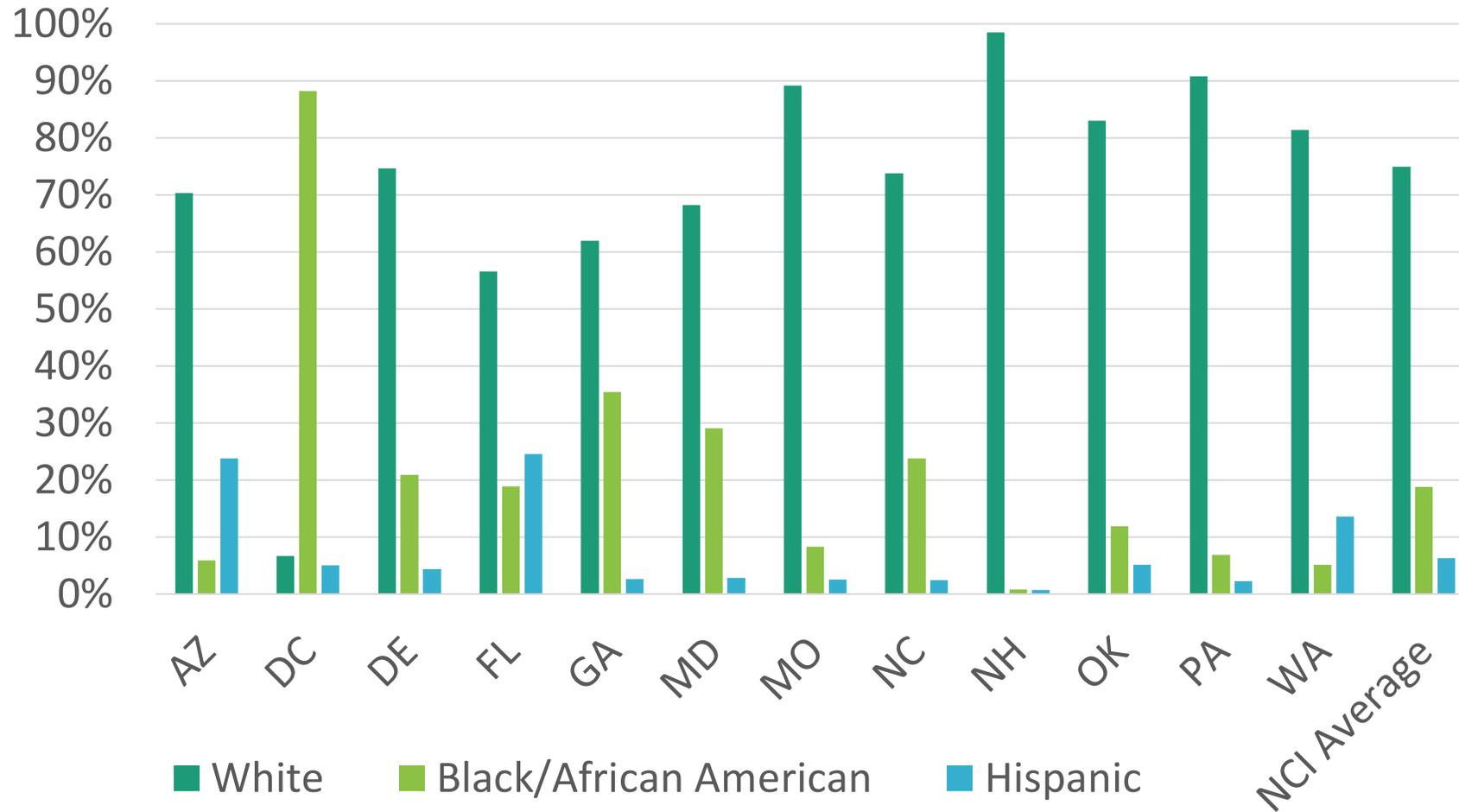
Adult Family Survey 2017-18:

5,221 valid surveys from

AZ, DC, DE, FL, GA, MD, MO, NC, NH, OK, PA, WA

Race/ethnicity of adult with disability	N=4885
White	75.0%
Black/African American	18.8%
Hispanic	6.3%

Race/ethnicity by state



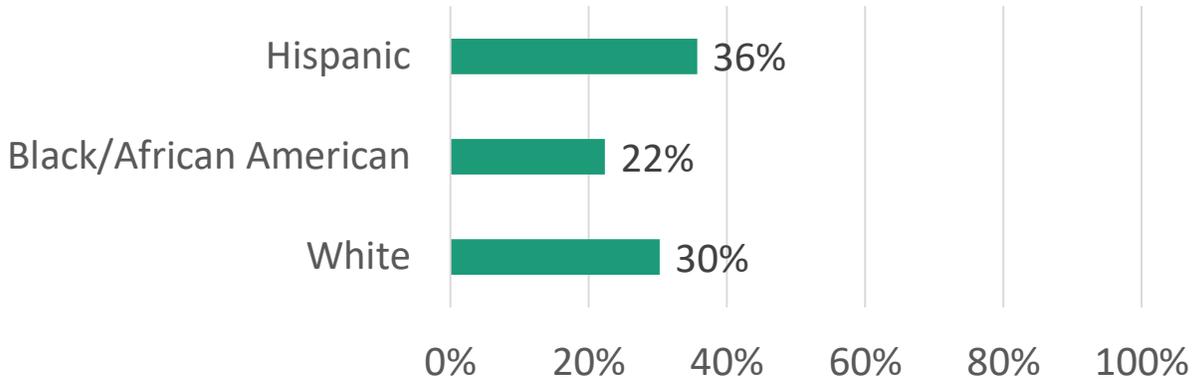
Compare to general population racial/ethnic breakdown

Compare to served population racial/ethnic breakdown

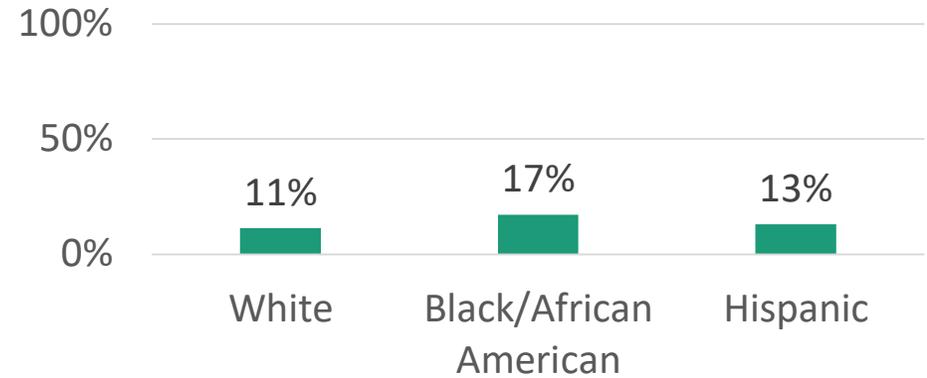
Where are the disparities?

Can get idea of family situation

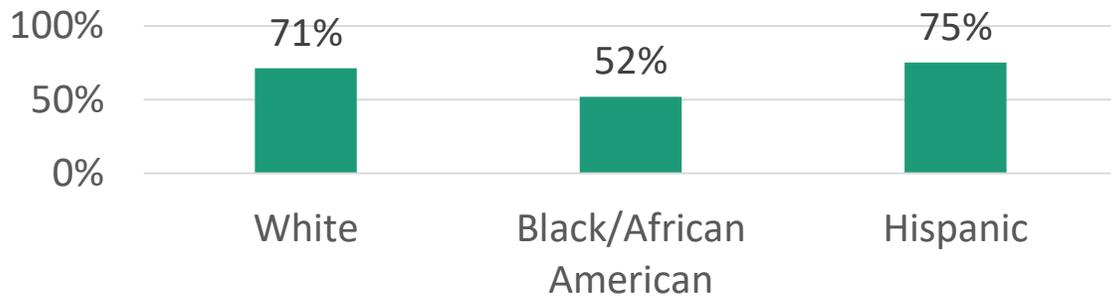
A Family member is paid to provide support



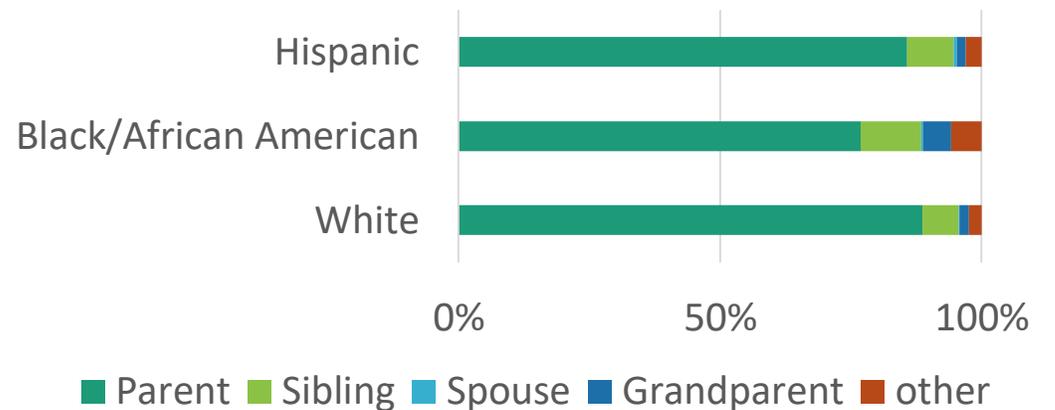
More than one person with I/DD lives in the home



What does family member with I/DD typically do during the day? STAYS AT HOME

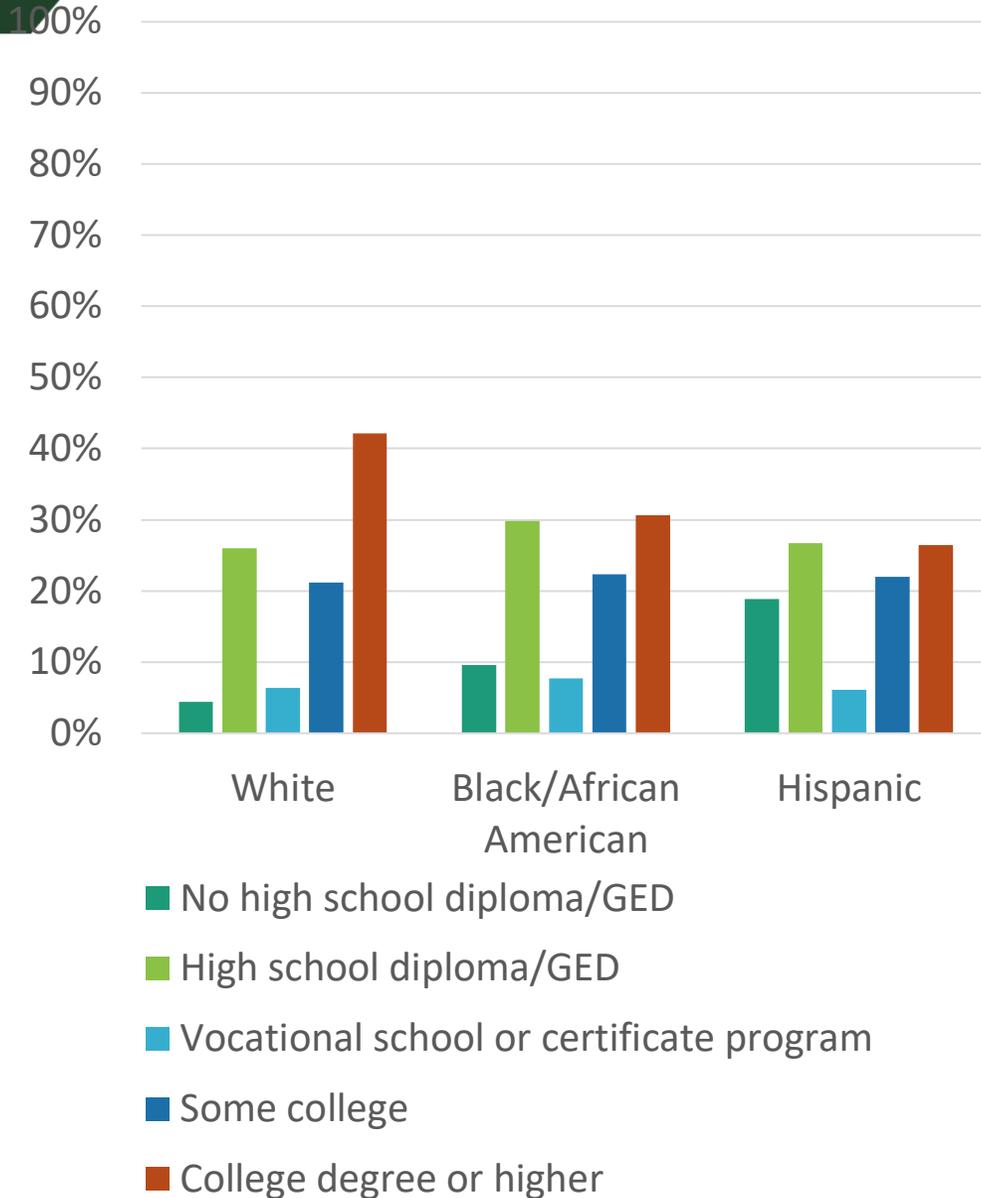


How is respondent related to adult with I/DD



■ Usually/often (every week or more) or Sometimes (less than every week)

Respondent's highest level of education

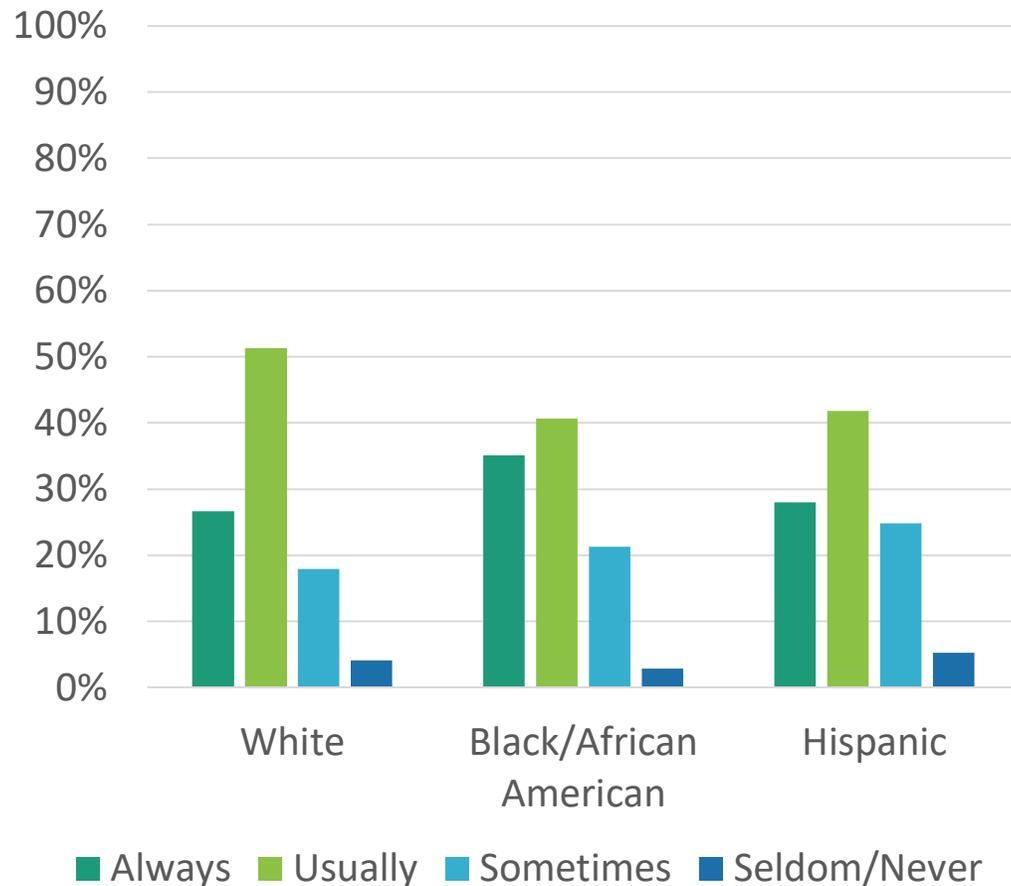


Total taxable household income

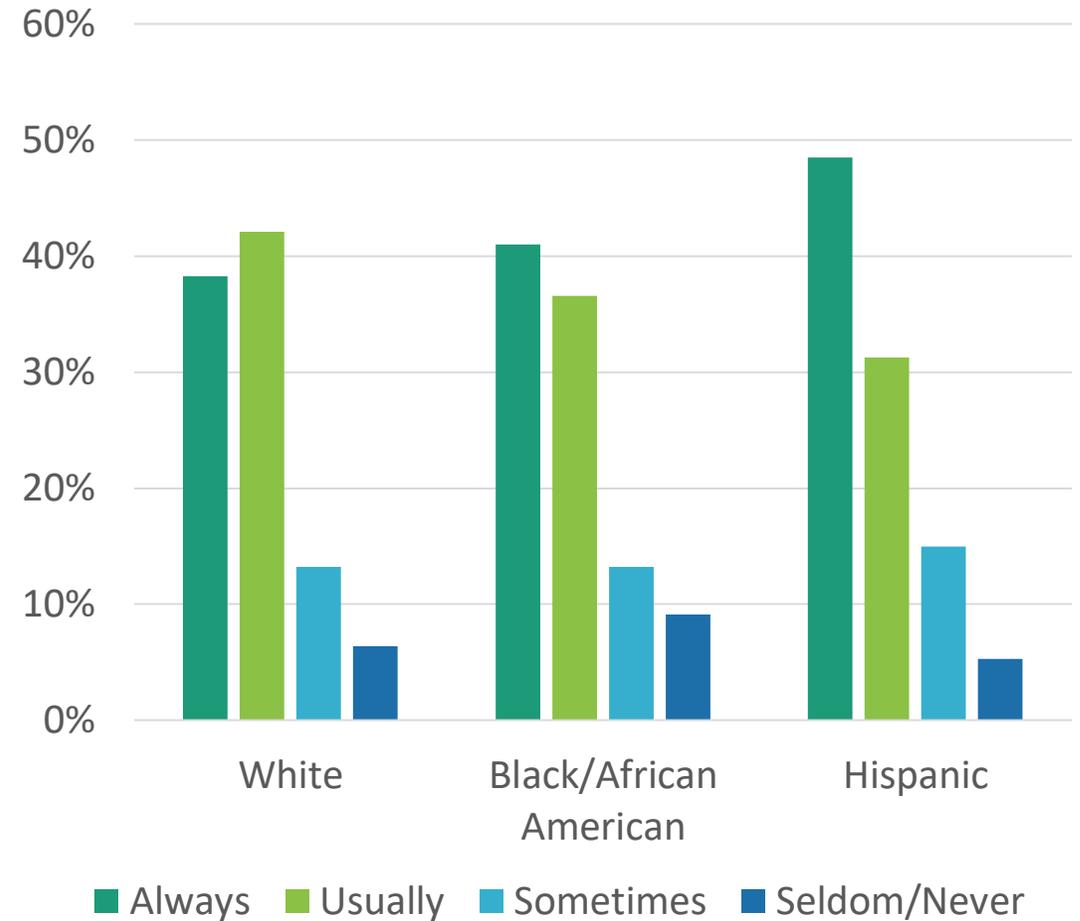
	No earned income	Up to \$15,000	\$15,001-\$25,000	\$25,001-\$50,000	\$50,001-\$75,000	Over \$75,000	Prefer not to say
White	8%	6%	10%	19%	14%	22%	22%
Black/AA	15%	10%	12%	20%	10%	10%	23%
Hispanic	13%	11%	15%	25%	9%	10%	18%

Family responses

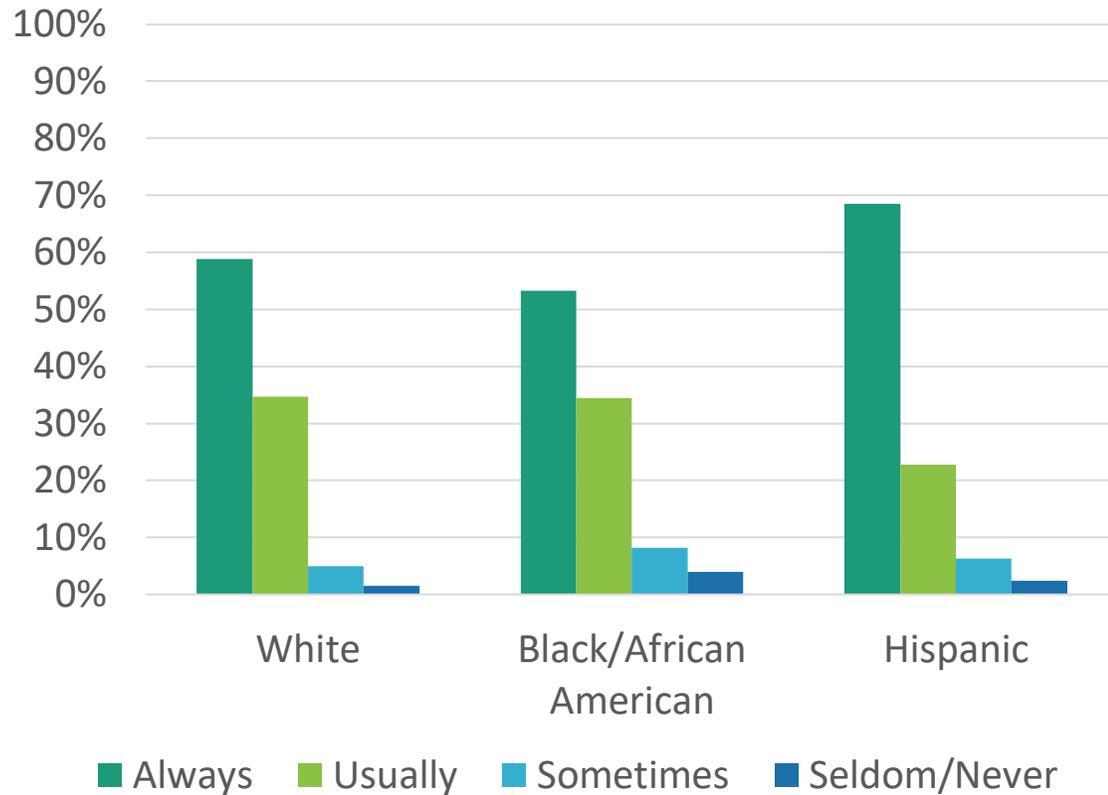
Is the information you get about services and supports easy to understand?



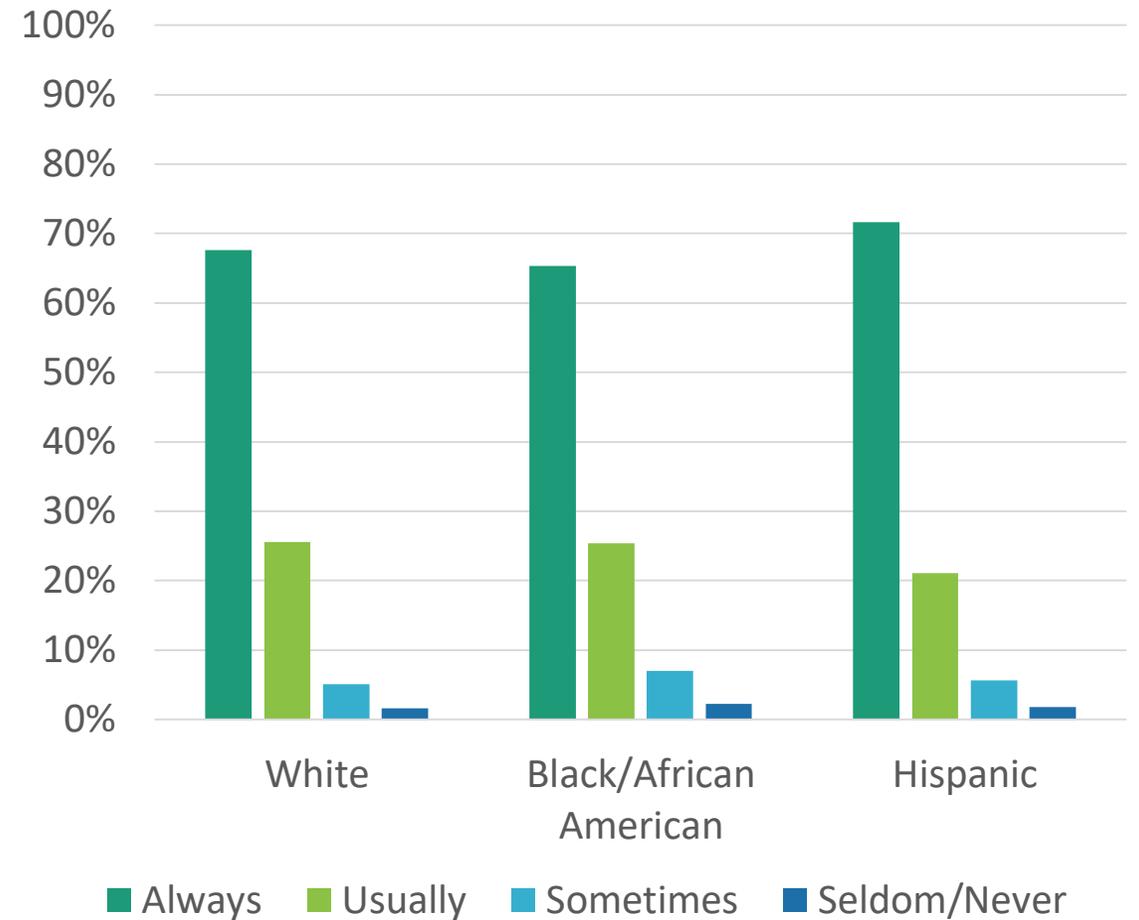
Do services and supports change when your family's needs change?



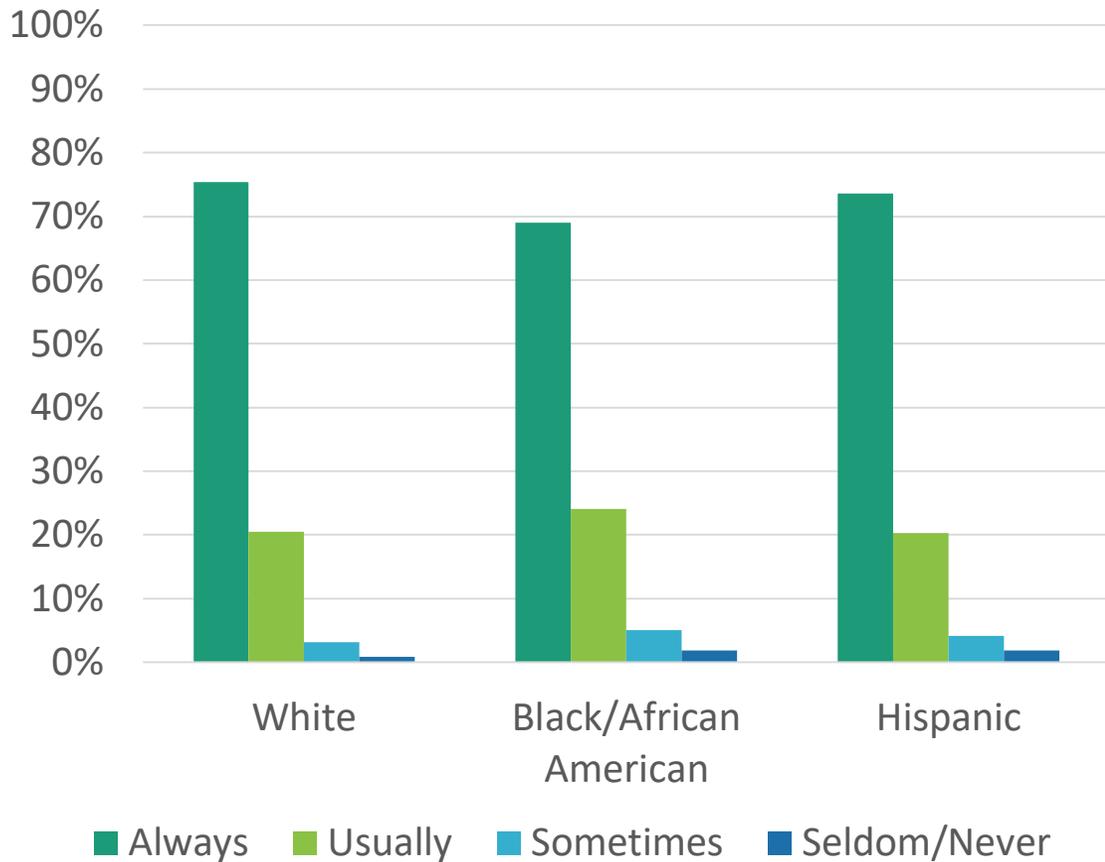
Do support workers come and leave when they are supposed to? (Do they show up on time? Do they show up when they say they will?)



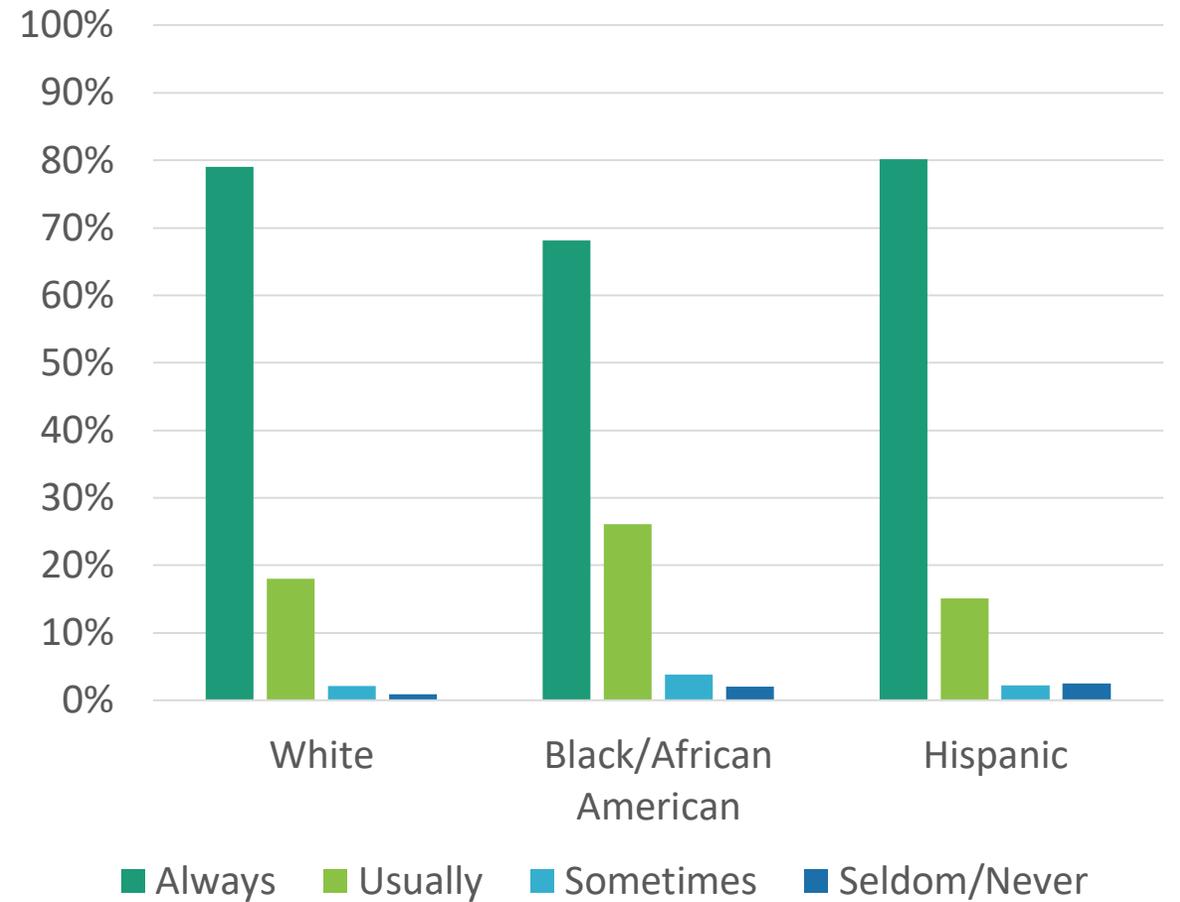
Does the case manager/service coordinator respect your family's choices and opinions?



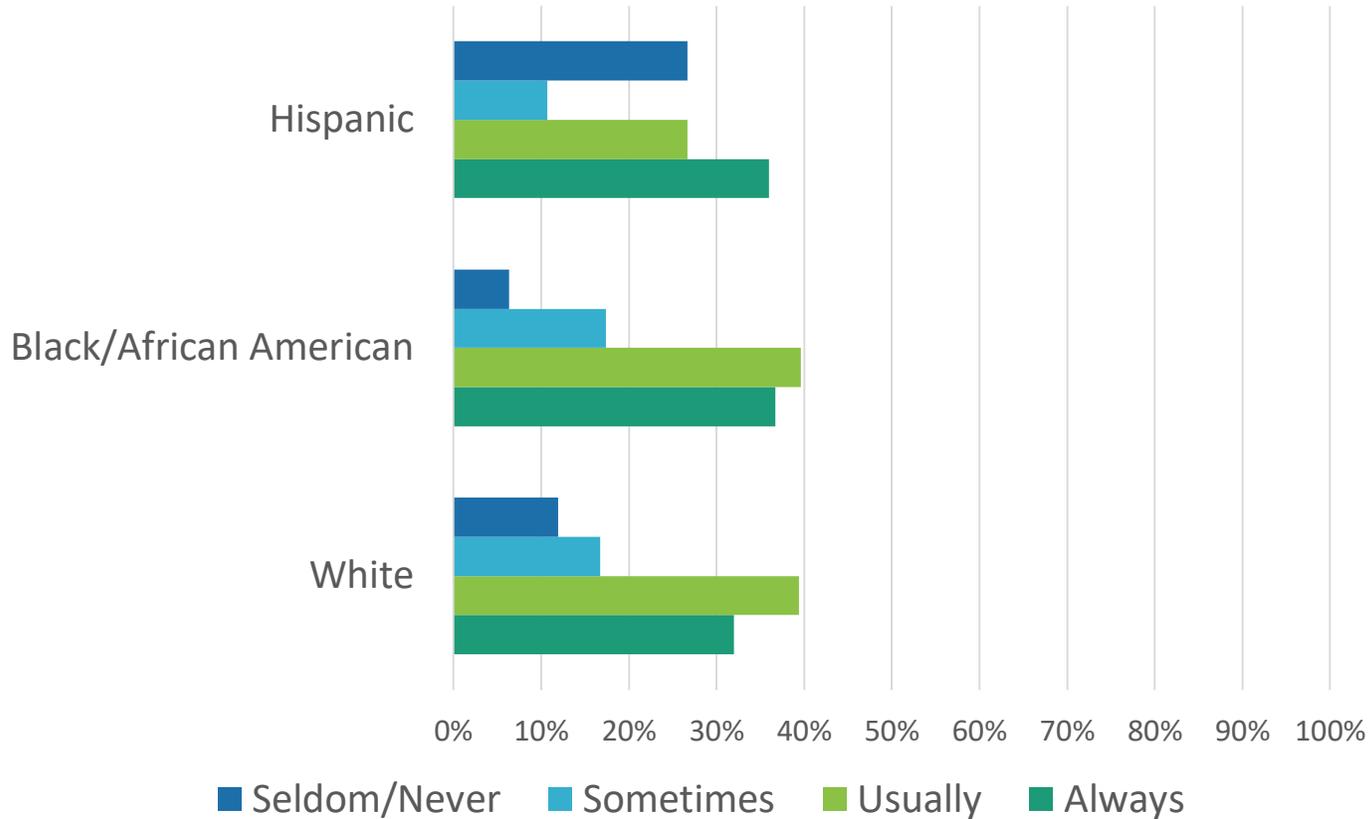
Do support workers speak to you in a way that you understand?



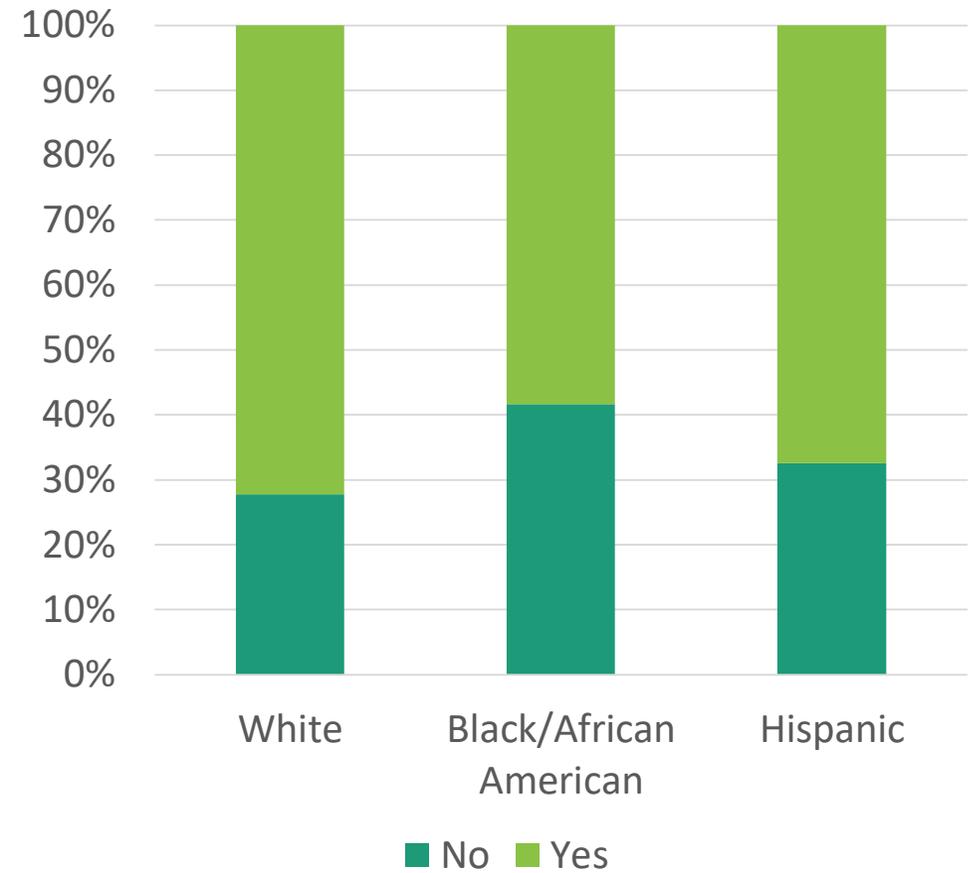
Are services delivered in a way that is respectful of your family's culture?



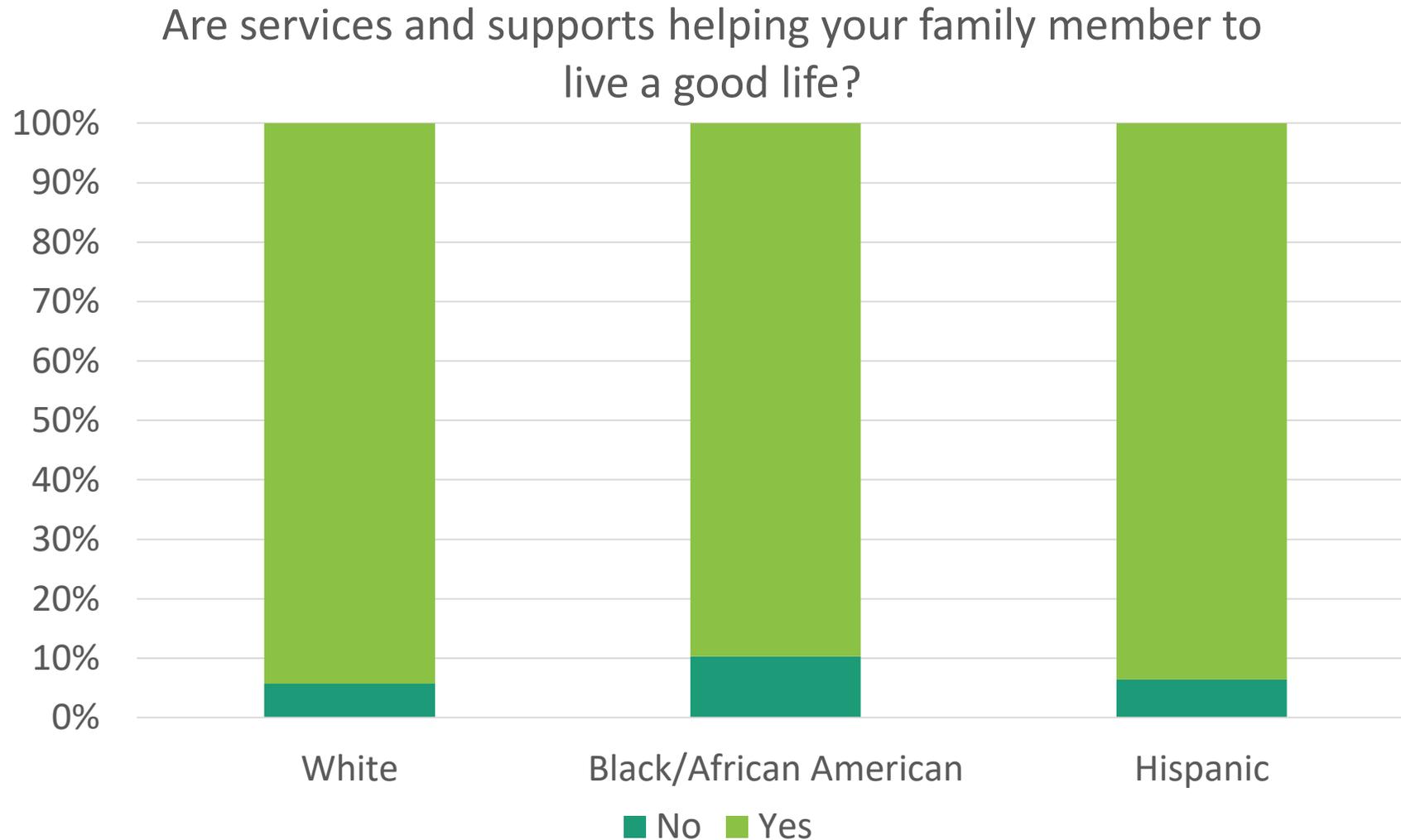
If your family member does not communicate verbally (for example, uses gestures or sign language, uses communication aid), are there support workers who can communicate with him/her?



Have services and supports reduced your family's out-of-pocket expenses for your family member's care?



QoL allows for person-centered definition of “good life”



States can add questions

CA-3 Are there staff at your job who speak your preferred language?

- 98. Not Applicable – no job in the community
- 2. Yes
- 3. Sometimes
- 1. No
- 99. Don't know, no response, unclear response

CA-7 Do your staff support you in a way that is respectful to your culture?

- 98. Not Applicable – doesn't have staff
- 2. Yes – all staff, always
- 3. Sometimes or some staff
- 1. No
- 99. Don't know, no response, unclear response

CA-6 Did you get a copy of your IPP in your preferred language?

- 98. Not Applicable –no IPP
- 2. Yes
- 1. No
- 99. Don't know, no response, unclear response

CA-4 Are there staff at your day program or workshop who speak your preferred language?

- 98. Not Applicable, does not attend day program or sheltered workshop
- 2. Yes
- 3. Sometimes
- 1. No
- 99. Don't know, no response, unclear response

CA-1 Are there staff (or a family member) at your home where you live who speak your preferred language?

- 2. Yes
- 3. Sometimes
- 1. No
- 99. Don't know, no response, unclear response, or staff do not come into your home

CA-8 If you did out for religious or spiritual practice, did you choose the religious service or spiritual practice you went to?

- 98. Not Applicable – person didn't go out for religious/spiritual practice
- 2. Yes
- 1. No
- 99. Don't know, no response, unclear response

NCI Chart Generator

<https://www.nationalcoreindicators.org/charts/2015-16/>

Filter any question by different factors

NCI Charts (2015-16)

Generate a Chart

Please select a measure below to generate a chart.

Generate Chart

1.) Select a State

NCI Average

2.) Select a Measure

- ▶ Descriptive
- ▶ Health, Welfare, and Rights
- ▶ Individual Outcomes
- ▶ System Performance

3.) Filter (Optional)

(0 of 2 selected)

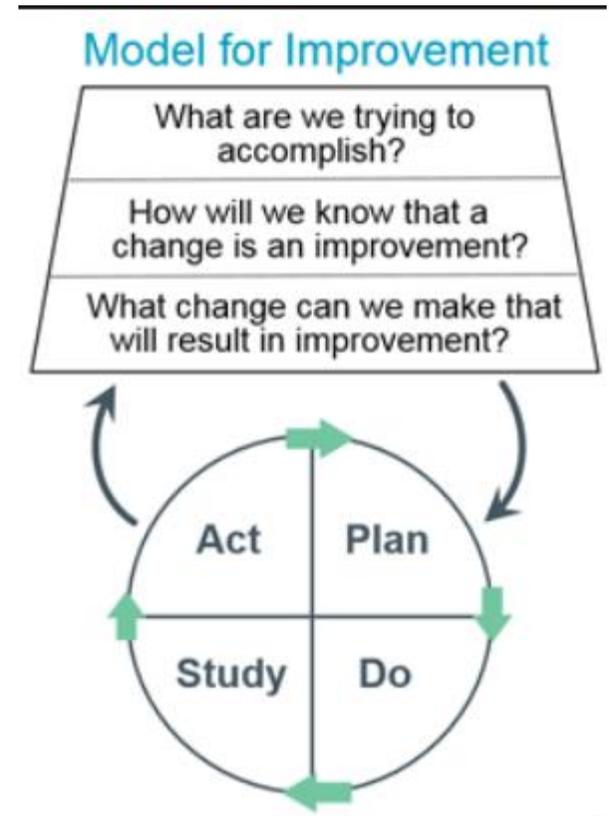
Level of ID	+
Type of Residence	+
Race/Ethnicity	+
Gender	+
Age Categories	+
Mental Illness/Psychiatric Diagnosis	+
Other Diagnoses: Autism Spectrum Disorder	+
Primary Means Of Expression	+



LOOKING AHEAD



- Improvements in complex areas such as cultural competence should be monitored using a multi-faceted quality improvement approach that incorporates measures representing the voice of the “customer”, the voice of the workforce, and the voice of system.
- The Model for Improvement asks key questions that need to be asked in order to advance positive change.
- NCI may assist in providing voice at a systems level to the people who are receiving supports and allow for monitoring outcomes by racial and ethnic group.
- NCI, as a system level survey has limitations in the ability to drill down by population unless states choose to expand their sample.
- Additional questions could assist in learning about variance by people’s preferred language and other important cultural characteristics.



The Improvement Guide: A Practical Approach to Enhancing Organizational Performance, Langley, Moen et al.



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Thank You.



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CORE
INDICATORS™