



NATIONAL
CORE
INDICATORS®
NASDDDS & HSRI

Uncovering Racial & Ethnic Disparities In Reported Experience & Outcomes Among People with IDD

[See the data brief here](#)

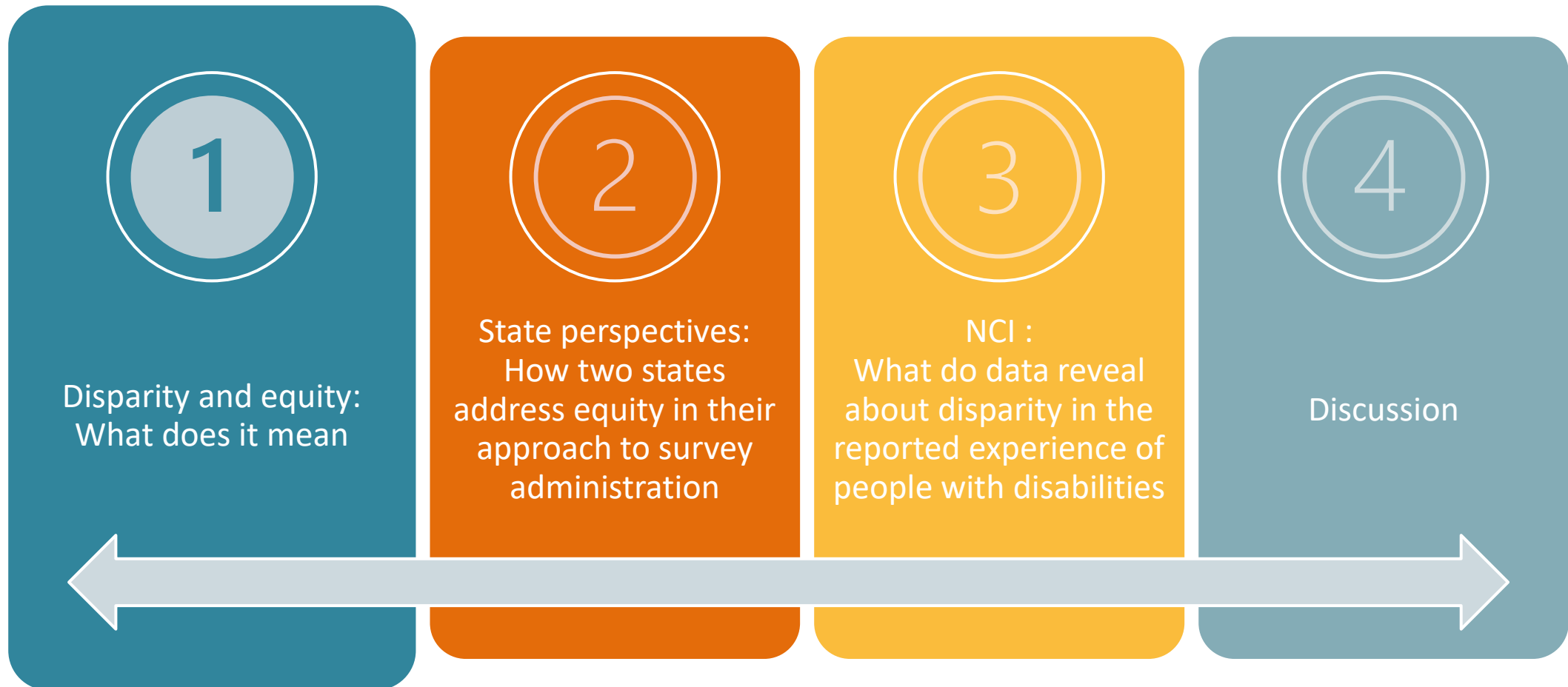
[See the data spotlight here](#)

Sarah Taub Series

Introduction and Welcome



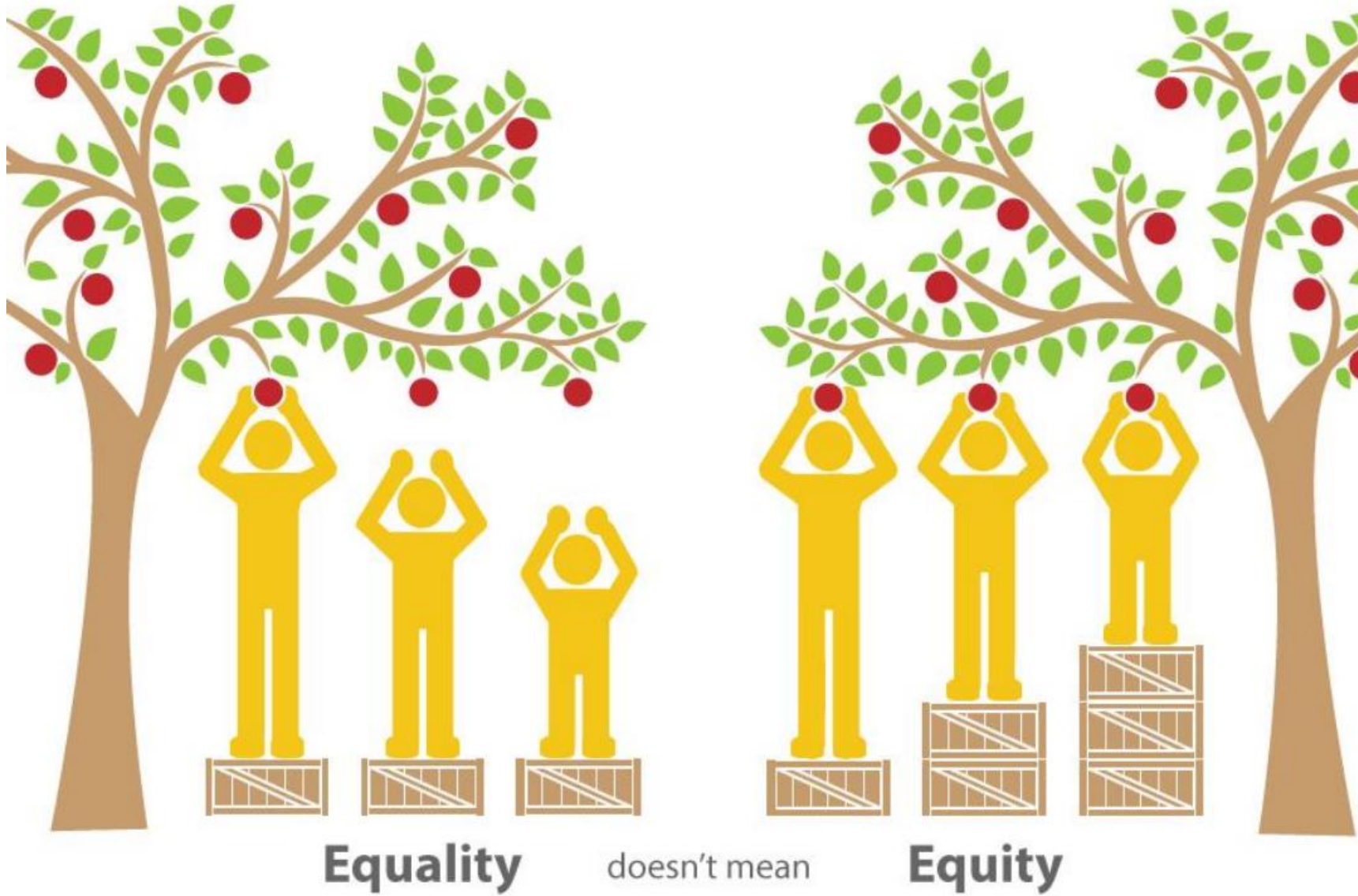
On the agenda





Equality, Disparity and Policy Equity

Definitions and the role of NCI data in achieving equity



Disparities, Equality and Equity

Disparities are observed differences between groups (“differences”) . This can be by race and ethnicity, age groups, language, or geography, to name a few.

Equality is providing the same level of opportunity and assistance to all segments of society, such as races and genders.

Equity is defined as “the state, quality or ideal of being just, impartial and fair.” ¹ The concept of equity is synonymous with fairness and justice. “ Equity is providing various levels of support and assistance depending on specific needs or abilities”.

Laws such as the Civil Rights Act of 1964 provide equality, while policies such as affirmative action provide equity.

¹ [Equity vs. Equality and Other Racial Justice Definitions - The Annie E. Casey Foundation \(aecf.org\)](https://www.aecf.org/equity-vs-equality-and-other-racial-justice-definitions)

Intersectionality



Kimberlé Crenshaw writes that “because the intersectional experience is greater than the sum of racism and sexism, any analysis that does not take intersectionality into account cannot sufficiently address the particular manner in which Black women are subordinated.”

Crenshaw uses intersectionality to describe overlapping social identities and related systems of oppression, domination, or discrimination and their complex and cumulative effect specially focused on Black women because of their membership in multiple social groups.

Crenshaw, K. (1991). Mapping the Margins: Intersectionality, Identity Politics, and Violence against Women of Color. Stanford Law Review, Vol. 43, No. 6 (Jul., 1991), pp. 1241-1299.



Data is essential to move towards equity

- Data are essential to show what are the systemic inequities lie.
- Data describing the population with IDD is limited. ²
- ² [The Importance of Data in Achieving Health Equity for Individuals with Intellectual and Developmental Disabilities | ACL Administration for Community Living](#)

Policy Equity

“When it comes to human value, we need equality. Equality is valuing all phenotypes, ethnicities, and cultures equally, placing all groups on the same level. To create a world where every human group is valued equally is to create a world where every human is valued equally. But when it comes to policy, we need equity. Not equality. Policy *equality* is providing the same to unequally resourced groups. Policy *equity* is allocating resources to unequally resourced groups based on need”

....

- “Policy equality only replicates and amplifies the inequality that is there from the start. Policy equity, on the other hand, repairs that inequality.”

We Still Don't Know Who the Coronavirus Victims Were _ The Atlantic
Ibram X. Kendi <https://www.theatlantic.com/ideas/archive/2021/05/we-still-dont-know-who-the-coronaviruss-victims-were/618776/>

NCI is one source to examine experiences and move towards equity.

- NCI data provides valuable insights into experiences and outcomes for people with IDD living in the community.
- How do we know we are collecting information from a representative population?
- What systemic inequities exist?
- [NCI Data Brief: Racial Equity \(nationalcoreindicators.org\)](https://nationalcoreindicators.org)



National Core Indicators®

DATA BRIEF

FEBRUARY 2021



What Do NCI Data Tell Us About Significant Racial & Ethnic Disparities Across Quality of Life & Health Domains?

By Valerie J. Bradley, Dorothy Hiersteiner, Tawara D. Goode, Alexandra Bonardi, Stephanie Giordano, Mary Lou Bourne, and Laura Vegas



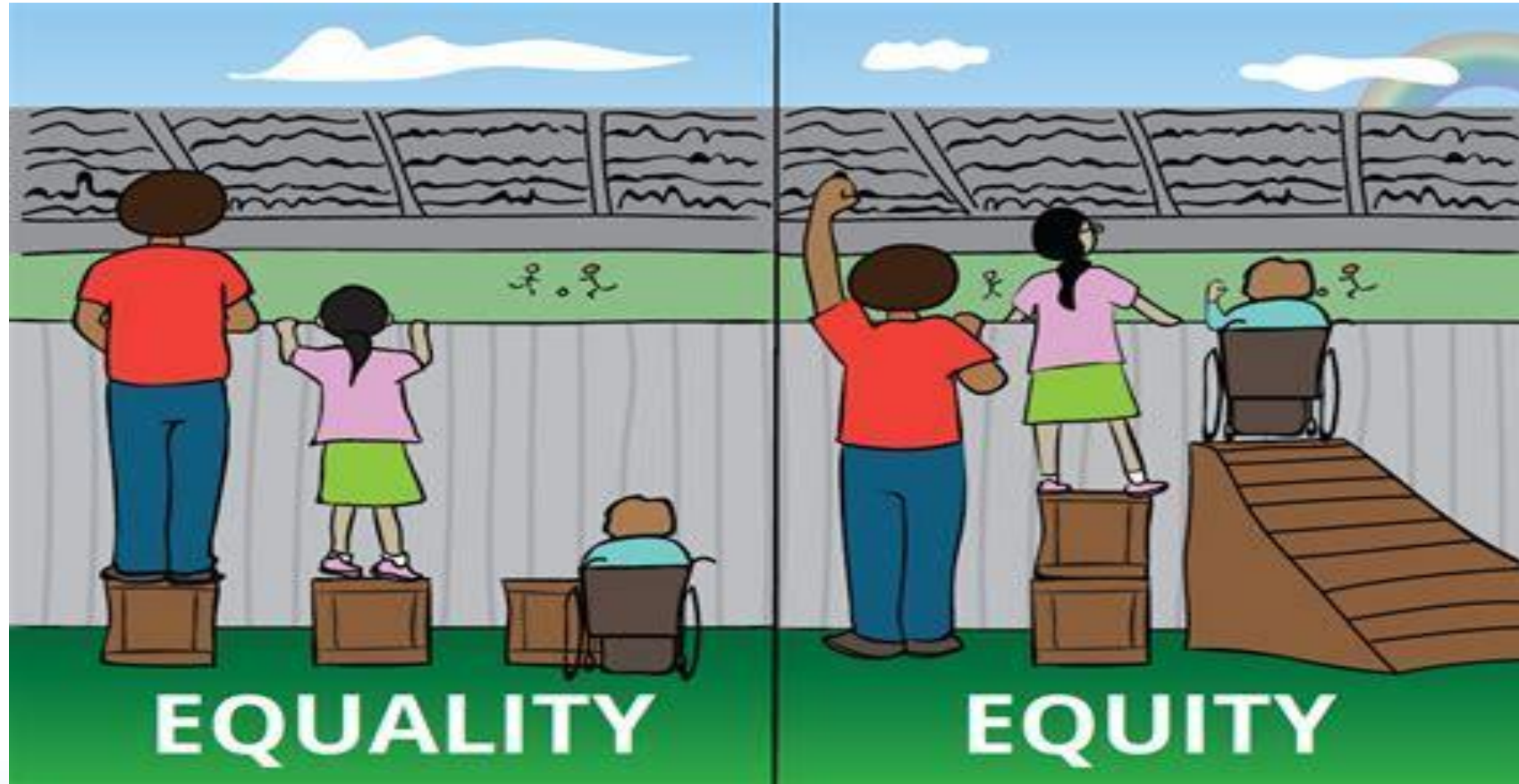
State perspective

How two states address equity in their approach to survey administration

California



Service Access and Equity Initiatives



California Department of
Developmental Services

In-Person Survey (IPS) FY 20/21

- **CA Language Modifications**

- Added 12 additional languages to:
 - BI-14 What is this persons preferred language?
 - I-1 In What language was the survey conducted?

- **12 Additional Languages**

- Mandarin
- Tagalong
- Vietnamese
- Korean
- Arabic
- Armenian
- Farsi
- Hmong
- Khmer
- Laos
- Russian
- American Sign Language (ASL)

IPS FY 17/18 Data

Preferred Languages from IPS 17/18 Data

Total respondents who answered BI-14 = 8,280

- English = 6,765
- Spanish = 1,231
- Other = 53
- Vietnamese = 50
- Tagalong = 45
- Armenian = 43
- American Sign Language (ASL) = 32
- Korean = 15
- Mandarin = 12
- Arabic = 12
- Farsi = 9
- Hmong = 6
- Russian = 5
- Khmer = 1
- Laos = 1

IPS FY 20/21 CA Questions

- **CA Questions for Cultural & Language Competence**
 - Are there staff (or a family member) at your home where you live who speak your preferred language?
 - Are there staff at your job who speak your preferred language?
 - Are there staff at your day program or work program who speak your preferred language?
 - Did you get a copy of your IPP in your preferred language?
 - Do your staff support you in a way that is respectful to your culture?

IPS FY 20/21 Sample Strategy

- **Stratified Sampling Plan**
 - Sample size by Race/Ethnicity and Regional Centers
 - 400 per Regional Center divided among 5 race/ethnicity categories
 - Based on % of Regional Centers total population
- **5 Race/Ethnicity Categories**
 - African America
 - Asian
 - Hispanic/Latino
 - White
 - Other

Race/Ethnicity Categories

- **Total Eligible Population**

- Total eligible 144,398
- 3,033 missing race/ethnicity removed
- 141,365 identified as 1 or >1 of 24 unique race/ethnicity categories
 - 141,365 grouped using method created by the Research Branch of DDS into 5 race/ethnicity categories

- **5 Race/Ethnicity Category Breakdown**

- *African American* = Black/African American.
- *Asian* = Filipino, Cambodian, Chinese, Guamanian, Asian Indian, Japanese, Korean, Laotian, Hmong, Thai, Vietnamese, Other Asian.
- *Hispanic/Latino* = Hispanic.
- *White* = White, Russian
- *Other* = Multi-racial, Native American, Other, Unknown, Native Hawaiian, Other Pacific Islander, Samoan.



Nebraska

Nebraska's NCI and NCI-AD Cultural Competency Efforts

Rachel Ray, M.A.
Nebraska NCI and NCI-AD Project Manager



University of Nebraska
Medical Center

MUNROE-MEYER INSTITUTE

NE's Cultural Competency Efforts

1. Hire a diverse workforce; the Nebraska survey team is:

- ❖ 35% African American
- ❖ 20% White
- ❖ 18% Latina
- ❖ 18% Native American
- ❖ 9% Asian American

2. Nebraska's demographics

- ❖ 88% White
- ❖ 11% Hispanic or Latino
- ❖ 5% African American
- ❖ 3% Asian
- ❖ 2% Native American



Increasing Consent within Marginalized Communities

We work closely with community agencies and providers

- ❖ Tribal hospitals and clinics
- ❖ Tribal nursing homes
- ❖ Community centers and events
- ❖ Refugee Empowerment Centers
- ❖ Places of worship
- ❖ Providers that specialize in a culturally competent and multilingual workforce to meet the in-home healthcare needs of diverse communities (i.e., Karen, Sudanese, and Latin American communities)



How we work with communities

State specific NCI and NCI-AD brochure is shared with providers, community centers, nursing facilities, assisted living facilities, libraries, senior centers, day providers, home health agencies, etc.

Schedule surveys within community centers and senior centers—coordinate with the centers to conduct surveys on days in which resource coordination can take place to address unmet needs following a survey.

We reach out to specific providers to alert them that we will be in their communities to conduct surveys.

We communicate the importance of data collection—if we cannot highlight that there is a need, then things most likely will not change.

The hard work is getting in—once we are in a location, the momentum carries across survey cycles.

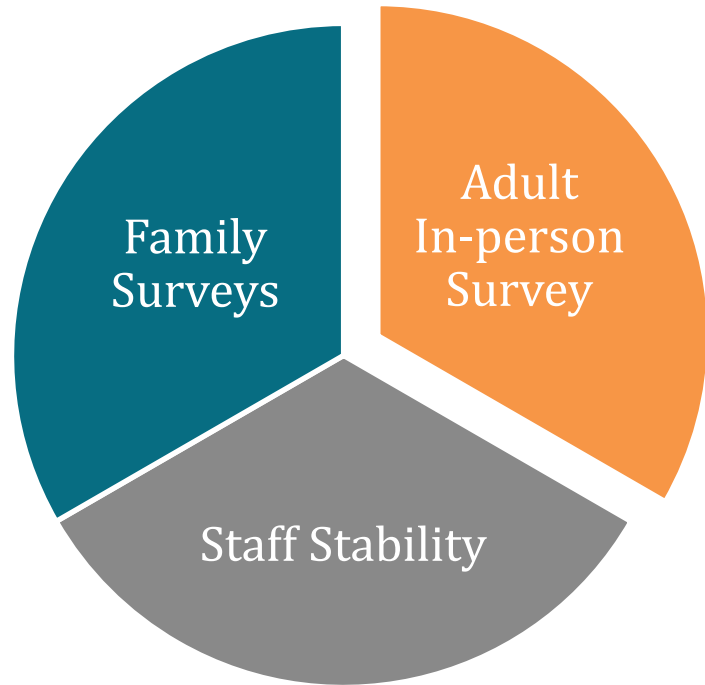




What do NCI data reveal?

What do data reveal about disparity in the reported experience of people with IDD
with a focus on community engagement

NCI Tools and the In-Person Survey



- **In-Person Survey**

- People who receive at least one service in addition to case management from the IDD agency
- Face-to-face survey with the person receiving services
- Survey includes three main parts:
 - Background information – largely collected from state records
 - Section I – Subjective questions only the person can answer
 - Section II – Objective questions can be answered by a proxy when needed

Data for Analysis

Data from 2018-19 IPS collected via direct conversation with people receiving services

- 39 states represented

For purpose of this analysis, include only respondents whose race was indicated as 'White' or 'Black'

- 15,566 White respondents
- 3,180 Black respondents

All comparisons shown are significant at .01

Notes on Data

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- Data identifying respondents' race/ethnicity come from administrative data in most cases. Sometimes race/ethnicity is not known.

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- The proportions of Black participants vary widely by state.

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- The race/ethnicity categories in both surveys mirror the U.S. Census categories.
 - These broad categories do not account for the diversity of culture, language, and national origin within the larger race categories.

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- The development of the NCI IPS did not include a review to determine the cultural competence of the survey questions or the survey administration mode.

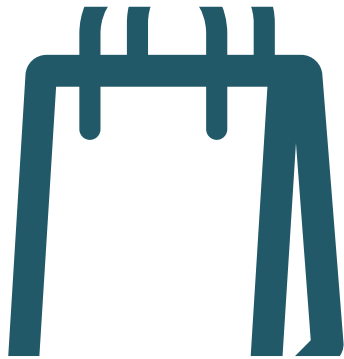
Black respondents were more likely to live with family

Lives with family

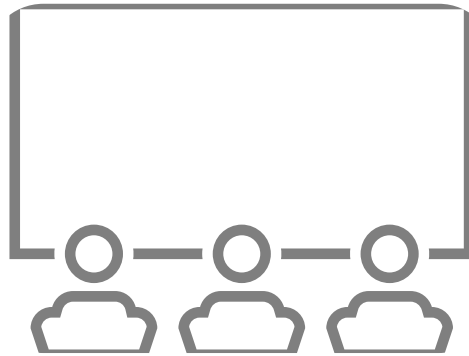
- **42%** Black respondents
- **35%** White respondents



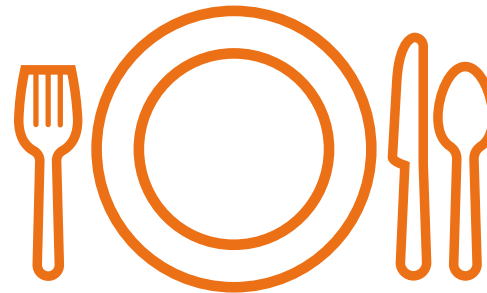
Black respondents were more likely to report wanting to go out more...



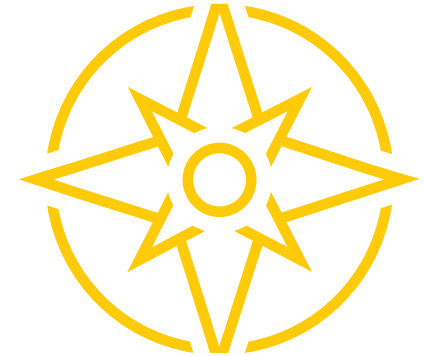
38% v 29%
to go shopping



49% v 42%
for entertainment



49% v 42%
to eat



29% v 20%
for religious service or
spiritual practice



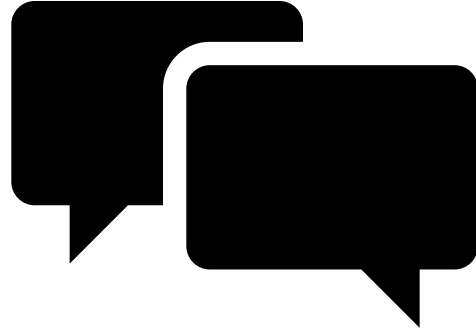
Black respondents were less likely to have a paid community job

- **16%** Black respondents
- **21%** White respondents

Black respondents were less likely to report having at least some input in choosing daily schedule

- **82%** Black respondents
- **87%** White respondents





Discussion

What's next?

A Disparities Framework: Intellectual and Developmental Disabilities Services and Supports

FULL PARTICIPATION OF INDIVIDUALS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES
across the life course in all facets of community life

Health ♦ Housing ♦ Child Care ♦ Recreation ♦ Employment ♦ Education ♦ Early Intervention ♦ Transportation



Policy & Resources
(Public & Private Sectors)

Moving Forward

- NASDDDS and HSRI statements on Racial Equity
- Data Highlight is first step
- NCI examining techniques for ensuring Cultural Humility for surveyors
- Tools, documents, publications, etc... multiple languages
- Support NCI states in developing and sharing promising practices and innovative approaches regarding equity and diversity
- NCI data use to publish regarding equity in the IDD service delivery system

Questions

