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

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In 2020, the confluence of the COVID 19 pandemic and the events surrounding the death of George Floyd exposed indisputable disparities and injustice experienced by racial and ethnic groups in the United States. Health disparities were glaringly apparent in the higher mortality and morbidity rates among Black citizens^a who contracted the novel coronavirus. Demonstrations against racial injustice grew over the summer in response to George Floyd’s murder and other Black men and women who died at the hands of police. Following the dramatic events of the summer of 2020, many human service organizations across the country began to take a deeper look at inequities that have produced disparities in areas such as housing, income, employment, and nutrition. To be more precise, in this data brief, we distinguish between disparities or differences

^a The authors are using the designation “Black” to describe people who self-identify as African American and also Black. We have also chosen to capitalize “Black” but not “white.” For this Data Brief, we are following the precedent set by the [New York Times](#) on this matter.

in outcomes experienced between groups, and the lack of equity or equality of opportunity that may explain some of those differences.

For people with intellectual and developmental disabilities (IDD) who are part of marginalized racial and ethnic groups, issues of racial equity and disparities overlap and intersect with the stigma associated with ableism. Researchers have called this the “double burden” of racial and ethnic disparities among people living with disabilities.¹ Since 2000, the Developmental Disabilities Assistance and Bill of Rights Act² has included language specifically focusing on disparities affecting those with IDD from marginalized racial and ethnic backgrounds and from underserved populations. Specifically, the Act states that

. . . efforts must be made to ensure that individuals with developmental disabilities from racial and ethnic minority backgrounds and their families enjoy increased and meaningful opportunities to access and use community services, individualized supports, and other forms of assistance available to other individuals with developmental disabilities and their families. (§101(c) (5) Policy)

The term “unserved and underserved” includes populations such as individuals from racial and ethnic minority backgrounds, disadvantaged individuals, individuals with limited English proficiency, individuals from underserved geographic areas (rural or urban), and specific groups of individuals within the population of individuals with developmental disabilities, including individuals who require assistive technology in order to participate in and contribute to community life. (§102 Definitions (32))

This recognition of the interests and needs of unserved and underserved groups of people with IDD underscores the importance of collecting the data necessary to uncover and eliminate disparities through changes in public policy and practice. For this data brief, we have chosen to concentrate on potential disparities between Black and white respondents to the NCI In-Person Survey because of the racial inequities made manifest during the summer of 2020. Using National Core Indicators® data, we will describe differences in personal characteristics, demographics, and outcomes of Black respondents to the In-Person Survey when compared to white respondents. We also provide suggestions for public managers, service providers, people with lived experience and other stakeholders regarding how they might use this information to plan for and support equity in service delivery.

Background

One example of the compounding impact of IDD and minority status was described by Scott and Havercamp (2014) who found that in addition to the challenges that people with IDD experience in gaining access to healthcare, people who had IDD and who were members of a minority group had decreased odds of having a recent dentist visit, visit with a general practitioner, and a flu shot.³ In 2013 a study in a southeastern state found that Black women with IDD were less like to get mammograms than white participants with IDD.⁴

In 2016, using data from linked, aggregated 2000-2011 National Health Interview Survey and the Medical Expenditure Panel Study, researchers found that Latino and non-Latino Black adults with IDD had markedly worse health than both white adults with IDD and nondisabled Latino and Black adults, respectively.⁵ Worse outcomes were noted in health and mental health for Black adults with IDD. The authors noted that the disparities identified were of an “alarming”

magnitude, and that results indicated that racial/ethnic groups are disadvantaged in several essential areas of health care utilization. An analysis⁶ of National Core Indicators data on utilization of preventive health care also found that non-Hispanic Black respondents were significantly less likely to have had a dentist visit, a flu vaccination, a pneumonia vaccination, or a physical examination during the past year.^b

With respect to resource allocation, evidence has begun to emerge showing that individuals from racial and ethnic groups who have IDD may not receive the same level of public resources that white participants receive. A study of the distribution of resources in the developmental disabilities in one state found that non-white racial groups were more likely to be receiving no services, and if they did receive services, they had significantly lower expenditures.⁷ One possible explanation for this finding that has emerged more recently is that some racial and ethnic groups did not opt for the service array available because the offerings were not culturally and linguistically competent. Further, lower expenditures may be explained by the fact that people with IDD from particular racial and ethnic groups are more likely to live at home with family and not in more expensive out-of-home arrangements.

Another recent study found that children with IDD from racial and ethnic groups received fewer resources in terms of the distribution of services and the level of expenditures.⁸ Finally, Leigh et al. (2016) found that Black participants with an ASD diagnosis enrolled in a state's community services network received lower expenditure levels than non-Hispanic white participants.⁹

A further indication of differential treatment of people with IDD from minority groups is reflected in a study by Durkin et al. (2017) that looked at the relationship between minority status and autism diagnosis.¹⁰ The study found that minority groups—even controlling for social economic status—were less likely to be diagnosed with autism. Even when the diagnosis was present, the level of resources received by minority participants was less than those received by white participants. Similarly, Mandell et al. (2009) reviewed on over 2,500 eight-year-olds who met surveillance criteria for ASD.¹¹ They found that Black children were significantly less likely than white children to have received an ASD diagnosis.

This data brief is a beginning step in what is intended to be a comprehensive examination of disparities experienced by Black participants in the public IDD system. Using data from the National Core Indicators In-Person Survey, the brief highlights statistically significant differences among a range of outcomes experienced by Black participants compared to white participants. NCI data do not cover all the domains noted in the Developmental Disabilities Act—including education, childcare, and housing—but do provide some insights into health, employment, and assistive technology, as well as domains not explicitly in the Act, including legal rights, relationships, choice, community inclusion, and living arrangements.

National Core Indicators Data

The NCI In-Person Survey offers a unique opportunity to examine the outcomes and personal characteristics of the population of people who receive supports from public DD systems and, in this case, any differential outcomes experienced by Black participants. The data for this analysis come from states that participated in the 2018-2019 In-Person Survey data cycle. The total

^b For a comprehensive review of the intersection of health equity, race and ethnicity and disability, see Yee, S., Breslin, M.S., Goode, T.D., Havercamp, S.M., Horner-Johnson, W., Iezzoni, L.J. & Krahn, G. (2018). [Compounded disparities: Health equity at the intersection of disability, race, and ethnicity. Disability Rights and Education Fund.](#)

sample for 2018-2019 was 22,009 individuals from 39 states. The question on race/ethnicity is in the Background Information Section of the In-Person Survey and is collected from existing administrative data records. The question is framed as follows, and is consistent with US Census categories, with the exception that the Census provides an additional category: “Two or more races.”

What is this person’s race and ethnicity? Check ONE or MORE boxes to indicate what this person considers themselves to be:

- American Indian or Alaska Native
 - Asian (Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese, or Other Asian)
 - Black or African-American
 - Pacific Islander (Native Hawaiian, Guamanian or Chamorro, Samoan, or Other Pacific Islander)
 - White
 - Hispanic/Latino (Mexican, Mexican-American, Chicano, Puerto Rican, Cuban, or Other Spanish/Hispanic/Latino)
 - Other race not listed
 - Don’t know
-

“Don’t know” or “missing data” from background section and in-person survey responses were excluded from analysis.

With respect to the administration of the survey to individuals who don’t speak English or don’t use spoken words to communicate, NCI has developed guidelines for implementing the survey in other languages including sign language.

Limitations

Data in the In-Person Survey that identify the race/ethnicity of respondents come from administrative data in most cases. The source of the race/ethnicity data in administrative records is not always known. Further, data on race/ethnicity is not universally reported on every participant, which results in missing data. Cases with missing data on race/ethnicity are not included in this brief, and it is unknown whether data are systematically missing for certain populations, thus limiting the representativeness of the data. It should also be noted that the proportions of Black participants vary widely by state, so the data demonstrated may not represent the experience of Black respondents in some states over others.

The development of the original NCI In-Person Survey did not include an assessment of the cultural competence of questions or survey administration. We intend to address those issues going forward. For this data brief, however, please note the following areas of uncertainty:

- Are some racial/ethnic groups in the random sample less likely to agree to be surveyed? To be asked to be surveyed?^c
- Are there certain questions that may be viewed by some groups as more invasive to privacy?

^c We carried out a preliminary analysis of nonrespondents in one state that collected data on people who were not surveyed. Findings suggested slight but significant differences between those who were surveyed and those who were not. White respondents were more likely to be surveyed. (Analysis not yet published.)

- Is there implicit bias in the language and design of the In-Person Survey?
- Can we be sure that racial and ethnic groups have equitable access to IDD supports? If not, are they underrepresented in the NCI sample? Does the proportion of participants from racial and ethnic groups match the proportion in the general population?

This analysis does not provide answers to those questions. Further, in the following analysis, we did not control for other variables (state of residence, state-specific policies, outreach to minority communities, diversity of provider community, etc.). Controlling for other factors ensures that the measured effect or difference isn't influenced by those other factors, instead of the factor of interest.

Finally, as mentioned above, the race/ethnicity categories in the In-Person Survey mirror the U.S. Census categories. It should be noted that the broad race/ethnicity categories do not reflect the diversity of culture, language, and national origin within the larger race categories.

To summarize, these data are presented as a starting point for conversation. To gain a deeper understanding of the data and to address the limitations noted above, it will be important to ask the following: In what ways are the outcomes driven by access to services, diagnosis, and response rate?

- **Access:** Are there people who have greater access to services because of where they live, their primary language, who supports them, and their racial or ethnic identities?
- **Diagnosis:** Who gets diagnosed, what do various diagnoses mean for access to services, who gets support?
- **Response rate:** Who participates in the survey? Who does not participate due to opportunity or access or for other reasons?

Findings

The tables below illustrate areas in which there are significant differences between Black and white respondents to the NCI In-Person Survey. Results are grouped by NCI "domain" (outcome area). Data included in the following tables are limited to those items that demonstrated significant differences between the Black and white respondents. We include only those data that show a significance level of $p \leq .000$ unless otherwise noted. At this significance level, the observed differences are unlikely to be the result of chance.

Demographics and Personal Characteristics

Black respondents are significantly more likely to...

Result	Black/White
Live in a metropolitan area	86% / 73%
Live with parents or relatives	42% / 35%
Be reported to have severe or profound ID (of those with an ID diagnosis)	24% / 20%
Be reported to have been diagnosed with high blood pressure	32% / 21%
Be reported to have a language other than English as their primary language	2% / 1%
Be reported as able to move themselves around their environment <i>without</i> aids	81% / 75%

Result	Black/White
Be reported to be diagnosed with a psychotic disorder	19% / 10%
Be reported to have guardianship or conservatorship	42% / 57%

Black respondents are significantly more less to need support for behavior challenges...

Result	Black/White
Self-injurious behavior	83% / 78%
Disruptive behavior	67% / 61%
Destructive behavior	77% / 74%

NCI findings on demographics and personal characteristics of people receiving services reveal interesting differences that merit further investigation. For instance, Black participants are more likely to have high blood pressure as an underlying condition. Black participants are less likely to need mobility aids (possibly because they skew younger).

Black participants are more likely to be diagnosed with a psychotic disorder and less likely to need support for behavior challenges. This is somewhat consistent with research on Black Americans in the general population who are 3 to 4 times more likely to be diagnosed with a psychotic disorder than white citizens.¹²

Black respondents are significantly less likely to be ...

Result	Black / White
Diagnosed with Down Syndrome	5% / 10%
Diagnosed with Alzheimer's or other dementia	1% / 4%

Black respondents are significantly less likely to...

Result	Black / White
Have had a routine dentist visit in the past year	78% / 83%
Have had a flu vaccine in the past year	66% / 74%
Have a behavior plan	21% / 24%
Take at least one medication for mood, anxiety, psychotic and/or behavior challenges	48% / 57%

Black respondents were less likely to have received preventive health care such as flu shots, or to have had routine dental care in the past year. Further Black participants were less likely to have a behavior plan.

Access, Community Participation, and Work

Black respondents are significantly more likely to...

Result	Black / White
Report wanting to go out and do these activities in the community more than they did in the previous month:	<i>shopping: 38% / 29%</i> <i>entertainment: 50% / 42%</i> <i>out to eat: 48% / 39%</i> <i>attend religious service/spiritual practice: 29% / 20%</i>
Report they want a job (if they do not currently have a paid community job)	55% / 41%
Have gone to religious services or spiritual practices in the past month	55% / 40%

Black respondents are significantly less likely to ...

Result	Black / White
Have a paid community job	16% / 21%

Black respondents reported a desire for greater community involvement. This may suggest barriers to community access that could include economic or social barriers to community participation and other variables such as geographic location and living arrangement.

Among people receiving IDD supports, white respondents were more likely to have a paid community job. Furthermore, Black respondents without a paid job in the community were significantly more likely to want a paid community job than white respondents without a paid community job. For all participants, less than 40% of people who wanted a job had employment as a goal in their service plan.

Rights, Respect, and Relationships

Black respondents are significantly more likely to...

Result	Black / White
Report there are rules about having friends or visitors at their house*	39% / 33%
Have a cell phone or smart phone	60% / 55%
Be able to lock their bedroom if they want to	55% / 51%
Need more help to keep in contact with friends or make new friends	54% / 47%

* Significant difference at $p \leq .001$

Black respondents are significantly less likely to...

Result	Black / White
Have a place to be alone in their home	95% / 97%
Say they can be alone with guests who are in their home*	83% / 85%

* Significant difference at $p \leq .001$

These results demonstrate that Black NCI respondents are significantly more likely to experience social isolation (more likely to have rules around having friends over to their house, less likely to report being able to be alone with guests who are in their home, and more likely to want more help to keep in contact with friends).

Choice, Control, and Self-Direction

Black respondents are significantly more likely to...

Result	Black / White
Report their staff have the needed training	92% / 89%
Have been able to choose the services received as part of their service plan	79% / 73%

Black respondents are significantly less likely to...

Result	Black / White
Have had at least some input in choosing their home (if not living in the family home)	52% / 58%
Have had at least some input in choosing their housemates (of those not living in the family home)	38% / 45%
Have had at least some input in choosing their daily schedule	82% / 87%
Be reported to be using a self-directed supports option (in the NCI population)	7% / 12%

Although Black respondents were significantly more likely to report being able to choose the services included in their support plans, they were significantly less likely to report having had input in other life choices such as where they live,^d with whom they live, and their daily schedule. They were also less likely to participate in self-direction.

Summary and Implications

To summarize, the data described above suggest that there are significant disparities in some of the outcomes experienced between Black and white respondents with IDD. Some of the differences uncovered and possible explanations that should lead to further examination include:

- Vaccination rates:** Lower vaccination rates among minority groups are well-documented in literature, especially older Black adults.¹³ Some of the contributing factors include distrust of the health care system due to discrimination and inequity (past and present), reluctance to seek the vaccinations, provider practices, number of physician visits in the past 12 months, and health insurance.¹⁴ While providing medical and dental care is not necessarily the responsibility of the IDD system, facilitating referrals and access to health care is a requirement for the coordination of services to meet needs within many service coordination/case management service definitions.
- Behavior plans:** The finding that Black participants are less likely to have a behavior plan requires further study, especially given the disproportionate number of Black individuals

^d This question is not asked of people who live with their families

who have been diagnosed with a psychotic disorder. Are white participants with similar characteristics receiving different diagnoses (e.g., being described as having “behavioral issues” compared to a mental illness)?

- **Desire for more community involvement:** The finding that Black participants are more likely to want additional opportunities to be out in the community may suggest that Black participants are more likely to encounter barriers to community access. These barriers could include economic or social barriers to community participation and other variables such as geographic location and living arrangement.
- **Social isolation:** Further research should consider the variables that can explain possible increased social isolation among Black participants compared to white participants, including size of the residential setting, nature of the provider organization, etc.
- **Employment:** Barriers to employment exist for people with IDD and are also present for Black Americans in general whose unemployment rate is consistently twice as high as that of white people.¹⁵ These disparities intersect in this finding and merit further investigation.
- **Choice and control:** Some of the factors that may explain this difference in the ability of Black participants to choose where and with whom to live compared to white participants may be: 1) where the respondents live (in their own homes, with parents, in group home settings); 2) whether respondents have received support in the area of self-direction; and 3) cultural differences in exactly what self-direction means.

What is needed to address the issues raised in this brief is a more focused examination of the potential inequities contributing to the existence of these disparities. Uncovering those reasons will require a more intentional effort to dig deeper into the underlying context—including the ways in which public policies are interpreted and implemented as well as the attitudinal barriers, implicit and explicit biases, and often resource allocation disparities.

Going Forward

The IDD field has developed measures that reflect performance on such issues as person-centered practices, inclusion, choice and rights, and some states are making similar investments in the collection and analysis of administrative data that can track differences in access and outcomes experienced by racial and ethnic groups. While some national data do exist (e.g., The National Survey of Children’s Health), many current datasets do not allow for the types of analyses described above or have been walled off in silos (e.g., Medicaid data).^e There is a need to have the data to be able to say with confidence that we are working toward an equitable system in which “race” does not predict “in a statistical sense, how one would fare.”¹⁶

States should consider how they can ensure that their quality improvement system aims to identify and reduce inequities and disparities. A project planning team should identify potential contributing factors and proceed to “test” changes that can be made to address those factors. The possible explanations for variation in results provided in this discussion could serve as potential contributing factors for each of the noted outcomes. This provides a foundation from which states can analyze their own NCI data and launch robust quality improvement projects that will result in increased equity in home and community-based supports. This level of

^e It should be noted that [CMS has made major investments](#) in improving access to Medicaid data. “With the on-going changes to the national health care environment, the Centers for Medicare & Medicaid Services (CMS) has made significant investments to meet the organizational and information technology (IT) infrastructure to adequately represent CMS’ role in the healthcare marketplace.”

exploration will require improvement in state data systems to ensure the consistent reporting of accurate information on race and ethnicity across data systems.

One possible framework to analyze the components of public systems that may result in disparities has been proposed by the World Health Organization¹⁷ to assess gender equality in health care. The components of the WHO framework include four criteria for assessing disparities: Availability, Accessibility, Acceptability, and Quality. The Georgetown University National Center for Cultural Competence (NCCC)¹⁸ has used these categories—in addition to Utilization—as components of a framework to examine potential causes for racial and ethnic disparities. Tawara Goode, [in a video introducing the NCCC Disparities Framework](#), notes that once a disparity is identified, one can use the criteria to examine the potential reasons for that disparity. Goode describes the five criteria as variations on the following:

- **Availability** – the array, type and intensity of services and supports being offered, and whether it fits the needs of different races/ethnicities.
- **Accessibility** – the geographic distribution, hours of service, accommodations, and universal design of services and supports and whether these factors are systematically disenfranchising certain populations.
- **Acceptability** – the degree to which services reflect a respect for the values, histories, expectations, language, and experiences of a group. The capacity to plan and deliver culturally and linguistically competent services may affect whether services are acceptable to different races/ethnicities.
- **Quality** – the overall quality of services and supports. Does quality differ depending on to whom a service is being provided? This may alienate racial and ethnic groups.
- **Utilization** – rates of utilization of services and supports may differ by race/ethnicity. Research would be needed to identify the reasons behind this difference.

The NCCC framework also includes an examination of the nature of policies and level of resources that may contribute to any disparities in any one or more of the criteria. Finally, this framework, when applied to a service system, can be used to assess disparities in the many services and supports that human services participants rely on (e.g., housing, transportation, education, mental health, etc.).

The framework provides public managers and researchers with an analytic approach to seeking answers when their data show differential outcomes. Applying the framework should lead to a more systematic approach and, as Professor Goode suggests, the process should include the people who receive supports and services from this system or with lived experience. This in-depth exploration, however, will not be possible unless state datasets include robust information on race, ethnicity, and languages spoken in information systems across multiple agencies.

Promising Practices in State DD Systems

State DD systems across the nation are working to ensure issues of racial and ethnic disparities are identified and addressed in their service delivery systems. State DD agencies recognize the importance of understanding equity and using data to describe the experience of people supported by the statewide service system. Several states have cultural and linguistic competency efforts underway, while other states have moved into more active approaches to addressing issues of equity.

California’s Department of Developmental Services (CA DDS) demonstrates such an approach. Working closely with the Regional Centers^f and broader stakeholder communities through the Developmental Services Task Force, CA DDS undertook to first understand and describe, and then to address and correct, conditions that contribute to racial and ethnic disparities. Since 2012, CA DDS launched several initiatives to clarify the types and extent of disparities across the state. The information provided through [public reporting of DDS Disparity Measures](#)^g currently gives an opportunity for all stakeholders in the DD system to track progress in reducing disparities across the broad landscape of Regional Centers. The 11 measures, established through an iterative process with stakeholders, range from access to Early Start services (birth through age 2), to equity in Supported Living and Independent Living Services (adults), and equity in Supported Work programs (working age adults).

As a result of a robust effort to examine the causes of disparities, themes were identified across the diverse communities of people living in California. These four primary themes emerged as contributors to disparities in service access:

- Supply of culturally and linguistically appropriate and accessible information, service options, providers.
- Cultural barriers and discomfort challenging authority figures that prevent some families from requesting needed services and exercising their rights.
- Mistrust of public systems by some communities of color.
- Socioeconomic factors that present challenges to securing access to Regional Center services.

Legislation passed in 2016 appropriated \$11 million annually to the Regional Centers, and expanded to community-based organizations in 2017, to support implementation strategies to reduce disparities and increase equity in Regional Center services. Projects range from outreach to African American parents of graduating high school students to help navigate the eligibility process, to a Leadership Academy for African American and Hispanic families to establish parent leaders, and programs aimed at Early Start screenings and referrals to understand options available for African American and Hispanic and Asian communities. The Disparity Funds Program —now referred to as the Promoting Service Access and Equity Grant—each include a data collection requirement to measure effectiveness and achievement of the project’s goals.

In Fall 2019, California’s Developmental Services Task Force reconstituted the membership of the task force and added workgroups including the Service Access and Equity work group to explore specific ideas and make recommendations for improving access among all racial and ethnic groups. The work group recently held specific focus groups of Black families and professionals working in the DD system. The lessons learned from listening to Black families are expected to forge new community partnerships, expand understanding of the diversity and depth of the Black community, increase leadership and participation from the Black community, and raise awareness of the needs of Black families served in the developmental services system. December 2020 recommendations made to the Developmental Services Task Force by the

^f Regional Centers are a statewide network of 21 community-based, nonprofit agencies responsible for coordinating, developing, purchasing and managing services for individuals and their families. <https://www.dds.ca.gov/rc/>

^g [DDS Disparity Measures](#) Accessed Feb. 10, 2021

Service Access and Equity work group can be found here: [Service Access and Equity Recommendations](#).

For the past four years, California has undertaken a holistic, meaningful and action-oriented approach to making lasting change to address equity across the breadth of the state’s developmental service system. Many of these practices can be replicated across other state I/DD systems. States participating in NCI can replicate CA DDS’s revisions to its sampling methods to ensure that the NCI sample population reflects the diversity of its population. Each of the 21 Regional Centers in California followed the same method for pulling samples for the 2020-2021 In-Person Survey data collection cycle. Changes in the data available will allow individual states to carry out analysis of the NCI results based on race and ethnicity. Such analysis can inform a state on the impact of changes operationalized to increase equity.

Conclusion

This data brief was meant to start a more systematic examination of disparities among racial, linguistic, and ethnic groups. It also includes information from one state where public IDD managers have begun to pick up this challenge and are implementing new ways to identify and eliminate any existing disparities in services, supports, and resource allocation. It is also important to acknowledge potential movement toward increased racial and ethnic equality at the national level with the January 2021 Presidential Executive Order on Advancing Racial Equity and Support for Underserved Communities Through the Federal Government.¹⁹ Increased awareness of disparities and the will to overcome them will be necessary to ensure that people with IDD from racial and ethnic groups are treated equally compared to their white peers and in a culturally and linguistically appropriate fashion.

Questions? Comments? Contact Us

For additional information on the National Core Indicators initiative, public reports, and past data briefs, please visit: www.nationalcoreindicators.org.

We welcome your feedback and questions. If you want to discuss this report or have questions about the NCI project, please contact Alexandra Bonardi, NCI Project Director, abonardi@hsri.org.

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