## National Core Indicators® COVID-19 Bulletin #4: Data on Racial Disparities



## Using NCI to understand racial disparities among adults with intellectual and developmental disabilities during the COVID-19 pandemic



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As we learn more about the impact of COVID-19, data are demonstrating that the virus has disproportionately affected communities of color. The reasons for this disparity include the effects of long-standing systemic racism and health and social inequities. These factors contribute to the increased COVID-19 infection risk faced by members of racial and ethnic minority groups. According to the CDC American Indians, Alaska Natives, and Black¹ people are approximately 5 times more likely to die from the virus than non-Hispanic white people, and Latinx people are 4 times more likely to die than non-Hispanic white people. The compounding intersection of racial and ethnic disparities brings increased vulnerability to minority groups with IDD in the face of this dangerous virus. Current data sources cannot yet provide reliable statistics regarding the incidence of COVID-19 among the population with IDD. We may expect though that some of the racial disparities in COVID-19 incidence rates in the general population may also be present among Black people receiving state DD system services. This bulletin examines racial disparities in the NCI data from the 2018-19 In-Person Survey

<sup>&</sup>lt;sup>1</sup> For the purposes of this bulletin, NCI has decided to capitalize the word "Black" when describing people and cultures of African origin. In this bulletin, NCI has decided not to capitalize "white." For this bulletin, NCI decided to follow the precedent set by the <a href="New York Times">New York Times</a> on this matter.

(IPS). The respondents to this survey are adults receiving at least one service (in addition to case management) from their state developmental disability service system. Though these data were collected prior to the COVID-19 pandemic, the data demonstrate factors that may affect the vulnerability of respondents to the virus. Furthermore, these data show potential disparities in outcomes between Black and white respondents that may be heightened during COVID-19 and during other emergency situations. Specifically, this bulletin focuses on the areas of health, communication, and location (rural, urban, suburban).

With respect to health, prior to the pandemic, *Black respondents to the IPS were significantly more likely than white respondents to have been diagnosed with diabetes and high blood pressure.*According to the Centers for Disease Control people with diabetes are at increased risk of having a more severe case of the virus, and people with high blood pressure may be at increased risk severe illness if they contract COVID-19. Another risk factor is obesity. Of the 36% of respondents who were obese based on Body Mass Index (BMI), Black respondents were just as likely to be obese as their white counterparts.

Further, results from the IPS indicate that Black respondents are significantly less likely than white respondents to get flu shots, a disparity that clearly must be examined and addressed in anticipation of a vaccine for COVID-19 in the coming months. Communication and outreach efforts, as well as communication to health care providers of the increased risks in this population, can encourage vaccine efforts. Additionally, if access to a vaccine is limited, it will be important to highlight the increased risk factors among Black participants.

Public IDD systems can mount programs and policies that minimize health disparities that may contribute to the vulnerability to COVID-19 infection.

- Historically, Black people have experienced inadequate access to and delivery of quality
  healthcare. Black people with IDD experience the double challenge of having a disability and
  being a member of a racial minority. Going forward, it will be important for public IDD
  systems to continue to improve the collection of data that track possible racial and ethnic
  disparities in access and use of quality healthcare and to increase the ability to use data to
  minimize potential disparities.
- Healthcare also includes mental health treatment. While mental health conditions are significantly lower among Black respondents (with the exception of psychotic disease) than among white respondents, Black people in general are more likely to have experienced trauma and violence and are less likely to receive treatment from a Black therapist given their smaller numbers in the workforce. The pandemic may bring new trauma (uncertainty, isolation, grief, etc.) on top of existing trauma to people which could lead to increased mental health needs for all people, particularly Black participants. Mental health providers should ensure the use of culturally competent and trauma-informed approaches to the inevitable mental health issues that Black people with IDD will experience.
- Many psychologists have posited that Black people experience stress in culturally
  determined ways and therefore should be supported to seek out wellness strategies tailored
  to their needs.

NCI data show that Black respondents are less likely to get routine flu vaccinations. Getting vaccine protection is important at any time but is particularly important during this pandemic.
 Programs such as the federal Vaccinations for Children program (administered by the CDC)
 were developed to reduce disparities in immunizations. The Vaccinations for Children program provides funds to state health departments to ensure that minority and low-income children can get access to vaccinations. Families with children with disabilities should be made aware of the program and how to get access to affordable vaccinations.

Where and how people live can also make them more or less vulnerable to infection. According to the NCI data, *Black respondents are more likely than their white peers to live with their family* as opposed to in a group home or independently. The extent to which family living is safer—or riskier—depends on several factors related to the household. Further, *Black respondents are less likely to report that they have a place to be alone in their homes, less likely to like where they live, and significantly less likely to have had at least some support in choosing their home.* 

- Black respondents living at home may also have parents with underlying health conditions given the racial disparities in healthcare described above. Family members may not have a private physician and may rely on long waits in emergency rooms to get care. During this Public Health Emergency, state IDD staff may take the opportunity to work with public health officials to ensure that information on the pandemic is provided to participants and family members within minority communities and that access to care is assured.
- Given that Black respondents were more likely to report that they didn't have a place to be
  alone in their homes, it will be doubly important to ensure that individuals for whom that is
  the case are given additional supports to help them understand hygiene requirements and
  social distancing to the extent possible.
- The fact that Black respondents were less likely to like where they live and less likely to have some support in choosing their home suggests that there is a need to enhance personcentered planning among this group of participants. The HCBS Settings rule requires that the individual service plan provide people with choices about services and providers. Given the isolation experienced during this pandemic, living in a place where you are comfortable would contribute emotional well-being.

The ability to communicate during a health crisis is important for many reasons. First people with IDD need to be able to convey any symptoms indicating they may have contracted the virus. If participants don't have staff or others around them who are fluent in their language or who understand the ways they communicate, they may be unable to understand important information about their health, mental health, and safety during the pandemic. People who can't communicate with words or who don't speak English may need help to communicate if they are hospitalized or need to get access to telehealth. The NCI IPS data indicate that *Black respondents with IDD are significantly less likely to use English for communication, either because they do not use any spoken language to communicate or they speak a language other than English.* 

- People who don't speak English have the potential to be even more isolated during this crisis
  unless they have access to information in their language. <u>The Centers for Disease Control</u>
  <u>has developed COVID-19 resources in multiple languages</u> which could be adapted and
  disseminated for use by non-English speaking participants.
- To increase the ability of people with IDD to convey important information, individuals should be assessed to determine whether they can benefit <a href="from augmentative and alternative communication">from augmentative and alternative communication</a> (AAC). AAC is used by people who cannot use speech and may include any existing speech or vocalizations, gestures, manual signs, and aided communication.
- Though some states have developed rules allowing people with disabilities to bring a staff of family member if they must go to the hospital, some do not. For people with communication issues, such support is crucial. There are several steps that staff and family members can take to ensure that they can accompany the person with IDD—including calling ahead and getting the need for support in the person's chart. Further, the Americans With Disabilities Act dictates that hospitals should have a range of communication supports available to people with disabilities including translation and sign language.

## Conclusion

NCI data collected prior to the COVID-19 pandemic demonstrate disparities in health and other outcomes experienced by Black respondents when compared to White respondents. These data may indicate areas in which Black recipients of DD supports may experience the effects of COVID-19 differently than their white peers. Public IDD systems can closely examine these inequities and create culturally relevant supports that begin to close the gaps in care and opportunity that have been so dramatically demonstrated during this pandemic.

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