

Research In Focus: A Weekly Digest of New Research from the NIDILRR Community

Adults with Intellectual and Developmental Disabilities from Racial and Ethnic Minority Groups May Perceive Different Barriers to Healthcare than Their White Peers

A study funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR).

Access to healthcare is an important factor for individuals to have positive health outcomes and to maintain a positive health status. It is, therefore, important to minimize barriers to healthcare access, real or perceived. Prior research has also suggested that there are persistent health disparities between individuals from racial and ethnic minority groups and white Americans. The research suggests the disparities may be related to mistrust of healthcare providers and the healthcare system among Black and Latinx individuals, due in part to prior history of discrimination, medical injustices (e.g. Tuskegee Experiment), and negative perception of the medical industry. Among the Latinx community, barriers and sources of mistrust include lack of language translation services and concerns about immigration status.

Based on past research, people with intellectual and developmental disabilities (IDD), in particular, may face significant barriers to healthcare access. Examples of barriers they encounter may include unaffordable cost, lack of providers trained in the healthcare needs of people with IDD, and long waiting times for appointments due, in part, to that lack of trained providers. Additional barriers to healthcare access may exist for individuals in ethnic and racial minority groups with IDD. However, there's no known prior research done to investigate barriers to healthcare access in this specific population. In a recent NIDILRR-funded study, researchers looked at healthcare data for individuals with IDD living in the community. The researchers wanted to know whether people with IDD who were Latinx, White (Non-Latinx), and Black (Non-Latinx) experienced different barriers to healthcare access.

Researchers from the [Rehabilitation Research and Training Center on Developmental Disabilities and Health](#) looked at data collected from two multi-year surveys: 2002-2011 Medical Expenditure Panel Survey (MEPS) and 2000-2010 National Health Interview Survey (NHIS). They looked at data from 1,131 individuals who were between 18 and 65 and had a diagnosis of intellectual or developmental disabilities. The participants included 223 Latinx, 615 White, and 293 Black individuals. After reviewing data about the individuals' demographics and health status, the researchers looked at whether these individuals had a usual source of care (usual source of care is defined as any provider or location they regularly go to for healthcare needs) and, if not, what the reasons were if they didn't. The researchers also looked at whether any of the participants had foregone or delayed medical or care or prescriptions and their reasons for not getting timely care.

The researchers found the following results:

- The percentage of individuals with a usual source of care was similar for all three groups: 84% for Black, 83% for White, and 77% for Latinx.
- Individuals who were Black or Latinx cited not liking or trusting doctors and not using doctors or opting to treat themselves among their top reasons for not having a usual source of care. Individuals who were White cited recently moving or lack of health insurance as their top reasons. The White individuals did not mention not liking or trusting doctors as a reason.
- Among those who chose to forego needed care, inability to afford care was the top reason for all three groups. However, a higher percentage of Black and Latinx individuals cited this reason than White individuals. Black and Latinx individuals also cited problems getting to a provider's office and not knowing where to get care. White individuals cited problems with providers accepting their insurance or lack of coverage for costs.
- Among those who delayed needed care, inability to afford care was the top reason for all three groups and all three groups also cited problems getting to a doctor's office. Black and Latinx individuals also cited lack of time and not knowing where to get care. White individuals cited lack of insurance coverage as another reason for delaying care.

The authors noted that while the three groups were comparable with each other regarding having and not having a usual source of care, their reasons for lacking a usual place of care were different among the groups. In addition, while factors such as lack of affordability and lack of transportation or knowledge of where to get care led to delayed care in the White group, the same factors led many Black and Latinx individuals to forego care altogether. The authors suggested this may lead to additional preventable health problems in those two groups.

The authors noted that prior research regarding access to healthcare for adults with IDD may have assumed that they all faced similar challenges with accessing healthcare, regardless of other factors such as race and ethnicity. However, this current study may challenge that notion and highlight the need for future research to address barriers to healthcare access for adults with IDD in diverse communities. Service and healthcare providers may want to implement programs to educate adults with IDD about accessing healthcare in their community and their options for transportation, insurance, and benefit programs. Due to barriers specific to the Black and Latinx groups, especially mistrust of healthcare providers, the authors suggested that future interventions aim to address institutional racism and develop trust between the racially and ethnically diverse disability community and health professions in an effort to reduce barriers to healthcare access for Black and Latinx individuals with IDD.

To Learn More

Impact, the journal of the Rehabilitation Research and Training Center on Community Living, [dedicated an issue to supporting wellness for adults with IDD](#), touching on all facets (physical, emotional, vocational, spiritual, social, and psychological) with a focus on choice-making and inclusion.

For people with IDD and their supporters, the Centers for Medicare and Medicaid Services developed [From Coverage to Care \(C2C\)](#) to help people understand their health coverage and connect to primary care and preventative services that meet their needs.

Healthcare providers and practitioners may be interested in [Think Cultural Health](#), a website from the Office of Minority Health featuring information, continuing education opportunities, and other resources to learn about culturally and linguistically appropriate services.

Updates to the National Outcomes Health Indicators study can be found on [the project's ResearchGate webpage](#).

To Learn More About this Study

Li, H., Parish, S.L., Magaña, S., and Morales, M.A. (2021) [Racial and ethnic disparities in perceived barriers to healthcare among US adults with intellectual and developmental disabilities](#). *Intellectual and Developmental Disabilities*, 59(1), 84-94. This article is available from the NARIC collection under Accession Number J86188.

Research In Focus is a publication of the National Rehabilitation Information Center (NARIC), a library and information center focusing on disability and rehabilitation research, with a special focus on the research funded by NIDILRR. NARIC provides information, referral, and document delivery on a wide range of disability and rehabilitation topics. To learn more about this study and the work of the greater NIDILRR grantee community, visit NARIC at www.naric.com or call 800/346-2742 to speak to an information specialist.

NARIC operates under a contract from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), Administration for Community Living, Department of Health and Human Services, contract #GS-06F-0726Z.