



Improving Primary Care for People With Disabilities

The [National Association of Councils on Developmental Disabilities \(NACDD\)](#), with support of [UnitedHealthcare Community & State \(UHCCS\)](#), partnered with the UHCCS [National Federally Qualified Health Center \(FQHC\) Advisory Board](#) and the [National Advisory Board \(Boards\)](#) to more fully understand the challenges individuals with disabilities face when accessing primary care and to identify ways the health care system can be strengthened to deliver comprehensive, person-centered care that best meets their needs. NACDD coordinated community surveys of individuals with disabilities, caregivers, state Developmental Disability (DD) Council leaders, and health care professionals from across the nation in August 2021 to collect feedback and anecdotal evidence on primary care access. These surveys were promoted through the Boards, within the NACDD network of consumers and advocates, and to health care provider partners. The following provides an overview of those findings with insights from members of the Boards.

Primary Care Access Among People With Disabilities

Primary care can greatly influence and improve the quality of life for people with disabilities, including those with physical disabilities, intellectual and developmental disabilities (I/DD),¹ and other functional disabilities. Primary care is defined here as “the provision of integrated, accessible health care services by clinicians who are accountable for addressing a large majority of personal health care needs, developing a sustained partnership with patients, and practicing in the context of family and community.”² Primary care providers get to know a patient over time, making them the best source of more personalized and targeted care that addresses their ongoing total health needs.³ For the general population, access to and use of primary care has been correlated with greater use of preventive health care services, fewer hospitalizations, and fewer emergency room visits.⁴

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of individuals with disabilities have delayed or missed needed health care in the last year and almost half have yet to schedule missed primary or preventive health care.

Individuals with disabilities may experience barriers to accessing timely primary care services across the United States.⁵ It is also the case that the natural supports and direct support professionals caring for individuals with disabilities may experience their own barriers to care. The current COVID-19 pandemic and related concerns have created delayed use of health care services and barriers to accessing care, including primary care, in the United States. A recent study by the Centers for Disease Control and Prevention noted that “because of concerns about COVID-19, an estimated 41% of U.S. adults had delayed or avoided medical care including urgent or emergency care (12%) and routine care (32%). Avoidance of urgent or emergency care was more prevalent among unpaid caregivers for adults, persons with underlying medical conditions, Black adults, Hispanic adults, young adults, and persons with disabilities.”⁶ According to the NACDD community survey, 36% of individuals with disabilities reported delaying or missing needed health care in the last year and almost half have yet to schedule missed primary or preventive health care.

Medicaid is the primary insurer for individuals with disabilities.^{7,8} And with managed care organizations (MCOs) serving upwards of 75% of all Medicaid beneficiaries, a growing number of individuals with disabilities are also served by MCOs.⁹ Additionally, FQHCs make up the largest primary care network in the United States and currently serve 1 in 5 people covered by Medicaid.¹⁰ As a result, Medicaid, in partnership with managed care, plays a particularly important role in ensuring access to primary care services for individuals with disabilities, and FQHCs can serve as a common site for accessing those services for all populations.

Barriers to Comprehensive Primary Care Among Individuals With Disabilities

Individuals with disabilities and caregivers who responded to the community survey reported difficulties dealing with complex medical issues and identified several barriers to accessing primary care, including:



Transportation: In 2017, 5.8 million people delayed getting medical care in the U.S. because they did not have transportation. Those with a functional disability are more likely to experience transportation barriers.¹¹ Challenges reported by survey respondents included transportation costs, distance, availability, and accessibility. For example, one individual shared that they can sit in their wheelchair only for 3-hour intervals without negative impacts to their health, but trips to a qualified provider often require them to be in their wheelchair for 4 to 6 hours at a time. Multiple individuals shared experiences where personal care supports were not available to support getting to appointments.



Facility and treatment challenges: Accessibility of health care office locations and facilities often create barriers for individuals with disabilities. For example, office and diagnostic equipment (e.g., Hoyer lift, exam tables, scales, and imaging machines) may be physically inaccessible, while diagnostic devices with light or noise may trigger sensory issues. Accessing valuable preventive care — such as mammograms, annual checkups, and regular dental cleanings and exams — can be particularly difficult.



Sensitivity or sensory issues: The health care environment can be busy, noisy and bright, contributing to sensory overload for some individuals with certain intellectual and developmental disabilities. This can impact their ability to engage in their care or even remain in the setting to receive health care services.



Communications challenges: Both patients and caregivers reported challenges communicating with health care providers, accessing medical information, and understanding policies they were being asked to consent to or instructions they were being provided regarding their care. Some also reported that practice staff and clinicians often lack disability etiquette.



Insurance coverage and network gaps: Respondents reported experiences where valuable services were not covered, or preferred providers were not included in their insurance network.



Funding: Several respondents noted inadequate funding to support needed services or supports along with concerns about the cost associated with primary care visits.



COVID-19: Most recently, concerns about safety due to the pandemic have impacted access or willingness to access health care services.

Barriers Identified by Health Care Professionals

Across the country, many primary care providers and health care professionals agree that individuals with disabilities are not receiving adequate primary care services or are facing barriers in accessing primary care.¹² However, a recent study found that only 40.7% of physicians were very confident about their ability to provide the same quality of care to patients with disabilities, and 56.5% strongly agreed that they welcomed patients with disability into their practices. Health care professionals who responded to the NACDD community survey identified the following barriers to offering people with disabilities comprehensive primary care:



Lack of patient resources and supports: A lack of resources and supports for individuals with disabilities was the most common barrier identified, including personal care supports, transportation, and access to telehealth.



Medical complexity: Patients with disabilities can have complex health care needs due to the severity of disability and/or comorbidities, which require a different level of medical treatment and care coordination.

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Source: [Health Affairs](#)



Limited training: Nearly 20% of health care professionals identified a need for relevant training that would equip primary care providers with a better understanding of access and sensory and/or sensitivity issues of patients with disabilities. The most reported training needs included disability cultural competency, clinical education, and best practices.

“ *...training should start with people’s first language, disability etiquette, the role of listening and asking questions.* ”

— Health care professional survey respondent



Inaccessible facilities and equipment: Like the responses received from individuals with disabilities and caregivers, health care professionals also reported that health care facilities and equipment made it impossible for some patients to access necessary care comfortably and effectively.



Payment structures: Fee-for-service reimbursement is the most common payment model used in primary care and often requires providers to see a minimum number of patients a day to meet financial sustainability. Some respondents identified such payment models as barriers to serving individuals with disabilities who are likely to benefit from home visits or longer appointments. Similarly, Medicaid incentive programs for MCOs, which influence provider incentives and value-based agreements, rarely include measures focused on outcomes among members with disabilities.

Learnings From Disability and Primary Care Communities

While individuals, caregivers, DD Councils, and health care professionals surveyed noted that individuals with disabilities are largely able to access primary care, there was universal acknowledgment of areas to improve access in both getting to medical appointments and ensuring that those appointments are facilitated with sensitivity to the needs of those with physical, I/DD, or other functional disabilities.

Based on the NACDD community survey, there are possible benefits to encouraging primary and preventive health care visits in the midst of COVID-19 to help address the delays in care that could harm or exacerbate health conditions that could endanger lives. There are also opportunities to support primary care providers, particularly FQHCs, in serving individuals with disabilities in accessing the primary care and other integrated services (e.g., behavioral health, dental, vision services, referrals to social supports) they need. While telehealth improves access for individuals with disabilities, it has the added benefit of providers’ “eyes on” the patient. And the use of telehealth can give providers an opportunity to plan accommodations for future in-person visits.

“ *Lack of disability education/knowledge. Accessible locations as well as exam tables and restrooms.* ”

— DD Council survey respondent

“ *Individual is terrified of blood draws. Individual is autistic and non-binary so finding a supportive primary caregiver is our current challenge.* ”

— Caregiver survey respondent

Opportunities to Strengthen Primary Care Access for People With Disabilities

Based on their collective experiences and the responses received through the community surveys conducted by NACDD, the following actions are recommended to support individuals with disabilities in accessing needed primary and preventive care services.

<p>Policymakers</p>	<ul style="list-style-type: none"> • Enable and incentivize MCOs to equip and strengthen provider networks to better meet the health and social needs of members with disabilities. • Support Medicaid initiatives that increase or enhance access, including: <ul style="list-style-type: none"> ◦ Coverage of technology, hardware, internet services, and training for such technologies that can help individuals with disabilities access and utilize telehealth. ◦ Alternative payment models that offer FQHCs and other primary care providers additional flexibility to best meet the care needs of individuals with disabilities. ◦ Support for primary care facility modifications to ensure accessibility.
<p>MCOs</p>	<ul style="list-style-type: none"> • Incentivize providers to pursue practice changes that improve patient experiences and clinical outcomes among members with disabilities, including offering home visits. • Collaborate with disability advocates and other interested parties to offer relevant provider trainings that enrich disability cultural competency and promote clinical tools and best practices for serving people with disabilities. • Partner with primary care providers to advance integrated care. • Strengthen training and supports to equip those who provide support to people with disabilities, including assisting them in accessing needed care.
<p>Providers</p>	<ul style="list-style-type: none"> • Leverage trainings to build knowledge among staff and clinicians to create a welcoming and responsive practice. • Review patient population needs, operations, clinical practices, and partnerships to identify opportunities to enhance care delivered to individuals with disabilities. • Support local and state efforts to advance equity and address barriers to primary care for all patients but particularly those with accessibility challenges such as individuals with disabilities.
<p>Disability Advocates</p>	<ul style="list-style-type: none"> • Promote promising practices and community-based partnerships that improve access and health outcomes among people with disabilities. • Collaborate with MCOs and other interested parties to offer relevant provider trainings to enrich disability cultural competency and promote best practices for serving people with disabilities.

To support these actions, UHCCS and the members of the National FQHC Advisory Board and the National Advisory Board are continuing to collaborate to capture insights and promising practices related to primary care access for individuals with disabilities. The Boards will release a set of issue briefs throughout 2022 and 2023 that will explore opportunities for states, MCOs, health care providers, and disability advocates to work together to improve primary care access for people with disabilities. The briefs will focus on the following areas:

- 1 Life Transitions:** Considerations for providing comprehensive primary care across the life course.
- 2 Community Partnerships:** Promising practices for improving health through multi-sector partnerships.
- 3 Provider Training & Education:** Core competencies for offering people with disabilities culturally competent and comprehensive care and available resources.
- 4 Patient Access:** Tools and resources for improving access to care, including those related to telehealth, transportation, facility design and health care equipment.
- 5 Managed Care and Provider Quality and Performance:** Promising practices for understanding and meeting care needs through Medicaid policy and program design that incentivizes positive member experiences and health outcomes, including alternative payment models.

“ *So grateful for telemedicine. We were able to see our doctor without the added risk of Covid exposure. It also saves me two hours of driving for his appointments!* ”

— Individual survey respondent

Sources:

¹ A developmental disability is defined by the Developmentally Disabled Assistance and Bill of Rights Act of 1975 as a severe, chronic disability that occurs before an individual is 22 that is likely to continue indefinitely, and results in substantial functional limitations in three or more of the following areas of major life activity: self-care; receptive and expressive language; learning; mobility; self-direction; capacity for independent living; and economic self-sufficiency.

² [Institute of Medicine](#)

³ [American Family Physician](#)

⁴ [Intellectual and Developmental Disabilities](#)

⁵ [Disability and Health Disability Barriers | CDC](#)

⁶ [Morbidity and Mortality Weekly Report | CDC](#)

⁷ [The Arc](#)

⁸ [Frontiers in public health](#)

⁹ [New Study: States Increase Transition to Medicaid Managed Care - AHIP; Intellectual and Developmental Disability: Healthcare Financing \(nih.gov\)](#)

¹⁰ [National Association of Community Health Centers](#)

¹¹ [American Journal of Public Health](#)

¹² [Harder + Company Community Research](#)



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