

Disability Health Policy Brief

Highlights

- It is crucial to address unmet healthcare needs and barriers to care experienced by people with disabilities.
- Researchers and health practitioners must dismantle discriminatory and ableist views in healthcare settings and be trained on taking care of, and understanding the specific needs of people with disabilities.
- Healthcare system-wide programs can improve access to healthcare services and improve health outcomes for people with disabilities through cultivating an inclusive, collaborative clinical environment, and through leveraging comprehensive digital accessibility policies and appropriate assistive technologies.
- Government entities can support these efforts by funding initiatives to increase access to transportation options for people with disabilities, establishing accessibility standards for technology, and providing incentives for healthcare systems to hire and retain health personnel with disabilities.

Introduction

Over 1 in 4 adults in the United States face some kind of disability—a staggering 27 percent.¹ However, care for people with disabilities is not always met with the sustained effort that it deserves in healthcare systems. In a survey of U.S. physicians, only 47% reported that they felt “very confident” in providing equal care to patients with

“The doctors should be trained...on how to deal with persons with disabilities and also with women with disabilities.”

Video reference: World Health Organization
“People with Disabilities share their experiences of accessing health services”²

disabilities.³ This policy brief presents pressing issues of inequities in medical care for people with disabilities and recommendations for increased attention and resources to address the needs of people with disabilities in clinical settings. It is imperative that healthcare systems strive to provide the best care, and continuously adapt and innovate to achieve such goals, so all patients have the opportunity to access healthcare services and achieve optimal health outcomes.

Background Information

There is a lack of high-quality care for people with disabilities, which includes, but is not limited to the following barriers as described by the U.S. Centers for Disease Control and Prevention:⁴

- Attitudinal: Negative attitudes such as stereotyping, prejudice, and discrimination prevent high-quality care in healthcare services for people with disabilities. Disabilities are viewed as personal deficits rather than as societal gaps. It is the responsibility of society as a whole to ensure people with disabilities can live fulfilling, independent lives.
- Communication: Disabilities that affect hearing, speaking, reading, writing, and understanding require differing modes of communication and accessibility of health appointments, especially telehealth. It is important we tailor care to be inclusive of specific needs of patients, such as including closed captions or audio descriptions in health messages for those with hearing and/or visual impairments.
- Physical: Structural hurdles in built environments (e.g. clinics, hospitals) that block mobility or access. Barriers include steps/curbs and the absence of medical equipment to accommodate those with disabilities, such as accessible weight scales for those in wheelchairs.
- Policy: Lack of awareness or enforcement of laws and regulations that would promote and sustain accessibility for people with disabilities, such as not providing knowledge or access to federally funded health services or programs.
- Programmatic: Inadequate delivery of public health or healthcare programs for people with disabilities, such as lack of protocols to furnish accessible equipment, effective communication, and the provider knowledge regarding care for people with disabilities.
- Social: Social determinants of health that contribute to functional difficulties for people with disabilities. These include socioeconomic status, as people with disabilities are less likely to be employed or complete high school and tend to be of lower income.
- Transportation: Lack of accessible transportation options which allow people with disabilities to attend in-person health appointments. It may be difficult for people with disabilities with vision or mobility issues to use public transportation.

Dr. Lisa I. Iezzoni, professor and disability health researcher at the Harvard School of Medicine, has noted in her research that patients with disabilities face barriers to basic health care services, such as physical examinations, weight measurement, and effective communication with their physicians.³

These barriers to care contribute to poor health outcomes among people with disabilities. Health disparities among people with disabilities include poor chronic disease outcomes and higher mortality rates among patients with breast cancer.⁵ People with disabilities often feel invisible because of the lack of accessible and equitable healthcare services. This has contributed to an increase in mental distress and exacerbated poor health outcomes among people with disabilities, which underscores the urgency of rectifying these gaps in care.⁶

Healthcare systems need to better serve patients with disabilities and center care on their lived experiences. It is important for healthcare staff to recognize that people with disabilities face barriers to accessing healthcare and care coordination. Healthcare teams should work to improve coordination of care for patients during healthcare visits. For example, administrative staff should work with doctors to ensure accommodations for people with disabilities, given challenges with in-person or virtual appointments.⁷

Further, it is important to acknowledge healthcare services are often ableist, ignoring the needs of those who are disabled, possessing biased and discriminatory views toward people with disabilities, and lacking awareness of, and research on, the unique care people with disabilities need.⁷ There needs to be increased awareness of the impact of disabilities on patient quality of life and the different barriers experienced in receiving care. A patient-centered approach needs to be adapted and implemented to address these needs. These disparities underscore the urgency of healthcare systems taking action to improve the quality of care and healthcare outcomes of people with disabilities.

The situation is challenging for caregivers as well, who may not have the resources or skills to care for people with disabilities. Negative stereotypes held by some caregivers may shape relationships and may stem from a lack of knowledge about disabilities and feeling overwhelmed. Education for caregivers is important to ensure successful care for people with disabilities. Support systems for caregivers can reduce caregiver burnout and improve quality of life for people with disabilities. Care models must ensure home care staff are paid fairly and above the minimum wage.

Recommendations

Healthcare systems and researchers

The following recommendations are for healthcare systems and researchers to increase the accessibility and quality of healthcare services, and inclusiveness of research studies.

- Training for healthcare system employees on disability inclusion in clinical settings and disability consciousness.
- Adapting the clinical built environment to be inclusive of all patients (e.g. waiting rooms that can accommodate wheelchairs, sensory maps) to reduce the need for patients or staff to ask for accommodations. A universal design approach for clinical settings will ensure all patients are able to navigate and access these spaces.
- Leverage assistive technologies to increase the accessibility of healthcare services, such as sensor-based devices, navigational or spatial guides, and text-to-speech software. Remote patient monitoring is one approach for monitoring patient health metrics (e.g. blood pressure, glucose) between medical appointments and for patients who face challenges in attending in-person appointments.⁸ These digital health tools will require ensuring patient access to and education on using these technologies.⁹
- Implement orientation and mobility (O&M) guided training using virtual reality. O&M training can improve health outcomes for those who are blind or visually impaired, specifically improving their quality of life by providing assistance with daily activities linked to their health and well-being. Both providers and patients must first be well-oriented with the use and methods of O&M training or designate trainers.¹⁰
- Collaborate with the healthcare team, such as administrative staff, to build strong personal relationships with people with disabilities and their caregivers. Effective communication and teamwork, from the administration to the physician, can mitigate the barriers people with disabilities experience and greatly enhance their healthcare experiences. People with disabilities may have improved adherence to treatment plans if they feel their needs are adequately addressed.⁷
- Researchers should adopt inclusive recruitment strategies and participant opportunities for people with disabilities, such as partnering with disability advocacy organizations on study protocols and data collection instruments, and ensuring study participation is accessible for all potential participants.

Policymakers

There are a number of recommendations policymakers at the local, state, and federal levels can make to facilitate care for people with disabilities, increase their autonomy, and address their health needs.

Federal

- Provides grants to increase access to transportation options for people with disabilities.
- Establish broader accessibility standards for websites and software applications.
- Eliminate waiting period for disability insurance benefits for people with disabilities.
- Increase low-income housing tax credit to serve housing needs of people with disabilities.

- Provide grants to recruit and train direct-care workforce and support family caregivers and ensure home care staff are paid fair wages.
- Include disability status in public health data collection and assessment of health outcomes.

State

- Remove restrictions on eligibility for personal and home care services under Medicaid, which will allow for self-directed home care.
- Establish a State office to oversee assisting individuals with intellectual or developmental disabilities to ensure that they receive coverage from managed care organizations that is appropriate in meeting their individual service needs.
- Offer a professional education course for the healthcare workforce on risk management strategies for patients with developmental or intellectual disabilities.
- Require court approval for termination of or failure to renew leases for tenants in rental buildings who have a disability.
- Ensure equitable salaries for people with disabilities and increase employment opportunities for people with disabilities.

Local

- Create an accessible online system for residents to apply for and renew social service benefits.
- Increase funding for community organizations that support people with disabilities.
- Expand disability exemption programs for transportation taxes or fees.

Conclusion

People with disabilities face significant barriers when accessing and using healthcare systems, public transportation, educational spaces, and social services, which shape their health and well-being. Health researchers and healthcare systems have an important role to play in addressing these disparities, specifically ensuring inclusion of people with disabilities in research studies, advocating for people with disabilities, ensuring healthcare facilities are accessible to all patients, and educating healthcare providers and staff on providing care to people with disabilities. These efforts should be conducted in conjunction with policy efforts at the federal, state, and local level that provide funding for accessibility initiatives, housing options and employment opportunities for people with disabilities, and support for caregivers.

Disability Health Expert

John-Ross Rizzo, MD

Health System Director of
Disability Inclusion

Contact Us

Website: [NYU Institute for Excellence in Health Equity](#)

Email: iehegeneraladministration@nyulangone.org

Twitter: @nyugsom_iehe

Instagram: nyugsom_iehe

Authors: Zara Nadeem, Sata Cham, Rebecca Berger, Jonathan Martinez, Naheed Ahmed, John-Ross Rizzo

Design and Layout: Lindsey Osagiede, Naheed Ahmed, and Nadia Islam

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