

The Americans with Disabilities Act and the Health Care System: Experiences of Young Adults

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The Americans with Disabilities Act (ADA) celebrates its 25th anniversary this year. The groundbreaking civil rights law prohibits discrimination against people with disabilities in all areas of life, including jobs, schools, and transportation. For the past 25 years, the ADA has changed life for Americans with disabilities by impacting employers, schools, businesses and transportation providers, and other institutions.¹

A critical component of the ADA is its requirement for doctors and hospitals to provide equal access to health care to all Americans. The law prohibits discrimination against people with disabilities in public and private hospitals and health care facilities, including making medical facilities accessible by removing physical barriers, providing aids and services for effective communication, and modifying practices and procedures to provide services that fit the needs of individuals with disabilities. Mallory Cyr and Teresa Nguyen, Consumer Consultants for Got Transition/Center for Health Care Transition Improvement, offer their thoughts on the successes and needed improvements of the ADA in the health care system.

1. What modifications made by health care providers have been most important to you and other youth and young adults in accessing health care services?

Mallory Cyr: I think there is a **critical need to continue to incorporate health into the world of disability** as they are often considered separately. While living in Boston, I was fortunate to have a primary care provider who really understood my busy lifestyle as someone who was trying to stay healthy while working and going to school. She would create flexible appointment times, even offering to make a home visit, if needed. She worked diligently to **make sure my care was coordinated**, following up on things like prescriptions and scheduling future appointments during my visit so that I did not leave with a long list of things to do on my own. She also put me in touch with people who could service my mobility equipment when it broke down. When I moved to a new state, she helped me find new providers, and before my moving date, she made sure that I was in adequate health to travel and that no needs were left outstanding. Because of **her support to manage my complex health needs**, I was able to devote my energy to being successful in my job and academic career without feeling like my health was going to suffer.

Teresa Nguyen: The Americans with Disabilities Act has increased my access to health care as a young adult and has **enhanced my experience as a patient**. Some of the most important “accessible features” for me include: exam tables that are able to adjust to different heights (beneficial for wheelchair users); being able to go to a clinic that is **accessible by public transportation** (maximizing independence for young adults); having **different modes and options for communication** with my providers (email, texting, and patient portals enable young patients to manage their health in addition to their hectic life); **and interpreter services** for families who need it (with a multicultural background, my family couldn’t have navigated the health care system without this crucial service).

2. What additional improvements are needed to make health care services accessible to youth and young adults with disabilities?

Mallory Cyr: Although the ADA has been in place for 25 years, **physical access in health care is still a huge barrier**. Many people believe that all medical facilities are accessible, but that is far from the truth, especially in some urban areas with older structures. Buildings oftentimes lack ramps, ground level entrances, and elevators. Along with basic entrances, things like **accessible exam tables and scales** are hard to come by. Where I received primary care, there was fortunately a wheelchair scale, but it was part of another clinic located thirty minutes away that was not easy to get to during the visit. Being of short stature and having fragile bones, it can be difficult for me to climb onto the exam table unassisted, and **people often do not know how to help**. So, aside from physical changes, I think many practices could benefit from **cultural competency training** in order to respectfully assist individuals with disabilities. This also includes supporting people with disabilities to have fulfilling lives, such as being respectful of their schedules and trying to schedule appointments at times that work for them, rather than assuming that the life of a person with a disability is completely devoted to managing their condition, and thus scheduling inconvenient appointments without consent.

Teresa Nguyen: Although the health care system has made some tremendous strides in ensuring that services are more accessible to youth and young adults with disabilities, it’s important to remember **there is always more we can do to be more inclusive of all youth and young adults** – with and without disabilities. **Telehealth** is a great way to provide certain health care services to populations with fewer options for physically traveling to a clinic – expanding/increasing these services would be an incredible way to improve health care accessibility for the disability community. Cultural competency and sensitivity is another way to increase health care service accessibility for the disability community. **Respecting and understanding** that even though a health care plan may work for one patient, it may need to be modified or changed for it to work for another patient in the same way – this is one key to patient-centered care that is important for people with different health care needs.

Check out www.GotTransition.org to learn more about health care transition for youth and young adults with disabilities and their families!

¹ “10 Things to Know about the Americans with Disabilities Act,” *Disability Connection Newsletter*. 17 July 2015. <https://www.disability.gov/disability-connection-newsletter-july-2015/#content>, accessed 2 August 2015.