

Why is it So Hard to Get the Health Care Accommodations that I Need?

BY MEGAN A. MORRIS, STEPHEN LOCKHART AND KORI EBERLE

Health care organizations (HCOs) are required by federal laws, including the Americans with Disability Act (ADA), to provide patients with disabilities accommodations to ensure that they receive equitable health care services. Health care accommodations for persons with hearing loss might include aids such as personal amplification devices, as well as strategies such as having doctors and nurses face the patient while they are speaking. Unfortunately, these accommodations often are not provided during patient's visits.

Section 1557 of the Affordable Care Act strengthens the national mandate for accessible health care by prohibiting discrimination against patients based on demographic characteristics including disability status. Additionally, it mandates HCOs with 15 or more employees designate a co-worker to oversee compliance with the statute. Consequently, HCOs have hired employees to lead these disability compliance efforts. This is an important step since accessible health care does not "just happen." Instead, someone needs to champion the process and be responsible for implementing initiatives to ensure accessible health care.

To understand how organizations are implementing the role, we conducted interviews with individuals who lead disability initiatives within 18 organizations across the United States. Participants represented organizations ranging in size from one hospital to a system with 40 hospitals and more than 100 outpatient clinics.

An important finding was that those who lead disability accessibility programs had very diverse job titles. We found a total of 20 unique job titles among the interviewees! The most common job titles were Section 1557 coordinator, ADA coordinator, and interpretive services coordinator. Additionally, these individuals were located in a range of departments within their organizations, such as patient care services, quality and safety, and interpretive services. Despite diverse job titles, the individuals had similar goals in their roles: 1) ensure that the organization adhered to legal requirements, and 2) develop an organizational culture that prioritizes equal access to health care for patients with disabilities.

Almost all of the participants were the first person in their position; the length of time in the position ranged from six months to nine years. Unfortunately, there is no manual on how to lead an accessibility program. These individuals often had to blaze their own paths with little guidance and few resources. The most common activities and types of initiatives they led included: documenting and tracking patient's disability status and requested accommodations, responding to patient complaints, implementing trainings, ensuring facilities and equipment are physically accessible, overseeing service animal policies and processes, developing effective communication policies and procedures, and overseeing accessibility of electronic materials.

Many individuals reported significant challenges within their positions. The role was often ill-defined, with the basic instruction of protecting the organization from potential lawsuits. Additionally, these individuals were often overwhelmed with the amount of duties the job required. To establish a successful disability accessibility program, they reported the need for leadership support, a dedicated budget, sufficient personnel to execute the work, and an organizational culture that prioritizes accessible, equitable health care.

Health care organizations need to take actionable steps toward meeting the needs of people with hearing loss and other types of disabilities. First, we need a designated title for who leads disability accessibility programs. This will allow patients to know who to contact for requesting accommodations or filing a complaint. Second, we need established standards for what accommodations should be provided and how they should be provided. This will help define the roles and responsibilities of these individuals. Third, organizations need to have leadership support for the initiatives to be successful. This includes having a defined and appropriate budget to carry out disability accessibility initiatives.

What can you do today as a person with a hearing loss? First, recognize it is your right to have your health care team provide accommodations. Second, contact your health care team before your appointment to

request that your specific accommodations are available at the time of your appointment. This might require multiple phone calls or emails, and diligence in finding the right person to address your request. Be patient but persistent. Third, at your appointment, let your team know about your disability and accommodation needs. Ask them to document the information in your medical chart so that everyone on your team knows about your disability and needs.

While there is a long journey ahead until accessible and equitable care is achieved for all people with disabilities, there are practical steps that we can all take today to work toward our goal. **HL**

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A Communication Success Story

BY BETTY V. HAUCK

I was so tired of the typical encounter in a health care setting where I have to repeatedly tell the health care worker I'm talking to that I need to be able to see their face while they're talking. They already have so much on their minds, and they aren't trained to accommodate hearing loss. What to do? I decided to print out a prominent sign in big letters that said, I am partially DEAF. Please face me and speak slowly and clearly. Thank you!

When I went in for a routine colonoscopy, I wore this sign pinned to my chest. The nurse who was assisting took one look at it and put on a transparent face mask. She taped the sign pinned to my johnny to my monitor so everyone could see it. After the procedure when I was coming to, the doctor bent down, his head just inches from mine, and spoke to me in a very exaggerated voice. And then it hit me. The SIGN! It worked!

While this happy ending was a result of my self-advocating and the responsiveness of the hospital staff, positive outcomes for all patients should be routine. This will happen only when effective accommodations are fully integrated into the health care system by providers. **HL**



Before retiring due to progressive sensorineural hearing loss, Betty Hauck was a professional concertizing violist who played at the White House, performed with Yo-Yo Ma, was a founder and violist-in-residence at the Apple Hill Center for Chamber Music in Nelson NH, and toured the Middle East annually in the "Playing for Peace" program. Since then, she has been advocating and educating about hearing loss through her program, "A Life in Music Lost and Found — My Journey as a Musician with Hearing Loss," which she presented in Rochester at the HLAA 2019 Convention as well as in many other venues. In 2018 Betty was featured in a story on NPR's "Here and Now" which was selected as a top story of the year. Email Betty at bettiola@comcast.net.

Program Update

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