FAST READ: Though there’s been increasing recognition of health care disparities among adults with physical disabilities, this awareness has not extended to patients with communication disabilities. In fact, a new study finds that these patients have a harder time finding quality care than any other group—for a complicated set of reasons.

TAGS > HEALTH CARE DISPARITIES, COMMUNICATION DISORDERS

Communication: It’s Critical to Care

Adults with communication disabilities struggle to access quality health care—significantly more than typical peers. How can we get them needed health information and services?

BY MICHELLE L. STRANSKY AND MEGAN A. MORRIS
Judith*, age 62, has cerebral palsy, uses a speech-generating device, and brings her personal care assistant (PCA) to all of her doctors' appointments. She's grateful that she and her primary care physician have a close relationship, and that he takes the time to learn how best to communicate with her. For example, he always schedules appointments to allow for extra time—care that led him to detect her breast cancer early.

Unfortunately, Judith's experience with her oncologist has not been as positive. The oncologist always speaks first (and primarily) to Judith's PCA. If she does speak with Judith, she uses “baby talk.” Judith repeatedly asks the oncologist to use her normal voice and speak directly to her, but she never grants this request. Frustrated, Judith questions whether she receives the same quality of care that she would have if she did not have a disability.

Alas, the research suggests that the quality of care Judith receives is not just lower because of her disability—it's compromised by the type of disability she has: a communication disability.

In fact, in a new peer-reviewed research study we published in the December 2018 issue of the Journal of General Internal Medicine with Kristin M. Jensen, we find that adults with speech, language and voice (SLV) disabilities face greater challenges accessing health care than their peers without SLV disabilities (bit.ly/hc-access). These challenges include increased trouble finding medical care providers, seldom receiving quality emergency and routine health care, and delaying or foregoing medical care due to the cost and availability of services.

In statistical analyses, we found that these disparities persisted even after accounting for non-SLV disabilities and chronic health conditions. This finding is especially important because people with SLV disabilities have more chronic conditions, such as arthritis, cardiovascular disease...
and emphysema, than their peers without communication disabilities.

What accounts for this decreased access among people with SLV disabilities? And what can providers in communications sciences and disorders and other fields do to help counter this disparity? Let’s take a closer look.

**The disability disparity**

A growing body of literature indicates that adults with disabilities face poorer health and medical care outcomes compared to their peers without disabilities (see sources). The literature defines these comparatively poor outcomes as disparities: differences in health and medical care outcomes and experiences based on some characteristic of a group of people that places the group at a social, economic or other type of disadvantage.

In response, we aim for health equity—the principle of reducing such disparities and giving all people the opportunity to attain the best possible health and medical care.

Historically, disparities work has focused on race and ethnicity, while disability was assessed as an outcome to be avoided. For example, we have evidence that adults who identify as non-white are less likely to receive speech-language treatment following stroke than their white counterparts (see sources). And although racial/ethnic disparity is a critical problem that needs to be addressed, patients with disabilities are themselves a vulnerable population and are at risk for poor health and medical care outcomes.

A person’s disability might be related to poor health (for example, a patient may suffer a stroke as a result of uncontrolled hypertension), but increasing evidence indicates that environmental, economic and social factors contribute to poor health and, thus, health disparities for people with disabilities (see sources). For example, adults with physical disabilities have fewer opportunities to exercise due to factors such as inaccessible fitness equipment at local gyms or inadequate neighborhood sidewalks. As a consequence, adults with physical disabilities have higher rates of obesity and obesity-related chronic conditions (such as hypertension and diabetes) compared with people without physical disabilities.

Medical care disparities are disparities in access to and receipt of health care in general, our analysis revealed that these patients are more medically complex.
Adults with speech, language and voice (SLV) disabilities:

- Have more chronic conditions
- Often struggle to find health care providers
- Seldom receive quality emergency/routine care
- Often delay or forego care due to cost/availability
- Experience more medical errors
- Are unlikely to have providers use visual supports
high-quality medical care services. As with health disparities, we see medical care disparities across adults with disabilities. For example, multiple studies have demonstrated that women with physical disabilities have lower rates of preventative cancer screenings than their peers without disabilities (see sources). This difference is due to such factors as inaccessible medical equipment—including examination tables and mammography machines—and medical providers’ inaccurate perceptions of women with disabilities.

Overlooked: Communication disabilities

Even as recognition of health and medical care disparities among adults with physical disabilities grows, adults with SLV disabilities are often left behind. Very few studies have focused on adults with such disabilities, resulting in little evidence about the quality of health and medical care services they receive.

Section 4302 of the Patient Protection and Affordable Care Act of 2010 requires that all federal
Researchers found that people with SLV disabilities were three times more likely to experience a preventable medical error.
outpatient visits of patients with aphasia. Findings revealed that physicians rarely used supportive communication strategies that speech-language pathologists commonly train communication partners to use. Across 25 recorded visits, no physician wrote down key words while speaking, only one used a visual aid, and physicians inconsistently used meaningful gestures, despite all of the patients reporting benefits of these strategies. Providers used a wide variety of communication strategies, with some using different strategies during the same encounter. Interestingly, physicians and patients reported using similar strategies to communicate during the encounter.

Another Morris-led study based on interviews with adults who use augmentative and alternative communication (bit.ly/AAC-comm) identified time constraints, inappropriate assumptions about people's cognitive or hearing abilities, and difficulties communicating with physicians as barriers to receiving high-quality care.

**The fix:**

**Addressing disparities**

What can be done to help turn the tide and improve health care access for patients with SLV disabilities? Education of providers is key, and medical schools, health facility administration, and continuing education programs should promote efforts to improve the health care experiences of patients with SLV disabilities.

Audiologists and SLPs can be prime ambassadors in this regard. They can do much to champion the needs of adults with SLV disabilities in their work settings and communities.

Promoting communication is not just ethical. It is specified in regulations mandating hospitals and clinics (Section 1557 of the Patient Protection and Affordable Care Act; Nondiscrimination in Health Programs and Activities 2016) and state and local government services, as well as public accommodations and commercial facilities (U.S. Department of Justice), to provide people with disabilities with auxiliary aids and services to ensure equitable access to communication.

These regulations are supported by the Joint Commission, which designates people with communication disabilities as high risk for ineffective communication and calls for medical care systems and clinicians to provide additional...
supports to ensure effective communication with patients with communication disabilities (bit.ly/JC-equity). SLPs and other providers can employ four strategies to promote use of such supports:

- **Partner with leadership at your organizations** to help create and implement institutional policies for effective communication. Ensure that policies are informed by evidence and implemented according to best-practice guidelines. ASHA offers extensive information on evidence and implementation in its Evidence Maps (www.asha.org/evidence-maps). Incorporating these practices is not easy or simple, given the constraints of time and money. But consider the severe legal ramifications of not addressing the needs of adults with SLV disabilities.

- **Educate staff and providers using informal and formal methods.** Given the high rates of chronic conditions in patients with SLV disabilities, providers likely interact with a wide range of medical care providers and teams when treating them. Formally, audiologists and SLPs can provide in-service trainings and help develop educational materials, including pamphlets and signs, for colleagues. Remember that most medical care providers receive little to no training on effectively communicating with patients with SLV disabilities. General education on patient-provider communication is available, but advanced training to address the needs of people with communication disabilities is rare. This specific training should become part of medical school curricula and continuing education.

- Informally, audiologists and SLPs can model effective communication strategies with these patients and alert their colleagues about suggested strategies, including presenting information in ways that the patient can understand and not interrupting the patient.

- **List key communication strategies to use with patients** in a prominent place, such as the patient’s medical chart. How to do this differs by institution and electronic medical record (EMR) systems, but many EMRs offer a demographic field in which to describe a patient’s disability and needed accommodations. Documenting SLV disabilities and strategies that work is key: Many adults with SLV disabilities visit multiple medical care providers, many of whom are unaware of the patients’ needs.
Be aware of the medical complexity and difficulties that patients with SLV disabilities face accessing medical care services. These complexities can significantly affect patients' ability to attend to treatment-related instructions and tasks. For example, if a patient has uncontrolled diabetes, kidney pain (or other such symptoms) could hamper their concentration during an audiology or speech-language treatment session. Providers need to individualize treatment and care-delivery styles to each patient's specific needs.

The pages of this magazine contain countless stories of audiologists and SLPs partnering with physicians and organizations to share tools and best practices for work with adults with SLV disabilities (for example, Tiffany Turner’s 2018 article “Widening Her Circle,” on.asha.org/wide-circle).

Judith’s story, which began this article, underscores the value of using effective communication strategies with this population, as well as the need to partner with physicians and other health care providers to improve their medical care outcomes. Federal regulations and our ethical responsibilities as medical care providers require that we work together to improve patient care and outcomes across the medical care system. With support from administrators and other providers, audiologists and SLPs are well-poised to help improve health care access, quality and outcomes for patients living with all types of SLV disabilities.

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*A patient’s name has been changed for identity protection.*
Sources


