

Issue Brief

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Listen to those who don't hear: *Members of Colorado's Deaf community demand equal and effective communication*

You're at a medical appointment, trying to explain your abdominal pain to the physician. She doesn't understand you, and the more you try to communicate, the more impatient she becomes. Maybe she starts pacing around the room. When she communicates to you, you don't understand the terms she's using, which increases the tension. Then she starts talking to the nurse in a language you can't understand. It's

clear they are talking about you, but you don't know what's being said. You've asked for an interpreter, but your request was ignored.

You'd probably want to walk out, right? But you are sick and need the care. So you suck it up.

That's the situation many Deaf¹ people face when they deal with the health care system. And in Colorado, members of the Deaf community are coming together to support and advocate for each other and to educate providers about how to communicate with Deaf patients.

What is Deaf Culture?



"Deaf people as a linguistic minority have a common experience of life, and this manifests itself in Deaf culture. This includes beliefs, attitudes, history, norms, values, literary traditions, and art shared by Deaf people." [...] "A person is a member of the Deaf community if he or she self-identifies as a member of the Deaf community, and if other members accept that person as a member. Very often this acceptance is strongly linked to competence in a signed language."

—World Federation of the Deaf

Understanding the basics

The Americans with Disabilities Act requires physician practices, hospitals and other health care providers to provide—and pay for—qualified sign language interpreters when a patient needs one to "effectively communicate" with a provider about the patient's medical condition, treatment or prognosis.²

¹ When discussing the condition of not hearing—being *deaf*—the lower-case *d* is used. When referring to a particular group of people who share a language—in this case, ASL—and a culture, the uppercase "D" is used. (National Association of the Deaf).

² "Complying with disability rules for hearing-impaired patients," *Medical Economics*, Jan. 8, 2014.

But many health care settings still don't provide American Sign Language (ASL) interpreters when they are needed.³ In fact, members of the Deaf community report that, in their experience, neither doctors nor front-desk staff were aware of the requirement that Deaf patients are entitled to equal and effective communication.

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Frequently, practices have no policies or arrangements to provide interpretation services. "They don't seem to understand—or want to follow—the ADA requirement," observed one Deaf advocate and patient. "It's their responsibility to arrange for one, not mine."

Jana Glassmeyer, a resident of Fort Collins and member of the Larimer County Bridging Communication Group, always requests an interpreter when she makes an appointment. And she gets one—about 25 percent of the time. "They expect me to read lips," she says. One time, a physician suggested her child interpret for her. She rejected the idea. It's not unusual for providers to ask that children interpret for their parents, but children do not constitute qualified medical interpreters, regardless of the language.^{4,5}

Sandy Smith, also a member of the Larimer County Bridging Communication Group and an advocate for the Deaf community, has encountered the problem frequently. She shares one example: "When I called to set up the appointment, I said 'please have an interpreter there.'" She was assured there would be. Just to be sure, she called the next day, to confirm. Yes, she was told, we'll have a live interpreter.

³ The Deaf and Hard of Hearing community is broad, and can include individuals with different hearing levels. For the purpose of this brief, we focus on those for whom ASL is the primary language. Many of these individuals are prelingually deaf and identify as members of the Deaf community.

⁴ "Hospitals often ignore policies on using qualified medical interpreters," *Modern Healthcare* Aug. 30, 2014.

⁵ American Speech-Language-Hearing Association, Collaborating with Interpreters

They didn't. "When I arrived, I asked if they had reserved an interpreter. They said there was no note in the file about needing one." Rather than wait or use video remote interpreting (VRI), she decided to go ahead with the appointment, suggesting they communicate via writing. (For more on why someone might prefer writing to VRI, see sidebar below.)

But that didn't work, either. The physician didn't appear to understand her writing, and she didn't understand the medical terminology he used.

It was frustrating for everyone. "Doctors aren't patient with writing," she says. "It feels very offensive that I'm the person in the room who does not understand what's happening." In this encounter, and others, she has felt trapped: It was demeaning to stay, but she needed the care.

She says she didn't feel she had been given the opportunity to be involved in her health care; that was a common sentiment among those interviewed for this brief. The language issue posed a barrier, of course, but there's also a stigma to deafness. Deaf people report that health care professionals often—intentionally or not—treat them with condescension, as if they are mentally deficient. "I'm not dumb," Smith says. Her message to providers: "Think of me as an equal."

Why technology VRIs: isn't always the best solution

VRIs: Video Remote Interpreting (VRI) uses videoconferencing technology to provide the services of an ASL interpreter. It is not an ideal solution, say Deaf advocates. Sometimes, the facilities don't have enough internet bandwidth, so the connection is bad. In addition, the technology can be unreliable, interpreters may not be certified and, if the patient is lying down, it can be hard for the interpreter and patient to see each other.

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— Jana Glassmeyer; member, Larimer County Bridging Communication Group; advocate for Deaf community in Colorado

Glassmeyer has run into that attitude, too. Deafness, she has to explain, is not a cognitive disorder. “Deaf people are just like everyone else, except that we can’t hear. All we need is an interpreter. Then we can advocate for ourselves.”

Self-advocacy in a backless paper gown

Even those in the Deaf community who advocate most strongly for health care equity find it difficult to advocate for themselves as patients. “When I’m in a health crisis, I’m vulnerable and afraid,” one woman—who wishes to remain anonymous—explains. She’s had situations where there was no live interpreter and the VRI connection was poor. “I feel like I’m stuck. I can’t ask for another interpreter, because the doctor may see me as a troublemaker. If I’m an annoyance, he may not want to take care of me.”

And that touches on a distressing power dynamic in these encounters, says Jenny Miller, a deaf services specialist who works with Disabled Resource Services, one of nine Centers for Independent Living in Colorado. Deaf people are being required to negotiate with an authority figure, a physician, over their right to have a sign language interpreter—over their right to communication access.

She has seen firsthand what Deaf patients have to endure. She often must advocate for and intervene on behalf of her clients before or after their appointments. “It’s unfortunate. Often the medical staff pays more attention to me because I have a comma and letters after my name—or, even more unfortunately, because I am hearing.”

That attitude about deafness interferes with care in other ways. Instead of focusing on the actual illness, some providers consider deafness a condition to be treated. Miller sees this happen with many of her clients.

One member of the Deaf community says this is common: Her actual ailment receives less attention than her deafness. “Being Deaf has nothing to do with my heart condition or my cold. It’s really a cultural misunderstanding. I’m not broken. I have a hearing loss, but that’s part of who I am. The doctor sees a medical condition he needs to fix: an impairment,” she says. “A drunk person is impaired. I am not impaired.”

Emergency care is the worst

During medical emergencies, it’s even harder to get an interpreter. “If I’m in an ambulance, EMTs should be able to call ahead and ask for an interpreter to be ready,” Smith says, adding that there should be a protocol in place. “Most of the time, that doesn’t happen—there’s no interpreter and no request has been put in.”

But the problems start even before the ambulance is dispatched. “Another problem we encounter is contacting 911. You can call 911 through a video relay service, but they won’t always accept the call. I’ve been hung up on before. Once, I had to call my mother and ask her to call 911 for me,” Smith recounts.

“We can send texts to 911, but dispatchers often won’t accept them. They ignore the text. It could be snobbishness, but it could also be because of language barriers.”

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For many Deaf ASL speakers, English is a second language. ASL, their first language, is visual, Smith explains. “Facial expressions are part of the grammar of ASL. So when we write in English, sometimes it’s very basic. Instead of ‘I need to go to the hospital,’ a Deaf person may write ‘I go hospital.’” That can be confusing to someone unfamiliar with ASL, she says. (For more on ASL language issues, see sidebar below.)

Poor communication, bad care, worse outcomes

None of this is exclusive to Colorado, of course. And it cannot be dismissed as anecdotal: Research shows that Deaf people around the country report fear, mistrust and frustration in health care encounters.⁶

ASL *as a language*



An estimated 500,000 to 2 million people in the U.S. use American Sign Language, which has its own grammar and syntax that are distinctly different from spoken English.[†] It is, nevertheless, speech: The brain’s left hemisphere is dominant for sign language, just as it is for oral speech, and the same sort of brain damage that affects speech will affect signing (spatial and visual functions generally take place in the right hemisphere). As a *Scientific American* review of the literature put it, “The organization of the brain for language does not appear to be particularly affected by the way in which language is perceived and produced.”^{††}

[†] Gallaudet University Library, “Sign Language” <http://libguides.gallaudet.edu/content.php?pid=114804&sid=991835>

^{††} Hickok G, Bellugi U and Klima, ES “Sign language in the brain.” *Scientific American* June 2011.

Moreover, communication barriers erode the physician/patient bond, make it difficult to exchange critical information, and ultimately affect the quality of diagnosis and treatment.^{7,8}

“Talk to the Deaf community about services they need. Then develop the appropriate policies and procedures.”

— Jana Glassmeyer; member, Larimer County Bridging Communication Group; advocate for Deaf community in Colorado

It’s no surprise, then, that Deaf patients face significant disparities in terms of both health care and access to it.⁹ One example: In the United States, adults who have been deaf since birth or early childhood are less likely to have seen a physician than adults in the general population.¹⁰

Better workflow, better communication

Health care organizations need to make changes to accommodate Deaf patients, say Deaf advocates. Just as they would for a Spanish or German speaker, hospitals, clinics and emergency services need to take the steps to communicate with Deaf patients who use ASL.

They can do that by listening to the Deaf community.

“They need to have policies in place. Talk to the Deaf community about services they need. Then develop the appropriate policies and procedures.

⁶ Kuenburg, A, et al. “Health Care Access Among Deaf People.” *J Deaf Stud Deaf Educ* 2016; 21 (1): 1-10 <https://academic.oup.com/jdsde/article/21/1/1/2404217/Health-Care-Access-Among-Deaf-People>

⁷ Chaveiro, N, et al. “The relation between deaf patients and the doctor.” *Brazilian Journal of Otorhinolaryngology*, 75(1), 147-150. http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0034-72992009000100023&lng=pt&nrm=iso&tlng=en

⁸ Kuenburg, A, et al. “Health Care Access Among Deaf People.” op. cit.

⁹ American Psychological Association *Spotlight on Disparities*, 2013 <http://www.apa.org/pi/disability/resources/publications/newsletter/2013/11/deaf-community.aspx>

¹⁰ Barnett, Steven et al. “Deaf Sign Language Users, Health Inequities, and Public Health: Opportunity for Social Justice.” *Preventing Chronic Disease* 8.2 (2011).

Then do staff training. People need to be reminded," says Glassmeyer, who helps train practices to communicate more effectively with Deaf patients. She points out that often the problem begins with the staff: There's a breakdown in communication between the staff and the physicians. The physicians understand the law, but that message doesn't make it to the person setting appointments.

Much of this could be addressed by improving workflow issues so the interpreter is scheduled when the appointment is scheduled, say Glassmeyer and Smith. Tell the front desk staff the steps to follow. Set up a contract with an interpreter service so finding one isn't a last-minute crisis. Some things need advance preparation. The need for an interpreter should also be included in the patient record.

Education as a solution

Glassmeyer, Smith, Miller and others have hit the road to get that message out. They are participating in meetings across the state to help providers improve their services and to help them anticipate the needs of Deaf patients. Research is on their side: Deaf cultural competency training has been shown to significantly enhance skills in caring for Deaf community members, thereby reducing health care disparities.¹¹

At the meetings, they and their colleagues share resources with medical professionals. For instance,

"Health care professionals have asked us how we can help them improve services. We're happy to be part of that, to help them figure out what to do."

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they hand out cards that explain when ASL interpreters are needed and how to schedule one. (To see video from one of these meetings, visit www.rmhpcommunity.org/video/larimer-county-bridging-communication-townhall-november-4-2016.)

Physicians and other health care professionals are interested, and they've been coming to the meetings. "Health care professionals have asked us how we can help them improve services. We're happy to be part of that, to help them figure out what to do," says Smith.

Deaf cultural competency training has been shown to significantly enhance skills in caring for Deaf community members, thereby reducing health care disparities.

Resources abound. One good starting place is the National Association of the Deaf's **Questions and Answers for Health Care Providers** and its position paper, **Position Statement on Health Care Access for Deaf Patients**.

It can be a fraught situation. "I understand why doctors get frustrated," Smith says. "Often, they don't understand why the patient is mad—what has happened to them historically to make them angry." For the provider dealing with a Deaf patient, it's a rare encounter. For the Deaf patient, dealing with a hearing doctor is not, and he or she encounters similar challenges with each visit.

"We don't want it to be negative or to be agitating," she says. "What we want to do is to move across Colorado, tell them how to improve access, to explain how and where they can get interpreters who will be ready to show up at the assigned time. It's a work in progress. We would like to see Colorado become more effective at treating Deaf patients. We want Colorado to be a role model for other states." ■

¹¹ Hoang L, LaHousse SF, Nakaji MC, Sadler GR. "Assessing deaf cultural competency of physicians and medical students." *J Cancer Educ*. 2011 Mar;26(1):175-82.



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JENNY MILLER
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JENNY MILLER has worked at Disabled Resource Services for 15 years as their specialist for the deaf and hard of hearing. She is a member of the Bridging Communication/Deaf Access to Healthcare group and is proud of the work it is doing to ensure everyone in the community has communication access in health care. She has been a professional sign language interpreter for 25 years.



SANDY SMITH
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SANDY SMITH is a member of the Larimer County Bridging Communication/Deaf Access to Healthcare. A member of and advocate for the Deaf community, she lives in Fort Collins.

About Rocky Mountain Health Plans

Founded in Grand Junction, Colo. in 1974, as a locally owned, not-for-profit organization, Rocky Mountain Health Plans provides access to affordable, quality health care enabling its more than 229,000 members across the Western Slope to live longer, healthier lives.

About the Community

Western Colorado is creating an accountable community that uses health IT in a meaningful way, adopts value-based payment models, coordinates care and empowers patients to take charge of their health.

We aspire to ensure the following:

- High-quality health care is affordable and accessible to all.
- Those who purchase health care are assured that care is effective, safe and appropriate.
- Patient care is a team effort, with roles that are well-defined, connected and collaborative.
- Patients have access to the support and information they need to take charge of their health and make their own decisions.

- Payment reform will foster reimbursement models that support accountability for population health and resource use.
- Information technology supports population health, helping providers predict outcomes, prioritize interventions and prevent disease.
- Health data is a community resource used in a secure way to support coordinated care at the population, practice and personal levels.
- Investments in information technology and health system transformation will improve quality of life and economic well-being across the state.
- Health is a community resource that requires leadership, stewardship, individual responsibility, community support and ongoing maintenance.

For more information:

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