

**Mediated Communication in Context:
Narrative Approaches to Understanding Encounters
between Health Care Providers and Deaf People**

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Abstract

Deaf people experience disparities in health care that are often the result of (or exacerbated by) difficulties of communication. Health care providers often lack cultural understandings of Deaf communication and culture and thus do not provide effective communication access. U.S. disability law is meant to guarantee communication access, but deaf people's stories of access indicate that they may still encounter barriers to effective access. We report on an action research project designed to enhance communication among deaf people, health care professionals, and sign-language interpreters. We draw upon a social model of disability, which locates barriers to inclusion in society and the environment rather than the embodied difference or impairment, and extend that to the condition of deafness. We argue that narrative and dialogue that develops cultural understandings of Deaf communication and culture can offer a means of facilitating mutual understanding among the parties involved. Our hope is that interventions based on this approach will contribute to greater health-care access for deaf people.

A Deaf¹ participant in an interview study recounted a recent experience with a doctor who canceled her appointment because he did not want to provide her with an interpreter:

I was having trouble with my neck. I was getting dizzy spells, and I didn't understand why. My doctor sent me for an MRI. There was an interpreter for that. They found two herniated disks in my vertebrae, so my doctor wanted me to see a neurologist, to see if I needed therapy to improve the situation, because of the dizziness. He referred me to a doctor, and I called the doctor's office in November to set up the appointment. I told them I needed an interpreter. They said fine, and I thought it was all set up. Two days later, I heard from the interpreter referral service saying that the doctor refused to provide the interpreter....They canceled the appointment....

She did not contact the doctor again and instead filed a civil rights complaint with the United States Department of Justice (Schwartz 2006: 157-158).

This narrative describes a breakdown in communication that precedes the communication breakdown that would likely have occurred if this Deaf person had seen the neurologist without a sign language interpreter. We contend that the breakdown in communication occurs for a host of reasons and began long before the Deaf person called to schedule the appointment, with the failure of education for the physician and her or his staff in ethical, let alone legal, requirements for Deaf access to health care playing a significant role (Barnett 2002, Harmer 1999). This failure of education is not exclusive to Deaf access but extends to issues of access for disabled people and, more broadly, those who for a host of reasons fall outside of the norms and expectations of patient performance.² The result is that, like disabled people and people who come from minority, ethnic, racialized and/or lower socio-economic backgrounds, Deaf and hard-of-hearing people experience disparities in health care (Harmer 1999, Iezzoni et al. 2004, Pollard et al. 2009, Scheier 2009, Tamaskar 2000).

This brief narrative is one of many such stories that Deaf people tell about their efforts to access equitable health care in what are all too often inaccessible medical settings that presume the capacity to hear and interact through spoken language. The Deaf person's medical visit is a triadic encounter, which involves the patient, the health care provider/s, and the (too often absent, as in this story) interpreter. Such encounters have given rise to our interdisciplinary project, which involves collaborative research and dialogue with Deaf community advocates, health care providers, and sign-language interpreters in our local community. We are faculty members in three different fields, at two neighboring institutions, but with overlapping interests and commitments to the social justice project associated with critical Disability Studies. Drawing upon the insights of critical Disability Studies, Deaf studies, disability law, health humanities and ethics, narrative studies, and the sociology of health-care

work, we are working together to promote and facilitate conversation among the parties involved in mediated communication in this kind of health-care encounter.

Our approach is one that builds upon stories such as the one presented above and treats narrative as a site not only for constructing and sharing experience but also for building intercultural understanding. Health educators are increasingly aware of diversity within the populations they serve in contemporary health-care settings and committed to the development of "cultural competence," and a few researchers have made recommendations for improving communication with deaf and hard-of-hearing people in the medical setting, in some cases collecting brief stories from Deaf people and drawing upon that material to develop these recommendations about how to conduct clinical encounters for more effective communication (*e.g.*, Barnett 2002, Harmer 1999, Iezzoni et al. 2004, Kashar 2009, Middleton et al. 2010, Scheier 2009).

The dominant model of training in cultural competence, and the literature in which these studies are embedded, is one that, for the most part, leaves a "medical model" of difference in place; distinctive cultural groups are defined in terms of their differences from an unremarked "normal" patient, with the idea that clinicians should learn basic facts about each cultural group and will then be able to modify their practice as necessary.³ By contrast, we draw upon a "social model" of difference in our approach to communication access, locating problems of access in the interaction of embodied difference, society, and the environment, rather than in the embodied difference itself. We are using narratives—stories told not only by patients but also by health care providers and interpreters—to understand the social construction of deafness as disability and to help build bridges among these participants in medical encounters. Bringing these social and environmental contexts into the picture requires a deeper engagement with narrative; thus, we look at longer stretches of story in order to fill out their contexts, and we also attempt to consider the potential effects of stories by attending to the actual occasions in which they are told and heard by others—the contexts in which people communicate face to face and one can see how they respond to one another. Communication is a critical aspect of any medical encounter, and some failures of communication may have catastrophic consequences for patients.

In this article, we discuss the conceptual tools we are developing as we analyze this kind of mediated medical communication. We also provide a discussion and analysis of one moment of dialogue that occurred in the context of our outreach to health care professionals and students. Before we move to that story, we provide some necessary background: on Deaf culture and communication; on legal requirements for communication access in health care; and on the work that Deaf people must do to access health care.

Deaf Culture: Modes of Communication, Education and Literacy

Medical professionals—trained to know and focus on the body—often think of deafness as a spectrum of hearing loss. Many individuals who are born deaf or become deaf early in life, and communicate primarily through a signed language, understand Deafness quite differently,

seeing it as a cultural or linguistic identity (Padden and Humphries, 2006; Lane 1999). This culture is constituted in the places where Deaf people come together—historically, in residential schools and in Deaf clubs that have served as primary meeting places for many Deaf people and their families. Although the significance of such sites has been somewhat reduced in recent years by moves to include Deaf students in hearing educational settings, Deaf culture has been transformed by these changes, not extinguished or diminished.

Deafness crosses many identities, associated with ethnicity and racialized groups, gender, age, and disability; there are Deaf people in every group of human beings. We are cautious about using the term *Deaf community* (preferring *Deaf culture*), given that it may mask more than it reveals, and since there are many communities rather than a unified and homogenous one. Like any culture, Deaf culture is diverse, layered, and sometimes divided and contentious. To find this division and contentiousness, one has only to examine the history of Deaf education, which has long been a site of controversy, with longstanding debates over whether to encourage "manual" (signed-language) or "oral" (lipreading and spoken) communication. Proponents of oralism argued that lipreading and speech would allow deaf people to integrate more easily into hearing society, but proponents of manual approaches point out that young children need a "natural" language they can learn and use easily, in order to develop their capacities for communication; linguists now understand that signing is a natural outcome and expression of deafness. As a result of this history, Deaf people have learned signed languages in various ways. In the United States, those who are born deaf to Deaf parents who sign typically learn American Sign Language (ASL) as a native language; hearing children born into Deaf families will also learn sign language in that way. Most deaf children, however, are born to hearing parents, who typically know little about Deaf culture (Mitchell and Karchmer 2004); these children may be educated orally—even prevented from learning a signed language—until they "discover" Deaf culture later in life.

Such diversity in communication preferences is a critical factor in the mediated-communication encounter. Some Deaf people communicate only through ASL, others can speak and may also be able to lipread. In addition, communication is affected by the conditions in which the communication takes place and by factors such as the ability of the parties—hearing and deaf—to understand each other and the ability and expressiveness of the hearing person when communicating to a Deaf person who is lipreading. Writing notes may or may not be an effective mode of communication, given that for many Deaf people, ASL is their native language, not spoken or even written English. But even when Deaf individuals read and write easily, written notes cannot provide the kind of rich and complex communication that occurs in a spoken exchange.⁴

Deaf cultures are situated in relation to the dominant hearing cultures in various ways. Rochester, New York—a mere 90 miles from our community—has the highest per capita Deaf population of any U.S. city. The home of the National Technical Institute for the Deaf (a two-year college of the Rochester Institute of Technology [RIT] which provides a bi-lingual education and allows students to transfer to RIT to continue their higher education), Rochester offers relatively good employment and social networking opportunities for Deaf professionals, a

relatively large Deaf community, and impressive services for Deaf residents, including a Deaf Wellness Center.⁵ By contrast, in Syracuse, New York, where our project is located, the Deaf community is smaller and less visible; while there certainly are Deaf community organizations, events, and advocacy organizations offering advocacy and interpretation services, the Deaf community seems to be less visible in the hearing "world." In our preliminary interviews with health care professionals, many of them can remember only one (or no) encounter with Deaf patients, and some of the providers we talk with wonder whether there are "enough" Deaf patients to warrant spending money for the provision of communication access. While this argument may be easily reversed (having so few Deaf people as patients should make accommodation more affordable to health care providers), the question of the visibility of Deaf culture and the problem Deaf people have in accessing equitable health care lead us to consider how best to frame our arguments made to providers for communication access. Do we "compel a conversation" (Schwartz 2007) using the leverage of the law? Or do we move beyond litigation and "beyond compliance" (a notion that will be discussed below) through cultural and ethical arguments—or adopt a nuanced combination of all of these strategies?

The Legal Requirements for Communication Access

Obviously medical personnel, whether in a hospital, clinic or a doctor's office, must comply with the Americans with Disabilities Act (ADA).⁶ This is because the ADA defines a public accommodation as a private entity (an entity other than a public one) that owns, operates or leases a place of public accommodation.⁷ A place of public accommodation means a facility operated by a private entity whose operations affect commerce and includes, for example, a service establishment like the professional office of a health care provider, a medical clinic or a hospital.⁸

The ADA defines disability, with respect to an individual, as a physical or mental impairment that substantially limits one or more of the major life activities of such individual; a record of such an impairment; or being regarded as having such an impairment.⁹ Since deafness is a physical impairment that substantially limits the "major life activities" hearing and speech, Deaf and hard of hearing people come within the protection of the ADA.¹⁰ The ADA gives expression to the idea that the physical environment as well as attitudes about disability are key players in disabling people who happen to have a certain physical or mental condition.

Generally, the ADA prohibits discrimination against people "on the basis of disability in the full and equal enjoyment of the goods, services, facilities, privileges, advantages, or accommodations of any place of public accommodation by any private entity who owns, leases (or leases to), or operates a place of public accommodation."¹¹ Specifically, this means that a place of public accommodation like a hospital, doctor's office or a medical clinic cannot deny a person with a disability participation,¹² allow the person participation in an unequal benefit,¹³ or provide him or her with a separate benefit.¹⁴

Effective communication access in the medical setting often means providing the Deaf patient or family member with a qualified interpreter.¹⁵ The ADA defines such an interpreter as one

"who, via a video remote interpreting (VRI) service or an on-site appearance, is able to interpret effectively, accurately, and impartially, both receptively and expressively, using any necessary specialized vocabulary."¹⁶ Thus, a doctor who knows the fingerspelling alphabet and a few signs hardly qualifies as a sign language interpreter up to the task of facilitating communication.

When it comes to policies, practices, or procedures, the general rule is that a doctor must "make reasonable modifications in policies, practices, or procedures, when the modifications are necessary to afford goods, services, facilities, privileges, advantages, or accommodations to individuals with disabilities, unless the [doctor] can demonstrate that making the modifications would fundamentally alter the nature of the goods, services, facilities, privileges, advantages, or accommodations."¹⁷ The regulations make it clear the final decision on communication access belongs to the doctor, but if the doctor fails to provide effective access, he or she becomes liable.¹⁸

A doctor "shall take those steps that may be necessary to ensure that no individual with a disability is excluded, denied services, segregated or otherwise treated differently than other individuals because of the absence of auxiliary aids and services, unless the public accommodation can demonstrate that taking those steps would fundamentally alter the nature of the goods, services, facilities, privileges, advantages, or accommodations being offered or would result in an undue burden, *i.e.*, significant difficulty or expense."¹⁹ Examples of "auxiliary aids and services include "qualified interpreters on-site or through video remote interpreting (VRI) services; note takers; real-time computer-aided transcription services; written materials; exchange of written notes; telephone handset amplifiers; assistive listening devices; assistive listening systems; telephones compatible with hearing aids; closed caption decoders; open and closed captioning, including real-time captioning; voice, text, and video-based telecommunications products and systems, including text telephones (TTYs), videophones, and captioned telephones, or equally effective telecommunications devices; videotext displays; accessible electronic and information technology; or other effective methods of making aurally delivered information available to individuals who are Deaf or hard of hearing."²⁰

The bottom line for a doctor is effective communication. The doctor must furnish appropriate auxiliary aids and services where necessary to ensure effective communication with Deaf people, and this includes companions who are also Deaf.²¹ The type of auxiliary aid or service necessary to ensure effective communication depends on the method of communication used by the Deaf patient; the nature, length, and complexity of the communication involved; and the context in which the communication is taking place.²² For example, a Deaf patient may need a qualified interpreter to discuss with the doctor a diagnosis, procedures, tests, treatment options, surgery, or prescribed medication (*e.g.*, dosage, side effects, drug interactions, etc.), whereas in comparison, a Deaf person who purchases an item in the hospital gift shop may need only an exchange of written notes to achieve effective communication.²³ The ADA encourages the doctor to consult with Deaf patients whenever possible to determine what type of auxiliary aid is needed to ensure effective communication, but the ultimate decision rests with the doctor, provided that the aid chosen results in effective communication.²⁴ In order to

be effective, auxiliary aids and services must be provided in accessible formats, in a timely manner, and in such a way as to protect the privacy and independence of the patient.²⁵

The regulations explicitly state that a doctor cannot require a Deaf patient to bring another individual to interpret for him or her.²⁶ Likewise a doctor cannot rely on an adult accompanying the Deaf patient to interpret or facilitate communication, except in an emergency involving an imminent threat to the safety or welfare of an individual or the public where there is no interpreter available; or where the patient specifically requests that the accompanying adult interpret or facilitate communication, the accompanying adult agrees to provide such assistance, and reliance on that adult for such assistance is appropriate under the circumstances.²⁷ And, a doctor cannot "rely on a minor child to interpret or facilitate communication, except in an emergency involving an imminent threat to the safety or welfare of an individual or the public where there is no interpreter available."²⁸

A doctor can defend an ADA charge of discrimination by arguing "undue burden," which means significant difficulty or expense. In determining whether an action would result in an undue burden, factors to be considered include:

- the nature and cost of the action needed under this part;
- the overall financial resources of the site or sites involved in the action; the number of persons employed at the site; the effect on expenses and resources; legitimate safety requirements that are necessary for safe operation, including crime prevention measures; or the impact otherwise of the action upon the operation of the site;
- the geographic separateness, and the administrative or fiscal relationship of the site or sites in question to any parent corporation or entity;
- if applicable, the overall financial resources of any parent corporation or entity; the overall size of the parent corporation or entity with respect to the number of its employees; the number, type, and location of its facilities; and,
- if applicable, the type of operation or operations of any parent corporation or entity, including the composition, structure, and functions of the workforce of the parent corporation or entity.²⁹

Given that doctors and hospitals generate income that enables them to pay an interpreter's bill for services rendered, it is exceedingly rare, if ever, for a doctor to prevail on this point, particularly where there is tax relief available for all accommodation-related expenses.

In a recent case settled by consent decree, the United States Government forced a private, non-profit organization operating a health care system including a hospital to establish a comprehensive system for providing sign language interpreters for Deaf patients.³⁰ The decree compelled the defendant to do the following:

- provide effective communication access wherever and whenever needed, in activities ranging from patient intake to discharge;

- establish a timetable for providing auxiliary aids and services; set forth procedures for securing on-site interpreters; and promise "interpreter continuity" for the deaf patient;³¹
- maintain a maintenance log, provide a complaint resolution procedure, and give patients notice not only of updates with respect to searching for interpreters, but also of their rights under the law;³²
- refrain from imposing a surcharge on the Deaf patient for interpreter services and other access-related costs, and from forcing family and friends of the Deaf patient to interpret for the patient. In the event an interpreter could not be immediately retained, the hospital had to engage in other means of communication until the interpreter arrived on the scene.

Training and reporting requirements rounded out the decree, and the private plaintiffs were awarded \$95,000 and the Government \$25,000.³³ This decision provides a comprehensive model for doctors, clinics and hospitals.

Compliance with the law should be the floor—the minimum—not the ceiling. Doctors, clinics and hospitals would benefit from a "beyond compliance" mindset.³⁴ Thinking "beyond compliance" with the law conceptualizes disability as more than just a physical, sensory, cognitive or mental impairment and conceptualizes accessibility for Deaf patients and their families as more than just compliance with federal and state anti-discrimination laws. Disability is not just about a physical or mental impairment. It is not merely located in the body, but lies at the intersection between the body and social practices and policies that operate to disable people. For example, a Deaf person is not disabled simply because the person is deaf, but also because the hospital's practices and policies operate to disable the Deaf person by failing to provide an interpreter, captions, visual material, and any other appropriate auxiliary aid or service that would result in effective communication access. The same failure also operates—though less visibly—to disable the doctor; he or she cannot communicate effectively and consequently cannot perform his or her medical duties in a competent and ethical way. Thus, not only Deaf patients, but also the medical community will be aided by a broader conceptualization of disability that closely examines the impact of practices and policies on access. Compliance with the law is the starting point, not the bottom line, for all of us, and for the provision of effective and equitable care.

Arrangements for Communication Access: An Imbalance of Power and Work

It is easy to see and remember that health care professionals are hard at work in medical facilities: they wear official clothing, nametags that identify their professional credentials, and they are visibly "occupied" as they walk quickly through the setting, attend to paperwork, and so on. It is less obvious that patients also work to produce successful encounters, and we wish to bring their efforts to the forefront. In fact, all patients are expected to "do their part," even if their work is unpaid and often invisible. Patients are expected to show up for appointments at specific times and to bring health insurance, personal financial resources, or, far less welcome, Medicaid reimbursement to pay for their appointments. They are expected to wait patiently if

the provider is not ready to see them at the appointed time. They have to provide accurate information on intake forms and in initial conversations with providers, in which providers make assessments and set the agenda, and they need to do that efficiently, without spending time offering "extraneous" information. They are expected to ask appropriate questions if they do not understand, and to be involved in decision-making about treatment options, but they must determine in the course of the interaction which decisions are theirs and which options are not meant to be questioned. They are expected to follow treatment plans by filling prescriptions at pharmacies or supermarkets (to which patients may or may not have easy access) and taking them as directed (when the directions may or may not be understood and the patient may or may not have the ability to maintain the regimen). Patients are further expected to perform physicians' recommendations for good health by exercising, losing weight, quitting smoking, drinking less, eating better (all of which may pose challenges due to context—home and community environments, the rigors of work, social pressures, cultural norms, the challenges of addictions, and the confounding effects of emotional states such as depression, anxiety, or hopelessness, that may be primarily internal but may also derive from social and cultural circumstances).

These issues are increasingly although still imperfectly raised in health care education. They are quickly and often completely masked by the socio-cultural environment of the clinic, where the pressures of effective as well as financially efficient practice all too often reduce these factors of difference to questions of patient "compliance," or, in the new terminology, "patient adherence," a term that purports to but does not in fact suitably question the norms of these settings. Less formally, in everyday work, practitioners may perceive and discuss patients who do not hold up their end of the work properly as "difficult." When these expectations and professional responses remain unrecognized, the health care encounter is at risk of becoming less of a relationship in which knowledge is shared and actions are collaborative than a quick handoff of directives, a script and a treatment plan that may be caught and acted on, or partly or entirely dropped. This kind of issue has not to date been discussed extensively in the discourse of "bioethics," but we will argue that the resulting problems of expectations and communication do indeed have ethical dimensions. Deaf patients carry additional work burdens in the mediated medical encounter, which we will discuss below as we develop our analysis.

The Campaign for Deaf Access

Our "campaign for access" has roots in Schwartz's frustration with litigation as a solution to problems of communication access.³⁵ Although legal action can sometimes produce exemplary results, as in the consent decree discussed above, litigation is time-consuming and expensive. It does not provide solutions in real time, when particular patients need recourse, and it may not produce lasting change. There is an uneasy relationship between medicine and law; often, when we meet with clinicians, we hear nervous jokes about doctors and lawyers. In one of our early presentations to health care professionals, a physician told us emphatically that discussing patients' legal rights would not be an effective strategy with physicians and trainees. Instead, we should appeal to physicians' "empathy." Given the historical construction of impairment as pitiable and deserving of charity rather than being understood as difference to be welcomed

and included (beyond accommodation and compliance), we were uncomfortable with that suggestion. Nonetheless, we use the comment as a real-world reminder of the challenges of bridging medical and disability-rights perspectives.

We have designed our project in part as training and education for the students we work with in law, health care, and social research, aiming to provide them with new models for professional work and identity, models that reach across their bounded disciplines and will allow them to work more collaboratively and effectively on these issues. With Schwartz's doctoral research on Deaf patients' experiences (2006) as a foundation, we have begun a series of interviews with health care providers and sign-language interpreters, in order to understand the contexts in which they do their work and their views of encounters in which communication is at issue. We have also undertaken a series of community-based educational events, aimed at bringing together Deaf community representatives, health care professional and students, and sign-language interpreters. We believe that accounts from these community events can illuminate the potential of storytelling as a tool for bridge building that might take us "beyond compliance" with disability law.

A Story—and a Conversation

In September, 2010, our Campaign for Deaf Access organized a panel discussion as a part of the local Deaf Awareness Week, organized by Syracuse's Deaf Advocacy Council. Our panelists included two Deaf people with stories to tell about their health care experiences; a CODA (child of Deaf adults—in this case, the daughter of a Deaf mother and hearing father) who works now as a sign language interpreter; and another interpreter who is also the director of a local interpreter referral service. There were over 80 people in our audience. By offering a lunch of free pizza, we attracted students from medical, nursing, and allied health programs, and by advertising widely through our health-care and Deaf-community networks, we reached staff and some faculty from the teaching hospital, members of the Deaf community, and Deaf-community allies and staff in service agencies and local interpreting education programs.

One of our panelists—Jeff Sterly, a Deaf man who holds a professional position in a state agency and who also teaches ASL at a local college—told a brief story, which was voiced as follows by one of our interpreters (and transcribed from a videotape of the panel discussion):

My experiences with doctors started way back when, when I lived in New Jersey. [...] Many doctors there refused to provide interpreting services. Now remember, this is before the ADA was established [...] in 1990. And I was really struggling with the situation. I moved here to Syracuse in '93, and, sure enough, I started to face the same problem here. I met a lot of family doctors. [...] I went to a variety, and they said, "You're deaf, we're not going to take you as a patient." Actually, at that time they'd say, "We're not accepting any new patients," but the real problem was that they were not willing to provide an interpreter. It was a big struggle. Finally, I found one that was willing.

So you have to understand, if I have a cold or just a sore wrist, I don't need an interpreter for that situation, but if it's a serious situation, if I have a heart condition or something that's serious, that's when I absolutely require an interpreter. And the doctor and I agreed on that. Let me see, we didn't use an interpreter for 17 years. Then when I became 50 just recently, I said, "You know what? I think I need an interpreter." Here I am 50, I've got more serious health problems, and so, sure enough, they pulled in an interpreter when I turned 50. And the doctor, the *doctor* was astounded at the end of the appointment. And the doctor said, "Why have you not been having an interpreter for every appointment?" It's like a whole paradigm shift happened to him. He needed an interpreter for himself! I thought he'd be upset to pay the cost of providing an interpreter, but he'd enjoyed having an interpreter in this situation. That's when I started to realize—and since then, the situation's been much better. He's been happy to provide an interpreter; I've been perfectly happy with my doctor. [...] I found out the doctor himself preferred having an interpreter. I didn't know that for 17 years! Here he is, here we are...He was an SU [Syracuse University] basketball fan. It was great that I could find this out about him now that we had an interpreter in the room.

Mr. Sterly is clearly a thoughtful and savvy narrator. He chose a story that revealed—in a modest and friendly, engaging way—that there were lessons here for health care professionals: the doctor "was astounded" and learned that he himself "preferred having an interpreter." With an interpreter, Sterly and his physician not only communicate more effectively about health care, they can also have the kind of friendly "small talk" that hearing patients often experience with providers. The interpreter serves as a bridge—not just an accommodation for the deaf patient, but also for the doctor. Our narrator told a story that includes problems, but has a "happy ending."

In the question and answer portion of this event, a physician educator offered an extended response to our panelist-narrator. Her comment, in which one could hear emotion in her voice, included the observation that he had been deprived of good care for many years. She spoke "as someone who's been in the position of the person in the white coat," saying, "I was utterly horrified and disgraced by your stories." And she wondered why Sterly had waited so long to ask for an interpreter, asking "Why shortchange yourself? Why do yourself that disservice?" His response was voiced as follows:

Some Deaf clients can read the expressions on doctor's faces. Unfortunately, I know that they're thinking, "Oh, I have to pay for that damn interpreter." You can read that on their expressions, and that's when it gets very difficult. It's very hard to hear that negative response all the time. I was brainwashed since I was very young that, "We are not going to find an interpreter for you." It was very difficult for me to find an appropriate doctor. [...] There was one doctor that I didn't particularly care for that would provide an interpreter, and the doctor that I wanted would not provide an interpreter, so it's very frustrating. I had to learn how to kind of play the system, and it took me a lot of courage. Here I was, now I'm 50 years old, I've got all these life experiences, and to ask that doctor to provide an interpreter, and when he said, "Yes,"

and that he enjoyed the experience, I thought, "Oh, good grief, I wish I had done this sooner."

You know, that individual was my family doctor. It was his boss—he was under the actual doctor that ran the office that was actually saying no to the interpreter provision. So when that family doctor set up his own office independently, that's when I had the courage, and I felt empowered to actually ask for the interpreter. So I thought, Wow, the problem wasn't him all along, it was the doctor above him who was refusing to provide the services, and that was really interesting. I didn't know that.

In this extension of his story, Sterly reveals additional layers of his work in these encounters. He has to "read the expressions on doctors' faces" and consider what they may be thinking, weigh the pros and cons of physicians who may or will not provide interpretation, "learn to play the system," and summon the "courage" to say what he needs. He clearly thinks that the doctor may be worried about money, and this weighs on him. And there is the fascinating observation that the physician was perhaps prevented by higher-ups from bringing in an interpreter years earlier.

In these short stretches of talk, the audience hears a story—some or all of which Sterly may have told and re-told in the past—and that has a particular effect. In this case, the effect may be to create a "bridge" between health care providers and Deaf people. The first segment provides the perfect bridge story: there's no blame, and there's a happy ending. Then when a doctor in the audience observes that Sterly was deprived of good care all along, he opens up and tells a more complex story, one about being turned away repeatedly—not able to get the doctor he wanted *and* an interpreter—and thus losing the courage to ask for what he has a right to. The story extension also refers to another critical factor, the hierarchy in the medical world, which may have made it more difficult for the physician to provide an interpreter until he started his own practice. We cannot know what the doctor was thinking as the story unfolds, but we can offer a suggestive portrait of a paradigm shift in the relationship that benefited the doctor as well as the patient.

When teaching first-year medical students about disability and Deaf cultures and health care during a year-long course on medical ethics, the law, and socio-cultural and economic issues in health care, Garden used the first segment of this story as a video clip. She selected it based on an assumption that the story would serve as a "bridge" in communication where a gap or breakdown may occur. This breakdown in communication may be caused not only by linguistic differences but also by broader cultural differences—the differences between Deaf and medical cultures—and the defensiveness and even resentments among the parties that can develop as a result of those differences.

Health-profession students, who are in the midst of an intensive professionalization and acculturation process, are particularly prone to defensiveness about perceived criticisms of medical culture whenever the "medical model" is being critiqued. Garden and other instructors for this course have observed what medical educators (Wear and Aultman 2005) have called

"medical student resistance to confronting inequality and oppression" among first-year students. Some medical students have critiqued required lectures and courses on cultural and class issues and disparities in health care as unfairly and negatively judging physicians and trainees and as exaggerating the difficulties that people from marginalized groups experience in health care. Anticipating the potential for this sort of resistance or critique in response to a lecture about disability, Deafness, and health care, Garden chose this story because it illustrates how sign language interpreters provide access for clinicians as well as Deaf people and that communication access enables not just better relationships, which are critical to healing, but better medical care (the point with which the students, engaged as they are in the biomedical educational paradigm, are most concerned).

In this context, Sterly's story portrays a physician's enthusiastic embrace of interpretation as enabling his or her own access to understanding and relationship building. The physician's "paradigm shift" and question—"Why have you not been having an interpreter for every appointment?"—could be read as the "happy ending" which points to the communication bridge being built between the Deaf person and the health care provider. However, our closer reading initiated a deeper analysis of the fuller story, including the extension and complication in the question and answer section of the panel discussion, which has called into question—or at least complicated—the happy ending and the imperative to avoid appearing to critique medicine and its convention. In this case, the narrator has borne the labor of that ending by concealing the difficulties and complexities of its negotiations. Further, bringing a sign language interpreter into the encounter is a complex beginning: it ushers in another level of mediation with attendant complexities and nuances to be negotiated, primarily by the Deaf person.

Beyond a Single Story: Bridging Work in Health-Care Communication

Sign language interpreters can often provide a bridge for communication between the Deaf person and the health care provider. But even when an interpreter is provided, there are many opportunities for slippage in communication. The interpreter may not fully understand the Deaf person's communication mode, which could be American Sign Language, which is always regionally inflected; Signed English; Contact Signing or Pidgin Sign; a mode based on fingerspelling (the Rochester method); Cued Speech; or a combination of oral methods and sign called Total Communication.³⁶ Of course, at times the interpreter might simply misunderstand a key word or phrase. The interpreter may not completely understand the physician's language, the medical terminology or concepts. (Ideally, only interpreters who are knowledgeable about medical terminology should be assigned to medical settings; however the reality is that when interpreters are scarce, those without the ideal training may be involved in medical interpretation.) The introduction of an interpreter can undermine the rapport between physician and patient or make that interaction more challenging, particularly if the physician looks at the interpreter while speaking, rather than at the patient, or if the physician resents having to pay for the interpreter, or is simply distracted by the unfamiliar mode of communication. When physicians refuse to provide interpreters—whether as individual agents or because the physician who manages their practice forbids it—the barriers to communication make good medical care, let alone excellent patient-centered care, difficult to achieve. In this

situation, the Deaf person bears an often unrecognized burden of work—the labor of bridging communication and coping when it fails.

Typically, health care providers and staff are not familiar with deafness and communicating with Deaf people; thus the Deaf person is responsible for arranging the elements necessary for effective communication. At the beginning of the medical encounter, the Deaf person usually encounters a staff person behind a counter or window who may speak while looking down at a computer screen or schedule and thus make lipreading difficult. The Deaf person must communicate that she or he is deaf. The staff person, who may be unfamiliar with Deaf communication and therefore at least to some degree uncomfortable about how to proceed, may respond ambivalently, particularly when an unexpected mode of communication seems to demand more effort and time. When hearing staff and providers react as if disturbed by the need for more time and effort or merely by the fact of deafness as difference—or even if the Deaf person simply perceives this to be the case because of previous experiences with hearing people flustered by the encounter with deafness—the Deaf person often takes on the burden of managing the response, as well as make the practical arrangements for communication (see Schwartz 2006).

The work of communication begins with the Deaf person contacting the health care facility for an appointment (hospitals generally arrange for sign language interpreters). The Deaf person may contact the health care facility using a telecommunications device or a video relay service (VRS). Due to experience with or perceptions about discrimination against deaf people, some Deaf people may ask a hearing person to schedule the appointment, thus postponing being identified as Deaf and refused an appointment at the outset. The work of communication continues through each level of interaction at the health care facility, even when a sign language interpreter is provided. Without an interpreter, the Deaf person must work strenuously to set others at ease, to catch all the visual cues, and to communicate with clarity about her or his health. This would cause frustrations during a wellness visit, but is particularly draining when the Deaf person is ill, injured, and/or anxious about his or her health concerns.

In Schwartz's research (2006), a Deaf man describes his experience in an emergency room where he and his wife had brought his daughter and an interpreter was not available: "The doctor started to talk very quickly, and I told him I was deaf....He spoke slowly, and I could lip read him. He explained and gestured, and we were able to speak with each other" (156). However the work of communication increased when another physician arrived: "[Communication] wasn't so good, we wrote back and forth" (156). The Deaf man says that, "The communication was frustrating....they would talk too fast, sometimes I had to make sure I understood—and I had to try hard to get all they were saying" (157). This Deaf person is typical in resorting to a range of communication strategies: lipreading and asking follow up questions for clarity, writing notes, body language, and gestures. Ironically, his success in communicating with one doctor, who is easily understood, probably makes it difficult for these providers to understand why he needs a different kind of accommodation with another professional.

As noted earlier, the law gives health care providers responsibility for providing effective communication. However, many are not aware of the legal requirement, or they ignore it—presumably because they believe that they can achieve sufficient communication without it. While providers have the ultimate responsibility for ensuring access, when they are insufficiently attentive to the character and variety of people's modes of communication, they likely cannot make that determination. In such cases, health care professionals need to consult with, and listen to, their Deaf patients and to resist resorting to any one-size-fits-all solution. Simply requesting a sign language interpreter, in and of itself, creates a sometimes-daunting amount of work for Deaf people. One Deaf person explains that she is reluctant to deal with the "frustration and the hassle of setting the stage for that....I find that they resist as a matter of course....It's a little too much and frustrating for me....So sometimes it's just easier to go to the doctor without [the interpreter]" (Schwartz 145).

Jeremy Brunson (2010), in research on video-based telephone services for the Deaf, describes the work that Deaf people perform in order to communicate with hearing people as "*calculated consumer labor*, labor that is unpaid and performed by the consumer, who calculates the advantages and disadvantages of not performing the labor." The consumer must calculate whether the benefits of receiving a particular service outweigh the costs (financially or emotionally) associated with trying to get the service. In some cases, it is merely a calculation of the amount of time and energy the recipient is willing to expend to receive a particular service. Brunson draws on the concept of *emotional labor* as developed in feminist scholarship and in Cahill and Eggleston's (1994) description of the emotion work exacted of wheelchair users when negotiating the embarrassment, unwelcome sympathy, or lack of understanding of nondisabled people.

The basis for our analysis is attention to all of the work that patients do in the medical setting, and especially to the additional work—including emotion work—that Deaf patients take on as they enter settings that presume the capacity to hear. Brunson's analysis highlights the strand of work that involves managing one's own and others' emotions, and the emotional work of Deaf people (and others with disabilities) who are seeking accommodation is especially significant. The concept underlines the fact that too often patients bear the primary burden of facilitating the differences of an impairment in the medical setting, where the smooth functioning of the clinic depends on patients complying with the norms established by the system (*e.g.*, being able to wait, to hear questions and directions, to get up onto an exam table or scale, to hold still for examination, and so on). While health care providers may range in their ability and commitment to take on the work of accommodating difference, they are in the position of offering a service, while the patient is in need, and therefore must bear whatever portion of the burden the providers are not able or willing to support. The term *emotional labor* does not entirely describe this imbalance of work and responsibility in the clinic, which has many dimensions and is shaped and sustained by the organization of the facility as a work organization and a physical space. However, an understanding of work that includes emotion management is useful, in part because it identifies the deeper, emotional costs of patients' efforts, and also because it makes visible what is not seen by those who do not have these experiences: that there is work being done. Unlike those business leaders who build consumer

work into their business model (*e.g.*, by developing self-service gas pumps and check-out procedures in which customers scan their own purchases), clinicians who are not educated about Deaf communication and who do not take it upon themselves to learn are subtly and indirectly shifting the burden of work to the Deaf person. The lack of intention does not make the additional work of patients who need some accommodation any less burdensome—perhaps, indeed, quite the opposite (stores with self-service check-out procedures generally at least provide an employee to oversee customers' work and assist with problems that arise). The lack of awareness of the imbalance of work contributes to the work burden for the patient. It is a barrier to effective communication.

Those whose differences demand additional work to facilitate communication and accommodation may not always shoulder that burden, whether cheerfully or reluctantly. Communication may further fail when the Deaf person in the medical setting just "lets go" of that responsibility. Schwartz (2006) identifies a phenomenon expressed repeatedly in interviews with Deaf people about their health care experiences that is linked to a fairly universal sign ("arms raised, palms outward, arms going down, hands flicking downward" [223]) which signifies, in spoken English, something like "letting go." *Letting go* may refer to choosing not to seek medical care for an illness or injury that is not serious, particularly when the work of communication or attempting to arrange for an interpreter outweighs the pain, discomfort, and/or anxiety of the malady. It may mean seeing a physician who is less desirable than others because she or he provides a sign language interpreter. Even when a physician provides a sign language interpreter, the Deaf person must work to maintain clarity in communication if, for example, the interpreter does not completely comprehend the Deaf person's mode of communication or the clinician's jargon and does not stop for clarification. The Deaf person or the interpreter may need to slow down the communication process in order to fingerspell each medical term and/or ask for clarification of the meanings of medical terminology. The Deaf person may, however, "let it go" and accept the communication as is.

Breakdowns in communication that result in (or from) "letting go" or just misunderstanding and that interfere with the Deaf person's ability or enthusiasm to follow the treatment regimen may then be characterized as a lack of "patient adherence" and linked, without further analysis or problem-solving, to deafness as an impairment and perhaps deaf people as somehow vaguely problematic or as "difficult" patients. However, in many such cases, it is likely hearing clinicians' lack of knowledge of Deaf culture and communication, rather than the physiological difference of deafness itself, that contributes to the communication breakdown and barriers to Deaf access to health care. We argue that by making health care providers and health care educators more aware of how Deaf communication works and how Deaf and medical cultures factor into health care interactions, those involved can improve medical care for Deaf people, as well as the experiences of Deaf people in health care settings and their relationships with providers. We suggest that this way of understanding medical encounters can be extrapolated not only to disabled people but to all whose differences are not understood and *worked with* by health care educators and providers., including ethnic and racialized identities and cultures, as well as other physiological and intellectual differences, and those of class, gender, and sexuality. It is important to note, however, that each of these dimensions of identity is associated with quite

different histories, cultures, and visibilities within medical work. Since our argument is that health care providers need to understand the particularities of these histories, identities, and cultures—or at least to be open to learning about them—we are not suggesting that there are one-sized or simple solutions to the challenges of serving these varied groups effectively. However, clinicians and health care educators who quail in the face of a seemingly ever-expanding catalog of difference that needs to be mastered can turn to those who seek health care as the authority on their differences, as well as their experiences of illness or disability. Thus, while education is needed to improve health care for women and minorities, that education should not displace the patient as the real expert on her or his experience. In the next, concluding section, we develop further implications of our approach to these issues.

The Power and Limits of Narrative

In order to produce effectively mediated communication in the medical encounter, health care professionals need to engage in conversation with Deaf people (and with sign-language interpreters). Schwartz has suggested elsewhere (2008) that one of the shortcomings of the ADA, as its implementation has been spelled out in regulatory guidelines, is that physicians are given authority to make decisions on their own about effective communication access; he argues that the law should "compel a conversation" with Deaf patients, so that they can provide input about the kind of accommodations they prefer in particular circumstances. Whether compelled or voluntary, we suggest that the conversation between health care provider and Deaf patient—and the education of health care professionals—would be enriched and enhanced by the inclusion of storytelling to invite, encourage, facilitate, and sustain conversations among the parties to medical encounters. That kind of dialogue could help to move health care professionals and facilities beyond mere compliance with disability law, toward more just, humane, and effective care.

Stories are fundamental to the ways that people make meaning of their own lives, their worlds, and the lives of others (Bruner 1991, Kleinman 1989, Lindemann 2001, Mattingly 1998, Mishler 2005). People tell stories about coming of age and coming out (or passing as "normal"), stories of trouble and triumph, stories of belonging and exclusion, and many more. Some stories are widely known and shared (stories such as the American story of "discovery"), while others are too easily forgotten or even actively suppressed (such as the stories of indigenous life in the Americas). Stories also take shape in the telling, in encounters between narrator and listener (or writer and readers); some stories are easily heard, while others may be misheard, or incompletely understood. Stories may be especially powerful as vehicles for sharing suppressed and subordinated experiences. They have the potential to bring marginalized lives into public view and into policy discussions. This potential lies behind the narrative scholarship that has flourished over the past several decades in law, medicine, and the social sciences (for foundations in law, see Bell 1992, Delgado and Stefancic 2001, Williams 1992; in medicine, Charon 2006, Engel et al. 2008, Frank 1996, Kleinman 1989; in the social sciences, Mishler 1984, Riessman 2008).

Storytelling has particular significance in Deaf culture, due to its historical reliance on face-to-face communication as a mechanism of cultural transmission. According to Lane, Hoffmeister, and Bahan (1996), storytelling has been crucial for bonding among students at Deaf residential schools, and some students begin to emerge early on as especially skilled and to identify as storytellers: "their craft is perfected as they watch Deaf adults tell stories at home, at school, at the Deaf club, or at various cultural events" (153). These authors discuss "archtypical" stories in the Deaf world that tell of origins and successes and that construct and affirm Deaf community; there are also stories, often humorous, that deal with oppression. They point out that many Deaf stories are recorded in written English even if they originate in a native, signed language. In recent years, video technologies have offered new spaces in which Deaf community members can share visually based stories more widely and easily.³⁷ Padden and Humphries (2005) assert that, "The struggle to use voice and to manage voice and to make sign language intelligible underlies nearly every political act of the [Deaf] community" (142). This observation suggests that storytelling may be an especially powerful tool for bridging Deaf and hearing medical cultures; it also calls us to be vigilant in assessing the politics of storytelling encounters.

We have argued that the power relations of health care produce situations that make patients' work largely invisible. One thing that personal stories can do is to reveal some of the distinct forms of work that Deaf patients undertake in mediated communication encounters. Until those labors are recognized, clinicians may continue to experience the accommodations they make as unequal burdens. When the experiences of all parties to the encounter (patients, interpreters, and providers) are given "equal time" for storytelling, it is easier to see and acknowledge that all share the obligation (and the work) of communication, and that all benefit from optimal arrangements for access.

At the same time, it is important to look beyond initial interpretations of brief stories and to unpack the circumstances of their telling. It is possible that the "trouble stories" told by Deaf people about health care may contribute to a stereotype of clinical insensitivity and intransigence that could produce defensiveness and guilt among health care providers, rather than a desire for change. Such a concern may perhaps have motivated the kind of story our Deaf panelist told—one in which the physician eventually accommodates the Deaf patient and learns the value of accommodation. On the other hand, such "happy ending stories" may gloss over the troubles that come before success, and the work that Deaf patients often shoulder without acknowledgement. Jeff Sterly's story as it is initially told at our panel discussion is one that seems to be shaped by conventions (the happy ending) as well as by his intentions (bridge building). Because he at first suppressed the parts about his initial difficulties finding a doctor, and about the physician not being able to hire an interpreter even if he wanted one, he seems to focus on what he wants the story to convey: that the physician needed access, too, and was himself pleased to have an interpreter once it was arranged. In any case, Sterly's shaping of the story, for a particular audience (before encountering a physician who says what no one on the panel chose to say—that she was "horrified" by how the Deaf people were treated by their doctors) can also be seen as labor—as work done to build the bridges necessary for effective communication and care.

It is important also to note that the kind of narrative work and analysis we recommend does not lead to definitive interpretation of "what happened" but rather recognizes that the story is open to differing readings. For example, we have discussed among ourselves the significance of Sterly's physician's two employment contexts—first working for someone else in a group practice and then on his own. We can all see and agree that the power to authorize expenditures for access is critical. But did the physician, initially, wish to provide an interpreter? Was it someone else's power of the purse that prevented accommodation years earlier? Stories present experience in ways that open up such questions, and discussing stories with many audiences will typically raise more questions. As we see it, that openness is not a problem of stories, but a feature that makes them a fruitful site for conversation among parties to the mediated medical encounter.

We are grateful to all of the Deaf community members, interpreters, and health-care professionals who have participated in our public events, sharing their expertise in order to enhance communication access. We extend special thanks to Jeff Sterly, for his willingness to offer his story for discussion here.

Works Cited

- Americans with Disabilities Act, as amended. <http://www.ada.gov/pubs/adastatute08.htm>
- Barnett, Steven. "Communication with deaf and hard-of-hearing people: a guide for medical education," *Academic Medicine* 77, no. 7 (2002): 694-700.
- Bell, Derrick A. *Faces at the Bottom of the Well: The Permanence of Racism*. (BasicBooks, 1992).
- Bruner, Jerome S. "The narrative construction of reality," *Critical inquiry* 18, no. 1 (1991): 1-21.
- Brunson, Jeremy L. "Visually experiencing a phone call: the calculated consumer labor Deaf people perform to gain access through video relay service," *Disability Studies Quarterly* 30, no. 2 (2010): <http://www.dsqsds.org/article/view/1245/1273>.
- Cahill, Spencer E. and Robin Eggleston. "Managing emotions in public: the case of wheelchair users." *Social Psychology Quarterly*, 57, no. 4 (1994): 300-312.
- Charon, Rita. *Narrative Medicine: Honoring the Stories of Illness*. (Oxford, 2006).
- Corey, Rebecca C., Julia M. White, and Zosha Stuckey. "Using Disability Studies theory to change disability services: a case study in student activism." *Journal of Postsecondary Education and Disability* 23, no. 1 (2010): 29-37.

- "Definitions of Methods of Deaf Communication," Deaf Web Ring. 14 June, 2011
http://webspaces.webring.com/people/wu/um_10156/10-cm.html.
- Delgado, Richard, and Jean Stefancic. *Critical Race Theory: An Introduction*. (New York University Press, 2001).
- Engel, John D., Joseph Zarconi, Lura L. Pethel, Sally A. Missimi. *Narratives in Health Care: Healing Patients, Practitioners, Profession, and Community* (Oxford: Radcliffe, 2008).
- Frank, Arthur W. *The Wounded Storyteller: Body, Illness, and Ethics*. (University of Chicago Press, 1996).
- Harmer, Lisa M. "Health care delivery and deaf people: practice, problems, and recommendations for change." *Journal of Deaf Studies and Deaf Education* 4, no. 2 (March 20, 1999): 73 -110.
- Iezzoni, Lisa I. et al. "Communicating about health care: observations from persons who are deaf or hard of hearing." *Annals of Internal Medicine* 140, no. 5 (2004): 356-363.
- Kashar, Alexis. "Doctor, can we please communicate?" *Views* (Fall, 2009): 12-13 [originally published in NADmag, March/April 2009].
- Kleinman, Arthur. *The Illness Narratives: Suffering, Healing, And The Human Condition* (Basic Books, 1989).
- Lane, Harlan. *The Mask of Benevolence: Disabling the Deaf Community* (DawnSignPress, 1999).
- Lane, Harlan, Robert Hoffmeister, and Ben Bahan. *A Journey into the Deaf-World*. (DawnSignPress, 1996).
- Lindemann Nelson, Hilde. *Damaged Identities, Narrative Repair* (Cornell University Press, 2001).
- Mattingly, Cheryl. *Healing Dramas and Clinical Plots: The Narrative Structure of Experience*, 1st ed. (Cambridge University Press, 1998).
- Middleton, Anna, et al., "Communicating in a healthcare setting with people who have hearing loss," *BMJ* 341, no. 3 (September 2010): c4672-c4672.
- Mishler, Elliot G. *The Discourse of Medicine: Dialectics of Medical Interviews*. (Ablex, 1984).
- Mishler, Elliot G. "Patient stories, narratives of resistance and the ethics of humane care: a la recherche du temps perdu," *Health* 9, no. 4 (October 2005): 431-451.

- Mitchell, Ross E. and Michael A. Karchmer. "Chasing the mythical ten percent: parental hearing status of deaf and hard of hearing students in the United States," *Sign Language Studies* 4, no. 2 (2004): 138-163.
- Padden, Carol A. and Tom L. Humphries. *Inside Deaf Culture* (Harvard University Press, 2006).
- Pollard Jr., Robert Q., Robyn K. Dean, Amanda O'Hearn, Sharon L. Haynes. "Adapting health education material for deaf audiences." *Rehabilitation Psychology* 54, no. 2 (2009): 232-238.
- Riessman, Catherine Kohler. *Narrative Methods for the Human Sciences*. (Sage, 2008).
- Scheier, Donna B. "Barriers to health care for people with hearing loss: A review of the literature," *Journal of the New York State Nurses Association* (Spring/Summer 2009): 4-10.
- Schwartz, Michael A. *Communication in the Doctor's Office: Deaf Patients Talk About Their Physicians*. Ph.D. Dissertation (2006), Syracuse University.
- Schwartz, Michael A. "Deaf Patients, Doctors, and the Law: Compelling a Conversation about Communication," *Florida State University Law Review*. 35 (2007): 947-1002.
- Tamaskar, Prashant, et al. "Preventive attitudes and beliefs of deaf and hard-of-hearing individuals," *Archives of Family Medicine* 9, no. 6 (June 1, 2000): 518-525.
- Wear, Delese and Julie M. Aultman. "The limits of narrative: medical student resistance to confronting inequality and oppression in literature and beyond." *Medical Education* 35, no. 10 (2005): 1056-1065.
- Wear, Delese and Mark G. Kuczewski. "The Professionalism Movement: Can We Pause?" *The American Journal of Bioethics and Humanities* December 2010; 4(2): 1-10.
- Williams, Patricia J. *The Alchemy of Race and Rights: A Diary of a Law Professor*. (Harvard University Press, 1992).

Endnotes

1. The capitalized term *Deaf* typically refers to those who view themselves as a cultural or linguistic minority (using sign language) and/or identify with Deaf culture. The term *deaf*

typically refers to those who view their deafness as an impairment rather than a cultural or linguistic identity. The issue is complex. For example, a person who is hard of hearing and does not sign may identify with Deaf culture; a person who elects to receive a cochlear implant, thus treating deafness at least in part as an impairment, may nonetheless identify with Deaf culture and use sign. In this essay we try to simplify the terminology by avoiding the use of *D/deaf* and *D/deafness* when we may be referring to both groups or overlap in between. In this article, we have tended to use the capitalized term *Deaf*, because we are primarily concerned with issues of communication access for those who identify as culturally Deaf, and we wish to underline the cultural aspects of the health-care encounter. We recognize that this approach does not fully address the complexity of identification and belonging.

2. In this essay, we use the term *disabled people* rather than the "person first" language, *people with disability*, to reinforce the social model, which posits that disability is the interaction of embodied difference or impairment with social and environmental norms. Thus people are disabled by barriers in society rather than by having some objective human condition. We recognize that this distinction ignores many complexities, but these do not detract from the core insights of the social model.
3. See Wear and Kuczewski (2010) for a discussion of "cultural competence" and the tendency to reduce the need for cultural awareness and a critique of the sources of inequity in institutions, policies, and practices to a focus on attitudes or finite units of knowledge that are easily taught, mastered, and measured.
4. For the legality of a health care provider's use of written notes with a Deaf patient, see our discussion below.
5. See: <http://www.urmc.rochester.edu/deaf-wellness-center/>.
6. In this discussion of the legal requirements involving Deaf communication, we use the term *doctor* to reference those who will see patients, diagnose, and prescribe treatment, as well as authorize the hiring of a sign language interpreter, in the medical setting; we recognize that nurses, nurse practitioners and physicians assistants also perform these functions.
7. 28 CFR Part 36, Section 36.104 (Definitions). See http://www.ada.gov/regs2010/titleIII_2010/titleIII_2010_withbold.htm.
8. *Id.* Commerce is defined as travel, trade, traffic, commerce, transportation, or communication (1) among the several States; (2) between any foreign country or any territory or possession and any State; or (3) between points in the same State but through another State or foreign country. It is broadly defined to encompass hospitals, clinics and offices on the theory that the work carried on ultimately impacts on interstate commercial transactions — for instance, medicines and supplies often cross

state borders.

9. See <http://www.ada.gov/pubs/adastatute08.htm>.
10. *Id.*
11. Section 36.201(a).
12. "A public accommodation shall not subject an individual or class of individuals on the basis of a disability or disabilities of such individual or class, directly, or through contractual, licensing, or other arrangements, to a denial of the opportunity of the individual or class to participate in or benefit from the goods, services, facilities, privileges, advantages, or accommodations of a place of public accommodation." Section 36.202(a).
13. "A public accommodation shall not afford an individual or class of individuals, on the basis of a disability or disabilities of such individual or class, directly, or through contractual, licensing, or other arrangements, with the opportunity to participate in or benefit from a good, service, facility, privilege, advantage, or accommodation that is not equal to that afforded to other individuals." Section 36.202(b).
14. "A public accommodation shall not provide an individual or class of individuals, on the basis of a disability or disabilities of such individual or class, directly, or through contractual, licensing, or other arrangements with a good, service, facility, privilege, advantage, or accommodation that is different or separate from that provided to other individuals, unless such action is necessary to provide the individual or class of individuals with a good, service, facility, privilege, advantage, or accommodation, or other opportunity that is as effective as that provided to others." Section 36.202(c).
15. The law requires the provision of a "qualified" interpreter, and one way to check on an interpreter's qualification is to ask if the person is certified. Certification does not guarantee qualification but is an important marker of the interpreter's ability to facilitate communication.
16. Section 36.104. Qualified interpreters include, for example, sign language interpreters, oral transliterators, and cued-language transliterators.
17. Section 36.302(a).
18. A medical specialist such as an oncologist or an ophthalmologist may refer an individual with a disability to another doctor, if that individual needs treatment or services the referring doctor does not offer. Section 36.302(b)(1). The regulations offer a specific illustration: "A health care provider may refer an individual with a disability to another provider, if that individual is seeking, or requires, treatment or services outside of the

referring provider's area of specialization, and if the referring provider would make a similar referral for an individual without a disability who seeks or requires the same treatment or services. A physician who specializes in treating only a particular condition cannot refuse to treat an individual with a disability for that condition, but is not required to treat the individual for a different condition." Section 36.302(b)(2).

19. Section 36.303(a). The likelihood that a court would find the provision of an interpreter to a Deaf patient to be a "significant expense" is virtually nil. We know of no such case.
20. Section 36.303(b)(1). Also included are acquisition or modification of equipment or devices. Section 36.303(b)(3).
21. Section 36.303(c)(1). A "companion" means a family member, friend, or associate of an individual seeking access to, or participating in, the goods, services, facilities, privileges, advantages, or accommodations of a public accommodation, who, along with such individual, is an appropriate person with whom the public accommodation should communicate. Section 36.303(c)(1)(i).
22. Section 36.303(c)(1)(ii).
23. http://www.ada.gov/regs2010/titleIII_2010/titleIII_2010_regulations.htm#a104.
24. *Id.*
25. *Id.*
26. Section 36.303(c)(2).
27. Section 36.303(c)(3).
28. Section 36.303(c)(4).
29. Section 36.104.
30. <http://www.ada.gov/inova.htm>.
31. *Id.* "Interpreter continuity" ensures that the replacement interpreter is familiar with what has transpired with the patient and is ready to continue the level of effective communication access left off by the previous interpreter.
32. *Id.*
33. *Id.*

34. We draw here upon the language and insights of the Beyond Compliance Coordinating Committee, a student advocacy group at Syracuse University, of which Schwartz was a founding member. See Corey, White, and Stuckey (2010) for a history of the group.
35. As an Assistant Attorney General in the Civil Rights Bureau of the New York State Department of Law in 1994, Michael Schwartz brought the first lawsuit under the ADA by the Attorney General's Office against a medical clinic in Poughkeepsie, New York; see *People by Vacco v. Mid Hudson Medical Group*, 877 F.Supp. 143 (S.D.N.Y. 1995). The lawsuit firmly established the right of a State Attorney General's Office to enforce the ADA, and as a result the medical clinic complied with the law in providing effective communication access to Deaf people. However, in 2010, Schwartz received word from the original complainant alleging that since the settlement agreement with the clinic had expired some time ago, the clinic was back to its old practice of refusing to provide sign language interpreters.
36. See "Definitions of Methods of Deaf Communication," Deaf Web Ring: http://webspace.webring.com/people/wu/um_10156/10-cm.html.
37. Witness the explosion of "vlogs"—video blogs—where signers sign their messages just as writers write blogs. See, e.g., <http://deafyouvideo.blogspot.com/>.

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