

August 27, 2025

Responses to Update of August 3, 2025, Hearing Loss Advocacy in a Hospital or Medical Setting

On August 3, 2025, I posted this column seeking opinions and discussion about advocacy in medical setting situations.

This is a compilation of the responses. The sources are marked in italics.

Pocker Opines

Well, not really an opinion but seeking some discussion.

First, some background. For several years now I have advocated hearing loops in health care scenarios. I have successfully spearheaded the installation of hearing loops in Sarasota Memorial Hospital in Venice Florida in every department (It is now the only hospital in the state that is fully accessible to hearing aid and cochlear implant users who have a telecoil). In addition, all ten walk-in emergency clinics are now equipped with hearing loops. How many are functional is another issue and as hearing aid manufacturers are eliminating telecoils in anticipation of Auracast means there will be a gap for several years to come.

As I posted two weeks ago, I had a trip and fall and landed on a cement driveway face first. It was my first visit to the emergency room in decades. (Yes, I had eye surgery, and my sight is sloooowly coming back).

What has changed is the use of cell phones. Every doctor and tech were using the phone to do diagnostics or take directions for protocol. Every single one.

I think we can agree that the cell phone has shifted the paradigm in our lives in so many ways. This led me to consider the role the patient takes for their own advocacy. We have spent decades demanding compliance with the ADA. In many cases successfully and in others, especially for accommodations for hearing loss, it is still a struggle. Our invisible disability simply makes it harder for others to understand.

When HLAA was started back in the late 1970s, it was originally called SHHH or Self Help for the Hard of Hearing. SELF HELP was the key to making our own way. ADA shifted the responsibility to the government and others. It was never entirely effective because non-compliance was not attached to a financial penalty but to cure.

But on reflection, we now have our phones to be the tools for self-help. Live Transcribe or any other voice to text assures us we understand the doctor or

technician. AI gives us access to medical information that they might be too harried to explain.

I would welcome some conversation and opinions about returning to more self-help rather than depending on others.

Your thoughts?

From the Facebook site: Bilateral CI Warrior

Steve Meredith

Being born legally blind to a family who was inconvenienced by my blindness and later hearing loss, I had to fight for every inch of territory I gained in terms of rights without regard to whose feelings this hurt. I am hardwired to take the self-help approach to every issue to the greatest extent possible. That said, I'm all for ferocious advocacy to force as much as ADA compliance as possible. Finding that magic balance is not always as easy as tying our shoes, and we sometimes have to feel out the situation to know how much to push for self-help and how much to push for compliance through education and firm tactics.

Kelly Floodin

I am a huge advocate for self-help. I try my best to be independent of outside help to the best of my ability. If I don't know how to do something, I read and study up on it best I can and try it on my own until I figure things out. I may make mistakes, I may spend more money on tools and equipment than necessary, etc. But in the end, I usually get whatever it is done, I'm happy with it, and I've learned a new thing.

It seems like most times I do not take this approach; I am less than satisfied with the results and end up doing something over anyway.

I take this same approach with my hearing. I try new stuff out in comfortable settings, see what works and what doesn't work. Practice runs with new tech with friends is much easier than trying to figure stuff out under the gun in the emergency room.

And try to learn as much about our hardware as possible. They are our tools for hearing. The better we know our tools, their capabilities and limitations, the better we can do with them out in our environments.

As Dad used to say, if you want something done right, do it yourself...

Hope you continue to heal up well. Good vibes your way

Kate Bailey

I'm fairly new to being deaf, I received my implants in 2022 and 2023. I wear kanso2s so telecoil wouldn't work for me. I use transcribe on my phone if I feel I can't hear what a dr is saying. I used to make sure things were ADA compliant in stores. It was a visible thing that could be fixed if out of compliance. Sidewalks, building entrances, door widths are all ADA compliant in newer areas and buildings. I was in a wheelchair for a year and found out how many things weren't compliant, mainly store aisles. I also read in these groups that deafness isn't a disability and the argument that deafness is a disability. Walking with a cane and leg brace and being deaf I still never see myself as disabled. I guess I'm very much in the self-help mindset. I'm also all for deafness being accommodated for. I just don't know how the government ADA can make that happen for every deaf person.

Kim Brown

I'm all for self-help as much as possible. I'm sure much of this has to do with how I was raised. I'm from the "suck it up buttercup" "school of parenting! Even though I am a career IT professional I do not have a lot of faith in AI but believe a little research using multiple resources can be a healthy thing. As far as medicine goes, I always emphasize that it is the "practice" of medicine which to me means medical professionals are doing their best based on their training and experience, but they too are imperfect. Educate yourself, learn what you can, do what you are capable of doing. My 2 cents.

Facebook group: Cochlear Implant Experiences

Phil Eigner

It seems like this might be an opportunity for hospitals to plan for the rollout of Auracast. I don't know how it would work room to room, but it would be great if it implemented well.

My reply: It is some time off in the future. Primary made for large spaces so I don't know how it will work on a one-to-one basis. Thanks for your input

Beth Morgan

You have been The Voice of Reason for me in dealing with CIs. Yes, the medical community needs to step up in this case. During the pandemic I was often floored at their inability to deal with a deaf person. My CI audiologist wore a face mask ... meaning the entire visit was a waste of my time.

Rebecca Hanson

It would be helpful in medical facilities if there were more accommodation for those of us with hearing Impairments.

My reply: That was the reason I spearheaded the installation of hearing loops in the hospital. Sarasota had over 130 looped venues, houses of worship, entertainment, etc. Not one single place of public safety. Since that time, as mentioned elsewhere, the hospital, the walk-in clinics and in addition, all ten public libraries, the sheriff's office and one or two police departments. Without financial penalties for non-compliance, it is very, very difficult to get cooperation. It is the weak spot of the ADA legislation. Hence our phones are our lifeline.

Facebook group: Living with Hearing Loss Group

Judy Shugarts

I look at my hearing aids as my wheelchair and think venues should provide accessibility (a wheelchair ramp) with loops or other current technology. I don't have the stamina to push for loops because it's an uphill battle, even though I think they should've been provided ever since the ADA was signed. Our HLAA has a huge mailing list but not too many have the drive to advocate for themselves or others. I don't understand the apathy in the hearing loss community. Not too many people want to learn or find out about accessibility devices.

So now I depend on myself for my accessibility and drive to be able to hear. [🗣️] I have a Roger on, Partner Mic, tablet for live transcribe, and TV link. I just took an Auditory training class and signed up for lip reading. I am practicing my communication skills, telling people I have Hearing Loss and asking people more often for what I need. So, I guess I'd say I've mostly given up on others providing a wheelchair ramp and am doing what I need to do.

☞A friend of mine who just got a Cochlear and is a great advocate, loaned me three Roger clip-on mics's that link with Roger on. They are the best but are too expensive. I don't know about buying more tech as I'm waiting to see if Phonak comes out with the Infinio with Sphere chip in a BiCros.

Libbie Bramson

Are you thinking about adult education classes, seminars and webinars to teach patients how to use their smart phones to: 1) do daily basic wellness checks, 2) monitor chronic conditions, 3) respond to an emergency situation? When dealing with deaf patients, there would be an extra overlay of how to do these things using our phones plus the additional devices we rely on to communicate.

When I first got my smart phone, I remember attending adult education classes to learn how to use the phone as an administrative assistant, library, travel planner, source for news and weather updates, entertainment, and later, my primary camera. My hearing aid app is on my phone, and I think of it as the Command-and-Control area for my aids, Each time there was a significant update, I attended adult education classes sponsored by Florida Gulf coast University.

I know my phone is busy gathering all my vital data points, but I never check them! I believe there is a large senior market that barely knows how to make a phone call on their smart phones, but who could be taught how to use it as a medical reporting tool. Those are a few of my initial thoughts. An educated patient is always a better patient.

Facebook group: Hearing Aid and Hearing Loss Support Group

Carlton Whatley

Hello!... I very much admire your advocating and agree with the installation of hearing loops in health care scenarios - especially the E.R. ...as I am a retired E.R. & I.C.U. nurse. I am also, since about age 32 (I'm now 71), a hearing aid wearer due to an acute hearing loss at age 28 due to antibiotic toxicity. in year 2001, I visited London, and experienced hearing loop technology as almost all taxis had them, as well as many museums, and using that technology was wonderful! i also

think it would be excellent to have it in airports and inside airplanes due to so much background noise.

.... Anyway, what I want to ask is, when you said, "Every doctor and tech were using the phone to do diagnostics or take directions for protocol.", did you ask any of the doctors or techs what they were doing with the phones? I ask because there is a possibility that they may have been using them as you said - and in addition, they may have also been using them to document your visit to their medical facility and to build your EMR "Electronic Medical Record" or "Electric Chart", as it is sometimes referred to - using the phones as a wireless connection to the mainframe to order tests, x-rays, communicate with other departments, etc.

My reply: Yes, I could tell they were using them to document the visit as my discharge papers were so detailed they must have been doing that as well. They were also communicating with specialists to be sure I did not have a concussion. As I tried to say in my post, whatever tech we can take advantage of, we need to think of using it. While I will still advocate for hearing technology, I was concerned about those who do not self-advocate and only look for outside help. Whatever the reason the medical professionals were using their phones, as patients we can too, BTW, I lost my hearing at age from medical toxicity. Maycin drugs used to combat my scarlet fever. It was a long decline, and I wore HAs from the age of seven until I had a collapse of all my hearing in a month when I was 30 and spent 35 years in total deafness until receiving simultaneous bilateral CI surgery just before my 65th birthday.

Forest Jane Jacobson

I've had medical professionals refuse to let me use voice to text software on my phone because they thought I would be recording them. Despite me reassuring them it was ephemeral, they still refused.

My reply: Me too. I walked out. Obviously, I would not be able to do it in an emergency but otherwise it would not be a problem. It only happened once but I left that practice and found a new doctor.

Facebook group: Cochlear Implant Users

Dana Mulvany

Although Google's Live Transcribe is very good for most clear speech, it has not provided me effective communication in noisy situations or when people have accents. In cases like those, a human Realtime captioner may be needed to provide effective communication.

A possible alternative that could be developed is the training of human revoices who can repeat what other people are saying into an excellent speech recognition system, possibly transmitting to the patient's phone and developing/providing the use of smart glasses in order to see the captions below other important visual information (and also provide to the patient the running transcript on a mobile device because it's often necessary to look back at what had been transcribed). (Tech like this might also help patients who need translation services.)

It often seems forgotten that many people who call themselves hard of hearing may still not have 100% speech recognition in certain situations and may still need visual information to supplement what they can't hear clearly. I usually benefit a great deal from hearing as clearly as possible but there are still some speech sounds, I can't discern clearly, and I'm really thrown by accents (which often distort the very sounds I rely upon hearing into completely unrecognizable speech). So, although I have Google Live Transcribe available to me, I know it hasn't provided effective access to me in many situations. Patients still need to be able to obtain effective communication from health care facilities.

Robin Chisholm-Seymour

Richard, first off, what's most important is I'm glad your eye is healing and I'm so sorry you had to go through all of that!

Your message is timely for me also, because I did recently both have a procedure myself as well as take my husband in for some surgery. Neither was an emergency, but both were in different medical facilities.

And thinking about this, I try to be open minded to the fact that there are many individuals who experience Sudden unexpected hearing loss and don't have the experience that some of us have with years of managing hearing loss, including prior to the advancements in technology that are available today for communications and notification, etc.

My experience in both medical facilities recently was that I communicated via my phone and text messaging. I also would notify the facility staff about my hearing challenges, so they were aware of that, I had no issues whatsoever at either facility or for each particular situation.

My personal journey over the years, again, beginning prior to the available technologies of today, I from the very beginning of my hearing loss many years ago, didn't know to do anything but advocate for myself and do what I needed to do to accomplish whatever it was I wanted or needed to. I've always been very independent about it and self-advocated for what I needed and that includes today. I did get hearing aids as soon as it was determined they were necessary, I upgraded those as needed, and when I qualified, I got cochlear implants as fast as I could. Other than that, I use no apps or accessories even now. I do read lips, and that has been the most important tool in my toolbox, and I feel that it has enabled me to communicate as independently as possible. I will say that it was pretty cool that the facilities would send me text messages About my husband and his surgery and the status and so I didn't have to pay particular attention or sit right next to the information station. My own procedure went smoothly as well, and I had absolutely no issues with that.

I'll also add that we for years provided a loop system in our local cochlear support group meetings and realized over time very few were taking advantage of it, so we do not offer that anymore. We do, however, provide live captioning. I've always been very supportive of loop systems, primarily in large venues, like theaters or meetings in auditoriums. So even as I write this, I'm somewhat ambivalent. I'm sensitive again to the fact that there are those newly exposed to managing hearing loss and then there's those of us who have figured out a way to manage, maintaining independence and self-advocacy. So, I don't know if that answers your question. My personal opinion is that I always try to encourage everyone to self-advocate, stay engaged, try to find the tools and hacks that are going to work best for them, but try to do it in a way that they can be as independent as possible. But back to the healthcare facilities, I think it's wonderful all the hard work you put in and my guess would be it does benefit many. But from my own experience, what I love now is text messages to my phone, which seems to be the way everybody is going these days, including when I took my car in to be worked on. I hope you continue with a smooth recovery!

My reply: Thanks Robin. I think the key word is ambivalence. Yes, I would like to keep pushing for ADA compliance and at the same time educate HOH/deaf how to self-advocate using the new technology we have. The hearing loop-Auracast is

going to be a major disruption for several years. I think we need to be prepared today because when there is an emergency, we can't wait for future solutions.

Mary Beth Napoli

I am glad your eyesight is slowly improving.

I tend to prefer accessibility methods that I have complete control over. I have experienced theaters with loops when the loops were not working and no one in the theater was even aware of the issue. So, when I can I prefer accessibility that I control. Whether that is attaching via cable to their remote receivers on tours or having a speech to text option at the ready on my iPhone. The fast advancement in accessibility features on phones in recent years is encouraging. It becomes more limited when there is no cellular/Wi-Fi access, or we are in locations where cell phones are not permitted.

Jamie Samuelsen Kinsella (in reply to Mary Beth Napoli)

I grew up hearing challenged and never wanted attention called upon myself so I gravitated toward being as normal as I could be, fending for myself. My HA always had telecoil as it was the only way I could hear on a telephone. But I lived in a location where looping buildings was not an option...not enough people with telecoil to make the expense worth the organizations' bottom line. I grew up in Rapid City, SD, and lived in Bismarck, ND for 40 years now.

When I explored the CI option in 2005-2006, getting one in 2007, it was the first time I ever heard of the neck loop. I used one for a year thinking it was the best thing ever, until the wire broke. I didn't feel inclined to purchase a new one on a yearly basis as landfills were filling up too fast as it was. I then got the BT neck loop, but never really used it because I was confused with how the BT technology worked. But soon my HA did not have telecoil and I am now able to stream into both ears due to BT technology and cellphone. I need to hear both ears at the same time because my HA ear is my speech understanding ear, and my CI ear provides high frequencies I need to help the HA ear hear all parts of the words as many are in the high frequency range.

Self-help is better because you do have control over using the tools that work for your specific needs because everyone is different.

I think the biggest hurdle is ensuring that everyone knows what options are available for different needs. And as Mary Beth said, cell phones also have their limitations with WiFi/cell tower accessibility.

Agata Jurkiewicz

My opinion, based on my own experience, is that the tools you mention (Live Transcribe, AI) are promising, but not yet ready to be a reliable source of help for us, especially in difficult situations. Live Transcribe has only helped me once, in other situations it failed. AI-generated subtitles in class were, repeatedly, a disaster. It is all OK if it's not that important. I can always ask someone what was said. But in a situation where my health or my life is on the line - I know I cannot rely on these tools.

Anonymous member:

Hearing loops for telecoil aren't important for me because my CIs aren't always perfect. I'm grateful for ASL interpreters and VRI with Live Transcribe in the emergency room. Just respect for anyone who has CIs still needs sign language interpreters available at the ER and hospitals because of the ADA.

Carol Geanaldi

I am very assertive in medical or business environments. I am fortunate that my cardiologists are extremely attentive to my needs. At admission, they present me with a deaf/hard of hearing needs statement asking if I need an interpreter or assistant to ensure that I fully understand the communication. I am a patient at Deborah Heart and Lung Hospital in NJ. Elsewhere, in other med environments I always announce my hearing loss, point to my CI processor, and am assertive to make sure I understand. Recently i was stopped by a policeman while I was driving. Soon as he approached my window, I told him I was deaf and please face me while speaking to me. I never forgot Sam Trychin at a HLAA lecture to "tell them what you need for communication." I firmly believe in the aphorism: "Forewarned is forearmed." I attended a Bar Mitzvah, and the temple provided FM for my neck loop, and there was a large screen behind the lectern that provided captions. I sent a letter of thanks to the rabbi for this accommodation. The 14-year-old boy celebrating his Bar Mitzvah had 2 cochlear implants. So, in many

places there are accommodations we did not see several decades ago. " The squeaky wheel gets the oil".

Facebook group; Cochlear Implant Support Group

Karen Britton

WE need BOTH I feel. I have been hard of hearing since my 30's and am now nearly 70. I got by ok with my hearing aids till I suffered and SSHL in my left ear (which was my better one) back in April this year. Yes, it's been hard as now I don't really hear anything apart from really loud noises like planes etc. I am waiting for my cochlear assessment. In the meantime, I have adjusted my way of thinking. I don't think ' I can't do that ' but instead work out ways in which I CAN do something. Like you said, I use Live Transcribe, I have found live captions on my phone so can now take and make phone calls when at first, I thought I can't use the phone anymore. So, I have adjusted my mental outlook BUT at the same time I also have kept pushing and pushing the hospitals both for my initial referral to be sent and now for my initial cochlear appt We are not medical professionals though so self-help can only go so far. It needs co-operation from both the HOH/deaf and the medical world etc. I don't think self-help alone is enough.

William Madden

69-year-old with a 64-year struggle of profound nerve loss hearing disability caused by ototoxicity here. As a child I had to depend on others to guide and assist me in my plight- primarily audiologist, parents and teachers. As I came into adulthood, I saw that self-effort and advocacy was the most immediate and effective strategy for me. Yet, every organizational/government assistance was highly appreciated, and I advocated privately for prospective future assistance technologies no matter how they might be funded. I celebrate the explosive technological advances such as cell phones, Bluetooth, loop systems, etc. I'm disappointed that all those things were slow in coming and that I'll likely not get to explore some amazing future tech. I needed cochlear implants when they were first introduced but could not take advantage because insurance did not pay for them nor could I afford any type of insurance that might (come) later. It wasn't till I was on Medicare and the guidelines for CI were open that I could get them. I do resent

that fact. I also find myself resenting the fact that mobility disabilities are the primary focus of governmental regulation enforcement of the disability act. I've had issues in court where I was placed at significant disadvantage due to my disability and the judge didn't give a damn.

On the whole of the issues you put forth, I think both the individual and community, i.e. Government, corporate, and social entities like churches etc. have a moral obligation to provide/engage opportunities for assistance for any disabilities. It should all mesh to bring all people the best experience possible all the time. So, loop systems? Yes, both in HA/CI manufacturers government regulatory efforts, corporate and social entities should engage. Users should be more intensely informed and trained to use it. Same could be said for future tech like Auracast. So, captioning? Yes, in the same terms as above.

It should be noted that providing such assistance not only provides help for the disabled but with such tech as ear buds and Bluetooth folks who are not hearing challenged will gain some advantages as well. Example: airports can be noisy and distracting environments but with new Bluetooth tech anyone with a cell phone and earbuds may be able to privately hear info they need unhindered for their journey. The way I see it, like so many issues we face, it's not an either/or matter but one of both/and.

Summing Up

I received an email from Janine Katomski, the President of HLAA Eastern Connecticut chapter with information that is important to include in this report:

The attached message was researched by a very competent HLAA'er, Alan Katsura, of HLAA Diablo Valley. I hope this additional information is helpful to you. I have always enjoyed chatting with you and am willing to collaborate with you on issues, such as this.

Let me know your thoughts on this topic.

Best,
Janine Katomski
President

HIPAA & Accessibility: Key Points

- **HIPAA protects patient privacy**, specifically the confidentiality of Protected Health Information (PHI). It applies to healthcare providers, insurers, and their business associates.
- **Patients have the right to use accessibility tools** to understand their own care. HIPAA does not prohibit patients from using personal devices like Live Transcribe to aid communication.
- **Live Transcribe is not HIPAA-compliant software**, meaning healthcare providers should not use it to transcribe or store PHI on behalf of the patient. However, using it for your own understanding is not a HIPAA violation.
- **Objections from staff often stem from misunderstandings.** HIPAA restricts what *they* can do with your data—not what *you* can do to access it.
- **ADA requires reasonable accommodation**, including communication aids for people with hearing loss. Healthcare providers are legally obligated to ensure effective communication, which may include CART, captioning, or transcription apps.
- **HIPAA does not override ADA obligations.** If a provider refuses to accommodate your hearing needs citing HIPAA, they may be violating ADA, not protecting privacy.