

POWER OF CITIZEN ADVOCACY: USING OUR PASSIONS – POOLING OUR VOICES

CHAIR OF PANEL: Lauren E. Storck

PANEL MEMBERS: Kathy Evans, Bill Graham, Claude Stout, John Waldo

Lauren Storck: The topic of this panel is about the power of citizen advocacy, which means using our passions and pooling our voices. It's working together to convince the rest of the world that we need subtitles and captioning for all media. We're going to explore our passion for advocacy and access for all. That's the TDI motto and the theme of this joint conference. We will begin with panelists sharing their background and personal history with accessibility. Then we want to continue talking, socializing, sharing experiences and hopefully planning more collaboration together.

I don't know how you define passion, but Oprah once said, "Passion is energy. Feel the power that comes from focusing on what excites you." On the other hand, Ben Franklin once said, "If passion drives you, let reason hold the reins." What we aim to do is to use our emotional energies to brainstorm ideas about how we can move advocacy forward. Sometimes as leaders or when involved with wonderful, long-established associations, we can feel powerless. We wonder if anyone's listening. We feel burnout at times when we wonder whether we're doing the right thing, or whether we should change direction.

A brief exercise might help you think of what you might like to share. Close your eyes if you care to and think about when you first felt excluded, or when you tried to ask for captioning and you couldn't get it. You were told "No." and you gave up. Now is the time to think about asking again. Thus a way to move forward is by sharing our stories and sharing our questions. Without further ado, I am going to introduce Claude Stout.

Claude has been executive director of TDI since 1997. He is also Chair of a coalition that some people with acquired hearing loss, like me, may not know about it. It's the Deaf and Hard of Hearing Consumer Advocacy Network, DHHCAN. He is also a member of the FCC Consumer Advisory Committee. Prior to TDI, Claude was active in community affairs in North Carolina for the Division of Services for the Deaf and Hard of Hearing, Executive Director of the Missouri Commission, Director of Business Services of the National Association for the Deaf. He also did some teaching at Gallaudet University.

Claude Stout: Thank you, Dr. Storck, for inviting me to participate in this panel. I was born deaf and my parents did not sign with me. They tried to speak some, gesture some and I got along. My parents, don't get me wrong, were wonderful with me from the time I was a baby to the day they died. When I was 5 years old, I went to the North Carolina School for the Deaf with five words in my vocabulary. However, the School for the Deaf prepared me well for 14 years after which I attended Gallaudet and earned my degree. When I was that little 5 or 6-year-old boy living with my folks, I remember watching black and white television where I could understand the gist of some programs. I used to love to watch the Jack Benny program. I can remember Ed Sullivan and Jerry Lewis as well and I tried to figure out what they were saying on TV. It wasn't easy. I had to make a whole lot of guesses and fill in a whole lot of gaps. I would ask, "What did they say, Mama? What did they say, Daddy?" They would tell me in a few sentences that sometimes I would get and sometimes not. Often when my parents were on a phone call, I would look at them and wonder whom they were calling, or who was calling them and what was the call about. My parents tried to communicate things to me, but they would often do so in short sentences of one, two or three words about who was talking and what the point was. Sometimes they did that and sometimes they didn't. That early childhood experience taught me that this was the experience of deaf people.

Back then we didn't say, "hard of hearing," we didn't say, "late deafened;" only years later did we begin to identify these sub-categories of hearing loss. I realized that we deaf and hard of hearing people and late-deafened people have to speak up for ourselves in order to get services. We have to have the technology that will help us live independently and experience a self-sufficient existence. We have to have what we now call "functional equivalence." At Gallaudet when I was Student Body Government President, I was involved in organizations such as those Dr. Storck mentioned. I became wholly immersed in the National Association of the Deaf (NAD) at the state level as well, and now with TDI. With TDI, I know very well that my organization cannot create and implement, for example, a national agenda with caption services or broadband access. We have to work in coalition with other national organizations such as the NAD, HLAA, ALDA, etc. If we cooperate, we can file joint comments to the Federal Communications Commission, to the Department of Justice and to the Department of Homeland Security. We come on with a united voice. Once we have aired our grievances internally in and among ourselves, compromising where necessary, and then submit something to those government agencies, they recognize that we've already collaborated. Our united voice, in turn, makes their jobs easier. From the national government agency's point of view, we need to do our job and be in cooperation with one another at the national, the state and local level.

Lauren Storck: Thank you, Claude. Next on the panel is Kathy Evans. Kathy is Utah's advocate for deaf and hard of hearing people. She helped pull together a

coalition of leaders into something called the Popcorn Coalition, now called Utah Communication Access Network. For short, Utah CAN. Yes, we can, all of us. Utah CAN promoted better communication access in public venues such as at movies and museums and got captioning for public health service announcements. Kathy and the group worked with local television stations to improve the quality of captioning (another very important topic). More recently Kathy shared some communication materials that deaf and hard of hearing could use for funeral homes and hospitals where access is sorely needed. She works with many individuals as well.

Kathy Evans: Like Claude, I'm going to give you a personal advocacy story and then a group advocacy story. Unlike Claude though, I was born hearing. In childhood I started losing my hearing, which has been a progressive loss until I am now deafened. I don't know how long ago this was, maybe 10 years ago. I was involved in family history work and taught others how to do family history or genealogy. I wanted to attend a conference that was being held in Salt Lake City. I hadn't been doing things like that because my hearing had gotten so bad. I used two hearing aids and an assistive listening device, but I decided I would go to the conference and ask for access.

With my own assistive listening device with a transmitter and receiver, I went up to the first presenter, introduced myself and told him that I had a hearing loss. I asked him if he would wear my microphone so I could participate in the workshop? He was so kind, really gracious; he was very nice about it and happy to wear it. I said, "There is one other thing. If people ask questions from the audience, would you please repeat the questions into the microphone so that I'll know what you are responding to?" He said he would. That's the part he forgot but because I was sitting right there in the front row, when he forgot, I raised my hand and he would say, "Oh, the question was..."

He just did a great job. I enjoyed that workshop so much, I thought, "This is good!" I can advocate for myself and get what I need and really enjoy being out again. At the end of workshop, as I went to get my microphone, he was talking to someone and I had to wait a few minutes. By the time I retrieved my microphone and had gotten to the second workshop, I didn't have time to give the presenter my microphone or tell him my needs and all of the front row seats were taken. I got choked up over everything and realized I had a problem. Will I just go to every *other* workshop? Next year, should I bring a friend with me who will get front row the seats for us? I hadn't yet figured this out and it was frustrating to me because I realized I couldn't be independent. I couldn't do it all by myself and I so much wanted.

I did learn that people are kind and accommodating when they understand what our needs are, especially if you ask them to do something simple, like wearing my microphone. They can handle that. I also learned that it's hard to be totally

independent in self-advocacy and there are times I just couldn't do it all myself. It makes a difference to have someone else speak for our needs. I am grateful for my friends who have helped me that way. I also learned through this that it really is okay to ask for the accommodations that we need. Also, it's okay to ask for the advocating as well.

About the same time, the President of UAD, Utah Association for the Deaf, wanted to reach out to the Self-help for Hard of Hearing people in Salt Lake City, where I was the President. We setup a meeting to get together. I was a little nervous about it because I hadn't worked with a Deaf person before and it surprised me that I was worried about it. At this meeting, the Division of Services for the Deaf and Hard of Hearing provided an interpreter for us. Later I found out that the President of UAD was even more nervous than I was about our getting together. Nevertheless, we hit it off and we decided that we wanted to create a project that would bring our two groups together. We talked about four or five different things, and we finally decided we would work on bringing more captioned movies to Utah. Well, we started there but realized that we didn't have the reputation we needed because ALDA wasn't at the table. Then, we invited the President of ALDA at that time to Salt Lake Valley and we invited a board member from the Alexander Graham Bell Association. After we invited a representative from the Q-language Network of America, the five of us sat down together and really started moving ahead. We called ourselves the Popcorn Coalition.

How exciting it was to feel the energy of all of these people as we talked through our differences and our similarities, as we tried to find the kind of access that we wanted, and how we wanted to reach out to different theaters and then to different agencies and organizations. We found that together we had a strong voice because we represented all the deaf and hard of hearing people in the state of Utah. With that as a strong welcome mat, the people we invited from television stations and different businesses came to our meetings! We opened a dialogue with them and it really did make a big difference. I think we did a good job. We also we got inspired by what John Waldo was doing in the state of Washington. We re-structured a little bit and became a little bit more active again. We renamed our organization the Utah Communication Access Network.

Advocating has been a lot of work and I am tired. Yet, I keep doing it partly because of the satisfaction of helping one person at a time. Partly, it is the energy that I feel when a new advocate joins us and starts to take hold of the reigns. To see someone else posting the notices is such a wonderful feeling. I don't have to be the sole link between the national organizations and our local one. It's been wonderful and that does keep me going. It's all about people. I found the longer that I have been in this, the more contacts that I have, the more I am able to put two people together who need each other. That's satisfying! That's why I'm still an advocate.

Lauren Storck: Thank you, Kathy. I want to emphasize two things that you mentioned. The first thing was about the importance of taking some time to re-charge your batteries. The second thing Kathy mentioned that struck me here is the wonderful accessibility of having the interpreters here so someone like me who doesn't use sign language at all can talk to anyone. There are millions of us hard of hearing and deafened who don't use sign language. We want to reach out and talk so having these interpreters here is a wonderful experience. Now moving along from Kathy to Bill Graham. I think everybody knows Bill is a co-founder of ALDA. In 1989, ALDA was the first organization to provide captioning for all workshops and plenary sessions at a multi-day conference. ALDA folks are very proud of that. Bill served on several boards related to captioning, including the National Court Reporter's Association and VITAC, one of the largest closed-captioning and media access companies. At MicroSoft, Bill helped drive closed captioning of Encarta encyclopedia, the first multi-media reference product with captioning and the first MicroSoft employee to use remote captioning. In 2012, Bill launched his own captioning company, Speech Text Access. It has evolved and is now Caption Now with Bill as managing partner.

Bill Graham: Lauren, I want to say that I'm honored to be with you on the panel. I know I've told you over the last three years what a great job you are doing with the captioning advocacy organization that you started online. Like my part Polish ancestors would say, "*Solastolat*, may you live 100 years." I became deaf as an adult. It was nothing I aspired to, but it was the only way I could get on this panel. So I carried through with it!

Yes, I was there in the early days of ALDA. The issue we faced in ALDA was that people who had become deaf as adults didn't have a language to communicate with each other. Some, very few, knew a sign language, crappy sign language, CSL, that is the native sign language of people who become deaf. A few knew how to lip read fairly well. Some could do neither. If we were going to have an organization, if we were going to communicate in a group, we had to resolve this issue so that every one could understand every one else. The first thing we did when we got a group together was to have a hearing person type on a Smith-Corona, with three or four carbon papers in the typewriter. Then every 10 minutes or so, she would pass around the carbons so we could catch up on what everybody was saying. That was kind of an ancient form of captioning. Eventually we moved to connecting a standard computer keyboard to a television monitor. Back then, that wasn't an easy thing to do. When we were able to do that, the typist did not have to pass out carbons. We could actually see the words on a screen. That speeded things up a bit, too.

Soon afterwards, the National Court Reporter's Association learned about what we were doing. When the President of the organization was in Chicago where I lived at the time, he called me down to the courthouse in downtown Chicago. There, he took me into the chambers where sat a court reporter with a computer. I don't think that they had laptops then. He showed me what a court reporter

could do on a computer in real-time. When I saw this...it was "Oh my God, I'm talking and the words are coming up right there." I was in heaven!

In any case, ALDA formed an alliance with the National Court Reporter's Association who followed us everywhere we went. We were like the Johnny Appleseed of captioning. Everywhere an ALDA person went, we had someone captioning. Many of the court reporters who became C.A.R.T. writers volunteered at ALDA meetings just to improve their skills. Pat Graves from Caption First was one of them. She volunteered for a year with ALDA Chicago and now she has a captioning business. So that was ALDA. We were one of the pioneers in captioning, the only consumer organization that was totally obsessed with captioning.

When I worked for MicroSoft, I was managing editor of Encarta, a multimedia resource product that had a lot of audio clips. Of course, since I couldn't hear the hundreds of audio clips that were in Encarta, I couldn't do my job right or as well as other people expected. Thus, a co-worker and I had the motivation to bring closed captioning to Encarta. We created the first multimedia reference tool to have closed captioning. I was also the first person in MicroSoft to use C.A.R.T. at meetings, both on site and remotely. I got it because I asked for it, which is something advocacy is all about: getting things when you ask for them. At Gallaudet, I needed captioning to take part in meetings, to contribute to the meetings. I was really the only one who was asking for this system. After awhile, you could see the other board members using the captioning more and more, looking at the monitors that had the captioning. That's just an example of how so many people benefit from captioning who don't even know it until they're exposed to it. Then they get it. The same thing happened at MicroSoft. I was getting the accommodations but my team and others in meetings were getting the transcripts along with me. If somebody missed a meeting or fell asleep at a meeting, that person would have the transcript to fall back on. That's just another indication that hearing people don't always understand how important captioning can be to them, too.

Now I have a business where I provide captioning services. It's sort of like the circle of life. Captioning gave me so much in my life and let me do things I wouldn't believe I could do when I became deaf. Now I am providing the services, like giving back. We have a tagline in the company that says, "We want to caption the world, one word at a time." To me, that's not just a tagline. It's my mission. I'm an unabashed advocate, even as a guy who provides captioning as a business, I just cannot see an event or some media that is inaccessible and not do something about it. I actually say to people, "You know, this isn't accessible. Can we make it accessible?" That's where I'm at now. Captioning just changed my life incredibly for the better. I hope that other people will experience the same gratification and success that I have had and will advocate as I hope I have done, fairly well.

Lauren Storck: Thanks, Bill. My organization, the CCAC, Collaborative for Communication via Access, also uses a motto similar to Bill's company. They want to caption the world, one word at a time. CCAC says we just want to caption the world. We want to caption; we want captioning on by default. We want it on without begging for it, we want access for all, the TDI model. For Bill and me, captioning really brings us back to life. It was heaven when we discovered it. It's just amazing how many people don't even know that they can turn on television captioning. By the way, all the panelists today are CCAC members because all of us belong to several different organizations. We like to say we come together in the CCAC to share as a hub for captioning advocacy. I just want to say that one of John Waldo's presentations at an ALDA conference five years ago in Seattle, contained one very important ingredient for starting up the CCAC. But to a more formal and proper introduction, John Waldo is an attorney whose practice focuses on improving access to public life for people with hearing loss. He is counsel to advocacy groups in Washington State and Oregon and he has represented ALDA on matters in California. His work in and out of court contributes to the widespread availability of caption viewing equipment today in so many movie theaters. He has also successfully advocated for captions at live theater in Washington State and Oregon and visual display of messages in Washington State. I live on an island off of the coast of Maine, and the ferry is our transportation. If I could ever get text messages, I would be in heaven. I have always been impressed by that particular piece of advocacy.

John Waldo: I guess the first time I did any self-advocacy when I think about it was when I went to law school at age 32 and I realized that my hearing was not really going to let me just sit in the back of the big classrooms and participate in classes that had an awful lot of discussion and interaction between the professors and the students. So before my first class, my first day, I went around and I put notes in every one of my professors' boxes that read, "Please don't seat me alphabetically with everybody else, which with a "W" last name puts me in the back, but let me sit front and center." Everybody was cooperative. A couple of the professors said, "You know, I don't hear well either. So I am happy to do that for you." Anyhow, it was a great experience. I got through law school fine. Fast-forward 25 years. I had a reasonably good legal career as that is generally defined. In other words, I protected a lot of bottom lines for a lot of corporations, but I realized that I hadn't actually done anything that I felt made a difference in the lives of any individuals.

So I thought, it's time to change that, to do something that matters. It occurred to me that I really had a kind of a built-in issue here. Using my own legal training and my life experience as a person with hearing loss, I thought we could put those things together and using the wonderful tools provided us by our state and federal disabilities law, create on the ground the kind of accessibility promised by those laws. To do that, we put together the Washington Communication Access Project with a notion that we would take a systematic and strategic approach to creating greater access throughout Washington.

Now, you know, I've talked to a lot of these conventions before and I suspect that I've spoken to almost all of you. You know about our lawsuits and all of that kind of business. That's been rewarding and sometimes in ways that you can actually take to the bank is pretty cool. But the coolest thing really has been not when we have to go to court and argue with somebody, but when we have the opportunity to come in and simply talk to people and explain our needs. We explain why we need what we're asking for and how our needs can be met, and they get it. They say, "We are so happy to do that for you." Those are the real rewards.

I want to talk about a couple of times that's happened. We started out with live theater in Seattle. We went to the Paramount Theater first, which is the biggest of the Seattle venues. We discussed things back and forth with them for a while. They agreed that they would start offering captioning of one performance of each of their productions. I think it was the summer of 2008 when we had the first **captioned performance on the West Coast. It was "A Chorus Line."**

We had a fabulous turnout for that. We had 40-50 people out for that one. That was the high-watermark; attendance has gone down since then. Nevertheless, the feedback we get from the people at Paramount is that they are so happy to do this. They recognize that it's something that really needs to happen, and they're glad to see it happen.

We lived on an island then, too. A lot of times when we would be going home on the ferry boat from the play, there would be other people that we knew. They would talk us to about the plays. More often than not somebody would say, "I saw that captioning there, and, you know what? I found myself looking at it, too." That was a good kind of feedback.

A couple of years ago we started talking to the University of Oregon about captioning at their athletic venues. We battled back and forth basically to try to get them to do the captioning on the scoreboard where it was visible to everybody, and they finally agreed to do it. They had been quite good about it. We went down there last year for sort of a debriefing after they did their first season of football with captions on the scoreboard. We had a group of people working with us with the University. One of them was a student who has a hearing loss, and she said at this debriefing, "You know, I have been going to football games with my dad since I was a little girl. But I never realized how much more I could enjoy it until the captions came on and I could understand what the public address announcer was saying. I could be part of the crowd experience." That was super gratifying. Then the Assistant Athletic Director said, "My hearing's normal, but it is so noisy in there I found myself looking at the scoreboard captioning, too."

That kind of was an "aha" moment for me. Hearing loss, you know, is kind of a strange sort of condition or disability because there are times and circumstances when everybody is hard of hearing. So we started then saying, captioning does

not just improve accessibility for those of us with hearing loss, but it improves the experience for everybody. We were glad to see the University of Oregon get it. This last year we started talking to the Seattle Seahawks organization. Now, they had been doing captioning for three or four years, but they were giving us these handheld deals that didn't work for so many reasons. We soon sent them a letter and said, "Guys, here is why it doesn't work. We would really like to see you do it on the scoreboard."

I was dealing with the General Counsel who is actually a pretty nice guy and he asked, "Can you come up to our office and have a meeting?"

My WACAP President and I went to the meeting, thinking this might not be good. What are they going to tell us? We get there. They take us up to the executive suite where we can see the whole magnificent field, and then they said, "Thank you for bringing us this to your attention. We are going to install ribbon boards in that corner, so that everybody in the stadium can see it. We're going to start captioning all of our public address announcements, and we are so sorry that the handhelds we gave you didn't work well." Once again, somebody gets it.

Most recently I was up in Bainbridge Island, Washington, where we used to live, talking to the owner of a chain of small movie theaters that are in small towns in Washington. Now, here is a guy converting to digital projection, which is quite expensive. He had to take out a second mortgage on his house to afford it. This is not a guy that I want to play hardball with and threaten to shut down his theaters. We just wanted to talk to him about other ways that we can maybe engage a little open captioning for a couple of performances of the movie. About a week before a meeting with him, I said, "Why don't you just check and see what the latest prices are on closed captioning equipment?" At the meeting then, he said, "I checked. I was pleasantly surprised. In fact, I was amazed at how low the cost has gotten. So here is what we're going to do. In order to provide captioning, we have to put a little emitter device in each auditorium of our multiplex. Then we buy viewing devices. We going to start with one auditorium, and then a second, and then a third and so forth until we have all of the auditoriums captioned. We are going to rotate the movies through the one auditorium that does have the equipment so that at least you will be able to see every movie, even if you can't see every movie everyday."

The company that he found and got these good prices from makes both glasses and this little solid device that you stick in the cup holder. Both of them can work at the same time, in the same theater. So he decided, "I'll just buy a bunch of each, and that way people can choose which kind they want to look at?"

So we said, "Man, you can't do any better than that. You have absolutely leapt ahead of the field now." All I can say is that the advocacy work that I have done has been really, really rewarding. I mean, when King Jordan tells me today, "I think about you every time I go to the movies," man, that's great! I am just grateful I have had the opportunity to do it.

Lauren Storck: Thanks very much, John.

The two things that John mentioned is that movies and sports are so enriching for so many people, those two things are the places where we re-enter humanity by being included, by being able to participate.

Now I want to open this up to everybody to hear some of your stories, whether you are a seasoned advocate or you would like to become more active for yourself, and your community.

Audience Member: Thank you. My question is about airline travel. Is anything happening where we'll be able to read on captions what is being said from the cockpit or by a flight attendant? The other nightmare, of course, is inside of the airport. Sometimes there are reader boards, sometimes there are not. It depends on what's going on. Can you share or enlighten me about what's happening with airline travel?

Lauren Storck: That's a great question! There is a lot going on in airline advocacy. Senator Harkins introduced Senate Bill 556 to require captioning on all media on board all flights coming into the U.S. or leaving the U.S. Whether that bill ever gets to a vote is uncertain. However, we certainly want to advocate a lot more for airline captioning and the bill is a good way to start raising awareness about this.

Audience Member: I know that the safety videos they demonstrate before take off are certainly required by law to be captioned. That aside, while you are inflight, the most boring part of your trip, the Department of Transportation had something going on. The bill that Senator Tom Harkins just proposed in Congress has one part on captioning the movies and another part about captioning in flight.

Audience Member: On trains and buses and all of those, please.

Audience Member: Other forms of transportation should be included, you are right, in that transportation language.

Audience Member: I wanted to say that we have some captioning proceedings that are still in progress at the Department of Transportation to deal with other things like if you are going to the airport and they make an announcement with a microphone about the next flight, we have asked for them to have visual display. That would be not very expensive or hard to do. But a lot of delay is the proceedings are being held up. They need to have more pressure from us.

John Waldo: I was just going to say that the Americans With Disabilities Act really doesn't apply to airlines, certainly not inflight, and it doesn't apply to most airports once we get past the security gates. You are dealing with something called the Air Carrier Access Act, which is a bit of a misnomer because it provides a lot less access than the ADA does. The Harkins bill would apply to movies and things like that shown in flight. It's really just a practical problem here, trying to caption the announcements that are made on board. Who is going to type them in? I mean, do you really want the pilot sitting there typing M-a-y D-a-y?

We ran into the same problem with the ferry system. It's just who is going to do it? So what we get is a sort of drop-down menu that provides you with a lot of the

information, but maybe not all of the specifics. I think frankly that's likely what we're going to end up with at best for the airlines.

Audience Member: More about the airlines--I don't know if you can speak and type at the same time, but there should be some kind of device so the pilot can speak and render the message in text while he is speaking. Of course, they show emergency announcements or alerts, and since the captions are in English and Spanish, there should be the ability to caption what the pilot is saying. When a movie is shown, it's another story. When the announcements override and the movie is stopped, I don't know what the message is. There are no captions on the screen to tell me what the pilot's message is coming over the public address system. There is no reason why we shouldn't be able to have that option to today.

Lauren Storck: This is something we have to keep asking for. There will be solutions to this. I agree that we need some kind of text system for special announcements on board. We pay the same price for flying. We need to have some kind of equal communication access on board as well. As you know it's step by step. It's going to happen, but only if everyone or you and all your friends keep asking for it. Advocacy means ask. There are different kinds of advocacy, of course, but essentially you have to ask. That's the first vital step.

Audience Member: It's when technology changes that we can get things done. There are times when the technology is evolving, and it gets to the point where access gets easier, for example, with the movies. There was a struggle for some years until the digital cinema came into being which made it much easier to do the captioning. That's of course a result of our previous advocacy efforts doing all of the legwork prior to that. With the airplanes, you may have a hard time seeing captions on the planes until the time comes that all of the airplanes are actually improved, until those seat-back monitors are improved. Maybe that's when we'll have captioning.

Audience Member: I am going to go back to the original question that Lauren asked about when the first time was that when asking for accommodations or accessibility, we were met with barriers. Or someone asked us not to ask. A painful thought came to me right away. About ten years ago, I had just started grad school, and was just to the point where I could no longer hear the professors without the assistance of captioning, or a sign language interpreter. I went to the Disability Resource Coordinator at one of the campuses, and asked for caption support for one of the classes. The disability resource person told me I needed to work harder to hear the instruction and that they couldn't provide me the captioning that I needed in the class. That was extremely frustrating for me. But fortunately at that time that was one of my wake-up calls for needing to do some self-advocacy because I had already learned a lot about C.A.R.T. I had to resist the temptation to jump over the desk and strangle this guy. Instead, I calmly explained to him that no matter how hard I tried, that I would not be able to hear the instructor, and that I thought that it was offensive that he said that, and that if

he worked with deaf and hard of hearing students, he should know better. Then his tune, for lack of a better word, changed very quickly. But, like I said, that was one of the wake-up calls for me by not just accepting what someone says you can't because you can. Things are obviously always changing.

I've only been working in advocacy and self-advocacy for about the last 7-10 years. I do also have a question for the panel. As far as advocacy goes for myself, I am on a committee with the FCC, the Emergency Access Advisory Committee; I'm on the Florida State Coordinating Council for the Deaf and Hard of Hearing. I hold the ALDA seat for the State of Florida. I am on the Disability Task Force for the State of Florida. I am so fortunate I have an employer who is fully supportive, including me to be involved in some of these things nationally. Not only do people with disabilities and people with hearing loss have the right to work, we have a right not to starve. So when talking about advocacy, I believe Bill Graham mentioned before that as a businessman he had a hard time seeing a venue remain inaccessible, even though you may not be able to provide that. How do you separate being a good advocate while also wanting to remain employed as a person with a hearing loss? We all have rights to be gainfully employed and we're trying to be good advocates as well. So what are some of the suggestions, or what questions or answers might I have sparked in comments I think that made?

Lauren Storck: Does anyone on the panel want to say anything about this fine line we all walk between making good, polite noise and asking for what we need but not being too threatening? How do you ask so that your employer or your physician or attorney, or anyone you are working with doesn't turn against you? One approach is to think about this first as education and awareness raising. When you advocate for yourself, it's going to affect many other people. You are really not threatening a lawsuit to begin with although sometimes that may be the final step. You first want to explain in detail what it feels like not to be equal, not to have the communication that you need. From my experience with groups I have to ask where do I begin? Then I ask myself, what is it going to cost? Those are the two big hurdles. Does anybody want to add to that?

Claude Stout: Let me give you two ideas on how you might approach things when it comes to accessibility. One thing that really gets my goat is when parents of children who are may be late-deafened or hard of hearing constantly struggle with the superintendents of the public school system or the directors of private school programs to allow the parent's definition of what an adequate level of access might be. The schools say, "Oh, I'm just so sorry. We don't have the resources available. And oh my goodness, I don't even know where to begin to make this accessible." Those school districts and private school programs need to quit making excuses for themselves.

The thing to bear in mind when you approach those kinds of power structures is they cannot provide less than 100%. In the past, we said we would like to have

100% captioning of TV for deaf and hard of hearing consumers. If you subscribe to cable services or television service, they are going to have to caption all of the TV programs. The point is that if I'm shelling out for the subscription just like anybody else, the services cannot reduce access provided to me as a subscriber. The same thing holds true for the schools. When it comes to education, you can talk about the legal protections and rights that deaf and hard of hearing people enjoy to function in the classroom.

Also, use your common sense and talk about property taxes. Your taxes support school boards; they make annual budgetary decisions for the institution. If you want to talk about accessibility for your child, go to the school board and say, "I pay into the system. I need to get something out of it." Property taxes are one revenue stream. State income taxes are another. The Federal Government also provides fund to states that are dispersed throughout the local school districts. Use that leverage and say, "I pay my federal taxes. Your program is funded from that revenue stream." Tie that back to what your deaf and hard of hearing kids need. I think that that would be a good, positive self-advocacy strategy.

Lauren Storck: Please come up to us and ask your questions and please stay in touch. If you send CCAC an email for anybody on the panel, I promise to forward it to Claude, Kathy, John, or Bill. We would really like to keep talking with you. Thank you, yourself, Audience. Without all of you, there would be no leaders of any organization.

Lauren E. Storck, Ph.D, is President of the CCAC, a non-profit consumer-driven, volunteer advocacy organization. CCAC recently launched a non-profit service, CaptionMatch, to boost awareness and captioning inclusion.