

ALDAcon17
SELF-ADVOCACY IN YOUR STATE
SHERRI COLLINS & MICHELE MICHAELS
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MICHELE MICHAELS:

I want to introduce executive director, Sherri Collins. She is the executive director of the Arizona Commission for the Deaf and Hard of Hearing (ACDHH). Sherri has been leading our agency for almost 20 years now. I have been with the State for about ten years. We also have Heidi, our newest staff person who is our executive assistant.

My first question: Does anyone consider themselves an advocate? Yes, most of you do. Perhaps some of you haven't started along that path yet but are here today to learn a little bit more about self-advocacy and how you can enact systems change. We are going to be talking about that today.

Some of the main points Sherri Collins wants to talk about include looping the capitol and the emergency response interpreter credentialing program, text 911 and the airport looping.

SHERRI COLLINS:

I have been the Executive Director of the ACDHH for almost 20 years. I am the longest serving director in the United States, not the oldest, but the longest. I am the President of the National Association which serves all state agencies for the Deaf and Hard of Hearing in the nation. If you have questions about your state, or do not know what resources are available in your state, come see me after this presentation. I can help you connect with your state representatives. I want to make sure that you go back home and connect with the right people if you do not know what is available.

I am also the first Deaf director in our office. I know what it is like to be deaf. I was born deaf and I sign fluently. I also wear a hearing aid and I received a cochlear implant twelve years ago. That changed my life for the better. Personally, that was a decision I made, and it opened doors.

I am the first deaf officially registered lobbyist in the United States. I lobby in our state capitol, which helped our agency make changes. ACDHH does not provide direct services such as counseling or social work. We focus on removing barriers in the state of Arizona and are active in advocating for the community and we encourage members of the community to become their own advocate. We cannot do it without their support.

The more advocates that we have, the better we can enforce change. On the political side, Arizona is very strongly Republican and a narrow-minded state. That's a fact. Does that make it more challenging for us to address our politicians on social and human services issues? That's just – the reality of our political environment. It means more work from us to really deal with our legislators. I try to find a Republican

“moderate.” Usually those are the people that have a soft side about helping our community. And the reason I share these things is because they are important strategies when advocating for a specific issue.

And what we are going to be talking about today is just one of the levels. (There many levels of advocacy that we could talk about but we cannot cover it all in an hour.) One of the things that you might want to consider in future ALDA conventions is more in-depth advocacy training.

Over the last 20 years, we have made a lot of changes. The first change was to the name of the agency. Back then, we were the Arizona Council for the Hearing Impaired. Then we changed the name and licensure. We now are a state agency funded through our telephone relay fund, 100 percent. We oversee relay contracts, and licensure, provide information referral, and send out a weekly electronic newsletter (see our website). You can follow us on social media as well. We provide a lot of training which Michele will explain.

Your advocacy might be personal, or it might be a systems change. This is why I talk about different levels. Michele will take continue the presentation now. I might chime in, but I want to make sure you understand who we are, and our role.

MICHELE MICHAELS:

ACDHH uses the best practices from other states, like North Carolina and Texas who have some great programs. I have been the hard of hearing program manager for 10 years. Our 15 staff members are serving a community of over one million hard of hearing people in Arizona and 20 to 30 thousand culturally Deaf people. So, it's a huge population to serve with only 15 staff. We sit on different boards and commissions and councils. For example, our “Loop Deaf specialists” are part of the City of Phoenix mayor's commission on disability. The City of Phoenix is the fifth largest city in the country, so when we sit on those boards and agencies, we have access to lots of information and can develop allies, coalitions and partnerships.

Before continuing, I want to make sure that you understand that when you advocate for yourself or your organization to create systems of change, the laws are on your side and on our side. We have the ADA, we have the ADA amendments act, we have Section 504, we have the EEOC, and DOJ, and FCC, all of those organizations, plus your state Attorney General probably has a civil rights discrimination option for you. That means that there are a lot of different things that you can do, based in the law. As John Waldo mentioned in another presentation yesterday, do not ever approach somebody and say “Here is my lawyer's card” because that totally puts people on the defensive. If, I as an employer, had somebody giving me their lawyer's card, I would go to my lawyer - end of discussion. We do not want to do that.

Self-advocacy has brought about many helpful changes. Captioning in movie theaters exists, because ALDA sued and got it to happen. People needing assistive listening devices self-advocated by standing up and saying “I need access to this program or

service.” The accessibility of outdoor theater or the open captioned films that we are going to see later all involved self-advocacy as did the captioned phone program. Think of our service animals; back in the day, only blind people had service dogs. Now, many of us have service animals, because again, we said this is what we need and we are going to advocate for ourselves - whether we advocated individually or in small groups. Even if we went to Washington, D.C., we were self-advocating. All of those things happen because individuals start to become advocates.

How do we create change?

I am all about relationships. It is my thing. I create relationships with people all the time. I sit next to somebody at lunch and we talk about how I do things and how you could do things. I am really good at getting myself to the table where things are happening, and identifying what motivates and interests a person. I have developed a theory of creating change through relationships.

Some people like to start at the level of *collaboration*, which is the big picture. Other people feel more comfortable starting at the level of *membership*, which could be an individual member of ALDA or an individual member of HLAA. Wherever you start in the cycle of creating change through relationships, you will be successful.

Let me break it down for you just a little bit more.

Collaboration is linking two or more people. The purpose is to broaden, to make bigger and to deepen knowledge, skills and experience. It is the idea that we are going to create something bigger and better. When Steve Jobs, for example, decided that he wanted to make an iPhone, he did not do it by himself. He created a team, he collaborated, he got all kinds of people involved. That was a big picture kind of thing.

Partnership is about collaborating with another individual or a small team basis. It is based on mutual interest, “you want this, I want that, so let’s work together on both of these issues.”

Alliance or Coalition occurs when members of one community understand the importance of developing allies with other communities. With an ally or in a coalition, you provide support for each other. Sometimes you come together to engage in action and sometimes you are doing separate actions.

Membership refers to belonging to an organization where you can jump in and start at the bottom. If you have never been involved in advocacy before, start at the membership level.

At the very basic level, you belong to ALDA. You are here. You are a member of ALDA. Maybe you are a member of HLAA. Maybe you are a member of another organization. Maybe you are volunteering. Maybe you volunteer for something like hospice. Volunteering is a significant first step after becoming a member.

Sherri has asked Heidi, who is recently late-deafened and a new member of our staff, to share her story about what it meant to her to become a member and to volunteer for our organization.

HEIDI:

I started wearing hearing aids in 2011. Looking back, how it all started for me, as far as advocacy, was that I did not have the comfort zone that I once knew. It was completely gone. I was not comfortable anymore. I did not know what to do. I struggled in my career. I had been working my way up the corporate ladder, when all of a sudden my hearing started to dissipate and rocked my whole world and threw me for a loop. What I did know about life though, was that I love to learn and that knowledge is power. I start looking at resources to help myself, because no one I knew, no one in my family had a hearing loss. I did not know one person with a hearing aid or anyone who was Deaf. I felt really alone.

The first thing I did was use my good friend, *Google*. I googled hearing loss organizations in the state of Arizona. I came across the Arizona Commission for the Deaf and Hard of Hearing. I sent an e-mail to the general information address asking about different resources, and Michele Michaels responded. She sent me a whole bunch of information at that time. (She still has that e-mail, the very first e-mail that I sent. When I look back, that was a desperate e-mail.)

This is kind of an interesting turn of events because the very first workshop I decided to attend was an advocacy workshop at an organization that we call Ability 360, which is for people with all disabilities. The workshop is about advocating for state legislation. Even though I did not really know much about state legislation, I decided to go because I wanted to open my mind to something different. And it was at that particular workshop that I sat at a table with another lady who happened to be hard of hearing too. We started talking. We were both in the workforce. She said that she was looking for other people who are like us, people who want to start a working adults group for the Hearing Loss Association of America. I said "I'm in" and that I would help her start a support group because I needed support. It was then that we started forming the Arizona Working Adults chapter of which I am President. And Michele and the ACDHH, have been a great support system for me in that process of leading a group of other working adults with hearing loss. That workshop was a changing point for me. It was not one huge leap. This was over several years and different contacts and networking. So, it was all about relationships and building a network at every level.

Two months ago, I started a new career at the Arizona Commission for the Deaf and Hard of Hearing. The place that I reached out to is now the place where I work. And I get to help other people every day.

It starts at a basic level of membership, that is where it started with me. You find other people who are like you, and then you move together. When you help others, you are helping yourself.

MICHELE MICHAELS:

Thank you, Heidi.

It was wonderful to watch Heidi grow and blossom and become such a wonderful leader in the community. That is what happens, when Sherri hires us. She finds us, hires us and she develops and grows us. And then we go out to make positive changes in the larger community. Plus, we get to be great role models! We love what we do. We are always accessible no matter where you live in the country. When you contact us, we will help connect you to your local resources.

Membership and volunteerism at a very basic level is important whether it is being a member of ALDA, HLAA, Hand and Voices, your local Deaf school, your PTA, or the area agency on aging. It could be the hospice group, your government's council on disabilities, or your mayor's commission. Whatever it might be, find a way to become a member, to start volunteering and to begin associating with other like-minded people because from there, you will grow. You will start creating those alliances with other groups.

Walk for Hearing, which is the HLAA event, creates alliances with other groups to support the walk, and also to raise awareness. In Arizona, we have the Arizona Disability Coalition, which is all of these disability groups from autism to special needs kids, to TBI (traumatic brain injury). All of these groups come together once a month and they talk about what's happening on a federal level and a state level and they create calls to action. We go down to the capitol together and advocate for things. We have to show up and be counted. If you are scared to try showing up on your own, you can become a part of an alliance group or a coalition where you have strength in numbers and where you can lean on each other and learn from each other.

You must care about what others care about, though and not say, "okay, I'm here and this is what I need and you need to care about me." It has to be a mutual give and take. "I buy into what you are doing, you buy into what I'm doing. We each have a time and a place at the table."

SHERRI COLLINS:

I want to share. When I first moved to Arizona 20 years ago, and started going to different disability events, people had no idea who we at the Arizona Council for the Deaf and Hard of Hearing were. We had not been physically active in these events. I encourage you to be part of these events. Even though you may not share a common interest on specific issues, other groups will support you, if you become an ally with them. Our responsibility is to go out and be part of their community event, to be part of their support system. It took me several years to build relationships. I did not simply show up and make changes. I built relationships. When I did that, people began to recognize the Arizona Commission for the Deaf and Hard of Hearing.

MICHELE MICHAELS:

Partnership: I think becoming a partner is a lot like dating. First you become a member, and then you start dating the allies and coalitions. You

start figuring out what they like, and learn new things about them. And it gets more serious, and then we do this partner thing. And maybe we will get married, or collaborate. When we collaborate it can be like we are going to have a family. It just grows and grows.

Partnerships are about equality and obligation to each other.

Here are some examples of partnerships I am involved with.

Alzheimer's Association of America

One of the partnerships that I am engaged in is the Alzheimer's Association in Arizona. Why? Because people with untreated hearing loss get dementia earlier than others. So I have been showing up at meeting after meeting with my copies of the research of Dr. Frank Lin that shows a connection between Alzheimer's/dementia and hearing loss. The people in the group started learning about this. They were not aware of it until I started saying it.

Arizona has a Governor's Falls Prevention Task Force We know that older adults fall and when they fall and break a hip, half of them die. It costs the State of Arizona \$60-100,000 in hospitalization costs. This task force did not know that people with hearing loss fall more often. People who cannot hear often have balance issues. They fall more. When I attended meetings saying "hey, falls and hearing loss, falls and hearing loss" over and over they finally realized that what I had been saying is actually true.

Fire Departments/Smoke Alarms

Most fire departments give out free smoke alarms. Those are the \$20 ones that work great for hearing people. Deaf and hard of hearing people need the smoke alarms that light up and vibrate. I have gone to firefighters and the conversation has been something like this:

>>Me: Is my life worth any less than that hearing person? Do you want to pull me out of a house dead or burned up?

>>Firefighter: No, ma'am, we don't want to do that.

>>Me: Well, then why don't you get me a smoke detector that I need for free. I know it costs more. But why don't you do that?

>>Firefighter: We don't have the money,

>>Me: Let's find a grant"

I knew that the International Firefighters Association has grants and I wanted to help lead the fire department to a grant. You have to be ready to help them help you. Here are some other possible partnerships.

Domestic Violence Prevention Groups

We know that deaf women are abused more frequently than hearing women. It is sad, but they are abused and controlled more their hearing partners. We cannot allow that to happen. Maybe you could get involved in groups the deal with domestic violence.

Senior Centers

They are everywhere. All of these older adults have hearing loss but they do not know what to do. These \$30 “devices” from a magazine do not work so they throw them in the drawer. You could go to the senior centers and start volunteering to be the hearing loss advocate. There are lots of things you can do, so consider partnerships with these organizations.

Collaboration

Collaboration is about the bigger picture. Collaborations take time and are often slow. People sometimes criticize government but there is a reason for the red tape. Government must check all the boxes, make sure the public is aware, and follow all the rules. In the end, it is your money that government is spending. As government officials, we have to be very careful and methodical, and it takes time. If you want your council or division or department to do something (if you want a specific product included on the phone program for example), then that could take two years. There are requests for proposals and personal service contracts and all kinds of things that have to be developed to ensure that every vendor has equal rights. There are reasons why government is slow.

Even bigger organizations like the Red Cross, receive a lot of criticism. (Think of Puerto Rico). The Red Cross is a big organization and it may not be moving as quickly as it should but these things take time.

Here is a list of ACDHH collaborations:

Independent Living Center

Protection and Advocacy Center (PNA): The legal center that does protection and advocacy for people with disabilities.

Emergency preparedness: When it comes to emergency preparedness ACDHH is out there and involved. I have been a dirty bomb victim, a plane crash victim, an evacuation person and have been given anthrax (the placebo medication), I have been at these emergency preparedness drills saying, *“what about us, what about us? What are you going to do? How are you going to communicate with me? I'm deaf, where is the interpreter? I'm hard of hearing, do you have CART? What about the service dog, you ain't taking this dog from me.”* We are out there at all these different events.

This is the point at which I like to open it up to find out about any successes or challenges that you have had in your state. Share something you are doing or thinking about doing or something that you did do, that you want to share.

AUDIENCE MEMBER #1:

I'm involved with the Illinois Association for the Deaf. My role is dealing with senior citizens and states. I reach out to as many states as I can to get educated about what other states are doing for people who are older and transitioning from work life to doing what all we old people are supposed to do. Are you guys aware of the Illinois commission and the issues?

MICHELE MICHAELS:

Yes.

AUDIENCE MEMBER #1:

Is there anything that we at IAD can do to try to help boost our commission so that we can bring it to respectability, because what's been happening with the state is really sad. I am open to all kinds of advice so I can bring that back to our president and try to get more involved. Thank you.

SHERRI COLLINS:

In response to your second question, I will be very brief. I would prefer to talk privately, on the Illinois commission issue. I have been in contact with your president. Just so you know, I am from Illinois. I am aware of your commission issues. Concerning the seniors part of your question, there is a whole list. Michele will answer, she mentioned her involvement with area council on aging, she can talk about their five-year plan.

I want mention a new development that I was successful with this year because of HLAA's position on the "Over-the-counter Hearing Aid Act." Arizona opposed that. And we were very vocal. We are not opposed to purchasing hearing aids; we are opposed to some of the issues that were in that bill. We decided to take a proactive approach because we wanted a conversation to start. We wanted to get people to pay attention. Do not listen to everything that's happening on a national level in any organization. Do not believe that it is right, because the organizations do not check with the state for their input. HLAA did not check with their members for their input on that position. I am going to be very vocal about that because it's a fact. So, we reached out to the Arizona AARP because they support AARP on a national level to support the "Over-the-counter Hearing Aid Act", which is the bill that passed in Congress. I want us to build that relationship, so I reached out to them and I met with their lobbyist. We were very successful partnering with them. I told them we want to be proactive about educating people about getting their hearing checked and they agreed.

What ACDHH wants to avoid is individuals self-dealing with their hearing loss. That was the whole point. We want to encourage people to get their hearing checked. As of yesterday, I was checking my workshop e-mail, AARP wants to do an educational article about hearing loss in its publication. We are talking about over 60,000 members in the state of Arizona.

I'm going to turn this over to Michele. She can kind briefly answer some of your questions.

MICHELE MICHAELS:

I started with the Area Agency on Aging. In the U.S., every single place in the country has an Area Agency on Aging. It is a wonderful organization to get involved with. It is not just about older people. It is about people with disabilities too. I have gotten a lot of things done. For example, every single skilled nursing facility and assisted living facility in the largest county in Arizona, where 4 million people live, now has a nursing station with a document that talks about hearing loss. I got that accomplished through the Area

Agency on Aging. Also, the Governor's Council permanently posted a document which I developed on their website. It is about fast facts and fast resources.

AUDIENCE MEMBER #2:

I noticed you have not mentioned much about deaf and hard of hearing children, and the language.

MICHELE MICHAELS: I failed to mention what we are presenting here today is mostly concerning the hard of hearing and late-deafened. I have a whole other hour on the Deaf part including language acquisition, the new-born hearing screening, interpreter licensure, educational interpreters. That is a whole other topic. We also have not talked about our effort with the deaf-blind community.

AUDIENCE MEMBER #3: I just wanted to share a story of advocacy. In 2008, I joined the Aging Advisory Council for the county. It is a citizens' advisory board that advises senior citizens. I was the first openly hard of hearing person to serve on that board. I decided to volunteer because I was terrified of going out alone. And I also wanted to represent hearing loss issues because I was not sure that they had information. The question that I kept asking by my very presence on that board was, if one-third to one-half of your target audience has a hearing loss, how are you adapting your programs for that? I call it my devil question, because everyone got this incredibly guilty look on their face when I asked that. It is appropriate though. I served on that board for two three-year terms. (I was term limited and had to quit.) In those six years, by being in the room, every single month, I got captioning. That cost was enormous. I went to committee meetings. They bumped the cost up to the county commissioners to get it out of their budget, so everybody was happy. By being in the room, people started to look at me when an issue that might impact hearing came up. I said I cannot hear on the phone. They were doing this aging and disability research database thing and were calling it "one call does it all." Well, one call does not do anything for me. I have to go through a whole process to make one call. Again, I said "for people with hearing loss, how is one call going to help us?" They thought about that and changed its structure from it being a phone-based to an internet-based. Towards the end of my tenure, the state got extra money, so we got the county's money. We had \$60,000 that they had to spend in two months which was too short of time to set up projects. I raised my hand and said how about assistive listening devices for deafened people. We used the money and we bought seven sets of FM systems for the senior centers plus an extra set as a floater. Anybody with hearing loss and without hearing aids could go to the senior center and request these systems. Now they are putting it in all the catalogs. So, this is one person, scared of her own shadow, sitting in the room for six years and being a persistent reminder that we exist and we never stand up for ourselves. But if one of us does, it means something has happened.

MICHELE MICHAELS:

That is wonderful! Good job.

AUDIENCE MEMBER #4:

I just wanted to say that, regarding short term advocacy, I showed up to some advocacy at the convention center in Dallas, where they had a big shelter of 5,000. I was able to get four major manufacturers to donate brand new hearing aids to anyone who had lost their hearing aids in the flood. And the audiologists also donated their time.

I went to the Red Cross and I said I have all of this, can I have a table to go in and do it? They said go see him, go see him. Three days I was running place to place trying to get into the shelter, offering free things. Finally, I got in contact with a medical doctor, and he said I will meet with you. He said we would love to have you here. This gentleman will show you where you can put a table. The gentleman takes me out in the room and said I do not want you here, and refused to let me put the table up.

I did not give up. I went back and called the City of Dallas that actually hosts these shelters. They said I could be in there and I was in there a couple hours later. As a result, an 18-month-old baby and several adults were able to get brand new hearing aids replaced in the space of about five days before that shelter was closed. That's my short story, but very touching and I met some people that still need help. I did not give up.

AUDIENCE MEMBER #5: Michele, you mentioned doing an event, I think it was with emergency employees, and you said you fitted them with ear molds so they could know what it's like to be hard of hearing for a day. How did you do that?

MICHELE MICHAELS:

What happened was, about three years ago, when ALDA started planning their ALDAcon 2015, which was in Scottsdale, Arizona, an ALDA member suggested hosting a panel of hearing people, such as athletes or whatever, who would get to be deaf for a day. There is no way to actually deafen someone for a day, but there are certainly ways to make them hard of hearing for a day. ALDA approached the ACDHH, and asked can you do this? Can you make this happen? And we pulled in our PR firm, and I had a contact with the lady who runs disability services for the Phoenix Sun's basketball team and the Phoenix Diamondbacks baseball team. We used our connections and we got Gonzalez, the Diamondback player, fitted with an ear mold. We followed him as he tried to order a pizza at the food court and stuff. We also got a basketball player, a fire department captain, and a newspaper reporter. We got two audiologists to make the molds and stick them in their ears to block the sound. The reporter, couple months after the event, wrote a huge article about what it was like to be hard of hearing for a day. We used our network and connections and our PR firm and got them to show the video at ALDAcon. The panel was on Saturday and it was open to the public. It was very well attended; it was really, really successful. If you want to do that again somewhere, just contact me and I will walk you through exactly how we did it.

This is my method: it's called the BEE method. We have honey bees out there, collecting the pollen, we want to be the bee that makes the honey, makes things sweeter for everybody. How do all of us do that? Basically, by always being courteous,

polite and persistent when advocating. We do not go in arguing and being angry. All of us, as we deal with our hearing loss, the initial part of our journey often means grief and sadness and frustration. Do not dump all that on people. Deal with all that and then go in and be courteous. Educate yourself like you are doing today. You have to be educated before you can educate somebody else. You cannot teach something that you do not know.

When I deal with ADA Title III public accommodation complaints at the agency, most of the time what I see is that people just do NOT know any better. They really don't know. They have never been asked, they have never been approached, they are not sure what to do.

So, educate them and explain. Tell them "I'm hard-of-hearing and I wear hearing aids that have telecoils in them. That's why a headphone doesn't work for me. But there's this thing called a neck loop and it works just like a headphone, but it doesn't block my hearing aids." And then you can talk about the ADA. Expect some resistance though. Initially, they might be, "oh, we don't know if we could do that." There might be a little resistance, but do not worry about the resistance, just keep being courteous and polite and educating and asking. Be patient. Request specific accommodations like captioning, then explain to them about captioning or give them a brochure.

What are the openings that we have? Be willing to compromise. We are not getting everything we want right now, but we will get it soon. Be positive, all of these are bee, bee, bee. Bee positive!

Thank you for listening to me today. I appreciate the time that you spent listening to my concerns. I know that pretty soon you will be able to make change and help me and a million other people in Arizona who are hard of hearing.

Document everything! You have to document, just in case. You do have the law on your side. You could always contact your state commission, but very last thing you ever want to do is go the legal route and file a complaint or a lawsuit. If you do all these other things, most of the time you won't even have to file a complaint or a lawsuit. When it happens, though, we often win. Every one of these lawsuits in Arizona, California, AMC, the Arizona Cardinals we won - every single one of those lawsuits, and now we have captioning at every one of those events.

Another example: The musical instrument museum was my first legal complaint. They spent \$250 million building this in Scottsdale; it's amazing. I walked in, no accommodations for the deaf and hard of hearing at all. Now they welcome service animals and that is because of my advocacy.

At Celebrity theater, Sherri Collins filed a complaint because they would not make access for her with assistive listening devices. They do now.

Butterfly Wonderland, these are all examples of where we did go the legal route. We

filed a complaint, we won, and accommodations are there.

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AUDIENCE MEMBER #6: I am really hoping that you and Sherri seriously think about making a proposal for next year's con to do a half day or full day training, because all of this is wonderful. We are just getting our toes in the water, and I think we are ready to jump in and get involved on a state level.

MICHELE MICHAELS: Thank you so much.

Sherri Collins is a nationally recognized advocate for the Deaf and the Hard of Hearing. She became the Executive Director of the Arizona Commission for the Deaf and the Hard of Hearing (ACDHH) in 1998, where she is involved in advocating, strengthening and implementing state policies affecting deaf and hard of hearing individuals. She has served on the boards of several national and local hearing loss organizations. Sherri has a Bachelor of Science degree in Child Development from Gallaudet University, Washington, DC. and a Master's in Education in Adult Education/Organizational Development from North Carolina State University

Michele Michaels is the Hearing Healthcare Program Manager at the Arizona Commission for the Deaf and the Hard of Hearing (ACDHH). In her role at ACDHH she manages the Hard of Hearing Program providing assistance to over 1 million hard of hearing Arizonans. As a passionate advocate for persons with hearing loss, she provides outreach, education, training, resources, empowerment, information, and referrals to Arizonans. She serves on several boards and councils. She holds a BA and CPM from Arizona State University. She is hard of hearing and a member of ALDA.