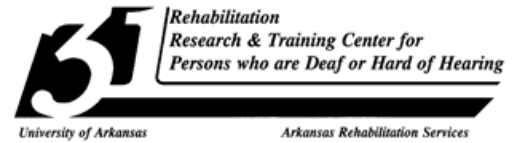




Selected Proceedings of ALDAcon 2005



A POPCORN COALITION

Presenter: KATHY EVANS

KATHY EVANS: I am a member of the Utah Popcorn Coalition. And I am thrilled that we are here today to talk to you about what we have been doing. We have five members of our coalition. I'm going to let them introduce themselves. The thing that's unique about our group is that we each represent a different organization for the deaf and hard of hearing. And we have learned to work together to respect our similarities and our differences and to learn that how we communicate is not as important as that we communicate. Does that sound like ALDA? You know, it's good.

We all enjoy it. I represent SHHH on the popcorn coalition. And as such, I need to keep in mind the particular people that are in SHHH—those with less hearing loss than ALDA, those who still use assistive technology. I represent many aging people. The people who have no acceptance or idea how to handle their hearing loss. That's the group that I represent. And hopefully, we help them become more accepting of their hearing loss and better advocates. In the meantime, I need to be sure that those people's needs are not forgotten as we meet in the coalition.

I'll introduce you to Ron Nelson and Ron can tell you about his group on the Popcorn Coalition.

RON NELSON: My name is Ron Nelson. And I represent the Utah Association for the Deaf. Our organization includes people who are Deaf, who use sign language. They are culturally Deaf. They have a strong belief in the culture in the coalition of keeping each other and passing on our culture, our language and our traditions.

LINDA LEWIS: I'm Linda Lewis. I represent our ALDA group here in Salt Lake City. And, of course, we have a little bit of everybody in our group. The nice thing about this particular coalition is that we all can be a little bit like the ALDA group here. We have signers. We have just everything you can imagine for the group.

EMILIE BURROW: My name is Emilie Burrow. I'm the representative of Cued Language Network of America. Our organization consists of a little bit of everybody

else as well that are hard of hearing and teachers and professionals and who use the method of communication of cued languages.

ANN LOVELL: Hi. I'm Ann Lovell and I'm here as the representative of the Alexander Graham Bell Association of America for the deaf and hard of hearing. One of the things that we do is advocate to the hearing that you do have and learn to speak.

KATHY EVANS: For a long time, our organizations didn't interact. We were very separate. And we found as leaders that we can change that. I will ask Ron to fill us in on the history.

RON NELSON: Let me go ahead and begin. I guess about four years ago, in the year 2001, Utah association of the deaf, the board, we got together and decided we establish our priorities with the board. The board's first priority that members established to improve hospitals. The second priority is the coalition. The members felt strongly during that time that we all come together with other organizations and we realized, over the year, that we were not able to if alone, able to go to colleges, to the legislators, were not doing all these things alone, that people had the right and that was very difficult and our numbers were very small.

During that time, we all got together with some other organizations for more split call political power. There are only 1.8% of Deaf people in Utah. That's a small number. There may be 22,000 hard of hearing people (8.3%) in Utah. If we can come together and work together, we would be able to represent 10% of the population of the people in Utah. That gives us more political power.

I think I remember several people's names and phone numbers and exactly how to get into contact with SHHH and ALDA, and how to set up a meeting and how we could come together. At first, I was a little nervous because, during all these years, organizations have never come together and discussed things. This would have been the first time. I don't know if Kathy, you know, was as nervous as I was, but we did it. We met together at the Deaf Center with an interpreter. We found it very enjoyable. It was very pleasant to speak and talk with Kathy. She was not angry, so I was very relieved. And when we began our discussion, we realized very quickly that we had many issues that we could work together if we put aside the way we communicated and focused on the issues. Such as public accessibility to music, to movies, to the TV news, to colleges, we had the same issues. The issue was accessibility and that was a frustrating issue.

One of the rules that we established was if you wanted to join the Popcorn Coalition, you had to enjoy popcorn. It shows the dates when each organization joined the coalition. The five of us, we met for about two and a half years. It was very successful. The attitudes were positive. You would never see us get angry or mad with one another. You know, we never really disagreed on anything. We could all look at the

different perspectives. We would have a good discussion. And we worked together very well. There are not any lazy people up here.

KATHY EVANS: Thanks, Ron. The first issue and the one that is continuous before us is to bring more captioned movies to the state of Utah. What we had to do was telling some of the problems we had setting up. The major problem was communication. We had a need for an interpreter. And there was only one problem: None of the organization could provide an interpreter because we really did not have the funds to provide it.

Thank goodness, the Sanderson Center supported us in this particular option, so they provided interpreters for us, whenever we needed it. We had to work around their schedule, but that's okay. They also had to work around ours.

MARILYN: I want to add that in other states, the commission for the deaf and hard of hearing also provides interpreters.

LINDA LEWIS: We really appreciate that. Kathy didn't know sign language well enough to even communicate. Ron was very good at it, but it was hard for him to understand us and vice versa. That's why we needed the interpreter. When Ann came on, she knew sign language so it was not really a problem there. Just to let you know, there are two of us with cochlear implants, two with hearing aids, one who knows cued speech, two who know sign language and then two who know only a small bit of sign. That's kinds of the makeup of our particular group. Now, oral and sign language for a long time, were given a kind of a division. When I first came back to Utah from Washington, D.C., I noticed that the oral people did not want to have anything to do with signing and vice versa. That's what happened when Ann came on. AG Bell is very good about the approach to teaching oral people in that viper. They didn't want to teach sign language, but they started to pick up sign language because of her work at school. Emilie is somewhat interesting. She picked up sign language when she was a little bit younger. She knew sign language because of her friends. But she had difficulty getting transliterators, sometimes, and, sometimes, she had to depend on a particular interpreter for what was going on. In the cued language area in Utah alone, there were only about 16 families. So there weren't many translators. It was very hard to get.

Another issue was that we had to limit the group and the associations that were part of the group. One of the groups we had to limit was the deaf-blind group. First, we could not afford an interpreter for them. Second, since they really could not see captioned movies, which was the first issue we were working on, we didn't think it was really a viable group for them to be in at that particular time. There are other issues that they could work with us on, but the problem is they really need to get an interpreter for whatever representative they bring to this particular group.

Another thing, we refused to have anybody from a government organization in the association. We did not want to be tied down to somebody saying, you can't do it. It's

nice to be able to have the backing of our own group without the government organization saying, hey, I can't support this. We have been able to be a good influence for a lot of the facilities that we have contacted and visited, because we don't really have the power to say, you can't do it or I can't do anything about this particular thing. We feel as a group that we are being able to exert, empower and say, "Hey, we need this, can you help us?"

The other problem we had, all of us in our group are movers and shakers of our particular organization. We are so busy that we don't always get time to get a lot done. We have a big problem getting meeting times, because we have to work around everybody's schedule. Many of us work, take classes, have other responsibility, family, and are busy in our own organization.

EMILIE BURROW: I will be talking about our mission statement. Our mission of the Popcorn Coalition is to be able to help every person in the deaf and hard of hearing community, regardless of communication methodology. It does not matter if you read lips. It does not matter if you use ASL versus Contact sign or cued speech. It does not matter. Our point is to be able to help every single one and it does not matter what community, organization you belong. We want to be able to help who we can with this. However, we cannot provide the services ourselves. We don't have the money to do that. We are a volunteer organization. But we can help point you into the right direction of where to go and we can help give you numbers for movie theaters or other places and new stations and so forth. If you have problems or you want to adjust, we can start working on it to help all of the organizations have a voice in everything. And that's our mission statement.

Our vision statement is a little bit different. Our mission statement is what we're going to do to accomplish our vision statement. We hope to be able to strengthen advocacy and community relationships as a means of improving and increasing services and support for individuals who are deaf and hard of hearing. Our vision is to bring all the organizations together as a community so that everyone can help each other out.

KATHY EVANS: I want to add one thing to Emilie's statement. We decided we needed a mission statement because we had people asking us to help with things that were not part of what we thought we should be doing. So we finally realized we needed a focus and that was hard for us to do. But it really pulled us together, too.

This is an example of what we do. We wanted more captioned movies in Utah. At the time we started, there was one theater that showed a movie two nights a week, roughly once a month. We wanted more. But we realized that we were a small audience and small audiences don't get their way. We started pulling together some ideas for how we could get our audience a little bit bigger. Our first problem was simply that deaf and hard of hearing people don't go to the movies. It's not a habit we have. So we needed to educate our people and we needed to help the theaters not have such high expectations of 80 people at every showing but to help them realize that their good will

would help build the audiences. A lot of deaf and hard of hearing people did not know that there were even captioned movies available. They didn't know that the theater experience was an option to them.

One of the big problems we ran into was that we could not find out when the show times were. If you didn't know the specific movie, it was so hard to look up in the paper. You had to read every single ad to find that little symbol that indicated a captioned movie. You could not call the theater because they have those horrible voice response systems that don't work with anything. We knew we had to get away from that.

The theater was not a particularly friendly environment for us. The lights were down, we could not communicate with each other. Captioned movies were only shown on weekdays as if we had nothing else to do like school to prepare for or work or anything the next day. So what did we do? We established a website where we list all the captioned movies coming. And everyone in Utah who wanted to look at it, could. We established an E-mail group for people who were interested and we sent them a weekly E-mail to let them know what's playing that coming week.

One of the advantages of that E-mail list is that we can see how many more people we are reaching. We started out with just a few. I remember when we celebrated because we had 100. And then we kind of let 200 pass without noticing. We are at 400 people. We are over 415 people. You know, we've made a difference. And our audiences are growing. And we are excited about that, but the listserv has helped us kind of keep track of that growth.

We created flyers and passed them out in different places, especially our organization meetings. We invited the theater managers to come to one of our Popcorn Coalition meetings. That helped. We need to do more of that. One of the theaters has a big turnover in managers. But we also found that the man who was over these two theaters in Utah was really sensitive to our needs and he is telling the managers what to do. And that has really helped a lot. We have also become familiar with Insight Cinema and with Carmike, which has two of its theaters in Utah. We have learned to advocate and ask what we want. They know us. They will hear more from us next week unless they have added more movies in October. We keep writing them and they responded. It's been wonderful.

There was only one theater in Utah showing them. And I'm not sure that we were particularly influential in making this change. We found the theater managers, as a whole, were really, really not able to see a potential in the audience. Plus the populations in Utah is largely a rural one. There are not a lot of pockets of deaf and hard of hearing people. There are a lot that are scattered, but only a handful of cities that have enough to really demand the theater do it. One of the big problems that we've run into is that the theater might share the profit for those who provide the captioned movies. We had one big theater owner in Salt Lake City who was negotiating to do it,

but he was not willing to share that much of the profit with Insight Cinema, which was unfortunate, but it fell through. We never did pick that one up.

We have had people in other Utah cities who have said, we want captioned movies, too and we have one person that I think is going to make it happen. We'll see. She contacted me at the time, but I was really getting busy on this convention. I got her in touch with the people she needed to talk to and I'll follow up. Give me a few more weeks and I will be in touch with her again. We do have someone talking about installing rear window captioning that could happen in 2006 as they build a new 20-theater megaplex. We'll see what happens there. The five of us are not excited about rear window captioning, but it's probably better than nothing at all.

AUDIENCE MEMBER: Would there be more movies available? How does rear window work?

KATHY EVANS: Rear window captioning gives you the option of having captioning on every movie that comes to town. You have a reflective plastic shield and there is a second projector that runs with the first. The second one shows the captions on a screen in back and your reflective shield picks that up so you could go with your family. You would see captions through the screen through that shield that you have as you look at the screen and your family would not see captions. It's a huge advantage that way for the movies that have that, and it is growing quite a bit.

AUDIENCE MEMBER: So you would have a lot more movies available to see?

KATHY EVANS: I think so. Do any of you live where there is rear window captioning?

AUDIENCE MEMBER: I live in Colorado and we have two theaters that have rear window. I love it, because I can go to any movie during the week. I hate being told that I must go at 4:00 on Tuesday. I hate that. Now I have my choice. I can go to the early movie and save money or I can go to the late show. I can choose any showing.

KATHY EVANS: Yes. You know, we'll see what happens as that grows but we have been in touch with them. They know how much we wanted. We want something from that theater, which is a big chain, and it could make a big difference.

We also look at the fact that the generation coming up is not experiencing movies. The movies were shown on Tuesday and Wednesday. We did manage to get them to always show them at 4:00 and 7:00, which has been wonderful. But these children with school the next day were not getting the movies. We have just recently started getting the theater to show one family-oriented movie once every month or two on a Saturday, which, to me, is a huge step forward.

With the school year just starting, we will be starting a big promotion to get those children here, just what that promotion is has not been decided. But at our next

meeting, that will be a big part of it. We did consider foreign films. We listed them for about a month. Didn't really get any feedback and realized that it was a chore for us to find out about the foreign films. The theaters were not working well with us. We could not guarantee any kind of quality on the captions. And when we dropped them, no one said a word so we don't do foreign films anymore.

We are not alone. There are many coalitions for movie captions. There's one on the national level with our organizations working to the. Cheryl Heppner is part of that. We get ideas from them and consider where they are going and plod our way the same. We've also found that in our individual organizations, there is a lot of discussion about it.

ANN LOVELL: What we found out, as part of that Popcorn Coalition name, people know who we are, and they are requesting to meet with us. One of the first groups we had was the Utah Department of Health, talking about getting captioning on announcements about the West Nile virus. Also, our goal there was we wanted to build a connection because one of the things that we talked about as a coalition is advocating for a rest home for deaf and hard of hearing patients to be stationed and that was one of the reasons of us wanting to have contact in the department of health.

The other thing that we have done is we have had our action center at the Sanderson center. We have talked to him about hospital access, increasing accessibility for hospitals. And Kathy has chaired from her group a hospital kit that they could use in the hospital to make it easier for them to let all the different workers in there know what they need. We have also spoken with the adult education director at one of our meetings and talked about some of the classes that we thought would benefit people in our different populations.

We had ADA compliance specialists and patrons services managers from Salt Lake County come to our meeting, wanting to talk to us about accessibility. The Church of Jesus Christ of Latter-day Saints has a big presence here and has a lot of programming. We met with them. One of the things that we were trying to work on was to increase accessibility at Temple Square and at the conference center. We were trying to get improvement to that accessibility by the time of this conference so that those of you who could be visiting could reap the benefits of that. We also talked to them about improving the captioning for the Mormon Tabernacle Choir and other shows. We talked to them about putting DVDs with captions with the periodical that they have, called the Ensign Magazine. Here is one area where it didn't matter whether any of us were involved in a religious group. We were not government agencies, we were consumers and we could advocate for something that could benefit many people out there.

We met with the local PBS channels and they have been doing a fantastic job of captioning, but they were not advertising that their shows were captioned. We had people that were not watching their program because it didn't show that they were captioned. So we encouraged them to make it so it can be seen by other folks that these are captioned shows. We also met with the Western Region Outreach Center and

Consortia Outreach. They wanted to feedback on how they could communicate with us on areas that they could work with.

We have been concerned for a long time about captioning for emergencies on TV. We have noticed in recent times that different states have actually sued the TV stations for not showing caption for emergencies. The FCC has been reminding the states that they are required to do that. We had a town hall meeting with all of the different organizations invited to attend, and we had relatively high representatives from most of the TV stations, such as news directors and those who were in management position. That was very enlightening and built some areas that we could keep contact with.

We did HUD authority. We were trying to look into what it would take to have a nursing home where deaf and hard of hearing people can be so that they are not in separate homes all over—they could all be together and not be isolated for communication reasons. We have talked with them, but the woman talked so fast in business acronyms, we were completely confused. We had talked with the Department of Public Safety Communications Bureau. We also publicized the Popcorn Coalition in various newsletters. UAD put it in their newsletters. The Utah School for the Deaf and Blind has a newsletter called *Sights and Sounds*. The A.G. Bell Association also put it in their newsletters. We did a lot of things to make people aware.

AUDIENCE MEMBER: I wanted to let you know something that you may not be aware of. And for those people in the room who don't quite know who I am, I am the director of the Gallaudet University Regional Center at Ohlone College and as that director, I also run the Gallaudet University Western Regional Academic School for Deaf and Hard of Hearing Students. U-A D and U.S. D B and the Sanderson Center all worked together to be host for the academic bowl to be held next February.

I want to tell what you the impact of what you did had on the academic bowl, not just in terms of volunteering in the actual event itself. But when we were trying to decide what to do for the kids, we talked about all kinds of different things and Ron mentioned that there are captioned movies at a theater that is right near the hotel where we stayed. I looked on their website and their website had a link for the captioned movies. And, darn, it was not the same week that we were there. So I thought, well, okay, let's find out who sends their movies? I found out that it was Insight Cinema and contacted them.

I sent one E-mail and the guy said, "Sure, we'll change the week. What movie do you want? Pick one." So, I got to pick the movie. He asked what day of the week I wanted it shown. I picked Wednesday, because that's their free day. I don't know how many people from the academic bowl went to the movies Wednesday night. I hope somebody did, but we advertised it. But what I want to let you know is that all the work that you did made it very, very simple for me to put in that request. I was really surprised. You guys did a great job with that.

AUDIENCE MEMBER: I had a question on the technology with the rear window. Is that something that has to be put in when the movies are built or is that something that can be added maybe later?

AUDIENCE MEMBER: It's a system that I believe costs about 10,000 to install at a theater. So, that's a limitation, because theaters maybe don't want to spend that money. But the other thing that's really cool about it is that it comes bundled with accessibility for blind people. Audio description.

Does anyone know about audio description for blind people? You rent a headset and you get a tape. On the tape, there's things like, man opens door and he sees a green meadow outside. It describes in words what's happening visually on the screen. So blind people, they can go to a movie with blind or low vision and they have things described interspersed with the dialogue. When movie theaters buy the system, they are simultaneously committed to making it accessible for blind and deaf people. I think that's really positive. I work with the disability group in Colorado, and that means we can go to the movies as a mixed group with blind people, people in wheelchairs, people that can't hear and walk and talk and do everything. And we can all go together and see the same movie and then we can discuss it afterwards if we can communicate. We are all different and we are there in the theater with the hearing people, too. It's really cool. I like that. So that's one of the requirements with rear window—they have to buy both. You can't buy them separately.

ANN LOVELL: One of the reasons why I think some of you looked at us a oddly because we were saying we weren't very excited about it. Basically, none of us have any personal experience with it. We heard from other people and some people have talked about how it's hard to see and you have to get low and crane your neck and it sounds like this woman here has more experience with that and it's okay. We can definitely use feedback on that. We have a chain or a theater at one of our malls that has it for the blind but not for the deaf. And we've talked to them. They said it would cost too much or something.

KATHY EVANS: They said the blind audience has not been very big and we don't really want to put the money down to expanding. Their idea was to do one or the other and I contacted them to remind them they had not done the other yet. They are the ones that are planning to build a new theater in another part of the valley and said, when we build this new theater, we'll put it in. I'm going to keep reminding them.

I want to explain something about the interpreter for the deaf and blind. In Utah, the financial responsibility for that has been given to the organization. They get their services from the Blind Center. So, their interpreter needs to be provided by them and their response was, well, let us just send one of our staff members. We said, no, that's not how we work. We want the people who are being represented to have the voice on the Popcorn Coalition. And, so, because the responsibility for the interpreter lies

elsewhere, the Sanderson Center could not help us with it. It's kind of stayed up in the air and has never materialized any farther.

AUDIENCE MEMBER: Some people in other states put together a coalition like what you've done using you as the model. Do you object to that group being called the Popcorn Coalition? Would that be okay?

KATHY EVANS: No, I'd be honored.

LINDA LEWIS: We are called Utah Popcorn Coalition.

MARILYN: I just want to say I think you guys are doing a fantastic job and some of the projects you've taken on, like you say, it's very hard for a state agency to take on. I can't imagine that in other states, their commissioners would not just be thrilled to see this happen in their states and then be very willing to have the resources there. I think to support the communication for all these organizations to get together, just makes sense. It makes everyone's job easier and to not have groups fighting. I mean, things have changed so much now in the 13 years I've been there where I know when I started to work there, people said, don't you let those hard of hearing people start coming in here. You guys are doing a great job and I hope you go on forever.

AUDIENCE MEMBER: When you talked about improving hospital access, specifically what issues were you looking at? What issues did you want to improve in the hospitals? What kinds of things did you target?

KATHY EVANS: One of the things that we are concerned about is the staff sensitivity to the issues involving having a patient who does not hear them. We just hear the horror stories of deaf and hard of hearing people in the hospital who missed their pain medication because they seemed to be sleeping so soundly, they didn't respond when their name was called. You know, things like that. The hospital staff needs to understand. Ron, UAD has had a lot to do with this since we last tackled it with the Popcorn Coalition. Why don't you add to that?

RON NELSON: The five of us on the Popcorn Coalition did meet with someone from the government or someone at the hospital. When we talked to them that we had 10% of the population in Utah with hearing impairment, it was funny to see their eyes. They started to look at the numbers and multiplying in their head and realized they really needed to listen to us. The Utah Association of the Deaf has set up to focus on the needs of the deaf and hard of hearing patients in the hospital. Last year, we had deaf families sue one of the hospitals for not providing an interpreter in the emergency room when their daughter was brought into the ER.

A little bit before that, an attorney had moved to Utah from Boston and he was a very proficient signer and he was also an interpreter for the Sanderson Center. We were fortunate to have the attorney here and we were able to use him a lot. Right now, he is

working for the Utah Association of the Deaf and also for the hospital in Utah. We began a discussion based on policies, access, accessibility and that maybe was on a Wednesday that we all met. We had a lot of hope for that meeting. We hoped there would be many benefits and the hospital would begin to consider the policies. The Utah Association of the Deaf continues the meeting and we hope that the process will continue and it will also meet the needs of the people who are hard of hearing. I know their needs are a little bit different than ours.

AUDIENCE MEMBER: I know, down in southern Utah when they opened the new I-H-C hospital, there had been a kit developed from somewhere. I know Kathy was involved with it. If a person has a hearing problem, that is flagged immediately and they get a kit to make sure that the staff and everybody knows. Color coding, and there's things put on the doors so they know that that person in that room is either deaf or hard of hearing. Many times, maybe the nurse does not know. That's one of the things they do when a person is admitted. They try to find out that kind of information and then they will have that and make it part of that person's file so that everybody knows the condition of that person.

Kathy Evans, Emilie Burrow, Linda Lewis, Ann Lovell and Ron Nelson are leaders of the Utah groups for SHHH, CLNA, ALDA, AG Bell and UAD, respectively. All have different kinds of hearing loss and different preferences for communication accommodations, but have chosen to work together on many issues to make changes that are beneficial to all D/deaf and hard of hearing people in Utah.