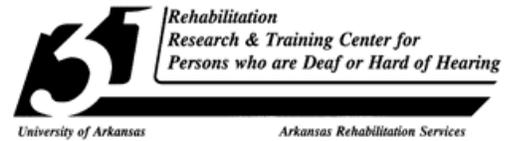




## Selected Proceedings of ALDAcon 2005



### **ADVOCACY**

Presenter: ROY MILLER

I'm delighted to be here to talk about one of my favorite subjects, and that is "advocacy." But first I want to share with you a little bit about different hats that I have worn. Back in 1992, I was selected as the second president of ALDA. I was privileged to be involved with ALDA as an officer in the very early years when we were doing things like creating all of the awards that ALDA gives out. I remember all of the hassles that we had just trying to get agreement on the names that we were going to give the ALDA awards. And it's just fantastic for me to be able to sit back sixteen years later and watch all of the people who are so pleased to receive those awards, and to see how meaningful the awards have become in ALDA's life. So that's one hat that I have worn – that of the president of ALDA.

After completion of my service as ALDA president, I joined the Board of Directors of Telecommunications for the Deaf and Hard of Hearing, Inc., or simply "TDI" as it's more commonly known. I was elected president of TDI in 1997, and I continue to wear that hat to this day.

Finally, I should mention that I formerly taught at Southern Illinois University at Carbondale. I taught there in the Political Science department for thirty-two years, and I retired in 1999. But when I retired I was not yet quite ready to hit the rocking chair. So I grabbed an opportunity and accepted the position of Executive Director of the Missouri Commission for the Deaf and Hard of Hearing – another hat that I still wear.

But today I am here to talk to you about advocacy. I need to acknowledge the fact that I have borrowed a few of these ideas from two very good friends and wonderful advocates for deaf and hard of hearing people, namely Pam Young-Holmes of UltraTec and Cheryl Heppner of the Northern Virginia Resource Center for Deaf and Hard of Hearing Persons. I want to publicly acknowledge their contributions to this workshop and thank them for allowing me to incorporate a few of their thoughts.

I'm going to try to deal with the topic of advocacy by answering some old familiar questions, namely, "what," "when," "where," "who," "why" and "how?" And I want to begin by discussing "what" I mean by advocacy.

I like to think of three different types of advocacy. The first type is what I would call "systemic advocacy." In systemic advocacy, the goal is to change the basic rules of the game. Those rules can be at any of several different levels of government. With systemic advocacy you are trying to change the rules under which people or agencies operate.

The second type of advocacy is "individual advocacy." In individual advocacy, the goal is to try to change the behavior of one person or one entity. You are not trying to change the rules. You know what the rules are, and you accept them as being good, fair and reasonable. But the person or agency with whom you are concerned does not play by the rules. So you have to try to change the behavior of that person or agency, and get them to follow the rules.

The last type of advocacy is "environmental advocacy." The goal there is to change the physical environment in which behavior occurs. Let me give you some examples of each type of advocacy.

Systemic advocacy occurs at many levels. For example, some people work primarily at the international level where they try to get changes made to international treaties, laws, agreements between governments, and so forth. In contrast, many others work primarily at the national level. At the national level, advocacy may be directed at trying to change the constitution, federal laws, administrative rules and policies of federal agencies, and so forth. At the state level, advocates try to change state laws, state court decisions, administrative rules and policies of state agencies, and so forth. People can also advocate at the local, neighborhood, or organizational level, and even at the family level where they might try to change the rules of the game within a household. In fact, I often think that one of the most critical advocacy efforts for people who are late-deafened after they become deaf is to try and persuade our own family members that we have got to change the way that we do some things.

I have been asked whether or not we should include war as a form of systemic advocacy? And my answer to that question would be "no," because I don't think that advocacy is a matter of using physical force. When we advocate, we never hit a person in the mouth, or maim, or kill a person. Advocacy involves a nonviolent approach to resolving conflicts.

Individual advocacy has many players and many different kinds of people whose behavior one might try to alter. Examples might include advocating to get your doctor to talk a little slower when he is talking to you, or advocating to get your lawyer to look at you when he is speaking, or advocating to get your dentist to send you appointment confirmations by e-mail rather than by phone. We may be advocating with hotel clerks,

airline ticket-counter agents, bus drivers or police officers to change their behavior. Any time you try to get an individual to change their behavior to conform to rules that you think are acceptable, that's individual advocacy.

In environmental advocacy, you may be doing things as simple as asking people to please close blinds or draw curtains so that you don't have bright sunlight glaring into your eyes and interfering with your speechreading efforts. You may be asking hotel personnel to bring a visual fire alarm to your room. You may go to a dark restaurant and ask the waiter to please turn up the lights so you can see the people you are with better and thus facilitate communications. All of these are examples of environmental advocacy where you are simply trying to change the environment around you. Changes in the environment can be needed in many places, including offices, stores, hotels, airports, restaurants, jails, and so forth.

“When” do we advocate? I would suggest that the answer to that is easy. We basically advocate any time and all the time that it's needed.

“Where” do we advocate? Again, there's a simple answer to that. We advocate anywhere and everywhere that it's needed.

“Who” do we attempt to influence with our advocacy efforts? Anyone who can help us create the desired change.

“Why” do we advocate? I think different people advocate for different reasons. Some of us advocate to improve the quality of life for ourselves. Some of us advocate in order to exercise control over our lives. Some of us are basically doing it to provide payback. We know that many people in the past advocated and their efforts improved the situation for us, so we are advocating as payback. Many persons advocate because they want to do what they see as the “right thing,” and others advocate simply to improve society.

The bottom line is clear. We advocate to produce change -- either change in the rules, change in the behavior of an individual person or entity, or change in the environment in which we are operating.

Deaf and hard of hearing people have had a lot of advocacy successes in recent decades. For example, none of us would enjoy the life that we now enjoy without the Americans with Disabilities Act of 1990 (ADA). We would never have had the ADA if lots and lots of people had not advocated as strong as they could in Washington to get that bill passed.

Another advocacy success was the Hearing Aid Compatibility Act. There was a time in our history when telephoning created all sorts of havoc for people wearing hearing aids. Congress passed a law saying that all telephones had to be compatible with hearing aids. Did they do that out of the goodness of their hearts? No way! Many people worked in Washington advocating for that change in the rules.

We have television captioning today, and that provided a whole new world of communications access for people with hearing loss. Do you think that captions on TV happened by luck? Or that the big-hearted producers of television programs got together and decided, "Oh, there's some deaf and hard of hearing people who can't understand our programs and it would be nice to caption them." Wrong! The Federal Communications Commission (FCC) initiated a rulemaking on TV captioning only as a result of the advocacy efforts of many people.

All of these are examples of how advocacy has improved our lives. Are we done yet? No way! We have barely started on the long road that lies ahead of us. For example, what about high definition television (HDTV)? Everybody knows that the Federal Communications Commission has mandated that all analog television broadcasting is to be replaced by digital broadcasts. HDTV is growing and will probably become dominant in our country within the next decade. Today, you can watch the captions on your analog TV set. But do we have any rules about captioning on HDTV? None! There are no rules that require it, no rules that say where captions are going to be located, or what color they must be, or what size they must be. The plasma screen is not a television set under current FCC rules. So you have to be very careful when you go out shopping for a new TV. You may have just bought that large, flat screen HDTV to hang on your wall and replace that big analog set with a cathode ray tube sitting in the corner. The HDTV set is a beautiful thing. But when you take it home you may find that there are no captions. We have a problem, and it's going to take years before it gets all sorted out with the new technologies. It will require our ongoing advocacy efforts.

How about assistive listening systems in theaters? How many of you can go to theaters and ask for an FM system today? The vast majority don't have them. OK, maybe a few theaters have them, but not many. Why not? They are supposed to have them. That's the law. This shows the need for continuing advocacy at the local level to change the behavior of individual theaters.

What about captioned telephone relay services? Many people with hearing loss have fallen in love with the Cap Tel phone, and use of captioned telephone relay services has dramatically improved their lives. But do you realize that captioned relay service is not a mandatory service according to the FCC? It is completely optional, and there are many states that don't provide that service! Each individual state must decide whether or not to offer captioned relay, and each state can decide at any time to stop offering captioned relay because they view it as too expensive. Why don't we have a federal rule issued by the FCC mandating that every state must provide captioned relay services, just like we have a rule that mandates that every state has to provide traditional relay services? We don't have any such rule. In order to get it people with hearing loss are going to have to mount a strong advocacy effort with the FCC.

How many of you understand how the relay services are funded? They are funded by a small monthly surcharge on all landline telephones. The amount of the surcharge

varies from state to state. It could be 9 cents a month, 13 cents a month, or more. It varies because the rate is set by the individual states. Only the people who have what we call a "landline" pay the surcharge to support the relay fund. If your home telephone is directly connected into the wall, then you pay this surcharge every month. However, in the last ten years, a growing number of people been acquiring cell phones. And after awhile they look at the landline phone and say to themselves "I don't want to keep that. I don't need that anymore. I take my cell phone wherever I go and I've got my telephone service always at my hip. Why should I pay for two separate phone services? I'll get rid of my landline phone!" The number of cell phone users who are doing this is increasing. Therefore, the amount of money to pay for relay services is decreasing. Relay services have to get funding relief, such as by adding the surcharge to cell phones because that's the new and growing technology. Please believe me when I say that there are all kinds of issues that we will face during the rest of our lifetimes that will require advocacy.

I want to focus now on some lessons that I have learned during almost two decades of advocacy. The most important lesson that I have learned during this time is called "the power of one." You don't need to be wealthy. You don't need to be a politician. You don't need to be a military general. You don't need to be the chief executive officer of a big company. And you don't need to be a movie star in order to cause change to happen in our society.

Philosophers, researchers, inventors and academicians have single-handedly either changed the rules, the behavior of millions of people, or the environment in which we live, and I want to give you some examples. Let's think about the philosopher Karl Marx. For more than a half century millions of people lived under the oppressive yolk of "communism," which was a political philosophy basically created by the ideas of a single person – Karl Marx. How the world would have been different without the Berlin Wall, the Cold War, the Cuban Missile Crisis, and all the other things that were spawned by communist ideology.

Another individual who changed the world was Thomas Edison, himself a late-deafened adult. What would our world be like without the incandescent light? He invented the electric light bulb and had over 1,000 other patents. Indeed he was one man who changed the world.

Another individual who changed our environment was Philo T. Farnsworth. He developed the world's first television set, and he was only twenty-one years old at the time. Can you imagine a world without television?

And what about Sir Alexander Fleming, the bacteriologist who discovered penicillin. What would our world be like if we did not have the many drugs that have evolved from the discovery of penicillin.

$E=MC^2$  is a very small equation, but one that has had worldwide effects beyond belief. One man, Albert Einstein, gave the world the theory of relativity that later produced nuclear energy – for both good and evil. What would our world be like without the atomic bomb or nuclear power plants?

Last, let me mention Jack Kilby. He invented the integrated circuit, the microchip. And today a microchip is in almost everything we own. It's in your computer, in your car, in your refrigerator, in your microwave, and so forth. What would our world be like except for this one man and his mind?

These people that we have looked at have all been creators. They have all been inventors. They have been discoverers. But what about advocates? Have advocates changed our world?

What about Jesus of Nazareth? Because of him millions of people now live their lives as Christians. What about Susan B. Anthony? The only reason women now are entitled to vote is because of Susan Anthony and the woman's suffrage movement. How about Mohandas Gandhi? Without this man, India may never have become independent from England. How about Cesar Chavez? Because of his efforts migrant farm workers organized and became the Migrant Farm Workers of America. How about Martin Luther King, Jr., the acknowledged leader of the civil rights movement. Without him, there would have been no Civil Rights Act of 1964. He was awarded the Nobel Peace Prize at age thirty-five. What about Justin Dart, Jr.? Justin is often called the father of the ADA. He traveled around the country, visiting every state in the union, not once, but twice, while advocating for passage of the ADA. He was definitely one advocate who changed the world.

So, just like a teeny pebble that you drop in a pond, the resultant wave grows bigger and bigger. One person's advocacy can have results far beyond what you can ever imagine.

Now, let's look at some things that I want to suggest are appropriate "to do" when advocating. Always work in teams. It's a whole lot easier if several heads are involved than if there's only one. The burden of the advocacy effort is distributed when working in teams. If you're going to advocate, don't advocate out of ignorance. Don't advocate strictly out of emotional need or desire. You always need to know what you are talking about. You want to do your homework and be on top of your subject. You've got to read newspapers, attend legislative hearings, peruse relevant magazines, and listen to serious discussions of your issue on television. Remember that anyone can give their opinion about almost anything, but successful advocates always do their homework.

You want to collaborate with key stakeholders. It's always better to bring all affected parties together in trying to find a solution to a problem than it is to work individually or separately. Similarly, you want to involve key decision makers in your activities as often as is possible.

Always, always, always, say “thank you.” We have to show appreciation for whatever help that we get and for whatever agreements and compromises that are reached.

Now that we have reviewed some of the things that you should “do” when advocating, let’s look at some things that you need to “avoid” when advocating. Don't burn your bridges. It takes too long to build them. Once your bridges are damaged, how will you ever reach your goal? If you are trying to convince a legislator to go your way on a particular issue, don't blow up in his face and say, “I'm through trying to reason with you.” Believe me when I say that he'll remember that. Legislators have memories like elephants!

When you are advocating, don't get mad because you don't seem to be getting anywhere. I want to recommend that you never lose control as an advocate. Always stay calm, reasonable and able to think logically. If you lose control of your emotions, you are no longer an effective advocate. Don't be afraid. Don't be afraid to speak up, to ask questions, or to say “let me speak with your supervisor.” Don't be afraid to disagree with people and don't be afraid to make mistakes. We all make mistakes.

I think, too, that you always need to show respect for other people, even if they don't agree with you. I think that's very important. Don't be rude. You don't make many friends or persuade many people being nasty, inconsiderate, impolite or “in your face.” I know there are some advocates who disagree with that. They think that “in your face” advocacy is an effective way to advocate, but I don't believe that.

Now let's talk about a few things to remember when advocating. These are not things to do, or things to avoid doing, but merely things to remember. Remember that whenever possible you should be creative in your advocacy efforts. Remember that you catch more flies with honey than you do with vinegar. Be polite, mannerly, and respectful at all times. Remember that you have to take the first step, just like Neil Armstrong when he took the first step on the moon. Advocacy can be scary. You are uncertain of what's going to be down the road. You don't even know if you are coming back from where you are going. But as an advocate, after you take that first step it usually gets a lot easier.

Remember that the press can be your friend. It's nice to be interviewed by people who can put you on TV for thirty seconds in the local news broadcast. But only go to the press when you are sure of your facts. Whatever you do, do not spread lies or half-truths. Don't make factual mistakes when you are talking to the press. They'll come back to hurt you.

Remember that you should never, never hesitate to ask legislators to vote the way you want them to. Why? Because they are elected to serve the public. You pay their salary. Don't ever hesitate to say, “I would like for you to vote this way on that bill.” They may

not do it. They may disagree, but that does not, in any way, adversely affect your right to ask them to vote the way you want.

Remember to be prepared for a long uphill journey. Sometimes it takes many months and sometimes many years before you ever see even a glimmer of hope that your final advocacy goal might be achieved.

Remember that it's always easier to advocate for somebody else other than yourself, especially if that somebody else is a little baby, or a homeless person, or a migrant worker because then people don't accuse you of being motivated because of "self interest." But if you never advocate for yourself, then who will? You have to remember it's easier to advocate for other people in need, but there are some times that you simply have to advocate for yourself.

Remember that you have to expect some hard times. The life of an advocate can be filled with frustration, obstacles, and defeats. Remember the old adage that "the squeaky wheel gets the grease." Be a pest. It's a noble profession. You can be a pest without being rude, and you can be a pest without being "in your face." So be a pest; that's OK.

Remember to document, document, document. Now with the Xerox copier, that's relatively easy to do. What happens in the real world is that oftentimes if you didn't document it, as far as much of the world is concerned, you didn't do it. Keep track of times, places, people's names, and so forth. When you advocate, you have to be able to document your activities.

Remember that team agreement is absolutely necessary. Make sure that everybody is pulling in the same direction when you are involved in team advocacy. If people are going in different directions, the advocacy effort often goes no where. There is no change.

Always remember to be professional in what you are trying to do. As an advocate you always want to win, to accomplish your goal, but you always need to remain professional. Just because a person disagrees with you does not mean that they are dumb, incompetent, or stupid. Sometimes in the world of advocacy you're simply going to have to agree to disagree and go on with life.

And last, remember that there's power in just showing up. The "Deaf President Now" rally on the mall in front of the capitol in 1988 would never have been as effective except for the thousands of people who just "showed up." This was probably the first time in history that congress was clearly faced with the fact that deaf and hard of hearing people really were upset about constantly being told how to run their lives (and university) by hearing people.

“How” do we advocate? We use all kinds of different techniques, as some work better than others in given circumstances. We use petitions; we go to demonstrations; we use E-mail. We write letters, some going to newspaper editors and some being personal letters. You can publish things and you can use face-to-face contact. Some advocates are good at one, and not so good at another. Only a few advocates are good at everything.

If you're going to go out and be an advocate, what kind of a person do you need to be? You need to be assertive, persistent, tenacious, courageous, patient, articulate, and well prepared. If you have those traits, you probably can become a very effective advocate. And you don't have to do it alone. If you need information about an issue, you can always go to the websites of NAD, HLAA, ALDA, and TDI. One of these sources can usually help you out. There are many, many resources available today to help deaf and hard of hearing advocates.

Yes, you can be a “dreamer” and you can be a “doer,” but you have to get rid of one word -- impossible. Get rid of it; put it in the trash. Johann Von Goethe said a long time ago that knowing is not enough. You've got to apply your knowledge and be willing to do something. You have to go out there and do it. The “week that the world heard Gallaudet” is an example of advocacy that changed the world for deaf and hard of hearing people. Because many advocates were willing to “do it,” our world will never be the same.

In closing I want to leave you with just one thought. Remember that most great moments in history started with the idea or the activity of just one person. Advocates can, have, and will continue to change the world!

Dr. Roy E. Miller is a former president of the Southern Illinois Center for Independent Living, Hearing Loss Link, and the Association of Late-Deafened Adults. He is a former Distinguished Mary E. Switzer Rehabilitation Research Fellow of the National Institute on Disability and Rehabilitation Research, and a former member of the Statewide Independent Living Council of Illinois. He currently serves as a member of the Missouri State Rehabilitation Council, the president of TDI (formerly Telecommunications for the Deaf, Inc.), and as the Executive Director of the Missouri Commission for the Deaf and Hard of Hearing.