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LEADERSHIP PANEL

Robert Davila, Roz Rosen, Nancy Bloch, Edna Shipley Conner, Marylyn Howe

MARY CLARK: I would like to introduce the panelists. I'm going to give a one-sentence introduction, and then I'm going to let them introduce themselves. We have Marylyn Howe, who is past president of ALDA. We have Nancy Bloch, director of the National Association of the Deaf (NAD). We have Robert Davila, vice president of the National Technical Institute for the Deaf (NTID). Finally, we have Roz Rosen. She's a professor at Gallaudet University. We're going to be asking the panelists questions related to leadership and advocacy. What I would like everybody to do is introduce themselves.

MARYLYN HOWE: The interesting thing about Orlando is this is where I first met Bill Graham, who is the actual founder of ALDA. We came here to attend a convention for the National Court Reporters Association. Both of us were struggling to find a way to communicate by using text. We knew that there was such a thing called court reporting which did real time translation and we wanted to know more about how we could take advantage of that. That's when we decided to hit the road running and get off to a start with ALDA.

We knew that text communications was the common denominator. A lot of us could not understand sign language and a lot of us could not speech read, but we knew that we could depend on the written word. That's how ALDA began. I went back to Boston and Bill went back to Chicago and we started the organization that brings us here today. Then I started the first chapter outside of Chicago, which was the Boston chapter of the Association of Late-Deafened Adults. .

NANCY BLOCH: I'm originally from Miami, Florida. I was born deaf and went to a hearing college until I got to Gallaudet, where I went to Graduate School. I've been involved in the field of deafness ever since. I was in the human service field for about 15

years, then I moved into program and administration and ended up at NAD, where I have been since 1992. The NAD itself is the oldest and largest disability organization advocacy for the civil rights and access for deaf and hard-of-hearing individuals.

NAD has fought for benefits for deaf, hard of hearing, late-deafened and deaf-blind individuals. Since my tenure, we have become more diverse. Our conferences are not fully accessible for individuals who are late-deafened and hard-of-hearing as well as individuals who are deaf-blind. Almost 100% of everything is captioned or interpreted.

ROBERT DAVILA: I became deaf prior to my eighth birthday. I was born into a Spanish-speaking family. At that time I only spoke one language, which was Spanish. My mom made the right connections once I lost my hearing and I went to the school of the deaf and stayed there for my entire elementary and secondary years. After that, I went to Gallaudet University for my undergraduate degree and to universities in New York for my graduate degrees. I then began my professional career as a high school teacher of math and later began to participate as a leader in difference organizations related to the education of deaf children.

Today, I am chairman of the board for the New York School for the Deaf in White Plains. I'm also vice-chair of Hillside Children's Center in Rochester, New York. It's one of New York State's most important residential treatment facilities focusing on emotionally disturbed hearing children, including a small number of ED deaf children.

ROZ ROSEN: I was born deaf in a Deaf family. I grew up thinking that sign language was a normal thing to do and I felt sorry for people who couldn't sign. I thought something was wrong with them.

I am from New York City and attended the Lexington School for the Deaf. I then went to Gallaudet. I became a teacher at the Model Secondary School for the Deaf, MSSD, and later was responsible for the Public Law 94-142. After that, I became the dean for the continuing education at Gallaudet University and then vice president for academic affairs. At the same time, I was still involved with community services through NAD and was a board member for them for 13 years. Three of those years I served as president-elect for the organization. Now I am on the board of the World Federation of the Deaf and also am the new executive director.

EDNA SHIPLEY CONNER: I became deaf very slowly over a period of about 20 years. When I could no longer teach, I went to the Department for Rehabilitation to get some help and was very fortunate to get into a training program. I knew community affairs and resources, so I did that for three years. During that time, I regained a lot of my self-confidence. My boss asked me to set up a program for deafened adults and hard-of-hearing people at the agency that I worked for, which was DCARA. After I started developing that program, Gallaudet set up regional centers all over the United States and Nancy Bloch and I had worked together on the first Deaf Women's conference. Many of the people who went through my program moved on to be leaders in SHHH. And when

ALDA was established, many of my clients also became leaders in the ALDA East Bay chapter.

MARY CLARK: What do you think ALDA needs for leadership to its people?

NANCY BLOCH: Really the responsibility, speaking from the NAD perspective, is to keep pulse of the membership through national and regional conferences, individual contacts, committee actions, and the board of directors. So there are many different venues that we find ways to make sure our members get what they want. Our numbers are very large. ALDA has smaller numbers, but I think that you have a lot of cohesiveness among your members. You have a common thread that runs through your membership, individuals who have experienced late-deafenedness. You have experiences that you share in common. You have a lot more things in common to build on. And that is the beauty of your organization. You build on the talents that every member can offer. The responsibility of ALDA is to find out exactly what the members want. As you grow, those wants are going to change.

ROBERT DAVILA: I think we all understand that, as a group or organization, you charter the course to your success. If all deaf people had exactly the same needs, there would be no need for different organizations. So the leadership's responsibility is to understand exactly what those areas of needs are and to know the membership and be able to get a read on what the membership would like by way of services. Develop programs from that and disseminate them throughout the organizations. For some individuals, it might be developing skills and for others it may be acquiring better understanding of their disabilities and how to cope with them.

When you have a large group of people in an organization, you're not going to get a 100% consensus on any topic. But you must never lose sight of what your goals are. You have to have a clear vision of what the organizational needs are and where the organization is going.

ROZ ROSEN: A leader needs to first know him or herself and understand the purpose of the organization. Those two things work hand in hand. They need to be able to communicate, be able to listen to people and be able to articulate the organization's goal, mission and vision or create such a vision that will inspire people.

EDNA SHIPLEY CONNER: I was thinking of more limited focus with responsibility. The responsibility of the leaders in the organization is to maintain the organization and help it to grow.

MARY CLARK: I would like to ask the panel how they think that the members in ALDA could do self-advocacy. How do you think that ALDA as an organization itself could do advocacy?

MARYLYN HOWE: The first thing that we recognized when I advocated for CART was that most people who become deaf are dependent upon English. How are we going to communicate? And when we knew that there was software available and skills available,

we thought that's it! We can all read and understand the spoken word. So a few of us worked together with the National Court Reporter's Association to help us get a better understanding of what their capabilities were. The very first time we had a conference was in Chicago in 1989, and we had Harcourt reporters come, and we were blown away by the fact that we could read what was being said almost in real time. The software was not as well developed as it is today. So we needed to promote that, and we needed to find the leaders of the National Court Reporters Association and the Caption Center in Boston, who could work for us, help us make this happen.

EDNA SHIPLEY CONNER: I think that you advocate in self-advocacy in the same way that you do as an organization.

ROBERT DAVILA: When using the word "self-advocacy," we're not talking about just one person. We're talking about everyone within our organization. There is a responsibility to promote and pursue the goals of our organization. You have to have a clear understanding of what ALDA is all about. You have to find out where your strengths are as an organization. You have to identify your priorities. It's important for you to be also politically knowledgeable on a local, state, national and federal level. For example, NAD, used to be a small organization with only a few hundred paid members, but they have grown from a small operation to a huge organization with a multi-million dollar budget and many vital programs serving deaf and hard of hearing persons after many years. It's important for ALDA to know where the organization is going in the 21st century. I think your leaders need to communicate that and you have a responsibility as members to support them.

NANCY BLOCH: Yes, NAD is at federal and national level focus, but we would not be able to do the work that we do without the individual members. Every one of you in this room is an advocate. Maybe some of you don't think yourself in that way, but think about the things that you say and do to you're your life more pleasant and enhance the quality of your life; enhance the quality of other individual's lives. It may be just the small things you do, but that is self-advocacy. The more you do for yourself, the more you help others. It's kind of a ripple effect. I think ALDA has a very powerful goal and powerful tool, and that is your bond to the English language. You write up a storm and influence Capitol Hill and the policy makers in your state and local areas.

We have found that, at NAD, the more information that we put on our web site, the more tools it gives people and helps them grow towards self-advocacy. ALDA needs to figure out which things you can do within a reasonable period of time to provide your members the tools that they can use to do things for themselves on their own in their lives. ALDA cannot succeed without the individual advocacy effort that you do in your home communities. All of you together really can make a difference.

MARY CLARK: What kinds of things do you volunteer for and how could we, as leaders, promote volunteerism

ROBERT DAVILA: Volunteerism is very critical. Anyone who serves in any organization, such as a board member or committee member, is involved in promoting

the organization. Nobody gets paid with volunteerism. It's part of the community responsibility that we have. The community we serve cannot be successful without volunteerism. It would not move forward.

There are limitations on the number of members that come out and get involved. As an organization, you need to be able to provide good quality membership services, even if it's on a limited basis with limited financial resources. Without good volunteers and not having a commitment from everyone, it will be very difficult to be successful. Get involved in the organization and understand up front your commitment and pledge to yourself and your peers that you want to be a part of it. We need to be personally motivated and committed to the support and success of our organizations.

NANCY BLOCH: NAD has a very small staff, but we're very loud. We have to be loud because we rely heavily on volunteers to serve in the different NAD committees and help NAD in a variety of ways. Some help by coming to the office, helping us with mailings or preparing documents.

I think it would be good if ALDA could harness more of that volunteer spirit. You do that at the board level. The board needs to decide what things are critical and what needs to be done. Members themselves need to offer their ideas and resources. You really need people to come forward and say, "I have a skill to help in this particular area," otherwise, how would the board know? The more you do that, the more leadership ALDA can help.

EDNA SHIPLEY CONNER: One of the things that we decided to do is a volunteer profile. In doing this, not only will we know who is willing to volunteer, but also we will know what their skills and interest are. We'll be putting that on our web site because we've not been using our volunteers efficiently. The more you recognize what volunteers do and encourage them to do it, the more they will accomplish. We did a lot of self-advocacy kinds of workshops when we were first beginning. No one has provided that kind of training recently. I think we need to encourage some of those workshops again for the net conference so that people who want to be advocated have the tools to do it successfully.

ROZ ROSEN: People volunteer because they like to be involved. They like to feel needed. It's important that the organization actually have a system that can provide information to them to help them continue on that volunteer basis. It takes time and resources to set up a system for actually and efficiently using those volunteers. I know that NAD has an annual volunteer appreciation program and it's mentioned on the web site. Volunteers are really the backbone and foundation of an organization. Especially an organization that is really strapped for resources.

The Association of Parents with Deaf Children has a lot of grants; grassroots people who are involved, and their various chapters. It's fairly similar to the ALDA structure. Those parents are volunteering by becoming advocates or being buddies to new parents of deaf children. That's a simple way that volunteers can help other late-deafened individuals that are going through the same experience. ALDA, as a self-advocacy organization, also needs to think about the power of statistics and data because it inspires people to become

more involved. Many people don't know about the ADA. They don't know how to help and get involved. Many students in my class have never heard of ALDA. So I think that there's just such a potential here. It's very important to work with organizations such as NAD and SHHH, which are of, by and for individuals who are deaf and hard of hearing. The networking really helps a lot. Volunteers can help with everyday management such as looking at the web site and finding out what are the new developments. Volunteers can do some of those things, but it takes time in order for that to be successful.

MARY CLARK: I would like to ask the panel members for some last words of wisdom for those in this audience who may be struggling with starting a chapter or group or making ALDA grow.

ROBERT DAVILA: People within any organization have special talents, skills and knowledge. Tapping these talents and abilities can be useful to the organization. That's one thing leaders can do. ALDA and their leadership need to make an effort to access knowledge, abilities, and skills represented in many members within the organization. There's going to come a time that you're going to need to harness all that strength and ability for the good of the organization and you have to identify more and more individuals who can provide that kind of support. That will be very important. Another thing I would like to share with everyone, and this doesn't necessarily relate to ALDA is that many individuals do not understand the purpose or the goals of the organizations they belong to. Therefore, an organization has the responsibility to the membership to be clear on what it is doing and what it can do for the membership. Leaders must have a thick skin. They must be able to take personal criticism. There's a lot of hidden talent within ALDA and you need to go out there and find it. The time will come when you will need it.

NANCY BLOCH: I would like to emphasize that, for ALDA, the importance is in the short and long term plans. Where do you want to go? What do you want to achieve in the next five years? That in itself is a difficult job. SO that means really working closely together with your members in the planning process. That takes two or three years alone, just to come up with a very simple set of goals and objectives. But that's the one thing I would encourage an organization to do.

MARYLYN HOWE: When we think of our individual members, some of us are going through different stages of grieving for our hearing loss. Some of us have completely accepted it and want to move on with our lives. Others are just beginning to start to grieve and are filled with anger or remorse. One of the difficult things that I think our organization has, is recognizing the individual needs of members and respecting them. Respect that the process is real and that they process is something they have to work out for themselves until they finally get to the acceptance stage. That's the very difficult task that we have in hand.

NANCY BLOCH: I understand what you mean. The attention to the individual members is important and you can't lose sight of that. But, at the same time, from an organizational perspective, ALDA needs to be part of the planning process to decide what programs and activities that can happen from the top down as well as from the bottom up at the local

level and come up to the national level in combining that and finding those crossroads. You'll get to a point where you'll need an office and a director. You'll need a more formal structure. And the process of getting there is difficult. I recognize that you don't want to lose sight of the individual needs of your members, but if you plan well, you won't.

ROZ ROSEN: I'm reading a new book by Rudy Giuliani, the former mayor of New York City. The first chapter of his book says, "First things first." That means, with everything that's going on, you have to figure out how to get from here to there. That includes strategic planning and vision. That's where you begin, whether it's at an individual level or an organizational level. You take care of those things first and then everything else will fall into place.

EDNA SHIPLEY CONNER: You have power. You have the ability to make ALDA into what someone said was a sleeping giant. You have the ability to wake up that giant. I really hope you help us to wake up ourselves and all the people out there, who can help us to become the kind of organization all of us envision in our better moments.

SPEAKER: I think it would be interesting for Nancy to describe the mechanism used at each biannual convention for NAD. Describe the topics, the terms, how the membership themselves organize their priorities for the next two years.

NANCY BLOCH: It's quite a complicated process. Traditionally, our state associations, the affiliates, propose bills or motions from the regional level and bring that to the national level. We've always had what we call a general assembly, where members can also propose motions or bills. Three conventions ago, we changed the general assembly structure so it has become now a symposium structure, where we had originally ten forums, with topic areas such as education, human services, civil rights, technical, and telecommunications. Our recent conference had six forums. Members attended each forum, worked on the recommendations, voted on them, prioritized them, and then that was delivered to the business meeting, where the delegates and the council of representatives got involved. The delegates of ALDA can also affiliate with NAD and have a voice at the council of representatives' level. We're trying to be welcoming as a national, state and local organization, to make sure that we have diversity. The symposium is actually where we provided individual members a voice for NAD. The delegates often do what the individual members subscribe to and they are learning to lobby. They are learning to track their bills within the symposium system to make sure that NAD has provided that at the convention.

Edna Shipley-Conner is Program Developer for the Deaf Counseling, Advocacy, & Referral Agency (DCARA) in the San Francisco Bay Area where she developed DCARA's Deafened Adult Program and facilitated it for more than 15 years. She is active at most ALDAcons working with newcomers and has received the I. King Jordan award for her contributions to deafened people. She is an avid MF player, a teller of "grandma stories", and is current President of ALDA.

[Marylyn Howe](#) earned her post-graduate degrees in audiology and speech-language pathology. She is a Past President of the Association of Late Deafened Adults. Her special interests are in the fields of information technology, speech recognition, and acquired deafness. Marylyn is an avid golfer and karaoke singer. She is a mother of three lovely children and resident of Marshfield Hills, Massachusetts. She can be reached at juneymoon@aol.com

Biographical Sketch for Nancy J. Bloch

Executive Director

National Association of the Deaf

Nancy J. Bloch is executive director of the National Association of the Deaf (NAD), the nation's oldest and largest consumer-based organization safeguarding the accessibility and civil rights of deaf and hard of hearing individuals in the United States of America. Headquartered in Silver Spring, MD, the NAD is represented on various boards, coalitions and councils including the Council on Education of the Deaf, the Consortium for Citizens with Disabilities, the Consumer Action Network and the Council of Organizational Representatives.

Since 1992, Bloch has expanded the role of the NAD on the policy and legislative fronts, promoted certification programs for sign language interpreters as well as American Sign Language educators, strengthened youth leadership endeavors, and ensured accessibility in a broad range of areas including education, employment, transportation and telecommunications. The NAD also administers the Captioned Media Program under cooperative agreement with the U.S. Department of Education, which includes education and outreach activities to promote increased use of captioned media technologies.

Previously, Bloch was director of the Management Institute and adjunct professor in the School of Management at Gallaudet University in Washington, DC. At that time she was also president of GNB Consultants, a management and technology consulting enterprise. Raised in Miami, FL and deaf since birth, Bloch holds a Bachelor of Arts degree in Psychology from the University of Miami and a Master of Arts degree in Counseling and Guidance from Gallaudet. During the past 23 years, Bloch has been involved with nonprofit, community and education-based organizations serving deaf and hard of hearing children, adults and families.

Bloch has also served on various educational and nonprofit boards, including the American Association of People with Disabilities, National Consumer Advisory Board for Bell Atlantic (now Verizon), Consumer Action Network, Deaf Women United, National Advisory Group at the National Technical Institute for the Deaf, National Mission Programs Advisory Panel for Pre-College Programs at Gallaudet, President's Committee on Employment of People with Disabilities, Telecommunications for the Deaf, Inc., and the U.S. Architectural Barriers Compliance Board.

Current service includes the AOL Accessibility Advisory Committee and the WGBH/The Caption Center National Digital TV Consumer Advisory Board.

This publication is available to the public in this on-line format. If you are interested in using any portion of this publication the reference is as follows:

Davila, R., Rozen, R., Bloch, N., Conner, E.S., & Howe, M. (2003). Leadership Panel with Robert Davila, Roz Rosen, Nancy Bloch, Edna Shipley Conner, Marylyn Howe. In L. Piper & D. Watson (Eds.), *Selected proceedings of 2002 conference of the Association of Late-Deafened Adults*. [on-line] available: <http://www.alda.org/aldapubs.htm> and <http://www.uark.edu/deafrtc/publications.html>