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ADVOCACY: YOU, TOO, CAN CHANGE THE WORLD

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I'm going to talk about advocacy, and while I am doing that I want you to remember that "You, too, can change the world!"

What is advocacy? I think of three types of advocacy. There is what I call "systemic advocacy." The goal in systemic advocacy is basically to change the rules of the game, for example, to change the constitution, to change a law, to change an administrative rule, or to change an organizational or agency policy. In systemic advocacy the goal is to change the rules that govern our lives.

In contrast to that, there is 'individual advocacy.' With individual advocacy, you are basically happy with the rules of the game. What you want to do is to change a person's or an agency's behavior so that they in fact comply with the rules of the game. You want them to do what they are supposed to do, rather than whatever they are doing. An example of individual advocacy would be trying to convince a doctor that the law required him to provide you with a sign language interpreter upon request even though the doctor refused to do it because from his perspective it cost too much.

Last, there is "environmental advocacy." In that situation, we're happy with the rules of the game, and we're not trying to change a person's behavior. Rather, we are trying to change the situation or the environment in which we find ourselves at that moment in time. An example of environmental advocacy would be when a group of hard of hearing people asked the manager of

a restaurant at which they were having dinner to turn up the lighting in their area of the restaurant so that they could see each other better in order to facilitate speech reading. That would be advocating changing their environment.

Many of us have different reasons for advocating, and our reasons may vary from time to time. Some of us advocate for one reason, while some of us advocate for a different reason. The reasons range all the way from an honest desire to improve the quality of our lives, to doing the right thing, to simply making ourselves feel good that day. We may be having a bad hair day, so we go out to advocate a bit to make ourselves feel better. But the bottom line is always simple. We advocate to “produce change,” either a change in the rules, change in an individual's behavior, or change in the circumstances (environment) in which we are living.

How do we advocate? Just like our reasons for advocating vary, we advocate in a variety of ways, including such activities as signing petitions, meeting with decision makers, attending demonstrations, writing letters, and sometimes simply being a positive role model. Some of us may not function very well in face-to-face advocacy work, but we indicate to others how we want them to behave by using a variety of telecommunication technologies, including snail mail, pagers, e-mail, relay services, cell phones, TTY's and any other device available that will help us communicate our desires.

In the past two decades, the deaf and hard of hearing communities have had a variety of advocacy successes, including passage of the 1988 law that required all landline phones to be hearing aid compatible; the Decoder Chip act of 1990, which required that all television sets manufactured or sold in the United States with a diagonal screen size of at least 13 inches must be able to display closed captions; Title IV of the Americans with Disabilities Act of 1990 (ADA), which mandated the development of a nationwide system of relay services; and a series of decisions by the Federal Communications Commission (FCC) agreeing to reimburse vendors for a variety of developments in relay services, including Voice Carry Over (VCO), Internet Protocol Relay (IP Relay), CapTel Relay, and Video Relay Service (VRS).

Other successful advocacy efforts by the deaf and hard of hearing community during that time include such things as getting a minimum speed of answer and minimum typing qualifications added to the rule for relay services, getting a captioning rule that required increasing percentages of television programs to be captioned, and getting the FCC to allocate a simple, easy to remember number for accessing relay services nationwide, namely 7-1-1. Let's think about the advocacy effort that was needed to get 7-1-1 just a little bit.

Can you remember back in the early 1990's when if you wanted to call the relay service you had to dial 1-800-XXX-XXXX, where XXX-XXXX was the number for the relay service in your state? You had to dial an eleven-digit number to get relay service. And every state had a different number for relay. So anybody who traveled a lot, like I did at that time, went crazy trying to figure out how to get in touch with the relay service in the state they happened to be in at the time. Where do you think this little magical number "7-1-1" came from? Did the FCC just wake up one day and decide that it would just be better if we had only one number to access relay services all over the country. Or did somebody in Congress just think that it would be very nice to simplify things for deaf and hard-of-hearing people? Do you think that's how it happened?

No way, Jose! What was then Telecommunications for the Deaf, Inc. (TDI) petitioned the FCC and asked for two N-1-1 numbers. TDI asked for 5-1-1 and 7-1-1 because at that time it would be easier and perhaps necessary to have one number for hearing people to call and a different number for a TTY caller to use. The FCC sat on the request for a couple of years, but TDI and other advocates kept badgering them. At that time a lot of businesses wanted N-1-1 numbers. For example several banks wanted one and ATM distributors wanted one. The corporate world wanted N-1-1 numbers because they knew that if they had a very easy telephone number for people to call they would get more business. But the number of N-1-1 numbers is extremely limited, there can only be ten N-1-1 numbers, so the competition for them was intense.

Deaf and hard of hearing advocates really had to fight hard with the FCC in order to get any N-1-1 numbers. Finally, a compromise was struck and the FCC reserved one N-1-1 number for relay access, namely, 7-1-1. That was the result of a lot of advocacy work in Washington, D.C. back

around 1993 and 1994. Government agencies usually don't give you anything for free. You basically have to ask, and then you have to fight for it.

Although the deaf and hard of hearing community has achieved many advocacy successes, there is still a lot on our advocacy agenda. There are many, many things that we all want and/or need in our lives, for example, 100 percent captioning on TV. Do you sometimes stay up past two o'clock in the morning? If so, do you turn on your TV once in a while? Is everything captioned at two o'clock in the morning? You look and look and look for a captioned program, but there's almost none on the air. Why? Because the FCC captioning rules say that nothing has to be captioned between two and six o'clock in the morning except emergency announcements. I guess they think that deaf and hard of hearing people never watch television during the wee hours. We're just part-time residents of the television world. Nonsense! We want 100 percent captioning, that is to say, that every program on television ought to be captioned.

What about a global positioning system (GPS) capability in all of our pagers? Many people with hearing loss now have pagers, but very few of those pagers have a GPS capability. A person's pager ought to have the capability to specify where you are located if you are in a car wreck out in the boondocks. All you should have to do is dial 9-1-1 and the emergency service immediately identifies where you are because you have GPS capability embedded in your pager. Every pager ought to have that, but it is going to take a lot of advocacy work to get GPS on all of them.

What about Internet streaming videos? Does anybody like to watch movies on the Internet? Are they captioned? Once in a great while. I basically want all streaming movies on the Internet to be captioned, not just one from that group or one from this company or one on that channel. They should all be captioned. It's a future advocacy battle for us.

And we certainly want all telephones to be hearing aid compatible. Perhaps not a lot of deaf people use the telephone, but millions of hard of hearing people still struggle with that technology, many of whom are migrating to cell phones. Do cell phones have to be hearing aid compatible? Yes and no. It depends on how you look at it. The FCC rule says that every cell

phone manufacturer, starting this year, has to have at least 50 percent of their cell phone models hearing aid compatible. So hard of hearing people have to spend many hours trying to find the right phone that works with their hearing aids because half of the cell phone models on the market will not be hearing aid compatible. The point is we should not be satisfied with 50 percent compatibility. We want 100 percent of cell phones to work well with hearing aids.

Yes, there are many things still on our plate of advocacy issues. And what is the most important thing to remember about advocating for our diverse needs? The primary lesson I have learned about advocacy is the “power of one.” The actions of a single person can change the world. You don't need to be wealthy. You don't need to be a politician. You don't need to be a military general. And you don't need to be a Hollywood star in order to cause change. Although we may think that those people cause most of the change in the world, you don't need to be any of those people in order to cause change. Many philosophers, scientists, inventors, researchers, and technicians have changed the world all by themselves, and we're going to look at just a few.

Karl Marx was a philosopher, social scientist and revolutionary who co-authored a book with Friedrich Engels titled “The Communist Manifesto,” which explained the principles of communism. As a result, Marx is often called the “Father of Communism.” Can you imagine what the last century would have been like if communist governments had not developed? I can't begin to picture what a different world it would have been without communism.

Philo Farnsworth was a young man who invented television when he was 21 years old. Can you imagine our world today without television? One or more television sets are in almost every house, every restaurant, every bar, every airport and every train station in the developed world. Television is everywhere! Philo Farnsworth changed the world.

Alexander Fleming was a bacteriologist in England and discovered penicillin. Can you imagine what our world would have been like without the whole family of sulfa drugs?

Albert Einstein was a physicist who developed the simple little equation that energy equals mass times the speed of light squared ($E = MC^2$). That equation enabled the development of nuclear

energy, which first showed its awesome power in the form of the atomic bomb (which many say was responsible for ending World War II) and now flexes its muscle in the hundreds of nuclear power plants scattered all around the world. Certainly Einstein changed the world -- all by himself.

Jack Kilby was an electrical engineer with Texas Instruments when he developed the integrated circuit or what we think of as the microchip. And what would the world be like today without the microchip? A microchip is in every car sold today, in every refrigerator, in every microwave, in every cell phone, in every television set – in almost everything. Microchips are everywhere. Without a doubt, Jack Kilby changed the world.

Rob Engelke received his degree in Electrical Engineering from the University of Wisconsin at Madison, and later developed the captioned telephone (CapTel) for hard of hearing people. For the first time, people with some usable hearing were able to both hear a telephone conversation and simultaneously see a textual transcript of the other party's words to fill in the gaps that might result from their hearing loss. Rob is the founder and president of Ultratec, Incorporated in Wisconsin, which has developed and sold TTY's for many years. He is certainly responsible for changing the telecommunications world of deaf and hard of hearing people.

So clearly we have seen that numerous philosophers, researchers, and inventors have changed the world. But what about advocates changing the world? Have there been any advocates who have been responsible for changing the contours of the world we live in? Most definitely! Let's take a look at a few.

Jesus of Nazareth was a man who walked around in the Middle East some 2000 years ago with a small group of followers. He advocated for a change in the way that people dealt with other people on this globe. Can you imagine what the last two millennium would have been like without the development of Christianity?

Susan B. Anthony is probably the primary reason why women can go to the polls today and vote for the people they want to run their government. In 1869 she co-founded the National Women's

Suffrage Association, and she gave 75 to 100 speeches per year on women's rights for 45 years. As a result of her advocacy, the 19th amendment to the U.S. constitution was passed, giving women the right to vote. Susan B. Anthony certainly changed the world, directly for women and indirectly for men.

Mahatma Gandhi was an exponent of the nonviolent (passive) resistance philosophy. After leading a successful nonviolent campaign for the rights of Indians in South Africa, he returned to India and led a nonviolent campaign against British colonial rule. He coordinated the protests of millions of Indians nationwide, and was imprisoned several times. But his advocacy efforts finally led to Great Britain granting independence to India.

Cesar Chavez was a Mexican American farm worker, labor leader, and civil rights advocate who co-founded the National Farm Workers Association (which later became the United Farm Workers). By organizing strikes, boycotts, and mass marches, as well as fasting to get public attention, he obtained labor settlements that included higher wages and improved worker safety rules. He certainly changed the world for migrant farm workers.

Martin Luther King, Jr was a Baptist minister and one of the main leaders of the American civil rights movement in the 1950's and 1960's. He led the Montgomery bus boycott, helped found the Southern Christian Leadership Conference, and led the 1963 March on Washington. At age 35, he was awarded the Nobel peace prize for his efforts to end segregation and racial discrimination. Partly as a result of his efforts, the Civil Rights Act of 1964 was passed. He was not a general, and he was not rich. He was just an advocate who changed the world for African Americans.

Justin Dart was an advocate for the rights of people with disabilities. He co-founded the American Association of People with Disabilities (AAPD) and traveled to all 50 states advocating for passage of the Americans with Disability Act (ADA). For his dedicated efforts, he is often referred to as the "Father of the ADA." He was awarded the presidential Medal of Freedom by President Clinton in 1998, and because of him the world was certainly changed for people with disabilities.

So we see that many advocates have changed the world by their individual actions. But what about deaf and hard of hearing people? Did any persons with hearing loss do anything important enough to change the world? I think so. Let's consider a few.

Ludwig van Beethoven was a German composer and virtuoso pianist. His hearing began to deteriorate in his early twenties, yet he continued to compose masterpieces, conduct and perform, even after he was completely deaf. He wrote some of his most memorable music after he became deaf, such as his ninth symphony, and he remains one of the most famous composers of all time. What would the world be like without the “Da-Da-Da-Dum” of Beethoven's fifth symphony? He changed the world of music.

Thomas Edison was another late-deafened individual who changed the world. Besides inventing the phonograph, the first commercially available fluoroscope (X-ray machine), and the first long lasting electric light bulb, he had over a thousand other patents. Can you imagine what the world would be like without electric lights and doctors taking x-rays for medical diagnostic purposes? He changed our world.

Helen Keller was a deaf-blind activist, lecturer and author of twelve books. She became deaf and blind at nineteen months of age, possibly due to either scarlet fever or meningitis. Nevertheless, she learned to read, write and speak English, and to read and write Latin, Greek, French, and German. At the age of 24 she graduated magna cum laude from Radcliffe, becoming the first deaf-blind person to earn a Bachelor of Arts degree. She was a suffragist, pacifist, radical socialist, birth control supporter, and an advocate for deaf and blind people for many years. She received the presidential Medal of Freedom from president Lyndon B. Johnson in 1964, and certainly was responsible for changing the attitudes of many people in concerning persons who are deaf-blind.

Robert Weitbrecht was a deaf scientist in California who invented an acoustic coupler (modem) that would enable a deaf person with a teletypewriter to communicate over the Public Switched Telephone Network (PSTN). This enabled deaf people for the first time in history to access the

telephone network -- some 94 years after the telephone was invented. Indeed, he changed the world for deaf people.

I. Lee Brody was a deaf man who developed a Braille TTY a few years after Weitbrecht developed the acoustic modem that enabled TTY's to communicate over the PSTN. Brody's Braille TTY gave deaf-blind people access to the telephone network for the first time in their history, thus changing their world.

Vint Cerf is a hard of hearing computer scientist and the person most often referred to as the "Father of the Internet." He is the co-developer of the TCP/IP protocol, which is the communications protocol that makes the Internet work. Everything that goes over the Internet uses that protocol. What would our world be like without such Internet applications as e-mail and the World Wide Web? Cerf truly changed the world.

Ben Soukup is the deaf son of a deaf farmer in South Dakota. He started the first interpreter referral service for the deaf in 1975 from an office in a small closet at the South Dakota School for the Deaf. That small beginning grew into Communication Service for the Deaf (CSD), the largest deaf-run agency of its kind in the world, an agency that provides a variety of services to deaf people in numerous states. As founder, president and CEO of CSD Soukup has indeed changed the world for deaf people.

Marlee Matlin is a deaf actress who in 1987 was the first deaf academy award winner for her role in "Children of a Lesser God." It was her first movie, and at age 21 she became the youngest person to win the Oscar in the Best Actress category. Since then she has appeared in numerous movies and TV shows, and currently serves as the national spokeswoman for the National Captioning Institute (NCI). As a role model, she has opened many doors in Hollywood and elsewhere for deaf and hard of hearing actors and actresses.

I. King Jordan is a late-deafened adult who became deaf at age 21 as a result of a motorcycle accident. He received his Ph.D. from the University of Tennessee, and made history in 1988 by becoming the first deaf president of Gallaudet University since the institution was established in

1864. With his famous statement that “Deaf people can do anything but hear” he energized a new spirit in the Deaf community and changed the way the hearing world looked at deaf people.

Howard “Rocky” Stone founded Self Help for Hard of Hearing People (SHHH) in 1979 and was its executive director until 1993. He started SHHH (now renamed Hearing Loss Association of America) in his basement after he had retired from the CIA due to a hearing loss that had begun in his late teens. Certainly the lives of countless thousands of hard of hearing people have been changed because of what Rocky did.

Heather Whitestone in 1994 became the first Miss America with a disability in the pageant’s 75-year history. Prior to that time every Miss America had been beautiful, talented, and ”normal.” But Heather had been profoundly deaf since she was 18 months old. During her reign as Miss America Heather traveled an average of 20,000 miles per month and spoke in a different city every other day. She has been an outstanding role model for deaf and hard of hearing women, and is another example of a deaf person who changed the world’s perception of people with hearing loss.

Robert Davila was born into a large family (five boys and three girls) of Mexican migrant farm workers. His family spoke only Spanish, and as a child he had no permanent home (the family moved all around California following the crops). His father died when he was six years old, and he became deaf at age eight due to spinal meningitis. Soon afterwards, his mother put him on a train alone and sent him to the California School for the Deaf in Berkeley (which later moved to Fremont). Davila went on to get his bachelor’s degree from Gallaudet University, his master’s degree from Hunter College, and his Ph.D. from Syracuse University. Among his many professional accomplishments, Davila served as the Assistant Secretary for the Office of Special Education and Rehabilitative Services (OSERS) from 1989 to 1993. As such, Davila was the highest-ranking deaf person in the United States government, and no deaf person has held such a high office since. Davila went on to serve as the CEO of the National Technical Institute for the Deaf, and is now the Interim President of Gallaudet University. Davila’s leadership has helped shape a different world for deaf and hard of hearing people.

Yes, there have been many philosophers, inventors and advocates who have changed the world, and among them have been many deaf and hard of hearing people. So please remember that you, too, can change the world. Just like when you toss a rock in a pond the ripples just get bigger and bigger and bigger. The rock has an effect that just keeps growing. The actions of a single advocate can have a ripple effect such that they affect many, many, many people far beyond what one could have ever imagined. This ripple effect I call the “Power of One,” and, as I have said, it’s the primary lesson that I’ve learned about advocacy.

Now let’s highlight some of the things that you ought to do when you’re advocating. You should always work in teams if that’s at all possible. Several heads are always better than one. Whatever one person can’t think of, somebody else on the team will.

You should involve key decision makers in your activities as much as possible. For example, TDI always invites members of the FCC to attend our conferences, interact with us, and learn about the access needs of deaf and hard of hearing people.

You always need to do your homework. If you’re an advocate, you want to know your facts. You want to be sure that you know what’s happening in the world. Anybody can stand up and tell you what they think. Anybody can give you their opinion about an issue. But successful advocates always do their homework first.

You want to collaborate with key stakeholders. Working with all of the people affected by an issue generally turns out to provide a better solution than trying to deal with some as adversaries when you’re developing your ideas.

And last, you should always say “Thank you.” Strong advocacy involves showing appreciation for the fact that something has changed, that somebody has been willing to change his or her behavior or is willing to change the rules of the game. Whenever that happens, you should show your appreciation.

Now let's highlight some things that you shouldn't do when you're advocating. Admittedly, different views exist about what a person should and should not do when advocating, but these are my views about some things you shouldn't do.

Don't burn your bridges. It takes a long time to develop relationships and the interpersonal bridges of trust and respect that are necessary to accomplish your goals. If you burn those bridges, how are you ever going to achieve your desired ends?

Don't get mad. Anger can cause you to lose control over what you're thinking about or what you're saying. Always try and stay calm and reasonable in your advocacy efforts.

Don't be afraid. Don't be afraid to speak up. Don't be afraid to ask questions. Don't be afraid to say, "Let me talk to your boss." Don't be afraid to disagree with other people, and very importantly, don't be afraid to make mistakes. We all make them. In advocacy work you're always going to make some, so don't be afraid of that.

Don't be rude. You won't persuade many people by being nasty, inconsiderate or impolite. Remember, as my grandma always said, "You catch more flies with honey than with vinegar." Be polite, mannerly and respectful at all times. Just because you're advocating for a cause that you believe in doesn't justify you being vulgar and offensive.

Now, let's look at some things that you always need to keep in mind when you are advocating. Remember that you can usually get a person's attention easier and quicker with a little creativity. Advocating is a little like selling. Before you can get anyone to buy your product (idea) you first have to get their attention. And in a world where people are constantly bombarded with marketing stimuli, it may require a lot of creativity on your part.

Remember that you have to take the first step. When Neil Armstrong first stepped out on the moon, he didn't really know what was going to happen. He didn't know what to expect because no man had ever been there before. But he took the first step. The next thing we knew, we saw

pictures of Armstrong bouncing around all over the moon having a good time! So remember, you've got to take that first step. It gets a lot easier after that.

Remember that the press can be your friend. Talk to reporters, get your picture on television, and enjoy your moment of celebrity. But only go to the press if you've done your homework and you're sure of your facts. If you go to the press and tell them something wrong or stupid, it's going to hurt your advocacy effort much more than help it.

Never hesitate to ask a legislator to vote the way you want them to vote. They are elected to serve the public. Granted, our political system sometimes doesn't look like it works that way, but given that it is supposed to work that way, you should never hesitate to approach your legislators. Go up to your Congressman and say, "I know that you're considering bill such and such, and I would appreciate it if you would vote for that bill because I think it's good for deaf and hard of hearing people." He or she may look at you a bit funny, and may say, "I want to think about it." Or maybe say, "I'm sorry, I don't think I can vote for it." But you should never feel bad about going up and directly asking your legislators to vote the way that you want.

You need to be prepared for a long uphill battle in this business. Sometimes advocacy can require many months or years before you even see a glimmer of light at the end of the tunnel. You have to go into it for the long term. If you advocate with short-term thinking, you're probably going to become very frustrated.

You should expect some very rough times. Advocacy can be a real roller coaster ride. Sometimes you're up. Sometimes you're down. Sometimes you're close, but not close enough. Sometimes you feel as if you are never going to reach your goal due to the many unforeseen obstacles that always pop up. You've got to expect some very difficult challenges when you're advocating.

Remember that it's always easier to advocate for someone else than it is to advocate for yourself. For example, it's a whole lot easier to ask someone to meet the needs of a small child than to

meet your needs! But if you don't advocate for yourself, who is going to do it? Always remember that if you don't advocate for yourself, maybe no one will advocate for you.

My grandpa used to tell me “the squeaky wheel gets the grease.” Well, in the world of advocacy that’s certainly true. As an advocate, you have to be a pest! It's a noble profession. Be prepared to go back again and again and again. Successful advocacy efforts are seldom if ever one-shot deals. As the old saying goes, “If at first you don’t succeed, try, try again.”

Remember to document your activities. Computers and copy machines have made documenting a lot easier than it once was. But if you're going to advocate, you have to keep track of such things as who you spoke with, when you spoke with them, and basically what was said. You need to keep copies of letters and memos, and written transcripts of phone calls if at all possible. In a lot of situations, especially when trying to affect governmental policies, keeping a paper trail is extremely important. For some people, if it's not documented on paper then you didn't do it.

Remember that team agreement is absolutely necessary. You've got to make sure that everybody on your team is pulling in the same direction. Nothing can hurt an advocacy effort’s chances of success worse than having key proponents seeking different goals.

Remember to always be a professional. The former heavyweight boxing champion of the world, Mike Tyson, once said, "My main objective is to be professional, but to kill him." Well, we don’t need to go quite that far. We certainly want to be professional, but we also want to win!

Remember that you may disagree with your adversary, but that doesn't mean that she or he is stupid, that they're wrong, or that they're incompetent. Sometimes we simply have to agree to disagree and go on with life.

Remember that there's power in just showing up. Congress may pay very little attention to a dozen protesters carrying signs walking back and forth in front of the Capitol, but they certainly will listen when 200,000 people gather on the Mall to advocate for a certain cause. The

cumulative effect of many hundreds and thousands of people simply "showing up" adds great strength to an advocacy event.

And you need to remember that you don't have to struggle as an advocate all alone. There are many places where you can find resources to help you in your advocacy efforts. Useful information, suggestions and advice are freely available in all kinds of places today, especially on the Web. The websites of NAD, ALDA, HLAA, and TDI may be of great assistance to the deaf or hard of hearing advocate.

As Robert Schuller once said, "Yes, you can be a dreamer and a doer if you remove one word from your vocabulary: impossible." And deleting that word (impossible) from one's vocabulary can also help in making one a successful advocate. But, as Johann van Goethe once said, "Knowing is not enough; We must apply. Willing is not enough; we must do." Just to know about something or how to do something, that's not enough. You've got to apply your knowledge." And being willing to help is not enough. You've got to, in fact, go out and do it.

In closing I want to leave you with one last piece of advice. Use your personal skills. People in the deaf and hard of hearing community have a great variety of skills. Please, go out and make a difference. Advocate for your needs and the needs of others with hearing loss. And remember that most great moments in history started with just one person, and that "You, too, can change the world!"

Dr. Roy Miller is a past president of Hearing Loss Link in Chicago , as well as a past president of the Association of Late-Deafened Adults. He currently serves as the president of TDI, and is recently retired from his position of executive director of the Missouri Commission for the Deaf and Hard of Hearing.