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EARLY HEARING DETECTION AND INTERVENTION (EHDI)

MARCH 9, 2015

PLENARY II

KEYS TO SUCCESS: COMMUNICATION, COMMITMENT, CONVICTION

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>> KARL WHITE: Please come in and take your seats, and we'll get started in just a moment. We're looking forward to this final plenary session of today. I hope that you've had a great day and learned a lot. We'll give it about another minute for people across the hall to come in, and then we'll get started. So find a seat and get comfortable. We've got a great session planned for you.
(Pause).

>> KARL WHITE: Welcome back to our second plenary of the day. We're delighted to have all of you here in Louisville, and we hope that have you had as productive a day as I have. We are very pleased today to open our final plenary session of the day to welcome Congressman Brett Guthrie to our meeting. Mr. Guthrie represents the 2nd congressional district in the U.S. House of Representatives. He serves on both the House energy and commerce committee, and the House committee on education and the workforce. It's unusual to have a sitting member of Congress be able to attend with us, and we are so grateful to have him here. Very soon as he will be explaining to you, he will be introducing legislation that will reauthorize the federal funding for EHDI programs which is a key element in enabling us to do everything that we have been doing for the last 15 years. So we are grateful to him for his leadership, and his efforts on

behave of children and families who are deaf and hard of hearing. Mr. Guthrie is a graduate of the U.S. military academy at West Point with a degree in economics, and went on to serve as a field artillery officer in the 101st Airborne Division. He later earned a master's degree from Yale University in public and private management. He is a proven leader and well acquainted with issues related to public health, education, and how a little bit of federal money, if it's properly managed, can work wonders in the lives of children and families. He has devoted much of his life to public service at both the State and national level, and we are honored that he would take time from his very busy schedule to speak to us today and to provide us with an overview of congressional action on hearing health. So, Mr. Guthrie, we look forward to hearing your remarks.

[Laughter]

>> CONGRESSMAN GUTHRIE: Thank you so much! And welcome to Kentucky! I represent just south of here, so if you take I-65 south, you have Abraham Lincoln's birthplace, the Corvette museum, mammoth national park, so hopefully as you experience this great city you have a chance to visit the 2nd district as well. Welcome to Kentucky! I was just in a meeting with our NATO allies, and I was with a guy named Lord Joplin who is from the British House of Lords. And he said young man aren't you from Kentucky? And I said, Lord Joplin, you are obviously a man of great breeding and manners, but in America it's rude to ask someone if they're from Kentucky. And he said why is that? I said, well, Kentuckians are very proud people. If we're from Kentucky we'll tell new a minute or-to. And if an American is not from Kentucky, it's very rude to point out their disadvantages.

[Laughter]

So thank you, and I'm here as Vice Chairman of the sub-committee. Some people came to me to talk about the bill. I said I really want to get involved because I was involved in this in the state legislature, and I serve in the state Senate from 1998 to 2008. And it's interesting when you run for office, you don't go around campaigning. Send me to Washington, and I will bring you newborn screening. It's just not something that comes up when you are doing your platform or what you hear about. But when you get elected to office, you find things that are critically important that you never thought about, that you get involved in, and kind of my story with newborn screening, when I first got elected, it was late 1990s, early 2000s. It's 2000 in Kentucky session, when if you remember there was a whole movement about the first three years of life. And the idea was about how your brain did synapses, and they would come together as you were developing and your brain would start clipping off the ones you didn't need. And so there was a big theory that went around the country, and it was actually led by Rob Reiner, Meat Head from "All in the Family," and so the theory was, if you remember baby

Einstein and all of the things out there, the theory was if kids' brains are forming when they're 0-3, and if we overstimulate them they're going to be even smarter. So we can create these super smart kids by early intervention and moving forward. We were going to spend a lot of money as a state going down that path. I thought I owed it to do my homework. I started doing research the first three years. I went down to Vanderbilt University. So I go down and I say is it true that you can create super smart kids by overstimulating them? Because some parents were doing that. That was the big thing. And the lady who did a lot of research said not really. If a parent coddles and holds his or her baby and does things for the baby, the baby is going to develop the way they're supposed to develop. So you can't create super synapses. And she said, yeah, it's true. If you took a baby and put it in the closet where it couldn't hear or see for the first three years of its life, then it would have permanent effect on it but normal stimulation the baby will develop normally. So I went to her, 18 said what if a baby couldn't hear or couldn't see? You are not putting them in a closet. But nature took away their hearing, or took away their screening and seeing. So if you knew about the Kentucky kids now project, it was a massive project by the Governor, and I had been one kind of not going all the way. I thought it was a big spend of a lot of money. So I went to see Governor Patten who was our governor at the time. And I said, I know, Governor, I have been your nemesis in this and I have been questioning the research in a lot of this, but there are two things I want to get involved in he said, what's that? I said it's the newborn screening, and the eye screening. So what we did because newborn you can screen it for hearing at newborn, but you can't really screen for eyesight at newborn. So we mandate in Kentucky by the time you that enter kindergarten at 5 years old, you have to have a screening by an optometrist. So we had a not so famous at the point doctor in Bowling Green who was a good friend of mine, who was Rand Paul who was at that point just a Dr. so I called Senator Paul who was then Dr. Paul. We're going to mandate every parent before they go to kindergarten, take their kid to an optometrist and he said they get eyesight screening by their pediatrician before they go, but quite honestly there will be 2-3% of every kid that goes through there at that level of testing they won't find. This is after the bill passed. So the bill passes, and my wife takes my 5-year-old son at the time who is now 19 to the optometrist to get his screening to go to kindergarten, and guess what? We're one of the 2-3%. So my son got glasses at 5 years old, which he would have been 13 or 14 before he realized he couldn't see what everybody else could see, because he knew he couldn't see it and he would already be behind. So I say that going back to the image of kind of the absurd, if a parent put their kid in a closet where they couldn't see or hear, their brain would never fully develop because they just lose that

function. That if you can't hear when you're born, it has the same effect. So the earlier as you all know, which is why I became convinced the earlier you can catch that and you can correct that, then the less function you are going to lose over time. And so I became very passionate. As a matter of fact, the biggest supporter of it in the legislature. Every time I see Governor Patton at a ballgame, we play basketball in Kentucky, he is usually at the ballgame. And he says I remember you. He has a growly voice like Bear Bryant did. So we're in Washington trying to authorize the early detection. So I'm working on the bill with Lois Kapps. She was voted the nicest member of Congress. So I'm getting to work with her. I was voted runner-up for the nicest member of Congress.

[Laughter]

So since she is a female, she is the nicest member, but that makes me the nicest man in Congress. I came in second to her, but also the nicest Republican. She is the nicest Democrat. So we're working together. It was voted by our staff -- not our staff, but the staff, so I feel proud of that because the people who work with you are the ones who said it and not your colleagues. So we're working on a bill. So tomorrow we think that it will be introduced. We're not in Washington, but there is a pro forma session that opens the floor tomorrow to keep the floor moving we'll hopefully introduce it tomorrow. I wish I could give you a bill number it will hopefully have one tomorrow. This group will be very good at disseminating that information and getting a bill number because a lot of you will go to D.C. on Friday. And that's why we're doing it tomorrow. So when you go see members of Congress, their staff, ask them to cosponsor. I'm the vice chairman of the committee. We've talked to the chairman of the sub-committee that hears this bill, I think that this bill will move forward quickly. You hear a lot of dysfunction in Washington. A lot of dysfunction is over big issues, and there are a lot of big issues to debate. And I'm not dismissing that we organize over some big things and should. If you read our history they've done it since the continental Congress. But things that happen to children that aren't political or partisan, these things do work in Washington, D.C. So I certainly expect it to happen. We're trying to expedite it so that we don't get to the end of your authorization period and we have to do something by midnight. We want to do it before. Two things, is one when you meet your Congressman, if you are not going send a note or e-mail to say here is a bill that's out there. It's the KAPPS/Guthrie bill, and we want you to -- and ask them to cosponsor, and they'll probably say, we have no -- I would have I have no problem with it from what you tell me, but we read the bills before we sign our name to them. So sometimes we do but we might forget. So after a little while, follow up. Follow up is appropriate. Ask them to cosponsor and then follow up until you get an answer yes or no, or we've done it, or we're not

going to do it. I don't know why people wouldn't, but there are people that for some reason don't cosponsor some bills, or just any bills, so you might run into that I don't see any reason not to and what the bill does focus on, because my concern is how early do you detect children from hearing from my experience as I was describing. But what we want to do and it comes from input that you've given is not just focus on the newborn screenings, but you guys have been extremely successful. Kentucky only started this in 2000. So like how many children born in our great Commonwealth before 2000 that got screening. But it started in 2000. But I think that most states do it. And you may be from some states that don't, but I think that it's universal now to get the newborn screening. We want to refocus on the reauthorization is the follow up. Because if you tell the parent their child has hearing issues when they're born, but they don't know or they don't do the follow up, I think that almost every parent would as long as they're completely educated in it. And then the child's not going to get the intervention that they need, and as we know lose permanent ability to recover that as they move -- as they get older. So the focus of the bill is going to be the newborn screening, but also ensuring that parents go through follow up, and they move forward, and in that direction, and have the ability and the knowledge and the options for their child. Because I can tell you that as a parent that found out that my child had sight problems, we immediately started trying to find all of the information, all the questions, how permanent was it going to be? He still wears glasses to this day. He will, unless there is some surgery that fixes it, but he didn't go through kindergarten to about 8th grade struggling until that point people would figure out, well, let's check his eyes. Maybe that's the problem. And he said, boy, I didn't know I could see things -- I wasn't seeing things, because he wasn't seeing them. So I benefited from mandated screenings. My family has benefited. I know that your children, the children that you work with have benefited from screenings. The question is let's move forward now. That's what our focus is. Let's move forward from the screenings to make sure that children get the corrections that they need because we don't want to lose -- because the longer, and every minute you go, and everyday you, go you lose the ability to recover, recover that hearing, even if you can fix it, you lose that. So welcome here, and what do you is important. And the reason I just want to close with this, because sometimes you say I go to D.C., I meet with staff people, or I meet with my member Congress, and you are walking out while another group is walking in. You know, if I hadn't had people to help me do my homework, I wouldn't know this is an issue that I needed to spend time in because I don't have the hearing personally in my family. But because people came and presented, and I did my homework, I realized that, you know, anybody could be in this situation. And though I said I never sit down when I wrote my first

platform early newborn hearing detection, but because people advocate, and people have the most powerful thing that you could have if you are a parent is your story, the story of your child, and how it's detected. We all believe -- some people, if you watch news, they think we don't have hearts. Believe us, all of us do have hearts. And some of my dearest friends that I have been elected that live in my district are people who came with families in health situations. Not necessarily newborn, but Lou Gehrig's disease and others. And you show up, and you get to know people. I get to know their stories, and I will see them out and I will say how is your child doing? How is your husband doing? How is your family doing? Because a congressional district, even though we represent 70,000 people, there are few people that are energetic, active, and showing up for their issues. I mean, we may see a few hundred people in our office over the course of a year, but that's a few hundred people out of 750,000. I always said that you can take the highest paid lobbyist in Washington, D.C., and they're not worth a penny compared to an active group who is organized and networked and bring constituents, and we have people here from your district. I would rather meet with people from my district than anybody in Washington, D.C. So your advocacy is important, and what you are doing is important. And I understand that what we're doing this year to get this through, kind of the quagmire of what's happening in Washington, D.C., is vitally important you to and the children and the people that you serve, if you are not here for that. And thank you for being here, and thank you for being in Kentucky, and God bless you all. Thanks!

[Applause]

>> KARL WHITE: Thank you! So we've been given marching orders, and I think that it was well done. We're lucky to have someone who is so well informed, and so passionate about identifying babies early, and providing them and their families with the support that they need. So the way that this process works, for those of you that don't know, is that legislation has to be introduced and approved in both the House and the Senate before it moves forward. So Mr. Guthrie will take care of getting it introduced in the House. We will need your support and advocacy if you are in favor of this legislation to contact your Congress person, and to get them to cosponsor. But we also need to find people in the Senate to do the same thing. So ASHA has taken the lead for a group of advocacy and professional organizations, and they will continue to do that. They've done a wonderful job. ASHA will be working through us to let you know about what the status with both the Senate side and the House side is, and so we hope that you will all leave here ready to put in place what Mr. Guthrie has challenged us to do but also to do it on the Senate side. So thank you, Mr. Guthrie, very much! We're now ready for our second plenary session. I will have some housekeeping things that I

will deal at the end of the session. But I think that we should move right in now to listening to Rachel Kolb who is currently at the University of Oxford. She is a native of Albuquerque, New Mexico, has been profoundly deaf since birth. She received her bachelor's and master's degree in English literature from Stanford University in 2012 and 2013, and was named a Rhodes Scholar in November of 2012. Since going to Oxford, she has completed one master's degree and is currently working on another one that focuses on accessibility in higher education. She aspires to become a writer and a public disability advocate. She has blogged and published essays in opinion pieces in venues ranging from the "Stanford Daily" and Stanford magazine to the "Albuquerque Journal" and the "International Journal of Medical Students". She also has presented at conferences across the country, including the TEDx Stanford presentation in May of 2013. Most of you are familiar with the TED talks which are billed as "Ideas worth spreading," and I think that I'm excited to listen to Rachel's ideas that are worth spreading today. So we invite Rachel to come up, and to talk us to.

[Applause]

>> RACHEL KOLB: Good afternoon, everyone. Sometimes I try to imagine my life without early intervention. And all of a sudden I realize I can't! Because I know that without the tireless involvement and time and patience of so many individuals I wouldn't have gotten the extra boost I needed to get where I am today. The life I lead would be unimaginable, at least for the person that I am now. Good afternoon. I know I was using ASL, but now I'm switching communication modalities. Can you hear me? Is that better? Good! Can all of you hear me? Okay? I said Good afternoon to new ASL, and now I'm switching communication modalities. I want to show you that there are so many ways to be a Deaf person in the 21st Century, and language is a major factor of that process. I often feel like I'm split in two what was -- Halves, the part of me that enjoys spoken English and being part of the hearing world. I am here to speak you to today in that context, but I could just as easily have chosen to sign. I'm very thankful for my ability to do both. I'm conscious that the skills I have, the ability to switch back and forth between communication modalities. And I want deaf children to have that choice. I want them to have the ability and the skills to pursue something that is really a privilege. The ability to pursue opportunities and to decide what they would like to become in the world. I think that we're all here today because we agree on that point. We promote the potential of deaf children. So how do we give deaf child this privilege of choice? A lot of those opportunities begin with family. In other words, the future success of the children begins with our family support and resources and dedication. For deaf children, early intervention can kick-start this process and help educate and empower their families. Today, I'm going to share

my personal story with you, and I'm going to breakdown this concept of enabling choice, and the three "C's", communication, commitment, and conviction. These are fundamental to the family support I received in the early years of my life, and they are things that I will return to throughout this talk. I will tell you a bit of where I am now. A lot has happened along the way. But I can trace the opportunities that I have had all the way back to the first three years of my life. At the moment, I'm living overseas in the UK where I'm attending Oxford on a Rhodes scholarship and currently working on my third master's degree. I would sit in class working on my dissertation, and my family has a joke that I have a professional student problem. But the setup where I am now is so far removed from what my family members might have been able to imagine when I was born 25 years ago, much less when I was diagnosed as being profoundly deaf.

But it's not news for me to say that on the whole, social expectations for deaf children tend to be low. There are a lot of statistics building around the reduced academic achievements of deaf children compared to their hearing peers. Mainly if you have seen those. I can put some in front of you today, but my goal is not to dwell on those topics, even if we need to recognize that those challenging realities combine with persistent social attitudes about deafness, can make it easy for us to turn toward a story of under achievement. By "us," I'm referring to normative social expectations. Society at large, not necessarily the specific individuals in this room, tends to look at a deaf kid and focus on all of the "can'ts" that come to mind. She might never learn to speak. She might never perform on par with her hearing peers. She might never do "X," "Y," "Z." hold on. Instead of doing this, we should be pouring all of our energy into that far more productive word, "can."

A quick note before I continue with this idea of abilities, which is a far more exciting topic to me than so-called disabilities. I'll be the first person to tell you that being deaf in a predominantly hearing world can, indeed, be a challenge. I've done it. It's hard. But it's mostly hard because the dominant hearing mode of going about everyday life, spoken language, listening, overhearing, auditory feedback, and how that influences language development, and even more. None of those things are designed for deaf people. There are so many access and awareness issues that could change in the world, and I'll put those aside for another day. I firmly believe, really I know, that deaf children are inherently capable of doing anything hearing children can do. Except hear, of course. The way they do those things may look different, or it may operate on a different timeline, or it may require different strategies and a whole lot of support. I should also mention that there are different kinds of success by primarily academics, but other people have different

unique skills and capabilities from specialists to technical knowledge. What I would really like to emphasize is that deaf parents will take their own excellence, whatever that excellence is. And that ability, that choice, that empowerment begins with my first point, communication. Study after study has shown that the deaf kids who are the most successful are the ones whose parents have communicated effectively with them from an early age. My family was one of those families. I think that's the key reason I'm here speaking to you right now. To be honest, I grew up feeling like the level of communication I got at home from my parents was pretty ordinary. I thought there was nothing that unusual about the level of support and love that my family gave to me. I took them for granted, because it only seemed normal that every family would be so involved, too. And it's only now as an adult that I am able to look back and realize that's not true, even if it should be. As you might have guessed, I was born deaf. Here I am. As a baby with my hearing aids, sort of falling out of my ears there. I was born in the days before postnatal screenings at the hospital which we had been talking about at this conference, detected deafness immediately after birth. I have a cousin who is deaf, and so it's genetically in the family, but both my parents are hearing. They knew almost nothing about deafness when they had me. My mom maybe knew a few signs, "milk," "more," "A, B, C," but nothing else. That was it neither of my parents had ever anticipated raising a deaf child. They took me home and thought I was a hearing baby and went about their lives. And I think for a lot of hearing parents who have deaf children, there's a moment when it becomes clear that this child is different. Maybe not an alien, no, but still this child is not hearing. My parents started to suspect that I was deaf when I was around four months old. But they didn't receive confirmation until two months later. I was six months old. We were at home, my mom and dad, and the fire alarm went off in hour house. It was a very loud noise, and my mom jumped in fright when she heard it. Her first thought, "Oh, no. The baby."

So she ran to the next room and got there and expected me to be upset and crying, but I was just sitting there playing with some toy on the floor. My mom watched me and she knew something was up. That was the beginning. From that moment, my parents had many choices to make about how to raise me. In the end, once they had sought out guidance and had various options on the table in front of them, when it came down to what this: Them, and me. That was it. They came home each day and I was there. They were the principal adults in my life and my primary caretakers, and they knew that their actions would have a far greater impact than anyone else's. All of the early intervention resources and skills and professional guidance, all of those things, did make a big impact on my life. But they made an impact because my parents put them into action. I know there is a variety of people here today. We all have different perspectives and

skills and backgrounds. We all care about empowering young deaf children. What we need to work towards as well is empowering families first and foremost. So that parents have the tools and the positive self-belief to help their children. Being a parent, especially a hearing parent, of a young deaf child is hard. It's completely unknown and unexpected. There's a steep learning curve. It's emotionally draining. There is a lot of pressure, and a lot of advice to make the right choices especially where language learning is concerned. Parents are often told, quick! There's only a short language learning window! I've only started to appreciate those immense pressures as I've gotten older. Part of me cannot imagine what my parents went through. Of course, there were wonderful parts about it, too, and parenting is hard work no matter how it comes about. So my parents took their first steps on our family journey right after the fire alarm incident. They were observant, and they took me to my pediatrician right away. That pediatrician then referred us to a hearing specialist. That was when they found out. I was deaf. I wish I could go back in time to that moment and say, "Hey, mom, dad, roll up your sleeves. It's show time. Get ready to discover a world you never knew existed."

And, indeed, they did. My parents are very driven and motivated people, and they are also very committed once they put their minds to something. Finding out I was deaf, if I'll be blunt, was a shock and a big challenge, and looking back I can't speak very much to that aspect of their experience. But I can try to speak to their commitment. I can mention all of the things that they do, and all of the other people who were involved. My parents did their homework right after I was diagnosed trying to figure out how to communicate with me, how to send me to school, how to do all of those things that suddenly seemed much more complicated. Early on, they decided they wanted to learn sign language. The story behind that is an interesting one. They decided to learn sign even after the first doctor they talked to told them not to. He thought if I signed I would never learn to speak. It was another manifestation of this old oralist idea that using sign impedes the development of normative spoken language. That is an idea that's since been disproven in the scientific literature. And my mom didn't buy it either. She thought, "Well, wouldn't two languages be better than one? Didn't it make sense to give me a visual language I could access?" Both my parents wanted me to have that tool to communicate with them at home, but also to have access to the Deaf world if I wanted. I cannot emphasize enough how grateful I am for that choice. While I'm on the subject, I also want to say something else about sign language. One of those things I took for granted as a kid was the fact that both my parents signed. Both of them communicated well with me. I always felt empowered to understand and interact with both of them. Yes, my father, as well as my mother. See, here I am with me dad. Now,

fathers of deaf children are far less likely to learn to sign than mothers, from everything I've ever read, seen, talked about, or witnessed. I can't tell you all of the reasons for this, but I suspect part of it might come back to the social expectations we can have for men. Women are expected to be nurturing and communicative, while the man it's been more socially acceptable to be disengaged and less communicative. My dad wasn't that way. He worked at sign, and he learned. After encountering too many stories of deaf people who never felt like they could communicate with their fathers, I wish all men, all fathers, would embrace that communication challenge exactly as he did. So when I was six months old, my parents signed up for ASL classes, bought ASL books, and started learning as much as they could. As they were taking those first steps toward learning to sign, becoming children themselves in a sense with that unfamiliar language, I was taking my first steps toward the hearing world. I was fitted with hearing aids when I was six months old, and I started speech therapy right away. My parents wanted me to have that additional tool in my toolbox to engage with as wide a variety of people as I could. Speech and speech therapy would stay in my life for 18 years, until I left home to start college. I always felt like the people in my life, from my parents, to my speech therapists, believed in me, and so I stuck with it even when I felt frustrated. I do not remember any time in my life when I didn't have both languages, English and ASL. I really do believe the more language we can give children across different communication modalities the better. It takes a village to raise a child, especially if that child is deaf. A lot of people came into our lives in those early years, and my parents were committed to learning from them as part of their journey. They had early intervention specialists come to our house for regular visits through the local New Mexico program, Step-Hi. They met and talked with other successful deaf adults, which from a role model standpoint I think is essential for deaf children and for families in general. I started preschool at the New Mexico School for the Deaf as early as I could have, when I was two years old. 23 years later, I still have not left school. I told you I had a perpetual student problem. My preschool teachers supported me in the classroom, and helped my parents with strategies they could use for communication and language development at home. Later on, when I entered a mainstreamed school, I started working with some incredible sign language interpreters, some of whom I still consider my friends. I also had a network of other deaf education specialists checking in with me. So, let's see. At this point in my story we have: Pediatricians, audiologists, speech therapists, sign language teachers, teachers of the deaf, older deaf mentors, early intervention professionals and specialists, sign language interpreters, and, of course, parents and other family members. That's quite a village, right? My younger sister, who I haven't

mentioned yet, also learned to sign as her first language, even though she's hearing and became part of our family's communication journey. So here are the three of us all together. I woke up Christmas morning. And I have no idea what I'm signing in that picture. Your guess is as good as mine. The advice of all these people had an impact on my parents and on our family culture. My parents made sure that I had support from all sides. But I want to come back to another idea, which is what had even more of an impact was how my parents used that advice. They got creative, and they put time and energy toward supporting my development. I want to give you a few examples. One, my parents worried about me struggling with learning written language because I lacked the constant auditory input that's so valuable to learning English. So they plastered index cards with words on them all over the house. The chair said "chair."

The picture frame said "picture frame."

The mirror said "mirror."

And so on. So probably labeled a thousand items in the house. If you walked in, you would have been overwhelmed by all of those written words. It would have felt like the flurry of paper envelopes that chase Harry Potter out of the fireplace at the Dursleys' house. But you know what? Those words stuck. Look here at how many letters I have on the walls in my childhood bedroom. Two, my parents read to me constantly, which I loved. That is, I loved it until I wasn't all that old, probably about five. I turned to my dad one night when he was reading to me as he did every night, and I told him, you read too slow!

[Laughter]

Because I had started getting to the end of the page, wanting to turn the page to see what happened next, and he was still all the way back here on this side.

[Laughter]

So I grabbed the book from his hands, and I told him I would much rather read it by myself, thank you very much.

[Laughter]

And so I did. And so I continued to, with many books after that. Now I've got a master's in literature, so I think that kind of reading my parents encouraged took me pretty far. Three, my parents incorporated language constantly into our daily interactions and games. One thing about deaf and hard-of-hearing children is they never acquire incidental information in a hearing-world context. They never overhear anything in their environment. Everything they learn, through language, has to be given to them in a very direct, very visual, and very intentional way. Communication has to be intentional, and my parents were aware of that. They described to me all the time during our games and talks, they signed to me constantly about the past, and the present, and future. In fact, things like

this, like visiting the zoo or a farm, they'd talk to me about it for days afterwards just to incorporate that language. My mom says that kind of intentionality made her a better communicator for all areas of her life. And it made her more aware of how conversations and social relationships worked among her friends, or in the workplace. She worked harder to be clear, and to cultivate understanding, and I can only imagine how eye-opening that was for her. Four, aside from our family life, my parents made sure I felt like I could access outside information, too. Whenever we would go out to a museum or a guided tour or something, my mom would sign everything and interpret everything for me. I remember once, when I was 5 years old, I wanted to go see the movie, "The Lion King" so badly because it had just come out in theaters. That was the popular movie back then. But it wasn't captioned. So my mom took me to the movies one day, and sat there with me in that dark theater, and she interpreted the whole thing for one hour and a half. When I look back, I feel overwhelmed by thinking about family moments like that. I feel overwhelmed by thinking about how much my parents loved me and how much they wanted me to succeed. I could go on, but in short, the way my parents raised me did start with a village of early intervention support. It started with the people who had knowledge to share, skills to use, and advice to give. Those people taught my parents about sign language, about hearing aids, audiology, speech, child development, about teaching and reading and using language, about the million complex things that go into a deaf child's development. When I reflect on it, early intervention and parent support were two sides of the same coin in my life. I would not be as successful today without either one. Somehow, my parents figured out how to take advantage of the wealth of resources around them, and then they figured out how to make and act upon the decisions they thought were best for me. They gained knowledge from the people they met, all of those wonderful people, but most importantly they bought into that knowledge for themselves and then took action. And you know what parents like that can do for a kid? Give that kid confidence. My parents always made me feel like I could do anything I wanted to. "can't," that word wasn't in their vocabulary. And so I believe that I could do anything. My parents encouraged me to try hard, to work hard, but they always made sure I had access to the hearing, as well as to the Deaf world. Again, the other people around them lit this fire and helped them think this way. One of the most important moments that ever happened in my life arose when I was just a baby. I was starting speech therapy, still pretty early on, and one day at the end of a speech therapy session my speech therapist pulled my mother aside. "I want to tell you something."

She said. "Never put limitations on this child. She can do anything she wants to."

I started this talk today by saying more or less the same thing

this woman told my mother, that deaf kids with the right support can do anything they want to still, hearing this from a professional at an early moment was such a revelation for my mother. It was probably one of the most extraordinarily significant things she had ever heard. Maybe some of you professionals here can be that person for a parent today. Both my parents took that belief in my potential firmly to heart. They took their commitment and they took their communication skills that they had developed, and they paired those things with a deep-set conviction in my abilities. Once they believed in me, never looked back. They became my biggest advocates, and this enabled my own self-belief.

If we are convinced that deaf kids can do anything they want to, if we believe in their remarkable potential, but if we also recognize the firm commitment and the support it takes to get there, well, then, imagine what we can do. I'm not saying that it will be easy. It will be very hard, and there are still questions that we must answer about how to keep striving for that excellence. Together we can work so that parents and families get a wider range and strategies. We can help them feel empowered, because I do believe that family involvement and support is where all of the magic begins. We can work on all of the other systems in place to support that core family involvement: Our schools, our audiology clinics, our ongoing education and state Early Intervention Programs. In the end, the only authority I have is my own life and my own story. But even based just on that, I'd like to invite everyone in this room to set their goals high, and also to embrace the three principles I've alluded to today: Communication, commitment, and conviction for our children. As well as a healthy dose of humor and creativity, which are always useful tools for any enterprise. With our clear communication, with our commitment, and with our conviction, we can promote the success of deaf children and their families, in whatever sphere of society they go into, and in what whatever endeavor they choose. Thank you very much.

[Applause]

>> KARL WHITE: Thank you, Rachel, for providing us with such a great example of what happens when we don't put limits on deaf children. And how central it is to have families that are empowered to support and to learn about how to be the best parents possible so that they can make their children the best children possible. You've given us a great example, and much to think about, and we appreciate it.

In just a moment, we will present the 2015 Antonia Brancia Maxon Award for EHDI Excellence. Just before we do that, however, I'd like to remind all of you that we will start again tomorrow morning. Breakfast will be available at 6:45 A.M. there will be the shared learning sessions at 7:00. Exhibits will be open at 7:00 A.M., and we hope that you will take the opportunity to visit the exhibits.

Not only do they provide some financial support for this meeting, but also they provide many tools and information that is essential for us to provide the kinds of support to families that Rachel has talked about, and to do our other work to make EHDI programs successful. We want to give particular recognition to our silver-level sponsors this year, Otometrics audiology system, Natus Medical Incorporated-Peloton, and Vivosonic, and also to Oticon pediatrics who is a bronze-level sponsor. We also remind you that if you are presenting a breakout session tomorrow at any time, that you make sure to go to the speaker ready room. This afternoon would be great, but tomorrow morning would be acceptable as well to make sure that your presentation file is loaded on the computer so that that will work. The speaker room is in the Brown room on this floor. For those of how are checking out on Tuesday, luggage storage will be available. If you just bring your luggage to the bellman stand near the hotel's front desk, they will have a space that they can store it for you until the meeting is over. For lunch tomorrow, we will, again, have the grab-and-go items available for purchase. You will need cash for those purchases. Today it was a little slow. We apologize for that. We think we've worked with the hotel, and identified some ways that it can go much quicker tomorrow. So that will be available. There is an ATM outside of AJ's conservatory.

So also I would remind you that a little different from past years, the reception was last night instead of in the past we've had it on Monday night. But last year we tried holding it on Sunday night, and that was so successful and we got a lot of feedback from people that they appreciated having Monday evening free. So do you have Monday evening free, unless you've made other arrangements, and we hope that you will enjoy Louisville. And then be ready bright and early tomorrow morning for the second day of our conference. So now we'd like to present the Antonia Maxon Award. And is there a slide advancer up here? Maybe you can just advance it when I ask you to. That will work. That's okay. Thanks. So each year we ask people in the EHDI community to submit nominations for the Antonia, Bronson, Maxon Award for EHDI excellence. Each of this year's nominees has made outstanding contributions to EHDI programs. In my mind, the people nominated for this award really are super stars. Their passion about what they do, innovative, and persistent. They invite each of the people who are appearing on this screen here maybe. There we go! To come up and join me on the stage. Their information about them is available in your program book. So we have Julie Beeler from Tennessee. Diane Miller.

[Laughter]

[Applause]

If I could ask you to hold your applause until they're all here. So Diane Miller from Nevada Hallie Morrow from California. Elizabeth Seeliger from Wisconsin. Susan Wiley from Ohio.

[Applause]

We have all five of them here. So we're glad to have you here. I'm honored to be on the stage with them at the same time. They really have done some remarkable things, as you can read about in your program books.

We have a gift for each of them that is a book that is a recently published best seller called "A Path Appears."

And, Jamie, if you could come up and hand them to them. The title of the book comes from a Chinese philosopher named Lu Xun who said hope is like a path in the country side. Originally there is nothing, but as people walk, this way again and again, a path appears. In other words, as a result of being willing to take a new path, and by being persistent in following that path, we can find the solutions that were always there but unrecognized. A path appears. So with this copy of the book that we're giving you today, we want to express to each of you just how much we appreciate what you have done for EHDI, and I have a brief clip from a PBS special about the book that I would like to play and have you reflect on how the principles in this little video really describe the kind of innovative and important solutions each of these people has contributed to EHDI. So if you could play that clip right now.

>> A path appears. The title is from a prominent Chinese writer who said that hope is like a path in the country side. At first there is no path, but as more and more people walk again and again, a path appears. Maybe a solution appears. It's about innovative strategies for making a difference. In half the sky, we were asking how do you begin to tackle seemingly insurmountable problems?

>> Is that red door? Is that a brothel?

>> He doesn't have a pulse.

>> In a path appears, we take it to a new level. We look at the roots of vulnerability and talk about solutions that really address those roots.

>> It's easier to look at problems outside of the country than it is to look at stuff in our own backyard.

>> 300,000 girls go miss every year.

>> In the United States?

>> In the U.S., and 100,000 of them are sold for sex and other things.

>> They use stories to capture attention. Because stories are powerful.

>> That's her.

>> That's her?

>> That's Naomi.

>> From Haiti to Chicago, from Colombia to Kenya to Boston, the central problem as we see it is poverty.

>> This trailer is a home where they said they may have 14 people at a time.

>> Yes.

>> Poverty is much more than just not having enough money. It's not having hope.

>> From sex trafficking, to teen pregnancy, to unemployment, to substance abuse, to violence against women. Cheryl and I are traveling to new parts of the world.

>> It's overwhelming. I don't know if I've seen this much despair before. You're lucky if you just are struggling. The vast majority are just alive.

>> Cheryl and I are sharing real human stories of struggle and challenge and transformation.

>> I am tired.

>> Are you tired?

>> Yeah.

>> Are you ready to go today?

>> No.

>> None of these problems exist in isolation.

>> She had 14 kids.

>> And those babies are going to grow up poor. And they're going to remain in the cycle of poverty forever.

>> We now understand how a tiny intervention can have a transformative impact on a child's life a generation later.

>> Oh, wow! Yes.

>> It's important to keep bearing witness, keep telling the story.

>> Our world is now a global village.

>> When we look at these monumental problems, they seem so daunting. But we can change the course of history. We can set these young children on to a much more promising path.

>> One girl at a time.

>> Yes.

>> It all goes back to early childhood intervention in this country and, of course, around the world.

>> What you have to do is dream about the future and have hope for the future, and that's how the future changes.

>> There is a solution. It takes the parents, it takes the teachers, it takes the whole community. It's just up to us to care. I definitely walk away feeling hopeful. I think that we are capable of great things.

>> Everyone everywhere gave half an impact to humanity, through hope we can achieve our dreams. (music).

>> KARL WHITE: So we hope that you will enjoy the book, just like the people described in this book, and in the film clip here. Each of you has found solutions because of your vision and persistence. In the words of the book that were repeated in the video we just saw, "All of you have demonstrated with your actions that what you have to do is dream about the future, have hope for the future, and that's how the future changes. Everyone everywhere can have an impact on

humanity, and it's through hope that we can achieve our dreams."

So the selection committee had a difficult decision because all of these people have demonstrated that kind of hope and achievement. Recognizing the wonderful accomplishments of each person standing here on this stage, we have selected Elizabeth Seeliger as the recipient.

[Cheers and applause]

So as the recipient of the 2015 Antonia Brancia Maxon Award for excellence. So Elizabeth?

>> Elizabeth Seeliger: Thank you. Wow. Okay. So I am completely speechless. And for those of how know me well that is a really difficult task.

[Laughter]

I guess I would like to take a few minutes just to pause and acknowledge that I think one of the statements in that really powerful video was that together we can do great things, and I certainly do not deserve this award in isolation because just about every single thing I've done in my life as far as EHDI is concerned has involved partnerships and relationships with other people. So I am going to first say amongst all of these amazing ladies up here who feel more like family than friends and colleagues, I'm really honored to share the stage with you. It's their guidance and inspiration and wisdom that keep me dreaming big and moving forward. So thank you, ladies so much! And then I would also like to take a minute to acknowledge my Wisconsin Sound Beginnings Team. Wow. I never get nervous. I'm really nervous all of a sudden. So in times of relative calm in our State EHDI program, my team is creative and steadfast and dependable and in times of crisis which we all know comes up at least twice a year when grant reports are due, they step up and step in without hesitation. And in 2013 out of 66,000 babies important in the State of Wisconsin, we lost 86 to follow up. And I would like to just take a moment to acknowledge my team. So Connie, Rebecca, Gretchen, Susan, and Christie, would you please just stand up for a second and share this award with me?

[Applause]

I think that we also know that we couldn't do work that we do everyday if we didn't have such incredible support at the federal level. Irene and you are so approachable and make my job so easy everyday, and are such a guiding light in our field, and so we're so honored to work with you and Marcus, as well. I mean, who else can make data interesting and fun?

[Laughter]

You certainly do. And Karl I once stole your computer. I feel like it has changed our relationship forever, and what a way to make lemonade out of lemons. So thank you for that. So I was just reflecting a little bit when I got the letter of nomination from my team, so, of course, that made me cry really hard. And why I love my

job so much, and one of the shining moments of my career has nothing to do with what was on that letter. And in 2010 the State of Wisconsin passed legislation to have insurance companies fund hearing aids and cochlear implants. And that was one of those scenarios where I kept hearing over and over those really powerful stories from families about how they desperately wanted auditory access for their kids and couldn't financially afford it, or the incredible sacrifices that they were making in order to make that happen for their children. And so as many of my days at work do, it starts with a problem, and then I get to go out and start to discover solutions. And I got to work with offices I never knew existed, like the office for the commissioner on insurance. Who knew? I got to find extended partners that I never knew existed. I got to find unlikely advocates in my communities. And when I got to the point where I realized that this was not a problem that I could solve alone, I got to work with our Wisconsin families for Hands & Voices organization, and I got to see the true power, you know, in my field. And that is the power of parents and their children. And when that bill came up in front of our legislature, and there were hundreds of families and their children who showed up, I got to take a really big step back and watch deaf and hard-of-hearing children stand up and testify in front of their legislatures about what that meant to them. With articulation, and confidence, and grace that I could only hope for my own children, and I realize that these kids had been born in a time when EHDI existed, and that in some small way I had something to do with that, and that's why I continue to do my job and will forever be proud to be a part of this field. Lastly, I believe so strongly that the reason we can do what we do is because of relationships, and I commit to all of you that I will continue to try to improve the world for kids who are deaf or hard of hearing and their families one relationship at a time. So thank you so much for this award!

[Applause]

>> KARL WHITE: Before closing today, we have one more award we would like to make. This is a data that I hoped would not come. But Irene Forsman announced that she will be retiring on April 30th. So after more than two decades of leading EHDI in so many different ways, Irene Forsman, if you wouldn't mind joining me here. Irene shuns the limelight. So I'm ruining my relationship.

[Laughter]

Irene's steady hand on the rudder has guided us through storms and droughts, and good times as well. It's because of her wisdom and persistence, in my opinion, that has enabled the EHDI program to not only survive but to prosper. She is the epitome of what the authors of "A Path Appears" are helping us to understand how to bring transformative changes. With no fuss or bother, she just moves steadily ahead making EHDI what it has been. So we will miss you, but we will not forget you. You have told me that you are not going

to go away. I'm grateful for that. And we hope that you will come back frequently. You have a lifetime free registration at this meeting.

[Laughter]

So we hope that you will be here often. This copy of "A Path Appears" has been signed by dozens and dozens of the people here, and we also have a plaque that reads: Honoring Irene Forsman for a lifetime of making a difference in the lives of children and families. So thank you for all that you are, for all that you've given us.

[Laughter]

[Applause]

[Applause]

>> IRENE FORSMAN: Thank you all. I can only reiterate what Elizabeth said, and what a dear friend of mine who happens to be the most famous midwife in the world, Anna MacArthur Fellow says everyday it's relationships that count, Irene. It's personal relationships that count. And I firmly believe that. I've been fortunate to develop personal relationships with many of you. It's been a pleasure to work with you. We've achieved a great deal. But the achievements are not mine. They are yours. They really are yours. And I'm sure that you will continue to go forward. I'm succeeded, I hope, by my able colleague over here, Sadie Silcott who is smart, and she can take the program forward if they let her. There is this little government thing of, you know, you have to compete for positions, but we're hoping that goes well. I need to tell you that I'm not going far. Nearly everybody has my phone number.

[Laughter]

Many of you know where I live and have been in my house. I'm not leaving. And I have a brother who lives in San Diego.

[Laughter]

So I'm not going far. Thank you very much for all of your support, for all of the years of your support. And thank you, Karl, for being you. Thank you.

[Applause]

>> KARL WHITE: So that concludes our afternoon session. Have wonderful evening. Come back tomorrow and continue to enjoy being part of the EHDI family. Thank you!