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EHDI: The Community Code of Kindness

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3:10 – 3:35 (MDT)

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(Captions provided by a live Captioner.)

The Community Code of Kindness.

>> Captioner is standing by.

>> Hi, everyone, it's almost 3:10 so we'll go ahead and get started. My name is Amy Sanders, and I'm the room moderator for this session. Thank you all for coming today. Before we get started, just a few quick reminders. We have three different exits for this room. There's one located at the front right behind me, one to our side, and one behind us. If you're looking for the restroom, go out the back and it should be to your right.

I also wanted to let everyone know that I'm handing out some information about the presentation today titled "Community Code of Kindness." If you didn't get one, feel free to raise your hand and I'll give one to you. Otherwise, I'll put the extras at the back of the room. So I'll hand it over to our wonderful presenters for today. Thank you.

>> JANET DESGEORGES: Good afternoon. Thank you so much for joining us this session. Who wouldn't want to come to something called the Community Code of Kindness? So I guess the other people who didn't show up should've been like the code of antagonism, anger, controversy. Why would we even need to even talk about such a thing as Community Code of Kindness. We have 25 minutes to explain that together. We're here as a group. Today we're going to each introduce ourselves, and before we introduce ourselves, we'll talk about what the summit is and the collaborators. We did this project along with family voices, national cued speech association, hearing first, and national center on deafblindness. Are there any representatives from these organizations here in the room? Awesome. Thank you, yes.

So anyway, I'm Janet DesGeorges with hands and voices and I'm pleased to be a part of the team today. I'm also a mom of three daughters. Our youngest daughter Sarah is deaf, living her best life.

>> And.

>> CHERI DOWLING: I'm Cheri doweling with the American Society for Deaf Children. I'm also a parent of two children. My oldest is 29 and is deaf with intellectual disabilities. He's also living his best life right now.

>> Awesome.

>> GAYLA GUIGNARD: I'm Gayla Guignard, I'm a specialist in this area. I'm also a mom of a young woman with intellectual superpowers. She is not deaf or hard of hearing but informs my life, let me tell you.

>> Awesome.

>> We want to give you background on why this project and why now. We created at the FL3 center we had goals around national partnership, so we had the opportunity to think we actually have a list of 47 national organizations that we collaborate with in some way, but one of our goals had been to start thinking about the opportunity to bring together the group of organizations that in some way have a direct parent to parent support mechanism within their organizations. we were not trying to be exclusive as much as saying can we create a table where organizations like ours have been around for a really long time could have an opportunity to get together. What we really did in our first meeting was think about what are some of the needs ‑‑ we went through kind of a swat analysis, what are some of the needs within the EHDI system, and we covered all kinds of topics. Let me tell you. And you've been in rooms where problem admiration is not hard to get to because there are so many challenges in this system. We wanted to ask and challenge ourselves as parent organizations what is something that we might think about doing together. So as we, we had not gathered at a table these particular organizations in a really long time if at all. So we wanted to give ourselves a chance to hear about each other's organizations, what we're doing. We learned so much along the way. It was really fun. But in the end when we had this huge list, we just threw out a survey monkey is and said what would we like to look at together. It came back to this central theme, not about what we could do as organizations but what is it that families need from us as organizations. And what does it feel like for families who report historically that the it was kind of like whoever gets to the family first wins, this idea that, that we're all in competition somehow for the lives and the decisions that our families made.

And we wanted to address that. So and we needed to do it in, in a way that's made sense, within our time capacity, so you're going to hear why we came together and started talking about the community code of kindness. I want to say that the journey was part of the outcome. As we began to meet over time, we learned so much from one another, even the absolute thing I hate the worst is wordsmithing. One of the things that wordsmithing does is bring in the perspectives of one another to do some learning, even around whether we should use a dash or a slash in certain terminology in that word. So the process along the way was really great. And then I just also want to encourage you at the end of this session, when you walk out, you can adopt this, feel free, we would love you to, but also think about the challenging relationships you're in right now and think about what you could do maybe using this model towards coming and finding common ground together.

>> So really when we started this process, it was, it was actually we did it very quickly overall. But you all have the document that is our final document, and it really is, it can be changed. It can be added. We can add organizations that are interested in joining us along with this, so if someone's interested in that, they're going to contact Janet and let her know. But really we all came together and thought about, you know, what is our mission, and all of our missions are pretty much the same. We're all here to help and support children who are deaf and hard of hearing. And we took that and ran with it, and developed this, this document, and I'm not going to read it all to you but we do have, we have three commitments that all the organizations committed to. And then we have our agreements of what we all agreed to. And it was really easy I think to make this happen. I think we, we all, we all worked together really, really well. So that was really exciting. That's me.

>> So our first commitment, do you want to switch the side?

>> Oh, yeah.

>> So our first commitment is that we will be kind and respectful to anyone with lived experiences as families with children who are deaf, hard of hearing, Deaf Plus and deaf‑blind. We will do this by carefully listening and is talking to many people and communities because we want to understand. So ultimately, we developed this because we all really want to work together. I know with ASDC, our whole philosophy is why reinvent the wheel if another organization has done it, let's collaborate, let's work together, let's share it, let's listen to the people that are in the know when we're dealing with deaf children and deaf‑blind children and children with Deaf Plus. I don't particularly care for Deaf Plus, but children with disabilities.

>> I don't particularly care with deaf with disabilities.

>> That's fine, but we work together.

>> That's part of the conversation.

>> Exactly. Exactly. So that's the first commitment that we've made that we will all respect each other's opinions, and get along and move forward.

>> I joke before we got started, I said should we start with prayer because so many people think that you can't put us together. A.G. bell, American Society for Deaf Children, Hands and Voices and that's really just simply not true. For us I think it's very fair to say it's not so much about how it is a child's going to communicate. It's that they communicate, they learn language, they thrive regardless of what choices their parents, not us, make for them. That's the most important thing, and so when we look at this next commitment that we'll be honest about anything we don't know enough about concerning the experiences, resources, and topics regarding ‑‑ related to children or adults who are deaf or hard of hearing, deaf‑blind, Deaf Plus, to avoid providing misinformation. I've heard it more than once, you probably have too. Maybe you've been at a booth and you've heard somebody mention something that's like way out there. You're like, no, children with cochlear implants don't start developing their speech perception skills at 9. There's not some automatic thing that happens. Or everybody doesn't learn to listen and talk, and everybody doesn't sign or everybody doesn't cue.

And so the reality is, we saw ourselves better together as organizations because it's not about being in competition with each other. It's about lifting all the families up so wherever they turn, they're going to get a really important message of you can do this, and we will help you in our own specialized ways.

>> I just thought of a story about this. When I was a parent, I feel like I had gotten some pretty good information about sign language, American sign language, listening and spoken language but the only thing I heard about cued language or cued speech is that was not the language deaf adults use and sort of that in that tone so I sort of had this reaction when I heard of anyone talk about that. I sort of, you know, clinched up a little bit. Well, I happened to meet another mom in an exhibit hall at a conference and we were chatting and like I'm hey, what do you do with your kid and she was like we use cued speech and I'm not kidding I was about to say those words out my mouth well that's not the language adults use. The clouds parted A voice from heaven said, Janet, listen. I didn't say anything and for the next 20 minutes she talked about why they were using this, how they were using it, the benefit it had done for their son, and I walked away from that one 20‑minute conversation for the rest of my life anytime I hear anyone talking about that as a strategy or as a part of their tool kit with their child, I have a positive feeling about it. So you need, we all need to ask ourselves, what do we think about when we hear, you know, any given communication, language, methodology, does it trigger, does it trigger a reaction because we don't know enough about it? Or when people share their lived experience, we want to just immediately go yeah, but. Yeah, but. Instead of just, like, opening your mind and heart. Even if you don't, even when you're done and don't quite agree with it, you have to be open‑minded, and I think that helps you be able to say we need to be more honest about what we don't know.

>> So Janet, you're saying you changed?

>> Yeah. Yeah.

>> Yeah. It's amazing how that happens.

>> Uh‑huh.

>> Yeah.

>> All right. So this is not planned. I was in a different conference recently, and the presenter put up a quote from A.G. Bell from the mid‑1800s. And you know, it was a quote that A.G. Bell said, Alexander Graham Bell and I've seen this used in a lot of different things. We're not up here because we don't ‑‑ because nothing's ever ‑‑ bad has happened between the war on methodology, right? There is a deep, long history that families have been subject to, that organizations, even at this conference I'm telling you I can walk across from one hallway and listen to a lecture to the other and even the research that's put up, I'm, like, well, that shows part of the picture but I thought it was a really unfair use of that quote from a long, you know, whether it was a long time ago or last week, we're on social media all the time, and something I heard someone say was that when I walk ‑‑ she said this. When I walk into a room and that, that is not represented in this room, I have their back. And I think part of this process for us is building trust with one another and to not use, use what we are providing or supporting as a sword or a weapon against one another.

And I think we have way more that unites us than divides us, so my section is our commitment was we will recognize the resources other organizations provide and refer and share appropriately. And you know, it's a, for us at Hands and Voices, we, we're sort of the now what organization. Like, okay, you sign and/or you speak or combination or cue, you have deaf plus, deaf‑blind children. Now what? And so we tend to focus on more the topics and things that unite us all in terms of that. So when we get a family who explicitly asks us, can you define or explain or I want more resources about cued language, we send them to the national cued speech association. Or one day at my desk within 20 minutes a family called and said I need more information about listening and spoken language, I'm yep, I got your back. I'm, I'll send you this e‑mail and here's some different links. They were almost all to hearing first or A.G. Bell. Those are not the kind of resources that we seek to really keep here, and then 20 minutes later, it was just the epitome of the family journey and family needs, which was a family calling and asking for information about American sign language. So, to American Society for Deaf Children. And we really worked to keep our list. One of the things we learn while we're together over the course of this year and a half are the resources that each of are us building where we're like wow, I didn't know about that. So we want to make sure that we have the resources. I went to my first conference last week that had some sessions on deaf‑blindness. I realized how little I knew about deaf‑blindness and it was such a great opportunity to learn, but thinking about when families who have kids who are deaf‑blind, the national deaf blind center or whatever. So I think this was part of our commitments, and if you think about wherever you're at, a family‑based organization, an audiology clinic, an early intervention program that focuses and specializes on American sign language, we have to all I think make a commitment to know one another's resources and understand that it doesn't, it doesn't harm our position to share with families so that ‑‑ we want families to do informed decision making.

>> Janet, if I may, I want to tell a story too. Something that came out of our work together, and again, there were several, we're just three of the organizations that participated is that A.G. Bell was asked to write an article for parent magazine and in the article when I had a small place to put other resources, I mentioned their organizations. I have known Janet and Hands and Voices for 20 years and I'm getting to know Cheri. I did that because I felt confident, I had spent time with them lately, I was confident about their resources not because they weren't good enough to begin but because I took the time to take a deeper look. I appreciate said that. But the other piece of that is that when you decide you're going to get along with other people that means don't talk about them. So you talk about Janet or Cheri unless somebody's going to catch me saying something good or something positive or shedding a kind light on them.

>> So how are we actually using this piece of paper? And hopefully nobody has it in the piles in their offices that it's lost somewhere, and you're thinking oh, I think it's here somewhere, I know it's here somewhere. I actually have mine framed in my office, and have it up on my wall. You know.

>> That is so impressive.

>> I had to do it. And that's what I should've taken a picture of and put on here, but I didn't. But I have mine on the wall so how can you use it? You can use it as education and awareness, share it on your web site. We have it on our web site. I think you guys have it on your web site. You have it on your web site. Hopefully the other organizations haven't looked at all them yet to see if they have it, but you know, add it to the web site. Have people refer to it. Have it prominent so people can actually see it. Like I have it in my office. My office is in my house so not a lot of people see it, but when I'm on Zoom people see it. So there is showing up there. You can talk about it. You know, bring awareness. Bring it into the light of what it is that you're doing. What you're agreeing to. That we all want to get along together. We all want to work together because if we don't, our children are not going to prosper. And that's our ultimate goal is to have successful children out there. Integrated into the policies of your organizations, of your schools, just the schools themselves with their children. Think about leadership modeling. You know, follow it. We're examples. I think we, we're the examples showing that yes, we can use it and we can work together, and I think Gayla and I are going to a dinner tonight together and last year we sat together.

>> I wasn't invited.

>> We had great conversations, you know.

>> You have your own dinner tonight. You know? But yeah, I mean, it's take the minute to get along and talk to people and find out who they are. You might find out you have a lot more in common than you really think you did, so you know by modeling what we have, I think that's a way of using it and then accountability by demonstrating that you're using it.

>> So I think the point is, do we agree on everything? No. We are three human beings, that's the way it works, right is? But do we respect each other? Yes, and will we take the time when we're presented with something that feels really, really uncomfortable? I believe we will do that because we've done it. We've practiced that. So that's one of the things you have to do as well. How others can use it, thank you for this slide, forgot to copy it. If you're an individual or an consideration we hope you consider how you will use this in part or whole in your daily life. if you're an organization and you can actually sign onto it, we won't allow anybody to change it. It's complete the way it is, and sometimes you do have to go with good enough, so if you want to sign onto it, we're not really opening it up again. Janet did a heroine's job trying to bring everybody together. The things we didn't agree on were primarily words. And a little bit of the cultural stuff just feeling like it has to feel like our organizations but she did a great job with it, and so that part's done, so can you as an organization, would you like to sign on? We'd love for you to do that. How do you do that? You contact Janet DesGeorges through the FL3 center, so Hands and Voices has that FL3 grant and this is part of the work. I don't even know if you said that Janet, at the beginning. It was part of a project that you had agreed to do which was great. And so she's also willing to take the lead if you as an ‑‑ you and/or your organization are interested in just saying, hey, wield be interested in signing onto this. We hope a lot of people will or a lot of organizations will.

>> You know, I have to admit being with you guys, I can feel the affinity. We barely practiced, that doesn't show, we got together in a meeting and decided what we're going to talk about, but I have to admit just some vulnerability, I still go into the hallways and walk by certain groups, certain people, certain individuals, where I don't have the same level of trust or even the ability to express what I'm thinking or feeling with them. I'm really guarded about what I say and how do we make progress together as a system or entity without authentic relationships. I hate like smiling and just saying hi to people that I just, I don't feel connected to at all. It just takes time. It takes a commitment. And it takes relationship building. And so I think we can all sort of embrace, I love the Community Code of Kindness. It just feels right. We have built this together in an era of sort of togetherness. (Laughter) it's late in the day. But I'm telling you, and you will see it, some day on social media, you're going to see some sort of juxtaposition of some group of people or some one organization coming out with a statement where underneath someone's going to make a statement that we have absolutely no control over and rather than feeling the need to respond or defend ourselves, we have committed to contacting one another, particularly around social media. If something starts going on on social media before we respond and make a statement or go to our legislature, we are going to get connected so that this was really built in a time of peace so that in a time of maybe upheaval, we are committed to falling back on that. We have a couple, three or four minutes, does anybody have any comments or questions?

>> So I may need a cue. I want to thank you for this effort because language or words matter, and the equity, the inclusion, federal law is often not reflected either words and in language we use. So I've been like advocate even here at EHDI. To understand a path. so my question to you ‑‑ the deaf community how, where do you plan to communicate your efforts to the public at large. There is a disconnect between the ground and what we do behind the scenes. It's important work.

>> It's a great question, both individually and organizationally. I think all of us, when we're asked to be at tables and the conversations are around, you know, the sort of American sign language or listening spoken language, we, if there is no one at the table for cued language, we need to start speaking up because I do think there is, there is, it is very difficult in this, in sort of where the system is moving or the conversations are having, so we can be advocates for that individually when we're often setting places at the table, have we considered that? And/or whatever is missing to say, you know, how can we ensure the integrity of input. And then I just think organizationally we're committed to keep putting this out there to other organizations. We're now committed ‑‑ you know, ask, sending, handing it over to you, you know, if you work for a hearing aid or cochlear implant company, maybe you'll take this and say how could we help think about, you know, three or four cochlear implant companies who are, you know, looking at the patient population. Is there any ‑‑ are there any common ground for us to think about for this. Any other answers?

>> I have one more thing to say. is this on? Okay. You know, it starts with love, and I know that's so cheesy, right? But sometimes we have to go outside of ourselves and love other people well, and I think that the way you do that is just to say you don't have to believe exactly like me, and the other thing, and I think that's definitely, I feel like we were, and also understanding again that whatever choice any given family makes, Janet, Cheri, and Gayla and our organizations respect that. And it's not our decision. I think it goes back to just saying we're going to love you more in this moment than we're going to love ourselves because we're going to listen to understand. We're going to learn. We're going to have a conversation. And sometimes that's where you start.

>> Thank you very much. Good afternoon. Be kind. Oh, we got one more. All right. Do we have one more or no? Yeah. Okay.

>> So I'm sitting here and I do feel uneasy about some of this. I'm from Delaware, and we're dealing with the ACLU complaint there. And of course everyone wants to work together to provide all options, all services available for any deaf and hard of hearing student, but there are some specific organizations that have written a letter of support for that new bill in order to take away these, you know, these extremely important things. So this is, so I'm just wondering how do you deal with that? How is that factored in because I feel like you're saying one thing, but you're actions are speaking differently.

And then the other question that I had that I wrote down, the official organizations that, I see that there's kind of an imbalance. There is, you know, a very heavy representation of organizations that focus on spoken language, but I don't see the same number of organizations focused on cued speech and sign language. Thank you.

>> I'll answer the first question about the ‑‑ now remember, Delaware it's not a bill. It was an ACLU complaint that was made, and it's not against any one group. It's about something that's missing.

>> Let me clarify.

>> Okay.

>> I do want to clarify. It was proposed as a new bill. The year before.

>>> Oh, okay.

>> It was not sponsored. It had ended up being dropped and that was when it was changed to an ACLU complaint.

>> Ah, okay.

>> It was sponsored by A.G. Bell and several other different organizations that are represented here.

>> Okay.

>> That are on this list.

>> Well, it's ‑‑ so let me just say for the record, it is never, never A.G. Bell's desire to do away with any other choices that families might have because we believe families have the right to know all of the opportunities that are available to their children. So if it comes out that way, that's certainly not the way it's intended.

>> I'm so sorry, we're completely out of time. We promised to end on time, so we have to finish and this is a great example of a particular topic that needs to be discussed at a table so there is a bit more clearer understanding when things like this happen. Thank you.