Promoting Self-Advocacy in Children Who are Deaf or Hard of Hearing.

>> Cindy Camp: So, we're having some technical problems with -- oh, the interpreter is here. We can go ahead and start. Awesome.

Good afternoon, everyone. My name is Cindy Camp. I'm your presenter. And I work with The Described and Captioned Media Program. We're going to be talking about self-advocacy for children who are deaf and hard of hearing. You'll notice that I have a QR Code up here on this screen, because I work for The Described and Captioned Media Program, which I will tell you a little bit about, we're federally funded, and so I have to do lot of reporting. If you capture the QR Code, it will take you to a short evaluation, and that helps me collect the data I need to continue funding. I will put it up again at the end.

It is also going to allow me to send you a copy of the presentation. It should be available to you in the app for the conference, but I will e-mail it to you just to make sure you have it.

So, DCMP is a great resource. If you haven't come by my booth in the exhibit hall, please do. Many of the resources I'm going to be talking about are available to you free through us. So, on to what is self-advocacy? In general, it is just the action of representing oneself, one's views or one's interests. How of us struggle if we're going out to lunch and they pick a place you don't like. Do you struggle to say, I don't want to go there or do you just sit back and go along with the group? Even for adults, it is not always comfortable to speak out against the group.

Or if there's a group of hearing people, and you're the only one who's hard of hearing or deaf and you need everybody to sign for you, or to look at you when they are speaking, and they don't tend to do that. And it gets really old to remind people over and over, because hearing people can be really stupid sometimes, right? It's not easy. And yet, we tell our kiddos, speak up for yourself.

So, it's not easy. Self-advocacy is really learning how to speak up for yourself, making your own decisions about your own life, learning how to get information, so you can understand things that are of interest to you. Finding out who will support you in your journey, knowing your rights and responsibilities, problem solving, listening and learning, reaching out to others when you need help and friendships, and learning about self-determination.

So, this quote actually comes from the Wrights Law website. And I've got that noted in the presentation handouts, so you'll be able to find it. I think it is really interesting that in the 1960's that self-advocacy came into its own in relation to disability rights. And that is when it came about that, especially those with intellectual disabilities, those who supported that group decided they really needed to be able to make decisions on their own.

Think about prior to the 1960's and the whole idea of anyone with a disability, it was shameful. You hid, you know, crazy aunt away in the attic. You didn't talk about disabilities. People with disabilities weren't out in the public, and if you had a disability, you really didn't have a lot of choices, as far as what you could do as a profession. And even not so long ago, I was doing a training in a state for some vocational rehabilitation counselors and I had a relatively new counselor come up and as me, can you give me a list of jobs that deaf people can do, so when I have a deaf client then I can help them better? I kind of gave them a funny look. We eventually got on the same page, because they really thought, there are these five or 10 jobs and that is the only thing deaf people can do.

I had to explain, no, we're way passed that. Deaf can do anything except hear. We have heard that famous quote. We want to make sure our kiddos are growing up knowing they have all of this potential, and let's help them achieve it.

This video, I've got lots of videos in here, I'm not able to play them all. But again, it is going to be linked in the handout. It is Harpa who is a deafblind lawyer and she did a whole presentation for the American federation of the blind and it is phenomenal. This little clip, she's talking about when she was in high school, and she wanted to go on a mission's trip to build schools. Let me see. I can't remember what country she was going to, but her parents, as you might suspect a little bit leery of her leaving the country as a deafblind individual and helping to build schools in a third world country.

She goes through and talks about how she talked with her parents, and they are like, absolutely not. And they tried to scare her and her mother said, well, there are snakes there and they are very poisonous and what if you step on one? She persevered and talked with her teacher and her teacher advocated for her and she was able to go and this was a wonderful experience. I'm thinking, you know, I don't have a disability, and as a high school student, my mother never would have let me out of her sight. As a fully grown adult, my mother does like that I travel.

[LAUGHTER]

I understand that fear, but she had such a wonderful experience and she has grown into the adult that she is, and is such an amazing person because her parents were able to let her have those experiences. And so, the more we can encourage parents and teachers to really let the students branch out and have those experiences, the more they are going to be able to self-advocate. It is just a self-perpetuating thing. It gets better and better.

So, when does self-advocacy start? Any ideas? Birth. Yes, you are absolutely right. So, anyone who has children, you know that babies at birth start telling us what they want. They tell us when they are hungry. They tell us when their diaper needs changing, and they tell us very loudly sometimes. And we try and mold that as they get older, so that they are telling us more appropriately. But we want to encourage that as opposed to damping it down.

And there are very good ways of doing this. You'll notice in the picture on the right, the little girl has two shirts or dresses she is holding up. Both of them are similar. So, let's give our kids appropriate choices at a very early age. Don't start out by asking your kids to choose from their entire wardrobe what they want to wear. Give them two things to choose from. Both of them, things you deem appropriate or else in the middle of winter, they will choose their favorite summer shirt and you will tell them no. But if you say, would you like to wear this sweater or this sweater? There is no wrong choice and as they get older, you give them more and more options and at some point, you start introducing things that are not appropriate, so you give them the opportunity to fail or to make the wrong choice. Because when you are there as a safety net, that's when you want them to start making those decisions, and to be able to fail.

One of the things that I find very disheartening is that students with any disability, a lot of times, we don't give them the opportunity to fail. We build them up, teachers in schools, make sure they pass, that they get the passing grade even if they don't learn the content. Has anyone ever had that experience? They give them the answers. They make sure that, oh, well, little Johnny didn't really understand that, but we're going to gloss it over. Have the Interpreter just tell them the answers on the test. Let's pass them along. Let's make sure. They need the opportunity to fail just like their classmates do, because we learn so much from our failures as well.

But again, at the appropriate time. Let them build up confidence. Let them get used to making good decisions at a young age, and then you slowly introduce the opportunities to make bad decisions.

This is another video, and this one is actually in the DCMP library. So, I courage you to go and watch it if you like. It is called "I am not a stranger, a deaf's child view of growing up in a hearing family." This one talks about the importance of communication. It goes through the same scenarios, and it shows the form of communication is not as responsibility as the child being included in the family. So, it is very important that whatever communication that child is using that the family includes the child in all of the decisions being made in everything. So, it gives examples of the mother actually, the child waking up in the morning, and the child has a flashing alarm clock. And then the mother giving the child choices between what to wear and letting them know what they are going to be doing and a choice of what they are going to eat for breakfast.

So, making sure that the child is included in the family, and knows what is going on is very important to developing that self-confidence to be able to self-advocate.

So, these are some strategies that you will find very useful, again, start early. From birth, they are telling you what they want. Go ahead and start helping them focus that in the appropriate direction. Encourage self-awareness. It is so important with students who have a disability to make sure that they are able to communicate their needs to others.

I have a friend who has a son with -- who is hard of hearing on one side. And it took him forever to be able to tell his friends, I need to sit on this end of the table. I need you to be on my right side, so I can hear you. Because if you're sitting on my left side, I can't hear you. I can't participant in the conversation. And so, those little things that let the children be more involved help them feel comfortable, role play with them how they can tell others what their needs are.

Stay positive. Don't always focus on the negatives. That's one of the things that can be really disheartening is if we come across as negative. Play it up as, what can we do to make this fun? Role play, make it positive. Support critical thinking. Help them learn how to problem solve. If they come and say, you know, the other kids wouldn't play with me, well, what could we do different tomorrow? How can we make the situation better? Help them to learn to self-advocate.

You know, we watched a video in school today and I didn't understand it, because it didn't have captions. Well, how could you tell your teacher tomorrow to turn the captions on? Make sure they are involved even at a very young age, if they understand their needs, then they are going to be able to let people know, their teachers and their friends how they can be more involved in making sure they get what they need. Help them to plan for their future.

With hearing children, we always ask them what do you want to be when you grow up, and I think too often with children who are deaf or hard of hearing, we don't do that. We don't let them dream. Or if we ask them what they want to be, and they say, I want to be an astronaut, well, I don't think you can be an astronaut, because you can't hear and astronauts have to hear. Let them dream. Because, how long do they want to be an astronaut? Tomorrow, they are going to want to be a ballerina. So what? Who knows? In 10 or 15 years, maybe everybody in the space program will be deaf or blind. We never know. Encourage them to be whatever they want to be. If we didn't dream, we would have never gotten to the moon.

And help build self-esteem. This is another video in our collection, and it talks about the difference between self-determination and self-advocacy. It is part of a transition curriculum ma Map It. I love it, because these are two high school students who are deaf and they talk about that and it is great for students.

So, there's are three parts of self-advocacy, the first is knowing yourself, and you will also see a list here of videos that are in the DCMP collection from Leo the late bloomer down the achieving goals. These are videos for all ages, from pre-K through high school level.

The second part of self-advocacy is knowing your needs. Again, these videos are in the DCMP collection and they are for different ages. And all of this will be in your handouts that you're going to get, and they will be hyperlinks in there.

I do want to show you this video, because I think it is really important. It is a mother and daughter, and it talks about the importance of involving the student in the decision-making process. So, we're going to take time to watch it.

[video with captions]

>> Cindy Camp: So, this full video is in the DCMP collection and several others along this line. I think it is great when you see the students be able to talk about their experiences. Amy, at this time, was a student at NTID. She is now a graduate, and a working professional. So, all of her hard work and that of her mother paid off even though as they both said, it wasn't easy.

The third part of self-advocacy is knowing how to get what you need. Again, knowing how to get it appropriately. That's why I love this picture, because a lot of people don't have those interpersonal skill, and these are some of the videos in the DCMP collection that help to teach that to our students.

Here are some other videos that are going to help teach self-advocacy, self-determination, and self-respect. Again, you can see they start at the preschool level and they go all the way up. Some additional resources and websites. And then, what I want you to take away is self-advocacy is very important skill that's going to help children do better in school, but also in being independent for life. There are specific steps that you can help give children to develop self-advocacy throughout their lifetime, but it isn't easy and you need to start early, but it is never too late to start.

So, we want to make sure that the children, the students that we work with have those skills they need to be independent as they grow up, and they can go out into the world and get what they need. Hopefully, you can get that from some of these tips.

This is another video with Roger and Sheri Williams who have several deaf children and hearing. And they talk about how they helped all of their children self-advocate throughout their school. And so, I want to leave a couple of minutes for question and put the QR Code back up if you were not able to get that in the beginning. It is helpful if you wouldn't mind filling out the little survey, just because as I said, DCMP is a federally funded project, and the more data we collect, the more likely it is that we're able to continue being funded. Most all of the videos that I've talked about they are in our collection, and they are all available to you free of charge. Anyone who works with students birth through high school age. Does anyone have a question or comment?

>> Audience: I just want to comment that I'm excited that you used the example of Haben. I'm surprised how little I hear about her, especially in places like EHDI. I think she is inspiring.

>> Cindy Camp: Definitely. I think we need a lot more role models for students to see what the possibilities are, because too often they get the idea, "I can't do" something, because they haven't seen a deaf adult who has done it.

>> Audience: Hi, I just wanted to ask, when involving our children in these meetings, there are times, so that you're talking about sensitive subjects, like my children have usher syndrome and we're open with them and talk to them age appropriately, so they can understand, there are things coming in their future that they are not going to completely comprehend and they are somewhat sensitive in nature. They are not prepared or mature enough to be a part of that conversation yet. So, how would you -- what would be your advice for a parent that wants to involve their child, but recognizes there may be times that are not always appropriate?

>> Cindy Camp: I think you can schedule the meeting, so that your child can be involved throughout the parts, and let them be able to give their input as to their goals, what they want in their future education, and then it's a natural transition. They have given their input, the teachers have listened to that and now it is time for you to go back to class and we say goodbye, and they don't know that the meeting continues without them. But at that point, anything that might not be age appropriate for them, you can continue with the group.

And I will say, not all schools are going to want to do this, because it takes more time. However, all schools are mandated to include students in their own IEP process. So, don't let them talk you out of it, because the kids need to be in there. It is their futures we're talking about, and so, they deserve to be included, but schools and teachers have time limits and they are trying to get it done as quickly as possible, but don't let that dissuade you from getting what is best for your child.

I have my cards up here if anybody would like to get one. Thank you very much for coming this afternoon.