## ROUGH EDITED COPY

NCHAM

Don't Wait to Communicate! Augmentative and Alternative Communication 5/3/17

CART CAPTIONING PROVIDED BY:
ALTERNATIVE COMMUNICATION SERVICES, LLC
PO BOX 278
LOMBARD, IL 60148

\* \* \* \* \*

This is being provided in a rough-draft format. Communication Access Realtime Translation (CART) is provided in order to facilitate communication accessibility and may not be a totally verbatim record of the proceedings.

\* \* \* \*

>> WILLIAM EISENMAN: I would like to welcome everybody to today's webinar entitled don't wait to communicate, augmentative and alternative communication. In a moment I am going to hand over the mic to our presenters and introducers. I am William Eisenman from the national assessment of hearing assessment and management at Utah State University and we are sharing our webinar platform today with all of our presenters who are participating in better hearing and speech month and this webinar series.

Once our presenter has completed her remarks for today in about 15 minutes, I will reveal a text screen through which you can submit a question or comment. So you will see that just at the end of her remarks.

Also notice in the lower left-hand corner of your screen are two downloadable files. One is from yesterday's webinar and the other is from today. They are the slides from which our presenters are speaking. So if you are interested in those, you can download those at any point.

And also know that today's webinar series, as with all of them as a part of the series, is being recorded and will be posted online within the next week and you will receive a communication email about where you will find those once they have been posted.

So without further ado I will hand over the mic to those who will be introducing today's webinar.

>> Thank you so much, William, this is Sarah Merrill with the division of early childhood development with the ministration of children and families, and on behalf of ACF and our colleagues from the Department of Education we are really happy you joined us today and hopefully you are participating in all of the series. We are really happy to have with us Jacqueline Hess who is the director of the disability studies and services in early care and education within the center of technology and disability. She has worked hard on the planning of the series and she is anxiously awaiting to share all of her expertise and information. I will not go on and on, Jacqueline I will let you take the floor and carry on the conversation and we are really looking forward to hearing from you today.

>> JACQUELINE HESS: Thank you so much thereof. Let me just say that today's presentation is going to be an introductory and overview level for those of you consider yourselves AAC gurus and practitioners already, I would refer you to a whole series of webinars that the center on technology and disability does where we bring in experts who go through specific AAC apps with you, but that is not what we are going to do. We have about 10 minutes today so this is going to be, as I say, introductory and an overview.

So let's start with a few quick definitions just so that we are all on the same page. Assistive technology, both devices and services, allow children and youth with disabilities to participate in activities at home, at school, in the community that they would not be able to do otherwise. So things that may not be AT for children become AT when it enables a child with a disability to participate in an activity or accomplish a task.

AT can be something you make, there is a growing maker community, it can be something you buy from a store and adapt or it can be something you purchase and use as is.

Augmentative and alternative communication, AAC devices and services, are a type of AT that focuses on both expressive and receptive communication. AAC poles and approaches range from no tech to high-tech and as the term implies they can either augment or replace oral speech.

AAC includes both unaided and aided communication systems. So when we talk about unaided communication we are talking about a

person's use of his or her body to communicate. Sorry, I have kind of got a head cold from hell here so my apologies.

Unaided communication would include facial expressions, gestures, body language that is pretty universal like a child raising her arms when she wants to be picked up or clenching her mouth shut when she does not want to eat something.

It can include sign language and also whatever sounds, words, or partial words that a child may have at his or her disposal.

Aided communication includes pictures, symbols, object and alphabet boards, and recording devices. Aided and unaided AAC reinforce each other. It is not an either/or, and importantly there is not a hierarchy of device use or approach. You don't have to start with a low task single message device before you move up to a communication board with four pictures. Likewise you don't have to start with a three ring binder with static communication pages or boards before using a customizable voice output device.

Knowing where to start is part of the AAC assessment that should look for the best child's feature match at the time but that also allows for growth. We will get back to that in just a little bit.

So I will state the obvious -- by virtue of its ability to help a child express their needs and wants, their emotions and their opinions, AAC fosters development and social interaction and learning which reduces frustration and isolation.

So it is pretty important.

We are working very hard in the disabilities field to give families, service providers, and other professionals who work with children to recognize that children are never too young to use AAC. I think Bridget [can't understand] said this in her webinar yesterday; infants and toddlers are not too young to use AAC, and first, last, and foremost AAC does not hinder the development of oral language. We have a good deal of sound research on that front.

Oral language is always going to be the fastest and the most efficient way to communicate for people who can use it. So there was a lot of motivation to use whatever speech that I child may develop.

And of course AAC can just be used for a limited period of time. As well as for a child's entire life. We should remember to think of it as a very fluid situation, just as language acquisition and use in neurologically and physically typical children change for at least the first 15 years of their lives, so they do for the majority of children with disabilities, particularly when the intervention is done early.

So we need to check regularly to see if the current AAC strategies need to be enhanced or changed in some way. Some of these things sound so basic, but I can tell you there is some of the biggest mistakes that we see made at the school level and at the clinician or practitioner level.

So let's move on here. So moving from some of the conceptual basics to some of the technical basics. An increasing percentage of AAC devices fall into the VOCA voice output communication aids or SGD, speech generating devices, and those of the same things, there is really notice things in between them. Those of the devices that allow the user to select messages to be spoken aloud. They can range from a simple single recording device that might allow a child to voice a single word or a longer phrase or sentence to a multiscreen device or an app that can be set to start with a few words and then progress with the child to hundreds and even thousands of words and phrases and sentences.

It is now pretty standard for SGD devices to include a selection of voices. Male and female, child, team, and adult so that everybody doesn't have to sound like Stephen Hawking who of course wants to sound like Stephen Hawking because of his branding, you know, he could choose something else of the liked.

So a couple of important takeaways here. Keep your expectations high and insist that others who deal with the child keep affairs high as well. So if you are the parent you need to insist that the teachers and the therapists keep their expectations high. If you are the teacher or therapist, the parent may be mired in some previous developmental level.

A very common error with AAC use is to impose too low a limit when the number of words or boards or screens that are available to a child, and then to kind of keep them trapped there for too long particularly when there is maybe a review of their AAC every six months or a year that really can hinder development and you get back to that frustration level.

Another error is swapping AAC tools to often so that I child literally has to relearn where everything is on a communication board or screen. You can see the screenshot here on the lower left where some of the images are there and some of them are grayed out. Those are areas where the words would exist but whoever is dealing with the child has decided it is not time for those yet. But when it is time to add those, the placement of the other images will remain the same so you are not having to go in and find where everything is again.

It's as if we asked typical children to relearn how to process text on a page every so often, likely taught you how to read left to right but now we want you to read right to left or down to outboard to skip every other word. So you really want to think this through with the beginning so that once the child Masters the placement of an image, that images always going to be there as you add another two words and another 10 words and another screen.

So you want to be flexible obviously in trying different devices. So this isn't the law in stone, but once you find the pool that is appropriate and that provides growing room for the child, you are going to want to stick with it unless there is a compelling reason to switch.

And of course you are going to want to model the use of the tool as often as possible and not just at school but at home, in the community. Sometimes we find that the child has access to a device in one environment but not in another in which case they suddenly kind of lose their voice. So you want to get as many people trained on the device or the app as possible. Siblings, neighbors, significant people in the child's life.

And then you are going to want to model. Some people get a second device for a child -- a sibling who doesn't particularly needed but that allows the children to be modeling use between the two of them.

Finally a bit about initial vocabulary. As you build medication boards or books or app screens try to include a mix of core words -- and those are of course I, me, eat, play, want -- with personal core words. So those are going to fit a particular family with maybe displaying their culture or their belief system. Some families -- this is where you instead of using an icon or just a neutral image for mom or dad or brother, you are going to want to take a picture of the actual person and put that into the system.

And then you also want to use fringe words. Fringe words can be very motivating for a child or young person. You know, in addition to things like please and thank you which may be more motivating for the adult than the child, you also want to include things like whoops or silly mommy, or for older children maybe something with an attitude like no way or duh. I'm a little out of touch with current teenage vernacular, but whatever it is you can record it in the device.

So whether you are a parent or a professional, you want to encourage use of AAC in natural routines throughout the day, not just in a clinical environment or another structured practice environment.

Use AAC to let a child make choices, to help them understand if I do this then I can do that. So AAC becomes not only a tool for communicating but for understanding cause and effect and for strengthening executive functioning skills such as planning, transitioning from one activity to another, or putting things in the right context for the activity.

And don't be afraid to use AAC in concert with other AT products, particularly for older or higher functioning children. For instance tools that provide access to text or that help a child customize learning materials can be just as effective for an AAC user as a non-AAC user. So just as each child is not issued one disability at the door, they should not also necessarily be issued just one type of AT.

Next week I will be doing one of these short sessions on free resources that are available through the center of technology disability, and there we can look at some of -- where you can find more information about AAC and I can point out some of the archived webinars that look at specific AAC apps and devices.

Okay, so I have tried to speed through that. If there are any questions or comments that we have a couple of minutes for them.

>> WILLIAM EISENMAN: Great, thank you Jackie, that was excellent. I have revealed a questions box in the lower left-hand corner of the screen. And I think we have a few questions that are coming in already.

Can you talk about the cost implications of technology and how that may influence choices that families might be making?

>> JACQUELINE HESS: Right. So caused is one of those elephants in the room. It is absolutely there and that is why it is great that there is a whole range of appropriate options. There are definitely things you can make yourself. You can sit there with a newspaper or a magazine or with family photos and put together a communication board that is not electronic at all, but even then I would encourage people to think about the placement so as they build on those that the child is not having to hunt for them all over the place.

There are some very easy recording devices, now you can get I think for \$0.99 at the dollar store where you can record just one message or a couple of messages, you can hook it up to one of those big easy buttons that are inexpensive and let the child just select a couple of choices if that is an option.

There are AAC apps that are absolutely free. There is some that are very low cost. And then for those children for whom you really want to build an extended language system the cost may go up to a couple of hundred dollars. But now because most of these are available for tablet computers, people have tablets, you are not having to invest in the kind of high-priced kind of esoteric only available in a special needs catalog that we did years ago. Now it is far more accessible pricewise.

>> WILLIAM EISENMAN: Great. The next question is -- and for those of you that are interested in a copy of today's slides they are posted in the middle of your screen now for you to download, it is the one called don't wait to communicate. So for those of you that are asking for that -- and also there is a couple of questions about whether this has been recorded, and it has been. It will be posted in several places and you will get an email telling you where to go look for that with a link to that once they are posted.

The next question, Jackie, can you explain how peers of a child needing this type of assistance can learn to use the technology as well?

- >> JACQUELINE HESS: Peers of the child?
- >> WILLIAM EISENMAN: Yes.
- >> JACQUELINE HESS: Well, obviously they need to have access to the same device that the child is using. That is where you are going to want to model the activity and you are going to want to do that in a natural environment. So when they are playing

together, when they are sharing a meal together, when they are being a study buddy in school together.

And kids are kind of naturally social. You know, we teach them pretty early how to share things, and certainly the child who was using, whether it is a simple, medium, or high-tech device, is going to be very motivated to have the peer learn how to work with them on the device.

And is it more motivating for the nondisabled child to work on an iPad or some other kind of tablet? Well, probably yes, you are probably going to get a little more interest factor there. But there are a lot of kids who are good kids and they are going to want to point to pictures or push a single message button if that is the way that they can see that they are connecting with their friend.

>> WILLIAM EISENMAN: Jackie, the next question has to do with children who are from non-English-speaking families. Are there limitations to be concerned about pertaining to a child's family language?

>> JACQUELINE HESS: Right, and I have never understood why we don't use the multilingual capacity of AAC devices more often. Most of these, if we talk about ones that are, say, on tablets or on phones, they are so easy to customize. I mean they literally will say record your message here, and you can on some of the apps -- and this could be a factor on why you decide to choose one product versus another -- some of the apps just have space for one language and you can choose to make it the family language or to make it English, but some of the apps let you do multiple recordings for the same image.

So you could set in English recording and then you could set another language recording. For things that are not electronic where you are using an image with a title, a caption, clearly you can use the English caption and the non-English caption, we use that to teach people foreign-language is all the time.

So I really would encourage people to think about how to use the AAC tool or product to its maximum and to absolutely incorporate the family's language into it.

>> WILLIAM EISENMAN: The next question is about who is it that specializes in this kind of work? The question reads in looking for a specialist who can help us what kind of credentials should we be looking for?

>> JACQUELINE HESS: Yes, that is a great question. A little bit political and we will not have time to unpack that. Generally in most school systems and in most places where parents perhaps are not in the school system but are being connected with a therapist through child find, they are going to be appointed toward a speech language pathologist, an SLP. So I would say the biggest group of people who work with AAC right now are the SLPs.

However, there is both a pro and a con there because some SLPs are kind of steeped in the past and they don't necessarily want to be open to some of the newer approaches to AAC. Hopefully nobody on the phone falls into that category, I am sure.

But there are lots of other people. There are social workers, there are teachers, parents. Parents are probably the most motivated and parents can teach themselves about AAC. There is all sorts of information online, there are parent training and information centers around the country, and there is nothing magical about it, I would say. You definitely want to try different approaches. The parent probably knows the child the best, but the SLP or the teacher might be the one to push the child a little bit further than the parent would think to.

So a team approach, just like we have a team approach developing IEPs and ISEPs, a team approach is sometimes the best if you have those resources available to you.

- >> WILLIAM EISENMAN: The next question is kind of turning the tables around a bit, and it is asking if AAC is useful for a Deaf parent to use with a hearing child?
- >> JACQUELINE HESS: I would think so. I am not in the Deaf community but I have studied sign language for quite a few years and so have seen a number of people in the Deaf community use AAC with their children. I think their preference is that the people around them learn sign language, but that is simply not realistic particularly when you get past their immediate family and even their immediate family may not be fluent, and so you are going to kind of cap the nuance of your communication.

So I would think that this is a creative and effective use of AAC. Again not just between a person who is Deaf with their children, but to take to the store, to interact with all sorts of people who otherwise are not likely to know ASL. So yes, I think it is a great idea.

>> WILLIAM EISENMAN: Yes, so much of the speech recognition software that is available on tablets and phones now have really opened up communication possibilities that not too long ago simply were not available.

The next question is are there any special considerations for young children with autism who may have the need for an AAC device?

>> JACQUELINE HESS: Well, let's see. So children with autism obviously have a series of complex needs. So everybody should get an assessment. That can be sort of informal or formal. You might want multiple assessments if the first one does not quite seem right. So with children with autism who are dealing with -- possibly dealing with multiple issues -- the communication piece of the pie is just one piece of the pie. So the choices you are going to make are going to reflect what some of the other pieces of the pie might be.

But for instance let's take -- sometimes children with autism, particularly when they are young, might have a self-regulatory issue, some Haverhill self-modulation issues. They are not particularly good at reading nuanced facial cues. And so AAC, the earlier you can use it to reduce the child's frustration, to make them have a sense of cause and effect -- when a child tries to communicate and nothing happens you really have a problem. And children with autism can have a problem already with cause and effect. So and AAC device, bringing it in when they are just a couple of months old, when children are very young they are learning about cause and effect, and if children have a problem in that regard the AAC device can really help with that.

The same thing with emotional nuance. If a child cannot voice various aspects of I like you, I don't like you, this makes me uncomfortable, I love you, then that exacerbates aspects of the autism, whereas if you can give the child those options very early, children want to express those things very, very young in life, and so you want to give those options. And children start recognizing -- well, let me leave it at that because I can see how long we are going on time.

>> WILLIAM EISENMAN: That's great. One of our participants today offered a resource. She said it's a great read for young teenagers to understand CP and AAC devices, and it is called "out of my mind." And she is also thanking you for all of the information you have provided today.

Without I think we will wrap it up for now. I am posting once again on the screen here information about our upcoming coffee break webinars. The next one is Friday which is going to be focusing on quality hearing screening practices for children birth to 5 years of age. We will be doing that one, my group, which is the ECHO initiative out of Utah State University.

On Monday there will be another one that is focusing on using a multimodal approach to supporting children with hearing loss.

And then on Tuesday the center on technology, Jackie will be back to talk about those resources to support the use of assistive technology in young children with disabilities.

Once again today's webinar has been recorded and will be posted in several locations that you will be getting more information about once they are posted. And I know one of the locations will be InfantHearing.org at Utah State University, and if any of you have organizational websites that you would like to link people directly over to where it will be archived on InfantHearing.org, we always welcome the opportunity for those kind of direct links.

So know that if you would like to post it as somebody asked about, we would be happy to have you direct people over to where it will be archived on InfantHearing.org.

Any final remarks from you, Jackie, or Sarah or anybody else?

- >> We just want to express our thanks. We thought it was very informative and very thorough, and Jackie, I am just in all of how quickly you can respond and so articulately to all of the questions that came to you. Thank you very much for sharing your expertise and William thank you for hosting.
- >> WILLIAM EISENMAN: Of course, and we look forward to seeing you again on Friday, Monday, and Tuesday, same time and same place in the same URL that you used together today is what will work next time.

As we close out today's session your screen will shift over to a quick evaluation screen. If you can take a moment to answer the three questions, I think they are, that will appear on your screen that helps us to improve our ability to provide these kinds of information opportunities. So if you can take a minute to do that, that is always helpful.

Thanks everybody.