

**NCHAM-Don't Wait to Communicate: Augmentative and Alternative
Communication**
Tuesday, May 17, 2016
2 p.m. Eastern Time

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>> The three of us are in the same cohort of model demonstration products to promote the use of assistive technology by very young children.

>> Maybe when we start in a couple minutes, you should repeat what you just said so everybody who is on can hear that.

>> Okay.

>> That would be great.

And Traci, are you about ready to begin? We've got another couple of minutes, but I wanted to make sure you're cued up and ready to go.

>> Yep, I'm ready to go!

>> Okay, great.

While we wait to start, our presenter has created a couple of polls. Here is the first one. We would just be interested in knowing a little bit about who is with us today. If you can tell us a little bit about your role, that will be informative for our presenter and for all of us to have a little sense of the perspectives that the various participants are bringing today. It's nice to see such a diverse range of participants.

>> It is. I'm kind of comparing it to who participated in yesterday's webinar with Bridget and Elizabeth. Yesterday the two big groups were SLPs and early childhood providers. It's interesting to see who we have coming in today.

>> I'm going to pause for one moment. By the way my name is William Eiserman. I work at Utah State University. We are offering our webinar platform for all of the webinars this week.

And so that's why you're hearing me managing this. But I'm going to turn this over to Traci Dixon from the office of Special Education Programs in just a moment. But before I do that, I'm going to initiate the recording of this webinar and let you all know that the way this is going to go is that our presenter today is going to present for about 15 minutes and then we'll open up a questions field for you to raise any questions that you would like answered. She has graciously offered to remain with us as long as it takes to answer those questions.

I'm going to initiate recording now and I'll be back in a second.

>> Audio recording for this meeting has begun.

>> Good afternoon. And welcome to the second webinar in the better hearing and speech month coffee webinar series. I'm Traci Dixon from the U.S. Department of Education, and the project officers for the early childhood model demonstration products. I am pleased to say I was joined by my colleagues to sponsor this series. We wanted to support the American Speech Language Hearing Association in celebrating this year's theme "Communication takes care." We field these webinars offer a way for all of us to learn more about hearing screening and the use of assistive technology to support young children with disabilities and their families. We appreciate all of you for taking the time out of your busy schedule for today to attend our schedule for today. Please join me in welcoming Jacqueline Hess. Jackie will be talking with you today about augmentative and alternative communication devices that support young children with disabilities who may have communication delays or disorders. Jackie?

>> JACQUELINE HESS: Thank you Traci, and despite your nice invitation to restate what I described when we first opened, I think Traci has done a great job of introducing both me and the projects that I represent. So why don't we start with a quick poll to get a sense of where everybody is at on the AAC spectrum?

It basically said I am new to AAC. I would like to start with the basics. I have some experience, but I'm looking forward to a review. I have quite a bit of experience, and I'll jump in with insights as we go along. And very experienced, I could give this webinar. And I know that there is at least four people among the participants who could not only give this webinar, but give it on steroids. I see how the results are coming in and this is great.

We have enough people who are at the basic and the let's review level. So let's start with a review of what we know. Assistive technology devices and services, we sometimes forget the services allow children with a range of abilities and disabilities to participate in activities at home, in school, in the community, that they wouldn't

otherwise be able to do without the A.T. And augmentative and alternative communication, AAC devices are a subset of that. They are a type of A.T. that focuses on both expressive and receptive communication.

AAC ranges from high tech to no tech. And they can either augment or replace oral speech. We are working very hard in the disability field to get families, service providers and other professionals to recognize that children are never too young to use AAC if it's appropriate for them. And that AAC tools are useful for a broader spectrum of developmental, functional, and learning challenges than we sometimes think about. AAC includes both unaided and aided communication systems and we're going to define those in just a minute. And as most of you know, AAC often involves the use of symbols, pictures, and photos for customization. By virtue of their ability to help a child express his or her needs or emotions or opinions, they foster the child's development and of course their social interaction, which very understandably reduces their frustration and sense of isolation.

So let's run through a few more of the basics. When we talk about unaided communication, we're talking about a person's use of his or her body to communicate. So that includes facial expressions, gestures, body language that is pretty universal like child is raising her arms when she wants to be picked up or clenching her mouth shut when she doesn't want to eat something. It can include sign language and it can include whatever sounds, words, or partial words that a child may have at his or her disposal. Aided communication is, you know, that's where we include the pictures, the symbols. Object and alphabet boards. And recording devices. Aided and unaided AAC reinforce each other. It shouldn't be thought. They're not an either or. There's also not a hierarchy of device use or approach. Likewise, you don't have to start with a three-ring binder with static communication boards before using a customizable voice output device. We're going to talk in a minute or two about AAC assessments. But obviously we need an assessment to figure out where to begin with the child. And finally, you don't need to forego non-core words. Even at the beginning of AAC use. It's good to include words like please and thank you or oops, no way, silly mommy. Those types. And words that would fit a particular family. The family's culture, or their belief system.

AAC can be used for just a limited period of time. Yesterday Bridget used the metaphor of providing a bridge from one skill level to another or for the child's entire life. We should always 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, we also need to check regularly to see if the current AAC strategies need to be enhanced or changed in any way. Not only to reflect changes in the child's development, but also changes in the environments in which the child needs to participate.

Again, as Bridget and Elizabeth Berrey said, they are not too young to use AAC. And last, first, and foremost, I cannot say this enough, AAC does not hinder the development

of oral language. Oral speech is always going to be the fastest and most efficient way to communicate for people who can use it. So there's a lot of motivation to use speech as soon as the child develops it.

This communication board just shows some of the words that I just mentioned including excuse me, thank you is there, you're welcome. They've got awesome. No way! Totally. And those types of non-core words can really help a child fit in with his or her peers and they're motivating to them.

So this week we're focusing on early childhood. So I thought I would include some information about initial vocabulary. That vocabulary should include a mix of core words. There's a few of them here. I, you, eat, play. And that includes personal core words. So family member names and nicknames. Words that might relate to a child's particular medical situation that will come up again and again. Or words that might have to do with the family's belief system.

And you want to include in that fringe words, including the highly motivating fringe words. You saw a few of those on the board we just looked at. There's of course going to be trial and error in discovering which fringe words are accessible to the child and highly motivating to a particular child. So how do we determine what a particular child needs? We do it through an AAC assessment or evaluation. I find that most people tend to use those terms interchangeably. Personally, I tend to think of assessment as being the upfront activity and then evaluation as being the post-device strategy and trial. But that may just be a potato-Po-Ta-Toe issue.

First of course you want to identify the communication and the participation goals for the child. And if the child is old enough, those goals should absolutely reflect the child's input. In general, assessments are done by the speech language pathologist, the SLP, but they definitely can benefit from the involvement of the physical therapist and/or an occupational therapist. They can be done in the course of the initial development of or the subsequent review of a child's individualized family service plan, the IFSP, for the zero-three crew, or later in their individualized education plan, the IEP. Or it can be done outside of either one, simply as an independent AAC assessment.

The assessment should consider the child's current language, cognitive, sensory, and motor skill levels, as well as any changes in any of those levels that you can reasonably anticipate for the near future.

The plan should identify the child's primary communication partners. So that includes family members, it may include teachers. It's really anyone who has significant interaction with the child. The assessment needs to consider of course the child's environment. That includes his schedule and routines, the family dynamics, and family culture, and any unique issues that may impact the use of AAC.

And then finally you want to identify the child's previous use and current use of AAC

including unaided communication. The gestures, the expression, the facial expressions, the body language that we talked about a minute ago.

So this slide gives you some visuals about a range of low-tech AAC tools from the single message recording device to non-voice output communication, pictures, and symbols. And sometimes people of course get very creative about the environment as you can see with the pictures being put on the picture board, being on the grocery cart.

All right. So on the high tech range of the AAC spectrum, we have voice output communication aids, VOCA, which are sometimes referred to as speech-generating devices, particularly if you're looking for Medicare or Medicaid funding, since those sources of funding specifically recognize SGD. So VOCA SGD as a category comprise electronic devices that let the user select messages to be spoken aloud. So those messages can range from a single word to multiple sentences. There's a lot of debate within the field about the wisdom of using phrases and sentences in lieu of individual words to build language acquisition and use.

Many SLPs feel that there's no or not enough language development in having just a talking picture. And it is true that quite a few AAC apps, particularly the ones that are cheap are developed by individuals or teams that don't have a strong background in communication.

So we don't have time today to engage in that debate, but if you want to read or hear more about those positions, there are archived webinars within the center on technologies and disabilities website. There is Dana Needers blog that Bridget mentioned yesterday called "Uncommon Sense" and some of you may have favorite links or your own opinions that you want to post when we get to that part of the webinar.

So this slide shows the apps that run on many devices. And there's also a picture of a single purpose AAC device, which the field has generally been moving away from as the world has adopted mobile devices. But there is still a portion for AAC users, for which the single purpose devices are appropriate.

If anyone wants to ask the names of the many VOCA apps, I can reel off a dozen and other people can, too. What's more important is what criteria are you going to bring to the selection of those apps. We decided in planning this week's webinars not to do demos of individual products. There is a Youtube how-to video on virtually every app that you could want to explore. So you're going to want to know more about what is it you're looking for? What are best practices? How do I assess the appropriateness for this particular child?

So I'm trying to keep an eye on the time here, because I would like to reserve three minutes to show you just a couple of videos of this child that we're all so crazy about, Dana's daughter Maya. One of the reasons that we all like Maya videos so much is that

Maya had been identified early in life, by professionals, as never being able to progress past an 18-month level of development. And we're all getting a big kick of watching her grow and largely she's got a fantastic family. But very largely through the help of all the AAC devices.

So here are some tips from Dana and other power users. Provide AAC as early as possible. Keep your expectations for the child high. Presume confidence. That sounds like such a duh, but I can tell you as a mother of a child with disabilities, after a while whether you're the teacher or the long-time SLP or the parent, you kind of get in a rut about what you expect from the child. And every once in a while you got to shake yourself up and say hey, I need to think about, you know, maybe we're pegging this child too low. Maybe we need to keep pushing higher. We talked about the next point. And I don't know why it's displaying a little funky here. But using a system that can be customized for immediate use and for long-term use. The important thing here and you can see a little bit in the picture is the beauty of a system where you can block out all but a few words or phrases at the beginning and then allow more and more words and pictures and photos is the child doesn't need to relearn the placement of each of the objects and photos every time they progress to another level, which is really unfair if you're just having them look at a board where yes and no and potty and eating are, you know, in one spot. In one communication board. And then they're in a totally different spot in another one. So the beauty. One of the criteria that you might want to use is does the system allow the child to build a replacement for everything they learned before. And now we're going to have to shake it all up. Model, model a lot. Sometimes people will if they have the ability to buy multiple, if you're working with a tablet-based app, let children, siblings who don't need the AAC but can use it to model with their sibling and they can have the conversation, both using the same communication device and certainly the parent and teacher and anyone communicating with the child in a conversation wants to be modeling the use.

Okay. And these. Some of these are her favorite points about using AAC within natural routines. I see we're at 2:22. So given that we've already had our 15 minutes, what I would like to do, Will, is let's pull up the two Maya videos. The Maya games first and then the reading. And then we'll, let's open it up to Q&A and some comments. Okay?

>> If there's things you want to do, we might be able to do them before you go back to school.

>> Duck, duck, goose.

>> You want to play duck, duck, goose? Who should play?

>> Daddy!

>> Daddy says he wants to play duck, duck, goose. Do you think we could teach it to Will? Does Will no how to play?

>> No.

>> Not yet? Okay, duck, duck goose would be a good thing we can do. What else do you want to do while we're on vacation?

>> Duck, duck, goose.

>> What else?

>> Guess who?

>> You want to play Guess Who?

You do? Okay, we could try. Remember, I have all of the little cards with the Disney characters, but some of them popped off. Do you want to try to fix it?

>> Yeah!

>> Okay, so we saw some modeling there. We saw the enthusiasm and the encouragement of the use. And we saw that Maya has a couple of words that she integrates with her AAC use. So Will, now we have Maya much farther --

Okay, I think you've already started it. So I'll stop talking.

>> (Laughing) Can you read that one for me?

>> I want to eat -- (Laughing)

>> Okay, let's now say it with Minney. I'm going to clear out your old sentence. That's too funny!

First that word. Now the whole sentence. Where is that?

>> I want.

>> Very nice. What does that say?

>> Eat.

>> That one?

>> Chocolate.

>> That's a big word. Where is that one? Do you have it?

>> No.

>> That's right. That's the wrong screen. Press the blue button to go back. Do you remember where it is?

>> Chocolate.

>> And what is this?

>> (Laughing)

>> Tell me with Minnie.

>> Ice cream.

>> And that last one? What does that say?

>> Tomorrow.

>> Yay!

>> So I have gone ahead and opened up the question field.

>> Okay. That's great. And so again we're looking at -- I'm sorry Will.

>> WILL: No, and Jeff Hoffman is going to go ahead. And once you're ready, present the questions when they come in. Go ahead and Jeff will jump in when you're done.

>> JACQUELINE HESS: Okay. I was simply going to say we're looking at a child who was expected by the experts not to develop beyond an 18-month level of development. And her mother is very committed to full language use and if you want to see more pictures of her from the first time she saw an AAC device, through now reading with one and expressing somewhat complex thoughts, you can look at Uncommon Sense, Dana's blog.

Okay, so we're ready for Q&A.

>> JEFF: Yes. Jackie, this is Jeff. Barb had a question. On the slide. I'm not familiar with it. It had three apps on the top and pics of food on the bottom.

>> JACQUELINE HESS: Okay, I see this one right here. I cannot tell you off the top of my head its name. But I'll tell you what, how can we get that to you? If you want to e-mail me, I think the contact information is on the left. I will figure out which of the, you know, we have just so many dozens and dozens of them. But I'll figure out which one I grabbed that screen shot from and send it to you.

>> Great. Thanks Jackie.

>> JACQUELINE HESS: I don't know if Bridget or Susanne or someone else recognizes it. Feel free to put it in there.

>> Another question. How long has she been educated using AAC? I believe that's probably Maya.

>> JACQUELINE HESS: Yes. They started AAC with them I believe when she was two years old. But they went through a whole series of different approaches. They certainly used more traditional static communication boards. They tried a number of different VOCA devices and apps. They definitely tried some single-purpose devices. But Maya uses "Speak for Yourself" now and Dana just loves it. They started Speak for Yourself with her I think by the time she was three. I don't think she was quite three when they started that with her.

>> JEFF: Great, thank you. And another question that has come in, Jackie. Do you have the resources that address practitioners who believe a child needs to have readiness skills in order to consider AAC devices?

>> JACQUELINE HESS: Ah. Again, that's one of those debates. I'm not real sure in terms of resources. I would refer everyone to a number of great sites with resources. The Center on Technology and Disability has a pretty robust library of resources that address various aspects of AAC and we also have archived webinars on AAC that address some of this. The Pacer Center has quite a few resources on their website, as well, about AAC readiness. But I will say that this does fall into that debate of, you know, what needs to come first. What kind of prerequisites do you need to have? And we are really trying to encourage people not to think so much about prerequisites, because you will be surprised at what children can do before we think that they should be able to do that.

Okay?

>> JEFF: Okay. Another question here Jackie. Is Speak for Yourself an app?

>> JACQUELINE HESS: It is. And it for a long time was just available for iOS, but I'm pretty sure it's available for Android now. If anybody thinks otherwise, they can correct me. But I'm pretty sure it's available now for both.

>> JEFF: Here's another question. I have a niece with Downs who is 19 years old who can speak but it's very difficult to understand her. I don't want to discourage her from speaking, but the cousins don't understand her. How can I implement an AAC without discouraging her?

>> JACQUELINE HESS: I would go back to what I said at the beginning. First, last, and foremost, the use of AAC will in no way discourage the use of her oral speech. She will move to oral speech as she has it and it's being recognized by her cousins as understanding her. That will be extremely motivating. But it's really frustrating for her at the moment not to be understood. So you want to jump right in with an AAC device. You want to have an assessment, decide which. It sounds like VOCA, a voice output communication aid or speech-generating device, is going to be something that would be good for her. And you want to get on it right now. This will not be discouraging her oral speech at all. And by the way, I love the comment made above that about there are no prerequisites. I didn't want to sound heavy handed about that, but I totally agree. There are no prerequisites.

Okay, now somebody says Speak for Yourself was available on Android, but now only for Apple devices. And it's currently on sale for half price! So thank you for whomever posted that.

Bridget posted the thing to think about with readiness is that we don't wait -- Yes, she is saying the same thing we all are. Model and there are no prerequisites. Other comments, questions?

>> JEFF: There are a couple here. For children who are birth to three years of age, would you recommend or encourage, or what would you recommend or encourage for the AAC assessment. I'm in a birth to three program and I do home visits using a primary service model and routine based interventions. I use signs, but have not incorporated higher tech stuff.

>> JACQUELINE HESS: In terms of an assessment, it sounds as if the person would be not quite comfortable doing the assessment themselves, because you want to have that comfort level with a higher tech device. So you can certainly bring in an A.T. specialist. A.T. specialists are far too rare in various localities, so you may or may not be able to find one easily. I think that involving a P.T. might be a good idea, particularly if you can find a P.T. who is familiar with some of the higher tech AAC devices and sometimes the O.T.s are, as well. You can even, if you have in mind a potential product, there are companies who will send somebody to work with you on the assessment who really know their AAC. And they have some people whose role it is to help you understand whether it's their advice. Most of them are really good people. They're not just going to try to sell you something. If they are familiar with the field, they will help you sort out. This may not work, but let us tell you about some of the other things that are available.

Also, some of the parent training and information centers, which every state has, they don't generally have A.T. specialists, but places like Pacer Center and CTD are trying to get the PTIs to be more a center of expertise for A.T. devices so they can help provide some A.T. expertise in those assessments.

>> JEFF: Okay, Jackie. There's a couple of others. Here is one that came in. It's more

of a comment. There's a brand new communication bill of rights found at ASHA.org/NGC. It can be a great resource for the fundamental rights of communication for which all people are entitled. Do you have any more additional information Jackie?

>> JACQUELINE HESS: That is very useful. We do a lot of work with awareness and advocacy. This is one of those things where I think that parents, faculty members, and anyone who works with them. The SLPs, the therapists, all the advocates for the child, everything works better if people know the rights that they are entitled to. That said, I will tell you honestly, that disability laws are routinely scoffed by even well-meaning people. We try to educate parents about the need. For instance, IDEA, the Individuals with Disabilities Education Act mandates that every IEP include a consideration of accommodations including assistive technology. And if the A.T. is identified in the I.E.P. as something the child should have, then the school system, it may not be the particular school, it may be the LEA, the Local Education Agency, is required to provide it. And, you know, I can't tell you how many I was going to say dozens, hundreds, just how many principals of schools have said "You know, my budget is X for Y number of kids, and don't ask me to spend \$1,000 for one particular child. I can't have it, and I won't do it." We also educate people about the rights if they want to disagree with the school. If they want to go into some type of mediation. We always ask people to start at the lowest level to start with the Brownies and good vibes part of the negotiation, but to document every single thing. So if you do have to start citing these various laws and making a case for your child to get this provided by a school system or by the state, that you have all the ammunition that you need.

>> JEFF: Jackie, there are several comments that came in that are down at the bottom of the text field there. You may want to read through those and just make comments on those. They're comments rather than questions.

>> JACQUELINE HESS: I'm not seeing them. The last one is Susane's.

>> JEFF: There are several up above that. You may need to scroll up. Or I can read them all.

>> JACQUELINE HESS: Oh, I see the comment. Somebody has answered the question about the image that the other person was asking about. That is Pro Lo Quo 2 Go. Thank you for posting that. Would we be able to get type of documentation for proof of training? I will. CTD always offers certificates of participation for some of our webinars and E-learning events, we also offer CEUs, but this is maybe more a you question.

>> JEFF: Yes, and I'm not familiar with that. What I would suggestion if it's okay with you Jackie for that person to e-mail you directly on your e-mail and we can get that figured out. Would that be okay?

>> JACQUELINE HESS: Absolutely.

Let me know when you want to cut it off. I know people can vote with their feet. I appreciate everybody who has attended the and everybody have stayed with us this far. We'll just continue. And anybody who has to go onto the next meeting, again, thank you. And do we have, let me make sure that my contact information slide. Do we have contact information? There we go. I have that slide here. Please feel free to e-mail me. Please feel free. Although, let's participate is a model demo program, there is a website that we're happy for people to go take a look at if they want with some resources on A.T. for everily childhood, including communication. Although, there's not as much of that as some other A.T. And that would be letsparticipate.org.

>> JEFF: Another question that has come in Jackie is I'm doing service work in a rural area of Nicaragua, so high tech is not in use. Where do I look for resources in English and Spanish?

>> JACQUELINE HESS: There are so many Pinterest boards with access to low tech. If you have access to a printer. There are so many free communication boards. You can get them in English or in Spanish. You can get them in other languages, as well. But Spanish being the second language in the U.S. There are quite a few communication products that include Spanish communication boards. And there are some things that, you know, might cost a dollar to download. If you want more extensive pictures, they might cost a couple of dollars. But there's an awful lot that is free. You must have some internet connection. You're with us today. So I would encourage you to do a simple search. If you need help with that search, again get in touch with us at the Center on Technology and Disability. We will help you with that. We're even able to do the downloads and the print for you and we'll send them to you through snail mail if that will help you.

>> JEFF: We're challenged by A.T. lending libraries that have short time periods to try a device out. What's a reasonable time for toddlers? It seems that they would need more than just the four-six weeks to try out a device.

>> JACQUELINE HESS: You know, we discuss that all the time. And so much of this is not based on best practice. It's based on the limited inventories that sometimes exist. And they are establishing 4-6 weeks' time so that they can serve more people. The other part of that is infants and toddlers develop so quickly that, you know, if you're trialing a device for three or four months, you have to take into consideration the child's normal developmental growth within that time and that might kind of throw off the assessment. It's like, you know, where do you stop? So four weeks does seem too short. Some of it is about how often will the child have access to the device. In a perfect world, you want the child to be using it every single day as much as practical. But that depends on how often a therapist may be visiting the child. Once or twice a week. The device trial may be limited to that. If you're looking at 4-6 weeks, you're looking at four or eight or twelve opportunities. And is that enough? Some of it depends on the family. You know, are the parents or grandparents or other family

members, are they quick studies? Are they interested and able in mastering it right away so they can use it with the child every day? So a lot of how long depends on how much sustained interaction the child can have. And yes, having a device for two-three months could be much better than four-six weeks. But there really isn't a hard and fast rule here.

>> Great, thanks Jackie. Sherry Whaley sent in a comment. I'm reading a book called Ghost Boy. And she highly recommends it. I don't know if you're familiar with that or not. But that's out for everybody who is still on the webinar here.

>> JACQUELINE HESS: Thank you for that. That's lovely. And thank you Bridget for the shout out. I appreciate that.

>> JEFF: We have several questions here about will the PowerPoints be posted anywhere? Or the slides? We will be sending out a link to the recorded webinar within a week or so to anyone who got the initial announcement. That will be available as soon as it gets processed and posted. So be looking in your inbox for that. It looks like we don't have any more questions at this point. Jackie, do you have any last words? I have a couple of things in wrapup here. But if you want to finalize anything?

>> JACQUELINE HESS: Well, with respect to getting access to, you know, the PowerPoint, unless ASHA has some problem with it, we will put the PowerPoint in the Center on Technology and Disability's library, and you can access it there. You can just use the search word to get to it. We could also put it on the let's participate website also if that's useful, particularly for early intervention providers. We have a section of the CTD library that's specific to early childhood, but that again particularly with Tracy on the phone, I want to make it clear that the Let's Participate website, although not designed to serve a national audience, there is nothing that is posted there that we would have a problem with anybody accessing and using.

>> JEFF: Great. Thanks so much, Jackie. Very, very interesting presentation. And lots of lively discussions. Lots of good comments and questions that have come in. Just to remind everyone, this is a series of webinars this week. We will have three more on Wednesday, Thursday, and Friday at the same time and place. Tomorrow is quality hearing screening practices for children birth to five years of age. And William who was here earlier and myself will be presenting that.

Thursday is using a multi-modal approach to support children with hearing loss.

And then on Friday the Center on Technology and Disability will have free resource to support the use of assistive technology in young children with disabilities.

Thank you for joining us everyone. And with that, we're going to go ahead and close the webinar. Thank you very much, Jackie, for your presentation. And once again, the presentation will be available for the recorded presentation will be available in a week or

so. We'll get you that. Thank you all very much.

>> JACQUELINE HESS: Thanks. Bye everybody.

>> JEFF: Good-bye.

(The webinar ended at 2:48 p.m. Eastern Time)