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**NCHAM**

**COORDINATING CARE FOR CHILDREN AND YOUTH: PRACTICAL APPLICATION  
FOR EARLY HEARING DETECTION AND INTERVENTION PROGRAMS**

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>> Hello and welcome to today's webinar "Coordinating Care for Children and Youth: Practical Application for Early Hearing Detection and Intervention Programs". The webinar will start at the top of the hour. So 3 p.m. Eastern Time. But in the meantime we would like you to answer a few polling questions so we can get to know our audience a little bit better.

So our first question for you, let me just expand it here, is to just answer the question posed on your screen. What is your role in your EHDI system? And you can mark all that apply. Thank you. It looks like a lot of state EHDI team members. And remember, you can mark more than one answer. We recognize that a lot of people have multiple roles within EHDI.

I'll just let that keep running for just a few minutes, or another minute. As people join in on the webinar.

Okay. Thank you, I'm going to end that poll. And I'll pull out the next question for you.

Our second question is: Are you involved in your state's Learning Community? Excellent. It looks like the majority of the attendees today are. Which is perfect.

And then our last polling question for you is: Are you aware of and following the JCIH 1-3-6 recommended guidelines?

Okay. It looks like most of you are. And these questions just help us understand our audience for today's webinar just a little bit more. We'll just give it another couple of

minutes as people join in. And people will begin in about 2 minutes  
(Standing by)

"Integrating Care for Children and Youth: Practical Application for Early Hearing Detection and Intervention Programs".

>> ALYSON WARD: Okay let's go ahead and get started welcome to today's webinar "Coordinating Care for Children and Youth: Practical Application for Early Hearing Detection and Intervention Programs". Today's webinar will be recorded and posted on [infanthearing.org](http://infanthearing.org) within one week we'll open the webinar the last 10 to 15 minutes of the webinar for questions and answers and during that time a chat box will appear in the lower right-hand side of your screen. So please enter your questions when the time comes and the moderator will pose your questions to the presenters.

If we don't have time to answer all of the questions we'll collect and respond to each of the questions and post them on [infanthearing.org](http://infanthearing.org) along with the recording of today's webinar. We also have the PowerPoints for today's webinar accessible on the lower left side of your screen. You can see there's a little box. You can click on download files and download the PowerPoint to your computer.

Lastly at the end of the webinar, please take a moment to complete our short evaluation questions. There's about 4 questions. We would really appreciate for you to answer.

I will turn the time over to Michelle Esquivel with the American Academy of Pediatrics to provide a webinar overview and present the speakers. And in the meantime, I'm going to go ahead and start the recording.

>> MICHELLE ESQUIVEL: Thank you so much Alyson we're so excited that so many people registered.

>> OPERATOR: Audio recording for this meeting has begun.

>> MICHELLE ESQUIVEL: Also that so many of you are able to participate live right now today so thank you for that. We have participants involved today from a variety of different backgrounds. So we have state EHDI program staff. We have individuals from clinical practice, whether that's medicine or audiology or some other health care profession. And we have numerous family leaders and representatives from family support organizations on the call. So welcome to everyone. And again, thank you for your participation.

As Alyson mentioned, my name is Michelle Esquivel. I oversee the division of children with special needs at the American Academy of Pediatrics and I also oversee the academy's National Center for Medical Home Implementation. We have been working on EHDI as an organization for almost two decades and the Early Hearing Detection and Intervention projects and activities in the academy fall under the purview of my division.

We wanted to thank the Maternal and Child Health Bureau for their support of the EHDI activities. Not just for the Academy of Pediatrics but also for our partners at the

National Center for Hearing Assessment and Management. And Hands & Voices, who collaborated with us in the development of this webinar that you'll be listening to today.

And we also collaborate at the national level on a lot of different projects and activities.

As grantees of the Maternal and Child Health Bureau.

We're also very, very excited about our faculty today. We have partnered with the National Center for Care Coordination Technical Assistance which is based at Boston Children's Hospital to bring this webinar and the information in the webinar to you today.

So I just wanted to take a minute to step back and provide a little bit of context for why we're offering this webinar and why we're all here today.

You all know the new funding announcement that was made available to you and to your state EHDI programs within the last year and that you're working on right now. And many of you who have been involved in EHDI for a while also know that the change of direction and the focus for the state funding opportunities was something that many of you are just now learning about and getting used to implementing.

And so we wanted to make sure that we focused on the core elements of what was applied through the funding opportunities through state EHDI programs and that was really focused on developing statewide comprehensive and coordinated systems of care targeted towards ensuring that newborns and infants are receiving appropriate and timely services, including screening, evaluation, diagnosis and early intervention and again specific to children who are deaf and hard of hearing.

As you know, there were a lot of outcome -- there were measures and outcomes in the funding opportunity announcement. Some that were aligning with the Joint Committee on Infant Hearing recommendations. Some that focused on a number of participants involved in your activities. Some also focused on the integration of shared plans of care. Into your Learning Community activities. And also referrals to early intervention. Some of those activities are things that many states have begun. Other states are just planning. And some states are even at the implementation phase. Because they started doing some planning even a little bit earlier at the state level.

A lot of what we're going to be talking about today is really fundamental and foundational to the work that you'll be doing going forward so this webinar is the first webinar in a series of three.

Today we'll focus on what care coordination is and the framework for care coordination as it relates specifically to Early Hearing Detection and Intervention and we'll be focusing on what integrated care means in the context of children and families who are deaf and hard of hearing. The second webinar, which we haven't announced the date and time for yet, we will be doing that soon. Will be led by Jeannie McAllister who spend her years working on a development for shared plans of care those involved in state EHDI programs know that developing a state shared plan of care for kids who are deaf and hard of hearing is what is -- a big part of what's being required in your

community of work we'll also provide vignettes and insights from state EHDI programs that will be highlighted where the shared plans of care are being used. So stay tuned for more information about that from us at the academy or from NCHAM and then the third webinar will be offered in the beginning of 2018 and that will focus more on the specifics of implementation of care coordination as a process but also shared plans of care. In your quality improvement work at the state level.

And that will be an opportunity for dialogue and information sharing and a lot of question and answer.

Ongoing technical assistance is available through the National Center for Hearing Assessment and Management, through Hands & Voices and through the academy depending on which group you sort of align yourself most closely with or not and we're here to help you. As national partners we want to make sure that you have all of the support that you need in order to implement successful programs at the state level.

So with that, I'm going to move forward quickly and introduce our faculty today it's really my pleasure to introduce Richard Antonelli and Hannah Rosenberg who I consider to be colleagues and friends and experts in the area of care coordination Dr. Antonelli is the medical director of Boston Children's Hospital and on faculty at Harvard Medical School his area of expertise is care coordination services for all children and youth but in particular for children and youth with special health care needs and their families he's consulted all over the country on care coordination and methodology and also been integral to the development of family reported measure on care integration which you'll hear just a little bit about today. Dr. Antonelli is the director of the National Center for Care Coordination Technical Assistance he also spends some time in clinical care still as a general pediatrician at Boston Children's Hospital.

And Hannah, who works very closely with Dr. Antonelli focusing on -- focuses on research and quality improvement work regarding care coordination for kids with special health care needs and their families in the integrated care program at Boston Children's Hospital she's been involved in projects that have included the development and implementation of the measurement tool that assesses family reported perceptions of pediatric integrated care. And the development of care coordination workforce capacity and Hannah really brings a lot of expertise in that area, as well

She's the manager for the National Center for Care Coordination Technical Assistance.

And then Patricia Burk is also joining us today. And Patricia is going to sort of bring this all home as it relates to EHDI and state EHDI programs and kids and families who are deaf or hard of hearing. She's the EHDI coordinator in Oklahoma. And works in the State Department of Health there. She works on early identification diagnosis and early intervention placement of kids with hearing loss throughout the state of Oklahoma.

She leads the Oklahoma Audiology Task Force to address specific pediatric audiology initiatives across the state. She's a Master's trained speech-language

pathologist. And she is internationally certified as a listening and spoken language specialist, certified auditory-verbal therapist she's also one of the quality improvement advisors for NCHAM so some of you may have worked with her in that capacity, as well Patricia is a member of the Joint Committee on Infant Hearing currently so we want to make sure that you know what we hope to accomplish today so we're going to show you on the screen our learning objectives for the presentation. I'm not going to read these outloud. You can certainly take a look at them yourself. But just know we're focusing on providing you a basic framework for care coordination because we want to help you know best what care coordination is. And let you know that there are tools and resources out there that you can use as you're building your capacity to implement your Learning Community and also your other work related to care coordination and shared plans of care for kids who are deaf or hard of hearing I'll turn the presentation now over to Hannah and Dr. Antonelli and they will talk with you through the next few slides and then after they present, Patricia Burk will present. So thank you so much again for your participation

>> HANNAH ROSENBERG: Great thank you so much Michelle I'm from Boston Children's Hospital and for the National Center for Care Coordination Technical Assistance I'm going to go flu the next set of slides of the course over the next 20, 25 minutes and Rich will join, as well as we start to discuss with Patricia as Michelle said, this is really meant to be very foundational we'll be talking about the framework around care coordination. We'll be discussing some definitions and we'll also be presenting some tools, measures and resources over the course of this webinar and really they are meant to kind of give you an idea and have you start thinking about how you might take pieces of these and implement them into your work we often through the National Center for Care Coordination Technical Assistance it's really our mission to help them meet people where they are and to help use tools or pieces of tools to best serve their purpose and we'll have a little bit of a discussion at the end after we go through a vignette and please do feel free to follow up with us after the webinar, as well I'll say that again but our center is really intended to help and serve anyone who is focused on care coordination for the pediatric population.

So why discuss care coordination? So all of you do care coordination as part of your day-to-day work but in order to kind of systemize it and come up with methods to provide care coordination across a system, we need to think kind of where the gaps are. And when we were brainstorming with kind of the planning team for this call, some of the things that came up that will most likely resonate with you is there are a lot of gaps in coordination and communication between different players for the EHDI population. So between primary care providers and other health care providers, between the PCP and the audiologist, between PCP, audiologist and EHDI or Title V programs and between EI programs and everyone else so everyone is working with the families maybe individually But it is -- then when you get to the point of trying to get everyone to

communicate with each other, and the family as part of a larger care team, sometimes things fall through the cracks.

When we -- oops.

When we were talking as a planning team, one of the things we kind of initially looked for was is there some sort of data that shows us that this is occurring. And one of the things that the CDC had put out and this is kind of dated data. But I imagine that it's similar currently now is there's some data that only 64.9% of children who were screened positive in hearing and early detection were actually enrolled in EI. So there's a big gap in people who are maybe meeting with one specialist so either the PCP or the audiologist. And then there's a gap in how they are connected and enrolled in EI. So there is this opportunity for improvement is what we call it we say how can we take that as a starting point and think through what are some processes and tools that we can put in place and we can use as EHDI coordinators to close that gap?

And I'm sure that when we hear from you, there will be many more kind of examples and instances in your case where you see this gap occurring.

So really what resonated with us is families are experiencing these gaps. And what we say at the National Center for Care Coordination Technical Assistance that these gaps can be identified and measured. And once they are identified and measured, then they can be remediated and care coordination is a big part of that.

So we say care coordination is the actual set of activities in the space between. And that's between these in-person touches. So in person visits, in between different providers, in between hospital stays. In between procedures. So all of the time that a care team member isn't actually seeing a patient face-to-face, a lot can happen and all of that care coordination which imagine is a lot of what you're doing isn't always necessarily tracked or really accounted for. So it's all of those phone calls and connections that you're making. And all of those kind of follow-ups that you're doing with the families and ensuring that they are getting resources and services that they need. Those are the activities. That's what we identify as care coordination.

And then we say those activities together make up what we call a shared care plan. And that's something as Michelle said that we will get into further in the second and the third webinar.

And then we say integrated care is the seamless provision of health care services across the continuum. But it's from the perspective of the family. So we have -- one of the tools that I will talk about is the Pediatric Integrated Care Survey. And that we call it the PICS and that's intended to measure care integration. It's a family reported measure of how well they feel that their child's care team members are communicating together, are working together to provide continuous seamless care. Regardless of institutional, departmental, community based organizational boundaries.

So everyone might be working really well within their institution or within their group. But if they are not communicating across different providers outside of that group, these

patients and children are seeing, then they are really -- then those gaps become much more apparent.

So this is a slide that I just wanted to show. And I won't dive into this. But this resulted from some research that we did that ended up resulting in the Pediatric Integrated Care Survey and we asked families what they felt needed to happen in order for them to feel that their child's care was integrated.

And from all of talking to families in focus groups and interviews, we came up with this framework. For those of you who do practice care coordination as part of your everyday work, I'm sure that some of these will resonate with you.

So team based care and understanding who is part of the team. Not just staying in the medical silo but also connecting to these really rich community services.

And then doing care planning. So thinking about what the next steps are and who is accountable for helping families get to those next steps.

So this -- again, I said I won't really dive much into this. But this could be a really great resource as you're starting to think through, you know, some things that you might do with families in terms of shared care.

So we often kind of say these broad recommendations. So people will come to the center and say, okay, how do we do care coordination and who should do it? And really that depends. As you know, configurations in different institutions, in different states, in different areas and for different families are very different.

So there's really not one care coordination model that works for every family.

For example, one family might really rely on their Primary Care Provider's office to help them to coordinate care. Another family might do most of the coordination themselves but need a little bit of support. And then another family might find a great resource in a community setting. And that person really helps to drive their care.

We also hear that, you know, peer-to-peer support is a great resource for a lot of families and they might find that their -- that they are getting resources in that setting

So our broad recommendations are just meant to be kind of a guidepost.

So the first one is promote Interdisciplinary Team functioning through training. And that's one of the things that these groups are doing through these webinars. So getting people together in a room or virtually in a room and kind of learning from each other's experiences.

Collecting family experience to assess gaps and using the data to inform intervention. So those of you who work with families every day know that really families know best. Because they are the ones who day in and day out are working with their children and providing their care and doing much of the care coordination. So gathering these experiences and actually coming back to families and saying, how do you think we can make things better?

And that's a lot of the work that we do in our program. We always involve families in

that work. And when we're working on an initiative to improve care integration, families are always the ones that we go to first.

Collecting care coordination activities and outcomes data to inform quality improvement and prepare for value-based care.

So this might be kind of a little out of what you're thinking of in terms of your kind of day-to-day but really what we say is oftentimes care coordination really isn't quantified. We'll show a tool a little later that might help -- or you can maybe think through how you might start collecting some of that data.

But we help groups to say, okay, you're doing all of this care coordination that's really not being tracked. How can you track it? And then really make a case for the value of providing the care coordination. How can we link these activities to positive outcomes for families? So we'll talk a little about that, as well.

Co-creating and implementing a care plan that includes care team members and families who are part of the care team. And again, as Michelle said, that will be a lot of the second webinar will really be focused on that.

And then systematizing handoffs between care team members and families. So in the integrated care program here at Boston Children's Hospital, we talk a lot about handoffs. I think traditionally people think of handoffs between inpatient to ambulatory settings. But we think about handoffs as when you're passing a patient or a child onto -- from another provider or passing them to a community agency or back to school, how are you making that handoff? And we talk about the importance of a warm handoff. So giving people information and the resources they need.

So a lot of kind of the time I'm going to talk about in the second half of this is really some tools that you might start to think about thinking through what are the elements of a warm handoff? And how maybe can you take some of those and systematize the way that people are communicating across the care team for the EHDI population.

Family partnership is also another thing that we really focus on. And as I said, we include families in the quality improvement work that we do. But this pyramid is just to show there's multiple different ways to engage families and to work with them and to help them become empowered and better advocates for their child's care, as well.

So as I said, we always include families as part of what we call care redesign. So improving things from the system level. And in the health care delivery side

We also work on setting expectations by sharing family experience surveys. Sharing needs assessments, sharing care mapping and planning tools. And some of these I'll show, as well. But really what we hear a lot from families is the phrase you don't know what you don't know.

So you might be completely satisfied with an experience without really realizing all of the things that you should be expecting.

One of our surveys the Pediatric Integrated Care Survey which I mentioned before and I will talk about helps families -- one of the ways we're using it is to kind of help



families to walk through really what should you be expecting? So an example before is one of the things that we found a lot in research and I mentioned -- I alluded to this earlier is families say peer groups provide a lot of support. And really it's kind of drawing from experiences of people who have come before you in this space and kind of learning what they learned.

So not reinventing the wheel

And what we hear a lot is families don't think of asking for this resource until they learn more or later down the road but this peer resource might have been really helpful to them earlier on so connecting to a Family Voices chapter or another type of organization. So the survey that I'll show you, that can kind of get families thinking about those type of things and that might be a great resource to bring in with your families.

And then giving families tools to partner with child's care team members. So again, giving them -- handing them the tools. Not just waiting for one of their providers to bring the tools in. But really sharing with them.

I will say that all of our tools are not disease or condition specific. So we really think that our tools can span across the population of children with special health care needs. They can certainly be adapted to reflect differences in the population. But they should be applicable across the board.

So the Pediatric Integrated Care Survey. Which I mentioned before is a family experience measure of care integration. It is intended to be used as I said to conduct quality measurements so basically to assess where are the gaps that families are experiencing. And then once interventions are put in place, so you try to improve those gaps, measuring is it really making a difference from the perspective of the families? And when I say intervention sometimes people think of these kind of big overwhelming projects. But interventions can be pretty small.

So we'll give an example, just to kind of make this seem more reasonable. Is one of the things that we recently have been doing work with is working with clinics to subspecialty clinics to implement the survey and measure change in families' experiences over time.

And one of the questions on the PICS survey asks does someone on your child's care team asked if you needed help getting resources in the community. So it's a question around that. And one of the teams we worked with, they got a pretty low score on that. So they had a lot of families saying now.

And when they were talking about it as a team, they said, oh, that's interesting because our social worker really does ask families that at the initial meeting but what they found through discussion was families really only got asked that when they were initially onboarded to the clinic and then that wasn't a question that was asked repeatedly over time so while the care team assumed that families knew to go to the social worker if they had any questions, that really wasn't the experience of the families.

They didn't identify that that was the resource. So their intervention -- and I'm using quotes because I know I'm trying to make intervention seem more feasible. Their intervention was the social worker now started just asking that additional question every time he met with a family

So it really made a difference from the perspective of the families. It improved their experience and improved kind of their clarity around where to go when they did need these additional community services.

Again, it's not -- this tool is not intended to solely be in the medical setting. So we also have groups that are using this in the community space. We do have Title V programs administering the survey and we have family groups using the survey to evaluate the services that their population is getting.

And the tool is intended to look across the care team. Or what we help groups do is make it specific to their entity.

So I did want to show you just two types of questions. And kind of how the survey could look.

So one of the -- the first question is, and this is for the Smith clinic, how often did you feel that your child's care team members in those clinics knew about advice that you got from your child's other care team members. You can see that we have two years. You can see that as you make changes, you can evaluate how these responses are changing.

Another sample question is, how often have your child's care team members in the Smith clinic treated you as a full partner in the care of your child?

And so some of you might say, okay, what does that really mean? So this question can identify that families are either feeling as a full partner or not and if they are not the next step would then be meeting with families and saying how can we move that dial for you? What can we change so that you do feel more as a partner

This tool is available in the public domain. And you're able to look at it and use it as you please. So if you're interested in getting a copy of it, you can email me. And I can walk you through the different tools that we have in this set of surveys.

The other types of tools that I wanted to talk about are what we call care planning tools. So they -- again, they are helping families and care team members partner together to provide the best care and coordination for their families.

The first one, and this is on this slide, is the care map. And the care map was developed by a family partner. Her name is Kristin Lind (phonetic) she used to be at Massachusetts Family Voices. She's not anymore but she still does work in this space. And she developed this map to be for her son who had special health care needs to really demonstrate all of the different players that were contributing to her child's care.

And one of the things she found was through this exercise, she was really able to see and visualize all of the different people, individual people, who contributed. And was able to identify if there were you know -- you know if there were redundancies in

care, if there was anything that they could cut out, if there was any duplication of services.

But most of all, she was able to then take this tool and share it with her care team members. With her son's care team members. To really be able to drive the conversation.

So as you can see, it's a great visual. It's not a clinical document. What we often hear from families is they really feel that some of these forms that they fill out are very -- they are very much from the clinical perspective and not the family perspective so this is a great tool as you start to think about how to make a care plan and use a care plan with families. This is a great tool to think about and a great exercise to do with the families you serve.

On our Web site and the Web site is right at the bottom in the bottom left hand corner, there are guides for care team members from providers who are helping families to fill this out and for families themselves, so that's a great resource to check out, as well.

The second tool is the strengths and Needs Assessment. This was developed by the Massachusetts Child Health Quality Coalition. And the purpose of this was to give individuals a guide to think through what questions and what types of questions should they be asking and working with families on. So I know this is difficult to see. The Web site at the bottom, if you go there, you can download this tool, you can download a compendium of example tools. But just to show you kind of larger there's one section that is called help needed by domain. So it gives you different categories of questions and again this is just something to start thinking about that you might kind of pull in as you start to develop this shared care plan or thinking about how to use that. But just different types of questions. And kind of a guide for you to say okay did we talk to the family about medical and health care, about behavioral, social and educational, financial, what else? So it's a really great resource to start thinking about. I know I said this before but I will reiterate, our purpose through the national center and we know that all of these kind of groups we partner with feel the same, as well, really the kind of key is taking what works for you and then adapting it so it's not saying, okay, I need to use this tool in it's full form but maybe taking a piece of it or taking some questions and incorporating it into the work that you're already doing to support you and the families that you serve.

Two of the what we call care planning tools what we have here at BCH are the clinician reason for BCH visit and the action grid the action grid is on the next slide and I'll just talk about this for a minute. These might be, again, as I just said, something that you're kind of thinking about, okay, that's interesting that this information is in this form. Maybe we could use this in some sort of way. The clinician reason for BCH visit is a form and we have a screenshot at the top of the form on here is a form that we have started using with referring primary care providers and specialty providers. So what we

found early on and this will resonate with all of you based on the data is that a very small percentage of the time a child is referred to a specialist does the specialist really know the reason. So they have not then communicated with the Primary Care Provider They have not gotten any preinformation.

So as you can imagine that doesn't lead to a very productive visit. So what we have started implementing among these providers are these forms in which the Primary Care Provider will send ahead of the visit information about the patient. They will send what we call the reason for visit so why they are referring them. They will send any kind of relevant clinical or psychosocial information. They will send any kind of background documentation. And then kind of most importantly what they will -- most importantly to shared care planning is they will send what we call the requested referral relationship.

So they will say, okay, am I sending this patient to you because I just want you to see them once and let me know what you think or am I sending them to you because I want to now engage in shared care planning with them? So we're now going to co-manage the patient.

Or am I not sure but I want to discuss this further?

So that's what that requested referral relationship is. And even if you're not using this form, that's a great kind of concept to start thinking about.

As you're working with children who have special health care needs, obviously you know they see many different people. And so a great thing to start thinking about is how are you communicating? And kind of defining relationships with their other care team members.

One of the things that we often hear, and I'll talk about this in the next slide, as well, is that oftentimes when people are working with a patient -- a child with special health care needs and they say, okay well this is our recommendation, it's really unclear who is taking accountability for that and who is following up.

So that's why what we have also been piloting and using in our team is what we call an action grid.

So after there's an in-person visit and this, again, doesn't have to just be in the medical setting, it can be in a community setting, oftentimes the child and the family will leave with recommendations.

And I'll just talk about our example here in the clinical setting but know that this doesn't have to sit in a clinic. This can also sit in a community group.

But what we have found and what actually resulted from data that we got back from the Pediatric Integrated Care Survey is that many times when families leave a visit, they are really unsure what the next steps are. So during the course of the visit, some action steps or recommendations might have been defined but it's hard for them to track that in a list. And then even harder it's often not decided in that conversation what is really accountable for that. If they are in a specialist visit is it the specialist who will take accountability for the next steps? Are they giving that to the family. Is the PCP going to

take responsibility, is somebody else, is the care coordinator. So this grid helps families and care team members across the continuum kind of identify that. Identify what the action steps are, who is responsible, what the timeline is and what we call contingency planning. It's the first if it doesn't work, what do you do next? Again this is a great thing to think about when you're working with families maybe pulling some of these components or even talking to families about this might be a great step.

So I just want to reiterate again the importance of simplifying this. These tools are not intended to be just downloaded and start using it tomorrow. But really think through what elements of these tools might work for you and might support your work.

I know I'm running out of time because we do want to get to the case but what I will say just briefly is we wanted to talk a little bit about measurement. So we said kind of at the beginning when you identify gaps, the best thing to do is be able to measure those gaps. And then put in place interventions. And then measure change over time to see if you're making a difference.

And so what we have is the care coordination measurement tool. And this is a great -- we generally recommend that people who are doing care coordination but not tracking it in any sort of way take a look at this tool. To be able to what we say kind of create a value stream for their work. So to be able to show that the activities that they are doing day in and day out are actually leading to positive outcomes and preventing negative outcomes.

So I'll just show this to you briefly. If any of you are looking -- are interested in kind of thinking through how you might use this in your day-to-day work, as well, please do reach out to our center. We provide technical assistance and help with anyone who is thinking about using this. And we can certainly have individual conversations with you about that.

Then lastly what I'll say is just kind of talk a little about the curriculum that we have.

So we currently have a four-module curriculum that's intended to teach the care competencies of care coordination it's available in the public domain on the link at the bottom of the screen. And again, what we -- we think it's a really great kind of resource as you're starting to think through you know some tools and resources that you might use, there's a lot of great information in there. We also are currently working on the Second Edition that will be published later this year and in 2018. And that's a great -- you know if you're interested in getting that when it comes out, just shoot me a quick email and we'll put you on the list, as well but it's a great resource so just kind of start flipping through as you're thinking through some of these things.

And that is our web page.

So I'm going to turn it over to Patricia, she's going to walk through a case and we're all going to kind of discuss how we might approach this from a care coordination perspective.

>> PATRICIA BURK: Okay. Well this is Patricia. I hope you all can hear me. Thank

you, Hannah, for all of this information. And I hope all of the EHDI coordinators are out there, I know this is a lot of information so just a quick reminder that we are going to have several different webinars to help us learn this information. Obviously there's the great resource that Hannah just mentioned.

So at this point we're just going to talk EHDI. Right? I think that -- this is what we love to talk about. So we're going to go through a vignette maybe a best case scenario.

So before I start I wanted to say thank to Brian Shakespeare and Nancy Payjack who helped create some of the things we will be talking about and a special thank you to the AAP as we were creating this best case scenario coming up we really talked about where each partner sees themselves and really where we would like to see the other partners joining in so we'll go ahead and start there. We always start at the very beginning care coordination within EHDI and a process and break it down for the next few minutes and once again this is maybe a best case scenario and we know it will vary from site to site so one thing we encourage for programs to see is everything that's being said you don't have to complete every single part of this. In fact, maybe at least I would say encourage maybe take it and break it into parts and do some quality improvement with it. Small systems of change. Everything doesn't have to change tomorrow. But we can just start taking pieces and look at it. Feel free to use your quality improvement advisors as you're hearing things talk through those and of course use resources like EHDI chat. What I love with what Hannah just presented was we don't have -- there's really great resources out there and we can easily use those I'm not going to lie Hannah I really loved the slide that says simplifying how do these tools work for you here is the example of how maybe this process we've been talking about today could really be put into the EHDI model. So let's go through our 1-3-6.

So hopefully by one month we'll have our babies screened at the hospital and of course as a speech pathologist who worked in a cochlear implant clinic I had a supervisor once say if you had a magic wand, what would you like to happen? So ideally, if the baby -- get the baby referred, the parent would be educated by the hospital staff to immediately follow up with audiology and rescreen depending on what happens in the state. The hospital would also educate the parent to talk with their PCP, as well. Then of course in an ideal dream world, which should be happening, is that the results would be shared with the EHDI program. And we can start that case management. And continue to help families along the path. Because I think Hannah mentioned earlier, sometimes it's the in between. And that's where we can also come. So often for me, I see EHDI as a bungee cord between all of these things holding everything together so hopefully we go to EHDI. And depending on your state for instance in our state in Oklahoma we actually send a letter to the parent providing them the information regarding follow-up. And we send it to the PCP letting them know the follow-up should occur then we get to the PCP office and just looking at the sentence it could look very simple and basic but it's really packed with a lot of power.

We don't just want the PCP to assume what the results were. We want the PCP to actively engage and ask the parents, what are the hearing results? And then speak with the parents about those results. The delay -- was it the baby did not pass or passed? Really our hope at this point is that hearing health care would be on the radar of the PCP. They are really getting connected early on and they are really helping along the process because we know that our children go to the PCP several times in those early months.

So then the parent -- the PCP would then talk to the parent about the importance of follow-up. And even assist with the follow-up and the referrals to audiology and other specialists as needed.

And then we would like the PCP to even establish a follow-up procedure to ensure that appointments are kept I know that so many of our programs are currently sending additional letters here in Oklahoma we send an initial letter and 45 days later if they haven't followed up our follow-up coordinator actually calls the parent and PCP about the follow-up but ideally that could occur early on where PCP is helping to ensure appointments are kept and they are becoming an advocate along the way.

All right. So we're onto our 3. So the family completes the hearing rescreen depending on the state or attends a diagnostic evaluation. And then of course there's going to be several steps that go from there. So the audiologist determines the hearing and of course I think every EHDI coordinator is saying, yes, yes, they would actually report the results to EHDI for tracking and surveillance but that could also be something that kicks off the next step. For instance, that might be in your state sending a packet to the PCP with resources at the very moment they see a child with hearing loss in their clinic because we know it doesn't happen every day in their clinic. And so sometimes they can learn information today but it may not put into practice until later.

But really this is where we can start developing that shared plan of care. It can actually begin then where the team is identified and we really work together for our 1-3-6 goal.

I love this part here it says we can connect with Hands & Voices, Family Voices, other parent-to-parent support we really want to look at who is the team.

We have identified them to working towards the 1-3-6 we have the PCP, the audiologist we have EHDI involved, parent to parent, maybe a deaf mentor and hopefully once we get onto EI that partner will join us as well. One of the things I was thinking as I was listening to the webinar is the other thing we have to consider is that we have to also be speaking the same language. You know I'm reminded of the -- the talks about the Ad Age that says it takes a village to raise a child and it really does but within our village we have to also be speaking the same lingo and making sure we're getting the right information. Earlier there was a slide and it talked about 64.9% screened positive who were enrolled in earlier intervention from CDC data and what does screen positive mean to different groups? Maybe for medical or even a newborn

screening, screen positive can mean one thing where really in EHDI we see it more as a diagnosis so really making sure we're all on the same page and moving in the same direction and all providing the same support I always think if we have the same lingo and information, a parent is more likely to move forward.

So then the family would actually hopefully meet again with the PCP to discuss their next steps of care. Whether it's early intervention, communication and hearing technology options, parent-to-parent support and even just the overall impact because we do know that finding out that your child has hearing loss can be a shock to many parents even the grief process is something that can be caused with the PCP but looking at who else do we need to add to our team and how can we as a teamwork together? And then finally heading to 1-3-6, at 6 months we want the families to follow up with the early intervention services and the child not only is enrolled but they have an IFSP planned that it's done in a timely manner because if we're honest sometimes it takes a while to get to IFSP and even once that's in place sometimes it takes a while to get the services started.

But if we are doing more of a care coordination plan then we can actually work together to make sure okay well you got your referral what is happening now when is your next appointment. So we also want to make sure that not only are they getting the services, that the different partners are speaking together that EI is reporting that the child is seen they are reporting the IFSP date they are reporting when services are started and I know that can be difficult for some states because we don't have jurisdictional authority over certain things. And sometimes there's just obstacles along the way but looking at the care coordination to figure out how can we overcome those obstacles to come together.

And then finally just the PCP is notified of the actual EI services and they continue to monitor it as outlined by the shared plan of care.

With that we'll give it back to you, Hannah.

>> MICHELLE ESQUIVEL: I'm going to jump in right now and thank Hannah and Patricia for sharing their expertise and their insights with us I think you all will agree that Hannah laid the foundation and provided such a great overview of not only what care coordination is but also some of the tools and resources that are available to assess and monitor and keep track of care coordination. And then Patricia really did bring it home with a very practical real life EHDI perspective on what could go on related to care coordination. I think now we're available and we're open for discussion and for questions So if you do have questions, you can type them into the chat box. And we'll take a look to see if anybody is posing anything. In addition to that, we have contact information on the slides for all of the people who presented or the staff who presented. And you can take a look at that and if you have any questions that you want to direct specifically to those individuals, their emails are listed on this slide.

But again, what questions do you have now or what things would you like us to --



since we have our faculty at the ready, what things would you like to know?

>> I think somebody asked -- I'm just seeing this in the chat box can you provide examples of how family organizations are using care coordination plans in their work.

So I can kind of answer broadly. That really varies. And so kind of that first piece that I said where really it depends on kind of the setup of the organization. How they interact with other organizations and with other families. But generally, really what I would say is that family groups, if they are providing coordination services for families, they can use a care plan similarly to how it's used on the health care delivery side so that kind of example of the strengths and Needs Assessment, a family group could use that to do kind of a needs and -- a strengths and needs intake form.

And then say, okay, based on that, how can they help serve the family and kind of guide the family towards coordination.

>> Then the next question is, can you list again ideas for measurements of gaps or improvements?

>> That's for you Hannah again.

>> Sorry I'm listing the question can you list ideas for measurements of gaps or improvements? So is this kind of -- is the person who asked that question, are you able to kind of clarify are you looking for measurement tools or kind of how to measure gaps? I don't know if they can speak up.

>> No they are not able to voice.

>> They are not able to speak, okay.

>> Yeah, I do see -- specific issues is what the additional -- tools for specific issues.

>> Tools for specific issues absolutely so what I would say is go back to that kind of PICS slide we talked about the Pediatric Integrated Care Survey and that's where I would start. As I said we really like to keep focus on gathering family experience because as I think I had said this earlier, families really know best what the gaps are. Because they are the ones who are working and kind of providing care and coordination for their children every day.

So the first step in kind of identifying those gaps is I would use the family experience survey tool.

There are other tools, as well. PICS is not the only one that's in this space. But I would say it is kind of the experience of care integration tool in this space.

What I also might kind of recommend is the family experiences with coordination of care. That is out of Seattle Children's Hospital. That's a measure of care coordination. And so I would take a look at these. And administer those to really identify what are the gaps that is right families are experiencing. And then use those gaps to kind of measure the improvements that you're putting in place. So those interventions.

What I also might kind of start out with is measuring those handoffs. So whether that's measuring whether you can kind of do that measurement or whether it's you know kind of taking some family experience data around that.

But kind of thinking through, how many times that hearing loss comes back as a positive result, how many times are those children being immediately referred to an audiologist or to early intervention. And so measuring those what I would say those handoffs between care team members or care providers is a great thing to start with, as well.

And then lastly, just I'll reiterate that care coordination measurement tool. The CCMT. That can measure the work that you're doing in between or for those kind of transitions of care or handoffs. So that measures the activities that you're doing to support that. And then the outcomes on the -- that are resulting from the time that you are connecting families, connecting with other care team members.

>> Great, thank you.

>> And then Hannah, the next question is, who is the PCP who will be in charge of follow-up with the shared plan of care? Who do you suggest? And then an additional question that goes along with this is what are some of the strategies you have used to gain position buy-in.

>> HANNAH ROSENBERG: So I think that I would turn the PCP question around potentially to -- back to you. I don't know that question in terms of the shared plan of care that you would be working with.

Alyson, would that be a question for you?

>> PATRICIA BURK: I'm wong if it would be more --

>> ALYSON WARD: I'm wong if it would be more for Michelle at this point.

>> MICHELLE ESQUIVEL: I don't know that we would say there's one person who would necessarily be in charge of it especially as we see this as a process that everyone who is a part of the team at any given period of time would be involved in. So in the -- we have a practice-based quality improvement project on EHDI that we implemented at the national level with five or six practices from across the United States, primary care. And in each situation the care coordination probably was handled by someone else. In some cases, it is the physician. And they feel like it's their responsibility and they want to be the one sort of at the center of it. In some cases it's actually the family. If the family feels like they have a really good handle on the situation and they feel competent and confident enough to be the person who is sort of in charge then that's the go-to person but I don't think there's one specific job or role or person with a certain responsibility that would necessarily be in charge.

I think it's highly dependent on the individual situation.

>> HANNAH ROSENBERG: Then I can -- I can answer the physician buy-in question or at least kind of contribute to that. So one of the things that we really found is that once we are kind of able to successfully onboard these tools, it really does improve provider experience. Because what we're trying to do through these tools is say all of this should not fit within the Primary Care Provider. But we are trying to kind of identify and systematize the way in which multiple care team members are

contributing to the care of one child. And are kind of identifying the responsibilities that make sense for their role to do.

So implementing these tools isn't intended to just be an additional burden. But it's intended to help each individual feel that they are -- they can adequately support what they are agreeing to do.

So for example, with the -- with kind of the example of that Patricia went through it's kind of identifying here are the specific rules for the PCP but not necessarily we're asking the PCP to do ten more things than they are already doing. We might be asking them to do -- to ask a question or do a follow-up And communicate with the other care team members. But overall, it should improve their experience as a provider because they now have a team to rely onto share kind of management and to co-manage one patient.

So we have actually found that, you know, once these tools are successfully up and running, it really improves provider experience.

And then the other really tactical suggestion that I would give is we talk about -- and I don't know if this group kind of knows about Triple Aim but we always try to focus on addressing all three items in Triple Aim when we're putting a new initiative in place so improving patient and family experience, improving health outcomes and reducing costs. And then the fourth thing that we add to that is improving provider experience and what that means is evaluating every time we implement something new we're asking providers, we're sending them a survey, we are asking them to fill out a form to inform is this making things better for them? Is it allowing them to better care for their patients?

Is it a bigger burden for them? And if so, how? And then we are really trying to address that. Because what we know is that quality improvement won't be sustainable unless it's improving providers' experience, as well.

>> Great, thank you, Hannah. And then the last question I think we'll have time for, there's a question regarding pediatricians or primary care providers saying that this presentation is really focused on the medical professionals. And that they are not often the most consistent providers who are working with the family. So the individual -- this sounds almost like -- more like a comment but in terms of turn it into a question, how does this model work when audiologists or speech-language pathologists and other early intervention providers are really the most consistent provider within the child or family's life.

>> HANNAH ROSENBERG: Yeah, so I -- and I would just -- I would say that that's something that we focus on a lot. And I apologize if I didn't make this clear But this really isn't intended to simply fit in the pediatric Primary Care Provider space. These tools and kind of these processes are intended to be across the board.

So the same thing with if you're sitting -- if you're an audiologist or if you're a speech-language pathologist, and you're identifying I'll just go back for example to that

action grid that I shared. If you have a visit with a patient, it's not necessarily waiting to get you know action steps from the Primary Care Provider but maybe it's you taking that form or a piece of that form and saying I'm now identifying that these are the five things that need to get done. I think two of them make sense for the Primary Care Provider to do so I'll communicate that back to him or her These are the things that I'm going to be doing. And then I need -- you know, I need a community support person to do the third and fourth thing who is part care team so all of these tools are intended, again, to be across the continuum. They are not meant to sit -- and actually very much not meant to sit just in the primary care space.

>> Thank you.

>> I would also like to add we also want to remind when looking at our EHDI data a lot of places where the gap falls is between diagnosis and early intervention placement and so even though we do know the EI provider is obviously going to play a huge role and in fact they have been doing care coordination by the nature of what they do, you know this has continued to expand that section to make sure we get them to the EI in a timely manner because we know nationally we haven't fully been meeting that mark to be honest and it's an area we all want to see improved.

>> Well, thank you we're at the top of the hour I do just want to remind you that we have recorded today's webinar and we will post it up on [infanthearing.org](http://infanthearing.org) along with answers to the questions that we were not able to get to today.

So rest assured that your inquiries will be responded to. And then we'll also make sure that we upload the PowerPoint that we used today. It was available during our webinar. But we'll make sure that it's also uploaded to [infanthearing.org](http://infanthearing.org). Thank you so much for your time today. And thank you to the presenters for planning the webinar and I know it definitely took a lot of time on our end so again thank you so much and have an excellent weekend.

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