>> Once again, this is an audio check for today's webinar, brought to you for the Center for Disease Control and NCHAM at Utah State University. We'll be starting in about 4 minutes. You can adjust the volume to your liking on your headsets or speakers, and know if for any reason the quality of the transmission today is not adequate, today's webinar will be posted on infanthearing.org next week, so you can view it that way. But it seems like from the feedback that we've gotten that nearly everyone is getting a good quality of audio transmission, which is what we like to see!

I will play music for the next couple of minutes while we wait so you know in fact that you are connected still with the audio.

(Music playing)

>> Steve Richardson: We are about to start today's webinar, and I would like to do a quick audio check with each of our presenters today. Could I have each of you unmute your mics, and I'll just do a quick roll call just to make sure we're all set to go. Allison, can you say hello to us?

>> ALLISON SEDEY: Hello. Can you hear me?

>> Steve: You're fine. Ellen?

>> ELLEN AMORE: Hello. Can you hear me?

>> Steve: Perfect. Janet?

>> JANET FARRELL: Hi.

>> Steve: Perfect.

Kate.

>> KATHRYN TULLIS: Good afternoon, Will.

>> Will: And Steve.

>> Steve: Hi.

>> Will: And Toni.

>> TONI WALL: Hi Will.

>> Will: I'm going to take one second of silence to activate the recording of today's webinar. There we go. My name is Will. And I'm from the National Center for Hearing Assessment and Management at Utah State University, also known as NCHAM. We'd like to welcome everybody to today's webinar. Today's webinar is brought to you by the Centers for Disease Control and NCHAM, the National Center for Hearing Assessment and Management at Utah State University. This webinar, as I said is being recorded and it will be posted on the NCHAM website within the next week at infanthearing.org.

You can adjust the volume of your speakers or headset today to your liking on your end. Once our presenters are completed with their presentations, we'll be opening up a Q&A field, which will appear in the lower left-hand corner of your screen that I'm displaying right now. But we're going to wait for those to be available to you after the presenters are completed. I would now like to turn the mic over to today's moderator, Steve Richardson from CDC. Steve?

>> Steve: Thanks Dr. Iserman. Before we start the presentations, it might be useful to have a little background about how this topic came to the forefront. Last October the CDC EDHI program hosted a conference. Participants discussed possibilities, barriers, and next steps. And it turns out that a few states are collecting developmental outcome data or are preparing to do so. And in the next 45 minutes, you'll hear from four states that are collecting this data, and also from a researcher who has been collaborating to collect developmental outcome data for the past three years with funding from CDC. We'll learn what strategies appear to work best with their partners, what kind of developmental outcome data they're now collecting, and how they structured the data, and some benefits of using developmental outcome data. The last 15 minutes of the program will be dedicated to responding to your questions.

Now our first speaker is Janet Farrell from the Massachusetts EHDI program. Please take the floor.

>> Janet, remember to unmute your mic.

>> JANET FARRELL: Hello. Can you hear me?

>> We can. You're good to go.

>> JANET FARRELL: Good. Thank you. The Massachusetts universal Newborn Infant hearing Screening are both in the same bureau of the department of family nutrition.

So we are early in the process and I will say that up front. But I want to talk to you about our planning process and what we've been working on. So we've been discussing what the benefits are of collecting developmental outcome data for children with hearing loss. And both of our programs want to evaluate the success and challenges for the universal newborn hearing screening program and early intervention programs related to services for children who are deaf and hard of hearing. We hope to provide greater understanding of childhood hearing loss. We hope to gain insight into services and the relationship these services have on child outcome. We are committed to identifying potential disparities and care and further document and developmental impact of later diagnosis of hearing loss and later access to EI. So how are we going to do this? In Massachusetts, our capacity, I'm to describe that in the next two slides and provide you some information about our EHDI IS and some of our systems capacity.

Massachusetts Early Hearing Detection and intervention program has employed someone with sophisticated analysis skills.

(Phone ringing)

Excuse me.

Excuse me. There was a phone here that I didn't know that was on. Having someone with sophisticated analysis skills will help in guiding the analysis to better understand statistical significance particular when numbers are small. Our screening data is populated by the electronic birth certificate. And this includes screening results, demographic tracking information, followup audiological data, such as when the followup appointment will occur and the date of the next appointment, and primary contact information.

Massachusetts audiological data includes diagnosis, risk indicators for hearing loss, including EI, and information on missed appointments. All of the data above is used in our efforts around family outreach and follow-up. And family contact information is included and includes self-report of information and primary care provider information.

We have a department agreement in place, and early intervention referral and enrollment. So I want to tell you a little bit about another system available in Massachusetts called the Pregnancy to Early Life Longitudinal Database.

In addition to EHDI database, we have this system called PEL. It has the capacity to track mothers and infants over time. The universal newborn hearing screening and early intervention data are each integrated into PEL. And we anticipate this will provide a robust platform to analyze data in early hearing detection data.

We have demonstrated the ability to analyze data such as downs syndrome and hearing loss. We have also used PEL in development of our risk indicator algorithm to help us better understand risk that babies may have for hearing loss. And this is a permanent document in our birth facility newborn hearing screening guidelines. PEL data is also being used currently to look at cochlear implants in childhood.

So the next step is sort of talking about our planning efforts and feasibility. We've done our planning process to collect developmental data through our statewide planning program. Collaboration is a key step in developing our plan to do this evaluation. Our steps have included meeting with the early intervention director of specialty services who oversees services for children with hearing loss in early intervention in Massachusetts.

We've met with the early intervention information systems coordinator, who will receive statewide data in Massachusetts, and also the associate director of the EI training center to better understand tools used to understand developmental outcome. And all of this planning work is important to make sure everything is laid out in a very detailed way so we're all satisfied with what we're working on as we move forward.

Our planning process has either happened or will include a literature review, a process to determine who the primary audience will be to benefit from the analysis. Some examples are the EI program, the newborn hearing screening program, other states, and national partners. We are determining data items to collect and documenting how this data will be used and we're identifying plans.

We will update our EI. We have an interdepartmental data use agreement for access to confidential data and this will have to be done before we're able to actually analyze the data. And we will work with the DPH legal office to gain legal approval to analyze the data including linking EI and universal newborn hearing screening data in PEL.

So what are the data considerations?

The independent variables that we're talking about and hoping to consider now are data information of hearing loss, and EI enrollment data. We want to look at other special health needs of the child, primary language spoken in the home, and then some

demographic information such as regional, demographic, health insurance. Whether the child has a documented primary carer.

And when you think about comparison groups, there may be several that we consider over time, but right now we want to look at the difference between early enrollment and later intervention.

We have not completely decided what we expect. We need to learn more about the data available. Coming up with a timeline is very important to motivate and keep the analysis on track. And we will include planning, data approval, analysis of the data and presentation of the data. It's important to discuss the use of the data with all of our stakeholders to be certain everyone is on the same page for how the analysis will be used. This includes presentation, potential presentation, and potential developing any kind of written documents that will be sent out to the public.

Or articles that may go into a journal.

Now I wanted to talk a little bit about the developmental tool that we're learning more about that Massachusetts is currently using, and then a little bit about what kind of data is in the system. Massachusetts is currently using the Patel Early Intervention 2 for early intervention to determine availability. It's referred to as the BDI2. It has four domains. The BDI2 has been used statewide since 2012 and was used optionally in Massachusetts from 2005 to 2012. There will be some limits on our ability to analyze long term databased on the fact that we may be using more than one tool.

Previously the early intervention program was using various tools including the developmental profile, which had six developmental levels or skills containing milestones. It was issued statewide in 2004 and was used optionally after that. We will learn more about what makes the most sense to analyze and what limits we have to analyze the data prior to 2012.

Okay. So we want to talk a little bit about our challenges and some of the things that we've been discussing as challenges here at the department.

So one of the things that we have talked about is our numbers may be small. And we may have some skewed results based on that. We know we have limited longitudinal BDI-2 data.
And that may limit the amount of information that we're able to look at. We may not be able to look back several years. Some families refused exit assessments, and that may hamper our ability to include that family's data in our assessment. And the exit assessment may be included months prior to discharge. And that will have to be taken into consideration. There may be limited information on service types, as well.

We also have to take into consideration political considerations and instruments are

limited sometimes in their ability to assess language development.

There is cost or staff time necessary to document the analysis plan, carry out, and present the analysis.

So what our lessons learned? And this is what we've learned today. Our cooperative environment is needed and we are very fortunate to work in such a close working relationship with our early intervention program, that we feel like this is a strength in Massachusetts.

Advanced epidemiological expertise must be acquired, and this could be internal to your department or agency or to an external source.

Requires reliable and valid outcome measures. And data sharing involves legal agreements.

I would like to close by saying that although we believe this may be a timeconsuming process and have some challenges, the efforts will be extremely beneficial to helping our program understand the value of early identification of hearing loss and timely intervention. Thank you.

(No one is speaking)

>> Our next presenter is Ellen Amore from Rhode Island.

>> ELLEN AMORE: Good afternoon everybody. Thanks for the opportunity to tell you a little bit about what we're doing here in Rhode Island related to collecting developmental outcome data.

So to start, I just want to describe a little bit about a system calls KIDSNET that we have in Rhode Island. It is a web-based child health information system that helps us connect our EHDI screening and diagnostic data with various community partners who help us assure followup. And KIDSNET basically ensures sharing data among authorized users to make sure kids are screened and offer early intervention.

We have a variety of partners who can access the EHDI data in KIDSNET. That includes the screening data, the diagnostic data that audiologists submit, as well as early intervention data. And many of our community partners continue to follow children as they grow. And they're out there collecting information about cognitive, emotional, speech and language, and other developmental outcomes.

So by collecting our linking the developmental outcomes to all of our partners through

KIDSNET, we can sort of better coordinate the developmental screening and services that are going on in the states. As a community, we can focus on the children who really need those services and not duplicate services to others. And having this information is also going to allow us to evaluate if what we're doing is really working. Obviously, the ultimate goal is to promote school and long-term success for kids. And we all work under the assumption that what we're doing is leading towards that goal. But we need to evaluate that.

So I'm going to briefly talk about four partnerships related to collecting developmental screening or testing data in Rhode Island. The first one I'll talk about is early intervention.

We have been working with early intervention to try and monitor speech-language development, similar to what Janet just talked about in Massachusetts. We've been promoting the use of the McArthur Bate Communicative Developmental Inventors. We like it because it works with sign language. But many others prefer other tools.

Our Rhode Island EHDI will do the data entry if they fax the results to us. But really we've been working with various EI contractors and others in the state who work with children with hearing loss. And many of them are willing to both administer the tool and to data enter the results.

And then because it's early intervention, there are issues of FERPA legislation that require signed consent. But that's really pretty easy because the folks that are administering the tool are working directly with the children and are in contact with the families.

So this is what the data entry screen looks like. And the user goes in and enters in which screening tool they're going to be. Which version of the screening tool they're going to use. There's different versions based on whether it's words and gestures or other tools, other forms.

And this is the actual data that will be collected. The various scores. We're still in the process of rolling this out and training folks on how to enter it and administer the tools. So we really don't have a lot of data yet, but we're really excited about getting it and learning a little bit more about our kids who have hearing loss.

The second partnership I want to tell you about is with the State Department of Education. And it's part of a federal Race to the Top grant that has two components that we're working on.

One is to link KIDSNET to Department of Education data. And that will include kindergarten-readiness scores. Standardized testing that's done in the schools. In Rhode Island they use the New England standardized assessment tool. And they're moving to something else next year. There's reading test scores, et cetera. And all the

data requests that we would have for this system would go through they have a data governance process at the Department of Education. And those data analyses would obviously be done at the aggregate level. But I think they provide us an opportunity to really learn about our kids as they grow and progress through school.

The second project with the Department of Education was to actually build a database for the child outreach screening down in the state by school districts. This is the child find requirement under the Federal IDEA Part B. And that screening includes screening for vision, hearing, speech-language, general development, and social-emotional. We just went life with that this Fall, so we're working through all of the new system issues, but it's very exciting to have that data coming in.

So these are all the three, four, and five-year-olds in the state that are getting screened. And with the school departments again, this of course falls under FERPA. They get signed consent from the families when the children are screened. And there's also been ongoing work with the Department of Education with their lawyers. And the department of ed has received technical assistance related to FERPA to make sure we're not breaking any laws.

So this is a screen shot of the screening results summary. You'll see that there are the five domains. The vision, hearing, speech language, general development, and social emotional. And at the bottom of the page, you get the status of whether the child passed, or were referred or some other indicator.

And then you can click on either the blue, either the blue domain or one of the tabs and get more details about any of the individual screening, screenings that were done. This is the one that is for the speech-language page. So you can see the date it was done, the language it was done in, and what tool they used. And for each tool there's a different outcomes that went along with it.

So really a large amount of data that is being collected for us. And we're very excited to do some analysis on that. The third partnership I wanted to tell you about was with the early childhood team in the NCH division. We're working on bringing developmental screening data from KIDSNET from our home screening programs, and all the primary care providers whose screen development as part of well child care. Data entry is a familiar challenge. I talked about that with early intervention. The home visitors have to enter the information in, because it's part of their contracts. But healthcare providers have no such requirement. And initially when we piloted it, we had some Americorps volunteers who were entering the information directly into KIDSNET. Certainly others have the capacity to do that, and some did.

But in our state we're really moving to online screening tools that are connected to electronic healthcare records. One is called CHATIS and another one is Patient Tools. I think that's really the way it's going to end up going. As time goes by. Because it gets the information into the doctor's electronic health record, but it also sends a file to

KIDSNET.

So this is a draft screen shot of what we think the developmental screening results will look like in KIDSNET. It includes all the tools that are commonly used in Rhode Island and also the common, the tools that are used in those online screening programs.

And last but not least, we've been working with Head Start and Early Head Start. They do screening all the time. Unfortunately the data system that most of them use is somewhat limited in the capacity to export health-related data. We're starting first just with enrollment data so at least we can see who is in the various Head Start and Early Head Start programs and follow up by phone. And then we hope to phase in additional data as time goes by, including hearing screening and other developmental screening data.

For those agencies who were not considered HIPAA covered agencies, we're going to have to include a businesses associates agreement, because the exchange of personal information falls under HIPAA. And again, the Head Start agencies get permissions from families before they share that information with us.

And just a word about matching. KIDSNET has been matching data files since 1997. And we have a fairly sophisticated probablistic matching process that looks at names, dates of birth, and program IDs. We store all the IDs in one table from all different programs. The hearing screening ID number, et cetera. And so once we store it, the subsequent matches are a lot easier, and high probability matches just are made automatically. And low probability matches create a new record, which may or may not be removed later, when we run an automated deduplication process, and those in the middle are the more labor-intensive ones, and those are reviewed manually.

Since I started here 20 years ago, there's been a lot of talk about and fits and starts about unique identifiers. But in those 20 years, it's never gone anywhere. There's always issues and reasons.

And to me unique identifiers are really nice to have, but they're really not necessary, and they're certainly not sufficient. You wouldn't match just on the basis of one number. You would want to have additional numbers, because a typo can throw you off track. So you have to have several fields to match on anyway. And in my experience in trying to work on a unique identifier can be such a major distraction and time drain that it takes you away from working on the data exchange. So I'm a little bit wary about that. I just sort of watch and if other people are going to figure it out, they can. But so far in 20 years, it hasn't happened. I'm not too worried about it. And some final thoughts. It really requires collecting additional data really requires a lot of leadership, thoughtful and thorough business analysis with stakeholders. I know Janet talked a lot about that. Some funding. It's really not cheap for us to develop it. And then, you have to consider ongoing data analysis. Data management.

The matching and the data analysis just build up the more data you collect. And at some point existing staff just can't absorb more responsibilities and more data. But good outcomes are why we screen babies. So we really need to collect some outcome data and look at it. We're very excited to be doing that in Rhode Island. And please don't hesitate to reach out to me at any time to talk about what we're doing.

>> Steve: So our next presentation is linking Maine department -- I think Steve is having some audio difficulty here, so I jumped into introduce our next presenter, which is Toni.

>> TONI WALL: Thank you, Will. A little over a year ago the Maine State Legislature, and specifically the Joint Standing committee on education and cultural affairs approved a work plan for the Maine Education Policy Research Institute called MEPRE.

So the information that I'm going to present today is a result of that initiative. I would like to take this opportunity to thank Dr. Mason and Tu and Qanshen Song and Bill Hurwitz for their expertise.

Today I would like to provide you with an overview of Child LINK. I'll briefly describe the linking methodology, look at some results and then look at future considerations as Maine moves forward with this project.

So I noticed that Massachusetts and Rhode Island, and I always like to have a little bit of comment on Maine. Maine has the distinction of being the northern most and largest of all the New England states, and the eastern most state in the U.S. Connecticut, Massachusetts, Rhode Island, and New Hampshire and Vermont can easily fit into Maine. It's predominantly white and our birthrate continues to decline, and recently a little over 12,000 this past year. The program was established in 2000.

ChildLINK was created in 2002. It is a population-based data system that links records from children with various special health need programs. It includes information from all births in Maine. This information is linked with data from Maine Newborn Hearing Screening Program, the birth defects program, and the newborn blood spots screening program.

Modules that are currently under development include the clinical heart defect program, autism screening. And thank you Ellen for a great presentation. I will be giving you a call.

So what is ChildLINK. ChildLINK was developed and is housed at the University Of Maine and started data collection in 2003. For the data geeks, it's a SQL server since 2012, and our goal is for families to raise healthy children through screening, followup, and initiation into early intervention services.

Who uses ChildLINK? It's used by a variety of individuals, including most of the

employees of children of the special health needs program. All of the hospitals in the state download information for newborn hearing and birth defects. Audiologists upload diagnostic information. And birth defect abstractors provide online information through a system that we have.

The Department of Education State Longitudinal Data System. Their primary objective is to house a centralized data warehouse that captures all pre-K through higher education information regardless of a student's movement between schools or school districts.

This project involved linking data extracted from the state longitudinal data system. The project was possible because of the members of MEPRE. As I said before that's the Maine Education Policy Research Institute had access to both data systems. We did obtain IRB approval from all: The Department of Education, the department of health and human services, and the University Of Maine System.

ChildLINK data for children born from 2003 to 2005. All children born in Maine as well as hearing screening and diagnostic results. The state longitudinal data system consisted of data from 2010 enrollment data. 2013 NCAP, or the New England common assessment program. And the 2013 special education data that included special education status, and placement.

And finally we linked data again with NCAP looking specifically at the proficiency for data with English and math. So again for those of you who are data geeks on the call, I won't be going through or showing the linkage methodology. This is not my specialty and it would really take more time than I have. I can tell you that this was an exhaustive process and used approximately 11 iterations with varying criteria to get down to the information we were looking for.

Therefore I have selected just a few slides to show you the complexity of linking data from the two very different data sources. So the first step was to link ChildLINK data with the state longitudinal system enrollment data, sorry, for 2010. The linkage process involved an iterative approach. Matches were removed and remaining unmatched records were used in other attempts. This was a very lengthy process, and I have probably 20 more slides, but I've only chosen four really to show you.

Okay. So as you can see from this slide, there were approximately 7500 children that were not in ChildLINK. And that's, oh. Will, I'm trying to figure it out. There we go. That's over. Over here. That were not in ChildLINK, leaving one to assume that these children were really born outside of Maine because we have no birth certificate record of them.

So all three of these data sets here. All three of these data sets here with links to enrollment data. I'm just trying to get my arrow. And then subsequently were linked to the NCAP assessment data, which is shown down here. So as you can see, going from

the ChildLINK data, down to enrollment data, down to the NCAP data, it's not a really simple process. It takes expertise and population-based linking, which Dr. Mason and Dr. Tu have.

Okay. I need to go back, I'm sorry.

So one advantage of linking to the state longitudinal data system was accessing the state longitudinal data system unique identifier. And what we found with the Department of Education's data is this unique identifier does not change regardless of a child's movement between schools or districts. So it really allowed the MEPRI researchers to begin to look at linking data to the 2013 assessment data.

So analysis of this data shows that of the 30,227 children in the matched. Let me get this again. Sorry. Up in here. In the matched data set, only 27,000 of them linked with assessment data. These were children who attended Maine schools in 2010 and then they also took the 2013 New England assessment.

So another analysis that we have is again the 7500 children that were born outside of Maine. We were able to link 5,828 with assessment data indicating at some point in these children's lives they went back to Maine in 2010, began attending schools, and took the test.

Finally the 11,000 children who again were in ChildLINK, but were not linked to the 2010 enrollment data. They did take the test. So we believe that some of those children could have either have been in homeschools, private schools, moved out of state, and various other -- what did I say? Attending private school.

So as you can see, there is a lot of data within the Department of Education. Okay. So we decided to try expanding to special education data. And we used similar processes. And at this point we really began to see some interesting data.

30.2% of children who referred on their newborn screening tests were enrolled at some point in 2013 in special ed. However, what we found is that of the 610, 67 of them had a confirmed diagnosis of hearing loss. And what's even more interesting of them is when you begin to look at this data over here, almost half of them, 46% weren't even enrolled in special education.

And 22 were enrolled under the classification I should say of deaf and hearing impairment. And then a small percentage of 15 were in speech and language. These numbers are really small. But it's interesting. And I was very surprised that 46% were not enrolled in some type of special education. But I'll get to that in a few minutes.

This is a little bit more data on special education. We also found interesting data on the 543 children who referred on their newborn hearing screening, but were found to have normal hearing. 35% of those were enrolled at some point in 2013 in special education.

Listed in categories of speech-language impairment, autism, and multiple disabilities. So this really triggered a question for me on the importance of expanding Maine's developmental screening process at the 9, 18, and 24 month. And really start identifying children who need early identification purposes prior to school enrollment.

I've gotten my two-minute warning, so I'll hurry up.

Finally when we looked at the assessment for those 67 with confirmed hearing loss, we did notice that there was a slight trend toward meeting the standards of the NCAP assessment, however the numbers are really too small to do a table format. And then we saw a stronger trend in the proficient or proficient with distinction in math.

So what does all this mean? Well, we don't have enough data actually to figure this out. We have 67 kids. So one question for me was did these 67 children have early intervention services? That were either provided through Part C or early intervention services. At this point we don't know because we aren't connected with Part C. So quickly lessons learned. MEPRI was instrumental in linking the data across the states to agencies. They're recognized as experts in linking population data. And they had access to both ChildLINK and the state longitudinal data system.

Establishing a qualifying set of identifiers. The child's first, middle and last name and date of birth. Adding mom's first, middle, and last name would be helpful. Looking at the place of birth, we could have immediately removed children who were born outside of Maine.

If finally for Maine and the country, this is the first step in understanding the importance of early identification, diagnosis, and early intervention services on long-term educational successes. So I would like to thank you, and again if you're looking for more information on the methodology on how everything was linked, please get in touch with either Craig or Quanshang. Thank you very much.

>> Thanks Miss Wall. The next speaker is Dr. Allison Sedey from the University Of Colorado-Boulder.

>> ALLISON SEDEY: Thank you so much. What I'm going to be talking about today is two different programs. One is the program in the state of Colorado where we have been collecting outcome data on children in early intervention for over 25 years. And for the last several years have been putting that data into the outcome data into the EHDI database. And I'll also talk briefly about a national project that we're managing now where we have 12 different states contributing data. All of the same outcome data so we can start to create a national database.

So our goal in collecting outcome data here in our state and also nationally has been driven by national agendas that demand accountability systems be established to look at outcomes for deaf and hard of hearing children, recommendations from the CDC task

force to include outcome data in the EHDI database. And we have a long-term partnership in our state between our statewide intervention program. It's the Colorado Home Intervention Program, under the Colorado School for the Deaf and the Blind.

That agency for many, many years has partnered with the University Of Colorado and also our department of public health, which houses our EHDI database.

The Colorado Home Intervention Program or CHIP, again as I said is under the Colorado School for the Deaf or the Blind. It's a statewide early intervention program and they serve over 90% of the children who have hearing loss in our state who are receiving early intervention in that birth to three period.

The program provides in-home services, family centered. Usually on a weekly basis.

So in terms of how the assessment process works in our state and how we're gathering outcomes. This will just illustrate the partnership that I spoke about. The interventionists who work under the CHIP program complete assessments with the families they work with every six months. And the program has agreed to use a common set of instruments across all families in the program. The interventionists on the six-month basis when they complete the assessment with the family send those developmental questionnaires and demographic forms that they do with the family to the University Of Colorado at Boulder. Our staff in Boulder scores the assessment, they write up a report, and they send that information back to the interventionist who works for CHIP. The interventionist then shares that information, the results of the assessment with the families that they work with.

Personnel at the University Of Colorado have for many years, again over 25 years been entering that outcome data in a database housed at the University Of Colorado. And in the last three years have also populated outcome data fields in our state's EHDI database.

So at this point, given that we've been doing this for several years, um, the EHDI database has results on about 600 children. Outcome data on about 600 children that has been integrated with the hearing screening data, the diagnosis of hearing loss, the intervention that the children are receiving, et cetera. It's a nicely integrated system when we can then pull out the subgroups of children and examine their outcome data.

As far as data sharing, because we are talking about three different entities in our state that are sharing outcome data, the families when they do the assessment with their home interventionist sign an informed consent form so they are aware and agreeing that their outcome data will be shared with the University Of Colorado at Boulder. So an individual consent form is signed by each family for that data sharing.

And interagency agreements are in place between the department of health and the Colorado School for the Deaf and the blind. And families when they start the

intervention program sign a release that they understand the CHIP program and the Colorado School for the Deaf and the Blind are going to be sharing data with the department of health.

Two personnel at the University Of Colorado have signed health security documents, and we're able to access select parts of the EHDI database, in order to access it for children within the EHDI database.

And to date, we have entered outcome data in the EHDI database for say 600 assessments, within our University Of Colorado database because we've been doing it for the last 25 years, we have over 5,000.

The assessment instruments that we are using, we have because we've been doing it for a long time, we've kind of gradually added assessments over time, we've made modifications based on interest of the providers, the families, et cetera. But the ones that we are entering into our EHDI database are the Minnesota Child Development Inventory, which is similar to the Batelle, that a previous speaker spoke about their state using that looks across a variety of developmental domains. That's used with children from the age of 14 months up to 3 years. The instrument goes higher, but our program ends at 36 months.

For our younger infants, we're using a similar assessment called the Kent. It's developed for children. And as another presenter mentioned that they're used in Rhode Island, we also use the McArthur-Bates, which is specifically a language instrument.

Kent, or Minnesota, depending on the child's age, plus the McArthur is going to be used on all the children and that outcome data will be put into our EHDI database. We do use additional assessments every six months with the families, and those outcomes are put into the Colorado university database. A play assessment. Either the auditory checklist developed in Cincinnati. If the children are 18-36 months. If they're younger, we use the Little Ears Auditory Checklist. We have also developed a parent sign vocabulary checklist to measure increases in the parents' sign language vocabulary, if they're using that method to communicate with their child. We have a functional vision screening in the assessment, and a checklist of family needs. Information the family wants to receive during the intervention process.

We also have a speech intelligibility rating scale. And depending on the child's age, a video tape is often made which is then analyzed here at the University Of Colorado where we look at a language sample and also a spontaneous speech sample.

When the children are ready to transition to Part B. So about 33 to 36 months of age, the interventionist administers the one word picture vocabulary test and also the Goldman-Frisco Test of Articulation.

Of course there's numerous benefits of doing assessment for the children themselves,

and the families. I just listed a few of them here. Our assessment being that we have a variety of instruments looks at skills across a wide variety of areas. We're able to identify delays in the children in a timely fashion, because we do this every six months. We're able to objectively monitor a child's progress over time to make sure that in the six-month period they're gaining the skills that we want them to have. And all of the instruments we use compare their performance to hearing children, so we're able to see if they're on target relative to their hearing peers at each of the assessment points.

Most of the assessment tools we use involve parent input, so we're able to include that in the assessment process. And by doing so, it really teaches the family very careful observation of their child's developmental skills, and also informs them of what the developmental milestones are and what to expect in the coming months as they're interacting with their child.

Some of the benefits that we find for our interventionists, is in our state children with unilateral hearing loss are not categorically eligible. They need to demonstrate a delay. For all children, the interventionist is able to monitor the child's progress. It alerts them to referral. Some of the instruments are looking to areas outside of their expertise, but might refer them to a motor problem. It gives them solid, objective data to help plan the child's transition from Part B to Part C, and it assists across all of the early intervention. And then a transition for the IEP.

And it also provides a data-driven approach to making the educational decisions that they make, whether it's about communication method, frequency of service, type of techniques they're using with the child and family, et cetera.

And then for the program overall, because we are collecting this data and entering it into a database, it is providing accountability data. We typically do it annually. We're able to look at outcomes in specific subgroups of children. Children with cochlear implants, children identified early, children identified late, children with additional disabilities. Whatever the subgroup, we can look within that group and examine how those children are doing. And it informs our program about personnel preparation needs. If there's areas that we see across the state where children are having particular difficulties, that's something that we can then convey to interventionists and provide training on if needed.

So in terms of building the outcome fields for the EHDI database, this is relatively new. So sort of the logistics of how this happened is for a long time we thought this was a good idea. And the director of our CHIP program, personnel from the university, and a programmer from the health department met once and designed how we wanted the fields to look within the EHDI database. And speaking to the programmer at the health department, he said it took about four weeks from basically start to finish, from our meeting to having the fields ready to roll, to develop them and build them into our EHDI database, test it out, make revisions when there were some problems with it initially. That was about a four-week period. And he said he would describe it to be at an intermediate level. A little beyond basic, but not difficult.

You can see up here it says Minnesota CDI. So this is where we enter the data from the Minnesota Child Development Inventory. We enter the date when it was completed, how old the child was at the time, whether they completed the form in English or in Spanish. And then the actual data are here. Each of these initials stands for a different skill within the Minnesota. So we have the social, self-help, gross motor, fine motor, expressive language, language comprehension, general development, and situation comprehension.

So these numbers are the age scores in months that the child obtained on each of those subtests. And then he built in a nice little feature here where we just have to click on development quotient and it divides the age score by the chronological age of the child.

You're looking hopefully for a 100.

Date completed, the age of the child, whether they did it in English or Spanish. Whether they completed words and gestures or words and sentences. There's more data that you can get from the McArthur, and we saw that in another presenter's database. But we just enter this and compute the developmental quotient for that, as well.

We think the benefits for us is it provides a seamless statewide system. We can track our children from screening to early diagnosis to outcomes of early intervention. Numerous parties can access the system and look at the efficacy data for our state and can generate reports on subgroups of children.

So just in my last couple of minutes, I want to talk about a national program that we're doing. Not to be confused for Maine's NCAP. This is sa completely different NCAP. This is a project that has been supported by the CDC to assist other states in doing a subset of what we're doing. The Minnesota Child Development Inventory or Kent and the McArthur Communicative Development Inventory. We welcome states to join us. We have 10 states who are participating, and two more who will be participating in February.

And the goal is to develop a national database. Some of the pitfalls that others talked about, we're also experiencing here in Colorado. Insufficient number of children. Wondering if this is just representative of the United States as a whole, or whether we're just looking at what's happening in our program, in our state. So we're trying to create a national database to better understand the language strengths and challenges. We're able to create profile sheets that can be shared with the family. We write a written report of the results that can be sent to the provider and shared with the family. And we maintain a database for the individual state and also the national database. We can provide states with annual accountability reports on the state's outcome. And again, the states are contributing to a national effort. Many of the participating states are participants on today's webinar. It's allowing us to look in a bigger way not just how one

state or one program is doing, but how children across the United States with hearing loss, what are their strengths, what are the limitations they're facing, and what's predicting more successful outcomes.

So if anybody is interested in joining the effort, feel free to contact me. And thank you very much.

>> Thanks, Dr. Sedey. Our final speaker is Dr. Kathryn Tullis from Delaware. When you're ready, please go ahead.

When you're ready, please check your microphone for muting and go ahead. Thank you.

>> KATHRYN TULLIS: Thank you, Steve. I apologize. First of all I want to thank you for inviting me. And all I can say right now is wow, what a tour deforce of presentations that we've had. Very inspiring. For those of you from states who may not be in the same space as the previous presentations, I hope Delaware will make you feel better. We are very much in the beginning of the process to look for outcome data for our EHDI program.

And yes, my objective here is just to show where Delaware is and what our approach is to collecting our outcome. And maybe a few reasons why we're a little bit different.

I came into the EHDI program here three years ago as the director of the newborn screening program. Our EHDI program was not staffed for several years. And there was a lot of concern from our advocates that children were first not being identified and some concern that once identified they were not presented with all available intervention options to them.

From this nervousness in the community, some really great legislation was passed in 2012, which created a governor-appointed advisory board, which I was able to use to sort of start to make something happen in the state.

Delaware is a birth mandate state. And that is a little bit different I think than other states. Children in Delaware who are deaf or hard of hearing, visually impaired, deaf-blind, or autistic are entitled to free and appropriate public education from birth. And the services provided to these children are referred to as birth mandate services under IDEA.

They're also entitled to part three services from 0-3 years of age. They have a dual eligibility. And what that means programmatically for me is when I have a child identified with hearing loss, I have to make sure that both our Part B partners and Part C partners are contacted.

And Delaware is a small state but seems to have a quite complicated hierarchal program here. The EHDI program is way down within the department of public health, which in our state is the Department of Health and Social Services. Part C is connected to public health remotely through its funding, which is through the division of Management Services, which is another separate division of the Public Health, of the Department of Health and Social Services.

Our Part B is over in the Department of Education. And Delaware has also a unique system there where our 619 program resides in our Department of Education, our state DOE. Where it's under the exceptional children services resource program. We also have something called state-wide programs for the deaf and hard of hearing, which reside in an individual school district, but which serves the entire state.

And the mission of the statewide programs for the deaf and hard of hearing is to ensure that all deaf and hard of hearing students throughout the state of Delaware have access to their educational environment, become active and confident self-advocates, and active participants in their schools and communities.

Under the statewide programs, there is a FACAE program, family advocacy and child education program, which serves birth to five.

Because children are dually eligible, in Delaware a school district may decide to refer the Part B services to this statewide program.

So I was very lucky when the board was forming here. There was a very loose connection between the division of public health and the Department of Education, and I was able to get a representative on the board who is also a coordinator for the 6-19 program in the state.

Also, EHDI is housed in our department of health and social services. The delegate from the department of health and social services to the board is the Part C coordinator. We also have a very active Hands and Voices representative on the board who is a parent guide for our guide by your side program.

So what I've been doing is identifying my friends. The Part C overseer was a wonderful participant in our NICHQ process. She understood some of the unique issues around identifying children who are deaf and hard of hearing. I've also been able to identify contacts as the director of the FACEP program.

Laurie has been very helpful in helping with the EHDI program, as has several of the 6-19 program coordinators. Delaware is a small state. We take advantage of things. I was able to find money in different venues to invite a handful of people to the EHDI program in Jacksonville. We all sat together in our state meeting and realized that we had everyone in the room who could follow a child in Delaware with hearing loss through to the school system.

And we decided to make that happen. This was really our chapter champion Dr. Carlos Duran was sort of the master controller here and brought us all together. We now meet as a group. The EHDI audiologist, our pediatric audiologist. Again Delaware is a small state with one children's hospital. It's really helpful for us to find the person who can access their electronic health record system.

The director of our FACEP program is a Part B support. And we have two Part C programs in the north and south of the state. And we have representatives from each program who oversee children with hearing loss for their respective programs.

I am meeting, we meet quarterly to track a child right now. Again, we're at the very beginning of this. We have quarterly tracking meetings. We actually are waiting to decide what outcome measures to track, hoping that there will be directives from CDC so we can put in place one measure or a general measure and move forward with that.

I am in awe of the unified databases that were presented. I don't think that will happen here in Delaware. But I don't think it will be hard to collect developmental measures. And to, um, maintain them. But I also don't think in the near future we'll be able to access any educational database very easily.

I know we're running short on time. I have questions for the presenters, so I just wanted to thank everyone. Again, Delaware is at the very beginning of this process. And Steve, if you would like to take over with questions?

>> Steve: Sure. Thanks Dr. Tullis. I appreciate it. Now is the time we'll be able to respond to the questions you submitted. If you're writing a question now, please indicate when you write in which speaker you would like to answer your question. Otherwise our presenters will decide who will offer a response to that.

We ask the presenter who is responding, please give your name to help the participants identify the source of the answer.

So we are open to questions that you can type in electronically on your Q&A.

Okay, the first question: How significant is the problem of lost to follow-up in each of your states? Also, as the newest Illinois EHDI co-champion, I would like to know how I can improve that? Is there a strategy for improving that? Or is that beyond the scope of this webinar.

I'll open it up to each of our presenters as they would like to chime in.

>> ELLEN AMORE: Well, this is Ellen Amore from Rhode Island. We do have some lost to follow-up. I don't think it's a huge problem. The biggest problem that we have is

getting diagnostic audiology results reported. And we have used our data systems to try to collect that information to try to make it easier for audiologist to report. And in general, our lost to follow-up are kids who, you know, we're just getting ready to submit our 2014 data. And really the ones who are truly lost to follow-up are ones who are children who have been seen by an audiologist, and their results were inconclusive, and they were supposed to come back, but they never did. That is the bulk of ours.
But I really think that integrating data helps a lot in the lost to followup in tracking kids down.

>> TONI WALL: This is Toni Wall from Maine. I just had to grab my data from 2012.I agree with Ellen. It's not lost to followup that's really the problem. It's usually getting data from the audiologist. During 2012, no diagnostic evaluation. And a lot of those the families were unresponsive to multiple attempts. Many families moved out of state. And we had a couple PCPs that did not help us make referrals to children. So as your new chapter champion, that I would think would be a big area to work in as the importance of if they don't pass the screening, that they need to get in for an evaluation. Thanks.

>> Since we have a number of questions, I'm going to move to the next one even though more discussion could take place.

This is a question for Toni Wall. For the percentage of children in hearing loss in special ed versus not. Did you look at degree or type of children? Were the ones getting no special ed services more likely to be unilateral or mild hearing loss, or were some severe, bilateral, et cetera?

>> TONI WALL: Thank you for the question. And no, at this time we did not look at that particular piece of information. But we would like to.

>> Okay. This is for any presenter. How can we use the outcome data that's being collected to determine the efficacy of the early intervention that is being provided as compared to maturation? Again, for any presenter.

>> ALLISON SEDEY: You know, basically that's impossible. (Laughing) Because what it would mean is denying early intervention service to a group of children and comparing them to a group of children who did receive the services. Yeah. You could compare different programs, and different amounts of children, families who make different choices in terms of the nature of the intervention that they receive. But to separate out children based on maturation versus the contribution of early intervention. We would never deny a group of families services just in the interest of science.

>> How many of you have used your CDC funding to build your EDEI outcomes database?

>> ALLISON SEDEY: This is Allison again in Colorado. I'll speak a little bit to that. I

think the programmer who works for the department of health who works for divisions other than just EHDI, but does devote a fair bit of time to the EHDI database. It was his time and salary that went into putting in those outcome fields.

I'm hazarding a guess, because I don't work in the Department of Health, but I think the money was more the money that the programmer sees from MCH. So it was just determined by the staff at the Health Department to be an important part of this programmer's job to build these fields in. So he was allowed to use some of his work time to do that.

>> Any other programs use that money?

>> ELLEN AMORE: Yes. We did use some of our CDC funding to help develop import and export processes so that the early intervention data would, but we did it both for importing just sort of participation and the IFSP dates from early intervention. But we also used CDC EHDI funding to develop the data entry screen for the McArthur-Bates inventories.

>> JANET FARRELL: I was just going to say that our epidemiologist is paid through our CDC grant, and she will be taking a leadership role in helping us to do this analysis.

>> Okay. There were a couple of questions on this next issue related for all presenters. For American Indian Students, attending the bureau of Indian education schools, were they included in the data?

>> ALLISON SEDEY: This is Allison in Colorado. I wasn't able to present any numbers in today's presentation. It was more about our program and what we do. I can't really address that question. We don't have a large American Indian population in the state of Colorado. They certainly wouldn't be excluded for any reason. We include all children participating in our statewide intervention program. And I'm not that familiar with the Bureau you're speaking of. I don't know if that goes down from birth to three or starts at school age. But the program I was talking about today was just specifically up to Part C up to age 3.

>> Any other programs working with the Bureau of Indian Education Programs?

>> ELLEN AMORE: This is Ellen in Rhode Island. We also have a small American Indian population. And we do not have any bureau of Indian education schools in Rhode Island.

>> I'm curious to know how many births are there annually in Colorado, and what might be entailed with the state joining NCAP?

>> ALLISON SEDEY: I can answer the first question better than the first. 66,000 births in Colorado. But since I looked at that very quickly, you might want to research that very quickly. But as far as joining NCAP, we would welcome any state to join. It's really

a matter of just having a conversation with me and seeing how it would work for your state. The logistics of it. Kind of what you're interested in doing. It's very flexible in terms of we do assess our children here every six months, but that's not required to be part of NCAP. We suggest that both the Minnesota and the McArthur be used, but one of those two instruments can be selected if a state doesn't want to use both of them. There is flexibility state to state. So really it's a matter of having a conversation and seeing if it will work for you.

>> Okay, the next question is for Ellen. How do you differentiate sign versus spoken language responses on the McArthur CDI? I've only used this tool for spoken language. I could see this skewing results if it's not clear whether parents should indicate sign or spoken language.

>> ELLEN AMORE: Unfortunately I'm not an expert on the McArthur. But there are two different forms that they can use. One is sign. I think it's words and gestures.
But the other is help me Allison.

>> ALLISON SEDEY: It's words and sentences is the other one.

>> ELLEN AMORE: Words and sentences. There's one that's specific for sign language, and there's one for children who are using spoken language. So there are two different tests.

>> Can I jump in on that one? I am familiar with the instrument. We've used it a long time here. There are different versions. The words and gestures versus the words and sentence are actually an age-related distinction. You give older children words and sentences. The published form is going to basically say which of these forms does a child produce. And that could be interpreted by someone could include sign language, might not include sign language. We slightly adapted the form where we have two columns, and one is titled "says" and the other is titled "signs." So for each of if words, the family can check if they said that word or signed that word or they could check both. And we get separate counts for each of those. And we can report back to the family interventionist how long is the sign vocabulary. How large is the spoken vocabulary. How many words are they just saying, just signing, using both modalities for. And we get just a big combined total that we just look at the age score so we make sure we're not discounting any mode of communication that the child is using to express themselves.

There is also, you know, I think what Toni was trying to get at, there is a version of the McArthur that is specific to sign language. An ASL version. It's a bit in the preliminary phase. Although it's been around for many, many years it's still in the process of being normed. It's a difficult population to collect norms on. Because they're looking for children whose parents are native sign users. The population is small in number.

If you're interested, I can put you in touch with the right person to get that particular form

if that's of interest to you. But our modification of the McArthur does account for sign and spoken language.

>> We have a few more minutes. Do you have children receiving private intervention, and how do you track them? Are they lost to documentation?

>> ALLISON SEDEY: Yes, we do have children getting private intervention, but typically they're also getting our state-wide intervention program, too. So the private is in addition to. If they were to select private only, they're not lost to followup in terms of hearing screening and diagnosis, but we would not be collecting outcome data on those children. But in our state, that's a very small number that would choose only private intervention and not also receive the CHIP program.

>> Anyone have something different?

>> TONI WALL: Hi, this is Toni.

>> Hi.

>> TONI WALL: Sorry. There are families who choose to have private intervention services. That's mainly through the Maine Center for the Deaf and Hard of Hearing. We have an agreement with them if they do receive services there, they let us know.

>> ELLEN AMORE: In Rhode Island, I'm not aware of anybody who is. We obviously wouldn't get the information from early intervention on those children. But we would get developmental screening from other sources on those children.

>> Okay. And the last just couple of minutes. A question for anyone on the panel, do you include children who are identified as deaf-blind in your outcome data?

>> ALLISON SEDEY: We do.

>> TONI WALL: We did not with this particular project.

>> ELLEN AMORE: We would not know that information. We just know about the deafness.

>> JANET FARRELL: And we would plan to look at special health needs in general, all types.

>> We for Toni or Ellen. How were you able to get managing audiologists to enter information into the online managing systems? KIDSNET and ChildLINK.

>> ELLEN AMORE: It's an ongoing challenge. Some of them, and it's very individual. Some are fantastic. And really are committed and have worked it into their workflow in

the office. And report regularly. Others never report at all. We just continue. We do make it, make the other information in KIDSNET available to them. So they can see who the primary care provider is. They see newborn hearing screening results. They see results that other audiologist haves put in. And we try to present it as a community. They see demographic information, birth information. So there's a lot of helpful information to them. Early intervention. Even immunization information. So they can see if kids with cochlear implants have had meningitis vaccine.

So really, oh lead screening information, because lead poisoning can interfere with audiology. We try to make our system supportive of them, but it's definitely an ongoing challenge.

>> Okay, we have time I think for one more question. For Allison. Is the state annual accountability report for participating states in NCAP a report that gives states the report of all kids to give the outcomes of kids in that particular state?

>> ALLISON SEDEY: Yeah, what we do in the outcomes report for the state is we have the outcome data for that individual state and right next to it all states. So an individual state can look at their results relative to a compilation of all the participating states.

>> Okay, we've come to the end of the appointed time. And out of respect for everyone's schedule, we'll bring it to a close. If we didn't get to your question today, the organizers will review the question, and work to get an answer from the person most knowledgeable about that particular topic. And those answers will be sent to all of today's participants whose e-mail is on file with NCHAM. If you think of a question later please send it to wchung@cdc.gov. And our thanks to the national center for hearing assessment and management, NCHAM, and the health resources and services administration, HRSA, for their help in broadcasting this webinar.

And our thanks to our expert speakers today.

This concludes today's program.

(The presentation ended at 4:32 p.m. Eastern Time)