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NATIONAL CENTER FOR HEARING ASSESSMENT AND MANAGEMENT
TRENDS AND OPPORTUNITIES FROM EI SNAPSHOT
LESSONS LEARNED FROM FAMILIES, PROVIDERS AND EI
AUGUST 24, 2017, 12:45 P.M.

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>> Hello, everyone. I would like to welcome you to today's webinar brought to you by the National Center for Hearing assessment and management known as NCHAM. My name is Alex. I'm a graduate research assistant with NCHAM and I'm delighted to be able to introduce our presenters today who will be speaking on an exciting study known as the EI snapshot. First you will hear from Diane Behl. Diane has applied her expertise in evaluating the effectiveness of service coordination and systems change to the EI SNAPSHOT project and coordinates -- supported by NCHAM and in addition you will hear from Sara Dautre who is a PhD student with expertise of special education. She is the mother of three children including a six-year-old daughter who is deaf. Both Diane and Sara's contact information is posted on the left of your screen for your convenience of I will hand the microphone to Diane and welcome Diane to today's webinar.

>> Thank you, Alex. And thank you to everyone who is joining us today. I appreciate you taking time for this study that we have been working hard on. And in addition to myself and Sara, we are fortunate to kind of represent a really hard working research staff. Karl White is the principle investigator, Juliana Plucinik and Heather Mariger also work as key staff members on this and most importantly I want to thank all of the participants that made this study a success from -- this study a success from

families who responded to surveys to early intervention providers, state leaders, the family-to-family organization, personnel preparation program directors, just a lot of people committed time to make this a success.

So first before we go on to the objectives, I want to also highlight what EI SNAPSHOT stands for. Its actually a huge acronym that stands for the systematic nationwide analysis of program strengths, hurdles, opportunities and trends. And so EI SNAPSHOT if you look at logo is kind of an opportunity to remind you that we are getting a broad panorama of how early intervention system is working. So if we go on now to today's objectives, we hope to provide an overview of the EI SNAPSHOT study for you. But then move into more of a concentrated focus on the family survey and sharing those findings.

Next we will highlight the trends that we saw from other data sources that highlight what was found in the family survey and then discuss opportunities for how we can address the needs that we learned from families.

Let me then just provide you an overview of EI SNAPSHOT. This was a one year study funded by the Maternal and Child Health Bureau and the a foundation. It had a broad scope in that we wanted to be assessing how the early intervention system is operating from the perspective of families, early intervention providers and audiologists. We also looked at the EHDI and part C system infrastructure through interviews with the state leaders. And we took a look at deaf education personnel preparation programs to find out how that piece is fitting in to potentially impacting access to specialized providers. And then we also looked at a very important component which was what's in place in terms of family-to-family sources of information, particularly through the family-to-family organizations and other sources like the part C websites.

Let me now begin with some information about the methodology and the population that went into the family survey. In terms of methods, we approached states with their interests in participating in this study and we had ten diverse states with giving us a total of 318 families that responded to the survey. Roughly 10% response rate. The way we identified these families were through working with the EHDI in part C coordinators to say based on your data systems -- you help us identify families who were had a child who was deaf or hard-of-hearing. We also for

the methods then asked those providers to send out surveys that we provided and families were given the option of completing the survey through a hard copy paper version or going through an on-line link and doing it that way.

In terms of the child characteristics for those families who had a child that responded, we first had families who had children in the age group of two to six years. And this was something that we sought out from the beginning of selecting the families. And we did this because we really wanted the opportunity to include families who had sufficient experience with the early intervention system and could give us that long term perspective. When we looked at the range of hearing loss, there was a diverse range from unilateral to bilateral profound loss represented in the sample. We asked them about additional delays or disabilities. And the parents reported that it was primarily speech language delays. Then there were some other more diverse developmental delays in disabilities also represented in that population.

In terms of family characteristics, we had a fairly educated cohort with this survey. About only 10% had a high school diploma or less. 63% had some college or a Bachelor's degree. And 27% had a masters or doctorate degree. In terms of insurance coverage, we had less than 1% of the families that reported no insurance. And so 48% reported they had public insurance such as Medicaid. 70% reported private insurance but recognize this is not exclusive. Some families reported having perhaps both types of insurance. We had 9% of families that identified themselves as having Latino heritage. 83% reported themselves as Caucasian. 12% African-American. And 11% other races.

To give you a sense of what the paper survey was like, we have a snapshot of the survey letting you know how we presented the survey to the family, giving them options, for example, to call someone if they needed to complete the survey in another language. The survey was available in English as well as Spanish. But then we provided an opportunity that a family needed it in a different language they could call and contact us.

So in this survey one of the things we wanted to find out is when you -- to what extent our families reporting that they got connected to early intervention services in the timely fashion. Ie, meeting the 1-3-6 goal for EHDI. If you look here

you can see that for those children diagnosed in the top line for before three, we have 72% of the families reported getting connected to early intervention by six months. 18% reporting it getting connected between six and 12 months and then roughly 10% were later than that. And so if you look at those children identified not until they were four to six months of age, you got about 57% that reported still getting in there in a relatively cool amount of time by six months. 33% got connected between six to 12 months of age and again 10% after that. And then you will see here for children identified later, you might be kind of scratching your head saying, how can 22% have gotten into EI before they were even identified? And most likely those are children that entered the early intervention system on eligibility due to some other criteria and then were later identified as having hearing loss.

The next thing we asked the family is to give us a sense how early intervention impacted their family overall for example did it increase their quality of life. And so you can see by this, if you look at the black bar and the orange bar they reflect those that say strongly agree and agree. And you can see on these elements here that they say it improved our quality of life. I felt more confident in my skills as a parent because of early intervention services. And early intervention taught me how to stand up for my child's needs. You got 75 to 80% of families reporting this which reflects how important early intervention is from the family's perspective. Next building on this a little further, we asked about the early intervention experiences. So as you can see by these bars again, you had few families reported that were frustrated in trying to get early intervention. Few really felt pressured in terms of choosing one communication mode over another. In general, the families reported -- strongly agreed that they felt they were given choices. They were supported in their goals and they were part 6 of their child's early intervention team.

With this one, what we have here is some information that we tried to glean from families in terms of what's happening in terms of communication modalities. And so one of the things -- the way we went about doing this was offering families an array of communication options. For example, listening to spoken language, sign language only, total communication, cued speech. And then we asked them to tell us what percentage of the time in an average day they spent using those different communication modalities. And as you can see from this table, Sara did some

great analysis on this because it really was complex. And not very cut and dry in terms of various communication modalities, families report they are using with their children. And so for example what you can see here is you only have about 49% that said they were using listening and spoken communicate language only. Only 3% reported sign language only, but then if you look a little farther you can see some that said, well, we use mostly listening and spoken language and supplement with other things like sign language or cued speech. And again some smaller percent said we use mostly sign language but bringing in other things. Same with cued speech. 14% said we are using equal part sign language and listening and spoken language. And this also was the group that reported using total communication. One of the things we found from this also was in terms of finding out a if families use total communication, it's important to really clarify what the definition of that is because I think those terms mean different things to different families.

Let's go on. So given that what they are using, we wanted to find out about, well, what about the quality of information provided about those communication choices? And so we asked this about the information provided upon diagnosis. So keep that in mind. And so what we found here is that families reported excellent to good information regarding listening to spoken language, sign language and total communication the majority reported that. Cued speech information was provided perhaps not as good as if you looked for example there were less than half that reported receiving excellent or good information in regard to cued speech.

Now a chance for you to interact. Before we go on to sharing with you what families said. I would like you to answer this question, please. Alex is going pull up a poll and give me one answer in terms of what you think is the most difficult for families to access. So click on the ones. Let's stop here for the sake of time and so what we are seeing is the most of you are saying that it's most difficult for families to access opportunities to interact with adults who are deaf or hard-of-hearing following by meeting with other families of children who are deaf or hard-of-hearing. And then some of those other things that are sign language instruction and other coming in minimally. Thank you. Now let's take a look at what the families in the survey told us. We have a smart audience here. Because in fact we provided an array of services that we asked families about and what we are sharing with you are the ones that

were reported by families as services that they needed and then whether they didn't have any problems getting them or if they had problems getting them. And in fact it was opportunities to interact with adults who are deaf or hard-of-hearing that was one of the highest as having problems getting followed by meeting with other families of children who are deaf or hard-of-hearing. The other ones like genetic counsel, sign language, speech language therapy, those specialized services came in the same amount, 15% not insignificant amount reporting trouble getting those. Auditory verbal or listening to spoken language at the bottom, 14% reported. Meeting it was having trouble getting it.

Here is another poll question for you. How would you rate the degree of financial burden most families face in terms of meeting their child's hearing related needs. I will take a look at a what you told us thus far and go on in the sake of time. We've got 43% of you saying a large burden, about 56% saying moderate with not much. With only 1% thinking it's hardly noticeable. Let's take a look now at the survey results. And if you look here, what you have is in reality almost half of the families who responded to the survey reported financial burdens in the moderate to large to unbearable level. Almost half of families falling in that category. In terms of no burden 39% of families reported that and 14% saying hardly noticeable. What I think is interesting is if you recall the insurance status. We only had less than 1% of families reporting that they had no insurance. And so I think those -- when you look at the portion of families that are reporting, at least the moderate to large and bearable burden, it -- one interpretation is that its insurance is definitely not covering everything in terms of saving families from these burdens.

Let's go on to another facet of early intervention which is service coordination. We asked families to report on the service coordination and the degree of help that they got in accessing services. What I would like you to do in looking at this is perhaps a attend to the green, yellow and blue bars on here which reflect the percentage of families that disagree strongly, or don't know about the help that they got in regard to service coordination. For example, my service coordinator helped me get services like child care transportation, food stamps, et cetera, those broader based supports that families are often looking for and how you got a good amount of families that are saying, no, they disagreed they got the help and a good portion saying that they don't know. Helping them get in touch with other parents

for help and support, that's a little better. Their service coordinator asked whether services are meeting their needs. The service coordinators seem to be doing a good job on that from the family's perspective. And here is another interesting one when you think about the importance of the medical home. My child's doctor got information about our services. You've got real good amount of the parents reporting that they disagree with that in a real good -- and 20% reporting that they don't know if their doctor got the information or not.

Now we will give you one more poll question. How would you rate the quality of information. Like your PTI, your family health information center like hands and voices in your state.

Okay, let's stop there and what we see is the majority of you are saying fair, about 46% of you. 14% say we think it's poor and then roughly about 40% saying excellent or good. All right. Let's take a look at what the families reported in our survey.

First, let me give you background how we asked families this question. We did not say to them how would you rate the quality of information received by your F2FHIC? What we did is with partnership with the state part C and EHDI coordinators and asked them to identify the state specific names of those organizations. So when the families got their survey, it was tailored just for their state and we listed the names of those organizations. So for example, we would ask them about Hands & Voices, but then also the peak center which is serving as the PTI and the F2FHIC. Because I don't think it's necessarily important that parents know those federal acronyms so to speak, but rather do they know of those important resources in their state. So if you look at the results, families reported that they -- the majority reported that they did get information regarding Hands & Voices that the majority said excellent and good. But families in general were less familiar with the family to family health information center and the parent training and information centers where you've got pretty identical there where you only have let's see, roughly about 35% to 40% saying excellent or good. And so this is something to keep in mind about how we've got some terrific partners out there. The work that family to family health information centers and the PTIs is absolutely wonderful in terms of the resources that they have available and their ability to connect families with other resources. And so I think this is important for all of us to be thinking about in

terms of how we can reach out to those different groups. And so I will do one more slide and that's to let you also know that we gave families who completed the survey an opportunity to give us just some open ended perspectives. So we asked what advice would you have to other families about who had an infant or toddler who was deaf or hard-of-hearing. And we have done some analyses on those open ended responses and you will see them here. For example, the advice was don't wait, for example, for getting services. To be able to really act quickly. Make sure that you are asking for what you need. Speak up. Use all resources at our -- that are available to you. And then advocate. Know how to advocate for your child. In terms of barriers, what president barriers that were most difficult for you. The insurance troubles came up like we saw in the data. Travels to appointments is something that challenge for families, just the distance they know how to travel and get specialized care. Financial burden, struggling with cost. Aspect of being unaware of services. Not knowing where to go for them. And that in general I think related to that I wish I had known sooner, for example, that I should have started working on learning ASL sooner. I should have gotten second opinions. And just that aspect of services in general. And then on the other side of the slide you have got some actual verbatim comments from the families that reflect those kinds of things. Like, for example, a particular therapy was never offered. I wished I had educated myself more. I was just going off of what I was told through the program he was in. I had a difficult time trying to find speech pathologists to come to my house. Child cochlear implant was in place. Months went by. The third one shows how many families can feel overwhelmed that it's a lot all at once. It was confusing overwhelming. And then and now I see my child isn't getting everything he needs to improve in the area. They feel like it's like pulling teeth.

So those comments there again just kind of -- I think, gives a voice to the families who really put a lot of their effort into completing these surveys for us. And really sharing what their lives were like.

At this point I would like to turn it over to my colleague, Sara Doutré to highlight some of the important trends and communities we saw.

>> Thank you, Diane. And in the beginning Diane talks about that when we undertook the SNAPSHOT project we wanted to take -- how

this was working for families. But we wanted to look at how the system is working for all of the stakeholders involved. And so we used all of those broad areas she talks about. Looking at the infrastructure of part C and EHDI system in states. Looking at personnel prep programs for deaf educator. Looking at reviewing surveys from earlier intervention providers and audiologists to determine whether there were trends. Whether we could find consistent themes across methodologies and stakeholders. So if parents said one thing that was provided by the providers and the state system and then we could -- we felt like we could call that a trend and from those trends come up with some opportunities.

I'm going to talk about opportunities. I want you all to think about these as opportunities for yourselves. As we look at participant list today, we see a lot of names we recognize as people from state EHDI systems. People from state part C system and people from the family organizations that we are talking about. So when we say opportunities, these aren't necessarily opportunities for NCHAM to do something, but opportunities for you all to take to your state system, talk to your stakeholders and talk about how you can act on the trends that we found. So the first trend I'm going to talk about is I'm going to follow a little bit of Diane's order is talk about how the other pieces supported that. So most families, 90% are very positive about early intervention. It's really easy to get through that process. It's easy to get in. Early intervention improved my child's life. Everyone is very positive. Early intervention providers are also very positive about their jobs in serving children. They enjoy their jobs. They feel like they make a difference for children. So the opportunity there going back to the first data from families is that we really need to continue to work to increase the number of children who receive early intervention by six months. Those children that are identified early identified by three months, we need to -- three months we need to take down barriers. That's the overarching piece and we will talk more details that will help douse that.

The next trends are the trends about having to arrange for private services that one sort of family's reported that they arranged for supplemental private early intervention services for their child. And almost two-thirds of audiologists are receiving requests from parents seeking supplemental early intervention services. Those audiologists reported that in the last year they have received requests from parents saying, hey, my kid might be getting early intervention or not where can I get more private

therapy and where can I get more private sign language lessons and where can I get private services. To complement that we found that very few personnel preparation programs for teachers of the deaf provide course work or practical experience focused on early intervention. So the opportunity there is that we need to look at if parents are seeking supplemental early intervention and are getting great services, that's good and like we found that most families are happy with the services their child is getting so they are trying to get even more of a good thing. But we need to make sure that we have those providers available within the early intervention system and that our system is prepared to refer families for supplemental services that we have a good handle on who those private providers are knowing that audiologists are being asked to read for kids -- refer kids and other kids are asking for referrals. When we think about our system we may need to expand to personnel just beyond our early intervention providers.

The next trend again that ties back Diane kind of brought the family perspective into this is that 40% of families reported that their medical home or their pediatrician did not receive information about their early intervention services. So there wasn't communication back to the pediatrician about services. About a quarter of service coordinators reported that coordination with the medical home providers and family support organizations needs more work. So the service coordinators themselves would like to improve that coordination. And interestingly only 32% of audiologists reported receiving copies of their clients IFPS and only 30% reported they participated in an IFFP meeting. So if we think about levels of collaboration, probably just providing copies of an IFSP is a pretty basic level of -- I don't know if we would quite call it collaboration but sharing information. So there are opportunities to begin that may not be intense collaboration but simply sharing information providing copies and letting other providers know what types of services the family is getting. And that opportunity includes providing better training to part C service coordinators and audiologists and I would say on early intervention or on hearing loss and then better training back to those hearing professionals on how service coordination works and those type of things. There is some opportunity for some training back and forth between those groups.

The next trend is a trend across -- it's not just families. So about two-thirds of families reported they received little to

no information about the general of those PTIs and F2FHIPs. Those broad disability organizations and equally as concern being that is nearly half of the early intervention providers and audiologists we surveyed reported that they had inadequate knowledge about those family to family support organizations.

And then again looking at the other side of that, one of the pieces of our project is that we hired parents of children who are deaf and hard of hearing to make phone calls to the PTIs and the family to family help information centers in each state and those parents called and informed the organization that they were helping with the research study and walked through a script with the families with the family organization with the families that work with the family to family support organization asking them questions that a parent of a child with hearing loss might ask. And very concerning we found that family to family organizations don't know about EHDI systems and they might have resources to families. So we found those organizations did a great job of referring families to early interventions. Those organizations know the early intervention system very well and they know the family to family help information centers know that insurance side of things really well and they can help families with that. What we found was that just as we found that we -- families weren't learning about the organizations from EHDI. The family to family organizations also don't know much about EHDI and potential resources for families that are available for those systems.

We did a review had those same trained parents of children with hearing loss who are deaf and hard-of-hearing review part C websites. Which is an initial source of information for a lot of families a lot of family goes online to look at EHDI websites and part C websites to find more information and fewer than half of the part C websites had information about family to family support organizations. Again either those broad parent training information centers or more narrow disability specific like Hands & Voices. So a great opportunity here is to create new partnerships between EHDI systems, the part C systems and family to family support organizations that this again if something is something that maybe we may be able to get a lot of bang for our buck in that we aren't having to create new resources that is ensuring we are aware of the resources we each offer so that we can direct families to each other and not duplicate efforts and recreate something some we would hate for a family-to-family organization to develop a lot of new materials on hearing loss

and try to put together a directory of all pediatric audiologists in the state when we know the EHDI system already has that information and it could be linked from that family to family support organization.

Another piece again that was a family piece that we felt like was worth bringing up again is that the majority of families reported little or no opportunities to meet with other parents of children who are deaf and hard-of-hearing. And 25% of parents reported that they wanted to interact with deaf adults and other families that had problems getting that service. And this relates back to again like Diane said and like you all knew, this is nothing new to you because you answered the poll exactly correct that this is an area that families are having a hard time getting those opportunities and it's very exciting that the maternal and health bureau has recently funded the Hands & Voices family language learning and leadership. Did I -- I think I got the order wrong but the three Ls. Learning language and leadership centers so that is going to be a center that will work with the EHDI systems and the family organizations and this is one of their main areas of focus. We look forward to opportunities and resources and learning more about how we can make these opportunities available to families and ensure that they are able to access them that they come at the right time or the right people offer them.

So we can talk more about the financial burden. Again, I think Diane covered this well that about half of the families reported that hearing related needs were a moderate to unbearable financial burden. Along with this -- the families are facing a burden about two-thirds of families reported their service coordinator had not helped them get non-therapeutic services such as child care or food stamps. And this is an area -- this was supported by the service coordinators who 18% reported that they had never helped families get these kind of community services, child care, food stamps, respite care and only 22% of the EI providers reported that they always helped families connect to these community services. So both families and providers supported each other in saying this is a burden. We may need extra assistance but we may not always be reaching out to families and recognizing that because of that financial burden they may be eligible for other services they don't know about. So what we found in the open ended responses about this was that a lot of families said, oh, I didn't know part C could help me connect to food stamps. I didn't know part C early intervention

could help me look into child care. I didn't realize they could help me coordinate those services. While part C doesn't offer those, we believe that is practice of the service coordinator would be talking about and ensuring families connect to those other pieces. We often look at part C as the glue that holds together a lot of different services for families.

Again, one thing that came to mind here is making sure that we know to refer families to that family-to-family help information center that can again connect families with this. So it may not be developing a lot of new things, but just making sure we are connecting families to those correct resources which will be that opportunity of ensuring that service coordinators understand what's available and that families understand that the help can be greater than just coordinating speech therapy or toddler group or something else like that.

Toward the state system level and looking at how part C and EHDI systems worked together, we were very impressed to find that great working relationships are in place between EHDI and part C systems. The early intervention systems in states. States have formal referral processes. They have rules for referring and they ensure children get referred. However, we found that many states reported to us that federal and state laws including HIPPA especially can be barriers to sharing data to improve those processes to making sure we know really what is the outcome of that referral. Does the child end up receiving services in early intervention.

A few states are able to share child specific data across agencies. And we know that many of these organizations are not in the same agency. I'm going to talk about that in just a minute. But even when they are not, a few states have figured out how to do that. Have been creative. Have pushed back to the attorneys and said we have to figure out how to do this within those laws. And so we need to continue to do that. To create ways to share the most important data back and forth between the EHDI system and the part C system. And like I alluded to, one of the things that makes that difficult is that in only 43% of states in the country are the part C early intervention and EHDI programs in the same agency or department. So in 57% of our states, we are working not only across the divisions or programs that are across agencies which makes it really difficult. We also found that those referral systems while every state has one in place, they really vary across states. So in some states,

EHDI programs refer children directly and there is a direct referral and communication between EHDI and part C early intervention. In some states there is a third party like the audiologist generally who is responsible for that referral. So while both sides are working with those audiologists to make sure those referrals happen, there is that -- isn't that direct referral.

We also found that eligibility criteria for part C early intervention vary across states. In some states every child with a hearing loss is eligible with any level of hearing loss. In some states that loss must reach a certain threshold before that child is eligible for early intervention. And adding to that which we believe is confusing for families is sometimes those criteria vary across programs within a state. So sometimes there are similar programs that are -- I don't want to call them duplicate programs, but programs that work side by side to serve these families and children such as the part C early intervention and another early intervention program through the School for the Deaf, through special division for services for the deaf and hard-of-hearing. Or some other agency that provides parallel services that are also complementary but sometimes the child will be eligible for one and not the other and that can be very confusing for families and for programs. So the opportunity there is for us to explore those effect of those differences. Are those differences affecting outcome for kids and whether those kids get into early intervention early enough to have a positive outcomes we know early intervention can have. We need to do more exploring there and then as we find that out, advocate for change in those statewide systems.

And that wraps up the trends and opportunities section. If you have questions about it when we open it up for questions or ideas how we can capitalize on some of those opportunities, we would love to hear those from you. Some of the limitations and next steps kind of a summary of the study are family survey return rate was pretty low. About a 10% response rate. Which we felt was low but we had a broad depth clearly from again the beginning of the presentation you know that we would like to have greater socioeconomic status and cultural diversity represented in this study that we have a fairly homogeneous population that maybe represents a higher level of education and not as much diversity as we would like it to represent.

It is difficult to determine services provided by part C

and broader easterly intervention system. We have a lot of families that are getting private services to supplement the early intervention. We had families who are receiving early intervention from multiple sources so maybe some through part C and some through another agency. And it's really difficult to -- for families to separate that out and for them to report especially in the past to think about which services were part C services. And that may be good for families. We may not want families to see those, but we need to make sure we can look at what's happening. We plan to drill down in the data to learn more and welcome you to do that as well. Including analyzing the very rich information from the open ended comments. And along those lines, we have a digital copy of the final report is available on NCHAM's website. This is a link to it we can also put the link in the chat box or something -- and it's on the side. On the left hand side. Right, Alex? So there is a link to that report. If you are with the EHDI system or the part C system in your state or one of fat loom organizations that we interview -- one of the family organizations that we interviewed you will receive a hard copy of the report if you go to the website and find the final report and below a that final report we have included some categorized open ended questions and so again, if you want to dig into this and read about what families told us, I think we were really impressed with the depths that they went into as well as providers and audiologists talking about early intervention services for children who are deaf and hard-of-hearing.

We also provide on the website copies of our materials including all of the surveys. Copies of -- I guess we could probably add this presentation but also copies of presentations we did at the EHDI meeting summarizing some of the different pieces. And we invite you to dig in and then contact us with any questions you have.

>> All right, thank you to Diane and Sara. You both have -- a fantastic job and I'm sure a lot of the information will be helpful to those who are visiting. We have now reached the time to open it up for questions. If there are any questions that you have in the lower left of your screen, go ahead and type those in and we will copy them over. Looks like we have one question that's come in from one of our viewers. And this is for either Diane or Sara. Could other states look at using your surveys for families and early intervention providers?

>> Yes, I'm glad you asked that. This is Diane. And, yes, we encourage you to use those surveys and again you can find them on that website. We ask if you are to use them to do two things. First we really appreciate it if you contacted NCHAM and let us know you are using it but that's very helpful information for us. Secondly, to just ensure that you give authorship credit that it is a survey developed by NCHAM or adapted from NCHAM So again we are happy to help you with that. Since you asked about other states, it's also an opportunity to specifically mention the states that were involved because I see several of you are on today's call and I want to be able to thank you personally in that those states that help with the family surveys were Nevada, Montana, Georgia, South Carolina, Louisiana, Vermont, Massachusetts, Colorado, Minnesota and Iowa.

>> There is one commenter who would like to seat income burden slide again. We will scroll back to that one.

Another question really quick for either Sara or Diane, is do you have any demographics of how many surveys were received from each state? And someone came in a little late and they may have missed that. Did you individually collect demographics by each state and are you going to make that information available?

>> Yes. We've made that available to the individual states who participated. Based on the size of the responses in some states and our confidentiality obligations. We won't post those publicly for every state but each state that participated received a report from the information about the participants from their state.

>> It looks like two people have that same question. And another question comes in from Cindy Brown. She said, you mentioned HIPPA but not FERPA, wondering why are you able to share information about how states have -- let's just copy that.

>> How states have figured out how to share data between part C and EHDI. I mentioned HIPPA, FERPA is equal as hard. HIPPA generally the EHDI side of things is a little more HIPPA focused because of their general location in the Department of Health. Equally. One thing that we would like to do that we are working on from NCHAM as far as helping with that is getting some copies of memorandums of agreement and those interagency agreements between agencies to share more than just very basic data and providing those as examples on the NCHAM website. That's

something that will definitely come out of this. If not, more information on that. But definitely getting some of those examples states that have figured out how to do that well that other states can take and use as a model in developing their own interagency agreement.

>> And this is Diane. There are also a few excerpts from such cooperative agreements that are provided in the EI SNAPSHOT report. With the verbiage regarding the data sharing that we hope is helpful.

>> Someone had another comment that they believe the survey is being sent to families in New Hampshire right now. Is the EI SNAPSHOT being continued right now, being sent to other surveys?

>> We have stopped collection of data. That closed several months ago. However, I would love to follow up with whoever is in New Hampshire to learn about the data you are collecting. You know, again, we have no objection at all. We are just very interested in broadening our knowledge base. If you wouldn't mind contacting Sara or myself at the e-mail address on the left and tell us more, please.

>> Thank you. Another question is will this presentation be made available to attendees and I can answer that. And we will make a recording available on infanthearing.org. Go to our education and recorded webinar resources there within two weeks this presentation should be made available.

One more question here from Lisa. She asks for the PTIs to have -- chapters contacted the partner and encouraging family in the macro not personally identified families to look for, complete or return the surveys.

>> We didn't. This is Sara. We didn't use the family to family organizations in that way. That is a very good suggestion that may have helped improve our response rate. I will say that we did find that those broader organizations that the PTIs and the F2FHICs have generally have a very interaction with the very small number of parents who are of children who are deaf and hard-of-hearing now when we ask them what their reach is with them it was generally pretty small. I think in the future to engage them in helping encourage families to respond would be a great improvement.

>> This is Diane. And just adding to that about why we didn't do that. One of the things we wanted to have from an analysis perspective was to get a sense of how many of kind of knowing what our denominator so to speak. With some surveys it's a appropriate, I think, to disperse it wildly -- widely and have it open to whom ever chooses to respond. What we felt important for this study was for us to really understand the set of people who are receiving the survey so we can tell what that response rate was going to be.

>> Maybe one last question for time. We have three minutes or so before we end. Did you find differences in coordination amongst states that had EHDI and part C in the same department?

>> This is Sara. I would say yes. I tried to devise a way -- devise a way to quantify those degrees of separation between programs. And even within one department or agency there could be no degrees of separation. The EHDI and part C system are in the same program. Basically there are a couple of states where part C supervises EHDI or vice versa that it's one program. But within a department it could also be as many degrees of separation as when they are in different departments. So I would say, yes, even when they are in the same department there is a lot of difference across states on how they work together.

>> All righty. Well, it looks like those are all the questions. If any of you have any additional questions you would like to ask, both Diane and Sara have provided their e-mail addresses for you and you can contact them as well as reach out to some of the report at infanthearing.org/ei-SNAPSHOTS or any of the reports you mentioned today. So we are about two minutes or so at the top of the hour. We want to thank all of you for your participation in today's webinar and also remind you that a recording of today's presentation will be available on our website within about two weeks. At the close of this meeting, if you have a quick second there will be a brief survey for you to provide some feedback about today's presentation. Should take you no more than one to two minutes and this information is used to help us improve future webinars and research. We again want to thank Diane and Sara for the presentation and research on the EI SNAPSHOT project. And we sincerely hope the information provided was helpful and we hope to see you again at our next NCHAM webinar. Thank you very much.