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2018 EHDI Annual Meeting

USING EI SNAPSHOT FOR STATE EHDI –

EI SYSTEMS EVALUATION AND IMPROVEMENT:

APPLICATIONS FROM THE FIELD

Topical Session 2

Capitol 2

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>> DIANE BEHL: Good afternoon, everyone. Thanks so much for coming to our session, for coming back after lunchtime. I'm Diane Behl and I work at the National Center for Hearing Management and Assessment. First we have Linda Hazard, the Vermont EHDI Coordinator, and next to her we have Melinda Marsolek with the Newborn and Child FollowUp Unit at the Minnesota Department of Health. And Sara Doutre, my colleague on the EI SNAPSHOT study, also will be helping us out in getting some great dialogue going with all of you.

The title of this session is the use of EI SNAPSHOT for state EHDI and EI systems building: Applications from the field. And last year, we presented a lot of the specific data from this project, and so what we want to do in this session is kind of remind you of the highlights of what we learned, but then jump in more to what the panel members have to say about how they were able to use this information to guide their own systems‑building.

So our objectives today are to share those key findings with you from the study, identify tools to guide your systems building, and provide you with some examples of how state EHDI Programs have been working on this. So quick overview again: If anyone can tell me what the SNAPSHOT acronym stands for, I think you're gonna win a free cup of coffee because I still struggle with this one. SNAPSHOT actually stands for Early Intervention Systematic Nationwide Analysis of Programs' Strengths, Hurdles, Opportunities, and Trends, so those are some things that I'm going to be sharing with you. We had a variety of methodologies. We used a family survey to get information from families directly about how Early Intervention worked for them.

We sent surveys to Early Intervention providers and pediatric audiologists to talk about their role in Early Intervention. We also conducted interviews with state Part C and EHDI Coordinators to find out how they were working at a systems level, and we did interviews and collected data from family to family support organizations. We looked at Part C websites, and also looked into the Deaf Education personnel preparation programs to find out how are they contributing to the field in terms of providing Early Intervention providers?

So these are some of the questions we were exploring: How are families getting connected to Early Intervention? What services are they receiving and are those services meeting their needs? What about connections with other families? What about connections with deaf mentors?

What are the characteristics and challenges from that provider perspective? How do families access information? Are they going to the web? And if so, what kind of information can they find there? And what about state policies that support or perhaps are actually hindering access to Early Intervention and coordination? So that's what we wanted to find out about.

And so I'm going to quickly go over our results. Usually you see all the specific data, but we've talked about that, so I just want to hit on the trends, which I'm going to define as those consistent themes that we found across all those different methodologies and the stakeholders that we heard from.

And the opportunities, then. So okay, we learned all this great information. How do you really use that to improve the system?

And so I've got a few slides here that are going to say: Okay, here are our take‑home messages. The first is the trends are pointed to the need for increased specialized services for families in intervention. For example, 1/3 of the families said they had to arrange for supplemental Early Intervention services beyond what the Part C a program was serving.

We had 2/3 of the audiologists said that in the past year, they had gotten requests from parents to help them find supplemental services. Half the EI providers said, you know, our training really in D/HH specific training wasn't very adequate, and so all that ‑‑ those kinds of things are really pointing to a need for specialized services. So what could we potentially do about that?

One of the things you can work on is support the expansion of Deaf Education to comprehensively cover Early Intervention. The programs have a school focus so they're not getting that training in Early Intervention. What about increasing training and technical assistance for Early Intervention staff and audiologists and EHDI? So that collaborative training is going on. And increasing that access to information about supplemental services. That's still something that parents are struggling to find out.

The second take‑home message was the need for improving coordination, improving coordination, particularly with audiologists and the medical homes. Again you can see the trends here: What we learned from those data sources were about 40% of families reported their Medical Home did not receive information about their Early Intervention services, and that's something that's been particularly important, particularly coming from the Maternal and Child Health goals.

We had about 43% of the service Coordinators said that they thought their coordination with Medical Home providers and family support needed more work. They were recognizing their own needs.

When we asked audiologists, do you get copies of IFSPs or participate in meetings? Only a small portion did. 32% got copies of IFSPs. Only 13% said that they had participated in a meeting and so again, there's opportunities there to improve those trainings of the service Coordinators in particular, and audiologists in how to ensure that we really have that full team present.

The third trend is improving those family to family support connections. What we found is 66% of those families reported that they had little or no information given to them about those general disability family to family support organizations. As you may know or maybe don't know, each state has a state Family Voices Chapter. Each state has a parent training and information program, along with those D/HH‑specific programs such as Hands & Voices, for example, ASDC, et cetera.

But that information isn't getting to the families. 44% families said they received little or no information about those specific groups, even. A third to half of EI providers reported they have inadequate knowledge about those support organizations so we've got a lot of work to do and when we interviewed those family to family support organizations, fewer than 10% knew about EHDI resources, and so we've got great opportunities here for improving that access to providing those connections.

I'm just watching my time. Okay.

And so if we can create more opportunities there for parents to interact one on one with one another, as well as with adults who are D/HH, that's something our system really needs. And increasing information available on the websites. If you look at Part C websites, do they all contain information about those important family organizations? So we really identified opportunities there.

One tool that NCHAM developed is a resource that you can post on your website called the Just in Time resources. That lists all those family organizations, and what they offer to families, and so we really have a lot of work to do on getting that word out.

Okay, number 4, the big trend here, was families really needing help with financial supports. We asked families about the degree of financial burden as a result of their child's hearing related needs, and about half of the families reported those hearing related needs posed a moderate to unbearable financial burden for them. So I think that's quite significant.

We had about 2/3 reported that their Service Coordinator had not helped them with getting services that you think tie to those financial resources like child care, Food Stamps, help with transportation, those things that can help ease financial burdens, we're still not doing a real good job at having coordination that's addressing those needs for families.

And about 22%, less than a quarter of the EI providers, said that they always helped families get those kinds of services, so more work to do there. And so if we can work on ensuring that service coordination really is addressing all those needs, that they know the sources for economic support, that's important. Partnering with those family to family organizations. So, for example, with the parent groups that are in your state, do they have opportunities to be working with the EHDI Program that we really are developing those bridges and working together?

And are we also educating our state legislators on the needs of families, particularly when it comes to hearing aid coverage?

Okay, and then I think this is my last one on the take‑home messages, that need to improve interagency communication. There seem to be some fine referral processes in place for going from EHDI to Part C intervention and you often see that those EHDI Advisory Boards at the state level have Part C representation on them, but it's not necessarily the other way around. EHDI's rarely represented on those Part C Interagency Coordinating Councils.

You've got some structural issues, like 43% of the states have their Part C and EHDI under the same Department, usually Department of Health. When they're not in the same Department, that's causing some additional challenges.

Referral systems really vary. Some have a very streamlined state process, but a lot of states really are still leaving it up to the local level.

We've got eligibility criteria that vary immensely in terms of to what extent children who are deaf or hard of hearing qualify for Part C, and if your audiologists who are making the referral aren't really clear on, is a child with a unilateral loss able to get Part C services, you end up with problems.

What we also found is few states are really able to share child specific data across agencies. If EHDI wants to find out are in fact those children getting Early Intervention services it's not a real easy question to answer. So again opportunities for data sharing, improving those policies, creating online data systems and really talking about HIPAA security solutions as well as well as privacy because they're often thrown up there as reasons why they can't share data but you can work through them.

So what we're going to be highlighting today and hearing firsthand from our panel members are a way we can say: Okay, we learned lots of important information from EI SNAPSHOT. How is that going to help you when you go back the your states?

And here are just some ideas. Even just sharing these data with your interagency team I think can begin some great conversation about how is this working out in our state? Does it apply in what can we do about it? You can use our surveys, if you want, to collect your own state‑specific data. You can adopt ‑‑ excuse me, adapt the surveys, if you want. All of that's available to you free of charge.

Look at, we'd love to talk with you about saying: Well, that paper survey for families, how did that work out? Well, we learned a lot and can offer some great strategies for you to maybe even get a greater response rate in your states.

Consider hiring parents of children who are deaf or hard of hearing to help you collect the data. That's one of the things that we found really gave us some useful information, when we were able to have actual families make sure that they ask the right follow‑up questions.

The online surveys, if you can send an email to providers, it's a really easy, cheap way to do it. We've got some interview protocols to help you explore how family to family organizations are able to respond to families, if they call and say, you know, I'm concerned about my child's hearing. What should I do?

Great tools there that you could use, and could really help improve your collaboration. All right.

And so where can you find this stuff? Well, it's actually on our NCHAM website. You can go to infanthearing.org and plus in EI SNAPSHOT in the search, or the very first link, if you just put in EISNAPSHOT.org, it's going to take you to a place where you can find out all our reports, the executive summary, all our survey tools. As you can see, I just got a clip of it here. You could get the parent survey in English and in Spanish. Take a look at it. See if it's going to be useful to you. All our reports are on there, as well.

And so we're really hoping that this is a project that is going to be helping you all say: How do we really improve that communication between EHDI and Early Intervention?

So on that note, I'm going to turn it over to Linda Hazard, who ‑‑ from Vermont. Participated in the EI SNAPSHOT as did Melinda in Minnesota. Thank you.

>> LINDA HAZARD: Hi, everyone. So I started my first page off with my favorite pictures, including our maple syrup twins, because most of you know that Vermont is known for their incredible maple syrup. So Vermont did participate in the National ‑‑ oops, sorry. Got a little ‑‑ participated in the nationwide Early Intervention survey project, and we sent out 60 surveys, and we received ‑‑ 20% of families responded. And I want to speak for a minute about the surveys we sent out, and a little history about Vermont and Early Intervention. So it was approximately a 5 year period that we looked at families.

Three years ago, our Early Intervention, our residential School for the Deaf and our consultants for deaf and hard of hearing closed their doors. We had a one‑week warning that they were closing. We were able to work closely together to get our EI program up and running within three weeks, with a for‑profit organization called Nine East Network and our consultants back in the schools, so all those who were employed by the Vermont Center became employees of Nine East Network within a three week period so we knew that we had families in this survey that might not be as happy with their experiences in Early Intervention as some of our other families.

But we wanted that information. Two of the families had moved out of state, and I ensured that those families received surveys, because I thought it was important for us to have that information, as well.

So the survey was sent to babies born in the years 2010 through 2015. And I've already spoken a little bit about what happened with the Vermont Center.

So the first slide talks about the rate the information that you received about each communication choice when your child was first diagnosed, and you can see that overall, the responses to total communication, sign language, listening and spoken language, cued speech, was really either excellent or good, with a couple of areas where families felt like it had been fair, fair to poor. And that was really an accurate representation of that time when we were ‑‑ when the center ‑‑ it actually went into bankruptcy and partially because there were only 4 students left in the residential program so it was a tough time. So this is really an accurate representation of what we already knew, and what we knew that we were going to moving forward begin working on quality improvement.

So the next slide just talks a little bit about how much do you agree with the following statements Early Intervention? For example, I was given choices concerning my family's services and supports. And you can see again, it's not a surprise in what we saw. There were absolutely a few families that felt like their needs had really not been met by our programs. And it was very, very concerning to our program, and to the Vermont EHDI Program.

And then additional information about services that they really wished they had received, or were helped in obtaining from occupational therapy, right on down through physical therapy, family training, so you can see the variety in that. So this was the SNAPSHOT.

So what did we decide to do after the SNAPSHOT information that we received? I'll be honest with you, not any of it was a surprise to us. We could have told you exactly what was going on. We are a small state with 5800 births. We have a single point of entry for Early Intervention which as you can tell can be good news and it can be bad news so we do have an extremely good handle.

The other ‑‑ before I go into the collaborative between Maine, New Hampshire, and Vermont, I just want to talk about the relationship that we have always had with our Early Intervention Program. So not only is it a single point of entry, but there's been a contract since 2007 with Early Intervention. Through our HRSA funding, we have always helped fund our Early Intervention parent‑infant program with a small amount of funds. And that has allowed us to have clear communication between Early Intervention and between the Vermont EHDI Program. So we share data.

We receive a quarterly report from Early Intervention, both a narrative to talk about what they have done as far as deliverables. We receive a list of all children that have been referred and entered into Early Intervention with their IFSP dates, and birth dates, so that information clearly goes between the two organizations.

In addition to that, we have a fully integrated database at the Health Department which means our Vital Records, our immunization Social Security, our developmental screening, our newborn screening, our newborn hearing screening, all communicate and our external providers through password‑protected, they have to receive a password, have access to that, so our pediatricians, our audiologists, our Early Interventionists can all go into the database and look up the children that are under their care, and know ‑‑ they can see their hearing screening, their diagnostic information. It is all available to them, including some of the EI information.

So the New England Collaborative began a few years ago. It was with Oberkotter Funding. We really wanted to look at a gap analysis between the three New England states, and that was our first step.

Our second step was we then took the EI SNAPSHOT survey, with Diane's permission, and help, and we worked on it over several months to come up with something that would work for the three states that was going to be more aligned with the information that we wanted, and we focused on our birth to 3 year of age population currently in Early Intervention services.

And that was helpful to us, because what we wanted to know is: Okay, while we were in transition, there were some things we didn't do so well, and now that we're no longer in transition, I just wanted to make sure that we were able to provide ‑‑ to have a better feel for some of the quality improvement initiatives that we had put in place.

Whoops.

So the families that were surveyed as I said, were currently in Early Intervention. The Vermont's new provider was fully embedded at that point in time. So what are some of the things that we learned from the survey results?

So we rated again the information that they received from Early Intervention. There was definitely improvement across the board. But one of the comments that families came back to us about was some of our families with mild hearing loss or unilateral hearing loss said: We would really have liked to know more about all options, not just those that were appropriate for us, so that was really a lesson learned for our parent infant providers, is that they can provide them with what are the most appropriate opportunities, but also explain all of the opportunities out there.

The second area on this survey was: Please respond regarding the presentation of information you received in the previous question. And I will not read through all of this, but one of the things that we learned is that families wanted to know more about ‑‑ and this again, you know, speaks to the choices that they were presented with ‑‑ but one of the highlights that really came out of this is that parents really also want to be able to talk with other families, and Vermont's a very rural area.

We have, in the entire state of Vermont, we have about 486 babies that either are deaf or hard of hearing, but we have 25 children between birth and 22 who are deaf. Most of those children have cochlear implants, and may ‑‑ some may use some sign support but they're fully mainstreamed into the regular classroom. The rest of the children are either unilateral hearing loss, or hard of hearing children across the state.

So as you can see, we have a very small rural population, so matching families has not always been an easy ‑‑ successful process, but we need to work on that.

Again, we wanted to rate the information they heard from Early Intervention, and one of the areas that they really wanted to hear more about was brain development, or excuse me, language information, and that's an area that we are also looking to improve.

Another area that we are struggling with, because we are so small, and to get the hours, it's very difficult to find someone who can be certified in listening and spoken language.

I am sorry. I am just not good with this for now. So I apologize. It is a bad clicker, so I'm going to just say that's what it is.

So I'm going to move through this a little bit, and talk about some of our conclusions. One of the things that struck me was the fact that we had one family who said they hadn't received any services, so when we sent our surveys out, we sent them to all families that had been referred to Early Intervention. Vermont typically has 25 babies in Early Intervention services between birth and 3 years of age, so we were all like: Okay, how can that be?

Well, in the last year, we now have 35 babies, so we're seeing a significant increase in our birth to 3 population. Well, one family had not followed up even though they'd been referred to Early Intervention. They decided not to proceed with that. They had pretty much declined ‑‑ they were not returning phone calls. After they received the survey, they showed up on the radar, and they actually are now enrolled in Early Intervention services. So we were quite excited about that, because it meant that they really did follow through.

So the survey for us is driving quality improvement. Another piece of what we did in September to engage families was to have a care project retreat and that really did bring families together, and it was an amazing experience for all of us to have a learning community around the emotional journey for families. So that's another area that through the original SNAPSHOT of connecting families that we really felt was, you know, a process that we wanted to become involved with.

Again, I mentioned more information on brain development, and as far as language development, and also the last area, which I did not put on here, is we really need to work on our materials, and identify non‑biased information that we're sending to parents in a non‑biased manner, and our parent infant providers are working on that right now, in collaboration with our family organizations, and Vermont EHDI, and we will introduce that in a very specific quality improvement way, where we will test it with some families, test it with some of the programs, and then, you know, expand it and introduce that.

And as part of the collaborative with Maine, New Hampshire, and Vermont, that's kind of our next steps, to see if we can develop a website together which would have options for going to individual states. The three states had some similarities. New Hampshire had also gone through a transition with their Early Intervention, and I just want to quickly say that the collaborative included Part C, Early Intervention, parents, and EHDI Coordinators, and it has been a wonderful opportunity. So thank you.

>> If you don't mind, I'm going to propose we hold questions until the end for everyone.

>> MELINDA MARSOLEK: Hi. So we already did that.

I'm going to talk a little bit about a collaborative we have in Minnesota, and how we are using or plan to use some of the results from the SNAPSHOT to inform the work on that collaborative. I know it has a longer name but we just call it the collaborative. I found out this morning it's been around for 10 years. It's done some really great work. The goal of the group is to improve outcomes for children who are deaf, deaf‑blind ‑‑ oh. Is that so? Is that better?

Okay. To improve outcomes for children who are deaf, deaf‑blind or hard of hearing, and that's really 0 all the way through transitioning into careers.

My agency, I work for the state EHDI Program, we work primarily through a work group that works with the birth to 5 population. There's a broad group of stakeholders, agencies, organizations that are part of the collaborative. That birth to 5 group has Department of Education, Department of Health, Minnesota Hands & Voices, deaf Mentor Role Model program, lots of others I'm probably forgetting but it's a nice broad group of people involved. One of the things the birth to 5 group did several years ago, 2012, was to do a survey that was really similar questions to what the SNAPSHOT looked at so we were excited about the opportunity to participate in the SNAPSHOT and take another look with a more recent cohort of families with those questions we had looked at before, and also to kind of put some more things into the National context.

So for the birth to 5 work group of the collaborative, they've been using a self‑assessment tool to work on ensuring progress on the JCIH, the joint committee on infant hearing 2013 recommendations. That's a big meaty document, lots of stuff in there. Lots of things we'd love to be doing. What are the things we think we can work on? A couple of the priorities identified for the work group currently were to one, ensure families have access to accurate, balanced and comprehensive resources and information. And then another one was to identify how many families are receiving timely access to service providers who have that specialized knowledge and skills for working with children who are deaf or hard of hearing.

So I'm just going to go through some of the results of the survey that helped inform, give us more information about those priority areas. So one of the questions that was asked on the parent survey was for them to rate the information they received about different communication choices when their child was first diagnosed.

So you can see that for most of the communication options, families felt like they got pretty good information, with the exception of cued speech, where fewer than half felt like they had good information about that communication option and that was pretty consistent with what was seen in the National survey, as well.

So another survey question that I'm not going to show was asking about whether or not families felt pressured to choose one option over another. And close to 90% of families said they did not feel pressure and that's similar to the 2012 survey where we asked a similar question, so that was an example of how we were able to compare results over time using the SNAPSHOT survey.

Another question looking at the access to information, families were given a long list of different family supports and asked to rate the quality of information that they received about each one. For this one it was interesting to see that the supports that we tend to highlight in our outreach materials were the ones that families felt like they had better quality information about. So that was some good feedback for us in terms of how our outreach efforts are working.

The primary way that we provide information to families, not primary but one of the main ways we make sure everybody gets information is through this resource binder. It's a physical binder full of resources we send out to all families at the time of diagnosis. This binder was worked on with that collaborative group, so people from across the state, different agencies and organizations came together to think about, what is the information we want all families to have? We want it to be consistent. We want to make sure it's unbiased. Let's think about what we can all agree on so they came up with this binder that goes out.

One thing that was kind of that they found over time is that it's pretty expensive to produce the binder so we send it to families but a lot of the providers don't necessarily have easy access to that information and so they worked on creating an accessible version and putting it up online so now everyone can access the materials in there, which has been helpful I think for the providers. They know the families are getting this information. They can look at it and go through it with them, as well.

And so the work group has a process of reviewing this binder annually and I think the results of the SNAPSHOT survey will be really helpful for thinking about, are there things we want to include? Are there additional things we need to add or change. Perhaps we need to add more information about cued speech since that was an area where people didn't feel like they got good information. One other question that helped us think about access to information was around the cost of questions about hearing related services and technology. A lot of families felt it was quite burdensome, the cost of this so one little tweak we did was to, we now provide audiologists with a little book mark that advertises the online resource binder, online resources, that has information about paying for hearing aids, about our hearing aid loaner bank so we're hoping if families can get access to the online version before they get that physical binder in the mail because they can have access to information when they're making that decision about hearing aids.

Okay, so then the other priority area I talked about was understanding the trainer of the providers working with the population so there are a couple of questions that looked at this. This is on the provider not the parent survey and also what certifications do you hold that pertain to serving children who are deaf or hard of hearing? So I grouped those in through groups. About a quarter of respondents had D/HH specific training. 30% were speech‑language pathologists and close to half didn't have any D/HH specific training so maybe like an Early Interventionist without D/HH specific training. We're not how representative this is, the respondents of the total population that serves families but other information sources suggests this is probably not far off. We know there are providers who don't have that specific training who are working with children who are deaf or hard of hearing.

Then there was a question about how providers felt their educational programs prepared them for working with families and children who are deaf or hard of hearing. And I broke those results out by those three groups. Overall, about 44% felt that they were not adequately prepared. And that was a little bit higher for the ones who did not have that certification in deaf or hard of hearing specific.

There were also several points in the survey where they could provide comments. So we looked at the comments to see a little bit more about this. What we saw was that for providers who don't have that D/HH specific training, that's what they feel they're missing is that specific skills and knowledge, whereas for the people who had the D/HH specific certification their comments were more about how do I work with really young children? What's ideas for providing Early Intervention and doing home based services so I think it kind of speaks that both of those pieces are really important and I think for the collaborative it's a question of what are the training implications? What is the collaborative's role in perhaps working at making sure providers have what they need when working with these families.

And then I just wanted to talk a little bit about the service coordination piece. It's not called out specifically as a priority right now, but I knew Diane was going to talk about it, and I wanted to touch on it, too. There's one question on the family survey: Are child providers coordinated well with one another? Most families said they agreed. There were more questions about asking about how often they needed specific services, and whether or not they were difficult to obtain.

So what we saw was that services that are really frequently need for instance like audiologists, people felt like it wasn't difficult to obtain but then some of the services that were not needed by as many families, but were kind of hard to obtain. For instance respite care. Not many families indicated they need it but most of the ones who did felt it was difficult to obtain.

And then that kind of fit pretty well with there was a similar question for the providers, the EI providers, about how they felt their ability to help families access these different services, so again the things that I think they feel really comfortable with, like ensuring families feel confident, they're part of the team, and coordinating with other providers, they felt very confident. Some of the things they do less often they felt less confident. Like helping families get services like child care, transportation, respite care or Food Stamps.

Again just kind of speaking to that broadening that service coordination role.

So in Minnesota, as Diane was saying, there are different structures in Minnesota. Part C is under our Department of Education. And so there's a strong education focus understandably. I know that the Department of Education has been working to try to provide some more resources and trainings for service Coordinators so they feel more comfortable with broader services.

Another thing in Minnesota we do to try to address this gap is by referring to a couple other places. So we refer all families to local public health agencies, who are very well equipped to deal with things like referring to family home visiting, helping with insurance, helping with Food Stamps, that kind of thing.

And so that's one way we try to kind of make sure that families are getting that piece of things.

Another way is by referring all families to Hands & Voices, so Hands & Voices calls all families and of course they're good with those D/HH specific services and resources, getting families connected. Just another example of how the SNAPSHOT survey has kind of helped us understand how we're doing in an area where we've been focusing.

>> So I volunteered for the easy part of this presentation, and I'm going to facilitate you all asking these lovely presenters questions.

So feel free to ask questions specifically about the National survey, the piece we did at NCHAM.

[ CART Captioner cannot hear speaker ]

We have a few copies of the full report you can take with you and also an executive summary that goes through those trends that Diane talked through. You can get those on EI SNAPSHOT.org or on the NCHAM website. We have those. Feel free to ask questions in general about EI SNAPSHOT or especially to Linda and Melinda about their application in their states.

Who has a question?

>> We have one question about the question that you asked professionals, whether they felt they had adequate training and I find that's an interesting question because how do you know if you've had adequate training? Do you know what you don't know?

>> Yeah? Okay. That's an excellent point, because that is your self‑perception. But I think the fact that they said: You know what, I think we really need more training, speaks volumes, that they weren't feeling like: I don't want to look bad here, so I'm going to say: No, I got great training. I'm so knowledgeable about that. So that is a perception question.

The other thing I think about that's valuable with these SNAPSHOT methodologies, it allowed us to be able to get data from other sources and triangulate. So when you hear kind of the same response from families that they're also not getting those other partners connected, or getting together with those family support organizations, well, I think you gotta take a look at one of the reasons is the providers aren't feeling like they've got that knowledge. But that's an excellent point there.

>> Okay, who's next?

>> Really, in general, with each state, talking about deaf and hard of hearing and the services regarding Early Intervention, do the states separate out low incidence deafness versus deaf plus? Or are those children lumped together? Or are they divvied out into the separate groups?

With your data, in your states.

>> So in the National data from our survey, what we found, we can separate those out, so we asked families when they completed the survey to talk about other delays their child might have. And I think what we found is about 24%, maybe 22%, around 22 to 24%, had delays beyond just related to speech or language that would be attributed to their deafness.

So they had issues with motor delays or vision delays, or specific cognitive delays, other pieces, so that was about the piece as far as in our survey. I think what we found in states is there are kind of different models of serving those kids and maybe Linda or Melinda could talk about that from their experiences in their states, how the state system works for that referral to Early Intervention, and how they assign providers. Do you want to...

>> So I'll use this one instead. So in Vermont, all children are eligible for Part C, which means that our children are referred and enrolled with the Nine East Network, which is our provider of our parent infant program, so any of the services that a child may need, including OT, PT, speech, is all in collaboration two Nine East Network, so it's all arranged through the organization, and it was the same way before, with the Vermont Center, as well.

>> In Minnesota as well. All children who are deaf or hard of hearing are eligible for Part C. In terms of who's on their team for EI, I think ideally everyone has a D/HH teacher. I'm not sure if that's happening all the time but yeah, it depends. If there are other needs going on, it's just kind of tailored to what the child needs.

The other thing... Oh, so in terms of how we separate them out in the data, that's been kind of an interesting thing. Maybe this is true everywhere, but they have a primary disability label, and so if that label is deaf or hard of hearing, it's easier to look at them across other data systems, whereas it can be trickier to pull them out if they've got other things going on and they have a different primary label.

>> And I'm just going to add to that: In Vermont, any children who are, you know, are deaf with other medical conditions, those ‑‑ we are aware of those, and we do separate them out so that we know what services in addition to a teacher of the deaf need to be included.

>> Does that answer your question?

Okay.

One of the things I'd encourage you to think about, if you want to take a look at how different services may be for children, depending on their degree of hearing loss, consider looking at the survey and collecting some data in your state.

>> Any other questions?

I was going to say: I have a question I can kind of ask and we can answer and that is what were some of the limitations? Lessons learned? One of the things we didn't mention is that on our family survey we had nationwide about a 10% response rate. So I know Linda mentioned her response rate and that brought that up for me. Our population of families that responded were relatively highly educated, and not ‑‑ probably not completely demographically representative of the population we serve.

And so some of the things that we identified that if you were going to go on our website and pull down our survey and use it to survey families, it was way too long. I think that's the feedback we got when we talked to families. Our survey was really long. We wanted to know a lot of information. We wanted to know about the types of services they got, the barriers they faced. We wanted to know about the families ‑‑ it was a really long survey and Diane and I have been kind of looking back and saying what could we have done differently? And started with a short survey and dug deeper with a subgroup of families. We may have got a higher response rate on some of the broad issues we were interested in, because we did get some really great detailed data we can dig deeply into. I think it's really good.

But again, our ‑‑ I think one improvement that could be made to this if people use it is to go through and really carefully think about each question and make it a lot smaller, and I feel like we did that. You would hate to see what it looked like before we made it shorter but I would say that's one limitation of that. I think we did a much better job, the audiologist and provider surveys, our response rates were really high on those. I think it was partly because they were a lot faster to complete.

>> I'm just going to add to that comment which is that when Maine, New Hampshire, and Vermont came together to adapt the survey we shortened it because that's one of our comments is that it was too long, and we also adapted some of the questions, as well.

>> Right. Well, just to add to that, I think the other thing that would be worth taking a look at, though, are the questions, and kind of looking at the Gestalt there, and if you're looking at don't focus groups, like, I think particularly if you want to reach families with a lower literacy level perhaps that aren't going to respond to the survey, look at those, though, and it could be a really useful guide I think for focus groups.

>> Absolutely, I think that could have been another strategy we could have used.

>> You had mentioned that you had had some of the questions being asked by parents to parents. So which ‑‑ what portion of the survey was asked by other parents? And why do you think that that ‑‑ why were those questions chosen?

>> Do you want to go ahead with that?

>> I can. I'm sorry if I misrepresented it. One of the components we used in methodology was in contacting those broader family to family organizations so we contacted the Family Voices and the parent training information centers and Parent to Parent USA, for example, and we had parents call and ask those questions of those groups.

And so, for example, in Utah, Gina [ inaudible ] who is working closely with EHDI and is the Family Voices person, so we had a protocol of 10 questions that were asked, and those families called and asked those questions to them, and so I think there was that opportunity there for the parent who's asking the questions to hear about it and say: Does that reply make sense to me? And is that useful?

The other way we used parents was also to look at the Part C program websites, because we wanted to find out if a parent's saying, where do I go for help with my child's special needs, where do I go for therapy, for example, often those Part C websites come up, but yet can the parent really find information that makes sense to them? Or is the information written for professionals?

And so that's one way that using those parents to really help us get information to find out if it makes sense to families was helpful. Did I forget anything, Sara, on that?

>> SARA DOUTRE: I don't think so. I think again thinking about that if we'd moved ‑‑ originally, SNAPSHOT was supposed to be a 5‑year project. Anyway, we had very little funding and we tried to squeeze a lot into one year and had we gotten to the focus group piece of the original plan, I think we probably could have used those families again in a good way, those families that had been trained enough to know what they were looking for, but still I wouldn't call them professional parents.

>> I'm wondering if, you know, we hope we whetted your appetite a bit on the kinds of information we were seeking. I'm wondering if you all have questions about what's going on in your own state's Early Intervention relationship with EHDI that you'd like to share, that we can get a sense of if these things could be useful to you.

Or what do you see perhaps as the challenges in your state that you'd like to find more about?

>> This was actually the primary focus of our stakeholders meeting. They were trying to figure out, apparently there's a breakdown in communication between the parent, the EI professionals, and trying to figure out, why are these kids getting lost? Or why the referrals are taking so long, you know. So I was like, I need to go to this so I can gather as much... And then me, as a parent, I experience the negative side of Early Intervention, but I'm also a professional, so I knew what I needed to do to go beyond with what I was provided, but thinking as these other parents, who aren't as educated, or who are in rural areas, and who don't get as much access to, you know, technology or whatever, they don't have all those resources.

So with EI, just getting down on a parent's level, frustration, emotion, everything like that, so this was very helpful, so I was trying to take notes so I can kind of help with what we can do in my state to do better, because we found out that we all have something to share, but just getting us all together and having one common goal in mind to share, and also with all the laws with sharing of information, privacy act and things like that, that's also a hindrance and we were trying to figure out ways to go not really bypass it but just to be able to access all families.

Because if I didn't have my background ‑‑ I'm a teacher. I was a teacher first before I became a parent of a child with a hearing loss ‑‑ if I didn't have that background first, I probably would have just like been given what they gave me. When my son, the experience I had was not very positive, I would have just given up and just been like, I'm done, but I had some support and I'm that type of person that when it comes to my child, I'm going to do whatever it takes. If I have to hunt you down, call you 5,000 times, email you, that's what I'm gonna do. So this is my first time at the EHDI Conference and I'm not very vocal.

So I want to take what I'm learning now and learn to be an advocate not just for me and my son but for other people so this has actually been very helpful, so all the data, although I'm not the best person at math but I can read a survey. So I can probably help with those, so this is actually good information. And I was like: Yes, this is what I need to do for my brain. It's like in overload. I'm trying to figure out when I leave here, what do I need to do to get started? I'm on spring break trying to enjoy it, but also I want to take in as much, and be a resource to other parents and teachers and educators who aren't exposed to the deaf and hard of hearing world.

Because I was only exposed because of my son. Like, I'm a special educator but I've never dealt with deaf or hard of hearing children till my son was born three years ago. I'm starting over and I'm like a sponge trying to soak in all I can and that way, I can share with other people.

>> Where do you live?

>> I'm from Arkansas.

>> Okay, good, thanks. You just did a great job emphasizing, too, how you need to have families at the table to be working on developing your survey questions, you know, because sometimes you write something up and a parent's like: I don't know what you're asking me for that, as well as interpreting.

It's like with some of our questions you'd look and you'd say oh 75% of families said that they were able to get everything they needed. Well, what about 25% that couldn't? That's a significant amount.

>> We have one more question over here.

>> Actually, a comment real quick. As you mentioned, in states they have Hands & Voices, Family Voices, the state parent training and information center and hopefully as efforts go forward, we are kind of like in our state how we're set up that we all are working together very closely with EHDI but we get a lot of questions from professionals and why would I refer to you versus you? And hopefully that they're just referring to any parent organization to start off with but to add that in our state, we do have the Parent Consultants that have children that are deaf, and then they actually make sure that we're connected with them from Family Voices and the Utah parent center to look at those pieces beyond Early Intervention to make sure that in the education system, that they're getting their needs met either through an IEP or 504, and with Family Voices, really looking at the education piece, or all of this as we call them beautifully complex conditions that having ‑‑ or being deaf is one of them, and we can help find those funding sources, health insurance and such.

So hopefully, that comprehensive system of also parent support.

>> And I think that's a great point, that for all of these challenges we've identified, the great thing is there are starting to be models, right, to look at, as we start to do that better, so we just want to close with: If you have any questions or comments, please feel free to contact any of us.

But also, tomorrow, we do have several other presentations where we will be digging deeper into the data from SNAPSHOT. Tomorrow at 11:30 about the referral process and how that differs across states. At 3:45 we'll be going in detail into the audiologist survey results, and then at 4:20, talking about that service coordination piece that we brought up. How do we ensure that it's comprehensive and covers all of the needs of the families?

So thank you very much for coming, and please let us know if we can help you apply these things in your state.

[ Applause ]

[ End of session ]

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