

## **MCHB/ NHS August 30, 2006 Webcast**

### **Why EHDI Programs Need to Include Family Support**

PATTI MARTIN: The first person I would like to introduce is Kathleen Watts. She's been with the National Center for Hearing Assessment and Management for the last six years. She has a master's degree in health education and promotion and is located at the university. Utah State University and is responsible for putting this all together as well as presenting so we appreciate that. Irene Forsman has been at Maternal and Child Health Bureau for more than two decades. That happens to all of us sooner or later. She's always worked in positions that focus on children who have special healthcare needs and their families. Irene has been responsible for HRSA and MCHB newborn hearing screening and intervention program since we've had legislation for that. The program is operational now between the U.S. and two Pacific Rim territories and Puerto Rico. Our final presenter is Carla Wood Jackson. Dr. Jackson is an assistant professor in communicative disorders at Florida State University. She served as director of children and family programs at the institute for persons who are hard of hearing or deaf. Since 1994 she's provided and supervised services to children who are hard of hearing or deaf in birth to three networks and general education settings. Her research includes early intervention. Deafness and she's presented and written and published in this area for quite some time. So we're really glad to have her here with us today. That said, I will have us move on then.

CARLA WOOD JACKSON: This is Carla. I think we move right into my section if I'm not mistaken. It is my pleasure to share some ongoing research that began at the University

of Kansas in partnership with Anne turn bull and I've had the pleasure of being part of this research where wonderful families have steered the project and shared their experiences and insights in an effort to improve family-centered services. It really -- the initiative started out of our desire here we have this great opportunity to work with families so much earlier after newborn hearing screening and over the years we've really recognized the shift in paradigm from a very child-centered model to a more family-centered paradigm and our focus has needed to shift to the entire family as opposed to looking maybe as narrowly as we used to at our own little disciplines. So really, this research, I'm just kind of wanting to share a snapshot of several projects that are ongoing in looking at family support and family quality of life after early identification of deafness.

The next slide is a wonderful quote about the importance of families. It's a little delayed but on the next slide you see a quote about the value of families and we all recognize the important role that families play in nourishing young children. And really need to capitalize on in our intervention support. We have a lot of research that suggests the more involved families are and the more we can enable that primary caregiver to integrate supports and services, the better the outcomes are for the child. And so with that in mind, we really want to recognize the centrality of the family in the child's life and really structure our early intervention so that it really bolsters the family's ability to thrive, not just survive after early identification.

The next slide gives you a definition kind of puts us all on the same page in terms of what we're thinking about when we talk about family well-being or family quality of life. We're

really referring to the overall degree that families needs are met so the extent to which they enjoy their time together, the extent to which they're able to nourish the child and the extent to which they're able to do things that are important to them. Again, this research goes back a couple years at the beach center at the University of Kansas but these are really the multiple areas that we're thinking of when we're researching and studying general family quality of life.

On the next slide you see a very dynamic model of family quality of life. Again, so much of the child's early development is really influenced by family well-being that it's important we get a better grasp of those critical cogs or influencing factors that affect family's ability to nourish a child. And that dynamic sense of family well-being, this visual, is pretty complicated. But it really, I think, portrays how interconnected lots of different aspects of life are. Family interaction, parenting, family resources, health and safety and having resources to meet physical well-being can be a critical piece in daily life and this visual kind of makes you realize how one area impacts other areas and how one individual member of a family can impact all the family unit. There are some very well-known analogies to a mobile that as one piece is affected, the whole structure can get out of sync and pieces then are at risk for falling. Again, if we're bolstering the family to meet those needs we need to have a better picture of the whole family system. On the next slide.

PATTI MARTIN: Could I interrupt you for a minute? I think a couple of people do not have their phone on mute because we are able to hear you all in the background. If everybody would—If you would double-check that at this point that would be good.

CARLA WOOD JACKSON: Thank you, Patti.

PATTI MARTIN: Is it possible for the sites to move quicker to catch up with her?

CADE MODERATOR: The slides are moving in realtime. What you need to do is you need to set the slide delay on the upper right-hand side of your interface if you're listening on the telephone. Set the slide delete to zero. I've sent a couple of marquees out. There is a 20 second delay for the processing of real player code. If you set it to zero they'll be in real times.

PATTI MARTIN: Sorry to interrupt.

CARLA WOOD JACKSON: That's very helpful. Mine was delayed as well. I was feeling like I was stalling waiting for the next one to come up. Very good.

UNIDENTIFIED SPEAKER: Also to mute is it star 6 to mute, is that correct?

CARLA WOOD JACKSON: Thank you.

CARLA WOOD JACKSON: Okay. As we think about that dynamic view of family life, we know that families are going to be under stress after early identification. There is no way around it. We all face crisis events and there are going to be challenges. No doubt

obstacles will be there but what we want to try to capture is that balancing act that you see maybe in this visual of trying to balance the risk with the resilience. So really bolstering the family resilience so that challenges don't put them in a state of crisis. And they're able to continue to be involved in intervention, take an active role, integrate those early strategies and therapies. We don't want families to be so overburdened by the risks that they're immobilized in the process. We want to maximize outcomes.

The next slide, then, again is kind of a visual to help us remember as we shift from that very child-oriented paradigm to a more family-focused paradigm that we're not completely centered on the child. As this picture shows, we recognize that that child is being supported through the primary caregivers and so if ultimately our desire, our child outcomes sometimes the way to get there is through the family support there. Supporting the person, supporting the child, right? Supporting that unit. So all too often I think we try to handle each of the child event crisis or child-related pieces and we forget that underlying foundation or soil that's there. So not to downplay the need for child oriented outcomes but again to kind of emphasize the strong importance of those underlying family supports.

The next slide, when we set out to look, then, at both the needs and general well-being of families after early identification we really relied on some earlier research. There have been three large national field tests that had asked families with members with disabilities to really identify areas that were important to their family function or family well-being. Again, because we want to capture those critical pieces, right, those influencing factors.

And those items that they identified over the three different field tests kind of clustered in these different domains. So you see parenting, family interaction, emotional well-being, physical well-being, financial well-being and support for special needs or service-related. Special services. And there are multiple items in each of these domains that we used in our research, then, the try to capture the overall family quality of life and identify areas where we might need additional family support.

If you'll look at the next slide, I'm going to go through the next five or six very quickly because they really just give you a sample of what each of those areas involve. The first one there is the parenting area, referring to, again, just general activities that adult family members do to help children grow and develop. Some of the items on our different research protocols ask families about their satisfaction and how things are going, how deafness impacts these areas and how satisfied they are with each area. These are just some sample items from the surveys. The next area of family life that has been included in the research data is family interaction.

The next slide here focusing on communication and general relationships among family members. A lot of the items you see in the samples there relate to communication but also some social/emotional interactions between extended family members and others. On the next slide emotional well-being again captures the state or feeling of crisis and stress. A lot of families emphasize the importance of having enough time to pursue their own interests. Again, this is kind of the affective part and pulls social interactions in some of the sample items having social supports in place. The next area, physical, material well-being,

do family have enough physical resources. Transportation, access to medical care, feeling safe that their physical needs are met. And the last area support for special needs looked at areas related to special services. Were they able to access the agencies that provided the support they needed? What were their relationships like? Did they have good partnerships? Were they able to access benefits as they needed to? And receive the supports they needed for different settings?

So in the first study that I would like to just give an overview on, we compiled a survey based on those areas with multiple items in each area asking families about the impact of deafness on those areas and how satisfied they were with how things were going. We distributed that survey nationally through part C networks, private parent/infant programs, state coordinators, various venues trying to capture a very diverse sample and we had 207 of the packets were returned and of those children ranged from birth to 72 months with a mean of 44 months. The average age of identification in the respondents was nine months. There were 36 different dates represented in the responses and fortunately for us about half were children who use hearing aids, half use cochlear implants. 95 hearing aids, 23 used both an implant and hearing aid. We really wanted representational snapshot and we did get a very diverse group and kind of clustered. A third had low income backgrounds, a third middle and a third high income. Really slightly more skewed in the middle range but not bad. We were not -- in the return surveys they were not distributed in terms of ethnic distribution in a way we would have liked. We had a high percentage of white Caucasian respondents and that's difficult with a survey to capture

really diverse sample but just so you kind of know the voices that you're hearing in these responses.

The next slide and I would like to just hit highlights of areas where families ranked high satisfaction and lower satisfaction. And again, there were -- this is an eight-page survey. If we collapse those items based on the area of family life, we see the higher numbers are where they indicated higher satisfaction and that first column you see the area family life from health, financial, physical well-being down to special support services. You see the average of the mean rating of satisfaction, again the higher the number, the higher the satisfaction. Then next to it you see the standard deviation. So just in visually looking at the numbers you can see the one that stands out slightly is that emotional well-being area. And that's pretty consistent as we move through the next slides that families are identifying that repeatedly as an area where they feel less satisfied or desire additional support. If you look at the next slide, if we don't collapse them by area and look at individual items that they responded to, again with their mean satisfaction and standard deviation listed there, as these are the top five items where they were the least satisfied. And these individual ones were time to pursue interests. Having ways to manage or relieve stress. Accessing support from local agencies, accessing desired support from local agencies, feeling that their child was included and could access community activities and resources, and then financial well-being having the financial resources to meet their needs. So those were the top areas where families reported the least satisfaction.

The next slide, if we flip that, then, and look at their ratings of the degree of impact that deafness had on each of those areas or items, it's very similar in that the areas where they perceived the lowest satisfaction are also the areas where they perceived the highest degree of effective deafness or impact on their daily life. Again, if we collapse all those items by their domain or their area, the one where they perceive the highest impact is on the items related to emotional well-being. And if you look at the next slide, by individual item the items that they reported the highest impact of deafness on family life, the top one there was their time demands. They felt again more stretched to make all those appointments and meet all those individual needs. So time to do individual needs and interest was the top impact. Support for the special needs of all the children in the family was high. Time for needs of all children. Their perception of stress. And being -- having the information they needed to make decisions. These were all ranked among the highest areas. I think those are -- it's a snapshot of some complex data but I think they're indicators to us of where families desire additional family support.

On the next slide I have a rather complicated visual that you can't blink at but this domain of emotional well-being is kind of elusive in that there are a lot of different items in that area that they are rating and when we look at what might influence, then, their low satisfaction in that area, of course stress and time and the perception of being able to meet everyone's needs, having friends or social supports kept coming up again and again both in the survey and also in our interviews, our qualitative studies with families, having that social network in place, being able to relate with other families who were going through the same thing appeared to be a real critical cog in family's responses. Looking at

the next slide, this is a visual and taking a little turn here to a follow-up study. As we really considered these responses, again, our motivation was to see families as involved in early intervention and as invested as we could and we wanted to maximize their family quality of life so they would be able to be involved in intervention. We have a lot of nice emerging data that shows the more involved families are, the better the outcomes are. This is to remind us we aren't just helping families survive but we really want them to thrive because it leads to improve family and child outcomes and we have some nice data to support that. In a follow-up, we sent a survey out to all of these families who had initially participated and asked them this time to rate what is important to their involvement, how are they involved and what influences their involvement in intervention? What things facilitated and what things seemed to impede their ability to be involved in intervention?

So as you look at the next slide, again families rated -- here you have some of the top areas that they were involved. And I've just pulled those mean ratings to see the ones that are closer to five are happening more frequently as they indicate how frequently they participate in various aspects. And if I just skim that top listing, you see there they report being very involved in decision making and in determining the goals for their child in implementing use of a sensory device. They're involved in selecting service providers. They feel they're involved in intervention by serving the role as an informant informing providers about their child. They take an active involvement in integrating strategies and everyday activities and asking questions or seeking information. These are the top areas where families reported the most frequent involvement in early intervention.

And if you look at the next slide, these trickle down in terms of the frequency of how often they participate or how consistently they report being involved. One of the lower items in frequency is socializing with other parents who have children who are deaf or hard of hearing and it really surprised me at the time of the survey that 20% of the parents reported -- indicated they had never, never socialized with other parents of children who are deaf and hard of hearing. This is a tough obstacle of us. As service providers we've moved more into homes and there are so many positive outcomes of that in doing the intervention in the home and working in the home but at the same time some of our birth to three families are feeling more and more isolated because they aren't connecting with other families of children who are deaf and hard of hearing. This was somewhat of a surprise to us in the data that it was reflected that strongly.

The next slide when we split the data by age group to see if there were any differences by age of the child and the frequency or involvement of the parents, we see some significant changes by age. So again these are the means in the higher the number, the more frequently that involvement is occurring. And for the children who are birth to three, you see a reported very high frequency of 4.09 and 4.0 in participating in therapy and sessions and a low frequency in social gathering and socializing with other parents. As the child hits pre-school from 36 to 60 months old you see the parent involvement in sessions in terms of frequency decrease and you see more involvement with other kids who are deaf and hard of hearing or more opportunities to interact. It doesn't change really significantly into school age by numbers but not statistically significant. Some of that is, I think, what common sense we observe but the data certainly reflects that and I guess to us it was a

little red flag to see how low the social networks in terms of frequency were occurring for birth to 3-year-olds.

If you'll look at the next slide you see some -- I apologize this is so busy. This is a rather busy slide. But as parents in the follow-up survey indicated aspects that facilitated their involvement and then other items that really impeded their involvement in early intervention. You see some interesting, I think, overlap between how frequently these items -- some are very strong themes and others occur less frequently. Having the skills needed to integrate strategies was one of the highest things where family felt if they were capable of doing it, they would do it. If they didn't feel comfortable or competent in integrating a strategy it wasn't going to happen, right? And so a lot of our efforts in parent training are critical in how much follow through parents or caregivers are able to give. The attitude of the professional was also rated incredibly high. 85% in terms of how important that was to families involvement in an early intervention. Access to information, access to the service providers, again, in many networks we find the services take place at a time caregivers can't be around or aren't involved. Support of extended family members. Financial influences come up with both columns. This is sort of a make or break. If you have the financial means, obviously it's helpful in facilitating your involvement and availability for the services.

And yet on the other column on the other hand if you are not having the financial resources to make ends meet you are -- it is going to strongly impede your involvement in intervention. Sort of a 50/50 split there in terms of how families rated it. It seemed to be

either really high or really low. Location of services was ranked as a strong influencing factor. Access to mentors and cultural sensitivity of service providers. And on the flip side those items that heavily influenced their involvement negatively were their time demands, their stress level, the need to balance time for all family members, lack of cultural sensitivity. Financial influences and location of services. Again these are probably -- I'm guessing they're probably things that you perceive in your own programs as influencing factors but sometimes the data is very helpful to build some responsiveness among programs.

So on the following slide I've really just shared some written comments on the surveys from family members and we were quite moved by the responses of the families. Some wrote pages of information and that led to a follow-up study where we've been doing phone interviews with families. The following quotes help capture some of the areas that they felt strongly about needing additional family support, as well as just capturing the overall impact of deafness on family life in a time where we really haven't had a lot of opportunity to observe in the past because our age of identification has shifted so dramatically. In helping us understand the impact across multiple areas of family life.

The next slide again is a quote on the need for informational support. You would think we saw very specific trends and specific information families couldn't access and it was really varied. We had probably an equal number of families saying we couldn't get information about sign language or classes for sign. An equal half saying we really wanted information about oral options and no one around us could give us any. Families are equally frustrated

regardless of their desires for specific information in having access to all of the options and support.

The next slide again captures the family's perception of stress and times and as you can I'm sure imagine how that impacts their involvement and their buy-in into early intervention. The next slide addresses the parent support, emotional/social networks. I can't tell you how frequently this came up in terms of families really emphasizing either how much they value connecting with other families or how isolated they feel in not being able to connect with other families. Next slide again on emotional well-being, some parents said it better than I possibly could. I felt the quote probably captured it well. And finally, the next slide, this quote, again, just kind of captures the rather dynamic aspect in that we know deafness effects multiple domains of family life and certainly it is not just one piece that we could intervene in terms of communication but looking at that total affect on time, ability to interact and communicate and the emotional demands there just speaks to multiple areas. This last quote is not from a family member but I think it is very inspiring. It states families have shown remarkable resiliency or flexible adjustments. As I read this, it just reminds me of how critical it is, again, to cultivate family strengths and help them thrive in nourishing a young child's development and I guess we -- it's so easy to lose sight of that value of family support and focus very specifically in our own domain and discipline areas and provide child-oriented supports.

So the final slide there I just listed out some very broad suggestions for programs as you start to evaluate existing family supports and resources in your programs and networks

and then areas where additional family support is desired. Part of the process is just really identifying what barriers exist in specific communities. It's very different among various programs. But setting action steps and plans out to really address those hurdles. I think one of the critical cogs in a lot of networks I've visited with has been identifying key personnel who can help pull the pieces together, who can serve as family resource specialists or putting networks in place. I'll be quiet. I'll let someone else.

PATTI MARTIN: Carla, thank you so much. That was great. It addresses so many of the issues that all of us are concerned about. That's what we'll move on to Irene. I will just let you take it from there.

IRENE FORSMAN: I will do that. May I have the first slide, please? That's not it. Nope. No, these are not my slides. Are they yours, Kathleen?

KATHLEEN WATTS: Yes, these are mine.

IRENE FORSMAN: Maybe you better talk.

KATHLEEN WATTS: Okay. If you could go back one slide, can you do that for me? Okay. I think everyone who is probably on the call knows that we're hosting a meeting in September investing in family support. And that will be the 25th and the 26th of September. If you go to the next slide, about a year ago a group of people got together and we were talking about family support and what we would do if we were to have a

meeting around the idea of family support. And one of the things that we thought was that we need to look at family support from a holistic approach, not just from one thing or another. And so a lot of states have developed information that they can provide to families but that's only a piece of what family support is. And so looking at the whole thing, some of the other things we came up with are parent-to-parent support such as family voices or hands and voices which provide direct support from another parent who has been through a similar situation. And had to go through some of the decision making and things that the professionals working with the family have most often not had to go through.

There are also the adults who are deaf or hard of hearing who can be role models or mentors for the family to help them learn what it is like to have a child or a family member who is deaf or hard of hearing. There are those professionals who provide family support. Oftentimes provided through early intervention services, although that's not the only way that they can come into contact with the family. So there are those professional people who come in and help the family learn about what it is like to have a child who is deaf or has a hearing loss. And then family support also comes through the existing communities for that family. It may be a spiritual community, it may be neighbors or friends, the extended family. But support can come through the communities that already existed for the family prior to the diagnosis of having a child with a hearing loss. So we need to look at all these different aspects to family support to have a comprehensive program. Could I have the next slide, please? The goals for the meeting are for participants to develop an understanding that family support is multi-dimensional and to look at their programs and

see what they already have. They may have more than they are really aware of. We want them to prioritize their goals. Some states have developed a lot of family support and others are just starting to do that. So definitely the goals will not be the same from state to state and we want the state to look at what the resources are and go from there in terms of developing their family support program. And we want them to come out with a written action plan that will develop or expand the family support part of their EHDI programs. So starting from where they are and expanding, or starting, you know, even if they seem like - or feel like they're at ground zero developing a program that programs is families whose children have been identified with hearing loss with support as they go through the process. So those are the goals for the workshop.

If I could have the next slide. And the meeting is going to be the 25th and 26th of September. I hope that people have registered. Fortunately we don't really have too much more room but if we do have a state that decides they can send people and has not at this point registered we'll definitely give you consideration because we would love to work with all states in terms of developing this. So I think it's Irene's turn now.

PATTI MARTIN: Irene?

IRENE FORSMAN: I'm here.

PATTI MARTIN: Okay. Looks like your slides are ready to go.

IRENE FORSMAN: I'm going to be echoing much of what Kathleen and Carla said and I'm going to talk a little bit about what the bureau is doing relative to family-centered care. We have had a major initiative, really, on family-centered care since the early 1980s, meaning a person and dollars put into promoting family-centered care. I hope I have to say as a former clinician, at least, that we all espoused family-centered care forever. We've done a number of things. I could really, if I just wanted to talk about the things that the bureau has done, I could go on forever. So I won't do that. A few years ago, three years to be precise, we pulled out our thoughts, written thoughts, documents, about family-centered care and got a group of families and professionals together to sort of re-examine and update. And that's what I'm going to give you today. Before I do that, I want to thank my colleague, Diana, these are her slides. So we have a new definition of family-centered care. It assures the health and well-being of children and families through respectful family/professional partnerships. I don't want to read this whole thing. Family-centered care is the standard practice now and results in high quality services. Foundation of family-centered care is really the relationship between -- the partnership between families and professionals. It's no longer family comes and asks and says we have a problem and the professional says we'll fix it. It's a real partnership.

May I have the next slide, please? Trust is acknowledged as fundamental. Communication and information sharing are open and objective and participants make decisions together. There is willingness to negotiate. Based on the partnership of family-centered care acknowledges the family is the constant in the child's life. This is sort of what Carla said in a different way. We're talking about infants and young children with hearing loss. And it's

the family, not the professional that does most of the work in helping the child. So we build on family strength and support the child in learning. Honors cultural diversity and family traditions and all of the research that I could find, at least, with children for special healthcare needs generally and to infants and young children with hearing loss specifically, sort of supports this. Also, recognize the importance of community-based services and relative to this, what Kathleen said about family to family support systems from state to state is much a function, I think, of the lack of community-based services in some areas.

From the survey conducted in early 2006, we know that 65 -- only 65% of states report they have a family to family support system in place and only 45% of families nationally are linked. The range across the states is from 0 to 100%. So the data support exactly what Kathleen said. And this, despite the fact that family-to-family support has been one of the hallmarks of the program since it began six years ago. Now, next I want to say a little bit about family and professional partnerships and cultural competence because I have found they really cannot be separated. Why do we go together? We've had a national survey of children with special healthcare needs done a few years ago. This was a telephone survey. It was random telephone dial. And we discovered that only 57% of families who had a child with special healthcare need reported that they participated in decision making and were satisfied with the services they received. And a little more than half of disadvantaged families report receiving care lacking at least one component of family-centered care. 47% Hispanic and 43% of non-Hispanic black families. I will also say that there are these who have cross cutting values and there are reporting requirements

that we adhere to across the bureau for both family-centered care and cultural competence. For those of you who do fill out those forms, you know that.

Skip now to the levels of family-centered care. And we see that family-centered care should exist at every level. It's policy, program and at the practice level. And the ways to achieve family-centered care, we feel, are families as advocates, families as staff, families of faculty and families as users of healthcare. I know many of the states have hired on either in the special healthcare needs program or specifically relative to the hearing screening program, a parent as a staff person or as a consultant to help them in expanding their family-to-family support system and finally we have done a great deal -- we promote as a bureau family-centered care. Promote the inclusion of families as decision makers. We have also assisted in the training of family leaders advocating for community assistance on behalf of others' rights or honor. We're supporting at the moment family voices and family-to-family health information centers. We've supported other family-driven grassroots organizations in the past. The components that are essential, listening, open to new opportunities, establishing clear expectations, roles and responsibilities, acknowledging mutual respect and commitment. That's my remarks.

CADE MODERATOR: Terrific. We're actually open for questions and answers now if the moderator can step back in. You can submit questions by using the messaging interface in your lower right-hand side of your screen and you can select question for speaker and then you can actually in that message signify which person you want to answer the question and we'll relay that on. At this time I have several questions that have come in

from the audience. The first one comes in from Penny Hatcher. It says what are the dates of the survey and she was referring to the first speaker. So Carla, if you could unmute your phone and take a chance at answering that question. She wants to know what are the dates of the survey?

PATTI MARTIN: Are you there?

CADE MODERATOR: Hello, Carla.

CARLA WOOD JACKSON: I'm sorry, it was on mute. Can you hear me now?

CADE MODERATOR: Yes.

CARLA WOOD JACKSON: The initial survey was in 2004-2005 and the following was done in the spring. So again it's been an ongoing survey but it began in the fall of 2004 and went to the spring of 2005. That first satisfaction and impact rating, that survey and those results are in press now so it should be coming out in print very soon and then the follow-up survey has just been submitted so it's not in print yet.

CADE MODERATOR: We have another question from Penny Hatcher which has to do with the results. What is the rating scale for the responses?

CADE CARLA WOOD JACKSON: That's a one to five rating scale.

CADE MODERATOR: Great. Next question is, are there support groups for the families that have children who are D/HH?

CARLA WOOD JACKSON: Is it what other support.

CADE MODERATOR: Are there support groups for families that have children who are I imagine it's deaf or hard of hearing?

CARLA WOOD JACKSON: I'm going to -- they're looking for are there supports?

CADE MODERATOR: I think they're looking for, are there support groups, do they exist for the family?

CARLA WOOD JACKSON: I can speak to at least our participants in that. Some were in states which there were active support groups and a lot of their written comments reiterated the value of the interactions they had with other parents who had shared some thoughts. Really those groups vary from state to state. Some had active groups, others had guide by your side.

CADE MODERATOR: The next question is concerning this same survey. They're asking what is the ethnic population involved in this research?

CARLA WOOD JACKSON: Sure. The first group, the 210 participants of those respondents were white Caucasian, 6% Hispanic, 4% Asia. 2% African-American, 1% American Indian and 1% checked other.

CADE MODERATOR: Okay. This right here I'm not sure when this question came in. They didn't specify speaker so it may be open. It says when a child is identified as hearing impaired how is this diagnosis communicated if a family speaks English as a second language?

CARLA WOOD JACKSON: I'm not sure if that's directed to me but I'll be happy to answer that it varies by state program again. Some programs such as Colorado, for one, have a very strong thread of bilingual support so the networks themselves identify kind of a support track for families who are bilingual and then the children are referred specifically to intervention and that can either work through an interpreter or have some training in working with populations who are –

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IRENE FORSMAN: This is Irene if I can add to that, the answer to that question. I think this is another place where it sort of varies widely. A group of families in a focus group with Terry Davis. Actually the families were from New Mexico, reported that that communications were very poor and I think that that happens more than we would like it to happen. It's not always so good in English, either, I might add.

CADE MODERATOR: The next question comes from Donna in Tennessee. She is asking if there will be help in developing good needs assessments.

KATHLEEN WATTS: Is she referring to at the -- if she's referring to at the family support meeting, we can provide some help with that. And if that's where they need to start, that would certainly be one of their goals and we'd work with them on it.

CADE MODERATOR: And the next question is for Kathleen. Who are the presenters for the September meeting?

KATHLEEN WATTS: We have a long list of presenters so if -- probably the easiest way to answer that question would be for them to check later on [infanthearing.org](http://infanthearing.org) and there will be an agenda up which -- later today which will have the presenters' names.

CADE MODERATOR: The next question is for Irene. She's wondering if she'll be presenting at the -- Don is wondering if you'll be presenting at the Salt Lake City event.

IRENE FORSMAN: I don't -- I'm not on the agenda, am I, Kathleen?

KATHLEEN WATTS: No, you're not.

CADE MODERATOR: Next question is for Carla. It says in what ways do you think the variables such as not enough time for personal pursuits, stress management etc. differ for

families of children with hearing loss and families of children without hearing loss? Is there a difference in intensity or is there a qualitative difference?

CARLA WOOD JACKSON: That's a really interesting question. As we looked at the surveys, it was -- to us it was they also ranked the impact of deafness as particularly high on the same items. It made us believe they were more correlated than being just random life events that were responsible for that additional stress or perception of time demands. In the qualitative follow-ups that we've done with families, it has -- that feeling of trying to meet all of the appointments and get the kids where they need to be at the same time integrating therapies and in some ways we've created stress by really emphasizing the frequency that everything has to be done. You know, there are times when families can implement these across the day every day and other times when -- I think one mom coined it so well. My child has many therapists but no mother in terms of roles. She felt like she had become so much of a teacher that there wasn't time for Jello, down time. So as an interventionist it tells us that we need to proceed very cautiously and be responsive to families when they start sending the red flags and cues out. Stress and time and those vary differently for families of children with special needs than typical.

CADE MODERATOR: The next question comes in from Barbara. Do you know research that has documented families wanting professional with background in hearing loss as initial part C contacts?

CARLA WOOD JACKSON: I can think of just a couple studies where that was one of the items on a needs assessment survey. I think American speech and language hearing association has a needs assessment report in which parents and service providers both, I think, indicated how available that specialty area was in their community. But I really can't think of a study that states it as explicitly as what you're looking for.

CADE MODERATOR: The next question it looks like is there research about pairing parent's willingness to participate in parent-to-parent support programs and -- this is a three-part question. The first part is there research about parent willingness to participate in parent-to-parent support resources?

CARLA WOOD JACKSON: I think the outcomes from our surveys indicated parents were not only willing but expressed a strong desire to have those parent support -- parent-to-parent networks available. I think the timing of it really varied for parents. Some said they wanted those supports right after identification right upfront whereas other parents seemed to feel so overwhelmed by everything right up front that they couldn't -- they just wanted to be left alone for a little while and then, you know, there was a turning point where they wanted all the information they could get. But the timing of it in terms of their willingness seemed to vary. When they would really want those connections.

CADE MODERATOR: The follow-up to that question is do parents need to be trained to speak to other parents and is there any suggestions for training if this is required?

CARLA WOOD JACKSON: I hate to keep responding to all these. Everybody can chime in. I think that would be a great question for guide by your side. I'm not as experienced with that program but I know that in implementing it they've gained a lot of insight into training parents to be guides for other parents and I would love to hear some of their experiences because I think that's going to tell us a lot about lessons they've learned along the way.

CADE MODERATOR: Are there additional resources on the web for the hearing impaired? If yes, what are some of the suggestions of the professional? Anyone out there got any recommendations for great websites for the hearing impaired?

KATHLEEN WATTS: Well, there are the standard ones for -- there is infant hearing.com. Baby hearing.org, bell has a website. There are quite a few out there.

IRENE FORSMAN: Are they all linked to infant hearing.org?

KATHLEEN WATTS: Yes, the majority of them are linked to infant hearing.org. If you go there you should be able to find the other websites.

CADE MODERATOR: Great. Now that Kathleen is on the line we have a question regarding the meeting in September and Debra is questioning whether they will be given information on how to develop a family support program.

KATHLEEN WATTS: Yes, they will.

CADE MODERATOR: Great. I have another question here this one is quite long so I'll read it off. This is Theresa in Tennessee. I've been surprised that families are still feeling they do not receive support for their children in communication mode. I had the same problem 15 years ago with my daughter. Why do you think this is still a major problem between professionals and parents? Do professionals not realize that parent stress is intensified when support of the parents' choice is lacking?

CARLA WOOD JACKSON: Theresa, this is Carla Jackson. I really sympathize. Truly, these same arguments and these same divisions still exist. I would like to think that what I call communication neutral in putting a heavy value on any one particular modality but presenting all options and being more communication neutral. It's not necessarily the reality yet. I think there are still such strong feelings of bias across different professionals that parents are still feeling like they get a very jaded amount of information.

IRENE FORSMAN: If I can add on to what Carla said. What she said is absolutely true. There are parts of the country where all options are not available. And it's -- I am not happy about it but I know that parents may not be told about all options because they don't exist in their area.

CADE MODERATOR: Great. Anyone that is speaking in the background can mute their phone would be beautiful. The next question comes from Donna. The question is, is there any data on the percentage of deaf or hard of hearing that have additional disabilities?

IRENE FORSMAN: Would you repeat that question, Nate? There was somebody babbling in the background.

CADE MODERATOR: Right. The question again is, is there any data on the percentage of deaf or hard of hearing people who have additional disabilities?

IRENE FORSMAN: There are data and I think it's -- I don't want to give you a number but ask that person to email me at I Forsman at HRSA.gov.

CADE MODERATOR: The next question is for Carla. From your surveys would you say the families want content to assist them in a decision-making or do they want information about the process of decision making, IE, decision making strategies? Actually this says thanks, Nanette. She must be using someone else's computer.

CARLA WOOD JACKSON: In the qualitative follow-up parents were very clear that they valued the participatory decision making role and they wanted that strong voice but they felt overwhelmed with information they needed to make an informed decision so I think in those aspects where they rated that as a really high area for desired support, in most of the follow-ups they indicated it is very content information geared that was causing that.

CADE MODERATOR: That's all the questions we have at this time.

CARLA WOOD JACKSON: I could go back for a second, one of the questions related to a needs survey or needs analysis for states and that is something that we're really motivated right now to conduct kind of a pre and post. It may be a nice opportunity if there was a statewide program that wanted needs assessment data, it would probably serve both of our purposes. We would be willing to do the data and the research crunching to distribute the surveys and do a needs assessment and give the data back to you but we want to do a follow-up after you've implemented some type of support rather it's hands and voices or guide by your side and look at a different time point and see if that has changed dramatically. If a statewide program is interested in partnering I would appreciate an email.

KATHLEEN WATTS: Carla, is your email address on your first slide?

CARLA WOOD JACKSON: It is. Thanks for letting me get my little plug in.

CADE MODERATOR: Next question, it says are there levels of services provided to the families in this research?

CARLA WOOD JACKSON: Were there levels of services provided to families in this research?

From the survey research, the families were asked to really identify what types of supports they were getting and how frequently and so that's a whole other several slides on each service that they received and how frequently they received it. I can just -- actually, I would be happy to email those to you if you're interested. General ideas family-support wise 75% were enrolled in a parent support group or some type of parent-to-parent network. 28% received some type of financial assistance. 15% reported a transportation support. 3.4 received some type of respite and 8% received other. Reported other family supports in place. As far as child supports I'd be happy to outline them for you in some attachments.

CARLA WOOD JACKSON: Thank you.

CADE MODERATOR: The next question comes from Jan. She was questioning whether the slides will be available for download and we won't actually be posting the original Power Point slides but we'll be posting a PDF with the archive that people can download. The archive will be posted in about four business days.

IRENE FORSMAN: I'll get it on Thursday.

CADE MODERATOR: Next question comes from Jan. Was there a need indicated by families to meet deaf or hard of hearing adults?

CARLA WOOD JACKSON: You know, unfortunately it's probably the way we asked the question in terms of our survey we didn't get that specific data. We had a high rating for

the desire to connect with other parents of children who are deaf and hard of hearing but we didn't ask them about adult deaf mentors. That is an oversight on our part. Where the qualitative interviews we've had very few so far that have either had access or have participated in a deaf mentor program. So we really don't have data to offer in that area.

IRENE FORSMAN: The Colorado hands and voices people probably do have some information.

CADE MODERATOR: That's it for our questions at this time.

IRENE FORSMAN: Okay. Thank you, Nate.

PATTI MARTIN: Thank you, everyone for being on. I hope you gathered some information and I'll be sending out links so that you can get the webcast information at a later date.

Thanks. Bye-bye.