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Family Support Organization Telephone Protocol

The following will be recorded: State, Organization name, Caller name, Date, Start Time and End Time

Call and ask to speak to someone who can answer questions about resources for parents.

When they answer:

Introduction: *Hello, my name is (caller name), and I am a parent consulting with the National Center for Hearing Assessment and Management at Utah State University as part of a research study. I am contacting you today as part of this study to ask you about the resources and information you share with families who have concerns about their child's hearing or who are in need of assistance. This should take between 15 and 30 minutes.*

Do you have time to talk right now?

(if no) *Is there someone else at [name of organization] who might be willing to participate?*

(If not now, need to ask superior, etc.)

Thank you. Can we set up a time now to follow up? If not, my phone number is [number]. You can call me and I'll call you back to follow up in [less than one week].

(if yes) *Thank you. The information you provide will help us understand the important role family organizations such as yours play in supporting families. We will share the overall findings with you to help you understand the strengths and challenges family organizations face in helping families to guide your own program goals. We will not share anything specific about your organization.*

There is minimal risk involved. No information about your specific organization will be reported; instead, information across all states will be summarized. Your individual name will be replaced with an ID number that is linked with your answers. You may decline answering any questions that you do not want to answer. You also can ask me to call you back if this is not a good time or you may refer me to someone else in your program.

Do you agree to participate?

(if yes) *Thank you, I'll get started with the questions.*

(if no) *Thank you for your time. Is there someone else at [name of organization] who might be willing to participate?*

(If yes, but not now, need to ask superior, etc.)

Thank you. Can we set up a time now to follow up? If not, my cell number is [number]. You can call me and I'll call you back to follow up in [less than one week]. **(If they need more information before agreeing to participate.)** I will have the study team at Utah State University contact you to provide additional information.

Can I please record your **name and contact information** in case I need to follow up?

Interview Protocol: I am going to provide seven scenarios to you and would like you to respond how you would to any parent calling and asking the questions in the scenario. I understand that your conversations with a family calling in would be much more personalized and include more details. It is okay to just list for me the information and resources you would provide for a parent with that specific question.

Please keep in mind that there are no right and wrong answers to these questions. We are trying to get an idea of the resources available to families. This will help us find out if there is a need for additional resources that we can develop that will better help **you** to help families. I also know that your responses to these questions may include repeat information so please feel free to tell me that you would repeat previous information. There is no need to describe a resource to me more than once.

If you would typically send families something by email or mail, would you please send that information to me. [provide addresses if needed]

Let's get started.

[Interviewer Instructions:

For each of the scenarios, please check each of the resources or types of assistance that are offered. If a link or hard paper resource is offered, please put the link or the name of the resource in the notes box along with any specific notes that you think are important. There is no need to repeat information from the yes/no questions in the notes box.]

1. I just found out that my two-week old infant has a hearing loss. We found out through the newborn hearing screening. How can you help me?
 - Refer to early intervention/Part C (may have a specific name in the state)
 - Specific EI for D/HH
 - Refer to audiology (unspecific)
 - Mention pediatric audiology
 - Provided list of pediatric audiologists
 - Refer to EHDI
 - Refer to pediatrician

- Refer to other organization(s): _____
- Connection to other parents
 - Specific support groups
 - Contact information for a specific family/families
- Shared or will send resources on early intervention
- Shared or will send resources specific to hearing loss

2. *My baby failed his newborn hearing screening and is now two months old, but my pediatrician said not to worry about it. What would you recommend I do? Can I really wait until he's one to do something?*

- Refer to early intervention/Part C (may have a specific name in the state)
 - Specific EI for D/HH
- Refer to audiology (unspecific)
 - Mention pediatric audiology
 - Provided list of pediatric audiologists
- Refer to EHDI
- Refer to pediatrician
- Refer to other organization(s): _____
- Connection to other parents
 - Specific support groups
 - Contact information for a specific family/families
- Shared or will send resources on early intervention
- Shared or will send resources specific to hearing loss

3. *I am worried that my 6-month old baby girl cannot hear me, I'm wondering if she has a hearing loss, do you know how I can find out?*

- Refer to early intervention/Part C (may have a specific name in the state)
 - Specific EI for D/HH
- Refer to audiology (unspecific)
 - Mention pediatric audiology
 - Provided list of pediatric audiologists
- Refer to EHDI
- Refer to pediatrician
- Refer to other organization(s): _____
- Connection to other parents
 - Specific support groups
 - Contact information for a specific family/families
- Shared or will send resources on early intervention
- Shared or will send resources specific to hearing loss

4. *My son is two years old I am hearing a lot about sign language vs Listening and Spoken Language and people are very passionate about both. Can you explain a bit about the different options and tell me more about potential benefits and disadvantages of each?*

- Refer to early intervention/Part C (may have a specific name in the state)
- Refer to EHDI

- Refer to pediatrician
- Refer to other organization(s): _____
- Connection to other parents
 - Specific support groups
 - Contact information for a specific family/families
- Stated that it is your family's choice
- Gave unbiased advice (fair to both sides)
- Gave biased information
 - Biased to ASL/Manual
 - Biased to LSL/Cochlear Implants/etc.

5. *I think my child needs hearing aids or cochlear implants. Who should I contact to get them?*

- a. *Do you know about any money available to help to pay for hearing aids or implants? (assume I have insurance)*
 - i. *What if I don't have insurance?*
 - ii. *What if my insurance said no?*

- Refer to early intervention/Part C (may have a specific name in the state)
- Refer to audiology (unspecific)
 - Mention pediatric audiology
 - Provided list of pediatric audiologists
- Refer to EHDI
- Refer to pediatrician
- Refer to private insurance
- Refer to Disability Law Center
- Refer to State Insurance/Medicaid
- Refer to other organization(s): _____
- Connection to other families who have successfully raised money
- Shared or will send resources specific to funding

6. *I am frustrated that my two-year-old daughter who is deaf is not getting the amount of early intervention services she needs. She only gets two visits a month and I want her to get therapy every week because she isn't making progress.*

- a. *I'm also worried that her provider is just an aide.*
- b. *What if I can't remember all of these questions to ask at her meeting?*
- c. *What if I ask and they say no? They said no last time I asked.*

- Refer to early intervention/Part C (may have a specific name in the state)
 - Specific EI for D/HH
- Information on family rights
- Information on dispute resolution
- Gives questions to ask at IFSP meeting
- Offers to look at IFSP for you
- Offer to assist at IFSP meeting
- Offer to assist with dispute resolution

Information about where to get supplemental services (insurance, private, etc.)

Refer to other organization(s): _____

Connection to other parents who have had similar problems

Shared or will share resources

7. *I would like the chance to talk to other families of children who are deaf or hard of hearing. Who could help connect me with other families?*

Refer to early intervention

Refer to EHDI

Refer to Hands & Voices

Refer to other organization(s): _____

Contact information for a specific family/families

Thank you so much. I just have a couple questions to finish up.

First, are there any other questions or concerns that you get from parents about infants and children who are deaf or hard of hearing that we didn't cover today?

We also are interested in learning more about how your program interacts with the State's EHDI and early intervention programs. Who is the best person to talk to about interagency work? Can you give me their phone number and email address?

Thank you for your time today. Your participation was extremely valuable. We will be sharing a summary of our findings with you and other organizations upon completion of this study (but no identifiable information), which will likely be by the end of 2016.