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Family Support Organizations

Family Support Organization Calls Thank you for your assistance with this project Enter all information about a single organization in one one form You will need to complete the information on one organization and click the "Submit" button before you can start entering information on another organization.

Your Name

- John Doe
- Lisa Smith
- Ann Wilson
- Other

Display This Question:

If Your Name Other Is Selected

What is your name?

Which State is the Family Organization In?

What is the name of the Organization?

What type of organization was it? *Note: this information was given in the email when the organization was assigned*

- PTI
- F2F
- Both

Were you given a name and contact number when the Family Org was assigned?

- Yes
- No

Display This Question:

If Were you given a name and contact number when the Family Org was assigned? No Is Selected

If no, how would you describe their Participation from your first call to the organization? please choose the situation that best applies:

- Agreed to participate right then
- Agreed to participate at a later time
- Declined to Participate
- Needed more information or to check with someone else before participating but ultimately agreed to participate
- Needed more information or to check with someone else before participating but ultimately declined to participate
- Referred you to someone else who agreed to participate
- Referred you to someone else who declined to participate
- Other (please explain) _____
- Sent at least 3 emails AND called 3 times but was not able to coordinate/complete an interview

Please list the number of times you called in addition to the call where you were able to conduct the interview: Do not include the call where you were able to complete to interview

- No answer at number / left voice mail message: _____
- Correct person was not there: _____
- Scheduled interview for later - you called them: _____
- They called you: _____
- Other - please describe: _____

Please enter any additional information about contacting the agency here

Date of the Interview mm/dd/yyyy: _____

Survey Start and End Times

	Time use 24 hour time (e.g. 5:00pm would be entered as 17:00)
Start Time	
End Time	

Interviewee Contact Information

Name

Email

Direct Phone #

Scenario 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 Check any of the following that is mentioned:

- 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) - please specify: _____
- 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

Put any additional notes regarding Scenario 1 here:

Scenario 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? Check any of the following that is mentioned:

- 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) - please specify: _____
- 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

Put any additional notes regarding Scenario 2 here:

Scenario 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? Check any of the following that is mentioned:

- 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) - please specify: _____
- 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

Put any additional notes regarding Scenario 3 here:

Scenario 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? Check any of the following that is mentioned:

- 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) - please specify: _____
- 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...

Put any additional notes regarding Scenario 4 here:

Scenario 5 - I think my child needs hearing aids or cochlear implants. Who should I contact to get them? Do you know about any money available to help to pay for hearing aids or implants? (assume I have insurance) What if I don't have insurance?

What if my insurance said no? Check any of the following that is mentioned:

- 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

Put any additional notes regarding Scenario 5 here:

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

Check any of the following that is mentioned:

- 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

Put any additional notes regarding Scenario 6 here:

Scenario 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): _____
- Connection to other parents

Put any additional notes regarding Scenario 7 here:

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?

- Yes
- No

If yes, what were the questions/concerns

Add any additional notes about the interview here:

Please upload a copy of the worksheet with notes you used during your interview Note: please attach only one file. If you have multiple files or if the file size is larger than 15MB, please email them as attachments