Newborn Hearing Screening

This survey is sent to all parents with young children diagnosed with hearing loss. Please respond to the questions that you can answer.

1)	Your relationship to baby:(Example: mother, father, grandmother, grandfather, foster parent, etc.)
2)	When did you first learn that your baby's hearing would be screened or needed to be screened? Before hospital admission While in the hospital After hospital discharge Not sure Other:
3)	How did you feel when you first learned that your baby would have his or her hearing screened? Not at all anxious or worried Somewhat anxious or worried Anxious or worried Very anxious or worried

	How were you first told about the results of your baby's hearing screening? (Please check one) The staff at the hospital or office where my baby's hearing was screened told me before I went home.
	The doctor told me before I went home from the hospital or office where my baby's screening was done.
	I received a card or note before I went homeThe staff at the hospital or office where my baby's hearing was screened told me after I went home.
	The doctor told me after I went home from the hospital or office where my baby's screening was done.
	I got a letter with the results mailed to my homeI was never told the resultsOther:
5)	What were the results of your baby's hearing screening? Passed
	Referred for more testingNot sure
:)	Dlagge mark the centence helow that heat describes how you understood the regults of the hearing
5)	Please mark the sentence below that best describes how you understood the results of the hearing screening your baby had.
	My baby did not have a hearing lossIt was possible, but rather unlikely, that my baby had a hearing loss.
	It was possible that my baby had a hearing lossIt was very likely that my baby had a hearing loss.
	It was certain that my baby had a hearing lossI did not understand the results.
')	When you learned the results of your baby's hearing screening, how did you feel?
')	Not at all anxious or worriedSomewhat anxious or worried
")	Not at all anxious or worried
")	Not at all anxious or worriedSomewhat anxious or worriedAnxious or worried
7)	Not at all anxious or worriedSomewhat anxious or worriedAnxious or worried
")	Not at all anxious or worriedSomewhat anxious or worriedAnxious or worried

8) Thinking back on your baby's hearing you felt for each statement.	g screening, ple	ase circ	cle the	number t	hat shows how	
The people doing the screening were experienced with the equipment	Definitely yes	2	3		Definitely no 5	Not sure
The people doing the screening seemed to have lots of experience working with infants	Definitely yes 1	2		4	Definitely no 5	Not sure
The test and explanations were done	Professionally	2	3	4	Unprofessionally 5	Not sure
Explanations and answers to your questions were	Clear 1	2	3	4	Confusing 5	Not sure
What you were told to do next was	Clear 1	2	3		Confusing 5	Not sure
The time from start to finish was	About right <	2	3	4	Too long 5	Not sure
Your opinions and suggestions were	Listened to <	2	3	4	Not listened to 5	Not sure

9)	Overall, how satisfied were you with the people who provided hearing screening services to your baby? Very satisfiedSatisfiedSomewhat satisfiedNot very satisfiedNot at all satisfied
10)	Overall, how satisfied were you with the hearing screening services provided to your baby and family? Very satisfiedSatisfiedSomewhat satisfiedNot very satisfiedNot at all satisfied
11)	After your baby's hearing screening what happened next? We returned to the hospital for another screen. We were referred to the hospital audiology department for re-testing. We were referred to an audiologist outside of the hospital for re-testing. My baby's doctor re-tested my baby's hearing in his or her office.
12)	How did you feel when you first learned that your baby needed his or her hearing re-tested ? Not at all anxious or worried Somewhat anxious or worried Anxious or worried Very anxious or worried
13)	Did you have any problems making and/or getting the outpatient hearing re-testing appointment(s)? Yes GO to 13a GO to 13b

13a) What problems did you have with the outpatient re-testing appointment? (Please check all that apply)
 Difficulty making the appointment The hospital made the appointment for me but it was not convenient. I did not know where to call to make the appointment. There were no appointments available for a time that I could be there. Making phone calls for the appointment was difficult.
<u>Difficulty with transportation</u> It took too long to travel to the appointment. It was difficult to get transportation to go to the appointment.
Other responsibilities My baby was frequently sick. It was difficult to take time off work. It was hard to find someone to take care of my other children while I went to the appointment.
Paying for the appointment The re-testing was not covered by my baby's health plan. The re-testing was too expensive. Other:
13b) Approximately how long was it from the time you or the hospital first tried to make an outpatient re-testing appointment until the time your baby had that appointment? Less than one week1 to 2 weeks2 weeks to 1 month1 to 2 monthsMore than 2 months
How many different times did you take your baby to an outpatient re-testing site before all the testing was completed? One time Two times Three times More than three times GO to 14a GO to 14a GO to 14a

14a)	If it took more than one appointment to complete the re-testing, what was the reason(s)? (Please check all that apply) My baby was fussy. The equipment didn't work right. Not enough time was scheduled for the appointment. The audiologist or person who tested my baby's hearing was running late. I was running late. The results were unclear or inconclusive. Other:
15)	How were you first told about the results of your baby's outpatient hearing re-testing ? (Please check one) The staff at the hospital or office where my baby's hearing was re-tested told me before I went home. The staff at the hospital or office where my baby's hearing was re-tested told me after I went home. The doctor told me after I went home from the hospital or office where my baby's hearing was re-tested. I got a letter with the results mailed to my home. Other:
16)	Please mark the sentence below that best describes how you understood the results of the outpatient hearing re-testing your child had. My baby did not have a hearing loss. It was possible, but rather unlikely, that my baby had a hearing loss. It was possible that my baby had a hearing loss. It was very likely that my baby had a hearing loss. It did not understand the results.
17)	When you found out about the results of your baby's outpatient hearing re-testing how did you feel? Not at all anxious or worried Somewhat anxious or worried Anxious or worried Very anxious or worried

18) Thinking back on when your baby's that shows how you felt for each state	hearing was re-tested as an outpatient, please circle tement.	the number
The people doing the re-testing were experienced with the equipment	Definitely yes 1 2 3 4 5	Not sure
The people doing the re-testing seemed to have lots of experience working with infants	Definitely yes Definitely no 1 2 3 4 5	Not sure
The tests and explanations were done	Professionally 1 2 3 4 5	Not sure
Explanations and answers to your questions were	Clear Confusing 1 2 3 4 5	Not sure
What you were told to do next was	Clear Confusing 1 2 3 4 5	Not sure
The time from start to finish was	About right Too long 1 2 3 4 5	Not sure
Your opinions and suggestions were	Listened to $\begin{array}{c ccccccccccccccccccccccccccccccccccc$	Not sure

19)	Overall, how satisfied were you with the people who provided re-testing services to your baby? Very satisfied Satisfied Somewhat satisfied Not very satisfied Not at all satisfied
20)	Overall, how satisfied were you with the re-testing services provided to your baby and family? Very satisfied Satisfied Somewhat satisfied Not very satisfied Not at all satisfied
21)	How often did people at the hospital or office where you received services communicate with you in a language you use at home? AlwaysMost of the timeSometimesRarelyNever
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22)	After your baby was diagnosed with a hearing loss, how many times has he or she been to an appointment with an audiologist? 012-34-56 or more
23)	How satisfied are you with the audiologist's experience working with infants and young children? Very satisfied Satisfied Somewhat satisfied Not very satisfied Not at all satisfied

23a) T	How satisfied are you with the care and services your baby's audiologist is providing?
24)	If your baby has not been to an audiologist since you learned that he or she had a hearing loss, what are the reasons? (Please check all that apply)
25)	Is your baby in an early intervention program? No Yes GO to 26
25a)	What are the reason(s) your baby is not getting early intervention services? (Please mark all that apply) Insurance does not cover early intervention services. I was told that my baby was not eligible for early intervention services. By whom? I chose not to have my baby participate in early intervention services. The doctor told me that my baby did not need early intervention services. The audiologist told me that my baby did not need early intervention services. No one contacted me after my baby was referred to early intervention. I have not been told about early intervention services. Other: GO to 28

26) How satisfied are you with the early inVery satisfiedSatisfiedSomewhat satisfiedNot very satisfiedNot at all satisfied	nterventi	on progra	m's kno	owledge o	of hearing l	oss and de	rafness?
 How satisfied are you with your baby's early intervention services? Very satisfied Satisfied Somewhat satisfied Not very satisfied Not at all satisfied 28) This is a chart that will help us understand the information you were given and when you got that information.							
1. Please mark an X in the box that describes HOW MUCH information you got. 2. Please mark an X in the box that describes WHEN you got that information.					s WHEN		
TOPIC	None	Not	Just	Too	Too	Just	Too
		Enough	Right	Much	Early	Right	Late
How hearing works							
Degrees of hearing loss							
Causes of hearing loss							
Hearing aids & amplification technologies							
Stages of grief/acceptance							
Speech & language development							
Communication Options:							
-ASL/English as a Second Language -Auditory/Oral							
-Auditory/Oral -Auditory/Verbal							
-Cued Speech							
-Signing Exact English							
-Total Communication							
Financial support							
Emotional support							
Other parents to contact							
Where to get services							

29)	Do you feel that the information you were given about intervention/communication options was equally presented? — We were given the information and encouraged to make our own decisions. The information was unbiased. — We were given information and encouraged to make our own decisions but we knew professionals wanted us to choose the one they thought was best. The information was somewhat unbiased. — We were strongly encouraged to choose the intervention option the professionals working with us thought was best but we still had the option to make a different decision. The information was somewhat biased. — We were told that there was only one way that was good for our baby. The information was very biased. — Other:
30)	Do any of your baby's family members have a hearing loss that began during childhood?
20)	Yes GO to 30a
	No
30a)	If yes, which ones? MotherGrandmotherSisterAuntCousinFatherGrandfatherBrotherUncleOther:
31)	We would like to know about your baby's overall health. Please choose the word that you think
	best describes your baby's overall health. Excellent Very Good
	Very Good Good
	Fair Poor
32)	Does your baby have any health problems or special needs?
	Yes, please specify:No

3)	How are your baby's medical expenses paid? Medicaid Medicaid HMO Private Other HMO Self payOther:
+)	Looking back at the activities involved in finding out that your child had a hearing loss (tests, doctor visits, etc), did the benefits outweigh the negative (such as extra time for doing tests, concerns you felt, any costs, etc)? Definitely yes, many more benefits than negativesYes, a few more benefits that negativesNo, a few more negatives than benefitsDefinitely no, many more negatives than benefits
))	Do you agree or disagree with the following statements about newborn hearing screening? Agree Disagree Screening allows parents to do something positive if their baby has a hearing loss. Screening leads to early diagnosis if the baby has a hearing loss. Screening leads to early treatment if it is needed. Screening makes parents worry unnecessarily. Screening takes too much effort. Screening wakes or upsets the baby.
5)	If you had another baby would you want him or her to have his or her hearing screened? YesNo
")	Please list any suggestions you have for improving the newborn hearing screening, re-testing, and intervention process.

Thank you for your help with this survey. Your responses will be used to help improve the hearing screening process for all families