Hear Me Out: An Evaluation of the Services Provided to Parents Prior to a Diagnosis of Hearing Loss

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Hear Me Out:
An Evaluation of the Services Provided to Parents Prior to a Diagnosis of Hearing Loss

Amber N. Wagster
Harding University
Abstract

This study seeks to identify and evaluate the services provided to parents of children who did not pass their newborn hearing screening. This study will determine what educational services were offered and if they effectively-prepared parents for navigating the process of their child's potential hearing loss diagnosis. A questionnaire was distributed to parents through the offices of audiologists and through Hands & Voices, a parental advocacy organization.
HEAR ME OUT

Hear Me Out:

An Evaluation of the Services Provided to Parents Prior to a Diagnosis of Hearing Loss

Introduction

Universal newborn hearing screenings (UNHS) are typically administered to newborns before leaving the hospital. These screenings indicate whether the child has normal hearing or a possibility of hearing loss. Screenings result in either a pass or a refer. When a child’s screening ends with a refer, parents may face significant anxiety about having a child who is deaf or hard-of-hearing. Before the child’s diagnosis, health care professionals should provide services such as education and counseling to families. This research study was designed to evaluate what services are provided to families, how effective the services are in preparing the families, and examine what input these families have regarding the diagnostic process. This research will not explore the Deaf culture and its implications on health care decision-making.

Newborn Hearing Screening

Newborn screenings are being advocated for, due to the significant effects that unscreened health conditions can have on an individual’s life (Dhondt, 2010). When a hearing loss diagnosis is delayed, a child’s speech and language development are also delayed. This delay is due to the interruption of the child’s speech sound acquisition. When a child does not hear some or all speech sounds, they cannot accurately understand speech and/or express language (Runnior & Gray, 2019). The first three years of a child’s life are critical for speech and language development, so hearing is crucial. Expressive language delays are often present when children do not receive a diagnosis nor treatment for hearing loss. Runnior and Gray (2019) discussed that reading outcomes are low for children with hearing loss. According to
HEAR ME OUT
Patel, Feldman, Canadian Paediatric Society, and Community Paediatrics Committee (2011), as children with untreated hearing loss age, they tend to exhibit negative social and psychological characteristics. They also exhibit lower academic achievement and underemployment due to a lower literacy level and language deficiencies (Larsen, Muñoz, DesGeorges, Nelson, and Kennedy, 2012)

Patel et al (2011) discussed the adverse effects of screenings and focused on the anxiety parents face when follow-up testing is suggested. The same study stated that parental concern for hearing loss, due to the parent’s observation of a child’s behavior, is predictive of a child’s hearing loss. This study also suggested that parents should receive counseling and information from a UNHS program. A limitation of this study was that universal newborn hearing screenings often do not detect low levels of hearing loss or hearing loss occurring later on, such as from an inherited condition. Although the screening does not detect 100 percent of children with hearing loss, Patel et al (2011) recommended that all newborns receive a hearing screening before being released from the hospital. Russ, Hanna, DesGeorges, and Forsman (2010) stated that it is beneficial for the parents to identify health care professionals, such as pediatricians, before being released from the hospital. Larsen et al (2012) stated that the hearing loss diagnosis process is an emotionally taxing experience for parents.

**Services Provided to Parents**

Russ et al (2010) suggested that providing information about the diagnostic process and intervention options would be helpful for future parents. The parents in this study were given a “road map” for the diagnostic process. The road map was found to be beneficial for the families
HEAR ME OUT
due to the clearly defined timeline. However, the study did not assess what services were given
to families before implementing the procedures.

Larsen et al (2012) suggested that 91 percent of surveyed parents received information
about their child’s hearing loss, while only 48 percent received resources about childhood
hearing loss. Parents of children with hearing loss were surveyed on what challenges affected
them regarding the diagnostic process. However, their research did not specifically address the
services provided to families and how the services affected the families.

The Arkansas Department of Health provided a list of materials/information that should
be provided to parents. These materials include the purposes and benefits of newborn hearing
screenings; the milestones of speech, language, and hearing development; the screening
procedures; results of the screening; and recommendations for further testing.

Two common themes emerged from the studies: unmet parental needs and the effects of
unaided hearing loss on children. The studies suggest that parents need more information and
counseling on the impacts of hearing loss, and health care professionals need to assist through
counseling and identifying the next steps in the process. Each study stated that additional
counseling and informational services would be beneficial to families. Russ et al (2010) provided
the parents information and involved parents in their child’s health care. This study highlighted
the need for more parental involvement but is different from other studies due to the
experimental nature. Their research focused on how a collaborative health care experience would
affect the efficacy of newborn hearing screenings. However, since the study focused on the
efficacy of the experience, the parental perspective was not thoroughly observed.

Parent Perspectives and Involvement
Russ et al (2010) conducted a study where parents served a more active role in their child’s diagnosis and treatment process. Health care providers worked as a team, rather than individual providers, providing a more holistic approach. Unlike the average health care delivery system, the parents participated as part of the health care team in their study. Typically, the norm in health care is to advise parents rather than work alongside them.

Studies conducted by Larsen et al (2012) and Russ et al (2010) stated that primary care providers lack information with which to guide families. Hyde (2005) stated that parental education should begin with pamphlets and informational videos and be enforced by health care professionals. According to Hyde (2005), health care professionals bridge the informational gap, facilitating the understanding of the resources and information provided to families. Sass-Lehrer and Bodner-Johnson (2003) stated that early intervention programs allow families to have a more family-centered system. Sass-Lehrer and Bodner-Johnson (2003) suggested that a child’s development is best understood by looking at the family, so the family-centered approach allows the focus to be shifted to the family where the child’s primary development occurs.

Traci and Koester (2003) stated that a child’s development is directly affected by family stress. A child’s development was found to be improved when parental stress was low and when parents were provided resources. Dhondt (2010) stated that families need attention and encouragement when they are given education about their children’s health conditions. The study suggested that families would benefit from receiving information about the long-term outcomes for children who did not pass their screening. Many parents are not knowledgeable on the legal aspect of consent forms which are intended to safeguard a patient’s autonomy (Dhondt, 2010).
Patel et al (2011) found that parental follow-up and involvement is crucial. Parents should be attentive to the development of their children because hearing loss may not be detected with screening. If a child's hearing loss is not detected early, the child could suffer irreversible deficits in language and cognition (Patel et al, 2011).

Summary

The existing literature does not evaluate what services were provided to parents after receiving the screening results nor does it incorporate their perspective during the journey. Understanding of the parents’ experiences will be valuable as health care professionals and policymakers assess how to improve the process. This non-experimental mixed-method study will research what services were provided to parents, evaluate the efficacy of those services, and report the recommendations of parents whose children did not pass their hearing screenings.

Purpose

The purpose of this study is to evaluate what services were provided to families and how beneficial the services were in preparing them for the hearing loss diagnostic process.

Method

Participants

The participants in this study are the parents of children who have been diagnosed with hearing loss.

Instrumentation

The Hear Me Out: An Evaluation of the Services Provided to Parents Prior to a Diagnosis of Hearing Loss questionnaire was created through Google Sheets. The questionnaire was distributed through the Arkansas Board of Examiners for Speech-Language Pathologists and
Audiologists database which contained a list of audiologists. The questionnaire was also sent to each Hands & Voices chapter in the United States.

This research was designed as a mixed-methods study; however, because the researcher received only six usable responses, the results will be discussed with regard to demographic statistics and qualitative data. The questionnaire included questions regarding the demographics of the family, services provided to the family, and the efficacy of the services for parents going through the diagnosis process. The open-ended response items asked the families to discuss their experiences and their suggestions. This questionnaire is included in Appendix A.

**Procedure**

Following the approval for an IRB exemption, I contacted audiologists in Arkansas asking them to distribute the *Hear Me Out* questionnaire to parents of children with hearing loss. I also contacted the Arkansas Board of Examiners for Speech-Language Pathologists and Audiologists (ABESPA) who provided access to a database of audiologists and Hands & Voices chapters, parental advocacy organizations. State chapter presidents of Hands & Voices consented to the study and distributed the survey through their Facebook groups.

The *Hear Me Out* questionnaire did not collect personal, identifying information about the participants. The survey explored the participants’ demographics and questions about the services provided to families. Individuals were not compensated for their participation in the study.

**Results**

There were nine responses to the *Hear Me Out* questionnaire. Three of the responses were omitted from the data analysis because the participants’ children had passed their newborn
HEAR ME OUT

hearing screening. This study focuses on what services were provided to parents of children who failed their newborn hearing screening before the child left the hospital. The following themes emerged from the six respondents: parental anxiety, lack of information, excessive assurance/given alternative explanations as to why the child did not pass, and dissatisfaction with the services provided by health care professionals, such as time spent educating and counseling the parents.

Demographics

Of the six responses, the age of the child at the time of diagnosis ranged from newborn to six months, with a mean of two and a half months. The mother’s age ranged from 25 to 28, with a mean of 26.8 years. The father’s age ranged from 25 to 30, with a mean of 27.8 years. All respondents were married. Four out of the six nominally claimed Christianity while the other two indicated no religious preference. All of the respondents were white/Caucasian females. One of the participants indicated that the interactions she had with health care professionals were easier because she was white/Caucasian. She stated, “I probably had an easier time than many others. There were no language barriers and I'm a white female.” Each participant claimed English as her primary language and stated that language did not affect her interactions with health care providers. The socioeconomic status of the participants ranged from $50,000 to $74,999 to over $100,000 (see Table 1). The participants were also asked about their highest level of education. The participants’ education level ranged from some college, no degree to Bachelor’s Degree (see Table 2).
HEAR ME OUT

| Table 1 | 
| Participant’s Socioeconomic Status |
|———|——|
| Income Level | Response |
| Less than $20,000 | - |
| $20,000 to $34,999 | - |
| $35,000 to $49,999 | - |
| $50,000 to $74,999 | 1 |
| $75,000 to $99,999 | 2 |
| Over $100,000 | 3 |
| Prefer not to say | - |

*Note.* Zero is represented by a hyphen (-).

| Table 2 | 
| Participant’s Highest Level of Education |
|———|——|
| Education Level | Response |
| Less than a high school diploma | - |
| High school degree or equivalent (e.g. GED) | - |
| Some college, no degree | 1 |
| Associate degree (e.g. AA, AS) | - |
| Bachelor’s degree (e.g. BA, BS) | 3 |
| Master’s degree (e.g. MA, MS, MEd) | 2 |
| Professional degree (e.g. MD, DDS, DVM) | - |
| Doctorate (e.g. PhD, EdD) | - |
| Prefer not to say | - |

*Note.* Zero is represented by a hyphen (-).
Parental Anxiety

Half of the participants strongly agreed that they faced anxiety regarding the hearing screening results and strongly disagreed that health care professionals provided services that lessened their anxiety. One of the parents explained that her child had life-threatening health conditions that required greater attention, until three months of age. She explained that the health care providers suggested the screening results were due to fluid in the child’s ear. She stated, “It was crap advice but I felt less anxiety.”

<table>
<thead>
<tr>
<th>Statement</th>
<th>Mean</th>
<th>Mode</th>
</tr>
</thead>
<tbody>
<tr>
<td>I experienced anxiety regarding my child’s hearing screening.</td>
<td>5.00</td>
<td>7</td>
</tr>
<tr>
<td>Before leaving the hospital, health care professionals provided services that lessened my anxiety regarding my child's potential hearing loss.</td>
<td>2.19</td>
<td>1</td>
</tr>
</tbody>
</table>

*Note.* The Likert scale was a 7-point scale from Strongly Disagree (1) to Strongly Agree (7)

Lack of Information

When asked about what services were provided at the time of the results, five out of the six participants received instructions for retesting, but only two of the six participants received a timeline for retesting. Two out of the six participants received contact information for another health care professional, but only one of the participants was provided information about children’s hearing loss (see Table 4). When asked what services were received before leaving the
HEAR ME OUT

birth hospital, one parent said, “Our child had other health problems that were glaringly ‘larger’ at the time. I wish someone had given me a step by step and shared with me the importance of follow up testing.” None of the parents indicated they received counseling prior to leaving the hospital (see Table 4).

Table 4

<table>
<thead>
<tr>
<th>Services</th>
<th>Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Counseling</td>
<td>-</td>
</tr>
<tr>
<td>Information about children’s hearing loss</td>
<td>1</td>
</tr>
<tr>
<td>Instructions for retesting</td>
<td>5</td>
</tr>
<tr>
<td>Timeline for retesting</td>
<td>2</td>
</tr>
<tr>
<td>Contact information of another professional for retesting</td>
<td>2</td>
</tr>
<tr>
<td>Information regarding other reasons the child did not pass the screening</td>
<td>2</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
</tr>
</tbody>
</table>

*Note. Zero is represented by a hyphen (-).*

Five of the six respondents indicated they were told about their child’s screening results prior to leaving the hospital. Four stated a nurse delivered the initial screening results, one indicated an audiologist delivered the results, and the other participant was unsure but believed it to have been a nurse. Four participants discussed their children’s screening results with an additional health care professional, including a nurse, pediatrician, speech-language pathologist, psychologist, and social worker. One parent indicated she did not recall what kind of health care
HEAR ME OUT

professional she discussed the information with. When the participants were asked to scale the statement, “I am satisfied with the amount of services I received from the health care professionals before leaving the hospital” on the seven-point Likert scale, the mean response was a 3 (See Table 5). The participants indicated they disagreed that health care professionals provided adequate information, with a mean score of 2.66. When the participants were prompted to scale this statement, “I had the opportunity to ask questions,” their mean answer was 4.19 (see Table 5).

<table>
<thead>
<tr>
<th>Table 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Likert Scale Statements Regarding Lack of Information</td>
</tr>
<tr>
<td>Statement</td>
</tr>
<tr>
<td>I am satisfied with the amount of services I received from the health care professionals before leaving the hospital.</td>
</tr>
<tr>
<td>The health care professional(s) provided adequate information.</td>
</tr>
<tr>
<td>I had the opportunity to ask questions.</td>
</tr>
</tbody>
</table>

*Note. The Likert scale was a 7-point scale from Strongly Disagree (1) to Strongly Agree (7)*

Excessive Assurance

Three of the participants stated that health care professionals should make a greater effort to inform parents that further testing might find a child has hearing loss. Parents reported feeling distressed due to being excessively assured and given false hope that their children would not
HEAR ME OUT

have hearing loss. One parent admitted to feeling unprepared to receive the news of her child’s hearing loss after being assured it was due to fluid in the child’s ear. Another parent wrote,

Everyone approached the initial results assuming they were wrong due to her being a newborn and kept telling me as such - the results were CORRECT (we are now 12mo later). It was amazingly unfair and emotionally abusive to not provide accurate [percentages] when discussing the results of the initial screening test and provided no trust in the system.

Dissatisfaction with the Services

Four of the participants were dissatisfied with the time professionals spent providing services attempting to educate the parents. Three of the participants strongly disagreed with feeling prepared to navigate the process of further testing and potential diagnosis at the time of release from the birth hospital, with a mean response of 2.66 (see Table 6). Parents were asked to scale a statement suggesting health care professionals were compassionate towards them and another statement suggesting the instructions for follow-up testing was clear, the mean result of each was 4.66, where 1 means Strongly Disagree and 7 means Strongly Agree. When given a statement suggesting health care providers answered questions promptly, the parents gave a mean score of 4.33, on this scale 4 suggests the participant did not agree nor disagree. Most participants disagreed with being satisfied with the quality of the services provided before leaving the birth hospital. Four of the six participants disagreed that the screenings were delivered in a supportive manner. Three of the six participants disagreed the results were delivered in an unhurried manner.
HEAR ME OUT

Participants were asked if they would alter any services provided to them. They were
asked to explain the changes they would make and how these changes would have benefited
them. One of the participants said that she would have liked to have been provided contact
information for parents who have gone through the process.

Table 6

<table>
<thead>
<tr>
<th>Statement</th>
<th>Mean</th>
<th>Mode</th>
</tr>
</thead>
<tbody>
<tr>
<td>When leaving the hospital, I felt prepared to navigate the process of</td>
<td>2.66</td>
<td>1</td>
</tr>
<tr>
<td>further testing and possible diagnosis.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The health care professional(s) were compassionate towards me.</td>
<td>4.66</td>
<td>5</td>
</tr>
<tr>
<td>The health care professional(s) answered my questions in a timely</td>
<td>4.33</td>
<td>4</td>
</tr>
<tr>
<td>manner.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am satisfied with the quality of the services provided to me before</td>
<td>3.50</td>
<td>4</td>
</tr>
<tr>
<td>leaving the hospital.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am satisfied with the amount of time the professional(s) spent</td>
<td>2.50</td>
<td>1, 2</td>
</tr>
<tr>
<td>educating me.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The instructions for follow-up testing were clear.</td>
<td>4.66</td>
<td>6</td>
</tr>
<tr>
<td>The results of the hearing screening were delivered in a supportive</td>
<td>3.33</td>
<td>3</td>
</tr>
<tr>
<td>manner.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The results of the hearing screening were delivered in an unhurried</td>
<td>3.50</td>
<td>4</td>
</tr>
<tr>
<td>manner.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>At the time I left the hospital with my newborn, I felt prepared for the</td>
<td>2.66</td>
<td>1</td>
</tr>
<tr>
<td>next steps in the process.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Note.* The Likert scale was a 7-point scale from Strongly Disagree (1) to Strongly Agree (7)

Discussion

General information about the research study and the *Hear Me Out* questionnaire was
sent to audiologists in Arkansas, however, no responses were received. The researcher contacted
the Early Hearing Detection and Intervention (EHDI) office in Arkansas to collect parents’
contact information. To EHDI office informed the researcher that a request must be made
through the Arkansas Department of Health. The request was not made due to time constraints.
The researcher then contacted the Arkansas Board of Examiners for Speech-Language
Pathologists and Audiologists (ABESPA). ABESPA provided a database which provided the
researcher with contact information for audiologists in Alabama, Arkansas, California, Colorado,
Connecticut, Florida, Georgia, Illinois, Indiana, Kentucky, Louisiana, Minnesota, Missouri,
Mississippi, North Carolina, Nebraska, New Jersey, New York, Ohio, Oklahoma, Oregon, South
Carolina, Tennessee, Texas, Utah, Virginia, and Washington. After receiving no response from
the audiologists nor survey responses, the researcher contacted administrators of a Facebook
group for parents of children with hearing loss. The administrators of the Facebook group did not
respond, so the researcher also contacted Hands & Voices chapters, a parental advocacy
organization. State chapter presidents of Hands & Voices responded and distributed the survey
through their Facebook groups.

The results of this study found that parents require more education regarding the
diagnostic process. Four main themes emerged from the participant’s responses including
parental anxiety, lack of information, excessive assurance/given alternative explanations as to
why the child did not pass, and dissatisfaction with the services provided by health care
professionals, such as time spent educating and counseling the parents. Four of the six
participants were dissatisfied with the amount of time health care professionals spent attempting
to provide education. The participants indicated they felt anxious and discussed that health care
providers provided alternative reasons the child did not pass their hearing screening. The
HEAR ME OUT

alternative explanations and excessive assurance provided parents with false hope and left them feeling unprepared for their child’s hearing loss diagnosis. The participants were asked how health care professionals prepared them for their children’s testing. Three of the six participants indicated they did not receive services that prepared them for retesting. Another participant stated she had an appointment scheduled before leaving the hospital, while the other two indicated they were provided instructions on who to contact and a timeline to complete the testing.

Parents were asked how they would alter their experiences and how these changes would have benefitted them. Two parents stated that it would have been helpful to have been in contact with someone during the time between the screening and the diagnostic testing, such as a parent who had been through the diagnostic process. Four parents reported health care professionals should assure parents, but focus on educating parents that the screening results could mean their child has hearing loss. Participants were asked, “With no change to the system, do you think future parents will receive adequate information and services before leaving the hospital?” None of the participants responded positively to the question, and most participants expressed that improvements must be made to the system.

Limitations

This study was subject to several limitations including a low response rate, only regional data collection, time constraints, and the accuracy of the participants’ memories. The research study received only six responses during the time allotted. The survey was sent to 50 Hands & Voices chapters and 341 audiologists. Only three of the Hands & Voices groups confirmed that they distributed the survey to parents, responses may have been limited to only Colorado,
Connecticut, and North Carolina. The geographical restrictions combined with the low response rate prevented the data from capturing an accurate representation of the experiences of parents across the United States. Additionally, the survey was distributed to parents regardless of how long ago they went through the process with their child. As such, some participants may have relayed their potentially inaccurate memories of the process while some narrated their relatively recent experiences. For example, one participant could not remember what health care professionals she discussed the hearing screening results with.

Participation in this research study required participants to fill out a survey, which may not appeal to them unless they come from extreme circumstances, such as having an experience that was very satisfying or very displeasing. Due to the design of this study, parents from lower socioeconomic status may have been limited from participating in this study because participants were required to access the internet.

Implications

This study sought to improve the interactions between health care professionals and parents. Parents require more educational services, such as instructions regarding the next steps, a timeline of those steps, counseling, contact information for additional health care providers such as audiologists, and information regarding their child’s hearing loss. Parents must be educated about the reality of hearing loss and receive reassurance as they navigate through the process. There also should be standard procedures, ensuring parents receive the same services and education.

Future Research
HEAR ME OUT

The health care system would benefit from research regarding how ethnicity and primary language affects the interactions between families and health care professionals, and how those interactions affect decision-making. Further research should also examine how the severity of the hearing loss diagnosis affects the interactions between the families and health care providers. Research should also address the difference in the mothers’ perspectives when compared to those of the fathers.
References


Appendix A
Hear Me Out: An Evaluation of the Services Provided to Parents Prior to a Diagnosis of Hearing Loss

You are being invited to participate in a research study titled "Hear Me Out: An Evaluation of the Services Provided to Parents Prior to a Diagnosis of Hearing Loss". This study is being conducted by Amber Wagster, an undergraduate student at Harding University. This message is being distributed through your local Hands & Voices Chapter, who indicated that your child has been diagnosed with hearing loss.

This study will explore what services are provided to parents of children who have been diagnosed with hearing loss. Specifically, the study will discuss how efficient the services were in preparing parents for the diagnosis process as well as the next steps, and the parents' anxiety levels regarding their child's possible hearing loss.

If you agree to take part in this study, you will be asked to complete an online survey. This survey will ask about the services you received and the quality of those services. The survey will then ask for your suggestions for improving the diagnosis process. It will take you approximately 10 minutes to complete.

Participants in this study will receive no direct benefit or compensation from their participation; however, the results from the survey will contribute to advances in the process to benefit parents and children in the future.

This researcher believes there are no known risks associated with this research study; however, as with any online related activity the risk of a breach of confidentiality is always possible. Your responses to this survey are anonymous and will be handled in a confidential manner. Your confidentiality will be protected because no identifying information will be requested or collected by your participation in the study. All confidential data will be stored electronically and will be password protected.

Your participation in this study is voluntary, and you can withdraw at any time.

By clicking I agree below, you are indicating that you are a parent/caretaker of a child with hearing loss, have read and understood this consent form, and agree to participate in this research study. Please print a copy of this page for your records.

* Required

- I am a parent/caretaker of a child with hearing loss and I agree to participate.

- I am a parent/caretaker of a child with hearing loss, however I do not wish to participate.

- I am not a parent/caretaker of a child with hearing loss and do not wish to participate.
HEAR ME OUT

<table>
<thead>
<tr>
<th>Age of Child when Diagnosed with Hearing Loss</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.  Newborn</td>
</tr>
<tr>
<td>2.  1 month</td>
</tr>
<tr>
<td>3.  2 months</td>
</tr>
<tr>
<td>4.  3 months</td>
</tr>
<tr>
<td>5.  4 months</td>
</tr>
<tr>
<td>6.  5 months</td>
</tr>
<tr>
<td>7.  6 months</td>
</tr>
<tr>
<td>8.  7 months</td>
</tr>
<tr>
<td>9.  8 months</td>
</tr>
<tr>
<td>10. 9 months</td>
</tr>
<tr>
<td>11. 10 months</td>
</tr>
<tr>
<td>12. 11 months</td>
</tr>
<tr>
<td>13. 12 months</td>
</tr>
<tr>
<td>14. 13 months</td>
</tr>
<tr>
<td>15. 14 months</td>
</tr>
<tr>
<td>16. 15 months</td>
</tr>
</tbody>
</table>
HEAR ME OUT

17. 16 months
18. 17 months
19. 18 months
20. 19 months
21. 20 months
22. 21 months
23. 22 months
24. 23 months
25. 2 years
26. 3 years
27. 4 years
28. Prefer not to say
29. Other

Age of Mother

1. Younger than 18
2. 18
3. 19
HEAR ME OUT

4. 20
5. 21
6. 22
7. 23
8. 24
9. 25
10. 26
11. 27
12. 28
13. 29
14. 30
15. 31
16. 32
17. 33
18. 34
19. 35
20. 36
21. 37
22. 38
23. 39
HEAR ME OUT

24. 40
25. 41
26. 42
27. 43
28. 44
29. 45
30. 46
31. 47
32. 48
33. 49
34. 50
35. Prefer not to say
36. Other

Age of Father

1. Younger than 18
2. 18
3. 19
4. 20
5. 21
HEAR ME OUT

26. 42

27. 43

28. 44

29. 45

30. 46

31. 47

32. 48

33. 49

34. 50

35. Prefer not to say

36. Other

Sex of Participant (Individual who is filling out this form) *
- Female
- Male
- Prefer not to say
- Other

Ethnicity of Parents (Check all that apply) *
- American Indian or Alaska Native
- Asian
- Black or African American
- Native Hawaiian or Other Pacific Islander
- White/Caucasian
- Hispanic/Latino
- Prefer not to say
- Other: __________________________

Do you believe your ethnicity affected your interactions with health care professionals in any way? *
- Yes
- No
How did your ethnicity affect the interactions with the health care professionals? *

Your answer

Native/Primary Language *

- English
- Spanish
- Chinese
- German
- French
- Vietnamese
- Tagalog
- Other Pacific Island Language
- Other:

Was language a limitation in your communication with health care providers? *

- Yes
- No
- Maybe

How did language limit your communication with health care providers? *

Your answer
HEAR ME OUT

<table>
<thead>
<tr>
<th>Marital Status of the Individual Filling out this Form *</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ Single</td>
</tr>
<tr>
<td>☐ Living in common law (Cohabiting)</td>
</tr>
<tr>
<td>☐ Married</td>
</tr>
<tr>
<td>☐ Divorced</td>
</tr>
<tr>
<td>☐ Widowed</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Religious preference *</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ No Religion</td>
</tr>
<tr>
<td>☐ Christian (all denominations)</td>
</tr>
<tr>
<td>☐ Buddhist</td>
</tr>
<tr>
<td>☐ Hindu</td>
</tr>
<tr>
<td>☐ Jewish</td>
</tr>
<tr>
<td>☐ Muslim</td>
</tr>
<tr>
<td>☐ Sikh</td>
</tr>
<tr>
<td>☐ Other:</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Socioeconomic status*</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ Less than $20,000</td>
</tr>
<tr>
<td>☐ $20,000 to $34,999</td>
</tr>
<tr>
<td>☐ $35,000 to $49,999</td>
</tr>
<tr>
<td>☐ $50,000 to $74,999</td>
</tr>
<tr>
<td>☐ $75,000 to $99,999</td>
</tr>
<tr>
<td>☐ Over $100,000</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Highest Education Level of Participant *</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ Less than a high school diploma</td>
</tr>
<tr>
<td>☐ High school degree or equivalent (e.g. GED)</td>
</tr>
<tr>
<td>☐ Some college, no degree</td>
</tr>
<tr>
<td>☐ Associate degree (e.g. AA, AS)</td>
</tr>
<tr>
<td>☐ Bachelor's degree (e.g. BA, BS)</td>
</tr>
<tr>
<td>☐ Master’s degree (e.g. MA, MS, MED)</td>
</tr>
<tr>
<td>☐ Professional degree (e.g. MD, DDS, DVM)</td>
</tr>
<tr>
<td>☐ Doctorate (e.g. PhD, EdD)</td>
</tr>
<tr>
<td>☐ Prefer not to say</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Did your child pass their newborn hearing screening? *</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ Yes</td>
</tr>
<tr>
<td>☐ No</td>
</tr>
</tbody>
</table>
Were you told about your child’s hearing screening results before leaving the hospital? *

- Yes
- No

What health care professional told you the results of your child’s hearing screening? (Audiologist, Pediatrician, etc.) *

- Audiologist
- Nurse
- Pediatrician
- Do not recall
- Other: __________________________

Did you discuss the results with any other health care professional at the hospital? *

- Yes
- No
- NA

What health care professional did you discuss this information with? (Audiologist, Nurse, etc.) *

- Audiologist
- Nurse
- Pediatrician
- Do not recall
- Other: __________________________

Which of these services did you receive before leaving the hospital? *

- Counseling
- Information about children’s hearing loss
- Instructions for retesting
- Timeline for retesting
- Contact information of another professional for retesting
- Information regarding other reasons the child did not pass the screening
- Other: __________________________
Please answer these questions using the scale response as follows:
1. Strongly Disagree
2. Disagree
3. Somewhat Disagree
4. Neither Disagree nor Agree
5. Somewhat Agree
6. Agree
7. Strongly Agree

I experienced anxiety regarding my child's hearing screening results. *

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
<tbody>
<tr>
<td>SD</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>SA</td>
</tr>
</tbody>
</table>

Before leaving the hospital, health care professionals provided services that lessened my anxiety regarding my child's potential hearing loss. *

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</table>

When leaving the hospital, I felt prepared to navigate the process of further testing and possible diagnosis. *

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</table>

I am satisfied with the amount of services I received from the health care professionals before leaving the hospital. *

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I am satisfied with the quality of the services provided to me before leaving the hospital. *

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<td>SA</td>
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</table>
I am satisfied with the amount of time the professional(s) spent educating me. *

Strongly Disagree ○ ○ ○ ○ ○ ○ ○ ○ ○ ○ Strongly Agree

The instructions for follow-up testing were clear. *

Strongly Disagree ○ ○ ○ ○ ○ ○ ○ ○ ○ ○ Strongly Agree

The health care professionals were knowledgeable on newborn hearing screenings. *

Strongly Disagree ○ ○ ○ ○ ○ ○ ○ ○ ○ ○ Strongly Agree

The health care professionals were knowledgeable on what parents should do after the child is referred. *

Strongly Disagree ○ ○ ○ ○ ○ ○ ○ ○ ○ ○ Strongly Agree

The results of the hearing screening were delivered in a supportive manner. *

Strongly Disagree ○ ○ ○ ○ ○ ○ ○ ○ ○ ○ Strongly Agree

The results of the hearing screening were delivered in an unhurried manner. *

Strongly Disagree ○ ○ ○ ○ ○ ○ ○ ○ ○ ○ Strongly Agree
HEAR ME OUT

The health care professional(s) provided adequate information.  *

1 2 3 4 5 6 7  
Strongly Disagree ○ ○ ○ ○ ○ ○ ○  Strongly Agree

I had the opportunity to ask questions.  *

1 2 3 4 5 6 7  
Strongly Disagree ○ ○ ○ ○ ○ ○ ○  Strongly Agree

The health care professional(s) answered my questions in a timely manner.  *

1 2 3 4 5 6 7  
Strongly Disagree ○ ○ ○ ○ ○ ○ ○  Strongly Agree

The health care professional(s) were compassionate towards me.  *

1 2 3 4 5 6 7  
Strongly Disagree ○ ○ ○ ○ ○ ○ ○  Strongly Agree

At the time I left the hospital with my newborn, I felt prepared for the next steps in the process.  *

1 2 3 4 5 6 7  
Strongly Disagree ○ ○ ○ ○ ○ ○ ○  Strongly Agree

Please take time to answer these questions to the best of your ability.

How did the health care professionals ease anxiety towards your child's hearing screening results?  *

Your answer

Regarding the interactions you had before leaving the hospital, how did the health care professionals prepare you for your child's retesting?  *

Your answer

Would you alter any service provided to you? If so, please explain.  *

Your answer

If so, how do you think these services would have been beneficial to you and to future parents?  *

Your answer

With no change, do you think future parents will receive adequate information and services before leaving the hospital? If so, please explain.  *

Your answer

Do you have any additional comments on your experiences with the health care professionals?  *

Your answer