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Abstract

In 2016, the Washington State Early Hearing Detection Diagnosis and Intervention program determined that only 56% of infants diagnosed with hearing loss were identified by three months of age. The aim of the present study was to determine what “barriers” families face when obtaining a diagnosis for their child with hearing loss. A sixteen-question survey was developed using Qualtrics, distributed via email and on the Washington State Hands and Voices Facebook page. The survey collected feedback from parents who were (1) at least 18 years of age, (2) a parent or legal guardian of a child with hearing loss, and (3) a resident of Washington state. Factors were categorized as negative (barriers) or positive. A five point Likert scale was used for responses. The average score for each factor was used in various correlational analyses. Three negative factors were identified and included grief, uncertainty about what steps to take, and the person testing their child’s hearing told them not to worry. Positive factors included resources to use at home and case managers. This study found a significant positive correlation between age of identification and the impact of a child passing an earlier screening, and a significant negative correlation between age of identification and impact of grief, impact of family or friends reassuring the family not to worry, and impact of having a case manager.

Keywords: early intervention, EHDDI, Washington, deaf, hard of hearing, hearing loss, family perspectives

Family Experiences Related to Early Hearing Intervention Guidelines in Washington State

Undiagnosed hearing loss can be devastating, especially for very young children. Without proper assessment, a child may have limited auditory input and access to spoken language. As a result, their speech and language development may be negatively impacted. Therefore, it is beneficial for these children and their families to receive support as early as possible. A network of organizations throughout the United States has developed to support this demographic on the federal, state, and local levels. While many organizations can provide resources for these families, the Joint Committee for Infant Hearing (JCIH) was formed to specifically address the challenges they face. The JCIH has condensed its recommendations into a list of goals for early detection, diagnosis, and intervention. These goals for early intervention are promoted across the country, however data from the Washington State Early Hearing Detection Diagnosis suggests that, as of 2016, these goals were not being met within the state of Washington. The present study will evaluate the implementation of two out of the three specific goals outlined by the JCIH, and seeks to determine what factors negatively and positively influence the experience of families in Washington State when obtaining a diagnosis of hearing loss for their children.

Congenital hearing loss can result from abnormal function of the outer, middle, or inner ear, the auditory nerve, or in rare cases, the central auditory system. Hearing loss from birth can be the result of genetic and environmental factors. The loss may be of varying degree and type, and may exist with other diagnoses or in isolation. Hearing loss is typically an unexpected diagnosis and can have serious consequences such as delay in spoken language development, academic delays, and even emotional or behavioral difficulties (Ching et al., 2017; Stevenson, Kreppner, Pimperton, Worsfold, & Kennedy, 2015). Research has found that similar to other processes, there exists a critical period during development when a child's brain has higher plasticity related to auditory development (Kral, 2013). For a child with hearing loss, technology such as hearing aids or cochlear implants have the greatest positive impact on auditory processing skills and language skills when provided early within this critical period (Yoshinaga-Itano, Sedey, Coulter, & Mehl, 1998). Hearing professionals and early intervention specialists have prioritized the development of an extensive support network, seeking to serve infants and families and circumvent problems resulting from undiagnosed hearing loss.

Most families are underprepared to raise a child with hearing loss because the majority of deaf or hard of hearing infants are born to hearing parents (Kushalnagar et al., 2010). Research has shown that appropriate early intervention benefits the family unit. Specifically, access to comprehensive early intervention services reduces family stress (Meadow-Orlans, 1995), and supports parental self-confidence (Meadow-Orlans & Steinberg, 1993). Families who are supported by early intervention services and follow best practice guidelines offer their children early access to the services dedicated to optimizing communication abilities.

Support for young children with hearing loss and their families exist at the federal, state, and local levels. Infants aged birth to three years who are diagnosed with hearing loss are entitled to early intervention services under the Individuals with Disabilities Education Act (IDEA) Part C federal legislation. In the state of Washington individuals qualify for Part C services based on identified medical risk factors, including: bilateral or unilateral sensorineural or persistent conductive hearing loss (Washington State Department of Early Learning, 2016). Additional state and local organizations within Washington that support this population include: the Washington State Department of Health, the Office of the Deaf and Hard of Hearing, the Children with Special Health Care Needs program, the Early Hearing-loss Detection Diagnosis and Intervention program, the Washington State Department of Early Learning, the Early Support for Infants and Toddlers program, and the Washington State Hands and Voices. Each of these programs was created with the intent to connect families with the appropriate diagnostic and intervention services for their child.

In order to integrate efforts made on the federal, state, and local levels, health care professionals formed the Joint Committee on Infant Hearing (JCIH) in 1969. The committee was dedicated to the early identification of children with hearing loss and the support of newborn hearing screening. Since then, a growing body of research has formed in favor of early intervention, maintaining that individualized early intervention offers this population the best chance of developing language skills in stride with typically developing peers (Moeller, 2000; Yoshinaga-Itano et al., 1998). In 2007, the JCIH released an updated statement concerning infant hearing health and outlined specific goals for newborn hearing screening. The basic three step approach will be referred to in this study as the “1-3-6” goals or guidelines. According to the JCIH, (1) infants should have their hearing screened by one month of age, (2) if an infant fails the first screening and a secondary rescreening they should receive a full diagnostic evaluation by a trained professional by three months of age, and finally (3) all infants who are diagnosed with a permanent hearing loss should receive intervention services by six months of age. The guidelines outlined by the JCIH have been promoted by early intervention specialists and hearing professionals across the country and many state organizations collect information about the implementation of these guidelines. For example, within Washington State, the Early Hearing-loss Detection Diagnosis and Intervention program (EHDDI) collects data on newborn hearing screenings, diagnosis of hearing loss, and enrollment in early intervention.

Nevertheless, the JCIH reported in 2007 “almost half of newborn infants who do not pass the initial screening fail to have appropriate follow-up to confirm the presence of a hearing loss and/or initiate appropriate early intervention services.” (American Speech-Language-Hearing Association, 2007). More recently, in 2016 the Washington State EHDDI program determined that only 56% of infants diagnosed with hearing loss were identified by three months of age. The average age of identification of infants in Washington with permanent hearing loss was 111 days, significantly more than the recommended 90-day goal. This data indicates that while positive progress has been made in Washington State in terms of establishing newborn hearing screening, on average infants are not being identified by 3 months of age. Additionally, of the 183 infants identified with a hearing loss in 2016, 128 enrolled in intervention services, 23 declined services, 14 were not enrolled based on EHDDI’s knowledge, and 18 were not enrolled based on other conditions (Washington State Department of Health, 2017). Without conclusive results from a diagnostic evaluation, infants with hearing loss are at risk of developmental delay and are less likely to be enrolled in intervention services by 6 months of age per JCIH recommendations. These patterns do not comply with the JCIH’s “1-3-6” goals and do not reflect best practices for infants with hearing loss.

The present research seeks to examine the implementation of the “1-3-6” protocol in Washington State. Specifically, this survey will attempt to determine specific factors that have negatively impacted or positively impacted the experience of families in Washington State while pursuing a diagnosis of hearing loss for their child. Identified factors may reveal areas of weakness in the early intervention process that require additional support for Washington families. The hypothesized potential obstacles to follow up include lack of transportation, families living in rural locations, family schedule, availability at the audiologist, administrative error, problems with insurance, cultural differences, misinformation, and a general lack of understanding of the severity of the infant's diagnosis. The complications that these obstacles pose may be exacerbated by a lack of consistency between organizations concerning the regulation of the "1-3-6" protocol in Washington State. Parents and caregivers play an integral role in connecting their child with early intervention services. Without the trust and cooperation of the families infants with hearing loss lose access to the services dedicated to helping them develop to their communication potential.

Methods

Participants

In an attempt to reveal what factors may influence a family's experience in early intervention, the survey measure used in this study was aimed at the parents or legal guardians of children diagnosed with hearing loss. According to Washington State EHDDI, 183 infants were diagnosed with a hearing loss in Washington State in 2016. Researchers estimated that if a similar number of children was diagnosed throughout 2017 and the first part of 2018, then there are approximately 400 families with children diagnosed in the past two years. It was predicted by researchers that the older a child with hearing loss becomes, the less likely their parents were to complete the survey because the family may be less involved with WA Hands and Voices, or simply be less interested in early intervention services. Participants were required to be (1) at least 18 years of age, (2) a parent or legal guardian of a child with hearing loss, and (3) a resident of Washington state. Data related to sex, gender, race, ethnicity, family configuration, socio-economic status, education level or other demographic information was not explicitly included in the study. The participant had the opportunity to include information related to these demographics if they believed it was relevant to the survey questions.

Survey

Survey questions were developed in line with the guidance of the EHDDI coordinators and two families interviewed informally at the start of the study. The survey consisted of 5 questions related to family demographics and 11 questions related to their experience with early intervention specific to one child, resulting in 16 questions total (see Appendix A). However, for families with multiple children who are deaf or hard of hearing, the 11 non-demographic questions were repeated for each additional child. Of the 16 total questions, 9 questions were multiple choice, 5 questions were text entry, and 2 questions were Likert scale questions. There were 7 questions total with an optional text-box where families had the opportunity to write in information. Survey question 13 addressed barriers to diagnosis (Table 1), and survey question 16 addressed positive factors (Table 2). Once participants started the survey, they had one week to complete it. Respondents were able to save their progress and return later to complete the survey if they wished. There was also a back button, so participants were able to revisit questions. The survey was available for approximately three weeks, from May 7th to May 30th and took families, on average, 13 minutes to complete. As a result of its online format, the survey was more accessible to busy families, was easier to distribute, and was able to yield a high number of responses in a short time frame.

Procedures

Participants were linked to a secure and anonymous online survey that was developed using Qualtrics, a survey building program licensed through Western Washington University. A single reusable anonymous link and scripted instructions were emailed to the Washington State Hands and Voices organization (see Appendix B). This link and scripted instructions were distributed via two methods. The link and instructions were posted to the Washington State Hands and Voices official Facebook page and distributed via email to families in Washington State who have at least one child who has been diagnosed with hearing loss, according to Washington State Hands and Voices correspondence. Participants were informed of their rights and the nature of the present study via an informed consent form at the start of the survey per Western Washington University's Human Subjects Research protocol. They were required to indicate that they had read and agreed to the initial consent form before proceeding to the following questions.

Results

Data

Data here reflects 42 children across 39 surveys. Three of the 39 families did not respond to some questions; however, their responses were included in the overall data. Three (7.7%) families reported that their household had two children with a hearing loss. Eight (20.5%) families reported a definite history of hearing loss in their family. All participants were Washington State residents, at least 18 years of age, and the parent or guardian of a child who is deaf or hard of hearing. Families reported that 40 of the 42 children were screened at birth. Screening results for 41 of 42 children indicated Pass LEFT- Pass RIGHT (29.3%), Refer LEFT - Pass RIGHT (9.8%), Pass LEFT - Refer RIGHT (12.1%), and Refer LEFT - Refer RIGHT (48.8%). As stated earlier, it was predicted by researchers that the older a child with hearing loss becomes, the less likely their parents were to complete the survey because the family may be less involved with WA Hands and Voices, or simply be less interested in early intervention services. However, the median current age of child was 7 years old, ranging from 5 months to 22 years. The average age of child at the time of diagnosis was 13.6 months, with a median age at diagnosis of 4 months. Survey question 13 found that three negative factors averaged above a neutral score of 3: factor 10, factor 18, and factor 20 (Figure 1). Survey question 16 identified one positive factor above a neutral score of 3: factor 5 (Figure 2).

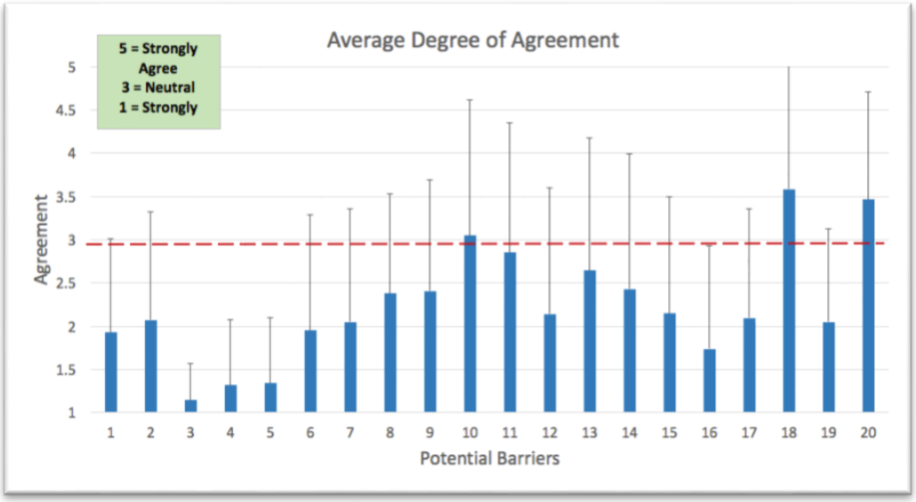

Figure 1: Bar graph of the average degree of agreement in question 13. Families were asked “Do you feel this factor ***negatively*** impacted your family in obtaining a diagnosis for your child's hearing loss?” and were asked to respond on a five-point Likert scale, from 1 = strongly disagree to 5 = strongly agree. The averages showed factor 10, factor 18, and factor 20 scored above a neutral score of 3, represented by the red dashed line.

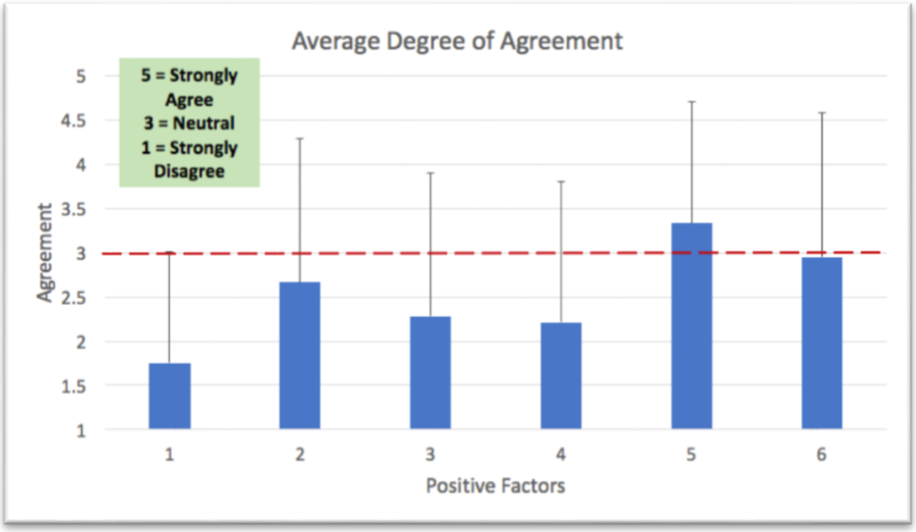

Figure 2: Bar graph of the average degree of agreement in question 16. Families were asked “Do you feel this factor ***positively*** impacted your family in obtaining a diagnosis for your child's hearing loss?” and were asked to respond on a five-point Likert scale, from 1 = strongly disagree to 5 = strongly agree. The averages showed factor 5 scored above a neutral score of 3, represented by the red dashed line.

Negative Factor #	Variable name	Factor statement
1	Family_schedule	Our family schedule conflicted with appointments
2	Audiologist_schedule	We were unable to schedule at the audiologist or other medical professional
3	Transportation	We did not have transportation to appointments
4	Travel_Expenses	We were worried about travel expenses (i.e. gas, parking, bus fare)
5	No_insurance	We did not have insure coverage
6	Cost_of_Appointments	We were worried about the cost of appointments
7	Limited_Services_in_area	There were limited options for services in our area
8	Misinformation_about_HL	We had misinformation about hearing loss in general
9	Unclear_hearing_status	We had a misunderstanding specific to our child's hearing status
10	Person_testing	The person testing our child's hearing told us not to worry when our child did not pass the hearing screenings
11	Family/Friends	Our family/friends told us not to worry when our child did not pass the hearing screenings
12	Ear_Infections	We were waiting for our child's ear infections to resolve
13	Wait_For_Results	It took a long time and multiple appointments before the results of the hearing tests were certain
14	Multiple_Screenings	Our childs hearing was screened more than two times before being referred for an evaluation
15	Passed_Earlier	Our child passed previous hearing screenings, so we were not concerned about their hearing
16	Other_Conditions	Our child's other medical conditions were a priority over their hearing
17	Not_Family_Priority	Potential hearing loss was not our family's priority
18	Grief	We experienced grief or an emotional response after our child did not pass the hearing screenings
19	Child_Seemed_Fine	We weren't confident in the results of the hearing screenings because our child seemed to hear fine
20	Uncertainty	We were not sure what the first steps or next steps should be

Table 1: Negative factors 1-20 from survey question 14.

Positive Factor #	Variable name	Factor statement
1	My_Other_Children	I have been through this process before with my other children
2	Someone_Else	I know someone else with a hearing loss
3	Other_Parents	I was connected with or knew other parents of children with hearing loss
4	Support_Groups	I was connected with or knew of family support groups
5	Home_Resources	I was given resources to use at home
6	Case_Manager	We had case managers

Table 2: Positive factors 1-6 from survey question 16.

	Negative factor	**1. Family Schedule**	**2. Audiologist Schedule**	**3. Transpor-tation**	**4. Travel Expenses**	**5. No Insurance**
Age at Diagnosis	Pearson Correlation	-.274	-.170	-.075	-.128	-.043
	Sig. (2-tailed)	.083	.287	.640	.424	.787
	N	41	41	41	41	41
	Negative factor	**6. Cost of Appointments**	**7. Limited Services in Area**	**8. Misinformation about Hearing Loss**	**9. Unclear Hearing Status**	**10. Person Testing**
Age at Diagnosis	Pearson Correlation	-.111	.023	.046	.132	-.176
	Sig. (2-tailed)	.490	.883	.773	.405	.270
	N	41	42	42	42	41
	Negative factor	**11. Family/Friends**	**12. Ear Infections**	**13. Wait for results**	**14. Multiple screenings**	**15. Passed Earlier**
Age at Diagnosis	Pearson Correlation	-.347*	.039	-.146	-.264	.516**
	Sig. (2-tailed)	0.26	.805	.357	.091	.001
	N	41	42	42	42	41
	Negative factor	**16. Other Conditions**	**17. Not Family Priority**	**18. Grief**	**19. Child Seemed Fine**	**20. Uncertainty**
Age at Diagnosis	Pearson Correlation	-.208	-.225	-.347*	-.259	.118
	Sig. (2-tailed)	.187	.151	.026	.097	.462
	N	42	42	41	42	41

Table 3: Correlations between age of child at the time of diagnosis and negative factors 1-20.

*. Correlation is significant at the 0.05 level (2-tailed)

**. Correlation is significant at the 0.01 level (2-tailed)

	Positive factor	**1. My Other Children**	**2. Someone Else with Hearing Loss**	**3. Other Parents**
Age at Diagnosis	Pearson Correlation	-.236	-.010	-.257
	Sig. (2-tailed)	.137	.950	.100
	N	41	42	42
	Positive factor	**4. Support Groups**	**5. Home Resources**	**6. Case Managers**
Age at Diagnosis	Pearson Correlation	-.189	-.261	-.383*
	Sig. (2-tailed)	.232	.095	.012
	N	42	42	42

Table 4: Correlations between age of child at the time of diagnosis and positive factors 1-6.
*. Correlation is significant at the 0.05 level (2-tailed)
**. Correlation is significant at the 0.01 level (2-tailed)

Discussion

The data collected from these families confirms that for the majority of this group of Washington State families, the national JCIH guidelines were not met. Only 48% (20 of 42 children) of children in this study were diagnosed by three months of age. Recall that in 2016, Washington State EHDDI reported that only 56% of infants in Washington State diagnosed with a hearing loss were identified by three months of age, indicating a persistent problem with identification of hearing loss in our state.

Initially researchers had expected to see positive correlations between reported negative factors, or potential barriers, and the age at diagnosis. A positive correlation would show that as a family reported these negative factors as having a greater impact on their experience, their child's age at the time of diagnosis would increase, driving it farther from the JCIH recommendations. While not a causal relationship, a positive correlation would suggest that the potential barriers played some role in delaying the time of diagnosis. Researchers also predicted negative correlations between reported positive factors and the age at diagnosis. In this context, a negative correlation might suggest that positive factors played some role in the family obtaining an earlier diagnosis.

First, researchers examined correlations between the age at diagnosis and the reported negative factors or potential barriers with an average score above neutral (Table 3). These negative factors were: factor 10: "*The person testing our child's hearing told us not to worry when our child did not pass the hearing screenings*", factor 20: "*We were not sure what the first steps or next steps should be*", and factor 18: "*We experienced grief or an emotional response after our child did not pass the hearing screenings*", averaging 3.05, 3.46, and 3.59 respectively. There was no significant correlation between either the child's age at diagnosis and negative factor 10, or the child's age at diagnosis and negative factor 20. While on average parents reported that factors 10 and 20 had a negative impact on the diagnostic process, there is no significant correlation to suggest they were related to the child's age at the time of diagnosis. However, factors 10 and 20 were still significant from the parent perspective, and self-perceived barriers to diagnosis are noteworthy even in the absence of a significant correlation to age at diagnosis. Contrastingly, there was a significant negative correlation between factor 18 and age at diagnosis. This negative correlation showed that as age at the time of diagnosis increased, the reported impact of grief decreased.

Two additional negative factors that did not average above 3 showed significant correlations to age at diagnosis (Table 3). These negative factors were: factor 11: "*Our family/friends told us not to worry when our child did not pass the hearing screenings*", and factor 15: "*Our child passed previous hearing screenings, so we were not concerned about their hearing*", averaging 2.85 and 2.15 respectively. Factor 11 displayed a significant negative correlation. As the age of ID increased, the impact of family/friends telling family not to worry decreased. On the other hand, factor 15 displayed a significant positive correlation. This positive correlation is unique among all the correlations we found because it matches the prediction made by researchers at the beginning of this study. As the reported negative impact from a passed earlier screen increased, age at diagnosis also increased. Logically, if a child passed a previous screening, the family may not be aware of a potential hearing loss and it is less likely that the family would be concerned about obtaining a diagnosis.

Finally, researchers examined correlations between the age at diagnosis and reported positive factors, which resulted in two cases of interest (Table 4). These positive factors were: factor 5: "*I was given resources to use at home*", and factor 6: "*We had case managers*", averaging 3.33 and 2.95 respectively. While people reported that resources to use at home had a positive impact on their ability to obtain a diagnosis, no significant correlation was found between age at diagnosis and positive factor 5. Conversely, factor 6 displayed a significant negative correlation with age at diagnosis. Families who reported that case managers had a positive impact on their ability to obtain a diagnosis were receiving a diagnosis at an earlier age.

While this study collected useful feedback from Washington State families, some limitations to the study design have been identified. The data collected in this study was self-reported data from families. Several of these families went through the process of diagnosis many years ago and some of these children were identified up to two decades ago. This may impact the families' memory of the diagnostic process, as well as impact the relevance of their experience to this study. Future research may benefit from focusing specifically on children and families who have been diagnosed more recently. For example, focusing the study on families who have been diagnosed within the past five years would provide more current feedback on Washington's early intervention programs. In addition, 3 of the 39 families in this study reported multiple children with hearing loss. Families responded to influencing factors related to their experience with each child, however their unique experiences were still given a larger representation in this study.

This survey itself did not account for factors such as socioeconomic status or geographical location. Demographic information such as this may have been useful in characterizing the respondents as well as in providing context to the reported barriers to diagnosis and intervention. The survey also did not collect specific data concerning the child's hearing loss, such as degree or type of hearing loss or underlying etiology. Information such as the underlying etiology may have been useful for determining if the child's hearing loss was congenital or late onset in nature, which would impact their age at the time of diagnosis.

Finally, this survey did not reach families who were not connected to the organization used to distribute the survey, such as Washington State Hands and Voices or Facebook. As a result, their perspectives and experiences which may have provided useful feedback were not included in the study.

Conclusion

There are complex issues with the way that families move through the early hearing intervention process within Washington State. This study sought to further examine early hearing intervention, attempting to determine potential barriers that may be affecting a Washington family's ability to obtain a diagnosis by the JCIH recommendation of three months of age. Further research into this subject is necessary, however the present study collected useful feedback from Washington State families. Surveys that measure self-perceived barriers as well as factors that positively impacted individual experiences provide important feedback from families to early intervention providers. This feedback may be used to create materials, procedures, or programs that support families as they seek a diagnosis for their child's hearing loss. In addition, this feedback and research surrounding family experiences may be used by activists or organizations seeking to further shape laws or policies concerning early hearing intervention. Strategies to eliminate these potential barriers or perceived barriers to diagnosis must be developed in order to mitigate delays in age of diagnosis and connect children to appropriate interventions services as soon as possible.

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Appendix A

Honors Capstone

Start of Block: WELCOME AND CONSENT STATEMENT

Welcome! The goal of this study is to examine childhood hearing loss in Washington State. Specifically, this research is focused on the intervention process. Research has shown that early intervention is related to positive developmental outcomes in children with hearing loss. This study will look at the time that passes between each step of this process. Your perspective as a parent is valuable to this topic. Your responses in this survey may reveal patterns related to early intervention in our state. The survey will take about 10 minutes to complete. You may use the back button to visit earlier questions. You will have the option to **save your progress**, exit, and return to complete the survey later. If you have more than one child diagnosed with hearing loss, the survey will collect data for **each** child. None of your personal information will be collected in this survey. **The data collected here will <u>not</u> be traceable back to you.** There is no predicted risk or discomfort related to these questions.
Your participation in this study is voluntary. You may choose to **<u>NOT</u>** answer any question, or exit the survey at any time. If you do not know the answer to a question, you can leave it blank. **If you have any questions, please contact us directly. - Rachel Tennant, tennanr@wwu.edu - Douglas Sladen, douglas.sladen@wwu.edu** Thank you for your time!

1. I have read the above information and agree to participate in this survey.
o Yes, I agree to participate (1)
o No, I do not agree to participate (2)

End of Block: WELCOME AND CONSENT STATEMENT
Start of Block: FAMILY BACKGROUND INFORMATION

2. Are you at least 18 years of age?
o Yes (1)
o No (2)

3. Are you the parent or guardian of a child (or children) with hearing loss?
o Yes (1)
o No (2)

4. Are you a resident of Washington State?
o Yes (1)
o No (2)

5. Is there a history of hearing loss in your family?
o Definitely yes (1)
o Probably yes (2)
o Might or might not (3)
o Probably not (4)
o Definitely not (5)

6. How many children in your household have a hearing loss?
▼ One (1) ... More than three (4)
End of Block: FAMILY BACKGROUND INFORMATION
Start of Block: 1st Child

Please complete the following questions for your first child with a hearing loss.

7a. For your FIRST child with hearing loss: How old is your child?
(Enter age with the following format.
Ex: 10 years and 2 months
Ex: 0 years and 3 months)
____

8a. For your FIRST child with hearing loss: Did your child have your hearing screened at birth (or before one month of age)?
o Yes (1)
o No (2)
o Do not know (3)

9a. For your FIRST child with hearing loss: At what age did your child first have their hearing screened?
____

10a. For your FIRST child with hearing loss: What were the results of your child's newborn hearing screening (the first screening)?
o Pass LEFT- Pass RIGHT (1)
o Pass LEFT - Refer RIGHT (2)
o Refer LEFT - Pass RIGHT (3)
o Refer LEFT - Refer RIGHT (4)

11a. For your FIRST child with hearing loss: If your child did not pass the screening in one or both ears, how much time passed between the first screening and the next time their hearing was screened?
o 0-2 weeks (1)
o 2-4 weeks (2)
o 4-6 weeks (3)
o 6-8 weeks (4)
o 8-10 weeks (5)
o 10-12 weeks (6)
o Other (please specify) (7) ____

12a. For your FIRST child with hearing loss: After the initial and follow up screenings, how much time passed before your child returned to be diagnosed?
o 0-2 weeks (1)
o 2-4 weeks (2)
o 4-6 weeks (3)
o 6-8 weeks (4)
o 8-10 weeks (5)
o 10-12 weeks (6)
o Other (please specify) (7) ____

13a. For your FIRST child with hearing loss: At what age was your child diagnosed with a hearing loss?
____

Page Break

The next two questions are about your experience in obtaining a diagnosis of hearing loss for your child. You will be asked to reflect on what negatively and positively impacted your family in this process. If you have more than one child diagnosed with hearing loss, you will be asked these questions for each child. Please answer the following in the context of your FIRST (or only) child who has been diagnosed with hearing loss.

Page Break

14a. *For your FIRST child with hearing loss:*
For each factor listed, please select the choice that best answers the following question:
Do you feel this factor ***negatively*** impacted your family in obtaining a diagnosis for your child's hearing loss?

	Strongly disagree (1)	Disagree (2)	Neutral (3)	Agree (4)	Strongly Agree (5)
Our family schedule conflicted with appointments (1)	○	○	○	○	○
We were unable to schedule at the audiologist or other medical professional (2)	○	○	○	○	○
We did not have transportation to appointments (3)	○	○	○	○	○
We were worried about travel expenses (i.e. gas, parking, bus fare) (4)	○	○	○	○	○
We did not have insurance coverage (5)	○	○	○	○	○
We were worried about the cost of appointments (6)	○	○	○	○	○
There were limited options for services in our area (7)	○	○	○	○	○
We had misinformation about hearing loss in general (8)	○	○	○	○	○
We had a misunderstanding specific to our child's hearing status (9)	○	○	○	○	○
The person testing our child's hearing told us not to worry when our child did not pass the hearing screenings (10)	○	○	○	○	○
Our family/friends told us not to worry when our child did not pass the hearing screenings (11)	○	○	○	○	○
We were waiting for our child's ear infections to resolve (12)	○	○	○	○	○
It took a long time and multiple appointments before the results of the hearing tests were certain (13)	○	○	○	○	○
Our child's hearing was screened more than two times before being referred for an evaluation (14)	○	○	○	○	○

Our child passed previous hearing screenings, so we were not concerned about their hearing (15)	○	○	○	○	○
Our child's other medical conditions were a priority over their hearing (16)	○	○	○	○	○
Potential hearing loss was not our family's priority (17)	○	○	○	○	○
We experienced grief or an emotional response after our child did not pass the hearing screenings (18)	○	○	○	○	○
We weren't confident in the results of the hearing screenings because our child seemed to hear fine (19)	○	○	○	○	○
We were not sure what the first steps or next steps should be (20)	○	○	○	○	○

15a. Please use the space below to briefly describe any other factors that you feel **negatively** influenced your family's ability to reach a diagnosis of hearing loss for your child.

____

Page Break

16a. *For your FIRST child with hearing loss:*

For each factor listed, please select the choice that best answers the following question:

Do you feel that this factor **positively** impacted your family in obtaining a diagnosis for your child's hearing loss?

	Strongly Disagree (1)	Disagree (2)	Neutral (3)	Agree (4)	Strongly agree (5)
I have been through this process before with my other children (1)	○	○	○	○	○
I know someone else with a hearing loss (2)	○	○	○	○	○
I was connected with or knew other parents of children with hearing loss (3)	○	○	○	○	○
I was connected with or knew of family support groups (4)	○	○	○	○	○

I was given resources to use at home (5)	○	○	○	○	○
We had case managers (6)	○	○	○	○	○

17a. Please use the space below to briefly describe any other factors that you feel positively influenced your family's ability to reach a diagnosis of hearing loss for your child.

____

End of Block: 1st Child

Start of Block: 2nd Child

Please complete the following questions for your second child with a hearing loss.

7b. For your SECOND child with hearing loss: How old is your child?
(Enter age with the following format.
Ex: 10 years and 2 months
Ex: 0 years and 3 months)

____

8b. For your SECOND child with hearing loss: Did your child have their hearing screened at birth (or before one month of age)?

o Yes (1)
o No (2)
o Do not know (3)

9b. For your SECOND child with hearing loss: At what age did your child first have their hearing screened?

____

10b. For your SECOND child with hearing loss: What were the results of your child's newborn hearing screening (the first screening)?

o Pass LEFT - Pass RIGHT (1)
o Pass LEFT - Refer RIGHT (2)
o Refer LEFT - Pass RIGHT (3)
o Refer LEFT - Refer RIGHT (4)

11b. For your SECOND child with hearing loss: If your child did not pass the screening in one or both ears, how much time passed between the first screening and the next time their hearing was screened?

o 0-2 weeks (1)
o 2-4 weeks (2)
o 4-6 weeks (3)
o 6-8 weeks (4)
o 8-10 weeks (5)
o 10-12 weeks (6)
o Other (please specify) (7) ____

12b. For your SECOND child with hearing loss: After the initial and follow up screenings, how much time passed before your child returned to be diagnosed?

o 0-2 weeks (1)
o 2-4 weeks (2)
o 4-6 weeks (3)
o 6-8 weeks (4)

o 8-10 weeks (5)
o 10-12 weeks (6)
o Other (please specify) (7) ____

13b. For your SECOND child with hearing loss: At what age was your child diagnosed with a hearing loss?
____

Page Break

The next two questions are about your experience in obtaining a diagnosis of hearing loss for your child. You will be asked to reflect on what negatively and positively impacted your family in this process. If you have more than one child diagnosed with hearing loss, you will be asked these questions for each child. Please answer the following in the context of your SECOND child who has been diagnosed with hearing loss.

Page Break

14b. *For your SECOND child with hearing loss:*
For each factor listed, please select the choice that best answers the following question:
Do you feel that this factor negatively impacted your family in obtaining a diagnosis for your child's hearing loss?

	Strongly Disagree (1)	Disagree (2)	Neutral (3)	Agree (4)	Strongly agree (5)
Our family schedule conflicted with appointments (x1)	○	○	○	○	○
We were unable to schedule at the audiologist or other medical professional (x2)	○	○	○	○	○
We did not have transportation to appointments (x3)	○	○	○	○	○
We were worried about travel expenses (i.e. gas, parking, bus fare) (x4)	○	○	○	○	○
We did not have insurance coverage (x5)	○	○	○	○	○
We were worried about the cost of appointments (x6)	○	○	○	○	○
There were limited options for services in our area (x7)	○	○	○	○	○
We had misinformation about hearing loss in general (x8)	○	○	○	○	○
We had a misunderstanding specific to our child's hearing status (x9)	○	○	○	○	○
The person testing our child's hearing told us not to worry	○	○	○	○	○

when our child did not pass the hearing screenings (x10)					
Our family/friends told us not to worry when our child did not pass the hearing screenings (x11)	○	○	○	○	○
We were waiting for our child's ear infections to resolve (x12)	○	○	○	○	○
It took a long time and multiple appointments before the results of the hearing tests were certain (x13)	○	○	○	○	○
Our child's hearing was screened more than two times before being referred for an evaluation (x14)	○	○	○	○	○
Our child passed previous hearing screenings, so we were not concerned about their hearing (x15)	○	○	○	○	○
Our child's other medical conditions were a priority over their hearing (x16)	○	○	○	○	○
Potential hearing loss was not our family's priority (x17)	○	○	○	○	○
We experienced grief or an emotional response after our child did not pass the hearing screenings (x18)	○	○	○	○	○
We weren't confident in the results of the hearing screenings because our child seemed to hear fine (x19)	○	○	○	○	○
We were not sure what the first steps or next steps should be (x20)	○	○	○	○	○

15b. Please use the space below to briefly describe any other factors that you feel negatively influenced your family's ability to reach a diagnosis of hearing loss for your SECOND child with hearing loss.

____

Page Break

16b. *<u>For your SECOND child with hearing loss:</u>*
For each factor listed, please select the choice that best answers the following question:
Do you feel that this factor **positively** impacted your family in obtaining a diagnosis for your child's hearing loss?

	Strongly Disagree (1)	Disagree (2)	Neutral (3)	Agree (4)	Strongly agree (5)
I have been through this process before with my other children (x1)	○	○	○	○	○
I know someone else with a hearing loss (x2)	○	○	○	○	○
I was connected with or knew other parents of children with hearing loss (x3)	○	○	○	○	○
I was connected with or knew of family support groups (x4)	○	○	○	○	○
I was given resources to use at home (x5)	○	○	○	○	○
We had case managers (x6)	○	○	○	○	○

17b. Please use the space below to briefly describe any other factors that you feel positively influenced your family's ability to reach a diagnosis of hearing loss for your SECOND child with hearing loss.

____

End of Block: 2nd Child
Start of Block: 3rd Child

Please complete the following questions for your third child with a hearing loss.

7c. For your THIRD child with hearing loss: How old is your child?
(Enter age with the following format.
Ex: 10 years and 2 months
Ex: 0 years and 3 months)

____

8c. For your THIRD child with hearing loss: Did your child have their hearing screened at birth (or before one month of age)?

o Yes (1)
o No (2)
o Do not know (3)

9c. For your THIRD child with hearing loss: At what age did your child first have their hearing screened?

____

10c. For your THIRD child with hearing loss: What were the results of your child's newborn hearing screening (the first screening)?

o Pass LEFT - Pass RIGHT (1)
o Pass LEFT - Refer RIGHT (2)
o Refer LEFT - Pass RIGHT (3)
o Refer LEFT - Refer RIGHT (4)

11c. For your THIRD child with hearing loss: If your child did not pass the screening in one or both ears, how much time passed between the first screening and the next time their hearing was screened?
o 0-2 weeks (1)
o 2-4 weeks (2)
o 4-6 weeks (3)
o 6-8 weeks (4)
o 8-10 weeks (5)
o 10-12 weeks (6)
o Other (please specify) (7) ____

12c. For your THIRD child with hearing loss: After the initial and follow up screenings, how much time passed before your child returned to be diagnosed?
o 0-2 weeks (1)
o 2-4 weeks (2)
o 4-6 weeks (3)
o 6-8 weeks (4)
o 8-10 weeks (5)
o 10-12 weeks (6)
o Other (please specify) (7) ____

13c. For your THIRD child with hearing loss: At what age was your child diagnosed with a hearing loss?
____

Page Break

The next two questions are about your experience in obtaining a diagnosis of hearing loss for your child. You will be asked to reflect on what negatively and positively impacted your family in this process. If you have more than one child diagnosed with hearing loss, you will be asked these questions for each child. Please answer the following in the context of your THIRD child who has been diagnosed with hearing loss.

Page Break

14c. *For your THIRD child with hearing loss:*
For each factor listed, please select the choice that best answers the following question:
Do you feel that this factor negatively impacted your family in obtaining a diagnosis for your child's hearing loss?

	Strongly Disagree (1)	Disagree (2)	Neutral (3)	Agree (4)	Strongly agree (5)
Our family schedule conflicted with appointments (x1)	○	○	○	○	○
We were unable to schedule at the audiologist or other medical professional (x2)	○	○	○	○	○
We did not have transportation to appointments (x3)	○	○	○	○	○
We were worried about travel expenses (i.e. gas, parking, bus fare) (x4)	○	○	○	○	○

We did not have insurance coverage (x5)	○	○	○	○	○
We were worried about the cost of appointments (x6)	○	○	○	○	○
There were limited options for services in our area (x7)	○	○	○	○	○
We had misinformation about hearing loss in general (x8)	○	○	○	○	○
We had a misunderstanding specific to our child's hearing status (x9)	○	○	○	○	○
The person testing our child's hearing told us not to worry when our child did not pass the hearing screenings (x10)	○	○	○	○	○
Our family/friends told us not to worry when our child did not pass the hearing screenings (x11)	○	○	○	○	○
We were waiting for our child's ear infections to resolve (x12)	○	○	○	○	○
It took a long time and multiple appointments before the results of the hearing tests were certain (x13)	○	○	○	○	○
Our child's hearing was screened more than two times before being referred for an evaluation (x14)	○	○	○	○	○
Our child passed previous hearing screenings, so we were not concerned about their hearing (x15)	○	○	○	○	○
Our child's other medical conditions were a priority over their hearing (x16)	○	○	○	○	○
Potential hearing loss was not our family's priority (x17)	○	○	○	○	○
We experienced grief or an emotional response after our child did not pass the hearing screenings (x18)	○	○	○	○	○

We weren't confident in the results of the hearing screenings because our child seemed to hear fine (x19)	○	○	○	○	○
We were not sure what the first steps or next steps should be (x20)	○	○	○	○	○

15c. Please use the space below to briefly describe any other factors that you feel negatively influenced your family's ability to reach a diagnosis of hearing loss for your THIRD child with hearing loss.

____

Page Break

16c. *For your THIRD child with hearing loss:*
For each factor listed, please select the choice that best answers the following question:
Do you feel this factor positively impacted your family in obtaining a diagnosis for your child's hearing loss?

	Strongly Disagree (1)	Disagree (2)	Neutral (3)	Agree (4)	Strongly agree (5)
I have been through this process before with my other children (x1)	○	○	○	○	○
I know someone else with a hearing loss (x2)	○	○	○	○	○
I was connected with or knew other parents of children with hearing loss (x3)	○	○	○	○	○
I was connected with or knew of family support groups (x4)	○	○	○	○	○
I was given resources to use at home (x5)	○	○	○	○	○
We had case managers (x6)	○	○	○	○	○

17c. Please use the space below to briefly describe any other factors that you feel positively influenced your family's ability to reach a diagnosis of hearing loss for your THIRD child with hearing loss.

____

End of Block: 3rd Child

Appendix B

Dear Participant,

My name is Rachel Tennant and I am an undergraduate student at Western Washington University studying Communication Sciences and Disorders. I am researching the experiences of Washington State families with children who are deaf or hard of hearing. The goal of this study is to identify the barriers that families face when working through the identification of hearing loss.

We are interested in feedback from families of children who are 18-years-old or younger. If you choose to participate in this study, you will complete a short 5-10 minute survey. The survey is in English and there are about 20 questions. There are more questions if you have more than one child who is deaf or hard of hearing. You may skip any question or quit the survey at any time. No compensation will be provided for your participation. However, your responses may help us understand more about the experience of families going through the intervention process in our state.

The survey will collect no identifying information from you and your responses will not be traceable back to you.

My advisor for this project is Doug Sladen, Ph.D. If you have any questions please contact us directly.

Survey Link: https://wwu.az1.qualtrics.com/jfe/form/SV_3ISfwkZ9hHqR5Ot

Thank you for your time,

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