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Family Experiences Related to Early Hearing Intervention Guidelines in Washington State

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Introduction

Undiagnosed hearing loss can have an especially devastating effect on young children. Without proper assessment, a child may have limited access to language and auditory input, and their speech and language skills may be negatively impacted. Research has shown that early intervention is related to positive developmental outcomes in children with hearing loss [1].

Therefore, it is beneficial for these children and their families to receive support as early as possible. According to the Joint Committee on Infant Hearing:

- (1) infants should have their hearing screened by one month of age,
- (2) if an infant does not pass the first screening or a secondary rescreening, they should receive a full diagnostic evaluation 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. [2]

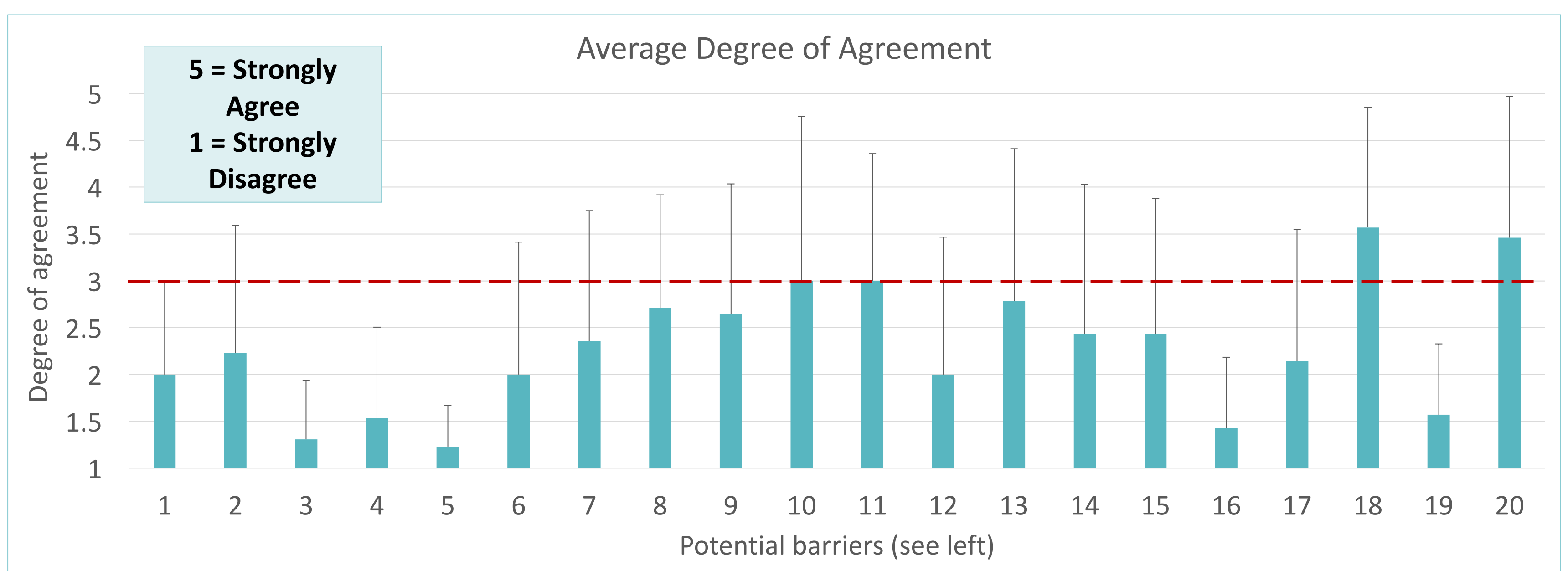
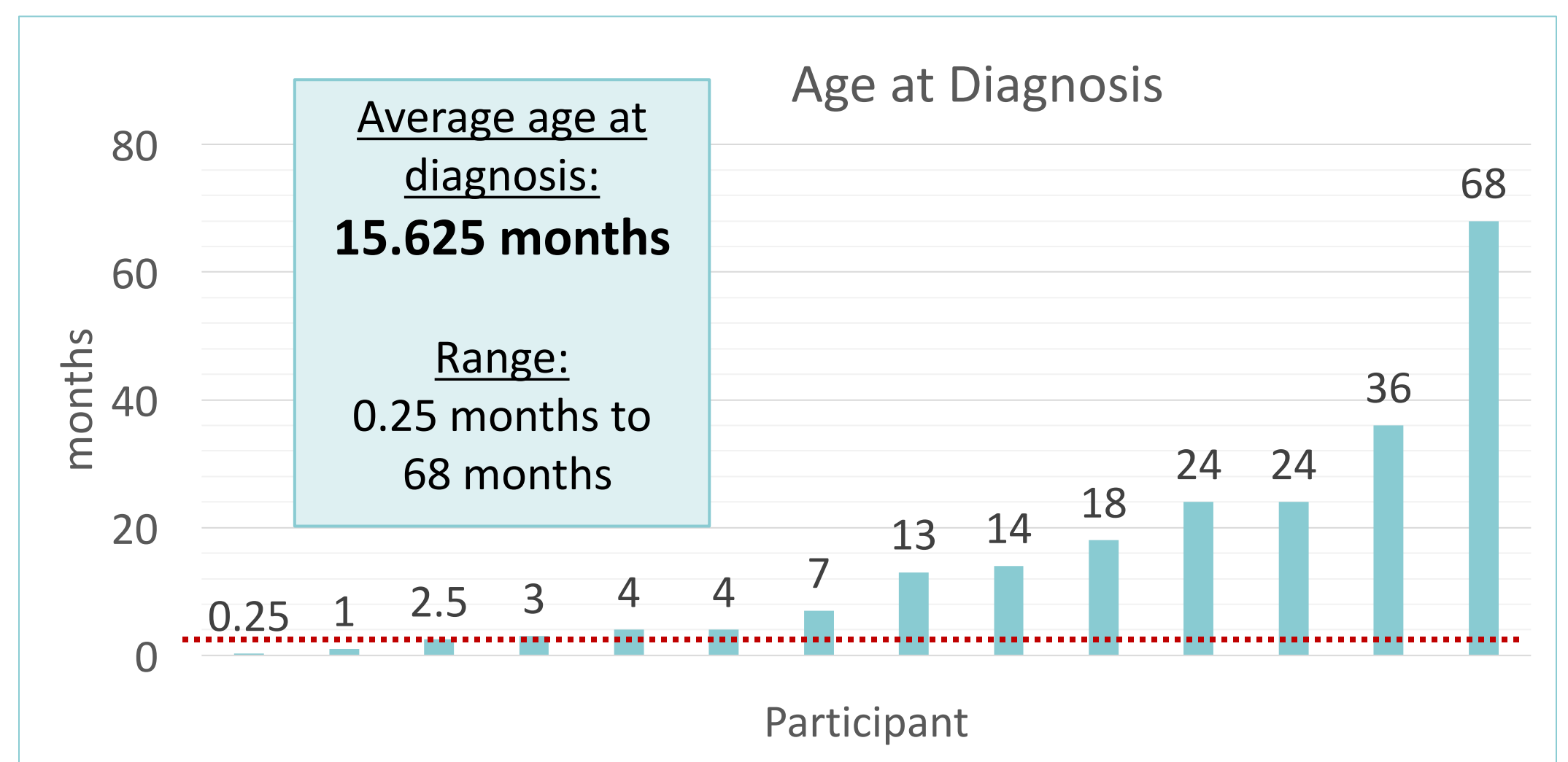
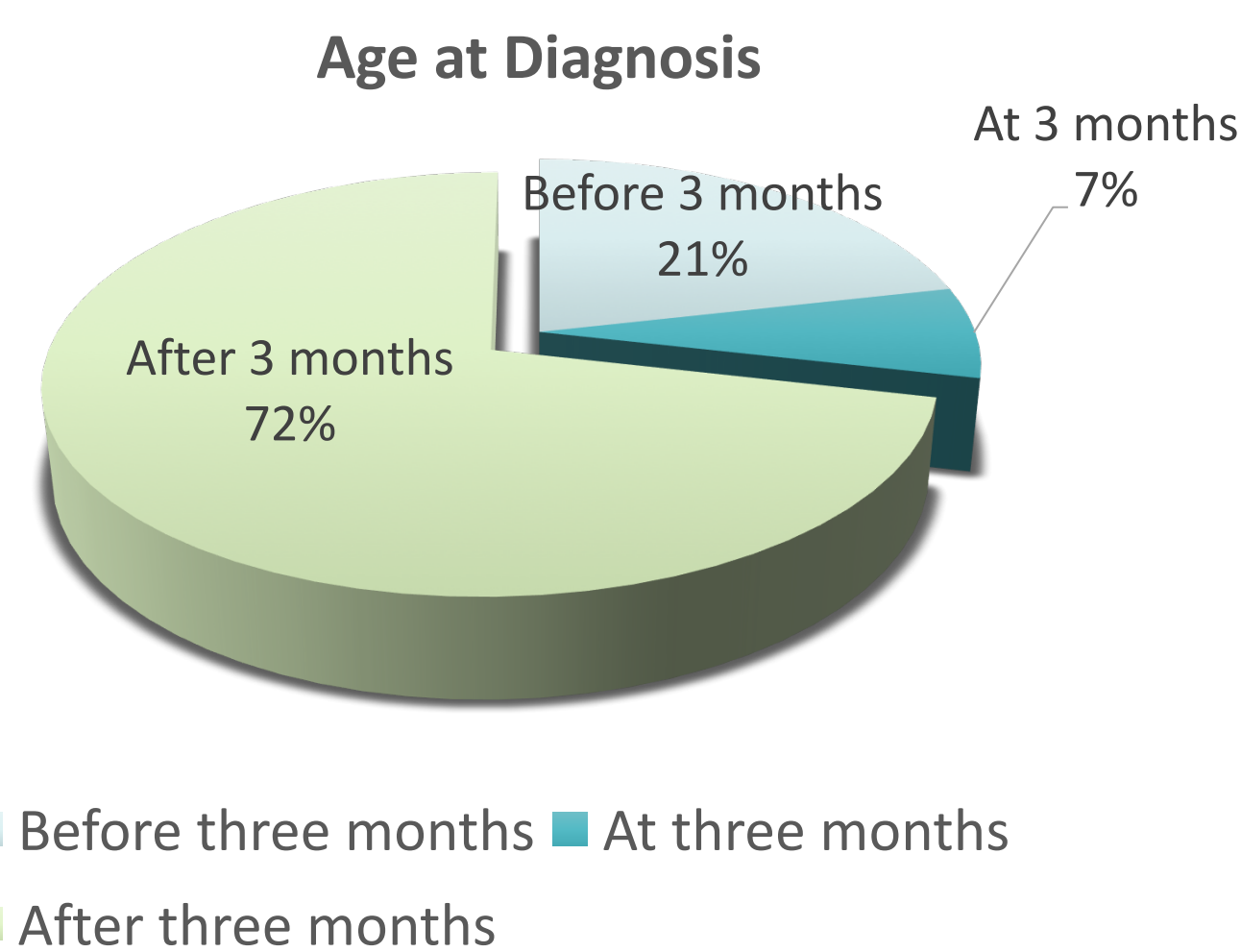
In 2016, the Washington State EHDDI program determined that only 56% of infants diagnosed with hearing loss were identified by three months of age. The average age of identification of infants in Washington with permanent hearing loss was 111 days. [3]

The aim of the present study is to determine what barriers families face when obtaining a diagnosis for their child with hearing loss.

Identified factors may reveal areas of weakness in the early intervention process that require additional support for Washington families.

Potential Barriers

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



Results

Data here reflects 14 children across 13 surveys. One family reported two children with hearing loss. Two families reported a definite history of hearing loss in their family. All participants were Washington State residents. The median current age of child was 65.5 months, ranging from 5 months to 222 months. The average age of child at the time of diagnosis was 15.625 months. Families reported that all 14 children had their hearing screening at birth. Screening results indicated Pass LEFT- Pass RIGHT (28.57%), Refer LEFT - Pass RIGHT (14.29%), Pass LEFT - Refer RIGHT (7.14%), and Refer LEFT - Refer RIGHT (50%). One family did not respond to half of the question related to potential barriers, however their response was still included.

Discussion

- On average, a **family's grief or emotional response to their child's hearing status and uncertainty about first or next steps in the diagnosis process** were most often reported to have had a negative impact on a family's ability to obtain a diagnosis for their child.
- "We experienced grief or an emotional response after our child did not pass the hearing screenings" 3 of 14 cases – strongly agree; 6 of 14 – agree,
- "We were not sure what the first steps or next steps should be" 4 of 13 – strongly agree; 4 of 13 – agree,
- "The person testing our child's hearing told us not to worry when our child did not pass the hearing screenings" 4 of 14 cases – strongly agree; 3 of 14 cases – agree,
- "It took a long time and multiple appointments before the results of the hearing tests were certain" 4 of 14 cases – strongly agree,
- Other factors written in by families reflected themes of inconsistency from providers during the screening process and false reassurance from providers

Limitations to Study

- Survey may not reach the families who never came back, especially those who are not connected to the organizations we used to disperse the survey
- Data surrounding only the most recent experiences may give a more accurate picture of early hearing intervention at present.

References

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