



Oregon EHDI Program

It's as Easy as 1,3,6!

Early Hearing Detection and Intervention Parent Survey

Sharon Coryell
10/1/2013

Survey Results

Oregon Early Hearing Detection and Intervention Program Parent Survey October 2013

Summary

The Oregon Early Hearing Detection and Intervention (EHDI) program implemented a small-scale survey to evaluate Early Intervention (EI) program satisfaction of families whose children were diagnosed with hearing loss and are/were participating in early intervention.

Page | 2

The main purpose of the survey was to:

- Explore the type and extent of information and services that children with hearing loss and their families receive from Oregon's EI program
- Assess families' satisfaction with EI program services.
- Generate discussion and enhancement of the current program methods of EI and EHDI programs.

The survey was conducted using SurveyMonkey and was open from July 1, 2013 to September 30, 2013. A total of 77 respondents (47.2%) completed the survey.

- The survey found that the Oregon Early Intervention program had many strengths. On average (74.1%) respondents reported "yes, very well" when asked "Do you feel that your early intervention program is providing services that will help your child successfully communicate?" although some reported that more visits with EI services were needed/wanted.
- Over 77% of respondents reported that they were "very satisfied" with communication between their child's doctor and other health care providers, and about the care their child is receiving. 5.5% reported being "somewhat dissatisfied".
- Over 88% reported having talked with an Early Intervention Specialist about their child's hearing.
- 97.0% of respondents reported that a public early intervention program provided services to their child.
- 54.4% of respondents reported having Medicaid/Oregon Health Plan insurance. 2.7% reported to having no insurance.
- 71.6% of respondents reported "always" being given the specific information they needed about their child's hearing loss from their doctors and other health care providers.
- Of the 77 respondents, 80.5% (62 respondents) reported to be receiving early intervention services.
- Several barriers to parents in receiving early intervention services were identified, including delays in being contacted, transportation challenges, difficulties scheduling appointments, and lack of child care.
- Over 21% of respondents reported there having been problems with health insurance not paying for services or equipment that was needed for the child.

Survey Results

Background

Oregon's Early Hearing Detection and Intervention (EHDI) program is administered by the Center for Prevention and Health Promotion (CP and HP), which is part of the Public Health Division (PHD) of the Oregon Health Authority (OHA). In collaboration with hospitals, audiologists, local public health departments, and Oregon's Early Intervention (EI) program, the EHDI program ensures that the following Center for Disease Control and Prevention's (CDC) national recommendations are met.

- All newborns screen for hearing loss before 1 month of age
- Diagnostic audiology evaluations provided before 3 months of age
- Enrollment in early intervention before 6 months of age

Administered by the Oregon Department of Education (ODE), the EI program provides children under three years of age with an array of interventions, which, for those children with hearing loss, includes hearing aid fitting, speech/language stimulation, and family support.

The survey population consisted of families with children diagnosed with hearing loss in 2011-2012 and participating in Oregon's EI program. The survey was a half mailed and half emailed survey questionnaire for English speakers. Recommended by Nurit Fischler, Spanish speaking families received a phoned survey translation for an increased response rate. There were two rounds of surveys as well as a reminder letter following the first survey release. Those that did not respond by email were sent a mailed survey on the second round. [22 respondents (29%) completed the survey online, 43 respondents (56%) completed the survey by mail, and 12 respondents (16%) completed the survey by phone].

No question was mandatory and several respondents skipped questions, thus the percentages in the analysis are based on those respondents who answered the question rather than skipped it. Procedures were developed by Heather Morrow-Almeida, MPH, EHDI Program Coordinator and the Maternal and Child Health assessment and evaluation staff under the guidance of the Oregon EHDI Advisory Committee.

Preliminary analysis plan:

- What are the opportunities for improvement?
- Where are parents getting support and information?
- What are parents' communication goals for child?
- Are there differences / disparities in experiences by language?
- Are communication goals influenced by information received/provider of information?
- Are parent communication goals being met?
- Are children meeting milestones?
- What types of support are families receiving/being impacted by?
- How often do diagnosed children with hearing loss have additional disabilities?
- What are some barriers to success for families?
- What is the perceived quality of EI services being received?
- What is the perceived quality of care coordination and information provided?

Survey Results

Respondent roles:

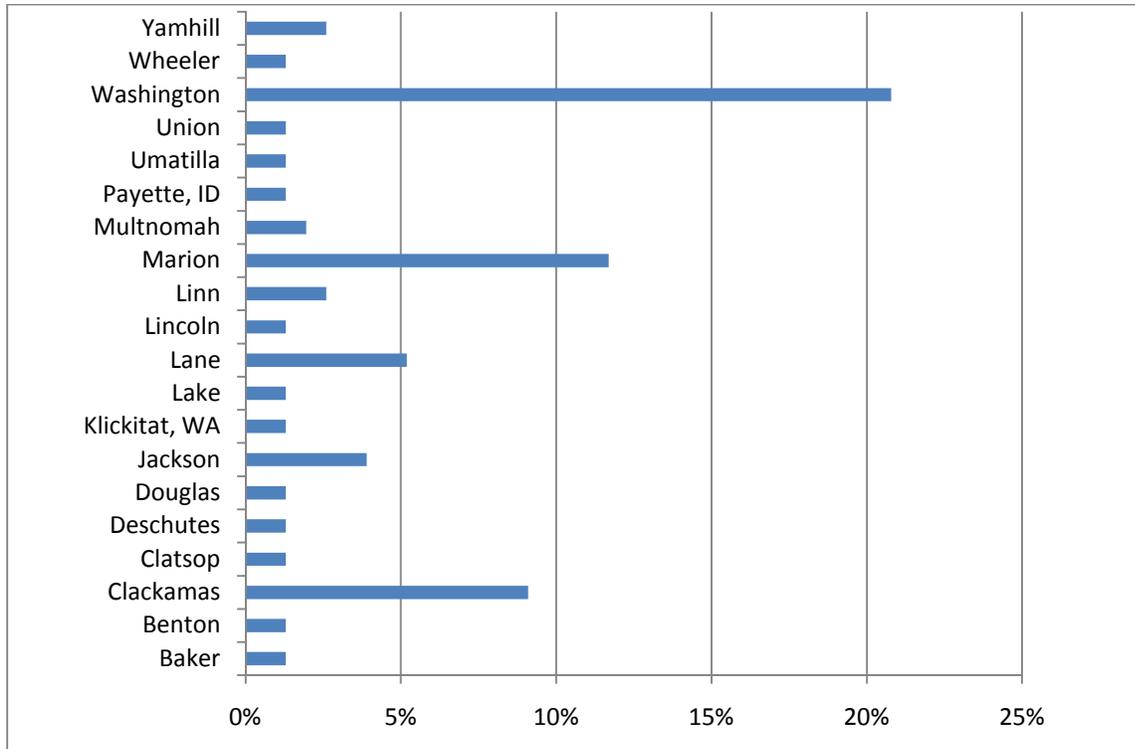
Table 1. All but one of those who responded to the survey were the mothers of children diagnosed with hearing loss in 2011-2012 and participating in an early intervention program.

	Response Percent	Response Count
Relationship to child		
Mother	98.7%	76
Father	1.3%	1
Grandparent	0.0%	0
Foster Parent	0.0%	0
Other (please specify)	0.0%	0
Primary Language Used in the Home		
English	78.1%	57
Spanish	17.8%	13
Russian	1.4%	1
Chinese	1.4%	1
American Sign	1.4%	1
Other (please specify)	11.0%	8

Page | 4

*****Other languages include Somalian, Ukrainian, Vietnamese, Arabic, and German**

Figure 1. Respondents based on county



Survey Results

Effectiveness of Early Intervention services

Respondents were asked, “How can the state Early Hearing Detection and Intervention Program better support families, like yours, at this time?” On average, respondents reported that they were satisfied with the EHDI program but a few reported the following areas of improvement.

- More information to include all types of communication
- More home visits
- More events for families in rural areas
- A step by step guide such as a “map” of who is involved
- A calendar of suggested or important milestones
- A tip sheet on next steps
- Need for more information in Spanish
- Provide families with sign language classes to better help them communicate with their children

Effectiveness of Birth Provider

Most (84%) respondents reported that their child’s hearing loss was identified at birth and that there was nothing further their birth provider could have done differently.

The following represent reported areas where birth providers could improve:

- Inadequate information about seriousness of first failed hearing test and so did not retest as soon as needed/recommended
- Lack of general information about hearing loss
- Impatience and insensitivity to child’s failed screening

Effectiveness of Audiologist

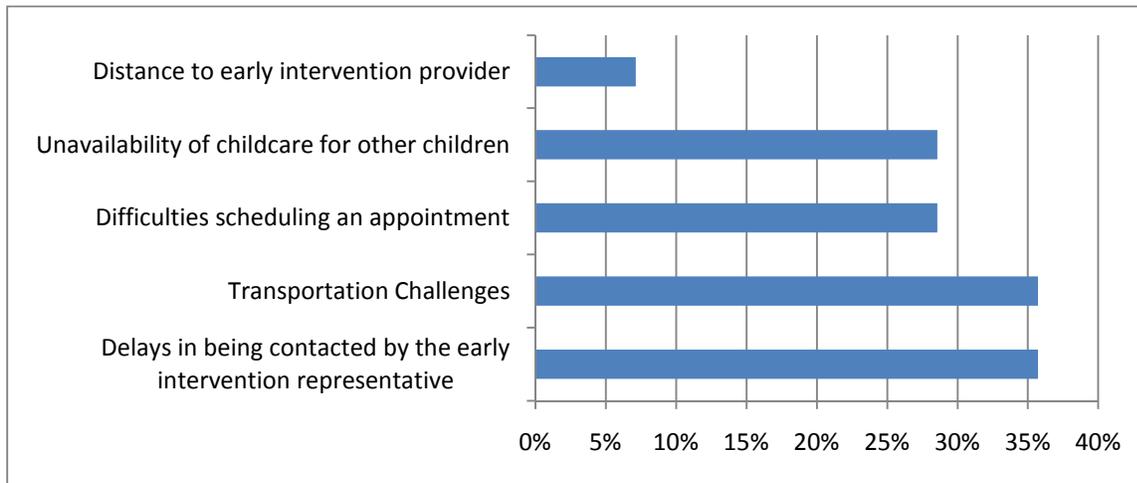
The majority (90%) of respondents reported their audiologists did everything necessary to diagnose their child by three months. Of those reporting weaknesses, appointment scheduling was the greatest barrier to having their child diagnosed by the benchmark.

Effectiveness of Pediatrician

Most (93%) of respondents reported that their child’s hearing loss was diagnosed by three months. Areas of improvement were identified to be pediatrician’s lack of follow-up.

Survey Results

Figure 2. Barriers to families receiving early intervention services



*****Other barriers reported included cuts to funding and program interruptions.**

******69% of families skipped this question stating that no barriers were present**

Figure 3. Barriers to families getting their child's hearing loss diagnosed

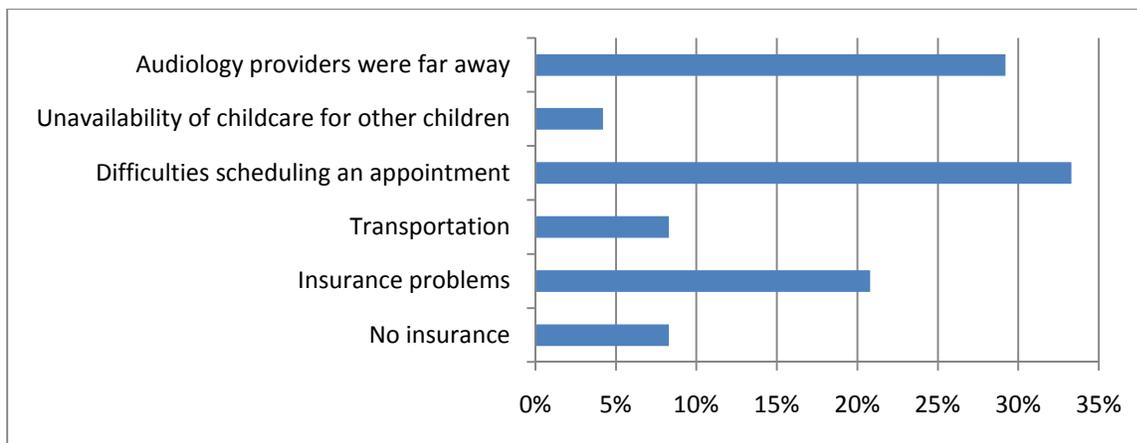


Table 2. Reported insurance problems not paying for services or equipment needed

	Response Percent	Response Count
Yes	21.1%	15
No	78.9%	56
Descriptions of problems respondents have encountered		
	Payment for Cochlear Implant surgery	
	Payment for ear molds, hearing aids	
	Payment for Oticon Bone Anchor Hearing Aids (BAHA)	
	Only pay for 30 visits per calendar year	

Survey Results

Figure 4: Families were asked to describe their child’s hearing to the best of their ability. Responses were cross-referenced with EHDI-IS diagnostic record to determine accuracy. Respondents were rated on a point system where there were 2 points possible per ear (4 points total). Respondents received 1 point for correct concept of diagnoses with incorrect vocabulary. Respondents received zero points if neither ear was correct in vocabulary or concept.

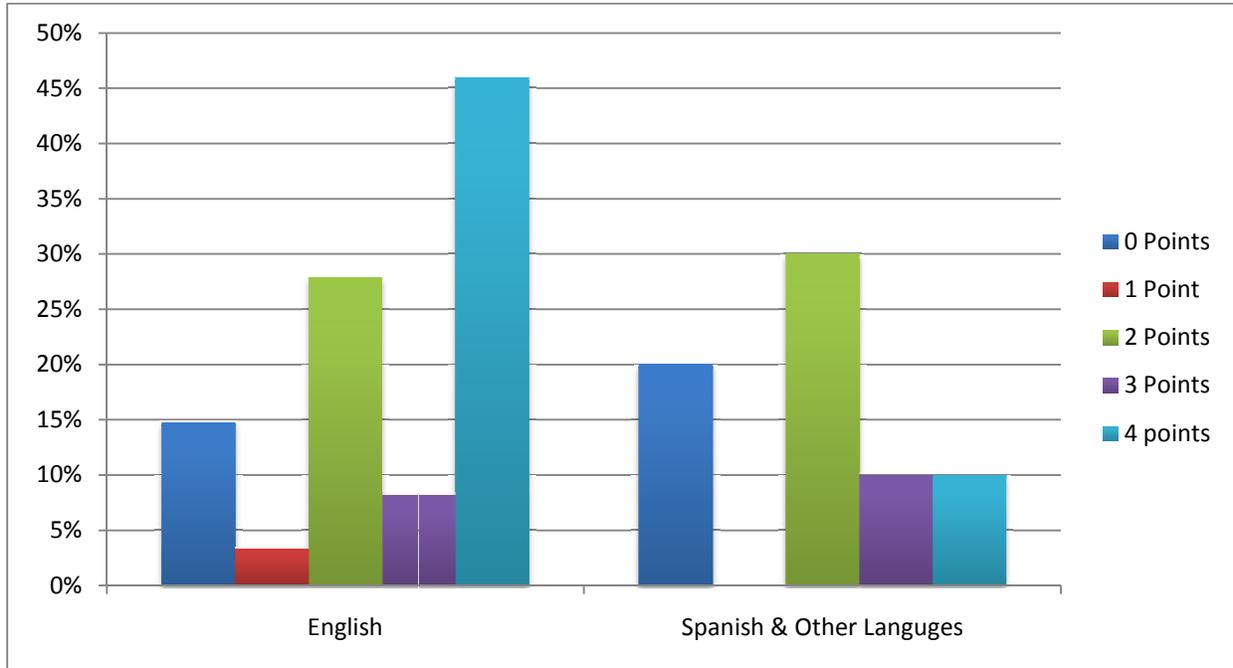


Table 3. Reported siblings with hearing loss

	Response Percent	Response Count
Yes	5.4%	4
No	94.6%	70
If yes, please describe each sibling’s hearing loss:		
	Severe hearing loss	
	Mild to moderate bilateral loss- Loss of mid-frequencies	
	Possible bone fusion, 90% loss	
	Slight hearing loss	

Survey Results

Figure 5. Reported communication goals child with hearing loss

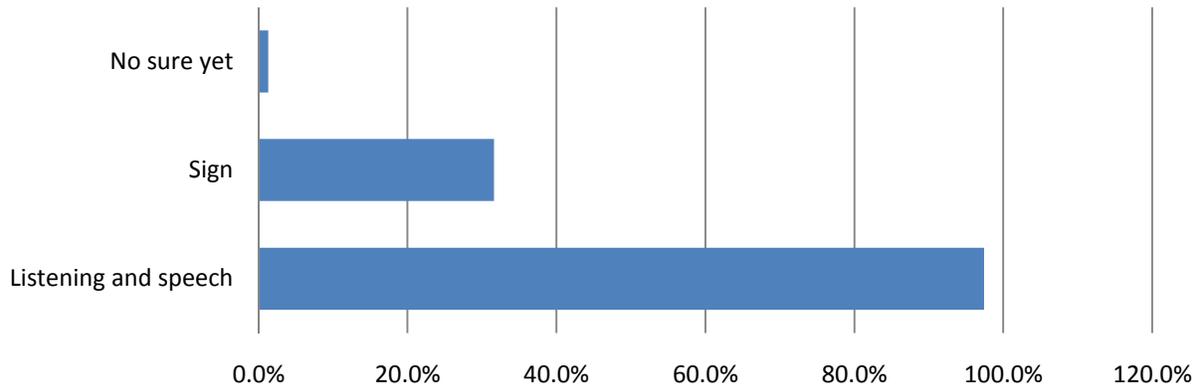
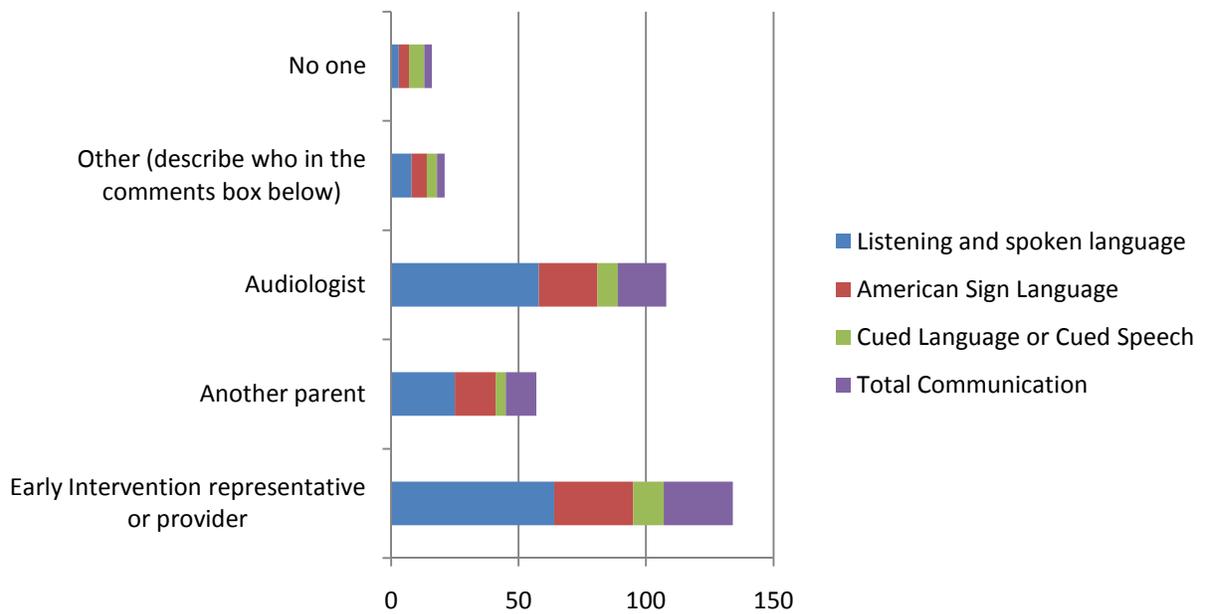


Figure 6. Communication options discussed with specific individuals



***Some others described were Guide by Your Side, Hands and Voices, teachers, doctors, CaCoon Nurse, speech therapists, and Tucker Maxon.

Survey Results

Table 4. Besides hearing loss, does your child have other health issues?

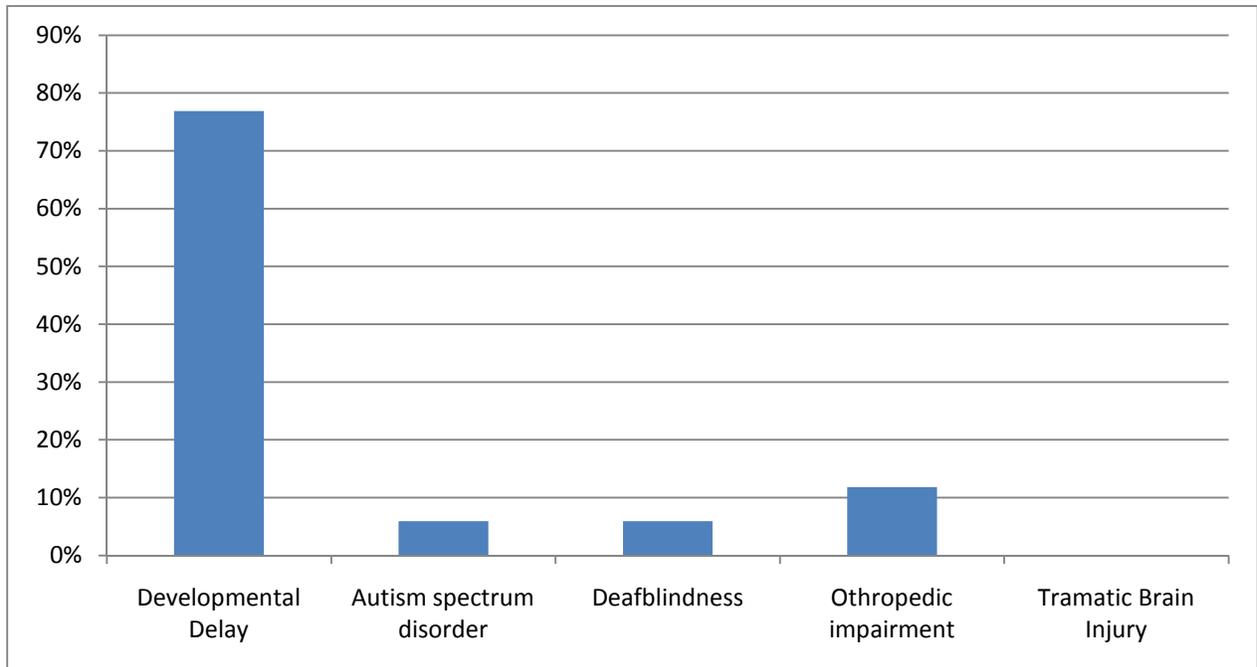
	Response Percent	Response Count
Chronic health condition (asthma, down syndrome, autism, other)	13.2%	9
Need for therapy or special health services	14.7%	10
Ongoing need for medication, special foods, or equipment	7.4%	5
No, my child does not have other health issues	76.5%	52

Page | 9

Table 5. Does your child have any other diagnosed conditions in addition to hearing impairment?

	Response Percent	Response Count
Yes	29.9%	20
No	65.7%	44
I do not know	4.5%	3

Figure 7. Of those parents who reported their child having additional diagnosed conditions, parents selected all of the early intervention eligibilities s/he has been given



Survey Results

Figure 8. Respondents reported who they talked with about their child's hearing

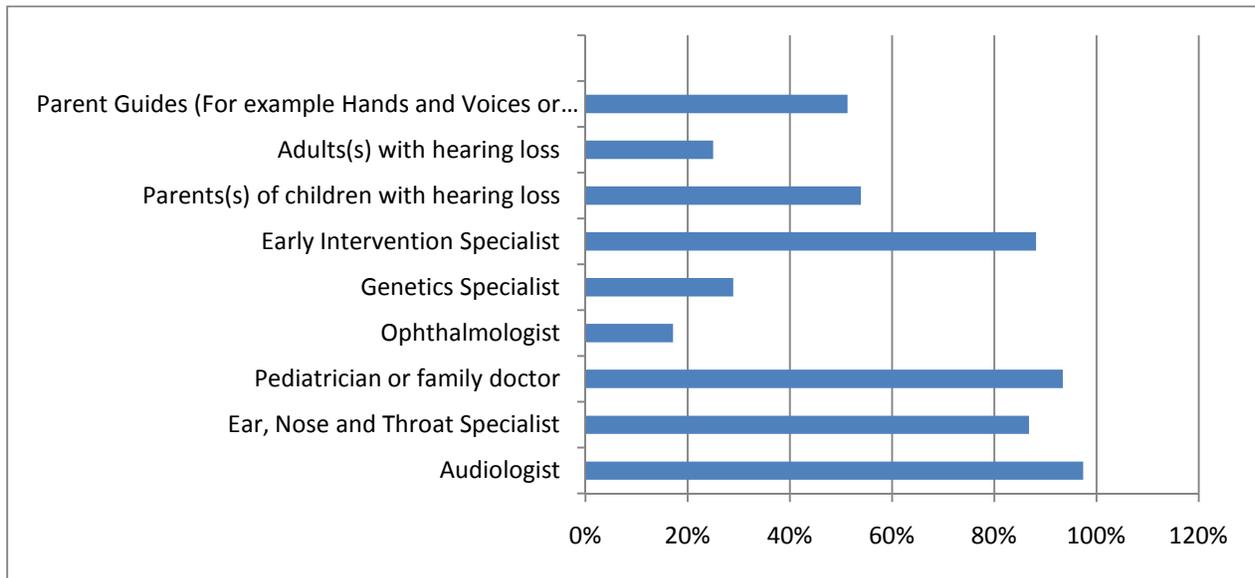
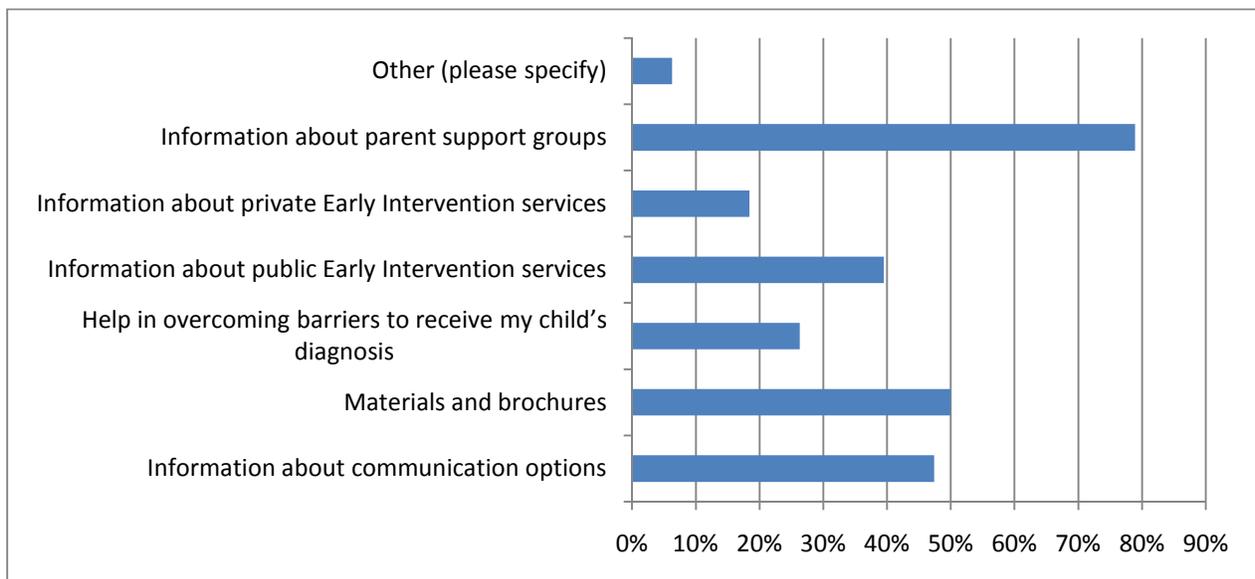


Table 6. Reported contact with Parent Guide

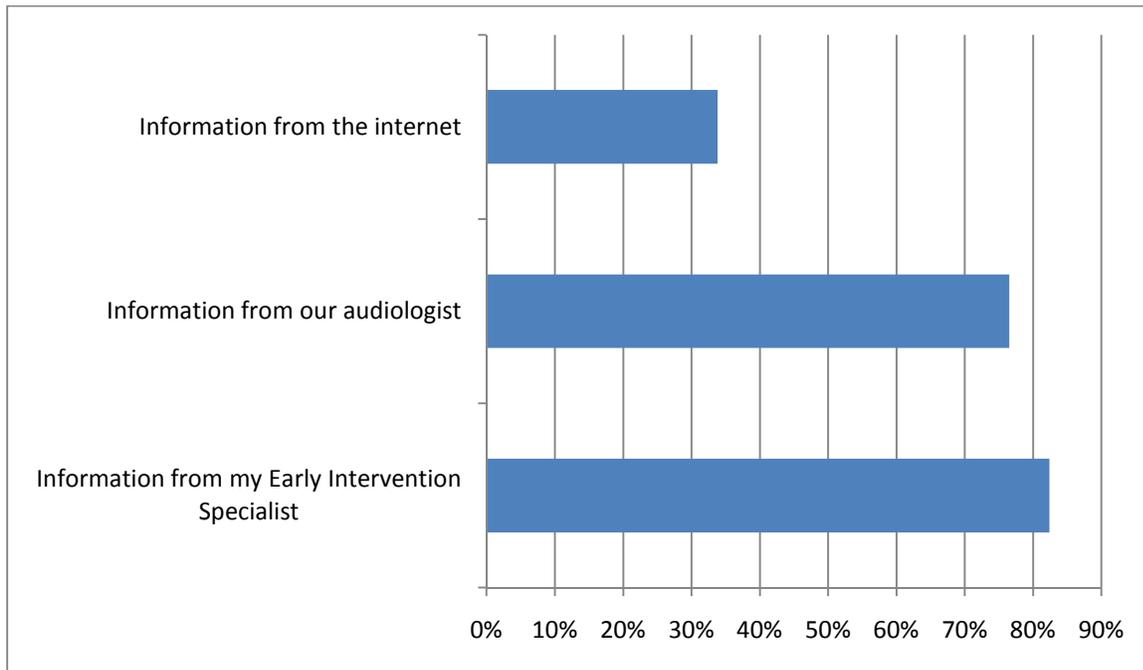
	Response Percent	Response Count
Contacted by a parent guide?		
Yes	57.9%	44
No	27.6%	21
I don't know	14.5%	11

Figure 9. Types of Parent Guide support that families reported receiving



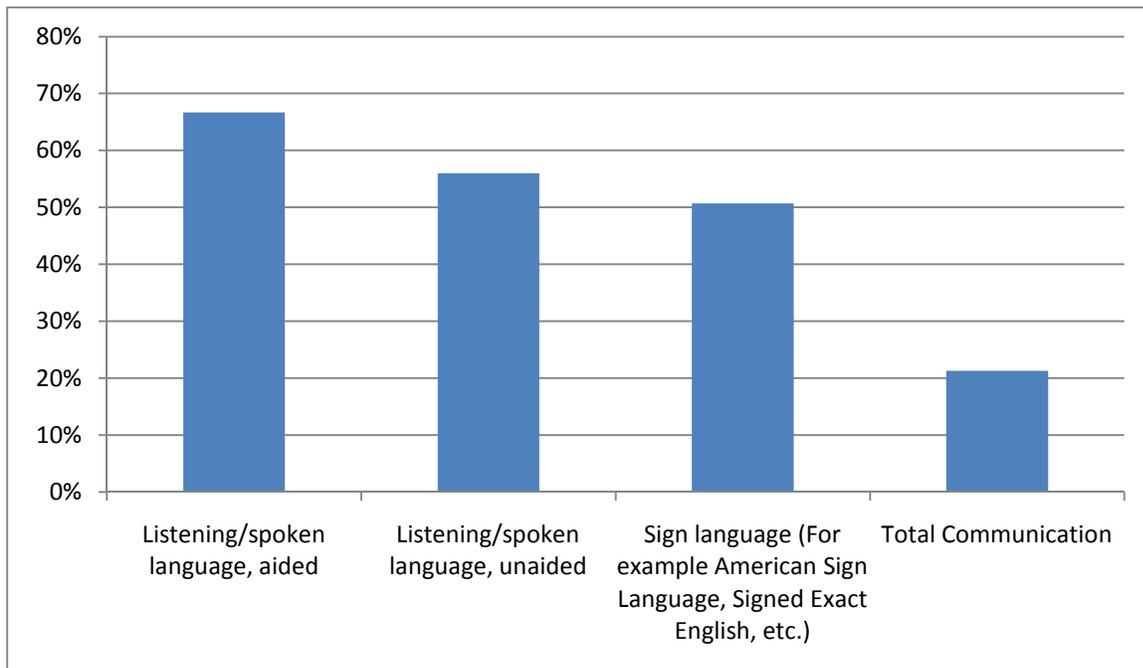
Survey Results

Figure 10. Parents reported using these forms of assistance in deciding what communication choice would be best for their child



***Other sources of information reported were Parent Guides, Ear Nose and Throat Doctor (ENT), Tucker Maxon, speech therapist, doctor, family, daycare provider, and child observation

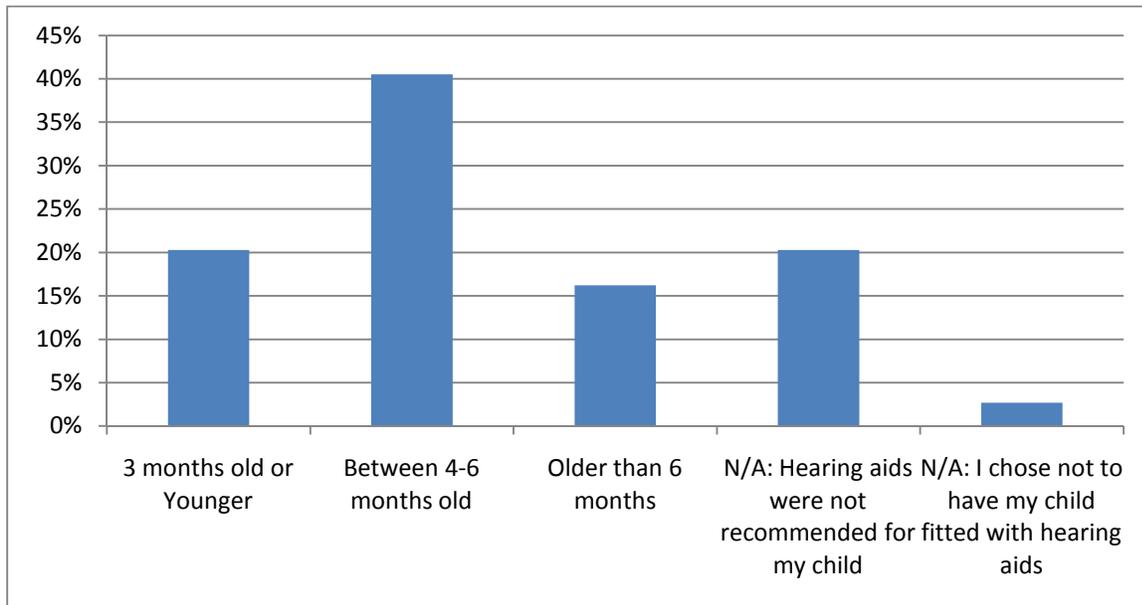
Figure 11. Current Modes of Communication Reported



*** Other mode reported was baby signs

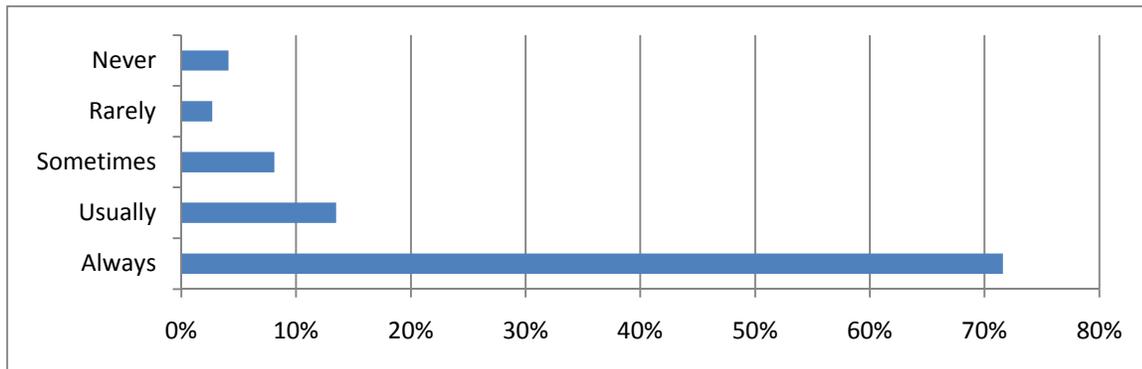
Survey Results

Figure 12. Reported age of child when s/he was first fitted with hearing aids



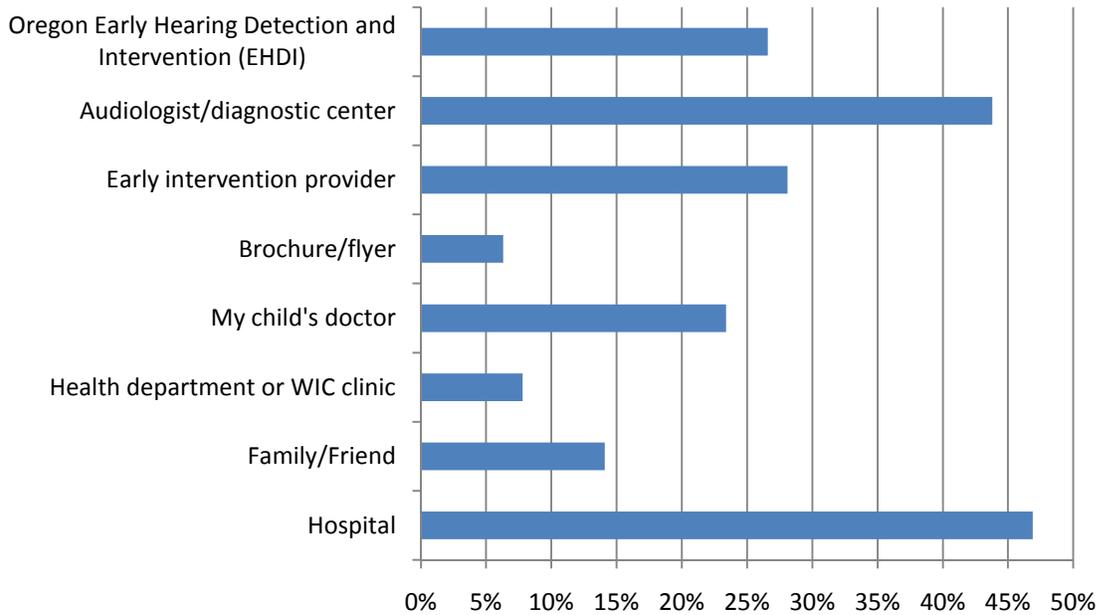
*****Reasons noted for the delays included waiting on doctors to approve CI Surgery, undecided, and scheduling complications**

Figure 13. Respondents reported how often they received the specific information needed from their doctor or health care provider



Survey Results

Figure 14. Sources of information reported about early intervention services



***Other sources reported Hands and Voices, and nurse.

Figure 15. Report by respondents to be most helpful during their child's hearing loss diagnoses

