



Parent Experiences with Infant Hearing Testing

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Early Diagnosis of Hearing Loss

- The objective of Early Hearing Detection and Intervention (EHDI) programs is to provide an opportunity for early identification and intervention for babies born with hearing loss.
 - Screening: complete before 1 month of age
 - Diagnostic hearing test: complete before 3 months of age
 - Hearing aid fitting: within one month of diagnosis for parents that choose amplification
 - Intervention: begin before 6 months of age

Intervention cannot begin until a diagnosis has been confirmed with appropriate detail to guide intervention decisions

Purpose of the Survey

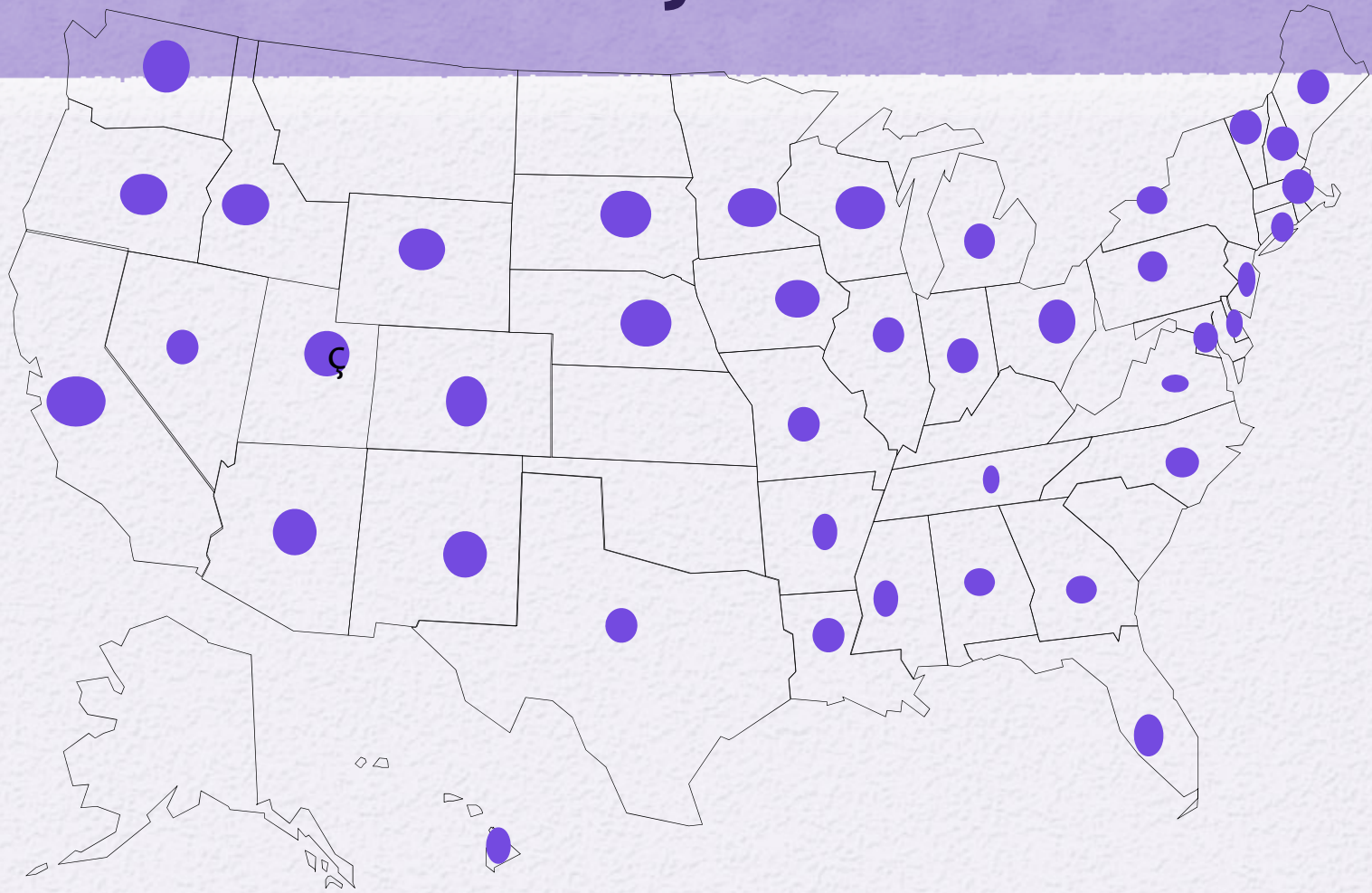
The survey was designed to ask parents:

- about their experiences with the diagnostic process,
- the information they received after the diagnosis, and
- if they knew what they needed to do next following the diagnosis.

Participants

- The survey was distributed to parents through Parent Organizations:
 - The Hands & Voices December 2009 newsletter
 - American Society for Deaf Children
- Data collection period
 - December 2009 – February 2010
- 339 surveys received to date

Preliminary Results



Age at Diagnosis

- Median age: 3 months
- Range: <1 month to 8 years
- Responses from parents included children born in the following years:
 - 1979 – 1996 (44)
 - 2 states mandated NHS
 - 1997 – 2001 (59)
 - 34 additional states mandated NHS
 - 2002 – 2005 (95)
 - 3 additional states mandated NHS
 - 2006 – 2009 (138)
 - 5 additional states mandated NHS

Scheduling Support

- Doctor advised parent: 22%
- Nurse scheduled appointment: 18%
- List of audiologists provided: 13%
- No information provided: 10%
- Other: 34%
 - Hospital had audiologist; Found information on own; tested in NICU; baby passed NHS; referral from friend or other professional; baby missed screening

Wait Time for Appointment

- Median: 2 weeks
 - Same day: 10%
 - Within 2 weeks: 39%
 - 15 days to 4 weeks: 23%
 - 5 weeks to 8 weeks: 10%
 - > 2 months: 6%

ABR Test Condition:

Natural sleep, Sedation, Operating Room

- Option Offered
 - No: 51%
 - Yes: 48%
 - Natural Sleep: 41%
 - Sedation: 30%
 - Operating Room: 5%
- Preferred Option
 - Natural Sleep: 73%
 - Sedation: 17%
 - Operating Room: 2%

ABR Test Condition:

Natural sleep, Sedation, Operating Room

- Support for parent's Preferred option
 - Supportive: 67%
 - Somewhat supportive: 14%
 - Not supportive: 13%
- Test Condition Used:
 - Natural Sleep: 59%
 - Sedation: 33%
 - Operating Room: 5%

Number of Tests to Diagnose

- 1 appointment: 41%
- 2 appointments: 26%
- 3 appointments: 18%
- Other: 14%
 - 4 to 5 appointments, many more than 5 appointments

Challenges to Obtaining Test Prior to 3 Months of Age

CHALLENGE	FREQUENCY
Delay in appointment availability	86
ABR noisy repeat testing needed	52
Live far from testing facility	52
Sedation only option	50
Baby had middle ear fluid	48
Baby had other health problems	47
Unsure where to get test done	36
Missed newborn hearing screening	32
Testing problems: equipment; obtaining accurate results	27

Challenges to Obtaining Test Prior to 3 Months of Age

Challenge	Frequency
Screening results not provided	19
Doctor not helpful, poor communication	12
Passed NHS	10
Transportation problems	8
Unable to afford	4
Missed appointment	4
Other reasons	70

Other Challenges

- Other Challenges:
 - Screening was not available
 - Differing opinions among professionals
 - No support
 - Family situations (e.g. moving)
 - Lack of available providers
 - Given wrong information
 - Feared results of testing
- **Parent reported experiencing NO Challenges (47)**

Information Provided Following Diagnosis

Information Provided	Frequency	Percent
Hearing Aids	195	58%
Early Intervention System	190	56%
Resources on Childhood hearing loss	164	48%
Medical referrals	151	45%
Parent Support Organizations	113	33%

Knowing Next Steps Following Diagnosis

- After talking with the audiologist at the time the hearing loss was diagnosed I was comfortable with what I needed to do next for my child:

Response	Frequency	Percent
Strongly Agree	77	23%
Agree	143	42%
Disagree	58	17%
Strongly Disagree	61	18%

Parent Comments: Challenges

- Provide accurate and unbiased resource information

“There should be some sort of guide for babies who failed the screening, outlining the steps from fitting hearing aids to and regular testing afterwards. More resources should be provided in explaining the steps in the whole process so that parents know what to expect instead of not knowing until the next appointment.”

Parent Comments: Challenges

- Need well trained pediatric professionals in testing as well as counseling parents

“Our newborn hearing screening... was correct but no one could tell us what failing this test meant, and that made me more worried, but once we met the audiologist all of my concerns were removed and I got all of the answers I needed.”

Parent Comments: Successes

- Positive relationships with caring professionals

“It was a very smooth experience for our son... our audiologist was wonderful.”

“Testing and diagnosis went as smoothly as possible, our son had aids at two months of age and immediately started speech therapy. Our audiologist specializes in pediatrics and she has been outstanding.”

Parent Comments: Successes

- Coordinated and supportive process

“Everyone did their jobs exceedingly well, and as a result our family received the critical support needed to provide the best care for our child. Within just one month we had a complete medical diagnosis and were fully supported by the [Center].”

Questions?

