

Journey From 8% To 45% Parent Survey Response Rate: What We Did and What We Learned in Alaska

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Kansas City, Missouri

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UAA Center for
Human Development
UNIVERSITY of ALASKA ANCHORAGE

AMAZING STORIES
BEING WRITTEN EVERY DAY.

Objectives

Participant will be able to:

- Describe the usefulness of parent surveys to guide program activities.
- Identify strategies to develop a useful parent survey
- Assess the value of investing in a personalized parent survey.

EHDI Program Evaluation Guidance

- The survey was recommended as a tool to understand and identify the barriers for families receiving follow-up services after a referral on newborn hearing screening
- Understanding the barriers will guide the Alaska program's change strategies to improve services
- An Institutional Review Board (IRB) approved survey was chosen to increase confidence in validity of the results

Partnership: University of Alaska-Anchorage Center for Human Development (CHD)

- EHDI had current relationship with CHD through the Leadership in Neurodevelopment Education Program (LEND) Fellowship Program.
- CHD also conducts others infant-childhood surveys.
- CHD is member of the Association of University Centers on Disabilities (AUCD)

EHDI Survey Project Stages



Planning &
Research
Design



Interviewer
Recruitment,
Orientation,
Training



Data
Collection



Report/
Presentations

Survey Development

- Previous EHDI survey established 10 open-ended questions for survey. Response rate 7%. |
- 2018 EHDI Advisory Committee commissioned LTFU (lost to follow-up) Survey
- 2018-2019 EHDI and CHD met to identify research questions. Developed survey to answer research questions. IRB approval.
- 2019-20 EHDI and CHD updated survey. IRB approval. Data collection in process. Plan to publish journal article.

Planning

- The evaluation survey for Alaska's newborn screening program was designed to
 - determine referral patterns and satisfaction with services provided
 - understand how the current follow-up system is perceived by families at each stage of referral or services
- EHDI design requirement: survey interviewers would be parents of deaf or hard of hearing children

Research Questions

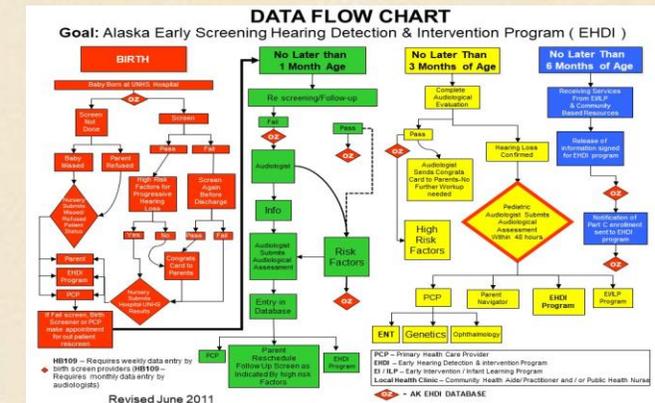
1. When an infant is referred on to an audiologist (i.e., doesn't pass the final hearing screening) how is that referral managed?
2. If no appointment was made or kept, why not?
3. Was the diagnosis explained to the parent?
4. Were treatment options offered?
5. Was a referral made to a state-sponsored early intervention and/or to a family navigator? Were these services useful?
6. Were non-state sponsored therapy services engaged?

Survey Protocol and Strategies

- Well-trained interviewers. CITI certification, mock interviews/attempts.
- CHD protocol for contacting families designed to maximize the response rate:
 - Call at different times of the day and/or days of the week (morning, afternoon, evening, weekday, weekend)
 - Leave messages every other attempt
 - Make up to 15 contact attempts
 - Efficient for participants. Complete survey takes about 10 minutes
- Use a Qualtrics survey database to track and facilitate call protocol and data collection. Quantitative and qualitative data collected.
- Participant incentive: Enter into \$50 drawing

Sample Population

- Participants were parents of infants who were referred on for follow-up hearing screening, but whose infants did not receive:
 - follow-up screening
 - diagnostic testing
 - early intervention, or
 - were late in receiving follow-up (later) than is recommended in the JCIH (Joint Commission on Infant Hearing)



Demographics and Response Rate

- 45% response rate (96 in the sample and 43 responded)
- 70% of participants had Medicaid or Denali KidCare insurance
- Only three infants received a permanent hearing loss diagnosis

Parent/Interviewer Perspective

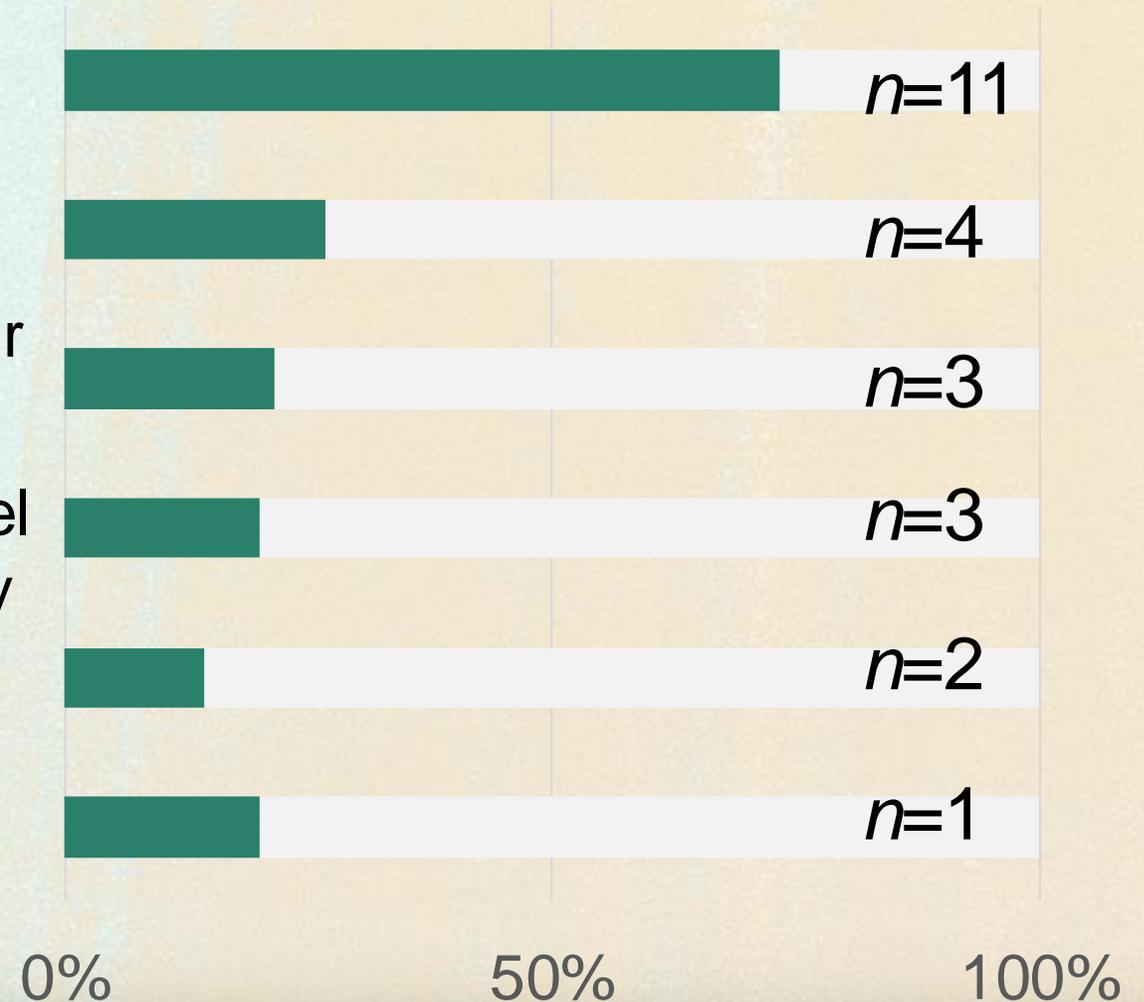
- Engagement with Families
- Qualitative Comment Data
 - A participant was not sure if the child “needed to go because he sounded like he had hearing.”
- Resources

Key Findings



Reasons appointment were missed ($n=15$)

- Did not think the infant need to go
- Did not have time to attend an appointment
- Could not find a time that worked in their schedule
- Could not afford the time/money to travel to an appointment outside of community
- Could not afford the appointment
- Another reason they could not make or attend



Things to Consider and Discuss...

- Note that 70% of respondents used Medicaid or Denali KidCare. EHDI plans to deliver education to this population of parents.
- 14 of the 17 referred who did not make appointments, discussed the results with their medical providers. EHDI has plan for further outreach to medical providers (AAP, ALPHA)
- Posters created in partnership with ANMC. Parent self-advocates attending ECHO Training

Dissemination

- Parents – education outreach efforts
- Healthcare providers
 - Jen Soble, Alaska American Academy of Pediatrics, 12/19/2019
- Statewide
 - Alaska Health Summit (Alaska Public Health Association)
January 23, 2020
- National
 - EHDI Conference

FY 2020 Survey

- Additional or Refined Questions:
 - Demographics (rural, remote, urban)
 - Affordability (travel vs. appointment costs)
- Sample
 - Including those who received a diagnosis
- Connection between hearing and language acquisition

Contact Information

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Participant perspective on the referral process

“A little bit more information as far as what the process will be with the referral. They just assume that things will be explained in the next step. If parents are more informed, parent[s] will be more willing.”

Reasons participants did not scheduling or attending appointments...(continued)

- A participant who had not yet gone to the audiology appointment...
- "...not too concerned about it because it was done within 24 hours of birth and nurses said it was common."

Reasons participants gave for not scheduling or attending appointments.....

- “Responded with normal hearing; I didn't think my infant needed it.”
- “Waiting to see what the ENT says.”
- “Was difficult to make it into the clinic.”
- “Rescheduled for January.”

Participant Comments

- A participant was not sure if the child “needed to go because he sounded like he had hearing.”
- A participant did not have insurance but received a referral for an appointment but nobody contacted him/her. This participant did receive a letter from EHDI and discussed hearing screening with a doctor.