

NORTH DAKOTA EARLY HEARING DETECTION AND INTERVENTION (EHDI) HEARNOW PROJECT REPORT

Quality Improvement Survey 2009

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TABLE OF CONTENTS

Introduction.....	2
Birth Screening Responses.....	3
Outpatient Screening Responses.....	9
Audiology Responses.....	12
Early Intervention Responses.....	16
Medical Home.....	21
Program Evaluation.....	23
Appendix A.....	27
Appendix B.....	29

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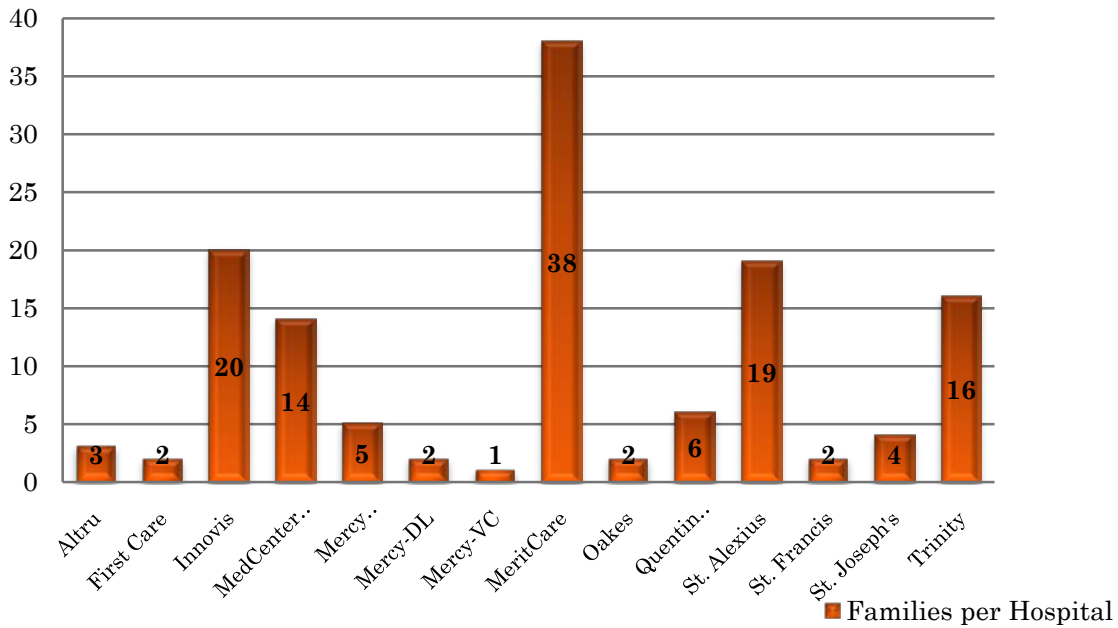
Introduction

In April of 2009, ND EHDI staff sent out a survey to 894 ND families whose children were birthed in 2008 and had a referred or missed birth screen. Of the 894 surveys sent, 15% (n= 136) of families responded. Six infants were reported as not having a birth screen, one family reported the birth screen as “unknown”, and two infants of the 136 respondents demised 3 days after birth and are not included in further survey results. Of the remaining 134 surveys returned, 5 infants birthed in 2008 were reported as receiving audiological care for hearing loss. According to the parents surveyed, a need exists to: a) increase screener knowledge about the screening process, b) increase provider’s ability to relay accurate information back to families, c) receive written documentation of screening results at discharge, d) involve the family in the screening process, and e) increase access to pediatric hearing care providers. A number of parents indicated that they appreciated receiving written letters from the ND EHDI office informing them of their child’s hearing results and encouraging parents to access follow-up care.

Birth Screen Responses

North Dakota’s six largest facilities are located in four communities (Minot, Bismarck, Grand Forks, and Fargo) and account for over 80% of all ND births. The chart for Question 1 below provides a breakdown by hospital where each respondent’s child was birthed. Please note that one major birthing hospital (Altru) typically does not include family contact information in the statewide database. During the survey process, the absence of family contact information resulted in a skewed representation of those families birthed at Altru.

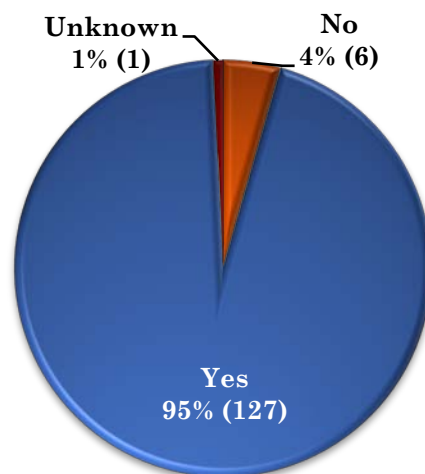
Question 1: At which hospital was your child born?



According to the Joint Committee on Infant Hearing (2007), hearing management guidelines for EHDI is to complete screening activities before one month of age, diagnose hearing loss before three months of age, and provide early intervention before six months of age. Timeliness of services is key in providing adequate hearing health management for infants with possible hearing loss. These benchmarks are closely monitored by ND HearNow staff for quality improvement purposes.

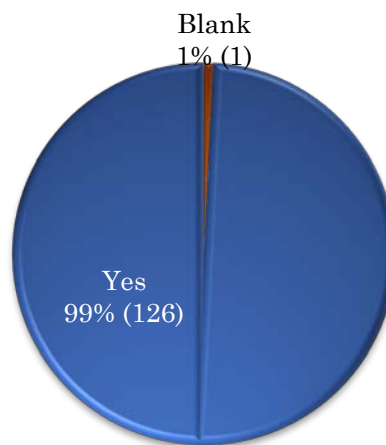
Question 2 of the survey asks, “Did your child receive a hearing screening while in the hospital?” Of the 134 tallied surveys, 95% (n=127) indicated “yes”, 4% (n=6) indicated “no”, and 1% (n=1) indicated “unknown”. The low percentage of “unknown” is encouraging to note as our state EHDI program has worked to ensure that families are informed about the results of their child’s hearing screening upon hospital discharge.

Question 2: Did your child receive a hearing screening while in the hospital?



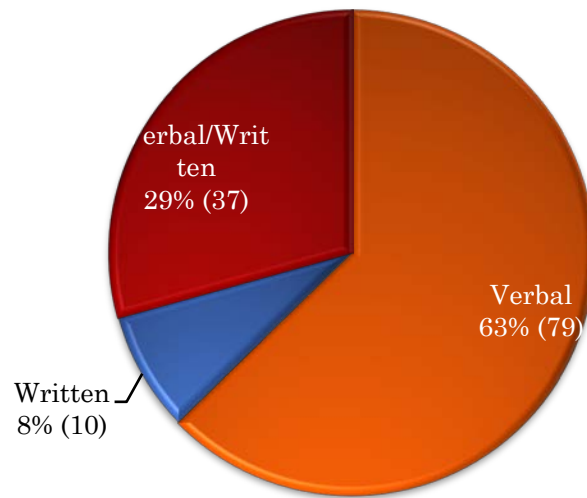
Question 3 asks parents to indicate if they were notified of their child's hearing screening results. Of the 127 parents who indicated receiving a hearing screening, 126 (99%) were aware of their child's screening and indicated receiving notification of the results. One parent left this question blank.

Question 3: If yes, were you notified of the results?



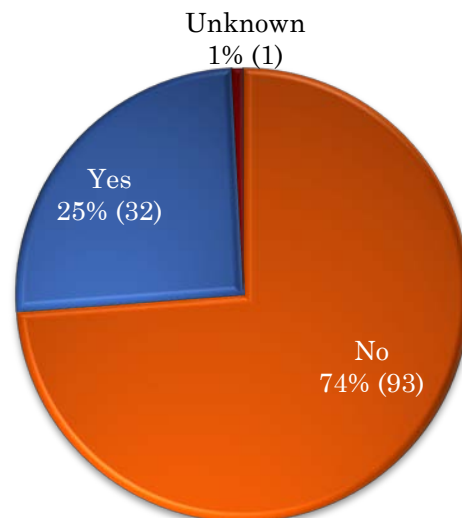
Another primary training focus for ND HearNow staff is to encourage hospital staff to present families with some form of written notification of hearing screening results. Results of Question 4 shows that of the 126 parents indicating notification of results, 63% (n= 79) indicated receiving verbal notification, 8% (n=10) indicated receiving written notification, and 29% (n=37) indicated receiving verbal *and* written notification.

Question 4: How did you receive notification?



Of the 126 respondents whose child received a birth screen, 74% (n=93) indicated that their child did not pass the birth screening, 25% (n=32) indicated that their child did pass the birth screening, and 1% (n=1) indicated “unknown”.

Question 5: Did your child pass?



Question 6: Were you informed that your child did not receive a hearing screening?

Of the six infants who did not receive a hearing screening (as answered in Question 2), 83% (n=5) indicated that they were informed of this missed screening and one respondent indicated that they were not informed of the missed screening. This is encouraging to see as it indicates an effort on the hospital's part to notify parents of a missed screening to reduce loss-to-follow-up rates.

Question 7: Was an appointment set up for your child to receive a hearing screening at a later date?

Another major training effort conducted by ND HearNow staff is to encourage hospitals to make follow-up appointments for families at the time of hospital discharge. It is encouraging to note that of the six respondents who indicated not receiving a hearing screening at the hospital; five indicated that an appointment was scheduled for a later date.

Outpatient Screening Responses

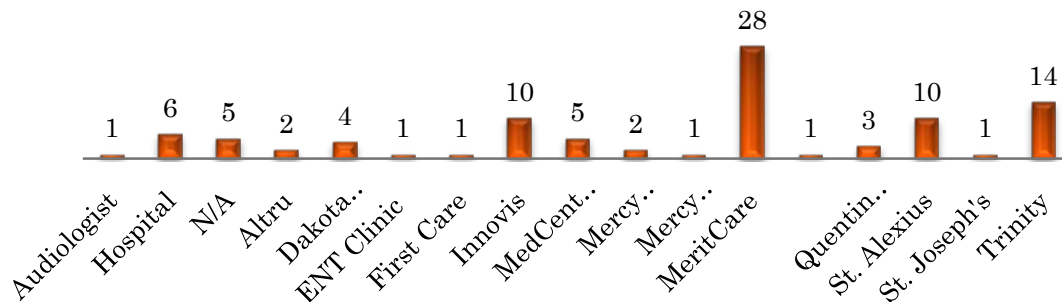
Question 8: Did your child visit a hospital or Audiologist for a follow-up hearing screen?

Of the 134 tallied surveys, 71% (n=95) indicated visiting a hospital or audiologist for a follow-up hearing screening.

Question 9: If yes, where was this done?

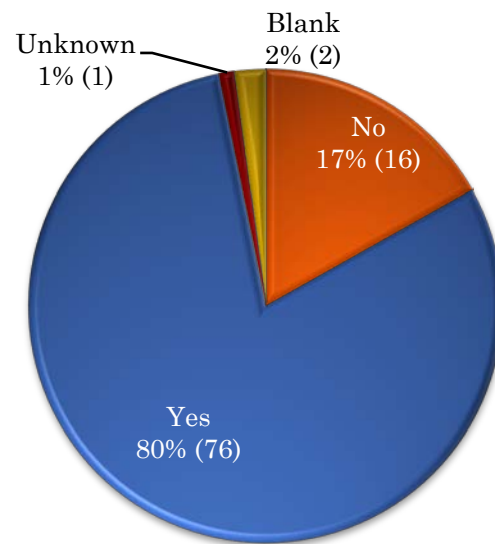
Question 9 indicates the site in which the outpatient or follow-up screening was performed. As indicated in the figure below, the majority of infants returned to a birth hospital to receive this service.

Follow-Up Screening Site



Of the 95 who indicated having a follow-up hearing screening, 80% (n=76) indicated passing the follow-up screen and 17% (n=16) did not pass the follow-up screen. One response was “unknown” and two responses were blank.

Question 10: Did your child pass the follow-up screen?

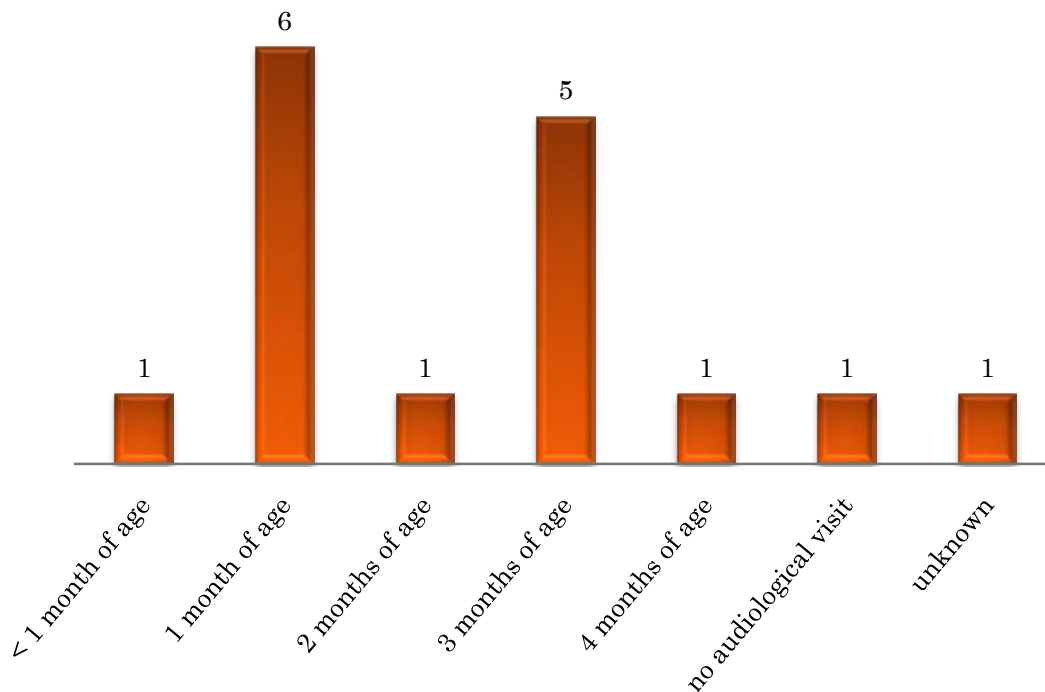


Audiology Responses

Question 11

Did your child pass the follow-up screen?

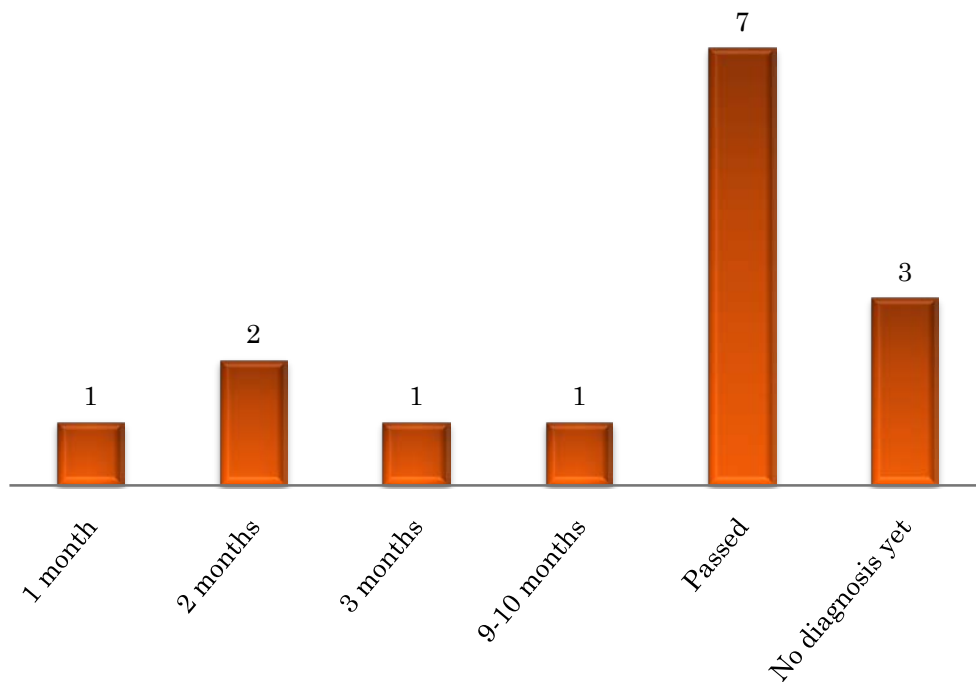
If no, when did your child visit an audiologist for follow-up?



The chart for Question 11 shows that of the 16 infants who did not pass their follow-up screening, 81% (n=13) saw an audiologist between 0 and 3 months of age, 6% (n=1) saw an audiologist at 4 months of age, 6% (n=1) did not see an audiologist, and the remaining respondent indicated “unknown” for this question. The results of this question are encouraging in that infants who needed to see an audiologist after not passing the screening process did so early in age.

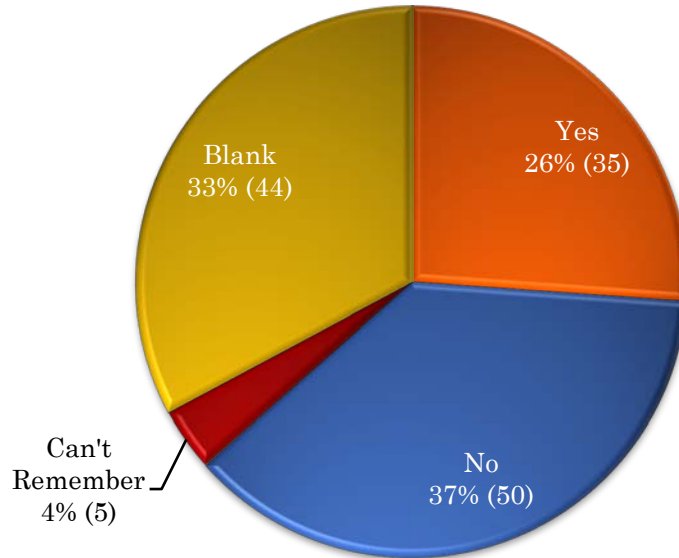
Of the 15 who indicated seeing an audiologist nearly half (47%) passed, three (20%) did not receive a diagnosis yet, and one third (n=5) were diagnosed with hearing loss. The figure for Question 12 below indicates the age of diagnosis for these five infants.

Question12: How old was your child when he/she was diagnosed by an audiologist with a hearing loss?



Of great interest to ND HearNow staff is whether or not parents recall receiving letters generated from our office. Of the 134 tallied responses, 50 said no, 35 said yes, 5 could not remember receiving notification, and 44 were blank.

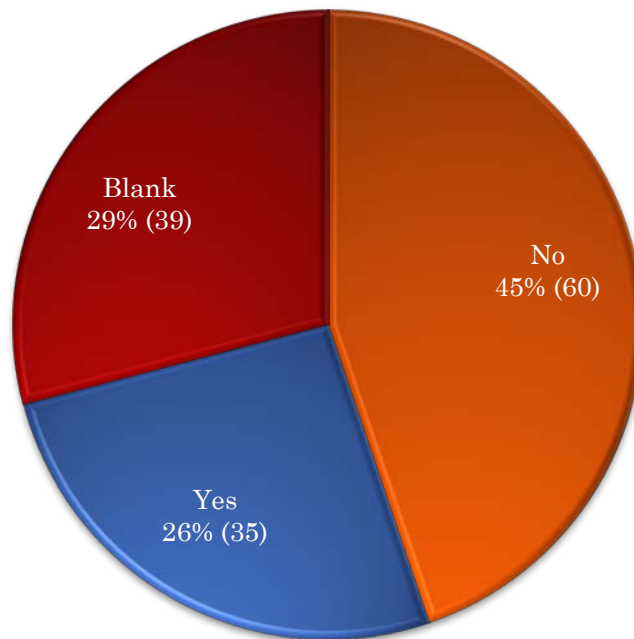
Question 13: Did you receive a letter from the ND EHDI HearNow project?



Early Intervention Responses

According to the ND EHDI protocol (see Appendix B), all infants who refer or miss their birth screen are automatically referred to the Right Track Program for follow-up services. In the case of this survey, all respondents should have been referred by ND HearNow staff to the Right Track Program for assistance in gaining follow-up care. Of the 134 tallied responses: 60 said they were not contacted by the Right Track Program, 35 said they were contacted by the Right Track Program, and 39 were blank.

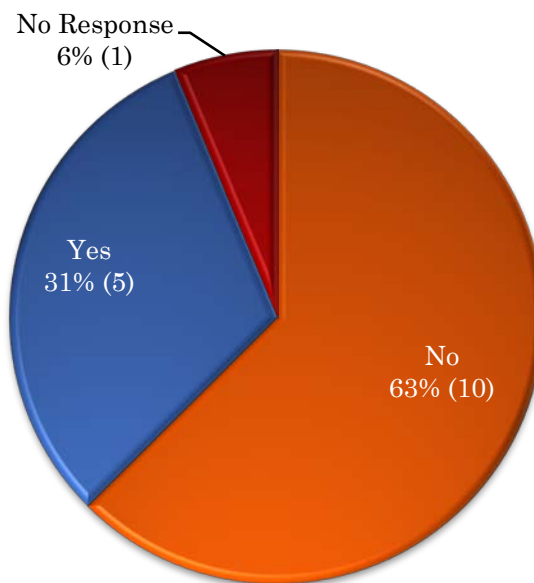
Question 14: Were you contacted by the Right Track Program?



Question 15: If yes, did you meet with the Right Track Program?

Of the 35 respondents who were contacted by Right Track, 17 said they met with them and 18 said they did not meet with a Right Track representative.

Question 16: Were you contacted by the Parent Infant Program?



Of the 16 who did not pass the follow-up screening, 63% (n=10) said they were not contacted by the Parent Infant Program; 31% (n=5) said they were contacted by the Parent Infant Program; and 1 respondent did not answer the question.

Question 17: If yes, did you meet with the Parent Infant Program?

Four out of five respondents met with a representative of the Parent Infant Program.

Question 18: Were you contacted by North Dakota's Part C Program?

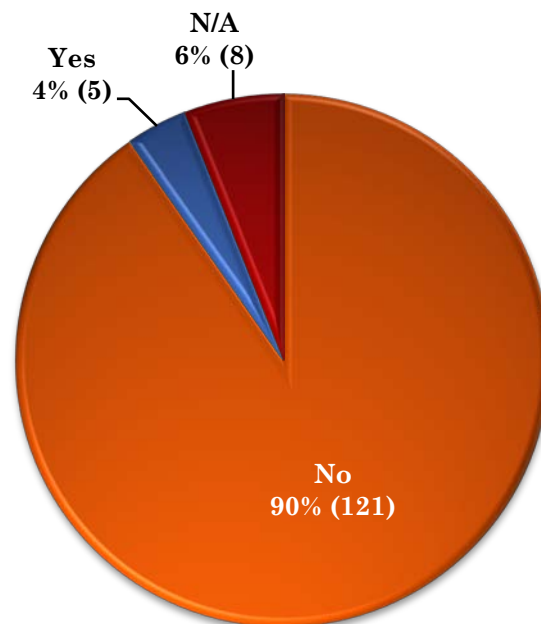
Of the five diagnosed with hearing loss, one was contacted by North Dakota's Part C Early Intervention program, 2 said they were not contacted by Part C, 1 was not sure, and 1 was blank.

Question 19: Is your child currently enrolled in North Dakota's Part C Program?

Of the five diagnosed with hearing loss, none indicated they were enrolled, 2 said they were not enrolled, 2 were unknown or not sure, and 1 was blank.

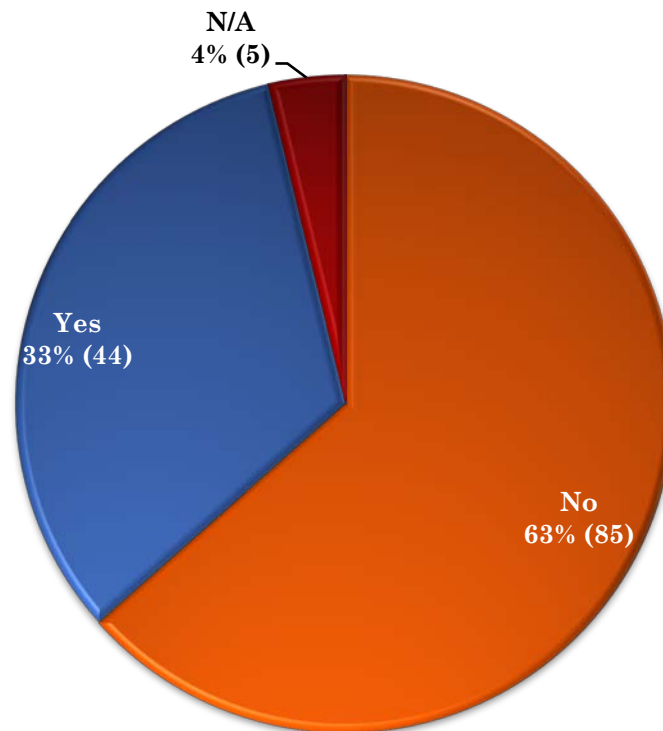
Question 20: Is your child receiving services for their hearing loss?

Of the five diagnosed with hearing loss, 4 indicated receiving services and 1 said they were not receiving services for hearing loss at this time.



Medical Home

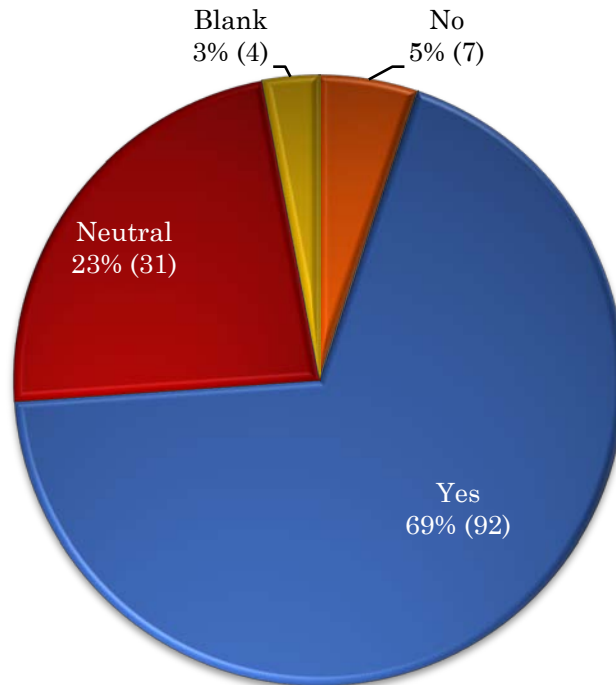
Question 21: Has your child's Pediatrician or Primary Care Physician discussed your infant's hearing screening results and the role it plays with childhood development?



Provider education has also been a training effort by ND HearNow staff over the past five years. Increased provider involvement in the ND EHDI process is encouraging to see. Recently, the ND HearNow project employed a physician to visit with local birth hospitals to identify a local EHDI champion within their facilities and increase provider involvement with the ND EHDI program.

Program Evaluation

Question 22: Were you satisfied with the hearing screening process?



The majority (69%) of respondents were satisfied with the hearing screening process. A low percentage (5%) were not satisfied with the hearing screening process and the remaining respondents were either neutral (23%) or left the question blank (3%).

Question 23: What could be done to improve the EHDI system?

- Explain to parents that just because they failed the first screen, it doesn't always mean its permanent hearing loss.
- Did not receive very much explanation or information besides to return and have another test done.
- I wish I could have been in the room with my daughter when she was getting the test.
- More follow up
- Our son passed the 2nd hearing test when he was only a couple weeks old. The process was very nice and the nurses were very friendly.
- More information
- I would suggest making sure the hospital had the proper resources and equipment to do complete hearing exams on newborns. That is the reason we had to take our daughter to the audiologist.
- That every new parent be informed about hearing screenings and how important hearing is to the development of the child. This should be done for all parents, even if their child passes the hearing screen. Not all new parents may know how important hearing is.
- I saw on the magnet that it says evaluate before 3 mos. What does this mean? If or should it be done at the regular check-ups? I find the "Parenting In the First Year" very helpful & informative. These Child Development letters are from the NDDHS.
- It seems that there is quite a bit of trouble and lack of skill of nurses using the hearing testing equipment. My daughter was tested 4 times and the equipment didn't function properly or the nurses had trouble all but one time. It was a lot of stress.
- I was not a part of the screening. I would've liked to be so I could see how it works and be explained more of it.
- I was notified that [child's name] had not passed her initial hearing screening at her 2 week checkup. After that we went to the hospital to have her re-screened. The letter came about a month and a half after she was born.
- It would be nice to receive written results at the hospital for the newborn hearing screen. The only reason I knew the results was because the nurse mentioned them to me but it is hard to remember which ear didn't pass when there is so much going on.
- Still waiting on rescheduling hearing tests in [name of town], to find out about what type of hearing loss she has and how much.
- It is fine; follow-up was appropriate/accomplished. The nurse at the hospital did the initial screening too soon & daughter failed (it probably was a given that she would fail; she was just born-fluid still present in ears.
- Explain more. Offer parent to be present, I happened to be there while it was done. Maybe print results-offer pamphlet w/ info & results. Overall good.
- I was happy to get a letter from ND EHDI Hear Now Project. It stressed the importance of early diagnosis of hearing loss, and reminded me again to make an appointment for a follow up screening test with an audiologist. I knew the follow up test was important.
- My daughter failed 2 hearing tests-the initial test right after being born, and a follow-up test done at her two week check-up. The nurse who did the test was adamant about having the test done again before my baby was a month old, but our doctor was not.

- My daughters hearing test was first given when she was two days old. I believe she was too young and that possibly caused her to fail. We knew she had fluid in her ears which mostly caused her to fail.
- Wait until an actual hearing loss has been diagnosed before sending so much information. As a new parent, it was very alarming, and ultimately unnecessary. We were told at the hospital that it is common for babies to not pass due to fluid build-up in the ears.
- Could possibly educate nurses how the screening works. I asked the nurse how it works and she said she really didn't know. She just lays the probe in the child's ear and presses the button. The computer does it.
- Maybe you could provide information to clinics to have posted so during pre-natal checkups women can read about EHDI and what questions to ask.
- We received a letter from you stating that our son had not passed his screening & needed a follow-up evaluation. However, at the hospital, we were told he passed the screening. We also received written confirmation that he had passed.
- My son was 3 mo. old when we saw the specialist for the re-screen. The specialist was quite clear at how disgusted he was that our "primary care" doctor did not get our son in sooner. We see a family physician.
- Have the doctor discuss everything they are doing and explain everything that's going on during the testing.

Conclusion

Overall, survey respondents were generally satisfied with their child's hearing screening process. A need still exists to provide training to hearing screening providers; promote increased physician involvement with EHDI; and increase care coordination through written notification of results, early referrals to North Dakota's early intervention providers (i.e., Right Track, Parent Infant Program and Part C agencies) and accurate data entry into the ND EHDI statewide database.

Appendix A

North Dakota EHDI HearNow Quality Improvement Questionnaire

Dear:

The North Dakota Early Hearing Detection and Intervention (ND EHDI) program would like to ask for your assistance in assessing North Dakota's Hearing Screening process. As a parent whose child participated in the screening process, you are the most valuable resource of information available for understanding our strengths and weaknesses. To better serve the children being birthed in North Dakota, we ask that you take the time to answer the following questions and return them in the postage paid envelope provided to you. In advance, ND EHDI would like to thank you for your participation and assistance with this quality improvement effort.

1. At which hospital was your child born? _____
2. Did your child receive a hearing screening while in the hospital?
Yes No (skip to Q # 6) Unknown
3. If yes, were you notified of the results? Yes No Unknown
4. How did you receive notification? Verbal Written Other _____
5. Did your child pass? Yes (skip to Q #21) No Unknown
6. Were you informed that your child did not receive a hearing screening? Yes No
7. Was an appointment set up for your child to receive a hearing screening at a later date?
Yes No
8. Did your child visit a hospital or Audiologist for a follow-up hearing screen? Yes No
9. If yes, where was this done? _____
10. Did your child pass the follow-up screen? Yes (skip to Q #21) No Unknown
11. If no, when did your child visit an audiologist for follow-up? _____
12. How old was your child when he/she was diagnosed by an audiologist with a hearing loss? _____
13. Did you receive a letter from the ND EHDI HearNow project? Yes No
14. Were you contacted by the Right Track Program? Yes No
15. If yes, did you meet with the Right Track Program? Yes No
16. Were you contacted by the Parent Infant Program? Yes No
17. If yes, did you meet with the Parent Infant Program? Yes No
18. Were you contacted by North Dakota's Part C Program? Yes No
19. Is your child currently enrolled in North Dakota's Part C Program? Yes No
20. Is your child receiving services for their hearing loss? Yes No
21. Has your child's Pediatrician or Primary Care Physician discussed your infants hearing screening results and the role it plays with childhood development? Yes No
22. Were you satisfied with the hearing screening process? Yes No Neutral
23. What could be done to improve the EHDI system? *Please, write your comments and suggestions on the back of this form. Thank you.*

Appendix B

North Dakota EHDI Hearing Screening Protocol

