

Performance Narrative

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Project Title: Reducing Loss to Followup after Failure to Pass Newborn Hearing Screening

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Accomplishments and Barriers:

During the current funding year the New Jersey Early Hearing Detection and Intervention (EHDI) program completed participation in the National Initiative for Children's Healthcare Quality (NICHQ) Improving Hearing Screening and Intervention Systems (IHSIS) Learning Collaborative. This project utilized quality improvement techniques to identify successful strategies for improving follow-up. Funding allowed continuation of efforts to contact parents and physicians of children that need additional follow-up testing and provide specialized education about Early Intervention to parents of children newly diagnosed with hearing loss.

Goals and Objectives:

Goal 1: By March 31, 2015, reduce the rate of infants lost to follow-up between hospital discharge and outpatient screening to no more than 8%.

Objective 1.1: Hospital technical assistance will create annual improvements on rates of infants receiving timely follow-up after referring on inpatient screening.

The Public Health Consultant - Nursing (PHCN) began annual conference calls to hospitals on September 5, 2013 and completed 12 calls in September, 14 in October, 14 in

November and 14 in December. Calls included discussion of successful strategies identified during the NICHQ Learning Collaborative. The EHDI Audiologist also attended the calls.

Quarterly reports continued to be distributed to each birthing facility. They include a detailed listing of children still needing documentation of follow-up status and biannually include summary statistics comparing hospital and statewide screening and follow-up rates.

Objective 1.2: Decreasing family barriers to rescreening will create annual improvements on rates of infants receiving timely follow-up after referring on inpatient screening.

Beginning April 1, 2013 HRSA funding was suspended for the five Federally Qualified Health Centers (FQHC) that were previously offering free rescreening to reduce financial barriers to follow-up. Funding was redirected to other grant activities since very few families were utilizing this service with only 27 rescreening exams reported at these facilities during the prior funding cycle. These centers are all keeping their rescreening equipment and assuming the responsibility for maintenance so that they can continue to conduct rescreening on their own patients. Since April 1 of this year, 15 children have been screened by these FQHCs.

The Pediatric Hearing Health Care Directory was updated in July 2013 to reduce inability to locate facilities as a barrier to rescreening. The information is available to parents and health care providers on the Department's internet site at www.hearinghelp4kids.nj.gov.

Case managers at the Mercer County Special Child Health Services case management unit continued to conduct reminder phone calls to parents and physicians of children that refer on inpatient rescreening and have not had additional testing completed within six weeks. From April 1 through December 1, case managers contacted 648 families and 58% of those children had additional audiologic follow-up reported. The case managers report that they feel the call to remind parents of the need for follow up is very important since sometimes parents are

overwhelmed with other issues and forgotten about the need for a repeat hearing test. Their expertise as Case Managers has been beneficial because the parents often need information about health insurance options and coverage. Their familiarity with New Jersey's Early Intervention system has also been beneficial since they frequently reassure families that in the event their child has a hearing loss, there are professionals available to assist them as needed. They are accustomed to reaching out to providers on behalf of families and will call facilities to make appointments on the child's behalf as needed or contact the pediatrician's office to remind providers to discuss appropriate follow up when the child has an office visit. They note it is most challenging when they cannot reach the parent by phone and need to rely on mailing a letter, but that the letter is effective in cases where parents were not aware of the need for further testing.

Objective 1.3: Improved outpatient reporting of rescreening and diagnostic exams will create annual improvements on documentation of follow-up after referring on inpatient screening.

The EHDI audiologist continued to make individual contacts with audiologists when families or case managers reported that follow-up had been completed, but the documentation had not been submitted to the EHDI program, which averages two or three cases per week. In November 2013, the EHDI program distributed a newly developed audiology facility report to aid facilities in assessing their performance and identifying children that need to return for further follow-up. An initial draft of the report was reviewed by the NICHQ collaborative audiology subgroup for feedback. The purpose and interpretation of the reports were reviewed on a webinar held on December 17, 2013 and attended by 24 audiologists.

The PHCN continues to conduct individual outreach and education about reporting requirements to physicians who are conducting rescreening in their offices, averaging approximately two or three cases per week.

The EHDI program has also implemented a routine process to fax notices to pediatrician offices for children with no follow-up documented. The forms are designed for the office to reply and fax back to the EHDI program. In October 2013, 152 faxes were sent for children born between January and June with no follow-up documented. Responses to the faxes varied, including cases where testing was done, either by the pediatrician or an audiologist, but not reported to the EHDI program; cases where no follow-up was done and the provider indicated they would make the referral; cases where the provider noted referrals had been given to the family (sometimes several times) but the parents had been non-compliant; cases where the provider receiving the form was never or no longer the primary provider; and, unfortunately, many cases where the provider did not reply to the EHDI program. Of the cases for whom faxes were sent, 23.7% have had some additional follow-up testing reported.

Goal 2: By March 31, 2015, reduce the rate of infants lost to follow-up between outpatient rescreening and diagnostic testing to no more than 10%.

Objective 2.1: Outreach to parents after a refer result on outpatient rescreening will create annual improvements on rates of infants receiving timely follow-up after referring on outpatient rescreening.

Between April 1 and December 1, case managers conducted outreach to 146 families of children that had referred on outpatient rescreening or inconclusive diagnostic testing and had not had additional follow-up. Additional follow-up was completed on 50% of these children.

Objective 2.2: Outreach to physicians after a refer result on outpatient rescreening will create annual improvements on rates of infants receiving timely follow-up after referring on outpatient rescreening.

The physician fax back process noted in Objective 1.3 is also being utilized for infants with incomplete outpatient follow-up testing with revised wording to indicate testing is incomplete. As with the faxes for children with no testing, this has been somewhat successful, but responses are not received from the provider for a majority of the cases.

Objective 2.3: Outreach to audiologists will create annual improvements on rates of infants receiving timely follow-up after referring on outpatient rescreening.

The audiology reports noted in Objective 1.3 also includes a page providing child-level details of infants whose last outpatient visit was a rescreening refer, or inconclusive diagnostic testing due to a middle ear infection, an uncooperative infant, or other issues. The goal is to encourage audiologists to recall these infants for further testing, or to identify children that may have been referred to other facilities for further follow-up, such as sedated ABR testing, but who have not followed through on that recommendation.

Goal 3: By March 31, 2015, reduce the rate of infants lost to follow-up between hearing loss diagnosis and early intervention enrollment to no more than 10%.

Objective 3.1: Rate of early intervention enrollment after a hearing loss diagnosis will increase annually during the grant cycle.

The EHDI program continues annual reconciliation of EHDI and EI data to ensure all children with hearing loss are accounted for in the tracking system as part of the annual data report to the Centers for Disease Control and Prevention. In addition, the EHDI and EI programs completed quarterly data matching to submit data for the NICHQ Learning Collaborative. EI enrollments rates documented during these quarterly reviews varied from 40% to 78%.

The EI Hearing Consultants funded through this grant began their family contacts in July 2012. They are making initial family contact with newly diagnosed families via telephone and

participating via webconferencing in the Family Information Meeting. From April through November they provided services to 83 families, with 5-17 new referrals each month. Parent surveys have been sent to all of those families, with 16 responses during the grant year to date, all reflecting highly satisfied responses.

Goal 4: By March 31, 2015, implement at least six effective interventions to decrease loss to follow-up via participation in the Learning Collaborative model.

Objective 4.1: By March 31, 2015, achieve success on at least two Learning Collaborative objectives targeting outpatient follow-up after hospital discharge.

Objective 4.2: By March 31, 2015, achieve success on at least two Learning Collaborative objectives targeting diagnostic evaluation after rescreening refer.

Objective 4.3: By March 31, 2015, achieve success on at least two Learning Collaborative objectives targeting early intervention enrollment after hearing loss diagnosis.

Throughout the past year, New Jersey participated in the multistate National Initiative for Children's Healthcare Quality (NICHQ)/Improving Hearing Screening and Intervention Systems (IHSIS) collaborative with the aim of improving infant hearing follow-up and intervention through small tests of change. Several of those successful NICHQ/IHSIS strategies were eventually adopted and spread to others as part of this process. The "Plan-Do-Study-Act" (PDSA) process was utilized for this purpose and found to be so effective that we will continue this process and expand our partnerships.

In addition to our committee work with our New Jersey NICHQ Core team and the multistate NICHQ team, we recruited partners throughout the State comprised of parents, physicians, audiologists, nurses, early intervention service coordinators, genetic counselors, hospital hearing screening techs, birth certificate managers, social service consultants, parent

support professionals and others. In all there was representation from 38 members from around the State. We also brought together a committee of audiologists to focus on the multifaceted process of identification of hearing loss. Each committee met at least monthly and were also included in the larger extended team meetings. The committees identified issues that could be tested with PDSAs.

The monthly extended team meetings were also used to deliver partner-produced webinars focused on infant hearing from the team member's perspective. Beginning with an overview of NICHQ and the PDSA process, we followed with information from the medical home, Early Intervention, audiology, and parent insights. Including input from extended team members was a great help to our EHDI team as we gained information from the perspective of those stakeholders. The members also indicated that they valued this process during the evaluation at the conclusion of our formal NICHQ experience.

During the NICHQ collaborative, our team developed many successful PDSAs, as well as a few less successful initiatives. Our farthest reaching success was the development of the "Next Steps" form. During a NICHQ audiology team meeting, one audiologist shared a form that she developed and routinely gave out to families of infants newly identified with hearing loss. The form was colorful, literacy friendly and had four steps for follow-up, each with a picture identifier attached. Following discussion of the form, the audiologist would ask the parents to restate the steps so that she could assess their level of understanding. The entire audiology team embraced this idea and made some simple and group driven changes. The PDSA began on a small scale, increased slowly and was adopted by many as a result. As an example of a challenge to this process, one hospital who was very interested in this form was not able to conduct a small test, since their hospital has strict protocols about the standardization of all

documentation that is given to patients so they were unable to try the form with just a few patients as the NICHQ process proposes.

When the audiology Next Steps form was shared with the NICHQ extended committee, another committee member thought this form could be adapted for use with families whose babies did not pass their hospital hearing screening. She developed a Next Steps discharge instruction form for families of babies that refer for her facility. As with The PDSA process, she started small, “tweaked” the form and adopted the form after several successful trials. Next Steps forms have now been shared with all 54 birthing hospitals for consideration and discussed during our annual hospital conference calls.

The State EHDI office also piloted and adopted two Medical Home Next Steps. One is mailed to the medical home of infants newly identified with hearing loss outlining follow-up steps and including Early Intervention and parent group information. A copy for the physician to provide to the parents is also enclosed. Since some medical homes may only ever see one or two infants with hearing loss in their practice over many years, the feedback that we have gotten from physicians has been very positive. We have also developed a Next Steps form specific to babies with external auditory canal atresia. We are currently working with our county based case managers to develop a Next Steps form help them with recommendations with services for families of babies with newly identified hearing loss including Early Intervention and contact information for parent groups such as Statewide Parent to Parent and our new Chapter of Hands & Voices. The PCHN, along with the audiologist and hospital staff member that initiated the Next Steps forms, will present this information at a session at the National EHDI Meeting in Jacksonville Florida in April, 2014.

Other successful PDSAs have also been piloted. A PDSA to have physicians write offer prescriptions for audiology referral before nursery discharge yielded such a dramatic increase in timely follow-up that it was adopted in only a few months after the PDSA was introduced. This PDSA also became a discussion topic for our hospital conference calls and we discovered this practice already in use at a few other hospitals with excellent follow-up rates. An audiology committee member piloted a PDSA to mail out written instructions to families returning for an infant hearing evaluation. The instructions noted what insurance information to bring along as well as instructions to ensure a sleepy (thus cooperative) infant. She found the PDSA to be successful but by adding a phone call reminder following the mailing, she dramatically decreased the missed appointment rate. Two other audiology offices saw excellent results when testing a PDSA for making appointment reminder calls to families but they have found it difficult to enlist hospital support for staffing time to continue this effort.

Our New Jersey state EHDI team will conduct the first post NICHQ meeting in February 2014 to strategize future PDSA ideas and team building ideas for the extended partner meetings.

Significant Changes:

There were no project personnel changes during the reporting period and no changes to contracts, methodologies, or funding.

Plans for Upcoming Budget Year:

The EHDI program plans to continue the spread the successful tests of change that were identified during the NICHQ Learning Collaborative through upcoming funding year. We plan to re-engage the members of the NICHQ extended team and open the group to include a larger team by inviting hospital contacts, additional audiologist, parents and others. This process will begin during the first quarter of 2014. Our focus will be to continue to engage our stakeholders in exploring ideas to improve screening and intervention through the PDSA process.

Other ongoing activities to be continued through the upcoming year are the case management outreach to families in need of follow-up and the family contacts by the EI Hearing Consultants. The EHDI program will also continue to provide technical support and benchmarking reports to the hospitals.

The newly developed audiology facility reports will continue to be distributed at regular intervals. Additionally, the audiologist will begin conference calls with individual facilities to review reports, discuss reporting issues, and review EHDI goals.

Milestones:

- February 2014: Reconvene/expand QI stakeholder team
- February, May, August & November 2014, February 2015: Distribute hospital-specific quarterly reports
- April 2014: Initiation of audiology facility conference calls

Process objectives:

- Count number of hospitals implementing Next Steps forms.
- Monitor number of contacts made by case managers and EI Hearing Consultants.
- Monitor biannual hospital-specific data report for improvements in follow-up rates.