

Attachment 7: Summary Progress Report

Colorado faced many challenges during this past grant cycle. Leadership changed in the administrative Children with Special Health Care Needs (CSHCN) and Grants and Contract units at the Colorado Department of Public Health and Environment (CDPHE). These changes resulted in little understanding of the importance for family support in the newborn hearing screening program beginning in January 2011. Contracts with Colorado Hands & Voices were delayed by two years. The director and the parent guides were given individual contracts during this time. Vickie Thomson, the director of the newborn screening programs moved to the University of Colorado Denver, Marion Downs Hearing Center, in April 2012. As the principal investigator for the grant, she was able to move the grant to UCD thus facilitating the contract with Hands & Voices. The transfer of the grant took nine months. The replacement for the EHDI director position at CDPHE took an additional nine months. During this time Erica McKiever, EHDI Follow-up Coordinator, was performing both the director and coordinator positions. The HRSA MCHB block grant was reduced in funding. The decision was made to reduce the EHDI Follow-up Coordinator from 1.0FTE to .5FTE. In August 2013, CDPHE hired a part-time EHDI Follow-up Coordinator and Erica McKiever became the director and EHDI Coordinator. The Colorado EHDI team and their partners continue to be very dedicated to the success of the program to benefit families and their children despite these major setbacks.

In the 2011-2014 grant cycle the EHDI program had the following goals, objectives and activities.

Goal 1: All infants will receive a hearing screen by one month of age

Objective 1.a: By December 31, 2012, 100% of newborns will be screened for hearing loss prior to hospital discharge or within one month of age, in both the well-baby nursery and the NICU.

Progress: Colorado has successfully been able to screen 99.2% of all hospital births.

Activities included:

- ✓ Education to hospitals regarding the importance of ensuring all NICU infants received a screen prior to hospital discharge.
- ✓ Developing individual hospital protocols so that primary care physicians and nursery staff clearly understood the newborn hearing screening processes.
- ✓ Developed customized hospital parent roadmaps to give to parents whose infant failed the newborn hearing screening. COH&V has supported a parent guide to participate in every regularly scheduled regional EHDI team meeting in the last three years, and those parent guides have participated in problem solving for barriers to the 1-3-6 model for families in those communities.
- ✓ The Colorado Customized version of the Hands & Voices “Loss & Found” video was distributed to all birthing hospitals in CO.

Objective 1.b: By December 31, 2012, 60% of all home births will be screened by one month of age.

Progress: Colorado has increased the home birth screening rate from 28% to 32%. This will continue to be a targeted population.

Activities included:

- ✓ Identifying resources statewide where an infant can receive an objective hearing screen. This is a moving target as school districts and local public health offices discontinue hearing screening. The new follow-up coordinator, Hands & Voices, and the Audiology Regional Coordinators are now focusing on this effort. The goal is to have a resource list available on the CDPHE website by January 31, 2014.
- ✓ Guidelines for midwives were to be developed but due to staff shortages did not take place. This will be part of the new grant activities.
- ✓ Midwives were to be identified and receive packets of information. This has happened randomly but an effort in the next grant cycle will be to actively pursue educational efforts. The CIHAC is going to add a key midwife to the group for input and to gain their support. H&V is also reaching out to midwives to identify a key midwife (a previous selection has not been able to follow through with supporting EHDI.)
- ✓ There are 3 OAE units that have been purchased with HRSA Grant money. The EHDI team will be reviewing a map of the population of homebirths to strategically enlist, distribute and train midwives

Objective 1.c: By December, 2012, increase from 70% to 90% the number of non-English-speaking families who return for the follow-up screen or diagnostic evaluation.

Progress: A Focus group was held by CO H&V in collaboration with the Colorado Home Intervention Program for Spanish speaking families, Deaf families, and rural families in November 2011 and results shared with the program in January 2012. Based on that feedback, larger centers began distributing the CO Resource Guide or the one page flyer about parent support resources.

Due to delays in funding and lack of FTE the survey that was going to be disseminated could not be developed or distributed. A new survey will be sent this January to obtain baseline data on hospital protocols including how the results are given to parents. Based on NICHQ tests of change the guidelines were enhanced to recommend that hospitals make the outpatient appointments prior to hospital discharge and the results are given to families in their native language.

Activities included:

- ✓ H&V Loss & Found DVD distributed with Spanish voiceover.
- ✓ Roadmaps are posted and updated for hospitals in both English and Spanish.

Goal 2: All infants who fail the initial screen will receive an outpatient rescreen or audiology evaluation before one month of age.

Objective 2.a: By March 31, 2013,
Increase from 80% to 90% the number of infants in the well-baby nursery who receive an outpatient rescreen by one month of age.

Progress: This statistic remained stable at 80%. This next grant cycle will continue to focus on QI project to increase the number of infants who obtain follow-up after a failed screen at hospital discharge.

Activities included:

- ✓ Family Roadmaps were updated and posted at www.cohandsandvoices.org
- ✓ Parent Focus groups were created to look at barriers of three populations – Spanish speaking, D/HH parents, rural families to determine what was working well in EHDI and where we could improve. Parents requested more connection with parent to parent support, written Spanish resources, and connection with other parents at events. The Spanish Forum: Collaborating Towards Success was formed and met for 18 months with a report generated with current supports available to Spanish families and presented to the CO Infant Hearing Advisory Council. The barriers faced by Spanish speaking families in the area of availability and quality of Spanish translators were addressed.
- ✓ A Spanish COHV newsletter is published at least annually and housed on website.
- ✓ A Spanish only COHV Facebook page Manos y Voces de Colorado was begun in Feb 2012 and is now up to 104 members.

Objective 2.b: By March 31, 2013, increase from 69% to 90% the number of NICU graduates who receive a diagnostic audiology evaluation following a failed hearing screen.

Progress: This objective (98%) was successfully achieved by presenting to the Perinatal Care Council and providing education to the hospitals on the high risks of NICU infants and the importance of a newborn hearing screening prior to hospital discharge.

Goal 3: All infants who fail the rescreen will receive a comprehensive diagnostic evaluation by a pediatric audiologist before three months of age.

Objective 3.a: By March 31, 2013, 95% of all infants who fail the rescreen will receive a complete diagnostic evaluation before three months of age

Progress: This objective was successful as 99% of infants who made it to the audiology evaluation were diagnosed by 3 months of age.

Activities included:

- ✓ Meet with audiologists who are not submitting results or referring to the CO-Hear in a timely and appropriate manner.
- ✓ Due to lack of funding and FTE a survey was not disseminated to audiologists.
- ✓ Requiring the Department of Regulator Agencies who license audiologists to include pediatric requirements into the licensure.
- ✓ Presentation given by EHDI core committee (Vickie Thomson, Sara Kennedy, Dinah Beams, Erica McKiever) to Colorado Academy of Audiology in 2012, on the importance of early referral to EI and parent support shared at regional EHDI meetings regularly.

Objective 3.b: By March 31, 2012, increase from four to seven the number of rural audiology diagnostic sites using telehealth for training and ongoing monitoring.

Progress: Two other sites were slated to begin telehealth. One site was hospital based and felt telehealth violated HIPAA. Despite significant education this site opted not to participate. Sadly families have to travel one to two hours to be evaluated by a pediatric audiologist. The second site opted out due to lack of interest. They continue to provide poor audiology services as a result families are commuting six hours to work with audiologists in Denver.

Goal 4. All infants with a permanent hearing loss will be enrolled in early intervention before six months of age.

Objective 4. a: By March 31, 2013, 100% of infants identified with a permanent hearing loss will be referred to the CO-Hear Coordinator within 48 hours of diagnosis by the audiologist.

Progress: Although this improved from 55% to 60% this will continue to be an objective for the coming grant cycle.

Activities:

- ✓ Information was disseminated to all licensed audiologists on the regulation regarding the referral to early intervention within 48 hours of diagnosis.
- ✓ A webinar was held in May 2013 to impress upon pediatric audiologists the importance of submitting the audiology report and referring to the CO-Hear. The webinar was only attended by 10 audiologists however it was made available on the CDPHE website.

Objective 4. b. By March 31, 2013, increase from 80% to 100% the number of infants with bilateral hearing loss enrolled into an early intervention program before six months of age.

Progress: An MOU has been developed between Part C and CSDB in local communities so the early interventionists working with families can be reimbursed and provide Part C services.

Objective 4.c. By March 31, 2012, increase from 25% to 50% the number of infants with a unilateral hearing (UHL) loss who participate in the FAMILY Assessment to monitor developmental outcomes.

Progress: There was an increase in families who participated from 25% to 30%. Education to individual audiologists continues to take place annually to remind them of the UHL services available and the importance of reporting. One of the activities was to write a peer reviewed paper on the outcomes of children with UHL however due to difficulty transferring the grant that did not occur.

Goal 5. All families will be offered parent support throughout the EHDI process.

Objective 5.a: By March 31, 2013, 100% of all families with permanent hearing loss will be given a referral to CO Hands & Voices.

Progress: One of the activities was to create a module in the EHDI IDS that would allow the Parent Guides to enter the date and type of support they provided to families. There would also be an automatic referral from the CO-Hear Coordinator. Due to contractual issues with Hands &

Voices and the move of the grant funding to a different agency this did not occur but is being added to the list of activities again. Hands & Voices does report that they saw 68 new families and over 132 families of older children, which is ____% of the newly identified families in 2012. 68 Welcome Bags were disseminated from July 2012 to June 2013. Numbers of referrals are slightly lower due to a change in the referral system through the Co-Hear system.

Activities included:

- ✓ Updating Roadmaps for Families that included the local Parent Guide
- ✓ Promoting parent support at local EHDI meetings
- ✓ Local Parent Guides meet with screeners to tell them inspiring stories about early identification and the importance of the work they do (St. Francis Hospital was one example)
- ✓ Welcome bags are disseminated to new families
- ✓ Interactive Roadmap on website was updated to include information to families in Early Head Start Programs.
- ✓ Family Stories posted on CO website.
- ✓ The H&V Book of Choice disseminated to all new families in English and Spanish versions.
- ✓ Created CO H&V Facebook Page which disseminates information and creates dialogue amongst families now at 340 members,
- ✓ Spanish Facebook page at 104 members, begun Feb 2012.
- ✓ Component of reaching out to 'Teen Moms' was incorporated into H&V GBYS training modules.
- ✓ Resources to families about increased risk of child abuse and neglect was distributed to families through the newspaper, website, O.U.R. project, and Facebook Page.
- ✓ A release of information form was updated and distributed to major audiology centers in Denver for Audiologists to share with families re: Hands & Voices. In the next grant period this will be enhanced and enlarged.
- ✓ Spanish speaking newsletter was disseminated at least annually.
- ✓ Spanish section of the CO H&V website was enhanced.
- ✓ Resources for families who have children who are D/HH with additional special needs was created and housed on the CO H&V website.
- ✓ CO H&V and Marion Downs Center hosted a "Beyond the Audiogram" seminar for families.
- ✓ CO H&V and Marion Downs Center and CHIP program hosted annual picnic and holiday gathering for families.
- ✓ COH&V presented to families of upper elementary students at Colorado Children's Hospital Events, to students at Marion Downs Center Teen Day, provided outreach at Track and Field Day, and to families at Mountain BOCES family event in Vail among other events. (See annual report for more detail.)
- ✓ CO H&V hosted a regional activity in each area for both social and educational supports (e.g. CO Springs Family Cochlear Implant Workshop May 2013, Northeast CO family picnic, May 2013.
- ✓ Direct parent-to-parent support was delivered at a monthly multi-disciplinary audiology clinic.

Goal 6: All infants who fail a hearing screen will have a medical home approach that is coordinated, culturally responsive, and family centered, to ensure timely and appropriate follow-up.

Objective 6.a: By April 30, 2013, 95% of infants who fail the newborn hearing screen will have a primary care provider documented in the EHDI IDS.

Progress: The newborn screening results are now being tested on the immunization registry. This will go into full effect in February 2014. This allows the PCP to view the results of the screen at the first well-baby visit. Due to FTE challenges hospitals did not participate in a fax-back QI measure with the PCP. This is planned for the next grant cycle.

Objective 6.b: By April 30, 2012, 100% of primary care providers who attend local continuing medical education presentations will understand the follow-up protocol for their community.

Progress: CME's were offered to 30% of the hospitals. We found this is not the best way to reach physicians as they are poorly attended. This year we will work the Chapter Champion to provide an educational campaign.

Activities included:

- ✓ During the grant cycle, a statewide EHDI team visited all 55 birthing hospitals including the State EHDI coordinator, a parent representative from Hands & Voices, the regional Audiology consultant and other local team members.
- ✓ H&V collaborated with Children's Hospital for CI Consortium

Objective 6.c: By March 31, 2014, 90% of primary care physicians who have a newly identified infant with hearing loss will have the screening, diagnostic, and early intervention results from the respective providers.

Progress: Guidelines were sent to audiology providers and the CO-Hears stressing the importance of keeping the PCP informed. Fields are being added to the EHDI IDS for audiologists and the CO-Hear Coordinator to check off that they have sent a report to the PCP. Depending on funding future activities include allowing the PCP to obtain reports from the EHDI IDS via the immunization registry.

Objective 6.d: By March 31, 2012, 100% of local EHDI teams will identify barriers for follow-up for at-risk populations (low income, teen mothers, single mothers, non-English-speaking families).

Progress: This is an ongoing activity using the PDSA cycles to improve follow-up specific to populations in a particular area of the state.

Objective 6.e: By March 31, 2013, 100% of local EHDI teams will increase their cultural responsiveness for Hispanic, American Indian, Culturally Deaf populations, and others.

Activities included:

- ✓ A parent forum was conducted through the “Spanish Forum group” where parents identified the barriers and challenges of working with Spanish translators. Report on findings was submitted to the CIHAC.
- ✓ A Spanish speaking H&V GBYS parent guide worked at one major hospital to make phone calls to Spanish speaking families to ensure that they returned for follow up appointments.
- ✓ Draft guidelines (based on the Center for Cultural Competency) are in process for the updated CIHAC guideline revisions.
- ✓ Guides receive at least one annual training on the topic of cultural responsiveness.

Goal 7. All children, birth to age three, will be screened early and continuously for hearing loss to identify late onset and progressive hearing loss not identified in the newborn period.

Objective 7.a: Increase the number of Early Head Start programs and Part C/ Child Find evaluation teams that provide an OAE screen and appropriate referral protocols for follow-up.

Progress: The Colorado EHDI program continues to provide support to Early Head Start programs and Parents as Teachers. Due to staff shortages and budget cuts this objective did not receive priority however it will continue to be supported as part of the sustainability plan.

Activities:

- ✓ Early Head Start programs were contacted that are enrolled in the Early Childhood Hearing Outreach (ECHO) program to provide an assessment on current status and screening and referral processes
- ✓ Partners were convened from Colorado Department of Education to develop a protocol for Child Find teams to ensure that objective screening (OAE) and timely follow-up to audiologists are implemented.

Objective 7.b: Increase from 0 to 2 the number of Federally Qualified Health Centers (FQHC)/primary care practices that routinely provide an OAE screen.

Progress: Due to staff reductions and delays in the grant this was not pursued.

Objective 7.c. By March 31, 2014, screening data will be shared between the state EHDI and Child Find programs for all children who fail a screen from birth through two years of age.

Progress: CDPHE is working with the Department of Human Services where Part C is housed to develop a child health profile that will include immunizations, hearing, newborn, developmental and autism screenings that can be shared with providers. Funding is being considered by several foundations.

Activities:

- ✓ Stakeholders convene on a quarterly basis to move forward with the implementation of a childhealth profile database.

Goal 8. Families will be satisfied with the services they receive from screening through early intervention.

Objective 8.a: By March 2013, a random sample of families will be surveyed to determine if they were satisfied with the hearing screen, rescreen, diagnostic evaluation, early intervention program, and referral processes.

Progress: Due to the hard work of the CO chapter of Hands and Voices this continues to be a strength of the CO EHDI program.

Activities:

- ✓ A paper based or online survey was disseminated during 2012 to parents through CO H&V. Outreach through the Colorado School for the Deaf was also planning on disseminating the survey.
- ✓ 76 parents responded (65 mothers, 8 fathers, and 3 grandparents or guardians).
- ✓ Participants were primary in Metro Denver and Pikes Peak, with 25% from either northeast CO or the western slope.
- ✓ 68% of families had a child with profound hearing loss (overrepresented statistically.) More than half of the children were identified before 6 months of age.
- ✓ 25% of respondents had children aged newborn to five years. For those families, all were satisfied or very satisfied with early intervention through the CHIP program. One parent noted that they would have marked “very satisfied” had there not been turnover in their rural area with CHIP service providers.
- ✓ 25% of families were referred by the CO-Hear or CHIP program, 16% found the program on their own. A future survey will ask for satisfaction in a simpler manner as results appeared to be confusing with participant’s possibly selecting only one response.
- ✓ Of note, parents strongly preferred regional in person social or educational events with childcare on weekends or evenings, and next was conference calls of an educational nature.