

## Colorado EHDI Work Plan

The following work plan is based on the assumption that families provide permission to any QI measure that directly affects them such as a referral to a Parent Guide. Colorado EHDI firmly believe that parents have a choice in the decisions they make for their child.

TITLE	AGENCY
Vickie Thomson, PhD, PI	University of Colorado Denver, MDHC
Erica McKiever, MS, EHDI Coordinator	CDPHE, CSHCN unit
Erica Gillenwater, EHDI Follow-up Coordinator	CDPHE
Sara Kennedy, ,	COHV Executive Director
Janet DesGeorges	COHV staff
Dinah Beams, MA, Lead CO-Hear Coordinator	CO School for the Deaf and the Blind
Bruce Straw	EHDI IDS Programmer, CDPHE
Local EHDI Teams	Multiple agencies

**Goal 1: Increase from 98% to 99% the number of infants who are screened for hearing loss.**

### Aim Statement 1

By March 31, 2015, increase from 30% to 40% the number of infants who are home birthed receives an outpatient screen.

Changes / Activities	Start Date	Estimated Completion Date	Lead Staff and Partner Support	Process Measures	Outcome Measures
1. Map out the areas where home births occur.	4/1/2014	4/10/2014	Erica Gillenwater	Statewide map completed	Identify where current screening equipment is located.
2. Identify a midwife (via the CO Midwife Association) who	4/1/2014	4/30/2014	Vickie Thomson	A midwife is identified and willing to participate. She will be given information	A midwife joins the CIHAC for the May 2014 meeting.

will participate on the CIHAC				about the CO EHDI program and the importance of early identification.	
3. Re-educate midwives that have screening equipment on the importance of documentation and follow-up.	4/10/2014	5/30/2014	Erica Gillenwater Local EHDI Teams Midwife representative	Provide a webinar to educate midwives statewide with particular emphasis on reporting due to loss of documentation.	EHDI IDS shows an increase in infants being screened through documentation via the EBC or directly reported to the f/u coordinator.
4. Provide face to face meetings at the local level with midwives.	6/1/2013	3/31/2014	Erica Gillenwater Local EHDI Teams	Meetings documented	EHDI IDS shows an increase in infants being screened through documentation via the EBC or directly reported to the f/u coordinator.
5. Disseminate screening equipment and train 4 additional home birth sites (including a large birthing center).	7/1/2014	3/31/2015	Erica Gillenwater Local EHDI Teams	Meetings and trainings documents	EHDI IDS shows an increase in infants being screened through documentation via the EBC or directly reported to the f/u coordinator.
6. Develop Roadmaps for Families specifically for local midwives with local resources such as where to obtain a screen or diagnostic	4/1/2014	5/30/2014	Erica McKiever Sara Kennedy Local EHDI Teams	Create a template of local resources for families who birth at home or a birthing center	All midwives statewide have a Roadmap for Families, pertinent to their local area.

evaluation.					
7. Provide the Loss & Found DVD to all midwives to share with families including a letter on the importance of follow-up along with the Roadmap.	6/1/2014	6/30/2014	Vickie Thomson Sara Kennedy Erica McKiever	Letter is developed and materials disseminated.	The percent of infants who are home birthed increases.

**Goal 2: Increase from 80% to 90% the number of infants who fail the inpatient screen and receive a follow-up rescreen or diagnostic evaluation by one month of age.**

**Aim Statement 2**

By March 31, 2015 the number of infants LTF, from hospital discharge will be reduced from 20% to 17%
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Changes / Activities	Start Date	Estimated Completion Date	Lead Staff and Partner Support	Process Measures	Outcome Measures
1. Provide training to local EHDI Teams on QI methods and processes for statewide implementation & improvement for phase I of QI process cycles.	4/1/2014	9/30/2014	Vickie Thomson Erica McKiever Sara Kennedy Dinah Beams	Develop a training plan to disseminate to local EHDI Teams as local areas are identified for improvement to facilitate just in time "QI" learning.	All local EHDI Teams, whose area is identified for improvement in follow-up, are trained and understand the QI methods and processes
2. Identify 3 Denver hospitals (based on survey	5/1/2014	6/30/2014	Vickie Thomson Erica McKiever Erica Gillenwater	Provide education and training to hospitals. Recommend	If successful hospitals chosen will have an increase improvement in

disseminated in 2/2014) that are not making the outpatient rescreen appt. prior to hospital discharge.				immediate results into the EHDI IDS to monitor improvement and prevent loss to documentation.	f/u and 3 more hospitals will be selected.
3. Identify and train 3 Denver area hospitals who have poor f/u and develop a PDSA to identify the PCP prior to hospital discharge and implement the use of the fax back form to the PCP	5/1/2014	6/30/2014	Vickie Thomson Erica McKiever	Hospitals are trained and are testing the fax back form with the PCP. They will enter the PCP into the EHDI IDS. They will be trained to make a note into the EDHI IDS that they used the form and if the infant returns they will immediately input the results into the EHDI IDS for monitoring improvement and prevent loss to documentation.	If successful hospitals chosen have an increase in infants who return for a f/u rescreen and 3 more hospitals are selected.
4. Identify 2 hospitals that will give the screening results verbally to parents in their native language.	4/1/2014	7/30/2014	Erica McKiever Sara Kennedy Local EHDI Teams	Instruct hospital coordinators the importance of sharing health information in a families native language;utilize Roadmaps as possible resource	EHDI IDS will demonstrate an increase in f/u for non-English speaking families.
5. Update	4/1/2014	9/30/2014	Sara Kennedy	Local EHDI Teams	Updated Roadmaps with

Roadmaps for Families for all hospitals and ensure they are using the Loss & Found DVD			Local EHDI Teams/Parent Guides	meet to update the Roadmap for Families and implement the use of the Loss & Found DVD if not being shown to families whose infants fail a screen.	QR code for Loss & Found video added for each birthing hospital and homebirth resource list, as listed at <a href="http://www.cohandsandvoices.org">www.cohandsandvoices.org</a>
6. Create and disseminate a bookmark for one hospital, to give to families with QR code to link to online interactive roadmap	8/14	12/15/14	Janet DesGeorges	Bookmark created with QR code. Bookmarks disseminated in first year to 3 hospitals. COHV website monitors if there is an increase in the number of hits for the interactive Roadmap.	Families access the interactive Roadmap for resource and referral information. If successful add 3 more hospitals.
7. Identify 1 Nurse Family Partnership Community and 1 Home Visiting Program to collaborate with on improving follow-up	7/1/2014	9/30/2014	Vickie Thomson Erica McKiever Sara Kennedy	Work with local nurse partnerships/home visiting program to identify QI activities to improve follow-up from failed newborns screens into rescreens, diagnostic evaluations & early intervention. Share current resources such as the Loss & Found DVD and Roadmaps for Families	QI processes are developed are ready for implementation.
8. Implement QI/PDSA's with nurse home	10/1/2014	1/30/2015	Vickie Thomson Erica McKiever	Monitor outcomes via PDSA forms or via the EHDI IDS.	If successful there will be an increase in the f/u rate for infants who are enrolled

visitor and family partnership program					in these programs and 2 more communities will be targeted.
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**Goal 3: Increase from 92% to 99% the number of infants who fail the outpatient screen and obtain a complete audiologic diagnostic evaluation by 3 months of age.**

Aim Statement 3

By March 31, 2015 the number of infants LTF the failed outpatient screen will increase from 92% to 95%.

Changes / Activities	Start Date	Estimated Completion Date	Lead Staff and Partner Support	Process Measures	Outcome Measures
1. Select 1 hospital to disseminate the Roadmap for Families to PCP's accompanied with a letter from the Chapter Champion. The PCP will then identify which audiologist listed on the Roadmap, they would prefer their patients be referred too.	9/1/2014	9/30/2014	Vickie Thomson Al Mehl, MD Sara Kennedy	Letters and Roadmaps disseminated. PCP's identify their preference for audiology referral.	Screeners are given a list of PCP's and their preference for referral.
2. The above hospital would	9/1/2014	12/31/2014	Vickie Thomson Erica McKiever	Hospital Screener contacts the audiologist	There is an increase in referrals and a decrease

make the diagnostic appt. following a failed outpatient screen for 5 infants.			Sara Kennedy	based upon the PCP's recommendation and documents the name and date of the referral into the EHDI IDS. The EHDI IDS is monitored to determine if families follow through with the appt.	in diagnostic time for infants in receiving a comprehensive audiology evaluation. Spread to more hospitals. If it is determined that appointments are further out than two weeks an additional PDSA with the audiologists will be developed.
3. Audiologists will have appt. times available within two weeks of a failed screen.	10/1/2014	12/31/2014	Vickie Thomson	Audiologist will conduct a PDSA to determine the first available appointment and how to adjust schedules to accommodate new referrals sooner.	Families are given an audiology appointment within two weeks of failing an outpatient screen.
4. Follow-up Coordinator and a Spanish speaking Parent Guide will contact families of infants who failed the outpatient screen and have not been seen by a pediatric audiologist.			Sara Kennedy Erica Gillenwater	Spanish speaking parent guide will contract for follow up calls through CDPHE to avoid call screening from CO State Gov't caller ID.	Rate of follow up for contacted group increases from 55 to 80% with systems change recommendations given by parent guide.
5. Disseminate the "What Else Checklist for Audiologists"	7/1/14	7/31/14	Janet DesGeorges	COHV will disseminate checklist to all audiologists via the CO Academy of Audiology	Additional connections to EHDI system ensured at Audiology audiology referrals to EI < 6 months,

produced by the CDC				listserve.	referrals to parent support directly
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**Goal 4: Increase from 69% to 80% the number of eligible infants who have enrolled into early intervention and have a documented Individual Family Service Plan (IFSP) by six months of age.**

**Aim Statement 4**

By March 31, 2015 the number of infants enrolled in EI and have an IFSP by six months of age will increase from 69% to 75%.

Changes / Activities	Start Date	Estimated Completion Date	Lead Staff and Partner Support	Process Measures	Outcome Measures
1. Require in the Audiology Report a mandatory field before entering the CO-Hear name and date of referral.	5/1/2014	6/30/2014	Erica McKiever Bruce Straw	Program the required CO-Hear referral fields into the electronic audiology report in EHDI IDS.	Report tested with 3 audiologists.
2. Identify 3 audiology practices to educate on the requirement and importance of referral to the CO-Hear Coordinator	7/1/2013	9/30/2013	Erica McKiever Dinah Beams Sara Kennedy	EHDI Team presentation on importance of timely referral, education re IDS, effects of late entrance to EI.	There will be an increase in the number of infants who receive a timely referral and enrollment into EI. If successful spread to the other audiologists.
3. Increase Use of IFSP Communication Plan for families as IFSP Meetings	4/1/14	ongoing	Janet DesGeorges COHV Staff	IFSP Communication Plan will be disseminated.	Number of IFSPs with Communication Plans attached will increase by 25%.
4. Increase referral	4/1/2014	Ongoing	Dinah Beams	State and local Part C	There is an increase in the



from Child Find and Part C			Vickie Thomson Local EHDI Teams	Coordinators will develop a plan to ensure that infants and young children who are found to have hearing loss are reported to the State and referred to the CO-Hear.	number of referrals to the state EHDI program and to the CO-Hears.
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**Goal 5: Increase from 64 to 80 the percent of families that receive parent support.**

Aim Statement 5

By March 31, 2015 the number of families who receive parent support will be increased from 64% to 70%.
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Changes / Activities	Start Date	Estimated Completion Date	Lead Staff and Partner Support	Process Measures	Outcome Measures
1. Develop a Parent Guide module in EHDI IDS.	4/1/2015	6/30/2014	Bruce Straw Sara Kennedy	A module will be developed that will allow the Parent Guides to enter the date of contact, the type of resource and referral for monitoring and tracking information given to families.	The module is completed and tested by 2 Parent Guides. The remaining Parent Guides will be trained following the initial testing.
2. Provide H&V Newspaper in English and Spanish to parents and professionals	4/1/14	quarterly	COHV Staff	Newspapers disseminated to parents and professionals in CO.	Increased exposure to EHDI Best Practices.

3. Provide parent support in a clinic based setting	4/1/14	3/31/16	Janet DesGeorges	Parent support time built in to interdisciplinary clinic once a month. Parent support time offered to one additional site	3 Parents each month are provided parent to parent support at University and Children's Hospital multidisciplinary clinics.
4. Proved training at statewide El Grupo Via Conference re: EHDI in Spanish	Annually		COHV Staff Sara Kennedy	Reach out to Spanish Speaking Families at largest Spanish support Conference in State	There is an increase in follow-up for Spanish speaking families. Parent Guides track stories of Spanish speaking families experience with EHDI systems for CIHAC review.
5. Increase opportunities for joint visits from CO-Hear and GBYS Guides.	4/14/13	5/1/15	Sara Kennedy COHV Staff CO-Hear Coordinators	Local CO-Hears and Parent Guides will develop a plan to meet with families together at the 2 <sup>nd</sup> CO-Hears visit if the family provides permission Parent Guides will document in the EHDI IDS the visit.	Families will receive direct parent support in a more timely and appropriate way.
6. Develop one training for parents on the increased risk of child abuse and neglect and safety guidelines	4/1/15	3/31/16	Sara Kennedy Janet DesGeorges	Develop and implement one parent workshop on Children's Safety. Handouts on strategies and protective factors for families.	Parent's confidence in positive parenting skills increased.

7. Disseminate Welcome bags to new families from CO H&V GBYS Program.	4/1/14	3/31/16	Sara Kennedy	Welcome bags will be disseminated.	Families report increased confidence in parenting through parent survey.
8. Identify one audiology practice and modify the release of information (ROI) that is given to families to allow them to share information with the CO-Hear, the State and COHV.	8/1/2013	8/30/2013	Vickie Thomson Sara Kennedy	Audiologist is selected for the QI process. The ROI is modified.	Evidence of direct audiology referrals to parent support in IDS. Will modify 3 more audiology ROI forms.
9. Develop a field in the EHDI IDS for audiologist to document the release has been signed.	7/1/2014	7/30/2014	Erica McKiever Sara Kennedy Bruce Straw	Audiology EHDI IDS modified to include the referral and signed ROI to COHV.	80% of releases signed by parents
10. Expand parent online interactive Roadmap with specific information about connecting to D/HH Adults	7/1/14	12/15/14	Janet DesGeorges	Information put online at <a href="http://www.cohandsandvoices.org">www.cohandsandvoices.org</a> Newspaper Enews Facebook pages Welcome bag handouts	Families have opportunity to connect with D/HH Adult role models including Virtual Role Model and regionally available role models or at parent support events.

**Goal 6: 100% of primary care providers receives screening, diagnostic and early intervention results in a timely manner to promote the medical home approach.**

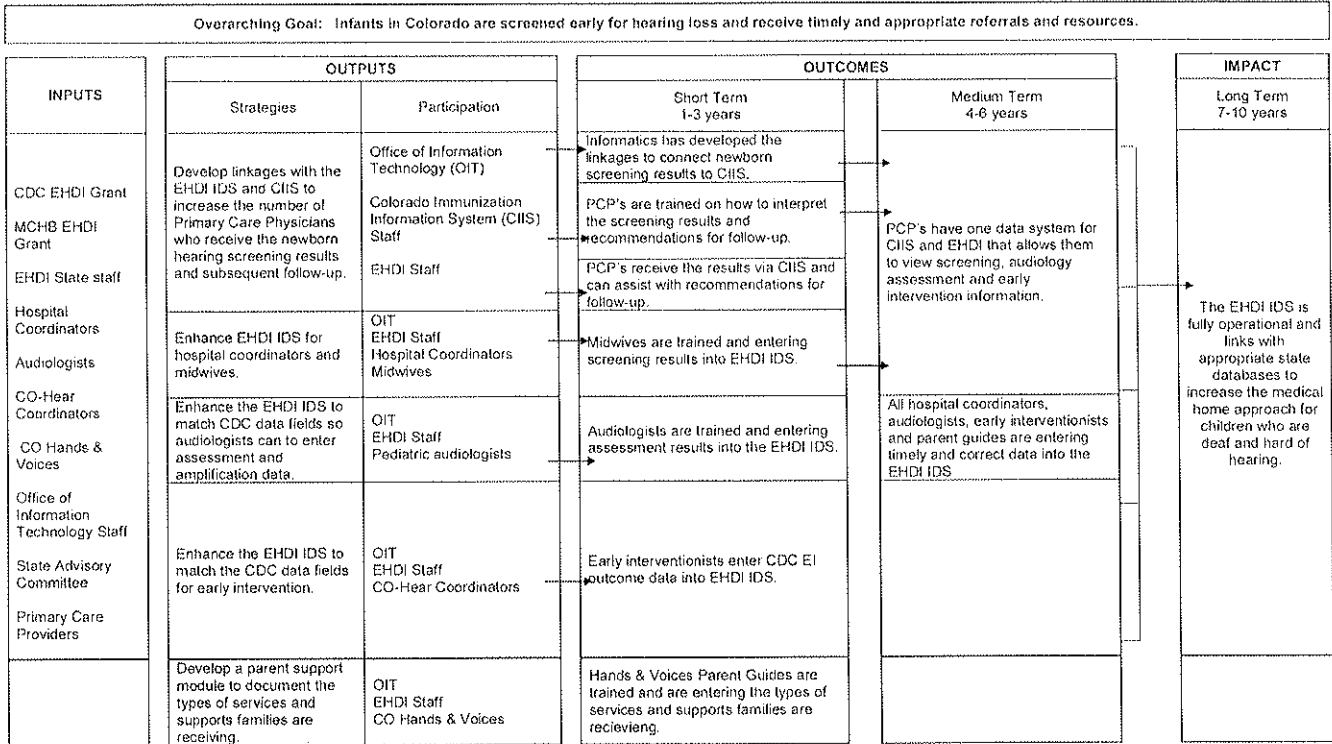
**Aim Statement 5**

By March 31, 2015 the number of PCP's who receive screening, diagnostic, EI and Parent support results/reports will be documented in 70%.

Changes / Activities	Start Date	Estimated Completion Date	Lead Staff and Partner Support	Process Measures	Outcome Measures
1. H&VAAP Chapter champion and H&V Collaboration project	4/1/14		Sara Kennedy	Via national AAP Committee, collaborating efforts between AAP Chapter champion and HV chapter are established	Pediatricians increase knowledge of parent perspective of EHDI, use of local roadmaps, issues effecting referral to audiology and EI.
2. Continue to add the names, addresses and email information of PCP's into the EHDI database.	ongoing		Erica Gillenwater Erica McKiever	As new PCP's are identified through the immunization registry or fields in the EHDI IDS, their contact information will be loaded into the EHDI IDS so providers can access this information.	Providers will have access to the PCP's contact information.
3. Develop a report form for audiologists, CO-Hears and Parent Guides that can be sent to the PCP.	12/1/2014	3/31/2016	Vickie Thomson Dinah Beams Sara Kennedy	Providers will continue to be educated on the importance of a medical home approach. Reports will be available based on the	PCP's have timely results and information regarding the audiology, early intervention and parent support results and recommendations made for their patient.

				<p>data entered into IDS for providers to mail, email or fax to PCP. Providers will indicate that they have submitted a report to the PCP. EHDI IDS will be able to determine if reports have been downloaded and sent to the PCP.</p>	
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CO CDC EHDl State-level Logic Model



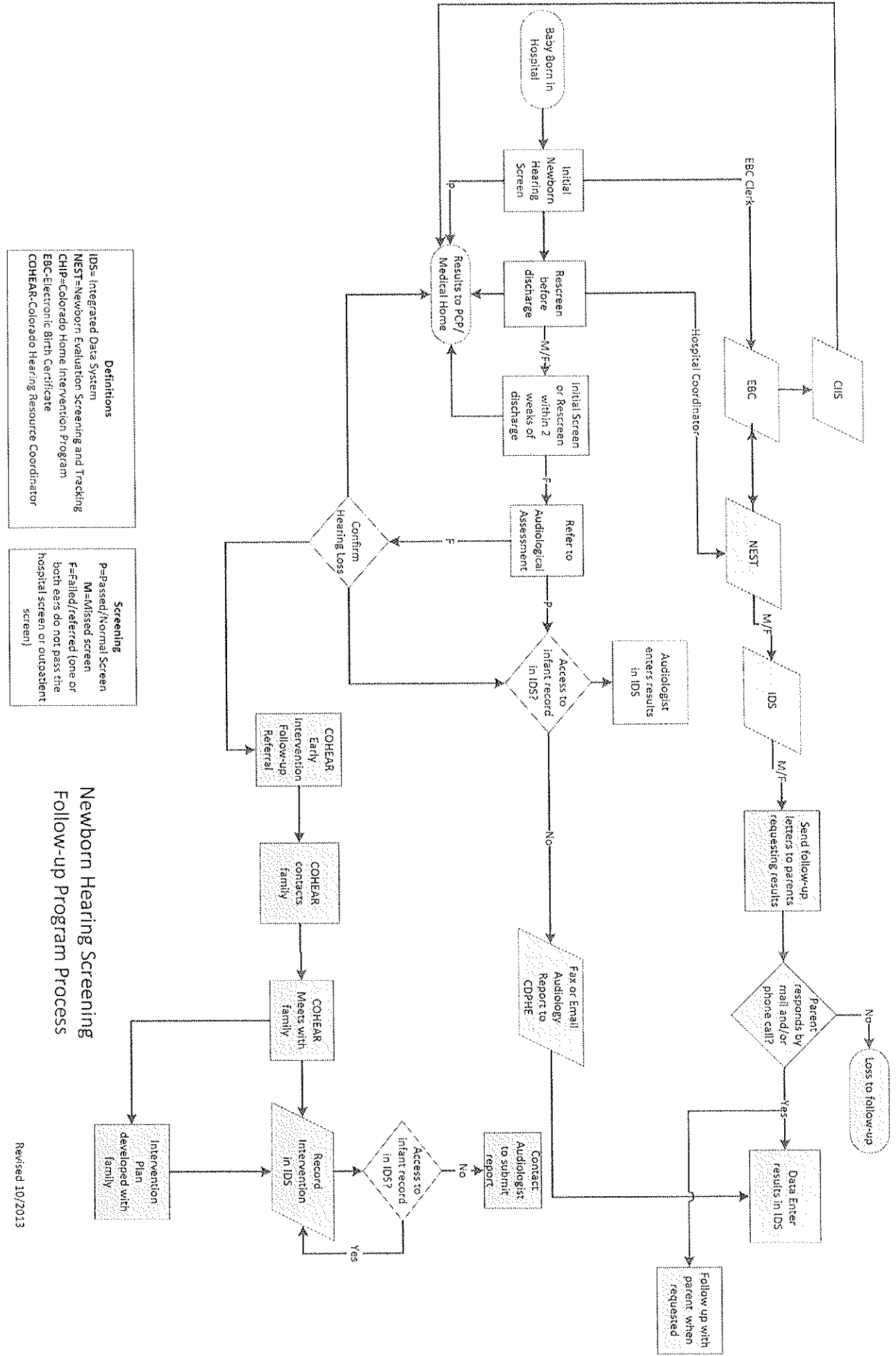
LOGIC ASSUMPTIONS	EXTERNAL FACTORS
<p>The EHDl program is supported by state and local partnership to develop comprehensive community based system of care from screening through early intervention.</p> <p>Research has shown that early screening leads to early identification and improved outcomes for young children.</p> <p>Increasing the follow-up from screening utilizing a medical home approach supports coordinated, high quality care.</p> <p>Identified barriers to implementing standardized screening</p> <ul style="list-style-type: none"> <li>Lack of provider support to ensure appropriate and timely referrals</li> <li>Lack of parent knowledge on the importance of early identification and intervention</li> <li>Lack of coordinated systems within a community to develop timely and appropriate referral and interventions.</li> </ul>	<p>Contributions of external partners, such as other state agencies; private foundations; individual/youth/family advocacy organizations; provider organizations; and other participants of the Medical Home Coalition and Medical Home Community Forum, etc.</p> <p>Federal funding for the MCH Block Grant</p> <p>Health Care Reform</p> <p>The Joint Committee on Infant Hearing has a position paper that outlines best practices for EHDl programs.</p>

EVALUATION FOCUS - OUTPUTS	EVALUATION FOCUS - OUTCOMES
<p>Data demonstrates the percent of infants who are receiving a hearing screen by 1 month</p> <p>Data demonstrates the percent of children who failed a screen received timely and appropriate audiology follow-up by 3 months</p> <p>Data demonstrates the percent of children who have a confirmed permanent hearing loss receive early intervention services by 6 months</p> <p>Data demonstrates the percent of infants who have a documented medical home.</p>	<p>Increase the percent of infants who are screened and receive timely and appropriate referrals and services.</p> <p>Increase parent knowledge on the importance of screening, referral, evaluation and early intervention.</p>

**Background and Context**

The primary audience for this logic model is the State and CDC EHDl Staff

This logic model outlines state-level strategies to enhance the EHDl IDS to improve surveillance, follow-up and tracking of infants.



## 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 EHDl director position at CDPHE took an additional nine months. During this time Erica McKiever, EHDl 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 EHDl Follow-up Coordinator from 1.0FTE to .5FTE. In August 2013, CDPHE hired a part-time EHDl Follow-up Coordinator and Erica McKiever became the director and EHDl Coordinator. The Colorado EHDl 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 EHDl 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 EHDl 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](http://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 are 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.

## BIOGRAPHICAL SKETCH

Provide the following information for the key personnel and other significant contributors in the order listed on Form Page 2.  
Follow this format for each person. **DO NOT EXCEED FOUR PAGES.**

NAME Vickie Thomson	POSITION TITLE
eRA COMMONS USER NAME	Program Director, Newborn Screening Programs

EDUCATION/TRAINING <i>(Begin with baccalaureate or other initial professional education, such as nursing, and</i>			
INSTITUTION AND LOCATION	DEGREE <i>(if applicable)</i>	YEAR(s)	FIELD OF STUDY
University of Colorado, Boulder	PhD	2003-2007	Audiology, Public Health
University of Northern Colorado, Greeley	MA	1978	Audiology
University of Northern Colorado, Greeley	BA	1977	Communication Disorders

### A. Position

**University of Colorado Denver, Marion Downs Hearing Center Foundation, Denver, CO April, 2012 - present**

*Program Director.* Responsibilities include strategic planning, program implementation and infrastructure, personnel management, public relations, fiscal responsibility and all aspect of administration. Support hearing programs including newborn hearing systems. Participate in state and national efforts to provide technical assistance to Early Hearing Detection and Intervention (EHDI) programs.

**Colorado Department of Public Health and Environment, Health Care Program for Children with Special Needs, Denver, CO, 1991- March, 2012**

*Program Director, Newborn Screening Programs.* Provide consultation and coordination in the development of statewide activities for newborn hearing screening programs per HB 1095-97; develop data management and tracking systems for newborn hearing screening programs; assurance that a comprehensive system from screening through intervention for infants identified with hearing loss; provide technical assistance to other MCH programs through out the United States; Co-Chair the Colorado Infant Hearing Advisory Committee. Assure comprehensive audiological services for children birth through 21 years of age; promote statewide interagency collaboration to assure community based services; develop statewide audiology policies and procedures; provide indirect supervision to the state regional coordinators; provide inservice and training.

### B. Positions and Honors

Positions and Employment

1998-2002	Clinical Audiologist, Boulder Community Hospital, Mapleton Center for Rehabilitation
1996-2000	Project Coordinator, University of Colorado, Boulder, CO, 1996-2000
2003-2007	Graduate Professional, Teacher, University of Colorado, Boulder, 2003-2007
1991-present	Director, Newborn Screening Programs, CO Dept of Public Health and Environment

### C. Selected peer-reviewed publications (in chronological order)

1. Christensen, M., Thomson, V., Letson, G.W. (2007). Evaluating the Reach of Universal Newborn Hearing Screening in Colorado. *American Journal of Preventative Medicine*, 2008; 35, 594-597
2. Yoshinaga-Itano, C., Coulter, C., Thomson, V. Developmental Outcomes of Children with Hearing Loss Born in Colorado Hospitals with and without Universal Newborn Hearing Screening Programs. *Seminars in Neonatology* 2001; 6: 521-529.
3. Yoshinaga-Itano C, Coulter D, Thomson V. The Colorado Newborn Hearing



- Screening Project: Effects on Speech and Language Development for Children with Hearing Loss. *Journal of Perinatology*. 2000; 20:S132-S137.
4. Mehl, A., Thomson, V. The Colorado Newborn Hearing Screening Project, 1992-1999 On the Threshold of Effective Population based Universal Newborn Hearing Screening. *Pediatrics* vol. 109, Jan 2000
  5. Thomson, V., et.al. The Marion Downs National Center for Infant Hearing: Developing Comprehensive State Systems. *The Otolaryngologic Clinics of North America*. Vol 32, no.6, Dec. 1999
  6. Arehart K.H., Yoshinaga-Itano C., Thomson V. State of the States: The Status of Universal Newborn Hearing Screening, Assessment, and Intervention Systems in 16 States. *American Journal of Audiology*, vol 7, no.2, 101-104, 1998.
  7. Thomson V. The Colorado Newborn Hearing Screening Project. *American Journal of Audiology*, 1997.
  8. Thomson V., Rose L., O'Neal J. Statewide Implementation of Universal Newborn Hearing Screening. *Seminars in Hearing*, vol.19, no.3, 287-300, 1998.
  9. Mehl A., Thomson V. Newborn Hearing Screening: The Great Omission. *Pediatrics*, 101-108, 1998.
  10. Gabbard S., Thomson V., Stredler Brown A. Considerations for Universal Newborn Hearing Screening, Audiologic Assessment, and Intervention. *Audiology Today* 8-10, 1998
  11. Arehart, K., Yoshinaga-Itano, C., Thomson, V., Gabbard, S., Brown, A. The Status of Universal Newborn Hearing Screening, Assessment, and Intervention Systems in 16 States. *American Journal of Audiology*, 101-115, 1998.
  12. Mehl A., Thomson V. Universal Newborn Hearing Screening: An Evolving Standard of Care for Neonates. *Audiology Today*, 28-29, 1998
  13. Yoshinaga-Itano C, Coulter D, Thomson V. The Colorado Newborn Hearing Screening Project: Effects on Speech and Language Development for Children with Hearing Loss. *Journal of Perinatology*. 2000; 20:S132-S137.

#### **D. Research Support.**

##### Ongoing Research Support

HRSA #U22MC10761 Vickie Thomson (PI) 10/01/10-09/30/2011  
Mountain States Genetics Regional Collaborative Center in collaboration with the Health Resources and Services Administration (HRSA). The goal is to develop opportunities for delivering genetic counseling services via telehealth in rural Colorado.

HRSA #H61MC09030 Vickie Thomson (PI) 04/01/2011 -03/31/2014  
Universal Newborn Hearing Screening and Intervention. The goal is to develop comprehensive, community based, culturally competent systems of care from screening through early intervention for families and their children who are deaf and hard of hearing.

CDC DDO8-803 Vickie Thomson (PI) 07/01/2005 – 06/30/2011  
Centers for Disease Control, Early Hearing Detection and Intervention Tracking, Surveillance, and Integration. The goal is create a data tracking and management system from screening through early intervention that includes outcome data.

AUCD #0811-072 Sandra Gabbard (PI) 01/15/2009 – 01/14/2012  
Maternal and Child Health Bureau in collaboration with the Association of University Centers on Disabilities, Audiology Training Grant. The goal is to increase the knowledge of 4<sup>th</sup> year audiology doctoral students in multidisciplinary training and to increase pediatric audiology skills in practicing rural audiologists.

HRSA-09-242 Chris Wells (PI) 11/01/2009 – 10/31/2012  
Health Resources and Services Administration, Effective Follow-up in Newborn Screening.  
The goal is to increase the use of electronic medical records between the public health newborn screening programs, primary care providers, and specialists.

##### Completed Research Support

2007 -Completed a Ph.D (2007) in audiology and public health. The research focus was an analysis of the Colorado EHDI system. The goal was to identify factors associated with infants who did not receive the outpatient rescreen and factors associated with infants who are identified after six months of age.

### BIOGRAPHICAL SKETCH

Provide the following information for the Senior/key personnel and other significant contributors in the order listed on Form Page 2.  
Follow this format for each person. **DO NOT EXCEED FOUR PAGES.**

NAME Erica McKiever	POSITION TITLE Newborn Screening Programs Supervisor		
eRA COMMONS USER NAME (credential, e.g., agency login)			
EDUCATION/TRAINING <i>(Begin with baccalaureate or other initial professional education, such as nursing, include postdoctoral training and residency training if applicable.)</i>			
INSTITUTION AND LOCATION	DEGREE <i>(if applicable)</i>	MM/YY	FIELD OF STUDY
Licensed Professional Counselor (LPC) Lesley University University of Notre Dame	- MA BA	2005 1997 1995	Psychology Expressive Therapies Psychology/Fine Arts

**NOTE: The Biographical Sketch may not exceed four pages. Follow the formats and instructions below.**

#### A. Personal Statement

I worked as the Newborn Hearing Screening Program Coordinator for just under 2 years while simultaneously cross-training and working with the Newborn Metabolic Screening Program, thus effectively gaining a deep understanding of newborn screening programs. Prior to my involvement with the Newborn Hearing Screening Program, I was fortunate to work in a 6 month temporary position at CDPHE in the Prenatal Plus Program Director role. That opportunity was presented to me while I was the Prenatal Plus Program Coordinator at the local level. I successfully administered this program for 3 years and served as the mental health professional for 4 years before that. Since 2008, I have served as a collaborative member of the Aurora Healthier Beginnings for African American/Black Communities, which is a public health program dedicated to closing the disparity gap and improve birth outcomes for African American women. These rich experiences have given me a combined 11 years of experience in public health, with 5 of those years providing program management and leadership. My work has always involved infant health and maternal child health initiatives as I find this work to be both rewarding and gratifying.

It was during my time working as the Prenatal Plus Program Coordinator at the Salud Family Health Center that I worked with a state database (IRIS), provided management of Prenatal Plus Program client scheduling and insurance verification, as well as guidance regarding program billing protocol while providing direct mental health and case management services to clients. I am currently the Principle Investigator for the Centers for Disease Control Early Hearing Detection (EHDI) and Intervention program grant in which I work to assure goals and objectives are met and managing grant budget. This grant provides funding to develop and maintain the State EHDI Integrated Database (IDS) for the State of Colorado. I also manage and assure goals and deliverables are met for the Health Resources and Services Administration (HRSA) which focuses on follow-up services for the program.

I am the Co-Chair of the Colorado Infant Hearing Advisory Committee in which I convene and facilitate the meetings while utilizing the committee to gain advice regarding program needs. I also oversee the implementation process to provide newborn hearing screening results in the state immunization registry.

As the current supervisor of the Colorado Newborn Hearing Screening Program, I supervise the Newborn Hearing Screening Follow-up Coordinator as well as assure that the follow-up requirements in state statute are met.

My public health experience serves as a valuable supplement to my Master's Degree in Counseling and my Bachelor's Degree in Psychology. My education, along with my experience as a licensed psychotherapist, has helped me to form strong interpersonal skills and provide optimal oral communication with others, giving me the ability to establish strong relationships with internal and external partners thus positively affecting programmatic goals and objectives. These skills have also allowed me to possess the ability to assess various situations and problem solve in an efficient manner.

## **B. Positions and Honors**

### **2012 – present**

Newborn Screening Programs Supervisor, Colorado Dept of Public Health and Environment, Denver, CO

### **2010-2012**

Screening Coordinator, Newborn Hearing Screening/Assuring Better Child Health and Development, Colorado Dept of Public Health and Environment, Denver, CO

### **2010-2011**

Independent Contractor, Tri-County Health Department, Aurora Healthier Beginnings, Aurora, CO,

### **2008 - present**

Community Collaborative Member/Leadership Team Member, Healthier Beginnings for African American/Black Communities, Aurora Healthy Baby Initiative, Aurora, CO,

### **2009**

Therapist – Postpartum Depression Clinic (Professional Training), Kempe Center, Perinatal Mental Health Program, Denver, CO

### **2009-2010**

Prenatal Plus Program Director Colorado Department of Public Health and Environment, Women's Health, Denver, CO

### **2008-2009**

Care Manager II, Colorado Access, Coordinated Clinical Services, Healthy Moms/Healthy Babies Program, Denver, CO

### **1999-2008**

ClinicalTherapist/Prenatal Plus Program Coordinator/Health Educator, Salud Family Health Centers, Women's Clinic, New Horizons Teen Clinic, Brighton, CO

### **1998-2000**

Therapist - Rapid Response Crisis Team, Adams Community Mental Health Center (Community Reach), Thornton, CO

### **Professional Affiliations:**

Pregnancy and Postpartum Partnership (P3)  
Aurora Healthier Beginnings Collaborative  
Blue Ribbon Policy Council  
Project CASCADE (Collaborative Addressing System Change in ASD and other Developmental disabilities)

### **Special Trainings:**

Social Determinants of Health  
Life Course Model  
Preconception Health  
Motivational Interviewing  
DC:0-3R (Diagnostic Classification of Mental Health and Developmental Disorders of Infancy and Early Childhood)

### BIOGRAPHICAL SKETCH

Provide the following information for the Senior/key personnel and other significant contributors in the order listed on Form Page 2. Follow this format for each person. **DO NOT EXCEED FOUR PAGES.**

NAME Gillenwater, Erica		POSITION TITLE Newborn Hearing Screening Coordinator	
eRA COMMONS USER NAME (credential, e.g., agency login)			
EDUCATION/TRAINING (Begin with baccalaureate or other initial professional education, such as nursing, include postdoctoral training and residency training if applicable.)			
INSTITUTION AND LOCATION	DEGREE (if applicable)	MM/YY	FIELD OF STUDY
University of Northern Colorado, Greeley CO	B.A.	12/03	Psychology

**NOTE: The Biographical Sketch may not exceed four pages. Follow the formats and instructions below.**

#### A. Personal Statement

During my time teaching at Head Start, I experienced firsthand the importance of proper development of young children and understand the value of identifying children early with developmental or sensory issues. I participated in IEP development and execution as I had one child in my classroom that had been diagnosed with hearing loss and benefitted greatly from early intervention. In this position I also gained knowledge of program development and implementation as well as evidence-based practices and measurable outcomes.

With my experience as a Medicaid case manager, I am able to create and implement effective methods of tracking and follow-up in order to provide productive follow-up. I am able to set goals and accomplish priorities according to timetables to achieve maximum productivity. In this position I became very familiar with both state and federal funding programs, grants and contracts, and gained a broad understanding of goals and deliverables and the ability to produce timely, measurable, high quality outcomes.

Perhaps most relevant to my role, I possess extensive experience and a well rounded background working not only with children and families, but with numerous healthcare facilities, healthcare and home health providers, hospitals, and local agencies and community resources.

#### B. Positions and Honors

##### Positions and Employment:

2001-2002 Child Advocacy, Resource, and Education Center; Group Leader, Greeley CO  
 2004-2005 Lead Teacher, Headstart, Iliiff CO  
 2005-2007 Social Services Representative/Neighborhood Advocate, Fairacres Manor, Greeley CO  
 2007-2012 Long Term Care Case Manager, Weld County Human Services Area Agency on Aging, Greeley CO  
 2013- present Newborn Hearing Screening Coordinator, Colorado Department of Public Health and Environment, Denver, CO

##### Professional Memberships:

2013 Member - Newborn Hearing Screening Advisory Committee  
 2013 Member - Newborn Screening Advisory Committee

**BIOGRAPHICAL SKETCH**

Provide the following information for the Senior/key personnel and other significant contributors in the order listed on Form Page 2.  
Follow this format for each person. **DO NOT EXCEED FOUR PAGES.**

NAME Sara Kennedy		POSITION TITLE Executive Director, Colorado Families for Hands & Voices	
eRA COMMONS USER NAME (credential, e.g., agency login)			
EDUCATION/TRAINING <i>(Begin with baccalaureate or other initial professional education, such as nursing, include postdoctoral training and residency training if applicable.)</i>			
INSTITUTION AND LOCATION	DEGREE <i>(if applicable)</i>	MM/YY	FIELD OF STUDY
University of Kansas The Advocacy Training Institute	BS certificate	05/1987 2006	Occupational Therapy Educational Advocacy

**NOTE: The Biographical Sketch may not exceed four pages. Follow the formats and instructions below.**

**A. Personal Statement**

As a parent of a late identified child who was not identified through the EHDI system in Colorado, I continue to be highly motivated to assist the system in removing barriers to timely screening, referral for quality follow up care, and swift entry into developmentally appropriate, holistic early intervention services. I have worked with Hands & Voices in Colorado as a parent guide since 2000, becoming an assistant director in 2008 and director in 2011. I worked in the health care field until 1999, about nine months after our daughter was identified with hearing loss, when it became apparent that no child care situation could commit to the wide variety of supports that she needed to overcome a significant language delay.

**B. Positions and Honors**

2012 Colorado Academy of Audiology Peak Performance Award  
2011 – Present: Executive Director, Colorado Families for Hands & Voices  
2008 – 2011 Assistant Director, Colorado Families for Hands & Voices  
2001 – present: Features Editor, the Hands & Voices Communicator , Headquarters Staff  
2004-2007 Family Consultant, El Paso County Health Department, Colorado Springs, CO  
1994-1999 Director of Occupational Therapy, Cheyenne Mountain Rehabilitation, Colorado Springs, CO  
1992-1994 Director of Occupational Therapy, Wesley Rehabilitation Hospital, Wichita, KS  
1987-1992 Occupational Therapist, St. Vincent Hospital (Rehabilitation Center), Billings, MT

**C. Selected Peer-reviewed Publications**

Early Hearing Detection and Intervention: Parent Experiences with the Diagnostic Hearing Assessment.  
Rebecca Larsen, Karen Muñoz, Janet DesGeorges, Lauri Nelson, Sara Kennedy, American Journal of Audiology, Vol. 21, 91–99, June 2012

**D. Research Support**

While I have participated in many research projects as a parent, such as the Quality of Life Study for Children with Hearing Loss (UC Boulder) the longitudinal study of children with hearing loss through UC Boulder and Dr. Christie Yoshinaga-Itano, and various formal parent and professional surveys, I have not been a listed author on these efforts.

**BIOGRAPHICAL SKETCH**

Provide the following information for the Senior/key personnel and other significant contributors in the order listed on Form Page 2. Follow this format for each person. **DO NOT EXCEED FOUR PAGES.**

NAME Janet DesGeorges		POSITION TITLE Parent Co-coordinator of Grant	
eRA COMMONS USER NAME (credential, e.g., agency login)			
EDUCATION/TRAINING <i>(Begin with baccalaureate or other initial professional education, such as nursing, include postdoctoral training and residency training if applicable.)</i>			
INSTITUTION AND LOCATION	DEGREE <i>(if applicable)</i>	MM/YY	FIELD OF STUDY
Ventura High School	HS Diploma	1979	General
MCH Public Health Leadership Institute University of North Carolina – Chapel Hill	Certificate completion	2011-2012	Public Health Leadership
National Early Hearing, Detection and Intervention Conferences,		2000 - 2013	EHDI Systems
Community Resource Center: Non-Profit Leadership and Management Program ( 6: 2-day trainings 2002)		2002	Non-Profit Management

**NOTE: The Biographical Sketch may not exceed four pages. Follow the formats and instructions below.**

**A. Personal Statement**

**Life Experience:**

- Mother of three daughters; Parent of a daughter who is Hard of Hearing
- Parent who has personally experienced and navigated the educational Part C and Part B systems for our child, and the health systems designed to serve us.
- Content expert on Quality Improvement methodology

**Major Professional Interest(s)**

Parent Advocacy; implementation of parent participation of systems building of Universal Newborn Hearing Screening systems; parent-to-parent support; Deaf Education Reform movement, parent advocacy in school systems; IDEA, NCLB Part C and Part B Training to Parents; Medical Home Initiative; Parent Involvement in Quality Improvement methodology.

**B. Positions and Honors**

- 1999 – 2011 Executive Director, Colorado Families for Hands & Voices
- 2000 – 2011 Outreach Director, Hands & Voices National
- 1996 – 2011 Parent Consultant, Colorado Home Intervention Program
- 2005 – 2013 Parent Faculty, NICHQ Learning Collaboratives (all 50 states)
- 1999 - present Advisor on Parent Support, Marion Downs Hearing Center
- 2011 – present Executive Director, Hands & Voices Headquarters

Program Director/Principal Investigator (Last, First, Middle):

Honors:

Colorado Academy of Audiology Peak Performance Award (2012)

Antonia Maxon National EHDI Award (2009)

Advocacy Award – Developmental Disabilities Center (1998)

### **Peer-reviewed Publications**

Early Hearing Detection and Intervention: Parent Experiences With the Diagnostic Hearing Assessment  
Rebecca Larsen, Karen Muñoz, Janet DesGeorges, Lauri Nelson, and Sara Kennedy *American Journal of Audiology* • Vol. 21 • 91–99 (2012)

Improving Follow-up to Newborn Hearing Screening: A Learning-Collaborative Experience  
Shirley A. Russ, Doris Hanna, Janet DesGeorges and Irene Forsman (2010) DOI: 10.1542/peds.2010-0354K *Pediatrics* 2010;126;S59-S69

DesGeorges, J; 9:89-93(2003) Family Perceptions of Early Hearing, Detection, and Intervention Systems: Listening to and Learning from Families "Mental Retardation and Developmental Disabilities Research Reviews: The Official Journal of the Society for Developmental Pediatrics, Inc" For the issue on: Infants and Children with Hearing Loss

DesGeorges, Thomson, Arehart, Gabbard, Stredler Brown, Pruitt, Mehl, Feehs (1999) The Marion Downs National Center for Infant Hearing: Developing Comprehensive State Systems. *Otolaryngologic Clinics of North America*.

### **Additional recent publications of importance to the field (in chronological order)**

DesGeorges, J. (2013, June). The Three P's: Enhancing a student's education through private audiology services, public education audiology, and parents. *AudiologyOnline*, Article #11868. Retrieved

DesGeorges, J (2012) NCHAM E-Book Family Support chapter 10

Powerful Partnerships DesGeorges J., Aquino E., Britol, T., Crowe V., Heinrich, P. National Initiative for Children's Healthcare Quality (NICHQ publications) (2012)

What Does it Mean to be Parent-Driven? DesGeorges J., *Hands & Voices Communicator* Volume XV-Issue 4 (2012)

DesGeorges, J. Thomson, V. (2006) Parents give Input through Surveys *Hands & Voices, The Communicator, Volume X, Issue 3*

DesGeorges, J (2004) Parent Support and the First Home Visits; *Ski\*Hi Early Childhood Curriculum for Deaf and Hard of Hearing Infants and Toddlers* *Ski\*Hi Institute*

DesGeorges, J Seaver, L; (2003) Special Education Law: A New IDEA for Students Who Are Deaf or Hard of Hearing ; *Auditory Disorders in Children*, revised 2003 textbook

### **Research Support**

2009 – 2013 University of Colorado, Boulder NECAP: EHDI Developmental Outcomes Study - DesGeorges/ Hands & Voices is participating in this research grant under the direction of Dr. Christine Yoshinaga Itano gathering data on child development outcomes for children who are Deaf/Hard of Hearing.

### BIOGRAPHICAL SKETCH

Provide the following information for the key personnel and other significant contributors in the order listed on Form Page 2.  
Follow this format for each person. **DO NOT EXCEED FOUR PAGES.**

NAME Amy Carol Dodd		POSITION TITLE Assessment Coordinator	
eRA COMMONS USER NAME (credential, e.g., agency login)			
EDUCATION/TRAINING <i>(Begin with baccalaureate or other initial professional education, such as nursing, and include postdoctoral training.)</i>			
INSTITUTION AND LOCATION	DEGREE <i>(if applicable)</i>	YEAR(s)	FIELD OF STUDY
University of Arizona, Tucson, AZ	B.A.	1967-1972	Early Childhood Education
University of Colorado, Boulder, CO		1977-1981	Education
University of Northern Colorado, Greeley, CO		1977-1981	Education

#### A. Personal Statement

I have been managing all aspects of the assessment process for evaluating the speech and language outcomes of children who are deaf or hard of hearing for the past 18 years through research grants from NIH, the US Department of Education and the Department of Health and Human Services. There are over 300 of these assessments each year coming from all areas of Colorado. I maintain an Access database to manage the assessment schedule and have devised efficient systems for all phases of the data collection process including tracking incoming and outgoing assessments, moving each videotaped interaction through eight different transcribers/coders, report writing and distribution of results. I maintain an on-going communication and working relationship with deafness and speech specialists throughout the state of Colorado besides working closely with a team here at the University of Colorado.

#### B. Positions

- 1976 – 1981 Elementary School Teacher – St. Vrain Valley Public Schools, Longmont, CO
- \*Developed and implemented educational programs while working with education teams
  - \*Established academic goals and implemented teaching strategies
  - \*Organized conferences and class/community interaction
- 1990 – 1993 Paraprofessional – Academic year and Summer Day Treatment: Boulder Valley Public Schools, Boulder County Mental Health & Boulder Parks & Recreation tri-agency program, Boulder, CO
- \*Developed academic and recreational activities for children with emotion/behavioral challenges
  - \*Coordinated schedules and worked with academic, therapy and recreational teams
  - \*Established goals and evaluated programs
- 1993 – 1995 Paraprofessional – Flatirons Elementary School, Boulder Valley Schools.
- \*Worked with teaching team to create individual instructional materials for children with special needs in a school-wide inclusion program
  - \*Provided one-to-one and small group instruction to children within the inclusion environment
- 1993 – present Professional Research Assistant – University of Colorado at Boulder, CO
- Coordinate and oversee the videotape assessment portion of grants to study the speech and language development of children who are deaf or hard of hearing including:
- \*Scheduling and tracking of videotapes through the coding process
  - \*Supervising, scheduling and consulting with the coding and work-study staff
  - \*Collecting & summarizing project evaluation materials



- \*Balancing & dispersing grant funds, Medicaid billing
- \*Managing human resources via PeopleSoft service software including recruiting, hiring and payroll

#### D. Research Support

##### Completed Research Support

HRSA 08-030 CFDA 93.251 Vickie Thomson (PI) 4/1/08 – 3/31/12  
Department of Health & Human Services – Health Resources & Services Administration – Maternal & Child Health Bureau  
Reducing Loss to Follow-up after Failure to Pass Newborn Hearing Screening

The major goal of this project is to reduce loss to follow-up after failure to pass newborn hearing screening through state & local systems development to ensure positive outcomes for children who are deaf or hard of hearing

Role: Professional Research Assistant – Assessment Coordinator

UCD RTOI 2008-999-01 Christine Yoshinaga-Itano (PI) 10/1/08 – 9/30/11  
Association of University Centers on Disabilities in collaboration with the Centers for Disease Control and Prevention, National Center on Birth Defects and Developmental Disabilities

Developmental Outcome Feasibility Study: Deaf/Hard of Hearing

The major goal of this project is to assist states in establishing a statewide developmental and language assessment protocol for children with hearing loss ages birth to 3 and to determine the feasibility of establishing a national database of developmental and language outcomes for children who are deaf or hard of hearing.

Role: Data Coordinator

UCD Award number 7H61MC25317-01-00 CFDA 93.251 Vickie Thomson (PI) 11/1/12 – 3/31/13  
Department of Health and Human Services, Health Resources and Services Administration  
Universal Newborn Hearing Screening and Intervention

The major goal of this project is to reduce loss to follow-up after failure to pass newborn hearing screening through state & local systems development to ensure positive outcomes for children who are deaf or hard of hearing

Role: Data Coordinator

**BIOGRAPHICAL SKETCH**

Provide the following information for the Senior/key personnel and other significant contributors in the order listed on Form Page 2. Follow this format for each person. **DO NOT EXCEED FOUR PAGES.**

NAME Beams, Dinah		POSITION TITLE Program Coordinator	
eRA COMMONS USER NAME (credential, e.g., agency login)			
EDUCATION/TRAINING (Begin with baccalaureate or other initial professional education, such as nursing, include postdoctoral training and residency training if applicable.)			
INSTITUTION AND LOCATION	DEGREE (if applicable)	MM/YY	FIELD OF STUDY
Southern Methodist University	B.S.	05/76	Communication Disorders
University of Colorado - Boulder	M.A.	05/02	Speech and Hearing Science

**NOTE: The Biographical Sketch may not exceed four pages. Follow the formats and instructions below.**

**A. Personal Statement**

This project focuses on universal newborn hearing screening and early intervention, specifically reducing the loss to follow-up. My interest in this topic is both personal and professional: as the older sister of a brother born with profound bilateral hearing loss I have personally experienced the impact on language development of children who are late-identified and do not receive appropriate intervention services; professionally, for many years I taught these late-identified children. Through my more than 17 years work in the area of early intervention in North Carolina and Colorado, I have personally witnessed the difference made in the lives of children and families when a hearing loss is identified in the first few weeks of life and appropriate intervention services begun. I am passionate about the topic of loss to follow-up and providing a system addressing the support needs of children and families. It is impossible to address the issues involved in loss to follow-up without accurate, timely data. As Program Coordinator for the Colorado Home Intervention Program I have worked closely with state and local agencies to ensure follow-up is respectful, timely, and well-documented. I have been involved in the development of our state database since its inception and have worked closely with CDPHE staff on data collection and analysis. I also serve on the Board of Directors of Colorado Families for Hands and Voices, recognizing and supporting parent partnership throughout the process. Other leadership positions include serving on the Colorado Infant Hearing Advisory committee, the Task Force for Children with Combined Vision and Hearing Loss, and the Colorado Cochlear Implant Consortium. I am the author of the CHIP Parent Manual, the curriculum for early intervention in our state, and the Curriculum for Sign Language Instructors and co-developer of the materials for the Integrated Reading Project (IRP), part of Colorado's Early Literacy Development initiative for young children who are deaf and hard of hearing.

**B. Positions and Honors**

- 1976-1981 Teacher of the Deaf, Jefferson County Public Schools, Golden, CO
- 1981-1991 Substitute Teacher Jefferson County Public Schools, Golden, CO  
Interpreter for the Deaf, Various, Lakewood, CO
- 1991-1992 Teacher of the Deaf, Jefferson County Public Schools, Golden, CO
- 1992-1995 Teacher, Foothills Academy, Wheat Ridge, CO
- 1995-1997 Outreach Specialist, Beginnings for Parents of Children who are Deaf and Hard of Hearing,

Program Director/Principal Investigator (Last, First, Middle):

Raleigh, NC

1997-2001 Lead Colorado Hearing Resource Coordinator, Colorado Department of Health and Environment

2001-2010 Lead Colorado Hearing Resource Coordinator, Colorado School for the Deaf and the Blind

2010-2013 Program Coordinator, Colorado School for the Deaf and the Blind

### C. Selected Peer-reviewed Publications

1. Goberis, D., Beams, D., Dalphes, M. Abrish, A., Baca, R., Yoshinaga-Itano, C. (2012). The missing link in language development of deaf and hard of hearing children: pragmatic language development. *Seminars in Speech and Hearing*, 33 (04),297-309.

### D. Research Support

UNIVERSAL NEWBORN HEARING SCREENING AND INTERVENTION  
REDUCING LOSS TO FOLLOW-UP AFTER FAILURE TO PASS NEWBORN SCREENING

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    Vickie Thomson

    Erica McKiever

    Erica Gillenwater

    Sara Kennedy

    Janet DesGeorges

    Dinah Beams

    Bruce Straw

    Amy Dodd

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    Hands & Voices

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    Colorado School for the Deaf and the Blind

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## Acronyms and Terms

AUCD – Association of University Centers on Disabilities

CDC – Centers for Disease Control

CDE – Colorado Department of Education

CDPHE – Colorado Department of Public Health and Environment

Child Find – a component of IDEA that requires states to identify, locate, and evaluate all children with disabilities, aged birth to 21, who are in need of early intervention or special education services

CHIP – Colorado Home Intervention Program (CSDB)

CHP+ – Child Health Plan Plus

CIHAC – Colorado Infant Hearing Advisory Committee

CIHAC Guidelines – *Colorado Infant Hearing Advisory Committee: Guidelines for Infant Hearing Screening, Audiologic Assessment and Early Intervention*

Colorado Infant Hearing Guidelines – *Colorado Infant Hearing Advisory Committee: Guidelines for Infant Hearing Screening, Audiologic Assessment, and Early Intervention*

CO Hands & Voices – Colorado for Hands & Voices; Colorado Chapter national Hands & Voices

CO Hands & Voices website ([www.cohandsandvoices.org](http://www.cohandsandvoices.org))

COHV – CO Hands & Voices

CO-Hear Coordinator – Colorado Hearing Resource Coordinator

CSDB – Colorado School for the Deaf and the Blind

CSHCN – Children with Special Health Care Needs

EBC – Electronic Birth Certificate

EHDI – Early Hearing Detection and Intervention

EHDI website – [www.hcpcolorado.org](http://www.hcpcolorado.org)

EHDI IDS – EHDI program database

EPE – Epidemiology, Planning, and Evaluation Branch (CDPHE)

FQHC – Federally Qualified Health Centers

f/u – Follow-up

GBYS – Guide by Your Side program (CO Hands & Voices)

Guidelines – *Colorado Infant Hearing Advisory Committee: Guidelines for Infant Hearing Screening, Audiologic Assessment, and Early Intervention*

HCP – Health Care Program for Children with Special Needs

HRSA – Health Resources and Services Administration

IDEA – Individuals with Disabilities Education Act

IDS – Integrated Data System

JCIH - Joint Committee on Infant Hearing (American Academy of Audiology, American

Academy of Pediatrics and others)  
LEND – Leadership in Neurodevelopment and Related Disabilities  
MCHB – Maternal and Child Health Bureau  
MDHC – Marion Downs Hearing Center (University of Colorado)  
MOU – Memorandum of Understanding  
NCHAM – National Center for Hearing Assessment and Management (Univ. of Utah)  
NICHQ – National Initiative for Children’s Healthcare Quality  
NICU – Neonatal Intensive Care Unit  
OAE – Otoacoustic emissions (hearing screening method)  
Part B – Part B of the Individuals with Disabilities Education Act (services to school-age children)  
Part C – Part C of the Individuals with Disabilities Education Act (early intervention)  
PCP – Primary care provider  
PDSA – Plan-Do-Study-Act tool (Institute for Healthcare Improvement)  
Roadmap – Roadmap for Families  
Telehealth – the delivery of health-related services and information via telecommunication technologies  
Title V – Title V of the Social Security Act (MCHB, CSHCN)  
UHL – unilateral hearing loss

## PROJECT ABSTRACT

**Title:** Colorado - Reducing Loss to Follow-up after Failure to Pass Newborn Hearing Screening

**Applicant Name:** Vickie Thomson, Ph.D., University of Colorado Denver, Dept. of Otolaryngology

**Address:** Anschutz Medical Campus, Bldg. 500, Mail Stop F428, PO Box 6508

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**Email:** Vickie.Thomson@ucdenver.edu

**Project Need & Proposal:** Colorado has approximately 66,000 live births and 120 infants identified with permanent hearing loss each year. For the last three years Colorado follow-up rate has improved slightly from 78% to 80%. However there are approximately 600 infants who have failed the initial screen that never receive an outpatient rescreen or diagnosis. Colorado has also focused on increasing the screening rate for home births which has improved from 10 to 35% however far below the goal of 98%. The majority (95%) of infants are identified by three months of age. In 2011, of the 119 infants who were identified with permanent hearing loss, 80 were eligible for early intervention and although they all received early intervention services only 55 (69%) received services by six months of age. Only 64% of families received parent support. Quality improvement methods and processes will be implemented throughout the EHDI process.

**Methodology:** Education will be provided at the local level to hospital coordinators, physicians, audiologists, early interventionists and parents on the importance of follow-up at each step of the EHDI process. The EHDI IDS will be used to gather outcome data on recommended QI interventions to improve the follow-up.

**Goals:** 1. Increase from 98 to 99 the percent of infants who are screened for hearing loss; 2. Increase from 80 to 90 the percent of infants who receive a follow-up rescreen and/or audiologic assessment by one month of age; 3. Increase from 92% to 99% the number of infants who fail an outpatient screen and obtain a complete audiologic diagnostic assessment by three months of age; 4. Increase from 69 to 80 the percent of eligible infants who have enrolled into early intervention and have a documented Individual Family Service Plan (IFSP) by six months of age; 5. Increase from 64 to 80 the percent of families that receive parent support; 6. Ninety percent of primary care providers will receive screening, diagnostic and early intervention results in a timely manner to promote the medical home approach.

**Evaluation:** All activities will be measured using the EHDI Integrated Data System or data collection forms to measure Plan, Do, Study, Act (PDSA) QI cycles. The Colorado Infant Hearing Advisory Committee and respective work groups will provide input for grant activities to assist with their completion.

**Coordination:** Grant activities will be coordinated at the state and local level with the Colorado Department of Public Health and Environment, Colorado Hands & Voices, Colorado School for the Deaf and the Blind, the Marion Downs Hearing Center, the Colorado Chapters of the American Academy of Pediatrics and Academy of Family Physicians, hospitals and local providers.

**Funding:** Contracts will be given to the Colorado Hands & Voices, Colorado Department of Public Health and Environment, University of Colorado Boulder and the Marion Downs Hearing Center Foundation through the University of Colorado Denver (main agency).

## PROJECT NARRATIVE

### INTRODUCTION

As a result of 22 years of experience in early hearing detection and intervention (EHDI) Colorado has achieved a 98% screen rate. Colorado has approximately 66,000 live births and 120 infants identified with permanent hearing loss each year. For the last three years Colorado's follow-up rate has improved slightly from 78% to 80%. However there are approximately 600 infants who have failed the initial screen that never receive an outpatient rescreen or diagnosis. Colorado has also focused on increasing the screening rate for home births which has improved from 10 to 35% however far below the goal of 98%.

The Colorado Infant Hearing Program (newborn hearing screening program) is housed at the Colorado Department of Public Health and Environment (CDPHE), in the Children with Special Health Care Needs (CSHCN) unit. The Colorado Infant Hearing Program began in 1992 and was legislated in 1997. The legislation required the development of an advisory committee. The Colorado Infant Hearing Advisory continues to meet quarterly. The chair is Albert Mehl, MD who is also the American Academy of Pediatrics Joint Committee on Infant Hearing chair. Members are added when the system identifies new partnerships to enhance the EHDI system. The Committee is planning on adding a midwife, a representative from the nurse family partnership program and an OB/GYN.

Colorado has successfully reached the benchmark of screening 98% of infant and 95% diagnosis by 3 months of age, due in part to a robust data management and tracking system. In 1998 the Health Care Program for Children with Special Needs (HCP) developed a data management system that is populated from Colorado's electronic birth certificate (EBC) data. The Early Hearing Detection and Intervention (EHDI) Integrated Data System (IDS) became web based in 2010. Colorado has had CDC EHDI funding for the past 13 years to support the data system design and implementation. Designated newborn hearing screening hospital coordinators electronically update screening results directly into the EHDI IDS, thus eliminating the use of a monthly paper report system. Updated results include those infants whose birth certificates were submitted prior to the newborn screen (such as infants who are in the neonatal intensive care unit) or infants who return for an outpatient screen. If an infant fails the outpatient screen (rescreen) in one or both ears the baby is referred to an audiologist who has the expertise and equipment to assess hearing in young infants. Colorado has 57 birthing hospitals but only four hospitals have audiologists on staff who can provide the recommended diagnostic assessment. Therefore, the majority of infants are referred outside of their birthing hospitals. In addition, this funding provides for contracts with local audiologists (Audiology Regional Coordinators) to provide technical assistance to hospitals and providers. These regional coordinators do not provide direct services for the EHDI program and typically have full-time jobs in a different setting. They assist the hospital and providers to identify the nearest pediatric audiologist who can provide an infant assessment. Diagnosing audiologists are being trained to enter diagnostic information directly into the EHDI IDS. Results are entered for every child from birth to seven years of age who has a confirmed hearing loss or subsequently passes a failed newborn screen



(i.e., has normal hearing). When an audiologist identifies an infant with a hearing loss, he or she submits an Audiological Assessment Form to the EHDI program and refers the family to a local Colorado Hearing Resource Coordinator (CO-Hear).

Colorado has developed a system of referral from diagnosis to early intervention using the expertise of CO-Hear Coordinators. There are nine CO-Hear Coordinators; among them they cover every area of the state. Each CO-Hear Coordinator is an expert in deafness and holds a master's degree in speech pathology, audiology, or deaf education. The CO-Hear Coordinators are employed by the Colorado School for the Deaf and the Blind (CSDB). They work collaboratively with Part C of the Individuals with Disabilities Education Act (IDEA) to ensure that families receive unbiased information and resources on early intervention programs for their infants. The CO-Hear Coordinators input information directly into the EHDI database. The audiologists and CO-Hears provide data on each child diagnosed with a hearing loss, including the degree of hearing loss, type of hearing loss, age of amplification, type of amplification, high risk factors associated with hearing loss, name of medical home/primary care provider, age of enrollment into early intervention, the date of the Individual Family Service Plan (IFSP) and types of services families are choosing. Currently unilateral hearing loss is not an eligible diagnosis, in the absence of documented developmental delay, for receiving Part C services and consequently children with a unilateral hearing loss (UHL) do not receive early intervention services from the CO-Hears. However, families of infants with a unilateral hearing loss receive information from the CO-Hear Coordinators on the importance of ongoing audiologic follow-up and monitoring of language development. The state EHDI Follow-up Coordinator will contact the audiologist when he or she has not filed an Audiological Assessment Form on a child being followed by a CO-Hear. Reporting continues to be a challenge as both the CO-Hear Coordinators and diagnosing audiologists forget to report or delay reporting. Correcting this problem continues to be a focus of the state EHDI program.

The CO-Hear Coordinators extend invitations to every family who has a child with either a unilateral or bilateral hearing loss to participate in the FAMILY Assessment. The FAMILY Assessment was started by the Colorado School for the Deaf and the Blind's (CSDB) Colorado Home Intervention Program (CHIP), which serves families who have a young child (birth to age three) with a hearing loss. The FAMILY Assessment is a multi-disciplinary assessment tool used to evaluate the abilities of the child as the child interacts with family members and peers. The assessment data is used to identify present skills and to plan learning objectives for each child. The FAMILY Assessment helps the parents to effectively guide their child's development. The assessment begins with a videotaped session of the family or caregiver interacting with the child. The tape is then analyzed and scored for receptive and expressive language, fine and gross motor skills, social and cognitive development. These analyses are the basis for ongoing research being conducted at the University of Colorado. Christie Yoshinaga-Itano, Ph.D. at the University of Colorado, Boulder, is the principal investigator of the National Early Childhood Assessment Project (NECAP) funded by the Centers for Disease Control. This funding allows for the development of a national database of early intervention outcomes for state EHDI programs. Outcomes are also entered into the EHDI IDS.

Colorado Families for Hands & Voices (CO Hands & Voices) is a non-profit parent support network that started in Colorado 18 years ago and has been the impetus to the national movement known as Hands & Voices. With a statewide membership of over 1,800 parents and professionals, the influence of parent-to-parent support and advocacy, as well as the participation of parents at the systems level, is a model of successful parent involvement in the statewide EHDI system.

CO Hands & Voices has strategically placed local Parent Guides throughout the state through their Guide by Your Side Program. Parent Guides are individuals who have been hired to serve families with children who are deaf or hard of hearing, including those who have a unilateral hearing loss (UHL), families that are Spanish-speaking and families that use American Sign Language for communication. CoHears, audiologists and teachers of the deaf/hard of hearing refer families who have a newly identified infant with a hearing loss to Parent Guides; families may self-refer as well. Parent Guides are active members of regional EHDI teams in their communities. A past Parent Guides serves as the chair of the statewide Colorado Interagency Coordinating Council committee to represent the needs of families in Part C programs.

Many resources for families are being developed and/or revised as needed. These resources can be found at [www.cohandsandvoices.org](http://www.cohandsandvoices.org). Resources include customized “Roadmaps” that assist families who have a child with a positive newborn screen to negotiate the subsequent steps in the process to diagnosis and early intervention (see Attachment 9). Roadmaps have been customized with local resources for 50 of Colorado’s 57 birthing hospitals. These Roadmaps are available as hard-copy documents and an extended interactive version is available on the CO Hands & Voices web site. The *Colorado Resource Guide* provides 60 pages of resources, including parenting tips, education information, and funding sources. “Communication Considerations” is a new series being developed by CO Hands & Voices to help parents make informed decisions about communication modalities. *Bridges to Transition* is a 40-page guide for families transitioning from Part C to Part B, including information on eligibility and moving into the “preschool” years). The *Parent Funding Tool Kit* has been developed to help families navigate the options for obtaining funding for their children’s amplification and technology needs. Hearing aids are now a covered benefit in Colorado for most private insurance companies due to the parent-led efforts to pass legislation in 2009. Public health programs such as Medicaid or Child Health Plan Plus also cover hearing aids. The state has a hearing aid loaner bank for audiologists to use when families are waiting for funding. “Just in Time” materials have been developed for providers and parents so information can be given at the time an infant or child is identified with a hearing loss. In the past year CO Hands & Voices has provided one-on-one support to over 200 families and has produced 30 regional events (social gatherings and educational workshops) that have been attended by 575 families. Sixty-eight Welcome Bags were distributed to families with newly identified babies. In addition to managing the program, the director of CO Hands & Voices serves as a consultant to the Colorado Infant Hearing Advisory Committee, the CO-Hear Program, and other statewide and regional task forces and committees.

In 2014 a parent guide module for the EHDI database will be developed with CDC funds to monitor the activities and the outcomes of parent support for families of newly identified infants and young children. Direct referrals from the EHDI database are expected to increase referrals from the EHDI program for new families from the current paper or phone call based system as well as more opportunity for referral tracking and quality measures. Hands & Voices will be working with a LEND (Leadership in Neurodevelopment and Related Disabilities) audiology graduate student to disseminate a family satisfaction survey that will cover aspects from screening through early intervention including parent support.

The newborn hearing screening results have been added to the state's immunization registry. Over 90% of hospitals, pediatricians, Indian Health Services and Community Health Centers are actively participating in the registry. Family practice is at 75% with efforts in place to increase this number to 90% by the end of 2014. This part of the registry is in the testing phase and complete roll out is expected in February 2014. Electronically populating the immunization registry with the hearing screen results and diagnostic results will increase physicians' capacity to obtain real time results and will assist with ensuring appropriate and timely follow-up. Educating PCP's will be important so that they understand resources and referrals available to families.

Colorado has participated in the Early Childhood Hearing Outreach (ECHO) program through the National Center for Hearing Assessment and Management (NCHAM). This program has promoted the use of OAE screening in Early Head Start and Parents as Teacher programs. This funding will further promote the Maternal and Child Health Bureau (MCHB) outcome of early and continuous screening by strengthening education, support, and technical assistance to Head Start programs, Part C programs, day care programs and primary care practices. The Audiology Regional Coordinators provide technical assistance to these programs. Parents as Teachers (PAT) have purchased OAE equipment for local chapters. The EHDI program just found out that they are testing infants and toddlers. The EHDI Team will work with the PAT program to develop QI measures to ensure results are reported to the state for the EHDI IDS to capture any loss to follow-up or documentation.

The Colorado EHDI data management system has been in development and refinement for 15 years. The advantage of an active (data collected directly from the electronic birth certificate) and passive (data collected from providers) data management system allows the opportunity to analyze factors that prevent an infant from receiving a newborn hearing screen by one month, diagnosis by three months, and enrollment into early intervention by six months. Chart 1 shows all the factors that are collected from the birth certificate, Audiology Assessment Forms, and the CO-Hear Coordinators. Previous analyses have demonstrated that infants in the Neonatal Intensive Care Unit (NICU) and infants born at home are the least likely to obtain a hearing screen. Infants who are born to Hispanic, low-income, or teen mothers are less likely to obtain a rescreen or diagnostic evaluation. These analyses have provided the program with opportunities to develop evidence-based strategies for improving follow-up.

Chart 1: Factors collected in the EHDI IDS

<b>Hospital Data</b>	<b>Audiology Assessment Forms</b>	<b>CO-Hear Coordinator</b>
Date of birth	Date of evaluation	Date of referral
Mother's age	Date of report	Date of first contact
Race, Ethnicity	Language spoken	Language spoken
Mother's education level	High-risk factors	Insurance
Admission to NICU	Screen results	Date of transition to preschool
Infant's Gender	Type of hearing loss (auditory neuropathy, sensorineural, conductive)	Individual Family Service Plan date
Birth weight	Degree of hearing loss (mild, moderate, severe, profound)	Date of first home visit
Apgar score at 5 minutes	Date referred to CO-Hear	Names of audiologists, Part C coordinator, early interventionists
Date of hearing screen	Type of amplification	Type of early intervention provided
Screen results	Date of amplification fit	
Reason not screened (e.g., deceased, parent refused, transferred, missed)	Date of next audiology appointment	
	Insurance	

## **Project Proposal**

Program data analyses, development and implementation of follow-up protocols, and purchasing equipment for midwives have all improved the screening rate and follow-up rates. In 2012 the screening rate stabilized at 98.0%. However, this equates to 2% or 1,399 children not receiving a newborn hearing screen. The follow-up for infants who failed the screen improved from 78% to 80%. However, this equates to 600 infants never receiving an outpatient rescreen or diagnostic evaluation. The majority (95%) of infants are identified by three months of age. Of the 119 infants who were identified with permanent hearing loss, 80 were eligible for early intervention and although they all received early intervention services only 55 (69%) received services by six months of age. There is currently not a method to determine if the PCP is receiving reports/results from the screening, diagnosing audiologist, CO-Hear or Parent Guide. This funding will develop tools to implement reports and monitoring into the EHDI IDS.

Over the next three years the Colorado EHDI program will aim to:

- **Increase from 98 to 99 the percent of infants who are screened for hearing loss focusing on the home birth population**
- **Increase from 80 to 90 the percent of infants who receive a follow-up rescreen and/or audiologic assessment.**

- Increase from 92 to 99 the percent of infants who fail an outpatient screen and obtain a complete audiologic diagnostic assessment by three months of age.
- Increase from 69 to 80 the percent of eligible infants who have enrolled into early intervention and have a documented Individual Family Service Plan (IFSP) by six months of age.
- Increase from 64 to 80 the percent of families that receive parent support.
- 90% of the primary care provider receives screening, diagnostic and early intervention results in a timely manner to promote the medical home approach.

## NEEDS ASSESSMENT

Over the past 22 years Colorado has made great strides in developing a comprehensive Early Hearing Detection and Intervention (EHDI) program. Despite the progress, there are still a percentage of infants who never receive a screen or timely and appropriate follow-up for a failed screen. There are several factors that affect the loss to follow-up such as the lack of provider and parent knowledge, the lack of pediatric audiologists, and the state's geography and demographics.

The state of Colorado comprises 103,717 square miles and is populated by 4,301,261 individuals (2010 census). It is the 8<sup>th</sup> largest state by land mass in the United States. Although primarily of white, non-Hispanic ethnicity (71.3%), Colorado has a large and growing Hispanic population (19.9%). Babies born to Hispanic families accounted for 29% of Colorado births in 2011. A language other than English is spoken in the home of 15% of the Colorado population. An analysis of the data did show that infants born to Hispanic mothers were 46% less likely to receive the follow-up rescreen. A bilingual Parent Guide has previously been hired to work at two of Colorado's hospitals that serve low income and Spanish speaking families. She would call families if they do not return for the follow-up. The main reason families did not return is they did not understand the results of the screening or the recommendations/instructions for follow-up. Although this quality improvement project was successful, funding was decreased and the Parent Guide found full time employment. This effort will be readdressed in this next grant cycle.

The population of Colorado has been growing each year, increasing 14.8% between April 1, 2000 and July 1, 2008 with predicted population growth by 2020 of an additional 14%. Children < 5 years of age comprised 7.2% of the population and children < 18 years of age comprised 24.5% of the population in 2010 (Colorado Department of Local Affairs) . Unfortunately, this growth in infants and young children has not been reflected in increased availability of audiology, genetic and early intervention services. The majority of hospital staff, audiologists, and other health providers are monolingual English speakers. As a result, existing capacity for delivering culturally and linguistically appropriate information throughout the EHDI process is limited.

The geography of the state presents multiple factors that influence the efficiency and equality of health services delivery. Long distances between cities and towns and from regional

audiology centers, winter travel, and mountain passes are factors that impede delivery of services. Colorado is a rural state; 73% of Colorado's counties are designated rural or frontier (defined as fewer than 6 people per square mile). Colorado is served by 90 primary care physicians per 100,000 persons (2011), usually concentrated in the urban areas with limited local care in rural areas. Of Colorado's counties, eight have only one full-time primary care physician. Six additional rural counties lack even one full-time primary care physician. One rural county has no full- or part-time primary care physician at all. Almost every county in rural Colorado is designated as a Medically Underserved Area or a Health Professional Shortage Area, which demonstrates that access to care is severely limited. Recruiting and retaining health care professionals for rural Colorado is a tremendous challenge. Even health care providers who come from rural areas become accustomed to urban amenities during their education and training, which generally takes place in urban settings. This helps account for the geographic disparities in physician placement in Colorado. Of physicians responding to a 2012 Colorado Health Institute workforce survey of Colorado physicians, 89% reported practicing in an urban setting compared to 11% who reported practicing in a rural Colorado community ( Colorado Health Institute). Sadly this statistic has remained unchanged. In short, Colorado's rural and frontier counties have extreme difficulty recruiting and retaining an adequate number of primary health care providers including specialists. Consequently, care for rare and often confusing disorders is especially limited. Most primary care providers have limited knowledge of or experience with hearing loss and many are unaware of the local and state resources available to provide diagnostic and early intervention services for families and their children who are deaf or hard of hearing. Most pediatric audiologists who have the expertise and the proper equipment to diagnosis and fit an infant with hearing aids are located along the more populated Front Range (eastern side of the mountains) from Ft. Collins in the north to Colorado Springs in the south.

Funding provided by the Association of University Centers on Disabilities (AUCD) Leadership in Neurodevelopment and Related Disabilities (LEND), has increased the number of pediatric audiology sites from 12 to 14. The EHDI program has partnered with the Marion Downs Hearing Center (MDHC) to provide intensive training to fourth-year audiology doctoral students and rural audiologists who have the desire and equipment to test young infants. Training for rural audiologists is provided in a variety of ways. Pediatric audiologists from the MDHC travel to the audiologists' rural sites, the audiologists travel to Denver, and telehealth technology is used for ongoing monitoring of evaluation and counseling. Despite the additional education and training, there remains a paucity of audiologists to provide infant hearing care, which places additional burdens on physicians and public health nurses. The Health Care Program for Children with Special Needs (HCP) has 14 HCP Regional Offices that provide care coordination services to families. They are instrumental partners with families and providers in locating resources and funding to meet the needs of families.

Colorado is home to 170,000 uninsured children (13.7% of Colorado children) and has the seventh-highest rate of uninsured children in the nation. In 2012, the average annual out-of-pocket cost to an employee for employer-provided family insurance coverage in Colorado was ██████, an amount that is more than 8 percent of the annual income for a family of three

earning ██████ (twice the federal poverty level). For parents who are forced to seek coverage in the private market because they do not have access to affordable employer-based coverage, costs are even higher. Colorado has 11.5% of its population living below the federal poverty level (2007). This results in families not being able to afford comprehensive diagnostic services. Primary care physicians may take a “wait and see” attitude rather than refer the family to a pediatric audiologist, if there are financial concerns. It unclear what impact the affordable health care act will have on Colorado.

Despite the state’s economic, geographic, and demographic challenges, the EHDI program, with MCHB funding, has developed interventions in an attempt to overcome these obstacles. The current and ongoing interventions include (See Attachment 7 for the Summary Progress Report):

1. The development of local EHDI teams to provide consultation and education to local providers. The EHDI teams meet as needed to address concerns and barriers at the local level. Team members include the CO Hands & Voices Parent Guide, hospital hearing screening coordinator, audiology regional coordinator, HCP director, CO-Hear coordinator, physicians, and other stakeholders. The state EHDI staff provides consultation to the local teams.
2. The Roadmaps for Families describe the follow-up protocol for each hospital and community, from screening through early intervention, and provides local resource and referral information. The Roadmap is used by families and primary care providers. The Roadmap for Families has also been formatted to be an interactive tool on the Hands & Voices website.
3. The inclusion of the Parent Guides in the local EHDI teams has helped providers recognize the importance of early identification and intervention from the parent perspective.
4. Ongoing education by the EHDI staff and Part C NICU liaisons to NICU staff, neonatologists, and parents of infants in the NICU strives to ensure that an appropriate newborn hearing screen is administered prior to hospital discharge and that follow-up is received.
5. The *Loss and Found* DVD, developed by the national Hands & Voices, has been disseminated to all hospitals as a tool to improve screening follow-up. The DVD has actual families describing their experience and why it is important for parents to follow through with the hospital recommendations. The DVD includes Hands & Voices contact information in the event a family would like to connect with a parent at the time of screening. Further surveys and data analysis will determine if the DVDs are being used and are promoting prompt follow-up by families.
6. Education and training on the importance of screening and early identification have been provided to midwives. MCHB funding provided OAE screening equipment for several midwives. The increased access to screening has increased the percentage of infants born at home who are screened from 25% to 35% in 2010.
7. Contracting with a unilateral hearing loss coordinator to increase the number of families and children participating in the FAMILY Assessment to monitor speech, language, and developmental outcomes of children diagnosed with a unilateral hearing loss.

8. The promotion of a medical home approach for all children through reporting of screening, diagnostic, and early intervention outcomes to the primary care physician.
9. Improving the use of electronic records to share critical information among providers to create the medical home approach for improved outcomes.
10. Promoting the use of telehealth technology to provide audiology, early intervention, and genetic services for families residing in rural areas.

This proposal will continue to use the current and new interventions to improve follow-up at all steps in the EHDI process. The Colorado Infant Hearing Program uses ongoing analyses of data for evidence-based practices. In addition, the principle investigator, the state EHDI staff, the CO Hands & Voices director, and the CO-Hear director, the AAP Chapter Champion will participate actively using NICHQ processes to identify best practices and innovative ways to improve the EHDI process and hearing screening throughout the early childhood years. Ideas will be shared with the Colorado Infant Hearing Advisory Committee (CIHAC) to gain their support and suggestions for improvement in their respective disciplines. This funding will also provide support to the Audiology Regional Coordinators and Hands & Voices to provide support to local families, hospitals and communities.

Colorado is building upon past success with improved data management and tracking systems, parent support infrastructure, and the medical home approach in order to increase the percentage of infants who receive timely and appropriate referrals for newborn and early childhood hearing screening. During the next three years, Colorado will maintain its previous success by striving to developing systems that ensure all infants and their families are offered and have access to a hearing screen, comprehensive diagnostic evaluations performed by qualified audiologists, parent support at all stages of the EHDI system, early intervention services and access to a medical home approach that is family centered, culturally competent, and community based.

## **METHODOLOGY**

The ultimate goal of the Colorado EHDI program is to ensure that all infants are screened for hearing loss, infants who fail the screen are diagnosed by three months of age, and to ensure early intervention by six months, for the development of normal speech, language, and cognition through a medical home approach. The EHDI IDS database will provide the data to evaluate if an activity or intervention is improving the outcomes of: the percentage of infants screened born in hospitals and at home; the percentage of infants who fail the hospital screen that receive an outpatient rescreen or diagnostic evaluation by one month; the percentage of infants who fail the rescreen that receive a comprehensive audiology evaluation before three months of age; the percentage of infants with confirmed hearing loss who are enrolled in early intervention by six months of age; the percentage of families that are receiving support from Hands & Voices; and the number of children who are screened for late onset hearing loss and are receiving intervention. Quality Improvement activities will be infused throughout the work plan to enhance the goal that families receive culturally competent support through the EHDI process. When a QI intervention, through data analysis, is found to be successful it will be



implemented statewide. Local EHDI teams will be trained to assist in QI activities to improve the follow-up throughout the EHDI process. EHDI teams will be trained as their community is identified as needing improvement in a specific area of follow-up. This method will provide “just in time” training but also an excellent opportunity to gather local support from key stakeholders to improve the system for families. Updated guidelines will reflect these best evidence based practices for sustainability.

CDPHE is also partnering with the University of Colorado Denver, School of Public Health. A pediatrician who is obtaining her master’s degree in public health is re-analyzing data to determine if there are still follow-up concerns with Spanish speaking, low income and single mothers. She will also be surveying hospital coordinators to determine if previous recommendations are being utilized such as making the outpatient appointment (for a failed inpatient screen) prior to hospital discharge; if hospitals are using the Roadmap for Families; and are they showing the Loss and Found DVD to parents whose infant did not pass the screen; and providing the screening results in the parents native language (Attachment 8).

The Colorado Commission for the Deaf and Hard of Hearing (CCDHH) has awarded Colorado Hands & Voices a grant to convene a task force to improve education outcomes from birth through secondary education. The goal is to outline the needs for children and identify funding streams to support early intervention and the transitions into and throughout the school years. The Joint Budget Committee of the Colorado legislation is meeting with CDPHE administration to determine which of the CDPHE priorities will be addressed in the next budget year. Administration is encouraged that they will identify newborn hearing screening as a need and thus be able to justify the increase in the newborn screening fee to provide funding for the EHDI program. Due to significant state budget shortfalls it may require that the fee increase will cover certain aspects of the EHDI program while other resources will need to support and enhance the early intervention program.

**WORK PLAN**

The Work Plan will be the used as the framework for prioritizing the activities to meet the goals and objectives set forth in the Methodology section. The methodology tool for this grant will include the PDSA (Plan/Do/Study/Act) cycle as utilized by the NICHQ Learning Collaborative to implement the Goals, Objectives, and Activities of the Work Plan as appropriate. The PDSA tool will help the local and state EHDI teams to visualize the implementation and evaluation aspects to document change. Individual people and groups responsible for activities are:

The following goals and objectives will be implemented to increase the screening and follow-up in each step of the EHDI process and early childhood hearing screening. Activities and timelines are outlined in the Work Plan (Attachment 1).

Goals	Objectives/Aim Statements
1. Increase from 98 to 99 the percent of infants who are screened for hearing loss.	By March 31, 2015, increase from 30% to 40% the number of infants who are home birthed receives an outpatient screen.

2. Increase from 80 to 90 the percent of infants who receive a follow-up rescreen and/or audiologic assessment by one month of age.	By March 31, 2015 the number of infants LTF, from hospital discharge will be reduced from 20% to 17%
3. Increase from 92% to 99% the number of infants who fail an outpatient screen and obtain a complete audiologic diagnostic assessment by three months of age.	By March 31, 2015 the number of infants LTF the failed outpatient screen will increase from 92% to 95%.
4. Increase from 69 to 80 the percent of eligible infants who have enrolled into early intervention and have a documented Individual Family Service Plan (IFSP) by six months of age.	By March 31, 2015 the number of infants enrolled in EI and have an IFSP by six months of age will increase from 69% to 75%.
5. Increase from 64 to 80 the percent of families that receive parent support.	By March 31, 2015 the number of families who receive parent support will be increased from 64% to 70%.
6. 90% of primary care providers receive screening, diagnostic and early intervention results in a timely manner to promote the medical home approach.	By March 31, 2015 the number of PCP's who receive screening, diagnostic, EI and Parent support results/reports will be documented in 70%.

## RESOLUTION OF CHALLENGES

Every effort will be made to ensure every newborn is screened. Parents still have the option to refuse the screening. Providing education to physicians and hospital staff to encourage families to have the hearing screen has reduced the number of families who opt out of the screen. Families who have their babies at home will also be given more education, resources and opportunities to obtain a screen. The challenges are providing the screens that are convenient for families when they may reside in very mountainous or rural areas where there are not a lot of home births to justify placing equipment with a midwife. Most educational audiologists are willing to provide an OAE screen and they are located throughout the state.

Colorado has rural and frontier areas which make it challenging to provide comprehensive, community-based services for every family. This may still require families to travel long distances but may significantly reduce the transportation barriers to obtaining services for most Colorado families. Funding from the LEND grant supports training but not the purchase of costly diagnostic equipment or hearing aid analyzers. Local EHDI teams will identify the barriers for families receiving a diagnostic evaluation and identify resources (e.g., funding for travel expenses, funding for the evaluation) for families, to improve outcomes. The lack of non-English-speaking providers results in families not understanding the follow-up instructions and implications. Further enhancing the use of interpreters to ensure families understand the results of the follow-up processes from screening through early intervention will provide the opportunity to improve outcomes for these families.

Due to the geographical issues, "primary care" means a large portion of infants and children are being served by Federally Qualified Health Centers, family practice physicians, and public health nurses. The EHDI program at state and local levels must provide education to these providers

on the importance of follow-up and must develop protocols that make the coordination of hearing services accessible, family friendly, and culturally responsive. The addition of the screening results to the immunization registry will assist the EHDI program in the first step of the informing the medical home of screening and diagnostic results, to assist the primary care provider with coordinated care for ensuring timely follow-up.

As mentioned in the methodology, Colorado is in the process of developing a sustainable funding structure beyond grant funding. This funding, if awarded, cannot fully solve all the issues and challenges addressed but it will help to build the infrastructure needed to build sustainable EHDI systems at the local and state level, to ensure that every family and child receive the timely follow-up and resources they need.

## **EVALUATION AND TECHNICAL SUPPORT CAPACITY**

The Children with Special Health Care Needs is located within the Prevention Services Division (PSD) of the Colorado Department of Public Health and Environment. PSD has an Epidemiology, Planning, and Evaluation unit (EPE) that is rich with staff that has expertise in data analysis, evaluation, and planning. The goal is to develop an EHDI program that will implement essential public health services from assurance to developing public health policy, using a data-driven approach that is sustainable throughout the EHDI processes.

Dr. Vickie Thomson, Co-principle investigator, completed her doctoral degree in audiology, with a minor in public health, bringing additional research expertise to the program. Dr. Thomson started one of the first newborn screening programs in the state and the nation. She has provided workshops and presentations on EHDI systems building statewide, nationally, and internationally. In addition she has published widely on the topic. Dr. Thomson moved from CDPHE to the University of Colorado Denver. She was allowed to transfer the grant from CDPHE to UCD due to her expertise in the area. Dr. Thomson will be working with the EHDI team to develop and implement QI strategies focusing on the follow-up from screening to diagnosis, early intervention and parent support.

Erica McKiever, Co-principal Investigator and the EHDI Coordinator, has a master's degree in psychotherapy and is bilingual in English and Spanish. Her experience in counseling families and serving low-income Hispanic populations has proven invaluable in her work with families and providers. Ms. McKiever previously served as the EHDI Follow-up Coordinator. She has developed a close working relationship with the hospital coordinators, audiologists and early interventionists through her dedicated work on the EHDI IDS. She is very involved in the link between the EDHI IDS and the immunization registry. Erica is employed by CDPHE.

Erica Gillenwater, EHDI Follow-up Coordinator at CDPHE, is new to the position however quickly learning the role hospital coordinators play in providing the screen and accurately reporting the data. Ms. Gillenwater will work with the EHDI team to develop and implement QI strategies with hospitals and midwives.

Sara Kennedy is the director of Colorado Hands & Voices. She is a parent of a daughter who is deaf and was late identified due to a home birth. Sara has worked locally in her community for the past ten years to ensure that all home births are screened. She has been a part of the EHDI team for many years to infuse parent leadership in the EHDI programs at the local level.

Janet DesGeorges is the director of Hands & Voices National. She is the parent of a daughter with hearing loss. Janet has helped establish Hands & Voices chapters in 40 states. She has published many articles on the topic of parent support in EHDI systems and has presented statewide, nationally, and internationally.

Dinah Beams has a master's degree in deaf education and has been the lead CO-Hear for 12 years. She works for the Colorado School for the Deaf and the Blind. She has worked in the field of early intervention for children who are deaf and hard of hearing her entire career. She works closely with Part C and other agencies to develop a sustainable early intervention program for children who are deaf and hard of hearing. Ms. Beams will be working with EHDI team and the CO-Hears to develop and implement QI strategies for improving the follow-up from diagnosis into early intervention, referring to Hands & Voices and reporting to the PCP.

CDPHE, Children with Special Health Care Needs unit has designated support staff to assist the EHDI staff and contractors with developing materials, writing documents, and preparing presentations. The University of Colorado Denver, fiscal staff, works with the principal investigator to establish the contracts, memorandums of understanding/agreements, and the fiscal responsibility required for this grant. Job descriptions are located in Attachment 2 and biographical sketches of key personnel are in Attachment 3.

## **ORGANIZATIONAL INFORMATION**

The lead organization for this application is the University of Colorado Denver with direct collaboration with the Title V, Children with Special Health Care Needs (CSHCN) unit at the Colorado Department of Public Health and Environment (CDPHE). The University of Colorado Denver has the advantage to work with graduate students in public health and audiology. The Marion Downs Hearing Center, at the University of Colorado Hospital provides opportunities to test many of the QI strategies at all stages of the EHDI process due to both having a nursery and pediatric audiology clinic. The Marion Downs Hearing Center Foundation under the direction of Vickie Thomson will oversee the Audiology Regional Coordinators and the Unilateral CO-Hear Coordinator activities, training and QI strategies.

The CSHCN unit at CDPHE believes that all families deserve the opportunity to promote the maximum potential of their children. The CSHCN unit is responsible for building family-driven, sustainable systems of health services and supports for all families of children with special health care needs in Colorado. The CSHCN program structure consists of a state office, 14 local offices, and 38 county nursing agencies. The state office supports the regional office network and eight of the regional offices provide technical assistance and training to the 38 smaller

county nursing agencies. This creates a community-based network for serving families of children with special health care needs in every county in Colorado. The regional and nursing offices work with other programs, agencies, and organizations to develop coordinated, culturally competent, and community-based systems of care to meet the needs of families.

The Colorado EHDI program is within the CSHCN unit. The 1997 legislation required the development of an advisory board. The Colorado Infant Hearing Advisory Committee has a wealth of representation from parents, consumers, experts, and agencies that work to develop guidelines for providers and address issues that create barriers for ensuring the outcome of early identification and intervention for the families and children this program serves.

The Colorado EHDI program works collaboratively with Colorado Hands & Voices, Part C, the Colorado School for the Deaf and the Blind, Early Head Start, the Colorado Department of Education, The Marion Downs Hearing Center, the Bill Daniels Center for Children's Hearing, the Colorado Midwives Association, the Colorado Commission for the Deaf, and the Colorado chapters of the American Academy of Pediatrics and Academy of Family Physicians. The EHDI staff and partners serve on many committees for the National Center for Hearing Assessment and Management, the Maternal and Child Health Bureau, and the Centers for Disease Control. Together we work to build sustainable systems of care for families who have children who are deaf and hard of hearing. Letters of agreement and support are located in Attachments 4 and 8, respectively.

Colorado was one of the first states to implement a statewide newborn screening program. MCHB and CDC funding has assisted in the development of building sustainable EHDI programs at the local level through an integrated data management and tracking system, enhanced parent support, increased screening capacity for home births, and medical home implementation. Colorado will continue to identify opportunities to reduce barriers to follow-up and develop comprehensive, culturally responsive, community based systems that ensure all infants and their families are offered and have access to a hearing screen, comprehensive diagnostic evaluations performed by qualified audiologists, parent support at all stages of the EHDI system and access to a medical home approach that is family centered, culturally competent, and community based.

#### References:

Colorado Department of Local Affairs, Population Data. [www.colorado.gov](http://www.colorado.gov)  
Colorado Health Institute. [www.coloradohealthinstitute.org](http://www.coloradohealthinstitute.org)