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PROJECT NARRATIVE

Acronyms

CDC – Centers for Disease Control
CDPHE – Colorado Department of Public Health and Environment
CDE - Colorado Department of Education
CHP+ – Child Health Plan Plus
CHIRP – Clinical Health Information Records of Patients (data base)
CO-Hear Coordinators – Colorado Hearing Resource Coordinators
CRCSN – Colorado Responds to Children with Special Needs (birth defects registry)
CSDB – Colorado School for the Deaf and Blind
CSHCN – Children with Special Health Care Needs
EBC – Electronic Birth Certificate
EHDI – Early Hearing Detection and Intervention
EPSDT – Early Periodic Screening Diagnostic and Treatment
FQHC – Federally Qualified Health Centers
HCP – Health Care Program for Children with Special Needs
HRSA – Health Resources and Services Administration
MCHB – Maternal and Child Health Bureau
NEST – Newborn Evaluation Screening and Tracking (data base)
NICHQ – National Initiative for Children's Healthcare Quality
NICU – Neonatal Intensive Care Unit
Part C – Early Childhood Connection

BACKGROUND and NEED

Historical Information

The Colorado Infant Hearing Program began as a pilot project in 1992 to determine if universal newborn hearing screening was feasible prior to hospital discharge. The Colorado Department of Public Health and Environment (CDPHE), Children with Special Health Care Needs (CSHCN) sponsored this effort in collaboration with The Children's Hospital and the University of Colorado Health Sciences Center. Research at the University of Colorado provided invaluable evidence that early identification by six months of age compared to later identification after six months was associated with subsequent differences in receptive and expressive language skills. Yoshinaga-Itano, et al.[1] compared 72 children born with congenital hearing loss that were

identified by six months with 78 children identified after six months of age. The language difference between the two groups was so large that nearly a full standard deviation separated them.

As a result of the emerging findings from the University of Colorado, the Colorado legislature mandated in 1997 that all birthing hospitals offer a newborn hearing screen. The mandate stated that if the statewide screening rate fell below 85%, then rules and regulations would be promulgated to ensure a higher hospital-screening rate. The legislation also required the creation of an advisory committee to provide guidance to hospitals, physicians, audiologists and early intervention provides, and to ensure a coordinated, comprehensive system of care from screening to early intervention. The Colorado Infant Hearing Advisory Committee therefore, has developed guidelines that are available online at **www.hcpcolorado.org**. In 2005 the Colorado legislature passed an amendment to increase the mandated screening rate from 85% to 95%, and to maintain the advisory committee. The Colorado Infant Hearing Advisory is co-chaired by the state Early Hearing, Detection, and Intervention (EHDI) coordinator, Vickie Thomson, Ph.D., and Albert Mehl, M.D., who also serves as the American Academy of Pediatrics (AAP) representative on the Joint Committee for Infant Hearing (JCIH). The Advisory meets face to face on a quarterly basis. Screening, Assessment, and Early Intervention task forces were developed to provide collaboration and partnership with providers in developing best practice guidelines. The task forces currently meet as needed. An additional task force called the Colorado EHDI Medical Home Collaborative was recently established.

Data Management System

Colorado has successfully reached the benchmark of screening 95% or greater since 2002, due in part to the data management and tracking system funded by a CDC cooperative agreement. There are many challenges in developing a comprehensive statewide Early Hearing

Detection and Intervention (EHDI) program. Effective tracking of infants from screening through diagnosis and then to early intervention was and remains the most difficult task. In 1998 the CSHCN unit developed a data management system that was populated by data from Colorado's electronic birth certificate (EBC) data. Fields were added to the Genesis™ EBC application that included specific ear results of pass or fail, and the reasons if there was not a screen completed (e.g. missed, transferred, deceased, parent refusal). Colorado was awarded a Center for Disease Control and Prevention (CDC) Early Hearing Detection and Intervention (EHDI) data integration cooperative agreement in 2000. This cooperative agreement allowed CSHCN to develop and implement a more comprehensive application to manage the EHDI follow-up program. This agreement has greatly improved the data integrity for the program. The EHDI data management program also has the capability to build capacity and to enhance the processes of reporting by other providers. The next step was to design, develop, and implement the NEST (Newborn Evaluation, Screening and Tracking), which is a centralized database and application. NEST integrates newborn hearing screening, Colorado Responds to Children with Special Needs (CRCSN, Colorado's birth defects surveillance registry), the newborn metabolic screening program (blood spot), and the local HCP offices, who provide care coordination services. Each individual program (metabolic screening, birth defects, local CSHCN offices) have their own database called the Clinical Health Information Records of Patients (CHIRP) that interfaces with the NEST. This data integration allows HCP to integrate referral services and makes those referrals more efficient and timely. NEST has the capability to report individual identifiable data on screening results including child's date of birth, infant gender, maternal race, maternal ethnicity, maternal education level, date of screen, results of the screen, or reason not screened. The NEST provides comprehensive data for surveillance of newborn screens, which allows the EHDI program to use a data driven approach for strategic planning. The data in the

EHDI CHIRP can be analyzed to monitor hospital-screening activities, racial disparities in screening and follow-up, and clusters of hearing loss that may indicate genetic disorders. The current NEST and CHIRP systems use a Citrix® virtual private network. With current CDC funding the entire system is moving to a web based application to allow a more user-friendly application for the providers.

In addition, HCP hired a full time EHDI Follow-up Coordinator. The Follow-up Coordinator has been instrumental in monitoring hospital and provider data that allows tracking and surveillance activities for newborn hearing. During the early development of the Colorado EHDI program, hospitals were encouraged to bring infants back for an outpatient rescreen if they failed the inpatient screen. This reduced the referral for more costly diagnostic evaluations, especially in areas of the state where significant travel would be required. This quickly became the standard of care. Every hospital has a designated EHDI hospital coordinator. Each month the EHDI Follow-up Coordinator disseminates a report to the hospital coordinator with a list of infants born in their hospital that either failed the screen in one or both ears or were not screened. The hospital coordinator then updates the information on any new screens or rescreens and submits the report to the Follow-up Coordinator. This data entry process is currently not automated. Pilot hospitals have been selected to begin direct input and updates to the EHDI CHIRP in May 2008.

Audiologists submit an Audiological Follow-up Form on every child from birth to seven years of age who has a confirmed hearing loss. These reports include demographic information, diagnostic results, and high risk factors. Audiologists also submit this report on infants who are referred from newborn hearing screening and subsequently pass an evaluation. These reports are submitted on paper and entered manually into the data system. The Audiology Follow-up Form is currently being redesigned. Several audiologists will begin entering data directly into CHIRP

via CITRI, beginning in May 2008. In Colorado, all the audiology providers are private licensed providers. There is not a national or state 'certification' program, which designates who can provide pediatric services to an infant. The state EHDI program can only recommend best practices', including reporting, but has no licensure or statutory authority to mandate best practices or reporting. The Colorado Infant Hearing Advisory recommends a full battery of tests (Auditory Brainstem Response, Auditory Steady State Response and/or tone bursts, Otoacoustic emissions, high frequency tympanometry, and behavioral testing) to complete a comprehensive diagnostic evaluation that will identify frequency specificity, the type of loss, and degree of loss. This parameters are necessary for accurate fitting of amplification. This process may take several weeks or months, postponing the referral to early intervention. Audiology staff at the Marion Downs Hearing Center will provide clinical expertise in determining the minimum test battery to confirm a permanent hearing loss versus a complete diagnostic test battery for the purposes of hearing aid fitting. This will allow earlier referral to early intervention and provide families the support they need during the diagnostic process. This proposal will look at options to begin the referral to early intervention once a hearing loss is identified, but prior to the completion of a full test battery.

At three months after birth, the EHDI Follow-up Coordinator sends a letter to the parents of all infants who failed the hospital screen in one or both ears, or were missed, or were home-birthed, and with no indication of subsequent follow-up, and encourages them to obtain a screen or rescreen. This notification also gives the family the opportunity to report results or gives the family information on how to obtain a screen. This process has increased the percentage of infants born at home who receive a hearing screen from 10% in 2003 to 30% in 2006. The data management system has been essential in providing the demographic information to increase the rescreen rate and home births screens.

The EHDI Medical Home Collaborative is an effort to ensure that every child, at the minimum has a primary care physician. The primary care physician is identified on the Audiological Report Form and the CO-Hear Intake Form and entered into the EHDI CHIRP database. Efforts are underway to identify the primary care physicians by linking the newborn blood spot screen to the EHDI CHIRP database. The physician currently listed on the electronic birth certificate is usually the physician who delivered the infant and not the primary physician of record. Colorado requires a second metabolic screen and the primary care physician is recorded on the screening form. As a result, the program is able to capture, with greater reliability, an infant's primary care physician. Additionally, between the first and second metabolic screens, many infants undergo a name change. Because the State Lab does not use the electronic birth certificate to populate its database, the matching of infants (following name changes) must be done manually. Once the State Lab can begin using the electronic birth certificate to fill in its database, this process can be automated.

Colorado was also one of five state selected to participate in the National Initiative for Child Health Quality (NICHQ) EHDI Medical Home Collaborative. The first training was held April 8-9, 2008. The Colorado Core Team is represented by Kathy Watters (CSHCN Director), Vickie Thomson (EHDI Director), Emily Fields (EHDI Follow-up Coordinator), Laura Pickler, M.D (CSHCN Physician Consultant), Sara Kennedy (Hands & Voices Parent Guide), Sandra Gabbard (Audiology Consultant), and Jennie Germano (Director of Early Intervention). The intended goal of these trainings is to improve follow-up from screening to rescreening, into diagnosis and early intervention, including parent support.

Additionally, the Colorado legislatures recently passed a new bill requiring the immunization registry be moved to the health department, and potentially interface with the newborn screening programs. This is very new legislation that holds the promise of expanding

the integrated data system for providers. This new development will allow providers' to access a Child's Health Profile, which contains information on immunization records as well as screening results for both newborn metabolic and newborn hearing.

Early Intervention System

In the early 1980's Christie Yoshinaga-Itano, Ph.D, founded the Colorado Home Intervention Program (CHIP). This was an early intervention program for children who are deaf and hard of hearing, ages birth through three. Dr. Yoshinaga-Itano's research, at the University of Colorado, has provided the efficacy of early identification and intervention of hearing loss. Prior to universal newborn hearing screening, Colorado developed a system of referral from diagnosis to early intervention using the expertise of the CHIP early intervention coordinators (now known as the Colorado Hearing (CO-Hear) Resource Coordinators.

Currently when an audiologist identifies an infant with a hearing loss he/she notifies the EHDI program with the Audiological Follow-up Form, and refers the family to a local CO-Hear Coordinator. 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 through the Colorado School for the Deaf and Blind (CSDB). They work collaboratively with Part C of the Individuals with Disabilities Education Act (IDEA) to assure that families receive unbiased information and referrals to resources on early intervention programs for their infant. The CO-Hear Coordinators input information directly into the EHDI CHIRP database via CITRIX. The Audiological Follow-up Form and the Intake Form completed by the audiologists and the CO-Hears provide individual data on 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, and types of

services families have chosen. The Follow-up Coordinator will contact the audiologist when he/she has not filed an Follow-up Audiological Form on a child being followed by a CO-Hear. Thus, this process serves as an additional safety net. Data, however, continue to either not be reported by these two groups or are delayed in reporting and correcting this problem continues to be a focus of the state EHDI program.

Smart Start Colorado is the framework for the Early Childhood State Systems Grant funded by the Maternal and Child Health Bureau. This program is housed in the lieutenant governor's office and staffed by state public health MCH staff. There are eight goals to ensure that services and supports are provided for all children and families. There are local Early Childhood Councils that interface with the Part C Early Childhood Connections. Colorado was recently awarded a grant to initiate the Assuring Better Child Health and Development (ABCD) Project. This project is under the umbrella of Smart Start to train primary care providers, public health nurses and other professionals how to use a standardized developmental screening tool at regular intervals beginning at 4 months of age. The EHDI program is working with the ABCD Project to ensure that children who are determined to be at risk, for developmental delay, receive appropriate hearing screenings. It has been well documented that many children pass their newborn hearing screen and are later identified with hearing. The ABCD Project is one vehicle for early identification of these children earlier.

The CO-Hear Coordinators extends invitations to every family to participate in developmental assessments every six-months until children are three years olds. The assessment begins with a video taped session of the family/caregiver interacting with the child. The tape is then analyzed and scored for receptive and expressive language, fine and gross motor, social, and cognitive development. These analyses are the basis for ongoing research being conducted at the

University of Colorado. Currently, there is not a direct data interface between the University of Colorado and HCP to capture outcome measures for the infants enrolled in the EHDI program.

Parent Support

Colorado Families for Hands & Voices is a non-profit parent support network. They are celebrating their 11th year as an organization as the flagship group, who birthed the national movement now known as Hands & Voices. With a statewide membership of over 1800 parents and professionals, the influence of parent-to-parent support and advocacy, as well as the participation at the systems level, is a model of successful parent involvement. CO Hands & Voices has geographically placed Parent Guides throughout the state through their Guide by Your Side Program (Attachment 3, Job Description). Parent Guides have also been hired to serve families with children who have a unilateral hearing loss (UHL), are Spanish-speaking, and are American Sign Language (ASL) Deaf Families. The Unilateral Hearing Loss Parent Coordinator serves families with children with unilateral hearing loss and microtia statewide, and also represents this population in different venues around the state. Unique considerations for UHL children and their families (i.e. eligibility in Part C, amount of 'parent support' needed, and UHL specific information) are the impetus for providing this Parent Guide position.

Many resources for families are being developed and/or revised as needed. These resources can be found at www.handsandvoices.org. Resources include: The Colorado Resource Guide (with over 60 pages of resources, parenting tips, education information, and funding sources); Communication Considerations (a new series being developed by Hands & Voices to help parents make information decisions about communication modality); Bridges to Transition (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 was developed to

help families navigate options for obtaining funding for their children's amplification. Hearing aids are not a covered benefit in Colorado for most private insurance companies. Public health programs such as Medicaid or Child Health Program Plus does cover hearing aids. Families must either appeal their insurances denial or find other ways to fund hearing aid. The state has a loaner bank for audiologists to use when families are waiting for funding. CO Hands & Voices has also taken the lead in obtaining legislation to require insurance companies to provide hearing aids as a benefit for children birth through twenty years of age.

CO-Hear Coordinators, audiologists, physicians, or self-referral links families who have an infant newly identified with a hearing loss to Parent Guides. The Parent Guides serve families in a variety of ways (Attachment 3). In the past year, over 175 families were contacted/supported through one-to-one support and over 475 families attended over 20 regional events (social and workshop gatherings) over the course of the year. The state Director oversees statewide management of the program and also serves as a co-chair/consultant to the Medical Home Projects, the CO Infant Hearing Advisory Committee, consultant to the CO-Hear Program, and other statewide task forces and committees.

Implications for Funding

The Colorado EHDI program 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) management system is that these systems allow 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. In a study of the Colorado Infant Hearing Program, Christensen, Thomson, and Letson[2] looked at which factors may be associated with receiving/not receiving the initial or outpatient follow-up screen. Variables in the database included maternal demographics and birth-related characteristics as

well as hospital of birth. Demographic factors included mother's age at delivery, infant gender, marital status, mother's smoking status, maternal education, birth hospital, race/ethnicity, birth weight, and APGAR score at 5 minutes. The analysis demonstrated that infants who had high risk factors of low birth weight (less than 2500 grams) and APGAR scores of less than 7 at 5 minutes were most likely not to receive the initial screen. The average follow-up screening rate from 2002-2005 across 57 hospitals was 82%. Some hospitals have follow-up rates above 95%, and other hospitals have follow-up rates around 60%. Findings showed that hospital screening rates were influenced by maternal education, and that Latina mothers were much more likely than non-Latina mothers to report low education levels. Additional research has shown that hospitals that have an audiologist on staff or involved with the screening program have better outcomes (lower refer rates and higher rescreen rates). These types of analyses allow the Colorado EHDI program to develop strategies for targeting those populations at greatest risk for not receiving timely and appropriate follow-up.

The Colorado Infant Hearing Program has significantly improved its screening follow-up rates from 76% in 2001 to 86% in 2004. Important improvements were made to the Colorado system that improved the follow-up rates. These improvements included: 1) the development of the data management system that tracks individual infants from birth through the screening and rescreening processes, 2) better reporting from diagnostic facilities, 3) the ability of the CO-Hear Coordinators to directly access the data management system, for documenting early intervention enrollment. However, in 2006 there were 71,082 births, 69,268 (97.5%) screened, 3,369 (4.9%) referred at hospital discharge, and 2,654 (78.8%) with documented rescreen or audiological follow-up. Colorado has recently been awarded an MCHB EHDI grant to develop the medical home concept in EHDI program. Using this funding, Colorado will develop local EHDI teams consisting of the Audiology Regional Coordinator, Hospital Coordinator, CO-Hear Coordinator,

Parent Guide, local CSHCN Team Leader, and a primary care physician or nurse. These teams will develop a protocol from screening through intervention, unique to each community in the state, that will ensure families and providers have a guide for next steps in every process of the EHDI system. Data integration will be key to monitoring the effectiveness of these protocols and tracking infants through the EHDI system. Improving the follow-up rate will be the main goal of this proposal.

This requested funding will provide an opportunity for the CSHCN unit to enhance the EHDI CHIRP database to reduce the number of infants who are lost to follow-up by automating the data systems between the providers (hospital coordinators, audiologists), decrease the time for receiving services from screening through early intervention including parent support, and ensure that every child has a coordinated system of care through a medical home.

WORK PLAN

The purpose of this proposal is to enhance the EDHI program by improving the follow-up rates for infants who fail the newborn hearing screen and decrease the time between diagnosis and referral to early intervention through a coordinated medical home system of care. Activities for each objective show the key personnel responsible, the time line for completion, and the evaluation method that will be used to measure improvement.

Key Personnel responsible for activities are:

TITLE	**AGENCY**
Vickie Thomson, Ph.D., EHDI Coordinator	CDPHE, HCP
Chris Wells, Ph.D. candidate, IT Project Manager	CDPHE, IT
Emily Fields, M.S., EHDI Follow-up Coordinator	CDPHE, HCP
Janet DesGeorges, Director	CO Hands & Voices
Jennie Germano, M.A., Director of Early Intervention	CO School for the Deaf and Blind
Sandra Gabbard, Ph.D, Audiology Consultant	University of Colorado Hospital

Goal 1: Enhance the medical home system for infants who do not pass or miss the newborn hearing screen by linking to the primary care physician via the EBC to the Newborn Metabolic CHIRP.

Objective 1.1: By the end of June 2009, 80% of all EBC records will include the metabolic screening card number.

ACTIVITY	RESPONSIBLE	TIME LINE	EVALUATION
1. Identify a system/requirement for obtaining and entering the card number on the EBC	Chris Wells Vickie Thomson	Nov. 2008	Require field implemented on the EBC
2. Train the EBC clerks on the importance of entering this number	Emily Fields	January 2009	EBC records have the card number in NEST

Objective 1.2: By the end of January 2010, 80% of the demographic portion of the EBC records will be submitted within 24 hours after birth to link with the metabolic screen.

ACTIVITY	RESPONSIBLE	TIME LINE	EVALUATION
1. Identify a system for submission of the demographic part of the EBC to be submitted within 24 hours after birth.	Chris Wells Vickie Thomson	March 2009	
2. Train EBC clerks on the importance of the EBC submission and encourage participation.	Vickie Thomson Emily Fields	Dec 2009	EBC records integrate with newborn metabolic and newborn hearing screening records

Objective 1.3: By June 2009, 90% of the infants who fail/miss the newborn hearing screen will have a documented primary care provider identified through the second newborn metabolic screen.

ACTIVITY	RESPONSIBLE	TIME LINE	EVALUATION
1. Integrate fully the newborn hearing and metabolic databases with the NEST	Chris Wells	June 09	All infants who fail/miss the newborn hearing screen will have a documented primary care provider.

Objective 1.4: By December 2009, 90% of primary care providers will receive a follow-up letter on any infant who fails/misses the newborn hearing screen at discharge.

ACTIVITY	RESPONSIBLE	TIME LINE	EVALUATION
1. Develop a letter to be sent to the primary care provider.	Emily Fields	August 2009	Letter completed and added to the EHDI CHIRP database.
2. Automate the submission of letter to the PCP through the EHDI CHIRP database.	Chris Wells	Oct 2009	
3. Send letters to PCP's.	Emily Fields	Dec 2009	Monitor the increase in follow-up through the EHDI CHIRP reports.

Objective 1.5: The CSHCN information technology and EHDI staff will meet quarterly with the immunization registry staff to develop an operational strategic plan to integrated newborn screening results with immunization records.

ACTIVITY	RESPONSIBLE	TIME LINE	EVALUATION
1. Establish a task force to develop an operational strategic plan.	Chris Wells	Sept. 2009	
2. Write an operational strategic plan for implementation.	Vickie Thomson Emily Fields	June 2009	Plan written and submitted to the Board of Health for approval.

Goal 2: Improve the screening follow-up rate by automating the Monthly Follow-up

Report between CSHCN and birthing hospitals.

Objective 2.1: By April 2009, 5 birthing hospitals will enter outpatient missed/ rescreen results, the primary care provider (PCP), and an additional point of parent contact, directly into the new web based EHDI CHIRP.

ACTIVITY	RESPONSIBLE	TIME LINE	EVALUATION
1. Develop the data requirements for adding these fields to the EHDI CHIRP database.	Chris Wells	Sept.2008	
2. Define the procedure for entering data directly into EHDI CHIRP including security rules.	Chris Wells Vickie Thomson	Jan 2009	
3. Develop a procedure for screeners on how to collect this information prior to discharge and submit to EBC clerks	Vickie Thomson Emily Fields	Jan. 2009	
4. Train 5 hospital coordinators on how to enter the follow-up rescreens, contact information and PCP.	Emily Fields	July 2009	85% of all infants who miss/fail the screen will have documentation of these fields in the EHDI CHIRP database.
5. Refine procedures based on pilot project	Emily Fields Chris Wells	Sept 2010	Written procedure added to the Colorado Infant Hearing Guidelines for screeners

Objective 2.2: By December 2009, 100% of all birthing hospitals will enter follow-up screening results directly into EHDI CHIRP.

ACTIVITY	RESPONSIBLE	TIME LINE	EVALUATION
1. Develop a training manual and timeline to train all hospital coordinators.	Vickie Thomson Emily Fields	July 2009	
2. Train the remaining hospitals.	Emily Fields	Dec 2009	All Monthly reports are submitted electronically.

Objective 2.3: By December 2009, the EHDI Follow-up Coordinator or Parent Guide will contact 90% of all families whose infant failed the outpatient screen after 30 days, if there is no documentation of an audiology assessment.

ACTIVITY	RESPONSIBLE	TIME LINE	EVALUATION
1. Develop a procedure for contacting families either through the state or local CSHCN offices.	Vickie Thomson Emily Fields Janet DesGeorges	March 2009	
2. Implement the procedure.	Emily Fields Janet DesGeorges	Dec 2009	Documentation of parent contact entered into the EHDI CHIRP database.

Goal 3: Improve the audiology diagnostic process by decreasing the referral time to audiology services and early intervention services through automating data systems.

Objective 3.1: By December 2008, five audiology clinics will enter diagnostic results directly into the EHDI CHIRP database.

ACTIVITY	RESPONSIBLE	TIME LINE	EVALUATION
1. Develop a procedure for entering data into the EHDI CHIRP database.	Vickie Thomson Emily Fields Sandra Gabbard	August 2008	
2. Train and implement the procedure with 5 audiology clinics.	Emily Fields	Dec 2008	Documentation of Audiology Follow-up Forms entered into the EHDI CHIRP database.

Objective 3.2: By September 2009 all audiologists who provide pediatric assessments will enter results into the CHIRP EHDI database.

ACTIVITY	RESPONSIBLE	TIME LINE	EVALUATION
1. Develop a strategy and timeline for implementation statewide.	Vickie Thomson Emily Fields	Feb 2009	
2. Train and implement the procedure with all pediatric audiologists	Vickie Thomson Emily Fields	Sept 2009	All Audiology Follow-up Forms are submitted electronically.

Objective 3.3: By March 2010, a data analysis of Audiology Follow-up Reports will determine the minimum test battery needed to confirm a permanent hearing loss in order to refer to the CO-Hear Coordinator for early intervention services.

ACTIVITY	RESPONSIBLE	TIME LINE	EVALUATION
1. Analyze data to determine which infants are confirmed with a permanent hearing loss based on the initial audiology evaluation.	Vickie Thomson Sandra Gabbard	Jan. 2010	Report
2. Determine reliability and sensitivity to the analysis for implementation as a protocol to expedite the referral into early intervention.	Vickie Thomson Sandra Gabbard	Jan. 2010	Publish findings.
3. Develop a strategic plan for implementation if results are successful.	Vickie Thomson	April 2010	Date of early intervention is occurring within 48 hours of the initial diagnosis.

Objective 3.4: By December 2009, create an alarm in the EHDI CHIRP database to notify the EHDI Follow-up Coordinator that a CO-Hear has entered a newly diagnosed infant into the database that does not have an Audiology Follow-up Report in CHIRP.

ACTIVITY	RESPONSIBLE	TIME LINE	EVALUATION
1. Develop software codes into the EHDI CHIRP database to alert the Follow-up Coordinator when a CO-Hear has entered data and there is no audiological record.	Chris Wells Emily Fields	Dec 2009	
2. Contact the audiologist from the CO-Hear entry and request an Audiology Follow-up Assessment Form	Emily Fields	Dec 2009	Documentation of Audiology Follow-up Forms in EHDI CHIRP database.

Objective 3.5: By December 2009, 100% of all birthing hospitals will have a follow-up protocol and a list of audiologists who can provide assessments on infants' birth to six months of age.

ACTIVITY	RESPONSIBLE	TIME LINE	EVALUATION
1. Local EHDI teams will meet with each hospital to determine the nearest audiologist who can provide pediatric assessment for infants.	Vickie Thomson	Dec. 2009	List created for pediatric audiology providers and placed on the CSHCN website.
2. Develop a plan to disseminate follow-up protocols and resources to primary care providers.	Vickie Thomson	Feb 2010	
2. Information is disseminated to all local primary care providers regarding the follow-up protocol and appropriate referral resources.	Vickie Thomson Emily Fields		Documentation of primary care providers trainings and/or newsletters, and follow-up letters.

Objective 3.6: By November 2009, 90% of all infants with a confirmed permanent hearing loss will have documentation in EHDI CHIRP that they received a referral to the CO-Hear within 48 hours.

ACTIVITY	RESPONSIBLE	TIME LINE	EVALUATION
1. Develop a training procedure to ensure that all families are referred to the CO-Hear Coordinator within 48 hours of diagnosis.	Vickie Thomson Sandra Gabbard Jennie Germano	Dec 2008	Procedure outlined and added to the Colorado Infant Hearing Guidelines.
2. Information is disseminated to all licensed audiologists.			

Goal 4: Improve documentation of parent support through data integration with the EHDI CHIRP data system.

Objective 4.1: By March 2009, develop a data system that will allow the Parent Guides to enter demographic and contact data directly into the EHDI CHIRP data system for newly identified infants.

ACTIVITY	RESPONSIBLE	TIME LINE	EVALUATION
1. Identify the data fields for the Parent Guides to measure contacts and parent satisfaction.	Janet DesGeorges	Nov 2009	Data fields are identified.
2. Define the procedure for entering data directly into EHDI CHIRP including security rules.	Chris Wells Vickie Thomson	Jan 2009	

Objective 4.2: By June 2009, 100% of Parent Guides will enter data into CHIRP for newly identified infants and families.

ACTIVITY	RESPONSIBLE	TIME LINE	EVALUATION
1. Identify training procedures for the Parent Guides.	Janet DesGeorges Chris Wells	April 2009	
2. Implement training procedures statewide.	Janet DesGeorges	June 2009	Documentation of parent contact is documented in EHDI CHIRP.
3. Parent satisfaction with the EHDI system is analyzed.	Vickie Thomson Janet DesGeorges	Dec 2009	Publish findings for improvement in the EHDI system for future grant goals.

Goal 5: Integrate the Early Intervention System with the EHDI CHIRP data system.

Objective 5.1: By July 2008, identify all the reported fields required by the EHDI program, Colorado Department of Education (ChildFind), Colorado School for the Deaf and Blind (CSDB), and the Department of Human Resources (Part C) to de-duplicate the reporting processes for the CO-Hear Coordinator and obtain accurate data for all agencies.

ACTIVITY	RESPONSIBLE	TIME LINE	EVALUATION
1. Convene the above agencies to identify data fields for integration for EI services.	Jennie Germano Vickie Thomson	July 2008	
2. Develop a template that meets the reporting requirements.	Jennie Germano	Oct 2008	Template developed

Objective 5.2: By March 2009, identify a task force (representation from the above agencies, families, and information technology staff) that will determine integration opportunities between agencies considering HIPAA/FERPA issues and funding issues.

ACTIVITY	RESPONSIBLE	TIME LINE	EVALUATION
1. Convene a task force to determine issues related to HIPAA/FERPA for data integration and funding.	Vickie Thomson Jennie Germano	Mar 2009	Documentation of issues and concerns.
2. Develop a strategic plan for data integration.	Jennie Germano	Jan 2010	Documentation of strategic plan

Goal 6: Increase the percentage of infants who have documented developmental outcomes

in the EHDI CHIRP database.

Objective 6.1: By September 2010, identify the developmental outcome data that will be collected in the EHDI CHIRP database for sustainability of collecting outcome data.

ACTIVITY	RESPONSIBLE	TIME LINE	EVALUATION
1. Convene a task force to identify outcome data that will be entered into the EHDI CHIRP database.	Vickie Thomson Jennie Germano	Sept 2010	Data fields defined for integration into the EHDI CHIRP database.

COLLABORATIVE EFFORTS

The CSHCN unit has strong collaborations with many agencies, parents, and consumers who are deaf and hard of hearing to develop comprehensive systems statewide for the EHDI program. CSHCN supports financially Colorado Families for Hands & Voices to ensure the EHDI program meets the needs of families. CSHCN unit supports financially the Colorado School for the Deaf and Blind early intervention program. This grant funding will provide support to the Marion Downs Hearing Center and Bill Daniels Hearing Center for the training and implementation of data integration for pediatric audiology programs. A memorandum of agreement is currently being revised to address the roles between the Department of Human Services, Early Childhood Connections (Part C) and the CSHCN EHDI program.

Nationally the staff of the Colorado EHDI program are very involved with the Directors of Speech and Hearing Programs in State Health and Welfare Agencies (DSHPSHWA) and the American Academy of Audiology. In addition the EHDI program works collaboratively with the National Center for Hearing Assessment and Management (NCHAM). Vickie Thomson has recently worked with Karl White, Ph.D. on work groups to develop a white paper on HIPAA/FERPA issues; participation in the Project ECHO (Early Childhood Hearing Outreach); assisted in developing training materials for hospitals hearing screeners. Letters of support/agreement and MOU's are located in the appendices.

PROGRAM CAPACITY

The Children with Special Health Care Needs unit is responsible for building family driven, sustainable systems of health services and supports for all families of CYSHCN in Colorado. The CSHCN program structure consists of a state office, 14 HCP administrative offices, and 38 rural 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 CYSHCN 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. These local CSHCN providers have the skill and experience in the ten essential public health services including community assessment, convening stakeholders, monitoring and evaluating. Every local CSHCN program has an Audiology Regional Coordinator to provide technical assistance to local hospitals and audiologists. They work closely with the local CO-Hear Coordinators, Part C Coordinators, and Parent Guides to develop local EHDI systems and implementation of best practices and data integration.

STAFFING AND MANAGEMENT PLAN

The CSHCN unit is located within the Preventive Services Division (PSD). PSD has created an Epidemiology, Planning, and Evaluation unit. This unit is rich with staff that has an expertise in data analysis, evaluation, and planning. Mathew Christensen, Ph.D. and the EHDI Coordinator, Vickie Thomson, Ph.D. has analyzed the infant demographic data and hospital data. Using this data as a starting place, the goal is to develop an EHDI program that will implement the essential public health services from assurance to public health policy development, using a data driven approach. Dr. Thomson recently completed her doctoral degree in audiology, with a minor in public health, to provide 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. In addition, she has published many articles on the topic. The EHDI Follow-up Coordinator, Emily Fields, is a genetic counselor by profession. Although in her current position she is not providing genetic counseling, her experience in counseling has proven invaluable in her work with families and providers.

Chris Wells is the CSHCN unit Project Manager for the Data Integration System which is responsible for the development of the CHIRPs and NEST applications. Chris is completing his

Ph.D. in Clinical Science, Health Information Technology. In addition, he is the Director of the Public Health Informatics Unit, which exists to collaboratively foster the increasing use of sound informatics principles and methodologies as a means to improve public health practice, and to improve the health of communities.

Janet DesGeorges is the director of Colorado Hands & Voices. She is the parent of a daughter with hearing loss. Janet has helped establish Hands & Voices chapters in 38 states. She has published many articles on the topic of parent support in EHDI systems and has presented statewide, nationally, and internationally.

Jennie Germano, M.A. is the Director of Early Intervention Services for Children who are Deaf and Hard of Hearing through the Colorado School for the Deaf and Blind. Although Jennie is new to Colorado she brings a wealth of experience. Her new vision has created fulltime staff positions for the CO-Hear Coordinators who more recently were only on a contractual basis.

Sandra Gabbard, Ph.D. is the Director of Audiology Services for the Marion Downs Hearing Center at the University of Colorado Hospital. Dr.Gabbard serves as the chair of the Audiology Task Force for the Colorado Infant Hearing Program. She assists the EHDI program in developing best practices for clinical audiologists statewide.

The CSHCN unit has designated support staff that can assist the EHDI staff and contractors with developing materials, writing documents, and presentations. The fiscal staff can work with the principal investigator to establish the contracts, memorandums of understanding/agreements, and the fiscal responsibility required for this grant.

EVALUATION PLAN

EHDI, IT, and key personnel will continue to meet monthly to review timelines for the activities listed in the work plan. The evaluation of the EHDI plan will be continuously monitored through data collected in the EHDI CHIRP data system. Time and effort strategies

will be implemented to measure the efficiency of automated systems and improvement in the EHDI system. Data analysis will document progress towards increasing the percentage of infants who receive follow-up rescreens and audiology assessments by one month and 3 months, respectively. The CO-Hear Coordinators will document enrollment into early intervention to ensure that infants are being referred within 48 hours of diagnosis. Hands & Voices parent guides will document contacts with families and monitor parent satisfaction through survey data. The implementation strategies of contacting the primary care provider as part of the medical home initiative will be documented and reported. In addition strategies that improve the system will be written for a peer reviewed publication to encourage lessons learned and best practices for other state EHDI programs.

REFERENCES

1. Yoshinaga-Itano C, Sedey AL, Coulter DK, Mehl AL. Language of early and later-identified children with hearing loss. *Pediatrics.* 1998; 102:1161
2. Christensen, M., Thomson, V., Letson, G.W. (2007). Evaluating universal newborn hearing screening in Colorado: From population determinants to system-improvement actions. In review.