

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

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ABSTRACT

Introduction:

The Colorado Early Hearing Detection and Intervention system (EHDI) has been in place since 1992. Legislation was passed in 1997 requiring all birthing hospitals to implement a newborn hearing screening program. Program improvements have been made and Colorado is successfully screening over 97% of their infants. Colorado has a data management system which is populated by the electronic birth certificate (EBC). Screening results are reported via the EBC. Follow-up from screening after hospital discharge continues to be a problem because over 25% of the infants who fail screening do not receive follow-up. Follow-up from outpatient screening to audiological assessment and into early intervention also continues to be a critical issue. This grant proposal will focus on the follow-up interventions that will increase access to screening, improve the follow-up for the families who speak Spanish, increase education to parents and providers, increase parent support, and pilot telemedicine for audiology and early intervention services in rural communities.

Goals & Objectives:

Goal 1: Increase universal newborn hearing screening for Colorado infants.

Objective 1: By August 31, 2010, increase from 30% to 50% the number of infants born at home who receive a newborn hearing screen.

Goal 2: Increase EHDI follow-up (screening, diagnosis and early intervention) in Colorado.

Objective 2.1: By August 31, 2010, increase from 75% to 80% the number of infants who failed a newborn hearing screen who receive a rescreen or diagnostic evaluation.

Objective 2.2: Increase the number of pediatric audiologists who have expertise in diagnosing infants from 13 to 16 to increase the capacity and accessibility statewide for families whose infants are deaf and hard of hearing.

Objective 2.3: By August 31, 2010 increase the number of infants who receive early intervention services by six months of age from 65% to 90%.

Objective 2.4: Increase surveillance of unilateral hearing loss (UHL) from 0%-50%.

Objective 2.5: Increase from 43% to 70% the number of Spanish speaking families who return for follow-up rescreens or evaluations.

Goal 3: Increase knowledge and awareness of families and providers on the EHDI process (screening, diagnosis and early intervention).

Objective 3.1: Increase the awareness and knowledge of 5 health-care providers in the Denver-metro area.

Objective 3.2: Increase the awareness and knowledge of 5 families in the Denver-metro area.

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

EPE – Epidemiology, Evaluation and Planning unit

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

NCHAM – National Center for Hearing Assessment and Management

NEST – Newborn Evaluation Screening and Tracking (data base)

NICHQ – National Initiative for Children’s Healthcare Quality

NICU – Neonatal Intensive Care Unit

OBRA – Omnibus Budget Reconciliation Act

Part C – Early Childhood Connection

INTRODUCTION

Historical Information

The Colorado Infant Hearing Program is housed in the Prevention Services Division, Children with Special Care Needs (CSHCN) unit, within the Colorado Department of Public Health (CDPHE). 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. 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 providers, 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.hpcolorado.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.

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. 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 Health Care Program for Children with Special Needs (HCP) developed a data management system that was populated by the 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 NEST (Newborn Evaluation, Screening and Tracking), 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 with the local HCP offices, for care coordination services. Each individual program (metabolic screening, birth defects, local HCP 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, and 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 evidence based research 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.

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. The data system is being converted to a web based application which will be completed by fall 2009.

Audiologists submit an Audiological Assessment report 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. 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 introduction of the web based system will allow audiologists to directly enter diagnostic and follow-up information into the EHDI database.

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 22% in 2006. Processes are in place to electronically match the newborn metabolic/genetic screen with the newborn hearing screening in order to identify the primary care physician whose name is on the newborn screen. This will allow the EHDI program to send letters to physicians to assist with follow-up. In 2008, Colorado passed legislation requiring the implementation of an immunization registry. This is also housed at CDPHE. The Colorado EHDI program is developing a strategic plan to integrate with the registry so providers have access to hearing screening results potentially in real-time.

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, age's 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 Assessment report, and refers the family to the 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. This is currently being accomplished with virtual private network software CITRIX. The Follow-up Report 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 are choosing. The Follow-up Coordinator will contact the audiologist when he/she has not filed an Audiological Assessment form on a child being followed by a CO-Hear. Thus, the 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 housed in the lieutenant governor's office and staffed by state 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 identifying these children earlier than later.

The CO-Hear Coordinators extend invitations to every family to participate in developmental assessments every six-month until children are age three. 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 direct data interface between the University of Colorado and the EHDI program to capture outcome measures for the infants enrolled in the EHDI program. The CU and EHDI staff serves on a national CDC data committee to begin discussion on data fields that will be implemented into the program electronically

Parent Support

Colorado Families for Hands & Voices is a non-profit parent support network. They are celebrating their 13th year as an organization, which 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. 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 Deaf Families.

CO-Hear Coordinators, audiologists, or self-referral links families who have a newly identified infant with a hearing loss to Parent Guides. The Parent Guides serve families in a variety of ways. In the past year, over 175 families were contacted 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.

Colorado's Medical Home Initiative

The lead agency for the Colorado Medical Home Initiative is the Colorado Department of Public Health and Environment, the Children with Special Health Care Needs (HCP) Unit (see Attachment 1). HCP is dedicated to developing and implementing the infrastructure to support this effort. HCP has a full time parent dedicated to coordinating the Medical Home Initiative. Colorado also participated in the National Initiative on Child Health Quality (NICHQ) Medical Home Collaborative. This training provided the tools to implement the medical home approach, which HCP defines, as “A Medical Home is not a building, house or hospital, but a team approach to providing health care. A Medical Home originates in a primary health care setting that is family-centered and compassionate. A partnership develops between the family and the primary health care practitioner. Together they access all medical and non-medical services needed by the child and family to achieve maximum potential. The Medical Home maintains a centralized, comprehensive record of all health related services to promote continuity of care.”

The Colorado Medical Home Initiative is a systems-building effort to promote quality health care systems for all children in Colorado. Bringing together a group of more than 40 people representing various agencies, families, hospitals, organizations and policy-makers, the Colorado Medical Home Initiative is dedicated to building a sustainable system that delivers quality health care for all children. Positioned within the Colorado Department of Public Health and Environment, the Colorado Medical Home Initiative is a neutral facilitator in identifying barriers while promoting solutions in developing a quality-based system of health care for children. Since this effort relies on the cooperation of many agencies, the unit has worked closely with many partners.

Senate bill 07-130 was passed by the Colorado legislature in 2007. It requires Health Care Policy and Finance (Medicaid) to define the term “Medical Home” and to describe the approach to care that provides for continuous and accessible coordination of primary, mental, oral, and specialty care. Both the Senate bill and the Medical Home Initiative are developing

standards based on values of family centered, continuous, comprehensive, coordinated, compassionate, culturally competent, and accessible. The State EDHI Coordinator and the director of CO Families for Hands & Voices serve on the Medical Home Initiative task force to ensure that the efforts for the EHDI system and this potential funding mesh with those of the state initiative, legislation, and medical home values.

The Health Care Program for Children with Special Needs (HCP) has 14 HCP Regional Offices (Attachment 1) 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.

Implications for Funding

The Colorado EHDI program has been in development and refinement for 17 years. The advantage of an active (data collected directly from the electronic birth certificate) and passive (data collected from providers) 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. In a study of the Colorado Infant Hearing Program, Christensen, Thomson, and Letson² 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. 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 Prevention Services Division has an Epidemiology, Evaluation, and Planning (EPE) unit to provide technical assistance in data analysis.

Colorado participated in the National Initiative for Children’s Healthcare Quality (NICHQ) Newborn Hearing Screening Learning Collaborative. A NICHQ EHDI team was developed. The team participated in collaborative meetings and focused on small changes to improve the follow-up from screening and diagnosis. These changes referred to as Plan, Do, Study, Act (PDSA’S) offered the team the opportunity to investigate changes that resulted in successful outcomes. Changes, such as scheduling the outpatient rescreen prior to hospital discharge, are being written into the Guidelines as best practices. The current MCHB funding has provided the Colorado EHDI team the opportunity to implement the NICHQ project goals to improve the follow-up through the medical home and parent support. Primarily the current funding is being used to improve the follow-up rates by increasing the audiology regional coordinator time to develop comprehensive follow-up rescreen programs; increase the role of the Hands & Voices Parent Coordinators at every level of the follow-up process; the development of the “Roadmap for Families” (see Attachment 1); the develop of EHDI regional teams (Audiology Regional, Parent, Part C and CO-Hear Coordinators) to work with hospitals, physicians, and other providers to ensure that every child who fails the screen or has a permanent hearing loss has a medical home. This new funding will allow Colorado to purchase equipment to ensure newborns born at home receive a hearing screening; increase the time of the Spanish speaking Hands & Voices parent guide to contact families who fail the newborn screen; collaborate with Hands & Voices National to develop a parent focused video to encourage follow-up prior to be viewed prior to hospital discharge; and to pilot telemedicine for audiologists and early interventionists in rural communities. This funding will provide resources to develop systems that will support hospitals and providers by creating efficiencies and potentially decreasing liability to ensure infants receive timely and appropriate follow-up in every aspect of the EHDI program. The ultimate goal is to develop comprehensive seamless systems that will meet the needs of the families and children served statewide through the HCP program.

NEEDS ASSESSMENT

The Colorado Infant Hearing Program had significantly improved its screening follow-up rates from 76% in 2001 to 86% in 2004. Important improvements were made to the Colorado system that increased 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 intervention programming.

Unfortunately the rescreen rates have decreased significantly from 86% in 2004 to 75.7% in 2008. Summary reports by hospital are in Attachment 7. See the table below for statistical summary.

<u>Year</u>	<u>Hospitals</u>	<u>Births</u>	<u>Screened</u>	<u>Referred*</u>	<u>Rescreened</u>	<u>LTF</u>	<u>Confirmed</u>	<u>EI</u>
2007	56	70,518	68,890 = 98%	3,270 = 4.7%	2,424 = 74%	724= 22%	122	83= 76.9%
2008	56	69,848	68,167 = 98%	2,777 = 4.1%	2,104 = 75.7%	520= 19%	113	TBD

* Initial failed screen at hospital discharge

Screening

There are approximately 800 (1.1%) home births in Colorado annually. Otoacoustic Emission (OAE) units have been placed with three trained midwives. They routinely screen and report their results to the program. They also offer free or low cost screens to families of other midwives. This funding would provide additional screening equipment to be placed strategically in areas where homebirths occur frequently or where a midwife covers a large geographical area. Equipment may be placed with midwives or in the local CSHCN regional office. Training would be provided by the local Audiology Regional Coordinator including the distribution of the Roadmap for Families.

The Colorado EHDI program recognizes the need to identify the medical home for assistance with follow-up at each stage of the EHDI process. The primary care physician is identified on the Audiological Report Form and the CO-Hear Intake Form and entered into the EHDI CHIRP database. As mentioned in the introduction, efforts are underway to identify the primary care physicians by linking the newborn blood spot screen to the EHDI CHIRP database and the immunization registry. Current CDC funding is addressing these projects. The Roadmap for Families will be disseminated to all pediatric providers so they understand the next steps for their patients who fail a newborn hearing screen. An unmet need is educating the Nurse Family Partnership program about the importance of follow-up for newborn hearing screening. The NFP

program is located within the MCH division. This funding will provide a webinar to educate the nurses, who often serve as the medical home for low income mothers and infants, resource and referral information to reduce loss to follow-up with this population.

A significant portion of the infants who failed the screen do not return for follow-up either to the birth hospital or recommended audiology clinic. There has been a current trend in Colorado to close audiology programs in hospitals for financial reasons. Three of the largest birthing hospitals in Colorado have discontinued their pediatric audiology services. In addition they are choosing not to provide outpatient rescreens. They refer directly to The Children's Hospital (TCH) outpatient satellite clinics. We have documentation that a significant percent of families do not follow through with the protocol. Current funding is providing the opportunity to contract with the TCH pediatric audiologists located strategically near birthing facilities that do not have audiologists on staff. They will serve as the Audiology Regional Coordinator for the hospital and the county they serve. The intention is to create a direct protocol and link for referral to The Children's Hospital clinic to improve follow-up for screening and referral for diagnostic services. This contract will be finalized in June 2009.

Current funding provided the distribution of the "Newborn Hearing Screening Training Curriculum" DVDs, developed by NCHAM, to each birthing hospital. Hospitals have embraced this as an opportunity to train current and new staff. A survey is being developed and disseminated to each hospital coordinator to determine if the DVD is being used or if further training is needed by the local EHDI Team. Data will be monitored to evaluate whether training increased the rescreen rates at specific hospitals. This current funding would allow collaboration between the CO EHDI program, CO Hands & Voices, and Hands & Voices National in the development of a parent video. The video called "Loss and Found" will focus on the importance of follow-up after a failed screen from the parent perspective (see Attachment 7). This will be added to the hospital's patient education library for parents and staff. Local Audiology Regional Coordinators and Hands & Voices parent guides will provide hands on training to hospital staff and the importance of having parents whose infants failed the screen to view the video prior to discharge.

Audiology Diagnostic Services

An Audiology list was created in 2002 to identify those audiologists who had the expertise and equipment to diagnosis infants. The list proved inadequate because many of the

audiologists actually did not have the equipment or skills to serve this population. Current funding is increasing the role of the Audiology Regional Coordinators to assist the State EHDI team in creating a new, updated list of audiologists who can evaluate infants. Identified audiologists are also listed on the local Roadmap for Families. Colorado has many rural and frontier communities. As a result the nearest audiologist, who can provide assessments on infants' maybe located several hundred miles away. If funded, a telemedicine model of training and diagnostic equipment will be strategically placed to provide access to parents. Colorado was awarded an Association of University Centers on Disabilities (AUCD) grant through the Colorado Leadership Education in Neurodevelopment Disabilities (LEND) program at JFK Partners. One of the goals of this grant is to provide training to rural audiologists. Four sites were targeted in the Western Slope, South Central, and Southwest areas of the state. One of the sites has an audiologist with previous pediatric experience but she does not have access to diagnostic equipment (auditory brainstem response or otoacoustic emissions). The addition of a pediatric audiology diagnostic center in the southwest corner of the state will enhance services for infants from the Southern Ute Tribes who typically are referred to a clinic in New Mexico for services. The LEND funding also does not provide funding for telemedicine equipment. In addition, the Colorado EHDI program, Marion Downs Hearing Center, and NCHAM will coordinate an audiology workshop to provide continuing education credits. There has been some discussion that audiologists will be required to attend this training to maintain their names on the list of pediatric providers and on the Roadmap for Families. As mentioned earlier the NEST/CHIRP data management system is being converted to a web based application. We hope this will result in better compliance from audiologists for reporting screening and diagnostic results. We recognize that a percentage of the 'lost to follow-up' maybe due to lack of reporting.

Early Intervention Services

The CO-Hear Coordinators have become more compliant in documenting early intervention fields into CHIRP. Current CDC funding is integrating the CHIRP database with the Colorado School for the Deaf and the Blind (CSDB) infinite campus database. We have also added fields that are required by Part C with the target of creating one database that will produce reports for all agencies and follow-up letters to providers. Again, lack of reporting is also affecting data reported to federal partners. There can be a significant lag time between the first home visit for a family and the actual implementation of early intervention services. This

funding would increase the capacity of telemedicine across the state. A model project at the Marion Downs Hearing Center has demonstrated success using telemedicine for early intervention with a family in a very rural part of Colorado. Although the CO-Hear Coordinators are located statewide, several have a very large territory. It is also difficult to find early interventionists who can provide specialized communication (auditory verbal, sign language) options in rural communities. This would allow an experienced interventionist to work directly with a local interventionist and family via telemedicine.

Colorado had a MCHB Genetics grant from 2003-2007 which provided the opportunity to contract with a genetic counselor who specialized in hearing loss. She worked part time at The Children's Hospital and part time at the Marion Downs Hearing Center. When the genetics grants were no longer funded her position was not able to be supported through the Marion Downs Hearing Center. This funding would provide genetic counseling services to families who participate in the Marion Downs Hearing Center multidisciplinary program. Parents have the opportunity to meet with an audiologist, parent, otologist, early interventionist, and social worker within one day long visit. Parents do not typically have access to genetic services without this valuable component.

Infants with unilateral hearing loss now qualify for Part C services in Colorado. This change in policy has not been widely disseminated. The lack of referral from the audiologist to the CO-Hear and Part C system continues to be an issue. These infants are often not documented by the CO-Hear Coordinator since they may only be receiving consultation. This funding will provide additional training to audiologists via a statewide webinar in collaboration with the Marion Downs Hearing Center, Hands & Voices, and CSDB. This funding will also support a Unilateral Hearing Coordinator to assist in the development of the webinar, contact families for support and monitor follow-up activities via CHIRP.

Parent Support

Parent support through Hands & Voices has gained momentum and families are referred directly upon diagnosis. However there are opportunities to utilize Hands & Voices sooner in the process. Research demonstrated that infants born to Latino mothers are most likely not to return for follow-up. This funding would increase the FTE of the Parent Coordinator who speaks Spanish to contact families directly who do not return for the follow-up rescreen or diagnostic evaluation. Having a parent who understands their culture and can speak their language can

potentially increase follow-up for this population. Janet DesGeorges has been providing parent support in a multidisciplinary clinic held through the Marion Downs Hearing Center. The Center reports increased parent compliance with follow-up visits as a result of this interaction. This funding will provide additional parent guide support and develop an evaluation plan to document the parent satisfaction in having support provided following the diagnostic evaluation.

“Just in Time” resources and best practices for providers and families is another opportunity for education to encourage follow-up and referral. The Colorado EHDI program website is under construction. There are restrictions placed upon the program from department and the state. This funding would be utilized to link providers and families to the Hands & Voices website. This project will take the Roadmap for Families and create an online, interactive tool for utilization by parents and professionals. Boystown has created an online tool (www.babyhearing.org) for a nationally based audience. Additionally, the state of Wisconsin has created a template. A derivation of the Colorado Road map and the Boystown tool will be created for the Colorado EHDI program. The online tool will be placed on www.cohandsandvoices.org for long term maintenance and sustainability. Marketing to Physicians will occur, with a special section for the Medical Home. Resources such as the Roadmap for Families, Loss and Found video, and other training opportunities will be streamed or linked to the website.

METHODOLOGY

The ultimate goal of the Colorado EHDI program is infants who are deaf and hard of hearing will receive early screening to ensure early identification and early intervention for the development of normal speech and language. The EDHI CHIRP data base will provide the actual evaluation by demonstrating the improved outcomes of: 1) An increase in the percentage (80% to 90%) of infants who receive an outpatient rescreen by one month of age. 2). All infants who fail the outpatient rescreen receive an audiological evaluation by three months of age. 3). All infants with confirmed hearing loss are enrolled in early intervention and receiving parent support by six months of age.

The following goals and objectives will be implemented to increase the follow-up in each step from screening to early intervention. Activities and timelines are outlined in the Work Plan.

Goal 1: By August 31, 2010, increase from 30% to 50% the number of infants who born at home receive a newborn hearing screen.

Objective 1.1: Provide OAE screening equipment for 3 midwives or local public health offices to offer newborn hearing screens and/or rescreens to families who birth at home.

Activities:

1. Develop and disseminate mini-grant opportunities for midwives to obtain equipment with requirements for use such as willingness to share with other midwives or the local health department.
2. Identify the areas of the state where equipment will be best utilized by families and midwives.
3. Train midwives on newborn hearing screening equipment and follow-up protocols.
4. Train midwives to enter hearing screening results into the CHIRP database or on the electronic birth certificate.
5. Connect the local midwives in the EHDI Regional Teams to assist with the dissemination and ongoing updates to the Roadmap for Families.
6. Provide in-service trainings to the Colorado Midwife Association on the importance of screening and follow-up.

Goal 2: By August 31, 2010, increase from 75% to 80% the number of infants who failed a newborn hearing screen receive a rescreen or diagnostic evaluation.

Objective 2.1: Enhance training and resources for hospital staff, providers and parents.

Activities:

1. Collaborate with Hands & Voices National to develop a customized “Loss and Found” DVD.
2. Implement a training program for hospital staff (if feasible, to be coordinated with the new web based CHIRP system) to review the “Newborn Hearing Screening Training Curriculum” and introduce the Loss and Found DVD.
3. Update, disseminate, and train hospital screening staff on the Colorado Infant Hearing Guidelines that includes: documentation the results were given to families in their spoken language verbally and written; the primary care provider is identified and documented on the metabolic blood spot card; outpatient rescreens are scheduled prior to hospital discharge; infants in the neonatal intensive care unit have a documented screen and

recommendations for follow-up in the infant's chart; infants that are transferred receive a screen prior to discharge and documented in the CHIRP database; two points of contact are documented in the infants chart for follow-up purposes.

4. Develop the Roadmap for Families as an interactive tool on the Hands & Voices website.
5. Using the Wisconsin model, create a web based education tool for physicians and providers using best practice guidelines from the Joint Committee on Infant Hearing and the Colorado Infant Hearing Guidelines.
6. Develop a webinar for the Nurse Family Partnership Program.

Objective 2.2: Increase the number of pediatric audiology clinics from 13 to 16 to increase the capacity and accessibility statewide for families whose infants are deaf and hard of hearing.

Activities:

1. Purchase diagnostic equipment for one experienced pediatric audiologist located in Southern area of Colorado.
2. Establish a telemedicine network between three practices in rural Colorado and the Marion Downs Hearing Center.
3. Develop and implement an audiology workshop with NCHAM and the Marion Downs Hearing Center for Spring/Summer 2010.

Goal 3: By August 31, 2010 increase the number of infants who receive early intervention services by six months of age from 65% to 90%.

Objective 3.1: Increase the use of telemedicine for early intervention providers from one to six families.

Activities:

1. Identify the location appropriate for telemedicine equipment in the state based on need and location of current families.
2. Provide training to CO-Hear Coordinators, Parent facilitators, audiologists.
3. Develop a plan to document the use of telemedicine in the CHIRP database.
4. Develop a survey to determine parent satisfaction with telemedicine early intervention services.
5. Provide access to a genetic counselor at the Marion Downs Hearing Center and via telemedicine.

Objective 3.2: Increase the number of infants with unilateral hearing loss (UHL) who are documented by audiologists and receive early intervention services.

Activities:

1. Determine the baseline data from the 2008 CHIRP database.
2. Hire a UHL coordinator and develop a protocol for contacting families and referring them to the CO Hear Coordinator for early intervention consultation
3. Develop a tracking mechanism in CHIRP to monitor UHL documentation by audiologists and referral to early intervention.
4. Develop a UHL webinar in collaboration with the Marion Downs Hearing Center, CSDB and University of Colorado, for fall 2008.

Goal 4: By August 30, 2010, increase the parent support throughout the EHDI process beginning with screening through early intervention.

Objective 4.1: Increase from 43% to 70% the number of Spanish speaking families that return for follow-up rescreens or evaluations.

Activities:

1. Hire a Spanish speaking follow-up coordinator to contact families after a failed screen or rescreen.
2. Develop a protocol for contacting families and disseminate to hospital coordinators and audiologists.
3. Identify pediatric audiologists who either speak Spanish or have access to translators for families.

Objective 4.2: Increase the use of parent support in multidisciplinary clinics.

Activities:

1. Increase the FTE of Janet DesGeorges to attend monthly multidisciplinary clinics at the Marion Downs Hearing Center.
2. Create a survey to measure family satisfaction with the multidisciplinary clinics and parent support.

Objective 4.3: Increase parent and provider education statewide through webinars based on parent focused topics to reduce loss to follow-up and increase knowledge of critical next steps following diagnosis.

Activities:

1. Develop a training curriculum; identify appropriate audiences, and timeline for each topic.
2. Identify technology needed for interpreters (ASL and Spanish) services and captioning.
3. Develop and implement webinars on topics such as: Parent’s Wish list for Screeners; Encountering Emotions: The Parent Perspective on Supporting Families through Their Journey of Hearing Loss; Developing a Sound IFSP: Self Advocacy from the Start.
4. Develop and disseminate a participant evaluation survey.
5. Based upon recommends from the evaluation, offer the webinars to National Hands & Voices and/or HRSA for national education to families and providers.

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/Activities of the Work Plan as appropriate. The PSDA tool will help the local and state EHDI teams to visualize the implementation and evaluation aspects to document change. Data will be monitored on the reduction of the loss to follow-up through the EHDI CHIRP database. The EPE unit will provide technical assistance for data analysis and writing surveys for evaluation purposes.

Data is currently collected via EHDI CHIRP and the Audiology Follow-up Forms to determine whether audiologists are providing a comprehensive evaluation per the CO Infant Hearing Guidelines and the Joint Committee on Infant Hearing (e.g. ABR, tone bursts, OAE). Training interventions will be measure before and after improvements in evaluations by audiologists who serve infants.

Individual people responsible for activities are:

TITLE	AGENCY
Vickie Thomson, Ph.D., EHDI Coordinator	CDPHE, HCP
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., Director of Audiology	Marion Downs Hearing Center

Karen Robinson, CPM, RM, President	Colorado Midwives Association
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Goal 1: By August 31, 2010, increase from 30% to 50% the number of infants who born at home receive a newborn hearing screen.

Objective 1.1: Provide OAE screening equipment for 3 midwives or local public health offices to offer newborn hearing screens and/or rescreens to families who birth at home.

ACTIVITY	PERSON RESPONSIBLE	COMPLETION DATE	EVALUATION
1. Develop and disseminate mini-grant opportunities for midwives	Vickie Thomson Karen Robinson	Oct. 2009	Document completed
2. Identify the equipment distribution sites	Vickie Thomson Karen Robinson	Nov. 2009	Letters of agreement sent and returned to state
3. Train midwives on newborn hearing screening equipment and follow-up protocols.	Vickie Thomson Audiology Regional Coordinators	Jan. 2010	Document training
4. Train midwives to enter hearing screening results into the CHIRP database or on the electronic birth certificate.	Emily Fields Audiology Regional Coordinators	Jan. 2010	Document training and monitor screening improvement monthly in CHIRP database
5. Connect the local midwives in the EHDI Regional Teams to assist with the dissemination and ongoing updates to the Roadmap for Families.	Emily Fields Audiology Regional Coordinators	Jan. 2010	Document training and monitor screening improvement monthly in CHIRP database
Provide in-service trainings to the Colorado Midwife Association on the importance of screening and follow-up.	Vickie Thomson Emily Fields Janet DesGeorges Karen Robinson	TBA	Documentation of training and evaluation

Goal 2: By August 31, 2010, increase from 75% to 80% the number of infants who failed a newborn hearing screen receive a rescreen or diagnostic evaluation.

Objective 2.1: Enhance training and resources for hospital staff, providers and parents.

ACTIVITY	PERSON RESPONSIBLE	COMPLETION DATE	EVALUATION
1. Collaborate with Hands & Voices National to develop a customized "Loss and Found" DVD.	Janet DesGeorges	Jan 2010	DVD completed
2. Implement a training program for hospital staff on training curriculum and Loss & Found DVD	Vickie Thomson Emily Fields EHDI Regional Teams	March 2010	Documentation of training
3. Update, disseminate, and train hospital screening staff on the Colorado Infant Hearing Guidelines	CO Infant Hearing Advisory EHDI Regional Teams	March 2010	Guidelines available on website; documentation of training to hospitals; improved loss to f/u
4. Develop the Roadmap for Families as an interactive tool	Janet DesGeorges	March 2010	Roadmap available on Hands & Voices website
5. Create a web based education tool for physicians and providers	CO Infant Hearing Advisory	August 2010	Tool available on CO EHDI website
6. Develop a webinar for the Nurse Family Partnership Program	Vickie Thomson Emily Fields Janet DesGeorges	Dec 2010	Documentation of webinar presentation and participant evaluation

Objective 2.2: Increase the number of pediatric audiology clinics from 13 to 16 to increase the capacity and accessibility statewide for families whose infants are deaf and hard of hearing.

ACTIVITY	PERSON RESPONSIBLE	COMPLETION DATE	EVALUATION
1. Purchase diagnostic equipment	Vickie Thomson	Oct. 2009	Increased number of infants being served in Southern CO
2. Establish a telemedicine network with 3 practices	Sandra Gabbard Vickie Thomson	Nov. 2009	Increased number of infants who are receiving comprehensive evaluations locally.
3. Develop and implement an audiology workshop with NCHAM	Sandra Gabbard	August 2010	Documentation of workshop & evaluation; increased number of infants receiving appropriate diagnostic evaluations

Goal 3: By August 31, 2010 increase the number of infants who receive early intervention services by six months of age from 65% to 95%.

Objective 3.1: Increase the use of telemedicine for early intervention providers from one to six families.

ACTIVITY	PERSON RESPONSIBLE	COMPLETION DATE	EVALUATION
1. Identify the location appropriate for telemedicine equipment	Jennie Germano Sandra Gabbard	Oct. 2009	Justification completed and submitted to state EHDI coordinator.
2. Provide training to CO-Hear Coordinators , Parent facilitators, audiologists	Jennie Germano Sandra Gabbard	Feb 2010	Training documented
3. Develop and implement a plan to document the use of telemedicine in the CHIRP database	Emily Fields Jennie Germano	Feb 2010	CHIRP analysis of telemedicine usage
4. Develop, disseminate and analyze a survey to determine parent satisfaction with telemedicine early intervention services.	Jennie Germano Sandra Gabbard Janet DesGeorges EPE Unit	June 2010	Survey completed and analyzed.
5. Provide access to a genetic counselor at the Marion Downs Hearing Center and via telemedicine.	Sandra Gabbard	Nov 2010	Documentation in CHIRP of genetic services received.

Objective 3.2: Increase the number of infants with unilateral hearing loss (UHL) who are documented by audiologists and receive early intervention services.

ACTIVITY	PERSON RESPONSIBLE	COMPLETION DATE	EVALUATION
1. Determine the baseline data from the 2008 CHIRP database	Vickie Thomson	Sept. 2009	CHIRP data report completed
2. Hire a UHL coordinator and develop a protocol	Vickie Thomson	Sept. 2009	Protocol developed and disseminated to providers.
3. Develop a tracking mechanism in CHIRP to monitor UHL documentation	Emily Fields Sandra Gabbard Jennie Germano	Nov 2009	CHIRP documentation of UHL referrals into audiology and early intervention
4. Develop a UHL webinar in collaboration with MDHC	Sandra Gabbard Jennie Germano	April 2009	Webinar presented and evaluation completed

Goal 4: By August 30, 2010, increase the parent support throughout the EHDI process beginning with screening through early intervention.

Objective 4.1: Increase from 43% to 70% the number of Spanish speaking families that return for follow-up rescreens or evaluations.

ACTIVITY	PERSON RESPONSIBLE	COMPLETION DATE	EVALUATION
1. Hire a parent Spanish speaking follow-up coordinator	Janet DesGeorges	Sept 2009	Documentation of increased f/u in CHIRP for families that speak Spanish
2. Develop a protocol for contacting families	Janet DesGeorges	Oct 2009	Documentation of protocol disseminated to hospitals and audiologists
3. Identify pediatric audiologists who either speak Spanish or have access to translators for families.	Vickie Thomson	Oct 2009	List of Spanish speaking audiologist is available on Hands & Voices website

Objective 4.2: Increase the use of parent support in multidisciplinary clinics.

ACTIVITY	PERSON RESPONSIBLE	COMPLETION DATE	EVALUATION
Increase the FTE of Janet DesGeorges to attend monthly multidisciplinary clinics	Sandra Gabbard	Sept 09	Documentation of Parent support in clinics
Create, disseminate and analyze a survey to measure family satisfaction with the multidisciplinary clinics	Janet DesGeorges EPE Unit	Mar 2010	Evaluation of survey

Objective 4.3: Increase parent and provider education statewide through webinars based on parent focused topics to reduce loss to follow-up and increase knowledge of critical next steps following diagnosis.

ACTIVITY	PERSON RESPONSIBLE	COMPLETION DATE	EVALUATION
1. Develop a training curriculum	Janet DesGeorges	Sept 09	Training Curriculum available on Hands & Voices website
2. Identify technology needed for interpreters (ASL and Spanish) services and captioning.	Janet DesGeorges	Oct 09	Documentation of technology identified and a plan for implementation.
3. Develop and implement webinars on parent topics	Janet DesGeorges	June 09	Webinar presentation documented and recorded
4. Develop, disseminate and analyze a participant evaluation survey	Janet DesGeorges EPE Unit	Dec 09	Analysis complete
5. Offer webinar series to Hands & Voices National and/or HRSA for national education to families and providers.	Janet DesGeorges	August 2010	Documentation of national dissemination plan including recommendations for improvement based on survey analysis.

RESOLUTION OF CHALLENGES

Colorado has many challenges in establishing a comprehensive EHDI system statewide. Geographically Colorado is a large state with frontier, rural, and urban areas. Many families are not returning for the follow-up outpatient screen. Analysis has shown that infants admitted to the NICU, born to Latino mothers, and mothers with lower education are less likely to receive the outpatient rescreen. The EHDI program has been working to identify hospital and local community resources that will increase the rescreen rates for this population. The development of the local EHDI teams has helped to build this infrastructure by identifying the needs of individual communities. The Roadmap for Families has been a welcomed addition and future data will be available to demonstrate the success of just in time resources for families at the time of a failed screen. The challenges are ensuring that local hospitals are disseminating the Roadmaps and will utilize the Loss and Found DVD.

As mentioned previously it is not reasonable to expect a local audiologist, located in a rural community, to be able to afford the expensive diagnostic equipment for providing infant assessments. Nor would the audiologist have a large enough population base to gain the expertise required adequately performing the assessments, interpreting the results, and providing the families with confidence in the results. Recently we have had two pediatric audiologists relocate to rural areas of the state. This funding will help to provide training and equipment. The challenge will be whether they can capture the population in a geographical area and prevent families from traveling longer distances. Education to medical homes on the availability of new pediatric audiology services will be required. Telemedicine will be used with this funding to provide training to audiologists and deliver early intervention services.

The Medical Home Initiative is an important aspect of the HCP program and recent legislation has made it important for the state of Colorado. Due to the geographical issues just stated “primary care” does mean a pediatrician provides that care. Colorado has federally qualified health centers, family practice physicians, and public health nurses who are providing ‘primary care’ for the majority of infants and children. The EHDI program at state and local levels must provide education on the importance of follow-up and develop protocols that make the coordination of services accessible, family friendly, and culturally responsible. This funding will help to the EHDI Regional Teams continue this important work through in-service training

and the development of the physician road map. The state can continue to look at opportunities to integrate data systems to create the true virtual medical home and patient profile. Discussions with key stakeholders regarding the integration of the immunization registry with newborn hearing and newborn metabolic screening are beginning to take place. These types of data improvement and integration projects 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 physician/nurse with coordinated care for ensuring timely follow-up.

Funding resources have always been an issue and major concern for Colorado. Colorado has developed a sustainable program through collaborative efforts between the HCP, CSDB, CDE, and individual hospitals. Small hospitals have difficulty finding funding for equipment and large hospitals have difficulty funding the FTE to monitor their newborn screening program. Continued support from the state EHDI staff and the Audiology Regional Coordinators will help hospitals to identify the most efficient technology for their population (e.g. a less expensive hand held OAE unit vs. an expensive OAE/AABR unit). The local EHDI teams can assist hospitals in defining follow-up protocols that make tracking and reporting more efficient for hospital staff. Funding for services is also an issue. Many areas of the state do not have primary care or specialty providers who will see families or children on Medicaid. New medical home legislation is an attempt to increase reimbursement for primary care physicians who are willing to see children on Medicaid. Part C is the payer of last resort for direct services, which most families need (early intervention, amplification). Part C coordinators provide resource and referral information which is typically performed by the CO-Hear Coordinator. All infants with a permanent hearing loss, regardless if the loss is only unilateral, are referred to a CO-Hear Coordinator for resource information. In several counties Part C reimburses the CO-Hear Coordinator for providing this service for children with bilateral or unilateral hearing.

Demographics and cultural diversity are changing dramatically in Colorado. The proportion of Spanish speaking families continues to grow. Most service providers (audiologists and early interventionists) do not speak Spanish. Most hospitals may have an interpreter but families report that often the interpreter was called away during a diagnostic evaluation for someone admitted to the emergency room. The regional EHDI teams will work with communities to identify resources. Ongoing training for state and local EHDI staff will help to

foster and understand the needs of different cultures and allow the system to be more culturally responsive.

This funding, if awarded, can not fully solve all the issues and challenges addressed but it can 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 Health Care Program for Children with Special Needs is located within the Preventive Services Division (PSD). PSD has created an Epidemiology, Planning, and Evaluation unit. This unit is rich with staff who have expertise in data analysis, evaluation, and planning. The goal is to develop an EHDI program that will implement the essential public health services from assurance to developing public health policy, 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 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.

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. Janet serves on the NICHQ faculty representing the parent perspective.

Sandra Gabbard is director of Audiology at the Marion Downs Hearing Center. She has over 25 years of pediatric experience. She also serves on the NICHQ faculty. Dr. Gabbard and Ms. DesGeorges will continue to share lessons learned from the current NICHQ project to enrich our program and foster new planning ideas.

Jennie Germano is director of Early Intervention Programs for Children who are Deaf and Hard of Hearing through the Colorado School for the Deaf and Blind. Her new vision has

created fulltime staff positions for the CO-Hear Coordinators who more recently were only on a contractual basis.

HCP 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.

ORGANIZATIONAL INFORMATION

The Colorado Department of Public Health and Environment's (CDPHE) section for Children and Youth with Special Health Care Needs (CYSHCN) believes that all families deserve the opportunity to promote the maximum potential of their children. The Health Care Program for Children with Special Needs (HCP) is the Title V, CYSHCN program for Colorado and is located within this section. HCP is responsible for building family driven, sustainable systems of health services and supports for all families of CYSHCN in Colorado. The HCP 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. Organizational charts are available in Attachment 1.

The Colorado Infant Hearing Program or EHDI program is within the CYSHCN unit. Legislation passed in 1997 requiring all birthing hospitals to offer a screening program and all midwives need to inform their patients how to locate a newborn hearing screening. Initially the legislation required 85% of the statewide population be screened before rules and regulation would be promulgated. In 2006 the legislature increased the screening rate to 95% to be consistent with national benchmarks set forth by the Joint Committee on Infant Hearing and the American Academy of Audiology. The legislation also requires the development of an advisory board. The Colorado Infant Hearing Advisory Committee is has a wealth of representation from parents, consumers, experts, and agencies that work to develop guidelines for provider and

address issues that create barriers for ensuring the outcome of early identification and intervention for the families and children this program is aimed to serve.

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