TABLE OF CONTENTS

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
CYSHCN – Children and Youth 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
OBRA – Omnibus Budget Reconciliation Act
Part C – Early Childhood Connection

INTRODUCTION

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), Health Care Program for Children with Special Needs (HCP) sponsored this effort in collaboration with 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.

Another study by Yoshinaga-Itano, et. al.,[2] compared the language development of 25 children (1 to 6 years of age) with congenital hearing loss that were born in hospitals providing newborn hearing screening, with 25 matched children with congenital hearing loss born in hospitals *not* providing newborn hearing screening. Results showed that the infants born in hospitals with newborn hearing screening had higher scores in expressive and receptive language ($p < 0.001$) and vocabulary production ($p < 0.001$) on standardized inventories; speech intelligibility ($p = 0.015$) from independent ratings; number of different simple consonants ($p < 0.01$) and consonant blends ($p = 0.026$) from phonological transcripts; and total number of intelligible words ($p < 0.01$) and number of different words produced ($p < 0.01$) from computer analysis of videotaped language samples. These findings were associated with early identification in hospitals with universal newborn hearing screening.

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 the best practice guidelines. The task forces currently meet as needed. A new task force called the Colorado EHDI Medical Home Collaborative is currently being 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. 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 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 HCP 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 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 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.

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 Fall, 2007.

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.

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. Beginning October 1, 2007 letters were to be sent to the primary care physician of record (as obtained on the second newborn metabolic screen) for infants who have failed or missed a screen or rescreen. This goal has been placed on hold until the State Laboratory, which is responsible for the newborn metabolic screen, can better integrate its data systems for more accurate data to interface with the EHDI CHIRP. The lab is considering populating its database with the electronic birth certificate, which will make matching names a much easier process through the NEST's deduplication efforts.

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 Assessment report, 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. 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 extends initiations 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 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, 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 (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 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 behind 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 does have 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, 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 (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.

Colorado's Deaf and Hard of Hearing Connections Program

The Deaf and Hard of Hearing Connections program is a collaborative effort supported by the Colorado Department of Education and the Colorado School for the Deaf and the Blind. The program was established in 1987. The goal of the Deaf and Hard of Hearing Connections is to create a program that consists of a diverse group of motivated people who enjoy working with children and adults. The program nurtures the belief that adult role models need to be open minded about personal philosophies and the individual communication style of each child. It is a team composed of adults who are deaf or hard of hearing who utilize a myriad of communication methods, to include American Sign Language or Spoken English. These individuals have been trained to provide and share information regarding their own hearing loss and personal experiences to students who are deaf or hard of hearing. They also meet with families to increase families' awareness of hearing loss. Adult role models are available to provide trainings and workshops statewide. These trainings and workshops include: a classroom utilizing a unit on deafness, service providers who support students in the mainstream, professionals who need information regarding hearing loss, and agencies servicing individuals who are deaf or hard-of hearing. Many of the families live in a rural area where there might not be peers who are deaf or hard of hearing. The program provides an opportunity for these families and children to have learning experiences with the role models.

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. 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 (Attachment 2).

Senate bill 07-130 was passed by the Colorado legislature this past spring. 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 2) 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 15 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 Letson[3] 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.

Although Colorado did not participate in the National Initiative for Children's Healthcare Quality (NICHQ) Newborn Hearing Screening Learning Collaborative, Janet DesGeorges, director of Colorado Families for Hands & Voices, served as the Parent Chair on the planning group faculty. The requested funding will provide 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 this funding will be 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; develop regional teams (Audiology Regional Coordinator, Parent Coordinator, and CO-Hear Coordinator) 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.

Colorado's legislation is an unfunded mandate. Opportunities are being discussed increase potential funding in the future. In the meantime 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 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) ability of the CO-Hear Coordinators to directly access the data management system for documenting intervention programming.

A comprehensive analysis was performed on the 2005 data to determine demographic and hospital factors that would be associated with obtaining a follow-up rescreen. The program is also concerned that the rescreen rate has dropped from 86% in 2004 to 80% in 2005. Colorado had 69,533 births and 68,478 of those births occurred in 56 birthing hospitals. Resident births that occurred at home, out of state, in transit, and in unknown facilities were excluded from the analysis for this project. There were 67,261 (98.22%) infants who were screened and 1,217(1.78%) infants who did not receive a screen. Additionally, 3,153 (4.7%) infants failed the initial inpatient screen and 622 (20%) of those infants did not receive a follow-up outpatient screen. Of the 2,531 infants who did receive the outpatient follow-up screen there were 143 infants who failed the outpatient follow-up screen and should have been referred to a pediatric audiologist. Fifty-one infants (35.7%) were confirmed with a permanent hearing loss, 10 infants (7%) passed an audiologic evaluation, and 82 (57%) did not have any documentation of follow-up. There were 115 infants identified with permanent hearing loss from this birth cohort and 59 (52.7%) of the infants who ‘missed’ the follow-up rescreen were confirmed with a hearing loss.

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. Further analysis of this birth cohort is being completed.

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. 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. 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' access to a Child's Health Profile, which contains information on immunization records as well as screening results for both newborn metabolic and newborn hearing.

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. A goal of this grant will be to request the Audiology Regional Coordinators assist the State EHDI team in creating a new, updated list of audiologists who can evaluate infants. Colorado has many rural and frontier communities. As a result the nearest audiologist, who can provide assessments on infants, may be several hundred miles away. This project will assist in providing funding that can create local follow-up protocols and potential needed resources to ensure that infants receive a comprehensive audiological evaluation from a qualified audiologist.

In 2005, Parent surveys were disseminated as part of Centers for Disease cooperative agreement. A pilot study using the drafted survey instruments was conducted on three groups of families in Colorado. The three groups of families surveyed include: 1) families with a newborn who passed their initial hearing screening; 2) families whose infants did not pass on their initial screening but subsequently passed on an outpatient re-screen or diagnostic evaluation; and 3) families with infants who are identified with permanent hearing loss. Surveys sent to each of these populations included items on the accessibility, timing, and efficiency of services delivered in each stage of the EHDI process. Also included were families' anxiety levels and overall ratings on satisfaction with services and with staff who deliver services in each stage of the EHDI process. The surveys contained questions about the satisfaction and anxiety for the initial screen, outpatient rescreen, the diagnostic assessment, and early intervention processes. Overall parents were generally satisfied with the EHDI processes. Parents were given the opportunity to share specific concerns such as scheduling the follow-up appointment, finding a qualified audiologist, finding transportation to an audiologist, and understanding the follow-up results from the initial screen. The survey also reported the importance of parent-to-parent support for families entering the system. To continue to address the needs of the families they serve for both English and Spanish speaking populations, Colorado Hands & Voices also disseminates parent satisfaction surveys annually. Survey results are used to enhance the EHDI program at every level to meet the needs of families.

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. In Attachment 6 a draft logic model has been developed for the reader to visualize how the program works. 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 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: To increase the percentage of infants who fail or miss the initial newborn hearing screening in receiving a follow-up outpatient rescreen by one month of age, diagnosis by 3 months, and early intervention by six months.

Objective 1.1: Develop a Regional EHDI team to provide training and support for each birthing hospital.

Activities:

1. Identify the Regional EHDI teams based on the existing Audiology Regional Coordinators, CO-Hear Coordinators, H&V Coordinators, and hospital coordinators.
2. Develop a protocol from inpatient screening to outpatient screening that includes scheduling the appointment before hospital discharge. The protocol should be in a flow chart format that

can be implemented into the parent and physician ‘road map’ for navigating through the EHDI system for that local community.

3. Provide training using the National Center for Hearing and Assessment (NCHAM) Screener Training Tools to provide the hospital screeners troubleshooting techniques, the importance of early identification of hearing loss, and the appropriate message for families when their infant fails the hearing screen. The Screening Training Tools will come with assessment exams that hospital coordinators can use to measure the knowledge gained by the screeners.
4. Regional EHDI teams will address concerns and increase the follow up from diagnosis to intervention by meeting with stakeholders and audiologists in each region. Stakeholders will include but not be limited to the Part C Coordinator, Deaf/Hard of Hearing Connections liaisons, local primary care physician, and HCP Regional Office Team leader.
5. Regional EDHI teams will meet with the NICU liaisons to ensure all infants are screened prior to hospital discharge.
6. The local EHDI team will identify resources for families if there are transportation or financial barriers in obtaining the recommended rescreens or evaluations. Resource information will be shared with providers and families.

Objective 1.2: Enhance the role of the parent coordinator in the screening, rescreening, and diagnostic follow-up systems.

Activities:

1. Develop a guide that will provide parents resource information and next steps for follow-up that are specific to the local community (in 14 geographic regions of the state) as an accompaniment to the statewide CO Resource Guide for Families, utilizing the NICHQ

model of the ‘Parent Road Map’ as a template. Create “Parent Road Map” from NICHQ template in both English and Spanish and update the Hands & Voices website.

2. Update the Hands & Voices website with ‘Just in Time’ learning for parents whose infants have failed the newborn hearing screen, outpatient rescreen, referral to audiologic assessment, and early intervention.
3. Develop inserts to accompany the Colorado Newborn Hearing Screening Brochure that will include parent resources and the parent perspective to encourage parent support if needed at the time of the screening process(es).
4. Create and disseminate ‘family stories’ about EHDI process, including information about medical home to share with families and professionals
5. Disseminate information about parent-to-parent contact information in follow up letters sent to families from the State Follow-up Coordinator when infants fail or miss the newborn hearing screen.

Objective 1.3: Enhance cultural responsiveness in local EHDI teams (Audiology Regional Coordinator, CO-Hear Coordinator, Parent Coordinator), hospitals, and providers for Spanish speaking families and families who use sign language.

Activities:

1. Partner with federal and state agencies to identify trainings on cultural competency for state and local EHDI teams targeting Spanish speaking families and Deaf culture.
2. Ensure every birthing hospital has access to interpreter services for all families, including those that use sign language.

3. Partner with Latino resources at the state and local levels to promote the importance of newborn hearing screening and follow-up. (CSDB Spanish Coordinator; El Grupo Vida; Spanish Parent Guide).
4. Utilize Parent Guides who are Spanish Speaking for follow-up to Spanish Speaking Families such as providing follow-up phone calls to schedule rescreening or diagnostic evaluations.
5. Increase resources about follow-up in Spanish on CO Hands & Voices Website.
6. Publish quarterly newsletters in Spanish (focus on loss to follow up and entry into early intervention).
7. Enhance the Deaf and Hard of Hearing Connection Program by working collaboratively with the Colorado Department of Education and the Colorado School for the Deaf and the Blind to provide role model visits as part of the routine part of the CO-Hear visits.

Objective 1.4: Increase the number of identified primary care physicians for children who fail or miss the newborn hearing screen at discharge, fail the outpatient rescreen, and are identified with permanent hearing loss.

Activities:

1. Ensure that every birthing hospital identifies the PCP on their monthly follow-up report for infants who fail or miss the newborn hearing screen.
2. Hospitals will develop a system to notify the PCP of the screening results.
3. Hospitals will develop an “alert” system to notify the PCP when an infant fails or misses the newborn hearing screen.
4. Regional EHDI Teams will work with the local HCP Regional Office to develop a protocol for families who do not have a PCP. The HCP Regional Office will provide care coordination to assist the family in obtaining a PCP and completion of Medicaid/CHIP+ forms if

appropriate. Systems building will include working with other agencies such as Part C and EPSDT.

5. Regional EHDI Teams will work with midwives to develop a screening report form to send results to the PCP and to the State EHDI Follow-up Coordinator.
6. The EHDI Medical Home Collaborative will develop Medical Home Follow-up letters to be sent to the PCP on next steps for follow-up when an infant fails the outpatient screen or is identified with a permanent hearing loss, which will include local resource information. The EHDI Follow-up Coordinator will send the Medical Home Follow-up letter to the PCP either electronically or by fax.
7. The state EHDI staff will work with the diagnostic audiologists who are submitting reports to assure they are also reporting to the PCP and providing recommendations for follow-up.
8. CSDB will develop a report that the CO-Hears will submit to the PCP after the initial home visit that will include recommendations for early intervention based on the parents desires.
9. The CO AAP Chapter Champion will work with the state and local EHDI teams to help identify local chapter champions who can provide education to their peers on follow-up and best practices. A local physician will provide insights into the physician road map that will be developed for each community.
10. Provide presentations at the state and local level about the EHDI systems and the importance of follow-up including appropriate and timely referrals to audiologists with pediatric expertise. These meeting should occur at hospital physician meetings, AAP and AAFP chapter conferences, and newsletters.

Objective 1.5: Identify audiologists who have the expertise and equipment to provide a comprehensive diagnostic assessment in infants below six months of age.

Activities:

1. The local EHDI teams will develop a list of audiologists who have the equipment and expertise to provide pediatric assessments, in the community or nearest community, where an infant should receive services and disseminate to local hospitals, providers, and medical homes.
2. The lists of audiologists will be published on the CDPHE and Hands & Voices website.

Objective 1.6: Improve access to early interventionists and audiologists who specialize in deafness and hearing loss statewide.

Activity.

1. Provide tele-health/conference meetings and trainings for families and providers in more remote regions of the state. Collaborate with University Hospital, Marion Downs, Colorado School for the Deaf and the Blind, and Colorado Department of Education to continue support and development of the services.

Goal 2: Increase parent support statewide for families who have children who are deaf or hard of hearing.

Objective 2.1. Offer support to families through a regionalized network of Parent Guides statewide.

Activities:

1. Develop strategies with the local EHDI Teams to ensure every family is given the opportunity to connect (via email, phone calls, or face-to-face visits) with a Parent Guide at the time of identification.
2. Develop strategies to at the state level to ensure every family who has a child with a unilateral hearing loss has the opportunity to connect (via email, phone calls, or face-to-face

visits) with the Unilateral Hearing Loss Parent Coordinator via email, phone, or face-to-face visits.

Objective 2.2. Offer information and provide access to families on all communication options.

Activities:

1. Utilize Hands & Voices Communication Considerations Series in all home visits with families and at trainings.
2. Train Hands &Voices Parent Guides to provide unbiased information.
3. Provide cross training with Parent Guides, CO-Hears and CO Deaf/HH Adult mentors on unbiased support.

Objective 2.3 Enhance the Parent Resource Guide(s).

Activities:

1. Update Resource guide bi-annually and publish or link to websites that includes additional information such as the medical home concepts, Communication Consideration Series,
2. Bridges to Transitions Packet from Part C to Part B, and AG Bells Early Start Campaign (Co Hands & Voices, CDPHE, Colorado School for the Deaf and Blind).
3. Update the Parent Funding Toolkit (co authored by CO Hands &Voices, CO AG Bell, CO Family Voices) with updated information about legislation efforts/accomplishments during 2007-08.

Objective 2.4. Formalize links and increase collaboration between parent, community, public health, and educational systems to build a sustainable EHDI system statewide.

Activities:

1. Implement, evaluate, and revise the CO CIHAC guidelines for parent leadership in EHDI systems.

2. Parent Guides will be participating members of all committees involved in systems building for EHDI systems including at state and local levels including the Interagency Coordinating Councils (ICC's) through Part C.
3. CO Hands & Voices will partner with other parent organizations (e.g. Colorado Family Voices, CO Alexander Graham Bell, CO Association for the Deaf) to build supportive EHDI Systems for all families regardless of choice of language method or culture.
4. Articles will be published in state professional newsletters (CSDB, Colorado Academy of Audiology, and CO Deaf News etc).
5. Provide parent perspectives at in-service and pre-service trainings to professionals and students in higher education settings.

Goal 3: Enhance the Integrated Data Management System for EHDI to ensure timely follow-up and accurate data.

Objective 3.1: Increase the use of the EHDI CHIRP with providers.

Activities:

1. Director of the Colorado Home Intervention Program will meet quarterly with EHDI coordinator and data management staff to ensure quality data collection and input.
2. Provide CHIRP access to hospital coordinators and audiologists for electronic transfer of data rather than paper reports starting with a pilot project of three hospitals (this is funded through CDC) to improve data integrity.
3. Investigate with CDPHE information technology (IT) staff the potential for Parent Guides to document visits that will interface with the EHDI CHIRP data system to demonstrate increased parent support using data.

4. Develop a plan to integrate common data fields between the CU and EHDI databases to eliminate duplication and the potential for error. Future plans will include sharing outcome data to meet federal guidelines for reporting.

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. 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
Dinah Beams, M.A., Lead CO-Hear Coordinator	CO School for the Deaf and Blind

Goal 1: To increase the percentage of infants who fail or miss the initial newborn hearing screening in receiving a follow-up outpatient rescreen by one month of age, diagnosis by 3 months, and early intervention by six months.

Objective 1.1: Develop a Regional EHDI team to provide training and support for each birthing hospital.

ACTIVITY	**PERSON RESPONSIBLE**	**TIME LINE** Completion Date	**EVALUATION**
1. Identify Regional EHDI Teams for every birth hospital.	Vickie Thomson Janet DesGeorges Jennie Germano	8/08	Documentation of teams posted on HCP EHDI website
2. Develop a follow-up protocol for the outpatient rescreen for each hospital	EHDI Teams	10/08	Completion of protocols and posted on the EHDI website.
3. Local EHDI teams will provide hospital staff training using the NCHAM Screener Training Tools	EHDI Teams Vickie Thomson	12/08	Hospital Coordinators have screeners complete trainer evaluation forms and report to State EHDI coordinator
4. Local EHDI teams will convene community forums to address follow-up issues/concerns	EHDI Teams	3/09	Using the NICHQ PSDA form identify areas that need improvement. Submit forms to state EHDI team.
5.Local EHDI teams will work with the Part C NICU Liaison to develop a protocol to ensure screening prior to hospital discharge	EHDI Teams NICU Liaisons Emily Fields	12/08	Improved screening rates in the NICU population as documented in the EHDI CHIRP system.
6. Local EHDI teams will identify resources for families who may have transportation and financial barriers.	EHDI Teams	3/09	Documented in local resource guides and/or road maps.

Objective 1.2: Enhance the role of the parent coordinator in the screening, rescreening, and diagnostic follow-up systems.

ACTIVITY	**PERSON RESPONSIBLE**	**TIME LINE** Completion Date	**EVALUATION**
1. Develop a parent 'road map' with local community resources in English and Spanish.	Janet DesGeorges Parent Guides	2/09	Road maps completed and on the CO Hands & Voices website
2. Update the Just in Time learning for parents	Janet DesGeorges Vickie Thomson Jennie Germano	8/08	Update EHDI and Hands & Voices website
3. Develop parent inserts for the Colorado Infant Hearing Brochure to encourage parent support at the time of screening	Janet DesGeorges Vickie Thomson Parent Guides	4/09	Inserts developed or potentially a new screening brochure.
4. Create family stories for training and education about the medical home concepts.	Janet DesGeorges Parent Guides	10/08	Provide stories to state and local EHDI teams for training at the local level.
5. Include local Parent Guide contact information with the letters sent to families from the EHDI Follow-up Coordinator .	Janet DesGeorges Emily Fields	10/08	Letters to families include local Parent Guide contact information.

Objective 1.3: Enhance cultural responsiveness in local EHDI teams (Audiology Regional Coordinator, CO-Hear Coordinator, Parent Coordinator), hospitals, and providers for Spanish speaking families and families who use sign language.

ACTIVITY	**PERSON RESPONSIBLE**	**TIME LINE** Completion Date	**EVALUATION**
1. Identify trainings and workshops on culture competency that target Spanish speaking families and Deaf culture.	Vickie Thomson Janet DesGeorges Jennie Germano EHDI teams	6/08	Documentation of attendance at trainings.
2. Identify interpreter services to ensure every hospital has interpreters for families including those that use sign language	EHDI teams	12/08	Define the interpreter resources in the development of the hospitals protocols and educate nursery and physician staff about interpreter resources.
3. Partner with other Spanish resources and agencies to enhance awareness of EHDI systems in the Latino communities statewide.	Janet DesGeorges Jennie Germano	12/08	Identify resources and utilize the NICHQ PSDA tool to develop a plan for implementation.
4. Utilize a Spanish speaking Parent Guide to make phone calls with the EHDI Follow-up Coordinator.	Emily Fields Janet DesGeorges	3/09	Increased percentage of Latino infants who received audiological assessments as document in the EHDI CHIRP database.
5. Increase resources for follow-up in Spanish on the Hands & Voices website.	Janet DesGeorges	Ongoing	Documentation of resources on the Hands & Voices website.
6. Publish quarterly newsletters in Spanish that focus on medical home and follow-up.	Janet DesGeorges	Ongoing	Newsletters published and available on the Hands & Voices website.
7. Offer Deaf and Hard of Hearing role models at regular intervals during the first year of identification.	Janet DesGeorges Jennie Germano Dinah Beams	12/08	Develop and disseminate a protocol for introducing the role models during the CO-Hear visits.

Objective 1.4: Increase the number of identified primary care physicians for children who fail or miss the newborn hearing screen at discharge, fail the outpatient rescreen, and are identified with permanent hearing loss.

ACTIVITY	**PERSON RESPONSIBLE**	**TIME LINE** Completion Date	**EVALUATION**
1. Develop a protocol with every hospital to document the PCP/medical home the Monthly Follow-up Reports.	Emily Fields Hospital Coordinator	12/08	PCP/medical home name 80% of the infants who failed or missed a screen.
2. Develop a system to notify the PCP/medical home of the screening results.	Emily Fields Hospital Coordinator	12/08	Documented on the hospital follow-up protocol.
3. Hospitals will develop an alert system for the PCP when an infant fails the inpatient or outpatient newborn screen.	EHDI Teams Local PCP		
4. Develop a system to link families to local HCP Regional Offices for care coordination if a family does not a PCP and/or insurance.	EHDI Teams HCP Regional Office	12/08	Policy and procedure developed between by HCP that describes appropriate agencies and individuals responsible for care and case management.
5. Develop a report form that midwives can use to send screening results to PCP and state	EHDI Teams Midwives	3/09	Reports received by the State Follow-up Coordinator resulting in an increase in the number of homebirths being screened and documented in the EHDI CHIRP database
6. Letters will be sent to the PCP on next steps when an infant fails the screening (inpatient or outpatient).	Vickie Thomson Emily Fields	4/09	Documentation of letter sent on EHDI CHIRP database
7. Work with audiology providers to ensure they are submitting reports to PCP's regarding diagnostic results.	Vickie Thomson Audiology Regional Coordinators	4/09	Documentation of meeting with local audiology providers.
8. Develop a report the CO-Hears will send to the PCP.	Dinah Beams CO-Hear Coordinators	4/09	Documentation of letters sent by the CO-Hears on the EHDI CHIRP Database.
9. Provide presentations to physicians at the local and state levels	Vickie Thomson Jennie Germano Janet DesGeorges EHDI Teams	Ongoing	Documentation of presentations

Objective 1.5: Identify audiologists who have the expertise and equipment to provide a comprehensive diagnostic assessment in infants below six months of age.

ACTIVITY	**PERSON RESPONSIBLE**	**TIME LINE** Completion Date	**EVALUATION**
1. EHDI Teams will identify audiologists with pediatric expertise.	EHDI Teams	7/08	Lists created and sent to state EHDI program, local hospitals, physicians, providers
2. Local resources made available on websites and local parent road maps.	Vickie Thomson Janet DesGeorges	9/08	Documented on website and road maps.
3. Investigate the potential for telehealth between urban and rural areas.	Vickie Thomson	Ongoing	Document available resources.

Objective 1.6: Improve access to early interventionists and audiologists who specialize in deafness and hearing loss statewide.

ACTIVITY	**PERSON RESPONSIBLE**	**TIME LINE** Completion Date	**EVALUATION**
1. Investigate opportunities for telehealth between the rural and urban audiologists and early interventionists.	Jennie Germano Vickie Thomson	12/08	Documentation of a plan to implement telehealth in pilot areas of the state.

Goal 2: Increase parent support statewide for families who have children who are deaf or hard of hearing.

Objective 2.1. Offer support to families through a regionalized network of parent advocates statewide.

ACTIVITY	**PERSON RESPONSIBLE**	**TIME LINE** Completion Date	**EVALUATION**
1. Develop strategies to ensure parents are offered the support of a Parent Guide at the time of identification.	EHDI Teams Janet DesGeorges Dinah Beams	12/08	Using the NICHQ PSDA form document strategies at the local level. Submit forms to the state EHDI program.
2.Develop strategies to ensure parents are offered the support of a Parent Guide at the time of identification for children with unilateral hearing loss.	Janet DesGeorges Dinah Beams UHL Parent Guide	3/09	Documentation of protocol added to the Colorado Infant Hearing Guidelines.

Objective 2.2. Offer information and provide access to families on all communication options.

ACTIVITY	**PERSON RESPONSIBLE**	**TIME LINE** Completion Date	**EVALUATION**
1. Utilize the Communication Series with home visits	Janet DesGeorges	3/09	Documentation in Parent Guide reports to Hands & Voices
2. Provide training to Parent Guides on how to deliver unbiased information.	Janet DesGeorges Dinah Beams	3/09	Documentation of training.
3. Cross train Parent Guides, CO-Hear Coordinators, and Deaf mentors on how to deliver unbiased information	Janet DesGeorges Dinah Beams Jennie Germano	3/09	Documentation of training.

Objective 2.3 Enhance the Parent Resource Guide(s).

ACTIVITY	**PERSON RESPONSIBLE**	**TIME LINE** Completion Date	**EVALUATION**
1. Update the Resource Guide bi-annually	Janet DesGeorges	11/09	Completion of revisions on websites.
2. Update the Parent Funding Toolkit	Janet DesGeorge	11/09	Completion of revision on websites.

Objective 2.4. Formalize links and increase collaboration between parent, community, public health, and educational systems to build a sustainable EHDI system statewide

ACTIVITY	**PERSON RESPONSIBLE**	**TIME LINE** Completion Date	**EVALUATION**
1. Revise and implement the parent leadership section of the CIHAC Guidelines.	Janet DesGeorges	4/09	Guidelines revised and on the EHDI and Hands & Voices website.
2. Ensure Parent Guides are participating members of systems building committees at state and local levels.	Parent Guides Janet DesGeorges	4/09	Documentation of Parent Guide membership on committee rosters. Attendance of Parent Guides through reports to Hands & Voices.
3. Partner with other parent organizations.	Janet DesGeorges	12/08	Documentation of meeting minutes with concerns and outcomes.
4. Publish parent perspective articles in local organization newsletters.	Janet DesGeorges	Ongoing	Copies of published articles.
5. Provide parent perspective trainings.	Janet DesGeorges	Ongoing	Documentation of trainings.

Goal 3: Enhance the Integrated Data Management System for EHDI to ensure timely follow-up and accurate data.

ACTIVITY	**PERSON RESPONSIBLE**	**TIME LINE** Completion Date	**EVALUATION**
1. Meet quarterly to review data being entered into the EHDI CHIRP database by the CO-Hears	Jennie Germano Emily Fields	Ongoing	Data matches between CSDB and HCP
2. Implement CHIRP access for audiology and hospital providers	Emily Fields	4/08	Elimination of paper reports and data directly entered into EHDI CHIRP
3. Investigate the feasibility of an interface between Hands & Voices and EHDI CHIRP for data entry.	Emily Fields Jennie Germano	10/08	Plan developed with CDPHE IT and Hands & Voices for implementation.
4. Investigate the feasibility of interfacing common data fields between CU and EHDI CHIRP	Vickie Thomson	12/08	Plan developed with CDPHE IT and CU for implementation.

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 must identify hospital and local community resources that will increase the rescreen rates for this population. The development of the local EHDI teams will undoubtedly help to build this infrastructure by identifying the needs of individual communities. In addition the EHDI data system can provide each community with the demographic data needed to focus on a specific population within a community. The EHDI Follow-up Coordinator and the data system can also support protocols. For example if a small birthing hospital transfers an infant to a hospital with a Level III NICU, the Follow-up Coordinator can make those changes in the database. The Level III hospital coordinator will then receive notification. The NICU will be responsible for ensuring the screen is completed and then this information, with the screening results, can be sent back to the birthing hospital electronically.

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 to adequately perform the assessments, interpret the results, and provide the families with confidence in the results. Consequently we need to first identify who the audiologists are in the state that can perform infant evaluations and where they are located. For many families this will still require a significant amount of time and money in travel expenses. Tele-health may be one viable solution that will be investigated in the grant. Early interventionists with an expertise in deafness and hearing loss who can provide unbiased information have also been a challenge. Currently several of the CO-Hear Coordinators cover a very large area of the state. It is challenging for them to provide home visits when it takes over four hours to reach a family. Tele-health has been used in the Cochlear Implant mentor program at the Colorado Department of Education through the Marion Downs Hearing Center. This option will be investigated for the CO-Hear Coordinators as well.

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 create the local EHDI teams who can begin 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. For example one hospital recently had a 30 page monthly report to complete. When the EHDI Follow-up Coordinator reviewed their report she discovered that many of the screening results were not being reported electronically on the birth certificate. She met with the hospital coordinator and the electronic birth certificate clerk and found that the clerk was submitting the EBC before the screen was complete. The EBC clerk was reeducated on the submission of the two-part EBC and now the results are being submitted electronically decreasing the coordinators report to 2 pages. These type of efficiencies save both hospital and state staff in data entry.

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. Currently Medicaid does cover hearing aids for children but third party insurance payers do not. Families and professionals are constantly spending time either fund raising or writing grants to purchase amplification for children. Hands & Voices is pursing legislation to change this but until then families must rely on the hearing aid loaner bank and seek out resources to purchase hearing aids.

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 hearing but unilateral hearing loss is not an eligible disability for Part C. Those children with a bilateral hearing loss automatically receive early intervention services and this is often funded by CDSB through the Colorado Home Intervention Program. Discussions are taking place at the state level to address unilateral and funding issues.

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 EHDI program will more actively collaborate with the Latino organizations that can assist us in providing information about the importance of follow-up. Families, who use sign language, report they have requested an interpreter be present for an appointment, only to arrive and arrangements were not made. The EHDI coordinator is appointed to the Colorado Commission for the Deaf and Hard of Hearing. The issue of hospitals and providers meeting the Americans with Disabilities Act requirements for people who are deaf and hard of hearing is a statewide concern. The local 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 has an expertise in data analysis, evaluation, and planning. Mathew Christensen, Ph.D. has been working with the EHDI Coordinator, Vickie Thomson, to analyze the infant demographic data and hospital data. 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.

Jennie Germano and Dinah Beams work for 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. Dinah Beams has been a lead CO-Hear Coordinator for 10 years. She has worked in the field of early intervention for children who are deaf and hard of hearing her entire career.

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.

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.

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. Yoshinaga-Itano C, Coulter D, Thomson V. The Colorado newborn Hearing Screening Project: effects on speech and language development for children with hearing loss. *Journal of Perinatology.* 2000; 20;S132-S137.
3. Christensen, M., Thomson, V., Letson, G.W. (2007). Evaluating universal newborn hearing screening in Colorado: From population determinants to system-improvement actions. In review.