PROJECT NARRATIVE

1.0 Purpose of the Project

1.1 Describe the problem with supporting evidence that clearly reflects the magnitude of the problem

During the past five years, the development of Colorado's universal newborn hearing screening system has benefited from the support provided by MCHB funding. Our most recent statistics, for calendar year 2003, indicate a birthing census of 69,765 live births. Of the 56 birthing hospitals in the state, 84% screened 95% or more of their births and 16% screened 90% or more of their births. Added together, 97% of all newborns received a hearing screen before hospital discharge. The referral rate for children receiving a newborn hearing screening was appropriate at 3.5%. Four percent of the births missed the newborn hearing screen and only .2% refused the screening. Colorado is satisfied with the screening rate. However, an analysis of the populations not receiving a hearing screen fit nicely into two categories; children born out-of-state and children born at home. Specifically, 1% of children in the state are birthed at home an only 13.5% of these children received a newborn hearing screen. It is the responsibility of the EHDI system to aggressively offer hearing screening to these populations.

Furthermore, 74% of the children with hearing loss had their hearing loss identified before three months of age, with the average age of diagnosis occurring at 2 months of age. And, 66% of children identified with hearing loss started early intervention by six months of age. These statistics illustrate the success of Colorado's follow-up system, a dynamic system which continues to evolve. But, an analysis of these statistics targets specific areas for more improvement.

First, while only 15% of the children who referred on the newborn screen did not return for a follow-up screening or an audiologic evaluation, it is important to identify and ameliorate the causes for this 15% of the population who are at risk for hearing loss. Second, twenty-four percent of the children diagnosed with hearing loss receive this diagnosis after 4 months. This too needs to be improved. Third, Colorado is interested in identifying the reasons that 34% of the children started early intervention after six months of age. Fourth, we have evidence that only 9% of the children with hearing loss have their medical home identified in their data record. Fifth, while all families who had a child identified with hearing loss accepted a free subscription to the Hands & Voices quarterly publication, other services available through our statewide parent organization were under utilized. A home visit and/or phone call from a regional parent coordinator was made to approximately 12% of the families. Approximately 10% of the families attended a bi-yearly welcome picnic. And, only 22% attended educational workshops and regional conferences.

Colorado's EHDI system, under the guidance of the Colorado Infant Hearing Advisory Committee (CIHAC), strives to obtain these goals: (1) to improve follow-up when children refer on a newborn hearing screen; (2) to give all children, including those birthed at home or in other states, access to a hearing screen; (3) to have a greater percentage of children with hearing loss diagnosed by 4 months of age; (4) for more children to enter early intervention by 6 months of age; (5) to discover ways to identify the child's medical home early and to input this information into the the statewide data tracking system; (6) and to encourage more families to receive support from other parents.

1.2 Provide rationale and evidence supporting the proposed intervention/demonstration

It is well-accepted that newborn hearing screening is effective only when a system is in place that assures timely follow-up. Follow-up assures effective transition from one part of the system to another and includes these transition steps: (1) referral from initial screening to re-screen or audiologic evaluation; (2) referral from a positive re-screening to an audiologic evaluation; (3) identification of the child's medical home; (4) referral from the audiologist diagnosing the hearing loss to the early intervention system; (5) multiple opportunities to link parents and other caregivers with other parents. These goals are supported by the Joint Committee on Infant Hearing (JCIH), the American Academy of Pediatrics (AAP), the American Academy of Audiology (AAA), the American Speech/Language/Hearing Association (ASHA), the Educational Audiology Association (EAA), and other national organizations and their state affiliates.

Since 1993, when newborn hearing screening was initiated on a voluntary basis, Colorado has made steady progress assuring follow-up during all stages of the EHDI system. Our screening rates have been within an acceptable rate of 4% since the inception of the program. We have a higher per capita of clinical audiologists than most states and a statewide network of educational audiologists who are in every school district in the State. The state's public early intervention program, The Colorado Home Intervention Program (CHIP), has thrived since its inception in 1969 and continues to have more funding and a more stable infrastructure since moving to the Colorado School for the Deaf and the Blind (CSDB) in 2001. Parent-to-parent support and leadership is provided by two well-established parent organizations; Colorado's AG Bell Association for the Deaf and Colorado Families for Hands & Voices.

There are aspects of the system that need improvement and these issues exist in each part of the system. Screening needs to be accessible to children born at home or in hospitals out of state. In addition, some hospitals have unusually low refer rates which suggests the need for additional training and/or monitoring of those hospital screening programs. Referral for a rescreen or audiologic evaluation needs to be conducted on every child that fails the initial screen. The medical home needs to be identified early so the child's primary care physician can be an active member of team. Colorado's growing medical home initiative believes that coordination of care is an essential activity to assure communication and planning amongst team members, including family, primary health care practitioners, specialists, community programs and insurance plans. For many years, the diagnosing audiologist has referred the family to one of ten Regional Colorado Hearing Resource (CO-Hear) Coordinators. These CO-Hear Coordinators are experts in hearing loss, the development of infants and toddlers, family-centered care, and are knowledgeable about the services in their respective regions. They meet the family, in the family's home, shortly after the diagnosis is made to provide specific information about hearing loss, to explain communication approaches and early intervention program options, and to identify potential funding sources for amplification and early intervention. In addition, the CO-Hear Coordinator contacts local agencies such as Early Childhood Connections (Part C), Community Centered Boards, the local health department, and Child Find to ensure coordination of all necessary services for the child. However, the increased number of children identified with hearing loss is taxing the CO-Hear system. At least one more CO-Hear Coordinator should be hired and all CO-Hear Coordinators need to be in contact with the child's

medical home. Concerning access to parent-to-parent support, research (Turnbull & Jackson, 2004) has reported that everyone in a family is affected by a child's disability. Since more than 95% of the children in Colorado's program are born to hearing parents, the family must learn novel ways to communication with their child. Child outcomes are heavily influenced by everyone's willingness to employ these specific communication strategies. Also, access to deaf and hard of hearing role models is gaining more attention as this, too, has been cited as an effective way to teach parents about the impact of hearing loss. Indeed, Turnbull & Jackson (2004) report that those parents who have a lot of contact with adults who are deaf bond with their children better. Lastly, our data tracking and surveillance system has been supported by both Level I and Level II grants from the Centers for Disease Control and is a state-of-the-art program. This system has benefited from four years of funding and is receiving funding at this level for only one more year. While permanent staff have been hired by the Colorado Department of Public Health and Environment (CDPHE) to sustain the data tracking and surveillance system after the end of the current grant, there will be a need to assure a smooth transition.

Colorado currently has funding from many agencies to actively support its EHDI system. As existing committees and task forces continue to identify elements of the system that need improvement, there is much benefit from additional funding to implement the specific activities to ameliorate the problems identified here. In this way, Colorado will continue to refine, enhance and sustain its system to meet state and federal goals.

1.3 Identify anticipated benefits in terms of the program's purpose and goals

This grant will provide Colorado with additional funds to increase its capacity to provide appropriate and timely follow-up for those infants for whom further assessment and/or early intervention are appropriate. Screening will be conducted on the small percentage of children who are currently missed (e.g., home births, out-of-state births). Opportunities to perform a hearing screen will be offered in local school districts by educational audiologists, by the nurses in regional public health offices, and by hospital screeners. Continuing and new screening efforts will also be implemented to include identification of high risk factors such as CMV and ongoing screening in Head Start programs through Project ECHO, a program operating as part of the National Center for Hearing Assessment and Management (NCHAM). And, because there is a large turn-over in staff providing the hearing screen in the hospital nurseries, ongoing education must be provided to the screeners so they are familiar with the resources available for a re-screen, resources that are available for children diagnosed with hearing loss, and how to deliver this information so that parents see the importance of follow-up. In addition, because turn-over among the clerks reporting screening data on the electronic birth certificate is also high, ongoing training must be provided to these hospital personnel.

Colorado anticipates an increase in the number of children who return for follow-up when s/he fails an initial screen or a re-screen. This will result from letters sent from the CDPHE to families and to the child's medical home. The Clinical Health Information Record for Patients (CHIRP), the state's data tracking system, can identify a child's medical home. Activities in this grant will integrate with the current medical home initiative adding a specific focus on children with hearing loss. Efforts will be made to increase the identification of the child's medical home in their patient record at CDPHE, Regional CO-Hear Coordinators will connect with the child's medical home, and Hands &

Voices will support parent activities to increase physician awareness about the implications of hearing loss for a very young child. In addition, education and training will be provided to hospital screeners who exhibit a high rate of turn over.

Appropriate diagnostic assessment will be conducted by audiologists with pediatric experience and expertise and amplification will be available and fit by the time a child is three and four months of age, respectively. To accomplish this, consultation will be provided to audiologists to assure they implement best practices as defined in the *Guidelines for Guidelines for Infant Hearing Screening, Audiologic Assessment, and Early Intervention* (2003). New procedures that have been recently developed for evaluating and monitoring children with unilateral hearing loss (UHL) will be promoted. The newly established hearing aid loaner bank, housed at the Colorado School for the Deaf and the Blind (CSDB) will be well-stocked with a variety of makes and models of hearing aids and accessible to all audiologists statewide. And, the feasibility of creating regional centers of excellence to support appropriate services in rural areas of the state will be explored.

A comprehensive, seamless system for families to access early intervention by six months of age will be available with parent-to-parent supports and access to deaf or hard of hearing consumers. The early intervention system, including service coordination and direct services, will be enhanced through training of early interventionists, coordination with other state and federal programs (e.g., Part C, CSDB, Community Centered Boards, not-for-profit organizations, etc), and access to genetic testing and genetic counseling. Demographics for the state indicate a rapid increase in the number of families who speak a language other than English as their primary language at home and the ensuing cost of translation services to support early intervention for these families has tripled from 2003 to 2004. Services must be culturally-sensitive and funding to support training of bilingual interventionists and/or translators for mono-lingual interventionists must be provided. This grant will support ongoing efforts and add to other funding that are organizing the provision of services to children with UHL. The plan is to provide consultative services to all children with UHL and direct services to those experiencing documented delays in communication and/or language. Another challenging population are those children with additional disabilities in addition to their hearing loss. Early interventionists are asking for training and mentoring from the CO-Hear Coordinators to become more comfortable serving these children and their families. Colorado depends on evidence-based outcomes to drive its early intervention programs. All families are asked to use the FAMILY Assessment to monitor outcomes of the early intervention. This assessment is a naturalistic evaluation process that was developed by program staff more than 15 years ago. This multi-disciplinary assessment process is comprised of a videotaped interaction between the parent and child along with a series of questionnaires completed by the parents. The information gleaned from the assessment is used to: set intervention goals for the child, select the appropriate techniques to achieve those goals. In addition, the aggregate data is used to identify program priorities and assure efficacy of the early intervention program.

Making parent-to-parent connections is the priority of Colorado Families for Hands and Voices. Hands & Voices is a parent driven, non-profit organization dedicated to providing unbiased support to families with children who are deaf or hard of hearing. It provides information and support activities concerning children who are deaf and hard of hearing to parents and

professionals that may include outreach events, educational seminars, parent to parent networking, and a newsletter. Hands & Voices strives to connect families with resources and information to make informed decisions regarding hearing loss. Parent Regional Coordinators (PRC) cover eight regions of the state. Funding comes from several public agencies and many grants. Hands & Voices will support families through their network of PRCs, funding one PRC who is Spanish-speaking and able to talk with and translate written materials for families who speak only Spanish. Hands & Voices, at the state and regional levels, participates in all aspects of the EHDI system, creating awareness, offering education to stakeholders (e.g., PCPs, audiologists, early interventionists) and providing leadership for families. The initiative to provide information and support to families of children with UHL is supported by a PRC who focuses only on the needs of this population.

Colorado's data tracking and surveillance system permits the State to monitor the delivery of services to infants and toddlers who need them. This system needs to plan for its ongoing needs as the federal funding for this project from CDC will be ending within one year.

2.0 Needs Assessment

2.1 Activities already initiated and/or completed to determine the need for the proposed activities

Screening: The CIHAC, and the task forces for screening, assessment and early intervention that report to the CIHAC, have effectively guided the development of the newborn hearing screening system in Colorado. Colorado effectively screened 97% of the live births in Colorado, out of a total of 69,765 live births, in 2003. Hospitals select their own technology, with some hospitals using AABR, some using OAE, and others using a combination of these two technologies. Our statewide referral rate from the initial screen is 3.4%, an acceptable referral rate according to national guidelines. Only those born at home or out-of-state are yet to be captured by the screening program.

Follow-up to Failed Screen: While 85% of the children who fail the initial screen have documented follow-up, our tracking system indicates some audiologists are not sending all of the required information on these children to the Health Department to be entered into the tracking system. This needs to be improved and can be with the consultation and technical assistance provided by the statewide network of Audiology Regional Coordinators (ARC). The CDPHE funds ?? ARCs at a cost of ~$35,000 annually.

Medical Home: While physicians are supported by several state initiatives to provide comprehensive services in a compassionate medical home, the state tracking system currently has medical home information for only 9% of these children. Physicians could benefit from increased awareness about the early intervention opportunities for children with hearing loss. This can be provided by staff in regional public health offices, the CO-Hear Coordinators, and the early interventionists providing ongoing direct services. Physicians also need to become aware of the impact of UHL on infants and children. This can be accomplished through educational materials and reports from audiologists and early interventionists.

Audiologic Assessment & Amplification: Audiologic assessment by clinical audiologists, with support from educational audiologists, is working well with 74% of children identified by 3 months. However, not all audiologists are using the full battery of diagnostic tests recommended by the CIHAC (see page ?? in the appendix). Training to audiologists, supported by funding from CDPHE, the Marion Downs Hearing Center (MDHC), the Colorado Department of Education, and manufacturers of diagnostic equipment, has improved the diagnostic skills of both clinical and educational audiologists. Investigation of the creation of centers of excellence in areas of the state without audiologists with pediatric experience will help address this need. The age at which children are fit with amplification needs to be younger. The most significant barrier to achieving this goal is the lack of funding for amplification. A new hearing aid loaner bank, housed at CSDB, was created in July, 2004. This has reduced the urgency that existed to identify funding sources for amplification. Funding from multiple agencies including CDPHE and CSDB has supplied the loaner bank with a variety of aids. Additional funding will assure there are a sufficient number of aids and an appropriate variety of aids. Pilot data from Colorado indicates that 14% of the children with UHL have either a progressive hearing loss or an unidentified bilateral hearing loss and 35% exhibit delays in communication and/or language. With this in mind, audiological assessment of children with UHL must be more frequent than current reports indicate and newly-identified service coordination, consultative, and direct services must be sustained.

Early Intervention: As of October, 2004, there are 226 children with bilateral hearing loss enrolled in early intervention and 45 children with UHL in early intervention programs. The average age at which children enter early intervention is five months of age. While there are a sufficient number of early interventionists in the State with expertise working with very young D/HH children, survey results (CHIP Parent Survey, 2003 and 2004) indicate they need additional training in the use of family-centered strategies. The FAMILY Assessment (Hafer & Stredler-Brown, 2003), is an appropriate evaluation measure to assess the progress made by individual children and to assure the early intervention program has appropriate outcomes. The total number of assessments completed during the 2003-04 school year indicates that 70% of the children receiving services from CHIP received the FAMILY Assessment. Those not participating in the assessment need to do so and the CO-Hear Coordinators are posed with this task. Approximately 40% of the children receiving early intervention from CHIP have an additional disability. Early interventionists are asking for technical assistance and training to provide appropriate methods to work with these children and their families.

Parent-to-Parent Information, Support, Leadership: Parent-to-parent support is offered to all families and 100% of the families enrolled in early intervention services are receiving the Hands & Voices Communicator, a newsletter created by parents, for parents. However, only a small percentage of families request a home visit and/or phone call from a regional parent coordinator (12%), attend welcome picnics (10%) or attend educational workshops & conferences (22%).

Data Tracking & Surveillance: and surveillance has made excellent progress during the past five years. Unmet needs include identification of amplification on the CHIRP database and the age at which amplification was fit. And, only 9% of children with hearing loss on this database have information identifying their medical home. The medical home initiative can receive support from this grant's activities to remedy this problem. And, in the final year of the CDC grant, integration of

other databases (e.g., Part C, CSDB, CU-Boulder) with the CHIRP system at CDPHE can be accomplished.

2.2 Determine unmet needs, barriers and specific problems to be overcome

There are several issues that the CIHAC has identified that address the unmet needs of the Colorado system.

Screening and Follow-up to Failed Screen: In order to screen the entire population, children birthed at home or out-of-state need to be screened. Data suggests that those hospitals that do not have an audiologist on site have lower follow-up rates; this problem needs to be rectified.

Medical Home: While there is a medical home initiative in the state, the newborn hearing system has not actively participated in this effort. Physicians can benefit by receiving more information about children with hearing loss from the child's CO-Hear Coordinator, from their early interventionist, and/or from the parents of children with hearing loss who are in their medical practice. In addition, the implications of UHL, both progression in 14% of the children and communication/language delays for 35% of the children, need to be share with physicians. Genetic counseling is now available in six regional clinics in the state. However, parents need to become aware of this opportunity for genetic counseling and the benefits it provides.

Audiologic Assessment: Some clinical audiologists, especially those in rural areas, often do not have sufficient training or experience diagnosing very young children to adequately assess these children and to fit them appropriately with amplification. And, based on pilot data collected on children with UHL, it is important for audiologists to test these children at frequent intervals. The state guidelines issued by the CIHAC recommend testing at 3 month intervals during the first 18 months of life. Audiologists in large metropolitan hospitals are providing culturally-sensitive practices by providing translation services to families who do not speak English. There is evidence to show that audiologists in other areas of the state may not be providing these same practices.

Amplification: Legislation requiring insurance companies to pay for amplification was vetoed by Colorado's Governor in 2002. In order to amplify children by four months of age, a hearing aid loaner bank was established. This loaner bank needs to have an adequate number of hearing aids and there needs to be sufficient administrative time to manage distribution of the aids.

Early Intervention: Based on an annual survey of early interventionists working with the Colorado Home Intervention Program (CHIP), 22%-42% of the early interventionists are not providing family-centered practices. Improvement in providing this type of intervention can be accomplished through statewide and regional trainings and through mentoring experiences provided by the Regional CO-Hear Coordinators. Seventy percent of the families use the FAMILY Assessment to objectively evaluate their child's skills. Aggregate data from this assessment identifies individual child needs as well as program needs. For instance, we have learned from this assessment data that the MLU (mean length of utterance) of parents talking/signing to their child needs to increase in order for the children to have an opportunity to develop age-appropriate MLUs. In order to deliver culturally-sensitive, early intervention

practices and parent-to-parent supports, these services must be provided in the family's primary language. The most common language, other than English, is Spanish. The Spring Institute provides translation services at a significant discount for families in early intervention. With the support of their grant funds, the Spring Institute offers CHIP > 42% discount for translation services. However, additional funds are needed to meet this growing need. In addition to being sensitive to families who speak a language other than English, audiologists and early interventionists need to be sensitive to the language and cultural needs of Deaf adults. There are currently very few families who are D/HH themselves with D/HH children who choose to receive early intervention services. Yet, many of these children demonstrate delays in communication and language when they enter school. More involvement of deaf and hard of hearing adults in the early intervention program is an effective way to promote services to these families. While it is estimated that 1 child in every 1000 births has UHL, only 38 children with UHL are currently registered in the early intervention system. This is less than 20% of the estimated number of children, under three years of age, with UHL in the state.

Parent-to-Parent Information, Support, Leadership: Information from parents, parent support, and parent leadership opportunities need to be available to all families statewide. The network of Parent Regional Coordinators (PRCs) needs to be monitored and expanded as needed. The role of parents as leaders can be formalized through links with and increased collaboration with community, public health, and educational systems.

Data Tracking & Surveillance: The integrity of CHIRP, the data tracking and surveillance system at CDPHE, can be improved by obtaining additional data from home births, children born out-of-state, and audiologists when they report their data. Specifically, additional data on the date of amplification fit needs to be entered into the database. CHIRP has the capability of integrating its data with other data systems for children in early intervention. It is feasible to reduce the amount of time CO-Hear Coordinators enter data by reducing the number of databases they population with their information. And, there are many problems that lead to poor reporting of the medical home in each child's tracking report. Physicians have not yet recognized the importance of having this information entered. And, audiologists and early interventionists have not yet made a concerted effort to collect and/or report this information to the statewide data reporting system.

2.3 Identify current successful strategies to meet identified needs

To date, the CIHAC and the task forces for screening, assessment, and early intervention have effectively sought and implemented solutions to identified needs. Each of these committees has representation from each state agency that has an investment and/or responsibility for children under three years of age with disabilities. This includes, in most cases, funding from community, state, regional, and national initiatives.

Screening: In order to screen the entire population, children birthed at home or out-of-state need to be screened. Relationships have been established with the Colorado Midwifery Association and this relationship has increased the number of children born at home who receive a newborn hearing screen to 13.5% of this population. Data suggests that those hospitals that do not have an audiologist on site have lower follow-up rates. To address this problem, the Regional

Audiology Regional Coordinator (ARCs) have been funded by CDPHE at ~$35,000/year to provide technical assistance to those hospitals who do not have an audiologist on site.

Follow-up to Failed Screen: There are many reasons Colorado's system currently supports an exceptionally good follow-up rate of 85%. Referral rates from the newborn screen are reasonable at 3.5%. Many hospitals have audiologists on staff to provide consultation and/or oversight to the newborn hearing screening process. ARCs provide technical assistance to those conducting hospital screens. And, the CDPHE has recently started sending letters to those families whose children failed the newborn hearing screen but have no record of follow-up.

Medical Home: To promote the medical home initiative for children with hearing loss, Dr. James Ledbetter, an employee of CDPHE and the leader of the medical home initiative has joined the CIHAC. The CIHAC has included the medical home in its current revision of the guidelines. Dr. Ledbetter has met with the coordinator for early intervention and discussions are underway to identify a system whereby the child's CO-Hear Coordinator sends information to each child's medical home when the child enters early intervention. Genetic counseling is now available through a grant housed at the CDPHE. This grant provides the services of a genetics counselor, at no charge to families, and can be accessed in six regional clinics throughout the state.

Audiologic Evaluation: To assure clinical audiologists, especially those in rural areas, have sufficient training and experience diagnosing very young children, training has been provided at state and regional workshops. These workshops have been sponsored by state funds, grant funds and the manufacturers of diagnostic equipment. To increase the audiologists' awareness about the significance of UHL, information has been presented at workshops and published in the CAA newsletter.

Amplification: The new CIHAC guidelines identify appropriate steps to fit amplification on very young children. In 2003, the need for a hearing aid loaner bank became critical. At that time, an ad hoc committee representing CDPHE, CDE, and CSDB met to look for funding to start this loaner bank. The results were spectacular with CDPHE and CSDB providing funding to open the loaner bank with 70 hearing aids during the first year. CSDB provides in-kind support for the operation of the loaner bank.

Early Intervention: (1) To enhance provision of family-centered strategies by early interventionists, statewide and regional trainings have been provided at statewide, regional, and multi-state conferences. In addition, one-on-one mentoring has been provided by the ten Regional CO-Hear Coordinators. (2) At it's lowest point, only 20% of the children receiving early intervention services from CHIP were participating in the FAMILY Assessment (Hafer & Stredler-Brown, 2003), the evaluation protocol used to guide individual programming and to provide program accountability. After use of this evaluation protocol became a "requirement" of the program, participation steadily increased. In addition, the Regional CO-Hear Coordinators provide technical assistance to the early interventionists to help them use these evidence-based practices in their work with families. In 2003, 70% of the children completed a FAMILY Assessment. (3) In SY 2003-04, the state coordinator for early intervention with D/HH children worked with the State Child Find Coordinator in the Colorado Department of Education to

discuss the use of the FAMILY Assessment to meet Child Find's requirement to provide a multi-disciplinary assessment to all children receiving Part C services. As a result, presentations on the FAMILY Assessment were made to all local Child Find Coordinators in the state. (4) In order to deliver culturally-sensitive early intervention, CHIP contracted with The Spring Institute to provide translation services. With the support of their grant funds, the Spring Institute offers CHIP > 42% discount for translation services. (5) Audiologists and early interventionists need to be sensitive to the language and culture of Deaf adults. CHIP has contracted for many years with deaf and hard of hearing adults who participate in the early intervention program. Deaf and hard of hearing adults work as early interventionists, sign language instructors, and role models in many areas of the state. CHIP also has an adult who is deaf on its administrative team. (6) While it is estimated that 1 child in every 1000 births has UHL, only 38 children with UHL are currently registered in the early intervention system. With in-kind support from the University of Colorado's Speech/Language/Hearing Sciences Department, a pilot study was conducted in 2000 – 2003 identifying the characteristics of young. children with UHL. This pilot study indicates the hearing loss 7% of children with UHL progresses to bilateral hearing loss. An additional 7% had bilateral hearing loss all long but only referred on one ear during the hearing screen. And, 35% of the children experienced delays in communication and/or language. To address these needs, the CO-Hear Coordinators provided consultative services to families of children with UHL.

Parent-to-Parent Information, Support, Leadership: These parent-to-parent services are available statewide and funded by an array of grants and agencies. The network of Parent Regional Coordinators (PRCs) has been expanded to include a parent familiar with UHL, a parent who speaks Spanish, and a parent who understands the issues of children with multiple disabilities.

Data Tracking & Surveillance: The coordinator of CHIRP, Cathy Gunderson, has met with CO-Hear Coodinators to provide necessary consultation and technical assistance to help populate the early intervention data fields. She has also worked with the coordinators of other data systems (e.g., Part C, CSDB, CU) to investigate the feasibility of integrating the data in multiple databases into one primary data base. Staff at CDPHE are investigating ways to acquire the name of the medical home from other databases within the Department of Health (e.g., CRCSN, metabolic screen, etc

3.0 Data Requirements

Colorado has a sophisticated tracking system at the CDPHE that has excellent data-reporting capabilities. In addition, much of the early intervention data is gathered and reported by the CSDB and Part C. Colorado will continue to report annually on the number of live births in the state, the number of infants screened prior to hospital discharge, the number of infants suspected of a hearing loss with an audiologic diagnosis by 3 months of age, the number of infants diagnosed with a hearing loss enrolled in early intervention before 6 months of age, the number of infants with a medical home, and the number of families linked to family-to-family support. In addition, the State will report annually on the performance measures outlined by MCHB.

4.0 Identification of Target Population

4.1 Description of the target population for proposed activities

There are many constituents in the newborn hearing system and each will benefit from project activities. Infants and toddlers, under three years of age, with bilateral, unilateral, conductive, sensorineural, and/or mixed losses will benefit. And the families of these infants and toddlers will benefit as well.

Other constituents are those providing services to these children and their families including; hospital staff in the newborn nursery, hospital staff working in vital records who submit the electronic birth certificates, clinical audiologists, school audiologists, early interventionists, physicians, Parent Regional Coordinators, and deaf/hard of hearing adults.

The stakeholders participating in the system, at state, regional, and local levels will benefit including; Part C, Community Centered Boards, JFK Partners, EHDI staff at CDPHE, CRCSN staff at CDPHE, and the staff working to develop, enhance and maintain the data tracking and surveillance system at CDPHE.

4.2 Describe current understanding of the needs, special problems, and barriers facing the target population

Screening: At the screening level, there is a need to address these gaps; (1) children born at home are not routinely screened, (2) midwives do not regularly endorse the technological procedure used in the screening, especially when it is offered in a hospital, (3) children born in hospitals in other states may not receive a hearing screen and/or the screening results are not sent to the Vital Statistics Department at CDPHE, (4) information on a child's risk factors is not currently being collected, (5) some children have progressive hearing loss and need to receive another hearing screening when they are older.

Follow-up to Failed Screen: To increase follow-up when a child fails a newborn screen, the system must (1) increase the number of children who return for follow-up (re-screen or audiological assessment) when they fail the initial screen, (2) assure an audiologist is affiliated with each birthing hospital, (3) assure there are an adequate number of places in a community to obtain a hearing screen, (4) continue to educate physicians on the importance of a hearing screen, (5) train screeners to deliver information in ways that stress the importance of follow-up to parents, (6) investigate screening children with high risk factors, (7) investigate the feasibility of testing all children for CMV.

Medical Home: There are many needs when trying to associate the newborn hearing screening system with a child's medical home including; (1) some primary care physicians are not yet familiar with or supportive of newborn hearing screening, (2) physicians are not aware of the significance of UHL, (3) physicians are unaware of the early intervention system, particularly the disability-specific programs in Colorado, (4) the medical home is often not indicated on the child's EBC which limits opportunities to instruct physicians about the newborn hearing initiative, (5) the medical home is not listed on 91% of children's data records, (6) knowing that genetic counseling services are now available in six regional clinics and when to refer children for genetic counseling.

Audiologic Evaluation: While the capacity of audiologists in Colorado to provide services is stellar, some gaps exist including; (1) having appropriately trained and experienced audiologists in rural areas, (2) understanding the importance of following children with UHL, (3) having procedures for following children with UHL, (4) assuring diagnosis by 3 months of age and amplification fit shortly after, (5) providing culturally-sensitive services, (6) having adequate supplies of loaner hearing aids available.

Early Intervention: The early intervention system has these needs, barriers, and special problems; (1) training early interventionist to deliver family-centered services, (2) providing sufficient in-service training to early interventionists so they have the competencies and knowledge to provide appropriate intervention, (3) assuring there is an adequate number of early interventionists who provide and objective, unbiased approach to communication, (4) utilizing the state's disability-specific assessment procedure, the FAMILY Assessment, to monitor progress of individual children and program outcomes, (5) adequately supporting families whose native language is not English (e.g., Spanish-speaking, ASL signers, etc), (6) understanding then need for genetic counseling services and promoting this to families, (7) identifying procedures and securing adequate funding to serve children with UHL, (8) serving children with additional disabilities.

Parent-to-Parent Information, Support, Leadership: While unique and trend-setting parent-to-parent services are an integral part of Colorado's system, services can be enhanced to include; (1) maintaining an adequate number of appropriately trained parents to provide information, support, and leadership, (2) offering culturally-sensitive services, (3) supporting parents' selection of an effective communication approach, (4) creating new resources for parents, (5) integrating parent-to-parent activities with other initiatives in the state that provide parent support (e.g., AG Bell, Family Voices, etc).

Consumer Participation: A new need has been identified to address utilization of the newborn hearing system by deaf or hard of hearing consumers. Specific needs include; (1) using culturally-sensitive practices when approaching D/HH parents with D/HH children, and (2) having an adequate number of D/HH role models in each community in the state.

Data Tracking & Surveillance: Needs, problems and barriers in this area include; (1) improving the completion of more data fields on CHIRP, (2) integrating data on CHIRP with other data management programs that reside in other agencies.

4.3 Existing services and support available at the community, State, regional and/or national levels to support the project

Colorado's EHDI program is supported well, and for many years, by other initiatives in a variety of agencies. Refer to pages ??? - ??? for letters of support from these agencies. At the community level, these programs provide activities and funding; (1) regional public health offices monitor follow-up and provide OAE screening, (2) all local education associations (LEAs) have educational audiologists who can perform some of the audiologic diagnostic tests at no cost to the family and also provide some assistance to find funding sources for amplification,

(3) county Part C agencies support the EHDI system, often funding direct services (~ $90,000 statewide) and occasionally funding service coordination delivered by the Regional CO-Hear Coordinators (~$6000 statewide), (4) county Community Centered Boards (CCBs) operate under the structure of Part C but receive their funding from the Department of Developmental Disabilities which often funds direct services and partial funding for amplification (~$200,000 statewide); (5) Child Find programs in LEAs work with the CO-Hear Coordinators to assure an appropriate multi-disciplinary assessment is conducted on each child (in-kind), (6) translation for early intervention services is provided at a steep discount of 42% by the Spring Institute for families in the Denver-metro area.

At the State level, (1) Part C serves as the umbrella organization supporting the EHDI system, (2) CSDB supports the infrastructure of the early intervention program, provides ~ $500,000 in costs for personnel services, direct services, the hearing aid loaner bank (in-kind), translation services ($7000), material development for the public early intervention program (~$10,000), and operating expenses for the early intervention program (~$18,000). (3) Medicaid funds early intervention for children under four years of age (~$100,000) and school-based Medicaid funds targeted case management activities of the Regional CO-Hear Coordinators (~$3800), (4) the Colorado Department of Education supports activities for educational audiologists, early interventionists, D/HH role models, and assessment through state set-aside grants ($125,000 per year), (5) university programs (University of Northern Colorado, University of Colorado – Boulder), provide training and support for the FAMILY Assessment (in-kind).

At the regional level, (1) Colorado participates in the regional teleconferences sponsored by NCHAM, (2) early intervention programs in the 7-state western region work collaboratively at an administrative level to strengthen each state's early intervention program and provide a multi-state training program bi-annually, (3) early intervention programs in Utah, Colorado, New Mexico, and Nebraska meet regularly to define best practices for early intervention, (4) Colorado benefits directly from activities supported by the Marion Downs Hearing Center at University Hospital, (5) Colorado participates in the Cente-R at UNC-Greensboro to identify best-practices in early intervention.

Federal priorities from MCHB result in implementation of many activities by our Title V program at CDPHE including; funding for the NHS Coordinator at .60 FTE, maintaining and enhancing the CHIRP database for tracking and surveillance, funding 14 Audiology Regional Coordinators ($34,000), providing funding to support the hearing aid loaner bank (~$8000), supporting the medical home initiative (in-kind), organizing provision of genetic counseling to families (in-kind), financially supports a parent consultant (~$7,500/year) and an early intervention data management liaison (~$6550/year), and financially supports our parent network ($19,000). In addition, the Colorado Department of Education supports technical assistance to children with dual sensory impairments ($9000).

In addition to these public funds, many private agencies support Colorado's EHDI initiative including; (1) Colorado Hearing Foundation supports funding for audiologic, cochlear implant, and developmental diagnostic services through the Marion Downs Hearing Center at University Hospital (~$8000), The Listen Foundation co-funds the Oral Communication Consultant who offers technical assistance to early interventionists ($5000), The A.G. Bell Association

participates in committees providing support to parents (in-kind), Family Voices provides parent education workshops statewide about health and funding issues (in-kind), El Grupo Vida is a Spanish support network and works with Hands & Voices (in-kind).

A description of the funding sources for each activity proposed in the grant is included in the Project Activities Time Allocation Table on pages ??? - ???.

5.0 Goals and Objectives

Refer to chart on pages ???? - ???? for a detailed explanation of goals, activities, timelines, funding sources and evaluation measures.

6.0 Project Methodology

6.1 Methodology to be used to accomplish the specified goals and objectives

The goals and activities identified in the chart on pages ??? - ??? identify a comprehensive list of activities to implement, enhance, and sustain Colorado's EHDI system. Agencies in Colorado have a long history of supporting the EHDI system. This is due, in large part, to inter-agency collaboration. Letters of support in the appendices on pages ??? - ??? reinforce the broad-based support offered by many agencies in the state. The advisory committees, task forces, and inter-agency committee meetings that are conducted throughout the year will assure the goals and objectives are addressed and accomplished. In addition, Colorado has professionals representing all strands in the EHDI program – screening, assessment, early intervention, parent-to-parent support, D/HH consumers – who are nationally known, published, and well-traveled experts in this field. The far-reaching experiences of these professionals have been brought by these professionals back to Colorado and have enhanced our system in many ways. We have essentially selected the best practices demonstrated by EHDI projects in other states and in other countries and implemented them here. These boards, committees, and task forces design the program and prioritize activities on a regular basis. All of these professionals will continue to have extensive experience visiting other programs through their association with the CDC-funded grant that established the Marion Downs Hearing Center at University of Colorado Hospital this year. The only limitations we have experienced are financial ones. Colorado has established what is fondly referred to as a "patchwork quilt" of funding. This multi-agency funding, with additional funding from grants, not-for-profit organizations, and donations from service organizations has been a signature of success for enhancing and sustaining Colorado's successful EHDI program.

6.2 How the activities will lead to accomplishment of the intended goals and objectives as stated in the preceding section

The goals, objectives and activities identified in the chart on pages ??? - ??? are divided into seven areas; (1) screening, (2) assuring follow-up after newborn screen, (3) linking each child with a medical home, (4) audiologic assessment and amplification, (5) early intervention, (6) parent and consumer support, (7)tracking and surveillance. Each activity identified in the chart

has adequate funding from multiple sources. Services are listed as "in-kind" or "direct funding". "Direct funding: - MCHB" identifies activities that will be funded by this grant.

Each activity has timelines, some of which will extend throughout the duration of the 3-year grant and are indicated as such when the timeline says "ongoing".

Because Colorado's system is enhanced, rather than dependent, on the funds from this grant, there is a realistic expectation that all activities will secure additional funding to sustain the activities beyond the duration of the grant. The far-right column on the chart on pages ??? - ??? identifies specific tracking and evaluation procedures that will document outcomes of the activities and fulfillment of the goals and objectives.

6.3 Identify different groups outlining which agency/grant will support the activity

The Project Activities Time Allocation Table on pages ??? - ??? includes identification of the specific agencies that will provide fiscal support and/or in-kind support for each activity. The charts on pages ?? - ?? graphically illustrate different elements of the system: (1) On page ???? insert charts and list their relevance here…

7.0 Collaboration and Coordination

7.1 Describe the existing and planned methods of collaboration and coordination with other agencies, organizations, key public and private providers, consumer groups, insurers, professional membership organizations, and other partnerships

Colorado's EHDI program is supported by many agencies including the following agencies and the programs within them. Collaboration takes place when the stakeholders listed below meet, on a regular basis, at state-level and regional meetings of advisory boards, task forces, and committees. The funding provided by each public and private agency has been carefully crafted to serve specific needs that are not duplicative.

State agencies collaborate and coordinate activities, representing the following elements of the EHDI program: (1) Colorado Department of Public Health and Environment (CDPHE) that houses the Vital Records Department, the MCHB block grant, the CRCSN, a genetics grant, Level I and Level II grants from CDC for tracking and surveillance, the Health Care Program for Children with Special Needs with its regionalized public health offices, and a grant supporting the medical home initiative; (2) State Medicaid programs, both school-based and health-based programs support service coordination and home-based early intervention services; (3) Colorado School for the Deaf and the Blind (CSDB) supports the infrastructure for the statewide, publicly funded early intervention program, pays for some direct early intervention services, and assures assessment to support outcome-based early intervention services; (4) Part C at the Colorado Department of Education (CDE) provides the infrastructure for service coordination, development of IFSPs, and provision of all entitlements provided by Part C of IDEA; (5) CDE's Special Education Services Unit houses the Consultant for Deaf Education and Audiology

Services and supports a statewide network of educational audiologists, training for early interventionists, funding for some direct services, and funding for deaf and hard of hearing role models; (6) Local Community Centered Boards (CCBs), funded through the Division for Developmental Disabilities at the Colorado Department of Human Services provides a significant amount of funding for direct services and some funding for service coordination; (7) The University of Colorado-Boulder partially funds and manages data analysis for children in early intervention; (8) Child Find at CDE is responsible for conducting a multi-disciplinary assessment for all children and supports use of the FAMILY Assessment as the appropriate tool for deaf and hard of hearing children.

In addition to these statewide agencies, there many organizations and programs that support the EHDI initiative: (1) The Marion Downs Hearing Center (MDHC) at the University of Colorado Hospital has funding from CDC to investigate and analyze issues related to hearing and balance disorders for all individuals, including infants and toddlers. The MDHC also provides funding for in-service training and fellowships in otology, audiology, and early intervention.; (2) Colorado Families for Hands & Voices provides a statewide network of information, support, and leadership that is delivered by parents, for parents. Families of children with hearing loss have benefited from the activities of this organization and, as informed parents, become key to their child's success.; (3) the Listen Foundation supports oral communication approaches, including Auditory-Verbal therapy, for children and co-funds an Oral Communication Consultant who provides mentoring to early interventionists statewide; (4) Colorado's AG Bell Association For the Deaf supports, with in-kind contributions, the hearing aid loaner bank and training for early interventionists; (5) Family Voices, provides parent education workshops; (6) El Grupo Vida, a Spanish-speaking parent group.

Other activities include participation and support from consumer groups (e.g., The Colorado Association of the Deaf), key public and private providers (e.g., The Children's Hospital, the Colorado Hospital Association, Pediatrix), professional membership organizations (e.g., Colorado Speech/Language Hearing Association, Colorado Academy of Audiology, Colorado's AAP, Colorado Academy of Family Physicians), and partnerships with individual otolaryngologists, neurotologists, geneticists, and other medical practitioners.

7.2 Copies of formal agreements defining these relationships

Copies of Memorandums of Understanding, Memorandums of Agreement, and other letters of commitment and support are in the appendices on pages ??? - ???.

8.0 Administration and Organization

Charts representing the administration and organization of Colorado's system are included in the appendices on pages ??? - ???. There are several charts representing the Colorado Infant Hearing Program (page ??), the funding sources for early intervention (page ??), the Medical Home Initiative (page ??), and the organizational chart for CSDB (??).

9.0 Organization Experience, Capacity, Available Resources

9.1 Demonstrate evidence of organizational experience and capability to coordinate and support planning, implementation, and evaluation of a comprehensive approach that will meet the stated objectives of the program

Colorado has the support of a large body of professionals and parent advocates, as well as the experience, to accomplish the goals of this grant. Colorado's EHDI program was started in 1993 by CDPHE's Health Care Program for Children with Special Needs (HCP) in collaboration with audiologists in major clinical settings. At that time, and ever since, the state had a publicly funded early intervention program, the Colorado Home Intervention Program (CHIP), that provided follow-up. This early intervention program has been enhanced and is more stable than ever since it transferred its infrastructure to the Colorado School for the Deaf and the Blind (CSDB) in 2001.

Advisory Board and Task Forces: Colorado's 1997 legislation required the establishment of the Colorado Infant Hearing Advisory Committee (CIHAC) which receives input from four task forces; Screening Task Force, Audiologic Assessment/Amplification Task Force, Early Intervention Task Force, and a Medical Task Force. Members of each task force are composed of professionals, parents, consumers who are D/HH, and representatives from agencies that contribute to these individual areas (refer to appendices on pages ??? - ??? for the lists of members of the respective task forces). Activities of the task forces includes: (1) The Screening Task Force develops guidelines for hospital screening, re-screening, and referral for an audiologic evaluation. They are responsible for maintaining hospital screening rates, assuring children born out-of-state receive a hearing screen, and are investigating opportunities to conduct continuous screening (e.g., through NCHAM's Project ECHO). (2) The Audiologic Assessment/Amplification Task Force develops guidelines for a comprehensive infant audiologic assessment that incorporates new technology (e.g., ASSR). They have developed a Newborn Audiological Assessment Checklist (Appendix page ??). The Task Force continues to be responsible for assessing the training needs of audiologists in the state. They support the ongoing new Hearing Aid Loaner Bank at CSDB and use their contacts with hearing aid manufacturers to purchase aids at a significantly reduced cost. (3) The Early Intervention Task Force continues to distinguish itself with success to the degree that other states are using their guidelines and practices as a model. Significant accomplishments of this task force are the provision of service coordination by Colorado Hearing Resource (CO-Hear) Coordinators who have expertise and experience working with parents of infants and toddlers with hearing loss, know community resources and funding sources, and also have knowledge and proficiencies working with infants and toddlers with all degrees of hearing loss. Another widely replicated accomplishment of this task force is the implementation of ongoing assessment for all children receiving early intervention services to assure evidence-based practices are provided. The data is used not only to guide the individualized early intervention program, but aggregate data identifies program outcomes, both accomplishments and areas of need. This aggregate data is managed at the University of Colorado-Boulder. Furthermore, CHIP offers all communication approaches to all families. Indeed, the distraction of the age-old "methodology debate" no longer exists in Colorado. The Early Intervention Task Force assures culturally-sensitive practices are implemented in all regions of the state. The successful implementation of culturally-sensitive practices has spread to other aspects of the EHDI program including screening and audiologic assessment. The Early Intervention Task Force has made a

recommendation for consultative services to be provided to families of all children with unilateral hearing loss (UHL). Based on a pilot study conducted in this state, Colorado showed that 35% of the children with UHL have delays in communication/language and direct services are provided to those children.

Parent and Consumer Support: Families for Hands & Voices is a parent-driven organization that supports all communication approaches. It has played a vital leadership role in our EHDI system by offering families information, support, and opportunities for parent leadership. Hands & Voices has its roots in Colorado and has expanded to many other states. Deaf and hard of hearing consumers are an integral part of our EHDI system. A statewide network of 38 D/HH adults are trained to serve as role models to families of infants and toddlers with hearing loss in the comfort of the family's own home. In keeping with a coveted trait of Colorado's EHDI system, all of the D/HH adults are committed to giving parents information on all communication approaches. In addition, CHIP hires a deaf adult as a consumer advisor, ~8 early interventionists who are D/HH, 21 sign language instructors who are D/HH, and contracts with a psychologist who is deaf himself.

NCHAM Initiatives: Colorado has shared its interest in participating in Project ECHO in order to investigate the advantages of continuous screening. Colorado has also expressed its intent to participate in an annual workshop on family support being proposed by the EHDI National Resource Center in collaboration with Beginnings in North Carolina.

Marion Downs Hearing Center (MDHC) at University of Colorado Hospital (UCH): The coordinators of the EHDI Task Forces are also on staff at the MDHC, giving them opportunities to investigate best practices in other states and other countries, an opportunity for collegiality and learning, and opportunities to attend state, national and international conferences. The information gleaned by these professionals puts them in the unique position to implement and evaluate the success and needs of Colorado's EHDI program.

Sustainability: Two members of Colorado's EHDI program, Vickie Thomson and Arlene Stredler Brown, attended the Sustainability Workshop sponsored by MCHB in February, 2004. Ways to assure the likelihood of sustaining Colorado's EHDI program were identified and include; developing a plan for sustainability, building the capacity of communities, taking a leading role in making policy changes to secure more cost-effective and more long-term outcomes, integrating current efforts within other systems (e.g., CDPHE, CDE, Part C, CSDB, etc), having alliances with other groups (both private and not-for-profit) that have a similar mission, and building new relationships with not-for-profit funders (e.g., Hear Now, SERTOMA, MDHC, etc). We have a justification for continued support that will continuously be shared with other agencies such as the Colorado Commission for the D/HH, Part C, CDE, and CDPHE. This justification is perpetually reinforced as more and more outcome data on the skills of children "graduating" from early intervention are collect, shared, and published. And, Colorado has identified potential financial strategies to perpetuate our EHDI program to include; shared positions and resources among organizations, grants, in-kind support, third-party funding, and plans for more public funding.

9.2 Capability to collect and report individual data from multiple sources

Colorado has data tracking and surveillance systems in place that include data fields for all elements of the EHDI system including; screening, linking each child with a medical home, audiologic assessment and amplification, early intervention, and parent support. These systems are supported by several data programs: (1) screening is supported by the electronic birth certificate and the CHIRP database at CDPHE; (2) audiologic assessment and amplification are recorded on CHIRP with data supplied by the audiologists (See page ?? in the Appendices for a copy of the Follow-Up Hearing Loss Report that is submitted by audiologists when a child is diagnosed with hearing loss); (3) early intervention data is entered into four databases, each database sponsored by a different agency (CDPHE, CSDB, Part C, CU-Boulder). This grant proposes integration of these early intervention databases to increase efficiency. In so doing, collaboration among these agencies will be enhanced. (Refer to the pages ???, ???, ??? and ??? in the Appendices for these documents). (4) medical home information is entered into CHIRP when available and can be captured from other databases (e.g., CRCSN, metabolic screening program); (5) Families for Hands & Voices maintains a database of all families entering early intervention and maintains this database throughout a child's school years. While our data systems are comprehensive, easily capturing statewide information at any point in time, there are areas that need improvement that are mentioned in the activities on the Project Activities Time Allocation Table on pages ??? - ???. Targeted areas for improving the CHIRP database include more comprehensive reporting of; amplification fit, age when early intervention starts, and a child's medical home.

References:

Parent Survey for the Colorado Home Intervention Program (2003, 2004). Colorado School for the Deaf and the Blind. Colorado Springs, CO.

Colorado Infant Hearing Advisory Committee (2003). Guidelines for Guidelines for Infant Hearing Screening, Audiologic Assessment, and Early Intervention. Colorado Department of Public Health and Environment.

Hafer, J.C. & Stredler-Brown, A. (2003). "Family-Centered Developmental Assessment". In Bodner-Johnson, B. and Sass-Lehrer, M. (Eds): The Young Deaf or Hard of Hearing Child: A Family-Centered Approach to Early Education. Paul H. Brookes Publishing Co; MD.

Turnbull, A. and Jackson, C (2004). Topics in Early Childhood Special Education.

Goals & Objectives: Project Activities Table

Goals & Objectives	**Activities**	**Start Date**	**Completion Date**	**Funding Source**	**Tracking/Evaluation Methods and Outcomes – Quantitative & Qualitative**
SCREENING	*Activities & goals in this section are to assure that all infants have access to a newborn hearing screen & receive timely follow-up*				
Maintain hospital screening rates	1. Evaluate refer rates from individual hospitals. 2. Determine cause of refer rate if >4% 3. Determine cause of unreasonably low refer rates 4. Improve hospital screening rate for hospitals screening <95%	Ongoing	Ongoing	In-kind: CDPHE/ HCP	Audiology Regional Coordinators Clinical Health Information Records of Patients (CHIRP)
Increase screening for births conducted at home or in hospitals in other states	1. Have OAE equipment in each HCP Regional Office 2. Publish articles/notices in newsletters for CO Midwives Association 3. Send letters to parents of children born at home about newborn hearing screening 4. Educational materials for Colorado Midwives Association to support NHS 5. Send letter to parents of children born in out-of-state hospitals 6. Send letters to parents of children who miss a screen	Ongoing	Ongoing	In-kind: CDPHE/ HCP, Hands & Voices (H&V)	▪ Audiology Regional Coordinators ▪ State Audiology Consultant ▪ Clinical Health Information Records of Patients (CHIRP) ▪ State Audiology Consultant ▪ Clinical Health Information Records of Patients (CHIRP) ▪ Clinical Health Information Records of Patients (CHIRP)
Provide continuous screening for children	1. Conduct a needs assessment and strategic planning for working with the ECHO Project and Head Start agencies	4/1/05	3/31/08	Year 1 – in-kind: CDPHE, MDHC, CSDB	Children in Head Start programs are screened and referred for services

				Year 2-3 – direct funding: MCHB, ECHO Project	
ASSURING FOLLOW-UP AFTER SCREEN	*Activities and goals in this section are to assure that all infants who fail a newborn hearing screen receive follow-up*				
Increase return for follow-up when child fails an initial screen	1. Educate screeners on importance of follow-up 2. Assure OAE equipment is in all communities 3. Send letter from State Health Dept. to families when child fails 2 screenings 4. Send letter from State Health Dept. to child's medical home when child fails a hearing screen 5. Continuing education of PCPs about importance of NHS 6. Create posters for dissemination to physicians'offices	ongoing 4/1/05 ongoing 4/1/07	ongoing 3/31/06 ongoing 3/31/08	In-kind: CDPHE/ HCP, MDHC, H&V Direct funding: MCHB	Audiology Regional Coordinators provide education. Follow-up rate increases.
Establish a procedure for collecting high risk information	1. Identify high risk factors on EBC & that are entered into State data systems 2. Educate physicians on high risk factors for individual infants 3. Identify the number of infants who test positive for CMV on blood spot screen & consider screening for CMV	Ongoing	Ongoing	In-kind; CDPHE/ HCP	Procedures are identified to determine high risk factors
Assure each hospital has an audiologist participating in the NHS program	1. Identify hospitals that do not have an audiologist on staff 2. Audiology Regional Coordinators provide supervision	Ongoing	Ongoing	In-kind; CDPHE/ HCP, MCHB	Each hospital has an audiologist consulting with the NHS program

LINKING EACH CHILD WITH A MEDICAL HOME	*Activities and goals in this section are to assure that infants have a medical home*				
Join current state initiatives related to the medical home initiative	1. Identify stakeholders who have medical home initiatives 2. Participate in meetings at CDPHE/HCP on medical home initiative	Ongoing	Ongoing	In-kind: CDPHE/ HCP, MCHB	Attend meetings to support the medical home initiative
Create links with parent organizations	1. Parent Regional Coordinators will make presentations to physicians	4/1/05	3/31/08	Direct funding: MCHB	Presentations to physicians will be conducted
Provide information to physicians about hearing loss	1. CO-Hear Coordinators send intervention enrollment information to medical home 2. Families distribute Resource Guide to their child's PCP 3. Early interventionists from CHIP send quarterly progress reports to medical home	4/1/06 4/1/07 4/1/07	3/31/08 3/31/08 3/31/08	Direct funding: MCHB In-kind: CSDB	More physicians receive information about HDI
Identify the outpatient medical home for each child with hearing loss	1. CIHAC discusses ways to obtain/update information about the child's medical home in the State tracking system 2. Access databases from other screening programs (e.g., CRCSN, Part C), to identify the child's medical home. 3. CDPHE will report on the number of children with medical home 4. CO-Hear Coordinators obtain information to identify the medical home	ongoing ongoing ongoing ongoing	ongoing ongoing ongoing ongoing	In-kind: CDPHE/ HCP Direct funding: MCHB	Increase number of children on CHIRP database with medical home identified
Increase awareness of the significance of UHL	1. Distribute materials about UHL to physicians	Ongoing	Ongoing	In-kind: MDHC, H&V	Materials for UHL are created and disseminated
Increase physician awareness of the	1. Collaborate with CDPHE to disseminate information to medical homes about the	Ongoing	ongoing	In-kind: CDPHE/	▪ Collaboration with CDPHE ▪ Information about start of early

early intervention system & their participation in the system	state's EHDI program 2. CHIRP identifies medical home and gives this information to CO-Hear Coor. 3. CO-Hear Coordinators contact child's medical home with information about the child's early intervention	4/1/06	3/31/08	HCP	intervention services is sent to physicians ▪ Improved communication between medical home and early intervention providers
AUDOLOGIC ASSESSMENT & AMPLIFICATION	*Activities and goals in this section assure infants receive diagnostic services by 3 months and amplification by 6 months*				
Educate stakeholders to refer families to audiologists w/ pediatric expertise	1. Identify pediatric audiologists with equipment and training that meets CIHAC guidelines 2. Provide training to staff in Regional Public Health offices to identify appropriate audiology providers	Ongoing	Ongoing	In-kind: CDPHE/ HCP	Audiologists providing appropriate pediatric services are identified
Identify appropriately trained and qualified audiologists	1. Establish a peer-review process to monitor pediatric audiologists providing an acceptable standard of practice 2. Publish list of audiologists providing an acceptable standard of practice 3. Discuss development of regional centers 4. ARCs provide 1:1 mentoring to clinical audiologists who do not meet acceptable standards of practice 5. Provide statewide & regional training to clinical and educational audiologists	Ongoing ongoing 4/1/06 ongoing ongoing	ongoing ongoing 3/31/07 ongoing ongoing	In-kind: CDPHE/ HCP, MDHC, H&V Direct funding: MCHB	Audiologists providing appropriate pediatric services are identified Resource Guide publishes list of audiologists
Identify children by 3 months of age	1. Provide consultation, mentoring, and TA to clinical centers that do not complete evaluations in a timely manner	Ongoing	Ongoing	In-kind: CDPHE/ HCP	Audiologists provide acceptable diagnostic practices
Investigate creation of regional centers of excellence	1. Collect information from other states (e.g., CA, LA, VA) about efficacy of establishing regional centers 2. Conduct needs assessment and strategic	Ongoing	Ongoig	In-kind: CDPHE/ HCP Direct	Regional centers of excellence will be discussed and created if approved by CIHAC

	planning to develop regional centers			funding: MCHB	
Assure children receive appropriate amplification by six months of age	1. Utilize the CHIRP database to identify the average age of first amplification 2. ARCs provide consultation and technical assistance to clinical audiologists who do not meet acceptable standards of practice 3. Parents Accessing Resources (PAR) manual is revised annually and distributed to newly identified children 4. Clinical audiologists access hearing aid loan bank for hearing aids as needed 5. Audiologists help parents to obtain funding for amplification 6. Create working groups to identify activities supporting fund of amplification	Ongoing	Ongoing	In-kind: CDPHE/ HCP, Hands & Voices, MDHC Direct funding: MCHB	CHIRP reports document amplification fit by six months of age Survey results from Hands & Voices survey Parents receive materials about this new initiative
Increase follow-up for children with Unilateral Hearing Loss (UHL)	1. Materials on significance of UHL are developed and disseminated to audiologists 2. CIHAC guidelines for audiological assessments for UHL are disseminated to clinical audiologists 3. Training is provided to clinical audiologists regarding best practices (4. Clinical audiologists refer family to early intervention point of entry 5. Children with UHL are on CHIRP 6. Letters are sent from the Health Dept to families who have children with UHL	4/1/05 ongoing 4/1/06 4/1/05 ongoing 4/1/07	3/31/08 ongoing 3/31/08 3/31/08 ongoing 3/31/08	In-kind: CDPHE/ HCP, MDHC Direct funding: MCHB	Children with UHL are identified, tracked, and receive services as needed
Assure diagnostic audiologists provide cultural sensitivity	1. Conduct survey of audiologists/hospitals regarding availability of translation services & analyze results	4/1/06	3/31/07	Direct funding: MCHB	Families receive information in their primary language

practices	2. Assure interpreters are available to families during diagnostic evaluations 4. Publish article/s on the status of translation services in audiology clinics 5. Create glossary of audiology terms in Spanish and disseminate to audiologists 6. Hands & Voices to conduct needs assessment (survey) of parents who do not speak English	4/1/06 4/1/07 4/1/07 4/1/06	3/31/07 3/31/08 3/31/08 3/31/07		Survey conducted – action plan developed based on outcomes
Expand and sustain Hearing Aid Loaner Bank	1. Expand inventory in the hearing aid loaner bank 2. Adequately fund management of hearing aid loaner bank at the Colorado School for the Deaf and the Blind (CSDB)	4/1/05 4/1/05	3/31/08 3/31/08	In-kind: CDPHE/ HCP, CDE, CSDB Direct Funding: MCHB	All children are fit with amplification by 6 months of age
Assure families have materials in their language and/or interpreters available	1. Utilize hospital-based interpreter services 2. Fund translation services for CO-Hear Coordinators 3. Translate intervention materials to Spanish	ongoing	Ongoing	In-kind: CDE, CSDB	Translation completed
Assure families have access to public/private funds to pay for diagnostic services and amplification	2. Child Find pays for diagnostic services if other funding options are not available 3. Audiologists offer parents funding options for hearing aids 4. Funding Tool Kit is developed, printed, and distributed by Families for Hands & Voices to audiologists and to parents	Ongoing 4/1/05	Ongoing 3/31/08	In-kind: CDPHE/ HCP, LEAs Direct funding: MCHB	All families have funding for assessment & amplification Funding options published on Hands Voices website
EARLY INTERVENTION	*Activities in this section will assure families and their infants receive services by six*				

	months of age				
Provide comprehensive, seamless system for families for easy access to early intervention	1. Members of State ICC are represented on Early Intervention Task Force 2. CSDB is represented on State ICC 3. Continue to look at other sources to co-fund cost of service coordination	Ongoing 4/1/05 ongoing	Ongoing 3/31/08 ongoing	In-kind: CDE, CSDB, CDPHE, CCB, Part C	▪ Meeting documentation ▪ Part C (and CCBs) co-fund CO-Hear Coordinators
Fund training for professionals working in parent-centered programs	1. Participation in conferences sponsored by Part C, Child Find, newborn hearing, state education agency, CSDB 2. Funding provided to underwrite cost for interventionists to attend trainings	Ongoing	ongoing	In-kind: CSDB, CDE, MDHC Direct funding: MCHB	Conference evaluations
Offer information and provide access to families on all communication approaches	1. Disseminate videotapes about communication approaches to families 2. Train early interventionists to provide unbiased information and objective analysis of communication approaches	ongoing	Ongoing	In-kind: CSDB, CDE, MDHC	Material development & dissemination
Increase participation of families in FAMILY Assessment	1. Achieve 80% compliance with assessment 2. Publish aggregate data on early intervention outcomes	Ongoing	Ongoing	In-kind: CU-B, CSDB, CDE	• Identify written materials supporting assessment • Documentation on CU database • Annual report published and disseminated
Provide support to families who speak only Spanish	1. Provide bilingual early interventionists or provide translator 2. Translate written information 3. Train Spanish-speaking parent about intervention & culturally-sensitive practices 4. Investigate grant opportunities to support funding for translation services	Ongoing	Ongoing	In-kind: CSDB Direct funding: MCHB	Translation of materials Parent Coordinator is trained in culturally-sensitive practices Increase number of parents on H&V database

	5. Provide training opportunities to bilingual early interventionists				
Increase the number of families receiving genetic counseling/ testing	1. Identify a genetics counselor to work with families in (6) regional genetics clinics	Ongoing	Ongoing	In-kind: CDPHE/ HCP, MDHC	Families receive genetic counseling
Provide early intervention services to children with Unilateral Hearing Loss (UHL)	1. Identify 3 consultants to receive referrals, meet families, help complete assessment 2. Fund adequate time for a Parent Regional Coordinator to work with families 3. Identify a protocol for consultants and parent coordinator to use with families 4. Develop and disseminate informational material to parents 5. Develop and disseminate informational material to audiologists 6. Develop and disseminate informational material to physicians 7. Monitor development at 6-month intervals and possible progression of loss 8. Provide ongoing treatment to the families of children exhibiting delays 9.Develop curriculum treating children experiencing developmental delays 10.Support data collection and data analysis at CU-Boulder 11.Publish outcomes of 2002 pilot data and new data	4/1/05 ongoing ongoing ongoing 4/1/06 4/1/07 ongoing ongoing 4/1/06 ongoing 4/1/07	3/31/08 ongoing ongoing ongoing 3/31/08 3/31/08 ongoing ongoing 3/31/08 ongoing 3/31/08	In-kind: MDHC Direct funding: MCHB	• Children with UHL are identified • Children with UHL receive service coordination • Children with UHL who experience developmental delays receive services • Outcome data is collected and published

Provide enhanced services to children who are D/HH with additional disabilities	1. Train early interventionists to work with children with additional disabilities 2. Discuss feasibility of establishing regional centers at the CIHAC 3. Contract with specialists (e.g., OT, PT, psychologist, Social Worker)	4/1/05 4/1/06 4/1/07	3/31/08 3/31/08 3/31/08	In-kind: CSDB, CDE	Comprehensive services are delivered to children with additional disabilities
Develop a "Welcome Packet" as enroll in early intervention	1. Develop materials 2. Print and disseminate materials	4/1/05 4/1/06	3/31/08 3/31/08	In-kind: CSDB, MDHC	New "Welcome Packet" is available All newly identified families receive "Welcome Packet"
Project ECHO	1. Provide services to children identified with hearing loss in Head Start Programs	4/1/06	4/1/08	Year 1 – in-kind: CDPHE, MDHC, CSDB Year 2-3 – direct funding: MCHB, ECHO Project	Coordination with Project ECHO
PARENT AND CONSUMER	*Activities in this section will assure EHDI system and families receive parent-to-parent support and access to D/HH adults*				
Maintain and expand the regional deaf/hard of hearing role model program (Deaf/Hard of Hearing Connections)	1. Maintain involvement by deaf and hard of hearing consultants in administration of early intervention program 2. Ongoing training of role models 3. Train role models to work with families of children with UHL 4. Hire additional role models as needed	4/1/05 4/1/05 4/1/05 4/1/05	3/31/08 3/31/08 3/31/08 3/31/08		Role models are identified and trained Survey is administered, results analyzed Increased utilization of role models

	5. Disseminate request for role models 6. Survey of parent satisfaction	4/1/05	3/31/08		
Contract a D/HH adult to serve as consumer advisor to early intervention	1. Expand the SOW based on needs assessment and input from other states 2. Enhance knowledge of EHDI system with D/HH adults who have D/HH children	4/1/05	3/31/08	In-kind: CSDB, CDE MCHB	Parent consumer represents early intervention initiative
Offer support to families through a regionalized network of parent advocates statewide	1. Information disseminated to families 2. Assure there is adequate parent representation for families in rural areas 3. Pilot joint home visits by PRC and CO-Hear Coordinators in one region of the state.	4/1/05 4/1/06 4/1/06	3/31/08 3/31/07 3/31/08	In-kind: CDPHE, CSDB Direct Funding: MCHB	Information published, families meet PRCs # of families receiving home visit from PRC increases from 12% - 30% in pilot region
Use culturally-sensitive practices in all work with non-English speaking and D/HH families	1. Publish quarterly newsletters in Spanish 2. Revise Spanish edition - Resource Guide 3. Create Spanish section on the Hands & Voices website 4. Adapt services to meet needs identified by Spanish-speaking parents when then complete their bi-annual survey 5. Offer workshops in Spanish 6. Add a D/HH parent of D/HH children to the H&V advisory board 7. Identify a D/HH parent with a D/HH child to represent the needs of the D/HH community	4/1/06 4/1/05 4/1/06 4/1/05 4/1/06 4/1/07	3/31/08 3/31/06 3/31/08 3/31/06 3/31/08 3/31/08	In-kind: MDHC, H&V	▪ Materials will be translated into Spanish and available to families ▪ PRCs receive training in delivering culturally-sensitive practices ▪ Workshops specifically for Spanish-speaking families conducted ▪ Translators available at all parent events ▪ D/HH families will have more representation and programs will be adapted
Offer information and provide access to families on all communication approaches	1. Train Parent Regional Coordinators to provide unbiased information 2. Create a mentorship project of PRCs to other parent volunteers	4/1/05	3/31/08	In-kind: H&V MCHB	Material development & dissemination
Enhance the Parent	1. Update Resource Guide	4/1/07	3/31/08		New Resource Guide published bi-

Resource Guide, a bi-annual publication	2. Consider web-based access 3. Publish materials in H&V Communicator specific to families with children B-3 4. Include information about children with additional disabilities	4/1/07 4/1/05	3/31/08 3/31/08		annually Parent representation of child with additional disabilities on H&V Board
Formalize links and increase collaboration between parent, community, public health, and education systems to build a sustainable EHDI system statewide	1. Implement and evaluate use of the CIHAC guidelines for parent leadership in EHDI systems 2. Regional parent coordinators will be members of committees, task forces, and advisory boards at county and state levels 3. Families for Hands & Voices partners with other parent organizations (e.g., Colorado Voices, A.G. Bell Assoc.) 4. Develop recommendations for children as they transition from Part C to Part B 5. Articles will be published 6. Provide in-service training to professionals 7. Measure parent satisfaction with EHDI system	4/1/06 4/1/05 4/1/05 4/1/07 4/1/05 4/1/06	3/31/08 3/31/08 3/31/08 3/31/08 3/31/08 3/31/07		Information for parents, parent support, and parent leadership will be more extensive throughout the state. Evaluation tool developed Brochure created CDC survey disseminated, results analyzed CHIP Parent Survey disseminated annually, results analyzed
Parents will participate in the medical home initiative	1. Parents included in the planning activities for Colorado's medical home initiative 2. Develop resources and information for physicians 3. Participate in dissemination of parent surveys –through CDC-EHDI programs 4. Information about the medical home initiative will be disseminated to parents of children with hearing loss 5. Hands & Voices will partner with Family Voices to create a brochure about the medical home initiative	4/1/05 4/1/06 4/1/05 4/1/07 4/1/05	3/31/08 3/31/08 3/31/06 3/31/08 3/31/06	In-kind: CDPHE/ HCP	Parents are represented on committees Parents report on physician awareness will increase

Parents will support families who have children with unilateral hearing loss (UHL)	1. Parent materials are collected and disseminated 2. Training is offered to parents by regional parent coordinator representing UHL	4/1/05 4/1/06 4/1/06	3/31/08 3/31/08 3/31/08	In-kind: MDHC, H&V Direct funding: MCHB	Parents of children with UHL will receive parent-to-parent support Families of newly-identified children attend semi-annual picnic
TRACKING AND SURVEILLANCE	*Activities in this section assures screening, assessment, and intervention data is entered into appropriate databases, analyzed, and coordinated with other data programs*				
Improve the integrity of the newborn hearing screening database (Clinical Health Information Records for Patients – CHIRP)	1. Offer presentations to EBC personnel 2. Offer presentations to midwives 3. Train audiologists to submit Audiology Follow-Up forms including information on amplification fit 4. Train other personnel providing newborn hearing screening to complete the Hearing Follow-Up form 5. Develop reciprocity agreements with neighboring states to share screening	Ongoing	ongoing	In-kind: CDPHE	• More data will be available from CHIRP • Documentation of increased follow-up rates for children birthed out of state
Improve information given to parents whose children do not receive a hearing screen	1. CDPHE sends letters to parents when child did not receive a hearing screen 2. CDPHE sends letters to parents when there is no follow-up to the screen 3. CDPHE sends letters to HCP Regional Offices for infants who failed a hearing screen but did not receive follow-up 4. CDPHE sends letters to the child's medical home when screen was missed 5. CDPHE sends letters to the child's medical home when follow-up to a failed screen has not occurred	Ongoing	Ongoing	In-kind: CDPHE	Follow-up rates will improve

Integrate CHIRP data with other data systems	1. Enter early intervention information from CO-Hear Coordinators into CHIRP 2. Coordinate early intervention databases among CHIRP, CSDB, Part C 3. Work with JFK Partners, the agency responsible for managing the Part C database, to collect accurate data on all children with hearing loss 4. Integrate the newborn hearing and newborn metabolic screens to identify the medical home	Ongoing	Ongoing	In-kind: CDPHE, CSDB, Part C/ CDE, CSDB	Data will be complete and available