

Maternal and Child Health Bureau
Reducing Loss to Follow-up after Failure to Pass Newborn Hearing Screening
The California Newborn Hearing Screening and Intervention Project
Project Narrative

INTRODUCTION

In 1998, California passed Assembly Bill 2780, investing approximately [REDACTED] in the development and implementation of the California Newborn Hearing Screening Program (NHSP). Effective January 2008, this legislation was expanded to all general acute care hospitals with licensed perinatal services, a total of 258 facilities. The NHSP has established a comprehensive, coordinated system of identifying infants with hearing loss and linking them with appropriate intervention services, including the Individuals with Disabilities Education Improvement Act (IDEA) Part C early intervention services (called Early Start in California). With over 500,000 births per year in California, it is estimated that 1000 infants are born each year with hearing loss. It is the purpose of the California Newborn Hearing Screening and Intervention Project to utilize the existing infrastructure of the NHSP and the Early Start system to complement the program of statewide universal physiologic newborn hearing screening prior to hospital discharge with linkages to a medical home, diagnostic evaluation by three months of age, enhanced family-to-family support, enrollment in a program of early intervention by six months of age, implementation and feasibility assessment of a pilot telemedicine project in rural Northern California to provide diagnostic audiologic evaluations for infants in areas with no local audiology providers.

Research has shown that when infants with hearing loss are identified by three months of age, and enrolled in appropriate early intervention programs by six months of age, they can acquire language skills at the same rate as their hearing peers, commensurate with their cognitive and developmental abilities (Yoshinaga-Itano, 1995, Moeller, 1998). It is well known that language proficiency is the most significant prerequisite skill predicting the ability of deaf and hard of hearing children to acquire the literacy skills that will enable them to achieve academic and vocational success (Moores, 1978,

Ogden, 1996, Marschark, 2010). It is also well known that academic and vocational success are linked to adult health status and life expectancy (Healthy People, 2010). California is committed to ensuring that our state's deaf and hard of hearing children will receive all of the services necessary to achieve the core outcomes set forth by the Maternal and Child Health Bureau (MCHB). Accordingly, we want to assure that deaf and hard of hearing children will grow up healthy and ready for school and work.

The California Department of Health Care Services (DHCS) Children's Medical Services (CMS) Branch contracts with health care organizations to operate geographically-based Hearing Coordination Centers (HCCs). These HCCs are responsible for certification and monitoring of newborn hearing screening programs in the hospitals. They are further responsible to assure that the NHSP operates efficiently, that screenings and services are of high quality, and most importantly, that infants failing the hearing screening test receive necessary services. The state NHSP staff have developed provider standards and certification criteria, program policies, and a Tracking and Monitoring Procedure Manual and flowcharts to assure quality in the program statewide.

The enabling legislation requires the state to have a reporting and tracking system that provides information and data to effectively plan, establish, monitor, and evaluate the NHSP, including the screening and follow-up components, as well as the comprehensive system of services for newborns and infants who are deaf or hard of hearing and their families. The statute further requires that screening providers as well as those providing audiological follow-up and diagnostic services must report data to the NHSP. Information reported and maintained within the system must be treated as medical information, which requires the program to adhere to confidentiality regulations and laws. The statute also provides that such information shall be available to those public and private entities that must carry out the intent of the NHSP. The DHCS is in the process of transitioning from a paper-based system to a statewide automated data management service to collect infant data and to track and monitor follow-up appointments for the assessment of hearing in NHSP infants.

In the United States, an average of 45 percent of the infants who fail newborn hearing screening do not receive, or there is no evidence that they receive, the necessary follow-up services to verify if a hearing loss is present. It is essential that infants who do not pass the screening tests receive prompt evaluation and intervention, if necessary. Otherwise, the benefits of early screening and identification are lost. As reported to the Centers for Disease Control and Prevention (CDC), only 18 percent of the infants in California are lost to follow-up between their final screen and completion of a diagnostic evaluation, a direct result of the HCC activities.

The NHSP has invested significant resources to outreach to and develop collaborative relationships with local public health programs, providers, local early intervention programs, and other state departments. The local California Children's Services (CCS) programs (California's Title V Children with Special Health Care Needs program) and Early Periodic Screening Diagnosis and Treatment (EPSDT) programs provide critical services to ensure that the infants who need follow-up receive it in a timely manner. The NHSP has worked in partnership with the provider community to assure that appropriate services are available to infants who need evaluation for hearing loss and those identified as deaf or hard of hearing. The HCCs have each developed collaborative relationships with the local early intervention programs in their geographic service areas.

The Early Start program is administered by two different state agencies. The California Department of Developmental Services (DDS) is the lead agency and provides services to infants and toddlers who have developmental delays through a network of 21 Regional Centers throughout the state. The California Department of Education (CDE) is responsible for services to children with solely low-incidence conditions (hearing, vision, and orthopedic conditions) through over 1000 local education agencies (LEAs). Although each LEA is financially responsible for providing Early Start services to all children who reside in its catchment area, most LEAs contract with a regional LEA to provide the services. There are 104 LEAs that provide Early Start services to children in California. The NHSP has worked closely with both departments to assure timely

referral and receipt of early intervention services for infants identified with hearing loss and their families.

The two primary purposes of the project to be funded by this grant are to continue early identification and intervention services for infants with hearing loss, focusing on 1) continuing a pilot teleaudiology project to provide diagnostic evaluations on infants who do not pass their newborn hearing screens in order to improve access to services and decrease the age of identification of hearing loss for infants in rural northern California and 2) continuing to assure that parents access needed services by providing appropriate parent-to-parent support through the Parent Links program. The University of Kansas Beach Center Study (1989-1993) has shown us that appropriate parent-to-parent support increases parents' acceptance of and capacity to cope with the situation they face having a child with hearing loss. The study strongly suggests that the kind of support parents offer is unique and probably cannot come from any other source.

The anticipated benefits of this project will be:

- All infants born in California will be screened for hearing loss at birth, with parent permission, before leaving the hospital.
- Infants with hearing loss will be identified by three months of age.
- The loss to follow-up rate for infants in the rural Northern California region who need diagnostic evaluation after an outpatient screen will be reduced by 50 percent through implementation of teleaudiology.
- Pediatric audiology capacity in the rural Northern California region will be increased by utilizing existing local audiology providers.
- Teleaudiology services will be established as efficacious and sustainable.
- Infants with hearing loss will be enrolled in Early Start services by six months of age.
- Families of deaf and hard of hearing infants and toddlers will receive comprehensive information and culturally competent family-to-family support services from trained Parent Links Mentors and trained Key Parent Links

Volunteers (KPLVs) through designated IDEA funded Family Resource Centers (FRCs).

- Infants with hearing loss and their families will receive services coordinated by the primary care physician (PCP) through a medical home.

NEEDS ASSESSMENT

The California NHSP is the largest Early Hearing Detection and Intervention (EHDI) program in the country. To effectively manage data on such a large scale, each HCC has developed an Access database to track the infants. The current data contain inherent problems associated with paper-based reporting, aggregation of data from different databases, and incomplete reporting from hospital providers. Implementation of a statewide data management service is currently underway, and when fully implemented in the HCCs, the hospitals, and the state, the data reporting capabilities will significantly improve.

California Data – Calendar Year 2010	
Number of live births	510,981
Number of hospitals with licensed perinatal services	258
Number of out-of-hospital births (est)	3,080
Number (%) of infants screened	505,847 (99%)
% refer at time of hospital discharge	2.4%
Number (%) needing outpatient screen	13,392 (2.6%)
Number (%) referred for diagnostic evaluation after outpatient screen	2765 (0.5%)
Number (%) who completed diagnostic evaluation	2012 (73%)
Number (%) identified with hearing loss [Number of additional infants with hearing loss for whom the NHSP has no screening data]	925 (0.18%) [41]

Number (%) identified with hearing loss by three months of age	620 (67%)
Number (%) known by NHSP to be enrolled in early intervention*	809 (87%)
Number (%) known by NHSP to be enrolled in early intervention by six months of age	593 (73%)
Number (%) of infants needing a diagnostic evaluation after an outpatient screen who have an identified PCP	2121 (77%)
Number (%) of infants lost to follow-up between final screen and diagnostic evaluation (as reported to the CDC)	572 (18%)
Number (%) of infants lost between hospital discharge and outpatient (re)screening	392 (2.9%)
Number (%) of infants lost between outpatient (re)screening and audiologic diagnosis	125 (4.5%)
Number (%) of infants lost to follow-up between audiologic diagnosis and entry into early intervention	3 (0.3%)

*The number of infants who are enrolled in early intervention is under-represented in the data above. The NHSP has experienced difficulty obtaining this information, as the Early Start programs in California are not relieved of their confidentiality restrictions by the legislation authorizing the NHSP.

There are 77 audiology facilities in the state that have been approved by the CCS program to serve infants and children under three years of age. However, the quality of services provided continues to be a challenge. Very few providers utilize bone conduction when performing diagnostic testing. Consequently, the identification of the type of hearing loss is either not determined or significantly delayed. Audiologists send these infants to an otolaryngologist or have them return to the audiology office after several months to see if the hearing has normalized or if the shape of the tympanogram has improved. These repeated return visits result in delayed diagnosis in addition to

reducing the number of appointments available to perform testing on other infants and children.

The audiology facilities approved to see infants are not evenly distributed throughout the state. In the rural northern third of the state, between Sacramento and the Oregon border, there are only two audiology providers, located on the coast, willing to see low-income infants and children. In this large rural area of the state, 22 percent of the infants who did not pass the outpatient screen and needed diagnostic evaluations in 2010 were lost to follow-up. This compares with an average of 4.5 percent of infants in the state lost to follow-up at this stage of the identification process. There are an estimated 13,300 annual births in the counties north of the Sacramento/Lake Tahoe region. Of this number of screened infants, approximately 80 will need a diagnostic evaluation. Assuming a lost to follow-up rate of 22 percent, up to 18 infants will be lost between the outpatient screen and the diagnostic evaluation. The teleaudiology project expects to decrease this loss to follow-up rate by 50 percent.

The telemedicine project provides audiology services closer to the infant's home, thereby eliminating the problems inherent in traveling long distances. Most of these infants would otherwise be given appointments with providers in the San Francisco Bay Area (who are reaching capacity with wait times for appointments up to three to four months). The travel time by car to access these appointments can be up to eight hours each way, a significant deterrent for families. Having services available within two to three hours of the infant's home is cost saving for families, reduces their carbon footprint and is particularly useful in cases where more than one visit is required to complete the diagnostic testing. Continued funding of the project will allow more infants to receive services closer to home and potentially expand to include remote hearing aid fittings.

California has reached a crisis in access to appropriate pediatric audiology for infants who do not pass their newborn hearing screen. A study conducted in 2005 by Mathematica Policy Research identified California as one of the states with the fewest

audiologists per capita (2 per 10,000 or fewer). To compound that situation, a clinical doctorate (Au.D.) has replaced the Masters degree as the minimum standard for clinical practice, but only a single Au.D. program is operating in California (with a maximum enrollment of 10 candidates per year). Therefore, few new audiologists are being trained in California. Teleaudiology is a viable and potentially sustainable approach to improve the critical access issue in northern California.

Once children are identified with hearing loss through the NHSP, there is an urgent need to provide comprehensive, parent-to-parent support that meets the needs of families with a deaf or hard of hearing infant. Each HCC has a parent coordinator that can provide a minimal level of family-to-family support for parents. In January 2009, the HCCs began referring parents of newly identified infants to the Parent Links program. CDE is utilizing MCHB funds to provide grants to three regional IDEA funded FRCs to provide the Parent Links parent-to-parent support program. Each of these three FRCs employs two or more parents of a child who is deaf or hard of hearing. There are eight Parent Links Mentors in all. Two of the Parent Mentors are native Spanish speakers, one speaks German, and all are fluent in American Sign Language (ASL). Staff at the HCCs receive parent permission to refer the families to the Parent Links program when they make the first parent contact one week after identification of a confirmed hearing loss. If the family declines referral, HCC staff asks at the next parent contact. Parents are not always ready for this family-to-family connection at these very early stages, so the Parent Links staff has made outreach efforts to the school districts and regional centers that provide Early Start services to deaf and hard of hearing infants and their families. Since January 2009, more than 900 families have requested referral to Parent Links. Award of this grant would allow continuation of this critical parent-to-parent support throughout California, with the goal of providing training to staff at other FRCs, and establishing a viable parent support organization in our state, in order to sustain an appropriate family support system when grant funding is no longer available. This family support will become even more critical in the next years, as the California budget crisis has caused State General Funds that supplement federal IDEA Part C funds to be reduced.

METHODOLOGY

The activities used to support the needs of the program mirror the 1-3-6 national EHDI goals: screening, evaluation, and intervention. However, the programmatic foundation that supports each activity includes the use of advisory committees and quality improvement measures. The information and direction from advisory committees and quality improvement measures traverse all program activities and result in more efficient strategies for overcoming barriers and reaching program goals.

Advisory Committees

The NHSP has long valued connection to advocates, providers, families, and other stakeholders as an integral part of the development of policies and procedures and on-going quality assurance activities. Prior to and during initial implementation phases of the NHSP, decisions were guided by an advisory committee composed of stakeholders, advocates for and parents of deaf and hard of hearing children, early interventionists, deaf educators, audiologists, physicians, as well as representatives of children's hospitals and state agencies. The advisory committee met quarterly, reviewing program infrastructure, procedural issues, and parent materials. In 2005, then Governor Arnold Schwarzenegger, in an effort to reduce spending, ordered the elimination of all non-legislated advisory boards and committees. While a valuable resource, provisions for the NHSP advisory committee were not included in legislation. Consequently, California is prohibited from convening meetings of the now disbanded advisory committee. To maintain communication and to solicit input from the community, CDE recently convened a committee of parents to develop a Parent Resource Guide, with the goal of ensuring that parents receive comprehensive and balanced information about all language opportunities and communication tools available to them. The guide will emphasize for parents the importance of monitoring their children's language growth, so that their children have age appropriate language when entering kindergarten. The

guide will also include lists of local, state and national resources, including schools, camps, organizations, deaf access agencies, web sites, books, and research articles. The group, comprised of 14 parents, has a Northern California and a Southern California representative from each of the following: Parent Links, HCCs, public schools, state schools, nonpublic schools, IMPACT (parents' organization) and members of Hands and Voices. Three of the parents are Deaf. The group met four times between September 2011, and January 2012, and is continuing its work by email. Additionally, DHCS audiology consultants conduct quarterly meetings with the HCC audiology staff to identify issues around the state as well as quarterly meetings with approved cochlear implant centers. NHSP staff, HCC Directors, and American Academy of Pediatrics (AAP) Chapter Champions have conference calls every other month to address physician education strategies and approaches. CDE staff meets monthly, by telephone with FRC Parent Links mentors.

Quality Improvement

Quality improvement strategies to reduce loss to follow-up from the inpatient hearing screen to the diagnostic appointment have been tested by the NHSP quality improvement learning collaborative. Focused on the Los Angeles area and the region served by the Southern California Hearing Coordination Center (SCHCC), California was one of the states that participated in the first National Initiative for Children's Healthcare Quality (NICHQ) learning collaborative focused on improving follow-up in the EHDI process by implementing "small tests of change" and evaluating the success of those tests. The collaborative has been meeting every two weeks by conference call since it was originally established in June 2006. Collaborative members include the DHCS NHSP program, CDE, DDS, University of California Los Angeles (UCLA) nursery (2000 births/year), UCLA audiology clinic, Los Angeles Unified School District and the Orange County Office of Education (local Early Start providers), California School for the Deaf, SCHCC, parents/deaf adults/deaf and hard of hearing advocates, Parent Links, AAP Chapter Champion, a representative from a medical home project, and a health insurance representative.

Because the California NHSP model is unique, our approach to quality improvement has been tailored to take advantage of the role of the HCC as a key central coordinating agency. Examples of strategies to reduce loss-to-follow-up include:

- HCC role-playing sessions for hospital staff in how to (and how not to) provide results of inpatient hearing screens to parents. This was identified as an issue by the HCC in their follow-up phone calls with families. The HCC has developed scripts and provided them to hospital staff.
- Education of parents of infants with atresia. HCC staff identified a problem with the information these parents received from hospital staff. Hospital procedures were modified at UCLA to notify the audiology clinic when an infant is born with atresia. An audiologist now provides counseling to the parents prior to hospital discharge.
- Obtaining an additional contact person for all infants prior to discharge from the hospital. This is a required component in the Inpatient Infant Hearing Screening Provider standards. However, it is not well reported by hospitals (baseline 76 percent). Infant Reporting Forms (IRFs) are returned to the hospital if this information is not provided. The HCC reports on this data quarterly and provides updates to hospitals during semi-annual director meetings.
- Reporting of the PCP that will see the infant as an outpatient. This is also a requirement of the Inpatient Infant Hearing Screening Providers standards. Reporting of this item occurs 86 percent of the time. Returning the incomplete IRFs has been a successful strategy. As hospitals move to online data reporting, this issue will need to be closely monitored.

- Scheduling outpatient rescreen appointments prior to hospital discharge for all infants who do not pass the inpatient screen. This is a requirement of the Inpatient Infant Hearing Screening Provider standards and is an item that has not been noted to be an issue.
- Strategies to reduce no-show appointments for outpatient screens and diagnostic evaluations. Several approaches have been tried, including education/reminder calls to the family prior to all outpatient rescreen and diagnostic evaluation appointments, sending an introductory letter with information about the importance of follow-up and the role of the HCC, sending reminder letters prior to the appointments and calls if a family no-shows an appointment, and educating hospital staff in explaining the importance of follow-up to the families. Some of these strategies proved to be too labor-intensive to continue on a regular basis. At the beginning of the collaborative the baseline no-show rate for the region was 12.4 percent. Most recently it was 10 percent for outpatient rescreens and 7.5 percent for diagnostic evaluations.
- Scheduling two audiology appointments two weeks apart for diagnostic evaluation. This has proven to be a successful strategy for UCLA. However, it has been difficult to spread to other providers. This approach is also being tested in the Teleaudiology Project.
- Facilitating a three-way call with the family and diagnostic provider to expedite the process to schedule a diagnostic appointment after an authorization for service has been issued. This has improved the timeliness of appointment scheduling.

Program Activity 1: Infant Hearing Screening

As stated earlier, California legislation requires that all infants born in general acute care hospitals with licensed perinatal services be screened for hearing loss at birth, with parent permission, before leaving the hospital. To ensure compliance with program guidelines, the HCCs evaluate every inpatient infant hearing screening provider prior to certification. Additionally, the HCCs monitor hospital data to ensure that the facilities consistently adhere to the NHSP standards for refer, miss, and waive rates and report results and admissions accurately. With only five hospitals remaining for certification, all current general acute care hospitals with licensed perinatal services in the state will be certified by and participate in the NHSP by 2013 and will be able to bill Medicaid (Medi-Cal in California) for screening services provided to eligible children. To assist in identifying children with later onset hearing loss, DHCS intends to explore collaborative activities with DDS regional centers, Early Head Start and Head Start to encourage the adoption of OAE hearing screenings. DHCS also intends to explore collaborative activities with the Home Visiting program established by the Department of Public Health.

Program Activity 2: Infant Diagnostic Audiologic Evaluations

The NHSP is working towards a goal where infants with hearing loss will be identified by three months of age and have initiation of Early Start services by six months of age. DHCS aims to reduce the number of children lost to follow-up with the continuation of the California Teleaudiology program, and potential exploration of remote hearing aid fittings.

The needs assessment clearly portrays the Northern California region as a critical area for focus of additional activities to lower the loss to follow-up rate. The size and topography of the region, as well as a shortage of qualified pediatric audiology providers, results in overwhelming obstacles to quality and timely services for the diagnostic appointment. While there are outpatient screening facilities accessible in

most of the rural counties of the north, the driving distance (between 200 to 460 miles through mountainous terrain) necessary to access a diagnostic appointment is not only a deterrent, but a hardship for most families, putting these infants at risk for lost to follow-up.

According to the Joint Committee on Infant Hearing Year 2007 Position Statement, an infant diagnostic evaluation should include child and family history, auditory brainstem response (ABR) through air and bone conduction, otoacoustic emissions, high frequency tympanometry, and clinical observation as a cross-check to the electrophysiologic measures. The ABR is an electrical signal evoked from the brainstem as a response to a repetitive auditory stimulus, either a click or frequency specific tonal bursts. Electrodes are placed on the infant at the ears and the cortex, and while in a sleep state, the response through the cochlear nerve is averaged by the computer and interpreted by the audiologist. Hearing loss can be estimated by changing the intensity of the stimulus and measuring the deterioration of the response. When a stimulus is presented using a combination of air conduction (through an insert earphone) and bone conduction (a bone oscillator placed on the forehead or mastoid which stimulates the cochlea), the type of hearing loss can be determined. This is essential in determining if the infant has a conductive hearing loss which may be caused by middle ear fluid, or a sensorineural hearing loss which would be permanent and require amplification. Otoacoustic emissions (OAEs), though not a measure of hearing acuity, can demonstrate inner ear health and also be an indication of the site of lesion for hearing loss in infants. Tympanometry is an objective test of middle ear function and measures the mobility of the ear drum, and therefore indirectly can determine middle ear effusion and the possible presence of otitis media. A high frequency probe tone is specifically indicated for infants due to the greater mass contribution to middle ear impedance.

These three critical components of infant audiology assessment are measured and recorded through computerized technology, which is ideal for telehealth practice. With the addition of video otoscopy and a clinical history interview conducted through web-based video communication, a complete diagnostic evaluation can occur electronically

and in real-time without the clinician and the family ever being in the same room. Diagnostic equipment is available with the capability for synchronous, or real-time data sharing, as well as store-and-forward.

The California Teleaudiology Project uses a synchronous teleaudiology approach where the clinician, equipment, and patient are connected via telecommunication in real time. The infant diagnostic evaluation looks and feels much like a traditional appointment in the practitioner's office. The infant and family report to a local health facility (referred to as the "remote site") for the appointment. A technician specifically trained in teleaudiology escorts the patient and family to the examination room where the infant is prepped for the evaluation. As soon as the family is ready for either communication with the audiologist or for the assessment to begin, the real-time connection to the audiologist at the host site using the telemedicine video equipment is activated. The technician's responsibilities include inserting the otoscope for video transmission to the audiologist, placing the tympanometry probe tip in the ear of the infant, placing the probe tip for the OAE measurement, and placing the electrodes and the appropriate earphones on the infant for the ABR. The audiologist at the host site, through the synchronous telemedicine connection, manipulates settings, intensity levels, and stimulus as she would if the infant were at her own facility. The technician is trained to follow all instructions from the audiologist with regard to probe, electrode, or ear phone placement and remains in the room with the patient and family during the course of the evaluation. Any pre- or post-evaluation counseling is conducted by the audiologist through the video equipment and the computerized connection between the remote and host site. A complete evaluation can be accomplished, and should results be questionable, the audiologist has the option to request the family to come directly to the host site for further testing or counseling. Experience with the California project indicates that in the majority of cases, one or two visits to the remote site provides sufficient information to determine the hearing status and potential treatment of an identified hearing loss.

Telehealth is infrequent in current audiology practice, though it is beginning to be recognized as a viable option as the importance of early identification and limited number of audiologists are realized. There have been limited studies published, some exploring telemedicine and tinnitus, video nystagmography, cochlear implant mapping, pure tone threshold testing, infant hearing screenings, and some auditory brainstem response testing. Generalization to clinical practice has not yet occurred, as research studies have had small sample sizes, most subjects have not had hearing loss, and laboratory settings have been used instead of authentic health care environments. In 2005 the American Speech-Language Hearing Association (ASHA) recognized the progress of telemedicine, established a workgroup for telepractice, and published a technical report for audiologists providing clinical services through telepractice. In this document, ASHA advocates for the reimbursement of teleaudiology, continued research in technology and applications of teleaudiology, statewide acceptance of teleaudiology through licensure, and institutional and administrative support. Likewise, the American Academy of Audiology has offered courses regarding telemedicine and its use in audiology. ABR evaluations in infants have been successfully implemented since 2002 in Canada by the Ontario Infant Hearing Program. If a child does not pass the ABR evaluation in that program, a face-to-face diagnostic assessment is conducted. Likewise, Minot State University in North Dakota is developing protocols for teleaudiology, but has not implemented this technology on a large scale.

The practice of telemedicine is currently utilized in Northern California, with the University of California, Davis Health Systems (UCDHS) playing a significant role. The UC Davis (UCD) Telehealth Program was established in 1996. The UCD Telehealth Program currently offers inpatient and outpatient telemedicine and telehealth subspecialties. Pediatric outpatient services include dermatology, endocrinology, genetics, infectious disease, nephrology, orthopedics soft tissue, otolaryngology, weight management, and most recently, audiology through the California project. UCD has continued to be a leader in research, publications, education, and the clinical practice of telemedicine. Collaborating with the UCD Telehealth Program and the UCD Audiology

Clinic combines expertise and experience, and offers the same high quality of care to infants requiring a diagnostic appointment in the rural areas.

For the purposes of this project, the teleaudiology is limited to infants under the age of four months referred from the NHSP in Shasta County and the surrounding counties in Northern California. The major city in this region, Redding, is 160 miles from Sacramento and has a population of approximately 84,000. While there are five birthing centers near Redding, no medical center houses an audiology department for the diagnostic evaluation of infants. Private practice audiologists in the area are limited by cost, capacity, and infant diagnostic experience. The infants seen through the teleaudiology project will not require sedation, thereby eliminating the need for the additional monitoring necessary when using sedation. Continued audiologic management of the infant, should a hearing loss be identified through the electrophysiologic measures performed through teleaudiology, will be a collaborative effort between the UCD pediatric audiologist and a local audiologist.

The project will also explore the possibility of remote hearing aid fittings for children, if additional funding becomes available. We plan to work with a very small number of patients in the second and third years to determine how this can be accomplished. Hearing aid fittings would be initially conducted in a location separate from the location of the audiologist on the UCD campus, then transitioning the patient location to a community audiology/hearing aid dispensing office, thereby eliminating the need to purchase additional equipment. Patients would be referred to the UCD otolaryngology department for hearing aid clearance and the CCS program for authorization and payment of the hearing aid.

The need for teleaudiology will not diminish with time, and establishing protocols and adequate funding will be essential for its long-term viability. With the foundation of telemedicine established in California through the California Telemedicine Development Act (1996), Medi-Cal has applied this law to evaluation and management (E&M), psychiatry, ophthalmology, and dermatology. While ophthalmology and dermatology

employ the asynchronous, store-and-forward method, E&M and psychiatry practice the synchronous system, with the patient contact occurring in real-time or near real-time (delayed only in seconds). Specified Current Procedural Terminology (CPT) codes for E&M and psychiatry are reimbursable and billed with a modifier that indicates the service is rendered via interactive audio and telecommunications systems. The use of this modifier does not alter the reimbursement of the CPT code, but merely allows for tracking of services rendered using this approach. Additionally, the remote site is authorized a site facility fee billable with the Healthcare Common Procedure Coding System (HCPCS) code Q3014 and the transmission costs per minute, using T1014, for up to 90 minutes per day per patient and provider contact. With this groundwork already accomplished, and the recent 2011 expansion of the Telemedicine Act to include licensed providers, extending the current reimbursement policy and system programming to audiology CPT and HCPCS codes is a reasonable and achievable approach. Consultation between the DHCS audiology consultant, the telemedicine medical consultant, and the Medi-Cal fiscal intermediary, during the course of the project, will result in an authorization and reimbursement process for the long-term financial support of teleaudiology.

Through this project data will be collected to measure the efficacy of teleaudiology and for publication to share findings with the audiology and telemedicine community nationally for further application to rural and urban areas in need of infant diagnostic services. While the HCC will continue to collect the NHSP data and track the individual infant, the UCD audiologist and the NHSP audiologist will actively monitor the progress of the teleaudiology program. A database will be developed for the UCD audiologist to record infant name, date of birth, city and county of residence, date of referral, date of contact, date and time of first and subsequent scheduled appointments, length of audiology time in the appointments, appointment status (did not show, unable to complete, diagnosis completed), and results of first and subsequent appointments (rescheduled, second appointment necessary, diagnostic results). A results section and brief treatment plan (hearing aids, cochlear implant, continued follow-up with pediatrician), as well as the referral to the local audiologist and physician will also be

tracked on each evaluated infant. A second database or spreadsheet will separately track the infants diagnosed with hearing loss, the referrals for hearing aids, any mentoring questions, problems, comments, and results with the local audiologist. Additionally, a brief follow-up questionnaire will be given to the parents following their appointment to measure parent experience and satisfaction.

The teleaudiology pilot project in Northern California offers the medical community an authentic clinical approach to new practice methodologies, as well as the measurable outcomes needed in current research and publications. Northern California is rural and, not unlike a majority of the nation, finds itself in need of quality care without imposing a hardship on the families. Easing the burden of care and reducing barriers through the innovative use of technology will support the national EHDI goals to decrease the loss to follow-up rate and improve the early detection of hearing loss by three months of age. Continued monitoring and revision of protocols through this grant will result in a tested rural care teleaudiology program that can be shared and adapted throughout the nation. Finally, with cooperation from the research experts from the UCD Telehealth Program, outcome measures can be analyzed and validated for the long term, clinical use of teleaudiology.

Program Activity 3: Early Intervention

CDE, DDS, and DHCS have implemented a single-point-of-entry toll-free phone referral line at the CDE Deaf and Hard of Hearing (DHH) Unit Office to streamline the process for referring infants to Early Start. In addition, CDE and DHCS collaborated to develop and disseminate a referral form, so that audiologists may fax the referral to CDE, if they prefer, to a dedicated fax line in the DHH Unit. CDE and DDS have informed all Early Start providers of the process, and DHCS has informed all audiologists approved to serve children through the CCS program regarding this process. The number of referrals and age is monitored both by the HCCs and CDE. The HCCs provide a safety net by reminding providers to make the referral, as well as referring the child themselves. CDE accepts referrals of all children birth-three, including those who were

not identified through the NHSP (e.g., children who were born in other states or countries, or have later onset hearing loss), so the number of referrals exceeds the number of infants identified through the NHSP.

Beginning in January 2009, and to be continued provided this grant is approved, parents of infants identified with hearing loss through the NHSP have been referred to the regional FRC Parent Links program. Three regional FRCs, the Rowell Family Empowerment Center (RFEC) in Northern California, Exceptional Parents Unlimited (EPU) in Central California, and the Family Focus Resource and Empowerment Center (FFREC) in Southern California, have been awarded grants utilizing MCHB funding to provide parent-to-parent support for families of infants identified through the NHSP. Each of these FRCs has two or more Parent Mentors (parents of children who are deaf or hard of hearing). There are eight Parent Mentors in all. They have received training from former Parent Links Mentors and from the American Society for Deaf Children (ASDC). All of the Parent Mentors have many years of experience working in FRCs and are trained in parent driven, professionally collaborative mentorship. Two of the Parent Mentors are native Spanish speakers, one speaks German and all of the Parent Mentors are fluent in ASL.

Using the resources of the Parent Links program capitalizes on our greatest resource - parents. Our belief is that another parent of a child with hearing loss will be the most supportive influence for a family of a deaf or hard of hearing infant. No one better understands what these parents are going through than another parent who has been through the same experience. One of the Parent Links Mentors, who was a beneficiary of parent-to-parent support herself, expressed it this way, "Finding out information through professionals is a co-pay and a call away. However, I have found that there is more truth from the experiences of other families. Parent-to-parent support is essential for a holistic approach of a DHH child's development and the difficult choices each family must make. I am honored to be a Parent Mentor. It's my goal to create a safe, supportive place to listen, share, and encourage families to love their little miracles."

The CDE is collaborating with Parent Links to develop a list of Key Parent Links Volunteers (KPLVs), who can provide parent-to-parent support for parents of infants identified through the NHSP. The KPLVs will learn how to provide parents with comprehensive information, and will guide and support parents in exploring choices about language and communication that are right for their child and their family. Parent-to-parent support must also guide parents in the process of working collaboratively with Early Start providers. To date, seven KPLVs have been trained, and four more parents have been identified to be trained in the near future. In addition, the FRCs collaborate with the outreach centers at the California Schools for the Deaf, which have identified and trained 25 parents in the provision of family-to-family support.

Additional support for ongoing intervention can be found in the medical home. The medical home is, for NHSP programmatic purposes, the PCP identified by the hospital, family, or another provider as the ongoing care provider for an infant who did not pass the inpatient screen. The PCP is notified by the HCC of the results of all outpatient screenings and diagnostic evaluations, along with any scheduled or recommended follow-up appointments. The PCP has the responsibility of assisting families with the follow-up appointments and coordination of services. To ensure that California's PCPs understand the coordination of services through the medical home model, the EHDI Coordinator will collaborate with the AAP Chapter Champions and the HCCs to get information and education to local physicians regarding their role in the coordination of services for infants served by the NHSP. Currently, the EHDI Coordinator and the NHSP Audiologist meet every other month with the HCC Directors and AAP Chapter Champions in California. The collaboration is focused on educating primary care providers or medical homes about the NHSP to foster coordination of care. Dr. Sarah Eitzman, AAP Chapter Champion in northern California, is creating a podcast describing the NHSP and the role of the medical home as it relates to the program and infants identified with hearing loss.

WORK PLAN

Program Activity 1: Infant Hearing Screening

GOAL 1. All infants born in California will be screened for hearing loss at birth, with parent permission, before leaving the hospital.

Objectives	Required Staff and Resources	Timeline	Evaluation
<p>DHCS will complete implementation of the NHSP expansion to all general acute care hospitals with licensed perinatal services</p>	<p>DHCS staff, led by EHDI Coordinator and assisted by HCC staff</p> <p>█ from this grant. These activities are funded by the California State Legislature through the California NHSP.</p>	<p>9/1/12 – 8/31/13</p>	<p>All general acute care hospitals with licensed perinatal services in California will be certified and participate in the NHSP.</p>
<p>DHCS will maintain and monitor the quality of the NHSP, screening over 500,000 infants each year.</p>	<p>DHCS staff, led by EHDI Coordinator and assisted by HCC staff</p> <p>█ from this grant. These activities are funded by the California State Legislature through the California NHSP.</p>	<p>9/1/12 – 8/31/15</p>	<p>DHCS HCCs will collect and maintain data on the number of infants screened. The data will be reported to DHCS. DHCS will monitor the data to evaluate the success of the NHSP, and the need for technical assistance for hospitals.</p>

To date, 253 hospitals have been certified to participate in the NHSP. Five hospitals are pending certification and the rest are military hospitals that are not licensed in California and not required to participate. DHCS recertifies hospitals as continuing to meet

program standards, monitors program quality, and provides on-going technical assistance to the certified hospitals.

Program Activity 2: Infant Diagnostic Audiologic Evaluations

GOAL 2: Infants with hearing loss will be identified by three months of age.

Objectives	Required Staff and Resources	Timeline	Evaluation
DHCS HCCs will continue to track infants referred for outpatient screenings and diagnostic evaluations and follow up with families to ensure that appointments for screenings and diagnostic evaluations are kept.	HCC staff, with monitoring by EHDI Coordinator █ from this grant. These activities are funded by the California State Legislature through the California NHSP.	9/1/12 – 8/31/15	HCCs will collect and maintain data on the number and ages of infants receiving diagnostic evaluations and those identified with hearing loss through the NHSP, and on the number of infants who are lost to follow-up.
To improve loss to follow-up and timeliness of identification, the Northern California HCC will refer infants who refer from the outpatient screen and reside in pre-identified Northern California counties to the Teleaudiology Pilot Program.	HCC staff, UCD staff, and DHCS Program Audiologist █ from this grant. These activities are funded by the California State Legislature through the California NHSP.	9/1/12 – 8/31/15	The Northern California HCC will closely track the time of referral from the outpatient screen to the diagnostic evaluation and monitor missed appointments/lost to follow-up. DHCS, in collaboration with UCD, will also track appointments missed, average travel, and results.

Tracking and follow-up activities are a required component of the HCC contracts and are funded by the California State Legislature. In California, the majority of infants lost to follow-up are those whose families fail to show for outpatient screening within two

weeks after leaving the birthing facility. To combat this, the HCCs notify the PCP of the no-show and contact the families to:

- Find out and document (for program evaluation and quality improvement purposes) why the family failed to show for the appointment
- Help the family solve issues that prevented them from keeping the appointment (e.g., by providing parents with names of audiology providers close to their home)
- Stress the importance of making and keeping a new appointment
- Answer any questions the family may have
- Give the parents their name and phone number, so that the parents may call the HCC

Rural counties in Northern California were identified as having the worst loss to follow-up rates in the state for infants requiring a diagnostic evaluation. This is, in part, due to the paucity of audiology providers in that region of the state willing or able to evaluate infants, and the distance required to travel for a complete diagnostic evaluation (See Goal 3).

GOAL 3. The loss to follow-up rate for infants in the rural Northern California region who need diagnostic evaluation after an outpatient screen will be reduced by 50 percent through the implementation of teleaudiology.

Objectives	Required Staff and Resources	Timeline	Evaluation
DHCS will execute a new interagency agreement with UCD for the teleaudiology project	DHCS staff and UCD staff █ from this grant	9/1/12 – 12/31/12	Interagency agreements in place.
UCD will provide diagnostic evaluations via teleaudiology to families of infants less than four months of age	UCD staff and Mercy Redding staff with monitoring by DHCS Program Audiologist █ per year	1/1/13 – 8/31/15	Infant data being collected. Loss to follow-up rate and age at completion of diagnostic evaluation will be tracked for Northern California counties.

Our plan is to continue funding the Teleaudiology Pilot Project, which was implemented in Fall 2011 with the UCDHS through MCHB funding. The NHSP manager, audiologist, and EHDI Coordinator will work with UCD to finalize the scope of work and budget for the interagency agreement. The DHCS team will shepherd the agreement through the department review process for signature and execution. Funding will provide for the pediatric audiologist, assistant research professor, and project manager at UCD, and the remote site space and technician. Once the contract is executed, the technician at the remote site in Redding will schedule appointments for the diagnostic evaluations, assist the families upon arrival, connect the patient to the equipment, assist the UCD audiologist with probe placement, and monitor the telemedicine connection with the UCD audiologist. The UCD audiologist will perform the evaluations and counsel the families regarding the results using the telehealth connection, cameras, and monitors. Follow up reports will be sent to the UCD medical record, the HCC, DHCS, the family, and if necessary, Early Start. Results will be reported to the HCC for tracking and monitoring.

GOAL 4. Pediatric audiology capacity in the rural Northern California region will be increased by utilizing existing local audiology providers.

Objectives	Required Staff and Resources	Timelines	Evaluation
A mentoring component between host and local audiologists will be implemented.	DHCS Program Audiologist and UCD Audiologist Will be funded with money in Goal 3.	7/1/13-8/31/15	Local audiology provider identified. Mechanism for communication and consultation is in place. Infant data being collected. Number and percent of infants with hearing loss who receive ongoing audiologic management within the targeted region will be tracked.

The feasibility of fitting hearing aids using telemedicine will be explored.	UCD Audiologist Will be funded with money in Goal 3.	7/1/13-8/31/15	Infants in location separate from the audiologist will be fit with hearing aids by UCD audiologist .
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In order to prevent infants with hearing loss from having to travel long distances for their ongoing audiologic management, the DHCS audiologist will attempt to identify at least one local audiologist who is interested in participating in this pilot project. The DHCS audiologist will coordinate communication between the local and UCD audiologists for mentoring activities. The UCD audiologist will provide consultation, technical assistance, and support to the local audiology provider for on-going management of infants through the teleaudiology pilot project.

For continuity of care, the mentored audiologist or a local hearing aid dispenser will be identified to test the feasibility of the UCD pediatric audiologist to remotely fit a hearing aid. UCD staff will develop and implement a protocol to fit hearing aids on infants and children in a location on the medical campus separate from the audiologist, beta testing the protocol on adults prior to implementation on infants. If this is successful, the mentored audiologist or hearing aid dispenser can be recruited to serve as the remote location. This objective is limited to the willingness of participation by local providers and the current equipment capabilities.

GOAL 5. Teleaudiology services will be established as efficacious and sustainable.

Objectives	Required Staff and Resources	Timelines	Evaluation
The use of teleaudiology for diagnostic evaluations will prove efficacious.	UCD Assistant Research Professor and DHCS Program Audiologist Funding in Goal 3	1/1/13 – 8/31/15	UCD and DHCS will collect and analyze data related to the cost of no-show appointments, travel, lost to follow-up, and patient satisfaction.

<p>An authorization and reimbursement system for teleaudiology will be established.</p>	<p>DHCS staff, led by Program Audiologist ■ from this grant</p>	<p>9/1/13 – 8/31/15</p>	<p>HCPCS and CPT codes will be activated in the Medi-Cal claims reimbursement system, and payment will be realized by UCD and Mercy Redding Medical Center.</p>
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Data collected from the HCC, DHCS, and UCD will be aggregated and analyzed by the UCD Assistant Research Professor for decreases in loss to follow-up, cost effectiveness related to travel and missed appointments, and parent satisfaction. For teleaudiology services to be sustainable, a reimbursement process must be in place. DHCS staff will meet with state Medi-Cal staff to discuss and agree on codes and modifiers. Once approved, the remote and host sites will submit claims to test the authorization and reimbursement system. DHCS staff will follow claims through the process to ensure payment.

Program Activity 3: Early Intervention

GOAL 6: Infants with hearing loss will be enrolled in Early Start services by six months of age.

Objective	Required Staff and Resources	Timeline	Evaluation
<p>DHCS and the CDE DHH Unit will continue to improve upon established procedures for referrals to Early Start.</p>	<p>CDE Coordinator ■ from this grant. CDE has provided the funding for the toll-free phone line and a dedicated fax line. DHH Unit staff time is in-kind from CDE.</p>	<p>9/1/12 – 8/31/15</p>	<p>CDE will maintain data on the number of referrals received via the toll-free line and by fax, and the referrals made to Early Start. The data will include the age, in months, at which the infant was referred to Early Start. CDE staff will report information regarding the referrals to DHCS. CDE and DDS will maintain and report the numbers of deaf and hard of hearing infants enrolled in Early Start.</p>

From a single-point-of-entry toll-free phone referral line and a dedicated fax line at the CDE DHH Unit Office, audiologists may call or fax the Early Start referral to CDE. When a referral is received, CDE DHH Unit staff forwards the referral to the appropriate local Early Start provider within 48 hours. Funding for the toll-free phone line, the fax line, and staff time is in-kind from CDE.

GOAL 7. Families of deaf and hard of hearing infants and toddlers will receive comprehensive, culturally competent, family-to-family information and support services from trained Parent Mentors and trained Key Parent Links Volunteers through designated Family Resource Centers.

Objectives	Required Staff and Resources	Timeline	Evaluation
<p>DHCS will make available materials related to the NHSP in a variety of languages, and CDE will publish a resource guide, which will include information about available language opportunities and communication tools, as well as about hearing loss.</p>	<p>EHDI Coordinator and CDE Co-Director</p> <p>█ from this grant.</p>	<p>9/1/12 – 8/31/15</p>	<p>Parents of infants identified through the NHSP and enrolled in Early Start will be surveyed regularly by the Parent Links Mentors to determine their satisfaction with services throughout the entire screening, diagnostic, and enrollment in Early Start process, as well as connection to family-to-family support.</p>
<p>Early Start programs will provide all written information to parents in the parents’ home languages. Translators will be available at meetings with parents, to ensure parents understand and are able to participate at all stages of the assessment and</p>	<p>Monitoring by CDE Special Education Division</p> <p>█ from this grant.</p> <p>These activities are a requirement of state and federal law.</p>	<p>9/1/12 – 8/31/15</p>	<p>Evidence of these activities is already a required component of the Compliance Review process conducted by DDS and CDE.</p> <p>Parent Links Mentors will inquire about and maintain data about the provision of services in the parents’ home language.</p>

development of the Individualized Family Service Plan (IFSP).			
CDE and DHCS will collaborate with existing FRCs to provide appropriate, parent-to-parent support for families of infants identified through the NHSP.	CDE, DHCS, and FRC staff, led by CDE Co-Director ██████████ per year	9/1/12 – 8/31/15	FRCs will collect and report data on the number of parents trained as KPLVs, and the number of families provided parent-to-parent support through the Parent Mentors and KPLVs. Parent Links Mentors will ask parents about their experiences with parent-to-parent support. The FFREC will establish a database to maintain quantitative and qualitative data regarding parent support and parent satisfaction.

All parents of infants with a hearing loss identified through the NHSP will receive parent materials that include descriptions of the various language opportunities and communication tools available. General NHSP information pamphlets and brochures that explain the results of hearing screening and referrals are available for download on the NHSP website.

Early Start Programs provide written information to parents in the parents' home languages. Translators will be available at meetings with parents, to ensure that parents understand and are able to participate at all stages of the assessment and development of the IFSP. These activities are already a requirement of both state and federal law. Compliance with the requirements will be monitored through the already established CDE/DDS procedures for compliance monitoring.


The CDE has provided grant money from current MCHB grant funding to establish the Parent Links program at three IDEA funded FRCs, RFEC in Redding, EPU in Fresno, and the FFREC in Northridge. The FRC Parent Links Mentor will provide each family referred with six-ten hours of services, which will include the following:

- Discussion with the family about their needs
- Information about hearing loss
- Comprehensive information about language opportunities and communication tools, and the importance of language development during the ages of birth-three
- Discussion of how to access information about opportunities/assistance to start the family on the path to conducting its own research
- Information on how to connect to Early Start, if the family is not already connected
- Information about Early Start and what kinds of services family can expect to receive
- Information about FRCs and information about what to expect from the FRC
- Connection of the family to the local FRC
- Connection of the family with a local trained KPLV for ongoing support

The Parent Links mentors are developing a list of KPLVs and are providing them with training in how to provide parent-to-parent support for parents of infants identified through the NHSP. In addition, each of the Parent Links Mentors and KPLVs will set up family events, such as picnics, to provide families with opportunities to meet with other families, and to meet deaf and hard of hearing adults.

GOAL 8: Infants with hearing loss and their families will receive services coordinated through a medical home.

Objective	Required Staff and Resources	Timeline	Evaluation
To increase PCP's understanding of the coordination of services through a medical home, the	EHDI Coordinator, HCC staff, and California AAP Chapter	9/1/12 – 8/31/15	DHCS will report the number of infants in the NHSP needing a diagnostic evaluation who have a PCP identified.

<p>EHDI Coordinator will work with the HCCs and AAP Chapter Champions to provide information and education to local physicians.</p>	<p>Champions  from this grant. EHDI Coordinator, HCCs, and Chapter Champions' time is in-kind.</p>		
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DHCS and AAP Chapter Champions are currently developing a podcast for providers that will be posted on the NHSP website, in an effort to educate PCPs on their role in management of an infant with hearing loss.

RESOLUTION OF CHALLENGES

California faces a number of challenges in implementing and maintaining a comprehensive, coordinated newborn hearing screening, tracking, and intervention program, with the two foremost including:

- A diminishing numbers of audiologists willing or able to see low income children, particularly in the rural Northern California region.
- The provision of appropriate, comprehensive, parent-to-parent support for families during the hearing assessment process and after a hearing loss has been identified.

The scope of this grant is to undertake these challenges, while proactively diminishing the barriers that could stall progress toward the goals. The two principal projects funded by this grant, the Teleaudiology Project and the Parent Links program, have the advantage of being established by previous MCHB grant funding, which will eliminate the delay met in initial implementation activities and has revealed the challenges that

were previously encountered. Perhaps the largest barrier at this time is the execution of contracts within and outside the California state system. Since recent contract revisions were made, DHCS and CDE now know who specifically to work with in the various agencies, and having executed, approved contracts as models, will assist in expediting contracts.

The Teleaudiology Project will directly address the challenge of access to care by providing services and mentoring. Technical challenges, such as ensuring initial and on-going communication between the host and remote sites for scheduling appointments and conducting the clinical evaluations, will continue to be the responsibility of the UCD Telehealth Program. On-going management of children identified with hearing loss through the project remains a challenge, as providers are hesitant to work with the complicated California Medi-Cal claims and reimbursement system. The teleaudiology team is in discussions whether hearing aid fitting and management can be offered remotely with the assistance of a hearing aid dispenser. Until there are one or more local audiologists in the rural region who are willing and capable to follow these infants and fit them with hearing aids, the children will be referred to the San Francisco Bay Area where there are capable providers. While this solution is not ideal, it is necessary to ensure that the infants receive appropriate intervention. Finally, establishing an authorization and reimbursement procedure for teleaudiology through the State Medi-Cal program will undoubtedly prove to be an arduous and time-consuming task, though recent telemedicine legislation has mandated that all California licensed provider types can bill Medi-Cal for services rendered via telemedicine. The challenge will be to establish cost-neutrality for the program and to convince Medi-Cal to commit the resources to comply with the law.

The Parent Links program will have its challenges as well. The limitations of funding will continue to be a concern to the current FRCs participating in the project. The FRC Parent Links Mentors have already faced capacity issues. On the one hand, the Parent Links Mentors are frustrated that not all parents agree to a referral to Parent Links, yet they struggle to meet the needs of the families who are receiving Parent Links support.

Because of the limitations geographically, the FRCs have worked with families via telephone and internet. However, the Parent Links Mentors have found that having family events, such as potlucks, where families can meet each other and deaf and hard of hearing adults, have been more successful than contacting families by phone, to reduce families' feelings of isolation and lack of support. These activities will need to be limited to low-cost outreach and awareness. Using KPLVs to handle local activities will help increase the capacity of Parent Links to provide family activities in various regions of the state.

EVALUATION AND TECHNICAL SUPPORT CAPACITY

Delineated in the Work Plan section, the evaluation methods combine quantitative and qualitative measures of all the grant goals and objectives. Quantitative measures include data from tracking and monitoring infants through the 1-3-6 process for the following categories:

- The number of hospitals certified to participate in the NHSP
- The number of inpatient infants screened, passed, referred to outpatient screen, missed, and waived screen.
- The number of outpatient infants screened, passed, referred to diagnostic, and lost to follow-up
- The number of infants evaluated for hearing loss, age at evaluation, the number identified with hearing loss, age at identification, and infants lost to follow-up
- The number of infants referred by the HCCs to the FRCs for parent-to-parent support
- The number of families connected to the Parent Links program by sources other than the HCCs
- For infants participating in the Teleaudiology Pilot Project, the number of infants who receive diagnostic services, age at identification, and the distance of travel averted by using the remote location

Through the quality improvement learning collaborative, data collection for the SCHCC region will include appointment no-show rates, inpatient reporting of PCP and additional contact information, and appointment scheduling and completion of diagnostic evaluations by three months of age.

Qualitative measures include parent satisfaction surveys and documentation of parent experience in the teleaudiology pilot project and parents' reported experience through the use of the FRCs and Parent Links support. Weekly meetings with UCD and DHCS staff following teleaudiology appointments allow for regular monitoring of parent satisfaction and experience. The CDE Co-Director also regularly meets with FRC staff for reporting activities and parent responses, and follow-up phone calls from HCC staff allows for parents to share their concerns and experiences from both projects.

The technical support capacity of the staffing plan combines leaders in their respective fields and is the strength of this project. Hallie Morrow, MD, MPH, is one of the founders and champions of the NHSP and has worked since the program's inception on legislative analysis and support, program policy and procedures, data analysis, and the tracking and monitoring of the individual infants in a state with a birth rate of approximately 500,000 infants a year. Dr. Morrow has been a regular presenter at the EHDI Conferences. She organized the California team that participated in the first quality improvement collaborative managed by the NICHQ, which she continues to facilitate in California. As the medical director of the NHSP and the primary grant coordinator in several federal grants, Dr. Morrow brings medical and epidemiologic expertise, program evaluation, and knowledge of government systems. Jennifer Sherwood, MA, is a licensed audiologist who comes from a pediatric clinical background and is the original audiology consultant for the NHSP. She has experience with tracking and monitoring, provider consultation, data collection and analysis, program regulations, quality assurance measures, and case management. She will monitor the teleaudiology project, assuring that activities are completed and will review evaluation and outcome measures.

Anne Simon, AuD, is a Senior Audiologist for the UCDHS, and has been practicing audiology for 10 years. She began her career at House Ear Institute in Los Angeles, and immediately went into pediatric patient care. Anne expanded her training in infant diagnostics by participating in the National Center for Hearing Assessment and Management workshops on the Auditory Evaluation for Infants and the Ongoing Audiologic Assessment for Infants that were offered in California, as well as the National Symposium of Hearing in Infants by the Marion Downs Hearing Center Foundation. She is the audiology consultant for the UCDHS Craniofacial team, and has served as the newborn hearing screening audiology consultant for UCDHS since 2004. Because of her extensive knowledge in infant diagnostics and experience consulting and training in a teaching medical facility, she is able to offer the project subject expertise and quality care for the infants seen through the project.

It is fortunate that DHCS is able to work with one of the leading telehealth centers in the country, with nationally-known, widely published staff. James Marcin, MD, MPH, is a professor of Pediatric Critical Care at UCDHS and has extensive experience in developing systems and providing pediatric care through telemedicine. Dr. Marcin has twice received awards from the University for his contributions to the pediatric community. His current research support includes grants from the Office of Statewide Health Planning and Development in California for the Cardiac Surgery Reporting Program, MCHB for improving care to abused children in rural, underserved hospitals through telemedicine, and the Office of the Assistant Secretary of Preparedness and Response for the development of the Healthcare Facilities Emergency Care Partnership Program. A selected list of publications can be found in the biographical sketch in Attachment 3. Dr. Marcin's colleague, Madan Dharmar, MBBS, PhD, completed his surgical residency in 2001 and his Doctorate in Epidemiology in 2009. He has been involved in research in the UCDHS Pediatric Telemedicine Program since 2005 and is assisting Dr. Marcin with the child abuse grant and the Healthcare Facilities Emergency Care Partnership Program. A selected list of his publications is also found in the biographical sketch in Attachment 3.

At CDE, the Parent Links program is overseen by Nancy Grosz Sager MA, DHH Programs Consultant. Nancy has credentials from the California Commission on Teacher Credentialing in Deaf Education, General Education, and Administrative Services. Nancy's experience includes working as a teacher of the deaf for 14 years, a Special Education Principal for 7 years, and DHH Consultant for 13 years. As DHH Consultant, she has collaborated with DHCS since the beginning of the NHSP, serving on the NHSP Advisory Committee, and establishing the single-point-of-referral to Early Start, ensuring that every baby identified through the NHSP is referred to appropriate Early Start services. As Co-Director of the MCHB Newborn Hearing Screening and Intervention grant, she has facilitated a diverse workgroup that developed Best Practices for Early Start for Infants and Toddlers Who Are Deaf or Hard of Hearing, facilitated early intervention curriculum training for over 300 Early Start professionals in California, and provides technical support to the 104 local educational agencies that provide Early Start services to DHH infants and their families.

All together, the Parent Links Mentors have more than 50 years of experience providing support to families of children with disabilities, through FRCs, parent organizations, and school programs. The Parent Links program at FFREC is headed by Rachel Friedman Narr, Ph.D., Director of the Deaf Education and Families Project. She leads a team of four Parent Links mentors (Apryl Chauhan, Irma Sanchez, Cora Shahid, and Kristal Molina). At EPU, Darla Shwehr, BA, leads the program, assisted by Parent Links mentor Victoria Olea. At RFEC, Kat Lowrance, MA, leads the program, assisted by Parent Links mentor Barb Ciukowski.

ORGANIZATIONAL INFORMATION

California Department of Health Care Services (DHCS)

The mission of the DHCS is to preserve and improve the health status of all Californians. The California NHSP is one of several programs administered by CMS in

the Systems of Care Division. The CCS program, which is the state's Title V Children with Special Health Care Needs program, provides case management and payment of services for children who meet the program eligibility criteria. The program also establishes standards for providers, hospitals, and special care centers for the delivery of health care in tertiary medical settings and in local communities. The Child Health and Disability Prevention (CHDP) program is also managed by CMS. CHDP provides the screening and preventive health component of the Federal EPSDT program. It assures preventive services, including health assessments, immunizations, screening tests, dental screening, and referral for further diagnosis and treatment for Medi-Cal and low-income children.

The NHSP establishes a comprehensive, coordinated system of early identification and provision of appropriate services for infants with hearing loss by:

- Screening newborns for hearing loss prior to hospital discharge
- Tracking and monitoring infants to assure that appropriate follow-up testing and diagnostic evaluations are completed, if necessary
- Communicating with the infant's medical home provider regarding follow-up appointments and results
- Providing access to medical treatment and appropriate educational and parent-to-parent support services
- Providing coordinated care through collaboration with those agencies delivering early intervention services to infants and their families

The major focus of the program is to assure that every infant who does not pass a hearing test is linked quickly and efficiently with the appropriate screening, diagnostic and treatment services and with other necessary intervention services.

California Department of Education (CDE)

The CDE's mission is to "provide a world-class education for all students, from early childhood to adulthood. The Department of Education serves our state by innovating and collaborating with educators, schools, parents, and community partners. Together, as a team, we prepare students to live, work, and thrive in a highly connected world." The CDE is responsible for providing Early Start services to infants and toddlers who have low-incidence disabilities (vision, hearing, and severe orthopedic impairments). DDS is the lead agency for IDEA Part C Early Start services. Multiply disabled children with hearing loss are dually eligible for services from both DDS through the Regional Centers and CDE through local educational agencies (LEAs). The CDE Special Education Division and the State Special Schools and Services Division (DHH Unit) consult and collaborate with DDS and other state and local agencies to provide Part C Early Start services. The Special Education Division develops and administers programs that are coordinated by 130 Special Education Local Plan Areas (SELPA) and are provided by more than 1000 LEAs. The DHH Unit provides technical assistance to LEAs serving children who are deaf or hard of hearing, birth to age 22. CDE closely partners with California's 53 IDEA funded FRCs, which are represented on all CDE Special Education Task Forces, including the Partnership Committee on Special Education (PCSE), the Least Restrictive Environment (LRE) Task Force, the Individualized Educational Program (IEP) Task Force, and the Parent Resource Guide Committee.

California Department of Developmental Services (DDS)

DDS is committed to providing quality services to the people of California and assures the opportunity for individuals with developmental disabilities to exercise their right to make choices. DDS coordinates services for persons with disabilities in community based regional centers. Early Start services are provided, purchased, or arranged by regional centers based on the unique needs of the child and the family. Regional centers may contract with LEAs to provide special instruction and related services. DDS provides the IDEA funding to the 53 FRCs, which provide parent-to-parent support to families of infants and toddlers at risk of or with developmental delays. FRCs may

provide parent-to-parent support, peer counseling and home visits, information and referral, public awareness, parent education, and support services in many languages.

University of California Davis Health System

The UCDHS is a comprehensive care facility that includes multi-disciplinary teams, affiliations and partnerships with outside resources, and evidence-based practice methodologies. The overarching mission of UCDHS is "...discovering and sharing knowledge to advance health." This is accomplished through the education of physicians and health professionals; research and application of new medical knowledge; high quality, compassionate patient care; and community engagement for the local and global population. The Audiology Clinic within the Department of Otolaryngology supports the mission through their expertise in pediatric audiology evaluation and treatment, training of otolaryngology residents, involvement in research with otolaryngology, and being one of the only facilities to offer the comprehensive care of infants in the Northern California region. The UCD Center for Health and Technology is a leader in telemedicine research and application and currently offers inpatient and outpatient telemedicine and telehealth to pediatrics and other disciplines. Collaborative clinical relationships with rural and community based clinics are actively developed through the Telehealth Program, and medical continuing education is available through the Telemedicine Education Program for physicians and health care professionals. UCD continues to be a leader in research, publications, education, and the clinical practice of audiology and telemedicine.

**Narrative Progress Report
Maternal and Child Health Bureau Grant H61 MC 00095
September 1, 2012 – August 31, 2013**

1) Project Identifier Information

- a) Grant Number: H61 MC 00095
- b) Project Title: The California Newborn Hearing Screening and Intervention Project
- c) Organization Name: California Department of Education
- d) Mailing Address: 1430 N Street, Suite 2305, Sacramento, CA 95814
- e) Primary Contact Information:

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2) Accomplishments and Barriers

In 1998, California passed Assembly Bill 2780, creating the California Newborn Hearing Screening Program (NHSP). Effective January 2008, this legislation was expanded to all general acute care hospitals with licensed perinatal services, encompassing a total of 255 facilities (excluding military hospitals). The NHSP has established a comprehensive, coordinated system of identifying infants with hearing loss and linking them with appropriate intervention services, including the Individuals with Disabilities Education Act (IDEA) Part C early intervention services (called Early Start in California). With 503,000 births per year in California, it is estimated that approximately 900 infants are born each year with hearing loss. This project utilizes the existing infrastructure of the NHSP and the Early Start system to improve early linkage to a medical home, diagnostic evaluation by three months of age, enhanced family-to-family support, enrollment in a program of early intervention by six months of age for those infants identified with hearing loss, and implementation of a pilot telemedicine project in rural Northern California in collaboration with the University of California Davis (UCD) Medical Center to provide diagnostic audiologic evaluations for infants in areas with no or limited access to local audiology providers.

The California Department of Health Care Services (DHCS) Children's Medical Services (CMS) currently contracts with three organizations to operate geographically-based Hearing Coordination Centers (HCCs) in four regions.

These HCCs are responsible for certification and monitoring of newborn hearing screening programs in the hospitals. They are further responsible to assure that the NHSP operates efficiently, that screenings and services are of high quality, that hospitals meet the NHSP standards through the initial certification and the recertification process, and most importantly, that infants failing the hearing screening test receive necessary services. The State NHSP staff has developed provider standards and certification criteria, program policies and procedures, and a Tracking and Monitoring Procedure Manual to assure quality in the program statewide.

The HCC serving Northern California unexpectedly terminated services in January 2013. An interim contractor (Natus Medical) was selected the end of April to perform the HCC activities and to catch up on the data entry backlog of infant reports into the DMS. This has impacted the timeliness of tracking and monitoring activities in the affected regions, data quality, and referrals to the teleaudiology project.

The NHSP is in the process of implementing an automated Data Management Service (DMS) in all participating hospitals, HCCs, and the state NHSP office. The program selected Neometrics, a Division of Natus, through a competitive procurement process. The DMS has been implemented in all HCC offices and is in the process of statewide roll-out to all NHSP certified hospitals.

Access to pediatric audiologists to provide follow-up for infants who do not pass their newborn hearing screens is a significant issue in California, particularly in the northern rural part of the state. There is one audiology provider north of Sacramento that is willing and capable of seeing the low-income infants for diagnostic evaluations and on-going management. The NHSP has implemented telemedicine technology in partnership with the University of California Davis (UCD) to perform infant diagnostic evaluations and is struggling to identify local audiologists interested in being mentored to provide follow-up care. The project has had many challenges related to the contract implementation (detailed in Goal 2) and referral of infants.

Because California has established a single-point-of-entry to Early Start through the California Department of Education (CDE), all babies identified through the NHSP are referred to IDEA Part C Early Start services. Obtaining follow-up information on the referrals to Early Start to determine if children are receiving services continues to be a challenge. To overcome this challenge, Nancy Grosz Sager at CDE, continues to work closely with the NHSP HCCs to gather information from the Part C Early Start programs.

In order to acquire data regarding language acquisition of infants identified through the NHSP, CDE contracted with the University of Colorado National Early Childhood Education Project (NECAP). Some deaf and hard of hearing infants and toddlers in the Los Angeles Unified School District (LAUSD) and at

the California School for the Deaf, Fremont (CSDF) were assessed using the MacArthur Communication Development Index (CDI), beginning in May 2011. LAUSD has continued to use the Early Learning Assessment Profile (ELAP) to assess cognitive skills, but will switch to the Minnesota Child Development Inventory in the fall. The Minnesota assessment is the tool recommended by the NECAP.

To provide appropriate parent-to-parent support to families of infants identified through the NHSP, CDE has contracted with three IDEA Part C funded Family Resource Centers (FRCs) to establish the Parent Links – Hope! Dream! Achieve! program. Since September 1, 2009, nine Parent Links mentors, who are all parents of children who are deaf or hard of hearing, have provided support to almost 1000 families of infants identified through the NHSP. To meet the challenge of low numbers of referrals in Central and Northern California, CDE and the Parent Links program have expanded outreach activities to Part C Early Start programs and to audiologists. This outreach has been very successful and referrals to the Central and Northern California Parent Links programs have greatly increased.

A California chapter of Hands and Voices has been approved by the national organization. The chapter has established by-laws, recorded them with the California Secretary of State, and received 501-C3 status. Nancy Sager and Parent Links are working closely with the new California Hands and Voices chapter to help its growth and development. In June 2013, the new chapter held its first event, a highly successful Family Camp in Julian, California, which is outside of San Diego, in Southern California. A Northern California Family Camp is being planned for August, 2013, at Shasta Lake.

In September 2012, the CDE established a work group of 14 parents of children who are Deaf or Hard of Hearing to develop a Resource Guide for Parents of Infants and Toddlers who are Deaf or Hard of Hearing. The committee has completed the Resource Guide. A summary version of the Resource Guide has been approved and is being distributed to parents of newly identified infants through the HCCs. The summary will soon be distributed to all audiologists and Early Start program providers, who will be asked to provide a copy of the summary to parents of children who are deaf or hard of hearing. The summary will be posted on the CDE web site, pending approval of having met all requirements for universal design. The complete 112 page Resource Guide will be posted on the CDE web site, once it has been through the approval process.

The CDE, in collaboration with California State University, Northridge, developed a DVD for parents entitled “Through Your Child’s Eyes: American Sign Language.” In addition, CDE has published a Position Statement on Access to Language for Students who are Deaf or Hard of Hearing. Both the DVD and the

Position Statement have been posted on the CDE web site at www.cde.ca.gov/sd/dh.

Finally, Nancy Sager, Parent Links Mentor Victoria Olea, and Early Start teacher Jennifer Kysella, have participated in the National Center for Hearing Assessment and Management(NCHAM)'s Cultural Competence Collaborative, and plan to continue the work of enhancing cultural competence in the areas of family support and Early Start after the Collaborative ends its work in the fall.

An on-going challenge in California Early Start has been ensuring that infants who are deaf or hard of hearing and have additional disabilities receive services related to their hearing loss. Additionally, there have been challenges associated with ensuring that Part C Early Start programs operate year-round and provide services in alignment with the California *Education Code*. To help with these challenges, Nancy Sager and the Parent Links Mentors have been providing regional Early Start/Parent Links workshops around the state, to provide guidance to Early Start Providers. Seven regional workshops have been held so far, with four more planned for July and August 2013.

3) Goals and Objectives

Goal 1 - All infants born in California will be screened for hearing loss at birth, with parent permission, before leaving the hospital.

California legislation expanded the NHSP to all general acute care hospitals with licensed perinatal services effective in January 2008. This mandate requires that screening be performed (instead of offered) on all infants unless screening violates a parent's beliefs. As of April 2013, all of the 255 hospitals with licensed perinatal services have been certified and are participating in the NHSP.

The California NHSP screened over 492,000 infants in 2011. This represents 98% of the total births in the state. Acceptance of newborn hearing screening is quite high, with only 0.1% of parents waiving screening. Only 0.02% of infants "missed" screening.

The HCCs continue to monitor quality indicators at certified hospitals and are recertifying those hospitals whose prior certification period is expiring.

Goal 2 – Infants with hearing loss will be identified by three months of age.

The Southern California and Southeastern California HCCs are continuing their tracking and monitoring activities. The contractor for the Northern California HCC abruptly terminated services in January 2013. An interim contractor was put into place at the end of April. During the four month period when there was no contractor, no HCC data entry or tracking and monitoring activities were performed.

Of the infants born in 2011, according to data reported from the HCCs, 894 were identified with hearing loss through the NHSP, for an incidence rate of 1.8/1000. Sixty-nine percent (69%) of these infants were identified by 3 months of age. Only eight percent (8%) of the infants who did not pass their final screen were lost to follow-up, as reported to the Early Hearing Detection and Intervention program of the Centers for Disease Control and Prevention (CDC).

The NHSP has identified some barriers that impact the audiology capacity to expedite the identification of hearing loss in infants. Provider reimbursement and clinical quality issues have been ongoing problems. The NHSP staff have worked with Medi-Cal and its fiscal intermediary to address authorization and claiming complications that have become a deterrent to participation in the Title V Children with Special Health Care Needs program, California Children's Services (CCS). The NHSP audiologist maintains ongoing communication with provider organizations, key provider stakeholders opinion leaders, and licensing bodies regarding policy and program matters impacting provider participation and to address the quality of services.

There continue to be inappropriate delays in the testing and diagnosis of young infants, even by audiologists who have participated in diagnostic evaluation workshops the NHSP has provided. The Program is still receiving reports from audiologists who specify the type of hearing loss as "undetermined" with no bone conduction testing performed. It is not uncommon for these children to be referred to otolaryngology with no follow-up appointment in audiology scheduled. In some cases the recommendation is for the child to return after six months of age, at which point the audiologist will perform a behavioral evaluation, which may or may not include ear inserts.

Most diagnostic providers refuse to schedule an appointment for an audiologic evaluation until after they received an authorization from the CCS program or the infant's insurance provider. Once an authorization is received, the provider office usually does not contact the family to schedule the appointment but waits for the family to call. This results in significant delay and sometimes loss to follow-up. The HCCs proactively contact the local CCS programs to obtain a copy of the authorization, assure the provider office has a copy, and contact the families to facilitate scheduling the diagnostic evaluation appointments.

California continues to maintain the NHSP Quality Improvement Learning Collaborative that was begun in 2006. This unfunded project is mainly focused in the Los Angeles area. The collaborative team includes parents, the Southern California HCC, Parent Links, University of California Los Angeles (UCLA) audiology, UCLA inpatient NHSP program, American Academy of Pediatrics (AAP) Chapter Champions, insurance representative, LAUSD, Los Angeles Medical Home Project, CSDF, the California Departments of Developmental Services (DDS), Education, and Health Care Services. There is a core group of about 10 partners who usually participate in at least one of the two scheduled phone calls each month. The team is updating and revising the current Aim Statement. This year, the team will continue to focus on reducing the number of “no-show” appointments and collecting additional contact and primary care provider (PCP) information. With the implementation of the DMS, these data items may be difficult to measure. The team will also evaluate how families receive screening results in the hospital, confirm that screening is performed using appropriate equipment, assure that audiologists inform families about the hearing loss for all children referred to Early Start, improve the referral process to Early Start for children who are Regional Center clients, and assure that intervention services address the child and family’s language acquisition needs.

The NHSP has implemented telemedicine technology to help address the access to audiology services in the northern rural part of the state through collaboration with the UCD Pediatric Telehealth Program and the Audiology Department. Eighteen (18) children have received diagnostic evaluations since the start of the project, and nine infants have been identified with hearing loss. However, due to delays in processing, the Interagency Agreements (IA) between CDE and DHCS, and between DHCS and UCD, have yet to be executed for this project period. There has been a drop off in the number of referrals for teleaudiology, and no referrals have been made from the HCC since January.

Goal 3a – The loss to follow-up rate for infants in the rural Northern California region who need diagnostic evaluation after an outpatient screen will be reduced by 50 percent through the implementation of teleaudiology.

The NHSP has implemented telemedicine technology to help address the access to audiology services in the northern rural part of the state through collaboration with the UCD Pediatric Telehealth Program and the Audiology Department. Eighteen (18) children have received diagnostic evaluations since the start of the project, and nine infants with hearing loss have been identified. However, due to delays in processing, the Interagency Agreements (IA) between CDE and DHCS, and between DHCS and UCD, have yet to be executed for this project period. There has been a drop off in the number of referrals for teleaudiology, and no referrals have been made from the HCC since January.

Goal 4a - Pediatric audiology capacity in the rural Northern California region will be increased by utilizing existing local audiology providers.

The activities related to this goal are projected to begin later this year. It is anticipated that finding local community audiologists who are interested and willing to take care of these children will be a difficult task.

Goal 4b - Teleaudiology services will be established as efficacious and sustainable.

Data analysis cannot be initiated until the interagency agreements are signed and executed. The Department is currently working on a policy regarding reimbursement for telehealth services. Once this is released, the NHSP audiologist will contact the Medi-Cal Benefits staff to discuss teleaudiology codes and process.

Goal 5 – Infants will be enrolled in Early Start services by six months of age.

When the California NHSP began operating in 2000, a toll-free telephone number was established at the CDE Deaf and Hard of Hearing Unit, as a single point of referral into Early Start for infants and toddlers (birth to three) with hearing loss. Audiologists, other providers, and parents may call to refer an infant or toddler with an identified hearing loss to Early Start. Referrals may also be made by fax. Most providers prefer to fax, even though the fax number is not toll free. Recently, CDE has converted the system to a secure electronic system, so that faxes received from audiologists are sent electronically to a designated Outlook e-mail box. Once a referral is received, CDE staff forwards the referral information by secure e-mail or fax to the appropriate local educational agency (LEA) Early Start program. The referral is also e-mailed or faxed to the HCC responsible for follow-up, and it is e-mailed or faxed back to the referring audiologist. By this method, the LEA, the HCC, and the audiologist are connected, and are able to work together as a team.

Since the single point of entry referral service was established in July 2000, CDE has received 10,783 referrals of infants and toddlers with identified or suspected hearing loss. The following demonstrates excellent program effectiveness. CDE received only 11 referrals in the year 2000, but has since received 233 referrals in 2001 (19.42 per month), 329 in 2002 (27.42 per month), 615 in 2003 (51.25 per month), 878 in 2004 (73.17 per month), 868 in 2005 (72.33 per month), 1040 in 2006 (86.67 per month), 946 in 2007 (78.83 per month), 1161 in 2008 (96.75 per month), 1159 in 2009 (96.58 per month), 1188 in 2010 (99 per month), 1167 in 2011 (97.25 per month), and 1162 in 2012 (96.83 per month) , as shown in the table below.

Referrals to Early Start 2000 - 2012

Year	Number of Referrals	Number of Referrals per Month
2000	11	
2001	233	19.42
2002	329	27.42
2003	615	51.25
2004	878	73.17
2005	868	72.33
2006	1040	86.67
2007	946	78.83
2008	1161	96.75
2009	1159	96.58
2010	1188	99
2011	1167	97.25
2012	1162	96.83

All of the infants whose hearing loss is identified through the NHSP are referred to the Early Start program, either by the audiologist or by the HCC. The HCC will generally err on the side of making a redundant referral to ensure every infant is referred. The staff of each HCC have frequent contact with Nancy Sager of CDE to verify receipt of referrals and identify local Early Start programs serving NHSP infants. Of the children with hearing loss that were born in 2009, 86% are known to be enrolled in Early Start. Of those, 79% were enrolled by six months of age.

Information from the California Special Education Management Information System (CASEMIS), shows that since the California NHSP was implemented in the year 2000, the number of deaf and hard of hearing infants enrolled in local educational agency Early Start programs before one year of age has grown from 51 in the 2000-01 school year to 425 in the 2011-12 school year. The total number of deaf and hard of hearing children, birth to three, in the Part C program has increased from 416 to 1,763. These numbers include only those infants who are enrolled in Early Start programs through local educational agencies (LEAs), under the authority of CDE.

Deaf and Hard of Hearing Infants and Toddlers Age at Entry to California Public School Early Start Programs

Year	Number Enrolled Before One Year of Age	Number Between 1-2 Years of Age	Number Between 2-3 Years of Age	Total Numbers Birth-3
2000-01	51	133	232	416
2001-02	84	149	216	439
2002-03	100	198	250	548

2003-04	189	256	299	744
2004-05	240	414	347	1001
2005-06	294	446	430	1170
2006-07	317	548	485	1350
2007-08	271	542	543	1356
2008-09	334	532	572	1438
2009-10	385	546	575	1506
2010-11	342	637	557	1536
2011-12	425	657	681	1763

Deaf and hard of hearing infants and toddlers with additional disabilities are served by DDS through the regional centers. The NHSP has implemented a Data Use Agreement with DDS to obtain the date of the initial Individualized Family Service Plan (IFSP) for infants receiving Early Start services from the regional centers

Goal 6 – Infants identified through the California Newborn Hearing Screening Program will develop language skills commensurate with their age and developmental levels, in the communication mode(s) of the family’s choice.

A 2006 study conducted by CDE and Sonoma State University showed a correlation between age of identification and language development, as shown in the following table.

**Comparison of Cognitive Skills and Communication Skills
by Age of Entry in Early Start**

Age in months at entry to Early Start	# of infants and toddlers	# of infants with normal cognitive skills	% of infants with normal cognitive skills	# of infants with normal cognitive and communication skills	% of infants with normal cognitive skills who also have normal communication skills
1-6	657	505	77%	261	52%
7-12	191	137	72%	52	38%
13-18	70	59	84%	23	39%
19-24	75	53	71%	16	30%
25-30	15	10	67%	0	0%
30-36	8	6	75%	0	0%

This data clearly shows the benefit of early entry into Early Start, but also shows that California needs to continue to improve services to infants and toddlers, including those who are enrolled by six months of age.

In September 2008, LAUSD, our state's largest school district, began assessing all bilaterally deaf or hard of hearing infants and toddlers with the Rossetti Infant Language Scale, and reporting assessment data to our state's NHSP Quality Improvement Learning Collaborative. The LAUSD Early Start teachers expressed a number of concerns about using the Rossetti. The major concern was that the teachers did not feel the scores on the Rossetti were an accurate reflection of the children's language skills. There was also concern that the Rossetti is not a normed evaluation tool. Additionally, teachers had concern about the amount of time it took to administer the Rossetti.

Consequently, LAUSD agreed to begin participating in the NECAP, and to assess their Early Start infants and toddlers using the MacArthur CDI. Dr. Allison Sedey, NECAP Co-Director, has trained the LAUSD Early Start teachers on the use of the MacArthur. A contract between CDE and the University of Colorado, where Dr. Sedey works, was fully executed in January 2011. Dr. Sedey and LAUSD staff have developed a demographic reporting form for the district. Dr. Sedey has also developed a parent consent letter for LAUSD. On April 5, 2011, Dr. Sedey met with the LAUSD Early Start teachers to finalize plans for the project. In 2011-12, LAUSD Early Start teachers assessed 30 children between the ages of 12-36 months, and sent the completed assessment protocols to Dr. Sedey at the University of Colorado. There, the assessments were scored, and a parent reporting form was developed. The district received individual reports, as well as a report for the district. This allows the district to compare its children's acquisition of language skills to national norms. This project will also provide the district with assessment data that can be used to assist in making decisions about service delivery to deaf and hard of hearing infants and toddlers and their families. Dr. Sedey has provided aggregate data to CDE. The CDE does not receive any child specific data. Because the federal grant has been reduced for the 2012-13 year, CDE is not able to renew the contract with the NECAP, but the University has agreed to continue assessing LAUSD children during this year.

The Early Start program at CSDF has been working with Dr. Diane Anderson at the University of California, Berkeley, to establish American Sign Language (ASL) norms for the MacArthur CDI.

Goal 7 – Families of deaf and hard of hearing infants and toddlers will receive comprehensive, culturally competent, family-to-family information and support services from trained Parent Mentors and trained Key Parent Links Volunteers through designated Family Resource Centers.

In January 2009, CDE established the Parent Links – Hope! Dream! Achieve! program. The CDE used MCHB funds to give grants to three FRCs to provide parent-to-parent support to families of infants and toddlers who are deaf or hard of hearing. Rowell Family Empowerment of Northern California (RFENC) provides support to families in 28 sparsely populated counties of Northern California. Exceptional Parents Unlimited (EPU) provides support in 16 Central

California counties. The Family Focus Resource and Empowerment Center (FFREC) provides support to families in 12 counties in Southern California. Each of these FRCs provides support by two or more parents of a child who is deaf or hard of hearing. Each FRC has a parent mentor who speaks Spanish.

The mission of Parent Links – Hope! Dream! Achieve! is to empower parents of deaf and hard of hearing babies with comprehensive information and awareness through mentoring, networking, and resources, and to honor the family’s relationship with their child and their choices in language development. The purpose of the program is to provide emotional and social support to parents who have infants and toddlers who are deaf or hard of hearing, and to provide unbiased and comprehensive understanding of communication opportunities and the services that can be provided for their child and their family.

Between September 1, 2009 and the present, the Parent Links – Hope! Dream! Achieve! program has received almost 1000 referrals, as shown in the table below.

**Referrals to Parent Links – Hope! Dream! Achieve!
September 1, 2009 – May 31, 2011**

Family Resource Center	English Speaking Families	Spanish Speaking Families	Families that Speak Other Languages	Total
RFEC (North)	37	37	0	74
EPU (Central)	78	55	0	133
FFREC(South)	553	174	18	745
Total	668	266	18	952

When the Parent Links program receives a referral, a Parent Links mentor phones the parents to provide six to ten hours of over the telephone parent-to-parent support, including listening to the parents’ story, answering any questions the parents have, referring them to another person or agency if they cannot answer the questions, making sure the child and family are linked to Early Start, and linking them with resources in their local area. The amount of time spent talking with a family really depends on the individual needs of the family. Parent Links tries to reconnect with any family they haven’t heard from for more than two months. When possible, Parent Links mentors meet face-to-face with new parents.

The Parent Links mentors provide a packet of information that includes the following:

- The Newborn Hearing Screening Program (an overview)
- A Good Start
- Understanding Hearing Loss

- Audiogram of Familiar Sounds
- Information on Hearing Loss
- Getting Started with Early Intervention
- Facts about Developing Communication
- Language and Communication – A Parent’s Perspective
- Increasing Literacy Skills with Your Deaf Infant
- Resource Guide for Parents of Infants and Toddlers who are Deaf or Hard of Hearing Summary

These documents are also available on the Parent Links – Hope! Dream! Achieve! website at www.myparentlinks.org. The documents are available in English and Spanish. The Parent Links website was developed by EPU Parent Links Mentor, Darla Schwehr. During this past year, the website has had more than 500 visits per month. Ms. Schwehr has also accepted the responsibility of preparing a monthly Parent Links newsletter, which is distributed by e-mail, and posted on the Parent Links website. The newsletter is in both English and Spanish.

Other written or electronic information may be provided, depending on the family’s needs or wishes. Such information may include information about Supplemental Security Income (SSI), CCS, hearing aid loaner banks, specific types of hearing loss (e.g., atresia, auditory neuropathy), or specific language or communication opportunities.

The Parent Links mentors have stressed that the most important function they serve is providing a parent-to-parent connection. Listening and talking to a parent one-on-one, and responding to the family’s individualized questions and needs is more valuable than any written information that is provided. The Parent Links mentors report that the most frequent questions from families include the following:

- Will my child learn to speak Spanish?
- Where does your child go to school?
- How is your child doing?
- Does your child wear hearing aids or use a cochlear implant?
- How do I find funding for hearing aids?

Families are referred to other resources, including but not limited to the following:

- Deaf consumer agencies
- Key Parent Links Volunteers in the family’s local area
- Parent organizations (Hands & Voices, American Society for Deaf Children)
- *Deaf Latinos*, a Los Angeles based non-profit group that specifically supports Latino families with DHH children.

- Early Start providers
- John Tracy Clinic
- Outreach programs at the California Schools for the Deaf
- Cochlear implant centers
- The family's local FRC
- Internet-based discussion groups

In addition to one-on-one parent-to-parent support, each of the Parent Links FRCs provides additional parent support activities and supports, including the following:

- Family support groups
- ASL classes
- Family fun events (e.g. picnics, play days)
- Connection with Key Parent Links volunteers

In Southern California, approximately 90 percent (90%) of referrals to Parent Links come from the HCCs. The other 10 percent (10%) come from other sources, including audiologists, IDEA Part C Early Start providers, and other parents. In Central and Northern California, almost all of the referrals have come from sources other than the HCC.

Each of the FRCs has engaged in outreach activities to promote referrals to the Parent Links program. All three FRCs have provided information about Parent Links to Early Start programs, audiologists, and other FRCs in their geographical areas. The CDE has also sent information to Early Start programs and to referring audiologists to increase referrals to Parent Links.

In Northern California, RFEC Parent Links mentors Kat Lowrance and Cynthia Sandoval have done the following:

- With Nancy Grosz Sager, presented Early Start/Parent Links workshops in Sacramento, Redding, and Placer Counties.
- With Nancy Grosz Sager, Kat Lowrance did a presentation at the northern California Infant Development Association Conference.
- With Nancy Grosz Sager, Cynthia Sandoval did a presentation at the Family Resources and Supports Institute.
- Kat Lowrance helped plan the Family Fun Weekend at CSDF, had a Parent Links booth at the Weekend, and provided scholarships for several families to attend. Cynthia Sandoval participated on a panel presentation at the Weekend.

- Kat Lowrance and Cynthia Sandoval both participated in the development of CDE's Resource Guide for Parents of Infants and Toddlers who are Deaf or Hard of Hearing.
- Kat Lowrance has started a parent support group in Shasta County.
- Cynthia Sandoval did a presentation at the Fiesta de Festiva Conference.
- Kat Lowrance did outreach to UC Davis audiologists, Mercy Clinic, Stanford Clinic Baby Talk, and Jean Weingarten Peninsula Oral School for the deaf.
- Kat Lowrance and Cynthia Sandoval are setting up a family camp, to be held at Shasta Lake in August 2013.

In Central California, EPU Parent Links mentors Darla Schwehr and Victoria Olea have provided the following activities:

- Ms. Schwehr provided ongoing e-mail and phone support for the Santa Clara Early Start Program Cochlear Implant Family Support Groups.
- With Nancy Grosz Sager, provided Early Start/Parent Links workshops in Alameda, San Joaquin, Fresno, and Monterey Counties.
- Darla Schwehr has provided outreach activities with CSDF, the Deaf Counseling and Referral Agency (DCARA), the Deaf and Hard of Hearing Services Center (DHHSC), the Center for Early Intervention on Deafness (CEID), and the Oakland Unified School District.
- Darla Schwehr and Victoria Olea have provided weekly parent support groups and ASL classes.
- Victoria Olea participated on the NCHAM Cultural Competence Learning Collaborative.

In Southern California, FFREC Parent Links mentors Irma Sanchez, Cynthia Lemus-Ramos, Edith Wysinger, Kristal Molina, and Cora Shahid, and their director, Rachel Friedman Narr, have provided numerous outreach activities, including the following:

- Collaborated with the HCCs, LEA and regional center Early Start programs, audiologists, private and non-profit agencies, and with the NICHQ Learning Collaborative.

- Provided ASL classes for parents throughout Southern California, including a Deaf Latinos ASL class facilitated by Irma Sanchez, and taught by Janette Duran, who is Deaf and is trilingual.
- Coordinated fun family events, including a field trip to the Kids' Space Museum, Sign and Run events, a Deaf Latinos rodeo, pot lucks, nature park events, picnics, and beach days.
- Cora Shahid coordinated San Diego Community Night at Lafayette School, with various organizations setting up exhibit tables.
- Sold tri-lingual calendars to raise funds to support parents' attendance at conferences.
- Irma Sanchez was interviewed on Los Angeles Channel 54 regarding ASL classes for Spanish speaking families.
- Irma Sanchez and her husband, Miguel, were invited to Massachusetts to meet with Latino parents in Boston and at the Learning Center.
- Rachel Narr coordinated a parent panel at the national Early Hearing Detection and Intervention (EHDI) Conference in Phoenix in April 2013. Parents Cora Shahid, Irit Spector, Athena Troy, and Victoria Olea discussed their experiences with Newborn Hearing Screening and Early Start. One parent, Irit, had high praise for her LAUSD Early Start teacher, Lydia Sussman, who spoke her family's language, Hebrew, and encouraged the Troys to raise their daughter with both English and Hebrew.
- Cora Shahid participated on the CDE Parent Resource Guide committee.
- With Nancy Sager, Rachel Narr, Cora Shahid, and Kristal Molina presented at the Southern California Infant Development Association Conference in April 2013.
- Kristal Molina and Cora Shahid coordinated the first California Hands and Voices activity, a Family Camp in Julian, California, in June 2013.

Together, all of the Parent Links mentors (with Nancy Grosz Sager) have done the following:

- They attended the EHDI Conference in Phoenix in April 2013.
- They provided an exhibit booth at the CAL-ED Conference in Marina Del Rey in March 2013.

- They participated on the CDC Parent-to-Parent Support committee.
- Nancy Grosz Sager has participated on the CDC Provider Education Committee and the Data Collection Committee.

The most significant successes noted by the Parent Links mentors include the following:

- Helping Hispanic parents believe that their children will be able to learn Spanish
- Providing opportunities for families and children to meet other families and children and to meet adults who are deaf or hard of hearing

The most significant challenges noted include the following:

- Meeting the demand for parent-to-parent support, due to large numbers of referrals (southern California)
- Not being able to contact families

Goal 8 - Infants with hearing loss and their families will receive services coordinated through a medical home.

Hospitals and outpatient providers are required to report PCP information to the HCCs. Unfortunately, hospitals do not always have this information prior to discharge, and outpatient providers do not consistently verify this information. Consequently, the HCCs have experienced difficulty identifying the appropriate PCP for each infant. When the PCP is known, the HCCs send results and follow-up information by letter to each infant's PCP to assist the PCP in coordinating care. These letters are intended to prompt action by the PCP, regardless of whether the provider is considered a medical home for patients with hearing loss.

Only one of the four American Academy of Pediatrics (AAP) Chapter Champions was able to attend the National EHDI Conference in February 2011. Dr. Morrow facilitates every other month conference calls to provide a forum for communication, coordination, and planning among the AAP Chapter Champions. The HCC Directors have been invited to participate in these calls. This presents an opportunity to link issues identified by the HCCs with the Chapter Champions' interests. The group is trying to identify ways to reach pediatricians and other PCPs. One idea is to institute a "hearing corner" in the Chapter newsletters using a question and answer format. The Chapter Champion from Northern California is working on an article for the District magazine and has presented at hospital grand rounds sessions. The Chapter Champion from San Diego recently resigned, and a new one has not been appointed to date.

The Southern California HCC provides on-site outreach to physician offices in their region. The HCC staff visit the physicians and their office staff and provide information about newborn hearing screening, follow-up, the importance of early identification and intervention, statistics, educational materials developed by the NHSP and the AAP, screening and diagnostic provider lists, and HCC contact information.

4) Significant Changes

A reorganization of the Children's Medical Services has occurred over the past year. Two branches (Children's Medical Services and Medical Case Management) have combined to become the Systems of Care Division. A name change of the Division may occur over the next year. The Branch Chief and Assistant Branch Chief positions have been transformed into the Chief Medical Officer and the Chief Operating Officer of the Division. Both of these positions have been filled over the past year. Internal reorganization of programs and sections within the Division has occurred. The Newborn Hearing Screening Program remains in the Hearing and Audiology Services Unit (HASU) within the Statewide Programs Section and reports to the Chief Operating Officer. However, the Medical Consultant of the NHSP, Dr. Morrow, reports to the Chief Medical Officer.

There have also been significant staffing changes related to the NHSP at DHCS. The Chief of the Hearing and Audiology Services Unit left the position in April 2011, as did the Section Chief for the Statewide Programs Section. The administrative and programmatic oversight responsibilities have been taken over by David Banda, Acting Chief of the Statewide Programs Section, pending approval to fill the HASU manager position.

The program's administrative and programmatic oversight responsibilities were temporarily taken over by two interim managers, Adam Quintana followed by James Delgado (Chief of Dependent County Operation Section) serving as acting Section Chief until Thomas Bone was hired the end of May 2013, to fill this position.

5) Plans for Upcoming Budget Year

1. Certification of remaining hospitals
2. Continue HCC tracking and monitoring to assure infants receive appropriate services in a timely manner
3. Continue the NHSP Quality Improvement Learning Collaborative
4. Teleaudiology

- a. Work with the new Northern California HCC to re-establish referrals of infants who are less than 4 months of age, reside in rural Northern California and did not pass their outpatient hearing screening.
 - b. Continue to provide diagnostic audiologic evaluations for infants prior to 4 months of age who refer from the NHSP and alternative routes (UCD NICU, Parent Links) and reside in rural Northern California
 - c. Re-evaluate policies and procedures to assess their accuracy now that the program has experience.
 - d. Identify a local audiologist and begin coordination of mentoring activities
 - e. Work with the Medi-Cal Benefits staff to identify teleaudiology billing codes and process.
5. Continue to work with LAUSD and CSDF on the NECAP, if funding is available through the NECAP itself, or if carryover funds are sufficient to help support this effort.
 6. Continue to provide family-to-family support through Parent Links, focusing on the following:
 - a. Continuing outreach to Early Start and audiologists to increase referrals, especially in central and northern California
 - b. Continuing education to other FRCs about the unique needs of DHH infants and toddlers and their families.
 - c. Continuing recruitment and training of Parent Links volunteers around the state.
 - d. Increasing the numbers of family outreach events in all regions of California.
 - e. Continuing and improving upon collaboration with California Hands and Voices.
 7. Disseminate and provide trainings regarding the Resource Guide for Parents of Infants and Toddlers who are Deaf or Hard of Hearing (funded by the CDE Special Education Division).

8. Continue collaboration between CDE, Parent Links and the California chapter of Hands and Voices
9. Continuation of technical assistance by CDE to improve outcomes for infants and toddlers who are deaf or hard of hearing, including ensuring that infants with additional disabilities receive appropriate services related to hearing loss, and that Early Start programs understand and comply with all provisions of California *Education Code*.