

**Narrative Progress Report
Maternal and Child Health Bureau Grant H61 MC 00095
September 1, 2013 – August 31, 2014**

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
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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 almost 505,000 births per year in California, over 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 an Early Start program by six months of age, 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) Systems of Care Division 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 who do not pass the hearing screening 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 contractor serving Northern California (Natus Medical) has spent the past year reducing the backlog of follow-up activities that resulted from the unexpected termination of services by the prior contractor in January 2013. This has impacted the timeliness of tracking and monitoring activities in this area, data quality, and referrals to the teleaudiology project.

The NHSP has almost completed the implementation of the automated Data Management Service (DMS) in all participating hospitals, HCCs, and the state NHSP office. The program selected as the DMS vendor, through a competitive procurement process, was Neometrics, a Division of Natus.

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 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 contracting process (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 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 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 informed CDE and the NECAP that it is no longer able to participate in the NECAP project, as all school districts in California are now required to assess infants and toddlers using CDE's Desired Results Developmental Profile (DRDP). Nancy Grosz Sager will contact other school districts to ask them to participate in the NECAP project.

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 program. There are now 10 Parent Links mentors, who are all parents of children who are Deaf or Hard of Hearing. Four of the

parents speak Spanish. To date, Parent Links has provided support to more than 1300 families of infants identified through the NHSP. In 2013, the Southern California Parent Links program received 236 referrals, mostly from the Southern and Southeastern California Hearing Coordination Centers. To meet the challenge of low numbers of referrals from the Hearing Coordination Center in Northern California, CDE and the Parent Links program expanded outreach activities to Part C Early Start programs and to audiologists. This outreach was very successful and referrals to the Central and Northern California Parent Links programs increased greatly. In 2013, the Central California Parent Links program received 62 referrals, and the Northern California program received 29 referrals. All of the referrals in Central and Northern California came from Early Start programs or audiologists.

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 work closely with the new California Hands and Voices chapter to help its growth and development. In June 2013, a Southern California Family Camp was held in Julian, California, with 40 families in attendance. The first Northern California Family Camp was held at Lake Almanor in November 2013, with 11 families, 4 of them monolingual Spanish, in attendance. Both camps were highly successful. California Hands & Voices now has 160 members, and 375 families participate in the California Hands & Voices Facebook page.

In September 2012, the CDE established a work group of 14 parents to develop a Resource Guide for Parents of Infants and Toddlers who are Deaf or Hard of Hearing. A summary version of the Resource Guide (in both English and Spanish) has been approved and is being distributed to parents of newly identified infants through the HCCs. The summary has been distributed to all Early Start program providers, who provide a copy of the summary to parents of children who are Deaf or Hard of Hearing. The summary is posted on the CDE web site. The complete 112 page Resource Guide is posted on the Parent Links and on the California Hands & Voices web sites.

Nancy Sager, Parent Links Mentor Victoria Olea, and Early Start teacher Jennifer Kysella, participated in the National Center for Hearing Assessment and Management (NCHAM)'s Cultural Competence Learning Collaborative. Nancy Sager, along with Collaborative members from New Jersey and Wisconsin, provided a workshop on the importance of teaching children about their cultural heritage as members of the Deaf and Hard of Hearing community.

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 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. Ten (10) regional workshops

have been held so far, with one more planned for the fall of 2014. The Early Start teachers who have attended the workshops have formed an on-line Community of Learners in order to share information, ask questions, and discuss common concerns.

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 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 (this does not include the six military hospitals). The HCCs work with new hospitals and ones that open new delivery services to certify that their programs meet our programmatic standards and reporting requirements.

Due to the unexpected change in HCC contractor and the delay in the development of the CDC EHDI report by the DMS vendor, the data for 2012 is incomplete and preliminary. Based on the information available to date, the California NHSP screened over 484,000 infants in 2012. This represents 96% of the total births in the state. Acceptance of newborn hearing screening is quite high, with only 0.07% of parents waiving screening. The HCCs continue to monitor quality indicators at certified hospitals and recertify those hospitals whose prior certification period is expiring.

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

The HCCs continue their tracking and monitoring activities. Due to the unexpected change in contractor for the Northern California HCC in 2013, the timeliness of tracking activities in this region has been delayed. Significant backlog in family contact was identified in November 2013, and tracked on a monthly basis. The HCC is now current with the tracking actions.

There has been a delay in the development of data reports in the DMS. The 2012 data reported are preliminary and may be subject to change as the final report is prepared. Of the infants born in 2012, according to the preliminary data entered in the DMS, 933 were identified with hearing loss through the NHSP, for an incidence rate of 1.9/1000. Sixty-four percent (64%) of these infants were identified by 3 months of age. Fourteen percent (14%) of the infants who did not pass their final screen were lost to follow-up, as defined by 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. Bone conduction testing is not routinely performed. Children are referred to otolaryngology with no follow-up appointment in audiology scheduled. Many times audiologists wait until they can 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 began in 2006. This unfunded project is mainly focused in the Los Angeles area. The collaborative team includes the Southern California HCC, Parent Links, University of California Los Angeles (UCLA) audiology, UCLA inpatient NHSP program, LAUSD, Foothill Special Education Local Planning Area (SELPA), Covina Valley School District, Los Angeles County Office of Education Early Head Start, 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 providing input into an evaluation of the NHSP. 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, assuring that audiologists inform families about the hearing loss for all children referred to Early Start, improving the referral process to Early Start for children who are Regional Center clients, and exploring collaboration with Early Head Start..

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. The target population includes infants under four months of age who did not pass newborn hearing screening. Twenty-three (23) children have received diagnostic evaluations since the start of the project, and twelve 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, were only recently executed for this project period. There has been a drop off in the number of referrals for teleaudiology, in part due to the tracking delays in the Northern California HCC. We have also become aware that the

one audiology provider in the rural target area has been aggressively pursuing referrals rather than have them sent to the teleaudiology project.

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. The NHSP is working with the DMS vendor to compile the final statewide loss to follow-up rate, after which a rate for the rural Northern California region will be determined.

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

Finding local community audiologists who are interested and willing to take care of these children is proving to be a difficult task. The one audiology provider currently seeing young infants in this region is not interested in following infants from the teleaudiology project. A meeting is scheduled with this provider to discuss the situation and attempt to find some feasible solutions.

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

UCD is working on analyzing the data collected to date. The Department has released a policy regarding reimbursement for telehealth services. The UCD teleaudiology program was recently approved as a CCS audiology facility. This will allow CCS to authorize the diagnostic evaluations performed by teleaudiology and allow billing. We will work with UCD teleaudiology to submit a test case and track it for reimbursement.

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

When the California NHSP began operating in 2000, as the CDE developed 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. Since the single point of entry referral service was established in July 2000, CDE has received 11,748 referrals of infants and toddlers with identified or suspected hearing loss. The number of referrals has increased each year, from 11 in 2000, to 1163 in 2013.

All of the infants identified through the NHSP are referred to the Early Start program, either by the audiologist or by the HCC. Of the children with hearing loss that were born in 2012, preliminary data show that 74% are known to be enrolled in Early Start. Of those, 78% were enrolled by six months of age.

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 school year to 439 in the 2012 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 1,772. 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 with additional disabilities are served by DDS through the regional centers. The HCCs usually obtain the date of the initial Individualized Family Service Plan (IFSP) from the parents 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.

In 2010, the LAUSD Early Start program agreed to begin participating in the NECAP and to assess their Early Start infants and toddlers using the MacArthur CDI. Unfortunately, LAUSD has informed Dr. Sedey that it cannot longer continue to participate in the NECAP, as all districts in California are now required to assess infants and toddlers using the Desired Results Developmental Profile (DRDP). Nancy Grosz Sager will recruit new school districts who are willing to participate in the NECAP.

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 Parent Links Volunteers through designated Family Resource Centers.

In January 2009, CDE established the Parent Links 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 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 a comprehensive understanding of language and 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 program has received almost 1300 referrals.

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.

Parent Links documents are available on the Parent Links 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.

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. Families are referred to other resources, including Deaf consumer agencies, local Parent Links volunteers, Hands & Voices, American Society for Deaf Children, Deaf Latinos, the California Schools for the Deaf, cochlear implant centers, local FRCs, and others. In addition to one-on-one parent-to-parent support, each of the Parent Links FRCs provides additional parent support activities and supports, including family support groups, ASL classes, and family fun events, such as picnics and play days. Each of the FRCs has engaged in numerous 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.

The most significant successes noted by the Parent Links mentors include helping Hispanic parents believe that their children will be able to learn Spanish, and providing

opportunities for families to meet other families and to meet adults who are Deaf or Hard of Hearing. The most significant challenges noted include meeting the demand for parent-to-parent support, due to large numbers of referrals, and 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. The Southern California HCC staff have made a concerted effort to educate their hospitals about the importance of including the PCP for all infants who either refer on or miss inpatient screening. Consequently, those hospitals are reporting PCP for the targeted infants over 90% of the time. 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.

California only has American Academy of Pediatrics (AAP) Chapter Champions for two of the four chapters. One Chapter Champion was able to attend the National EHDI Conference in April 2014. Dr. Morrow facilitates every other month conference calls to provide a forum for communication, coordination, and planning among the AAP Chapter Champions and the HCC Directors. This presents an opportunity to link issues identified by the HCCs with the Chapter Champions' interests. The group is interested in providing Just-In-Time materials to PCPs and in educating otolaryngologists on the appropriate work-up for infants with hearing loss.

4) Significant Changes

The reorganization of Children's Medical Services has resulted in a name change to the Systems of Care Division. The Newborn Hearing Screening Program remains in the Hearing and Audiology Services Unit (HASU) within the Statewide Programs Section, however, the Medical Consultant of the NHSP, Dr. Morrow, reports to the Chief Medical Officer, and is not in the Statewide Programs Section. The Statewide Programs Section and the HASU have relatively new managers who both joined the Division the end of May 2013. Their resumes are attached.

5) Plans for Upcoming Budget Year

- 1) Certification of any new hospitals or new perinatal services
- 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 Northern California HCC to increase referrals of infants who are less than four 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) Work with the one local audiologist in this area to seek solutions for providing ongoing maintenance services for infants identified with hearing loss.
 - d) Attempt to identify a local audiologist and begin coordination of mentoring activities
 - e) Work with UCD to submit test case billing to assure that the teleaudiology services can be appropriately reimbursed.
- 5) Find new local educational agencies to participate in the NECAP.
- 6) Continue to provide family-to-family support through Parent Links, focusing on the following:
 - a) Continuing outreach to Early Start and audiologists.
 - 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) Continue collaboration between CDE, Parent Links, and Hands and Voices
- 8) 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*.