

ABSTRACT: Early Hearing Detection and Intervention Program New Mexico
HRSA-20-047 CFDA No.93.251

PURPOSE OF THE PROJECT: The purpose of the New Mexico Early Hearing Detection and Intervention (NMEHDI) Program proposed project is to improve developmental outcomes of children who are Deaf of Hard of Hearing (DHH) by engaging stakeholders, improving EHDI infrastructure, expanding EHDI systems, educating health professionals and engaging DHH adults as mentors for families. Such a program is defined as the screening of all newborns prior to hospital discharge, audiologic diagnosis before three months of age, enrollment in an early intervention program before six months of age, collaboration with the Medical Home and access to family-to-family support for all infants diagnosed with a hearing loss. These services will be provided in a family centered, community based, and culturally competent, coordinated manner.

Objectives:

- 1) Increase by 1% from the baseline of 95% the number of infants that completed a newborn hearing screen no later than 1 month of age
- 2) Increase by 10% from the baseline of 38% the number of newborn that completed a diagnostic audiological evaluation no later than 3 months of age
- 3) Increase by 15% from the baseline of 77% the number of infants identified to be DHH that are enrolled in EI services no later than 6 months of age.

Using data collected from Year 1 as baseline data the program will also:

- 1) Increase by 20% from baseline the number of families enrolled in family-to-family support services by no later than 6 months of age
- 2) Increase by 10% the number of families enrolled in DHH adult-to-family support services by no later than 9 months of age.
- 3) Increase by 10% the number of health professionals and service providers trained on key aspects of the EHDI program.

METHODOLOGY: Implementation of the project including the work plan will be dependent on the collaborative work of the NMEHDI Coordinator with the many expert stakeholders including audiologists, primary care physicians, early intervention, early head start and parent organizations such as Hands & Voices, Navajo Family Voices and the Education of Parents of Indian Children with Special Needs and Quality Improvement staff. The program will utilize the Model for Improvement (MFI) to address the stated objectives as part of quality improvement initiatives. The community participants described in this proposal will receive hands-on support and training as they implement processes that improve performance of early childhood systems for infants identified with hearing loss. This collaboration will be key to identifying and implementing sustainable changes to the overall system of care.

COORDINATION: The NMEHDI program is integrated within the Public Health Division of the NM Department Health. Oversight of the program is the responsibility of the state's Title V Children and Youth with Special Health Care Needs program and implementation will be in collaboration with the Title V Maternal and Child Health Epidemiology program. The program is well supported by community, state and national partners. The NNEHDI Advisory Council is representative of many of these partners.

EVALUATION: The results of the project are included in the Title V MCH performance measures and objectives, which are reported annually. The data linkage between the programs, the birth files from Vital Records and Health Statistics, Newborn Genetic screening and birth defects will ensure that infants in need of services are identified. The Title V Program Children's Medical Services has oversight of implementation of goals and objectives.

Project Narrative

I. INTRODUCTION

The purpose of the New Mexico Early Hearing Detection and Intervention (NM EHDI) Program proposed project is to improve developmental outcomes of children who are deaf or hard-of-hearing (DHH) by engaging stakeholders, improving EHDI infrastructure, expanding EHDI systems, educating health professionals, and engaging DHH adults as mentors for families.

Population:

New Mexico (NM) is the fifth largest state in the United States by geographic area but is 36th in population size, with its 2,085,287-people scattered across vast, open spaces (US Census, 2017). NM is demographically a "majority-minority" state where minority groups constitute a majority of the population. According to the University of New Mexico (UNM) Bureau of Business and Economic Research, NM's total population in 2017 was 49% Hispanic, 38% non-Hispanic White, 9% American Indian, 2% African American/Black, and 2% Asian and Pacific Islander (comparing, respectively, to the US percentages of 18% Hispanic, 61% non-Hispanic White, 1% American Indian/Alaska Native, 13% Black/African American, and 6% Asian/Pacific Islander). In terms of age distribution, over a quarter (25.0%) of the NM population was younger than the age of 18, almost equal to the population over the age of 44 (28.5%).

NM is bordered by Arizona, Utah, Colorado, Oklahoma, Texas, and the Republic of Mexico and is defined as a frontier state according to the National Center for Frontier Communities. Over 7% of the population resides in frontier or sub-frontier areas (identified by remoteness and geographic isolation, with sparse populations and long travel times to services of any kind).

Poverty:

Up to 55% of children live in poverty in certain pockets of the state. In the majority of geographic areas, between 18 and 40% of children experience ongoing poverty. New Mexico is one of the four poorest states in the nation with a median household income of \$44,927 compared to the US median of nearly \$10,000 more. According to 2013-2017 American Community Survey estimates, more than half a million New Mexicans are living in poverty (20%), including 30% of NM's children and 13% of people 65 years old and over. In NM, 14% of all families and 40% of families with a female householder and no husband present had incomes below the poverty level.

Retrieved from: <http://quickfacts.census.gov/qfd/states/35000.html>.

The "children in poverty" rate based on household income in 2017 ranked NM as the second poorest state in the nation with 29% of children living in poverty (compared to 23% nationally); over 20% of New Mexicans lived below the poverty level in 2013-2017 (compared to 16% nationally). Twenty-five percent of all families and 40% of single-parent families had incomes below the poverty level (Annie E. Casey Foundation, 2014). Over half (52%) of NM births are to single-parent households as measured by marital status on the birth certificate, but this does not account for co-habitation or long-term, co-parenting families. Retrieved from: <http://datacenter.kidscount.org/data/tables/7-births-to-unmarried-women?loc=33&loct=2#detailed/2/33/false/868,867,133,38,35/any/257,258>.

In 2017's four-year graduation cohort, only 70% of all 9th graders in NM graduated from high school four years later (NM IBIS, 2017). Eight percent of teens ages 16-19 were both not in school and not high school graduates, ranking NM as one of the worst in the nation (Annie E. Casey Foundation, KIDS COUNT). New Mexico struggles to provide comprehensive, wrap-around services to children and adolescents, and this is a significant area of focus for improvement. In addition, women and mothers require support to assure adequate screening, identification, and referrals to appropriate behavioral and mental health services.

Access to Health Care:

Many factors limit access to health care in NM including a lack of insurance availability, or unawareness of its availability, and a large, spread-out geographical area, creating long travel distances to primary health clinics and hospitals. In addition, distrust of the healthcare system and lack of cultural sensitivity among providers make healthcare utilization a disparity for some areas of the state, most notably among women and children residing on tribal reservations. The number and distribution of health care professionals are critical and often-overlooked pieces of this equation. NM needs more healthcare providers in nearly every health-related profession. Thirty-two of NM's 33 counties are "health professional shortage areas," demonstrating the need to address this critical access to care problem. Only one of NM's counties, Los Alamos, is designated as neither "Medically Under-served" nor a "Health Professional Shortage Area (HPSA)." The remaining 32 counties are considered either entirely or partially HPSAs (HRSA, 2017). In addition, NM ranks poorly in health insurance coverage and utilization among women, especially those of childbearing age.

More New Mexicans are insured than ever before which should help increase access somewhat, although having insurance does not guarantee access to a healthcare provider. Immediately after the Affordable Care Act (ACA) implementation, the state's uninsured rate was down to 12.8% from a high of 20%, and current estimates are approximately 10%. In many ways, NM has been a leader in trying innovative ways to improve access to care: promoting the use of midwives and birthing centers; use of community health workers; use of social workers as care coordinators; utilizing telehealth for training and provider access; and flying pediatric specialists to rural areas to staff one-day specialty clinics for children with chronic medical conditions such as asthma, cerebral palsy, epilepsy, diabetes, and congenital heart conditions.

NM Medicaid provides many health services for children under a federal Medicaid policy which requires that children receive Early Period Screening, Diagnostic, and Treatment (EPSDT) services. This policy includes preventive health services, maintenance health services, and treatment of medical conditions. It also includes mental health or behavioral health services. Enrollment of children 0-18 years in Medicaid or SCHIP increased significantly between 2013- and 2017, prior to ACA implementation. Retrieved from: <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-State/new-mexico.html>.

The children of New Mexico are in the dismal rank of 49th on the KID'S COUNT measures of well-being which range from early infant birth outcomes to child maltreatment, and poverty or systemic barriers to care. Retrieved from: http://www.aecf.org/m/databook/2015KC_profile_NM.pdf. Multi-state studies also indicate that childhood risks associated with poor adult health and behavioral problems are disproportionately experienced at a population level in NM compared to other states. Retrieved from: <http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5949a1.htm>. The burden of Adverse Child

Experiences (ACE) among the NM adult population presents immediate child health risks, spanning several generations both in impact and effective solutions. From a life-course perspective, the population needs related to achieving developmental milestones in early childhood are clearly hindered by adult health status, barriers to adequate family healthcare, and thin behavioral health resources. The NM Pregnancy Risk Assessment and Monitoring System (PRAMS) data indicate that from 2004-2013 17.5% of women giving live birth experienced symptoms of post-partum depression (PPD). In comparison with results from PRAMS in other states there is a significantly higher prevalence of PPD in NM (2005-2008 births); however, the measures used in PRAMS changed twice, once in 2009, and again in 2012, so a reliable state trend is difficult to assess. Regardless, the national estimates for PPD range between 9-12%, and NM is well above this average. Among women who expressed PPD symptoms in 2012-2013, just 12.7% had received counseling or attended a support group for depression *during* pregnancy, and even fewer (10.6%) received help after their baby was born. CYFD Home Visiting Program quarterly and annual reports reflect numbers of women screened with the Edinburgh Postnatal Depression Scale. The annual home visiting report for the past three years reflects that among those screened, 25% had depressive symptoms in 2018, and this represents a significant percent of new mothers needing help (estimates exclude data collected in the tribal MIECHV programs). Retrieved from:

https://cyfd.org/docs/FY18_Home_Visiting_Annual_Outcomes_Report_Final_12_18_%281%29.pdf

These socioeconomic conditions are a concern for the Early Hearing Detection and Intervention (EHDI) Program as they impact overall child health and increase the likelihood of children being lost to follow-up. This increases the need for strengthening statewide partnerships and collaboration. The use of emerging technology and development of local systems of care sensitive to the cultural and linguistic needs of the community are critical elements to improving access to EHDI services.

The purpose of the proposed project for Universal Newborn Hearing Screening and Intervention is to ensure that all children in NM receive optimum services through a statewide newborn hearing screening and intervention program in adherence to the Joint Commission on Infant Hearing best practices of 1-3-6. The goals for these services are to screen all newborns prior to hospital discharge or before one month of age, to achieve audiologic diagnosis before three months of age, and to enroll all children with hearing loss in early intervention before six months of age, in collaboration with the child's medical home. In addition, the NM EHDI Program has a goal of promoting access to family-to-family support for all infants diagnosed with hearing loss. Program services are provided in a family centered, community-based, culturally competent, and coordinated manner, with emphasis placed on ensuring that all infants who do not pass their initial hearing screen receive timely follow-up services.

II. NEEDS ASSESSMENT

Maternal and Child Health:

The state of New Mexico continuously assesses, through quantitative and qualitative data collection, the needs and capacity for the Maternal Child Health (MCH) population and reports these results annually. The Title V Needs Assessment is conducted every five years, led by the

MCH epidemiologist. Children's health is reported annually in the New Mexico KIDS COUNT report and in the New Mexico Children's Cabinet Report Card. New Mexico also participates in the Youth Risk Behavior Surveillance System (known in New Mexico as the Youth Risk and Resiliency Survey) at both the middle and high-school levels, and those reports are published biennially. The Bureau of Vital Records and Health Statistics publishes its data on all New Mexicans annually, and reports specific to health disparities and to New Mexico's Native American population are also published regularly.

In New Mexico the Title V Children with Special Health Care Needs (CYSHCN) Program is called Children's Medical Services (CMS). This program is housed in the Family Health Bureau (FHB) in the Public Health Division of the NM Department of Health. The vision of FHB and the CMS program is that children and families will be physically and mentally healthy and have access to care that is family centered, comprehensive, community-based, coordinated, and culturally competent. Newborn Screening, which includes both the metabolic and hearing screening, is under the CMS umbrella of programs.

For the 2015 Title V Needs Assessment, FHB leadership completed an environmental scan of existing databases, assessments, and surveillance resources by population domain. The teams identified gaps in knowledge for NM MCH assessment and determined that there were three primary areas of concern: 1) Lack of existing information on the impact of Affordable Care Act (ACA) provisions on the NM MCH population; 2) Lack of focus on the U.S.-Mexico border region health, and 3) A desire to be more inclusive of tribal communities and health organizations as it pertains to the assessment and planning for the Maternal Child Health population. Both quantitative and qualitative methods were employed to assess, describe, and begin to identify priorities for each population domain group. Stakeholders from a variety of health-related organizations provided qualitative data, family input, and survey responses for prioritization.

Children and Youth with Special Health Care Needs:

CMS receives feedback on gaps in services from various sources including the Newborn Hearing Screening Stakeholder Advisory Team, the Newborn Genetic Screening Advisory Council, the New Mexico Pediatric Society, and the CMS Advisory Board of the NM Medical Society. The advisory boards are comprised of various stakeholders including professionals, CMS staff, and parents of children with hearing loss and/or genetic conditions. The program meets with the chiefs of the Pediatric and Neurology Departments at UNM annually to negotiate the number of multidisciplinary outreach clinics and the locations of these clinics statewide and receives feedback from them on the unmet need for services around the state. The National Survey of Children with Special Health Care Needs (NSCSHCN), sponsored by the Maternal and Child Health Bureau, provides national and state-level information about the numbers of children and youth, 0-17 years old, who have special health care needs. The survey is conducted annually with the most recent in 2016-2017. The surveyors asked 750 families of Children and Youth with Special Healthcare Needs (CYSHCN) in each state about:

- Access to health care and unmet needs
- CYSHCN health and functioning

- Health care quality and satisfaction
- Impact of child’s health on family activities, finances, and employment
- Adequacy of health insurance to cover needed services.

Table One details the 2016-2017 survey results for New Mexico compared to the U.S. as a whole. For example, 21% of children with special health care needs in New Mexico report that community-based services are organized so families can use them easily which is higher than the national rate of 19% but clearly indicates area for improvement in the system of care. Additionally, only 43% of CYSHCN in New Mexico receive coordinated, comprehensive care within a medical home, compared to 48% nationally.

Table One

**Results of the 2016-2017 National Survey of Children with Special Healthcare Needs:
Core Outcomes**

Core Outcomes	% of CYSHCN Achieving Outcome in New Mexico	% of CYSHCN Achieving Outcome in the Nation
Families of children and youth with special health care needs partner in decision making at all levels and are satisfied with the services they receive	81	86
Children and youth with special health care needs receive coordinated, ongoing, comprehensive care within a Medical Home	43	48
Families of CYSHCN have adequate private and/or public insurance to pay for the services they need	79	74
Children are screened early and continuously for special health care needs	36	31
Community-based services for children and youth with special health care needs are organized so families can use them easily	21	19
Youth with special health care needs receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.	15	13

Early Hearing Detection and Intervention (EHDI):

According to the Center for Disease Control Early Hearing Detection and Intervention Program annual survey in January 2017, New Mexico reported 22,313 occurrent births. The birth population diversity by race and ethnicity has already been referenced; however, of note is that

38% of births are to young mothers under the age of 24, and 44% of this maternal population has a high school degree or less.

Data points: NM CDC EHDI Annual Survey 2017

- 95% screened before one month
- 38% audiology diagnosis before three months
- 77% referred to early intervention before six months
- 53 infants with confirmed hearing loss enrolled into early intervention

Significant findings 2017

Month of Age Passed Final screen	(Total Pass 21,216)
Before 1 month	20,776
After 1 month but before 3 months	440
After 3 months	
Age unknown	

Month of age documented permanent hearing loss	(Total hearing loss 53)
Before 3 months	30
After 3 months but before 6 months	14
After 6 months	8
Age unknown	1

Month of age enrolled into Part C	(Total eligible 53)
Before 6 months	20
After 6 months but before 12 months	9
After 12 months	
Age unknown	0

Total with no documented EI Services/Undetermined: 24

The current loss to follow-up rate is 40% which includes lost to documentation. Reasons for loss to follow-up continue to include non-responsiveness of parents and the mobility of the population, which includes relocation within state boundaries, out of state and Mexico, and other factors that are still unknown and need to be explored further. If an infant enters the follow-up

system with Children's Medical Services and program procedure is followed, then the loss to follow-up drops to 5%. The loss to follow-up in this instance is related to parents declining our help.

In accordance with this funding opportunity and utilizing data from the states 2017 Centers for Disease Control and Prevention (CDC) EHDI Hearing Screening and Follow-up Survey, the program objectives over the next four years will be to:

- 4) Increase by 1% from the baseline of 95% the number of infants that completed a newborn hearing screen no later than 1 month of age
- 5) Increase by 10% from the baseline of 38% the number of newborns that completed a diagnostic audiological evaluation no later than 3 months of age
- 6) Increase by 15% from the baseline of 77% the number of infants identified to be DHH that are enrolled in EI services no later than 6 months of age.

Using data collected from Year 1 as baseline data the program will also:

- 4) Increase by 20% from baseline the number of families enrolled in family-to-family support services by no later than 6 months of age
- 5) Increase by 10% the number of families enrolled in DHH adult-to-family support services by no later than 9 months of age.
- 6) Increase by 10% the number of health professionals and service providers trained on key aspects of the EHDI Program.

The program has 3 dedicated follow-up coordinators that are responsible for improving loss to follow-up rates. One coordinator is bilingual and works specifically with monolingual Spanish speaking families. The coordinators have worked for the program for many years and have developed solid relationships with community primary care providers who work in collaboration with the follow-up coordinators to assure that newborns receive follow-up care.

The EHDI Program office in Santa Fe receives faxed referrals from the birthing hospitals on all infants requiring follow-up. The following conditions require a referral to the CMS state office from the hospitals: "refer" on newborn hearing screen, discharge without a screen, transferred to another facility, or the infant has an identified risk factor at birth. The CMS follow-up coordinators contact families within 48-96 hours to provide education regarding the importance of scheduling follow-up hearing screens; to help schedule needed follow-up services, including audiologic testing; and to make referrals to early intervention and other social services including Women, Infants, and Children (WIC), food stamps, housing, financial assistance, etc. This is done in coordination with the child's medical home. A fax or a letter indicating that a child in the practice needs follow-up on a newborn hearing screen is sent to the primary care provider within 48-96 hours after receipt of the referral from the hospital.

For Navajo families, the follow-up coordinators sometimes contact the Regional New Mexico School for the Deaf outreach supervisor to attempt the initial contact after hospital discharge. The program acquired a portable otoacoustic emission screener (OAE)/auditory brain response system (ABR) screener and will make a home visit to perform the follow-up screen if that is easier for the family. A similar system is in place for the Mescalero Apache tribe in Southern

New Mexico but is not yet in place for the other Native American tribes in NM. The EHDI follow-up coordinators work with the Navajo Nation Early Intervention program, Indian Health Services, community-based family organizations that serve the tribal communities, and the New Mexico School for the Deaf to support Native American families in accessing the hearing follow-up their infants need, but these efforts are not always successful, and the loss to follow-up rates are often higher for these communities.

There are 5 audiologists in the state that will evaluate infants and young children. This number was determined based on the number of licensed audiologists in the state and information on who is serving infants and young children as provided to the EHDI coordinator by CMS social workers, early intervention providers, and audiologists on the EHDI Advisory Council. One area of concern is that there is not an equal distribution of these audiologists around the state, with the majority located in Albuquerque, in central New Mexico. Diagnostic evaluations are only available in 3 locations: Albuquerque, Santa Fe, and Las Cruces, which are the more urban areas of the state. Statewide appointments are difficult to schedule, and often there is a three to six month wait before diagnostic testing can occur. The EHDI follow-up coordinators are able to obtain audiological results directly from the audiology practices by requesting the information via a phone call or by sending a fax request. Audiology practices either fax the child's audiology report or they complete our Report of Audiological Results form and fax it to the program.

Albuquerque is home to both the University of New Mexico Health Sciences Center (UNMH) and Presbyterian Hospital, which are the only tertiary newborn intensive care units (NICUs) in the state. These hospitals are also the only facilities staffed to perform *sedated* diagnostic audiologic evaluations. Families often need to travel long distances (including an overnight stay) to have a sedated diagnostic evaluation. Some families receive diagnostic services in El Paso or Lubbock Texas, which can be closer than services in New Mexico. The EHDI follow-up coordinators assist families in scheduling out of state audiological appointments in El Paso and Lubbock as needed. The follow-up coordinators are able to obtain audiological results from these practices. As soon as the coordinators know a baby has been diagnosed as deaf or hard-of-hearing, they immediately refer to the NM School for the Deaf Early (NMSD) Intervention Program. They in turn automatically refer these same babies to the local Part C, Family Infant Toddler (FIT) program for the Comprehensive Multidisciplinary Evaluation (CME) and for service coordination. NMSD is then written into the Individual Family Service Plan (IFSP). According to New Mexico Part C Regulations and Standards, *“The CME must address the child’s hearing through either documented Newborn Hearing Screening results (valid for only 6 months from the date of the screen); or a hearing screening that utilizes OAE and tympanometer or formal hearing test results. A statement summarizing the results must be provided in the written evaluation report. Children failing/referring on more than two consecutive hearing screens will be referred to their Primary Care Provider for medical/audiological follow-up. FIT providers will contact the NMSD Regional Supervisor for consultation and guidance regarding all children who have been identified as having a hearing concern. Once a permanent hearing loss is identified or suspected, a formal referral for services will be made to the NMSD Regional Supervisor, with family consent. The Family Service Coordinator is responsible for following up on any hearing concerns.”* These standards help to strengthen the safety net among community early childhood providers to identify children who may “fall-out” of the established system that CMS has developed for referral on failure to pass hospital newborn hearing screen.

A Memorandum of Understanding (MOU) has been in place for over 10 years between the Department of Health (where the Part C Family Infant Toddler Program and Children's Medical Services EHDI Program reside) and the New Mexico School for the Deaf. The MOU solidifies the legal relationship between the two entities and develops a referral and consultation mechanism when an infant is diagnosed with hearing loss. It also allows for data sharing. The MOU can be found in Attachment 4.

Due to New Mexico's proximity to Mexico, barriers occur when babies are born in border NM hospitals and need a follow-up hearing screen, but their mothers are unable to cross the border again to receive the services once they have returned to Mexico. The bilingual follow-up coordinator has been able to provide information and support to mothers that had to return to Mexico with their infants by mailing an information packet to their New Mexico mailing address, which can be a relative in the border community. These relatives in NM are helping the program provide information on the need for follow-up to the family member in Mexico. Families either obtain hearing follow-up for their infants in Mexico, or they come back to New Mexico for follow-up. The program has also developed a relationship with a Federally Qualified Health Center on the border, and the "promotoras" (community health workers) who provide support have helped a few mothers find resources in Mexico.

Licensed midwives are a strong force in New Mexico attending over 300 home births per year. The EHDI coordinator has been invited to the NM Midwives Association Meeting several times, and several challenges were identified: lack of access to screening equipment; reluctance of this home birth population to go to a hospital to be screened; reluctance of audiologists to take a referral from the midwife even though they are the medical home for the infant and the mother for the first six weeks of life; and lack of a protocol for reporting to the EHDI Program. Many of these issues are beginning to be addressed through the quality improvement process. For example, the EHDI Program developed an information packet that midwives can give to parents and a referral form that midwives use to report referrals to the program. The EHDI follow-up coordinators assist families in obtaining initial screens. One large midwifery practice in Albuquerque purchased an OAE for home births and sets up appointments for other local midwives to help with access for this population.

The Title V Children and Youth with Special Health Care Needs (CYSHCN) Program, Children's Medical Services (CMS) provides comprehensive medical care and critical care coordination for children with chronic medical conditions ages birth to 21. The program has licensed medical social workers housed in the local county public health offices that provide care coordination for infants referred by the EHDI coordinators who may have co-morbid medical conditions or risk factors after a diagnosis of hearing loss. A comprehensive family assessment is performed, and a care plan is developed to help with the coordination of medical care and linkage to needed psycho-social services. The CMS social workers are currently engaged in a quality improvement activity to address the coordination of care for children with complex medical needs and the development of a shared plan of care and communication tools between parent, social worker, primary care, and specialty care and to increase referrals from early intervention providers to assist with transition from to preschool. As the EHDI Program is housed in CMS, the work is coordinated across programs.

The program has an active EHDI Stakeholders Advisory Committee that meets quarterly to provide input into program priorities and activities. The stakeholders engage in projects such as

development and revision of the Family Resource Guide, legislative and policy development, and a range of advocacy initiatives. Stakeholders include representatives from audiology, early intervention, midwives, hospital screeners, parents of different cultural and ethnic background, Otolaryngologists and primary care. A complete list of current stakeholders may be found in Attachment 7.

Family Engagement

The program utilizes the cultural liaison, a strategy highlighted by the National Center for Cultural Competence at Georgetown University and the National Center for Family Professional Partnerships (NCFPP). According to the NCFPP at Family Voices a cultural liaison is defined as a: *“trusted individuals who may or may not live in a certain community, yet have knowledge of a community’s strengths, preferences and needs.” Community liaisons can act as relationship brokers, providing information and linkages between individuals, families and communities and the organizations and systems that seek to provide services and supports”*

New Mexico is perfectly situated to utilize a cultural liaison model to reduce loss to follow-up across the EHDI 1-3-6 especially in the Native American population. The CMS Title V program has a history of working with the Education of Parents of Indian Children with Special Needs (EPICS), a Native American Parent Training and Resource Center. EPICS has provided cultural competency training to the CMS staff for the past several years. CMS provided funding for an EPICS staff member to attend the annual EHDI Meeting and helps to bring the Native American perspective to attendees. EPICS provides parent trainings and parent-to-parent connection to the New Mexico urban and reservation Native communities.

Funds from this award will be used to contract with EPICS to provide parent training on the EHDI 1-3-6 and be a resource to parents who have an infant diagnosed with a hearing loss. One of the staff members of EPICS is the mother of a child with a hearing loss who was lost to follow-up and knows firsthand the barriers to receiving timely intervention. EPICS will continue to serve as the cultural broker between Native families and the western modalities related to screening, diagnosis, and intervention of hearing loss. Funds would also be used to support Native American families in the family learning and support activities offered through NMSD. Parent leadership opportunities are also a successful way to build family involvement on many levels of program and policy development. Funds will be used to support the annual Family Leadership Conference which attracts over 400 Native families from all over the country who have children with disabilities and special needs.

The CMS program has also begun working with a newly funded Family to Family Health Information Center named Navajo Family Voices who specifically work with families who have special needs children on the Navajo Reservation. This organization utilizes family mentors and advocates who live on the Navajo Nation and have learned how to navigate limited healthcare resources and services. They provide mentoring and training to families and communities focused on health--incorporating traditional cultural practices and principles. They are very interested in partnering to help the EHDI Program better understand the barriers for families accessing EHDI services and develop successful strategies to make positive change.

The EHDI Program has been working with the NM chapter of Hands & Voices for several years. Goals include: to provide support to and advocacy for families with children who are deaf or hard-of-hearing (DHH) without bias around communication modes or methodology, and to

provide families and organizations/agencies in New Mexico with resources, networks, and information they need to improve communication access and educational outcomes. Activities that will be implemented over the next several years include: quarterly educational/informational meetings with families and representatives from agencies working with children and youth with special health care needs to discuss issues affecting families of children who are DHH, participating in task forces and committees serving as advocates and advisors for New Mexico families in improving educational outcomes for DHH students; maintaining its social media presence including Facebook, blogs, and other avenues; hosting social events for families that have children that are DHH; and participating in the EHDI Quality Improvement activities to assure family input.

Each year, the New Mexico School for the Deaf (NMSD) provides numerous opportunities for parent-to-parent support and networking. The activities are open to any family whose child has any degree or configuration of permanent or suspected hearing loss. The child(ren) do not need to be attending NMSD school services

- Weekly play groups are held in Roswell, Santa Fe, Las Cruces, and Albuquerque. These groups include educational components and incorporate a range of topics and venues. One week, families may visit a train station with their children and the next week have a surgeon provide a training on what is involved with a repair on an atretic ear.
- Monthly events are held statewide in many cities and towns in New Mexico. They may be a variety of events, such as a holiday party or a visit to a library for story time. These events are planned jointly with parents.
- American Sign Language Classes are offered biweekly.
- Conferences and Family-to-Family Weekends are held in various parts of the state at least quarterly. These events are always very well received with approximately 120 families attending the most recent event.
- The Early Intervention and Involvement Department of the New Mexico School for the Deaf houses two nationally recognized programs: the *Parent Infant Child Program* and the *Deaf Mentor Program*. Each year, the *Parent Infant Child Program* provides early intervention services throughout the state of New Mexico to nearly 250 children who are deaf or hard-of-hearing, age birth to six, and their families. All services are free of cost and occur in the young child's most natural learning environment – home and community. Home visits occur weekly from each program at a time that best suits the family. Services are individually tailored through state and federally regulated practices to meet each child's and family's strengths and needs. The *Deaf Mentor Program* facilitates the understanding that with early and ongoing access to language, being deaf is a difference, not a disability. Most parents who have a deaf or hard-of-hearing child have never even met a deaf person other than their own baby. They are filled with questions. By simply introducing a parent to a Deaf Mentor, many of the anxieties that parents have can be drastically reduced. Deaf Mentors are also state-certified Developmental Specialists. The services they provide work in tandem with the *Parent Infant Child Program* services that a family receives, focusing on such areas as deaf culture, literacy, positive self-identity, and acquisition of American Sign Language. Currently 140 families per year receive Deaf Mentor services, but only 37 are under three years of age, and 17 are under one year of age. No children received this service before 6 months of age. Most of families accessing EI services from a deaf adult had

children between the ages of 4-5 years. The 2018 Parent Satisfaction Survey results indicate that 36% of families wished they had taken advantage of these opportunities when they were first offered. Improving earlier access to a Deaf Role Model for parents of young children will be target for improvement under this funding opportunity.

Data System

The State has created the New Mexico Indicator Based Information System (IBIS) data query system which provides data just a few weeks or months after the close of the previous calendar year. This system includes birth and death records, hospital inpatient discharge data, and health surveys such as the Youth Risk and Resiliency Survey (YRRS), the Behavioral Risk Factor Surveillance System (BRFSS), and the Pregnancy Risk Assessment Monitoring System (PRAMS). The State is developing a Health Information Exchange which will include emergency department data, hospital in-patient data, ambulatory medical records data, and laboratory data. Children's Medical Services collects data for a variety of programs.

A new data system which included the EHDI program was rolled out in 2016 and replaced both the older case management system (InPHORM) and the newborn screening system (that was in ChallengerSoft). Families FIRST, a perinatal case management program, is also utilizing the same system as CMS. In addition, the Newborn Genetic Screening program which is also housed in CMS has joined this data system.

The system, which was named CACTUS (Connecting Adults and Children to Unique Services), integrates the Children with Special Health Care Needs program, the Newborn Hearing Screening program, and the Newborn Genetic Screening program in the hopes of improving the coordination of care for clients and increasing tracking and surveillance capabilities. The data links all 4 programs (the three CMS programs plus Families FIRST) with a shared demographic page and a single patient identifier.

The datasets are used for quality assurance, providing services such as early intervention and also surveillance with a goal of a seamless system of care for infants through newborn screening. Overall the data CMS maintains are good for conducting follow up. All hospitals are now reporting monthly to the program and can provide this information through electronic file transfer. The files are either a spreadsheet with all data fields or an upload from the ABR in the nursery. This monthly data upload now provides the program real time information on all babies born and the results of their newborn hearing screen. The referrals for follow-up are sent electronically to the follow-up coordinators who document their activities in the electronic medical record. CACTUS is updating and improving the electronic interface with hospital data. The daily interface with Oregon Public Health Lab, which is the lab that provides all the testing for the metabolic program, is being used to create the initial infant record and provides demographic information and infant's primary care provider (PCP). The metabolic screening program has a 98% initial referral rate, and plans are being developed to utilize birth and screening rates by hospital to compare with newborn hearing screening rates as part of a quality assurance improvement project.

The EDHI Program continues to improve in data collected from audiologists as well. The collection form was revised by the audiology subcommittee of the Stakeholder Advisory Committee, and the EHDI coordinator communicates with the audiologists monthly requesting

data on diagnostic testing that may have occurred. The audiology committee is also working on standardizing diagnostic protocols including reporting to the State.

The program has an agreement with the New Mexico School for the Deaf (NMSD) Early Intervention Program that a referral may be made while a family is waiting for an audiology appointment. This agreement has been a way to address the long wait times for audiology appointments in some areas of the state by providing support services and education to families during the interim. NMSD is also reporting to the EHDI Program on the dates of Individual Family Service Plan (IFSP) completion for infants referred for early intervention after diagnosis, and this is documented in the infant record in CACTUS.

We are now able to run reports in CACTUS to help us track screening results, dates, referrals to audiology, diagnostic information, and early intervention referral dates which has greatly improved our ability to assess the health of our system.

III. METHODOLOGY

In this section, we describe the several methods that apply to each specific goal in the initiative in support of the long-term outcomes of this initiative: The NM EHDI Program will utilize a variety of methods to improve developmental outcomes of children who are deaf or hard-of-hearing (DHH) by engaging stakeholders, improving EHDI infrastructure, expanding EHDI systems, educating health professionals, and engaging DHH adults as mentors for families. Each level (target community, learning community, and state) is linked in the logic model and in the methodology. The five goals in the methods section require similar work with stakeholders and individual provider groups in the healthcare and community sectors. The overlap in objectives and activities, especially at the community and county level, is intentional. Many of the strategies for process improvement and development of meaningful outcome measures through learning community activities are highly inter-related and may involve some of the same individuals and organizations

Many of the required contracts and Memorandum of Understanding's (MOU) are already in place and will continue throughout the funding cycle. These include:

- Contract with EPICS to assist with addressing cultural and health equity among Native American families
- Contract with Hands & Voices
- Contract with Parents' Reaching Out (F2F)-through a different funding source
- MOU with Part C Family Infant Toddler Program and the New Mexico School for the Deaf.
- Contract with New Mexico Quality Improvement Partnership (NMQIP) for the Care Coordination Project and the EHDI Program.

The EHDI coordinator and the project coordinator from NMQIP will work very closely together throughout the project and will rely on extensive communication with the local advisory committee and parent organizations. Frequent planning and development meetings are seen as critical elements to getting project activities rolled out with buy-in from local stakeholders. Children's Medical Service leaders, in addition to the project director and select members of the NM EHDI staff, will be expected to make multiple site visits to the target communities to meet

with the advisory committee and local stakeholders at many points during the project. New Mexico, with many rural and geographically isolated communities, has a long history of project personnel driving many miles in order to establish and nurture the relationships that are critical to project activities.

NM EHDI will utilize quality improvement (QI) and the Model for Improvement (MFI) to positively impact healthcare provider practice and healthcare delivery systems for infants birth to 3 years and their families. A benefit of this model and approach is the explicit capacity building in programs that participate. Programs practice and apply strategies to strengthen leadership and expertise in QI. This approach is financially and programmatically sustainable since the MFI approach emphasizes recognizing gaps in care and using currently available staff and resources to improve the EHDI system.

With a goal of creating a common agenda to improve age-appropriate developmental skills, the target community and learning community level organizations described in this proposal will receive hands-on support and training by NMQIP staff as they implement processes that improve performance of the EHDI systems and outcomes for children and families. The primary contractor engaged in this proposal, New Mexico Quality Improvement Partnership (NMQIP), has worked with early childhood programs in NM since 2005. NMQIP uses practice facilitation (coaching) by staff members who are experts in QI. NMQIP has well-developed protocol, tools, data measures, and data feedback mechanisms that can be used immediately in the target communities as they start their QI work and engage in learning community activities.

The Model for Improvement (MFI), developed by Associates in Process Improvement, is a simple and powerful tool for accelerating improvement. The Model for Improvement has two parts of equal importance: 1) Answers to three fundamental questions are essential for guiding improvement work and can be addressed in any order: What are we trying to accomplish? How will we know whether a change is an improvement? What changes can we make that will result in improvement?, and 2) The Plan, Do, Study, Act (PDSA) cycle tests and implements changes in actual work settings. Five critical components are needed to apply the Model for Improvement: 1) An improvement project that can be process-focused related to saving time, money, or improving quality of a service or system, or it can be outcome-focused related to improving health status, behavior, attitude, and/or knowledge; 2) People who will test the interventions or changes; 3) A family of measures, including impact and process measures. A few of the measures should have the potential of being tracked at least monthly; 4) Interventions to be tested that are grounded in science; and 5) Time, usually 6 to 16 months, to allow for multiple tests of interventions.

The NM EHDI will provide access to video conferencing and call-in access for monthly meetings using ZOOM to facilitate communication, especially during winter months when traveling can be dangerous.

New Mexico has several existing programs that serve communities across the state that promote child and family well-being and would benefit from the new information and lessons learned via the learning community activities that will be implemented in this project. These include: County Health Councils, Head Start and Early Head Start, NM DOH, Health Promotion Specialists located in key regions/counties, the state home visiting system and its network of training and technical assistance, the outreach projects to Early Childhood Investment Zones,

funded by a mix of MIECHV and Race to the Top funds, and the New Mexico Pediatric Society with its focus on disseminating new information to members.

The EHDI Program recognizes that there are several areas that need continued improvement which includes: assuring that hospitals are accurately reporting infants that do not pass the screening; addressing issues related to access to audiology services; improving communication between the program and audiologists, especially related to receiving timely results of follow-up testing; improving the communication between the program and the medical home; and improving outreach and support to parents through a parent-to-parent program and Deaf Role Models, especially for culturally diverse populations. Learning Communities will be established in two regions of the state where QI activities will be concentrated. The Northwest region of the state includes the New Mexico portion of the Four Corners. There are three birthing hospitals in the area, two of which are operated by Indian Health Services. The area is rural and frontier with 38% of the population Native American from the Navajo Nation and the Zuni Pueblo. This is the largest land area retained by a Native American tribe in the United States. The population continues to disproportionately struggle with health problems, unemployment, and the effects of past uranium mining incidents. Access to health care is influenced by a dearth of providers, poor infrastructure including poor and often impassable roads, and lack of basic needs such as running water and electricity. We lose more babies to follow-up in this region than in any other region of the state, and there is a critical window of time to make contact with families and coordinate follow-up appointments. The Southeast region of the state is another area with scant resources. Although recently part of an oil and natural gas production boon, there are many health inequities in this region including higher rates of teen pregnancy, less access to prenatal care, and high rates of children with chronic health conditions. The community has a higher number of migrant workers who work the oil and gas fields and the ranches and dairy farms. There is limited access to audiology, and the EHDI Program is dependent on birthing hospitals to perform rescreens on a referred newborn hearing screen. There is an early intervention program in each county and Early Head Start and Head Start, making this an ideal region to utilize the QI model to improve the EHDI infrastructure and expand the system.

The methodology will address five critical areas:

Goal 1: Engage and coordinate all EHDI stakeholders in NM:

Objective 1.1: Expand partnership to expand awareness of EHDI 1-3-6.

Objective 1.2: Develop a plan to address diversity and inclusion.

Objective 1.3: Utilize the CoIIN and Learning Communities in the Northwest and Southeast to develop new partnerships and strategies to improve EHDI outcomes.

Implementation of this part of the work plan will be dependent on the active engagement of the stakeholder team which meets quarterly at EHDI Stakeholder Meetings. The stakeholders include; the NM EHDI program coordinator, the Title V CYSHCN director, the (contracted) follow-up coordinators, audiologists, the AAP EHDI Chapter Champion, New Mexico School for the Deaf Early Intervention Program, Presbyterian Ear Institute Oral School, midwives, Family Voices, and several contractors with specific expertise in the areas of family involvement and cultural competency. Contracts will be continued with EPICS to support their work as cultural liaisons with Native American families and the NM Chapter of Hands &Voices to

implement Guide by Your Side statewide, and a new partnership with Navajo Family Voices. Of the 16 regular members, four of these members are parents of DHH children and another is a deaf teacher at the New Mexico School for the Deaf. NM EHDI is continuing to work to strengthen its efforts to include more deaf and hard-of-hearing parents and professionals to create a parent only committee that include parents of deaf and hard-of-hearing children 0-4 years of age.

As the EHDI under the Title V CMS Program for NM, CMS/EHDI understands the importance of collaborating with other groups who also serve the CYSHCN population in order to reduce duplication and maximize efforts. New Mexico is fortunate in that the HRSA-funded MCH programs meet regularly in the MCH Collaborative to discuss how to work together and support each other. These programs include the Leadership in Neurodevelopmental Disabilities (LEND program) (and LEND trainees will include this project as part of their Capstone), the Governor's Commission for Deaf and Hard-of-Hearing Persons, the Deaf Mentor Coordinator, Family Voices, EPICS (Education of Parents of Indian Children with Special Needs), and CMS. In terms of this proposal, CMS intends to enhance and build on our existing partnerships with these MCH entities, with specific focus on expanding partnerships with community-based family organizations such as Navajo Family Voices, Early Head Start, and Head Start to help expand screening and monitoring for hearing loss in children.

Objective 2: Improve referral and follow-up process as part of the EHDI infrastructure:

Goal 2.1: Increase reporting to the NM EHDI Program of screening results for newborns prior to one month of age.

Goal 2.2: Improve timeliness of referrals and documentation of diagnostic audiology services to the NM EHDI Program for infants that do not pass their newborn screening test.

Goal 2.3: Improve timeliness of referrals to early intervention for infants that are diagnosed with a hearing loss.

A pilot telehealth project was developed to address the shortage of audiologists in the Northwest region of the state. CMS worked in collaboration with Utah State University, the University of New Mexico (UNM), the Department of Audiology at UNM, Rehoboth McKinley Hospital, Gallup Indian Hospital, and Growing in Beauty, the Part C provider on the Navajo Nation. Babies born at either of these hospitals in Gallup NM who need a rescreen on their hospital screen were eligible to participate in 2010. Unfortunately, due to a number of equipment and personnel issues this project never got off the ground, but there is excitement and interest from the medical community at both hospitals, the UNM Audiology Department, and the Navajo Nation to revise this project. The telehealth equipment will need to be assessed for usability, and other resources will need to be obtained to cover the cost of replacement part.

Utilizing the Model for Improvement (MFI) developed by Associates in Process Improvement, the Newborn Hearing Screen Quality Improvement Initiative for 2017 which included Newborn Hearing Screening (NBHS) measures as part of the Developmental Screening Initiative (DSI). The DSI provides the framework for introducing the NBHS and the Early Hearing Detection and Intervention (EHDI) 1-3-6 goals. The NBHS Initiative piloted additional measures related to

reporting to EHDI in preparation for further work at the state systems level. The results were encouraging and showed that tying together Developmental Screening to NBHS measures increased the awareness of 1-3-6 from 73%-100%.

Program data/quality team created a hospital report card that utilizes annual CDC/HSFS data and compares the following for each hospital: the number of live births with the number of children that were screened; the number of children who did not pass the initial hearing screening to with the number of children who were referred to NM EHDI; and the number of children who did not pass the initial hearing screening with the number of children who were found to have hearing loss. Hospitals will be able to view their outcomes with state averages. The hospital report cards have been shared with each hospital through a site visit from the program's needs assessor and have sparked productive conversations about improvements in reporting and screening practices. The production and distribution of the report cards will be an annual occurrence.

NM EHDI has developed a hospital newsletter that is being used as a communication tool with New Mexico's birthing hospitals. The newsletter includes links to the National Center for Hearing Assessment and Management (NCHAM) training curriculum and other resources for hearing screeners, reporting requirements, and a discussion about what is considered a valid passed hearing screen according to the Joint Commission on Infant Hearing. The newsletter is being used as a starting point for conversations with New Mexico's hospitals regarding their needs and challenges.

Several of the larger audiology practices have at least one of their pediatric audiologists serving on the EHDI Program's Advisory Council which meets semi-annually. The Advisory Council has a subcommittee of audiologists who work with the EHDI Program to identify and address issues related to documentation of diagnostic results to the State EHDI Program. NM EHDI and its Audiology Committee are beginning a shared decision-making process to improve reporting to NM EHDI including direct uploads of audiological reporting into the EHDI-IS system, updated risk factor reporting, late onset reporting and mechanical interventions. The audiology committee will also be disseminating "best practices" regarding diagnosis and reporting, and an *Audiology Report Card* which will include the EHDI 1-3-6 Guidelines as a measure.

Goal 3: Expand EDHI systems:

Objective 3.1: Refine state plan to expand infrastructure for hearing screening up to age three.

Objective 3.2: Develop, implement, and evaluate use of electronic shared plan of care with external EHDI partners.

Objective 3.3: Work with partners including the NM AAP EHDI Chapter Champion and the National Center for Hearing Assessment and Management to educate and train on the use of appropriate hearing screening equipment.

The Newborn Genetic Screening Program which includes EHDI is part of the Mountain States Regional Genetics Collaborative (MSGRC) and is participating in the second year of Underserved Populations Project (UPP) which develops strategies to increase access to genetic services for individuals in rural, Hispanic, and American Indian communities in the Mountain States. This project is parent-driven and targets families from underserved regions of the state. There has been a focus on using telehealth to improve access to genetic services for families in

rural areas and especially tribal lands. The MSGRC also sponsors an opportunity for programs to host “Pop-up Events” around genetics, and several states have used this opportunity to talk about EHDI with different stakeholder groups. This could be a way to reach other partners in the early childhood field to help with EHDI expansion. Retrieved from:

https://www.surveymonkey.com/r/GAPOPUP?utm_source=+March+2019+Mountain+States+Genetics+Network+Message+from+the&utm_campaign=March+2019+PD+message&utm_medium=email

During the previous EHDI funding series, the Learning Community worked hard to complete the Shared Plan of Care which is a health passport for families of children who are diagnosed as deaf or hard-of-hearing who are 0-4 years old. The passport is designed to provide a communication tool between parents, PCPs, and specialists, and to be utilized as a tool for health literacy for families of children who are DHH. The Shared Plan of Care is a modification of the plan utilized by NM EHDI’s parent agency Children’s Medical Services (CMS) who serves New Mexico Children or Youth with Special Health Care Needs (CYSHCN) experiencing a moderate to severe medical condition. There was not widespread support for this shared plan of care, but it may be useful as we look to expand EHDI systems, and we will use the QI process to test its usefulness with expanded stakeholders. A contract will be established with the NM AAP EHDI Chapter Champion Dr. Julia Hecht who will provide guidance on use of OAE for follow-up and on-going testing which has been a focus of study for her. She will bring a clinical perspective and will use data for QI as part of her activities with expanded stakeholders on the predictive value of screening. Her integration with the pediatric medical community is a huge asset to this project. NM EHDI has been a more active participant in the past with Early Childhood Hearing Outreach (ECHO) Initiative at the National Center for Hearing Assessment and Management (NCHAM) as part of outreach and training to Early Head Start and Head Start programs. With the Reauthorization of the Early Hearing Detection and Intervention (EHDI) Act of 2017 and an expanded focus on identifying children who are deaf or hard of hearing up to three years age is a priority. This is an opportunity to refocus work in this area and utilize the expertise of the ECHO staff out of NCHAM to help us to expand evidence-based hearing screening practices to a broader range of early care and education providers for the benefit of a wider population of children. NM has an existing statute that requires reporting to the DOH for suspected and confirmed hearing loss for children up to age 4 which can be leveraged to achieve this goal. http://www.health.state.nm.us/epi/NotifiableConditions_Final_063006.pdf. The creation of the new Cabinet Level Department of Early Childhood Education and Care Department will incorporate most of the early childhood programs in New Mexico including home visiting, childcare, and behavioral health. Efforts will be made to meet with staff in the new department and engage them in this objective to establish a statewide system for universal periodic hearing screening of young children using evidenced based practices.

Goal 4: Create a blueprint of integrated care for children who are DHH for NM Primary Care Provider’s:

Objective 4.1: Improve provider awareness and adherence to EHDI guidelines.

Objective 4.2: Implement and evaluate the use of CoIIn to guide newborn hearing screening and care activities.

Objective 4.3: Train healthcare provider and other providers in EHDI guidelines.

Objective 4.4: Link PCP's to NM Medical Home Portal and EHDI resources.

To address care coordination for CYSHCN including children identified through EHDI that are DHH, the program is continuing its work with New Mexico Quality Improvement Partnership (NMQIP). This project includes improvement activities to address the coordination of health care and social services for children in New Mexico who have disabilities and chronic medical conditions. Complex and uncoordinated care is a contributing factor to poor health outcomes in the pediatric population of Children with Special Health Care Needs (CYSHCN). There is an increased demand for services for CYSHCN and families at all levels necessitating health care from multiple organizations and programs. Initiatives for this multiyear project include: improve the coordination of care across service providers for CYSHCN in partnership with the medical home and lead the quality improvement activities in the regional Learning Communities in the Northwestern Region and the Southeast Region. Included in these activities will be the establishment and maintenance of a Care Coordination Consortium (CCC) to be a source of information, resources, tools, expert advice, and peer learning and support for pediatric and family practice staff, managed care organizations, Medicaid, family organizations, Title V staff, and other service providers who focus on coordinating care for children, with an emphasis on those with chronic conditions and special health care needs. This will be a forum to discuss unique needs and issues for children who are DHH.

CMS continues to support and promote the use of the Medical Home Portal (MHP) maintained at the University of Utah as a useful resource for families and providers to obtain accurate information on pediatric medical conditions including newborn screening. It also links families to community resources to address psychosocial needs as well. The community resources page is kept up to date in partnership with the University of New Mexico Center for Development and Disability Information Network. The CMS program manager participate in the Medical Home Portal Advisory Committee that began meeting quarterly to review portal metrics and usefulness and to provide input into additions that would be helpful for New Mexico families. The MHP received considerable attention this year from the NM Pediatric Society, the Early Childhood Comprehensive Services Advisory Committee, and the Act Early Committee. All of these groups decided to embrace the MHP as the “go to” for their respective stakeholders. A New Mexico team was formed to provide input to the MHP staff in Utah. At the annual NM Pediatric Society conference, a brief survey was available to pediatricians to elicit level of knowledge and interest of the MHP. The results proved that there was enough interest that the Pediatric Society invested resources to develop promotional materials that are being distributed to encourage use.

Goal 5: Strengthen support to families with children who are DHH including access to Deaf Role Models:

Objective 5.1: Support expansion of family-to-family support services to reflect the diversity of the families of New Mexico.

Objective 5.2: Test and refine a data tracking measure to enhance family centered care for children with hearing impairment.

Objective 5.3: Support the NMSD Deaf Mentor program and identify opportunities for expansion.

The program has been working with Hands & Voices for several years. Plans are underway to develop a Guide by Your Side program in New Mexico. This will be a very helpful mechanism to provide support to families especially in rural areas where families often feel isolated.

Activities that will be implemented over the next four years include: 1) quarterly educational/informational meetings with families and representatives from agencies working with children and youth with special health care needs to discuss issues affecting families of children who are deaf or hard-of-hearing; 2) provide support to and advocacy for families with children who are deaf or hard-of-hearing without bias around communication modes or methodology; 3) provide families and organizations/agencies in New Mexico with resources, networks and information they need to improve communication access and educational outcomes; 4) create and maintain parent advocacy group of families with children who are deaf and hard of hearing, 0-4 years of age designed to inform the Newborn Hearing screening program of issues that families are experiencing with Newborn Screening and Follow-up to Audiology. With the support of Hands and Voices Headquarters, New Mexico School for the Deaf (NMSD), the Early Intervention Family Infant Toddler Program (EI FIT), and the Newborn Hearing Screening Program will design and implement a parent survey to ascertain the needs of parents 0-4 years of age in regard to parent advocacy. In partnership with the New Mexico School for the Deaf and the Newborn Hearing Screening Program, utilizing the results of the parent survey mentioned above, assist in designing a parent referral system for Guide by Your Side and the Deaf Role Model program. A representative will also attend the semi-annual NM EHDI Stakeholder Committee Meeting and attend the Learning Community Collaborative.

The New Mexico School for the Deaf has a nationally recognized program. The Deaf Mentor Program is a service for families and their infants and young children who are deaf or hard-of-hearing. Services through this program are offered statewide and occur in the child's natural learning environments, home and community.

The Deaf Mentor Program is a public program and free of cost to New Mexico residents. Services are individually tailored through state and federally regulated practices to meet each child's and family's strengths and needs. Deaf Mentors are trained in the Deaf Mentor Curriculum and Shared Reading Project and are experienced in working with families and their young deaf or hard-of-hearing children. Providers live in, or close to, communities. Capitalizing on this already established program and expanding its scope to include referrals to families of infants that are DHH are important parts of the work plan.

NM EHDI has also been working with EPICS for many years to liaison into New Mexico tribes and Nations to provide education and family-to-family support to Native American families who have a child who is DHH. This contract will continue to be supported by this funding opportunity.

Activities that will be maintained to assist in meeting the goals of the work plan will be:

- Provide community outreach and trainings to Pueblo and Tribal entities on the importance of early hearing detection and intervention;
- Educate parents, individuals, and communities on the importance of follow-up for the following: infants who do not pass their newborn hearing screening, infants who are identified with risk factor(s) for hearing loss, and the importance of early intervention for those with a confirmed diagnosis of hearing loss;

- Consult with the Newborn Hearing Screening Program with HRSA and CDC grant applications, and consult with the program and tribal government agencies that may be involved in any grant award;
- Consult with the EDHI Program with issues that may increase loss to follow-up in tribal jurisdictions and assist EDHI with follow-up policies and procedures that are designed to reduce loss to follow-up rates and consult with other parent organizations (Hands and Voices, Parents Reaching Out) who are engaging in parent advocacy efforts.

CMS has a partnership that is being developed with a newly funded Family to Family Support Organization, Navajo Family Voices which focuses on the Northwest Region and specifically Navajo families who have CYSHCN. This is an exciting opportunity to engage with the EHDI community especially as a goal of this project to improve access to audiology services and decrease delays in referrals to early intervention for these communities. Funds will be used to support educational and community activities to discuss EHDI initiatives including referral to the Deaf Mentor Program in this community which is hard to access.

IV: WORK PLAN

The work plan is outlined in table format and details the QI activities, integration of Learning Community activities, and communication between the NM EHDI team and target communities along with outcomes that are projected for each year of the four-year grant cycle. The work plan describes how the elements of the logic model will be divided among community, county, and state participants demonstrating distribution of proposed activities to obtain maximum benefit from the funding. The work plan and logic model may be found in **Attachment 1**.

Note: Some activities and outcomes in the work plan are specific. When not specified, any activities or outcomes apply to all project goals.

V. RESOLUTION OF CHALLENGES

Children who bypass the CMS system and are identified with congenital hearing loss at a late age: A system of screening and referral for follow-up has been established for infants who do not pass the newborn hearing screen and is documented in the introduction section. There continue to be 18-20 infants annually, however, who are identified as deaf or hard of hearing between the ages of 2 and 4 years. This creates a sense of urgency for the EDHI program. Analysis of these occurrences shows that many times the infant had a home birth and may have been cared for outside the traditional medical community; there was no documentation from a birthing hospital that the screening was a refer; the provider took a “wait and see” approach; or the family ‘went missing’ and was finally referred for services. Our intention is that with this funding project and its goals of improving awareness of 1-3-6; engaging families; improving tracking and surveillance and integrating core EHDI measures into the early childhood system, we will reduce the number of late identification.

Workforce development and education: Most New Mexico counties are categorized as a Health Professional Shortage Area and Medically Underserved Areas/Populations (HPSAs). This includes audiologists especially for the pediatric population. The exploration of telehealth to

improve access to audiology in targeted regions of the state is a strategy that will be used to address this challenge. The use of the additional funding to assess the educational needs of providers, especially PCP's, on their roles and responsibilities will also assist in the development of community based educational interventions.

Challenges implementing QI: Implementing QI with healthcare providers exposes challenges to making system improvements. Many of these challenges are related to the real and perceived burden of adding additional responsibilities to an already stressed healthcare delivery system.

Provider time: Physicians are busy, particularly in rural and frontier areas of New Mexico where time and distance increase barriers to care. Project staff will work through this challenge by making the QI work relevant to their clinics' desired outcomes and by working to improve clinic flow such that the continuous quality improvement (QI) work is seen as beneficial and transformational to all staff involved. Staff will deliver relevant and useful materials via telehealth, email, video conference and other means as determined.

Lack of QI exposure: Pediatric, family medicine, and other healthcare or education entities that have little or no exposure to continuous quality improvement work and need added time to orient to and engage in QI methodology. Many physicians have openly admitted that their participation in our program was driven by their need for Maintenance of Certification (MOC) credit rather than a genuine enthusiasm for learning about systems change and QI. However, data from post survey responses from previous QI projects indicate that at the end they are satisfied with the changes in their clinic flow and believe the QI work positively influenced patient outcomes.

Staff turnover: New Mexico in general has a less developed work force, long distances to travel, low wages, and other barriers to consistent staff in primary care clinics. Many areas in NM experience high rates of staff change and therefore clinic disruption. We will develop methodology to work at redesigning health clinic flow to mitigate the negative impact of staff turnover. Further, creating optimal systems for screening, referral and follow-up decreases interruption as the system is designed to achieve the results and is not dependent on individuals in the clinic.

Equipment use and protocols for use: All New Mexico hospitals use an ABR to screen for the initial newborn hearing test. There is variation across the state in protocols for the rescreen with some agencies utilizing an OAE to perform this test thus ruling out a screen for auditory neuropathy. Children that are currently in early intervention and have a developmental delay and language delay receive an OAE annual screening which is preferable to a check-list which is the minimum requirement. However, as part of NM's protocol for Part C hearing screening, if a child has not passed ABR screening as part of Newborn Hearing Screening, an OAE will not be used and the child will be referred for audiological services to help rule out mild hearing loss or auditory neuropathy. Each year between 8-12 children with acquired or progressive hearing loss are identified through Part C from the OAE screenings. Most of these children have cytomegalovirus (CMV), but not all. To date, we have not had any children identified with hearing loss during their transition. They have all been identified earlier during their annual or initial screens. Children who have passed their hearing screen but are considered "at risk" due to a risk factor may also not be receiving appropriate audiology follow-up as they are often asymptomatic, and PCP's may not be aware of recommended protocols. The audiology and

physician sub-committees under EHDI are aware of these issues and will continue to evaluate and develop statewide recommendations.

IFSP Completion time: There are delays due to lack of audiology services which includes accessing transportation services and childcare which increases the time to diagnosis thus the referral to EI. The coordination between the primary care physician, family, and early intervention program also needs improvement. There can also be a lack of timely reporting to the EHDI follow-up coordinator by the early intervention programs of completion dates as many children are referred to the local early intervention program who are responsible for the IFSP. The NM School for the Deaf (NMSD) serves as consultant and sometimes the services coordinator. Some of these issues could be mitigated with regular meetings and communication with the early intervention lead agency, the Family Infant Toddler (FIT) program which would include real-time reporting so that this information could be entered into the EHDI database. The MOU between CMS, NMSD, and FIT is up for renewal, and this could be outlined in the new agreement. The integration of care and communication between providers and the program is part of the larger work that CMS is undertaking to address the overall system of care for children with special health care needs in the state, inclusive of the Care Coordination Consortium.

Inconsistent data sharing between early childhood providers: New Mexico did have Reach to the Top funding and developed an Early Childhood Integrated Data System; however, it did not include MCH Title V data and thus any data on hearing screening is missing. This past legislative session, a bill was passed and signed into law establishing a new department in the state, the New Mexico Early Childhood Education and Care Department. The new department will include childcare licensing and services, early childhood education, home visiting, child behavioral health, and early intervention services with a focus on providing high quality education and services for children from birth to age 5. A major focus is to align early childhood program and use a common data system to reduce redundancy and increase effectiveness. This new high priority focus on early childhood provides the EHDI Program a perfect opportunity to improve communication and collaboration with other early childhood programs to address data sharing and to expand EHDI infrastructure and screening up to age 3.

Transportation and other barriers for families to engage in services: Transportation issues in rural areas of NM are a major concern, including transportation to health care appointments as well as to employment or job training. Public transportation is limited, and it is not always possible for family members to drive long distances for appointments, missing work and paying high costs for gas and car maintenance. CMS assists families with transportation issues and provides care and support funds for travel whenever possible under program guidelines. The Medicaid Managed Care Organizations also have transportation as a covered benefit. Understanding what the barriers are for families for keeping appointments for follow-up will be an important component to address this challenge. Coordinating with our community-based family organizations to better understand this issue, and hearing directly from families, will help us make positive changes. The follow-up coordinators work with staff from the New Mexico School for the Deaf who will provide a limited number of AABR and OAE second screens for infants. These second screens are provided in the family home which alleviates the need for travel. In addition, a number of physician practices and Child Find entities throughout the state provide OAE screening. The follow-up coordinators assist families in accessing these resources for second hearing screens.

We know that additional challenges will emerge during the course of this initiative and will address them collaboratively as they arise.

Plans that will sustain the project beyond Federal funding

The program is housed in the Title V Children with Special Health Care Needs program, which financially and administratively supports the goals and objectives of this project to the best of its ability within the budget climate of both state and federal environments.

VI. EVALUATION AND TECHNICAL SUPPORT CAPACITY

Terms and Guiding Approaches Used in Evaluation

The overall evaluation approach includes a quality improvement lens with these guiding framework elements: (1) establishes an ongoing data collection mechanism; (2) provides timely and meaningful feedback of information collected for continuous quality improvement; (3) provides timely and meaningful feedback to families and providers- regarding improvement efforts; (4) continuously and collaboratively identifies and establishes essential data elements that will be aggregated at the state level to inform systems improvements and outcomes; (5) and disseminate relevant results of efforts to stakeholders and community.

Background on NM QIP

NM-QIP's mission is to work with NM pediatric healthcare practitioners to make sustainable changes in healthcare practices to improve the quality of care for children and families using evidence-based quality improvement (QI) methodology. The vision is to build sustainable partnerships that promote and improve child health and family well-being in communities across New Mexico. NM-QIP has a combined eighty years in child health, wellness and education and have worked together over the last decade on QI initiatives.

Sustainable partnerships/stakeholders for NM EDHDI that support improved patient/family care consistent with evidence-based approaches to screening, referral, access to care and care coordination for NM infants with hearing loss

Activities: (1) Convene monthly CoIIN for healthcare providers, families and state stakeholders (2) recruit primary provider practice through contacts generated by CoIIN activities; (3) conduct QI with up to 5 practices per year in the target communities; (4) conduct community and stakeholder level QI on barriers to needed services, duplicate screens and other processes identified with the learning community; (5) process and award MOCs and CME/CEUs for providers at completion of QI.

Community and health providers and stakeholders will receive hands-on support and training by New Mexico Quality Improvement Partnership (NM-QIP) staff. NM-QIP uses practice facilitation by staff members who are experts in QI. NM-QIP has well-developed protocols, tools, data measures and data feedback mechanisms for QI that can be used immediately in the target communities as they start their QI work and engage in proposal implementation activities.

The Model for Improvement (MFI), developed by Associates in Process Improvement, is another powerful tool NM-QIP uses for accelerating improvement. Five critical components are needed for the Model for Improvement to be effective and are included in this proposal. These elements are:

1. An initiative that can be process-focused related to saving time, money or improving quality of a service or system or can be outcome-focused related to improving health status, behavior, attitude and/or knowledge
2. People committed to testing the interventions or changes
3. A family of measures, including impact and process measures, some of which should have the potential of being tracked at least monthly
4. Interventions to be tested that are evidence-based
5. Time to allow for multiple tests of interventions and evaluation of the impact of interventions or changes.
6. Improving family engagement, partnership and leadership with the EHDI program system

Outcomes of interest and evaluation focus

The NM EHDI program has a goal of promoting access to family-to-family support for all infants diagnosed with hearing loss especially when encouraging adults with hearing loss to take a role in peer support and mentorship for families living with a new diagnosis of hearing loss. Program services are provided in a family centered, community-based, culturally competent and coordinated manner, with emphasis placed on ensuring that all infants who do not pass their initial hearing screen receive timely follow-up services. Geography, rural residence and health provider shortage areas mean that approaches to improvement require coordination between parents, advocates and health systems.

An over-arching focus of process improvement is in overall provider awareness and adherence to EHDI guidelines in NE and SE regions of New Mexico where access and barriers to care are particularly challenging and can be problematic for health providers and families. We also include needs assessment and family survey process measures to assess the level and areas of need and to connect family advocate organizations to families where the need is greatest.

Activities for Evaluation:

Develop, implement and evaluate using CoIIN to guide newborn hearing screening and care activities;

Test and refine shared data tracking and measures to enhance family-centered care for children with hearing impairment;

Train healthcare and other providers on EHDI guidelines for screening, referral and follow up;

Implement QI activities a participating provider practices that target adherence to EHDI guidelines.

Additional process measures include:

1. Family satisfaction with trainings and participation in collaboratives
2. Provider satisfaction with trainings and QI supports
3. Provider knowledge gains in best practice guidelines

Baseline and follow-up data and characteristics of clients/participants served. Data collection that involves survey tools will be developed using an online survey application consistent with required safeguards to protect privacy. All surveys will be kept anonymous. Attendance data will be collected with each activity. Process and monitoring activities related to all project goals are: (1) Ongoing data collection, and data management; (2) regular data analysis and reporting to funder and stakeholders; (3) monthly meeting with funder; (4) Maintenance of Certification and CME/CEU award management for practitioners participating in relevant QI; and (5) QI trainings as needed.

NM EHDI- Evaluation Plan

Universal Newborn Hearing Screening and Intervention is to ensure that all children in NM receive optimum services through a statewide newborn hearing screening and intervention program in adherence to the Joint Commission on Infant Hearing best practices of 1,3,6. The goals for these services are to screen all newborns prior to hospital discharge or before one month of age, to achieve audiologic diagnosis before three months of age, and to enroll all children with hearing loss in early intervention before six months of age, in collaboration with the child's Medical Home.

(1) provider and family participation and satisfaction; (2) provider adherence to standards of care as a result of proposal activities

Goal 1: Engage and coordinate all EHDI stakeholders in NM:

Objective 1.1: Expand partnership to expand awareness of EHDI 1,3,6

Objective 1.2 Develop a plan to address diversity and inclusion

Objective 1.3 Utilize the CoIIN and Learning Communities in the Northwest and Southeast to develop new partnerships and strategies to improve EHDI outcomes.

1.1 Preliminary activities expand partnerships and awareness of EHDI. Building on partnerships through Hands & Voices, Family Voices and New Mexico Quality Improvement Partnership, we will assess opportunities to expand awareness and partnerships.

Measures for 1.1:

-Number of social media outlets identified for outreach for families of DHH

- Number of community events attended
- Number of families participating in a survey of transportation and access needs
- Completion of a community needs assessment

1.2 Geographic, social and cultural barriers impact access in New Mexico (NM) to services for CYSHCN and those with hearing loss or impairment resulting in delayed diagnosis, management inconsistent with best practice guidelines and uncoordinated care. We will promote health equity in underserved communities in NM by improving access and enhancing provider communication shared care plans for clinical services and care coordination.

Measures for 1.2

- NM Learning Community (LC) panel established with representation from rural SE and NW geographies
- Number of new LC panel members participating in the learning community and CoIIN
- Assessment of adequate telehealth equipment completed and reviewed by State EHDI team
- Number of sites and providers participating in test of referral Dx approach

1.3 With findings from panel, family survey and provider input, we will develop new strategies to improve EHDI outcomes

Measures for 1.3

- Number of strategies tested with referral improvement and deployment of Telehealth equipment

Objective 2: Improve referral and follow-up process as part of the EHDI infrastructure

Goal 2.1: Increase reporting to the State EHDI program of screening results for newborns prior to one month of age

Goal 2.2: Improve timeliness of referrals and documentation of diagnostic audiology services to the State EHDI program for infants that do not pass their newborn screening test from

Goal 2.3: Improve timeliness of referrals to early intervention for infants that are diagnosed with a hearing loss from

2.1 We aim to expand use of hospital newsletters, provider networks and hospital report cards and telehealth platform and protocols to improve timely diagnosis of hearing

Measures for 2.1

- Number of participants from Rehoboth McKinley Hospital and Gallup Indian Hospital in Telehealth sessions and result in accurate diagnosis
- Agreement or MOU in place between Navajo Nation, NM Department of Health and facilities to assure access and funding to audiology and appropriate equipment

-Establish quarterly reporting back to hospitals on their metrics with support from MCH Epidemiology staff – to include referral rate, and reduction of false positive

2.2. We aim to increase the number of live births with the number of children that were screened; the number of children who did not pass the initial hearing screening to with the number of children who were referred to NM-EHDI and to improve the efficiency of reporting time to the State EHDI program

Measures for 2.2

-Number of infants reported to State among live birth count for each facility and increase, from baseline, improved rate in the proportion screened

-Quarterly data cleaning protocols by State EHDI staff to track statewide coverage of screening and follow up in Vital Records and Hospital data

-Number of days between birth and report to State EHDI coordinator and improvement in annual metric

Measures for 2.3

-Number of days between diagnosis and referrals to follow-up for Early Intervention

- Increase in frequency of Part C and NM EHDI communications or meetings to assess opportunities for improvement

Goal 3: Expand EDHI systems of care

Objective 3.1: Refine state plan to expand infrastructure for hearing screening up to age three

Objective 3.2: Develop, implement and evaluate use of electronic shared plan of care with external EHDI partners

Objective 3.3: Work with partners including the NM AAP EHDI Chapter Champion and the National Center for Hearing Assessment and Management to educate and train on the use of appropriate hearing screening equipment.

3.1 State plan for infrastructure will be refined and shared with parents and health providers to develop strategies to increase access to genetic services for individuals in rural, Hispanic, and American Indian communities in the Mountain States

Measures for 3.1

-Number of meetings or webinars held regionally with NM Pediatric Society champion and facility staff

-Plan drafted with updates and shared with stakeholders

-Training and education on continuous screening and tracking from birth to age 3 expanded. Number of early childhood services programs trained in continuous screening for hearing loss.

3.2 Electronic plan of care platform will be piloted with one regional EHDI team

Measures for 3.2

-Established regional team identified to test and deploy electronic platform (REDCap Qualtrics or hospitalization data portal)

3.3 AAP – NM Pediatric Society Champion leveraged and engaged with network of providers

Measures for 3.3

-Implemented contract with AAP EHDI Chapter Champion to educate PCPs on appropriate screening, proper use and interpretation of hearing results

- Decrease in false negative results

- CME mechanism established for participating providers

-Feedback obtained from participating providers to assess impact of training

Goal 4: Create a blueprint of integrated care for children who are DHH for NM Primary Care Providers:

Objective 4.1: Improve provider awareness and adherence to EHDI guidelines.

Objective 4.2: Implement and evaluate the use of CoIIN to guide newborn hearing screening and care activities.

Objective 4.3 Train healthcare provider and other providers in EHDI guidelines

Objective 4.4 Link PCP's to NM Medical Home Portal and EHDI resources

4.1 We aim to increase provider awareness on their baseline and improvement to meet EHDI guidelines in primary care. Our goal is to assure that staff at every level are informed and able to meet the requirements for intervention and referrals. As in our efforts to enhance awareness among hospital/birthing facility staff, we intend to expand our efforts in primary care.

Measures for 4.1

-Blueprint updated with mapping to identify where EHDI reporting is delayed or in error. Mechanism for feedback to those systems and providers has support and in place with support from pediatric champions and QI experts.

4.2 The continuation of a CoIIN/provider network is important to evaluate, and our process for evaluation includes short provider surveys and family follow up. Because feedback from families requires time and resources from staff and from the families, we will consider a short paper survey given to families by front desk staff when families have well-child visits or when they are specifically seen for hearing-related concerns. Providers will also be asked to share their concerns or challenges with timely reporting and follow-up for children flagged for intervention.

Measures for 4.2

-Number of providers and families agreeing to provide feedback on EHDI guidelines and barriers.

-Proportion of baseline to mid-year and annual improvement

-Number of feasible, actionable solutions to address barriers identified by families and providers

4.3 Provider training is contingent on feedback provided on current barriers and improvements from baseline. Trainings may be offered via Project ECHO or telehealth sessions to address difficulty of convening professionals in an expansive, rural state. Trainings may not be well accepted or impactful if they are not based on input received through the CoIIN, so the network requires skilled facilitation and interaction.

Measures for 4.3

-Number of recommendations incorporated and addressed into trainings

-Proportion of sites with at least 10% improvement at mid-year and annual reporting

4.4 The NM Medical Home Portal is an important, sometimes under-utilized resource for health providers and parents in New Mexico. We will assess provider awareness and experiences with the portal. And families will be advised to utilize the portal to discuss resources with their primary care physicians and practitioners.

Measures for 4.4

-Number of PCP's aware of the NM Medical Home Portal resource as a source of accurate information on EHDI standards and a place to find community resources

-Completion of one in-person input session (via CoIIN or QI process event) from providers regarding the usefulness of the portal

-Number of families familiar and able to access the portal.

Goal 5: Strengthen support to families with children who are DHH including access to Deaf Role Models:

Objective 5.1: Support expansion of family to family support services to reflect the diversity of the families of New Mexico

Objective 5.2: Test and refine a date tracking measure to enhance family centered care for children with hearing impairment.

Objective 5.3: Support the NMSD Deaf Mentor program and identify opportunities for expansion.

5.1 We will continue to develop and assess the Guide by Your Side program and reception by families residing in rural areas of New Mexico. We partner with the New Mexico School for the Deaf and the Newborn Hearing Screening program on a parent survey to inform the parent referral system for Guide by Your Side and the Deaf Role Model program.

Measures for 5.1

- Number of new families participating in the Guide by Your Side Program/Deaf Role Model
- Change from baseline in support services utilized by families

5.2 Establish new tracking measures with input from the family survey and refine outreach and referral strategies

Measures for 5.2

- Number of strategies tested in over the year and metrics defined for tracking
- Analysis complete for family survey and recommendations determined actionable
- Number of organizations committed to standardize metrics to measure change

5.3 We continue partner with EPICs and Hands & Voices to offer community outreach and trainings to Pueblo and Tribe-serving organizations on the importance of early hearing detection and intervention. We support these organizations to educate parents, individuals and communities on the importance of follow-up for hearing loss detection, referrals and follow-up.

Measures for 5.3

- Numbers of trainings provided
- Proportion of families confident in their awareness of and access to referral sources
- Number of community input and education events held or attended

VII. ORGANIZATIONAL INFORMATION

See Attachment 2 (Staffing Plan and Job Descriptions), Attachment 43(Biographical Sketches of Key Personnel), Attachment 5 (Project Organizational Chart)

The New Mexico Department of Health (NMDOH) is one of the executive branch agencies of the State of New Mexico. Our mission is to promote health and wellness, improve health outcomes, and assure safety net services for all people in New Mexico.

The Department consists of seven Divisions, including the Public Health Division (PHD). The Title V Maternal & Child Health (MCH) Block Grant recipient is PHD's Family Health Bureau (FHB), which serves reproductive age women, mothers, infants, children, adolescents/youth, including children and youth with special health care needs, and their families. The needs of these populations are continually assessed, and data is collected for use in policy formation and decision-making.

The New Mexico Title V Program, Children's Medical Services has a family-centered approach and provides comprehensive care coordination for children and youth ages birth to 21 who meet established medical criteria, and payment for medical coverage (including diagnostics, primary care, specialty services and surgery) to eligible CYSHCN whose families are at or below 200% of the federal poverty level. CMS improves access to pediatric specialty care in rural

areas of the state through the coordination of 130 specialty clinics staffed by pediatric providers from the University of New Mexico Health Sciences Centers. Clinics include cleft palate, genetics/metabolic, neurology, pulmonary, cardiology, endocrine, nephrology and GI. This program has 90 statewide staff consisting of licensed medical social workers, 4 nutritionists, and administrative staff. CMS makes direct referrals to family support organizations for family to family connections. This includes referrals to Parents Reaching Out (PRO), Education of Parents of Indian Children with Special Needs (EPICS), the family liaisons from the NM School for the Deaf (NMSD), and family guides through Hands & Voices for children deaf or hard of hearing. The cleft palate clinics employ a family support agent who is available to families during the clinic. CMS sustains family participation in the Maternal and Child Health (MCH) Collaborative, NM Interagency Coordinating Council (ICC), Newborn Hearing Screening (NBHS) Advisory Council, Early Hearing Detection and Intervention (EHDI) Advisory Council and the Association of Maternal and Child Health Programs (AMCHP) Annual Conference. CMS recruited a parent representative to join the Newborn Genetic Screening Advisory Council, which includes participation in the Mountain States Regional Advisory Collaborative. Family Organizations are invited to provide input into the CYSHCN Program activities and the Title V Block Grant during scheduled MCH Collaborative Meetings.

CMS contracts with and provides funding to family organizations to ensure that families who have children with special needs have input into programming and serve in an advisory role regarding policy. The funding also supports family participation in local, state and national meetings/conferences and provides training for staff/families. Funds from the CMS Program support an annual family leadership conference sponsored by EPICS and PRO where over 400 families who have children with special needs gain new skills, support, and resources

Newborn Hearing Screening (EHDI) and Newborn Genetic Screening are housed under the CMS Program. The newborn screen is a blood test that is initially done between 24- 48 hours of age, and the second newborn screen is done 10 – 14 days after birth. The program screens for genetic/metabolic/endocrine and other disorders. Early detection of these rare conditions can be lifesaving. The program provides long term support services to families who have an infant identified by the screening test. the Newborn Hearing Screening Program (EHDI) promotes and supports statewide newborn hearing screening and follow-up services to assure that all infants with hearing loss are identified as early as possible and provided with timely and appropriate audiological, medical, and early intervention services.

MCH Epidemiology (MCH Epi) program coordinates the Title V Block Grant and Needs Assessment, the State Systems Development Initiative (SSDI) grant, and the Pregnancy Risk Assessment Monitoring System (PRAMS), including a CDC-Kellogg Foundation collaboration to over-sample Native American women in New Mexico.

Women, Infant, & Children (WIC) helps to safeguard the health of nutritionally at-risk, low-income, pregnant, postpartum, and breastfeeding women, infants, and children. WIC provides nutritious foods to supplement their diets, healthy eating information, health counseling, breastfeeding support, cooking classes, and referrals to health care providers and social services. WIC serves pregnant, breastfeeding, and postpartum women, infants, and children up to age 5 at 45 clinics and 37 satellites clinics statewide. All public health offices provide

referrals to WIC. EHDI currently collaborates with WIC to help locate infants who have changing addresses and contact numbers.

Though not a part of the FHB, the *Family Infant Toddler Program (FIT)*, New Mexico's Part C Program, is a program within NMDOH. FIT is a statewide program that provides early intervention services to infants and toddlers who have or are at risk for developmental delays in New Mexico. Early intervention provides activities and strategies for families to use to promote their child's development throughout the day. Early intervention can make a lifetime of difference.

The Family Health Bureau has been a proponent of the Medical Home Model, featured in the proposal. Staff collaborated with NMDOH Children's Medical Services and the UNM Center for Development and Disability to select appropriate pediatric-specific resources for the New Mexico Medical Home Portal <http://www.medicalhomeportal.org/>. Staff also collaborated to create an on-line training that focuses on Medical Home and Health Literacy, used by a variety of early childhood providers and parents.