

Program Narrative

I. Introduction:

New Mexico (NM) is the fifth largest state geographically, yet its relatively small population (1.95 million) is widely scattered across more than 121,000 square miles of desert and mountains. There are 33 counties in New Mexico: fourteen are frontier or sub-frontier with 6.8% of the population; eighteen are rural counties with 63.5% of the population; and one county is urban, with 29.7% of the population.ⁱ The rural nature of the state leads to unique challenges for improving child health outcomes, as shown in the recent report from HRSA on the health and well-being of children in rural areas.ⁱⁱ

New Mexico's population is one of the most diverse in the United States, consisting of 45% Hispanic, 42% White-non-Hispanic, 10% American Indian, 1.6% African-American and 1.4% Asian and Pacific Islander. A 2007 press release from the US Census Bureau noted that New Mexico is one of four states, and the District of Columbia, that is "majority-minority" with 57% of its population being classified as "minority."

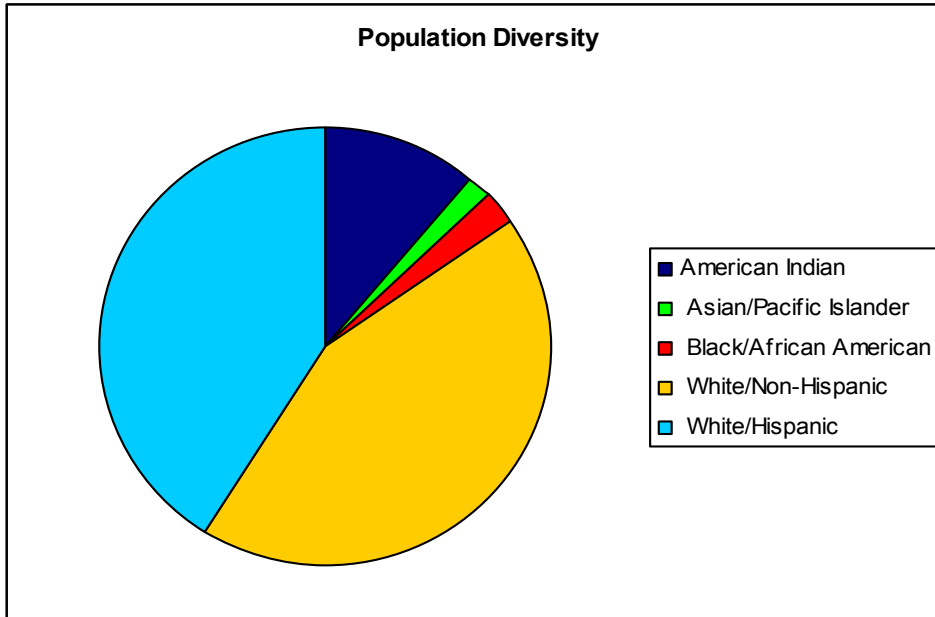
According to the Census Bureau, in 2008 New Mexico had the highest percentage (45%) of Hispanics of any state with 83% of these native-born and 17% foreign-born. There are 51.5 % Hispanic children, 13.2% American Indian-Alaska Natives children, 2.2% Black-African American children, 1.3% Asian-Pacific Islander, and 31.7% Non-Hispanic White children.ⁱⁱⁱ

New Mexico has many barriers to accessing health care, including very high rates of poverty (22.2%) and uninsured individuals (26%).^{iv} The state is one of the four poorest in the nation, with a median household income of [REDACTED]. Another barrier is language; over a third of New Mexico's population (36.5%) speaks a language other than English at home, the second highest percentage among all states.^v

In 2008, the total estimated MCH population in NM was 1,012,105.^{vi} The 2009-2010 National Survey of Children with Special Health Care Needs estimated that there were 70,725 children and youth with special healthcare needs aged 0-17 in New Mexico, or 13.8% of children in that age group.^{vii} This was an increase of 11,490 children over the 2005-06 estimate.

The 2007 estimated racial and ethnic distribution of New Mexico children is as follows:

- Age 0-4 Years: 66,689 Hispanic, 38,225 Non-Hispanic White, 16,261 American Indian, 2,624 Black, and 1,782 Asian.
- Age 5-9 Years: 65,667 Hispanic, 36,243 Non-Hispanic White, 14,758 American Indian, 2,760 Black, and 1,806 Asian.
- Age 10-14 Years: 81,174 Hispanic, 50,158 Non-Hispanic White, 22,121 American Indian, 3,527 Black, and 2,013 Asian.
- Age 15-19 Years: 81,591 Hispanic, 57,339 Non-Hispanic White, 22,546 American Indian, 3,783 Black, and 2,101 Asian.



As of 2009, the unemployment rate in New Mexico was 6.6%.^{viii} In 2006-2008, 18 percent of New Mexicans were living below poverty level. Twenty-five percent of related children under 18 were below the poverty level, compared with 13 percent of people 65 years old and over. Fourteen percent of all families and 35 percent of families with a female head-of-household had incomes below the poverty level.^{ix} The 2009 UNM BBER reported a per capita personal income of [REDACTED] placing New Mexicans 42nd in the US, and earning [REDACTED] less than the US average of [REDACTED].^x

A significant portion of New Mexicans are at risk for lack of access to needed primary care. Only one of New Mexico’s counties, Los Alamos, is designated by HRSA as neither “Medically Underserved,” nor a “Health Professional Shortage Area (HPSA).” The remaining 32 counties are either entirely or partially underserved and are considered HPSAs. More than 700,000 people live in these areas. While not everyone in the HPSAs is without care, many people get less health care than they need.^{xi} Specialty care is also lacking, especially for children, as almost all pediatric subspecialists are located in the Albuquerque metro area.

An estimated 20% of New Mexico’s children were born of immigrant parents, and many live in mixed citizenship status families. Undocumented parents may be reluctant to approach publicly funded services, despite their child's eligibility based on birth status. Many of these children live in families with low incomes, have parents with low education levels and limited English proficiency, and interact less often with their parents than do other, non-immigrant children. These factors may also be associated with poor school performance by the children. Young children of immigrants are substantially more likely to be poor, to experience food and housing related hardship, to have fair or poor health and to lack health insurance or a medical home.

These socioeconomic conditions are a concern for the Early Hearing Detection and Intervention (EHDI) Program as they 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. 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 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:

II.A. Maternal and Child Health

The State continuously assesses, through quantitative and qualitative data collection, the needs and capacity for the 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,^{xii} and in the New Mexico Children's Cabinet Report Card.^{xiii} 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.^{xiv} 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.

The Maternal and Child Health Epidemiology program examines MCH data as soon as they become available to assess changes in the status of the population. The Family Health Bureau (FHB) management team meets every week to discuss data analysis results and program activities and challenges, and to identify opportunities for collaboration that can support positive outcomes in the MCH population. The program receives invaluable support from the MCH Epidemiology staff around the collection and analysis of newborn screening data from multiple sources.

In New Mexico the Title V 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 Children's Medical Services (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. The Newborn Screening program is under the CMS umbrella of programs.

For the 2010 Title V Needs Assessment, FHB leadership and staff, along with partners and stakeholders from each of New Mexico's five public health regions, began meeting in 2008 to identify maternal and child health issues that were prevalent at the local, regional and state levels. Through these meetings, 25 health issues were selected for inclusion in an online priority ranking survey, and over 500 complete responses to the online survey were received and analyzed. Formal qualitative methods included focus groups with regional partners, staff and stakeholders, and a comment box at the end of the online MCH priorities survey which yielded over 200 comments.

As a result of the Title V Needs Assessment activities, New Mexico's Maternal and Child Health Title V Program identified the MCH Priority Needs for 2011-2015, which included the following: 1) maintain specialty outreach clinics for children and youth with special health care needs; and 2) improve the infrastructure for care coordination of children and youth with special health care needs.

II.B. Children and Youth with Special Health Care Needs

CMS receives feedback on gaps in services from various sources including the Newborn Hearing Screening Advisory Council, the Newborn Genetic Screening Advisory Council, the Pediatric Council, the New Mexico Pediatric Society, and the CMS Advisory Board. The advisory boards are comprised of various stakeholders including professionals, CMS staff and parents. The program meets with the Chiefs of the Pediatric and Neurology Departments at UNM annually to negotiate the number of multidisciplinary 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 every five years, most recently in 2009-2010. 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 2009-2010 survey results for New Mexico compared to the U.S. as a whole. The survey demonstrates a clear need for improvement in transition services for youth with special health care needs in New Mexico. For example, only 55.5% of children with special health care needs in New Mexico report that community based services are organized so families can use them easily compared to 65.1% for the nation as a whole. Additionally, only 34.9% of

CYSHCN in New Mexico receive coordinated, comprehensive care within a medical home, compared to 43% nationally.

Table One

**Results of the 2009-2010 National Survey of Children with Special Healthcare Needs:
Core Outcomes**

Core Outcomes	% of CSHCN Achieving Outcome in New Mexico	% of CSHCN 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	67.9	70.3
Children and youth with special health care needs receive coordinated, ongoing comprehensive care within a medical home	34.9	43
Families of CSHCN have adequate private and/or public insurance to pay for the services they need	60.6	60.6
Children are screened early and continuously for special health care needs	77.0	78.6
Community-based services for children and youth with special health care needs are organized so families can use them easily	55.5	65.1
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	35.7	40.0

II.C. Early Hearing Detection and Intervention (EHDI)

According to the Center for Disease Control Early Hearing Detection and Intervention program annual survey January 2013, New Mexico reported 26,414 births. The birth population diversity by race and ethnicity has already been referenced; however, of note is that 39% of births are to
 HRSA-14-006 Reducing Loss to Follow-up after Failure to Pass Newborn Hearing Screening-New Mexico December, 2013

young mothers under the age of 24 and 48% of this maternal population has a high school degree or less. Unfortunately the data as reported gives the impression that over half of the birth population was not screened, which is a function of poor and missing documentation by the hospitals and lack of reporting to the State EHDI program. It is not reflective of actual screening practice and numbers of referrals reported to the state program for follow-up. The program has 2 dedicated follow-up coordinators that are responsible for improving lost to follow-up rates over the past several years. 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 to assure that newborns receive follow-up care.

When the EHDI Follow-up Coordinators make the initial contact with the child's parent, they request the name of the child's physician and the name of the practice. When they know the physician, even if the parent refuses assistance, the Coordinators will work with the physician to assure the child receives the audiological follow-up needed. When the Follow-up Coordinators have to close a referral, they make a phone call and they send a closing memo to the physician alerting him/her of this and stressing that it is the physician's responsibility to continue supporting the hearing follow-up the child needs. The closing memo also stresses that there is mandatory reporting of audiological results to the Newborn Hearing Screening Program for children birth to age 4 years. An audiological reporting form is included so the physician can record the child's audiological results and fax the completed form or fax a copy of the child's audiological report to the EHDI Program. Our data shows that even when a referral was initially closed because the parent refused assistance, which can result in a loss to documentation, audiological results were later sent to us by the child's physician or by an audiology practice. The data manager is able to go in the database and update the child's record with the audiological results. The EHDI Follow-up Coordinators will also utilize these audiological results to make needed referrals.

Data points: CDC EHDI Annual Survey 2011

58% screened before one month

52% audiology diagnosis before three months

53% receiving early intervention before six months

Number of infants with hearing loss identified- 42

The current lost to follow-up rate is now approximately 5%. We do have loss to documentation that may be as high as 10% but that is mostly when parents refuse our assistance.

Other reasons for lost to follow-up continue to include lack of reporting from birthing hospitals and the mobility of the population, which includes relocation within state boundaries, out of state and Mexico.

The program also receives feedback from the EHDI advisory committee regarding gaps in coverage for pediatric audiology, specifically diagnostic services. When supplemental funding

HRSA-14-006 Reducing Loss to Follow-up after Failure to Pass Newborn Hearing Screening-New Mexico December, 2013

was available from MCHB, this need was prioritized based on years of feedback from providers and community partners. Several initiatives occurred to address these issues: diagnostic equipment was purchased for a practice in the Southeast; hands-on training on diagnostic procedures was given to audiologists at their annual meeting in Albuquerque; and a telehealth project in Gallup NM was instituted. Lack of access to timely audiologic diagnostic procedures and poor communication by audiologists back to the Program continue to be significant factors that negatively affect the program's ability to meet the standards.

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 us.

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 WIC, food stamps, housing, financial assistance, etc. This is done in coordination with the child's medical home.

For Navajo families, the Growing in Beauty program attempts the initial contact after hospital discharge. The program acquired a portable OAE/ABR screener and is able to make a home visit to perform the follow-up screen if that is easier for the family. Growing in Beauty serves as a "cultural broker" for these families. A similar system is in place for the Mescalero Apache tribe in Southern New Mexico, but is not in place for the other Native American tribes in NM as of yet. The EHDI Follow-Up Coordinators work with Growing in Beauty, Indian Health Services, and the New Mexico School for the Deaf to support Native American families in accessing the hearing follow-up their infants need.

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 4 locations: Albuquerque, Santa Fe and Las Cruces, which are the more urban areas of the state, and in Roswell, NM where diagnostic equipment was purchased by the program with MCH supplemental funds several years ago. This has increased access for this segment of the population; however, statewide appointments are difficult to schedule and often there is a three to six month wait before diagnostic testing can occur.

Albuquerque is home to 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) in order to have a sedated diagnostic evaluation. Some families receive diagnostic services in El Paso and 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 Intervention program. They in turn automatically refer these same babies to the local Part C program for the Comprehensive Multidisciplinary Evaluation (CME) and for service coordination. NMSD is then written into the Individual Family Service Plan (IFSP). The immediacy of the referral is however, dependent on timely information on diagnosis from audiology taking into consideration times for appointments wait.

Due to New Mexico's proximity to Mexico, there is a problem with babies born in the border NM hospitals who 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 families 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 the 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 there who provide support and have helped a few mothers find resources in Mexico.

Delays in obtaining data have resulted in difficulties in accurately tracking trends and detecting important changes in a timely fashion, and limit the state's capacity for program planning. Critical data reports are often delayed because of issues with IT systems changes, staffing shortages, and legal issues. The state also has limited linkage capacity due to staff and resource limitations. County-level data is sometimes unavailable in national data sets, or suppressed in state-collected data to protect privacy or when numbers are too low to constitute statistical significance.

Many of these issues are being resolved. The State has created the New Mexico 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. Most datasets have basic demographic information on the individual such as name, date of birth, and address. The newborn screening data sets -- both hearing and bloodspot, which are located on a separate database called Challenger Soft, -- are linked to Vital Records data, which can provide information such as mother's name, date of birth and education. The datasets are used for quality assurance, providing services such as early intervention (secondary prevention) and also surveillance with a goal of primary prevention. Overall the data CMS maintains are good for conducting follow up. Most hospitals are now reporting monthly to the program and several are able to provide this information through electronic transfer.

The program continues to improve in the area of data collection with audiologists as well. The collection form was revised by the audiology subcommittee of the Advisory committee and the EHDI Coordinator communicates with the audiologists monthly requesting data on diagnostic testing that may have occurred. The program has an agreement with the New Mexico School for the Deaf 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. 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 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.

III. Methodology

The CMS EHDI program will utilize the Quality Improvement methodology Plan, Do, Study, Act (PDSA) to improve loss to follow-up after failure to pass the hospital screen. We were fortunate to be part of the 2011-2012 NICHQ Collaborative cohort to learn how to implement and utilize the PDSA process to focus on improvement in areas that have been difficult to address by conventional means. Through the NICHQ Collaborative we were successful in designing and implementing several quality improvement initiatives including the development of a family roadmap, a physician roadmap and specific reporting forms and processes for midwives.

The program recognizes that there are several areas that need continued improvement; this 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, especially for culturally diverse populations. Thus our overall goal/aim and objectives are defined as:

Goal/Aim 1: Increase reporting to the State EHDI program of screening results for newborns prior to one month of age from 58% to 95%.

Objective/Aim 1.1: Implement quality improvement activities (PDSA's) with hospital screeners to improve loss to follow-up and lack of documentation for infants that do not pass the hearing screening from 58% to 95%.

Objective/Aim 1.2: Implement quality improvement activities (PDSA's) with midwives to increase the identification, referral for first screens and documentation of the screening for infants born at home attended by a midwife.

Objective/Aim 1.3: Implement quality improvement activities (PDSA's) with primary care providers to increase their involvement with assuring infants receive their newborn hearing screen prior to one month of age and appropriate referrals for follow-up if the infant does not pass the initial screen.

Goal/Aim 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 52% to 95%.

Objective/Aim 2.1: Implement quality improvement activities (PDSA's) with audiologists to improve timeliness of testing and documentation of diagnostic results to the State EHDI program.

Objective/Aim 2.2: Implement quality improvement activities (PDSA's) with stakeholder team (i.e. EPICS, Hands & Voices, NM School for the Deaf, Presbyterian Ear Institute) to improve timeliness of diagnostic testing for infants that do not pass their newborn hearing screening by addressing additional family needs related to culture, language, economic situation and other psychosocial factors.

Goal/Aim 3: Improve timeliness of referrals to early intervention for infants that are diagnosed with a hearing loss from 53% to 95%.

Objective /Aim3.1: Implement quality improvement activities (PDSA's) with stakeholder team (i.e. Audiologists, EPICS, Hands & Voices, NM School for the Deaf, Presbyterian Ear Institute) to improve timeliness of referrals to early intervention by addressing additional family needs related to culture, language, economic situation, other psychosocial factors and other structural issues.

Objective/Aim 3.2: Implement quality improvement activities (PDSA's) with those hospitals that have been identified by the data manager to referring less than 100% of infants who do not pass the initial newborn screen to the EHDI program. Lack of referral causes delays in follow-up and lost to follow-up.

Objective/Aim 3.3: Implement quality improvement activities (PDSA's) with audiologists to improve timeliness of reporting of results to the EHDI program to address referral to early intervention after diagnosis to meet the six month of age timeframe.

Goal/Aim 4: Formalize links and increase collaboration between stakeholders to improve and maintain a sustainable EHDI System statewide.

Objective/Aim 4.1: Implement quality improvement activities (PDSA's) with stakeholder team (i.e. Audiologists, EPICS, Hands & Voices, NM School for the Deaf, Presbyterian Ear Institute, AAP) to address systematic issues that affect the achievement of the overall goals of the EHDI program.

Implementation of the Work Plan will be dependent on the active engagement of the stakeholder team which meets quarterly at EHDI Advisory Council meetings. The stakeholders include; the State EHDI Program Coordinator, the Title V CYSHCN Director, the Short-Term 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 brokers with Native American families and the NM Chapter of Hands & Voices to implement Guide by Your Side statewide.

The methodology will continue to address several critical areas:

1.) Provide culturally competent care to Native American families who require follow-up on a newborn hearing and/or have an infant diagnosed with a hearing loss through the use of a cultural broker.

A cultural broker is a strategy highlighted by the National Center for Cultural Competence at Georgetown University as a way of delivering health care to diverse communities. Wengner (1995) defined cultural brokering as a "health care intervention through which the professional increasingly uses cultural and health science knowledge and skills to negotiate with the client and the health care system for an effective, beneficial health care plan."

Numerous rationales exist for using a cultural broker, including but not limited to: emergent and projected demographic trends documented in the 2000 Census in which the diversity in the United States is more complex than ever; diverse belief systems related to health, healing and wellness; cultural variations in the perception of illness and disease and their causes; cultural influences; the use of indigenous and traditional health practices among many cultural groups; and the need for cultural and linguistic competence in health care delivery systems as a fundamental approach in the goal to eliminate racial and ethnic disparities in health care. (NCCC 2004: Bridging the Cultural Divide in Health Care Settings)

New Mexico is perfectly situated to utilize a cultural broker program to reduce loss to follow-up across the EHDI spectrum in the Native American population. The CMS Title V program has a history of working with EPICS, a Native American Parent Training and Resource Center.

HRSA-14-006 Reducing Loss to Follow-up after Failure to Pass Newborn Hearing Screening-New Mexico December, 2013

EPICS has provided cultural competency training to the CMS staff on a yearly basis for the past four years. CMS provided funding for two EPICS staff to attend the annual AMCHP (Association of Maternal and Child Health Programs) conference in Washington DC. EPICS provides parent trainings and parent to parent connection to the New Mexico urban and reservation communities. For the past 3 years staff members participated in the annual EHDI conference and helped to bring the Native American perspective to attendees.

Funds from this application would be contracted to EPICS to provide parent training on the EHDI spectrum 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 would continue to serve as the cultural broker between Native families and the western modalities related to screening, diagnosis and intervention of hearing loss.

2.) Improve access to audiology services for rural and frontier areas. Access to care remains a barrier for families in rural areas. This issue requires the concerted efforts of the stakeholder group to identify barriers such as timeliness of enrollment onto Medicaid; increasing timeliness of the second screen to minimize the need for a sedated ABR; and addressing systemic issues such as access to transportation and practice issues that have emerged with referrals from midwives who are the infants medical home for the first six weeks of life but are unable to make referrals to specialists.

3) Improve family to family support networks and collaboration with the State EHDI program. The program has been working with Hands & Voices for several years. A change in Hands & Voices leadership has brought in new energy and new ideas. Last winter the National Hands & Voices Executive leadership came to New Mexico to provide training and support to the local chapter and has been supportive in providing direction and guidance. 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 who often feel isolated. 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 deaf or hard of hearing : serving as advocates and advisors for New Mexico families in improving educational outcomes for Deaf and Hard of Hearing students and implementation of a pilot “Guide By Your Side” (GBYS) training to be held in the spring of 2014. This training will include access to nationally recognized trainers and curriculum to train parent leaders in:

- providing timely parent-to-parent support at the time of confirmation of hearing loss
- offering specific support and resource dissemination about deafness/hearing loss
- reducing the risk of loss to follow up by timely connection to Parent Guides
- many other aspects of working with families of children who are deaf/hard of hearing

Many of the NICHQ strategies that have been developed have already been successfully implemented through the work of the dedicated follow-up coordinators.

Successful strategies that have already been implemented include:

- Scripting the message given the parents when an infant does not pass the initial screening test
- Getting a second point of contact for the family, e.g. relative or friend
- Making the next appointment for the family and explaining why it is important to keep the appointment before they leave the hospital
- Reminder calls before appointments that include the reasons why the appointment is important
- Use of the fax-back to alert the primary care provider (PCP) of screening results and the need for prompt follow-up
- Use of the fax-back between medical providers including the audiologist and the primary care provider
- Asking Early Intervention staff to obtain a consent for release of information to facilitate entering data into the State database
- Adhering to the state protocol of contacting families within 48 hours of referral to mitigate issues of working with transient families.
- Implementation of a newborn screening tracking and surveillance case management system (Challenger soft) with links to the NBGS Program and the Families FIRST perinatal case management program
- Continued collaboration with the NM Commission for the Deaf and Hard of Hearing and the NM School for the Deaf (NMSD) to increase safety net services and access to audiology for the birth to three populations

Other strategies that have been more difficult to implement and will be a focus of the PDSA activities with stakeholders:

- Verify the identity of the primary care provider before the family leaves the hospital
- Provide families whose infant passed the newborn screening but has a risk factor educational information prior to discharge from the hospital
- Require hospitals to report weekly rather than monthly
- Work with primary care providers to track down infants lost to follow-up
- Translate materials for families in their Native language (i.e. Navajo)
- Provide midwives with referral resources or screening equipment to improve access to screening for babies born at home.
- Make two audiology appointments for the infant who can't be completely tested at the first appointment to ensure that the infant is already scheduled to return in a reasonable time frame
- Implement a public awareness campaign

Working with partners will continue to be essential to achieving successful outcomes. This includes engagement of additional stakeholders that may not be part of the EHDI Advisory
HRSA-14-006 Reducing Loss to Follow-up after Failure to Pass Newborn Hearing Screening-New Mexico
December, 2013

Council already such as Early Head Start, rural medical providers, home visiting programs and other early childhood advocates.

IV. Work Plan

See attachments for work plan.

V. Resolution of Challenges

Staff shortages-all providers statewide: Medical providers in NM are experiencing workforce shortages including social workers. This includes programs within the Family Health Bureau. Staff vacancies within the MCH Epidemiology program affect the ability of the CMS NBHS program to receive technical assistance on data analysis, quality improvement and evaluation activities.

Training issues -- hospitals, PCP's, CMS staff, audiologists: The Newborn Screening Program provides ongoing QA, reviewing hospital and midwife compliance with standards to which these professionals have been trained. The high turnover rate of hospital staff requires ongoing QA and communication. A list serve has been set up for each entity (hospital screeners, audiologists and midwives) as a mechanism for on-going communication around practice issues, trends and educational materials. A Lead Person has been assigned to each list serve to monitor use and to post information, tips and questions. PDSA cycles are being planned to identify strategies that will increase use of the list serves.

Medicaid eligibility process is slow and delays audiology appointments, and most practices will see a client only with a valid payer source. The effects of the Affordable Care Act are still unknown but part of implementation in the State was to rebuild the eligibility system to enhance functionality and hopefully speed up the eligibility process. Regionally, the CMS staff provide the majority of Medicaid enrollment services in the health offices. Because the CMS staff now have 'read' capacity for the Medicaid Omnicaid system, they are able to easily determine a client's eligibility status. The EHDI Follow-Up Coordinators provide information and support to parents who are waiting for their child's Medicaid card before scheduling audiological follow-up. This ongoing contact with parents is essential to avoid losing contact with each child's parents and to avoid loss to follow-up. The Follow-Up Coordinators also establish and maintain telephone contact with each child's physician to support physicians in providing needed referrals. Follow-Up Coordinators' personal communication with each child's medical home has resulted in a significant reduction in loss to follow-up and loss to documentation.

Hospital issues -- high refer rates at community hospitals due to equipment malfunction and/or technique or training issues: The EHDI Coordinator assists hospitals in identifying resources for equipment replacement and provides encouragement, support and patient liability information to assist hospitals in prioritizing this critical role. Assisting hospitals with high refer rates is a significant ongoing part of training and technical assistance. As part of the 2011-2012 NICHQ learning collaborative, a PDSA was conducted with two birthing hospitals. These

HRSA-14-006 Reducing Loss to Follow-up after Failure to Pass Newborn Hearing Screening-New Mexico
December, 2013

hospitals were asked to attach laminated screening steps and quick screening tips to the screening carts. Pre PDSA and post PDSA monitoring of the referrals from these two hospitals showed that the hospitals stopped doing multiple hearing resccreens to try to get babies to pass. Also, the expected monthly number of referrals decreased indicating that screeners were doing a better job at screening each baby's hearing. The EHDI Program is continuing to encourage other birthing hospitals to attach the laminated screening steps and quick screening tips to the screening carts.

Babies must be able to geographically access institutions that are able to provide sedation when diagnostic testing is needed – only 2 tertiary hospitals have this capacity: This is a planning role that is inclusive of, but not limited to the EHDI program. The CMS leadership continues to meet with UNM leadership to identify areas of cooperation and partnership. Utilization of this committee would provide an opportunity for statewide planning for institutions statewide as families are often unable to travel to Albuquerque in this fifth largest state. The continued improvement activities around timeliness of the second screen are also a mitigating factor that will be part of the next funding cycle. The EHDI Follow-Up Coordinators provide ongoing support to assist families in accessing a second screen and/or traveling for a sedated hearing test. This support includes providing information about Safe Rides in addition to identifying and accessing other resources for second screens. 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.

Transient population: While a transient population provides a challenge, it is not possible to alleviate the need for families to travel for employment. Cultural training makes it more likely that social workers are able to work successfully with migrant families. For instance, implementing a follow-up call within 24 hours is believed to be the most helpful strategy to reach migrant families. The EHDI Follow-Up Coordinators establish initial contact with parents through a mailed information packet. The packet includes a cover letter with instruction and the Follow-Up Coordinator's contact information, a statewide list of the audiologists who test infants, and reasons why parents obtain needed hearing follow-up for their babies. The Follow-Up Coordinators then make telephone contact with the parents and continue telephone contact until the infant has completed needed follow-up. In addition, the Follow-Up Coordinators establish and maintain contact with each child's physician. Working with each child's physician has resulted in timely follow-up as well as significantly reduced loss to follow-up / loss to documentation. The Follow-Up Coordinators also utilize the WIC and Medicaid data bases to find families who move and/or change their phone numbers. Improving the ability to provide family to family outreach/support by continuing to work with EPICS and Hands & Voices can also help to mitigate this issue.

Need for family and public awareness of the importance of follow-up of NBH screens: There is an ongoing need for increased public awareness of the importance of following up on newborn hearing screens. To address this issue, the EHDI Advisory Council decided that a media campaign would be a good strategy; however, this campaign has not yet been feasible due

to fiscal constraints. The website was updated and redone and program materials are now readily available to the public. The program is proposing to develop a short you tube video in English and Spanish for the Department website over the next grant period.

Physician training: We continue to have some PCP's who advocate for the "wait and see approach." This crosses over all areas of newborn screening, and also impacts referrals for early intervention. The EHDI Advisory Council, which includes family members, together with the CMS Medical Director and AAP EHDI Chapter Champion, Dr. Janis Gonzales, presented on EHDI to pediatricians at their annual meeting in 2012. This included a nationally recognized speaker and a New Mexico expert panel to discuss current recommendations and practice. A PCP roadmap was developed as part of the NICHQ Collaborative and was found to be a successful tool to improving communication with PCP's.

Integrated data collection system: Challenger Soft, an integrated data system for birth defects and newborn screening, has been in place for the past 5 years and functionality and reporting by hospitals and audiologists has greatly improved over the past 2 years. The 2012 CDC EDHCI survey indicated that 20 out of the 33 New Mexico birthing hospitals were reporting all results of newborn hearing directly to the program. This did not include the largest hospital in the State, the University of New Mexico Health Sciences Center. This issue is now resolved and all hospitals are reporting directly to the program, but the process requires on-going monitoring, training and trouble shooting by the CMS staff.

Over 300 births in New Mexico are home births attended by licensed midwives: Midwives play an important role in the lives of woman and infants in New Mexico. The EHDI Coordinator has been attending the Midwife Association meetings and has been working to address several challenges that were identified: development of a reporting protocol on home births to the State program; assistance to families identifying a referral source for an initial hearing screen; development of a specific reporting form and information letter to parents which was also located on the program website; working with the Maternal program in the Family Health Bureau to begin addressing practice issues within the licensure rules that would allow midwives to refer to an audiologist without having to go through a PCP. All of these issues need continued monitoring and improvement activities over the next grant period in order to reach all 75 midwives in the State.

Home Visiting Collaboration: Title V Home Visiting Funding was given the Children Youth and Families Department as lead agency instead of the Title V program. Although CMS participated in the Needs Assessment that was mandated as part of the Home Visiting funding, collaboration with the lead agency has been challenging and information on implementation of the Home Visiting program has been difficult to access. The CMS program will continue to try to "find a seat at the table" as programmatic decisions are made regarding implementation. The CMS Medical Director will be in a good position to advocate for the needs of the Title V program (especially regarding newborn hearing screening) with her various roles as member of the Early Childhood Comprehensive Systems advisory board appointee to the Interagency Coordinating Council, and the AAP EHDI Chapter Champion for New Mexico.

The Title V agency's capacity to promote the health of all mothers and children, including CYSHCN, is extensive, yet there remain serious challenges to that objective due to the high vacancy levels in CMS staffing which have continued for several years, and the lack of funding which has limited training for CMS social workers. Resolution of these challenges will require an increase in funding and infrastructure in the state, and support and training for the CMS care coordinators. Some of this training and infrastructure will be provided through the Annual Statewide meeting for CMS staff funded through another HRSA grant, as well as the online training social workers will be able to access. Advocacy will continue around efforts to maintain and increase CMS social work staffing.

Resolution of these challenges will also require collaboration with other agencies and entities. CMS will continue to strive for partnership with Medicaid around Medical Home issues and care coordination, which will increase financial solvency of the program. The partnership with the stakeholders in the Advisory Committee facilitated by this grant will help address the needs of families with infants newly diagnosed with hearing loss through advocacy, support and education especially for families and providers in rural areas to obtain the information they need without having to deal with the challenging aspects of transportation and lack of specialty care.

CMS attempts to collaborate as much as possible with the New Mexico Human Services Department/Medical Assistance Division (HSD/MAD) to address quality of care issues such as care coordination, EPSDT and Medical Home. The Maternal and Child Health Collaborative is a focal point for addressing MCH initiatives. The Collaborative addresses Medical Home, Newborn Screening, the Transition of Youth with Special Health Care Needs and the Cultural Competence and Family Involvement initiatives. Core partners include: UNM LEND, UNM Continuum of Care, UNM PPC, Family Voices, Parents Reaching Out and Children's Medical Services

VI. Evaluation and Technical Support

Children's Medical Services is committed to ensuring that all activities described in this proposal undergo a systematic, comprehensive evaluation that both documents the progress being made towards achieving project objectives and assesses the impact the grant activities have on the target population of youth with special health care needs and their families.

The EHDI Program has assistance and oversight regarding the evaluation process with the MCH Epidemiology program and a dedicated data manager contracting with the EHDI program. The Epidemiology program has a team made up of only two epidemiologists who are responsible for the Title V grant, The Title V and Title V CYSHCN performance measures, the state performance measures, special assignments and evaluation for the SSDI, PRAMS, Child Health, Families First Programs and other Family Health Bureau programs. The data manager also works with the Newborn Genetic Screening program which is also under the CMS Title V program. The case management data collection system developed by Challenger Soft provides an expanded capacity regarding data collection to enhance the program's ability to evaluate the indicators. The EHDI coordinator will oversee the reliability of the data input. This program, along with the Vital Records and newborn bloodspot data will provide reports that will address

the outcome measures specifically. In addition, the EHDI Advisory Council will provide professional critique/analysis of the process and the outcome measures and provide on-going feedback. The Council is made up of representatives from parent, agency and partner/professional communities. The EHDI Program, as well as the NBGS Program, is integrated within the Title V Children with Special Health Care Needs program. Therefore, effectiveness of the NBHS program's efforts and plan to reduce loss to follow-up will be included in the Title V needs assessment in FY2015 and the annual Title V Report and Application.

The goal of the evaluation system is to produce reliable, valid information on the progress CMS EHDI and project partners make on each of the major objectives in order to:

- document the impact of the project;
- ensure accountability for the public funds being spent on the project; and
- provide meaningful information to both CMS EHDI project staff that can be used to revise programs and projects as needed.

The evaluation will utilize three types of indicators that together will provide both project staff and the funding agency with information on the success of the project.

Process Evaluation

A process evaluation will provide key pieces of information to senior project staff on progress being made towards achieving project objectives. Process indicators focus on what is done with the resources employed by the project and how they are used in order to accomplish project objectives. The goal of process evaluation is to spot potential problems at an early stage in the PDSA cycle and, in consultation with CMS project staff, design strategies to mitigate those problems.

The goal of the process evaluation is to identify not only progress being made towards project milestones and timelines, but to identify and report to CMS potential gaps or problems before they can have a significant impact on the progress of the project. Project evaluators will regularly report results of the process evaluation to CMS project staff, creating a "continuous feedback loop" of information that they can use to guide and, where needed, revise project activities or reconfigure project resources.

Output Evaluation

Output indicators that measure the volume of work or services provided by project staff and partners are useful yardsticks that provide information on the reach and scope of the project described in this proposal. A subset of illustrative output indicators taken from the four major goal tables earlier in this proposal include:

Output Measure 1: Assessment of number and percentage of infants born in NM who are screened by one month of age.

Output Measure 2: Assessment of the number and percentage of infants that fail the screen who received appropriate follow-up in a timely manner and in a culturally responsive way.

Output Measure 3: Assessment of the number and percentage of infants who are determined to have hearing loss, including the time it takes from screen to diagnosis.

Output Measure 4: Assessment of the number and percentage of infants with hearing loss who are referred to and enrolled in early intervention, including the time to that referral and enrollment.

Output Measure 5: Percentage of PCP's receiving timely information on infants in their practice who refer on the initial hearing screen and/or are diagnosed with a hearing loss.

Output Measure 6: Assessment of the number and percentage of infants with hearing loss whose families have access to family to family support.

Output 7: Assessment of the number and percentage of infants born at home attended by a midwife who are screened by one month of age.

Impact Evaluation

While output indicators provide useful information on the scope of project activities, they do not address the impact that project activities have on the knowledge, attitudes and behaviors of target populations identified in this proposal, including health care and other professionals providing screening, diagnosis and early intervention services for infants and their families. The project impact evaluation will provide valid, reliable knowledge on the impact that project activities have on achieving project objectives: in short, what difference have project activities made in the knowledge and skills and professional practice of those serving infants who do not pass their newborn hearing screen and their families?

A subset of illustrative output indicators taken from the four major goal tables earlier in this proposal include:

- Increases in knowledge and changes in professional practice of hospital screeners and other providers to improve newborn hearing screening and reporting of results to the State EHDI program (Goal One);
- Increases in knowledge and changes in professional practice of providers to improve timeliness of referrals and documentation of diagnostic audiology results to the State EHDI program (Goal Two);
- Increases in the knowledge and changes in professional practice of providers to improve timeliness of referrals to early intervention for those infants diagnosed with a hearing loss. (Goal Three);
- Impact of project efforts on improving the sustainability of the overall EHDI system statewide (Goal Four).

Evaluation Methods

The methods used to collect evaluation data embedded in the tables earlier in this proposal range from collection of data from hospital referrals, hospital reports, audiology reports, vital records data, bloodspot data, and early intervention data by project evaluators for process and output indicators, to surveys and focus groups to collect data on outcome indicators to measure change in knowledge and behavior of providers.. The annual CDC EHDI report is also a very useful tool to assist with the evaluation process.

The EHDI Coordinator Ms. Tammy Voisine, will meet monthly with EPICS and Hands & Voices to assess progress and identify other areas where quality improvement initiatives could be implemented.

Data for each objective during the first two years will be used to improve the projects in the second and third years. Data concerning effectiveness of work plan activities will be shared with the CMS Management Team and the EHDI Advisory Council to assist the program with further activity development as well as allowing them the opportunity to revise and refine strategies to reach the goal of reducing lost to follow-up.

Evaluation will be on-going and integrated into the quality assurance process that is already in place.

VII. Organizational Information

The mission of the New Mexico Department of Health is to promote health and sound health policy, prevent disease and disability, improve health services systems and assure that essential public health functions and safety net services are available to New Mexicans. Children's Medical Services (CMS) is a program of the Family Health Bureau (FHB) in the Public Health Division (PHD) of the New Mexico Department of Health (NMDOH), and is the officially designated Title V CYSHCN program for New Mexico, funded by the Title V Block Grant with related matching from the State General Fund.

Children's Medical Services (CMS) is comprised of several sub-programs addressing the ongoing needs of the CYSHCN population of New Mexico. These sub-programs include:

1.) Children and Youth with Special Health Care Needs (CYSHCN): This program 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. This program currently serves approximately 4500 New Mexico CYSHCN, utilizing the state-wide CMS staff of 29 social workers, 2 nutritionists and 12 CMS State Office Staff.

2.) Multidisciplinary Pediatric Specialty Clinics: Pediatric subspecialty consultation and medical care coordination are provided to 2720 children and youth in 130 community based outreach clinics each year. Clinics are provided in the following specialties: cleft lip and palate,

asthma, nephrology, neurology, endocrine, metabolic and genetic. These clinics provide access to needed specialty care in rural areas of the state where such care is otherwise unavailable.

3.) Early Hearing Detection and Intervention Program: This program currently oversees the screening of more than 94% of 29,000 newborns state-wide, through state-mandated screening procedures at all state-licensed birthing facilities (hospitals) and some audiology centers. Referrals are made as needed for additional testing, follow-up, and early intervention services. The program is funded by a HRSA/MCH grant and a CDC Cooperative Agreement.

4.) Newborn Genetic Screening Program: This program screens newborns throughout the state for possible genetic, metabolic, hematologic and endocrine conditions. The program is currently screening 99% of 29,000 newborns at all state-licensed birthing hospitals. Testing is conducted by the Oregon State Public Health Laboratory (OSPHL). CMS Nurse Consultants work with the CMS State Office and the OSPHL to ensure follow-up occurs promptly. CMS social workers provide long term follow-up and care coordination for eligible clients with these diagnoses.

5.) The New Mexico Medical Insurance Pool (NMMIP): Recognizing that CMS funding is very limited, CMS negotiated a Provider Agreement with the New Mexico Medical Insurance Pool (administered by Blue Cross / Blue Shield) in 2005. CMS pays the premiums, co-pays and deductibles for CMS clients placed on NMMIP. This program has been especially valuable to clients with very high cost conditions, including those needing transplants and those with disorders such as cystic fibrosis which require expensive medications.

CMS staff and leadership are involved in the New Mexico Interagency Impacting Minority Participation and Recruitment Team (IMPART) whose focus is cultural competence training within DOH and other agencies. The Title V CYSHCN Director (previously the EHDI Coordinator) has been Chair of the EHDI Diversity Committee for the past ten years. The goal of this Committee is to raise awareness and promote best practice in the provision of culturally and linguistically competent care. The EHDI Coordinator is now in her second year with the program and participated in the NICHQ Learning Collaborative.

ⁱ Maternal and Child Health Services Title V Block Grant: State Narrative for New Mexico; Application for 2009, Annual Report for 2005.

ⁱⁱ The Health and Well-Being of Children in Rural Areas: A Portrait of the Nation in 2007: mchb.hrsa.gov/nsch/07rural.

ⁱⁱⁱ Maternal and Child Health Services Title V Block Grant: State Narrative for New Mexico; Application for 2009, Annual Report for 2005.

^{iv} Kaiser State Health Facts <http://www.statehealthfacts.org/>

^v Maternal and Child Health Services Title V Block Grant: State Narrative for New Mexico; Application for 2009, Annual Report for 2005.

^{vi} University of New Mexico Bureau of Business and Economic Research <http://bber.unm.edu/>

^{vii} <http://www.childhealthdata.org/browse/snapshots/cchcn-profiles>

^{viii} Department of Workforce Solutions <http://www.dws.state.nm.us/LMI/dws-surr.html>

^{ix} US Census <http://quickfacts.census.gov/qfd/index.html>

^x University of New Mexico Bureau of Business and Economic Research <http://bber.unm.edu/>

^{xi} HRSA <http://hpsafind.hrsa.gov/>

^{xii} http://www.nmvoices.org/attachments/nmkc_databook_09.pdf

^{xiii} <http://nmchildrenscabinet.com/2009Report.pdf>

^{xiv} <http://nmhealth.org/ERD/HealthData/yrrs.shtml>