PROGRAM NARRATIVE:

I. Introduction:

New Mexico 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. Much of the state is rural; there is one major urban center and only six other cities with populations of over 30,000. Population densities in some counties are approximately half a person per square mile. NM remains a young state with 30% of the population under age 20, compared to 28.1% for the U.S; an estimated 12% is over age 65, compared to 12.3% for the U.S.

In 2003, NM ranked 46th in per capita personal income at $25,502, which was 81.1% of the national average. The state's poverty rate remains one of the highest in the nation. For many years NM has ranked among the four worst states for the proportion of children living at or below 100% FPL and of low income children living at or below 200% FPL. In 2007, an estimated 22% of New Mexicans lived at or below the poverty level, compared to 18% nationally. Significant disparities were reported for racial-ethnic groups: 31.6% for Blacks; 30.6% for Native Americans; 24% for people of Hispanic origin; and 16.4% for Whites.

Lack of health insurance is another major barrier in providing care for many New Mexicans. New Mexico is among the five states with the highest rates

of uninsured children. An estimated 22.5% of New Mexicans are uninsured, including 15.5% of those under age l8, compared to a national median of 9.2%. While the economy of New Mexico strengthened under Governor Richardson's economic development strategies, New Mexico, like other states, is currently facing a monetary shortfall now that the entire U.S is in a recession. During the last 6 years, New Mexico's employment increased by over 100,000 jobs; consequently, though in a financial shortfall, the unemployment rate is 4.9% as compared to a national unemployment rate of 7.6%.

New Mexico is a state and community that is multi-ethnic and multi-cultural, spanning centuries of cultural change. New Mexico's diverse population includes Native Americans belonging to 19 pueblos and the Navajo Nation; a Spanish Hispanic community dating back to the early 1600's; an immigrant Mexican community that is historical but also includes recent immigrants; and Anglos who came with the development of the Santa Fe Trail and span several centuries in terms of immigration. This community also includes a Jewish community within the Hispanic culture, the Crypto-Jewish population that was hidden until recent times. According to 2003 population estimates, 85.6% of New Mexicans were white (includes individuals of Hispanic origin), 2.5% were Black, 10.3% were American Indian and 1.55 were Asian or Pacific Islander. Hispanics made up 43.2% of the population; non-Hispanics 56.8%. An estimated 67% of N.M. children and 55% of adults were of a minority

group. Nearly 55% of the state's children were Hispanic, the highest proportion of any state.

Children of immigrants are the fasted growing part of the U.S. population. An estimated 20% of NM 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 and to experience food and housing related hardship --56% compared to 40% of young children of natives. Children of immigrants are more likely to have fair or poor health and to lack health insurance or a medical home.

In addition, New Mexico has long experienced a dearth of health care providers in both primary care and specialty areas, and health care centers in the rural parts of the state are separated by long distances. Although the state's population continues to grow, the number of licensed health care professionals per capita is decreasing. All but five of the state's 33 counties have been federally designated as being "partial or full health care shortage areas for primary care."

Georgetown National Center for Cultural Competence

In 2000, the Georgetown University National Center for Cultural Competence (NCCC) conducted a cultural competence organizational self-assessment with the CMS program. Recommendations included: 1) increasing pediatric specialists, including more geographically accessible specialists, 2) financial support for travel and accommodations for family members, 3) increased community outreach for CMS services, 4) more brokering and information sharing, 5) need for specialized training and planning for adolescents, and 6) the need to take psychosocial aspects of family life into consideration.

A series of focus groups with consumers was also conducted by the NCCC. The key issues regarding access to health care in New Mexico for CYSHCN included: 1) the lack of availability of appropriate linguistic services within the hospital environment; 2) linguistic and cultural biases and insensitivity to families' economic circumstances, privacy issues and families' time and responsibilities regarding scheduling; 3) a need for humanized treatment, including training for medical providers on psychosocial and cultural issues, increased understanding of alternative health practices, and the need to respect families' opinions and their role as decision makers in the care of their children; and 4) concern by family members about the larger social service delivery system, especially fears about stereotyping and threats of deportation.

Based on the NCCC Assessment, the CMS CYSHCN management team ultimately made a decision to work within local communities to address cultural competency issues. The CMS CYSHCN Program is housed in 41 public health offices spread throughout the state of New Mexico. Twelve of the CMS social workers have been trained to provide Part C Service coordination through the state's Family Infant Toddler (FIT) program. The FIT program provides services to children with or at risk for developmental delay. The CMS FIT social workers are integrally involved with the local communities and assist families in accessing services after not passing the hospital newborn hearing screen. In this way, the services to CYSHCN within the program are community-based, and because the staff is bi-lingual and bi-cultural, the access to care is improved. CMS FIT social workers who use the bilingual skills to assist clients receive additional pay from the Department thus validating the need for culturally competent care. Additionally, the DOH has supported CMS staff from Region I and II to become trained medical interpreters and also funds on-going on-site Spanish classes. For languages not represented this Title V program contracts for interpreter services.

The NM Department of Health created the Office of Policy and Multicultural Health (OPMH) in 2005 in response to the need to improve the over health of New Mexicans and to address multicultural disparities. OPMH provides leadership in terms of assuring that cultural and linguistic standards are integrated in service delivery whether through the local public health offices

or through contracted services. The OPMH provides training opportunities to DOH staff on cultural competence, bilingual medical interpretation in Spanish and Navajo. It also provides Spanish translation services for DOH written materials that meet the cultural and literacy needs of the community.

The licensed social workers in CMS are now required by statute to engage in eight hours of cultural competence training annually to renew their licenses. The care coordination in CMS is done primarily by social workers, with 2 positions filled by nurses. CMS, located regionally in the health offices decided in past years to learn and address cultural competency regionally. Working with Hispanic communities of different origins and arrival in New Mexico, pueblos and the Navajo Nation, each region develops its own plan to carry out cultural competence training and delivery of services. While the Public Health Division under which falls the CMS Program focuses on translation for services and has allocated funding reimbursement of bilingual, bicultural staff, each region has its own issues and its own plan to assure clients receive culturally and linguistically competent care. These plans are the following:

Region 1/3 (metropolitan Albuquerque area and the Northwestern Region of the state): The assessment of cultural competency showed that knowledge of the needs of the African American community were lacking. Alicia Williams, Region 1/3 CMS Program Manager, encouraged Vivian Tucker, Children's Medical Services Family Infant Toddler Social Worker, to take a leadership role in increasing outreach to the African American Community in Region 1/3. Ms.

Tucker attended the NAACP Conference in Albuquerque, NM. She also attended a health workshop that provided information on the HIV/AIDS epidemic within the African American Community, specifically the increase of the disease among women. Ms. Tucker is working toward sharing this information with African American churches throughout Albuquerque. Ms. Tucker is also a member of the New Mexico Department of Health Increasing Minority Participation Task Group (IMPART).

The Region 1/3 Cultural and Linguistic Access Services (CLAS) Committee was created in 1998 through the efforts of Dr. Maria Goldstein Regional Health Officer (retired), Alicia Williams, CMS Program Manager and Lorenzo Garcia, Health Promotion Specialist Program Manager to address issues of cultural competency, linguistic access and health disparities. The CLAS committee is a multidisciplinary team of Public Health professionals that include a Children's Medical Services Social Worker, a Health Promotion Specialist Program Manager, a WIC Nutritionist Supervisor, a physician (Regional Health Officer), a Director of Nursing Services, other nurses, and clerks from throughout Region 1/3. Activities in 2007 have included: Removing barriers to access of public health services for limited English proficient individuals by facilitating the training of Public Health Staff as bilingual interpreters, educating Public Health staff on how to access interpreters and a recent cultural sensitivity presentation at the Region 1/3 Annual Meeting.

Region 1/3 is fortunate in having a large number of social workers fluent in speaking, writing, and reading Spanish. CMS has experienced need, particularly during Cleft Palate Clinic, for medical interpreters. It had become apparent that despite the staff's knowledge of Spanish, that they could benefit from additional training. In response to that need, in March of 2005 three Children's Medical Services Social Workers completed a medical interpreter's training. A CMS clerk in Region 1/3 was trained in medical interpretation in 2003.

While CMS works primarily with children diagnosed with chronic medical conditions, we have discovered that we cannot look at the issue of special healthcare needs in a vacuum. Alicia Williams, Region 1/3 Program Manager for CMS, for the past six years has worked with Native American Tribes throughout the State of New Mexico on case reviews and service planning for high- risk Native American adolescents.

Arthur Fuldauer, Family Infant Toddler Social Worker, in 2006 began outreach visits to Santo Domingo and San Felipe Pueblos. Arthur performs developmental evaluations and refers eligible children to early intervention services. Formation of Region 3 Diversity Committee was formed with the following goals in mind:

1. Support staff in the area of diversity.
2. Support our clients.

Learn from other cultures on how to provide better services to our clients.

3. Listen to what the children we serve are saying. They are letting us know we have a lot of work to do.
4. Explore what we can do to support a diverse work force.

Region 2 (Santa Fe and the Northeastern part of the state):

The Region 2 CMS Cultural Competency Process includes a branch of IMPART Group (Increasing Minority Participation Task Group), has worked on the development and implementation of an Intercultural Communication Training Module. The module is presented as a series of exercises to build skills of intercultural communication including: art and listening exercises; Video; Case Studies; Diversity Panel; and understanding Steps toward Cultural Proficiency Continuum. The Cultural Competency Module has been presented in the local community to varying medical professionals.

Additionally, Region 2 CMS Cultural Competency committee meet on a monthly basis with a focus on: increasing cultural awareness through planned trainings and cultural learning experiences; sharing resources and advocacy for immigrant communities and increasing outreach and collaboration with Indian Health Services and Pueblo communities especially increasing competency linguistic access.

A Region 2 CMS Medical Management Social Worker serves as board member of the Immigrant Task Force and provides information and updates for the District 2 CMS team regarding legislation and opportunities for the immigrant population served.

Region 2 CMS social workers provide service coordination for children and youth with special health care needs for all Pueblos and Native American's living within the Northeast Region of the state. This service increases access to care and timely intervention for children with special health care needs. Social Worker(s) in the Santa Fe office cover San Felipe, Santo Domingo, Cochiti, Pojoaque, Nambe and Tesuque. There are two CMS Social Workers out of the Espanola office covering San Ildefonso, Santa Clara, San Juan. In Taos, there is one CMS social worker that covers Taos Pueblo and Picuris. The staff in Espanola and Taos have had long standing partnerships with the Pueblo's and tribes in the Northern part of the district. The Region 2 CMS staff nutritionist provides training in specialized diets for Pueblo schools and Indian School food service for children and teens with chronic illness (i.e.: diabetes). The CMS staff Nutritionist also provides direct service (nutritional counseling) for Native American families of children with Special Health Care Needs. Specialty Pediatric outreach clinics are offered (for Asthma, Cleft Lip and Palate, Neurology, Nephrology and Genetics), thus making access to specialty care possible.

Santa Fe Medical Management Social Worker has been working closely with Dr. Anne Kusava at the Santa Fe Indian Hospital. Ms. Belanger provides medical social work services to Dr. Kusava at her Santo Domingo monthly (children's) chronic disease clinic. Since Dr. Kusava became chief of staff at the Indian Hospital here in Santa Fe, Medical Management Social Worker meets

twice monthly with the physicians to identify children and youth with special health care needs who need service coordination. The physicians reported that they needed a medical social worker to assist families, especially for newborns who are identified as being at risk, and/or diagnosed with conditions. A partnership has been developed between CMS and the Santa Fe Indian Hospital. Children's Medical Services is point of entry for all newborns identified as being at risk and/or diagnosed with a condition. In this way, Children's Medical Services is able to receive referrals directly and link the families with the CMS Social worker in their area. The service coordination offered by Children's Medical Services entails coordination of health, medical and other community resources in order to develop and reach child and family goals. The social workers are able to help families understand not only their child's disability but also how to access the medical and educational services that their child needs.

Region 2 Linguistic Access: CMS staff coordinate Spanish classes at the Santa Fe Public Health Office. Employees and community members attend weekly. Cultural competency professional development is addressed throughout the classes.

The staff of Region 2 is bilingual and bicultural in every office.

Region 4 (the Southeastern part of the state) requires eight hours of cultural training where one or two hours must be related to medical beliefs in a different culture such as the Deaf culture. The training must be approved by the supervisor. This region's quarterly meetings schedule a cultural learning

opportunity such as immigration issues. There is a Mennonite Mexican population in this region, where medical needs and beliefs regarding illness and disability, are different then the mainstream This population speaks Mexican and German and the families work in the dairies and farms. They continue to try and recruit bilingual social workers as much as possible.

Region 5 (the Southwestern part of the state on the border with Mexico) will continue to maintain a bilingual bicultural staff at the existing 90%; and cultural competence continuing education for social workers

The Title V CYSHCN Director continues to be a resource nationally to other programs seeking Cultural Competence consultation. Susan Chacon, the NBHS Coordinator was selected in 2005 to Chair the CDC sponsored EHDI Diversity Committee which meets monthly by conference call to address issues of access to EHDI services for minority and underrepresented populations. The committee consists of representation by state EHDI coordinators, University faculty, CDC, and Indian Health Services. Educational material was created for Spanish-speaking families who have an infant with hearing loss that addresses the linguistic and cultural needs of the community. The Committee has developed guidelines and recommendations to programs to assist in the provision of culturally competent care for minorities and underrepresented populations who are in need of EDHI services. This includes the development of a culturally and linguistically competent handbook for Spanish-speaking families. This material will also be available for University staff and can be used

in curriculum when training the next generation of EHDI professionals. Ms. Chacon and representatives of the EHDI Diversity Committee has been asked to present on outreach to diverse families for EHDI services at several national conferences. Ms. Chacon was also selected by the National Center for Cultural Competence at Georgetown University to represent New Mexico in a "Community of Learners" to improve services to culturally and linguistically diverse families who have a child with special health care needs.

II. Needs Assessment:

There are 34 birthing hospitals in New Mexico which includes private, public and Indian Health Services (IHS) facilities. All of the hospitals participate in the Newborn Hearing Screening (NBHS) program. The 25 Native American tribes in New Mexico are Sovereign Nations and are not required to follow State of New Mexico law, however, all the Indian Health facilities do screen newborns for hearing prior to discharge. Gallup Indian Medical Center does utilize the CMS program to assist with follow-up. The remaining three IHS hospitals work within their own systems to provide follow-up on newborn screening.

In 2007 the Bureau of Vital Records changed their reporting to a web-based system statewide. There were numerous implementation issues thus the 2007 data set is incomplete. In 2006 hospitals were reporting births onto a disk and mailing to Vital Records. The data is also incomplete but more accurate than 2007.

In 2006 the total occurent birth was 28,688. Approximately 1% of all births are out of hospital births. The infants born out of hospital receive their newborn hearing screen either at a local audiologist or at a community hospital who has agreed to provide screenings for this population.

Data reported to the Centers for Disease Control in 2006 for the annual Screening and Follow-up Survey from New Mexico Vital Records were the following:

Total occurent births: 28,688

Percent lost to follow-up at birthing hospital: 28%

Total percent receiving diagnostic evaluation prior to three months of age: 37%

Total enrolled into early intervention prior to six months of age: 50%

Baseline data by race, ethnicity and region has not been tabulated and would need to be part of the initial start up for this project if funded.

The Children's Medical Services (CMS) program, the State Title V Children with Special Health Care Needs (CYSHCN) State 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 Coordinator or Growing in Beauty early intervention program on the Navajo receive referrals from the CMS State Office on infants who upon discharge from the hospital did not have a screen (due to early

discharge or transfer), received a "refer" on one or both ears, or carry an "at-risk" diagnosis. The families are contacted to provide education regarding the importance of scheduling subsequent 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. The CMS Follow-up Coordinator works with an interpreter from the CMS State office when working with mono-lingual Spanish speaking families. The program contracts with a bilingual professional to assist with follow-up as well.

For Navajo families, the Growing in Beauty program attempts the initial contact after hospital discharge. The program recently acquired a portable OAE/ABR screener and will make a home visit to perform the follow-up screen if that is easier for the family.

This system is proving to be an effective mechanism for reducing those infants lost to follow-up on the Navajo reservation. Growing in Beauty serves as a "cultural broker" for these families. This system is not in place for the other Native American tribes as of yet.

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 NBHS Coordinator by CMS social workers, early

intervention providers and audiologists on the NBHS Advisory Council. There is not an equal distribution of these audiologists around the state. The majority are located in Albuquerque, in Central New Mexico. Appointments are difficult to schedule and often there is a three to six month wait before a follow-up 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 as well. Furthermore diagnostic evaluations are only available in 3 locations; Albuquerque, Santa Fe and Las Cruces which are the more urban areas of the state. Families often need to travel long distances to have a diagnostic evaluation which usually includes an overnight stay. Some families receive diagnostic services in El Paso and Lubbock Texas which can be closer than services in New Mexico. Due to NM proximity to Mexico there is also the issue of babies born in the border hospitals who need a follow-up hearing screen but their mothers are unable to cross the border to receive the services.

The EHDI Coordinator held a conference call on June 3rd, 2009 with the Newborn Hearing Screening Advisory to solicit input on this new funding application. The consensus regarding the most critically needed services in New Mexico included; increased audiology capacity statewide, training for audiologists including CEU's, purchase of equipment for diagnostics, a mobile audiology van, and gas money for families.

The program had explored the possibility of a mobile audiology van and in fact had access to an old WIC trailer but decided that the long term up keep and maintenance would be too costly. Gas money is always a good idea but would be hard to maintain after the funding was gone.

III. Methodology:

The methodology will address two priority issues. 1) Provide culturally competent care to Native Americans in New Mexico to reduce health disparities and improve access to care and 2) improve access to diagnostic evaluations in rural areas of the state and increase capacity of audiologists in the state to provide services to infants and young children.

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 measured; 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; 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 implement 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, (Education for Parents of Indian Children with Special Needs) a Parent Training and Resource Center. EPICS have provided cultural competency training to the CMS staff on yearly basis for the past four years. CMS provides funding for two EPICS staff to attend the annual AMCHP (Association of Maternal and Child Health Programs) in Washington DC. EPICS provide parent trainings and parent to parent connection to the New Mexico urban and reservation communities.

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 first hand the barriers to receiving timely intervention. EPICS would serve as the cultural broker between Indian families and the western modalities related to screening, diagnosis and intervention of hearing loss.

The contract would continue in years two and three. CMS would work with EPICS over the three years to develop ways to sustain the program. Initially however, during year one the CMS program would work with MCH Epidemiology to better identify lost to follow-up rates by race, ethnicity and region. This would be done utilizing Vital Records data which the program already has access to and the Challenger Soft data system being used by the program to track referral and follow-up information. Once identifying the initial lost to follow-up rate the overall goal would be to reduce this rate by 30% by the end of Year Three.

2.) Improve access to audiology services for rural and frontier areas

Year One funds would be utilized to contract with Audio Acoustics in Roswell, NM in the southeastern part of the state. The audiologist is currently rescreening infants after failure to pass the newborn hearing screen but does not have the technical capacity to perform diagnostic evaluations. Funds would be utilized to purchase diagnostic equipment and to provide needed training.

The counties surrounding the Roswell area include frontier towns, farming and ranching communities an Air Force base and gas and oil production areas. The population is mixed with a large mono-lingual Mexican immigrant community that provides much of the labor. This is a highly mobile population.
The families in this region currently have to travel great distances to receive diagnostic evaluations. The opportunity to have a regional diagnostic site would decrease the time between screening and diagnosis and most likely reduce the number of infants lost to follow-up

In Years Two and Three a contract would be established with the New Mexico Speech and Hearing Association (NMSHA) which is the state organization for audiologists. NMSHA holds an annual conference in Albuquerque that attracts audiologists from around the state as well as other speech and hearing professionals. The conference has a history of being well attended and CEU's are available.

NMSHA would use the funds to sponsor an EHDI tract for both Year Two and Year Three. This has not been done before in NM before. The NMSHA Board of Directors is in support of this project and would assist in the recruitment of national speakers to address diagnostic and intervention services for infants who are deaf or hard of hearing.
Stipends would be made available to help cover the travel costs of audiologists in rural areas to encourage participation.

By utilizing the lost to follow-up rates by region, race and ethnicity identified during the initial stages of the project CMS will monitor the impact of the purchase of the diagnostic equipment and the audiology trainings.

A goal will be set of reducing overall lost to follow-up by 30% by the end of the project period.

IV. Work Plan:

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:

Year One:

1. Identify baseline data on lost to follow-up rates by race, ethnicity and region

By: November 2009

Susan Chacon EHDI Coordinator and Jennifer Hudson MCH Epidemiologist

2. Develop contract with EPICS per state regulations

By: December 2009

Susan Chacon EHDI Coordinator

3. Develop parent training curriculum regarding EHDI spectrum

By: January 2010

EPICS with assistance from Susan Chacon

4. Deliver two parent trainings

By: August 2010

EPICS

5. Develop parent to parent resource database for Native American families.

By: March 2010

EPICS

6. Research funds to sustain program

By: ongoing activity through year one, two and three.

EPICS and Susan Chacon

7. Reduce lost to follow-up for Native American families by 10%

By: August 2010

Susan Chacon to monitor this progress

Year Two:

1. Deliver 4 family trainings on EHDI spectrum

By: August 2011

EPICS

2. Provide parent to parent support

By: August 2011

EPICS

3. Reduce loss to follow-up for Native American families by 10%

By: August 2011

Susan Chacon to monitor

Year Three:

1. Deliver 4 family trainings on EHDI spectrum

By: August 2012

EPICS

2. Provide parent to parent support

By: August 2012

EPICS

3. Reduce loss to follow-up for Native American families by 10%

By: August 2012

Susan Chacon to monitor

Improve access to audiology services for rural and frontier areas

Year One:

1. Identify baseline data on lost to follow-up rates by race, ethnicity and region

By: November 2009

Susan Chacon EHDI Coordinator and Jennifer Hudson MCH Epidemiologist

2. Develop contract with Audio Acoustics to deliver diagnostic audiology services to the Southeast region of New Mexico.

By: December 2009

Susan Chacon

3. Reduce lost to follow-up from refer on hospital screen to diagnosis to early intervention by 30%

By: August 2012

Susan Chacon to monitor services provided by Audio Acoustics and data reported by Vital Records as well as referrals tracked by Challenger Soft.

Year Two:

1. Develop contract with NMSHA for EHDI training at annual conference

By: September 2010

Susan Chacon

2. NMSHA Conference with EHDI tract fall of 2010

By: Fall 2010

NMSHA

3. Review results of training and evaluations and number of audiologists attending

By: December 2010

NMSAH board and Susan Chacon

4. Monitor lost to follow-up rates statewide

By: August 2011

Susan Chacon

Year Three:

1. Renew contract with NMSHA for EHDI training at annual conference.

By: September 2010

Susan Chacon

2. NMSHA Conference with EHDI tract fall of 2011

By: Fall 2011

NMSHA

3. Review conference evaluations and attendance by audiologists.

By: December 2011

Susan Chacon and NMSHA board

4. Review statewide lost to follow-up rates to assess impact of trainings overall

By: August 2019

Susan Chacon and CMS Management Team

V. Resolution of Challenges:

Staff shortages-all providers statewide: Medical providers, including social workers are experiencing workforce shortages statewide. The CMS Program continues to advocate to increase the social worker salaries that have been a major barrier to hiring. With the state hiring freeze however salary increases have been put on hold .The priority at this time for the CMS Management is to fill vacant social work positions by obtaining approval from the Administration to exempt public health social workers from the hiring freeze.

Training issues-hospitals, PCP's CMS staff, audiology: The NBGS Program together with the NBHS Program Coordinators visited and provided training for nurses, lab technicians, physicians, hospital administrators, audiologists and CMS social workers in every birthing hospital facility and midwives in New Mexico in FY '07. This is being repeated on individual sites as barriers to quality assurance surface, with a follow-up training in FY '09. Ongoing QA continues to be provided to review hospital and midwife compliance with standards to which these professionals have been trained. The EHDI Coordinator is participating in the Developmental Screening Initiative which provides telehealth trainings to Medical Home practices throughout the state. A presentation was

delivered by the EHDI Coordinator, the AAP EHDI chapter champion and the New Mexico School for the Deaf Early Intervention Coordinator. It was well received and other trainings will be scheduled.

Medicaid eligibility process is slow and delays audiology appointments and most practices will see a client only with a valid payor source. The NBHS Coordinator is assigned to the Medicaid Outreach Interagency Task Force that is addressing increasing the enrollment of eligible clients. Regionally, the CMS staff work on Medicaid enrollment in the health offices including presumptive eligibility which speeds the application process. Because the CMS staff now have 'read' capacity for the Medicaid Omnicaid system, they are able to easily determine a client's eligibility status.

Hospital issues-high refer rates at three community hospitals due to equipment malfunction and/or technique or training issues: The NBHS Coordinator assists hospitals in identifying resources for equipment replacement, provide encouragement, support and patient liability information to assist hospitals in prioritizing this critical role. While not resolved, the need for feedback to hospitals is a significant ongoing portion of QA regarding high refer rates. Vital records provide the high refer rate information – thus necessitating the nurturing of this inter-agency role. The information obtained through vital records assists the NBHS Coordinator in planning intervention points for QA. The Coordinator recently provided training to two community hospitals in the southeastern part of the state.

Babies must be able to geographically access institutions that are able to provide sedation when diagnostic test is needed – only 2 tertiary hospitals have this capacity: This is a planning role that is inclusive, but not limited to the NBHS program. The CMS

leadership is meeting 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. A telehealth project is in the stages of development with UNM and two hospitals in the northwest, Gallup Indian Hospital and Rehoboth McKinley Hospital. There is no audiologist in this region. Many of the families live remotely on reservation land. The telehealth project will allow families to receiving a follow-up screen at the community hospital. The UNM Chief of Audiology will review the results and procedure via telehealth in Albuquerque thus negating the need for families to travel long distances for follow-up.

The purchase of diagnostic equipment for an audiology practice in the Southeast will greatly reduce the need for families in that region to travel to receive this service.

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, however as described above, 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.

Need for family and public awareness of the importance of follow-up of NBH screens in a culturally competent manner: The program continues to look for opportunities for public awareness.

The contract with EPICS will provide an opportunity for family education within the Native communities on the importance of EHDI.

Physician training. We still have some PCP's in the Southeastern part of the state who advocate for the "wait and see approach" to follow-up. This crosses over and impacts referral for early intervention. The NBHS Coordinator was invited to participate in a telehealth training as part of the statewide Developmental Initiative program out of UNM. The training included the AAP EHDI Chapter Champion, Dr. Julia Hecht, and Joanne Corwin the Director of Step*Hi the early intervention program through the New Mexico School for the Deaf. The target audience was medical providers across the state which included a large practice in the southeast. The focus of the training was EHDI and the primary care provider's role. The training was well received and more training will be scheduled as they add more telehealth sites to the Initiative.

Integrated data collection system: As discussed earlier, this plan is in process now, with the prospect of a more comprehensive data linkage with the implementation of Challenger Soft. Grant requests and plans will continue to reach the desired level of data integration statewide.

VI. Evaluation and Technical Support:

Evaluation will be on-going and integrated into the quality assurance process that is already in place. The state is currently under a hiring freeze. No additional staff will be allowed at this time.

The Project Director will be the NM EHDI Coordinator, Susan Chacon who has been with the program for seven years. Ms Chacon will meet monthly with EPICS to assess progress and identify areas were technical assistance is needed.

Ms. Chacon will require monthly reports from Audio Acoustics on the number of infants evaluated, and age of diagnosis to continuously monitor follow-up rates. Ms. Chacon meets quarterly with the Newborn Hearing Advisory Committee and will report on progress at this quarterly meeting.

An evaluation form will be required after completion of the conference sponsored by NMSHA and before CEU's are awarded to audiologists. Ms. Chacon will meet with the NMSH board to review evaluations and make appropriate adjustments to the curriculum for year three. Attendance by audiologists will be monitored by the NMSH board and reported back to Ms. Chacon.

The CMS Medical Director will oversee medical issues and will work closely with the Ms. Chacon in overseeing implementation activities. Dr. Janis Gonzales is the Title V CYSHCN Medical Director for Children's Medical Services. She is a board certified Pediatrician with a Masters Degree in Public Health. She is also a Fellow of the American Academy of Pediatrics. She has 13 years in Maternal and Child Health experience, working with children and youth with special health care needs.

The CMS State Program Manager is the Title V CYSHCN Director for New Mexico with almost 10 years in this role. She is a licensed social worker with a MSW and over 25 years in Maternal and Child Health experience. The State Program Manager will supervise the Project Coordinator.

The CMS Financial Manager will provide financial oversight and administration of the budget and contracting process. The Financial Manager has a Master's Degree in Public Administration.

Ms. Jennifer Hudson, MPH is an epidemiologist with the Maternal Child Health and assists the Newborn Hearing Screeningprogram with data collection and analysis. Data sources include Vital Records, Hospital referral forms, audiology reports and Part C child specific information. Ms Hudson will continue to work with the program evaluating lost to follow-up rates based on the data collected from these sources.

Ms. Hudson is a regular participant in the Challenger Soft work group which meets weekly to assess and enhance the integrated data system used by Newborn Hearing and Genetic Screening programs and Birth Defects Surveillance. Ms. Hudson will continue to run monthly reports from Vital Records on babies that did not receive and hospital screen and on hospital refer rates which are used by the EHDI Coordinator for follow-up and quality assurance activities.

VII: Organizational Information

Mission: The mission of the 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.

Structure: Children's Medical Services (CMS), is a program of the Family Health Bureau (FHB), The Public Health Division (PHD) of the New Mexico Department of Health (NMDOH), and as such is the officially designated, statewide Title V CYSHCN program for Maternal and Child Health Bureau (MCH), Title V Block Grant with related matching from the State General Fund.

The Family Health Bureau (FHB) includes programs funded by Title V MCH, Title X Family Planning, Medicaid-reimbursed Families FIRST Case Management, and the NM WIC. The New Mexico Title V programs continue to transition toward a balance of direct and enabling services along with population-based and infrastructure building initiatives. The mix is created by developments in the delivery of prenatal care and child health services, rapidly changing health care policies and financing, community needs assessments and the response of the Title V Program to federal, state and community initiatives affecting the MCH population. Many programs comprise state and community level partnerships that include the Title V MCH.

Children's Medical Services (CMS) is comprised of a series of programs addressing early intervention issues, as well as the ongoing needs of the CYSHCN population of New Mexico, ages birth through 21. CMS services include a long-standing series of contractual partnerships with over 900 medical providers and with the University of New Mexico Hospital (Health Sciences Center), Presbyterian Hospital, and the staffs of eight of their pediatric subspecialty departments in the provision of a series of over 130 subspecialty

outreach clinics throughout the state annually. These clinics currently offered are pulmonology, cleft palate, genetics, metabolic, neurology, nephrology, and endocrinology.

The programs that comprise CMS are:

Children and Youth with Special Health Care Needs (CYSHCN): Provides comprehensive medical coverage, including diagnostics, primary care, clinical services, surgery, and care coordination for children and youth ages birth to 21 who meet established medical criteria and 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 52 social workers, 5 family liaisons, 4 nutritionists and 12 CMS State Office Staff. The CYSHCN program covers a number of chronic, or life-threatening medical conditions, as described in the CMS Manual and Medical Appendix, and provides payment for medical services up to $15,000 per client for those who are not Medicaid eligible and have no other source of insurance. For CYSHCN with high cost diagnoses, CMS purchases insurance through a high risk pool that is available for those previously considered uninsurable.

Multidisciplinary Pediatric Specialty Clinics: Pediatric sub-specialty consultation and care coordination for clinic recipients are provided to 2720 children and youth in community based clinics. Children and youth served in the clinics include children and youth who receive Medicaid and insurance, and

for whom clinic services are billed. There are approximately 137 clinics statewide annually.

Healthier Kids Fund: was created through the State Legislature in 1995 to provide health coverage to children ages 3-19 years old, who are at or below 300% of poverty, are not Medicaid eligible, and have no other insurance coverage, or who have deductibles of $500 or more per individual if insured. Over 600 children and youth in this program receive health care coverage that includes primary care office visits, two specialty visits, labs, basic dental, glasses, and limited mental health coverage.

Newborn Hearing Screening Program: is currently screening 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.

In 2001, NM Senate Bill 101 was passed and signed into law mandating that all birthing hospitals "screen all newborns for hearing sensitivity prior to discharge and arrange for hearing screening for all newborns admitted after birth that have not been screened." The regulations do not require reporting by the hospitals to the state agency; however, most of the hospitals follow the protocol on managing children who refer or are discharged or transferred without a screen.

CMS implemented a case management, tracking and surveillance system for newborn hearing screening, newborn genetic screening and birth defects surveillance programs January 1, 2009. This system is being funded collaboratively by the three programs. Challenger Soft, the vendor which developed the Families FIRST perinatal case management program in the bureau is the system that was selected first. A work group provides technical information as the Challenger Soft system every week. The work group includes: the PHD Medical Director Dr. Maggi Gallaher; the Title V Children with Special Health Care Needs Director, Lynn Christiansen; the CMS Medical Director, Dr. Janis Gonzales; Barbara Toth and Heidi Krapfl with the Environmental Epidemiology program who are the epidemiologists that oversee birth defects surveillance; the Newborn Genetics Screening State Coordinator, Brenda Romero; the Newborn Genetics Screening Follow-up Nurse, Carla Ortiz; the Newborn Hearing Screening Coordinator, Susan Chacon; the CMS Part C Coordinator, Krista ScottPlionis; the MCH Epidemiologist , Jennifer Hudson.

Newborn Genetic Screening Program: is currently screening 99% of 29,000 newborns, state-wide, through state-mandated screening procedures at all state-licensed birthing hospitals. Testing is conducted in partnership with the Oregon State Public Health Laboratory (OSPHL) through contractual agreements that provide for newborn screening and metabolic consultation of all babies born at state-wide birthing facilities in NM, and CMS Nurse Consultants who work with the CMS State Office and the OSPHL. This testing screens newborns throughout

the state for possible genetic conditions, and was expanded by the NM Legislature in 2006 to include 26 metabolic and genetic conditions.

The Family, Infant & Toddler Program (FIT): provides services to approximately 200 infants and toddlers and is charged with providing early intervention services to those babies with, or at risk for, developmental delays and disabilities. It is housed at the Developmental Disabilities Services Division of the Department of Health. A Joint Powers Agreement between CMS, FIT and HSD developed approximately 12 years ago used to fund 12 state-wide CMS FIT social workers who provide service coordination to children and families in need of early intervention services. At this time, funding for these social workers is provided by a combination of Medicaid billing and State general funds.

In addition to these Children's Medical Services programs there are two areas in which significant infrastructure and partnering is also well under way at CMS. These are:

CYSHCN Youth in Transition: This has been an area of need continuously addressed by CMS for over a decade. In recognition of the many challenges faced by YSHCN youth in transition, as well as mandates specified in the Maternal and Child Health (MCH) Title V Block Grant, CMS founded a state-wide, interagency, multi-disciplinary council in the year 2000, known as the Healthy Transitions New Mexico Coordinating Council (HTNMCC). The membership was composed of different public and private sector agencies, such as the

Department of Health (DOH), the Department of Vocational Rehabilitation (DVR), the Center for Developmental Disabilities (CDD), special education programs and their related public school systems, the University of New Mexico, Parents Reaching Out (PRO), Education For Parents of Indian Children With Special Needs (EPICS)/Abrazos Family Support Services, and the state Department of Education. The council (which received no financial support) began to build a statewide infrastructure, which supports the real needs of New Mexico YSHCN youth in transition, utilizing the Medical Home Model in providing education, support, local partners, and family support. The council created and sponsored two statewide, annual transition conferences, and produced a video on transition (with some supplemental funding). In addition, the CMS-specific Transition Team created a youth transition survey which is being implemented by field social workers. All of this was done in a fiscal climate that is becoming increasingly more restrictive, offering little support in this area of need.

Birth Defects Prevention and Surveillance System (BDPASS):

Under the guidance of the Birth Defects Prevention Task Force, and funded by a Cooperative Agreement with the CDC, a preconception health education teaching tool, the Life Long Happiness Module, was designed and produced in 2003. The Module was designed to be used by a health educator working with a small group of women in a dialog presentation that encourages the women to share information with each other as well as receive information on five

preconception health topics. The results of birth defects surveillance results indicated that Dona Ana, Chaves and Sandoval Counties are at high risk for birth defects, and these counties were selected for a Pilot Project from July 2003 through February 2004. Each county was assigned a coordinator to provide coaching and training support to participating organizations. Seventeen community organizations volunteered to be part of the Pilot Project. Four hundred women participated by attending presentations by educators at the organization and by completing a series of surveys. Results indicated that the Module is effective in helping women change from making unhealthy choices to making healthy choices that contribute to preventing birth defects.

The coordinator in Dona Ana County made important connections with the Promotoras that provide direct care to the impoverished border populations. She also worked with teenagers in high-risk environments and will be following up on this experience by developing a new methodology for presenting the folic acid awareness message within the academic environment rather than in the preconception environment. The Sandoval County coordinator developed relationships with the five Sandoval County Pueblo Tribes that are served by the 5-Sandoval WIC program. She will work with the Santo Domingo Tribe to develop a methodology for introducing the Life Long Happiness project to their community and to introduce a Folic Acid Awareness Pilot Project into the education system.

The New Mexico Medical Insurance Pool: Recognizing that there are a select number of CYSHCN children already enrolled in the CMS program, whose chronic medical conditions will result in excessively high medical costs over time, CMS negotiated a Provider Agreement with the New Mexico Medical Insurance Pool (a partnership with Blue Cross / Blue Shield). This program helps to provide a separate and distinct insurance vehicle for this particular group, and, with infusion of future funding, could be expanded to cover additional children.

CMS is also housed in the same building as the New Mexico Pregnancy Risk Assessment Monitoring System (PRAMS), which collects a considerable amount of data relating to CYSHCN children and youth, through such data-gathering mechanisms as the New Mexico Behavioral Risk Factor Surveillance System (BRFSS) and the New Mexico Youth Risk Resiliency Survey.

The Title V agency's capacity to promote and protect the health of all mothers and children, including CYSHCN is extensive, yet there remain serious challenges to that objective due to the high rate of poverty of the State and the lack of additional General Fund monies to meet those challenges. Therefore, the NM Title V programs rely heavily on an extensive network of federal, state and local partners who are essential to the implementation of services and programs. New Mexico's multiculturalism adds additional barriers in addressing the health care needs of the state's immigrant. While CMS programs do not specifically

indicate that they provide for immigrant population, the vast majority of CMS non-Medicaid clients are immigrant children.

While Children's Medical Services spans a major portion of the health care spectrum for the CYSHCN population of New Mexico from birth through early adulthood, staff and budget constraints have limited CMS's ability to create a more far-reaching and integrated health care delivery system. CMS has worked closely with family organizations such as Parents Reaching Out, Family Voices and Educating Parents of Indian Children with Special Needs (EPICS)/Abrazos Family Support Services who serve in an advisory capacity for materials and all levels of program implementation by CMS. Efforts are made to elicit feedback, ensuring that CMS services are culturally competent and family-friendly. CMS has also supported family organizations' involvement in trainings and conferences at the local, State and National levels.

CMS continues to work with partners including Medicaid managed care programs, the provider community, the University of New Mexico Hospital, the UNM LEND Program, and the UNM Continuum of Care Program in implementing the Medical Home project in five sites in New Mexico. CMS provides the social work component of the medical home team in clinics that are receiving training.

CMS collaborates with Human Service Department/Medical Assistance Division (HSD/MAD) to address quality of care issues such as care coordination, adolescent transition and Medical Home, and partners with HSD/MAD and Lovelace SALUD!, a

managed care organization serving Medicaid clients. The partnerships generate participation in the MCH Collaborative, addressing statewide efforts to bring families into medical homes and to educate providers/families about the medical home concept. The Maternal and Child Health Collaborative is a focal point for addressing MCH initiatives. The Collaborative addresses Medical Home, 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 LEEP, Family Voices, Parents Reaching Out and Children's Medical Services.

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 was elected as Region VI representative to the national AMCHP Board. She has served on the Institute for Child Health Policy (ICHP) Advisory Board and was selected to assist in the development of a monograph for services for the National Center for Cultural Competence Advisory Committee. She served on the Planning Committee for the past MCH Leadership Conference. The CMS CYSHCN Medical Director has previously worked as a Pediatrician conducting developmental evaluations and providing medical care for children with special health care needs. She is also the parent of a daughter with special needs.