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**Right:** An infant takes part in newborn hearing screening.

## EFFECTIVE PARTNERING OF STATE AGENCIES TO ACHIEVE

# early hearing detection and intervention benchmarks

*By Joanne Corwin*

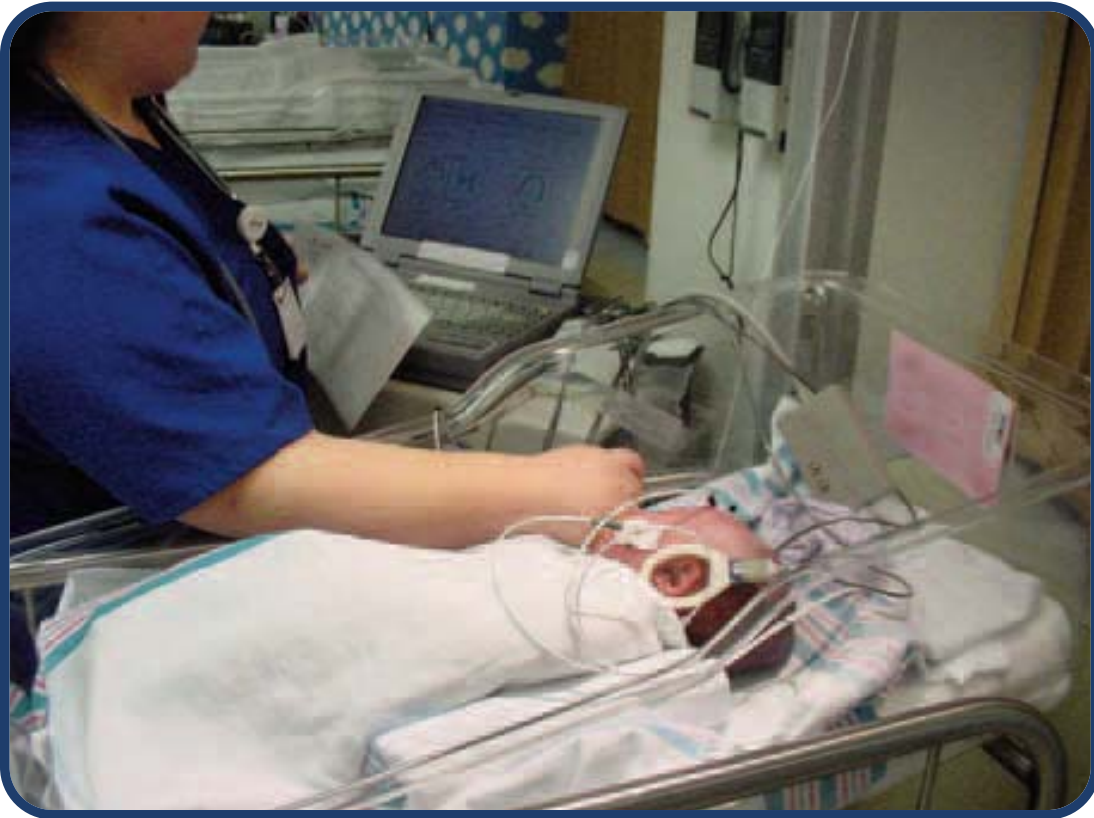
New Mexico is geographically the fifth largest state in America, and its relatively small population of 1.95 million people is widely scattered. The city of Albuquerque is the sole major urban center, and only six other cities have populations of over 30,000. The state's poverty rate remains one of the highest in the nation. An estimated 20 percent of New Mexico children are born to immigrant parents, many of whom are of undocumented status. And, although the state's population continues to grow, the number of licensed health care professionals per capita is decreasing. (Chacon, 2009)

Relative to Early Hearing Detection and Intervention (EHDI), New Mexico struggles with multiple points of referral into early intervention in the same way most states do. Referrals are not systematized through a single point of entry. The Step\*Hi (statewide Parent-Infant) Program of the New Mexico School for the Deaf (NMSD) receives referrals from sources such as hospitals, doctors, audiologists, Part C programs, the Department of Health, parents self-referring, and audiologists. Babies may or may not receive timely early intervention based upon the system they are moving through.

Given these demographics, it is probably not surprising that the EHDI standards of screening by 1 month of age, diagnosis by 3 months, and entrance into early intervention specific to hearing loss by 6 months have not completely been met. What is surprising, amazing actually, is that, even given all of the barriers New Mexico faces, the average age of entry into early intervention is currently 11 months and continues to slowly decline.

So how has New Mexico, with multiple barriers, continued to reduce the age at which children receive early intervention? New Mexico state agencies, as key stakeholders in the success of the EHDI system, do more than just "play nicely in the sandbox" together. There is a systemic commitment to decrease the number of children "lost to follow-up" and to decrease the age at which a child receives early intervention. This commitment has led to strategic interagency planning and implementation of these plans. Following are some of the strategies that New Mexico has found to be successful.

*Photo of newborn hearing screening courtesy of Joanne Corwin*



### **Make Collaborative Relationships Official**

Bringing together key players in the EHDI process, such as medical home providers, pediatric audiologists, parent advocacy programs, and state agencies, and meeting with them often, is critical. This allows for creating strategic plans to assure EHDI benchmarks are met. However, if relationships are person dependent, they can be short-lived given the potential turnover in staff. In New Mexico, the decision was made to create a Procedures and Protocol document as well as a Memorandum of Agreement that would ensure collaborative services through the state school for the deaf, the Part C program, and the Newborn Hearing Screening Program. (It is

important to note that in New Mexico both the newborn hearing screening program and the Part C lead agency are housed within the Department of Health.) This document ensures that young children identified through EHDI are able to receive early intervention from providers specifically trained to work with young children who are deaf or hard of hearing and their families.

The Procedures and Protocol agreement has been in place since 2001 and is periodically reissued and signed by both the superintendent of NMSD and the cabinet secretary of the New Mexico Department of Health. (For copies of this document, please e-mail [joannecorwin@gmail.com](mailto:joannecorwin@gmail.com).)

### **Heighten Awareness/ Be Part of the Community**

The number of children served by NMSD's early intervention program has grown exponentially in the last 10 years. The primary reason for the growth of the program is directly attributable to NMSD's commitment to outreach. The Outreach Department at NMSD is dynamic and includes:

- Early intervention birth through age 6
- Outreach to School-aged Children
- Deaf Role Model Program
- The AmeriCorps Project

The early intervention program has eight full-time and 14 part-time staff members positioned in every part of the state. Five of the full-time positions are



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filled by regional supervisors, who supervise the early interventionists in their regions of the state, serve families directly, and provide community supports. Providing community supports means that each month the regional supervisors are involved in activities such as: working on committees at the community level; providing trainings to doctors, agencies, Head Start programs, etc.; lending expertise related to screenings and

language evaluations; and working on state initiatives for young children. Consequently, when someone in the community learns of a child who is deaf or hard of hearing or who is going through the diagnostic process, he or she knows who to call—the regional supervisors. They know them and they trust them because the regional supervisors are seen as part of the community.

### Create Safety Nets

Given the rural nature of New Mexico and the transient population of the state, the medical home and Newborn Hearing Screening Program can quickly lose track of families, even with careful tracking. New Mexico has made a concerted effort, therefore, to ensure that at least some of the hearing screening equipment placed at the Part C agencies around the state is compatible with the auditory brainstem response (ABR) screening equipment used for newborn hearing screening. This means that in any region of the state, a child and family should have access to a second ABR screen if they refer on their newborn hearing screening and have somehow fallen outside of the medical home or hospital rescreen.

Part C agencies have made the added commitment to hearing health by implementing new standards that encourage yearly screening of hearing for the Part C population. This population is at high risk for progressive hearing loss and, given that the number of cases of pediatric hearing loss doubles by the age of 9, this safety net has helped identify about eight children a year who were missed by other primary systems. NMSD has contributed to this net by helping write numerous grants for equipment, and the school has lent audiological and early intervention staff to Part C programs for initial and ongoing trainings.

### Collect and Share Data

There is a problem when you don't know what you don't know. Shared data across agencies allows the state's EHDI system to be assessed for effectiveness, especially as it relates to child outcomes. In New Mexico, the state school for the deaf, the Part C program, and the Newborn Hearing Screening Program all collect data for different purposes. This data is shared at least twice a year as these three programs meet to plan. The Newborn Hearing Screening Program collects data on the number of children screened and diagnosed. NMSD keeps data on age of



entry into early intervention and longitudinal information about the developmental trajectory of the children. The Part C program analyzes their data to insure that children with hearing loss who are referred to generalized services are quickly referred to the school for the deaf for specialized follow-up.

As a result of shared data, New Mexico has been able to chart progress in systems development and child outcomes. In 2001, NMSD was providing services to an average of 36 children, birth to age 3, each month. In 2010, NMSD provided services to an average of 142 children each month in this same age category. Likewise, in 2001, only 12 percent of children without global delays and within the birth to age 3 population were maintaining a typical developmental trajectory. In 2010, assessment and evaluation data indicated that 71 percent of children without global delays who were identified and into early intervention before the age of 6 months maintained a typical developmental trajectory.

### Create Solutions Based on Your State's Demographics

New Mexico has a tiny handful of pediatric audiologists with the equipment and expertise to diagnosis young children with hearing loss. Almost all of these audiologists are located in the city of Albuquerque, which is eight hours from some towns in the state. In a state challenged by poverty, the resources needed for a family to travel this distance with their



newborn for diagnosis are prohibitive. For children in the more rural parts of New Mexico, diagnosis of hearing loss frequently takes between 12-13 months, which is clearly well behind EHDI standards. Part of the problem has been not just the lack of diagnostic resources but also the multiple steps involved before a child is referred for early intervention. A lot of time is lost with so many steps and with the lack of resources. Therefore, referral to early intervention is now happening on a more frequent basis after a failed second screen. This not only cuts out additional steps, but often shaves six to eight months off of the time between the newborn hearing screen and entry into the early intervention system.

New Mexico agencies were initially reticent to make these early referrals because of the concerns that they might overload the state school for the deaf with children whose screens were false positives. There were additional fears that families would be unduly concerned about a potential hearing loss and burdened with early intervention even before a hearing loss was accurately confirmed. Happily, families have reported just the opposite. Far from having their concerns about a potential hearing loss heightened, they felt supported and calmed through the diagnostic process by a knowledgeable provider. Families whose child ended up not having a hearing loss after all

reported that they enjoyed early intervention services and gained a lot of applicable information related to supporting early language development and creating good listening environments. Timely referrals are still a great challenge in New Mexico because of the many private systems spread out across a rural state, but with the public system creating procedures and protocol as well as increasing awareness throughout the state, we are making progress.

New Mexico is committed to the understanding that if a child does not enter into early intervention in a timely manner, regardless of what other outcomes have been achieved, EHDI



PHOTO BY SUSAN FLAINGAN

benchmarks have not been met. It is clear that as the last step in the system, early intervention is the primary indicator of the health of the entire EHDI system and its effectiveness. If children are not screened or diagnosed, if medical and audiological professionals are unfamiliar with how to make appropriate referrals, early intervention cannot happen in a timely fashion.

#### Reference

Chacon, S. (2009). *Reducing lost to follow-up after failure to pass newborn hearing screening NM*. Health Resources and Services Administration (Grant 09-241).