

Front Page Feature

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Strengthening Families Protective Factors

Pediatric clinicians strive to provide the highest quality of care, in the timeliest way, and work toward both a comprehensive and family-centered approach in that effort. There are many unique challenges that families face – toxic stress, social determinants of health, adverse childhood experiences (ACEs) - and clinicians must find a way to connect individually with each one. We know that not all families are the same. Families come to the table with different life experiences, and with varying capacity to partner with providers in the care of their child. Having a common framework to address the challenges around effective partnering with families is helpful for all everyone, especially families who have a child who has a special need such as having been identified as Deaf or Hard of Hearing (D/HH).

The *Strengthening Families Framework of Five Protective Factors* is a framework that overviews five important elements to incorporate into work with families. These factors can impact our interactions by informing our approach and grounding our conversations. By strengthening partnerships, we help build the overall capacity for that family to cope and manage. The strength of this relationship can also impact outcomes for children who are D/HH.

By building capacity as professionals and adept family support advocates, our role as the primary medical home provider contributes to the potential success of both that family and the child.

The five protective factors listed below have direct relevance to our work with families who have a child identified as Deaf or Hard of Hearing. The following content, except for the EHDI comments (in italics), are excerpted from the Center for the Study of Social Policy's Strengthening Families "[Core Meanings of the Strengthening Families Protective Factors](#)" document.

1. **Parental Resilience:** Managing stress and functioning well when faced with challenges, adversity and trauma. *Within EHDI, we discuss the importance of empowering families to be their child's advocate, and maintaining confidence as they navigate the journey. This knowledge and control helps build parental resilience and provides a coping strategy that can reduce stress as it relates to their child's diagnosis.*
2. **Social Connections:** Having a sense of connectedness with constructive, supportive people and institutions. *Family support is central for families who have a child identified as Deaf or Hard of Hearing. Both a family's general social supports, as well as connections with families who understand the EHDI*

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experience, are important. Understanding each family situation is vital to your ability to provide support resources to best meet their needs.

3. **Knowledge of Parenting and Child Development:** Understanding parenting best practices and developmentally appropriate child skills and behaviors. *This can be one of the more challenging parts of a family's journey. Part of our role as clinicians is to make sure families are educated and supported with resources that build their confidence and skills in nurturing, communicating with, and parenting a child who is D/HH.*

Concrete Support in Times of Need: Identifying, accessing and receiving needed adult, child and family services. *The range of support and services that families may need include everything from assisting with access to technology not covered by insurance, to helping them understand the process of referring for Early Intervention services. EHDl we work with could include everything from helping to provide access to technology not covered by insurance to helping them understand the IEP process. But for families who are struggling or in crisis, this also means making sure families have stable housing and food security, that the family structure is stable and custodial issues are supported and issues around family mental health and family violence are explored.*
4. **Social and Emotional Competence of Children:** Forming secure adult and peer relationships; experiencing, regulating and expressing emotions. *Family dynamics and positive and supportive family interactions help children develop the ability to communicate clearly, recognize and regulate their emotions and establish and maintain relationships. Building trust and respect between care provider and family—and assisting the family in developing secure and nurturing bonds with their child—will raise the potential of empowering families to be strong, capable and better able to foster confidence in their child.*

Family Partnerships

Communication is the Key!

For many parents, it can be overwhelming when they first learn that their child has a hearing condition. Ninety-five (95%) percent of all children who are deaf or hard of hearing are born into families where parents do hear (Mitchell & Karchmer 2004), and 90% of these families have no background in deafness or connections to the deaf community (Center for Demographic Studies 1984).

One of the early decisions families need to explore is how will they wish to begin to communicate with their child. Ensuring that parents have access to resources to support them including tools to assist them with important informed decision making is the responsibility of all providers who work with and support the family.

Resources available to share with families are as follows:

- [CDC Decision Guide to Communication Choices](#)
- [Communicate with Your Child](#)
- [Making a Plan for Your Child](#)

Clinical Corner

How Many Babies with Hearing Loss Will Be Missed by Repeated Newborn Hearing Screening with Transient Evoked Otoacoustic Emissions Due to Statistical Artifact?

Otoacoustic emissions (OAE) testing is used worldwide to test cochlear function. The most common use of OAE testing is in hospital-based newborn hearing screening programs, and is an objective measure to identify infants who require additional diagnostic audiologic testing to confirm status as deaf or hard of hearing. This [study](#) evaluated the accuracy of the recommendation regarding repeated OAE hearing screening, and the increased probability of false-negatives (i.e., passing babies who have permanent hearing loss).

The risks of over-testing or under-testing illustrate the importance of effective and appropriate screening protocols. As program administrators re-evaluate their procedures, improvements can be implemented that are likely to increase the accuracy of hearing screenings. Potential procedures to review are: clarification on when to test, how to test, and provision of clear protocols for what constitutes proper environment for a testing attempt.

Findings showed that if 100,000 newborn ears were each tested 10 times, only 1% of the ears with hearing loss would be missed due to statistical probability of false-negatives resulting from repeated testing. Excessive repeated testing in a newborn hearing screening program waste time, raises questions about the accuracy of the test, and may disturb the infant, family, or hospital staff. However, repeated OAE testing does not cause a significant number of babies with hearing loss to pass the test. Additionally, not repeating screening tests often enough can cause serious problems.

Once a baby has failed the newborn hearing screening test, diagnostic assessment to determine the baby's hearing status should be done as soon as possible. Newborn hearing screening programs should have well-trained screeners who recognize when to attempt testing and when to repeat OAE testing to obtain an accurate test result rather than focusing on the number of tests performed.

Citation:

White, K R, Nelson, L H, Munoz, K F. How many babies with hearing loss will be missed by repeated newborn hearing screening with otoacoustic emissions due to statistical artifact? *Journal of Early Hearing Detection and Intervention*. 2016;1 (2), 56-62.

Quality Improvement (QI) Buzz



Reflections: The Use of Quality Improvement Methodology in EHDl Programs

Background and Challenge

Since 2006, all state EHDl programs have been encouraged by the Maternal and Child Health Bureau to plan and implement Quality Improvement (QI) activities and initiatives. By 2013, all EHDl programs participated in a learning collaborative (short term program comprised of several teams who seek improvement in a focused topic area). In 2014, based on a review of state and national outcomes from the collaboratives, the National Center for Hearing Assessment and Management (NCHAM) sought qualitative and quantitative feedback from EHDl programs about their competence and continued use of QI to improve their program. Despite participation in the learning collaboratives and in combination with staff turnover, state EHDl feedback revealed that many states still struggled with the application of QI, and more than 70% of states requested additional assistance. Moreover, only 19% of states reported that they regularly used QI to improve their program.

Aim

By March 2016, increase by 30%, the number of states who regularly use QI in state EHDl programs.

Action Taken

In response to surveys and interviews with state EHDl programs, NCHAM did the following:

- Iteratively tested the effectiveness of individualized state assistance, guided by improvement advisors, via monthly conference calls and yearly in person meetings
- Developed opportunities to increase interstate communication via a virtual learning collaborative and began a yearly in-person storyboard roundtable meetings for states to share their concrete improvement work
- Built a professional development program for QI advisors that involves monthly sharing meetings, literature conversations, and a variety of training opportunities

Summary of Results

By February 2016, advisors reported that **46%** of their states were regularly using QI and **75%** of their states had made improvements in their EHDl processes and outcomes. This progress has continued over the past year. In fact, at the 2017 EHDl meeting, all 50 state and 9 territory EHDl programs presented on their work over the last year that focused on engaging partners to accomplish improvement.

States demonstrated their diverse QI work such as the following:

- decreasing no show rates for audiology appointments
- improving reporting by outsourced hearing screening organizations
- increasing percentage of babies in rural areas who receive a diagnosis through tele-audiology services
- increasing families who are enrolled in a family support program
- working with providers to follow up with families
- improving internal workflow of EHDl program
- matching birth records with screening results

Medical Home Resources

New Jersey Medical Home Collaboratives: Promising Practice in Pediatric Medical Home Implementation

Selected as an evidence-informed promising practice, [this project utilized a quality improvement approach to facilitate practice transformation](#), build capacity among diverse family leaders, and strengthen systems of care for children and youth with special healthcare needs.

Pediatric medical home implementation strategies such as engaging community-based partners and connecting children and families to local resources, are an important part of care provided to children who are identified as Deaf or Hard of Hearing.

And More....

The Role of Family-led Disability Organizations in Supporting Families with Hearing-Related Concerns

A [survey](#) was conducted with participation from state level chapters of Family Voices, Parent Training and Information Centers, and Parent-to-Parent USA to better understand how their current activities support families of children with hearing-related concerns, and to identify gaps in their ability to support families of children who are Deaf or Hard of Hearing (D/HH).

Because these organizations are frequently contacted by parents or caregivers with requests for information, it was important to understand the areas of support most frequently requested. Topics in the survey included the following: connections for family support, referrals for early intervention, information regarding specific hearing concerns, requests for financial support, and legal counsel.

Results of the survey showed that the greatest challenges for these organizations were related to the following:

- financial resources pertaining to hearing-related needs
- engaging families of children who are deaf/hard of hearing in their organization's activities
- having resources available in other languages
- identifying pediatric providers that serve children who are identified as D/HH.

Outcomes from these findings will further efforts around collaboration and shared leadership to ensure that all families who have children who are D/HH obtain the knowledge, support, and decision-making skills in accordance with their needs.

Citation:

Behl, DD, DesGeorges, J, White, KR. The Role of family-led disability organizations in supporting families with hearing-related concerns. *Journal of Early Hearing Detection and Intervention*. 2016;1(1);13-20.

The AAP EHDl program implementation staff send this e-mail update to the Academy's EHDl Chapter Champions, other interested AAP members, state EHDl coordinators, and other stakeholders. For additional information on hearing screening and to access previous editions of the EHDl E-mail Express, click [here](#). If you would like to unsubscribe to the updates, contact Sandi Ring at sring@aap.org or 847/434-4738.