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beyond the clinic:

PROVIDING SERVICES, SUPPORTS, AND CONNECTIONS TO HELP CHILDREN AND THEIR FAMILIES THRIVE

By Kevin J. Nolan, Jr.

As one of the premier pediatric hospitals in the United States, Boston Children's Hospital serves a wide range of children and provides top quality medical care, including a program for deaf and hard of hearing children that extends services beyond the medical scope. Within this program is a unique and particularly critical position—that of outreach and support services coordinator for the Deaf and Hard of Hearing Program.

While doctors and clinical personnel on the team focus on specialty care appointments, the outreach and support services coordinator provides essential information and connections to services that reach beyond what otolaryngologists and audiologists traditionally provide. The essence of the work done by the individual in this position is to offer reassurance and understanding to deaf and hard of hearing children and their families.

For over 30 years, Boston Children's Hospital has had an interdisciplinary team serving deaf and hard of hearing children. The team includes psychologists, speech-language pathologists, American Sign Language (ASL) specialists, a psychiatrist, audiologists, doctors, and surgeons. Working together, these specialists provide a truly multi-disciplinary unit that offers a wide range of information about technological interventions, habilitative regimes, and programmatic services. The outreach and support services coordinator, a relatively new addition to the team, ensures that patients have access to a full range of support and information.

When a child is diagnosed with a hearing loss, the first contacts that parents often

Photos courtesy of Kevin J. Nolan, Jr.

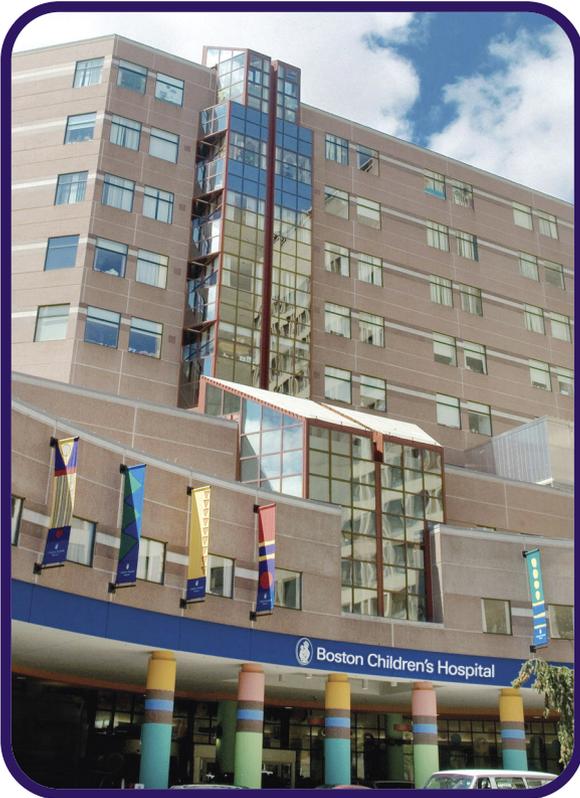


have are with audiologists and medical personnel. Doctors and audiologists are specialists in the clinical aspects of hearing loss, but they may not be familiar with all of the services, supports, and connections that help children and their families thrive. As a professional with a wider knowledge of services and community connections, I, as the outreach and support services coordinator, frequently participate in clinical meetings with families who have recently been informed that their child has a hearing loss. My presence contributes to a broader and deeper approach to the deaf or hard of hearing child; the clinicians focus on the medical aspect of the diagnoses while I provide information about programs and resources for stimulating language acquisition, options regarding day care providers,

parent support groups, a full array of early intervention options, and agency professionals.

Every situation is different so flexibility is paramount. In the morning I may assist a family for whom the oral/aural approach is used and spoken English is the primary language, and in the afternoon I may meet and relate comfortably with a family who is fostering ASL as their child's primary language. The goal remains the same: to support the families—parents and children—while appreciating the uniqueness of each one.

One of my most important roles is helping parents navigate the myriad of agencies and resources available. Many parents beginning the journey of raising a child who is deaf or hard of hearing feel overwhelmed by the amount of



information that they receive. I can sit down with each in turn, helping parents understand the information in an objective way. Before parents can make informed decisions regarding their child, it is important for them to have access to as much information as possible and to fully understand the resources at hand. Only then can they truly make informed decisions that are best for their child and family. In a field that has experienced conflicts of opinion almost since its inception, I remain neutral and present factual information without biases. This is crucial.

Here in Massachusetts, we are fortunate to have a number of resources we can offer to our patients and their families. Families of infants and toddlers can learn ASL through the Family Sign Language Program, which is now run through the Gallaudet University Regional Center at Northern Essex Community College. Massachusetts has numerous regional Parent-Infant/Toddler Programs. Parents can choose from a variety of language intervention options, ranging from emphasis on acquisition of ASL as a first language to

the acquisition of spoken language as a priority.

My involvement does not end after the initial meetings. My role helps ensure coordinated care among providers, specialty programs, early intervention providers, school districts, mentors, and a variety of community resources. A crucial, and often overlooked, aspect of the outreach and support services coordinator's role is aiding parents in their introduction to and learning about the deaf and hard of hearing community, providing the parents with information, and modeling cultural awareness and sensitivity. Parent support groups and information

sessions, sponsored by the hospital and facilitated by the outreach and support services coordinator, deepen levels of knowledge and awareness.

Working in our urban medical center, with its constant influx of new patients and their concerned families, the interdisciplinary team works together on a daily basis to provide the best possible care. Through my position, the child and family members are also offered a reassuring and understanding "bridge" that serves to connect them with clinicians and support services. As most clinicians are not free to travel to meetings, participate on advisory committees, conduct observations outside the clinic, or offer in-service training off site, the outreach and support services coordinator represents the clinical team at such venues. Thus the duties vary from day to day. One day I consult in a public school setting; another day I serve as a resource specialist for a family; still another day I represent our team on a statewide committee that advocates on behalf of the interests of deaf and hard of hearing children. I also arrange inspiring and

informative speakers for family forums and workshops. Ultimately, my position ensures that the families in our program have access to all the information and support services available—both through our hospital-based program and through our community-based, educational, therapeutic, and social organizations.

Perhaps for parents who do not have an outreach and support services coordinator for deaf and hard of hearing children within a medical center in their community, the breadth of services we offer may be a challenge to find. Yet there are professionals and parent organizations that provide information and guidance for families in a variety of other settings. Many states have specialists who focus on children's services within state agencies that serve deaf and hard of hearing people. Many educational programs and schools for the deaf offer outreach and support for parents and family members. Many early childhood specialty programs have strong parent support components. By developing cooperative relationships among or between state agencies, school programs, and/or specialty programs and medical centers or clinics where deaf and hard of hearing children are followed, bridges that support families and professionals can be constructively forged. Such bridges benefit clinicians and physicians as well as families who are raising children who are deaf or hard of hearing.

Author's note: *I feel very fortunate to be able to work in a caring medical environment with team members who provide world-class medical care and who maintain a deep appreciation and understanding of the importance of culture and robust language acquisition. The outreach and support services coordinator position ensures that the focus is never on just a child's ears and mouth but on the developing and complex individual who is the child. In that role, I am able to create bridges that these children and families may never have known existed but absolutely deserve.*