Helping Children with Hearing Loss in Developing Countries Listen, Talk, and Thrive

By Paige Stringer, MA, MPH

This is the first article in a series. Future articles will discuss the work of the Global Foundation For Children With Hearing Loss and lessons learned from its international programs.

hen I stepped out of the van at the government school for the deaf in rural Vietnam on that humid November day in 2008, I had no idea that the course of my life was about to change. I had been invited there on a volunteer basis to lend support to Vietnamese teachers teaching English to their deaf students, but it quickly became apparent that there would be a second and much larger purpose to my weekslong visit.

The director of the school, Thuy Nguyen, greeted me upon my arrival. Until then, our communication had been entirely via email. She was surprised to discover that I could listen and talk in spite of being deaf. With an empathetic nature and inquisitive mind, she made it a personal mission over the next several weeks to understand how this was possible.

Thuy and I sat together in her office for hours sharing bowls of mangosteens and jackfruit as we traded stories and developed a friendship. She asked me questions about my upbringing and the services I had received when I was young, and I learned from her about the day-to-day experiences of the boarding school and the 300 children it served. She and her fellow teachers peered into my ears with otoscopes and closely examined my hearing aids while talking excitedly to each other in Vietnamese.

At one point, I was asked to have a hearing test to confirm that I indeed was as deaf as I indicated I was. They just couldn't believe that someone with as significant a hearing loss as mine would be able to communicate as I did. They compared my test results with the audiograms of the children at the school, taking note at how similar they were, and in some cases, that my hearing was worse. Despite our similarities in hearing acumen, however, the children in this school were very delayed in their development because of the limited support available to them when they were young. It was the first time in my life that I was happy to have such a terrible



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Paige Stringer and Thuy Nguyen

audiogram because it provided the Vietnamese with compelling evidence of the benefits of early identification and intervention in the life of a child who is deaf or hard of hearing.

I was born with a severe-to-profound hearing loss but successfully learned to listen and talk thanks to the services I received as a baby. I was born in the United States to a family with no history of hearing loss, as over 90% of children who are deaf or hard of hearing are, at a time before newborn hearing screening programs. My family moved to England shortly after I was born. It was a British public health nurse who suspected a challenge with my hearing during tests she administered at our home as part of her routine well-baby visit. I was quickly referred to a doctor who confirmed my hearing loss. I was immediately fit with hearing aids and, over the next few years, speech therapists lent support to my family, providing the necessary guidance to enable them to help me develop my listening and spoken language skills.

As a result of this holistic and timely progression of care, I was able to join my typically hearing peers in mainstream schools starting at kindergarten when my family returned to the United States. I went on to attend the University of Washington on a tennis scholarship, earned two master's degrees, including one in public health, and worked for several years at Fortune 500 companies. Along the way, I have enjoyed my friends and family and an independent, successful life. I know that my life experiences would not have been possible without the support I received in my earliest years.

During my conversations with Thuy during that initial visit to Vietnam, I learned that she and some other Vietnamese aca-

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GFCHL audiology training in Vietnam.

demic leaders had been directed by the government to introduce early intervention services for children with disabilities into the Vietnamese education system. However, there was little understanding or guidance about how to approach this task. Thuy felt that if a core group of Vietnamese professionals who work with children with hearing loss could be trained in this area, they could share their new knowledge with others in Vietnam. They would then work collectively to strengthen services for young children with hearing loss and their families over time. I was inspired by her vision and sense of responsibility and offered to help.

By the time my initial visit to Vietnam ended, Thuy and I had designed the framework for a program that we would implement together. The multiyear initiative would aim to train Vietnamese professionals and families in Vietnam about how to help babies and young children under 6 years of age who are deaf or hard of hearing learn to listen and talk and prepare these children for integration into mainstream schools.

I sought out existing organizations to lend support to our proposed initiative when I returned home to the United States. However, I quickly discovered that while there were many groups that carried out humanitarian ear and hearing care programs, they were generally targeted to one area of care (i.e., hearing aid fitting). I was unable to find any organizations that were addressing the entire care continuum and the capacity building required across both health care and early education to enable young children with hearing loss in developing countries to learn to listen and talk during their formative years of development.

I also learned that although disabling hearing loss is prevalent in over 34 million children worldwide, there was (and continues to be) a significant lack of awareness about the negative and permanent impact of untreated hearing loss on young children. The solutions already exist to mitigate its effects. However, the services and expertise to provide such solutions are often fragmented or do not exist at all in many countries. As a result, thousands of children are unnecessarily limited in their potential. They often face stigma and have few academic or employment opportunities, leaving them to grow up dependent on their families or the state for support.

I was determined to help change this reality and to start with the children and families in Vietnam. I established the Global Foundation For Children With Hearing Loss in 2009

shortly after my first visit to Vietnam to achieve this purpose. My 13 years thus far as Executive Director of the Global Foundation have been a tremendous gift, and I am humbled to have had the opportunity to give back in this way. It has been the most inspiring, challenging, maddening, fulfilling, illuminating—and important—achievement of my life.

THE GFCHL MODEL

The Global Foundation For Children With Hearing Loss collaborates with government agencies and other organizations in low-resource countries to develop local expertise and services that young children age 0-6 with hearing loss need to listen, talk, and thrive.

Our holistic programs emphasize the entire Continuum of Care, which includes: 1) early identification of hearing loss, 2) timely fitting of hearing technology, 3) access to locally based professionals trained in otolaryngology, audiology, and auditory-verbal practice, and 4) family/caregiver education and support required to make this reality possible. We customize our programs to meet the unique needs of a given country and meet them where they are in the development of that Continuum of Care. We emphasize relationship building to develop the trust and shared accountability that is so important for successful programs.

We launched our training program with Thuy in Vietnam in 2010 and spent the next nine years helping to build capacity and strengthening services and support across the country so their young children with hearing loss could learn to listen and talk. Initially focused on southern Vietnam, we were invited to expand our program to the central and northern areas in later years, effectively making it a national initiative.

Our Global Foundation team of pediatric audiologists, therapists, and early intervention specialists developed and taught the Global Foundation's proprietary, in-country training curriculum to hundreds of Vietnamese teachers, therapists, medical professionals, and audiology technicians in schools, hospitals, early intervention centers, and clinics across the country. We hosted family education seminars for parents, caregivers, and other family members. We donated new hearing technology to children in need who were then supported ongoing by the local professionals we trained. As Thuy envisioned would happen, those we trained took responsibility to



GFCHL auditory verbal therapy training in Vietnam.

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train others and the knowledge rippled out to benefit even more children and families.

Over the years, the Global Foundation has always prioritized empowering local people with the tools and knowledge they need to ultimately serve their own country's children with hearing loss across the Continuum of Care. Our approach is unique to the traditional humanitarian model where foreign experts travel to a country to administer specific services directly to patients themselves. While the direct service model certainly can play an important role in responding to urgent needs, we feel that our approach is more sustainable over the long term because of the shared accountability.

For example:

- One of our Vietnam program participants established a new school that provides early intervention, therapy, and audiology services to over 70 young children every year in a province that previously did not have such care.
- A Vietnamese professor integrated what she learned from the Global Foundation's training program into her courses for aspiring teachers of the deaf at her university.
- Several Vietnamese audiology technicians initiated a volunteer association that travels to rural areas on select

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weekends to share their knowledge with families and support the children's audiology and therapy needs.

• After spending a great deal of time together in our training programs, the participants developed strong professional networks that they continue to tap today for support in their work and to respond to the audiology, therapy, and early intervention needs of families of children with hearing loss throughout Vietnam. They also have successfully worked together to promote new services in the country such as hospital-based newborn hearing screening.

PROGRAM DEVELOPMENT CONSIDERATIONS

In addition to Vietnam, the GFCHL has worked in Ecuador, currently has a program in Mongolia, and just launched its



Two beneficiaries of the GFCHL program in Vietnam.

newest initiative in Bhutan this year. Every country has unique needs and challenges that need to be recognized. For instance, Vietnam has made amazing strides to support their young children with hearing loss and their families. Yet, the country's health care system still does not offset the cost of hearing technology, which makes it challenging for many families to afford.

In contrast, Mongolia's universal health care does subsidize the cost of hearing technology and habilitation and supports newborn hearing screening. However, the concentration of pediatric hearing care services and a limited number of trained Mongolian professionals in the capital combined with the vastness of the country and a sporadic population makes accessibility to services a challenging issue.

What is consistent across all countries is the need for the entire Continuum of Care to be in place for children with hearing loss. None of the elements that enable young deaf children to develop listening and spoken occur in a vacuum. It is not enough to implement hearing screening programs if no solutions are in place to address the needs of the children after they are identified. Fitting hearing aids or executing cochlear implant surgeries on young deaf children without considering local habilitation services (auditory-verbal therapy, early intervention) is not constructive. Habilitation services will not produce successful outcomes if the children are late identified or provided with insufficient hearing technology. Thus, it is so important that all the elements in the Continuum of Care are holistically considered during the development of pediatric hearing care programs. Services also need to be integrated into the health system and rolled out in a way that ensures the children are served at each stage of the process.

It has been an incredible journey with the Global Foundation For Children With Hearing Loss. I look forward to continuing our work with our partners so that more young children with hearing loss have the opportunity to listen, talk, and thrive, no matter where in the world they live.

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