Challenges to EHDI Systems Amid the COVID-19 Crisis

By Christine Yoshinaga-Itano, PhD

Birthing hospitals, universal newborn hearing screening/early hearing detection and intervention (UNHS/EHDI), and diagnostic audiology services across the United States are faced with ever-changing and escalating challenges due to the COVID-19 pandemic. Finding new ways to address these challenges is vital to ensuring continuous care for children who are deaf or hard of hearing (D/HH) and their families.

In some birthing hospitals, UNHS/EHDI and audiology services are proceeding as usual. However, even when some systems are operational, families may have concerns about taking their newborns outside of their homes and going to a hospital or clinic for outpatient screening or diagnostic audiology appointments. Counseling for parents at the time of referral for further diagnostics may need to be modified. Parents who express concerns about follow-up appointments during this crisis may need to be reassured. All professionals involved in UNHS/EHDI systems, of course, would like to follow up as soon as possible because the sooner hearing loss is diagnosed, the sooner the child can be fit with amplification (if this is the family's desire) and the family is referred to early intervention services, resulting in a higher probability of optimal outcomes. However, we've also seen good outcomes in children who are D/HH even prior to universal newborn hearing screening. For these families, the sooner they feel comfortable in following through with the child's hearing care, the better. Until that time, they should focus on enjoying the wonderful early days of bonding with their newborn, which lays the foundation for later communication development and socioemotional well-being.

Counseling parents and families can be tricky, particularly allaying their concerns so that they don't get overwhelmed with stress and anxiety. Impress upon parents and families the importance of early diagnosis because children's outcomes are best with earlier diagnosis and intervention. Assure them that there are effective habilitation and interventions for infants and children with pediatric hearing loss. Even if the diagnosis and intervention initiation are done later than in typical situations, such as at 6-9 months of age instead of 3 months of age, there is evidence that early intervention can still be highly successful. When UNHS began in the United States, the average age of identification of hearing loss was between

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6 and 9 months of age, and very positive outcomes were still achieved. What we have learned since then is that the likelihood of success increases the sooner the intervention is provided, even to children at the greatest risks.

In the United States alone, approximately 70 to 80 percent of women will experience postpartum depression (PPD) or baby blues. The reported rate of clinical PPD among new mothers is between 10-20 percent, with some experiencing more severe depression. PPD often occurs within a few months to a year after birth and lasts for more than six months among 25 to 50 percent of those affected. Fear of a disability diagnosis can exacerbate the likelihood of depression among mothers, especially when they are unable to get a definitive answer on time. With the COVID-19 pandemic, many families are also experiencing severe anxieties about housing and food insufficiencies, job losses, and economic insecurities. As a health care provider, make sure that you have contact information of mental health care workers who can provide support via telehealth.

FAMILY-TO-FAMILY SUPPORT. A critical element in the 1-3-6 EHDI system is family-to-family support. Family-based organizations (FBOs) across the country have supports in place for families.[1] As of this writing, FBOs have reported that they continue to provide virtual support for families, including group and one-to-one support and online activities for kids. Resources for families are available in English and Spanish on the Hands & Voices website.[2] Hearing care professionals should consider these messaging examples from family-to-family support providers:

- "You are not alone. Even if you can't meet face-to-face, there are ways to connect with other parents. I encourage you to do so."

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- "This is a season, not your entire journey. You will get through this."
- "You can use this time for planning your next steps so when you can get out, you can prioritize what you want to accomplish for your child and your family."
- "This experience is a marathon, not a sprint. You have time."
- "I know this is a very difficult time to wait. As a parent myself, I want you to know that this journey and your baby is going to be OK."
- "What is your vision for your child? Your child can be …"
- "If you have to wait on amplification, you don't have to wait for communication. There are many ways that families can expose their child to communication."

GUIDE BY YOUR SIDE SUPPORT. Twenty-seven U.S. states have a Guide By Your Side (GBYS) program through Hands & Voices, wherein parent leaders are trained to provide parent-to-parent support to families of children with hearing loss.[3] Some GBYS programs may also contact families that have already been referred but are still waiting for an appointment to help ease their anxiety.

ADDRESSING CONCERNS ABOUT NEWBORNS WHO MISSED UNHS/EHDI

If universal hearing screenings cannot be conducted, hearing care providers should keep accurate records of newborns who have missed a hearing screening and those who have been referred for additional testing to make sure that they are contacted as soon as services resume. EHDI programs may want to survey diagnostic evaluation facilities capable of conducting outpatient screening during the pandemic.

Provide early intervention contact to families of infants who have been referred for additional screening or diagnostic evaluation. Whenever possible, contact information for early intervention services should be given to families whose child was screened and referred but may be unable to get a diagnostic audiologic evaluation or an outpatient screening at this time. Early intervention for parents or families whose infant has been referred but not yet diagnosed may need a short-term change/adaptation in the typical system. In the event that parents and families experience elevated stress because of the referral and/or their inability to get a follow-up diagnostic evaluation, these families may need to be in contact with someone who can provide counseling and give them reassurance and tips that are good for all infants.

Emphasize the importance of maternal/parent bonding with their infant. Counsel parents and families about the importance of forming a strong emotional bond with their newborn. Some notable exchanges between parent and infant include reciprocal smile and vocalization, eye gaze (when culturally appropriate), giggles, and gestures. Positive touching such as hugging, rocking, and massaging are important ways to communicate. Singing and talking transmit tactile and vibrotactile information that infants will enjoy whether or not they hear spoken language. Recommend that parents sing to an infant while maintaining a head-to-head contact, e.g., while holding the infant. Various online resources offer helpful tips and videos.[4,5]

Explain how some children with hearing loss can hear sounds without amplification, but that what they hear is not sufficient to understand spoken language. Provide information about how children with hearing loss could hear someone speak but not necessarily understand. Some children may not hear enough to learn all sounds of the spoken language. Seeing an infant respond to sounds in their environments, such as dogs barking, doors shutting, vacuum cleaners, or even talking, may make the families less likely to follow up for outpatient screening and/or diagnostic audiological evaluations. Even when children respond to sounds, they can still have a significant hearing loss. Using a visual analogy might help in explaining this better to parents: People with vision problems may be able to see without glasses, but it may not be enough for them to see, identify, and differentiate letters in words so that they can learn to read or even differentiate similar objects from one another.

How Families Can Support Their Child who is Deaf or Hard of Hearing

- Engage in as much communication exchanges as possible through gestures, facial expressions, touch, spoken/visual language, and emotional exchange.
- Play with your infant/child. Play encourages language, cognitive, and emotional development.
- Focus on finding joy in interacting as a family.
- For spoken language, make every effort to keep amplification use all day long.
- Check out online resources for parents during the COVID-19 crisis including https://handsandvoices.org/covid-19.html.

ADDRESSING CONCERNS ABOUT TELE-INTERVENTION

What services can we continue to provide with stay-at-home orders? The good news is that early intervention services can be provided via tele-intervention—and we know that it works. Many early intervention providers have been conducting successful remote sessions for quite a few years via different available platforms. The provider and the family need to have internet access and a computer, smartphone, or iPad. Go online for a list of helpful resources on tele-intervention as well as state and professional organization responses to COVID-19 as it relates to EHDI/UNHS programs: https://bit.ly/2wXlZlO.

Is there a way to get ear molds replaced during this crisis? Families may be more comfortable going to private health care offices than hospitals—if these offices are still providing ear mold impression services. However, some of these clinics may also be closed during this crisis. While it is hoped that some businesses will be able to reopen at some point soon, this may not occur until rapid and reliable testing for COVID-19 is widely available. As such, concerning earmolds/repairs, encourage families to contact their audiologist who may be offering telepractice services. A request to build up the earmolds may be sent to the manufacturer. Some clinics have an audiologist on call (AOC), prioritizing families who

have children who are without sound, e.g., broken equipment, no earmold, etc.

What can be done for a child who can't wear a hearing aid because s/he has outgrown an earmold that is causing unavoidable feedback? Even when every effort is made to get well-fit earmolds, not all families have access to these audiology services. Parents and families should observe whether or not the inability to use amplification is causing stress on the child. During a child's development, there are times when he or she can concentrate on some areas of development but not on others. For example, communication development tends to slow down when the child is focusing on motor development such as crawling, standing, or walking. A short period without amplification is unlikely to cause any long-term harm. When children go through their independent period often called the terrible twos, they may fight significantly with their parents over wearing hearing aids, and the use of amplification may decrease during this period. Parents and families must strive hard to have their child wear amplification 10 hours per day. The sooner families can return to regular amplification use, the better.

Sign Language Learning. Children who can communicate via both spoken and visual language will have the least frustration when their hearing device is not available. However, many children communicate via a single language in a single modality. Now may be the time to begin to learn some sign language to keep communication between the parent/family and their infant/child, particularly if parents are noticing a high degree of frustration because of lack or reduced auditory input. Learning some sign language could be a fun activity for parents, families, and their infant/child. A significant number of children who are D/HH are bilingually fluent in either two spoken languages, two visual languages, or a spoken language and a visual language. The goal of UNHS/EHDI programs is to keep all doors open for these children. If hearing children can have access to learning another spoken language or sign language, then these same options should be available for children who are D/HH.

OTHER CONSIDERATIONS FOR PROVIDERS

This is an ideal time for early intervention providers to share relevant resources with families, such as cochlear implants, American Sign Language, listening and spoken language strategies, and strategies that can involve older siblings. They can share music and storytime resources that are not necessarily specific to children who are D/HH. Early intervention providers should also check in with families by phone. Families may be overwhelmed with many e-mails, and may just need a phone call. This might be needed to encourage families to try tele-intervention. Here are additional considerations:

Families may experience trauma during this pandemic. Some families may be at high risk of contracting COVID-19, such as those with family members working in health care, grocery stores, post offices, etc. Some may have family members who have become seriously ill—or have died—from COVID-19. Other families may find themselves unemployed, without health insurance, or with insufficient food and housing. For these families, basic needs will take precedence over obtaining services for their child who is D/HH. Early intervention providers should be familiar with community providers for families who are experiencing housing, food, or health issues, as well as referrals for mental health workers who can provide support for these families.

Families may be experiencing loneliness. Tele-intervention may just be the highlight in a family's week—particularly when family members know what to expect and do something familiar. Encourage families to reach out to other family members using video call applications such as FaceTime, Zoom, Skype, etc.

Families may be juggling many responsibilities because of this crisis. Many families are trying to navigate being at home all day every day. Some parents are expected to work from home and homeschool their children. Families may be dealing with various concerns such as contracting COVID-19, economic stresses, worries about grandparents who are typically the primary daycare providers of children, etc. They may not have the time and resources to devote exclusively to their child who is D/HH. During this time, parents and families may need to be reassured that the best thing that they can do is to take care of their family's basic needs and socio-emotional well-being. Children are incredibly resilient, and when things return to a more normal routine, they will too, as long as their family does as well.

Providers and families can get through the crisis together as we continue to learn the best and most effective ways to provide optimal services to families amid COVID-19.

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References for this article can be found at http://bit.ly/HJcurrent.