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## A CASE FOR DIRECT REFERRALS TO PARENT-TO-PARENT SUPPORT PROGRAMS FOR FAMILIES WITH CHILDREN WHO ARE DEAF/HARD OF HEARING

Programs offering local parent-to-parent support to families with children who are deaf and hard of hearing (D/HH) are most effective when they are able to reach all families, regardless of the family's ability to initiate contact. Direct referrals from Early Hearing Detection and Intervention (EHDI) programs and diagnosing audiologists in a timely manner ensures health equity by providing all families access to trained parent-to-parent support providers who offer resources, information, and emotional support. The following information provides guidance to EHDI system stakeholders including but not limited to; state/territory EHDI programs and family-led parent-to-parent support programs to increase the number of families who are offered parent-to-parent support including those from underrepresented populations. <sup>i</sup>

### ❖ WHY FAMILY-TO-FAMILY SUPPORT PROGRAMMING?<sup>ii</sup>

The opportunity for a family to meet another family early in the journey of raising a child who is D/HH through direct parent-to-parent support can have a profound impact for everyone involved. Raising a child who is D/HH is a delicate, complex and beautiful journey. There is something incredibly unique and important in receiving support from other parents and families who have children that are deaf or hard of hearing and have experiential knowledge of both raising/parenting a child who is deaf or hard of hearing and navigating the systems available to



support them. Parents with children who are deaf and hard of hearing (D/HH) often report feeling isolated from others sharing a similar experience. They also often report they lack the information, tools and resources to effectively support their child’s specific needs and desire more opportunity to build the leadership skills necessary to provide important feedback to the systems serving their child and family.

One proven strategy to address these issues is the development of formal parent-to-parent support designed to address the unique challenges and impact hearing loss has on the developing infant/child. Research supporting this practice state “Families rank family-to-family support as one of the most helpful forms of support for the family.”<sup>iii</sup> <sup>iv</sup> “Parents/families reporting participation in social networks with other parents/families of D/HH children had less isolation, greater acceptance of their child, and improved interactional responsiveness.”<sup>v</sup> Ensuring **all** families have the opportunity to meet with other trained parents and removing barriers that may interfere with those connections are critical components.

## ❖ OPTIONS TO PROVIDE DIRECT REFERRALS

EHDI systems and parent-to-parent support programs have several different options for how to provide families with a child newly identified as deaf or hard of hearing access to trained family support providers as early as possible. Families who must “opt in” or initiate contact to family support<sup>vi</sup> services must first recognize the benefits of family support before ever receiving it, as well as having no other barriers. **Optimally, an EHDI system is designed so families have as few barriers to getting family support services as possible, such as in an “opt out” arrangement where all families automatically are offered family support services unless a family actively declines.** Removing barriers increases health equity, continuity of care and better outcomes for children who are D/HH by assuring that all families are provided ample opportunity to get family-to-family support services. Direct referrals from the state/territory EHDI program to the Family-Based Organization (FBO) can aid in tracking/measuring/reporting that all families are offered the service. Direct referrals from a diagnosing audiologist to an FBO can potentially speed up the timing of the referral, helping families get connected sooner while emotional support is potentially most needed and critical decisions are being made. The following are examples of several strategies to achieve this end:

### ⇒ CONTRACTOR AS EXTENSION OF EHDI PROGRAM

A family-to-family support program that has a contract with an EHDI program may be considered an extension of the EHDI program and therefore provided access to family/child information to do outreach and follow-up services. In some cases, an integrated computer



based EHDI surveillance database can include parent support organization access to limited data.

⇒ **BUSINESS ASSOCIATE AGREEMENT/MEMORANDUM OF AGREEMENT (MOA)**

⇒ An EHDI program could designate an FBO as a “Business Associate” or an individual or entity that receives protected health information (PHI) from a covered entity, such as a medical practice, so that the business associate may perform services or functions, or assist in the performance of services or functions, on behalf of the covered entity. HIPAA mandates the covered entity, such as an audiology center, require a Business Associate (BA), in this case an FBO, to sign a Business Associate Agreement (BAA).<sup>vii</sup> A Memorandum of Agreement (MOA) establishes arrangements to share data between agencies and family-to-family support organizations.

⇒ **SIGNED PARENT CONSENT FORM**

Signed consent from the parent/caregiver permits protected health information (under HIPAA) or personally identifiable information under Part C privacy regulations to be shared with a parent-to-parent support organization. A FBO could create a consent form to be given to a parent to sign or an existing consent form used by audiology centers and EHDI programs could be updated to include the parent-to-parent support organization.

## ❖ TIPS WHEN ADVOCATING FOR DIRECT REFERRALS

Explaining the benefits and impact of direct referrals of all families to parent-to-parent support organizations can open communication and create opportunities to move towards making direct referrals possible. The following are some tips:

⇒ **Provide Data:** Collecting demographic information about the number and characteristics (including underrepresented populations<sup>viii</sup>) of families served by a parent-to-parent support organization under an “opt in” arrangement and then comparing that data to the numbers and characteristics of all children/families identified through EHDI programs can shed light on the disparities of who can be served by outreach efforts versus direct referrals.

⇒ **Share other successful models from other states/territories:** There are several states that have successfully implemented direct referral models that can be shown to be effective.<sup>ix</sup> Offering a ‘test’ through a quality improvement process (PDSA) may be effective in getting to an initial willingness for a program to establish direct referral model in a given state/territory.

⇒ **Establish the Validity of Family Support:** The 2013 Supplement to the Joint Commission on Infant Hearing (JCIH) Goal 9 recommends: “All Families Will Have Access to Other Families Who Have Children Who Are D/HH and Who Are Appropriately Trained to Provide Culturally and Linguistically Sensitive Support, Mentorship, and Guidance.” This establishes family-to-



family support as part of an EHDI system is best practice and ensures families, even those who are low resourced, have the equity in support.<sup>x</sup>

- ⇒ **Achieve Common Goals:** Family-to-Family support organizations can help EHDI programs achieve their goals by tackling important issues such as: increasing the number of families served by parent-to-parent support organizations (state/territory HRSA EHDI grant requirement), helping increase enrollment in early intervention by explaining benefits to families, assisting families in understanding follow-up services, or engaging families who are Spanish-speaking through support by a Spanish-speaking parent leader.<sup>xi</sup>
- ⇒ **Adhere to Privacy Laws:** Providing examples for how other states/territories have maintained patient privacy while ensuring continuity of care and referring to family support organizations can be helpful. Initial and annual privacy training for family support staff can provide structure and relieve fears.
- ⇒ **Emphasize the Focus:** Parent-to-parent support providers are uniquely equipped to help families feel emotionally supported, understand the benefits of taking next steps such as follow up care, considering use of technology, exploring communication opportunities and more. Assurance that parent support providers know their role, and when to refer families to others is helpful.
- ⇒ **Underscore the Importance of Unbiased Support:** Sharing details about initial and ongoing training in the art of providing unbiased support and offering data on the diverse information shared with families regarding the range of options chosen by families served can help demonstrate the family support program's commitment. Families without contact with a trained parent-to-parent support provider may not find or be encouraged to seek comprehensive accurate information.
- ⇒ **Provide a Network:** Families who are networked to trained parent leaders and to other families have access to more resources locally, regionally, and nationally.<sup>xii</sup> Better supported and resourced families are known to be indicative of families who have protective factors in place for the safety of their children, well-being and children who have better outcomes.<sup>xiii</sup>
- ⇒ **Highlight Resources:** Showcasing the many resources a family support organization has such as a packet of information for new families, parent educational trainings, resource directory or parent roadmap can bring awareness to the depths of information provided.
- ⇒ **Explain Advocacy:** Parents benefit from reassurance that they have the skills needed to be a strong advocate for their child. This confidence in effectively speaking up for their child becomes the foundation for providing critical input to improve EHDI systems. Having access to all families helps family support organizations build diverse parent leadership and engagement.
- ⇒ **Provide Testimonials:** Data from parent satisfaction surveys, quotes from families, and stories where family support made an impact are powerful and memorable.



- ⇒ **Reduce Time:** Efficiency of the referral process is important for busy professionals so creating ways to make referring a family as quick, easy and secure as possible is important. Decreasing the burden from professionals and parents having to remember to refer/self-refer is imperative.

## ❖ PRIVACY LAWS

Each EHDI program works within systems designed to assist children in getting the services they need, while ensuring protection for their personal health information. The following is a brief overview of the privacy laws in play.

- ⇒ **The Health Insurance Portability and Accountability Act of 1996 (HIPAA)** gives individuals rights over their health information, including the right to get a copy of their information, make sure it is correct and know who has seen it.<sup>xiv</sup> It also sets rules for “covered entities,” such as health care providers and health insurance companies, and provides clarification about who can look at and receive health information. In addition to “covered entities”, business associates of covered entities (such as contractors, subcontractors and outside persons and companies) may need access to health information when providing services to the covered entity. Covered entities must have contracts in place with business associates and business associates with subcontractors to safeguard information. While state agencies like Departments of Health may not be required to follow HIPAA Law, they are held to a high standard of privacy protection.<sup>xv</sup>
- ⇒ **The Family Educational Rights and Privacy Act of 1974 (FERPA)** is a law protecting a student’s education records. Education agencies and programs receiving funding from the US Department of Education must follow rules about the access to and sharing of educational and health information.
- ⇒ **Part C of the Individuals with Disabilities Education Act (IDEA)**, the U.S. Department of Education provides funds to a lead agency to establish a state-wide system of early intervention services for children with disabilities. Part C regulations states that anyone who suspects that a child under the age of three who may have or be at-risk for a disability is obligated to refer the child to Part C as part of the Child Find provisions of Part C regulations. Once a child is referred, a “participating agency” must obtain signed consent before disclosing personal information about a child or their family.

For more information about HIPAA, FERPA and IDEA Part C Privacy Regulations and the impact on EHDI systems, contact your local EHDI program. Resources are available to better understand the impact of these laws on the relationships with family support organizations.<sup>xvi</sup>



## ❖ CONCLUSION

Family-to-family support is recognized as an essential component of the EHDI system<sup>xvii</sup>. Every family deserves the opportunity for this connection. Ensuring the path to this opportunity is incumbent upon all EHDI stakeholders in the most effective and equitable way possible.

While privacy laws are a necessary and important component of EHDI systems of care, they are not meant to be a roadblock to equitably providing families with the services they need. EHDI programs and family support organizations can work collaboratively to determine the most appropriate strategies to ensure all families and children have access to trained family support providers.

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<sup>i</sup> Disclaimer: This document is for informational purposes only. Hands & Voices HQ does not provide legal advice and advises seeking legal counsel as needed.

<sup>ii</sup> HRSA definition of family-to-family support: “‘family-to-family support program’ consists of services and supports provided in response to the needs of a given family through a family-led organization or program. Types of support and services provided will be based on the capacity of the family-led organization or program and may include but are not limited to: direct parent-to-parent support, information, education, technical assistance, training, and referral.”

<sup>iii</sup> Jackson CW. Family involvement in early intervention for children who are deaf or hard of hearing. *Early Childhood Services*. 2009;3(1):77–97

<sup>iv</sup> Jackson CW, Wegner JR, Turnbull AP. Family quality of life following early identification of deafness. *Lang Speech Hear Serv Sch*. 2010;41(2):194–205

<sup>v</sup> Hintermair M. Hearing impairment, social networks, and coping: the need for families with hearing-impaired children to relate to other parents and to hearing-impaired adults. *Am Ann Deaf*. 2000;145:41–53

<sup>vi</sup> HRSA states, “Family support is defined as ‘the practices that ensure that the holistic nature of the process for families is sustained through the timelines, policies, and procedures by the varying entities that the family encounters through hearing screening, diagnosis, EI, and beyond.’ Family support should come from professionals, other families who have children who are DHH, adults who are DHH, and current, up-to-date evidence-based information and resources.”

<sup>vii</sup> <https://www.hippa.com/>



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<sup>viii</sup> HRSA defines underrepresented populations as: “underrepresented populations” is intended to be inclusive of but is not limited to: underrepresented racial and ethnic groups (i.e., Hispanic or Latino, American Indian or Alaskan Native, Asian, Black or African-American, Native Hawaiian or Pacific Islander, two or more races (OMB), nationality, language, locality, sex, sexual orientation, gender identity, disability, socio-economic status, and those who have adopted children who are DHH, etc.

<https://www.hrsa.gov/grants/find-funding/hrsa-20-051>, Notice of Funding Opportunity (page 7)

<sup>ix</sup> <https://handsandvoices.org/fl3/resources/comms-read-articles.html>

<sup>x</sup> <https://pediatrics.aappublications.org/content/131/4/e1324>

<sup>xi</sup> <http://improveehdi.org/mn/library/files/2015ehdiannualreport.pdf> (Pages 11 and 14)

<sup>xii</sup> [https://pubs.asha.org/doi/10.1044/2014\\_AJA-14-0029](https://pubs.asha.org/doi/10.1044/2014_AJA-14-0029)

<sup>xiii</sup> <https://www.americanmentalwellness.org/prevention/risk-and-protective-factors/>

<sup>xiv</sup> [https://www.hhs.gov/sites/default/files/ocr/privacy/hipaa/understanding/consumers/consumer\\_rights.pdf](https://www.hhs.gov/sites/default/files/ocr/privacy/hipaa/understanding/consumers/consumer_rights.pdf)

<sup>xv</sup> <https://www.hhs.gov/hipaa/for-individuals/guidance-materials-for-consumers/index.html>

<sup>xvi</sup> <http://www.infanthearing.org/privacy/docs/PrivacyWhitePaper.pdf>

<sup>xvii</sup> JCIH EI Recommendations - Goal 8,

<https://pediatrics.aappublications.org/content/pediatrics/early/2013/03/18/peds.2013-0008.full.pdf>