



# **A Community of Support**

**CONNECTING FAMILIES  
OF CHILDREN WHO  
ARE DEAF OR HARD OF  
HEARING PLUS (DHH  
PLUS) WITH RESOURCES  
AND SUPPORT**

**2021**

Developed by the Early  
Hearing Detection &  
Intervention Parent to  
Parent Committee



# A COMMUNITY OF SUPPORT:

## CONNECTING YOUR FAMILY WITH A CHILD WHO IS DEAF OR HARD OF HEARING PLUS (DHH PLUS) WITH RESOURCES AND SUPPORT

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Language is always in flux when used to “categorize” people for purposes of discussion and services, but for ease and clarity of communication, a term was chosen for this document’s focus.

**DHH Plus:** For the purposes of this document, this term refers to children who experience any type of deafness and additional considerations adding to complexities in support and services for the whole child. Those additional considerations may be medical, developmental, sensory, cognitive, physical and/or social-emotional in nature. DHH Plus is meant to indicate the child’s unique needs and the expanded team, including the parents, necessary for positive future development. Other designations/terms we want to acknowledge are Deaf Disabled, Deaf/hard of hearing Disabled, Deaf Plus, Deaf/hard of hearing Plus, deaf with disabilities, DeafBlind and others.

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## About this Guide

This Guide was developed by the Early Hearing Detection and Intervention (EHDI) Parent to Parent Committee, which is an interdisciplinary, inter-agency/ inter-organizational and diverse parent/ professional group.

This committee is open to anyone who is interested – professionals, parents, DHH adults. For more information contact Janet DesGeorges, Co-chair for this committee:  
[janet@handsandvoices.org](mailto:janet@handsandvoices.org)

### *“What are the keys to unlocking our DHH Plus child’s full potential?”*

For families who have children who are DHH Plus, supporting our child’s ability to reach their individual potential is at the heart of the issue in the journey of raising a child who is DHH Plus. Approximately 35-40% ([Gallaudet Research Institute, 2011](#)) of children who are DHH also have additional/other needs. The combined effect of hearing loss and additional needs presents a unique and complex challenge to professionals and parents. Additionally, a review of the literature provides little specific information on successful educational strategies and programs for our children. We know that the most important factors in a student’s success is parent involvement, early identification, and appropriate, individualized supports.

As one parent put it, *“DHH Plus is meant to be a positive term, not in any way negative or insensitive to the child who has medical issues along with hearing loss. In fact, I see it as an ‘A+’ or ‘B+,’ meaning the child carries additional positive qualities. It is a gift that needs to be carefully unwrapped and it may not appear to be a gift when you first receive it. Time helps you appreciate, understand, and unfold the possibilities. and the ‘Plus’ most often means the child and family have added responsibilities and require additional expertise.”* – Candace Lindow-Davies.

With these questions and considerations in mind, this guide for parents was developed by the Early Hearing Detection and Intervention (EHDI) Parent to Parent Committee, who are parents of children who are deaf or hard of hearing and DHH Plus, as well as a diverse group of professionals who support our families in early intervention and beyond. We hope that you find this information helpful in your journey.

*“It’s very important to keep positive people in your circle and people that have already been down the road you are traveling. Demonstrate what your child CAN do rather than letting people tell you what they CAN’T do so assumptions are not made about your child without asking first!”*

- Anonymous

## The Purpose:

- To ensure your family knows how, where, and why to access expertise, resources and information for your child who is DHH Plus.
- To share information about the benefits and availability of connections to other families and adults who are DHH Plus, so you know you are not alone.
- To assert your right to have high expectations for your child.

## Terminology:

### Acronyms and terms you will see in this document:

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|---|--|
| • AAC - Augmentative & Alternative Communication  | • EI – Early Intervention                      |
| • ADA- American Disabilities Act                  | • FAPE – Free Appropriate Public Education     |
| • ASL – American Sign Language                    | • IDEA - Individual Disabilities Education Act |
| • AUD - Audiologist                               | • IEP – Individualized Education Program       |
| • CMV - Cytomegalovirus                           | • IFSP – Individualized Family Service Plan    |
| • DHH – Deaf or Hard of Hearing                   | • LRE – Least Restrictive Environment          |
| • DB - DeafBlind                                  | • SLP – Speech Language Pathologist            |
| • DHH Plus – Deaf/Hard of Hearing Plus            | • TOD – Teacher of the Deaf                    |
| • EHDI – Early Hearing Detection and Intervention |  |

## How to use this Guide:

### There are seven topics in this Guide:

- Topic 1: Identify and Prioritize Needs
- Topic 2: Language Development
- Topic 3: Who is on our Team? Benefit from Different Specialists for Different Needs
- Topic 4: Family to Family Support and DHH Individuals to Family Support
- Topic 5: Social-Emotional Development and Identity
- Topic 6: Parent Self-Care
- Topic 7: Educational Advocacy

### For each of the seven topic areas you will find three areas to explore:

- **What this means to me:** Brief outline of what the topic means to families (global description of topic).
- **Things to think about:** Ideas and concepts that your family might want to consider.
- **Where can I learn more:** Interacting with others, resources, and suggested supports.

Let's look at each topic in this guide to see what it means for children and families.

## TOPIC 1: IDENTIFY AND PRIORITIZE NEEDS

*“It can be hard to get news of another issue. I try to focus on a child’s strengths and also build a path forward together. I have heard one parent say they didn’t view a diagnosis as a label but rather a handle. It opened more doors that ultimately supported their child to make more developmental progress.”*

- Dr. Susan Wiley

### What this means to me:

Families with children who are DHH Plus often have many competing priorities on a daily basis. For each family, prioritizing needs is an individualized experience. Families are in the best position to identify their own needs. Families may encounter situations in which they must reprioritize their child’s needs and some needs may take immediate precedence over other needs. While there are things other families might take for granted in their everyday lives, for children who are DHH Plus, there is an even greater degree of appreciation. Families with DHH Plus juggle multiple tasks daily, attending several challenges at once. This may be overwhelming. The ability to reprioritize, as needed, will result in your empowerment as a parent. You as the parent have the most information about your child’s current needs and are encouraged to communicate those needs to your child’s providers to assist in any decisions and/or extra steps that need to be taken.

### Things to think about:

- Supports that you seek should be meaningful to you based on your own needs, experiences, and on the needs you see in individual family members and your family as a whole.
- Prioritizing your needs means having your attention on the right things at the right time.
- Adapting and changing is part of the process and is okay.
- Write down/identify your current needs for both the short term and the future/long range.
- You have the right to ask/challenge the resources/providers when the team’s priorities differ from your family’s priorities.
- The day to day lives for families can be complicated. What is typical for other kids in everyday tasks may not be as simple. At the end of the day, you are doing the best that you can and adapting.

## Where can I learn more:

[Charting the Life Course](#) offers foundational tools for person centered planning - what is working, what is not working, and what goals you/your child may have.

[The Trajectory Planning Tool](#) highlights the past life experiences that are leading or moving you away from your vision and then provides space for current goals and things to avoid moving forward.

## TOPIC 2: LANGUAGE DEVELOPMENT

*"Observe me. I don't always communicate clearly, but I know what I like and dislike."*

– Malik Morris, Deaf Plus Young Adult

## What this means to me:

What is language? Language is the words that a child understands and uses, as well as how words are put together to express thoughts. All people are born ready to communicate, and language is expressed through communication. For most parents, language development is our biggest worry about our deaf or hard of hearing child. How will our child communicate ideas back and forth, or express and understand feelings? Language development also supports thinking and problem-solving, and developing and maintaining relationships. Learning to understand, use and enjoy language is a critical first step in literacy, and the basis for learning to read and write. For our DHH Plus children, communication may look different, but is just as, if not more, important. Communication is the exchange of a message between two or more people. For our children who are DHH Plus to reach their language potential, extra effort may be necessary to ensure our child has access to a variety of communication strategies that fit our child's unique receptive and expressive needs in a rich and accessible language environment.

## Things to think about:

- Assessment(s) of your child's strengths, which may include hearing level, visual acuity, physical abilities, cognition, sensory issues, attention, stamina, and more, should be considered.
- The expressive (communicating thoughts) and receptive (understanding information) language needs may differ and/or rely on different communication systems while in different environments.

- There are different levels of communication behaviors (pre-symbolic, concrete, and abstract), that can help you understand where your child is in their development.
- Maximizing your child's language foundation creates insight into their abilities in other developmental areas, including behavior and their future potential.
- Modifications to language development milestones, implementation, and adaptation may be needed.
- A child's development and needs change over time, expressive or receptive preferences may change, as well.

## Where can I learn more:

- [Language and Literacy Tip Sheets for Families](#)
- [Communication Matrix: Especially for Parents](#) (adapted from the original Communication Matrix created for professionals)
- [Communication Considerations for Deaf Plus](#)
- [Communication Basics for Families](#)
- [Open Hands Open Access Modules](#)
- [Speech and Language Developmental Milestones](#)
- [Your Baby's Hearing and Communicative Development Checklist](#)

## TOPIC 3: WHO IS ON OUR TEAM? BENEFIT FROM DIFFERENT SPECIALISTS FOR DIFFERENT NEEDS

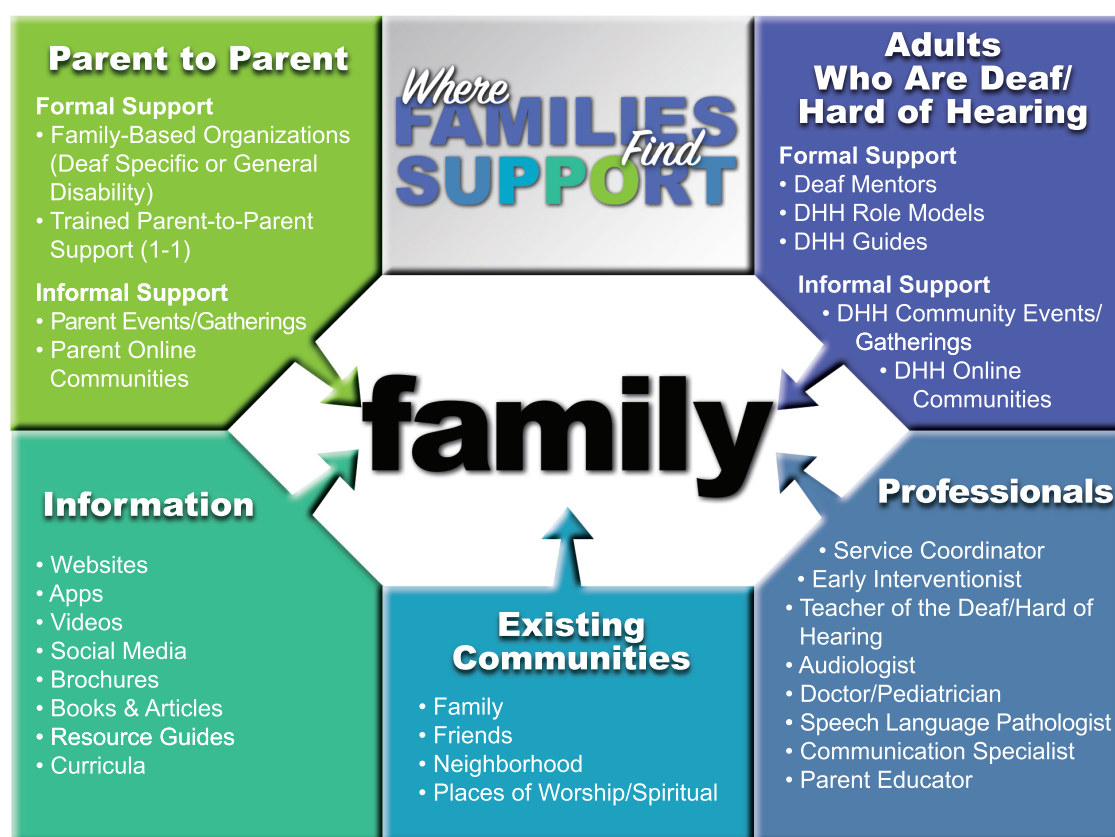
*"After years of trying different team members, I feel more confident in seeing who has the personality and vision for my kiddo- saying yes to them and no to those that might not have that vision. I feel like starting with the right people means everything!"*

— Parent

## What this means to me:

It is important for parents to recognize areas where team members are qualified/proficient and areas where additional outside expertise is needed. Having a diverse team of professionals (including DHH adults) who communicate effectively, allows your child to be supported better overall. Each provider interprets your child through their specialty to

offer varying explanations and recommendations to benefit your child. According to the Individual Disabilities Education Act (IDEA), you as the parent are considered an integral part of the team to meaningfully participate and contribute your expertise on your child. Your child who is DHH Plus may have complex needs and could benefit from the expertise of a variety of team members specially trained and experienced in the additional health needs of your child, such as: Experts in physical needs (Occupational and Physical Therapy or Adapted Physical Education), Early Interventionists (Teachers of the Deaf and Hard of Hearing, Teachers of the DeafBlind and Interveners for the DeafBlind, Audiologists, SLP, ASL Specialists), Medical professionals (Gastroenterologist, Cardiologist, Otolaryngologist, etc.) , Psychologists and Social Workers, Applied Behavior Analyst, State DeafBlind Project staff, Diagnosis-specific support organizations.



## Things to think about:

- Appropriate assessments, progress monitoring, and qualified evaluators who are experienced in your child's needs.
- Support sought from a variety of places/people, including professionals, other parents, DHH Adults (also including Adults who are DHH Plus, as much as possible).



- You can advocate for resources/providers who have appropriate qualifications to provide services and have the right to request the credentials of the service provider.
- You can advocate for continued consultations between providers and educators and administrators even if direct services are no longer required. Example: OT/PT consults for programming that may involve need for safety precautions, etc.
- Parents, being knowledgeable about their child, should feel confident when encouraging the team to presume competence and maintain high expectations for the child, particularly complex children.
- Team should foster opportunities for independence for your child as soon as and whenever possible.
- Team members, staff members and administrators whom your child will meet would benefit from in-service trainings from experts such as DHH educators or Deafblind professionals, to explain additional needs, considerations, including cultural considerations, communication, and advice.
- Parents are an equal participant on any team related to their child. Ex: IFSP, IEP, medical, regional centers, Vocational Rehabilitation (VR).
- Your child is the central member of the team, and over time as your child develops/grows, their participation is vital.
- Teams should recognize that ADA requires an interpreter or other communication accommodation be provided for any DHH adult on the team who is appearing at a meeting or appointment as a companion of the parent and/or child.
- Skilled providers with expertise in childhood hearing are critical to maximizing your child's success. Specialty providers in other areas of need may also be necessary (mobility specialists, vision, system navigators [insurance/waivers]). Sometimes, parents may have to advocate for the inclusion of these providers on the interdisciplinary team. Services should always be a coordinated and collaborative effort.

## **Where can I learn more:**

- [Make-up of the IEP team](#)
- [NAD Advocacy letters](#)
- [Local advocacy and support groups for families with children who are Deaf/Hard of Hearing Plus](#)
- [NCDB Practice Guide: Appropriate Assessment Strategies](#)
- [Children who are Deaf/Hard of Hearing Plus](#)
- [Scope of Practice in Audiology](#)
- [Roles of Educational Audiologists and TODs](#)

## TOPIC 4: FAMILY TO FAMILY SUPPORT AND DHH INDIVIDUALS TO FAMILY SUPPORT

*“We love the connection to other families who have been down that road - we would be so hopeless without the bravery of other families sharing their journey.”*

– Parent

*“I’d be lost without the Deaf/HH adults in my life...grandparents and other special needs parents too. I look for people who are further along on their journey, stop them and ask, ‘Can I ask you a few questions?’”*

– Parent

### What this means to me:

The opportunity to connect with other families whose child/children share a similar diagnosis or experience can make a huge impact on families with children who are DHH Plus. Parent-to-parent support especially in the early years, can help new families, 90% of which are hearing parents, understand their child’s medical, emotional, communication and social needs. The knowledge that approximately 40% of DHH children have additional health challenges can be comforting and reduce the sense of isolation for parents, realizing they are by no means a rarity within the larger DHH community. DHH adult mentors/role models, especially those who are also DHH Plus, provide parents the opportunity to see that their DHH Plus child’s life is filled with possibilities and successes. Parent support groups are available in every state/territory to educate and connect parents around topics related to raising a DHH/DHH Plus child.

### Things to think about:

- **Family-to-Family Support**
  - » Connecting with other families who have DHH/DHH Plus children can provide a safe place to express feelings, find emotional support, share similar challenges, locate resources, see diverse models of success, and gain access to a strong network.
  - » Linking parents and children with similar healthcare needs, cultural backgrounds and linguistic (home language) similarities can be beneficial.
  - » Experienced parents have real-world working knowledge of resources within the

medical, educational, and social network.

- » The family-to-family support you receive should be of a high standard (i.e., parents who provide support to other parents are trained/prepared/equipped, know the resources available, and can provide their own stories in an unbiased manner). There are guidelines/standards available.
  - » Ask your providers about where you can find opportunities to connect with a family support organization or other families.
  - » Explore organizations that provide family-to-family support, resources, and opportunities to connect with other families.
  - » Explore social media platforms for groups that provide family to family support.
- **DHH/DHH Plus Individuals to Family Support**
    - » Search out DHH/DHH Plus individuals with diverse backgrounds, experiences, cultures, languages, and communication modes/methods who are positive and trained/prepared/equipped role models. Such interactions may also provide a comforting sneak preview into the future of your child. Find these DHH adult programs through the School for the Deaf, Early Intervention programs, Deaf Organizations, Parent Support Organizations etc.
    - » DHH/DHH Plus Individuals have lived experiences to recognize DHH Plus children's needs for community, for acceptance and self-expression.
    - » Access to diverse supports and resources within the medical, educational, and social network.

## Where can I learn more:

- [State Deaf-Blind Project Contact List](#) (state specific)
- [For Families Page](#) (National Center on Deaf-Blindness)
- Facebook/social media parent groups
- Diagnosis-specific support organizations (some examples below)
  - » [National Family Association for Deaf-Blind](#)
  - » [Charge Syndrome Foundation](#)
  - » [Usher Syndrome Coalition](#)
  - » [Global Foundation for Peroxisomal Disorders](#)
  - » [Ear Community Microtia/Atresia](#)
- [Family-to-Family Support Guidelines](#)
- [JCIH Early Intervention Guidelines](#)

- [Early Hearing Detection & Intervention programs](#) (state specific)
- [Schools for the Deaf](#) (state specific)
- Family Based Organizations (some examples below)
  - » [Hands & Voices](#) (look for specific state chapters)
  - » [American Society for Deaf Children](#)
  - » [A.G. Bell](#) (look for specific state chapters)
  - » [Family Voices](#)
  - » [Parent to Parent USA](#) (general disabilities group but 38 state orgs)
- [National Cued Speech Association](#)
- [National Center for Hearing Assessment and Management](#) (NCHAM)
- [NCHAM Database of DHH Adult Programs](#)

## TOPIC 5: SOCIAL-EMOTIONAL DEVELOPMENT AND IDENTITY

*“We were blessed to live in an area with a strong vibrant deaf/hard of hearing community & the gift of a dear DHH neighbor who informally mentored us. This served our daughter well as she grew & developed her DHH identity.”*

- Parent

### What this means to me:

Social and emotional development is the process by which children start to understand who they are, what they are feeling and what to expect when interacting with others. A child's social-emotional development sets the foundation for relationships with others and is important for creating a positive sense of self-identity. Making sure that your child feels included in the family and accepted for who they are, no matter their unique characteristics, will get them started on the right path to a healthy social-emotional development and later, a strong sense of self-identity. When a child who is DHH has additional challenges, it's important to address the impact this can have on a child's growth and development, including self-identity and community. There is much diversity in children who are DHH Plus, and the possible ways they may identify also can vary from a strong connection to Deaf Community and Culture and/or to an identity as a person who benefits from hearing

aids or cochlear implants. Acceptance and community can take extra work for the child who is DHH Plus. Attachment is built through recognizing the child's attempts at engaging, and family members reinforcing and reciprocating eye contact, facial expression, touch, and movement to match their child is the basis for language. (Adapted from [https://pediatrics.aappublications.org/content/146/Supplement\\_3/S246](https://pediatrics.aappublications.org/content/146/Supplement_3/S246) on attachment.)

## Things to think about:

Recognize your role in your child's wellbeing. Communication or the lack of it can be a barrier to natural bonding and access to caring adults. Model using language to describe your feelings and those of your child. Build your child's vocabulary of words/signs/cues for emotions.

Among exploration of communication through listening and spoken language, cued speech and American Sign Language, parents can benefit from exploration and knowledge of Deaf Culture viewed as a separate culture and not a disability, including its shared history, shared values, and shared customs; Deaf Community - athletics/social/political organizations; Deaf identity. This can lead to the development of a wholistic view of deafness beyond a medical model of deafness as a 'condition'.

When applicable, explore AAC (Augmentative & Alternative Communication) and how it provides a way for the child to express and understand their feelings and emotions.

Discuss social-emotional development and factors that may impede it with your child's provider and in the IFSP and IEP process: attachment, empathy, and friendships. (Hartshorne & Scmittel, 2016)

Parents can broaden their understanding of a positive sense of deafness through meaningful interactions with adult mentors and other families with children who are DHH Plus. When DHH Plus adults and peers are not available, it may be beneficial to expand the search to individuals and families who share your child's health challenges, even if they are not deaf or hard of hearing.

Allow your child to reach their full potential by creating environments that support your child's social-emotional wellbeing.

Ensure children feel safe and respected. Respond to emotional states with understanding and calmness.

Consider the benefits of Including visual, auditory, and tactile charts and rewards at home and school.

## Where can I learn more:

- [VL2: Raising the Whole Child: Social Emotional Development in Deaf Children](#)
- [Secrets for Deaf & Hearing Sibling Success: Giving Them an Early Start for a Lifetime Together](#)

- [Pragmatics in Deaf and Hard of Hearing Children](#)
- [National Deaf Children's Society- "Families" Magazine](#)
- [A Place at the Table](#)
- [Table of co-existing conditions](#)
- [Trust and High-Quality Interactions](#)

## TOPIC 6: PARENT SELF-CARE

*"Making sure to remember the things I'm grateful for.... plenty of challenges come to mind everyday.... pushing the thought of 'what is great about him' a bit everyday changes my mood."*

- Parent

### What this means to me:

Parenting a child who is DHH Plus is a very individualized journey as no two children have the same strengths and challenges. Because of this, it may be natural to feel isolated even among family and friends. Sometimes the added responsibilities and demands on your time and resources can become overwhelming and it can become easy to lose oneself in the process. *"Among families with deaf or hard of hearing children, taking care of the special needs of family members and having insufficient relief from stress were rated as having the greatest negative impact on Family Quality of Life."* (Jackson, Wegner & Turnbull, 2010). Without taking care of yourself, it is hard to take care of your child and family. Taking the time to rejuvenate, recover from stressors, revitalize your energy, and invest in your relationships are all acts of self-care. Self-care is not selfish. It is the foundation on which you can build the strength and resiliency to navigate systems, learn new information, and think of creative strategies to help your child flourish. A strong healthy parent can model and foster the development of a strong healthy child.

### Things to think about:

- Build a network of respite care whether it be a formal program through your county/ local area or an informal babysitting swap with friends with those who have the necessary skills or training to care for your child. Bring family to medical appointments to help train and educate them.
- Create time to prioritize and nurture relationships such as a spouse/significant other, other children, friendships.

- Set up rituals that revive: yoga, meditation, massage, long walks, reading, conversations with a friend, hobbies, exercise, a gratitude practice, journaling, organizing/cleaning, baths, essential oils, favorite cup of tea.
- Carve out time for fun and create joy moments throughout your day.
- Connect virtually or in-person with other families who have children who have special needs or are DHH Plus.
- Be comfortable seeking professional help or therapy, especially with those who have experience with parents raising children with health challenges.
- Take time to just be alone. To do nothing. Sleep. Or just allow yourself to feel all the feelings that are weighing on you. And then make the decision to let them go and move on.

## Where can I learn more:

- [Hands & Voices DHH Plus Parent Group](#)
- [Hands & Voices Fostering Joy Parent Group](#)
- [Hands & Voices Fostering Joy Home Page](#)
- [Information/Funding for Respite Care](#)
- [Hands & Voices articles on DHH Plus](#)
- [Hands & Voices FL3 Parent Tip Sheet on Social Emotional Development](#)
- [Self-Care for Parents — PEPS](#)
- [“Why Self-Care Is Essential to Parenting”](#)
- [For Better or For Worse: Keeping Relationships Strong while Parenting Deaf and Hard-of-Hearing Children](#)
- [Self-Care in the For Families Section of the NCDB Website](#)

## TOPIC 7: EDUCATIONAL ADVOCACY

*“I wish I had asked for the professionals I wanted – I wish I had the advocacy skills and assertiveness to do this sooner.”*

- Parent

## What this means to me:

As soon as your child is born, education begins. They are learning about the world around them and how to communicate. The first and most important educator is you -- the parent/caregiver. You are your child's best teacher from day one! For children who are DHH Plus,

additional support is often needed to gain knowledge specific to your child's needs. Build your team with expertise that will be most helpful to you. Whether your child is in Early Intervention (EI), transitioning to preschool, or receiving school-based services, advocacy is critical.

Early Intervention sets the stage for your child's future education. You will learn to advocate, which means speaking up on behalf of your child and their needs. You will grow into this role for your DHH Plus child by asking questions, reminding the team about critical issues, and inspiring your interdisciplinary team to reach for what is possible throughout all steps of the child's educational journey. You speak up when your child cannot. The parent/caregiver's voice, input, and collaboration are critical throughout all steps of the child's educational journey and is key to the child's success.

## Things to think about:

- Advocacy for our children is complex. Finding the unique solutions for the combination of the individual needs and strengths of your child is vital.
- Creating an education plan for your child and their many needs often requires additional time and may include many team members. Longer and more frequent team meetings may be needed to understand how your child's hearing, communication and special health issues interact and require creative strategies. Here is one parent's story of her first IFSP meeting with her child's team. [https://handsandvoices.org/articles/deafhh-plus/v23-4\\_living-inside.html](https://handsandvoices.org/articles/deafhh-plus/v23-4_living-inside.html)
- **Careful assessment and ongoing progress monitoring** build a strong education plan. Considerations include language and communication needs and your child's and family's preferred mode(s) of communication, linguistic needs, hearing level, academic level, social, emotional, and cultural needs, curriculum content and method of delivery.
- If your child was late-identified with hearing loss, your existing team will want to thoughtfully integrate expertise around deafness and language learning to address gaps.
- **Transition from EI to Preschool:** You will want to educate yourself about the timeline that begins six months before your child turns three. Including the expertise of all the providers to date is key to developing a solid Individualized Education Program (IEP) moving forward into preschool. Your EI team can proactively work with you to identify or create programs that will support your child when they begin preschool. In addition to school-based programs, some families choose to access private therapy/services as a bridge to help with transition. Introducing your child by video, in-person, and/or through a packet, can positively kick off this long-term relationship.
- Your child's "**Least Restrictive Environment**" (LRE), a special education legal term, exists along a continuum of program and service options. Under the IDEA, the more separated a child is from peers who are typically developing, the more restrictive the placement is considered as the starting point for discussions. For DHH Plus students, LRE may *not* be the general education placement, where a child may need better access to language models, peers, specialists, and the curriculum. Consider what will be the "language rich



environment” based on Special Considerations in the IDEA. The perfect placement does not exist; however, with effort a great fit can be created!

- **Definitions** within Individuals with Disabilities Education Act (IDEA)
  - » **FAPE:** Free and Appropriate Public Education, a right listed in the IDEA.
  - » **IFSP:** The Individualized Family Service Plan documents the family’s goals, priorities and services for their child and is updated every six months until age three. Families can request an IFSP update at any time and are critical members of the team.
  - » **IEP:** An Individualized Educational Program designed with a team of educators, including the parents and the child, from preschool through graduation including transition services. A child must be found eligible for an IEP through a qualifying disability and a need for specialized instruction. Your child’s right to specialized instruction is protected under an IEP, and parents can ask for an IEP review at any time.
  - » A **504 Plan**, often a list of accommodations, is developed for a child to ensure access to the learning environment. For example, one accommodation might be doing a listening check for hearing aids each day. A 504 Plan does not provide for specialized instruction.
  - » Private evaluations must be considered. If the school-based assessments given do not seem to paint a picture of your child’s needs, parents can also ask for an **Independent Educational Evaluation**. (During the IFSP, parents can continue to ask for assessments during the process.)
  - » **Parent input statement:** a statement crafted by parents to assist them in providing input into the IFSP or IEP about the child’s needs, strengths, and goals. These statements can be a powerful strategy to ensure parent input is included.
  - » **The IDEA Special Considerations** offers additional supports to students who are deaf/hard of hearing including opportunities to communicate directly with peers and educators, exposure to role models, access to all curricula including extracurricular programs, and ensuring qualified staff and instruction for staff. Some states have passed further legislation to increase these supports in Communication Plans.

## Where can I learn more:

- Educational Advocacy support is available through parent support organizations like [Hands & Voices](#), your state [Parent Information and Training Center](#).
- Special education law and advocacy Information:
  - » [Wrightslaw](#)
  - » [Educational Advocacy Tools and Strategies designed by parents for parents of children who are DHH](#)
- [Transition to Preschool: \(CO Sample\)](#)
- [IEP/504 Checklist \(accommodations\)](#)

- [“Children with Hearing Loss Need an Educational Audiologist on their Education Team”](#)
- [Teachers of the Deaf/hard of hearing provide specialized instruction as part of an IEP](#)
- [U.S. Department of Education’s Office for Civil Rights \(OCR\)](#) or contact OCR at (800) 421-3481 (TDD: 800-877-8339) or at [ocr@ed.gov](mailto:ocr@ed.gov).
- [U.S. Department of Justice’s Civil Rights Division](#) or contact DOJ at (877) 292-3804 or at [education@usdoj.gov](mailto:education@usdoj.gov).
- [Special Considerations / Communication Plans for NASDSE](#)
- [The Basics of Special Education Law, from Disability Law Center](#)
- [NCDB - Transition from Early Intervention to Preschool](#)

## Conclusion:

There is a large community of parents and professionals who can support your journey. We hope this guide has given you some ideas, resources, and reassurance as you and your child journey together. Most of all, we want you to know that you are not alone. Please feel free to reach out to our committee for more information and for any questions at: [parentadvocate@handsandvoices.org](mailto:parentadvocate@handsandvoices.org)

*“I felt supported once I found Hands & Voices in Vermont and New Hampshire. My initial meeting was at a farm in Colchester, VT and I knew I would be able to ask questions about my son. I was so emotional and needed a group who understood what our family was going through. I love that the program is now expanding to create a document to help children and families who are DeafPlus and experiencing DeafBlindness. These pages will give families new ways to navigate the Deaf and Hard of Hearing resources and the medical system. An amazing organization with amazing people!” - Beth Greeno*