

Parent Support for Deaf/Hard of Hearing Plus Children

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and

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congenital Cytomegalovirus (cCMV)

Bilateral profound sensorineural hearing loss

Bilateral cochlear implants

G-tube

NPO

Complete oral aversion

Optic nerve hypoplasia

Hyperekplexia

Deviated Septum

Spastic quadraplegic cerebral palsy

Brain malformation due to congenital CMV

GERD

Microcephaly

Global developmental delay

Seizures



THIS IS **US**

34 week preemie

congenital Cytomegalovirus (cCMV)

Bilateral profound sensorineural hearing loss

Bilateral cochlear implants

Vestibular Dysfunction

Cysts on his brain

Childhood Apraxia of Speech

Vision Loss

Type One Diabetes




THIS IS **US**

What is D/HH Plus?

40 to 60% of D/HH population is estimated to have additional health challenges that may include:

- Intellectual/cognitive processing
- Emotional, mental health and behavioral functioning
- Learning
- ADD/ADHD
- Down Syndrome
- Vision loss or blindness
- Cerebral palsy, orthopedic involvement or other physical challenges
- Autism
- Seizures
- Other

- Can affect child's ability to utilize sign language
- Child may use sign approximations that others do not understand
- Communication device may be needed
- Changing Routines
- Stimming
- Cognitive skills and physical skills do not align
- A lot more...
- No crystal ball to the future



DHH Plus and Communication Challenges



- Axel is 5 years old and in kindergarten. He attends a DHH / life skills program
- Receptively using oral communication and ASL/signed English
- Expressively using sign approximations and an AAC device with two switch access
- Cognitive ability is much higher than physical ability making vocabulary with AAC device difficult
- Unable to finger isolate to sign or touch icon on device
- At a crossroad of changing communication devices



- Continuous Diagnosis
- Finding the right medical providers who will work together
- Getting past all the “red tape”
- A new diagnosis means new equipment and routine changes
- Stimming (doors, drawers, light switches, buttons)
- Blood sugar changes, cause extreme fatigue and mood swings.
- Overall misinformation from providers

Throughout our time in family support programs

we have found that when working with

D/HH Plus families:

- Child is battling several other medical diagnosis, that at times take the “front burner”
- Forget information that was given to us because its too much at once, too many acronyms, and/or too much medical terminology
- Having to utilize multiple pieces of medical equipment seems unmanageable, and financially impossible
- Cognitive ability of child unknown (risk vs benefit)



Guide By Your Side (GBYS) is a program that provides:

- Unbiased information
- One on one support and resources
- Trained Parent Guides to talk and/or meet with you.
- Provide unbiased information and resources regarding communication, educational and technological choices.
- Helping families identify their options... not tell them which options to choose.
- Support families. Support is all about listening first... and meeting families where they are emotionally.
- Help families navigate through the many systems and services available.
- Work as a team with professionals offering a well-rounded care system for families.
- Many Chapters have a DHH Plus Parent Guide, giving families a support system past the hearing difference.



Social Media

The Good. The Bad. The Ugly

- Individual state Hands & Voices FB Pages and Groups
- Hands & Voices Deaf/Harding of Hearing Plus Group
- Specialized support groups for you child's diagnosis
- Individual family stories on personal pages
- Making connections with people "who get it" all over the world
- Misinformation
- Felling excluded from certain groups because your child isn't "medically fragile enough"
- Hard to connect in-person



DHH Plus Documents

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

- [“Connecting Families of Children who are Deaf or Hard of Hearing Plus \(DHH Plus\) with Resources and Support”](#) was developed by the Early Hearing Detection and Intervention Parent to Parent Committee, for families who have children who are DHH Plus, because we know that 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. The purpose of this guide is to ensure that:
- 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.

But we don't want to leave you with the struggle...

These children give us:

- New purpose in life
- A new way to see the world
- Strength in ourselves, that we might have never known
- So many hugs, smiles, and laughter
- New friends and community



“I wish I could take away my child's pain and struggles, but I wouldn't change him for the world. I am so proud of who he is, and I am thankful every day that he continues to show me the way through his eyes.” –Jami Fries

Questions?

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& D/HH Plus Parent Guide



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GUIDE BY
YOUR SIDE™

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