

Courage + Dreams = Success:

A Call to Support Children Who Are Deaf/Hard of Hearing Plus

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I. Background, Experience, and Role in Supporting Families w/ Children who are DHH Plus

a. Personal background as a Deaf adult

My bio sketch has been provided but I want to add the following: People ask what drives me and why I continue to be passionate about what I do. For the last 50 years I have met a huge range of wonderful families raising their DHH plus children, and interacting as well as socializing with DHH plus adults. I feel at ease with the families, friends and the DHH plus children and adults simply because I attended a private school for Deaf children in St. Louis for ten years. There were many who had health care needs ... a huge range ... but back in the 1950s and the 1960s many teachers and professionals were not always aware of their additional needs. I grew up with peers of all abilities, talents and skills. but we lived together, interacted with each other. We played baseball, football, card games. We were curious and learned to accept and respect and accept all our peers. We often could see that teachers and dormitory counselors did not always grasp: that they were DHH plus.

When I started my graduate studies, took classes and met professionals working with DHH plus, I learned more and more – even the medical terms and professional labels. I even learned a bit about myself, especially that I had hereditary heart condition and vision condition but they were not major enough to sidetrack me. I was limited from vigorous activities like skiing, cross country and track.

Through social interaction with families of my DHH friends I found myself talking a lot with them. I've always been easy to talk with and I enjoyed being with people. My undergraduate major was in mathematics, computer sciences and psychology, which you wouldn't think would develop great social skills. But I chose those because they were simply easier to manage than other majors, as I did not have interpreting services. One visiting professor who stopped by a computer lab where I was doing a work-study program internship through Antioch College at Stanford University convinced me that I could do a lot more for the world through Deaf Education. The professor was really charming and persuasive. We met only once but I could not let go of her insightful advice. The funny thing is that I found her two years ago to thank her and she had no memory of meeting me – but she admitted that she loved giving everyone advice. I said right there it was God who sent her to me with a message!

b. Professional experience in the field of deafness

I joined the Deaf education program at California State University, Fresno where I taught for 40 years before I was invited by the administration to dream big. That is how I created The Silent Garden and became the master gardener. It is an endowment supporting university students, teachers, interpreters, professionals, and also all families with free lectures, workshops, and conferences.

The endowment was one major step beyond authoring a parent's guidebook for raising DHH in 1982. It is now it is in third edition with David H. Smith the second author who will write the new edition in five or

ten years when there is a need for inclusion of new research and information. After all the talks with families for many years, I knew how important it is to have a complete guide for parents and I am pleased to say it is still the only leading guide praised everywhere as a classic.

c. Supporting families with children who are DHH and DHH plus

As stated above, growing up with DHH plus and meeting families of DHH plus wherever I went helped me understand the needs. The founder of Deaf Education at Fresno State, Karen Jensen Coles, was a huge believer in training teachers to become skilled in working with a wide variety of student learners, to understand the complexity of a child's health and educational needs, as teachers were usually the first to recognize DHH plus in school programs and make referrals. That was a huge inspiration for me. Very few teacher training programs offered courses on DHH plus. I became acutely aware how our Deaf Education has gone in the direction primarily focusing on DHH as if there were no other health needs of any kind. Everyone has been passionate about educating Deaf children so they can be successful and become first-class citizens. Now we know we have left out DHH plus children, adults and their communities.

As the master gardener of The Silent Garden at Fresno State, I do a lot of fundraising and establishing endowments for scholarship for our students, for lectures, workshops and conferences – a rotating schedule focusing on Deaf education, interpreting, dealing with hearing loss among the seniors, and Spanish speaking families. The more we grow, the more opportunities we can provide for everyone in the field to support families of DHH and DHH plus.

One day, an out-of-state individual who asks to remain anonymous and I were “walking” in The Silent Garden. He immediately noticed what had *not* been planted – an endowment focusing on DHH plus. I just did not have any donors but I was enthusiastically open to the idea of another garden. He donated one million dollars and requested that it be named Scarlett's Park with the specific rule that we offer a conference every year focusing on DHH plus. I felt so honored and blessed to be able to make this happen. For the first two years, we had a two-day conference on the Fresno State campus, the first focusing on the needs of DHH plus children and adults and the following on autism.

The Silent Garden was transformed in a most amazing way when COVID hit. We began offering Zoom conferences. We went national and international. It was not part of my plan, but I got many emails begging that we continue with Zoom. So many people are so passionate and caring about DHH plus children and adults – a huge need especially for those who are alone in schools and programs where they have to fight for the rights of the DHH plus. Yes, we will stay on Zoom every year in September for Scarlett's Park Conference. Details can be found on our [Silent Garden website](#) at Fresno State.

d. More than research - support, inclusion and allyship

I am been blessed to have Dunbar Ogden, Jr., as my father. He was involved in the Civil Rights movement in the 1950s and the 1960s, starting with a major role of supporting African American families and leading their nine children to integrate Central High School in Little Rock, Arkansas, in 1957. Martin Luther King, Jr. came in person to support my father. Growing up with a father who was a champion for the underdog and passionate in fighting injustice everywhere made a positive, indelible mark on me.

II. Prevalence of DHH Plus

Research suggests the prevalence of other healthcare needs in the DHH population is significant. Between 40% to 60% of children who are Deaf and hard of hearing may also have additional healthcare needs that could delay the age of identification and intervention services, and therefore, impact a child's language, future academic performance, and social connections.

Additional healthcare needs can be related to cognition, physical health, vision, emotional regulation, ADHD, autism, specific learning disability, etc.

While labels are deeply personal and best left for each individual to decide how they wish to describe themselves, I am using the term “DHH plus” today. Some of you may use the term “Deaf/Hard of Hearing with Disabilities” or “Deaf Disabled.” My intent is to be respectful and inclusive.

What can be challenging for Early Hearing Detection and Intervention Systems, providers and families is the diverse range of healthcare needs among this population, the severity of each need, and how the combination can affect the child.

And these complexities can greatly impact the health and well-being of the child AND the family who cares for them. With often seemingly competing priorities, families and caregivers can become overwhelmed.

Systems and providers who are sensitive to the stressors families experience can acknowledge the challenges, share the statistics about the prevalence of additional needs so families know they are not alone, and empower the family by helping them find the resources, knowledge and supports they need.

Families with children who are DHH plus are a high percentage, so focusing attention, training, and resources specifically for this population is a wise and necessary investment.

III. Challenges Faced by Children who are DHH Plus and Their Families

Families with children who are DHH plus have shared how they face a variety of challenges over time – some that are chronic and recur, some that are life threatening, some with a sudden onset. Others may persist slowly and have the potential to chip away at the resilience of caretakers.

With medical and emotional issues, families have described how their lives can be complex and they may struggle with competing priorities. And even then, when a life-threatening emergency arises, plans can drastically change and families may scramble to care for other children or family members, take leave from work and more. Families with children who are DHH plus describe it best:

“Originally, life was the main priority. We needed to keep our child alive and we worked hard at that. As he gained health, he had a list of disabilities and I used to think that being DHH was at the bottom because deafness is not life and death. And walking seemed pretty important, too.

As time went on, I realized being DHH is at the top. Without the ability to communicate, what is life? We're relational beings that have a desire to connect with others. Whether that's through verbal, sign, or an Augmentative and Alternative Communication (ACC) device, the need for language and communication becomes the most important issue to address.”

In order to prioritize communication and language, families have wanted access to expertise for their child’s specific healthcare needs and in particular, individuals who are also trained in deafness and/or collaborate with others who are trained in deafness. Families can quickly become overwhelmed and overburdened with hunting down providers with the right skill set.

Here, another parent echoes the need to focus on communication:

“Every child has the human right to communication. Every. Single. Child. It is our EHDI community that ensures that! We cannot stop when it becomes difficult or when we need to be creative. We cannot stop when we feel challenged. Imagine the difference it makes in a child’s life to express their wants and needs or to understand what will come next in their day. The tools and strategies exist. Let’s do better at connecting with one another to ensure that each family and each child understands the process.”

Another issue families with children who are DHH plus have shared is safety. When the child is medically stable, has access to qualified providers, and can communicate their needs, the world can open up to them. But statistically we know that children with perceived communication barriers are more at risk for abuse and neglect. One parent asks for help:

“I would like to have more discussions of keeping our children who are DHH plus safe, knowing they are at risk and need many allies to guard their safety.”

Social isolation, even among DHH peers, can be a struggle for children who are DHH plus. Some families have reported that their children who are DHH and who have specific healthcare needs may be in classrooms with students who do not share their method of communication. Or in classrooms with DHH peers, their child with additional needs wasn't integrated into activities. One parent explains:

“I want to stress the importance of seeing the child and not just the disability. So many times you hear the pleas for our DHH children to be treated the same as a "typical" child yet within our DHH community the same consideration is often not given to a "plus" child. They have the same human need to be accepted and included. If you're uncomfortable or uncertain how to include them ... if you don't know how ... ask ... they are worthy of the effort. “

Access to peers is also critical at DHH events and as part of any services to Deaf and Hard of Hearing. Inclusion for these children and their families matter and can be the difference between getting the support, education, and connection they need or not. Parents have told us:

“I would like our children to be seen. It can feel isolating to have a child who is DHH plus. We would like our children to be treated as equals and to fit into the greater DHH community.”

“DHH plus kiddos represent a lot of our kiddos, and the more they can find a home in this "DHH world," the more access our children will have to the world around them.

IV. Strengths/Joys/Dreams of Children Who are DHH Plus and Their Families

Raising a child who is DHH plus can be incredibly rewarding and many parents have reported great lessons learned from the experience. From assisting the child in all aspects of development, to advocating for access, to being flexible and an expert trouble-shooter who can pivot on a dime, or for learning how to homeschool, these parents and caregivers develop incredible skills. These skills often become professions or volunteer work, and parents have expressed how much joy they find in creating community and sharing their triumphs and successes with others who understand.

More important than the impact on the family is the impact some of the challenges have had on the child. Parents have reported that their children have amazing patience, compassion, courage, and perseverance.

“Our kids range in personalities and abilities, but most of our kiddos have a similar trait that helps them succeed – resilience. Our kids often learn to smile through the pain, work harder than anyone else and don't give up. It is through their everyday challenges that they learn to be strong and keep moving forward.”


Children who are DHH plus have such incredible talent and plentiful gifts that too often may only be enjoyed by those who make extra time to get to know them. Parents describe the exquisite and precious nature of these moments. The jokes they tell ARE funnier, the victories they achieve ARE sweeter because they are hard won and there is often a backstory of incredible effort to get there. I am told that one of the advantages of the Hands & Voices DHH Plus Facebook group for families is the chance to celebrate these joys in community:

“My son has the most amazing perseverance. He always wants to do things himself even when they are incredibly challenging for him. He has cerebral palsy among other things and has difficulty grasping with his left hand. This week he spent an hour trying to grab and lift a hula hoop with his left hand and he DID it!!!”

“My son is on the autism spectrum and is also hard of hearing. He tends to be very shy and doesn't like to be in front of people or be called out on something. He decided (on his own - he comes from a long line of

unathletic family) to be on the basketball team. I got off work an hour and a half early last night to watch him play a grand total of 30 seconds while being yelled at by the coach. Is he the best player? By far no. But he is the bravest. He is out there battling himself to be better and to rise above his own challenges. I am so proud of him and he is my inspiration.”

“My son’s biggest accomplishment has yet to happen. But he knows more about the solar system than anyone I know.”

“The challenges she faces do not phase her. I have learned to have a whole different perspective .”

V. Strategies/Opportunities to Support Children who are DHH Plus and Their Families

- a. Expand systems that continuously screen for healthcare issues after a child is identified as Deaf or hard of hearing. Families may be overwhelmed and not able to follow up on additional screenings, so please give them concrete reasons for why follow up is important.
- b. Help families find specialized providers. Goal 4 of the 2013 Supplement by the Joint Commission on Infant Hearing states: “that all children who are DHH with additional disabilities and their families have access to specialists who have the professional qualification and specialized knowledge and skills to support and promote optimal developmental outcomes.” It would be helpful for families to have access to a network of professionals without having to search them out.
- c. Partner with professionals with Plus expertise. The professionals who make their life’s work to educate themselves and dive into the needs of DHH plus kids ... amazing! Who are they? Where are they? How do we tap into their expertise? How do we grow this field? How do we help school districts understand the need to consult if they don’t have this expertise on-site?
- d. Provide training on the care of children who are DHH plus. Training is a basic necessity for families and professionals to enhance the care of DHH plus. While resources do exist, many families and professionals do not have access to them. We need more resources and more opportunities for families and professionals to network with each other. Access to free or low-cost training should be readily available.
- e. Communication is Key – in whatever form or combination. For their cognitive development and safety. We have to do better and raise the expectations for these kids. And their language and social needs may at times override the need for a school to keep kids with other kids with the “other” issues.
- f. Empower, Engage and Connect Families with Children who are DHH plus. As one parent explains:
“Families with children who are DHH plus need a place at the table, representation in all systems and supports so that our families/children’s needs are not missed. More representation of our children on flyers, websites, in trainings, advisory councils, planning committees, etc.”
- g. Develop parent leaders with children who are DHH plus. As we assess our family support efforts, ensure that growth opportunities for parents who have lived experience raising children who are DHH plus are extended so there is a workforce of trained parent leaders.
- h. Seek out DHH plus role models and connect them with families. As we create ways for families to engage with DHH leaders, also consider including individuals who are DHH and have healthcare needs who can inspire families.
- i. Keep expectations high. Providers can best serve the child when expectations for the child are kept high. The wisest approach is to assume the child is able to do something until proven otherwise. Simply, let these kids dream. And dream big. Why not? Who are we to put limits on their futures?

“If DHH plus children cannot develop to their fullest potential, this is a failure in the systems of care that are supposed to support, empower, and educate families and their DHH children. The inequities are obvious when you work with families of DHH plus children. They are not welcomed in the same schools; they cannot access the wide array of services they need in a single educational environment and they must spend many more hours in transportation to receive the therapies they need. So, the impact starts from the moment they wake up, try to learn, and make progress in all areas of need in the same amount of time as other DHH children that do not present additional needs. Over time, the gap between them and their peers is very apparent and impossible to close. They have so much potential to become contributing members of society within their abilities and in their own way. If we fail to see their potential, we will always fail to support them appropriately.”

Do we ask kids who are DHH plus what their dreams are? Are they that different from hearing peers? From their DHH peers? What can each of us do to help them reach their full potential?

- j. Connect families to resources. In the handout, I have provided a number of resources available to assist families with children who are deaf and hard of hearing. Make time to ask parents what else they need, what are they lacking in support. In the handout is the highly recommended resources. Also, make time to ask parents what else they need, what are they lacking in support?
- k. Become a “Plus Ally.” Not to take over the role Plus individuals can play, but to be there when an advocate is needed, and no one is there. Families can teach us how to do this well.

VI. Call to Action

So, when we leave this conference, I call on each of us to commit to taking some action to improve our care and support of families with children who are DHH plus. The actions are two-fold:

Professional: Are you someone with DHH plus expertise? What can you do to become better networked with other colleagues? How can you promote the development of more providers with expertise? What can you do to increase visibility of DHH plus children in systems?

Are you someone who wants to expand your connection to and education about children who are DHH plus? Who can you reach out to gain experience? Who can you ensure is on board who can represent DHH plus needs? What can be done to increase involvement of families with children who are DHH plus? How can individuals who are DHH plus be more integrated into our programs and services?

Who is willing to commit to being an ally?

Personal: What can you do on a personal level to truly connect with families and their children who are DHH plus? How can each of us teach our children/grandchildren/nieces and nephews to value the talents and skills of children and adults who are DHH plus? What books are they reading, what shows are they watching, how are they being introduced to people of all abilities? How can we spread advocacy in our communities? Do we encourage and support hiring DHH plus? When we see someone working, do we make a point to tell a manager of how important it is for you to patron a business with equitable hiring practices?

One adult who is DHH plus said:

“Please see our strengths instead of what you think we lack. If each one of you make a friend with one of us, think how both our lives would be better.”

Can we pledge to invite, encourage, support DHH plus kids...in all our communities and intervene and advocate when they are not? This takes courage. If we need inspiration for this courage, then think of the families and the courage they need to advocate for their children. Think of the kids who have the courage

to face other people's doubt, insensitivity and barriers to inclusion. And then dream. Dream of what we can do together to make a difference, become an ally, and clear the hurdles for these kids.

Deaf people are closely knitted together with much pride in their Deaf community and how they communicate. They value communication so much and everything we do depends on good communication that is fully accessible. We professionals and parents of DHH plus need to reach out to them with much respect for who they are and invite them to play a role. We should honor them, value what they think and say. Once they are fully respected it becomes much easier to bond with them and they in turn can be the advocates.

At lectures, workshops and conferences at local, state and national levels we should invite DHH people and their leaders to participate when we offer programs on how to work with DHH plus and to point out what is needed. We need to focus on those who are passionate about DHH plus and they will play a major role ... give them respect and support in their efforts to reach out to other DHH.

I always tell this story and it helps me evaluate how the person responds, which can be a good predictor of their interest in the DHH plus. When my wife and I were in New York City walking on a busy Broadway street with our hearing dog, a five-year-old child with Down syndrome with his family coming from the opposite direction saw our Lab and gave her a big hug, burying his face in the fur, then sat down on the sidewalk. His parents obviously were worried how we would react. But Anne and I sat down on the sidewalk, giving the child full attention. Soon his two siblings sat down. We were all on the sidewalk with people walking around all of us. You could immediately sense how much everyone cared and stopped worrying about racing to their destinations. We were happily visiting. It was our reaction to the situation that made all the difference and drew the best from other people.

During the last five Scarlett's Park Conferences sponsored by Fresno State, it was obvious how many people throughout the U.S. care and were eager to learn everything they could about DHH plus. They were eager to network with others where they live. They tell us how much work they have to do in bringing more support to families with DHH plus. They care so much and many are hard-working pioneers. They are fiercely advocating for more support from schools, government, leaders and policy makers. We need to hear them to help them.

The fact that they care so much means the world to me.

“Look out for kids, help them dream and be inspired. We teach calculus in schools, but I believe the most important formula is courage plus dreams equals success.”

- Marlee Matlin

RESOURCES

[Assuming Competence: What to do if you don't know what to do! | November 9th, 2023 | NCHAM \(infanthearing.org\)](#)

[“Connecting Families of Children who are Deaf or Hard of Hearing Plus \(DHH Plus\) with Resources and Support”](#)

[Scarlett's Park - The Silent Garden \(fresnostate.edu\)](#)

[Silent Garden: A Parent's Guide to Raising a Deaf Child by Paul W. Ogden and David H. Smith \(Spanish & English\)](#)

[NCHAM eBook, "Children Who Are Deaf or Hard of Hearing PLUS"](#)

[Hands & Voices DHH Plus webpage](#)

[Hands & Voices DHH Plus Facebook group for Families](#)

[Hands & Voices DHH Plus Inclusion Checklist](#)

[National Family Association for DeafBlind - Welcome \(nfadb.org\)](#)

<https://www.nationaldb.org/>

<https://www.nationaldb.org/state-deaf-blind-projects/>

<https://www.chargesyndrome.org/>

<https://www.usher-syndrome.org/>

<https://www.thegfpd.org/>

<https://earcommunity.org/>

<https://www.helenkeller.org/>

<https://www.perkins.org/>