

What it Means to Hold Space: Applications for EHDI Providers

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Disclaimer: This is written from the perspective of hearing parents working with hearing professionals within a medical model. In this article, we use medical terms like “diagnosis” to emphasize the gravity of the first moments of identification for some parents. Additionally, this is the synthesis of more than one person’s story in order to maintain confidentiality.

Although it only took a few months to learn that my son Billy had a severe hearing loss, it felt like a lifetime had already gone by. It started with a challenging pregnancy, long labor, a stay in the NICU, multiple “failed” newborn hearing screens, and a horrifying experience with our first audiologist. It was only when we got to our current pediatric audiologist, Laura, that we felt secure, even though the news Laura shared during our first meeting changed our lives forever.

I can remember the diagnostic process like it was yesterday. In reality, it was eight years ago on August 26. I remember the date as clearly as I remember what the sterile hospital chair felt like under me while I held Billy in my arms. Laura talked to us throughout the test, giving us information along the way, rather than leaving us to guess at what the waves meant on the computer screen. Then, the words that shattered the life that I had been imagining came: “Billy has a bilateral severe hearing loss.” I didn’t even know what that meant, but I knew that everything had changed for me in that moment. I knew that our life would not be as simple as just taking our sweet boy home.

I had no idea how Billy’s hearing would impact his development or our relationship with him. In fact, since Billy was my first child, I wasn’t totally sure I knew how to raise a child with typical hearing. My partner, our families, our friends, all tried to be supportive, but the reality was that none of us knew anything about raising a child who was hard of hearing. With that gap in knowledge, a deep and unsettling period of grief and uncertainty ensued. I had what seemed like a million questions, but only a few that I was brave enough to utter out loud. Most of my silent questions contained too much guilt and shame to actually speak. I remember some of my first thoughts, images, and questions about the future...

Flashes of Billy wearing huge, ugly, skin-colored hearing aids, and being made fun of by kids on the playground intruded my thoughts often...

Is he going to be able to speak?

What type of school will he go to?

Does this mean that his cognitive abilities will be limited?

Am I a terrible mother if I get sad sometimes when I look at him?

Am I going to be able to do this and be all right? Are we?

Did I cause this?

Anyone of these thoughts could keep me awake long into the night.

Laura’s gift of support and attunement enabled my husband and me to support Billy’s growth and development. She learned how much information we needed, educated us on our choices and what options existed for Billy, and nurtured space for us to express our thoughts, feelings, fears, concerns, accomplishments, and the things that were important to us. Laura was always patient and calm. She was thorough when answering our questions about technology, communication modalities, and next steps, including our future involvement in the early intervention program. Laura also spoke to us about the things we *weren’t* asking.

She would check in, “Are you sleeping, feeling anxious or worried about anything?” or ask “How are the grandparents adjusting to Billy’s hearing aids?” She also forecasted what we might anticipate in the coming months. She taught us how to insert the earmolds, how to keep the hearing aids from squealing, and how to know if the batteries were dead. She also reminded us to trust our intuition; we knew how to relate to our son. She celebrated our triumphs with us, but she always left plenty of space in the room for the struggles and challenges. Most importantly, she gave us the time, power, knowledge and courage we needed to make some very important decisions.

“Take your time,” she said. “You don’t need to make all of these decisions until you’re ready. Gather information, meet people with lived experience, talk with your loved ones about the things that matter most to them, measure them against the things that matter most to you. Hold your baby, sing to him, tell him stories and love on him exactly as if he hears every word you say. Start with what you already know.” Laura gave us an incredible gift in those early days. Though they were emotional months, we knew that we were being held by someone who was only a phone call away.

In the eight years since then, I’ve often thought about Laura and the important role she played in our lives immediately after Billy’s identification. She was much more than what can fit in the title of “audiologist”. She was **supporter, content /medical expert, coach, friend and guide**. By offering gentle, nonjudgmental support and guidance, she helped us navigate one of the most confusing, overwhelming, difficult journeys of our lives.

The work that Laura did with us in those early days can be defined by a term that has become more and more commonplace. She was *holding space* for us.

What does it mean to **hold space**? It means that we walk alongside another person in whatever journey they’re on without judging them, making them feel inadequate, trying to fix them, or trying to impact the outcome. When we **hold space** for others, we open our hearts, offer unconditional support, and let go of judgment and control.

Sometimes we find ourselves **holding space** for people while they **hold space** for others. In our situation, for example, Laura was **holding space** for us while we **held space** for Billy. Though I know nothing about her support system, I suspect that there are others **holding space** for Laura as she does this challenging and meaningful work. It’s virtually impossible to be a strong space holder unless we have support. Even the strongest leaders, therapists, coaches, interventionists, etc. need to know that there are people with whom they can be vulnerable without fear of being criticized or judged.

We have to be prepared to step to the side so that they can make their own choices, offer them unconditional love and support, give gentle guidance when it’s needed and invited, and make them feel safe even when they appear to be making mistakes, or choices that contrast with our own beliefs. We don’t truly support people in their own growth, transformation, grief, etc by taking their power away (i.e. trying to fix their problems), shaming them (i.e. implying that they should know more than they do), or overwhelming them (i.e. giving them wrong information or even correct information at the wrong time).

Holding space is not something that’s exclusive to facilitators, coaches, or therapists. It is something that ALL of us can do for each other – for our partners, children, friends, neighbors, and even strangers who strike up conversations as we’re riding the bus to work.

Holding Space is a multidimensional skill set with applications across professional disciplines. For that reason, this article was written in collaboration with Elizabeth (pediatric audiologist) and Jess (therapist/early interventionist) to share our different perspectives on the lessons we’ve learned by *holding space* for others and from others, who have *held space* for us. Here are our tips:

1. Give people permission to trust their own intuition and wisdom.

Audiologist/EI: The transition to parenthood can be full of experiences that set a parent up to feel competent and capable...or not. By gently pointing out all the ways parents are experts on their baby, that their instincts about basic parenting skills are trustworthy, the audiologist can help parents begin to trust themselves. Parents can then begin to move through their fear and scaffold the bridge to self-confidence, mobilizing them to make harder decisions about their child’s hearing.

Parent: When we were first learning to support Billy after his diagnosis, we had no experience to rely on, and yet, intuitively, we knew what he needed. We took comfort in knowing when he was communicating his hunger; when we couldn’t soothe him we learned that he responded to harder pats on the bottom; and we knew how to communicate our love to him. Each time our parenting was reinforced, we learned to trust our ability to make important decisions about his hearing care and communication.

2. Give people appropriate information in ways they can handle it.

Audiologist/EI: Providing the right type and amount of information is like a dance. Some parents and caregivers will visibly zone out while you are talking (this is a good sign that their brains are already overloaded). Some will demand a lot of information and come to the next meeting asking for it again, as if the previous meeting had not happened. Most will fluctuate among asking questions, readily integrating information, zoning out, and being overwhelmed with decisions. In school we were taught that the provision of information should be identical across families. That isn’t real life. This is one of our biggest opportunities to practice non-judgement. There is no such thing as “The parent *should* be able to understand...”

Parent: Laura gave us some simple instructions and left us with a few meaningful resources, but did not overwhelm us with far more than we could process in our tender time of shock and grief. Too much information would have left us feeling incompetent and overwhelmed. However, we never felt that she was withholding information either. She was consistently checking in with us about what we needed next.

3. Don’t take people’s power away.

Audiologist/EI: When we take decision-making power away from parents, we leave them feeling useless and incompetent, and even victimized. It’s important to remember that the diagnosis of hearing loss may have left parents frozen--immobilized by their new reality. It is important to give back the control that was taken from them in respect to their child’s hearing. If we make a decision that turns out to be the wrong one for our patients, they can end up with regret and resentment. There may be some times in life when we need to step in and make hard decisions for other people (i.e. when an intervention feels like the only way to interrupt the cycle of addiction), but in almost every other case, people need autonomy to make their own choices (children too!).

Parent: Laura knew that we needed to feel empowered to make decisions on Billy's behalf, and so she offered options but never tried to direct or control us. She educated us on various choices we had, and then let us make the best decisions we could in that moment for our baby and family. I am certain that Laura believed aiding Billy as soon as possible was in his best interest. I also know if she pushed when we were frozen, she could have lost us for good.

4. Keep your own ego out of it.

Audiologist/EI: This is a big one. We all get caught in this trap now and then--when we believe that someone else's success is dependent on our intervention, or when we think that their struggles reflect poorly on us. If the child isn't making anticipated developmental progress, we worry that people are going to blame the fit of the hearing aids, or the amplification choice we made, or our ability to get families to follow through with an intervention strategy. We feel that if the child succeeds, then we have somehow succeeded. But, if we allow ourselves to own the child's (and the family's) successes, then we dare not get defensive when families or others blame us for their failures.

Parent: The ego trap is one I find myself slipping into often. I question whether my friends think I am a bad parent if Billy doesn't develop at the same rate as their children. Will the other parents at playgroup judge me or my decisions? Do they think that if I were more competent in ASL, Billy's vocabulary would be broader? Or conversely, to the audiologist, "look how I have taught Billy to keep his hearing aids on?" At its worst, I can make myself mad trying to prove that I am a competent parent and can become more concerned about my own success than about the success of my son. That doesn't serve anyone--not even me. To truly support his growth, I need to keep my ego out of it and create the space where I can follow his lead and make sure he has the opportunity to grow and learn. Laura became a trusted model for removing ego from the equation. However, we have had doctor's/professionals take credit for the achievements that Billy has made with our support. For example: "I knew that intervention was going to lead to Billy's clear and intelligible speech." Those experiences took the wind out of our sails and felt very invalidating, as though we hadn't put in hours of language modeling with him or as though Billy was not a developing human, but an object that they could control with one isolated decision.

5. Make people feel safe enough to fail.

Audiologist/EI: When people are learning, growing, or going through grief or transition, they are bound to make mistakes along the way. When we, as their space holders, withhold judgement and shame, we offer them the opportunity to reach inside themselves to find the courage to take risks and the resilience to keep going even when they fail. When we let them know that failure is simply part of the journey, they'll spend less time beating themselves up, and more time learning from their mistakes and moving forward on the path towards success.

Parent: If you tell me what to do and it fails, I will blame you. Even if we would have decided it on our own anyway. It's easier that way. I remember the early days after Billy's diagnosis; my brain was like scrambled eggs. I had no clarity due to the shock, grief, and the sleep deprivation from having a premie. There's no way I was making "good" decisions, even with my spouse's relentless support. However, Laura normalized my experience and never judged me. When you partner with us in the decision-making process by creating space to try something without the risk of shame and judgment, we can maintain our relationship long enough to find the things that work together. We may even be able to appropriately redefine success based on who my child is, rather than an arbitrary norm or standard.

6. Give guidance and help with humility and thoughtfulness.

Audiologist/EI: A wise space holder knows when to withhold guidance (i.e. when it makes a person feel foolish and inadequate) and when to offer it gently (i.e. when a person asks for it or is too lost to know what to ask for). Knowing both when and how to give guidance is a delicate art. Recognizing the areas in which people feel most vulnerable and incapable, and offering support without shame takes practice and humility. Generally, we can see it on their faces and/or in their bodies when we mess this up--I am always ready to apologize for how my timing, tone or word choice impacted them emotionally.

Parent: Laura did not take our power or autonomy away by directing us or giving us “the answer.” She offered gentle guidance, sometimes sharing stories of other families’ struggle, process and decisions for their kids. When pressed she even shared what she would do if it were her child, in a way that made it safe for us to still make another choice. It is hard to define this art, but we know it when we experience it.

7. Create a container for complex emotions: fear, trauma, etc.

Audiologist/EI: When people feel that they are held in a deeper way than they are used to, they will feel safe enough to allow complex emotions to surface that might normally remain hidden. Someone who is practiced at **holding space** knows that this can happen and will be prepared to hold it gently, while offering strength and courage. This is not easy work, and it is work that we continue to learn about. We can’t do it if we are flooded by emotions ourselves, if we haven’t done the hard work of looking at our own shadow, or if we don’t trust the innate wisdom in our clients. I remember one family returning for a follow-up appointment, which had been very engaged and compliant initially, admitting that they had not been using the aids, nor providing any other linguistic support to the child. I was furious...until there was enough space for the family to share about the mom’s recent cancer diagnosis, and a simultaneous death in the family...

Parent: In Laura’s case, she created a safe container for us slowly, over time, by showing up with tenderness, compassion, and confidence. If she had shown up in a way that didn’t offer us the assurance that she could handle difficult emotions, we wouldn’t have been able to trust her as we did, and still do. It was an immeasurable gift to not have to filter my thoughts and struggles.

8. Allow people to make different decisions and to have different experiences than you would.

Audiologist/EI: Holding space is about respecting each person’s differences and recognizing that those differences may lead them to make choices that we would not make. Sometimes, for example, they make choices based on cultural norms that we can’t understand from within our own experience. When we hold space, we release control and we honor differences. We even leave space to be surprised by positive outcomes that we did not expect.

Parent: There were times that I could tell that my husband and I were making different decisions than Laura would have. Instead of questioning us in a way that felt demeaning and loaded with judgment, Laura would get curious and ask inquisitive questions to get to know us and the roots of our decisions. Her curiosity felt like she wanted to get to know us as people, our family beliefs and values, rather than a means to convincing us to do something different.

Holding space is not something that can be mastered overnight or adequately addressed in a list of tips like the ones we’ve just given. It’s a complex practice that evolves as we practice it, and it is unique to each person and each situation.

We are committed to lifelong learning in what it means to *hold space* for others, so if you have experience that's different than ours in *holding space* for clients and families you work with and want to add to this conversation, please send us a message.

Editor's note: This article was adapted for EHDI (Early Hearing Detection and Intervention) providers with permission from Heather Plett, author of *What it Means to "Hold Space" for People, Plus Eight Tips on How to Do it Well*. The authors presented a full day workshop and a shorter overview of this material at EHDI 2018.

Holding Space: Reflection Questions

1) What comes up for you around the idea of "not knowing" how to be with someone in their vulnerability/pain?

Do you think this is harder with someone you love (i.e. a family member), or someone you don't know well (i.e. a patient)?

2) Who has "held" you in your difficult times?

Who do you know who models/teaches that kind of non-judgmental presence?

If you can't think of someone, when are some times that you wish you had a compassionate guide through the darkness?

3) Which of the listed lessons are most impactful to you?

Which do you think will be the hardest to practice?

4) Where are the places that you are not willing to go with someone?

What is too scary, too unknown?