



## **Hands & Voices: Supporting Families Without Bias**

*by Leanne Seaver*

In the early-1990s, the Smithsonian Institute in Washington, D.C., was preparing an exhibit called “Silent America.” It was intended to raise positive awareness of the Deaf Community, highlighting cultural and linguistic (American Sign Language) aspects of the Deaf experience. Meanwhile, a number of people who were deaf or hard of hearing, but who were not living with those aspects of the Deaf experience, had a problem with the exhibit. From their perspective, it did not represent who they were—specifically, listening/oral communicators. They resented what they perceived to be the exclusionary nature of Silent America’s point of view. Controversy roiled across the land. Both camps fired off angry letters towards each other, and at the Smithsonian exhibit planners. In the end, the Smithsonian scrapped the whole project.

Regardless of what side any one was on, we all lost that battle.

### **We Are Hands & Voices**

As individuals who are in so many ways connected to each other through deafness or hearing loss — professionally, parentally, or otherwise—we’d had an opportunity to rally around the things that unite us and show the whole world, but instead we burned ourselves out in the same old heated arguments over communication methodology. Those events were the coming of age for Hands & Voices. Twelve years ago, we were just a fledgling Colorado parent support group (who would become Hands & Voices) watching the whole Silent America debacle take flame. It was incredible, as in ‘not believable’. Why didn’t they just ask us how to do this? Perhaps through natural selection or just by serendipity, our group was increasingly comprised of diversely communicating parents, professionals, and deaf and hard of hearing adults fully united by our cause. As we grew, we became galvanized by the need to create strength and unity in our community. Certainly, we’re not the first or only who have ever wanted to accomplish that, but in many ways, joining all camps together towards a common goal continues to be the unique selling point of Hands & Voices.

### **On a Mission**

Our mission is to improve the social and academic experience of our children, students, and mentees who are deaf or hard of hearing (d/hh). Whether we’re talking, cueing, signing, or combining, we all believe passionately in what we’re doing, and we’ve become strong advocates for our own kids and for each others. This approach has exposed us to many families using a wide variety of communication choices—all that have resulted in really successful kids. Conversely, we’ve seen many other kids and their families not reaching their goals via a particular mode or method. In every situation, the many variables are entirely unique to the child, the etiology, his or her family, their goals, the available resources, and a host of other considerations. As such, it is simply inappropriate and unproductive to impose a notion of methodological superiority over

each other. We've come to understand that it is not the child who "fails" with a method, but the method that can fail the child and family. This perspective keeps us child- and family-focused—an essential value for a parent-driven organization.

## **Not Broadcasting Our PBS**

Hands & Voices developed this slogan to articulate our philosophy that "what makes the choice work for your child and family is what makes the choice right." So at Hands & Voices, we would advocate for the child with a cochlear implant as surely as we would for the child using American Sign Language. And we train diligently to prepare ourselves to support families without "broadcasting" our own personal belief system (PBS) or predisposing their outcome through our own biases.

## **PBS vs Bias**

Among the first questions anyone asks us at Hands & Voices are "So, you're trying to tell me it isn't ok to have a personal opinions on d/hh topics? Hey, I know what I know!" or "I don't think anyone is truly unbiased when it comes to communication methodology." These are very legitimate concerns, and we spend hours interactively workshopping the answers with our new state chapter leaders, parents, early interventionists, deaf educators, audiologists, doctors, general educators, school and hospital administrators, health department staffers, and more.

## **What do we say? At the risk of oversimplifying this, it all comes down to intention.**

Let's start with semantics. Our Personal Belief Systems (PBS) form our opinions, which must be distinguished from objective fact. Our opinions are a set of propositions held to be true based on our own experiences, assumptions, and education. Personal belief systems are unique and inherently applicable only to their author. They may not be accurately extrapolated onto anyone else. Still, we know what we know, right? It's human nature to seek validation of our choices, and to find a true peer group—a set of people who share our opinions and experiences. Many families with newly diagnosed babies want to hear from our own direct, personal experience, and we need to respond at that level as parent mentors and professionals working with families.

However, when sharing from our own PBS, it's important to question our intentions. What's motivating them? Do we have an outcome in mind for this family? What are our preconceived notions, and how are we predisposing this family to our 'truth'? Indeed, what is informing our 'truth'? Has our experience been broad enough to have seen successful kids using a variety of modes or methods of communication, or are we coming from a one-method perspective? Are we couching our statements in a way that represents them as facts, and generalizing them for this new family? Are we sharing information in a way that's skewing the family's decision-making process? Are we relaying misconceptions, (i.e., 'he'll never talk if you sign to him" or "she'll never sign well coming from hearing parents") to this family? What is our body language and vocabulary telling them about our point of view? Do we truly know what's best for them? When we have shifted from appropriately sharing the benefit of our experience and knowledge into intentionally manipulating a family, we've crossed the line into bias.

## From Theory to Practice

There's never been a time when we've presented our Hands & Voices Non-Biased Workshop that we don't become deeply engaged in an introspective question & answer dialogue with the audience. Practically speaking, most of us want to know if it's ok to say 'this' or was it right to suggest 'that'. Some professionals share well-documented examples of a family whom they believed was making terribly wrong choices for a communication-starved child, while others share success stories about kids who rose like a phoenix out of the ashes of such bad choices. We are constantly reminded that sometimes a 'wrong' choice leads to the 'right' decision, and sometimes the 'right' decision leads to the 'wrong' outcome. A common theme for all of this reflection is the confirmation of our belief at Hands & Voices that there is no one right way to do this.

As mentors, guides, interventionists, advocates, teachers, role models, audiologists, et al, we must filter all our input to a family through our sense of respect for their own unique experience. What has been true for any of us, may not be true for them. So we encourage a vocabulary that promotes this value:

- ❖ “Well, I can tell you what happened with our baby, but remember, everybody's situation is different.”
- ❖ “This was true for us, but it might be different for you.”
- ❖ “I think the person with the answers is lying right there in your arms...let's keep looking at what your baby is telling us.”

There are many more effective 'disclaimers' and techniques to use that acknowledge that we simply aren't all going to make the same choices or have the same outcomes. But make no mistake, this is not about being non-committal. Remaining unbiased doesn't mean you can't feel passionately about the communication choice you've made, or righteous about the philosophy you've built your career around, but it does mean you're not going to take your truth and evangelize a new recruit. It means you're sensitive and capable of distinguishing between your experience and someone else's, and that you're above manipulating them with your foregone conclusion. At the very least, even professionals who are practicing with condoned bias (ex: private practitioners or schools with a published communication philosophy) should do their clients the favor of acknowledging their limitations. “I am biased, so you need to take that into consideration here. There may be other viable options for you to explore, and I strongly encourage you to do so,” demonstrates very evolved thinking indeed. It honors the unique experience that family will have, whereas biased manipulation can compromise or destroy the authenticity of the process for the family. Many parents describe those interactions as the point when they divested of all the “help” they were getting from the therapist / audiologist / teacher / mentor or system.

If we release our need or inclination to have someone validate our own choices or PBS, we're providing them with a much more effective means of support. We're empowering

that family's personal investment in their choices, and their ownership of choice is integral to the child's success.

## **The Benefits of UnBiased Support**

Not slanting our input means we avoid having to defend our choices or 'bias' to the family later. Too often arguments of methodological superiority are based on subjectively pointing out the perceived flaws or "inferiorities" of the other methods or modes. Winning an argument on a platform of such "negative campaigning" is really missing the point. (Think about it: does negative political campaigning make you feel great about either candidate—the one slinging the mud or the one with it on his face?) This tactic dismisses and dishonors the integrity and efficacy of all the communication approaches, and it can derail a family's exploration of which mode or method will be a good match to their child's inclinations, abilities, and all the other considerations that play into this dynamic. Whatever the strengths or weaknesses of a given mode or method, they will be realized differently for each child. This is an unavoidable fact. Being unbiased means we aren't committing to an outcome we can't control.

Ultimately, we'll experience greater trust in the relationship with the family when we approach them with an open mind. Encouraging their independent thought serves the greater good: increased sensitivity and awareness of this child-driven process, deeper investment and ownership of their choices, and more effective advocacy for their child.

## **The Need for an Unbiased Support Organization**

At Hands & Voices, we figured out how to co-exist with our different communication approaches in a non-judgmental way that makes families and professionals feel respected when attending our events, reading our newsletter, participating in a training, or contacting us via our website or toll free number (voice or TTY). If we missed the mark for somebody, we tried harder the next time. We haven't been perfect, but over time, we have gotten better at this. Our mission led us to become a driving force in the passage of d/hh legislation in Colorado including The Deaf Child's Bill of Rights, the Educational Interpreter Standards Act, and the bill that created the Colorado Commission for the Deaf and Hard of Hearing. Do we personally agree on the many controversial d/hh issues that confront us all? Absolutely not, but we discovered that we're all on the same page when it comes to wanting the best for these kids. At Hands & Voices, our membership includes many who are also members of AG Bell, American Society for Deaf Children, Auditory-Verbal International, the National Association of the Deaf, and more. We do not supplant these other fine organizations, and in fact, routinely refer inquiries to them and promote their participation on our Advisory Boards. But there is a need for an organization like Hands & Voices that brings us all together. We're stronger united for our children than divided by communication controversy, so respectful collaboration is our mantra.

## **On a Mission**

Would we tell other states how to do this? YES! The only thing better than one state organization that's united on behalf of our d/hh kids is a whole nation working together towards this cause, so that process is already underway. Presently there are Hands &

Voices chapters in Colorado, Michigan, Wisconsin, Illinois, Iowa, New Mexico, Idaho, and start-ups in Indiana, Louisiana, Kentucky, and California. We also have hundreds of individual members all over the country (even internationally). Our Hands & Voices National endeavors are now benefiting from the financial support of the Marion Downs National Center (MDHC) in partnership with the Center for Disease Control (CDC) in Atlanta, Georgia. This funding will enable Hands & Voices to provide outreach and support to our state chapters, and to start-up efforts. If you're interested in becoming a new Hands & Voices member, or in starting a chapter in your state, you'll find everything you need to know on our website, [www.handsandvoices.org](http://www.handsandvoices.org). Contact us there at [parentadvocate@handsandvoices.org](mailto:parentadvocate@handsandvoices.org), or you can call us at 1-866-422-0422 (V/TTY).

It's going to take all of us uniting our efforts to change the world for the better for children who are deaf or hard of hearing. If we commit to this, the next time the Smithsonian calls, we'll be ready to say "yes, let's celebrate how many ways there are to live life as a person who is deaf or hard of hearing."

*by Leanne Seaver, Copyright 2004 to Hands & Voices.*