

# "We choose to unite ourselves for new purposes."

Lennard Davis

By Leeanne Seaver, Executive Director, Hands & Voices National

Here at Hands & Voices, we know we don't live in a perfect world, but we can easily envision one. In a perfect world, we'd have a staff of paid personnel, real offices, at least a part-time lobbyist at the capitol, and on-going, sustainable funding for our organization. In a perfect world, our children (and students) who are deaf or hard of hearing would leave the nest of our homes and schools fully prepared for a rich, fulfilling future both professionally and socially. I was about to say that there wouldn't even be a need for a Hands & Voices in a perfect world, but I can't make that claim. As long as the need to connect with others on common ground remains part of the human psyche, a parent-driven organization like Hands & Voices will always be relevant.

### "Who Are Those Guys?" (Butch Cassidy)

We are Hands & Voices. At ten years old, the new kid on the block compared to our family support cohorts, the American Society for Deaf Children, and the Alexander Graham Bell Association. Each organization fills an important niche in the broad community of individuals who are related by blood, career, or interest in deaf or hard of hearing (DHH) people and issues. We share many goals, but are occasionally asked is unique about H&V. Here's what we say (in **bold**):

#### **Crossing the Great Divide**

First and foremost, it's important to realize that Hands & Voices doesn't supplant ASDC or AGBell. In fact, most of us at H&V are also members of those organizations for the

great information, networking and resources they provide to us as individual families and professionals. Both are doing important work, and there's more than enough work for us all.

Historically, many families affiliated with these existing support organizations based on their communication methodology or modality choice. Generally, the signers belonged to ASDC, and the oralists joined AGBell. There wasn't a lot of congeniality between the two. Times have changed, and I don't think the boundaries are so deeply drawn nowadays between the groups, at least not at the national level. But a decade back, the big divide between modality camps fighting the "methodology wars" was the status quo. That just didn't work for a small group of tenacious parents and like-minded professionals in Colorado. So we decided to come together on issues that weren't based on or associated with a communication ideology or philosophy. Voila! Hands & Voices was born. And we've been growing exponentially ever since.

The need to unify on some important issues is critical as we work to genuinely impact and improve the systems and programs designed to serve us as families. We need the strength of pure numbers of us demanding the same thing: better educational and social outcomes for our kids--regardless of how they communicate.

You can read more about how Hands & Voices got started and why on our website at <a href="http://www.handsandvoices.org/about/rallycry.htm">http://www.handsandvoices.org/about/rallycry.htm</a> or <a href="http://www.handsandvoices.org/articles/fam\_perspectives/wo\_bias\_V8-2.htm">http://www.handsandvoices.org/articles/fam\_perspectives/wo\_bias\_V8-2.htm</a>

#### **Advocacy for All Communicators**

Out of pure necessity, we started honing our advocacy skills and attending each other's IEP meetings early on at Hands & Voices. There were oral families at ASL-family IEP meetings, and vice versa. Across the U.S., this practice is growing in our state chapters. We've gotten to know each other's issues, and how the law speaks to our student population specifically or theoretically. **Direct advocacy training and support that's DHH specific but applicable to all communication modalities and methodologies** continues to be one of the most distinguishing features of our organizational approach. We draw shamelessly from wrightslaw.com, AGBell, ASDC, NASDSE, LRP, case law, or any source for a strategy that may work. This process validated our belief that DHH unity is possible, and highly effective.

## "Nothing About Us Without Us"

When I first read that phrase, I loved how its author articulated **the point of a parent-driven organization** so beautifully: if you want to know what families really need, let us lead! Then I learned that "Us" refers to "Deaf" people, and its author is the NAD powerhouse, Roz Rosen. So forgive me for co-opting the message, Roz, just briefly to make a point. Parent perspectives produce better, more effective, user-tested programmatic results, which is why Hands & Voices is a parent-majority, parent-driven (but professionally collaborative) organization. "Parent-driven" means that our agenda is

always filtered through a parent perspective for applications to our real-world situations and needs...then influenced by our knowledge of the "systems" that serve us, to which we return feedback and "end-user" knowledge. It's all quite symbiotic!

#### **Affiliation & Collaboration**

Hands & Voices has partnered with many other agencies and organizations, including Family Voices, AGBell and ASDC on important projects including:

- . Research and production of The Parent Funding Tool Kit (with AGBell in Colorado)
- . Co-chairing proposed legislation committees (with AGBell in Colorado)
- . Co-presentation at state and national conferences (with AGBell & ASDC at EHDI '07, at the 2008 AGBell Convention)
- . Advisory input to national committees on which we sit with ASDC and AGBell colleagues including the national Deaf and Hard of Hearing Alliance (DHHA)
- . Routine family referrals to all of these organizations
- . H&V Families First Awards to leaders in both organizations
- . Solicited contributions from these groups on selected topics in our "Communication Considerations" series
- . ASDC and AGBell are invited members of the H&V National Advisory Board

# **Our Many Fine Features**

- . We do not nor have we ever promoted one form of *communication* over another.
- . Hands &Voices *chapters* can be established at the local level, with memberships feeding the chapter (not our national organization) to build strong networks and support where it's most needed and effective—right where families live.
- . Members of our organization including chapter leaders feature *a diversity of communication choices* from ASL to Cochlear Implants to Cued Speech to Oral to Total Communication, and combinations of any.
- . Hands & Voices serves families across the full spectrum from unilateral hearing loss to profoundly deaf.
- . We believe in *parent leadership, and provide on-going* training to prepare parents to take on roles of leadership and influence; then we leverage parents into positions of influence whenever possible. The annual Hands & Voices Parent Leadership conference is the only one of its kind available to families with deaf or hard of hearing children.
- . Parents and professionals work as colleagues and peers at Hands & Voices; *there is no professional hierarchy*
- . Hands & Voices develops its own programs to meet the needs that have been identified by our parent and professional membership. Our *Guide By Your Side* program is an example of this initiative: Parent Mentors and Deaf or Hard of Hearing Adults provide invaluable guidance to families with DHH babies, children and teenagers.

- . Hosting a *website where we bring many points of view* together in articles from individuals and families sharing their own experiences, insights, auditory-oral values or Cultural Deaf perspectives—all in an atmosphere of respect.
- . Finally, we believe that we can make a difference. We're ready to change the world for the better for our kids. One great example of this is the *website repository of all deaf education reform activities and documents*, <u>www.ndepnow.org</u> that created, underwritten and maintained by Hands & Voices.

## "We choose to unite ourselves for new purposes." (Lennard J. Davis)

In a perfect world, families make good choices for their children about communication, language, education, socialization, and a thousand other things. In the real world, those choices don't always have clear and simple answers. Which way should we go? If we only had a map drawn by someone who already passed this way... Better still, a really detailed map left by lots of people who've found many different routes through. That would be the Hands & Voices map. Your journey with your child will be uniquely your own, and Hands & Voices National along with our chapters and start-up group efforts in over 35 states across North America (and growing internationally) have banded together to help you make it. Contact us via our website <a href="www.handsandvoices.org">www.handsandvoices.org</a> and join us as we try to make our world a better place for all children who are deaf or hard of hearing.