Hands & Voices' Family/Professional Model for Effective Advocacy: Reflections on Training

By Janet DesGeorges

I was surprised by the call. It came from someone I knew, a high-powered attorney, who was raising a deaf child. He wanted me to come with him to advocate for his son's Individualized Education Program (IEP) at their upcoming meeting. As a trainer and educational advocate, I am often requested to attend such meetings. Still, his desire for my presence surprised me. Who better than a lawyer to advocate for the IEP goals? Who better than a lawyer to explain the needs of his son to the school's teachers and professional support staff? However, this dad told me that he had not felt his input was respected at the meetings. In fact, he said, he had never felt his input so discounted as in the IEP meetings he had recently attended.

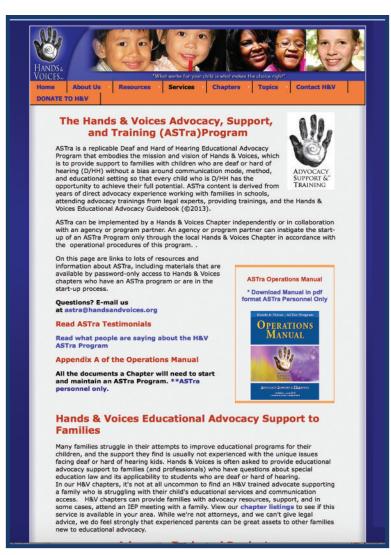
Whether as an educational advocate sitting through scores of IEP meetings with families who feel like they have to fight the system for basic access for their deaf or hard of hearing child or as part of our work at Hands & Voices, the parent support and advocacy organization that supports families who have deaf or hard of hearing children whatever their communication preference or educational placement, I often feel like we are taking "one step forward, three steps back" in our work for educational systemic improvement. Why? Partly because progress towards successful outcomes for students who are deaf or hard of hearing is an individual experience, and solutions for deaf and hard of hearing students are often complex. Partly because each child's education is affected by the policies, laws, people, and politics of three historically different professional fields—education, special education, and deaf education—and this makes advocacy complicated.

As those who care about deaf and hard of hearing children's education, we do not just advocate for a child's communication, language, literacy, and social-emotional

Photo and illustrations courtesy of Janet DesGeorges

Janet DesGeorges, cofounder and executive director of Hands & Voices, serves as a trainer for the Hands & Voices Advocacy, Support, and Training Program. DesGeorges believes in educating deaf and hard of hearing children through a parentdriven, professionally collaborative approach. She lives in Boulder, Colo., with her husband, Joe, and has three daughters—Leah; Danielle; and Sara, who is deaf/hard of hearing. DesGeorges has presented to groups worldwide about the experiences of families as they journey through life with a child who is deaf or hard of hearing. She welcomes questions and comments about this article at janet@

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development. We must advocate for all these things, and we must do so in systems and within a world where deafness is often not understood. Further, even within the Deaf community and among parents and educational professionals, opinions differ. Stakeholders often argue about student communication, language, and school placement; proclaim what is right; and apply it to all deaf and hard of hearing children. At times, it's enough to evoke a sense of hopelessness for any advocate. Thankfully, the law provides for parental input, and this is a critical component for successful student outcomes. Meeting the needs of a deaf or hard of hearing child is not something to be negotiated by teams whose members each have different motivations for what the outcome might be. (Team members may have motivations as diverse as saving the school system money or the overarching importance of a single communication methodology; some may simply lack information.) It is something that should be based on that child's needs as a unique individual, and this is most appropriately represented through the parents.

Enter Promising Practice

Hands & Voices Advocacy, Support, and Training Program

Hands & Voices has been conducting training informally and formally with parents and professionals for many years. In 2015, we launched the Hands & Voices Advocacy, Support, and Training (ASTra) Program with a belief in parent-educator partnership at its core. Rather than creating separate trainings for parents and professionals, we believed that what we had to say from the parent perspective could be helpful for professionals as well. The dual parent/professional focus and the sometimes intense but respectful discussions that follow benefit both groups. Parents learn about the stressors that tug on professionals, and professionals learn about the frustrations of parents; both learn and work together towards more effective education for deaf and hard of hearing students. We consistently receive high ratings from professionals and parents, and a new sense of shared purpose often arises towards the end of each session.

ASTra embodies the mission of Hands & Voices, which is to provide support to families with children who are deaf or hard of hearing without a bias around communication mode, method, or educational setting so that every child who is deaf or hard of hearing has the opportunity to achieve his or her full potential. The content of ASTra trainings is derived from years of direct advocacy experience working with families in schools, attending advocacy trainings from legal experts, providing trainings, and the *Hands & Voices Educational Advocacy Guidebook* (DesGeorges, Johnson, & Seaver, 2013). ASTra offers a flexible program to provide parents and professionals with resources that focus specifically on deaf and hard of

hearing educational issues.

ASTra offers training on three levels:

- Basic Training Level 1—Tailored for parents, family
 members, and professionals, this training is for those who
 seek to increase their knowledge and skills in advocating for
 their own child and the children with whom they work.
- Advocate Training Level 2—Intended for parents, deaf and hard of hearing adults, and professionals, this training is for those who seek to be designated Hands & Voices ASTra advocates, to advocate for families other than their own as official representatives of Hands & Voices.
- Train the Trainer Training Level 3—Designed for parents, deaf or hard of hearing adults, and professionals, this training is for those who seek to become ASTra trainers themselves.



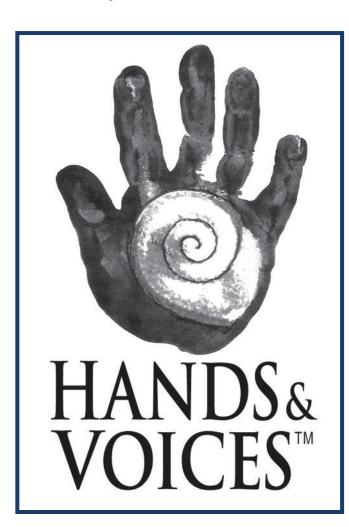
Moving Forward:

Treasuring Hope

Despite my moments of despair, I see and participate in important moments of progress and hope. Recently, for example, I attended an IEP meeting during which the professional team struggled to qualify a hard of hearing student for services. While the team focused on academic scores, the family—understanding the need for the presence of other deaf and hard of hearing students in their child's life—focused on issues that were more social-emotional. As I watched, the professionals addressed the family's concerns and discussed them openly. Ultimately, they were able to ensure services by assessing the student's needs based on the family's input and utilizing the appropriate assessment tools.

Partnerships between parents and professionals have the potential to create a brighter future for all children, and partnerships are growing. They are evident in movements such as:

 The Radical Middle (http://radicalmiddledhh.org), an organization that attempts to bridge the gap between research and practice in deaf education





Above: DesGeorges with her daughter Sara, who is deaf/hard of hearing.

- A.G. Bell/Lead-K Agreement (www.agbell.org/Resources/Articles-Documents/View/AG-Bell-Statement-on-LEAD-K-Agreement), two organizations coming together to support state-level legislation efforts for all deaf and hard of hearing children
- Common Ground Project (www.ceasd.org/childfirst/common-ground-project), which seeks understandings across different school settings

In each of these groups, individuals come together with a common goal and willingness to truly partner.

When I have my moments of despair, I reflect on the work of Hands & Voices, bringing together the parents, professionals, and, above all, the students we have assisted and the partnerships that have been formed based on shared understandings and, at times, compromise. I predict partnerships between educators and parents will continue to gain momentum; these partnerships will help us emerge into a better future and allow all our children to receive the education and access that is their birthright.

Reference

DesGeorges, J., Johnson, C., & Seaver, L. (2013). *Hands & Voices educational advocacy guidebook*. Boulder, CO: Hands & Voices Publishing.



Partnership: More Than Cooperation

By Janet DesGeorges

Partnership is ... a relationship where professionals and families share power to plan and deliver support together, [each group] recognizing that [the other has] vital contributions to make in order to improve quality of life for people and communities (National Co-Production Critical Friends, 2015). Often groups use the term *partnership* when, in fact, partnership is not at all what they have in mind. The following shows the levels of support and assistance that accumulate to result in a relationship that may be considered a partnership (Craig, 2004).

- 1. Coexistence—Parents and educators may be aware of each other but do nothing to elicit support or assistance from each other:
 - Families and family-based organizations know about professionals and professional systems and vice versa, but neither seeks out or works with the other.
 - Direct relationships between families and professionals are nonexistent.
 - There is no interdependency or perceived need to collaborate.
- **2. Networking**—As parents begin to get involved with children's education, contact with educators leads to increased awareness on the part of both parents and educators about ways each can contribute to the education of children:
 - Informal discussions are held with families and professionals.
 - Information is shared.
 - Formal visions, missions, or tasks do not exist between parents and professionals.
- 3. Cooperation—In response to individual challenges, parents and educators begin to cooperate on discrete issues:
 - No long-term relationship is implied; no ongoing or formal commitment to each other exists.
 - Parents and educators may acknowledge some common issues, interests, and agendas.
 - Some documentation may exist that parents and families are formally working with professionals.
- **4. Collaboration**—Parents and educators are aware of the importance of each other's contribution to their child's education and anticipate each other's input as decisions are anticipated:
 - Trust begins to develop; it is based on negotiated and agreed-on actions.
 - Shared decision making exists.
 - Families and professionals feel they add value to each other's work.
 - Each may give up some power or control; each may experience a cultural shift.
- 5. Partnerships—The importance of working together is accepted, and parents and educators rely on each other's assistance:
 - Parents, families, caregivers, and professionals work from an agreement based on shared values.
 - Risks, rewards, resources, accountability, vision, ideas, and decision making are shared.
 - Each accepts formal relationship obligations; accountability exists for families as well as for professionals.
 - Supporting structures, processes, systems, and mechanisms are developed. There may be employment, funding, or contracting of parent partners within the educational agency.

References

Craig, D. (2004). *The potential of partnership*. Waitakere, New Zealand: Local Partnerships and Governance Research Group. Retrieved from www.waitakere.govt.nz/ourpar/pdf/potentialofpartnership.pdf

National Co-Production Critical Friends. (2015). *Co-production of healthcare service*. Retrieved from http://qualitysafety. bmj.com/content/early/2015/09/16/bmjgs-2015-004315.abstract