



Transitions in Advocacy: Confessions of a Controlling Mother

By Janet DesGeorges

Janet DesGeorges is the Executive Director and co-founder of Hands & Voices Headquarters. (www.handsandvoices.org) She is the parent of a daughter, Sara, who is deaf/hard of hearing.

From the moment my daughter Sara was identified with special needs, I began the journey as a parent of learning how to advocate for her needs. For many parents, becoming an effective advocate for their child may not occur naturally but is something that is learned over time and modeled by other parents and the professionals that serve them.

I'll always remember the day I stood in front of a room full of people, where I was sharing the story of my involvement and advocacy strategies as a parent in navigating the medical and educational systems that were serving our family. One of the professionals raised her hand and commented, "I wish we had parents like you in our state." I was flattered, of course. But later as I began to reflect on that comment, I began to think of the hundreds of families I have had the honor to meet through my work as a director for a non-profit organization, Hands & Voicesⁱ, and realized – of course there were "other parents like me." I knew that I was not born a natural advocate and had learned the ropes along the way.

My daughter Sara is now 21 years old. When I look back on my advocacy efforts for her educational and medical needs, I am really proud of that. But what I would like to share with you in this article are some reflections on moving from my identity as *the* advocate for my daughter Sara to that of a support role, or as in the words of Eileen Forlenza, moving from 'Advocate to Ally.'

It is pretty easy to slip in to your own role and self-identity as that of an advocate, and because it is so empowering, a role that may not easily be relinquished if you're not careful. Here are some tips that helped me over the years 'let go' and let Sara take the lead:

- **It's not about you.** Always remember the point of advocacy, which is not about you, but about your child. In other words don't let *empowerment* go to your head!
- **Let go of the idea that your child will make the same choices as you did for them.** Start early and often in allowing your child to begin to make decisions on their own, when possible. In our case, we needed to make decisions on behalf of Sara when she was very young, but as she grew, she was able to clearly begin to decide what was working and what was not. On occasion, I really fought her when she wanted to make a different choice than one I had thoughtfully made for her earlier in life. I had to learn that decisions I made for her were not necessarily right for her from her point of view later in life. In the words of my friend and author of the book, *The Parenting Journey*², Karen Putz puts it, "Sometimes on the course of the journey of raising deaf and hard of hearing kids, the path changes in ways we can't imagine. As our kids get older, they begin to weigh in on our decisions and make decisions of their own. Sometimes their decisions go against everything we've known on the journey."
- **Professionals need to 'let go' too.** When working with professionals, make sure that they are also transitioning to your child's articulated needs rather than your own areas of focus for your child, and for that matter, the professional's focus. (sometimes they are the same, sometimes not) I remember the first time I was sitting in the Doctor's office and thought, 'the doctor really didn't need my input at all today - this was between Sara and her in defining what her needs were. Sara was eight years old and able to articulate clearly what intervention was working and what was not. I was amazed.
- **'Letting go' might look different for each of us as parents.** There is a continuum of 'letting go' for all of us, based on the individual needs of your child. Some of us will really get to loosen the reins, where others, due to their child's needs will need a

more 'in between' approach of transitions in advocacy. Be that as it may, there is a place for ALL of us to let go and let our children lead, according to their capabilities.

The most amazing result for me – as a parent who had the privilege of learning the importance of parent involvement and advocacy from some amazing professionals and other parents who have shaped my life – was to see my own child begin to effectively advocate and take personal responsibility for her own education. My daughter, due to her disability, was statistically expected to do poorly in school. I began to see that she had been watching me all these years. She learned advocacy skills from me. She learned that she had a right to stand up for herself and her needs. She learned accountability and responsibility, which resulted in a successful education with opportunities to follow her dreams. I was able to begin to lessen my role as an advocate in her education as she began to take it upon herself. After all, what is the point of families being meaningfully involved and effective advocates unless, at the end of the day, our children begin to take that mantle upon themselves and create a positive cycle for the next generation of parents and children that are coming along?

The author can be reached at janet@handsandvoices.org and welcomes your comments and stories

ⁱ *Hands & Voices* is a family support and advocacy organization for families who have children who are deaf/hard of hearing. More information can be found at www.handsandvoices.org

²Putz, K. (2012) *The Parenting Journey: Raising Deaf and Hard of Hearing Children*. Barefoot Publications