

Embrace the Past, Change the Future

©By Janet DesGeorges

This speech was given by Janet DesGeorges, Executive Director of Hands & Voices at The Deaf and Hard of Hearing Program Presentation Thriving Together Friday, May 5, 2017 Boston Children's Hospital.

I am the mom of a beautiful, smart, talented accomplished well educated Deaf/Hard of Hearing daughter named Sara.

18 years ago, I sat in a meeting hall at an ASL Deaf retreat where the entertainment one night was a group of Deaf individuals who performed a satirical skit about the ineptitude of hearing parents of Deaf children.

*I said in my heart, "I **am** hearing, but I am Sara's mother."*

12 years ago, I sat in a medical conference surrounded by hundreds of physicians who were listening to a passionate lecture on genetics and deafness. At the conclusion of the presentation, the Researcher stated, "...and the eradication of deafness is at hand", which received a standing ovation.

I said in my heart, "my deaf daughter will not be eradicated."

10 years ago, I sat in an educational conference surrounded by thousands of special education directors in the audience, and every time the presenter used the term 'parent' she put the word 'angry' in front of it.

I said in my heart, "that is not how it has to be."

In my work at Hands & Voices, every day I am surrounded by parents of children who are Deaf/Hard of Hearing, where we share the journey of raising our children – who desperately need the support of D/HH individuals, medical professionals, and educators to help us ensure success.

But you must capture and know our hearts if you want to partner with us in this journey.

(I know what you are thinking right now... man, she sure goes to a lot of conferences...)

Of course those are not my only stories. My life experience is woven with a rich fabric of deaf individuals who have come along side me, have not judged me, have sometimes challenged me in a good way, and ultimately helped me to open the door to my heart to make decisions for my daughter based on her needs as a deaf child, and look beyond the filter of my life as a hearing person.

There have been audiologists and other professionals who have come along side our family and supported our choices and also made technology useful and functional in the real world for Sara, and given her the freedom to use her technology when and how she wanted to, and to be in control of that as she grew up.

There have been educators who have stood up and demanded educational excellence from my daughter, from her schools and not backed down when it came to her communication access, and also provided me with the tools to be effectively involved in her education.

The thousands of parents at Hands & Voices have their own stories that have framed their journey, and though I am the one up on the stage today, I carry their stories in my heart as well.

Regarding Deaf Education....

DEAF education/deaf EDUCATION

I met a deaf educator who left the field of deaf education to immerse herself in traditional and new models of education for all students and came out the other end telling me that we must never minimize either of the words when talking about DEAF EDUCATION. We must never dissect these two aspects apart from one another. Yes our kids are Deaf AND yes our kids need an education. Let's call the Deaf Education.

Not just the what but the how

It's not just about what we know or don't know about deaf education. It's not just about communication, language, literacy, and social/emotional development of Deaf children. We must now advocate for these things in a system and a world where it's not often understood.

But when it works well, it can be brilliant.

Here is one tiny snippet of one tiny issue during one tiny piece of a 13 year old's day at school. A mom went to the school and said that she had been arguing with her daughter about homework every night. Her daughter said she didn't have any. Was this a communication access thing? Was it a teenage thing? Was it a school thing?

It got worked out...

Every day the teacher in the classroom, when announcing homework assignments said it both verbally, making sure she was facing the student (who used an FM system and lipread), and also then turned and wrote it on the board to provide visual accommodation. The student could also turn and look at the sign language interpreter who was also there for her. The special education specialist in the school had arranged with the general education teachers that homework assignments would come to him and then also be posted for parents to have access to, so that they could check in with the student and help with any homework as necessary.

When all team members are pulling together, access happens!

The Power Seat of Advocacy

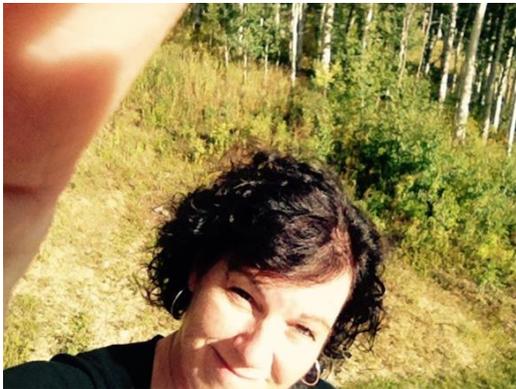
I'll always remember the father who called and asked if I could come to the IEP for their son. I knew this Dad, he was a high powered attorney. He told me that he had never been into a meeting like IEP meetings where he felt so discounted in what he had to say.

Even if the law provides for parents to be at the table we must continue to create a future where true collaboration exists, and where meeting the needs of deaf child is not something to be negotiated by teams who all have different motivations for what the outcome might be (fiscal, methodological, lack of information) but be based on that child's needs, as an individual who is unique. We must continue to create this in our educational system and to have hope that this can be accomplished.

Parent Advocacy

One day I was in the mountains of Colorado and the sun was setting in a beautiful grove of Aspen trees. My husband is a professional photographer so I barely ever take pictures, but I was alone, so decided I would take a picture of this beautiful scene. As I was standing there, I thought, "I think I'll do a selfie with me in front of the trees." I don't do selfies very often, so I kept trying to figure out how to hold the camera, press the button, and get both myself and the trees in the photo, while still trying to capture the beautiful light in that moment. As I was juggling the camera, at the very last moment, I remembered my friend had told me that if you take a selfie looking down on yourself from above, you look thinner, so I held the camera up high, and then took the shot.

Here it is.



When I think about the power of parents, parent engagement, parent advocacy, parents whatever...ruling the world - I think of this photo.

If we as parents forget what the point of all this is.... In this case our children who are D/HH - it's not about ourselves as parents – we will miss our goal. Beautiful, light filled successful children. We do not need to put ourselves in the middle of the picture. We want to stay clear on whose ultimate journey this is. But as Parents - we are the holders of the camera, we are the photographers in our children's lives, we are the ones with the right and ultimate responsibility to frame the picture and ensure a good photograph. But we could use your help (educators, health professionals, Deaf and Hard of Hearing adults) in framing the photo and knowing how to use the camera.

I challenge you today

I challenge you. Whether you are a Deaf individual, a researcher, a teacher/educator, a medical professional - don't forget that the point of all this is not about you, just like it's not about me....it's about our kids, each one individual and unique.

If you commit to doing that, so will I, and so will all parents who only at the end of the day want their kids to succeed. But if we stay separated as we have done over the centuries, I don't know, truly if there is any hope.

I am not a Pollyanna, I know that we will not all agree in this room and/or across organizations and systems. Ghandi said, "Honest disagreement is often a good sign of progress" But we have no hope if we only focus on our own selves. I am so enheartened by movements right now in the field like the Common Ground project and the Radical Middle, and of course...Hands & Voices.

We must stand together...

I am learning that everyone has a story and is a human being behind their 'role' in this conversation. We often come together in rooms where we do not stop to listen and reflect on different perspectives in deaf education – and partly because we do not view one another as human beings with respect. I know that the history of deaf education over the past 200 years has been played out with passionate forces each clamoring for their stake in education of Deaf children. The stories I shared with you at the beginning of this presentation are my stories, and I know each one of you brings your own story to this conversation, and I thank you for it. I carry in my heart those who have come before us to make a path for my daughter today. – whether they communicated like my daughter does today or not. I am grateful for those in this world who are passionate and fight to keep the path for all our kids.

I am a mom of a beautiful smart talented accomplished well educated Deaf/Hard of Hearing daughter named Sara. Does she speak or does she sign? Does she use both or not? Why does that matter? For my daughter or for any of our daughters or sons who are successful human beings in this world. Yes – we must all stand together to help our children attain success

through one means or another, but the light on the trees must be successful outcomes for ALL kids, not the means by which we achieved it.

Thanks to the organizers of this extraordinary opportunity to be a part of this experience today.