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A career working with parents of children with disabilities

BY GARY SHULMAN

My first week on the job as an advocate at Resources for Children with Special Needs was almost 25 years ago. I was fresh from serving as the special-needs coordinator for 10 years at the Brooklyn Children's Museum, where I got to play and revel in the wonderful artifacts and collections. I was all enthused and ready to change the world for the better.

So, as a very inexperienced advocate, I picked up the phone one day, and on the other end was a very thick accent that I quickly learned was Pakistani.

"How can I help you?" I eagerly responded.

"My niece is going to die!"

Suddenly, the reality and importance of this new journey I had chosen became crystal clear. Was I up to that task? Well, you never know unless you give it a try and dive in head first! I probed further, barely able to understand this gentleman, but what I was able to decipher was that his young niece had a very serious heart condition and his family could not find nor afford a medical facility where he lived. Of course, where he lived was Pakistan! I was told that my position entailed serving New York City families only — that was our mandate. So, the question was, do I tell this gentleman, "Sorry, sir, but I am a cold-uncaring bureaucrat," or do I live by what Plato had taught me — "be kinder than necessary because everyone you meet is fighting some kind of battle." Isn't it all about making

this world a better place?

Ignoring the mandate to only serve city families, within a two-week period of time, I found the Gift of Life program on Long Island, which performs free heart operations, and agreed to perform the operation if I was able to bring the family to New York. I feverishly contacted all the airlines that flew from Pakistan to New York — not many! They had all met their quota for free flights for sick children, so my strategy quickly reverted to finding an organization that would just fit the bill of getting them here. Bless the Sunshine Foundation, one of the many wish-granting-type angelic entities, which paid for the flight for the whole family!

A couple of weeks transpired and I again received a call from a gentleman with a

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heavy Pakistani accent — no, not the uncle — but the dad.

“Mr. Shulman, you have saved my child’s life. Thank you! Thank you! Thank you!”

So began this wonderful, heartwarming, sometimes frustrating, but always deeply gratifying, journey of working as an advocate for parents of children with disabilities.

I have learned a thing or two during those many wonderful years of supporting parents. And when I say parents, I mean all those who have raised and nurtured children with special needs — including foster parents, adoptive parents, birth parents, and all relatives and friends who have dedicated their hearts, souls, and spirits to the task of maximizing the abilities of those children while tirelessly fighting for rights, entitlements programs, and services.

The caregivers I have met have taught me to appreciate the small joys and pleasures in life. Those are profound in their impact on the human spirit. I remember during one particular workshop where I, of course, had my agenda to complete within a given time period, a parent shared that her child was just diagnosed with an autism spectrum disorder. I acknowledged her sharing, thanked her, and proceeded to continue with my lesson. That quickly came to a halt when a mom stood up, walked in front of me, took that parent in her arms and hugged her — both crying with cathartic tears. That’s what needed to happen!

I learned a very important lesson that day. Stop and listen, really listen. Know what is truly important, and let the parents lead, teach, and share


as only a parent of a child with a disability can. That wonderful parent who interceded on that day, a dedicated self-advocate with two children both having disabilities, left this world a few years later, stricken down with cancer. To me, her legacy will always be the lesson she taught me on that day — stop, listen, react with compassion, and do the right thing.

I left my position at Resources for Children with Special Needs in November of 2013 to transition to private consulting and providing training to professionals and caregivers of children with disabilities. My gratification continues, as well as my journey of enlightenment.

So, what’s my point in all this? There is value in every child. Caregivers of children with disabilities need to be heard. This is a very imperfect world, but there is richness in that imperfection if you just stop and see, hear, appreciate and give, give, give. This life I have chosen is a life so many selfless caring people have also chosen. They are teachers, therapists, volunteers, social workers, advocates, para-professionals, and on and on.

Parents of children with disabilities teach us that small victories are all around us and need to be treasured. We are all in this world together. Life is about leaving this world a better place than we found it. That takes a team effort. I am proud to continue being part of that remarkable team.

Gary Shulman is a private special-needs consultant and trainer in New York City. His passion is helping and supporting families of children with disabilities. He can be reached at (646) 596-5642, or shulman.gary@yahoo.com.



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