Takes a village

BY TAMI A. GOLDSTEIN, WLMT, CST

It wasn’t really an interest of mine to seek or join organizations until I was in a new town, in a new state with no extended family nearby, no friends and a husband working forced overtime and traveling. I soon realized I had no support system. Who would pick my children up from school if they couldn’t get in touch with me at work?

Then my daughter, Heather was vaccine injured. Her health deteriorated into autism, seizures, severe allergies, sensory processing disorders and many other health, behavioral and educational concerns. Where would I get help? How do I decide what are the best options? Who would I ask for advice? Who could I ask for recommendations? How do I make knowledgeable decisions regarding her issues if I didn’t have people I could trust to ask questions, give me insight or use as a sounding board? Two heads are better than one, and my emotional meter was on high; my child was ill! Doctors were suggesting institutionalization, many more pharmaceuticals and they simple weren’t working!

This was my catalyst to become a joiner and the benefits pleasantly surprised me. Initially, I joined autism groups in the hopes I would learn about autism. There was a wealth of information and some wonderful parents who were going through the same journey. We could cry, commiserate and learn together.

We quickly learned autism is a syndrome disorder with many facets requiring many therapies and many different types of therapy. We parents dispersed quickly into new organizations to learn the therapies that addressed our child’s needs.

We also learned the power of networking. How great to have a room full of Moms/parents whose kids exhibited a similar behavior? We could get information quickly from unbiased sources willing to give us free insight into the appropriate therapy. The average cost to get a child to functioning recovery is about $70,000 per year; so any help we could get to narrow down which therapies may best suit our child was a godsend!

For the record, now there are hundreds of different therapy options, but not all are suited for your child. The best chance at recovery is finding the combination of supports, medically, biomedically, behaviorally, socially, emotionally, and educationally for your child. Along with some luck and a lot of prayers, recovery is possible for many children.

For our family, Sensory Processing Disorders groups were our next choice. Additional organizations provided continual access to the sensory supports we needed such as hippotherapy (therapeutic horseback riding), music therapy and movement therapy.

We branched out into Biomedical Therapy and their supporting organizations when Heather entered 10th grade. I remembered thinking, “would we ever get on top of this; would it get easier?” By participating with these organizations, we entered into a wealth of information through social media contacts. We could ask parents about dietary help, their experiences with supplements, resources to access supplements, educational questions, and what the recovery process could look like.

Biomedical therapy was needed to understand the special dietary needs and how to cook appropriately. They also educated us on what vitamins and mineral replacements were needed, which enzymes or probiotics to use to repair the gut, and which protocols were appropriate for chelation of heavy metals out of the body. I needed education, and I needed it fast! I joined several sponsoring organizations to gain access to their seminars and information.

We accessed social skills organizations to address social needs, social skill building and educational support groups to augment learning style versus teaching style and augment her education. Whew! What a journey and we still had a ways to go!

The energy needed to sustain this journey was fueled by the fact that it was paying off. Applying the information we were learning was helping Heather; but we still had a lot to learn.

Along the way, it became clear that professional organizations are important because there is power in numbers. And those numbers are needed to address legal issues, bring educational opportunities closer to you, and build a referral system. Networking with others in your profession helps to obtain discounts for products, find a mentor; and meet new people with common concerns.

Organizations provide a wealth of knowledge that brings people together with a common interest, goal or passion.

In writing this, I’m thinking about Warrior Moms, (we know there are many warrior Dads too). But it is the group of people that came together out of passion who risked their reputation, friendships, and subjected themselves to ridicule when they came together to support and organize their efforts. Warrior Moms is a common nickname used in autism circles. I wasn’t sure what it meant at first. I asked how to join this group the first time I heard about it and realized it was a term directed at me too, because I had become this...
Integration because my clients brought me so many specific problems that were not covered and they did not fit a 10 session model. I was spending more and more time going to the FSMTA meetings and conventions and feeling very supported with the people I was meeting and sharing what I was learning. I found osteopathic cranial classes, craniosacral, worked with other cranial therapists and developed Cranial/Structural Therapy that is the “golden nugget” for aligning the core distortion. By this time my work had evolved into Structural Energetic Therapy®, a name that I coined.

For the first time I took a booth at an FSMTA convention to demonstrate my work and found even more support from the FSMTA tribe. CE’s were now becoming a requirement for massage therapists and since much of my work was different from what therapists had learned from other classes I developed CE classes. At one of the conventions the State President of the FSMTA asked me if I would be interested in the State Education Standards chair for the FSMTA. At first I said no, then reconsidered and joined the FSMTA board, eventually spending three years as the state president. Obviously, I found my tribe and have been a member serving in many ways.

My pathway now involves teaching my passion, Structural Energetic Therapy®, which includes the Cranial/Structural work that focuses on releasing the core distortion, and the Cranial/Structural Frontal/Occipital Decompression that has been effective with concussions, Alzheimer’s, autism, learning disabilities, detoxing the brain, and many other conditions associated with the cranium and brain. I am teaching Structural Energetic Therapy® skills nationwide, instructing at FSMTA Conventions and presenting CE programs at FSMTA Chapters. I have also written SET TALK articles since 2000 for the Massage Message. Today I am as busy as ever with a practice in Structural Energetic Therapy®, a busy teaching schedule, and the FSMTA. Yes, my tribe is massage and bodywork and I now am being supported by my involvement in the FSMTA. Thank you for being here!

Please visit our website for more information – www.StructuralEnergeticTherapy.com. You may also contact me through that site with any questions you may have.

THE AUTHOR – Tami A. Goldstein is certified in Upledger CranioSacral Therapy (U-CST) and Massage with over fourteen year’s experience as advocate, speaker, educator & facilitator of bodywork to individuals on the autism spectrum.

> fierce advocate and now belonged in the group.

In this informal organization, I found education, friendship, networking opportunities and support with a unique understanding of the magnitude of raising a child with autism. It brought me insight that no other organization could provide.

This is what happens when your needs veer from the established organizations and the protocols of the establishment.

When Heather was well on her way to recovery, I went back to school and was certified in Massage and Upledger - CranioSacral Therapy. Joining groups that supported facilitating this therapy enabled me to enhance my education, profession and training. Recently, through this aspect of the journey, I have met a number of craniosacral therapists from all over the country who are also parents of children on the autism spectrum. This is yet another organization, those therapists with unique insight into the journey of autism. Some with children who have recovered and many, many others still working on it.

We have reached out to one another; problem solved, referred each other for additional work and personal related issues. The discussion now is working together facilitating therapy for children on the autism spectrum. It is through this organization I realized I was, we were all building our own network.

It takes a village to raise a child, but it takes an autistic child to change the conciseness of the village. Aren’t we all just searching for our village?

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