

The Last Years

One family's journey to recovery from autism

BY TAMI A. GOLDSTEIN, WLMT, CST



My daughter, Heather, was diagnosed with autism just before her 13th birthday. She was vaccine injured into medical and behavioral decline. Every time I asked a pediatrician about vaccine injury, my concerns were dismissed. Due to my husband's career, that meant seven pediatricians in four states by age 13.

I watched my child break down a little more after each vaccine; lose eye contact, stop connecting with people, parallel play, immune system disorders, systemic rashes, severe environmental and food allergies, attention deficient disorder, attention deficient hyperactive disorder, obsessive compulsive disorder, obsessive defiant disorder, and full body tic.

I stopped all vaccines after the hepatitis B vaccine was administered for middle school. Heather deteriorated further. She had a 20 plus pound weight loss while consuming thousands of calories a day. Neurological testing revealed she was having 40 seizures a day; endocrine studies showed she produced life-threatening levels of adrenal stress hormones and sleep studies showed she had no REM cycle in her sleep stage. She disappeared further into a fog.... We would refer to those next five to six years as the lost years.

Eight years of traditional medical and pharmaceutical supports did nothing, and at times, made the situation worse.

I was called a bad parent by multiple doctors; my child was dismissed from their care when I questioned a diagnosis or questioned continued use of failed treatment options.

We had a pediatrician initiate a lawsuit against us after he recommended a child psychologist and a medication change. When I told the pediatrician the child psychologist diagnosed autism, he refused to talk to the psychologist or provide a medication change. When I requested a second

opinion, he dismissed Heather as a patient and refused to relinquish her medical records. The medical facility lost the suit because the pediatrician's

colleagues and the psychologist came to our defense.

Heather continued to deteriorate; new diagnosis included serotonin disorder, neurotransmitter disorder, auto immune disorder and SPD (sensory processing disorder).

The educational domain was just as difficult to work with.

In 7th grade, the child I dropped off at 8am was not the same child I picked up at 3pm. As is typical for higher functioning autism, Heather would hold everything in during school then breakdown following. Heather's tic became uncontrollable. She would ring her hands until the skin was torn and damaged. After we drove the 3 1/2 blocks home from school, Heather would crawl into a cubby hole in the closet and spend 8-10 hours rocking and stimming. She couldn't or wouldn't talk. Some days her speech wasn't in sequential order or she repeated a mantra like, "can't make head work" or "can't make body work." By 9th grade, the meltdowns would evolve into shut down where she couldn't walk or talk for up to five days.

I would have the term 'Munchausen by proxy' directed at me as school administration implied I was lying about my child's presentation of autism or somehow making her sick.

In a public school your child's uncontrollable full body tic is ignored if they do not qualify for special education. Your child is required to be educated in the same manner as the other students. For my child, that meant during a technical education class she was required to use a band saw, at which she subsequently

sliced the tip of her finger off. There were no special education accommodations to provide for her safety and alter educational requirements.

Occupational Therapists evaluate for SPD, but we were turned away from every therapist in a two-hour radius except one, because they did not want to deal with a school district.

We would learn occupational therapists employed in the educational domain are held to different standards for evaluation and services than their counterparts in the medical domain.

The eight members of Heather's medical team all recommended a modified school day as the best protocol to reduce her anxiety. The pediatrician wrote 12 letters of explanation to my daughter's serious health concerns only to have the recommendation denied by the school district who threatened truancy and juvenile detention for failure to attend a full school day.

I had a meeting with the Director in charge of juvenile detention. After seeing the same medical recommendations I had shown the school, he advised he would not detain arrest or place Heather in juvenile detention.

Thank goodness I thought to call the office of civil rights. Their recommendation was to have the doctor write a medical excuse for absenteeism for the first 3 and half hours of school every day and any full day Heather needed off to address her health. The attendance policy allowed for absenteeism with a doctor's excuse and it would be discriminatory not to honor that.

Boys with autism tend to be overt and aggressive towards others. Girls with Autism tend to shut down or self-abuse. The one and only time Heather broke down enough to hurt herself, it took multiple sessions with a private social worker >

> to find out why. Heather's guidance counselor at school, knowing she had recommendations to be excused from gym, advised Heather it was in her best interest to take gym and not tell her doctor or parents.

Heather didn't want the guidance counselor to get in trouble and was confused who to listen to, her doctors and parents or the counselor.

I informed school administration of the situation and they sent social services to our home. I had been forewarned by other families in the community that this would happen, so I was prepared and nothing came of it.

My daughter would be denied special education eligibility a second time in 11th grade. She was missing 75 days of school a year; could only sustain 3.5 hours in the school environment, had shutdown up to 5 days where she could not walk or talk and 40 seizures a day. The school claimed she did not present her disability in school and passed educational standards.

We learned from our special education attorney, who charged 17 thousand dollars, that the educational definition of autism is different than the medical definition; schools are not required to use current evaluations tools or follow doctor recommendations.

This guarantees to hurt a child with autism medically, undermines any therapy they are getting independently and could be the difference between functioning recovery of autism or not. An increase in maladaptive behaviors and or a decrease in learned skills is the number one sign the child's disability is being impacted.

Independent testing for Heather showed she has a very high IQ, genius level nonverbal problem-solving ability, and verbal skills at a college level, written skills at a 4th-5th grade level that had significantly declined by 8th grade.

Wisconsin does not recognize the same language as the federal law for special education. Federal law recognizes grade equivalents.

Wisconsin educational law recognizes a 1-100 % bell curve, the student must be 4% or below to qualify. Heather's scores were 99 % verbal skills and written skill areas as low as 18%. Educational law does not recognize wide gaps in individuals' raw scores, a typical characteristic for individuals on the autism spectrum.

My attorney explained it would take six to ten years and another 25 thousand dollars to win at the federal level. First, we would have to exhaust the Wisconsin judicial system. As long as Wisconsin law fails to recognize the term grade equivalent, we would lose.

We took a firm stand with the school. Sensory Integration supports for SPD in school were needed to improve her health and well-being. In Heather's presents, we informed the school that she would be attending 3.5 hours a day to learn to modulate her sensory system as directed by her medical team. Over their objections, we informed them that Heather would not serve detention or suspension. Heather was concerned she would not graduate but we assured her she'd get a high school diploma, but it might not be from that school district. There was ample documentation to show why. We supplied Heather with the sensory integration supports needed, and continued to augment her education out of our own pocket as we had since the 2nd grade.

Heather took ownership of her "sensory diet." She reduced her absenteeism from 75 days to 23, increased her ability to sustain from 3.5 to 6 hours and stopped having shutdown periods. Daily, in every environment, she monitors her sensory state, so she can self-access the sensory supports needed in that environment to keep herself in check.

Sensory Integration Therapy, Upledger - CranioSacral Therapy, and Biomedical Therapies are what healed Heather from autism. All considered alternative and none were initially covered by insurance.

Two years we appealed to our insurance company until they approved coverage for sensory integration. Denials were received because Heather was school age and should be receiving those supports in school.

Appeals for the Biomedical therapies to rebuild the damaged immune system would eventually cover the expense for the syringes but none of the therapeutic levels of vitamins and supplements used.

Upledger - CranioSacral Therapy was never covered, but is the therapy Heather says helped her the most. It remains a crucial support for her, which is why I became educated in it, and so I could help others.

These therapies helped Heather come

through the fog and into functioning recovery. She lives a sensory lifestyle and because of it she did graduated high school, a secondary school, and drives, works part time, and bought her own home in 2012.

My husband and I spent every penny we had; we 2nd mortgaged our house, used our retirement fund, charged every cent of credit to our name and borrowed from family to get Heather to recovery.

I wrote Heather's recovery journey in my book, *Coming through the Fog*, to let parents know recovery is possible, provide resources, tips to navigate the schools, help parents juggle the insurance obstacles and so others could see what families dealing with autism are up against.

Bridging the gap between the medical and education domain is imperative for our future. My daughter's health was compromised by the medical domain that refused to even consider that vaccines played a role in her decline in health.

Heather only had 14 dosages of 4 vaccines – I can't image what her fate would be if I was legally mandated to follow the current vaccine schedule of 74 vaccines from birth to age 18.

My daughter's health and education were impacted in the educational domain every time they told her she did not have autism by their definition and therefore was not entitled to access supports while at school.

Sadly, I've learned from speaking to other families, that our story echoes in the homes of children with autism across this country.

When parents ask me how I survived it all, I tell them – there were many times I didn't think I would.

I had to find the patience of a saint, complete flexibility with an endless supply of plan B, C, D, etc. A fast-track education to understand it all, resources I didn't have, nor did I know from where they would come. I kept my running shoes on and prayed I could maintain my emotional sanity because I would be tested repeatedly in ways I never knew parenting could be tested. I was ill prepared and appalled at what I learned which is why I now help kids and families anyway I can.

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