



AUTISM: SHIFTING ATTITUDES ENCOURAGING WELLNESS

by:
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This is a story of gratitude! It will not sound like it in the beginning. I feel strongly about allowing others a peek at the reality of autism after having spent 22 years parenting a child who has had autism as her journey mate.

AUTISM ~ a stark, dark, and lonely place. A place from which there feels like no escape. Children are lost to autism, figuratively and literally. Children should not be losing their families, or their lives, because of a lack of information, understanding, or appropriate assistance.

Those of us chosen to embark on a journey with autism desperately need to be offered hope and an opportunity to create joy from the long list of phrases beginning with, "these kids can't" or "these kids don't," phrases which are heard all too often from well meaning, misinformed professionals trying to fix them...

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Our daughter, Kelly Jo, was born in 1980. She was a beautiful baby girl with brilliant, dark, brown eyes; lights of hope so full of eager anticipation they filled our hearts with joy thinking about the wonderful years ahead of us.



When those lights dimmed at 16 months old and the search for a medical explanation began, we entered the first of many years of frustration. I felt patronized by doctors for six months in my search for answers. When I would ask why she was so tiny, below the graph on all the growth charts, I was literally looked up and down and asked, “Mrs. Hazard, how big do you want her to be, look at you?” (I weigh about 100 pounds.)

One doctor, familiar with our family, actually patted me on the shoulder when I asked about the developmental milestones she was missing and said, “You can’t compare her to Ricky, (our older son with a rather high IQ), although it is quite common to do so; it is unfair to both of them!” I wanted to believe it was just me being an over concerned parent, but my heart knew better.

Finally, at 22 months old, we had our diagnosis. Autism.

I was actually relieved at first because, although I had never heard of it before, it wasn’t the “c” word (cancer), so now that we had a diagnosis the doctors could fix it. They could fix anything as long as it wasn’t cancer, couldn’t they? As I began talking with people about her diagnosis no one else had heard of it, either. I learned that four times more boys than girls were affected and the incidence of autism in 1982 was 1 in 10,000!

We returned to the developmental neurologist who gave the diagnosis, after he had an opportunity to review the tests they had done, and his suggestion was to institutionalize her, seek counseling to learn to live with our decision, and move on with our lives. That was absolutely not an option for us. We were still remembering the lights in those brilliant, dark eyes and we knew there were answers out there, somewhere. . .

We searched for those answers of how to fix it for years. Our family ran a fruitless gauntlet of tests and

interventions presented as ways to cope with, and lay the foundation to change, behaviors that were “just autistic” and in need of modifying.

We tried everything from preschool and school programs intended to offer fresh insight and one-on-one assistance

to a “brain patterning specialist” teaching us how to maneuver our child through a series of floor exercises designed to take her through developmental milestones she may have missed—investigating the philosophy of “you have to learn to crawl before you walk.” Looking back on trying to manipulate a non-compliant, screaming, kicking, biting child into contortions such as the “cat’s cradle” and the “sleepy bear roll” seems absolutely cruel but at the time, in the desperate mode that becomes your way of life, it was something we could DO to try and make a difference that might improve the quality of our lives, and fix her.

We learned everything from sign language to facilitated communication and all about hand held augmentative devices (which, by the way, always became projectiles) as ways we might help our daughter communicate. We visited doctor after doctor for test after test. Psychiatrists, psychologists, educators, occupational, physical and speech therapists, the gauntlet of “professionals” we have seen now fills a five inch binder. Behavior modification plans so carefully designed only seemed to escalate “behavior” and made the words *behavior modification* become a phrase that, along with those well meaning professionals, helped us pave our personal road to hell.

What resulted from those years of chasing the silver bullet to “fix” her? Battle scars, emotional and physical, from the attempts to reach a child so lost. We saw little that was advantageous and nothing that was long lasting in any of our endeavors. A costly lesson in time, money, and emotion.

Our home had become a battle ground. She hardly slept and when she did, it was not a peaceful sleep. The pitch of the screams an autistic child can reach defy description and can go on for days! I watched a relentless and unforgiving clock tick all too quickly

against us and I watched as the lights in her eyes constantly grew dimmer. We were suffering what I refer to as “the beaten dog syndrome.” It got to the point that anyone around Kelly Jo would flinch in anticipation of being struck, if she simply reached to move her hair or scratch an itch.

She would react to the full moon with such aggression and alarming weirdness that I thought she might grow fangs and fur. Not a single professional would acknowledge there might be something to it. I lived it with her, I was conditioned to feel the chronic anxiety because I knew the violence and self abuse would escalate at those times. We would be especially sleep deprived, and during the long night just before the full moon she might possibly break another window with her head. Again, in the search for a reason I was told, “It is just her autistic behavior, we don’t know why they do what they do.”

There were all those times of cleaning fecal smearing from the walls of a bedroom that had become barren, save a toy box nailed to the floor containing only soft, stuffed items that would not hurt as much when they made impact after having become projectiles. A lone mattress placed on the floor so she wouldn’t hurt herself flinging off the bed. No head or footboards to bang her head against as she had done in the past when the only thing left to do with an inconsolable child was to lock her inside that empty room.

Our entire home had become barren. No homey little knick knacks around to define our taste or interest. The ones not already broken were stored away for the time we could “fix” her and our taste and interest turned into the art of surviving. I had become a 24 hour a day caretaker to catastrophe, trying to gauge and conserve energy for the next disaster. You become accustomed to losing friends and family who do not want to be around the volatility, but you never become accustomed to losing your child, the lights now only a momentary flicker, appearing so swiftly and fleeting you wonder if it is wishful thinking when you catch



a glimpse . . . you’re losing yourself. Who were you before?

I tried to find ways to hide or cover the bruises, the dig and bite marks inflicted by a little girl no one could reach, one in such untreatable torment. You hide them for fear of being asked the questions you can’t answer. You hide them because you can’t believe it is happening. You hide them because you are the mom and you are suppose to be able to “FIX” it!

At just about this time, I happened to see the Phil Donahue show whose guest was Dr. Doris Rapp, M.D. She was talking about allergies causing aggressive behavior. One woman in the audience stood up and gave credit to Dr. Rapp for saving her son, who, at one time or another, had broken every one of their home’s fifteen windows with his head! We chased after that protocol for a considerable amount of time restricted by such things as physicians not accepting our insurance and fees for service that were astronomical and untouchable. We finally found a local allergist that accepted our insurance and subjected our daughter to allergy testing in the form of pricking her with needles up and down both arms and all over her back resulting in a diagnosis of “allergic to some molds, not severe enough to warrant treatment.”

Only when we ran out of options, when there were no more phone numbers to call for help, no more suggestions or interventions offered; and when I was being called constantly by the school, from people with fancy degrees to prove they know things and they have answers, to “come and get your child, she’s out of control,” and only when the last resort was drugging Kelly Jo with Mellaril, an anti-psychotic and major tranquilizer to keep her and those around her safe, did we allow the words from the original diagnostician to be replayed!

Indeed, what resulted from all those years of attempting to find the light in her eyes that dimmed at 16 months and now appeared non-existent, was the institutionalization of our daughter at 10 years old due to self abuse and

violence, exhaustion of available programs, funds, energy and emotion.

We took our daughter to a residential school in July of 1991. As I rode away something died inside. My child who had filled me with such hope, love and joy, which had turned to such fear and desperation, was left behind in a place of strangers being paid to take care of her. The people in her local school had been paid to take care of her as well and they were calling me to come and get her when she was out of control. Who were these people going to call when she was out of control and I was three hours away? I went to bed each night wondering . . . Was she soiled or cold, hungry or hurt? When you are not allowed the parental last glance at your child sleeping in the room next to you when you go to bed at night, it is only half living. The questions still haunted me. What happened? Why couldn't we fix it? Where had she gone and why had she gone there?

The residential placement was merely respite for our family. Kelly Jo had benefit of consistency between day and night care and behavior modification programs run by "fresh and rested" staff. Everything we had been told was going to be good for her when forced with the decision of residential placement. Still, we brought her home for vacations with the same "behaviors" that sent her away in the first place.

Four years later, in January of 1995, we received a letter stating her school would close its residential program in June of that year due to budget cuts. Our options were to find another residential program with an available bed or bring her home. Having four years of "respite" behind us I felt rested, ready and willing to run another gauntlet. Placing her in another residential setting felt wrong, yet bringing her home under the same circumstances in which she would return for vacations was not an option, either.

Once again, remembering Dr. Rapp, we began searching for a physician to lead us through a more thorough investigation of the role allergies might play. The restrictions were still there, but we were not as tired and beaten. We chose to view this as an incredible opportunity for a second chance to find our child.

The search led us to Maureen McDonnell, a health education specialist in New Jersey. We made arrangements to pick our daughter up for the February, 1995 vacation from school and drive straight to New Jersey for an appointment.

I will be forever grateful to Maureen for offering us that amazing, albeit intimidating, first step toward the lifestyle change that has produced the kinds of results we previously saw only in our dreams.

It was the beginning of many AHA! moments. As we listened to Maureen talk about the role antibiotics play in eliminating good bacteria (along with bad bacteria) in the gastrointestinal tract and setting the stage for yeast overgrowth, we thought about all those infections that began at two months of age and remained through bringing a penicillin prescription home with us at just about every vacation from her residential school. Chronic ear and upper respiratory infections, bronchitis, diarrhea, the list of illnesses is endless, and not one time did I ever hear the word "pro-biotic."

Armed with the new information, we made the commitment to give it our best effort and brought her home in June of 1995. It was at this time that I learned the incidence of autism had risen to 1 in 500!

I will never forget the look of angst on Kelly Jo's face when she took the first bite of toasted rice bread with cashew butter and puffed millet cereal with rice milk as an alternative to her usual "western breakfast" of white bread toast with peanut butter and sugar rich cereal with whole milk.

As I read my new found information, which included an article called "Autism and Picky Eating" by Kelly Dorfman, I gained confidence in what I was presenting for food. We needed to learn many lessons, not the least of which was how to eat to live, not live to eat. Embracing a more health conscious lifestyle should be the first approach one is encouraged to try, not the last resort left to chance or the availability of information!

In just five days of our dietary protocol, which included the elimination of casein and gluten, and the removal of all foods with additives and preservatives, she was sleeping all night, the rash that had plagued her

disappeared and the most motivating, exhilarating, and phenomenal change was the light of hope, so long vacant from those beautiful, brown eyes, returning with a clarity and brilliance I find no words to describe! My daughter looked at me, once again, as she had all those years ago, with eager anticipation of what life might hold in store.

The key is learning to listen to your child, in the ways they have been given to communicate with you, without trying to "fix" them with wrongful, disrespectful,

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sometimes dangerous interventions, aimed at proving the professionals have the answers.

Often times you are offered valuable interventions that are simply not attempted in the best order, negating the most beneficial results.

Given the opportunity to know our daughter by "peeling away the layers of the onion," as I have heard it referred to, is the most amazing gift I have ever or will ever receive. I no longer live in fear of her. I live in constant awe of who she is and how she survived all the years we didn't know how to listen to her cries for help.

Her behaviors, in need of modification, were symptoms in need of healing. The children of autism struggle with language, that is one of the defining markers for the diagnosis in the first place, many are non-verbal. One can not modify behavior when it is the body's messaging system announcing dis-ease. It will simply offer you a louder and more obvious "behavior" / symptom until you no longer ignore the cries for help and take appropriate steps to end the distress. Too often, once a diagnosis of autism has been made, the professionals you turn to for help treat the body and the brain as separate. A quote from Brenda O'Reilly was monumental for me to change how I viewed my daughter, "Autism is a physical illness that presents itself as a mental

disorder." The body has the amazing ability to balance itself when given the right tools. When I could see my child as the messenger, the proverbial canary in the coal mines that God intended her to be and learn to quietly listen to the song she was singing, we were able to find a place of joy, peace, and hopefulness. A place where we could live our lives as a family, learning and growing together and not merely attempting to survive! Kelly Jo has been my greatest teacher.

Many 'incidents' began to make sense, for example: The

phone calls from school to come and get your child, she is out of control. Not only had breakfast been an assault for her but she was riding a diesel school bus for an hour, with its constant idling producing exhaust while picking up other students who were more than likely full of fabric softener smells, she was sitting in a plastic car seat, being driven by a bus driver loaded with perfume. Top all this off with the snacks she was presented at school upon arrival such as cereal (oats-gluten) or raisins (dried-mold) and you have set the stage for "out of control!"

The lessons are endless and I now look eagerly forward every day to whatever our journey holds in store. We will never recover the 15 years she stayed locked in autism's grip. Our hope is by sharing our story, other families will not spend so much time there and some may have contributions to make that will enhance our journey.

The year after we brought her home I started a support group for autism. I was feeling very isolated because we were now running an all together different gauntlet. A gauntlet of red tape-filled bureaucracy, frustrating, fragmented, and often times contradictory information, all needing to be sorted through and challenged. Having been given the treasured gift of our re-united family, I wished to not only share our story to try and help others, but gain support and assistance as well. I heard

similar stories replayed all around the table during our first meeting, chronic infections, antibiotic use, diarrhea and/or constipation. The MMR vaccine seeming to play a role in the onset of autism but families were lost and struggling because of all the contradiction and expense

of service negating their best intentions. What I was made maddeningly aware of is how much easier the system makes it to send your child away then to help incorporate truly beneficial interventions.

As I listed the amenities which would have served our family best, I kept coming back to how much time was spent looking and sifting through the maze of interventions that can and did take years to wade through. The interventions, paramount to Kelly Jo's renewed quality of life, make us feel isolated and, sometimes condemned, now because we refuse to sit neatly and obediently in society's tidy box.

We have mortgaged our home twice since 1995 to continue providing Kelly Jo with the dietary strategies, and the holistic approaches, proven to offer long lasting and measurable gain so long non-existent in her life. Thankfully we owned our home to mortgage, what about the families that don't?

In 1997, completely frustrated, I began to think, "in a perfect world, Kelly Jo and I should have had the benefit of _____?" The question of where Kelly Jo and I could have turned for guidance was answered when the idea for Kelly Jo's Frontier House for Autism (KJFH) was born.

Since then many steps have been taken toward the mission of providing information and guidance for families affected by autism.

One of our most daunting tasks is to secure funds from corporate and private America ensuring access to this information by everyone ready for change. It should never be left to chance, luck, or being in the right place at the right time, to hear of an advantageous strategy when the cost at a human level is so great. Bureaucracy plays a huge role in keeping useable, life



saving information inaccessible and unattainable for far too many.

Kelly Jo's Frontier House for Autism is dedicated to reaching its goal of providing individualized, effective, affordable care. Our intention is that autistic individuals, along with a

caregiver, will spend time at KJFH learning various techniques for treatment beginning with biochemical and physiological markers. Consultants would assess and interpret the relevant information with the caregiver and the autistic individual. Ways of incorporating dietary strategies, as well as how to record data, will be demonstrated as they are guided through the transition stages of their individual dietary strategy. As they begin to regain their physical health, a staff will help co-create protocols to implement other interventions. These may include access to sensory integration techniques, auditory training, vision therapy, animal and physical therapy, yoga, kinesiology, and a host of others.

In a homelike environment, built as toxin free as possible, we will guide them through and help them use a variety of complimentary strategies which will most respectfully nurture the family in finding its way back to health. With that guidance and support, they will gain confidence to face school districts and professionals upon their return home.

My gratitude continues today for the discovery of the Certified Natural Health Professionals program. I was already a believer in kinesiology due to our positive experience with a local chiropractor using TBM (total body modification). However, try as he may to teach me how to muscle test, it would not work for me. The response I received never felt strong so I was never confident with the answer. It was in the nutrition course for CNHP with Dr. Elaine Newkirk, who now sits on the board of directors for Kelly Jo's Frontier House, that her subtle change in technique made all the difference. What a remarkable find! I no longer had to run the risk of Kelly Jo having a negative reaction to a supplement. I could muscle test to make sure it was what she needed, and given in the right amount. My husband was a true skeptic, but he soon learned that there truly was

something to the Muscle Response Testing and that you don't have to understand how everything works to take advantage of the benefits offered.

I've not only had many more AHA! moments sitting in those classes listening to and meeting individuals who are passionate about creating healthy lifestyles, but also learned more strategies that have created additional positive changes for Kelly Jo. It has given me the confidence to pursue the opportunity to foster change for the under or wrongfully served individuals with autism and their families on a political level.

We now embrace a "first do no harm approach" and are the proud parents of a daughter who has grown from an isolated and feared non-entity, treated almost as if she were an alien, to a beautiful, young woman. She can now go into a dentist's office and have an hour long cleaning with no sedation. If there is a parent of an autistic child reading this, you understand the power of that statement. She can be given responsibilities in the horse barn she helped build after we learned about her love of horses and the benefit they could offer her. She does such things as measure and give their morning grain and push the wheelbarrow.

When we are able to adhere to the strategies which, at the present time must include avoidance of such things as chemicals, perfumes, hairsprays, polyester clothes, air fresheners, fumes from cars and open waste receptacles, to name a few, Kelly Jo can function far above any previous level or expectation. She is loving and intelligent, but we had to first learn to view her behaviors as symptoms and allow her the role of teacher for her to be able to show us that love and intelligence.

It scares me more than I can say because I am still hearing people in decision making positions for autism programs start sentences with "these kids can't," and "these kids don't." How much success will "these kids" meet when the people in charge of creating programs on their behalf start with that pessimistic view of their different abilities.

I remember listening to Dr. Mary Ann Block, a woman who became an osteopath in order to help her daughter with ADHD, and author of the book, "No More Ritalin," finish a lecture with this statement; "Mothers should

not have to go to medical school in order to help their children." Unfortunately, I feel this may still be the case.

The last seminar on autism I attended was October 12, 2003. It was there that I learned the divorce rate is 80% among parents of autism and the incidence of autism is now estimated as high as 1 in 100. The spectrum of the disorder is extreme. The individuals can range from being a little aloof at the high functioning end, to being non-verbal, self-abusive, and violent, at the low functioning end . . . the place where Kelly Jo resided for much of her first 15 years of life. This helps keep the disorder confusing for so many.

We need help to spread the word and we need able bodied people willing to begin listening to these children's song to become involved in helping us reach our goal.

We must rally to forge a new Frontier! To help forge the new Frontier your contributions or inquiries may be sent to:

Kelly Jo's Frontier House for Autism, Inc.
P.O. Box 75, Mannsville, N.Y. 13661

A video chronicle called "A Journey Thru Autism," intended to help raise awareness of the deep pain and great joy life with autism can hold, will soon be available by contacting info@vestedmedia.com. **HK**



Margo Hazard parents a 23 year old daughter with Autism and is Founder and President of Kelly Jo's Frontier House for Autism, a not for profit corporation aspiring to offer a comprehensive program of innovative approaches for this ever increasing disorder. Margo is a passionate spokesperson of an individual with autism's right to reach their truest quality of life by first addressing their "behaviors" as symptoms. She feels this is a much more respectful approach to learn how to help them reach their greatest potential.

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