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Center for Persons With Disabilities

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CPD LEGACY STORY: MADELINE & CALEB GAUTHIER

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We knew when Madeline was a day old that not everything was going as planned. Her sucking and rooting reflexes were undeveloped and she lost an unhealthy amount of her birth weight after her third day of life. We went to a breast-feeding specialist for 6 weeks in an unsuccessful attempt to find ways to help her learn to latch and feed properly. For the first 7 months of her life, committed to providing “the best” for our child, we fed her pumped breast milk in a bottle. She did not allow us to hold her for feedings, cried all the time, smiled little and showed a hyper-alertness that is not typical for most children. For the first three months of her life, she had a burning liquid diarrhea that blistered her bottom. We spent a fortune on pediatrician visits and were continually told we were worried about things that would resolve naturally.

Between 5 and 15 months Madeline did bond well with us, but sensory issues continued to interrupt the natural equilibrium that typically developing infants establish. Eating and drinking remained problematic; she could not tolerate strangers or acquaintances, sunlight in her face, the texture of grass on her feet; she frequently held her hands over her ears.

When Maddie was around 18 months, we began searching desperately for answers and stumbled upon something called, “sensory processing disorder”. We read Carol Kranowitz’s book, The Out of Sync Child and everything started to fall into place. We implemented some of the sensory diet strategies and began to realize we could help our daughter by changing her environment.

One day my mother dared to mention the word “autism”, and we responded with angry defensiveness, but at nearly two years of age, Maddie began turning inward, almost disappearing right before our eyes and we knew she was probably right to be concerned. In a chance meeting that we viewed as divine intervention, a neighbor’s visiting friend from the Mississippi Department of Mental Health did a quick MCHAT and “saw” her autism.

We were dazed but started making calls to get early intervention services involved. Our attempts to reach out for help coincided with an unfortunate investigation of fraud and subsequent freeze on services provided by the Mississippi Department of Health, the administrators of Early Intervention in Mississippi. Getting an evaluation for Madeline required a degree in social work and the tenacity to make phone calls to the highest levels, holding the State of Mississippi accountable for it’s commitment to provide desperately needed intervention services for some of the most impoverished and vulnerable children in the US. We were able to get some OT services in place for Madeline and while it was not nearly enough, we were grateful for anything.

Caleb was born when Madeline was 15 months old. Caleb’s infancy was a lot more typical than Maddie’s though he always had tremendous gastrointestinal discomfort. At about 10 months, Caleb began to lose words, cover his eyes with his hands, make motions with his fingers near his eyes as he was falling asleep, and he stopped gazing into our eyes while feeding. Our hearts sunk and we prayed a desperate prayer that he would stay with us and not disappear into himself.

When we received word that Chris was being offered a position in the Department of Art at Utah State University, we immediately began researching the services available, and found The Center for Persons with Disabilities. I will never forget the professional, compassionate response from Sue Olsen (Director of the Up to 3 Early Intervention program), the phone calls that ensued, and the evaluation process that opened the doors to intervention for our children. We felt like the cavalry had arrived. Madeline was 2 and a half, Caleb, 12 months. Both were evaluated and qualified for Occupational Therapy, Speech Therapy and Autism related intervention.
Our ASD early intervention specialist, Janel Preston, introduced us to a book written by Dr. Stanley Greenspan, Engaging Autism. This book, and the mentorship provided by The ABC class were critical to keeping our children relating and communicating, adaptive and creative. Understanding the DIR/Floortime intervention model made it possible for us to provide what the kids needed at home during their toddler years. We read Dr. Bock’s book, Healing the New Childhood Epidemics: Autism, ADHD, Asthma, and Allergies: The Groundbreaking Program for the 4-A Disordersand started a gluten, casein, and soy free diet. While we understand that dietary interventions don’t work for every child on the spectrum, it made a huge difference for ours. We added probiotics, and other supplements, including the anti-inflammatory, yeast fighter, Enhansa.

We have amazingly creative and expressive children, but the road has been rocky, and our journey as a family has really just begun. Madeline and Caleb aged-out of early intervention when they turned three, barely qualifying for services at the time of transition, but if there is one thing we have learned over the past couple of years, it’s that the intensity of their autism is directly related to systemic health issues, including inflammation from an erratic immune response. And so for us, progress ebbs and flows.

As a result of our experience parenting children affected by ASD, we have become exposed to the local to global “autism community” and have been stirred to start a collaborative long-term photographic project called Evidence and Artifacts: 1 in 110 (some photos shown below). His collection of portraits compels the viewer’s engagement, and demands a sensitive visual inquiry of the individual faces. In the act of looking, the viewer may experience a sense of being “seen” by the children, in their delight and anguish; “seen” by the fierce and loving families in their grief and hope; “seen” by the teachers and therapists in their commitment to the notion that all children can learn; “seen” by the compassionate medical professionals in their search for ways to relieve human suffering and “seen” by the scientific and academic research community who dare to raise disquiet in their pursuit of truth. We believe what is revealed by the portraits has the power to push the conversation past the political entanglements preventing funding for a massive and comprehensive research effort to find answers for our children.

“Each time a man stands up for an ideal, or acts to improve the lot of others, or strikes out against injustice, he sends forth a tiny ripple of hope, and crossing each other from a million different centers of energy and daring, those ripples build a current that can sweep down the mightiest walls of oppression and resistance.” – Robert F. Kennedy

We are humbled by the warm reception of Evidence and Artifacts: 1 in 110 and are grateful for the opportunity to impact the national dialogue on autism. If you are interested in participating in the project, feel free to contact us for a portrait sitting.

Christopher and Jacqueline Gauthier

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