

## The Story of Team Jackson

By Elaine Jackson

Jackson was born May 26th, 2009, at a healthy 8 pounds, 6 ounces, 21 inches long. Following the pediatrician's advice, he was vaccinated right away. Jackson was a well behaved baby. He slept well, ate well, never had an ear infection or irregular fevers. He rolled over, sat up, crawled and met his milestones. We had his older sister, Sophie (DOB 8/30/07), to compare him to, and we were never concerned with his development. At 9 months, Jackson was happy sitting in the living room with a basket of toys by himself. Jackson was never overly emotional, either overly happy or upset. He stayed in the middle of the road - mellow, didn't ask for much, and was fine hanging out with his toys.

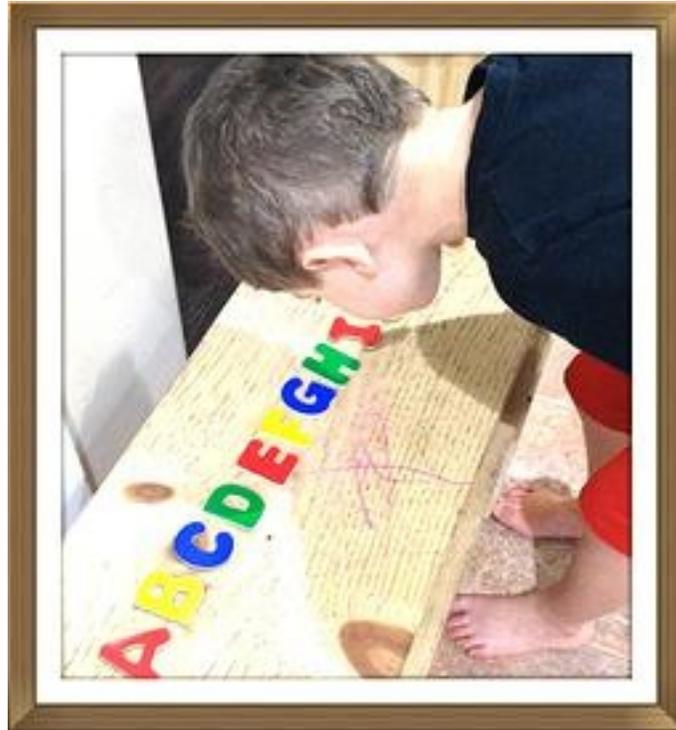


By 15 months of age, Jackson had just started walking, wasn't talking, and did not engage like his older sister Sophie. We stood behind him, clapping our

hands, yelling, “Jackson, Jackson!” but he didn’t respond. We immediately took him to the audiologist to get his hearing checked. He passed all the hearing tests. Jackson wouldn’t point or wave or show attachment to me or his father Misha. He was happy being by himself, exclusively in his own world.

At around 18 months, he began shrieking an ‘eeeeeeee’ sound while flapping his hands. I didn’t know anything about Autism, but knew something wasn’t right. Misha and I turned in the paperwork to Early Start and the San Andreas Regional Center to have Jackson assessed for Autism. When the results came in, Jackson was diagnosed with Autism Spectrum Disorder. Our pediatrician and a neurologist also confirmed our worst nightmare. We knew we were in for a long road ahead. Jackson was so different from his neurotypical sister, Sophie and other children. Sophie would laugh, interact, play and engage with us. Jackson just sat there, was a “go with the flow” kind of boy, mellow, in his own world and didn’t care about much. We didn’t know any better and continued to have Jackson vaccinated until he was 3 years old.

Right from the beginning, Jackson received 20 hours of ABA (Applied Behavioral Analysis) and 1 hour of Speech Therapy each week. This was the only option offered to us, and because we were shocked, in survival mode, we took what was offered without question. Because Jackson’s therapy and special needs were so time intensive, we figured out how make it financially possible for me to take a year off of my teaching career. With so much therapy and me staying home to be involved, we had high hopes we’d see Jackson progress. As the days, months and weeks went by, Jackson continued his inability to communicate. We had amazing, loving, caring ABA therapists for Jackson. They worked with him day in and out using imitation, sign language, following simple commands. And Jackson didn’t know what to do. He wanted to be compliant to make the therapists happy. He tried to figure out which sign to use to get his reward, but he didn’t understand what was being asked for him.



He was frustrated. He would sit criss cross on the ground in front of his therapist:

Therapist: “Jackson, touch head.” Jackson: Sitting there, flapping his hand saying ‘eeeeeeee’ Therapist: “no, quiet hands. Jackson, touch head.” Jackson: Does the sign for more, open, all done, a confused mess. Therapist: “mmmmm, nope, try again, Jackson, touch head.” This is what I remember of ABA. Thousands of hours. Jackson never learned to touch his head or reach any of his goals. My heart was breaking. Jackson began dreading the sound of our doorbell ringing because he knew it would probably his therapist for him - the therapist trying to stamp out Jackson’s “problem” behaviors and making him do things he didn’t want to do.

Jackson’s unhappiness and lack of progress was not sitting well with me. I wanted and needed to know I was doing everything humanly possible for this boy I love so much. I began reading books about Autism, starting with those by Jenny McCarthy. I began going to support groups, both in San Jose (Parents Helping Parents), at Stanford University and joining Facebook Groups. I joined a research study at Stanford hoping it would open doors and give me insight I hadn’t been exposed to about Autism. We began Jackson on a Gluten Free, Casein Free Diet. Misha and I went to the Autism Research Conference in

New Jersey in April, 2012. I couldn't think of anything else to do except embark the expensive journey of going to see a DAN doctor.

The Jenny McCarthy books opened my eyes to an acronym I had never heard before - DAN (Defeat Autism Now!). I was then on a search to find a DAN doctor who would examine Jackson and tell us what to do with our boy that nobody could get through to. Since our pediatrician had limited knowledge of the latest Autism research, I was determined to find a doctor up to date with the latest Autism information. I found a couple of DAN doctors in the San Francisco Bay Area and finally decided on one. I've heard different things from different people regarding DAN doctors. Most said the doctors are expensive and use unproven treatments. I didn't care, it was worth a try. We held Jackson down as they drew countless vials of blood, and stool, urine and hair samples. With a binder full of test results, the DAN doctor put Jackson on tons of supplements - over 30/day. Crushing, syringing, mixing, spooning in. Eight months on the DAN protocol and we saw no changes.

We then rented a Hyperbaric Oxygen Chamber and did 55-hour long dives, moved on to 8 months of Homeopathy with an expert Homeopath who had recovered thousands of kids, Osteopath, Naturopath, Homotoxicology, attended the Autism One conference in Chicago - searching and searching for what would crack Jackson's world.

One thing I know for sure is that Autism parents stick together. Coming home from the Autism One conference, I was re-energized. With these amazing parents, we shared, cried, brainstormed and compared notes. I was determined to find Jackson's path to healing. One of my favorite blogs is The Thinking Moms Revolution. They had on a guest blogger who wrote a book called, 'Finding Lina.' Her story included a therapy I had never heard of. The Son-Rise Program. Son Rise? I have to go to Boston? I have to recruit volunteers? It isn't going to work for Jackson. I couldn't leave my family for a week.

My parents are amazing. They are the most involved grandparents. Instead of traveling the world in their retirement, they are involved, helping, supporting and loving. My dad arranged to speak to a Son-Rise Program counselor from the Autism Treatment Center of America. We told her all about Jackson's history, his challenges, our struggles and our dreams for Jackson. The counselor gave us tons of advice and helped us understand how The Son-Rise Program

would help not only Jackson, but our whole family.

We spoke to the counselor in September 2013, and we signed up right away for the Son-Rise Program Start Up in October. Since Misha couldn't take the time off from work, my mom and I arranged to go to Sheffield, Massachusetts while my dad and Misha would hold down the fort with the kids at home.

For me, magic happened at the Autism Treatment Center. There's no way I can put into words the magic that happens there. Five days of learning, loving, accepting, changing, understanding, connecting, and opening, and I was ready to get home to start The Son-Rise Program with Jackson. I knew this was it. I was forever changed. My attitude shifted. My priorities were crystal clear. I have been blessed with Jackson. I love Jackson right where he's at. I accept his "isms" - his self-regulating behaviors. I accept Jackson fully. Before The Son-Rise Program, I would never have said those words. I was always trying to 'fix' Jackson and change his behaviors. Being in Sheffield, Massachusetts I discovered the peace that I needed.

Arriving back at home, the dynamic in our house shifted. We were a team. My parents made a huge sacrifice of leaving their house 2 hours away and renting an apartment near our house to be more available to help with Jackson's playroom. My dad and Misha got the playroom ready with padded flooring, shelves, mirrors, a camera, a door to the bathroom - every child's dream. Jackson's social gym was ready within 10 days of our returning home. Team Jackson emerged: me, Misha, my mom and dad. The Son-Rise Program takes a village. The Program takes an attitude. The Son-Rise Program is love. This safe, predictable room where he is loved and accepted was where Jackson would show us the way out of his Autism.

The other thing we cut out right away was his screen time. Prior to the Son-Rise Program, Jackson was an iPad pro. He knew how to find his games, movies and songs. He'd be sucked into his iPad for hours, not caring if anyone was around him. We took away the iPad cold turkey. The first few days, Jackson was confused and obviously annoyed, checking the spot where his iPad always charged. After those first few days, he got over it. Jackson's day was filled either at preschool or in the playroom that not much time was left for iPad. Without the iPad, Jackson was connecting to us more, looking at us, noticing what we were doing, and began pulling us to show us what he wanted. Jackson was

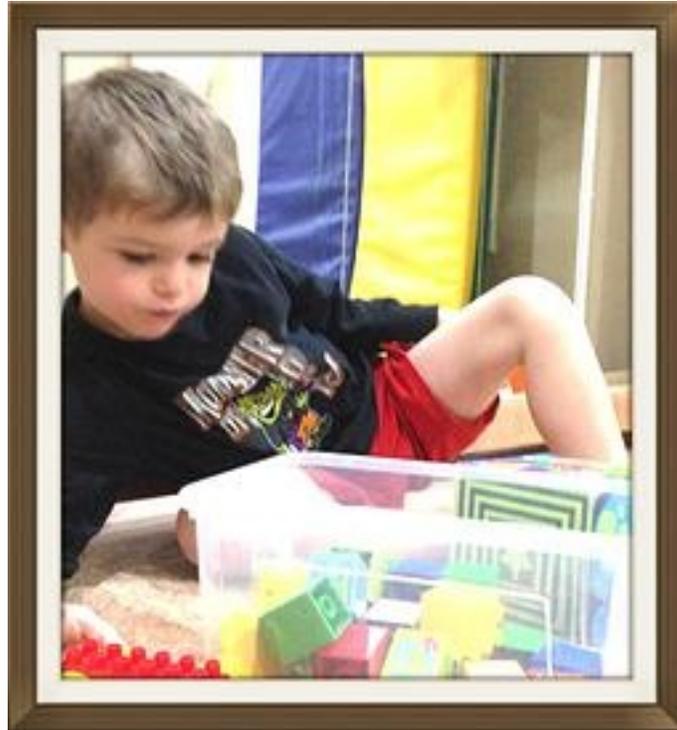
communicating - something he had never done!

The playroom was ready. Our new attitudes were there. Love and acceptance permeated our house. What happened next? We recruited volunteers. Starbucks has lovely community bulletin boards where we posted fliers. Local universities, high schools, websites, Facebook..looking for happy, energetic, accepting people who wanted to embark on an amazing journey with Jackson and our family. Volunteers called and emailed. Team Jackson was growing. Soon, we had enough volunteers for a part time Son-Rise Program: Jackson continued his preschool from 8am-12noon, then came home from 12:30-5:30pm to be in the playroom.

While working the part time program, we got reports back from Jackson's preschool teacher that he was unhappy, crying and not himself. We brainstormed what could be the reason for Jackson's change in attitude at school, and we figured it out pretty quick.

School was ABA based. Jackson checked his schedule, went to circle time, traced letters, did puzzles, had his work station and had his day mapped out for him. Though we *love*d his teacher and aides, Jackson had little choice throughout the day. He was expected to perform each task whether he wanted to or not.

When he arrived home to his playroom, Jackson was happy. This was his playroom. Volunteers came in and celebrated what Jackson did. Jackson's playroom was predictable, safe, and Jackson ran the show.



After about 2 months of running a part time Son-Rise Program, and getting daily reports from Jackson's school about his unhappiness, we requested an IEP (Individualized Education Plan) meeting. My parents, Misha and I discussed when the right moment would be to make the jump into Jackson's full time Son Rise program. We figured there would never be a perfect time. Though we didn't have enough volunteers to create a perfect weekly schedule, we knew we wanted Jackson in his playroom. When Jackson was in his playroom, he was happy! We were seeing great things!

We had reached our goal of Jackson's full time Son Rise program. To be sure, it took a lot of work. Setting up the room, recruiting, training, emailing, feedback, team meetings and best of all, playing in the playroom! And let me tell you, **it is all worth it!** It takes a village of love, acceptance and drive, but what an amazing beginning to the journey! After 3 months, we really began noticing some changes. More eye contact, tons of nonverbal communication, less verbalisms ('eeeeeee'), less hand flapping, more interest in people, more lovey-dovey, more interactive, communicated his desires, more word approximations, more babbling, and more overall happiness.



Jackson wakes up every morning, and the first place he runs is into his playroom. It's his safe-haven. He's got everything he needs in that room and thrives daily. So far, it's been 5 months running our program. I'm 100% confident we are on the right path with the social-relational philosophy of the Son-Rise Program. Jackson is learning that people can help him, people can get him what he wants, and we do it every day, happily playing, smiling, celebrating, joining, accepting and loving Jackson. Jackson is showing us the way in, so we can show him the way out.

It's been a magical 5 months. I am optimistic and sure of amazing things to come. Soon, we'll be hearing Jackson's first words, see him initiating games, requesting tickles and hugs, and telling us all the fun things he wants to do with us in the playroom. Jackson has got a Team that loves him, an endless support system, and we're going to help him reach his fullest, thriving potential.

**To Learn More about Jackson's Son-Rise Story visit:**

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