

selah,
a precious mosaic:
a mother's
journey
THROUGH AUTISM
WITH HER DEAF CHILD

By Stefanie D. Ellis-Gonzales

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Above: Stefanie Ellis-Gonzales, MSW

Far right: Selah is part of a loving family.

The Saddest Birthday Party Ever

I remember Selah's third birthday party two years ago as if it were yesterday. It was supposed to be a festive, joyous, and lighthearted occasion celebrating my beautiful daughter's embarkment upon another year of life surrounded by her friends and family.

Instead, it was the most heartbreaking party I'd ever been to.

Just a couple of weeks before, we had discovered that Selah was not the child we envisioned. Our view of her would never be the same, and her future would forever be redefined. Our many dreams for her were shattered. We had learned that Selah had autism.

During the birthday party, it was all I could do to hold back my tears, keep a smile on my face, and hide the pain that seared my heart. Every now and then, I would find an excuse to leave for a while—I'd go to the kitchen to get some more food, or, if I found my resolve to keep this party from turning into shambles starting to crack, I'd slip into the bathroom, take some deep breaths, and try desperately to regroup.

All the parents and the children at the party had no idea anything was amiss—the only ones who knew were my husband, Len, me, and Selah's grandparents. Throughout the party, we kept seeing all the signs that pointed to autism: Selah's odd way of interacting (or lack thereof) with her peers, her obsessive interest in playing with her toy cars (rather than jumping with the other children on the bouncer we had rented for the occasion), and, hardest of all, her absolute lack of interest in the pile of presents that would fill any child with anticipation of what was under the bright, cheery wrapping paper.

Len and I could not wait for the hellish day to be over, for everybody to just

Photos courtesy of the Ellis-Gonzales family



go home, so we could be alone in our desperate grief. When the final guest left, happily dragging his goody bag behind him, we closed the door, held each other tight, and cried our hearts out as we stood amid the remains of what appeared to be a typical birthday party: crepe paper hanging across the room, balloons, and the remains of a birthday cake. Our daughter had autism. Autism. We were shaken to the core; our souls were racked with grief. We were terrified of what lay ahead of us. Everything seemed so unknown, so foreign to us—even our own daughter.

Doing So Well at First

Throughout her first year of life, Selah hit all of her milestones at the appropriate ages. She flashed her beautiful grin for the first time at 2 weeks of age, held her head up while lying on her tummy at almost 3 months old, rolled over at 4 months, and, at 5 months, began to sit up. She crawled at

8 months and took her first steps at 11 months, and I remember so well how outrageously proud she was of herself, and how the world suddenly and wonderfully was within reach now that she could venture over to explore whatever captured her attention. Selah signed her very first word at 8 months old in her high chair as she eyed a jar of mashed bananas. Her chubby little hands moved together perfectly, making the sign for “more.” We would have given her all the mashed bananas in the world, we were so proud of her.

Selah loved looking at picture books and would ask us to read to her endlessly. She began putting two words together at 11 months old. She was incredibly curious, attentive, and observant. At 22 months, she began the infant-toddler program and simply adored it. She would sign “Time go school now!” in the morning as I dressed her. In her class, Selah was able to recite the song “Tick Tock” from start to end, could identify every one of her

classmates at circle time, and took absolute delight in playing with her friends. She was your typical happy-go-lucky and curious toddler. But then things started to become quite different.

Warning Flags Start Unfurling

When Selah was 26 or 27 months old, Len and I began to notice peculiar behaviors and mannerisms emerging. Our daughter would become fixated on the most mundane things: opening and shutting the doors of her play kitchen repeatedly, constantly putting things on the shelves and taking them out, pushing her dolly stroller throughout the house, retracing her exact steps over and over again until we became dizzy just watching her. At school, she started withdrawing from her friends and going off to a quiet corner more often to play by herself. We all thought that maybe it was a phase she was going through. “Chase” was still her favorite game in the whole world; when her friends chased her around, she was ecstatic. That relieved us; she still enjoyed being with her friends after all, so we told ourselves that this was probably a stage that would pass.

It was also around that time that Selah started to develop the strangest habit: She would rock her body from side to side while lying on the floor or in bed. She would do it for the longest time, until we had to stop her, distracting her with some other activity or toy. I asked her pediatrician about this behavior and got this response: “That is what is called self-soothing behavior; toddlers develop strategies to comfort themselves when they are faced with challenges or uncertainty, or when they become overwhelmed. It is normal behavior for children that age.” We believed that made perfect sense, for Selah’s little brother had just been born, so her perfect little world had been thrown topsy-turvy with his arrival. (Having to share attention is never easy.) We swept our mounting concerns aside (or at least



Left and bottom right: Selah is a happy deaf child with autism and an unknown future.

tried to) for a while, and focused on the blessings in our lives: We were a young, healthy family in a nice new house with two adorable little children.

I have a psychology background, and my training enables me to recognize certain red flags. I was working as a school counselor at that time and had a number of students with behavioral and developmental challenges. Looking back, I now recognize that my gut instinct from the very beginning had been that there was something very, very wrong with my daughter. Deep down, I had known something was terribly “off.” But mothers are fiercely protective, and every mother believes her child is perfect. I was no exception. However, I clearly remember one afternoon when I forced myself out of my defensive mode—my “denial.” While Selah rocked back and forth on the family room floor, I turned to Len abruptly and told him that this unusual, obsessive behavior was an indicator of autism. He looked at me with concern. But that window of recognition was open only fleetingly; my rock-solid defense mechanism took over again immediately. Of course that wasn’t true of my daughter. It couldn’t possibly be.

Downhill at a Dizzying Rate

Over the next few months, as Selah approached the age of 3, we became

increasingly concerned about her. She went downhill at a dizzying rate. Her eye contact deteriorated rapidly. We could hold her attention for hardly more than a few seconds. She would not take a second look at picture books she used to pore over, and she no longer demanded that we read with her.

Her language declined as well—she went from five- to six-word sentences to a mere one or two words at a time. Her behavior became worse, too—she would throw fits if she did not get what she wanted. Selah also became increasingly preoccupied with getting as messy as possible, whether it was painting, drawing with markers, or playing with bubbles or lotions. She would seek out anything gooey and smear it over any surface and all over her arms, legs, tummy, face, and feet.

My husband and I consulted a team of educational specialists about these concerns. They told us that they suspected that Selah had sensory processing disorder (SPD). Simply put, this means that the brain is unable to process information from the senses properly. As a result, children with SPD misinterpret everyday sensory information, such as touch, sound, and movement. Many children with SPD feel so overwhelmed by information that they end up seeking out more intense or longer sensory experiences to regulate themselves. Selah’s craving for anything she could smear could be considered an example of this. In some cases, children with this disorder try to cope with it in the exact opposite way: by avoiding sensory information.

The specialists’ diagnosis made total sense to us; we felt that it described Selah perfectly. The team then determined that our daughter would benefit from attending to her sensory needs first and foremost. Once these needs were met, she would be able to

focus better on other tasks and acquire more skills. The team recommended that she obtain occupational therapy to address this problem, and that we provide her with as many tactile opportunities as possible at home as well.

This was an overwhelming period for us, but we refused to waste any time, so we set out to learn as much as we could about SPD. We bought books on the subject, researched for hours on the Internet, and ordered hundreds of dollars worth of sensory equipment and toys to provide Selah with the stimulation she craved. We would do absolutely anything for our precious daughter and would stop at nothing to help her.

Toward the end of the school year, Len was offered a position at the California School for the Deaf (CSD)—Fremont, so we decided to go for it and put our house up for sale. To characterize that summer as a whirlwind would be a tremendous understatement—we managed to sell the house, pack up, move, then unpack and get settled into our new home in a matter of a few months—all with an extremely active toddler and a baby. To this day, I still don’t know how, but we managed to get through it. Everything went by in a blur, and before we knew it, summer was over.

And then the time came for Selah’s first day of school at CSD.

The Diagnosis—Or “D” Day

Selah was three months shy of her third birthday when she started in the infant-toddler program at CSD. Len and I went with her to take the usual photos and videos of this special occasion, and to help with the transition. We expected some anxiety and uncertainty on Selah’s part, as we knew that everything would be new and overwhelming for her. However, what we saw struck us as very odd. Instead of standing in a corner and observing the goings-on around her as a shy new student would, or exploring her new environment and the things that

surrounded her like a curious toddler, Selah ran around the room with no purpose whatsoever, seemingly searching for something, yet there actually was nothing she was looking for. Neither we nor her teachers could get her to make eye contact with any of us. She barely acknowledged any of the other children in the room. Then she took a pillow from one corner of the classroom and began her rocking ritual on the floor. Her teachers simply said that change was difficult, and there was so much newness in her life: new brother, new house, new neighborhood, new school, new classroom, new teachers, new classmates, new routine. It would take some time, but she would adapt.

But I went home with an incredibly heavy heart; for the rest of the day I couldn't stop the tears from falling. A feeling deep down in my core kept gnawing at me, growing stronger and more urgent—we were somehow, for some reason, slowly losing our daughter. I knew we had to find out what it was and get help—fast.

I promptly requested a psychological evaluation. A few weeks had gone by, and Selah did not seem to be adjusting any better. Her IFSP (Individualized Family Service Plan) meeting was coming up, and we needed to do one before she turned 3 years old. Our school district sent us to see a clinical psychologist who, fortunately, was able to sign relatively well, so there was no need for an interpreter. Dr. Johnstone, direct and matter-of-fact, wasted no time. She began by interviewing Len and me, collecting reports from us and from Selah's teachers, and examining our daughter's



previous reports and academic documents. She also gathered medical information from before I got pregnant with Selah.

Dr. Johnstone administered a number of tests. These included the Bayley Scales of Infant Development (BSID), the Southern California Ordinal Scales of Development (SCOSD), the Autism Diagnostic Observation Schedule (ADOS), and the second edition of the Behavior Assessment System for Children (BASC2). She also reviewed an existing video of Selah.

Dr. Johnstone began her clinical observation by running a few tests with Selah in her office, most of which included doing puzzles, matching colors, playing simple games, and generally attempting to engage our daughter. After that evaluation, I insisted that Dr. Johnstone observe Selah in her more “natural” environments as well, that is, at school and at home, a request to which she acquiesced.

The third and final clinical observation took place at home a couple of weeks later. It was November 1, 2005, just before Selah's third birthday. Dr. Johnstone and I were sitting on the floor in Selah's bedroom while Selah was making faces at herself in the mirror and laughing. With anticipation building to the point where it was almost overwhelming, I asked Dr. Johnstone point-blank what she thought Selah's issues were. I was ready to know. I wanted to know. She looked at me with this sympathetic face and said she did not like to share results without first consolidating the data to be certain. I

told her to just tell me, I needed to know. What was it, please? I remember the exact words as she formed each one. Time stood still, and everything suddenly became chillingly clear, yet surreal. I felt as if I had been struck head-on by an 18-wheeler going at top speed.

“Selah has autism.”

Sharing Our News

Shortly after Selah's disastrous (or so it was to us) third birthday party, we decided to share the news with our extended family, friends, and the Deaf community. If there was one thing we knew, it was that we had to open up to the people around us, even though our immediate gut instinct was to do just the opposite in order to protect Selah and give her privacy. However, we are a part of the deaf world, and since the fabric of our community is so tightly interwoven, keeping Selah's diagnosis to ourselves would be impossible. We accepted that right away. We needed to be completely open and honest, mainly so that Selah could lead as normal a life as possible, and because we wanted to help the people in her life understand her. We needed to remove the stigma surrounding autism; we wanted Selah to have a secure place in our world where she would be accepted, loved, and supported unconditionally.

Each time we broke the news to people about Selah's autism, we felt as if our wounds had been ripped open again, over and over—especially as we dealt with the various reactions and the questions. But slowly it began to get easier—until at some point, it actually felt cleansing to talk about it. The more we opened up, the more we found that others were even more willing to embrace Selah and make every effort to reach out to her. That was truly heartwarming. The Bay Area deaf community's response was so receptive and positive; we already knew how wonderful this community was, but to experience it so powerfully through our daughter simply confirmed how



fortunate we were to be part of it. As we learned, it would be an impossible feat to make this journey by ourselves—a close-knit community and a solid support system are key to providing a sound foundation for raising a child with autism.

No Time to Waste

Now we had to decide on the best plan of action for Selah. The team for her Individualized Education Program—Len and me, Selah’s teachers at CSD, the early childhood education principal at CSD, Dr. Johnstone, the assistant director of special education for our school district (Pleasanton Unified School District, PUSD), a program specialist, and an occupational therapist—met to discuss placement options. The team was in unanimous agreement that Selah was a deaf child, first and foremost, who had an autistic disorder. Selah had a deaf family and communicated in ASL, and for that reason she belonged in a signing environment where deaf culture, continued language growth opportunities, and social development among deaf peers would contribute to her total development.

We also knew that Selah needed additional services directed toward her autism, since early intervention was essential. Dr. Johnstone’s recommendation was that Selah receive

25 hours of applied behavior analysis (ABA) a week. There was, unfortunately, no ABA program specifically serving deaf children with autism in the area, so we were caught between a rock and a hard place. We also determined that Selah would receive occupational therapy for 25 minutes twice a week to address her sensory needs, as well as speech therapy once a week for 20 minutes.

We must have had angels looking out for us when we made our decision to live in Pleasanton—before we even found out about Selah’s autism—for it turned out that PUSD had a wonderful program for children with autism: LASS (Language and Social Skills). Employing the verbal behavior approach, a derivative of ABA, it is one of the better-known ways to teach language skills to children with autism. There must have also been a VIA (Very Important Angel)

looking after us because Dr. Mark Sundberg, an autism expert and the coauthor of the ABLLS–R (Assessment of Basic Language and Learning Skills), a popular and effective tool for creating an individualized program for teaching language, worked for PUSD as a behaviorist. To top it off, Dr. Sundberg himself knew how to sign, which helped us feel more comfortable about the idea of placing Selah in his program, armed with the knowledge that he would be able to communicate directly with our daughter and monitor her programming.

So although we were filled with trepidation about placing Selah in the LASS program since she would be the

only deaf child in the entire classroom, we also knew that she needed the “autism expertise,” additional support, intensive work, and structured environment that this program provides. We hesitantly agreed that Selah would attend the LASS program three days a week as long as PUSD provided an ASL-fluent aide or other support person to serve as the primary individual working with her under the supervision of Dr. Sundberg in addition to the classroom teacher.

PUSD also agreed that this support person would go to CSD with Selah on the two days of the week when she was part of the prekindergarten class there. We have since come to recognize that this support person’s role is absolutely critical. She functions as a bridge between both programs and is responsible for implementing the same standards and expectations so that there is as much consistency for Selah as possible as she

alternates between her two schools

throughout the week. The support person performs many roles,

including encouraging Selah to stay focused on tasks at hand, since she has a tendency to get distracted and to resist work if it is challenging or insufficiently motivating. The

support person also helps to facilitate the development

of stronger social skills by modeling appropriate reciprocal conversation and encouraging appropriate play with peers. We truly do not know what we would do without this classroom support person. Without her, Selah would have been utterly deprived of the quality, equal education and services to which she is fully entitled.

What is good about this arrangement is that Selah is able to immerse herself in



a typical deaf classroom surrounded by ASL-fluent peers and teachers who provide her with the total communication, language access, and socialization she needs in order to thrive. She also is able to take advantage of the additional services and support provided by the LASS program under PUSD—an excellent team of experts and professionals in the field of autism. On the flip side, Len and I still struggle with the fact that there is no program in our area that specifically serves deaf children with autism because Selah does have her share of challenges at either placement. There are specific language, communication, processing, and socialization needs that would be more adeptly addressed for deaf children on the autism spectrum if such a program existed. We constantly have to be Selah's strongest advocates; we often find ourselves in the position where we have to stand up and speak out for her best interests, no matter how difficult or uncomfortable it is.

How Far We've Come...and How Far We Have to Go

Selah has grown a great deal since her diagnosis. She is now 5 years old and continues to improve slowly but surely in every aspect of her life. Of course she has her ups and downs, but don't we all? She has a large vocabulary base and is working on forming simple sentences (noun and verb pairings); answering basic, specific questions and making independent requests; and developing writing skills.

Selah has a knack for acquiring new information and applying it later, and she's extremely observant of her surroundings and the activity around her. She is also more assertively trying to engage and socialize with her peers, and her eye contact has improved to the point where she can sit and attend (with reinforcement) for as long as 20 minutes at a time. She continues to have a passion for cars or anything with wheels but seems to have outgrown her fascination with pushing her dolly stroller around.

Food for Thought

Throughout our journey as parents of a deaf child with autism, we have come across many startling truths. The saddest thing we have learned is that there is a dire lack, first and foremost, of research and information concerning deaf children on the autism spectrum. There is also a shocking lack of resources, services, training, and programs for these children and their families. The number of children with autism is skyrocketing in the United States: Recent statistics indicate that 1 out of 150 children, and 1 out of 94 boys, has autism (Centers for Disease Control and Prevention, 2007). There can be no doubt that there will be a parallel increase in the incidence of deaf children with this disorder.

If our teachers are going to be properly equipped to work with deaf children with autism, they will need more teacher training programs, special-topic seminars, and conferences specifically focused on this population. Early childhood education teachers must be provided with appropriate training in order to be able to identify the red flags and other warning signs of autism because early diagnosis and intervention is critical. Because teachers from primary school through the college level deserve to be armed with knowledge and appropriate training on how to work with deaf students with autism, the topic merits in-depth treatment in their graduate studies.

Because there are so many underlying or hidden issues associated with a deaf child's development (for example, late exposure to language), those who are qualified to diagnose have to have better diagnostic tools and better training. Autism can be easily overlooked or misunderstood in very young deaf children—clinicians can mistake their lack of eye contact or language for other developmental delays.

The lack of resources does not end with educators and other professionals. Families of deaf children with autism often find themselves at a loss as to where to turn for resources and professional assistance, and where to find other families like themselves for mutual understanding and encouragement. It can get very lonely at times. For this reason, families and caregivers sorely need increased support.

—*Stefanie D. Ellis-Gonzales*

Selah is loving and affectionate toward her family and friends and often gives hugs and kisses to let others know how happy she is to be with them.

Two years have passed since Selah's diagnosis rocked our lives and thrust us into a completely new world that we never knew existed. My husband and I are amazed at how far we have come since then, and how much we have grown individually, as a couple, and as a family. We are the same, yet we are very different. Selah's autism has redefined many things for us. We know that a long, difficult, and often bumpy road with many detours, obstacles, and potholes lies before us. Yet we are as prepared as we can ever be to walk that road, armed with what has carried us thus far: our unwavering love for our daughter and our faith that everything works out as it is meant to.

Yes, Selah has autism, but we have learned that autism does not have her and it does not define her. Autism is not who she is, nor does it make up her entire personality. Selah is like a complex mosaic, composed of many distinctive pieces, each making up varying aspects of her, so intricately interconnected that one has to look closely to fully appreciate all that she has to offer. She is our daughter: our beautiful, shining, loving, independent, headstrong, and unique Selah, and that is forever who she will be.

Reference

Centers for Disease Control and Prevention. (2007). *Autism spectrum disorders overview*. Retrieved from <http://www.cdc.gov/ncbddd/autism/overview.htm>