

The Portraiture of Nick: Scene one the early years.

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In 2007, the Autism Society of America (ASA) estimated that 1.5 million Americans and their families were affected by autism. As the current ASD prevalence rates continue to rise (10%-17% each year) so does the awareness that ASD is no respecter of persons. ASD touches children of every racial, ethnic, and socioeconomic background. Additionally, ASD has no known cause and no known cure but forever changes the lives of those it touches. The scientific facts and statistics on ASD albeit important lack a consequential understanding of the human impact of the disability. Therein lays the purpose of this portraiture, to provide a visual representation and a voice to Nick and his family who are living twenty-four hours a day with an ASD. This portraiture is what (Featherstone, 1989) terms “a people’s scholarship”- a study in which “scientific facts gathered in the field give voice to a people’s experience.” This is the first scene of the portraiture of Nick. Nick’s portrait creates a narrative that is authentic, multifaceted, intimate, and holistic. This case study of Nick will hopefully illuminate the complexity of Autistic Spectrum Disorders. This researcher believes that by providing this qualitative model, ultimately parents, specialists, professionals, and teachers will have research they can use when working with students with Autistic Spectrum Disorders.

Autistic Spectrum Disorders, Autism, Supports, Resources, Least Restrictive Environment.

“I do not want the peace which passeth understanding, I want the understanding which bringeth peace.” Helen Keller’s famous quote (as cited in Random House, 2005) espouses the universal need for understanding that all people share. We are not meant to live cut off from each other and from ourselves, and we can see this demonstrated throughout history. Throughout history people have been born with disabilities which too often made these individuals feel both isolated and segregated from their surroundings. Society has not only been slow to embrace these people with disabilities, but also has forced them into separate services within schools, employment, and living arrangements. In short, exclusionary practices were often the norm in society until the eighteenth and nineteenth centuries when European philosophers and physicians began making occasional attempts to provide education to children with disabilities.

Today, much has changed regarding how society responds to people with disabilities. Currently, children and adults with disabilities have more rights than ever before but these rights continue to be challenged in both the courts and in the political arena. Legislation and litigation now guarantee basic human rights for all Americans who live with disabilities. Despite these changes there is still much work to be done in the twenty-first century especially regarding the accessibility rights, services, and supports for children and their families living with Autism Spectrum Disorders (ASD’s).

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“They lost the manual for that kid; he is happy and healthy it is the rest of the world that has to get used to him.”-Mary

My right turn signal was still blinking as I turned off the busy highway and immediately caught a glimpse of the small white house where I would first meet Nick. As I exited my vehicle my attention was drawn to the glare of the sun on the metal fence that surrounded a standard white house with grey shutters. How curious this house looks surrounded by a large security fence amidst a row of other neatly landscaped houses sitting directly off the public road. Nick’s mother Mary greets me warmly from the back porch on this warm August day. “I’m glad you found our home come on in.” I watch as Mary purposely navigates a series of safety locks and alarms as we close the back door. A series of lights cover a large board by the back door. The puzzled look on my face illicit a quick response from Mary. “That is an elopement protection system...If Nick gets out of the house we are alerted and know by looking at this board from what door or window he left.” As we make our way to the kitchen table my mind begins to contemplate what it must be like to be a parent of Nick. As I place my notebook, pen, and digital voice recorder in front of me on the table I am startled by a high-pitched sound that comes from the living room.

Mary says that Nick is watching a favorite movie in the living room and invites me to meet him. Nick is sitting on the couch intensely engrossed in his show. “Nick say hello to our

guest.” I say hi Nick it is very nice to meet you as I deliberately place myself in his line of vision. Our eyes meet but Nick being nonverbal does not respond. Nick commences watching his movie as we make our way back to the kitchen table.

I comment to Mary that Nick has good eye contact which seems to seldom occur in children with autism. “I decided very early that these skills were important. From the time Nick was in preschool I’d make up my own goals to include in his IEP.” Mary articulates that greeting people and making eye contact are “what typical people do” and I have always included these as goals in Nick’s IEP’s. I am encouraged to hear that Mary recognizes the importance of helping Nick communicate and form relationships with those around him. I am struck by the irony that I am the stranger, the outsider, who has entered Nick’s place of abode. I am here to engage in “human archeology” (Lawrence-Lightfoot & Hoffman Davis, 1997). I am here to explore the life story of Nick.

I begin by asking Mary to tell me about Nick’s early years. A gleam comes to her eyes and she opens with, “Nick was a terrific baby...nine pounds and fourteen ounces.” Mary continues, “We were blessed because Nick’s Apgar score was right on target.” Indeed, he was a healthy baby and met every milestone that typically developing babies meet his first year. “In fact, I noticed no differences between Nick’s growth and my older son who was then eighteen months old.” By his eleventh month Nick was walking and talking with a vocabulary of roughly two dozen words that included, “Barney, Doggie, Juice, and Mommy.” One month later all of that changed. “Nick the happy, healthy, typically developing child was no more.”

“When the nurse gave him his vaccine he started screaming; he didn’t stop for three days.”-Mary

Two days after his first birthday Nick received his vaccine for measles, mumps, and rubella at his local pediatrician’s office. Mary said that she took Nick to the doctor because he had an ongoing ear infection. While there the doctor advised getting Nick’s MMR vaccine; because it was now two days after his first birthday. “Nick was never the same after this vaccine.” Sorrowfully Mary asserts, “I took my baby to the doctor that day and I brought home someone else’s child.”

Repeated return visits to the pediatrician proved to be fruitless in understanding what was happening with Nick. “I thought maybe Nick was deaf because he no longer responded to my verbal cues.” The pediatrician clapped his hands and reported, “Nick can hear just fine, he has probably learned to ignore you...don’t give him things unless he asks for them.” Although Mary thought this was odd she trusted the doctor. The pediatrician reasoned that, “Nick has learned that he will get the same things that his older brother gets without asking for them.” Pausing for a moment Mary deliberately and remorsefully utters, “I tortured my son...he would lay in front of the refrigerator crying, screaming, kicking, desperately trying to communicate his desires and needs.” I waited as Mary collected her thoughts. “Nick wasn’t going to talk, he couldn’t talk...I didn’t know autism and neither did his pediatrician.”

“On a good night Nick slept about two hours.”-Mary

The changes in Nick were dramatic. Nick the happy and bubbly two year old was now nonverbal and often detached. My inquisitive look encouraged Mary to offer the following explanation. Nick was no longer Nick. “He used to love to play with his brother now; he played alone, by spinning the wheels on his trucks or by rocking back and forth often flapping his hands with his fists.” Moreover, Nick had developed a fascination with putting things in his mouth. “Everything he got his hands on went into his mouth including: strings, wash cloths, towels, and

even his bedspread.” Nick’s oral exploration would ultimately result in “sucking on and swallowing the strings from the items he had acquired.” Consequentially, Nick’s favorite foods such as mashed potatoes and pudding were now rejected in favor of crispy and chewy foods like Doritos, pretzels, and chicken nuggets. “He now refused silverware and would only eat finger foods that were crunchy and tough to chew.” The changes in Nick’s demeanor, temperament, play, and eating were dramatic but paled in comparison to his precarious new sleeping patterns.

Nick went from being a “good sleeper to an insomniac.” Mary said, “That on a good night Nick slept about two hours.” This was an enormous worry and burden on the entire family. In fact there was no longer such a thing as a sound night’s sleep. Mary wrestled with the ongoing questions of: “Where was Nick? What was he doing? What was he getting into? Was he eating or drinking something? Was he trying to get out of the house? Was he getting into something harmful or dangerous?” Mary knew that these atypical sleep patterns were not only uncharacteristic for Nick but also another symptom that “something was drastically” wrong with her youngest son. She wanted answers, information, and solutions. There would be no stone left unturned in Mary’s quest to help Nick.

“Does your son do that with his hands quite often?”-Pediatric Intern

Seven months had passed by before an intern who was filling in at Nick’s pediatrician office recognized Nick’s symptoms as “indicative signs of autism.” Mary smiled at the intern and said, “Oh yes Nick moves around like that all the time...he’s got rhythm.” The intern referred Nick and his parents to the Child Development unit at Children’s Hospital for an extensive battery of tests. After an exhausting day of test after test such as rolling a ball, putting pegs in a peg board, bouncing a ball, blowing bubbles and so on, the team of experts issued their formal diagnosis. “Based on the testing we know what your son has, he has autism.” Nick’s parents stared at each other with palpable relief. While Mary cried Nick’s father asked, “Well now that we have a name for this, how did he get it and how can we get rid of it?” The doctors said that the cause was unknown and that “there is no cure for autism.” The full impact of these words had yet to be absorbed as Nick and his parents were ushered out the door of the hospital with two phone numbers in hand...one for the Special Kids Network and the other for Parents to Parents.

“It was 1997; however, you would have thought it was 1897 because there were few to no resources.”-Mary

Mary said softly, “They say life is a journey and that the longest journey begins with a single step.” “My first step was to call the phone numbers that I was given at the Child Development Unit.” Call it luck, divine intervention, or an uncanny coincidence the individual who answered the phone had a grandchild who lived close by Mary with an ASD. Mary talked with this person twice because she answered the phone at both the Special Kids Network and the Parents to Parents organization. The fact that this woman answered the phone at both places denoted the lack of resources and volunteers in the field of ASD. “There was a deafening silence on the internet and at our local library on the topic of autism.” “It was 1997; however, you would have thought it was 1897 because there were few to no resources to help parents.” Repeatedly professionals told Mary to move closer to Pittsburgh because “there were resources available” if she relocated to the city. “I thought this was ludicrous...I shouldn’t have to sell my home and relocate to another county to get services for Nick.” Mary reached out to woman she was told about who lived in close proximity to her. These two women form a long-lasting relationship that ultimately gives birth to the first Autistic Spectrum Support group in their

county. Meanwhile, Mary's desire to acquire services for Nick takes on greater importance as Nick continues to transform before her eyes.

“After his MMR vaccine he fell off the curve and that just isn't normal.”-Mary

Nick grew rapidly. According to Mary Nick “jumped off the weight and height” charts in his subsequent visits to the pediatrician. Nick was always in the 95th percentile during his first two years of development. “After his MMR vaccine he fell off the curve and that just isn't normal.” Nick ended up becoming a “very big boy” who at one point “weighed 265 pounds.” Both his size and conditions made it less problematic for him to receive in-home services. Mary articulated that Nick did not have a “Mental Retardation” diagnosis but the fact that his needs were “so severe” qualified him for five in-home therapists. “Nick had a therapist from the United Cerebral Palsy agency, an occupational therapist, an early intervention behavior therapist, a physical therapist, and a Therapeutic Support Staff (TSS). Everyone involved in this intensive process “learned by doing.” Mary, herself a licensed teacher, said, “I've always believed that the best way to learn is to teach...and Nick taught us all.” As Nick got closer to age three, changes in his placement loomed in the distance.

“I had to do a lot of investigating to find a suitable preschool that would be appropriate for Nick.”-Mary

Age three for many children with disabilities means the start of pre-school. Mary said, “I had to do a lot of investigating to find a suitable preschool that would be appropriate for Nick.” Many of these preschool programs were either “inappropriate or downright alarming” in how they operated. For example, “One preschool for children with multiple disabilities had a young boy with autism sitting alone under a table while the other children ate their morning snack.” Mary declared, “My eyes were glued to that boy and I asked the director why he was sitting alone.”

The director conceitedly said that this boy “kept trying to turn off the lights and refused to play a musical instrument with the other students.” “My heart was breaking because here was a child who had an ASD and major sensory issues being isolated because no one here understands his disability.” “I knew all too well that Nick would be that boy sitting under the table day after day isolated without help and understanding.” The daunting task of finding an acceptable preschool was not, however, all for naught. “We found a program named LEAP Preschool (Learning Experiences: an Alternative Program for preschoolers and parents) that had both a behavioral and developmental approach for teaching children with autism in an early childhood environment.” This program was unique because it focuses on developing the skills of children with autism by having them interact with their “typically-developing peers.” “We saw the children on the playground and I inquired about which children had ASD.” Indeed, this was an “Aha moment” because there was no visible distinction between the two groups. “I knew this was where I wanted Nick to go to school.”

Leap was a full day preschool with an extended school year for Nick. Consistent with Mary's belief in a “team approach” to help Nick was the concept that “parents would help design the social, adaptive, and academic goals” for their child at Leap. Mary noted that often times, “Parents know more about their kid than the professionals.” Consequently, the LEAP preschool was cognizant about the role parents' play and Mary had a lot of latitude in creating Nick's IEP goals and objectives. Additionally, Mary knew that Nick needed a paraprofessional on the bus to get him safely to and from preschool. “We had it written in Nick's goals that he was allowed to take toys, putty, and snacks on the bus with him.” Providing these items helped Nick feel safe and preempted his desire to engage in “negative behaviors” such as “lashing out, hitting,

scratching, or kicking.” Educating the aide on the bus became a “teachable moment about Autistic Spectrum Disorders.”

“It was evident that bus drivers and aides had little to no training regarding children who were not typical.” Mary and her husband created a training program in which over 200 bus drivers and paraprofessionals attended. According to Mary this was a “win-win-win situation” because it benefitted Nick, the transportation personnel, and all children with an Autistic Spectrum Disorder. As Mary shared this vignette about the training it became evident to me that she had taken one more step in her journey with her son. Not only was she advocating for Nick by assisting, monitoring, educating, and pushing “the system” to provide services and opportunities; but also (now that Nick was in preschool) she was a teacher, ambassador, and spokesperson for all children with an ASD. Her long and winding journey through Nick’s developmental path was just beginning. Mary, however, was finding her voice as well as her calling. Both her drive and right to be heard were crescendoing at the most appropriate time. Indeed, the time when Nick’s journey was taking him from preschool to the rough, unknown, and tumultuous terrain of elementary school.

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