The portraiture of Nick: Scene two, the middle years

Vaughn L. Bicehouse
University of Pittsburgh-Bradford

ABSTRACT

In 2007, the Autism Society of America (ASA) estimated that 1.5 million Americans and their families were affected by autism. As the current Autistic Spectrum Disorder (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 second 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.

Keywords: Autistic Spectrum Disorders, Autism, Supports, Resources, Transitioning Services

“I had to pick a school for Nick since it was already July and school started in September.”-Mary

Transitioning a child from pre-school to elementary school can be a daunting task for children and their parents. Anticipation, enthusiasm, apprehension, and insecurity are common side effects as the thought of a new school looms on the horizon like high, icy, cirrus, cloud. Parents who have children with Autistic Spectrum Disorders (ASD) have the additional stressors of sending their son or daughter into mysterious educational terrain; knowing that their child has limitations with socializing, communication, and adaptive skills (Strain & Bovey, 2011). Mary’s search for an elementary school for Nick seemed like a never-ending quest for both “knowledge and comfort.”

Mary told me that when Nick was first diagnosed; “I didn’t know autism.” As she toured potential elementary schools she came to the frightening conclusion that many of the schools that she visited “didn’t know autism either.” The first school with the term “Special” in its’ title refused to even consider Nick. The principal said, “We don’t take kids with autism in our school you are wasting your time.” Mary was appalled because she saw a familiar little girl at the school who she knew had been diagnosed with autism. Her mind raced wondering what type of education and care this young girl was receiving. This inexcusable event paled in comparison to what she witnessed at her second school. “I heard a blood curdling scream coming from a classroom.” Mary’s face grimaced as she relived this episode. According to the teacher the screaming was coming from a boy with autism who had been placed in a room all by himself where paper covered most of the window. “Why is he in that room?” Nonchalantly the teacher replied, “Because he is bad and he gets placed in there for timeout.” Horrified, Mary thought to herself that is Nick. Nick will be in that room every day because he doesn’t know he has done something wrong. He will be the boy cooped up in the room all alone screaming and crying uncontrollably. Needless to say the visit to this school was over for Mary. “If I had known either the boy or his parents I would have called them and told them what I had witnessed.”

“I cried as I got into my car.”-Mary

Mary’s heart was broken as she drove out of the driveway from the second school. The reality of this day was shaking Mary’s deep felt belief that there was a place for Nick. Indeed, a setting where trained professionals would nurture and protect Nick’s potential and unique gifts. Exasperated but yet determined; Mary organized three more visits to schools that educated students with disabilities.

The third school seemed to have the temperament that was needed to educate students with autistic spectrum disorders; but lacked the all- important physical structure, work systems, and daily routines that a child like Nick requires. The fourth school was similar to third with its lack of management, communication, social, emotional, and developmental skills. Mary said, “The room was flooded with puzzles, pictures, books, and colorful artwork hanging from the ceiling.” Mary envisioned Nick in the corner self-stimming while the artwork blew back and forth from the forced air ventilation system.

The room was a hodgepodge of distractions; however, it was utterly sterile in picture exchange communication and visual schedules. Mary asked the teacher if they didn’t use PECS or magnets to help their students communicate.” The teacher indicated that those items “were in the cupboard.” She continued, “Our goal is to mainstream all of our students and we don’t want our students to become dependent on these devices.” Mary thought to herself, (Really? that means that children like Nick have no way to make choices and communicate his/her requests). In addition, it is recipe for failure for students who need a very systematic and structured program to meet their special communication needs. Overall, this program offered Nick very little to capitalize on his ability to learn. It was time to look elsewhere.

The fifth school fared even worse. It put students in “straps.” The administrator explained, “this was absolutely necessary” for the safety of students with autism. Without these straps students would run and “become a threat to themselves and to others.” Mary told me that, “I knew special supports may be needed for some children in the classroom setting, but I vehemently disagreed with this type of support and restraints for my child.” As I listened in astonishment I thought to myself that this is a very strong, resolute, and astute woman. A timeworn Japanese proverb says, “Fall seven times and stand up eight.” I had no doubt that this family was not only standing but also successfully navigating a problematic labyrinth of schools that would lead them to an enlightened, supportive, and suitable program for Nick.

“We don’t believe in discipline…we believe in redirection.”-Principal

After what appeared to be a never-ending series of dead ends one new school (yet to open) gave Mary some much needed hope. Could there in fact be a school that truly valued redirection over discipline? This question whirled in Mary’s mind as she listened attentively to this principal at this soon to be opened school for children with autism. Briefly, the principal “seemed to have all the right answers” claiming that the school would provide “an individualized, strengths-based approach to academic and behavioral growth.” The principal spoke about a “holistic” program that included: a sensory room, occupational therapy, speech therapy, and very small classes. Each class was to include two teachers, a behavior support specialist, and several aides to help reinforce instruction.

The most striking comment was that, “We value families and their input.” Moreover, Mary was assured that a family liaison would be assigned to each student to work closely with families to assist with carry-over of skills to the home setting as well as to access needed services. Since it was now July and school started in a month Mary had two pressing concerns. First, would this school be open for the fall term? Second, would Nick be accepted as a student? Acceptance, however, was no guarantee that his home school district would agree that this was the developmentally appropriate placement that Nick required to meet his unique needs. Helen Keller (as cited in Random House, 2005) once said that, “Life is a succession of lessons which must be lived to be understood.” Whether by fate or divine intervention the promise of this new school penned a new chapter in the evolving syllabus of Nick’s life.

“I believe in an open door policy, if you can help come on in”-Mary

The backdrop of fall is awe-inspiring with its cataclysm of colors and beautiful early sunsets. The hard work of the planting season gives way to the shared bounty of the labors of the harvest. Indeed fall was plentiful the year Nick began elementary school. The toil of Mary’s efforts resulted in Nick being the very first student admitted into the new private school for autism near Pittsburgh, Pennsylvania. “I was thrilled that Nick was headed to a school that knew autism.” Mary told me that she was heartened by this school’s shared vision. “This school believed in an ideal scenario whereby each child would develop to his/her full potential; so that they can be successful in their homes and in their communities." Mary and her husband have always believed that Nick can and should be able to communicate. "Right from the start we did what we could to help Nick communicate." Working in conjunction with Pittsburgh Children's hospital the family became fluent in sign language. Mary indicated that by age three Nick began to learn to sign. He has a vocabulary of roughly twenty-five words that he can sign including; "water, help, candy, and sorry." "If it works use it." Advocating for total communication Mary balks at parents and professionals alike who get too attached to one particular methodology, principle, or discipline to help children with autism.

Mary was adamant that "whatever is going to help Nick is what I believe in." Interestingly, her background training as a secondary teacher helped shaped her belief that experiential learning through trial and error is often the greatest teacher. She said, "I've always had an open-door policy with Nick…if you think you can help us then come on in." In addition to sign Nick has been taught with speech, visuals, PECs, auditory training, and his Dynavox speech-generating device. Nick's autistic school is also a proponent of using multiple methods of communication and teaching. "They use a variety of best practices including: visual support strategies, video modeling, social stories, structured teaching and organizational strategies from TEACCH, sensory-friendly classrooms, and a state-of-the-art sensory room." The program also involves community-based learning and pre-vocational skill development. Nick's program has been designed around his special interests. His real life authentic experiences have included field trips to the community post office, fire house, grocery store, and local job training center. In addition, Nick learns life skills at a green house where he plants flowers, uses the hose to water plants, cleans up the grounds, and empties the trash.

Nick's training has not been without challenges. Not unlike anyone his age he lets his wishes be known when he is unhappy. According to Mary, he "hit the receptionist" at one job center when he realized he was back for a second day of work that he did not like. No doubt Nick's communication and safety needs present additional considerations for his teachers and professionals. He is fortunate, however, to have an IEP team who realizes the importance of not only being responsive to Nick's needs and interests but also maximize his opportunities with nondisabled peers which is helping to facilitate his socialization needs. Sadly, it is the community who is often lacking in understanding and patience when it comes to children and adults with ASD's.

"Shame on you…a boy his age should not be using a bottle."-Bystander

In one of our quiet moments I asked Mary what needs to change the most to help people with autism. Her answer although not surprising, weighed heavily on my mind. "We must have more community acceptance!" My puzzled expression elicited further clarification and explanation. "Parents are too often isolated and alone in their quest for help and understanding." Having a child with autism is "an emotional rollercoaster" with its constant ups and downs. "People are quick to judge and slow to lend a hand." Mary shared the story of when Nick was nearly four years old and given a bottle in public. "You can't imagine the stares and horrified gawks you often receive from bystanders." One older woman took it upon herself to lecture Mary on how it was time for Nick to get off the bottle. Even more upsetting is when the lack of understanding and empathy comes from sources that should be providing support. "We have been kicked out of countless doctor and dental offices." Mary shared that her son was even banned from a pediatric dentist's office that specializes in children with disabilities. After being told not to come back Mary asked how her son would get the dental procedure he needed and was told, "We don't know maybe Nick will have to go to Children's Hospital to get his dental work done" This was extremely disappointing but even more egregious has been the reaction of some parishioners at Mary's place of worship.

Mary asked, "Wouldn't you think that you could turn to your church for support?" Regrettably this has not been the case. More than one church has asked Mary not to return with her son. According to Mary this rejection is an all too often occurrence for caretakers of individuals with ASD. Many families experience guilt, shame, humiliation, and embarrassment because of the indignation they receive from friends, neighbors, acquaintances, and so-called professionals who should know better. In 2007, author Wes Stafford wrote, "If God places a child before you and you're too busy to wield either a positive or negative influence…you just did the later! You communicated that the child doesn't matter and isn't important." How apropos to what Mary was describing. Have we as a society become too busy, too self-absorbed, too indifferent, and too uncaring to take a pause in our busy lives and experience genuine empathy for families dealing with autism? Mary tried to give people the benefit of the doubt when she said, "Maybe it is a lack of lack of knowledge that causes people to be so aloof and unkind." Consequently, Mary indicated that her "teacher-hat" is always on. "Families who have children with autism are always ambassadors for not only their child but also the disability."

"Education about autism is a life and death matter."-Mary

Mary and her husband feel compelled to run training workshops to educate people about autism. She shared several heart wrenching facts about what took place when the local institutions were closed. "People with autism suffered from a lack of knowledge; six died within the first year after the institutions closed." One man died in a bathtub, another died in a neighbor's swimming pool, and someone else died from an ordinary fall. All of these individuals had been moved to group homes where the staff, although well-intentioned, lacked a thorough understanding of autism and its impact on the specific individuals under their supervision. For example, the gentleman who drowned in the bathtub only knew showers. There were no bathtubs in the institution. The individual who drowned in the swimming pool had never even seen a swimming pool. The person who died from the fall wore a helmet as protective head gear and someone deemed that to be unimportant or unnecessary. These anecdotes demonstrate the fact that people working with the autistic population need to do a better job supporting those individuals. Especially understanding the challenges many of these individuals have with communication, social skills, and reacting to the world around them. This knowledge gap can lead to misunderstandings with dire consequences. Indeed, authority figures have a responsibility to at the very least recognize the "signs of autism."

Emergency responders and judges are one group that must be knowledgeable about the face of ASDs' "There are countless stories of abuse and neglect in the field of law and emergency protection regarding individuals with autism." Mary grimaced as she told me about a boy with autism who was abused by a policeman when the child, who was nonverbal, refused to answer any of the officer's questions. Another child with sensory and communication issues was burned to death when he hid in his house and failed to respond to a firefighter's inquiry "Is there was anyone in here." Mary and her husband are in the process of organizing a training session for emergency management personnel and local magistrates and judges since many people with autism do not understand "the role of law enforcement" in society. In her local community Mary has been successful getting stickers placed on homes where an individual with autism resides to help local emergency providers recognize these families. According to Mary, “We have come so far in providing for the health and safety of our kids but we still have got a great deal of work to do.” Nevertheless, one area that offers a great deal of promise is the improvement in “advanced tracking technologies.”

“The need for help is so great it is draining my heart because these are my kids.”-Mary

Because of Nick’s communication needs, he cannot be left alone and his parents rely on a tracking system when he gets lost. Mary told me of two separate occasions when Nick was lost at school. On one occasion he was on a field trip at a city museum and unbeknown to his teachers he walked out the front door. “Everyone was frantic and the entire museum was placed on lock down.” Nick was found outside in the city playing in a mud puddle by a van. Mary noted that they have “run the gamut” of tracing devices with Nick with” little success.” Nick’s sensory integration issues cause him to remove any type of tag or identification device on his person. Technology is advancing in this area and Mary continues to try out new systems, however, the out of pocket costs for these systems is “tremendous.” The local ASD support group that she runs has been earmarking monies they raise from fundraising efforts for families who need these tracking systems. Mary got very quiet and then she told me how, “The need for help is so great it is draining my heart because these are my kids.” Mary reiterated how she receives call after call from parents who are in desperate need of help for their son or daughter. Sadly, there is little to no state funding for autism and the only cash support her ASD group receives is from fundraising and individual donations. Already sensing what her answer would be I asked Mary what she needed the most for Nick.

“Nick needs what all children with autism need love, attention, and support.”-Mary

Mary said, “Autism accentuates problems in families.” Many fathers deny their child has a problem and sometimes they “take a back seat, run away, stay late at work, or pick up additional work to help with the added financial burden.” In addition, many dads who have a son with an ASD realize that their son isn’t communicating, may always be in diapers, may never play sports or become independent; and they alienate themselves from “both the child and the family.” Time and again Mary watches “motherly instinct” kick in as mothers and sometimes grandparents seek out services and supports for their child or grandchild. Mary believes in constantly reinforcing parents and families, “That autism is not their fault.” “That we are all in this together and that we’re all doing the best that we can.”

As Nick gets older he is in a large group of children with autism who will soon be graduating and requiring more help and support from their local communities. Mary said, “I realize that Nick will be a part of my life forever but I won’t live forever.” Mary feels strongly that Nick’s brother needs to “live his life to the fullest” and not feel that “he has to be his brother’s keeper.” Therefore, much of Mary’s future energies and endeavors are going to be directed toward making certain that “Nick has a bright future.” Mary’s eyes twinkled as she spoke about the possibility of starting group homes that are “different” from other community living arrangements that currently service individuals with intellectual disabilities. “Adults like Nick will require homes that will use start of the art technology to keep them safe and as independent as possible.”

These futuristic homes will be able to monitor the intake of medication, anticipate potential pitfalls, and have the lighting, provisions, and electronics that will support care givers as they work with their adult population of individuals with autism. Some might say that these plans seem costly, unrealistic, unreasonable, or unattainable. I would like to remind them of an old Jewish proverb that says God could not be everywhere therefore he made mothers. I'd take that one step further…God needed help with children with autism so created Mary; a mother to stand in the gap for these children. I have no doubt that Mary will succeed in constructing these homes.

The sun was setting as I backed my car out of Mary and Nick's home. A sense of serenity engulfed me as I reminded myself of Mary's words. "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." I have a feeling that is very true. I for one can't wait to get started.

REFERENCES

The Autism Society of America. 7910 Woodmont Avenue, Suite 300, Bethesda, MD 20814- . 3015.<http://www.autism-society.org>

Featherstone, J. (1989). To make the wounded whole. *Harvard Educational Review, 59,* 367-378.

Random House. (2005). *Helen Keller: The story of my life restored edition,* New York, NY Bantam Dell: A Division of Random House Inc.

Stafford, W., & Merrill, D. (2007). *Too small to ignore: Why the least of these matters most* (1st trade pbk. ed.). Colorado Springs, Colo.: Waterbrook Press.

Strain, P., & Bovey II, E. (2011). Randomized, Controlled Trial of the LEAP Model of Early Intervention for Young Children with Autism Spectrum Disorders. Topics in Early Childhood Special Education, 31, 133-154.