Kimberly Manchester

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Dr. Karen Paley

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The Curious Case of Matthew T. Brown:

How Scientifically Radical Intervention Methods Helped an Autistic Child Find His Voice

Imagine that you are in a restaurant. You are hungry, and would like to order some food. The menu does not have pictures of the food, so you must read the description of each offering and decide if it is something you would like to eat. When the waitress comes to take your order, you try to voice your order, but she cannot understand a word you are saying because you unknowingly walked into an authentic Haitian restaurant where they only understand Creole, a mix of French, African, Arabic, and English tongues. You consider trying a different restaurant, but you are *really hungry* – your stomach is grumbling – so you just speak louder, in the illogical hope that the waitress will understand you. When this tactic does not work, you try pointing to the menu; but without pictures of the food the attempt is misunderstood and the waitress brings you the wrong dish. You are *still* hungry, are now frustrated, and have been presented with a dish that is not to your taste. How might you react? Do you burst into tears? React with a display of anger? Give up and walk away, hungry and dispirited?

This hypothetical situation offers an inside look of what it feels like to suffer from Pervasive Developmental Delay, or PDD for short, a form of autism that affects a person's ability to communicate verbally. For some, only unintelligible sounds are able to be formed; for others, no sound at all can be expelled, in spite of the ability to comprehend questions and formulate appropriate answers. Researchers at the Mayo Clinic believe that there is a breakdown

of the nerves and/or chemical neurotransmitters that control the nerve impulses between the brain and the larynx, caused by "environmental exposures, such as to a toxin or infection" or an autoimmune response, leave those with PDD unable to speak the words they are intoning in their mind, leading to frustration, anger, and emotional despair (Mayo Clinic). Within the last twenty years, the belief – and practice – that autistic children can be taught to communicate and even speak intelligently has been gaining recognition and acceptance among medical professionals, but much of what society believes is still tainted by negative and outdated stereotypes that leave autistic children marginalized. The following narrative will seek to show a side of autism that is rarely seen: the success story.

Matthew T. Brown looks like a typical American teenager. At thirteen years old, he is riding the crest between childhood and adolescence; moving on from *Spongebob Squarepants* to Stewie from *Family Guy*; growing his hair longer and slightly altering his formerly clean-cut, boyish appearance; and dealing with the mood swings and voracious appetite that come with being a teenager. Sitting across the kitchen table from him and looking at his preferred meal of French fries and grilled cheese, his tastes appear no different than any other boy or girl his age; for all intents and purposes, Matthew appears to be the All-American Teen Dream. However, Matthew's life is not all that is appears. Matthew was diagnosed with Pervasive Developmental Delay at the age of two, a milder form of Childhood Disintegrative Disorder (which is another form of autism; one that affects motor skills, in addition to speech communication ability). If you look beyond the surface of Mathew's interests and eating habits, you will see the symptoms of his autism. Note that I have not written that Matthew *suffers* from autism because, quite frankly, he has never expressed a sense of suffering; nor does not appear to suffer at all. In fact,

Matthew has never referred to himself as being autistic, nor does he see himself as limited in any way, shape, or form by this often socially debilitating disability.

Like Dr. Temple Grandin, Matthew T. Brown's life reads like the success story of one who has been cured of autism, so to speak, to the point where he can live a normal life. Although Matthew goes to a private Catholic school, he is mainstreamed into the classroom for the duration of the school day and has reached the point where there is no extraordinary special treatment required to prevent disruption of classroom learning. If he feels overwhelmed, Matthew is allowed to quietly slip out into the hallway to recover his sense of inner peace. However, things were not always this way. In fact, had Matthew's parents listened to the diagnosing doctor's advice Matthew would have been institutionalized in a hospital for the mentally retarded. He would never have learned to speak; he would never have attended school. Matthew's mother, Maria Raspallo-Brown, told me Matthew's back-story in an earlier interview.

> [My husband] and I first noticed a problem right after [Matthew's] measles/mumps/rubella shot at twelve months. I realize the science says there is no connection, but I believe that Matthew did have some kind of allergic reaction that caused his [PPD]*. He stopped making sounds, eventually losing all the words he had up to that point in time. Then he stopped making eye contact. Then, he began to not eat various textures and finally, stopped responding to sound, his name etc…
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> At 18 months [my husband and I] brought our concerns to [Matthew's] pediatrician. At 24 months we accessed Early Intervention, on site therapy, speech therapy, occupational therapy, physical therapy and a home-based education program. We incorporated body brushing, picture schedule and sign language. At three years old he entered [a] Developmental Learners Program where he stayed for one and a half years, at which time

> he had outgrown the program and was being held back. I removed him from the school and put him in private pre-school where he flourished. He was independently reading before he was 4...he toilet-trained in one day. We knew there was an intelligent mind inside of him; that he could comprehend all that he was being told; he just couldn't communicate with us verbally.

The therapeutic methods that Ms. Raspallo-Brown mentions – body brushing, picture schedule and sign language – were considered *radical* at the time that they were being incorporated into Matthew's care because in spite of research on the topic and some success in individual case studies, large-scale clinical trials had not yet commenced. In scientific terms, this is the very definition of radical. The question is: why did these methods show promise?

Autistic children are notorious for eschewing human contact due to symptoms from sensory integration disorder, a common side-affect of their disability and a disability in itself; the result of which is a sensory overload in reaction to touch stimuli. This overload presents a quandary when faced with the human need for affection. Traditionally, the cumbersome hug-box has been used to meet this need and soothe the agitated nerves of autistic children, but a hug-box is far from portable; a body brush, however, is compact enough to fit in a woman's purse.

A body brush is exactly what it sounds like: a surgical grade brush with soft bristles used to brush the skin and in turn soothe the nerve endings of an agitated child. Training on the use of a body brush – also called the Wilbarger Protocol – is provided by an Occupational Therapist and, once both brusher and brushed are comfortable with the technique, can be administered to the child by a parent, teacher, or other care provider. Originally developed in the 1990's by the late Stephen Clarke of the British Institute for Neuro-Physiological Psychology, body brushing has only recently received attention in clinical studies. In spite of the fact that parents and

caregivers – including Ms. Raspallo-Brown – swear by its effectiveness, these studies have shown "that the brushing protocol had no marked affect on levels of stereotypy" (the repetitive or ritualistic movements that outwardly identify autistic children) as displayed over a period of time, making Matthew T. Brown's positive and prolonged response (and the response of others) to this therapy, and his consequent progress, all the more intriguing. (David, Durand, & Chan 2011)

Also making an initial appearance in the 1990's were the first studies on the concept of teaching non-verbal autistic children to communicate through pictures. Compiled as a part of her PhD dissertation, through the University of Toledo (OH) and later published with a colleague in the scholarly journal *Perspectives on Augmentative and Alternative Communication*, author Joanne M. Cafiero pointed out that the root of communication breakdowns among autistic children was the stress of not being understood – illustrated through the restaurant analogy at the opening of this paper.

Cafiero argues that a picture exchange system – or a Pragmatic Organization Dynamic Display (PODD) Communication Book, to use the scientific term – uses "strategies to support the design, production, and implementation of [augmentative or alternative] communication systems that enable genuine communication for a variety of functions in all daily environments" (Porter, G., and J. M. Cafiero 128). Cafiero furthers that the resulting reduction of stress on the autistic child would result in better quality communications and that, for the sake of the autistic child's communication development, it is "critically important to design strategies [such as a picture exchange] that enable [parents and teachers] to provide aided language input" (Porter, G., and J. M. Cafiero 121).

In Matthew T. Brown's case, the picture exchange concept worked so well that duplicate prints were used to create a portable photo album that Matthew could carry with him to school. By pointing to the picture of what he sought, his teacher was able to teach him the sign language for the word he so desperately wanted to speak, allowing him to communicate in a way that allowed others to understand him. Once able to communicate through pictures and signing, Matthew's intelligence was discernable, which allowed his parents and educators to understand his actual and full potential. "Encouraging Matthew to reach and surpass his comfort level has helped [him] develop in a more typical manner" for a child his age (Maria Raspallo-Brown Interview 04/07/12).

What sorts of challenges were placed before Matthew? In particular, toilet-training can be difficult for children with autism. According to AutismToday.com, "There are no statistics on delayed toilet training in late talkers or developmentally delayed children [but] there certainly seems to be evidence that supports the theory that children with delays tend to be late potty trainers" (online). Matthew T. Brown was no exception to this scientifically anecdotal evidence; however, once able to communicate through his picture exchange and sign language, Matthew broke through whatever barriers were holding him back from achieving this milestone. Understanding what was expected of him – and the benefits of using a toilet instead of a diaper – Matthew was toilet-trained in only *one day*. "After he started using the toilet that first day, he never had an 'accident' and he never asked to go back to wearing a diaper" (Maria Raspallo-Brown). For Matthew T. Brown, the link that connected him with others – the ability to communicate – was the key that unlocked the door to his development.

Toilet-training is an incredible milestone for an autistic child to reach – some autistic children "are never successfully toilet trained. And it's rarely an easy task" (Numberg online) –

but Matthew T. Brown achieved it in a *single day*, giving hope to his parents that he would be able to overcome other challenges that his autism presented. But speech? Could Matthew, who by the age of 18 months had been completely robbed of his ability to speak, find his voice again? It was a chance his parents were willing to take, one that involved daily speech therapy and the expansion of Matthew's picture exchange system; but the more Matthew was pushed the further he responded – there was no challenge that he could not meet. In fact, his mother responds, "While recognizing and acknowledging potential limits and obstacles, Matthew has met every challenge put in front of him and blown past his own expectations". For the curious case of Matthew T. Brown, the radical idea of a picture exchange system and body brushing was just what the doctor *should have* ordered. Today, Matthew's speech patterns and abilities *are no different than those of a non-autistic child*.

While interviewing Matthew over coffee and chocolate chip muffins from Dunkin' Donuts (although it turns out Matthew does not eat muffins; he does not like the texture, a rare outward sign of his autism), I asked him a series of conversational questions that might be asked of any middle-school aged child – questions about school, music, working together with others versus working alone, and how he handles it all. Although his answers were very straightforward and he was able to maintain eye-contact with me (something he has been practicing for years), I could see through changes in his body language that the thought of some activities was stressful to him. These activities included working with others in a group project – as either a leader or a follower – and the thought of peer tutoring his classmates in subjects like Math or Languages, both areas where Matthew excels. The suggestion that Matthew could teach his mother Algebra drew laughter that left Matthew very relaxed (his mother is famously bad at

math); but the thought of assisting a classmate with the same left him very tense as he responded that this was something he "would not feel comfortable doing".

During the interview, Matthew's twelve-year-old brother Jacob dropped in for a muffin and to investigate the goings-on between us [for the record, Jacob suffers from a mild case of Tourette's syndrome, which is also a part of the Autism Spectrum]. I noticed how well the two boys got along, and asked if they always got along so well. In unison, they replied "No!" Using this moment as a spring-board, I asked Matthew if working on a project with his brother was easier than working on a project with a classmate, but he responded that there is no difference; both are equally stressful. He prefers to work alone because, as he put it, "I have ideas in my head of how things should look and nobody but me can see those ideas, and it's hard to explain them in words because they are very complicated". This way of constructing – from mental pictures instead of written instruction – is a common mark of people with autism, one that belies the oft-held assumption that they lack even the most basic intelligence; and illustrates their genius potential to those who would doubt them.

Like many autistic children, Matthew has an unfathomably high ability to comprehend complicated academic subjects like math, music composition, and mechanical engineering. Unlike many autistic children, Matthew does not have an all-consuming and uninterrupted focus on just one subject; rather, he enjoys participating in many activities all at once. Currently, he enjoys building professional quality sculptures out of Legos'©; is writing a symphony; is busy translating nursery rhymes into a new language he created (complete with phonetic pronunciations, so others may learn, too, as found in the appendix of this report); and serves as Class Representative to his school's Student Council, a position that requires a great deal of public speaking, something that Matthew admits makes him "nervous sometimes, but not

scared". Further discussion revealed that Matthew does not live by a set schedule, but likes to "go with the flow of things" and do whatever he is "in the mood to do at a particular time". This lack of unwavering structure is unusual in an autistic child, and when asked if he ever feels overwhelmed by everything he has going on in his life Matthew leaned back in his chair and replied in a straightforward tone, "You have no idea!"

What has changed in the field of autism research since Matthew T. Brown was first diagnosed with an Autism Spectrum Disorder? In 2011, the idea of a Picture Exchange Communication System (PECS) was re-evaluated. In an article discussing clinical trials of PECS system use among non-verbal autistic children, it was revealed that "spontaneous communication using picture cards, speech, or both increased significantly following training" with a PECS system; and what was once considered a futile attempt to treat the incurable "increased spontaneous speech in children who could talk a little" at the start of the study (Gordon, et al 447).

Matthew T. Brown is more than a simple success story in the fight to teach the autistic how to communicate; he is a case study in what to do to assist autistic children learn to communicate – at first with their families; and then with the outside world. The first step in the process is to control the environment that surrounds the autistic child, in order to bypass the stressors that cause an emotional meltdown and a subsequent intellectual breakdown. As Ms. Raspallo-Brown and her husband discovered, control of the parents' stress-levels is a key factor in controlling the stress levels of an autistic child. As his mother states, "In the beginning of my getting to know Matthew with this diagnosis, I would often question my expectation as to how Matthew would deal with whatever stress was thrown his way. More often than not, I would

become SO stressed at the thought that Matthew would be stressed, which resulted in a regression of Matthew's progress.

According to the research of Michael Siller and Marian Sigman, such regression is not unusual. They discovered that children with autism are easily stressed, and will express this stress in ways that are considered socially unacceptable – usually in the form of a temper tantrum, which in turn stresses the parent, starting a vicious cycle as the child becomes further stressed by the parents' agitation. Studies completed in which the parent's behaviors and movements mirrored those of the autistic child showed that the child's stress level was reduced accordingly with that of the parents'. Further findings "suggest a developmental link between parental sensitivity and the child's subsequent development of communication skills" (Siller & Sigman 88), showing that the lower the stress levels in the home, the higher the likelihood of the autistic child developing better communications skills from an early age.

Once control of the stress levels in the home has been mastered, the next step should be to teach the child to move beyond demands and complaints, and learn to use the limited communications skills they do possess in order to seek out information; to find answers to questions and to develop a healthy sense of curiosity, something that has "long been recognized" as being of key importance in the process of language learning (Lynn K. Koegel, et al. 509). Studies by Lynn Kern Koegel and Roger L. Koegel have revealed that an autistic child "could rapidly acquire and generalize the query" when pushed to inquire about something, and "that there were collateral improvements in the children's use of language structures" when referring to the subject or object of the question that had been asked (Kogel, et. al 509). These more recent findings fly in the face of historical research on autism which has suggested that autistic children are incapable of expressing a desire for knowledge.

The third – but hardly final – step in helping the autistic child overcome his or her inability to communicate will differ from child to child. This must be understood among those who would seek to help the autistic child grow and learn. As pointed out by Dr. Bernie Siegel in his book *Love, Medicine and Miracles*, "The people in a patient's emotional support network often need to be educated, too" (188), so it is advisable that parents seek counseling and training in how to deal with their non-verbal autistic child in order to assist them in their journey from being a disabled person to being a person with a disability.

As both an Early Childhood Education Teacher and a mother to two children on the autism spectrum, Ms. Raspallo-Brown explains that, "Every child learns differently [and that] 'shooting down the middle' is not always the most effective way to teach, and often limits children of all learning levels and styles" By working directly with each child's unique needs on a personal basis, parents and caregivers can learn how to assist their autistic child in overcoming the communication difficulties that they are experiencing and to teach their child to sing their own song – literally and figuratively – instead of attempting to march in an awkward lockstep to the beat that is being played.

Endnotes:

[*]Although the hypothesis that the preservatives used in the MMR vaccine cause autism has been proven null, the concept of an allergic reaction in some children has not been fully investigated. Matthew's younger brother, Jacob, had a bad reaction to his MMR vaccine, which resulted in temporary but acute alopecia.

Appendices

Works Cited

"Autism Today, Latest News and Resources for Autism and Autism Related Issues." *Autism Today*. Exceptional Resources, Inc. Web. 21 Apr. 2012.

Brown, Matthew T. Personal interview. 7 Apr. 2012.

Davis, Tonya N., Shannon Durand, and Jeffrey M. Chan. "The Effects of a Brushing Procedure on Stereotypical Behavior." *Research in Autism Spectrum Disorders* 5.3 (2011): 1053-058. Print.

Gordon, Kate, Greg Pasco, Fiona McElduff, Angie Wade, Pat Howlin, Tony Charman. "A Communication-Based Intervention for Nonverbal Children with Autism: What changes? Who benefits?" *Journal of Consulting and Clinical Psychology*, 79.4 (Aug 2011), 447-457. Print.

Koegel, Lynn Kern, Robert L. Koegel, Israel Green-Hopkins, and Cynthia Carter Barnes. "Brief Report: Question-Asking and Collateral Language Acquisition in Children with Autism." *Journal of Autism and Developmental Disorders* 40.4 (2010): 509-15.*SpringerLink*. Springer Science and Business Media, 20 Nov. 2009. Web. 05 Apr. 2012.

Mayo Clinic. "Definition." *Mayo Clinic*. Mayo Foundation for Medical Education and Research, 16 Sept. 2010. Web. 05 Apr. 2012.

Numberg, Shane. "Autism Potty Training; Help Has Arrived!" *Autism Potty Training; Tired of Changing Poopey Diapers?* Autism Epicenter, 2008. Web. 28 Apr. 2012.

Porter, G., and J. M. Cafiero. "Pragmatic Organization Dynamic Display (PODD) Communication Books: A Promising Practice for Individuals With Autism Spectrum Disorders." *Perspectives on Augmentative and Alternative Communication* 18.4 (2009): 121-29. American Speech-Language-Hearing Association, 2009. Web. 05 Apr. 2012.

Raspallo-Brown, Maria. Personal interview. 7 Apr. 2012.

Siegel, Bernie S. "Becoming Exceptional." *Love, Medicine & Miracles: Lessons Learned about Self-healing from a Surgeon's Experience with Exceptional Patients : With a New Introduction by the Author*. New York: Harper Perrenial, 1990. 161-204. Print.

Siller, Michael, and Marian Sigman. "The Behaviors of Parents of Children with Autism Predict the Subsequent Development of Their Children's Communication." *Journal of Autism and Developmental Disorders* 32.2 (2007): 77-89. *SpringerLink*. Springer Science and Business Media, 2002. Web. 05 Apr. 2012.