

Growing Up with Mark: Living with PDD-NOS

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by

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Abstract

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By Sarah Long

Autism Spectrum Disorder, as a growing disability category in past years, has received a great deal of attention, in particular, for the classic autism disorder that most individuals have become so familiar with. However, it is rare that we hear about other disabilities that fall under the autism spectrum, such as Pervasive Developmental Disorder – Not Otherwise Specified, or PDD-NOS. Growing up with a sibling with this condition has been an impacting experience riddled with obstacles for every member of my family. However, it is through these experiences that I have grown and have developed to become the person that I am today. It is with this personal understanding and sincere interest in the disability that I elected to embark upon the task of creating a memoir surrounding the circumstances under which my brother grew up with his disability.

For the sake of creating a paper that would best capture the multiple perspectives of various members of my family, I elected to interview the various members of my family in order to create vignettes that best represented their perceptions of Mark. Each memory varies in length, from a sentence or two, to a full page. These memories are intended to capture the essence of Mark's childhood and elementary school years. I hoped that through these memories, readers would be able to understand some of the thoughts that my family experienced as Mark grew up, as well as to give them some firsthand insight into the events that occurred during our lives over the years. I felt that through seeing how a family copes with a disability - going through the grieving process, struggling with the challenges posed, and celebrating the accomplishments – that the readers might get a more complete picture of how life can be impacted so profoundly by one such event. It is difficult to get perspective into such a difficult situation until one has lived through such an experience, and this is something I hoped could be shared through this memoir.

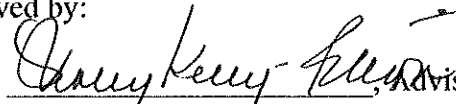
In order to give these vignettes more perspective, however, I realized that I could not simply list the vignettes one after another in written form. As a result, I elected to analyze each vignette from my own perspective. Therefore, each memory in italicized font is followed by my own analysis and additional relevant memories I have added to contextualize each described instance. In doing this, I hoped to not only provide more background on my family's situation, but also to add some additional information on what might be expected of other families coping with a similar situation.

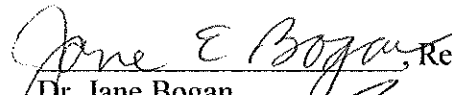
Through the format of a memoir centered around snapshots of Mark's childhood, I hoped to make the delivery of this impacting experience as personal and relevant as possible to the readers, helping them to see the meaningful nature that is experienced by so many families who are impacted by the diagnosis of a disability.

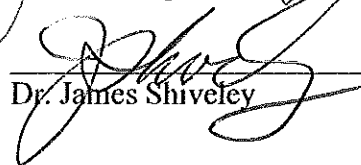
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Acknowledgments

Completing this endeavor was a daunting task that would have been utterly impossible without the support of the many people who contributed to this memoir. I would first like to thank my family for contributing all of their memories to this piece in order to create a multi-dimensional view of my brother and the circumstances surrounding his life. The memories were all very poignant and I would not have been able to attain the emotional component I desired without all of their time and effort. In addition, I would like to thank Molly Kelly-Elliott for agreeing to act as my Thesis Advisor, helping me to organize all the intricacies of my thesis, and ultimately assisting me in completing the paper in a timely fashion. Thanks must also be extended to Dr. James Shiveley and Dr. Jane Bogan for acting as my Thesis Readers and providing valuable feedback on my writing and aiding me in the editing process.

However, I must extend the greatest thanks to my brother, Mark, for giving me permission to compose this paper around his own experiences, as well as for giving me so much insight throughout the whole writing process. Mark's willingness to explore such a personal and difficult topic did not go unnoticed, and I am very appreciative that he was so open to the concept of a paper on his own disability. His attitude was both moving and motivating, and the memoir would never have come to fruition without his contributions.

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Introduction

Pervasive Developmental Disorder – Not Otherwise Specified is just one of the five disabilities listed under the title, “Autism Spectrum Disorders,” according to the American Psychiatric Society. Although the ‘classic’ form of Autism is the disability that most individuals have come to recognize, the five disabilities that fall under this category all share some common traits. The most common aspects that have come to be regarded as the hallmarks of the autism spectrum include communication problems, difficulty relating to other people in a social context, atypical behavior when playing with toys or other objects, difficulty adapting to changes in routine, and repetitive body movements or motions (“Autism,” 2012). These qualities appear at varying levels of severity, and will be visible and are most often diagnosed before the age of three.

While there is no specifically known cause for any of the Autism Spectrum Disorders, it is believed that neurological differences or chemical imbalances may be the cause of the disorder (“Autism,” 2012). However, while it is uncertain what causes these disabilities, what is known is that the number of children diagnosed with an Autism Spectrum Disorder is increasing rapidly, and today one in every 110 children is diagnosed in the United States today (“Autism,” 2012).

The five disorders qualified as Autism Spectrum Disorders include autism, Asperger Syndrome, Rett Syndrome, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder – Not Otherwise Specified (or PDD-NOS). PDD-NOS is a disorder that is often applied to a child by a physician when the diagnosis is most vague. According to the National Dissemination Center for Children with Disabilities, it is

considered “the least specific diagnosis” as it is given to the child who has many autistic-like symptoms, yet does not fall under any of the other four categories (“Autism,” 2012). Children diagnosed with PDD-NOS often fulfill the qualities of one category, such as social deficits, but not in other areas typical of classic autism, such as a lack of repetitive behaviors. Their behaviors are often milder than those of children who have diagnosed autism, and as a result, PDD-NOS is often referred to as “subthreshold autism” (“Autism speaks,” 2012).

Treatment and interventions for PDD-NOS vary significantly from child to child. Each child diagnosed with PDD-NOS will display unique traits that one single intervention cannot possibly encompass.

On November 2nd, 1991, Pervasive Developmental Disorder – Not Otherwise Specified became a vividly real part of my life, although I did not realize it at the time. That was the day that ultimately changed my life forever, determining every step I took for the rest of my life, and all that I would become in the future. For that was the day my younger brother, Mark David was born. Mark was diagnosed with PDD-NOS, and the impact he has left on not only my life, but also on the lives of the rest of my family, remains to this day. This memoir is a documentation of the way Mark changed our lives forever. This is Mark’s story. This is my sister’s story. This is my parent’s story. This is my story.

Dad

“We knew that something was amiss when Mark was not talking at the age of two and a half. He had walked at a normal age, about eleven months, but the words refused to come. We attributed this (actually, I attributed this) to the fact that he was a boy and his big sisters were doing all of the talking for him. Finally, my wife convinced me that something was wrong. We had fears that it could be a neurological disorder; he could be deaf, or he could have all sorts of terrible problems. We went to the top of the house and had him evaluated by the Head of Neurology at Children’s Memorial Hospital. Dr. Charles Swisher observed him for about 45 minutes, then summoned my wife and me into a separate room. The doctor explained to us that he could diagnose 99 out of every 100 patients he saw. Mark was the one out of 100 that he could not diagnose. He said that one of three things would happen. First, he might stay at this non-communicative level for the rest of his life and require institutional care his whole adult life. Second, he might improve for a few years, then plateau, and never progress beyond that. Third, Mark might have a slow start in life, then (almost overnight) catch up to his peers, and end up leading a totally normal life. Dr. Swisher concluded by remarking that, ‘All you can do is pray.’”

With two children already, ages two and four years old, my parents never could have dreamed that their third and youngest child would lead such an incredibly different life than his siblings. When Mark was born, he seemed as typical as any child of his age. He reached the same milestones with walking and other motor skills at the right time. He had an engaging smile, and when his hair began growing in, he had a curly tangle of brown hair that framed his innocent, angelic face. He laughed like any other child and was doted upon by not only my nuclear family, but also extended family and relatives, as well. He was a beautiful child, and the most precious baby my parents could have ever imagined or wished for.

My parents were thrilled by the third addition to the Long family, but quickly realized that there were some bumps in the road. When the time when Mark should have uttered his first words came and went, my mother began to panic and much to my father's chagrin (since he viewed the situation as an overreaction), my parents finally brought Mark to be observed by a doctor.

I cannot even begin to imagine how my parents reacted when they heard that Mark was diagnosed with PDD-NOS. Going through the grief cycle cannot even begin to cover what they must have felt. To have what seemed like such a typically developing child, only to find that he had an undiagnosed disability must have been terrifying and crushing.

When many families first find that their child has a disability, the most difficult first step is realizing that all of their aspirations and hopes for the child must be completely altered. I imagine that many parents want their child to perhaps participate in

the same sports or activities as they did in school, earning good grades, having sleepovers with friends, attending group get-togethers, and growing up carefree, as any child should. To realize that this is not a dream that their child may ever achieve is a shocking blow to any parent. I can just imagine how my parents received this devastating news, completely unsure of what Mark's future would be or what he would ever achieve.

Since it was also unknown whether Mark ever could reach typical development, it suddenly became a distant dream that my parents found themselves scrambling to reach. Not knowing what would fall into place for Mark and what would not, my parents immediately searched for educational programs that had the best special education services, as well as the most qualified speech services they could locate. Over the course of my brother's elementary school years, Mark was moved from school to school in order to find programs that best accommodated his needs, attending four different schools in just six short years. My parents signed my brother up for program after program, and every week, we would make the commute to a clinic offering speech services for an hour or two at a time.

Our life quickly came to revolve around Mark and finding the elusive "solution" to his problems. It was a constant dream, hope, and prayer to see what would finally fall into place for Mark. But it was searching for something we were neither sure existed nor worked. Mark's disability became our lives and everyday we clung to the hope that Mark would get better. For my family never truly saw his disability as a permanent, lasting condition. Despite the fact that the doctor had warned my parents that Mark might remain in the same condition for the rest of his life, my family refused to believe that this

would be the case. Perhaps this had something to do with the fact that my parents were unwilling to tolerate the idea that anyone in our family would have a disability. I believe that this intolerance ultimately became something that propelled our efforts forward. It was this strong, lasting belief that Mark *had* to overcome his obstacles that led my parents to spend hours of time and effort into all the programs that ultimately helped him to improve.

While many families willingly accept the presence of a disability in their lives, this was something that my family never truly embraced. While this may seem counterintuitive to some, it ultimately shaped the way that Mark was raised and the decisions my parents made in furthering Mark's education. Right or wrong, my family plowed forward, with the constant dream of Mark's successful recovery.

Mom

“Mark tiptoed a lot when he would walk around the room. He cried a lot and was difficult to bring to public places...I would join him in the class almost every day, serving as a parent helper. I would ride the bus with him when his class went on field trips. In the classroom, I would hold Mark in my lap to ensure that he didn't run around the classroom as the teacher was talking. His attention span was limited and he would get frustrated easily.”

Among of the most noticeable aspects of Mark's condition were the behaviors he displayed. Like many children with autism, Mark had some behaviors that could best be described as self-stimulating. Although he did not display the typical hand flapping motions one might expect, he did have a tendency to make loud prolonged, nasal noises usually varying in volume depending on his level of excitement. These noises would usually be performed in accompaniment to his frequent laps around the house, or whatever environment we were currently situated in. He would run and run for hours, emitting the noise the whole while. However, adding to the list of atypical behaviors my brother showcased, Mark was constantly moving about on his tiptoes. I do not know why this became such a habit for my brother, but I do remember that he moved in this manner since he was first able to walk, and all my memories included Mark perched on his toes, as if he were about to complete a 50-meter dash. Basically, a snapshot of Mark would consist of a young child running through the house on his tiptoes, arms extended outward in front of him, all the while making his typical shrill noises.

Mark was a very hyperactive child. Not only would Mark frequently run as a form of stimulation, but he rarely would sit still, bobbing around the house in his own little world. When Mark was in "the zone," no words could compete for his attention. He would be completely involved in his current mindset, usually fixated on a certain toy, if not simply pacing, as usual. When any of us would try to raise him from his reveries, this is when the emotional component usually became involved. My mother mentioned that he frequently cried, and this was certainly the truth. When asked to participate in an unwanted activity, Mark would typically resort to crying, and he seemed more emotional

than a typical child, as the outbursts of tears often occurred without explanation whatsoever.

All of this made Mark difficult to bring to public places, as my mom pointed out. Unless a person has a child with a disability, it is really difficult to imagine the challenges that are posed to a parent when it comes to doing everyday tasks such as running errands or going on social outings. Due to the fact that Mark could get so emotional at any given moment and had such a tendency to act hyperactively, it was very difficult to have him around when doing everyday tasks, such as purchasing groceries, going shopping, or even going to a restaurant. While my family still managed, I truly admire my parents for not only lugging along my brother on errands that needed to be performed, but also for bringing along two other young children (my sister and myself). I understand that having a family of three children must have been a challenge I could never even imagine, in particular with one who was as hyperactive as my brother.

I can imagine that my brother's frequent outbursts left my parents frustrated, limited, and possibly even embarrassed at times. It was so easy (and also typical) for my brother to wander away at any given moment (I distinctly recall an occasion in which my brother wandered away from my parents' watchful eyes in an art museum and was midway through removing an expensive portrait off the wall before my dad came barreling over). With his frequent, odd noises, I can imagine the gazes my parents received from other disapproving parents who most likely simply did not understand Mark's condition, assuming that my parents simply didn't have my brother "under control" in public. These are all things I never considered when I was a young child, but

with years of perspective and a foundation in the Special Education major, these thoughts have really made me reconsider the difficulties my parents faced as Mark grew up.

In addition, it has been with time that I have truly acknowledged the commitment my mother made to helping Mark in whatever way possible she could. She committed her life to Mark, essentially. She eventually gave up her career as a nurse to stay at home with my brother, gave away hours of each day to work with Mark on his reading through a program called, "Hooked on Phonics," spent hours reading the stories and textbooks in advance so she had mastered the same material Mark would cover in class, and even spent every day in Mark's classroom when he was in preschool and kindergarten so she could keep his behaviors in check and help him keep up with the material. My mom sacrificed a great deal for my younger brother, and it has been reflecting on these sacrifices that I have truly come to see how much she truly loved my brother and was committed to helping him improve in any way possible.

Dad

“When Mark was a preschooler, we received a lot of telemarketing calls. (This was before the creation of a “Do Not Call” List.) On one occasion, the same telemarketer did not take ‘no’ for an answer and called us back twice. The second time he called, we handed the phone to Mark. He talked in baby talk for about twenty seconds, then looked at the juice cup in his hands and said loudly into the phone, “Juuu.” He babbled for another thirty seconds, again looked at his hand, and said, “Juuu.” The telemarketer hung up and never called us again.”

My dad's memory of Mark when he was three years old had a few note-worthy points to it. The first point was a simple observation of Mark's speaking abilities. The typical child is producing speech at approximately one year of age. Mark's speech, which consisted of the word "juuuu," did not begin until the age of two, and remained at this level for years. This was limiting for an obvious number of reasons. First, it was difficult to communicate with Mark. Due to the fact that Mark did not use speech at the typical rate of a child, it was very challenging to know what he wanted. Additionally, this was really limiting to his education. My family worked in whatever ways we could to help Mark move further along in his education. However, with his vocabulary at the extent of one word, it was difficult to see improvement and challenging to see how we could expand what he understood, when his vocabulary encompassed only the word for "juice."

This memory also makes it very clear how little Mark understood about the world around him. While most children at the age of three grasp the concept of a phone as a means of talking to someone, Mark did not recognize this at all. When given the phone, he simply "babbed," as my father stated, not comprehending what was being placed in front of him, or what purpose it served. There was a clear disconnect between Mark's comprehension of everyday items that surrounded him at the age of three, and that of a typically-developing child peer of the same age.

However, this memory does bring light to one more aspect of Mark's childhood. No matter what others might think, my family still considered Mark to be a blessing in our lives. While he was difficult at times to manage and his behaviors were often

disruptive, he really could bring light to so many situations. My dad's memory makes this quite clear. My family encountered many of the same obstacles and frustrations that any family would encounter, the frequent, inconsiderate telemarketer call being just one of them. We integrated Mark into the family as much as any other child would be integrated into a family, and even found humor in the situation when possible. In my opinion, this instance demonstrates the ability my family had to function as we believed a typical family would, sharing all the laughter and happy instances any other family might. Using Mark to ward off an annoyance to the family may seem like a strange thing to do with a child, but it is a way in which my family found an opportunity to laugh and feel "normal," so to speak. My family found times to appreciate our time together just as much as any other family, something that often becomes lost when thinking of all the trials and tribulations that face a family with a child with a disability.

Sam

“When Mark was really young, he used to like to watch Blue's Clues a lot. Consequently, he obtained his own ‘handy dandy notebook,’ along with a kit that included ‘clues’ (Blue's blue pawprints) to place onto random objects to create your own mysteries. While Mark wanted to play his own rendition of Blue's Clues, he did not initially grasp the concept of the ‘clues’ being simple and following a logical progression. Therefore, when we first began, he'd place the ‘clues’ over random objects, with no ties to one another... and then tell us that the answer was something completely unrelated.”

As aforementioned with the instance involving the telemarketer, Mark really did not have the same level of comprehension as would be expected of a child of his age. At this point, Mark had increased his vocabulary a bit, and had the ability to hold a simple conversation. Speech therapy and seeing various speech pathologists for special services outside of the school day were instrumental in expanding Mark's communication abilities. However, he clearly had some deficits in his understanding.

While no other child in the family was granted such an allowance, Mark was permitted to watch TV shows whenever he so desired. As a result, he came to select TV shows such as "Blue's Clues" which he would pore over at an alarming frequency. Even as a child, I noticed that the shows he watched were probably not appropriate for a child of his age, but I always understood that Mark marched to the beat of his own drum, so I never really questioned these choices. Instead, my sister and I learned to adapt.

I found that over the years, Sam and I often had to adapt to Mark and his unbending will. We were raised in an environment in which our parents basically engrained in us the idea that all of our choices and actions should revolve around what was best for Mark. We were to always consider Mark first in all of our actions. It was never about what we wanted first. It was about what Mark wanted. So when choosing games, we always were to select one that Mark was interested in. When selecting a dinner location, we were supposed to consider what he wanted and where he would behave the best. When deciding the events of our family's vacation, we always had to incorporate Mark's needs and wants before we considered what the rest of the family wanted to do. This mentality continued for several years, and even now my sister and I

still operate under this thought process. Our family essentially revolved around my brother. His wants became our wants and his needs became our needs.

Since my sister and I were so used to adapting to Mark's interests, we watched several episodes of his beloved "Blue's Clues" with him, resulting in our intimate familiarity with the characters of Blue and Steve and that "handy dandy notebook" that made an appearance every episode. As a sort of interactive activity, my sister and I would always try to engage Mark through play that he was interested most in. We had found in the past that attempting our own games with Mark was fruitless, as he would refuse to play or simply wander away. However, Mark would willingly be included if the game centered around a show he enjoyed, and "Blue's Clues" was usually our best option. Mark was always eager to participate in this activity. However, it was my sister and I who became quickly disinterested in this game, as opposed to the other way around. This was due to the fact that whenever Mark would attempt the game, as my sister stated, he would fail to grasp the concept of the activity.

In the TV show, Blue the dog would attempt to inform her owner, Steve, of what she wanted to do at that moment. Over the course of the show, she would leave blue pawprint marks on three different objects around the house. These three pawprints would quickly be transferred to Steve's notebook, and at the end of the episode, he would sit down and ponder what Blue could possibly want to do that day. In the same manner, Sam and I would place our fake "pawprints" on to items around the house, and upon finding the other two, we would sit on the couch and consider what the activity of choice could possibly be. While Sam and I went out of our way to design clever activities that

the clues related to, Mark clearly did not grasp this concept. Mark would stick the “pawprints” on random items and at the end of the game when we simply could not fathom his intentions, Mark would get frustrated.

There was an obvious disconnect in Mark’s comprehension level that continued long after he passed the age of three, as in the instance with the telemarketer call. Mark did not follow the chain of reasoning necessary to play a simple game, a fact that frustrated not only his sisters, but also him, personally. While he clearly grasped the concept of the activity, to reach the end result, he could not see how all the little pieces lined up. It was as if he could see the big picture, but not the small details.

I feel that this memory truly showcases the difficulty Mark had in his education catching up with his peers. Mark, even after his vocabulary expanded, was still so limited by what he conceptually understood that he still was behind. This meant that Mark still had a long way to go, in terms of improvement, and Mark had the difficult task of not only expanding his vocabulary, but also expanding his comprehension of even what might seem like the simplest of concepts. I feel that this contributed to Mark’s growing frustration over the years, as well as his difficulty relating to other children.

Me

Even when I was little I saw Mark as a student that I was obligated to teach. I would haul out the old 2' by 3' chalkboard and would carefully print the alphabet, letter by letter, in the uneven scrawl of a kindergartner. I would set Mark in front of the chalkboard and cautiously and methodically go through the alphabet. Most of the time I would simply read the letters aloud to hear my own voice, and if I heard even a slight grunt from my brother, I would assume that he was mastering the material, repeating the words with me.

I was ecstatic to have such a 'devoted' pupil and we would repeat this day after day, much to my amusement. However, one day Mark apparently decided that he was no longer interested in playing 'school' with me. He suddenly stood up midway through the alphabet in an apparent attempt to liberate himself from my monotony. Feeling my instincts as the 'teacher' kicking in immediately, I grabbed Mark by the shoulders and attempted to force him back down to a seated position. It was at that point that I realized how truly strong my brother was.

Squirming out my arms, he took to a frequent aggressive habit of his, which was pinching. Pushing me toward the couch, Mark began pinching me hard and repeatedly, over and over again, emitting these loud nasal sounds, "Eeee," "Eeee," while baring his teeth. I became hysterical, trying to dislodge myself from him and distinctly remember being terrified by this child who had so quickly and completely snapped in front of me. I remember screaming until my parents ran over and hauled him off of me and out of the room.

It can certainly be said that Mark was a challenge for my family. We struggled with his disinterest in certain activities, as well as his lack of comprehension of certain aspects of the world around him. However, some aspects of Mark's behavior were less difficult to ignore than others. Mark had one rather aggressive tendency that everyone in our family absolutely dreaded, and that was the way in which he showed anger, through pinching. While it could have been much more destructive habit, such as biting or throwing temper tantrums, the pinching itself was very painful and repetitive when he was upset. Since Mark was unable to communicate many of his feelings and thoughts, he found this as a means of expressing himself, and my family simply had to learn to cope with it. This was obviously much more of a challenge for my sister and myself than it was for our parents, considering that we were still young and just as willful as our brother, in many ways.

As a child, I had a great deal of patience as a direct result of dealing with my brother and I had no choice but to gain insight on my brother's predicament (or face the consequences). However, this did not prevent me from making the occasional slip-up, as in the instance with the chalkboard. Mark was disinterested in the activity and was attempting to leave of his own accord, which should have been immediate warning signs for me. So, through forcing Mark into an undesired activity, I should have realized that this would set him to his breaking point.

The terror I felt as a child in this situation is really difficult to describe. It is confusing and disorienting to see someone you know and have come to love snap in such a way, so instantly. Mark had certainly pinched me in countless situations before, but it

was always still an experience that would leave me in complete shock afterwards, each time. It was almost as if I felt like I understood Mark's emotional complexity and could anticipate his reactions, only to be completely taken off guard and forcefully reminded that Mark's complex emotional state was unpredictable and perhaps even unstable at times.

My family found that his pinching was something that could not easily be eliminated, and it was only after several years that Mark finally stopped pinching. However, before this behavior stopped, my family was terrified of what could set him off. For me, it ultimately became a constant concern of mine to tiptoe around these invisible landmines that might instantly set off my brother at any given point.

Dad

“Mark was the most challenging of our three children to discipline. When the girls misbehaved, we would have them turn around and face the corner and stand there for about five minutes. I remember one occasion when Mark was bedeviling Sarah and we were forced to call a time out. In frustration, I instructed Mark to turn around face the corner. He cried and cried and refused to face the corner. For some reason, facing away from everyone scared him a great deal. We relented, recognizing that the crime did not fit the consequences.”

The instance my father described serves as a reminder to me that despite growing up with my brother and seeing his condition on a daily basis, there are aspects of his life that I will never truly understand. While any other child caught acting inappropriately by a parent figure may have cried out of embarrassment or shame, most would still face the corner willingly over another punishment, such as getting a toy removed from their company. However, for reasons that I do not quite understand, the concept of facing the corner and turning himself away from my family members was something that my brother, as a young child, found completely abhorrent. He would much rather have had a toy taken away from him than be placed in the corner.

To this day, I do not know what was going through my brother's head in those moments, and perhaps he would not know himself. However, I believe that Mark so feared being alone that this type of punishment was the worst imaginable. I recall, as a young child, always feeling slightly bitter that Mark never seemed to receive punishment despite acting inappropriately in circumstances I felt would have earned me hours of time-outs. While my sister and I lamented this fact on more than one occasion, we eventually came to accept that this was just the way it was with Mark. He was given different treatment than we were because his needs were different than ours. We quickly realized that he could not cope with the same type of punishment we were capable of, and we came to accept this, although grudgingly.

Reflection on my father's memory now, as an adult, has helped me to truly understand why discipline, while necessary, was something that was utilized more sparingly with Mark. The true nature of Mark's condition left him with a much more

unique mindset. He viewed the world differently, and even a time-out was not an appropriate disciplinary action for Mark, and to force him into such a punishment would have seemed cruel. The horror Mark sensed when being told to face the corner really puts the differences in his thought process into perspective and has helped me to appreciate how differently Mark saw the world, particularly in his younger years.

Mom

“Mark enjoyed riding the bus and enjoyed looking around. As he got older, he had a photographic memory of roads, routes to take, and directions. This carried on as he got older.”

Although my family was initially unsure of my brother's capabilities and what he was and was not able to do, it became quickly apparent that Mark had a gift for navigating. Mark was so skilled with directions, in fact, that he became a human atlas for the rest of my family, to the point where road maps were basically unnecessary for my family. Mark was always directionally oriented, even in the most challenging of situations, and he was able to get us out of more than one situation in which we were completely and utterly lost.

This first became obvious to my family when, in the middle of Hawaii around 9pm at night on a family vacation, my dad, never a proponent of asking for directions, finally admitted that we were completely lost. In the chaos that ensued in the next few minutes in which my mother berated my dad for refusing to look up proper directions in advance, and my sister and I loudly lamented our untimely end in the middle of a foreign land, my brother remained quiet and waited until the uproar died down. Then he simply and matter-of-factly directed my dad to the nearest freeway through a series of left and right turns that eventually brought us back to the main road. As we finally pulled onto the highway again, silence filled the car as we all grappled to comprehend what had just happened. From that point on, any navigational issue was immediately directed to my brother.

What I find most crucial about this particular memory is the fact that it showcased one of Mark's strengths. Many times, it is easy to hear the word "disability," and immediately think of a person simply struggling to get by from day to day, faced with so many challenges and adversities. However, while there are many difficulties in the lives

of individuals with disabilities, every one of these individuals has some strengths and gifts. In the case of my brother, this was his directional prowess. While Mark struggled with his speech and comprehension, he still had qualities that differentiated him from others, and I believe that this is something that should be remembered and valued.

Today, when we think about my brother, the first thing that comes to our heads is still the accomplishments he has, and not the existence of his disability. We have learned that there are so many more dimensions to Mark than simply his disability. Who Mark is should be determined by his personal character and all that he has come to achieve in his life – not simply by the label he was given. It is so simple to define a person by his disability. However, it is so much harder to define a person by his capabilities. Through growing up with Mark, I learned that this is a crucial part of respecting individuals with disabilities and celebrating the many qualities they have to offer.

Dad

“We were praying every day for Mark. My uncle, who was a Catholic priest for 62 years and who was the individual who married my wife and me, came to our house periodically and gave Mark a special blessing. My mother-in-law prayed for Mark. My mom prayed for Mark. My wife and I prayed for Mark. We instructed both of our daughters to pray for their little brother. Our Parish had an Anointing of the Sick service every year at one of the Masses. My wife and I consistently would pull Mark out of the “nursery” area of the Church (he was the oldest child there) to ensure that he received this blessing at these special Masses.”

Of all the things that pulled my family through the tough times we experienced with Mark, one of the most influential and meaningful to my family was our religion. I have found that many families of children with disabilities will often turn to religion as a form of comfort and a means of coping with the hardship of the disability. Growing up as devout practitioners of the Catholic religion, my family was no different. In fact, our faith was only strengthened and solidified by my brother's disability. Struggling to cope with Mark's condition, we found comfort in a higher power and in beliefs that ran deeply on both sides of our family. We found solace in praying to God that my brother would get better and that his condition would improve.

I remember as a child being encouraged to pray daily for my brother, and this became engrained in me over so many years. We attended church religiously, never missing a week, and despite Mark's complaints and tendency toward hyperactive behaviors, he often was brought with us to church, although he was frequently placed in the church's nursery care or children's bible study during the mass.

One of my earliest memories concerning religion was when my dad used holy water collected by a relative from the waters of Fatima, where the Blessed Mary appeared to three children, to bless my brother in the hopes that he would become well. While, as a child, I couldn't really understand this concept, I knew that somehow God would help us through our time of need and everything would turn out all right in the end.

This extreme faith in God is still a trait of my family today as we all continue to practice our faith in the Catholic Church. Regardless of what an outsider might make of the situation – perhaps assuming us to be a family so desperate for a solution, we turned

the situation over to “someone else” – I do truly believe that God guided us through these troubled times and continues to watch over my family today. Our religion is still the most integral part of our lives, and we believe that Mark’s disability was not a ‘curse,’ so to speak, bestowed upon us by God, but rather a blessing in disguise that really altered our family’s composition forever and showed us the strength of faith. Mark and our family all had our cross to bear, and we truly believe that we came out as better, changed individuals as a result.

Me

"I don't get it."

"Mark, you're doing fine. Just read the directions again."

"No, Sarah, I really don't get it."

"Just read it again."

"Sarah, you don't understand! I'm not smart! I just wish that I could be smart - like you guys. But I'm not! So just let it go already! I will NEVER get it!"

"Mark-"

"No, Sarah. Don't even try. I'm stupid."

This will always be one of the most poignant memories for me, although, sadly enough, this is one of the most frequently reoccurring memories that I have of my brother. As Mark grew in age from a toddler with such a limited vocabulary, to an adolescent with a stronger understanding of the world around him, he began to really struggle with the differences he saw between himself and other children. In particular, growing up with two older siblings, he began to compare himself frequently to my sister and myself. This in particular made the situation much worse due to the fact that both my sister and I had qualified for the “gifted” program as middle schoolers – a detail that did not escape my brother’s attention.

As my sister and I continued through high school, still placed in all Advanced Placement classes, with mostly A’s on our report cards, Mark continued to feel as though he floundered through middle school with average grades, and with no hope of being placed into an advanced class. When Mark would face a particularly difficult assignment, this is when his spirits would be at their lowest and he would begin to berate himself the most. While my whole family discouraged this type of behavior, Mark continued to view himself negatively, as would be the instinct of a child who feels isolated from his peers. As a result, Mark participated in a great deal of self-negating behaviors, and his self-esteem was never high.

The particular instance I described was just one of many times in which Mark described himself as ‘stupid.’ Unfortunately, not only Mark, but many children with disabilities display this type of negative affect towards themselves and their abilities. Through student teaching this last semester, I saw children with all forms of disabilities

questioning their intelligence and giving up on themselves since they felt they were just too 'stupid.' This is one of the most heart-breaking things to me. So many children do not realize what gifts they have and all they have to offer. To belittle themselves in such a way and to break themselves time and time again is truly a tragedy. I believe there is so much more to a child than their academics, so for a child to base all of their worth off this one single aspect of their life is not a fair assessment of themselves.

Mark really did beat himself up over what he believed to be his academic failings (which really and truly were not failings at all). As a sibling, standing by and watching such behavior was the most representative of the difficulties Mark went through with PDD-NOS. No words I could say would ever alter Mark's mindset, and it hurt me so much to see him in such a condition. He truly did not see what I saw -- a strong, determined young man who had already come so far and accomplished so much. He did not see the talent, promise, and ability that I saw. Mark is many things, but 'stupid,' has never been among them, and to suggest otherwise is simply offensive.

Regardless of what he believes, Mark will always be one of the most outstanding students I have ever met. He has gone through trial upon trial and continued on persistently, despite all obstacles in front of him. How anyone could ever find 'stupidity' in that is beyond me.

Mark

"While there have been many positive aspects to it, I have been very cautious of how people perceive me, which is why only my closest friends know about my disability. This is not information I volunteer to other people. As sad as it sounds, I like to give the illusion to people that I never had that obstacle to overcome. It is something that still affects me even to this day.

I honestly feel like more than anything else it's really one of those things where you just have to walk in the shoes of a person in order to fully understand the heartbreaking struggles that one has to deal with to overcome something. But it's overcoming that obstacle that really lets you appreciate the beauty of the situation more, and that, if you can overcome it, there's hope for other people as well.

During my childhood I was criticized a lot for not being socially on par with other people because they didn't understand what I was doing and I was too embarrassed to actually come out and say what my problem was. Though, granted I didn't even know I had a problem until first or second grade? Was it fourth grade? Yeah, fourth grade I think. That being said though, it's honestly one of those things, though, where I wouldn't trade anything in the world to get rid of those obstacles, even though I didn't really have any friends in elementary school or junior high. I would say that learning to overcome that situation just made everything better.

*No matter what the situation is, it honestly has to be you who has to come out and it, knowing you have to change something about your life. For me, it could have been so easy to forget about "Hooked on Phonics" and to have skipped out on everything, but when it comes down to it, no matter what anyone else says, it has to be **you** who changes your lifestyle. That realization hit me in fifth grade when my parents tried to convince me that Read 180 was doing good for me. The only problem, though, was that Read 180 was holding me to lower standards when I aspired to reach for higher standards. It was at that point that I realized that I was capable of so much more than what was being taught to me. It was at that point that I insisted that I get out of the Special Education classes and into Inclusion classes.*

I haven't regretted the decision ever since. Looking back on it, I truly have to accredit my mom for helping me to learn how to read. I honestly don't believe I would have gotten as far with just the elementary school Special Education classes without my mom's help.

I have taken every day of school, not only in high school, but also in college, not as a normal "learning experience," but a gift everyday. I see that I have the ability to do something that others diagnosed with similar conditions to me may never be able to do as they have obstacles they may never overcome.

I'm truly fortunate for the gifts that I have and how I have been able to take them to Marquette University. I work just as hard today studying Accounting now as I did back then, when I was learning how to read with my mom and my Special Education teachers in first and second grade. Today, I have a double major in Finance and Accounting with a minor in Public Relations. Others have trusted me enough to employ me not only at Target, but also for the third summer in a row at an internship through Articulate Promotions.

Ultimately, the biggest thing I want people to learn from me is the fact that the most important things you want in life should not be easily obtainable. They should be obtained through hard work and perseverance. If you work hard and set your mind to it, then what you desire will be obtainable. Using these principles, this is how I live my life everyday."

Today, Mark is doing as well as our family could have ever dreamed for. Very few who know Mark, even those who know him intimately well, know of his past condition. As far as we are concerned, it no longer exists, and Mark shows no trace of his past struggles. He has come far since those early elementary school days. As a Junior in High School, he qualified for an Advanced Engineering Class which he excelled in. He became involved in multiple activities in high school and eventually went on to participate in our school's Speech Team, ultimately winning a fourth place speaking award in Prose, as well as a second in State award for his Impromptu Speaking in an Engineering competition.

However, the most impacting and moving moment for me is, and always will be, when at the end of Mark's Junior year of high school, he qualified for the Advanced Placement English class as an incoming Senior. For a child who at the age of three had the vocabulary of one word and who consistently berated himself throughout his life as 'stupid,' to speak and write eloquently enough to be placed in an Advanced Placement English classroom is incredible. Mark has come so far that words cannot even begin to describe the pride I feel for Mark after all that he has achieved and all that he has come to be.

Mark continues to amaze us, even today. He is a sophomore at Marquette University, having received a hefty scholarship to attend the university. He is active in several organizations and just last semester qualified for the Dean's List due to his strong academics. He continues to practice his faith at masses, lecturing at his local church on a frequent basis.

If someone were to tell me that this Mark would go on to achieve all of this with his life, my family would have been speechless. And yet, somehow I am not surprised in the least. Mark, despite his frequent berating, never sold himself short, and always pushed himself harder than anyone else I know. He realizes all that could have been, and instead chooses to appreciate all that has come to be. He is a strong-willed, independent-minded individual who I have no doubt will go far in life. Mark recognizes what he wants and is willing to do all that is necessary to achieve his goals. He knows that he truly can accomplish anything he truly desires, and I truly believe that he can be whatever he dreams of.

It is often said that at some point without knowing it, you will meet the person who ultimately changes your whole life forever. Well, I have already met this person. In fact, I grew up with him. Mark has ultimately altered every aspect of my life in a way that he could never possibly imagine. When I say this, I not only refer to the fact that I am now a Special Education major, or the fact that I now have a specific interest in working with children with different forms of autism. Rather, Mark has truly changed the way I view the world, and the person I am today. Mark has instilled me with invaluable qualities, such as my patience, persistence, and my steadfast commitment to see worth and value in all individuals. Mark has shown me what it is to fight the good fight, to battle uphill obstacles, and to fail time and time again, only to get back up and try once more.

For that, I know that I have become a better person, despite all the good and bad. Mark will always be my hero for that, and will leave an impact in my life that can never

be erased. He is a walking success story, and to have been a part of his self-discovery process has been life-altering. I truly love my brother, and not because of the life experiences he has provided me, but rather for the lessons he has taught me. To have been a part of my brother's life had been an honor and a privilege. It is impossible for me to imagine my life without my brother, as his influence has molded me into the person that I am today.

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