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Book Review

Stacey, P. (2003). *The boy who loved windows: opening the heart and mind of a child threatened with autism*. United States of America: Da Capo Press.

Patricia Stacey writes about the first five years of her child Walker's life in the book, *The Boy Who Loved Windows: Opening the Heart and Mind of a Child Threatened with Autism*. From almost the moment Walker was born she noticed something was not right. Through infancy she constantly worried and knew that Walker was developing and growing like her older daughter Elizabeth had as a baby. He would stare out towards the window, rarely cried, and wasn't meeting developmental milestones. She was told by people in the medical field that Walker may never walk, speak, or grow as other children do, but she refused to accept such limitations for her baby. Patricia sought out the help of REACH, an early intervention program, that diagnosed Walker with sensory integration disorder (SID). This early diagnosis allowed for interventions with REACH workers to begin and started Patricia on a path of discovery, research, and hard work to help Walker overcome his sensory issues.

Many other individuals became a part of this family's life that proved beneficial in helping Walker work through his sensory issues, food allergies, and cognitive and emotional impairments. One important individual was Stanley Greenspan, a well known child psychiatrist, known for his developmental, individual-difference, relationship-based model. With his help, extremely beneficial interventions were introduced into Walker's daily routine.

Walker was never officially diagnosed with Autism, but with the knowledge and perseverance of his mother Patricia, father Cliff, and all those involved in his treatment, Walker grew to become a 5 year old meeting developmental skill levels for his age. While at one point possessing traits that would be found on the autism spectrum, he has become a bright, vocal, and socially interactive child.

Ever since Walker was born, his mother noticed something did not seem right. She described her baby as looking ill and frail. He hardly ever cried, was unable to stay awake and alert, struggled with breathing, and didn't enjoy being held or touched. These concerns continued, as Walker lost weight, couldn't keep down food, and seemed content lying in odd and uncomfortable positions, staring constantly out the window towards the light.

When Walker was six months, Patricia and Cliff were told by a doctor that their son's abilities would be limited. They were told he was delayed in all areas and may never be able to walk or talk. This vague diagnosis didn't seem accurate to Patricia and Cliff so they kept on searching. She then contacted an early intervention program called REACH. Soon after, Walker was diagnosed with sensory integration disorder. Arlene and Dawn were two workers from REACH that were key part of Walker's success. Autism was never ruled out, but was also never mentioned to Patricia or Cliff by the REACH workers at this early of an age.

Patricia and Cliff continued to look at different doctors including a nutritionist and allergist, and forms of treatment such as chiropractics. She was referred to Lenore, a Body-Mind Centering expert, by a friend. Lenore worked with Walker on form and achieving movement. Walker continued to struggle with breathing issues, eczema, and weight loss, along with the other developmental delays. Still being told there was nothing inherently wrong with their child by their pediatrician, Patricia found a new pediatrician who finally acknowledged something was not right with their baby. This was another critical turning point as they realized Walker needed to be taken off breast milk and put on a hypoallergenic formula. Immediately, his breathing got better and eczema cleared up. The new pediatrician also was the first to actually say the word autism to them. Patricia continued to express her concerns with allergies and eventually Walker saw a Pediatric Gastroenterologist. They found allergies with wheat, milk and other foods. Walker was put on another special formula called Neocate. On this formula, he was able to keep his food down much better. Patricia continued to be pro-active and began researching the nervous system and its connections with senses. They were eventually able to get Walker into a Neurologist. The Neurologist was yet another doctor who was unsure of whether it was autism they were seeing in Walker and referred Walker to a psychologist for motor and cognitive tests. The psychologist felt that Walker, still a baby, was intelligent but it was too early to diagnose. The idea of waiting until he was older to see didn't sit well with the REACH worker Dawn. She urged Patricia to continue to work with Walker and search for the help he needs. She introduced Patricia to the work of Dr. Stanley Greenspan.

Child psychiatrist Stanley Greenspan and his D.I.R. therapeutic model was another major turning point in Walker's life. While there still was no diagnosis, further interventions such as floor time were put in place, along with the interventions being done with REACH. Their intensive work with floor time continued as Walker turned one and continued until he was in preschool. As Walker got older, and began to make progress Patricia, realized a diagnosis was needed in order to keep receiving services from REACH. While autism was never Walker's diagnosis, he had been too young and she was now in need of that diagnosis to keep the services Walker desperately needed. Dr. Greenspan agreed with the other doctors and psychologist that it was still too young to diagnosis him, but did write a letter stating that Walker had pre-autistic tendencies.

Over the course of the next few years, Walker continued with the early interventions set in place by REACH and Greenspan. The pre-autistic tendencies label would no longer grant them services when Walker turned two and half years old. Patricia once again knew that a diagnosis was needed, but her husband urged her to realize all of the progress Walker had already made. She didn't follow up with trying to get Walker diagnosed as Autistic. Instead, Cliff and Patricia continued to implement the floor time intervention with Walker. Patricia continued to research new ideas and strategies and they continued to work with Dr. Greenspan in setting new and challenging goals for their little boy that would help him reach all of the appropriate developmental milestones cognitively, emotionally, socially, and physically.

The early interventions that were put into place when Walker was a baby were major influences on Walker's success and growth. As a baby, Lenore, a Mind-Body Centering worker, and Arlene from REACH, worked on ways to connect Walker's senses

and to help him understand his environment. Arlene would get Walker to focus on objects and use his senses. To do this, she would use objects and eventually people to gain his attention and draw his eyes away from the light of the window that always held his gaze. Lenore would help with his movements and taught Patricia and Cliff to hold him in a crescent shape. Another intervention used when Walker was a baby was to stimulate his senses using movements such as bouncing and making noises. Dawn from REACH, was an autism specialist and she worked with Walker to address his sensitivities and processing problems.

REACH set goals for Walker as a baby such as mastering the primary reflex of protective extensions. This meant that they wanted him to recognize his environment and have the reflex of protecting himself. To help him meet this goal they would use a large ball and would roll Walker on his stomach over it. He eventually mastered the reflex when he learned to raise his hands up as he moved toward the floor in protection of his head.

Right before the age of one, Walker was seen by Dr. Stanley Greenspan and Patricia and Cliff were introduced and taught floor time. This was an intervention that required parent involvement. It involved Patricia and Cliff playing and interacting with Walker in a way that helped create emotional relationships. The interactions that occurred between the parent and child during floor time are meant to help increase attention, cognition, and motor functioning, but do so using a full speed and intense approach. Dr. Greenspan showed Patricia and Cliff ways to help increase his deficits, such as attention and motor functioning, by playing games with him such as hiding a toy and having him search for it. During floor time, Walker needed to be in a constant flow of learning and interaction. He needed to create full circles. For instance, if the parent made a sound, then Walker needed to make a sound. Developing Walker's problem-solving skills was another goal that Dr. Greenspan wanted Patricia and Cliff to work on, and he wanted Walker's focus to be on problem-solving with people and not objects. When working on Walker's reaction and focus, it had to be about his relations with people. Floor time required interactions with not just toys, but the person completing floor time with him. Floor time was meant to always push Walker by trying new ways to increase his skills.

With Dr. Greenspan's recommendations, an intensive intervention regimen was put in place for Walker and continued over the next couple of years. They were to have Walker do 2 sessions a week of sensory-based therapy. These included floor time with an educator, such as Dawn, 2 times a week, and 8 to 10 sessions of 20 to 30 minutes of floor time with Cliff and Patricia. The goal of all this hard work was for Walker to climb Dr. Greenspan's developmental ladder. The ladder consisted of six developmental milestones. First was self-regulation and interest in the world. Second was intimacy. Third was two-way communication. Fourth was complex communication. Fifth was emotional ideas and the sixth milestone was emotional thinking.

During floor time they would continue to focus on cognitive and social skills using mirrors, books, and playing games together. They focused on body development, hiding toys on the couch and encouraging Walker to retrieve them by lifting himself up. Arlene continued to work on visual processing with Walker which helped lead to motor skills. She would take a flashlight and have him follow the light, or hide puzzle pieces and have him find them and put together the puzzle.

While these interventions were taking place, Amy, a student from Smith College, began working with Walker on speech acquisition. Amy wanted to see if Walker could learn how to make gestures and then be able to transfer those gestures into words. The goal of her intervention was to teach Walker to show when he felt full so they could help regulate his intake of food. To do this, after every bite that Walker would take, Amy would take his hand and pound it flat on the table to indicate “more” She would then reinforce the gesture by voicing the words. When he looked full, she would pull the food away. She would gesture “no more” by making an X formation, crossing her arms over Walker’s high-chair tray. The intervention was a success and Walker was able to use gestures to communicate and those gestures eventually flowed into using words.

The success of all the interventions was evident. By almost two, Walker was able to say his name, speak using 4 to 5 word sentences, and could play games such as searching for toys. He could smile, laugh, crawl, recognize friends and family in photos, and had increased his ability to focus. By almost two and a half, Walker had mastered the first four developmental milestones. He was approaching his parents, taking social initiative, and playing with his sister Elizabeth. There were still concerns such as tolerating groups of children and people, and still being behind in motor skills. The interventions continued and Walker was proving that he was gifted socially and intellectually. He had a very large vocabulary for his age.

New goals were set and mastered with floor time, such as teaching Walker how to play out pretend scenarios. He was even learning how to use an action figure toy to represent himself. Arlene set up socialization sessions with other children that required the kids to play as well as work on motor and sensory issues.

They continued to visit Dr. Greenspan and least once a year. On Walker’s third visit, he showed that he had passed milestone five and was working toward six. During this visit, Dr. Greenspan interacted with Walker during playtime. Walker wanted to take the wheels off a truck but couldn’t explain to Dr. Greenspan why he wanted to do so. Floor time required challenging the child, and through Dr. Greenspan’s questioning and involvement of Walker’s sister, Walker was eventually to explain why he wanted the wheels off. This demonstrated a sophisticated level of thinking.

At the age of three he had his final REACH evaluation. Walker was given the Michigan Early Intervention Developmental Profile and Preschool Language Scale. He passed both, yet still couldn’t jump. He was able to receive physical therapy in preschool and eventually was able to jump, run, and complete fine and gross motor skills. The interventions continued but became less and less a part of Walker’s daily routine. Dr. Greenspan recommended they continue to work on sensory-motor skills, have play dates with children, and have Walker work with a speech therapist, occupational therapist, and physical therapist. The occupation therapist suggested a desensitizing therapy which required Patricia to rub Walker’s gum line by pressing on it two times, five to six times a day.

The interventions proved to be successful. By the age of five, Walker had mastered the developmental skills appropriate for children his age. Some of the final skills he mastered included that he was no longer excessively sensitive to loud noises, he wasn’t as easily excitable, he was eager to get up in the morning, he had an appetite, he could show love and aggression through play, and he had strong emotional and cognitive skills for his age.

I believe that all the interventions employed were extremely successful for Walker. The early interventions that took place with Arlene, Lenore, and Dawn while Walker was under the age of one worked to gain Walker's focus, to strengthen his low upper-body tone so motor skills were able to develop, and worked with his extreme sensitivities to noise and touch. Once floor time was added to his daily routine, all the previous interventions seemed to come together. When Walker would make a gain, a new goal would be set for him. Eventually by the age of one, he was proving to have receptive language skills, some social referencing skills, and some sensory tolerance.

The floor time intervention really enabled Patricia, Cliff, and all those who worked with Walker, to push him towards new challenges. Floor time worked on Walker's motor, cognitive, and social issues, and at the same time allowed Walker to make emotional connections. The earlier interventions with Arlene helped Walker learn how to gain focus on objects instead of gazing at the light from window. Floor time then took that focus and shifted it towards teaching Walker how to focus on people. They learned how to use objects that Walker was interested as a way to make themselves interesting for Walker.

There were also short-lived interventions that proved extremely successful as well. For instance, Amy's intervention teaching Walker gestures helped push Walker towards speaking. By the age of five, Walker had a large vocabulary for his age and proved to be very intelligent. Other interventions such as changing his diet, using vibrating toys to help with stimulation, adding peer playgroups, and continuing work on visual processing through the use of flashlights and hiding games, all assisted Walker in his growth.

Walker was never formally diagnosed with ASD. However, it did seem as if the diagnosis process became an obsession for Patricia. When Patricia recognized that something was not right with Walker after birth, it was far too early to suggest ASD or even diagnose Walker with ASD. Doctors seemed to not accept the difficulties Walker was facing. Patricia turned to research and the newly found search engines that the internet provided at that time to gain awareness of how the body and mind worked and how she could help Walker. She was her sons advocate, and stopped at nothing to find what he needed and who could help him. Even though Walker was never diagnosed with ASD, when autism was finally brought up to Patricia and Cliff, it almost seemed like a relief; as if they were finally getting the answers they had searched for.

The love and devotion that Patricia had for her son did take a toll on her marriage. There was a period of resentment between husband and wife that strained their marriage. There were also human limitations felt, as Patricia lost friends because she simply didn't have the time and energy to put into maintaining relationships with other adults. All of her time was spent working with Walker, making phone calls, talking to experts, doing research, and taking Walker to appointments. She even felt like she had missed out on watching her older daughter grow.

Beyond the toll on her marriage and loss of social relationships, there were financial issues. The special formula Walker was put on, the appointments, and the tutors that were needed to help support Walker were all costly. The financial issues and the fact that Walker's interventions were so time consuming made finding a diagnosis a

continued obsession for Patricia. She knew Walker would need a diagnosis in order to keep and receive the services they needed. The pre-autistic tendencies diagnosis helped them receive support and tutors for a period of time.

While the family went through a very challenging few years, their sacrifices seemed to pay off. Eventually, Cliff and Patricia became closer and began to reconnect. Patricia and her daughter Elizabeth started to spend more quality time together and Walker showed huge gains, all due to the choices they made as a family.

I believe this book emphasizes the importance of early intervention in children who show signs of ASD. While Walker was too young to diagnose, his mother dedicated herself to becoming aware of the options and treatments that had the potential to be beneficial for her son. In the book, Patricia describes her findings on issues such as recent neurological findings and allergy factors. A large part of the book was about sensory issues and how sensory integration and sensory processing problems can have a huge impact on an individual. The sensory integration theory she discusses describes how children's sensory processing capacity, receptive language skills, and motor-planning abilities affect them their entire life. Other professionals, such as occupational therapists, physical therapists, and nutritionists were to be beneficial in helping Walker overcome his limitations.

Patricia's research and search for answers led her to REACH, which allowed for early interventions to be put into place before Walker turned one. I believe that these early interventions are a major reason why, today, Walker is not on the autism spectrum. I believe that this book could serve as an inspiration for other parents. While parents can't expect to have the same outcomes that Patricia and Cliff had with Walker, because every child is different, it does show that it is never too early to begin intensive work with a child. Sensory integration disorder is often seen in children diagnosed with ASD and therefore working on issues related to SID at a young age can help a child as they grow.

I think that Patricia's story and her journey showcase the complexity of ASD and how complicated early diagnosis and intervention can be. It's unsettling to think about what the outcome of Walker's story may have been had Patricia not been so vigilant and dedicated to gaining the knowledge and resources her son needed. I believe this book can spread awareness to not only those associated with ASD intervention, but to doctors and specialists as well. There seems to be a significant amount of variation amongst the practices and beliefs of those who work in early care. As the number of children with ASD and other developmental delays continues to rise, I believe that stories such as Walker's could help connect doctors, professionals, and parents. While ASD is a complicated disorder, I think that books such as this can spread awareness and knowledge, and contribute to the growing amount of information available about the role of early intervention.

I know that this book, *The Boy Who Loved Windows*, will impact my current and future professional career and practice.

This book has opened my eyes to the issue of sensory integration disorder. Currently, as a first grade teacher in a general education classroom, I have a child in the classroom that has sensory issues. He has poor fine and gross motor skills, is unable to hold his body upright for long periods of time, and seems affected by loud noises. This

book has helped me to better understand the issues he may be having with his senses and provided me with resources to I could use to assist him.

As a classroom teacher that works with young children, this book has impacted my thinking about how important it is that I continue to gain awareness and knowledge about a variety of early learning issues. I believe that my continued learning will enable me to better understand and accommodate a variety of needs that may be present in my classroom. The importance of communication amongst professionals is something I value and I believe that in the future, it will be extremely important to establish professional relationships with others working with my students. Whether this means talking with a school specialists or a child's private physical therapist, I believe that in order to create and maintain a supportive classroom and learning environment, constant communication and collaboration is needed.

In the future, I know that my insights and observations may be needed during a child's evaluation process. I think that as I continue to gain knowledge about ASD, I will be better able to identify early signs and characteristics that can influence interventions and services.

Walker's story has reminded me how vital it is that I continue to be a teacher who enables all of my students to have a voice.