

ASPERGER SYNDROME, PARENTAL LEADERSHIP, AND ADVOCACY

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This work explores advocacy strategies for parents to support their Asperger Syndrome child in a public school setting, particularly in a classroom environment. This work represents a maternal act of love for my own Asperger Syndrome child and is an exploration of my own journey to develop better advocacy strategies from a theoretically informed perspective. A detailed explanation of Asperger Syndrome demonstrates how individuals with this disorder require advocacy. My own personal illustration creates a connection between parental advocacy and the formation of personal leadership. Michael Powers, a noted expert in Autistic Disorders and Director of the Center for Children with Special Needs located in Tolland, Connecticut underscores my experience with a theoretical overview. Peter Senge's work and three of his five disciplines explore how parents might construct a personal framework to interpret Powers' work. Senge is nationally renowned and is the Director for the Center of Organizational Learning. His work helped me construct a "learningful" framework to better construct personal leadership and a parental advocacy model. Leadership formation strengthens parents' credibility to advocate. Leadership strengthens voice. Voice strengthens advocacy. I offer personal and theoretical strategies to support other parents in their parenting journey, because these strategies enabled me to be highly successful in my advocacy work for my own son.

Asperger Syndrome

Asperger Syndrome is part of the "autistic spectrum" of disabilities (Powers, 2002, pp. 10–11). Hans Asperger, after whom the disability is named, and Leo Kanner,

both described a group of individuals characterized by inappropriate social interactions, failure of communication, and the development of special interests (Atwood, 1998, p. 15). Sacks (1995) wrote that autism conveys a dreadful meaning to many. Individuals envision a child that is totally inaccessible to the outside world and characterized by uncontrollable rocking and screaming. At one extreme, some might envision a child typified by isolation and muteness, erased totally from human contact. Others envision the autistic “savant,” or someone cut off from normal life with amazing powers of arithmetic facility, recall, or artwork. Individuals with Asperger Syndrome might also resemble the “Raymond” character portrayed by Dustin Hoffman in the movie *Rain Man* (1995, pp. 11-12). Adding to this description of Asperger Syndrome, Wing (2001) indicated that learning difficulties and autistic disorders often go together. She reported that one-third of all individuals afflicted with this disorder suffer from learning disabilities (p. 46). Learning deficits further impair those already afflicted by this troubling condition. Sacks (1995) indicated there are forms of autism that do not incapacitate as deeply. Sacks contended that some of these individuals possess high intelligence, benefit from education, and can live eventful and accomplished lives filled with unique insights and courage (p. 12). Asperger Syndrome is less debilitating than some other forms of Autistic Disorder and individuals typically function at a higher level.

Jimmy

I am the parent of an Asperger Syndrome child. He is blond with mesmerizing blue eyes and angelic looking features. (I am his Mother!) Everyday he has struggled in school. I spent many of his early days crying in disbelief and discord, dragging him to

doctors. When he started talking, I laughed with amazement at his incredible wit, his perseverant fascination with fish, and his ability to perceive situations and events with a remarkable sense of wisdom seemingly beyond his years. However, most of all when I have observed him, I have been fascinated and awed that he is my child. I learn from him every moment. In order to begin a process of developing my strengths as a parental advocate, I had to know and understand my son and learn how Asperger Syndrome could potentially impact his learning and social interactions. Then, I had to understand that he needed an advocate; he needed someone to serve his interests, because I know my child better than anyone else. I know him better than his teachers and all of the clinicians that work with him. I know that he has social and academic weaknesses, but he also possesses vast strengths. As his mother, I claim the responsibility to advocate for him. I serve him through advocacy, particularly in a public school setting. I will not allow anyone working with Jimmy to forget his strengths. When we forget the strengths of others our minds erase part of another person's humanity. I will not allow that to happen to my child.

Parental Advocacy

Whyte (2001) wrote "Every work begins as an intimation and discovery" (p. 64). The work for me as a parent is deeply tied to parental advocacy. In order to see my parental work more clearly, I began to see my experiences as a personal journey. Whyte also wrote, "At its best, work seems never-ending only because, like life, it is a pilgrimage, a journey in which we progress not only through the world but through the stages of understanding" (p. 12). Along this journey, I spotlighted my prior notions of

parenthood and education and reframed a new definition of how I could best parent my special needs son. My previous parenting model would not work in this situation. As Whyte described, I had to look down on the edge of myself at the cliff edge of life, then I put myself in “conversation with the edge;” it was terrifying. I looked “down over that edge” and that’s when I began to see my own parental potential (p. 21). After I personalized my own reactions to my son’s condition then I took steps toward developing my own personal leadership. In large part, this sense of journey had a practical application. If I became an expert, then I could be both an advocate and a leader for my son and myself. Subsequently, I could be the painter of a new portrait lavishly blending colors and ideas and reframing these new ideas for others, including all of the school staff working with my son, instead of feeling numb and helpless living a gray, powerless existence.

At last, my goal became the journey of working toward parental advocacy. This journey led me on a winding path comprised of cliffs and valleys, straight avenues and tunnels, lined with obstacles tripping me one right after the other then clearing to reveal uncluttered passages on which I could run freely. Leadership became the vehicle to travel on the path to achieve my goal. Parental advocacy became my goal as the term was defined by Greenleaf (1977); the goal was the “big dream, the visionary concept, the ultimate consummation that one approaches (p. 29).

The journey toward personal leadership also sprang from the desire to serve my child. Greenleaf (1977) supported my decision to explore servant leadership as a bridge to build personal leadership. Greenleaf wrote, “The servant-leader is servant first. This

idea begins with the natural feeling that one wants to serve first. Then conscious choice brings one to aspire to lead” (p. 27). The epiphany rang for me that I needed to be a leader and stand firm against any person that might misunderstand Jimmy’s condition. My fear was that misidentification would result in misunderstandings and inappropriate educational interventions. My interest in Asperger Syndrome, my training as a professional educator and doctoral work in leadership studies enable me to be a strong advocate for my son.

Personal leadership development became the vehicle for advocacy. The transformative process of developing leadership supported me to change my emotional framework. I understood that Rosof (1994) concluded that a child exists as two separate entities. First, there is the real and separate person. Second and equally real is the child we create in our mind, as a part of our self. Even before a child is conceived, parents have fantasized about it, and endowed it with their hopes and longings. Our sense of our own self, both good and bad aspects, interweaves with our growing knowledge of our child to form this internal image” (p. 9). Boss (1999) supported this belief and wrote, “The family that exists in people’s minds is more important than the one recorded in the census taker’s notebook.” In relationship to this statement, ambiguous loss is “incomplete or uncertain loss” (p. 3). Boss concluded, “Families are psychological as well as physical entities. Family members can become so preoccupied with loss that they withdraw from one another. The family becomes a system with nobody in it” (p. 11). Boss further noted that, ambiguous loss “is the most stressful loss people can face” (p. 20).

I experienced an ambiguous loss when my child was born with a disability. I did not disconnect from my family or my child. However, I disconnected from previously held maternal fantasies about the perfect child in the system of the perfect family. This experience for me was best defined as grief without closure.

Boss (1999) suggested that an important factor that influences how people make sense out of ambiguous loss is their way of thinking and whether they are optimistic or pessimistic (p. 124). Boss noted that psychologist Martin Seligman called such ways of thinking “habits of thinking” (p. 125). “Habits of thinking” were similarly explored by Daloz et al. (1996). Individuals interviewed by Daloz et al. were not immune to being overwhelmed, discouraged or bewildered, but they exhibited “habits of the mind” grounded in the habits of dialogue, interpersonal perspective taking, critical systemic thought, dialectical thought, and holistic thought (pp. 107-108). The habit of dialectical thought, or “the ability to recognize and work effectively with contradictions by resisting closure or by reframing one’s response” (p. 108) enabled participants to reframe their responses.

Powers (2002) suggested that parents accept their feelings, face them, and honor them. He indicated that parents’ initial reaction to a child’s disability of shock and denial, followed by guilt, anger, and belief eventually transforms to renewed focus and determination (pp. 57–58). As parents educate themselves and others about their child’s disability they take their first steps toward becoming their child’s advocate. This role will evolve as the child grows. Advocacy is a lifelong process (p. 65).

Creating a Holding Environment

Parents can facilitate the creation of a holding environment for their child. The term “holding environment” originated in psychoanalysis. Heifetz (1994) wrote, “A holding environment consists of any relationship in which one party has the power to hold the attention of another party and facilitates adaptive work.” For a child, the holding environment serves as a containing vessel for developmental steps, problems, crises, and stresses for the growing child. That requires both technical knowledge and process expertise (pp. 104–105). Higgins (1994) stressed that “*any ‘holding environment,’ therapeutic or otherwise, that fails to dignify the ‘adult without’—that more competent gardener tending to the ‘children within’—ignores the great complexity of the human psyche and spirit.*” Higgins’ definition of a holding environment compounded Kegan’s idea of “good enough holding,” which is “the ‘holding’ necessary for us to complete developmental tasks” (p. 71). For parents, much of the work they do is foster an environment for growth. However, Asperger Syndrome children require a different kind of “holding environment.” For example, they need to be taught explicit skills like selecting appropriate topics for discussion, modeling suitable methods for shifting topics while providing adequate background information, and reading facial and social cues of others (Powers, 2002, p. 121). Significantly, Powers described specific strategies for how parents can create the best holding environment for the Asperger Syndrome child in a classroom environment by becoming involved in classroom processes and routines.

The Individual Education Plan defines classroom procedures that outline a disabled child’s specific needs, and the document serves as a set of guidelines that

establishes how a disabled child's needs should be met. Powers (2002) indicated that parents should be heavily involved with the Individual Education Plan or IEP. This plan should include the child's present level of development, strengths and weaknesses, specific educational services the child should receive, benchmarks for achievement, the extent of the child's inclusion in the regular classroom setting, other interventions, and parental concerns. To the meeting, he further recommended that parents bring a spouse or other advocate. He asserted that parents should know their rights accorded to them by law. Parents must know their child and know what works for the child and what does not. During the meeting, parents must be cooperative and assertive and expect cooperation from educational staff, but they should also be prepared to assert their rights if they feel that their child's needs are not being met. He further explained that parents should fully understand Asperger Syndrome and educate staff about Asperger Syndrome and their child. Finally, he suggested that parents write detailed notes during the meeting and compare the agreed upon Individual Education Plan with the copy sent after the meeting. Parents should make necessary corrections and return the document if necessary (pp. 135-136).

I integrated many of these strategies during Individual Education Plan meetings for my child. Specifically, teaching educational staff about my son's strengths has been the most strategic advocacy skill from Powers' work. As I have educated educational staff about Jimmy's strengths, I clearly articulate these strengths to myself and for Jimmy. The most clarifying aspect about Jimmy is that he seems gifted in some areas

while possessing learning disabilities. The twice exceptional definition seems most applicable as described by Silverman (2002, p. 141).

Silverman (2002) wrote about twice exceptional children. Silverman wrote that many twice exceptional children and their abilities are misunderstood. Intelligence testing serves as a predictor for academic success and is part of the Individualized Education Plan. Intelligence test scores are part of the diagnosis and treatment for children with learning disabilities, as well. According to Silverman, intelligence test scores mask both strengths and weaknesses and unfair comparisons to average children depreciate some children's strengths and may not fully consider a twice-exceptional child's strengths and weaknesses (pp. 174 –175). She concluded that parents should be careful when deciding to commit to intelligence testing as a sole determinant to a twice exceptional child's success (p. 141).

Grandin (1986) provided her own account of intelligence testing. For example, on one un-timed, spatial reasoning test, Grandin's performance was extraordinary. On a similar timed test, Grandin received an inferior result. On a phonics test, Grandin scored at the second grade level, because many of the words were slowly sounded out and evoked an inappropriate mental image. On two other tests, she scored at the fourth grade level, because the test required prolonged concentration, and she often experienced lapses in concentration during the test (pp. 132 – 133). Grandin's own understanding of her weaknesses appeared to allow her to take control of her own education and realize her own strengths and weaknesses. She pursued goals and developed independence. At the end of a lecture, Grandin concluded, "If I could snap my fingers and be non-autistic, I

would not—because then I would not be me. Autism is part of who I am” (1995, p. 16).

Parents of Asperger Syndrome children can help their child develop similar strengths and achieve success.

Powers (2002) described the most effective classroom environments to support the Asperger Syndrome child. He recommended small classroom settings, because children with Asperger Syndrome require considerable individualized attention. Furthermore, small work groups enable children with Asperger Syndrome to maximize opportunities to assimilate information and better understand tasks. Powers also suggested creating an orderly and predictable learning environment providing minimal transitions between subject areas and classroom activities characterized by advanced visual cues and verbal reminders. He further suggested prior rehearsal for new routines to minimize confusion and maximize classroom effectiveness. Prone to confusion and emotional meltdowns, these behaviors can be ameliorated by seating Asperger Syndrome students closer to the front of the classroom to help students focus on appropriate social cues (p. 136). Also, classmates easily irritate Asperger Syndrome students. Therefore, seating arrangements that foster negative socialization should be avoided. Finally, Powers advised that real life settings are the most appropriate for socialization. For example, lunchroom behaviors are best taught in the lunchroom; appropriate playground behaviors are best taught on the playground. Optimally, all staff that works with the Asperger Syndrome child should be well informed regarding presenting behaviors and prescribed interventions so that consistency presides in all educational situations and

settings (pp. 136-138). Heininger (2001) further supported Powers theoretical framework for classroom interventions (p. 108).

Powers (2002) emphasized other specific strategies to foster academic success for the Asperger Syndrome child in a classroom environment. Among these strategies for success, he pointed out that individualized instruction that specifically addresses the child's precise strengths and weaknesses is optimal. Furthermore, individualized instruction should be coordinated so that all service providers can work together to optimize educational services and delivery to the child. Additionally, the classroom teacher and the specialists delivering educational services must coordinate their services so that consistency in the educational environment can be established and maintained. Powers further emphasized that it is essential that all adults should be aware of the child's needs and then utilize the same techniques to teach the child. Also, since Asperger Syndrome is a social learning disability; therefore, teachers should be aware of how to best seize opportunities for social learning. Rote instruction must be emphasized without ambiguity. Idioms, sarcastic comments, and jokes with double meanings should be avoided. Finally, Asperger Syndrome children possess outstanding memory function; however, "intellectualized learning" should not be confused with conceptual learning. The teacher working with these children should be sure that the child understands the subject from a conceptual perspective (pp. 138-140).

Silverman (2002) further supplied accompanying educational strategies to promote understanding for educators and parental advocacy to insure greater equality for alternative learners. She stressed the importance of parental understanding of the twice-

exceptional children as a means of advocacy for a more effective educational environment. According to Silverman, “the higher the child’s intelligence, the greater the gap between mental abilities and physical skills.” As a result of late neurological development, some learners bloom early while twice-exceptional children bloom late” (p. 111). Also, twice exceptional children may be highly creative and gifted in areas that are non-academic. Parents should be ready to advocate for their child by insuring the best educational approach is used with their child (p. 187).

Twice exceptional characteristics certainly portray Temple Grandin and Albert Einstein as well as many of the noted geniuses of our time. Upon further examination, one could conclude that many of these disabilities are hallmark characteristics of autistic spectrum disorder and particularly Asperger Syndrome. To overlook these characteristics and prescribed educational interventions could limit the best approach to advocacy for the parent of a child with Asperger Syndrome.

Powers (2002) recognized that children with Asperger Syndrome have “splinter skills.” He defined these “splinter skills’ as areas of considerable ability that often relate to the child’s specific area of interest (p. 141). My son’s specific area of interest is sea life. To provide enrichment in this area, our family has allowed Jimmy to maintain eight different fish tanks, including a marine aquarium. As a result, my son raises and sells fish. This interest may result in a career opportunity for him. Also, his academic ability, specifically in the areas of reading and math has improved, because of this interest. Most importantly his social interactions have improved, because his interests have enabled him to form friendships with other people that have similar interests.

To model appropriate behaviors, Powers (2002) suggested mentoring the Asperger Syndrome child. He reported that mentored Asperger Syndrome adults related that their mentors were key to development and learning. Mentors can also be extremely helpful to assist the Asperger Syndrome child with their organizational skills. This type of friendship and support can definitively impact the child's learning experience in a classroom environment. These children look to their peers when they are unclear about what to do in a specific situation (p. 218). Sinetar (1998) wrote that "A mentor is a person, a guide, or a teacher – the keeper of selective wisdoms that we hope to gain" (p. 7). "A mentor can mean the difference between a successful and satisfying life and one in which a person becomes a loner, remaining on the fringes of society and feeling miserable" (Ledgin, 2002, p. xiii). Powers (2002) suggested, multiple mentors in the areas of job related services, community and social liaisons, and clergy are helpful (p. 218). A three-step success strategy for Asperger Syndrome children includes looking to their neighbor and copy what he or she is doing; asking the neighbor what to do and following appropriate instructions, and raising a hand to ask an adult for help (p. 149).

The Parenting Journey as a Leader

I have found Senge's (1990) work especially relevant to my work as a parental advocate and leader. Peter Senge's work overlaps with Powers' work. Of Senge's five disciplines, three underscore Powers' parental advocacy work and include mental models, team learning, and systems' learning. These theories reminded me that the external work of parental advocacy is not enough to help the Asperger Syndrome child. In order to truly

enter a helping relationship, the parent has to undergo a process of acceptance and integration to help with this internal transformation.

Senge (1990) wrote that mental models are “what we carry in our heads [that] are images, assumptions, and stories. Philosophers have discussed mental models for centuries, going back at least to Plato’s parable of the cave” (Senge, 1990, p. 175). Senge described, “Mental models can be simple generalizations such as ‘people are untrustworthy,’ or they can be complex theories, such as my assumptions about why members of my family interact as they do” (p. 175). Senge further wrote, “if mental models can impede learning; why can’t they also help accelerate learning (p. 178). Senge quoted Chris Argyris on the topic of defensive routines. He resonated with Argyris’ idea that long held defensive routines disable individuals from recognizing their own “leaps of abstraction,” exposing the “left-hand column,” balancing inquiry and advocacy, and facing up to distinctions between espoused theories and theories-in-use (Senge, 1990, p. 186).

Parents of children with Asperger Syndrome faced with changing their own mental models, must understand that part of the change is in realizing their new advocacy role to be played in their child’s educational environment. I struggled defensively with the notion that my son even had a problem. A dramatic gulf exists between admitting that a problem exists to directly confronting the problem to advance to an internal place to advocate. Senge’s (1990) work empowered me to make this internal leap. In order to change the family’s approach to how they view and handle their child’s disability, personal transformation is required.

Powers' (2002) indicated that Asperger Syndrome is part of a family dynamic. When diagnosis occurred, the familial roles were altered. After the diagnosis, accommodations were identified to best meet the needs of the Asperger Syndrome child. Modified parental roles were introduced. Perhaps the mother became the disability expert and school advocate, while the father's role became homework supervisor. During the process of learning these roles, another disruption redefined familial roles again and another routine had to replace the previous (pp. 91 – 92). In our family, team learning became central to determining every aspect of how we would approach parenting our child. Senge (1990) examined this same idea of team learning through an organizational lens.

Senge (1990) wrote, "Organizations learn only through individuals who learn. Individual learning does not guarantee organizational learning. But without it no organizational learning occurs" (p. 139). I reframed how I viewed my relationship to the educational staff working with Jimmy, and I changed how I viewed my relationships within my family. It was only through this change, that I could envision a team effort. "When a team becomes more aligned, a commonality of direction emerges, and individuals' energies harmonize. There is less wasted energy. In fact, a resonance or synergy develops" (p. 234). As I became more a part of the family and educational teams, I found myself working in harmony toward the vision of embracing Jimmy's uniqueness as a person. I began to see Jimmy as a precious gift given to only me.

Lastly, the overarching applicability of Goldenberg and Goldenberg (2000) family systems approach can play the most important role in how individuals view the

disabilities of others and our own relationships with others within familial relationships. Goldenberg and Goldenberg indicated that continuity and change characterize a family system as the family progresses through time. Some changes are orderly, gradual, and continuous, while other changes are sudden like the birth of a handicapped child (p. 25). The stress on the family system during a transition can actually provide an opportunity for the family to break out of its customary coping mechanisms and develop new ways of growth-enhanced coping strategies. Such ways of coping are called “relational resilience” (p. 27). Such resilience can lead to improved parental advocacy strategies as parents begin to understand that family movement through time is cyclical and inevitable (p. 30). As a result of my own resilience and systemic understanding, I presented at the Council for Exceptional Children’s National Conference.

My presentation was entitled, *The Seven Steps for Families to Augment Educational Practices for Mildly Autistic Children*. This presentation was based on the work of Powers and Senge. The seven steps I identified were: (1) build confidence with the school-based team; (2) create successful interactions with key professionals to strengthen the bond between family and educational professionals that impact the child and family on a daily basis; (3) build positive relationships with educational staff that enable parents to work pro-actively with educational staff and the professional team that works with the child; (4) create a network to extend the educational team to include non-school professionals to provide resources for school professionals as a support mechanism; (5) work with extended family members for consistent reinforcement for the child when they are away from home; (6) focus on the child’s fixations to motivate the

child academically to augment the educational process; and (7) use all of these strategies to drive the Individual Education Process. I recommend these strategies as leadership strategies to best advocate for the Asperger Syndrome child, because these strategies have helped me to advocate for my own child.

I end this paper with a poem, I wrote entitled Autistic Son. This personal reflection captures the essence of my feelings about my Asperger Syndrome child. I offer it as a source of hope and strength for other struggling parents to help them in their parenting journey.

Poem

Autistic Son

When you learn for the first time
there is a diagnosis
you weep with grief.
You think of all that was
before you and
all that he will miss.
Your joy is expressed in chapters.
I was reading a novel adept at my conviction,
now I am reading a short story
with big words filling the page.
Words seem disjointed
and it is nearly impossible to
make sense of the theme.
The first day, I watched him sleep.
Coming home in the car after the clinic
cuddling with his rubber Iguana.
The next day, I firmly planted
my feet advocating for every right
he is entitled convincing myself that
early intervention is the key.
Perhaps not the well used key
laying on the floor bruised by the
heel of a shoe;
Instead the jagged key with rough
brand new teeth wrenching your stomach
and then your heart.
The week after you begin
the conversation; he reveals himself.
The joy of knowing him convinces you
this was not an accident.
Events are not random.
When you stop mourning
and gauge the wisdom of him
and the breadth of his comments
you begin the process to your own
self discovery and recovery
and all that you thought you had lost
you find again.

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