

A Reflection on Asperger Syndrome

Disability Paper

Hilary Chubb

The Pennsylvania State University

“My ever intriguing thoughts and ideas were locked up in my head and I couldn’t communicate them to others” – Marc Segar, 1997

Introduction

As I begin this reflection I must consider how naïve it would be to think that I can truly imagine what my life would be like if I had Asperger Syndrome (AS). What I can do is reflect on the ways this syndrome is manifested in people and how each of those ways has an impact on daily living. In my reflection I am making a clear distinction between imagining various aspects of AS and their impact on my life and having AS.

While AS was once considered rare, recent data suggests that 1 in every 150 people has this syndrome (Matson, 2008). Asperger Syndrome falls under the broader category of Autism Spectrum Disorders (ASDs) which also includes Autism, Pervasive Development Disorder- not otherwise specified (PDD-NOS), Childhood Disintegrative Disorder, and Rett’s Disorder (Matson, 2008; Woodbury-Smith, 2009). ASDs are estimated to occur in 2% of the general population (VanBergijk, 2008). The primary differences between AS and autism are that autism can be identified as early as 2 years of age while AS cannot be identified until 3 years of age and often is not until much later, and that speech for a child diagnosed with AS is typically not delayed early in life as it is for a child diagnosed with autism (Matson, 2008). Statistically, the number of children diagnosed with AS is one fifth the number of children diagnosed with autism (Woodbury-Smith, 2009).

Autism was first described by Austrian pediatrician, Hans Asperger, in 1944 (Woodbury-Smith, 2009). It is a chronic disorder of social interaction, communication, and restricted behaviors or interests (Woodbury-Smith, 2009). While the neurologic cause is still unknown, there is now evidence for a genetic base for autism from family and twin studies (Woodbury-Smith, 2009).

Impact on Daily Life

In starting to reflect on the impact Asperger Syndrome has on a persons’ daily life, I found it helpful to read a descriptive case history of a child diagnosed with AS. The case history shared that at nine years old the Tom had no friends, limited interpersonal skills, as well as signs of depression, and a fascination with clocks. Interestingly, the impression of the author was that the father has similar problems. At twelve years old Tom had an issue where he stopped while using a crosswalk in the middle of the street because the signal light changed to ‘Don’t Walk’ (Volkmar, 1996).

Currently, one of the biggest parts of my life is education, and I was fortunate to find a good amount of literature on students with AS in higher education. This is because of the implementation of ADA and IDEA has allowed student to receive the appropriate support in the K-12 education system, which has made it possible for students with AS to graduate from high school and go to college (Hughes, 2010). Just as with any other prospective college student, the size and type of school has an impact on the adjustment of a student with AS. Choosing a small college would offer familiarity and the small, personalized learning environment that many AS students thrive in, as well as offer the opportunity to avoid being over stimulated by large crowds (VanBergijk, 2008; Woodbury-Smith, 2009). On the other side of that, there are large institutions which offer faculty and staff who may be more familiar with the autism spectrum, and provide the opportunity to find where the student belongs socially and vocationally (VanBergijk, 2008). Some of the issues a student with AS may face in college could be addressed through faculty. One article suggested that faculty establish boundaries before the semester begins, provide clear information in written format, and allow the student to leave the

room if they become upset or agitated (Faculty Suggestions, 2010). A student with AS may have trouble discerning when it is appropriate to speak up in class, which is why the suggestion for faculty to establish boundaries was made. Another suggestion to promote academic success in college for students with AS is to break down larger assignments (Vanbergijk, 2008) to encourage time management (Hughes, 2010). Common academic adjustments provided for students with AS are additional time on exams, exams in separate and distraction reduced environments, tutoring, and mentors (Hughes, 2010).

An issue that interested me in the literature is that males are diagnosed more often with AS than females are (Hughes, 2010). Some professionals believe that AS is simply more common in males. There are also opinions that because a male prototype is used in diagnosis, and AS was originally identified in a population of male adolescents that this causes fewer diagnosis of females but that the number of females who actually have AS may be comparable to that of males (Hughes, 2010). This can lead to misdiagnosis because of the many other disorders that AS shares characteristics with as well as the comorbidities of AS. My concern is that females with AS therefore do not receive the same type of support and interventions as males do. Additionally, females in the general population are more vulnerable to disorders such as depression and anxiety which are common in people with AS, creating an even more emotionally difficult situation (Woodbury-Smith, 2009). AS is also commonly associated with seizures, sleep problems, Tourettes', and ADHD (Woodbury-Smith, 2009).

I need also to reflect on manifestations of AS that would have occurred earlier in my life if I had this syndrome. Social isolation is a major factor in childhood for children with AS (Information). Often children benefit from early interventions which focus on behavior management and training on social skills to learn the unwritten rules of socializing and communicating (Mayo Clinic; Woodbury-Smith, 2009). Children can also learn, often most successfully when taught in a rote and straight forward manner, how to speak with more natural rhythm, volume, and inflection (Mayo Clinic; Woodbury-Smith, 2009). In addition to Cognitive Behavioral Therapy, there are medications which can treat some of the symptoms of AS including irritability, hyperactivity, depression, and repetitive behaviors (Mayo Clinic).

The most valuable thing for me to read to be able to identify with a person who has AS was a book written by a man with AS, *Coping: a survival guide for people with Asperger Syndrome* by Marc Segar. While I read in most of the other literature that those with AS perceive the world differently, have difficulty with social interaction and coping with change as well as other things, it was invaluable to hear how someone with AS copes in this world that they have difficulty understanding, in the form of advice to others with AS. Segar set out rules in a very linear way to lay out the 'unwritten rules' of society. He also provided a positive spin (i.e. good at worrying, photogenic memory, musical talent, remain level headed in situations stressful to others) (1997). Every single piece of advice made sense to me, but as I read, I tried to force myself to think about why those things are. An example is, why do I have to look at a person when I am talking to them? For me, someone without AS, I have just always done it because 'that's what you're supposed to do', but that is not actually a reason. Segar did an excellent job explaining the unexplainable, that people might think you are lying or do not want to be talking to them if you are not looking at them.

Overall, everyday life could be a constant struggle if I had to continuously think about unspoken rules of society and worry about the way others will judge me if I do not follow those rules. That is something I can imagine but I doubt I could ever imagine the high level of stress that could produce, especially when just learning about what these social rules are.

Interpersonal Relationships

Before looking at any literature on Asperger Syndrome, I thought about what I knew about it from my own experiences, pop culture, and a few varied readings. The main thing I knew was that it impaired social skills, which could result in a limited number of and/or difficult interpersonal relationships. The symptoms of AS (as defined in the DSM IV) are social impairment, deficits in communication and sensory-motor functioning, and restricted or repetitive behaviors and interests (Matson, 2008; VanBergik, 2008). This includes possibly absent nonverbal affect and repetitive motor behaviors, the latter of which is also associated with autism (Matson, 2008). In terms of interpersonal communications, a person with AS may demonstrate difficulty with semantics (VanBerijk, 2008), their speech may also be verbose and tend to go on tangents (Woodbury-Smith, 2009). Challenges such as age appropriate behavior, making eye contact and rate, inflection, and volume of speech can make forming and maintaining relationships difficult, both personally and professionally (VanBergijk, 2008; Information).

Often times people have the impression that people with AS do not want to interact with others, but truly they typically are motivated to do so and find it difficult and themselves socially isolated because of the oddities in their communication (Woodbury-Smith, 2009). On subject matter the biggest interpersonal communication barrier for people with AS is that they often have a topic or subject they prefer which takes precedence over conversation topics others may be engaging in (Woodbury-Smith, 2009). This can lead to one sided conversations, which the person with AS may not notice (Woodbury-Smith, 2009) and can ultimately lead to further social isolation.

According to Segar, one of the most difficult things is that despite not being aware of or knowing the unwritten rules of society people without AS expect people with AS to know and live by the rules. A great deal of the advice in Segar's book touched on social interaction. One piece was to pay attention to the 'plot' of the conversation, not the details, because people without AS typically remember the plot. He also spent a good portion on body language, explaining why it was so important and the various aspects of it, especially boundaries. Something he pointed out was difficulty understanding distortions of truth. While various pieces of literature did touch on the literal manner people with AS may interpret information, Segar's explanation led to a much deeper understanding. Not only does a person with AS possibly have difficulty understanding sarcasm, but also exaggeration and white lies among other things (1997). As someone without AS, reading Segar's instructions on learning to tell when something is an exaggeration or sarcasm, I could not imagine being that perceptive.

Interpersonal relationships are an area where the existence of AS is quite evident but I think it is important to understand how that can affect a person's emotional health, interactions with their environment, and career or life planning.

Interactions with Environment

From my perspective, the most extensive difficulty with environment for a person with Asperger Syndrome is the adaptation and coping with change. Life is always changing and for a great deal of it, we as humans have no control over it. However there are aspects of a person's environment that can be controlled, such as in the classroom as I mentioned earlier. If a student with AS has been told at the start of the semester, in a very forward and outright manner, that they should not speak without being called on, and should only speak a certain number of times per class period, they can then be prepared for the expectations for that block of time (Faculty Suggestions, 2010). In the transition to a higher education environment a person with AS may

be easily overwhelmed because of the new surroundings, new people, new schedule, and many things out of their control. Something that adds to that difficulty is that individuals with AS may not demonstrate that they are struggling to adjust or that they are experiencing a high level of stress (Glennon, 2010). The physical and social environment can cause a great deal of anxiety for a person with AS because of the fast pace of information (VanBergijk, 2008). This is part of why it is so important for students with AS to receive what are not typical accommodations in higher education (Hughes, 2010), even including a stress management plan which may provide a safe place for the student to go when they feel overly stressed or stimulated (Glennon, 2010)

The physical environment can even be problematic due to motor deficits a person with AS may have, which was not something I had ever considered in terms of AS (Information). Additionally, obsessive compulsive behaviors can be common in people with AS which could add another layer of stress to an environment (Matson, 2008; VanBergijk, 2008).

Future Goals

Some of the research states that many people with a diagnosis of Asperger Syndrome will experience improvements in their communication and social skills, especially if they receive intervention services (VanBergijk, 2008) but that is not to say is what amount of improvement. The literature also suggests that between 70% and 80% of those with an ASD diagnosis will demonstrate social impairment through adolescence and adulthood (VanBergijk, 2008), leaving 20% of those diagnosed in childhood who will not meet the diagnostic criteria by the time they reach adulthood (Woodbury-Smith, 2009). It is likely that someone with less social or communication skills would be uncomfortable working in certain professions, especially those that would be majorly personal interactions. Segar provided the following chart of suggestions of suitable and unsuitable jobs for people who have AS.

<i>Suitable jobs</i>	<i>Unsuitable jobs</i>
Graphic designer Computer programmer Computer technician or operator Research scientist Medical research scientist Architect Pharmacist	Salesman Manager Solicitor or lawyer Police officer Doctor, dentist or health inspector Secondary school teacher Airline pilot
<p>(Which are respected professions which generally take place in environments with people who tend to be perhaps just a little bit more accepting of the needs of those who worry. Please note that I have specifically chosen to show quite difficult careers here and there are plenty of easier careers available.)</p>	<p>(All of which can be highly stressful and competitive occupations that involve making difficult decisions and compromises under intense pressure from other people; some also involve using and interpreting body language in a subtle way.)</p>

(Segar, 1997).

Something that Segar did not note, which I feel is important, is that there are going to be exceptions to this. Certain people, whether or not they have AS, are going to be suited to be a

doctor rather than a graphic designer or a chemist rather than a salesperson. It may majorly depend on the persons interests, which as we know in someone with AS, may be very focused. The fictional example which comes to mind is Dr. Virginia Dixon from the ABC television series, Grey's Anatomy. She shares with her coworkers that she has AS, but more importantly she has always been interested in the heart; all the chambers, the color, and the way it works. While the fact that she has AS does cause some difficulties in her job, her singular fascination with the heart also made her an extraordinary cardiovascular surgeon. While this is fictional, I believe its applicable, especially because she learned the social skills she knew were necessary for her job, and was obviously very successful at it. As with many other disabilities, I believe that a diagnosis of AS should not and cannot be the only defining factor in career choice and a person's path in life.

Other Factors

The most recent development in Asperger Syndrome is the change which came with the publication of the DSM V in May of this year (2013). There is no longer a separate category for AS, in addition to that the social elements of autism were also reduced (Society). An ongoing debate in the ASD community has been whether there is a marked difference between High Functioning Autism (HFA) and AS (Matson, 2008). In adults, many of the symptoms of HFA and AS are very similar and overlap, making a differential diagnosis difficult (Matson, 2008). This was one of the strongest supports for the condensing of the autism and AS diagnosis in the DSM V (Matson, 2008). Matson, in 2008 stated that it was necessary for the next version of the DSM to provide more detailed information on AS to determine if it is a distinct disorder. That point was made moot with the publication of the DSM V. While technically a person who has already been diagnosed with AS will not be reclassified due to the changes in the DSM V, certain program providers may choose to have people re-diagnosed under the new definitions in determining eligibility for services (Society). My opinion on this has been strong for months. I have had discussions with people in the past who saw no difference between AS and autism. While I do not have the qualifications or experience to determine whether AS and autism are two distinct disorders, I do have an ethical belief that people deserve individual support. By differentiating the diagnoses, it becomes more difficult to create a 'prescribed course of treatment' for a person diagnosed with autism. Every person with AS will react to interventions differently and learn at a different pace, as is the case with other people with different disabilities and with people without disabilities. My concern with the changes to the DSM V is that students will not be given the same educational opportunities in the K-12 system and will also not be given the appropriate support. I also believe that this non-differential diagnosis only contributes to stigmas that already exist about people with Asperger Syndrome.

References

- Faculty Suggestions (2002). Proceedings from Embracing Challenges 2002: *The 9th Annual Disability Symposium*. Philadelphia, PA: University of Pennsylvania.
- Glennon, T. (2010). The stress of the university experience for students with Asperger Syndrome. *Occupational Therapy Practice, 1*, 183-191.
- Hughes, J. (2010). Supporting college students with Asperger Syndrome: Possible strategies for academic advisors to use. *The Mentor: An Academic Advising Journal, 1*, 1-7.
- Information. (n.d.). *Asperger's Disorder Homepage*. Retrieved September 8, 2013, from <http://www.aspergers.com/aspclin.html>
- Matson, J., & Wilkins, J. (2008). Nosology and diagnosis of Asperger's Syndrome. *Research in Autism Spectrum Disorders, 2*, 288-300. Retrieved September 8, 2013, from <http://ees.elsevier.com/RASD/default.asp>
- Mayo Clinic. Asperger's syndrome: Treatments and drugs - MayoClinic.com. (n.d.). *Mayo Clinic*. Retrieved September 8, 2013, from <http://www.mayoclinic.com/health/aspergers-syndrome/DS00551/DSECTION=treatments-and-drugs>
- Segar, M. (1997). *Coping: a survival guide for people with Asperger Syndrome*. Ravenshead, Nottinghamshire: Early Years Diagnostic Centre.
- Society. (n.d.). Autism Society - Update on the Diagnosis Statistical Manual of Mental Disorders (DSM-5) . *Autism Society* . Retrieved September 8, 2013, from <http://www.autism-society.org/news/update-on-the-diagnosis-statistical-manual-of-mental-disorders-dsm-5.html>
- VanBergeijk, E., Klin, A., & Volkmar, F. (2008). Supporting more able students on the autism spectrum: College and Beyond. *Juvenile Autism Development Disorder, 38*, 1359-1370.

Volkmar, F., Klin, A., Schultz, R., Bronen, R., Marans, W., Sparrow, S., et al. (1996). Asperger's Syndrome. *Journal of the American Academy of Child and Adolescent Psychiatry, 1*,

118-123. Retrieved September 8, 2013, from

<http://www.ncbi.nlm.nih.gov/pubmed/8567603>

Woodbury-Smith, M., & Volkmar, F. (2009). Asperger Syndrome. *European Child and Adolescent Psychiatry, 18*, 2-11. Retrieved September 8, 2013, from

<http://www.ncbi.nlm.nih.gov/pubmed/18563474>