



ASPERGER
CENTER FOR EDUCATION AND TRAINING

Asperger Syndrome in Adulthood Does Diagnosis Matter?

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A week does not go by when I do not receive a telephone or email inquiry from an adult who wonders if he or she has Asperger Syndrome. It is not surprising that this idea is coming to mind for many individuals. The media is more and more often covering stories about individuals on the autism spectrum and we see many television shows with characters with Asperger Syndrome. In addition, a frequent source for this question was that another family member, usually a child, had received the diagnosis. Asperger Syndrome came into our diagnostic nomenclature only in 1994, so most adults alive today were children when the diagnosis was not known. If they had problems as children another explanation might have been considered such as ADHD, learning disability, or conduct disorder. Now that more information is coming into the public domain, these adults are reconsidering both their childhood past and their current issues and wondering if Asperger Syndrome explains some important aspects of their being. What advantages might there be for an adult to seek a diagnosis? I always ask individuals who contact me what their reasons are and I have received quite varying responses. Some of the most common include:

1. Having difficulty with the social aspects of work and needing specific support in that area. Many individuals with Asperger Syndrome have work histories that include seldom being chosen after an interview, being fired for reasons they do not understand, not understanding basic elements of a job because they had trouble processing instructions, and being very underemployed for their skill set. Solutions for these issues might range from assessing processing problems and learning how to advocate for oneself about these differences to having therapy that includes social autopsies of difficult moments at work to obtaining a job coach who can understand and support adults on the spectrum.

2. Having difficulty with establishing or maintaining relationships. Individuals with Asperger Syndrome typically have difficulty with relationships. Sometimes it is helpful for a spouse to understand the origin of these difficulties to better accept and support a partner. Sometimes the diagnosis helps children better understand a parent. For individuals attempting to form relationships, therapy designed to support skill development may be helpful if it is designed for individuals on the spectrum, but may not be useful if it is simply generic psychotherapy.

3. Struggling with the less structured life of a college student. Often high school students with Asperger Syndrome are quite academically successful, yet find themselves at sea in the much more self-directed and less structured life of college. Disability offices frequently do not fully appreciate the obstacles that such students have trying to function at college. Their difficulty with self-advocacy coupled with true disabilities in organizational skills can lead to college failure of a potentially successful student. Diagnosing Asperger Syndrome and examining specific co-occurring executive function deficits can lead to the right kind of college support being designed.

4. Understanding their child's Asperger Syndrome. As Asperger Syndrome has genetic elements it is not uncommon for multiple family members to share the diagnosis or, at least, display a number of similar traits. Many adults come to their own diagnosis after their child has been diagnosed. Having a consultation about their own traits and the experiences they had growing up can be therapeutic for them and helpful in understanding their own child better.

5. Eligibility for support services. Every state is different in the eligibility requirements to receive services from the mental health and developmental disability systems (see the policy research study at AspFi.org). In addition, eligibility for SSI, Medicare, or Medicaid requires specific assessment and justification. For individuals who need a greater level of support, attaining eligibility for these supports can be life saving. Often mature adults with Asperger Syndrome are living with elderly parents without knowledge that they could qualify for various support services. As their adult children seem very bright, and may have advanced education, it does not occur to families that someone with Asperger Syndrome can be eligible for significant supports to live more independently, be employed, and receive needed therapies. Obtaining a diagnosis and life skills assessment can be critical to obtaining needed support services.

6. Finding a common bond with others. Many adults with Asperger Syndrome never dreamed that there were so many others like themselves who have experienced similar challenges and discrimination. In finding a support group, they may feel validated for the first time in their lives. Obtaining a diagnosis of Asperger Syndrome may lead them to others who can share their triumphs and defeats from a similar life perspective. Obtaining a diagnosis can be a liberating, supportive, essential, critical, and defining experience. Finding a professional who can guide one to appropriate avenues of intervention or support is as important as the diagnosis itself. Professionals who say, "You have Asperger Syndrome," but can offer little else are generally not useful for adults struggling with the meaning of the potential diagnosis. Asperger Syndrome or autism support groups for individuals or families typically can often refer adults who are wondering where to find an appropriate diagnostician. Academic medical centers, university affiliated programs in developmental disabilities, or autism and Asperger Syndrome centers can also be sources for finding such specialists. Adults may choose to read "The Complete Guide to Asperger Syndrome," by Tony Attwood as a first step to thinking about the appropriateness of the diagnosis for themselves.