

Latrobe Bulletin

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Adults with high-level spectrum disorders often not recognized

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For The Bulletin

(Editor's Note: April has been Autism Awareness Month and promoted awareness often focuses on children or adults who have been diagnosed because of obviously typical characteristics. Yet there are countless others who were diagnosed as adults after living a lifetime of not knowing why they had certain difficulties with social experiences, relationships and other behaviors. Or they have not been diagnosed at all.)

Thomas Jefferson would have been diagnosed with high-functioning autism if he were alive today. Author Norman Ledgin comes to that conclusion in his book "Diagnosing Jefferson," a detailed evaluation of the third president's "peculiarities," social awkwardness, failure to recognize social cues, lack of emotional reciprocity and other typical characteristics of a person with high-functioning autism, or HFA.

Ledgin calls it by its common name of Asperger's, a syndrome that is no longer listed as a distinct diagnosis in the fifth edition of the Diagnostic & Statistical Manual of Mental Disorders. The book, also known as the DSM-V, was written and is periodically updated by the American Psychiatric Association. Instead of a breakdown of different diagnoses such as autism, Asperger's and pervasive developmental disorder, the current manual describes them all under autism spectrum disorders (ASD).

By definition, that's a general term that describes a group of complex developmental brain disorders that in varying degrees can cause anything from being socially awkward to being non-verbal. Current research indicates that the condition develops in utero and that a genetic component may be among the causes. (The belief that autism is caused by vaccines has been refuted by extensive and responsible research.)

Although autism has been named and diagnosed only in recent generations, the condition has long been recognized by its characteristics. It shows up in literature describing behaviors of famous people in the past, like Amadeus Mozart, Mark Twain, Albert Einstein, Beethoven, Vincent Van Gogh, Henry Ford, George Bernard Shaw, Thomas Edison and Emily Dickinson. Add to that contemporary names like Bill Gates, Steve Jobs, Bobby Fischer, Stanley Kubrick, Andy Warhol, Dan Akroyd, Tim Burton, Courtney Love and Jerry Seinfeld.

All of them are believed to have had (or have) HFA or Asperger's. In the mental health field, there are disagreements over whether those are two distinct diagnoses or if they are indistinguishable.

Whatever it's officially called, it often goes unrecognized.

"Up until now and even now, it's undiagnosed in many individuals," said Melissa Fligger of Harrison City, who is president of the Westmoreland County affiliate of the Autism Society of America. "Back when I was in high school — I am now in my 30s — there were people who came off as different, but now that I have so much more experience, I can see that they are falling somewhere on the spectrum and are not diagnosed."

Fligger teaches at Clelian Heights School for Exceptional Children in Hempfield where students tend to have more behavior issues and lower academic levels than those with HFA.

"What the general public may not understand is that there are adults who have autism and are not exposing that they do, or they don't accept it," she said. "That's easy to understand because when someone has a label, the stigma can saddle them for the rest of their lives, and they look at that in a negative way."

For that reason, adults who suspect that they are on the spectrum may not want to get a diagnosis, she added, because they think "if you are on the autism spectrum, there's something wrong with you, and that's unfortunate. You can go out and amazing things."

People with HFA tend to be of average or high intelligence, but that doesn't mean that they will all be geniuses, gifted composers, artists or inventors. Some will, most won't. The same obsessive traits that can produce a chess grandmaster or someone who discovers the theory of relativity can also cause social and relationship problems. The detailed focus that leads to solving scientific problems means that the person with HFA misses the broader picture in communication — "reading" people and interacting in ways that make connections.

No wonder that statistics point to an 80% divorce rate for people on the spectrum.

According to the ebook "Living With An Asperger's Partner," people with HFA often find it difficult to understand the emotions of others and to express themselves. Social cues and body language are missed, eye contact is difficult, and conversations that include sarcasm, satire or metaphors

can be misunderstood by individuals whose brains are wired to be more literal. That all can spell doom to friendships and relationships. The person on the spectrum just doesn't "get it" and is likely not even aware that they don't.

Mark Hutten, M.A., the ebook's author, points out that such seemingly cold behavior leaves the partner with a sense of isolation. Even if there is a diagnosis, the partner may feel despair, frustration and disappointment that the other will never "get better" and that their own needs won't be met. They may lack support from family and friends who don't fully understand the strain that they're under, especially if the person appears to be "normal" to outsiders. The partners may frequently wonder whether they should end the relationship.

Then there may be meltdowns that appear to be precipitated by minor incidents. But the person with HFA may be coping badly with a series of small stresses that build to an explosion that often ends with a need to isolate by storming out of the house or hiding under a layer of blankets.

If a person with HFA has not been diagnosed, those behaviors and characteristics, paired with isolating with obsessive interests, can lead to criticism and intolerance from others.

"Someone having interests and abilities that are so different obviously leads to social and relationship barriers, and being able to negotiate through social circumstances is always a challenge," Fligger said. "I think that if you are at an intelligent level, you can understand your diagnosis and fake it when you need to."

That can mean making an effort to hug a significant other in order to create a bond, even when the person on the spectrum would rather not. That can mean deliberately making eye contact when the tendency is to look away. Learning those and other skills can help a person with HFA to make vital connections with others.

There are numerous books, websites, chat rooms, blogs, support groups and other resources available for adults on how to manage life on the spectrum, and how to pursue getting a diagnosis if HFA is suspected. There are similar resources for partners of people on the spectrum, and therapists who specialize in helping individuals and couples facing HFA.

"If you don't get the necessary assistance, that could stand in the way of making sure that you are successful in careers and relationships," Fligger said. "It's a catch-22 where you don't want to disclose that you have this diagnosis, but you don't want people to think that you are 'strange.' But it's really important that people in relationships —whether romantic, a friendship or with coworkers — understand you. There are so many layers to this that it's important to be honest with who you are. It prepares you better, and it prepares other people better. I can understand why people would not want to have a label, but we should celebrate everyone for their differences."

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