

A long shadow is lifted on Asperger's in adults

By Suzanne Leigh, Special for USA TODAY



Liane Holliday Willey, with daughters Meredith, left, and Jenna, both 16, husband Tom and Lindsey, 20, at home at their pool in Rockford, Mich., was diagnosed with Asperger's syndrome at age 40 and wrote a memoir about the condition.

Ten years ago, Kathy Marshack, a psychologist in Vancouver, Wash., was unfamiliar with Asperger's syndrome in adults.

Asperger's is a condition on the spectrum of autism disorders that most people associate with children and teens, but Marshack has about 15 patients who are either adults with Asperger's or are the spouses or grown children of them.

Marshack, who says her late mother had Asperger's and her adopted daughter has it, believes the condition is widely undiagnosed. In many cases, it doesn't come to light until a spouse or adult child seeks therapy for depression or poor self-esteem that results from the coldness and egocentricity Asperger's adults demonstrate in relationships, she says.

DIFFERENCES BETWEEN ASDS

Autism-spectrum disorders afflict 1 in 150 8-year-olds, according to government figures. Most children with ASDs have been identified by that age. People who have all five ASDs demonstrate poor social interaction and communication skills and repetitive behavior or interests. The severity of these deficits varies from disorder to disorder.

Autism

Accompanied by mental retardation in 70% of cases. Delay or abnormal functioning in social interaction, language or imaginative play is evident by age 3.

Asperger's syndrome

Symptoms are typically milder. No "clinically significant" delay in language or "cognitive development." Speech may lack inflection or be too formal.

Pervasive developmental disorder not otherwise specified (PDD-NOS)

"Subthreshold" condition in which some, but not all, features of autism or Asperger's are identified.

Rett syndrome

Affecting 1 in 10,000-15,000 females. At 6-18 months, autism-like symptoms become apparent, including characteristic hand-wringing. The child's mental and social development regresses.

Childhood disintegrative disorder

Occurs in 2 in 100,000 children with ASDs. Average onset is between ages 3 and 4; regression is usually more dramatic than in Rett syndrome.

Sources: Autism clinic at the University of California-San Francisco; *Diagnostic and Statistical Manual of Mental Disorders IV*; National Institute of Mental Health; Autism Society of America.

The number of Asperger's adults, like the diagnosis, is hard to pin down. Anecdotal growth in their ranks and a burgeoning online "Aspie" adult subculture that includes dating sites, advocacy groups and chat rooms raises the question: Are we starting to discover generations who escaped diagnosis? The condition officially wasn't recognized until 1994, which leads people such as Marshack to believe doctors are playing catch-up with adult diagnoses.

Because some Asperger's adults are spouses and parents and have enduring careers, others suggest that the diagnostic criteria are being interpreted too loosely.

"Almost by definition, an Asperger's person would not form an intimate relationship, get married and have children," says research scientist Katherine Tsatsanis of the Yale Developmental Disabilities Clinic. "They don't form connections. The desire, the drive and the social knowledge is lacking."

An explanation for behavior

What is not disputed is the testimony of those who say their diagnosis helps explain their lives.

When Liane Holliday Willey was diagnosed with Asperger's at 40, she felt she had been offered a key that would "unlock the mysteries that were me."

The Rockford, Mich., married mother of three wrote of her suspicions that she had the disorder in her memoir, *Pretending to be Normal*, published in 1999. In it she described an "overwhelming childhood desire to be away from my peers," preferring pretend tea parties in which "the fun came from setting up and arranging things."

The criteria for Asperger's, according to the *Diagnostic and Statistical Manual of Mental Disorders*, the clinicians' diagnostic handbook, are "qualitative impairments in social interaction," which may include poor eye-to-eye gaze, failure to develop relationships and lack of "emotional reciprocity." The syndrome also is marked by "restricted repetitive and stereotyped"

behavior, such as inflexible adherence to routine, hand flapping or twisting and an abnormal preoccupation with certain interests.

For William Loughman of Berkeley, Calif., a retired director of a hospital cytogenetics lab and grandfather of six, reading about Asperger's led to an epiphany when his conviction that he had the condition was confirmed by a psychologist three years ago. Loughman, 74, says that like many people with Asperger's, he has difficulty making eye contact and tends to rock back and forth ("stimming" in Asperger's parlance).

He believes Asperger's explains why he flourished in the highly structured environment of the U.S. Army and partially explains why his first wife of 10 years divorced him. (His second marriage, which has lasted 40 years, has weathered decades of turmoil but is now calm, he reports.)

Disparities in diagnoses

Like other conditions on the autism spectrum, Asperger's is believed to be caused primarily by errant genes, and it is not typically associated with low IQ. Although there's no consensus on prevalence, a study in May's *Journal of the American Academy of Child and Adolescent Psychiatry* pins it at 1 in 400 among 8-year-olds, more often in boys than girls.

Though professionals use the same diagnostic criteria, interpretations make for wide disparities in diagnosis. Ami Klin, head of the Yale Developmental Disabilities Clinic, says some people may have family members with autism-spectrum disorders and exhibit features of Asperger's, such as "social deficits and a great deal of rigidities," but these traits are not tantamount to the diagnosable condition.

Forming close friendships and dating run counter to Asperger's adults' goals, colleague Tsatsanis says; Klin says he has never known a parent with Asperger's.

Bryna Siegel, director of the Autism Clinic at the University of California-San Francisco, concurs that an Asperger's parent would be rare, and she knows of just one short-lived marriage. Recently she does more "un-diagnosing" than diagnosing, she says.

But Marshack, whose self-published *A Sliver in My Mind: Loving Those With Asperger Syndrome* arrives this year, says experts who say Asperger's adults don't marry or have children either "have their heads stuck in the sand" or do not believe many have learned to compensate for their deficits.

Diagnosis can offer fresh hope to those who have been struggling, she says.

Holliday Willey says she fails to understand concern about overdiagnosis. "The idea that too many are being diagnosed — so what? I'd rather gather in more folks than leave one out."

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