Autism in adults: Mostly undiagnosed or misdiagnosed

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While autism awareness has improved, people's ability to recognize what autism looks like in everyday life is lagging. That's according to Theresa Regan, PhD, the lead neuropsychologist at OSF HealthCare Saint Francis Medical Center in Peoria, Illinois.

"Autism is a neurologic diagnosis. It is about how the brain is wired from development. It's largely genetically driven, so it's medical, physical and neurological. It's not connected to intellect at all. It occurs across the whole continuum of intellect, and it occurs across the whole continuum of how people are doing," Dr. Regan says. "We probably have misconceptions about it being tied to learning problems or intellectual disability. These myths have held us back from understanding what the neurology of autism looks like."

To be diagnosed with autism, the characteristics need to be present in childhood.

"The diagnostic manual explains they may not be manifest or noticeable to people until the environment gets complex enough that they start to feel lost or have difficulty navigating certain situations," Dr. Regan says.

But that doesn't stop adults, from their late teens to their late 80s, from being diagnosed.

"The great majority of adults who are autistic are either undiagnosed or misdiagnosed with other mental health conditions," Dr. Regan adds. "So, we want to rectify that and have the right diagnosis for every person every time."

Researchers estimate that as many as 95% of autistic adults are missing a correct diagnosis.

## Three social criteria that have to be met

- 1: Difficulty approaching and having a back-and-forth conversation with social emotional content.
- 2: Challenges communicating effectively with a wide range of nonverbal elements.
- 3: Difficulty making, maintaining, and navigating social relationships.

"Some people might do great with play dates their parents arranged, but then you hit middle school and you're supposed to navigate starting a relationship. What does a person mean by this? Why is it a roller coaster? That's the real navigation of relationships. Then they realize, I feel lost, and it seems to me like other people know what to do and I'm feeling lost," Dr. Regan says.

In addition to social criteria, there are criteria that capture repetitive behaviors, a preference for routine, a deep dive into interests, and differences in the way the individual experiences sensory inputs like noise and light.

"Those pathways are in charge of leaning the brain toward repetition. The individual on the spectrum may have repetitive movements or speech. They may use objects repetitively," Dr. Regan adds. "They like the same schedule, and they tend to dive really deep into their favorite topics."

OSF Saint Francis Medical Center is home to the Adult Diagnostic Autism Clinic. While this is a great resource to have in the community, Dr. Regan says currently there is a wait list of four years to be seen.

To learn more about autism and the resources OSF offers, head to the OSF HealthCare website.