

## Diagnose or not to Self-Diagnose

Getting an autism diagnosis is a difficult matter. Less than a year ago, I was identified as autistic at age thirty-nine. My son was diagnosed almost five years ago.

I am proud about getting a formal diagnosis from the Centre for Addiction and Mental Health (CAMH). The letter declaring my autistic diagnosis is proudly framed at home.

It is hard to talk about autism without borrowing medical terminology. Parents can almost pass for clinicians. My preference is identity-based words that preserve our human dignity.

Genetically-speaking autism is older than the words used to grasp it.

Professor Roy Richard Grinker of George Washington University talks about one recent discovery: "Scientists have found that genes associated with autism are adjacent to areas of the genome that are distinctly human, the areas called HARS (human accelerated regions)."

We are only starting to understand this human neurotype.

Grinker adds researchers found "autism is inextricably linked to the same genetic pathways that make us such extraordinary mammals, capable of education, creativity, and high intelligence."

Autism was only coined in 1911 by a Swiss psychiatrist named Eugen Bleuler. He observed those with schizophrenia suffered a "detachment from reality, together with the relative and absolute predominance of the inner life, we term autism."

Today medical diagnosis of autism is the only way to receive a formal diagnosis. Formal diagnosis exists predominantly for therapeutic purposes.

Translator and novelist David Mitchell humanizes autism for readers in his introduction to Naoki Higashida's *The Reason I Jump*. He tells us how the "functions that genetics bestows on the rest of us" the "editors" "as a birthright, people with autism must spend their lives learning to simulate."

Getting a formal diagnosis of autism is largely for medical reasons. The world according to neurotypicals can be harmful to autistic experience. Diagnosis lets us try to restore our dignity with specialized therapies.

The process for sussing out this diagnosis can feel intrusive at times. Assessment is predominantly conducted with children and their families by a pediatrician following standards developed by the American Psychiatric Association for the DSM-5 or Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition.

Doctors rely on observations about behavior with the assistance of testimony from parents to diagnose.

Some like Dr. Luke Beardon from Sheffield Hallam University in England criticize diagnostic assumptions: "there is no behaviour that an autistic person displays that isn't displayed by the non-autistic population. There is no behaviour displayed by the PNT that isn't found in the autistic population."

Yet the number of kids diagnosed with autism is growing each day. Approximately 1 in 66 children are diagnosed with autism in Canada.

Undergoing a diagnosis can be a distressing affair. You have to allow someone to nose about your every-day personal habits and

interactions. The report from CAMH about me missed nothing: "David spoke with a normal cadence but his speech was notable for lack of variation in tone."

My adult assessment was conducted using ADOS<sup>®</sup>-2 an alternate diagnostic used for teenagers and adults. We started by discussing my childhood history of stimming, finicky eating, sensory sensitivities, and poor social skills.

The CAMH psychiatrist also tried to improvise a verbal story collaboratively. I was largely disinterested in keeping up her narrative over the perplexing dreamscape art of David Wisener's Tuesday.

Soon enough my wife Vivian will have to sit down for our determination of needs meeting with AccessOAP. Formal diagnosis permits us to apply for various allotments of government funding.

Funds will be determined by a care coordinator working for a third-party company under the AccessOAP brand. The onus will be on Vivian to prove Solomon requires therapeutic supports. We can bolster our claim with testimony from certified professionals we paid to assist him.

This is what already beleaguered parents can look forward to post-diagnosis. More work to prove autistic probity even after diagnosis.

Orangeville's own Michael McCreary recalls how his parents struggled to find a doctor willing to diagnose him in his book *Funny, You Don't Look Autistic*.

He says tongue placed firmly in cheek: "My diagnosis was a life-changing moment for my folks. As for me, well, I was five years old. I just wanted to get out of there and rent *Walking with Dinosaurs* from the library, not listen to this doctor who was saying things I couldn't really comprehend."

Still he admits ruefully, "I wish I had been more grateful. That diagnosis would end up helping me more than I could've imagined."

Adult diagnosis at early middle age means I have only access to counselling and classes. The CAMH psychiatrist considered me too functional to qualify for disability funding. My fault for graduating from the school of hard knocks.

Today we are starting to see growing interest for the idea of self-diagnosing.

It is also becoming commonplace for middle-aged parents 50 or older to get diagnosed after their children.

I heard a support worker describe my childhood years ago attending an introductory course about autism. Self-diagnosis encouraged me to explore autism before rushing into a formal diagnosis.

A two-tiered approach to autism diagnosis would be more pragmatic. Countless more undiagnosed adults might discover others like themselves.

Dr. Devon Price, assistant professor at Loyola University Chicago's School of Continuing and Professional Studies, discusses how self-diagnosis can be more inclusive in his book *Unmasking Autism*.

He explains how formal diagnosis "slams its heavy bars in the face of anyone who is too poor, too busy, too Black, too feminine, too queer, and too gender nonconforming, among others. The Autistics who lack access to fair diagnoses need solidarity and justice the most desperately out of all of us, and we can't just shut them out."

Self-diagnosis is a more user-friendly option. When asked about autism I always recommend trying the Nipissing District Developmental Screen. This is what professionals already use in practice.

One day I hope we will not have to keep repeating this conversation. We are a living neurotype not a disorder.

David Vahey

Orangeville