Why it took thirty-five years to get my diagnosis

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by Carrie Beckwith-Fellowes

When I was four years old a speech therapist told my mother that my inability to speak would right itself. A GP told her not to worry about my severe sleep problems and that I was simply a fussy eater for only eating jam sandwiches and yogurt.

The self-harm and eating disorder I developed as a teen was put down to depression and when I tried to end my life aged eighteen, I was called selfish by the nurse who pumped my stomach.

For ten years psychiatrists struggled to pin down a label, admitting I didn't fit into any box. Eventually they gave up and misdiagnosed me with bipolar disorder, mixed anxiety disorder and borderline personality disorder. My meltdowns were misdiagnosed as "non epileptic seizures" in my early twenties and my intermittent selective mutism was put down to depression. When medication failed to improve my mental health I was subjected to multiple sessions of ECT and when that failed they increased my lithium which left me blind for two years. I discharged myself from the mental health service and weaned off medication. My doctors warned my mood would crash within a year.

Seven years later my mood is still stable and at the age of thirty-five, I was told I was autistic.

I Still Had A Nine Year Wait To Get A Diagnosis

A neuropsychologist first mentioned autism in 2009. We'd talked about the difficulties I had making friends and how I preferred to spend days on my own avoiding contact with anyone. He noted my above average IQ and exceptionally strong visual processing skills and photographic memory. When I asked my doctor if I could be assessed she told me autism only affects little boys, and they grow out of it anyway. I asked my GP and was told the same. I didn't utter the word a*utism* again for seven years. I was married six months before I told my wife and thankfully she suggested I look into it further and self-refer for a diagnostic assessment.

In September 2016 I met the Adult Autism Diagnostic Team. My mother told them how I refused to eat anything that wasn't pureed as a child and that I never sought cuddles or affection as a baby. She shared how I taught myself to read as a toddler and fixated on a subject which would dominate my conversation. Looking back she could see I was clearly autistic and was angry that doctors assumed she was just an anxious mother.

My wife shared how I find it hard to talk on the phone and that I will simply walk away from a conversation with someone when I have had enough. She explained that I simply don't understand social rules and sarcasm is alien to me. She described my brutal meltdowns, how I can be rocking and wailing while hitting myself and biting my arms but she can't hug me to calm me down because I can't stand being touched. I provided pages of written notes and school reports which praised my dedication to perfecting my work yet struggled to recognise my own achievements. It didn't take the team long to agree that I fulfilled the criteria for an Autism Spectrum Disorder diagnosis and that I had significant sensory issues, social communication issues, repetitive behaviours and obsessive interests.

(https://www.autistica.org.uk/wp-content/uploads/2017/03/My-Wife-and-I.jpg)
Carrie and her partner, Lisa who helped her to get her diagnosis

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I "Mask" So My Autism Is Not Obvious To Others

The problem is, to everyone else I am a bubbly, confident focused young woman. I talk, I chat with friends. I don't *look* autistic because, like many autistic women, I mask my autism. I hide it after a lifetime of being taught by unknowing family, teachers and friends that my stimming is embarrassing and I must make eye contact with people.

Autism is more than the stereotype of the little boy lining up his toy cars and flapping his hands. It is not just Dustin Hoffman's *Rainman*, Sheldon Cooper or Saga from *The Bridge.*

Autism is me as a little girl crying and squeezing my hands over my ears because the hoover is deafening and overwhelming. At six years old I spent hours with my father's atlas rather than playing with dolls and wanted history magazines instead of comics. Alone in my room I paced and flapped my hands, smelled the wallpaper and would observe the world from my window for hours. That same little girl was pack leader at Brownies, top of her class and a favourite among peers at her mainstream school.

Autism is I, the grown woman rocking in the corner of my room hitting my head and sobbing because something is out of place and I can't stop the ensuing meltdown. It is the mask I wear as a freelance writer and giving my acceptance speech as an award winning artist. The mask I wore as a vocal coach laughing yet forcing eye contact as I taught my students. It is me without my mask; like a child, jumping up and down flapping my hands repeating single lines of Disney lyrics over and over and collecting children's sticker books. It is me chatting with the postman about the weather and an hour later, bouncing vocal stims of "Clck Clck" and "OOooooo" off the wall in the hallway so I can feel the sound on my face.

Autism is I, and all the other women who fall through the cracks in the system because medical professionals do not understand that little girls with autism learn to hide it.

How Can We Prevent Late-Diagnosis In Autistic Women?

Research is desperately needed to ensure that young girls don't suffer because their therapists and GPs don't ask the right questions. No teenager should be subjected to the treatment I was because my mental health professionals did not think of autism. Research is needed and policies changed so that women who enter the mental health system with self-harm, eating disorders or mood instability are automatically assessed for autism.

I was ashamed of my autism but now I am proud of what I have achieved. I am learning what autism means for me and working hard to drop my mask. But, despite having a diagnosis, there are no services to support me as an adult with autism and I have been left to figure it all out on my own.

Research organisations like Autistica are working with other providers and people with autism to ensure that we learn more about the condition. It's listening to women on the spectrum that will allow us to understand what changes need to be made, so that little girls with autism receive early diagnosis and support is available for women on the spectrum, no matter their level of function or ability.

My diagnosis came late, but now I have it now I'm determined to understand myself, the world and what it means to be an autistic woman.

Read Carrie's blog: www.ruralteacake.com (http://www.ruralteacake.com)

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