Carly Jones


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Dr. Carly Jones, MBE (Member of the Order of the British Empire) is an autistic woman and campaigner for the rights of autistic women and girls. She shares her story about experiencing sensory overload as an autistic parent to autistic children…

On Sunday evening, in the middle of a service station, I reached my limit. After a full week of work, traveling to London, and my daughter's birthday party, I had to leave my children with my parents and remove myself immediately from the people passing by, chitter chatter, blaring lights, and contrasting shop music. I retreated to the car. Luckily, my dad was the designated driver, so I kept my eyes shut on the way home, just pretending to sleep. Everyone sounded like they were underwater. After the rest of the family went to bed that evening, I turned all the household lights off and slept for ten hours.

Sensory overload is agony. It's like one hundred people scraping nails down a blackboard.

With so few adult autistic women portrayed in media, sensory overload is often considered something that happens to children. It's certainly not to be expected from a fully grown woman. Being a parent who is autistic also requires a transition from being the live wire to insulating our natural reactions. We don't want to embarrass our children and are often too busy catering for their sensory needs to even consider our own. As a home educator for my secondary school-age child, professional campaigner, and leader of local groups for autistic children, I work very hard to schedule my life to make it work for my family.

I feel that masking as a parent is draining, but often necessary. As your children grow up, it becomes easier to have your own identity and quirks accepted by other parents, but when they are small, it's tough. You can't roll up to mother and baby coffee mornings wearing sunglasses and not chat or make eye contact. The whole setup is designed for mass communication, singing songs, and teaching baby eye contact. Some days, the subject matters varied from what fabric conditioner everyone was using or what time their husbands ended work; it was soul-destroying. I love being a mum, so I'd mask my way through the mother and baby groups for my child's sake, but I'll never fathom the small talk, cliques, and competing post-natal mothers. The consequence of masking your sensory needs in noisy soft play areas, echoing public swimming pools, and blinking fairground rides is that you have to schedule the rest of your life around them. I know if I am planning anything sensory-triggering, I have to make sacrifices. I then need to be alone at home with the lights off to compensate.

Two of my three daughters were diagnosed as autistic at six and two years old. After a lifetime of challenges, vulnerability, and misunderstanding, I finally understood why I react to things differently. When I was at school, a teacher shouted at me for daydreaming and covering my head with my arms under the bright strip lighting in class. I was 15, but she made me sit with the 11-year-olds as I was "acting like a baby." I was in so much pain. Autistic women and girls are often better at masking their difficulties or are brought up to be more compliant. The effect of this is that autism is being missed, leaving autistic women vulnerable to physical and emotional abuse. When I was finally diagnosed as autistic, I was 32-years-old.

I sometimes recall the challenges, disbelief, and discrimination we faced as a family of autistic females who felt physically sick. I never dreamed there would be whole conferences, shows, and news articles just about autistic women. But if I could wave a magic wand when the Government reviews its autism strategy this year, autistic women and girls would have legislative plans for autistic-specific sex education, safeguarding, access to smear tests, healthcare, and criminal justice understandings. We may confuse control with care or have fewer body boundaries due to different care needs. I was invited to speak at the United Nations Social Forum on the theme of disabilities, gender quality, and education and shared models of the good changes I have seen develop in the UK since I started campaigning for autistic people, highlighting why autistic women and girls must not be left behind in any process nationally or internationally ever again.

I want autistic girls to know they are limitless, persistence pays off, and, more importantly, that we can push harder, go further and help more people than ever. There is a phrase that says, “I didn’t get this far to get this far.“ We’re seeing a new start to awareness and equality for autistic people, not the end.