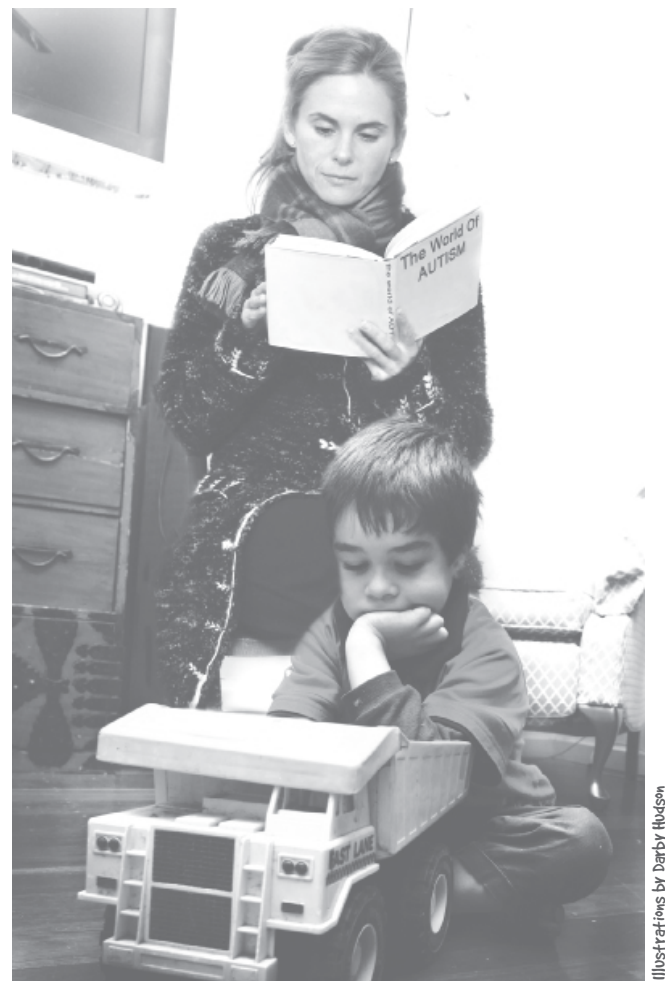




Of Angst And Acceptance

Rozanna Lilley initially resisted the diagnosis of her son's autism.



Illustrations by Darby Hudson

Last December my son, Ewan, wept because it was my birthday. I explained that I had been 45 and now I was 46. "I don't want you to change numbers. I want everything to stay the same," he sobbed, vehemently.

Ewan has a very limited tolerance of change. He is extremely anxious, for instance, about holidays. Once, on a drive to a coastal town, he muttered darkly the whole trip: "This is not a good day for me; this is not a good day for me".

About four years ago, we moved from a cottage to a large terrace. Ewan still refers to it as "the new house". For years, we have been visiting video-rental stores. Ewan has a passion for PlayStation. More importantly, he finds going to the stores and checking all the items soothing. It gives him something to look forward to after school each day. We still visit the 'old' video store in our old suburb. But since our move, we have expanded our options and now also sometimes visit the 'new' video store

nearby. Things do change and sometimes even Ewan becomes familiar with those changes.

Ewan has a diagnosis of autism and is currently categorised as having a borderline intellectual disability. This year he turns eight.

Like many mothers of children with autism, I initially resisted his placement in that diagnostic category. My own stereotypes of autism (a sullen and

sometimes aggressive child silently hunched in the corner of a bare room, endlessly fidgeting with a ball of string) meant I literally could not recognise my child as autistic. "But he laughs," I remonstrated with the paediatrician. "He loves to be tickled. He enjoys so much!" Of course, I could have added other characteristics to this list: he

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doesn't speak; he runs away from me and seems oblivious to danger, as though that astonishing invisible thread that connects mother and child had been severed; he climbs up into the supermarket shelf and lies there, surprising people scanning the shelves for groceries; if he falls and hits his head very hard on concrete, he just stands up and walks away; when a child of the same age or younger is nearby, he shakes uncontrollably and hides underneath furniture, refusing to come out.

Ewan was on the path to diagnosis long before he turned three. I invented many ways of avoiding that seeming finality. I did my best to act like a good middle-class mum. I took him to kindergym. Indifferent to the gym component, he fixated on a toy fire engine. I had to carry him out screaming because he could not keep it. I took him to Montessori play sessions. The instructor suggested that I needed to give him different toys at home, so that he could take his aggression out in the safe confines of a domestic environment. Ewan and I went to the train station and watched the trains go by instead.

At one point, I asked a former child-health nurse who had started her own consultancy to visit us at home and tell me whether or not she thought Ewan was autistic. A GP told me that the nurse was not qualified to make that call. I didn't care. She had seen Ewan when he was a baby; she had recorded his growth on

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charts. She was from a familiar, safe world of neighbourhood health and the seemingly certain regularities of child development. She asked me whether Ewan had any "German blood" in him. When I confirmed that this was, indeed, the case, she assured me that he was simply more intelligent than other children – a leader not a follower. She pointed to his very large head as evidence for her eugenicist fantasies. Despite realising this woman was, at a minimum, racist, I chose

to believe her, delaying the cold fact of diagnosis for another few months.

Ewan is often much smarter than I am. When he was three, for months he would place a face washer in my handbag before we went out. I had no idea why. One day I noticed that the washer had a label with a Target logo. I realised that this boy who could not speak had been entreating me to take him to the toy department at Target. No wonder he wailed in despair when we ended up elsewhere!

The moment of diagnosis was, for me, one of black despair. My world contracted, literally. I no longer wanted to leave the house. I found watching other women's 'normal' children incredibly painful. I was afraid for my son and hovered over him, ever vigilant. I blamed myself. Maybe I drank too much? My mother died when Ewan was one. Maybe I was depressed and had not given him the right type of attention at that time?

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Other women I have talked with were relieved to get a diagnosis of autism; to have a reason for their child's oddities and difficulties. Often, the older the child, the greater that relief is. We live in a society that holds parents responsible for their children. Mothers, in particular, are held publicly accountable for their child's behaviour. People glare; people stare; some even tell you that sexual abuse is the cause of your wayward offspring's unusual behaviour. A diagnosis offers essential access to services and support. It also offers an explanation.

A diagnosis of autism, indeed of any developmental disability, forces families to rethink their relationship to each other and to their history. I struggled with the fact of intellectual disability. I come from a family that values brains and talent. We were taught to think of ourselves as both unconventional and brilliant. My daughter, now studying Arts/Law, was labelled 'gifted'. The more work I put into reshaping our family history to fit Ewan, the odder that history started to seem. I already knew about the niece diagnosed with a developmental disability in the 1960s, the nephew with odd eye contact, the other nephew with schizophrenia. I added my eccentric father to this list and began to view my mother's long confinement to her bed and proud refusal of conventional morality with deep suspicion. Then I found out that my husband's mother had spent time in a sanatorium. The stories kept coming. My aunt had in-laws who hid

a grown man's autism from his emigrating war bride. The now faded war bride still cares for their autistic son.

Everywhere I looked, there were people who were different. Now I only have to walk to my local shopping mall to notice an array of individuals, some with quirks, some with alcohol-related conditions, others with disabilities. They

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are everywhere. It is just that once upon a time I chose not to see them.

Ewan's diagnosis has changed my life. But I no longer hide from the world. Instead of running away from autism, I am now immersed in it. In the last couple of years I have used my training as a social anthropologist to research the experiences of other mothers who have kids 'on the spectrum'. I have recently started a second PhD on parent perspectives on early-

primary schooling for children with autism. My son's passion is still PlayStation. Mine is autism.

I am not religious. Nevertheless, at some point as I watched Ewan form signs with his hands in his sleep – the way other people might mumble – I made a bargain with a higher power. I promised that if Ewan ever spoke, I would never wish for

anything more. He began talking at three-and-a-half, and these days is rarely quiet. It turns out that I am greedy. I've moved my sights to literacy now.

Autism is a big box. As Roy Richard Grinker, in his 2008 book *Unstrange Minds: A Father Remaps the World of Autism*, succinctly expresses it, the rubric of autism is now "so imprecise that it tells us mainly that the person has deficits in communication and social interaction,

has restricted interests and activities, and falls somewhere between profoundly mentally retarded and exceptionally intelligent". My son has learning difficulties and is not fully toilet-trained. He also has a vivid imagination and a love of pretend play so intense that it frequently leaves my partner and me happily exhausted.

We need the autism diagnosis to access people who can help our children. Ewan, for example, had a fantastic speech pathologist before he started using spoken language regularly. For the past three years he has attended a very supportive classroom setting, courtesy of Autism Spectrum Australia (Aspect). We also need the diagnosis to help us to understand our children. A large amount of clinical literature and, importantly, autobiographical writing by high-functioning individuals, helps to shape our empathy and our admiration.

Finally, an autism diagnosis allows us to find other parents whose stories have so much in common with our own. Each one has feared that they will not be up to the enormity of the task of parenting an autistic child; and each one has discovered reserves of strength and depths of emotion of which they were previously unaware. They have also learnt, firsthand, that people are amazingly different and that, as a community, we need to value and respect that difference. ■

Rozanna Lilley is a social anthropologist based at the Children and Families Research Centre at Macquarie University.

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