Who is Findlay Rose Reid?

I am Findlay Rose Reid. I want to make it clear that I am not a psychologist, psychiatrist or doctor of any kind, nor do I have training in childhood development.

I am a single mum from South Australia. My daughter was diagnosed with Autism Spectrum Disorder (ASD or Autism for short) when she was 16 years old.

When my daughter was a young child I never suspected that she might have some kind of 'condition', like ASD. She met all of her childhood milestones and showed no signs of delayed development, and her verbal and social skills seemed fine, although she tended to be a bit shy and clingy. I never had any reports from her teachers that she was struggling with her schoolwork or exhibiting behavioural problems. None of my daughter's teachers or health professionals ever flagged that she might have ASD.

It was not until my daughter was 13 years old, that one health professional (a psychologist) raised the possibility that she might have ASD. When my daughter started her first year of high school (Year 8), at age 12, she developed severe 'anxiety', which was well beyond the level of anxiety that most teenagers would experience when they start high school. I therefore arranged for her to see a psychologist at her school. It was this psychologist who was the first and only health/childhood professional to raise the possibility that my daughter might have ASD.

When she was a baby and young child, although I never suspected that my daughter might have some kind of 'condition', like ASD, I would not say that she was ever an 'easy' child. As a baby, she was never a good sleeper, and even as she grew older, she always had difficulty falling asleep. She was quite a fussy eater. As a young baby, she often cried, especially when out in public. At social gatherings, she tended not to sleep, it was very difficult to get her to feed, and she would cry when unfamiliar people tried to hold her. When out in public, or at social gatherings, once she started crying, I had to take her home. Otherwise, her distress would simply escalate, she would cry harder and harder, and no-one could settle her in that environment.

My daughter was not naughty or destructive, and most people saw her as a quiet, shy, well-behaved child. However, at home she could be emotionally draining. It's hard to explain, but if there was something that bothered her, it could be very difficult to distract her from that, and she would just not let it go.

I learnt that she did not cope well with change, and so I always tried to ensure that her life had routine, without too many changes or new things at any one time, whilst also allowing and encouraging her to try things that she showed interest in. I always tried to ensure that I prepared her for any changes, especially major changes, and that these were implemented gradually. I learnt that I simply could not push her to do something before she was ready. If I tried to push too hard it would actually just set her back and make it even more difficult to get her to do it in the future. When my daughter was very young, I was a stay-at-home mum, so I was able to spend a lot of time with her, and be very patient with her.

Since I have never raised any other child besides my daughter, and I am not an early childhood expert, I simply thought of my daughter as being a bit shy and highly strung. To me, she seemed like a very bright, creative and unique little individual, not a child with any kind of neurological/neurobiological disorder.

In early primary school, the teachers tend to be very caring and patient, the lessons tend to be quite basic, and the children are taught in a manner that is not too complex. My daughter was always shy, quiet and well-behaved at school, and seemed to cope well with her schoolwork. She had a group of familiar friends, who, I believe, gave her guidance and support. She told me that she would often ask her friends for help when she didn't understand something. However, to me it did not seem as though she lacked intelligence, but, rather, that she lacked confidence, or needed a bit of extra explanation. If she had a question to ask the teacher, she would even tend to ask her friends to ask the teacher for her, as she was too shy to ask herself. However, to me, she didn't seem to be shy when interacting with her friends, and she was always very talkative with me.

When my daughter was 10 years old, her dad and I split up. I had expected her to struggle emotionally with this significant event, but she seemed to struggle even more than I had anticipated. However, about a year after her dad and I had split up, my daughter seemed to have settled down.

Then my daughter started high school (at age 12), when she developed severe ‘anxiety’, and I arranged for her to see a school counsellor, and the psychologist who raised the possibility that my daughter might have ASD. My daughter really liked this psychologist. However, this psychologist could not provide a diagnosis of ASD. She explained that in order to seek an assessment for ASD for my daughter, I could try either the public, or the private route. I looked into the public route, but it was going to take many months before my daughter would even get a first appointment. At that point, I felt that my daughter’s mental health was at a crisis point, and that she could not wait many months for appropriate treatment. The psychologist recommended a private clinic that did ASD assessments. I did take my daughter to this private clinic when she was in Year 8, but based on the information that I was able to provide to them at that point, they recommended that I seek to have her assessed by a psychiatrist for possible symptoms of psychosis. However, this was easier said than done.

Meanwhile, the school counsellors did not seem to listen to the psychologist’s recommendations, and refused to change their approach to enable my daughter to cope with attending school. I had really tried as hard as I could to encourage my daughter to persist with attending school, and she really tried hard for months, despite the fact that the approach taken by the school counsellors was actually exacerbating her anxiety. In the end, she simply could not attend that school any more, which, in turn, meant that she could no longer see the psychologist at the school. Of course, the school counsellors would have been following the school’s protocols, which would have been based on limited knowledge and resources. However, I felt that the approach taken by the school counsellors had ‘broken’ my daughter.

I enquired with the school counsellors if there was any alternative type of school that my daughter could be referred to, since she clearly was not coping with normal school. She ended up being referred to an online school. From that point on (i.e., the middle of Year 8), my daughter never again attended a normal face-to-face school. She was therefore not engaging in the normal daily social interaction of face-to-face school. Trying to enable her to engage in social interaction was extremely difficult, and an ongoing source of concern for me.

When she was in Year 8, my daughter had suffered what I can only describe as a total mental and emotional breakdown. Her mental health issues continued, to varying degrees, from that point on, and I sought help from various mental health professionals over the years. For four years, I felt like I was being pointed first in one direction, then another, trying to seek professional help for my daughter, who was clearly having severe difficulties. For four years, I felt like I was beating my head against a brick wall without getting any clear answers, or treatment that really helped my daughter. It took four years, from the time that ASD was first flagged as a possibility, before my daughter finally obtained the correct diagnosis of ASD.

My daughter was assessed and diagnosed with ASD by the same private clinicians who I had taken her to back in Year 8. They provided me with an ASD assessment report for my daughter. The report contained a list of some very good resources that related specifically to “girls with Aspergers”, as opposed to the very broad range of symptoms and issues covered by the term “ASD”, many of which were not at all relevant to my daughter. Once I had obtained the correct diagnosis of ASD for my daughter, and had been pointed in the right direction, I was able to educate myself about “girls with Aspergers”. Everything I read about this specific area of ASD further confirmed to me, without a doubt, that my daughter had finally received the correct diagnosis.

I also found that I could relate to a lot of the traits of “girls with Aspergers”, which I was reading about, myself. I even read that it is not uncommon, when a young female is diagnosed with ASD, for her mother to realise she shares the same traits as her daughter, and to seek a diagnosis herself. Autistic females of my generation were rarely diagnosed in childhood, because ASD in females simply wasn’t understood or recognised very well when I was a child (even today, it’s still not understood or recognised well enough in females). I wondered if this could be me. However, at that time, my daughter’s mental health was in crisis, and I had to focus on her. I did not have time to ponder too much about whether I might have ASD myself.

I am grateful to the clinicians who assessed and diagnosed my daughter with ASD, and I understand why they were not able to provide this diagnosis when I first took my daughter to see them, as my daughter’s case was not a glaringly obvious one at that time. However, the delay in diagnosis meant that my daughter had suffered mental and emotional distress to varying degrees for four years, without any clear explanation as to the cause, and without appropriate support and/or treatment, which could have greatly alleviated her suffering.

Don't get me wrong, during this four year period, my daughter did have happy times, and I got to know her quirky teenage personality. She even did quite well with her schoolwork during Year 9, 10, and the first half of Year 11. However, the four year delay in her diagnosis, and the resulting confusion and lack of appropriate support and/or treatment, took a great mental and emotional toll on my daughter, not to mention myself. By the time my daughter received the diagnosis of ASD, she had been experiencing suicidal ideation for some months. Shortly after her diagnosis, my daughter attempted suicide for the first time. I don't actually think that it was the diagnosis, in and of itself, which prompted this, but, rather, being on the wrong medication, and still not having the appropriate support and/or treatment in place at that time.

Even once my daughter was diagnosed, there was still a lot of work ahead of me before I could get the appropriate support and/or treatment in place for her. I had to apply for NDIS funding, which is a complicated process. I had to apply for Carer Payment (another complicated process) to be able to afford to stay at home with my daughter, because I couldn't leave her at home alone whilst she was suicidal, and she did not feel comfortable to be left with anyone else.

I then had to try to figure out what sort of treatment my daughter actually needed. In her case, she really needed a good private psychologist who specialised in "girls with Aspergers". However, there just aren't enough of these sorts of psychologists, and their waiting lists are very long, so it takes many months before a first appointment is available.

I also had to educate myself about my daughter's condition, and try to understand my daughter in a completely new way. She wasn't diagnosed with ASD until she was 16 years old, but she'd had it since birth, as it's not a condition you acquire, nor can it be cured. It is a condition you have for life, even though, as I've discovered, the symptoms are not always obvious, especially in females.

My daughter had seemed 'normal' when she was a young child, and I had assumed that she would continue to develop into a 'normal' teenager, and then a 'normal' adult. Of course, I had known that she had been experiencing severe mental health issues on and off since the age of 12, and I knew that she would need a lot of support to get through that. However, I had still assumed that she would eventually be able to become quite independent as an adult, albeit probably living a simple lifestyle to minimise her stress factors, and with mental health support. Once my daughter had received the diagnosis of ASD, and I started to better understand her condition, I realised that my daughter might not ever be completely independent as an adult, and would need a lot more support than I had previously imagined, perhaps for life.

Once my daughter had the correct diagnosis of ASD, and I was pointed in the right direction of “girls with Aspergers”, everything became clear to me. I just wish that, back when my daughter was in Year 8, there had been clear, specific, relevant information about my daughter’s condition, which I could have easily found when I was conducting Google searches, looking for answers, rather than just the broad term of ASD, and so much information that was not relevant to my daughter, and which was therefore confusing, and threw me off track. Once my daughter had been diagnosed with ASD, I wish there had been clear, specific, relevant, practical guidance for what to do next, as opposed to just a lot of general information and different options, from which I had to try to figure out what specific support and/or treatment my daughter needed, and how to obtain it.

Since my daughter was diagnosed with ASD, two friends of mine who have teenage daughters, obtained a diagnosis of ASD for their daughters. Both of those friends had experienced difficulty and/or delay in obtaining a correct diagnosis of ASD for their daughters. I have another friend, who, at the time of writing this, has fairly recently booked an ASD assessment appointment for her teenage daughter through the public health system. This friend’s teenage daughter’s mental and physical health are currently at what I would call crisis point. The ASD assessment appointment is still many months away. I also met a number of other mothers at a local support group for carers of teenagers with mental health issues, all of whom had experienced difficulty in obtaining appropriate support and/or treatment for their teenagers.

After my daughter was diagnosed with ASD, as time went on, I gradually started processing certain things that had happened with my daughter, and also in my own life experience, mainly by writing a lot. I started to realise that I needed to find out, one way or another, if I had ASD myself, in order to be able to fully understand what the hell had happened with my life. It was a part of the puzzle. So I booked an ASD assessment with the same clinic that diagnosed my daughter. Two years after my daughter was diagnosed, I too received a diagnosis of ASD.

For me, my diagnosis of ASD is a positive thing. It explains a lot about certain aspects of my emotions, thought processes and personality that I have always found confusing. It is validation.

No, I am not a psychologist, psychiatrist or doctor of any kind, nor do I have training in childhood development. However, given everything I have observed and experienced in relation to my daughter and myself, and everything I have had to seek out and learn for myself, I feel like I have become much more of an expert in “girls with Aspergers” than the average psychologist, psychiatrist, doctor, teacher or school counsellor. And I know that there are a lot of teenagers with ASD/Aspergers, and their parents, out there, who are in desperate need of answers, and guidance for how to get appropriate help.

So I decided to create this website to share what I have learnt, in the hope that it can provide some help to other teenagers with ASD/Aspergers, and their parents, who are going through a similar experience to what my daughter and I went through.