

Background

I am ASD/ADHD, and I have one son who is also ASD/ADHD and another son who is ADHD.

The system which supports people with ASD/ADHD (that includes the NDIS, but also other services such from GPs all the way to psychiatrists, etc) is extremely hard to navigate, and even harder for those with the classic symptoms/traits/preferences of ASD/ADHD.

There are hoops to jump through, a highly questionable level of professionalism, and an awful lot of inconsistency - "you need this, no you need that, no we can't see you without a referral".

It is a self-deprecating money making machine without actually providing any assistance of substance to the consumers of the services.

The level of professionalism in the industry is a disgrace, and there is a very noticeable aura of questioning those who need assistance. Cases in point:

- I have been mis-diagnosed on multiple occasions. Either no assistance has been given, and when I have pushed for assessments I have been diagnosed with symptoms related to ASD/ADHD rather than the root cause. Eg. being diagnosed with anxiety (GAD) when the root cause of that was extreme social anxiety stemming from ASD.
- In one of my son's assessments, the report was clearly a generic template, and even listed his name incorrectly in more than 50% of use cases.
- The "professional" who made this assessment and diagnosis was clearly only interested in on-selling us to services she provided, pushing us to several services and gleefully telling us "the NDIS will cover that for you now". Some services were absolutely not what he required, and yet the pressure was very much unabating. There was also use of shaming, schmaltzing and gaslighting - strongly making us feel like my wife and I were doing the wrong thing by our son if we didn't sign up to her services.
- There have been all too numerous cases of ostensibly professionals who are clearly more intent on drawing money out of the system rather than serving those before them.
- When seeking help, I have been turned away for numerous reasons including "conflict of interest". This is serious, as it is not always easy for people with ASD to reach out for help when they need it. We are constantly told to "reach out for help when we need it" and "help is always there" - and when they do reach out for help, being turned away is extraordinarily traumatic.
- When seeking help with a rare provider who actually was useful, we were turned away due to negligent booking practices, with the provider "booked out" and unable to provide further services.
- On another occasion, a psychologist called me "really weird" when I was seeking help for a family issue.

Professionals in the system in Australia

For me personally, despite numerous attempts at reaching out for help, and suffering through a clumsy, unhelpful, self-serving system, I was ultimately diagnosed by my child's paediatrician. This diagnosis was made completely independent of me or my requests, and only commenced when discussions about our son led to further discussions about my parenting style, and subsequently joining the dots (so to speak). If

NDIS

I say nothing more, I think this probably illustrates as a case-in-point all that needs to be said about such a broken unhelpful, and self-serving system.

I think the root cause of most of these issues; [and if not, certainly a very significant exacerbation]; is the broken NDIS system. It has resulted in making care harder to obtain, more expensive, less relevant, less helpful, and lower quality.

It is very sad that the system seems to serve neurotypicals who can exploit, defraud and graft the system more than those who actually need the assistance. There is concurrently so much evidence of fraud and graft, and yet at the same time so much evidence of those with ASD/ADHD who need services being unable to obtain them. I don't know how to fix that - but it's a huge problem.

The indiscriminate expansion of services under the NDIS has made it a haven for unqualified people of questionable backgrounds to work for questionable modus operandi. There are countless unqualified people providing very low and often irrelevant services. In one example, I found my son sitting in the corner playing with a vacuum cleaner when he should have been at a "social skills" session.

In another example, I have been waiting upwards of six months for a medication review by my treating doctor, such is the demand on these services. I can't see another doctor, because they will not prescribe the medication I need, and will demand I go through the whole diagnosis trauma again. This is not only expensive, but unsettling, traumatic and patently unnecessary.

More specific and relevant models of care are now funnelled through the NDIS, and the system is too generic to provide substantial benefit to anyone.

ADHD is highly co-morbid with ASD, and therefore I would be remiss if I didn't include some discussion on that. I have heard over and over that it is a condition "treatable with medication", however every hurdle imaginable to obtaining that "treatment through medication" is put up in front of us. Couple that of course, that many people trying to jump through those hurdles also have ASD and are probably the least placed in the community to deal with the issues, and you have a very cruel system.

Despite a letter from my diagnosing / treating doctor, I have been repeatedly denied the medication I need, and when I am able to obtain it I need to sit through a half-hour appointment including waiting on the phone on hold at the doctor's surgery.

Community

Personally, I believe that many of the serious issues facing those with ASD/ADHD can be dealt with socially, in the community. I don't consider myself (or my sons) disabled in any way. In fact, I am proud of who I am and wouldn't want to be any other way. What makes ASD/ADHD a "disability" is solely the expectation that people with the conditions "fit in" to a world designed and run by neurotypicals.

In short, you can't force a square peg in a round hole - and if you do try to do that, then it's not the square peg's fault! If you do force the issue, then:

>>> That this creates immense stress and distress for those who experience this

>>> That this means a whole cohort of the population are not contributing (or under contributing) to society - not because they are unable or unwilling, but because society won't let them contribute - just because they are not the same as the neurotypicals are.

Community

>>> Both points (above) mean there are no winners with the status quo. It has to change.

Autistic people have unique skills, talents and abilities, and can make an extraordinary contribution to society - but all too often, that contribution is shunned because we do not meet the neurotypical "style". Couple that with even professional psychologists labelling us as "really weird" and again, we have a immensely stressful and traumatic world in which to live. But more importantly, unnecessarily stressful traumatic. It doesn't have to be that way.

The most important thing I can say is that more needs to be done about acknowledging neurodiverse people operate in a different way, and (if not make allowances for it), at least stop blocking it, labelling it "weird / lazy / stupid / all manner of pejoratives we hear every day" and allow these people to be themselves and contribute in their own way. What we have to contribute is highly valuable, and just because it doesn't meet the style of a neurotypical person, doesn't mean it has no value.