

National Autism Strategy Submission

Thank you for the opportunity to contribute to the National Autism Strategy.

I will address Centrelink, the NDIS application process, and ASD profiles. On the basis of my experience with them, there is room for much improvement, considering the 'invisibility' of many symptoms especially in women.

The outcomes I would like to see included in the National Autism Strategy are listed at the end of this submission. Firstly, I provide context for my concerns, because I have a pathological compulsion to explain (sorry):

After 4.5 years of seeing a clinical psychologist following a traumatic life event, I was diagnosed as autistic shortly before my 58th birthday in 2021. Suddenly I had context for what I thought was wrong with me throughout my life.

Since then, my diagnosis has expanded to include Major Depressive Disorder and Panic Disorder.

For much of my life I had familial support and/or the support of a long term partner. When there's someone right there who makes most decisions for you, it's easy to remain unaware of your pathological inability to make them yourself. But when my twenty-year relationship broke down concurrently with my mother succumbing to dementia, suddenly I found myself on my own in a life that was falling apart. I continued to run my small home business while grieving for my mother's decline and placement in a nursing home, and trying to cope with an increasingly adversarial ex and the soul-destroying toxicity of Family Court and lawyers. My Mum was my last family in Australia, bar a distant cousin I rarely see.

My psychologist suggested I apply for NDIS and supported me through the complicated and often bewildering process (I get easily overwhelmed by bureaucracy, and technical information is like algebra - and I am hopeless at algebra too). My claim was declined by someone who never met me.

Then along came COVID and my business suffered. At some point during all the above I applied to Centrelink for JobSeeker to supplement my business income.

Re Centrelink:

Dealing with Centrelink is challenging at the best of times, but things deteriorated so badly in the past few months that I needed to see my psychologist urgently in an effort to avert depression. Even Centrelink noticed my distress enough to refer me to a Services Australia social worker. It took three weeks for a social worker to contact me. She was kind and helpful, but I experienced many dark thoughts and feelings during that three weeks.

Meanwhile, on the outside I looked fine, of course. Masking has been my superpower.

I kept a 'Centrelink Diary' of my experiences as of July this year, and it is largely a record of misinformation, lack of communication, unforgivable delays, 'lost' documents and, relevant to the National Autism Strategy, little-to-no awareness of, let alone compassion for, the needs of autistic clients. Dealing with Centrelink's system has been enough of an ordeal to compel me to write an email entitled 'Centrelink is Broken' to Ms Tania Lawrence, my local Federal MP (sent 27/09/2023 with Centrelink Diary attached; 4716 words).

There are many ongoing issues, e.g. phoning Centrelink seems to involve a consistent two-hour wait on hold before being connected with a service agent; or lengthy wait times in my local branch; and forget about receiving a response when making a written query on their website. However, I was compelled to write to Ms Lawrence by Centrelink's handling of the following:

- My mother died in April last year, after a soul-destroying, eleven-year decline to dementia.
- I received inheritance in September 2022.
- I notified Centrelink thereof on 23 September 2022 by telephone, and 30/09/2022 in writing (the latter uploaded via their app).
- During a phonecall (I believe it was the one mentioned above) I was told the inheritance itself would not affect my JobSeeker but the interest would; I needed only to submit my tax return after the end of financial year, as usual.
- I met with a financial advisor soon after. Making decisions is one of my profound deficits, and I find financial decisions particularly difficult, so avoid them. I am also very trusting and gullible.
- I still haven't been able to make a decision about my inheritance so it continues to sit in a bank.
- On 1 September this year I checked my bank account to find my JobSeeker hadn't been paid.
- I checked the app. Where it had previously said 'Next scheduled payment' it now said 'No scheduled payment'.
- There was a new 'task' listed below 'No scheduled payment'. I was ordered to provide all bank statements for all accounts from 31/12/22 to 31/08/23. I became deeply distressed.
- I point out I received neither warning that my JobSeeker wouldn't be paid, nor explanation as to why. As someone who always needs to know 'why', I found it particularly distressing.
- I tried phoning Centrelink for explanation, but the automated system took me right through the identification process, looped, and then terminated the call. This added to my distress, and I couldn't face trying to call them again at that time.
- Thus I wrote a complaint via their Feedback & Complaints portal on their website, requesting a written response (which is offered as an option during the process). I wrote that not notifying me prior to not paying my JobSeeker, and suddenly demanding all bank statements, was cruel.
- On 04/09/23 I received a letter from Centrelink via MyGov re the bank statements. The letter referred to my 'cancelled' JobSeeker'. This was the first I'd heard it was cancelled. There was still no explanation.
- A person contacted me to give me a new Employment Services Assessment (ESAt); he assisted me by arranging an urgent in-person meeting with a service agent at Centrelink Midland on 07/09/23.
- I attended the meeting, where the service agent confirmed my inheritance took me over the assets threshold for JobSeeker and I should not have received any payments since the time I received it.
- I asked, if that was the case, why did Centrelink demand I send all my bank statements for the prior eight months? It would have made no difference to the outcome. She could not give me a reason.
- I reiterate I notified Centrelink of my inheritance by phone and in writing in September last year. I noticed my JobSeeker hadn't been paid on 1 September this year. It literally took Centrelink a year to get around to my notification.
- The Midland service agent showed me a letter Centrelink supposedly sent me at (if I remember correctly) the beginning of August. That letter demanded my bank statements. I was told that my JobSeeker was initially cancelled because I didn't respond to the letter. I didn't respond because I didn't, to the best of my memory, receive it. I showed her it wasn't in my MyGov inbox, and I did not receive it by post.
- It is on my file that I'm autistic. Why didn't someone contact me when I didn't respond to that letter?
- The service agent warned me a debt may be raised against me to recoup JobSeeker I received after my inheritance. She also said I would have right to appeal, given I had done everything required of me. This didn't make me feel better; I got upset.
- She kept telling me to not get upset, and tried to arrange a meeting with one of their branch social workers. The social workers were all in a meeting and therefore unavailable.
- Under the circumstances, and given their career choice, shouldn't assisting an autistic person who has just received devastating news and become distressed have taken precedence over their meeting?
- The service agent took me to meet a Financial Information Officer who happened to be free.

- I told him I have no head for technical financial information, but he did his job and gave me technical financial information that made little sense at first, and rapidly deteriorated into gobbledegook.
- Incidentally, the day before this meeting I'd been informed (a year too late) I should have been offered the services of a financial information officer at the time I notified Centrelink of my inheritance. It is a service Centrelink is supposed to offer to any client who receives a lump sum.
- The next day I was contacted by another service agent who had been keeping tabs on me since I followed up my original written complaint (I'd written two) because I'd not received a response for a month after sending it via Centrelink's Feedback & Complaints portal. When I started crying, she asked if I wanted to speak to a social worker, and booked me in.
- I was told the social worker should get back within two business days.
- During that call, the Midland service agent also called to say my Pensioner Concession card, which I received because of my autism, was cancelled because my JobSeeker was cancelled. She'd applied for a Low Income Healthcare card on my behalf.
- I asked why was it cancelled, since I'm still autistic and officially receiving 'low income'. It's 'just how it's done'. That card makes a big difference in terms of my rates, etc.
- It took almost three weeks before a Services Australia social worker contacted me. She was very nice. I, on the other hand, was an emotional wreck given I've lived with three weeks of very dark thoughts that intruded when I wasn't distracted, noticeably during the night while I tried to sleep or woke up in a stressed state.

Being hyperaware of injustice means I feel I've been treated as someone who intentionally rorted Centrelink for a year, especially by the anonymous, nameless, faceless person who cancelled my JobSeeker with neither warning nor explanation.

My Centrelink Diary can be supplied if required.

Re the NDIS:

At my psychologist's suggestion, and with her support, I applied to access the NDIS in 2021. My claim was declined. I am at a loss as to how someone who has never met me can deem me ineligible to access the NDIS, especially considering much of autism can be 'invisible', and especially so in women. This is more confusing when at the time of my application, I had been in my psychologist's care for nearly five years, and she recommended I apply.

In addition, it has been suggested to me by several professionals, that there is certain 'language' that can be used in an application that increases its chances of a favourable outcome. It has also been suggested that using an outdated form e.g. report, in supporting material can compromise an application's chances.

I am unsure if this is correct, but if it is, it is reprehensible.

Also, I was recently informed that to simplify the NDIS Access Request Form, it was redesigned with 24 pages instead of the original eight. I suggest this is not simplification; it is bureaucracy.

Re Autistic Profiles:

I am a Highly Sensitive Person (HSP) but Australia does not officially recognise this profile so I cannot be diagnosed as such. I could if I lived in Belgium.

I have Pathological Demand Avoidance (PDA) but Australia does not officially recognise this profile so I cannot be diagnosed as such. I could if I lived in the UK.

The fact those profiles are not officially recognised in my home country doesn't make them easier to live with. It is a constant battle.

Also, I am officially in autistic burnout, and experiencing a most unexpected consequence - adult autistic skill regression. It's taken a lifetime to get here, but I am 'forgetting' skills I used to have, which were largely propelled by masking and burning up much of my energy without realising it.

Desired Outcomes:

- NDIS:

I would like to see the NDIS Access Application simplified. It speaks volumes that the application process for a scheme designed to assist people with disabilities, and includes autistic people, even flummoxes neurotypicals who are not familiar with it. I suggest a separate application form for neurodiverse applicants. It might be helpful to include a panel of those very people in such an application's design.

I suggest the National Autism Strategy include that NDIS decision-makers give more credence to professionals who have worked with individual autistic clients for a significant amount of time.

The National Autism Strategy might include specific instruction to the NDIS that all applications be given equal and just consideration, regardless of 'language' or whether outdated forms are used.

- Centrelink:

Centrelink (the entity) is a 'living' example of Chaos Theory in action and I am unsure it can be fixed without a complete overhaul. But if it can address just some of its shortcomings, it should become aware of autistic clients' needs. It must stop overtly treating clients with what can be arguably called contempt. I envision some bored Centrelink employee discovering and triumphantly cancelling a payment with no explanation and complete anonymity, as though they are The Invisible Hammer of Centrelink Thor. Is it necessary for them to consider, or even care, whether they cause a human being trauma if there's little, if any, accountability for their actions? Admittedly, I am reduced to cynicism by my awful experience as described earlier in this submission.

What will compel Centrelink to do better with autistic clients? The fallout from an 'Autistic Robodebt'?

Autodebt?

- ASD Profiles:

Please, National Autism Strategy - aim towards having those profiles mentioned above (PDA, HSP) formally recognised so that autistic people can be diagnosed with them. No formal recognition invalidates my experience, and that experience is very real and very challenging.

- Adult Autistic Skill Regression:

This too needs to be part of the conversation. I had no language for this until two weeks ago when I randomly read something written by an autistic person that described my experience. I would like to see adult skill regression included in the Australian ASD vernacular as a matter of course, because it is real, and as I read on Autism NJ, 'can be heartbreaking'.

Thank you again for the opportunity to make a submission as an autistic person to the National Autism Strategy.

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