

Friday, 13 March 2020

Page 1 of 13

## Cover Letter

Hello, I'm \_\_\_\_\_, I'm a single 46-year-old female who's a little over weight, way over educated (seriously I have 3 university degrees) and I'm autistic. Sounds like a bad Tinder Profile right but that is about as much as anyone ever bothers to find out about me.

I've struggled my entire life to "fit in" and "be normal" but it wasn't until I was 42 and undergoing Psychiatric evaluation for possible Bi-Polar Mood Disorder (which I don't have) that by accident I was diagnosed as being Autistic. You'd think getting my diagnoses of Autism Spectrum Disorder (Level 2) would be the turning point where magically services become available to me to help me live a full and happy life within the limits that my disability creates. Yeah Nah I'm 4 years post diagnosis, fought hard to get a full NDIS Package and be granted a Disability Support Pension and I'm still trying to find Services to help autistic adults live a full and happy life within the limits of their disability.

Below is my Response to Terms of Reference written from my point of view, so it doesn't contain lots of Psycho-babble, statistics and long descriptive sentences that don't actually answer the question. Could I have written the impersonal statistic filled report as my response? Yes I have 3 university degrees one of which is Psychology and I spent the start of my career as an Information Management Specialist working for Defence so I'm very capable of writing an impersonal statistic filled report. I deliberately did not write it that way because I need you to see ME and hear my voice about the reality of daily survival when you have an invisible disability that effects how you communicate, how you think and how you cope with things outside your control.

I have 5 things I want you to think about as you progress through this enquiry about people like me

1. Language is a powerful tool and for as long as autism has been written about in Medical and Scientific literature it has and still is described in negative and discriminatory language. From the point of view of people studying to be Nurses, Doctors, Psychologists, Psychiatrists or Social Workers if the ONLY description you are provided with about what an Autistic Person is like is very negative and even frightening then your brain has already been pre-programmed to think the worst of someone like me. Autism is a multi-dimensional disability we come in all shapes, sizes, colours, cultural backgrounds, ages and genders and we have vastly different personalities, coping skills and traits. However the descriptions used to depict us (autistic people) is one-dimensional and quite frankly horrid. Lecturers at universities still teach their students autistic people are emotionless manipulative psychopaths, autism is a form of brain damaged, someone is only autistic if they have low IQ and autistic people are incapable of making their own decisions therefor their treatment is not up to them. Textbooks aren't any better they will portray either a none-verbal, highly aggressive, male, who rocks back and forth and smears poo on the walls or extremely intelligent, male, with limited social

communication skills, rigid adherence to routine and a total lack of emotion and detests physical contact. The first thing that needs to change for Autistic people to be accepted as they are is the language used to describe and depict us in everything including Lectures, Tutorials, Textbooks, TEDTalks and pop-culture like movies and books. The more the Autism Myths are left to fester in society the more we become viewed as being somehow not quite as human as “normal” people, which leads to things like the abuse of autistic kids in school as being acceptable because “they not like the normal children”. Eventually those of us that society views as being sub-human become a target and eventually people start to view forced sterilisation or worse extermination as a way of eliminating their perfect society from those “others”. Remember before they built Auschwitz they first convinced the people that forced sterilisation and then elimination of families who had genetic abnormalities like autism would benefit society as a whole. Their propaganda worked so well that when the NAZIs systematically killed thousands of people in hospitals, mental institutions and villages because they were “not normal” no one protested.

2. Almost none of the research is done on autistic adults because funding and thus services is skewed heavily toward children and families of children below the age of 13. Oddly when the autistic person gets to the age where they start to become critical of the services and care they are receiving everyone stops listening to them!
3. Autism doesn't discriminate people do! Autism doesn't care what age you are at diagnosis, what colour your skin is, what culture you come from, what ways you've learnt to cope with your autism or what your gender is. As far as Autism is concerned you're a person and that's it. However normal people who decided what services we are allowed, what treatment is best, where we can live and all the other stuff that effects autistic people. Those normal people they discriminate based on gender, age, skin colour, geographic location, cultural background or any number of other things we the autistic person has no control over.
4. Autism Is Life Long – you are born autistic, you will go to school autistic, you will turn into an autistic teenager, become a young autistic adult, go to work as an autistic adult, become an autistic pensioner and eventually die as hopefully a very old autistic adult. Services need to be available for the autistic persons entire life not just so **families** can cope with the first 6 years of schooling!
5. WE DO NOT NEED TO BE CURED! Not one of the scientist I've seen give TEDTalks or read scientific papers from has ever asked the question “Do you want to be cured” to actually autistic people. They might occasionally ask it of parents of young children severely impacted by their autism, who naturally say yes because they want a “normal” child. But no where have I seen or read “we asked x number of autistic people ‘do you want to be cured’ and they said .....

## **Responses to Terms of Reference From My Prospective.**

### *a. Current approaches and barriers to consistent, timely and best practice autism diagnosis*

#### **Response:**

1. Most medical professionals and the general public have no idea that the DSM-V radically changed the diagnostic criteria for Autism Spectrum Disorder to include adult diagnosis, female diagnosis and culturally diverse diagnosis. So getting someone to actually refer you to an expert for diagnosis if you're not male, white and a child is incredibly difficult.

2. There are simply not enough people qualified to do Autism Spectrum Disorder (ASD) Diagnosis for adults, females and people from culturally diverse backgrounds. Where I live for a population of 350,000 there is as far as I know 2 Psychologist and 1 Psychiatrist who do the diagnostic testing for ASD on young adult needing an updated diagnosis for NDIS Application, adults, females or people from culturally diverse backgrounds. All other services are exclusively for Children and mostly for families of Children who are trying to get NDIS Funding.

3. Time required for Diagnosis: Diagnosis for ASD is not quick and simple nor something you can do via a blood test, urine sample, x-ray, CTScan or MRI. Before you even start the time consuming task of diagnosis you will be placed on a wait list to get in to see whomever you've been referred to. My wait time was 4 months from referral to initial appointment and that was 4 years ago, wait times are now up to 8 months. Diagnosis takes time because it is done by observation by your psychiatric specialist, repeatedly doing various tests and answering a lot of questions. Not everyone is comfortable telling their employer, educational facility or CenterLink/Employment Service Provider that they are undergoing Psychiatric evaluation. So because you need repeated time off work or away from school or employment encouragement activities but don't want to explain why you may find your suddenly earning less money, your grades drop or you get your CenterLink payment suspended, all of which just adds pressure to an already stressful situation.

4. Cost: Getting a psychiatric evaluation for ASD as an adult via the Public Wait List system is almost impossibly even if you've had repeated psychiatric hospital admissions. The lack of psychiatric specialists that deal with autistic adults means it's a specialist field with a price tag to match. Me for example – Initial Consultation + Continues Diagnostic Visits for 6 month + Second Opinion to Confirm Diagnosis = \$1722.15 (note this was 4 years ago it's gone up since then). If you make \$30,000 per year or more that might not seem like a lot but when you're unemployed, a student, a casual employee living pay-check to pay-check that's money you don't have. Oh and it's pay up front per visit and then claim back from Medicare IF you're eligible. If you have private health cover they wont reimburse any costs because Medicare might pay some of it back to you. Post diagnosis you will need ongoing Psychiatric care and that's not cheap, on average I pay \$2200 per year just to see my Psychiatrist. Medicare does eventually pay me some of that money back but every visit I have to pay up front and on going Psychiatric Care and Medication is not cheep and NOT covered by NDIS Funding or Private Health Insurance.

Friday, 13 March 2020

Page 4 of 13

*b. The prevalence of autism in Australia*

**Response:** Anyone who gives you a statistic about the “prevalence” of autism in Australia is either lying or guessing. The data used for estimating the autistic population is primarily based on reports from clinics and programs solely focused on children currently being treated so they can continue to receive funding and grants. So if your child is not currently enrolled in a clinic/program or if you are diagnosed as a teenager, young adult or adult you will not be included in the statistics gathered by Children’s Clinics. The other method of collecting data is done by the ABS with the Survey of Disability, Ageing and Caring (SDAC) last done in 2018. Quick internet survey to everyone I know who is either autistic, has family that are autistic or has autistic children as to IF they had every been asked to participant in the SDAC was a 100% NO (actually it was mostly WTF is the SDAC). From a researchers prospective and yes I’m a qualified researcher this makes the data unusable because it is evidently NOT capturing the correct information but the SDACs incorrect information is being used to push harmful agendas, allocate resources and make policy decision that effect a huge number of people not included in the data.

Even the Australian Bureau Statistics admits their data is incorrect

ABS Website 4430.0 - Disability, Ageing and Carers, Australia: Summary of Findings, 2018 - Autism in Australia

Does prevalence change with age? There is variation in the prevalence of autism across age groups, with a marked drop off commencing in the late teens. Data are not presented in any detail for people aged over 40 years because the identified prevalence rates are too low for reliable estimates to be produced.

Considering that Autism is a life long condition and most Children’s Clinics have been keeping statistics for decades to keep getting funding why is there **“a marked drop off commencing in the late teens”**? It’s not as if we are magically cured on our 13<sup>th</sup>, 16<sup>th</sup> or 18<sup>th</sup> birthdays..... but the above statement would imply that somehow the people previously included in the “childhood autistic” statistics no longer exist or are no longer autistic. In reality there is a marked drop off in statistical information about the prevalence of autism in Australia for the groups of people who are above 13 years of age is because there was and largely still is no funding for services for teens, young adults and adults so they stopped including previously diagnosed autistic children in the statistics. Also the DSM-V radical shift their diagnostic criteria for who could get an ASD Diagnosis meaning a large amount of previously undiagnosed adults (mainly women) now had a clinical diagnosis but no services are there to help and collect statistics so this is largely a population about that data is not being collected from or about.

*c. Misdiagnosis and under representation of females in autism data, and gender bias in autism assessment and support services;*

**Response:** I could actually write a PhD thesis in this topic by now but I’ll attempt to keep this short. There is NO support service for autistic adults where I live but females in particular are discriminated against on the grounds they do not present with the same traits as males. There needs to be more focus on informing the medical community that autistic females exist, that we will present differently in diagnostic criteria and we will reacted totally differently to treatment both medication based and therapeutic.

Friday, 13 March 2020

Page 5 of 13

Like most females diagnosed as Autistic I was diagnosed by accident. After changing doctors because I was dissatisfied with the treatment I was receiving my new GP after reviewing my file took me off all medication and weened me off a 20-year opioid addiction (I was taking up to 8 Codeine based pills a day). Once the opioids were out of my system he quickly realised I suffered crippling Social Anxiety, Suicidal Depressive Episodes, Chronic Insomnia and severe Mood Instability, the symptoms' of which had been suppressed by my daily opioid use. Through a friend who works in the Mental Healthcare Industry I found a really good local Psychiatrist who my GP was happy to refer me to for diagnosis and treatment for suspected Bi-Polar Mood Disorder. It only took 2 visits for my Psychiatrist to work out I was NOT Bi-Polar and medicating me for that condition would have had seriously detrimental effects on my health. Like most female adult autistics I'm incredibly adapted at appearing 'NORMAL' for short periods of time so it took a little while for my Psychiatrist to twig that I was effectively playing the part of a NORMAL person and tell me to stop doing it. Realising I wasn't going to get correctly diagnosed I stopped pretending to be NORMAL and acted as I would in a safe place like at home and my Psychiatrist had the AhHa moment. Just to ensure he had as much information as possibly he with my permission interviewed my mum and dad, got information from my sisters and others as well as read his way through the plethora of paperwork my mum had kept, everything from my first K1 school report onward. It took 6 months of testing, interviews, information gathering and a second opinion to confirm my official diagnosis of Autism Spectrum Disorder (Level 2) with Co-Morbid ADHD and other associated mental health issues.

I was incredibly lucky firstly that my GP didn't just medicate me for Bi-Polar Disorder or any of the other mental health problems GPs routinely medicate people for without a full psychiatric diagnosis. Secondly that I had someone who works in the Mental Healthcare Industry who I could ask for advice on which Psychiatric specialist were good and which to avoid. Thirdly I had financial support from my retired parents to be able to pay for my Psychiatric assessment and ongoing treatment until I was well enough to attempt to get a new job. Most females are not as lucky as I have been and spend years being given medication they should never have been prescribed, told that they are over reacting, accused of not wanting to get better and so on until by accident they hit the jack-pot and get a correct diagnosis and then discover there is no services available to help!

~~d. International best practice with regards to diagnosis, support services and education, effectiveness, cost and required intensity;~~

*e. The demand for and adequacy of Commonwealth, state and local government services to meet the needs of autistic people at all life stages;*

**Response:** Once I stopped rolling around laughing I thought "you don't even know how many autistic older teens, young adults, adults or pensioners there are in the community let alone what supports we need." Before you can even begin to get a rough estimation of how lacking the support for autistic people over age 13 is you first need to figure out a reliable way of getting solid statistical data on exactly how many older autistic teens, young autistic adults, autistic adults, autistic parents (not parents with autistic kids but actual parents who are autistic themselves), single autistic adults, autistic adults looking after aging family and autistic pensioners actually exist in the community. Once you figure those numbers out you're then going to have to look at what supports each of those groups needs. I would suggest

Friday, 13 March 2020

Page 6 of 13

the best way to find out what assistance we need and are not getting is to ask US the actually autistic people not the so called “autism experts” who frankly do more harm than good. But if you’re like everyone else you’ll ignore that advice because we haven’t written a PhD thesis on what we think living with autism is like and apparently “lived experience isn’t relevant” (yes I have actually been told that by a so called autism expert).

~~f. The interaction between services provided by the Commonwealth, state and local governments, including:~~

~~g. The social and economic cost of failing to provide adequate and appropriate services, including to support key life stage transitions of autistic people;~~

*h. The adequacy and efficacy of the National Disability Insurance Scheme (NDIS) for autistic people, including:*

*i. Autism understanding within the NDIS,*

**Response:** The NDIA and it’s contracted client management firms seem to have some understanding of Autism in male children however their knowledge about autism in teens, young adults and adults especially females is somewhere between little and totally none existent. As for NDIS Registered Providers they have ZERO idea autistic adults of any gender even exist. I literally contacted every NDIS Registered Service Provider who came up on the NDIS Website search under Autism or Autistic and NONE of them take adult clients. One clueless receptionist at a NDIS Registered Provider who on their website claims to be Autism Experts actually said to me “why would you need OT Assessment and Assistance for autism it’s a childhood illness” (not kidding and our tax dollars are paying for this)!

~~ii. the utility of the Early Childhood Early Intervention Pathway for autistic children;~~

~~iii. the ability of the NDIS to support autistic people with complex needs, including those transitioning from prison settings;~~

*iv. The adequacy and appropriateness of supports to empower autistic people to participate in the NDIS planning process, and exercise self-determination through choice and control over their support services;*

**Response:** If you are an independent autistic adult and you actually manage to get an NDIS Package you will have to opt for Self Managed so you can put Contracts in place for Service Providers not registered with the NDIS. This limits what you can use the NDIS Participant Portal for because if you are Self Managed but like me for Physiotherapy want to use a Registered NDIS Service Provider you can’t do it via the NDIS Website you still have to put a Private Service Agreement in place and book your appointments privately and pay up front then claim back instead of being able to do it via the NDIS Website. Some Registered NDIS Service Providers won’t take Self Managed Clients because their systems for managing NDIS Clients is done totally through the NDIS Website and Self Managed NDIS is not accessible to them for booking/billing.

Friday, 13 March 2020

Page 7 of 13

Purely from the point of view of someone who made a very good living as an Information Management Specialist the NDIS Website was incredibly badly designed and needs a massive overhaul.

1. The NDIS Service Provider Search Function is badly coded. If I search for OT with-in a 25km radius of my location not only do I get the same company appear multiple times the physical office locations listed for the company say SA, NT, ACT. This happens because the parent company might have a PO Box in say Maroochydore and so despite the fact the actual Office Locations aren't even in the same state as me they've all been linked to the Parent Companies PO Box address and thus come up as being within 25km of my location.
2. Add Payment Request – badly thought out. To start with if you're Self Managed 99% of the system doesn't work. Secondly there should be a drop down list or box where you can add a Service Description eg Physiotherapy and a box where you can put Invoice Number information. Why? It makes it a lot simpler to do an audit if you know what the money was being spent on and you can match physical invoice (which we are required to keep) to data listed on the system. It also means that whomever is supposed to be helping you manage your NDIS Package can check you are spending the money correctly not say using CB Funds for Core Supports (that's illegal according to the NDIS Guidelines in case you don't know).
3. Removal of redundant data. I'm on my second plan and it is significantly different from my original plan because my original plan was so totally and had my funding in incorrect categories (whole other rant). My new plan has CB Social Community and Civic Participation, which is where the money should be. My old plan had Social Community and Civic Participation (Core Support) totally the wrong bucket of money BUT both of them are still on the drop down list in the Add Payment Request. The Core Support one should NOT still be on my file and able to be used it should have zero funds attached to it and have been removed.
4. Original Data Input – Don't change how someone's name is spelt, check you have their data of birth right and so on (basic stuff but NDIS get it wrong a lot). However my biggest irritation with this is if I tick Aboriginal or I tick Torres Strait Islander don't argue with me about it and don't un-tick it because you think I incorrectly ticked that box. Not only did the person interviewing me for my original plan say to me "oh you've ticked Aboriginal that's ok we can fix that" with my father an elder in our community sitting in the room with us but she then proceeded to tell me I don't look like I'm Aboriginal was I sure I had my facts straight! When I got my NDIS Participant Portal sign-in first thing I did was check the Profile Information and sure enough Aboriginal had been un-ticked so I had to ring up and get it re-ticked. I'm very proud of my Koori heritage and just because I didn't inherit my dad's darker skin tone like my older sister it does not make me any less Aboriginal.

Friday, 13 March 2020

Page 8 of 13

- i. *The development of a National Autism Strategy and its interaction with the next phase of the National Disability Strategy;*

**Response:** When you develop this National Autism Strategy could you please ensure you include independent autistic teens, young adults, adults, autistic parents, single autistic people and autistic pensioners from every area of Australia and of all genders, nationalities and ages in the process. Frankly I personally am sick to death of being told by none autistic people who claim to be autism experts that I AN ACTUALLY AUTISTIC ADULT FEMALE who is a qualified researcher and has a post graduate degree in Psychology doesn't know anything about autism. I'm also sick of hearing "lived experience is not relevant" and thus anything we actually autistic people say is ignored because we didn't write a PhD paper on autism.

~~j. The adequacy of funding for research into autism;~~

- k. *The social inclusion and participation of autistic people within the economy and community;*

**Response:** Unless you want to totally change how people are employed the participation of autistic adults within the economy and thus the community will stay incredible low.

The process of getting employed is harrowing for someone like me an autistic adult female with 3 university degrees, Defence Security Clearance and the ability to see patterns in data even computers struggle to find. Why? Well to start with there is the Responses To Selection Criteria, as it turns out employers don't actually ask questions they want the answer to but you're expected to just know when they say "list your hobbies" that they actually want to know how many "teams and groups" you belong to not what your actual hobbies are.

If I make it to interview things get worse because I'm suddenly expected to talk to people I have never met before and I suffer crippling Social Anxiety as part of my autism. Communication in person is so very difficult for me because I can't read facial expressions, I don't hear tone change in voice which would indicated someone asked a question but said it like a statement of fact and I answer the questions you ask me so I miss the subtext that you actually want to know something totally different to what you asked. Oh and if you present me with questions where the answer can be Yes or No then more than like you'll get a Yes or No as the answer.

From the Interviewers point of view I'm the Candidate From Hell because they will have read up on me, checked LinkedIn, asked around and got mixed responses like "she's amazing with data and her report writing is incredibly detailed but she a little reserved in social situations". Now they have me sitting in front of them and I'm probably not dressed correctly for a job interview, I'm so tense you can see it because every muscle in my body is ridged and I can't look at anyone directly without visible flinching as it makes my brain hurt. Then they start asking questions and expect to get similar responses to what the previous 10 Candidates have given and they don't. They suddenly find that the person sitting in front of them doesn't give a response they are expecting and they have to think about why this response was so totally off the wall different. The person who doesn't ask direct questions is met with total silence and then asks "are you going to answer my question" to be told "you haven't asked me a question you made a statement of fact", which trust me is the wrong thing to say to



Friday, 13 March 2020

Page 9 of 13

the CEO or an Army General. Harder still for the Interviewers is the fact that I have what is technically termed Flat Effect meaning I do not have variation of pitch or tone in my voice and I have zero facial expressions not even micro expressions. I also don't move my hands or body when in job interviews because someone long ago told me not to fidget when talking to people as it gives a bad impression. So the Interviewers have none of the normal non-verbal cues unconsciously used by Normal People to tell if I'm stressed, happy, sad, worried, thinking about how to respond, lying or just plain bored out of my brain. Since I lack the ability to know when to stop talking if the Interviewers ask me a question I can answer in detail they'll either have to spend 45 minutes listening to a mini lecture on the topic or tell me to stop talking, neither option goes well in an interview.

Post Interview I'm firmly expecting to get told I'm just not the candidate they are looking for, which is code for you could do the job brilliantly and in half the time but we want someone who's more of a team player and not an independent thinker. However on average out of the 100 jobs I've applied for and 10 interviews I've had at least one company will call to say I've got the job or contract and could I come in to do the paperwork with HR. HR will spend a large amount of time talking while I'm attempting to read my contract and don't tend to respond well to being told to shut up so I can concentrate. As soon as I find the part that says "Other Administrative Duties" things start to go wrong because I will insist that it's either removed or a full list of these "Other Administrative Duties" is written into the Contract. Why? Because I've learnt the hard way that no matter what the CEO promises about adapting policies and procedures to accommodate disability employee needs, HR and Management don't give a damn about adapting workplace policy and procedures to be inclusive of disability employees. And the clause "Other Administrative Duties" is a catch all for making you do things like take meeting minutes, work reception every Tuesday, answer all calls to your work area because you're the only girl on the team which are both NOT part of your job description and vomit inducingly stressful for someone like me.

If miraculously I'm still offered the contract minus any reference to things not directly related to my actual job description things do not get easier. I will spend the first few days or weeks repeating the phrase "Well that wasn't in the instructions" irritating the person attempting to help me learn my way around their systems. My lack of ability to correctly socialise will at first be tolerantly viewed as me being shy until other staff start to realise that I have no interest in wasting 2 hours daily with social chit chat, that I'm not the slightest bit interested in them and their lives outside of work and that I won't remember anything about them 5 minutes after they walk away from me (including their name). Within about a month the lunchroom gossip and whispers will start which frankly I don't care about I always find it slightly amusing to hear what people think about me. And yes despite the fact the lunchroom is at the other end of a long hallway I will be able to hear what is being said because one of my fun autistic traits is incredible acute hearing.

The gossip and whispers will generally be speculation about my sexual preferences since I failed to respond correctly to the office play-boys flirtatious moves. They will wonder why I don't follow company dress code, why I won't answer the phone that is not supposed to be on my desk, why I don't tell them things about myself. There will be some resentment about the fact I'm not like every other female in the office required to work the reception desk and why I'm not tasked with doing things like booking meeting rooms, managing my bosses diary and all the other little

Friday, 13 March 2020

Page 10 of 13

administration tasks women are routinely tasked with despite the fact it's NOT in our job description. The fact I'm female but flatly refuse to be like all the other women in the office will eventually lead to tension with whoever my boss is because in their mind I'm a glorified office admin not a specialist brought in to do a specific task.

The fact I don't play office politics, I won't join any of the group/team things that happen after work and I politely say thanks for the invitation but I already have plans but then fail to elaborate on what those plans are doesn't exactly make me popular because "group cohesion" and "team spirit" are what the company has trained its staff to expect from all employees.

The fact my brain has problems filtering out what should be unrequired information means that the whole time I'm working I hear every conversation in the whole office, I get distracted by things that click/buzz/ring and my survival instinct sits at Extreme Danger so at all times my brain is mentally tracking what everyone around me is doing looking for abnormal patterns of behaviour that would signal danger. As you can imagine with my brain doing 90% more processing for irrelevant stuff than it should staying focused on my task takes a LOT of mental effort so when people come up to my desk I will ignore them hoping they go away (they never do). Inevitably the "are you busy", "can I interrupt you for a minute" conversation will happen. The more tired, stressed or focused I am will largely dictate how tactfully (or not) I answer this question but mostly the reply will be something like "yes I'm busy, no you can't interrupt me go away" (apparently this is considered an impolite response according to HR).

If I'm interrupted I have to write notes to myself about what I was doing and where I got up to before I can deal with whatever it is the person interrupting me wants me to do. Multi-tasking is NOT in my skill set so I can't write my notes and listen to someone prattling on about a totally unrelated topic at the same time. Saying something like "shhh I'm trying to concentrate" inevitable upsets the person interrupting me and for the umpteenth time I find I'm the one having to say Sorry, even though I'm not sorry I'm cranky at being interrupted. Once I've done whatever urgent task needed doing or sat through a meeting I didn't need to be in I have to attempt to get back into my focus zone to do my actual job. If I'm really lucky my request to be able to wear Noise-Cancelling Headphones (NCH) will have been granted by HR so the constant interruptions by people drops significantly. NCH mean I spend more time getting work done and less time re-doing the same thing over and over because every time someone interrupts my workflow I have to restart from a previous point to ensure I do the job right. I know it's ritualistic and not how Normal People work but it's how I work and uninterrupted I do my job really well. However the fact people have to make an effort to interrupt me inevitable becomes an issue and firstly Management will attempt to tell me I can't wear my NCH as it disrupts the cohesive team environment. I'll try to politely remind him/her that yes I can wear NCH because HR granted it under my "disability adaptations" in my work contract. From the time we have that conversation I can just about set the date/time in my calendar that I'll get a request from HR to discuss the wearing of NCH as my Manager is upset that it disrupts the "group dynamics" or "team functionality" of his/her staff. In one memorable show down over me wearing NCH it got to the point that HR decided it was an OHS Violation so no staff member (contract, temp or fulltime) was permitted to use any type of Headphones in the office (I was 1 week away from finishing my 3 month contract when this happened).

Friday, 13 March 2020

Page 11 of 13

If I'm on a short to medium term contract there might be a few trips to HR because my boss is sick of hearing some version of "No that's not in my job description" when they try tasking me with work that is both not in my job description and frankly I don't have the skill base to do. If I'm on my "probationary period" more than likely at the end of the 3 or 6 months I'll politely be told by HR that although I'm doing the job well I just don't fit the company culture and I'll be let go. Occasionally I tell them at the end of the probation period that I don't wish to remain working for the company as I find their company culture to be toxic or I'm being made to do work I was not hired to do.

As you can imagine the constant level of hyper-stress I suffer going to work is both physically, mentally and emotionally draining. As a result my cluster migraines increase, I fail to eat properly because I get so stressed about going to work I vomit up breakfast and by the end of the day I'm too exhausted to cook so breakfast cereal for dinner becomes increasingly common. I constantly stress that due to the constant interruptions I'll have forgotten to do something correctly so I don't sleep well. I start going in early and staying late to get my job done without interruptions. Because I'm hyper-anxious about my job performance the only thing my brain focuses on is my job. As a consequence of hyper-job-focus my domestic life falls apart as I forget to pay bills, I forget to buy groceries until I run out of toilet paper or coffee and I avoid social situations because I'm just too tired to cope with more people. As a result of this level of anxiety about my job the longer I'm in that job the more stressed I get to the point I will become physically ill and unable to work.

So routinely every 3 to 18 months I find myself out of work and firstly living off whatever savings I have and applying for any job I'm capable of doing. If I'm lucky before I get to the point of having to borrow money off my retired parents to pay the bills I'll have found another job and the same problems start all over again. If I'm unlucky I end up having to claim NewStart Allowance from CenterLink, which comes with a whole new set of problems. As you are hopefully aware CenterLink will as quickly as possible assign you to a Employment Service Provider (ESP). If I argue enough and get lucky I'll be assigned to a Disability Employment Service Provider (DESP) who won't believe I'm autistic because I'm an adult and I'm female! Since ESP or DESP only get paid the big BONUS PAYMENTS when you (the client) firstly find a job and then stay in the job for 13 weeks and then 6 months they are highly motivated to place you in employment even if it's a job you are totally unsuited to do e.g. putting an autistic client in a Call Centre Operator or Receptionist role despite the fact you've told them you can't do those types of jobs. If you the Disable Person refuse to take the job your ESP or DESP reports you as "uncooperative" to CenterLink and your NewStart is suspended firstly for 8 weeks, second time 13 weeks, third time it's Cancelled and you have to reapply for your benefits. The really fun part about this whole set up is that the ESP or DESP can complain to CenterLink about you and get your payments stopped but you can't complain to CenterLink about the ESP or DESP behaviour.... the ESP or DESP are firms contracted to work for CenterLink by the Department of Employment, Skills, Small and Family Business and you have to put your complaint in to that Department but they are not allowed to discuss your complaint with CenterLink (In the mean time you're now broke and homeless).

CenterLink pays just enough money if I'm very careful to pay most of my bills so long as they are spread throughout the month. Since things like paying my utility bills, eating, seeing my psychiatrist, taking my medication and being able to put

Friday, 13 March 2020

Page 12 of 13

money on my TransitCard so I can get to appointments take up 95% of my NewStart Allowance even if I did have a social life or community involvement I couldn't attend because I literally can't afford to.

I finally in 2019 caved into pressure from my family and medical team and put in an application for Disability Support Pension (DSP), which took 8 months to be processed and approved. However despite the fact DSP pays a slightly more liveable payment it's still not a lot of money and there is always the risk I'll break some rule I didn't even know existed and have my payment stopped. As much as DSP means I technically don't have to go through the stress of finding yet another job it also means I've become increasingly socially isolated. At least when I was working if I didn't show up to work and didn't call in sick eventually (I hope) someone would have called the authorities to check on me.

If companies were encouraged to have work from home options for people like me, where we do our job, do most of our communication via e-mail and occasionally attend meetings either in person or via video-link I'd probably still be able to work. However for businesses to embrace work from home options it would take a massive shift in employer psychology from thinking that if they can't see you at your desk working then you're not being a productive employee to actually trusting employees to do their job minus micro management. Australia would also have to vastly upgrade its IT infrastructure and telecommunication networks but that's not what this enquiry is looking at.

The next thing you'll say is "start your own small business"..... Hmm exactly what would I start a small business in? And even if I have a brilliant idea for a small business I lack all the resources and skills needed to actually build a small business up to be economically viable. What do I mean by that? Well firstly small business relies on the ability to build and maintain useful contacts and build networks by attending things like networking events, this is not within my skill base if it was I'd have a thriving network of x-work colleges, people I went to Uni with and so on. Secondly to be successful at selling your business to other people you have to be able to talk to people who are for the most part random strangers and have amazing customer service skills, did I already mention I suffer crippling social anxiety and find talking to people nauseatingly stressful. However the resource I lack the most is MONEY, I am flat broke and that's not likely to change any time soon. My Disability Support Payment is set at \$933 per fortnight, which is literally on the poverty line so no lending institution is ever going to give me a business loan and line of credit, even the dodgy ones with super high repayment rates wont lend me money (I know I asked when my car got totalled in a hit-n-run).

The reality is that at 46 years old I'm single, childless and I have less than \$5000 in the bank. I don't own property, I have exactly 400 Telstra Shares, I share a car with my mum and if you sold every possession I own I might get \$2000. I live in the top half of my parent's home so if they have to sell the house I become homeless. As I age the risk factor that I will become even less financially secure and homeless goes up. My parents are aging and with their increasing health issues I don't know how long they have to live, my sisters live overseas and I do not have close friends or family to turn for support.

Autism has given me some wonderful gifts to be creative and to see the world very differently. But autism has also robbed me of the ability to stay gainfully employed

Friday, 13 March 2020

Page 13 of 13

and thus build up savings and superannuation, the ability to have a lasting long-term relationship and the ability build networks. Normal People will look at my life and decided that forcing me into a group home or into some “social inclusion program” will fix the problem. It will not fix the problem it would simply end my life because it would make me suicidal. The solution lies in things like the ability to work from home, making it easier to access what limited superannuation we have if we end up on things like Disability Support Pension and either lowering the cost of Psychiatric treatment and medication or making NDIS funds available to cover them. But the most important thing is to take the focus off children and families of autistic children because it’s not a balance view of the autistic community as a whole. The entire model of how information about the autistic community is collected and how funding is calculated and how services are delivered needs to change dramatically. Funding and services needs to be life long and able to be easily access no matter what stage of life you are at when you are diagnosed so that we can live a full and happy life within the limits our disability creates.

- ~~l. The capacity and sustainability of advocacy, self advocacy and self determination supports for autistic people, including mechanisms to self represent to government as enshrined in the United Nations Convention on the Rights of Persons with Disabilities;~~
- ~~m. Any bill that relates to matters within the scope of this inquiry that is referred to this committee;~~
- n. Any other related matters.*

**Response:** The baby boomer generation is currently the support network for a large number of autistic adults who may live with them or may live somewhat independently but either way they are the people we have always turned to for help. However the baby boomer generation are ageing and developing health issue that mean they now need care and often like in my case it is their autistic adult children that are expected to become their careers. Even if I had the money to move somewhere else I no longer can because I care for my aging parents and there is no support to help me with this. The mental, emotional and physical strain of caring for my aging parents is not covered by my NDIS Package or my Disability Support Pension but the reality is the stress and physical work will increase as dad becomes less mobile and mum’s dementia get’s worse. Someone really needs to be looking at this as a whole package not as separated areas of “age care”, “disability support pension”, “NDIS Funding” because it’s going to blow up into a massive and messy problem in the next few years.