

## **Key Theme 1: Social Inclusion**

Regarding the 4 Discussion Questions:

1. To potentially add to the Access to supports, services and information section:

This section also needs to mention how key it is for autistic people to have access to meaningful, supportive, ongoing paid employment. Everyone in the community needs and deserves the right to be able to work and be paid fairly for their work. Although this area is discussed in Key Theme 2 (Economic Inclusion), it is such a key, crucial issue for autistic people that it warrants inclusion in the first section.

Autistic people such as me really struggle to gain access to meaningful paid employment. When we are employed, we are often forced to work in environments that are unsupportive of our differences. Because of our innate differences and communication difficulties, we are also often working in roles that are poorly remunerated and that do not recognize or reflect our education, qualifications, intellect, or creativity. While autistic people are in paid employment, we experience a raft of difficulties throughout, including social exclusion within the workplace, difficulty with workplace communication, and bullying and harassment due to our innate differences. Autistic people are much more likely than any other section of the population to either be sacked due to their innate differences or must frequently be forced to resign due to significant workplace issues such as unresolved bullying, harassment, and discrimination. This takes an immense toll on our mental health and wellbeing, our confidence, and our financial wellbeing.

As a woman in her mid-forties who is self-diagnosed autistic, I have experienced over twenty years struggling to find and retain meaningful paid employment, so that I can feel valued and included in society. As a result, my work history has been patchy, as I cannot hold down regular work for more than a year or two at most. Therefore, any potential employers are highly reticent to recruit me for future roles. Since I have autism, chronic mental health issues (due to undiagnosed autism), and chronic pain syndromes, I can only work 10 or 12 hours per week, which means that my opportunities for paid employment are extremely limited. As an autistic, queer, disabled woman, I experience intersectional disadvantage at many levels. This substantially affects my life, as I cannot get meaningful paid employment that reflects my higher-level qualifications, experience, and expertise. The results are that my life frequently feels worthless, as I cannot participate fully in society in meaningful ways, unlike my other neurotypical peers.

Also, it would be good to mention in this section that autistic people experience higher rates of loneliness than neurotypical people, due to their autism and living in a world that isn't designed for them. This contributes substantially to the higher rates of mental illness that autistic people experience generally.

2. How could services and supports be improved to help autistic people live the lives they want (and deserve)?

-Properly fund an education campaign to inform employers about the benefits of recruiting and retaining neurodiverse folks such as autistic people and those with ADHD.

-Amend the NDIS system so that all diagnosed autistic and neurodiverse people regardless of “level of functioning” (which is essentially meaningless) can access funding and support.

-Stop throwing people with psychosocial disability off the NDIS, as many people with psychosocial disability are undiagnosed autistic people, or self-diagnosed autistic people who cannot afford or access a diagnosis or supports.

-Change the discriminatory policy that means that people on the disability support pension under a certain age must engage with volunteering or utilize disability employment services. This further punishes autistic people for their innate differences.

-At present, adult psychiatrists are essentially unable to diagnose autism in adults, particularly those deemed “highly functioning” (aka intelligent folks or ones that have learned to heavily mask, such as women). So, autistic adults that are undiagnosed must spend thousands of dollars and wait many months to see the few privately operating psychologists that specialize in this field. This is unacceptable.

To fix this, the government needs to properly fund psychiatric hospitals (public and private) and the Royal Australian College of Psychiatrists, to fix this. The Royal Australian College of Psychiatrists must be required by government to ensure that their specialist training programs teach psychiatric registrars in how to diagnose autism in adults. Currently, psychiatrists receive very little to no training about how to diagnose autism in adults (and specifically women), so many autistic people are left undiagnosed and unsupported for an unacceptably long time.

3. How can we improve community attitudes to autistic people and employment?

The government needs to set up a properly funded campaign to educate employers about neurodiverse individuals, and their immense value and contribution in the workplace.

And, the government needs to fund a public advertising campaign, emphasizing the immense and wonderful contribution of neurodiverse folks in the world generally.

The government also needs to free up more funding for research for Autism advocacy organizations. For instance, the government should continue to better fund organizations such as Autism SA, so that they can continue to meaningful research into improving the outcomes for people with autism, by removing some of the myriad of barriers to employment that exist for autistic people. They need to work with these advocacy organizations to engage both with employers and neurodiverse folk. They need to work together, to improve the recruitment pathways for neurodiverse people into paid employment, and to support autistic folks throughout their paid employment journeys, so

that both employers and the employees will benefit from better health and productivity outcomes in the workplace.

The government also needs to improve the existing appalling state of disability employment service providers. These private service providers have zero understanding or tolerance of the lived experiences of autistic adults. They are an appalling waste of valuable taxpayer money. They operate in a one size fits all capacity, with a cookie cutter approach, that in no way helps or supports autistic people. These services just leave vulnerable disabled autistic people feeling more marginalized, stressed, and traumatized than before we engaged with their services. These services are incredibly unhelpful and further stigmatize this vulnerable population. These dubiously run private entities currently just exploit some of the most vulnerable people in the community for profit. This is appalling.

Instead, the government needs to reclaim disability employment services to the public sector. This way, the employment services are more likely to be understanding and embrace neurodiverse peoples' experiences and differences. It's also likely that government staff may put less pressure on autistic folks to apply for a ridiculous number of jobs that they are ill suited for, because they are not solely working for private sector profit. This may mean that autistic people might have more of a chance of finding meaningful work that is suitable for their circumstances.

4. How would I describe better social inclusion for autistic people?

I would start by ensuring that autistic people have an equal opportunity to engage in well paid, stable, meaningful employment in the workplace. And to me, it would also mean that autistic people can feel comfortable working in mainstream workplaces, where they felt they could live their lives authentically without the constant need to mask their differences. It would mean having workplaces that truly embrace others' diversity, not ones that seek to persecute and further marginalize people with neurodiverse brains.

It would also involve getting rid of the appalling and abusive system via which disability employment enterprises exploit disabled and autistic folks by paying them less than non-disabled folks. Governments writing and passing legislation that allows commercial enterprises to pay disabled folks less than abled folks is unequivocally ableist and appalling, and it needs to stop immediately.

Also:

Under Access to supports, services and information:

Some acknowledgements should be given regarding the intersection of autism with sex/ gender (e.g. girls and women with autism), as well as the intersection of autism with other chronic illnesses and disability. Similarly, we need to acknowledge the intersection of autism with people from culturally and linguistically diverse backgrounds, and with those of the LGBTIQ+ community, including the experience of trans and non-binary folks.

Under Autism awareness and acceptance section:

Some acknowledgements should be given (perhaps add this to the “Barriers to inclusive communities” section) to health practitioners’ lack of understanding how autism presents in girls and women. This results in girls and women remaining undiagnosed sometimes until midlife or later, meaning that autistic girls and women really struggle to live fulfilling and meaningful lives as a result.

Please also add a section addressing the inherent intersection of autism and ableism with other vulnerable groups, as well as indigenous folks. This includes women, people from culturally and linguistically diverse communities, the queer community, and people with other chronic illness and disability.

Under the Intersectionality box in purple:

Please also mention the intersection of disadvantage and discrimination between autism and the experiences of girls and women, queer folk, culturally diverse folk, and people with intellectual and physical disability.

## **Key Theme 2: Economic Inclusion**

### Education

Please note here that even highly intelligent women such as me who have autism have their diagnosis missed at the primary, secondary and tertiary education levels. Not a single teacher throughout primary or high school was aware of how autism presented in intelligent girls and young women or was able to indicate to myself or my family that I might be autistic. Similarly, even when I completed a bachelor’s degree in medicine and surgery (with Honours) in 2001, not one tutor, lecturer or doctor who taught me at one of the supposed best teaching hospitals in metropolitan Melbourne ever raised with me the possibility that I might have undiagnosed autism, to explain my executive function troubles and difficulty with time management and emotional regulation. Admittedly, I studied quite some time ago, but I have little doubt that even bright autistic medical students today remain undiagnosed, due to the general lack of knowledge of their teaching medical staff.

Since then, even when I developed severe and debilitating depression and anxiety and was diagnosed with other complex mental health conditions, and I sought help from many different GPs, psychologists, other mental health care providers, and psychiatrists over the next twenty years, not one health practitioner ever picked up on either my ADHD or autism spectrum disorder. This is because the medical profession remains woefully unaware of how autism, ADHD and other neurodiverse brain states present in women. Women like me who have struggled for years in and outside of all levels of tertiary education are still unable to succeed in life. We must rely often on self-diagnosis, and we must endure a lengthy wait time for proper assessment and diagnosis. In the interim, it’s left up to us to teach and train our treating doctors (who are supposed to be specialists in their field), which is exhausting mentally and physically. And, once we gain access to a clinic that can diagnose us, we must

save money for months on end, to be able to pay the exorbitant fees that private psychologists charge.

## Employment

Please add a section discussing how there is little to no support once autistic people gain employment, to keep them in the workplace. We are very often highly intelligent, capable, and motivated people, who can flourish in the right supportive work environment. But we often must work in environments where understanding of autism is non-existent. This means that autistic women are routinely harassed, discriminated against, and bullied in the workplace, due to our innate neurodiversity and people holding antiquated sexist views about women's appropriate behaviour.

Please mention something here about the lack of supports that exist for autistic and disabled people within the state and federal governments. At present, the only specific state and federal government recruitment initiatives are directed at those autistic people who are lucky enough to have their autism or other disability diagnosed at a sufficiently young age during their secondary or tertiary education. But this means a whole generation of older autistic workers are excluded from such opportunities. If older disabled and autistic folks like me could qualify for these supportive and inclusive employment programs, we would have a much better experience of working life, rather than being forced into relying on meagre Centrelink payments to survive.

Similarly, any job agencies that recruit autistic people for jobs either in the government or the private sector currently have a very narrow understanding of how autistic people can present. And their recruitment for private and public sector jobs only caters to a very limited subsection of the autistic population. They only cater basically to autistic males who fit the traditional male savant stereotype- namely white straight men of a certain age, who have degrees in highly restricted and technical fields, who they expect can work 40 plus hours per week. This does a huge disservice to the entire autistic community, if only a small percentage of autistic folks can get meaningful paid employment in government roles. It means that women, people with chronic illnesses or disabilities such as me (who cannot work full time), queer folks, and people from culturally diverse backgrounds are actively excluded from these opportunities. The government and these independent recruitment agencies need to understand that all autistic people have value, regardless of our age or whether we fit a narrow historical understanding of how an autistic person should or does present. And both the government bodies and the external recruitment organizations need to change their recruitment policies for autistic people to be far less restrictive, so they can develop a more legitimately diverse workforce.

Regarding the 4 Discussion Questions.

1. Other issues affecting autistic people that affect their economic inclusion.

Many autistic people such as me experience multiple comorbid mental health conditions and medical conditions which significantly limit our ability to work. In my case, because of my

mental health struggles due to autism, and my chronic pain syndromes, I can only work between 10 to 12 hours per week.

## 2. How do you think we can better support the economic inclusion of autistic people?

Currently, as it stands, workplaces all over the country are still permitted to advertise jobs that routinely exclude disabled people from participating in paid employment. Even though we have a disability discrimination act, it is essentially useless, because the reality is that it doesn't allow autistic and disabled people to gain any paid employment that is meaningful or appropriate. When people like me, who are intelligent, hardworking, motivated, and highly educated (with post graduate qualifications) can't get work because of the inherent ableism of employers all over the country, we are being systemically failed by government and private enterprise alike.

The government needs to pass more meaningful, specific, and practical legislation that ensures that people living with a disability (including neurodiverse people) have a basic right to paid employment, that outlaws the routine exclusion of disabled people from the paid workplace. (Perhaps this could take the form of a Disability Rights Act). Governments (state or federal) should pass laws that require employers to proactively hire certain quotas of disabled people, and to then ensure that no existing employee is discriminated against due to their disability. This could be done in a similar fashion to the recently passed Victorian laws, that require employers to proactively take action to prevent their staff from being bullied and harassed. And, to ensure this happens in the workplace in a meaningful fashion, governments will also need to set up monitoring and enforcement bodies, such as employer watchdogs, which have statutory authority over both government and private organizations alike. Such bodies would be empowered to scrutinize employers throughout their recruitment practices, to ensure that disabled people are not routinely been excluded from gaining new roles, and to monitor how employers are supporting their current disabled employees. Without this, unethical employers all over the country will only continue to recruit people who are not neurodiverse and not disabled, meaning that neurodiverse and disabled people will continue to be financially disadvantaged across society. Similarly, governments will also need to abolish disability employment enterprises, that act to systemically abuse and exploit vulnerable disabled employees and pay them substantially less than abled workers.

The government also needs to educate all employers about how to support their autistic and neurodiverse staff members, to keep them employed and contributing to the workplace meaningfully. This needs to be done in consultation with autistic people at all stages, whether it be asking for reasonable accommodation in the workplace, asking for flexible working conditions, or other accommodations. Employers and managers need to believe autistic people when we come to them with problems regarding our executive function issues, such as time management or task prioritization. And managers and employers need to provide their neurodivergent staff members with support and understanding, rather than treating us like we are consistently the problem. And managers need to support autistic staff when they experience bullying and harassment in the workplace, by believing them when they report these toxic behaviours, and by taking appropriate measures to support autistic staff in any practical achievable way. There also needs to be clearer training for managers

and HR staff about how autism presents in workers, and how they can support us when we inevitably experience difficulties in the workplace.

Regarding Transport issues specifically:

To make public transport more autism-inclusive, perhaps the government need to expand the eligibility for people living with a disability so that autistic folks with sensory needs and executive function issues can get access to discounted public transport tickets or taxi vouchers.

3. How do you think we can better support autistic people in education, employment, and the workforce?

Please see answer to question 2 regarding employment and the workforce issues.

Regarding education- we need to better educate teachers and staff working in primary and secondary schools, as well as staff at higher education institutes (universities and TAFES) about how autism and other neurodiverse folks (such as people with ADHD) present in boys, girls, and trans and non-binary folks. This needs funding from the government at state and federal levels.

Also, we need to improve the general medical community's understanding of autism. When I studied for my medical degree twenty years ago, there was very little to no teaching regarding how autism and ADHD presents in children or adults, in either the psychiatric or paediatric education blocks. And I honestly expect that this is still the case in medical school curricula around the country. Perhaps governments need to fund higher education institutions, so that they can better educate future health professionals of all stripes (but particularly doctors, nurses, psychologists, and mental health care workers) about how autism and ADHD present in both children and adults. Higher education institutes need to proactively involve (and pay) autistic and neurodivergent folks to help educate the next generation of healthcare providers how these conditions present and explain how their lives are affected. And, finally, tertiary education providers like TAFES and universities need funding to try and recruit and retain more neurodiverse staff members, so that we can be a part of educating the next generation of professionals about how these conditions affect our lives.

4. Better economic inclusion for autistic people would involve  
-everyone who is autistic who wants to work in paid employment being able to find culturally and socially safe and supportive and meaningful paid work.

-it would also mean that autistic people have much higher rates of paid employment in the mainstream job market, in all fields (government, and private sector)

-it would also mean therefore that autistic people didn't have to rely on as much government funding to live day to, and we could enjoy a better quality of life.

-it would also mean funding the disability pension better, so that autistic disabled folks can have better quality of life, by being able to afford things like mental health care, autism diagnosis/assessments, and any relevant supports we need

-Also, it would mean that organizations (government and private) that want people to work in areas of disability and autism advocacy would be required to PAY US FAIRLY for our work and efforts. Too many times, private organizations and the public sector alike have advertised roles for disability inclusion as if they are paid roles (implying that the organization values disabled peoples' opinions and work), only for us disabled folks to discover in the fine print somewhere that the role is entirely voluntary and unpaid. This is highly distressing, as it tells autistic and disabled people explicitly and implicitly that our lives, our work, and our contributions are worth nothing. Government departments and private organizations alike must be made to properly fund disability advocacy and inclusion work, by paying autistic people and disabled people as expert consultants. This would prevent government departments and private enterprises from seeing disability advocacy and inclusion as some extraneous, luxurious add-on to their operations, rather than a key core component of their everyday work.

Continuing to allow governments and the private sector to profit and benefit from the unpaid and volunteer labour of disabled folks in the name of disability advocacy needs to stop immediately. Allowing these practices to continue does an immense disservice to the autistic and disabled community more generally, as we are already getting paid so little in the roles where we can work, and often we are also volunteering in other advocacy roles where we are not financially remunerated at all.

### **Key Theme 3: Diagnosis, Services and Supports**

-Under the Assessment and Diagnosis Section

Perhaps in here can we also mention that women who are autistic are much more likely to have multiple comorbid mental health conditions and have much higher rates of suicide than the neurotypical community. This means many undiagnosed autistic women are having to undergo extreme levels of unnecessary distress and potential misdiagnosis of mental health conditions as a result.

Please also mention the need for diagnostic criteria to not only rely on DSM-V. Mention that need new diagnostic criteria which diagnoses autism in women and doesn't just reflect historical research in white boys and young men.

-Under Research and Data

Mention the government needs to fund research into autism and how it presents in women, trans, and non-binary folks. And the government also needs to fund research into the effects that autism spectrum disorder has on adults generally, not just children.



## Discussion Questions:

1. Are there any other issues about diagnosis, services and supports experienced by Autistic people that you would like to add?

- Difficulties preventing autistic adults from getting a diagnosis:

This discussion paper needs to recognize that public assessment services for autism diagnoses for adults are essentially non-existent in this country. In metropolitan Melbourne, only one clinic (the University of Melbourne neuropsychology teaching clinic) provides autism assessments for adults who do not experience intellectual disability at a remotely affordable rate. (Please note that this service isn't part of a public hospital service, as it costs about \$800 to \$900 for an individual assessment. And for this service, the wait list is about 18 months, which is impossibly long).

The only other option for adults who do not have an intellectual disability seeking a diagnosis for autism is to pay exorbitant fees for private neuropsychology or psychology clinics. One private neuropsychology clinic in the greater Melbourne area charges \$3000 or more for a cognitive and autism assessment, and others charge approximately \$1500 for an assessment. And the wait lists for these clinics is anywhere from 3 to 6 months or longer. This is appalling, as many autistic women, trans and non-binary folks remain undiagnosed until adulthood, and therefore we experience extreme financial hardship, and a multitude of intersectional disadvantages. To expect that some of the most disadvantaged folks in the community to pay these types of fees to private providers is extremely discriminatory.

The federal government also needs to do away with the discriminatory practices of only allowing people with autism spectrum disorder level 2 and 3 severity to access the NDIS. These levels of function are not meaningful in terms of autistic peoples' everyday lives. They are just a remnant of some misguided advice which was taken on board by the DSM 5 diagnostic manual. They do not help patients or practitioners to understand individual patients' needs better, they just operate to exclude autistic people from accessing the services, funds and supports that they so desperately need.

- Regarding which services and supports that would me live the life that I want:

It would be ideal if all major public hospitals in the country had specific clinics established to diagnose and manage autism in adults. This can include those with dual diagnosis (intellectual disability), but it should not exclude those adults without an intellectual disability. These clinics can be part of adult mental health services. (And public adult mental health services are basically non-existent and massively underfunded at present). These clinics need to have psychiatrists, clinical psychologists, and neuropsychologists on staff, to diagnose and assess adults with suspected autism spectrum disorder. And they need paid occupational therapists and other therapists to help us manage behavioural issues, provide counselling, and support, and manage our stressful daily lives. But no such clinics exist in

public hospitals in this country. This would mean that autism assessment for adults would be much more affordable and accessible for autistic adults.

Similarly, it would be best if future training psychiatrists, psychologists and neuropsychologists could all be trained to recognize the symptoms, signs, and presentation of autism in a variety of people, not just white boys under the age of 18. This may require additional funding from governments, but it would significantly improve the lives of the many autistic adults who are continuing to struggle in their lives due to undiagnosed autism.

2. How could we improve access to diagnosis, services and supports for Autistic people? What has helped you to access a diagnosis, services or supports?

The only thing that has helped me access a diagnosis so far (not that I have yet received a formal diagnosis of autism spectrum disorder) is the fact that I happen to be an intelligent white tertiary educated woman, who has a financially supportive family. I am very lucky in that my family can support me with my finances and accommodation. Without their support, I would not be able to have any stable accommodation, or the financial capacity to gain a diagnosis, let alone the physical health or mental wellbeing to manage any of my other chronic health conditions. I am one of so very few autistic women who have the luxury of being able to afford to get a formal diagnosis, when so many other autistic folks out there do not have this privilege. But I am still waiting to get an initial assessment with a private psychology clinic that can diagnose adult women with this condition (I have waited almost 3 months so far). And my assessment will cost me \$1500, with no Medicare rebate. This is terrible for someone who relies solely on the disability support pension (which provides me with approximately \$500 per week for all my expenses).

The government really needs to change the rules such that private and public neuropsychologists, psychiatrists, and psychologists can claim Medicare rebates for autism and cognitive assessments (for diagnosis especially). The current system is biased against those people with little or no money, so only those who are fortunate enough to have rich families can even get a diagnosis in the first place.

The government also needs to fund public and private hospitals, to establish adult autism assessment services as part of their outpatient clinics, so that undiagnosed autistic adults can receive free or low-cost assessments in a timely fashion.

The government also similarly needs to change the discriminatory rules for NDIS eligibility regarding neurodivergent people. They need to change the criteria so that folks with moderate to severe ADHD can access the scheme. They also need to remove the discriminatory "levels of severity" model for autism spectrum disorder that results in seriously disabled folks lacking any kind of practical everyday support that would make their lives meaningful.

3. How can we better support access to neurodiversity-affirming, person-centred services and supports for Autistic people?

Change the Medicare rebate system so that autism diagnostic assessment and cognitive assessments are eligible for Medicare rebates.

Improve funding to the relevant training bodies overseeing training of future psychiatrists, psychologists, and neuropsychologists, but make it a requirement that these funds be used to improve training in autism, ADHD, and other neurodiverse conditions.

Improve funding to the Royal Australian College of GPs, so that GP training registrars get proper tuition in how autism and ADHD presents in their patients.

Improve funding for the Royal Australian College of GPs, that requires qualified and current practicing GPs to do a certain component of continuing education around the varied presentations of autism, ADHD, and other neurodiverse conditions in their patients.

Improve funding for clinics in public hospitals, private hospitals and research organizations which can diagnose and manage mental health conditions in women specifically. (As we know that lots of adult women with autism have comorbid mental health conditions and remain undiagnosed for long periods of time). For instance, funding should be provided to services such as the Monash Alfred Psychiatry Research Centre, which runs a women's mental health service (headed by Professor Jayashri Kulkarni). Services like this provide crucial specialized women's mental health clinic services to all women, which is entirely free. These services allow women to be assessed for various mental health conditions by highly trained, qualified doctors, and the clinic provides specialist feedback on ongoing treatment and management of the relevant conditions to the women's GP, psychiatrist, or other referring doctor. But at present, their waitlists are so full that they only have capacity to see a woman once, which really isn't at all sufficient support for women with complex mental health issues and autism. This is because these services are woefully funded by the government and have very limited capacity overall. This means that all women (including autistic women) find it incredibly difficult to access to crucial mental health services in the public sector in a timely and affordable fashion.

4. How can we better make sure that diagnosis, services and supports for Autistic people are strengths-based, culturally responsive and trauma-informed?

Governments need to hire more disabled people generally. And, specifically, governments need to see the value of neurodiverse people in the workforce in all areas and all departments. Governments must stop seeing neurodiverse folks as useful tools for only very narrow roles. Currently governments effectively only recruit adult neurodivergent folks for very limited and restricted roles (e.g., doing mundane meaningless work such as scanning documents or organizing filing; or only doing highly specialised IT tech jobs with an incredibly narrow scope.). Neurodiverse people have a huge variety of strengths and can contribute positively and constructively to the workplace if they are allowed to do so, and they are supported and understood along the way.

Perhaps governments need to introduce mandatory quotas within their own departments for employing disabled and neurodiverse people. Perhaps they could introduce measures like the federal Labor party did for minimum quotas for women, which requires a certain percentage of roles in government departments be filled by disabled and neurodiverse folks.

The government also needs to set up an advisory board of neurodiverse people, who are fairly and appropriately paid to do the work for that board/committee, to provide advice at all levels of government. This advisory board of disabled and neurodiverse folks would give advice and feedback regarding all aspects of the government process, from the initial stages of developing and refining legislation and government regulations, all the way to implementing these policies within all government departments. We particularly need more neurodiverse people working with Services Australia, especially with Centrelink, and within the health department.

And within government departments, we need to develop proactive hiring and recruitment policies for neurodivergent folks, and to establish programs that help existing neurodivergent folks keep their roles and excel in the workplace. Neurodivergent people need to be recruited into not just entry level roles, but we need to be included at all levels of management, so our voices can be heard, and we can have a meaningful impact on government policy. The government also needs to set up specialist pathways for neurodiverse employees within government organizations, that help these employees with positive and meaningful mentoring experiences. Such mentoring and professional development pathways would help neurodivergent folks both negotiate the workplace both on a day-to-day basis and help them ascend the career ladder within government. This would mean that less neurodivergent employees would remain stuck in just entry level positions for long periods of time, and less of them would be forced to resign due to workplace isolation, harassment, bullying etc.

5. How would you describe what better access to diagnosis, services and supports looks like for Autistic people?

Better access to diagnosis, supports and services for autistic people would look like this:

- Having several large public hospitals in cities and large metro centres around Australia with specialized neurodiversity clinics, where people with autism, ADHD and other neurodiverse brains can seek the diagnosis and support they need.

- Having more publicly funded and either free or affordable women's mental health clinics- either in public hospitals, private hospitals, as part of research organizations, or university teaching clinics.

- Having Centrelink and Medicare offices be much more autism friendly, with quiet chillout spaces and zones.

- Having all government departments and buildings with designated low sensory input rooms, for neurodiverse people to take time out as required. This might involve having rooms for staff, but also having similar chillout rooms for clients if the government department provides services to the public.

-Having properly funded, specialized sub sections of psychiatric inpatient wards in public and private hospitals which are allocated to the neurodiverse population. This might include having rooms which have dimmed lights, or are more soundproof, and single occupant only.

-Having all training psychiatrists, psychologists and neuropsychologists be taught about autism and other neurodiverse presentations as core parts of their training schedules, so they are more aware of how neurodiverse people present in practice.

-Having all GPs during their training program to do a mandatory unit about neurodiverse populations, so they can learn how neurodivergent people present in practice. And requiring all fully qualified GPs as part of their continuing education to gain some minimum amount of training in recognizing autism, ADHD, and other neurodiverse conditions in their patients.

-Having the NDIS not exclude people with ADHD from getting services and supports

-Doing away with the NDIS "levels of severity" as a key determinant of whether people with autism spectrum disorder are eligible for the scheme or not

-Doing away with the unnecessarily burdensome requirements for autistic people with ADHD to jump through so many hoops when it comes to getting scripts for stimulant medications, which can be literally lifesaving. At present, there is an excess of red tape for psychiatrists to provide scripts for stimulant medications, which are all based on out-of-date, inaccurate 1960s era American ideas about stimulants being harmful drugs of abuse. Stimulant medications which are prescribed by qualified psychiatrists to patients with ADHD are not addictive or harmful. And having regulations and guidelines that make it incredibly difficult for psychiatrists to prescribe these medications and for patients to access these treatments is unnecessary, and ableist, especially when there is no scientific evidence whatsoever that stimulant usage is addictive or has abuse potential in patients with ADHD.

-Changing the laws such that patients who have ADHD who are on stimulant medications cannot be prosecuted by police if they are found to have stimulant medications in their system while driving. These laws are unnecessarily punishing neurodivergent people for their disability, and this needs to stop immediately.

-As many people with autism and other neurodivergent brains have multiple associated chronic illnesses and chronic pain syndromes, governments must change the laws so that police also cannot prosecute people who need to take Cannabis Oil for their chronic pain. Allowing police officers to punish disabled people for taking pain relieving medication is deeply ableist and needs to stop immediately.

## **Key Theme 4: National Roadmap to improve the health and mental health of autistic people**

### Discussion Questions:

1. Are there other health and mental health issues experienced by autistic people that the National Autism strategy should help to address?

Can we please mention about specifically the effect of autistic burnout on women? Autistic women are constantly required to mask in society, to function on a day-to-day basis. This is due to a variety of reasons, but it mostly occurs due to outdated and sexist ideas about how women and girls must behave and appear, to be accepted in society. But the cost of constant masking of our innate behaviours and attributes on girls and women is immense. We are already burdened by brains that have executive function limitations. Then, if you are forced to constantly mask to make other people more comfortable and to feel like you fit into society, the mental and physical toll on the woman or girl is immense and debilitating. So, it makes sense that autistic women are constantly in a state of near or total burn out.

The toll that chronic autistic burnout this takes on autistic women and the other people in their lives is also immense. It means that women such as me are routinely having to be admitted to inpatient mental health facilities, to manage their debilitating symptoms of depression, anxiety, trauma, and exhaustion. In my case, every 8 weeks I need to be admitted to a private adult inpatient psychiatric unit for several days, just so I can continue to get through the next 8 weeks of my life. I have been constantly anxious and depressed and stressed for 20 years, and the result is that I cannot find any work or maintain regular secure employment. It means that I routinely experience suicidal ideation, which is debilitating. It also means that the mainstays psychiatric treatment, including medication such as antidepressants and anxiolytic medications and psychotherapy, are ineffective for me. The only treatment that helps me is accessing regular maintenance Transcranial Magnetic Stimulation (TMS) treatment, which must be done as an inpatient (or as an outpatient at an exorbitant out of pocket expense). Without the benefit of regular Transcranial Magnetic Stimulation, I would have undoubtedly died from suicide several years ago. The suicide rates of women with autism are 3 to 4 times higher than other neurotypical people. And this is appalling.

In terms of other health issues, many autistic folks such as myself struggle with multiple comorbid chronic illnesses.

I have had severe and debilitating irritable bowel syndrome for over 20 years now. It causes debilitating pain, constipation, and diarrhoea. I have seen many private gastroenterologists over this time, none of whom have been able to give me much helpful relief for my symptoms. My symptoms are so severe on some days that I must rush to the toilet at work or at home for fear of soiling myself, so that both my work performance and quality of life is seriously affected. About 8 years ago, I saw a private gastroenterologist who pressured me into paying for exorbitantly expensive tests of my gut microbiome (costing over \$350 for an assessment), which meant that he diagnosed me with some intestinal parasites. This specialist then prescribed me with a very expensive and dangerous cocktail of antibiotics and

herbal treatments (this treatment cost me several hundred dollars, and the herbs and antibiotics prescribed are not backed by mainstream scientific studies). This dangerous cocktail of medications and unproven therapies resulted in me experiencing such severe diarrhoea and vomiting that I lost 8 percent of my body weight in 48 hours (moderate severity dehydration), and I could not eat or keep down any fluids. It also prompted me to become acutely suicidal and consider admission into my local emergency department. This sort of dangerous unregulated and unproven practice by private gastroenterologists to manage irritable bowel syndrome must not continue, as it nearly cost me my life. My irritable bowel syndrome has also meant that for almost twenty years I have had to survive off an extremely limited low FODMAP diet. This has resulted in me experiencing severe and debilitating iron deficiency anaemia, which required multiple iron infusions in recent years. (My gynaecologist recently joked that she was surprised I could even walk around and speak with a ferritin level of 6- it explained why I was so incredibly fatigued, depressed, anxious, and exhausted for so long).

As an autistic woman, like many others, I was also misdiagnosed with borderline personality disorder in the past. This is because I have been raped and sexually assaulted multiple times as a young woman, and I have experienced repeated episodes of trauma (referred to now as complex trauma) over many years due to my autism. And autistic women generally have much higher rates of experiencing sexual assault and rape than neurotypical women. But being mislabeled with borderline personality disorder is a highly distressing and stigmatizing process. It makes women feel they are defective human beings. I recall in medical school twenty years ago that during my psychiatric rounds we were taught that people with borderline personality disorder were labelled “bad”, and they were treated as if they were defective and manipulative individuals who couldn’t be trusted. I honestly wonder how many other women who have been (mis)diagnosed with borderline personality disorder have undiagnosed autism.

Many autistic women are similarly misdiagnosed with a raft of other mental health conditions, ranging from generalized and social anxiety disorder, borderline personality disorder, obsessive compulsive disorder. Sometimes we do have both autism and other comorbid mental health issues, but sometimes these other issues may just be ‘best guess’ placeholder diagnoses for individuals for whom autism is a better explanation. Again, great harm is done to women when they are misdiagnosed with other psychiatric disorders when, in fact, they just have an undiagnosed and unrecognized neurodevelopmental difference.

## 2. How can we better support health and mental health outcomes for autistic people?

At present, life saving interventions such as maintenance Transcranial Magnetic Stimulation (TMS) for people with severe, chronic debilitating depression (in autistic and non-autistic folks) is only available for patients who have the luxury of coming from money. It’s only available at a few select private inpatient facilities, where private health insurance can cover most of the cost, or the only other alternative is to pay thousands of dollars out of pocket to access TMS via private psychiatric clinics. But, at a cost of \$800 to \$1000 per maintenance TMS treatment regimen, the cost is obviously prohibitive to people who often cannot work or are on fixed government pension incomes.

For most people who cannot afford private health insurance, they are left to languish in the public mental health system. Here, public mental health inpatient units are grossly underfunded and are only reserved for the most debilitatingly unwell clients who are a danger to themselves or others. And even if a public patient gets access to an inpatient unit, they do not get access to initial or maintenance TMS treatment at present, and their experiences in public mental health units are often so unhelpful as to exacerbate any preexisting mental health complaints they presented with. And when they are discharged, there is little to no ongoing support in terms of mental health outpatient clinics for these people. So, they are left to their own devices, and they exist entirely unsupported by the system.

There is also very little research about how autism presents in girls and women, the LGBTIQ+ community, people from culturally and ethnically diverse backgrounds and first nations people. The only research that exists to date is based on studies of the archetypal white autistic boy. This means that the diagnostic criteria used to diagnose women in anyone in the population who isn't a white boy or young white man are not applicable or valid. Similarly, all these diagnostic criteria are presently based on the external manifestations of autism (e.g., noticeable behavioural differences that clinicians or family can observe in autistic people), rather than being based on an autistic person's internal lived experience. This means again that many girls, women, queer, and culturally diverse folks remain undiagnosed, as we may not present with many very visible external behavioural manifestations. Therefore, these diagnostic criteria for autism need to change, based on newer research on how autism affects everyone, not just white men, and boys.

And the diagnostic criteria used currently for autism in adults do not sufficiently detect autism in women and girls. (This is particularly the case for the ADOS, which is only sufficiently sensitive to detect autism in young children and leads to high rates of autism being missed in adult women).

So, to change this, several things must happen.

- Public mental health inpatient and outpatient clinics should be given much more funding, so that they can have increased capacity to see patients and give them timely assessment and treatment options.
- Public mental health clinics must be established, which specialize in the assessment, diagnosis, and ongoing management of autism spectrum disorder and other neurodiverse conditions such as ADHD in adults. This means providing care for all people with autism spectrum disorder, including women, the LGBTIQ+ community, and people from diverse cultural backgrounds (not just straight white men).
- Private mental health institutions and private mental hospitals need proper funding from government to provide TMS treatment to their inpatients who have chronic depression (due to autism and other mental health diagnoses). These institutions and hospitals should not have to rely on private health insurers alone to fund these life saving procedures. The government needs to step up to better support TMS programs in inpatient settings in private hospitals.
- Governments must ensure that all private mental hospitals DO offer TMS for all inpatients. Until 2019, the Ramsay Clinic (which operates the Albert Road Hospital, amongst many others) was offering initial and maintenance TMS treatments for all patients with severe



depression. But, due to the Clinic prioritizing money over depressed peoples' lives, they changed their policy, such that no maintenance TMS sessions can now be offered to inpatients. Presently, such clinics effectively do not offer any TMS treatment to inpatients, unless it's either the patient has never had TMS before or they need a lengthy admission for some other reason (e.g., for changing antidepressants). This means that people with severe chronic debilitating depression are unable to access this life saving treatment. Therefore, the government needs to crack down on privately owned hospitals, to ensure that patients can gain access to both initial TMS treatment and maintenance TMS treatment, regardless of the length of hospital stay. Perhaps this might involve the government establishing a private hospital and private health provider watchdog, to ensure that these organizations comply with the guidelines.

-Governments need to fund more research in this country into autism generally. But it also needs to fund research specifically into how autism presents in women, in queer folks, in first nations people, in people from culturally and linguistically diverse communities. This means funding universities and other research bodies into researching these 'different' presentations of autism.

-The Australian Federal Government needs to review the National Guidelines on Autism once again (e.g., the Summary and Recommendations document published in 2018 needs review and updating). It appears that these guidelines were only authored by specialists in the field, and it therefore lacked input from the neurodiverse community directly. It really needs reviewing with the neurodiverse community included in these discussions, so that the voices and opinions of autistic people can be included.

-The National Guidelines on Autism group also need to review the pros and cons of each of the different diagnostic criteria for autism, and perhaps deemphasize the idea that many practitioners have that the DSM 5 is the best and most correct diagnostic tool for detecting autism in adults. They need to have an open and honest discussion with both professionals that diagnose and manage autism AND the neurodiverse community. Such discussions need to address both which diagnostic criteria are likely to be both the most valid and sensitive and address those methods that lead to the most practical support and positive outcomes for the neurodiverse population generally. They then need to disseminate this information to professionals who diagnose autism, so they can be better informed as to how to diagnose people and support them into the future in equal amounts.

-Governments need to fund the training colleges for future psychiatrists, clinical psychologists, and neuropsychologists in recognizing and diagnosing autism in adults and children

-Governments also need to fund training for all existing GPs and psychiatrists dealing with adult populations in recognizing undiagnosed autism spectrum disorders in all their patients

-Governments need to start properly funding free, public support services for the myriad of women like me who have experienced sexual assault and rape. At present, these services are not government funded at all, and they rely solely on the generous donations of women who are generally survivors of sexual assault and rape themselves.

### 3. What needs to improve about health and mental health services and supports?

- All mental health services in public and private hospitals must be better funded to support everyone, and autistic people specifically.
- Governments need to provide extra funding to major hospital emergency departments so that they can establish quieter areas (special beds or private rooms) where neurodivergent

folks experiencing distress can manage their sensory processing issues (as emergency departments are notoriously triggering for neurodivergent folks)

- Governments must fund public and private hospitals to establish new outpatient clinics for neurodiverse folks with Autism, ADHD, and other similar conditions.
- Governments must require public and private hospitals to establish specialized teams to assess, diagnose and treat people with neurodiverse conditions.
- Inpatient mental health units in public and private hospitals must have separate sections for neurodiverse people to manage their various sensory needs whilst they are in care.
- Governments must fund research into how Autism presents in girls and women, as well as queer folks, and in other 'minority' groups such as people from culturally and linguistically diverse backgrounds.
- Governments also need to fund research into evidence-based effective management strategies for autism, which include both medication and non-medication interventions.
- Governments must review the National Autism Guidelines for diagnosis and update them to deemphasize the use of diagnostic tools which can be used to discriminate against certain subsections of the autistic community based on "levels of function".
- Governments must amend the NDIS eligibility criteria to include people with psychosocial disability, and to remove the discriminatory practice of only allowing people with autism spectrum disorder level 2 and 3 to access funding.
- Governments must also stop kicking people with psychosocial disabilities off the NDIS.
- The government also needs to increase the rate of the disability pension, so that people with autism who are not currently eligible for the NDIS can have a more meaningful and better quality of life, and can afford the healthcare and services that they so desperately need