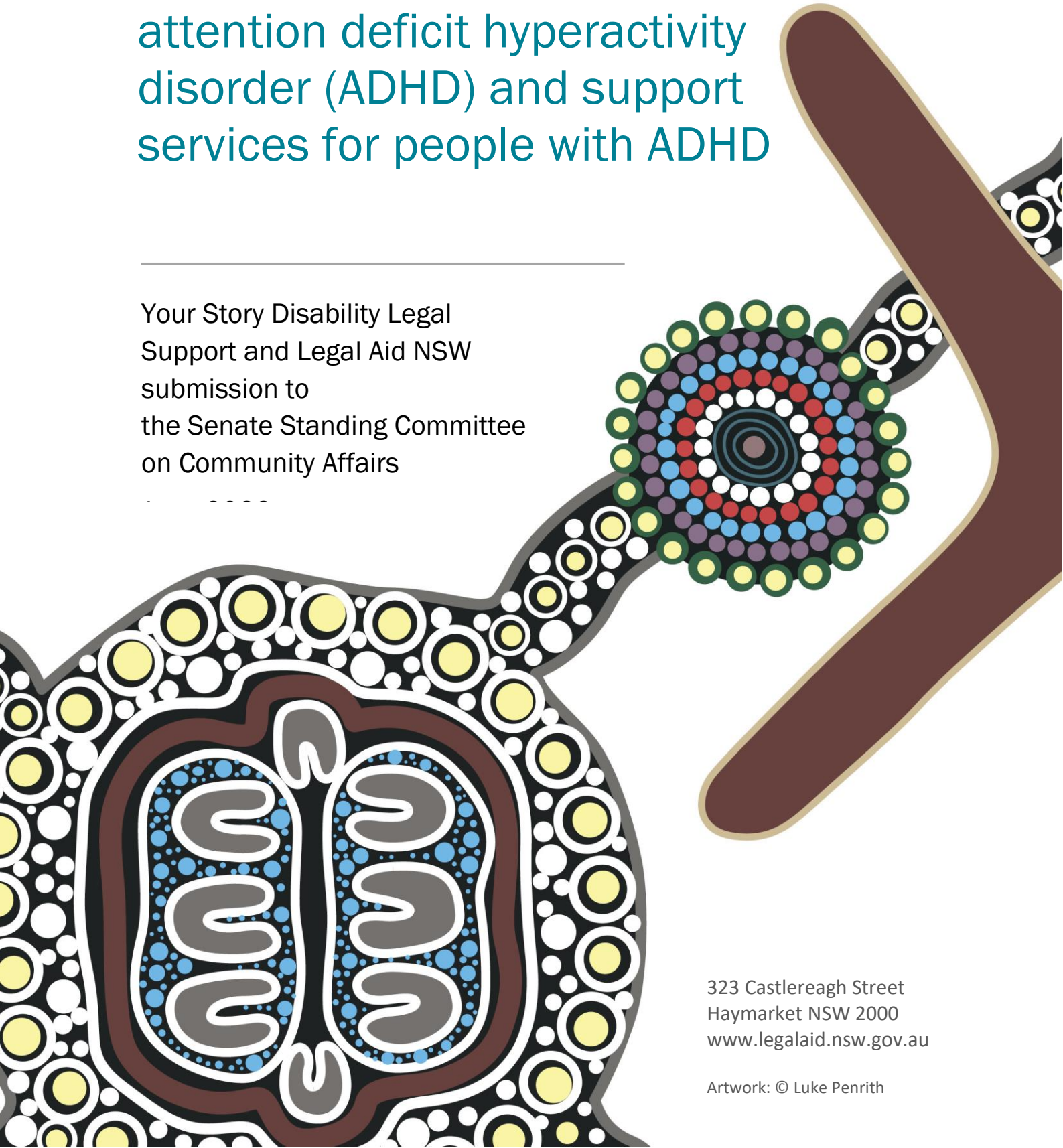
Senate Inquiry into barriers to consistent, timely and best practice assessment of attention deficit hyperactivity disorder (ADHD) and support services for people with ADHD

Your Story Disability Legal Support and Legal Aid NSW submission to the Senate Standing Committee on Community Affairs



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Acknowledgement

We acknowledge the traditional owners of the land we live and work on within New South Wales. We recognise continuing connection to land, water, and community.

We pay our respects to Elders both past and present and extend that respect to all Aboriginal and Torres Strait Islander people.

Legal Aid NSW is committed to working in partnership with community and providing culturally competent services to Aboriginal and Torres Strait Islander people.

1. About Legal Aid NSW

Our service delivery

Legal Aid NSW is an independent statutory body established under the Legal Aid Commission Act 1979 (NSW). It provides legal services across NSW through a statewide network of 25 offices and 243 regular outreach locations, with a particular focus on the needs of people who are socially and economically disadvantaged. Legal Aid NSW assists with legal problems through a comprehensive suite of services across civil, criminal, and family law. Services range from legal information, education, advice, minor assistance, dispute resolution and duty services, through to an extensive litigation practice. Legal Aid NSW also works in partnership with private lawyers who receive funding from Legal Aid NSW to represent legally aided clients. It maintains close partnerships with community legal centres, the Aboriginal Legal Service (NSW/ACT) Limited and pro bono legal services. Legal Aid NSW provides state-wide civil law services through the in-house Civil Law Division and private practitioners. Civil law services cover a range of civil matters before state and federal conciliation bodies, the Local Courts, District Court, Supreme Court of NSW, Federal Circuit and Federal Court, Administrative Appeals Tribunal, NSW Civil and Administrative Tribunal, Mental Health Review Tribunal and the High Court of Australia.

Working with people with disability

Legal Aid NSW recognises that people with disability are from diverse cultural groups and backgrounds and have needs, priorities and perspectives related to their age, sex, gender, sexual orientation, race, cultural and linguistic backgrounds, among other factors. We acknowledge the diversity of disability and experience among people with disability. Legal Aid NSW is a member of National Legal Aid which represents the eight independent state and territory legal aid commissions in Australia.

Your Story Disability Legal Support (Your Story) is a service of National Legal Aid (NLA) providing services to people with disability through State and Territory legal aid commissions and community controlled Aboriginal and Torres Strait Islander legal services, including Legal Aid NSW. Your Story supports people with disability to make submissions to the Disability Royal Commission, provides accessible community legal education, social work support and comprehensive referrals for specialist legal

assistance with criminal, civil and family law matters including domestic violence and child protection.

Since 2019, Your Story has received over 11,000 calls and enquiries and provided over 15,000 legal and social work services. Your Story has established a phone line for people with disability in all adult and correctional facilities across Australia which has received over 3,000 calls. Your Story has provided over 2,000 legal services to people in closed environments in Australia (prison, youth detention, mental health facilities, immigration detention and group homes).

Your Story has also delivered a range of accessible resources and education activities including for people with disability in custody. Your Story works closely with its legal service partners, including Legal Aid NSW, to meet the needs of people with disability across Australia.

Legal Aid NSW and Your Story Disability Legal Support are therefore well positioned to comment on issues and barriers regarding assessment and support services for people with ADHD. Our insights and experiences have also informed our recommendations for positive change.

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2. Executive Summary

Legal Aid NSW welcomes the opportunity to provide a submission to the Senate Community Affairs References Committee's inquiry into the *Assessment and Support Services for People with ADHD.*

Your Story works within Legal Aid NSW and provides legal services to people with disability, their carers, and supporters.

This submission was produced with input from staff members who identify as neurodiverse and have been diagnosed with ADHD. We acknowledge their lived experience, the strengths they bring to the organisation and the benefit this neurodiversity brings to our clients. This submission contains de-identified client case studies and is informed by our work with people with disabilities and our submissions and support for people speaking to the Disability Royal Commission.

Outlined below is a summary of the primary areas of concern and Your Story recommendations. There has been specific focus on the legislation, policy development, funding and community reform required to remove barriers for people with ADHD.

2.1 Recommendations

Children with ADHD in Out of Home Care

1. Children and young people who are in out of home care are treated as a priority group for diagnosis, treatment, and support of ADHD.

2. Mandatory screening for ADHD be conducted for all children placed in out of home care.

3. The Commonwealth work with the States and Territories on a National framework to address and reduce the trajectory of children with ADHD in out of home interacting with the youth justice system and ultimately, prison.

4. To address the criminalisation of children with ADHD, anyone who works with children in out of home care should receive training about ADHD to raise awareness, develop expertise, and avoid inappropriate responses. This includes carers, support workers, healthcare professionals, and educational professionals. That this training also be offered to parents.

5. Strategies must be developed to prevent and reduce student exclusion from schools for children with ADHD.

6. Education institutions should prioritise a supportive approach rather than a punitive approach with particular focus on children diagnosed with ADHD from out of home care.

7. Children and young people with ADHD should have an advocate appointed as soon as they enter a detention centre. This is consistent with other recommendations Your Story and Legal Aid NSW have made for anyone who has a disability within prison.

8. Processes be established to ensure that communication occurs between the detention centre and a young person's treating GP, specialist, and mental health/disability professionals. This will ensure detention centre staff have knowledge of current treatment plans and relevant history.

9. Prison staff receive focussed training to equip them to appropriately work with children with ADHD.

Persons with ADHD in the criminal justice system

1. Prisoners are given access to ADHD diagnosis, treatment, and support in prison. This includes providing stimulant medication in an appropriate and safe way.

2. Prior to coming into prison all prisoners are screened for ADHD and provided with diagnosis and treatment of required.

3. That the principle of equivalency of care be upheld for persons entering prison.

4. That continuity of care is ensured in relation to treatment and support that was being received by a person in the community prior to their incarceration. That processes are established to ensure that communication occurs between the detention centre or prison and a person's treating GP, specialist, and mental health/disability supports so that staff at the facility have knowledge of current treatment plans and relevant history.

5. Prior to release, throughcare planning and referrals must be made so that the person has the necessary pathways for continued support and treatment for their ADHD to better their chances of reintegrating into the community.

6. The Australian Government should conduct a national review of neurodiversity in the criminal justice system, informed by the landmark review that was conducted in the United Kingdom (referenced below). The review should focus on understanding neurodivergence in the criminal justice system, propose new solutions and provide training to staff involved. Further this review should also investigate non-custodial and non-criminal (such as parking fines) interaction of people with ADHD and the justice system.

7. Establish an internal ADHD screening program for existing prisoners. If diagnosed with ADHD prisoners would be offered interdisciplinary care and support services, as well as medication with the goal of reducing recidivism and transition a person out of the criminal justice system.

Adequacy of access to ADHD diagnosis, supports and medication after assessment

1. That strategies be implemented to reduce the barriers to diagnosis of ADHD, which include extensive wait times, no affordable options, and a shortage of professionals who can diagnose the condition in regional and rural areas.

2. That public educational campaigns be implemented to reduce the impact of stigma on persons considering their options for assessment and treatment and increase understanding on ADHD.

3. A 'Hub and Spoke' model be adopted for services to ADHD to connect services and reduce administrative burden on people with ADHD.

4. ADHD medication must be made affordable, accessible, and reliable.

5. All ADHD medication should be included on the PBS.

The Law and ADHD medication and treatment

1. Legislation across the various states and territories be rationalised and standardised based on the most up to date medical evidence and knowledge.

2. That the legislation allows seamless transferal of ADHD scripts across jurisdictions without the need for further psychiatrist appointments.

3. Where medically appropriate that psychiatrists can prescribe and treat across jurisdictional borders.

4. That the laws be relaxed to allow easier access to medication and that more health professional can prescribe medication.

The Australian ADHD Professionals Association Guidelines

1. Your Story broadly supports the recommendations made by the Australia ADHD Professionals Association (AAPA).

2. In future guidelines the prioritisation of prisoners and those in the criminal justice system should be reframed around criminalisation of ADHD behaviours and disability, rather than framing ADHD as causal of criminal behaviour.

3. Future guidelines and research should be directed towards understanding and supporting the strengths inherent in those with ADHD. It is important to recognise the disabling elements of ADHD and remove such barriers. However, it is equally as important to highlight and promote the inherent strengths people with ADHD can have.

4. Future reviews and guidelines take a broader view and contextualise the treatment of ADHD in its history. This is so mistakes, myths and previous inappropriate treatment approaches can be identified and addressed.

5. Future reviews, guidelines, and research into people with ADHD who have engaged with health services and had poor experiences, discrimination, or abuse. Explore how this contributed to continuing stigma, substandard care, and disengagement with health services.

6. Greater understanding, incorporation, and recognition of the knowledge of people with ADHD and the community into future guidelines development. This should include greater consultation of people with lived experiences.

The Role of the NDIS in Supporting people with ADHD

1. The NDIS recognise ADHD in its list A and B conditions.

2. NDIA obtain and publish expert medical advice about the inclusion of ADHD on List A or B. That advice should consider the different diagnostic criteria for those aged under and over 17 years of age.

3. The NDIA should use its powers in s 6 of the NDIS Act to provide support and assistance, including financial assistance, to prospective participants.

4. ADHD professionals, advocate and other making representations to the NDIS need to be clear that the condition is lifelong. This is to enable access to early interventions with children to reduce the lifelong impacts of ADHD.

5. NDIA ensure that children are not caught between systems and assist parents of children with ADHD to get the supports their children need within educational settings.

Gender bias and ADHD

1. That health professionals, educational institutions and professionals in the justice system be trained to better recognise the different presentations of ADHD in women and provide appropriate support.

2. That research be conducted into the intersectionality of gender and disability discrimination, to promote a better understanding of the societal factors leading to the incarceration of women with ADHD.

3. That longitudinal studies be funded and conducted to examine the female experience of living with ADHD and the impact this has on daily life inclusive of mental and physical health (e.g. side effects of medication), career and relationships.

4. That media and public education campaigns promoting positive representations of women with ADHD be facilitated and incentivised, to empower women and girls with ADHD to not feel held back by their diagnosis in terms of their life plans and aspirations.

5. There is an urgent need for research determining the safety of continuing ADHD medication while trying to conceive and while pregnant.

3. Children with ADHD in Out of Home Care

3.1 Children with ADHD in out of home care

As of 2021 there were 46,200 children in out of home care.[1] The prevalence of ADHD amongst children in out of home care is thought to be higher than that in the community, however further research is required. There are many intersectional issues facing children in out of home care, including poverty, trauma, and disability.

3.2 Criminalisation of children with ADHD in out of home care

Criminalisation of disability is an insidious problem which is not limited to ADHD. Children in out of care homes with disability are at a far greater risk of having their disability criminalised. In the out of home care setting children who display ADHD behaviours are often treated as misbehaving leading to higher rates of disciplinary action and school exclusion. This predisposes at risk children to greater contact with the criminal law system and ultimately imprisonment, as recognised in the recent *Research Report – Care Criminalisation of Children with Disability in Child Protection Systems* to the Disability Royal Commission (DRC).[2] This correlates with Your Story and Legal Aid NSW's experience of working with young people in out of home care.

The report made to the DRC brings together much of the contemporary research both within Australia and overseas exploring the intersection point between ADHD, out of home care and criminalisation of children.[3] Your Story recommends the Senate refers to this report for guidance. For ease we have highlighted below some of the key information:

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[1] Child protection Australia 2020–21, How many children were in out-of-home care? - Australian Institute of Health and Welfare (aihw.gov.au).

[2] Baidawi, S., Ball, R., Newitt, R., Turnbull, L., Kembhavi-Tam, G., Avery, S., & Sheehan, R. (2022). *Research Report – Care Criminalisation of Children with Disability in Child Protection Systems*. Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.

[3] Ibid.

- Children who had ADHD and involvement with child protection were 50% more likely to have contact with the criminal justice system.
- Some studies found children with ADHD were more likely to be involved in violent or serious offending.
- There is a link between school suspension and other school infractions and arrest or contact with the criminal justice system. This is concerning with 56% of students in out of home care with ADHD experiencing school exclusion.
- Criminalisation of children though punitive responses to disability behaviour is a common pathway to the criminal justice system.
- Delayed ADHD assessments of children lead to worse outcomes in the criminal justice system.
- Maltreated children with ADHD had increased contact with the justice system of up to 60%, compared to 16% of non-disabled maltreated children.
- Positively when support was given with schools' better outcomes were achieved. Children who got an assessment of special education found a 40% decrease in involvement with the justice system.

3.3 Children in the prison system

Children in the justice system are particularly vulnerable to abuse and exploitation. Criminalising ADHD behaviours at a young age can have outsized impacts on a person's life. Your Story is particularly concerned that children are being undiagnosed and going untreated and through a series of failures in the education system and care systems are landing within the criminal justice system.

Case Study: Public Hearing 27 of the Disability Royal Commission examined conditions in detention in the criminal justice system.

During the public hearing evidence was provided by the parents of a child, Aaron, who began coming into contact with police at the age of 12 as a result of behaviour that was directly related to his ADHD. When Aaron was remanded in custody his parents tried to tell the youth detention centre staff about his disability and medication needs. However, he was not provided with some of the medication that his parents indicated he needed for his conditions. Two weeks after being remanded in custody, Aaron was sexually assaulted. His parents gave evidence about how poorly the aftermath of the assault was handled, and the trauma this event continues to have on both themselves and their son.

Aaron's father, Terry, stated:

> 'It was a very difficult time for both him and ourselves. There were very – we tried to provide the prison with all information regarding his diagnosis of ADHD and autism and the medications that he was on, and also supply what medication we had to the prison so that he could start and continue, obviously, with the medication regime that he was on. We were informed, obviously, that medication would not be given in prison because of the type of medication and that he would only have his medication that he would be given at night, which was the clonidine.'

When asked about any information he was given as to the process for getting back on medication, Aaron's father gave evidence that 'there would only be the Clonidine that would be given at night and no other medication. And no program or consultation with anybody as to an alternative medication that he could have.'

Concerningly, Aaron's medication was not tapered off and nor was he afforded any medical supervision when this medication was discontinued. His father observed that after coming off the medication Aaron became very withdrawn, that his behaviours escalated, and that it would have been very difficult for him to understand what was expected of him without his medication.

4. ADHD and the Criminal Justice System

4.1 Criminalisation of ADHD

Some of the attributes of ADHD, such as poor impulse control, emotional dysregulation, and risk-taking behaviours, if unsupported or unrecognised can lead to a criminalisation response from the criminal justice system. At present, there is no diagnosis, medication, or treatment for people with ADHD within prisons. There is no continuity of care in prison, and this severs the connection with treating teams that a person with ADHD may have had in the community prior to incarceration.

Globally, it is estimated that 33%-41% of young people in detention had ADHD and 25% of adults. In Australia, surveys vary with between 17% and 35% of prisoners meeting some criteria for ADHD.[4] This is thought to be an underestimation given the broader under diagnosis. In the experience of Your Story and Legal Aid NSW the actual numbers or prisoners with ADHD are likely to be significantly higher, particularly in women.

A study in Western Australian found that boys were two and half times more likely and girls three times more likely to have contact with non-custodial community corrections if they had ADHD. Girls are seven times more likely and boys two and half times more likely to receive a custodial sentence than their non-ADHD peer's.[5]

It is likely again rates are underestimated as it is known that medication and treatment are effective in 80% of diagnosed cases and it is known that treatment and support can radically reduce negative outcomes. The impact of this is that offending and other criminalised behaviours likely occur in a population with a greater chance of having undiagnosed and untreated ADHD. Other studies identified self-reported amounts in the criminal justice figures can be higher at more than 40% of the population.[6]

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[4]Lane, Corey J, and Chong, Mark David (2019) A hard pill to swallow: the need to identify and treat ADHD to reduce sufferers' potential involvement in the criminal justice system. James Cook University Law Review, 25. pp. 119-136.

[5]Ibid.

[6]Ibid.

Once imprisoned people with ADHD spend longer in jail due to lack of support and treatment within jail. Recidivism rates for people with ADHD are higher and reoffending occurs by two and a half more quickly.[7]

Imprisonment can prevent treatment, support and receiving a diagnosis of ADHD. Long wait times for diagnosis and treatment are additional barriers for prisoners to receive the necessary support and may reoffend before obtaining medical intervention.

ADHD by its nature makes engaging with services considerably more challenging. This may contribute to people missing parole requirements, unintended breaches of bail and failure to engage with available support. This increases the likelihood of reoffending and compromises reintegration to the community.

Your Story is not suggesting causation, in that ADHD symptoms cause criminal offending. Rather, the justice system criminalises and punishes people with these traits through its poor responses that are not fit for purpose. This amounts to a failure of care and an affront to the rights of people with ADHD who fall through the cracks as a consequence.

4.2 Medication and supports

Your Story strongly supports ADHD medication being provided to prisoners in a safe and controlled manner. Consideration could be made to medication being given in an injectable form. This could help to prevent it from being sold on by the prisoner as well as preventing other prisoners from standing over or stealing the medication from prisoners with ADHD. This medication should be supported by counselling, coaching and education to give the person the best chance as success.

[7]Philipp-Wiegmann F, Rösler M, Clasen O, Zinnow T, Retz-Junginger P, Retz W. ADHD modulates the course of delinquency: a 15-year follow-up study of young incarcerated man. Eur Arch Psychiatry Clin Neurosci. 2018 Jun; 268(4):391-399

Case Study: 'Tom'

Tom is a Your Story client in his early 30s, who a submission to the DRC.

Tom was diagnosed with ADHD as a child and placed on medication which he found useful and helpful. However, when he was about 16, he was told he no longer needed the medication by a doctor and was taken off all supports. After this school became hard and he began to have behavioural issues. He couldn't focus on anything and nothing seemed to go right at school with his grades plummeting. Around this time, he started using drugs; marijuana at first but also later ice and speed. He found that whilst other people got high and enjoyed the drugs, he found he reacted differently and that they levelled him out. He now believes he was self-medicating.

He tired many times to do different things. He knew he had a lot of potential; knew he could do more and tired very hard many times to go back and study. But he just couldn't seem to finish anything or finalise anything. He tried to get jobs but couldn't manage to hold anything down. He stated that he had just had so much trouble listening and remembering things. In the end it became so dispiriting for him that he gave up and felt it was better to not try at all than try and keep failing.

He tried to see a psychiatrist, but the waitlist was so long that he couldn't get in and couldn't get access to help before he was reincarcerated. The client lives in a regional area and services are limited. He tried for 2 years but could not find anyone who could help him. He also applied for NDIS but got knocked back and could not work out how to navigate the system.

Within jail he has no support for ADHD and no medication. Tom reports that he cannot even get someone to talk to him about ADHD as it is not seen as important. The corrections staff treat him poorly because of the ADHD. He feels that he is perceived as deliberately difficult when he forgets things or doesn't listen, and that the corrections staff view his behaviours as insubordination or deliberate and treat him as a troublemaker.

5. The Law and ADHD medication and treatment

The law that governs ADHD medication is currently a patchwork across the various states and territories. Your Story strongly recommends reforms in this area to improve the experience of people moving across jurisdictions, access to medication and reduce the administrative burden on people with ADHD.

The following table outlines the current legislation across jurisdictions in relation to ADHD and medication as well relevant other resources.

Jurisdiction	Legislation	Resources
Federal	• *Therapeutic Goods Act 1989* (Cth) • Therapeutic Goods (Poisons Standard—June 2023) Instrument 2023 (Enabling Act: *Therapeutic Goods Act 1989* (Cth))	• Controlled Substances List (*Dpt of Health and Aged Care – Office of Drug Control*) • The Poisons Standard • TGA and The Poisons Standard
NSW	• *Poisons and Therapeutic Goods Act 1966* (NSW) • *Poisons and Therapeutic Goods Regulation 2008* (NSW)	• NSW Health • NSW Health 2 • NSW Health FAQ • Prescribe a psychostimulant medication
ACT	• *Medicines, Poisons and Therapeutic Goods Regulation 2008* (ACT) • *Medicines, Poisons and Therapeutic Goods Act 2008* (ACT) • *Medicines, Poisons and Therapeutic Goods Controlled Medicines Prescribing Standards 2021 (No 1)* (ACT)	• Controlled Medicines | Health (act.gov.au)
VIC	• *Drugs, Poisons and Controlled Substances Act 1981* (Vic) • *Drugs, Poisons and Controlled Substances Regulations 2017* (Vic)	• Stimulants for ADHD - Permit Requirements • Schedule 8 Treatment Options

	• *Therapeutic Goods (Victoria) Act 2010* (Vic)	
QLD	• *Therapeutic Goods Act 2019* (QLD) • *Therapeutic Goods Regulation 2021* (QLD) • Medicines and Poisons Act 2019 • *Medicine and Poisons Regulations 2021* (QLD)	• QScript | Health and wellbeing | Queensland Government (www.qld.gov.au)
TAS	• *Poisons Act 1971* (Tas) • *Poisons Regulation 2008* (Tas)	• Forms and guidelines for doctors | Tasmanian Department of Health
NT	• *Medicines, Poisons and Therapeutic Goods Act 2012* (NT) • *Medicines, Poisons and Therapeutic Goods Regulations 2014* (NT)	• Medical practitioners and schedule 8 medicines | NT Health
SA	• *Controlled Substances Act 1984* (SA) • Regulations	Prescribing medicines and drugs: Regulations and requirements | SA Health Prescribing drugs of dependence | SA Health
WA	• Medicines and Poisons Act 2014 • Medicines and Poisons Regulations 2016	Medicines and poisons (health.wa.gov.au)

5.1 Australian legislative regime

As can be seen above there are variety of pieces of legislation, regulations, and resources across each jurisdiction. Some States and Territories have provided more information and support than others to the general public. This patchwork legislative approach is complex and confusing for even lawyers to fully understand let alone health professionals and people with ADHD. There should be a standardised national approach which is seamless for both health professionals and users.

Currently there is no uniformity between jurisdictions on any of the following:

- The differences between what is prescribed to children versus adults,
- The requirements for drug dependant adults,
- The amount of medication that is dispensed at one time,
- The length of time a prescription is valid for,
- Dosage amounts per Mg for each medication,
- The procedural steps health professional must complete when prescribing.

5.2 Moving between jurisdictions

At present each jurisdiction has its own rules which differ from on another when it comes to dispensing prescriptions issued in other jurisdictions. Currently only Victoria and the ACT offers interstate prescriptions to be filled but with some restrictions, there is also some limited dispensing from interstate in South Australia. This means that someone who moves interstate may have to go through a costly and time-consuming process of getting a new psychiatrist and prescription. This incompatibility prevents telehealth and other virtual health supports for people who may have a long term and trusted relationship with a health professional.

This creates gaps which vulnerable cohorts and people from lower socio-economic backgrounds may fall through. This could result in people having periods of being medicated and supported right at a difficult and stressful time of moving interstate. This needless bureaucracy adds a further an administrative burden which is precisely the type of work that people with ADHD struggle with.

6. Adequacy of Access to ADHD diagnosis, supports and medication after assessment

Your Story has heard from clients and staff who continue to face significant barriers to seeking diagnosis, treatment, and support. The wait times are extensive with people waiting often 18 months or more, and the costs can reach many thousands of dollars which is simply unaffordable for many people. There is a particular shortage of professionals who can diagnose the condition in regional and rural areas. Once diagnosed the cost of medication can also be high. Moving between jurisdictions requires obtaining a new prescriber, development of a new relationship and leads to further costs being incurred. Your Story and Legal Aid clients often have several intersectional challenges including poverty, domestic violence, and other health issues, these can have significant additional barriers to seeking treatment.

Your Story strongly supports a Hub and Spoke Model in which a central health professional, likely a GP (the Hub) co-ordinate the services (the spokes) for the person with ADHD.[8] This could be to help refer and recommend a psychiatrist for initial diagnosis and medication, psychologists, and counselling for comorbid conditions, such as depression or anxiety, and referral to coaching or support groups. A hub and spoke model would help to alleviate the difficulty that many people with ADHD have with organisation and administration when it comes to seeking support.

A common theme among our clients and staff is the shame felt from seeking a diagnosis and help. There is a significant amount of stigma and misunderstanding about ADHD in the community that needs to be corrected. Many have faced discrimination and mistreatment at school, in employment and in the wider community. Education, advocacy, and greater awareness all need to be combined to remove the stigma and combat discrimination. Public awareness and media campaigns have an important role to play.

[8] Elrod, J.K., Fortenberry, J.L. The hub-and-spoke organization design: an avenue for serving patients well. *BMC Health Serv Res* 17 (Suppl 1), 457 (2017).

Case Study: "Sam"

Growing up Sam felt as if she couldn't succeed at things and was prone to emotional blow ups. After discovering ADHD through a friend Sam sought help and was diagnosed in her early 20s. She found the diagnosis process took about 6 months but during covid her psychiatrist stopped practicing and it took another 6 months for her to see a psychiatrist and most places gave her a wait list of 2 years or turned her away.

Sam was diagnosed later in life and her treating psychiatrist told her males were typically diagnosed early in life as they were overactive and would have fits such as throwing chairs and things that are more associated with the hyperactivity side of ADHD whilst girls are often a lot more quiet and presented differently.

She still to this day feels uninformed about her condition, and what her legal rights are.

She finds the medication expensive, and it is not one size fits all. This means that it can take time to find the right medication type a dosage, short acting versus long acting. Each time she needs to buy a new prescription of 30 pills and these costs with each test adds up. People with ADHD need to keep paying to see a psychiatrist when getting the medication correct and for at least a year after that until you can be prescribed by a GP. Her sessions are $200 each and this quickly adds up.

Sam has faced discrimination in the workplace both to do with her performance and when she informed her employer about her diagnosis it did not go well. She was not offered any supports, follow ups or acknowledgement. This interaction made her feel terrible and ultimately regret disclosing it in the workplace.

Sam would like more supports that are easily understood, accessible and greater understanding broadly in society and by employers.

Case Study: “Magnus”

Magnus is someone who struggled for many years with mental health issues. He often struggled with employment, education, and many life things. He was dragonised with ADHD late in life and prescribed with Vyvanse. He was diagnosed in March or April of 2023, within in a few months he began to develop strange thinking. During this time, he was also smoking a lot of cannabis.

His consultations were almost all virtual either over the phone or online. By May to June, he developed serious negative symptoms and psychosis. His mental health began to deteriorate, and he developed psychosis. Ultimately, he had to be hospitalised after a call to the ambulance by his mates. He has been now diagnosed with bi-polar but prior to his medication he had no symptoms.

Magnus believes that the doctors should have taken far more care in his diagnosis and his ongoing treatment. He feels he should not have been left to become so unwell and that the doctors should have asked basic questions about his life. Psychosis whilst rare was a known side effect of the medication and there should have been more awareness about the risk of this impacting him, including by establishing if other substances were being used. Magnus feels incredibly let down by his treatment and it has set him back a long way, he lost his job and his house, and he has moved back in with his parents.

7. The Australian ADHD Professional Guidelines

Your Story has reviewed the AAPA guidelines and broadly endorses the recommendations outlined. These guidelines appear to be a significant improvement on the current treating regime and if implemented would greatly improve the experience of people with ADHD. Your Story has provided critiques and suggestions for future guidelines, research and change outlined below.

7.1 AAPA Guideline Recommendations

Your Story strongly agrees with the following recommendations:

- Identification of at-risk groups which require extra attention and resources by policy makers. Notably children in out of home care and prisoners.
- Approach to diagnosis and strongly encourages the improvement of information given to people with ADHD after diagnosis as a priority area.
- Treatment recommendations, in particular the holistic wrap around care and patient centred healthcare that empowers people with ADHD Access to care people in correctional systems.
- Culturally appropriate and safe treatment for Indigenous peoples
- All of recommendations for policy change and further research.

7.2 Criminalisation

The wording of the report suggests that prison is causal for ADHD or that ADHD may cause people to commit crimes. We believe it is essential to stress that ADHD may be criminalised by educational institutions, out of home care and the criminal justice system. This framing is important as it shows that neither prison causes ADHD nor is there something inherently criminal in the ADHD experience. This criminalisation is a result of a failure of treatment and support. It is important to get this wording correct so as not to perpetuate unhelpful stereotypes and a history of criminalising disability.

7.3 ADHD Strengths

This guideline ADHD focuses mainly on mitigating the weakness and disabling elements of ADHD, which is undoubtably a good thing, but this does not go far enough. There is a growing body of evidence exploring the numerous strengths, abilities, and positive aspects of people with ADHD.[9] There needs to be improved recognition of the many strengths of ADHD. ADHD has many features such as ability to generate novel ideas, hyperfocus, energy, ability to make connections that are noted strengths. Guidelines should be developed to highlight these strengths and promote them. This can be implemented within educational settings, by health care providers and become part of the holistic hub-spoke model of care and support. Removing barriers is not enough the strengths of ADHD must also be promoted and nurtured so that people with ADHD can live to their full potential.

7.4 The History of ADHD

The history of the treatment of ADHD in Australia is chequered with abuse, control, and othering. Like many other forms of neurodiversity and disability, ADHD has been framed as a problem, burden, or deficit in need of 'fixing'. It is important to recognise the history so that the frameworks used to treat ADHD in the past are discarded and not renamed or recreated. This submission would like to draw attention to the persistent paradigm of the medical model as the lens with which ADHD has been viewed.

ADHD has had a long string of names since it was first described in 1902. ADHD like symptoms have been recorded in historical records over thousands of years.[10] It was generally recognised as a behavioural disorder of childhood, but it was only in the 1990's that it became widely acknowledged that symptoms of ADHD persisted into adult life.

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[9] Sedgwick, J.A., Merwood, A. & Asherson, P. The positive aspects of attention deficit hyperactivity disorder: a qualitative investigation of successful adults with ADHD. ADHD Atten Def Hyp Disord 11, 241–253 (2019).

[10] Martinez-Badía J, Martinez-Raga J. Who says this is a modern disorder? The early history of attention deficit hyperactivity disorder. World J Psychiatry. 2015 Dec 22;5(4):379-86.

The dominant narratives through the different editions of the Diagnostic and Statistical Manual of Mental Disorders (DSM) has been to view the features of ADHD as a set of symptoms to diagnose and treat, this submission contends that much of these challenges faced by people with ADHD stem from inaccessibility and barriers to justice rather than as problems inherent to the children or adults themselves.

Your Story supports the social or rights-based model, removing barriers to education, employment, mental and physical health treatments, the intersecting barriers to assistance faced by people from low socio-economic backgrounds and addressing the criminal legal system's persistent under-acknowledgment on effects on behaviour.

7.5 Challenges and stigma

This submission supports research into challenges faced by people with ADHD. Your Story's work has heard from our clients about the extent of discrimination and abuse of those engaging with health services. Future guidelines should examine ways to address stigma, substandard care, and disengagement with health services by engaging with affected communities and individuals. In Your Story's experience, this would need to include systemic advocacy for attitudinal change and a commitment to practical support in diverse areas of life.

7.6 Greater incorporation of people with ADHD

This submission contends that future editions of the guidelines reflect the experiences of those with ADHD to incorporate a rights-based approach to treatment, shifting the paradigm from the medical model.

Your Story have heard the voices of those with ADHD through our work assisting people to the Disability Royal Commission. We heard from people who have felt unheard and confused as to where to seek help. Engaging with people is key to development of future guidelines and accessible forms of healthcare, employment, education, and justice. The focus should be on removing barriers to the same extent as the individual is to be treated.

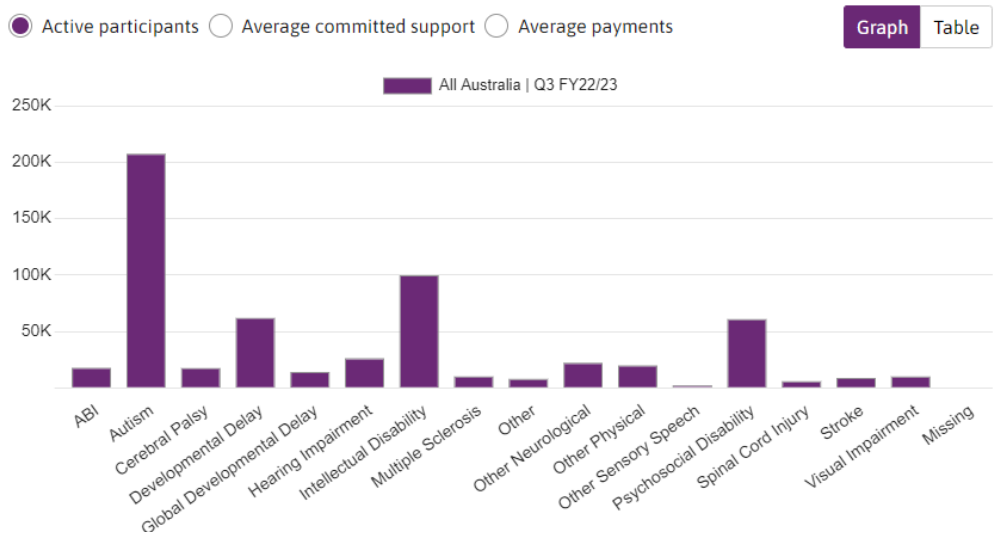
8. The Role of the NDIS in Supporting people with ADHD

Legal Aid NSW has made several submissions about the NDIS to various bodies and inquiries.

Under the *National Disability Insurance Scheme Act 2013,* there is no concept of a primary or secondary disability. Access to the NDIS is based on an assessment of the impairment or impairments that a person experiences to their intellectual, cognitive, neurological, sensory, or physical functioning. It is not the case that ADHD is excluded or included from the NDIS, access decisions are made on a case-by-case basis by primarily assessing the permanency of impairments and their impact on a person's functioning.

However, the following issues contribute to an overall impression that ADHD is not covered by the NDIS or needs to be recognised as a primary disability. Firstly, the NIDA do not report on the number of participants in the Scheme with ADHD. Figure 1.0 outlines the categories of impairment they do report on:

Figure 1.0 – Graph of NDIS reported impairments.



Numbers of participants with ADHD may be recorded under 'other neurological' or in a category for another condition the participant has, for example, autism.

Secondly ADHD is not included in the NDIA's List A and B conditions. List A outlines conditions that are likely to meet the disability requirements, and List B are conditions that are likely to result in a permanent impairment (satisfying part of the requirements for access to the Scheme).

Thirdly It's common for people seeking access to the NDIS to do so on the basis that ADHD is among other diagnoses contributing to a neurological or psychosocial impairment. This means it is rare for the Tribunal to assess the impact on a person's functioning from ADHD alone. For reference, *Gardner and National Disability Insurance Agency* [2023] AATA 1287, where the applicant experienced major depressive disorder, ADHD and obsessive-compulsive disorder, or *Ray and National Disability Insurance Agency* [2020] AATA 3452, where the applicant experienced autism spectrum disorder, ADHD, anxiety, and depression.

8.1 ADHD as a permanent impairment

Historically, there was a view that ADHD was a diagnosis that would remit or recede by adulthood in most people. This has been disproven and yet there are still some healthcare providers who find themselves unable to say whether a child experiencing ADHD in childhood will continue to experience it in adulthood. This impacts prospective participants (other than children under six years of age with a delay in their development) as they are required to show that their impairments are permanent, even if they are seeking early intervention supports to reduce the impact of their impairments and need for future supports.

For access under the early intervention requirements, a person must show their impairments are permanent and that supports now will reduce their future needs for care in relation to disability. If doctors are not informed of this distinction, or NDIA decision makers are inflexible about how they interpret information they receive from doctors, it can lead to people with ADHD being incorrectly excluded from the NDIS. This is on the basis that the early intervention support they need is incorrectly understood to be treatment capable of remedying an impairment.

Many children with ADHD the impacts of their impairments are felt most in learning environments. For early intervention participants (s 25(3) NDIS Act) as well as in all

decisions to approve statements of participant supports (s 34(1)(f) NDIS Act) there is a requirement to show that support is most appropriately funded by the NDIS and not by another system, including early childhood development and school education systems. For the school education system, r 7.13 excludes supports from the NDIS that are "primarily related to education or training attainment" and notes that "any supports funded by the NDIS will recognise the operational requirements and educational objectives of schools": National Disability Insurance Scheme (Supports for Participants) Rules 2013 r 7.13. While the rules reflect the principle that the NDIS is not designed to replace all systems for people with disability, it's important that they don't result in people with disability being caught between systems and unable to receive support from either. This involves decision makers considering what is actually available under early childhood development and school education systems: Burchell and National Disability Insurance Agency [2019] AATA 1256 at [34]-[36].

9. Gender Bias and ADHD

Your Story has heard from women with ADHD and the impact that sexism and gender bias has on women. Women with ADHD are far less likely to be diagnosed correctly, receive a diagnosis far later than their male counterpart, less likely to be treated and receive less support. Women with ADHD often present differently to the stereotyped appearance of ADHD and do not reflect the male biased body of medical knowledge on ADHD. There is an urgent need for increased research which is specific on the female experience of ADHD, the impact on women of ADHD medication and difference on women over their life span.

Case Study: "Margaret", a client with ADHD who is currently in prison.

I was diagnosed with ADHD as a child and still suffer from it. People don't consider that ADHD can hold you back and that in a correctional centre setting it is not recognised as a disability or impairment, so you have no access to medication. Out in the community I have access to my medication which helps me function but whilst I am incarcerated, I have no access to my medication. This means I can't focus on topics/jobs, and I have brain fog.

When I look around in here, I see that quite a few people may suffer from ADHD as I do. When people have outbursts and can't self-regulate because of possibly suffering from ADHD and not being able to be properly medicated, they are punished/charged which can set them back even further.

ADHD needs to be recognised more. I had access to my medication in the community yet when I came into prison the staff said, 'sorry no medication here for that, there's nothing we can do about it'.

A lot of people have invisible disabilities. My son was diagnosed with ADHD as a child and was on proper medication which helped him to concentrate at school. Now he is an adult and GP's, who have poor awareness because we are in a regional location, often won't give him the medication he needs to do well. I can see that he is struggling because local GPs are not well informed about ADHD and are reluctant to prescribe him the medication. Maybe they think he will misuse it or sell it, but the fact is, he needs it to do well in his life.

I have also noticed that a lot of female inmates suffer from ADHD. They go unmedicated and in some instances, undiagnosed, this needs to be addressed because people will seek to self-medicate via illegal means and this creates recidivism in itself.

I also think the mental health system in prison could be better. I've had different experiences in a regional prison – no easy access to counsellors or psychologists. City prisons have much better systems, it is much easier to access mental health support when you need it. When I was at another prison, they had psychologists in the education block, and you could walk in and make an appointment. Then you would be able to see someone quickly. Here it is difficult to get access to counselling. I hear this from other female inmates too. There is a gap in rural prisons with no psychiatrists at all as well.

Case Study: Misha

Single mother – regional NSW. Diagnosed with ADHD as an adult.

Misha struggled since primary school with anxiety and making friends and relationships my entire life. From a young age she was told there was something wrong with her, and was told she was lazy and naughty, and was choosing not to listen or do anything. I was labelled a “problematic kid”. She struggled with tasks, like cleaning her room.

Misha struggled at school and broke rules. Her life became challenging and eventually she became homeless and lost custody of her children ending up with a criminal record. She believes she self-medicated with methamphetamine. When she was using meth, she could have conversations without forgetting things, complete tasks and not be overwhelmed on a sensory level.

Micha was diagnosed with depression in 2009 and later was misdiagnosed with borderline personality disorder (BPD) after a parenting capacity and mental health capacity assessment. The assessment focused on the drug use, even though she had been clean for years by that stage. The assessment did not look at the underlying cause or take a complete history. It did not acknowledge I had been sexually assaulted and experienced domestic violence. These experiences had significant impacts but now in hindsight did not match BPD.

Misha was medicated for BPD, but it did not work, because that was not the correct diagnosis. Her mental health really deteriorated and eventually she self-referred and engaged with a mental health acute care team. It was here that a psychiatrist indicated she did not have BPD and raised the possibility of ADHD, explaining it presented differently in women, with hyperactivity less common.

Misha Said

> ‘I knew I was trying my best, but I had always been told I was not a good enough mother or person. I got labelled and it stuck. It damaged me, my children and all my relationships.’

It took Misha about 3 years to get a formal diagnosis of ADHD and she had to go to a private psychologist to get a diagnosis, because it takes time. It was too important to her

to just wait for public health.

The only way she could afford it was to live somewhere where the person did not expect her to pay rent. Micha used that money to see a private psychiatrist and have an assessment.

Misha felt she got an answer with her diagnosis but not a solution. Child Safety told her that they do not recognise ADHD as a disability. Despite her efforts the DSP did not really recognise it and the NDIS do not recognise it. She has trouble still with her ability to work and she feels very tired when she stops taking the medication. She feels alone and without adequate supports. Much of the education she has done about ADHD she has done herself without much support.

As a single parent and the medication cost Misha a lot; $50 every 3 weeks.

Misha states:

> ‘My struggle with ADHD has caused me other health issues and left me more likely to have other conditions and problems in later life. The self-medication from my younger years (drink and drugs) have taken a toll on me physically and damaged all aspects of my life.’