



**Carers Tasmania's Submission on the
Development of the National Autism Strategy**

October 2023



About Carers Tasmania

Carers Tasmania is the Peak Body representing the more than 80,000 informal carers (hereafter carers) in the state.

Carers Tasmania's vision is for an Australia that values and supports carers.

Our mission is to work to improve the health, wellbeing, resilience and financial security of carers and to ensure that caring is a shared responsibility of family, community, and government.

Our values drive everything we think, say, and do.

- **Carers first** – we listen to what carers need, commit to their desired action plan, and deliver results that matter most to carers
- **Care in all we do** – we care for our work, about each other, about Tasmania's family and friend carers, and the bigger world we all share
- **Integrity always** – we are transparent, act ethically, own when things don't go to plan and do what we say we will
- **Quality every time** – we don't accept 'good enough' because carers deserve our very best every time
- **Speed that matters** – we are agile and don't put off what can be done today.

These values represent how we engage with and serve carers, how we work with each other, and our commitment to the broader community. Carers Tasmania encourages partnership with governments and health and community sectors to enhance service provision and improve conditions for family or friend carers through policy development, research and advocacy.

We acknowledge and support people of all genders, sexualities, cultural beliefs, and abilities and understand that carers in Tasmania, whilst sharing the common theme of caring for a family member or friend, are diverse individuals with varying beliefs, experiences, and identities. We value and respect the diversity of carers, their lived and living experiences, and recognise that carers are the experts in their own lives.

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1. Background

Carers Tasmania is the Peak Body representing the more than 80,000 informal carers within the state.

A carer is a person who provides unpaid care and support to a family member, or friend, with disability, mental ill health, a chronic or life-limiting condition, alcohol or other drug dependence, or who is frail or aged. Informal kinship carers who care for a child under the age of 18, because the parent is unable to, are also recognised as carers. Carers are predominantly family members, but may also be friends, neighbours, or colleagues. Informal carers are not to be confused with paid support workers who are often called 'carers', with the difference being that support workers are fully employed and remunerated with all the benefits of employment. On the contrary, informal carers perform their caring duties without remuneration, other than minimal carer payments and allowances from the Australian Government.

In addition to representing carers through the Peak Body activities, Carers Tasmania provides support to carers living in Tasmania through its service delivery arm, Care2Serve. The Commonwealth Carer Gateway program is delivered through Care2Serve in Tasmania, as are other supports and services, such as the Tasmanian Government's Home and Community Care program.

The Carer Gateway program provides a range of services and supports for carers which are designed to build resilience, increase wellbeing, improve quality of life, and sustain carers to effectively continue their caring roles. The available supports include the provision of information, advice and referrals, holistic identification of carer strengths and needs through a carer support planning process, professional counselling, peer support, and coaching which aims to support carers in achieving specific goals.

Care2Serve, through the Carer Gateway, has capacity to fund certain instances of planned, practical support services such as in-home respite, personal care, domestic assistance, and meal preparation. Care2Serve may also fund items such as laptops to assist carers who are studying or trying to enter the workforce. Care2Serve also coordinates the provision of emergency support during instances where a carer may be unable to provide the care that they usually do, resulting from unexpected illness or injury of the carer.

2. Introduction

Carers Tasmania welcomes the opportunity to provide feedback on the ‘*Developing the National Autism Strategy Discussion Paper*’ (the Discussion Paper).¹ The development of a National Autism Strategy has been long-awaited, and this is an incredibly important opportunity to help shape a more positive and inclusive future for Autistic people across Australia and the Autism community who support them.

Throughout this response, we use the following language, as adopted by Autism Tasmania. Autism Tasmania promote the use of this language, as it has been guided by the advice of the Autism Cooperative Research Centre, and feedback from their members:

- Autistic person/people
- Autistic community (this refers collectively to Autistic people)
- Autism community (this refers collectively to the friends, carers, and family members of Autistic people).²

Furthermore, it is important to clarify that the term ‘carer’ is referring to any person who is providing support to a family member or friend who:

- a) has disability; or
- b) has mental ill health; or
- c) has a chronic or life-limiting condition; or
- d) has alcohol or other drug dependence; or
- e) is frail or aged; or
- f) is a child, if the person is an informal kinship carer of the child.³

In 2018, it was estimated that there were approximately 205,200 Autistic Australians,⁴ however, this number is increasing, with NDIS data from June 2023, reporting that 214,880 people with an active NDIS plan had Autism listed as their primary diagnosis. Of these, 78% were aged 18 or under, and 70% identified as male.⁵ Despite the proportion of Autistic people being supported by the NDIS, they continue to have significantly poorer life outcomes compared to other Australians. This indicates that the NDIS isn’t, and shouldn’t be, the only support for Autistic people. All Autistic people and their carers should be able to access the services and support they need.

It is estimated that two to three percent of Tasmanians are Autistic. This equates to between 11,400 and 17,100 people.⁶ This means that a large proportion of people in Tasmania are either Autistic, are a carer supporting someone who is Autistic, or know somebody who is Autistic.

Autism is common in families, often leading to multiple people within the same family being Autistic. Furthermore, it is common for Autistic people to experience other co-morbid

¹ Australian Government. (2023). What we have heard: Moving towards development of a National Autism Strategy Discussion Paper. <https://engage.dss.gov.au/wp-content/uploads/2023/09/national-autism-strategydiscussionpaper2.pdf>

² Autism Tasmania. (2021). Autism Tasmania Position Statement – Terminology Policy. <https://www.autismtas.org.au/wp-content/uploads/2021/04/Autism-Tasmania-Position-Statement-Terminology-September-2021.pdf>

³ *Tasmanian Carer Recognition Act* (2023). <https://www.legislation.tas.gov.au/view/whole/html/inforce/2023-04-20/act-2023-001>

⁴ Australian Bureau of Statistics. (2018). Survey of Disability, Ageing and Carers– Autism in Australia. <https://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/4430.02018?OpenDocument>

⁵ NDIS. (2023). Participant Dashboards. Autism. <https://data.ndis.gov.au/media/3817/download?attachment>

⁶ Australian Bureau of Statistics. (2018). Survey of Disability, Ageing and Carers– Autism in Australia. <https://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/4430.02018?OpenDocument>

conditions such as ADHD, learning or communication difficulties, mental ill-health, intellectual disabilities, sleep issues, epilepsy, oppositional defiance disorder (ODD) & obsessive-compulsive disorder (OCD).^{7,8} Whilst Autistic people tend to experience more significant challenges in some areas compared to non-Autistic people, they also often have significant strengths, skills, and knowledge in other areas.

The Discussion Paper considers four key themes:

- Social Inclusion
- Economic Inclusion
- Diagnosis, Services, and Supports
- The National Roadmap to Improve the Health and Mental Health of Autistic People.

Within each theme, several questions are posed in the Discussion Paper relating to long-term concerns and advocacy aims of Autistic people and the Autism Community.

Some particularly significant feedback is evident in the Senate Select Committee Inquiry report on *Services, Support and Life Outcomes for Autistic Australians*⁹ published in 2022, and more recently in the *Consultation Report from South Australia's First Autism Strategy*.¹⁰ We note that the Discussion Paper provides a list of relevant inquiries and key documents that also outline many of the significant issues raised by Autistic people, the Autism Community, researchers, and other professional and community members. Our submission outlines and reinforces the importance of addressing these ongoing and significant concerns. The strategy must articulate approaches that will address these ongoing issues, and importantly, it requires a collaborative commitment from a national perspective as well as by each state and territory.

3. Overview of concerns

Poor life outcomes for Autistic people

Research indicates that Autistic people have poor life outcomes compared with non-Autistic people. The following significant impacts on Autistic people have been identified by Autism Tasmania:

- High rates of school refusal and low rates of school completion
- Significant rates of underemployment and unemployment
- Extreme rates of mental ill health, including a seven-fold greater risk of suicide
- Poor health outcomes such as a 20 to 36 year gap in life expectancy
- Significant levels of marginalisation and social isolation.¹¹

Furthermore, the recent Select Committee Inquiry found that key challenges resulting in poor outcomes included:

⁷ The Spectrum. (2023). What other conditions co-occur with Autism? <https://thespectrum.org.au/autism-diagnosis/related-conditions/>

⁸ Mandy W, Roughan L, Skuse D. (2014). Three dimensions of oppositionality in autism spectrum disorder. *Journal of Abnormal Child Psychology*. 42(2):291-300. doi: 10.1007/s10802-013-9778-0. PMID: 23860740.

⁹ Commonwealth of Australia (2022). The Senate Select Committee on Autism. Services, support and life outcomes for Autistic Australians. https://parlinfo.aph.gov.au/parlInfo/download/committees/reportsen/024412/toc_pdf/Services,supportandlifeoutcomesforautisticAustralians.pdf;fileType=application%2Fpdf

¹⁰ Government of South Australia. (2023). South Australia's First Autism Strategy Discussion Paper. Consultation Report. <https://yoursay.sa.gov.au/state-autism-strategy>

¹¹ Autism Tasmania. (2023). Autism in Tasmania: State of the State 2023. <https://www.autismtas.org.au/wp-content/uploads/2023/10/StateOfTheState-V7.pdf>

- Low understanding of autism amongst the community and key service providers.
- Delays in accessing a diagnosis and early support
- Complex and poorly integrated service environments
- Services are not designed to meet the needs of Autistic people
- Autistic needs are not effectively being addressed in broader disability strategies and approaches.¹²

Poor wellbeing of carers

There is a growing body of evidence that continues to show that carers supporting Autistic people experience some of the lowest wellbeing levels of all carers. This is likely due to reasons such as:

- Poor access to diagnosis and support
- A general lack of understanding and awareness in the community
- A constant need to advocate particularly within educational and healthcare settings
- An increased need for planning to ensure that things run smoothly
- The provision of additional support
- The need to do some things differently or in a very specific way (eg cooking, cleaning, controlling sensory aspects)
- Experiencing increased social isolation
- Supporting emotional regulation
- Supporting social development
- Management of co-occurring conditions
- Experiencing judgement and stigma from others.^{13,14}

The 2021 and 2022 Carer Wellbeing Surveys, found that carers in the Autism Community supporting an Autistic person were at greater risk of experiencing psychological distress, and loneliness compared with other carers and the general population.¹⁵

Difficulties at school, in healthcare settings, and in the community

Carers of all ages often report experiencing difficulties or their Autistic children in mainstream schools. Autistic people often experience challenges in healthcare settings and when trying to access the community. These challenges have been articulated in responses to various inquiries over the years. More recent inquiries of relevance include the National Trend of School Refusal and Related Matters,¹⁶ the Early Years Strategy,¹⁷ the NDIS

¹² Commonwealth of Australia (2022). The Senate Select Committee on Autism. *Services, support and life outcomes for Autistic Australians*. https://parlinfo.aph.gov.au/parlInfo/download/committees/reportsen/024412/toc_pdf/Services,supportandlifeoutcomesforautisticAustralians.pdf;fileType=application%2Fpdf

¹³ Herrema R, Garland D, Osborne M, Freeston M, Honey E, Rodgers J. (2017). Mental Wellbeing of Family Members of Autistic Adults. *Journal of Autism Developmental Disorders*. 47(11):3589-3599. doi:10.1007/s10803-017-3269-z. PMID: 28861652; PMCID: PMC5633644.

¹⁴ Carers Australia. (2022). *Caring for Others and Yourself. 2022 Carer Wellbeing Survey Full Data Report*. https://www.carersaustralia.com.au/wp-content/uploads/2022/10/2022-CWS-Full-Report_221010_FINAL.pdf

¹⁵ Carers Australia. (2021). *Caring for Others and Yourself. 2021 Carer Wellbeing Survey*. https://www.carersaustralia.com.au/wp-content/uploads/2021/10/211011_Carer-Wellbeing-Survey_Final.pdf

¹⁶ Parliament of Australia. (2022). *The National trend of school refusal and related matters*. https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Education_and_Employment/SchoolRefusal

¹⁷ Australian Government. (2022). *Early Years Strategy*. <https://www.dss.gov.au/families-and-children-programs-services/early-years-strategy>

Review,¹⁸ and the Disability Royal Commission.¹⁹ Carers regularly report that there is simply not enough support, awareness, understanding, or inclusion at school. Carers Australia, in their response to the National Inquiry into School Refusal stated that:

“School refusal is becoming increasingly prevalent. Anxiety attending school, specifically for students with disability, is often a result of a lack of support and inclusivity. Stigma surrounding disability and mental ill health develops from young ages and school environments that do not provide adequate learning support and an inclusive community are at risk of developing hostile environments for these children.”²⁰

In Tasmania, concerns have been raised about the high number of suspensions in Tasmanian schools, particularly for children with disability. A report from June 2023 indicated that approximately 10,000 suspensions were expected across Tasmanian public schools this year.²¹ Furthermore, in 2022, 55% of all Tasmanian public school suspensions were handed down to students with disability, students who identified as Aboriginal or Torres Strait Islander, or students who were in out-of-home care. This is despite research that shows that the occurrence of frequent suspensions can lead to long-lasting impacts on educational outcomes for young people.

Recommendations 7.1 to 7.3 in the Disability Royal Commission Final Report provides further advice on supporting children with disability within the education system.²² In addition, the South Australian Government introduced some specific changes aiming to support more inclusive education for students with Autism including:

- Appointing an Autism Inclusion Teacher in every primary school
- Increasing the number of staff in preschools with qualifications in Autism
- Exploring opportunities to offer more early childhood intervention services in children’s centres
- Supporting schools to sign up to an Autism Friendly Charter
- Providing more specialist staff in schools.²³

These are initiatives that could be evaluated and if deemed successful could be rolled out across the broader Australian education system.

¹⁸ Australian Government. (2022). *About the NDIS Review*. <https://www.ndisreview.gov.au/about>

¹⁹ Commonwealth of Australia. (2023). *Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability*. <https://disability.royalcommission.gov.au/system/files/2023-09/Final%20Report%20-%20Executive%20Summary%2C%20Our%20vision%20for%20an%20inclusive%20Australia%20and%20Recom%20mendations.pdf>

²⁰ Carers Australia. (2023). *Carers Australia response to the Australian Government Senate Select Committee Inquiry into the National Trend of School Refusal and Related Matters*. https://www.carersaustralia.com.au/wp-content/uploads/2023/03/Carers-Australia_Response-to-Inquiry-into-School-Refusal_March-2023.pdf

²¹ The Mercury. (2023). *Tasmanian government schools in crisis*. <https://www.themercury.com.au/tasmania-education/tasmanian-government-schools-in-crisis-as-suspensions-escalate/news-story/c09dbbca3072e914ff8d75d7cc579e31>

²² Commonwealth of Australia. (2023). *Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability*. <https://disability.royalcommission.gov.au/system/files/2023-09/Final%20Report%20-%20Executive%20Summary%2C%20Our%20vision%20for%20an%20inclusive%20Australia%20and%20Recom%20mendations.pdf>

²³ Department for Education South Australia. (2023). *Improving support for children and students with autism*. <https://www.education.sa.gov.au/parents-and-families/student-health-and-disability-support/improving-support-children-and-students-autism>

Carer quote:

“Some teachers try to be supportive, but I think unless they have their own neurodiverse child, they will never truly understand. We just need them to keep trying different ways to connect with our children. They are not being ‘naughty’ on purpose, it’s just that they need a different approach. You can have a learning plan with strategies, but they won’t work for every situation. It’s like if they try a certain strategy and it doesn’t work, then my child is seen as difficult or not doing well. Yes, the teachers are overworked, and they don’t all have disability training, but that’s why there should be better-dedicated resources. It might take some pressure off the teachers, but most importantly those children will feel safer, more included, and supported. Then their strengths can be built on rather than expecting them to behave in the ‘normal’ way.”

Young carers often form part of the Autism Community. A young carer is a person under the age of 25 who provides care for someone with additional needs, such as a parent, sibling, friend, grandparent, or another relative. All children have the right to feel safe and supported at school, regardless of any additional needs. The following email shares a negative experience at school. This situation impacted both the Autistic child and their sibling. After Carers Tasmania staff followed up with the young carer and assisted in addressing their concerns, the young carer provided permission to share their de-identified story.

Email from a young carer:

“Hi, my name is Miss A, and I am a young carer. I care for my younger sister who has both ADHD and Autism.

A few weeks ago at school, my sister was treated very badly by a teacher (this isn’t the first time it has happened), The teacher was calling her an embarrassment and was screaming at her. My sister left the class and tried to speak to another teacher about what had happened, but she shut down and couldn’t talk. My sister then asked to get me (as her sister/young carer/support person) and he said no, knowing that she was almost in tears.

She later messaged me telling me about what was happening, so I went to find her and things got worse to the point where the teacher heard her telling me about what happened and started yelling, telling my sister not to bring me into this and kept following us and making the situation worse. My sister has always been taught in occupational therapy to take herself out of the situation (to the toilet or somewhere quiet) so she did but locked herself in the bathroom stall in tears. The teacher then followed in making things worse. My sister mentioned that she’d had a bad week.

After explaining what has happened, I have a few questions.

- *Are they legally allowed to refuse her wishes for her support person/young carer?*
- *Is there anyone from Carers Tasmania that I can call if this ever happens again?*
- *Are teachers allowed (without permission from that particular kid) to follow into bathrooms when a kid who has autism is having a meltdown/shutdown?*
- *What actions can I take if this happens again? (Any legal actions or just through school).*

Sorry for writing so much, this is just the simplified version.

Thank you for your time, I hope to hear back with some answers to my questions.”

Carers often report frustrating, and sometimes distressing experiences within healthcare settings. These settings can at times be overwhelming places for Autistic people. Healthcare settings, including hospitals, can be busy, bright, noisy, and stressful places. It can be difficult to feel comfortable with medical professionals who are time-poor and focused on treating the presenting issue. They don't have the capacity to build rapport or try to gain a more holistic understanding of a person's circumstances.

The following example was provided to Carers Tasmania whilst seeking feedback from carers about the draft Tasmanian Carer Recognition Bill, now the *Carer Recognition Act 2023* (Tas).

Healthcare setting case study:

Mr. B is a single father caring for his 9-year-old Autistic son. His son has an NDIS plan, but there is not enough funding in the plan for respite or activities. His son had to go to the emergency department in a North-West Tasmanian hospital and his father was told he was not allowed to accompany his son into the emergency room. This was during a time when COVID-19 was particularly prevalent across Tasmania.

Mr. B was assertive and insisted that it was critical for him to be in the room and that he was going to accompany his son regardless. The hospital director eventually came to speak with Mr. B, which resulted in him being permitted with his son in the emergency room. This is a distressing situation that could have ended badly. It could easily have been avoided if consideration of the boy's age, disability, and needs were taken into account and if value was placed on including carers in care planning.

Barriers to accessing a diagnosis

Carers often report difficulties they experience when trying to obtain a diagnosis for the person they care for. It is especially difficult for children in Tasmania at present, with long wait times for assessments in the public health system. In addition, all private paediatricians currently have their books closed due to significantly long wait lists, or because they are retiring. This is placing a higher demand on private psychologists but also means that some people are going without support as they are unable to access an assessment or obtain a diagnosis.

There are challenges in obtaining diagnostic reports that are worded correctly by professionals to support successful NDIS applications. This often leads to several attempts at application, a lot of frustration, and people going without support, creating more stress for carers.

Carer quote:

"My child was born with concerns. It took over 18 months to get on the NDIS despite blatant genetic issues in the family. NDIS should be offered as soon as a disability is identified. The application process needs to be so much simpler."

Inadequate and inequitable funding

Not all Autistic people are eligible for the NDIS, and although the NDIS was not designed to support all people with disability, greater support must be available for those who don't meet eligibility requirements. Just because a person doesn't meet eligibility requirements, it doesn't mean that they and the people who care for them don't require additional support. Often, these are the families who miss out. The Strategy must facilitate significant improvements to state-based support for Autistic people who are ineligible for the NDIS. Appropriate Medicare items must be allocated to ensure people are able to access the support they require no matter what their financial circumstances are.

With the NDIS review process being finalised, changes to the way in which NDIS operates are imminent. Commonwealth and State Governments must ensure that there will be fair and equitable access to support for Autistic people into the future. This includes both through the NDIS and other community services.

Within the context of the NDIS, many carers report that requests to support additional needs of Autistic children are considered to be part of 'parental responsibility' and deemed ineligible. This is detrimental and a contributing factor to poor wellbeing for carers of Autistic people. When programs and supports for Autistic people are designed, it is imperative that lived experience feedback is included from both Autistic people and their carers. If carers have access to what they need, they will be better able to support the person they care for on a more sustainable basis.

Poor community awareness and understanding

A factor that contributes to poor outcomes for Autistic people and their carers is the lack of appropriate community awareness and understanding of Autism. Autism is so diverse, and each Autistic person has different strengths, challenges, and needs. Like all humans, not one person with Autism is the same as another, and the stereotypes that exist within society can have harmful effects. Poor or limited understanding results in assumptions, stigma, and discrimination which can negatively impact Autistic people and their carers.

The Strategy must outline a plan to support services, community, healthcare, and education settings to better understand and respond to the needs of Autistic people and their carers. A strong focus is needed on stigma reduction and building an inclusive society, rather than filling gaps or supporting Autistic people to fit into 'mainstream' programs.

A notable initiative that is currently being piloted in Tasmania is the National Assistance Card Trial. The National Assistance Card was initially developed for people with brain injury, but in September 2022 it was expanded to the Tasmanian Autistic community. The card is a resource that aims to assist Autistic people in the community, providing them with reassurance, to help them feel more confident in social situations, to provide peace of mind to carers and family members, and to help increase community awareness and understanding of Autism. The card includes the following details:

- The person's first and last name
- A photo
- Their date of birth
- A nominated contact person when needed
- A space to outline specific areas of difficulty as chosen by the cardholder
- A QR code that can link to a video, or additional information as chosen by the cardholder

- The Police assistance phone number.²⁴

This initiative that could be evaluated to explore whether it is worth expanding on a national basis.

4. Recommendations

To truly make a difference in the lives of Autistic people, and their carers, the Strategy must be underpinned by the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD),²⁵ and it should be developed through the lens of the social model of disability, looking at how the functions of society can be improved to better support Autistic people. Improvements for Autistic people will also facilitate improvements for their carers. We recommend that the Strategy:

- Be centred on co-design, collaboration, shared governance, and monitoring with Autistic people and their carers throughout all stages of development and implementation.
- Utilise continued collaboration across all levels of government for effective systemic change.
- Be underpinned by the UNCRPD.
- Support and be supported by other Commonwealth and State-based strategies and legislation.
- Include clear and measurable KPIs and funding.
- Focus on improving the availability, affordability, and access to diagnosis, particularly for target groups such as females, First Nations people, people from culturally diverse communities, those in low socio-economic areas, and those with low literacies (health, digital, literacy/numeracy).
- Include a targeted approach to increase access to early intervention.
- Aim to expand education and increase the awareness and understanding of Autism (this could include expanding the National Assistance card trial).
- Focus on better funding so that more schools across Australia can incorporate Autism Inclusion Teachers (as in South Australia).
- Facilitate better education and support for teachers and school staff about Autism so they can better support their Autistic students.
- Focus on improving training and understanding about Autism in community, aged care, and disability services.
- Aim to increase Autism awareness education in healthcare settings and set clear KPIs for improvement.
- Commit to supporting carers of Autistic people and recognise that Autistic children or young people have unique needs that may place additional responsibilities or requirements on their carer/s.

²⁴ Australian Government Department of Social Services. (2022). *National Assistance Card – Autism Trial Tasmania*. <https://www.nationalassistancecard.com.au/news/autism-trial-tasmania>

²⁵ United Nations. (2006). *Convention on the Rights of Persons with Disabilities*. OHCHR. <https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-persons-disabilities>