



**Carers Tasmania Feedback on  
the draft National Autism Strategy**

**May 2024**



## 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.

Carers Tasmania has offices in Moonah, Launceston and Burnie.

Please direct any enquiries about this report to:

Samantha Fox  
Chief Executive Officer  
Phone: (03) 6144 3700  
Email: [ceo@carerstasmania.org](mailto:ceo@carerstasmania.org)

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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 Australian Government 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 respond to the draft National Autism Strategy (the Draft Strategy).<sup>1</sup>

In preparing this response, we use the language promoted by Autism Tasmania, guided by the advice of the Autism Cooperative Research Centre, and their members:

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

We also use the term ‘carer’ to refer to any person who is providing support to a family member or friend who:

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

We acknowledge and recognise that not all Autistic people have family or friend carers in their lives, however, a large proportion do. As highlighted by Autism Tasmania, every Autistic child has someone caring for them,<sup>4</sup> as do many Autistic adults in varying capacities. We acknowledge that many carers may identify as Autistic themselves, and that Autistic people may also be experiencing co-occurring health conditions or disability. Young carers, who are people under the age of 25 years old, are often not recognised, and sometimes even unaware of the significance of their important contributions. They must not be forgotten as key supports within the Autism Community.

We thank the carers who have, and continue to share their experiences, to enable us to effectively advocate on their behalf, and acknowledge that it can sometimes be difficult to share personal experiences, particularly when they are challenging or upsetting.

We recognise that the intention of the National Autism Strategy will be to provide a whole-of-life plan for all Autistic Australians. The Draft Strategy includes 24 commitments, underpinned by the four key outcome areas of:

- social inclusion
- economic inclusion
- diagnosis, services, and support, and
- health and mental health (via the National Roadmap led by the Department of Health and Aged Care).

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<sup>1</sup> Australian Government. (2024). Draft National Autism Strategy. Retrieved from: <https://engage.dss.gov.au/wp-content/uploads/2024/04/draft-national-autism-strategy.pdf>

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

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

<sup>4</sup> Autism Tasmania. (2023). Autism in Tasmania: The State of the State 2023. Retrieved from: <https://www.autismtas.org.au/wp-content/uploads/2023/10/StateOfTheState-V7.pdf>

As well as facilitating positive changes for Autistic people, we hope that this Strategy will also foster positive transformations to the quality of life for carers and the broader Autism Community. Whilst being conscious of efforts to move away from the largely deficit model of viewing Autism and acknowledging the need for a strengths-focus, data shows that carers, particularly parents of Autistic children, often experience very poor levels of wellbeing in comparison to other groups of carers. The 2021 and 2022 Carer Wellbeing Surveys found that Australian carers supporting Autistic people were at greater risk of experiencing psychological distress and loneliness compared with both those in other caring cohorts, and those in the general population.<sup>5</sup> There are many contributing factors to this, which we outlined within our 2023 Submission on the Development of the National Autism Strategy.<sup>6</sup>

We note that the Draft Strategy clarifies that specific actions to achieve the commitments will be detailed in correlating action plans, and pleasingly, that these actions plans will be co-designed with Autistic people and their families and carers, as well as researchers, policy makers and the broader Autism Community. Importantly, the Draft Strategy also states that these stakeholders will be involved in implementing, monitoring, and reporting on the Strategy.

Our response further details our reflections on the Draft strategy, outlining some pleasing areas, as well as areas for improvement and the critical need for greater investment and a long-term commitment between the Australian and State and Territory Governments.

### 3. Response to the Draft Strategy

We broadly support the aims of the Draft Strategy and its outcome areas. It is pleasing to see a focus on increasing awareness about using best practice language, explanation about broader neurodivergence, and the importance of a trauma-informed approach. The authentic, co-designed approach to its development is evident, and the important work by the oversight council is applauded. Pleasingly, carers and other family members have been mentioned throughout the Draft Strategy, and we are thankful for the recognition of the impacts on and needs of carers within the Autism community.

The overarching goal of the Strategy *“To improve life outcomes for all Autistic people,”*<sup>7</sup> is welcomed, and we acknowledge that by improving life outcomes for Autistic people, there will also be a flow on effect for their family, friends, and carers. The Draft Strategy outlines a comprehensive list of areas in which Autistic people face disadvantage and four primary focus areas of improvement. It is pleasing to see some of this inherent disadvantage recognised and a need for significant improvement articulated throughout the Draft Strategy. It is also positive to see a focus on the recognition of strengths of Autistic people as opposed to a deficit-based model.

The mechanisms for consultation could be strengthened further. Whilst seeking feedback from carers about their thoughts on this Draft Strategy, one carer who identifies as Autistic noted that it would be helpful to have a video with an audio description. She found an easy-read version, an AUSLAN video, and PDF reader capability, but no video with an audio and caption option, making it difficult for her to access the materials. Her feedback was that the

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<sup>5</sup> Carers Australia. (2021). Caring for Others and Yourself. 2021 Carer Wellbeing Survey. Retrieved from: [https://www.carersaustralia.com.au/wp-content/uploads/2021/10/211011\\_Carer-Wellbeing-Survey\\_Final.pdf](https://www.carersaustralia.com.au/wp-content/uploads/2021/10/211011_Carer-Wellbeing-Survey_Final.pdf)

<sup>6</sup> Carers Tasmania. (2023). Submission on the Development of the National Autism Strategy. Retrieved from: <https://carerstas.org/wp-content/uploads/2023/11/Carers-Tasmanias-Submission-on-the-National-Autism-Strategy.pdf>

<sup>7</sup> Australian Government. (2024). Draft National Autism Strategy. Retrieved from: <https://engage.dss.gov.au/wp-content/uploads/2024/04/draft-national-autism-strategy.pdf>

level of accessible content provided on Australia's Disability Strategy was a useful model, given its focus on accessibility.<sup>8</sup>

Other carers approached by Carers Tasmania shared their feedback that they did not know about this Draft Strategy or any of the consultation surrounding its development, as they are so busy juggling their caring responsibilities with life, that they often don't have the time to learn about relevant consultations, or to provide feedback.

It's important to acknowledge that although this Draft Strategy is intended to be an Australian Government Strategy relating to Commonwealth-funded services and supports, for this strategy to truly make a positive difference, a key priority must be a strong commitment and investment between relevant Australian Government Departments and State and Territory Governments. The Draft Strategy notes that *"This is an Australian Government strategy and is intended to operate alongside state and territory autism strategies, where they exist."*<sup>9</sup> Rather than this disjointed approach, we suggest that an aim of this strategy be to ensure that all States and Territories develop or implement (if they have not already done so) their own strategies on how they intend to deliver meaningful changes and supports to Autistic people and their carers. Like the National Cabinet agreement to work together on the NDIS Review Recommendations, there must be a strong, long-term agreement and investment between the Australian Government and States and Territories to ensure a collaborative and sustainable approach.

The National Strategy must foster a national commitment. Low levels of funding and resources applied in some States and Territories is exacerbating disadvantage and poor outcomes for community members. Simply stating that *"The Australian Government will refer to states and territories on issues raised in the development process that relate to responsibilities of states and territories, or local government. Areas of shared responsibility will be referred to Disability Reform Ministers to consider shared approaches, where relevant,"*<sup>10</sup> is not enough. State and Territory Governments must be supported to enable the delivery of supports and services that are needed.

A strong and ongoing commitment must be made between the Australian Government and each State and Territory, particularly given State Governments are responsible for education policy and programs, the justice system, health, housing, disability and aged care supports outside of Commonwealth funded supports. These are all key areas in supporting the Autism Communities and are incredibly relevant to improving the outcome areas identified within the Draft Strategy.

It is known that the outcome areas of social inclusion, economic inclusion, diagnosis, services, and support, and health and mental health are all priority areas for people with Autism due to the disadvantages they face across these particular domains. However, these are also areas of significant importance to carers of Autistic people. Consideration must be given to how to create positive outcomes in these areas for carers when developing the specific action plans.

Collaborative commitments and investment across Australian and State and Territory Governments in relation to the National Autism Strategy and associated action plans, will contribute to achieving the following two policy priorities from Australia's Disability Strategy, particularly with reference to Autistic people and their carers;

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<sup>8</sup> Commonwealth of Australia. Department of Social Services. (2021). Australia's Disability Strategy. Retrieved from: <https://www.disabilitygateway.gov.au/sites/default/files/documents/2021-11/1786-australias-disability.pdf>.

<sup>9</sup> Australian Government. (2024). Draft National Autism Strategy. Retrieved from: <https://engage.dss.gov.au/wp-content/uploads/2024/04/draft-national-autism-strategy.pdf>

<sup>10</sup> Ibid.

“Policy Priority 1: People with disability are able to access supports that meet their needs” and

“Policy Priority 3: The role of informal support is acknowledged and supported.”<sup>11</sup>

#### 4. Commitments and outcome areas

We agree with and support the commitments under each of the outcome areas, but for these to be achievable, it is critical that agreement is sought from each State and Territory to develop and implement their own long-term Autism Strategies. South Australia is currently leading the way in this area, with the first Autism Strategy enacted and an Office for Autism responsible for some incredible initiatives. In September 2023, a motion was passed for the ACT Government to consider a Neurodiversity Strategy. Following the announcement of the National Autism Strategy, members of the NSW Government have also called for a NSW Strategy.<sup>12</sup>

Other regions, such as Western Australia, are continuing to build on their knowledge, through inquiries, such as the Education and Health Standing Committee Inquiry into Support for Autistic Children and Young People in Schools.<sup>13</sup> Victoria has a state Autism Plan<sup>14</sup> that sits alongside the Victorian Disability Plan, and the Queensland Government has an Autism Hub.<sup>15</sup> The Western Australian Government is conducting a reform project to help improve outcomes for Autistic people.<sup>16</sup>

Without shared commitment and equitable support across government departments, initiatives become ineffective or fail particularly when key representatives change. This causes frustration and leaves already vulnerable people worse off. Whilst acknowledging the immense amount of change within Tasmanian Government over recent years, an example was the establishment of an Autism Advisory Panel in Tasmania in 2014, and a \$1million election commitment by the Tasmanian Government for the development of a long-term Autism Strategy.<sup>17</sup>

Trials were implemented within several Tasmanian primary schools and a *Rethink Autism* web-based training program was developed.<sup>18</sup> These initiatives were evaluated by the University of Tasmania, however, the report is under embargo. In 2024, there is no Tasmanian Autism Strategy, nor any publicly facing commitment for the establishment of such a strategy.

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<sup>11</sup> Commonwealth of Australia. Department of Social Services. (2021). Australia’s Disability Strategy. Retrieved from: <https://www.disabilitygateway.gov.au/sites/default/files/documents/2021-11/1786-australias-disability.pdf>.

<sup>12</sup> Janelle Saffin MP. (2024). Media release: Time for action on a NSW Autism Strategy. Retrieved from: <https://janellesaffin.com.au/2024/04/09/time-for-action-on-a-nsw-autism-strategy/>

<sup>13</sup> Parliament of Western Australia. (2023). Inquiry into support for autistic children and young people in schools. Retrieved from: <https://www.parliament.wa.gov.au/Parliament/commit.nsf/WCurrentNameNew/4E11DB398E902A4C482589B3000505A3?OpenDocument#Details>

<sup>14</sup> State of Victoria, Department of Health and Human Services. (2019). Victorian autism plan. Retrieved from: <https://www.vic.gov.au/victorian-autism-plan>

<sup>15</sup> Queensland Government, Department of Education. (2024). Autism Hub, Retrieved from: <https://autismhub.education.qld.gov.au/>

<sup>16</sup> Autism Association of Western Australia. (2024). Improving Health Outcomes for Autistic People. Retrieved from: <https://www.autism.org.au/accessing-mental-health-and-healthcare-services/improving-health-outcomes-for-autistic-people/>

<sup>17</sup> Tasmanian Government. (2015). Advisory panel helping to improve support for Tasmanians living with autism spectrum disorder. Retrieved from: [https://www.premier.tas.gov.au/releases/advisory\\_panel\\_helping\\_to\\_improve\\_support\\_for\\_tasmanians\\_living\\_with\\_autism\\_spectrum\\_disorder](https://www.premier.tas.gov.au/releases/advisory_panel_helping_to_improve_support_for_tasmanians_living_with_autism_spectrum_disorder)

<sup>18</sup> Ibid.



It is our hope that a National Strategy will support States and Territories to ensure that they have the resources to develop what is needed in their regions. It is important to acknowledge that Tasmania is a small jurisdiction, with a high prevalence of not only Autism, but other forms of disability, chronic health conditions, mental ill health, and a significantly ageing population. These rates are some of the highest in the country.<sup>19</sup> This places increased pressure on the Tasmanian Government to respond to all of these needs, within a small budget. It is also important to highlight that there are many significant areas of reform currently within the Tasmanian Government scope, especially within the areas of children and young people, and disability.

A major issue for parents and carers of Autistic children in Tasmania lies within the public school system. With the upmost respect to teaching and school staff, the Tasmanian education system is not resourced as well as other States and Territories with regards to supporting Autistic students. For example, South Australia has implemented Autism inclusion teachers into each public primary school and additional wellbeing staff.<sup>20</sup>

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Carer quote:

*“I’m the carer for my Autistic son who attends a public primary school. I have disability and some health issues myself which makes things harder. I have a great advocate, but I feel I am constantly fighting with the school, it feels like hitting my head against a brick wall. It’s just exhausting and frustrating. We shouldn’t need an advocate to get good outcomes for my son. They just don’t understand Autism and what it means for him. They don’t understand what stimming is and they don’t support him with what he needs when he has a meltdown. What he needs aren’t complex things, they are basic things like understanding, a quiet space when needed and being flexible. They think he is playing up and choosing to be naughty. He actually loves school. I’ve complained to the education department, but the school staff still just don’t get it. I want my son to be safe and supported at school, but the knowledge, skills and support just aren’t there.”*

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The recent 2024-2025 Federal Budget pleasingly included measures to further support national disability advocacy organisations, including Autism Alliance National. However, there does not appear to be any extension to State and Territory funding for Autism advocacy and support.<sup>21</sup> The 2023-2024 Federal Budget announced \$27.0 million of funding over 4 years to undertake early intervention pilot programs for infants with signs of Autism and to progress the development of the National Autism Strategy.<sup>22</sup> There don’t appear to be any clear additional funding measures for the implementation of the National Autism Strategy and its associated action plans in the recent Budget. Clarity must be provided on how the Australian Government and States and Territories will work together and how funding will be delivered to ensure that the Strategy is effective and implemented equitably across Australia.

Although the 2024-2025 Federal Budget outlines funding towards NDIS reforms, and ‘*getting the NDIS back on track*,’ there is a lack of clarity on funding measures for the development of foundational supports. This will be a crucial piece of work, especially for states such as

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<sup>19</sup> Australian Bureau of Statistics. (2021). Tasmania Census Quickstats. Retrieved from: <https://www.abs.gov.au/census/find-census-data/quickstats/2021/6>

<sup>20</sup> Government of South Australia, Department for Education. (2024). Improving support for Autistic Students. Retrieved from: <https://www.education.sa.gov.au/parents-and-families/student-health-and-disability-support/improving-support-children-and-students-autism>

<sup>21</sup> Commonwealth of Australia. (2024). Budget 2024-2025. Budget Measures Paper Number 2. Retrieved from: [https://budget.gov.au/content/bp2/download/bp2\\_2024-25.pdf](https://budget.gov.au/content/bp2/download/bp2_2024-25.pdf)

<sup>22</sup> Commonwealth of Australia. (2023). Budget 2023-2024. Budget Measures Paper Number 2. Retrieved from: [https://archive.budget.gov.au/2023-24/bp2/download/bp2\\_2023-24.pdf](https://archive.budget.gov.au/2023-24/bp2/download/bp2_2023-24.pdf)

Tasmania who have very limited support outside of the NDIS for Autistic people. We are hopeful that further information will be provided to ensure that in Tasmania, Autistic people and their carers are not disadvantaged by these reforms.

## 5. The outcome areas, commitments, and their relevance to carers

### Social inclusion:

Carers of Autistic people face both direct and indirect forms of social exclusion. Achieving the aims of the social inclusion commitments for Autistic people, will also help facilitate better social inclusion outcomes for carers of Autistic people. As well as providing care to their family members and friends, carers try to balance employment, study, volunteering, and other family or cultural responsibilities. Carers often report experiencing judgement from others (particularly from other parents) and may experience difficulties in attending social activities and events, especially with the person they are caring for.

All of the items listed under the social inclusion commitments must also consider carers. There is already some work underway for carers more broadly that can be utilised and built on. For example, the social inclusion outcome area describes a need for increased public education and awareness within workplaces. There are some related national initiatives, such as the Carer-Inclusive Workplace Initiative,<sup>23</sup> and the Carers + Employers accreditation program.<sup>24</sup> Although these initiatives aim to raise awareness and increase the employment participation and retention of people who are carers, creating inclusive workplaces can assist in building community awareness about what it's like to care for Autistic people, where workplaces have carers in these situations.

Increasing and improving accessible and sensory friendly spaces within communities, will also improve accessibility for carers who may not be able to attend these events if the person they care for is not comfortable. Another area that will promote social inclusion, not only for Autistic people, but also for their carers is the resourcing of advocacy organisations. Increasing the capability of advocacy organisations will assist in supporting carers who already provide informal advocacy but are sometimes still not included and heard.

### Economic inclusion:

Economic disadvantage is common for carers. There are significant impacts on employment, particularly for parents of children experiencing challenges such as 'School Can't', or any other number of difficulties related to schooling. Carers might take time off for appointments (assessment, planning, therapies), or be called regularly to pick up their child early when they are trying to work. Significantly improving access, acceptance, support, and inclusion across all education services, will directly support better economic inclusion of carers. This may reduce rates of home schooling, 'School Can't', and the prevalence of needing to frequently pick up children from school.

There can be huge costs for paying for assessments and therapies privately due to significantly long waiting times in the public system, and for items, services and supports that the NDIS won't cover, or that are not approved despite the significant positive impacts they can make.

Carers often report that workplaces for adults are not Autism inclusive, and that disability employment providers aren't always accessible, understanding, or supportive. This often

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<sup>23</sup> Carers Australia. (2024). Carer Inclusive Workplace Initiative. Retrieved from: <https://www.carersaustralia.com.au/programs-projects/carers-inclusive-workplace-initiative/>

<sup>24</sup> Carers NSW. (n.d). Carers+Employers. Retrieved from: <https://carersandemployers.org.au/>

leads to carers having time off work. By increasing meaningful employment opportunities for Autistic people, it will provide carers (where relevant) more opportunities to effectively participate in employment themselves.

### Diagnosis, services, and support:

For carers, there are significant layers of complexity and stress when navigating diagnosis, services and supports. There is a huge emotional toll, often through the diagnostic process, but also through a constant need to learn and advocate. Carers often report issues with navigating the NDIS, schools, workplaces, and future planning.

There are also carers who, through the diagnostic process for the person they care for, realise they are Autistic themselves but do not have the funds, time, or energy to go through the diagnostic process themselves. Carers often report that the diagnostic process is inequitable, therefore resulting also in inequitable and ineffective access to services. This not only negatively impacts Autistic people, but also increases caring responsibilities and stress, and increases the prevalence of negative impacts on carers such as social isolation, economic exclusion, and poor physical and mental health.

We welcome the focus in the Draft Strategy commitments on consideration of consistent screening, outcome and diagnostic tools and the development of a set of standardised, co-designed training resources for use across all relevant professional bodies. We hear from carers about significant difficulties in accessing referral pathways for diagnosis, crucial to accessing to support.

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Carer quote:

*“We scraped by to pay for an assessment for our son through a clinical psychologist due to long public wait times. They diagnosed both ADHD and Autism.*

*We then saw a paediatrician to confirm the diagnosis. We gave her the comprehensive report from the psychologist, but she could not see that our son has Autism. She confirmed the ADHD diagnosis, which is very apparent, but said there was not enough evidence to confirm Autism.*

*She mentioned how our son made eye contact with her, held some back-and-forth conversation and there were no clear repetitive behaviours during the meeting. She completely missed how Autism looks for him. She didn't notice the type of questions he was asking were all process questions, she didn't pick up on his constant need to know what was happening next, and she missed how he was upset about the noise of the clock and why some of the toys were not working. She was looking for stereotypical behaviour and it was clear she hadn't read the psychologist report.*

*I left that appointment feeling disappointed and followed up with an email bringing all of this to her attention. Health professionals need a better knowledge of Autism. We shouldn't have to constantly advocate to get the support needed. Now we're waiting to see if the NDIA will accept the psychologist diagnosis or if they require further evidence.”*

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The investments into increased training, and a stronger focus on equitable, neurodiversity-affirming supports are welcomed. It is also pleasing that the commitments outline encouragement for greater representation of lived-experience peer support and better decision-making tools. Across these commitments, we hope that carers of Autistic people will also be included, as they have valuable insights, experiences, and are invested in improving the quality of life for Autistic people.

We also welcome Commitment 20 *“Work with states and territories to improve service integration between the NDIS, foundational supports and mainstream services.”* As highlighted several times, to meet this commitment, long-term resourcing and agreement is required.

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Carer quote:

*“Why is it so hard to get what is needed? My son has Autism, ADHD, and Global Development Delay. Even though the OT has recommended specific supports to be implemented in his NDIS plan, they’ve been declined, and he goes without. It’s exhausting fighting the refusal of requests by the NDIA, despite recommendations from the OT.*

*The NDIA have not explained exactly what documentation they require to approve this support, despite it being well known that children with Autism and ADHD often like climbing and it supports their brains and bodies. It’s very stressful, exhausting, and deflating for carers who just want the best support for their Autistic family members. There is a huge power imbalance, and I wish the strategy would help address the impact of the values and attitudes of mainstream society on people who have these additional needs. It would help if there was investment into further research to back these requests for support, so we constantly don’t have to be fighting for the support we know is best.”*

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Carers of Autistic people often experience difficulties in accessing the assistance to support the whole family unit. For example, findings from the recent national NDIS review reinforce that the NDIS is not and should not be the only mechanism to providing support for people with disabilities, including Autism. However, the reality is, outside of the NDIS, in some states more so than others, there are little to no targeted, evidence-based, and accessible supports for people with Autism and their families.

Parents and carers of Autistic people often report that the things they require to ensure their family can manage are not available through the NDIS. More specifically, many requests are often declined and deemed as ‘normal parental responsibility’ without consideration of the extra extent to which these parents provide additional support and assistance that is above and beyond ‘normal’ parental responsibilities. Outside of the NDIS, there are limited supports available that are affordable, accessible, and available to support families with what they need.

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Carer quote:

*“A family member of mine has not been assessed for Autism, and I know they never will. It’s so clear to me that they are Autistic. Just their whole way of being, and the sensitivities they have. Things need to be structured, and always done in particular ways. I’m finding they need more help with things as they’re getting older, and even though they could probably get in-home support, I just know it won’t work. It would just be too hard. So, I continue to support them, because I know how things need to be done. It’s easier for now, but I know I can’t help forever.”*

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The service system which currently exists in Tasmania to support Autistic people and their carers requires better investment and resourcing. Care2Serve is the National Carer Gateway provider for Tasmania. This program is funded by the Commonwealth Department of Social Services (DSS). All informal carers, including carers of Autistic people, can access free supports such as information, referral, counselling, peer support groups, coaching, emergency respite and either a one-off practical item or a package of supports to assist their caring role. However, as per the Carer Gateway guidelines, there are capacity limits to these supports.

Carers Tasmania, as the Peak Body for Tasmanian carers, provides systemic advocacy for carers of Autistic people through its broad scope of supporting all caring cohorts. Autism Tasmania also exists to provide systemic advocacy, peer support and information for the Autism Community, but is not currently funded by the Tasmanian Government.<sup>25</sup>

The Tasmanian Autism Advisory Service (TADS) is funded by the Department for Education, Children and Young People Tasmania (DECYP) to provide free Autism diagnostic services for children, which is a greatly important initiative. However, current wait times for an initial appointment are 16-18 months once referred. In recent years, through the implementation of the Child and Youth Wellbeing Strategy, the Tasmanian Government committed to additional resourcing to support TADS, however, the Strategy's 2022<sup>26</sup> and 2023<sup>27</sup> Annual Reports only briefly refer to the progress and impact of these expansions.

St Giles is also funded by the Tasmanian Government to provide Autism assessments for pre-school children only. There are many private routes to access assessment and paid supports but these are costly and wait times can be lengthy.

The Association for Children with Disability Tasmania and Speak Out Disability Advocacy services both provide free and individual advocacy for people with Autism and their parents and carers. These services provide significant support to the Autism community.

Some disability support providers such as Nexus, in partnership with Autism Tasmania, are leading the way in being providers of high-quality support for Autistic people. Partnerships such as these are important to ensure that people can access neuro-affirming and person-centred support. Knowing that these support workers have an understanding of Autism provides peace of mind to carers, who may not otherwise choose to access this support. The important contributions that these organisations bring must be recognised and they must be adequately resourced, so they can continue to provide support to Autistic people and their carers.

Support at school varies greatly in Tasmania, and whilst there are departmental policies on support and inclusion of children with disability through the DECYP, there are no targeted and clear policies or supports provided for Autistic children, nor standardised training for teachers and education staff. Given the growing prevalence of Autism, it would be highly beneficial for the Strategy to promote the introduction of specific policies to support better inclusion of Autistic or other neurodivergent children across all State and Territory government schools.

We support the recommendations made by Autism Tasmania in their State of the State 2023 Report:

*“7. Support the education workforce to build autism understanding and include autism training as part of educator registration requirements.*

*8. Establish a service/ pathway to support the re-engagement of Autistic children and young people into education.”<sup>28</sup>*

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<sup>25</sup> Autism Tasmania. (2023). Autism in Tasmania: The State of the State 2023. Retrieved from: <https://www.autismtas.org.au/wp-content/uploads/2023/10/StateOfTheState-V7.pdf>

<sup>26</sup> Tasmanian Government. (2022). Child and Youth Wellbeing Strategy Annual Report. Retrieved from: [https://wellbeing.tas.gov.au/download\\_file/view\\_inline/1146](https://wellbeing.tas.gov.au/download_file/view_inline/1146)

<sup>27</sup> Tasmanian Government, (2023). Child and Youth Wellbeing Strategy Annual Report. Retrieved from: [https://hdp-au-prod-app-tas-shapewellbeing-files.s3.ap-southeast-2.amazonaws.com/2717/0553/1660/230377\\_DPAC\\_Child\\_and\\_Youth\\_Wellbeing\\_AR\\_2023\\_final\\_wcag.pdf](https://hdp-au-prod-app-tas-shapewellbeing-files.s3.ap-southeast-2.amazonaws.com/2717/0553/1660/230377_DPAC_Child_and_Youth_Wellbeing_AR_2023_final_wcag.pdf)

<sup>28</sup> Autism Tasmania. (2023). Autism in Tasmania: The State of the State 2023. Retrieved from: <https://www.autismtas.org.au/wp-content/uploads/2023/10/StateOfTheState-V7.pdf>

Whilst these are Tasmanian issues, the National Autism Strategy provides a good opportunity to support and work with all States and Territories to foster positive improvements such as these.

### Health and mental health:

As highlighted in our initial submission on the development of the National Autism Strategy,<sup>29</sup> the 2021 and 2022 Carer Wellbeing Surveys found that carers of Autistic people were at greater risk of experiencing psychological distress and loneliness compared with other carers and the general population. This is due to many factors.

As recognised in the Senate Select Committee on Autism 2022 Final Report:

*“The wellbeing of parents and carers is critical to the success of autistic people, however, there is overwhelming evidence that support for parents and carers is currently inadequate.”<sup>30</sup>*

The Mental Health Roadmap which will sit alongside the Strategy must not only include specific initiatives to support the mental health of Autistic people, but it must also provide increased supports for carers of Autistic people.

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Carer quote:

*“I’m a carer for my son who is Autistic. Through the process of his diagnosis and supporting him as he’s growing up, we’ve realised that I am Autistic and have ADHD myself. I have used Carer Gateway counselling before which is great in a counselling context, but I wish that Mental Health Care Plans could be increased for carers needing that additional layer of psychological support and therapy. I find that I use a lot of my subsidised psychology sessions talking about the impacts of constantly, and single-handedly supporting and advocating for my son, because I want the best for him. Then I don’t have many sessions left for myself. I can’t afford to pay the full price.”*

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By creating long-lasting changes in education, awareness, and better access to assessment and supports, through collaboration, shared investment, and commitment, we will begin to see improvements in the health of Autistic people and their carers.

## 6. Conclusion

Carers Tasmania is supportive of the development of the National Autism Strategy, and applauds the focus, outcome areas, and commitments outlined in the Draft Strategy. It is also pleasing to see recognition of carers throughout the Draft Strategy. We strongly urge the Australian Government to seek commitment and work collaboratively with State and Territory Governments, to ensure they have the resources required to advance jurisdictional supports that will improve the lives of Autistic people, their carers, and other family members.

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<sup>29</sup> Carers Tasmania. (2023). Submission on the Development of the National Autism Strategy. Retrieved from: <https://carerstas.org/wp-content/uploads/2023/11/Carers-Tasmanias-Submission-on-the-National-Autism-Strategy.pdf>

<sup>30</sup> Commonwealth of Australia. (2022). The Senate Select Committee on Autism. Services, support and life outcomes for autistic Australians. Retrieved from: [https://parlinfo.aph.gov.au/parlInfo/download/committees/reportsen/024412/toc\\_pdf/Services,supportandlifeoutcomesforautisticAustralians.pdf;fileType=application%2Fpdf](https://parlinfo.aph.gov.au/parlInfo/download/committees/reportsen/024412/toc_pdf/Services,supportandlifeoutcomesforautisticAustralians.pdf;fileType=application%2Fpdf)