

# Carers Tasmania's Response to the Draft List of NDIS Supports

August 2024







#### **About Carers Tasmania**

Carers Tasmania is the Peak Body representing the more than 87,000 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 partnerships 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 87,000 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 provide feedback on the recently released Draft List of NDIS Supports (*the Draft List*),<sup>1</sup> which includes proposed eligible and ineligible supports, as well as items that may be considered on a circumstantial basis, which have been described as "carve outs that may be considered NDIS supports for certain participants." We acknowledge the significant amount of reform being undertaken by the Australian Government to get the National Disability Insurance Scheme (NDIS) 'Back on Track' and to ensure that the scheme is effective in equitably supporting Australians with disability, recognising that the primary aim of the NDIS is to enable people with lifelong disability access to reasonable and necessary supports that will assist them to live fulfilling lives.

As of 31 March 2024, the NDIS was supporting 649,623 people with disability across Australia, with 13,947 of these participants from Tasmania.<sup>2</sup> While this is a significant level of support provided to Tasmanians, Carers Tasmania highlights the enormous contributions provided to people with disability by family and friend carers. We know the NDIS on its own cannot fulfill the needs of all people with disability, and carers provide vital additional informal supports. Carers pick up where services cannot deliver, providing both primary and complimentary support and reducing reliance on formal services. Family and friend carers must be supported to enable continuation of their caring roles, and to reduce the significant impacts they face due to caring for another person.

Whilst we acknowledge that not every person with disability receives informal support from a carer, or recognises that they do, current data from the Australian Bureau of Statistics (ABS) reports that approximately 80% of the 2.5 million people with disability in Australia who needed assistance, received it from informal supports.<sup>3</sup> Just over half of people with disability required this assistance and support on a daily basis.<sup>4</sup> People with disability who needed assistance were most likely to receive informal support with things such as communication, mobility, and reading or writing related tasks.

Carers Tasmania's response mostly focuses on the need to consider the supports required by people with disability that can also support informal carers. We emphasise that support must explicitly be provided to increase skills and understanding of carers when determining eligible and ineligible supports within the NDIS. Ensuring that carers of people with disability are considered and supported within the context of the NDIS aligns with Australia's Disability Strategy 2021-2031, Outcome Area: Personal and Community Support, Policy Priority 3: The role of informal support is acknowledged and supported.<sup>5</sup>

In addition to ensuring carers are considered, included and supported, we also draw attention to concerns that we have heard from carers and members of the disability community in Tasmania, about some aspects of the proposed excluded supports conflicting with the aims of the United Nations Conventions on the Rights of Persons with Disabilities

<sup>&</sup>lt;sup>1</sup> Australian Government Department of Social Services. (2024). The Draft List of NDIS Support. <u>2024-08-02-draft-ndis-support-lists.pdf (dss.gov.au)</u>

<sup>&</sup>lt;sup>2</sup> National Disability Insurance Scheme. (2024). Quarterly Reports. <u>PB Performance Dashboard Quarterly NAT</u> Q3 2324.pdf

<sup>&</sup>lt;sup>3</sup> Australian Bureau of Statistics. (2019). 2018 Survey of Disability, Ageing and Carers, available online at www.abs.gov.au

<sup>&</sup>lt;sup>4</sup> Ibid

<sup>&</sup>lt;sup>5</sup> Commonwealth of Australia (Department of Social Services). (2021). Australia's Disability Strategy. <u>Australia's Disability Strategy 2021-2031 (disabilitygateway.gov.au)</u>

(UNCRPD).<sup>6</sup> Although we are not in a position to comment directly on the impacts of every item on the full list of excluded items, we are concerned that this will increase anxiety and mistrust of the NDIS, leaving people with disability and their carers in vulnerable circumstances. We strongly urge that a more thorough consultation approach be taken before finalising any decisions.

We fully appreciate and support the need to tighten up the NDIS to reduce fraud, increase safeguarding of people with disability, ensure equitable access to the right supports, and to support the Scheme's financial longevity, however Carers Tasmania is concerned that initially only allowing a two-week duration for the community consultation period on these draft NDIS lists is inadequate. We highlight that Action 25.2 of the NDIS Review Recommendations states "The Department of Social Services should undertake deep public consultation and engagement on proposed package of legislative reforms." The initial short consultation timeframe has excluded many people with disability and their carers from participating, and although the timeframe has now been extended slightly, many people are unaware of the opportunity to contribute.

NDIS supports are fundamental to the lives of so many Australians. Therefore, thorough and inclusive consultation opportunities must be available. Consultation only appears to have been advertised via NDIS e-news, and online, accepting responses via email, writing, or the online survey. This is not a comprehensive or inclusive form of consultation. Many carers have their own health concerns due to disability, ageing or illness, meaning that there are carers who have their own NDIS plans that may not have the capacity to participate in this consultation opportunity. We also highlight that initially, there was not a publicly accessible easy-read version of the Draft Lists, with this only becoming available more than half-way through the short consultation period. This does not support authentic consultation and equitable accessibility.

Carers Tasmania is concerned that important supports will be removed from within the scope of the NDIS before state-based support is implemented. We draw your attention to the following actions from the NDIS Review Recommendations report:

- "Action 1.4: National Cabinet should agree to jointly invest in navigation support for people with disability outside the NDIS, and
- Action 1.5: National Cabinet should agree to jointly invest in achieving nationally consistent access to individual disability advocacy services."8

In Tasmania, several crucial organisations have recently not had their Australian Government funding renewed, despite them being providers of important supports that could be accessed both within and outside of the NDIS. Foundational supports must be developed and implemented first across Australia, before taking supports away from the NDIS, leaving people vulnerable.

<sup>&</sup>lt;sup>6</sup> United Nations. (2006). Convention on the Rights of Persons with Disabilities. OHCHR. https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-persons-disabilities <sup>7</sup> Commonwealth of Australia, Department of the Prime Minister and Cabinet. (2023). Working together to deliver the NDIS - Independent Review into the National Disability Insurance Scheme: Final Report. https://www.ndisreview.gov.au/sites/default/files/resource/download/working-together-ndis-review-final-report.pdf <sup>8</sup> Ibid.

#### 3. Response to the draft inclusions

After reviewing the list of possible inclusions, Carers Tasmania reinforces significant concerns that have previously been raised by Carers Australia and the National Carer Network, including that the newly proposed definition and lists of NDIS supports do not explicitly include supports aimed at building the capacity of carers to provide care or maintain their informal caring arrangements. It is concerning that supports for carers that either align with participant goals, support carers in caring for participants, or increasing the longevity of the caring role, are not explicitly stated. This will lead to confusion and a reduced likelihood of being considered or included in NDIS plans.

Many previous submissions on aspects of the NDIS have highlighted the need to improve support for carers and families of NDIS participants, particularly supports that are related to service navigation and respite, information and capacity building, and greater support for parents of children with disability. In addition, a long-standing issue is that of respite. Carers repeatedly report that they are still unable to access appropriate forms of respite, such as inhome respite, to provide meaningful breaks from the caring role for the participant and carers, as these forms of respite are not explicitly included service categories. In addition, it appears to be incredibility difficult for carers to access emergency forms of respite through the NDIS when required. This is an area that must be addressed.

Respite can be facilitated, supporting carers to take a break if the person they care for participates in an activity, or if someone keeps them company at home. Not all people with disability can articulate their wishes of social participation or express their goals for self-capacity building. For children with disability, such requests are frequently declined under the NDIS and considered 'normal parental responsibility', reducing the ability for parents to access adequate time for themselves. This negatively impacts carers in areas such as education, employment, financial stability, wellbeing and social connection, and has flow-on effects to the whole family unit.

The following items from the Draft Lists should be expanded, and clearly articulate they are relevant and accessible to carers as required:

## • "Assistance In Coordinating or Managing Life Stages, Transitions and Supports

Supports to establish assistance within the participant's home or community to develop skills. Includes support coordination, mentoring, peer support and individual skill development such as attending appointments, shopping, bill paying, taking part in social activities and maintaining contact with others. Active involvement in planning and transition supports on the basis of a person having reached a point of stability in regard to functional capacity, prior to hospital discharge (or equivalent for other healthcare settings) wherever there is a need for ongoing maintenance support.

#### Assistance With Daily Life Tasks in a Group or Shared Living Arrangement

Assistance with and/or supervision of tasks of daily life in a shared living environment, which is either temporary or ongoing, with a focus on developing the skills of each individual to live as autonomously as possible, including short term accommodation and respite.

#### Daily Personal Activities

Assistance with and/or supervision of personal tasks of daily life to enable a participant to live as autonomously as possible in a range of environments, including but not limited to, the participant's own home.

#### Development of Daily Care and Life Skills

Development of daily living and life skills focuses on training and development activities undertaken by a participant or their carer to increase their ability to live as autonomously as possible, including supports that will enhance the ability of the participant to travel and use public transport independently.

#### • Group and Centre Based Activities

Assistance for participants to access and participate in community, social and recreational activities provided in a group setting, either in the community or in a centre."

Within these support areas, we seek for respite opportunities for carers to be explicitly listed as a support, so that there is no doubt about including relevant supports for carers when required. Respite can be facilitated while the person with disability undertakes many of the listed activities, provided adequate time and support is allocated.

There are additional areas whereby the needs of carers should be considered. This includes:

#### • "Assistance With Travel/Transport Arrangements

Transport assistance, including training, activity-based transport, provider travel, and costs associated with the use of taxis/private transport, where the participant cannot travel independently or use public transport due to the impact of their impairment/s on their functional capacity. This includes transporting participants to funded supports and other activities including school, educational facility, employment, or the community."<sup>10</sup>

With regards to the specific area of transport assistance, we highlight that especially for children with disability, transport is not just a normal parental responsibility. Transport support for children must be considered where appropriate, as for adults with disability, to enable their family and friend carers opportunities to participate in education, employment and time for self. This must not be negated by the need to provide transport.

#### • "Specialist Positive Behaviour Support

Support provided by professionals with specialist skills in positive behaviour support including assessment, development and delivery of a comprehensive plan that aims to reduce and manage behaviours of concern, and training and ongoing monitoring of staff in plan implementation."<sup>11</sup>

We seek for carers to be explicitly recognised and listed under the description of eligible persons to access positive behaviour support. This is especially relevant to carers of children

<sup>&</sup>lt;sup>9</sup> Australian Government Department of Social Services. (2024). The Draft List of NDIS Support. <u>2024-08-02-draft-ndis-support-lists.pdf (dss.gov.au)</u>

<sup>&</sup>lt;sup>10</sup> Ibid.

<sup>&</sup>lt;sup>11</sup> Ibid.

who require this support, noting the NDIS Review Recommendation 6 "Create a continuum of support for children under the age of 9 and their families". 12

We know there are immense benefits to be had by connecting children and their families with early intervention support. It is essential that carers are equipped with the skills and knowledge available to build their capacity in providing the best support possible. This area is important, not only for those caring for young children, but also for those caring for adults who may be displaying behaviours of concern.

#### Carer quote:

"Nobody ever told me, until this meeting, that we could possibly access behaviour support to assist with strategies for when my son has violent outbursts. He's getting bigger and stronger, whilst I'm getting older. We've had to call the police several times." 13

Building the capacity of carers to support positive behaviour of those they are caring for must be explicitly listed under the area of specialist positive behaviour support. If it is not included, there will be confusion and doubt about whether the provision of such support is available for carers.

#### "Early Intervention Supports for Early Childhood

Provision of a mix of therapies, and a key worker for the family. Supports for all children 0-9 years with developmental delay or disability and their families to achieve better long-term outcomes, regardless of diagnosis."<sup>14</sup>

Carers Tasmania notes that this support category relates to Action 1.8 from the NDIS Review Recommendations: "National Cabinet should agree to jointly invest in a capacity building program for families and caregivers of children with development concerns and disability." 15

Within this support domain, we seek for wrap-around support for carers to be specifically included. Although, pleasingly, this category does refer to a key worker and supports for the child and their family, this is not currently occurring. We frequently hear from carers who haven't heard from their early childhood partner for a considerable amount of time, and they are left with no support in the timeframe between applying for support and the determination of whether they are eligible or not. In addition, carers are often not connected with other supports, such as Carer Gateway through this process. Routine referral of carers must be a standard part of the process within Early Intervention Supports.

We request for further clarification around what constitutes a developmental delay within this category as we have had significant feedback that children are not able to access early intervention supports without suspected or actual eligible diagnosis, despite the fact that this stipulates support is available 'regardless of diagnosis.'

<sup>&</sup>lt;sup>12</sup> Commonwealth of Australia, Department of the Prime Minister and Cabinet. (2023). Working together to deliver the NDIS - Independent Review into the National Disability Insurance Scheme: Final Report. https://www.ndisreview.gov.au/sites/default/files/resource/download/working-together-ndis-review-final-report.pdf

 <sup>&</sup>lt;sup>13</sup> Carers Tasmania. (2023). Carers Tasmania's Submission to the NDIS Review. <u>Carers-Tasmania-submission-to-the-22-23-NDIS-Review-2.pdf (carerstas.org)</u>
 <sup>14</sup> Australian Government Department of Social Services. (2024). The Draft List of NDIS Support. <u>2024-08-02-</u>

<sup>&</sup>lt;sup>14</sup> Australian Government Department of Social Services. (2024). The Draft List of NDIS Support. <u>2024-08-02-draft-ndis-support-lists.pdf (dss.gov.au)</u>

<sup>&</sup>lt;sup>15</sup> Commonwealth of Australia, Department of the Prime Minister and Cabinet. (2023). Working together to deliver the NDIS - Independent Review into the National Disability Insurance Scheme: Final Report. https://www.ndisreview.gov.au/sites/default/files/resource/download/working-together-ndis-review-final-report.pdf

#### "Household tasks

Essential household tasks that a participant is not able to undertake because of their disability, including meal preparation and delivery, house or yard maintenance, cleaning and laundry."<sup>16</sup>

This area of support must take account of the additional assistance often required with household tasks based on physical and psychosocial disability, rather than being an explicitly identified goal of a person with disability. For example, we hear from many carers who say that despite the person they care for not being able to participate fully or partially in household tasks, if the task is not a goal of the participant, even if it would be a reasonable task to be completed by a person without disability, then it will often not be approved. This means that many carers in these scenarios often take on considerably more responsibility with household tasks than what would be considered their fair share. This is also the case for parents of children with disability, with this being deemed as 'normal parental' responsibilities.

#### Carer Quote:

"Cleaning help around the house. My 10yo daughter is incontinent, dribbles, is clumsy with eating due to control and concentration and leaves plenty of mess. She would also constantly draw on walls, tip water, and empty out contents of pantry and bathroom cupboards. I am cleaning and scrubbing daily (and have 3 other children to care for), but my request for a few hours of help weekly has been denied." 17

#### 4. Response to the draft exclusions

In the following section, we offer comments on selected items that have been proposed as ineligible for NDIS support. We have not addressed each item individually but have focused on those that are particularly relevant to the experiences shared by carers. We strongly urge comprehensive consultation with people with disabilities and their carers to fully understand the implications of deeming these items ineligible before making any final decisions. We also urge that these exclusions are considered in terms of the United Nations Convention on the Rights of People with Disability (UNCRPD).

There is a long list of non-eligible items named 'lifestyle related' items, that must be considered on a case-by-case basis, specifically when recommended by an occupational therapist (OT) or other appropriate professional.

Technological items such as phones/smart phones and smart watches should be considered where they support the participant in organising their day, safety, independence, and keeping connected with family and community. Participants may also require phones with specific functionality due to their disability. As an example, we have heard from carers of children with disability some of the many benefits they have experienced by their child being able to access an appropriate smart watch when recommended by an OT. These benefits include the use of safety features such as GPS for children who wander due to their disability and the option to build in schedules and reminders of the structure of the day, for those children who need to be updated on routine, or those who need reminders to help them stay on track. This sort of assistive technology can provide carers with a sense of relief

<sup>&</sup>lt;sup>16</sup> Australian Government Department of Social Services. (2024). The Draft List of NDIS Support. <u>2024-08-02-draft-ndis-support-lists.pdf (dss.gov.au)</u>

<sup>&</sup>lt;sup>17</sup> Carers Tasmania. (2023). Carers Tasmania's Submission to the NDIS Review. <u>Carers-Tasmania-submission-to-the-22-23-NDIS-Review-2.pdf</u> (carerstas.org)

regarding the whereabouts of the child, and the knowledge that they have additional support to help keep them on schedule, or to assist with anxiety about routines.

In addition, we caution against banning mobile phone accessories, computer/tablet/iPads and related items as there are accessories that could be used for a mobile phone that may have dual purpose as another form of assistive technology or sensory support. Computers/tablets/iPads can provide social connection, promote independence and planning, and provide an avenue for access to a range of assistive technologies and therapies. Items that either provide assistive technology or sensory regulation, such as headphones, earphones, and noise cancelling devices must be considered when recommended by an OT. It is important that these items are not deemed to be an ineligible accessory.

Items such as trampolines and other general play equipment (indoor or outdoor) are listed as ineligible supports. Although under the eligible supports list, it is stated that "play equipment where it is specialist sensory equipment could be funded under Assisted Technology"<sup>18</sup> we are concerned that this will create confusion as to what is considered as disability or sensory specific. We seek clarification around this support area and request the need to consider recommendations by an OT. Items that can support a person in self-regulating, or participating in an activity, can support carers to undertake other tasks, without the need to constantly monitor, regulate or support.

#### 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."<sup>19</sup>

We request further consideration of the following items that have been deemed as 'not value for money'. Some of these supports should be considered, especially when recommended by an OT or other relevant professional.

One specific example is gaming therapy. We have heard from carers the benefits that some children with disabilities have experienced through participating in gaming therapies such as Minecraft or similar. Feedback includes that these forms of therapies can help to improve skills in communication, problem-solving and other social and regulation skills. When developed and conducted in a therapeutic manner, gaming therapy can provide effective support for people with disability and can also support carers to be able to take care of other tasks for the duration of the program. Some children and adults with disability may not want

<sup>&</sup>lt;sup>18</sup> Australian Government Department of Social Services. (2024). The Draft List of NDIS Support. <u>2024-08-02-draft-ndis-support-lists.pdf</u> (dss.gov.au)

<sup>&</sup>lt;sup>19</sup> Carers Tasmania. (2024). Feedback on the Draft National Autism Strategy. <u>Carers-Tasmania-Feedback-on-the-draft-National-Autism-Strategy-1.pdf</u> (carerstas.org)

to attend in-person activities. Therefore, participating in a monitored and psychologically safe gaming therapy program may be an option for them. We seek consideration of gaming therapy as an eligible support, provided the game meets required standards and is recommended by an appropriate professional.

There must be further clarification provided about the types of ineligible coaching that is listed such as life, wellness, career coach, and cultural coach. Although there are many people offering various coaching services, some of these goal and future planning coaching services can be extremely beneficial for people with disability. We recommend that some forms of coaching be considered as professionally recommended, provided they meet certain accreditation requirements. The specific accreditations required could be outlined within the NDIS provider registration rules. Through various forms of consultation, future planning has regularly been raised as a concern by carers who are worried that the person they are supporting does not have any future plans or goals. This future planning should be supported by a professional outside of the family.

Palliative care is listed as a non-eligible support item. Whilst recognising that palliative care services are provided outside of the NDIS, we strongly encourage a disclaimer alongside this, highlighting that people with disability who have a life-limiting or palliative condition are still able to apply and access disability related supports through the NDIS. In fact, recently a fast-track option has been implemented to support people with disability who are palliative to obtain access to disability support faster. If this is not clearly outlined in documentation, the risk of misunderstanding of eligibility is increased. This will add more pressure on to carers if they think the person they care for is not eligible for NDIS supports. Additional, clear information and awareness raising on this point is required.

Other items on the exclusions list include family therapy and parenting programs noting that parenting programs specific to a disability need may be considered as NDIS supports for certain participants. We request a strong commitment for disability specific family, parenting and information programs to be listed as eligible to ensure carers and their family can support people with disability, and function well as a family unit. These supports must be explicitly included and explained, to remove any confusion and ambiguity.

There are several items listed related to mental health support that are not eligible. Potential carve outs that may be considered for certain participants appear to include ongoing psychosocial recovery supports. This is unclear and there is not a good example of the types of psychosocial supports that may be accessible. We highlight Recommendation 7 from the NDIS Review Recommendations: "Introduce a new approach to NDIS supports for psychosocial disability, focused on personal recovery, and develop mental health reforms to better support people with severe mental illness."<sup>20</sup> Thorough and authentic community consultation is required to develop and agree on evidence-based and best practice mental health supports that can be available and accessible across all parts of Australia.

In the section regarding mainstream school education, there are several aspects listed as ineligible which instead must be considered on a case-by-case basis. More importantly, there must be adequate agreements and funding in place for educational supports and adjustments prior to any of these changes being implemented.

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<sup>&</sup>lt;sup>20</sup> Commonwealth of Australia, Department of the Prime Minister and Cabinet. (2023). Working together to deliver the NDIS - Independent Review into the National Disability Insurance Scheme: Final Report. https://www.ndisreview.gov.au/sites/default/files/resource/download/working-together-ndis-review-final-report.pdf

Some of the items listed as non-NDIS eligible education-related items include:

- "Personalised learning or supports for students that primarily relate to their educational attainment
- Aids and equipment for educational purposes (e.g. modified computer hardware, education software, braille textbooks)
- Textbooks and teaching aids (including alternative formats)
- Tutors, scribes
- Educational supports associated with home schooling
- School refusal programs<sup>21</sup>

Whilst we understand that state education departments are responsible for providing reasonable adjustments to support students with disability to participate effectively and safely in education, the reality is that schools are under-resourced and the processes to obtain additional funding for schools can be lengthy. The types of additional supports provided within schools differs greatly across Australia.

Limited supports within schools increases pressure on carers, in terms of them having to pay out-of-pocket, regularly pick up children from school early, or struggling with getting their child to go to school. This causes terms of stress, isolation, lack of employment income and financial insecurity. It also means that children with disability are missing out at school, which is evidenced by findings such as that of the Australian Institute of Health and Welfare, which states that "people with disability generally have lower educational attainment than people without disability."<sup>22</sup>

In this regard, we highlight the following action items from the NDIS Review Recommendations:

"Action 2.5: All Australian governments should take steps to protect the right to inclusive education for children with disability and developmental concerns in early childhood education and care and schools.

Action 2.8: The National Disability Insurance Agency and the Department of Education, with state and territory education and disability agencies, should develop a plan to better connect the NDIS and school education systems and improve educational outcomes for children with disability."<sup>23</sup>

Another area of ineligible supports is mainstream workplace supports. Work-specific aids and equipment required to perform a job (including modified hardware and software) are listed as ineligible items. Although workplaces should be providing people with disability the tools required for their job, we often hear from carers that the people they support struggle to obtain and retain appropriate employment that will support their disability needs and help them remain employed. Sometimes in these scenarios, carers will end up paying for the equipment or modifications required, impacting their own financial circumstances.

Australian Government Department of Social Services. (2024). The Draft List of NDIS Support. 2024-08-02-draft-ndis-support-lists.pdf (dss.gov.au)
 Australian Institute of Health and Welfare. (2024). People with disability in Australia, Summary. People with

Australian Institute of Health and Welfare. (2024). People with disability in Australia, Summary. People with disability in Australia, Summary - Australian Institute of Health and Welfare (aihw.gov.au)
 Commonwealth of Australia, Department of the Prime Minister and Cabinet. (2023). Working together to deliver

<sup>&</sup>lt;sup>23</sup> Commonwealth of Australia, Department of the Prime Minister and Cabinet. (2023). Working together to deliver the NDIS - Independent Review into the National Disability Insurance Scheme: Final Report. https://www.ndisreview.gov.au/sites/default/files/resource/download/working-together-ndis-review-final-report.pdf

The final area of ineligible support we wish to comment on specifically is "funding or providing out-of-home care or support to carers of children in out of-home care where these supports are not additional to the needs of children of similar age in similar out-of-home care arrangements." Whilst states are responsible for providing general support to families involved in out-of-home care, we hope that the NDIS will continue to work with state-funded programs to ensure that children with disability living in out-of-home care situations and their carers, are identified and supported effectively.

Many children living in out-of-home care situations, either formally through foster care or an order, or informally via informal kinship care arrangements, may have additional needs compared to other children. Children in these scenarios have often experienced significant trauma and may experience mental ill health or psychosocial disability. It is also not uncommon for children in these situations to have significant health concerns.

Whilst the draft lists don't propose any changes to NDIS support for children in out-of-home care, it does offer an opportunity to review how services can better ensure these children have sufficient opportunities to test their eligibility for the NDIS, especially when obtaining official diagnoses can challenging. The Australian Institute of Health and Welfare (AIHW) reported that in 2020-21, Australian data on disability status was only available for 63% of children living in out-of-home care. Of these children, about 30% were reported as having a disability.<sup>24</sup> This shows that gaps still exist in identifying children with disability, particularly for those who are living in out-of-home care. It is also important that carers of children with disability in out-of-home care situations can access information, capacity building, and respite options that are disability specific.

#### 5. Conclusion

Carers Tasmania thanks the Australian Government for the opportunity to respond to this stage of NDIS reforms. The NDIS supports many people across Australia with disability and their carers. We acknowledge the important work of the Australian Government and NDIA over recent years to improve experiences of the NDIS. However, Carers Tasmania believes that more thorough and inclusive consultation is required across all further aspects of the NDIS reforms to support ongoing confidence and trust in the NDIS, and to ensure that people can access the supports that they truly need, when they need it.

We encourage comprehensive consultation on the draft lists of ineligible and eligible supports, and to look at the functions of disability and these supports through the social model of disability, whilst ensuring that decisions for change uphold the principles of the UNCRPD.<sup>25</sup> We also highlight the need to ensure that that foundational supports for people with disability are developed and implemented across Australia before current supports start being withdrawn.

Lastly, we reinforce the critical need to ensure that there are specific support types available to carers to assist them in maintaining their caring roles, and that whenever planning for people with disability occurs within the NDIS, that carers are recognised, included, and supported, to support the whole family unit.

<sup>&</sup>lt;sup>24</sup> Australian Institute of Health and Welfare. (2020-2021). Child protection Australia, Characteristics of Children in Out-Of-Home-Care. Child protection Australia 2020-21, Characteristics of children in out-of-home care -Australian Institute of Health and Welfare (aihw.gov.au)

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