



**Carers Tasmania Feedback on the
draft Disability Inclusion Bill 2023**

September 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 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, and 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.

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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 referred to as '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 that 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 the 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 draft *Tasmanian Disability Inclusion Bill 2023* (the draft Bill). We note that this draft Bill is intended to be a more contemporary and inclusive version of the *Disability Services Act 2011* (Tas)¹ and we applaud the addition of the inclusion principles which appear to have a focus on rights. We strongly encourage that the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)² be referred to more explicitly in the draft Bill, alongside these inclusion principles.

Carers Tasmania supports the reform of this draft Bill, which seeks to ensure that legislation is “contemporary, and best practice in the regulation, reduction, and elimination of restrictive practices when they are used with people with disability.”³ Carers Tasmania provided a response in the initial stages of amending the Act, which focused on better recognition of carers, connecting them with support, and including them as valuable members of care planning teams.⁴

As the peak body representing the more than 80,000 carers in Tasmania,⁵ this response primarily focuses on how the draft Bill could better recognise and support carers who provide integral support to people with disability.

Compared with the rest of Australia, Tasmania is home to a large proportion of children who have disability, requiring significant support from a parent, or another family or friend carer.⁶ Despite this, carers often report they are not listened to or included by service providers and paid support workers. They are frequently dismissed and excluded in planning, and feel afraid to speak up, for fear of implications to support provision. In addition to the important role carers play for those they care for, just under half (43.7%) of Tasmanian carers report having some form of disability themselves.⁷

In April 2023, the *Tasmanian Carer Recognition Act 2023*⁸ was enacted. This Act formally recognises the significant contributions that unpaid carers in Tasmania provide to their family and friends who need support. It contains a Carers Charter which sets out obligations for state service agencies to recognise and support carers.

Carers Tasmania highlights the importance of including provisions to recognise, acknowledge and support carers of people with disability within the draft Bill.

¹ *Tasmanian Disability Services Act* (2011).

<https://www.legislation.tas.gov.au/view/whole/html/inforce/current/act-2011-027>

² United Nations. (2006). *Convention on the Rights of Persons with Disabilities*. OHCHR.

<https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-persons-disabilities>

³ Premier of Tasmania. (n.d).

https://www.premier.tas.gov.au/site_resources_2015/additional_releases/legislation-to-pave-a-new-way-for-tasmanians-with-disability

⁴ Carers Tasmania. (2021). *Carers Tasmania Submission to the Review of the Disability Services Act 2011*.

<https://www.carerstas.org/wp-content/uploads/2017/06/Carers-Tasmania-Submission-to-the-Review-of-the-Disability-Services-Act-2011-.pdf>

⁵ Australian Bureau of Statistics. (2021) 44300DO006_2018 *Disability, Ageing and Carers, Australia: Tasmania, 2018*. Released at 11:30am Wednesday 5 February 2020

⁶ Commissioner for Children and Young People Tasmania. (2016). *Health and Wellbeing of Tasmania’s Children, Young People and their Families Report*. <https://www.childcomm.tas.gov.au/wp-content/uploads/2016/07/CCYP-Health-and-Wellbeing-Report-Part12.pdf>

⁷ Department of Premier and Cabinet Tasmania. (n.d). *What the Data Tells us About Carers*.

https://www.dpac.tas.gov.au/divisions/cpp/community-policy-and-engagement/carer_policy_and_action_plan/carer-action-plan-2021-2025/what-the-data-tells-us-about-carers

⁸ *Tasmanian Carer Recognition Act* (2023). <https://www.legislation.tas.gov.au/view/whole/html/inforce/2023-04-20/act-2023-001>

This includes:

- Including the definition of a carer into the *Tasmanian Disability Inclusion Bill 2023*, that aligns with the *Carer Recognition Act 2023* (Tas)
- Ensuring that government agencies and disability service providers have clear pathways for the identification and referral of carers to support
- Clearly recognising carers as being essential informal advocates and integral when supported decision-making is required
- Improving inclusion of carers in support planning for people with disability
- Specific actions to foster improved engagement with carers in policy development and review, as well as within governance mechanisms.

3. Specific feedback

Whilst it is positive that the word 'carer' has been referred to several times in the draft, Carers Tasmania seeks for a definition of carer be included in the *Tasmanian Disability Inclusion Bill 2023* that reflects the definition in the *Carer Recognition Act 2023* (Tas). Without a clear definition of the term 'carer', there are opportunities for confusion. People regularly misunderstand the term carer to mean paid support worker. It must be clear that a carer is an unpaid family member or friend who provides additional support, that is separate from paid support workers. It must also be made clear that a family member, friend, or legal guardian may not necessarily always be a carer by default, rather, the term carer is dependent on whether the family member or friend provides the support that is needed. In Part 1 – Section 5: Interpretation, we recommend that the following definition be included.

Meaning of carer, as per the *Carer Recognition Act 2023* (Tas):

carer means a person who provides unpaid care and 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.⁹

Inclusion of this definition will support better understanding, recognition, and inclusion of carers, which in turn will lead to a more collaborative approach to achieve best outcomes for people with disability who have carers, or carers who themselves have disability.

The Bill must be explicit in ensuring that government agencies and disability service providers identify and refer carers to support. Carers within their own right deserve to be able to access services and information that will support their own wellbeing. This, in turn, can also assist in sustaining the caring role. Often, carers are so busy juggling their caring and other responsibilities, that they don't have time to investigate what services are available for themselves. Routine referral of carers, when identified by government agencies and disability services, is essential to ensure the wellbeing of the family unit.

⁹ Ibid.

We highlight that feedback provided to the *Disability Services and Inclusion Bill 2023* (Cth), by Carers Australia and the National Carer Network suggests the Commonwealth legislation should include a definition of the term ‘carer’, aligning to the *Carer Recognition Act 2010* (Cth).¹⁰ The important role of informal care by family members and friends is also recognised in the *Australian Disability Strategy 2021-2031*.¹¹

Carers Tasmania provided a response to the 2021 review of the *Disability Services Act 2011* (Tas). We specifically recommended referring to the upcoming Carer Recognition legislation and Carer Action Plan in any amended legislation. Pleasingly, The *DSA Review Consultation Outcomes Full Report* refers to both the Tasmanian Carer Recognition Legislation and Carer Action Plan.¹² We urge that this also be reflected in the amended Act.

Carers Tasmania also draws your attention to the items included in the Carers Charter within the *Carer Recognition Act 2023* (Tas).

1. Carers should be acknowledged as diverse and are to be treated as individuals with their own needs within, and beyond, their roles as carers.
2. Carers should be consulted in relation to the development and evaluation of policies and programs, and the provision of resources, in so far as those policies, programs and resources affect their role as carers.
3. Carers should be empowered to access information and services that are relevant to them in their role as carers.
4. Carers should be supported to participate in, and contribute to, the social, political, economic and cultural life of Tasmania, if they so desire.
5. Carers should be recognised and respected for their valuable caring role and should be supported in accessing, and engaging in, a wide range of services to ensure their well-being and to maintain their connections to their community.
6. Carers’ knowledge about the persons for whom they are caring should be respected, acknowledging that each carer, and each person being cared for, has both rights and responsibilities.
7. Carers should be able to raise concerns about decisions, and services, that affect them as carers or the persons for whom they are caring, without the carers or such persons suffering adverse repercussions, and those concerns should be dealt with as promptly as is reasonably practicable.¹³

¹⁰ Carers Australia. (2023). *Response to the Disability Services and Inclusion Bill 2023*. https://www.carersaustralia.com.au/wp-content/uploads/2023/08/110823_Response-to-Disability-Services-and-Inclusion-Bill-2023_Carers-Australia_Final.pdf

¹¹ Commonwealth Department of Social Services. (2021). *Australia’s Disability Strategy 2021-2023*. <https://www.disabilitygateway.gov.au/sites/default/files/documents/2021-11/1786-australias-disability.pdf>

¹² Department of Communities Tasmania. (2022). *DSA Review Consultation Outcomes Full Report*. https://www.dpac.tas.gov.au/___data/assets/pdf_file/0018/247320/DSA-Review-Consultation-Outcomes-Full-Report-Final.pdf

¹³ *Tasmanian Carer Recognition Act* (2023). <https://www.legislation.tas.gov.au/view/whole/html/inforce/2023-04-20/act-2023-001>

Carers Tasmania requests that the amended Act outlines how carers will be included in policy planning, development, review, and related governance mechanisms. This is not intended to take away any autonomy or decision-making capacity from people with disability, but it is important that carers have an avenue to share their experiences, thoughts, and ideas. This is specifically relevant to item two of the Carers Charter, as previously noted.

It is pleasing to see that *'family members of people with disability and carers of people with disability'* are noted under potential included members of the to-be-established Disability Inclusion Advisory Council. While it is imperative that the majority of members of this Council are people with disability, we seek for a carer to be included, and not just be listed as a possible inclusion.

A Minister's Carer Advisory Council (MCAC) has been established to monitor the implementation of the *Carer Recognition Act 2023* (Tas) and progress against the Tasmanian Carer Action Plan. The MCAC includes five members with lived or living experience as a carer. It may be appropriate to include one of the MCAC members who is a carer on the Disability Inclusion Advisory Council to ensure effective collaboration between the two Councils occurs. Likewise, a representative of the Disability Inclusion Advisory Council could also be invited to attend the MCAC.

Carers involved in the Disability Inclusion Advisory Council must be provided with adequate support and resources to enable them to participate. This may include paid respite, transport or travel reimbursement, training, and remuneration for their time and valuable expertise. It is also vitally important that people with disability have access to the resources they require to successfully support their participation.

Carers must be effectively and authentically engaged on program design and review, especially when it is relevant to their needs and circumstances. The design and review of respite is a specific and relevant example. For respite to be truly valuable, it must meet the needs of both people with disability and their carers.

The carer perspective is also incredibly important when considering the many other policy and service provisions. The valuable insight and experience that carers have to offer must not be excluded. There must always be a defined 'seat at the table' for carers. If carers are not provided with the opportunity to share their ideas on service provision, then the needs of the whole family may not be adequately met.

The following example is a quote from a carer regarding inadequate support provision. Ensuring that the carers of people with disability have their needs met is truly important to ensure that the whole family unit is supported effectively.

Carer quote:

*"I need cleaning help around the house. My 10 year old daughter is incontinent, dribbles, is clumsy with eating due to control and concentration and leaves plenty of mess. She also constantly draws on walls, tips water, and empties out contents of the 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."*¹⁴

¹⁴ Carers Tasmania. (2023). *Carers Tasmania Submission to the 22-23 NDIS Review*. <https://www.carerstas.org/wp-content/uploads/2017/06/Carers-Tasmania-submission-to-the-22-23-NDIS-Review-1.pdf>

The experiences, needs, and ideas of carers must also be considered within the context of accessible and inclusive childcare. The Honourable Federal Minister for Social Services, Amanda Rishworth has recently spoken in the media about the importance of early childhood services being inclusive and equipped to fully support children with disability. *“For children with identified disability or emerging developmental concerns, their first interactions with early intervention programs and supports can predict their future education success. It’s vital that early childhood educators have the knowledge, skills and resources at their disposal to best support young children and their families in accessing available support pathways.”*¹⁵

Childcare services and supports, particularly for children with disability or developmental delay, must understand what is required to fully support children in these circumstances. It is important that in Tasmania, carers are authentically consulted with, and included, in planning and reviewing the type of supports needed for children.

In addition to listening to, and valuing, the important knowledge provided by carers in terms of inclusive and accessible childcare for children with disability, there must be better support for children in schools who have disability, and a stronger, more collaborative approach to NDIS services being delivered at school. Again, carers must be consulted with, and truly listened to, so that children have equal opportunity to participate fully in education. This means that reasonable adjustments must be made to accommodate all children.

Carers Tasmania often hears from carers who are frustrated that there is inadequate support for their child to participate fully, safely, and effectively at school. Carers report that children are sent home or suspended when the schools don’t have the understanding or resources to effectively support them. The issue of high suspension rates in Tasmanian schools has received significant attention in the media. A recent report found that almost 9000 suspensions were handed down in Tasmanian schools last year, which included more than 60 children in kindergarten and prep.¹⁶ Another report found that in 2022, Tasmanian students with disability represented 30% of all school suspensions in Tasmanian schools.¹⁷

Upon consulting with carers to inform our responses to the *NDIS Review*¹⁸ and the *Senate Inquiry into Assessment and Support for People With ADHD*,¹⁹ Carers Tasmania heard from carers of children where their school had denied NDIS supports to be delivered at the school, despite a need for additional support to be provided. It is significant issues such as these where input from carers of children with disability or developmental delay is paramount to ensure that children can participate effectively in education with their peers and have happy and safe experiences at school.

¹⁵ Minister’s of the Education Portfolio. (2023). *New Resources to strengthen inclusion in early childhood education*. <https://ministers.education.gov.au/rishworth/new-resources-strengthen-inclusion-early-childhood-education-and-care>

¹⁶ Rob Inglis. (2022). *School figures case alarm*. https://edition.pagesuite.com/popovers/dynamic_article_popover.aspx?artguid=6fb70fe3-6227-4878-a1cd-b6c47526392a

¹⁷ The Examiner. (2023). *Tasmanian students with disability given more suspensions than others*. <https://www.examiner.com.au/story/8232018/education-head-concerned-about-vaping-and-school-suspensions/>

¹⁸ Carers Tasmania. (2023). *Carers Tasmania Submission to the 22-23 NDIS Review*. <https://www.carerstas.org/wp-content/uploads/2017/06/Carers-Tasmania-submission-to-the-22-23-NDIS-Review-1.pdf>

¹⁹ Carers Tasmania. (2023). *Carers Tasmania Submission on the Senate Inquiry into ADHD*. <https://www.carerstas.org/wp-content/uploads/2017/06/Carers-Tasmania-submission-on-the-Senate-Inquiry-into-ADHD-2023.pdf>

Carer quote:

“My son really wants to be at school, but he is ‘in the too-hard basket’. He is only 7 and has both Autism and ADHD and the school just doesn’t have the skills and resources to support him. He is frequently sent home and even suspended, suspended at the age of 7! He really wants to be there, and he deserves that opportunity. This is seriously affecting my mental health, I feel belittled, powerless, and so anxious. Not to mention how my son feels.”²⁰

Carers Tasmania requests that carers be better included and valued in supported decision-making when required by people with disability. As stated in *The United Nations Declaration of Human Rights*,²¹ and the *United Nations Convention on the Rights of Persons with a Disability* (UNCRPD),²² “all people have the right to make decisions about their own lives, including people with disability”. This includes choosing someone to assist them with decisions. Therefore, it is a fundamental right of people with disability to have someone support them with their decisions if they wish to. Carers Tasmania does not intend to diminish or remove autonomy, or decision-making capacity from people with disability, rather we seek for better inclusion of carers, when requested by people with disability, to assist in decision-making and support planning.

4. Summary of recommendations

In response to the draft *Tasmanian Disability Inclusion Bill 2023*, Carers Tasmania requests the following:

- Including the definition of a carer into the *Tasmanian Disability Inclusion Bill 2023*, that aligns with the *Carer Recognition Act 2023* (Tas)
- Ensuring that government agencies and disability service providers have clear pathways for the identification and referral of carers to support
- Clearly recognising carers as being essential informal advocates and integral when supported decision-making is required
- Improving inclusion of carers in support planning for people with disability
- Specific actions to foster improved engagement with carers in policy development and review, as well as within governance mechanisms.

²⁰ Ibid.

²¹ United Nations. (2015). *Universal Declaration of Human Rights*. https://www.un.org/en/udhrbook/pdf/udhr_booklet_en_web.pdf

²² United Nations. (2006). *Convention on the Rights of Persons with Disabilities*. OHCHR. <https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-persons-disabilities>