



**Response**  
**to the**  
**Review of the Disability Services Act 2011**  
**Discussion Paper**

**December 2021**

## 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 the 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 government and the health and community sectors to enhance service provision and improve the conditions for family carers through policy development, research and advocacy.

Carers Tasmania has offices in Moonah, Launceston and Burnie.

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## Background

Carers Tasmania acknowledge the Aboriginal and Torres Strait Islander peoples as the traditional owners of the land of lutruwita/Tasmania and we pay our respects to Elders past and present. 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.

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

Carers provide unwaged care and support to someone with disability, mental ill health, a chronic or life limiting condition, alcohol or drug dependence or who are frail or aged. Carers are predominantly family members, but may also be friends, neighbours or colleagues.

Informal carers are distinct from paid support workers who are also colloquially called 'carers', but who are fully employed and remunerated with all the benefits of employment. Conversely, informal carers perform their caring duties without remuneration, other than minimal carer payments and allowances from the Australian Government. Informal carers also do not include kinship or foster carers, unless they care for a child with disability, mental ill health or a condition as noted above.

In addition to representing carers through the Peak Body activities, Carers Tasmania also supports carers living in Tasmania through support provided by its service delivery arm, Care2Serve. The Commonwealth National Carer Gateway program is delivered through Care2Serve, as are other programs such as Home and Community Care. 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.

In addition, Care2Serve have capacity to fund certain types of planned, practical support services such as, but not limited to, in home respite, personal care, domestic assistance, and meal preparation. Care2Serve may also fund various items such as laptops to assist carers who are studying or trying to enter the workforce. Care2Serve also coordinate 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 for the carer.

## Introduction

Carers Tasmania are pleased to provide a submission on the Review of the Disability Services Act 2011 Discussion Paper ('the Paper'). We anticipate that the amended Disability Services Act ('the Act') will be inclusive of carers of people with disability and recognise the fundamental role they play in supporting their family members or friends across their life journey.

We are pleased that the consultation of carers in the process of reviewing this act was a direct action (1.6) listed in the Tasmanian Carer Action Plan.<sup>1</sup> We look forward to the Department reporting to the Carer Issues Reference Group about tangible progress made with respect to the inclusion of carers.

The review of the Act is a significant piece of work given that one in five Tasmanian's live with disability, placing Tasmania with the highest disability rate in the nation.<sup>2</sup> We acknowledge that some people with disability have carers, some do not, and some are also carers themselves.

Our submission has focused on the following priority areas, which are specifically relevant to people with disability and their carers:

- Inclusion, accessibility and leadership
- The DSA, NDIS and other national disability programs
- Regulation of providers
- Tasmanian Disability Commissioner and Disability Advisory Council
- Supported decision making

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<sup>1</sup> [https://www.communities.tas.gov.au/\\_\\_data/assets/pdf\\_file/0023/173480/Supporting-our-Carers-Action-Plan-2021-24\\_-JULY-2021.pdf](https://www.communities.tas.gov.au/__data/assets/pdf_file/0023/173480/Supporting-our-Carers-Action-Plan-2021-24_-JULY-2021.pdf)

<sup>2</sup> Survey of Disability, Ageing and Carers, 2009, Cat No 4430.0 ABS

## Key Statistics about Carers in Tasmania

The Australian Bureau of Statistics (ABS) 2018 Survey of Disability, Ageing and Carers (SDAC) revealed that there are 80,100 carers in Tasmania, representing 15.5% of the Tasmanian population.<sup>3</sup> Females accounted for 41,400 (51.7%) and males accounted for 38,000 (4.4%). The survey also found that there were 6,200 (or 11.6%) young carers aged under 25 years in Tasmania. It is pertinent to highlight that although young carers may not always be the primary carer of a person with disability, they do need to be acknowledged and supported for the contribution that they make to siblings and other family members with disability.

In the 2016 ABS Census, 49,528 people living in Tasmania reported that they were providing unpaid care to a person with disability.<sup>4</sup> This number is likely conservative as not all of these people necessarily identify themselves as a carer nor may they be recognised as carers by relevant service providers. Therefore, we are hopeful that the introduction of the Carer Recognition Legislation will assist services providing support to people with disability in Tasmania to improve the identification, inclusion and support for carers to sustain their caring roles and achieve best outcomes for the people with disability that they support.

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<sup>3</sup> 1 Australian Bureau of Statistics (2021) 44300DO006\_2018 Disability, Ageing and Carers, Australia: Tasmania, 2018. Released at 11:30am Wednesday 5 February 2020.

<sup>4</sup> Australian Bureau of Statistics Census 2016  
[http://www.censusdata.abs.gov.au/census\\_services/getproduct/census/2016/communityprofile/6?open=document](http://www.censusdata.abs.gov.au/census_services/getproduct/census/2016/communityprofile/6?open=document)

## Response to relevant topics

### Topic 1 – Inclusion, accessibility and leadership

‘The Paper’ poses the following three questions in relation to the area of inclusion, accessibility and leadership:

1. *How could the DSA be changed to advance and drive the inclusion of people with disability in the Tasmanian community?*
2. *In what ways could the DSA contribute to inclusion of people with disability in the social, economic, civic, political and cultural life of Tasmania?*
3. *What role could the DSA have in driving action and removing barriers in areas like community attitudes, employment, discrimination and in access to mainstream supports including education, health, transport and housing?*

Keeping these questions in mind, we recommend that upon release of the Act, that an updated disability framework be developed and publicly released to further assist the Tasmanian Community to implement the Act to meaningfully support people with disability in Tasmania.

There are many proposed actions noted in the *Accessible Island: Tasmania’s Disability Framework for Action 2018-2021*<sup>5</sup> and we recommend that these continue to be developed and implemented after the current framework ceases. It is our expectation that these will be reviewed regularly for progress by the Premier’s Disability Advisory Council (PDAC). We are pleased that carers are mentioned in this framework and that a place on the Council for family members of people with disability was noted in the terms of reference,<sup>6</sup> but we recommend that in future framework development that mandatory consideration be given to the inclusion of carers. By recognising, including, and supporting carers, there can be great benefit to people with disability as a result.

Further to the Act, we recommend that a Charter of Rights for people with disability in Tasmania be developed, implemented and reported upon. We envisage that the Act and Charter of Rights will assist people with disability, and their carers if required, to understand their rights and advocate to achieve their desired outcomes. We recommend that the Act and the Charter of Rights both recognise and encourage supported decision making where appropriate.

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<sup>5</sup>

[https://www.communities.tas.gov.au/\\_\\_data/assets/pdf\\_file/0033/17997/Accessible\\_Island\\_Disability\\_Framework\\_for\\_Action\\_2018-2021.pdf](https://www.communities.tas.gov.au/__data/assets/pdf_file/0033/17997/Accessible_Island_Disability_Framework_for_Action_2018-2021.pdf)

<sup>6</sup>

[https://www.communities.tas.gov.au/\\_\\_data/assets/pdf\\_file/0021/16365/PDAC\\_Terms\\_of\\_Reference\\_2021.pdf](https://www.communities.tas.gov.au/__data/assets/pdf_file/0021/16365/PDAC_Terms_of_Reference_2021.pdf)

### **Topic 3 – The DSA, NDIS and other national disability programs**

The Act needs to ensure that non-NDIS disability programs remain accessible and continue to link people with disability and their carers to adequate wrap around support. People with disability should not miss out on support regardless of their NDIS status. For some people, particularly those experiencing psychosocial disability, their symptoms can be episodic, and they may not want to apply for the NDIS. The Act must ensure that people with disability can access services appropriate to their needs. We also recommend that all disability services routinely identify carers of people with disability and refer them to access support to sustain their caring role.

### **Topic 5 – Regulation of providers**

The NDIS is now supporting over 10,000 Tasmanian participants.<sup>7</sup> Despite this number, there are still many people with disability who rely on non-NDIS supports, therefore it is essential that there is adequate regulation of these services through appropriate frameworks that are specific to each service providing support.

The NDIS Code of Conduct<sup>8</sup> and the NDIS Practice Standards<sup>9</sup> should not be relied on for use by non-NDIS providers as they are not specifically intended for those services. Despite that, the NDIS Code of Conduct does apply to unregistered providers despite these providers not being overseen by the Scheme. We recommend that all services adhere to the Tasmanian Disability Services Regulations<sup>10</sup> regardless of being an NDIS provider or not, but in addition, NDIS services must adhere to the national NDIS Practice Standards and the NDIS Code of Conduct.

In either scenario, what is essential is that people with disability and their carers are provided with information on the standards and code of conduct which directly relate to the support that they are in receipt of. We must not assume that all people with disability and their carers are able to access the standards and code of conduct relevant to their situations, and services should be providing these documents regularly as best practice.

### **Topic 6 – Tasmanian Disability Commissioner and Tasmanian Disability Advisory Council**

As an additional measure towards improving quality and safeguarding for people with disability, we welcomed the Tasmanian Government's funding commitment for the appointment and implementation of a Disability Services Commissioner. We support this as a positive movement which translates to a consistent approach nationally. We are hopeful that a Tasmanian Disability Commissioner will further support and strengthen the rights of people with disability in Tasmania and support continuous improvements in the provision of supports and services for people with

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<sup>7</sup> <https://tas.liberal.org.au/securing-tasmanias-future-supporting-people-disability>

<sup>8</sup> <https://www.ndiscommission.gov.au/providers/ndis-code-conduct>

<sup>9</sup> <https://www.ndiscommission.gov.au/providers/ndis-practice-standards>

<sup>10</sup> <https://www.legislation.tas.gov.au/view/html/inforce/current/sr-2015-016>



disability. A primary function of the Disability Commissioner must be to enable a clear pathway for people with disability, their carers or other relevant family members to raise concerns or complaints about the provision of any disability support service. It is essential for carers to be welcomed, supported and encouraged to raise any issues that they may identify regarding the people that they care for and in turn be provided appropriate information about their rights in relation to the issues that they seek assistance for. Furthermore, we are hopeful that the Disability Commissioner will be able to facilitate referrals to other services where appropriate and provide information and education to disability service providers.

We recently conducted a survey to explore and understand what carers believe should be included in the Carer Recognition Legislation. We identified that many carers are scared to complain about services for fear of reprisal or that they are unaware of how to make a complaint about services.<sup>11</sup> This is disappointing, particularly considering that these families may be accepting inadequate support, rather than the best support possible. Inadequate support provision can significantly reduce the quality of life for people with disability and their carers and has potential to cause negative outcomes. People with disability and their carers need to feel supported and able to make complaints without fear of negative consequences. We are optimistic that the introduction of the Disability Commissioner will facilitate an avenue for positive change in this respect.

In addition to the implementation of a Disability Commissioner, we support TasCOSS in their recommendation of establishing a Disability Advisory Council in Tasmania as part of the Act.<sup>12</sup> We understand that the Premier's Disability Advisory Council (PDAC) already exists, but we hope that the council could expand their work more broadly than the main focus of reporting on Tasmania's Disability Framework. Furthermore, we hope that the group will liaise regularly with the Minister for Disability, Ageing and Carers. For a fully collaborative approach, we recommend that the group include people with disability and their carers, in a similar makeup to the PDAC.

Carers Tasmania notes that for carers to assert their rights and to have support to advocate for those rights is problematic given that no specific advocacy service exists for individual carers. For carers of someone with disability, this is a service gap that must be addressed through targeted funding in future budget measures.

## **Topic 7– Supported Decision Making and consultation**

Supported decision making has been described as a best practice approach aiming to enhance the ability of people with disability in making their own decisions.<sup>13</sup> We recommend supported decision making to be included as a fundamental principle

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<sup>11</sup> <https://www.carerstas.org/wp-content/uploads/2021/12/Carers-Tasmania-Response-to-the-Carer-Recognition-Legislation-Discussion-Paper.pdf>

<sup>12</sup> [https://tascoss.org.au/disability-services-act-review/?utm\\_source=rss&utm\\_medium=rss&utm\\_campaign=disability-services-act-review](https://tascoss.org.au/disability-services-act-review/?utm_source=rss&utm_medium=rss&utm_campaign=disability-services-act-review)

<sup>13</sup> [https://www.nds.org.au/images/resources/People\\_with\\_Disability\\_and\\_SDM-Guide\\_for\\_NDIS\\_Providers\\_in\\_NSW.pdf](https://www.nds.org.au/images/resources/People_with_Disability_and_SDM-Guide_for_NDIS_Providers_in_NSW.pdf)

underpinning all functions of the Act. It is crucial to highlight the importance of ensuring the ongoing application of supported decision making and consultation.

As stated in *The United Nations Declaration of Human Rights*,<sup>14</sup> the *United Nations International Covenant on Civil and Political Rights*,<sup>15</sup> and the *United Nations Convention on the Rights of Persons with a Disability (CRPD)*,<sup>16</sup> all people have the right to make decisions about their own lives, including people with disability. This is based upon the concept that every person has the 'capacity' to make appropriate and safe decisions. Some people with disability rely heavily on support from carers such as family members or friends to assist them in making safe and appropriate decisions about things, such as health, medical treatments, which supports they would like, what they would like to do on a daily basis, what their own life goals and plans are and where they want to live. If a person with disability does have capacity to make their own decisions but would like support to do so from a family member or friend, it is imperative to include the carer throughout the decision-making process.

Carers Tasmania are certainly not proposing that carers are automatically made the decision maker for people with disability in every situation. However, carers must be routinely identified, recognised and provided with appropriate information about their own right to be included as part of the supported decision making process, either where a person with disability does not have capacity to make their own decisions, or where a person with disability wants their carer involved in any decision-making process.

There are cases where a person with disability may be deemed to legally not have capacity to make their own decisions, and in turn this results in the appointment of a guardian who is legally granted authority to make decisions. We recommend that decisions are still made in consultation with the person with disability or the family carer of the person with disability (in cases where there is a public guardian appointed).

In 2019, Carers Tasmania conducted the survey: *Impact of the NDIS on Carers in Tasmania: the story so far*.<sup>17</sup> The results demonstrated that whilst programs such as the NDIS have great potential to achieve positive outcomes for eligible people with disability, many carers reported that they had not been included in the process of planning or organising supports for their loved ones, nor where they provided adequate information, which resulted in inadequate funding and service provision, placing greater levels of stress on the carers. Sometimes people with disability are not able to fully articulate their needs or what their day-to-day life does or could look like. Carers play a vital role in ensuring that NDIS planners understand support needs and goals for people with disability. The provision of a Carer Impact Statement should be a mandated part of the NDIS planning and review processes.

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<sup>14</sup> [https://www.un.org/en/udhrbook/pdf/udhr\\_booklet\\_en\\_web.pdf](https://www.un.org/en/udhrbook/pdf/udhr_booklet_en_web.pdf)

<sup>15</sup> <https://www.ohchr.org/en/professionalinterest/pages/ccpr.aspx>

<sup>16</sup> [https://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg\\_no=IV-15&chapter=4&clang=\\_en](https://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg_no=IV-15&chapter=4&clang=_en)

<sup>17</sup> <https://www.carerstas.org/wp-content/uploads/2017/06/NDIS-Survey-2019.pdf>

Despite the great work that disability services provide, carers are the backbone supporting people with disability in Tasmania by ensuring that all the supports that disability services are unable to provide are provided. Caring can be both rewarding and challenging, and sometimes is a 24/7 journey. Carers go above and beyond, and more often than not put their own health and wellbeing at risk. By ensuring that people with disability receive adequate support, carers will also be supported to maintain their own wellbeing and fulfil their responsibilities and goals aside from their caring role.

## Conclusion

Carers Tasmania welcome the Tasmanian Government's commitment to further support people with disability living in Tasmania. We are hopeful that changes to the Act and associated frameworks will facilitate positive change for people with disability in Tasmania. We also acknowledge the work that many informal carers in Tasmania provide in supporting people with disability and recommend that they be recognised, included and supported, to enable the best support possible for people with disability by taking a safe, person-centred and inclusive approach.