



Response to the Australian Government

NDIS Review

‘Our Approach’ Paper

January 2023

About Carers Tasmania

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

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

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

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

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

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

Carers Tasmania has offices in Moonah, Launceston and Burnie.

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1. Background

Carers Tasmania acknowledges the Aboriginal and Torres Strait Islander peoples as the traditional custodians 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 in 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 are frail or aged. A carer may also be a kinship carer of a child under the age of 18. Carers are predominantly family members, but may also be friends, neighbours, or colleagues. Informal carers are not to be confused with paid support workers who are often called 'carers', with the difference being that support workers are fully employed and remunerated with all the benefits of employment. On the contrary, informal carers perform their caring duties without remuneration, other than minimal carer payments and allowances from the Australian Government.

In addition to representing carers through the Peak Body activities, Carers Tasmania provides support to carers living in Tasmania through its service delivery arm, Care2Serve. The Commonwealth Carer Gateway program is delivered through Care2Serve, 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 review of the National Disability Insurance Scheme (NDIS) which was announced by The Minister for NDIS, the Hon Bill Shorten MP on 18 October 2022. We strongly believe that this review has initiated an important opportunity to investigate the current strengths of the NDIS, the challenges, and the opportunities for improvement. We are pleased to provide this initial response to the ‘*Our Approach*’¹ paper.

The NDIS was first introduced in Tasmania on 1 July 2013 and is now available to all people who meet the disability evidence requirements prior to the age of 65 years. The last cohort of Tasmanians to be eligible to access the NDIS in Tasmania as of January 2019 were adults aged 50 to 64. Although the primary focus of Carers Tasmania is to support people who care for a family member or friend, this review is significant as many Tasmanian carers support someone with disability or mental ill health.

There are more than 80,000 carers in Tasmania, and it is estimated that over one quarter (26.8%) of all Tasmanian people have some form of disability,² and approximately 11.5% have mental ill health.³ In addition, many carers have some form of disability⁴ or health concern themselves.

In Tasmania, 13,103 participants (excluding children accessing early connections) have had an approved plan since July 2013 and as of 30 September 2022, there were 12,493 people in Tasmania in receipt of support under the NDIS.⁵ Furthermore, as of September 2022, Tasmanian Northern partner Baptcare had the highest number (3,605) of active participants, whilst the Tasmanian South Eastern partner Mission Australia had the lowest number of active participants (2,792). The North West partner Mission Australia had 2,799 active participants and the South West partner Baptcare had 3,296.⁶

Whilst 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, we highlight that a key priority of ours is improved recognition, consideration, and inclusion of informal carers. Without informal carers, the NDIS won’t work effectively. When there are barriers to accessing formal services and support, it is carers who end up providing what is required. This often results in carers missing out on employment, experiencing financial loss, lack of time for self, lack of connection with others, and poor health and wellbeing outcomes.

We must ensure that the voice of Tasmania’s carers is heard clearly, valued, and included throughout this NDIS review process, and we hope that carers in other parts of Australia also have this same opportunity. Whilst our submission will take specific focus on carers in Tasmania, we also advocate collectively with the National Carer Network of state and territory carer organisations for improved carer recognition, inclusion, and access to required and appropriate support.

¹ <https://www.ndisreview.gov.au/sites/default/files/resource/download/ndis-review-our-approach.pdf>

² [https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release#:~:text=over%20one%2Dquarter%20\(26.8%25\),South%20Australia%20\(both%2019.4%25\).](https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release#:~:text=over%20one%2Dquarter%20(26.8%25),South%20Australia%20(both%2019.4%25).)

³ <https://www.abs.gov.au/census/find-census-data/quickstats/2021/6>

⁴ https://www.dpac.tas.gov.au/divisions/cpp/community-policy-and-engagement/carers_policy_and_action_plan/carers-action-plan-2021-2025/what-the-data-tells-us-about-carers

⁵ <https://www.ndis.gov.au/about-us/publications/quarterly-reports>

⁶ Ibid.

Carers Tasmania has supported the development and distribution of the 2020⁷ and 2022⁸ *National Carer Surveys*, which have provided valuable insights into the experience of supporting a person who has an NDIS plan. We have also conducted two surveys, one in 2017⁹ and one in 2019¹⁰, both named *'The Impact of the NDIS on Carers in Tasmania – The Picture So Far'*.

3. What we already know

2017 Survey key findings

The 2017 survey¹¹ provided carers an opportunity to share their experience in supporting someone on the NDIS. The results were not overly positive and outlined key issues such as:

- Not feeling heard or included, creating a need to advocate for involvement
- Limited availability of appropriate supports
- Issues with communication and processes
- A continued need to provide significant care, and navigate a complex system despite NDIS supports being in place
- The time-consuming nature of finding and accessing supports
- Forms of respite being counterbalanced by high administrative responsibilities
- Low confidence in receiving adequate high-quality support into the future

Furthermore, the survey found that almost 70% of respondents indicated that nothing had directly changed for them as a result of the NDIS plan for the person they care for. In terms of having more time for themselves, some carers reported they had less time with an NDIS plan in place, which was likely due to a high burden of administrative tasks.¹²

2019 Survey key findings

Results of the 2019 survey¹³ indicated that some carers had started seeing positive outcomes for the people they care for, which in turn has assisted the development of some confidence in navigating the system. Despite 30% of respondents reporting significant improvements for the person they cared for as a result of the NDIS, many carers indicated they felt overwhelmed and distressed. More than 20% of carers said they had experienced very little, or no improvement and 35% said it was still too early to tell.

75% of respondents caring for a person assessed as ineligible for the NDIS reported that they had no contact with a Local Area Co-ordinator (LAC), despite part of an LAC's role being to assist people ineligible for the scheme to access community support.

Varying levels of carer inclusion were reported in the development of plans and whilst this result may be reflective of the number of people who do not wish their carer to be involved in

⁷ https://www.carerstas.org/wp-content/uploads/2017/06/FINAL-CTAS-National-Carer-Survey-Report-3_compressed.pdf

⁸ <https://www.carersnsw.org.au/uploads/main/Files/5.About-us/Our-research/2022-National-Carer-Survey-National-Highlights.pdf>

⁹ <https://www.carerstas.org/wp-content/uploads/2017/06/010417CTAS-NDIS-Survey-Report.pdf>

¹⁰ <https://www.carerstas.org/wp-content/uploads/2017/06/NDIS-Survey-2019-FINAL.pdf>

¹¹ <https://www.carerstas.org/wp-content/uploads/2017/06/010417CTAS-NDIS-Survey-Report.pdf>

¹² Ibid.

¹³ <https://www.carerstas.org/wp-content/uploads/2017/06/NDIS-Survey-2019-FINAL.pdf>

their relationship with the NDIS, this may also suggest a lack of consistent carer-inclusive culture within the NDIS.

There were varying responses around whether carers thought that the plan for the person they care for would effectively meet their needs, and more than 60% of respondents said it was either challenging or very challenging to find services identified in the plan. When the needs of the participant are not being met in the plan, it is reasonable to conclude that the burden of care continues to fall to the carer.

Carers' general comments suggested there was difficulty in navigating the NDIS system, and that they often are provided only minimal information regarding opportunities for involvement.

Carer Recognition Legislation Survey

In 2021, Carers Tasmania conducted a survey to help inform our initial response to the introduction of Tasmanian carer recognition legislation.¹⁴ Carers Tasmania conducted a survey as part of engagement on the topic and it found that from 140 respondents supporting someone on the NDIS in Tasmania, over 80% had never been told that they could submit a carer impact statement ($n=116$). This alarming shows that the experiences of the carers supporting the person with the application are not considered.

Being encouraged to provide a carer impact statement fits within the banner of carer recognition and may support carers to access specific carer support. It may also have an effect on the level and types of funding implemented in a person's plan as a more holistic picture can be provided. Whilst we understand the importance of taking a person-centred focus on the participant and are cognisant that some carers may not want to provide a carer impact statement, we recommend that a consistent approach is taken and that as part of every planning stage, questions are asked about whether there is a family or friend carer and if so they should be asked if they would like to be connected to carer support such as carer gateway and provided with information and the opportunity on how to write a carer impact statement.

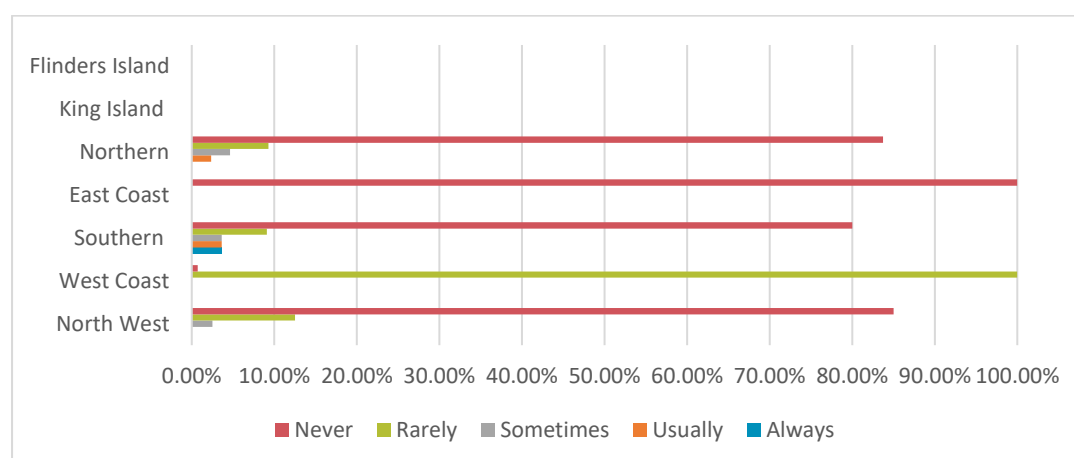


Figure 1: How often were you told about a carer impact statement?

¹⁴ <https://www.carerstas.org/wp-content/uploads/2017/06/Carers-Tasmania-Response-to-the-Carer-Recognition-Legislation-Discussion-Paper.pdf>

Initial Tasmanian results from the 2022 National Carer Survey

Initial Tasmanian results from the 2022 National Carer Survey¹⁵ highlighted a range of varying experiences in terms of whether carers felt included, asked about their own needs, and provided with relevant information throughout the NDIS process for the person they care for. The following tables show the varying experiences, positives, and challenges.

Alarming, more than 40% of carers (see figure 2 below) disagree or strongly disagree that they have been asked about their needs as a carer in the context of NDIS.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Strongly disagree	39	5.6	23.9	23.9
	Disagree	33	4.8	20.2	44.2
	Neither agree nor disagree	32	4.6	19.6	63.8
	Agree	41	5.9	25.2	89.0
	Strongly agree	18	2.6	11.0	100.0
	Total	163	23.6	100.0	
Missing	System	528	76.4		
Total		691	100.0		

Figure 2: Asked about my needs as a carer (NDIS)

72.1% reported that they agree or strongly agree that they have been involved in planning and decisions about NDIS (see figure 3), however, only 30.6% agreed or strongly agreed that the NDIS met their needs as a carer when they couldn't provide care. This shows that despite carer involvement, there is a lack of actual appropriate practical support that will lessen some carer responsibility (figure 4).

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Strongly disagree	8	1.2	4.8	4.8
	Disagree	14	2.0	8.5	13.3
	Neither agree nor disagree	24	3.5	14.5	27.9
	Agree	79	11.4	47.9	75.8
	Strongly agree	40	5.8	24.2	100.0
	Total	165	23.9	100.0	
Missing	System	526	76.1		
Total		691	100.0		

Figure 3: Involved in planning and decisions about services (NDIS)

¹⁵ Carers NSW, 2022: 2022 National Carer Survey. Unpublished Dataset. North Sydney: Carers NSW

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Strongly disagree	35	5.1	23.8	23.8
	Disagree	32	4.6	21.8	45.6
	Neither agree nor disagree	35	5.1	23.8	69.4
	Agree	30	4.3	20.4	89.8
	Strongly agree	15	2.2	10.2	100.0
	Total	147	21.3	100.0	
Missing	System	544	78.7		
Total		691	100.0		

Figure 4: NDIS met my needs as a carer (e.g were available when I couldn't provide care)

Less than half (48.2%) of carers agreed or strongly agreed that they received all of the information they required about the NDIS. Quite often, carers report feeling overwhelmed, stressed and not sure what they can and can't ask for, who they should talk to or what process they should follow to access the correct support for the person they care for.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Strongly disagree	17	2.5	10.2	10.2
	Disagree	26	3.8	15.7	25.9
	Neither agree nor disagree	43	6.2	25.9	51.8
	Agree	49	7.1	29.5	81.3
	Strongly agree	31	4.5	18.7	100.0
	Total	166	24.0	100.0	
Missing	System	525	76.0		
Total		691	100.0		

Figure 5: Provided with all the information I needed (NDIS)

Having adequate breaks from providing care is essential for maintaining the wellbeing of carers. Carers who have good wellbeing, as opposed to poor wellbeing, may also be more effective at caring. Despite this, we often hear from carers who are facing or have experienced burnout or other negative health events because they have little time for self. Only 40.7% of carers reported that they agree or strongly agree that the NDIS plan assisted them to have a break from care.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Strongly disagree	42	6.1	26.3	26.3
	Disagree	28	4.1	17.5	43.8
	Neither agree nor disagree	25	3.6	15.6	59.4
	Agree	39	5.6	24.4	83.8
	Strongly agree	26	3.8	16.3	100.0
	Total	160	23.2	100.0	
Missing	System	531	76.8		
Total		691	100.0		

Figure 6: Gave me a break from providing care (NDIS)

In addition, less than a quarter (24.3%) of carers reported that the NDIS enabled them to keep their job or go back to work.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Strongly disagree	36	5.2	35.0	35.0
	Disagree	19	2.7	18.4	53.4
	Neither agree nor disagree	23	3.3	22.3	75.7
	Agree	14	2.0	13.6	89.3
	Strongly agree	11	1.6	10.7	100.0
	Total	103	14.9	100.0	
Missing	System	588	85.1		
Total		691	100.0		

Figure 7: Enabled me to keep my job or go back to work

NDIS Quality and Safeguards Commission:

The following data represents the number of Tasmanian complaints to the NDIS Quality and Safeguards Commission throughout 2021 and 2022.¹⁶ Despite these being relatively small numbers compared with the number of NDIS participants in Tasmania, we know that many people do not complain for various reasons and accept support as it is.

Jan-June 2021	Jul-Dec 2021	Oct-Dec 2021	Jan-March 2022	April-June 2022	July 2022-September 2022
68	78	47	40	16	32

Figure 8: Tasmanian complaints to NDIS Quality and Safeguards Commission

¹⁶ <https://www.ndiscommission.gov.au/resources/reports-policies-and-frameworks/ndis-commission-activity-reports#paragraph-id-5981>

4. Our approach to the NDIS review

We are aiming to connect with many carers supporting someone on the NDIS, carers of people who have been deemed ineligible for the NDIS and carers who may have an NDIS plan themselves. It is vital that carers are able to have their say and that their own individual experiences and needs are heard in their own right, as well as the experiences they are able to share about those for whom they care.

We intend to widely share the NDIS review team surveys on social media and via communication methods such as email and post to carers, community, and stakeholders.

We have also developed a survey for people in Tasmania caring for someone who is an NDIS participant, or has a disability but is not an NDIS participant. We will be facilitating a range of statewide community discussions on the topic as well as connecting with relevant stakeholder groups and service providers.

Feedback by phone conversation, email, face-to-face discussions, and zoom sessions will be encouraged and we will collate the feedback and experiences we hear into written submissions towards the NDIS review.

5. Early recommendations

We understand that the review team is keen to hear about easy-to-implement changes throughout the whole review process. At this stage, we propose some small recommendations which could make a significant positive difference. We want to highlight that there is significant reform underway in the carer space with change happening in the areas of work and care and carer leave. There is also a commitment toward a National Carer Strategy and an updated National Carer Recognition Act. Progress is underway in Tasmania to finalise the long-awaited Carer Recognition Legislation to ensure increased recognition and better support of Tasmanian carers. We propose the following initial recommendations which mostly relate to routine identification and referral of carers within the scope of the NDIS:

- Including a specific question about whether applicants have a carer on the access request form (ARF)
- At the planning stage, participants must be routinely asked if there is a carer and carers should be informed of the opportunity to submit a carer impact statement
- Prompt referral to Carer Gateway must occur whenever a carer is identified. If a carer does not wish to be referred, they should be provided with relevant information to self-refer, noting that there are extremely low numbers of referrals from Tasmanian NDIS partners to Carer Gateway
- There must be clearer reporting about carers in the participant and families/carers outcomes reports as carers are bundled into families. There must be a clear differentiation between families, friends and carers throughout the NDIS and any NDIS documentation as carers and families are not always interchangeable terms. On the same token, carers must be clearly identified in the participant information packs for the NDIS Quality and Safeguards Commission Papers
- Carer awareness must be included as a standard element of the NDIS worker induction modules

6. A collaborative approach

We are optimistic that this review will provide an opportunity for increased carer awareness throughout the entirety of NDIS processes. Increased awareness and inclusion of carers will lead to better outcomes for participants. We are hopeful that the review team will take on board feedback from carers, Carers Tasmania, and the National Policy Working group of state and territory organisations, and further translate this feedback into effective actions to make positive change.

We strongly encourage the review team to remain connected with us throughout the whole review process to ensure that carers have the opportunity to be heard. Although we are effective and passionate conduits for sharing the voice of carers, there must be adequate opportunities for carers to share their thoughts and stories directly with the review team.

We will provide submissions and recommendations as relevant throughout the entirety of the review process and we look forward to hearing and sharing the voices of carers to the NDIS review team.