

Carers Tasmania



Introduction

Carers Tasmania is the main provider in Tasmania of support services to unpaid family and friend carers. There are 84,000 carers in Tasmania – a proportion of whom care for people with a disability under the age of 65 years and provides this feedback on the draft Individual Planning Framework as the peak body for carers in Tasmania.

Background

Carers Tasmania provided a submission to the Review of the Disability Services Act 2011. A number of issues we raised are listed as matters for consideration in future review in the Report of the Review Committee 29 June 2018 including:

- The role of Carers could be made more explicit under individual plans
- Carer roles could be made more explicit in a new state act and that the Anti-Discrimination Act may be relevant to the review, particularly where it states it is unlawful to discriminate on the basis of family responsibilities.
- That consumers, carers and family members need to be communicated with about the use of restrictive practices with “dignity respect and compassion” using the Principles for Communicating about Restrictive Practices with Consumers and Carers published by the National Health Commission.

Carers Tasmania bases these arguments on the following facts about carers:

Carers underpin the disability care system and provide 74% of all community care¹ some care for longer periods, some for shorter periods. In Tasmania, 28,300 are primary carers, 55% of whom provide care for >20 hours per week². In the 2016 ABS census 49,528 people in Tasmania reported that they provided unpaid assistance to a person with a disability³.

Caring can take an emotional, physical and financial toll on carers without the right level of support, and impact significantly on work, study and economic participation opportunities as well. Carers do not receive the benefits that come with paid employment either.

¹ Australian Bureau of Statistics (2014) Caring in the Community, Australian Summary of Findings, 2012.

² Australian Bureau of Statistics (2017) 2015 Survey of Disability, Ageing and Carers, <http://www.abs.gov.au/ausstats/abs@.nsf/mf/4430.0> accessed on 17/08/2017

³ Australian Bureau of Statistics Census 2016

http://www.censusdata.abs.gov.au/census_services/getproduct/census/2016/communityprofile/6?opendocument accessed on 21/08/2017

Carers and the NDIS

Almost 70% of carers who participated in Carers Tasmania's 2017 survey "The impact of the NDIS on Carers in Tasmania – the Impact So Far"⁴ said nothing had changed for them directly or they had less time out for themselves since the NDIS plan was activated. Carers Tasmania's 2018 survey is currently open, and we look forward to its findings one year further into the implementation of NDIS.

Carers Australia, and the State and Territory Associations have done significant work around the needs of carers supporting those they care for through the NDIS process, and how to articulate their right for inclusion in this process.

Issues for consideration in the Disability Service Individual Planning Framework

Carers Tasmania agrees the Individual Planning Framework used for Disability Services in Tasmania should replicate the approach of NDIA with a focus on self-determination, choice and community engagement. The approach taken could also take into account the Federal Carer Recognition Act 2010⁵; particularly its Statement for Australia's Carers which states:

- 1 All carers should have the same rights, choices and opportunities as other Australians, regardless of age, race, sex, disability, sexuality, religious or political beliefs, Aboriginal or Torres Strait Islander heritage, cultural or linguistic differences, socioeconomic status or locality.
- 2 Children and young people who are carers should have the same rights as all children and young people and should be supported to reach their full potential.
- 3 The valuable social and economic contribution that carers make to society should be recognised and supported.
- 4 Carers should be supported to enjoy optimum health and social wellbeing and to participate in family, social and community life.
- 5 Carers should be acknowledged as individuals with their own needs within and beyond the caring role.
- 6 The relationship between carers and the persons for whom they care should be recognised and respected.
- 7 Carers should be considered as partners with other care providers in the provision of care, acknowledging the unique knowledge and experience of carers.
- 8 Carers should be treated with dignity and respect.

⁴ Carter, D. Favelle, S, Arnold, J. (2017) A report on: "The Impact of the NDIS on Carers in Tasmania – The Picture So Far".

⁵ Australian Government (2010) Carer Recognition Act 2010

9 Carers should be supported to achieve greater economic wellbeing and sustainability and, where appropriate, should have opportunities to participate in employment and education.

10 Support for carers should be timely, responsive, appropriate and accessible.

Tasmania has a Tasmanian Carer Policy⁶ which could also be considered and includes principles relevant to the Individual Planning Framework including:

- Carers are to be acknowledged and treated as individuals with their own needs within and beyond their caring role.
- Carers are to be provided with relevant information and referred to appropriate services to assist them in their caring role.
- Carers are to be respected as valued members of a care team.
- To the extent possible, carers are to be supported to enjoy optimum health, social and economic wellbeing, and access to educational and employment opportunities.
- The carer and the person receiving care are to be regarded as a partnership, in which each person has rights and responsibilities.

Replication NDIS carer inclusion in the Individual Planning Framework

Based on these rights and the desire to provide a framework replicating the NDIS, the Individual Framework could consider including the following that are offered directly and indirectly through via NDIA in their plans:

- Family support and counselling due to a person's disability
- Building the skills and capacity of other family members to manage the impact of a participant's disability on family life
- Supports that increase the participants independence as well as supports that enable the participant to enjoy social and community activities independent of their informal carers
- Supports aimed at increasing the sustainability of family caring arrangement, including personal care and domestic assistance related to the person's disability
- Requesting a support worker to be included in family outings to provide assistance and guidance for the person with disability, especially where the family has other children to supervise and engage with. This allows for the person with disability to be included in family events and outings and provides opportunity for social participation.

⁶ Tasmanian Government Department of Premier and Cabinet, Communities, Sport and Recreation (2016) Tasmanian Carer Policy 2016

When Carers Tasmania supports a carer navigating the NDIS process with the person they care for, the following advice is provided.

- To complete Carers Australia's carer checklist to outline the type of care and support they currently provide to help consider the person with a disability's needs. This is helpful for the planning meeting.
- To consider the option of providing a Carer Statement or request a separate interview. The carer statement can include the impact of the caring role (on work, study, travel, social, cultural or religious engagement activities) , whether the carer is able and willing to keep caring for the person with disability in the same way into the future, any other informal supports the person has.

Specific Feedback on the Draft Individual Planning Framework

- There may be the need for an easy English version of the framework to be made available for individuals, including family and carers who are supporting a person with a disability.
- Carers Tasmania is pleased to see Disability and Community Services acknowledging the need for family focused planning that is respectful of each individual's role. This could be included as a separate principle. As it is currently written there is risk the need of family is missed under the heading of person centred, and particularly, "where relevant consider and respect the role of family", as this may leave family inclusion to the subjective approach of the service provider or worker.
- Carers could also have their own heading under roles and responsibilities and these could be taken directly from the Principles of the Tasmanian Carer Policy. While the carer may have the role of being the Person Responsible, they may not be, and their separate inclusion would allow for this, and their own needs and role to be acknowledged.
- Where an individual does not want to have a plan, the strategy of involving and providing the plan to a family member, with consent, could be included.
- Disability Service Provider Responsibilities could explicitly state the need to engage with family carers rather than "other parties" in the shared understanding of goals.
- The goals and strategies section of the individual plan could also have a section that includes and considers the needs of the carer and how they are best supported. This could include a referral to other supports such as Carers Tasmania who can then assess their individual health and wellbeing and make appropriate referrals. This ensures the carer is sustained in the care they provide to the individual.
- The relationships domain in the individual planning could also consider the current caring relationship and any issues that exist in this area. This could include an individual's desire to have more autonomy from the person they care for, the carer's desire to increase their work or study hours. It may also acknowledge the roles of more than one person as a carer – i.e. there may be siblings who are secondary

carers who also have their own needs that could be addressed through a referral to Carers Tasmania.

- It is positive to see actual and potential risks to an individual mentioned in the resources and supports section. This could also consider what supports are necessary for a family carer to sustain them in their role, or contingencies for the carers gradual decline in their capacity to provide support as they age, or if circumstances change.

Specific feedback on the Individual Plan Template:

Based on the need for carer inclusion mentioned throughout this feedback, it may be useful to provide a section dedicated to the carer. This could replicate the about you section for the individual and include:

- What is going well in terms of the caring role/what is difficult
 - Do they have any other caring responsibilities?
 - Are there any other family circumstances that may impact on the support they provide to the individual?
 - Are there any other family members who help support the individual?
 - Do they have any concerns about safety?
 - Are there any areas of care that haven't been mentioned by the individual that need to be included?
 - Do they have a role in co-ordinating/communicating with services? How would they like to be included?
 - How is their physical and mental health?
 - Do they have any needs that aren't able to be met due to caring –e.g. looking after health and wellbeing, meeting other family responsibilities, work/study?
 - What services do they have in place for themselves?
 - Would they like to talk about planning for a time when they are no longer able to continue to care?
- Daily life – this table may not provide adequate space for the complexity of the supports provided in this area.
 - Transport – carers should be included under the heading as they are often a key provider of transport.
 - A carer may need to be included in the development of goals, or be informed of what they are, as there may be strategies that need to include them or unexpected consequences without considering their perspective.
 - The checklist at the back of the plan could include have carers (including young carers) been identified and included.

Summary:

Carers are key contributors to the care of people with disability in Tasmania. As a peak body, Carers Tasmania has great interest in the inclusion and consideration of carers in any Tasmanian form and is interested and willing to assist in the further development of the Individual Planning Framework as required.