

Response to the Final Report for the Development of Tasmania's Community-wide Literacy Framework

**March 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 is the Peak Body representing the more than 80,000 informal carers within the state.

We acknowledge the traditional owners of the lands and waters upon which we work, live, and sustain ourselves. This land was never ceded, and we acknowledge that the Tasmanian Aboriginal people are its continuing custodians. 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. We value and respect the diversity of carers, their lived and living experiences, and recognise that carers are the experts in their own lives.

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.

#### 1. Introduction

Carers Tasmania believes that all Tasmanians should be supported to continuously develop their literacy skills to enable meaningful participation in their lives. However, we acknowledge the large gaps in literacy in Tasmania, with approximately 50% of Tasmanians struggling with basic literacy skills.<sup>1</sup>

Whilst we are pleased that carers have been briefly identified within the Framework Report,<sup>2</sup> the commentary around carers does not provide a deep enough insight into the literacy challenges and needs experienced by carers. Rather, the term carer has mostly been used within the context of the broader collective of parents, families, and carers. Carers Tasmania notes that it, as the peak carer organisation in the state was not invited to participate in this consultation process and hopes that this can be improved in the future.

The Australian Bureau of Statistics 2018 *Survey of Disability, Ageing and Carers* (SDAC)<sup>3</sup> revealed that there were 80,100 carers in Tasmania, representing 15.5% of the Tasmanian population. Of these carers, females accounted for 41,400 (51.7%) and males accounted for 38,000 (47.4%). The report also found that there were 9,300 (11.6%) young carers aged under 25 years living in Tasmania. Furthermore, 43.7% of carers living in Tasmania have disability themselves, which is higher than the 22.9% of people with disability from the Tasmanian population of non-carers.<sup>4</sup>

For carers, having adequate literacy skills is paramount to effectively support their needs and goals in life and those of the people for whom they care.

## 2. Carers and literacy

As described in our 2019 response<sup>5</sup> to the *Draft Tasmanian Adult Learning Strategy*,<sup>6</sup> "every component of adult learning is relevant to carers."

The following items were outlined in the Draft Strategy<sup>7</sup> and further explained in how they fit within the context of the caring role:

- Building literacy and numeracy: Carers may experience gaps in learning due to their caring responsibilities and should be supported in appropriate ways to strengthen and keep their skills up to date. Young, adult carers who are studying at college, TAFE, and university may need additional support and flexibility.
- **Digital literacy skills:** With the rapid progression of technology, digital literacy skills are required now more than ever by carers to enable them to successfully navigate online service systems such as My Aged Care, the NDIS Portal, and My Gov services. This can be particularly challenging for older Tasmanians, and for those with limited or no access to the internet and computer equipment.

<sup>&</sup>lt;sup>1</sup> https://26ten.tas.gov.au/Pages/Strategy.aspx

<sup>&</sup>lt;sup>2</sup> https://www.dpac.tas.gov.au/\_\_data/assets/pdf\_file/0031/282955/Final-Consultation-Report-for-the-Development-of-Tasmanias-Community-wide-Framework.pdf

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

<sup>&</sup>lt;sup>5</sup> https://www.carerstas.org/wp-content/uploads/2017/06/Adult-Education-Strategy-Submission.pdf

<sup>&</sup>lt;sup>6</sup> Skills Tasmania 2019, Tasmanian adult learning strategy 2019-2022 [draft], Department of State Growth, Hobart. http://hdl.voced.edu.au/10707/523282

<sup>&</sup>lt;sup>7</sup> Ibid.

- Employment skills relevant to the workplace: Carers or former carers often need support to enter or re-enter the workforce. They may need access to learning or upskilling opportunities to facilitate this.
- Reskilling for a promotion or another job: Carers are often underemployed due to their caring responsibilities and may not have the same opportunities for career progression as non-carers.
- Informal peer-led learning: Carers should be supported where relevant to share their skills with peers, including things such as self-care strategies, knowledge, and self-advocacy. There is increasing popularity of peer-led employment roles, but adequate training (e.g. certificate 4 in Mental Health Peer Work) is not always available within the state.
- Gaining formal qualifications: Formal or higher education qualifications, as well as vocational education qualifications, are becoming increasingly sought after by employers as a minimum standard. For carers or former carers wanting to enter or re-enter the workforce, they must be supported with appropriate access pathways.
- Gaining knowledge and life skills: Carers need to be supported to participate in sport, recreation, and other leisure activities that also build life skills. These can include community education that may also facilitate respite, reduce isolation and improve wellbeing.

Additional areas in which adequate literacy skills (including health and digital literacy) are required by carers include:

- The ability to understand and complete forms such as Centrelink, advance care directives, guardianship, power of attorney, and NDIS
- How to read and understand service agreements and contracts from providers
- The ability to understand relevant legislation that affects their lives, such as the Carer Recognition Bill, the Disability Services Act, and the National Employment Standards
- Having adequate health literacy skills such as understanding medications, diagnostic reports, and recommendations from specialists
- Understanding rights, responsibilities, and how to make a complaint
- Accessing support on how to provide additional learning support for children with disability and/or specific needs, as well as supporting children who may be regularly sent home from school due to behaviours
- Understanding how to find and navigate appropriate services
- How to write a resume and apply for employment opportunities
- How to effectively share their voice through participation in surveys, consultation, and focus groups

An integral factor that contributes directly to both health literacy and health outcomes for consumers is the support provided by informal carers. Where there is a health consumer, there is likely to be an informal carer trying to support them. Therefore, carers must be considered in all aspects of health planning, information provision, and service design, but they may require support to do so.

## 3. Young carers and literacy

As highlighted in the introduction, there are an estimated 9,300 young carers who are aged under 25 living in Tasmania. Caring responsibilities have significant impacts on educational outcomes for young people, with research highlighting that for young carers at year nine, boys who spent two or more hours per day in a caring role were the equivalent of 1.9 years behind their peers in NAPLAN reading, and girls caring for two hours or more per day were 1.6 years behind in NAPLAN reading. Both boys and girls in Year 9 caring for two or more hours per day were approximately fifteen months behind their peers in NAPLAN numeracy. Young carers are also less likely to have completed year 12 or equivalent than their peers, and nationally, over 60% of primary carers aged 15 – 25 are not studying.

This can have lifelong impacts on how the social determinants of health (SDH) play a role in the life of a young carer. Poor education impacts childhood development, employment, finances, social connection, food security, discrimination, housing and basic necessities, and access to health services. As a result, young carers are a marginalised and at-risk group. Appropriately addressing education as major SDH for young carers is fundamental to improving their quality of life, and reducing further inequity.

We continuously advocate for routine identification and referral of young carers in schools to the Carer Gateway as well as updated resources for student carers and teachers. It is important that young carers feel safe to speak with their teachers and that their needs are met in a responsive and supportive manner. Young carers may need additional learning support and adjustments such as longer times to complete homework or assignments.

Young carers who are aged 12-25 may be able to apply for the annual Young Carer Bursary, 10 which provides financial assistance of \$3000 that can be used by young carers to pay for expenses related to their education. In addition, young carers are eligible to access Carer Gateway supports such as counselling, coaching, peer support, information, financial, and practical support that can assist in closing the gap of disadvantage they face compared with non-carers.

As stated in the Carers Australia report – *No Space in my Brain to Learn*,<sup>11</sup> the additional responsibilities faced by young carers impacts their ability to attend and stay at school, to study effectively, to make suitable academic progress, to have social interaction with friends, and participate in extra-curricular activities. Participation in school and related activities can increase levels of literacy and numeracy and foster a sense of belonging.

Some young carers support siblings, whereas others provide support to parents with mental ill health and/or alcohol or other drug dependence, disability, or chronic or life-limiting illness. For young carers supporting a parent, they may not always have the parental support a non-carer does when completing tasks such as homework due to the health status of their parents. It is crucial for young carers in these situations to have access to additional and appropriate learning support options when required.

<sup>&</sup>lt;sup>8</sup> https://www.communities.tas.gov.au/csr/policy/Policy\_Work/carer\_policy\_and\_action\_plan/carer-action-plan-2021-2025/what-the-data-tells-us-about-carers

<sup>&</sup>lt;sup>9</sup> Australian Institute of Family Studies (2017) Longitudinal Study of Australian Children 2016 Annual Statistical Report Young Carers

<sup>&</sup>lt;sup>10</sup> https://youngcarersnetwork.com.au/bursary/young-carer-bursary/

<sup>&</sup>lt;sup>11</sup> https://www.carersaustralia.com.au/wp-content/uploads/2020/10/Young-Carers-Report-FINAL\_vsmall\_compressed1.pdf

#### 4. Access for carers to information about Covid

In our 2022 Covid Impact Survey,<sup>12</sup> we wanted to understand the experience of carers in being able to access appropriate and timely information and what their preferred method of accessing this information was. It is important to note that these results are reflective of only carers who were able to complete this survey online.

The survey found that more than three-quarters of carers were able to access information about COVID to an acceptable level, with 63.69% of carers reporting they were able to access information well enough and 18.15% able to access this information to a very well standard.

When asked to report on the main methods used for keeping up to date with this information, we found that 43.5% of carers indicated that tv or radio was their primary method of accessing this information. This was followed by internet websites at 24.6%, and social media at 19.17%. The other methods each had responses of less than 10%, which were newspaper (5.11%), friends or family (3.19%), and service providers (3.83%).

Broken down further, for carers aged 65 years or more, the preferred method (at 54.86%) of accessing information was via the news (tv or radio). This was followed by the internet at 21.53%. For carers under the age of 65, the preferred method was news (tv and radio) at 33.14%. This was followed by social media at 29.65%.

The fact that most carers identified their preferred method of keeping up to date with information as being tv or radio, could be an indicator of a way to provide information to people in a way that is easily understood, through hearing as opposed to reading.

## 5. Literacy and the Carer Recognition Legislation

Enactment of the proposed Tasmanian Carer Recognition Legislation<sup>13</sup> is expected to occur by April 2023. For successful implementation of the following items as outlined in the Carers Charter, a focus on literacy in the context of carers must be thoughtfully considered. Each of these items can be related to requiring adequate literacy skills and support:

- "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.

<sup>&</sup>lt;sup>12</sup> https://www.carerstas.org/wp-content/uploads/2017/06/Carers-Tasmania-COVID-Impact-Survey-2022-Report.pdf

https://www.parliament.tas.gov.au/Bills/Bills2022/reprint/33\_of\_2022.pdf
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- 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."

Each of these items relies heavily on carers having the literacy skills to access and understand information about their rights and responsibilities, as well as the policies, programs, and services that affect them. Carers must be considered when developing policies, strategies, and programs to improve literacy in Tasmania,