



**Response to the
Guardianship and Administration
Amendment Bill 2022**

November 2022

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 government and the 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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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 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. 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. The term 'informal carers' does not automatically include kinship or foster carers, unless they care for a child with disability, mental ill health or other condition as previously noted.

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.

Introduction

Carers Tasmania welcomes the opportunity to provide a response to the Tasmanian Department of Justice on the draft Guardianship and Administration Amendment Bill 2022 (hereafter referred to as the 'draft Bill'). Our response is written placing value on the significant roles that the more than 80,000 informal carers in Tasmania play in supporting their family members or friends. Our response places human rights at the forefront, and advocates for better inclusion of supported decision-making to respect and promote person-centred choices.

A significant amount of work has been undertaken in Tasmania to elevate the contribution and needs of carers. The Carer Recognition Bill 2022¹ is currently awaiting debate in Tasmanian Parliament. The Bill aims to increase identification, recognition, self-advocacy, and equal access to supports, services, and information, relevant to the needs of carers in Tasmania. We have included some suggestions on how to ensure that this draft bill, where relevant, aligns with the aims of the upcoming Carer Recognition Bill.

Despite the significant supports they do provide, carers don't always end up being the person appointed as guardian. We often hear from carers in this situation who face barriers in accessing the information, support and services they need to best support the person they care for. We hope that with the introduction of carer recognition legislation in Tasmania, carers who are not the appointed guardian will be provided with the information and support that is needed to best support the individuals being cared for.

In this response, we have provided comments on the topic of medical research which has emerged in the amended draft bill as opposed to the treatment focus which underpinned the Principal Act – the Guardianship and Administration Act 1995.²

We support the reform of guardianship and administration legislation and processes in Tasmania and hope that this delivers positive change for people who need support in their decision-making under guardianship. It is important to highlight that data from the Australian Adult Guardianship and Administration council³ reported that for the 2020/2021 period in Tasmania, there were 373 applications and 218 new guardianship orders made. Of the approved orders in that timeframe, 140 were appointed to the public guardian and 78 were private orders. These figures do not include temporary, emergency or interim orders that may have translated into a longer-term order.

The Act must aim to protect and support those who are most vulnerable and require supported decision-making. Decisions must be driven first and foremost by the individual's own autonomy, preferences, and wishes, and where there is a family member or friend carer who is not the appointed guardian, they must be consulted with as part of the supported decision-making process.

¹ https://www.parliament.tas.gov.au/Bills/current/33_of_2022.html

² <https://www.legislation.tas.gov.au/view/whole/html/inforce/current/act-1995-044>

³ https://www.agac.org.au/assets/images/Annual-Report-on-Adult-Guardianship-Orders-2020-2021_2022-03-14-014828.pdf

Long title

We note that the following proposed amendments to the long title:

Long Title Amended (page 7)

‘The Principal Act is amended as follows:

(a) by omitting from the long title “a disability” first occurring and substituting “impaired decision-making ability”;

(b) by inserting in the long title “, to provide a process for obtaining consent for the conduct of medical research on persons with impaired decision-making ability” after “directives”;

(c) by omitting from the long title “with a disability” second occurring and substituting “who are unable by reason of impaired decision-making ability to make decisions in respect of such treatment”.’

We support the proposed change in the long title to remove the word ‘*disability*’ and change the wording to read ‘*impaired decision-making ability*’, as this places a greater focus on the actual ability of the person as opposed to their disability. This was a recommendation if the Tasmania Law Reform Institute’s 2018 Review of the Guardianship and Administration Act 1995 (Tas).⁴ However, we are concerned about the lack of specific detail on what constitutes impaired decision-making ability and who specifically has the authority to make these determinations.

We note that beginning at section 8-part 2, point 10, decision-making ability is described, however, this section does not refer specifically to any capacity-based assessment(s) that may be considered appropriate in determining level of decision-making ability. The draft describes the requirement of a ‘*person or body responsible for assessing decision-making ability under the Act*’, but it is not made clear who the appropriate people or bodies or occupation may be or detail on which frameworks may be used to determine ability. Any framework used to determine capacity should adhere to the United Nations Convention on the Rights of Persons with Disability.⁵

Even if a person is ‘deemed’ to need a guardian because of impaired decision-making ability, it is still that person’s fundamental right to make decisions about things about their life and things that affect them. In section 9: Decision-making process, we believe that reference needs to be made to the use of supported decision-making frameworks, as this aligns with the articles in the United Nations Convention on the Rights of Persons with Disabilities (CRPD).⁶ ‘Article 3 states ‘*Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons*’.

We do not agree to the proposed inclusions in the long title around medical research.

⁴ Tasmanian Law Reform Institute (TLRI), ‘Review of the Guardianship and Administration Act 1995 (Tas) – Final Report No 26’ (December 2018),

⁵ United Nations Convention on the Rights of Persons with Disability.

⁶ <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-19-living-independently-and-being-included-in-the-community.html>

Interpretation of the Act

We note and agree with the following proposed amendments of Section 3-pages 8-9, (*Interpretation*) of the draft bill:

‘(b) by inserting the following definition after the definition of appointor in subsection (1): close relative, in relation to a person, means any of the following persons who are in a close and continuing relationship with that person:

(a) a spouse of the person;

(b) a parent of the person;

(c) a person who has one or both parents in common with the person;

(d) a child of the person;

(e) a child of, or a parent of, the spouse of the person;

(f) a grandparent of the person;

(g) an aunt or uncle of the person;’

We suggest the inclusion of the additional clause:

(f) any of the above who is also considered an informal carer to the person

In the 1995 Principal Act – ‘*person responsible*’ is described. We also suggest that carer is identified as an option under the person responsible definition.

Medical research

We are deeply concerned about the emphasis on the inclusion of medical research throughout the proposed draft bill. Section 7, part 2 describes the meaning of medical research in the context of the Act. It is also concerning that the draft bill frequently refers to conducting medical research ‘*on*’ people as opposed to *with* or *in agreement with* people. The following are some, but not all of the examples of this presentation throughout the draft bill:

- **Section 3, point 4, part (b):** ‘*a process for obtaining consent for the conduct of medical research on persons with impaired decision-making ability....*”
- **48L, point 1:** ‘*A medical research practitioner may conduct medical research on a person under this Division without the consent of the person responsible for that person if...*’
- **Section 39, 48M, part (i):** ‘*the person on whom the medical research is being conducted..*’

We suggest changing to word ‘*on*’ to ‘*with*’ as it is our view that anyone who is involved in medical research may do so by their own informed choice. Article 15 of the CRPD⁷ states
‘No one shall be subjected to torture or to cruel, inhuman or degrading treatment or

⁷ <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-15-freedom-from-torture-or-cruel-inhuman-or-degrading-treatment-or-punishment.html>

punishment. In particular, no one shall be subjected without his or her free consent to medical or scientific experimentation.'

Although section **48R** does specify when medical research must not be conducted, including the clause:

(b) 'the person responsible for the person or any body or authority responsible for providing consent to the conduct of the medical research has consented to the medical research being conducted;'

if the person responsible for the individual or authority responsible provides consent for the research, there still may not be full and informed consent from the individual. Having someone make a decision such as this for them could be a violation of the individual's rights, wishes, and values. If there is sufficient reason to invite an individual to participate in medical research, the individual must be supported to understand information about the proposed research and be supported to make an informed choice.

Decisions around personal matters

The draft bill outlines in Section 5, clauses regarding decision-making around specified personal matters. The draft reads:

'personal matter, in relation to a person, means a matter relating to the personal affairs or lifestyle of the person, including, but not limited to, the following matters:

(a) where and with whom the person is to live, whether permanently or temporarily;

(b) who may visit the person, including –

(i) restrictions on visits necessary to promote the personal and social well being of the person; and

(ii) the prohibition on visits to the person by any person if those visits would have an adverse effect on the person;

(c) except as provided under Parts 5A and 6, consenting to or refusing or withdrawing consent to the provision of health care or medical or dental treatment to the person;

(d) consenting to or refusing or withdrawing consent to the conduct of medical research on the person; (e) the education, training or work that the person undertakes; (f) the retention of legal services and the bringing or defending of legal proceedings in relation to the person's personal matters'

If the appointed guardian is a family member or friend who is also the carer of the individual, they must make these decisions with the individual where the decisions are regarding or based on the documented wishes of the person.

If these decisions are to be made by a publicly appointed guardian, consultation with the individual and their carer or other person deemed responsible (if any) must occur in conjunction with referring to any documented wishes of the person. These details must be considered as part of the decision-making process.

Carers must be provided with the information and support throughout any public guardianship process or decision as in many cases, family and friend carers understand best the wishes of the person, their specific needs, goals, and values.

Ongoing education and planning

We believe that significant and ongoing community education is required on instruments such as guardianship, enduring guardianship, power of attorney, wills, advance care planning and directives. Early education and planning are fundamental to ensuring that all individuals have the best chance of their wishes being respected and adhered to if they no longer have the ability to make their own decisions. It is essential that planning such as this is not just left until later on in life, as people from all circumstances end up in positions, sometimes quite suddenly where guardianship is required.