

# **SUBMISSION**

**Recognition of Unpaid Carers**

<b>Submission Title:</b>	Recognition of Unpaid Carers
<b>Date:</b>	2 August 2023
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## CARERS QUEENSLAND

The activity and impact of providing care is best understood in terms of its context; as a relationship between two or more individuals, rooted in family, friendship, or community. Caring is a role rarely chosen by most, nor does it discriminate. Children and young people, people of working age and older people, people with disability, people who identify as culturally and linguistically diverse, First Nations Australians, people with diverse bodies, genders, relationships, and sexualities and those living in rural and remote Queensland provide care to family members or friends daily. For some caring is a short-term commitment whilst for others, it is a role that literally lasts a lifetime.

Family and friend carers provide unpaid care and support to family members and friends who have a disability, mental illness, chronic medical condition, terminal illness or are frail aged. Carers come from all walks of life.

Carers Queensland is the peak body representing the diverse concerns, needs and interests of caring families in Queensland. Carers Queensland believes that all carers regardless of their age, disability, gender or gender expression, sexual orientation, religion, socioeconomic status, geographical location, or their cultural and linguistic differences should have the same rights, choices and opportunities and be able to enjoy optimum health, social and economic wellbeing and participate in family and community life, employment, and education like other citizens. Carers Queensland's mission is to improve the quality of life of all carers throughout Queensland.

We aspire to provide an independent platform from which to advance the issues and concerns of the 533,200 carers in Queensland and believe our knowledge and expertise in carer issues means we can provide the Government with relevant and trusted information that will ensure that the needs of carers will be recognised, respected, and acted on.

Our submission is informed by national and international peer reviewed data, our own experience as a service provider and the personal and often difficult admissions of carers, those people who provide unpaid care and support.

## Introduction

Providing care for another person is a fundamental function of family and community, however, the concept of a carer, a specific population cohort, is a recent societal construct in Australia. To identify as or be identified as a carer creates an expectation in both the community and government that due to familial bonds a person has stepped-in and take on a caring role when a family member or close friend requires support.<sup>1</sup> Carers have told us that society generally believes carers to be an adult female caring for a child with disability, or an elderly parent. Despite this general assumption many female carers struggle to be recognised. Male carers, young carers, and those providing care for siblings, partners and other family members, friends or multiple people are not recognised in society.

Societal understanding of care leads to the formation of people's identities as a 'carer', as opposed to an individual identity who fulfils a caring role. This results in caring being seen as a moral undertaking rather than a role which requires recognition, respect and enforceable rights.

Carers Queensland has reviewed the *Carer Recognition Act 2010* and the *Queensland Carers Recognition Act 2008* and would like to put forward the following discourse for discussion.

## Discussion

Carers often feel unrecognised and undervalued, which contributes to their persistently low individual and collective wellbeing.<sup>2</sup> The Carer Recognition Act could be a vital tool for combatting this viewpoint and the associated problems, but only if carers and the wider community are aware of its existence. A recent consultation with carers conducted by Carers Queensland revealed that carers are not aware of the existence of The Act and have no knowledge of the Queensland Act which confers recognition, respect, or rights to them as a collective. We believe that any revisions to this Act must be widely publicised and promoted for it to effectively communicate its intention and for any meaningful change to occur.

The definition of who a carer is within the Act provides a limited coverage and does not adequately represent the carer population within Queensland. The current wording implies that all carers are adults, however more than 1 in 10 children provide care across Australia, without any formal recognition for the role they fulfil.<sup>3</sup> Additionally, thousands of carers provide care for more than one person and in many cases for more than one reason. The current definition implies that a carer provides care for an individual with disability or who is frail aged etc. as opposed to providing care to multiple individuals for multiple reasons. Carers Queensland advocates for a more accurate representation of carers in the carer definition, with the inclusion of children and young carers and the acknowledgement that a carer may provide care for multiple people with multiple conditions or reasons.

Children and young adult carers face many unique challenges, so it is essential for their health, wellbeing, and social inclusion that the Carer Recognition Act legitimise their status and mandate support services. Recognition of caring responsibilities is limited and inconsistent in schools, with very little support available. Unlike people with disability who are entitled to support mandated by law, young adult carers are not recognised or eligible for special accommodations when attending university, resulting in many falling through the gap and being unable to successfully complete their

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<sup>1</sup> Daly & Lewis, 2000. *The concept of social care and the analysis of the contemporary welfare states*. Care is located within a normative framework of obligations and responsibility.

<sup>2</sup> Tomy, Adrian & Cummins, Robert. (2007). *The Wellbeing of Australians: Carer health and wellbeing*.

<sup>3</sup> The Conversation, *One in 10 Aussie kids care for someone with a disability or drug dependence*, 2019

education.<sup>4</sup> Children and young adults who provide care are often less engaged in their education, require additional supports at school, are unable to complete homework, and generally feel less safe at school than their counterparts.<sup>5</sup> This has a significant detrimental impact upon their social and education outcomes, limiting their future opportunities in higher and further education and employment. It is vital that children and young people are recognised as carers, to enable the supports to be put in place to secure their future and economic and social participation.

There is a stigma associated with being a carer for a family member or friend which is pervasive across multiple societal and public spheres. Carers are often perceived as being overbearing and controlling due to their advocacy for the person they provide care for by the health, allied health and community care settings despite their dependency on carers to provide the care and support the Commonwealth and State governments cannot afford to purchase.<sup>6</sup> This reliance places carers at the intersection of the government, community, and the market, and yet, carers are not afforded any recognition, respect or value and are often threatened with guardianship action when their advocacy challenges the power of the involved professionals.

This stigma is further heightened in government agencies, educational, health and medical facilities across Queensland, often by the choice of promotional material and information leaflets found in these areas. Carers charters stating their right to feel welcome, respected, valued, and safe are not displayed, and nor are carers reflected in any leaflets or posters, with the exception of elder abuse information. In these areas, the only reflection of themselves carers see is the depiction of a carer perpetrating abuse towards an elderly person, a misguided and biased representation, one which does not make the carer feel like they will be trusted, valued, or are welcomed. The psychological theory of place attachment describes an emotional bond between an individual and an environment, in which the level of safety and attachment an individual feels is a significant predictor of how a person will act in that environment.<sup>7</sup> Therefore, the positive representation of carers in government offices, educational and health and medical settings is essential to enable the fulfillment of the caring role. Carers deserve to feel psychologically safe, trusted and valued within these environments, and this begins with mandating the way in which carers are to be represented and recognised in public agencies. Every carer deserves the right to feel safe, respected, valued, and welcome.

The medical sector does not recognise carers as genuine partners in care. There is much confusion around the term carer with many health and medical professionals assuming a carer is an individual who is paid to provide care services, so the actions undertaken by family carers are often not recognised or valued by medical staff. This places carers in a very difficult position, they are, on one hand, expected by healthcare professionals to fulfil treatment plans and provide ongoing care but are excluded from treatment discussions and considerations. Carers want to be seen, heard and valued as partners in care for the wellbeing of the person they support. Carers advised us that when attending appointments with the person they provide care for, their opinion, viewpoint and experiences are often unwanted and sidelined by professionals resulting in valuable information not being considered. Carers have informed us that the medical system disempowers them by not valuing the role they fulfil and in some cases results in harm to the person receiving care.

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<sup>4</sup> Moore, Tim & McArthur, Morag & Morrow, Ros. (2009). Attendance, Achievement and Participation: Young Carers' Experiences of School in Australia. *Australian Journal of Education*. 53. 5-18.

<sup>5</sup> The Conversation, *One in 10 Aussie kids care for someone with a disability or drug dependence*, 2019

<sup>6</sup> Estimated by the Allen Consulting Group to be 74% of all the care and support provided. Allen Consulting Group, *The Future of Community Care Report to the Community Care Coalition*, March 2007.

<sup>7</sup> Inalhan, Goksenin & Yang, Eunhwa & Weber, Clara. (2021). Place Attachment Theory

One carer advised us of a medical incident involving her adult child, in which he received emergency care without the medical professionals being aware of his disability, resulting in extreme amounts of distress. In this example, had the medical professionals contacted the family they would have been aware of his needs, and a support person could have been in place through the hospitalisation, reducing the emotional distress to a minimum. This experience is not singular, carers often are not included in treatment discussions but are expected to take the individual home and provide care with little to no new knowledge as to how best to provide care and support or any discussion as to their ongoing capacity to continue to provide care. Carers are seen and treated as an available and free resource of care with little carer specific interventions to ensure that they can provide the necessary care. Carers want to be active partners in care with the medical and health systems, in which formal services and interventions work with carers to ensure continuity and quality of care. Carers Queensland asserts that carers require the Carer Recognition Act to mandate their role as partners in care within the health, support, and medical systems.

The issue of recognition of the carer role is significant. Despite there being a definition contained within the Act, carers are routinely not recognised or identified. A universal system of recognition, for all carers who meet the Act's definition, is required, and can be mandated through the Act. A Carer Recognition Card provides legitimacy for the carer, irrespective of other entitlements, and would be beneficial. This type of system would reduce the misunderstandings that carers are paid support workers, increase recognition and identification, raise the awareness of carers, help carers feel valued in their role, and would assist carers in explaining to professionals why they require some level of involvement in appointments. Similar systems have been embedded in other countries, such as the U.K and are proving to be successful.<sup>8</sup> There is also a secondary benefit to this type of system being made available through the Recognition Act, and that is in instances in which a carer has a medical emergency or accident and is unable to communicate that they provide care and support to one or more people, a recognition system would enable professionals to check on the care recipient and ensure they have adequate care for the time in which the carer is unwell.

The Carer Recognition Act must legitimise the belief that carers need and deserve assistance in their own right independent to the person they provide care for. The only available support carers have available is a crisis intervention risk assessment, in which carers are provided an assessment in times of crisis. Carers who have sought assistance that they find this process to be traumatising and re-traumatising. Preventative support and care are required for people to continue their caring responsibilities without entering times of crisis. We support the introduction of a needs assessment specially for carers to access the services and supports that they require as their own person, which would have a positive and beneficial impact upon their wellbeing. The Queensland Carers Recognition Act states that "carers need access to a wide range of responsive and affordable services to support them", however because this Act provides guidance and does not provide a mandate to support services for carers there is no easily accessible support outside times of crisis for Queensland carers. This demonstrates the requirement for all Recognition Acts to provide legitimate mandated rights as opposed to the current guidance statements.

The lack of consistency across Australia with regard to carer recognition also poses a significant challenge and detriment to carers. Currently, each State and Territory has a different definition of who is a carer contained within their own Carer Recognition Act, which therefore makes the issue of recognition severely challenging and limiting. We believe the Carer Recognition Act 2010 needs to provide consistency and universal rights for carers, incorporating state-based legislation.

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<sup>8</sup> <https://www.carerpassport.uk/>

The Carer Recognition Act must provide carers with enforceable and irrefutable rights in their role as a carer for the benefit of the carer and the individual receiving care. It is necessary for the Act, to serve as a lynchpin to all other relevant legislation, providing carers with tangible social entitlements.

## Recommendations

Carers Queensland makes the following recommendations:

- Carer definition to include children and young people and those who provide care for multiple individuals.
- A rights-based Carers Charter to be included in the Act and promoted in government offices and government funded agencies.
- Carers are to be recognised as partners in care, with medical and health systems working in partnership with the carer for the best outcomes for the care recipient.
- A universal system of carer recognition to be included in the Carer Recognition Act, enabling all carers to be recognised and valued.
- The right to a preventative needs assessment to access support services for carers themselves independent of the care recipient to be included within the Act.