



15<sup>th</sup> February 2024

The Secretary  
Social Development Committee  
GPO Box 572, Adelaide 5001  
Via email: [sdcc@parliament.sa.gov.au](mailto:sdcc@parliament.sa.gov.au)

## **SUBMISSION TO THE INQUIRY INTO THE POTENTIAL FOR A HUMAN RIGHTS ACT FOR SOUTH AUSTRALIA**

Carers SA welcomes the opportunity to make a submission to this Inquiry.

### **About Carers SA**

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Carers SA is a charitable for purpose organisation and is the recognised representative body for Carers in South Australia. Carers SA is also a service provider, offering a range of services to caring families in metropolitan, rural and remote locations across South Australia. Carers SA is the lead provider of federally funded Carer Gateway services in South Australia and state funded breaks for Carers across South Australia and supports for Young Carers in multiple locations across the state.

Carers SA is part of a National Network of Carer Associations and a member of Carers Australia – the recognised national peak body representing and advocating on behalf of family and friend Carers throughout Australia. We are a member of the Carer Support Network South Australia (CSNSA) and other human services-related networks. In addition, we work in partnerships and collaborations with others who support or conduct research with a focus on Carers, and with organisations that connect with Carers.

Carers SA collaborates with Carers via extensive Carer Advisory Groups, Carer forums and Round Table events across the state, as well as large qualitative and quantitative Carer surveys to inform our local, state, and federal advocacy work for Carers. We provide evidence-based advice to all levels of Government, business and service sectors to improve the Recognition of Carers and awareness of their service needs and preferences. Carers SA ensures that the voices of South Australian Carers are being heard by key decision-makers across the country and that these voices shape the way the organisation does business.

Caring is a significant form of unpaid work in the community and is integral to the maintenance of our aged, disability, health, mental health, and palliative care systems. Caring however often comes at a cost to Carers with health and wellbeing consequences<sup>1</sup> and a degree of social isolation. A caring role is likely to impact an individual's work life and career as well as life aspirations having a significant and lasting impact on Carers financial security<sup>2</sup>. For example, Primary Carers will lose on average \$175,000 in superannuation and \$392,500 in lifetime earnings.

Although many (but not all) Carers report that they have taken on a caring role as part of their commitment to family, partners, or friends; Carers are very aware of the personal and financial impact a caring role has.

There are 2.7 million Carers in Australia. More than 856,000 Carers are primary Carers.

South Australia's Carer numbers are estimated at 245,000 with nearly 30,000 Young Carers 24 years or younger.

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<sup>1</sup> 2022 Carer Wellbeing Survey, Available via: [https://www.Carersaustralia.com.au/wp-content/uploads/2022/10/2022-CWS-Full-Report\\_221010\\_FINAL.pdf](https://www.Carersaustralia.com.au/wp-content/uploads/2022/10/2022-CWS-Full-Report_221010_FINAL.pdf)

<sup>2</sup> Carers Australia – Caring Cost Us, available via <https://www.Carersaustralia.com.au/caring-costs-us>

## South Australian Human Rights Act – as a key foundation document

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Carers SA is calling for the South Australian Government to set out succinctly, in one place, the rights necessary to ensure all people – including Carers - live with dignity and security.

**A South Australian Human Rights Act would be an appropriate and effective legislation to set the foundations within a ‘go-to’ document to achieve this goal.**

Currently, South Australian Human Rights are not supported by specific legislation, which results in unclear expectations and vulnerable communities lacking protection of their human rights.

South Australia has a South Australian Carer Recognition Act 2005 (the Act) which provides some guiding principles on the relationships between authorities under the Act and South Australian Carers. However well intended, guiding principles are not translating well into practice, nor do they assure that key human rights based practices are enforced or are legally enforceable.

Since the Act’s inception in 2005 (and review in 2010) the level of practical commitment of government departments and agencies, considered authorities under the Act, has been vastly different. These range from a lack of identifiable formal Carer Recognition under the Act to sporadic activities on a localised level, to a systemic collaborative policy advisory and active partnership, as it exists between SA Health and Carers SA.

The Act is currently under Review. Carers SA has made a submission to the Inquiry strongly suggesting that a reviewed Act will be adopting a Carer rights based approach<sup>3</sup>.

## Why is it important to protect the Rights of South Australian Carers?

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Carers are often unheard, unseen, un-recognised and tend to put the needs of the person they support before their own wellbeing and health needs.

As a result of their caring role, a substantial number of Carers are not able to access social and economic benefits that are essential to living a fulfilling life. This is reflected in data where Carers score poorly on a variety of key wellbeing indexes compared to the general population. The 2022 national Carer Wellbeing Survey<sup>4</sup> showed that Australia’s Carers are three times more likely to have low wellbeing than the average Australian adult, with 55% having low wellbeing compared to only 25% of the broader population. The wellbeing of Carers drops substantially even further with increasing intensity of the caring role.

Protecting the human rights of Carers is crucial for several reasons, all of which stem from the fundamental principles of dignity, equality, and respect for individuals' autonomy and well-being.

Carers SA refers the Inquiry to Carers Australia’s *Response to the Joint Committee on Human Rights: Inquiry into Australia’s Human Rights Framework*<sup>5</sup> which provides a comprehensive insight into Carers as a vulnerable population group in relation to Human Rights considerations. The discussions mirror the circumstances of South Australian Carers.

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<sup>3</sup> Carers SA Submission to the Review of the South Australian Carer Recognition Act 2005, available online: <https://www.Carerssa.com.au/wp-content/uploads/2024/01/Carers-SA-2023-Submission-Review-SA-Carers-RecAct-2005-publication-final.pdf>

<sup>4</sup> The 2022 Carer Wellbeing Survey - a collaboration between Carers Australia and the University of Canberra, funded by the Department of Social Services, available online via: <https://www.Carersaustralia.com.au/report/2022-Carer-wellbeing-survey-full-data-report>

<sup>5</sup> Carers Australia’s *Response to the Joint Committee on Human Rights: Inquiry into Australia’s Human Rights Framework* - July 2023 - Available online: <https://www.carersaustralia.com.au/wp-content/uploads/2023/07/Carers-Australia-Submission-to-Joint-House-Human-Rights-Framework-Inquiry.pdf>

**Recognition of Contribution:** Carers make significant contributions to society by providing essential care and support to others. Often this care and support is to the detriment of their own health and wellbeing, achieving their own life aspirations and securing their financial future. Acknowledging their role through the lens of human rights reinforces the value of their labour and the importance of their well-being.

**Preservation of Dignity:** Carers often undertake physically and emotionally demanding tasks, with often little or no opportunity to step away from their role to recharge and have time off – an option that is accommodated for any paid support person or other worker. Protecting Carers' human rights ensures that they are not subjected to exploitation, discrimination, or neglect, preserving their dignity as individuals deserving of respect and fair treatment.

**Right to Health and Social Services:** Carers have the right to access healthcare services, respite, and other forms of support that can help them fulfill their caregiving responsibilities without compromising their own health and wellbeing. South Australian Carers who responded to our 2023 Carer Recognition Survey however told us that they have experienced discrimination, with 28.6% of survey participants disclosing that they have experienced discrimination during their interactions with Government in general (including health and related services). This percentage is significantly higher for members of Australia's First Nations Peoples at 44%.

Upholding Carers' human rights means ensuring that they have access to adequate resources and support systems.

**Right to Work and Education:** Many Carers may face barriers to employment or education due to their caregiving responsibilities.

Carers can experience limited opportunities to pursue education or training to enhance their skills and qualifications due to time constraints and financial limitations. This can restrict their ability to access higher-paying or more fulfilling employment opportunities. Please also note the specific chapter discussing Young Carers and education outcomes below.

Key examples of Work and Education barriers include:

Financial constraints: Some Carers have to forego employment opportunities or reduce their working hours to provide care, leading to financial strain. The cost of caregiving itself, including medical expenses and other associated costs, can also contribute to financial difficulties. The cost of training and skills development is often prohibitive.

Employment discrimination: We know Carers are facing time constraints and those who may wish to enter or maintain employment struggle to find flexible employment options that accommodate their caregiving duties.

Carers told us that many South Australian employers are understanding and are willing to negotiate and accommodate the caring role needs where possible. However some employers may be reluctant to hire or accommodate Carers due to concerns about potential disruptions to work schedules or productivity. Carers may face discrimination in the hiring process or be overlooked for promotions and advancement opportunities.

Without adequate support from their employers, Carers may find it difficult to balance work and caregiving duties effectively. Addressing these barriers requires a comprehensive approach that includes supportive policies at the workplace and societal level.

Limited Young Carer Recognition within the Education System: Currently Young Carers are often not identified as a vulnerable population within SA education providers<sup>6</sup>. Please note the special Young Carer Chapter below for more details.

Protecting their human rights involves addressing these barriers and ensuring that Carers have opportunities to pursue their own goals and aspirations, without discrimination or undue burden.

**Protection from Discrimination and Stigma**: Carers may experience stigma or discrimination based on their caregiving roles, which can lead to social isolation and exclusion. Please note the examples providing further insights into two specific Carer populations: Young Carers and Older Carers.

Upholding Carers' human rights involves challenging stereotypes and promoting understanding and acceptance of caregiving as a valuable and legitimate role within society.

**Right to Privacy and Personal Autonomy**: Carers have the right to privacy and personal autonomy in their caregiving relationships. Protecting their human rights means respecting their autonomy and ensuring that they have control over decisions affecting their own lives and the lives of those receiving care.

**Promotion of Social Inclusion and Participation**: Protecting the human rights of Carers is essential for promoting their social inclusion and participation in all aspects of society. This includes ensuring access to community activities, social networks, and opportunities for civic engagement.

We know from our experience working with Carers, from our surveys, focus groups and Carer Round Tables, that many Carers often feel a profound loss of social and personal identity. Carers lose confidence in themselves, and they feel to some degree invisible and inconsequential – thoughts and emotions that are also attributed to people who are subjected to discrimination based on race, ethnicity, gender and sexual orientation.

In addition, intersectionality issues with other comparatively disadvantaged demographic cohorts also impact Carers as many Carers are:

- Aboriginal and Torres Strait Islanders and
  - many others adhere to cultural practices that are diverse from that of the current dominant culture,
  - many Carers' linguistic strength is founded in a language other than English,
  - a large group are senior Carers who experience discriminatory ageism,
  - it is estimated that nearly 2-3 students in every South Australian classroom can be Young Carers.
- Young Carers struggle like others with childhood development and general growing up issues, which is compounded by the competing priority demands of education versus their caring responsibilities.

Safeguarding the human rights of South Australian Carers is a matter of ethical responsibility and in addition, essential for promoting social justice, equality, and the well-being of both Carers and the individuals they care for. Recognising and upholding their human rights is fundamental to building an inclusive, humane, and compassionate society where all individuals are valued and respected.

A South Australian Human Rights Act would provide the foundation for the protection of the Human Rights of all people across the state, including Carers – and would set the expectations to harmonise other state legislation (including the SA Carer Recognition Act 2005), and ensure appropriate and considered governance and operational practices.

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<sup>6</sup> SA Commissioner for Children and Young People – Report: *'Take Care What can be done at school to support children and young people with caring responsibilities at home'*, available online: <https://www.cyp.com.au/wp-content/uploads/2022/03/Take-Care-What-can-be-done-at-school-to-support-children-and-young-people-with-caring-responsibilities-at-home.pdf>

## Examples of often unseen and vulnerable Carer populations:

### Protecting the Human Rights of Young Carers

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We identify a Young Carer as a child or young person 24 years and under, who provides care, assistance, or support to another family member, or friend<sup>7</sup>. Young Carers carry out significant caring tasks regularly and assume a level of responsibility that would usually be associated with an adult.

The person receiving care is often a parent, but can be a sibling, grandparent, or other relative, who has a disability, chronic illness, mental illness, or other condition necessitating a need for care, support and/or supervision.

Some Young Carers have told us that they are reluctant to disclose their caring role or the full extent of this role, even when non-disclosure is to the detriment of their educational experience or outcomes. This is often due to identifying as a Carer can result in bullying due to deficit assumptions and negative labelling assigned to the Young Carer, their family, or role.

Research data suggests<sup>8</sup> that Young Carers are more likely to have worse educational attainment, more likely to be NEET (not in education, employment, or training), and are less likely to be in higher education than those who do not have regular caring responsibilities. Educational outcomes are strongly linked to health outcomes in later life, and support for educational participation is vital to improve the life chances of these children and young people. Young Carers' educational outcomes fall behind that of their peers from early on. A study conducted in Australia found that Young Carers aged 14-15 years old already had poorer levels of reading and numeracy than their counterparts without caring responsibilities<sup>9</sup>.

It is estimated that there are about 30,000 Young Carers in South Australia. Obtaining precise estimates of the numbers of Young Carers is difficult because many qualitative studies note that young people may not identify as Carers either because of a reticence to admit caring responsibilities within the family, or because the young person themselves does not consider themselves as a Young Carer.

Population estimates of the prevalence of Young Carers also vary in Australia due to differences in how caring is defined, for example: the age group being considered; whether care is provided inside and outside of the household; and whether the young person or another adult in the household is reporting on caring circumstances<sup>10</sup>.

Having a South Australian Human Rights Act that protects the Status of Carers and their Rights across South Australian Government Departments, agencies and the community, will provide the necessary protective umbrella that will support the early identification and Recognition of Young Carers. It will bring focus to addressing any socially negative practices, ignorance-based, or even unintended discrimination; and the below par education and life outcomes experienced by Young Carers.

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<sup>7</sup> Carers SA – Young Carers online information: <https://www.Carerssa.com.au/services/young-Carers-services>

<sup>8</sup> State of Child Health, 2021 available online via <https://stateofchildhealth.rcpch.ac.uk/evidence/family-and-social-environment/young-Carers>

<sup>9</sup> Department of Social Services – Young Carers Research Report available via: <https://www.dss.gov.au/our-responsibilities/disability-and-Carers/publications-articles/young-Carers-research-project-final-report?HTML>

<sup>10</sup> Longitudinal Study of Australian Children, Chapter 5 – Young Carers, available online via: <https://growingupinaustralia.gov.au/research-findings/annual-statistical-report-2016/young-Carers>

## Protecting the Human Rights of Older Carers

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The 2018 Australian Bureau of Statistics (ABS) Survey of Disability, Ageing and Carers (SDAC) estimated there were 647,000 older people (aged 65 and over) providing care. Older Carers represented around 1 in 6 (17%) of the total older population and just over half (51%) of older Carers had a disability. In younger age groups the majority of Carers are women, however, this changes quickly for older Carer age groups. 57.7% of Carers who are 75-84 years of age are men and nearly 3 in 4 (71.9%) Carers 85 years and older are men<sup>11</sup>. According to the SDAC, of all older informal Carers over 1 in 3 were primary Carers (that is, the Carer providing the most informal assistance to a person). Around 6 in 10 older primary Carers were women. Of these older women who were primary Carers, 7 in 10 (71%) provided care to their partner, 13% provided care to their child, and 11% provided care to their parent. A rising number of older Carers are taking on caring roles for grandchildren with additional needs.

Recent research<sup>12</sup> by the Australian Human Rights Commission found that Ageism is the most accepted form of prejudice in Australia.

Research by the University of Melbourne<sup>13</sup> indicates that the most common type of ageism in Australia is 'Succession', followed by 'Stereotyping' of older people. This occurs when attitudes are formed out of incomplete, obsolete, or even completely mistaken beliefs; for example, the belief that older people 'live in the past', and that they 'cannot learn new skills'. Unfortunately, stereotypes are often maintained despite being untrue – hence stereotyping often leads to discriminatory practices and behaviour.

Older Carers are facing discrimination due to the general ageism that is currently quite common in the community and they are the only group in our community who cannot retire. Beyond its personal consequences, ageism is a social problem, especially as it leads to discrimination and the infringement of Human Rights.

It is therefore even more important that Carers have their Rights as Humans realised and protected by South Australian Human Rights legislation.

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<sup>11</sup> Australian Institute of Health and Welfare, Older Australians Report available online:

<https://www.aihw.gov.au/reports/older-people/older-australians/contents/social-support>

<sup>12</sup> 'What's age got to do with it? A snapshot of ageism across the Australian lifespan'. Australian Human Rights Commission, available online via: <https://humanrights.gov.au/about/news/new-research-finds-ageism-most-accepted-form-prejudice-australia-0>

<sup>13</sup> Research Snapshot: 'Are Australians Ageist?', University of Melbourne, available online via: [https://fbe.unimelb.edu.au/\\_data/assets/pdf\\_file/0007/2729140/Research-Snapshot.pdf](https://fbe.unimelb.edu.au/_data/assets/pdf_file/0007/2729140/Research-Snapshot.pdf)