

Carers Australia response to the Joint House Inquiry into Australia's Human Rights Framework

July 2023

Introduction

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

We have a deep interest in the rights of Australia's estimated 2.65 million family and friend carers of people with disability, chronic illness, mental illness or disorder, drug and alcohol problems or who are frail aged and the rights of the people they care for.¹

An evaluation of the "Value of informal care" undertaken by Deloitte Access Economics estimated that a total of nearly 2.2 billion hours of care were provided in 2020 and that the total cost to replace all family and friend care in that year would be \$77 billion. However, this contribution can come at great cost to many carers in terms of their employment, income, physical and mental health, and social inclusion.

The current Australian Human Rights Framework identifies that human rights are about "a fair go" and "each of us being able to realise our potential and having the chance to participate on our own merits as members of the Australian community".²

In many ways carers don't get a fair go.

Carers as a vulnerable cohort of Australian society

As a result of their caring role, a great many carers lack access to social and economic benefits that are essential to living a fulfilling life. Indeed, carers score poorly on a variety of key wellbeing indexes compared to the general population. For example, the 2022 national Carer Wellbeing Survey found 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.³ The wellbeing 'gap' becomes larger with the intensity of the caring role.

¹ Carers Australia uses the term 'carer' as defined by the Commonwealth Carer Recognition Act 2010 (the Act), where it should not be used broadly and without context to describe a paid care worker, volunteer, foster carer or a family member or friend who is not a carer. The terms 'informal carer', 'unpaid carer' or 'family and friend carer' are also often used by organisations, government and the community to describe a carer. Carers Australia may use these terms to assist in providing context and to differentiate between other types of care.

² Commonwealth of Australia, Australia's Human Rights Framework (2010), p.4 [accessed online](#)

³ The 2022 Carer Wellbeing Survey - a collaboration between Carers Australia and University of Canberra, and funded by the Department of Social Services [accessed online](#)

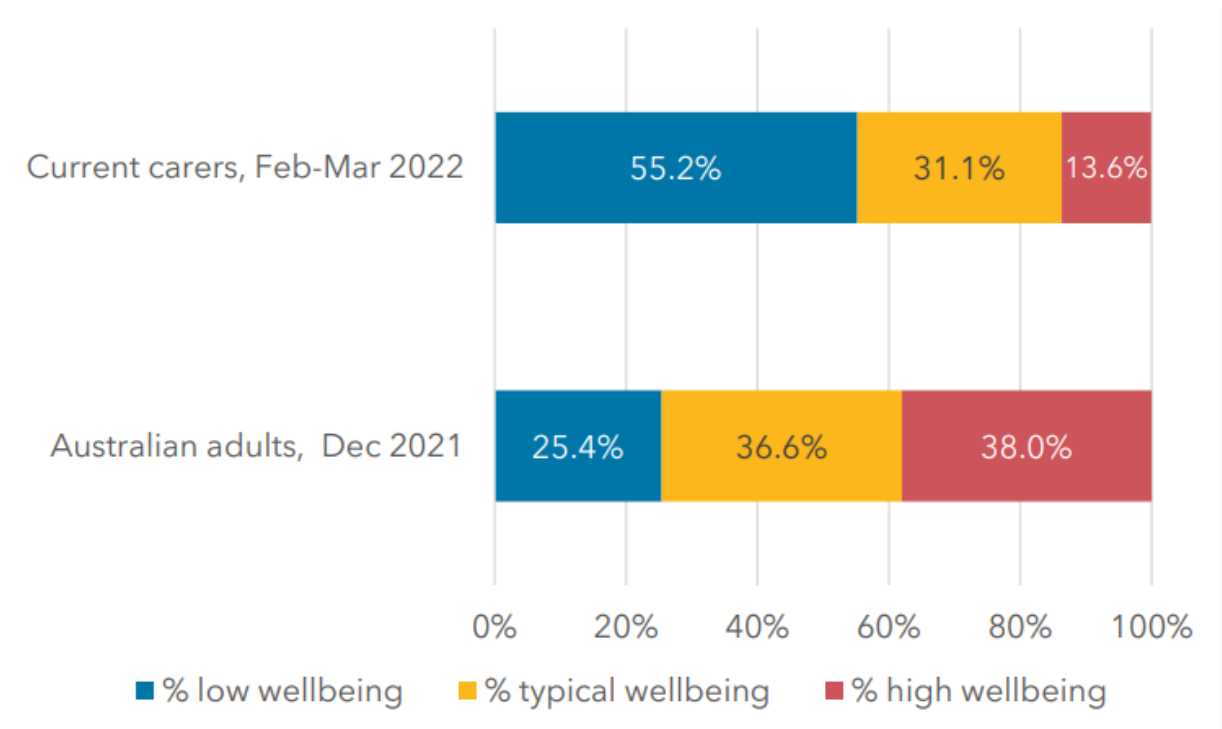


FIGURE E1 THE WELLBEING GAP BETWEEN CARERS AND THE AVERAGE AUSTRALIAN

According to the last Australian Bureau of Statistics (2018) Survey of Disability, Ageing and Carers (henceforth referred to as SDAC), primary carers were nearly twice as likely to be in the lowest income quintile than non-carers and half as likely to be in the highest income quintile. They were also twice as likely to rely on a Government pension or allowance than non-carers.⁴

The 2022 Carer Wellbeing Survey found that many working age carers work fewer hours than they want or feel that they need to, with underemployment much more common amongst carers compared to the general population. Reflecting this, many carers reported working part-time hours, with 38.4% of carers who had paid employment working less than 20 hours a week.⁵ The 2020 National Carers Survey found that less than a third (29%) reported that caring had not impacted their career. The most common impact reported was having to quit paid work to care (27.5% of respondents). Combined with having to retire early to continue caring, nearly half (44.5%) of carers reported having left the workforce due to their caring responsibilities. The second most common impact (27.4% of respondents) was reducing working hours, followed by not being able to keep skills/qualifications up to date, which was reported by 17.4% of working carers.⁶

Numerous surveys and studies over time have revealed that carers, especially primary carers, have significantly poorer health outcomes than non-carers. The results from SDAC 2018 showed that over one-third (37.4%) of primary carers had disability, at twice the rate of non-carers (15.3%).⁷ And the 2021 and 2022 Carer Wellbeing Surveys highlighted the poor health of carers, with just under half of respondents reporting just fair or poor health. In the 2022 survey, there was a decline in general health for some groups

⁴ Australian Bureau of Statistics (ABS), Survey of Disability, Ageing and Carers, 2018, [accessed online](#)

⁵ Op.cit.

⁶ Carers NSW, 2020 National Carers Survey [accessed online](#)

⁷ Op.cit

of carers, including those aged between 25 and 44, with more than a 10% increase in those reporting poor/fair health.⁸

The reasons carers are particularly prone to poor health vary with individual circumstances, but there are common elements. Carers have a very high level of psychological distress which closely aligns to very high levels of social isolation and anxiety for the person they care for. This is especially the case for carers of people with a mental illness or psychological disability, an intellectual disability and drug/alcohol dependency. In addition, carers are very time poor and tend to put their own physical and mental wellbeing second to that of the person they are caring for. And, with respect to poor physical health, about a third of carers are over the age of 65.⁹ However, poverty also has a role to play in determining poor health outcomes of carers.

Very significantly, many carers report social exclusion and high levels of loneliness. The 2022 Carer Wellbeing Survey revealed and a very high percentage of carers who experienced loneliness among younger carers and carers aged between 35 and 44¹⁰

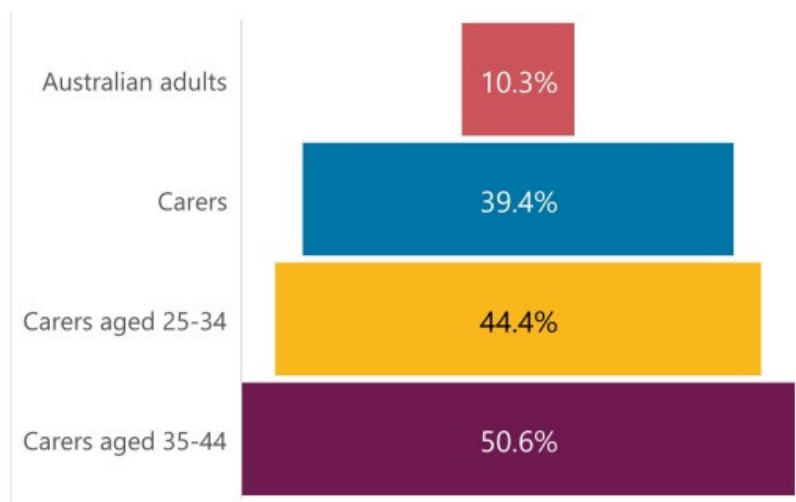


FIGURE E3 RATES OF LONELINESS AMONGST CARERS

This social exclusion arises at the individual level in part because carers are extremely time poor and many are essentially housebound. According to the 2018 SDAC, a third of primary carers spent more than 40 hours a week providing care and 29% identified that they had been caring for between 10 and 24 years with a further 6% for 25 years or more.¹¹ Even other family members often don't understand what they do or the value of what they do and don't relate to their lives.

Social exclusion is often exacerbated due to their inability to engage in employment and activities in the community. Exclusion can also take the form of not being recognised by medical professionals or in health environments which provide services to those they care. This lack of recognition can result in carers getting little information from medical professionals and other health workers which impacts, in turn, on

⁸ Carers Australia, 2022 Carer Wellbeing Survey [accessed online](#)

⁹ Australian Bureau of Statistics (ABS), Survey of Disability, Ageing and Carers, 2018, [accessed online](#)

¹⁰ Carers Australia, 2022 Carer Wellbeing Survey [accessed online](#)

¹¹ Op.cit.

their ability to provide care or to convey information which would assist in better diagnosis and treatment of the person they care for, again flowing on to higher challenges in relation to their caring role.

Many carers end up feeling a profound loss of social and personal identity, they lose confidence in themselves, and they feel to some degree invisible and inconsequential – thoughts and emotions which are also attributed to people who subjected to discrimination on the basis of race, ethnicity and gender and sexual orientation.

In addition, intersectionality issues with other comparatively disadvantaged demographic cohorts also impact on carers. For example, many carers are Aboriginal and Torres Strait Islanders and many others come from culturally and linguistically diverse backgrounds.

And finally, as noted above, over a third primary carers have disabilities themselves, twice that of the general population.¹²

The Human Rights Framework and carers' rights

To the extent that the Framework is based on seven core United Nations treaties to which Australia is a party, it doesn't embrace the rights of carers per se.

For example, seven in ten primary carers (those who provide the most substantial care) are women. While the United Nations *Convention on the Elimination of all Forms of Discrimination against Women* (CEDAW)¹³ is endorsed by Australia, the Articles relating to caring responsibilities and the elimination of gender inequalities in this area are focused on maternity and parental caring of typically developing children only. The Convention also embodies the rights of women in relation to employment. However, as noted by the Human Rights Commission, this excludes the still substantial number of primary carers who are male and who also face employment challenges.¹⁴

The only treaty which confers any relevant rights at all is the *Convention of the Rights of People with Disability* (CPRD).¹⁵

The Preamble recognises that

The family is the natural and fundamental group unit of society and is entitled to protection by society and the State, and that persons with disabilities and their family members should receive the necessary protection and assistance to enable families to contribute towards the full and equal enjoyment of the rights of persons with disabilities".

Article 16:2 states:

Parties shall also take all appropriate measures to prevent all forms of exploitation, violence and abuse by ensuring, inter alia, appropriate forms of gender- and age-sensitive assistance and support for persons with disabilities and their families and caregivers, including through the provision of information and education on how to avoid, recognize and report instances of exploitation, violence and abuse."

Article 23:3 states:

¹² Australian Bureau of Statistics (ABS), Survey of Disability, Ageing and Carers, 2018, [accessed online](#)

¹³ United Nations Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW) [accessed online](#)

¹⁴ Australian Human Rights Commission, Free and Equal: A Human Rights Act for Australia, 2022 [accessed online](#)

¹⁵ United Nations Convention on the Rights of People with Disabilities [accessed online](#)

Parties shall ensure that children with disabilities have equal rights with respect to family life. With a view to realizing these rights, and to prevent concealment, abandonment, neglect and segregation of children with disabilities, States Parties shall undertake to provide early and comprehensive information, services and support to children with disabilities and their families.

Article 28:1 on Adequate Standard of Living and Social protection states:

Parties recognize the right of persons with disabilities to an adequate standard of living for “themselves and their families, including adequate food, clothing and housing, and to the continuous improvement of living conditions, and shall take appropriate steps to safeguard and promote the realization of this right without discrimination on the basis of disability.

And Article 28:3 in relation to families living in poverty:

To ensure access by persons with disabilities and their families living in situations of poverty to assistance from the State with disability-related expenses, including adequate training, counselling, financial assistance and respite care (28.3).

However, not all carers are caring for people with disabilities, although we note that the now defunct 2012 Australia’s National Human Rights Action Plan¹⁶ which accompanied the Framework did incorporate some measures with respect to carers which included the National Carer Strategy and some supportive actions taken by the national government and some state and territory governments in relation to particular sub-sets of carers.

Carers Recognition Act

In the absence of protections, recognition and support embodied in treaties, specific national legislation is required to confer entitlements. In the case of carers, the key legislation is the Federal *Carers Recognition Act (2010)*¹⁷.which includes a Statement for Australia’s Carer.

Schedule 1—The Statement for Australia’s Carers

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.

¹⁶Australia’s National Human Rights Action Plan. 2012, [accessed online](#)

¹⁷Parliament of Australia, *Carers Recognition Act (2010)* [accessed online](#)

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.

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.

While the states and territories all have their own Carers Recognition Acts, they vary in respect to the kinds of carers included under the Acts. The contents of the Charters or Statements for carers have some common elements but they also vary. Except in relation to requirements on state and territory government public agencies with respect to compliance and reporting requirements, most states have caveats on enforceability. The one exception is the Queensland *Carers Recognition Act* which states that: “*This Act binds all persons, including the State*”.¹⁸ With respect to the other states and territories:

- The NSW *Carers Recognition Act* stipulates in Division 1:
 - (1) *Nothing in this Act gives rise to, or can be taken into account in, any civil cause of action, and without limiting the generality of the foregoing, nothing in this Act:*
 - (a) *operates to create in any person any legal rights not in existence before the enactment of this Act, or*
 - (b) *affects the validity, or provides grounds for review, of any judicial or administrative act or omission.*¹⁹
- The Western Australian *Carers Recognition Act* states that: *The care relationship principles set out in this Part do not create, or confer on any person, any right or entitlement enforceable at law*²⁰
- The Australian Capital Territory *Carers Recognition Act* stipulates that: *The Legislative Assembly does not intend by this Act to create in any person any legal right or give rise to any civil cause of action.*²¹
- The Victorian *Carers Recognition Act* says: *“If there is any inconsistency between this Act (other than section 12) and any other Act, the provisions of the other Act prevail.”*²²
- Part 8 of the Tasmanian *Carers Recognition Act* with respect to legal liability states that:
 - (1) *Nothing in this Act gives rise to, or is to be taken into account in, any civil cause of action.*
 - (2) *Without limiting subsection (1), nothing in this Act –*
 - (a) *operates to create in any person any legal rights; or*
 - (b) *affects the validity, or provides grounds for review, of any judicial or administrative act or omission.*

¹⁸ Queensland Carers Recognition Act (2006) [accessed online](#)

¹⁹ NSW Carers Recognition Act (2010) [accessed online](#)

²⁰ Western Australian Carers Recognition Act (2004) [accessed online](#)

²¹ Australian Capital Territory Carers Recognition Act (2021) [accessed online](#)

²¹ Victorian Carers Recognition Act (2014) [accessed online](#) (2004)

²² Victorian Carers Recognition Act (2014) [accessed online](#)

(3) If an Agency is required by another law to consider particular matters, or to comply with particular requirements, in the performance or exercise of the Agency's functions or powers, nothing in this Act is to be taken to require the Agency to act inconsistently with that law.²³

- The Northern Territory and South Australian *Carers Recognition Acts* are silent on the issue.²⁴

Carers deserve a national Charter of Rights which embodies key aspects of the national, state and territories' Acts and which is binding on other Acts which impact very directly on carers, including the *Aged Care Act*²⁵, *Disability Services Act*²⁶, and the *Fair Work Act*²⁷ (which allows carers to use their Personal Leave for caring purposes plus two days unpaid leave for casual workers and permanent and part-time employees who have exhausted their Personal Leave, but is not otherwise specifically carer inclusive). We need a national Carers Recognition Act which has some teeth.

The current list of carers covered in the Act should be expanded beyond carers of people with disability; a medical condition, mental illness or is frail aged. to include carers of people with drug and alcohol addiction. The stigma attached to the people being cared for and the inadequacy of services available to them than lead many of their carers to lack awareness that they too are eligible for support. They may also be unaware that drug and substance use is included in the impairment tables for the Disability Support Pension. The 2021 and 2022 Carer Wellbeing Survey identified that carer wellbeing was particularly low among those these carers and the person they cared for was least likely to access help of a medical or other support service.²⁸

The new Act should include services provided by the State identified in Article 28:3 of the Convention on the Rights of People with Disability to adequate training, counselling, financial assistance and respite care, but should not be restricted to people in poverty or to carers of people with disability but to all carers identified under the Act.²⁹

We draw to the Committee's attention that the House Standing Committee on Social Policy and Legal Affairs is holding a concurrent Inquiry into the recognition of unpaid carers.³⁰ Carers Australia will be responding to this Inquiry and we will be advocating for a *National Carers Recognition Act* which will confer enforceable rights for carers and expands on the principles currently embodied in the Statement for Carers in the 2010 Act.

Acts currently in development which should embody Carers Rights

The two most significant Acts which are currently under review and which directly impact on the rights of the people they care for and on carers themselves are the new *Aged Care Act* and the *Disability Services Act*.

Carers Australia fully appreciates that the major focus of these Acts will be on the rights of those they care for and that these rights will be centred around the right of consumers to autonomy in decision-making,

²³ Tasmanian Carers Recognition Act (2023) [accessed online](#)

²⁴ Northern Territory Carers Recognition Act (2006) [accessed online](#) and Carers South Australia Carers Recognition Act (2005) [accessed online](#)

²⁵ Parliament of Australia, Aged Care Act (1997) [accessed online](#)

²⁶ Parliament of Australia, Disability Services Act (1986) [accessed online](#)

²⁷ Parliament of Australia, Fair Work Act (2009) [accessed online](#)

²⁸ Op.cit.

²⁹ Op.cit.

³⁰ House Standing Committee on Social Policy and Legal Affairs, Inquiry into the recognition of unpaid carers, referred 7 June 2023 [accessed online](#)

choice and control, as well as such rights as freedom from discrimination, the right to safe and quality services, the right to social inclusion, and the right to inclusive and culturally safe services. However, such a focus does not negate the inclusion of the rights of those who care for them. The reality is that many people receiving care depend on carers and families to assist, support and advocate for them and the capacity for carers to perform this role relies on carers themselves being treated with dignity and respect, having their voice recognised and having access to supports which enable them to carry on in their caring role.

Aged Care Act

Under the current *Aged Care Act*³¹, carers are only specifically mentioned three times in the body of the Act and families once. These mentions are under the Objects of Act: Division 2:1 (g) identifies as an object of the act “to provide respite for families, and others, who care for older people.

Division 2:1 (f) covers:

- (g) to encourage diverse, flexible and responsive aged care services that:*
- (i) are appropriate to meet the needs of the recipients of those services and the carers of those recipients; and*
- (ii) facilitate the independence of, and choice available to, those recipients and carers.*

These inclusions do not include rights but rather promote best practice in the case of (g) and, while there are a number of references to respite in the Act, they refer to procedural requirements for accessing respite rather than establishing a right to respite.

We would expect the new *Aged Care Act* to firmly establish carers’ rights and be more carer inclusive throughout the body of the legislation. This expectation is based in part on the recommendations of the Royal Commission into Aged Care Quality and Safety. Indeed, in its first recommendation the Commission stipulates support for carers in the definition of aged care under the new Act.

Recommendation 1: A new Act

- 1) The Aged Care Act 1997 (Cth) should be replaced with a new Act to come into force by no later than 1 July 2023.
- 2) The new Act should define aged care as:
 - a) support and care for people to maintain their independence as they age, including support and care to ameliorate age-related deterioration their social, mental and physical capacities to function independently
 - b) supports, including respite for informal carers of people receiving aged care.³²

Importantly, the Royal Commission also recommended that: “the relationships that older people have with significant people in their lives should be acknowledged, respected and fostered”³³

We strongly advocate that the Statement for Carers in the *Carers Recognition* (2010) be recognised as conferring rights on carers under the new Act.

³¹Op.cit

³²Royal Commission into Aged Care Quality and Safety, 2021, Recommendation 1 [accessed online](#)

³³ Ibid. Recommendation 3 (vi)

Disability Services Act

The current *Disability Services Act* (1986) only reflects expectations of supports for families to information, training and respite but only in relation to process not to rights.³⁴

Australia's Disability Strategy 2021-31 does at least acknowledge the vital role of families and carers in providing both practical and emotional support and advocating for the people they care for.³⁵

However, we have yet to see if and how this translates into the provisions under the new Act reflecting carers rights. We are hoping that family and carers' need for recognition and support are not merely a by-product of the support offered to people with disability and that it is recognised that families and carers have separate needs and rights to supports of their own which are referenced under the Act.

Recommendations

Recommendation 1:

While ideally Australia should have a national Human Rights Act as do most other equivalent countries, if this is not possible a new Human Rights Framework should be less dependent on UN conventions.

Recommendation 2:

We need an amended national *Carers Recognition Act* which embodies rights as opposed to an exhortation to do the right thing by carers, as is the case in the current Acts.

This Act must recognise intersectional challenges that carers face and the need for accessible, culturally sensitive and safe services for carers who have special needs in relation to accessing supports.

It must also bind Acts which directly impact the rights and services of the people being cared for.

Recommendation 3:

Regardless of the introduction of a new *Carers Recognition Act*, reference to the Statement for Carers in the current Act should be included in the new *Aged Care Act*, *Disability Services Act*, the *Veterans' Entitlements Act*, the *Fair Work Act* and Acts relating to the care and education of children.

³⁴ Parliament of Australia, *Disability Services Act* (1986) [accessed online](#)

³⁵ Australia's National Disability Strategy 2021-2031, Policy Priority 3 [accessed online](#)

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About Carers Australia

Carers Australia is the national peak body representing the diversity of the 2.65 million Australians who provide unpaid care and support to family members and friends with a disability, chronic condition, mental illness or disorder, drug or alcohol problem, terminal illness, or who are frail aged.

In collaboration with our members, the peak carer organisations in each state and territory, we collectively form the National Carer Network and are an established infrastructure that represent the views of carers at the national level.

Our vision is an Australia that values and supports all carers, where all carers should have the same rights, choices, and opportunities as other Australians to enjoy optimum health, social and economic wellbeing and participate in family, social and community life, employment, and education.

This includes carers:

- Who have their own care needs
- Who are in multiple care relationships
- Who have employment and/or education commitments
- Aged under 25 years (young carers)
- Aged over 65 years, including 'grandparent carers'
- From culturally and linguistically diverse backgrounds
- Who identify as Aboriginal and Torres Strait Islander
- Who identify as lesbian, gay, bisexual, transgender, intersex (LGBTI+)
- Who are living in rural and remote Australia, and
- Who are no longer in a caring role (former carers).

Carers Australia acknowledges Aboriginal and/or Torres Strait Islander peoples and communities as the traditional custodians of the land we work on and pay our respects to Elders past, present and emerging. As an inclusive organisation we celebrate people of all backgrounds, genders, sexualities, cultures, bodies, and abilities.