

3 December 2019

Australian Human Rights Commission
Level 3, 175 Pitt Street
SYDNEY NSW 2000

Carers NSW thanks the Australian Human Rights Commission (AHRC) for the opportunity to provide a written submission in relation to its four papers: (1) *Free and Equal: An Australian conversation on human rights*; (2) *Discussion Paper: Priorities for federal discrimination law reform*; (3) *Discussion paper: A model for positive human rights reform in Australia* and (4) *Discussion paper: Ensuring effective national accountability for human rights*. Our submission focuses on the rights of family and friend carers, with a focus on rights relating to economic participation and service access.

Carers NSW is the peak non-government organisation for carers in NSW. A carer is any individual who provides care and support to a family member or friend who has a disability, mental illness, drug and/or alcohol dependency, chronic condition, terminal illness or who is frail. Our vision is an Australia that values and supports all carers, and our goals are to:

- Be a leading carer organisation in which carers have confidence
- Actively promote carer recognition and support
- Actively support carers to navigate a changing service landscape that will be characterised by ongoing policy reform
- Promote connected community experiences and opportunities for carers that are inclusive of diverse carer groups
- Lead and advocate for carer-specific and carer-inclusive policy making, research and service delivery
- Continue to be a quality-driven, responsive and carer-focused organisation.

Carers make key contributions to Australia's society and economy, however they are often not recognised, and many experience financial disadvantage, discrimination and poor health and wellbeing outcomes as a result of their caring role. Prioritising carers' human rights is a key way of acknowledging that carers deserve support and recognition in their own right, as well as in their capacity as a support for those they care for.

Carers NSW welcomes the opportunity to share our knowledge and concerns regarding carers' rights in the *Free and equal* national conversation, and urges the Australian Human Rights Commission to join us in promoting carers' human rights in Australia.

Thank you once again for accepting our submission. For further information, please contact Sarah Judd-Lam, Manager, Policy and Research at sarahj@carersnsw.org.au or on (02) 9280 4744.

Yours sincerely,



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Carers **NSW** Australia

Carers NSW submission:

*Free and Equal: An Australian
conversation on human rights*

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AN AUSTRALIA THAT VALUES AND SUPPORTS ALL CARERS

INTRODUCTION

A carer is any individual who provides care and support to a family member or friend who has a disability, mental illness, drug and/or alcohol dependency, chronic condition, terminal illness or who is frail. Carers come from all walks of life and have the same human rights as those who are not carers. However, like many other vulnerable groups, carers often miss out on key outcomes to which they are entitled, and in many cases do not have the knowledge or resources to seek redress. They also have some specific rights under legislation that can be upheld through complaints pathways.

Carer recognition legislation

Carers NSW interest in the topic of carer rights is centred in the obligations of public service agencies under carer recognition legislation at State and Commonwealth level.¹ Having been closely involved in the drafting, review and implementation of this important legislation, we are committed to increasing awareness among carers, service providers, employers and communities, of the principles of the NSW Carers Charter and the Statement for Australia's Carers (Schedule 1 of each legislative instrument).

"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."

- Statement for Australia's Carers

Unfortunately, while this legislation holds obligations for public sector agencies, there is little recourse for agencies that do not meet their obligations, and awareness is low overall, though growing. More importantly, the Acts specify that they do not create legally enforceable rights for individuals or establish specific complaints pathways or mechanisms to allow carers to keep agencies accountable. The only way in which public sector agencies are accountable to the Acts is in their annual reporting.

In order to highlight particular areas where the principles embedded in the legislation are being breached or neglected, individual carers and the groups and organisations that support them can only use the legislation as justification to urge agencies and political representatives to take action. For organisations like Carers NSW, this involves systemic advocacy through policy submissions and direct engagement with government agencies through consultations and committees. For individuals it means self-advocacy through contact with service providers, local political representatives or media. While these practices often do result in positive change, without binding legal rights it is difficult to achieve wide reaching or lasting change.

Systemic change in these areas also relies on the understanding and good will of decision makers, often drawn from their own personal experience of caring; and individual recourse may be achieved but with no broader implications for agency policy and practice that could benefit many carers. In this way, carers' 'rights', as established in carer recognition legislation, are similar to the many human rights that Australians have but for which there are no clear pathways for recourse.

Legal rights and formal complaints pathways

As with other Australians, carers do, however, have a range of legal rights across legislative instruments relating to specific service systems that also identify formal complaints mechanisms. It is in this context that Carers NSW has been working since 2018 with the NSW Department of Communities and Justice and a range of complaints agencies – including the Australian Human Rights Commission – and peak organisations as part of the Carer Rights & Complaints Network (CRCN).

¹ NSW Carers (Recognition) Act 2010, Cwth Carer Recognition Act 2010

The CRCN's focus to date has been to map carers' rights and complaints pathways across service systems and distil this information into clear, simple consumer-facing resources. At the time of writing, this has taken the form of between eight and ten draft fact sheets designed for a carer audience. The aim of this project is to improve carers' awareness of their rights and the opportunities they have to seek redress. It has also had the added benefit of raising awareness of carers' needs and experiences among complaints agencies with whom we have not previously engaged.

Carers NSW also plans to develop a self-advocacy toolkit for carers to complement the CRCN resources by equipping carers with practical suggestions for how to seek to have rights upheld which do not have any obvious complaints or appeals pathway. The principles embedded in the carer recognition legislation will be part of this, as will broader human rights as detailed in the issues paper for this national conversation.

Carers and human rights

Beyond the principles embedded in carer recognition legislation and the legal rights carers have in other legislation, carers have the same human rights as other Australians. Of the human rights domains identified in the original *Free and equal* issues paper, Carers NSW research, consultation and policy analysis have identified that several hold particular challenges for carers. These are addressed briefly below, with the following sections of this submission providing deeper analysis.

Cultural life, rest and leisure

Research clearly demonstrates that caring for a family member or friend can result in isolation from family, friends and community. For many carers, the time and energy associated with their caring role, especially when balanced with other responsibilities such as paid work and family life, reduces the time they are able to spend engaging in social and cultural activities. Further, the reduced income and additional living costs associated with caring limit carers' access to recreation, leisure and entertainment activities where there is a cost to participate or to travel. Finally, many carers have difficulty accessing adequate formal services for the person they care for in order to enable them to take a break from the caring role.²

For many carers, especially those living with care recipients who have complex care needs, the caring role is a 24-hour, seven-day per week, year-round commitment that is relieved only occasionally by alternative care arrangements, provided either by friends and family or by formal services.³ In NSW, nearly one in three primary carers (the individual providing the most care to a person) cares for more than 60 hours per week, and 34% have been caring for 10 years or more.⁴ The Carers NSW 2018 Carer Survey found that in more than one in four caring situations, care recipients could not be left alone at any time, and more than half of carers did not receive any assistance with caring from family members or friends. Only half of respondents accessing aged care services and 40% of those accessing disability services identified that these services provided them with a break from the caring role.⁵

While aged care and social security legislation entitle some carers to 'respite' from their caring role, beyond this official eligibility, carers' access to respite completely depends on the availability of timely, appropriate and affordable services. Increasingly, accessing these services can be very challenging

² Australian Bureau of Statistics (2016), *ABS Survey of Disability, Ageing and Carers: 4430.0 - Disability, Ageing and Carers, Australia: Summary of Findings, 2015*; Carers NSW (2018), *Carers NSW 2018 Carer Survey: Summary report*, Carers NSW, Sydney; Department of Social Services (DSS) (2016), *Designing the new integrated carer support service: A draft service concept for the delivery of interventions to improve outcomes for carers*, Australian Government, Canberra.

³ Bellamy, J., Paleologos, Z., Kemp, B., Carter, S. & King, S. (2014) *Caring into Old Age: The wellbeing and support needs of parent carers of people with disabilities*, Anglicare Diocese of Sydney, Sydney.

⁴ ABS (2016).

⁵ Carers NSW (2018).

for carers.⁶ When carers have no alternative to continue providing high intensity care day-in, day-out, with no opportunities to take a break or rest, this can have a significant impact on relationship stress, wellbeing and social participation.⁷

Physical and mental health

Reduced social engagement has considerable implications for physical and mental health, as limited time and resources to access recreational activities and connect with social networks reduces overall physical movement and more structured opportunities for exercise, limits access to informal emotional and practical support and deprives carers of the mental and physical relief that is often associated with a temporary break from the demands of caring.

Caring can involve significant emotional investment and physical activity, which, combined with minimal breaks, can take its toll on carers' physical and mental health. Unlike paid care workers performing similar tasks, health and safety protocols, injury insurance and break entitlements are completely unavailable to family and friend carers.⁸ As a result, carers have higher rates of long-term illness and disability than non-carers and experience considerably higher emotional distress.⁹ They also tend to neglect their own physical and mental health in order to prioritise that of the person they care for.¹⁰

Furthermore, the same barriers that prevent carers from engaging in social and recreational activities can also prevent carers from accessing critical health and wellbeing services in their own right. Less than half of the carers who responded to the Carers NSW 2018 Carer Survey reported that the disability and aged care services they accessed provided the time they needed to manage their own health needs.¹¹

Self-determination and privacy

In addition to the undeniable challenges that it brings, caring also has a range of positive aspects and can result in fulfilment, satisfaction, strengthened relationships and transferable skills.¹² Many carers choose to care in order to fulfil family or cultural responsibilities, demonstrate love and gratitude to their family members, apply their skills and experience and provide a higher quality of care than that which could be achieved through formal services only.¹³

However, the increasing 'consumer direction' of aged care and disability services has meant that carers' own needs and goals are often excluded from the service planning conversation and not prioritised when funded services are allocated.¹⁴ Furthermore, privacy considerations within a health care services setting often results in service related information being withheld from carers, even when their ongoing care is required.

In many cases, the exclusion of carers from service planning conversations results in a mismatch of formal service provision with what the carer is able and willing to provide. It is imperative that carers

⁶ Carers NSW (2016), *National survey of carers' respite needs*, Carers NSW, Sydney; Carers Australia (2018), *Improving access to aged residential respite care*, Carers Australia, Canberra; Carers NSW (2018).

⁷ Mental Health Carers NSW (2019) *Submission to the productivity commission inquiry into mental health: Submission from Mental Health Carers NSW Inc.* Available online at: https://www.pc.gov.au/__data/assets/pdf_file/0005/240692/sub245-mental-health.pdf, last viewed 01/10/2019.

⁸ Carers NSW (2017), *A just reward? A comparison of paid and unpaid care*, Carers NSW, Sydney.

⁹ ABS (2016); Carers NSW (2018).

¹⁰ Keesing, S., Rosenwax, L. and McNamara, B. (2011), "'Doubly deprived': a post-death qualitative study of primary carers of people who died in Western Australia", *Health and Social Care in the Community*, 19 (6): 636-644.

¹¹ Carers NSW (2018).

¹² Carers NSW (2018).

¹³ ABS (2016).

¹⁴ Carers NSW (2018) *Carers NSW 2018 Carer Survey: Summary Report*, Carers NSW, North Sydney.

be given a voice in relation to the care they provide and Carers NSW has long advocated for carers to be given formal opportunities to communicate their own goals, needs and concerns so that the funded services provided to the care recipient meets the needs of both parties. Balancing the needs of carers with those of care recipients is, however, a delicate balance which is explored in much greater depth in the third section of this submission.

Adequate standard of living and social security

Due to the time demands of caring and the limitations of formal care services, many carers are simply unable to balance care with paid employment. Others do balance the two, but with difficulty; and still others choose to remain out of the workforce in order to dedicate their time and energy to the important role of caring for a loved one. As a result, overall labour force participation and total hours worked in the paid workforce are lower among carers than non-carers, resulting in lower income, savings, assets and superannuation, and consequently, a greater risk of financial hardship.¹⁵

The Carers NSW 2018 Carer Survey found that 40% of carers had difficulty meeting their living expenses in the last 12 months, with figures higher for population groups facing additional disadvantage such as Aboriginal and Torres Strait Islander carers, LGBTQI+ carers, mental health carers and regional and remote carers.¹⁶ Caring at a younger age has also been associated with significant socioeconomic disadvantage as young carers are more likely to live in low-income and lone parent households compared to their non-caring counterparts.¹⁷

The extra costs associated with caring can also be substantial. Carers and their families often have to find resources to cover extra expenses like additional utility costs to maintain heating and cooling, medicines and therapies, disability aids, health care appointments and transport. A higher than average reliance on income support payments among carers and those for whom they care compounds the resource constraints these households experience, and though many carers are entitled to access income support and associated discounts and rebates, many remain ineligible or otherwise unable to access it, or when they do, find that it does not cover their costs.

Improving the standard of living of carers is therefore complex, and involves immediate financial support and relief as well as adequate income support, adequate free and subsidised services and supports, and assistance for carers to overcome barriers to earning income and accruing superannuation through improved overall economic participation.

Economic participation

Human rights related challenges experienced by carers in relation to economic participation are addressed in depth in the second section of this submission. Under the banner of economic participation, this submission refers to the following human rights domains mentioned in the issues paper: education, good working conditions, discrimination, social security and gender equity.

¹⁵ ABS (2016); Carers NSW (2018).

¹⁶ Carers NSW (2018), Carers NSW 2018 Carer Survey, unpublished data.

¹⁷ ABS (2016); Cass et al. (2011).

ECONOMIC PARTICIPATION

Approximately two thirds of the 2.65 million carers across Australia are of working age. More than one in four (29%) are not in the labour force compared to one in five (20%) non-carers,¹⁸ and carers commonly report having exited the workforce or reduced their engagement with paid work in order to attend to caring responsibilities.¹⁹ As a result, a larger proportion of carers than non-carers rely on an income support payment as their main source of income.²⁰

For carers who wish to maintain, increase or re-enter paid employment for financial or other reasons, significant barriers persist. These include limited workplace flexibility, stigma and discrimination within the workforce, inadequate 'replacement care' to enable carers to work, financial and policy barriers to upskilling, and limited tailored support to remain competitive in the job market. For carers who are unable to work or would prefer to focus on the caring role for personal, familial or cultural reasons, policy restrictions and budget constraints also reduce carers' social and economic participation.

Education

Barriers to employment and career development can start very early for young carers (aged 25 and under), who, without adequate recognition and support from schools and higher education institutions, often experience significant disadvantage as a result of the reduced engagement and performance associated with balancing study with caring responsibilities.²¹ A lack of awareness among education professionals and limited carer inclusion in institutional policies mean that young carers often remain hidden, and the stigma and social isolation associated with caring as a child or young person prevents many young carers from understanding the educational implications of, or disclosing, their situation.²²

It is not only young carers who seek to develop their skills and knowledge through formal education, however. Many working aged and mature aged carers seek to upskill or refresh their skills in order to re-enter the workforce or otherwise develop their career. While not all carers seeking employment require special consideration and tailored support to do so, carers have reported to Carers NSW that rigid policies, limited flexibility and financial cost can present significant barriers preventing them from further study. This is further complicated for carers receiving the Carer Payment from Centrelink, whose payment is affected if they participate in 25 hours or more per week (including travel) of education.

Small scale, government funded programs such as the Young Carer Bursary,²³ Upskilling Carers project,²⁴ SkillsLink2Work tool,²⁵ Try Test and Learn Fund projects²⁶ and Care2Work program are

¹⁸ ABS (2016).

¹⁹ Carers NSW (2018).

²⁰ ABS (2016).

²¹ Carers NSW (2017) *Young carers: Barriers to accessing education and employment*, Carers NSW, August 2017; Hamilton, M. and Redmond, G. (2019), 'Are Young Carers Less Engaged in School than Non-Carers? Evidence from a Representative Australian Study', *Child Indicators Research*.

²² Cass et al, 2009, 2011; Lloyd, K. (2013) Happiness and Well-Being of Young Carers: Extent, Nature and Correlates of Caring Among 10 and 11 Year Old School Children. *Journal of Happiness Studies*, 14(1), 67–80. The Children's Society (2013), *Hidden from View: The Experiences of Young Carers in England*, The Children's Society; London; Hamilton, M. and Redmond, G. (2019); Warren, D. and Edwards, B. (2017) *Young carers*, LSAC Annual Statistical Report 2016 chapter – August 2017.

²³ Young Carers Network (2019), *Young Carer Bursary*, available online at: <https://youngcarersnetwork.com.au/young-carer-bursary>, last viewed 2 December 2019.

²⁴ TAFE NSW (2019) *Carer to Career*, available online at: <https://visit.tafensw.edu.au/carers-to-career>, last viewed 2 December 2019.

²⁵ SkillsLink2Work (2019), *SkillsLink2Work*, available online at: <https://skillslink2work.com.au/>, last viewed 2 December 2019.

²⁶ Department of Social Services (2019), *Try, Test and Learn Fund*, available online at: <https://www.dss.gov.au/review-of-australias-welfare-system/australian-priority-investment-approach-to-welfare/try-test-and-learn-fund>, last viewed 2 December 2019.

beginning to address these barriers for some carers, however significant further investment, innovation and research in this area is required in order to achieve significant change.

Good working conditions

Australia has a strong labour rights framework that includes two specific entitlements for all working carers: the right to access carers leave (paid and unpaid)²⁷ and the right to request flexible working arrangements.²⁸ However, carers leave is taken out of an employee's sick leave balance, which is limited and must be accrued over time; and employers are not compelled to approve requests for flexible working arrangements if they believe they are unviable on business grounds.²⁹ This limits both the application and the effectiveness of these rights in assisting carers to balance ongoing caring responsibilities with paid employment.

Greater awareness and inclusion of carers by employers is required in order to implement the kind of flexibility that will enable the many employees with caring responsibilities to maintain both roles effectively. Some industries and roles are more amenable to flexibility than others (hence the higher concentration of carers within certain industries),³⁰ and specific types of employers (such as large corporates and government agencies) are more likely to invest proactively and innovatively in flexibility and inclusion due to existing incentives and regulation.

Initiatives such as the Carers + Employers program³¹ support employers of all sizes and sectors to improve their support, retention and recruitment of carers in line with a strong business case. Further, an increasing focus on both workplace diversity and flexibility, in relation to a range of employee cohorts, holds broader benefits for working carers. Proponents of 'flexibility by design' suggest that it prevents the need to accommodate individual scenarios and instead recognises that all employees are likely to have some form of caring commitment outside of work at some stage.³²

While a flexible, carer-friendly workplace is key to providing good working conditions to carers, carers, like other workers, should have access to work that is adequately paid, enjoyable and in line with their skills and experience, undertaken in a supportive workplace culture. At this point it is important to highlight carers' choice, both in whether to enter into paid employment, and in what kind of paid employment to enter into. The governmental emphasis on transitioning income support payment recipients into work can occur at the expense of supporting individuals to pursue career pathways that may be more competitive and require more time to train for, but which may ultimately result in greater satisfaction, job security and/or remuneration.

Furthermore, deficits in the direct care workforce that have been recently identified in the disability and aged care sectors has led, in combination with increasing public discourse surrounding carer employment, to an assumption that channelling unemployed carers into direct care professions will

²⁷ Fair Work Ombudsman (2019), *Sick and carers leave*, available online at:

<https://www.fairwork.gov.au/leave/sick-and-carers-leave>, last viewed 2 December 2019.

²⁸ Fair Work Ombudsman (2019), *The right to request flexible working arrangements*, available online at:

<https://www.fairwork.gov.au/how-we-will-help/templates-and-guides/best-practice-guides/the-right-to-request-flexible-working-arrangements>, last viewed 2 December 2019.

²⁹ Zeppel, M., Hofstaetter, L., Graham, P. and Loh, S.M. (2019), 'More carers' leave may help Australians look after elderly parents and stay in work', *The Conversation*, 28 November 2019.

³⁰ Carers NSW (2018); Skinner, N., Pocock, B. (2014), *The Persistent Challenge: Living, Working and Caring in Australia in 2014. The Australian Work and Life Index 2014*. Centre for Work and Life, University of South Australia: Adelaide, p. 38.

³¹ Carers + Employers (2019), *Carers + Employers*, available at: <https://carersandemployers.org.au/>, last viewed 2 December 2019.

³² Russell, G., O'Leary, J., Tilly, J., Brown, C. (2016), *Future-Flex: Mainstreaming Flexibility by Design: Redesigning work to make flexibility standard business practice in Australian retail workplaces*, Synopsis Report, Diversity Council Australia, available online at:

<https://www.dca.org.au/files/file/Research/DCA%20Future%20Flex%20Synopsis%20Online%20Accessible.pdf>; viewed 17 October 2016.

simply address both policy dilemmas. Importantly, the Carers NSW 2018 Carer Survey found that only around one quarter of respondents were already working, or would be willing to work, as a paid care worker. The majority were not interested in this trajectory.³³ This highlights the importance of supporting carers into both care related and other employment pathways in order to promote their right to choice and to good working conditions.

Discrimination

Carers are included in several discrimination focused Acts: the NSW *Anti-Discrimination Act 1977*, the Commonwealth *Sex Discrimination Act 1994* and the Commonwealth *Disability Discrimination Act 1992*. This legislation protects carers, or those providing care to dependents or associating with people with disability (including carers), against discrimination as a result of their caring role. While discrimination legislation is accompanied by defined complaints pathways, as noted in the first *Free and equal* discussion paper, *Priorities for federal discrimination law reform*, its scope and application is limited.

When considering the rights carers have in the workplace, particularly the right to be protected against discrimination, it is necessary to recognise that while legislation prescribes that all employees have the right to maintain family responsibilities, carers may not experience the full extent of this protection. This is because caring responsibilities often fall outside the prescribed scope of 'family responsibilities.' For example, many parents may need to engage in flexible work hours to accommodate school drop off or pick up, or have flexible leave arrangements in the event a child or children are sick. Caring responsibilities may, however, extend beyond what is perceived to be typical family or parental responsibilities, with many carers reporting that their caring role requires them to attend appointments during work hours or have earlier or later start or finish times to accommodate or maintain regulatory for the person they care for.

Carers as defined by the Commonwealth *Carer Recognition Act 2010* and NSW *Carers (Recognition) Act 2010* (and equivalent legislation in other states and territories) require explicit and consistent reference within discrimination legislation, and the broadening of the scope of discrimination rights to contexts other than the workplace, such as community and service settings. Further, many carers are unaware of the rights and opportunities for redress that they do have under the current legislation, a key reason for the Australian Human Rights Commission's involvement in the CRCN project mentioned in the introduction of this submission.

Finally, greater clarity and accountability regarding workplace discrimination is required in order to understand the extent to which carers are actively discriminated against in relation to recruitment, career progression opportunities and requests for flexible working arrangements. Carers often report that they are afraid to disclose their caring responsibilities in these contexts as they believe it will adversely impact how their managers and colleagues will perceive and treat them. In many cases, though this may be the case, active discrimination may be difficult to establish. More work needs to be done to assist employers to understand the productivity benefits of accommodating carers' needs so that these are fairly balanced with business interests that may be used as justification for refusing carers flexibility or denying them career opportunities. The Carers + Employers initiative is an important step in providing employers with such support.³⁴

³³ Carers NSW (2018).

³⁴ Carers + Employers (2019).

Gender equity

Both the impacts of care on economic participation, and the opportunities to address these, are highly gendered. Women are statistically far more likely to take on more intensive caring roles³⁵ in response to social conventions and expectations, and are also far more likely to take time out of work, exit the labour force, work part time, and work in casualised, lower paid occupations and industries in order to care.³⁶ This dynamic, alongside the impact of child care on workforce participation, is a key contributor to the well-established disadvantage women experience in relation to income level, asset ownership and superannuation balance.³⁷ Economic modelling has shown that if a woman leaves the workforce to care for a child with disability when she is 30 years old, her retirement income will be inadequate during her old age.³⁸ Indeed, the economic impacts of caring particularly amongst women has been identified as a significant factor resulting in insecure housing conditions in later life.³⁹

While men are less likely to become primary carers and tend to experience less marked career impacts when they do,⁴⁰ they are also less likely to access carer support services, to disclose their caring role, and to seek and obtain flexibility at work.⁴¹ Industrial and occupational segregation is often viewed through the lens of the disadvantage experienced by women, however, male carers also experience disadvantage in this context. Male segregated industries are typically characterised by full-time employment with cultures less accommodating of family and caring responsibilities. As a result, male carers can find it more difficult to balance work and care without facing discrimination in the workplace, such as being overlooked for promotions.⁴² According to recent data, men are twice as likely to be denied flexible working arrangements⁴³ and as a result, some male carers may be required to retrain and seek work in different sectors, or leave the workforce altogether. This dynamic also reinforces the gendered nature of care, incentivising women to reduce their workforce engagement to care.

The Workplace Gender Equality Agency (WGEA) has argued that creating flexible working arrangements for both men and women allows for greater staff retention and is fundamental for gender equity in the workplace. Further, the Business Council of Australia has identified the strength in creating tangible incentives, to ensure the stability of workforce participation, particularly for parents or carers.

³⁵ ABS (2016);

³⁶ ABS (2016); Carers NSW (2018); Finance and Public Administration References Committee (2017), *Gender segregation in the workplace and its impact on women's economic security*, Commonwealth of Australia, Canberra; WGEA Data Explorer (2016), *Health Care and Social Assistance summary for 2015*, available online at: <http://data.wgea.gov.au/industries/7>, viewed 19 February 2018.

³⁷ Durie, T. and Cavanough, E. (2017), *Guaranteeing Women's Super: How to close the gender gap in superannuation*, The McKell Institute, Sydney.

³⁸ Nepal, B., Brown, L., Ranmuthugala, G., Percival, R. (2008), Lifetime health and economic consequences of caring: modelling health and economic prospects of female carers in Australia, National Centre for Social and Economic Modelling.

³⁹ Sharam, A., Ralston, L. and Parkinson, S. (2016), 'Security in retirement: The impact of housing and key critical life events', Swinburne University of Technology: Melbourne; Stone, W., Sharam, A., Wiesel, I., Ralston, L., Markkanen, S. and James, A. (2015), 'Accessing and sustaining private rental tenancies: critical life events, housing shocks and insurances', AHURI Final Report No. 259, Australian Housing and Urban Research Institute; Swinburne University of Technology, The University of New South Wales and Curtin University; McFerran, L. (2010), *It could be you: single, older and homeless*, Homelessness NSW, Wolloomooloo, New South Wales.

⁴⁰ ABS (2016); Carers NSW (2018).

⁴¹ Ibid.

⁴² WGEA Data Explorer (2016), *All industries summary for 2016*, available online at:

<http://data.wgea.gov.au/industries/1>, viewed 6 February 2016; Wright, A., Crettenden, A., Skinner, N. (2016), 'Dads care too! Participation in paid employment and experiences of workplace flexibility for Australian fathers caring for children and young adults with disabilities', *Community, Work and Family*, vol. 19, no. 3, pp. 340-361.

⁴³ Bain & Company (2016), *The power of flexibility: A key enabler to boost gender parity and employee engagement*.

Social security

As previously noted, many carers are entitled to income support, but not all. In addition to the income and asset tests that determine eligibility for any income support payment, the carer-specific payments – the Carer Payment and Carer Allowance – have additional criteria, resulting in a relatively high eligibility threshold that excludes many carers. As a result, many carers requiring income support are directed to other payments such as the Newstart Allowance, which not only carries a lower rate, but also involves an emphasis on job seeking and mutual obligation that can fail to recognise, value and accommodate caring responsibilities as a form of unpaid work and an additional barrier to employment. Eligibility for Carer Payment is particularly problematic for carers of people living with a mental illness, whose needs are not always expressed in the same way as for those with physical or intellectual disability.

The difficulty carers have in accessing appropriate income support is in contrast to the rights carers have as citizens to social security. Furthermore, as a more recently established, and relatively high-cost, income support payment, the Carer Payment has come under recent scrutiny by the Federal Government, with efforts to reduce longer term ‘welfare reliance’ among young carers and carers more broadly.⁴⁴ While Carers NSW wishes to ensure that adequate support exists to enable carers to engage with employment where appropriate, we also believe that it is important to maintain a safety net that recognises the social and economic value of care and does not position carers as undeserving recipients of welfare.

A final challenge in relation to social security that warrants attention in this context is the ‘25 hour rule’, which causes a carer’s Carer Payment rate to be affected when they spend 25 hours or more per week in paid employment, formal education or volunteering, including travel. While the rationale behind tapering income support at this level of paid employment makes sense, this rule also unintentionally acts as a disincentive to carers improving their skills base (which can often be done largely from home and balanced with caring duties via flexible learning) and from accepting employment opportunities that involve significant travel to supplement their income. Carers NSW has long advocated for this policy to be reviewed and revised to remove the penalty from carers for studying, volunteering and seeking paid work far from home in order to improve their employability and further their career.

BALANCING THE RIGHTS OF CARERS AND CARE RECIPIENTS

Carers NSW believes that the rights of individuals receiving care – whatever their diagnosis, condition and level of care need – are just as important as the rights of carers. As such, we believe that the rights of both parties should be upheld. In many cases, the interests of carers and care recipients intersect, however sometimes they are at odds. As the peak non-government organisation for carers in NSW, carers’ rights are our focus, in particular carers’ rights in relation to the domains of self-determination and privacy, where carer and care recipient rights most commonly conflict. This section focuses on carers’ rights to be recognised, included and provided with information and support when there may be rights based conflict preventing these occurrences. In Carers NSW experience, the contexts in which these carer rights conflict most with those of the care recipient are the in the

⁴⁴ Department of Social Services (2019), *Australian Priority Investment Approach to Welfare*, available online at: <https://www.dss.gov.au/review-of-australias-welfare-system/australian-priority-investment-approach-to-welfare>, last viewed 2 December 2019.

determination of cognitive capacity and consent with respect to decision making and information sharing.

The NSW Carers Charter⁴⁵ and the Commonwealth Statement for Australia's Carers⁴⁶ each state that the valuable contribution of carers should be recognised and supported. They also denote that the relationship between carers and the people they care for should be respected, and carers should be considered partners in care, with providers acknowledging carer knowledge and experience. Throughout the course of a caring relationship, the intersection of carer and disability rights is common. However, when there is conflict, there is a risk of having one party's rights overtake the other's, with potential implications for both parties' wellbeing and safety. In these circumstances, it is fundamental that any intersection or conflict is considered holistically, so that barriers to achieving rights for carers are removed and the best interests of the care recipient are upheld.

Self-determination

In recent years, the aged care, disability and mental health sectors have been undergoing significant ideological shift in favour of individualised support packages driven by the concept of Consumer Directed Care (CDC), whereby the funding of individual supports is specifically tied to the goals of the person with care needs.⁴⁷ Self-determination is an increasingly central principle in the ongoing redesign of formal care service systems. It seeks to overcome a default position that many carers and other often well-meaning parties have taken in 'speaking for' people with disability and older people, which has in many cases led to disempowerment and indignity, and in some cases, abuse and neglect.

The growing focus on self-determination and rights of care recipients will significantly increase autonomy and opportunities for many people who have traditionally faced discrimination and systemic inequality. However, the ability to balance carer and care recipient rights within these systems is becoming increasingly challenging; there is often little scope to acknowledge or address the independent rights and needs of carers as individuals themselves.

Supported decision making

In the context of decision making, current policy and practice generally involves the presumption of capacity without substantial documentation to the contrary. Governments and service providers are intentionally moving away from traditional substitute decision making models such as guardianship, in favour of supported decision making approaches, which prioritise enabling people with cognitive impairment to express their needs and preferences. Carers are expected to play a supportive role in this process, however little guidance is often provided on exactly how to ensure a person's preferences are adequately captured and conveyed.

In essence, within a supported decision making paradigm, all practicable steps should be taken to support and build the capacity of a care recipient with cognitive and/or communication impairment such that their needs and preferences drive decision making, rather than the needs and preferences of their informal and formal supports. Decisions considered undesirable or unwise by other parties should be viewed in light of the concept of 'dignified risk', with the 'best interest' decision making paradigm considered to be a last resort.

Carers NSW supports the increased agency of people with disability and older people in making choices that affect them, provided that the carers who are expected to support this process are

⁴⁵ Carers (Recognition) Act 2010, Schedule 1 NSW Carers Charter

⁴⁶ Carer Recognition Act 2010, Schedule 1 The Statement for Australia's Carers

⁴⁷ Phillipson et al. (2019), Knowledge, help-seeking and efficacy to find respite services: an exploratory study in help-seeking carers of people with dementia in the context of aged care reforms, *BMC Geriatrics* (2019) 19:2.

provided adequate information and support and are treated with respect and dignity. Clarity and consistency with regard to the implementation of decision making support is also paramount, not only for the benefit of carers, but also to ensure effective support of people with disability and older people.

Inconsistent provisions within State and Commonwealth legislation, alongside inconsistent policies and practices within service agencies across the two levels of government, creates confusion and ambiguity for consumers, carers and service providers. Further conflict is noted between the mandate that family participate in supporting care recipients, and the lack of clarity with regards to those same carers' rights to participate in decision making and receive adequate information relevant to their caring role and individual wellbeing (explored further later in this section).

Within NSW, a number of formal appointments and roles are defined in legislation, providing carers and others specific rights and responsibilities with regard to decision making in order to safeguard the wellbeing of people with cognitive impairment. The Supreme Court of NSW or the NSW Civil and Administrative Tribunal (NCAT) can, following an application by someone (including, but not limited to, a carer) with concern for a person's welfare and ability to manage their financial affairs, appoint private individuals (including, but not limited to, carers) to do so.⁴⁸ It is preferable from a self-determination perspective that persons deemed to have legal capacity appoint an enduring power of attorney before support with financial matters is required, and those with a mild intellectual disability or in the early stages of dementia may still be able to do so.⁴⁹

An enduring guardian may also be appointed in advance of loss of capacity by a person to make lifestyle, health and medical decisions on their behalf if or when they lose capacity, and in some instances individuals (including, but not limited to, carers) may be appointed by the NSW Guardianship Tribunal,⁵⁰ however this is increasingly considered a last resort, with the NSW Government prioritising less formalised supported decision making measures wherever possible. The other legislatively supported appointment regarding receipt and provision of information about a care recipient is the NSW *Mental Health Act 2007*, which in a 2015 review incorporated additional provisions establishing and outlining the rights and responsibilities of 'designated carers' and 'principal care providers', who are individuals nominated by a person living with mental illness.⁵¹

These varying appointments and roles do not, however, correspond well at Commonwealth level, where the responsibility for policy and service delivery now sits for nearly all direct care services, causing much confusion and administrative complexity. The *National Disability Insurance Scheme Act 2013* (NDIS Act) recognises the requirement in some circumstances for a participant or National Disability Insurance Agency (NDIA) representative to appoint a 'nominee' "to act on behalf of, or make decisions on behalf of, a participant". This measure is framed as a last resort, only considered "when it is not possible for participants to be assisted to make decisions for themselves."⁵²

The Department of Human Services also allows for the appointment of nominees as authorised representatives who can obtain and provide financial information about a person, and in some cases

⁴⁸ NSW Trustee & Guardian (2019), *Financial management order*, available online at: <https://www.tag.nsw.gov.au/financial-management-order.html>, last viewed 3 December 2019.

⁴⁹ Legal Aid NSW (2019), *Speaking for myself*, available online at: <https://www.legalaid.nsw.gov.au/publications/factsheets-and-resources/speaking-for-myself/making-a-power-of-attorney>, last viewed 3 December 2019.

⁵⁰ NSW Trustee & Guardian (2019), *Who can be appointed as a guardian?* Available online at: https://www.publicguardian.justice.nsw.gov.au/Pages/publicguardian/pg_guardianship/pg_whoappoint.aspx, last viewed 3 December 2019.

⁵¹ NSW Health (2018) *Amendments to the NSW Mental Health Act 2007 – Carers and families*, available online at: <https://www.health.nsw.gov.au/mentalhealth/resources/Pages/carers.aspx>, last updated 5 October 2018.

⁵² NDIA (2019), *Guardians and nominees explained*, available online at: <https://www.ndis.gov.au/understanding/families-and-carers/guardians-and-nominees-explained>, last updated 5 November 2019.

receive payment on their behalf, in relation to residential care and Home Care Package asset tests and/or Centrelink payments.⁵³ In both of these contexts, people with other formally appointed roles such as guardian, power of attorney or financial manager are not automatically able to act as nominee and still need to be appointed, noting that the responsibilities of each role differ.

Confusingly, however, State and Territory appointments appear to have a much more flexible relationship in the context of the Commonwealth *Aged Care Act 1997*, for which the *Quality of Care Principles 2014* allow for individuals (including, but not limited to, carers) to be nominated as 'representatives' who can receive and provide information regarding the care recipient. Here, prospective representatives can nominate themselves, with confirmation from an 'approved provider' that is satisfied they are concerned for the safety, health and wellbeing of the care recipient and 'have a connection' with them, which is broadly defined and explicitly includes the existence of State and Territory appointments, family and spousal relationship and existing function in making contact on behalf of the care recipient.

While it is important to consider capacity on a spectrum, and not to remove or reduce a person's decision making power without due consideration, the limited and inconsistent interaction between Commonwealth designations and State and Territory appointments can, for carers acting with or on behalf of a care recipient, add multiple additional layers to already complex navigation between service systems. For example, an older person with dementia will commonly have had enduring power of attorney and guardianship enacted, be receiving aged care services and the Age Pension. For a carer to have to apply for two additional positions to support decision making when they have already been legally appointed by the person in another, related context seems excessive. This may also lead to unnecessary delays in decision making and support provision for the care recipient.

Carer choice and control

It is interesting and concerning to note that, amidst the 'choice and control' discourse that now dominates disability and aged care services, very little thought is generally given to carers' own choice and control, and indeed, their right to self-determination. There is no formalised entitlement or process for the carer's needs and preferences to be considered when individualised support planning occurs in either of these service systems, even when the carer's continuing presence and contribution to the care recipient's life is assumed or relied upon in the planning of formal services.

Indeed, the Carers NSW 2018 Carer Survey found that while most carers accessing disability or aged care services for care recipients were included in decision making, a minority were asked about their own needs. The same was true within the public and primary health care systems. As a result, many carers reported that these services did not really assist them to achieve their own needs and goals, such as taking a break from the caring role, attending to their own health, or increasing their engagement in the workforce.⁵⁴

Further, many services within the pre-reform aged care and disability systems previously addressed carers as either their primary or concurrent recipient of support, but with the shift to individualised support and CDC have either lost their funding or shifted to a sole focus on the care recipient, often at the expense of carer recognition, inclusion and support. Additionally, within care recipient focused systems, care recipients must initiate or at least consent to the inclusion of supports that specifically benefit the carer, if indeed these supports are considered within scope to fund.

The introduction of in-person supports for carers in their own right from April 2020 under the Carer Gateway will provide carers with the opportunity to access support directly. However, in spite of the

⁵³ Department of Human Services (2019), *Someone to deal with us on your behalf*, available online at: <https://www.humanservices.gov.au/individuals/topics/someone-deal-us-your-behalf/30251>, last updated 30 October 2019.

⁵⁴ Carers NSW (2018).

existence of Commonwealth and State and Territory carer recognition legislation, carers do not have the right to receive support per se; unlike the disability, aged care and mental health service systems, there is no specific legislation in relation to accessing the Carer Gateway and no clear pathway at this time for complaints regarding access and support. As the system is yet to fully roll out, Carers NSW hopes these components will develop, with reference to the right to assessment and support carers have under the UK *Care Act 2014*.

Strengthening carer recognition legislation to, among other rights, give carers the right to assessment and support, the right to self-determination regarding whether or not they provide care and the scope and nature of the care they provide is a straightforward way to improve carer outcomes. Alongside legislative change, simpler, more binding complaints pathways and carer-specific advocacy services are required to assist carers to have their rights upheld.

Privacy

Just as both care recipients and carers should have their right to self-determination upheld, both parties are entitled to protection of their privacy. The increasing emphasis on supported decision making and consumer direction has also resulted, in many cases, in a greater reluctance than in the past for government agencies and service providers to exchange information about care recipients with carers without their explicit consent. Privacy and confidentiality is, of course, paramount in all service interactions, especially where sensitive information being shared may compromise an individual's self-determination, dignity or safety. However, Carers NSW is also concerned that in some cases, principles of privacy and confidentiality are over-emphasised to the detriment of information sharing with carers that is critical in order for them to fulfil their caring responsibilities.

In Carers NSW experience, the main context in which this issue continually arises is in the mental health system, where challenges establishing legal capacity and rigid, risk averse systems often result in information about care recipients' diagnosis, treatment and status being automatically withheld, even when such information may be critical in order for carers to provide timely, safe and effective care to support the care recipient's recovery. A lack of appropriate and ethical information sharing may have a detrimental impact on care recipient outcomes, particularly with regards to physical and mental health, safety in the community, medication compliance, behaviour needs and potential relapse. Continuing to care without key information can also have implications for carer wellbeing and safety, and may negatively impact on the sustainability of the caring role.

A key example is the common failure of mental health services to convey to carers the timing of discharge even when there is an expectation for the care recipient to return to live with, and be supervised and supported by, the carer. While care recipients should maintain their right to privacy, this must in some cases be balanced with the importance and appropriateness of information sharing for safeguarding purposes. Given the complexity in relation to information sharing, there is an identified need for improved training and practical support for professionals to promote compliance under current legislation and ensure best outcomes for both consumer and carer. Decisions pertaining to privacy and confidentiality require sound professional judgement; therefore a stronger focus on ethics training may be beneficial.⁵⁵

⁵⁵McSherry, B. (2008). Health professional-patient confidentiality: Does the law really matter? *Journal of Law and Medicine*, 15, 489-493.

CONCLUSION

Carers NSW is pleased to have the timely opportunity to detail key rights challenges experienced by carers as part of the *Free and equal* national conversation. As detailed in this submission, carers experience particular barriers in having their human rights upheld, and though they have some access to legally enforceable rights and complaints mechanisms, legislative support for carer rights remains minimal. Alongside those they care for, carers need information and support to uphold the rights they have. A number of existing legislative and regulatory frameworks should also be strengthened to better address the particular challenges carers experience in regard to economic participation, self-determination and privacy.