

Joint Paper

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1. This joint paper has been submitted to the Royal Commission into Aged Care Quality and Safety (Royal Commission) in response to Notice to Give NTG-0286 (the Notice) addressed to Catherine Thomson and dated 19 July 2019.
2. This paper has been authored jointly by Catherine Thomson, Dr Trish Hill and Dr Myra Hamilton (the authors) of the Social Policy Research Centre (SPRC) at UNSW, Sydney.
3. Set out below are responses to the questions in the Notice. This paper represents a summary of the relevant and recent research conducted by the authors (as listed above from SPRC) in relation to the questions in the notice. The responses are supplemented by other key literature where our work has not directly examined specific issues or additional supporting evidence was required to address the issues and challenges posed in the notice.
4. *Please provide an overview of the work of the SPRC at UNSW. In particular, please provide an overview of its research relating to unpaid and informal carers of older Australians.*

Social Policy Research Centre at UNSW, Sydney

Founded in 1980 as Australia's first national research centre dedicated to shaping awareness of social welfare issues, SPRC is recognised as one of the leading centres for research in social policy in Australia, generating real change for individuals and communities.

SPRC is dedicated to making a positive impact through independent and leading research that explores the key social issues of poverty, inequality, wellbeing and justice. We also have unique expertise in evaluating government and industry programs to guide better practice and improved outcomes for individuals and communities.

Our research is organised into five research areas:

- Care
- Disability
- Families & Communities
- Measures of Social Inequality & Wellbeing
- Policy Design, Impact & Evaluation

Our researchers are leaders in their fields, with a strong reputation in the academic community, lending authority to our work and influence to public debate.

Our projects in the fields of ageing and care and the wellbeing of carers include national, international and cross-national research on:

- migration and care
- care organisations and the care workforce
- care for people with disabilities, chronic illness and mental illness
- out-of-home care
- care for ageing and older people.

This research brings attention to care relationships, the labour and tasks of care, the distribution of care between family, community, market and state, and the impact, benefits and costs of care. Our researchers engage with government, non-government, and advocacy organisations to develop policy and practice-relevant research projects.

This work provides an evidence base to inform policies and programs that support unpaid carers, paid care workers, and foster/kinship carers, and the children and adults they care for, and to foster productive ageing in the community.

5. *For each author of relevant articles and report of studies of the SPRC, please provide an overview of their current occupation, any relevant past occupations they have held, qualifications, areas of expertise, research and other professional activities. In particular, please provide an overview of your and your colleagues' research relating to unpaid and informal carers of older Australians.*

Cathy Thomson: BA USyd, MA UNSW, Sydney

Current occupation: Cathy is a Research Fellow at the Social Policy Research Centre, UNSW Sydney.

Areas of expertise: Cathy has been involved for over 20 years in academic and applied research and program evaluations based on mixed methods and quasi experimental design.

Cathy specialises in research on the characteristics and processes of service systems that assist or prevent vulnerable population groups such as older people and their carers accessing resources and support.

Cathy has worked on numerous research projects and evaluations where she has worked closely with commonwealth and state government departments and community organisations in the evaluation of the provision and coordination of social services.

Cathy has just completed and submitted her PhD thesis on the *Direct costs of care for Australian carers* using mixed methods. The qualitative components of the thesis focuses on the direct costs for carers of older people in Australia. The quantitative component analyses data from the *Household Income and Labour Dynamics in Australia* survey to estimate direct costs for carers of people with disability, chronic illnesses and frailty due

to ageing. Her PhD research was supported by a scholarship from the then Australian Institute for Population Ageing at the UNSW.

Relevant roles: Cathy’s expertise in the field of care has been recognised through the award of Australian Research Council grants where she was a co-Chief Investigator including: *Time for Care*, 2000-2002, *Identifying Isolated Carers*, 2002-2004, *Negotiating Caring and Employment*, 2004-2006 and *Young Carers*, 2006 -2009. Cathy undertook her PhD at UNSW, Sydney. Cathy participated in the co-design of the *NSW Carers Strategy (2014)* and the Carers NSW Carer Survey Reference Committee (2014, 2019). Cathy is a member of the UNSW Human Research Ethics Committee.

Overview of relevant research:

Current research related to unpaid care and informal care in Australia

2019 *Carers in the Balance*, Institute for Choice University of Adelaide

2019 *Mapping day care services for older people with dementia and their carers: A pilot study*, Mental Health and Wellbeing - Early Intervention and Prevention (Older People) Seed Funding Scheme, USYD/UNSW Visible Partnership in Mental Health, Addiction and Neuroscience.

Other selected research related to unpaid care and informal care and ageing in Australia:

2018 *Complex and changing needs of the ageing population living with viral hepatitis and/or HIV in the ACT*, ACT Health.

2016 *Research review on priority areas to inform the renewal of the NSW Ageing Strategy*, Family and Community Services

2015 *Carers and Social Inclusion: New frameworks, evidence and policy lessons*, Australian Research Council Linkage grant.

2013 *Investing in care: Recognising and valuing those who care*, Australian Human Rights Commission.

2012 *Care to work: Expanding choice and access to workforce participation for mature-aged workers*, HC Coombs Policy Forum

2011 *Changes in propensity to take on informal care roles*, Department of Housing, Community Services and Indigenous Affairs.

2011 *The costs of caring and the living standards of carers*, Australian Government Department of Families, Housing, Community Services and Indigenous Affairs.

2008 *Young Carers: Their Characteristics and Geographical Distribution. National Youth Affairs Research Scheme Project*, Australian Government Department of Families, Housing, Community Services and Indigenous Affairs

2006 *Young Carers: Social policy impacts of the caring responsibilities of children and young adults*, ARC Linkage Grant

2004 *Negotiating Caregiving and Employment* ARC Linkage Grant

- 2002 *Reaching Isolated Carers: Contacting Carers with Unmet Needs for Information and Support*, ARC Linkage Grant
- 2001 *Carers and Service Non-Use: Understanding why carers do not take up services*, University Research Support Program
- 2000 *The Time Determinants of Care: Informal Care and Time Use*, ARC SPIRT Grant

Dr Trish Hill BA (Hons 1) Murdoch, PhD (Economics) UNSW

Current occupation: Trish is a Senior Research Fellow at the Social Policy Research Centre, UNSW Sydney.

Areas of expertise: Trish has been engaged in research about, and with, carers since 2002. Her research training is in social and political theory and feminist economics. Her research encompasses analyses in the fields of poverty and inequality, informal care across the lifecourse, ageing, social inclusion and exclusion, and gender equity in the labour market and organizations.

Trish has led and undertaken research projects funded by the Australian Research Council and commissioned by governments and NGOs. She has been a member of teams conducting reviews and complex evaluations of programs in the fields of disability, mental health and other government programs and policies.

Trish has extensive experience in the design and application of quantitative research techniques to a wide range of ABS household surveys, community surveys and administrative data.

Relevant roles: Trish is a member of the Editorial Advisory Board for the *International Journal of Care and Caring* and a member of the Australian Bureau of Statistics *Survey of Disability, Ageing and Carers* Reference Group.

She is an invited collaborator in two international research networks on care: the UK Economic and Social Research Council funded *Sustainable Care: connecting people and systems (2017-2021)* and the *Centre of Excellence in Research on Ageing and Care* (funded by the Academy of Finland 2018-2025).

Trish has been the recipient of national and international fellowships and scholarships including an *Australian Government Office for Women Time Use Fellowship (2004-05)*; a *British Academy Visiting Fellowship (2007-08)*; and a *Care Connect Scholarship* at the University of Leeds, UK (2013). She participated in the co-design of the *NSW Carers Strategy (2014)* and the Carers NSW Carer Survey Reference Committee (2014-16).

Overview of relevant research:

- 2018 *Literature Review: Understanding the social and emotional needs of carers*, NSW Carers Advisory Council
- 2018 *Elder Abuse National Research Strengthening the Evidence Base - Stage One Component 3*, Australian Institute of Family Studies/Attorney-General's Department
- 2018 *Evaluation of Community Living Supports and the Housing and Accommodation Support Initiative*, NSW Health
- 2018 *Implementation of the NDIS in the early childhood sector*, Early Childhood Intervention Australia
- 2017 *Family Mental Health Support Services (FMHSS) evaluation readiness*, Department of Social Services
- 2017 *Evaluation of the Supported Decision Making Phase 2 (SDM2) project*, NSW Trustee & Guardian (2016-2017).
- 2016 *Carers and Social Inclusion: New frameworks, evidence and policy lessons*, Australian Research Council (ARC) Linkage grant.
- 2013 *Investing in care: Recognising and valuing those who care*. Australian Human Rights Commission
- 2012 *Care to work: Expanding choice and access to workforce participation for mature-aged workers*, HC Coombs Policy Forum
- 2011 *Changes in propensity to take on informal care roles*, Australian Government Department of Families, Housing, Community Services and Indigenous Affairs.
- 2011 *The costs of caring and the living standards of carers*, Australian Government Department of Families, Housing, Community Services and Indigenous Affairs.
- 2009 *Care in the social inclusion framework: constraint or contribution?* University of New South Wales Faculty of Arts and Social Sciences Early Career Researcher Grant
- 2008 *Indigenous carers*, Australian Government Department of Families, Housing, Community Services and Indigenous Affairs
- 2008 *Young Carers: Their Characteristics and Geographical Distribution. National Youth Affairs Research Scheme Project*, Australian Government Department of Families, Housing, Community Services and Indigenous Affairs
- 2006 *Young Carers: Social policy impacts of the caring responsibilities of children and young adults*, ARC Linkage Grant
- 2004 *Negotiating Caregiving and Employment*, ARC Linkage Grant
- 2002 *Reaching Isolated Carers: Contacting Carers with Unmet Needs for Information and Support*, ARC Linkage Grant

Dr Myra Hamilton BA (Hons 1), PhD (Sociology) University of Sydney

Current occupation: Myra is a Senior Research Fellow at SPRC, UNSW. Myra also leads the Gender Justice Research Programme at the Australian Human Rights Institute at UNSW.

Areas of expertise: Myra is a sociologist and social policy researcher whose expertise is in the fields of ageing and care across the life course. In particular, she has focused on the ways families organise the provision of unpaid care and the effects that unpaid care provision has on their lives, particularly their wellbeing, participation in paid work, education and training, and retirement incomes. She also conducts research on the organisation of care services. The focus in all of her work is on the ways in which policies and services support individuals and families to meet their care needs.

Relevant roles: Myra’s expertise in the fields of ageing and care have been recognised through the award of two Australian Research Council grants where she was a co-Chief Investigator: *Serodiscordance in Family Life*, 2016-2019 (exploring the experiences of family members of a person living with a blood borne virus) and *Young People and Adversity: Stories of Resourcing and Resourcefulness* 2016-2019 (focusing on the experiences of young carers, young parents, and young people in out of home care). She has also led a number of other projects focusing on ageing, care and caring. Myra is a member of the Work and Family Policy Roundtable, an Associate Investigator of the Centre of Excellence on Population Ageing Research, Lead Investigator of the Aged Care Stream in the UNSW Ageing Futures Institute, Secretary of the Research Committee on the Sociology of Ageing in the International Sociological Association, a member of the board of COTA NSW, academic member of Carers NSW Carer Respite Alliance, and a member of the Carer Survey Advisory Group with Carers NSW. Her work is internationally recognised and she has spent significant periods living and working in Europe, based at Collegio Carlo Alberto at the University of Turin in Italy (2019), as a Lecturer at the School for Policy Studies at the University of Bristol, UK (2010-2011), at the Centre for Research on Families and Relationships at the University of Edinburgh, UK (2010) and the Centre for Research on Ageing and Gender at the University of Surrey, UK (2007).

Overview of relevant research:

Current research related to unpaid care and informal care in Australia

2019-20 *Mapping day care services for older people with dementia and their carers: A pilot study, Mental Health and Wellbeing - Early Intervention and Prevention* (Older People) Seed Funding Scheme, USYD/UNSW Visible Partnership in Mental Health, Addiction and Neuroscience.

2019-20 *Security in older age for older single women without children*, CPA Global Research Perspectives Program Competitive Grant

2019 *Carers in the Balance*, Institute for Choice University of Adelaide

2016-19 *Markets, Migration and the Work of Care in Australia*, ARC Discovery Grant

Other selected research related to unpaid care and informal care and ageing in Australia:

2014 *Grandparent childcare and labour market participation in Australia*, National Seniors Productive Ageing Centre Grant.

2014 *Transitioning Australian Respite in Consumer-directed care markets* National Respite Association.

2013 *Investing in care: Recognising and valuing those who care*, Australian Human Rights Commission.

2009 *Young carers in Australia: Understanding the advantages and disadvantages of their care-giving and the implications for policy*, FaHCSIA

2009 *NSW Carers Action Plan Evaluation Framework*, NSW Health

2009 *Evaluation of the Building Capacity in Community Mental Health Family Support and Carer Respite Program*, Psychiatric Disability Services of Victoria

2006-09 *Young Carers: Social policy impacts of the caring responsibilities of children and young adults*, ARC Linkage Grant

2006 *Baby boomers and retirement: Dreams, fears and anxieties*, The Australia Institute

6. *Please identify the difficulties and issues that apply to the social and individual recognition of carer status.*

Carers provide unpaid support or assistance to one or more family members or friends because of needs arising from disability, chronic illness, mental illness, drug or alcohol dependence, and/or frailty due to old age.¹ According to the Australian Bureau of Statistics (ABS) Survey of Disability, Ageing and Carers, 2.7 million Australians were identified as carers in 2015, 31.7 per cent of whom were identified as *primary* carers, or the *main provider* of unpaid support or assistance to a person requiring care. Women represent 68.1 per cent of primary carers, and 55.5 per cent of all carers.²

In relation to carers of older Australians, the Australian Government Productivity Commission report *Caring for Older Australians* (2011) notes that, based on 2009 ABS data, ‘around 350 000 primary carers provided assistance to an older person aged 65 or over...The majority of primary carers of people aged 65 years and over care for their spouse or partner [69 per cent], while a smaller, but still significant proportion of older Australians are cared for by a son or daughter [24 per cent].’³

¹ Hill TL;Thomson C;Raven M;Wong M;Cass B;Yeandle S;Buckner L, 2016, Carers and Social Inclusion - Final Report, Social Policy Research Centre, Sydney, https://www.sprc.unsw.edu.au/media/SPRCFile/Carers_and_Social_Inclusion_Final_report.pdf

² ABS2016 *Disability, Ageing and Carers, Australia: Summary of Findings, 2015*, Cat no. 4430.0, Canberra <https://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/4430.0Main%20Features402015?op=endocument&tabname=Summary&prodno=4430.0&issue=2015&num=&view=>

³ Australian Government Productivity Commission *Caring for Older Australians* Report Volume 2, No.53, p 327.

Research suggests that the provision of unpaid care can have profound impacts on carers' participation in employment and education, on their incomes and retirement incomes, on their social relationships, and on their health and wellbeing.⁴ The social and economic contribution made by unpaid carers is considerable, and internationally researchers have begun attempting to estimate the value of replacing this unpaid care with formal, paid care.⁵ In 2015, Deloitte Access Economics estimated that the replacement value of the unpaid care provided by Australians was \$60.3 billion per year.⁶

In spite of this substantial social and economic contribution and the widespread recognition that carers incur considerable costs associated with their care responsibilities, recognition of the role of carers has faced some challenges in Australia. From the mid-2000s, in order to improve the formal recognition of carers in Australia, most of the states introduced carer recognition legislation and this was introduced at the national level in 2010 with the Commonwealth Carer Recognition Act 2010. As outlined in the Australian Human Rights Commission report *Investing in care: Recognising and valuing those who care* the Commonwealth Act, and an associated National Carer Strategy, formed part of a National Carer Recognition Framework designed to increase recognition and awareness of carers and acknowledge that carers should have the same rights and opportunities as Australians without care responsibilities.⁷ However, the Carer Recognition Acts at the Commonwealth and the state and territory levels do not create any legally enforceable rights for carers nor obligations for public services to provide support for carers, and there is no mechanism for complaints attached to the Acts.⁸ This is in contrast to several international carer recognition instruments, such as the one in the UK, which enshrines a right for carers to have their needs assessed and obligations on councils to provide services to carers.⁹ In Australia, the lack of access to legally enforceable rights or obligations limits the extent to which carers are able to have their needs acknowledged,

⁴ Australian Human Rights Commission 2013, *Investing in Care: Recognising and Valuing those who care*, Volume 2, Technical Papers
https://www.humanrights.gov.au/sites/default/files/UnpaidCaringVolume2_2013.pdf; Hill TL; Thomson C; Raven M; Wong M; Cass B; Yeandle S; Buckner L, 2016, *Carers and Social Inclusion - Final Report*, Social Policy Research Centre, Sydney,
https://www.sprc.unsw.edu.au/media/SPRCFile/Carers_and_Social_Inclusion_Final_report.pdf
 Hill T; Broady T, 2019, *Understanding the social and emotional needs of carers: Final Report*, Social Policy Research Centre, UNSW Sydney, Sydney,
<http://dx.doi.org/10.26190/5c59202697201>; Cass, B; Brennan, D; Thomson, C; Hill, T; Purcal, C; Hamilton, M; Adamson, E, 2011, *Young carers: Social policy impacts of the caring responsibilities of children and young adults*, Report prepared for ARC Linkage Partners, October 2011,
https://www.sprc.unsw.edu.au/media/SPRCFile/1_Young_Carers_Report_Final_2011.pdf

⁵ Hamilton, M and Thomson, C, 2017, 'Recognising unpaid care in private pension schemes', *Social Policy and Society*, 16(4), pp 517-534.

⁶ Deloitte Access Economics 2015, *The economic value of informal care in 2015*,
<http://carersaustralia.com.au/storage/Economic-Value-Informal-Care-Oct-2010.pdf>

⁷ Australian Human Rights Commission 2013, *Investing in Care: Recognising and Valuing those who care*, Volume 2, Technical Papers
https://www.humanrights.gov.au/sites/default/files/UnpaidCaringVolume2_2013.pdf

⁸ Phillips, J. and Magarey, K. 2010. *Carer Recognition Bill*, Parliament of Australia: Canberra

⁹ Australian Human Rights Commission 2013, *Investing in Care: Recognising and Valuing those who care*, Volume 2, Technical Papers
https://www.humanrights.gov.au/sites/default/files/UnpaidCaringVolume2_2013.pdf

assessed and met.¹⁰ As a consequence, some recent research suggests that carers do not feel recognised by the community.¹¹

From September 2019, under the new Integrated Carer Support Service, all carers will be able to apply to have their needs assessed.¹² However, there is no legislated entitlement to have their needs met, and the extent to which services will be available to meet the needs identified in the assessment is unclear.

7. *Please identify and explain what are, in your opinion, the three key challenges or issues in relation to the role of unpaid and informal carers in the context of the Australian aged care system.*

Based on our research and key literature, in our opinion the three key challenges for carers in the context of the Aged care system are:

- (1) Recognition of the *value and contribution* of unpaid care work and carers;
- (2) Recognition of carers' dual roles as *partners in care and co-client* in the service system; and
- (3) Supporting carers to participate in employment.

Recognition of the value and contribution of unpaid care work and carers

As noted by the former Australian Sex Discrimination Commissioner, Elizabeth Broderick, 'Caring is valuable, necessary work that benefits us as individuals as well as the well-being of our society as a whole. Care is something that will affect all of us in our lives, either as carers or as people who require care'.¹³ As noted in the response above, carers' unpaid work makes a significant economic contribution estimated to be equivalent to 3.8 per cent of estimated gross domestic product.¹⁴ Recognition and awareness of the valuable of role of unpaid carers and the impact of caring is a key challenge in the context of the Australian aged care system. Research by Carers NSW shows that since the introduction of the NSW *Carers (Recognition) Act 2010*, carer recognition in the broader community remains low and in 2019 'only one in four respondents [felt] their caring role was recognised by their community'.¹⁵

¹⁰ Australian Human Rights Commission 2013, Investing in Care: Recognising and Valuing those who care, Volume 2, Technical Papers
https://www.humanrights.gov.au/sites/default/files/UnpaidCaringVolume2_2013.pdf

¹¹ Carers NSW 2016 Carer Survey, Main Report:
<https://www.carersnsw.org.au/Assets/Files/Carers%20NSW%202016%20Carer%20Survey%20Report.pdf>

¹² Australian Government Department of Social Services (2019) New Services for carers coming in 2019, https://www.dss.gov.au/sites/default/files/documents/03_2019/new-services-carers-information-sheet_2.pdf

¹³ Australian Human Rights Commission (2013) Investing in care: Recognising and valuing those who care, Volume 1: Research Report, 2013 p1.

¹⁴ Deloitte Access Economics 2015, The economic value of informal care in 2015, p 55
<http://carersaustralia.com.au/storage/Economic-Value-Informal-Care-Oct-2010.pdf>

¹⁵ Carers NSW 2018, Carers NSW 2018 Carer Survey: Summary report. p 32, Available online at: <http://www.carersnsw.org.au/research/survey>

As noted in the Australian Human Rights Commission report *Investing in care: recognising and valuing those who care*:

Valuing the work of unpaid carers requires social and economic recognition of the importance of the relationships they build and foster, the assistance they provide to the people for whom they care, and the manifold contributions that they make to the whole community and economy. Caring relationships and roles are diverse and each care situation is unique and may change across the lifecycle.

Australian society in the past has failed to recognise, particularly in economic terms, both the worth and impact of unpaid caring roles, especially the caring roles undertaken by women.¹⁶

Recognition of carers' dual roles as partners in care and co-client in the service system

The second key challenge in relation to unpaid carers in the context of the Australian aged care system is the shift towards consumer-directed care in aged care services. Consumer-directed care has the potential to provide older people with more personalised aged care services that meet their individual needs and to offer them greater control over the type of support they receive, and the way services are delivered. However, as Cass and Yeandle note 'these developments undoubtedly place increased pressure on family members of working age to support their older parents...families play an increasing role, both in arranging and coordinating health and social care for their parents and by providing much of their care themselves'.¹⁷ And while carers remain essential 'partners in care', there is a potential for them to be conceived as a resource to be drawn on in supporting the aged care system, rather than as co-clients with their own needs.¹⁸ Research from Carers NSW found that although carers were included in decision-making about the types of support required for the older person, only just over 40 per cent of carers indicated that that general practitioners or health services asked about their needs.¹⁹ Consequently, one of the key challenges for the Australian aged care system is how to recognise carers' individual support needs within a context that is increasingly focused on the consumer (i.e. the older person). There is potential in the new Integrated Carer Support Service to begin addressing carer's support needs, however this brings new challenges associated

¹⁶ Australian Human Rights Commission (2013) *Investing in care: Recognising and valuing those who care*, Volume 1: Research Report, 2013 p 3

¹⁷ Yeandle, S and Cass 2013 *Working carers of older people: steps towards securing adequate support in Austria and England?* In Yeandle S and Kroger T (eds) *Combining caring and employment: Policies and experiences in international perspective*, Bristol University Press, England.

¹⁸ See Twigg, J. and Atkin, K. 1994. *Carers perceived: Policy and practice in informal care for a description of four types of models relating to the interaction between services and the way in which carers are perceived*. Also see Hill TL;Thomson C;Raven M;Wong M;Cass B;Yeandle S;Buckner L, 2016, *Carers and Social Inclusion - Final Report*, Social Policy Research Centre, Sydney, for a discussion of Twigg and Akin's models in relation to carers' needs and social inclusion
https://www.sprc.unsw.edu.au/media/SPRCFile/Carers_and_Social_Inclusion_Final_report.pdf

¹⁹ Carers NSW 2018 *Carers NSW Carer Survey, Summary Report*,
<http://www.carersnsw.org.au/Assets/Files/FINAL%202018%20Carer%20Survey%20Report.pdf>

with integrating the shifting aged care, disability, and carers services systems to provide seamless services to the care dyad.

Supporting carers to participate in paid employment

The third key issue relation to the role of unpaid and informal carers in the context of the Australian aged care system is how to best support carers to participate in paid employment. Research shows that carers have lower level of employment compared to non-carers.²⁰ Presently, the aged care and carer support service systems are focused on strengthening the sustainability of the care relationship and provides carers with short breaks from their caring role.²¹ Respondents to the 2018 Carers NSW survey indicated that access to aged care services enabled them to take a break and gave them time to attend to their own health needs but did not facilitate their participation in paid work.²² The challenge for the aged care system is to provide high quality, accessible, affordable services that, in conjunction with flexible workplace policies, practices and cultures, support carers to participate in paid employment of this kind. Providing better opportunities for carers to participate in paid employment may create better outcomes for carers health, wellbeing and financial security, which in itself has the potential to contribute to the sustainability of the caring role.

8. *What measures would enhance the prospects of greater levels of paid workforce participation by informal carers (or employment at levels more commensurate with qualification)?*

Carers have lower rates of participation in paid employment than their non-carer counterparts. *Primary* carers have particularly low rates of employment compared with all other groups. For example, according to SDAC 2009, less than 63 per cent of male primary carers and less than 60 per cent of female primary carers were employed at any point across the lifecycle.²³

Carers' lower levels of labour market participation are a consequence of a range of barriers to participation in paid work.²⁴ These barriers operate at: the individual level,

²⁰ Thomson C, Hill T Bittman M and Griffiths M Negotiating caring and employment (2008) Final Report , SPRC UNSW, Sydney; Australian Human Rights Commission 2013, Investing in Care: Recognising and Valuing those who care, Volume 2, Technical Papers https://www.humanrights.gov.au/sites/default/files/UnpaidCaringVolume2_2013.pdf; Carers NSW 2018 Carers NSW Carer Survey, Summary Report, <http://www.carersnsw.org.au/Assets/Files/FINAL%202018%20Carer%20Survey%20Report.pdf>

²¹ Hamilton, M., Giuntoli, G., Johnson, K., Kayess, R., & Fisher, K. R. 2016, Transitioning Australian Respite (SPRC Report 04/2016). Sydney: Social Policy Research Centre, UNSW Australia.

²² Carers NSW 2018 Carers NSW Carer Survey, Summary Report, <http://www.carersnsw.org.au/Assets/Files/FINAL%202018%20Carer%20Survey%20Report.pdf>

²³ Australian Human Rights Commission (2013) Investing in care: Recognising and valuing those who care, Volume 1 Research Report, Australian Human Rights Commission, Sydney. (Co-author) Available at: http://humanrights.gov.au/pdf/sex_discrim/publications/UnpaidCaringVolume1_2013.pdf

²⁴ Thomson C, Hill T Bittman M and Griffiths M Negotiating caring and employment (2008) Final Report, SPRC UNSW, Sydney; Australian Human Rights Commission 2013, Investing in Care: Recognising and Valuing those who care, Volume 2, Technical Papers https://www.humanrights.gov.au/sites/default/files/UnpaidCaringVolume2_2013.pdf

including challenges experienced with reference to carers' confidence, health and wellbeing, or outdated skills or qualifications; the family level, including the nature and extent of the care responsibilities, the existence of other care responsibilities (i.e. for young children) and the availability of other informal carers in the family; the workplace level including discrimination, or a lack of flexible workplace policies and care friendly cultures; and the broader level of community and/or government policy, such as the availability of services or legislated leave and flexible work provisions.²⁵

A range of measures would support carers to overcome some of these barriers and provide greater opportunities for carers to participate in work commensurate with their skills and qualifications and according to their preferences.

Alternative or replacement care is foundational for carers participation in paid work. Without accessible, affordable, high quality alternative care arrangements provided in a reliable and consistent fashion, it is very difficult for many carers to participate in paid employment in a manner that is consistent with their skills and expertise and according to their desires and preferences.²⁶ Presently in Australia, the availability of replacement care of the kind required by carers to participate in regular ongoing employment is highly limited.²⁷ While there is some access to respite care (although this in itself is patchy and has a number of limitations – see below, Question 14), the focus of the respite that is available is on providing carers with a short break or emergency respite.^{28 29}

²⁵ Australian Human Rights Commission 2013, Investing in Care: Recognising and Valuing those who care, Volume 2, Technical Papers https://www.humanrights.gov.au/sites/default/files/UnpaidCaringVolume2_2013.pdf; Hill TL; Thomson C; Raven M; Wong M; Cass B; Yeandle S; Buckner L, 2016, Carers and Social Inclusion - Final Report, Social Policy Research Centre, Sydney, https://www.sprc.unsw.edu.au/media/SPRCFile/Carers_and_Social_Inclusion_Final_report.pdf; Cass, B., Hill, T., Thomson, C, 2012, *Care to work: Expanding choice and access to workforce participation for mature-aged workers*, HC Coombs Policy Forum, https://devpolicy.crawford.anu.edu.au/public_policy_community/content/doc/Cass%20paper%2028-11.pdf

²⁶ Pickard, L; Brimblecombe, N, King, D., Knapp, M, 2018, Replacement care for working carers? A longitudinal study in England, 2013-2015, *Social Policy and Administration*, 52(3), pp 690-709. Australian Human Rights Commission (2013) Investing in care: Recognising and valuing those who care, Volume 1 Research Report, Australian Human Rights Commission, Sydney. (Co-author) Available at: http://humanrights.gov.au/pdf/sex_discrim/publications/UnpaidCaringVolume1_2013.pdf

²⁷ DSS 2018 Integrated Carer Support Service (ICSS) 2018 Webinar 2: Questions & Answers p18 https://www.dss.gov.au/sites/default/files/documents/11_2018/icss_webinar_2_questions_and_answers_v1.0.pdf (see p 18)

²⁸ DSS 2018 Integrated Carer Support Service (ICSS) 2018 Webinar 2: Questions & Answers p18 https://www.dss.gov.au/sites/default/files/documents/11_2018/icss_webinar_2_questions_and_answers_v1.0.pdf

²⁹ see DSS 2018 Integrated Carer Support Service (ICSS) 2018 Webinar 2: Questions & Answers p18 https://www.dss.gov.au/sites/default/files/documents/11_2018/icss_webinar_2_questions_and_answers_v1.0.pdf which outlines further information about Carer Directed services and emergency respite For example The amount of \$3,000 (over a 12-month period) is the total budget to which each eligible carer is entitled under the Carer Directed Support service. Under the ICSS carers can access \$3000 over one year under the Carer Directed Support service. A Carer Support Worker will work with the carer to plan supports and encourage them to manage the services themselves. It is envisaged that carers with the greatest strain and not accessing other sources of support will be prioritised

The focus is not on providing the kind of ongoing planned respite that facilitates employment participation. Adequate replacement care may provide many carers with the time required to participate in paid work, but would also enable carers to overcome a number of other barriers to participation in paid employment, like providing them with the time to address challenges to their health and wellbeing that are affecting their employment, or to participate in training to update their skills or qualifications.

According to the Australian Human Rights Commission Report *Investing in care: Recognising and valuing those who care*, also fundamental to increasing carers' opportunities for participation in employment that is commensurate with their skills and expertise is care-friendly workplace policies and practices such as flexible work and access to leave.³⁰ Currently, some carers find it difficult to access flexible work that is commensurate with their skills, with some choosing to work in sectors or roles below their skill-levels, and without job security or workplace entitlements, in order to have the flexibility they require to carry out their care responsibilities. The Australian Human Rights Commission Report presents a number of options for reform that could improve carers' access to care-friendly workplaces. Presently, employees have a right to request flexible working arrangements, but employers have no obligation to reasonably accommodate a request, there is no mechanism for appealing refusals of a request, and workplace cultures – especially in some sectors – make it difficult to make a request at all. In addition, casual employees may only request flexible work arrangements if they have been with an employer for at least 12 months and there is a reasonable expectation of continuing work with an employer. Improvements to the right to request provisions, such as extended entitlement to all casual employees and placing greater obligations on employers to reasonably accommodate such requests could create greater opportunities for carers to balance paid work and their care responsibilities, though education and awareness-raising among employers to build more care-friendly workplaces is also essential to create the conditions under which carers feel comfortable making a request for flexible work.³¹ Improving the availability and duration of carers leave would also support carers to maintain connection to paid employment.³²

According to the Australian Human Rights Commission report, *Investing in Care*: several other policy changes could remove barriers for carers to participate in work, such as

Carers will be able to access Emergency Respite Care service for 'an urgent, unplanned, and imminent event temporarily restricting their ability to continue caring when no other services are available.... Respite for an event that is known up to three months in advance would not be considered an emergency for the purposes of the Emergency Respite Care service' DSS, 2018 p 19

³⁰ Australian Human Rights Commission 2013, *Investing in Care: Recognising and Valuing those who care*, Volume 2, Technical Papers https://www.humanrights.gov.au/sites/default/files/UnpaidCaringVolume2_2013.pdf

³¹ Australian Human Rights Commission (2013) *Investing in care: Recognising and valuing those who care*, Volume 1 Research Report, Australian Human Rights Commission, Sydney. (Co-author) Available at: http://humanrights.gov.au/pdf/sex_discrim/publications/UnpaidCaringVolume1_2013.pdf

³² Australian Human Rights Commission (2013) *Investing in care: Recognising and valuing those who care*, Volume 1 Research Report, Australian Human Rights Commission, Sydney. (Co-author) Available at: http://humanrights.gov.au/pdf/sex_discrim/publications/UnpaidCaringVolume1_2013.pdf

changes to the ‘25 hour rule’ governing access to Carer Payment, which stipulates that carers can only participate in work or study for up to 25 hours per week (including travel time to and from work) before they lose entitlement to the payment, limiting their autonomy in balancing their paid employment and care responsibilities.

9. *Please identify and explain the spectrum of needs of carers of people over the age of 65.*

Carers of older people (like all carers) are a diverse group and will have different needs that depend on their specific care situation, their own context and the condition of the care recipient. In the Australian policy context, the Department of Social Services has indicated that the needs of carers in the Integrated Carer Support Service (ICSS) will be assessed through the implementation of the Carers’ StarTM. As outlined in Hill and Broady (2019), this tool encompasses the following domains:

- “Health – e.g. current health status and impact of caring role on physical health.
- The caring role – e.g. challenges and support needs, services and networks of support.
- Managing at home – e.g. managing day to day tasks and suitability of home.
- Time for yourself – e.g. time to attend to own needs, time with family and friends, hobbies and interests.
- How you feel – e.g. impact on mental health, support from family and friends, relationships stress and strain
- Finances – e.g. income support and impact of caring on financial situation
- Work – e.g. employment status, volunteer work and study, support from employers, impact of care on employment, support to return to work”³³

The following discussion identifying needs of carers of people over the age of 65 draws on research undertaken by Hill and Broady (2019) on *Understanding the social and emotional needs of carers*³⁴ and research undertaken by Thomson and Hill (2016) in the *Carers and Social Inclusion* project.³⁵

³³ Department of Social Security (DSS) (2018a). *Draft Carer Support Framework: Integrated Carer Support Service (ICSS) DRAFT Version 0.1, 26 October 2018*, DSS, Canberra. <https://www.dss.gov.au/disability-and-carers-carers-icss-implementation/carer-support-planning-framework>, pp.12-13, cited in Hill T;Broady T, 2019, *Understanding the social and emotional needs of carers: Final Report*, Social Policy Research Centre, UNSW Sydney, Sydney, <http://dx.doi.org/10.26190/5c59202697201>, p.7-8.

³⁴ Hill T;Broady T, 2019, *Understanding the social and emotional needs of carers: Final Report*, Social Policy Research Centre, UNSW Sydney, Sydney, <http://dx.doi.org/10.26190/5c59202697201>. This Rapid Literature Review was commissioned by Family & Community Services (FACS) on behalf of the NSW Carers Advisory Council. The review aimed to contribute to the evidence to help the Council to better understand the social and emotional health and wellbeing of the carer population and the specific issues and their impact in the carer population.

³⁵ The project ‘Carers and social inclusion: new frameworks, evidence and policy lessons’ was supported under the Australian Research Council’s Linkage Projects funding scheme (LP110400160) and funding from research partners. Research partners included: the University of Leeds, Carers Australia, the Department of Education, Employment and Workplace Relations, NSW Health, the NSW Department of Family & Community Services, and the SA Department for Communities and Social Inclusion. Chief Investigators: Dr Trish Hill, Emeritus Professor Bettina

The rapid literature review by Hill and Broady had a focus on what works to support carers' social and emotional needs, identified through key meta reviews and systematic reviews and some grey literature and noting a range of instruments used to identify carers' needs. As cautioned by Hill and Broady: “The literature search revealed numerous studies and evaluations of interventions for many groups of carers and given the time constraints of this review, it was not possible to review all studies comprehensively.”³⁶ The report also noted that “the majority of reviews of [interventions that work to support carers] focus on interventions aimed at carers of different care recipient conditions rather than the characteristics of carers.”³⁷

The research by Thomson and Hill (2016) involved focus groups with carers of different ages discussing what supported them in their caring role.

Generally speaking, the research by Hill and Broady (2019) and Thomson and Hill (2016) showed that the spectrum of needs of carers of older people include:

- Recognition and awareness of carer role – by self, family, service system, broader community, employers ³⁸
- Access to information about the older person's condition and services available to support the older person and the carer ³⁹
- Support and advocacy to navigate the service system⁴⁰
- Information, education and training programs to assist carers to manage their caring role⁴¹

Cass, Associate Professor and Susan Green; Partner Investigator: Professor Sue Yeandle; research team: Catherine Thomson, Dr Margaret Raven, Dr Melissa Wong and Dr Lisa Buckner. The views expressed in all publications from this project are those of the authors and not necessarily those of the Australian Research Council or the aforementioned departments or responsible ministers.

³⁶ Hill T; Broady T, 2019, Understanding the social and emotional needs of carers: Final Report, Social Policy Research Centre, UNSW Sydney, Sydney, http://dx.doi.org/10.26190/5c59202697201_p.35

³⁷ Hill T; Broady T, 2019, Understanding the social and emotional needs of carers: Final Report, Social Policy Research Centre, UNSW Sydney, Sydney, http://dx.doi.org/10.26190/5c59202697201_p.35

³⁸ Thomson and Hill (2016) “Social Inclusion Across the lifecourse” in Hill TL; Thomson C; Raven M; Wong M; Cass B; Yeandle S; Buckner L, 2016, Carers and Social Inclusion - Final Report, Social Policy Research Centre, Sydney, https://www.sprc.unsw.edu.au/media/SPRCFile/Carers_and_Social_Inclusion_Final_report.pdf

³⁹ Thomson and Hill (2016) “Social Inclusion Across the lifecourse” in Hill TL; Thomson C; Raven M; Wong M; Cass B; Yeandle S; Buckner L, 2016, Carers and Social Inclusion - Final Report, Social Policy Research Centre, Sydney, https://www.sprc.unsw.edu.au/media/SPRCFile/Carers_and_Social_Inclusion_Final_report.pdf

⁴⁰ Thomson and Hill (2016) “Social Inclusion Across the lifecourse” in Hill TL; Thomson C; Raven M; Wong M; Cass B; Yeandle S; Buckner L, 2016, Carers and Social Inclusion - Final Report, Social Policy Research Centre, Sydney, https://www.sprc.unsw.edu.au/media/SPRCFile/Carers_and_Social_Inclusion_Final_report.pdf

⁴¹ Thomson and Hill (2016) “Social Inclusion Across the lifecourse” in Hill TL; Thomson C; Raven M; Wong M; Cass B; Yeandle S; Buckner L, 2016, Carers and Social Inclusion - Final Report, Social Policy Research Centre, Sydney, https://www.sprc.unsw.edu.au/media/SPRCFile/Carers_and_Social_Inclusion_Final_report.pdf

- Practical help in the home (housework, home modification)⁴²
- Support to maintain their mental and physical health (counselling, physical exercise, technological supports)⁴³
- Quality respite or replacement care and time for themselves⁴⁴
- Flexible employment opportunities⁴⁵
- Financial support⁴⁶
- Support when the caring role ends⁴⁷

Carers of older people will often be working age carers caring for parents or older carers caring for a spouse or adult child. Hill and Broady’s review of the literature noted that:

- “Carers of working age may have specific needs if they are ‘sandwich carers’ (carers caring for children with or without disability and their ageing parents) and may need support to negotiate care and employment roles.”⁴⁸
- “Older carers are often caring for spouses and adult children. Milne and Hatzidimitriadou highlight that older carers are likely to provide care ‘within the context of a long-term relationship ... and having health problems of their own’ (2003 in Henwood et al 2017: 39) and are likely to be caring for people with ‘more complex health needs’ (Henwood et al 2017: 41)...Social isolation and the impact

⁴² Hill T;Broady T, 2019, Understanding the social and emotional needs of carers: Final Report, Social Policy Research Centre, UNSW Sydney, Sydney, http://dx.doi.org/10.26190/5c59202697201_p.31

⁴³ Thomson and Hill (2016) “Social Inclusion Across the lifecourse” in Hill TL;Thomson C;Raven M;Wong M;Cass B;Yeandle S;Buckner L, 2016, Carers and Social Inclusion - Final Report, Social Policy Research Centre, Sydney, https://www.sprc.unsw.edu.au/media/SPRCFile/Carers_and_Social_Inclusion_Final_report.pdf
Hill T;Broady T, 2019, Understanding the social and emotional needs of carers: Final Report, Social Policy Research Centre, UNSW Sydney, Sydney, http://dx.doi.org/10.26190/5c59202697201_p.31

⁴⁴ Thomson and Hill (2016) “Social Inclusion Across the lifecourse” in Hill TL;Thomson C;Raven M;Wong M;Cass B;Yeandle S;Buckner L, 2016, Carers and Social Inclusion - Final Report, Social Policy Research Centre, Sydney, https://www.sprc.unsw.edu.au/media/SPRCFile/Carers_and_Social_Inclusion_Final_report.pdf
Hill T;Broady T, 2019, Understanding the social and emotional needs of carers: Final Report, Social Policy Research Centre, UNSW Sydney, Sydney, http://dx.doi.org/10.26190/5c59202697201_p.31

⁴⁵ Thomson and Hill (2016) “Social Inclusion Across the lifecourse” in Hill TL;Thomson C;Raven M;Wong M;Cass B;Yeandle S;Buckner L, 2016, Carers and Social Inclusion - Final Report, Social Policy Research Centre, Sydney, https://www.sprc.unsw.edu.au/media/SPRCFile/Carers_and_Social_Inclusion_Final_report.pdf

⁴⁶ Thomson and Hill (2016) “Social Inclusion Across the lifecourse” in Hill TL;Thomson C;Raven M;Wong M;Cass B;Yeandle S;Buckner L, 2016, Carers and Social Inclusion - Final Report, Social Policy Research Centre, Sydney, https://www.sprc.unsw.edu.au/media/SPRCFile/Carers_and_Social_Inclusion_Final_report.pdf

⁴⁷ Thomson and Hill (2016) “Social Inclusion Across the lifecourse” in Hill TL;Thomson C;Raven M;Wong M;Cass B;Yeandle S;Buckner L, 2016, Carers and Social Inclusion - Final Report, Social Policy Research Centre, Sydney, https://www.sprc.unsw.edu.au/media/SPRCFile/Carers_and_Social_Inclusion_Final_report.pdf

⁴⁸ Hill T;Broady T, 2019, Understanding the social and emotional needs of carers: Final Report, Social Policy Research Centre, UNSW Sydney, Sydney, http://dx.doi.org/10.26190/5c59202697201_p.31

of changes in relationship between spouses can be key issues affecting older carers (Henwood et al. 2017).⁴⁹

- “The development of technological interventions requires that older carers are supported to develop digital literacy to be able to engage with technology, if it is to provide effective support.”⁵⁰
- “Studies have examined issues for parent carers of adult children with intellectual disability and mental health issues. These studies have identified issues such as ‘perpetual parenting’ and ‘futures planning’ that may have effects on older carers’ wellbeing (Walker and Hutchinson 2017, 2018).⁵¹

10. *What are the particular needs of the diverse cohorts of carers listed below and in what ways are their needs distinct: Aboriginal and Torres Strait Islander people; LGBTIQ; People from diverse backgrounds?*

Our research, at a general level, illustrates that diverse groups such as those listed above have distinct needs. However, our research has not specifically engaged with these groups to identify their needs and, in the short-time frame, we cannot review all the relevant research to adequately represent the context in which these carer needs arise, their economic and social contribution and the complex issues and challenges they face.

Our colleague at the Social Policy Research Centre, Dr Margaret Raven, has conducted specific research with Aboriginal carers (see https://www.sprc.unsw.edu.au/media/SPRCFile/Our_Experiences_as_Aboriginal_Carers__Port_Augusta.pdf; https://www.sprc.unsw.edu.au/media/SPRCFile/Our_Experiences_as_Aboriginal_Carers__Adelaide.pdf) See also chapters 7,8,9 in this report: https://www.sprc.unsw.edu.au/media/SPRCFile/Carers_and_Social_Inclusion__Final_report.pdf)

The research and policy work conducted by the following groups provides more insights into the needs of these groups of carers:

⁴⁹Milne, A., and Hatzidimitriadou, E. (2003). ‘The ‘Caring in later life’ report : a secondary analysis of the 1995 General Household Survey’, *Quality in Ageing*, 3(3), 3-15. and Henwood, M., Larkin M., and Milne, A. (2017). *Seeing the Wood for the Trees: Carer-related research and knowledge: A scoping review*, Social Care Institute of Excellence. <http://docs.scie-socialcareonline.org.uk/fulltext/058517.pdf> in Hill T;Broady T, 2019, Understanding the social and emotional needs of carers: Final Report, Social Policy Research Centre, UNSW Sydney, Sydney, <http://dx.doi.org/10.26190/5c59202697201>, p.32

⁵⁰ Hill T;Broady T, 2019, Understanding the social and emotional needs of carers: Final Report, Social Policy Research Centre, UNSW Sydney, Sydney, <http://dx.doi.org/10.26190/5c59202697201>, p.32

⁵¹ Walker R. and Hutchinson, C. (2017) ‘Planning for the future among older parents’ of adult offspring with intellectual disability living at home and in the community: A systematic review of qualitative studies’, *Journal of Intellectual & Developmental Disability*, DOI: 10.3109/13668250.2017.1310823; Walker, R., and Hutchinson, C. (2018). ‘Care-giving dynamics and futures planning among ageing parents of adult offspring with intellectual disability’, *Ageing and Society*, 1-16. doi:10.1017/S0144686X18000144 cited in Hill T;Broady T, 2019, Understanding the social and emotional needs of carers: Final Report, Social Policy Research Centre, UNSW Sydney, Sydney, <http://dx.doi.org/10.26190/5c59202697201>, p.32

- Carers Australia (see <https://www.carersaustralia.com.au/about-carers/aboriginalandtorresstraitislandercarers/>
<https://www.carersaustralia.com.au/media-centre/carers-national-news/article/?id=culturally-and-linguistically-diverse-carers-in-australia-background-report>)
- Carers NSW (see <https://www.carersnsw.org.au/Assets/Files/Aboriginal%20and%20Torres%20Strait%20Islander%20Carers.pdf>; <https://www.carersnsw.org.au/lgbti>,
<https://www.carersnsw.org.au/how-we-help/support/multicultural>)
- Federation of Ethnic Communities Council of Australia (FECCA) (see FECCA 2015, Review of Australian Research on Older People from Culturally and Linguistically Diverse Backgrounds @ <http://fecca.org.au/wp-content/uploads/2015/06/Review-of-Australian-Research-on-Older-People-from-Culturally-and-Linguistically-Diverse-Backgrounds-March-20151.pdf>)
- Barrett, C; Crameri, P (2015). An extra degree of difficulty: An evidence based resource exploring the experiences and needs of older LGBTI carers and the carers of older LGBTI people. Australian Research Centre in Sex, Health and Society, La Trobe University, Melbourne Australia).

11. *What is the cumulative impact on the health, social life and financial security of carers of people over the age of 65?*

Caring for older people, as with caring for people with disability or a chronic illness, can negatively affect carers' health and wellbeing. Research by Cummins et al (2007)⁵² indicates that carers have a lower overall rating of subjective wellbeing than other groups. Research also indicates that carers often ignore their own health needs due to their caring responsibilities.⁵³

Another impact of caring for older people, particularly for carers of people with dementia, is that social networks tend to constrict. Participants in the focus groups for the *Carers and Social Inclusion* project talked about losing contact with friends due to the stigma associated with certain conditions.⁵⁴

⁵² Cummins, R., Hughes, J., Tomy, A., Gibson, A., Woerner, J., and Lai, L. (2007). The Australian Unity Wellbeing Index, Survey 17.1. The Wellbeing of Australians-Carer Health and Wellbeing, Deakin University, Australian Unity and Carers Australia, Melbourne.

⁵³ See for example Thomson and Hill (2016) "Social Inclusion Across the lifecourse" in Hill TL;Thomson C;Raven M;Wong M;Cass B;Yeandle S;Buckner L, 2016, Carers and Social Inclusion - Final Report, Social Policy Research Centre, Sydney, https://www.sprc.unsw.edu.au/media/SPRCFile/Carers_and_Social_Inclusion_Final_report.pdf

⁵⁴ Thomson, C and Hill, T 2016, Older carers and social inclusion: Feedback report, Social Policy Research Centre, UNSW Sydney, Sydney, https://www.sprc.unsw.edu.au/media/SPRCFile/Older_Carers_and_Social_Inclusion_Feedback_report.pdf; Hill TL;Thomson C;Raven M;Wong M;Cass B;Yeandle S;Buckner L, 2016, Carers and Social Inclusion - Summary Report, Social Policy Research Centre, Sydney, p.5 https://www.sprc.unsw.edu.au/media/SPRCFile/Carers_and_Social_Inclusion_Summary_report.pdf

The financial impact of caring for older people and people with disabilities is an outcome of carers' lower levels of employment across the lifecycle compared to non-carers.⁵⁵ Periods outside the labour market, working reduced hours, or taking lower paid positions as a result of caring responsibilities all have a direct impact on current earnings and retirement incomes accumulation. As women undertake the largest share of unpaid caring work,⁵⁶ women disproportionately experience the financial impacts associated with caring. This is compounded for carers who also take on childcare responsibilities throughout their lives. As noted in the Australian Human Rights Commission *Accumulating Poverty* Report:

The aim of the current retirement income system is for individuals to accumulate wealth over their lifecycle to provide for their own financial security in retirement. However, this system does not serve women well, leaving a gender gap in retirement incomes and raising concerns about poverty and financial hardship for women in retirement. The gender gap arises from the linking of the retirement income system, specifically superannuation, to engagement in paid work and level of earnings. This disadvantages women on two levels. First, women commonly move in and out of the paid workforce due to caring responsibilities. Second, even when they are engaged in paid work, women generally earn less than men. This means that not only do women generally have lower levels of superannuation coverage over their lifecycle, but when they do engage in paid work, they accumulate lower amounts of superannuation... Instead of accumulating wealth through the retirement income system as intended, due to experiences of inequality over the lifecycle, women are more likely to be accumulating poverty.⁵⁷

12. *In what way does identifying as a carer influence the awareness of, and access to carer support services?*

A common finding in our research on carers is that many people do not recognise the support they provide as care or caring activities and therefore do not identify as a 'carer'.⁵⁸

⁵⁵ABS2016 *Disability, Ageing and Carers, Australia: Summary of Findings, 2015*, Cat no. 4430.0, Canberra

<https://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/4430.0Main%20Features402015?opendocument&tabname=Summary&prodno=4430.0&issue=2015&num=&view=>

Carers NSW 2018, Carers NSW 2018 Carer Survey: Summary report. , Available online at: <http://www.carersnsw.org.au/research/survey>

⁵⁶ABS2016 *Disability, Ageing and Carers, Australia: Summary of Findings, 2015*, Cat no. 4430.0, Canberra

<https://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/4430.0Main%20Features402015?opendocument&tabname=Summary&prodno=4430.0&issue=2015&num=&view=>

⁵⁷ Australian Human Rights Commission, 2009 *Accumulating poverty? Women's experiences of inequality over the lifecycle* (2009) p 1

⁵⁸ Thomson, C and Hill, P 2016, *Older carers and social inclusion: Feedback report*, Social Policy Research Centre, UNSW Sydney, Sydney, https://www.sprc.unsw.edu.au/media/SPRCFile/Older_Carers_and_Social_Inclusion_Feedback_report.pdf; Hill TL; Thomson C; Raven M; Wong M; Cass B; Yeandle S; Buckner L, 2016, *Carers and Social Inclusion - Summary Report*, Social Policy Research Centre, Sydney, p.5 https://www.sprc.unsw.edu.au/media/SPRCFile/Carers_and_Social_Inclusion_Summary_report.pdf

Differentiating between what is deemed ‘care time’ or caring activities and ‘non-care’ time or activities can be challenging for carers because their care activities are often subsumed into other household tasks or occur while undertaking other tasks; for example, monitoring the safety and needs of the care receiver while cleaning the house.⁵⁹ Often the identification of carer status is precipitated by a crisis or concerns about the future of the care receiver. For example, in a focus group conducted as part of the Carers and Social Inclusion project,⁶⁰ an older couple caring for their ageing adult child with a disability told us how they had cared for their child for 50 years without any formal support. It was only when consulting a solicitor friend about their son’s future that their friend pointed out that they were ‘carers’ and as such were eligible for Carer Payment. They then, accessed a range of supports for their child and themselves as ‘carers’.⁶¹

People providing care for a family member or friend may not identify as a ‘carer’ due to a range of other reasons, such as a “desire to protect the identity and independence of the cared for person, stigma and secrecy about the illness or care relationship, or the view that support for a relative is just part of family life.”⁶² These carers, often described as ‘hidden carers’, tend to be particularly under-recognised, and are less likely to access support services.⁶³

Conversely, the service environment itself can serve to ‘hide’ or ‘make visible’ the role of carers. For example, the greater emphasis on self-management or consumer-directed care in health, disability and aged care services can marginalise the needs and experiences of carers and “place pressure on carers not to disrupt the discourse of independence.”⁶⁴ Research suggests that for some carers, they only begin to identify as ‘carers’ and consequently, to seek out and access services, when a service provider informs them that what they are doing is ‘caring’.⁶⁵ Services have an important role,

⁵⁹ Bittman, Fast, J., M. Bittman, K. Fisher and C. Thomson (2004), ‘Making the Invisible Visible: The Life and Time(s) of Informal Caregivers’ in Bittman, M. and Folbre, N. (eds), *Family Time: The Social Organisation of Care*, New York:Routledge

⁶⁰ Hill TL;Thomson C;Raven M;Wong M;Cass B;Yeandle S;Buckner L, 2016, Carers and Social Inclusion - Summary Report, Social Policy Research Centre, Sydney, p.5 https://www.sprc.unsw.edu.au/media/SPRCFile/Carers_and_Social_Inclusion_Summary_report.pdf

⁶¹ Thomson, C and Hill, P 2016, Older carers and social inclusion: Feedback report, Social Policy Research Centre, UNSW Sydney, Sydney p3

⁶² Hamilton, M; Botfield, J; Newman, C; Persson, A; Bryant, J; valentine, k; Wallace, J, 2018, ‘Hidden carers? A scoping review of the needs of carers of people with HIV in the contemporary treatment era’, *International Journal of Care and Caring*, 2(4), pp. 529-549.

⁶³ Hamilton, M; Botfield, J; Newman, C; Persson, A; Bryant, J; valentine, k; Wallace, J, 2018, ‘Hidden carers? A scoping review of the needs of carers of people with HIV in the contemporary treatment era’, *International Journal of Care and Caring*, 2(4), pp. 529-549

⁶⁴ Hamilton, M; Botfield, J; Newman, C; Persson, A; Bryant, J; valentine, k; Wallace, J, 2018, ‘Hidden carers? A scoping review of the needs of carers of people with HIV in the contemporary treatment era’, *International Journal of Care and Caring*, 2(4), pp. 529-549

⁶⁵ Hamilton, M; Botfield, J; Newman, C; Persson, A; Bryant, J; valentine, k; Wallace, J, 2018, ‘Hidden carers? A scoping review of the needs of carers of people with HIV in the contemporary treatment era’, *International Journal of Care and Caring*, 2(4), pp. 529-549; Smyth, C., Blaxland, M. and Cass, B., 2011, “So that’s how I found out I was a young carer and that I actually had been a carer most of my life’. *Identifying and supporting hidden young carers*, *Journal of Youth Studies*, 14(2): 145-60.

therefore, in identifying and appropriately addressing the needs of hard to reach or ‘hidden’ carers, and failure to do so can lead to these carers remaining without support, with negative effects on their health, wellbeing and the sustainability of the care relationship.⁶⁶ A further consequence of carers remaining ‘hidden’ is the underreporting of carer status, creating probable underestimations in the number of carers in the administrative and survey data, with implications for policy and service provision which relies on such data.

13. *What is social inclusion, and what is the significance of understanding and measuring the social inclusion needs of carers of people over the age of 65?*

A large research project in Australia⁶⁷ has examined the concept and measures of social inclusion and their applicability to the ‘social practice of care, the role of carers and caring relationships in society’.⁶⁸ A publication from this project, Hill and Thomson (2017), emphasises the following key points, which are based on a critical review, informed by care theory, of the wide-ranging academic and policy literature regarding social inclusion:

- A broad definition of social inclusion is that the concept “describe[s] the ways a society’s parts fit together and share values” (Silver, 2015:3)⁶⁹
- Useful elements of the idea of social inclusion for examining the situation of carers are that it:
 - “describes forms of social inequalities and disadvantage”⁷⁰
 - is “a term that explores what is necessary for inclusion or social membership”⁷¹

⁶⁶ Hamilton, M; Botfield, J; Newman, C; Persson, A; Bryant, J; valentine, k; Wallace, J, 2018, ‘Hidden carers? A scoping review of the needs of carers of people with HIV in the contemporary treatment era’, *International Journal of Care and Caring*, 2(4), pp. 529-549

⁶⁷ .The project ‘Carers and social inclusion: new frameworks, evidence and policy lessons’ was supported under the Australian Research Council’s Linkage Projects funding scheme (LP110400160) and funding from research partners. Research partners included: the University of Leeds, Carers Australia, the Department of Education, Employment and Workplace Relations, NSW Health, the NSW Department of Family & Community Services, and the SA Department for Communities and Social Inclusion. Chief Investigators: Dr Trish Hill, Emeritus Professor Bettina Cass, Associate Professor and Susan Green; Partner Investigator: Professor Sue Yeandle; research team: Catherine Thomson, Dr Margaret Raven, Dr Melissa Wong and Dr Lisa Buckner. The views expressed in all publications from this project are those of the authors and not necessarily those of the Australian Research Council or the aforementioned departments or responsible ministers. Publications available at this link: <https://www.sprc.unsw.edu.au/research/projects/carers-and-social-inclusion/>

⁶⁸ Hill, T. and Thomson, C. (2017) ‘Revising social inclusion to take account of care’, *International Journal of Care and Caring*, 1(2): 175–90, DOI: 10.1332/239788217X14939696857871, p.175.

⁶⁹ Silver, H. (2015) *The contexts of social inclusion*, Working Paper No. 144, New York, NY: United Nations Department of Economic and Social Affairs, <http://ssrn.com/abstract=2641272> or, p.3 cited in Hill, T. and Thomson, C. (2017), Hill, T. and Thomson, C. (2017) ‘Revising social inclusion to take account of care’, *International Journal of Care and Caring*, 1(2): 175–90 p.176.

⁷⁰ Hill, T. and Thomson, C. (2017) ‘Revising social inclusion to take account of care’, *International Journal of Care and Caring*, 1(2): 175–90, DOI: 10.1332/239788217X14939696857871, p.175.

⁷¹ Daly, M. and Silver, H. (2008) ‘Social exclusion and social capital: a comparison and critique’, *Theory and Society*, 37(6): 537–66. Silver, H. (2010) ‘Understanding social inclusion and its meaning for Australia’, *Australian Journal of Social Issues*, 45(2): 183–211, cited in Hill, T. and Thomson, C.

- “focuses on ‘goals, social objectives’ and ‘social membership’, while [in contrast, the idea of] social exclusion refers to ‘social problems’ or groups perceived in some way to be outsiders”⁷²
- can bring attention “to the potential terms of inclusion”⁷³

Issues in relation to carers

Hill and Thomson contend that: “Care has often been rendered invisible, while carers have been allocated a contradictory status within social inclusion discourses.”⁷⁴ More specifically they note that:

- most approaches to conceptualising and measuring social inclusion “focus on... participation in work, study and political life...[and] neglect to recognise and value the profound and universal human activities of care within families, communities and broader social systems of care and support, and how these shape social inequalities”⁷⁵
- “in empirical assessments of inclusion that do recognise carers..., care has most commonly been identified as a barrier to inclusion, as a risk factor that can impede participation... or a social resource”⁷⁶

The significance of understanding and measuring the social inclusion needs of carers of people aged over 65

The research by Hill et al argues that, as carers are members of society, it is essential that we have adequate concepts and measures of social inclusion that can account for important aspects of carers’ lives.⁷⁷ Understanding and measuring social inclusion in such

(2017) ‘Revising social inclusion to take account of care’, *International Journal of Care and Caring*, 1(2): 175–90, p.177.

⁷² Woodward, A. and Kohli, M. (eds) (2001) *Inclusions and exclusions in European society*, London: Routledge. Cited in Silver, H. (2010) ‘Understanding social inclusion and its meaning for Australia’, *Australian Journal of Social Issues*, 45(2): 183–211 ; (Woodward and Kohli, 2001, cited in Silver, 2010; Levitas, R. (2003) *The idea of social inclusion*, Social Inclusion Research Conference, ‘What do we know and where do we go? Building a social inclusion research agenda’, Canada. Daly, M. and Silver, H. (2008) ‘Social exclusion and social capital: a comparison and critique’, *Theory and Society*, 37(6): 537–66. Cited in Hill, T. and Thomson, C. (2017) ‘Revising social inclusion to take account of care’, *International Journal of Care and Caring*, 1(2): 175–90, p.175.

⁷³ Levitas, R. (1998) *The inclusive society? Social exclusion and New Labour*, Basingstoke: Palgrave Macmillan. Silver, H. (2010) ‘Understanding social inclusion and its meaning for Australia’, *Australian Journal of Social Issues*, 45(2): 183–211, cited in Hill, T. and Thomson, C. (2017) ‘Revising social inclusion to take account of care’, *International Journal of Care and Caring*, 1(2): 175–90, DOI: 10.1332/239788217X14939696857871, p.177/8.

⁷⁴ Hill, T. and Thomson, C. (2017) ‘Revising social inclusion to take account of care’, *International Journal of Care and Caring*, 1(2): 175–90, DOI: 10.1332/239788217X14939696857871, p.176.

⁷⁵ Hill, T. and Thomson, C. (2017) ‘Revising social inclusion to take account of care’, *International Journal of Care and Caring*, 1(2): 175–90, DOI: 10.1332/239788217X14939696857871, p.176.

⁷⁶ See for example: Levitas, R., Pantazis, C., Fahmy, E., Gordon, D., Lloyd, E. and Patsios, D. (2007) *The multi-dimensional analysis of social exclusion*, Bristol: Department of Sociology and School for Social Policy, University of Bristol; Australian Government (2009) *A stronger, fairer Australia*, <http://www.voced.edu.au/content/ngv%3A45844>,

⁷⁷ Hill TL;Thomson C;Raven M;Wong M;Cass B;Yeandle S;Buckner L, 2016, *Carers and Social Inclusion - Summary Report*, Social Policy Research Centre, Sydney, p.5

a way can see carers' contributions better recognised and different aspects of advantage and disadvantage in carers lives revealed, and appropriate policies and supports for carers could then be developed.

According to Hill and Thomson, an approach to assessing social inclusion that takes account of the lives of carers would seek to identify:

- Carers' “social roles and relationships:... recognising the histories, complexities, obligations and responsibilities that individuals have with and for each other”⁷⁸
- How carers negotiate their multiple responsibilities and roles including examining “time stress, work–care reconciliation and positive and negative spillover effects – for example, whether paid employment provides a respite from the caring role or whether concerns about the quality of alternative care while at work undermine the capacity to engage in paid employment”⁷⁹
- “The quality of [carers'] participation in each sphere, the quality of paid work, the quality of the care relationship and the quality of other social relationships and connections”⁸⁰
- How carers' participation in a range of activities is valued by society or brings advantages or disadvantages to carers' lives including: Employment; Study; Political life; Volunteering or community work; Capacity for voice and advocacy; Recognition and respect⁸¹

Hill and Thomson also suggest that the “factors that enable or constrain carer's participation” and “can facilitate or create barriers to carers' social inclusion and underpin social inequalities based on care” include;

- social structures: such as “the legislative, regulatory and normative frameworks that generate structures of opportunity and constraint”⁸²
- institutional practices and mechanisms: such as access to information and services⁸³
- day-to-day interactions: “such as those between paid/unpaid carers and services, administrators, health experts, policymakers and other members of

https://www.sprc.unsw.edu.au/media/SPRCFile/Carers_and_Social_Inclusion_Summary_report.pdf

⁷⁸ Hill, T. and Thomson, C. (2017) 'Revising social inclusion to take account of care', *International Journal of Care and Caring*, 1(2): 175–90. p.183.

⁷⁹ Hill, T. and Thomson, C. (2017) 'Revising social inclusion to take account of care', *International Journal of Care and Caring*, 1(2): 175–90. p.184.

⁸⁰ Hill, T. and Thomson, C. (2017) 'Revising social inclusion to take account of care', *International Journal of Care and Caring*, 1(2): 175–90. p.184.

⁸¹ Hill, T. and Thomson, C. (2017) 'Revising social inclusion to take account of care', *International Journal of Care and Caring*, 1(2): 175–90. p.184/5.

⁸² Hill, T. and Thomson, C. (2017) 'Revising social inclusion to take account of care', *International Journal of Care and Caring*, 1(2): 175–90. p.184/5.

⁸³ Hill, T. and Thomson, C. (2017) 'Revising social inclusion to take account of care', *International Journal of Care and Caring*, 1(2): 175–90. p.186.

society, and... the ways in which information and advocacy is provided, and recognition and respect is accorded, to carers and to the people they care for”⁸⁴

14. *What supports would facilitate the social inclusion of carers’ for people over the age of 65?*

Carers of people over the age of 65 are most likely to be either working age carers (25-64 years) or older carers (65 years or over). Focus groups in the ARC Carers and Social Inclusion research project conducted by Thomson and Hill (2016)⁸⁵ asked carers to say what a socially inclusive society would mean for them. Overall, consistent themes for all age groups of carers were that “a socially inclusive society would provide:

- recognition for carers of their roles, relationships and responsibilities and the impact of caring on their lives
- support through information, services, and financial assistance for carers to manage their caring roles
- opportunities for choices about participating in other aspects of their lives: employment, school, community and social activities
- greater community awareness about ageing, illness and disability and better understanding of carers’ lives: what they value and what they need”⁸⁶

Carers also reported that they “prioritised their relatives’ health and social needs at the expense of their own.”⁸⁷ Hill et al state that “[a] socially inclusive society for carers would aim to eliminate the need to make that choice.”⁸⁸

⁸⁴ Hill, T. and Thomson, C. (2017) ‘Revising social inclusion to take account of care’, *International Journal of Care and Caring*, 1(2): 175–90. p.186.

⁸⁵ Thomson and Hill (2016) “Social Inclusion Across the lifecourse” in Hill TL;Thomson C;Raven M;Wong M;Cass B;Yeandle S;Buckner L, 2016, *Carers and Social Inclusion - Final Report*, Social Policy Research Centre, Sydney, https://www.sprc.unsw.edu.au/media/SPRCFile/Carers_and_Social_Inclusion_Final_report.pdf

⁸⁶ Hill TL;Thomson C;Raven M;Wong M;Cass B;Yeandle S;Buckner L, 2016, *Carers and Social Inclusion - Summary Report*, Social Policy Research Centre, Sydney, https://www.sprc.unsw.edu.au/media/SPRCFile/Carers_and_Social_Inclusion_Summary_report.pdf based on Thomson and Hill (2016) “Social Inclusion Across the lifecourse” in Hill TL;Thomson C;Raven M;Wong M;Cass B;Yeandle S;Buckner L, 2016, *Carers and Social Inclusion - Final Report*, Social Policy Research Centre, Sydney, https://www.sprc.unsw.edu.au/media/SPRCFile/Carers_and_Social_Inclusion_Final_report.pdf

⁸⁷Hill TL;Thomson C;Raven M;Wong M;Cass B;Yeandle S;Buckner L, 2016, *Carers and Social Inclusion - Summary Report*, Social Policy Research Centre, Sydney, https://www.sprc.unsw.edu.au/media/SPRCFile/Carers_and_Social_Inclusion_Summary_report.pdf based on Thomson and Hill (2016) “Social Inclusion Across the lifecourse” in Hill TL;Thomson C;Raven M;Wong M;Cass B;Yeandle S;Buckner L, 2016, *Carers and Social Inclusion - Final Report*, Social Policy Research Centre, Sydney, https://www.sprc.unsw.edu.au/media/SPRCFile/Carers_and_Social_Inclusion_Final_report.pdf, p.34

⁸⁸ Hill TL;Thomson C;Raven M;Wong M;Cass B;Yeandle S;Buckner L, 2016, *Carers and Social Inclusion - Summary Report*, Social Policy Research Centre, Sydney, p.35 https://www.sprc.unsw.edu.au/media/SPRCFile/Carers_and_Social_Inclusion_Summary_report.pdf p.35

The research identified specific issues with regard to social inclusion reported by working age and older carers. These issues were:

- “Public awareness of disability and caring to enhance a sense of belonging in the community.
- Access to information about services and assistance to develop ‘service literacy’ to enable them to access the support they needed.
- Flexible employment conditions, such as working part-time and understanding and supportive management.
- Time away from their caring role in the form of retreats or respite services to facilitate social connections to other carers.
- Access to flexible and high-quality respite and well-developed support networks, such as those found in retirement villages and from extended family.
- Accessibility in public spaces for carers and their relatives.”⁸⁹

15. *What do you understand to be the key unmet needs in services and supports for informal and unpaid carers including, but not limited to respite (by reference to different kinds of respite, as you consider appropriate).*

Research suggests that the use of respite services by carers of older people can improve the health and wellbeing of the carer and sustainability of the care relationship, including supporting carers to continue to provide care for the older person in the community.⁹⁰ However, carers experience a number of barriers to accessing respite services that meet their needs. In a recent analysis of the 2015 SDAC, Temple and Dow identify the most prevalent types of unmet need among primary carers of older Australians, with the most cited areas of unmet need being financial assistance (18 per cent), physical assistance (13 per cent), managing their health (12 per cent), emotional support (12 per cent) and respite (12 per cent), suggesting that roughly one in ten primary carers of an older person reported that more respite would support them in their caring role.⁹¹ Other studies, including surveys and qualitative research with carers, suggests that unmet need for respite is likely to be higher than this, and that the issue of unmet respite need involves complex considerations about the availability and accessibility of respite but also its quality, cultural appropriateness, and alignment with family needs, values and preferences.⁹² For example, carers may not express a need for ‘more respite’ because the respite services available to them are not appropriate for their needs or of a quality

⁸⁹ Hill TL;Thomson C;Raven M;Wong M;Cass B;Yeandle S;Buckner L, 2016, Carers and Social Inclusion - Summary Report, Social Policy Research Centre, Sydney, p.5

⁹⁰ Phillipson, L, Jones, S, Magee, C, 2014, ‘A review of factors associated with the non-use of respite services by carers of people with dementia: implications for policy and practice’, *Health and Social Care in the Community*, 22(1) pp 1-12.

⁹¹ Temple, J; Dow, B, 2018, The unmet support needs of carers of Older Australians: prevalence and mental health, *International Psychogeriatrics*, 30(2), pp 1849-1860.

⁹² See for example, Carers NSW 2016 Carer Survey, Main Report, <https://www.carersnsw.org.au/Assets/Files/Carers%20NSW%202016%20Carer%20Survey%20Report.pdf>; Carers NSW, 2016, National Survey of Carers’ Respite Needs, Final Report, <https://www.carersnsw.org.au/Assets/Files/Respite%20Survey%20Report.pdf>

that they are satisfied with and they therefore do not use respite services.⁹³ However, they can at the same time be in need of a break from their caring role, a need that the right kind of respite could fulfil.

According to report by Hamilton et al (2016) entitled *Transitioning Australian Respite*, recent changes in the way in which disability, aged care and carer services are configured in Australia have altered the availability of respite for carers.⁹⁴ The shift towards consumer-directed care in disability and aged care means that the focus of service provision is on meeting the needs of the person with the disability or older person. This creates considerable barriers in the area of disability services, which will not be explored in detail here. According to Hamilton et al (2016), in the area of aged care services, while carers are able to access respite through the Commonwealth Home Support Program, the focus is on sustaining the care relationship rather than meeting the carers' individual needs.⁹⁵ More generally, the greater focus on the consumer often brings with it a shift towards a 'respite effect' – whereby services tailored to the consumer provide a respite effect for the carer while the consumer is participating in an activity, but this may not meet the needs of the carer.⁹⁶ At the same time, the rolling of the National Respite for Carers Program into the Commonwealth Home Support Program means that, in order for a carer to access respite, the older person for whom they provide care must be accessing services through the CHSP.⁹⁷ The introduction of the Integrated Carer Support Service will see the provision of emergency respite and 'carer-directed packages' that will provide small sums of money for carers to purchase services, including planned respite. However, the sum of money and the number of packages available will be small.⁹⁸

Research suggests that carers in Australia face particular barriers in accessing some types of respite, especially longer periods of respite such as cottage respite (respite that is available overnight or over several days and provided in the community or in the home of a host family) and residential respite (a short stay in a residential aged care facility).⁹⁹ These types of respite are highly valued by many carers.¹⁰⁰ One barrier to accessing residential respite beds has been the increasing practice of 'try before you buy', whereby

⁹³ Hamilton, M., Giuntoli, G., Johnson, K., Kayess, R., & Fisher, K. R. 2016, *Transitioning Australian Respite* (SPRC Report 04/2016). Sydney: Social Policy Research Centre, UNSW Australia.

⁹⁴ Hamilton, M., Giuntoli, G., Johnson, K., Kayess, R., & Fisher, K. R. 2016, *Transitioning Australian Respite* (SPRC Report 04/2016). Sydney: Social Policy Research Centre, UNSW Australia

⁹⁵ Hamilton, M., Giuntoli, G., Johnson, K., Kayess, R., & Fisher, K. R. 2016, *Transitioning Australian Respite* (SPRC Report 04/2016). Sydney: Social Policy Research Centre, UNSW Australia

⁹⁶ Hamilton, M., Giuntoli, G., Johnson, K., Kayess, R., & Fisher, K. R. 2016, *Transitioning Australian Respite* (SPRC Report 04/2016). Sydney: Social Policy Research Centre, UNSW Australia.

⁹⁷ Hamilton, M., Giuntoli, G., Johnson, K., Kayess, R., & Fisher, K. R. 2016, *Transitioning Australian Respite* (SPRC Report 04/2016). Sydney: Social Policy Research Centre, UNSW Australia.

⁹⁸ DSS 2018 Integrated Carer Support Service (ICSS) 2018 Webinar 2: Questions & Answers p18 https://www.dss.gov.au/sites/default/files/documents/11_2018/icss_webinar_2_questions_and_answers_v1.0.pdf (see p 18)

⁹⁹ Carers Australia, 2017, *Improving Access to Aged Residential Respite Care*, <https://www.carersaustralia.com.au/storage/residential-respite-care-report.pdf>

¹⁰⁰ Carers Australia, 2017, *Improving Access to Aged Residential Respite Care*, <https://www.carersaustralia.com.au/storage/residential-respite-care-report.pdf>

families and providers use respite beds as a transition into a permanent residential aged care bed.¹⁰¹ While this process has benefits for older people and families (such as offering them an opportunity to ‘get a feel’ for a facility), it makes finding a residential respite bed for genuine respite purposes more difficult for others.¹⁰²

Finally, as mentioned in the response to Question 7, there is a lack of alternative care options that facilitate carers’ labour market participation – that is, ongoing, planned alternative/replacement care that matches carers’ desired working hours.

16. *What, in your view, works best in supporting carers in their role supporting older Australians? Could you describe any programs/services that work well to support unpaid and informal carers?*

As noted throughout this paper, carers’ needs are diverse and are affected by the care context and access to formal and other informal supports. In focus groups conducted in the ARC Carers and Social Inclusion project older carers identified characteristics of services that do or would better support them. These included:

- “Access to high quality care that was fun and engaging...
- Activities that carers and care recipients could attend together....
- Improved access to preventative respite and emergency respite
- Services tailored to the individual needs of carers and people in need of support
- More support for carers after caring ends
- Increase CALD-appropriate support for carers and their relatives.”¹⁰³

Carers of working age highlighted the need for:

- “Availability and access to training for carers, such as how to deal with the stress associated with caring, lifting and handling techniques.
- Increased support for GPs to be a key access point to services.
- Access to counselling or support workers to assist with the stress associated with caring and other mental health issues.
- Programs to help carers have the opportunity for exercise, such as gym membership.

¹⁰¹ Australian Government Aged Care Financing Authority, 2018, Report on Respite for Aged Care Recipients, https://agedcare.health.gov.au/sites/default/files/documents/11_2018/acfa_report_on_respite_care_for_aged_care_recipients.pdf

¹⁰² Australian Government Aged Care Financing Authority, 2018, Report on Respite for Aged Care Recipients, https://agedcare.health.gov.au/sites/default/files/documents/11_2018/acfa_report_on_respite_care_for_aged_care_recipients.pdf

¹⁰³ Thomson, C and Hill, T 2016, Older carers and social inclusion: Feedback report, Social Policy Research Centre, UNSW Sydney, Sydney, https://www.sprc.unsw.edu.au/media/SPRCFile/Older_Carers_and_Social_Inclusion_Feedback_report.pdf, p,17

- Greater access to services that target different needs i.e. different types of support groups, appropriate services for the care recipient encompassing things that they like and enjoy.
- Increased access to culturally appropriate services...
- Increased access to flexible employment conditions, such as job share.
- A carers' subsidy for employers as an incentive to employ carers, particularly those who had been out of the workforce and lacked the necessary skills to re-enter the workforce.
- An increase of the cap on the number of hours carers are allowed to work while receiving the Carer Payment.
- Allowance of carers on the Carer Payment to access support through employment agencies and training courses similar to recipients of the Newstart Allowance.
- Availability and access to workplace training for carers re-entering the workforce.”¹⁰⁴

As outlined in the response to Question 8, there are a range of measures found to be effective in supporting carers to begin or continue to participate in paid work, including having access to flexible working arrangements, policies designed to promote job security and access to adequate replacement care.¹⁰⁵

¹⁰⁴ Thomson, C and Hill, T 2016, Mid-age carers and social inclusion, Feedback report, https://www.sprc.unsw.edu.au/media/SPRCFile/MidAge_Carers_and_Social_Inclusion_Feedback_report.pdf, p17

¹⁰⁵ Hill, T; Thomson, C; Bittman, M and Griffiths, M, 2018. What Kinds of Jobs Help Carers Combine Care and Employment? [online]. Family Matters, No. 80, 2008: 27-32.
Availability: <<https://search.informit.com.au/documentSummary;dn=482084586386439;res=IELFSC>>ISSN: 1030-2646.